Recent Developments in Privacy Legislation

In this article, Ruth Carey takes a critical look at recent privacy-of-personal-information legislation drafted in three Canadian provinces – Ontario, Alberta, and British Columbia. The article begins with a historical overview of international legal instruments and other privacy guidelines, and the Canadian experience with privacy protection. It then critically analyzes the provincial initiatives in the context of the federal Personal Information Protection and Electronic Documents Act and accepted privacy principles. The article goes on to highlight certain types of legislative provisions of particular interest to people with HIV/AIDS and those who advocate on their behalf. It concludes that the numerous legislative initiatives underway in Canada provide an opportunity to alter the public discourse around the virus, thereby improving the lives of people with HIV/AIDS.

Introduction

We believe that health information is among the most sensitive personal information which exists. Within that class of information, ones HIV positive status is arguably the most sensitive piece of information of all. During the
Recent Developments in Privacy Legislation

course of our work, we have discovered that it is the norm, rather than the exception, that bad things happen to individuals living with HIV when their HIV status is disclosed without their consent.¹

Most Canadian jurisdictions, and much of the rest of the world, are currently experiencing a period of great change with respect to privacy legislation. There are legislative initiatives currently before a number of provincial legislatures, and privacy laws have recently been passed by the federal government and in the United States, Europe, and Australia.

The ability to control knowledge of one’s HIV status is a crucial right to be gained for people living with HIV/AIDS. The Ontario Advisory Committee on HIV/AIDS (OACHA) has stated that there is often stigma associated with having any disease, particularly a life-threatening, communicable disease. Since HIV infection is often associated with particular sexual and drug-related activities, stigmatization of PHAs is common. Disclosure can expose PHAs directly or indirectly to discrimination or rejection by family, friends and community.²

The law is an instrument of social policy and, as such, can have a positive (or negative) impact on the way societies treat minorities. In many ways, the stigmatization of people living with HIV/AIDS can be said to be a social construct. New laws are one way to change that social construct for the better. So, for people living with HIV/AIDS, the current flurry of legislative activity is important. It is an opportunity to influence the discourse, and to improve respect for the autonomy and dignity of people living with HIV/AIDS. Conversely, new privacy legislation is a potential threat to people living with HIV/AIDS. Legislatures may erode the few privacy rights people have by failing to use precise language, or by making deliberate policy choices that favour perceived scientific and other societal interests in disclosure over the individuals interest in privacy.

Historical Background

Historically, the vanguard of privacy protection has been within the arena of international law.³ Article 12 of the Declaration of Human Rights, adopted and proclaimed by the United Nations on 10 December 1948, 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.⁴

Article 17 of the International Covenant on Civil and Political Rights, adopted by the United Nations in December 1966, contains the same language.⁵ In 1988, the Office of the High Commissioner for Human Rights issued the following guideline for states that had adopted the International Covenant on Civil and Political Rights:

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.⁶

The first laws passed to protect information privacy were in European countries in the early 1970s.⁷ Sweden passed a Data Protection Act in 1973, with other European countries following suit (the German Federal Republic in 1977; and Norway, Denmark, and France in 1978).

The OECD Guidelines

As a result of this patchwork of European information privacy laws, the Organisation for Economic Cooperation and Development (OECD) became concerned that the protection of information privacy might impede trade or economic development. The OECD is an international organization of 30 member states (including Canada) with a commitment to a market economy and pluralistic democracy. Its goal is to promote economic development within a democratic framework. As a result of its concern about trade restrictions, in 1980 the OECD adopted Guidelines on the Protection of Privacy and Transborder Flows of Personal Data.⁸ The OECD
Guidelines were endorsed by all member states of the OECD (Canada endorsed them in 1984).

The OECD 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. 9 Nevertheless, the OECD Guidelines contain a series of fair information principles that have been incorporated into most of the new legislation in this area. One such principle is that if one has to collect personal information, the data collected should be limited to the information necessary to meet the purpose of collection. So, if you are a person living with HIV/AIDS and you arrive at an emergency room with a broken leg and choose to disclose your HIV status, you should not be asked how you became infected with the virus. That information is not necessary for the purposes of treating you and therefore should not be collected.

Another fair-information principle in the OECD Guidelines is that 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 any other purpose. It is worth noting that Canadian hospital practices regularly and systemically infringe this principle when using health information for public policy and research purposes.10

Other principles in the OECD Guidelines include the following:

- That personal data should be protected by adequate security measures;
- That individuals should be able to access their own personal information and challenge its accuracy;
- That there should be a general policy of openness about policies and practices with respect to personal information; and
- That there should be someone you can contact who is accountable for ensuring that the principles are followed.

Despite the fact that these principles have existed for over 20 years, and that Canada adopted them in 1984, Canada has only recently incorporated these principles in legislation.

The Canadian experience

Historically, in jurisdictions other than Quebec, 11 the Canadian experience with information privacy has been twofold. First, the common law has not adequately protected privacy rights — there is no generally accepted tort of breach of privacy12 — and attempts to create by statute a tort of breach of privacy have not been very successful.13 Second, information privacy legislation has generally been limited to information held by government. For example, the federal government passed the Privacy Act in 1983, but it only regulates the collection, retention, and disposal of personal information by federal government institutions and departments.14 Similar legislation (often combined in a single statute with provisions concerning access to government information) exists across Canada.15 Not only has the traditional legislative response in Canada been confined to government-held information, but the statutes themselves have provided little in the way of privacy protection. For example, in Ontario, if a police officer discloses your HIV-positive status to your neighbour, you can file a complaint with the Office of the Information and Privacy Commissioner. But the Commission has no authority under its governing statute to provide you with a remedy against the police force. It can recommend a remedy, but it has few (if any) tools to force compliance. Similar structural flaws exist in most of the legislative schemes in the country.

In the past, it was very difficult for people living with HIV/AIDS to obtain any effective legal remedy when their personal information was disclosed to others without their consent.

As a result, in the past it was very difficult for people living with HIV/AIDS to obtain any effective legal remedy when their personal information was disclosed to others without their consent. This is now changing, in large part because of 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.16 The Directive was introduced in 1995 and became effective in October 1998. The EU Directive requires that the laws of member states prohibit the transfer of information from European countries to any trading partner unless the partner
has adequate information privacy protections in place. As a result, Canada found itself in the position of being forced to adopt information protection measures or risk an interruption in its trade with Europe.

This pressure eventually led the federal government to pass the Personal Information Protection and Electronic Documents Act (PIPEDA).\textsuperscript{17} Similar pressure on other non-European trading partners has resulted in legislative initiatives around the world, including in Australia, Argentina, New Zealand, and the United States.

**Personal Information Protection and Electronic Documents Act**

PIPEDA is designed to regulate the collection, use, and disclosure of personal information in the private or commercial sector. PIPEDA comes into effect in stages. As of 1 January 2002, the law applied to personal information in the federally regulated private sector, such as airlines, banking, broadcasting, interprovincial transportation, and telecommunications. It now also applies to transfers of information across provincial borders where the transfer is made for commercial purposes. Although PIPEDA is federal legislation, it is designed to apply to provincial businesses and commercial enterprises as of 1 January 2004. Pursuant to sections 26 and 30 of PIPEDA, any province that has substantially similar legislation to PIPEDA is exempted from the provisions of the Act. To date, only Quebec has been acknowledged as having substantially similar legislation by George Radwanski, who was the federal Privacy Commissioner until June 2003.

PIPEDA is extremely important legislation in the context of promoting the right of people living with HIV/AIDS to control disclosure of their HIV status. Charnetski et al describe PIPEDA as follows:

> It is sweeping legislation of broad application, which purports to regulate all collection, use and disclosure of personal information by private enterprise in the course of commercial activities, irrespective of whether such information has been obtained through or is related to on-line transactions or e-commerce. It also provides an operational standard to which affected organizations may be held in contexts outside of the Act, such as private civil actions including tort claims. While regulation of privacy and the collection, use and disclosure of personal information has long been part of the legislative landscape applied to the public sector, the Act represents the first time federal legislation of general application in this area will regulate private enterprise. In addition, the Act confers on individuals what, in time and through refinement by judicial consideration, may prove to be very powerful enforcement mechanisms to ensure the protection of personal information.\textsuperscript{18}

PIPEDA explicitly incorporates the Canadian Standards Association’s Model Code for the Protection of Personal Information, a set of principles for information handling practices similar to those set out by the OECD.\textsuperscript{19} These principles reflect a fundamental improvement in information practices and privacy standards that will be of great interest to people living with HIV/AIDS. Of prime importance is the central concept that the disclosure of personal information, or the use or collection of personal information, should only occur with the individuals consent, except in narrowly defined and limited circumstances.

As a result of this opportunity to opt out of the application of the federal statute, the provinces and territories have adopted different strategies with respect to how to respond. The Atlantic provinces and the territories have decided not to enact provincial private-sector legislation; as a result, PIPEDA will apply to those jurisdictions as of 1 January 2004.\textsuperscript{20} Ontario, British Columbia, and Alberta have all announced legislative initiatives in response to PIPEDA. These initiatives are discussed below.

**New and Current Developments**

**Ontario**

Ontario’s response to the international and federal pressure to adopt fair information handling and privacy legislation has been to embark on numerous consultation processes in an attempt to draft legislation acceptable to multiple competing interests. In June 1996, the then Parliamentary Assistant to the Minister of Health, Helen Johns, released A Legal Framework for Health Information Consultation Paper.\textsuperscript{21} In the fall of 1997, the then Minister of Health, Jim Wilson, announced that the Ontario provincial government planned to introduce legislation regulating the collection, disclosure, and destruction of personal health information and records. Subsequently the government...
released a draft statute for consultation. The draft act was called the Personal Health Information Protection Act, 1997.

In September 2000, the Ministry of Health and Long-Term Care started another consultation process. This one was called Ontarios Proposed Personal Health Information Privacy Legislation for the Health Sector (Health Sector Privacy Rules). At the same time as the Health Sector Privacy Rules consultation was going on, the Ontario Ministry of Consumer and Business Affairs was starting its own consultation. The September 2000 proposals envisioned an overall privacy law for the private sector, with attached schedules for different sectors of the economy. In December 2000, the provincial government introduced Bill 159 in the legislature. The bill was called the Personal Health Information Act, 2000, and was the subject of instant controversy. The provincial Information and Privacy Commissioner described the bill as decidedly imperfect and in need of a lot of work. The federal Privacy Commissioner went further in his comments to the Standing Committee on General Government in February 2001:

I regretfully find that, in its current form, it is an assault on health privacy rights, not a defence of them. The legislation appears designed, in fact, to ensure that the government of Ontario and a virtually unlimited range of other organizations and individuals could have unrestricted access to the most private health information of every Ontarian.

Bill 159 died on the order paper when the legislative session came to an end a few weeks later. In February 2002, the Ministry of Consumer and Business Services published yet another consultation paper that included yet another draft statute, this time called the Privacy of Personal Information Act, 2002. Well over 200 organizations submitted comments in response. It was widely anticipated that the Ontario government would introduce a new bill in the fall of 2002. That did not and has not occurred, even though the final draft of the legislation is reported to have been completed. As a result, Ontarians wait in limbo, uncertain whether or not PIPEDA will apply as of 1 January 2004 or whether a bill will be rushed through the legislature in the fall of 2003.

**British Columbia**

In 1999, the British Columbia legislature established a Special Committee on Information Privacy in the Private Sector. The Committee held public hearings in January 2000 and issued an extensive report of its findings in March 2001. In 2002, the Ministry of Management Services Corporate Privacy and Information Access Branch issued a consultation paper and announced that it planned to introduce personal information privacy legislation prior to the 1 January 2004 implementation date of PIPEDA. At that time, British Columbia expected that Alberta and Ontario would be introducing similar legislation, and publicly announced that the three provinces were working together to ensure a harmonious approach.

In April 2003, the BC government introduced Bill 38, the Personal Information Protection Act. It received second reading on 1 May 2003. It was expected that the legislation would be rushed through the legislature and passed before the end of May 2003, as evidenced by opposition comments made in the legislature on 1 May 2003. But the federal Privacy Commissioner weighed in with a critical response to Bill 38 that appears to have delayed passage. On 7 May 2003, the Commissioner wrote to BCs Minister of Management Services regarding Bill 38 and posted his letter on his website in the form of a news release. The letter states that Bill 38 has a number of grave deficiencies that would in my view, make it impossible for the Government of Canada to recognize this legislation in its current form as substantially similar to the federal [PIPEDA].

The former federal Privacy Commissioners criticisms of Bill 38 include the fact that the bill proposes to grandfather existing collections of data. In other words, if one had collected information before Bill 38 came into effect, one could continue to use and disclose that information without needing to comply with the new legislation. Professional fundraisers lobbied for this provision to ensure that they would be able to continue to use old donor lists. The Privacy Commissioner advanced the following additional criticisms:

- ¥ the bill would permit implied consent to the collection, use, and disclosure of personal information;
- ¥ the bill would allow employers to disclose employee information without consent;
- ¥ the provisions in the bill concerning the ability of employees to access their own records, or to correct them, were inadequate; and
- ¥ the language in the bill that would permit disclosures of information for investigations was too broad.

One crucial difference between PIPEDA and Bill 38 that the former federal Privacy Commissioner did not raise in his letter is the difference in remedies available under Bill 38 compared with
PIPEDA. Under PIPEDA, complainants whose complaints are upheld can, in certain circumstances, file an application in a court for monetary damages when a breach of PIPEDA is established. Complainants are entitled to compensation for humiliation they may have suffered. As a result, it is possible to receive a damage award from the Federal Court under PIPEDA without proof of a monetary loss. In contrast, section 57 of Bill 38 specifically limits the damages remedy to damages for actual harm. It is often the case that a person living with HIV/AIDS will not be working, so a breach of privacy rights will not result in lost income, out-of-pocket expenses, or other monetary loss.

PIPEDA explicitly recognizes that a breach of one’s privacy engages the dignity interest and accepts that such breaches can be humiliating. 

Alberta

Alberta already has legislation in place that governs the collection, use, and disclosure of health information in the public sector. The Health Information Act came into force in April 2001. On 15 May 2003, Alberta introduced for first reading Bill 44, the Personal Information Protection Act, which would apply to the private sector and is Alberta’s response to PIPEDA. The Alberta legislature rose for the summer the next day.

As the former Privacy Commissioner of Canada observed, Alberta Bill 44 is very similar to BC’s Bill 38. Predictably, then, the Commissioner publicly criticized Alberta bill for many of the same reasons cited above. In addition, he drew attention to the fact that under Alberta’s bill people who request access to their own information may be charged a reasonable fee. In the context of a large file, a reasonable fee may in fact be quite costly. In contrast, PIPEDA says access to their own information must be given to a person at minimal or no cost. Alberta’s bill also contains provisions that would allow the government to pass regulations eroding much of the privacy protection that the bill is supposed to provide. Finally, the Alberta bill would permit the government to exempt non-profit organizations or bodies such as the College of Physicians and Surgeons from the application of the legislation.

To the knowledge of this writer, none of the other provinces or territories have initiated or are planning to introduce personal information protection legislation for the private sector prior to 1 January 2004.

As a result of the developments described above, the privacy rights of employees may vary, depending on where they live and who they work for. Employees in federally regulated industries are covered now by PIPEDA. Employees in provincially regulated industries will be covered by PIPEDA as of 1 January 2004 unless they live in provinces that have adopted substantially similar legislation: substantially similar does not mean identical.

What People with HIV/AIDS Should Keep an Eye On

Privacy rights are central to the exercise of other fundamental rights and full social participation by people living with HIV/AIDS. The former federal Privacy Commissioner stated that we must take the view that privacy is not just an individual right — it is a public good. It reflects decisions we have made as a people about how we will live as a society. Privacy is, as Justice La Forest of the Supreme Court of Canada has said, at the heart of liberty in a modern state. And we are, all of us, the loser if individual liberty is lost.

Those of us who work with HIV/AIDS-affected communities welcome additional tools that help people living with HIV/AIDS have greater control over the disclosure of their HIV status. When governments introduce and debate legislation that has the potential to deliver these tools, the draft
“We must take the view that privacy is not just an individual right – it is a public good. It reflects decisions we have made as a people about how we will live as a society.”

Conclusion

People living with HIV/AIDS have a pressing and substantial interest in any legislation regulating the collection, disclosure and use of personal health information. HIV positive people are particularly vulnerable to the unauthorized release of personal health information given their significant and ongoing interaction with the health care and related sectors which produces vast amounts of personal health information. Being HIV positive also means being particularly vulnerable to any erosion or failures of a system designed to protect the privacy of that personal health information. This is an exciting time for privacy issues in Canada. The legislative initiatives currently underway provide 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 federal Privacy Commissioner stated: Privacy will be the defining issue of this decade. - Ruth Carey

Ruth Carey is a Barrister and Solicitor and Executive Director of the HIV & AIDS Legal Clinic (Ontario). She is a member of the Ontario Advisory Committee on HIV/ AIDS and sits on the Board of Directors of the Canadian HIV/AIDS Legal Network. Ruth can be reached at careyr@lao.on.ca.

7 Higgins, Privacy Law,”Where did this come from?” Toronto: Ontario Bar Association, 20 November 2002, at 8. Much of this section of this article is based on John Higgins’s excellent paper.
10 Abstracts from discharge records from 85 percent of all Canadian hospitals are forwarded to the Canadian Institute for Health Information (CIHI). The abstracts do not contain patient names or addresses, but they do contain coded information on one’s personal health number; gender; date of birth; postal code, and limited details about one’s diagnosis, care, and treatment – such as the primary reason for one’s hospital stay and the length of stay. Putting aside the question whether the collection of this data is a good thing for Canadian society, patients being admitted to hospitals are not usually informed that this information about them is being forwarded to CIHI for research purposes. Research in Canada clearly indicates that while most patients are in favour of their health information being used for research purposes, the majority are of the view that some sort of consent should be sought first. Furthermore, patients do not seem to change their minds when comparing how they feel about data collection when personal identifiers are removed from their records. See, for example, DJ Willison et al. Patients’ consent preferences for research uses of information in electronic medical records: interview and survey data. British Medical Journal (15 February) 2003; 326:373, available at http://bmj.com/cgi/content/full/326/7385/373. If most patients believe consent to the collection of their health information for research purposes is important, then one can assume there is a general consensus among patients that they should be informed when their health information is forwarded to CIHI for research purposes.
11 The protection of privacy under the Civil Code of Lower Canada and the Civil Code of Quebec is not reviewed in this article. Quebec is the only province that has legislation in force, applicable to the private as well as the public sector; on the protection of personal information, including health information. Quebec is also the only province to have enacted legislation recognized by the Privacy Commissioner of Canada as substantially similar to PIPEDA. See An Act respecting the protection of personal information in the private sector (RSQ c P-39). An Act respecting access to documents held by public bodies and the protection of personal information, RSQ c A-2; and Privacy Commissioner of Canada. Report to Parliament Concerning Substantially Similar Provincial Legislation. Ottawa: Minister of Public Works and Government Services Canada, May 2002.
12 As Mr Justice Adams stated in Ontario (Attorney General) v Dietrich (1994), 117 DUR (4th) 449 (OCCGD) at 688: “It would appear that invasion of privacy in Canadian common law continues to be an inept, if not ephemeral, legal concept, primarily operating to extend the margins of existing tort doctrine.”
14 RSC 1985, c P-21. Interestingly enough, prior to the enactment of the federal Privacy Act, there were some statutory provisions in existence in federal law concerning the protection of privacy. Those provisions, which were contained in Part IV of the Canadian Human Rights Act, RSC 1985, c H-6, grew out of Canada’s commitments to implement the international human rights instruments mentioned above.
The most recent of these is Prince Edward Island’s Freedom of Information and Protection of Privacy Act, SPEI 2002, c F-15.01, proclaimed on 1 November 2002. A comprehensive list of the legislation of each province and territory can be found on the Privacy Commissioner of Canada’s website at www.privcom.gc.ca/information/comms_e.asp. The various pieces of legislation can be accessed via www.legis.ca/.

The European Directive is available in multiple languages via the EU’s website at www.europa.eu.int.

SC 2000, c 5.

Charnetski et al, supra, note 3 at 1.


Copy on file with the author:
