Use and Misuse of Genetic Information Outside the Therapeutic context

Yann Joly, DCL, AdE
Assistant Professor
Faculty of Medicine, McGill University
Outline

- Context
- Insurance
- Employment
- Immigration
- Family law
- Criminal law
Uses of genetic information for third parties

- Determining, with variable degree of accuracy, the probability that an individual will develop certain diseases in the future
- Confirming filiation/absence of filiation with a very high degree of confidence
- Uniquely identifying an individual with a minimal amount of his/her genetic material
The identifiability of genetic data

- An individual can be uniquely identified with access to just 75 single-nucleotide polymorphisms from that person (Lin et al., 2004).
- Re-identification of individuals is possible through genotype-phenotype inference and through methods such as genealogical information, trail re-identification or so-called dictionary attack (Malin et al., 2004).
- Knowing even some genetic information about an individual could lead to that individual being identified as belonging to the control or affected group within a study (Homer et al., 2008).
- Surname leakage, a technique relying on bioinformatic profiling of short tandem repeats (STR) on the Y-chromosome and querying massive Web 2.0 genealogical databases would jeopardize 10% of anonymized whole genome sequencing datasets of US individuals. (Erlich; 2012)
Genetics and insurance

Overview

- Current position of the Canadian Life and Health Insurance Association Inc.
- 2 recent Canadian surveys documenting the use of genetic relating to huntington’s disease by insurers.
- Methodological limits of existing surveys
- Lack of strong empirical data on the use of genetic information in the context of complex diseases
Genetics and insurance

Challenges

- Genetic results are difficult to interpret, insurers/actuaries can make mistakes
- Some genetic risks may never materialize
- Insurers could use genetic test results to raise the price (premium) of personal insurance contracts or reject applications from high risk individuals
- Possibility of reducing disease risk(s) through changes in lifestyle and preventive health management rarely considered by insurers
Genetics and insurance

Legal framework

- Insurance law

- Privacy law
  - informed consent: limit application of confidentiality protections
  - Recent work from the Privacy Commissioner of Canada on insurance and genetics

- Human rights law
Genetics and employment

Overview

- No research in Canada on this topic: complete absence of empirical data or legal analysis
- Several reported cases in the United States, United Kingdom and Australia (ex. screening of airline crew for sickle cell disease)
- Protective legislation and case law in the United States
  - Genetic Information Nondiscrimination Act of 2008
Genetics and employment

Uses of genetic data by employers

Genetic screening/genetic monitoring to identify:

- workers with higher risk of developing certain diseases due to the work environment
- workers that could pose a risk to the security of other employees or the public
- job candidates at higher risk of developing specific diseases
- job candidates with specific work-related qualities or traits
Genetics and employment

Legal framework

- Employment contract
- Applicability of privacy law (same as for insurance)
Genetics and immigration

Overview

• According to the CIC’s In-Canada Protection Unit, around 3500 individuals had to undergo a genetic test in the immigration context in 2009.

• Litigation around genetic testing in the immigration context has resulted in 3 court cases at the Federal Court level and 2 at the Immigration Appeal Division since 2000.
Genetics and immigration

Uses of genetic data in immigration

- Identifying applicants that could cause excessive demand on health or social services
- Confirming biological relationship between family members
- Confirming the identity of a national returning to the country in case of doubt
Genetics and immigration

Legal Framework

- Immigration law, its regulations and case law provide some degree of protection against abuses

- Human rights law, administrative law and, privacy law could provide additional protection

- International Convention on the Rights of the Child
Genetics and immigration

Case law

- Mohamad-Jabir v. Canada (2008) Immigration Appeal Division
- Tesfaye v. Canada (2008) Immigration Appeal Division
- Suaad Hagi Mohamud v. Minister of foreign affairs et al. (2010) Fed. Court
Genetics and criminal law

Forensic uses of DNA

- Linking crimes together when there are no suspects
- Helping to identify or eliminate suspects
- Determining whether a serial offender is involved
Genetics and criminal law

Canadian national DNA databank

- Profiles contained in the Data Bank
  - in the Convicted Offender Index: 263,657
  - in the Crime Scene Index: 82,437

- 13 specific DNA markers used to produce a DNA profile unique to each individual
- Restricted to convicted offenders of designated offenses
- Samples may only be used for forensic DNA analysis and, only to compare offender profiles with crime scene profiles
Genetics and criminal law

Issues

- Obtaining/using DNA evidence from suspected individuals
- Familial searches
- Incidental findings
- Validity, reliability, chain of custody
Questions?