Use and Misuse of Genetic Information Outside the Therapeutic context

Yann Joly, DCL, AdE
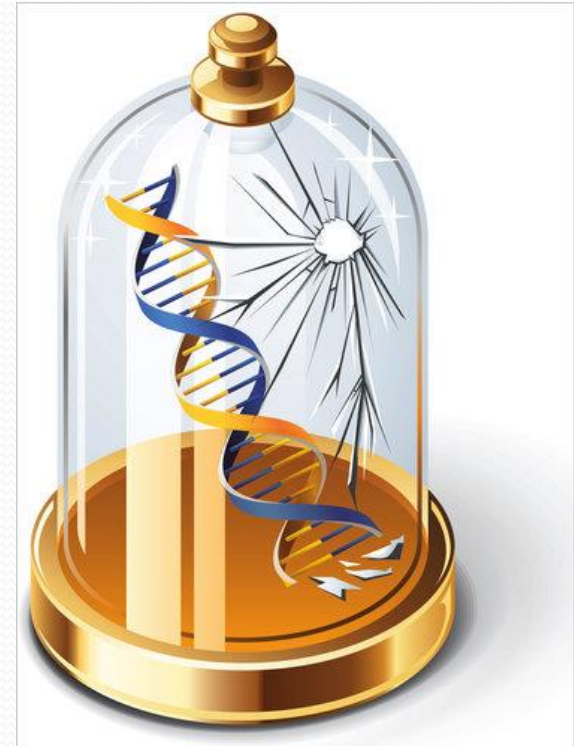
Assistant Professor

Faculty of Medicine, McGill University

Outline

- Context

- Insurance

- Employment

- Immigration

- Family law

- Criminal law

Context

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

Context

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
  - *Audet c. Industrielle-Alliance* [1990] R.R.A.500 (C.S.Q)
- Privacy law
  - informed consent: limit application of confidentiality protections
  - Recent work from the Privacy Commissioner of Canada on insurance and genetics
- Human rights law
  - *Quebec. v. Boisbriand*, SCC 27, [2000] 1 S.C.R. 665

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*
  - *EEOC v. Burlington N. & Santa Fe Ry. Co., No. C 01-4013-MWB* (N.D. Iowa Apr.18, 2001)

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)

- Human rights law : *Quebec. v. Boisbriand*, 2000 SCC 27, [2000] 1 S.C.R. 665 (very important)

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

- *M.A.O. v. Canada (2003) Fed. Court*

- *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*

- *Canada v. Martinez-Brito (2012) 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 wether 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
- *R* v. *Rodgers* (2006) SCC.

Genetics and criminal law

Issues

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

Questions?

New Crafts LLC