A milestone in genetics: A nightmare for privacy?

IN LATE FEBRUARY 2001, scientists published the first drafts of the human genetic code. Despite this milestone, genetic research is still in its early stages. The great bulk of the human genome – the so-called "junk" DNA – has not yet been deciphered.

Genetic information about individuals – personal genetic information – has many current and potential uses: to assist in predicting, diagnosing, treating and preventing health conditions; to assist with reproductive decisions; to decide suitability for employment; to assess the health consequences of exposure to workplace contaminants – for example, radiation; to assess eligibility for services such as insurance and credit; as an identification tool in criminal investigations; to advance medical research; to verify gender in sports competitions; to determine paternity; and to assess the susceptibility of ethnic groups to genetically-tuned biological weapons.

Genetic science therefore holds much promise. It also brings with it many concerns. Among these concerns are the violations of privacy inherent in collecting and analysing genetic material. The possible further consequence of these violations, and the consequence that many fear most, is genetic discrimination – discrimination on the basis of one's genetic "makeup." If present knowledge about human genetics has already led to discrimination, the greatly enhanced knowledge that will occur in future presages even more opportunities to discriminate.

Discrimination may take any number of forms – rejection for employment, or the offer of lesser employment, loss of access to credit or insurance, or access only under extraordinary conditions and at extraordinary expense, and even discriminatory treatment in the application of government social policies relating to reproduction and education. The unwanted collection and release of genetic information may also interfere with personal relationships. A potential marriage partner may reject someone with a genetic risk of contributing to a "defective" child.

Above all, the promise of genetics for improved health and health care may be severely compromised unless privacy and discrimination issues are addressed. For example, a 1998 survey conducted for the US National Center for Genome Resources found that almost two-thirds of the respondents said they probably or definitely would not take genetic tests if health insurers or employers could get access to the results. The possibility that genetic information will be used to the disadvantage of individuals, rather than to help them, may – justifiably – stifle acceptance of further genetic inquiry at a time when a major milestone in understanding genetics – the initial draft of the human genome – has just been reached.

Genetic science has introduced, or at least brought into sharp relief, many issues that touch on privacy.

TENSION BETWEEN THE POTENTIAL BENEFITS AND HARMS OF GENETIC TECHNOLOGY

At present, many benefits of genetic science remain theoretical. However, the misuse of genetic information about individuals has already led to genetic discrimination, sometimes about overt genetic characteristics such as skin colour or gender, and other times about genetic traits discoverable only through testing – sickle cell anemia, for example.

Debate continues about whether genetic information is somehow "exceptional", requiring different, perhaps more cautious and protective treatment than other types of personal information.

THE RIGHT NOT TO KNOW

Respect for individual autonomy can be used as the basis to argue that individuals should not be forced to acquire genetic information about themselves. Such knowledge could be catastrophic – such as learning, against one's wishes, that one has the gene that causes Huntington disease. As well, there is debate whether minors have or should have an equivalent right not to know, or whether their parents or guardians should be permitted to obtain information that the minors themselves might not later want?

SECRET AND PRIVATE TESTING

Individuals may soon be able to identify a number of genetic traits through commercially available testing kits. These kits will inevitably invite the surreptitious testing of others. Even if not used surreptitiously, the very availability of these kits to the general public may encourage misuse – for example, to defraud insurance companies.

DISCLOSURE TO BIOLOGICAL RELATIVES

Test results about a person may identify genetic traits of biological relatives. There is considerable debate about whether a duty or ethical obligation exists on professionals or individuals to share useful genetic information with biological relatives.

DISCRIMINATION ON THE BASIS OF PERCEIVED DISABILITY

Case law and legislation in some countries may extend the protection against discrimination on the basis of disability to cases of perceived genetic disability. However, the extent to which human rights legislation protects against discrimination because of a possible future genetically linked disability remains unclear.

A Residual Right of Genetic Privacy?

Even if legislation, codes, ethical standards and other instruments were to provide generous confidentiality protection, some argue that there is nonetheless a residual right to say "no" to further uses of one's genetic information. This issue is most germane in the context of research.

SPECIFIC AREAS OF CONCERN

Human Reproduction:

Governments will inevitably be drawn to programs that prevent the birth of children with expensive genetic "disabilities." Subsidiary issues also arise, among them how to prevent further dissemination of genetic information acquired by private reproductive clinics, and rights, if any, of children conceived as a result of a sperm or egg donation to learn the identity, or at least the genetic background, of the donor, and the potentially conflicting rights of the donor to confidentiality.

Employment:

Employers may want genetic information about employees or job applicants. If the burden of health care costs is borne by the private sector, employers may become even more interested in hiring only the healthiest employees.

Testing to Determine Eligibility for Services Such as Insurance and Credit:

Genetic information may further separate those who have access to insurance, credit and other services from those who, because of their genetic makeup, do not.

PL&B International Newsletter Associate Editor Eugene Oscapella delivered a report on genetic privacy and discrimination to the Canadian Biotechnology Advisory Committee in October 2000. The report, an expanded version of this analysis, is available online at: http://cbac.gc.ca/documents/Oscapella-English1.pdf. Mr. Oscapella was also the principal consultant to the Office of the Privacy Commissioner of Canada when it published its 1992 report, Genetic Testing and Privacy. This report is available online at: http://www.privcom.gc.ca/information/02_05_11_e.pdf.

Ontario considers private sector data protection legislation

In its April 12th 2001 edition, The Economist carried a major story on the implications of genetic science.

As an example of the growing concerns about genetic privacy, it referred to actions by Burlington Northern, a US railway company. The company had taken blood samples from employees who filed claims for carpal-tunnel injuries. The apparent goal was to determine if they had a genetic disposition to such ailments. The rail workers' union sued, backed by the Equal Employment Opportunity Commission, claiming the railway had violated the Americans with Disabilities Act.

The Economist further reported that only around one in a hundred Americans has a genetic test in any given year. Federal employees have legislative protection against genetic discrimination. Private-sector employees have no federal protection, but 18 states now have laws that limit life-insurers' ability to use genetic tests to reveal people's susceptibility to diseases.

This is odd, says The Economist. Insurance companies are allowed to discriminate on the basis of the gene that is most closely linked to specific diseases and shorter life-spans – the SRY gene that makes people male.