Dangerous curiosity: genetic testing by employers, police, insurers and governments

"No insurer should be able to use genetic data to underwrite or discriminate against any American seeking health insurance. This should not simply be a matter of principle, but a matter of law, period," announced US President Bill Clinton, in May this year.

In this forthright report, Eugene Oscapella claims that the unregulated collecting of genetic data in the insurance industry, for employment purposes and in criminal investigations, will inevitably be widely abused.

Uses of genetic information

Genetic information has many current and potential uses beyond those relating to the health care of the individual to whom the information relates:

- determining access to employment,
- determining access to insurance and other services, such as credit and schooling,
- decisions related to human reproduction,
- to help solve criminal investigations, and
- medical research.

Few people would object to making genetic information available to a consenting adult for decisions relating to personal medical care. But how many would accept it as a vehicle for determining eligibility for employment, insurance, schooling, or having a family? Some might question research involving genetics, since the knowledge acquired can also lead to harm.

Not only Luddites should worry about genetic technology and the information it generates. The highly sensitive information generated by genetic testing must be guarded jealously if the technology is to be used for the good of the individuals to whom it relates and not to their detriment. Unfortunately, many signals today point to the increasing use of genetic information for purposes that have nothing to do with the health or well-being of the individual to whom the information relates. In fact, many current and prospective uses of genetic information will work against the welfare of the individuals to whom the information relates.

Drugs - a model for genetic testing?

This viewpoint may seem unduly pessimistic. However, our ongoing flirtation with another form of biological testing - drug testing - and the ever-increasing thirst of the state and the private sector to intrude into the lives of individuals gives rise to considerable doubt that genetic technology will be used beneficially, or even benignly.

Drug testing - the testing of individuals to see if they have consumed certain drugs that our government has arbitrarily decided to call "illegal" - has taught us that you don't need a valid, scientific reason, for intruding into the body of an individual. This extraordinary procedure is touted as the way to make our society virtuous, noble, efficient and drug-free. Through drug testing, parents are encouraged to spy on children, employers to spy on employees, and governments to spy on citizens. Yet in fact, drug testing accomplishes none of these lofty goals of virtue, nobility, efficiency, and freedom from drugs.

Unprincipled McCarthyist drug testing is paving the way - and laying down the red carpet - for unprincipled genetic testing. We have begun through drug testing to institutionalise the right of the state, employers and service providers to ignore the fundamental human right of privacy. If you can justify drug testing on the flimsy justifications now being advanced, you can easily justify a state or employer interest in genetic information about individuals under their control.

With drug testing we have also seen the power of the profit-thirsty biotechnology industry to persuade ill-informed employers, parents and governments to test. Drug testing is a big business, regardless of its lack of utility, just as genetic testing of certain groups (employees amongst them) may become big business, despite its lack of utility in many circumstances.

Genetic data abuses

Let me give you some examples of how genetic information has been or could be used to harm the individual to whom it relates.

a) Genetic testing for sickle-cell trait in the 1970s may have been used in part to cloak racial discrimination with an air of respectability, since the trait appeared most frequently in people of African or Mediterranean origin.

b) Throughout much of this century, even in the so-called democratic countries, mentally deficient individuals or those with "undesirable" genetic traits as determined by the government of the day, have been sterilised or killed; ethnic cleansing, an excuse for murder, could be much more "efficient" if those in power have the genetic "goods" on everyone.

The pressure is growing to expand uses of genetic information, even within the same category of use - for example for forensic databases. In the US and Canada, some groups are bringing pressure on the government to expand DNA collection in criminal investigations so that anyone merely charged with a criminal offence - whether DNA is relevant to proving the offence or not - will be required to submit a DNA sample. In other cases, the very existence of genetic databases assembled for one purpose (e.g. PKU)[2] screening may tempt governments to use them for completely unrelated purposes.

Intruding on genetic privacy

The dynamic that will promote the expansion of genetic testing and the expanded uses of genetic information is twofold: money and power - money to be made by the biotechnology industry by persuading employers, governments and service providers that genetic testing is necessary to create a better, more profitable, more law abiding, more efficient society; power in the hands of those who have access to genetic information. The same dynamic will hold for genetic testing as now holds for drug testing and a myriad of other privacy intrusions. People stand to make a great deal of money, and gain a great deal of power, by intruding on genetic privacy.

Most chilling is the almost deafening silence from many governments when they are asked to protect the individuals from assaults on bodily integrity. We have seen little action - none in Canada - by government against drug testing. And the only legislation in Canada to date that has dealt specifically with genetic information is a law allowing the state to intrude and collect genetic information for criminal investigations.

Despite these pressures to use and expand the uses of genetic information, there is little legislation to protect against the misuse of that information and the abuse of the right to privacy.

My fear about genetic testing is that it will inevitably be misused - that its use will extend beyond the confines of individual medical care and become a vehicle for governments, service providers and employers to control others. It will become a vehicle to engage in massive discrimination, all the while basing this discrimination on "science."

Insurance and genetic information

The potential use of genetic testing for insurance has been of concern to privacy advocates in Canada for several years. However, there has been virtually no legislative action specifically to protect genetic information. Private sector data protection laws exist only in one province - Quebec. Laws protect the confidentiality of medical information in the health care setting, but these protections may not be sufficient to prevent the misuse of genetic information.

One must, however, acknowledge the damage that genetic information can do to the insurance industry if only one part has access to it. A person who knows that he or she has a particular genetic disability, when the insurance company does not, can use that knowledge to the detriment of the insurer. If this process of "adverse selection" occurs sufficiently often, it will undermine the private insurance industry, with possible harmful consequences to the whole of society.

In his 1992 study, *Genetic Testing and Privacy,* the Privacy Commissioner of Canada discussed the possible consequences flowing from the disclosure of genetic information to insurers and other providers of services:

- Genetic testing may provide more extensive information about persons applying for services or benefits than their [service] providers have been able to obtain to date. Should the providers use the deep-probing abilities of genetic testing to impose more stringent conditions on access to services?

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[2] Phenylketonuria (PKU) is a disease caused by lack of an enzyme which can be avoided by placing the person on a special diet early in life.

- The temptation will surely grow, particularly among cost-and-profit-conscious service providers, to use genetic technology to introduce additional hurdles before giving services or benefits. As test costs fall, their accuracy increases, and the amount of information they can reveal grows, the temptation to test will grow still further.

The report called for a moratorium by service providers on collecting new types of information that have become available through genetic testing.

In recommendation 5 the report says:

"As a general principle, there should be no denial of services or benefits to a person who refuses to undergo genetic testing to obtain a service or benefit. The person should be permitted to provide justifiably required information through testing other than genetic testing."

The report also adds:

"Even if the [service or benefit] provider can legally collect [genetic] information, no new types of information should be collected through genetic testing without a thorough review of the ethics and human rights implications of the additional collection."

"Why hire a job applicant who may have a genetically determined sensitivity to harm from contact with benzene, and be forced to make the factory safe for him or her?"

Balancing insurance industry and privacy interests

A 1996 report, *Genetics in Life, Disability and Additional Health Insurance in Canada*, prepared for the Canadian Genome Analysis and Technology Programme (CGAT), suggested two ways to balance the insurance industry's needs with privacy interests.

1. Guaranteed minimum insurance. A basic amount of insurance would be available to everyone after a minimum waiting period, with no restrictions on access. Medical information would not be required to determine eligibility for such insurance. For larger amounts of insurance, access by insurers to medical, including genetic, information would be permitted, but insurers themselves would not be allowed to impose genetic testing to obtain insurance.
2. The second possible insurance system would prohibit insurers from using medical information, including information about family members, in underwriting insurance policies. Insurers could, however, develop a list of specific high-risk diseases. If a person died from one of these diseases, insurance coverage would be limited. This system has the advantage of not requiring the individual to disclose medical information, no matter what amount of insurance is being sought.

The report recommended that the details and feasibility of these systems should be determined by a working group of representatives from government, insurance companies, scientists and patient interest groups.

The report also recommended that:

- Provincial privacy laws or insurance laws should provide additional protection of genetic and other medical information.
- If insurers need access to medical information, provisions should specify how to gain access and what information would be accessible.
- Consent from insurance applicants should be requested for re-disclosure to third parties.
- Information should be used strictly to evaluate individuals, not their families. Individuals should not have their insurability affected by information about family members.
- Furthermore, they should not be informed, through insurance, about their genetic risks.

Employment

Genetic testing has not been widely used in employment to date. Still, there have been examples from the 70's where people were denied employment because of the results of genetic tests - notably sickle cell anaemia. (Some will argue, correctly, that readily visible genetic traits have nonetheless long been a factor in employment decisions - for example race and gender).

Should your genes determine your employability? Why hire a job applicant who may have a genetically determined sensitivity to harm from contact with benzene, and be forced to make the factory safe for him or her? Why not simply pick a more genetically robust employee from society's collective gene pool? Why hire someone who may be at even an ever-so-slightly increased genetic risk for manic-depressive illness, alcoholism or early onset heart disease, when you can simply screen that person out of your employee roster?

Selecting the genetically fittest sounds somewhat like Darwinism - and therefore almost justifiable in a business environment premised on the survival of the most efficient. However, such a selection process is also profoundly Orwellian.

If our present willingness to embrace uncritically even the most intrusive technologies serves as the precedent, Orwell is sure to win out. We have embraced surveillance cameras in public and private spaces, massive databases of personal information, extraordinary police and other state powers - all with little resistance, all with little attempt to compel those who would use such technologies and powers to justify their use. The level of intrusion associated with Orwell is now part of everyday lives. Genetic testing in employment is just one more chapter in the surveillance book.

Genetic testing - for whose benefit?

Employment decisions are increasingly based on batteries of tests. Employee activities are being monitored through workplace cameras, remote surveillance of computer use, monitoring of e-mail and telephone conversations. Drug testing, one of the most unjustifiable intrusions yet introduced into the employment relationship, has nonetheless taken firm hold in North America. It has been led, not by science, but by the clever marketing of drug testing companies and by their empty assurances that testing will make the workplace safer, increase employee productivity and weed out bad sorts from the office or factory floor.

We should, therefore, not be surprised to see the same dynamic eventually at play to bring genetic testing into the employee selection process. Bio-technology companies stand to make enormous profits by persuading employers that genetic testing will improve the bottom line - whether or not evidence exists that it will do anything of the sort.

In his 1992 report, *Genetic Testing and Privacy*, the Privacy Commissioner of Canada concluded that he had found no employment situation that warranted the compulsory collection of genetic information by employers about employees. Without compelling arguments to the contrary, genetic testing for the benefit of the employer was inappropriate. Even in their employment lives, Canadians should have a "reasonable expectation of genetic privacy."

However, the Privacy Commissioner would not prohibit all employment-related genetic testing. Testing done for the employee's benefit - for example, to see if the employee has a genetic trait that might increase the danger of working in a particular environment - should be allowed, but the results of any genetic test would not be made available to the employer. The employee would receive the results and decide, as many employees now do in assessing other factors when they look at a particular job, whether they should take the risk of working in that environment.

Unfortunately, the Privacy Commissioner's recommendation to prohibit genetic testing for the benefit of employers has fallen on deaf ears.

Criminal investigations

In 1995, Canada's Parliament enacted legislation allowing DNA samples to be taken without consent from certain individuals suspected of criminal offences - generally offences involving serious violence against others. Those samples would be used to determine whether the suspect had in fact committed the specific offence being investigated. The Privacy Commissioner of Canada gave cautious support to the legislation, and to the Federal government's announced intention to establish a database containing DNA identification information about convicted offenders. However, the Privacy Commissioner opposed retaining the actual genetic samples taken from convicted offenders. His privacy concerns related to taking samples from convicted offenders, would be satisfied only if three major conditions were met:

1. The legislation would be reviewed within 3 to 5 years of its enactment, and that the

review would include a privacy audit, to determine the extent to which the intrusion involved in creating a database has been justified by an increase in the number of violent crimes solved through DNA evidence.

2. DNA samples would be taken only if:
   a) the person from whom the DNA was taken had been convicted of a violent offence
   b) the crime for which the person had been convicted had more than a minimal rate of repeat offending (people convicted of some crimes have a very low rate of repeat offences, so there would be little value in keeping the person's DNA profile, since their future crimes would be unlikely)
   c) there was more than a remote possibility that the offender would leave his or her genetic material at the scene of a crime if committing a subsequent offence.
3. The DNA samples themselves would be destroyed after identification information was extracted from them. Thus, only the analysis would remain on police files.

The purpose of performing a DNA analysis on samples taken from convicted offenders is to enable the police to solve unsolved crimes. This can be done without preserving the actual sample. Even if today's legislation proposes safeguards to prevent the misuse of the samples, tomorrow's legislation can easily change the rules.

The policy makers behind the DNA databank legislation had a choice. They could have chosen to introduce the least intrusive measures to give them the information they needed for forensic DNA identification, or they could have used the most intrusive measures. They chose the latter, involving the storage of DNA samples themselves.

In light of the serious privacy intrusion involved in the state digging into our bodies, it makes more sense first to use the least intrusive means - storage of identifying information only. If keeping the information only proves an unnecessary limitation on investigations, this can be addressed when the legislation is reviewed. On the other hand, if the most intrusive measure was adopted first, we will have no way of knowing whether that level of intrusion was necessary in the first place. And few of us would expect the state to surrender a power once it has acquired it.

Recommendations for change

Among the many measures that can be taken to protect genetic information from improper collection, use and disclosure are the following:

1. **Strictly control** the non-medical secondary uses of genetic information, and as far as possible, keep governments and the private sector out of the business of collecting and using genetic information. A genetic sample collected for one purpose - medical care, for example - must not be made available for any other unrelated purposes.
2. Make privacy protection **proactive**, not dependent on people making complaints. Legislation should establish a minimum standard of behaviour by all those otherwise in a position to abuse the privacy of individuals - governments, employers, service providers.
3. In insurance, **eliminate underwriting** for basic amounts of insurance. This would prevent HIV, drug and genetic testing and access by insurance companies to other sensitive medical information, yet still be fair to the insurance industry.
4. **Strictly control the dissemination of personal information across borders** where the information could be misused by governments that do not sufficiently protect genetic information.
5. **Ban genetic testing in employment,** except where the employee requests it. Even then the employee, not the employer should have the right to determine who can see the results of any genetic test.
6. **Carefully limit the collection** of genetic information in the first place. What has not been collected cannot be misused or improperly disclosed.

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