



Canadian Institutes
of Health Research

Instituts de recherche
en santé du Canada

Canada

A Compendium of Canadian Legislation Respecting the Protection of Personal Information in Health Research

Canadian Institutes of Health Research

April 2000





Canadian Institutes
of Health Research

Instituts de recherche
en santé du Canada

Canada

A Compendium of Canadian Legislation Respecting the Protection of Personal Information in Health Research

Edited and annotated by
Patricia Kosseim

April 2000

Canadian Institutes of Health Research
410 Laurier avenue West, 9th floor
Address Locator 4209A
Ottawa, ON K1A 0W9

© Public Works and Government Services Canada, 2000
Cat. No. MR21-22/2000E
ISBN 0-662-29010-0

Table of Contents

| | |
|---|------|
| Editor’s Preface..... | i |
| Right to Privacy..... | 1.0 |
| Statutory Tort of Invasion of Privacy..... | 2.0 |
| Definitions..... | 3.0 |
| Definition of Personal Information..... | 3.1 |
| Definition of Personal Health Information..... | 3.4 |
| Collection..... | 4.0 |
| Collection of Personal Information in the Public Sector..... | 4.1 |
| Collection of Personal Information in the Private Sector..... | 4.5 |
| Collection of Personal Health Information..... | 4.8 |
| Use and Disclosure..... | 5.0 |
| Use and Disclosure of Personal Information in the Public Sector..... | 5.1 |
| Use and Disclosure of Personal Information in the Private Sector..... | 5.7 |
| Use and Disclosure of Personal Health Information..... | 5.10 |
| Access to Clinical Records and Registries for Research Purposes..... | 5.21 |
| Consent & Substitute Decision-Making..... | 6.0 |
| Consent & Substitute Decision-Making respecting Personal Information in the Public Sector..... | 6.1 |
| Consent & Substitute Decision-Making respecting Personal Information in the Private Sector..... | 6.3 |
| Consent & Substitute Decision-Making respecting Personal Health Information..... | 6.6 |
| Safeguarding, Retention and Destruction..... | 7.0 |
| Safeguarding, Retention and Destruction of Personal Information in the Public Sector..... | 7.1 |
| Safeguarding, Retention and Destruction of Personal Information in the Private Sector..... | 7.6 |
| Safeguarding, Retention and Destruction of Personal Health Information..... | 7.8 |
| Electronic Records and Data Linkage..... | 8.0 |
| Ethical Norms..... | 9.0 |
| Appendix A..... | 10.0 |

Editor's Preface

The protection of personal health information is a matter of great concern for most Canadians given its fundamental and intimate connection with the right to dignity, integrity and autonomy. Yet, at the same time, access to such information is indispensable to researchers seeking to improve the health status of Canadians and the viability and sustainability of the health care system as a whole. This dilemma has perplexed legislators for some time and continues to raise even more complex questions, especially in this age of electronic data. Recent years have seen a plethora of privacy legislation emerge across the country. Stakeholders in the health research field are struggling to make sense of this increasing body of laws and regulations, hoping to understand how all of it may or may not ultimately affect them. Some argue that the laws and regulations have gone too far, while others argue, not far enough. All recognize, however, that there is undoubtedly more to come on the horizon and agree on the need to better understand the implications of the emerging legislative and regulatory framework.

Against this backdrop, the Medical Research Council of Canada (as it then was), Standing Committee on Ethics, Sub-Committee on Legislation (the "Sub-Committee") decided to examine this area of law more closely and to seriously reflect on how legislators have fared until now in striking an appropriate balance between the desire to protect the rights of individuals (and collectivities), on the one hand, and the desire to promote the improvement of Canada's health care system and overall health status, on the other. As a first step in its analysis, the Sub-Committee commissioned the editor to prepare

this *Compendium of Canadian Legislation Respecting the Protection of Personal Information in Health Research*.

This working tool was specifically designed to provide members of the Sub-Committee with a panoramic view of the legislative landscape across the country. Organized by theme and by jurisdiction, the compendium allows for comparisons to be drawn and certain trends to be deduced. Cross-links between relevant sections of various laws and regulations have been parenthetically noted for easy reference. This compendium is intended to serve as a springboard for organizing future discussion, developing common terminology and clarifying issues in the current privacy debate. Other stakeholders in the health research field may hopefully find this compendium useful as a means of surveying, at least in a preliminary fashion, the applicable law on various aspects of privacy and data protection in any given jurisdiction. This being said, there are important limitations to this document that potential users should bear in mind.

First, while comprehensive, this compendium does not purport to be an all-inclusive statement of the law on any one topic, in any one jurisdiction. For instance, it does not cover territorial legislation, nor does it include any jurisprudence or professional codes of conduct. Second, in order to facilitate comparison and analysis, statutory provisions necessarily had to be extracted from a whole. To interpret any one of these extracts meaningfully, it should properly be considered in its complete legislative context. Third, whether or not a provision applies to a specific stakeholder, carrying on a specific

activity, in a specific circumstance and in a specific sector, will ultimately and critically depend on the given law's scope of application. Such a determination extends beyond the purview of this compendium and requires a separate legal analysis on a case-by-case basis. Finally, not all of the legislation included in this compendium is in effect. Laws not yet assented to or not yet proclaimed in force are so indicated at the top of the relevant column in each of the tables. This status information is current through to January 2000.

The editor would like to acknowledge the members of the Sub-Committee, (Justice T. David Marshall (Chair), Pierre Deschamps, Bartha Maria Knoppers, Chris Levy, Neil MacDonald, Barbara McGillivray, Catherine Miller-Dolgoy, Francis Rolleston and Verna Skanes) for their astute foresight in identifying this area of the law as a matter of priority and for their ongoing support throughout this project. The editor would also like to thank: Leslie Rose, Margaret Hill-Campbell and Pierrot Péladeau for their insightful comments and suggestions; the law firm, Heenan Blaikie, for its generous loan of administrative and staff support during earlier iterations of this work; Chantal Quiniou, Hélène Beaudoin, Troy McEachren and Sophie Ouellette for their valuable assistance in collecting and collating all of the necessary materials. All annotations in this compendium are those of the editor alone.

Patricia Kosseim

Right to Privacy

As will become readily apparent throughout this document, there are many existing, pending and proposed laws in Canada that have as their purpose to protect the right to privacy. However, there are three legislative texts in particular that actually vest individuals with that fundamental right as a foundation for all other laws. These are: the *Canadian Charter of Rights and Freedoms* (the “*Canadian Charter*”), the *Quebec Charter of Human Rights and Freedoms* (the “*Quebec Charter*”) and the *Civil Code of Quebec* (the “*Civil Code*”).

Courts have recognized that an individual’s “*right to security of the person*” within the meaning of section 7 of the *Canadian Charter* encompasses the right to be free from interference with one’s physical, as well as psychological, integrity.¹ It has followed from this principle that section 7 includes the right to be free of the psychological stress resulting from unauthorized disclosure of one’s personal health information.²

The Supreme Court of Canada has confirmed that the “*right to be secure against unreasonable search or seizure*” enshrined in section 8 of the *Canadian Charter* likewise protects the individual’s informational privacy. The right to be secure against unreasonable search and seizure is based not merely on proprietary interests (eg. one’s home, car and/or personal belongings), but rather, on the very dignity and integrity of the individual.³ “...(W)hat is protected by section 8 is people, not places or things”⁴

This being said, the application of the *Canadian Charter* to the typical health research context would appear to be somewhat limited. Before a claim could succeed under section 7 or 8 of the *Canadian Charter*, the applicant would have to establish that the

breach of section 7 was contrary to principles of fundamental justice, or, in the case of section 8, that the breach was unreasonable. Moreover, one would have to show that the breach, in either case, could not be demonstrably justified in a free and democratic society as per section 1 of the *Canadian Charter*.

Even so, whether the scope of section 7 or 8 extends beyond the criminal law context or a specific regulatory scheme is not at all clear. Less clear still is whether or not the actions of public institutions (eg. hospital or university administrators, researchers employed by public health institutions, academic research ethics boards), are sufficiently “*governmental*”, within the meaning of section 32, to attract application of the *Canadian Charter* in the first place.⁵ The actions of private organizations (eg. health data managers, pharmaceutical companies, private research ethics boards), would almost certainly not be considered “*governmental*”. While a subject of fascinating debate, the applicability of the *Canadian Charter* is beyond the purview of this compendium. We simply raise it here and include the relevant sections of the *Canadian Charter* in the following table for interest purposes.

In Quebec, however, the right to privacy, as enshrined in the *Quebec Charter* and the *Civil Code*, could more easily be invoked in a typical health research situation. Both the *Quebec Charter* and the *Civil Code* clearly apply in a civil law, as opposed to criminal law context, and cover governmental, as well as private action.

¹ *R. v. Morgentaler*, [1988] 1 S.C.R. 30.

² *Ontario AIDS Society v. Ontario* (1995), 25 O.R. (3d) 388; appeal dismissed, (1996), 31 O.R. (3d) 798; leave to appeal to the Supreme Court of Canada denied, [1997] S.C.C.A. No. 33.

³ *R. v. Dymont*, [1988] 2 S.C.R. 417.

⁴ *Hunter v. Southam*, [1984] 2 S.C.R. 145 at 159; *R. v. Dymont*, *supra*, at 429; *R. v. Colarusso*, [1994] 1 S.C.R. 20 at 60.

⁵ For further discussion of the issue, see *Eldridge v B.C.*, [1997] 3 S.C.R. 624.

RIGHT TO PRIVACY

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Newfoundland and Labrador |
|--|------------------|---------|--------------|----------|---------|---|---------------|-------------|----------------------|---------------------------|
| <p>Canadian Charter of Rights and Freedoms, Part I of the Constitution Act, 1982, being enacted as Schedule B to the Canada Act 1982 (U.K.), 1982, c. 11</p> <p>Guarantee of Rights and Freedoms</p> <p>S. 1 The <i>Canadian Charter of Rights and Freedoms</i> guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.</p> <p>Legal Rights</p> <p>S. 7 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.</p> <p>S. 8 Everyone has the right to be secure against unreasonable search or seizure.</p> <p>Application of Charter</p> <p>S. 32(1) This Charter applies (a) to the Parliament and government of Canada in respect of all matters within the authority of Parliament including all matters relating to the Yukon Territory and Northwest Territories; and (b) to the legislature and government of each province in respect of all matters within the authority of the legislature of each province.</p> | | | | | | <p>Charter of Human Rights and Freedoms, R.S.Q. c. C-12</p> <p>Preamble</p> <p>Whereas every human being possesses intrinsic rights and freedoms designed to ensure his protection and development;</p> <p>Whereas all human beings are equal in worth and dignity, and are entitled to equal protection of the law;</p> <p>Whereas respect for the dignity of the human being and recognition of his rights and freedoms constitute the foundation of justice and peace;</p> <p>Whereas the rights and freedoms of the human person are inseparable from the rights and freedoms of others and from the common well-being;</p> <p>Whereas it is expedient to solemnly declare the fundamental human rights and freedoms in a Charter, so that they may be guaranteed by the collective will and better protected against any violation;</p> <p>Therefore, Her Majesty, with the advice and consent of the National Assembly of Québec, enacts as follows :</p> <p>Part I - Human Rights and Freedoms</p> <p>Chapter 1 - Fundamental freedoms and rights</p> <p>Art. 5. Every person has a right to respect for his private life.</p> <p>Art. 9. Every person has a right to non-disclosure of confidential information. No person bound to professional</p> | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Newfoundland and Labrador |
|---------|------------------|---------|--------------|----------|---------|--|---------------|-------------|----------------------|---------------------------|
| | | | | | | <p>secretary 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.</p> <p>The tribunal must, <i>ex officio</i>, ensure that professional secrecy is respected.</p> <p>Art. 9.1. In exercising his fundamental freedoms and rights, a person shall maintain a proper regard for democratic values, public order and the general well-being of the citizens of Québec,</p> <p>In this respect, the scope of the freedoms and rights, and limits to their exercise, may be fixed by law.</p> <p>Chapter V - Special and interpretative provisions</p> <p>Art. 49. Any unlawful interference with any right or freedom recognized by this Charter entitles the victim to obtain the cessation of such interference and compensation for the moral or material prejudice resulting therefrom.</p> <p>In case of unlawful and intentional interference, the tribunal may, in addition, condemn the person guilty of it to exemplary damages.</p> <p>-----</p> <p>Civil Code of Quebec, S.Q. 1991, c. 64</p> <p>PRELIMINARY PROVISION</p> <p>The Civil Code of Québec, in harmony with the Charter of human rights and freedoms and the general principles of law, governs persons, relations between persons, and property.</p> | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Newfoundland and Labrador |
|---------|------------------|---------|--------------|----------|---------|---|---------------|-------------|----------------------|---------------------------|
| | | | | | | <p>The Civil Code comprises a body of rules which, in all matters within the letter, spirit or object of its provisions, lay down the <i>jus commune</i>, expressly or by implication. In these matters, the Code is the foundation of all other laws, although other laws may complement the Code or make exceptions to it.</p> <p style="text-align: center;">BOOK ONE PERSONS</p> <p style="text-align: center;">TITLE TWO CERTAIN PERSONALITY RIGHTS</p> <p style="text-align: center;">Chapter III RESPECT OF REPUTATION AND PRIVACY</p> <p>Art. 35. Every person has a right to the respect of his reputation and privacy. No one may invade the privacy of a person without the consent of the person or his heirs unless authorized by law.</p> <p>Art. 37. Every person who establishes a file on another person shall have a serious and legitimate reason for doing so. He may gather only information which is relevant to the stated objective of the file, and may not, without the consent of the person concerned or authorization by law, communicate such information to third persons or use it for purposes that are inconsistent with the purposes for which the file was established. In addition, he may not, when establishing or using the file, otherwise invade the privacy or damage the reputation of the person concerned.</p> | | | | |

Statutory Tort of Invasion of Privacy

A tort is a legal wrong committed against a person or property, other than a breach of contract.¹ There are currently four jurisdictions in Canada that have established a statutory tort of invasion of privacy. In British Columbia, Saskatchewan, Manitoba and Newfoundland, it is a tort, actionable without proof of damage, for a person wilfully and without claim of right to violate the privacy of another.² A “wilful” act is one which a person knew or should have known would violate the privacy of another; a “claim of right” is an honest and reasonable belief in a state of facts which, if existing, would constitute a legal justification or excuse.³

Aside from minor variations in wording, and with the exception of a few slightly more substantive differences in the Manitoba legislation, the four statutes generally set out similar examples of the offence, conditions, constituent elements and defences.

First, acts which, in the absence of consent or other proper authorization, constitute proof of a violation of privacy, include: auditory or visual surveillance of a person; listening to or recording of a conversation in which a person participates; use of a person’s name, likeness or voice for commercial or other gain; and, use of a person’s letters, diaries or other personal documents. In all four statutes, such examples are cited for illustrative purposes only and are not meant to constitute an exhaustive list of all possible offences.

Second, the nature and degree of privacy to which a person is entitled in a given situation is that which is reasonable in the circumstances. In assessing what is reasonable, regard must be given to the lawful interests of others.

Third, in determining whether a person’s act or conduct constitutes a violation of another’s privacy - and, if so, in assessing the damages which should be awarded - a court will consider factors such as:

- the nature, incidence and occasion of the person’s act or conduct;
- its effect on the health, welfare, social, business or financial position of the other person or his family, including any distress, annoyance or embarrassment they may have suffered;
- the relationship, if any, between the parties to the action;
- and, the conduct of the parties, both before and after the violation, including any apology offered or amends made.

Finally, an act or conduct will generally not constitute a violation of privacy if: it was consented to (either expressly or implicitly) by the person affected; it was authorized or required by law or by a court; or, in the case of a publication, (it was reasonable to believe that) the matter published was of public interest or was fair comment on a matter of public interest.

¹ **BLACK’S LAW DICTIONARY**, 5th ed., (St. Paul: West Publishing Co., 1979) at 1335.

² As for the remaining common law provinces where no equivalent statute exists, (ie., Alberta, Ontario, New Brunswick, Nova Scotia and Prince Edward Island), some courts (particularly in Ontario) have recognized the intentional tort of invasion of privacy as a separate cause of action at common law: A.M.LINDEN, *Canadian Tort Law*, 4th ed. (Toronto: Butterworths, 1998) at 52-54; J.D.R. CRAIG, “Invasion of Privacy and Charter Values: The Common-Law Tort Awakens”, (1997) 42 *McGill L.J.* 355; *Krouse v. Chrysler Canada Ltd, et al.*, [1970] 3 O.R. 135, 12 D.L.R. (3d) 463; *Burnett v. Canada* (1979), 94 D.L.R. (3d) 281 (Ont. H.C.J.); *Capan v. Capan*, [1980] 14 C.C.L.T. 191 (Ont. H.C.J.); *Saccone v. Orr* (1981), 34 O.R. (2d) 317; *Roth v. Roth* (1991), 4 O.R. (3d) 740 (Ont. Gen. Div.); *Corlett-Lockyer v. Stephens*, [1996] B.C.J. No. 857 (B.C. Prov. Ct.); *Lipiec v. Borsa*, [1996] 31 C.C.L.T. (2d) 294 (Ont. H.C.J.); *Dyne Holdings Ltd. v. Royal Insurance Co. of Canada*, [1996] P.E.I.J. No. 28 (P.E.I.C.A.). A similar action is available under Quebec civil law by virtue of article 49 of the *Quebec Charter*. Article 49 provides that, where a person unlawfully and intentionally interferes with another’s right to privacy, a tribunal may condemn the guilty person to pay exemplary damages. By definition, exemplary damages are of a punitive nature, which do not require proof of moral or material prejudice. Article 49 of the *Quebec Charter* has been reproduced in “**Right to Privacy**”, above.

³ *Hollinsworth v. BCTV* (1998), CarswellBC 2281 (B.C.C.A.), confirming *Hollinsworth v. BCTV* (1996), CarswellBC 2828, 34 C.C.L.T. (2d) 95.

STATUTORY TORT OF INVASION OF PRIVACY

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Newfoundland and Labrador |
|---------|---|---------|---|--|---------|--------|---------------|-------------|----------------------|--|
| | <p><i>Privacy Act, R.S.B.C. 1996, c. 373</i></p> <p>S. 1(1) 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.</p> <p>(2) The nature and degree of privacy to which a person is entitled in a situation or in relation to a matter is that which is reasonable in the circumstances, giving due regard to the lawful interests of others.</p> <p>(3) In determining whether the act or conduct of a person is a violation of another's privacy, regard must be given to the nature, incidence and occasion of the act or conduct and to any domestic or other relationship between the parties.</p> <p>(4) Without limiting subsections (1) to (3), privacy may be violated by eavesdropping or surveillance, whether or not accomplished by trespass.</p> <p>S. 2(2) An act or conduct is not a violation of privacy if any of the following applies: (a) it is consented to by some person entitled to consent; (b) the act or conduct was incidental to the exercise of a lawful right of defence of person or property; (c) the act or conduct was authorized or required by or under a law in force in British</p> | | <p><i>The Privacy Act, R.S.S. 1978, c. P-24</i></p> <p>S. 2 It is a tort, actionable without proof of damage, for a person wilfully and without claim of right, to violate the privacy of another person.</p> <p>S. 3 Without limiting the generality of section 2, proof that there has been: (a) auditory or visual surveillance of a person by any means including eavesdropping, watching, spying, besetting or following and whether or not accomplished by trespass; (b) listening to or recording of a conversation in which a person participates, or listening to or recording of messages to or from that person passing by means of telecommunications, otherwise than as a lawful party thereto; (c) use of the name or likeness or voice of a person for the purposes of advertising or promoting the sale of, or any other trading in, any property or services, or for any other purpose of gain to the user if, in the course of the use, the person is identified or identifiable and the user intended to exploit the name or likeness or voice of that person; or (d) use of letters, diaries or other personal documents of a person; without the consent, expressed or implied, of the</p> | <p><i>The Privacy Act, R.S.M. 1987, c. P-125</i></p> <p>S. 2(1) A person who substantially, unreasonably, and without claim of right, violates the privacy of another person, commits a tort against that other person.</p> <p>(2) An action for violation of privacy may be brought without proof of damage.</p> <p>S. 3 Without limiting the generality of section 2, privacy of a person may be violated (a) by surveillance, auditory or visual, whether or not accomplished by trespass, of that person, his home other place of residence, or of any vehicle, by any means including eavesdropping, watching, spying, besetting or following; (b) by listening to or recording of a conversation in which that person participates, or messages to or from that person, passing along, over or through any telephone lines, otherwise than as a lawful party thereto or under lawful authority conferred to that end; (c) by the unauthorized use of the name or likeness or voice of that person for the purposes of advertising or promoting the sale of, or any other trading in, any property or services, or for any other purposes of gain to the user if, in the course of the use, that person is identified or identifiable and the user intended to exploit the name or likeness or voice of that person; or (d) by the use of his letters,</p> | | | | | | <p><i>The Privacy Act, R.S.N. 1990, c. P-22</i></p> <p>S. 3(1) It is a tort, actionable without proof of damage, for a person, wilfully and without a claim of right, to violate the privacy of an individual.</p> <p>(2) The nature and degree of privacy to which an individual is entitled in a situation or in relation to a matter is that which is reasonable in the circumstances, regard being given to the lawful interests of others; and in determining whether the act or conduct of a person constitutes a violation of the privacy of an individual, regard shall be given to the nature, incidence, and occasion of the act or conduct and to the relationship, whether domestic or other, between the parties.</p> <p>S. 4 Proof that there has been (a) surveillance, auditory or visual, whether or not accomplished by trespass, of an individual, by any means including eavesdropping, watching, spying, harassing or following; (b) listening to or recording of a conversation in which an individual participates, or listening to or recording of messages to or from that individual passing by means of telecommunications, otherwise than as a lawful party to them;</p> |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Newfoundland and Labrador |
|---------|--|---------|--|---|---------|--------|---------------|-------------|----------------------|--|
| | <p>Columbia, by a court or by any process of a court; [...]</p> <p>(3) A publication of a matter is not a violation of privacy if (a) the matter published was of public interest or was fair comment on a matter of public interest, or (b) the publication was privileged in accordance with the rules of law relating to defamation.</p> <p>(4) Subsection (3) does not extend to any other act or conduct by which the matter published was obtained if that other act or conduct was itself a violation of privacy.</p> | | <p>person or some other person who has the lawful authority to give the consent is prima facie evidence of a violation of the privacy of the person first mentioned.</p> <p>S. 4(1) An act, conduct or publication is not a violation of privacy where: (a) it is consented to, either expressly or impliedly by some person entitled to consent thereto; (b) it was incidental to the exercise of a lawful right of defence of person or property; (c) it was authorized or required by or under a law in force in the province or by a court or any process of a court; [...]</p> <p>(2) A publication of any matter is not a violation of privacy where: (a) there were reasonable grounds for belief that the matter published was of public interest or was fair comment on a matter of public interest; or (b) the publication was, in accordance with the rules of law relating to defamation, privileged; but this subsection does not extend to any other act or conduct whereby the matter published was obtained if such other act or conduct was itself a violation of privacy.</p> <p>S. 6(1) The nature and degree of privacy to which a person is entitled in any situation or in relation to any situation or matter is that which is reasonable in the circumstances, due regard being given to the lawful</p> | <p>diaries and other personal documents without his consent or without the consent of any other person who is in possession of them with his consent.</p> <p>S. 4(2) In awarding damages in an action for a violation of privacy of a person, the court shall have regard to all the circumstances of the case including (a) the nature, incidence and occasion of the act, conduct or publication constituting the violation of privacy of that person; (b) the effect of the violation of privacy on the health, welfare, social, business or financial position of that person or his family; (c) any relationship, whether domestic or otherwise, between the parties to the action; (d) any distress, annoyance or embarrassment suffered by that person or his family arising from the violation of privacy; and (e) the conduct of that person and the defendant, both before and after the commission of the violation of privacy, including any apology or offer of amends made by the defendant.</p> <p>S. 5 In an action for violation of privacy of a person, it is a defence for the defendant to show (a) that the person expressly or by implication consented to the act, conduct or publication constituting the violation; or (b) that the defendant, having acted reasonably in that regard, neither knew or should reasonably have known that the act, conduct or publication constituting the violation would have violated the privacy of any</p> | | | | | | <p>(c) use of the name or likeness or voice of an individual for the purpose of advertising or promoting the sale of, or other trading in, property or services, or for other purposes of advantage to the user where, in the course of the use, the individual is identified or identifiable and the user intended to exploit the name or likeness or voice of that individual; or (d) use of letters, diaries or other personal documents of an individual, without the consent, expressed or implied, of the individual or some other person who has the lawful authority to give the consent is, in the absence of evidence to the contrary, proof of a violation of the privacy of the individual first mentioned.</p> <p>S. 5(1) An act or conduct is not a violation of privacy where (a) it is consented to by some person entitled to consent; (b) the act or conduct was incidental to the exercise of a lawful right of defence of person or property; (c) the act or conduct was authorized or required under a law in force in the province or by a court or a process of a court; or [...]</p> <p>(2) A publication of a matter is not a violation of privacy where (a) the matter published was of public interest or was fair comment on a matter of public interest; or (b) the publication was, under the rules of law relating to</p> |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Newfoundland and Labrador |
|---------|------------------|---------|--|---|---------|--------|---------------|-------------|----------------------|---|
| | | | <p>interests of others.</p> <p>(2) Without limiting the generality of subsection (1) in determining whether any act, conduct or publication constitutes a violation of the privacy of a person, regard shall be given to:</p> <p>(a) the nature, incidence and occasion of the act, conduct or publication;</p> <p>(b) the effect of the act, conduct or publication on the health and welfare, or the social, business or financial position, of the person or his family or relatives;</p> <p>(c) any relationship whether domestic or otherwise between the parties to the action; and</p> <p>(d) the conduct of the person and of the defendant both before and after the act, conduct or publication, including any apology or offer or amends made by the defendant.</p> | <p>person; or</p> <p>(c) that the act, conduct or publication in issue was reasonable, necessary for, and incidental to, the exercise or protection of a lawful right of defence of person, property, or other interest of the defendant or any other person by whom the defendant was instructed or for whose benefit the defendant committed the act, conduct or publication constituting the violation; or</p> <p>(d) that the defendant acted under authority conferred upon him by a law in force in the province or by a court or any process of a court; or [...]</p> <p>(f) where the alleged violation was constituted by the publication of any matter</p> <p>(i) that there were reasonable grounds for the belief that the publication was in the public interest; or</p> <p>(ii) that the publication was, in accordance with the rules of law in force in the province relating to defamation, privileged; or</p> <p>(iii) that the matter was fair comment on a matter of public interest.</p> | | | | | | <p>defamation, privileged, but this section does not extend to another act or conduct where the matter published was obtained where the other act or conduct was itself a violation of privacy.</p> |

Definitions

In this section, we have divided relevant legislation into two general categories. The first category of statutes pertains to the protection of personal information in general. These statutes define “*personal information*” by enumerating a wide range of different types of information, including basic health information such as, an individual’s fingerprints, blood type or inheritable characteristics, medical history or health and health care history. All of these statutes provide that such personal information may be recorded in virtually any form.

The second category of statutes pertains more specifically to the protection of personal health information. These statutes specifically define “*personal health information*” in some detail. Such definitions include information about: the individual’s physical or mental health; any health services provided to the individual; any donation by the individual of a body part or bodily substance and any information derived from an examination of that body part or bodily substance; any sale or dispensing of a drug, device or equipment pursuant to a prescription; as well as any other information that is collected in the course of providing health services to the individual or incidentally to the provision of such services. Also included in most definitions of personal health information is registration information, such as, an individual’s personal health number, his or her health service eligibility information and any payment or billing information. These statutes likewise provide that personal health information may be recorded in virtually any form. Interestingly, Alberta’s *Health Information Act* (Bill 40) expressly protects the confidentiality of non-recorded personal health information (sections 29 and 44 *infra*).

Alberta’s *Health Information Act* (Bill 40) is, to date, the only statute that expressly incorporates, within its definition of personal health information, detailed information relating directly to health service providers, including their personal, business and professional data.

It is also worth noting a recent tendency by legislators to expressly define terms such as “*non-identifying health information*” and “*de-identified personal health information*”. As will become apparent in later sections, this tendency reflects a growing recognition that, given technological advances, personal health information can vary along a spectrum of identifiability and corresponding degree of risk, thereby warranting distinct legal treatment in each case.

The original version of Federal Bill C-6 defined “personal information” in very broad terms as information about an identifiable individual, other than the name, title or business address or telephone number of an employee of an organization. Although not expressly stated, this definition would encompass personal health information as well. In December 1999, representations were made before the Standing Senate Committee on Social Affairs, Science and Technology, opposing the Bill’s application to personal health information and raising serious concerns about the potential consequences of the Bill on the health care system. In its report, the Committee recommended amending Bill C-6 by including a specific definition of “personal health information” and suspending the Bill’s application to such personal health information for one year following the coming into force of the Bill. The Committee was of the view that this suspension would allow for the necessary time to address many of the concerns raised during consultations and resolve the uncertainties still outstanding. At the time of this publication, Bill C-6, as amended by the Senate, was back before the House of Commons.

DEFINITION OF PERSONAL INFORMATION AND RELATED PROVISIONS

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Newfoundland and Labrador |
|---|--|--|---|--|---|--|---|---|--|---|
| <p><i>Privacy Act, R.S.C. 1985, c. P-21</i></p> <p>INTERPRETATION</p> <p>S. 3 “personal information” means information about an identifiable individual that is recorded in any form including, without restricting the generality of the foregoing,</p> <p>(a) information relating to the race, national or ethnic origin, colour, religion, age or marital status of the individual,</p> <p>(b) information relating to the education or the medical, criminal or employment history of the individual or information relating to financial transactions in which the individual has been involved,</p> <p>(c) any identifying number, symbol or other particular assigned to the individual,</p> <p>(d) the address, fingerprints or blood type of the individual,</p> <p>(e) the personal opinions or views of the individual except where they are about another individual or about a proposal for a grant, an award or a prize to be made to another individual by a government institution or a part of a government institution specified in the regulations,</p> | <p><i>Freedom of Information and Protection of Privacy Act, R.S.B.C. 1996, c. 165, sch. 1</i></p> <p>SCHEDULE 1</p> <p>Definitions</p> <p>“personal information” means recorded information about an identifiable individual, including</p> <p>(a) the individual’s name, address or telephone number,</p> <p>(b) the individual’s race, national or ethnic origin, colour, or religious or political beliefs or associations,</p> <p>(c) the individual’s age, sex, sexual orientation, marital status or family status,</p> <p>(d) an identifying number, symbol or other particular assigned to the individual,</p> <p>(e) the individual’s fingerprints, blood type or inheritable characteristics,</p> <p>(f) information about the individual’s health care history, including a physical or mental disability,</p> <p>(g) information about the</p> | <p><i>Freedom of Information and Protection of Privacy Act, S.A. 1994, c. F-18.5</i></p> <p>Definitions</p> <p>S. 1(1)(n) “personal information” means recorded information about an identifiable individual, including</p> <p>(i) the individual’s name, home or business address or home or business telephone number,</p> <p>(ii) the individual’s race, national or ethnic origin, colour or religious or political beliefs or associations</p> <p>(iii) the individual’s age, sex, marital status or family status,</p> <p>(iv) an identifying number, symbol or other particular assigned to the individual,</p> <p>(v) the individual’s fingerprints, blood type or inheritable characteristics,</p> <p>(vi) information about the individual’s health and health care history, including information about a physical or mental disability,</p> <p>(vii) information about the individual’s educational, financial, employment or criminal history, including criminal</p> | <p><i>The Freedom of Information and Protection of Privacy Act, S.S. 1990-91, c. F-22.01</i></p> <p>PART IV Protection of Privacy</p> <p>S. 24(1) Subject to subsection (2), “personal information” means personal information about an identifiable individual that is recorded in any form, and includes:</p> <p>(a) information that relates to the race, creed, religion, colour, sex, family status or marital status,</p> <p>(b) information that relates to the education or the criminal or employment history of the individual or information relating to financial transactions in which the individual has been involved;</p> <p>(c) information that relates to health care that has been received by the individual or to the health history of the individual;</p> <p>(d) any identifying number, symbol or other particular assigned to the individual;</p> <p>(e) the home or</p> | <p><i>The Freedom of Information and Protection of Privacy Act, R.S.M. c. F-175</i></p> <p>PART I INTRODUCTORY PROVISIONS</p> <p>Definitions</p> <p>S. 1 “personal information” means recorded information about an identifiable individual, including</p> <p>(a) the individual’s name,</p> <p>(b) the individual’s home address, or home telephone, facsimile or e-mail number,</p> <p>(c) information about the individual’s age, sex, sexual orientation, marital or family status,</p> <p>(d) information about the individual’s ancestry, race, colour, nationality, or national or ethnic origin,</p> <p>(e) information about the individual’s religion or creed, or religious belief, association or activity,</p> <p>(f) personal health information about the individual,</p> <p>(g) the individual’s</p> | <p><i>Freedom of Information and Protection of Privacy Act, R.S.O. 1990, c. F-31</i></p> <p>Definitions</p> <p>S. 2(1) “personal information” means recorded information about an identifiable individual, including,</p> <p>(a) information relating to the race, national or ethnic origin, colour, religion, age, sex, sexual orientation or marital status of the individual,</p> <p>(b) information relating to the education or the medical, psychiatric, psychological, criminal or employment history of the individual or information relating to financial transactions in which the individual has been involved,</p> <p>(c) any identifying number, symbol or other particular assigned to the individual,</p> <p>(d) the address, telephone number, fingerprints or blood type of the individual,</p> <p>(e) the personal opinions or views of the individual except where they relate to another individual,</p> <p>(f) correspondence sent to an institution by the individual that is implicitly or explicitly of a private or confidential nature, and</p> | <p><i>Act respecting Access to documents held by public bodies and the Protection of personal information, R.S.Q. c. A-2.1</i></p> <p>CHAPTER 1 APPLICATION AND INTERPRETATION</p> <p>S. 1§2 This Act applies whether the documents are recorded in writing or print, on sound tape or film, in computerized form or otherwise.</p> <p>CHAPTER III PROTECTION OF PERSONAL INFORMATION</p> <p>Division 1 Confidentiality of Nominative Information</p> <p>S. 54 In any document, information concerning a natural person which allows the person to be identified is nominative information.</p> | <p><i>Protection of Personal Information Act, S.N.B. 1998, c. P-19.1</i> (Assented to 26 February 1998, not yet in force.)</p> <p>S. 1(1) In this Act, [...]</p> <p>“personal information” means information about an identifiable individual, recorded in any form;</p> <p>[...]</p> <p>(2) Information that relates to an identifiable individual but is collected, used or disclosed in a form in which the individual is not identifiable is not personal information when so collected, used or disclosed.</p> <p>(3) An individual is identifiable for the purposes of this Act if</p> <p>(a) information includes his or her name,</p> <p>(b) information makes his or her identity obvious, or</p> <p>(c) information does not itself include the name of the individual or make his or her identity obvious but is likely in the circumstances to be combined with other information that does.</p> | <p><i>Freedom of Information and Protection of Privacy Act, S.N.S. 1993, c. 5</i></p> <p>Interpretation</p> <p>S. 3 In this Act, [...]</p> <p>(i) “personal information” means recorded information about an identifiable individual, including</p> <p>(i) the individual’s name, address or telephone number,</p> <p>(ii) the individual’s race, national or ethnic origin, colour, or religious or political beliefs or associations,</p> <p>(iii) the individual’s age, sex, sexual orientation, marital status or family status,</p> <p>(iv) an identifying number, symbol or other particular assigned to the individual,</p> <p>(v) the individual’s fingerprints, blood type or inheritable characteristics,</p> <p>(vi) information about the individual’s health-care history, including a physical or mental disability,</p> <p>(vii) information</p> | <p><i>Bill 81, Freedom of Information and the Protection of Privacy Act, 1st Sess., 60th General Assembly, P.E.I. 1997</i> (Died on the Order Paper – Not in force)</p> <p>S. 1 In this Act, [...]</p> <p>(i) “personal information” means recorded information about an identifiable individual, including</p> <p>(i) the individual’s name, home or business address or home or business telephone number,</p> <p>(ii) the individual’s race, national or ethnic origin, colour or religious or political beliefs or associations,</p> <p>(iii) the individual’s age, sex, marital status or family status,</p> <p>(iv) an identifying number, symbol or other particular assigned to the individual,</p> <p>(v) the individual’s fingerprints, blood type or inheritable characteristics,</p> <p>(vi) information about the individual’s health and health care history, including information about a physical or mental disability;</p> <p>(vii) information</p> | <p><i>Freedom of Information Act, R.S.N., c. F-25</i></p> <p>S. 10(1) Notwithstanding section 4, a person shall not be permitted access to personal information respecting an identifiable individual including,</p> <p>(a) information relating to the race, national or ethnic origin, colour, religion, age or marital status of the individual;</p> <p>(b) information relating to the education or the medical, criminal or employment history of the individual or information relating to financial transactions in which the individual has been involved;</p> <p>(c) an identifying number, symbol or other particular assigned to the individual;</p> <p>(d) the address, fingerprints or blood type of the individual;</p> <p>(e) the personal opinions or views of the individual;</p> <p>(f) correspondence sent to a department by the individual that is implicitly or explicitly of a private or confidential nature, and replies to that correspondence that</p> |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Newfoundland and Labrador |
|---|--|---|---|--|--|---|---------------|---|---|---|
| <p>(f) correspondence sent to a government institution by the individual that is implicitly or explicitly of a private or confidential nature, and replies to such correspondence that would reveal the contents of the original correspondence,</p> <p>(g) the views or opinions of another individual about the individual,</p> <p>(h) the views or opinions of another individual about a proposal for a grant, an award or a prize to be made to the individual by an institution or a part of an institution referred to in paragraph (e), but excluding the name of the other individual where it appears with the views or opinions of the other individual, and</p> <p>(i) the name of the individual where it appears with other personal information relating to the individual or where the disclosure of the name itself would reveal information about the individual,</p> <p>but, for the purposes of sections 7, 8 (...), does not include [...]</p> <p>(m) information about an individual who has been dead for more than 20 years;</p> <p>[...]</p> <p>[Note: Sections 7 and 8 have been reproduced in "Use and Disclosure of Personal Information in the Public Sector", below] -----</p> | <p>individual's educational, financial, criminal or employment history,</p> <p>(h) anyone else's opinions about the individual, and</p> <p>(i) the individual's personal views or opinions, except if they are about someone else;</p> <p>"personal information bank" means a collection of personal information that is organized or retrievable by the name of an individual or by an identifying number, symbol or other particular assigned to an individual;</p> <p>"record" includes books, documents, maps, drawings, photographs, letters, vouchers, papers and any other thing on which information is recorded or stored by graphic, electronic, mechanical or other means, but does not include a computer program or any other mechanism that produces records;</p> <p>[...]</p> | <p>records where a pardon has been given,</p> <p>(viii) anyone else's opinions about the individual, and</p> <p>(ix) the individual's personal views or opinions, except if they are about someone else;</p> <p>(q) "record" means a record of information in any form and includes books, documents, maps, drawings, photographs, letters, vouchers and papers and any other information that is written, photographed, recorded or stored in any manner, but does not include software or any mechanism that produces records;</p> | <p>business address, home or business telephone number, fingerprints or blood type of the individual;</p> <p>(f) the personal opinions or views of the individual except where they are about another individual;</p> <p>(g) correspondence sent to a government institution by the individual that is implicitly or explicitly of a private or confidential nature, and replies to the correspondence that would reveal the content of the original correspondence, except where the correspondence contains the views or opinions of the individual with respect to another individual;</p> <p>(h) the views or opinions of another individual with respect to the individual;</p> <p>(i) information that was obtained on a tax return or gathered for the purpose of collecting a tax;</p> <p>(j) information that describes an individual's finances, assets, liabilities, net worth, bank balance, financial history or activities or credit worthiness; or</p> <p>(k) the name of the individual where:</p> <p>(i) it appears with other personal information that relates to the individual; or</p> <p>(ii) the disclosure of</p> | <p>blood type, fingerprints or other hereditary characteristics,</p> <p>(h) information about the individual's political belief, association or activity,</p> <p>(i) information about the individual's education, employment or occupation, or educational, employment or occupational history,</p> <p>(j) information about the individual's source of income or financial circumstances, activities or history,</p> <p>(k) information about the individual's criminal history, including regulatory offences,</p> <p>(1) the individual's own personal views or opinions, except if they are about another person,</p> <p>(m) the views or opinions expressed about the individual by another person, and</p> <p>(n) an identifying number, symbol or other particular assigned to the individual;</p> <p>"personal information bank" means a collection of personal information that is organized or retrievable by the name of an individual or by an</p> | <p>replies to that correspondence that would reveal the contents of the original correspondence,</p> <p>(g) the views or opinions of another individual about the individual, and</p> <p>(h) the individual's name where it appears with other personal information relating to the individual or where the disclosure of the name would reveal other personal information about the individual;</p> <p>"personal information bank" means a collection of personal information that is organized and capable of being retrieved using an individual's name or an identifying number or particular assigned to the individual;</p> <p>"record" means any record of information however recorded, whether in printed form, on film, by electronic means or otherwise, and includes,</p> <p>(a) correspondence, a memorandum, a book, a plan, a map, a drawing, a diagram, a pictorial or graphic work, a photograph, a film, a microfilm, a sound recording, a videotape, a machine readable record, any other documentary material, regardless of physical form or characteristics, and any copy thereof, and</p> <p>(b) subject to the</p> | <p><i>Act respecting the Protection of Personal Information in the Private Sector, R.S.Q., c. P-39.1</i></p> <p>DIVISION I APPLICATION AND INTERPRETATION</p> <p>S. 1§2 The Act applies to such information whatever the nature of its medium and whatever the form in which it is accessible, whether written, graphic, taped, filmed, computerized, or other.</p> <p>S. 2 Personal information is any information which relates to a natural person and allows that person to be identified.</p> | | <p>individual's educational, financial, criminal or employment history,</p> <p>(viii) anyone else's opinions about the individual, and</p> <p>(ix) the individual's personal views or opinions, except if they are about someone else;</p> <p>[...]</p> <p>(k) "record" includes books, documents, maps, drawings, photographs, letters, vouchers, papers and any other thing on which information is recorded or stored by graphic, electronic, mechanical or other means, but does not include a computer program or any other mechanism that produces records;</p> <p>[...]</p> | <p>about the individual's educational, financial, employment or criminal history, including criminal records where a pardon has been given;</p> <p>(viii) anyone else's opinions about the individual; and</p> <p>(ix) the individual's personal views or opinions, except if they are about someone else;</p> <p>[...]</p> <p>(1) "record" means a record of information in any form and includes books, documents, maps, drawings, photographs, letters, vouchers and papers and any other information that is written, photographed, recorded or stored in any manner, but does not include software or any mechanism that produces records;</p> <p>[...]</p> | <p>would reveal the content of the original correspondence; or</p> <p>(g) the views or opinions of another person in respect of the individual.</p> |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Newfoundland and Labrador |
|--|------------------|---------|---|--|---|--------|---------------|-------------|----------------------|---------------------------|
| <p>Bill C-6, <i>Personal Information Protection and Electronic Documents Act</i>, 2nd Sess., 36th Parl., 48 Elizabeth II, 1999 (Passed by the Senate with amendments, 10 December 1999 – not yet assented to.)</p> <p>PART 1 - PROTECTION OF PERSONAL INFORMATION IN THE PRIVATE SECTOR</p> <p>Interpretation</p> <p>S. 2(1) “personal information” means information about an identifiable individual, but does not include the name, title or business address or telephone number of an employee of an organization.</p> <p>“record” includes any correspondence, memorandum, book, plan, map, drawing, diagram, pictorial or graphic work, photograph, film, microform, sound recording, videotape, machine-readable record and any other documentary material, regardless of physical form or characteristics, and any copy of any of those things.</p> <p>[Note: The definition of “personal health information”, as proposed by the Senate, is reproduced in the following table entitled “Definition of Personal Health Information”.]</p> | | | <p>the name itself would reveal personal information about the individual.</p> <p>PART 1 Short Title, Interpretation and Application</p> <p>S. 2(1) In this Act, [...] (i) “record” means a record of information in any form and includes information that is written, photographed, recorded or stored in any manner, but does not include computer programs or other mechanisms that produce records; [...]</p> | <p>identifying number, symbol or other particular assigned to an individual;</p> <p>“record” means a record of 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;</p> <p>[Note: The definition of “personal health information” included in the <i>Freedom of Information and Protection of Privacy Act</i> of Manitoba is reproduced in the following table entitled “Definition of Personal Health Information”.]</p> | <p>regulations, any record that is capable of being produced from a machine readable record under the control of an institution by means of computer hardware and software or any other information storage equipment and technical expertise normally used by the institution;</p> | | | | | |

DEFINITION OF PERSONAL HEALTH INFORMATION AND RELATED PROVISIONS

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|--|------------------|---|---|---|---|--------|---------------|-------------|--------|--------------------|
| <p>Bill C-6, <i>Personal Information Protection and Electronic Documents Act</i>, 2nd Sess., 36th Parl., 48 Elizabeth II, 1999 (Passed by the Senate with amendments, 10 December 1999 – not yet assented to.)</p> <p>PART 1 - PROTECTION OF PERSONAL INFORMATION IN THE PRIVATE SECTOR</p> <p>Interpretation</p> <p>S. 2(1) “Personal health information”, with respect to an individual, whether living or deceased means:</p> <p>(a) information concerning the physical or mental health of the individual;</p> <p>(b) information concerning any health service provided to the individual;</p> <p>(c) information concerning the donation by the individual of any body part or any bodily substance of the individual or information derived from the testing or examination of a body part or bodily substance of the individual;</p> <p>(d) information that is collected in the course of providing health services to the individual; or</p> <p>(e) information that is collected incidentally to the provision of health services to the individual.</p> <p>S. 30(1.1) This Part does not</p> | | <p>Bill 40, <i>Health Information Act</i>, 3rd Sess., 24th Leg., Alberta, 1999 (Royal assent, 9 December, 1999 - not yet proclaimed in force.)</p> <p>PART I INTRODUCTORY MATTERS</p> <p>Interpretation</p> <p>S. 1(1)(k) “health information” means any or all of the following:</p> <p>(i) diagnostic, treatment and care information;</p> <p>(ii) health services provider information;</p> <p>(iii) registration information;</p> <p>(i) “diagnostic, treatment and care information” means information about any of the following:</p> <p>(i) the physical and mental health of an individual;</p> <p>(ii) a health service provided to an individual;</p> <p>(iii) the donation by an individual of a body part or bodily substance, including information derived from the testing or examination of a body part or bodily substance;</p> <p>(iv) a drug as defined in the <i>Pharmaceutical Profession Act</i> provided to an individual;</p> <p>(v) a health care aid, device, product, equipment or other item provided to an individual pursuant to a prescription or other authorization;</p> <p>(vi) the amount of any benefit paid or payable under the <i>Alberta Health Care Insurance Act</i> or any other amount payable in respect of a health service provided to an individual, and includes any other information about an individual that is collected when a health service is provided to the individual but does not include information that is not written, photographed, recorded or stored in some manner in a record;</p> | <p><i>The Health Information Protection Act</i>, S.S. 1999, c. H-0.021 (Royal Assent, 6 May 1999 - not yet proclaimed in force.)</p> <p>PART I PRELIMINARY MATTERS</p> <p>Interpretation</p> <p>S. 2(m) “personal health information” means, with respect to an individual, whether living or deceased:</p> <p>(i) information with respect to the physical or mental health of the individual;</p> <p>(ii) information with respect to any health service provided to the individual;</p> <p>(iii) information with respect to the donation by the individual of any body part or any bodily substance of the individual or information derived from the testing or examination of a body part or bodily substance of the individual;</p> <p>(iv) information that is collected:</p> <p>(A) in the course of providing health services to the individual; or</p> <p>(B) incidentally to the provision of health services to the individual; or</p> <p>(v) registration information;</p> <p>(q) “registration information” means information about an individual that is collected for the purpose of registering the individual for the provision of health services, and includes the individual’s health services number and any other number assigned to the individual as part of a system of unique identifying numbers that is prescribed in the regulations;</p> | <p><i>The Personal Health Information Act</i>, S.M. 1997, c. P-33.5</p> <p>PART I INTRODUCTORY PROVISIONS</p> <p>Definitions</p> <p>S. 1(1) “personal health information” means recorded information about an identifiable individual that relates to</p> <p>(a) the individual’s health, or health care history, including genetic information about the individual,</p> <p>(b) the provision of health care to the individual, or</p> <p>(c) payment for health care provided to the individual, and includes</p> <p>(d) the PHIN and any other identifying number, symbol or particular assigned to an individual, and</p> <p>(e) any identifying information about the individual that is collected in the course of, and is incidental to, the provision of health care or payment for health care;</p> <p>“health care” means any care, service or procedure</p> <p>(a) provided to diagnose, treat or maintain an individual’s physical or mental condition,</p> <p>(b) provided to prevent disease or injury or promote health, or</p> <p>(c) that affects the structure or a function of the body, and includes the sale or dispensing of a drug, device, equipment or other item pursuant to a prescription;</p> | <p><i>Draft Personal Health Information Protection Act</i>, 1997 (Not in force.)</p> <p>GENERAL</p> <p>Definitions</p> <p>S. 2(1) “personal health information” means information, whether or not recorded, and regardless of the form in which or the medium on which it is recorded, that relates to the past, present or future physical or mental health of an individual or the past, present or future provision of health care to an individual, if the information,</p> <p>(a) identifies the subject of the information,</p> <p>(b) can be used or manipulated by a foreseeable method to identify the subject of the information, or</p> <p>(c) can be linked or matched by a foreseeable method to other information that,</p> <p>(i) identifies the subject of the information, or</p> <p>(ii) can be used or manipulated by a foreseeable method to identify the subject of the information;</p> <p>“health care” means anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose and includes,</p> <p>(a) personal assistance services and community services that are related to health care,</p> <p>(b) examinations and assessments of an individual to determine his or her physical or mental health in order to determine the health care that the individual needs, and</p> <p>(c) the compounding, dispensing or selling of a drug, a device, equipment or any other item to an individual, or for the use of an individual, pursuant to a prescription;</p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|--|------------------|--|--|--|---|--------|---------------|-------------|--------|--------------------|
| <p>apply to any organization in respect of personal health information that it collects, uses or discloses.</p> <p>S. 30(2.1) Subsection (1.1) ceases to have effect one year after the day on which this section comes into force.</p> | | <p>(o) “health services provider information” means the following information relating to a health services provider:</p> <ul style="list-style-type: none"> (i) name; (ii) business and home mailing addresses and electronic addresses; (iii) business and home telephone numbers and facsimile numbers; (iv) gender; (v) date of birth (vi) unique identification number that <ul style="list-style-type: none"> (A) is assigned to the health services provider by a custodian for the purpose of the operations of the custodian, and (B) uniquely identifies the health services provider in relation to that custodian; (vii) type of health services provider and licence number, if a licence has been issued to the health services provider; (viii) date on which the health services provider became authorized to provide health services and the date, if any, on which the health services provider ceased to be authorized to provide health services; (ix) education completed, including entry level competencies attained in a basic education program and post-secondary educational degrees, diplomas or certificates completed; (x) continued competencies, skills and accreditations, including any specialty or advanced training acquired after completion of the education referred to in subclause (ix), and the dates they were acquired; (xi) restrictions that apply to the health services provider’s right to provide health services in Alberta; (xii) decisions of a health professional body, or any other body at an appeal of a decision of a health professional body, pursuant to which the health services provider’s right to provide health services in Alberta is suspended or cancelled or made subject to conditions, or a reprimand or fine is issued; (xiii) business arrangements relating to the payment of the health services provider’s accounts; | <p>(i) “health services number” means a unique number assigned to an individual who is or was registered as a beneficiary to receive insured services within the meaning of <i>The Saskatchewan Medical Care Insurance Act</i>;</p> <p>(p) “record” means a record of information in any form and includes information that is written, photographed, recorded, digitized or stored in any manner, but does not include computer programs or other mechanisms that produce records;</p> <p>(l) “networked electronic health record” means an electronic health record containing personal health information collected by one or more trustees for the purpose of creating a comprehensive profile of an individual’s personal health history to be made available, in whole or in part, over an electronic network to one or more trustees, but does not include electronic mail or other office or systems support services that may be provided over an electronic network;</p> <p>(d) “de-identified personal health information” means personal health information from which any information that may reasonably be expected to identify an individual has been removed;</p> | <p>“PHIN” means the personal health identification number assigned to an individual by the minister to uniquely identify the individual for health care purposes;</p> <p>“record” or “recorded information” means a record of 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 of any mechanism that produces records;</p> <p>-----</p> <p><i>The Freedom of Information and Protection of Privacy Act, S.M. 1997, c. F-175</i></p> <p>PART I INTRODUCTORY PROVISIONS</p> <p>Definitions</p> <p>S. 1 “personal health information” means recorded information about an identifiable individual that relates to</p> <ul style="list-style-type: none"> (a) the individual’s health, or health care history, including genetic information about the individual, (b) the provision of health care to the individual, or (c) payment for health care provided to the individual, <p>and includes</p> <ul style="list-style-type: none"> (d) the PHIN as defined in <i>The Personal Health Information Act</i> and any other identifying number, symbol or particular assigned to an individual, and (e) any identifying information about the individual that is collected in the course of, and is | <p>“health number” means a number assigned to an insured person within the meaning of the <i>Health Insurance Act</i> by the General Manager of the Ontario Health Insurance Plan;</p> <p>“personal health record” means recorded personal health information with respect to the subject of the information, regardless of the form in which or the medium on which it is recorded, and includes a copy of the information;</p> <p>(3) The information described in the definition of “personal health information” in subsection (1) includes,</p> <ul style="list-style-type: none"> (a) information relating to payments or eligibility for health care in respect of the subject of the personal health information; (b) the health number of the subject, and (c) demographic information or information about the provider of health care to the subject, if <ul style="list-style-type: none"> (i) it is linked to other information about the subject’s health or health care, or (ii) its use can be associated with other personal health information about the subject. | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|---|--------------|---|---------|--------|---------------|-------------|--------|--------------------|
| | | <p>(xiv) profession; (xv) job classification; (xvi) employment status; (xvii) number of years the health services provider has practised the profession; (xviii) employer; (xix) municipality in which the health services provider's practice is located, but does not include information that is not written, photographed, recorded or stored in some manner in a record;</p> <p>(u) "registration information" means information relating to an individual that falls within the following general categories and is more specifically described in the regulations: (i) demographic information, including the individual's personal health number; (ii) location information; (iii) telecommunications information; (iv) residency information; (v) health service eligibility information; (vi) billing information, but does not include information that is not written, photographed, recorded or stored in some manner in a record;</p> <p>(t) "record" means a record of health information in any form and includes notes, images, audiovisual recordings, x-rays, books, documents, maps, drawings, photographs, letters, vouchers and papers and any other information that is written, photographed, recorded or stored in any manner, but does not include software or any mechanism that produces records;</p> <p>(p) "individually identifying", when used to describe health information, means that the identity of the individual who is the subject of the information can be readily ascertained from the information;</p> <p>(r) "non-identifying", when used to describe health information, means that the identity of the individual who is the subject of the information cannot be readily ascertained from the information;</p> | | <p>incidental to, the provision of health care or payment for health care;</p> <p>[Note: For other related definitions in the <i>Freedom of Information and Protection of Privacy Act of Manitoba</i>, see table above on "Definition of Personal Information".]</p> | | | | | | |

In general, collection of personal (health) information must relate directly to an operating program or activity of a public institution, or to an identified and/or authorized purpose of the person or organization collecting the information. In some cases, the purpose or object of the file must be documented. The collection must be by fair and lawful means and must be limited to that which is reasonably necessary to accomplish the purpose for which the personal information is being collected. Interestingly, Bill C-6 further subjects the collection to an overriding “reasonable person” standard, requiring that collection be limited to only those purposes that a reasonable person would consider appropriate in the circumstances.

The collection must be made, wherever possible, directly from the individual to whom it relates. The individual must be informed of the legal authority for collecting personal information, the purpose for which it is being collected and, in some cases, its anticipated use and/or disclosure.

Exceptionally, personal (health) information may be collected from someone other than the individual the information is about, with or without the latter’s knowledge or consent. Such exceptions include situations where:

- collection from the individual directly is likely to result in inaccurate information, to defeat the purpose for which the information is being collected or to prejudice the health or safety of the individual or that of others;
- collection from the individual directly is not reasonably practicable;
- the personal (health) information is otherwise publicly available;
- collection is clearly in the interests of the individual, yet time and circumstances do not allow for the individual to be contacted directly;
- personal (health) information is elsewhere in the same Act permitted to be disclosed for a certain purpose, and the Act expressly includes a correlative permission to collect such information for the same purpose (eg. for research);

(note: Bill C-6 permits the use and disclosure of personal information “*for statistical, or scholarly study or research, purposes*” (sections 7(2)(c) and 7(3)(f), respectively), but, unlike most other statutes, does not expressly permit the collection of personal information for those same purposes);

- collection is authorized by law or regulations.

In both the Alberta and Saskatchewan Health Information Acts, personal health information may be collected from a person other than the subject of the information where the purpose is to assemble a family (or genetic) history. Whereas Alberta’s statute limits this latter exception to the health care context, Saskatchewan’s statute does not so specify.

It is interesting to note that in some of the statutes pertaining specifically to the protection of personal health information, separate rules exist for the collection of personal health numbers (eg. Alberta, Saskatchewan, Manitoba).

Also noteworthy is an increasing tendency to subject the collection of personal health information to a “need-to-know” test. A case in point is Alberta’s *Health Information Act* (Bill 40) that actually sets up a hierarchy of permissible collection. A custodian must first consider whether the collection of aggregate health information would be adequate for the intended purpose and, if so, must limit collection to that. If aggregate health information is not considered adequate for the intended purpose, the custodian must then consider whether other non-identifying health information would be adequate and, if so, must limit collection accordingly. Only if other non-identifying health information is still not adequate for the intended purpose, can the custodian then collect identifying personal health information in accordance with the Act.

COLLECTION OF PERSONAL INFORMATION IN THE PUBLIC SECTOR

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---|--|---|---|--|---|---|--|--|--|--------------------|
| <p><i>Privacy Act, R.S.C. 1985, c. P-21</i></p> <p>COLLECTION, RETENTION AND DISPOSAL OF PERSONAL INFORMATION</p> <p>S.4 No personal information shall be collected by a government institution unless it relates directly to an operating program or activity of the institution.</p> <p>S. 5(1) A government institution shall, wherever possible, collect personal information that is intended to be used for an administrative purpose directly from the individual to whom it relates except where the individual authorizes otherwise or where personal information may be disclosed to the institution under subsection 8(2). [Note: The relevant portions of subsection 8(2) have been reproduced in “Use and Disclosure of Personal Information in the Public Sector”, see below.]</p> <p>(2) A government</p> | <p><i>Freedom of Information and Protection of Privacy Act, R.S.B.C. 1996, c. 165</i></p> <p>PART 3 – PROTECTION OF PRIVACY</p> <p>Division 1 – Collection, Protection and Retention of Personal Information by Public Bodies</p> <p>S. 26 No personal information may be collected by or for a public body unless</p> <p>(a) the collection of that information is expressly authorized by or under an Act, [...] or</p> <p>(c) that information relates directly to and is necessary for an operating program or activity of the public body.</p> <p>S. 27(1) A public body must collect personal information directly from the individual the information is about unless</p> <p>(a) another method of collection is authorized by</p> <p>(i) that individual,</p> <p>(ii) the commissioner under section 42(1)(i), or</p> <p>(iii) another enactment,</p> <p>(b) the information may</p> | <p><i>Freedom of Information and Protection of Privacy Act, S.A. 1994, c. F-18.5</i></p> <p>PART 2 PROTECTION OF PRIVACY</p> <p>Division 1 – Collection of Personal Information</p> <p>S. 32 No personal information may be collected by or for a public body unless</p> <p>(a) the collection of that information is expressly authorized by or under an enactment of Alberta or Canada, [...] or</p> <p>(c) that information relates directly to and is necessary for an operating program or activity of the public body.</p> <p>S. 33(1) A public body must collect personal information directly from the individual the information is about unless</p> <p>(a) another method of collection is authorized by</p> <p>(i) that individual,</p> <p>(ii) another Act or a regulation under another Act, or</p> <p>(iii) the Commissioner under section 51(1)(h) of this Act,</p> <p>(b) the information may</p> | <p><i>Freedom of Information and Protection of Privacy Act, S.S. 1990-91, c. F-22.01</i></p> <p>PART IV PROTECTION OF PRIVACY</p> <p>S. 25 No government institution shall collect personal information unless the information is collected for a purpose that relates to an existing or proposed program or activity of the government institution.</p> <p>S. 26(1) A government institution shall, where reasonably practicable, collect personal information directly from the individual to whom it relates, except where:</p> <p>(a) the individual authorizes collection by other methods;</p> <p>(b) the information is information that may be disclosed to the government institution pursuant to subsection 29(2); [Note: The relevant provisions of subsection 29(2) have been reproduced in “Use and Disclosure of Personal Information in the Public Sector”, see below.]</p> <p>(g) the commissioner has, pursuant to clause 33(c), authorized</p> | <p><i>The Freedom of Information and Protection of Privacy Act, R.S.M. c. F-175</i></p> <p>PART 3 PROTECTION OF PRIVACY</p> <p>DIVISION 2 – COLLECTION, CORRECTION AND RETENTION OF PERSONAL INFORMATION</p> <p>S. 36(1) No personal information may be collected by or for a public body unless</p> <p>(a) collection of the information is authorized by or under an enactment of Manitoba or of Canada;</p> <p>(b) the information relates directly to and is necessary for an existing program or activity of the public body; or</p> <p>[...]</p> <p>(2) A public body shall collect only as much personal information about an individual as is reasonably necessary to accomplish the purpose for which it is collected.</p> <p>S. 37(1) Personal information must be collected by or for a</p> | <p><i>Freedom of Information and Protection of Privacy Act, R.S.O. 1990, c. F.31</i></p> <p>PART III PROTECTION OF INDIVIDUAL PRIVACY</p> <p>Collection and Retention of Personal Information</p> <p>S. 38(2) No person shall collect personal information on behalf of an institution unless the collection is expressly authorized by statute, used for the purposes of law enforcement or necessary to the proper administration of lawfully authorized activity.</p> <p>S. 39(1) Personal information shall only be collected by an institution directly from the individual to whom the information relates unless,</p> <p>(a) the individual authorizes another manner of collection;</p> <p>(b) the personal information may be disclosed to the institution concerned under section 42 (...); [Note : Section 42 has been reproduced in “Use and Disclosure of Personal</p> | <p><i>An Act respecting access to documents held by Public Bodies and the Protection of Personal Information, R.S.Q. c. A-2.1</i></p> <p>CHAPTER III PROTECTION OF PERSONAL INFORMATION</p> <p>Division II Collection, Keeping and Use of Nominative Information</p> <p>S. 64 No person may, on behalf of a public body, collect nominative information if it is not necessary for the carrying out of the attributions of the body or the implementation of a program under its management.</p> <p>S. 65 Every person who, on behalf of a public body, collects nominative information from the person concerned or from a third person must first identify himself and inform him</p> <p>(1) of the name and address of the public body on whose behalf the information is being collected;</p> <p>(2) of the use to which the information will be put;</p> <p>(3) of the categories of persons who will have access to the information;</p> <p>(4) of the fact that a reply is</p> | <p><i>Protection of Personal Information Act, S.N.B. 1998, c. P-19.1</i> (Assented to 26 February 1998, not in force.)</p> <p>S. 2(1) Every public body is subject to the Statutory Code of Practice.</p> <p>(2) The Statutory Code of Practice shall be interpreted and applied in accordance with Schedule B and with any regulations made under paragraph 7(b).</p> <p>Schedule A: The Statutory Code of Practice</p> <p>Principle 2: Identifying Purposes The purposes for which personal information is collected shall be identified by the public body at or before the time the information is collected.</p> <p>Principle 3: Consent The consent of the individual is required for the collection, use, or disclosure of personal information, except where inappropriate.</p> <p>Principle 4: Limiting Collection The collection of personal information shall be limited to that which is necessary for the</p> | <p><i>Freedom of Information and Protection of Privacy Act, S.N.S. 1993, c.5</i></p> <p>PROTECTION OF PRIVACY</p> <p>COLLECTION, PROTECTION AND RETENTION OF PERSONAL INFORMATION</p> <p>S. 24(1) Personal information shall not be collected by or for a public body unless</p> <p>(a) the collection of that information is expressly authorized by or pursuant to an enactment; [...]</p> <p>or</p> <p>(c) that information relates directly to and is necessary for an operating program or activity of the public body.</p> | <p>Bill No. 81, Freedom of Information and Protection of Privacy Act, 1st Sess., 60th General Assembly, P.E.I. 1997 (Died on the Order Paper – not in force)</p> <p>PART II PROTECTION OF PRIVACY</p> <p>Division 1</p> <p>Collection of Personal Information</p> <p>S. 31 No personal information may be collected by or for a public body unless</p> <p>(a) the collection of that information is expressly authorized by or under an Act of Prince Edward Island or Canada; [...]</p> <p>or</p> <p>(c) that information relates directly to and is necessary for an operating program or activity of the public body.</p> <p>S. 32(1) A public body shall collect personal information directly from the individual the information is about unless</p> | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|--|--|--|--|---|--|--|--|-------------|---|--------------------|
| <p>institution shall inform any individual from whom the institution collects personal information about the individual of the purpose for which the information is being collected.</p> <p>(3) Subsections (1) and (2) do not apply where compliance therewith might (a) result in the collection of inaccurate information; or (b) defeat the purpose or prejudice the use for which information is collected.</p> | <p>be disclosed to the public body under sections 33 to 36 [Note: Sections 33 to 36 have been reproduced in “Use and Disclosure of Personal Information in the Public Sector”, see below.] [...]</p> <p>(2) A public body must tell an individual from whom it collects personal information (a) the purpose for collecting it, (b) the legal authority for collecting it, and (c) the title, business address and business telephone number of an officer or employee of the public body who can answer the individual’s questions about the collection.</p> <p>(3) Subsection (2) does not apply if [...]</p> <p>(b) the minister responsible for this Act excuses a public body from complying with it because doing so would (i) result in the collection of inaccurate information, or (ii) defeat the purpose or prejudice the use for which the information is collected.</p> | <p>be disclosed to the public body under Division 2 of this Part; [Note: Relevant provisions permitting disclosure under Division 2 of the Act have been included in “Use and Disclosure of Personal Information in the Public Sector”, below.] [...]</p> <p>(2) A public body that collects personal information that is required by subsection 1) to be collected directly from the individual the information is about must inform the individual of (a) the purpose for which the information is collected, (b) the specific legal authority for the collection, and (c) the title, business address and business telephone number of an officer or employee of the public body who can answer the individual’s questions about the collection.</p> <p>(3) Subsections (1) and (2) do not apply if, in the opinion of the head of public body concerned, it could reasonably be expected that the information collected would be inaccurate.</p> | <p>collection of the information in a manner other than directly from the individual to whom it relates; or (h) another manner of collection is authorized pursuant to another Act or a regulation.</p> <p>(2) A government institution that collects personal information that is required by subsection (1) to be collected directly from an individual shall inform the individual of the purpose for which the information is collected unless the information is exempted by the regulations from the application of this subsection.</p> <p>(3) Subsections (1) and (2) do not apply where compliance with them might result in the collection of inaccurate information or defeat the purpose or prejudice the use for which the information is collected.</p> <p>PART VIII GENERAL</p> <p>S. 69 The Lieutenant Governor in Council may make regulations: [...]</p> <p>(l) exempting any information or category of information from the application of subsection 26(2); [...]</p> | <p>public body directly from the individual the information is about unless (a) another method of collection is authorized by that individual, or by an enactment of Manitoba or Canada; (b) collection of the information directly from the individual could reasonably be expected to cause harm to the individual or to another person; [...]</p> <p>(d) collection of the information directly from the individual could reasonably be expected to result in inaccurate information being collected; (e) the information may be disclosed to the public body under Division 3 of this Part; [Note: Relevant provisions permitting disclosure under Division 3 have been reproduced in “Use and Disclosure of Personal Information in the Public Sector”, see below.] [...]</p> <p>(2) A public body that collects personal information directly from the individual the information is about shall inform the individual of (a) the purpose for which the information is collected; (b) the legal authority for the collection; and (c) the title, business</p> | <p>Information in the Public Sector”, see below.]</p> <p>(c) the Commissioner has authorized the manner of collection under clause 59(c); [...]</p> <p>(h) another manner of collection is authorized by or under a statute.</p> <p>(2) Where personal information is collected on behalf of an institution, the head shall, unless notice is waived by the responsible minister, inform the individual to whom the information relates, of (a) the legal authority for the collection; (b) the principal purpose or purposes for which the personal information is intended to be used; and (c) the title, business address and business telephone number of a public official who can answer the individual’s questions about the collection.</p> | <p>obligatory, or that it is optional;</p> <p>(5) of the consequences for the person concerned or, as the case may be, for the third person, in case of a refusal to reply;</p> <p>(6) of the rights of access and correction provided by law.</p> <p>S. 66 Before obtaining from any person or private body nominative information that has already been assembled concerning one or several persons, public bodies must inform the Commission thereof.</p> <p>Division III Establishment and Maintenance of Files</p> <p>S. 71 Every public body shall file, in a personal information file established in accordance with this subdivision, all nominative information 1) that is identified or presented in such a manner as to be retrievable by reference to the name of a person or to a sign or symbol identifiable with that person; or 2) that has been or is intended to be used by it in making a decision concerning a person.</p> <p>S. 76 The establishment of a file must be the subject of a declaration to the Commission. The declaration must contain the following indications:</p> | <p>purposes identified by the public body. Information shall be collected by fair and lawful means.</p> <p>Schedule B: Interpretation and Application of the Statutory Code of Practice</p> <p>S. 2.1 The purposes identified by the public body must directly relate to an existing or proposed activity of the public body.</p> <p>S. 2.2 The public body must document, in relation to any personal records system, the purpose or purposes for which the personal information in the system is held.</p> <p>S.2.3 A “personal records system” is a computerized or manual records system which contains information about individuals and which is structured in such a way that information about specified individuals can be easily recovered.</p> <p>S. 3.4 Consent is not required when a public body collects, uses or discloses personal information [...]</p> <p>(e) for purposes of legitimate research in the interest of science, of learning or of public policy, or for archival purposes, [...]</p> | | <p>(a) another method of collection is authorized by (i) that individual (ii) another Act or a regulation under another Act, or (iii) the Commissioner under clause 50(1)(h) of this Act; (b) the information may be disclosed by the public body under Division 2 of this Part; [Note: Relevant provisions permitting disclosure under Division 2 have been reproduced in “Use and Disclosure of Personal Information in the Public Sector”, see below.] [...]</p> <p>(2) A public body that collects personal information that is required by subsection (1) to be collected directly from the individual the information is about shall inform the individual of (a) the purpose for which the information is collected; (b) the specific legal authority for the collection; and (c) the title, business address and business telephone number of an officer or employee of the public body who can answer the individual’s</p> | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|---------|--------------|--|---------|---|--|-------------|---|--------------------|
| | | | | <p>address and telephone number of an officer or employee of the public body who can answer the individual's questions about the collection.</p> | | <p>1) the title of the file, the kind of information it contains, the use to which the information is to be put and the method by which the file is maintained; 2) the source of the information entered in the file; 3) the categories of persons concerned in the information entered in the file; 4) the categories of persons who have access to the file in carrying on their duties; 5) the security measures taken within the public body to ensure the confidentiality of the nominative information and its use according to the purposes for which it was collected; 6) the title, address and telephone number of the person in charge of protection of personal information; 7) the modalities of access to the file of the person concerned; 8) any other indication prescribed by government regulation. The declaration must be made in accordance with the rules established by the Commission.</p> <p>S. 77 Every public body must notify the Commission of every change that renders the declaration provided for in section 76 inaccurate or incomplete.</p> <p>S. 78 Sections 64 to 77 do not apply to the processing of nominative information collected and used as a working tool by a natural person, to the extent that the information is not disclosed</p> | <p>S. 3.6 Before collecting, using or disclosing personal information without consent under paragraph 3.4 or 3.5, a public body shall consider the nature of the information in question and the purpose for which it is acting, and shall satisfy itself that in the circumstances that purpose justifies the action proposed.</p> <p>S. 3.7 Any collection, use or disclosure of personal information without consent shall be limited to the reasonable requirements of the situation.</p> <p>S. 4.1 A public body may collect personal information (a) from the individual, (b) from another person with the individual's consent, (c) from a source and by means available to the public at large, (d) from any source if the public body is acting under paragraphs 3.4 to 3.7.</p> <p>S. 4.2 An individual shall not be refused a service or benefit because he or she declines to provide personal information which is not necessary for a legitimate purpose of the public body.</p> | | <p>questions about the collection.</p> <p>(3) Subsections (1) and (2) do not apply if, in the opinion of the head of the public body concerned, compliance with them might result in the collection of inaccurate information.</p> | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|---------|--------------|----------|---------|--|---------------|-------------|--------|--------------------|
| | | | | | | <p>to any person other than the person concerned or to a body other than that to which he belongs, and that it is used judiciously.</p> <p>The same rule applies to the processing of nominative information collected by a natural person and which is used by him for scientific research purposes.</p> <p>The public body is subject to the said sections from the time the person contemplated in the first or second paragraph discloses to the public body nominative information that he has collected or which was obtained through processing.</p> <p>CHAPTER VI REGULATIONS</p> <p>S. 155 The Government may make regulations [...]</p> <p>(4) prescribing the rules according to which the collection of nominative information must be made; [...]</p> | | | | |

COLLECTION OF PERSONAL INFORMATION IN THE PRIVATE SECTOR

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Newfoundland and Labrador |
|---|------------------|---------|--------------|----------|---------|---|---------------|-------------|----------------------|---------------------------|
| <p>Bill C-6, <i>Personal Information Protection and Electronic Documents Act</i>, 2nd Sess., 36th Parl., 48 Elizabeth II, 1999 (Passed by the Senate with amendments, 10 December 1999 – not yet assented to.)</p> <p>PART I PROTECTION OF PERSONAL INFORMATION IN THE PRIVATE SECTOR</p> <p>Division 1 – Protection of Personal Information</p> <p>S. 5(3) An organization may collect, use or disclose personal information only for purposes that a reasonable person would consider are appropriate in the circumstances.</p> <p>S. 7(1) For the purpose of clause 4.3 of Schedule 1, and despite the note that accompanies that clause, an organization may collect personal information without the knowledge or consent of the individual only if</p> <p>(a) the collection is clearly in the interests of the individual and consent cannot be obtained in a timely way;</p> <p>(b) it is reasonable to expect that the collection with the knowledge or consent of the individual would compromise the availability or the accuracy of the information and the collection is reasonable for purposes related to investigating a breach of an agreement or a contravention of the laws of Canada or a province; or</p> <p>(c) the collection is solely for journalistic, artistic or literary purposes; or</p> <p>(d) the information is publicly available and is specified by the regulations.</p> <p>SCHEDULE 1</p> <p>Principles set out in the National Standard of Canada entitled <i>Model Code for the Protection of Personal Information</i>, CAN/CSA – Q830-96</p> <p>4.2 Principle 2 – Identifying Purposes</p> <p>The purposes for which personal information is collected shall be identified by the organization at or before the time the information is collected.</p> <p>4.2.1 The organization shall document the purposes for which personal information is collected in order to comply with the Openness principle (Clause 4.8) and the</p> | | | | | | <p><i>Act respecting the Protection of Personal Information in the Private Sector</i>, R.S.Q. c. P-39.1</p> <p>DIVISION II COLLECTION OF PERSONAL INFORMATION</p> <p>S. 4 Any person carrying on an enterprise who may, for a serious and legitimate reason, establish a file on another person must, when establishing the file, enter its object. The entry is considered to be part of the file.</p> <p>S. 5 Any person collecting personal information to establish a file on another person or to record personal information in such a file may collect only the information necessary for the object of the file. Such information must be collected by lawful means.</p> <p>S. 6 Any person collecting personal information relating to another person may collect such information only from the person concerned, unless the latter consents to collection from third persons. However, he may, without the consent of the person concerned, collect such information from a third person if the law so authorizes. He may also do so if he has a serious and legitimate reason and either of the following conditions is fulfilled:</p> <p>(1) the information is collected in the interest of the person concerned and cannot be collected from him in due time;</p> <p>(2) collection from a third person is necessary to ensure the accuracy of the information.</p> <p>S. 8 A person who collects personal information from the person concerned must, when establishing a file on that person, inform him</p> <p>(1) of the object of the file;</p> <p>(2) of the use which will be made of the information and the categories of persons who will have access to it within the enterprise;</p> <p>(3) of the place where the file will be kept and of the rights of access and rectification.</p> | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Newfoundland and Labrador |
|---|------------------|---------|--------------|----------|---------|--------|---------------|-------------|----------------------|---------------------------|
| <p>Individual Access principle (Clause 4.9).</p> <p>4.2.2 Identifying the purposes for which personal information is collected at or before the time of collection allows organizations to determine the information they need to collect to fulfil these purposes. The Limiting Collection principle (Clause 4.4) requires an organization to collect only that information necessary for the purposes that have been identified.</p> <p>4.2.3 The identified purposes should be specified at or before the time of collection to the individual from whom the personal information is collected. Depending upon the way in which the information is collected, this can be done orally or in writing. An application form, for example, may give notice of the purposes.</p> <p>4.2.4 When personal information that has been collected is to be used for a purpose not previously identified, the new purpose shall be identified prior to use. Unless the new purpose is required by law, the consent of the individual is required before information can be used for that purpose. For an elaboration on consent, please refer to the Consent principle (Clause 4.3).</p> <p>4.2.5 Persons collecting personal information should be able to explain to individuals the purposes for which the information is being collected.</p> <p>4.3 Principle 3 - Consent The knowledge and consent of the individual are required for the collection, use, or disclosure of personal information, except where inappropriate. Note: In certain circumstances personal information can be collected, used, or disclosed without the knowledge and consent of the individual. For example, legal, medical, or security reasons may make it impossible or impractical to seek consent. When information is being collected for the detection and prevention of fraud or for law enforcement, seeking the consent of the individual might defeat the purpose of collecting the information. Seeking consent may be impossible or inappropriate when the individual is a minor, seriously ill, or mentally incapacitated. In addition, organizations that do not have a direct relationship with the individual may not always be able to seek consent. For example, seeking consent may be impractical for a charity or a direct-marketing firm that wishes to acquire a mailing list from another organization. In such cases, the organization providing the list would be expected to obtain consent before disclosing personal information.</p> | | | | | | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Newfoundland and Labrador |
|---|------------------|---------|--------------|----------|---------|--------|---------------|-------------|----------------------|---------------------------|
| <p>4.3.1 Consent is required for the collection of personal information and the subsequent use or disclosure of this information. Typically, an organization will seek consent for the use or disclosure of the information at the time of collection. In certain circumstances, consent with respect to use or disclosure may be sought after the information has been collected but before use (for example, when an organization wants to use information for a purpose not previously identified).</p> <p>4.3.2 The principle requires “knowledge and consent”. Organizations shall make a reasonable effort to ensure that the individual is advised of the purposes for which the information will be used. To make the consent meaningful, the purposes must be stated in such a manner that the individual can reasonably understand how the information will be used or disclosed.</p> <p>4.3.3 An organization shall not, as a condition of the supply of a product or service, require an individual to consent to the collection, use or disclosure of information beyond that required to fulfil the explicitly specified, and legitimate purposes.</p> <p>4.4 Principle 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.</p> <p>4.4.1 Organizations shall not collect personal information indiscriminately. Both the amount and the type of information collected shall be limited to that which is necessary to fulfil the purposes identified. Organizations shall specify the type of information collected as part of their information-handling policies and practices, in accordance with the Openness principle (Clause 4.8).</p> <p>4.4.2 The requirement that personal information be collected by fair and lawful means is intended to prevent organizations from collecting information by misleading or deceiving individuals about the purpose for which information is being collected. This requirement implies that consent with respect to collection must not be obtained through deception.</p> | | | | | | | | | | |

COLLECTION OF PERSONAL HEALTH INFORMATION

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|--|--|---|--|--------|---------------|-------------|--------|--------------------|
| | | <p>Bill 40, <i>Health Information Act</i>, 3rd Sess., 24th Leg., Alberta, 1999 (Assented to 9 December, 1999, not yet proclaimed in force.)</p> <p>PART 3 COLLECTION OF HEALTH INFORMATION</p> <p>S. 18 No custodian shall collect health information except in accordance with this Act.</p> <p>[Note: In this Act, “custodian” means</p> <p>(i) the board of an approved hospital as defined in the <i>Hospitals Act</i> other than an approved hospital that is</p> <p>(A) owned and operated by a regional health authority established under the <i>Regional Health Authorities Act</i>, or</p> <p>(B) established and operated by the Alberta Cancer Board continued under the <i>Cancer Programs Act</i>;</p> <p>(ii) the operator of a nursing home as defined in the <i>Nursing Homes Act</i> other than a nursing home that is owned and operated by a regional health authority established under the <i>Regional Health Authorities Act</i>;</p> <p>(iii) a provincial health board established pursuant to regulations made under section 17(1)(a) of the <i>Regional Health Authorities Act</i>;</p> <p>(iv) a regional health authority established under the <i>Regional Health Authorities Act</i>;</p> <p>(v) a community health council as defined in the <i>Regional Health Authorities Act</i>;</p> <p>(vi) a subsidiary health corporation as defined in the <i>Regional Health Authorities Act</i>;</p> <p>(vii) the Alberta Cancer Board continued under the <i>Cancer Programs Act</i>;</p> <p>(viii) a board, council, committee, commission, panel, or agency that is created by a custodian referred to in subclauses (i) to (vii), if all or a majority of its members are appointed by, or on behalf of, that custodian, but does not include a committee that has as its primary purpose the carrying out of</p> | <p><i>The Health Information Protection Act</i>, S.S. 1999, c. H-0.021 (Assented to 6 May 1999, not yet proclaimed in force.)</p> <p>PART II Rights of the Individual</p> <p>S. 11(1) An individual has the right to refuse to produce his or her health services number or any other prescribed identifying number to any person, other than a trustee who is providing a health service, as a condition of receiving a service.</p> <p>[Note: In this Act, “trustee” means any of the following that have custody or control of personal health information:</p> <p>(i) a government institution;</p> <p>(ii) a district health board or an affiliate;</p> <p>(iii) a person who operates a special-care home as defined in <i>The Housing and Special-care Homes Act</i>;</p> <p>(iv) a licensee as defined in the <i>The Personal Care Homes Act</i>;</p> <p>(v) a person who operates a facility as defined in <i>The Mental Health Services Act</i>;</p> <p>(vi) a licensee as defined in <i>The Health Facilities Licensing Act</i>;</p> <p>(vii) an operator as defined in <i>The Ambulance Act</i>;</p> <p>(viii) a licensee as defined in <i>The Medical Laboratory Licensing Act, 1994</i>;</p> <p>(ix) a proprietor as defined in <i>The Pharmacy Act, 1996</i>;</p> <p>(x) a community clinic:</p> <p>(A) as defined in section 263 of <i>The Co-operatives Act, 1996</i>;</p> <p>(B) within the meaning of section 9 of <i>The Mutual Medical and Hospital Benefit Associations Act</i>; or</p> | <p><i>The Personal Health Information Act</i>, S.M. 1997, c. P-33.5</p> <p>PART 3 PROTECTION OF PRIVACY</p> <p>DIVISION I RESTRICTIONS ON COLLECTION AND RETENTION OF INFORMATION</p> <p>S. 13(1) A trustee shall not collect personal health information about an individual unless</p> <p>(a) the information is collected for a lawful purpose connected with a function or activity of the trustee; and</p> <p>(b) the collection of the information is necessary for that purpose.</p> <p>(2) A trustee shall collect only as much personal health information about an individual as is reasonably necessary to accomplish the purpose for which it is collected.</p> <p>[Note: In this Act, “trustee” means: a health professional, health care facility, public body, or health services agency that collects or maintains personal health information.]</p> <p>S. 14(1) Whenever possible, a trustee shall collect personal health information directly from the individual the information is about.</p> <p>(2) Subsection (1) does not apply if</p> <p>(a) the individual has authorized another method of collection;</p> <p>[...]</p> <p>(d) collection of the information directly from the individual could reasonably be expected to result in inaccurate information being collected; or</p> <p>(e) another method of collection is authorized or required by a court order</p> | <p><i>Draft Personal Health Information Protection Act, 1997</i> (Not in force.)</p> <p>PART I GENERAL</p> <p>S. 4(1) No health information custodian shall collect, use or disclose personal health information or retain a personal health record if information that is not personal health information will serve the purpose of the collection, use, disclosure or retention, as the case may be.</p> <p>[Note: In this Act, “health information custodian” means: one of the following persons who collect personal health information:</p> <p>1. An individual who practises a health profession within the meaning of the <i>Regulated Health Professions Act, 1991</i> but not when working as part of another health information custodian.</p> <p>2. A person who practises as a drugless practitioner registered under the <i>Drugless Practitioners Act</i> but not when working as part of another health information custodian.</p> <p>3. A service provider within the meaning of the <i>Long-Term Care Act, 1994</i> but not when working as part of another health information custodian.</p> <p>4. A service provider within the meaning of the <i>Child and Family Services Act</i> but not a young offenders service within the meaning of that Act.</p> <p>5. A person who operates,</p> <p>i. a hospital within the meaning of the <i>Public Hospitals Act</i>, a private hospital within the meaning of the <i>Private Hospitals Act</i>, a psychiatric facility within the meaning of the <i>Mental Health Act</i> or an institution within the meaning of the <i>Mental</i></p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|---|---|--|---|--------|---------------|-------------|--------|--------------------|
| | | <p>quality assurance activities within the meaning of section 9 of the <i>Alberta Evidence Act</i>;</p> <p>(ix) a health services provider who is paid under the Alberta Health Care Insurance Plan to provide health services;</p> <p>(x) a licensed pharmacy as defined in the <i>Pharmaceutical Profession Act</i>;</p> <p>(xi) a pharmacist as defined in the <i>Pharmaceutical Profession Act</i>;</p> <p>(xii) the Department;</p> <p>(xiii) the Minister;</p> <p>(xiv) an individual or board, council, committee, commission, panel, agency or corporation designated in the regulations as a custodian;</p> <p>but does not include</p> <p>(xv) the Alberta Alcohol and Drug Abuse Commission continued under the <i>Alcohol and Drug Abuse Act</i>;</p> <p>(xvi) a Community Board or a Facility Board, as those terms are defined in the <i>Persons with Developmental Disabilities Community Governance Act</i>.]</p> <p>S. 19 A custodian may collect non-identifying health information for any purpose.</p> <p>S. 20 A custodian may collect individually identifying health information</p> <p>(a) if the collection of that information is expressly authorized by an enactment of Alberta or Canada, or</p> <p>(b) if that information relates directly to and is necessary to enable the custodian to carry out a purpose that is authorized under s.27.</p> <p>[Note: The relevant provisions of section 27 have been reproduced in “Use and Disclosure of Personal Health Information”, see below.]</p> <p>S. 21(1) Only the following have the right to require an individual to provide the individual’s personal health number:</p> <p>(a) custodians;</p> <p>(b) persons authorized by the regulations to do so.</p> <p>(2) When requesting a personal health number from an individual, the person referred to in subsection (1) must advise the individual of the person’s authority under subsection (1).</p> | <p>(C) incorporated or continued pursuant to <i>The Non-profit Corporations Act, 1995</i>;</p> <p>(xi) the Saskatchewan Cancer Foundation;</p> <p>(xii) a person, other than an employee of a trustee, who is:</p> <p>(A) a health professional licensed or registered pursuant to an Act for which the minister is responsible; or</p> <p>(B) a member of a class of persons designated as health professionals in the regulations;</p> <p>(xiii) a health professional body that regulates members of a health profession pursuant to an Act;</p> <p>(xiv) a person, other than an employee of a trustee, who or body that provides a health service pursuant to an agreement with another trustee;</p> <p>(xv) any other prescribed person, body or class of persons or bodies.]</p> <p>(2) Except as otherwise provided in subsection (3), no person shall require an individual to produce a health services number as a condition of receiving any product or service.</p> <p>(3) A person may require the production of another person’s health services number:</p> <p>(a) For purposes related to:</p> <p>(i) the provision of publicly funded health services to the other person;</p> <p>(ii) the provision of a health service or program by a trustee; or</p> <p>(b) where authorized to do so by an Act or regulation.</p> <p>PART IV Limits on Collection, Use And Disclosure of Personal Health Information by Trustees</p> <p>S. 23(1) A trustee shall collect, use or disclose only the personal health</p> | <p>or an enactment of Manitoba or Canada.</p> <p>S. 15(1) A trustee who collects personal health information directly from the individual the information is about shall, before it is collected or as soon as practicable afterwards, take reasonable steps to inform the individual</p> <p>(a) of the purpose for which the information is being collected; and</p> <p>(b) if the trustee is not a health professional, how to contact an officer or employee of the trustee who can answer the individual’s questions about the collection.</p> <p>(2) A trustee need not comply with subsection (1) if the trustee has recently provided the individual with the information referred to in that subsection about the collection of the same or similar personal health information for the same or a related purpose.</p> <p>DIVISION 4 MISCELLANEOUS REQUIREMENTS</p> <p>PHIN</p> <p>S. 26(1) No person other than a trustee may require the production of another person’s PHIN (personal health information number) or collect or use another person’s PHIN.</p> <p>(2) Despite subsection (1), a person may collect or use another person’s PHIN</p> <p>(a) for purposes related to the provision of publicly funded health care to the other person;</p> <p>(b) for purposes of a health research project approved under section 24;</p> <p>[Note : Section 24 is reproduced in “Use and Disclosure of Personal Health Information, see below.]</p> <p>or</p> <p>(c) in circumstances permitted by the regulations.</p> | <p><i>Hospitals Act</i>,</p> <p>ii. a long-term care facility,</p> <p>iii. a home for special care within the meaning of the <i>Homes for Special Care Act</i>,</p> <p>iv. an independent health facility within the meaning of the <i>Independent Health Facilities Act</i>,</p> <p>v. a pharmacy within the meaning of Part VI of the <i>Drug and Pharmacies Regulation Act</i>,</p> <p>vi. a laboratory or a specimen collection centre as defined in section 5 of the <i>Laboratory and Specimen Collection Centre Licensing Act</i>,</p> <p>vii. an ambulance service within the meaning of the <i>Ambulance Act</i>,</p> <p>viii. a community service for physical or mental health care,</p> <p>ix. a program or service funded under the <i>Developmental Services Act</i>,</p> <p>x. a rehabilitation program established under section 5 of the <i>Vocational Rehabilitation Services Act</i>,</p> <p>or</p> <p>xi. a home for retarded persons within the meaning of the <i>Homes for Retarded Persons Act</i>.</p> <p>6. A division or administrative unit of a corporation, partnership, association or other entity, if the division or administrative unit provides health care to employees of the entity or to another limited class of persons, even if the division of administrative unit consists of only one individual.</p> <p>7. A board of health within the meaning of the <i>Health Protection and Promotion Act</i>.</p> <p>8. The Ministry.</p> <p>9. A health authority.</p> <p>10. A district health council established under the <i>Ministry of Health Act</i>.</p> <p>11. A College within the meaning of the <i>Regulated Health Professions Act, 1991</i>.</p> <p>12. The Family Benefits Program delivered by the Ministry of Community and Social Services.</p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|---|--|---|---|--------|---------------|-------------|--------|--------------------|
| | | <p>(3) An individual may refuse to provide the individual's personal health number where the person requesting it is not a person referred to in subsection (1).</p> <p>S. 22(1) A custodian must collect individually identifying health information directly from the individual who is the subject of the information unless subsection (2) applies.</p> <p>(2) A custodian may collect individually identifying health information from a person other than the individual who is the subject of the information in the following circumstances:</p> <p>(a) where the individual who is the subject of the information authorizes collection of the information from someone else;</p> <p>(b) where the individual who is the subject of the information is unable to provide the information and the custodian collects the information from a person referred to in section 104(1)(c) to (i) who is acting on behalf of that individual;</p> <p>[Note: Section 104(1) (c) to (i) can be found in "Consent and Substitute Decision-Making Respecting Personal Health Information", below.]</p> <p>(c) where the custodian believes, on reasonable grounds, that collection from the individual who is the subject of the information would prejudice</p> <p>(i) the interests of the individual,</p> <p>(ii) the purposes of collection, or</p> <p>(iii) the safety of any other individual,</p> <p>or would result in the collection of inaccurate information;</p> <p>(d) where collection from the individual who is the subject of the information is not reasonably practicable;</p> <p>(e) where collection is for any of the following purposes:</p> <p>(i) assembling a family or genetic history where the information collected is to be used in the context of providing a health service to the individual who is the subject of the information;</p> <p>[...]</p> <p>(f) where the information is available to the public;</p> <p>(g) where disclosure of the information is authorized under Part 5.</p> <p>[Note: Relevant provisions permitting disclosure under Part 5 are reproduced in</p> | <p>information that is reasonably necessary for the purpose for which it is being collected, used or disclosed. [...]</p> <p>S. 24(1) A trustee shall ensure that the primary purpose for collecting personal health information is for the purposes of a program, activity or service of the trustee that can reasonably be expected to benefit the subject individual.</p> <p>(2) A trustee may collect personal health information for a secondary purpose if the secondary purpose is consistent with any of the purposes for which personal health information may be disclosed pursuant to section 27, 28 or 29.</p> <p>[Note: The relevant provisions of sections 27, 28 and 29 have been reproduced in "Use and Disclosure of Personal Health Information", see below.]</p> <p>(3) Nothing in this Act prohibits the collection of personal health information where that collection is authorized by another Act or by a regulation made pursuant to another Act.</p> <p>(4) A trustee may collect personal health information for any purpose with the consent of the subject individual.</p> <p>S. 25(1) Subject to subsection (2), a trustee shall collect personal health information directly from the subject individual, except where:</p> <p>(a) the individual consents to collection of the information by other methods;</p> <p>(b) the individual is unable to provide the information;</p> <p>[...]</p> <p>(e) the information is available to the public;</p> <p>(f) the trustee collects the information by disclosure from another trustee</p> | <p>PART 6 GENERAL PROVISIONS</p> <p>S. 66(1) The Lieutenant Governor in Council may make regulations [...]</p> <p>(k) for the purpose of clause 26(2)(c), permitting the collection and use of a person's PHIN number for specified purposes or by specified persons or bodies;</p> <p>[...]</p> | <p>13. The General Welfare Assistance Program delivered by a municipality.</p> <p>14. The Public Guardian and Trustee.</p> <p>15. The person who maintains information reported to the Registrar of Motor Vehicles under section 203 or 204 of the Highway Traffic Act.</p> <p>16. The Workplace Safety and Insurance Board.</p> <p>17. An insurer licensed under the Insurance Act, but only in respect of the class of insurance for which the insurer is licensed.</p> <p>18. An association registered under the Prepaid Hospital and Medical Services Act.</p> <p>19. A division or administrative unit of a corporation, partnership, association or other entity, if the division or administrative unit administers an insurance plan of the employees of the entity, but only in respect of administering that plan.</p> <p>20. An assessment centre designated by the regulations made under the Insurance Act.</p> <p>21. A person who is not part of another health information custodian and who maintains a registry of personal health records that relate to a specific disease or condition or that relate to the storage or donation of body parts or bodily substances.</p> <p>22. A person who maintains a repository of personal health records for the primary purpose of data analysis or linkages.</p> <p>23. A person who manages a network or shared database of personal health records on behalf of more than one health information custodian.</p> <p>24. Any other person or class of persons prescribed by the regulations as health information custodians when performing the work prescribed by the regulations.</p> <p>A person described in any of the</p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|---|--|----------|--|--------|---------------|-------------|--------|--------------------|
| | | <p>“Use and Disclosure of Personal Health Information”, see below.]</p> <p>(3) When collecting individually identifying health information about an individual directly from the individual, the custodian must take reasonable steps to inform the individual</p> <p>(a) of the purpose for which the information is collected,</p> <p>(b) of the specific legal authority for the collection, and</p> <p>(c) of the title, business address and business telephone number of an affiliate of the custodian who can answer the individual’s questions about the collection.</p> <p>S. 23 A custodian that collects health information from an individual using a recording device or camera or any other device that may not be obvious to the individual must, before collecting the information, obtain the written consent of the individual to the use of the device or camera.</p> <p>S. 24 An affiliate of a custodian must not collect health information in any manner that is not in accordance with the affiliate’s duties to the custodian.</p> <p>PART 6 DUTIES AND POWERS OF CUSTODIANS RELATING TO HEALTH INFORMATION</p> <p>Division 1 - General Duties and Powers</p> <p>57(1) In this section, “aggregate health information” means non-identifying health information about groups of individuals.</p> <p>(2) A custodian that intends to collect, use or disclose health information must first consider whether collection, use or disclosure of aggregate health information is adequate for the intended purpose, and if so, the custodian must collect, use or disclose only aggregate health information.</p> <p>(3) If the custodian believes that collecting, using or disclosing aggregate health information is not adequate for the custodian’s intended purpose, the custodian must then consider whether collection, use or disclosure of other non-identifying health information is</p> | <p>pursuant to section 27, 28 or 29; [Note: The relevant provisions of sections 27, 28 and 29 have been reproduced in “Use and Disclosure of Personal Health Information”, see below.] or (g) prescribed circumstances exist.</p> <p>(2) Where the collection is for the purpose of assembling the family health history of an individual, a trustee may collect personal health information from the individual about other members of the individual's family.</p> <p>(3) Where a trustee collects personal health information from anyone other than the subject individual, the trustee must take reasonable steps to verify the accuracy of the information.</p> <p>PART VIII General</p> <p>S. 63(1) For the purpose of carrying out this Act according to its intent, the Lieutenant Governor in Council may make regulations: [...] (g) for the purposes of clause 11(3)(b), prescribing circumstances in which a person may require the production of another person’s health services number; [...] (l) for the purposes of clause 25(1)(g), prescribing circumstances in which a trustee may collect personal health information other than directly from the subject individual; [...]</p> | | <p>paragraphs above is not a health information custodian with respect to personal health information that the person collects other than as a result of or in connection with performing the work described in that paragraph.]</p> <p>(2) To the extent reasonably possible, a health information custodian may collect, use or disclose only as much personal health information or retain as much of a personal health record as is reasonably necessary to meet the purpose of the collection, use, disclosure or retention, as the case may be.</p> <p>(3) To the extent reasonably possible, a health information custodian who collects, uses or discloses personal health information or who retains a personal health record shall conceal the identity of the subject of the information or the record while still meeting the purpose of the collection, use, disclosure or retention, as the case may be.</p> <p>(4) For the purposes of subsections (1), (2) and, (3), a health information custodian shall comply with the standards, if any, prescribed in the regulations.</p> <p>PART III COLLECTION, USE AND DISCLOSURE OF PERSONAL HEALTH INFORMATION</p> <p>S. 11(1) A health information custodian shall not collect personal health information unless the collection is necessary for a lawful purpose connected with a function or activity of the custodian.</p> <p>(2) A health information custodian shall not collect personal health information by any unlawful means.</p> <p>(3) A health information custodian shall collect personal health information directly from the subject of the information unless, (a) the subject of the information consents to another manner of collection; (b) the information is collected from a person who is permitted or required by this</p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|---|--------------|----------|---|--------|---------------|-------------|--------|--------------------|
| | | <p>adequate for the intended purpose, and if so, the custodian may collect, use or disclose other non-identifying health information.</p> <p>(4) If the custodian believes that collecting, using or disclosing aggregate and other non-identifying health information is not adequate for the custodian's intended purpose, the custodian may collect, use or disclose individually identifying health information if the collection, use or disclosure (a) is authorized by this Act, and (b) is carried out in accordance with this Act.</p> <p>(5) This section does not apply where the collection, use or disclosure is for the purpose of (a) providing health services, or (b) determining or verifying the eligibility of an individual to receive a health service.</p> <p>S. 58(1) When collecting, using or disclosing health information, a custodian must, in addition to complying with section 57, collect, use or disclose only the amount of health information that is essential to enable the custodian or the recipient of the information, as the case may be, to carry out the intended purpose.</p> <p>PART 8 GENERAL PROVISIONS</p> <p>S. 108(1) The Lieutenant Governor in Council may make regulations [...] (d) authorizing persons other than custodians to require individuals to provide their personal health numbers; [...]</p> | | | <p>Act or any other Act to disclose the information to the custodian; (c) another Act permits another manner of collection; (d) collection of the information directly from the subject of the information is not reasonably practicable; or (e) collection of the information directly from the subject of the information could reasonably be expected to result in the collection of inaccurate information or to prejudice the purpose of the collection.</p> <p>(4) If a health information custodian collects personal health information directly from the subject of the information, the custodian shall take reasonable steps, before or while collecting the information or as soon as reasonably practicable afterwards, to inform the subject of the purpose or purposes for which the information is being collected.</p> <p>(5) Subsection 4 does not apply if the health information custodian, (a) is providing or about to provide the subject of the information with health care; (b) is facilitating the provision of health care to the subject of the information; or (c) is the Public Guardian and Trustee or a children's aid society</p> <p>PART IX MISCELLANEOUS</p> <p>S. 72(1) The Lieutenant Governor in Council may make regulations, [...] (d) specifying standards, or a process for setting standards, with which a health information custodian shall comply for the purpose of subsections 4(1) to (4) and specifying the circumstances in which the custodian is required to comply with the standards; [...]</p> | | | | | |

Use and Disclosure

In principle, personal (health) information can only be used and/or disclosed for the purpose for which it was collected or for a purpose consistent therewith. What constitutes a consistent purpose is usually defined in the statute in question. Any other proposed use or disclosure generally requires the consent of the individual the personal (health) information is about.

Notwithstanding this general principle, personal (health) information may be used and/or disclosed for a research purpose without the consent of the individual the information is about in certain limited conditions prescribed by law or regulation. As will become readily apparent, these conditions vary significantly in terms of stringency, complexity and level of detail.

For instance, these may range from the simple requirement of a *bona fide* or legitimate research purpose to more extensive conditions including any combination or variation of the following:

- the use/disclosure is limited to the extent necessary to carry out the described purpose;
- the purpose cannot reasonably be accomplished unless the information is in identifiable form;
- any record linkage is not harmful and the benefits of the record linkage are clearly in the public or societal interest;
- the purpose justifies the action proposed;
- the intended use/disclosure is not frivolous and the ends contemplated cannot be achieved unless the information is communicated in nominative form (Quebec);
- it is unreasonable, impractical or unfeasible to obtain consent;
- the purpose has been *approved* by the Privacy Commissioner (eg. Quebec) or the Privacy Commissioner has at least been *informed* thereof (Federal Bill C-6);
- the intended use/disclosure has been reviewed and/or approved by a research ethics committee (eg. Alberta) or some other designated review committee (eg. Manitoba);
- the researcher will not subsequently use and/or disclose identifiable information for another purpose without prior authorization;
- the researcher will not publish research findings in a form that would allow the subject of the information to be readily identified;
- the researcher will remove and/or destroy all identifying information at the earliest opportunity;
- the researcher is qualified to carry out the research (Alberta);
- the researcher will not contact the subject of the information directly, unless the original custodian of the information has first obtained the subject's consent to be contacted by the researcher;
- the researcher will take reasonable steps to ensure the security and confidentiality of the personal (health) information;
- the researcher has made a written undertaking, or has signed a research agreement with the original custodian of the personal (health) information, promising to comply with these and other conditions required by law. (In some cases, the specific content of such an agreement is set out in the Act itself or in accompanying regulations, eg. Alberta, Saskatchewan, Ontario. Interestingly, Alberta's *Health Information Act* also includes detailed provisions setting out available recourses in the event of breach of the agreement).

Typically, the above conditions will not apply to information that has been in existence for more than 100 years or if the person the information is about has been dead for over 25 years.

As mentioned above (see section on "Collection"), the provision which allows a custodian to disclose personal (health) information for a research purpose, is typically accompanied by a correlative provision which allows the researcher in question to collect the information for that same purpose. Curiously, while Bill C-6 allows for the use and disclosure of personal information "*for statistical, or scholarly study or research, purposes*" (sections 7(2)(c) and 7(3)(f), respectively), it does not expressly allow for the collection of personal information for those same purposes.

USE AND DISCLOSURE OF PERSONAL INFORMATION IN THE PUBLIC SECTOR

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Nfld. and Labrador |
|--|--|--|---|--|--|---|---|--|---|--------------------|
| <p><i>Privacy Act, R.S.C. 1985, c. P-21</i></p> <p>PROTECTION OF PERSONAL INFORMATION</p> <p>S. 7 Personal information under the control of a government institution shall not, without the consent of the individual to whom it relates, be used by the institution except</p> <p>(a) for the purpose for which the information was obtained or compiled by the institution or for a use consistent with that purpose; or</p> <p>(b) for a purpose for which the information may be disclosed to the institution under subsection 8(2).</p> <p>S. 8(1) Personal information under the control of a government institution shall not, without the consent of the individual to whom it relates, be disclosed by the institution except in accordance with this section.</p> <p>(2) Subject to any other Act of Parliament, personal information under the control of a government institution may be disclosed</p> <p>(a) for the purpose for which the information was obtained or compiled by the</p> | <p><i>Freedom of Information and Protection of Privacy Act, R.S.B.C. 1996, c. 165</i></p> <p>PART 3 – PROTECTION OF PRIVACY</p> <p>Division 2 – Use and Disclosure of Personal Information by Public Bodies</p> <p>S. 32 A public body may use personal information only</p> <p>(a) for the purpose for which that information was obtained or compiled, or for a use consistent with that purpose,</p> <p>(b) if the individual the information is about has identified the information and has consented, in the prescribed manner, to the use, or</p> <p>(c) for a purpose for which that information may be disclosed to that public body under sections 33 to 36.</p> <p>S. 33 A public body may disclose personal information only</p> <p>[...]</p> <p>(b) if the individual the information is about has identified the information and consented, in the prescribed manner, to</p> | <p><i>Freedom of Information and Protection of Privacy Act, S.A. 1994, c. F-18.5</i></p> <p>PART 2 PROTECTION OF PRIVACY</p> <p>Division 2 Use and Disclosure of Personal Information by Public Bodies</p> <p>S. 37(1) A public body may use personal information only</p> <p>(a) for the purpose for which the information was collected or compiled or for a use consistent with that purpose,</p> <p>(b) if the individual the information is about has identified the information and consented, in the prescribed manner, to the use, or</p> <p>(c) for a purpose for which that information may be disclosed to the public body under section 38, 40 or 41</p> <p>[...]</p> <p>(4) A public body may use personal information only to the extent necessary to enable the public body to carry out its purpose in a reasonable manner.</p> <p>S. 38(1) A public body may disclose personal information only</p> <p>[...]</p> <p>(b) for the purpose for which the information was</p> | <p><i>Freedom of Information and Protection of Privacy Act, S.S. 1990-91, c. F-22.01</i></p> <p>PART IV PROTECTION OF PRIVACY</p> <p>S. 28 No government institution shall use personal information under its control without the consent, given in the prescribed manner, of the individual to whom the information relates, except:</p> <p>(a) for the purpose of which the information was obtained or compiled, or for a use that is consistent with that purpose; or</p> <p>(b) for a purpose for which the information may be disclosed to the government institution pursuant to subsection 29(2).</p> <p>S. 29(1) No government institution shall disclose personal information in its possession or under its control without the consent, given in the prescribed manner, of the individual to whom the information relates except in accordance with this section or section 30.</p> <p>(2) Subject to any other Act or regulation,</p> | <p><i>The Freedom of Information and Protection of Privacy Act, R.S.M. c. F-175</i></p> <p>PART 3 PROTECTION OF PRIVACY</p> <p>DIVISION 3 - RESTRICTIONS ON USE AND DISCLOSURE OF PERSONAL INFORMATION</p> <p>GENERAL DUTIES OF PUBLIC BODIES</p> <p>S. 42(1) A public body shall not use or disclose personal information except as authorized under this Division.</p> <p>(2) Every use and disclosure by a public body of personal information must be limited to the minimum amount of information necessary to accomplish the purpose for which it is used or disclosed.</p> <p>(3) A public body shall limit the use and disclosure of personal information in its custody or under its control to those of its employees or agents who need to know the information to carry out the purpose for which the information was collected or received or to carry out a purpose authorized under Section 43.</p> <p>S. 43 A public body may</p> | <p><i>Freedom of Information and Protection of Privacy Act, R.S.O. 1990, c. F.31</i></p> <p>PART II FREEDOM OF INFORMATION</p> <p>Exemptions</p> <p>S. 21(1) A head shall refuse to disclose personal information to any person other than the individual to whom the information relates</p> <p>[...]</p> <p>(e) for a research purpose if,</p> <p>(i) the disclosure is consistent with the conditions or reasonable expectations of disclosure under which the personal information was provided, collected or obtained,</p> <p>(ii) the research purpose for which the disclosure is to be made cannot be reasonably accomplished unless the information is provided in individually identifiable form, and</p> <p>(iii) the person who is to receive the record has agreed to comply with the conditions relating to security and confidentiality prescribed by the regulations;</p> <p>[...]</p> | <p><i>Act respecting Access to documents held by public bodies and the Protection of personal information, R.S.Q. c. A-2.1</i></p> <p>CHAPTER III PROTECTION OF PERSONAL INFORMATION</p> <p>Division I Confidentiality of Nominative Information</p> <p>S. 59 A public body shall not release nominative information without the consent of the person concerned.</p> <p>Notwithstanding the foregoing, a public body may release nominative information without the consent of the person concerned in the following cases and strictly on the following conditions:</p> <p>[...]</p> <p>(5) to a person authorized by the Commission d'accès à l'information, in accordance with section 125, to use the information for study, research or statistics purposes;</p> <p>[...]</p> | <p><i>Protection of Personal Information Act, S.N.B. 1998, c. P-19.1</i></p> <p>(Assented to 26 February 1998 – not yet proclaimed in force.)</p> <p>S. 2(1) Every public body is subject to the Statutory Code of Practice.</p> <p>(2) The Statutory Code of Practice shall be interpreted and applied in accordance with Schedule B and with any regulations made under paragraph 7(b).</p> <p>Schedule A: The Statutory Code of Practice</p> <p>Principle 3: Consent</p> <p>The consent of the individual is required for the collection, use, or disclosure of personal information, except where inappropriate.</p> <p>Principle 5: Limiting Use, Disclosure and Retention</p> <p>Personal information shall not be used or disclosed for</p> | <p><i>Freedom of Information and Protection of Privacy Act, S.N.S. 1993, c. 5</i></p> <p>PROTECTION OF PRIVACY</p> <p>COLLECTION, PROTECTION AND RETENTION OF PERSONAL INFORMATION</p> <p>S. 26 A public body may use personal information only</p> <p>(a) for the purpose for which that information was obtained or compiled, or for a use compatible with that purpose;</p> <p>(b) if the individual the information is about has identified the information and has consented, in the prescribed manner, to the use; or</p> <p>(c) for a purpose for which that information may be disclosed to that public body pursuant to Sections 27 to 30.</p> <p>S. 27 A public body may disclose personal information only</p> <p>[...]</p> <p>(b) if the individual the information is about has identified the information and consented in writing</p> | <p><i>Bill 81, Freedom of Information and Protection of Privacy Act, 1st Sess., 60th</i></p> <p>General Assembly, P.E.I. 1997 (Died on the Order Paper – not in force)</p> <p>PART II PROTECTION OF PRIVACY</p> <p>Division 2 Use and Disclosure of Personal Information by Public Bodies</p> <p>S. 36 A public body may use personal information only</p> <p>(a) for the purpose for which the information was collected or compiled or for a use consistent with that purpose;</p> <p>(b) if the individual the information is about has identified the information and consented, in the prescribed manner, to the use; or</p> <p>(c) for a purpose for which that information may be disclosed to that public body under section 37, 39 or 40.</p> <p>S. 37(1) A public body may disclose personal information</p> | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Nfld. and Labrador |
|--|--|--|---|--|--|---|--|---|--|--------------------|
| <p>institution or for a use consistent with that purpose; (or) [...]</p> <p>(j) to any person or body for research or statistical purposes if the head of the government institution</p> <p>(i) is satisfied that the purpose for which the information is disclosed cannot reasonably be accomplished unless the information is provided in a form that would identify the individual to whom it relates, and (ii) obtains from the person or body a written undertaking that no subsequent disclosure of the information will be made in a form that could reasonably be expected to identify the individual to whom it relates; [...]</p> <p>S. 8(3) Subject to any other Act of Parliament, personal information under the custody or control of the National Archivist of Canada that has been transferred to the National Archivist by a government institution for archival or historical purposes may be disclosed in accordance with the regulations to any person or body for research or statistical purposes.</p> | <p>its disclosure, (or) (c) for the purpose for which it was obtained or compiled or for a use consistent with that purpose, (or) [...]</p> <p>(r) in accordance with sections 35 and 36.</p> <p>S. 34(1) A use of personal information is consistent under section 32 or 33 with the purposes for which the information was obtained or compiled if the use</p> <p>(a) has a reasonable and direct connection to that purpose, and (b) is necessary for performing the statutory duties of, or for operating a legally authorized program of, the public body that uses or discloses the information.</p> <p>(2) The minister responsible for this Act must publish annually a list of the consistent purposes for which personal information is used or disclosed.</p> <p>S. 35 A public body may disclose personal information for a research purpose, including statistical research, only if</p> <p>(a) the research purpose cannot reasonably be accomplished unless that information is provided in individually identifiable form or</p> | <p>collected or compiled or for a use consistent with that purpose,</p> <p>(c) if the individual the information is about has identified the information and consented, in the prescribed manner, to the disclosure, (or) [...]</p> <p>(r) in accordance with section 40 or 41, [...]</p> <p>(2) A public body may disclose personal information only to the extent necessary to enable the public body to carry out the purposes described in subsections (1), (1.1) and (1.2) in a reasonable manner.</p> <p>S. 39 For the purposes of sections 37(1)(a) and 38(1)(b), a use or disclosure of personal information is consistent with the purpose for which the information was collected or compiled if the use or disclosure</p> <p>(a) has a reasonable and direct connection to that purpose, and (b) is necessary for performing the statutory duties of, or for operating a legally authorized program of, the public body that uses or discloses the information.</p> <p>S. 40 A public body may disclose personal information for a research purpose, including statistical research, only if</p> <p>(a) the research purpose cannot reasonably be accomplished unless that information is provided in individually identifiable</p> | <p>personal information in the possession or under the control of a government institution may be disclosed:</p> <p>(a) for the purpose for which the information was obtained or compiled by the government institution or for a use that is consistent with that purpose; (or) [...]</p> <p>(k) to any person or body for research or statistical purposes if the head:</p> <p>(i) is satisfied that the purpose for which the information is to be disclosed is not contrary to the public interest and cannot reasonably be accomplished unless the information is provided in a form that would identify the individual to whom it relates; and</p> <p>(ii) obtains from the person or body a written agreement not to make a subsequent disclosure of the information in a form that could reasonably be expected to identify the individual to whom it relates; [...]</p> <p>S. 29(4) Subject to any other Act or regulation, the Provincial Archivist may release personal information that is in the possession or under the control of the Saskatchewan Archives</p> | <p>use personal information only</p> <p>(a) for the purpose for which the information was collected or compiled under subsection 36(l) [Note: see “Collection of Personal Information in the Public Sector”, above] or for a use consistent with that purpose under section 45;</p> <p>(b) if the individual the information is about has consented to the use; or (c) for a purpose for which that information may be disclosed to the public body under section 44, 46, 47 or 48 or for a use approved under section 46.</p> <p>RESTRICTIONS ON DISCLOSURE OF INFORMATION</p> <p>S. 44(1) A public body may disclose personal information only</p> <p>(a) for the purpose for which the information was collected or compiled under subsection 36(l) [Note: see “Collection of Personal Information in the Public Sector”, above] or for a use consistent with that purpose under section 45;</p> <p>(b) if the individual the information is about has consented to its disclosure; (or) [...]</p> <p>(cc) in accordance with sections 46, 47 or 48.</p> <p>S. 45 For the purpose of clauses 43(a) and 44(1)(a), a use or disclosure of personal information is consistent with the purpose for which the information was collected or compiled if the use or disclosure</p> | <p>PART III PROTECTION OF INDIVIDUAL PRIVACY</p> <p>Use and Disclosure of Personal Information</p> <p>S. 41 An institution shall not use personal information in its custody or under its control except,</p> <p>a) where the person to whom the information relates has identified that information in particular and consented to its use; b) for the purpose for which it was obtained or compiled or for a consistent purpose; or c) for a purpose for which the information may be disclosed to the institution under section 42 [...]</p> <p>S. 42 An institution shall not disclose personal information in its custody or under its control except,</p> <p>a) in accordance with Part II; [Note: Part II of this Act includes S. 21(1) cited above]</p> <p>b) where the person to whom the information relates has identified that information in particular and consented to its disclosure;</p> <p>c) for the purpose for which it was obtained or compiled or for a consistent purpose; [...]</p> <p>S. 43 Where the personal information has been collected directly from the individual to whom</p> | <p>CHAPTER IV COMMISSION D’ACCÈS À L’INFORMATION</p> <p>Division II Duties And Powers</p> <p>S. 125 The Commission may, on a written request, grant a person or an agency the authorization to receive communication of nominative information contained in a personal information file, for study, research or statistics purposes, without the consent of the persons concerned, if it is of the opinion</p> <p>(1) that the intended use is not frivolous and the ends contemplated cannot be achieved unless the information is communicated in nominative form;</p> <p>(2) that the nominative information will be used in a manner that will ensure its confidentiality.</p> <p>The authorization is granted for such period and on such conditions as may be fixed by the Commission. It may be revoked before the expiry of the period granted if the Commission has reason to believe that the authorized person or body does not respect the confidentiality of the information disclosed or the other conditions.</p> | <p>purposes other than those for which it was collected, except with the consent of the individual or as required or expressly authorized by law.</p> <p>Personal information shall be retained only as long as necessary for the fulfillment of those purposes.</p> <p>Schedule B: Interpretation and Application of the Statutory Code of Practice</p> <p>Principle 3: Consent</p> <p>S. 3.4 Consent is not required when a public body collects, uses or discloses personal information [...]</p> <p>(e) for purposes of legitimate research in the interest of science, of learning or of public policy, or for archival purposes, [...]</p> <p>S. 3.6 Before collecting, using or disclosing personal information without consent under paragraph 3.4 or 3.5, a public body shall consider the nature of the information in question and the purpose for which it is acting, and shall satisfy itself that in the circumstances that purpose justifies the action proposed.</p> | <p>to its disclosure;</p> <p>(c) for the purpose for which it was obtained or compiled, or a use compatible with that purpose; (or) [...]</p> <p>(q) in accordance with Section 29 or 30.</p> <p>S. 28 A use of personal information is a use compatible with the purpose for which the information was obtained within the meaning of Section 26 or 27 if the use</p> <p>(a) has a reasonable and direct connection to that purpose; and (b) is necessary for performing the statutory duties of, or for operating a legally authorized program of, the public body that uses the information or to which the information is disclosed.</p> <p>S. 29 A public body may disclose personal information for a research purpose, including statistical research, if</p> <p>(a) the research purpose cannot reasonably be accomplished unless that information is provided in individually identifiable form;</p> <p>(b) any record linkage is not harmful to the</p> | <p>only [...]</p> <p>(b) for the purpose for which the information was collected or compiled or for a use consistent with that purpose;</p> <p>(c) if the individual the information is about has identified the information and consented, in the prescribed manner, to the disclosure; (or) [...]</p> <p>(r) in accordance with section 39 or 40; [...]</p> <p>S. 38 For the purposes of clauses 36(1)(l) and 37(1)(b), a use or disclosure of personal information is consistent with the purpose for which the information was collected or compiled if the use or disclosure</p> <p>(a) has a reasonable and direct connection to that purpose; and (b) is necessary for performing the statutory duties of, or for operating a legally authorized program of, the public body that uses or discloses the information.</p> <p>S. 39 A public body may disclose personal information for a research purpose, including statistical research, only if</p> <p>(a) the research</p> | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Nfld. and Labrador |
|--|---|---|---|---|--|--------|--|--|---|--------------------|
| <p>----- Privacy Act Regulations, S.O.R./83-508</p> <p>S.6 Personal information that has been transferred to the control of the Public Archives by a government institution for archival or historical purposes may be disclosed to any person or body for research or statistical purposes where</p> <p>(a) the information is of such a nature that disclosure would not constitute an unwarranted invasion of the privacy of the individual to whom the information relates;</p> <p>(b) the disclosure is in accordance with paragraph 8(2)(j) or (k) of the Act;</p> <p>(c) 110 years have lapsed following the birth of the individual to whom the information relates; or</p> <p>(d) in cases where the information was obtained through the taking of a census or survey, 92 years have elapsed following the census or survey containing the information.</p> <hr/> | <p>the research purpose has been approved by the commissioner,</p> <p>(b) any record linkage is not harmful to the individuals that information is about and the benefits to be derived from the record linkage are clearly in the public interest,</p> <p>(c) the head of the public body concerned has approved conditions relating to the following:</p> <p>(i) security and confidentiality;</p> <p>(ii) the removal or destruction of individual identifiers at the earliest reasonable time;</p> <p>(iii) the prohibition of any subsequent use or disclosure of that information in individually identifiable form without the express authorization of that public body, and</p> <p>(d) the person to whom that information is disclosed has signed an agreement to comply with the approved conditions, this Act and any of the public body's policies and procedures relating to the confidentiality of personal information.</p> <p>S. 36 The British Columbia Archives and Record Service, or the archives of a public body, may disclose personal information for</p> | <p>form or the research purpose has been approved by the Commissioner,</p> <p>(b) any record linkage is not harmful to the individuals the information is about and the benefits to be derived from the record linkage are clearly in the public interest,</p> <p>(c) the head of the public body has approved conditions relating to the following:</p> <p>(i) security and confidentiality,</p> <p>(ii) the removal or destruction of individual identifiers at the earliest reasonable time, and</p> <p>(iii) the prohibition of any subsequent use or disclosure of the information in individually identifiable form without the express authorization of that public body,</p> <p>and</p> <p>(d) the person to whom the information is disclosed has signed an agreement to comply with the approved conditions, this Act and any of the public body's policies and procedures relating to the confidentiality of personal information.</p> <p>PART 2.1 DISCLOSURE OF INFORMATION IN ARCHIVES</p> <p>S. 41(1) The Provincial Archives of Alberta and the archives of a public</p> | <p>Board where, in opinion of the Provincial Archivist, the release would not constitute an unreasonable invasion of privacy.</p> <p>S. 30(1) Subject to subsection (2) and to any other Act, the personal information of a deceased individual shall not be disclosed until 25 years after the death of the individual.</p> <p>(2) Where, in the opinion of the head, disclosure of the personal information of a deceased individual to the individual's next of kin would not constitute an unreasonable invasion of privacy, the head may disclose that personal information before 25 years have elapsed after the individual's death.</p> | <p>(a) has a reasonable and direct connection to that purpose; and</p> <p>(b) is necessary for performing the statutory duties of, or for operating an authorized program or carrying out an activity of, the public body that uses or discloses the information.</p> <p>S. 47(1) A public body may disclose personal information for a research purpose only in accordance with this section.</p> <p>(2) The head of a public body that receives a request for disclosure of personal information for a research purpose may refer the request to the review committee for its advice.</p> <p>(3) The review committee shall assess the request and provide advice to the head of the public body about the matters referred to in subsection (4).</p> <p>(4) The head of the public body may disclose personal information for a research purpose only if</p> <p>(a) any advice that was requested from the review committee has been received and considered;</p> <p>(b) the head is satisfied that</p> <p>(i) the personal information is requested for a <i>bona fide</i> research purpose,</p> <p>(ii) the research purpose cannot reasonably be accomplished unless the personal information is provided in a form that identifies individuals,</p> <p>(iii) it is unreasonable or impractical for the</p> | <p>the information relates, the purpose of a use or disclosure of that information is a consistent purpose under clauses 41(b) and 42(c) only if the individual might reasonably have expected such a use or disclosure.</p> <p>Personal Information Banks</p> <p>S. 44 A head shall cause to be included in a personal information bank all personal information under the control of the institution that is organized or intended to be retrieved by the individual's name or by an identifying number, symbol or other particular assigned to the individual.</p> <p>S. 45 The responsible minister shall publish at least once each year an index of all personal information banks setting forth, in respect of each personal information bank,</p> <p>(a) its name and location;</p> <p>(b) the legal authority for its establishment;</p> <p>(c) the types of personal information maintained in it;</p> <p>(d) how the personal information is used on a regular basis;</p> <p>(e) to whom the personal information is disclosed on a regular basis;</p> <p>(f) the categories of individuals about whom personal information is maintained; and</p> <p>(g) the policies and</p> | | <p>S. 3.7 Any collection, use or disclosure of personal information without consent shall be limited to the reasonable requirements of the situation.</p> | <p>individuals that information is about and the benefits to be derived from the record linkage are clearly in the public interest;</p> <p>(c) the head of the public body concerned has approved conditions relating to</p> <p>(i) security and confidentiality,</p> <p>(ii) the removal or destruction of individual identifiers at the earliest reasonable time, and</p> <p>(iii) the prohibition of any subsequent use or disclosure of that information in individually identifiable form without the express authorization of that public body; and</p> <p>(d) the person to whom that information is disclosed has signed an agreement to comply with the approved conditions, this Act and any of the public body's policies and procedures relating to the confidentiality of personal information.</p> <p>S. 30 The Public Archives of Nova Scotia, or the archives of a public body, may disclose personal information for archival or historical purposes where</p> | <p>purpose cannot reasonably be accomplished unless that information is provided in individually identifiable form or the research purpose has been approved by the Commissioner;</p> <p>(b) any record linkage is not harmful to the individuals the information is about and the benefits to be derived from the record linkage are clearly in the public interest;</p> <p>(c) the head of a public body has approved conditions relating to the following:</p> <p>(i) security and confidentiality;</p> <p>(ii) the removal or destruction of individual identifiers at the earliest reasonable time; and</p> <p>(iii) the prohibition of any subsequent use or disclosure of the information in individually identifiable form without the express authorization of that public body; and</p> <p>(d) the person to whom the information is disclosed has signed an agreement to comply with the approved conditions, this Act and any of the public body's policies and</p> | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Nfld. and Labrador |
|---------|--|---|--------------|--|--|--------|---------------|---|--|--------------------|
| | <p>archival or historical purposes if:</p> <p>(a) the disclosure would not be an unreasonable invasion of personal privacy under section 22,</p> <p>(b) the disclosure is for historical research and is in accordance with section 35,</p> <p>(c) the information is about someone who has been dead for 20 or more years, or</p> <p>(d) the information is in a record that has been in existence for 100 or more years.</p> | <p>body may disclose for research purposes</p> <p>(a) personal information that</p> <p>(i) has been in existence for 25 years or more if the disclosure</p> <p>(A) would not be an unreasonable invasion of personal privacy under section 16, or</p> <p>(B) is in accordance with section 40,</p> <p>or</p> <p>(ii) is contained in a record that has been in existence for 75 years or more;</p> <p>[...]</p> <p>(2) The archives of a post-secondary educational body may disclose for research purposes information, including personal information, that has been in existence for 25 years or more if</p> <p>(a) the post-secondary educational body and the person to whom the information is disclosed have entered into a written agreement that</p> <p>(i) ensures security and confidentiality of the information, and</p> <p>(ii) prohibits subsequent use or disclosure of the personal information in individually identifiable form without the express authorization of the post-secondary educational body,</p> <p>and</p> <p>(b) access to the information is not restricted or prohibited by another Act of Alberta or Canada.</p> | | <p>person proposing the research to obtain consent from the individuals the personal information is about, and</p> <p>(iv) disclosure of the personal information, and any information linkage, is not likely to harm the individuals the information is about and the benefits to be derived from the research and any information linkage are clearly in the public interest;</p> <p>(c) the head of the public body has approved conditions relating to</p> <p>(i) the protection of the personal information, including use, security and confidentiality,</p> <p>(ii) the removal or destruction of individual identifiers at the earliest reasonable time, and</p> <p>(iii) the prohibition of any subsequent use or disclosure of the personal information in a form that identifies individuals without the express written authorization of the public body; and</p> <p>(d) the person to whom the personal information is disclosed has entered into a written agreement to comply with the approved conditions.</p> <p>S. 48 The head of a public body or the archives of a public body may disclose personal information in a record that is more than 100 years old.</p> | <p>practices applicable to the retention and disposal of the personal information.</p> <p>S. 46(1) A head shall attach or link to personal information in a personal information bank,</p> <p>(a) a record of any use of that personal information for a purpose other than a purpose described in clause 45(d); and</p> <p>(b) a record of any disclosure of that personal information to a person other than a person described in clause 45(e).</p> <p>(2) A record retained under subsection (1) forms part of the personal information to which it is attached or linked.</p> <p>(3) Where the personal information in a personal information bank under the control of an institution is used or disclosed for a use consistent with the purpose for which the information was obtained or compiled by the institution but the use is not one of the uses included under clauses 45(d) and (e), the head shall,</p> <p>(a) forthwith notify the responsible minister of the use or disclosure; and</p> <p>(b) ensure that the use is included in the index.</p> <p>PART V GENERAL</p> <p>S. 60(1) The Lieutenant Governor in Council may make regulations,</p> | | | <p>(a) the disclosure would not be an unreasonable invasion of personal privacy pursuant to section 20;</p> <p>(b) the disclosure is for historical research and is in accordance with Section 29;</p> <p>(c) the information is about someone who has been dead for twenty or more years ; or</p> <p>(d) the information is in a record that is in the custody or control of the archives and open for historical research on the coming in force of this Act.</p> | <p>procedures relating to the confidentiality of personal information.</p> <p>S. 40 The Public Archives and Records Office and the archives of a public body may disclose personal information for research purposes if</p> <p>(a) the disclosure would not be an unreasonable invasion of personal privacy under section 15;</p> <p>(b) the disclosure is in accordance with section 39;</p> <p>(c) the information is about someone who has been dead for 25 years or more; or</p> <p>(d) the information is in a record that has been in existence for 75 years or more.</p> | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Nfld. and Labrador |
|---------|------------------|---|--------------|--|--|--------|---------------|-------------|----------------------|--------------------|
| | | <p><i>Freedom of Information and Protection of Privacy Act, Alta. Reg. 200/95</i></p> <p>Researcher Agreements</p> <p>S. 8 An agreement under sections 40 and 41 of the Act must include the following:</p> <p>(a) that the person may use the personal information only for a research purpose set out in the agreement or for which the person has written authorization from the public body;</p> <p>(b) the names of any other persons who will be given access to the personal information;</p> <p>(c) that, before disclosing personal information to persons referred to in clause (b), the person must enter into an agreement with those persons to ensure that they will adhere to the same policies and procedures of confidentiality as described in section 40(d) of the Act;</p> <p>(d) that the person must keep the personal information in a secure location to which access is given only to the persons referred to in clause (b);</p> <p>(e) that the person must remove or destroy all individual identifiers in the personal information by the date and in the manner specified in the agreement;</p> <p>(f) that the person must not contact any individual to whom the personal information relates, directly or indirectly,</p> | | <p>PART 6 GENERAL PROVISIONS</p> <p>S. 87 The Lieutenant Governor in Council may make regulations [...]</p> <p>(i) respecting written agreements for the purposes of sections 44, 46 and 47; [...]</p> <p>(k) respecting the appointment of members of the review committee established under section 77 and governing the duties and functions of the review committee and all related matters; [...]</p> | <p>[...]</p> <p>(j) prescribing conditions relating to the security and confidentiality of records used for a research purpose;</p> <p>-----</p> <p>Freedom of Information and Protection of Privacy Act, General Regulations, R.R.O. 1990, Reg. 460</p> <p>S. 10(1) The following are the terms and conditions relating to security and confidentiality that a person is required to agree to before a head may disclose personal information to that person for a research purpose:</p> <p>1. The person shall use the information only for a research purpose set out in the agreement or for which the person has written authorization from the institution.</p> <p>2. The person shall name in the agreement any other persons who will be given access to personal information in a form in which the individual to whom it relates can be identified.</p> <p>3. Before disclosing personal information to other persons under paragraph 2, the person shall enter into an agreement with those persons to ensure that they will not disclose it to any other person.</p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Nfld. and Labrador |
|---------|------------------|--|--------------|----------|---|--------|---------------|-------------|----------------------|--------------------|
| | | <p>without the prior written authority of the public body;</p> <p>(g) that the person must ensure that no personal information will be used or disclosed in a form in which the individual to whom it relates can be identified without the written authority of the public body;</p> <p>(h) that the person must ensure that identifiable personal information about an individual is not used for an administrative purpose directly affecting the individual;</p> <p>(i) that the person must notify the public body in writing immediately if the person becomes aware that any of the conditions set out in the agreement have been breached;</p> <p>(j) that, if a person fails to meet the conditions of the agreement, the agreement may be immediately cancelled and the person may be guilty of an offence under section 86(1) of the Act.</p> | | | <p>4. The person shall keep the information in a physically secure location to which access is given only to the person and to the persons given access under paragraph 2.</p> <p>5. The person shall destroy all individual identifiers in the information by the date specified in the agreement.</p> <p>6. The person shall not contact any individual to whom personal information relates, directly or indirectly, without the prior written authority of the institution.</p> <p>7. The person shall ensure that no personal information will be used or disclosed in a form in which the individual to whom it relates can be identified without the written authority of the institution.</p> <p>8. The person shall notify the institution in writing immediately if the person becomes aware that any of the conditions set out in this section have been breached.</p> <p>S. 10(2) An agreement relating to the security and confidentiality of personal information to be disclosed for a research purpose shall be in Form 1. R.R.O., Reg. 460, s. 10.</p> <p>Form 1 [Note: See Appendix A.]</p> | | | | | |

USE AND DISCLOSURE OF PERSONAL INFORMATION IN THE PRIVATE SECTOR

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Newfoundland and Labrador |
|--|------------------|---------|--------------|----------|---------|--|---------------|-------------|----------------------|---------------------------|
| <p>Bill C-6, <i>Personal Information Protection and Electronic Documents Act</i>, 2nd Sess., 36th Parl., 48 Elizabeth II, 1999 (Passed by the Senate with amendments, 10 December 1999 – not yet assented to.)</p> <p>PART I - PROTECTION OF PERSONAL INFORMATION IN THE PRIVATE SECTOR</p> <p>DIVISION 1 PROTECTION OF PERSONAL INFORMATION</p> <p>S. 5(3) An organization may collect, use or disclose personal information only for purposes that a reasonable person would consider are appropriate in the circumstances.</p> <p>S. 7(2) For the purpose of clause 4.3 of Schedule 1, and despite the note that accompanies that clause, an organization may, without the knowledge or consent of the individual, use personal information only if [...] (c) it is used for statistical, or scholarly study or research, purposes that cannot be achieved without using the information, the information is used in a manner that will ensure its confidentiality, it is impracticable to obtain consent and the organization informs the Commissioner of the use before the information is used; [...]</p> <p>S. 7(3) For the purpose of clause 4.3 of Schedule 1, and despite the note that accompanies that clause, an organization may disclose personal information without the knowledge or consent of the individual only if the disclosure is [...] (f) for statistical, or scholarly study or research, purposes that cannot be achieved without disclosing the information, it is impracticable to obtain consent and the organization informs the Commissioner of the disclosure before the information is disclosed; [...]</p> | | | | | | <p><i>An Act respecting the Protection of Personal Information in the Private Sector</i>, R.S.Q. c. P-39.1</p> <p>DIVISION III CONFIDENTIALITY OF PERSONAL INFORMATION</p> <p>§1. – Retention, use and non-communication of information</p> <p>S. 12 Once the object of a file has been achieved, no information contained in it may be used otherwise than with the consent of the person concerned, subject to the time limit prescribed by law or by a retention schedule established by government regulation.</p> <p>S. 13 No person may communicate to a third person the personal information contained in a file he holds on another person, or use it for purposes not relevant to the object of the file, unless the person concerned consents thereto or such communication or use is provided for by this Act.</p> <p>S. 17 Every person carrying on an enterprise in Québec who communicates, outside Québec, information relating to persons residing in Québec or entrusts a person outside Québec with the task of holding, using or communicating such information on his behalf must take all reasonable steps to ensure (1) that the information will not be used for purposes not relevant to the object of the file or communicated to third persons without the consent of the persons concerned, except in cases similar to those described in sections 18 and 23; [...]</p> <p>S. 18 A person carrying on an enterprise may, without consent of the person concerned, communicate personal information contained in a file he holds on</p> | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Newfoundland and Labrador |
|--|------------------|---------|--------------|----------|---------|--|---------------|-------------|----------------------|---------------------------|
| <p>S. 7(4) Despite clause 4.5 of Schedule 1, an organization may use personal information for purposes other than those for which it was collected in any of the circumstances set out in subsection (2).</p> <p>S. 7(5) Despite clause 4.5 of Schedule 1, an organization may disclose personal information for purposes other than those for which it was collected in any of the circumstances set out in paragraphs (3)(a) to (h.1).</p> <p>SCHEDULE 1 Principles set out in the National Standard of Canada entitled <i>Model Code for the Protection of Personal Information</i>, CAN/CSA – Q830-96</p> <p>4.3 Principle 3 - Consent The knowledge and consent of the individual are required for the collection, use, or disclosure of personal information, except where inappropriate.</p> <p>Note: In certain circumstances personal information can be collected, used, or disclosed without the knowledge and consent of the individual. For example, legal, medical, or security reasons may make it impossible or impractical to seek consent. When information is being collected for the detection and prevention of fraud or for law enforcement, seeking the consent of the individual might defeat the purpose of collecting the information. Seeking consent may be impossible or inappropriate when the individual is a minor, seriously ill, or mentally incapacitated. In addition, organizations that do not have a direct relationship with the individual may not always be able to seek consent. For example, seeking consent may be impractical for a charity or a direct-marketing firm that wishes to acquire a mailing list from another organization. In such cases, the organization providing the list would be expected to obtain consent before disclosing personal information.</p> <p>4.3.1 Consent is required for the collection of personal information and the subsequent use or disclosure of this information. Typically, an organization will seek consent for the use or disclosure of the information at the time of collection. In certain circumstances, consent with</p> | | | | | | <p>that person [...]</p> <p>(8) to a person who is authorized to use the information for study, research or statistical purposes in accordance with section 21; [...]</p> <p>S. 21 The Commission d'accès à l'information, established by section 103 of the Act respecting Access to documents held by public bodies and the Protection of personal information (chapter A-2.1) may, on written request, grant a person authorization to receive communication of personal information for study, research or statistical purposes, without the consent of the persons concerned, if it is of the opinion that</p> <p>(1) the intended use is not frivolous and the ends contemplated cannot be achieved unless the information is communicated in a form allowing the persons to be identified;</p> <p>(2) the information will be used in a manner that will ensure its confidentiality.</p> <p>Such authorization is granted for the period and on the conditions fixed by the Commission. It may be revoked before the expiry of the period for which it is granted if the Commission has reasons to believe that the person authorized does not respect the confidentiality of the information communicated to him or does not respect the other conditions.</p> | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Newfoundland and Labrador |
|--|------------------|---------|--------------|----------|---------|--------|---------------|-------------|----------------------|---------------------------|
| <p>respect to use or disclosure may be sought after the information has been collected but before use (for example, when an organization wants to use information for a purpose not previously identified).</p> <p>4.3.2 The principle requires “knowledge and consent”. Organizations shall make a reasonable effort to ensure that the individual is advised of the purposes for which the information will be used. To make the consent meaningful, the purposes must be stated in such a manner that the individual can reasonably understand how the information will be used or disclosed.</p> <p>4.3.3 An organization shall not, as a condition of the supply of a product or service, require an individual to consent to the collection, use or disclosure of information beyond that required to fulfil the explicitly specified, and legitimate purposes.</p> <p>4.5 Principle 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 necessary for the fulfilment of those purposes. [Note: See Clause 4.2.4 in “Collection of Personal Information in the Private Sector”, above.]</p> <p>4.5.1 Organizations using personal information for a new purpose shall document this purpose. [Note: See Clause 4.2.1 in “Collection of Personal Information in the Private Sector”, above.]</p> | | | | | | | | | | |

USE AND DISCLOSURE OF PERSONAL HEALTH INFORMATION

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|--|---|--|---|--------|---------------|-------------|--------|--------------------|
| | | <p>Bill 40, Health Information Act, 3rd Sess., 24th Leg., Alberta, 1999 (Royal assent 9 December 1999 - not yet proclaimed in force.)</p> <p>PART 4 USE OF HEALTH INFORMATION</p> <p>S. 25 No custodian shall use health information except in accordance with this Act.</p> <p>[Note: “Custodian”, within the meaning of this Act, is defined in “Collection of Personal Health Information”, see above.]</p> <p>S. 26 A custodian may use non-identifying health information for any purpose.</p> <p>S. 27(1) A custodian may use individually identifying health information in its custody or under its control for the following purposes: [...]</p> <p>(d) conducting research</p> <p>(i) if the custodian has submitted a proposal to an ethics committee in accordance with section 49,</p> <p>(ii) if the ethics committee is satisfied as to the matters referred to in section 50(1)(b),</p> <p>(ii.1) if the custodian has complied with or has undertaken to comply with the conditions, if any, suggested by the ethics committee, and</p> <p>(iii) where the ethics committee recommends that consents should be obtained from the individuals who are the subjects of the health information to be used in the research, if those consents have been obtained;</p> <p>[Note: “research” is defined in s. 1(1)(v) as “academic, applied or scientific health-related research that necessitates the use of individually identifying diagnostic, treatment and care information or individually identifying registration information, or both”.]</p> <p>S. 28 An affiliate of a custodian must not use</p> | <p>The Health Information Protection Act, S.S. 1999, c. H-0.021 (Royal assent 6 May 1999 - not yet proclaimed in force.)</p> <p>PART II Rights of the Individual</p> <p>S. 5(1) An individual has the right to consent to the use or disclosure of personal health information about himself or herself.</p> <p>(2) Subject to subsections (3) and (4), a trustee must obtain the consent of the subject individual before using or disclosing personal health information.</p> <p>[Note: “Trustee”, within the meaning of this Act, is defined in “Collection of Personal Health Information”, see above.]</p> <p>(3) A trustee may use personal health information without the consent of the subject individual only in the circumstances set out in subsection 26(4) or 29(2) and only if the use is made in accordance with section 23.</p> <p>(4) A trustee may disclose personal health information without the consent of the subject individual only in the circumstances set out in subsection 27(4), section 28 or subsection 29(2) and only if the disclosure is made in accordance with section 23.</p> <p>S. 9(1) An individual has the right to be informed about the anticipated uses and disclosures of the individual's personal health information.</p> | <p>The Personal Health Information Act, S.M. 1997, c. P-33.5</p> <p>PART 3 PROTECTION OF PRIVACY</p> <p>DIVISION 3 RESTRICTIONS ON USE AND DISCLOSURE OF INFORMATION</p> <p>General Duties of Trustees</p> <p>S. 20(1) A trustee shall not use or disclose personal health information except as authorized under this Division.</p> <p>[Note: “Trustee”, within the meaning of this Act, is defined in “Collection of Personal Health Information”, see above.]</p> <p>(2) Every use and disclosure by a trustee of personal health information must be limited to the minimum amount of information necessary to accomplish the purpose for which it is used or disclosed.</p> <p>(3) A trustee shall limit the use and disclosure of personal health information it maintains to those of its employees and agents who need to know the information to carry out the purpose for which the information was collected or received or to carry out a purpose authorized under section 21.</p> <p>Restrictions on Use of Information</p> <p>S. 21 A trustee may use personal health information only for the purpose for which it was collected or received, and shall not use it for any other purpose, unless</p> <p>(a) the other purpose is directly related to the purpose for which the personal health information was collected or received;</p> | <p>Draft Personal Health Information Protection Act, 1997 (Not in force.)</p> <p>PART I GENERAL</p> <p>S. 4(1) No health information custodian shall collect, use or disclose personal health information or retain a personal health record if information that is not personal health information will serve the purpose of the collection, use, disclosure or retention, as the case may be.</p> <p>[Note: “Health information custodian”, within the meaning of this Act, is defined in “Collection of Personal Health Information”, see above.]</p> <p>(2) To the extent reasonably possible, a health information custodian may collect, use or disclose only as much personal health information or retain as much of a personal health record as is reasonably necessary to meet the purpose of the collection, use, disclosure or retention, as the case may be.</p> <p>(3) To the extent reasonably possible, a health information custodian who collects, uses or discloses personal health information or who retains a personal health record shall conceal the identity of the subject of the information or the record while still meeting the purpose of the collection, use, disclosure or retention, as the case may be.</p> <p>(4) For the purposes of subsections (1), (2) and (3), a health information custodian shall comply with the standards, if any, prescribed in the regulations.</p> <p>PART III COLLECTION, USE AND DISCLOSURE OF PERSONAL HEALTH INFORMATION</p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | PE.I. | Nfld. and Labrador |
|---------|------------------|--|--|---|---|--------|---------------|-------------|-------|--------------------|
| | | <p>health information in any manner that is not in accordance with the affiliate's duties to the custodian.</p> <p>S. 29 A custodian that collects information described in section 1(1)(I), (o) or (u) that is not written, photographed, recorded or stored in some manner in a record may use the information only for the purpose for which the information was provided to the custodian. [Note: Sections 1(1)(i), (o) or (u) refer to "diagnostic, treatment and care information", "health services provider information" or "registration information", respectively. See "Definition of Personal Health Information", above.]</p> <p>S. 30 A person who is authorized to require an individual to provide a personal health number pursuant to section 21(1)(b) may use that information only for the purpose for which the information was collected. [Note: Section 21(1)(b) is reproduced in "Collection of Personal Health Information", see above.]</p> <p>PART 5 DISCLOSURE OF HEALTH INFORMATION</p> <p>Division 1 General Disclosure Rules</p> <p>S. 31 No custodian shall disclose health information except in accordance with this Act.</p> <p>S. 32(1) A custodian may disclose non-identifying health information for any purpose.</p> <p>(2) If a disclosure under subsection (1) is to a person that is not a custodian, the custodian must inform the person that the person must notify the Commissioner of an intention to use the information for data matching before performing the data matching.</p> <p>S. 33 A custodian may disclose individually identifying health information to the individual who is the subject of the information or to a person referred to in section 104(1)(c) to (i) who is acting on behalf</p> | <p>(2) When a trustee is collecting personal health information from the subject individual, the trustee must take reasonable steps to inform the individual of the anticipated use and disclosure of the information by the trustee.</p> <p>(3) A trustee must establish policies and procedures to promote knowledge and awareness of the rights extended to individuals by this Act, including the right to request access to their personal health information and to request amendment of that personal health information.</p> <p>S. 10 A trustee must take reasonable steps to ensure that the trustee is able to inform an individual about any disclosures of that individual's personal health information made without the individual's consent after the coming into force of this section.</p> <p>PART III Duty of Trustee to Protect Personal Health Information</p> <p>S. 20(1) Where one trustee discloses personal health information to another trustee, the information may become a part of the records of the trustee to whom it is disclosed, while remaining part of the records of the trustee that makes the disclosure.</p> <p>(2) Where personal health information disclosed by one trustee becomes a part of the records of the trustee to whom the information is disclosed, the trustee to whom the information is disclosed is subject to the same duties with respect to that information as the trustee that discloses the information.</p> <p>S. 21 Where a trustee discloses personal health information to a person who is not a trustee, the</p> | <p>(b) the individual the personal health information is about has consented to the use; [...]</p> <p>(d) the trustee is a public body or a health care facility and the personal health information is used</p> <p>(i) to deliver, monitor or evaluate a program that relates to the provision of health care or payment for health care by the trustee, or</p> <p>(ii) for research and planning that relates to the provision of health care or payment for health care by the trustee; (or)</p> <p>(e) the purpose is one for which the information may be disclosed to the trustee under section 22; [...]</p> <p>Restrictions on Disclosure of Information</p> <p>S. 22(1) Except as permitted by subsection (2), a trustee may disclose personal health information only if</p> <p>(a) the disclosure is to the individual the personal health information is about or his or her representative; or</p> <p>(b) the individual the information is about has consented to the disclosure.</p> <p>S. 22(2) A trustee may disclose personal health information without the consent of the individual the information is about if the disclosure is [...]</p> <p>(f) in accordance with section 23 (disclosure to patient's family) 24 (disclosure for health research) or 25 (disclosure to an information manager);</p> <p>(g) for the purpose of</p> <p>(i) delivering, evaluating or monitoring a program of the trustee that relates to the provision of health care or payment for health care, or</p> <p>(ii) for [sic] research and planning that relates to the provision of health care or payment for health care by the trustee; (or)</p> <p>(h) to a computerized health information network and database,</p> | <p>S. 12(1) A health information custodian who has custody or control of personal health information shall maintain the confidentiality of the information and shall not use or disclose it except as permitted or required under this Act.</p> <p>(2) A person to whom a health information custodian discloses personal health information shall not use or disclose the information for any purpose other than the purpose for which the custodian disclosed it unless permitted or required by this Act or some other law.</p> <p>S. 13(1) A health information custodian may use personal health information,</p> <p>a) for the purpose for which the information was collected or created or for a consistent purpose;</p> <p>b) for a purpose to which the subject of the information consents; (or) [...]</p> <p>e) for the purpose of a research project of the custodian if,</p> <p>i) the research project is not contrary to the public interest, and</p> <p>ii) the approval of a research ethics review body has been obtained, if required; [...]</p> <p>(2) If personal health information has been collected from the subject of the information, the purpose of a use of that information is a consistent purpose under clause (1) (a) only if,</p> <p>a) the individual might reasonably have expected the use; or</p> <p>b) the use is reasonably compatible with the purpose for which the information was collected or created.</p> <p>S. 14(1) A health information custodian may disclose personal health information,</p> <p>1. to the subject of the information; [...]</p> <p>3. for a purpose to which the subject of the information consents; (or) [...]</p> <p>22. for the purpose of a research project if</p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | PE.I. | Nfld. and Labrador |
|---------|------------------|---|---|--|---|--------|---------------|-------------|-------|--------------------|
| | | <p>of that individual.</p> <p>[Note: Sections 104(1)(c) to (i) are reproduced in “Consent and Substitute Decision Making Respecting Personal Health Information”, see below.]</p> <p>S. 34(1) Subject to sections 35 to 40, a custodian may disclose individually identifying health information to a person other than the individual who is the subject of the information if the individual has consented to the disclosure. [...]</p> <p>(3) A disclosure of health information pursuant to this section must be carried out in accordance with the terms of the consent.</p> <p>S. 35(1) A custodian may disclose individually identifying diagnostic, treatment and care information without the consent of the individual who is the subject of the information (a) to another custodian for any or all of the purposes listed in section 27(1) or (2), as the case may be. [...]</p> <p>S.36 A custodian may disclose individually identifying registration information without the consent of the individual who is the subject of the information (a) for any of the purposes for which diagnostic, treatment and care information may be disclosed under section 35(1) or (4); [...] (c) to a person who is not a custodian if the disclosure is in accordance with the requirements set out in the regulations.</p> <p>S. 37(2) A custodian may disclose the health services provider information described in section 1(1)(o)(i) to (iii), (vii), (xiv), (xv), (xviii) and (xix) [note: see “Definition of Personal Health Information”, above] other than home address, telephone number and licence number, to any person for any purpose without the consent of the individual who is the subject of the information, unless the disclosure (a) would reveal other information about the health services provider, or (b) could reasonably be expected to result</p> | <p>trustee must:</p> <p>(a) verify the identity of the person to whom the information is disclosed; and (b) where the disclosure is made without the consent of the subject individual, take reasonable steps to ensure that the person to whom the information is disclosed is aware that the information must not be used or disclosed for any purpose other than the purpose for which it was disclosed unless otherwise authorized pursuant to this Act.</p> <p>PART IV Limits on Collection, Use and Disclosure of Personal Health Information by Trustees</p> <p>S. 23(1) A trustee shall collect, use or disclose only the personal health information that is reasonably necessary for the purpose for which it is being collected, used or disclosed.</p> <p>(2) A trustee shall not permit any of its employees to have access to personal health information that is available to the trustee except where: (a) the employees need to know the information to carry out the purpose for which the information was collected or to carry out a purpose authorized pursuant to section 26; or (b) the information will be used primarily to benefit the subject individual.</p> <p>(3) A trustee shall not use personal health information in any manner or disclose personal health information to any person other than the subject individual except in accordance with this Act.</p> <p>(4) A trustee must use or disclose only de-identified personal health information if it will serve the purpose.</p> | <p>established by the government or another trustee that is a public body specified in the regulations, in which personal health information is recorded for the purpose of facilitating (i) the delivery, evaluation or monitoring of a program that relates to the provision of health care or payment for health care, or (ii) research and planning that relates to the provision of health care or payment for health care; [...]</p> <p>(3) A trustee may disclose information under subsection (2) only to the extent the recipient needs to know the information.</p> <p>Health Research</p> <p>S. 24(1) A trustee may disclose personal health information to a person conducting a health research project only if the project has been approved under this section.</p> <p>(2) An approval may be given by (a) the health information privacy committee established under section 59, if the personal health information is maintained by the government or a government agency; and (b) an institutional research review committee, if the personal health information is maintained by a trustee other than the government or a government agency.</p> <p>(3) An approval may be given under this section only if the health information privacy committee or the institutional research review committee, as the case may be, has determined that (a) the research is of sufficient importance to outweigh the intrusion into privacy that would result from the disclosure of personal health information; (b) the research purpose cannot reasonably be accomplished unless the personal health information is provided in a form that identifies or may identify</p> | <p>the disclosure is made in accordance with section 15; [...]</p> <p>S. 15(1) A health information custodian may disclose personal health information under paragraph 22 of subsection 14 (1) for the purpose of a research project if, (a) the objective of the research project cannot reasonably be accomplished using other information; (b) the research project is not contrary to public interest; (c) the approval of a research ethics review body has been obtained, if the approval is required by law or by the person funding the research project or is requested by the custodian; and (d) subject to subsection (2), the person to whom the personal health information is to be disclosed has entered into an agreement with the custodian agreeing to the terms set out in subsection (3).</p> <p>[Note: Section 2(1) of the Act defines a “research project” as one which includes “an academic pursuit or the compilation of statistical data but does not include research for marketing purposes”.]</p> <p>(2) A health information custodian that disclosed personal health information for the purpose of a research project to a person before this section comes into force and that discloses personal health information to the person after this section comes into force is not required to enter into the agreement described in clause (1)(d) until the later of the time at which it discloses the information and one year after the day on which this section comes into force.</p> <p>(3) The following are the terms mentioned in clause (1)(d):</p> <ol style="list-style-type: none"> 1. The person shall conduct the research project in compliance with, <ol style="list-style-type: none"> i. this Act and the regulations, ii. the conditions and requirements, if any, attached to the approval, if any, given by a research ethics review body, and iii. the administrative, technical and | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | PE.I. | Nfld. and Labrador |
|---------|------------------|---|---|---|---|--------|---------------|-------------|-------|--------------------|
| | | <p>in</p> <p>(i) harm to the health services provider's mental or physical health or safety, or</p> <p>(ii) undue financial harm to the health services provider.</p> <p>S. 41(1) A custodian that discloses a record containing individually identifying diagnostic, treatment and care information under section 35(1) or (4) must make a note of the following information:</p> <p>(a) the name of the person to whom the custodian discloses the information;</p> <p>(b) the date and purpose of the disclosure;</p> <p>(c) a description of the information disclosed.</p> <p>(2) The information referred to in subsection (1) must be retained by the custodian for a period of 10 years following the date of the disclosure.</p> <p>(3) An individual who is the subject of information referred to in subsection (1) may ask a custodian for access to and a copy of the information, and Part 2 applies to the request.</p> <p>S. 42(1) A custodian that discloses individually identifying diagnostic, treatment and care information must inform the recipient in writing of the purpose of the disclosure and the authority under which the disclosure is made.</p> <p>(2) Subsection (1) does not apply where the disclosure is</p> <p>(a) to another custodian under section 35(1)(a);</p> <p>[...]</p> <p>S. 43 An affiliate of a custodian must not disclose health information in any manner that is not in accordance with the affiliate's duties to the custodian.</p> <p>S. 44 A custodian that collects information described in section 1(1)(i), (o) or (u) that is not written, photographed, recorded or stored in some manner in a record may disclose the information only for the purpose for which the information was provided to the custodian.</p> <p>[Note: Sections 1(1)(i), (o) or (u) refer to "diagnostic, treatment and care information", "health services provider</p> | <p>S. 26(1) A trustee may use personal health information for any purpose with the express consent of the subject individual.</p> <p>(2) Subject to subsection (4) and section 29, a trustee shall not use personal health information in the custody or control of the trustee except with the consent of the subject individual.</p> <p>(3) Consent to the use of personal health information must be express consent, except where it is reasonable for the trustee to infer that the subject individual would consent to the use and where the use:</p> <p>(a) is for the purpose for which the information was collected by the trustee or for a purpose that is consistent with that purpose; (or) [...]</p> <p>(c) occurs in prescribed circumstances.</p> <p>(4) A trustee may use personal health information in the custody or control of the trustee without the consent of the subject individual in the following cases:</p> <p>(a) where the personal health information is used for a purpose for which the information may be disclosed by the trustee pursuant to section 27, 28 or 29;</p> <p>(b) where the personal health information is being de-identified;</p> <p>(c) where the personal health information is used for a prescribed purpose.</p> <p>S. 27(1) A trustee may disclose personal health information to any person for any purpose with the express consent of the subject individual.</p> <p>(2) Subject to subsection (4) and sections 28 and 29, a trustee shall not disclose personal health</p> | <p>individuals;</p> <p>(c) it is unreasonable or impractical for the person proposing the research to obtain consent from the individuals the personal health information is about; and</p> <p>(d) the research project contains</p> <p>(i) reasonable safeguards to protect the confidentiality and security of the personal health information, and</p> <p>(ii) procedures to destroy the information or remove all identifying information at the earliest opportunity consistent with the purposes of the project.</p> <p>(4) An approval under this section is conditional on the person proposing the research project entering into an agreement with the trustee, in accordance with the regulations, in which the person agrees</p> <p>(a) not to publish the personal health information requested in a form that could reasonably be expected to identify the individuals concerned;</p> <p>(b) to use the personal health information requested solely for the purposes of the approved research project; and</p> <p>(c) to ensure that the research project complies with the safeguards and procedures described in clause (3)(d).</p> <p>(5) If a research project will require direct contact with individuals, a trustee shall not disclose personal health information about those individuals under this section without first obtaining their consent. However, the trustee need not obtain their consent if the information consists only of the individuals' names and addresses.</p> <p>PHIN</p> <p>S. 26(1) No person other than a trustee may require the production of another person's PHIN (personal health information number) or collect or use another person's PHIN.</p> <p>(2) Despite subsection (1), a person may</p> | <p>physical measures relating to the confidentiality and security of personal health information that the custodian specifies in the agreement.</p> <p>2. The person shall not use the personal health information except for the research project specified in the agreement or a new research project for which the person has written permission to use the information from the custodian.</p> <p>3. The person shall not disclose the personal health information except,</p> <p>i. to persons who need the information to assist in carrying out the project and who are named in the agreement, or</p> <p>ii. under paragraph 3, 11 or 24 of subsection 14 (1).</p> <p>4. The person shall not contact the subject of the personal health information, whether for the purpose of seeking additional information in relation to the research project, for the purpose of seeking consent to the disclosure of information pertaining to the research project or for any other purpose, unless the custodian has contacted the subject first, explained to the subject the purpose for which the person wishes to contact the subject and obtained the subject's consent to being contacted by the person.</p> <p>5. The person shall,</p> <p>i. by the date specified in the agreement, return to the custodian all original personal health records received from the custodian, and</p> <p>ii. by the date specified in the agreement, destroy all copies of the personal health records that were made or received by the person, or delete or destroy those parts of the copies that would permit identification of the subjects of the personal health records.</p> <p>6. The person shall provide the custodian with a copy of the reports that it prepares on the research project.</p> <p>(4) The <i>Freedom of Information and Protection of Privacy Act</i> and the <i>Municipal</i></p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | PE.I. | Nfld. and Labrador |
|---------|------------------|---|---|--|--|--------|---------------|-------------|-------|--------------------|
| | | <p>information” or “registration information”, respectively. See “Definition of Personal Health Information”, above.]</p> <p>S. 45 A custodian that discloses health information must make a reasonable effort to ensure that the person to whom the disclosure is made is the person intended and authorized to receive the information.</p> <p>Division 3 Disclosure for Research Purposes</p> <p>S. 48 In this Division, “health information” means individually identifying diagnostic, treatment and care information or individually identifying registration information, or both.</p> <p>S. 49 A person who intends to conduct research may submit a proposal to an ethics committee for review by that committee.</p> <p>S. 50(1) The ethics committee must (a) consider whether the researcher should be required to obtain consents for the disclosure of the health information to be used in the research from the individuals who are the subjects of the information, and (b) assess whether, in the opinion of the ethics committee, (i) the proposed research is of sufficient importance that the public interest in the proposed research outweighs to a substantial degree the public interest in protecting the privacy of the individuals who are the subjects of the health information to be used in the research, (ii) the researcher is qualified to carry out the research, (iii) adequate safeguards will be in place at the time the research will be carried out to protect the privacy of the individuals who are the subjects of the health information to be used in the research and the confidentiality of that information, and (iv) obtaining the consents referred to in clause (a) is unreasonable, impracticable or not feasible.</p> <p>(2) In making an assessment under subsection (1)(b), the ethics committee must consider the degree to which the proposed research may contribute to</p> | <p>information in the custody or control of the trustee except with the consent of the subject individual.</p> <p>(3) Consent to the disclosure of personal health information must be express consent, except where it is reasonable for the trustee to infer that the subject individual would consent to the disclosure and where the disclosure is being made: (a) for the same purpose as the purpose for which the information was collected by the trustee or for a purpose that is consistent with that purpose; [...] (d) in any cases prescribed in the regulations;</p> <p>(4) A trustee may disclose personal health information in the custody or control of the trustee without the consent of the subject individual in the following cases: [...] (q) where the disclosure is being made in cases prescribed in the regulations.</p> <p>S. 29(1) A trustee or a designated archive may use or disclose personal health information for research purposes with the express consent of the subject individual if: (a) in the opinion of the trustee or designated archive, the research project is not contrary to the public interest; (b) the research project has been approved by a research ethics committee approved by the minister; and (c) the person who is to receive the personal health information enters into an agreement with the trustee or designated archive that contains provisions: (i) providing that the person who is to receive the information must not disclose the information; (ii) providing that the person who</p> | <p>collect or use another person’s PHIN [...] (b) for purposes of a health research project approved under section 24; [...]</p> <p>PART 6 GENERAL PROVISIONS</p> <p>S. 66(1) The Lieutenant Governor in Council may make regulations [...] (d) requiring trustees to provide notice to individuals about [...] (ii) the practices of the trustee respecting the collection, use, retention and disclosure of personal health information, and providing for the form and content of such notices; [...] (g) requiring trustees to maintain a record of disclosures of personal health information made under this Act; [...] (i) specifying public bodies for the purpose of clause 22(2)(h); (j) respecting agreements for the purposes of subsections 24(4) and 25(3); [...] (l) governing the disclosure of personal health information to persons or bodies outside Manitoba; (m) respecting the appointment of members of the health information privacy committee established under section 59 and governing the duties and functions of the committee and all related matters; [...]</p> | <p><i>Freedom of Information and Protection of Privacy Act</i> do not apply to personal information within the meaning of those Acts that a person requires for the purpose of conducting a research project if the person has entered into an agreement mentioned in clause (1) (d) with respect to the project and in that case the agreement applies to that personal information, as well as to personal health information with respect to the project.</p> <p>(5) A custodian who has disclosed information under this section for the purpose of a research project shall not give the person to whom the information was disclosed permission to use the information for a new research project unless the conditions set out in clauses (1) (a) to (d) have been met with respect to the new research project.</p> <p>PART IX MISCELLANEOUS</p> <p>S. 72(1) The Lieutenant Governor in Council may make regulations, [...] (d) specifying standards, or a process for setting standards, with which a health information custodian shall comply for the purpose of subsections 4(1) to (4) and specifying the circumstances in which the custodian is required to comply with the standards; [...] (h) specifying the requirements with which a person shall comply when conducting a research project under section 15; [...]</p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|---|--|----------|---------|--------|---------------|-------------|--------|--------------------|
| | | <p>(a) identification, prevention or treatment of illness or disease, (b) scientific understanding relating to health, (c) promotion and protection of the health of individuals and communities, (d) improved delivery of health services, or (e) improvements in health system management.</p> <p>(3) The ethics committee must prepare a response setting out (a) its recommendation under subsection (1)(a), (b) its assessment of the matters set out in subsection (1)(b), and (c) any conditions that the ethics committee considers should be imposed on the researcher.</p> <p>(4) The ethics committee must send a copy of the response required in subsection (3) to the Commissioner.</p> <p>S. 51 If the ethics committee is not satisfied as to any of the matters referred to in section 50(1)(b), the researcher may not apply to a custodian under section 52.</p> <p>S. 52 If the ethics committee is satisfied as to the matters referred to in section 50(1)(b), the researcher may forward to one or more custodians (a) the response of the ethics committee to the researcher's proposal, and (b) a written application for disclosure of the health information to be used in the research.</p> <p>S. 53(1) A custodian who has received the documents referred to in section 52 may, but is not required to, disclose the health information applied for. (2) If the custodian decides to disclose the health information, (a) the custodian (i) must impose on the researcher any conditions suggested by the ethics committee, and (ii) may impose other conditions on the researcher, and (b) the researcher must obtain the consents referred to in section 50(1)(a), if recommended by the ethics committee, prior</p> | <p>is to receive the information will ensure that the information will be used only for the purpose set out in the agreement; (iii) providing that the person who is to receive the information will take reasonable steps to ensure the security and confidentiality of the information; and (iv) specifying when the person who is to receive the information must do all or any of the following: (A) return to the trustee or designated archive any original records or copies of records containing personal health information; (B) destroy any copies of records containing personal health information received from the trustee or designated archive or any copies made by the researcher of records containing personal health information received from the trustee or designated archive.</p> <p>(2) Where it is not reasonably practicable for the consent of the subject individual to be obtained, a trustee or designated archive may use or disclose personal health information for research purposes if: (a) the research purposes cannot reasonably be accomplished using de-identified personal health information or other information; (b) reasonable steps are taken to protect the privacy of the subject individual by removing all personal health information that is not required for the purposes of the research; (c) in the opinion of the research ethics committee, the potential benefits of the research project clearly outweigh the potential risk to the privacy of the subject individual; and (d) all of the requirements set out in</p> | | | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | PE.I. | Nfld. and Labrador | |
|---------|------------------|---|---|----------|---------|--------|---------------|-------------|-------|--------------------|--|
| | | <p>to the disclosure.</p> <p>S. 54(1) If the custodian decides to disclose health information to a researcher, the researcher must enter into an agreement with the custodian in which the researcher agrees</p> <p>(a) to comply with</p> <p>(i) this Act and the regulations made under this Act,</p> <p>(ii) any conditions imposed by the custodian relating to the use, protection, disclosure, return or disposal of the health information, and</p> <p>(iii) any requirement imposed by the custodian to provide safeguards against the identification, direct or indirect, of an individual who is the subject of the health information,</p> <p>(b) to use the health information only for the purpose of conducting the proposed research,</p> <p>(c) not to publish the health information in a form that could reasonably enable the identity of an individual who is the subject of the health information to be readily ascertained,</p> <p>(d) not to make any attempt to contact an individual who is the subject of the health information to obtain additional health information unless the individual has provided the custodian with the consent referred to in section 55,</p> <p>(e) to allow the custodian to access or inspect the researcher's premises to confirm that the researcher is complying with the enactments, conditions and requirements referred to in clause (a), and</p> <p>(f) to pay the costs referred to in subsection (3).</p> <p>(2) When an agreement referred to in subsection (1) has been entered into, the custodian may disclose to the researcher the health information requested under s. 52</p> <p>(a) with the consent of the individuals who are the subjects of the information, where the ethics committee recommends that consents should be obtained, or</p> <p>(b) without the consent of the individuals who are the subjects of the information, where the ethics committee does not recommend that consents be obtained.</p> <p>(3) The custodian may set the costs of</p> <p>(a) preparing information for disclosure,</p> | <p>clauses (1)(a) to (c) are met.</p> <p>S. 30(1) No person to whom a trustee has disclosed personal health information about another individual shall use or disclose the information for any purpose other than the purpose for which it was disclosed unless otherwise authorized pursuant to this Act.</p> <p>(2) Subsection (1) does not apply to personal health information disclosed by a trustee to a member of the subject individual's immediate family or to anyone else with whom the subject individual has a close personal relationship.</p> <p>(3) No person who acquires personal health information in contravention of this Act shall use or disclose the information.</p> <p>PART VIII General</p> <p>S. 57 Where information about a trustee or the activities of a trustee is collected in conjunction with the collection of personal health information and regulations are made pursuant to clause 63(1)(w) governing that information, no person shall use or disclose the information about the trustee or the trustee's activities except in accordance with those regulations.</p> <p>S. 63(1) For the purpose of carrying out this Act according to its intent, the Lieutenant Governor in Council may make regulations: [...] (m) for the purposes of clause 26(3)(c), prescribing purposes for which personal health information may be used without the express consent of the subject individual; (n) for the purposes of clause 26(4)(c), prescribing purposes for which personal health information</p> | | | | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | PE.I. | Nfld. and Labrador |
|---------|------------------|---|---|----------|---------|--------|---------------|-------------|-------|--------------------|
| | | <p>(b) making copies of health information, and (c) obtaining the consents referred to in s.55, which must not exceed the actual cost of providing that service.</p> <p>(4) If the researcher contravenes or fails to meet the terms and conditions of an agreement under this section, the agreement is cancelled.</p> <p>S. 55 If the researcher wishes to contact the individuals who are the subjects of the information disclosed under section 54(2) to obtain additional health information, the custodian or an affiliate of the custodian must first obtain consents from those individuals to their being contacted for that purpose.</p> <p>S. 56(1) If a researcher refuses to allow a custodian to access or inspect its premises in accordance with the agreement referred to in section 54, the custodian may apply to the Court of Queen’s Bench by notice of motion for an order under subsection (2).</p> <p>(2) If the Court is satisfied that there are reasonable and probable grounds to believe that access to premises or the production or removal of documents is necessary for the purpose of determining whether an agreement referred to in section 54 is being complied with, the Court may make any order it considers necessary to enforce compliance with the agreement.</p> <p>(3) Where authorized to do so by an order under subsection (2), a custodian may (a) enter and search any premises of the researcher where the research is conducted, (b) operate or cause to be operated any computer system of the researcher to search any data contained in or available to the system and produce a document from the data, and (c) seize and make copies of any documents of the researcher that are or may be relevant to the investigation.</p> <p>(4) An application for an order under this section may be made ex parte unless the Court orders otherwise.</p> <p>(5) The custodian must return any documents seized pursuant to a court order within 60 days</p> | <p>may be used without the consent of the subject individual; (o) prescribing and governing cases in which, persons to whom and purposes for which personal health information may be disclosed: (i) with implied consent pursuant to clause 27(3)(d); or (ii) without consent pursuant to clause 27(4)(q); [...] (w) for the purposes of section 57, governing the use and disclosure of information respecting trustees and their activities; [...]</p> | | | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|--|--------------|----------|---------|--------|---------------|-------------|--------|--------------------|
| | | <p>after the conclusion of the investigation that gave rise to the seizure, including any hearing or appeal.</p> <p>(6) In this section, “document” includes any correspondence, memorandum, book, plan, map, drawing, diagram, pictorial or graphic work, photograph, film, microfilm, sound recording, videotape, machine readable record or other material or thing, regardless of physical form or characteristics.</p> <p>PART 6 DUTIES AND POWERS OF CUSTODIANS RELATING TO HEALTH INFORMATION</p> <p>Division 1 General Duties and Powers</p> <p>57(1) In this section, “aggregate health information” means non-identifying health information about groups of individuals.</p> <p>(2) A custodian that intends to collect, use or disclose health information must first consider whether collection, use or disclosure of aggregate health information is adequate for the intended purpose, and if so, the custodian must collect, use or disclose only aggregate health information.</p> <p>(3) If the custodian believes that collecting, using or disclosing aggregate health information is not adequate for the custodian’s intended purpose, the custodian must then consider whether collection, use or disclosure of other non-identifying health information is adequate for the intended purpose, and if so, the custodian may collect, use or disclose other non-identifying health information.</p> <p>(4) If the custodian believes that collecting, using or disclosing aggregate and other non-identifying health information is not adequate for the custodian’s intended purpose, the custodian may collect, use or disclose individually identifying health information if the collection, use or disclosure</p> <p>(a) is authorized by this Act, and</p> <p>(b) is carried out in accordance with this Act.</p> | | | | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|--|--------------|----------|---------|--------|---------------|-------------|--------|--------------------|
| | | <p>(5) This section does not apply where the collection, use or disclosure is for the purpose of</p> <ul style="list-style-type: none"> (a) providing health services, or (b) determining or verifying the eligibility of an individual to receive a health service. <p>S. 58(1) When collecting, using or disclosing health information, a custodian must, in addition to complying with section 57, collect, use or disclose only the amount of health information that is essential to enable the custodian or the recipient of the information, as the case may be, to carry out the intended purpose.</p> <p>(2) In deciding how much health information to disclose, a custodian must consider as an important factor any expressed wishes of the individual who is the subject of the information relating to the disclosure of the information, together with any other factors the custodian considers relevant.</p> <p>S. 62(1) Each custodian must identify its affiliates who are responsible for ensuring that this Act, the regulations and the policies and procedures established or adopted under section 63 are complied with.</p> <p>(2) Any collection, use or disclosure of health information by an affiliate of a custodian is considered to be collection, use or disclosure by the custodian.</p> <p>(3) Any disclosure of health information to an affiliate of a custodian is considered to be disclosure to the custodian.</p> <p>(4) Each affiliate of a custodian must comply with</p> <ul style="list-style-type: none"> (a) this Act and the regulations, and (b) the policies and procedures established or adopted under section 63. <p>63(1) Each custodian must establish or adopt policies and procedures that will facilitate the implementation of this Act and the regulations.</p> <p>(2) A custodian must at the request of the Minister or the Department provide the Minister or the Department, as the case may be, with a copy of the policies and procedures</p> | | | | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | PE.I. | Nfld. and Labrador |
|---------|------------------|---|--------------|----------|---------|--------|---------------|-------------|-------|--------------------|
| | | <p>established or adopted under this section.</p> <p>S. 64(1) Each custodian must prepare a privacy impact assessment that describes how proposed administrative practices and information systems relating to the collection, use and disclosure of individually identifying health information may affect the privacy of the individual who is the subject of the information.</p> <p>(2) The custodian must submit the privacy impact assessment to the Commissioner for review and comment before implementing any proposed new practice or system described in subsection (1) or any proposed change to existing practices and systems described in subsection (1).</p> <p>S. 65 A custodian may, in accordance with the regulations, strip, encode or otherwise transform individually identifying health information to create non-identifying health information.</p> <p>PART 8 GENERAL PROVISIONS</p> <p>S. 108(1) The Lieutenant Governor in Council may make regulations [...] (f) respecting the disclosure of individually identifying registration information by custodians to persons who are not custodians for the purposes of section 36(c); [...] (i) respecting the stripping, encoding or other transformation of individually identifying health information to create non-identifying health information pursuant to section 65 ... [...]</p> <p>(2) The Minister may make regulations (a) designating committees as ethics committees for the purposes of sections 48 to 56; [...]</p> | | | | | | | | |

ACCESS TO CLINICAL RECORDS AND REGISTRIES FOR RESEARCH PURPOSES

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Newfoundland and Labrador |
|---|---|--|---|---|---|---|---|---|--------|---------------------------|
| <p><i>Health Act, R.S.B.C. 1996, c. 179</i></p> <p>PART 2 GOVERNMENT OFFICIALS AND REGULATIONS</p> <p>S. 9(1) The British Columbia Cancer Agency may request a person to supply it with information or records or classes of information or records that may be prescribed by the minister for the purposes of this section.</p> <p>(2) A request must not be made under subsection (1) unless reasonable grounds exist to believe that the information or records will facilitate medical research and that the benefit to the public of the research justifies the request for the information or records. [...]</p> <p>(7) A person who has obtained information or records pursuant to a request made under subsection (1) must not disclose the information or records to another person except (a) for the purpose of medical research and to a person engaged in medical research whether or not the</p> | <p><i>Hospitals Act, R.S.A. 1980, c. H-11</i></p> <p>PART 2 OPERATION OF APPROVED HOSPITALS</p> <p>S. 40(2) For the purposes of assessing the standards of care furnished to patients, improving hospital or medical procedures, compiling medical statistics, conducting medical research, enforcing the Crown's right of recovery under Part 5, or for any other purpose considered by the Minister to be in the public interest, the Minister, or a person authorized by the Minister, may require that all or any of the following be sent to him or a person designated by him: (a) medical and other records of any patient; (b) extracts from and copies of any medical or other records of any patient; (c) diagnoses, charts or any information available in respect of a patient.</p> <p>(3) Information obtained from hospital records or from persons having access thereto shall be treated as private and confidential information in respect of any individual patient and shall be used solely for the purposes described in subsection (2) and the information shall not be published, released or disclosed in any manner that would be detrimental to the personal interests, reputation or privacy of a patient or the patient's attending physician or any other person providing diagnostic or treatment services to a patient. [...]</p> <p>(6) Notwithstanding subsection (3) or any other law,</p> | <p><i>The Public Health Act, R.S.S. 1994, c. P-37.1</i></p> <p>PART VII</p> <p>General</p> <p>S. 65(1) Subject to subsection (2), no person shall disclose any information that comes to the person's knowledge in the course of carrying out responsibilities pursuant to this Act, the regulations or bylaws made pursuant to this Act concerning a person who: (a) is infected with or is suspected to be infected with a communicable disease; (b) is a carrier of or is suspected to be a carrier of a communicable disease; (c) is a contact of a person mentioned in clause (a) or (b); or (d) has or has had a non-communicable disease or an injury.</p> <p>(2) A person may disclose information described in subsection (1) where the disclosure: [...] (d) is made: [...] (ii) to a person who is conducting bona fide research or medical review if the disclosure is made in</p> | <p><i>The Mental Health Act, R.S.M. 1987, c. M-110</i></p> <p>PART I - ADMISSION TO PSYCHIATRIC FACILITIES</p> <p>Hearings and Appeals</p> <p>S. 26.9(2) Except as may be otherwise provided in this Act, no person shall disclose, transmit or examine a clinical record.</p> <p>(3) The medical officer in charge of a psychiatric facility in which a clinical record is prepared and maintained may disclose or transmit the record to, or permit the examination thereof by [...] (g) any person for the purpose of research, academic pursuit or the compilation of statistical data where the person agrees in writing not to disclose the name or other means of identification of the patient and not to use or communicate the information for any other purpose; [...]</p> | <p><i>Public Hospitals Act, R.R.O. 1990, Reg. 965.</i></p> <p>S. 22(1) Except as required by law or as provided in this section, no board shall permit any person to remove, inspect or receive information from medical records or from notes, charts and other material relating to patient care; [...]</p> <p>(6) A board may permit, [...] (d) a member of the medical, dental, midwifery or extended class nursing staff but only for (i) teaching purpose, or (ii) scientific research that has been approved by the medical advisory committee, (or) [...] (f) any person for the purposes of scientific research [...] to inspect and receive information from the medical records and from notes, charts and other material relating to patient care and to be given copies therefrom. -----</p> | <p><i>An Act respecting Health Services and Social Services, R.S.Q. c. S-4.2</i></p> <p>TITLE II RIGHTS OF USERS</p> <p>CHAPTER II USER'S RECORD</p> <p>S. 19 The record of a user is confidential and no person may have access to it except with the authorization of the user or the person qualified to give authorization on his behalf, on the order of a court or a coroner in the exercise of his functions, or where this Act provides that an institution may be required to release information contained in the record. However, a professional may examine a user's record for purposes of study, teaching or research, with the authorization of the director of professional services or, if there is no such director, with the authorization of the executive director granted in accordance with the criteria established in section 125 of the <i>Act respecting Access to documents held by public bodies and the protection of personal information</i> (c. A-2.1).</p> | <p><i>Public Health Act, R.S.N.B., c. P-22.4</i></p> <p>PART VI GENERAL</p> <p>Release of Information</p> <p>S. 66(1) Subject to subsection (2), no person shall disclose any information that comes to the person's knowledge in the course of carrying out responsibilities under this Act or the regulations under this Act concerning a person who (a) has or may have a notifiable disease or is or may be infected with an agent of a communicable disease, (b) is or is suspected of being a contact, or (c) is or may be affected by an injury or by a risk factor prescribed by the regulations or has suffered a reportable event prescribed by the regulations.</p> <p>(2) A person may disclose information described in subsection (1) where the disclosure is [...] (g) made to a person who is conducting bona fide research or medical review if the disclosure is made in a manner that ensures the anonymity of the person to whom the information relates, [...] -----</p> | <p><i>Hospitals Act, R.S.N.S. 1989, c. 208</i></p> <p>S. 71(1) The records and particulars of a hospital concerning a person or patient in the hospital or a person or patient formerly in the hospital shall be confidential and shall not be made available to any person or agency except with the consent or authorization of the person or patient concerned.</p> <p>(2) If a person or patient or former patient is not capable of giving consent in respect of his records and particulars then such consent may be given by the guardian of such person, and if there is no guardian, and if there is no spouse by the next of kin of that person, and if there is no next of kin with the consent of the Public Trustee.</p> <p>(6) Nothing in this Section prevents (a) the publication of reports or statistical information relating to research or study which do not identify individuals or sources of information; [...] -----</p> | <p><i>Hospitals Act, R.S.N. 1990, c. H-9</i></p> <p>PART III GENERAL</p> <p>S. 35(2) A hospital authority shall not allow a person access to, or disclose to a person information contained in the records of the hospital authority.</p> <p>(3) Subsection (2) does not apply in respect of information provided by a hospital authority to (a) a patient or former patient of the hospital controlled by the hospital authority, or where that patient is an infant or under disability, to the parent or guardian of that person; (b) a person authorized in writing by a patient or person referred to in paragraph (a); [...] when the information is provided at the request of that person...</p> <p>(4) A hospital authority may permit a person engaged in health or medical research access to the records of the hospital authority for the purposes of research where (a) in the opinion of the hospital authority it is in</p> | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Newfoundland and Labrador |
|---------|--|--|---|--|---|---|--|---|--------|--|
| | <p>person is engaged in medical research for the British Columbia Cancer Agency, [...]</p> <p>(c) under an agreement that</p> <p>(i) is between the British Columbia Cancer Agency and a government, government agency or another organization engaged in medical research,</p> <p>(ii) relates to medical research, and</p> <p>(iii) provides for the disclosure of information and records to that government, government agency or other organization, or</p> <p>(d) for the purpose of compiling statistical information by an organization, a government or a government agency if the information is compiled to facilitate medical research. [...]</p> <p>S. 10(1) A health status registry is continued in the ministry.</p> <p>(2) The health status registry may record and classify for statistical or for health research purposes information concerning congenital anomalies, genetic conditions or chronic handicapping</p> | <p>[...]</p> <p>(b) the board of an approved hospital may disclose any records of diagnostic and treatment services provided in respect of a patient in its hospital to any person without the consent of the patient, for the purpose of being used</p> <p>(i) in bona fide research or in medical review, if the disclosure is made in such a manner as to ensure confidentiality of those records,</p> <p>[...]</p> <p>-----</p> <p>Mental Health Act, S.A. 1988, c. M-13.1</p> <p>PART 2 - ADMINISTRATION</p> <p>S. 17(3) For the purpose of assessing the standards of care furnished to persons in a diagnostic and treatment centre or improving mental health care facilities or procedures or enforcing the Crown's right of recovery under Part 5 of the Hospitals Act or for any other purpose considered by the Minister to be in the public interest, the Minister or any person authorized in writing by the Minister may require that all or any of the following be sent to the Minister or any person designated by the Minister:</p> <p>(a) medical and other records in a centre;</p> <p>(b) extracts from and copies of those records;</p> <p>(c) diagnoses, charts or information available in respect of any person receiving diagnostic and treatment services in a centre.</p> <p>(4) Information obtained from records maintained in a diagnostic and treatment centre or from persons having access to them shall be treated as private and confidential information in respect of the person receiving diagnostic and treatment</p> | <p>a manner that ensures the anonymity of the information;</p> <p>[...]</p> | <p>Bill 35, The Mental Health and Consequential Amendments Act, 4th Sess., 36th Leg., Manitoba, 1998 (Assented to 14 July 1999. Not yet proclaimed in force.)</p> <p>PART 5 INFORMATION AND RECORDS</p> <p>Confidentiality of Clinical Records</p> <p>S. 36(1) Except as permitted under subsection (2), no medical director, and no person on the staff of a facility or otherwise involved in the assessment or treatment of a patient, shall disclose information in a clinical record without first obtaining</p> <p>(a) the patient's consent, if the patient is mentally competent;</p> <p>(b) the consent of the patient's guardian, if the patient is a minor who is not mentally competent; or</p> <p>(c) the consent of the patient's committee of both property and personal care.</p> <p>(2) The medical director of a facility in which a clinical record is maintained may disclose information in the record without the patient's consent or consent on the patient's behalf under subsection (1), if the disclosure is [...]</p> | <p>The Cancer Act, R.S.O. 1990, c. C.1</p> <p>PART I THE ONTARIO CANCER TREATMENT AND RESEARCH FOUNDATION</p> <p>S. 7(1) Any information or report respecting a case of cancer furnished to the Foundation by any person shall be kept confidential and shall not be used or disclosed by the Foundation to any person for any purpose other than for compiling statistics or carrying out medical or epidemiological research.</p> | <p>[Note: Section 125 of the Act respecting Access to documents held by public bodies and the protection of personal information (c. A-2.1) is reproduced in "Use and Disclosure of Personal Information in the Public Sector", see above.]</p> <p>-----</p> <p>Bill 27, Act to amend the Act respecting health services and social services as regards access to users' records, 1st Sess., 36th Leg., Quebec, 1999 (Assented to and entered into force 24 November 1999.)</p> <p>S. 2 The said Act is amended by inserting, after section 19, the following sections:</p> <p>"19.1 Consent to a request for access to a user's record for study, teaching or research purposes must be in writing; in addition, it must be free and enlightened and given for specific purposes. Otherwise, it is without effect.</p> <p>The consent is valid only for the time required for the attainment of the purposes for which it was granted or, in the case of a research project approved by an ethics committee, for the period determined, where that is</p> | <p>Health Act, R.S.N.B. , c. H-2</p> <p>PART III PENALTIES</p> <p>S. 33(1) The information, records of interviews, reports, statements, notes, memoranda or other data or material prepared by or supplied to or received by the officers of the Department of Health and Community Services in connection with research or studies relating to morbidity, mortality or the cause, prevention, treatment or incidence of disease, or prepared by, supplied to or received by any person engaged in such research or study with the approval of the Minister, shall be privileged and shall not be admissible in evidence in any court or before any other tribunal, board or agency except as and to the extent that the Minister directs.</p> <p>(2) Nothing in this section prevents the publication of reports or statistical compilations relating to such research or studies which do not identify individual cases or sources of information or religious affiliations.</p> | <p>The Health Act, R.S.N.S. 1989, c. 195</p> <p>S. 126(1) The information, records of interviews, reports, statements, notes, memoranda or other data or material prepared by or supplied to or received by the officers of the Department in connection with research or studies relating to morbidity, mortality or the cause, prevention, treatment or incidence of disease, or prepared by, supplied to or received by any person engaged in such research or study with the approval of the Minister, shall be privileged and shall not be admissible in evidence in any court or before any other tribunal, board or agency except as and to the extent that the Minister directs.</p> <p>(2) Nothing in this Section prevents the publication of reports or statistical compilations relating to such research or studies which do not identify individual cases or sources of information or religious affiliations.</p> | | <p>the public interest that the research be done; and</p> <p>(b) the hospital authority is satisfied in writing that the person engaging in the research understands the provisions of subsections (5) and (6).</p> <p>(5) A person to whom information is provided or who is permitted access under subsections (3) or (4) shall not publish or disclose information obtained from the records of the hospital authority where the publication or disclosure may or could be detrimental to the personal interest, reputation or privacy of</p> <p>(a) a patient;</p> <p>(b) a physician;</p> <p>(c) a member of the staff of a hospital; or</p> <p>(d) a person employed by the hospital authority.</p> <p>(6) A person who contravenes subsection (5) is guilty of an offence and liable on summary conviction to a fine not exceeding \$500 and in default of payment to a term of imprisonment not exceeding 30 days.</p> |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Newfoundland and Labrador |
|---------|--|---|--------------|--|---------|---|---------------|-------------|--------|---------------------------|
| | <p>conditions of individuals.</p> <p>(3) The health status registry may request that a person provide it with information concerning congenital anomalies, genetic conditions or chronic handicapping conditions of individuals.</p> <p>(4) A request must not be made under subsection (3) unless a reasonable basis exists for the belief that the information will facilitate recording and classification described in subsection (2) and that the likely benefit to the public justifies the request.</p> <p>(5) The person to whom a request under subsection (3) is made must comply in the manner and at the times requested and give the information requested that is within the possession or control of that person.</p> <p>(6) Section 9(4) to (6) applies if a person wishes to dispute a request the person received under subsection (3) of this section.</p> <p>(7) Persons acting on behalf of the health status registry must not communicate personally identifying information obtained under this section to</p> | <p>services in the centre and shall be used solely for the purposes described in subsection (3), and the information shall not be published, released or disclosed in any manner that would be detrimental to the personal interest, reputation or privacy of that person or that person's attending physician or any other person providing diagnostic or treatment services to that person.</p> <p>(6) Notwithstanding subsection (4) or any other law, the Minister, a person authorized by the Minister, a board, an employee of a board or a physician may disclose any diagnosis, record or information relating to a person receiving diagnostic and treatment services in a centre [...]</p> <p>(g) to a person conducting bona fide research or a medical review if the disclosure is made in a manner that ensures confidentiality of the diagnosis, record or information, [...]</p> <p>-----</p> <p>Public Health Act, S.A. 1984, c. P-27.1</p> <p>PART 4 COMMUNICABLE DISEASES</p> <p>General</p> <p>S. 63(1) Information contained in any file, record, document or paper maintained by the Chief Medical Officer or by a regional health authority or an employee or agent on its behalf that comes into existence through anything done under this Part and that indicates that a person is or was infected with a communicable disease shall be treated as private and confidential in respect of the person to whom the information relates and shall not be published, released or disclosed in</p> | | <p>(i) to a person for research purposes, if the medical director determines that</p> <p>(i) the research is of sufficient importance to outweigh the intrusion into privacy that would result from the disclosure,</p> <p>(ii) the research purpose cannot reasonably be accomplished unless the information is provided in a form that identifies or may identify the patient,</p> <p>(iii) it is unreasonable or impractical for the person proposing the research to obtain the patient's consent,</p> <p>(iv) the research project contains reasonable safeguards to protect the confidentiality of the information and procedures to destroy the information or remove all identifying information at the earliest opportunity consistent with the purposes of the project,</p> <p>(v) the research project has been approved by a research review committee acceptable to the medical director, and</p> <p>(vi) the person proposing the research project has entered into an agreement with the facility in which the person agrees not to publish the information requested in a form that could reasonably be expected to identify the patient, to use the</p> | | <p>the case, by the ethics committee.</p> <p>“19.2. Notwithstanding section 19, the director of professional services of an institution or, failing such a director, the executive director may authorize a professional to examine the record of a user for study, teaching or research purposes without the user's consent.</p> <p>Before granting such authorization, the director must, however, ascertain that the criteria determined under section 125 of the <i>Act respecting Access to documents held by public bodies and the Protection of personal information</i> (chapter A-2.1) are satisfied. If the director is of the opinion that the professional's project is not in compliance with generally accepted standards of ethics or scientific integrity, the director may refuse to grant the authorization</p> <p>The authorization must be granted for a limited period and may be subject to conditions. It may be revoked at any time if the director has reason to believe that the authorized professional is violating the confidentiality of the information obtained or is not complying with the conditions imposed or with generally accepted standards of ethics and scientific integrity.”</p> | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Newfoundland and Labrador |
|---------|--|---|--------------|--|---------|---|---------------|-------------|--------|---------------------------|
| | <p>persons who are not acting on behalf of the health status registry except to the extent necessary for the purposes of subsection (2).</p> | <p>any manner that would be detrimental to the personal interest, reputation or privacy of that person.</p> <p>(2) For the purposes of assessing and improving the standards of care furnished to persons suffering from communicable diseases, compiling statistics with respect to communicable diseases, conducting research into communicable diseases, or for any reason relating to communicable disease which the Chief Medical Officer considers to be in the interest of protecting the public health, the Chief Medical Officer may require any physician or health practitioner to furnish him with the following information:</p> <p>(a) a report containing the name and address of any patient of that physician or health practitioner who is, was or may have been suffering from a communicable disease and a description of the diagnostic and treatment services provided to him;</p> <p>(b) medical or other records, or extracts or copies thereof, in respect of that patient and in the possession of the physician or health practitioner.</p> <p>[...]</p> <p>(3) Information obtained by the Chief Medical Officer or by a regional health authority or an employee or agent on its behalf pursuant to this section shall be treated as private and confidential and, subject to subsection (4), shall not be published, released or disclosed in any manner that would be detrimental to the personal interest, reputation or privacy of the patient.</p> <p>(4) Information obtained by the Chief Medical Officer or by a regional health authority or an employee or agent on its behalf may be disclosed by the Chief Medical Officer or the regional health authority, employee or agent</p> | | <p>information solely for the purposes of the project, and to ensure that the project complies with the safeguards described in subclause (iv);</p> <p>[...]</p> <p>(3) Every disclosure under subsection (2) must be limited to the minimum amount of information necessary to accomplish the purpose for which the information is disclosed.</p> <p>[...]</p> <p>-----</p> <p><i>The Human Tissue Act, R.S.M. c. H-180</i></p> <p>S. 13 No person shall disclose the identity of another person</p> <p>(a) who has given or refused to give a direction or consent under this Act; or</p> <p>(b) with respect to whom a direction or consent has been given or refused under this Act; or</p> <p>(c) who is a recipient or potential recipient of tissue by way of transplant under this Act;</p> <p>unless that other person consents to the disclosure, or the disclosure is required by law or is made for the purposes of hospital administration or bona fide medical research.</p> | | <p>[Note: Section 125 of the Act respecting Access to documents held by public bodies and the protection of personal information (c. A-2.1) is reproduced in “Use and Disclosure of Personal Information in the Public Sector”, see above.]</p> <p>S. 3 Section 24 of the said Act is replaced by the following section:</p> <p>“24. At the request of a user, an institution must send a copy or summary of, or an extract from, the user’s record as soon as practicable to another institution or to a professional.</p> <p>However, where the request is made for study, teaching or research purposes, the institution may require consent in writing as provided for in section 19.1.”</p> | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Newfoundland and Labrador |
|---------|------------------|--|--------------|----------|---------|--------|---------------|-------------|--------|---------------------------|
| | | <p>[...]</p> <p>(c) in statistical form if the person to whom it relates is not revealed or made identifiable;</p> <p>(d) to a person conducting bona fide research or medical review if the disclosure is made so as to ensure confidentiality of the information;</p> <p>[...]</p> <p>-----</p> <p><i>Cancer Programs Act, R.S.A. 1980, c. C-11</i></p> <p>PART 1.1 CANCER REGISTRY</p> <p>S. 20.3(1) The information in the cancer registry is private and confidential.</p> <p>S. 20.3(2) Section 40 of the Hospitals Act does not apply to information in the cancer registry.</p> <p>S. 20.4 The information in the cancer registry is to be used for the following purposes:</p> <p>[...]</p> <p>(c) to assist in cancer research, education and prevention;</p> <p>(d) to compile statistics on cancer;</p> <p>[...]</p> <p>S. 20.7(1) The board may use the information in the cancer registry for the purposes referred to in section 20.4.</p> <p>(3) The board may disclose the information in the cancer registry</p> <p>(a) to the person who is the subject of the information or to that person's designate or legal representative;</p> <p>(b) in statistical form if the person who is the subject of the information is not revealed or made identifiable;</p> <p>(c) to a person conducting bona fide research or a medical review if the disclosure is made in a manner that ensures the confidentiality of the information; [...]</p> | | | | | | | | |

Consent & Substitute Decision-Making

Where consent is required for the collection, use and/or disclosure of personal (health) information, most statutes specify, to some extent, the constituent elements of a valid informed consent, the required form such consent must take and the manner in which such consent may be given and/or revoked. These provisions are either set out in the Act itself or in related regulations.

Furthermore, most statutes stipulate who may give substituted consent on behalf of minors, on behalf of adults who do not have the capacity to consent for themselves or on behalf of deceased persons. For this purpose, most statutes incorporate, by reference, substitute decision-makers appointed for related purposes under other statutes.

By far, the most elaborate provisions on consent and substitute decision-making respecting the collection, use and disclosure of personal health information can be found in Ontario's *Draft Personal Health Information Protection Act*. This Act not only provides the most detailed conditions for informed consent to be valid, but incorporates, within the Act itself, an entire scheme for the determination of individual capacity and the appointment process of substitute decision-makers, specific to the collection, use and disclosure of personal health information. Moreover, the powers of substitute decision-makers are carefully circumscribed by requiring that these decision-makers respect certain principles when purporting to act in accordance with the incapable person's wishes and that they consider specific factors when determining that person's best interests.

CONSENT & SUBSTITUTE DECISION-MAKING RESPECTING PERSONAL INFORMATION IN THE PUBLIC SECTOR

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|--|--|---|---|---|---|---|--|---|---|--------------------|
| <p><i>Privacy Act, R.S.C. 1985, c. P-21</i></p> <p>GENERAL</p> <p>S. 77(1) The Governor in Council may make regulations [...] (m) prescribing the class of individuals who may act on behalf of minors, incompetents, deceased persons or any other individuals under this Act and regulating the manner in which any rights or actions of individuals under this Act may be exercised or performed on their behalf; [...]</p> <p>-----</p> <p><i>Privacy Act, Regulations, S.O.R. / 83-508</i></p> <p>PROCEDURES</p> <p>S. 10 The rights or actions provided for under the Act and these Regulations may be exercised or performed (a) on behalf of a minor or an incompetent person by a person authorized by or</p> | <p><i>Freedom of Information and Protection of Privacy Act, R.S.B.C. 1996, c. 165</i></p> <p>PART 6 – GENERAL PROVISIONS</p> <p>S. 76(2) Without limiting subsection (1), the Lieutenant Governor in Council may make regulations as follows: [...]</p> <p>(h) prescribing the classes of individuals who may act for minors, incompetents, deceased persons or any other individuals under this Act and regulating the manner in which, and the extent to which, any rights or powers of individuals under this Act may be exercised on their behalf; [...]</p> | <p><i>Freedom of Information and Protection of Privacy Act, S.A. 1994, c. F-18.5</i></p> <p>PART 5 GENERAL PROVISIONS</p> <p>S. 79(1) Any right or power conferred on an individual by this Act may be exercised (a) if the individual is deceased, by the individual's personal representative if the exercise of the right or power relates to the administration of the individual's estate, (b) if a guardian or trustee has been appointed for the individual under the Dependent Adults Act, by the guardian or trustee if the exercise of the right or power relates to the powers and duties of the guardian or trustee, (b.1) if an agent has been designated under a personal directive under the Personal Directives Act, by the agent under the authority of the directive if the directive so authorizes, (c) if a power of attorney has been granted by the individual, by the attorney if the exercise of the right or power relates to the powers and duties of the attorney conferred by the power of attorney, (d) if the individual is a minor, by a guardian of the minor in circumstances where, in the opinion of the head of the public body concerned, the exercise of the right or power by the guardian would not</p> | <p><i>Freedom of Information and Protection of Privacy Act, R.S.S. 1990-91, c. F. 22.01</i></p> <p>PART VIII GENERAL</p> <p>S. 59 Any right or power conferred on an individual by this Act may be exercised: (a) where the individual is deceased, by the individual's personal representative if the exercise of the right or power relates to the administration of the individual's estate; (b) where a personal guardian or property guardian has been appointed for the individual, by the guardian if the exercise of the right or power relates to the powers and duties of the guardian; (c) where a power of attorney has been granted, by the attorney if the exercise of the right or power relates to the powers and duties of the attorney conferred by the power of attorney; (d) where the individual is less than 18 years of age, by the individual's legal custodian in situations where, in the opinion of the head, the exercise of the right or power would not constitute an unreasonable invasion of the privacy of the individual; or (e) by any person with</p> | <p><i>The Freedom of Information and Protection of Privacy Act, R.S.M. c. F-175</i></p> <p>PART 6 GENERAL PROVISIONS</p> <p>S. 79 Any right or power conferred on an individual by this Act may be exercised (a) by any person with written authorization from the individual to act on the individual's behalf; (b) by a committee appointed for the individual under <i>The Mental Health Act</i> or a substitute decision maker appointed for the individual under <i>The Vulnerable Persons Living with a Mental Disability Act</i>, if the exercise of the right or power relates to the powers and duties of the committee or substitute decision maker; (c) by an attorney acting under a power of attorney granted by the individual, if the exercise of the right or power relates to the powers and duties conferred by the power of attorney; (d) by the parent or guardian of a minor when, in the opinion of the head of the public body concerned, the exercise of the right or power by the parent or guardian would not constitute an</p> | <p><i>Freedom of Information and Protection of Privacy Act, R.S.O. 1990, c. F-31</i></p> <p>PART V GENERAL</p> <p>S. 66. Any right or power conferred on an individual by this Act may be exercised, (a) where the individual is deceased, by the individual's personal representative if exercise of the right or power relates to the administration of the individual's estate; (b) by the individual's attorney under a continuing power of attorney, the individual's attorney under a power of attorney for personal care, the individual's guardian of the person, or the individual's guardian of property; and (c) where the individual is less than sixteen years of age, by a person who has lawful custody of the individual.</p> | <p><i>Bill 27, Act to amend the Act respecting health services and social services as regards access to users' records, 1st Sess., 36th Leg., Quebec, 1999</i> (Assented to and entered into force 24 November 1999)</p> <p>S. 2 The said Act is amended by inserting, after section 19, the following sections:</p> <p>“19.1 Consent to a request for access to a user's record for study, teaching or research purposes must be in writing; in addition, it must be free and enlightened and given for specific purposes. Otherwise, it is without effect.</p> <p>The consent is valid only for the time required for the attainment of the purposes for which it was granted or, in the case of a research project approved by an ethics committee, for the period determined, where that is the case, by the ethics committee.” [...]</p> | <p><i>Protection of Personal Information Act, S.N.B. 1998, c. P-19.1</i> (Assented to 26 February 1998, not yet in force.)</p> <p>S. 2(1) Every public body is subject to the Statutory Code of Practice.</p> <p>(2) The Statutory Code of Practice shall be interpreted and applied in accordance with Schedule B and with any regulations made under paragraph 7(b).</p> <p>Schedule A: The Statutory Code of Practice</p> <p>Principle 3: Consent The consent of the individual is required for the collection, use, or disclosure of personal information, except where inappropriate.</p> <p>Schedule B: Interpretation and Application of the Statutory Code of Practice</p> <p>Principle 3: Consent</p> <p>3.1 Consent may be express or implied.</p> <p>3.2 The actions for which consent can be implied are those that an individual should</p> | <p><i>Freedom of Information and Protection of Privacy Act, S.N.S. 1993, c. 5</i></p> <p>GENERAL</p> <p>S.43 Any right or power conferred on an individual by this Act may be exercised (a) where the individual is deceased, by the individual's personal representative if the exercise of the right or power relates to the administration of the individual's estate; (b) where a personal guardian or property guardian has been appointed for the individual, by the guardian if the exercise of the right or power relates to the powers and duties of the guardian; (c) where a power of attorney has been granted, by the attorney if the exercise of the right or power relates to the powers and duties of the attorney conferred by the power of attorney; (d) where the individual is less than the age of majority, by the individual's legal custodian in situations where, in the opinion of the head of a public body, the exercise of the right or power would not constitute an unreasonable invasion of the privacy of the individual; or</p> | <p><i>Bill 81, Freedom of Information and the Protection of Privacy Act, 1st Sess., 60th General Assembly, P.E.I. 1997</i> (Died on the Order Paper – not in force)</p> <p>PART V GENERAL PROVISIONS</p> <p>S. 70(1) Any right or power conferred on an individual by this Act may be exercised (a) if the individual is deceased, by the individual's personal representative if the exercise of the right or power relates to the administration of the individual's estate; (b) if a guardian or trustee has been appointed for the individual by the guardian or trustee if the exercise of the right or power relates to the powers and duties of the guardian or trustee; (c) if a power of attorney has been granted by the individual, by the attorney if the exercise of the right or power relates to the powers and duties of the attorney conferred by the power of attorney; (d) if the individual is a minor, by a guardian of the minor in</p> | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|--|------------------|---|---|--|---------|--------|--|--|---|--------------------|
| <p>pursuant to the law of Canada or a province to administer the affairs or estate of that person;</p> <p>(b) on behalf of a deceased person by a person authorized by or pursuant to the law of Canada or a province to administer the estate of that person, but only for the purpose of such administration; and</p> <p>(c) on behalf of any other individual by any person authorized in writing to do so by the individual.</p> | | <p>constitute an unreasonable invasion of the personal privacy of the minor, or (e) by any person with written authorization from the individual to act on the individual's behalf.</p> <p>S. 88 The Lieutenant Governor in Council may make regulations [...]</p> <p>(i) respecting the manner of giving consent for the purposes of sections 37(1)(b) and 38(1)(c); [...]</p> <p>[Note: Sections 37(1)(b) and 38(1)(c) have been reproduced in “Use and Disclosure of Personal Information in the Public Sector”, see above.]</p> <p>-----</p> <p><i>Freedom of Information and Protection of Privacy Act, Alta. Reg. 200/95</i></p> <p>S. 6 The consent of an individual to a public body's using or disclosing any of the individual's personal information under sections 37(1)(b) or 38(1)(c) of the Act</p> <p>(a) must be in writing, and</p> <p>(b) must specify to whom the personal information may be disclosed and how the personal information may be used.</p> | <p>written authorization from the individual to act on the individual's behalf.</p> <p>s. 69 The Lieutenant Governor in Council may make regulations: [...]</p> <p>(p) prescribing manners in which the consent of an individual may be given; [...]</p> | <p>unreasonable invasion of the minor's privacy; or (e) if the individual is deceased, by the individual's personal representative if the exercise of the right or power relates to the administration of the individual's estate.</p> <p>S. 87 The Lieutenant Governor in Council may make regulations [...]</p> <p>(h) respecting the giving of consents by individuals under this Act; [...]</p> | | | <p>reasonably expect the public body to take, and would be unlikely to disapprove of, having regard to</p> <p>(a) the nature of the personal information in question, including whether it is or is not sensitive or confidential,</p> <p>(b) any benefit or detriment to the individual,</p> <p>(c) any explanation that the public body has given of its intended actions,</p> <p>(d) any indication that the individual has given of his or her actual wishes, and</p> <p>(e) the ease or difficulty with which the actual wishes of the individual might be discovered.</p> <p>3.3 Consent can be given by a parent, guardian or other representative of the individual in appropriate circumstances.</p> | <p>(e) by a person with written authorization from the individual to act on the individual's behalf.</p> | <p>circumstances where, in the opinion of the head of the public body concerned, the exercise of the right or power by the guardian would not constitute an unreasonable invasion of the personal privacy of the minor; or</p> <p>(e) by any person with written authorization from the individual to act on the individual's behalf.</p> | |

CONSENT & SUBSTITUTE DECISION-MAKING RESPECTING PERSONAL INFORMATION IN THE PRIVATE SECTOR

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Newfoundland and Labrador |
|--|------------------|---------|--------------|----------|---------|--|---------------|-------------|----------------------|---------------------------|
| <p>Bill C-6, <i>Personal Information Protection and Electronic Documents Act</i>, 2nd Sess., 36th Parl., 48 Elizabeth II, 1999 (Passed by the Senate with amendments, 10 December 1999 – not yet assented to.)</p> <p>Schedule 1</p> <p>4.3 Principle 3 – Consent The knowledge and consent of the individual are required for the collection, use, or disclosure of personal information, except where inappropriate. Note: In certain circumstances personal information can be collected, used, or disclosed without the knowledge and consent of the individual. For example, legal, medical, or security reasons may make it impossible or impractical to seek consent. When information is being collected for the detection and prevention of fraud or for law enforcement, seeking the consent of the individual might defeat the purpose of collecting the information. Seeking consent may be impossible or inappropriate when the individual is a minor, seriously ill, or mentally incapacitated. In addition, organizations that do not have a direct relationship with the individual may not always be able to seek consent. For example, seeking consent may be impractical for a charity or a direct-marketing firm that wishes to acquire a mailing list from another organization. In such cases, the organization providing the list would be expected to obtain consent before disclosing personal information.</p> <p>[Note: Sections 7(1), 7(2) and 7(3) of the Act, regarding the collection, use and disclosure of personal information, respectively, apply despite the note that accompanies clause 4.3. Section 7(1) has been reproduced in “Collection of Personal Information in the Private Sector” above ; sections 7(2) and 7(3) have been reproduced in “Use and Disclosure of Personal Information in the Private Sector”, above.]</p> | | | | | | <p><i>An Act respecting the Protection of Personal Information in the Private Sector</i>, R.S.Q. c. P-39.1</p> <p>DIVISION III CONFIDENTIALITY OF PERSONAL INFORMATION</p> <p><i>§1. – Retention, use and non-communication of information</i></p> <p>S. 14 Consent to the communication or use of personal information must be manifest, free, and enlightened, and must be given for specific purposes. Such consent is valid only for the length of time needed to achieve the purposes for which it was requested. Consent given otherwise than in accordance with the first paragraph is without effect.</p> | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Newfoundland and Labrador |
|--|------------------|---------|--------------|----------|---------|--------|---------------|-------------|----------------------|---------------------------|
| <p>4.3.1 Consent is required for the collection of personal information and the subsequent use or disclosure of this information. Typically, an organization will seek consent for the use or disclosure of the information at the time of collection. In certain circumstances, consent with respect to use or disclosure may be sought after the information has been collected but before use (for example, when an organization wants to use information for a purpose not previously identified).</p> <p>4.3.2 The principle requires “knowledge and consent”. Organizations shall make a reasonable effort to ensure that the individual is advised of the purposes for which the information will be used. To make the consent meaningful, the purposes must be stated in such a manner that the individual can reasonably understand how the information will be used or disclosed.</p> <p>4.3.3 An organization shall not, as a condition of the supply of a product or service, require an individual to consent to the collection, use or disclosure of information beyond that required to fulfil the explicitly specified, and legitimate purposes.</p> <p>4.3.4 The form of the consent sought by the organization may vary, depending upon the circumstances and the type of information. In determining the form of consent to use, organizations shall take into account the sensitivity of the information. Although some information (for example, medical records and income records) is almost always considered to be sensitive, any information can be sensitive, depending on the context. For example, the names and addresses of subscribers to a newsmagazine would generally not be considered sensitive information. However, the names and addresses of subscribers to some special-interest magazines might be considered sensitive.</p> <p>4.3.5 In obtaining consent, the reasonable expectations of the individual are also relevant. For example, an individual buying a subscription to a magazine should reasonably expect that the organization, in addition to using the individual’s name and address for mailing and billing purposes, would also contact the person to solicit the renewal of the</p> | | | | | | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Newfoundland and Labrador |
|---|------------------|---------|--------------|----------|---------|--------|---------------|-------------|----------------------|---------------------------|
| <p>subscription. In this case, the organization can assume that the individual's request constitutes consent for specific purposes. On the other hand, an individual would not reasonably expect that personal information given to a health-care professional would be given to a company selling health-care products, unless consent were obtained. Consent shall not be obtained through deception.</p> <p>4.3.6 The way in which an organization seeks consent may vary, depending on the circumstances and the type of information collected. An organization should generally seek express consent when the information is likely to be considered sensitive. Implied consent would generally be appropriate when the information is less sensitive. Consent can also be given by an authorized representative (such as a legal guardian or a person having power of attorney).</p> <p>4.3.7 Individuals can give consent in many ways. For example:</p> <ul style="list-style-type: none"> (a) an application form may be used to seek consent, collect information, and inform the individual of the use that will be made of the information. By completing and signing the form, the individual is giving consent to the collection and the specified uses; (b) a checkoff box may be used to allow individuals to request that their names and addresses not be given to other organizations. Individuals who do not check the box are assumed to consent to the transfer of this information to third parties; (c) consent may be given orally when information is collected over the telephone; or (d) consent may be given at the time that individuals use a product or service. <p>4.3.8 An individual may withdraw consent at any time, subject to legal or contractual restrictions and reasonable notice. The organization shall inform the individual of the implications of such withdrawal.</p> | | | | | | | | | | |

CONSENT & SUBSTITUTE DECISION-MAKING RESPECTING PERSONAL HEALTH INFORMATION

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|--|--|--|--|--------|---------------|-------------|--------|--------------------|
| | | <p>Bill 40, Health Information Act, 3rd Sess., 24th Leg., Alberta, 1999 (Assented to 9 December, 1999, not yet proclaimed in force.)</p> <p>PART 5 DISCLOSURE OF HEALTH INFORMATION</p> <p>Division 1 General Disclosure Rules</p> <p>S. 34(1) Subject to sections 35 to 40, a custodian may disclose individually identifying health information to a person other than the individual who is the subject of the information if the individual has consented to the disclosure.</p> <p>[Note: “Custodian”, within the meaning of this Act, is defined in “Collection of Personal Health Information”, see above.]</p> <p>(2) A consent referred to in subsection (1) must be provided in writing or electronically and must include</p> <ol style="list-style-type: none"> (a) an authorization for the custodian to disclose the health information specified in the consent, (b) the purpose for which the health information may be disclosed, (c) the identity of the person to whom the health information may be disclosed, (d) an acknowledgment that the individual providing the consent has been made aware of the reasons why the health information is needed and the risks and benefits to the individual of consenting or refusing to consent, | <p>The Health Information Protection Act, S.S. 1999, c. H-0.021 (Assented to 6 May 1999, not yet proclaimed in force.)</p> <p>PART II Rights of the Individual</p> <p>S. 6(1) Where consent is required by this Act for the collection, use or disclosure of personal health information, the consent:</p> <ol style="list-style-type: none"> (a) must relate to the purpose for which the information is required; (b) must be informed; (c) must be given voluntarily; and (d) must not be obtained through misrepresentation, fraud or coercion. <p>(2) A consent to the collection, use or disclosure of personal health information is informed if the individual who gives the consent is provided with the information that a reasonable person in the same circumstances would require in order to make a decision about the collection, use or disclosure of personal health information.</p> <p>(3) A consent may be given that is effective for a limited period.</p> <p>(4) Consent may be express or implied unless otherwise provided.</p> <p>(5) An express consent need not be in writing.</p> <p>(6) A trustee, other than the</p> | <p>The Personal Health Information Act, S.M. 1997, c. P33.5</p> <p>PART 6 GENERAL PROVISIONS</p> <p>S. 60 The rights of an individual under this Act may be exercised</p> <ol style="list-style-type: none"> (a) by any person with written authorization from the individual to act on the individual’s behalf; (b) by a proxy appointed by the individual under <i>The Mental Health Care Directives Act</i>; (c) by a committee appointed for the individual under <i>The Mental Health Act</i> if the committee has the power to make health care decisions on the individual’s behalf; (d) by a substitute decision maker for personal care appointed for the individual under <i>The Vulnerable Persons Living with a Mental Disability Act</i> if the exercise of the right relates to the powers and duties of the substitute decision maker; (e) by the parent or guardian of an individual who is a minor, if the minor does not have the capacity to make health care decisions; or (f) if the individual is deceased, by his or her personal representative. <p>S. 66(1) The Lieutenant Governor in Council may make regulations</p> | <p>Draft Personal Health Information Protection Act, 1997 (Not in force.)</p> <p>PART I GENERAL</p> <p>S. 6(1) A reference in this Act to consent by the subject of personal health information to a collection, use or disclosure of the information shall be read as a reference to consent by the following persons:</p> <ol style="list-style-type: none"> 1. If the subject is capable with respect to personal health information, <ol style="list-style-type: none"> i. the subject, or ii. the subject’s attorney for property, if the attorney has authority to give the consent. 2. If the subject is incapable with respect to personal health information, the person who is authorized under section 42 to give or refuse consent on behalf of the subject. 3. If the subject has died and the use or disclosure relates to the administration of the subject’s estate, the person who is authorized under section 43 to give or refuse consent in the place of the subject. 4. If the subject has died and the use or disclosure does not relate to the administration of the subject’s estate, the person who is authorized under section 44 to give or refuse consent in the place of the subject. <p>(2) The following are the elements required for consent to a collection, use or disclosure of personal health information:</p> <ol style="list-style-type: none"> 1. The consent must relate to the information. 2. The consent must be informed. 3. The consent must be given voluntarily. 4. The consent must not be obtained through misrepresentation or fraud. <p>(3) A consent to a use of personal health information is informed if the individual who gives the consent is aware of the following things before giving it:</p> <ol style="list-style-type: none"> 1. The person by whom the information is to be used. 2. If the information will be used outside Ontario, that it will be so used and that the confidentiality and privacy protection provided with respect to the information outside Ontario may be different from the protection provided within Ontario. 3. The purpose of the use. 4. The nature and extent of the information to be used. 5. The reasonably foreseeable consequences of a refusal to consent to the use. <p>(4) A consent to a disclosure of personal health information is</p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|---|---|--|--|--------|---------------|-------------|--------|--------------------|
| | | <p>(e) the date the consent is effective and the date, if any, on which the consent expires, and</p> <p>(f) a statement that the consent may be revoked at any time by the individual providing it.</p> <p>(3) A disclosure of health information pursuant to this section must be carried out in accordance with the terms of the consent.</p> <p>(4) A revocation of a consent must be provided in writing or electronically.</p> <p>(5) A consent or revocation of a consent that is provided in writing must be signed by the person providing it.</p> <p>(6) A consent or revocation of a consent that is provided electronically is valid only if it complies with the requirements set out in the regulations.</p> <p>PART 6 DUTIES AND POWERS OF CUSTODIANS RELATING TO HEALTH INFORMATION</p> <p>Division 1 General Duties and Powers</p> <p>S. 59(1) A custodian that intends to disclose individually identifying diagnostic, treatment and care information about an individual by electronic means must obtain the individual's consent to the disclosure or ensure that the individual's consent has been previously obtained.</p> <p>(2) A consent referred to in subsection (1) must be provided in writing or</p> | <p>trustee who obtained the consent, may act in accordance with an express consent in writing or a record of an express consent having been given without verifying that the consent meets the requirements of subsection (1) unless the trustee who intends to act has reason to believe that the consent does not meet those requirements.</p> <p>[Note: "Trustee", within the meaning of this Act, is defined in "Collection of Personal Health Information", see above.]</p> <p>S. 7(1) An individual may revoke his or her consent to the collection of personal health information or to the use or disclosure of personal health information in the custody or control of a trustee.</p> <p>(2) A consent may be revoked at any time, but no revocation shall have retroactive effect.</p> <p>(3) A trustee must take all reasonable steps to comply with a revocation of consent promptly after receiving the revocation.</p> <p>S. 15 An individual may designate in writing another person to exercise on behalf of the individual any of the individual's rights with respect to personal health information.</p> | <p>[...]</p> <p>(e) respecting the giving of authorizations and consents by individuals under this Act;</p> <p>[...]</p> | <p>informed if the individual who gives the consent is aware of the following things before giving it:</p> <ol style="list-style-type: none"> 1. The person by whom the information is to be disclosed. 2. The person to whom the information is to be disclosed. 3. If the information will be disclosed outside Ontario, that it will be so disclosed and that the confidentiality and privacy protection provided with respect to the information outside Ontario may be different from the protection provided within Ontario. 4. The purpose of the disclosure. 5. The nature and extent of the information to be disclosed. 6. The reasonably foreseeable consequences of a refusal to consent to the disclosure. <p>(5) A consent to a use or disclosure of personal health information may specify a time after which the consent will cease to be effective.</p> <p>(6) A person described in a paragraph of subsection (1) may at any time in writing revoke a consent to a collection, use or disclosure of personal health information but the revocation shall not have retroactive effect.</p> <p>PART V ADDITIONAL DUTIES RESPECTING PERSONAL HEALTH INFORMATION</p> <p>S. 34 A health information custodian shall have in place a written policy and procedures for,</p> <p>(a) determining or confirming an individual's capacity for the purposes of Part VI,</p> <p>[...]</p> <p>[Note: "Health information custodian", within the meaning of this Act, is defined in "Collection of Personal Health Information", see above.]</p> <p>PART VI SUBSTITUTE DECISIONS CONCERNING PERSONAL HEALTH INFORMATION</p> <p>S. 40(1) An individual is capable with respect to personal health information if the individual is able to understand the information that is relevant to making a decision about the personal health information and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.</p> <p>(2) An individual may be incapable with respect to personal health information at one time and capable at another.</p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|--|---|----------|---|--------|---------------|-------------|--------|--------------------|
| | | <p>electronically and must include</p> <p>(a) an authorization for any custodian to disclose individually identifying diagnostic, treatment and care information about the individual by electronic means for all of the purposes listed in section 27, [Note: Section 27 is reproduced in “Use and Disclosure of Personal Health Information”, above]</p> <p>(b) an acknowledgment that the individual providing the consent has been made aware of the reason for disclosure by electronic means and the risks and benefits to the individual of consenting or refusing to consent,</p> <p>(c) the date the consent is effective, and</p> <p>(d) a statement that the consent may be revoked at any time by the individual providing it.</p> <p>(3) A disclosure of health information pursuant to this section must be carried out in accordance with the terms of the consent.</p> <p>(4) A revocation of a consent must be provided in writing or electronically.</p> <p>(5) A consent or revocation of a consent that is provided in writing must be signed by the person providing it.</p> <p>(6) A consent or revocation of a consent that is provided electronically is valid only if it complies with the requirements set out in the regulations.</p> <p>(7) This section does not apply where the disclosure is for the purpose of obtaining or processing payment for health services.</p> | <p>PART IV Limits on Collection, Use and Disclosure of Personal Health Information by Trustees</p> <p>S. 26(3) Consent to the use of personal health information must be express consent, except where it is reasonable for the trustee to infer that the subject individual would consent to the use and where the use:</p> <p>(a) is for the purpose for which the information was collected by the trustee or for a purpose that is consistent with that purpose;</p> <p>(b) is necessary to obtain payment for health services provided to the subject individual; or</p> <p>(c) occurs in prescribed circumstances.</p> <p>S.27(3) Consent to the disclosure of personal health information must be express consent, except where it is reasonable for the trustee to infer that the subject individual would consent to the disclosure and where the disclosure is being made:</p> <p>(a) for the same purpose as the purpose for which the information was collected by the trustee or for a purpose that is consistent with that purpose;</p> <p>(b) where the subject individual is a patient of the trustee or a patient or resident in a health care facility, to a member of the subject individual’s immediate family or to anyone else with whom the subject individual has a close personal relationship, if the disclosure:</p> <p>(i) relates to health services currently being</p> | | <p>S. 41(1) An individual is presumed to be capable with respect to personal health information.</p> <p>(2) A person shall not rely on the presumption described in subsection (1) if the person has reasonable grounds to believe that the individual is incapable with respect to personal health information.</p> <p>S. 42(1) If a subject of personal health information is incapable with respect to personal health information, a person described in one of the following paragraphs may, on the subject’s behalf, give or refuse consent to a use or disclosure of the information:</p> <ol style="list-style-type: none"> 1. The subject’s guardian of the person or guardian of property, if the guardian has authority to give or refuse such consent. 2. The subject’s attorney for personal care or attorney for property, if the attorney has authority to give or refuse such consent. 3. The subject’s representative appointed by the Board under section 49, if the representative has authority to give or refuse such consent. 4. The subject’s spouse or partner. 5. A child or parent of the subject, or a children’s aid society or other person who is lawfully entitled to give or refuse such consent in the place of the parent. This paragraph does not include a parent who has only a right of access. If a children’s aid society or other person is lawfully entitled to give or refuse such consent in the place of the parent, this paragraph does not include the parent. 6. A parent of the subject with only a right of access. 7. A brother or sister of the subject. 8. Any other relative of the subject. <p>(2) A person described in subsection (1) may give or refuse consent only if the person,</p> <p>(a) is capable with respect to personal health information;</p> <p>(b) if the person is an individual, is at least 16 years old or is the subject’s parent;</p> <p>(c) is not prohibited by court order or separation agreement from having access to the subject or from giving or refusing consent on the subject’s behalf;</p> <p>(d) is available; and</p> <p>(e) is willing to assume the responsibility of giving or refusing consent.</p> <p>(3) For the purpose of clause (2)(d), a person is available if it is possible, within a time that is reasonable in the circumstances, to communicate with the person and obtain a consent or refusal.</p> <p>(4) A person described in a paragraph of subsection (1) may</p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|--|--|----------|--|--------|---------------|-------------|--------|--------------------|
| | | <p>PART 8 GENERAL PROVISIONS</p> <p>S. 104(1) Any right or power conferred on an individual by this Act may be exercised</p> <p>(a) if the individual is 18 years of age or older, by the individual,</p> <p>(b) if the individual is under 18 years of age and understands the nature of the right or power and the consequences of exercising the right or power, by the individual,</p> <p>(c) if the individual is under 18 years of age but does not meet the criterion in clause (b), by the guardian of the individual,</p> <p>(d) if the individual is deceased and was 18 years of age or over immediately before death, by the individual's personal representative if the exercise of the right or power relates to the administration of the individual's estate,</p> <p>(e) if a guardian or trustee has been appointed for the individual under the <i>Dependant Adults Act</i>, by the guardian or trustee if the exercise of the right or power relates to the powers and duties of the guardian or trustee,</p> <p>(f) if an agent has been designated under a personal directive under the <i>Personal Directives Act</i>, by the agent if the directive so authorizes,</p> <p>(g) if a power of attorney has been granted by the individual, by the attorney if the exercise of the right or power relates to the powers and duties conferred by the power of attorney,</p> <p>(h) if the individual is a formal patient as defined in the <i>Mental Health Act</i>, by the individual's nearest relative as defined in that Act if the exercise of the right or power is necessary to carry out the obligations of the</p> | <p>provided; and</p> <p>(ii) is made in accordance with the ethical practice of a health professional described in subclause 2(t)(xii);</p> <p>(c) to the extent that is necessary to obtain payment for health services provided to the subject individual; or</p> <p>(d) in any cases prescribed in the regulations.</p> <p>PART VIII General</p> <p>S. 56 Any right or power conferred on an individual by this Act may be exercised:</p> <p>(a) where the individual is deceased, by the individual's personal representative if the exercise of the right or power relates to the administration of the individual's estate;</p> <p>(b) where a personal guardian has been appointed for the individual, by the guardian if the exercise of the right or power relates to the powers and duties of the guardian;</p> <p>(c) by an individual who is less than 18 years of age in situations where, in the opinion of the trustee, the individual understands the nature of the right or power and the consequences of exercising the right or power;</p> <p>(d) where the individual is less than 18 years of age, by the individual's legal custodian in situations where, in the opinion of the trustee, the exercise of the right or power would not constitute an unreasonable invasion of the privacy of the individual;</p> <p>(e) where the individual does not have the capacity to give consent:</p> | | <p>give or refuse consent only if no person described in an earlier paragraph meets the requirements of subsection (2).</p> <p>(5) Despite subsection (4), a person described in a paragraph of subsection (1) who is present or has otherwise been contacted may give or refuse consent if the person believes that,</p> <p>(a) no other person described in an earlier paragraph or the same paragraph exists; or</p> <p>(b) although such other person exists, the other person is not a person described in paragraph 1, 2 or 3 of subsection (1) and would not object to the person who is present or has otherwise been contacted making the decision.</p> <p>(6) If no person described in subsection (1) meets the requirements of subsection (2), the Public Guardian and Trustee may make the decision to give or refuse consent.</p> <p>(7) If two or more persons who are described in the same paragraph of subsection (1) and who meet the requirements of subsection (2) disagree about whether to give or refuse consent, and if their claims rank ahead of all others, the Public Guardian and Trustee may make the decision in their stead.</p> <p>S. 43 If a use or disclosure of personal health information about a deceased subject relates to the administration of his or her estate, consent to the use or disclosure may be given or refused by,</p> <p>(a) the deceased's estate trustee; or</p> <p>(b) if the deceased does not have an estate trustee, the person who has assumed responsibility for the administration of the deceased's estate.</p> <p>S. 44(1) If a use or disclosure of personal health information about a deceased subject does not relate to the administration of his or her estate, consent to the use or disclosure may be given or refused by a person who, immediately before the subject's death, would have had authority under subsection 42 (1) to give or refuse the consent if the subject had been incapable with respect to personal health information.</p> <p>(2) Subsections 42 (2) to (7) apply with necessary modifications to the determination of who may give or refuse consent under subsection (1).</p> <p>S. 45(1) This Act applies to a representative whom a subject of personal health information appointed under section 36.1 of the <i>Mental Health Act</i> before the day this Act comes into force, as if the representative were the subject's attorney for personal care or attorney for property.</p> <p>(2) The authority conferred on the representative by subsection (1) is limited to the purposes for which the representative was</p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|--|---|----------|---|--------|---------------|-------------|--------|--------------------|
| | | <p>nearest relative under that Act, or</p> <p>(i) by any person with written authorization from the individual to act on the individual's behalf.</p> <p>(2) Any notice required to be given to an individual under this Act may be given to the person entitled to exercise the individual's rights or powers referred to in subsection (1).</p> <p>S. 108(1) The Lieutenant Governor in Council may make regulations [...]</p> <p>(e) respecting the requirements of a consent or a revocation of a consent that is provided electronically for the purposes of sections 34 and 59; [...]</p> | <p>(i) by a person designated by the Minister of Social Services if the individual is receiving services pursuant to <i>The Residential Services Act</i> or <i>The Rehabilitation Act</i>; or</p> <p>(ii) by a person who, pursuant to <i>The Health Care Directives and Substitute Health Care Decision Makers Act</i>, is entitled to make a health care decision, as defined in that Act, on behalf of the individual; or</p> <p>(f) by any person designated in writing by the individual pursuant to section 15.</p> | | <p>appointed.</p> <p>(3) A subject who is capable with respect to personal health information may revoke the appointment in writing.</p> <p>S. 46(1) This Act applies to a representative whom the Board appointed under section 36.2 of the <i>Mental Health Act</i> before the day this Act comes into force for a subject of personal health information, as if the representative were the subject's representative appointed by the Board under section 49.</p> <p>(2) The authority conferred on the representative by subsection (1) is limited to the purposes for which the representative was appointed.</p> <p>S. 47(1) A person who gives or refuses consent, on behalf of an incapable subject or in the place of a deceased subject, to a use or disclosure of personal health information shall do so in accordance with the following principles:</p> <ol style="list-style-type: none"> 1. If the person knows of a wish applicable to the circumstances that the subject expressed while capable and after attaining 16 years of age, the person shall act in accordance with the wish. 2. If the person does not know of a wish applicable to the circumstances that the subject expressed while capable and after attaining 16 years of age, or if it is impossible to comply with the wish, the person shall act in the subject's best interests. <p>(2) Later wishes expressed while capable prevail over earlier wishes.</p> <p>(3) In deciding what an incapable subject's best interests are, the person who gives or refuses consent on the subject's behalf shall take into consideration,</p> <p>(a) the values and beliefs that the person knows the subject held when capable and believes the subject would still follow if capable;</p> <p>(b) the wishes, if any, expressed by the subject with respect to personal health information that are not required to be followed under subsection(1); and</p> <p>(c) the following factors:</p> <ol style="list-style-type: none"> 1. Whether the use or disclosure is likely to benefit the subject. 2. Whether the benefit the subject is expected to obtain from the use or disclosure outweighs the risk of negative consequences occurring as a result of the use or disclosure. 3. Whether the purpose for which the use or disclosure is sought can be accomplished without the use or disclosure. 4. Whether accomplishing that purpose without the use or disclosure would be as beneficial to the subject as accomplishing that purpose with the use or disclosure. 5. Whether the use or disclosure is necessary to satisfy the | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|---------|--------------|----------|--|--------|---------------|-------------|--------|--------------------|
| | | | | | <p>legal obligations of the subject.</p> <p>(4) In deciding what a deceased subject's best interests are, the person who gives or refuses consent in the deceased's place shall take into consideration,</p> <p>(a) the values and beliefs that the person knows the deceased held when capable and believes the deceased would have wanted reflected in decisions made after his or her death concerning his or her personal health information;</p> <p>(b) the wishes, if any, expressed by the deceased with respect to personal health information that are not required to be followed under subsection(1); and</p> <p>(c) the following factors:</p> <ol style="list-style-type: none"> 1. Whether the benefit the person seeking to use the information or the person seeking disclosure of the information is expected to obtain from the use or disclosure outweighs the risk of negative consequences occurring as a result of the use or disclosure. 2. Whether the purpose for which the use or disclosure is sought can be accomplished without the use or disclosure. <p>(5) A person who gives or refuses consent on behalf of an incapable subject to the use or disclosure of personal health information shall, before giving or refusing consent,</p> <p>(a) give the subject information about the consequences of a determination of incapacity, to the extent reasonable in the circumstances; and</p> <p>(b) encourage the subject to participate, to the best of his or her abilities, in making the decision to give or refuse consent.</p> <p>S. 48(1) A subject of personal health information who is determined to be incapable with respect to personal health information may apply to the Board for a review of the determination.</p> <p>(2) Subsection (1) does not apply if the determination of incapacity is made for the purpose of deciding whether an individual is authorized to give or refuse consent on behalf of an incapable subject or in the place of a deceased subject.</p> <p>(3) The parties to the application are:</p> <ol style="list-style-type: none"> 1. The subject applying for the review. 2. The custodian of the personal health information. 3. All other persons whom the Board specifies. <p>(4) The Board may confirm the determination of incapacity or may determine that the subject is capable with respect to personal health information.</p> <p>(5) If a determination that a subject is incapable with respect to personal health information is confirmed on the final disposition of an application under this section, the subject shall not make a new application under this section within six</p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|---------|--------------|----------|--|--------|---------------|-------------|--------|--------------------|
| | | | | | <p>months after the final disposition of the earlier application, unless the Board gives leave in advance.</p> <p>(6) The Board may give leave for the new application to be made if it is satisfied that there has been a material change in circumstances that justifies reconsideration of the subject's capacity.</p> <p>(7) Sections 73 to 81 of the <i>Health Care Consent Act, 1996</i> apply with necessary modifications to an application under this section.</p> <p>S. 49(1) A subject of personal health information who is 16 years old or older and who is incapable with respect to personal health information may apply to the Board for appointment of a representative to give or refuse consent on his or her behalf to a use or disclosure of personal health information.</p> <p>(2) An individual who is 16 years old or older may apply to the Board to be appointed as the representative of a subject who is incapable with respect to personal health information, to give or refuse consent on behalf of the subject to a use or disclosure of personal health information.</p> <p>(3) Subsections (1) and (2) do not apply if the subject has a guardian of the person, a guardian of property, an attorney for personal care, or an attorney for property, who has authority to give or refuse consent to the use or disclosure.</p> <p>(4) The parties to the application are:</p> <ol style="list-style-type: none"> 1. The subject. 2. The proposed representative named in the application. 3. Every person who is described in paragraph 4, 5, 6 or 7 of subsection 42(1). 4. All other persons whom the Board specifies. <p>(5) In an appointment under this section, the Board may authorize the representative to give or refuse consent on the subject's behalf to,</p> <ol style="list-style-type: none"> (a) a particular use or disclosure at a particular time; (b) a use or disclosure of the type specified by the Board in circumstances specified by the Board, if the subject is determined to be incapable with respect to personal health information at the time the consent is sought; or (c) any use or disclosure at any time, if the subject is determined to be incapable with respect to personal health information at the time the consent is sought. <p>(6) The Board may make an appointment under this section if it is satisfied that the following requirements are met:</p> <ol style="list-style-type: none"> 1. The subject does not object to the appointment. 2. The representative consents to the appointment, is at | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|---------|--------------|----------|---|--------|---------------|-------------|--------|--------------------|
| | | | | | <p>least 16 years old and is capable with respect to personal health information.</p> <p>3. The appointment is in the subject's best interests.</p> <p>(7) Unless the subject objects, the Board may,</p> <ul style="list-style-type: none"> (a) appoint as representative a different individual than the one named in the application; (b) limit the duration of the appointment; (c) impose any other condition on the appointment; (d) on any person's application, remove, vary or suspend a condition imposed on the appointment or impose an additional condition on the appointment. <p>(8) The Board may, on any person's application, terminate an appointment made under this section if,</p> <ul style="list-style-type: none"> (a) the subject or the representative requests the termination; (b) the representative is no longer capable with respect to personal health information; (c) the appointment is no longer in the subject's best interests; <p>or</p> <ul style="list-style-type: none"> (d) the subject has a guardian of the person, a guardian of property, an attorney for personal care, or an attorney for property, who has authority to give or refuse consent to the types of uses and disclosures for which the appointment was made in the circumstances to which the appointment applies. <p>(9) Sections 73 to 81 of the <i>Health Care Consent Act, 1996</i> apply with necessary modifications to an application under this section.</p> | | | | | |

Safeguarding, Retention and Destruction

An often-understated responsibility of public institutions, private organizations and individual researchers is their obligation to adopt and implement reasonable security arrangements against unauthorized access, collection, use or disclosure of the personal (health) information they hold, transport, store, handle or otherwise control. Such security arrangements may include administrative safeguards (such as security clearance of persons allowed access and a detailed record of each access), technological safeguards (such as passwords, firewalls and encryption), physical safeguards (such as locked cabinets and restricted access to offices) and additional safeguards (such as ongoing training of employees and agents on how to implement security safeguards). Some statutes simply enunciate this general safeguarding obligation, while others set out detailed requirements either in the Act itself or in related regulations on how specifically to limit access to and ensure security of personal records. In principle, however, the nature of the safeguards adopted should vary and be commensurate with the sensitivity of the information to be protected.

Personal (health) information may be retained for as long as prescribed by law or regulation. Some statutes specify a minimum retention period of one or two years, in order to afford individuals with a reasonable opportunity to gain access thereto (typically in situations where the information might be used as the basis for a decision that could directly affect the individual). Maximum retention periods, however, are not usually specified. Statutes will more generally provide that personal (health) information may be retained only as long as necessary to fulfil the purpose for which it was collected.

Finally most statutes require that all reasonable steps be taken when actually destroying or disposing of the personal (health) information to protect the privacy of the individual the information is about and to ensure against later reconstruction or unauthorized retrieval. The maintenance of a disposal record is sometimes expressly required detailing the personal information that was destroyed and the time period to which it relates, the date and the method of destruction, including the name of the person responsible for supervising the destruction.

SAFEGUARDING, RETENTION AND DESTRUCTION OF PERSONAL INFORMATION IN THE PUBLIC SECTOR

| Federal | British Columbia | Alberta | Sask. | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I | Nfld. & Lab. |
|---|--|---|-------|---|---|---|---|---|--|--------------|
| <p><i>Privacy Act, R.S.C. 1985, c. P-21</i></p> <p>COLLECTION, RETENTION AND DISPOSAL OF PERSONAL INFORMATION</p> <p>S. 6(1) Personal information that has been used by a government institution for an administrative purpose shall be retained by the institution for such period of time after it is so used as may be prescribed by regulation in order to ensure that the individual to whom it relates has reasonable opportunity to obtain access to the information.</p> <p>(2) A government institution shall take all reasonable steps to ensure that personal information that is used for an administrative purpose by the institution is as accurate, up-to-date and complete as possible.</p> <p>S. 6(3) A government institution shall dispose of personal information under the control of the institution in accordance with the regulations and in accordance with any directives or guidelines issued by the designated minister in relation to the disposal of that</p> | <p><i>Freedom of Information and Protection of Privacy Act, R.S.B.C. 1996, c. 165</i></p> <p>PART 3 – PROTECTION OF PRIVACY</p> <p>Division 1 Collection, Protection and Retention of Personal Information by Public Bodies</p> <p>S. 28 If an individual’s personal information will be used by a public body to make a decision that directly affects the individual, the public body must make every reasonable effort to ensure that the information is accurate and complete.</p> <p>S. 30 The head of a public body must protect personal information by making reasonable security arrangements against such risks as unauthorized access, collection, use, disclosure or disposal.</p> <p>S. 31 If a public body uses an individual’s personal information to make a decision that directly affects the individual, the public body must retain that information for at least one year after using it so that the individual has reasonable opportunity to obtain access to it.</p> | <p><i>Freedom of Information and Protection of Privacy Act, S.A. 1994, c. F-18.5</i></p> <p>PART 2 PROTECTION OF PRIVACY</p> <p>Division 1 Collection of Personal Information</p> <p>S. 34 If an individual’s personal information will be used by a public body to make a decision that directly affects the individual, the public body must</p> <p>(a) make every reasonable effort to ensure that the information is accurate and complete, and</p> <p>(b) retain the personal information for at least one year after using it so that the individual has a reasonable opportunity to obtain access to it, or for any shorter period of time as agreed to in writing by</p> <p>(i) the individual,</p> <p>(ii) the public body, and</p> <p>(iii) if the body that approves the records and retention and disposition schedule for the public body is different from the public body, that body.</p> <p>S. 36 The head of a public body must protect personal</p> | | <p><i>The Freedom of Information and Protection of Privacy Act, R.S.M. c. F-175</i></p> <p>PART 3 PROTECTION OF PRIVACY</p> <p>Division 2 Collection, Correction and Retention of Personal Information</p> <p>S. 38 If personal information about an individual will be used by a public body to make a decision that directly affects the individual, the public body shall take reasonable steps to ensure that the information is accurate and complete.</p> <p>S. 40(1) A public body that uses personal information about an individual to make a decision that directly affects the individual shall, in the absence of another legal requirement to do so, establish and comply with a written policy concerning the retention of the personal information.</p> <p>(2) A policy under subsection (1) must</p> <p>(a) require that personal information be retained for a reasonable period of time so that the individual the information is about has a reasonable opportunity to obtain access to it; and</p> <p>(b) comply with any additional requirements set out in the regulations.</p> <p>S. 41 The head of a public</p> | <p><i>Freedom of Information and Protection of Privacy Act, R.S.O. 1990, c. F-31</i></p> <p>PART III PROTECTION OF INDIVIDUAL PRIVACY</p> <p>Collection and Retention of Personal Information</p> <p>S. 40(1) Personal information that has been used by an institution shall be retained after use by the institution for the period prescribed by regulation in order to ensure that the individual to whom it relates has a reasonable opportunity to obtain access to the personal information.</p> <p>S. 40(2) The head of an institution shall take reasonable steps to ensure that personal information on the records of the institution is not used unless it is accurate and up to date.</p> <p>S. 40(4) A head shall dispose of personal information under the control of the institution in accordance with the regulations.</p> <p>PART V GENERAL</p> <p>S. 60(1) The Lieutenant Governor in Council may make regulations,</p> <p>[...]</p> <p>(d) setting standards for and requiring administrative, technical and physical safeguards to ensure the security and confidentiality of records and personal information under the control</p> | <p><i>An Act respecting Access to Documents Held by Public Bodies and the Protection of Personal Information, R.S.Q. c. A-2.1</i></p> <p>CHAPTER III PROTECTION OF PERSONAL INFORMATION</p> <p>Division III Establishment and Maintenance of Files</p> <p>S. 72 Every public body must see to it that the nominative information kept by it is up to date, accurate and complete so as to serve the purposes for which it is collected.</p> <p>S. 73 When the object for which nominative information was collected has been achieved, the public body shall destroy the document, subject to the <i>Archives Act</i> (chapter A-21.1).</p> <p>S. 78 Sections 64 to 77 do not apply to the processing of nominative information collected and used as a working tool by a natural person, to the extent that the information is not disclosed to any person other than the person concerned or to a body other than that to which he belongs, and that it is used judiciously.</p> <p>The same rule applies to the processing of nominative information collected by a natural person and which is</p> | <p><i>Protection of Personal Information Act, S.N.B. 1998, c. P-19.1</i> (Assented to 26 February 1998, not yet in force.)</p> <p>S. 2(1) Every public body is subject to the Statutory Code of Practice.</p> <p>(2) The Statutory Code of Practice shall be interpreted and applied in accordance with Schedule B and with any regulations made under paragraph 7(b).</p> <p>Schedule A: The Statutory Code of Practice</p> <p>Principle 5: Limiting Use, Disclosure and Retention</p> <p>[...] Personal information shall be retained only as long as necessary for the fulfillment of those purposes.</p> <p>Principle 6: Accuracy</p> <p>Personal information shall be as accurate, complete and up-to-date as is necessary for the purposes for which it is to be used.</p> <p>Principle 7: Safeguards</p> <p>Personal information shall be protected by safeguards appropriate to the sensitivity of the information.</p> | <p><i>Freedom of Information and Protection of Privacy Act, S.N.S. 1993, c. 5</i></p> <p>COLLECTION, PROTECTION AND RETENTION OF PERSONAL INFORMATION</p> <p>S. 24(2) Where an individual’s personal information will be used by a public body to make a decision that directly affects the individual, the public body shall make every reasonable effort to ensure that the information is accurate and complete.</p> <p>(3) The head of the public body shall protect personal information by making reasonable security arrangements against such risks as unauthorized access, collection, use, disclosure or disposal.</p> <p>(4) Where a public body uses an individual’s personal information to make a decision that directly affects the individual, the public body shall retain that information for at least one year after using it so that the individual has a reasonable opportunity to obtain access to it.</p> | <p>Bill 81, Freedom of Information and Protection of Privacy Act, 1st Sess., 60th General Assembly P.E.I. 1997 (Died on the Order Paper – not in force)</p> <p>PART II PROTECTION OF PRIVACY</p> <p>Division 1 Collection of Personal Information</p> <p>S. 33 If an individual’s personal information will be used by a public body to make a decision that directly affects the individual, the public body shall</p> <p>(a) make every reasonable effort to ensure that the information is accurate and complete; and</p> <p>(b) retain the personal information for at least one year after using it so that the individual has a reasonable opportunity to obtain access to it.</p> <p>S. 35 The head of a public body shall protect personal information by making reasonable security arrangements against such risks as unauthorized access, collection, use, disclosure or disposal.</p> | |

| Federal | British Columbia | Alberta | Sask. | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I | Nfld. & Lab. |
|--|---|--|-------|---|--|--|--|-------------|-------|--------------|
| <p>information.</p> <p>GENERAL</p> <p>S. 77(1) The Governor in Council may make regulations [...]</p> <p>(b) prescribing the period of time for which any class of personal information is to be retained under subsection 6(1);</p> <p>(c) prescribing the circumstances and the manner in which personal information under the control of a government institution is to be disposed of under subsection 6(3); [...]</p> <p>-----</p> <p>Privacy Regulations, SOR/83-508</p> <p>RETENTION OF PERSONAL INFORMATION THAT HAS BEEN USED BY A GOVERNMENT INSTITUTION FOR AN ADMINISTRATIVE PURPOSE</p> <p>S. 4(1) Personal information concerning an individual that has been used by a government institution for an administrative purpose shall be retained by the institution</p> <p>(a) for at least two years</p> | <p>PART 6 – GENERAL PROVISIONS</p> <p>S. 76(2) [...] [T]he Lieutenant Governor in Council may make regulations as follows:</p> <p>[...]</p> <p>(m) providing for the retention and disposal of records by a public body if the <i>Document Disposal Act</i> does not apply to the public body;</p> <p>[...]</p> | <p>information by making reasonable security arrangements against such risks as unauthorized access, collection, use, disclosure or destruction.</p> | | <p>body shall, in accordance with any requirements set out in the regulations, protect personal information by making reasonable security arrangements against such risks as unauthorized access, use, disclosure or destruction.</p> <p>PART 6 GENERAL PROVISIONS</p> <p>S. 87 The Lieutenant Governor in Council may make regulations [...]</p> <p>(g) for the purpose of clause 40(2)(b), governing policies of public bodies concerning retention periods for personal information and respecting the destruction of personal information;</p> <p>[...]</p> <p>(j) respecting standards for and requiring administrative, technical and physical safeguards to ensure the security and confidentiality of records and personal information in the custody or under the control of public bodies;</p> <p>[...]</p> | <p>of institutions;</p> <p>(e) setting standards for the accuracy and completeness of personal information that is under the control of an institution;</p> <p>(f) prescribing time periods for the purposes of subsection 40(1); [...]</p> <p>(j) prescribing conditions relating to the security and confidentiality of records used for a research purpose; [...]</p> <p>-----</p> <p>Freedom of Information and Protection of Privacy Act, General Regulations, R.R.O. 1990, Reg. 460</p> <p>S. 4(1) Every head shall ensure that reasonable measures to prevent unauthorized access to the records in his or her institution are defined, documented and put in place, taking into account the nature of the records to be protected.</p> <p>(2) Every head shall ensure that only those individuals who need a record for the performance of their duties shall have access to it.</p> <p>(3) Every head shall ensure that reasonable measures to protect the records in his or her institution from inadvertent destruction or damage are defined, documented and put in place, taking into account the nature of the records to be protected.</p> <p>S. 5(1) Personal information that has been used by an institution shall be retained by</p> | <p>used by him for scientific research purposes.</p> <p>The public body is subject to the said sections from the time the person contemplated in the first or second paragraph discloses to the public body nominative information that he has collected or which was obtained through processing.</p> <p>CHAPTER VI REGULATIONS</p> <p>S. 155 The Government may make regulations [...]</p> <p>(5) fixing appropriate security standards to ensure the confidentiality of the information entered in a personal information file; [...]</p> | <p>Schedule B: Interpretation and Application of the Statutory Code of Practice</p> <p>Principle 5: Limiting Use, Disclosure and Retention</p> <p>S. 5.1 A public body may discharge its obligation not to retain personal information by converting that information into non-identifying form.</p> <p>S. 5.2 Personal information that is maintained outside a personal records system and is not readily accessible to a person who has no prior knowledge of the information shall be deemed to be converted into non-identifying form when the use of the information ceases.</p> <p>Principle 7: Safeguards</p> <p>S. 7.1 The safeguards to be adopted include training and administrative, technical, physical and other measures, as appropriate in the circumstances, and include safeguards that are to be adopted when a public body discloses personal information to a third party or makes arrangements for a third party to collect personal information on its behalf.</p> | | | |

| Federal | British Columbia | Alberta | Sask. | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I | Nfld. & Lab. |
|--|------------------|---------|-------|----------|---|--------|---------------|-------------|-------|--------------|
| <p>following the last time the personal information was used for an administrative purpose unless the individual consents to its disposal; [...]</p> | | | | | <p>the institution for at least one year after use, unless the individual to whom the information relates consents to its earlier disposal.</p> <p>S. 10(1) The following are the terms and conditions relating to security and confidentiality that a person is required to agree to before a head may disclose personal information to that person for a research purpose:</p> <ol style="list-style-type: none"> 1. The person shall use the information only for a research purpose set out in the agreement or for which the person has written authorization from the institution. 2. The person shall name in the agreement any other persons who will be given access to personal information in a form in which the individual to whom it relates can be identified. 3. Before disclosing personal information to other persons under paragraph 2, the person shall enter into an agreement with those persons to ensure that they will not disclose it to any other person. 4. The person shall keep the information in a physically secure location to which access is given only to the person and to the persons given access under paragraph 2. 5. The person shall destroy all individual identifiers in the information by the date specified in the agreement. 6. The person shall not contact any individual to whom personal information relates, directly or indirectly, without the prior written authority of the institution. 7. The person shall ensure that no personal information will be used or disclosed in a form in | | | | | |

| Federal | British Columbia | Alberta | Sask. | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I | Nfld. & Lab. |
|---------|------------------|---------|-------|----------|---|--------|---------------|-------------|-------|--------------|
| | | | | | <p>which the individual to whom it relates can be identified without the written authority of the institution.</p> <p>8. The person shall notify the institution in writing immediately if the person becomes aware that any of the conditions set out in this section have been breached.</p> <p>S. 10(2) An agreement relating to the security and confidentiality of personal information to be disclosed for a research purpose shall be in Form 1. R.R.O., Reg. 460, s. 10.</p> <p>Form 1 [Note: See “Appendix A”]</p> <p>-----</p> <p><i>Freedom of Information and Protection of Privacy Act, Disposal of Personal Information Regulation, R.R.O. 1990, Reg. 459</i></p> <p>S. 2 An institution may dispose of personal information only by transferring it to the Archives or by destroying it.</p> <p>S. 3 Where personal information is in the custody or under the control of an institution, no person shall destroy it without the authorization of the head.</p> <p>S. 4(1) Every head shall ensure that all reasonable steps are taken to protect the security and confidentiality of personal information that is to be destroyed, including protecting its security and confidentiality during its storage, transportation, handling and</p> | | | | | |

| Federal | British Columbia | Alberta | Sask. | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I | Nfld. & Lab. |
|---------|------------------|---------|-------|----------|--|--------|---------------|-------------|-------|--------------|
| | | | | | <p>destruction.</p> <p>(2) Every head shall ensure that all reasonable steps are taken to protect the security and confidentiality of personal information that is to be transferred to the Archives, including protecting its security and confidentiality during its storage, transportation and handling.</p> <p>(3) In determining whether all reasonable steps are taken under subsection (1) or (2), the head shall consider the nature of the personal information to be destroyed or transferred.</p> <p>S. 5 Every head shall take all reasonable steps to ensure that when personal information is to be destroyed, it is destroyed in such a way that it cannot be reconstructed or retrieved.</p> <p>S. 6(1) Every head of an institution shall ensure that the institution maintains a disposal record setting out what personal information has been destroyed or transferred to the Archives and the date of that destruction or transfer.</p> <p>(2) The head shall ensure that the disposal record maintained under subsection (1) does not contain personal information.</p> | | | | | |

SAFEGUARDING, RETENTION AND DESTRUCTION OF PERSONAL INFORMATION IN THE PRIVATE SECTOR

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Newfoundland and Labrador |
|---|------------------|---------|--------------|----------|---------|--|---------------|-------------|----------------------|---------------------------|
| <p>Bill C-6, Personal Information Protection and Electronic Documents Act, 2nd Sess., 36th Parl., 48 Elizabeth II, 1999 (Passed by the Senate with amendments, 10 December 1999 – not yet assented to.)</p> <p>Schedule 1</p> <p>4.7 Principle 7 – Safeguards Personal information shall be protected by security safeguards appropriate to the sensitivity of the information.</p> <p>4.7.1 The security safeguards shall protect personal information against loss or theft, as well as unauthorized access, disclosure, copying, use, or modification. Organizations shall protect personal information regardless of the format in which it is held.</p> <p>4.7.2 The nature of the safeguards will vary depending on the sensitivity of the information that has been collected, the amount, distribution and format of the information, and the method of storage. More sensitive information should be safeguarded by a higher level of protection. [...]</p> <p>4.7.3 The methods of protection should include (a) physical measures, for example, locked filing cabinets and restricted access to offices; (b) organizational measures, for example, security clearances and limiting access on a “need-to-know” basis; and (c) technological measures, for example, the use of passwords and encryption.</p> <p>4.7.4 Organizations shall make their employees aware of the importance of maintaining the confidentiality of personal information.</p> | | | | | | <p><i>An Act respecting the Protection of Personal Information in the Private Sector, R.S.Q. c. P-39.1</i></p> <p>DIVISION III CONFIDENTIALITY OF PERSONAL INFORMATION</p> <p><i>§1. – Retention, use and non-communication of information</i></p> <p>S. 10 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.</p> <p>S. 12 Once the object of a file has been achieved, no information contained in it may be used otherwise than with the consent of the person concerned, subject to the time limit prescribed by law or by a retention schedule established by government regulation.</p> | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | Prince Edward Island | Newfoundland and Labrador |
|--|------------------|---------|--------------|----------|---------|--------|---------------|-------------|----------------------|---------------------------|
| <p>4.7.5 Care shall be used in the disposal or destruction of personal information, to prevent unauthorized parties from gaining access to the information (see Clause 4.5.3).</p> <p>4.5 Principle 5 – Limiting Use, Disclosure, and Retention</p> <p>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 necessary for the fulfillment of those purposes.</p> <p>4.5.2 Organizations should develop guidelines and implement procedures with respect to the retention of personal information. These guidelines should include minimum and maximum retention periods. Personal information that has been used to make a decision about an individual shall be retained long enough to allow the individual access to the information after the decision has been made. An organization may be subject to legislative requirements with respect to retention periods.</p> <p>4.5.3 Personal information that is no longer required to fulfil the identified purposes should be destroyed, erased, or made anonymous. Organizations shall develop guidelines and implement procedures to govern the destruction of personal information.</p> | | | | | | | | | | |

SAFEGUARDING, RETENTION AND DESTRUCTION OF PERSONAL HEALTH INFORMATION

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|---|--|--|---|--------|---------------|-------------|--------|--------------------|
| | | <p>Bill 40, Health Information Act, 3rd Sess., 24th Leg., Alberta, 1999 (Royal assent 9 December, 1999 - not yet proclaimed in force.)</p> <p>PART 6 DUTIES AND POWERS OF CUSTODIANS RELATING TO HEALTH INFORMATION</p> <p>Division 1 General Duties and Powers</p> <p>S. 60(1) A custodian must take reasonable steps in accordance with the regulations to maintain administrative, technical and physical safeguards that will</p> <p>(a) protect the confidentiality of health information that is in its custody or under its control and the privacy of the individuals who are the subjects of that information,</p> <p>(b) protect the confidentiality of health information that is to be stored or used in a jurisdiction outside Alberta or that is to be disclosed by the custodian to a person in a jurisdiction outside Alberta and the privacy of the individuals who are the subjects of that information,</p> <p>(c) protect against any reasonably anticipated</p> <p>(i) threat or hazard to the security or integrity of the health information or of loss of the health information, or</p> <p>(ii) unauthorized use, disclosure or modification of the health information or unauthorized access to the health information, and</p> <p>(d) otherwise ensure compliance with this Act by the custodian and its affiliates.</p> | <p>The Health Information Protection Act, S.S. 1999, c. H-0.021 (Royal assent 6 May 1999 - not yet proclaimed in force.)</p> <p>PART III Duty of Trustee to Protect Personal Health Information</p> <p>S. 16 Subject to the regulations, a trustee that has custody or control of personal health information must establish policies and procedures to maintain administrative, technical and physical safeguards that will:</p> <p>(a) protect the integrity, accuracy and confidentiality of the information;</p> <p>(b) protect against any reasonably anticipated:</p> <p>(i) threat or hazard to the security or integrity of the information;</p> <p>(ii) loss of the information; or</p> <p>(iii) unauthorized access to or use, disclosure or modification of the information; and</p> <p>(c) otherwise ensure compliance with this Act by its employees.</p> <p>[Note: “Trustee”, within the meaning of this Act, is defined in “Collection of Personal Health Information”, see above.]</p> <p>S. 17(1) A trustee must:</p> <p>(a) have a written policy concerning the retention and destruction of personal health information that meets the requirements set out in the regulations; and</p> <p>(b) comply with that policy and any prescribed standards with respect to the retention and destruction of personal health information.</p> <p>(2) A trustee must ensure that:</p> | <p>The Personal Health Information Act, S.M. 1997, c. P-33.5</p> <p>PART 3 PROTECTION OF PRIVACY</p> <p>DIVISION 1 RESTRICTIONS ON COLLECTION AND RETENTION OF INFORMATION</p> <p>S. 17(1) A trustee shall establish a written policy concerning the retention and destruction of personal health information and shall comply with that policy.</p> <p>[Note: “Trustee”, within the meaning of this Act, is defined in “Collection of Personal Health Information”, see above.]</p> <p>(2) A policy under subsection (1) must conform with any requirements of the regulations.</p> <p>(3) In accordance with any requirements of the regulations, a trustee shall ensure that personal health information is destroyed in a manner that protects the privacy of the individual the information is about.</p> <p>(4) A trustee who destroys personal health information shall keep a record of</p> <p>(a) the individual whose personal health information is destroyed and the time period to which the information relates; and</p> <p>(b) the method of destruction and the person responsible for supervising the destruction.</p> <p>(5) This section does not override or modify any requirement in an enactment of Manitoba or Canada concerning the retention or destruction of records maintained by public bodies.</p> | <p>Draft Personal Health Information Protection Act, 1997 (Not in force.)</p> <p>PART V ADDITIONAL DUTIES RESPECTING PERSONAL HEALTH INFORMATION</p> <p>S. 33(1) A health information custodian shall protect personal health information that is in the custody or under the control of the custodian by adopting reasonable administrative, technical and physical safeguards to ensure the security, accuracy and integrity of the information.</p> <p>[Note: “Health information custodian”, within the meaning of this Act, is defined in “Collection of Personal Health Information”, see above.]</p> <p>(2) The safeguards shall include the following:</p> <p>1. Controls that limit the persons who are part of the custodian and who may collect, use or disclose personal health information to those persons who are specifically authorized by the custodian to do so.</p> <p>2. Controls to ensure that the persons who are part of the custodian and who are authorized to collect, use or disclose personal health information comply with the limitations set out in section 4. [Note: section 4 is reproduced in “Collection of Personal Information” as well as “Use and Disclosure of Personal Health Information”, above.]</p> <p>3. Controls to ensure that personal health information cannot be used or disclosed unless,</p> <p>i. the identity of the person seeking to use or to receive the information is verified as a person the custodian has authorized to use or receive it under this Act, and</p> <p>ii. the proposed use or disclosure is verified as being authorized under this Act.</p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|--|---|---|--|--------|---------------|-------------|--------|--------------------|
| | | <p>[Note: “Custodian”, within the meaning of this Act, is defined in “Collection of Personal Health Information”, see above.]</p> <p>(2) The safeguards to be maintained under subsection (1) must include appropriate measures for the proper disposal of records to prevent any reasonably anticipated unauthorized use or disclosure of the health information or unauthorized access to the health information following its disposal.</p> <p>PART 8 GENERAL PROVISIONS</p> <p>S. 108(1) The Lieutenant Governor in Council may make regulations [...]</p> <p>(g) respecting the retention, disposal and archival storage of records for the purposes of section 60;</p> <p>(h) respecting the administrative, technical and physical safeguards that a custodian must maintain in respect of health information pursuant to section 60; [...]</p> | <p>(a) personal health information stored in any format is retrievable, readable and useable for the purpose for which it was collected for the full retention period of the information established in the policy mentioned in subsection(1); and</p> <p>(b) personal health information is destroyed in a manner that protects the privacy of the subject individual.</p> <p>PART VIII GENERAL</p> <p>S. 63(1) For the purpose of carrying out this Act according to its intent, the Lieutenant Governor in Council may make regulations: [...]</p> <p>(h) prescribing and governing administrative, technical and physical safeguards for the protection of personal health information;</p> <p>(i) prescribing and governing standards for the retention and destruction of personal health information and governing retention and destruction policies; [...]</p> | <p>DIVISION 2 SECURITY SAFEGUARDS</p> <p>S. 18(1) In accordance with any requirements of the regulations, a trustee shall protect personal health information by adopting reasonable administrative, technical and physical safeguards that ensure the confidentiality, security, accuracy and integrity of the information.</p> <p>(2) Without limiting subsection (1), a trustee shall</p> <p>(a) implement controls that limit the persons who may use personal health information maintained by the trustee to those specifically authorized by the trustee to do so;</p> <p>(b) implement controls to ensure that personal health information maintained by the trustee cannot be used unless</p> <p>(i) the identity of the person seeking to use the information is verified as a person the trustee has authorized to use it, and</p> <p>(ii) the proposed use is verified as being authorized under this Act;</p> <p>(c) if the trustee uses electronic means to request disclosure of personal health information or to respond to requests for disclosure, implement procedures to prevent the interception of the information by unauthorized persons; and</p> <p>(d) when responding to requests for disclosure of personal health information, ensure that the request contains sufficient detail to uniquely identify the individual the information is about.</p> <p>(3) A trustee who maintains personal health information in electronic form shall implement any additional safeguards for such information required by the regulations.</p> <p>S. 19 In determining the reasonableness of security safeguards required under section 18, a trustee shall take into account the degree of sensitivity of the personal health information to be protected.</p> | <p>4. Controls to ensure that, when responding to a request for disclosure of personal health information, the request contains sufficient detail to identify uniquely the person making the request and the subject of the information.</p> <p>5. Controls to prevent the interception of the personal health information by unauthorized persons.</p> <p>6. The safeguards required by the regulations.</p> <p>(3) In determining the reasonableness of safeguards adopted under this section, consideration shall be given to the degree of sensitivity of the personal health information to be protected.</p> <p>S. 36(1) A health information custodian shall have in place a written policy concerning the retention and destruction of personal health records and shall comply with the policy.</p> <p>(2) The policy shall comply with the requirements, if any, of the regulations.</p> <p>(3) A health information custodian shall ensure that personal health records are destroyed in a manner that protects the privacy of the subject of each record.</p> <p>(4) A health information custodian who destroys a personal health record shall keep a record of,</p> <p>(a) the subject of the personal health record and the time period to which it relates; and</p> <p>(b) the method of destruction and the person responsible for supervising the destruction.</p> <p>(5) Despite section 67, this section does not override or modify the requirements concerning the retention or destruction of records under an Act of Canada or another Act of Ontario.</p> <p>S. 38 A health information custodian shall ensure that the members of the custodian’s staff who collect, create, use, modify or disclose personal health information or who retain or destroy personal health records receive training in relation to the custodian’s duties under this Act.</p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|---------|--------------|--|---|--------|---------------|-------------|--------|--------------------|
| | | | | <p>PART 6 GENERAL PROVISIONS</p> <p>S. 66(1) The Lieutenant Governor in Council may make regulations [...] (f) for the purpose of section 17, governing policies of trustees concerning retention periods for personal health information and respecting the destruction of that information, and requiring the policies to be made available to the public; [...] (h) respecting security safeguards for personal health information that trustees must establish, including requirements for information held in electronic form; [...]</p> <p>-----</p> <p><i>Personal Health Information Regulation, Man. Reg. 245/97</i></p> <p>S. 2 A trustee shall establish and comply with a written policy and procedures containing the following: (a) provisions for the security of personal health information during its collection, use, disclosure, storage, and destruction, including measures (i) to ensure the security of the personal health information when a record of the information is removed from a secure designated area, and (ii) to ensure the security of personal health information in electronic form when the computer hardware or removable electronic storage media on which it has been recorded is being disposed of or used for another purpose; (b) provisions for the recording of security breaches; (c) corrective procedures to address security breaches.</p> <p>S. 3 A trustee shall (a) ensure that personal health information is maintained in a designated area or areas and is subject to appropriate security safeguards; (b) limit physical access to designated areas containing personal health information to</p> | <p>PART IX MISCELLANEOUS</p> <p>S. 72(1) The Lieutenant Governor in Council may make regulations, [...] (i) requiring health information custodians to comply with certain standards as part of their obligation to adopt safeguards under subsection 33(1); (j) prescribing administrative, technical and physical safeguards for the purpose of paragraph 6 of subsection 33(2); (k) designating a body that may set or adopt the standards described in clause [...] (i) or specify a process for setting those standards; [...] (m) governing the retention and destruction of personal health information; [...]</p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|---------|--------------|---|---------|--------|---------------|-------------|--------|--------------------|
| | | | | <p>authorized persons;</p> <p>(c) take reasonable precautions to protect personal health information from fire, theft, vandalism, deterioration, accidental destruction or loss and other hazards; and</p> <p>(d) ensure that removable media used to record personal health information is stored securely when not in use.</p> <p>S. 4 A trustee who maintains personal health information in electronic form shall also</p> <p>(a) keep an electronic record of every successful or unsuccessful attempt to gain access to personal health information maintained in electronic form;</p> <p>(b) keep an electronic record of every addition to, deletion or modification of personal health information maintained in electronic form;</p> <p>(c) ensure that every transmission of personal health information maintained in electronic form is recorded; and</p> <p>(d) regularly review the electronic record to detect any security breaches.</p> <p>S.5 A trustee shall, for each of its employees and agents, determine the personal health information that he or she is authorized to access.</p> <p>S.6 A trustee shall provide orientation and ongoing training for its employees and agents about the trustee's policy and procedures referred to in section 2.</p> <p>S.7 A trustee shall ensure that each employee and agent signs a pledge of confidentiality that includes an acknowledgement that he or she is bound by the policy and procedures referred to in section 2 and is aware of the consequences of breaching them.</p> <p>S. 8(1) A trustee shall conduct an audit of its security safeguards at least every two years.</p> <p>(2) If an audit identifies deficiencies in the trustee's security safeguards, the trustee shall take steps to correct the deficiencies as soon as practicable.</p> | | | | | | |

Electronic Records and Data Linkage

As the following table indicates, there is an increasing attempt by legislators, particularly in sectoral statutes governing the protection of personal health information, to regulate more closely the collection, use, disclosure and linkage of electronic data.

A broader definition of health and health research has heightened the health researcher's need to access a wide range of personal information from a multitude of sources. Whereas, at one time, health researchers may have been predominantly interested in accessing clinical records in the strict sense, today's health researchers require access to a variety of health, social, economic, cultural, geographic and other data in order to determine the potential (and interrelated) impact of many different factors on health status.

Moreover, rapid technological progress, advances in statistical methods, the growing prevalence of electronic commerce and the movement towards integrated, comprehensive health information networks, have increased ease of access and facilitated the transportability and linkage of data. How to properly capture this new reality into law, in a way which protects the privacy of individuals and collectivities, while also promoting the improvement of health care and overall health status, is the current challenge of today's legislators.

ELECTRONIC RECORDS AND DATA LINKAGE

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|--|------------------|--|--|---|--|--|---------------|-------------|--------|--------------------|
| <p>Bill C-6, <i>Personal Information Protection and Electronic Documents Act</i>, 2nd Sess., 36th Parl., 48 Elizabeth II, 1999 (Passed by the Senate with amendments, 10 December 1999 – not yet assented to.)</p> <p>PART II ELECTRONIC DOCUMENTS</p> <p>S.32 The purpose of this Part is to provide for the use of electronic alternatives in the manner provided for in this Part where federal laws contemplate the use of paper to record or communicate information or transactions.</p> | | <p><i>Freedom of Information and Protection of Privacy Act</i>, S.A. 1994, c. F-18.5</p> <p>PART 2 PROTECTION OF PRIVACY</p> <p>Division 2 Use and Disclosure of Personal Information by Public Bodies</p> <p>S. 40 A public body may disclose personal information for a research purpose, including statistical research, only if [...]</p> <p>(b) any record linkage is not harmful to the individuals the information is about and the benefits to be derived from the record linkage are clearly in the public interest, [...]</p> <p>[Note: The other conditions of Section 40 are reproduced in “Use and Disclosure of Personal Information in the Public Sector”, see above.]</p> <p>-----</p> <p>Bill 40, <i>Health Information Act</i>, 3rd Sess., 24th Leg., Alberta, 1999 (Royal Assent 9 December 1999 - not yet proclaimed in force.)</p> <p>PART 6 DUTIES AND POWERS OF CUSTODIANS RELATING TO HEALTH INFORMATION</p> <p>Division 1 General Duties and Powers</p> | <p><i>The Health Information Protection Act</i>, S.S. 1999, c. H-0.021 (Royal Assent 6 May 1999 - not yet proclaimed in force.)</p> <p>PART II Rights of the Individual</p> <p>S. 8(1) An individual may require a trustee not to store a record or a portion of a record of the individual’s personal health information on the networked electronic health record maintained by the Saskatchewan Health Information Network or on any other prescribed network.</p> <p>[Note: “Trustee”, within the meaning of this Act, is defined in “Collection of Personal Health Information”, see above.]</p> <p>(2) Where an individual’s personal health information is stored on the networked electronic health record maintained by the Saskatchewan Health Information Network, the individual may require a trustee to prevent access by other trustees to all or part of that information from the network.</p> <p>(3) Where a trustee has entered into an agreement with the Saskatchewan Health Information Network for the purpose of storing and making available personal health information, the trustee must take reasonable steps to inform individuals from</p> | <p><i>The Freedom of Information and Protection of Privacy Act</i>, R.S.M. c. F-175</p> <p>PART 3 PROTECTION OF PRIVACY</p> <p>DIVISION 3 - RESTRICTIONS ON USE AND DISCLOSURE OF PERSONAL INFORMATION</p> <p>S. 46(1) This section applies only to uses and disclosures not otherwise authorized under this division.</p> <p>[Note: Use and disclosure for research purposes is otherwise authorized by this Act under certain conditions. See “Use and Disclosure of Personal Information in the Public Sector”, above.]</p> <p>(2) When a public body</p> <p>(a) proposes to use or disclose personal information in order to link information databases or match personal information in one information database with information in another; or</p> <p>(b) receives a request for disclosure on a volume or bulk basis of personal information in a public registry or another collection of personal information; the personal information may be used or disclosed only if an approval is given by the head of the public body under this section.</p> | <p><i>Draft Personal Health Information Protection Act</i>, 1997 (Not in force.)</p> <p>PART I GENERAL</p> <p>S. 4(5) A health information custodian shall comply with the requirements, if any, prescribed in the regulations with respect to the electronic transfer of personal health information.</p> <p>[Note: “Health information custodian”, within the meaning of this Act, is defined in “Collection of Personal Health Information”, see above.]</p> <p>PART IV COMPUTER LINKAGE OF PERSONAL HEALTH RECORDS</p> <p>S. 24 In this Part, “computer linkage” means the linking, matching or merging of records in two or more computerized databases or parts of databases, if the records in at least one of the databases include personal health records, whether the linking, matching or merging is made once, more than once, intermittently or continuously;</p> <p>“participanf” means a person having control of a database involved in a computer linkage of personal health records.</p> <p>S. 25 This Part, except for section 26, does not apply to computer linkage of personal health records if all of the databases involved in the linkage are in the custody or under the control of the same health</p> | <p><i>An Act respecting access to documents held by Public Bodies and the Protection of Personal Information</i>, R.S.Q. c. A-2.1</p> <p>CHAPTER III PROTECTION OF PERSONAL INFORMATION</p> <p>DIVISION II COLLECTION, KEEPING AND USE OF NOMINATIVE INFORMATION</p> <p>S. 68.1 A public body may, without the consent of the person concerned, release a personal information file for the purposes of comparing, pairing or matching it with a file held by a person or body, if the release is necessary for the carrying out of an Act in Québec.</p> <p>An operation under this section shall be carried out under the terms of a written agreement.</p> | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|---|---|---|---|--------|---------------|-------------|--------|--------------------|
| | | <p>S. 59(1) A custodian that intends to disclose individually identifying diagnostic, treatment and care information about an individual by electronic means must obtain the individual's consent to the disclosure or ensure that the individual's consent has been previously obtained.</p> <p>[Note: "Custodian", within the meaning of this Act, is defined in "Collection of Personal Health Information", see above.]</p> <p>(2) A consent referred to in subsection (1) must be provided in writing or electronically and must include</p> <p>(a) an authorization for any custodian to disclose individually identifying diagnostic, treatment and care information about the individual by electronic means for all of the purposes listed in section 27,</p> <p>[Note: Section 27 is reproduced in "Use and Disclosure of Personal Health Information", above]</p> <p>(b) an acknowledgment that the individual providing the consent has been made aware of the reason for disclosure by electronic means and the risks and benefits to the individual of consenting or refusing to consent,</p> <p>(c) the date the consent is effective, and</p> <p>(d) a statement that the consent may be revoked at any time by the individual providing it.</p> <p>(3) A disclosure of health information pursuant to this section must be carried out in accordance with the terms of the consent.</p> <p>(4) A revocation of a consent</p> | <p>whom the trustee collects personal health information that the trustee has entered into such an agreement.</p> | <p>(3) If a proposal or request is made under subsection (2) by or to a department or a government agency, the head must refer it to the review committee for its advice. [...]</p> <p>(5) The review committee shall assess a proposal or request referred to it under this section and provide advice to the head of the public body about the matters referred to in subsection (6).</p> <p>(6) The head may approve the proposal or request only if</p> <p>(a) any advice that was requested from the review committee has been received and considered;</p> <p>(b) the head is satisfied that</p> <p>(i) the purpose of the proposal or request cannot reasonably be accomplished unless the personal information is provided in a form that identifies individuals,</p> <p>(ii) it is unreasonable or impracticable to obtain consent from the individuals the personal information is about, and</p> <p>(iii) the use or disclosure is not likely to harm the individuals the personal information is about and the benefits to be derived from the use or disclosure are clearly in the public interest;</p> <p>(c) the head has approved conditions relating to</p> <p>(i) the use of the personal information,</p> <p>(ii) the protection of the personal information, including security and confidentiality,</p> <p>(iii) the removal or destruction of individual</p> | <p>information custodian and the records in all of the databases involved in the linkage were collected or created for the same purpose or purposes.</p> <p>S. 26 A health information custodian shall not engage in a computer linkage of personal health records unless the collection, use and disclosure by the custodian of personal health records involved in the linkage are otherwise permitted by this Act.</p> <p>S. 27(1) If at least one of the participants in a computer linkage of personal health records is a health information custodian, then at least 45 days before the linkage is implemented, the participants shall designate one of the participants that is a health information custodian to be responsible for implementing the linkage.</p> <p>(2) The designated participant shall ensure that an assessment relating to the linkage is prepared and submitted to the Commissioner.</p> <p>(3) The assessment shall,</p> <p>(a) name the participants in the computer linkage or describe the class to which they belong in a manner that is sufficient to identify them;</p> <p>(b) describe the type of records to be linked, matched or merged by the computer linkage;</p> <p>(c) describe the type of records that will result from the computer linkage;</p> <p>(d) set out the purpose or purposes, as the case may be, for which the records resulting from the computer linkage will be used;</p> <p>(e) set out the authority under this Act for each collection, use and disclosure of personal health records that the computer linkage will involve;</p> <p>(f) state the duration of the computer</p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|---|--------------|--|--|--------|---------------|-------------|--------|--------------------|
| | | <p>must be provided in writing or electronically.</p> <p>(5) A consent or revocation of a consent that is provided in writing must be signed by the person providing it.</p> <p>(6) A consent or revocation of a consent that is provided electronically is valid only if it complies with the requirements set out in the regulations.</p> <p>(7) This section does not apply where the disclosure is for the purpose of obtaining or processing payment for health services.</p> <p>Division 2 Data Matching</p> <p>S. 68 A custodian must not (a) collect the health information to be used in data matching, or (b) use or disclose the health information to be used in data matching or created through data matching in contravention of this Act.</p> <p>[Note: This Act defines “data matching” in Section (1)(1)(g) as “the creation of individually identifying health information by combining individually identifying or non-identifying health information or other information from 2 or more electronic databases, without the consent of the individuals who are the subjects of the information”.]</p> <p>S. 69 A custodian may perform data matching using information that is in its custody or under its control.</p> <p>S. 70(1) A custodian may perform data matching by</p> | | <p>identifiers at the earliest time, where appropriate, and (iv) any subsequent use or disclosure of the personal information in a form that identifies individuals without the express written authorization of the public body; and (d) the recipient of the personal information has entered into a written agreement to comply with the approved conditions.</p> <p>PART 6 GENERAL PROVISIONS</p> <p>S. 87 The Lieutenant Governor in Council may make regulations [...] (i) respecting written agreements for the purposes of sections 44, 46 and 47; [...] (k) respecting the appointment of members of the review committee established under section 77 and governing the duties and functions of the review committee and all related matters; [...]</p> <p>-----</p> <p><i>The Personal Health Information Act, S.M. 1997, c. P-33.5</i></p> <p>PART 3 PROTECTION OF PRIVACY</p> <p>DIVISION 2</p> <p>S. 18(3) A trustee who maintains personal health information in electronic form shall implement any additional</p> | <p>linkage; (g) set out the administrative, technical and physical safeguards that the participants in the computer linkage will implement in relation to the linkage to ensure the security, accuracy and integrity of the records; (h) set out an analysis of the expected costs and benefits of the computer linkage; and (i) describe when and how individuals who may be directly affected by the computer linkage have been or will be notified about the linkage or explain why individuals who may be directly affected by the linkage will not be notified.</p> <p>(4) This section does not apply to a computer linkage if, (a) each of the subjects of the personal health records to be linked, matched or merged by the linkage has consented to the linkage; (b) none of the databases involved in the linkage contains personal health records relating to more than 10 individuals; (c) the participants in the linkage do not use or disclose the records for a purpose that will directly affect any individual; or (d) the following conditions are met: 1. A designated participant in the linkage has previously had an assessment relating to the records that are to be linked, matched or merged by the linkage prepared under this section and submitted to the Commissioner. 2. A person who belongs to the class of participants described in the assessment becomes a participant in the linkage after the designated participant performs the acts described in paragraph 1.</p> <p>(5) Section 6 applies with necessary modifications to a consent mentioned in clause 4(a). [Note: see</p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|--|--------------|---|---|--------|---------------|-------------|--------|--------------------|
| | | <p>combining information that is in its custody or under its control with information that is in the custody or under the control of another custodian.</p> <p>(2) Before performing data matching under this section, the custodian in whose custody and control the information that is created through data matching will be stored must prepare a privacy impact assessment and submit the assessment to the Commissioner for review and comment.</p> <p>(3) A privacy impact assessment referred to in subsection (2) must</p> <p>(a) describe how the information to be used in the data matching is to be collected, and</p> <p>(b) set out how the information that is created through data matching is to be used or disclosed.</p> <p>S. 71(1) A custodian may perform data matching by combining information that is in its custody or under its control with information that is in the custody or under the control of a person that is not a custodian.</p> <p>(2) Before performing data matching under this section, the custodian must prepare a privacy impact assessment and submit the assessment to the Commissioner for review and comment.</p> <p>(3) A privacy impact assessment referred to in subsection (2) must meet the requirements of section 70(3).</p> <p>S. 72 If data matching is performed for the purpose of conducting research, sections 48 to 56 must be complied with</p> | | <p>safeguards for such information required by the regulations.</p> <p>[Note: “Trustee”, within the meaning of this Act, is defined in “Collection of Personal Health Information”, see above.]</p> <p>PART 6 GENERAL PROVISIONS</p> <p>S.66(1) The Lieutenant Governor in Council may make regulations</p> <p>[...]</p> <p>(h) respecting security safeguards for personal health information that trustees must establish, including requirements for information held in electronic form;</p> <p>[...]</p> | <p>“Consent and Substitute Decision-Making respecting Personal Health Information”, above.]</p> <p>S. 28 On receiving an assessment under section 27, the Commissioner may review it and may offer comments respecting the proposed computer linkage.</p> <p>S. 29(1) None of the participants in a computer linkage shall, at any time after the linkage is implemented, use or disclose the records resulting from the linkage for a purpose that differs from the purposes set out in an assessment under clause 27(3)(d) unless the designated participant under section 27 has a fresh assessment prepared under that section and submitted to the Commissioner at least 45 days before the records are used or disclosed.</p> <p>(2) Sections 27 and 28 apply to the fresh assessment, with necessary modifications.</p> <p>30(1) Before a health information custodian uses or discloses records obtained from a computer linkage of personal health records for a purpose that will adversely affect an individual, the custodian shall disclose the records to the individual and permit the individual to comment on their accuracy.</p> <p>(2) Subsection (1) does not apply if disclosure of the records to the individual would frustrate the purpose for which the records are intended to be used or disclosed.</p> <p>S. 31(1) If any of the participants in a computer linkage of personal health records is not a health information custodian, the health information custodians of the databases involved in the linkage shall take steps that are reasonable in the circumstances to ensure that,</p> | | | | | |

| Federal | British Columbia | Alberta | Saskatchewan | Manitoba | Ontario | Quebec | New Brunswick | Nova Scotia | P.E.I. | Nfld. and Labrador |
|---------|------------------|---|--------------|----------|---|--------|---------------|-------------|--------|--------------------|
| | | <p>before the data matching is performed. [Note: See “Use and Disclosure of Personal Health Information”, above.]</p> <p>PART 8 GENERAL PROVISIONS</p> <p>S. 108(1) The Lieutenant Governor in Council may make regulations [...] (e) respecting the requirements of a consent or a revocation of a consent that is provided electronically for the purposes of sections 34 and 59; [...]</p> | | | <p>(a) those participants have in place the administrative , technical and physical safeguards that are appropriate in the circumstances to ensure the security, accuracy and integrity of the records; (b) those participants use and disclose the records obtained from the linkage only for the specific purposes for which the custodians have disclosed the records to those participants, as set out in the agreement; and (c) before those participants use or disclose records obtained from the linkage for a purpose that will adversely affect an individual, they disclose records to the individual and permit the individual to comment on their accuracy.</p> <p>(2) Clause (1)(c) does not apply if disclosure of the records to the individual would frustrate the purpose for which the records are intended to be used or disclosed.</p> <p>PART IX MISCELLANEOUS</p> <p>S. 72(1) The Lieutenant Governor in Council may make regulations, [...] (e) specifying requirements with respect to the electronic transfer of personal health information with which a health information custodian shall comply for the purpose of subsection 4(5); (f) specifying standards, or a process for setting standards, with which a health information custodian shall comply when engaged in the electronic transfer of personal health records, including standards for transactions, data elements for transactions, code sets for data elements and procedures for the transmission and authentication of electronic signatures, and specifying the circumstances in which the custodian is required to comply with the standards; [...]</p> | | | | | |

Ethical Norms

In this final section of our Compendium, we reproduce relevant ethical guidelines respecting the protection of confidentiality and privacy in research involving human subjects in Canada. In particular, we have included the relevant sections of the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans* and the *Good Clinical Practice: Consolidated Guideline of the International Conference on Harmonisation of Technical Requirements for the Registration of Pharmaceuticals for Human Use*.

Although these norms are not law and do not have the force of law, they may, over time and continued usage, begin to establish the standard of care against which courts will eventually measure the conduct of health researchers.

Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, Medical Research Council of Canada, Natural Sciences and Engineering Research Council of Canada and Social Sciences and Humanities Research Council of Canada, August 1998. (Available at <http://www.nserc.ca/programs/ethics/english/index.htm>).

Section 3: Privacy and Confidentiality

Dignity and autonomy of human subjects is the ethical basis of respect for the privacy of research subjects. Privacy is a fundamental value, perceived by many as essential for the protection and promotion of human dignity. Hence, the access, control and dissemination of personal information are essential to ethical research.

Information that is disclosed in the context of a professional or research relationship must be held confidential. Thus, when a research subject confides personal information to a researcher, the researcher has a duty not to share the information with others without the subject's free and informed consent. Breaches of confidentiality may cause harm: to the trust relationship between the researcher and the research subject; to other individuals or groups; and/or to the reputation of the research community. Confidentiality applies to information obtained directly from subjects or from other researchers or organizations that have a legal obligation to maintain personal records confidential. In this regard, a subject-centred perspective on the nature of the research, its aims and its potential to invade sensitive interests may help researchers better to design and conduct research. A matter that is public in the researcher's culture may be private in a prospective subject's culture, for example.

There is a widespread agreement about the rights of prospective subjects to privacy and the corresponding duties of researchers to treat private information in a respectful and confidential manner. Indeed, the respect for privacy in research is an internationally recognized norm and ethical standard. It has been enshrined in Canadian law as a constitutional right and protected in both federal and provincial statutes. Model voluntary codes have also been adopted to govern access to, and the protection of, personal information.

The values underlying the respect and protection of privacy and confidentiality are not absolute, however. Compelling and specifically identified public interests, for example, the protection of health, life and safety, may justify infringement of privacy and confidentiality. Laws compelling mandatory reporting of child abuse, sexually transmitted diseases or intent to murder are grounded on such reasoning; so too are laws and regulations that protect whistle-blowers. Similarly, without access to personal information, it would be difficult, if not impossible, to conduct important societal research in such fields as epidemiology, history, genetics and politics, which has led to major advances in knowledge and to an improved quality of life. The public interest thus may justify allowing researchers access to personal information, both to advance knowledge and to achieve social goals such as designing adequate public health programmes.

Historically, the benefits of the confidential research use of personal data have been substantial. Two of many such examples are: the identification of the relationship between tobacco and lung cancer; and the use of employment or educational records to identify the benefits or harms of various social factors. In the last two decades, larger data bases and newer techniques have improved the capacity of researchers to evaluate the delivery of services and the outcomes of many procedures and products. These studies have contributed to more responsive and efficient service delivery in areas such as health, education, safety and the environment.

Ethics review is thus an important process for addressing this conflict of societal values. The REB plays an important role in balancing the need for research against infringements of privacy and minimizing any necessary invasions of privacy. Individuals should be protected from harm caused by unauthorized use of personal information in which they believed they had an expectation of privacy and the benefit of confidentiality.

The situation may arise where a third party attempts to gain access to research records, and hence to breach the promise of confidentiality given by the researcher as part of a research project approved by the REB. By that time, the matter has passed from the hands of the REB. The researcher is honour-bound to protect the confidentiality that was undertaken in the free and informed consent process, to the extent possible within the law. The institution should normally support the researcher in this regard, in part because it needs to protect the integrity of its own REB. If the third party attempts to secure the research data by subpoena, it is legitimate for the researcher and the institution to argue the issue in court. The records of the REB and of the consent might be useful as part of this counter-argument, or may be requested by those seeking access. However, if the court issues a subpoena, legal appeals will probably be the only legal option open to the researcher to protect the confidentiality of the records.

In the free and informed consent process, researchers should indicate to research subjects the extent of the confidentiality that can be promised, and hence should be aware of the relevant law.

The Articles below articulate the general rule to protect privacy and confidentiality through notification and consent of the individuals whose personal information is involved. For the purposes of this Policy, identifiable personal information means information relating to a reasonably identifiable person who has a reasonable expectation of privacy. It includes information about personal characteristics such as culture, age, religion and social status, as well as their life experience and educational, medical or employment histories. However, Article 1(1) (c) excludes from REB review research that is based exclusively on publicly available information. This includes documents, records, specimens or materials from public archives, published works and the like, to which the public is granted access.

As a general rule, the best protection of the confidentiality of personal information and records will be achieved through anonymity. If the data being stored are truly anonymous, the research project will need only minimal REB scrutiny.

A. Accessing Private Information: Personal Interviews

Article 3.1

Subject to the exceptions in Article 1(1)(c), researchers who intend to interview a human subject to secure identifiable personal information shall secure REB approval for the interview procedure used and shall ensure the free and informed consent of the interviewee as required in Article 2.4. As indicated in Article 1.1, REB approval is not required for access to publicly available information or materials, including archival documents and records of public interviews or performances.

Article 3.1 requires REB approval for collection of information through personal interviews, which may be described as including such means as face-to-face, telephone or other electronic encounters, or individualized questionnaires, which the researcher uses to gather materials for such purposes as a biographical study or other research involving specific personalities. To assist the review of such activities, REBs may wish to encourage faculties and departments which use individual interviews extensively to develop standard interview procedures based on Article 2.3, this Article, and on the requirements of their professional organizations, if they so wish. Prior approval of such interview procedures may greatly simplify further review of similar protocols, though the dangers of attempting to enforce a single interview procedure on the varied circumstances within a complex institution are evident.

The task of the REB is to ensure that individuals who are approached for interviews are given the information required by this Policy in order to be able to give free and informed consent. It is clear that individuals have the right to refuse to be interviewed, if they so wish.

Nothing in this article should be interpreted to mean that REBs should engage in prior censorship of research concerning those in the public arena or in artistic and literary life (see [Article 1.1\(c\)](#)).

B. Accessing Private Information: Surveys, Questionnaires and the Collection of Data

Article 3.2

Subject to Article 3.1 above, researchers shall secure REB approval for obtaining identifiable personal information about subjects. Approval for such research shall include such considerations as:

- a. The type of data to be collected;**

- b. The purpose for the which the data will be used;**
- c. Limits on the use, disclosure and retention of the data;**
- d. Appropriate safeguards for security and confidentiality;**
- e. Any modes of observation (e.g., photographs or videos) or access to information (e.g., sound recordings) in the research that allow identification of particular subjects;**
- f. Any anticipated secondary uses of identifiable data from the research;**
- g. Any anticipated linkage of data gathered in the research with other data about subjects, whether those data are contained in public or personal records; and**
- h. Provisions for confidentiality of data resulting from the research.**

Article 3.2 requires researchers to secure REB review before commencing research involving identifiable personal information collected from subjects by such means as interviews, questionnaires, observation, access to private files or records, etc.

Researchers should ensure that the data obtained are stored with all the precautions appropriate to the sensitivity of the data. Data released should not contain names, initials or other identifying information. While it may be important to preserve certain types of identifiers (e.g., region of residence), these should be masked as much as possible using a standardized protocol before the data are released for research purposes. However, legitimate circumstances may exist where such information is critical for the research project. Accordingly, information that identifies individuals or groups should be kept in different databases with unique identifiers. Researchers should take reasonable measures to ensure against inadvertent identification of individuals or groups, and must address this issue to the satisfaction of the REB.

Article 3.2 states that subjects have a right to know who will have access to identifying information and its nature. In particular, the researcher should inform the subject if the information will be provided to the government, government agencies, personnel from an agency that monitors the research, the research sponsor (e.g., a pharmaceutical company), the REB or a regulatory agency. This would also include situations in which mandatory reporting is required, such as under laws requiring reporting of child abuse, infectious diseases or homicidal intent. The REB and the researcher should be sensitive to the interests of those who might suffer from stigmatization. For example, when records of prisoners, employees, students or others are used for research purposes, the researcher should not provide authorities with results that could identify individuals, unless the prior written consent of the

subjects is obtained. Researchers may, however, provide aggregated data that cannot be linked to individuals to administrative bodies for policy decision-making purposes.

Article 3.2 refers not only to the secondary uses of information in research, but also for other purposes such as the subsequent use of research videos for educational purposes. It is essential that subsequent uses of data be specified in sufficient detail that prospective subjects may give free and informed consent; it is inappropriate to seek a blanket permission for "research in general." Article 3.2(g) is important because information that may on its own be seen as innocuous by the subject may take on a completely different meaning if linked to other data (see [Article 3.6](#)).

C. Secondary Use of Data

Secondary use of data refers to the use in research of data contained in records collected for a purpose other than the research itself. Common examples are patient or school records or biological specimens, originally produced for therapeutic or educational purposes, but now proposed for use in research. This issue becomes of concern only when data can be linked to individuals, and becomes critical when the possibility exists that individuals can be identified in the published reports.

Article 3.3

If identifying information is involved, REB approval shall be sought for secondary uses of data. Researchers may gain access to identifying information if they have demonstrated to the satisfaction of the REB that:

- a. **Identifying information is essential to the research; and**
- b. **They will take appropriate measures to protect the privacy of the individuals, to ensure the confidentiality of the data, and to minimize harms to subjects;**
- c. **Individuals to whom the data refer have not objected to secondary use.**

Data bases can vary greatly in the degree to which personal information is identifiable. A proportionate approach should be applied by the REB to evaluate the sensitivity of the information in the database and to modulate its requirements accordingly. If it is impossible to identify individuals whose records exist within a database, then researchers should be allowed access to that database. The REB must carefully appraise the possibility of identification, in particular with regard to the extent of the harm or stigma which might be attached to identification. The REB and the researcher should also be aware of legal provisions that affect the database(s) to be used in the research.

REBs and researchers should also be sensitive to the context in which the database was created, such as a confidential relationship, as well as to the expectations of the groups or individuals at the time of the collection of the data with regard to its use, retention and disclosure. When it is unclear as to whether information is to be regarded as personal, researchers should consult their REBs. Confidential information collected in this manner should normally not be transmitted to authorities, unless required by law, the courts or similar legally constituted bodies.

Article 3.4

The REB may also require that a researcher's access to secondary use of data involving identifying information be dependent on:

- a. **The informed consent of those who contributed data or of authorized third parties; or**
- b. **An appropriate strategy for informing the subjects; or**
- c. **Consultation with representatives of those who contributed data.**

Article 3.4 is based on the concept of a proportionate approach to ethical assessment of research. Under it, the REB should focus on projects above minimal risk, or modulate requirements and protection proportionate to the magnitude and probability of harms, including the likelihood that published data can be linked to individuals. In highly sensitive situations such as when identifiable data will be published or other instances when there is a significant risk of breach of confidentiality, Article 3.4(a) indicates that such deliberations and balancing may lead the REB to seek consent to use the stored data from those who made the contribution.

It may be impossible, difficult or economically unfeasible to contact all subjects in a study group to obtain informed consent. This can occur when the group is large or its members are deceased, geographically dispersed or difficult to track. In such cases, Article 3.4(b) requires that the researcher propose an appropriate strategy for informing the relevant parties or, in accord with Article 3.4(c), that there be consultation with representative members of the affected group (e.g., in an AIDS study, contacting one or a number of AIDS advocacy groups), or that there be some way to sample the opinions of a subset of individuals in the group.

Article 3.5

Researchers who wish to contact individuals to whom data refer shall seek the authorization of the REB prior to contact.

In certain cases, the research goal may only be achieved by follow-up contact and interviews with

persons. It is evident that individuals or groups might be sensitive if they discover that research was conducted on their data without their knowledge; others may not want any further contact. This potential harm underlines the importance for researchers to make all efforts to allow subjects the right to consent that their data and private information be part of a study.

D. Data Linkage

Article 3.6

The implications of approved data linkage in which research subjects may be identifiable shall be approved by the REB.

Advances in our abilities to link databases create both new research opportunities and new threats to privacy. These techniques may provide avenues for addressing previously unanswerable questions and for generating better social and health-related information. The values underlying the ethical obligation to respect privacy oblige researchers and REBs to exercise caution in the creation and use of data of this kind. REBs should also be aware of relevant statutory frameworks, and the criteria required by government for authorization of use of data in governmental data banks.

Section 8: Human Genetic Research

Human genetic research involves the study of genetic factors responsible for human traits and the interaction of those factors with each other and, in some instances, with the environment. Research in this area includes identification of the genes that make up the human genome, the functions of the genes, and the characterization of normal and disease conditions in individuals, biological relatives, families and groups. Observation of different forms of the gene may be important among biological relatives and within and among different groups.

Accordingly, human genetic research is concerned with the use of genetic material. Genes and their alleles are being identified as part of the Human Genome Project, but the function of each gene and its relationship to human health may not be clear. Although the research is both exciting and rapidly changing, the recently acquired knowledge regarding genes and their mutations is not yet matched with a full understanding of the implications for human subjects.

In single gene disorders, for example, a mutation altering a biochemical pathway is directly related to disease. However, the presence of other genes or environmental factors will modulate expression. In disorders that are influenced by multiple genes and environmental factors (i.e. multifactorial

inheritance), there may not be a clear differentiation between the normal and the abnormal. In addition, identification of genetic factors may only indicate predisposition because other genetic and non-genetic factors may also influence the development of disease (e.g., an inherited predisposition to breast cancer). Such factors indicate that identifying a particular genetic predisposition (e.g., by predictive testing) in individuals, biological relatives or a population may not mean that the person will definitely suffer from the disease, but may be perceived as such; the benefits of predictive testing, however, can include intervention strategies (e.g., such as dietary management with an inherited hypercholesterolemia).

Because genetic material is by its very nature shared by biological relatives, identifying a genetic causative agent has implications beyond the individual. Thus, issues of privacy and confidentiality may affect the individual, the family and the group to which the individual belongs. For example, in population studies, a particular group can be identified by common descent, geographic location, ethnic origin, etc. The results, if revealed and publicized, may stigmatize the other individuals in that group.

New technologies to analyze genetic material are being developed at an unprecedented rate. Indeed, new discoveries may be quickly incorporated into health care practices without sufficient research into their effectiveness or means of delivery. Given the present inability to know the limits or effects of such research, or the context in which genetic information is interpreted and used, caution should be exercised. These rapid changes and the potential financial gain from marketing the technologies drive the need to be sensitive to ethical issues in genetic research.

The potential ability to identify all human genes and their mutations has profound social implications. Misunderstanding or misuse of the results of genetic testing has the potential to interfere with an individual's self identity and sense of self-worth, and to stigmatize the entire group to which that individual belongs. A number of issues remain unresolved and require continuing deliberation by the research community and the public.

Accordingly, this Section reviews some of the major unique ethical issues presented by genetic research involving human subjects. The Section should be read particularly in the context of other Sections of this Policy.

B. Privacy, Confidentiality, Loss of Benefits and Other Harms

Article 8.2

The researcher and the REB shall ensure that the results of genetic testing and genetic counselling records are protected from access by third parties, unless free and informed consent is given by the subject. Family information in databanks shall be coded so as to remove the possibility of identification of subjects within the bank itself.

Because the potential for gathering genetic knowledge about biological relatives or groups by studying only a few individuals is unique to genetic studies, an individual may not be assured of privacy within the group, unless extra precautions are taken. The status of an individual may be known simply from data obtained on a parent or a child. Consequently, the knowledge by a third party (e.g., an employer or insurer) of a specific risk or diagnosis may lead to discrimination in employment, insurance, etc.

Article 8.2 should be read in conjunction with the general provisions on privacy and confidentiality of Section 3. The Article recognizes the special privacy and confidentiality issues that may arise due to the unique nature of genetic information. Unless special precautions are taken, for example, databases containing genetic information may identify multiple biological relatives. Similarly, publication of pedigrees from families having rare conditions may identify not only the particular family, but also specific individuals within that family, because such families tend to be known within the genetics research community. The researcher is then faced with a dilemma: maintaining accuracy of the data, or publishing an altered pedigree that potentially contains either sensitive social information (e.g., non-paternity) or sensitive diagnostic information (e.g., where individuals have inherited a particular disease allele); however, an altered pedigree can wrongly target others, and alteration may impair replication in future research or lead to flawed conclusions by other researchers.

DNA banking allows family histories, clinical details and genetic material to be available for other researchers to make specific diagnoses of genetic alterations, to allow studies of genotype/phenotype correlations, or to answer basic questions regarding human development. If appropriate guidelines are not respected, confidentiality may be compromised by DNA banking (see [Article 8.6](#)).

Accordingly, the researcher should be aware of these potential risks to confidentiality, and be able to inform the REB as to how the publication of data or other handling of such information will be accomplished. In particular, the researcher should clarify how subjects will be made aware of limits to the protection of confidentiality.

Article 8.3

Researchers and genetic counsellors involving families and groups in genetic research studies shall reveal potential harms to the REB and outline how such harms will be dealt with as part of the research project.

Article 8.3 obliges researchers to address the potential harms of genetic research. With the exception of gene therapy, physical risks in genetic research are generally similar to those seen in other forms of research. However, the potential for social and psychological harm as a consequence of genetic research is a reality. Harm in genetic research includes moral, physical, psychological

and social harms. Merely being involved in a study may lead to harm for a subject. For example, receiving information regarding susceptibility to genetic disease or even carrier status may provoke anxiety, disrupt relationships or undermine an individual's sense of life opportunities. The individual's position within the family may be challenged by the decision of whether to participate. Such issues may be exacerbated in cases involving single gene disorders where confirmation of high risk or carrier status cannot be followed by effective therapy or prevention. As well, even receiving information of low-risk status may be psychologically harmful if the individual is perceived as no longer sharing the family burden.

As in other areas of research ethics, genetic research involving children involves special ethical obligations and protection. Children may be at particular risk for stigmatization both within and beyond the family because of knowledge gained through genetic studies. Therefore, genetic research involving children should not be done unless an effective intervention is available and the information to be gained outweighs the risk of harm. It may be appropriate, for example, to offer testing to children in a family for an early onset condition such as polyposis coli, for which the knowledge affects treatment options, but inappropriate to test children for an adult onset condition such as Huntington Disease for which no effective prevention yet exists.

Section 10: Human Tissue

The use of human tissue for the purpose of research has proven to be of immense importance to the advancement of knowledge. The ethical considerations raised by research involving human tissue centre on the moral status of human tissue, on access to and the use of data from the tissue, and, consequently, on the standards that define precisely how those involved in research relate to one another. In this regard, it is a fundamental ethical principle that researchers, in the collection and use of human tissue, respect individual and community notions of human dignity and physical, spiritual and cultural integrity.

The status accorded the human body and its parts varies among individuals and cultures. It varies in part due to how people perceive, identify with or relate to their bodies. Some people or cultures take little interest in tissue removed from their bodies. Other cultures regard certain parts of the body (e.g., the placenta) as sacred. Other parts of the body may be regarded as appropriate for gift-giving, provided that the use for research does not compromise medical diagnosis or care. What some regard as an invasive method to acquire tissue samples, other individuals or cultures will not. These examples illustrate the continuing importance of assessing the ethics of research involving human subjects through a subject-centred perspective.

In Canadian society, it is generally held that human tissue itself deserves some degree of respect, for reasons of the dignity of the person from whom tissue is obtained. These principles are reflected in Canadian law and public policy, which generally allow competent individuals to donate, but not sell, human tissues for research. In this context, it is reasonable to draw the ethical conclusion that the use of tissue for research depends on an individual's altruism in donating the tissue with the expectation that social good will be advanced and human knowledge increased. In the case of genetic research, this altruistic gift has an added dimension: tissue obtained from the individual may reveal information about one's current or future health as well as that of biological relatives (see [Section 8](#)).

A. Privacy and Confidentiality

It is essential to protect the privacy of the individual and ensure confidentiality. Four categories of tissue can be distinguished:

- Identifiable tissue can be immediately linked to a specific individual (e.g., by way of an identifying tag or patient number).
- Traceable tissue is potentially traceable to a specific donor provided there is access to further information such as a patient record or a database.
- Anonymous tissue is anonymous due either to the absence of tags and records or the passage of time (e.g., tissue recovered from archaeological sites).
- Anonymized tissue was originally identified but has been permanently stripped of identifiers.

Genetic testing has greatly narrowed the concept of anonymous tissue (see [Section 8](#)), but the concept of traceable tissue is now wider, since it is now possible to identify biological relatives by using genetic markers.

A researcher may request REB approval for use of non-traceable tissue in research when such tissue was left over from different research or, for instance, from a pathological examination. In giving approval, the REB should address such issues as privacy, confidentiality, and, where appropriate, continuing consent or free and informed consent concerning the new research project.

The researcher and the REB should also address how likely it is that traceable tissue will be traced back to an individual. Although rendering tissue anonymous has the advantage of increasing confidentiality, it has the disadvantage of making it impossible to offer the benefits of research to donors and their families. This is particularly significant when research may disclose previously

undiagnosed conditions, such as HIV infection or an inherited predisposition to breast cancer.

In the case of incompetent individuals, the principles developed in [Section 2](#) regarding harm and third-party authorization should be observed. For example, the post-mortem acquisition of brain tissue from a person suffering from dementia would require the free and informed consent of an authorized third party if there were no prior directive of the deceased. Special care should also be taken to avoid apparent or real coercion when the subjects are drawn from groups in the care, or under the authority, power or control of others.

Good Clinical Practice: Consolidated Guideline, ICH Harmonised Tripartite Guideline, International Conference on Harmonisation of Technical Requirements for the Registration of Pharmaceuticals for Human Use, adopted by Therapeutic Products Program, Health Canada, September 1997. (available at: http://www.hc-sc.gc.ca/hpb-dgps/therapeut/zfiles/english/guides/ich/efficacy/goodclin_e.html)

1. GLOSSARY

1.16 Confidentiality

Prevention of disclosure, to other than authorized individuals, of a sponsor's proprietary information or of a subject's identity.

1.21 Direct Access

Permission to examine, analyze, verify, and reproduce any records and reports that are important to evaluation of a clinical trial. Any party (e.g., domestic and foreign regulatory authorities, sponsor's monitors and auditors) with direct access should take all reasonable precautions within the constraints of the applicable regulatory requirement(s) to maintain the confidentiality of subjects' identities and sponsor's proprietary information.

1.24 Good Clinical Practice (GCP)

A standard for the design, conduct, performance, monitoring, auditing, recording, analyses, and reporting of clinical trials that provides assurance that the data and reported results are credible and accurate, and that the rights, integrity, and confidentiality of trial subjects are protected.

2. THE PRINCIPLES OF ICH GCP

2.11 The confidentiality of records that could identify subjects should be protected, respecting the privacy and confidentiality rules in accordance with the applicable regulatory requirement(s).

4. INVESTIGATOR

4.8 Informed Consent of Trial Subjects

4.8.10 Both the informed consent discussion and the written informed consent form and any other written information to be provided to subjects should include explanations of the following:

[...]

(n) That the monitor(s), the auditor(s), the IRB/IEC, and the regulatory authority(ies) will be granted direct access to the subject's original medical records for verification of clinical trial procedures and/or data, without violating the confidentiality of the subject, to the extent permitted by the applicable laws and regulations and that, by signing a written informed consent form, the subject or the subject's legally acceptable representative is authorizing such access.

(o) that records identifying the subject will be kept confidential and, to the extent permitted by applicable laws and/or regulations, will not be made publicly available. If the results of the trial are published, the subject's identity will remain confidential.

[...]

5. SPONSOR

5.5 Trial Management, Data Handling, and Record Keeping

5.5.3 When using electronic trial data handling and/or remote electronic trial data systems, the sponsor should:

[...]

(d) maintain a security system that prevents unauthorized access to the data.

[...]

5.15 Record Access

5.15.1 The sponsor should ensure that it is specified in the protocol or other written agreement that the investigator(s)/institution(s) provide direct access to source data/documents for trial-related monitoring, audits, IRB/IEC review, and regulatory inspection.

5.15.2 The sponsor should verify that each subject has consented, in writing, to direct access to his/her original medical records for trial-related monitoring, audit, IRB/IEC review, and regulatory inspection.

8. ESSENTIAL DOCUMENTS FOR THE CONDUCT OF A CLINICAL TRIAL

8.3.12 SIGNED INFORMED CONSENT FORMS **(Purpose:** To document that consent is obtained in accordance with GCP and protocol and dated prior to participation of each subject in trial. Also to document direct access permission.)

8.3.21 SUBJECT IDENTIFICATION CODE LIST **(Purpose:** To document that investigator /institution keeps a confidential list of names of all subjects allocated to trial numbers on enrolling in the trial. Allows investigator/institution to reveal identity of any subject.)

8.4.3 COMPLETED SUBJECT IDENTIFICATION CODE LIST **(Purpose:** To permit identification of all subjects enrolled in the trial in case follow-up is required. List should be kept in confidential manner and for agreed upon time.)

APPENDIX A

SCHEDULE to the Ontario *Freedom of Information and Protection of Privacy Act*, General R.R.O. 1990, Reg. 460

AGREEMENT [Note: This agreement sets out the terms and conditions respecting to security and confidentiality that a person is required to agree to before the head of a public institution may disclose personal information to that person for a research purpose.]

Form 1

This agreement is made between (name of researcher) below as the researcher,
and (name of institution) below as the institution.

The researcher has requested access to the following records that contain personal information and are in the custody or under the control of the institution: (Describe the records below)

.....

The researcher understands and promises to abide by the following terms and conditions:

1. The researcher will not use the information in the records for any purpose other than the following research purpose unless the researcher has the institution's written authorization to do so: (Describe the research purpose below)
.....
2. The researcher will give access to personal information in a form in which the individual to whom it relates can be identified only to the following persons; (Name the persons below)
.....
3. Before disclosing personal information to persons mentioned above, the researcher will enter into an agreement with those persons to ensure that they will not disclose it to any other person.
4. The researcher will keep the information in a physically secure location to which access is given only to the researcher and to the persons mentioned above.
5. The researcher will destroy all individual identifiers in the information by (date)
6. The researcher will not contact any individual to whom personal information relates, directly or indirectly, without the prior written authorization of the institution.
7. The researcher will ensure that no personal information will be used or disclosed in a form in which the individual to whom it relates can be identified or without the written authority of the institution.
8. The researcher will notify the institution in writing immediately upon becoming aware that any of the conditions set out in this agreement have been breached.

Signed at this day of 199...