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## **GENETIC PRIVACY AND DISCRIMINATION**

**An Overview of  
Selected Major Issues**

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THE LAW  
FOUNDATION  
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# Genetic Privacy and Discrimination

## An Overview of Selected Major Issues

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## Introduction<sup>1</sup>

Like advances in many fields, those involving genetics bring both benefits and dangers to society. Among the promised benefits is the ability to identify health issues earlier than is now the case and to improve the prospects of successful prevention or treatment. In addition, forensic applications of genetic technology in criminal investigations have proven a powerful tool to help convict offenders and to prove the innocence of those suspected or wrongfully convicted of serious crimes.

One of the most significant dangers of genetic technology lies in its ability to provide extensive and highly sensitive information about individuals to governments and other organizations. A loss of control over this information can diminish individual freedom. This information can, or could one day, limit opportunities in employment, schooling and insurance matters, and even in decisions about reproductive choices. And there is a persisting danger that too ready reliance on genetic “discoveries” can lead to injustice through labelling individuals according to their supposed genetically-determined traits – for example, an alleged genetic propensity to anti-social behaviour.

Loss of control over personal genetic information not only opens individuals, but also their biological relatives and even, in some cases, their ethnic communities to increased risk of discrimination. The potential to use genetic information against the interests of individuals may discourage them from seeking that information for their own benefit – for example, to determine the likelihood of acquiring a particular disease or the most appropriate course of treatment. Attaining one of the primary stated goals of genetics – improved human health – may become all the more elusive because individuals may fear that genetic information will be used to their detriment. One report described this as the “unfortunate irony of genetic testing”:

[T]he promise of advances in genetics for improved health and health care may be compromised by the fear of discrimination. Genetic testing for purposes of improved health or reproductive decision-making may be avoided for fear that test results will be disclosed to insurers and employers. Rather than a major medical breakthrough that may in time be able to prevent, treat or even help cure some of the genetic diseases, genetic information may be viewed as a personal, familial and societal disadvantage.<sup>2</sup>

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<sup>1</sup> The author wishes to thank BCCLA Policy Director Micheal Vonn and intern Martin Twigg for their valuable advice and assistance.

<sup>2</sup> University of Toronto, Faculty of Law, *Genetic Information and the Law: Issues in the Insurance and Employment Settings: A Report* (May 20, 2005) at 2: [www.law.utoronto.ca/documents/Lemmens/Genetic%20Information%20and%20the%20Law.pdf](http://www.law.utoronto.ca/documents/Lemmens/Genetic%20Information%20and%20the%20Law.pdf); cited in Jo Anne Watton, *Fighting Genetic Discrimination in Canada* (December 16, 2009), in GeneWatch: [www.councilforresponsiblegenetics.org/GeneWatch/GeneWatchPage.aspx?pagelid=229](http://www.councilforresponsiblegenetics.org/GeneWatch/GeneWatchPage.aspx?pagelid=229).

A December 2011 presentation about the BC Personalized Medicine Initiative (BCPMI) highlights both the promise and the dangers flowing from the use of personal genetic information.<sup>3</sup>

The presentation identified “personalized medicine” as involving “an individualized approach to care based on the unique genetic and molecular makeup of every individual and the molecular nature of their disease.”<sup>4</sup> The presentation continued that personalized medicine would result in a “dramatically improved ability to predict, diagnose, treat and monitor disease.”<sup>5</sup> According to the presentation, this also offered other benefits: reduced per capita costs, better population based health care delivery and improved patient and provider care experience.<sup>6</sup>

All this sounds very promising from a public health perspective. However, there is a downside to the collection of genetic information about an entire population – the potential for loss of control by individuals over what can be highly sensitive personal information. For example, the presentation contained a slide with the caption, “I have my genome on my iPhone.”<sup>7</sup> To a reader concerned about privacy, this caption might also serve to highlight the concern about who else might have access to that individual’s genome – and what uses they might envisage for it beyond advancing individual and public health.

The BCPMI presentation made no specific mention of privacy or confidentiality – clearly, two significant issues when dealing with this information. Under the heading “Next Steps,” it did speak of “establishing public policy for personalized medicine.”<sup>8</sup> It later described this process as establishing “policies and practices in personalized medicine informed by engaging the public through deliberative democracy.”<sup>9</sup> Clearly, a discussion of measures to protect personal genetic information must be a significant component of this public policy discussion.

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<sup>3</sup> Pieter Cullis, David Huntsman, Michael Hayden, Bruce McManus, Michael Burgess, “Personalized Medicine Initiative,” Slide presentation, December 6, 2011: [www.sfu.ca/vpresearch/docs/BCPMI%20Presentation%20at%20SFU%20-%20December%206th,%202011.pdf](http://www.sfu.ca/vpresearch/docs/BCPMI%20Presentation%20at%20SFU%20-%20December%206th,%202011.pdf). See also the description of the BCPMI on the Simon Fraser University website: [www.sfu.ca/vpresearch/bcpmi.html](http://www.sfu.ca/vpresearch/bcpmi.html).

<sup>4</sup> *Ibid.*

<sup>5</sup> *Ibid.*

<sup>6</sup> *Ibid.*

<sup>7</sup> *Ibid.*

<sup>8</sup> *Ibid.*

<sup>9</sup> *Ibid.*

The promise of genetics for improving the health of individuals has been realized only in part to date. Ironically, the dangers of advances in genetics technology seem much closer to being realized. One of the most compelling examples comes from the United Kingdom (UK). Over the past decade and a half, DNA samples and profiles<sup>10</sup> of more than a million innocent individuals have been added to a national DNA database designed to facilitate matching DNA found at crime scenes with suspects. Intrusive collections of DNA have become the norm in UK police investigations. Only recently, and only in part, has the UK taken steps to change this.<sup>11</sup>

This paper briefly surveys the potential harms, including privacy violations and discrimination, flowing from several current and potential uses of genetic technology. It is beyond the paper's scope to examine these issues in depth. That could easily warrant a major thesis for each issue. The goal instead is to highlight issues that may warrant more comprehensive research, legislation or policy change. The paper concludes with several recommendations governing forensic DNA analysis in criminal investigations and genetic testing in employment and insurance matters.

This paper does not examine uses of genetic technology that relate primarily to relationships within families. For example, it does not examine issues arising when couples decide to undergo premarital genetic testing to determine their "genetic compatibility" for having children together, or a father who secretly tests his children to see if they are his biological offspring, or parents who have their children tested for genetic traits that may portend disease in adult life. These are significant issues, but they are primarily family issues. This paper instead focuses on important examples of two aspects of genetic privacy:

- those involving the relationship between the state and individuals – in particular, forensic DNA analysis in criminal justice matters; and
- those involving the relationship between the private sector and individuals (such as employer testing of employees or insurance company testing of insurance applicants or obtaining access to test results).

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<sup>10</sup> Parliamentary Office of Science and Technology, Postnote, "The National DNA Database", February 2006, Number 258: [www.parliament.uk/documents/post/postpn258.pdf](http://www.parliament.uk/documents/post/postpn258.pdf).

<sup>11</sup> In February 2011, the *Protection of Freedoms Bill (HL Bill 99)* was introduced in the British House of Commons. The Bill, undergoing review by the House of Lords at the time of writing of this report, changes many rules about retaining DNA and DNA profiles in criminal matters. These changes should greatly reduce the number of DNA profiles of innocent individuals kept in the National DNA Database. Legislation to remedy some of these problems was also enacted by the previous Parliament, but never implemented.

The paper reviews selected Canadian and foreign legislation on those uses of genetic technology. Until recently, Western countries had generally enacted little legislation dealing *specifically* with genetic privacy and discrimination. However, over the last few decades the list of laws and proposed laws applying specifically to genetics has been growing, particularly in three areas – insurance, employment and criminal forensics.

In Canada, apart from criminal legislation on using DNA in criminal investigations, most provisions relevant to genetic privacy and genetic discrimination are found in laws of more general application. These include the *Canadian Charter of Rights and Freedoms*, laws and codes governing professional confidentiality, data protection (privacy) and human rights laws, statutory torts, and the criminal law (protections against physical intrusions). Many of these general laws were drafted before genetic technology was sufficiently advanced to make genetic privacy and discrimination an issue. Still, these laws provide a substantial, if incomplete, legal framework for addressing some genetics issues.

Since advances in genetics potentially affect all Canadians, this paper is intended for a broad readership, not merely for specialists in law and genetics. All Canadians deserve to be able understand what those advances mean for them.

## **The Nature of Genetic Information**

The ARCTIC (Assessment of Risk for Colorectal Tumours in Canada) project web site describes the key features of genetic information:

**Identifying:** Genetic information is identifying not only on an individual level but a familial (and parentage) level as well.

**Ubiquitous:** Identity and genetic status can be gathered from a small amount of material and is permanent rather than transitory information.

**Longevity:** Genetic samples and data can be kept for indeterminate and unprecedented periods of time. Allows for infinite access (theoretically) and use and re use (test and re test) as technology and scientific understanding develops.

**Predictive:** The high predictive value of genetic information tends to be for clearly inherited, high penetrance, single gene disorders. Genetic information is less precise when predicting future health. Genetic information tends to be more about possibilities than certainties because only a proportion of people with a particular disease related mutation will go on to develop the disease.

**Individual and familial nature:** Although some genetic mutations arise spontaneously and can be regarded as truly individual, most genetic information flows between generations. These implications may extend beyond the family to larger groups of closely linked people with common ancestry, for example, indigenous, ethnic or ethno-religious communities.

**Shared Information:** Especially in the clinical setting, genetic information as shared information affects who may be regarded as the 'patient' since it may be the individual as well as the family. This raises unique challenges for individual autonomy and consent as well as the duty to warn and the right not to know.

Shared information is not only important within families but within communities and populations as well. Harm may arise by virtue of being part of a particularly vulnerable group or targeted research community, especially where the group or community has a noted vulnerability toward a particular genetic condition. The issue of consent and group consent remains important.

**Informational risks:** Genetic information may put individuals, families and communities at risk of discrimination and stigmatization especially in the context of employment and insurance, since it has the ability to uniquely reveal those who are asymptomatic or predisposed to disease, but who are not (and may never become) ill.

**Symbolic meaning:** Although bodily parts, especially the heart, brain and blood may have symbolic significance, genetic information tends to be regarded as particularly symbolic in part due to its social perception as a human blueprint representing the essence of life.<sup>12</sup>

These characteristics of genetic information lead some to conclude that one's genetic information is somehow "exceptional" personal information and that this warrants special rules governing its collection, use and disclosure. Certainly, as technology and science advance, there may be an increase in the volume of highly sensitive information available through DNA analysis. On the other hand, non-genetic information can also be highly sensitive. Some therefore argue that adequate privacy and anti-discrimination protections should extend to all such information, genetically based or not.

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<sup>12</sup> ARCTIC Research Group, *Genetic Information, Privacy & Biobanks: Features of Genetic Information*: [www.law.utoronto.ca/healthlaw/ARCTIC/info\\_features.html](http://www.law.utoronto.ca/healthlaw/ARCTIC/info_features.html). The web site describes the ARCTIC project as "working to develop a predictive test for colon cancer susceptibility that can be incorporated into population based screening tests."



The debate about the character of personal genetic information – that is, whether it is exceptional or not – remains unresolved. Is this information somehow exceptional, or at least exceptionally sensitive, demanding special care that is not warranted of other personal information? The special treatment of genetic information in some United States (US) and UK legislation suggests that it is exceptional, while the lack of specific legislation in Canada in employment and insurance matters suggests that genetic information is more likely to be viewed like other personal information: some genetic information will be seen as sensitive, other genetic information will not. A person’s health record may, for example, indicate that the person has a particular cancer. That is not genetic information (although some inferences about one’s genetic makeup might be drawn from the fact of having the cancer), yet this information is likely to be highly sensitive in both employment and insurance matters. Genetic information, on the other hand, might be relatively benign – information about eye colour and other readily observable traits, for example.

## Public Opinion about Genetics

### Canada

The Privacy Commissioner of Canada recently identified genetic privacy as one of four strategic priorities that will help guide policy, research, public education and investigative work of her office “in the coming few years.”<sup>13</sup>

In March 2009, the Privacy Commissioner received the results of a survey commissioned by her office to examine genetic privacy issues.<sup>14</sup> Just over half of the survey’s respondents concluded that genetic testing raised privacy issues.<sup>15</sup> Those who said they were concerned about genetic

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<sup>13</sup> See, for example, the following speeches by Jennifer Stoddart, Privacy Commissioner of Canada: “Remarks at the GE3LS Series: Online Direct to Consumer Genetic Testing,” June 29, 2010, Ottawa, Ontario: [www.priv.gc.ca/speech/2010/sp-d\\_20100629\\_e.cfm](http://www.priv.gc.ca/speech/2010/sp-d_20100629_e.cfm) and “Privacy Preoccupations: The policies and practices of the Office of the Privacy Commissioner of Canada: Remarks to the Public Sector Executive Network,” January 26, 2010, Ottawa, Ontario: [www.priv.gc.ca/speech/2010/sp-d\\_20100126\\_cb\\_e.cfm](http://www.priv.gc.ca/speech/2010/sp-d_20100126_cb_e.cfm). The Privacy Commissioner’s Office also did substantial work on genetic testing and privacy almost two decades earlier. It produced a report, *Genetic Testing and Privacy*, in 1992: [www.priv.gc.ca/information/02\\_05\\_11\\_e.pdf](http://www.priv.gc.ca/information/02_05_11_e.pdf).

<sup>14</sup> Ekos Research Associates, Inc., *Canadians and Privacy: Final Report*, March 2009: [http://priv.gc.ca/information/survey/2009/ekos\\_2009\\_01\\_e.cfm#sec4\\_8](http://priv.gc.ca/information/survey/2009/ekos_2009_01_e.cfm#sec4_8).

<sup>15</sup> *Ibid.*

privacy were asked to identify the specific privacy issues of concern to them.<sup>16</sup> About three in ten could not specify any particular concern. Of those who did provide a response, almost one in five mentioned confidentiality and privacy of information, and a further twelve per cent were concerned that genetic test results might be used for unintended purposes.<sup>17</sup> Slightly more one in ten feared that genetic information might affect insurance coverage.

Respondents were asked whether they supported or opposed health insurance companies using genetic testing results to determine who is insurable and at what premiums. Over two-thirds opposed such a use and only one in ten supported it.<sup>18</sup>

On testing in employment situations – to determine hiring and promotion – the survey showed even greater opposition. More than eight in ten respondents opposed such practices.

## United States

In 2008, a Congressional Research Service report noted that there had been few legal cases of genetic discrimination, but that public fear of discrimination was “substantial.”<sup>19</sup> This fear was a “negative influence” on the “uptake of genetic testing and the use of genetic information by consumers and health professionals”:

[The Secretary’s Advisory Committee on Genetics, Health and Society] ... learned that 68% of Americans are concerned about who would have access to their personal genetic information; 31% state this concern would prevent them from having a genetic test; and 68% agree that insurers would do everything possible to use genetic information to deny health coverage. A 2004 survey conducted by the Genetics and Public Policy Center found that 92% of Americans oppose employer access to personal genetic information and 80% oppose access to this information by health insurers.<sup>20</sup>

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<sup>16</sup> *Ibid.*

<sup>17</sup> *Ibid.*

<sup>18</sup> *Ibid.*

<sup>19</sup> Congressional Research Service, Report for Congress, *Genetic Information: Legal Issues Relating to Discrimination and Privacy* (updated March 10, 2008; Order Code RL30006) at 4.

<sup>20</sup> *Ibid.*

A study released in January 2011 found greater concern than ever about genetic privacy in the US.<sup>21</sup> However, the results also showed a broad lack of awareness of the *Genetic Information Nondiscrimination Act of 2008* (GINA), a federal law designed to protect Americans from discrimination by health insurers and employers due to differences in their DNA that may affect their health.

A representative of the company that conducted the survey suggested that Americans could see the promise of genetic testing and were very interested in it. However, “they say, “That’s kind of a scary prospect, getting my genetic information, having it be in my medical record, and then not knowing who might get access to that information.””<sup>22</sup> The representative noted that the survey identified an increase in interest in genetic testing among those who were unaware of existing legislative protections “[if they] were assured by law that no one could access ... [their] information ... And actually 64% of the people who were unaware of the protections said that they would be more interested, and 34% of them said they would be much more interested.”<sup>23</sup>

## United Kingdom

In 2000, the UK Human Genetics Commission began a major public consultation on the future uses of personal genetic information. It also commissioned a survey on people’s attitudes and reported its findings in 2001. Several of the relevant findings follow:

- There was “broad support for the advances becoming available through the responsible use of human genetic information”;
- Half of the respondents feared that the release of their genetic information to others would enable those other to “know too much” about the respondents;
- There was public support for using genetic information “to improve the diagnosis of diseases, to develop targeted drugs, and to better understand people’s susceptibility to certain diseases;”
- More than nine out of ten respondents thought genetics “should be used to identify or eliminate possible offenders” in police investigations. Support was strongest for the police taking DNA samples from “people charged with murder or sexual offences”. Respondents also saw taking samples from those charged with burglary or drunk driving as appropriate.

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<sup>21</sup> Council for Responsible Genetics, “Genetic Privacy Worries on the Rise By CRG staff - Interview with Christy White, Cogent Research”: [www.councilforresponsiblegenetics.org/GeneWatch/GeneWatchPage.aspx?pageId=324&archive=yes](http://www.councilforresponsiblegenetics.org/GeneWatch/GeneWatchPage.aspx?pageId=324&archive=yes).

<sup>22</sup> *Ibid.*

<sup>23</sup> *Ibid.*

- A majority thought it inappropriate for the police to take DNA samples from those charged with fraud and shoplifting;
- Opinion was “evenly split” about whether such samples “should be retained on the police genetic database after an individual has been acquitted”;
- Only one in six felt that “others, such as social researchers, should be permitted access to the police genetic database”;
- There was “considerable concern about how employers might use human genetic information. Seven in ten think it is inappropriate for an employer to see the results of an existing or potential employee’s genetic test that determines whether they are prone to an inherited disease or disability. Half think it inappropriate for an employer to see employees, or potential employees, test results to determine whether they may become a risk to colleagues or members of the public they come into contact with in their job. Respondents do, however, feel it is appropriate for employers to have access to information that indicates whether or not employees or potential employees may be sensitive to certain substances they may come into contact with in their job;”
- Respondents did not want insurance companies to “be able to ask to see the results from genetic tests to assess premium levels.” However, for policies with a more direct relationship to an applicant’s health, respondents were more likely to consider that it would be appropriate to provide this information to insurance companies;
- Seven out of ten had “little or no confidence that the rules and regulations are keeping pace with new research developments.”<sup>24</sup>

Collectively, these surveys show a need for further public education about the implications of genetic technology, about existing protections for genetic information and about gaps in that protection. They also in some cases show clear support for using the technology to improve health and help solve crimes, but a general reluctance to see its use in employment and insurance.

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<sup>24</sup> Human Genetics Commission, *Public attitudes to human genetic information: People’s Panel Quantitative Study conducted for the Human Genetics Commission* (March 2001) at 5-7: [www.hgc.gov.uk/UploadDocs/DocPub/Document/morigeneticattitudes.pdf](http://www.hgc.gov.uk/UploadDocs/DocPub/Document/morigeneticattitudes.pdf).

## Specific Applications of Genetic Technology

### Forensic DNA analysis in Criminal Investigations

Forensic applications of genetic technology in criminal investigations are among the better known uses of genetic technology.

In a 2006 Supreme Court of Canada decision, *R. v. Rodgers*, Justice Charron spoke both of the importance of forensic DNA evidence and of its threat to privacy and security of the person:

There is no question that DNA evidence has revolutionized the way many crimes are investigated and prosecuted. The use of this new technology has not only led to the successful identification and prosecution of many dangerous criminals, it has served to exonerate many persons who were wrongfully suspected or convicted. The importance of this forensic development to the administration of justice can hardly be overstated. At the same time, the profound implications of government seizure and use of DNA samples on the privacy and security of the person cannot be ignored. A proper balance between these competing interests must be achieved within our constitutional framework.<sup>25</sup>

DNA can be useful in some criminal investigations, particularly those involving violent crimes and “break-and-enter” offences, where the offender may well leave DNA at the scene of the crime. A December 2011 update about Canada’s National DNA Data Bank identified 20, 933 “offender hits - crime scene to offender.”<sup>26</sup> It reported 2,658 “forensic hits - crime scene to crime scene,”<sup>27</sup> an indication that the same person was involved in two or more crimes.<sup>28</sup>

However, taking a DNA sample is physically intrusive. Justice Lamer, in a 1987 Supreme Court of Canada decision, observed that “a violation of the sanctity of a person's body is much more serious than that of his office or even of his home.”<sup>29</sup> Taking a DNA sample represents one of the few instances under the criminal law where the state can intrude into the physical integrity

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<sup>25</sup> *R. v. Rodgers*, [2006] 1 S.C.R. 554, 2006 SCC 15 at para. 4.

<sup>26</sup> National DNA Databank of Canada, “National DNA Databank: Update” (Issued December 5, 2011): [www.nddb-bndg.org/images/stats\\_e.pdf](http://www.nddb-bndg.org/images/stats_e.pdf).

<sup>27</sup> *Ibid.*

<sup>28</sup> *Ibid.*

<sup>29</sup> *R. v. Pohoretsky*, [1987] 1 S.C.R. 945 at 949.

of an individual without the individual's consent.<sup>30</sup> It is particularly intrusive because DNA can reveal much about an individual – and biological relatives – beyond identifying information. The challenge lies in ensuring that criminal investigators are not denied access to DNA from suspects or convicted offenders in appropriate cases, while preventing state access to the DNA of individuals simply because they have been brought into the criminal justice system for a minor and non-violent criminal act. In other words, there may sometimes be value in compelling a suspect to surrender a DNA sample when DNA has been found at a crime scene, or compelling a person convicted of certain violent offences to surrender a sample. However, that does not mean that every suspect or convicted individual – for example, in a fraud or shoplifting case – should be required to surrender DNA during an investigation or after conviction.

Genetic technology has several potential criminal justice applications. Canadian law might not currently allow all these uses, but this paper sets them out here to explain the possible range of uses:

1. Where investigators already have a suspect in mind, forensic DNA analysis can compare a profile of a DNA sample found at a crime scene (“crime scene sample”) with the profile of the suspect’s DNA. A match provides very strong evidence that the suspect was at the crime scene. A lack of a match exonerates the suspect as being the source of the crime scene DNA;
2. Where DNA is left at a crime scene but investigators have not yet identified a suspect, they may check whether the profile of the crime scene DNA sample matches a profile from a DNA data bank. The data bank may contain profiles of individuals convicted of previous crimes, or it may be a non-criminal data bank to which the police have somehow obtained access. If the crime scene and data bank profiles match, this gives investigators very strong evidence that the person to whom the profile relates was at the crime scene;
3. Comparing a crime scene DNA profile with that from a DNA data bank may not produce an exact match. However, the two profiles may be sufficiently similar to conclude that the individual to whom the profile relates is a biological relative of the suspect. Investigators can then focus their investigation on relatives and seek to obtain a DNA sample from them for comparison with the crime scene sample;

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<sup>30</sup> Testing for driving while impaired by alcohol or drugs is among the few other situations where the state intrudes into the physical integrity of an individual. Even in these cases, however, the consent of the individual is normally required, although a refusal to consent to that intrusion can be an offence. For example, section 254(5) makes it an offence to refuse a demand made under section 254 of the *Criminal Code* to take a breathalyzer test.

4. Forensic DNA analysis can be used to attempt to identify physical characteristics of an unknown suspect who left DNA at a crime scene. DNA analysis may reveal or suggest traits such as race, gender or hair colour;
5. DNA analysis can be used to attempt to identify genetically-influenced behavioural traits, particularly anti-social traits that may express themselves in criminal behaviour. This information could theoretically be used, for example, in decisions about bail, sentencing or parole – or any other situation where decisions in the criminal justice system are based on the possible behaviour of an individual.

The following section examines each of these uses or potential uses of forensic DNA technology.

### **1. Comparing a profile of DNA found at a crime scene with suspect's profile**

An offender may leave his or her DNA at a crime scene, particularly during violent crimes. If police suspect an individual of having been a “party” to the crime and if certain additional conditions are met, the *Criminal Code* allows the police to ask for a warrant to take DNA samples from the suspect. The profile of the DNA sample from the crime scene is then compared with that of the DNA taken from the individual. If the profiles match, this becomes powerful evidence that the individual was present at the scene of the crime.<sup>31</sup> If two profiles do not match, this is equally strong evidence that the crime scene DNA was not from that individual.<sup>32</sup>

Parliament first enacted legislation authorizing the taking of bodily samples from criminal suspects for DNA analysis in 1995. The legislation *An Act to amend the Criminal Code and the Young Offenders Act (Forensic Data Analysis)* <sup>33</sup> enabled investigators to apply for a warrant to take such

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<sup>31</sup> It is possible to place an innocent person's DNA at a crime scene to incriminate them – for example, by leaving the person's cigarette butt or their used tissue at the scene. For this reason, DNA evidence alone is not conclusive evidence of the person's presence at the crime scene.

<sup>32</sup> Such a confirmation of innocence happened with David Milgaard, who had been wrongfully convicted in 1970 of murdering a Saskatoon nursing aide, Gail Miller. In *Reference re Milgaard (Can.)*, [1992] 1 S.C.R. 866, the Supreme Court of Canada concluded that the accused's continued conviction constituted a miscarriage of justice and recommended that the conviction be quashed and a new trial ordered. The Government of Saskatchewan, instead of ordering a new trial, stayed the proceedings against Milgaard. However, Milgaard was not completely exonerated in the public eye until several years later. In 1997, DNA tests conducted in the UK proved that DNA left at the scene of the crime did not belong to Milgaard. See the Association in Defence of the Wrongly Convicted “David Milgaard”: [www.aidwyc.org/Exonerations\\_5.html](http://www.aidwyc.org/Exonerations_5.html).

<sup>33</sup> S.C. 1995, c. 27.

samples for a limited number of crimes. The provisions of the Act were added to the *Criminal Code*. Several conditions must be met before a judge issues a warrant allowing DNA samples to be taken from a person. The judge must be satisfied that there are reasonable grounds to believe that:

- (a) ... a designated offence has been committed,
- (b) ... a bodily substance has been found or obtained
  - (i) at the place where the offence was committed,
  - (ii) on or within the body of the victim of the offence,
  - (iii) on anything worn or carried by the victim at the time when the offence was committed, or
  - (iv) on or within the body of any person or thing or at any place associated with the commission of the offence,
- (c) ... a person was a party to the offence, and
- (d) ... forensic DNA analysis of a bodily substance from the person will provide evidence about whether the bodily substance ... [mentioned above] ... was from that person.<sup>34</sup>

The judge must also be satisfied that it is in the best interests of the administration of justice to issue the warrant.<sup>35</sup>

The "designated offences" for which a warrant to obtain DNA samples from a person can be ordered consist of two categories of offences, both described in the *Criminal Code*. "Primary designated offences" include various sexual offences, offences involving violence, terrorist and hijacking offences, offences involving human trafficking, offences against internationally protected persons, breaking and entering a dwelling house, certain organized crime offences, and attempts to commit some of these offences. "Secondary designated offences" include any offence under the *Criminal Code* that may be prosecuted by indictment and for which the maximum punishment is imprisonment for five years or more, several offences under the *Controlled Drugs and Substances Act*, and a grab bag of offences that include assault, assaulting a peace officer, indecent acts, failure to stop the scene of an accident, criminal harassment, escaping and being at large without lawful excuse, permitting or assisting escape, breaking and entering a place other than a dwelling house, and attempts to commit some of these offences.<sup>36</sup>

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<sup>34</sup> *Criminal Code*, R.S.C. 1985, c. C-46, section 487.05(1).

<sup>35</sup> *Ibid.* Section 487.05(2) identifies further criteria that the judge must consider in deciding whether to issue a warrant.

<sup>36</sup> *Criminal Code*, section 487.04. The full list of primary and secondary designated offences appears in the Appendix to this report.



The *Criminal Code* controls uses of bodily substances taken for DNA analysis. They can be used only for the purpose of forensic DNA analysis in the course of an investigation of a designated offence.<sup>37</sup> Furthermore, bodily substances and the results of forensic DNA analysis must be destroyed or access to electronic records permanently removed in a range of situations. Among those situations are the following: a finding that the suspect's DNA did not match the crime scene sample; the final acquittal of the suspect; the expiry of one year after a discharge at a preliminary inquiry, the dismissal, or withdrawal of information against the suspect or a stay of proceedings.<sup>38</sup>

However, a provincial court judge may order the bodily substances and results of their analysis not be destroyed if the judge "is satisfied that the bodily substances or results might reasonably be required in an investigation or prosecution of the person for another designated offence or of another person for the designated offence or any other offence in respect of the same transaction."<sup>39</sup> Furthermore, the exact meaning of "permanently removing" access to electronic records is unclear. Does it mean that the records continue to exist? If so, this would be an invitation to future governments to relax the rules to permit access to those profiles for other purposes.

Where an individual volunteers a DNA sample to help further an investigation (perhaps during a rarely-used "DNA dragnet"), the *Criminal Code* requires that the bodily substances and the results of forensic DNA analysis be destroyed or, in the case of results in electronic form, that access to those results be permanently removed without delay after the results of the analysis show that the crime scene DNA was not from that individual.<sup>40</sup>

Former Privacy Commissioner of Canada Bruce Phillips described the 1995 DNA legislation as "by and large" striking a "workable balance between law enforcement and privacy interests."<sup>41</sup> However, the number of offences for which a DNA sample can be taken from a suspect has increased greatly since then. When the system of designated offences was introduced in 1995,

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<sup>37</sup> Section 487.08 (1).

<sup>38</sup> Section 487.09 (1).

<sup>39</sup> Section 487.09 (2).

<sup>40</sup> Section 487.09 (3).

<sup>41</sup> Bruce Phillips, Privacy Commissioner of Canada, "Presentation to the Standing Committee on Justice and Human Rights on Bill C-3, the DNA Identification Act," Ottawa, Ontario, February 12, 1998: [www.priv.gc.ca/speech/archive/02\\_05\\_a\\_980212\\_e.cfm](http://www.priv.gc.ca/speech/archive/02_05_a_980212_e.cfm).

the *Criminal Code* classified only 37 very serious violent or sexual offences as designated offences. Fifteen years later, more than 265 offences qualified as designated offences.<sup>42</sup>

The danger, as this seven-fold increase in “designated offences” over the past fifteen years shows, lies in “function creep.” Governments are not immune to following a politically popular “tough on crime” agenda. They may be tempted to relax the conditions that must be satisfied to obtain a warrant to take DNA from a suspect. They may also continue the already significant expansion in the range of offences for which investigators can seek a warrant to take DNA from a suspect. This would move Canada closer to the privacy excesses of the UK system (which are likely to continue even in the UK’s recently revised system). It would also move Canada closer to the American model, which authorizes or compels the taking of DNA in an increasing range of situations.

The UK has attracted both domestic and international criticism for allowing police to take DNA samples from individuals in even the most benign situations and then storing the samples and resulting profiles indefinitely even if the individual was entirely innocent.<sup>43</sup> Since April 2004, the police in England and Wales have been able to take DNA samples without consent from anyone arrested on suspicion of any “recordable” offence.<sup>44</sup> Recordable offences include begging, being drunk and disorderly and taking part in an illegal demonstration.<sup>45</sup>

Similarly, some in the US are concerned about what they see as the ever-widening, and not always justified, range of circumstances where DNA is being taken in the criminal process. A 2010 Congressional Research Service report discussed the expansion of DNA collection:

State laws vary, but nearly all states authorize compulsory DNA collection from people convicted for specified crimes, and a small but growing number of states also authorize compulsory collection from arrestees.

... In recent years ... laws have authorized compulsory DNA collection from people who have been detained or arrested but not convicted on criminal charges. The 109th Congress

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<sup>42</sup> Standing Senate Committee on Legal and Constitutional Affairs, *Public Protection, Privacy and the Search for Balance: A Statutory Review of the DNA Identification Act* (June 2010) at 37-38: [www.parl.gc.ca/Content/SEN/Committee/403/lega/rep/rep09jun10-e.pdf](http://www.parl.gc.ca/Content/SEN/Committee/403/lega/rep/rep09jun10-e.pdf).

<sup>43</sup> Legislation introduced in the UK in 2011 attempts to redress some of these excesses. It is discussed below in the section dealing with forensic DNA databases.

<sup>44</sup> GeneWatch UK, “The UK Police National DNA Database”: [www.genewatch.org/sub-539478](http://www.genewatch.org/sub-539478).

<sup>45</sup> *Ibid.*

authorized the Attorney General, in his discretion, to require collection from such individuals. Specifically, the DNA Fingerprinting Act of 2005 authorized collection “from individuals who are arrested or from non-U.S. persons who are detained under the authority of the United States.” The Adam Walsh Child Protection and Safety Act of 2006 subsequently substituted “arrested, facing charges, or convicted” for the word “arrested” in that authority. The U.S. Department of Justice implemented the authorization in a final rule that took effect January 9, 2009. Mirroring the statutory language, it requires U.S. agencies to collect DNA samples from “individuals who are arrested, facing charges, or convicted, and from non-United States persons who are detained under authority of the United States.” As mentioned, some states have likewise enacted laws authorizing collection of arrestees’ DNA.

... [T]he expansion to collection from arrestees appears to be a more legally significant step [than increases in the number of offences for which DNA is taken after conviction]. Overall, it seems Congress’ goal for the expansion to arrestees and those facing charges was to facilitate crime prevention through “the creation of a comprehensive, robust database that will make it possible to catch serial rapists and murderers before they commit more crimes.” In background material for its implementing rule, the Justice Department explains that collection from arrestees will facilitate more effective law enforcement for at least two reasons: (1) it will aid in crime prevention by ensuring that the government need not wait until a crime has been committed before creating an individual’s DNA profile; and (2) it will allow federal authorities to create DNA profiles for aliens detained in the United States, who might not otherwise undergo judicial proceedings in U.S. courts.<sup>46</sup>

The Congressional Research Service report noted the controversy about DNA collection before conviction raised by the Fourth Amendment to the US Constitution (the right “of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures”):

[O]nly a handful of state and federal judicial decisions address compulsory collection of DNA from persons awaiting a criminal trial. Two federal district courts have issued opinions on the issue. In *United States v. Pool*, the U.S. District Court for the Eastern District of California upheld such collection. In *United States v. Mitchell*, the U.S. District Court for the Western District of Pennsylvania reached the opposite result. ... On the privacy intrusion side, the *Pool* court viewed a DNA sample as no more intrusive than fingerprinting. In contrast, the *Mitchell* court noted that DNA has the potential to reveal a host of private genetic information and rejected the analogy to fingerprinting as “pure folly.”<sup>47</sup>

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<sup>46</sup> Congressional Research Service, *Compulsory DNA Collection: A Fourth Amendment Analysis* (February 16, 2010) at 34: [www.fas.org/sgp/crs/misc/R40077.pdf](http://www.fas.org/sgp/crs/misc/R40077.pdf).

<sup>47</sup> *Ibid.* at 11-12.

## 2. Comparing crime scene DNA profiles with DNA data bank profiles

Many countries have established data banks of DNA profiles of individuals convicted of serious criminal offences. These data banks are most useful when the DNA is left at a crime scene, but police have too little other information to identify a possible suspect for a DNA match. In such cases, the profile of the crime scene DNA can be compared with DNA profiles from the data banks. A profile match gives investigators powerful evidence that the DNA from the crime scene came from the individual with the matching profile.

Canada's initial 1995 forensic DNA legislation did not provide a process to create a DNA data bank containing the profiles of convicted offenders. However, the 1998 *DNA Identification Act*,<sup>48</sup> now incorporated in the *Criminal Code*, provided a structure for the creation and management of a DNA data bank. The Act describes its purpose as follows:

... to establish a national DNA data bank to help law enforcement agencies identify persons alleged to have committed designated offences, including those committed before the coming into force of this Act.<sup>49</sup>

The National DNA Data Bank consists of a crime scene index and a convicted offenders index, both maintained by the Commissioner of the RCMP.<sup>50</sup> The Crime Scene Index contains DNA profiles obtained from crime scene investigations of the designated offences identified in the Act.<sup>51</sup> The Convicted Offenders Index consists of DNA profiles taken from those convicted or discharged of certain, generally serious, criminal offences.<sup>52</sup>

The *Criminal Code* requires or authorizes a court to permit the taking of samples of bodily substances for the National DNA Data Bank in a range of situations. The RCMP *National DNA Data Bank of Canada, Annual Report: 2009-2010* summarizes these situations as involving four categories of offences: primary compulsory offences, presumptive primary offences, listed secondary offences and generic secondary offences. The category determines when a court must order the taking of a sample for the Convicted Offenders Index and when the court has discretion to order the taking of the sample. The RCMP summary is paraphrased below:

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<sup>48</sup> S.C. 1998, c. 37.

<sup>49</sup> *Ibid.* Section 3.

<sup>50</sup> *Ibid.* Section 5.

<sup>51</sup> *Ibid.* Section 5(3).

<sup>52</sup> *Ibid.* Section 5(4).

- **Primary compulsory offences:** These are 19 primary designated offences for which the court is compelled to make an order, such as murder, manslaughter, aggravated sexual assault and robbery;
- **Presumptive primary [designated] offences:** Here, the court must make an order unless the offender convinces the court that the impact of such an order on his/her privacy and security of the person is “grossly disproportionate” to the public interest in the protection of society and the proper administration of justice. Examples of offences in this category are sexual assault, breaking and entering a dwelling house and child pornography;
- **Listed secondary [designated] offences:** For these offences, the prosecutor may ask the court to make an order compelling the provision of a sample. The court may make the order if it is satisfied that it is in the best interests of the administration of justice to do so. Such offences include breaking and entering a place other than a dwelling-house, assault and indecent acts;
- **Generic secondary [designated] offences:** For these offences, the prosecutor may ask the court to make an order compelling the provision of a sample. The court may make the order if it is satisfied that it is in the best interests of the administration of justice to do so. This category includes all the other “non-listed” *Criminal Code* offences, including certain *Controlled Drug and Substance Act* offences that are prosecuted by indictment and for which the maximum punishment is imprisonment for five years or more. Examples include possession of explosives without lawful excuse, pointing a firearm, dangerous driving, dangerous driving causing bodily harm and causing death by criminal negligence, theft over \$5,000 and trafficking, possession for the purpose of trafficking, and the importing, exporting and production of controlled substances.<sup>53</sup>

A December 2011 update about the National DNA Data Bank reported that the Convicted Offenders Index contained 233,796 profiles and the Crime Scene Index contained 70,083 profiles.<sup>54</sup> The Convicted Offenders Index has not to date evolved into a data bank as extensive as those in countries such as the UK. The Convicted Offenders Index contains DNA profiles of less than

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<sup>53</sup> Royal Canadian Mounted Police, *The National DNA Data Bank of Canada, Annual Report 2009-2010* at 33: [www.nddb-bndg.org/train/docs/Annual\\_2009-2010\\_e.pdf](http://www.nddb-bndg.org/train/docs/Annual_2009-2010_e.pdf)

<sup>54</sup> National DNA Databank of Canada, “National DNA Databank: Update” (Issued December 5, 2011): [www.nddb-bndg.org/images/stats\\_e.pdf](http://www.nddb-bndg.org/images/stats_e.pdf).

0.7 per cent of the Canadian population, compared with the UK Police National DNA Database which contains DNA profiles of 8 per cent of the UK population.<sup>55</sup>

**United Kingdom:** The current UK criteria for including a person's DNA profile in its Police National DNA Database are much less restrictive than the Canadian criteria. Almost 6.1 million DNA profiles were stored on the database by the end of 2010. Almost 1.1 million of those profiles were from people without “a current conviction, caution, formal warning or reprimand.”<sup>56</sup>

GeneWatch UK<sup>57</sup> has been highly critical of the UK Database on several grounds, among them the permanent retention of DNA samples (which contain extensive genetic information beyond that needed for identification), rather than merely the retention of the DNA profile used for identification.<sup>58</sup>

In 2008, the European Court of Human Rights decided in *S. and Marper v. the United Kingdom* that the retention of DNA from innocent people breached human rights law.<sup>59</sup> In response, the UK enacted the *Crime and Security Act 2010*. The Act set out new rules about retaining and destroying DNA samples and DNA profiles that have been taken from an individual during an investigation of a recordable offence. Although enacted, the Act was never implemented because an election was called in 2010 and a new government took office.

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<sup>55</sup> GeneWatch UK, “The UK Police National DNA Database”: [www.genewatch.org/sub-539478](http://www.genewatch.org/sub-539478).

A report issued five years earlier by the UK Parliamentary Office of Science and Technology stated that “The NDNAD [National DNA Database] contains the largest number of DNA profiles in absolute numbers and in terms of the proportion of the population represented on the Database (5.2% in the UK compared to 1.13% in the European Union and 0.5% in the USA) in the world”: Parliamentary Office of Science and Technology, Postnote, “The National DNA Database” February 2006, Number 258 at 1: [www.parliament.uk/documents/post/postpn258.pdf](http://www.parliament.uk/documents/post/postpn258.pdf).

<sup>56</sup> Publicservice.co.uk, “Government store DNA of over 6 million,” March 4, 2011: [www.publicservice.co.uk/news\\_story.asp?id=15673](http://www.publicservice.co.uk/news_story.asp?id=15673).

<sup>57</sup> GeneWatch UK describes itself as a not-for-profit policy research and public interest group that investigates the impact of genetic science and technologies on food, health, agriculture, environment and society.

<sup>58</sup> GeneWatch UK, “The UK Police National DNA Database”: [www.genewatch.org/sub-539478](http://www.genewatch.org/sub-539478).

<sup>59</sup> *S. and Marper v. The United Kingdom* [2008] ECHR 1581.

In February 2011, the new UK government introduced the *Protection of Freedoms Bill*.<sup>60</sup> The Bill, undergoing review by UK House of Lords at the time of writing of this report, makes several significant changes to the rules about retaining DNA and DNA profiles in criminal matters. These changes should greatly reduce the number of DNA profiles kept in the National DNA Database.

The UK Home Secretary described these changes during second reading debate on the Bill in March 2011:

The police National DNA Database, established in 1995, has led to a great many criminals being convicted who otherwise would not have been caught, and I am sure all sensible people support it, but in a democracy there must be limits to any such form of police power, and we simply do not accept that innocent people's DNA should be kept for ever [sic] on a database, as the last Government seemed to think was appropriate. Storing indefinitely the DNA and fingerprints of more than 1 million innocent people undermines public trust in policing and goes against any sense of natural justice, so we will be taking innocent people off the DNA database and putting guilty people on.

The Bill introduces a new regime, whereby retention periods depend on a number of different factors, including the age of the individual concerned, the seriousness of the offence or alleged offence, whether they have been convicted, and, for under-18s, whether it is a first conviction. So in future, as now, an adult who is convicted or cautioned will have their fingerprints and DNA profile retained indefinitely, and we will take steps to plug the inexcusable gaps in the DNA database where the profiles of those who have previously been convicted of a serious offence are not currently included on the database.

... We would expect the DNA of the majority of the 1 million innocent people on the database would now be removed from it.

An adult who is charged with, but not convicted of, a serious offence will have their fingerprints and DNA profile retained for three years, with the option of a single extension for two years with the approval of a district judge in the magistrates court, and an adult who is arrested for a minor offence but not convicted will have their fingerprints and DNA profile destroyed as soon as possible once a decision has been taken not to charge them or once they have been found not guilty by the courts. Different arrangements will apply for under-18s who are convicted of a first minor offence, and there will be special provisions for DNA and fingerprints to be retained for national security purposes.

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<sup>60</sup> (HL Bill 99).

If the police believe there are sufficient public protection grounds to justify the retention of material following an arrest for a qualifying offence that does not lead to a charge, the Bill allows them to apply to the new commissioner for the retention and use of biometric material, who will decide whether retention of the DNA profile and fingerprints of the arrested person is justified.<sup>61</sup>

**United States:** In a March 2011 letter, the president of the Council for Responsible Genetics summarized the legislative framework for forensic DNA analysis in the United States:

The federal government and all fifty states have created permanent collections of DNA taken from ever-widening categories of persons and subjecting these collections to routine searches. Many of the same disparities in the U.S. criminal justice system are reflected in these databases: for example while African-Americans are only 12% of the U.S. population, their profiles constitute 40% of the Federal database (CODIS).<sup>62</sup>

A 2010 Congressional Research Service report more fully explains the legislative history and current status of laws permitting forensic DNA analysis in criminal investigations:

The categories of individuals from whom law enforcement officials may require DNA samples [have] expanded in recent years. The federal government and most states authorize compulsory collection of DNA samples from individuals convicted for specified criminal offenses, including all felonies in most jurisdictions and extending to misdemeanors, such as failure to register as a sex offender or crimes for which a sentence greater than six months applies, in some jurisdictions.

In addition, a federal and some state statutes now authorize compulsory collection from people whom the government has arrested or detained but not convicted. ... [T]he DNA Analysis Backlog Elimination Act 2000, as amended, authorizes compulsory collection from individuals in federal custody, including those detained, arrested, or facing charges, and from individuals on release, parole, or probation in the federal criminal justice system. Under the federal law, if an individual refuses to cooperate, relevant officials “may use or authorize the use of such means as are reasonably necessary to detain, restrain, and collect a DNA sample.”

... Expungement Provisions

Although Congress expanded statutory authority for DNA collection, it has also provided some protection for arrestees when arrest does not result in conviction.

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<sup>61</sup> Hon. Theresa May, UK Home Secretary, *Hansard*, March 1, 2011.

<sup>62</sup> Letter from Jeremy Gruber, President, Council for Responsible Genetics, to Dr. Amy Gutmann, Chair, The Presidential Commission for the Study of Bioethical Issues, March 22, 2011.



In particular, federal law mandates expungement of DNA samples upon an arrestee's showing of discharge or acquittal.

The FBI and relevant state agencies "shall promptly expunge" DNA information "from the index" upon receipt of "a final court order establishing that such charge has been dismissed or has resulted in an acquittal or that no charge was filed within the applicable time period." Officials must also expunge DNA data for convicts in cases where a conviction is overturned. These provisions apply to DNA collected by state and local law enforcement officers, in addition to DNA collected in the federal justice or detention systems.<sup>63</sup>

**Other Countries:** The 2008 judgment of European Court of Human Rights in *S. and Marper v. The United Kingdom* summarized the position of several Council of Europe member countries:

45. According to the information provided by the parties or otherwise available to the Court, a majority of the Council of Europe member States allow the compulsory taking of fingerprints and cellular samples in the context of criminal proceedings.

At least 20 member States make provision for the taking of DNA information and storing it on national data bases or in other forms (Austria, Belgium, the Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Luxembourg, the Netherlands, Norway, Poland, Spain, Sweden and Switzerland). This number is steadily increasing.

46. In most of these countries (including Austria, Belgium, Finland, France, Germany, Hungary, Ireland, Italy, Luxembourg, the Netherlands, Norway, Poland, Spain and Sweden), the taking of DNA information in the context of criminal proceedings is not systematic but limited to some specific circumstances and/or to more serious crimes, notably those punishable by certain terms of imprisonment.

47. The United Kingdom is the only member State expressly to permit the systematic and indefinite retention of DNA profiles and cellular samples of persons who have been acquitted or in respect of whom criminal proceedings have been discontinued. Five States (Belgium, Hungary, Ireland, Italy and Sweden) require such information to be destroyed *ex officio* upon acquittal or the discontinuance of the criminal proceedings. Ten other States apply the same general rule with certain very limited exceptions: Germany, Luxembourg and the Netherlands allow such information to be retained where suspicions remain about the person or if further investigations are needed in a separate case; Austria permits its retention where there is a risk that the suspect will commit a dangerous offence and Poland does likewise in relation to certain serious crimes; Norway and Spain allow the retention of

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<sup>63</sup> Congressional Research Service, *Compulsory DNA Collection: A Fourth Amendment Analysis* (February 16, 2010) at 2-3, 4-5.

profiles if the defendant is acquitted for lack of criminal accountability; Finland and Denmark allow retention for 1 and 10 years respectively in the event of an acquittal and Switzerland for 1 year when proceedings have been discontinued. In France DNA profiles can be retained for 25 years after an acquittal or discharge; during this period the public prosecutor may order their earlier deletion, either on his or her own motion or upon request, if their retention has ceased to be required for the purposes of identification in connection with a criminal investigation. Estonia and Latvia also appear to allow the retention of DNA profiles of suspects for certain periods after acquittal.

48. The retention of DNA profiles of convicted persons is allowed, as a general rule, for limited periods of time after the conviction or after the convicted person's death. The United Kingdom thus also appears to be the only member State expressly to allow the systematic and indefinite retention of both profiles and samples of convicted persons.

49. Complaint mechanisms before data-protection monitoring bodies and/or before courts are available in most of the member States with regard to decisions to take cellular samples or retain samples or DNA profiles.<sup>64</sup>

### **3. Familial DNA analysis**

DNA technology can sometimes help to identify a suspect through biological relatives. Investigators may have a DNA sample from a crime scene but have no other information about a possible suspect. In such situations, they may look for a match with a DNA profile from an existing data bank. Often, this will be a DNA data bank established for criminal investigations, but it could in practice be any data bank that permits a comparison with the DNA profile of the crime scene sample.

The comparison between the crime scene DNA and the data bank DNA may fail to produce an exact match. However, it may produce a partial match, which may suggest that the suspect is a biological relative of the person whose profile produced the partial match. Investigators can then narrow their search to family members of the person whose profile produced the partial match.

Familial searching of the Convicted Offenders Index could allow investigators to identify a suspect through the “back door” of a data bank that may contain a profile of a relative, when the government otherwise has no profile of the suspect for comparison with a crime scene

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<sup>64</sup> *S. and Marper v. The United Kingdom* [2008] ECHR 1581.

profile. Even though the suspect has no DNA profile stored in the Convicted Offenders Index, having a biological relative with a DNA profile stored in the Index could have almost the same effect.

Allowing familial searches of the Convicted Offenders Index might (likely only very marginally) increase the effectiveness of some investigations, but it would effectively expand the Index to include, not only the convicted offender, but also some biological relatives. In short, individuals with no record of offences that would justify placing their own profile on the Convicted Offenders Index might find themselves traceable through that Index by virtue of a biological relationship to a convicted offender. The result is somewhat akin to requiring relatives of an individual who has had (traditional) fingerprints taken during the criminal justice process to surrender their own fingerprints.

The only way to prevent this *de facto* expansion of the Convicted Offenders Index is to ban familial analysis. In other words, only an exact match between a crime scene sample and a sample profiled in the Convicted Offenders Index would be identified. Partial matches would not be identified.

A 2009 Library of Parliament report concluded that the *DNA Identification Act* does not currently permit familial searching of the DNA data bank. It explained that, “under the Act, the information from which an offender’s identity can be determined (and therefore from which relatives’ identities could be determined) may be transmitted only if there is an exact match between the offender’s DNA profile and a crime scene profile.”<sup>65</sup> The same report noted precedents for familial searches of data banks in the UK and some American states.

The 2009 report also noted the limited practical value of permitting familial searches of the Convicted Offenders Index. It suggested that, “from a practical perspective, the size of the data bank, with less than [in 2009] 0.5% of Canadians profiled (compared to more than 5% in the United Kingdom), reduces the chance of a finding a family member.”<sup>66</sup> The report added that using the Canadian Convicted Offenders Index to investigate individuals with no criminal background would be “a significant policy change, one that might be difficult to implement.”<sup>67</sup>

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<sup>65</sup> Library of Parliament, Parliamentary Information and Research Service, *New Frontiers in Forensic DNA Analysis: International Practices and Implications for Canada* (March 3, 2009: PRB 08-29E) at 12: [www.parl.gc.ca/Content/LOP/ResearchPublications/prb0829-e.pdf](http://www.parl.gc.ca/Content/LOP/ResearchPublications/prb0829-e.pdf).

<sup>66</sup> *Ibid.*

<sup>67</sup> *Ibid.*

However, the report noted that discussions were taking place about allowing familial searching in defined circumstances:

Familial searching has been discussed in reports of the DNA Data Bank Advisory Committee, an independent body established to advise the RCMP Commissioner on matters related to the establishment and operation of the data bank.

The committee's 2005—2006 annual report offered tentative support for the release of information where partial matches were detected in the course of normal searches, subject to "stringent operational procedures ... to avoid intrusive practices." In its 2006–2007 annual report, the committee recommended that the broader topic of familial searching "be discussed in a public forum where both the privacy rights of citizens as well as the right of the state to utilize this technology in the interests of the justice system can be discussed in some depth." They suggested that the statutory parliamentary review of the *DNA Identification Act* could provide one such opportunity for discussion.<sup>68</sup>

Even if the use of the Convicted Offenders Index for familial matching is not permitted, investigators may try to use other data banks. The 2009 Library of Parliament report noted that this has already occurred in Canada. The report cited a 2002 murder investigation in Alberta.<sup>69</sup> Partial matches between crime scene evidence and DNA samples that two men gave voluntarily led investigators to suspect a close relative of the men. The investigation ultimately led to the conviction of the son of one of the men after an exact match was made between the crime scene profile and that of the son.

Investigative efficiency is not the sole goal of a criminal justice system in a democracy. Other values, including privacy, are also important. And the idea that individuals who undergo genetic testing for reasons that have nothing to do with criminal investigations – in health matters, for example – might see their DNA used for familial analysis may add further reasons for people's reluctance to undergo genetic testing as part of their health care. This reluctance may be particularly acute among groups that have issues of trust relating to intelligence or policing. Some individuals will be more reticent about taking part in voluntary DNA "dragnets" for fear that their DNA profile might effectively make their family members open to searching by way of familial analysis. Ultimately, the use of DNA for familial analysis may produce few useful matches and yet jeopardize cooperation from some groups whose cooperation the police need.

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<sup>68</sup> *Ibid.* at 13.

<sup>69</sup> *Ibid.*

#### 4. Identifying physical characteristics of an unknown suspect through DNA

The Forensic DNA Phenotyping Project at the Penn Center for Bioethics describes the process of identifying physical characteristics of unknown suspects who leave DNA at crime scenes:

Genetic researchers have recently begun to develop a type of DNA-typing that can identify criminal suspects based on traits such as skin, hair, and eye color, geographical ancestry, gait, and predisposition to smoking. Such visual and behavioral characteristics are part of an individual's phenotype, the expression of his or her genes. Thus, we refer to this technology as forensic DNA phenotyping (FDP), although it is also known as phenotypic profiling, molecular photofitting, visual trait prediction, or ethnic inference.

... FDP ... [uses] the DNA left at a crime scene to create a genetically-based description of the unknown suspect's appearance that police can use to narrow their search for suspects. Unlike traditional DNA-typing, which confirms a suspect's identity, FDP predicts the suspect's appearance. Researchers anticipate it could one day even predict a suspect's behavior, such the likelihood of smoking.<sup>70</sup>

The US-based Council for Responsible Genetics describes this process as "constructing probabilistic phenotypic profiles of a perpetrator from DNA collected at a crime scene."<sup>71</sup>

The 2009 Library of Parliament report spoke of the theoretical possibility of using a complex DNA analysis to "generate a physical description of the person who is the source of the material. Hair, eye and skin colour and physical build are all at least partially determined by genetic traits, and could be determined from DNA samples. Such a "DNA-witness" description of a suspect could be available when eye witnesses are not, and would not be subject to the fallibilities of eye-witness descriptions."<sup>72</sup>

The Library of Parliament report also addressed the current limits of the technology:

[T]here are currently only a limited number of DNA analysis methods available which can predict physical traits, and even these are not guaranteed to be accurate. More common are DNA tests which predict a person's racial background as a combination of continental groupings (e.g., Sub-Saharan African, Indo-European, East Asian or Native American) by looking for DNA markers which are common in one group but rare in others. These tests are

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<sup>70</sup> Forensic DNA Ethics, "About Forensic DNA Phenotyping": <http://forensicdnaethics.org/about/about-fdp>.

<sup>71</sup> Letter from Jeremy Gruber, President, Council for Responsible Genetics, to Dr. Amy Gutmann, Chair, The Presidential Commission for the Study of Bioethical Issues, March 22, 2011.

<sup>72</sup> Library of Parliament, Parliamentary Information and Research Service, *New Frontiers in Forensic DNA Analysis: Implications for Canada's National DNA Data Bank* (March 3, 2009: PRB 08-29E) at 14-15: [www.parl.gc.ca/Content/LOP/ResearchPublications/prb0829-e.pdf](http://www.parl.gc.ca/Content/LOP/ResearchPublications/prb0829-e.pdf).

marketed to individuals who wish to determine their own genealogical ancestry, but are also marketed to forensic scientists.<sup>73</sup>

The Library of Parliament report spoke of other reports “that a number of Canadian police forces, including the RCMP, have used the services of a company which performs racial analysis of DNA found at crime scenes.”<sup>74</sup> It also noted that, “[t]here are no legislative or regulatory requirements that identify or limit the types of DNA analyses which may be used for forensic purposes in Canada.”<sup>75</sup>

Several concerns have been raised about DNA phenotyping. The Council for Responsible Genetics noted the lack of ethical guidelines for forensic DNA practices in the United States. It also spoke of the expanding uses of DNA by law enforcement, generally in a policy vacuum. These uses were then “being justified retroactively by a limited number of solved crimes aided by DNA data.”<sup>76</sup>

The 2009 Library of Parliament report raised the concern that the availability of DNA phenotyping could be used to justify DNA “dragnets.”<sup>77</sup> In other words, if DNA phenotyping led investigators to believe that the offender was possibly a tall male of Asian origin, this information might be used to justify collecting DNA samples from large groups of tall Asian males, even if there is no other reason to suspect them.<sup>78</sup> As well, the report noted that DNA tests based on racial background were “likely to provoke greater controversy than those that assess more objective physical characteristics, such as eye or hair colour.”<sup>79</sup> Among the other concerns the report raised about DNA phenotyping:

- The results may not be useful as a physical description of a person of mixed racial background;

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<sup>73</sup> *Ibid.*

<sup>74</sup> *Ibid.* at 16.

<sup>75</sup> *Ibid.*

<sup>76</sup> Letter from Jeremy Gruber, President, Council for Responsible Genetics, to Dr. Amy Gutmann, Chair, The Presidential Commission for the Study of Bioethical Issues, March 22, 2011.

<sup>77</sup> Library of Parliament Report, *New Frontiers in Forensic DNA Analysis: Implications for Canada's National DNA Data Bank* (n.65), at 16.

<sup>78</sup> *Ibid.*

<sup>79</sup> *Ibid.*

- “Investigators may incorrectly exclude a suspect who does not appear to match a description”;
- “[T]he benefit to police (from the elimination of suspects who do not match the description) would statistically be greatest when the identified racial group forms a minority in the community, and therefore investigations that use racial tests could disproportionately focus on minority communities;” and
- “[Any] proposal to use such analysis methods for data bank profiles would mark a significant departure from current policy, which has highlighted the use of “anonymous pieces of DNA” as an important privacy protection measure. It could also provoke new challenges of the data bank’s constitutionality and the Supreme Court’s assessment of the DNA data bank as an identification tool only.”<sup>80</sup>

## 5. Attempting to determine behavioural traits

In October 2002, the UK’s Nuffield Council on Bioethics published a report on genetic influences on behaviour.<sup>81</sup> The report identified three ways that information about genetic influences on behaviour could be used in the criminal justice system:

**As an excuse:** Genetic information about a behavioural trait could be used, for example, to explain a crime or even excuse the offender. The Nuffield Council report argued, however, “that genes are not deterministic, and that there is scope for an explanation of human behaviour that allows for genes to have some influence over our characteristics but also holds that we are responsible for our actions.” The report concluded that “genetic information about behaviours within the normal range does not absolve an individual from responsibility for an offence. Research in behavioural genetics does not pose a fundamental challenge to our notions of responsibility.”<sup>82</sup>

**When sentencing:** The Council’s report asked whether genetic information should affect the sentencing of convicted offenders. It noted that “judges already use additional

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<sup>80</sup> *Ibid.* at 17.

<sup>81</sup> Nuffield Council on Bioethics, *Genetics and human behaviour: the ethical context* (Nuffield Council on Bioethics, October 2002): [www.nuffieldbioethics.org/sites/default/files/Genetics%20and%20human%20behaviour.pdf](http://www.nuffieldbioethics.org/sites/default/files/Genetics%20and%20human%20behaviour.pdf).

<sup>82</sup> Nuffield Council on Bioethics, “Practical Applications”: [www.nuffieldbioethics.org/genetics-and-behaviour/genetics-and-behaviour-practical-applications](http://www.nuffieldbioethics.org/genetics-and-behaviour/genetics-and-behaviour-practical-applications).

information about offenders to help decide what sentence to give, including the offender's previous criminal record, the extent to which the crime was premeditated, and any mitigating, or explanatory, factors. These can include information about environmental influences, such as poverty or an abusive childhood, which may affect the likelihood of criminal behaviour." The report concluded that "[g]enetic information could be taken into account by judges when sentencing. If the information is to be used in this way, it is vital that the genetic link is convincing, and that the tests are accurate and reliable."<sup>83</sup>

In fact, seven years after the Nuffield Council report was released, an Italian appeal court reduced a murder sentence by one year "because, according to scientists ... [the offender] ... possessed genes that shortened his fuse."<sup>84</sup> The person's counsel argued that the person was "the victim of genetic misfortune: the owner of five genes known to be associated with violent behaviour."<sup>85</sup>

**Prediction:** The Council stated that it was "unlikely that genetic information will be accurate enough to justify using it on its own to predict antisocial behaviour." Still, it suggested that combining genetic with environmental information might allow more accurate predictions about behaviour. It saw two possible uses for such predictions: to detain someone as a precaution, or to target an intervention to help someone. The Council concluded that, "Where a person has not yet been convicted of a crime, neither genetic nor non-genetic information should be used to predict future behaviour with a view to detaining an individual. However, if information could be used for the benefit of the individual, for example, as a reason for improving particular environmental conditions, this may be justified. We recommend that genetic information should not be used in isolation in such cases."<sup>86</sup>

There is a danger that future Canadian governments, anxious to appeal to popular sentiment and misunderstandings about the predictive value of behavioural genetics, and perhaps misunderstanding it themselves, will be tempted to use genetic information to single out individuals as a preventive measure, however misguided such action may be. There is historical

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<sup>83</sup> *Ibid.*

<sup>84</sup> "The Get Out of Jail Free Gene," *The Times* (UK), November 17, 2009.

<sup>85</sup> *Ibid.*

<sup>86</sup> Nuffield Council on Bioethics, "Practical Applications" (n.82).

<sup>86</sup> Nuffield Council on Bioethics, "Practical Applications" (n.82).



precedent for misguided actions by governments in criminal justice matters, and behavioural genetics risks becoming another example. Even where genetic information could be used, in theory, to benefit an individual – for example, by showing the need to improve certain environmental conditions, as the Nuffield Council suggested – the danger remains that singling out individuals for special treatment could stigmatize them unfairly or could actually foster a self-fulfilling prophecy. The use of behavioural genetics as a tool to predict future behaviour and to determine future handling of individuals must be viewed with considerable caution.

This highlights the problem of retaining DNA samples, rather than simply the profile needed for identification. In a 1998 presentation to the Standing Committee on Justice and Human Rights, Privacy Commissioner Bruce Phillips argued that retaining a data bank of genetic samples from convicted offenders will inevitably attract researchers who want to analyze the samples for purposes that have nothing to do with forensic identification:

This scientific curiosity, coupled with growing pressure to reduce crime by whatever means, no matter how intrusive, will almost certainly lead to calls to use samples to look for genetic traits common to "*criminals*". This type of research, while perhaps of scientific interest and possible social value, raises complex legal, ethical and moral problems that we have yet to resolve.... [T]he goal of forensic DNA analysis, linking a person to a crime scene, can be served *without* keeping the offender's sample.<sup>87</sup>

Because of the danger of what Phillips called “ethically problematic research” and society’s failure to deal with the storage of genetic information produced by such research, he called for extreme caution in assembling a collection of samples from convicted offenders.

Section 487.08(1) of the *Criminal Code* restricts the use of bodily substances collected under a warrant to forensic DNA analysis in the course of an investigation. Justice Arbour, in the Supreme Court of Canada decision *R. v. S.A.B.* concluded that this means that only “those tests that may be useful in advancing the matching of the two samples, and nothing more, are permitted.”<sup>88</sup> This appears to forbid sharing the DNA samples with researchers or private companies, unlike in the UK, where such practices have occurred and have drawn criticism as a result. In addition, section 487.08(1.1) prohibits any person from using bodily substances taken under an order made under section 487.051 (the authorization to collect DNA for the Convicted Offenders Index) except to transmit them to the RCMP Commissioner for the purpose of forensic DNA analysis under the *DNA Identification Act*.

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<sup>87</sup> Bruce Phillips, Privacy Commissioner of Canada, “Presentation to the Standing Committee on Justice and Human Rights on Bill C-3, the DNA Identification Act”, Ottawa, Ontario, February 12, 1998: [www.priv.gc.ca/speech/archive/02\\_05\\_a\\_980212\\_e.cfm](http://www.priv.gc.ca/speech/archive/02_05_a_980212_e.cfm).

<sup>88</sup> *R. v. S.A.B.*, 2003 SCC 60, [2003] 2 SCR 678 at para. 13.

## Statutory Reviews of the *DNA Identification Act*

Both the House of Commons Standing Committee on Public Safety and National Security (2009) and the Standing Senate Committee on Legal and Constitutional Affairs (2010) conducted statutory reviews of the *DNA Identification Act*. Both committees proposed amending the provisions regarding the collection of DNA samples from convicted offenders.

The Commons committee spoke of numerous alleged problems with this system:

It was brought to the Committee's attention that a substantial amount of police time is spent on administrative tasks, such as returning defective orders, asking prosecutors to obtain corrected orders and sometimes obtaining a legal interpretation on whether the offence involved qualified for acceptance in the data bank. Witnesses also noted that applications for DNA orders vary greatly from one region to another. Certain provinces appear to require DNA samples more frequently than others.<sup>89</sup>

Both Senate and Commons committees recommended amending the DNA legislation to allow for the automatic taking of a DNA sample from anyone convicted of a designated offence immediately upon conviction. The current system allows judicial discretion in ordering the taking of samples for some designated offences. If these recommendations find their way into legislation, the number of DNA samples and the number of resulting DNA profiles contained in the Convicted Offenders Index will certainly increase, although the scale of that increase is difficult to predict. The Commons committee cited a Department of Justice estimate that the present registration system produced about 36,000 convicted offender profiles per year.

The committee noted further that, according to departmental estimates, taking a DNA sample automatically upon conviction in the case of all designated offences would lead to about 113,000 profiles per year – a significant increase over existing numbers.<sup>90</sup>

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<sup>89</sup> Canada, Senate, Standing Senate Committee on Legal and Constitutional Affairs, "Public Protection, Privacy and the Search for Balance: A Statutory Review of the *DNA Identification Act*: Final Report" (June 2010) (Chair: Hon. Joan Fraser) at 34-35: [www.parl.gc.ca/Content/SEN/Committee/403/lega/rep/rep09jun10-e.pdf](http://www.parl.gc.ca/Content/SEN/Committee/403/lega/rep/rep09jun10-e.pdf); Canada, House of Commons, Standing Committee on Public Safety and National Security, "Statutory Review of the *DNA Identification Act*: Report of the Standing Committee on Public Safety and National Security" (June 2009) (Chair: Gary Breitkreuz, MP) at 7-8: [http://publications.gc.ca/collections/collection\\_2009/parl/XC76-402-1-1-01E.pdf](http://publications.gc.ca/collections/collection_2009/parl/XC76-402-1-1-01E.pdf).

<sup>90</sup> House of Commons, Standing Committee on Public Safety and National Security, "Statutory Review of the *DNA Identification Act*: Report of the Standing Committee on Public Safety and National Security" at 8.

The Senate committee stated its concern about the significant increase in the number of offences that qualified as “designated offences”:

This committee also wishes to highlight that, in deciding to recommend the collection of DNA from all offenders convicted of those offences currently classified as designated offences, we are mindful of the concerns expressed by the Office of the Privacy Commissioner of Canada, the Criminal Lawyers’ Association, the John Howard Society of Canada and the Canadian Association of Elizabeth Fry Societies regarding the significant number of designated offences that have been added to the list of offences found at section 487.04 of the Code since the original DNA collection scheme was introduced. As stated previously in this report, while the legislative regime in 1995 classified only 37 very serious violent or sexual offences as designated offences, more than 265 offences are now classified in this manner. Some of these, like assault (section 266 of the Code), uttering threats (section 264.1) and intimidation (section 423), can apply to behaviour that is very serious in nature, but also to behaviour that is relatively minor.

Accordingly, while it may well be necessary, in the future, to add offences to the list found in section 487.04, or to change the classification system in accordance with the Department of Justice’s proposals, the committee urges the government to exercise caution in adding to the list, doing so only if such additions are demonstrably necessary. To do otherwise might distort the legislative framework and run the risk of violating the Charter.<sup>91</sup>

The Senate committee’s mention of concern about the expanding number of designated offences is reminiscent of the concern expressed 12 years earlier by Bruce Phillips, then federal Privacy Commissioner. Speaking before the House of Commons Standing Committee on Justice and Human Rights in 1998, Phillips argued that the range of offences for which samples can be taken from convicted offenders might be unnecessarily broad. He argued that casting too wide would result in privacy intrusions on a mass level. Phillips cited as an example provisions allowing a judge to order the taking of a DNA sample from someone convicted of even a relatively minor offence, such as common assault. “Thus,” he argued, “many relatively minor offenders could have their DNA added to the databank which eventually could encompass a large segment of the Canadian population.”<sup>92</sup>

Phillips acknowledged that the extent to which judges would order DNA taken from minor offenders would become clear only after the law was in operation for some time. Still, he argued,

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<sup>91</sup> Standing Senate Committee on Legal and Constitutional Affairs (2010) (n.42) at 37-38.

<sup>92</sup> Bruce Phillips, Privacy Commissioner of Canada, Presentation to the Standing Committee on Justice and Human Rights on Bill C-3, the *DNA Identification Act*, Ottawa, Ontario, February 12, 1998.

the DNA legislation introduced the “potential for the assembly of a DNA database on a significant portion of the Canadian (male) population.”<sup>93</sup>

Amending the *DNA Identification Act* to allow the automatic collection of DNA from all those convicted of designated offences – a hugely expanded category since that category of offences first appeared in the 1995 DNA legislation – will bring Phillips’ concern closer to being realized. Using the estimates provided by the Department of Justice to the House of Commons committee, cited above, the Convicted Offenders Index would hold about 1.14 million profiles – about one in every 33 Canadians – by 2020.<sup>94</sup>

The Senate committee addressed whether to amend the *Criminal Code* to allow the collection of DNA from those arrested and charged with indictable offences. It rejected such an amendment. At present, the *Criminal Code* allows the collection of DNA samples from suspects only under warrant and only under stringent conditions. Thus, the committee rejected a position that would have resulted in a significant increase in the number of DNA samples collected during criminal investigations (as opposed to after conviction).

### **Forensic DNA Analysis – Conclusion**

In Canada, the utility of forensic DNA analysis from certain suspects [and convicted offenders] has been acknowledged in several quarters, including by the Supreme Court of Canada. However, vigilance is required to ensure that evolving the DNA provisions of the *Criminal Code* do not relegate privacy to a position of secondary importance. The danger is that Canadian DNA legislation will eventually produce the types of excesses seen with the UK forensic DNA scheme and that appear to be evolving in some US jurisdictions. The *Charter of Rights and Freedoms* might help to control the worst potential excesses – for example, the taking of DNA samples from all persons on arrest. However, even with the *Charter* in place, there has been a large increase since 1995 in the types of offences for which DNA samples can be taken from suspects under warrant and from convicted offenders. The more punitive, less rights-focused, attitudes that have characterized Parliament since the 2006 election make it all the more likely that the government

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<sup>93</sup> *Ibid.*

<sup>94</sup> The Convicted Offender Index, as of December 2011, held 233,796 profiles. Adding 113,000 profiles to this Index every year for the next eight years would produce a Convicted Offender Index of 1,137,000 profiles – equivalent to about 3 per cent of the roughly-estimated Canadian population (in 2020) of 38 million. And this assumes no increase in the number of offences for which DNA samples will be taken from convicted offenders. Past experience suggests that the number of such offences will continue to increase, particularly in a “law and order” climate.

will attempt to expand the circumstances in which DNA can be collected from those drawn into the criminal justice system.

Increasing the number of DNA profiles in the Convicted Offenders Index could occur in several ways: requiring inclusion for a broader range of offences (essentially, continuing the Canadian trend since 1995, with the expansion in the number of designated offences); making inclusion automatic on conviction (the House of Commons and Senate committees' recommendation); including profiles from volunteers; including profiles of those merely arrested or charged, with no need for a conviction. These potential developments could transform the Convicted Offenders Index into a criminal data bank on a significant proportion of the Canadian population.

In the future, Parliament may also facilitate the co-opting (as opposed to volunteering) of DNA samples held outside the criminal justice system (by hospitals or research bodies, for example) for criminal investigations. Such measures might not withstand a *Charter* challenge, but there is no certainty about this. The result could be an even larger pool of stored DNA profiles, including from people with no criminal background.

Another concern is racially discriminatory enforcement of certain laws, which can lead to an over-representation of a racial or ethnic group in a DNA data bank. Offences relating to certain drugs may be a case in point. In several countries, minority groups are disproportionately targeted under these laws.<sup>95</sup> A DNA data bank will then have disproportionately great representation from those groups.<sup>96</sup> There is strong evidence of this result bias in the UK. An October 2011 submission to a British House of Commons committee cited one 2006 news report about the disproportionate representation of young black males in the UK database.<sup>97</sup> That report indicated that about,

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<sup>95</sup> See for example, Marc Mauer, *Race to Incarcerate*, 2<sup>nd</sup> ed. (New York: The New Press, 2006); Ontario, *Report of the Commission on Systemic Racism in the Ontario Criminal Justice System* (Queen's Printer for Ontario, 1995); see also the Testimony of Elizabeth Sheehy, University of Ottawa, Faculty of Law, before the Senate Standing Committee on Legal and Constitutional Affairs, on Bill C-15, October 29, 2009: "The reality of racial profiling by police in Canada has been demonstrated by numerous studies, acknowledged by police themselves and judicially noticed by our courts. ... [C]onscious and unconscious racism colours whom police and security forces in Canada monitor, arrest and charge."

<sup>96</sup> See, for example, the October 2011 GeneWatch UK briefing about amendments affecting the UK police DNA database: GeneWatch UK, "Protection of Freedoms Bill, Third Reading: Parliamentary Briefing," October 2011: [www.genewatch.org/uploads/f03c6d66a9b354535738483c1c3d49e4/FreedomsBill3rdReadingBrief.pdf](http://www.genewatch.org/uploads/f03c6d66a9b354535738483c1c3d49e4/FreedomsBill3rdReadingBrief.pdf).

<sup>97</sup> GeneWatch UK, "Protection of Freedoms Bill, Third Reading: Parliamentary Briefing," October 2011, at 2: [www.genewatch.org/uploads/f03c6d66a9b354535738483c1c3d49e4/FreedomsBill3rdReadingBrief.pdf](http://www.genewatch.org/uploads/f03c6d66a9b354535738483c1c3d49e4/FreedomsBill3rdReadingBrief.pdf).

135,000 black males aged 15 to 34 will be entered in the crime-fighting database by April [2007], equivalent to as many as 77 per cent of the young black male population in England and Wales. By contrast, only 22 per cent of young white males, and six per cent of the general population, will be on the database.<sup>98</sup>

Another investigative report by *The Guardian* newspaper earlier that year concluded that the DNA profiles of almost four in ten black men in the UK were on the police's national database; fewer than one in ten white men had their profiles on the database.<sup>99</sup>

As well, some offences are in essence “manufactured” crime – activities that are not inherently evil (*mala in se*) but that have been “manufactured” into crimes. This results in a larger Convicted Offenders Index than would be the case without these manufactured crimes.

Again, drug offences are a case in point. There are strongly held views about the appropriateness of characterizing some drug transactions as crimes (cannabis, opium, ecstasy, and cocaine, for example), while permitting (tobacco) or even promoting (alcohol) others. However, this author maintains that many “drug crimes” are in fact manufactured crimes and that other regulatory mechanisms could more successfully reduce the problems associated with the drugs we label “illegal” than our current criminal laws. There would also be privacy benefits: since these activities would no longer be dealt with through the criminal law, there would be no collection of DNA from suspects (since no crime would be involved). There would also be no DNA collected for the Convicted Offenders Index.

The UK system is on the cusp of changing to a more rational, rights-based, approach to DNA collection and DNA data banking, but signs are that the US is moving to more expansive collection from suspects and more comprehensive DNA data banks. And it is the US that seems to have become the model for many of the highly punitive criminal justice policies being adopted by Canada.

In the US, the Council for Responsible Genetics has urged the Presidential Commission for the Study of Bioethical Issues to “explore the massive growth of forensic DNA databases and collection practices in the United States and their far reaching implications.”<sup>100</sup> Canada should follow this

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<sup>98</sup> “Three in four young black men on the DNA database,” *The Telegraph* (UK), November 5, 2006: [www.telegraph.co.uk/news/uknews/1533295/Three-in-four-young-black-men-on-the-DNA-database.html](http://www.telegraph.co.uk/news/uknews/1533295/Three-in-four-young-black-men-on-the-DNA-database.html).

<sup>99</sup> “DNA of 37% of black men held by police,” *The Guardian* (UK), January 5, 2006: [www.guardian.co.uk/world/2006/jan/05/race.ukcrime](http://www.guardian.co.uk/world/2006/jan/05/race.ukcrime).

<sup>100</sup> Letter from Jeremy Gruber, President, Council for Responsible Genetics, to Dr. Amy Gutmann, Chair, The Presidential Commission for the Study of Bioethical Issues, March 22, 2011.

issue closely. In the UK, GeneWatch has been highly critical of the UK DNA Database on several grounds, arguing that there was no evidence to support the assumption that holding the DNA profiles of more individuals on the database will solve more crimes: “[a] massive expansion in the number of individuals on the Database has not led to any noticeable increase in the likelihood of identifying a suspect.”<sup>101</sup>

The Canadian Standing Senate Committee acknowledged the anecdotal information provided by many witnesses suggesting “that the Data Bank is tremendously useful both to law enforcement officials in their investigations and to the criminal justice system as a whole.”<sup>102</sup> However, “[a]nother issue that was raised by witnesses was that it can be difficult to determine, based on the statistics provided by National DNA Data Bank in its annual reports, the degree of assistance that Data Bank hits actually provide to police and to the criminal justice system generally in either providing persuasive evidence of guilt or in exonerating the innocent. ... [W]e are of the view that better data on how exactly the Data Bank assists law enforcement officials would help to demonstrate the value of the Data Bank in a more concrete and measurable fashion.”<sup>103</sup> Evidence of effectiveness is clearly an important issue, for it is the effectiveness of the forensic DNA measures that must be weighed against their intrusiveness.

To this point, the concerns about forensic DNA have focused on the *Criminal Code*. There are also concerns beyond the *Criminal Code* provisions. Even though the *Criminal Code* requirements limit the size of the Convicted Offenders Index, police may try to get access to other data banks to look for a match with a crime scene profile. Research bodies, businesses and other organizations may hold biological material or profiles that could be used for this purpose. The Convicted Offenders Index contains only the profiles of individuals convicted of fairly serious criminal offences; other data banks will largely relate to individuals with no serious criminal record.

There is authority in the *Personal Information Protection and Electronic Documents Act* (PIPEDA)<sup>104</sup> for organizations covered by the Act – those engaged in commercial activities<sup>105</sup> – to disclose

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<sup>101</sup> GeneWatch UK, “The UK Police National DNA Database”: [www.genewatch.org/sub-539478](http://www.genewatch.org/sub-539478).

<sup>102</sup> Standing Senate Committee on Legal and Constitutional Affairs, *Public Protection, Privacy and the Search for Balance: A Statutory Review of the DNA Identification Act* (June 2010) at 48: [www.parl.gc.ca/Content/SEN/Committee/403/lega/rep/rep09jun10-e.pdf](http://www.parl.gc.ca/Content/SEN/Committee/403/lega/rep/rep09jun10-e.pdf).

<sup>103</sup> *Ibid.* at 48-49.

<sup>104</sup> S.C. 2000, c. 5.

personal information voluntarily. An organization can do this of its own accord<sup>106</sup> or after a request by a government institution.<sup>107</sup> It can also do this to comply with a subpoena or warrant.<sup>108</sup> In all cases, the disclosure can occur without the knowledge or consent of the individual to whom the information relates. The exact limits of the “non-consensual” collection, use and disclosure provisions of PIPEDA, however, remain unclear and require further attention. It is important to ensure that they do not serve as the back door for the state to do what the *Criminal Code* DNA data bank scheme attempts to control so tightly.

Private sector organizations may therefore serve as vehicles to expand access to data banks for matching beyond those holding profiles of convicted offenders only. In essence, the private sector can help the police do by stealth – by volunteering information to the police – what they could not do directly. This might be lawful under PIPEDA and similar provincial privacy legislation. The issue is whether this is appropriate in a democratic society. To what extent should the private sector allow the police to look for DNA matches through the “back door” of relying on the private sector? If back-door attempts to match become commonplace, the Convicted Offenders Index will offer little more than the illusion of restraining the scope of searches for matches of profiles.

The voluntary sharing of data by the private sector with the police may help to solve crimes. However, the private sector is permitted to collect information about individuals with far fewer restrictions than the police. This should not be allowed to become a means for the police to sidestep the limits imposed on them by a democratic society – at least, not without a full public debate and understanding of the consequences of such an arrangement as it relates to genetic information. One possibility would be to make certain private sector or quasi-private sector organizations subject to stronger privacy obligations. For example, perhaps companies that handle identifiable genetic materials – a private laboratory, for example – might be made subject to more exacting privacy standards than currently exist under various privacy laws.

There are also concerns about the sharing of personal genetic information across borders. As with so much other information, genetic information would be subject to the *USA Patriot Act*, which provides significant powers of search and seizure relating to organizations operating

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<sup>105</sup> Most organizations that collect, use or disclose personal information in the course of commercial activities must comply with PIPEDA. Ontario (in respect of health information), Alberta, British Columbia and Quebec have equivalent legislation that applies instead of PIPEDA in some situations.

<sup>106</sup> Section 7(3)(d).

<sup>107</sup> Section 7(3)(c.1).

<sup>108</sup> Section 7(3)(c).



in the US. Those search and seizure powers may well lead a US-based organization to be required to attempt to obtain information held in Canada by a related organization. Canadian systems designed to protect personal information, including personal genetic information, must take this into account in their design. These systems must also take into account that the servers for certain new means of storing information, such as cloud computing, may be accessible under the *USA Patriot Act*. This may mean that personal genetic information, like other potentially sensitive personal information, should not be stored by means of cloud computing because of the risk that such information will be readily accessible under the *USA Patriot Act*.

Above all, governments and private sector organizations in Canada should not share identifiable biological samples with organizations in the United States that are subject to the *USA Patriot Act*.

## **Relationships between the Private Sector and Individuals – Insurance and Employment**

Like the state, the private sector has the potential to exert significant control over individuals through information gleaned from their DNA. For example, some employers might be interested in genetic tests that would indicate that a job applicant or employee is particularly susceptible to harm from exposure to certain workplace chemicals. Left to their own devices, the employers might prefer to discriminate against the applicant or employee and screen them out of a job rather than take measures to reduce their risk of exposure to those chemicals.

Similarly, insurers, left to their own devices, almost certainly want to use genetic testing information in the underwriting process. Applicants may be asked about their family history and current medical conditions. They may be asked to consent to (non-genetic) medical tests as part of the application process. As explained below, the insurance industry also wants access to information obtained through genetic testing. Genetic test results can provide one further layer of information for the underwriting process, particularly as our understanding of genetic links to health conditions increases.

Canadian privacy laws are much more porous than their titles might imply. Often, they are mere regulatory statutes, setting only the broadest – and often unenforceable – rules for the collection, use and disclosure of personal information. For genetic and other sensitive personal information, that may not be enough, particularly in an increasingly digital environment and one in which centrally stored personal health records is the stated goal of many health care systems.

Health records that were once protected because their information was held in manual files by individuals with professional confidentiality obligations – physicians, for example – have given way to electronic records that can easily be centralized and distributed. Professional obligations

of confidentiality may still work to protect information held by physicians and other healthcare providers. However, once that information moves beyond their control, as it so often does today, they can no longer effectively protect the information. The Canadian Medical Association acknowledges this in its *Principles for the Protection of Patients' Personal Health Information* when it states: “[p]atients should be informed that the treating physician cannot control access and guarantee confidentiality for an electronic health record (EHR) system.”<sup>109</sup>

## Insurance

Canadian human rights legislation does not prevent discrimination in insurance. In fact, current insurance law promotes the use of medical information for underwriting.<sup>110</sup> One author argues that Canada has “universal” health care, so genetic discrimination is not as much of an issue in health care as in countries without universal health care. As a result, the focus in Canada shifts to possible genetic discrimination in access to life, disability and critical care insurance.<sup>111</sup>

A 2004 Canadian Medical Association Journal cited the views of the Law Reform Commission of Canada and the Ontario Law Reform Commission that one’s genetic heritage should not bar access to a basic level of insurance. The same article spoke of a task force created in 2003 that had suggested debating the following options:

- No use of genetic test results (excluding family history) for a set, moderate amount of insurance coverage for a limited period of time (5 years). This amount and time limit could be revised if warranted.
- Creation of an independent standing body that includes consumers, government, clinicians, industry and researchers for ongoing review of criteria concerning the reliability of genetic information for underwriting purposes. This advisory body could also handle complaints and queries from consumers.<sup>112</sup>

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<sup>109</sup> Canadian Medical Association, *Principles for the Protection of Patients' Personal Health Information* (2011), principle 13: <http://policybase.cma.ca/dbtw-wpd/Policypdf/PD11-03.pdf>.

<sup>110</sup> See generally the discussion in Trudo Lemmens and Poupak Bahamin, “Genetics in Life, Disability and Additional Health Insurance in Canada: A Comparative Legal and Ethical Analysis”, in Bartha Knoppers, ed., *Socio-Ethical Issues in Human Genetics* (Cowansville: Les Éditions Yvon Blais, Inc. 1998) 114 at 271.

<sup>111</sup> Jo Anne Watton, *Fighting Genetic Discrimination in Canada* (December 16, 2009), in GeneWatch: [www.councilforresponsiblegenetics.org/GeneWatch/GeneWatchPage.aspx?pageId=229](http://www.councilforresponsiblegenetics.org/GeneWatch/GeneWatchPage.aspx?pageId=229).

<sup>112</sup> Bartha M. Knoppers, Yann Joly, “Physicians, genetics and life insurance,” *CMAJ* April 27, 2004, vol. 170 no. 9, 1421-1423 at 1422: [www.cmaj.ca/content/170/9/1421.full](http://www.cmaj.ca/content/170/9/1421.full). See also, Bartha M. Knoppers et al.,

The article noted that the recommendations of the two law reform bodies “did not affect the position taken by the insurance industry in Canada”:

The Canadian Institute of Actuaries, the Canadian Life Insurance Medical Officers Association and the Canadian Life and Health Insurance Association all stated that if genetic testing occurred and the results were available to the insurance applicant, insurers could request access to that information just as it would for other aspects of the applicant's health history.<sup>113</sup>

An April 2010 reference document issued by the Canadian Life and Health Insurance Association Inc. maintains its longstanding policy on genetic testing and use of genetic test results:

... if genetic testing has been done and the information is available to the applicant for insurance and/or the applicant's physician, the insurer would request access to that information just as it would for other aspects of the applicant's health history.<sup>114</sup>

Note, however, that the same 2010 reference document explains the industry's policy “that insurers would not require an applicant for insurance to undergo genetic testing.”<sup>115</sup>

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“Genetics and life insurance in Canada: points to consider,” CMAJ, April 27, 2004, vol. 170 no. (9) at Online-3: [www.cmaj.ca/content/suppl/2004/04/26/170.9.1421.DC2/genetics-knoppers-EN.pdf](http://www.cmaj.ca/content/suppl/2004/04/26/170.9.1421.DC2/genetics-knoppers-EN.pdf).

<sup>113</sup> Bartha M. Knoppers, Yann Joly, “Physicians, genetics and life insurance,” CMAJ April 27, 2004, vol. 170 no. 9, 1421-1423 at 1422: [www.cmaj.ca/content/170/9/1421.full](http://www.cmaj.ca/content/170/9/1421.full).

<sup>114</sup> Canadian Life and Health Insurance Association Inc., “Reference Document: CLHIA Position Statement on Genetic Testing” (April 2010) at 1: [www.clhia.ca/domino/html/clhia/CLHIA\\_LP4W\\_LND\\_Webstation.nsf/resources/Guidelines/\\$file/Genetic\\_Testing\\_CLHIA\\_Industry\\_Position\\_2010.pdf](http://www.clhia.ca/domino/html/clhia/CLHIA_LP4W_LND_Webstation.nsf/resources/Guidelines/$file/Genetic_Testing_CLHIA_Industry_Position_2010.pdf). Knoppers and Joly describe an earlier, possibly identical version of this statement in their 2004 CMAJ article: Bartha M. Knoppers and Yann Joly, “Physicians, genetics and life insurance,” CMAJ April 27, 2004, vol. 170 no. 9: [www.cmaj.ca/content/170/9/1421.full](http://www.cmaj.ca/content/170/9/1421.full).

<sup>115</sup> *ibid.*

In the UK, there appears to be no general legal prohibition of consensual genetic testing. However, a moratorium on the use of *predictive* genetic test results came into effect in 2001. The moratorium, agreed between the Association of British Insurers (ABI) and the UK Department of Health, was recently extended to 2017.

An April 2011, ABI news release described the moratorium as follows:

The moratorium means the results of a predictive genetic test will not affect a consumer's ability to take out any type of insurance other than life insurance over £500,000. Above this amount, insurers will not use adverse predictive genetic test results unless the test has been specifically approved by the Government. Only around 3% of all policies sold are above these limits. The only test that is approved is for Huntington's Disease.<sup>116</sup>

In addition, Article 21 of the *Charter of Fundamental Rights of the European Union* prohibits any discrimination based on "genetic features."<sup>117</sup>

In the UK, non-consensual testing of DNA is banned. The *Human Tissue Act 2004*<sup>118</sup> makes it an offence to take a sample from someone to test their DNA without their consent, except for medical purposes and lawful investigative purposes. The maximum penalty is three years in prison, a fine or both. This prohibition would not affect the insurance industry unless an insurer acquired and tested DNA without the consent of the applicant. This would rarely, if ever be the case, since insurance applicants typically consent to various medical tests and inquiries when they apply for insurance.

A 2002 report by the Nuffield Council on Bioethics specifically addressed genetic testing for behavioural traits in insurance matters. It recommended a moratorium:

We recommend that the use of genetic information about behavioural traits in the normal range should be interpreted as falling under the scope of the five-year moratorium agreed in the UK in 2001 [which was renewed in 2011], and should therefore not be used by insurance companies in setting premiums. Future discussion of possible legislation should include specific consideration of genetic information regarding behavioural traits. If the use of such

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<sup>116</sup> Association of British Insurers, News Release, "Insurance Genetics Moratorium extended to 2017" (April 5, 2011): [www.abi.org.uk/Media/Releases/2011/04/Insurance\\_Genetics\\_Moratorium\\_extended\\_to\\_2017.aspx](http://www.abi.org.uk/Media/Releases/2011/04/Insurance_Genetics_Moratorium_extended_to_2017.aspx).

<sup>117</sup> (2010/C 83/02).

<sup>118</sup> 2004 c. 30, section 45.

information were considered, a thorough examination of the accuracy and reliability of any genetic tests and their likely predictive power would be essential.<sup>119</sup>

In the US, the National Conference of State Legislatures published an analysis of laws protecting genetic privacy in employment and insurance. The summary, updated to 2008, is set out below:

The majority of state legislatures have taken steps to safeguard genetic information beyond the protections provided for other types of health information. This approach to genetics policy is known as genetic exceptionalism, which calls for special legal protections for genetic information as a result of its predictive, personal and familial nature and other unique characteristics. ... With respect to privacy, Washington is the only state that explicitly treats genetic information the same as other health information by including genetic information in the definition of health care information under the state health privacy law.

State genetic privacy laws typically restrict any or certain parties (such as insurers or employers) from carrying out a particular action without consent. Laws in 17 states require informed consent for a third party either to perform or require a genetic test or to obtain genetic information. Twenty-seven states require consent to disclose genetic information.

Alaska, Colorado, Florida, Georgia, and Louisiana explicitly define genetic information as personal property. Alaska also extends personal property rights to DNA samples. In 2001 Oregon repealed its property right to DNA samples and genetic information. Four states mandate individual access to personal genetic information, and 19 states have established specific penalties - civil, criminal or both - for violating genetic privacy laws.

The states with genetic privacy laws ... also may have laws concerning other, related genetics policy issues, such as the use of genetic information in insurance and employment. The legislature may have addressed these issues in conjunction with genetic privacy or separately.<sup>120</sup>

At the federal level in the US, GINA became law in 2008. It came into effect in stages during 2009 and 2010.<sup>121</sup> A publication of the Department of Health and Human Services (HHS) describes GINA

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<sup>119</sup> Nuffield Council on Bioethics, *Genetics and human behaviour: the ethical context* (Nuffield Council on Bioethics, October 2002) at xxxiii: [www.nuffieldbioethics.org/sites/default/files/Genetics%20and%20human%20behaviour.pdf](http://www.nuffieldbioethics.org/sites/default/files/Genetics%20and%20human%20behaviour.pdf).

<sup>120</sup> National Conference of State Legislatures, *Genetic Privacy Laws* (updated January 2008), "Genetic Information: Legal Issues Relating to Discrimination and Privacy": [www.ncsl.org/default.aspx?tabid=14287](http://www.ncsl.org/default.aspx?tabid=14287).

<sup>121</sup> Department of Health and Human Services (HHS), *"GINA" -- The Genetic Information Nondiscrimination Act of 2008: Information for Researchers and Health Care Professionals* (April 6, 2009): [www.genome.gov/Pages/PolicyEthics/GeneticDiscrimination/GINAInfoDoc.pdf](http://www.genome.gov/Pages/PolicyEthics/GeneticDiscrimination/GINAInfoDoc.pdf).

as giving Americans “a baseline level of protection against genetic discrimination.”<sup>122</sup> It notes that many states already have laws that protect against genetic discrimination in health insurance and employment.<sup>123</sup> Some of the state laws are more protective than GINA, others less protective; “[a]ll entities that are subject to GINA must, at a minimum, comply with all applicable GINA requirements”.<sup>124</sup> If the state laws are more restrictive, those entities may also have to comply with the state laws.<sup>125</sup>

The provisions in GINA about non-discrimination in health care do not extend to life insurance, disability insurance or long-term care insurance.

The HHS publication summarizes the provisions of GINA as follows:

GINA generally will prohibit discrimination in health coverage and employment on the basis of genetic information. GINA, together with already existing nondiscrimination provisions of the Health Insurance Portability and Accountability Act, generally prohibits health insurers or health plan administrators from requesting or requiring genetic information of an individual or the individual’s family members, or using it for decisions regarding coverage, rates, or preexisting conditions. The law also prohibits most employers from using genetic information for hiring, firing, or promotion decisions, and for any decisions regarding terms of employment.<sup>126</sup>

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<sup>122</sup> *ibid.*

<sup>123</sup> *ibid.*

<sup>124</sup> *ibid.*

<sup>125</sup> *ibid.*

<sup>126</sup> *ibid.* at 2.

## Employment

Employers may try to make a business case for obtaining genetic information about job applicants or employees. Such information might prove useful in making decisions about employing individuals and assigning them to certain tasks. Genetic testing in employment could take various forms:

- **susceptibility testing** – testing that leads to the identification of a genetic mutation that makes people more susceptible to developing a disease or condition when exposed to certain environmental hazards;
- **pre-symptomatic testing** – testing carried out on healthy individuals to determine whether they carry a genetic mutation that increases their likelihood of developing a genetic condition;
- **diagnostic testing** – confirming a particular diagnosis through a genetic test.<sup>127</sup>

In addition, employers may want to conduct genetic *monitoring* of current employees. This involves examining a person's genetic profile over time to determine if any genetic mutations (changes) occur.

In short, genetic information may be of interest to employers:

- to assess suitability for employment now (using diagnostic testing);
- to assess suitability for employment in the long term (using susceptibility or pre-symptomatic testing of a currently healthy individual);
- to assess the genetic consequences of exposure to certain workplace or environmental materials or contaminants – for example, radiation or chemicals (using genetic monitoring).

Employees or job applicants may also be interested in acquiring such information, but to advance their own welfare and assist them in decisions about which employment to take. However, they may well not want that information shared with employers who may then use it to the employees' disadvantage.

Canada appears to have no legislation specifically directed at genetic testing in employment. However, a range of more general legislation may apply. The *Charter of Rights and Freedoms* may govern attempts by government institutions to genetically test employees or job applicants. The *Charter* guarantees of equality would apply to federal and provincial government employers and could prevent discrimination on the basis of disability or perceived disability revealed by

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<sup>127</sup> Trudo Lemmens, Lisa Austin, "The challenges of regulating the use of genetic information," *Isuma – Canadian Journal of Policy Research*, Vol. 2, No. 3, Autumn 2001, 26 at 27.

genetic testing of a worker. As well, in the narrow circumstance of a private sector organization acting in furtherance of a specific governmental program or policy, the conduct of the private entity might be subject to the *Charter*.<sup>128</sup>

General privacy legislation might also apply: the federal *Privacy Act* for federal institutions, PIPEDA for employees of federally regulated private sector organizations, and provincial data protection legislation for provincially regulated private sector employees. In addition, four provinces have statutory privacy torts, and the *Civil Code of Québec* includes principles relating to respect for privacy. A common law right to privacy may be evolving, and several other common law principles may apply to genetic testing in employment – for example, civil battery or breach of contract.

Federal, provincial and territorial human rights codes prohibit discrimination in employment on the basis of disability. Case law has extended the protection to situations involving perceived disability. The *Charter of Rights and Freedoms* provides constitutional guarantees of equality. These would apply to federal and provincial government employers and could prevent discrimination on the basis of disability or perceived disability revealed by genetic testing of a worker.

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<sup>128</sup> “[A] private entity may be subject to the *Charter* in respect of certain inherently governmental actions. The factors that might serve to ground a finding that an activity engaged in by a private entity is “governmental” in nature do not readily admit of any *a priori* elucidation. *McKinney* makes it clear, however, that the *Charter* applies to private entities in so far as they act in furtherance of a specific governmental program or policy. In these circumstances, while it is a private actor that actually implements the program, it is government that retains responsibility for it. The rationale for this principle is readily apparent. Just as governments are not permitted to escape *Charter* scrutiny by entering into commercial contracts or other “private” arrangements, they should not be allowed to evade their constitutional responsibilities by delegating the implementation of their policies and programs to private entities”: *Eldridge v. British Columbia (Attorney General)*, [1997] 3 SCR 624 at para. 42, per Justice La Forest.



As noted, actual and perceived disability are clearly prohibited grounds of discrimination in employment.<sup>129</sup> The next question is whether a genetic *predisposition* to become disabled in future, or a perception of a genetic predisposition, is also a prohibited ground of discrimination. The reasoning set out in a 2000 Supreme Court of Canada decision<sup>130</sup> suggests that employment discrimination on the basis of a predisposition or a perceived predisposition would also be prohibited under human rights legislation. Thus, human rights codes and the decisions interpreting those codes significantly limit the potential for genetic discrimination in employment.<sup>131</sup> Employers may not discriminate against an individual on the basis of disability unless they can establish that the absence of that disability is a “*bona fide* occupational requirement” (or some language to equivalent effect). Even if the absence of the disability is a *bona fide* occupational requirement, employers are generally under a duty to make “reasonable accommodation” to the person to the point of undue hardship to the employer.

The protection offered by human rights laws is valuable in theory. However, human rights violations are often difficult to prove in practice. As well, the process for achieving redress under human rights legislation is cumbersome. As a practical matter, employees who raise complaints may face future reprisals by their employer. Perhaps the best course of action is to follow the approach of the UK Information Commissioner’s Office in its Employment Practices Code (excerpted below). The Code referred to the advice of the UK’s Human Genetics Commission that employers should not demand employees to take genetic tests. The Information Commissioner’s

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<sup>129</sup> Some human rights laws expressly prohibit discrimination on the basis of perceived disability, and court decisions in some other jurisdictions have ruled that perceived disability is a prohibited ground of discrimination. See the discussion of perceived disability as it applies both to the Quebec *Charter of Human Rights and Freedoms* and to section 15 of the *Canadian Charter of Rights* in *Quebec (Commission des droits de la personne et des droits de la jeunesse) v. Montréal (City)*; *Quebec (Commission des droits de la personne et des droits de la jeunesse) v. Boisbriand (City)*, 2000 SCC 27 (CanLII), [2000] 1 SCR 665 at paras. 49, 79-81. See also *British Columbia (Superintendent of Motor Vehicles) v. British Columbia (Council of Human Rights)*, 1999 CanLII 646 (SCC), [1999] 3 S.C.R. 868.

<sup>130</sup> *Quebec (Commission des droits de la personne et des droits de la jeunesse) v. Montréal (City)*; *Quebec (Commission des droits de la personne et des droits de la jeunesse) v. Boisbriand (City)*, [2000] 1 SCR 665.

<sup>131</sup> See generally the discussion in Trudo Lemmens and Poupak Bahamin, “Genetics in Life, Disability and Additional Health Insurance in Canada: A Comparative Legal and Ethical Analysis”, in Bartha Knoppers, ed., *Socio-Ethical Issues in Human Genetics* (Cowansville: Les Éditions Yvon Blais, Inc., 1998) 114 at 201-09.

Code was somewhat less categorical, but nonetheless concluded that genetic testing in employment should be introduced only “after very careful consideration, if at all.”<sup>132</sup>

Such a position against employer-required genetic testing would not exclude genetic testing for the benefit of employees or applicants. In a factory that handles chemicals, for example, it would be appropriate for an employer to offer tests to its employees to determine if they have a particular genetic susceptibility to harm from those chemicals. It might also be appropriate to offer genetic monitoring to employers. Test results would be made available to the employees, not the employer. In this way, employees with a genetic susceptibility to harm from a workplace chemical could decide whether to work in that environment. However, the decision would be theirs to make, not that of the employer. This would prevent employers from selecting employees who are genetically “resistant” to certain workplace chemicals instead of trying to make the workplace safer for all employees.

**United States:** GINA prohibits discrimination in employment based on genetic information. As well, as noted earlier, many states already have laws that protect against genetic discrimination in employment. The state laws may be more or less protective than GINA. All entities subject to GINA must comply with GINA requirements and, if state laws are more restrictive, with the state laws as well.

**United Kingdom:** GeneWatch UK suggests that fears about discrimination in employment on the basis of genetic tests have been allayed by the introduction of the *Equality Act 2010*.<sup>133</sup> The *Act* limits the information that employers can seek in pre-employment medical checks: “employers can only ask for information that is directly relevant to the applicant’s ability to carry out the work, or needed to make ‘reasonable adjustments’ to the workplace to enable a particular person to work there (as required by law).”<sup>134</sup> And, as noted above, the *Human Tissue Act 2004* banned taking DNA without consent.

The UK Information Commissioner’s Office has produced an Employment Practices Code to promote compliance with the *UK Data Protection Act*.<sup>135</sup>

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<sup>132</sup> Information Commissioner’s Office, *The Employment Practices Code* (June 2005) at 88: [www.ico.gov.uk/upload/documents/library/data\\_protection/practical\\_application/employment\\_practices\\_code.pdf](http://www.ico.gov.uk/upload/documents/library/data_protection/practical_application/employment_practices_code.pdf).

<sup>133</sup> 2010 c. 15.

<sup>134</sup> GeneWatch UK, “Genetic Testing in Insurance and Employment”: [www.genewatch.org/sub-529180](http://www.genewatch.org/sub-529180).

<sup>135</sup> Information Commissioner’s Office, *The Employment Practices Code* (June 2005): [www.ico.gov.uk/upload/documents/library/data\\_protection/practical\\_application/employment\\_practices\\_code.pdf](http://www.ico.gov.uk/upload/documents/library/data_protection/practical_application/employment_practices_code.pdf).

Part IV of the Code sets out rules for dealing with information such as that provided by genetic tests:

Genetic testing has the potential to provide employers with information predictive of the likely future general health of workers or with information about their genetic susceptibility to occupational diseases. Genetic testing is, though, still under development and in most cases has an uncertain predictive value. It is rarely, if ever, used in the employment context. The Human Genetics Commission advises that employers should not demand that an individual take a genetic test as a condition of employment. It should therefore only be introduced after very careful consideration, if at all.<sup>136</sup>

Among the Code provisions dealing with genetic testing are the following:

4.5.1 Do not use genetic testing in an effort to obtain information that is predictive of a worker's future general health.

4.5.2 Do not insist that a worker discloses the results of a previous genetic test.

4.5.3 Only use genetic testing to obtain information where it is clear that a worker with a particular, detectable genetic condition is likely to pose a serious safety risk to others or where it is known that a specific working environment or practice might pose specific risks to workers with particular genetic variations.

4.5.4 If a genetic test is used to obtain information for employment purposes ensure that it is valid and is subject to assured levels of accuracy and reliability.<sup>137</sup>

## **Insurance and Employment – Conclusion**

The issues surrounding genetic testing in employment and insurance will intensify as genetic information produces ever more information.

The insurance situation seems the more problematic of the two, since human rights legislation provides little protection in insurance matters. Here, there may need to be some specific legislative protection – perhaps a requirement that genetic testing or genetic information not be allowed in applications for insurance under a certain value. This would ensure that every individual could acquire a basic level of life or disability insurance. For large amounts of insurance, where “adverse selection” could lead to unfairness (and financial ruin) for insurers, it may be appropriate to allow some form of genetic testing or to require the results of earlier genetic tests to be disclosed.

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<sup>136</sup> *Ibid.* Part 4.5 at 88.

<sup>137</sup> *Ibid.* at 88-9.

Although cumbersome, human rights legislation does offer some protection against discrimination in employment. Still, there may be merit in specific legislation banning genetic testing in employment, or banning employer access to genetic test results, to prevent the abuse of genetic information. Another possible solution would be to create property rights in DNA or genetic information, as some US states have done. Stronger privacy laws of general application would offer yet another layer of protection.

## General Conclusion

The science and ethics of genetics represent a vast area of inquiry, periodically occupying the attention of legislatures, international organizations and research bodies around the world. It has been possible in this document only to survey some of the multitude of privacy and discrimination issues flowing from advances in genetics. The limited scope of this paper has not permitted an examination of many other important issues – state control over birth to ensure a genetically healthy population, genetic screening to determine access to high level athletic or academic training, and many intra-family issues among them. However, it is hoped that this paper has shown the complexity of the privacy and discrimination issues surrounding genetics and can help to serve as a template for inquiries into the issues that were not dealt with in this paper.

Whatever health benefits can flow from advances in genetic technology risk being eviscerated by a failure to offer sufficient protection to DNA and the information derived from that DNA. The risks of loss of privacy and discrimination flowing from the excessive acquisition and release of biological materials by state and private sector organizations, coupled with advances in information acquisition, sharing and processing, are not unique to genetic technology. However, the world of genetics brings these issues very sharply into focus.

This paper has identified several issues, and many of those remain to be resolved – among them, the appropriate limits of forensic DNA analysis, the role of genetics in insurance decisions, the role of genetics in employment, and whether genetic information is somehow exceptional. These issues will become more problematic over time as genetic testing becomes increasingly informative.

As noted earlier, Canadian privacy laws are often porous. The protections they offer may not be sufficiently robust to prevent misuse of the sensitive personal information that DNA analysis can generate, particularly in an era of electronic health records. There may be a need to create more heavily protected “silos” of sensitive personal information, including genetic information or biological samples. Creating property rights in DNA and genetic information may also enhance the control of individuals over their personal genetic information.

The guiding principle should be that all potential uses of genetic information should be for the benefit of individuals, not for some larger business or government interest, unless a compelling case can otherwise be made. We don't want to throw the baby out with the bathwater. We don't want genetic information – or indeed, other sensitive personal information – used in ways that will disadvantage individuals unless the case is made for doing so. We want to ensure that the original hopes about the benefits for individuals of advances in genetics will not be dashed by pressures to use the technology in ways that create disadvantage, rather than benefits, for many individuals.

## Recommendations

### Forensic Uses of DNA

1. Parliament should re-examine the growing list of offences for which a warrant may be sought under the *Criminal Code* to obtain DNA from suspects. The review should examine whether there is empirical evidence to support this increase, particularly because of the privacy intrusions involved in taking DNA from suspects.
2. Until this review is completed and published, there should be a moratorium on adding any new offences to the list of those for which the *Criminal Code* permits a warrant to seek DNA from a suspect.
3. In general, DNA profiles contained in the Convicted Offenders Index, and any DNA samples to which investigators may have access (this would include private data banks) should not be used to conduct familial DNA analysis. The burden should be on the Crown to justify an exception. Exceptions should be made only where the compelling evidence that the value of familial DNA analysis outweighs the harms to privacy interests. Circumstances that could merit an exception to the general rule might include cases involving serious offences such as homicide, coupled with an immediate and compelling public safety interest.
4. DNA samples collected to permit the addition of profiles to the Convicted Offenders Index should be placed on a destruction schedule unless the Crown presents compelling reasons to a court to justify retaining the sample.
5. Parliament should review the provisions in section 7 of PIPEDA that permit collection, use and disclosure of personal information without the consent of the individual to whom the information relates. This review should focus on collection and disclosure to law enforcement agencies to ensure that PIPEDA does not become a “back door” for investigators to obtain DNA profiles or DNA samples of suspects in situations that would not be permitted under the *Criminal Code*. These limitations should not, however, restrict access to such profiles or samples where there are overriding public or compassionate interests for that access.

### Insurance and Employment Uses of DNA

6. Genetic testing or monitoring by employers should be prohibited except where done to provide information to employees who volunteer for such testing or monitoring and where the results are provided to the employees alone. There should be no obligation on employees to disclose the results to employers. Employees should, however, be permitted to disclose such information to their employers – for example, in support of a request for accommodation in the workplace based on the results of the testing or monitoring.
7. In insurance matters, all individuals should have the right to purchase a reasonable amount of life, disability or health insurance without being required to undergo genetic testing or disclose results of previous genetic tests.



*(Continued) Civil offence that was prosecuted by indictment for which the maximum punishment is imprisonment for five years or more.*

47	High treason and treason	122	Breach of trust by public officer	280	Abduction of person under 16	394	Breaker picking stock by selling for his own account
48	Acti intended to alarm Her Majesty or break the public peace	123	Misconduct concerning	281	Abduction of person under 14	395	Fraudulent registration of title
50	Assault with intent to harm Canada or causing to person serious	124	Endangering or purchasing office	282	Abduction in contravention of custody order	396	Fraud in relation to valuable interests
51	Endangering Parliament or legislators	125	Endangering peace officer	283	Abduction	397	Procurement of notes or fraudulently obtained valuable interests
52	Endangering	126	Refusing to give constabulary evidence	284	Procuring intercourse	398	Obtaining an interest in money
53	Endangering	127	Refusing to give evidence	285	Procuring illegal marriage	399	Publication of goods & documents
54	Witness documents	128	Refusing to give evidence	286	Evadement by fraud	400	Fraud proceedings, etc.
57(2)	Force or use of force against	142	Complicity taking reward for recovery of goods	287	Adopting spouse	401	Procurement with intent
61	Purchasement of real and personal effects	144	Force on banks	288	Adopting spouse	402	Authorizing instrument in false name
62	Obtains in relation to military offences	145	Force on banks	289	Force on banks	403	Selling defective shares to Her Majesty
68	Procurement of officers	146	Force on banks	290	Force on banks	404	Force on banks
70	Unlawful detaining - Officer by Governor in Council	147	Force on banks	291	Force on banks	405	Force on banks
74	Privacy	148	Force on banks	292	Force on banks	406	Force on banks
78	Take weapons or explosives on board	149	Force on banks	293	Force on banks	407	Force on banks
80	Black duty of cars in explosive substances	150	Force on banks	294	Force on banks	408	Force on banks
82(1)	Explosives, possession with intent serious	151	Force on banks	295	Force on banks	409	Force on banks
82(2)	Explosives, for benefit of criminal organization	152	Force on banks	296	Force on banks	410	Force on banks
83	Printing or collection property for certain purposes	153	Force on banks	297	Force on banks	411	Force on banks
83(5)	Printing, making available, etc., property or services for certain purposes	154	Force on banks	298	Force on banks	412	Force on banks
83.04	Printing or posting property for certain purposes	155	Force on banks	299	Force on banks	413	Force on banks
83.174	Obtaining of property, documents, or other	156	Force on banks	300	Force on banks	414	Force on banks
83.214	Force on banks	157	Force on banks	301	Force on banks	415	Force on banks
83.217	Purchasement for terrorist activity (in case of second or subsequent offences)	158	Force on banks	302	Force on banks	416	Force on banks
86*	Carriage tax, receipt of firearms	159	Force on banks	303	Force on banks	417	Force on banks
87*	Carriage tax, receipt of firearms	160	Force on banks	304	Force on banks	418	Force on banks
88*	Carriage tax, receipt of firearms	161	Force on banks	305	Force on banks	419	Force on banks
89*	Carriage tax, receipt of firearms	162	Force on banks	306	Force on banks	420	Force on banks
91*	Unauthorized possession firearms, etc.	163	Force on banks	307	Force on banks	421	Force on banks
92*	Carriage tax, receipt of firearms	164	Force on banks	308	Force on banks	422	Force on banks
93*	Carriage tax, receipt of firearms	165	Force on banks	309	Force on banks	423	Force on banks
94*	Unauthorized possession in motor vehicle	166	Force on banks	310	Force on banks	424	Force on banks
95*	Unauthorized possession in motor vehicle	167	Force on banks	311	Force on banks	425	Force on banks
96*	Unauthorized possession in motor vehicle	168	Force on banks	312	Force on banks	426	Force on banks
97*	Unauthorized possession in motor vehicle	169	Force on banks	313	Force on banks	427	Force on banks
98*	Unauthorized possession in motor vehicle	170	Force on banks	314	Force on banks	428	Force on banks
99*	Unauthorized possession in motor vehicle	171	Force on banks	315	Force on banks	429	Force on banks
100*	Unauthorized possession in motor vehicle	172	Force on banks	316	Force on banks	430	Force on banks
101*	Unauthorized possession in motor vehicle	173	Force on banks	317	Force on banks	431	Force on banks
102*	Unauthorized possession in motor vehicle	174	Force on banks	318	Force on banks	432	Force on banks
103*	Unauthorized possession in motor vehicle	175	Force on banks	319	Force on banks	433	Force on banks
104*	Unauthorized possession in motor vehicle	176	Force on banks	320	Force on banks	434	Force on banks
105*	Unauthorized possession in motor vehicle	177	Force on banks	321	Force on banks	435	Force on banks
106*	Unauthorized possession in motor vehicle	178	Force on banks	322	Force on banks	436	Force on banks
107*	Unauthorized possession in motor vehicle	179	Force on banks	323	Force on banks	437	Force on banks
108*	Unauthorized possession in motor vehicle	180	Force on banks	324	Force on banks	438	Force on banks
109*	Unauthorized possession in motor vehicle	181	Force on banks	325	Force on banks	439	Force on banks
110*	Unauthorized possession in motor vehicle	182	Force on banks	326	Force on banks	440	Force on banks
111*	Unauthorized possession in motor vehicle	183	Force on banks	327	Force on banks	441	Force on banks
112*	Unauthorized possession in motor vehicle	184	Force on banks	328	Force on banks	442	Force on banks
113*	Unauthorized possession in motor vehicle	185	Force on banks	329	Force on banks	443	Force on banks
114*	Unauthorized possession in motor vehicle	186	Force on banks	330	Force on banks	444	Force on banks
115*	Unauthorized possession in motor vehicle	187	Force on banks	331	Force on banks	445	Force on banks
116*	Unauthorized possession in motor vehicle	188	Force on banks	332	Force on banks	446	Force on banks
117*	Unauthorized possession in motor vehicle	189	Force on banks	333	Force on banks	447	Force on banks
118*	Unauthorized possession in motor vehicle	190	Force on banks	334	Force on banks	448	Force on banks
119*	Unauthorized possession in motor vehicle	191	Force on banks	335	Force on banks	449	Force on banks
120*	Unauthorized possession in motor vehicle	192	Force on banks	336	Force on banks	450	Force on banks
121*	Unauthorized possession in motor vehicle	193	Force on banks	337	Force on banks	451	Force on banks
122*	Unauthorized possession in motor vehicle	194	Force on banks	338	Force on banks	452	Force on banks

*For example and complete, see page 1*