



## Genes are us: Ottawa forum identifies the privacy issues

"There exists an unrecognised art form which consists of bringing together the best resource people from around the world to achieve both wide-angle vision and sharp focus on a complex, multifaceted subject in a single, day-long seminar." According to Lise Moisan of Privacy Files, Canada, *Privacy Laws & Business* achieved this in September 1996, when we organised a workshop in Ottawa on Data Protection Law and Genetics.

It covered the data protection and privacy implications of genetics and genetic technologies in human reproduction and health, law enforcement, research ethics and the biotechnology industry.

The workshop consisted of ten experts (from six different countries) who delivered presentations, followed by information and discussion on a broad range of genetics, privacy and policy-related issues. Altogether, 25 people from ten countries, including the Privacy Commissioners from Australia, Belgium, Denmark, Germany, Hong Kong, Israel and New Zealand, carried on a seven and a half hour round-table marathon examination.

### The cost factor

Clearly, genetic information as a sub-set of health information is already of great interest to public-health care managers, to the insurance industry and to employers. Moreover, participants were concerned that, as the cost of genetic technology decreases, the pressure towards its more widespread, if not routine, use will increase. Indeed, in law enforcement, the high cost of DNA analysis used in police investigations and in establishing national or international databanks, seems to be one of the few reliable, albeit temporary, moderating forces.

Data protection and privacy is a serious concern. For example, New Zealand (Criminal Investigations Act 1995) and Canada have consulted their respective Privacy Commissioners before bringing forward legislation governing genetic technologies, be they used to fight the "battle against crime" or the battle against health disorders or rising health-care costs.

Detective Superintendent Ken Grange of the UK Home Office spoke about the implementation of the UK's Criminal Justice and Public Order Act 1994. This allows police to obtain samples from individuals convicted of or charged with a recordable offence, in order to produce DNA profiles that are then retained in the national database. Detective Superintendent Grange made an observation which speaks volumes about the level of *a priori* acceptance of, even faith in, technological fixes for profound systemic problems: "It took the courts 25 or 30 years to accept fingerprint evidence; it took them one year to accept DNA evidence."

### Unique character of genetic information

For a number of sound strategic reasons, some speakers were opposed to "genetic-specific legislation." Nevertheless, they adhered to the general view (expressed succinctly in the Human Rights Australia September 1996 information paper *The Privacy Implications of Genetic Testing*) that personal genetic information differs from other personal information in the following ways:

- knowing about someone's genetic makeup also reveals the makeup of genetic relatives;
- all DNA information is contained in nearly every body cell;
- it influences, albeit to varying degrees, personal identifiers such as "height, build, skin colour, intelligence and possibly propensity for some behaviours such as alcoholism";
- personal genetic information cannot be changed;
- it can indicate what will (or is likely to) happen to your health many years in the future; and
- tests can indicate the probability of a person exhibiting a certain "characteristic or condition."

### Which genetic technologies?

In addition to the collection and analysis of DNA material for the purpose of identifying suspected criminals, two other major technologies stood as a backdrop to the workshop discussions: genetic screening and genetic testing.

**Genetic screening**, such as screening the Canadian population for the cystic fibrosis gene, is



a process of looking for a particular marker to see if it is there. With **genetic testing**, however, there is already sufficient evidence (racial or family medical history) to indicate that a genetic marker is likely to be present, which justifies testing an individual or group of individuals to verify their likelihood of developing a particular genetic condition such as Huntington's disease.

These medical uses of DNA technology raise the issue of what the science of genetics can and cannot predict and with what degree of certainty. Indeed, there are very few single-gene disorders; most disorders, if they are genetic at all, involve multiple genes. And almost all disorders stem, not only from genes, but from environmental and behavioural factors. Hence, the very necessary distinction between low predictive tests and high predictive tests. Unfortunately, among laypersons and even among professionals in the field, human genetics too often falls prey to deterministic thinking of the one-gene one-effect variety.

Dr Alan Westin, Professor of Public Law and Government at Columbia University and academic advisor on leading public-opinion surveys on privacy in the United States and Canada, reported that a 1995 survey showed that over two-thirds of Americans held a positive view of forensic DNA uses. He said that, considering the specialised nature of the subject, this reflects an unusually "high penetration", which he attributed to the fact that, in addition to the Simpson trial media circus, the average American is bombarded by reports of new gene discoveries in medical cures.

### **Treating technology with caution**

Dr. Bartha Knoppers, Professor of Law at the University of Montréal and Chair of the International Ethics Committee of the Human Genome Project, emphasised that policy makers must fully understand the "symbolic power" of human genetics and take into account its "social representations": it is an area where people project their "fears, hopes, phobias, as well as their legitimate concerns."

Dr. Abby Lippman, geneticist and Professor at McGill's University Department of Epidemiology and Biostatistics, fears "reductionist assumptions" about human genetics and their interplay with "widespread systemic prejudices" that have been and remain injurious to certain targeted groups. She advised that, in considering any new

technology and its applications, we should "look upstream and ... ask whose interests are being served? Any technology has a valence; its mere presence changes everything," Dr Lippman observed, citing the example of prenatal testing (amniocentesis). "The very possibility of DNA evidence in criminal cases ups the ante."

This cautionary view echoes the words of Bruce Phillips, Canada's Privacy Commissioner. In his 1995-96 Annual Report (in the section entitled "Building a DNA Database - Carefully") he states his intention to "ensure that the database does not become subject to "function creep" and to avoid an ever-lengthening list of offences for which sampling is allowed. The pressure to do just that is present in our society, a product of the very existence of technology and the belief that technology can solve all our woes, if only we let it." In addition, Bruce Phillips proposed that DNA samples be discarded to prevent "unrelated secondary uses, including ethically problematic research into genetic links to crime."

Privacy consultant Eugene Oscapella, and other participants also identified research in the field as possibly problematic, especially considering what Dr. Bartha Knoppers identified as the increasing financial partnership between researchers and the biotechnological industry being imposed as a funding condition by public funding bodies.

### **Where to go from here?**

Answering this final and potentially disheartening question, Dr. Alan Westin bravely jumped in, calling for a sectoral (industry-based) approach, as opposed to general overarching legislation, supporting the development of model codes. He reiterated that genetic information should be dealt with as a subset of medical information. Dr. Bartha Knoppers then emphasised the need for both a regional and an international approach.

**An edited version of Lise Moisan's report in *Privacy Files*, Progesta Publishing Inc., 1788 rue D'Argenson, Ste-Julie, Quebec, J3E 1E3, Canada. Report used here with permission. Tel: + (1) 514 922 9151 Fax: + (1) 514 922 9152**

**Eugene Oscapella:** *Privacy Laws & Business* acknowledges the immense help given by Eugene Oscapella, Privacy Consultant, Barrister & Solicitor, Ottawa, in organising this workshop. He is chairing the genetics session at the Cambridge conference.