I. Introduction

The authority to exercise the rights and powers of the individual is a fundamental component of all health information privacy regimes. Legislative entitlements are meaningless without the ability to exercise rights or powers. Substitute or surrogate decision-making is a crucial issue not only for the individuals who are relying on surrogates, but also for the persons who are acting on behalf of individuals.

Health information is extremely sensitive information. Health conditions that disrupt mental capacity may require extensive health services and entail the accumulation of large amounts of sensitive information. Individuals relying on substitute decision-makers, such as those lacking legal capacity, are particularly vulnerable. The existence of substitute decision-making powers has far-reaching implications for individuals subject to them, as such powers could be exercised either for the benefit of said individuals, for the benefit of the ultimate decision-maker or, alternatively, for the benefit of third parties. The latter two possibilities risk violating the interests of the individual who is most in need.

Substitute decision-making authority allows a surrogate to step into the shoes of the individual. This authority creates extensive powers – essentially the exercise of all health information rights of the individual. Health information privacy legislation prescribes not only the categories of substitute decision-makers but also the rights and powers that surrogates can exercise on behalf of individuals. Health information rights and powers include the right of access, correction and amendment, as well as the right to make express wishes and give instructions. They also include the right to consent, refuse consent, or revoke consent for the collection, use and disclosure of health information, and the right to seek remedies for breaches of access and privacy.

It is acknowledged that substitute decision-making provisions do not exist in privacy law alone. Similar provisions can also be found in family law,¹ See *e.g.* Family Law Act, S.A. 2003, c. F-4.5. elder law, child welfare, youth criminal justice, civil litigation and administration of estates law. Furthermore, this legal nexus gives rise to many corollary issues such as the basis of authority in common law principles like *parens patriae*, the assessment of capacity and the criteria for consent. Such corollary issues are beyond the scope of this discussion, however. This paper will focus on the *Health Information Act* (HIA or the Act)² as the benchmark for a comparison of Alberta’s substitute decision-making provisions with those of other health information privacy regimes.

II. Health Information Privacy Legislation in Alberta

Substitute decision-makers for health information are addressed in *HIA* in Alberta, which has now been in force
since April 25, 2001; that is, for almost four years. HIA lists the categories of persons who can exercise rights or powers of individuals as follows:

104(1) Any right or power conferred on an individual by this Act may be exercised

(a) if the individual is 18 years of age or older, by the individual,
(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,
(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,
(d) 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,
(e) 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,
(f) if an agent has been designated under a personal directive under the Personal Directives Act, by the agent if the directive so authorizes,
(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,
(h) if the individual is a formal patient as defined in the Mental Health Act, by the individual’s nearest relative under that Act, or
(i) by any person with written authorization from the individual to act on the individual’s behalf.

104(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).³

The HIA list of health information decision-makers sets out the categories of persons who can make decisions for themselves as well as on behalf of other individuals. HIA allows substitute decision-makers to exercise all rights and powers that individuals could exercise under the Act. However, the powers that can be exercised by a surrogate may be restricted in the instrument that creates the authority, for example in the guardianship order, personal directive, power of attorney or enactment.

The specific enactments mentioned in section 104(1) of HIA provide the detailed explanation about who can act as substitute decision-makers under the various pieces of legislation mentioned. For example, the “nearest relative” of a formal patient is defined in the Mental Health Act⁴ as follows:

1 In this Act,

(i) “nearest relative” means, with respect to a formal patient, the adult person first listed in the following paragraphs, relatives of the whole blood being preferred to relatives of the same description of the half-blood and the elder or eldest of 2 or more relatives described in any subclause being preferred to the other of those relatives regardless of gender:

spouse;
son or daughter;
father or mother;
brother or sister;
grandfather or grandmother;
grandson or granddaughter;
uncle or aunt;
nephew or niece; or

(ii) any adult person the board designates in writing to act as the nearest relative if there is no nearest relative within any description in subclause (i) or if, in the opinion of the board, the nearest relative determined under subclause (i) would not act or is not acting in the best interest of the formal patient;⁵

The surrogate decision-making provision in section 104(1)(d) of HIA has been amended to allow personal representatives to exercise rights on behalf of deceased minors for the purpose of administration of the individual’s estate.⁶ This amendment was made after the finding of Frank Work,
Information and Privacy Commissioner, in Order H2002-004, that HIA did not allow custodians to provide access to personal representatives of deceased minors. The earlier provision in HIA that applied to personal representatives said:

104(1) Any right or power conferred on an individual by this Act may be exercised...

(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.

In that Order, the Commissioner recommended an amendment to the Act to allow custodians to provide access to and disclosure of the health information of deceased minors.

The HIA amendment broadened the provision to enable custodians to provide access and personal representatives to exercise powers on behalf of deceased individuals regardless of whether the deceased individual was an adult or a minor under 18 years of age. A concurrent HIA amendment created an additional category of disclosure that allows custodians to give information to family members of deceased individuals in certain circumstances (s. 35(1)(d.1)). In a Press Release, the Commissioner praised these amendments, saying:

Overall, I am very pleased to see these amendments, as they achieve the balance of allowing appropriate access to health information, while still protecting the privacy of deceased individuals.

The issue of substitute decision-makers in HIA was considered during the three year legislative review that was conducted by an all-party committee of the Legislature, entitled the Select Special Health Information Act Review Committee (the Committee). The Committee issued a Consultation Guide that asked participants to consider specific questions that included, “Is the list of substitute decision makers appropriate? If not, please explain and provide any suggestions for improvement.”

The Committee was advised that the issue of substitute decision-makers was concurrently under consideration in the draft preliminary pan-Canadian Health Information Privacy and Confidentiality Framework (the “Framework”). The Framework has been described as “a set of harmonized principles and provisions for the collection, use, disclosure and protection of personal health information.” The Framework is being developed pursuant to a 2001 harmonization resolution of the ministers of health to work towards developing harmonized principles and legislative approaches to the protection of the privacy of health information across Canada.

The Committee was asked to conduct a focussed review of several matters, including “consideration of whether amendments to the Health Information Act are required to address the intent to harmonize rules in the pan-Canadian health information privacy and confidentiality framework.” The significance of the Framework to the legislative review process was described as follows:

So this pan-Canadian framework has put together core rules in these types of areas for consultation and debate. The intent is that at the time of the review of the Health Information Act and looking at specific areas that could be subject to amendment, it will be important to take a look at the harmonized rules that have been put forward so that Alberta too, is in a position to be harmonized with core rules that are being looked at to harmonize across jurisdictions.

However, the legislative review was concluded in October of 2004 before the Framework was finalized. In regard to the Framework, the Final Report says:

The Committee recommended that:

A committee of the Legislature should be established early in 2005 to complete a focused review of several matters including:

…

Consideration of whether amendments to the Health Information Act are required to address the intent to harmonize rules in the pan-Canadian health information privacy and confidentiality framework.

The Committee considered many aspects of substitute decision-making and discussed a variety of issues such as the
appropriate categories of decision-makers, the determination of competence, minors, deceased individuals, dependent adults and guardians.\[19\] Issues and suggestions relating to substitute decision-makers were covered in a number of submissions. The comments and recommendations in the Final Report that specifically pertained to substitute decision-makers were:

Although a few suggestions were made to provide for substitute decision-makers, most of these are already covered in the Act. These include family members and disclosures without consent if in the opinion of the custodian; disclosure is in the best interest of the individual. However, the Alberta Rules of Court (Regulation 390/68) permit a next friend or guardian ad litem to represent infants or adults of unsound mind in litigation proceedings in certain circumstances. There is currently no authority for next friends or guardian ad litem to access or disclose health information on behalf of individuals they are representing in litigation.

The Committee recommended that:

52. The Act should be amended to provide a limited authority for a “next friend” or guardian ad litem to exercise the rights or powers of the individual where the exercise relates to the powers and duties of the next friend or guardian ad litem.

The Alberta Long Term Care Association proposed extensive specific provisions to provide for substitute decision-makers where the individual does not have the ability to name a substitute decision-maker and where a relative or friend is willing to assume responsibility but is not prepared or able to pursue the formal processes under other legislation. The committee acknowledged the importance of the matter in the long term care environment, especially in light of growing numbers of individuals in older age groups affected by Alzheimer’s and related disorders. The Committee also recognized the complexities of a new substitute decision-making scheme and the difficulties that can occur as families attempt to deal with these situations.

The Committee recommended that:

53. Alberta Health and Wellness should review the matter of substitute decision-makers for consideration by a committee of the Legislature during the next full review of the Act.\[20\]

III. Health Information Privacy Legislation in Other Canadian Jurisdictions

Manitoba, Saskatchewan and Ontario are the only other jurisdictions in Canada with health information privacy legislation in effect.

A. Manitoba

Manitoba was the first Canadian jurisdiction with health information legislation in effect since December of 1997. The Personal Health Information Act (PHIA)\[21\] came into force even before the Freedom of Information and Protection of Privacy Act (FIPPA)\[22\] in Manitoba. Section 60 of PHIA says:

60 The rights of an individual under this Act may be exercised by any person with written authorization from the individual to act on the individual’s behalf; by a proxy appointed by the individual under The Health Care Directives Act; by a committee appointed for the individual under The Mental Health Act if the exercise of the right relates to the powers and duties of the substitute decision maker; 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 if the individual is deceased, by his or her personal representative.\[23\]

The surrogate decision-making provisions in Manitoba and Alberta are similar as they both recognize personal directives, mental health legislation, appointed guardians, personal representatives and written authorization of the
individual. Parents or guardians of minors have substitute decision-making authority for minors only when minors do not have capacity to make health care decisions.\textsuperscript{24} Individuals with capacity can exercise their own rights or designate a substitute decision-maker.

Although the Manitoba approach to health information decision-makers is similar to \textit{HIA}, there are subtle differences. For example, \textit{PHIA} does not expressly acknowledge the categories of individuals who can exercise their own health information rights such as adults or minors with legal capacity. The Manitoba list of substitute decision-makers does not include an attorney who has been granted a power of attorney by the individual.

The Manitoba Government is conducting a concurrent five-year review of both \textit{FIPPA} and \textit{PHIA}, which has included extensive consultation.\textsuperscript{25} The Manitoba Ombudsman participated in the consultation and made the following comments about section 60 of \textit{PHIA} in a letter dated June 9, 2004:\textsuperscript{26}

\begin{center}
Third Parties, Exercising rights on behalf of an individual \textit{PHIA} section 60
\end{center}

\textbf{Incapacitated persons}

Section 60 sets out the criteria for allowing a third party to exercise the rights of another individual under \textit{PHIA}. In our view, there is a gap in the legislation for individuals who become incapacitated, but have no one who fits the criteria set out in this section to act on their behalf.

To address this gap, consideration should be given to incorporating a revised version of the nearest relative concept from the \textit{Mental Health Act}. We suggest expanding the concept of nearest relative to include anyone with whom the individual is known to have a close personal relationship, similar to section 23(1) of \textit{PHIA}. In our view, the information should only be provided if the trustee, believes the disclosure would be acceptable to the individual the information is about, similar to section 23(1)(c) of \textit{PHIA}.

\textbf{Deceased minors}

In our experience, there is also a gap in the legislation for parents seeking to exercise the \textit{PHIA} rights of their deceased minor children. To address this gap, consideration should be given to amending section 60(1)(e), which permits parents to exercise the rights of minor children, to explicitly include deceased minor children.\textsuperscript{27}

The legislative review consultation document acknowledged that the categories of persons who can exercise the rights of another individual may be inadequate and that there may be situations where individuals who are incapable of exercising their own rights have no legal representative to act on their behalf.\textsuperscript{28} The options presented included an expanded list of persons in \textit{PHIA} who would be authorized to exercise other individual’s rights including persons with a power of attorney or with a close personal relationship such as spouses, common-law partners or adult children.\textsuperscript{29}

\section*{B. Saskatchewan}

Saskatchewan was the second Canadian jurisdiction to enact health information legislation, but the third province to bring the legislation into force. The \textit{Health Information Protection Act (HIPA)}\textsuperscript{30} prescribes the categories of persons who can exercise rights or powers of individuals under the Act. Section 56 of \textit{HIPA} says:

\begin{center}
56 Any right or power conferred on an individual by this Act may be exercised:
\end{center}

(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 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) 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;

(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;

(e) where the individual does not have the capacity to give consent:
(i) by a person designated by the Minister of Social Services if the individual is receiving services pursuant to The Residential Services Act or The Rehabilitation Act; or
(ii) by a person who, pursuant to The Health Care Directives and Substitute Care Decision Makers Act, is entitled to make a health care decision, as defined in that Act, on behalf of the individual;

or (f) by any person designated in writing by the individual pursuant to section 15.31

The Saskatchewan approach to substitute decision-makers for health information is similar to HIA, but again there are differences. As in Manitoba, the Saskatchewan legislation does not recognize an attorney who has been granted a power of attorney by the individual as a substitute decision-maker.

Similar to Alberta, the Saskatchewan legislation explicitly recognizes the categories of personal representatives, appointed guardians, personal directives and written authorizations of individuals. HIPA says that minors can exercise their own rights when they have capacity. The Saskatchewan test for legal capacity of minors is similar to the test in Alberta, as minors must understand “the nature of the right or power and the consequences of exercising the right or power.”

However, in contrast to HIA in Alberta, HIPA explicitly says that the determination of whether a minor has capacity is based upon the opinion of the trustee. Additionally, Saskatchewan has a provision that says the legal custodian of a minor can exercise the right or power of the minor where the exercise in the opinion of the trustee would not be an unreasonable invasion of the privacy of the individual.

In contrast to both Alberta and Manitoba, Saskatchewan does not have a provision that explicitly applies to individuals governed by mental health legislation. However, when an individual does not have the capacity to consent and receives services under The Residential Services Act or The Rehabilitation Act, HIPA allows a person designated by the Minister of Social Services to exercise the rights and powers of the individual.

C. Ontario

Ontario recently enacted health information legislation, which came into force on November 1, 2004. The Personal Health Information Protection Act (PHIPA), which is also known as Bill 31, contains comprehensive provisions for substitute decision-makers.

In contrast to other Canadian jurisdictions, the Ontario legislation defines the terms used to describe mental capacity such as “capable” and “incapable.” The Ontario Act also defines the term “substitute decision-maker.” PHIPA describes the powers of surrogate decision-makers and how the new provisions will interface with existing health consent legislation.

The Ontario legislation contains the following provisions for substitute decision-makers:

23(1) If this Act or any other Act refers to a consent required of an individual to a collection, use or disclosure of personal health information about the individual, a person described in one of the following paragraphs may give, withhold or withdraw the consent:

1. If the individual is capable of consenting to the collection, use or disclosure of the information,

   (i) the individual, or

   (ii) if the individual is at least 16 years of age, any person who is capable of consenting, whom the individual has authorized in writing to act on his or her behalf and who, if a natural person, is at least 16 years of age.

2. If the individual is a child who is less than 16 years of age, a parent of the child or a children’s aid society or other person who is lawfully entitled to give or refuse consent in the place of the parent unless the information relates to,

   (i) treatment within the meaning of the Health Care Consent Act, 1966, about which the child has made a
decision on his or her own in accordance with that Act, or

(ii) counselling in which the child has participated on his or her own under the Child and Family Services Act.

3. If the individual is incapable of consenting to the collection, use or disclosure of the information, a person who is authorized under subsection 5(2), (3) or (4) or section 26 to consent on behalf of the individual.

4. If the individual is deceased, the deceased’s estate trustee or the person who has assumed responsibility for the administration of the deceased’s estate, if the estate does not have an estate trustee.

5. A person whom an Act of Ontario or Canada authorizes or requires to act on behalf of the individual.

23(2) In subsection (1), “parent” does not include a parent who has only a right of access to the child.

23(3) If the individual is a child who is less than 16 years of age and who is capable of consenting to the collection, use or disclosure of the information and if there is a person who is entitled to act as the substitute decision-maker of the child under paragraph 2 of subsection (1), a decision of the child to give, withhold or withdraw the consent or to provide the information prevails over a conflicting decision of that person.

....... 

26(1) If an individual is determined to be incapable of consenting to the collection, use or disclosure of personal health information by a health information custodian, a person described in one of the following paragraphs may, on the individual’s behalf and in the place of the individual, give, withhold or withdraw the consent.

1. The individual’s guardian of the person or guardian of property, if the consent relates to the guardian’s authority to make a decision on behalf of the individual.

2. The individual’s attorney for personal care or attorney for property, if the consent relates to the attorney’s authority to make a decision on behalf of the individual.

3. The individual’s representative appointed by the Board under section 27, if the representative has authority to give the consent.

4. The individual’s spouse or partner.

5. A child or parent of the individual, or a children’s aid society or other person who is lawfully entitled to give or refuse consent in the place of the parent. This paragraph does not include a parent who has only a right of access to the individual. If a children’s aid society or other person is lawfully entitled to consent in the place of the parent, this paragraph does not include the parent.

6. The parent of the individual with only a right of access to the individual.

7. A brother or sister of the individual.

8. Any other relative of the individual.

26(2) A person described in subsection (1) may consent only if the person,

(a) is capable of consenting to the collection, use or disclosure of personal health information by a health information custodian;

(b) in the case of an individual, is at least 16 years old or is the parent of the individual to whom the personal health information relates;

(c) is not prohibited by court order or separation agreement from having access to the individual to whom the personal health information relates or from giving or refusing consent on the individual’s behalf;
(d) is available; and

(e) is willing to assume the responsibility of making a decision on whether or not to consent.

26(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.

26(4) A person described in a paragraph of subsection (1) may consent only if no person described in an earlier paragraph meets the requirements of subsection (2).

26(5) Despite subsection (4), a person described in a paragraph of subsection (1) who is present or has otherwise been contacted may consent if the person believes that,

no other person described in an earlier paragraph or the same paragraph exists; or

although such other person exists, the other person is not a person described in paragraph 1 or 2 of subsection (1) and would not object to the person who is present or has otherwise been contacted making the decision.

26(6) If no person described in subsection (1) meets the requirements of subsection (2), the Public Guardian and Trustee may make the decision to consent.

26(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 consent, and if their claims rank ahead of all others, the Public Guardian and Trustee may make the decision in their stead.

26(8) Where an individual to whom personal health information relates, appointed a representative under section 36.1 of the Mental Health Act before the day this section comes into force, the representative shall be deemed to have the same authority as a person mentioned in paragraph 2 of subsection (1).

26(9) The authority conferred on the representative by subsection (8) is limited to the purposes for which the representative was appointed.

26(10) An individual who is capable of consenting with respect to personal health information may revoke the appointment mentioned in subsection (8) in writing.

26(11) A person who is entitled to be the substitute decision-maker of the individual under this section may act as the substitute decision-maker only in circumstances where there is no person who may act as the substitute decision-maker of the individual under subsection 5(2), (3) or (4).

Notwithstanding the greater level of detail, the Ontario approach to substitute decision-makers is similar in many respects to HIA and other provincial health information privacy legislation. For example, all categories of substitute decision-makers that are identified in the Alberta legislation are also addressed in the Ontario legislation.

However, PHIPA provides more categories of substitute decision-makers than the legislation in other Canadian jurisdictions. For example, persons can consent for another individual if authorized under an Ontario or a federal Act. Additional categories of substitute decision-makers in Ontario include the individual’s spouse or partner, parent with only a right of access, brother or sister and any other relative, which are set out in rank order.

The Ontario legislation has detailed provisions for making the determination of whether an individual has the capacity to provide consent for the collection, use or disclosure of health information. PHIPA also has detailed provisions that describe the factors to consider for consent and the process for appointment of a representative by the Consent and Capacity Board.

The test for capacity in PHIPA is somewhat different, as the individual must be capable of understanding the information relevant to making the decision and the reasonably foreseeable consequences of the decision. The rights and powers that substitute decision-makers can exercise in Ontario are explicitly described and include any request, instruction or steps the individual could take, including the right to give, withhold or withdraw consent.
Some of the differences in the Ontario approach are attributable to differences in the underlying provincial legislation. For example, the Consent and Capacity Board, created under Ontario’s Health Care Consent Act, 1996,51 can review determinations of incapacity and decide whether substitute decision-makers have considered the required factors for consent.52 The Consent and Capacity Board has the authority to appoint a representative as a substitute decision-maker for minors lacking legal capacity.53

In Ontario, health information rights and powers are accorded to individuals with capacity at 16 years of age. This approach is in contrast to the health information powers that arise at the age of majority that is 18 years in Alberta, Manitoba and Saskatchewan.

IV. Personal Information Privacy Legislation in Alberta

Substitute decision-makers for health information in the health sector under HIA will now be compared to substitute decision-makers for personal information in the privacy legislation that governs the broader public sector as well as the private sector in Alberta.

A. Public Sector

The privacy of personal information that is held in the public sector such as by government departments and local public bodies, is typically governed by freedom of information and protection of privacy legislation (often described by some such acronym as ‘FOIP’ or ‘FOIPPA’) across Canada.54 As a general rule, this type of legislation applies to the administrative or business information of public bodies as well as to the personal information that public bodies have about individuals. ‘Personal information’ as defined in FOIP legislation typically includes information about health.55

However, health information does not remain under FOIP legislation when that information is carved out. For example, all records in the custody or control of a public body are covered by the Freedom of Information and Protection of Privacy Act (FOIP) in Alberta56 unless the records are expressly exempted. Health information under HIA is carved out of FOIP, which means that FOIP does not apply to records that are health information in the custody or control of a public body where the public body is also a custodian under HIA.57 A similar exemption from FOIP exists for quality assurance records under the Alberta Evidence Act.58

FOIP continues to apply to the remaining information about health that is held by public bodies such as employee and occupational health information as well as to information held by public bodies that are not HIA custodians such as the Workers Compensation Board.

The categories of substitute decision-makers that are listed in FOIP in Alberta59 are similar to the categories listed in HIA. However, there are some differences. FOIP does not have a parallel provision to the HIA section that authorizes minors with capacity to exercise rights or powers.60 Nor does FOIP parallel the HIA section that authorizes the nearest relatives of formal patients under the Mental Health Act to exercise rights or powers.61

In regard to the guardian of a minor, FOIP says:

84(1) Any right or power conferred on an individual by this Act may be exercised

... 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 constitute an unreasonable invasion of the personal privacy of the minor.62

This FOIP requirement is similar to the Saskatchewan health information legislation provision for the ‘legal custodians’ of minors, except that HIPA includes an additional category that gives minors with capacity the right to exercise their own rights and powers.63

It is prudent to keep the provisions of the Canadian Charter of Rights and Freedoms64 in mind when considering issues relating to substitute decision-makers, such as the right to life, liberty and security of the person65 and the right to equal protection without discrimination based on age or mental or physical disability.66

B. Private Sector

Quebec, British Columbia and Alberta have private sector legislation in force that governs the privacy of personal information. As a general rule, private sector legislation applies to all personal information that is in the custody or control of an organization, which includes information about health. An exception to this general rule arises when
information about health is carved out of the private sector privacy legislation.

Records in the custody or control of an organization in Alberta are covered by the Personal Information Protection Act (PIPA)\(^6\) unless the records are expressly exempted. PIPA does not apply to personal information that falls under FOIP.\(^6\) PIPA does not apply to health information under HIA where that information is collected, used or disclosed by an organization for health care purposes including health research and management of the health care system.\(^\text{69}\)

However, PIPA does apply to information about health such as “personal employee information” and to organizations such as health professional regulatory bodies. The categories of substitute decision-makers for personal information in PIPA are almost identical to the categories listed in HIA. The only difference is that, similar to FOIP, PIPA does not have a category for the nearest relatives of individuals who are formal patients under the Mental Health Act.

The private sector legislation in British Columbia takes quite a different approach from PIPA and addresses the issue of substitute decision-makers through the regulatory powers under the Act.\(^\text{70}\) The categories included in the B.C. regulation differ from PIPA as they explicitly include a litigation guardian and a list of nearest relatives that includes a spouse, adult child, parent, adult brother or sister and other adult relation.\(^\text{71}\)

The private sector legislation in Quebec allows individuals who are 14 years of age or older to exercise some rights of access.\(^\text{72}\) Additionally, ascendants and descendants of deceased individuals have some rights of access to information relating to genetic or family disease.\(^\text{73}\) The federal private sector legislation, the Personal Information Protection and Electronic Documents Act (PIPEDA),\(^\text{74}\) does not address substitute decision-makers.\(^\text{73}\)

**Discussion of Issues**

Reference to legal capacity and age of majority are common themes in the above described legislative provisions. Legislation in the various jurisdictions authorizes adult individuals to exercise their own rights and powers and to appoint their own decision-makers. These entitlements are consistent with the presumption of capacity at the age of majority (i.e. adults are presumed to have mental capacity). This, of course, is a rebuttable presumption. Where adults lack capacity, other legislative provisions enable persons to exercise rights and powers on behalf of those individuals, such as by court appointed guardians or trustees.

Although 18 years is the most common age of majority in Canada, the age of majority is 19 years in British Columbia and the Yukon.\(^\text{75}\) PHIPA recognizes 16 years as the pivotal age in Ontario, and clearly says that the views of a child under 16 years of age who has capacity prevail over any conflicting decisions of a substitute decision-maker.\(^\text{77}\) Under the public sector legislation in Quebec, access rights may be exercised by persons over the age of 14.\(^\text{76}\) The United Kingdom’s Data Protection Act contains the presumption, specific to Scotland, that an individual of 12 years of age or more has legal capacity.\(^\text{79}\)

Another common theme in the above legislation is the recognition that individuals may achieve capacity, and therefore should be accorded rights and powers, before the age of majority. Individuals may be parents before they reach the age of majority. Although minors with capacity are contemplated in HIA, those individuals must meet a legislative test to ensure they understand the nature of the right or power and the consequences of exercising the right or power. Other legislation allows the legal guardian or custodian of a minor with capacity to exercise the minor’s rights or powers where the exercise is not an unreasonable invasion of privacy.\(^\text{80}\)

The right of competent minors to exercise their powers, the assessment of capacity and the criteria for determining capacity continue to be contentious issues.

It is a matter of debate whether the categories of prescribed decision-makers are broad enough to include all legitimate categories of surrogate decision-makers. Most of the above described legislative provisions recognize the following categories of substitute decision-makers: adults (rebuttable presumption of capacity), minors with capacity, guardians of minors without capacity, personal representatives of deceased, court or legislatively appointed guardians or trustees, agents in personal directives, attorneys under a power of attorney, nearest relatives under mental health legislation and persons with written authorization of the individual.

PHIPA contains the broadest categories of surrogate decision-makers among the Canadian jurisdictions discussed. PHIPA includes a list of next of kin including spouses and relatives,81 as well as a person authorized to act on behalf of the individual under an Act of Ontario or Canada.82 Some jurisdictions outside of Canada have even broader substitute decision-maker provisions. The U.S. Standards for Privacy
of Individually Identifiable Health Information (Privacy Rule) say the personal representative of an adult or emancipated minor includes a person with the authority to act on behalf of an individual for decisions related to health care “under applicable law.”

Notwithstanding this broad provision, the report of the first-year experiences under the Privacy Rule described access to information by patient advocates as an obstacle. The reasons given for access problems included liability concerns, excessive paperwork to account for disclosures, misunderstanding of the rule and reluctance of providers and health plans to share information with persons advocating for patients - even when the rule allows the disclosure as a matter of professional judgment and permits discretion.

Standard privacy requirements that govern surrogate decision-makers and access to information may work well for individuals who are mentally competent and suffering from physical illnesses. However, these same legal and policy frameworks have been criticized as jeopardizing the care of individuals who lack mental competency and suffer from mental illness or addiction. The recent Senate Report on Mental Health, Mental Illness and Addiction says that privacy and confidentiality rules may preclude the desirable flow of health information, interfere with the involvement of families and caregivers and work against the best interests of individuals.

Some perceptions of inadequacies in privacy legislation may arise due to lack of familiarity with the legislation. There may be confusion about the rights of substitute decision-makers as opposed to the authority for custodians to disclose information. To refer to PHIA as an example, one of the purposes of PHIA is to allow the sharing of information to provide health services. PHIA allows custodians to disclose health information without consent for many purposes that include: to provide health services, to persons providing continuing treatment and care, to family members and significant others in prescribed circumstances, to officials of custodial institutions where the individual is being detained, pursuant to an enactment, to minimize imminent danger to health or safety and when in the best interests of an individual lacking mental capacity.

The Manitoba Ombudsman has dealt with an issue that involved a husband’s attempt to exercise his wife’s right to access her health information under PHIA. The husband did not fall within the categories of substitute decision-makers under PHIA, so could not exercise his wife’s right of access. The situation was resolved as the hospital was allowed to disclose the information requested to the husband under the disclosure provisions for immediate family members in section 23(1) of PHIA. It is interesting to note that the Health Information Privacy Code in New Zealand describes the representative of an individual who lacks the capacity to consent as including “a person appearing to be lawfully acting on the individual’s behalf or in his or her interests.”

It is a contentious issue whether the policy principles and legal requirements captured in privacy legislation adequately address extremely complex issues such as fiduciary duties, substitute decision-makers and consent. Another area of debate is whether privacy regimes inappropriately preclude activities that are in the public interest. Examples of such activities include cancer surveillance, population health programs, health research and even medical treatment - particularly for groups such as minors or individuals who lack mental capacity.

Privacy legislation must attempt to achieve the right balance between all of the competing interests. All of the privacy regimes discussed allow health information to be collected, used and disclosed without consent in certain circumstances, providing that other safeguards such as adequate security are in place. Furthermore, access to and disclosure of health information does not necessarily depend upon the choices or decisions of individuals and surrogate decision-makers. For example, PHIA allows health information to be used or disclosed without consent for the purpose of providing health services, conducting research, public health surveillance, or when authorized by an enactment. In health research, PHIA creates the authority for research ethics boards to waive consent when the board determines that obtaining consent would be unreasonable, impractical or not feasible.

A further issue that arises is whether substitute decision-makers are acting in accordance with the expressed wishes of the individual. Where such wishes are unknown, the issue becomes whether substitute decision-makers are acting in accordance with the individual’s values or in their best interest. Even where expressed wishes are known, the mechanisms for their enforcement and the remedies for a failure to follow them may be unclear. The Health Records (Privacy and Access) Act in the Australian Capital Territory addresses this issue by providing that the consent of a legal representative is void where the representative knows or believes the consent is at variance with the expressed wishes of the individual.
VI. Summary

This discussion has focussed on the surrogate decision-maker provisions in the health information legislation in Alberta as a basis for comparison with other jurisdictions. Different health information privacy regimes have been described and emerging issues for substitute decision-makers have been discussed. One of the unanswered questions is whether the categories of substitute decision-makers in health information privacy legislation are comprehensive enough to enable individuals to exercise their rights and powers.97

Gaps or inadequacies in privacy legislation can be addressed in legislative amendments, such as the amendments that have already been made to HIA. Legislative reviews are mechanisms that enable individuals and stakeholders to actively participate in the debate and to identify shortcomings in privacy regimes. The legislative committees must balance competing interests and make recommendations to the Legislature. Manitoba is currently completing its first five-year legislative review of PHIA. Alberta has recently completed its first three-year legislative review of HIA, which was expedited due to an impending election.

The Final Report contained a recommendation to strike a Committee of the Legislature early in 2005 to complete a focused review of several outstanding matters including harmonization of the rules in HIA with the pan-Canadian Health Information Privacy and Confidentiality Framework.98 Hopefully, the pan-Canadian framework will assist to harmonize the legislative approaches across Canada and to answer some of the unanswered questions about substitute decision-makers. Legislative review initiatives should identify not only inadequacies but solutions as well, and act as a catalyst to achieve the best possible legislative privacy regimes for individuals and their substitute decision-makers.

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2. Health Information Act, R.S.A. 2000, c. H-5 [HIA]. This Act received Royal Assent on December 9, 1999 and was proclaimed in force on April 25, 2001.
3. Ibid., s. 104.
5. Ibid., s. 1(i).
8. HIA, supra note 2, s. 104(1)(d).
11. Ibid. at 25.
13. Canada, Working Group of the Strategic Directions for a pan-Canadian Health Infrastructure Initiative, Advisory Committee on Information and Emerging Technologies (ACIET), Preliminary Pan-Canadian Health Information Privacy and Confidentiality Framework (2003 Draft) [unpublished]; the ACIET was created in December 2002 by the Federal/Provincial/Territorial Deputy Ministers of Health with a mandate to “provide policy development and strategic advice on health information issues . . . to the Conference of Federal, Provincial and Territorial Deputy Ministers of Health,” online: <http://www.hc-sc.gc.ca/ohih-bsi/chics/aciet_ccint_e.html>.
14. Catarina Versaevel, “The Electronic Health Record - The Essentials For Confidentiality and Privacy in this New Environment” (Powerpoint presentation for Insight Conference: Electronic Health and Medical Re-
cords, December 2004) [unpublished]; see also supra note 12 at 17-22 (Ms. Versaevel).
15. Supra note 12 at 17-22 (Ms. Versaevel); Alberta, Legislative Assembly, Select Special Health Information Act Review Committee, in Official Reports of Debates (Hansard), 25-4-1 (8 June 2004) at 32 (Ms. Versaevel).
17. Supra note 12 at 20.
19. See e.g. Alberta, Legislative Assembly, Select Special Health Information Act Review Committee, in Official Reports of Debates (Hansard), 25-4-1 (1 June 2004) at 20 (Ms. Versaevel); Alberta, Legislative Assembly, Select Special Health Information Act Review Committee, in Official Reports of Debates (Hansard), 25-4-2 (8 June 2004) at 48-49 and 54 (Ms. Versaevel), 49 (Mr. Lukaszuk), 49 (Ms. Inions); Alberta, Legislative Assembly, Select Special Health Information Act Review Committee, in Official Reports of Debates (Hansard), 25-4-4 (12 August 2004) at 96 and 99 (Ms. Robillard); Alberta, Legislative Assembly, Select Special Health Information Act Review Committee, in Official Reports of Debates (Hansard), 24-4-5 (24 August 2004) at 112, 119, 125, 130, 143-145, 147 and 186 (Ms. Robillard), 143 (Mr. Broda); Alberta, Legislative Assembly, Select Special Health Information Act Review Committee, in Official Reports of Debates (Hansard), 25-4-6 (25 August 2004) at 164 (Ms. Versaevel), 181 (Mr. Herron).
23. Supra note 21, s. 60.
24. Ibid., s. 60(e).
27. Ibid. at 3 of Overview Appendix I.
29. Ibid. at 28-29.
30. Health Information Protection Act, S.S. 1999, c. H-0.021 [HIPA]. This Act was introduced on December 17, 2003, and received Royal Assent on May 20, 2004. Sections 1 to 72 and 75 to 98 came into force on November 1, 2004. This Act is part of the Health Information Protection Act, 2004, S.O. 2004, c. 3 [HIPA], which consists of two Acts that were enacted in tandem. The HIPA includes the PHIPA as Schedule A and the Quality of Care Information Protection Act, 2004, S.O. 2004, c. 3 as Schedule B.
31. Ibid., s. 56.
32. Ibid., s. 56(c).
33. Supra note 30.
34. Ibid., s. 56(d).
37. Ibid., s. 56(e)(i).
38. Personal Health Information Protection Act, 2004, S.O. 2004, c. 3 [PHIPA]. This Act was introduced on December 17, 2003, and received Royal Assent on May 20, 2004. Sections 1 to 72 and 75 to 98 came into force on November 1, 2004. This Act is part of the Health Information Protection Act, 2004, S.O. 2004, c. 3 [HIPA], which consists of two Acts that were enacted in tandem. The HIPA includes the PHIPA as Schedule A and the Quality of Care Information Protection Act, 2004, S.O. 2004, c. 3 as Schedule B.
39. PHIPA, ibid., s. 2:
2. In this Act, ...
“capable” means mentally capable, and “capacity” has a corresponding meaning;
...
40. Ibid., ss. 2, 5.
41. Ibid., ss. 5(2)-5(4), 25(1)-(2), 27(1)-(3), 28(1)(2).
5(2) a substitute decision-maker of an individual within the meaning of section 9 of the Health Care Consent Act, 1996, shall be deemed to be a substitute decision-maker of the individual in respect of the collection, use or disclosure of personal health information about the individual if the purpose of the collection, use or disclosure is necessary for, or ancillary to, a decision about a treatment under Part II of that Act.
5(3) A substitute decision-maker of an individual within the meaning of section 39 of the Health Care Consent Act, 1996 shall be deemed to be a substitute decision-maker of the individual in respect of the collection, use or disclosure of personal health information about the individual if the purpose of the collection, use or disclosure is necessary for, or ancil-
lary to, a decision about admission to a care facility under Part III of that Act.

27(1) An individual who is 16 years old or older and who is determined to be incapable of consenting with respect to personal health information may apply to the Board for appointment of a substitute decision-maker, and not to the individual.

27(2) If a substitute decision-maker makes a request, gives an instruction or takes a step on behalf of the individual, references in this Act to the individual with respect to the request made, use or disclosure of personal health information about the individual if the purpose of the collection, use or disclosure is necessary for, or ancillary to, a decision about a personal assistance service under Part IV of that Act.

25(2) If a substitute decision-maker makes a request, gives an instruction or takes a step under subsection (1) on behalf of an individual, references in this Act to the individual with respect to the request made, instruction given or the step taken by the substitute decision-maker shall be read as references to the substitute decision-maker, and not to the individual.

27(3) Subsections (1) and (2) do not apply if the individual to whom the personal health information relates 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 collection, use or disclosure.

28(1) This Act applies to a representative whom the Board appointed under section 36.2 of the Mental Health Act or who was deemed to be appointed under that section before the day this section comes into force for an individual with respect to the individual’s personal health information, as if the representative were the individual’s representative appointed by the Board under section 27.

28(2) The authority conferred on the representative by subsection (1) is limited to the purposes for which the representative was appointed.

42. Ibid., ss. 23, 25-28.
43. Ibid., s. 23(1)(5).
44. Ibid., s. 26(1).
45. Ibid., ss. 21-22.
46. Ibid., s. 24.
47. Ibid., ss. 27(4)-(9).
48. Ibid., s. 21.
49. Ibid., s. 25.
50. Ibid., s. 26(1).
52. Supra note 38, ss. 22(3), 24(3).
53. Ibid., ss. 27(1)-(2).
55. Some FOIP legislation explicitly includes health information in the definition of “personal information”, e.g., Freedom of Information and Protection of Pri-
76. Freedom of Information and Protection of Privacy Act, R.S.A. 2000, c. F-25, s. 4 [FOIP].
77. Ibid., s. 4(1)(u).
78. Ibid., s. 4(1)(c); Alberta Evidence Act, R.S.A. 2000, c. A-18.
79. Supra note 56, s. 84.
80. HIA, supra note 2, s. 104(1)(b).
81. Ibid., s. 104(1)(h).
82. Supra note 56, s. 84(1)(c).
83. HIPA, supra note 30, s. 56(c)-(d).
85. Ibid., s. 7.
86. Ibid., s. 15(1).
88. Ibid., s. 4(3)(e).
89. Ibid., s. 4(3)(f).
91. Regulations, ibid., ss. 1(a)-(e), 2(1)(c).
93. Ibid., s. 31.
96. Access to Information and Protection of Privacy Act, R.S.Y. 2002, c. 1, s. 62(d).
97. PHIPA, supra note 38, s. 23(3).
98. An Act Respecting Access to Documents Held by Public Bodies and the Protection of Personal Information, R.S.Q., c. A-2.1, s. 83. This Act was enacted on June 22, 1982.
100. HIPA, supra note 30, s. 56(d); FOIP, supra note 53, s. 84(1)(e).
101. PHIPA, supra note 38, s. 26(1).
102. Ibid., s. 23(1)(5).
105. Ibid. at 17-19.
107. Ibid. at 43-45 of Report III.
108. HIA, supra note 2, s. 2(b).
109. Ibid., s. 35(1).
111. Ibid.
112. Health Information Privacy Code (N.Z.), 1994, s. 3(1)(c).
Health L. Rev. 10; Francois Baylis, et al., “Children and Decisionmaking in Health Research” (2000) 8:2


94. HIA, supra note 2, s. 27.
95. HIA, supra note 2, s. 50(1)(b)(iv).
96. Health Records (Privacy and Access) Act 1997 (A.C.T.), s. 27(3).
98. Final Report, supra note 16 at 6-7.

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