



# **Privacy Protection and the Disclosure of Health Information: Legal Issues for People Living with HIV/AIDS in Canada**

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# Privacy Protection and the Disclosure of Health Information: Legal Issues for People Living with HIV/AIDS in Canada

Published by the Canadian HIV/AIDS Legal Network

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## **Executive Summary**

Extension of the right to confidentiality of personal medical information recognizes there are few matters that are quite so personal as the status of one's health, and few matters the dissemination of which one would prefer to maintain greater control over. Clearly, an individual's choice to inform others that she has contracted what is at this point invariably and sadly a fatal, incurable disease is one that she should normally be allowed to make for herself. An individual revealing that she is HIV seropositive potentially exposes herself not to understanding or compassion, but to discrimination and intolerance, further necessitating the extension of the right to confidentiality over such information.<sup>1</sup>

HIV, the disclosure of that kind of diagnosis, could result in someone losing their home, their job, their insurance, their health insurance, their life insurance. A whole number of losses can result from disclosure. Confidentiality is key to the relationship that we have with people that we are caring for.<sup>2</sup>

### **Why a report on privacy and the confidentiality of health information?**

Over twenty years into the HIV/AIDS epidemic, a climate of fear and stigma continues to surround HIV/AIDS. Much of the discrimination suffered by people living with HIV/AIDS is a result of the unauthorized disclosure of their HIV status. As a result of the disclosure of their HIV status, people living with HIV/AIDS have been deprived of housing and insurance, lost their jobs, and their family and social relationships have been compromised. Except in narrow circumstances that must be legally and ethically justified, people living with HIV/AIDS should decide how, when, to whom, and to what extent to share their personal health information.

People living with HIV/AIDS consult with teams of health-care professionals when accessing care, treatment, and support. The rapid growth of technology in the last decade has increased the ability of health-care professionals, hospitals, government, insurance

companies, and employers to both collect and transmit personal information. As greater quantities of information are collected and transmitted to a greater number of people, the ability of people living with HIV/AIDS to control the disclosure of their health information has been eroded.

Important ethical and policy reasons exist for ensuring that the medical information of persons with HIV/AIDS remains private and confidential and is not disclosed without consent. As a matter of public policy, the right to privacy and duty of confidentiality are fundamental human rights. The protection and promotion of human rights are necessary to both ensuring the inherent dignity of people affected by HIV/AIDS and to the public health goals of minimizing HIV transmission and lessening the impact of HIV/AIDS on individuals and communities. People will be less willing to get tested for HIV in the absence of strong privacy protections for health information. For those people who are HIV-positive, the provision of effective health care, including counselling, is dependent upon the full exchange of information with health professionals. Research aimed at reducing transmission of HIV and providing better care, treatment, and support for people living with HIV/AIDS depends upon the participation of those infected with HIV. Without strong privacy protections, this research risks being conducted in an unethical manner, or not at all if people are unwilling to participate because they fear that their health information will be used or disclosed without their consent. Therefore, it is in the interests of both the public and private sectors that the privacy of health information of people living with HIV/AIDS be safeguarded to the greatest extent possible.

Recently, both the federal and provincial governments have passed laws, or are in the process of doing so, to address the privacy of personal information. Some of these laws apply only to health information. Others apply to various types of personal information, including health information. In this report, the phrase “health information privacy legislation” refers to both types of laws. These laws regulate the collection, use, and disclosure of personal information. A stated purpose of a number of these laws is to protect the privacy of individuals and the confidentiality of their health information. However, privacy is often not the primary purpose, but rather one among many public policy goals that these laws seek to achieve.

This report examines in detail particular provisions in provincial health and personal information privacy legislation that give people who hold health information the legal authority to disclose that information without a person’s consent in a range of circumstances (eg: investigations and court proceedings; to prevent harm to third parties, to family and friends; and for health research). The inclusion of these “discretionary disclosure clauses” in health information privacy legislation often means that the legislation fails to provide the level of privacy protection accorded to health information under the Canadian Charter of Rights and Freedoms<sup>3</sup> and at common law. In many cases the legislation also fails to adhere to widely accepted privacy standards. Finally, the remedies in these statutes for the unauthorized disclosure of health information are weak, and statutory powers given to administrative agencies to investigate complaints and enforce compliance are inadequate.

This report responds to a need identified by the membership of the Canadian HIV/AIDS Legal Network, governments, and other interested parties. When consulted, these individuals and organizations indicated that the privacy of health information for people with HIV/AIDS is a pressing issue that deserves immediate and long-overdue attention from policymakers and legislators. A national workshop on Privacy and the Disclosure of Health Information was held in Montréal for two days in January 2002. Participants at the

workshop included representatives of HIV/AIDS service organizations, the offices of provincial privacy commissioners, physicians, public health and government officials, and people living with HIV/AIDS. A list of workshop participants and people consulted is contained in an appendix to this report.

## **What is the goal of this report?**

The goal of this report is to contribute to the informed development of Canadian laws and policies that support the right to privacy and the confidentiality of health information of people living with HIV/AIDS. It is intended for people living with HIV/AIDS and their advocates, for community-based organizations, and for legislators and policymakers. The report makes recommendations that, if implemented, would lead to better legal privacy protections for people living with HIV/AIDS.

## **What does the report contain?**

This report focuses on three important areas of concern:

- (1) the lack of adequate and effective protections in Canadian law for the right of people living with HIV/AIDS to keep their personal health information private;
- (2) clauses in legislation that permit a person to disclose another person's personal health information, including the health information of a person living with HIV/AIDS, without that person's consent ("discretionary disclosure"); and
- (3) the inadequacy of legislative remedies for breaches of confidentiality.

The first chapter (Privacy: Human Rights, Public Policy, and Law) examines the right to privacy, the duty of confidentiality and the rule of privilege, and the relationship between them. It then briefly describes the frequency with which personal health information in Canada is disclosed without the consent or knowledge of the individual(s) involved. Finally, it explores the relationship between the health of individuals and communities, and privacy as a human right, and how respect for privacy and the corresponding duty of confidentiality promotes responses to HIV/AIDS that respect the rights of individuals and communities affected by HIV/AIDS.

The second chapter (Recent Developments That Affect Privacy of Health Information) briefly reviews three recent developments that impact on the issues of privacy, confidentiality, and the disclosure of health information of people living with HIV/AIDS in Canada. The first and second developments – advancements in information technology and in health-care delivery – while offering potential benefits to people living with HIV/AIDS, also threaten the ability of people living with HIV/AIDS to keep their health information private and confidential. The third development reviewed is new legislation, either recently enacted or proposed, regulating the collection, use, and disclosure of personal health information.

The third chapter (Legal Protection of Privacy in Canadian Law) canvasses constitutional, other legislative, and common law protections for privacy and duties of confidentiality in Canadian law. It reviews the leading Supreme Court of Canada cases interpreting the Charter sections that protect privacy. The common law protections, or lack thereof, for health information are then reviewed. Finally, the chapter reviews and explains the significant features of Canadian privacy legislation.

The fourth chapter (Disclosure of Health Information) reviews the circumstances under which the health information of people living with HIV/AIDS is disclosed without consent. The distinction between mandatory and discretionary disclosures is explained at the outset. Then it focuses on mandatory disclosure of health information in investigations and legal

proceedings, and identifies the legal basis for challenging mandatory disclosure. The chapter then reviews in detail a number of discretionary disclosure clauses commonly found in existing provincial health information privacy legislation (Alberta, Manitoba, Saskatchewan), two recently enacted laws (Alberta and British Columbia) and a proposed bill (Ontario). It also refers to the federal Personal Information Protection and Electronics Documents Act (PIPEDA), where relevant.<sup>4</sup> Recommendations are made throughout the chapter. These recommendations aim at limiting discretionary disclosure clauses to those that are necessary and justifiable on public policy grounds, and ensuring that such clauses provide privacy protections at least as great as those available under the Charter and at common law.

The fifth chapter (Legislative Remedies for Breach of Confidentiality) examines the remedies for breaches of confidentiality set out in existing provincial health information privacy legislation (Manitoba, Saskatchewan, Alberta) and a proposed bill (Ontario). The remedies in federal legislation (PIPEDA) are compared with the provincial provisions. Recommendations are made throughout the chapter, aimed at improving access to and efficacy of remedies for people living with HIV/AIDS whose health information has been improperly used or disclosed by people or institutions holding personal health information.

The last chapter (Conclusion: Time to Act – An Opportunity for Change) concludes the report with a call to action to governments, policymakers, and people living with HIV/AIDS and the community-based organizations that serve them. Governments and policymakers must enact or amend laws to promote the legal and ethical values that underpin the privacy rights and confidentiality interests that people living with HIV/AIDS have in their health information. It also urges governments to provide adequate resources so that the administrative bodies mandated to oversee the protection of personal health information can fulfill their mandates. Finally, based on the belief that law can change the public discourse around HIV, thereby improving the lives of people living with HIV/AIDS, it calls on people living with HIV/AIDS and the community-based organizations that serve them to engage the legislative process and to work to make these new laws as effective as possible.

## **What are the recommendations in the report?**

This report presents a number of recommendations for action by governments in Canada regarding privacy protection and health information privacy legislation. The recommendations call on governments to take steps to ensure that legislation protects the personal health information of people living with HIV/AIDS. To comply with the recommendations, some provincial and territorial governments must enact new legislation. In provinces where legislation exists, governments will have to amend legislation.

There are two sets of recommendations. The first set of recommendations calls on governments to reduce the scope of discretionary disclosure clauses in privacy protection and health information privacy legislation. General recommendations include:

- only in exceptional and circumscribed situations should a custodian or trustee be permitted to disclose health information without the express and informed consent of a person living with HIV/AIDS; and
- federal, provincial, and territorial governments should review existing health information privacy legislation to ensure that it provides at least the protections for personal health information afforded under the Charter and at common law.

Numerous specific recommendations are made concerning *discretionary disclosure clauses*



in laws that regulate the collection, use, and disclosure of personal information, including health information:

- legislation should include purpose clauses and guiding principles and procedures for disclosure where disclosure is permitted;
- health-care professions must educate their members about their legal and ethical obligations with respect to the right of privacy and the duty of confidentiality;
- clauses that allow for disclosure in investigations and court proceedings should be removed;
- clauses aimed at preventing harm to third parties must reflect the principles stated by the Supreme Court of Canada;<sup>5</sup>
- health custodians should be prohibited from disclosing health information to family and friends without the consent of a competent person except where that person is a substitute decision-maker; and
- detailed recommendations concerning research that utilizes health information.

The second set of recommendations is intended to ensure that legislation contains effective and accessible *remedies* for people living with HIV/AIDS whose privacy rights have been violated. Generally, the report recommends that legislation include remedies to compensate people living with HIV/AIDS for the harms suffered as a result of unauthorized use or disclosure of their health information, and remedies and enforcement powers that serve as deterrents to the improper use and disclosure of personal health information. Specifically, laws that regulate the collection, use, and disclosure of personal information, including health information, should:

- not require the payment of a fee to initiate a complaint;
- give individuals the option of filing a complaint by means of audiotape or videotape as well as in written form;
- contain a two-year limitation period for filing a complaint, with the possibility of extension where there is a reasonable justification, including disability-related reasons;
- require the commissioner/ombudsman to investigate all complaints, unless they are “patently” frivolous or vexatious;
- give the commissioner/ombudsman broad statutory powers to investigate complaints, and provide both governments and individuals with the power to initiate quasi-criminal prosecutions against individuals or organizations for breaches of health information privacy legislation;
- protect employees who file complaints against retaliatory acts by employers; and
- permit individuals to bring lawsuits in civil courts to seek damages for breaches of privacy.

Provincial and federal governments should provide sufficient resources to ensure that people living with HIV/AIDS know about the remedial and enforcement procedures in legislation, and are able to access legal advice and representation.

## **Next steps**

This report will be sent to a broad range of individuals and organizations working in areas related to privacy protection and confidentiality of health information. It will also be sent to appropriate government policymakers such as ministers of health, justice, and consumer

affairs, to organizations of health-care professionals, privacy commissioners and ombudsmen, researchers, and advocates.

In addition, the Legal Network will publish and distribute a series of information sheets on legal issues related to privacy, confidentiality, and the disclosure of health information for people living with HIV/AIDS in Canada. These easier-to-read information sheets will make the contents of the report accessible to a wider audience and provide useful tools for education and discussion of these issues.

### **For further information...**

Contact the Canadian HIV/AIDS Legal Network at [info@aidslaw.ca](mailto:info@aidslaw.ca) or 514 397-6828.

Further copies of this report and the information sheets can be retrieved at the website of the Canadian HIV/AIDS Legal Network at [www.aidslaw.ca](http://www.aidslaw.ca), or ordered through the Canadian HIV/AIDS Information Centre, tel: 613 725-3434; fax: 613 725-1205; email: [aidssida@cpha.ca](mailto:aidssida@cpha.ca).

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<sup>1</sup> *Doe v City of New York*, 15 Fd 364 (2d Cir 1994) at 267.

<sup>2</sup> Testimony of a community health nurse, 1 June 1994, Case 91-240-0838 – Transcript of Coroner's Inquest re: "Unknown Female," quoted in T Palys, J Lowman. Protecting confidential research information. *Canadian Journal of Law and Society* 2000; 15(1): 39-80 at 58.

<sup>3</sup> Part I, Constitution Act, 1982, being Schedule B to the Canada Act 1982 (UK) 1982, c 11.

<sup>4</sup> SC 2000, c 5.

<sup>5</sup> *Smith v Jones*, [1999] 1 SCR 455.



## **Privacy: Human Rights, Public Policy, and Law**

The importance of protecting the confidentiality of medical information, particularly for people living with HIV/AIDS, has been highlighted in numerous articles, government submissions, and workshops of HIV/AIDS organizations.<sup>1</sup> Evidence indicates that people living with HIV/AIDS are subject to stigma and discrimination, both in Canada<sup>2</sup> and internationally.<sup>3</sup> There is also evidence that people living with HIV/AIDS suffer discrimination as a result of the unauthorized disclosure of their HIV status.<sup>4</sup> The potential repercussions include loss of housing, loss of jobs, loss of custody of children, criminal charges for exposing others to HIV infection through sex, and the simple but profound loss of personal relationships that often accompany the disclosure of HIV-positive status.

Personal health information is considered to be one of the most – if not the most – sensitive categories of information, deserving of special protection.<sup>5</sup> Personal health information contains intimate details about an individual's physical, emotional, and mental health. Judges, legal academics, and health-care professionals have repeatedly stressed the importance of protecting the confidentiality of personal health information. A report released in 2000 by a privacy working group consisting of representatives from the Canadian Nurses Association, the Canadian Medical Association, the Canadian Pharmaceutical Association, the Canadian Dental Association, the Canadian Health Care Association, and the Consumers Association of Canada argued that “higher levels of privacy protection must be afforded to health information than to other forms of personal information.”<sup>6</sup>

### **Protection of privacy: a cause for concern**

Canadians are unaware of the number of times their health information is disclosed to third parties without their consent. In the 1980 Royal Commission Report on the Confidentiality of Health Information, Justice Horace Krever documented hundreds of cases of unauthorized access to health files maintained by hospitals and the Ontario Health Insurance Plan.<sup>7</sup> This

Canadians are unaware of the number of times their health information is disclosed to third parties without their consent.

general lack of awareness was a concern for Ontario's Minister of Health 17 years later when he wrote that "people seem genuinely unaware of how easily their health information is relayed from some sources without their knowledge or consent and how limited the remedies are."<sup>8</sup>

Surveys conducted in Canada reveal that the general public is concerned that the privacy of their health information is not adequately safeguarded. According to one Gallup survey, 84 percent of respondents expressed concern that there are insufficient protections to ensure that health information is not disclosed without their consent.<sup>9</sup> Similar findings appeared in a mid-1990s survey that found that 76 percent of Canadians believe that their privacy is not adequately protected.<sup>10</sup> It was reported in this latter survey that almost one in five Canadians have experienced what they consider to be improper disclosure of their personal medical information.<sup>11</sup>

## **The relationship between the right to privacy, the duty of confidentiality, and the rule of privilege**

This report is about the privacy of health information of people living with HIV/AIDS. People living with HIV/AIDS have a right to privacy regarding their health information. Health professionals, and some other people who provide services to people living with HIV/AIDS, owe a duty to people living with HIV/AIDS to keep their health information confidential. This duty is called the duty of confidentiality. The rule of privilege is a rule of evidence. In some circumstances, it can prevent a person who owes a duty of confidentiality to a person living with HIV/AIDS from having to disclose that person's health information in a court case.

In the legal sense, privacy is a right. Privacy is a "fundamental human right, solidly embedded in international human rights law as well as in national constitutions, legislation and jurisprudence."<sup>12</sup> The right to privacy not only requires governments to abstain from interfering with the privacy of individuals, but also imposes a duty on governments to take measures to protect this right.<sup>13</sup> The right to privacy is based on the notion of a zone of personal freedom that cannot be interfered with by public authorities or third parties.<sup>14</sup> It has been argued that the freedom covered by privacy rights can be subdivided into physical and informational "zones" of privacy.<sup>15</sup> The physical zone takes into account respect for a person's bodily integrity, home, and correspondence. Informational privacy involves protection against the unauthorized collection, storage, use, and disclosure of personal information. Health information, including HIV status, is an example of information protected by the informational zone of privacy.

The duty of confidentiality is one way that the right to privacy people have in their personal information is protected.<sup>16</sup> Governments have imposed legal duties on certain people regarding the collection, use, and disclosure of personal information. From the perspective of people living with HIV/AIDS, the most important duty is the duty placed on certain people to keep personal health information confidential, except in exceptional circumstances and under specified conditions. There are both legal and ethical duties of confidentiality. In Canada, the ethical duty of confidentiality has been recognized as a legal duty for health-care professionals.

The rule of privilege is a common law rule of evidence. It prevents the disclosure of confidential information in a legal case, based on policy reasons. Where the rule applies,

someone who owes a duty of confidentiality to another person cannot be forced to disclose information regarding that person. The person in possession of the confidential information cannot be forced to testify in a court case about that information. Nor can that person be forced to disclose written communications (or other recorded information in his or her possession) for use as evidence in court.

A person living with HIV/AIDS can rely on the right to privacy, the duty of confidentiality, and the rule of privilege to control the disclosure of his or her personal health information. Each one can be relied upon to achieve this goal in different yet mutually reinforcing ways. The duty of confidentiality owed to a person protects that person's right to privacy regarding personal information. The rule of privilege protects the person who owes a duty of confidentiality from having to disclose another person's health information without that person's consent.

However, the right to privacy, duty of confidentiality, and rule of privilege do not completely protect the health information of people living with HIV/AIDS in all circumstances. The right to privacy is subject to reasonable limits that can be legally justified. The duty of confidentiality owed to a person only arises in certain relationships. The rule of privilege does not apply to all communications between a person and someone who owes him or her a duty of confidentiality. The limits on the right to privacy, duty of confidentiality, and rule of privilege can all be limited based on public policy considerations, and all are discussed in greater detail below.

A person living with HIV/AIDS can rely on the right to privacy, the duty of confidentiality, and the rule of privilege to control the disclosure of his or her personal health information.

## Protecting privacy as a human right

Confidentiality of health information is fundamental to the preservation of the ethical values of autonomy, dignity, and respect for the individual.<sup>17</sup> Canadian advocates for people living with HIV/AIDS have argued that “patient confidentiality is not only an essential pre-condition to successful treatment ... it's an issue of human dignity and respect.”<sup>18</sup> Stigma and discrimination are pervasive for people living with HIV/AIDS, both internationally and in Canada.<sup>19</sup> Given the climate of stigma and discrimination surrounding HIV/AIDS, it is fundamental that people living with HIV/AIDS control access to their personal health information.<sup>20</sup> As stated by the Privacy Working Group,

individuals have a right to determine to whom, when, how, and to what extent they will disclose their health information and to exercise control over use, disclosure, and access containing identifiable information collected about them. Individuals also have a right to know how their information, when identified, is to be used and safeguarded.<sup>21</sup>

## International human rights

The concepts of human dignity and respect are the basis of international human rights protections. “Historically, the vanguard of privacy protection has been within the arena of international law.”<sup>22</sup> Article 12 of the United Nations Declaration of Human Rights<sup>23</sup> states:

No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.

Canada, as a member of the United Nations, is obliged to respect, protect and fulfill the rights set out in the Declaration and in any UN covenants it has ratified.<sup>24</sup> Article 17 of the International Covenant on Civil and Political Rights<sup>25</sup> contains the same language. Canada ratified this Convention in May of 1976.

In 1988 the Office of the High Commissioner for Human Rights issued a comment for states that had adopted the International Covenant on Civil and Political Rights, which included the following provision:

As all persons live in society, the protection of privacy is necessarily relative. However, the competent public authorities should only be able to call for such information relating to an individual's private life the knowledge of which is essential in the interests of society as understood under the Covenant.<sup>26</sup>

The promotion and protection of human rights, such as privacy, not only protect the inherent dignity of persons affected by HIV/AIDS, but also advance the public health goals of minimizing HIV transmission and lessening the impact of HIV/AIDS on individuals and communities.

The report from the Second International Consultation on HIV/AIDS and Human Rights, taking as its basis the International Guidelines on HIV/AIDS and Human Rights,<sup>27</sup> recognized that the right to privacy of people living with HIV/AIDS includes respect for the confidentiality of all information relating to their HIV status.<sup>28</sup> The Guidelines, and the report, seek to create a positive, rights-based response to HIV/AIDS that is effective in reducing the transmission of and impact of HIV/AIDS and is consistent with human rights and fundamental freedoms. The purpose of the Guidelines is to assist governments in translating international human rights norms into practical measures. The report explains the importance of privacy protection in the context of the HIV/AIDS epidemic:

The individual's interest in his/her privacy is particularly compelling in the context of HIV/AIDS, firstly, in view of the invasive character of a mandatory HIV test and, secondly, by reason of the stigma and discrimination attached to the loss of privacy and confidentiality if HIV status is disclosed. The community has an interest in maintaining privacy so that people will feel safe and comfortable in using public health measures, such as HIV prevention and care services.<sup>29</sup>

The report affirms the inextricable connection and synergy between health and human rights. Generally, human rights and public health share the common objective to promote and protect the rights and well-being of people. The promotion and protection of human rights, such as privacy, not only protect the inherent dignity of persons affected by HIV/AIDS, but also advance the public health goals of minimizing HIV transmission and lessening the impact of HIV/AIDS on individuals and communities. Public health programs that respect privacy rights are more likely to lead to greater well-being for people.<sup>30</sup>

### **Human rights in Canada**

The pre-eminent source of human rights protection in Canada is the Charter. In both civil and criminal cases, Canadian judges have accorded great value to the notion of privacy, elevating it to a constitutional right under the Charter. The Supreme Court of Canada has affirmed in several decisions that privacy is at the heart of liberty in a modern state.<sup>31</sup> As stated in *R v O'Connor*: "Respect for individual privacy is an essential component of what it means to be free."<sup>32</sup> Privacy extends to "information which tends to reveal intimate details of the lifestyle or personal choices of the individual"<sup>33</sup> and includes the right of individuals to determine when, how, and to what extent information about themselves is communicated to others.<sup>34</sup>

Given Canada's obligations under international law and under the Charter, legislators and public policymakers are obliged to take into account the existence of HIV-related stigma and discrimination and right of the "informational" self-determination of people living with HIV/AIDS when formulating law and policy relating to the privacy and disclosure of health information.

## **HIV status, privacy, and public policy**

The ethical principles of respect, dignity, and autonomy are breached when a person's health information is released without his or her consent. When drafting policy and legislation regarding the protection and disclosure of personal health information, legislators must respect these ethical principles. People living with HIV/AIDS are arguably placed at great risk of harm when their health information becomes known. Given the pervasive climate of stigma and discrimination that surrounds HIV/AIDS, and legal responses that criminalize HIV transmission<sup>35</sup> and favour prohibition as a solution to drug addiction,<sup>36</sup> disclosure of health information can lead to a loss of respect, dignity, and autonomy. Disclosure of health information that describes one's sexual practices, drug use, or medical history could potentially result in prosecutions under the Controlled Drugs and Substances Act<sup>37</sup> as well as the Criminal Code,<sup>38</sup> loss of custody of one's children under provincial/territorial child protection legislation, or loss of employment. Where the right to privacy and the duty of confidentiality are not protected and promoted, individual and public health suffer.

For individuals, important policy reasons exist for ensuring that the medical information of patients, particularly people living with HIV/AIDS, is not disclosed without consent except in very limited and clearly delineated circumstances. Health information is considered by many to be the most sensitive of personal information,<sup>39</sup> and health professionals, community organizations, and Canadian courts have stressed the importance of people's interest in keeping health information private. Diagnosis and treatment are impeded in situations where the patient does not reveal aspects of his/her medical condition or history.<sup>40</sup>

The provision of effective health care is dependent upon the full exchange of information between the patient and the health-care professional.<sup>41</sup> Lack of confidentiality undermines HIV prevention, care, and treatment, and increases the impact of the HIV epidemic on individuals, families, communities, and nations.<sup>42</sup> There can be no effective physician/patient relationship unless patients can feel free to be totally open and candid about their symptoms, habits, lifestyles, and concerns.<sup>43</sup> Some individuals may choose not to seek medical care for fear that personal health information will be disclosed without their consent to third parties such as employers, governments, or family members. The problem is particularly acute for people with HIV/AIDS who often have contact with a multitude of health and non-health service providers.<sup>44</sup> In the course of a month, people living with HIV/AIDS may come into contact with multiple doctors, pharmacists, and complementary medical practitioners as well as government agencies, including home-care providers and income-support services.<sup>45</sup> It is therefore critical that a relationship of trust exist between patient and health-care professional.

All human rights are universal, indivisible, interdependent, and interrelated.<sup>46</sup> Given HIV-related stigma and discrimination, a breach of the right to privacy often leads to breaches of other human rights, such as the right to life, liberty, security of the person, the right to work and free choice of employment, and the right to adequate housing and medical care.<sup>47</sup> Central to all these breaches is the breach of the right to equality. The right of people living with HIV/AIDS to equality and non-discrimination on the basis of HIV status is protected under international<sup>48</sup> and Canadian law.<sup>49</sup>

Given HIV-related stigma and discrimination, a breach of the right to privacy often leads to breaches of other human rights, such as the right to life, liberty, security of the person, the right to work and free choice of employment, and the right to adequate housing and medical care.

Community-based AIDS service organizations report that the disclosure of health information of people living with HIV/AIDS to third parties can have “devastating” consequences for them.<sup>50</sup> The repercussions are economic, social, legal, and psychological. Often the discrimination suffered by people living with HIV/AIDS results from the unauthorized disclosure of their health information. People have been deprived of housing or jobs, and social relationships have been compromised.

From a public health perspective, “maximum confidentiality of personal information related to HIV/AIDS is an essential public health measure.”<sup>51</sup> As a former Privacy Commissioner of Canada has stated: “The privacy of personal health information is not only a fundamental human right, it is also a very important social good. We all have a stake in ensuring that our society as a whole is as healthy as possible.”<sup>52</sup> Threats to the privacy of medical information are contrary to the public interest in reducing health risks, ensuring early detection of illnesses, and ensuring that patients receive appropriate medical treatment.<sup>53</sup> The pervasiveness of HIV/AIDS-related stigma and discrimination combines with the potential for the unauthorized disclosure of the health information of people living with HIV/AIDS to undermine the public health goal of reducing HIV transmission.<sup>54</sup>

Health Canada has estimated that 17,000 people in Canada are HIV-positive but unaware of their HIV status.<sup>55</sup> Knowing that one is HIV-positive can have a significant impact on behaviour to prevent transmission of HIV infection.<sup>56</sup> Yet, people will be less likely to seek HIV testing and counselling if they are concerned that their HIV status will be disclosed without consent to third parties such as employers, insurance companies, the government, and relatives. If fewer people learn their status through testing (accompanied by appropriate pre- and post-test counselling), the risk of subsequent avoidable HIV transmission is increased.

A further public health consequence of the failure to protect and promote the right to privacy and duty of confidentiality is the impact on research activities. Where there are not sufficient privacy protections, people living with HIV/AIDS will be reluctant to participate in research studies that seek to enhance prevention efforts, treatment options, and ultimately discover a cure for HIV infection.<sup>57</sup> As the authors of *Ethical and Legal Issues in AIDS Research* write:

Those ... whose lives are intruded upon, and whose bodies serve as objects of examination are often are people who are already subject to discrimination even criminal punishment, who are hidden because of stigma, and who are poor and vulnerable.<sup>58</sup>

## The development of domestic privacy laws

The first laws to protect informational privacy were passed in European countries in the early 1970s.<sup>59</sup> Sweden passed the Data Protection Act in 1973, with other European countries following suit: the then German Federal Republic in 1977, and Norway, Denmark, and France in 1978.

As a result of this patchwork of European laws, the Organisation for Economic Co-operation and Development (OECD) became concerned that the protection of informational privacy might act to impede trade or economic development. As a result of its concern for



trade restrictions, in 1980 the OECD adopted *Guidelines on the Protection of Privacy and Transborder Flows of Personal Data*.<sup>60</sup> The Guidelines were endorsed by all member states of the OECD, and by Canada in 1984. The Guidelines are not about protecting privacy; rather, they are designed to guide states that choose to draft information privacy laws so that any new law is drafted in a way that ensures there is no “undue interference with flows of personal data between Member countries.”<sup>61</sup>

However, the Guidelines contain a series of “fair information practices” that have been incorporated into most of the new legislation in this area. For example, the Guidelines state that there should be limits on the collection of personal data. One such principle in the Guidelines is that the data collected should be limited to only that information that is necessary to meet the purpose for collection. In addition, when information is collected from you, you should be told what that information is going to be used for, and the data should not then be used for another purpose.

The fair-information principles originally set out in the OECD Guidelines also included:

- the core value that consent to disclosure or use of personal information was necessary unless it was otherwise authorized by law;
- personal data should be protected by adequate security measures;
- individuals should be able to access their own personal information and challenge its accuracy; and
- a general policy of openness about policies and practices with respect to personal information and someone you can contact who is accountable for ensuring the principles are followed.

Despite the fact that these principles have existed for over 20 years and that Canada adopted them in 1984, it is only recently that Canada has acted to create legislation that incorporates them.



## **Recent Developments That Affect Privacy of Health Information**

Three recent developments have had a profound effect on the privacy of health information. First, although advances in information technology in health care can result in better care for people living with HIV/AIDS, these technologies are challenging the ability of people living with HIV/AIDS to control their health information. Second, medical services are increasingly delivered based on the team approach, which requires information to be shared among and between teams of care providers. Third, the passage of legislation at the federal level provides the opportunity to advocate for provincial legislation based on recognized privacy principles. Each development will be briefly reviewed.

### **Developments in information technology – potential and dangers**

The rapid growth of technology in the last decade has increased the ability of health-care professionals, hospitals, the government, insurance companies, and employers to both collect and transmit personal information.<sup>62</sup> As stated by Ontario’s Information and Privacy Commissioner, “the development of networks of computerized information systems is revolutionizing the way in which information is accessed and exchanged ... through the evolution of digital technology, it is now possible to transmit vast quantities of complex computer generated information effortlessly and quickly over telecommunication lines.”<sup>63</sup> It has been argued that the electronic management of health information benefits health research, the management of health systems, the prevention of health fraud, and treatment outcomes.<sup>64</sup>

However, the increased electronic management of health information may have adverse consequences, principally that the privacy interests of patients may be placed in serious jeopardy by information technology. As one observer states,

the same technology that breathes life into outcomes, research and “remote” health care delivery has a darker side. In the rush to digitize and link health care information, the danger that unwelcome eyes will peer at private records has never been greater.<sup>65</sup>

As greater quantities of information are collected and shared among an ever-increasing number of users, patients’ ability to control the dissemination of personal information is sharply reduced.<sup>66</sup> Electronic databases are frequently created without sufficient thought or resources put into making them respectful of privacy rules, and the people who access the databases are not sufficiently trained or compliant with access protocols.<sup>67</sup> Bearing this in mind, it is possible to use technological advances to improve care and treatment for people living with HIV/AIDS without sacrificing privacy protections for personal health information. One example of such a database is the HIV Information Infrastructure Project (HIIP), a major program of the Ontario HIV Treatment Network (OHTN).<sup>68</sup> The development of HIIP has been guided by key stakeholders, including people living with HIV/AIDS, staff from community-based organizations, health-care providers, researchers, and government to ensure it was designed to provide maximum security of health information while providing researchers and health-care providers with valuable new tools for delivering care to people living with HIV/AIDS.

It is possible to use technological advances to improve care and treatment for people living with HIV/AIDS without sacrificing privacy protections for personal health information.

The role of technology in the Canadian health-care system was recently examined in the final report of the Commission on the Future of Health Care in Canada (Romanow Report).<sup>69</sup> The Romanow Report identifies leading-edge information technology assessment and research as the foundation of health-care reform.<sup>70</sup> Electronic health records are “one of the keys to modernizing Canada’s health system and improving access and outcomes for Canadians.”<sup>71</sup> The Romanow Report recommends the creation of a personal electronic health record for each Canadian and the development of a pan-Canadian electronic health record framework, assuring interoperability across provincial systems.<sup>72</sup> The Report envisions a system that will provide a “systemic, historic record of every interaction a person has with the health care system.”<sup>73</sup> Without specifying any standards, the Report recommends that the pan-Canadian framework address issues such as security standards and harmonizing privacy policies.<sup>74</sup> It makes two recommendations related to privacy and health information technology, one a general statement and one a call for a specific amendment to the Criminal Code. The Report recommends that individuals should have ownership over their personal health information, ready access to their personal health records, and clear protection of the privacy of their health records.<sup>75</sup> It also recommends that the Criminal Code be amended to protect Canadians’ privacy and to explicitly prevent the abuse or misuse of personal health information, with violations in this area considered a criminal offence.<sup>76</sup>

The Romanow Report accepts the “important advantages” of electronic over paper health-care records with very little discussion of the potential threat that technological innovations such as “a Web site to access personal electronic health records similar to on-line banking” represent to privacy interests. It recognizes that issues surrounding protection of privacy are “serious and complex,” and notes the need for rules and safeguards.<sup>77</sup> Yet, with the exception of a recommended amendment to the Criminal Code, the Report does not specifically address the measures required to protect personal health information contained in electronic health records. By failing to do so, the Report does not fully reflect the cautious approach to electronic health-records systems urged by the then Privacy Commissioner of Canada in a

letter to Romanow.<sup>78</sup> The Privacy Commissioner wrote that he was “troubled by the growing enthusiasm for electronic health records.”<sup>79</sup> He stated that “[c]entralized databases invite inappropriate use and disclosure” and cites several instances where this has occurred. He also stated that “it’s not even possible to identify all of the privacy risks that would result from storing more personal health information electronically” without further information about how data would flow, be linked, and be protected. He identified the almost inevitability of “function creep,” referring to the pressure to use personal information for wide-ranging purposes even though it was collected for a very specific purpose. He warned that if Canadians are not confident that the privacy of their health information can be protected, introduction of electronic health-records systems could make the health-care system less effective:

Doctors cannot provide good diagnosis and treatment without full information, and people are not likely to surrender full information if they fear it might somehow be used against them. If the privacy of health information is not protected by the systems we build, health care in Canada will inevitably suffer, at a tremendous social cost.<sup>80</sup>

## **Developments in health-care delivery – the “team” approach**

For many people living with HIV/AIDS, the progression of HIV illness causes a range of health problems. These health problems are physical and psychological, attributable to HIV infection itself and to the adverse effects of the medications used to treat HIV infection.

The disclosure of a patient’s HIV status to members of the medical team is of great concern to patients who are fearful of the social and economic consequences that may result if such confidential information is conveyed to third parties.

Often the health needs of people living with HIV can best be met by a number of health-care professionals working together as a team. In urban areas, where the majority of people living with HIV/AIDS live and health-care resources are concentrated, services are increasingly organized based on the team approach, and include psychosocial supports. However, the team approach to medical care, practised in recent years by health-care professionals, constitutes a further threat to the privacy interests of patients.<sup>81</sup> Because of the complexity of the health system, it is no longer possible for the patient to share medical information with only one trusted individual.<sup>82</sup> As explained by Rozovsky and Rozovsky:

The twentieth century has seen a vast expansion of the health care services. Rather than relying on one individual, a physician, the patient now looks directly and indirectly to dozens and sometimes hundreds of individuals to provide him with the services he requires. He is cared for not simply by his own physician but by a veritable army of nurses, numerous consulting physicians, technologists and technicians, other allied health personnel and administrative personnel.<sup>83</sup>

As a result of the team approach, patients have lost some of the control they previously exercised over their health information. Information previously held in confidence by one physician is now often disseminated to members of a medical team, particularly in the hospital setting, including health-care and administrative personnel. The Supreme Court of Canada has recognized this trend in health-care delivery when considering the difficulty that patients

encounter in accessing their health records and making sure they are accurate.<sup>84</sup> Confidential medical information is in the possession and control of people who may be unaware of its sanctity or who may not properly protect it.<sup>85</sup> The disclosure of a patient's HIV status to members of the medical team is of great concern to patients who are fearful of the social and economic consequences that may result if such confidential information is conveyed to third parties. Disclosure and discussion of patient medical information among health-care providers (often in common areas such as hospital hallways and elevators) increases the risk that the health information will not remain private, with potentially devastating consequences for the patient.

## **Legislative developments in Canada – privacy of personal information**

Since 1997, legislators at both the federal and provincial levels have introduced or enacted legislation regarding the privacy of personal information.<sup>86</sup> Some legislation specifically regulates health information; some is more general in its application, covering all sorts of personal information. These laws regulate the collection, use, and disclosure of personal information. They have a number of elements in common, if not exactly the same. Examples from federal and provincial laws include:

- “Personal information” means information about an identifiable individual.<sup>87</sup>
- “Record” is very broadly defined, and includes “information in any form, and includes information that is written, photographed, recorded or stored in any manner, on any storage medium or by any means, including by graphic, electronic or mechanical means, but does not include electronic software or any mechanism that produces records.”<sup>88</sup>
- “Custodians,” “trustees,” or “organizations” who collect or maintain personal information (including physicians and other health-care professionals), are assigned duties and obligation under the statutes.<sup>89</sup> These duties or obligations relate to the permitted, and prohibited, collection, use, and disclosure of personal information.
- Each statute contains provisions permitting disclosure of personal information without the consent of the person to whom the information relates in certain circumstances (ie, discretionary disclosure clauses).
- Individuals are provided with a right to access and correct their personal information held by a custodian, trustee, or organization.
- Each statute mandates a “commissioner” or an “ombudsman” to oversee its administration, to receive complaints related to it, and to enforce compliance with it.<sup>90</sup>

The Personal Information Protection and Electronics Documents Act (PIPEDA), enacted by the Parliament of Canada, came into effect on 1 January 2001 for matters within federal jurisdiction, with the exception of the provisions on health information, which came into effect on 1 January 2002. The purpose of PIPEDA is to regulate the collection, use, and disclosure of personal information by organizations carrying on commercial activities.<sup>91</sup> It is unclear whether or not PIPEDA applies to physicians engaged in “commercial” activities.<sup>92</sup> As of 1 January 2004, PIPEDA is binding on organizations that fall within provincial and territorial jurisdiction and that carry on commercial activities, unless the province or territory has passed legislation that is “substantially similar” to PIPEDA and been exempted from PIPEDA by the Governor in Council (ie, by order of the federal cabinet).<sup>93</sup>

On the whole, provincial legislation on the protection of health information (existing and proposed) does not adequately protect the privacy and confidentiality of the personal health information of people living with HIV/AIDS.

On the provincial level, in the last decade British Columbia, Québec, Manitoba, Saskatchewan, and Alberta have all passed legislation regulating personal information. Québec is the only province that has legislation in force that is applicable to the private

sector as well as the public sector.<sup>94</sup> Québec is also the only province to have enacted legislation<sup>95</sup> recognized by the Privacy Commissioner of Canada<sup>96</sup> (who is required to report on this issue to Parliament) and by Parliament<sup>97</sup> as substantially similar to PIPEDA. In the late 1990s, both Manitoba<sup>98</sup> and Alberta<sup>99</sup> passed legislation regarding personal health information applicable to the publicly funded health-care sector. In 1999, Saskatchewan enacted similar legislation, The Health Information Protection Act, but it has not yet been proclaimed.<sup>100</sup>

On several occasions the Ontario government has proposed bills regulating the collection, use, and disclosure of health information, including the Personal Health Information Privacy Act, 2000,<sup>101</sup> and recently, a draft Privacy of Personal Information Act, 2002,<sup>102</sup> which did not proceed to first reading in the legislature. If enacted in its

draft form, it would apply to commercial private enterprises as well as non-governmental organizations such as charities, the health sector (including private and public hospitals), health-care practitioners, the Ministry of Health, health-care clinics, pharmacies, and laboratories.<sup>103</sup> On 14 May 2003, Alberta introduced legislation in response to PIPEDA. (It was passed by the legislature in December 2003, with a number of amendments.<sup>104</sup>) The then Privacy Commissioner of Canada cited a number of “very grave deficiencies” in the first-reading draft of the Alberta bill, which in his view would make it impossible for the federal government to recognize the bill as substantially similar.<sup>105</sup> In November 2003, the British Columbia legislature passed legislation dealing with the protection of personal information.<sup>106</sup> In the opinion of the then Privacy Commissioner of Canada, the first-reading draft of the bill was not substantially similar to PIPEDA.<sup>107</sup> The first-reading draft of the bill was passed on second and third readings without amendment. Both the Alberta and British Columbia legislation come into force on 1 January 2004.

On the whole, provincial legislation on the protection of health information (existing and proposed) does not adequately protect the privacy and confidentiality of the personal health information of people living with HIV/AIDS. First, privacy is often one among many public policy goals that these laws seek to achieve. Second, existing legislation tends to focus on the sectors covered (private or government) or who is covered (definitions of custodian or trustee) rather than on protecting the information itself regardless of which sector or person holds it.<sup>108</sup> This leads to overly complex legislation and inconsistent use of concepts and coverage in different pieces of legislation, existing and proposed. Third, the discretionary disclosure clauses are overbroad. Health information custodians are given the statutory authority to disclose personal information to third parties without the patient’s consent beyond what is required to achieve the purported goal of the disclosure. The discretionary disclosure clauses also fail to protect personal health information to the same extent as existing Charter and common law protections. The shortcomings of the discretionary disclosure clauses for people living with HIV/AIDS are analyzed the chapter on Disclosure of Health Information, below.



## Legal Protection of Privacy in Canadian Law

The legal protection of privacy in Canada has been described as a patchwork of rules.<sup>109</sup> The laws are considered to be “comparatively underdeveloped” and excessively complicated.<sup>110</sup> Justice Krever noted in the 1980 *Report of the Royal Commission of Inquiry into the Confidentiality of Health Information in Ontario* that there is “no consistent treatment or coherent policy regarding the confidentiality of health information.”<sup>111</sup> In the same vein, the authors of a leading text on Canadian privacy law note that “there is a veritable hodge-podge of rules relating to the protection of personal health information.”<sup>112</sup> This chapter briefly discusses the protection of privacy interests in Canadian law, including Charter protections and the remedies available at common law for breach of confidentiality relating to the disclosure of health information. It then canvasses provincial legislation concerning specific professions and health facilities, general privacy statutes, more specific health information laws, and finally, federal legislation in the area (PIPEDA).

### Canadian Charter of Rights and Freedoms

The word “privacy” does not appear in the Charter. The Constitution of Canada, which includes the Charter, is the supreme law of Canada, and any law that is inconsistent with the provisions of the Constitution is, to the extent of the inconsistency, of no force or effect.<sup>113</sup> The Charter can also be used by people living with HIV/AIDS to prevent unconstitutional actions by people acting on behalf of the government.<sup>114</sup> The Charter addresses only the relationship between individuals and the state.<sup>115</sup> Respect for dignity is a value that underlies almost every right protected under the Charter.<sup>116</sup> As stated by the Supreme Court, “a fair

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legal system requires respect at all times for the complainant's personal dignity, and in particular his or her right to privacy, equality, and security of the person."<sup>117</sup> Privacy is an important value underlying the Charter section 7 guarantees of liberty and security of the person and the section 8 guarantees against unreasonable search and seizure.<sup>118</sup>

People living with HIV/AIDS may be charged with various offences under the Criminal Code if they expose others to a risk of HIV transmission. Even where criminal charges are not based on exposure to HIV, a Crown attorney may try to put evidence before a court about a person's HIV status. A person in either of these situations may be able to use sections 7 and 8 of the Charter to make arguments as to why his or her personal health information should not be put into evidence before a court.

### **Privacy and section 8 of the Charter**

Under s 8 of the Charter, "Everyone has a right to be secure against unreasonable search or seizure." Where a person claims that his or her s 8 rights have been breached, a court must balance competing interests and choose which one wins out. On the one hand is the person's interest in being left alone by the state. On the other is the state's interest in intruding on the individual's privacy in order to advance goals, such as law enforcement. In an early case, the Supreme Court stated that s 8 protects a reasonable expectation of privacy.<sup>119</sup> In another early s 8 case the Supreme Court characterized privacy as being

at the heart of liberty in the modern state.... Grounded in [one's] physical and moral autonomy, privacy is essential for the well-being of the individual.... [I]t is worthy of constitutional protection, but it also has profound significance for the public order."<sup>120</sup>

In that case the Supreme Court found that taking a blood sample from an accident victim without his knowledge or consent infringed his s 8 rights.

The Supreme Court has stated on numerous occasions that s 8 of the Charter should be broadly interpreted to give effect to its purpose, that is, to ensure the citizen's right to a reasonable expectation of privacy, and to prevent unjustified searches by the state.<sup>121</sup> In *R v Plant* the Supreme Court specified the type of information that s 8 is intended to protect:

In fostering the underlying values of dignity, integrity and autonomy, it is fitting that s. 8 of the Charter should seek to protect a *biographical core of personal information which individuals in a free and democratic society would wish to maintain and control from dissemination to the state*. This would include information which tends to reveal intimate details of the lifestyle and personal choices of the individual.<sup>122</sup> [emphasis added]

The Supreme Court has accorded medical information a high degree of constitutional protection under s 8 of the Charter.<sup>123</sup> Physical integrity, including bodily fluids, ranks high among the interests receiving constitutional protection.<sup>124</sup> The constitutionally protected privacy interests of an individual extend to hospital records. The Supreme Court has found that the release of patient information by a physician to the police without the consent of the patient violates the patient's right to privacy in s 8 of the Charter.<sup>125</sup> The Supreme Court has identified hospitals as "specific areas of concern in the protection of privacy, given the vulnerability of individuals seeking medical treatment."<sup>126</sup> The Court expressed concern about the "unwelcome complicity" between the police and hospital officials in the collection of evidence in criminal investigations:



The presence of the police in the emergency room can only serve to undermine the physician–patient relationship, as the accused would likely interpret these facts as a sign that the medical staff was operating in conjunction with the police investigation. Such a scenario could have catastrophic results if an accused resisted essential treatment for fear it might incriminate him in future criminal proceedings.... [S]uch complicity is at best unwise....<sup>127</sup>

The Supreme Court also analyzed the extent to which the Charter protects privacy interests in the criminal case of *R v Mills*.<sup>128</sup> In *Mills*, a man was charged with sexual assault and unlawful sexual touching of a woman. The man’s lawyer asked the court to order that the woman’s psychiatric and child-service records be disclosed. The Criminal Code contains provisions that guide a judge making such a decision. The woman challenged the constitutionality of those provisions, based on ss 7 and 8 of the Charter. The Supreme Court was asked to decide whether the provisions breached the woman’s constitutional rights. It recognized that the freedom not to be compelled to share our confidences with others is the very hallmark of a free society. It stated that the interest in being left alone by the state includes the ability to control the dissemination of confidential information about oneself.<sup>129</sup>

Police or other state actors must follow Charter principles when carrying out searches and seizures. What are those principles? Section 8 seeks to prevent unjustified searches by the state. Therefore, prior authorization, where feasible, is a precondition for a valid search and seizure by police officers.<sup>130</sup> Search warrants are used by police officers in the investigation of criminal or quasi-criminal offences to access records, including health records. In order to obtain a search warrant, a police officer must present sworn evidence to a justice of the peace.<sup>131</sup> The justice of the peace can issue a warrant only if he or she has reasonable grounds to believe that evidence of the commission of an offence in the Criminal Code or in another federal statute exists in the place to be searched under the warrant.<sup>132</sup> The justice of the peace must balance the privacy interests of the individual in a democratic society against the interest of the state in investigating and prosecuting crimes. Even after the requirements of the Criminal Code have been met, the process of determining if a search warrant should be issued may still be a difficult and complex process.<sup>133</sup>

Two Ontario courts have used s 8 of the Charter to read additional requirements into the search warrant provisions of the Criminal Code in order to protect medical records. In *R v JO*, the Crown obtained a search warrant to seize the psychiatric records of a criminal accused.<sup>134</sup> The court said that the search warrant should not have been issued without conditions. Relying on the Supreme Court decision in *O’Connor*, the Ontario court stated that

it seems to me that there should have been some attempt in the warrant to protect the privacy interest of patients treated by [the psychiatrist] by imposing conditions.... [T]here could have been conditions like the sealing of the records for a reasonable period of time until there was some judicial determination as to the probative value as opposed to the prejudicial effect of such records.<sup>135</sup>

In *R v Serendip Physiotherapy Clinic*, the police obtained a search warrant for physiotherapy records while investigating alleged fake claims for automobile insurance benefits.<sup>136</sup> Two physiotherapists challenged the legality of the search warrant. The Crown lawyer argued that physiotherapy records are not capable of raising important privacy interests. The Ontario Superior Court of Justice rejected this argument, stating that “all health information should be presumptively protected.”<sup>137</sup> The Ontario court proposed guidelines that justices of the peace should follow when deciding whether to grant a search warrant for health records. The

guidelines the court read in are significant and detailed. As a first step, the police must disclose in their application for the search warrant any evidence that might indicate the records are health records. If the justice of the peace determines that the documents are health records and that the patient may have a privacy interest in those records, the warrant should require the police to:

- seal the records immediately and keep them sealed until a judicial officer holds a hearing; and
- notify those in possession of the records and those who have a privacy interest in the records that they will have an opportunity to make submissions to a judicial officer.

The judicial officer must receive the submissions and make a decision whether and to what extent to require disclosure, after balancing the competing interests of the police need to investigate crime and a patient's right to privacy.<sup>138</sup> The judicial officer should consider examining the records to determine whether and to what extent they should be disclosed, and should consider restricting disclosure and mitigating the invasion of privacy by imposing conditions.

The power of police to search a person when carrying out an arrest (known as a search “incident to arrest”) has developed as a long-standing exception to requirement of a warrant. The power to search a person who is under arrest may include the authority to fingerprint<sup>139</sup> or conduct a “frisk” search<sup>140</sup> without a warrant. The police do not have the right to obtain bodily samples as evidence<sup>141</sup> except where an officer believes that a person is operating a vehicle while impaired.<sup>142</sup> Even where bodily samples are not taken, in the case of a person living with HIV/AIDS a police frisk search may indirectly reveal health information of a highly personal nature. If a person is arrested while carrying his or her HIV antiretroviral medications, a police officer may, based on the type of medications, correctly assume that the person is HIV-positive.

State actors other than police conduct investigations and undertake searches and seizures. Countless federal and provincial laws provide for powers of search (eg, rights of entry, powers of inspection) and seizure (eg, authority to make, take, and remove copies, samples, or documents). Some legislation grants the powers of search and seizure directly to individual state actors, while other legislation requires that administrative commissions, boards, or tribunals issue a warrant before a search is conducted. Personal health information is most likely to be searched for and seized under legislation regulating public health, health care, and regulated health professions. For example, the Ontario Health Protection and Promotion Act empowers an inspector appointed by the Minister, a medical officer of health, a public health inspector, or a person acting under a direction given by a medical officer of health, the power to enter and have access to, through, and over any premises to make examinations, investigations, tests, and inquiries for the purpose of enforcing the Act.<sup>143</sup> Further, that person may make, take, and remove or require the making, taking, and removal of copies, samples, or extracts related to an examination, investigation, test, or inquiry.<sup>144</sup> Significantly, there is no requirement that the person carrying out the inspection obtain a warrant, other than when searching a private residence, and then only if the occupier refuses to consent to entry.<sup>145</sup>

The Supreme Court considered the constitutional validity of a regulatory statute authorizing a warrantless search and seizure in the leading case of *Hunter v Southam*.<sup>146</sup> It held that while warrantless searches are prima facie unreasonable under s 8 of the Charter, the party seeking to justify a warrantless search may rebut the presumption of unreasonableness by demonstrating: (1) a meaningful authorization procedure presided over by someone able to assess the conflicting interests of the state and the individual in an entirely neutral and impar-

tial manner, and (2) reasonable and probable grounds, established upon oath, to believe that an offence has been committed and that there is evidence to be found at the place of the search.

### **Privacy and section 7 of the Charter**

Under s 7 of the Charter, “Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.” The s 7 rights to liberty and to security of the person protect privacy interests.<sup>147</sup> The Supreme Court has recognized that individuals have legal and enforceable privacy rights in some circumstances. It has determined that if those rights are to be limited, a certain scrutiny must occur and certain tests must be met. The Court has developed the s 7 privacy principles in criminal law cases.

In *R v Mills*, the Court stated that when a therapeutic relationship between a sexual assault victim and her physician is threatened by the disclosure of private records, the security of the person right in s 7 of the Charter is implicated.<sup>148</sup> In *R v O’Connor*, the Court recognized a witness’s right to privacy in his or her health records. Justice L’Heureux-Dubé stated that “respect for individual privacy is an essential component of what it means to be ‘free’” and that the “essence of privacy ... is that, once invaded, it can seldom be regained.”<sup>149</sup> Therefore, the reasonable expectation of privacy must be protected at the point of disclosure.

The Supreme Court has recognized that individuals have legal and enforceable privacy rights in some circumstances.

To that end, the Court held that s 7 of the Charter requires that before a court will order the disclosure of the private records of a witness in a legal case, a “reasonable system of ‘pre-authorization’” must be followed.<sup>150</sup> It set out a two-stage test.<sup>151</sup> First, the accused must show that the records are likely relevant to proving a fact in the case, or showing that a witness is mentally fit to testify. This aspect of the test is designed to prevent “fishing expeditions” by defence counsel. At the second stage of the test, a judge weighs the evidence. The judge is trying to determine whether the benefit of an order to disclose the records would outweigh the negative consequences. The judge is also trying to determine whether the ability of the accused to make full answer and defense would be unreasonably limited if the record is not disclosed. Chief Justice Lamer, and Justices L’Heureux-Dubé and Sopinka, agree that the principles behind the two-stage test apply to other records of witnesses, such as school records, records held by social workers, and other private records.<sup>152</sup>

### **The common law**

The “common law” is a body of law that derives from, and is developed through, judicial decisions. The common law is distinguished from statutory law, comprised of acts and regulations passed by the legislature or executive, as the case may be. The common law does not offer strong protection for privacy rights. As stated by Charnetski et al,

absent some duty arising out of the nature of the relationship in which the information is communicated or a contractual right to privacy of that information, the individual is left largely unprotected by the common law.<sup>153</sup>

### **Tort of invasion of privacy**

In contrast to courts in the United States, Canadian courts have been reluctant to recognize a common law tort of *invasion of privacy*.<sup>154</sup> A “tort” is a civil wrong (other than a breach of contract) that can be the basis of a lawsuit for damages. The law of torts is the body of law that defines torts and creates a right to sue when someone commits a tort. In the US, the right

to sue for an invasion of privacy has existed for many years.<sup>155</sup> The author of a leading text on Canadian tort law states that “[w]e seem to be drifting closer to the American model,”<sup>156</sup> while another author recognizes the “new tort of privacy invasion.”<sup>157</sup> However, neither the Supreme Court of Canada nor any provincial court of appeal has recognized the tort of invasion of privacy.<sup>158</sup> Yet a number of lower courts have recognized such a tort<sup>159</sup> or the fact that

Generally, courts are more willing to protect privacy interests arising out of special relationships, such as the duty of confidentiality health professionals owe to patients.

such a tort may exist.<sup>160</sup> However, people have been discouraged from initiating lawsuits for privacy breaches because of the uncertainty of the outcome in these cases, the high costs of litigation, and the public nature of court proceedings.<sup>161</sup> Where people have won their case, damage awards have ranged from nominal to modest.<sup>162</sup> As Flaherty argues, “the common law remedies do not appear to be very useful.”<sup>163</sup>

Judges in Canada have tended to rely upon existing torts such as negligence, nuisance, trespass, and defamation to compensate persons for violations of their personal privacy.<sup>164</sup> Generally, courts are more willing to protect privacy interests arising out of special relationships, such as the duty of confidentiality health professionals owe to patients. Courts have also been willing to protect business people and companies where their confidences have been breached and financial losses have resulted. This willingness reflects the fact that the law relating to professional duties is firmly established and also reflects the relative ease of quantifying damages where a commercial loss has been sustained. Courts’ protection of special relationships is analyzed in the next section.

### **Health professionals’ fiduciary duty, breach of fiduciary duty, and breach of confidence**

Health-care professionals owe patients a special obligation not to breach patient confidentiality. This special obligation is called a fiduciary obligation, and the courts have developed

Where a health professional breaches the fiduciary duty he or she owes to a patient regarding confidentiality of patient information, the patient can sue the health professional for damages.

it to protect the interests of a vulnerable party to a relationship. The law imposes a fiduciary obligation where one person (the fiduciary) must act in another person’s (the beneficiary’s) best interest by virtue of the relationship between the two. The common law holds the fiduciary to a strict standard of conduct. Where a health professional breaches the fiduciary duty he or she owes to a patient regarding confidentiality of patient information, the patient can sue the health professional for damages. The patient can recover money to compensate for economic and non-economic damages suffered as a result of the breach.<sup>165</sup>

A fiduciary obligation has been imposed in relationships that possess three general characteristics:

- (1) The fiduciary has scope for the exercise of some discretion or power.
- (2) The fiduciary can unilaterally exercise that power or discretion to affect the beneficiary’s legal or practical interests.
- (3) The beneficiary is particularly vulnerable to or at the mercy of the fiduciary holding the discretion or power.<sup>166</sup>

It is possible for a fiduciary relationship to be found even where not all of these characteristics are present. Nor will the presence of all three characteristics invariably identify the existence of a fiduciary relationship. The nature of the obligation will vary depending on the factual context of the relationship in which it arises.<sup>167</sup>

The Supreme Court has held that a fundamental characteristic of the doctor–patient relationship is its fiduciary nature, in which the patient places “trust and confidence” in the physician.<sup>168</sup> However, “not all fiduciary relationships and not all fiduciary obligations are the same; these are shaped by the demands of the situation” such that a “relationship may properly be described as ‘fiduciary’ for some purposes, but not for others.”<sup>169</sup> In *McInerney v MacDonald*, the Supreme Court stated that in the context of a doctor–patient relationship, the physician has the duty to act with utmost good faith and loyalty, and to hold information received from or about a patient in confidence.<sup>170</sup> La Forest J notes that when a patient seeks health care from a physician, he or she discloses highly sensitive and private information: “it is information that goes to the personal integrity and autonomy of the patient.”<sup>171</sup> The Court further stated that “information about oneself revealed to a doctor acting in a professional capacity remains in a fundamental sense one’s own.”<sup>172</sup> It is the decision of the individual patient whether to retain or communicate the information to others.<sup>173</sup> The Supreme Court stated that “the confiding of the information to the physician for medical purposes gives rise to an expectation that the patient’s interest in and control of the information will continue.”<sup>174</sup>

Although the fiduciary duty described in *McInerney* is confined to the physician–patient relationship, there is no reason in principle why it should not apply to other health-care providers.<sup>175</sup> Many sorts of regulated health professionals are governed by codes of professional ethics that impose a duty of confidentiality. The reasoning in *McInerney* should apply equally to these other health-care professionals. In the Saskatchewan case of *Parslow v Masters*, a dentist was held to be in a fiduciary relationship to his patient and consequently had a duty to maintain the confidentiality of the patient’s dental records.<sup>176</sup>

Where a physician (or other health-care professional) breaches his or her fiduciary duty of confidentiality owed to a patient by disclosing the patient’s confidential medical information without consent, the patient can sue the physician for breach of fiduciary duty. A patient whose confidence is breached by a health-care professional would also have grounds to bring an action for breach of confidence. The receipt of confidential information in circumstances of confidence generally establishes a duty not to use that information for any purpose other than that for which it was conveyed. If the information is used for another purpose and the person suffers damage as a result, he or she is entitled to a remedy – which can be sought by bringing an action for breach of confidence.<sup>177</sup> The Supreme Court set out the test for a breach of confidence in a commercial case involving breach of the duty of confidentiality regarding geological findings in mining and exploration.<sup>178</sup> To prove that there has been a breach of confidence, a plaintiff must establish that the information conveyed was:

- confidential;
- communicated in confidence; and
- misused by the party to whom it was communicated, to the detriment of the party who communicated the information.<sup>179</sup>

Despite the Supreme Court’s recognition of a fiduciary relationship between a physician and patient, including the duty of confidentiality in relation to health records, there are no reported cases of actions brought against a physician, other health-care professional, or hospital for breach of fiduciary duty or breach of confidence.<sup>180</sup>

In *McInerney v MacDonald*, the Supreme Court stated that in the context of a doctor–patient relationship, the physician has the duty to act with utmost good faith and loyalty, and to hold information received from or about a patient in confidence.

## The rule of privilege

The rule of privilege is a common law rule of evidence. Where the rule applies, it prevents the disclosure of confidential information in a legal case for policy reasons. In other words, someone who owes a duty of confidentiality to another person cannot be forced to disclose information regarding that person. The person in possession of the confidential information cannot be forced to testify in a court case about that information. Nor can that person be forced to disclose written (or other recorded information in his or her possession) communications for use as evidence in court. According to the rule of privilege, particular social values are “of such importance that [they] cannot be sacrificed to ascertain the truth in litigation.”<sup>181</sup> In practice, it is up to a witness or a party in a proceeding to claim privilege to protect information from disclosure.

There are two categories of privilege recognized in Canadian common law jurisdictions: “class” and “case-by-case” privilege. Under class privilege, it is presumed that information cannot be disclosed in a legal case.<sup>182</sup> At common law, communications between a health professional and a patient are *not* protected under a class privilege. Québec, where the common law does not apply, is the only province that has created by statute an evidentiary privilege in civil cases for communications between a physician and his or her patient.<sup>183</sup> Communications between a solicitor and a client and communications between spouses are two classes of privileged communications recognized in common law.<sup>184</sup> Communications between solicitors and clients, and between spouses, normally cannot be disclosed in a legal proceeding because of overriding policy reasons.<sup>185</sup> The primary policy reason for solicitor–client class privilege is to promote full and frank communications between the client and the lawyer to ensure effective legal representation, thus ensuring the integrity of the judicial process.<sup>186</sup> Avoiding marital discord and encouraging candour between spouses are the stated reasons for privileged marital communications.<sup>187</sup>

The second type of privilege – case-by-case – offers a more flexible and pragmatic approach to identifying and protecting privileged communications from disclosure.<sup>188</sup> The Supreme Court has found that case-by-case privilege can exist in both the civil and criminal contexts.<sup>189</sup> As stated above, communications between a health professional and a patient are not presumed to be privileged. However, in certain circumstances communication between a health professional and a client may be privileged. The Supreme Court has adopted the Wigmore criteria, a four-part test, to determine whether case-by-case privilege applies to a particular circumstance where it is claimed:

- (1) the communication must originate in a confidence that it will not be divulged;
- (2) the confidentiality must be essential to the relationship in which the communication arises;
- (3) the community believes that the relationship be sedulously fostered; and
- (4) the injury to the relation that would result from the disclosure of the communication must be greater than the benefit thereby gained for the correct disposal of litigation.<sup>190</sup>

The Supreme Court has indicated that the four criteria can be applied to communications or documents, not only relationships, individually or by sub-groups, on a case-by-case basis.<sup>191</sup> As a result, within the same confidential relationship, a court could order certain communications and documents to be disclosed, and protect others from disclosure. The Supreme Court has also stated that the common law rule of privilege must develop in a way that reflects Charter values.<sup>192</sup> Charter values come into play when a court is called upon to

balance interest under the fourth part of the Wigmore test. The particular Charter values referred to by the Supreme Court in *MA v Ryan* were the individual's right to privacy set out in s 8 and every person's right to equal treatment and benefit of the law under s 15.<sup>193</sup>

The communications between a person with HIV/AIDS and his or her pharmacist, doctor, social worker, counsellor, or psychologist will be privileged if the four criteria are met. The problem with the case-by-case privilege is the uncertainty it creates with respect to whether a court will compel disclosure of a confidential communication.

In Québec, the common law rules relating to privileged communications do not apply. However, the Québec Charter of Human Rights and Freedoms<sup>194</sup> (Québec Charter) and the Civil Code of Québec<sup>195</sup> (CCQ) protect professional privilege, and the Medical Act<sup>196</sup> specifically protects physician–client privilege.<sup>197</sup> It is important to note that the protection of physician–client privilege under the CCQ, Québec Charter, and Medical Act does not apply in criminal proceedings. In Canada, criminal law is a matter of federal jurisdiction, and federal criminal law does not recognize a physician–client privilege.<sup>198</sup>

The Supreme Court has indicated that a physician's duty of confidentiality is not absolute, and is subject to a "public safety exception."<sup>199</sup> Discussing the solicitor–client relationship, the Court stated that the duty of confidentiality must be balanced against other "compelling public needs," including individual or public safety. Solicitor–client privilege is the highest privilege recognized by the courts. Therefore, "if a public safety exception applies to solicitor–client privilege, it applies to all classifications of privileges and duties of confidentiality."<sup>200</sup> It is likely that a court would find that a physician may breach a duty of confidentiality owed to patients in circumstances where the public interest is less "compelling" than that needed to breach the solicitor–client privilege.

## The right to sue under provincial legislation

Four common law provinces (British Columbia, Manitoba, Saskatchewan, and Newfoundland) have enacted general privacy statutes that give a right to sue for violations of privacy.<sup>201</sup> Typically, the statutes state that "it is a tort, actionable without proof of damage, for a person, wilfully and without a claim of right, to violate the privacy of another."<sup>202</sup> In Québec, Canada's only civil law jurisdiction, articles 35 to 41 of the CCQ provide a right to privacy. Article 35 states:

Every person has a right to the respect of his reputation and privacy. No one may invade the privacy of a person without consent of the person or his heirs unless authorized by law.<sup>203</sup>

These provincial statutes do not specifically address actions for the breach of privacy relating to health information. But a person can rely on the general statutory right to sue for violation of privacy in order to sue for the disclosure of his or her private health information.

It is noteworthy that the plaintiff need not prove that he or she suffered harm in lawsuits under the privacy statutes.<sup>204</sup> This is because their purpose is to protect the plaintiff's security interests, as well as the tranquility expected in a well-ordered society.<sup>205</sup> This is a very positive aspect of the tort created by these privacy statutes.

Unfortunately, in order for a lawsuit to be successful under the privacy statutes of three of the four common law provinces, the plaintiff must establish that the defendant "wilfully"<sup>206</sup> and "without colour of right" violated his or her privacy. In *Davis v McArthur*, the

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court defined “wilfully” in the context of the British Columbia Privacy Act as “intentionally, knowingly and purposely without justifiable excuse” and “claim of right” as “an honest belief in a state of facts which, if it existed, would be a legal justification or excuse.”<sup>207</sup> In other words, under the privacy statutes, the court is authorized to consider whether the defendant’s conduct was reasonable in the circumstances in light of what the defendant knew. McNairn and Scott note that “Such a standard gives a high degree of leeway to an individual judge’s view of what is or what is not reasonable at least until a fuller jurisprudence analyzing the rationality of a defendant’s claim develops.”<sup>208</sup>

In addition, the statutes generally fail to define the meaning of the right to privacy. Further, several “strong” defences are available to persons who are sued by plaintiffs for breach of privacy.<sup>209</sup> An additional impediment to successful claims under the Privacy Act of Manitoba is that the invasion of privacy must be “substantial.”<sup>210</sup>

Few legal actions have been initiated under the provincial privacy acts.<sup>211</sup> Where lawsuits have been brought, “defendants have generally fared better than plaintiffs, succeeding in approximately three out of four cases.”<sup>212</sup> In the small number of successful lawsuits, the damages awarded have generally ranged from nominal to moderate.<sup>213</sup> As one observer concludes, the provincial privacy acts “are rarely used” and “have not been very successful.”<sup>214</sup> *Peters-Brown v Regina District Health Board* is relevant to the situation of people living with HIV/AIDS or hepatitis C. In that case a nurse sued the hospital where she worked because the hospital had circulated a list with her name on it. The list stated that bodily-fluid precautions should be taken when interacting with the people included on the list. The nurse based her lawsuit on the Saskatchewan Privacy Act, which said she had a right to privacy. The court rejected her argument that the disclosure of medical information was an invasion of her rights under the Privacy Act. The court held that the hospital did not “wilfully and without claim of right” violate her privacy rights. The court stated that “It is questionable whether such a right exists.”<sup>215</sup> Nevertheless, it decided that the hospital was negligent because it breached its duty to maintain the confidentiality of her health information, and awarded her \$5000 in damages for her suffering.

## **Statutes governing specific health professionals and health-care facilities**

Provincial laws regulating health professions and health-care facilities often set out duties of confidentiality owed to the patient/resident by the health-care professional or facility. Examples of such legislation applicable to physicians are the Québec Medical Act,<sup>216</sup> regulations made under the Ontario Medicine Act, 1991,<sup>217</sup> the Hospital Act in Newfoundland,<sup>218</sup> Nova Scotia,<sup>219</sup> and New Brunswick,<sup>220</sup> the Mental Health Act in Manitoba,<sup>221</sup> Ontario,<sup>222</sup> and Alberta,<sup>223</sup> and the Nursing Homes Act in New Brunswick<sup>224</sup> and Ontario.<sup>225</sup> In the case of an alleged breach of confidentiality by a regulated health-care professional, a patient can file a complaint with that professional regulatory body. Professional regulatory bodies do not have the power to award monetary damages to a patient. They do have the power to discipline health-care professionals for incompetence or misconduct, and can impose sanctions such as revoking, suspending, or placing conditions on the professional’s licence to practise, reprimanding the professional, or imposing a fine.

## **Provincial health information protection statutes**

Three provinces (Alberta, Manitoba, and Saskatchewan) have enacted specific legislation on the protection of health information. The Manitoba Personal Health Information Act<sup>226</sup> and the Alberta Health Information Act<sup>227</sup> are in effect. The Saskatchewan Health



Information Protection Act<sup>228</sup> has not yet been proclaimed in force, but has already been amended.<sup>229</sup> A principal stated purpose of these statutes is to protect medical records, considered to be intimate, highly personal information. The three provincial statutes place responsibilities on “trustees” or “custodians” to collect, use, and maintain the medical information of individuals. Trustees and custodians include health-care providers paid under the provincial insurance plan, health-care facilities such as hospitals and psychiatric institutions, and pharmacies and laboratories. The legislation is generally applicable to the publicly funded health-care sector.

The provincial statutes are alike in structure. Typically, they contain provisions on the right of access to one’s personal health information, the duties of trustees to protect personal health information, restrictions on the use and disclosure of information, and a complaints process for breaches of the statute. The three statutes provide a broad range of circumstances in which health information may be disclosed without consent to third parties (ie, discretionary disclosure clauses). The discretionary disclosure clauses will be analyzed in greater detail in “Discretionary disclosure of health information under provincial health information privacy legislation,” below.

## **The federal Personal Information Protection and Electronics Documents Act (PIPEDA)**

PIPEDA came into effect in 1 January 2001 for matters within federal jurisdiction, with the exception of the provisions on health information, which came into effect on 1 January 2002. The purpose of PIPEDA is to regulate the collection, use, and disclosure of personal information by private enterprises in the course of commercial activities.<sup>230</sup> It is the first time that federal legislation will regulate the information and privacy practices of private enterprises.<sup>231</sup> It is unclear whether or not PIPEDA is applicable to the publicly funded health-care sector (eg, personal health information in the possession of public hospitals) and to health-care professionals operating private practices.<sup>232</sup> PIPEDA is based on a set of internationally recognized fair information practices,<sup>233</sup> as well as the Canadian Standards Association *Model Code for the Protection of Personal Information* (CSA Model Code).<sup>234</sup> In his submissions to the Ontario Government on Bill 159, the Personal Health Information Act, the then Privacy Commissioner of Canada commented on the effect of PIPEDA on privacy rights:

There is no doubt that the federal legislation represents a significant step forward for privacy in Canada, but it really does no more than bring us to the minimal international standard. It recognizes the fundamental values of allowing individuals to retain some control over their personal information, and provides them with certain legal remedies and protections when they feel their privacy rights have been violated.<sup>235</sup>

As of 1 January 2004, PIPEDA will bind commercial activities that fall within provincial and territorial jurisdiction unless the province or territory fulfills two conditions.<sup>236</sup> First, the province or territory must have passed legislation “substantially similar” to PIPEDA. Second, where a province or territory has such legislation in place, the Governor in Council (ie, the federal cabinet) must exempt the province or territory from the application of PIPEDA.<sup>237</sup> The Privacy Commissioner of Canada is required under PIPEDA to report to Parliament on the extent to which the provinces have passed “substantially similar” legislation.<sup>238</sup> “Substantially similar” has been interpreted by the Privacy Commissioner of Canada as “equal or superior to the federal law in the quality of privacy protection

provided.”<sup>239</sup> Therefore, the provincial or territorial legislation must: (a) contain all ten principles of the CSA Model Code; (b) provide an independent and effective oversight and redress mechanism that includes adequate investigatory powers; and (c) restrict the collection, use, and disclosure of personal information to purposes that are appropriate or legitimate.

It is unclear whether or not PIPEDA is applicable to the publicly funded health-care sector (eg, personal health information in the possession of public hospitals) and to health-care professionals operating private practices.

Québec has enacted legislation that governs the private sector with regard to the collection, disclosure, and use of personal information. The Act Respecting the Protection of Personal Information in the Private Sector came into force in 1994.<sup>240</sup> Because the legislation is considered to meet the “substantially similar” standard of PIPEDA, private enterprises in Québec will continue to be exempt from the application of the federal law.<sup>241</sup> In late 2003, the British Columbia legislature passed legislation in response to PIPEDA that comes into force on 1 January 2004.<sup>242</sup>

In the opinion of the then Privacy Commissioner of Canada, the first-reading draft of the bill was not substantially similar to PIPEDA.<sup>243</sup> The draft of the bill introduced at first reading was passed, without any amendments, on third reading.

## Privacy protection under Québec law

### Civil Code of Québec (CCQ)

Québec law offers unique and significant privacy protections. The common law (including common law torts such as invasion of privacy and breach of confidence) does not apply in Québec. Québec is the only civil law jurisdiction in Canada, governed by the CCQ. The

Québec law offers unique and significant privacy protections.

CCQ governs persons, relations between persons, and property.<sup>244</sup> The CCQ is the foundation of all other laws enacted by the Québec legislature, although other laws may complement the CCQ or make exceptions to it.<sup>245</sup> The CCQ contains a chapter on respect for reputation and privacy.<sup>246</sup> No one may invade the privacy of a person without the consent of the person unless authorized by law.<sup>247</sup> Using correspondence, manuscripts, or other personal documents without consent is considered an invasion of privacy.<sup>248</sup> People are given the right to examine, receive copies of, and rectify files that contain information about them.<sup>249</sup> The CCQ gives people a right to sue where the privacy rules under the CCQ have been breached, a breach akin to the common law tort of negligence available in other provinces.<sup>250</sup>

### Québec Charter

The Québec Charter, analogous to human rights codes or acts in other provinces and territories but broader in its scope, contains explicit privacy protections.<sup>251</sup> Section 5 provides that “Every person has a right to respect for his private life” and section 9 provides that “Every person has a right to non-disclosure of confidential information.” Section 9 also establishes a qualified privilege for information given to professionals, which would include health professionals:

No person bound to professional secrecy by law and no priest or other minister of religion may, even in judicial proceedings, disclose confidential information revealed to him by reason of his position or profession, unless he is authorized to do so by the person who confided such information to him or by an express provision of law. The tribunal must, *ex officio*, ensure that professional secrecy is respected.

An individual who believes that his or her Québec Charter rights have been infringed can file a complaint with the Québec Human Rights Commission, whose powers include the investigation of complaints.<sup>252</sup> Unlike human rights systems in other provinces and territories where a commission exists, under the Québec Charter an individual can bring his or her complaint before the tribunal for a hearing even if the commission decides not to pursue the complaint.<sup>253</sup> A tribunal can order a person to stop interfering with another person's right, and award compensation for the moral and material prejudice suffered. In addition, the tribunal may award punitive damages in the case of unlawful and intentional interference with a right.<sup>254</sup>

### **Privilege under Québec law**

The common law rule of evidence known as privilege does not apply to civil cases in Québec. However, professional privilege is protected under the evidence provisions of the CCQ<sup>255</sup> and under the Medical Act.<sup>256</sup> Despite the categorical language of the provisions intended to protect professional privilege, Québec courts have treated the privilege as relative rather than absolute, and have assumed the discretion to order the disclosure of physician–client communications in the interests of justice. As one commentator concludes, the position in Québec is not very different than in other Canadian jurisdictions.<sup>257</sup> It is important to note that the protection of physician–client privilege under the CCQ, the Québec Charter, and the Medical Act does not apply in criminal proceedings. In Canada, criminal law is a matter of federal jurisdiction, and federal criminal law does not recognize a physician–client privilege.<sup>258</sup>

### **Statutory protection for personal information**

As stated above, Québec is the only province that has legislation in force, applicable to the private sector as well as the public sector, on the protection of personal information, including health information.<sup>259</sup> The Act Respecting Access to Documents Held by Public Bodies and the Protection of Personal Information applies to public bodies, as its title suggests, including health and social service institutions governed by legislation and those private institutions similarly governed that operate with government funding.<sup>260</sup> The Act governs access to documents held by a public body; collection, keeping, and use of personal information; protection of personal information; and a commission to administer the provisions of the Act relating to access to information. The system of protection of personal information is based on the concept of “nominative information,” which refers to information concerning a natural person that enables the person to be identified and is not public.<sup>261</sup> As a general rule, a public body may not release nominative information without consent.<sup>262</sup> Exceptionally, nominative information may be released without consent by a public body in a number of specified circumstances.<sup>263</sup> These circumstances are reviewed in the section “Purpose of legislation and discretionary disclosure clauses,” below.

The Act Respecting the Protection of Personal Information in the Private Sector establishes rules with respect to personal information that a person collects, holds, uses, or communicates to third persons in the course of carrying on an enterprise.<sup>264</sup> An enterprise is the carrying on by one or more persons of an organized economic activity, whether or not it is commercial in nature, consisting of producing, administering, or alienating property, or providing a service.<sup>265</sup> This could include enterprises that provide health services. The rules are intended to secure for persons the privacy rights set out in sections 35 to 41

Québec is the only province that has legislation in force, applicable to the private sector as well as the public sector, on the protection of personal information, including health information.

of the CCQ. Every person carrying on an enterprise who collects, holds, uses, or communicates personal information about other persons must establish and apply such safety measures as are appropriate to ensure the confidentiality of the information.<sup>266</sup> Generally, information in a person's file may be used only for a purpose consistent with the purpose for which the file was established, or with the person's consent.<sup>267</sup> Exceptionally, a person carrying on an enterprise may, without the consent of the person concerned, release information from that person's file in certain circumstances.<sup>268</sup> These circumstances are reviewed in the section, "Purpose of legislation and discretionary disclosure clauses," below. The Act also contains safeguards respecting nominative lists (containing name, address, or telephone numbers of natural persons) used for commercial or philanthropic purposes, which require enterprises to provide people with a valid opportunity to refuse that the information be used by a third party.<sup>269</sup>



# Disclosure of Health Information

This chapter reviews the situations in which the health information of people living with HIV/AIDS may be disclosed without their consent. In some situations, the law forces people who hold information to disclose it – for example, in investigations and legal cases (criminal, civil, and administrative). This is referred to in this chapter as *mandatory disclosure*. The laws that make disclosure mandatory are explained, and then the legal basis for challenging mandatory disclosure under these laws is reviewed. The chapter goes on to look in detail at a second type of disclosure, *discretionary disclosure*. These laws give people who hold personal information the authority (also known as discretion) to decide whether or not to disclose information without consent and to act on that decision.

Discretionary disclosure clauses are commonly found in provincial privacy laws that apply to personal health information. This chapter analyzes a number of the common discretionary disclosure clauses in provincial laws, and also looks at the federal legislation (PIPEDA) where relevant. Recommendations are made throughout the chapter. These recommendations are intended to limit unauthorized disclosure of personal health information to situations where the disclosure is necessary and justifiable on public policy grounds. The recommendations also seek to ensure that discretionary disclosure clauses protect the privacy of personal health information at least to the same extent as the Charter and the common law.

## Limits on the privacy of health information and limits on disclosure

Like many other human rights, privacy is not absolute. Competing values or interests may trump a person's right to privacy, and the corresponding duty of confidentiality owed to him or her. In a given situation, epidemiological research to stop the transmission of HIV, or

Like many other human rights, privacy is not absolute. Competing values or interests may trump a person's right to privacy, and the corresponding duty of confidentiality owed to him or her.

research to establish more effective treatment for HIV/AIDS, may be judged to be more important goals than preserving the absolute confidentiality of health information of people living with HIV/AIDS. A counsellor or health-care professional might disclose a client's HIV status to prevent harm to another person. The search for truth in criminal investigations, and in criminal and civil court proceedings, may require disclosure of a person's health information, including HIV status. These competing goals are recognized in legislation that requires or permits disclosure of health information without consent in certain circumstances.

A United Nations sub-commission has proposed that certain civil and political rights, including the right to privacy, may be legitimately restricted only when all the following criteria are met:

- the restriction is provided for and carried out in accordance with the law;
- it is in the interest of a legitimate objective;
- it is strictly necessary to achieve this objective;
- it is the least intrusive and least restrictive means available; and
- it is not drafted or imposed in an unreasonable or discriminatory way.<sup>270</sup>

These criteria are reflected in s 1 of the Canadian Charter, which states that the rights and freedoms set out in the Charter are "subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society."<sup>271</sup>

People living with HIV/AIDS may be able to rely on certain laws and legal rules to protect the privacy of their health information and to limit the reach of clauses in legislation that give discretion to someone to disclose personal health information.

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- The Charter offers the most important legal protection. It applies to all legislation, both federal and provincial, and state actors. In criminal proceedings and proceedings before administrative tribunals, a person living with HIV/AIDS can challenge under ss 7 or 8 of the Charter the mandatory disclosure of medical or other files that contain personal health information.
- The evidentiary principle of privilege can also be used to protect personal health information from mandatory disclosure and use as evidence.
- Finally, according to the legal rules of statutory interpretation, where the meaning of a statutory provision is unclear, exceptions in privacy and access-to-information legislation should be narrowly construed, with a view to achieving the ultimate purpose of the legislation.<sup>272</sup>

## **Mandatory disclosure in the administration of programs**

Mandatory disclosure refers to the situation in which health information must be disclosed "by operation of law." The phrase "by operation of law" means required by legislation or under an order of a court, tribunal, or other state actor. Mandatory disclosure provisions are found in legislation ranging from rules of court to provincial public health legislation to the Criminal Code. This section reviews mandatory disclosure required by legislation for the

purposes of administering programs. The next section analyzes mandatory disclosure in court and tribunal proceedings.

With respect to HIV/AIDS, in all provinces and territories cases of HIV infection are legally reportable under public health legislation in at least some circumstances.<sup>273</sup> However, not all provinces require the names of those who test positive to be reported in all circumstances. In Yukon, the Northwest Territories, Nunavut, and Newfoundland the person's name must always be reported. In Alberta, Saskatchewan, Manitoba, Québec, and New Brunswick the law does not require the person's name to be reported. In British Columbia, Ontario, Nova Scotia, and Prince Edward Island only the names of those people who choose to test using their names must be reported. In these provinces, the laws do not require the reporting of names of people who opt for non-nominal testing or anonymous testing (where available).

With respect to HIV/AIDS, in all provinces and territories cases of HIV infection are legally reportable under public health legislation in at least some circumstances.

In all provinces and territories except Yukon, both laboratories and physicians are responsible for reporting HIV infection according to provincial and territorial laws.<sup>274</sup> In Yukon, only physicians have this legal obligation. In the Northwest Territories, Nunavut, New Brunswick, and Prince Edward Island, registered nurses are also responsible for reporting cases of HIV infection.

Other legislation requires safety-related reporting of health information. Under highway traffic statutes in several provinces, physicians are under an obligation to report patients they consider unfit to operate a vehicle.<sup>275</sup> Similarly, the federal Aeronautics Act<sup>276</sup> requires optometrists and physicians to report the identity of a patient likely to constitute a hazard to aviation safety as a crewmember on a flight.

## **Mandatory disclosure in investigations and court proceedings**

In criminal and quasi-criminal investigations, and in criminal, quasi-criminal, and civil legal proceedings, courts may order that personal health information be disclosed without consent. Legislation can also give administrative decision-makers, actors, and tribunals the power to order the disclosure of information, including personal health information. Investigations and the production of evidence in legal proceedings (criminal, civil, and regulatory) are a potential threat to the confidentiality of health information of people living with HIV/AIDS. The Criminal Code, public health and other legislation all permit police or other state actors to search for and seize information of a private nature without the consent of the person to whom the information relates. In and of itself, the fact that a person is involved in a court proceeding does not entitle him or her to greater privacy protections. On the contrary, subpoenas and summonses issued in civil and criminal proceedings require individuals to attend court to testify or to produce records.<sup>277</sup> The effect of the subpoena or summons is that otherwise confidential information may enter the public domain and is at great risk of dissemination through, for example, the media. As Jürgens has commented, "once a subpoena is issued, it is potentially devastating to confidentiality."<sup>278</sup>

The effect of the subpoena or summons is that otherwise confidential information may enter the public domain and is at great risk of dissemination through, for example, the media.

People living with HIV/AIDS can assert their Charter rights in an attempt to prevent the search and seizure of their personal health information. They can also try to use the evidentiary rules about privileged communications to prevent that information from being disclosed as evidence in a court or tribunal proceeding.

## Challenging search and seizure of personal health information

The Charter, the common law evidentiary rule of privilege, and professional duties of confidentiality offer important protections for people living with HIV/AIDS, who may be able to protect their health information from search and seizure, or introduction into court as

In the criminal context, there are a number of ways to prevent the seizure of personal health information and its use as evidence in court.

evidence, by challenging the constitutionality of a search and seizure by relying on ss 7 and 8 of the Charter, the common law, and statutory duties. Charter privacy protections, the evidentiary principle of privilege, and professional duties of confidentiality are reviewed in detail above in the chapter on Legal Protection of Privacy in Canadian Law.

In the criminal context, there are a number of ways to prevent the seizure of personal health information and its use as evidence in court. Where a search warrant has been issued, the person in possession of the health information or the person living with HIV/AIDS can apply to a superior court to have the warrant

quashed. Faced with an attempt to compel the disclosure of health information, a medical professional, a counsellor, or a person living with HIV/AIDS may assert that the information is privileged, and therefore not compellable as evidence.<sup>279</sup> A person living with HIV/AIDS who stands accused of an offence in a criminal prosecution can try to keep his or her health information from being considered as evidence. Once it has been proved that the personal health information was obtained in breach of his or her Charter rights, the person in question can bring a motion to exclude the evidence under s 24(2) of the Charter.<sup>280</sup>

Whether or not the ss 7 and 8 Charter guarantees and the evidentiary rule of privilege will protect a person living with HIV/AIDS from the disclosure of health information will depend upon the facts of a particular case, and on the person's financial ability to raise the issue in court. If the person living with HIV/AIDS has little or no income and is not eligible for legal aid, it is unlikely that person will be able to effectively assert his or her Charter rights, or make arguments based on the evidentiary rule of privilege.

A person living with HIV/AIDS may find him or herself relying on another person to protect his or her privacy by upholding a duty of confidentiality. Someone like a health-care professional or other person who holds personal health information can claim privilege when faced with a warrant or subpoena. Whether or not the health-care professional or other person will take steps to protect the information is a further factor that may impact the confidentiality of personal health information of people living with HIV/AIDS. In most circumstances, the health information of a person living with HIV/AIDS's will be in a record held by a medical professional, a counsellor, or a community-based AIDS service organization. In practice, it may be up to that person or organization to bring an application to quash a search warrant, or to bring a motion to court to claim that the information is protected by privilege. Many counsellors, especially those in community-based AIDS service organizations, will not have the knowledge or expertise to do so, or the financial means necessary to retain a lawyer. Medical professionals working in institutional settings such as hospitals may have greater access to legal advice and representation, and thus be in better position to protect the privacy of clients' personal health information.

## Discretionary disclosure of health information under provincial health information privacy legislation

Discretionary disclosure refers to the situation in which health information privacy legislation, or the common law, gives *permission* to specified individuals to disclose another



person's health information without consent. This paper focuses on the discretionary disclosure clauses in provincial health information privacy legislation. These discretionary disclosure clauses are exceptions to the protections in such legislation. A review of the discretionary disclosure clauses reveals that they are often either unnecessary or overbroad, in the sense that they permit disclosure of personal health information of people living with HIV/AIDS beyond what is required to achieve the purpose of the exception.

Only in exceptional and circumscribed situations should a custodian or trustee be permitted to disclose health information without the express and informed consent of a person living with HIV/AIDS. Provincial health information protection laws contain many discretionary disclosure clauses that permit those responsible for health information to disclose the information in a wide variety of circumstances. A number of these discretionary disclosure clauses are problematic because they do not respect the privacy rights of people living with HIV/AIDS or the confidentiality of their personal health information. In some instances, health information privacy legislation provides fewer protections for confidentiality than the courts have imposed in similar contexts. The problematic discretionary disclosure clauses violate important Charter principles without sufficiently important policy reasons. In the vast majority of instances the legitimate objectives served by discretionary disclosure of health information for the purposes of an audit of a health professional or organization, public health surveillance, or the development of health policy may be achieved through means of de-identified information, which is less intrusive and potentially less damaging than disclosing personal health information.

Only in exceptional and circumscribed situations should a custodian or trustee be permitted to disclose health information without the express and informed consent of a person living with HIV/AIDS.

This chapter identifies the range of discretionary disclosure clauses in provincial health information privacy legislation; sets out the principles that should guide discretionary disclosure of personal health information of people living with HIV/AIDS; examines the discretionary disclosure clauses that do not respect the guiding principles; and makes recommendations for law reform. It concludes that some of the provisions should be repealed or amended.

## **RECOMMENDATION**

**Only in exceptional and circumscribed situations should legislation permit a custodian or trustee to disclose health information without the express and informed consent of a person living with HIV/AIDS.**

**Federal, provincial, and territorial governments should ensure that legislation that applies to personal health information provides at least the protections for personal health information afforded under the Charter and at common law.**

## **Purpose of legislation and discretionary disclosure clauses**

Provincial legislation about health information has as one of its stated purposes the protection of the privacy or confidentiality of health information. The preamble of the Manitoba Personal Health Information Act states that “health information is personal and sensitive and its confidentiality must be protected so that individuals are not afraid to seek health care or to disclose sensitive information to health professionals.”<sup>281</sup> The Alberta Health Information Act has as two stated purposes: “To establish strong and effective mechanisms to protect the privacy of individuals with respect to their health information and to protect the

confidentiality of that information” and “to prescribe rules for the collection, use and disclosure of health information, which are to be carried out in the most limited manner and with the highest degree of anonymity that is possible in the circumstances.”<sup>282</sup> The purposes of the Saskatchewan Health Information Protection Act, set out in the preamble, convey a consistent, client-based, and principled approach to the protection of health information that is lacking in the Manitoba and Alberta acts:

- personal health information is private and shall be dealt with in a manner that respects the continuing interests of the individuals to whom it relates;
- individuals provide personal health information with the expectation of confidentiality and personal privacy;
- trustees of personal health information shall protect the confidentiality of the information and the privacy of the individuals to whom it relates;
- the primary purpose of the collection, use, and disclosure of personal health information is to benefit the individuals to whom it relates;
- wherever possible, the collection, use, and disclosure of personal health information shall occur with the consent of the individuals to whom it relates;
- personal health information is essential to the provision of health services;
- wherever possible, personal health information shall be collected directly from the individual to whom it relates;
- personal health information shall be collected on a need-to-know basis;
- individuals shall be able to obtain access to records of their personal health information;
- the security, accuracy, and integrity of personal health information shall be protected;
- trustees shall be accountable to individuals with respect to the collection, use, disclosure, and exercise of custody and control of personal health information; and
- trustees shall be open about policies and practices with respect to the collection, use, and disclosure of personal health information.

Consent is the fundamental principle that animates the “protection” purpose of privacy protection legislation – a person’s knowledge and consent are required for the collection, use, or disclosure of his or her personal information. The Manitoba and Alberta health information

statutes contain provisions similar to s 5(1) of the Saskatchewan Health Information Protection Act: “an individual has the right to consent to the use or disclosure of personal health information about himself or herself.”<sup>283</sup>

Consent is the fundamental principle that animates the “protection” purpose of privacy protection legislation – a person’s knowledge and consent are required for the collection, use, or disclosure of his or her personal information.

Despite the importance of upholding the principle of consent to disclosure of health information, existing and proposed provincial laws that apply to personal health information contain numerous exceptions that allow unauthorized disclosure. Disclosure permitted by legislation should be exceptional, and the exceptions should be applied strictly. However, the Alberta, Manitoba, and Saskatchewan statutes contain broad discretionary disclosure clauses that allow people and organizations in possession of health information to transmit highly confidential, sensitive, and intimate information to

third parties without the consent of the patient who is the source of the information. Health-care custodians have the discretion under the provincial statutes to disclose personal health information in the following situations:

1. for the purpose of contacting a relative or friend of the individual, if the individual is injured or ill;
2. to any person if the custodian believes on reasonable grounds that disclosure will avert or minimize an imminent danger to the health or safety of any person;
3. when in the opinion of the custodian, disclosure is necessary for monitoring, preventing, or revealing fraudulent, abusive, or dangerous use of publicly funded health services;
4. for the purposes of determining or verifying the eligibility of the individual under a provincial or federal act to receive health care or health-related benefits;
5. for conducting investigations, disciplinary proceedings, reviews, or inspections relating to members of a health profession or health discipline;
6. for public health surveillance, health system management, health policy development, planning, and resource allocation;
7. for the purposes of research;
8. to an official of a penal or other custodial institution in which the individual is being lawfully detained if the purpose of the disclosure is to allow the provision of health services to the individual;
9. for the purpose of court proceedings or a proceeding by a quasi-judicial body to which the custodian is a party;
10. to a municipal or provincial police service for the purpose of investigating an offence under a law of Canada, a province, or a territory;
11. by the minister or the department to another minister for the purpose of developing public policy; and
12. to a person who requires the personal health information to perform an audit of the custodian.

The discretionary disclosure clauses in existing and proposed legislation have been criticized by privacy commissioners, community based HIV/AIDS organizations, the Canadian Civil Liberties Association, and members of the health and legal professions.

Existing and proposed statutes that apply to personal information, not limited to health information, also contain broad disclosure provisions. The British Columbia Personal Information Protection Act permits disclosure of personal information without consent in most of the above circumstances, as does the Draft Ontario Privacy of Personal Information Act, 2002.<sup>284</sup> PIPEDA grants expansive powers to custodians of personal information to transmit medical information to a third party without first obtaining consent.<sup>285</sup> The discretionary disclosure clauses in existing and proposed legislation have been criticized by privacy commissioners, community-based HIV/AIDS organizations, the Canadian Civil Liberties Association, and members of the health and legal professions.<sup>286</sup>

## **RECOMMENDATION**

**Provincial and territorial governments should ensure that legislation regarding personal information protection includes a preamble or purpose clause setting out a consistent and principled approach to the protection of health information.**

**Legislation that protects the privacy of personal information must recognize the particular importance of protecting health information, and should contain a preamble or purpose clause setting out a consistent, client-based, and principled approach to the protection of personal information.**

## **Guiding principles on the disclosure of personal health information**

The privacy principles set out in the CSA Model Code (incorporated as Schedule 1 to PIPEDA) should guide the drafting (or redrafting) of discretionary disclosure clauses and their interpretation and application. The ten principles can be summarized as follows:

1. **Accountability** – An organization is responsible for personal information under its control.
2. **Identifying purposes** – The purposes for which personal information is collected shall be identified by the organization at or before the time the information is collected.
3. **Consent** – The knowledge and consent of the individual are required for the collection, use, or disclosure of personal information except where inappropriate.
4. **Limiting Collection** – The collection of personal information shall be limited to that which is necessary for the purposes identified by the organization. Information shall be collected by fair and lawful means.
5. **Limiting Use, Disclosure, and Retention** – Personal information shall not be used or disclosed for purposes other than those for which it was collected, except with the consent of the individual or as required by law. Personal information shall be retained only as long as is necessary for the fulfilment of those purposes.
6. **Accuracy** – Personal information shall be as accurate, complete, and up to date as is necessary for the purposes for which it is to be used.
7. **Safeguards** – Personal information shall be protected by security safeguards appropriate to the sensitivity of the information.
8. **Openness** – An organization shall make readily available to individuals specific information about its policies and practices relating to the management of personal information.
9. **Individual Access** – Upon request, an individual shall be informed of the existence, use, and disclosure of his or her personal information and shall be given access to that information. An individual shall be able to challenge the accuracy and completeness of the information and have it amended as appropriate.
10. **Challenging Compliance** – An individual shall be able to address a challenge concerning compliance with the above principles to the designated individual or individuals accountable for the organization's compliance.

When applied to the disclosure of the health information of people living with HIV/AIDS, the CSA Model Code principles limit the potential for the harms associated with unauthorized disclosure of health information. From the perspective of people living with HIV/AIDS, the principles that should guide discretionary disclosure clauses in provincial health information privacy legislation are as follows.

First, the custodian should attempt to obtain consent to disclose information wherever possible.

Second, prior to the disclosure of the information, the custodian of health information must make best efforts to ensure that the information is complete, accurate, and not misleading.<sup>287</sup> This would include, wherever possible, providing the information to the person living with HIV/AIDS so that it could be reviewed and corrected, if necessary.

Third, the disclosure must be limited to the minimum amount of information necessary to accomplish the purpose for which the information is disclosed.<sup>288</sup>

Fourth, as a general rule, a custodian must make best efforts to inform the person living with HIV/AIDS of the anticipated disclosure of his or her personal information.<sup>289</sup> This will

give the person the opportunity to make a formal objection prior to the transmission of the information. The Privacy Working Group, consisting of representatives from various health professional associations in Canada, argued in its 2000 report that “individuals have the right to know by whom, when, how and to what extent and purpose their *identifiable* and *de-identified* health information is being collected, disclosed, stored, accessed, and used.”<sup>290</sup>

Fifth, the custodian should be required to maintain a record of every disclosure of health information to a third party.<sup>291</sup>

Sixth, all disclosures without consent must be limited to “de-identified” information if that will serve the relevant purpose.<sup>292</sup> The Draft Ontario Privacy of Personal Information Act, 2002, states that in relation to the personal information of an individual, “de-identify” means the removal of any information that:

1. identifies the individual,
2. can be manipulated by a reasonably foreseeable method to identify the individual, or
3. can be linked or matched by a reasonably foreseeable method to other information that identifies the individual or that can be used or manipulated by a reasonably foreseeable method to identify the individual.<sup>293</sup>

Seventh, the statutory list that delineates the situations in which custodians have the discretion to disclose the health information of people living with HIV/AIDS without consent should be *exhaustive*. Public officials should not be permitted by regulation to add further circumstances in which information without consent can be disclosed.<sup>294</sup> One common criticism of provincial health information privacy legislation is the wide regulatory powers of the government to broaden the provisions.<sup>295</sup>

The eighth and final principle is that the highest level of statutory protection for the privacy of personal health information should apply. This is reflected in legislation such as Manitoba’s Personal Health Information Act, which states that the health information statute “prevails unless another enactment more completely protects the confidentiality of personal health information.”<sup>296</sup> This principle should be imported into other provincial statutes to maximize the protection for personal health information.

## **RECOMMENDATION**

**Federal, provincial, and territorial governments should ensure that legislation limits the circumstances in which health information of a person is disclosed without consent. Legislation must also include principles and practices that must be followed where personal health information is going to be disclosed without consent:**

- (1) the custodian of health information must take measures to ensure that the information is as complete and accurate as possible prior to the disclosure of the information;**
- (2) all disclosures without consent must be limited to “de-identified” information if that will serve the purpose for which it is transmitted;**
- (3) the disclosure must be limited to the minimum amount necessary to accomplish the purpose for which the information is transmitted;**
- (4) the custodian should make best efforts to inform the person with HIV/AIDS of the anticipated disclosure of his or her personal information and attempt to seek consent to the disclosure;**
- (5) the custodian must maintain a record of every transmission of health information to a third party;**

- (6) the statutory list of permitted disclosures without consent should be exhaustive; government officials should not be authorized to add by regulation further circumstances in which information can be disclosed without consent;
- (7) the health information privacy statute should prevail unless another enactment provides more protection to people living with HIV/AIDS.

### **Ethical responsibilities of health-care professionals to their patients**

Under the discretionary disclosure clauses in provincial health information privacy legislation, custodians of health information are given the discretion (ie, are *permitted*) to disclose confidential information to a third party in a wide range of circumstances. These discretionary disclosure clauses potentially conflict with health-care professionals' ethical obligation of patient/client confidentiality. The ethical codes of the various health-care professions treat as sacrosanct the duty of confidentiality owed to a patient. Without the patient's consent or a legal duty to report, health-care professionals are required to respect the privacy of the patient. For example, a physician's Hippocratic Oath includes the following:

What I may see or hear in the course of treatment or even outside of treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself holding such things shameful to be spoken about.<sup>297</sup>

The World Medical Association also recognizes the importance of the duty of confidentiality to patients:

Confidential information can only be disclosed if the patient gives explicit consent *or if expressly provided for in the law*. Information can be disclosed to other health care providers only on a strictly "need to know" basis unless the patient has given explicit consent.<sup>298</sup> [emphasis added]

The World Medical Association has taken the position that all identifiable information about a patient's health status, medical condition, diagnosis, prognosis, treatment, and other personal information must be kept confidential, even after death. In exceptional circumstances, descendants have a right of access to information that would inform them of their own health risks.<sup>299</sup>

In Canada, doctors, nurses, dentists, psychologists, and various other health-care professionals are members of self-regulating professions whose governing bodies set standards and license them to practice, under the authority of provincial legislation.<sup>300</sup> In many provinces, health-care professionals' ethical obligation to maintain confidentiality is set out in a regulation to the profession's governing act. For example, under Ontario's Medicine Act, 1991, the following constitutes misconduct:

10. Giving information concerning the condition of a patient or any services rendered to a patient to a person other than the patient or his or her authorized representative except with the consent of the patient or his or her authorized representative *or as required by law*.<sup>301</sup> [emphasis added]

The Code of Ethics of the Canadian Medical Association requires that physicians:

Respect the patient's right to confidentiality except when this right conflicts with *your responsibility to the law*, or when the maintenance of confidentiality would result in a significant risk of substantial harm to others or to the patient if the

patient is incompetent; in such cases, take all reasonable steps to inform the patient that confidentiality will be breached.<sup>302</sup> [emphasis added]

In the three situations noted (responsibility to the law, significant risk of substantial harm, patient incompetence), the CMA Code of Ethics requires the physician to take reasonable steps to inform the patient that the physician will breach confidentiality.

On a cursory analysis, it would appear that health-care professionals are prohibited from disclosing patient information pursuant to discretionary disclosure clauses in provincial health information privacy legislation. As set out above, as a general rule health-care professionals are prohibited from disclosing patient information without consent. This prohibition is found in professional codes of ethics, as well as provincial statutes and regulations that govern self-regulating professions that have raised the ethical duty of confidentiality to a legal one. Exceptionally, provincial statutes or regulations permit a health-care professional to breach patient confidentiality where “*required by law.*” Yet by their very nature discretionary disclosure clauses are permissive and not mandatory, so the health-care professional is not required to disclose information in breach of patient confidentiality.

However, discretionary disclosure clauses in provincial health information privacy legislation may legally and in practice trump professional obligations of confidentiality. As a matter of law, under principles of statutory interpretation, a statute of particular application will override a regulation of general application (defining professional standards of practice and/or misconduct). On this basis, it could be argued that a specific legislative act dealing with health information protection and disclosure would supersede a regulation that generally governs professions and their conduct. Moreover, a number of the provincial health information privacy acts contain a “protection from liability” clause. These clauses exempt individuals from civil liability, which likely includes exemption from liability in professional discipline proceedings, when acting under the authority of the provincial health information privacy act. At the least, giving physicians discretion to disclose that they currently do not have undermines the traditional values that physicians have followed and that have been enshrined in codes of conduct. Permitting the erosion of physician/client confidentiality will ultimately undermine the relationship of trust that the codes were designed to foster.

Exceptionally, provincial statutes or regulations permit a health-care professional to breach patient confidentiality where “*required by law.*”

## **RECOMMENDATION**

**Health-care-profession regulating bodies and associations should educate and inform their members about the duty of confidentiality owed to patients, and about the effect of discretionary disclosure clauses in health information protection legislation on the duty of confidentiality. Specifically, they should advise their members that *discretionary disclosure clauses (ie, clauses that permit disclosure) do not require the disclosure of confidential patient information.***

## **“Discretionary” disclosure in investigations and court proceedings**

Provincial statutes give custodians of personal information the “discretion” to disclose an individual’s health information for the purposes of court proceedings and for police investigations.<sup>303</sup> Disclosure of personal health information pursuant to subpoenas, summonses,

warrants, or orders does not properly belong in the *discretionary* provisions of health information privacy legislation, for two reasons. First, such provisions are irrelevant and superfluous. Where personal health information is sought pursuant to a court order, warrant, or subpoena, the order makes disclosure *mandatory*. It is unnecessary and illogical to grant by statute the *discretion* to comply with a *mandatory* order. Second, it is ultimately up to a court, not the custodian, to determine if the law requires disclosure of personal health information in a given circumstance. Only a court can make this determination, based on ss 7 and 8 of the Charter and the criminal and civil rules of evidence relating to privileged communications.

To give custodians of health information discretion to disclose for the purpose of court proceedings or police investigations puts the custodian in a difficult position. It also invites the misuse or abuse of that discretion where there is not a clear legal duty to disclose. If health information is thought to be necessary and relevant to a court proceeding or police investigation, the appropriate course of action is for a party to seek a court order, or for the police to seek a search warrant, to compel the disclosure of that information. Because of their knowledge of the law and their independence, a court or justice of the peace is in a better position than a custodian of health information to determine if the legal requirements for compelling disclosure have been met.

## **RECOMMENDATION**

**Federal, provincial, and territorial governments should ensure that legislation does not give people who hold health information the discretion to disclose that information in investigations and court proceedings.**

### **Disclosure to prevent harm to third parties**

The health information privacy statutes in Manitoba,<sup>304</sup> Alberta,<sup>305</sup> and the Ontario draft bill<sup>306</sup> contain a provision similar to the following s 27(4)(a) of The Health Information Protection Act of Saskatchewan:<sup>307</sup>

A trustee may disclose personal health information in the custody or control of the trustee without consent of the subject individual ... where the trustee believes, on reasonable grounds, that the disclosure will avoid or minimize a danger to the health or safety of any person.

This type of disclosure of confidential information to minimize danger or prevent harm to a third party is often referred to as a “duty to warn.” Used in this way, the characterization of a “duty to warn” is misleading. It is more accurate to refer to steps taken to prevent harm to a third party. A person who possesses information given in confidence may be able to prevent harm to a known third party by disclosing the information to the third party. However, in other instances, the person possessing the confidential information may be able to prevent harm, and thus fulfill any duty he or she may have, by taking other steps short of disclosing confidential information to the known third party.

Disclosure of confidential information to prevent HIV transmission will not be discussed in detail in this report because it is a complex issue that deserves careful examination. What these clauses mean and whether or not they are useful is related to the separate question of whether or not the common law imposes a positive duty to disclose confidential information to protect third parties at risk of harm. The issue involves fundamental public policy



choices and balancing of interests.<sup>308</sup> Courts will ultimately be called upon to decide the nature and extent of a duty to prevent harm under tort law, and may be called upon to determine the constitutionality of disclosure of health information under statutory provisions.<sup>309</sup> The position taken here is that the language as it currently exists in several of the provincial statutes is too broad and should be redrafted to conform to the principles of the “public safety exception” articulated in the leading Supreme Court of Canada case of *Smith v Jones*.<sup>310</sup>

In *Smith v Jones*, the issue was whether a psychiatrist could disregard the rule of privilege, which protects information a patient gives to a physician from being disclosed in a legal case without consent, to protect another person from harm. The defence lawyer in the case referred his client to a psychiatrist, Dr Smith, for an assessment. The defence lawyer wanted to use the report from the assessment to make arguments about what sentence the court should impose. Dr Smith concluded in his report that the accused was potentially very dangerous. The defence lawyer chose not to provide the report to the court because it was not in his client’s best interest to do so. Dr Smith retained a lawyer and argued that he should be permitted to disclose his report to the sentencing judge because of the danger the client posed, despite the fact that it was solicitor/client-privileged. Solicitor–client privilege protected the report from being disclosed without the client’s consent because it was prepared for a court case.

The Supreme Court of Canada held that the duty of confidentiality is not absolute in either a solicitor–client or doctor–patient relationship and is subject to a public safety exception. Cory J stated that because solicitor–client is the highest privilege recognized by the courts, “[b]y necessary implication, if a public safety exception applies to solicitor/client privilege, it applies to all classifications of privilege and the duty of confidentiality.<sup>311</sup> So, communications between health professionals and their patients will be governed by the four criteria of the public safety exception enunciated in *Smith v Jones*. According to these criteria, a lawyer or physician (or counsellor or other health-care professional) *may* breach a duty of confidentiality owed to a client/patient where:

- there exists a clear risk to an identifiable person or group of persons;
- the risk is that serious bodily harm or death may occur;
- the danger is imminent; and
- the proposed disclosure is the one that will minimally impair the privacy right of the individual involved.<sup>312</sup>

The weight to be accorded to each of these factors will vary according to the circumstances of the particular case.<sup>313</sup> With respect to the first factor, a court should consider whether there is evidence of long-range planning, a prior history of violence or threats of violence, and whether the group or person is identifiable. The second factor – risk of serious bodily harm or death – requires that the intended victim be in danger of “being killed or suffering serious bodily harm.”<sup>314</sup> The Court stated that serious psychological harm may constitute serious bodily harm, but the “disclosure of planned future crimes *without an element of violence* would be an insufficient reason to satisfy solicitor/client privilege because of fears of public safety” [emphasis added].<sup>315</sup> With respect to the third factor, the threat must create a sense of urgency. In the event that the three factors are satisfied, privileged communications may be disclosed but the disclosure should be limited as much as possible.<sup>316</sup> The fourth factor, the importance of limiting disclosure, is emphasized in the dissenting judgment of Major J:

The Supreme Court of Canada held that the duty of confidentiality is not absolute in either a solicitor–client or doctor–patient relationship and is subject to a public safety exception.

The chilling effect of completely breaching the privilege would have the undesired effect of discouraging these individuals in need of treatment for serious and dangerous conditions from consulting professional help.<sup>317</sup>

This concern has been raised in the context of the relationship between people living with HIV/AIDS and their health-care providers and counsellors. The issue is raised where a health-care provider or counsellor is told by a person living with HIV/AIDS that he or she is engaging in behaviours that risk transmitting HIV to a sex or injection drug use partner. A warning to a partner (ie, the sex or injection drug use partner) breaches confidentiality and risks the therapeutic relationship between the health-care or other service provider and a person with HIV/AIDS. If the person with HIV/AIDS terminates the relationship as a result, his

*Smith v Jones* holds that a public safety exception to confidentiality exists in situations in which there is a clear and imminent threat of serious bodily harm or death to an identifiable person or group.

or her health will likely suffer, and the service provider's opportunity to affect changes in that person's behaviour aimed at reducing HIV transmission will be lost. Elsewhere, the Legal Network has suggested that community-based AIDS service organizations and those providing services to people living with HIV/AIDS should consider developing policies and guidelines regarding the counselling of HIV-positive clients and the confidentiality of health information.<sup>318</sup>

To summarize, *Smith v Jones* holds that a public safety exception to confidentiality exists in situations in which there is a clear and imminent threat of serious bodily harm or death to an identifiable person or group. In such cases, the health professional is *permitted*, not mandated, to breach confidentiality and warn the person who is at risk, if he or she does so in a manner that minimally impairs the patient's rights. The public safety exception as it currently exists in some of the provincial privacy of information statutes is broader and less explicit than the common law exception established in *Smith v Jones*. Because the criteria identified by the Supreme Court are clearer and give more guidance than the vague statutory language, the Supreme Court's four criteria should prevail. The disclosure of personal health information without consent due to the risk of harm to third parties should only be permitted under the statutes if the criteria set out in *Smith v Jones* are satisfied.<sup>319</sup>

## RECOMMENDATION

**Provincial and territorial governments should ensure that discretionary disclosure clauses in provincial legislation aimed at preventing harm to third parties reflect the principles enunciated by the Supreme Court of Canada in *Smith v Jones*. Disclosure should only be permitted where there is a clear and imminent threat of serious bodily harm or death to an identifiable person or group.**

### Disclosure to family and friends

Three provincial statutes permit a person who holds personal health information of a *competent* patient to disclose that information to family members and friends. Under the Manitoba Personal Health Information Act and the British Columbia Personal Information Protection Act, a person who holds personal health information may disclose that information without the consent of the individual if the disclosure is for the purpose of contacting a relative or friend of an individual who is injured, incapacitated, or ill.<sup>320</sup> Under the Alberta Health Information Act a custodian may disclose individually identifying diagnostic, treat-

ment, and care information without the consent of the individual who is the subject of the information to family members of the individual or to another person with whom the individual is believed to have a close personal relationship, if the information is given in general terms and concerns the presence, location, condition, diagnosis, progress, and prognosis of the individual on the day on which the information is disclosed and the disclosure is not contrary to the express request of the individual.<sup>321</sup>

It is not uncommon for people living with HIV/AIDS to have kept their diagnosis a secret from family and friends due to the inordinate degree of stigma associated with the disease. It is also commonly the case that if a person's location in a particular health facility is disclosed, so is his or her HIV status, since certain wards, facilities, and clinical areas are known to be used for HIV-positive patients. As a result, custodians should not have the discretion to disclose the health information of a competent, conscious person to family and friends without express consent. HALCO has argued that provisions such as those reproduced above are excessively broad and jeopardize the privacy of people with HIV/AIDS.<sup>322</sup> Given the extensive triage and admittance procedures that patients already go through when they are admitted to hospital or an emergency department, it is not an unreasonable burden to place on custodians that they be required to ask patients if the hospital can give out information to callers seeking to know their status or whereabouts within a facility.

Where a person is not competent, a substitute decision-maker (whether appointed by law or under a power of attorney or a living will) may need to know the incapacitated patient's HIV status in order to make an informed choice between treatment options. The Health Information Protection Act of Saskatchewan provides that a trustee may release health information "to a person who, pursuant to The Health Care Directives and Substitute Health Care Decision Makers Act, is entitled to make a health-care decision, as defined in that Act, on behalf of the subject individual, where the personal health information is required to make a health care decision with respect to that individual."<sup>323</sup> At a minimum, other health information privacy statutes should follow the Saskatchewan Act and refer to the relevant legislation on substitute medical decision-making, where such legislation exists.

Two further restrictions should be incorporated into clauses in health information privacy legislation that permit disclosure under substitute-decision legislation. First, the custodian of the information must be satisfied that the patient's incapacity will be sufficiently long-lasting that the treatment decision must be made by the substitute decision-maker. Second, any disclosure of information should be limited to only that information required by the substitute decision-maker. For example, if the treatment decision is one where the patient's HIV status is not clinically relevant to the treatment decision, it should not be disclosed to the substitute decision-maker.

## **RECOMMENDATION**

**Provincial and territorial governments should ensure that legislation prohibits custodians from disclosing any personal health information, or information that may reasonably reveal a person's health information, to family and friends without that person's consent.**

Under the Manitoba Personal Health Information Act and the British Columbia Personal Information Protection Act, a person who holds personal health information may disclose that information without the consent of the individual if the disclosure is for the purpose of contacting a relative or friend of an individual who is injured, incapacitated, or ill.

**Where a treatment decision needs to be made on behalf of an incompetent person, legislation should permit custodians to disclose that person's health information only to a substitute decision-maker. Furthermore, the legislation must limit disclosure to only that information relevant to the treatment decision at hand.**

### **Disclosure by health-information custodians for the purposes of health research**

The disclosure of health information without consent for the purposes of health research is a contentious issue. Those who oppose obtaining patient consent to use existing health information argue that important medical research may not be conducted if time-consuming and cumbersome authorization procedures are imposed on the academic and scientific community. It is argued that "rules that might marginally enhance patient privacy" do so at a "potentially steep cost to public health."<sup>324</sup> Sometimes it may be difficult or impossible to obtain the consent of a patient who has moved to another jurisdiction or who has died. Population-health researchers argue that the public interest in the resulting research would be seriously compromised if consent were required, as some people would choose not to participate and the results would as a result not accurately reflect the entire population.<sup>325</sup> Kulynch and Korn explain the public interest as follows:

Recorded clinical information has for generations been the basis for advancing our understanding of diseases and assessing the effectiveness of new therapies and preventive strategies. Every person who seeks medical care is a direct beneficiary of the knowledge and insights gained from studies involving other persons with similar disorders.<sup>326</sup>

Others take the position that data on the health of an individual should not be disclosed without his or her informed consent and that only anonymous health information should be disclosed to third parties for research purposes.<sup>327</sup> As stated by Annas:

Public support of medical research really is a function of public trust. Providing meaningful protection of privacy of medical records in research is an important goal in its own right and will also increase public trust in the entire medical-research enterprise.<sup>328</sup>

The provincial health information privacy statutes contain provisions that allow custodians to release health information for research purposes if specified conditions are met. Under The Health Information Protection Act of Saskatchewan, a trustee of information requires the consent of the individual before information can be disclosed for research purposes.<sup>329</sup> The consent may be sought only after the trustee is of the opinion that the research is in the public interest, has been approved by an ethics committee, and the researcher has entered into an agreement about the use, storage, return, and/or destruction of the information.<sup>330</sup> Exceptionally, a trustee can authorize research "where it is not reasonably practicable for the consent of the subject individual to be obtained."<sup>331</sup>

In Manitoba, The Personal Health Information Act recognizes two committees that have authority to approve health research: the health information privacy committee and an institutional research review committee.<sup>332</sup> Important restrictions are placed on the power of the Manitoba committees to approve research projects: the research must be of sufficient importance to outweigh the intrusion into privacy that would result from the disclosure of personal health information; the purpose cannot reasonably be accomplished unless the per-

sonal health information is provided in a form that identifies or may identify individuals; it is unreasonable or impractical for the person proposing the research to obtain consent from the individuals the personal health information is about; and the research project contains reasonable safeguards to protect the confidentiality and security of the personal health information, and procedures to destroy the information or remove all identifying information at the earliest opportunity consistent with the purposes of the project.<sup>333</sup> The British Columbia Personal Information Protection Act contains many of the same conditions, but does not require an organization conducting research to go to a review committee.<sup>334</sup>

The Alberta Health Information Act and the Draft Ontario Privacy of Personal Information Act, 2002 provisions on health research are the most detailed. The Alberta and Ontario provisions are based on the Tri-Council Policy Statement, *Ethical Conduct for Research Involving Humans*.<sup>335</sup> In order for a health information custodian to release the personal health information of a patient to a researcher under the Alberta legislation and the draft Ontario bill, a research ethics board must approve the proposed research.<sup>336</sup> In any consideration of a research plan, the research ethics board must consider:

- whether it is necessary to use personal health information without consent in order to accomplish the objectives of the research;
- whether, at the time the research is conducted, adequate safeguards will be in place to protect the privacy of the individuals to whom the personal health information relates and to preserve the confidentiality of the information;
- whether the researcher is qualified to conduct the research that is the subject of the plan;
- the degree of risk to the individuals whose personal health information is being disclosed and whether the researcher has a methodology to mitigate those risks; and
- the public interest in conducting the research and the public interest in protecting the privacy of the individuals whose personal health information is being disclosed.<sup>337</sup>

The research ethics board is required to assess the public interest in conducting the research and the public interest in protecting the privacy of the individual. In making this determination, the research ethics board is to consider the extent to which the research is likely to:

- assist in the identification, prevention, or treatment of illness or disease;
- further scientific understanding of the medical condition;
- further health protection and health promotion; and improve the delivery of health services.<sup>338</sup>

Both the Alberta legislation and the draft Ontario bill require a researcher to enter into an agreement with the health information custodian.<sup>339</sup> Finally, under the draft Ontario bill the research ethics board's power to approve research is subject to two further limitations. First, the board shall refuse to approve a research plan if de-identified information could be used for the research purposes instead of personal health information.<sup>340</sup> Second, if the personal health information is likely to be published or "otherwise disclosed," the research ethics board shall refuse to approve the research plan unless the individual whose information is subject to disclosure consents to the transmission of such information.<sup>341</sup>

Ontario's Information and Privacy Commissioner has proposed further limitations on the power of research ethics boards to assess whether disclosure of personal health information without consent should be permitted. In determining whether it is reasonably practical for the researcher to obtain consent, the research ethics board should consider:

- the size of the population involved in the research;
- the proportion of individuals who are likely to have moved or died since the personal health information was originally collected;
- the risk of introducing potential bias into the research, thereby affecting the generalizability and validity of the results;
- the risk of creating additional threats to privacy by having to link personal health information with other personal information in order to contact individuals to seek their consent;
- the risk of inflicting psychological, social, or other harm by contacting individuals with particular conditions or in certain circumstances;
- the difficulty of contacting individuals directly when there is no existing or continuing relationship between the organization and the individuals;
- the difficulty of contacting individuals indirectly through public means, such as advertisements and notices; and
- whether the additional resources needed to obtain consent will impose an undue hardship on the organization.<sup>342</sup>

Existing and proposed health information privacy legislation do not adequately regulate research ethics boards.

The Information and Privacy Commissioner of Ontario criticized the draft Ontario bill for failing to prohibit a researcher from directly contacting the person whose information is sought: “Having the custodian authorize contact does not provide sufficient privacy protection. Such a scheme unnecessarily restricts the individual’s control over his or her personal health information.”<sup>343</sup> The Commissioner took the position that the health custodian must obtain the individual’s consent prior to any contact between the researcher and the individual. The former federal Privacy Commissioner proposed that the draft Ontario bill be amended to prohibit anyone except a physician or primary health-care provider from contacting a patient.<sup>344</sup> Both the Alberta Health Information Act and The Personal Health Information Act of Manitoba require a trustee to obtain the person’s consent before a researcher can contact that person.<sup>345</sup>

Existing and proposed health information privacy legislation do not adequately regulate research ethics boards. Neither PIPEDA nor the provincial health information privacy legislation set out rules for the composition of research ethics boards or the qualifications of members. This raises the question of whether board members lack the training to properly fulfill the responsibilities assigned to research ethics boards by legislation. Legislative provisions regulating research and research ethics boards is needed, whether within health information privacy legislation or in a separate statute designed for that purpose.

### **RECOMMENDATION**

**Provincial and territorial governments should ensure that legislation prohibits a custodian from disclosing personal health information of a person with HIV/AIDS for the purposes of health research if de-identified information will serve the research purpose.**

**Legislation should prohibit contact between the researcher of a study approved by a research ethics board and the person whose medical information is sought**

unless the consent of the patient/client has first been obtained by the custodian holding the information.

Legislation should require that a research plan be submitted for approval to a research ethics board before health information can be disclosed without consent for the purposes of research. The legislation should prescribe the composition of the research ethics board and the qualifications and training of the board members. The legislation should also state the factors to be considered by the research ethics board in deciding whether it is reasonably practical for the researcher to obtain consent, and this should reflect the expert advice of privacy commissioners.

Legislation should require that the research ethics board assess the public interest in conducting the research and the public interest in protecting the privacy of the person with HIV/AIDS. In making this determination, the research ethics board should consider the extent to which the research is likely to:

1. assist in the identification, prevention, or treatment of illness or disease;
2. further scientific understanding of the medical condition;
3. further health protection and health promotion; and
4. improve the delivery of health services.



## Legislative Remedies for Breach of Confidentiality

It has been argued that without effective remedies under provincial health information privacy legislation, people living with HIV/AIDS will have no real recourse for breaches of their confidentiality.<sup>346</sup> Therefore, it is important that remedies under legislation that protects personal health information are accessible and effective. This chapter *briefly* reviews the extent to which effective remedies exist for the improper use, collection, and disclosure of personal health information. The accessibility of these remedies for people living with HIV/AIDS will be discussed. The recommendations made in this chapter are aimed at:

1. ensuring that effective remedies for improper disclosure of personal health information are accessible to people living with HIV/AIDS; and
2. ensuring that remedies and enforcement powers serve as deterrents to the improper disclosure of personal health information of people living with HIV/AIDS.

The remedial provisions contained in PIPEDA reflect a commitment to the protection of privacy and confidentiality interests. In general, PIPEDA's remedial provisions are equal to or exceed the remedial provisions in provincial health information privacy legislation. Provincial health information privacy legislation must include remedial provisions that offer privacy protections at least as great as those found in PIPEDA, except where existing provincial protections are stronger.

### RECOMMENDATION

Federal, provincial, and territorial governments should ensure that legislation contains effective and accessible remedies to address the improper disclosure of the personal health information of people living with HIV/AIDS. These remedies should deter the improper disclosure of personal health information of people living with HIV/AIDS.



## Initiating a complaint

Laws that protect personal health information must contain mandatory provisions requiring the commissioner/ombudsman to conduct public education. Commissioners/ombudsmen must have staff trained to provide education to people about the rights and the remedies available to them under health information privacy legislation. For example, under PIPEDA, the federal Privacy Commissioner is required to “develop and conduct information programs to foster public understanding” and to promote recognition of the statute’s purposes.<sup>347</sup> Only the Saskatchewan statute contains a similar provision, but the language is permissive rather than mandatory.<sup>348</sup> The provincial commissioners/ombudsmen should have the same responsibility regarding education as their federal counterpart. They should be required to develop education programs to inform the public about the existence of, and rights under, health information privacy legislation, the complaints process, and the remedies available for breaches of the legislation. Particular efforts should be made to target education to those for whom disclosure of personal health information may have particularly serious consequences, as is often the case for people living with HIV/AIDS and those segments of the population least likely to complain because of other systemic barriers.

Health information privacy legislation must respect, protect, and fulfill the rights of people living with HIV/AIDS. To this end, legislation must encourage people to seek remedies for the improper disclosure of their personal health information. The remedies provided must be accessible to people living with HIV/AIDS. This will only be the case if the complaints process does not create practical or legal obstacles to initiating and proceeding with a complaint. This section will briefly review each potential obstacle, including:

- restrictions on the form the complaint must take;
- lack of help for filing a complaint;
- fees charged to file a complaint;
- limitation periods for filing a complaint; and
- the power to dismiss a complaint without an investigation.

## Help filing complaints

Legislators at both the federal and provincial levels should broaden the manner in which complaints can be initiated. People must be able to file a complaint using means other than in writing, or be given the assistance to put a complaint in writing. Some may not be able to read or write English or French, or may not be able to properly express themselves and articulate their complaint in writing in a language other than their mother tongue. Disabilities that impair written communication may also pose a barrier to people filing written complaints – for example, a visually impaired person who reads and writes Braille. Individuals ought to be permitted to initiate a complaint by audiotape, videotape, or electronically, and/or be provided with assistance in filing a complaint in a format that can be processed by an ombudsman or commissioner.

As a basic principle of access to justice, payment of a fee should not be imposed on persons who seek redress for breaches of confidentiality.

## Fees

As a basic principle of access to justice, payment of a fee should not be imposed on persons who seek redress for breaches of confidentiality. The payment of a fee will serve as a barrier for those individuals who have a limited or no income, such as people who receive social assistance, other government benefits, or people who are homeless. The imposition of a pay-

ment may be onerous for many people living with HIV/AIDS, due to the financial losses that frequently accompany a chronic medical condition.

### **Limitation periods**

Another potential obstacle to redress is the limitation periods imposed by health information privacy legislation for filing complaints. A limitation period is a certain period of time allowed by a statute for taking action or enforcing rights. Limitation periods establish not only the period of time during which an action must be taken, but also set out when the period begins to run. Legislation may also grant the power to extend the period of time allowed for taking action or enforcing rights, and set out the criteria for when time should be extended. Given the public policy goals that underpin health information privacy legislation, the limitation periods for filing complaints should be *at least* as long as the limitation periods set out under provincial legislation that establishes a cause of action for invasion of privacy, which is two years.<sup>349</sup> The limitation period should start running no sooner than the time at which the person knows or ought reasonably to have known of the unauthorized use or disclosure of his or her health information.

The flexibility to extend the period of time for filing a complaint should exist in all provincial statutes. Because of the nature of HIV-disease progression, people living with HIV/AIDS may experience periods of severe illness and/or depression followed by periods of relative good health. When a complainant discovers an unauthorized disclosure, he or she may be too ill to file a complaint and may be unable or unwilling to do so for some time. Legislation should explicitly permit an extension of the limitation period due to illness, incapacity, or other reasonable circumstances. Arguably, a limitation period that prevents a person from filing a complaint because of disability discriminates against people living with HIV/AIDS due to their disability, and is contrary to the equality rights guaranteed by the s 5 Charter equality guarantee. In such circumstances, a number of courts have extended the limitation period relying on s 15 of the Charter.<sup>350</sup> Finally, a person whose rights under health information privacy legislation have been breached may not be aware of the remedies available under the legislation, and pursue in good faith remedies under other legislation, such as legislation regulating health professionals. People should not be penalized for attempts made in good faith to seek redress under other legislation.

### **RECOMMENDATION**

**Provincial and territorial governments should ensure that legislation makes it mandatory for the commissioner/ombudsman to develop education programs to inform the public about the existence of, and rights under, legislation that protects personal health information. Education programs should include information about the complaints process and the remedies available for statutory breaches.**

**Federal, provincial and territorial governments should ensure that legislation:**

- 1. requires the commissioner/ombudsman to make trained staff available to explain and to assist people with HIV/AIDS with the procedure to initiate a complaint for violation of the statute;**
- 2. gives individuals the option of filing a complaint by means of audiotape or videotape as well as in written form;**
- 3. does not require the payment of a fee in order to initiate a complaint with a commissioner/ombudsman for breach of the statute; and**

4. **provides the commissioner/ombudsman with discretion to extend the limitation period for filing a complaint, and explicitly permit an extension of the limitation period where illness or incapacity is the reason for the delay in filing.**

**The limitation period for filing a complaint should be at least two years, and should only begin to run when the individual knows or ought reasonably to have known that his or her privacy rights have been breached.**

### **Obligation of the commissioner/ombudsman to investigate complaints**

Some provincial statutes grant discretion to the privacy commissioner to determine whether a complaint should be investigated, and dismiss complaints that are frivolous or vexatious or should have been brought under another piece of legislation.<sup>351</sup> This is commonly referred to as “screening.” This is in contrast to PIPEDA, which requires that the federal Privacy Commissioner conduct investigations of complaints that have been filed.<sup>352</sup> In order to ensure that health professionals, employers, insurance companies, and other institutions respect the dignity and privacy of people with HIV/AIDS, it is important that the complainant have the right to an investigation by the body or the official that has been designated by the province/territory or federal government to oversee compliance with the statute and that has the necessary expertise in this area of law. Legislation should take into account the fact that a complaint may not appear to have merit on its face because of linguistic, cultural, educational, or disability-related barriers posed by the complaints process. The ability of a commission to “screen out” complaints should be subject to strict limits to ensure that the screening process does not become a tool to deal with backlogs or underfunding of commissions by government. As a minimum standard, an ombudsman or commissioner should only have the power to dismiss “patently” frivolous or vexatious complaints and the legislation should establish criteria for what constitutes a frivolous or vexatious complaint.

### **RECOMMENDATION**

**Provincial and territorial governments should ensure that legislation requires the commissioner/ombudsman to investigate all complaints, unless they are “patently” frivolous or vexatious. The legislation should establish criteria for making this determination.**

### **Powers of investigation and reporting**

The granting of broad powers to a privacy commissioner/ombudsman to investigate breaches of privacy is important both to assessing the seriousness and extent of the breach and to determining the remedies available to the complainant. PIPEDA contains broad investigatory powers.<sup>353</sup> The federal Privacy Commissioner and his delegates have the authority to enter business premises, to review and make copies of documents, to conduct interviews, and to make “any inquiries that the Commissioner sees fit.”<sup>354</sup> The Commissioner also has the authority to summon and enforce the appearance of individuals before him to give evidence under oath; it is not necessary that the testimony or the records submitted satisfy the evidentiary rules required in a court of law.<sup>355</sup> Under legislation in Alberta, British Columbia, Saskatchewan, Manitoba, and Québec, the ombudsman or privacy commissioner has the

authority to compel witnesses to testify, while that power does not exist in the draft Ontario legislation.<sup>356</sup>

The time frame in which the investigation of the complaint is to be completed and a report prepared by the ombudsman or privacy commissioner varies. For example, the Manitoba

Remedies must be timely in order to preserve the confidence of people living with HIV/AIDS in the system that has been given the mandate to protect the privacy of their personal health information. But time limits set out in legislation are unlikely to be met unless the oversight body has the necessary resources and staff.

Personal Health Information Act states that the investigation and report should be completed within 45 days after the complaint is filed if it concerns access to information, and within 90 days “if it is about privacy.”<sup>357</sup> The Ombudsman, however, has discretion to extend the time period.<sup>358</sup> Under PIPEDA the federal Privacy Commissioner has one year from the date the complaint is filed (or initiated by the Commissioner) to prepare the report and send it “without delay” to the parties.<sup>359</sup>

Remedies must be timely in order to preserve the confidence of people living with HIV/AIDS in the system that has been given the mandate to protect the privacy of their personal health information. But time limits set out in legislation are unlikely to be met unless the oversight body has the necessary resources and staff. Ninety days is a reasonable maximum time period for response by way of report from the commissioner/ombudsman, with the discretion to extend the 90-day period only in exceptional circum-

stances. Federal and provincial governments must provide the commissioner/ombudsman with sufficient resources to meet this time limit.

## **RECOMMENDATION**

**Provincial and territorial governments should ensure that legislation gives the commissioner/ombudsman broad statutory powers to investigate complaints, including the authority to conduct audits, to compel the production of records, and to require persons to give testimony.**

**Federal, provincial, and territorial governments should establish in legislation 90 days as the time within which the commissioner’s/ombudsman’s report on a complaint should be released. Discretion to extend this time should be available only in exceptional circumstances. Governments must provide the commissioner/ombudsman the financial resources needed to accomplish this.**

## **Power to issue recommendations and make orders**

Under PIPEDA and the British Columbia Personal Information Protection Act, a commissioner may attempt to resolve complaints by means of dispute resolution mechanisms such as mediation and conciliation.<sup>360</sup> Under the draft Ontario bill, the commissioner is also given the power to attempt to resolve a complaint through mediation.<sup>361</sup> Significantly, these statutes do not state whether the mediation or conciliation is voluntary or mandatory.

Any mediation of complaints must be voluntary. An inequality of bargaining power between complainants and custodians will likely exist in the mediation process, usually to the detriment of the complainant. An organization, health-care professional, or hospital official will likely have access to, or be accompanied at the mediation by, legal counsel who may possess a sophisticated understanding of the legislation, whereas a complainant may not have similar access to legal advice or representation. This unequal bargaining power may result in a settlement that does not adequately redress the person for past breaches of confi-

dentiality, or adequately protect the person from future breaches. Therefore, mediation should be offered, but not imposed, on a party who has filed a complaint under health information privacy legislation.

With the exception of Alberta's Health Information Act and British Columbia's Personal Information Protection Act, provincial legislation applicable to personal health information does not provide the commissioner and ombudsman with adequate powers to effectively address violations. Under the Manitoba and Saskatchewan statutes,<sup>362</sup> the commissioner/ombudsman can only "recommend" to a health-care custodian or organization guilty of breaching the statute that the custodian or organization "cease or modify a specified practice of collecting, using, disclosing, retaining or destroying personal health information" and "destroy a collection of personal health information that was collected in a manner contrary to this Act." This is also the case under PIPEDA.<sup>363</sup> Similarly, the federal Privacy Commissioner lacks the authority to issue an order requiring an organization to cease the wrongdoing, or to disclose or retrieve the personal information of the individual.<sup>364</sup> However, the federal Privacy Commissioner does have the authority to make an application to the Federal Court under certain circumstances on any matter relating to the Commissioner's report concerning a complaint.<sup>365</sup>

In contrast, under the Alberta Health Information Act, the Commissioner has the power to make a final order against a health-care custodian who has infringed the statute. The Commissioner can:

- require that a duty imposed by this Act or the regulations be performed;
- require a person to stop collecting, using, disclosing or creating health information in contravention of this Act;
- require a person to destroy health information collected or created in contravention of this Act.<sup>366</sup>

The Commissioner is also authorized to impose any terms or conditions in the order considered to be appropriate.<sup>367</sup> The order of the Commissioner is final<sup>368</sup> and a copy of the order may be filed with the Court of Queen's Bench, at which time it is enforceable as an order or judgment of that court.<sup>369</sup> The Commissioner's order is subject to judicial review; the application must be made within 45 days after the party receives the report.<sup>370</sup>

The British Columbia Personal Information Protection Act has sections similar to those in the Alberta legislation. In an order, the Commissioner can:<sup>371</sup>

- require an organization to stop collecting, using, or disclosing personal information in contravention of the Act;
- require an organization to destroy personal information collected in contravention of the Act; and
- specify any terms or conditions in the order.

Where provincial legislation does allow a commissioner to issue orders, it also imposes fines on people found guilty of failing to comply with a commissioner's order. Under the Alberta legislation, a person who *knowingly* fails to comply with an order made by a commissioner is guilty of an offence and liable to pay a fine of up to \$50,000.<sup>372</sup> Under the British Columbia legislation and Ontario draft legislation, there is no requirement that the person act *knowingly*. The British Columbia legislation imposes fines of up to \$10,000 for an individual or \$100,000 for a person other than an individual,<sup>373</sup> while the draft Ontario law sets the fines at up to \$50,000 for an individual or \$250,000 for a person other than an individual.<sup>374</sup>

Under The Personal Health Information Act of Manitoba, the Ombudsman has the authority, unless the complainant objects, to forward his or her report to “a body with statutory authority to regulate health professionals.”<sup>375</sup> This power can be used to ensure that the authority that licenses and regulates a particular health professional is aware of any breaches of confidentiality. The complaints, competence, and disciplinary functions of the self-governing profession (eg, the College of Physicians and Surgeons, the College of Nurses, the College of Dentists, the College of Physiotherapists) can take measures against the health professional as appropriate.

Another power aimed at securing compliance with the legislation is publicizing the improper practices of an organization. Under PIPEDA the federal Privacy Commissioner has the authority, if he or she considers it to be in the public interest, to publicize the personal information management practices of an organization.<sup>376</sup> A former federal Privacy Commissioner has referred to this as the “power of embarrassment.”<sup>377</sup> In addition, the Privacy Commissioner can include in his or her annual report submitted to Parliament the findings of an audit of an organization’s practices.<sup>378</sup>

## **RECOMMENDATION**

**Provincial and territorial governments should ensure that legislation grants the commissioner/ombudsman the power to issue an order, with terms and conditions he or she deems appropriate, to an organization or individual that is collecting, using, or disclosing health information in contravention of the legislation.**

**Federal, provincial, and territorial governments should ensure that legislation includes only voluntary mediation and conciliation as means to settle a complaint.**

**Provincial and territorial governments should ensure that people who cannot otherwise afford it are eligible to receive provincially funded legal advice and representation in pursuing complaints under health information privacy legislation.**

**Federal, provincial, and territorial governments should provide the commissioner/ombudsman with the authority to forward the findings in the report to a body that licenses or certifies a health professional or service provider, provided the consent of the complainant is obtained before doing so.**

## **Quasi-criminal offences and prosecutions**

Quasi-criminal offences are also known as regulatory offences. Quasi-criminal offences seek to punish individuals and corporate bodies who infringe non-criminal laws. The imposition of a fine or a term of imprisonment on an individual, or a substantial fine for a corporation, may deter individuals and organizations from breaching the privacy of people living with HIV/AIDS. Some provincial statutes provide that a person or corporation may be subject to prosecution for violating provisions in the statute.<sup>379</sup> If the prosecution is successful, the person found guilty of the offence may be subject to a fine and/or imprisonment. In Saskatchewan, no prosecution shall be commenced except with the express consent of the Attorney General.<sup>380</sup> The power to initiate quasi-criminal prosecutions should not be reserved for government. There may be situations where the government is unwilling or unable to initiate a prosecution, even in the face of overwhelming evidence of a breach of the statute. In that situation, the health information privacy legislation should include provisions empowering both the government and individuals to initiate quasi-criminal prosecutions for violations of the statute.

## **RECOMMENDATION**

**Federal, provincial, and territorial governments should ensure that legislation provides both governments and individuals with the power to initiate quasi-criminal prosecutions against individuals or organizations for breaches of health information privacy legislation.**

### **Non-retaliation clauses**

To help protect people living with HIV/AIDS from improper use or disclosures of personal health information, it is important that staff in an organization, hospital, or government aware of breaches or potential breaches of health information privacy legislation be able to report these acts to the appropriate authority with protection against retaliation. Without these safeguards and protections, the commissioner/ombudsman may not learn of the violations and consequently will not be able to take the needed measures to prevent the disclosure of this sensitive and personal information of people living with HIV/AIDS.

In order to encourage individuals to report breaches of privacy of people living with HIV/AIDS, a “non-retaliation clause” should be included in private and public sector health information privacy legislation. Employers should be prohibited from taking adverse actions against an employee who:

1. in good faith, reports a perceived violation of the statute to the Privacy Commissioner;
2. refuses to commit a violation of the statute; or
3. acts to prevent a breach of the statute.

PIPEDA, Manitoba,<sup>381</sup> and Alberta<sup>382</sup> legislation and the draft Ontario bill<sup>383</sup> contain these types of provisions. PIPEDA encourages individuals to report breaches of the statute by assuring individuals, upon request, that the Privacy Commissioner will not disclose their identity.<sup>384</sup>

## **RECOMMENDATION**

**Provincial and territorial governments should ensure that legislation protects employees against retaliatory acts by employers when an employee in good faith reports a breach of a health information privacy statute, refuses to violate a statutory provision, or takes action to prevent a breach of the statute.**

### **Access to the courts and the availability of damages**

Given the significance of the interests at stake, people living with HIV/AIDS whose privacy has been violated or confidentiality breached in contravention of privacy legislation should be able to go to court and sue for damages. PIPEDA offers complainants this access. Under PIPEDA, a complainant, upon receiving a Commissioner’s report, may apply to the Federal Court Trial Division “for a hearing in respect of any matter in respect of which the complaint was made or that is referred to in the Commissioner’s report.”<sup>385</sup> The Federal Court has broad remedial powers under PIPEDA.<sup>386</sup> In addition to any other remedies it may give, the Federal

In order to encourage individuals to report breaches of privacy of people living with HIV/AIDS, a “non-retaliation clause” should be included in private and public sector health information privacy legislation.

Court may “award damages to the complainant, including damages for any humiliation that the complainant has suffered.”<sup>387</sup> PIPEDA’s remedial provisions empower the Federal Court to award compensatory damages (including aggravated damages), punitive damages, and injunctive relief.<sup>388</sup>

A number of provincial statutes give people limited access to a court to recover damages. The British Columbia Personal Information Protection Act allows a person to sue for damages in court, subject to two limits not found in PIPEDA. First, only organizations can be sued. Second, a person can only sue to recover damages for actual harm resulting from a

A person with HIV/AIDS whose health information has been disclosed contrary to legislation should have recourse to the courts for the full range of damages available in a common law tort action.

breach of the Act. A person affected by an order can sue an organization for breach of the act once a commissioner’s order becomes final.<sup>389</sup> A person can also sue where an organization has been found guilty of an offence under this Act.<sup>390</sup> Under the Saskatchewan Act, a person cannot start a lawsuit in civil court when the Act has been breached. A person can only appeal an information trustee’s decision to follow, or not to follow, a recommendation of the information commissioner.<sup>391</sup> Where the court determines that an information trustee has contravened the Act, it has a broad remedial power to “make any order it considers appropriate.”<sup>392</sup> This power could include the power to award damages. The draft Ontario Privacy of Personal Information Act, 2002, permits individuals to bring a court

action for damages for harm suffered as a result of the breach of a provision under the Act. However, damages are limited to compensatory damages for “actual harm” experienced.

A person with HIV/AIDS whose health information has been disclosed contrary to legislation should have recourse to the courts for the full range of damages available in a common law tort action. Historically, under the direct intentional torts of battery, assault, and false imprisonment, proof of harm was unnecessary because the purpose of these torts is to protect the plaintiff’s security interests, as well as the tranquility expected in a well-ordered society.<sup>393</sup> It is only by doing so that damage awards will fulfill the important public policy objectives of restitution and deterrence, as required by the circumstances of a particular case, reflecting the severity of the breach, the loss, and the actions and motivations of the person who breached the statute.

## **RECOMMENDATION**

**Provincial and territorial governments should ensure that legislation permits a person living with HIV/AIDS to initiate a civil action in court where his or her privacy has been violated or confidentiality breached in contravention of legislation. The courts should have the authority to award damages without proof of harm, and should be able to award compensatory and punitive damages as well as injunctive and declaratory relief.**





## **Conclusion: Time to Act – An Opportunity for Change**

In 1990, the Parliamentary Ad Hoc Committee on AIDS endorsed the importance of protecting information about HIV test results and HIV status, and agreed that legislation should be reviewed, and amended where necessary, to ensure this.<sup>394</sup> In addition, it urged that more attention be given to the enforcement of existing legislation.<sup>395</sup> In 2003, Canadian law still does not adequately protect the health information of people living with HIV/AIDS. Common law and statutory tort actions to protect privacy are not well developed. Both the federal and a number of provincial governments have enacted, or have proposed, legislation that applies to health information. Many of the discretionary disclosure clauses in these acts are overbroad and threaten the privacy rights of, and confidentiality obligations owed to, people living with HIV/AIDS. The remedial provisions in health information privacy legislation do not inspire confidence that people living with HIV/AIDS will be able to access effective remedies for improper use or disclosure of their health information. And the enforcement provisions do not adequately deter future violations of the privacy rights contained in health information protection legislation.

This report has reviewed and analyzed health information privacy legislation. It makes recommendations for law reform that promote the legal and ethical values that underpin the privacy rights and confidentiality interests that people living with HIV/AIDS have in their health information. It also recommends that governments adequately fund the administrative bodies mandated to oversee the protection of personal health information so that they can fulfill their mandate.

Legislation in and of itself is an inadequate means of protecting the privacy of people living with HIV/AIDS. Therefore, this report recommends that the mandate of administrative bodies should include the development of education programs to inform the public about the existence of and rights under health information privacy legislation, the complaints process, and the remedies available for statutory breaches. It also recommends that

provincial governments make legal aid available to people pursuing complaints under health information privacy legislation.

Legislation in and of itself is an inadequate means of protecting the privacy of people living with HIV/AIDS.

Confidentiality of health information is fundamental to the preservation of the ethical values of autonomy, dignity, and respect for the individual. People living with HIV/AIDS suffer discrimination as a result of the unauthorized disclosure of their HIV status. The repercussions are legal, economic, social, and psychological. The time is long overdue for legislators and policymakers to put in place legislation and policies that protect the privacy rights of people living with HIV/AIDS. In doing so, legislators and policymakers must recognize the fundamental interests people living with HIV/AIDS have in the privacy of their health information, and their responsibility to enact laws and encourage policies that protect those fundamental interests. A lawyer who practises in a legal clinic exclusively serving the needs of people living with HIV/AIDS has summarized the challenges, and potential gains, that await legislators, community-based organizations, and people living with HIV/AIDS:

This is an exciting time for privacy in Canada. The legislative initiatives currently underway are an opportunity to alter the public discourse around HIV/AIDS and to slowly change what it is like to live with HIV in this country. It is my hope and belief that we should engage with the legislative process and work to make these new laws as effective as we collectively can. As the former Privacy Commissioner [of Canada] has stated: “Privacy will be the defining issue of this decade.”<sup>396</sup>



## Summary of Recommendations

**The recommendations in this report call on governments take steps to ensure that legislation protects the personal health information of people living with HIV/AIDS. To comply with the recommendations, some provincial and territorial governments must enact new legislation. In provinces where legislation exists, governments will have to amend legislation.**

### **Discretionary disclosure clauses**

Only in exceptional and circumscribed situations should legislation permit a custodian or trustee to disclose health information without the express and informed consent of a person living with HIV/AIDS.

Federal, provincial, and territorial governments should ensure that legislation that applies to personal health information provides at least the protections for personal health information afforded under the Charter and at common law.

### **Purpose of legislation**

Provincial and territorial governments should ensure that legislation regarding personal information protection includes a preamble or purpose clause setting out a consistent and principled approach to the protection of health information.

Legislation that protects the privacy of personal information must recognize the particular importance of protecting health information, and should contain a preamble or purpose clause setting out a consistent, client-based, and principled approach to the protection of personal information.

### **Guiding principles**

Federal, provincial, and territorial governments should ensure that legislation limits the circumstances in which health information of a person is disclosed without consent. Legislation

must also include principles and practices that must be followed where personal health information is going to be disclosed without consent:

1. the custodian of health information must take measures to ensure that the information is as complete and accurate as possible prior to the disclosure of the information;
2. all disclosures without consent must be limited to “de-identified” information if that will serve the purpose for which it is transmitted;
3. the disclosure must be limited to the minimum amount necessary to accomplish the purpose for which the information is transmitted;
4. the custodian should make best efforts to inform the person with HIV/AIDS of the anticipated disclosure of his or her personal information and attempt to seek consent to the disclosure;
5. the custodian must maintain a record of every transmission of health information to a third party;
6. the statutory list of permitted disclosures without consent should be exhaustive; government officials should not be authorized to add by regulation further circumstances in which information can be disclosed without consent;
7. the health information privacy statute should prevail unless another enactment provides more protection to persons living with HIV/AIDS.

### **Ethical responsibilities of health-care professionals**

Health-care-profession regulating bodies and associations should educate and inform their members about the duty of confidentiality owed to patients, and about the effect of discretionary disclosure clauses in health information protection legislation on the duty of confidentiality. Specifically, they should advise their members that *discretionary* disclosure clauses (ie, clauses that permit disclosure) do not *require* the disclosure of confidential patient information.

### **Investigations and court proceedings**

Federal, provincial, and territorial governments should ensure that legislation does not give people who hold health information the discretion to disclose that information in investigations and court proceedings.

### **Preventing harm to third parties**

Provincial and territorial governments should ensure that discretionary disclosure clauses in provincial legislation aimed at preventing harm to third parties reflect the principles enunciated by the Supreme Court of Canada in *Smith v Jones*. Disclosure should only be permitted where there is a clear and imminent threat of serious bodily harm or death to an identifiable person or group.

### **Family and friends**

Provincial and territorial governments should ensure that legislation prohibits custodians from disclosing any personal health information, or information that may reasonably reveal a person’s health information, to family and friends without that person’s consent.

Where a treatment decision needs to be made on behalf of an incompetent person, legislation should permit custodians to disclose that person’s health information only to a substitute decision-maker. Furthermore, the legislation must limit disclosure to only that information relevant to the treatment decision at hand.

## **Health research**

Provincial and territorial governments should ensure that legislation prohibits a custodian from disclosing personal health information of a person with HIV/AIDS for the purposes of health research if de-identified information will serve the research purpose.

Legislation should prohibit contact between the researcher of a study approved by a research ethics board and the person whose medical information is sought unless the consent of the patient/client has first been obtained by the custodian holding the information.

Legislation should require that a research plan be submitted for approval to a research ethics board before health information can be disclosed without consent for the purposes of research. The legislation should prescribe the composition of the research ethics board and the qualifications and training of the board members. The legislation should also state the factors to be considered by the research ethics board in deciding whether it is reasonably practical for the researcher to obtain consent, and this should reflect the expert advice of privacy commissioners.

Legislation should require that the research ethics board assess the public interest in conducting the research and the public interest in protecting the privacy of the person with HIV/AIDS. In making this determination, the research ethics board should consider the extent to which the research is likely to:

1. assist in the identification, prevention, or treatment of illness or disease;
2. further scientific understanding of the medical condition;
3. further health protection and health promotion; and
4. improve the delivery of health services.

## **Legislative remedies for breaches of confidentiality**

Federal, provincial, and territorial governments should ensure that legislation contains effective and accessible remedies to address the improper disclosure of the personal health information of people living with HIV/AIDS. These remedies should deter the improper disclosure of personal health information of people living with HIV/AIDS.

## **Initiating a complaint**

Provincial and territorial governments should ensure that legislation makes it mandatory for the commissioner/ombudsman to develop education programs to inform the public about the existence of, and rights under, legislation that protects personal health information. Education programs should include information about the complaints process and the remedies available for statutory breaches.

Federal, provincial, and territorial governments should ensure that legislation:

1. require the commissioner/ombudsman to make trained staff available to explain and to assist people with HIV/AIDS with the procedure to initiate a complaint for violation of the statute;
2. gives individuals the option of filing a complaint by means of audiotape or videotape as well as in written form;
3. does not require the payment of a fee in order to initiate a complaint with a commissioner/ombudsman for breach of the statute; and
4. provides the commissioner/ombudsman with discretion to extend the limitation period for filing a complaint, and explicitly permit an extension of the limitation period where illness or incapacity is the reason for the delay in filing.

The limitation period for filing a complaint should be at least two years, and should only begin to run when the individual knows or ought reasonably to have known that his or her privacy rights have been breached.

### **Obligation to investigate a complaint**

Provincial and territorial governments should ensure that legislation requires the commissioner/ombudsman to investigate all complaints, unless they are “patently” frivolous or vexatious. The legislation should establish criteria for making this determination.

### **Investigation and reporting**

Provincial and territorial governments should ensure that legislation gives the commissioner/ombudsman broad statutory powers to investigate complaints, including the authority to conduct audits, to compel the production of records, and to require persons to give testimony.

Federal, provincial, and territorial governments should establish in legislation 90 days as the time within which the commissioner’s/ombudsman’s report on a complaint should be released. Discretion to extend this time should be available only in exceptional circumstances. Governments must provide the commissioner/ombudsman the financial resources needed to accomplish this.

### **Recommendations and orders**

Provincial and territorial governments should ensure that legislation grants the commissioner/ombudsman the power to issue an order, with terms and conditions he or she deems appropriate, to an organization or individual that is collecting, using, or disclosing health information in contravention of the legislation.

Federal, provincial, and territorial governments should ensure that legislation includes only voluntary mediation and conciliation as a means to settle a complaint.

Provincial and territorial governments should ensure that people who cannot otherwise afford it are eligible to receive provincially funded legal advice and representation in pursuing complaints under health information privacy legislation.

Federal, provincial, and territorial governments should provide the commissioner/ombudsman with the authority to forward the findings in the report to a body that licenses or certifies a health professional or service provider, provided the consent of the complainant is obtained before doing so.

### **Quasi-criminal offences and prosecutions**

Federal, provincial, and territorial governments should ensure that legislation provides both governments and individuals with the power to initiate quasi-criminal prosecutions against individuals or organizations for breaches of health information privacy legislation.

### **Non-retaliation**

Provincial and territorial governments should ensure that legislation protects employees against retaliatory acts by employers when an employee in good faith reports a breach of a health information privacy statute, refuses to violate a statutory provision, or takes action to prevent a breach of the statute.

## **Access to courts and the availability of damages**

Provincial and territorial governments should ensure that legislation permits a person living with HIV/AIDS to initiate a civil action in court where his or her privacy has been violated or confidentiality breached in contravention of legislation. The courts should have the authority to award damages without proof of harm, and should be able to award compensatory and punitive damages as well as injunctive and declaratory relief.



## Notes

<sup>1</sup> See, eg.: AIDS Committee of Toronto. Submission to the Standing Committee on General Government (Ontario) on the *Personal Information Privacy Act, 2002*. Hansard 37<sup>th</sup> Parliament, Session 1, 27 February 2001, 1400-1420; Algoma AIDS Network. Submission to the Standing Committee on General Government (Ontario) on the *Personal Information Privacy Act, 2002*. Hansard 37<sup>th</sup> Parliament, Session 1, 26 February 2001, 1321-1339; J Bruce. *Privacy and Confidentiality of Health Care Information*. USA: American Hospital Publications Inc, 2<sup>nd</sup> ed, 1988, at 127; M Cameron. The Privacy Act and e-health. *National AIDS Bulletin* 2001; 14: 23-24; Commonwealth of Australia. *Report of the Privacy and HIV/AIDS Working Party*. Commonwealth of Australia: September 1992; H Glenn, N Gilmore, M Somerville, Y-M Morissette. *HIV Infection, AIDS and Privacy*. Montréal: McGill Centre for Medicine, Ethics and Law, March 1990; J Gray, P Lyons, G Melton. *Ethical and Legal Issues in AIDS Research*. Baltimore: The John Hopkins University Press, 1995; HIV/AIDS Community Ad Hoc Committee. *The HIV/AIDS Community Ad Hoc Committee on the Personal Health Information Protection Act, 1997*. Undated (available via [www.halco.org](http://www.halco.org)); HIV & AIDS Legal Clinic (Ontario). *Ontario Proposed Personal Health Information Privacy Legislation for the Health Sector (Health Sector Privacy Rules)*, 9 October 2000 (available via [www.halco.org](http://www.halco.org)); HIV & AIDS Legal Clinic (Ontario). *Submissions of the HIV & AIDS Legal Clinic (Ontario) on Bill 159: The Personal Health Information Privacy Act, 2000*, 26 February 2001 (available via [www.halco.org](http://www.halco.org)); HIV & AIDS Legal Clinic (Ontario). *Submission to the Ministry of Consumer and Business Services: Consultation Draft of the Privacy of Personal Information Act, 2002*. Undated (available via [www.halco.org](http://www.halco.org)); Information and Privacy Commissioner/Ontario. *HIV/AIDS: A Need for Privacy*, October 1990; R Jürgens. *HIV Testing and Confidentiality: Final Report*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, October 1998; Ontario AIDS Network. Submission to the Standing Committee on General Government (Ontario) on the *Personal Information Privacy Act, 2002*. Hansard 37<sup>th</sup> Parliament, Session 1, 27 February 2001, 1620-1640; Privacy Commissioner of Canada. *AIDS and the Privacy Act*. Ottawa: Minister of Supply and Services, 1989; S Rennert. *AIDS/HIV and Confidentiality: Model Policy and Procedures*. Washington DC: American Bar Association, 1991.

<sup>2</sup> T de Bruyn. *HIV/AIDS and Discrimination: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1998; S Matiation. *Discrimination, HIV/AIDS and Aboriginal People: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network and Canadian Aboriginal AIDS Network, 2<sup>nd</sup> ed, 2000; D Schneider et al. Attitudes and beliefs towards HIV and AIDS among Aboriginal peoples living in British Columbia. *Healing Our Spirit Research Papers*. Undated (available via [www.healingourspirit.org](http://www.healingourspirit.org)); Alliance for South Asian AIDS Prevention. *Discrimination and HIV/AIDS in South Asian Communities: Legal, Ethical and Human Rights Challenges. An Ethnocultural Perspective*. Toronto: Alliance for South Asian AIDS Prevention, 1999; W Lau et al. *Legal, Ethical and Human Rights Issues Facing East and Southeast Asian-Canadians in Accessing HIV/AIDS Services in Canada*. Toronto: Asian Community AIDS Services, 1999; C Olivier. HIV-related discrimination in New Brunswick increasing. *Canadian HIV/AIDS Policy & Law Newsletter* 2000; 5(2/3): 52; J Leech. Survey reveals human rights abuses in Alberta. *Canadian HIV/AIDS Policy & Law Newsletter* 2003; 8(1): 24; S Kellington et al. *Listen Up! Women are Talking About... The social determinants of women's risk for HIV infection and illness in lower mainland British Columbia*. Vancouver: Positive Women's Network, 1999; S Kellington et al. *Listen Up! Women are Talking About... Examining community-based strategies and solutions to address the social determinants of women's risk for HIV infection and illness progression in Lower Mainland British Columbia*. Vancouver: Positive Women's Network, 2000; HIV Endemic Task Force. *Complete Report of the Community Forum "For Us, By Us, About Us": An Opportunity for African and Caribbean Communities to Address the Issue of HIV/AIDS Related Stigma and Denial*. November 2001; HIV Endemic Task Force. *Summary Report of the Community Forum "For Us, By Us, About Us": An Opportunity for African and Caribbean Communities to Address the Issue of HIV/AIDS Related Stigma and Denial*. November 2001; EKOS Research Associates. *HIV/AIDS – An Attitudinal Survey. Final Report*. Ottawa: EKOS Research Associates, 24 June 2003, at 47-54.



<sup>3</sup> For a list of recent studies around the world, see T de Bruyn. HIV/AIDS-related stigma and discrimination – the epidemic continues. *Canadian HIV/AIDS Policy & Law Review* 2002; 7(1): 8-13 at 8.

<sup>4</sup> See, eg, Algoma AIDS Network, *supra*, note 1; AIDS Committee of Toronto, *supra*, note 1; Ontario AIDS Network, *supra*, note 1; D Dodek, A Dodek. From Hippocrates to facsimile: protecting patient confidentiality is more difficult and more important than ever before. *Canadian Medical Association Journal* 1997; 156: 847. T Pals, J Lowman. Protecting confidential research information. *Canadian Journal of Law and Society* 2000; 15(1): 39-80 at 58. A 2002 New Zealand study on discrimination experienced by people living with HIV/AIDS found that 12 percent had experienced discrimination with housing, 31 percent with health services, and 36 percent with insurance: see J Grierson, S Misson, K McDonald, M Pitts, M O'Brien. *HIV Futures 3: Positive Australians on Services, Health and Well-being*. Monograph Series Number 37. Melbourne, Australia: Australian Research Centre in Sex, Health and Society, La Trobe University, 2002.

<sup>5</sup> See, eg, Privacy Working Group. *Principles For Privacy Protection of Personal Information in Canada: A Background Document*. Ottawa: Government of Canada, December 2000, at 3-5; L Gostin, J Turck-Brezina, M Powers, R Kozloff, R Faden, D Steinauer. Privacy and security of personal information in a new health care system. *Journal of the American Medical Association* 1993; 27: 2487; B von Tigerstrom. The hidden story of Bill C-54: *The Personal Information Protection and Electronic Documents Act* and health information. *Health Law Review* 1999; 8: 13; A Cavoukian. Safeguarding health information. *Health Law in Canada* 1998; 18: 115. The Supreme Court has accorded medical information a high degree of constitutional protection under s 8 of the Charter. See, eg, *R v Pohoretsky* [1987] 1 SCR 945; *R v Dymnt* [1988] 2 SCR 417; *R v Dersch* [1993] 3 SCR 768; *R v Colarusso* [1994] 1 SCR 20.

<sup>6</sup> Privacy Working Group, *supra*, note 5 at 3.

<sup>7</sup> *Report of the Royal Commission of Inquiry into the Confidentiality of Health Information in Ontario*. Volume 1. Toronto: Queen's Printer, 1980. Cited in: A Cavoukian. A Private Sector Bill for Ontario: A Wish List. Presentation to the Ontario Bar Association, Privacy Law Section. 11 December 2001 (available via [www.ipc.on.ca](http://www.ipc.on.ca)); B Hoffman. Importance and limits of medical confidentiality. *Health Law in Canada* 1997; 17: 93 at 93.

<sup>8</sup> J Wilson. Government directions in the confidentiality of health information. *Health Law in Canada* 1997; 3: 67 at 68. See also Bruce, *supra*, note 1 at 15.

<sup>9</sup> M O'Reilly. Use of medical records information by computer networks raise major concerns about privacy. *Canadian Medical Association Journal* 1995; 153: 212-214 at 213.

<sup>10</sup> T Wright. The Privacy Commissioner's perspective. *Health Law in Canada* 1997; 17: 89 at 89.

<sup>11</sup> *Ibid*.

<sup>12</sup> S Gruskin, A Hendricks. The right to privacy: some implications for confidentiality in the context of HIV/AIDS. In T Orlin, A Ross, M Scheinin, eds. *The Jurisprudence of Human Rights Law: A Comparative Interpretive Approach*. Turku/Abo: Institute for Human Rights, Abo Akademi University, 2000, 223-252 at 223.

<sup>13</sup> *Ibid* at 230.

<sup>14</sup> *Ibid* at 226.

<sup>15</sup> This distinction was originally developed by A Westin. *Privacy and Freedom*. London: The Bodley Head, 1970. In *Dymnt*, *supra*, note 5 at para 19, Laforest J outlines three claims or zones of privacy: territorial or spatial, tied to property; those related to the person; and those that arise in the information context.

<sup>16</sup> Gruskin & Hendricks, *supra*, note 12 at 234.

<sup>17</sup> Hoffman, *supra*, note 7 at 94; L Gostin, Z Lazzarini, V Neslund, M Osterholm. The public health information infrastructure: a national review of the law on health information privacy. *Journal of the American Medical Association* 1996; 275: 1921 at 1922-1923.

<sup>18</sup> See, eg, Centre for Addiction and Mental Health. Submission to the Standing Committee on General Government (Ontario) on the *Personal Information Privacy Act, 2002*. Hansard 37<sup>th</sup> Parliament, Session 1, 28 February 2001, 940-1000.

<sup>19</sup> See, generally, *supra*, notes 2 and 3.

<sup>20</sup> AIDS Committee of Toronto, *supra*, note 1. See also, generally, M Powers. Bill C-6: federal legislation in the age of the Internet. *Manitoba Law Journal* 1998-1999; 26: 235 at 238.

<sup>21</sup> Privacy Working Group, *supra*, note 5 at 5.

<sup>22</sup> W Charnetski, P Flaherty, J Robinson. *The Personal Information Protection and Electronic Documents Act: A Comprehensive Guide*. Aurora, Ontario: Canada Law Book, 2001, at 8.

<sup>23</sup> Universal Declaration of Human Rights. GA res 217A (III), UN Doc A/810 at 71 (1948).

<sup>24</sup> Charter of the United Nations. June 26, 1945, 59 Stat 1031, TS 993, 3 Bevans 1153, entered into force 24 October 1945, at Art 2, 55, 56.

<sup>25</sup> International Covenant on Civil and Political Rights. GA res 2200A (XXI), 21 UN GAOR Supp (No 16) at 52, UN Doc A/6316 (1966), 999 UNTS 171, entered into force 23 March 1976.

- <sup>26</sup> Human Rights Committee, General Comment 16 (23<sup>rd</sup> session, 1988). *Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies*, UN Doc HRI/GEN/1/Re.1 at 21 (1994), at Art 7.
- <sup>27</sup> International Guidelines on HIV/AIDS and Human Rights. UNCHR res 1997/33, UN Doc E/CN.4/1997/150 (1997).
- <sup>28</sup> Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Program on HIV/AIDS. *HIV/AIDS and Human Rights: International Guidelines*. Second International Consultation on HIV/AIDS and Human Rights, Geneva, 23-25 September 1996. New York and Geneva: United Nations, 1988, at para 97 (hereinafter International Guidelines on HIV/AIDS).
- <sup>29</sup> *Ibid* at para 98.
- <sup>30</sup> *Ibid* at paras 72, 73. On the relationship between health and human rights see J Mann, S Gruskin, M Grondin, G Annas, eds. *Health and Human Rights: A Reader*. New York: Routledge, 1999; World Health Organization. *Question and Answers on Health and Human Rights*. Geneva, Switzerland: World Health Organization, July 2002 (available via [www.who.int](http://www.who.int)).
- <sup>31</sup> *Dyment*, *supra*, note 5 at para 17; *R v Edwards* [1996] 1 SCR 128 at para 61; *R v Sharpe* [2001] 1 SCR 45 at para 26.
- <sup>32</sup> *R v O'Connor* [1995] 4 SCR 411 at para 113 (per L'Heureux-Dubé J). In *O'Connor*, the Supreme Court analyzed ss 7 and 8 in the context of a pre-trial order requiring the Crown to disclose complainants' entire medical, counselling, and school records. The Court was called upon to decide: (1) when non-disclosure of evidence by the Crown prosecutor justifies an order stopping the legal case, and (2) the appropriate procedure to be followed when a person accused of a crime seeks disclosure of documents (eg, medical or therapeutic records) that are in the hands of people such as physicians and counsellors.
- <sup>33</sup> *R v Plant* [1993] 3 SCR 281 at para 20.
- <sup>34</sup> This principle was articulated by the Supreme Court in the criminal context in *Dyment*, *supra*, note 5; *Edwards*, *supra*, note 31; *Plant*, *supra*, note 33. The principle was articulated in the non-criminal context in *McInerney v MacDonald* [1992] 2 SCR 138.
- <sup>35</sup> The Supreme Court has confirmed that a person who exposes another person to a significant risk of HIV transmission can be found guilty of aggravated, or attempted aggravated, assault, and common nuisance under the Criminal Code, RSC 1985 c C-46. See *R v Cuerrier* [1988] 2 SCR 371; *R v Williams* 2003 SCC 41.
- <sup>36</sup> For a discussion of Canada's current prohibitionist approach to illegal drug use in the context of the HIV/AIDS epidemic, see, generally, Canadian HIV/AIDS Legal Network. *Injection Drug Use and HIV/AIDS: Legal and Ethical Issues*. Montréal: The Network, 1999.
- <sup>37</sup> SC 1996, c 19.
- <sup>38</sup> *Supra*, note 35.
- <sup>39</sup> See, eg, G Radwanski, Privacy Commissioner of Canada. *Submission to the Standing Committee on General Government (Ontario) on the Personal Information Privacy Act, 2002*. Hansard 37<sup>th</sup> Parliament, Session 1, 8 February 2001, 1119-1325 at 1120.
- <sup>40</sup> Gostin et al, *supra*, note 17 at 1940; Cavoukian, *supra*, note 5 at 115.
- <sup>41</sup> M Marshall, B von Tigerstrom. Health Information. In: J Downie, T Caulfield, C Flood, eds. *Canadian Health Law and Policy*. Toronto, Ontario: Butterworths, 2<sup>nd</sup> ed, 2002, at 144.
- <sup>42</sup> United Nations General Assembly Special Session on HIV/AIDS. Declaration of Commitment on HIV/AIDS. Resolution A/Res/S-26/2, 27 June 2001, para 13 (hereinafter UNGASS Declaration).
- <sup>43</sup> See the HIV & AIDS Legal Clinic (Ontario)'s various submissions to the Ontario government, *supra*, note 1.
- <sup>44</sup> Cameron, *supra*, note 1.
- <sup>45</sup> See the HIV & AIDS Legal Clinic (Ontario)'s various submissions to the Ontario government, *supra*, note 1.
- <sup>46</sup> Vienna Declaration and Programme of Action, World Conference on Human Rights, Vienna, 14-25 June 1993, UN Doc A/CONF.157/23 (Part I) at para 5.
- <sup>47</sup> Universal Declaration of Human Rights, *supra*, note 23. See right to life, liberty, security of the person (Art 3), the right to work and free choice of employment (Art 23), and the right to adequate housing and medical care (Art 25).
- <sup>48</sup> The UN Human Rights Commission on Human Rights has confirmed that "other status" in non-discrimination provisions is to be interpreted to include health status, including HIV/AIDS. See, eg, The protection of human rights in the context of human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS). CHR res 1995/44, ESCOR Supp (No 4) at 140, UN Doc E/CN.4/1995/44 (1995) at para 1; The protection of human rights in the context of human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS). CHR res 1996/43, ESCOR Supp (No 3) at 147, UN Doc E/CN.4/1996/43 (1996) at para 1.
- <sup>49</sup> The Supreme Court has affirmed the principle that human rights statutes protect people from discrimination on the basis of "handicap" even in the absence of functional limitations. See *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. Specific jurisdictions also have policies that affirm that asymptomatic HIV infection is a disability or handicap for the purposes of provincial

human rights protection. See, eg, Ontario Human Rights Commission. *Policy on HIV/AIDS-Related Discrimination*. 27 November 1996, at 2 (available at [www.ohrc.on.ca/english/publications/disability-policy.pdf](http://www.ohrc.on.ca/english/publications/disability-policy.pdf)).

<sup>50</sup> AIDS Committee of Toronto, *supra*, note 1; HIV & AIDS Legal Clinic (Ontario), *supra*, note 1; Ontario AIDS Network, *supra*, note 1.

<sup>51</sup> R. Jürgens, *supra*, note 1.

<sup>52</sup> Privacy Commissioner of Canada, *supra*, note 1.

<sup>53</sup> C. McNair, A. Scott. *Privacy Law In Canada*. Markham, Ontario: Butterworths, 2001, at 193.

<sup>54</sup> R. Jürgens. Global Aspects of AIDS. In: D. Webber, ed. *AIDS and the Law*. New York: Panel Publishers, 2000, 3<sup>rd</sup> ed. Cumulative Supplement at 180, 188.

<sup>55</sup> Health Canada (Division of HIV/AIDS Epidemiology and Surveillance, Centre for Infectious Disease Prevention and Control). *HIV and AIDS in Canada: Surveillance Report to June 30, 2003*. Ottawa: Minister of Public Works and Government Services, November 2003, at 1.

<sup>56</sup> M. Stein, K. Freddberg, L. Sullivan, J. Savetsky, S. Levenson, R. Hingson, J. Samet. Disclosure of HIV-positive status to partners. *Archives of Internal Medicine* 1998; 158: 253-257; L. Niccolai, D. Dorst, L. Myers, P. Kissinger. Disclosure of HIV status to sexual partners: predictors and temporal patterns. *Sexually Transmitted Diseases* 1999; 26(5): 281-285; D.H. Ciccarone et al. Sex without disclosure of positive HIV serostatus in a US probability sample of persons receiving medical care for HIV infection. *American Journal of Public Health* 2003; 93: 1-7.

<sup>57</sup> T. Pals, J. Lowman. Ethical and legal strategies for protecting confidential research information. *Canadian Journal of Law and Society* 2000; 15(1) 39-80.

<sup>58</sup> Gray et al, *supra*, note 1 at 6.

<sup>59</sup> J. Higgins. Privacy Law: "Where did this come from?" Toronto: Ontario Bar Association, 20 November 2002, at 8. Much of the background for this section has been taken from Higgins's excellent paper:

<sup>60</sup> Organization for Economic Cooperation and Development. *Guidelines on the Protection of Privacy and Transborder Flows of Personal Data*. Paris: OECD, 2001 (hereinafter OECD Guidelines) (available via [www.oecd.org](http://www.oecd.org)).

<sup>61</sup> C.J. Bennett. *Prospects for an International Standard for the Protection of Personal Information: A Report to the Standards Council of Canada*. August 1997. As reported in Higgins, *supra*, note 59 at 9.

<sup>62</sup> B. von Tigerstrom. Protection of health information privacy: the challenges and possibilities of technology. *Appeal Review: Current Law & Law Reform* 1998; 4: 44.

<sup>63</sup> Cavoukian, *supra*, note 5.

<sup>64</sup> Wright, *supra*, note 10 at 90; Canadian Nurses Association. *Position Statement – Privacy of Personal Health Information*. Ottawa, Ontario: CNA, June 2001 (available via [www.can-nurses.ca](http://www.can-nurses.ca)).

<sup>65</sup> O'Reilly, *supra*, note 9.

<sup>66</sup> Gostin et al, *supra*, note 17 at 1922.

<sup>67</sup> Personal communication with Ruth Carey, Executive Director of the HIV & AIDS Legal Clinic (Ontario). On file with the Network.

<sup>68</sup> For more information about the HIV Information Infrastructure Program, go to [www.ohntn.on.ca/index\\_hiip.html](http://www.ohntn.on.ca/index_hiip.html). The goal of HIIP is to improve treatment and care for people living with HIV/AIDS in Ontario, and increase the security and enhance the management of personal health information through the use of information technology. HIIP consists of three key components: (1) a Clinical Management System (CMS), which will include an electronic health record (EHR) for each patient and decision-making tools to assist physicians and other health-care providers in delivering improved care for people living with HIV/AIDS; (2) a Central Research Database, which is a voluntary and anonymous database to be used by researchers to answer important questions about HIV in Ontario; (3) a secure communications network that will link health-care providers and other health-care institutions with one another to ensure more efficient and secure communications between HIV care providers.

<sup>69</sup> R. Romanow. *Building on Values: The Future of Health Care in Canada*. Ottawa: Commission on the Future of Health Care in Canada, November 2002. Full documentation of the Romanow Commission's work is available via [www.hc-sc.gc.ca/english/care/romanow/index1.html](http://www.hc-sc.gc.ca/english/care/romanow/index1.html).

<sup>70</sup> *Ibid* at 76.

<sup>71</sup> *Ibid* at 77.

<sup>72</sup> *Ibid* at 76.

<sup>73</sup> *Ibid* at 77.

<sup>74</sup> *Ibid* at 76.

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

- <sup>76</sup> Ibid.
- <sup>77</sup> Ibid at 80.
- <sup>78</sup> Letter from G Radwanski to R Romanow, 27 June 2002 (available via [www.privcom.gc.ca](http://www.privcom.gc.ca)).
- <sup>79</sup> Ibid.
- <sup>80</sup> Ibid.
- <sup>81</sup> Dodek & Dodek, *supra*, note 4 at 848–849.
- <sup>82</sup> Marshall & von Tigerstrom, *supra*, note 41 at 157.
- <sup>83</sup> LE Rozovsky, FA Rozovsky. *The Canadian Law of Patient Records*. Toronto: Butterworths, 1984, at 73-74.
- <sup>84</sup> See the comments of LaForest J, writing for the Court, in *McInerney*, *supra*, note 34 at para 15: "Medical records continue to grow in importance as the health care field becomes more and more specialized."
- <sup>85</sup> Dodek & Dodek, *supra*, note 4 at 848.
- <sup>86</sup> SC 2000, c 5 (hereinafter PIPEDA); Health Information Act, SA 1999, c H-4.8 (Alberta); Personal Information Protection Act, RSA, c P-6.5 (Alberta); Personal Information Protection Act, SBC 2003, c 63 (British Columbia); The Personal Health Information Act, SM 1997, c 51 (Manitoba); Ontario Ministry of Consumer and Business Affairs. A Consultation on the Draft *Privacy of Personal Information Act, 2002* (available via [www.cbs.gov.on.ca/mcbs/english/welcome.htm](http://www.cbs.gov.on.ca/mcbs/english/welcome.htm)) (hereinafter Draft Ontario Privacy of Personal Information Act, 2002); An Act respecting the protection of personal information in the private sector, RSQ, c P-39.1 (Québec); An Act respecting access to documents held by public bodies and the protection of personal information, RSQ, c A-2.1 (Québec); The Health Information Protection Act, SS 1999, c H-0.021 (Saskatchewan).
- <sup>87</sup> See, eg, PIPEDA, *supra*, note 86 at s 2(1).
- <sup>88</sup> See, eg, The Personal Health Information Act (Manitoba), *supra*, note 86 at s 1(1).
- <sup>89</sup> See, eg, Health Information Act (Alberta), *supra*, note 86 at s 1(1)(f) ("custodian"); The Health Information Protection Act (Saskatchewan), *supra*, note 86 at s 2(t) ("trustee"). PIPEDA, *supra*, note 86, uses the term "organization" throughout.
- <sup>90</sup> See, eg, The Personal Health Information Act (Manitoba), *supra*, note 86 at s 1(1) ("Ombudsman"); Draft Ontario *Privacy of Personal Information Act, 2002*, *supra*, note 86 at s 2 ("Commissioner").
- <sup>91</sup> Charnetski et al, *supra*, note 22 at 1.
- <sup>92</sup> Personal correspondence with Debra Grant, Research Officer, Policy and Compliance Department, Office of the Information and Privacy Commissioner of Ontario. For an excellent analysis of the issue, see AD Fineberg. Personal health information: the "scope" issues. *Health Law in Canada* 2003; 23(4): 53-70.
- <sup>93</sup> PIPEDA, *supra*, note 86 at ss 26(2)(b), 30(2).
- <sup>94</sup> Act respecting the protection of personal information in the private sector (Québec), *supra*, note 86; Act respecting access to documents held by public bodies and the protection of personal information (Québec), *supra*, note 86. The statutes apply to personal information generally and are not limited to health information.
- <sup>95</sup> Act respecting the protection of personal information in the private sector (Québec), *supra*, note 86.
- <sup>96</sup> Privacy Commissioner of Canada. *Report to Parliament Concerning Substantially Similar Provincial Legislation*. Ottawa: Minister of Public Works and Government Services Canada, May 2002 (available at [www.privcom.gc.ca/legislation/leg-rp\\_e.asp](http://www.privcom.gc.ca/legislation/leg-rp_e.asp)).
- <sup>97</sup> SOR/03-1842, registered 19 November 2003.
- <sup>98</sup> The Personal Health Information Act (Manitoba), *supra*, note 86.
- <sup>99</sup> Health Information Act (Alberta), *supra*, note 86.
- <sup>100</sup> The Health Information Protection Act (Saskatchewan), *supra*, note 86.
- <sup>101</sup> Bill 159: Personal Health Information Privacy Act, 2000, 37<sup>th</sup> Parliament, 1<sup>st</sup> Session, 2000.
- <sup>102</sup> Draft Ontario *Privacy of Personal Information Act, 2002*, *supra*, note 86.
- <sup>103</sup> K Anderson. Initial Reflections on Ontario's Draft Privacy Bill. Presented at Insight Information Conference "Privacy Law in Ontario." Toronto: 28 February-1 March 2002; G Smith. Ontario proposes new privacy legislation. *Globe and Mail*, 26 January 2002.
- <sup>104</sup> Bill 44: Personal Information Protection Act, 25<sup>th</sup> Legislature, 3<sup>rd</sup> Session, 2003; enacted as Personal Information Protection Act, RSA c P-6.5. The amendments to the Bill passed on second reading are available at [www.assembly.ab.ca/pro/bills/ba-status.asp?SelectBill=044](http://www.assembly.ab.ca/pro/bills/ba-status.asp?SelectBill=044).
- <sup>105</sup> Letter from G Radwanski to Hon D Coutts, 26 May 2003 (available at [www.privcom.gc.ca/media/nr-c/2003/02\\_05\\_b\\_030527\\_e.asp](http://www.privcom.gc.ca/media/nr-c/2003/02_05_b_030527_e.asp)).

<sup>106</sup> Bill 38: Personal Information Privacy Act, 37<sup>th</sup> Parliament, 4<sup>th</sup> Session, 2003; enacted as Personal Information Protection Act, SBC 2003 c 63.

<sup>107</sup> Letter from G Radwanski to Hon G Santori, 7 May 2003 ([www.privcom.gc.ca/media/hr-c/2003/02\\_05\\_b\\_030508\\_e.asp](http://www.privcom.gc.ca/media/hr-c/2003/02_05_b_030508_e.asp)).

<sup>108</sup> The idea of focusing legislative protection on the information rather than the person holding the information is found in L Gostin, J Hodge, Model State Public Health Privacy Act (with comments), Model State Public Health Privacy Project (available at [www.critpath.org/msphpa/modellaw5.htm#5-101](http://www.critpath.org/msphpa/modellaw5.htm#5-101)). The core of the model legislation is the definition of "protected health information":

the Act protects the privacy and security of identifiable health-related information about individuals through various measures concerning the acquisition, use, disclosure, and storage of such information by public health agencies or public health officials. Critical to these objectives is the definition of "protected health information." For the purposes of the Act, this term means any information, whether oral, written, electronic, visual, pictorial, physical, or any other form, that relates to an individual's past, present, or future physical or mental health status, condition, treatment, service, products purchased, or provision of care, and which (a) reveals the identity of the individual whose health care is the subject of the information, or (b) where there is a reasonable basis to believe such information could be utilized (either alone or with other information that is, or should reasonably be known to be, available to predictable recipients of such information) to reveal the identity of that individual. Since non-identifiable health information does not implicate serious privacy and anti-discrimination concerns at the individual level, information which cannot freely be identified or linked with the identity of any individual is not subject to the Act's provisions.

In the Canadian context, the HIV & AIDS Legal Clinic (Ontario) has highlighted the shortcomings referred to in the above passage in its various submissions concerning the draft Ontario legislation. See HIV & AIDS Legal Clinic (Ontario), *supra*, note 1.

<sup>109</sup> Charnetski et al, *supra*, note 22 at 16; Cavoukian, *supra*, note 5 at 115. See also McNairn & Scott, *supra*, note 53 at 194.

<sup>110</sup> W Flanagan, Kinetic data and medical confidentiality, *Health Law Journal* 1995; 3: 269.

<sup>111</sup> Krever, *supra*, note 7 at 55. The Commission recommended the development of comprehensive health privacy legislation.

<sup>112</sup> McNairn & Scott, *supra*, note 53 at 194. See also Fineberg, *supra*, note 92 at 53.

<sup>113</sup> Constitution Act, 1982, being Schedule B to the Canada Act 1982 (U.K) 1982, c 11, at s 52(1).

<sup>114</sup> *Ibid* at s 32(1).

<sup>115</sup> *Ibid*.

<sup>116</sup> *Blencoe v British Columbia (Human Rights Commission)* [2000] 2 SCR 307 at paras 76, 77.

<sup>117</sup> *R v O'Connor*, *supra*, note 32 at para 154.

<sup>118</sup> *Sharpe*, *supra*, note 31 at para 26, citing *Hunter v Southam* [1984] 2 SCR 145; *R v Mills* [1999] 3 SCR 668; and *Edwards*, *supra*, note 31.

<sup>119</sup> *Hunter*, *supra*, note 118. The Fourth Amendment of the United States Constitution provides: "The right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures, shall not be violated, and no Warrants shall issue, but upon probably cause, supported by Oath or affirmation, and particularly describing the place to be searched, and the persons or things to be seized."

<sup>120</sup> *Dyment*, *supra*, note 5 at para 17, referring to A Westin, *Privacy and Freedom*, *supra*, note 15 at 349-350.

<sup>121</sup> See, eg, *R v Buhay* [2003] SCC 30 at para 18; *Colarusso*, *supra*, note 5; *Hunter*, *supra*, note 118.

<sup>122</sup> *Plant*, *supra*, note 33 at para 20.

<sup>123</sup> See, eg, *Pohoretsky*, *supra*, note 5; *Dyment*, *supra*, note 5; *Dersch*, *supra*, note 5; *Colarusso*, *supra*, note 5.

<sup>124</sup> *Colarusso*, *supra*, note 5 at para 70 (per LaForest J, writing for the majority of the Supreme Court).

<sup>125</sup> *Dersch*, *supra*, note 5.

<sup>126</sup> *Colarusso*, *supra*, note 5 at para 70.

<sup>127</sup> *Ibid* at para 79.

<sup>128</sup> *Mills*, *supra*, note 118.

<sup>129</sup> *Ibid* at para 80.

<sup>130</sup> *Hunter*, *supra*, note 118.

<sup>131</sup> Criminal Code, *supra*, note 35, s 487(1). See also Marshall & von Tigerstrom, *supra*, note 41 at 163-164.

<sup>132</sup> *Ibid*.

<sup>133</sup> *Canadian Broadcasting Corp v Lessard* [1991] 3 SCR 421.

<sup>134</sup> *R v JO* [1996] OJ No 4799 (QL) (Gen Div).

<sup>135</sup> *Ibid* at para 6.

<sup>136</sup> *R v Seredip Physiotherapy Clinic* (2003) 65 OR (3d) (SCJ).

<sup>137</sup> *Ibid* at para 59.

<sup>138</sup> *Ibid* at para 68. In making this determination the judicial officer should consider these factors: (i) is the record likely to be relevant to the alleged crime? (ii) the extent to which the records are necessary for the police to investigate a crime; (iii) the probative value of the record; (iv) the nature and extent of the reasonable expectation of privacy vested in that record; (v) the potential prejudice to the privacy of the person who is the subject of the record; (vi) the judicial officer should consider examining the records to determine whether and to what extent they should be disclosed.

<sup>139</sup> *R v Beare* [1988] 2 SCR 387.

<sup>140</sup> *Cloutier v Langlois* [1990] 1 SCR 158.

<sup>141</sup> *R v Stillman* [1997] 1 SCR 607.

<sup>142</sup> Under the Criminal Code, *supra*, note 35 at s 254, the police can take breath samples, or require a qualified medical practitioner to take a blood sample under certain circumstances. The offence of operating a vehicle while impaired is set out in s 253.

<sup>143</sup> RSO 1990, c H.7, ss 41-43.

<sup>144</sup> *Ibid*.

<sup>145</sup> *Ibid*.

<sup>146</sup> *Hunter*, *supra*, note 118.

<sup>147</sup> See *R v Morgentaler* [1988] 1 SCR 30; *O'Connor*, *supra*, note 32; *Mills*, *supra*, note 118.

<sup>148</sup> *Mills*, *supra*, note 118.

<sup>149</sup> *O'Connor*, *supra*, note 32 at para 119 (per L'Heureux-Dubé, LaForest, Gonthier JJ).

<sup>150</sup> *Ibid*.

<sup>151</sup> *Ibid* at paras 19-34 (per Lamer CJ, Sopinka J).

<sup>152</sup> *Ibid* at para 17 (per Lamer CJ, Sopinka J); at para 99 (per L'Heureux-Dubé J).

<sup>153</sup> *Chametski et al*, *supra*, note 22 at 17.

<sup>154</sup> *McNairn & Scott*, *supra*, note 53 at 42, 67. See, eg, *Lord v Canada (Attorney General)* (2000) 50 CCLT (2d) 206 (BCSC); *Ontario (Attorney General) v Dieleman* (1994) 117 DLR (4th) 449 at 452, where the Ontario Court General Division discusses the absence of a cause of action at common law for invasions of privacy:

it would appear that invasion of privacy in Canadian common law continues to be an inceptive, if not ephemeral, legal concept, primarily operating to extend the margins of existing tort doctrine. One significant explanation for this continuing "lack of legal profile" arises from the need to accommodate broad counter-privileges associated with free speech and the vast implications of living in a "crowded society".

<sup>155</sup> S Warren, L Brandeis. *The right to privacy*. *Harvard Law Review* 1890; 4: 193; W Prosser. *Privacy*. *California Law Review* 1968; 48: 383.

<sup>156</sup> A Linden. *Canadian Tort Law*. Toronto: Butterworths, 7th ed, 2001, at page 57.

<sup>157</sup> I Lawson, B Jeffrey. *Privacy and Free Enterprise*. Ottawa: Public Interest Advocacy Centre, 1997, at 220.

<sup>158</sup> *McNairn & Scott*, *supra*, note 53 at 45.

<sup>159</sup> See for example *Lipiec v Borsa* (1996) 31 CCLT (2d) 294 (Ont Gen Div); *Roth v Roth* (1991) 4 OR (3d) 740 (Gen Div); *Saccone v Orr* (1981) 34 OR (2d) 317 (District Ct); *Palad v Pantaleon* (14 June 1989) (Doc No 266930/86, Mandel DCJ (Ont Dist Ct)); *Dawe v Nova Collection Services (Nfld) Ltd* (1998) 160 Nfld & PEIR 266 (Nfld Prov Ct); *Corlett-Lockyer v Stephens* (19 February 1996) Doc No 95-20068 (BC Prov Ct Civ Div); *S & A Nagy Farm Ltd v Repsys* (13 March 1987), Doc No F54/85 McGarry DCJ (Ont Dist Ct); *MacKay v Buelow* (1995) 24 CCLT (2d) 184 (Ont Gen Div).

<sup>160</sup> *McNairn & Scott*, *supra*, note 53 at 53-55.

<sup>161</sup> *Ibid* at 42.

<sup>162</sup> *Ibid* at 61.

<sup>163</sup> D Flaherty. Some reflections on privacy in technology. *Manitoba Law Journal* 1998-1999; 26: 219 at 228.

- <sup>164</sup> Charnetski et al, supra, note 22 at 16; A Linden, supra, note 156 at 58; Lawson & Jeffrey, supra, note 157 at Chapters 5 and 6.
- <sup>165</sup> *Frame v Smith* [1987] 2 SCR 99 at para 68 (per Wilson J dissenting).
- <sup>166</sup> *Ibid* at para 60; *LAC Minerals Ltd v International Corona Resources Ltd* [1989] 2 SCR 574 at para 32 (per Sopinka J, dissenting in part).
- <sup>167</sup> *Ibid* at para 165 (per La Forest J).
- <sup>168</sup> *McInerney*, supra, note 34 at paras 19-22.
- <sup>169</sup> *Ibid* at para 20.
- <sup>170</sup> *Ibid* at para 26.
- <sup>171</sup> *Ibid* at para 18.
- <sup>172</sup> *Ibid* at para 22.
- <sup>173</sup> *Ibid* at para 18, citing *Dymont*, supra, note 5.
- <sup>174</sup> *Ibid*.
- <sup>175</sup> *McNairn & Scott*, supra, note 53 at 198.
- <sup>176</sup> *Parslow v Masters* [1993] 6 WWR 273 (Sask QB). *Parslow* is discussed in *McNairn & Scott*, supra, note 53.
- <sup>177</sup> *LAC Minerals*, supra, note 166 at para 135 (per LaForest J).
- <sup>178</sup> *Ibid*, passim.
- <sup>179</sup> *Ibid* at para 129 (per LaForest J).
- <sup>180</sup> The case in which the Supreme Court recognized a physician's duty of confidentiality in relation to patient records, *McInerney*, supra, note 34, was not an action for breach of confidence. The issue in *McInerney* was the patient's right of access to her medical record. In contrast, there are numerous cases in which courts have found a breach of confidence in a commercial relationship and imposed significant monetary damages. See, eg, *LAC Minerals*, supra, note 166; *Cadbury Schweppes Inc v FBI Foods Ltd* [1999] 1 SCR 142; *Visage v TVX Gold Inc* (2000) 49 OR (3d) 198 (CA); *Plananon Systeme Inc v Norman Wade Co* [1998] OJ 347 (Ont. Ct. Gen. Div.); *Capitanescu v Universal Weid Overlays Inc* [1997] AJ No 740 (Alta QB).
- <sup>181</sup> D Watt. *Watt's Manual of Criminal Evidence 2001*. Toronto: Thomson Canada Limited, 2001, at 110-111.
- <sup>182</sup> *R v Gruenke* [1991] 3 SCR 263.
- <sup>183</sup> Medical Act, RSQ 1977 c M-9, s 42. Note that in some provinces, statements made to a medical research group are treated as privileged communications. See, eg, the Alberta Evidence Act, RSA 2000, c A-18; British Columbia Evidence Act, RSBC 1996, c 124. See, generally, discussion in J Sopinka, S Lederman, A Bryant. *The Law of Evidence In Canada*. Toronto: Butterworths, 2<sup>nd</sup> ed, 1999, at 14-187.
- <sup>184</sup> *Solosky v The Queen* [1980] 1 SCR 21.
- <sup>185</sup> Sopinka et al, supra, note 183 at 14.1.
- <sup>186</sup> *Ibid* at 14.42.
- <sup>187</sup> *Ibid* at 14.129-14.130.
- <sup>188</sup> *Ibid* at 14.6.
- <sup>189</sup> *M(A) v Ryan* [1997] 1 SCR 157; *R v Gruenke*, supra, note 182; *Slavutych v Baker* [1976] 1 SCR 254.
- <sup>190</sup> *Slavutych*, supra, note 189.
- <sup>191</sup> *M(A) v Ryan*, supra, note 189.
- <sup>192</sup> *Ibid* at 22-23.
- <sup>193</sup> *M(A) v Ryan*, supra, note 189, was a civil case in which the plaintiff sought damages from her psychiatrist, Dr Ryan, who had sexual relations with her when she was 17 years old. In defending against the claim, Dr Ryan asked the court to compel the plaintiff to disclose records from another psychiatrist from whom the plaintiff had sought treatment as a result of the sexual assaults. The plaintiff argued that her privacy interest in the records ought to override Dr Ryan's interest in defending the lawsuit. The Supreme Court was of the view that "the interest in disclosure of a defendant in a civil suit may be less compelling than the parallel interest of an accused charged with a crime" given that the "defendant in a civil suit stands to lose money and repute; the accused in a criminal proceeding stands to lose his or her very liberty." As a result, "documents produced in a criminal case may not always be producible in a civil case, where the privacy interest of the complainant may more easily outweigh the defendant's interest in production" (at para 36, per MacLachlin J). The Court permitted only limited disclosure to the lawyers and expert witnesses for defendant Dr Ryan of the plaintiff's communications to her psychiatrist.

- <sup>194</sup> Québec Charter, RSQ, c C-12.
- <sup>195</sup> Civil Code of Québec, SQ 1991, c 64.
- <sup>196</sup> Medical Act, supra, note 183.
- <sup>197</sup> For more information see "Privacy protection under Québec law," *infra*.
- <sup>198</sup> *R v Potvin* (1971) 16 CRNS 233 (Qué CA). However, in *R v Perron* (1990) 54 CCC (3d) 108, the Québec Court of Appeal ruled solicitor–client privilege applies to communication between a psychiatrist and a lawyer, and to the psychiatrist's report prepared at the request of the lawyer.
- <sup>199</sup> *Smith v Jones* [1999] 1 SCR 455 at para 74.
- <sup>200</sup> *Ibid* at para 44.
- <sup>201</sup> British Columbia Privacy Act, RSBC 1996, c 373; Manitoba Privacy Act, CCSM 1987, c P125; Saskatchewan Privacy Act, RSS 1978, c P-24; Newfoundland Privacy Act, RSNL 1990, c P-22.
- <sup>202</sup> See, eg, British Columbia Privacy Act, supra, note 201 at s 1.
- <sup>203</sup> Supra, note 195. Note that the terms used in this provision echo those found in international human rights privacy protections. See "Protecting privacy as a human right," supra.
- <sup>204</sup> Charnetski et al, supra, note 22 at 17; McNairn & Scott, supra note 53 at 68.
- <sup>205</sup> L Klar, *Tort Law*, Toronto: Carswell, 2<sup>nd</sup> ed, 1996, at 26. In this aspect, the statutes create a tort similar to the direct intentional torts of battery, assault, and false imprisonment. Historically, proof of harm was unnecessary in this category of torts.
- <sup>206</sup> Note that under the Manitoba Privacy Act, supra, note 201, a person suing for the breach of his or her privacy need not prove that the act was "wilful."
- <sup>207</sup> (1969) 10 DLR (3d) 250 (BCSC), rev'd on other grounds (1970) 17 DLR (3d) 760 (BCCA).
- <sup>208</sup> McNairn & Scott, supra, note 53 at 78.
- <sup>209</sup> *Ibid* at 3, 78.
- <sup>210</sup> Manitoba Privacy Act, supra, note 201 at s 2(1).
- <sup>211</sup> McNairn & Scott, supra, note 53 at 73, state that less than 25 actions had been brought under the provincial privacy acts as of 2001, and the acts are rarely used outside British Columbia.
- <sup>212</sup> *Ibid* at 74.
- <sup>213</sup> *Ibid* at 85.
- <sup>214</sup> Flaherty, supra, note 163 at 222.
- <sup>215</sup> *Parslow*, supra, note 176. As discussed, supra, in "Tort of invasion of privacy", and supra, note 159, some courts have recognized a common law tort of invasion of privacy.
- <sup>216</sup> Supra, note 183 at s 42.
- <sup>217</sup> Professional Misconduct, O Reg 856/93, s 1(1)-10, made under the Medicine Act, 1991, SO 1991, c 30.
- <sup>218</sup> RSNL 1990, c H-9, s 35.
- <sup>219</sup> RSNS 1989, c 208, s 71.
- <sup>220</sup> General Regulation, NB Reg 92-84, s 21(1), made under the Hospitals Act, SNB 1992, c H-6.1.
- <sup>221</sup> SM 1998, c 36, s 36.
- <sup>222</sup> RSO 1990, c M.7, s 35(2).
- <sup>223</sup> RSA 2000, c M-13, s 17(1.1).
- <sup>224</sup> SNB 1982, c N-11, s 14(2).
- <sup>225</sup> RSO 1990, c N.7, ss 2(2)-6(iv). See also General Regulation, RRO 1990, Reg 832, s 95.
- <sup>226</sup> SM 1997, c 51.
- <sup>227</sup> SA 1999, c H-48.
- <sup>228</sup> SS 1999, c H-0.021.



<sup>229</sup> Bill 28: The Health Information Protection Amendment Act, 2003, 24<sup>th</sup> Legislature, 4<sup>th</sup> Session, 2003.

<sup>230</sup> Charnetski et al, supra, note 22 at 1.

<sup>231</sup> Ibid.

<sup>232</sup> PIPEDA, supra, note 86, applies to organizations that collect, use, or disclose personal information in the course of a "commercial activity" defined in s 2(1) as "any particular transaction, act, or any regular course of conduct that is of a commercial character; including the selling, bartering or leasing of donor, membership or other fundraising lists." There is a lively debate in the legal literature as to whether or not PIPEDA will apply to hospitals and physicians come 1 January 2004. Several commentators argue that the essential nature of a physician's private practice is of a commercial nature (ie, it is an exchange of services for a fee) and that the fact that there is a third party payor does not change the essential commercial nature of the transaction. The argument is supported by the fact that patients pay physicians for services not covered under provincial health insurance plans, or where the patient is not eligible under the provincial plan. For an excellent analysis of the issue, see Fineberg, supra, note 92.

<sup>233</sup> The European Union's Directive 95/46/EC on the Protection of Individuals with Regard to the Processing of Personal Data and on the Free Movement of Such Data (available at [www.cdt.org/privacy/eudirective/EU\\_Directive\\_.html](http://www.cdt.org/privacy/eudirective/EU_Directive_.html)). See also Council of the Organisation for Economic Co-operation and Development. *Recommendation Concerning Guidelines Governing the Protection of Privacy and Transborder Flows of Personal Data* (adopted 23 September 1980). Paris: OECD Publications, 2002 (available at [www1.oecd.org/publications/e-book/9302011E.PDF](http://www1.oecd.org/publications/e-book/9302011E.PDF)).

<sup>234</sup> *Model Code for the Protection of Personal Information* (CAN/CSA-Q830-96). Ottawa: Canadian Standards Association, 1996 (hereinafter CSA Model Code).

<sup>235</sup> G Radwanski, Privacy Commissioner of Canada. An address to the Legislative Assembly of Ontario, Standing Committee on General Government on the Government of Ontario's Proposed personal health information legislation (Bill 159) (available at [www.privcom.gc.ca/speech/02\\_05\\_a\\_010208\\_e.asp](http://www.privcom.gc.ca/speech/02_05_a_010208_e.asp)).

<sup>236</sup> The constitutional authority of the federal government to impose PIPEDA on business entities whose operations fall exclusively within provincial jurisdiction has been questioned, and may be the subject of future litigation. See Charnetski et al, supra, note 22, Chapter 7, "Constitutional Issues"; S Chester. Privacy set to become constitutional battleground. *Lawyer's Weekly*, 28 June 2002, at 11.

<sup>237</sup> PIPEDA, supra, note 86 at ss 26(2)(b), 30(2).

<sup>238</sup> Ibid at s 25.

<sup>239</sup> Radwanski, supra, note 235; G Radwanski, Privacy Commissioner of Canada. *Report to Parliament Concerning Substantially Similar Provincial Legislation*. Ottawa: Minister of Public Works and Government Services Canada, June 2003 (available at [www.privcom.gc.ca/legislation/leg-rp\\_030611\\_e.asp](http://www.privcom.gc.ca/legislation/leg-rp_030611_e.asp)).

<sup>240</sup> SQ 1993, c 17.

<sup>241</sup> Act respecting personal information in the private sector, supra, note 86.

<sup>242</sup> Personal Information Protection Act (British Columbia), supra, note 86.

<sup>243</sup> Letter from G Radwanski to Hon G Santori Re: Bill 38 – Personal Information Protection Act. 7 May 2003 (available at [http://www.privcom.gc.ca/media/nr-c/2003/02\\_05\\_b\\_030508\\_e.asp](http://www.privcom.gc.ca/media/nr-c/2003/02_05_b_030508_e.asp)).

<sup>244</sup> CCQ, supra, note 195 at "Preliminary Provision."

<sup>245</sup> Ibid.

<sup>246</sup> Ibid at Art 35 to 41.

<sup>247</sup> Ibid at Art 35.

<sup>248</sup> Ibid at Art 36(6).

<sup>249</sup> Ibid at Art 37 to 41.

<sup>250</sup> Ibid. Art 1457 provides:

Every person has a duty to abide by the rules of conduct which lie upon him, according to the circumstances, usage or law, so as not to cause injury to another:

Where he is endowed with reason and fails in this duty, he is responsible for any injury he causes to another person by such fault and is liable to reparation for the injury, whether it be bodily, moral or material in nature.

He is also liable, in certain cases, to reparation for injury caused to another by the act or fault of another person or by the act of things in his custody.

<sup>251</sup> Québec Charter, supra, note 194 at ss 5, 9.

<sup>252</sup> Ibid at ss 71, 74.

<sup>253</sup> *Ibid* at s 84.

<sup>254</sup> *Ibid* at s 49.

<sup>255</sup> CCQ, *supra*, note 195. Art 2858 provides:

The court shall, even of its own motion, reject any evidence obtained under such circumstances that fundamental rights and freedoms are breached and that its use would tend to bring the administration of justice into disrepute. The latter criterion is not taken into account in the case of violation of the right of professional privilege.

<sup>256</sup> *Supra*, note 183. Section 42 provides: "No physician may be compelled to declare what has been revealed to him in his professional character."

<sup>257</sup> McNair & Scott, *supra*, note 53 at 204, nn 33, 34.

<sup>258</sup> *Potvin*, *supra*, note 198.

<sup>259</sup> Act respecting the protection of personal information in the private sector; *supra*, note 86; Act respecting access to documents held by public bodies and the protection of personal information, *supra*, note 86. These acts apply to personal information generally, and are not limited to health information.

<sup>260</sup> Act respecting access to documents held by public bodies and the protection of personal information, *supra*, note 86 at s 7.

<sup>261</sup> *Ibid* at ss 54, 55.

<sup>262</sup> *Ibid* at s 59.

<sup>263</sup> *Ibid* at ss 59, 59.1, 61.

<sup>264</sup> *Ibid* at s 1.

<sup>265</sup> CCQ, *supra*, note 195 at Art 1525.

<sup>266</sup> Act respecting the protection of personal information in the private sector; *supra*, note 86 at s 10.

<sup>267</sup> *Ibid* at ss 12, 13.

<sup>268</sup> *Ibid* at ss 18, 18.1, 18.2, 21, 21.1.

<sup>269</sup> *Ibid* at ss 22-26.

<sup>270</sup> United Nations, Economic and Social Council, UN Sub-Commission on Prevention of Discrimination and Protection of Minorities, Siracusa Principles on the Limitation and Derogation of Provisions in the International Covenant on Civil and Political Rights, Annex, UN Doc E/CN.4/1985/4 (1985).

<sup>271</sup> Charter; *supra*, note 113 at s 1.

<sup>272</sup> See *Macdonell v Québec (Commission d'accès à l'information)* 2002 SCC 71 at para 18; *Lavigne v Canada (Office of the Commissioner of Official Languages)* 2002 SCC 53 at paras 30-32.

<sup>273</sup> Health Canada (Division of HIV/AIDS Epidemiology and Surveillance Centre for Infectious Disease Prevention and Control) *HIV/AIDS Epi Updates*. Ottawa: Minister of Public Works and Government Services, 2003 at Chapter 3 (HIV Infection Reporting in Canada) at 9, 11.

<sup>274</sup> *Ibid*.

<sup>275</sup> See, eg, Ontario's Highway Traffic Act, RSO 1990, c H.8, s 203.

<sup>276</sup> RSC 1985, c A-2, s 6.5 (1).

<sup>277</sup> Criminal Code, *supra*, note 35 at s 700. In civil cases, the rules of court or rules of civil procedure provide for a court's power to issue summonses and subpoenas, and other mechanisms to ensure evidence is available to the parties or brought before the court. See, eg, Federal Court Rules, 1998, SOR 98/106, ss 41-46; Rules of Civil Procedure, RRO 1990, Reg 194, ss 31, 33, 34, 53.

<sup>278</sup> *Jürgens*, *supra*, note 1 at 99.

<sup>279</sup> Criminal Code, *supra*, note 35 at s 488.1 sets out a procedure whereby lawyers can claim privilege over information in their possession when faced with a request of an officer who seeks to examine, copy, or seize a document pursuant to a federal statute. The Ontario Advisory Committee on HIV/AIDS (OACHA) has suggested that a counsellor or counselling agency may assert privilege over counselling records and medical information by relying on the same procedure set out under section 488.1. See Ontario Advisory Committee on HIV/AIDS. *HIV Disclosure Counselling Guidelines*. Toronto: Advisory Committee, June 2002, at 7 (on file with the Legal Network).

<sup>280</sup> Charter; *supra*, note 113 at s 24 provides: (1) Anyone whose rights or freedoms, as guaranteed by this Charter, have been infringed or denied may apply to a court of competent jurisdiction to obtain such remedy as the court considers appropriate and just in the cir-

cumstances. (2) Where, in proceedings under subsection (1), a court concludes that evidence was obtained in a manner that infringed or denied any rights or freedoms guaranteed by this Charter, the evidence shall be excluded if it is established that, having regard to all the circumstances, the admission of it in the proceedings would bring the administration of justice into disrepute.

<sup>281</sup> The Personal Health Information Act (Manitoba), supra, note 86.

<sup>282</sup> Health Information Act (Alberta), supra, note 86 at s 2(a), (c). Similarly, the Draft Ontario Privacy of Personal Information Act, 2002, supra, note 86 at s 1(a)(i), states that one of the purposes of the legislation is "to protect the privacy of individuals by establishing rules governing the collection, use and disclosure of personal information by organizations in accordance with the principle that individuals are entitled to provide or withhold consent with respect to the collection, use and disclosure of their personal information."

<sup>283</sup> See also The Health Information Protection Act (Saskatchewan), supra, note 86 at ss 6-15, which addresses issues related to consent over collection use and disclosure of health information; Health Information Act (Alberta), supra, note 86, ss 23, 35-40, 47, 50, 53, 55, 59; The Personal Health Information Act (Manitoba), supra, note 86, ss 21, 22, 24(5), 34(3).

<sup>284</sup> Personal Information Protection Act (British Columbia), supra, note 86 at s 18. See also the Draft Ontario Privacy of Personal Information Act, 2002, supra, note 86 at ss 37-48.

<sup>285</sup> PIPEDA, supra, note 86 at s 7.

<sup>286</sup> For example, the HIV & AIDS Legal Clinic (Ontario) in its *Submissions of the HIV & AIDS Legal Clinic (Ontario) on Bill 159: The Personal Health Information Privacy Act, 2000*, supra, note 1, argued that the bill permitted too many exceptions to the general rule that personal health information should only be disclosed with the express and informed consent of the individual. Both the former Privacy Commissioner of Canada and the Canadian Civil Liberties Association have argued that the disclosure of health information without an individual's consent should occur only in the most exceptional of circumstances, see Radwanski, supra, note 39; Canadian Civil Liberties Association. Submission to the Standing Committee on General Government (Ontario) on the *Personal Information Privacy Act, 2002*. Hansard 37<sup>th</sup> Parliament, Session 1, 11 March 2001, 1150-1220. The Information and Privacy Commissioner/Ontario has expressed concern regarding the broad discretionary disclosure provisions in the Draft Ontario Privacy of Personal Information Act, 2002, supra, note 86. See B White. Made-in-Ontario privacy legislation coming. *Law Times*, 11 March 2002, at 8. See also comments by Anderson, supra, note 103.

<sup>287</sup> See, eg, The Personal Health Information Act (Manitoba), supra, note 86, s 16. See also Privacy Working Group, supra, note 5 at 6; CSA Model Code, supra, note 234 at principle 6.

<sup>288</sup> See, eg, The Personal Health Information Act (Manitoba), supra, note 86, s 20(2). See also the CSA Model Code, supra, note 234 at principle 4.

<sup>289</sup> See, eg, The Health Information Protection Act (Saskatchewan), supra, note 86 at s 9.

<sup>290</sup> Privacy Working Group, supra, note 5.

<sup>291</sup> See, eg, Man Reg 245/97, s 4(c), made under The Personal Health Information Act (Manitoba), supra, note 86.

<sup>292</sup> See, eg, The Health Information Protection Act (Saskatchewan), supra, note 86 at s 23(4).

<sup>293</sup> Draft Ontario Privacy of Personal Information Act, 2002, supra, note 86 at s 2.

<sup>294</sup> White, supra, note 286; Anderson, supra, note 103.

<sup>295</sup> See, eg, Radwanski, supra, note 39.

<sup>296</sup> The Personal Health Information Act (Manitoba), supra, note 86 at s 4(2).

<sup>297</sup> Dodek & Dodek, supra, note 4 at 848.

<sup>298</sup> World Medical Association Declaration on the Rights of the Patient. 34<sup>th</sup> World Medical Assembly Lisbon, Portugal, September/October 1981, amended by the 47<sup>th</sup> General Assembly, Bali, Indonesia, September 1995, at s 8 (available at [www.wma.net/e/policy/14.htm](http://www.wma.net/e/policy/14.htm)).

<sup>299</sup> *Ibid.*

<sup>300</sup> Not all health-care practitioners are regulated by legislation or professional codes. Some practitioners of complementary/alternative health care are not recognized in legislation as health professionals and are not regulated in the same way, because they are not subject to clear legal and ethical guidelines.

<sup>301</sup> SO 1991, c 30; O Reg 856/93, s 1(1)10. A virtually identical provision can be found in Ontario's Nursing Act, 1991, SO 1991, c 32; O Reg 799/93, s 1(1)10.

<sup>302</sup> Canadian Medical Association. Code of Ethics of the Canadian Medical Association. *Canadian Medical Association Journal* 1996; 155(8): 1176A-B (available via [www.cma.ca](http://www.cma.ca)). The Canadian Medical Association also has a Health Information Privacy Code. *Canadian Medical Association Journal* 1998; 159: 1997 (available via [www.cma.ca](http://www.cma.ca)). Principle 1 of the Code states:

The right of privacy is fundamental in a free and democratic society. It includes a patient's right to determine with whom he or she will share information and to know of and exercise control over use, disclosure and access concerning any information

collected about him or her. The right of privacy and consent are essential to the trust and integrity of the patient-physician relationship. Non-consensual collection, use, access or disclosure violates the patient's right of privacy. The right of privacy is important and worthy of protection not just for the good of individuals in society but also for the good of society as a whole.

<sup>303</sup> Health Information Act (Alberta), supra, note 86 at s 35(1)(h), (i), (j); Personal Information Protection Act (British Columbia), supra, note 86 at s 18(1)(i), (j); The Personal Health Information Act (Manitoba), supra, note 86 at s 22(2)(k), (l); The Health Information Protection Act (Saskatchewan), supra, note 86 at s 35(1)(e). See also Draft Ontario Privacy of Personal Information Act, 2002, supra, note 86 at s 37(1)(i).

<sup>304</sup> The Personal Health Information Act (Manitoba), supra, note 86 at s 22(2).

<sup>305</sup> Health Information Act (Alberta), supra, note 86 at s 34(2).

<sup>306</sup> Draft Ontario Privacy of Personal Information Act, 2002, supra, note 86 at s 40.

<sup>307</sup> The Health Information Protection Act (Saskatchewan), supra, note 86 at s 27(4)(a).

<sup>308</sup> R Elliott. *After Cuerrier: Canadian Criminal Law and the Non-Disclosure of HIV-Positive Status*. Montréal: The Network, 1999, at 59; D Casswell. Disclosure by a physician of AIDS-related patient information: an ethical and legal dilemma. *Canadian Bar Review* 1989; 68: 225.

<sup>309</sup> Canadian courts have considered the liability of a number of professionals and institutions for failing to take steps to prevent harm: hospitals (*Wenden v Trikha* (1991) 8 CCLT (2d) 138 (Alta QB), aff'd (1993) 14 CCLT (2d) 225 (Alta CA)), psychiatrists (*Tanner v Norys* [1980] 4 WWR 33 (Alta CA)), social workers (*D(B) v British Columbia* (1995) 12 BCLR (3d) 306, [1996] 1 WWR 581 (SC)), and police (*Doe v Metro Toronto (Municipality) Commissioners of Police* (1988) 39 OR (3d) 487 (Gen Div)).

<sup>310</sup> Supra, note 199.

<sup>311</sup> Ibid at para 44.

<sup>312</sup> Ibid at paras 74 et seq.

<sup>313</sup> Ibid at para 78.

<sup>314</sup> Ibid at para 82.

<sup>315</sup> Ibid.

<sup>316</sup> Ibid at para 84.

<sup>317</sup> Ibid at para 21. See also J Haydon. Legal aspects of health information. *Health Law in Canada* 1999; 20: 1 at 11.

<sup>318</sup> Elliott, supra, note 308 at 62-63.

<sup>319</sup> See HIV & AIDS Legal Clinic (Ontario). *Submissions of the HIV & AIDS Legal Clinic (Ontario) on Bill 159: The Personal Health Information Privacy Act, 2000*, supra, note 1, in which it was stated that some health providers are ignorant of the actual risks of transmission of HIV/AIDS.

<sup>320</sup> Personal Information Protection Act (British Columbia), supra, note 86 at s 18(1)(l); The Personal Health Information Act (Manitoba), supra, note 86 at s 22(2)(c)(i).

<sup>321</sup> Health Information Act (Alberta), supra, note 86 at s 35(1)(c).

<sup>322</sup> HIV & AIDS Legal Clinic (Ontario). *Submissions of the HIV & AIDS Legal Clinic (Ontario) on Bill 159: The Personal Health Information Privacy Act, 2000*, supra, note 1.

<sup>323</sup> The Health Information Protection Act (Saskatchewan), supra, note 86 at s 27(4)(e).

<sup>324</sup> See LJ Melton. The threats to medical records research. *New England Journal of Medicine* 1997; 337: 1466-1470; and J Kulynych, D Korn. The effect of the new federal medical-privacy rules on research. *New England Journal of Medicine* 2002; 346(3): 201-204, for a discussion of the privacy concerns raised by regulations enacted in the United States under the Health Insurance Portability and Accountability Act of 1996.

<sup>325</sup> Ibid. See also G Sharpe. Regulating health information: the Ontario approach. *Health Law in Canada* 2000; 20: 69 at 74.

<sup>326</sup> Kulynych & Korn, supra, note 324 at 201.

<sup>327</sup> F White. Issues in the development of a statute governing health information. *Health Law in Canada* 1997; 17: 91 at 92; G Annas. Medical privacy and medical research – judging the new federal regulations. *New England Journal of Medicine* 2002; 346: 216-220.

<sup>328</sup> Annas, ibid at 219.

<sup>329</sup> The Health Information Protection Act (Saskatchewan), supra, note 86 at s 29(1).

<sup>330</sup> Ibid.

<sup>331</sup> Ibid at s 29(2).

<sup>332</sup> Ibid at s 24(2).

<sup>333</sup> Ibid at s 24(3).

<sup>334</sup> Personal Information Protection Act (British Columbia), supra, note 86 at s 21.

<sup>335</sup> Ottawa: Public Works and Government Services Canada, 1998. The three councils involved were the Medical Research Council, the Social Sciences and Humanities Research Council, and the Natural Sciences and Engineering Research Council. The Medical Research Council has been replaced by the Canadian Institutes for Health Research. The Tri-Council Policy Statement replaced the Medical Research Council of Canada's 1987 Guidelines on Research Involving Human Subjects. The Tri-Policy Statement is a guideline and has no statutory force. The Tri-Council Policy Statement is not law, although it is widely referenced and applied by ethics review boards reviewing research involving human subjects.

<sup>336</sup> Health Information Act (Alberta), supra, note 86 at s 49; Draft Ontario Privacy of Personal Information Act, 2002, supra, note 86 at s 45.

<sup>337</sup> Health Information Act (Alberta), supra, note 86 at s 50(1); Draft Ontario Privacy of Personal Information Act, 2002, supra, note 86 at s 45(2)(f).

<sup>338</sup> Health Information Act (Alberta), supra, note 86 at s 50(2); Draft Ontario Privacy of Personal Information Act, 2002, supra, note 86 at s 45(5)(e).

<sup>339</sup> Health Information Act (Alberta), supra, note 86 at s 54(1); Draft Ontario Privacy of Personal Information Act, 2002, supra, note 86 at s 45(9).

<sup>340</sup> Draft Ontario Privacy of Personal Information Act, 2002, supra, note 86 at s 45(8).

<sup>341</sup> Supra, note 86 at s 45(8).

<sup>342</sup> A Cavoukian, Information and Privacy Commissioner (Ontario). *Submission to the Ministry of Consumer and Business Services: Consultation Draft of the Privacy of Personal Information Act, 2002*. 27 February 2002 (available at [www.iipc.on.ca/english/pubpres/reports/cbs-0202.htm](http://www.iipc.on.ca/english/pubpres/reports/cbs-0202.htm)), citing Canadian Institutes of Health Research. *Recommendations for the Interpretation and Application of the Personal Information Protection and Electronic Documents Act (SC 2000 c 5) in the Health Research Context*. Ottawa: Canadian Institutes of Health Research, 30 November 2001 (available at [www.cihr-irsc.gc.ca/e/publications/recommendations\\_e.pdf](http://www.cihr-irsc.gc.ca/e/publications/recommendations_e.pdf)).

<sup>343</sup> Cavoukian, *ibid*.

<sup>344</sup> Radwanski, supra, note 39.

<sup>345</sup> Health Information Act (Alberta), supra, note 86 at s 54(1)(d); The Personal Health Information Act (Manitoba), supra, note 86 at s 24(5).

<sup>346</sup> HIV & AIDS Legal Clinic (Ontario). *Submissions of the HIV & AIDS Legal Clinic (Ontario) on Bill 159: The Personal Health Information Privacy Act, 2000*, supra, note 1; Privacy Working Group, supra, note 5 at 6-7.

<sup>347</sup> PIPEDA, supra, note 86 at s 24.

<sup>348</sup> The Health Information Protection Act (Saskatchewan), supra, note 86 at s 53.

<sup>349</sup> Limitations Act, RSBC 1996, c 266, s 3(2)(f); The Limitation of Actions Act, CCSM 1987, c L150, s 2(1)(d); The Privacy Act (Saskatchewan), supra, note 201 at s 9; Limitations Act, SNL 1995, c L-16.1, s 5(j).

<sup>350</sup> See, eg, *Snow (Guardian ad litem of) v Kashyap* [1995] NJ No 15 (Nfld CA) (QL); *Speerin v North Bay (City)* (1991) 85 DLR (4th) 365 (Ont Gen Div); *Streng et al v Township of Winchester* (1986) 56 OR (2d) 649 (High Ct).

<sup>351</sup> The Personal Health Information Act (Manitoba), supra, note 86 at s 41(1) states:

The Ombudsman may decide not to investigate a complaint if the Ombudsman is of the opinion that (a) the length of time that has elapsed since the date the subject matter of the complaint arose makes an investigation no longer practicable or desirable; (b) the subject matter of the complaint is trivial or the complaint is not made in good faith or is frivolous or vexatious; or (c) the circumstances of the complaint do not require investigation.

The Draft Ontario Privacy of Personal Information Act, 2002, supra, note 86 at s 64(5)(e) allows the Commissioner to refuse to review a complaint that is frivolous or vexatious.

<sup>352</sup> PIPEDA, supra, note 86 at s 12; McNairn & Scott, supra, note 53 at 130.

<sup>353</sup> E Hamden. *The Personal Information Protection Documents Act: what it means for federally regulated businesses and their employees*. *Focus* 2000; 5(4) at 3; Charnetski, supra, note 22 at 73.

<sup>354</sup> PIPEDA, supra, note 86, at s 12.

- <sup>355</sup> Ibid at s 12(1)(c).
- <sup>356</sup> White, supra, note 286 at 8; J Beardwood. Another piece of the puzzle: Ontario privacy legislation in the Canadian context. Presented at Insight Information Conference "Privacy Law in Ontario." Toronto: 28 February-1 March 2002. Compare with Personal Information Protection Act (British Columbia), supra, note 86 at s 38(1).
- <sup>357</sup> The Personal Health Information Act (Manitoba), supra, note 86 at s 46.
- <sup>358</sup> Ibid.
- <sup>359</sup> PIPEDA, supra, note 86 at 13.
- <sup>360</sup> Ibid at s 12; Personal Information Protection Act (British Columbia), supra, note 86 at s 49.
- <sup>361</sup> Draft Ontario Privacy of Personal Information Act, 2002, supra, note 86 at s 64(1)(c).
- <sup>362</sup> The Personal Health Information Act (Manitoba), supra, note 86 at s 47(3); The Health Information Protection Act (Saskatchewan), supra, note 91 at s 48.
- <sup>363</sup> PIPEDA, supra, note 86, at s 13; Charnetski et al, supra, note 22 at 75, 78-79.
- <sup>364</sup> Charnetski et al, supra, note 22 at 75.
- <sup>365</sup> PIPEDA, supra, note 86 at s 15(a).
- <sup>366</sup> Health Information Act (Alberta), supra, note 86 at s 80.
- <sup>367</sup> Ibid.
- <sup>368</sup> Ibid at s 81.
- <sup>369</sup> Ibid at s 80(6).
- <sup>370</sup> Ibid at s 82(3); see also Draft Ontario Privacy of Personal Information Act, 2002, supra, note 86 at s 70.
- <sup>371</sup> Personal Information Protection Act (British Columbia), supra, note 86 at s 52(3), (4).
- <sup>372</sup> Health Information Act (Alberta), supra, note 86 at s 107(1)(d), (e), s 107(2).
- <sup>373</sup> Personal Information Protection Act (British Columbia), supra, note 86 at s 56(1)(c), (f), s 56(2).
- <sup>374</sup> Draft Ontario Privacy of Personal Information Act, 2002, supra, note 86 at s 79(1)(e), (f), (g), s 79(4).
- <sup>375</sup> The Personal Health Information Act (Manitoba), supra, note 86 at s 48(2).
- <sup>376</sup> PIPEDA, supra, note 86 at s 20 (2).
- <sup>377</sup> Charnetski et al, supra, note 22 at 75.
- <sup>378</sup> PIPEDA, supra, note 86 at ss 19, 25.
- <sup>379</sup> Health Information Act (Alberta), supra, note 86 at s 107; The Personal Health Information Act (Manitoba), supra, note 86 at s 63; Draft Ontario Privacy of Personal Information Act, 2002, supra, note 86 at s 79; The Health Information Protection Act (Saskatchewan), supra, note 86 at s 64.
- <sup>380</sup> The Health Information Protection Act (Saskatchewan), supra, note 86 at s 64(4).
- <sup>381</sup> The Personal Health Information Act (Manitoba), supra, note 86 at s 65(2).
- <sup>382</sup> Health Information Act (Alberta), supra, note 86 at s 106.
- <sup>383</sup> Draft Ontario Privacy of Personal Information Act, 2002, supra, note 86 at s 78.
- <sup>384</sup> PIPEDA, supra, note 86 at s 27(2).
- <sup>385</sup> Ibid at s 14(1). See also *Thomas v Robinson* [2001] OJ No 4373 (SCJ) (QL).
- <sup>386</sup> Charnetski et al, supra, note 22 at s 84.
- <sup>387</sup> PIPEDA, supra, note 86 at s 16.
- <sup>388</sup> Ibid.
- <sup>389</sup> Personal Information Protection Act (British Columbia), supra, note 86 at s 57(1).
- <sup>390</sup> Ibid at s 57(2).
- <sup>391</sup> The Health Information Protection Act (Saskatchewan), supra, note 86 at s 50.

<sup>392</sup> Ibid at s 51(5).

<sup>393</sup> Klar, *supra*, note 205 at 26.

<sup>394</sup> Parliamentary Ad Hoc Committee on AIDS. *Confronting a Crisis: The Report of the Parliamentary Ad Hoc Committee on AIDS*. Ottawa: The Committee, 1990 at 41.

<sup>395</sup> Ibid.

<sup>396</sup> R. Carey. Recent developments in privacy legislation. *Canadian HIV/AIDS Policy & Law Review* 2003; 8(2): 1, 11-17 at 16.



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# Appendix A

## Workshop participants and people consulted

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