Information
and Privacy
Commissioner/
Ontario

Submission to the Ontario Law Reform Commission

Project on Genetic Testing

Tom Wright
Commissioner
September 1992

Information and Privacy
Commissioner/Ontario

2 Bloor Street East
Suite 1400
Toronto, Ontario
M4W 1A8

416-326-3333
1-800-387-0073
Fax: 416-325-9195
TTY (Teletypewriter): 416-325-7539
Website: www.ipc.on.ca

This publication is also available on the IPC website.

Table of Contents

Introduction 1

Implications of Genetic Testing 2

Privacy and Genetic Testing 3

Conclusions 4

Introduction

The Office of the Information and Privacy Commissioner/Ontario (IPC) welcomes the opportunity to comment on the Ontario Law Reform Commission's Project on Genetic Testing, particularly in regard to the issues of privacy and confidentiality. In conducting a study of the issues surrounding genetic testing, the Ontario Law Reform Commission has a unique opportunity to broaden the discussion of the social, legal and ethical implications relating to genetic testing.

It is becoming increasingly evident that the mapping of the human genome, which will undoubtedly result in enormous benefits in the field of medicine and health care, has raised a variety of concerns, not the least of which are questions involving privacy and confidentiality. A number of organizations in Canada and the United States have already begun to assess the impact that genetic testing could have across a wide spectrum of issues. The Privacy Commissioner of Canada has published a report on genetic testing that makes strong recommendations on how the issue should be dealt with from a privacy perspective. The Office of the Information and Privacy Commissioner/Ontario supports these recommendations and commends the report, *Genetic Testing and Privacy* issued by the Privacy Commissioner of Canada, for consideration by the Ontario Law Reform Commission.

The complex issues surrounding genetic testing have been succinctly summarized in a U.S. Congress report in the following way:

> The impact of genetic testing on privacy is one of the most significant and perplexing issues that society will face, as the availability and use of such testing practices becomes more widespread. If left unregulated, the potential exists for every individual to have his or her genetic code become publicly known. The implications of this possibility was recently characterized as follows:
>
> The routine availability of identifiable genetic information about individuals may have effects that reach far beyond the provision of medical care. As the amount of detailed genetic information grows, society may be required to re-examine the basic principles of health and life insurance, review the rules that govern employment and hiring, reconsider the confidentiality rules that are part of the doctor-patient relationship, and, in general reassess the way in which individuals are categorized and treated in a variety of social and economic relationships.

Implications of Genetic Testing

Genetic testing is already being used for purposes beyond medical research and therapy, for example, to deny individuals employment or insurance. The potential exists that both governments and the private sector will be tempted to test individuals regularly in order to determine their access to benefits and services. Moreover, in the context of criminal investigations, genetic information of an accused is being relied on as part of the evidence used to establish guilt.

How genetic information may be used in the future is raising concerns that a new eugenics movement may emerge, advocating the use of genetic information about individuals and their families in order to select those genes that should be passed on to the next generation. Governments may inadvertently legitimize the practice of eugenics by forcing choices on individuals for the sake of economy and efficiency. As health care costs rise, what pressures will be exerted on individuals to have prenatal testing of fetuses in order to determine “genetic fitness”?

Moreover, there is already evidence that justice authorities in some countries would welcome the development of genetic databanks for the entire population, to be used for identification purposes in the course of investigating crimes. In essence, this would amount to the genetic fingerprinting of the entire population.

Whether any of these potential abuses will come to pass is difficult to predict. However, what is certain is that abuses are more likely to occur if these issues relating to genetic testing are not addressed now. Evidence is mounting that the potential for abuse is real.

Privacy and Genetic Testing

The privacy interest in genetic information arises in several contexts:

- the right not to have one's genetic information collected;
- if the authority to collect exists, the right not to have one's genetic information used for unauthorized purposes;
- the right not to have one's genetic information disclosed to a third party; and
- the right not to know one's own genetic information.

Being in control of one's own genetic information, and being able to determine if and how that information should be collected and used, is the central question from a privacy perspective. Without an autonomous ability to have control over one's own genetic information, the individual could become vulnerable to a variety of adverse consequences that could alter one's life. In this context, the notion of "informational self-determination" as the right of an individual to determine the scope and degree to which he or she will reveal personal information about him or herself, takes on particular significance.

Each individual's genetic code goes to the heart of what he/she "is" as an individual. Much of what makes each individual unique is contained in the genetic code. No information about an individual could be more personal. In the hands of a person or an organization, genetic information could be used in a way that would result in serious limitations being placed on someone's "life chances" or opportunities. Much would depend on the benevolence of those who wield power over the individual.

Canadians can be justly proud of the progress they have made to guarantee civil and human rights, by providing the individual with protection against the arbitrary exercise of power. There are already indications that genetic information may be used in ways that lead to discrimination in employment practices, when, for example, someone is denied a job because she/he may have a predisposition to contract a particular disease.

An individual also has a right *not* to know, or be made aware of, his or her genetic code — the right not to know what genetic imperfections or flaws one may have. In some cases, this knowledge could have serious psychological consequences. Thus, knowledge that one possessed a gene that would predispose the individual to a high probability of contracting a debilitating disease, could prevent that individual from fully enjoying his/her life.

Conclusions

Informational self-determination in the context of genetic information should be safeguarded through appropriate legislative enactments, much the same way as human rights legislation has been adopted and civil rights have been incorporated into the *Charter of Rights and Freedoms*.

The Office of the Information and Privacy Commissioner/Ontario commends the adoption of the following general principles when assessing genetic testing from a privacy perspective:

1. As a general rule, there should be no mandatory testing of individuals.
2. No individuals should be advised of their genetic traits or disorders, absent their consent.
3. Genetic screening or monitoring of individuals in employment situations should be permitted only if the individual volunteers to be tested, and retains complete control over the use and disclosure of the resulting genetic information.
4. No individual should be denied any benefits or services for refusing to undergo genetic testing.
5. The establishment of databanks containing genetic information relating to an entire population should be prohibited.
6. Governments should abide by the principles of the 'Code of Fair Information Practices' as entrenched in Ontario's *Freedom of Information and Protection of Privacy Act* and *Municipal Freedom of Information and Protection or Privacy Act*, when collecting, retaining, using, and disclosing genetic information in their custody and control.

Lastly, the IPC concurs with Recommendations 21 and 22 of the *Genetic Testing and Privacy* report, namely:

> The federal government should explore, with the private sector and with other levels of government, the implementation of policies or laws to improve privacy protection in the private sector.
>
> Federal and provincial governments and the private sector should work towards the following:
>
> a) including explicit privacy protection in the form of a right to privacy, in the *Charter of Rights and Freedoms*;
>
> b) reviewing the *Privacy Act* (in Ontario, the *Freedom of Information and Protection of Privacy Act* and the *Municipal Freedom of Information and Protection of Privacy Act*), and strengthening its provisions;

c) introducing legislation to regulate specific aspects of genetic testing, such as forensic DNA analysis;

d) legislating and/or adopting policies, federally and provincially, to regulate private sector intrusions into genetic privacy; and

e) fostering respect for genetic privacy.

Information and Privacy
Commissioner/Ontario

2 Bloor Street East
Suite 1400
Toronto, Ontario
M4W 1A8

416-326-3333
1-800-387-0073
Fax: 416-325-9195
TTY (Teletypewriter): 416-325-7539
Website: www.ipc.on.ca