



Canadian Coalition for Genetic Fairness/ Coalition Canadienne Pour L'équité Génétique

Revisiting Genetic Discrimination Issues in 2010: Policy Options for Canada

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Genome Canada



Genetics Discrimination in Canada

- Genetic Discrimination occurs in Canada and internationally – Canada Lagging Behind (UK, US, EU)
- Real Life Discussion
 - Impacting on real Canadians with real issues
 - Beyond policy and academic discussion
- Not just insurance and employment:
 - Health
 - Research
 - Emerging technology and business



Fear of Discrimination

- Potential ramifications: Insurance, Employment, Personal
- Research agenda – e.g. participation in drug trials for treatments or cures
 - Concerns about levels of confidentiality for participating in research
 - Knowing genetic information for research purposes and then using this for other purposes (e.g. employment, insurance, etc.)
- Personalized Medicine
- Proactive life, health and reproductive choices



Genetics Discrimination in Canada

- Differences between:
 - policy (government/industry/employment)
 - practices (the experience of individual and families in communities)
- Multi-factorial problem – will require more than one solution and more than one participant
 - Anticipatory not “after the fact”
 - Each proposed policy option only addresses some issues not all



Genetics Discrimination in Canada

- Infrastructure is present to potentially accommodate but not strong enough (as outlined in document)
 - Canadian Charter of Rights and Freedoms (1982)
 - Canadian Human Rights Act (1985)
 - Personal Information Protection and Electronic Documents Act (2000)
 - Regulatory Review and Purpose-Scientific Approval
 - Industry Participation
- Policies are evolutionary
 - Development results from the social and political context
 - Need to evolve to adjust to new reality
 - Legislation has not kept up with changes in science

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What we know

- Information about genetic disease is growing – but still uncertain
 - Range for highly penetrate to multi-factorial disease
 - Family history does not equate to an individuals risk, many other factors (environment, lifestyle, etc)
- Discrimination is based on perceived or imputed disability
- Research: more willing participants; slowing of the research agenda



Faulty Assumptions

- Genetics information is often misunderstood.
- Genetics is complicated.
- Genetics is multidimensional.



Omissions

- “Duress” – requirement of genetic testing before people are ready to receive this information for employment, insurance purposes or other purposes
- “Recreational Genetics” and impact on the availability of direct to consumer test results
 - Reliability, Auditing
 - Genetic Counselling



Practical considerations

- Just because difficult and complex no reason to not pursue this
- Addressing other forms of discrimination has been equally difficult and complex



Research Questions

- Future Research questions should not slow the movement of the development of a response to genetic discrimination
- What has happened to other countries where protections have been put into play?
- Calls for more research on this issue with other disease groups



Final Thoughts

- Canadian solution must include clearer guidance:
 - Perceived and imputed disability
 - The onus to accommodate
 - Duress
 - Direct to Consumer Testing
 - Educational component for public at large – with enforcement mechanisms