

## A RIGHT TO GENETIC PRIVACY?

*Genetic testing offers undoubted benefits. However, there are also many ethical and moral dilemmas. Do we want to force people to learn their own genetic traits? How do we prevent the wrong people from getting this highly sensitive information? Should employers get the information? Should insurers get it? Should governments, including the police, get it?*

*These are some of the questions discussed by Eugene Oscapella at this month's 10th World Congress on Medical Law held in Jerusalem, Israel. He is author of Canada's Federal Privacy Commissioner's report, Genetic Testing and Privacy.*

### Screening, monitoring and analysis

Genetic screening takes a one-time "snapshot" of an individual to identify genetic traits. It tells whether we have the gene responsible for a peculiar trait or disease. Generally, one's genetic structure does not change over time, although mutations can occur.

Genetic monitoring is typically used to look for genetic mutations (changes) due to exposure to chemicals or radiation. A person is screened at the start of employment, then later on, to identify mutations.

Forensic DNA analysis, also known as genetic fingerprinting, is used by police to match genetic samples from a crime scene with those of a suspect.

Several genetic diseases can now be identified through genetic screening, including some types of kidney disease, cystic fibrosis, and Huntingtons. In the very near future we may be able to detect genetic traits giving rise to an increased risk of hypertension, dyslexia, some forms of cancer, manic depressive illness, Alzheimers, multiple sclerosis, and heart disease.

Once the technology enables us to identify such susceptibilities, there will be a very strong interest and incentive to obtain and use this information, particularly in areas such as employment and insurance. We will be able to identify many genetic traits that will be relevant to common situations like employment and insurance.

The Human Genome Initiative (HGI) is a three billion dollar, 15-year project, that is trying to "map" and "sequence" the human genome to identify the location of a gene on a particular chromosome and its elements. The project may take as long as 15 years, but could take far less time with a leap in technology. Scientists will identify more and more traits that are genetic and will also identify the genes that give rise to those traits. As a result of this, many more new tests will emerge.

### Universal expectation of genetic privacy

Two bodies in Canada have looked at genetic testing, the (now disbanded) Science Council of Canada and the Privacy Commission.

The latter concluded that: *"everyone should have a right to a reasonable expectation of genetic privacy."* People should not be forced to learn of genetic traits and conditions that they do not want to know. They should have a right to remain ignorant of their own genetic traits. This is consistent with current medical practice, where no one is forced to learn of a medical condition. Yet this approach may change over time, as diseases become more treatable and health care more expensive. We can perceive some kind of societal duty on people to find out what is wrong with them genetically. This would represent a massive shift in how we administer health care to force people to get medical check-ups and to take corrective action. Right now the issue is academic, for most of the genetic diseases or traits which we are able to identify, we can not do anything about.

## Genetics and the insurance industry

There is strong interest in genetic testing in the insurance industry. As the tests become less expensive and more accurate, testing for insurance could increase.

The Privacy Commission's genetics report said that for now there should be no testing for conditions that had not been tested for previously. Just because technology allows it, insurance companies should not start testing for a whole new raft of medical traits and conditions. The Commissioner's report requests a moratorium on more intrusive tests to determine access to services until the ethical and moral implications and the impact of the technology are thought through.

## Genetic testing and employment

The Privacy Commission opposes mandatory genetic testing in employment. Testing in employment should be done only with the employee's consent and in order to allow the employee to identify susceptibilities to workplace conditions or contaminants. The employee should have the right: to control the test results and to decide how to respond to the information. Making genetic testing available would help absolve the employers from responsibility for harm caused by workplace conditions.

There appears to be no genetic testing in employment in Canada. In the USA, a recent survey found minimal testing for employment purposes in the US. However, a significant percentage of personnel and medical officers considered genetic testing acceptable and believed the employer, and not the worker, should have the authority to decide whether to test.

In order to determine if an employee or potential employee is at risk of becoming an alcoholic, the employer may wish to test him/her for a gene that increases that risk. The results of such testing could, however, be misleading since for a person to become an alcoholic, other configurations of genes and environmental factors would also need to be present. Yet the employer might interpret the

one test that identifies an increased *risk* as meaning that the employee is *certain* to become alcoholic.

Further, certain genetic traits make individuals highly vulnerable to harm from chemicals such as benzene. It is useful for a worker to know of the danger of working in a factory where these chemicals are used. But should the employer have the right to test the worker and reject him or her on that basis? Although the employer may be doing a favour to the worker by refusing to employ him/her, still, this could be done with fewer intrusions. The employer could simply make this genetic test available to employees to see if they run the risk of being harmed by chemicals in a particular workplace. However, it is an employee/potential employee's decision to work in such environment. The employer has done what he can to inform them of any risks they may face.

Finally, genetic testing could be used to select people who are genetically resistant to harm from workplace chemicals. Thus, instead of reducing the amount of benzene flowing around a factory, it is simpler to hire people who have an unusual tolerance of benzene. Although this may be more economical for a factory, it may make many people "unemployable" in a particular environment. This could especially be a problem in a small town where one factory is the dominant employer.

## Forensic uses of genetic technology

There are several forensic uses of genetic technology:

- in criminal justice, for identifying suspects
- in immigration matters to establish paternity
- in estate matters to establish paternity.

In one UK case, 3,600 men in one town were tested in order to help police solve a murder. The perpetrator was caught, not through his own sample, but because he tried to persuade another man to give a sample for him. The police also used the collected samples to investigate and solve a previously unsolved

rape in the area, despite not having told those who gave the samples of this intended use beforehand.

The Canadian Privacy Commission did not object to forensic DNA analysis to match samples from an accused and scene of a crime. Canadian police are considering a nationwide genetic database, though the Commission has argued it should consist only of genetic records of people who have been convicted of crimes of serious violence. This information could be used to investigate further crimes, helping to show innocence or guilt.

However, not everyone sent to prison should be required to give a genetic sample. Someone who is in prison for white collar crime is not likely to leave a genetic sample at the scene of their next crime. We are really dealing with crimes of violence where blood or body fluids are left at the scene.

#### **Society balances fundamental values**

If the police were to take a genetic fingerprint of every male in the UK, as the Metropolitan Police Commissioner once proposed, they would solve more crimes. But if they were allowed to torture suspects, if they

### **CANADIAN PRIVACY COMMISSIONER CALLS FOR REVIEW OF ETHICAL AND PRIVACY IMPLICATIONS OF GENETICS**

***Bruce Phillips, Federal Privacy Commissioner, Canada, responded in Access Reports Canada, January 1994 to an announcement made in December 1993 by France's Pasteur Institute that scientists have completed a "map" of the human genome - our complement of genes.***

"Genetic technology", says Bruce Phillips, "will now permit a much deeper and more accurate type of enquiry. It will disclose a whole range of genetic traits about which individuals and insurance companies could once only speculate.

Genetic information should be used only to inform a person's own decisions about medical care.....From the individual's perspective, the price for learning one's detailed genetic profile (for valid medical reasons) may be a loss of genetic privacy and a refusal of insurance.

The issue is simply whether insurers should be permitted access to any or all of the highly personal information emerging from developments in genetic science."

Ronald Worton, chief geneticist at Toronto's Hospital for Sick Children and head of the 22 million dollar Canadian Genome and Technology Project, says insurance companies have legitimate grounds for concern. The whole future of the industry could be in jeopardy if accurate genetic testing becomes widely available.

"They couldn't continue to write life insurance policies for people if many of us were able to get a series of genetic tests that told us what our liabilities were.

What will happen then is the people who have the worst possible genetic make-up will be unable to get insurance or it will cost them a fortune. And yet, when you think about it, they're the ones who need it the most."

Charles Black, insurance industry spokesperson has said, "The position of the industry is that since insurance is a good-faith contract, the insurer must have access to all the information that the individual has."

Mr Phillips, the Privacy Commissioner, takes the view that it is time for governments to get involved. "Resolving this issue," he says, "will turn largely on how we view our rights to control genetic information, and the relationship between genetic privacy and insurance."

Mr Phillips has expressed the hope that Mr Oscapella's call for a moratorium on using newly available genetic information, expressed in the following report, will be heeded, to allow time for a thorough review of the ethics and human rights implications.

**Access Reports Canada is published by Harry Hammitt, Access Reports, Inc., 1624 Dogwood Lane, Lynchburg, VA 24503, USA. Tel: +(1) 804 384-5334. Fax: +(1) 804 384-8272.**

were allowed to keep them incommunicado, or not have them represented by counsel, they would also solve more crimes. We make trade-offs in society. Certain state conduct we will not condone. Some people are, therefore, going to escape prosecution, some people who are morally guilty will not be convicted, but we are preserving valuable rights.

Our society has decided not to allow some "efficient" police techniques because they harm other fundamental values. We say we could solve more crimes, but at what cost? Is the problem of violent crime so great, and is genetically fingerprinting the entire male population going to be so useful that it outweighs the privacy intrusion into the lives of tens of millions of innocent people who are not going to be guilty of these crimes?

#### **Need for regulation**

There is a need for improved policies and laws in the private sector dealing with genetics and privacy issues. In Canada, there is virtually no regulation of genetic privacy issues in the private sector.

The response from scientists and other groups to the Privacy Commissioner's genetics report has been favourable, but the Canadian federal government has been quiet and will likely be slow to act. Once the biotech industry gets going, and there are lobbies from the insurance industry, it is going to be very difficult to establish a policy that restricts mandatory genetic testing.

#### **Erosion of privacy does occur**

People are becoming conditioned to giving up their privacy, for example, in the area of drug testing. Yet it is a fundamental step to go from physical surveillance to actually intruding

into the body or taking bodily substances to incriminate people. People say they have nothing to hide. They have nothing to hide but a lot to lose - their privacy.

If you do not collect the information you cannot misuse it. It is preferable to stop privacy abuses from happening by tightly restricting collection and by assuming that some people are going to abuse information if they do collect it.

The biotechnology industry is going to make a great deal of money out of testing. There is such a very strong profit incentive here that it may persuade entrepreneurs to downplay other issues, such as privacy.

We may want our privacy rights - basic human rights - to determine the appropriate uses of technology, rather than having technology determine the extent of our human rights. Yet today it seems that technology is going to determine the extent of our human rights.

**This report was written by Mary Gooderham, a writer on privacy and technology. Eugene Oscapella, principal of E.L. Oscapella and Associates Consulting, Ottawa, Canada, gave a presentation on genetics and privacy at the 10th World Congress on Medical Law held in Jerusalem, Israel in September 1994. Mr. Oscapella is the author of three reports published by the Privacy Commissioner of Canada: Genetic Testing and Privacy, AIDS and the Privacy Act, Drug Testing and Privacy.**

**A fuller version of this report, also covering AIDS/HIV and drug testing, is available from *Privacy Laws & Business* on request.**