A REVIEW OF

# **The Personal Health Information Act:**

TELL US WHAT YOU THINK



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# Message from Manitoba's Minister of Health, Seniors and Active Living

am pleased to introduce this discussion document on The Personal Health Information Act (PHIA). It is an important discussion about a law that touches on issues affecting all Manitobans. PHIA protects our right to access our personal health information at the same time as it protects our right to privacy. It requires public bodies and health care providers that collect and store information they use to offer health care and other services to keep that information secure. PHIA ensures the protection of our rights and enhances the quality of life for us all.

This review will help ensure PHIA continues to appropriately balance the interests of patients and the needs of service providers. We intend to consider advice from both the public and from those who operate under PHIA requirements daily. Your comments will tell us if changes are necessary to keep PHIA current and appropriate. Your advice will help us ensure Manitoba's health information legislation continues to meet the needs of Manitobans and our health system.

I thank you in advance for your interest and for feedback you may provide

original signed by

Kelvin Goertzen, Minister Manitoba Health, Seniors and Active Living

# Introduction

he Personal Health Information Act (PHIA) became law on December 11, 1997. It's a law about the rights Manitobans to have access to their own personal health information while having that information protected from inappropriate collection, use, disclosure, retention or destruction.

PHIA legislation requires the Minister of Health, Seniors and Active Living to conduct a periodic public review, making sure the act continues to meet its objectives and reflect contemporary needs.

This document is an important part of that review process. It intends to stimulate interest and public debate. It takes readers through the current provisions of PHIA and the amendments made as a result of the review in 2004. It also provides some suggestions for further change.

Several specific issues are highlighted in this document for your consideration. These are by no means the only issues the government is willing to consider during the PHIA review process. Your comments and questions are encouraged about any personal health information or privacy issue that concerns you.

The Manitoba government has an ongoing commitment to managing health information access and privacy rights. Comments from health information trustees and members of the public during this review will help refine the act and ensure it continues serving both the public and our health system.

# Part 1

# 1.1 Personal Health Information Legislation in Manitoba

Personal health information legislation (PHIA) is about keeping health information private, while making it accessible to service providers who need it to provide services or help you stay healthy. In 1997, Manitoba put <u>The Personal Health Information Act</u> in place, basing it on internationally-accepted standards for handling medical records. Manitoba was the first Canadian jurisdiction to enact such legislation.

PHIA acknowledges that, barring specified exceptions, individuals should be able to control information about their health status and health care history. It recognizes that individuals may need to access their personal health information to make informed decisions about their health care and to correct inaccurate or incomplete information about themselves. PHIA also recognizes the sensitive nature of information about our health and provides for its confidentiality so that individuals are not afraid to seek health care or disclose sensitive information to health service providers and public bodies.

# **1.2 About PHIA**

PHIA grants individuals two primary rights with respect to personal health information maintained by health information trustees. The first is the right of access. This includes an individual's right to examine, obtain a copy of, or request a correction to recorded personal health information or to authorize another individual to do so on his or her behalf. The second is the right to privacy. This includes an individual's right to be assured that personal health information will be protected from unauthorized collection, use, disclosure, retention and destruction. PHIA upholds these rights by placing limitations on how trustees can handle an individual's personal health information. PHIA provides for an independent review mechanism to ensure that trustees are held accountable for compliance with the act.

# **1.3 Relationship of PHIA to FIPPA**

PHIA and <u>The Freedom of Information and Protection of Privacy Act</u> (FIPPA) are the key components of Manitoba's access and privacy legislative framework. The acts share a similar philosophy, purpose and structure.

The two acts differ from one another mainly in scope. PHIA deals exclusively with access to and privacy of personal health information, while FIPPA deals with access to, and privacy of, personal information (other than health information) as well as access to, and privacy of all other information held by public bodies. Both acts are binding on provincial government departments and other public bodies; PHIA also applies to health service providers.

# **1.4 The Public Review of PHIA**

The government of Manitoba is committed to upholding your rights of access to, and privacy of, personal health information. While that commitment will continue, the government recognizes that how we apply principles relating to access to and privacy of personal health information may need to be refined. Technical and scientific advancements, and the resulting opportunities for health service improvements, have created an information environment that is dramatically different from the one in which PHIA was enacted in 1997 and from the environment in which the first review of the act was done in 2004. The government recognizes that PHIA may need to be revised so that it continues to adequately address the rights of people to the privacy, confidentiality and security of their personal health information and health system information needs.

This document has been prepared to stimulate discussion among members of the public, stakeholders and government, in order to generate constructive recommendations for improving access to, and privacy of personal health information in Manitoba.

As you read through this document, you may want to refer to the legislation. A copy of PHIA can be accessed via the Internet, free of charge at <u>http://web2.gov.mb.ca/laws/statutes/ccsm/p033-5e.php</u>. The Personal Health Information Regulation is also available free of charge at <u>http://web2.gov.mb.ca/laws/regs/current/\_pdf-regs.php?reg=245/97</u>. Paper copies of both are available for a cost through the Statutory Publications Office in Winnipeg at 204-945-3101.

You may also find it useful to refer to Appendix A of this document, which contains descriptions of key concepts and terms. In this paper, the first use of each word described in appendix A will be shown in bold type to help readers recognize important phrases and words used in discussions about PHIA.

Information on making a submission is located at the back of this document in Section 3.2.

# Part 2

A number of issues are identified in Part 2 of this document. You are invited to respond to all or some of these. Related questions are posed at the end of each section. Most of these questions relate to principles and best practices, and are asked to obtain feedback from any interested party. Questions about operational issues may interest those who are charged with administering the requirements of the act.

This document focuses on particular issues but also recognizes these

are not the only issues. Please submit comments on any matter of concern to you that falls within the scope of PHIA. By sharing your views and comments, you will help ensure that the provisions set out in PHIA continue to reflect Manitobans' rights to access and privacy, as well as the realities of today's information environment.

Further information on how to submit your feedback is located at the back of this document (Section 3.2).

# 2.1 The Scope of PHIA

The scope of PHIA is defined primarily by two things: the people and organizations regulated by the act (trustees) and the type of information the act applies to (**personal health information**).

#### 2.1.1 Health Information Trustees

Trustees (so called because they hold information "in trust" for the individuals the information is about) are described in PHIA as:

- health professionals licensed or registered to provide health care under an act of the legislature or people designated as health professionals by law
- health care facilities, including hospitals, personal care homes, psychiatric facilities, medical clinics, laboratories and other facilities designated in the regulation
- health services agencies that provide health care, such as community or home-based health care, pursuant to an agreement with another trustee
- public bodies, including provincial government departments and agencies; public educational bodies such as public school divisions, universities and colleges; public health care bodies such as regional health authorities; and local public bodies such as cities and municipalities

PHIA does not include as trustees organizations outside the health care and public sectors, such as private sector employers, professional associations, regulatory bodies (including those that regulate health professionals) and private insurers.

It is important to note that groups that are not trustees under PHIA may be bound by the access and privacy requirements set out in the federal <u>Personal Information Protection and</u> <u>Electronic Documents Act</u> (PIPEDA), if they collect, use or disclose personal information or

# REMEMBER:

words in bold font are defined in Appendix A.

personal health information in the course of commercial activities. PIPEDA came into full effect on January 1, 2004. For more information on PIPEDA, visit the following webpage: <u>https://www.priv.gc.ca/leg\_c/leg\_c\_p\_e.asp</u>

# What do you think?

**2.1.1 (a)** Do you think that the definition of trustee should be expanded to cover people, organizations or entities other than those already covered? If so, please describe which ones and the reasons for including them.

**2.1.1 (b)** Do you think that the legislation is too broad and should be revised to exclude certain people, organizations or entities? If so, please describe which ones and the reasons for excluding them.

2.1.1 (c) Do you have any other comments on the definition of trustees?

#### 2.1.2 Personal Health Information

PHIA applies only when trustees handle information that falls within the definition of **personal health information**. Personal health information is described in PHIA as **recorded information** about an identifiable individual that relates to:

- the individual's health or health care history, including genetic information about the individual
- health care provided to the individual
- payment for health care provided to the individual and includes
- the Personal Health Identification Number (PHIN) or any other identifying number, symbol or particular assigned to an individual
- any identifying information about the individual (e.g. name, address, date of birth) that is collected in the course of providing or paying for health care

Following the previous review of PHIA, a separate definition of "demographic information" (name, address, telephone number and email address) was added to the act along with authority to disclose this information in specified circumstances, including for example, disclosing it for the purpose of verifying a person's eligibility for a program, service or benefit. These changes reflect the differing levels of sensitivity between demographic information and diagnostic, care and treatment information and provide additional flexibility in relation to the disclosure of demographic information.

# What do you think?

**2.1.2 (a)** Do you think that the current definition of personal health information is appropriate? If not, what do you think should be changed or added?

#### 2.1.3 Non-application of PHIA

PHIA does not apply to statistical health information that won't readily identify individuals by itself or when combined with other available information.

Other exemptions to the application of PHIA may deserve consideration. For instance, PHIA does not have a specific time frame for how long the act covers personal health information. As a result, it is unclear whether personal health information maintained by public archives can ever be released to members of the public.

The Province of Saskatchewan has addressed this in its <u>Health Information Protection</u> <u>Act</u> (HIPA), by exempting personal health information about an individual who has been deceased for more than 30 years and records that are more than 120 years old. The federal <u>Personal Information Protection and Electronic Documents Act</u> (PIPEDA) allows disclosure of personal information if the record is over 100 years old or if the individual the information is about has been deceased for 20 years, whichever is earlier. This issue is also addressed in Manitoba's <u>Freedom of Information and Protection of Privacy Act</u> (FIPPA) which allows the disclosure of personal information in records that are over 100 years old. Disclosure of personal information may also be permitted under FIPPA if the subject of the information has been deceased for more than 10 years.

Although such an approach (like those used in Saskatchewan's HIPA, Canada's PIPEDA or Manitoba's FIPPA) may support activities like genealogical and historical research, any privacy implications to the deceased individual, and his or her family, must be considered.

# What do you think?

**2.1.3 (a)** Do you think historical records of personal health information should be exempted from the application of PHIA?

**2.1.3 (b)** If you answered yes to (a), what is an appropriate period after which personal health information could be made available to the public?

2.1.3 (c) Do you have any other comments on the general application of PHIA?

# 2.2 Access to Personal Health Information

Part 2 of PHIA deals with the right of **access**, which refers to an individual's right to examine, obtain a copy of or request correction to his or her own recorded personal health information. The act also recognizes that individuals may require access to information about themselves to make informed decisions about their health and health care.

#### 2.2.1 General Right of Access

PHIA states that an individual has a right, upon request, to examine and receive a copy of his or her personal health information maintained by a trustee within a specified timeframe, or to authorize another individual to exercise these rights on his or her behalf.

Following the review of the act in 2004, PHIA amendments established shorter timelines for trustees to enable individuals to examine and receive a copy of their personal health information in certain circumstances. The act now requires trustees to respond to requests from individuals to examine or receive a copy of personal health information as promptly as required in the circumstances, but not later than:

(a) 24 hours after receiving a request, if the trustee is a hospital and the information is about health care currently being provided to an in-patient

(b) 72 hours after receiving a request, if the information is about health care the trustee is currently providing to a person who is not a hospital in-patient; and

(c) 30 days after receiving a request in any other case, unless the request is transferred to another trustee under the act.

Unlike most other jurisdictions in Canada, PHIA does not permit trustees to extend the time within which they must respond to access requests. For example, <u>Alberta's health information</u> <u>legislation</u> permits an additional period of up to 30 days or, with their privacy commissioner's permission, a longer period if:

- (i) the request does not give enough detail to enable the trustee to identify the record
- (ii) a large number of records are involved in the request and responding within the initial 30 days would unreasonably interfere with the operations of the trustee
- (iii) if more time is needed to consult with another trustee

In Manitoba, FIPPA also permits an additional period of up to 30 days, or a longer period if the ombudsman agrees, in similar circumstances.

PHIA does not clarify when an access request may be considered abandoned. Alberta's health information legislation says a trustee may, by written notice to an applicant, declare a request abandoned if, after 30 days, the applicant has failed to respond to a written notice from the trustee requesting more information or payment of a fee.

PHIA also does not set out when a trustee may disregard a request by a person for access to his or her personal health information. FIPPA allows the head of a public body to disregard requests for access to records if they are of the opinion that:

- (i) the request is incomprehensible, frivolous or vexatious
- (ii) because of their repetitious or systemic nature, the requests would unreasonably interfere with the operations of the public body or amount to abuse of the right to make requests
- (iii) the request is for information already provided to the applicant

Ontario's <u>Personal Health Information Protection Act</u> permits a trustee that believes on reasonable grounds that a request for access to personal health information is frivolous, vexatious or in bad faith, to refuse to grant the individual access to the requested information.

# What do you think?

**2.2.1 (a)** Do you consider the access request provisions and trustee response time frames in sections 5 to 9 of the act to be reasonable?

**2.2.1 (b)** From a trustee's perspective, are there operational difficulties in complying with these requirements?

**2.2.1 (c)** Have you experienced difficulties in accessing your own personal health information? If so, please describe them.

**2.2.1 (d)** Should PHIA set out when a trustee can extend an application for access? Please explain.

**2.2.1 (e)** Should PHIA set out when an application for access may be considered abandoned? Please explain.

**2.2.1 (f)** Should PHIA set out when an application for access may be disregarded? Please explain.

**2.2.1 (g)** Do you have other comments about the general access provisions in PHIA?

#### 2.2.2 Fees

PHIA allows for a reasonable fee to be charged by a trustee for providing an individual with access to their personal health information. These fees may include costs of permitting examination or providing copies of personal health information. Currently, there is no limitation on the amount trustees may charge for providing access to personal health information, but trustees do need to be able to justify any fee as reasonable.

One proposal is to adopt a fee schedule similar to the fee schedule developed under the Access and Privacy Regulation of FIPPA, which permits the following general charges:

- a copying fee of 20 cents per page for photocopying and computer printouts
- a copying fee of 50 cents per page for micro printer printouts
- the actual cost of reproduction for all other media
- two hours of search and preparation free of charge plus a fee of \$15 for every additional half hour
- internal programming or data processing fees of \$10 per fifteen minutes
- external programming or data processing fees charged at cost

For complete information on fees under FIPPA, please refer to sections 5 to 9 of the Access and Privacy Regulation made under FIPPA at <u>http://web2.gov.mb.ca/laws/regs/current/\_pdf-regs.php?reg=64/98</u>.

PHIA leaves waiving fees to the discretion of trustees. It does not set out rules for waiving access fees as some other jurisdictions do. For example, Alberta's health information legislation sets out that a trustee may excuse an applicant from paying all or part of a fee if, in the opinion of the trustee, the applicant cannot afford the fee or in any other circumstances provided for in the regulations.

# What do you think?

**2.2.2 (a)** Should the maximum fees a trustee may charge for providing access to personal health information be set out by regulation under PHIA?

**2.2.2 (b)** If you answered yes to (a), are the fees outlined above reasonable?

**2.2.2 (c)** Should PHIA set out the circumstances in which a fee for access to personal health information may be waived by trustees?

2.2.2 (d) Do you have additional comments about access fees under PHIA?

#### 2.2.3 Representative

Currently, under section 60(1) of PHIA, a person may exercise the rights granted to another individual under PHIA – namely the right of access to, and the right to consent to use and disclosure of the other individual's personal health information in the following circumstances:

- with written authorization from the individual to act on his/her behalf;
- as a proxy appointed by the individual under The Health Care Directives Act;
- as a committee appointed for the individual under The Mental Health Act, if the committee has the power to make health care decisions on the individual's behalf;
- as a substitute decision maker for personal care appointed for the individual under The Vulnerable Persons Living With a Mental Disability Act, if using the right relates to the powers and duties of the substitute decision maker;
- as the parent or guardian of an individual who is a minor, if the minor does not have the capacity to make health care decisions;
- if the individual is deceased, as his or her personal representative (usually interpreted as the executor or administrator of the deceased individual's estate).

PHIA was previously amended to enable a family member to act as an individual's representative when the individual lacks the capacity to exercise his or her own rights under PHIA, and the trustee reasonably believes that none of the representatives listed in section 60(1) as outlined above exist or are available. Section 60(2) of PHIA provides that in these circumstances the eldest adult person listed first in the following clauses may exercise the rights of the individual:

- the individual's spouse, or common-law partner, with whom the individual is cohabiting
- a son or daughter
- a parent, if the individual is an adult
- a brother or sister
- a person with whom the individual is known to have a close personal relationship
- a grandparent
- a grandchild
- an aunt or uncle
- a nephew or niece

This amendment was intended to help increase the likelihood that someone will be available to exercise an individual's rights under PHIA if they lack the capacity to do so.

The issue has been raised that an individual authorized to act under a power of attorney (the attorney) is not recognized as a representative by PHIA. Alberta's health information legislation includes as a representative an attorney if the exercise of the right or power relates to the powers and duties conferred by the power of attorney. A general power of attorney allows the attorney to make decisions concerning all of an individual's business and financial affairs. This includes the authority to manage the individual's banking and investments, and sign all documents with respect to the individual's property. For example, if an attorney is arranging payment for health care, or preparing a tax return in which the individual may qualify for certain medically related tax benefits, the attorney may need to access information related to prescription drugs and payment for health services for the person that they represent.

#### What do you think?

**2.2.3 (a)** Do you think that the amendment adding in section 60(2) of PHIA has helped to ensure that someone will be available to exercise an individual's rights under PHIA if they lack the capacity to do so? If not, why not?

**2.2.3 (b)** Should PHIA be amended to allow an individual with power of attorney to exercise the PHIA access rights of another individual if information is required to exercise the duties granted by the power of attorney?

**2.2.3(c)** Do you have any other comments about the ability of one person to exercise another individual's informational rights under PHIA as set out above?

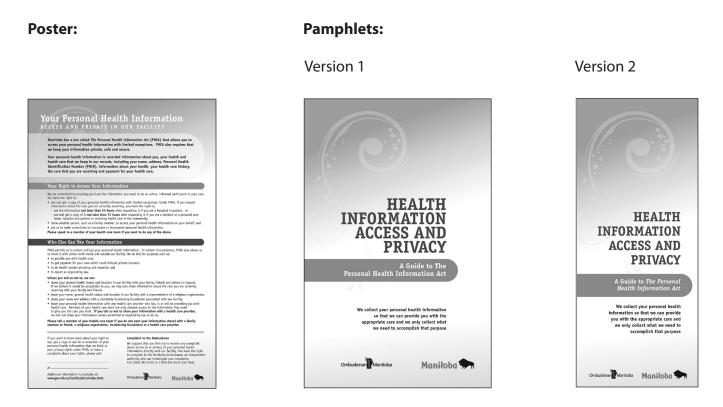
#### 2.2.4 Notice of Right to Access

The previous review of the act revealed concerns that many patients were not aware that they have specific rights under PHIA. As a result, section 9.1 was added to the act, which requires trustees to tell clients about their right to access their personal health information and how to exercise that right.

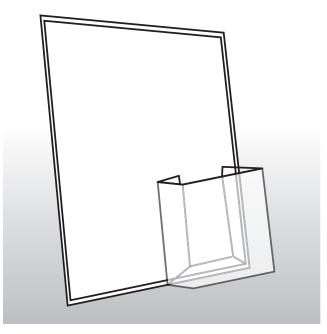
The Personal Health Information Regulation made under the act requires that trustees use a sign, poster, brochure or other similar type of notice and that the notice is prominently displayed in as many locations and in such numbers as is adequate to likely come to the attention of individuals.

The regulation also requires that the notice must state in a clear manner that the individual has a right to examine and receive a copy of his or her personal health information, and that the individual has a right to authorize another person to examine and receive a copy of the information.

To help trustees meet these requirements, Manitoba Health, Seniors and Active Living (MHSAL) developed a <u>poster</u> and pamphlets (shown below) in consultation with the <u>Manitoba Ombudsman</u>. The department provides them to trustees throughout the province on request.



In order to improve access to information about access and privacy rights under PHIA and to address issues raised by some health care organizations, a poster redesign is currently being considered by MHSAL. One option being considered is to reduce the amount of information on the poster itself and attach a pamphlet pocket (image below). This can then be hung on a wall or placed in a plastic stand and placed on a table or counter:



Graphics have also been designed by MHSAL which can be displayed on televisions monitors in waiting rooms if they are available:



#### What do you think?

**2.2.4 (a)** Do you think that posters and pamphlets are an effective way to make information available about privacy and access rights under PHIA? Please explain:

**2.2.4 (b)** Do you think that displaying information about privacy and access rights under PHIA on TV screens in health care facility waiting rooms is an effective method of informing the public about these rights? Please explain:

**2.2.4 (c)** Do you have any comments or other suggestions about ways to make this information more readily available?

#### 2.2.5 Exceptions to Access

PHIA sets out circumstances in which a trustee may refuse an individual's request to examine or obtain a copy of his or her personal health information. These are:

- where knowledge of the information could reasonably be expected to endanger the mental health, physical health or safety of the individual or another person
- where providing access would reveal personal health information about another person who has not consented to the sharing of their information
- where providing access could reasonably be expected to identify a third party who supplied the information in confidence, under circumstances where confidentiality was reasonably expected, unless the third party is another trustee
- where the information was compiled and is used solely for:
  - a peer review by health professionals
  - a review by a standards committee established to study or evaluate health care practices in a health care facility or health services agency

- a body with statutory responsibility for the discipline of health professionals, or for the quality or standards of professional services provided by health professionals
- a risk management assessment
- where the information was compiled anticipation of, or for use in, a civil, criminal or quasi-judicial proceeding

These provisions recognize that, while individuals have a general right of access, there are circumstances in which granting access could be inappropriate, unsafe or harmful to the individual, the trustee or a third party.

A case referred to the Information and Privacy Adjudicator by the Manitoba Ombudsman in November of 2014 (<u>Manitoba Ombudsman Case number: 2013-0419</u>) dealt with a trustee's refusal to provide access to certain psychological tests that were administered to the complainant in her health record. A core argument for refusing to provide access under PHIA to both the test results and the test questions themselves was that if information about the techniques and the specific questions used on the psychological tests were to become widely known (e.g. posted on the Internet), then the utility and validity of the tests could be compromised, rendering the tests ineffective for anyone who had seen them.

Alberta's health information legislation sets out that a trustee must refuse to disclose health information to an applicant if the information relates to standardized diagnostic tests or assessments used by a trustee, including intelligence tests, and disclosure of the information could reasonably be expected to prejudice the use or results of the diagnostic tests or assessments.

# What do you think?

**2.2.5 (a)** Are the exceptions to access as currently set out in section 11(1) reasonable? If not, how should they be modified?

**2.2.5 (b)** Do you think that standardized diagnostic tests or assessments, including intelligence and diagnostic tests or assessments, should be specifically exempt from the right of access under PHIA if their disclosure could reasonably be expected to prejudice the use or results of the tests or assessments?

**2.2.5 (c)** Do you have any other comments regarding exceptions to the right of access under *PHIA*?

#### 2.2.6 Correction of Personal Health Information

To ensure the accuracy and completeness of personal health information, PHIA provides for an individual's right to request a correction to their recorded personal health information. The trustee must either make the correction as requested, or if the trustee disagrees with the request, permit the individual to file a statement of disagreement, which must be attached to his or her file. The act does not set out the circumstances in which a trustee may refuse to make a correction.

Other provinces have set out in their health privacy legislation the circumstances in which a trustee may refuse to correct personal health information. For example, Ontario's <u>Personal</u> <u>Health Information Protection Act</u> provides that a request to correct personal health information may be denied if:

- (i) The information consists of a professional opinion or observation that a trustee has made in good faith about the individual.
- (ii) The information was not originally created by the trustee and the trustee does not have sufficient knowledge, expertise and authority to correct the information.
- (iii) The trustee believes on reasonable grounds that the request is frivolous, vexatious or made in bad faith.

# What do you think?

**2.2.6 (a)** Do you think that PHIA should define the circumstances in which a trustee may refuse to make a requested correction? Please explain.

**2.2.6 (b)** Do you have any other comments on the provisions that concern an individual's right to request a correction?

# 2.3 Privacy of Personal Health Information

PHIA deals broadly with the protection of personal health information and supports information privacy by imposing obligations on trustees when such information is collected, used, disclosed, retained or destroyed. Part 3 of the act recognizes the need to create an appropriate balance between an individual's right to privacy and other important interests, such as tracking the spread of infectious diseases and health system administration.

#### 2.3.1 General Limitations on Collection, Use and Disclosure

PHIA protects privacy by limiting the circumstances in which trustees can collect personal health information, and by limiting the circumstances in which trustees can use and disclose personal health information without consent.

Sections 13 and 14 of PHIA state that a trustee may only collect personal health information if the following conditions apply:

- The information is collected for a lawful purpose related to what the trustee (e.g. health provider or hospital) does.
- The collection is necessary for that function or activity.
- The trustee only collects the personal health information that is reasonably necessary to accomplish the purpose for which it is collected.
- The trustee collects the information directly from the person it is about, whenever possible, unless another indirect means of collection is authorized under PHIA.

Section 20 limits the amount of information a trustee may use or disclose. It must be the least amount of information necessary to accomplish the purpose for which it is used or disclosed. This requirement exists even in situations where the use or disclosure is authorized by statute or consent. Taken together, sections 13, 14 and 20 support the right to privacy by placing

limits on the amount of information trustees can collect and how the information is treated while it is held.

### What do you think?

2.3.1 (a) Do the limitations in PHIA effectively uphold individual rights to privacy?

**2.3.1 (b)** From a trustee's perspective, are there any operational difficulties in complying with these sections?

**2.3.1 (c)** Do you have any other comments on the principles of limiting collection, use and disclosure?

#### 2.3.2 Notice of Collection Practices

When collecting personal health information, trustees are bound by additional obligations beyond those outlined above. When collecting personal health information directly from the person the information is about, PHIA requires trustees to inform that person of the reason the information is being collected at the time of collection or as soon after as possible. This can be done by taking measures such as posting notices, including a statement on a form, or through a discussion with the individual. This requirement enables people to challenge a trustee's collection practices.

# What do you think?

**2.3.2 (a)** Does the requirement to inform individuals about collection practices assist in effectively upholding the right of privacy?

**2.3.2 (b)** If you are a trustee, are there any operational difficulties in complying with this requirement?

**2.3.2 (c)** Do you have any other comments on the requirement to inform individuals about collection practices?

#### 2.3.3 Requirements of Consent

Following the previous review of PHIA, Division 2.1 of Part 3 of PHIA was added to clarify the consent needed before a patient's personal health information could be used or disclosed unless the act permits the information to be used or disclosed without consent. The added division sets out that consent obtained under PHIA for the use and disclosure of personal health information must relate to the purpose for which the information is to be used or disclosed, and must be knowledgeable and voluntary and not obtained through misrepresentation. For more details about consent requirements under PHIA, please refer directly to sections 19.1 and 19.2 of the act.

# What do you think?

**2.3.3 (a)** Do you think that the elements of consent that are required by PHIA are reasonable and sufficient?

**2.3.3 (b)** If you are a trustee, have you experienced any particular challenges in meeting these requirements?

**2.3.3 (c)** Do you have any other comments or experiences regarding a consent issue to share?

#### 2.3.4 Use without Consent

PHIA allows trustees to use personal health information for the purpose the information was collected and permits specific additional uses without the consent of the individual the information is about based on the need to balance information privacy against other important interests, such as personal safety and health system administration. Some additional uses permitted without consent are to monitor or evaluate a health service or to plan for future programs that relate to health care delivery. The uses that are allowed without consent are set out in section 21 of PHIA.

#### 2.3.4.1 Use for Training Purposes

It has been suggested that PHIA be amended to add a specific provision which would authorize the use of personal health information without consent for the training of staff or students. For example, hospitals have extensive training programs for students that are studying at an educational institution but taking their practicum at the health facility. While PHIA clearly authorizes a physician employed by the hospital to check a patient's chart for the purpose of providing care to that patient, the authorization for that physician to share the patient's health information with students who are learning how to provide care, while present, is not so clear.

# What do you think?

**2.3.4.1 (a)** Are the current authorized uses without consent reasonable and appropriate?

**2.3.4.1 (b)** Should PHIA be amended to clarify the circumstances where personal health information can be used for training purposes? Why or why not?

**2.3.4.1 (c)** If you answered yes to (b), are there any limitations that you think should be placed on this?

# 2.3.4.2 Use for Employment Purposes

Trustees, depending on their function, sometimes maintain the personal health information of their employees that they have collected for the purpose of providing health care or other services to them. For example, an employee of a hospital may have visited that hospital as a patient prior to becoming an employee of the hospital, or even during the course of their employment. The Privacy Commissioner of Saskatchewan recently recommended that Saskatchewan's <u>Health Information Privacy Act</u> be amended to make it clear that nothing authorizes a trustee as an employer to use or obtain access to the personal health information of an individual who is an employee or prospective employee for any purpose related to the employment of the individual without the individual's express consent.

# What do you think?

**2.3.4.2 (a)** Should PHIA be amended to provide additional clarity that express consent is required before accessing the personal health information of any employee or prospective employee for any purpose related to employment, unless it was originally collected for that purpose?

**2.3.4.2 (b)** Do you have any comments or suggestions to add regarding the use of personal health information without consent?

#### 2.3.5 Disclosure without Consent

Although obtaining consent for disclosures is the preferred option from an information privacy protection perspective, getting that consent is not always possible, and in some cases may not be feasible.

This being the case, PHIA permits the disclosure of personal health information without consent in specific circumstances. Examples of permitted disclosures without consent, which are found in section 22(2), include:

- to another person providing health care to the individual
- to obtain payment for publicly funded health care services
- to lessen or prevent a serious and immediate threat to someone
- to notify family of someone who is injured, incapacitated or deceased
- to deliver, monitor or evaluate a program that relates to the provision of health care or payment for health care
- to a person conducting a health research study, if a designated committee has evaluated the study against specific criteria
- where the court or another law requires the disclosure, for example, The Public Health Act requires reporting certain diseases, and The Child and Family Services Act requires reporting when a child may be in need of protection

Section 23(1) authorizes the disclosure of information about current health-care services to family members and close friends of an individual who is a patient or resident in a health care facility, or is receiving health care services from a trustee at home, as long as the disclosure is made in accordance with good medical or other professional practice, and it is believed that the disclosure would be acceptable to the individual or his or her representative.

PHIA further requires that, in these circumstances, the information be disclosed as soon as reasonably possible, but no later than:

- 24 hours after the request is made, if the trustee is a hospital and the information is about health care currently being provided to an in-patient
- 72 hours after the request is made, in any other case

Please consult the act directly for a complete listing of permitted disclosures without consent. These appear in sections 22 through 25 inclusive.

#### What do you think?

**2.3.5 (a)** *Is it reasonable and appropriate for trustees to disclose personal health information without consent for the purposes described in section 22(2)? Please explain.* 

**2.3.5 (b)** *Is it reasonable and appropriate for trustees to disclose personal health information without consent in the circumstances described in section 23(1)? Please explain.* 

**2.3.5 (c)** Do you think non-consensual disclosures should be restricted or expanded in any way? If so, please describe how.

#### 2.3.6 Expanding the Disclosure Provisions

#### 2.3.6.1 Disclosure to Prevent or Lessen a Serious and Immediate Threat

Clause 22(2)(b) of PHIA authorizes a trustee to disclose personal health information without the consent of the person the information is about if the trustee reasonably believes that the disclosure is necessary to prevent or lessen a serious and immediate threat to the health or safety of that individual, another individual, or public health or public safety.

The question has been raised as to whether or not the wording **serious and immediate** is too restrictive. In particular, the need for the threat to be **immediate** means that the risk must create a sense of urgency and, if the threat is a future risk, it must be real enough that a reasonable person would believe that the harm would occur if no action was taken to prevent it from occurring. This can be difficult to determine in some circumstances.

Six other Canadian provinces have lower thresholds, for example:

- **BC** compelling circumstances that affect health or safety:
- **SK** a danger to health or safety
- ON a significant risk of serious bodily harm
- NB a risk of serious harm
- PEI a risk of serious harm
- NL a risk of serious harm

Recognizing the importance of protecting children in Manitoba from harm, <u>The Protecting</u> <u>Children (Information Sharing) Act</u>, includes amendments to PHIA that will permit the disclosure of personal health information to any person if it is necessary to prevent or lessen a risk of harm to the health or safety of a minor. This amendment will enable the disclosure of personal health information of minors or adults if necessary to prevent or lessen a risk of harm to a minor. This is a lower threshold than **to prevent or lessen a serious and immediate threat** which will continue to apply when an adult is the subject of the threat. It has been suggested that PHIA be amended to authorize notification by health care providers to the circle of care of an adult person when the individual is in mental distress or crisis. This includes family members, friends and other immediate caregivers, This would enable those notified to provide support to the individual. This authority would apply even if the individual does not want such notification to occur.

Currently, this notification cannot occur without the consent of the individual unless the trustee reasonably believes that it is necessary to prevent or lessen a serious and immediate threat to the health or safety of the individual or another person. Family members cannot be notified without consent if an individual is released from hospital or another health care facility. Generally, individuals will not be released if they present a serious and immediate threat to the health or safety of themselves or others.

Lowering the threshold for disclosure, for example, to authorize disclosure where reasonably required to prevent or lessen a risk of serious harm to the health or safety of an adult person would enable health care providers to adopt policies to disclose information to the individual's circle of care on a need to know basis in such circumstances even if the individual does not want such notification to occur.

# What do you think?

**2.3.6.1 (a)** Do you think that the threshold of serious and immediate threat is too restrictive? Please explain.

**2.3.6.1 (b)** If you feel the threshold is too restrictive, what threshold would be more appropriate?

#### 2.3.6.2 Disclosure to Report Suspected Criminal Activity

PHIA allows trustees to disclose personal health information to law enforcement agencies with the consent of the individual the information is about, or without consent, in the following circumstances:

- The disclosure is deemed necessary to lessen or prevent a serious and immediate threat to public safety or the safety of any individual.
- The disclosure is made for the purpose of contacting a relative or friend of an individual who is injured, incapacitated, ill or deceased.
- The disclosure is made for use in prosecuting an offence.
- The disclosure is made for the purpose of an investigation or enforcement of an enactment of Manitoba respecting payment for health care or an investigation or enforcement respecting a fraud relating to payment for health care.
- The disclosure is demographic information required by police to help them locate a person reported as missing.
- The disclosure is required by a court order, warrant or subpoena.
- Disclosure is made to officers, designated as investigators by the Chief Medical Examiner, who are seeking information for an investigation under The Fatality Inquiries Act.
- The disclosure is required by a provincial or federal law applicable in Manitoba.

Some law enforcement agencies have asked that PHIA be amended to allow for additional non-consensual disclosures. In particular, they have suggested that PHIA be amended to permit health care providers to disclose personal health information without consent, to report suspected criminal activity. They take the position that measures protecting the privacy of personal health information are overly restrictive and do not adequately permit law enforcement officers to obtain timely information for use in criminal investigations.

Alberta's health information legislation allows a trustee to disclose certain limited information about a patient to law enforcement without consent. The trustee must reasonably believe the information relates to the possible commission of a crime, and that disclosure will protect the health and safety of the public.

Safety and law enforcement are important public interests. These should be addressed while recognizing the importance of patient autonomy and the fact that some people may not seek health care if they believe their information may be reported to police without their consent.

**Example 1:** A dialysis unit administrator receives a request from the RCMP asking to be advised of the dates and times of dialysis treatments of a specific individual. The request says they are only seeking to ask the patient some questions related to a criminal investigation and that the patient is not a suspect. Currently, PHIA does not permit the dialysis unit to disclose this information to the RCMP in this circumstance.

**Example 2:** Mr. A arrives at an emergency department with serious injuries including a broken arm and a skull fracture. Dr. B treats Mr. A and is concerned that the injuries may have been caused during an assault. She asks Mr. A if she can contact the police. Mr. A states the injuries are the result of a motor vehicle accident. He asks Dr. B not to contact the police. Dr. B is still suspicious but currently, under PHIA, has no grounds to report the incident to the police without Mr. A's consent, because Dr. B has no firm reason to believe that the disclosure is necessary to lessen or prevent a serious and immediate threat to Mr. A or to someone else.

#### What do you think?

**2.3.6.2 (a)** Should the authority in PHIA for trustees to disclose personal health information to law enforcement without consent be expanded? If so, in what way?

#### 2.3.7 Retention and Destruction

Section 17 of PHIA says trustees must establish and comply with a written policy on the retention and destruction of personal health information. Policies must conform to requirements set out in the regulations.

Retention policies are important to respecting the rights granted under PHIA. They ensure information is available for a certain period of time to support the delivery of health services. During this time, individuals can exercise their right of access. In Manitoba, regulatory bodies set the retention periods for their members, but this varies between professions. Trustees are free to retain information for longer periods, as is often the practice.

There are no regulatory provisions stating the way trustees may destroy personal health information. One option is to require that personal health information be destroyed by incineration or shredding, and that electronic records be destroyed by permanent erasure or destruction of the media.

# What do you think?

**2.3.7 (a)** Do you have any comments about the retention and destruction of personal health information?

#### 2.3.8 Security Safeguards

PHIA requires that reasonable administrative, technical and physical safeguards be in place to protect the confidentiality, security, accuracy and integrity of personal health information. Administrative safeguards include policies, procedures, pledges and other obligations designed to ensure that the practices necessary to protect personal health information are followed. Physical safeguards are physical barriers that prevent unauthorized access to personal health information. Technical safeguards refer to technical barriers that ensure personal health information is protected when stored or transmitted via an electronic device.

A trustee's obligation to adopt administrative safeguards, as set out in the Personal Health Information Regulation, includes the requirements to:

- Develop written policies for the protection of personal health information.
- Provide education and training on the obligations set out in these policies.
- Ensure those dealing with the information sign a pledge of confidentiality acknowledging they are bound by the obligations set out in the policies.

Physical safeguard requirements include:

- Maintaining personal health information in designated areas under appropriate safeguards.
- Limiting physical access to health information storage areas.
- Taking reasonable steps to protect personal health information from fire, theft, vandalism, deterioration, accidental destruction, loss and other hazards.
- Ensuring all removable electronic storage media used to record personal health information is stored securely when not in use.

Technical safeguards include the requirement to ensure all electronic information systems used have the capability to:

- Produce an electronic record of all successful and unsuccessful attempts to access, add to, modify or delete personal health information maintained on the system.
- Record all transmissions of personal health information maintained on the system.

# What do you think?

**2.3.8 (a)** Do you think that the current administrative, physical and technical security requirements outlined in PHIA and the Personal Health Information Regulation adequately protect personal health information?

**2.3.8 (b)** Do you think these requirements should be strengthened, relaxed or modified in any way?

**2.3.8 (c)** If you are a trustee, are there any operational challenges in complying with these security requirements?

**2.3.8 (d)** Do you have any other comments about PHIA security requirements and the Personal Health Information Regulation?

#### 2.3.9 Data Matching

Recent innovations in information technology have dramatically improved the ability to match data collected from various sources and create extensive personal profiles. Data matching (sometimes referred to as data linking) can improve the delivery of health care and facilitate health research. However, where such activities are left unchecked or undertaken for illegitimate purposes, they can pose significant threats to information privacy.

PHIA indirectly regulates matching data from various data sets held by a single trustee through measures that limit the use of personal health information. Matching data from datasets held by more than one trustee, or a trustee and another organization, is regulated indirectly by the sections of PHIA that limit disclosure. PHIA does not, however, contain provisions specifically addressing the unique issues associated with data matching. It is possible that matching one set of non-identifiable personal health information with data from another source could potentially end up identifying individuals.

Saskatchewan's Information and Privacy Commissioner recently recommended that Saskatchewan's <u>Health Information Privacy Act</u> be amended to prohibit data matching without authorization for the collection, use or disclosure of the personal health information being used for the data matching or created as a result of the data matching. The recommendation acknowledged exceptions might involve authorization by another law or regulation made pursuant to another law.

#### What do you think?

**2.3.9 (a)** Should limitations on data matching, similar to those proposed in Saskatchewan, be added to PHIA?

**2.3.9 (b)** Should limitations on data matching be extended to non-trustees who have received personal health information through a trustee?

2.3.9 (c) Do you have any other comments regarding data matching?

#### 2.3.10 Health Research

Health research has played a significant role in efforts to provide safe and effective health care services. It depends largely on information that includes personal health information.

PHIA authorizes public body or health care trustees to use or disclose personal health information for research and planning related to providing health care and paying for it.

In addition, PHIA authorizes disclosure of personal health information by trustees to third party researchers for health research, if the research has been approved by:

- the <u>health information privacy committee</u> established under PHIA, when personal health information maintained by the government or a government agency is required
- an institutional research review committee formally established by a health care facility, university or similar body, if the information is maintained by a trustee other than the government or a government agency

Approval may only be given by a committee if the committee determines that the following criteria have been met:

- The research is of sufficient importance to outweigh the intrusion into privacy that would result from the disclosure of personal health information.
- The research cannot reasonably be accomplished unless the personal health information is provided in a form that identifies or may identify individuals.
- It is unreasonable or impractical for the person proposing the research to obtain consent from the individuals the personal health information is about.
- The research proposal contains reasonable safeguards to protect the confidentiality and security of the personal health information.

In addition to obtaining the approval of the health information privacy committee or an institutional research review committee, PHIA requires that a third party researcher must enter into an agreement with the trustee which meets requirements set out in PHIA.

It should be noted that research involving human subjects or personal health information is normally regulated by independent research guidelines and review bodies, as well as by PHIA. Guidelines, including the <u>Tri-Council Policy Statement on Ethical Conduct for Research</u> <u>Involving Humans</u>, have provisions on privacy, confidentiality and consent that are, in most cases, consistent with the current requirements under PHIA.

Following the previous review of PHIA, section 24.1 was added to PHIA to permit trustees to disclose personal health information to a health research organization, including the <u>Manitoba Centre for Health Policy</u> at the University of Manitoba and the Canadian Institute for Health Information, for the following purposes:

- analyzing the health status of the population
- identifying and describing patterns of illness
- describing and analyzing how health services are used
- analyzing the availability and adequacy of human resources required to provide health services
- measuring health system performance
- health system planning

PHIA sets out requirements, including security safeguards, that must be established by a health research organization to ensure the appropriate protection of individual privacy and the personal health information disclosed to an organization.

For more details about the requirements of PHIA regarding disclosure of personal health information to third party researchers or a health care organization, please refer directly to sections 24 and 24.1 of the act and to the <u>Personal Health Information Regulation</u> made under the act.

### What do you think?

**2.3.10 (a)** Do the current provisions of PHIA help ensure that the necessary information is available for health research while protecting the rights of individuals to privacy?

**2.3.10 (b)** As a trustee or a researcher, do you have any comments about the requirements of PHIA for the disclosure of personal health information for health research?

**2.3.10 (c)** Do you have any other general comments about the relationship between PHIA and health research?

#### 2.3.11 Mandatory Privacy Breach Notification

Currently, there is no legislated requirement in Manitoba for a trustee to provide notification to an individual or the <u>Manitoba Ombudsman</u> when the individual's personal health information is stolen, lost, used or disclosed without authority. However, the Manitoba Ombudsman advises that notification can be an important mitigation strategy in the appropriate circumstances. Currently, a key consideration in deciding whether to notify is whether notification is necessary in avoiding or mitigating harm to the individual.

For example, if a lost or stolen electronic storage device (e.g. computer hard drive) containing personal health information was properly encrypted, the trustee may decide not to provide notification since the information cannot reasonably be accessed without an encryption key.

A number of other jurisdictions, including Ontario, New Brunswick, Nova Scotia, Newfoundland and Labrador, the Yukon and the Northwest Territories already have notification provisions in their health information privacy legislation, and the <u>Saskatchewan</u> <u>Privacy Commissioner</u> has recommended that Saskatchewan's health information legislation be amended to require that a trustee notify both the individual the information is about and the Privacy Commissioner if a privacy breach occurs in relation to an individual's personal health information in the trustee's custody or control, and there are reasonable grounds to believe that the individual is at a real risk of significant harm as a result of the privacy breach.

# What do you think?

**2.3.11 (a)** Do you think that there should be mandatory breach notification requirements added to PHIA?

**2.3.11 (b)** If you answered yes to (a), please describe the circumstances in which you feel notification should be mandatory.

#### 2.3.12 Whistleblower Protection

In Manitoba, <u>The Public Interest Disclosure (Whistleblower Protection) Act</u> provides a clear process for reporting wrongdoing, including an act that is an offence under another statute like PHIA, in the Manitoba public service and provides protection from reprisal.

The law applies to employees and officers at all levels of provincial departments, offices of the legislative assembly and government bodies. These bodies include government agencies, such as Manitoba Hydro, the Manitoba Liquor Control Commission and the Workers Compensation Board. Included are regional health authorities, child and family services authorities and agencies, and other government bodies specified in regulations. The law also provides protection for private sector employees and contractors who disclose wrongdoings in the Manitoba public service to the <u>Manitoba Ombudsman</u>. However, the law does not apply to employees of trustees in the private sector, such as private medical clinics, who disclose wrongdoings in the private sector.

The Saskatchewan Information and Privacy Commissioner recently recommended that Saskatchewan's <u>Health Information Privacy Act</u> be amended to include whistleblower protection for employees of any trustee. The provision would prevent a private sector employer from dismissing, suspending, disciplining, demoting, harassing or otherwise disadvantaging or penalizing an individual where the individual, acting in good faith and on the basis of reasonable belief, discloses to the Commissioner that another person has contravened or is about to contravene a provision of the Saskatchewan legislation.

# What do you think?

**2.3.12 (a)** Do you think that whistleblower protection for all trustee employees should be added to PHIA?

#### 2.3.13 Big Data Analytics

Governments around the world now recognize that the vast amounts of data they hold are valuable assets. As the data held by government continues to increase, advances in technology are adding new types of data and new methods to analyze it. Governments can now answer questions they could not even ask in the past. The combination of vast quantities of data coupled with advanced analytic technologies is called big data analytics (BDA).

Government policy development and service delivery can benefit from the effective and sensible use of BDA. It can:

- help streamline service delivery
- create opportunities for innovation
- identify new service and policy approaches
- support and enhance the delivery of programs across a range of government operations
- help sustain effective social programs
- · enhance delivery of health services

The Manitoba government is a leader in the long-term collection of data from many of its programs and services. Investments have been made in developing a world famous research repository at the <u>Manitoba Centre for Health Policy</u> at the University of Manitoba, which now contains many decades of administrative data from departments dealing with health, families, education, housing, the health of children, justice and vital statistics. All of the data in this repository is secure and de-identified. This data is actively used to support approved health services policy research, but given the many social services datasets now included there, it could be used for much broader analyses directed at some of Manitoba's most pressing public program challenges.

With the capabilities of modern data analytics, Manitoba's data assets now not only include traditional rows and columns of data but also unstructured free text data such as client case notes, digitized diagnostic images, and even photographs and videos. Previous technical and practical limitations related to vast data quantities and multiple data varieties and formats have practically vanished through modern analytics capabilities. In Manitoba, it will be possible to comb through and link large collections of available data over many years and spanning different sectors (education, health, justice, etc.). This will reveal unclear relationships and hidden drivers that can be used to guide policy and steer practice to enable a wide range of better public program outcomes. Data management practices and technologies (including privacy technologies) are advancing at the same time.

One of several public sector BDA success stories comes from New Zealand where they tested a new approach to analyzing data to determine where social spending could be most effective. In 2010, government statistics showed that half the 4,300 teenage single mothers receiving benefits in that country were likely to remain in the welfare system for 20 years, at a total cost of about \$264,000 each. The government responded with \$23 million to assign individual case workers to help teenage mothers finish school and find work. After four years, the number of teenage single mothers on benefits had dropped to 2,600.

Other governments have had success in a variety of fields including: reducing child fatalities, improving high school graduation rates, addressing traffic congestion and detecting fraud. In the healthcare sector, BDA is driving major advances in cancer research, new drug therapies and many chronic conditions. A related use of BDA may involve publishing de-identified government data in the public domain where it can be used by the private sector. This has the potential to stimulate innovation, improve service delivery and support economic growth that benefits all Manitobans.

BDA in health and social sectors involves two basic enablers:

- 1. De-identification alters data to remove or obscure personal identifiers and personal information.
- 2. Data linking joins separate datasets for a more complete view of previously separated information.

If the de-identification process is not undertaken effectively or with sufficient effort, the power of data linking can render data identifiable once more. Referred to as the mosaic effect, it is a risk lowered by using appropriate security safeguards that include powerful de-identification techniques.

The power of big data to drive change, rapidly changing technology and community needs for privacy and security all demand close monitoring of big data use. This includes both internal and community engagement. Discussion on this needs to consider both the opportunity costs of heavily restricting information sharing and the risks related to unintended privacy breaches.

# What do you think?

**2.3.13 (a)** Would you support increased and improved data analytics in government using de-identified personal health information for the purpose of improving services to Manitobans?

**2.3.13 (b)** What issues and considerations are most important to you in this process?

# 2.4 Compliance Review

Parts 4 and 5 of PHIA deal with the role of the Manitoba Ombudsman under the act, and an individual's right to seek redress for breaches of his or her access and privacy rights.

#### 2.4.1 General Role of the Ombudsman

All access to information and protection of privacy legislation in Canada includes some form of independent review process to address complaints about a trustee's information practices and to ensure general compliance with the legislation. In Manitoba, under both PHIA and FIPPA, this role has been granted to the ombudsman. The ombudsman is an independent officer of the Manitoba Legislature.

The ombudsman's general powers and duties are:

- to conduct investigations and audits, and make recommendations to monitor and ensure compliance with PHIA
- to inform the public about PHIA
- to receive comments from the public about matters concerning the confidentiality of personal health information or access to that information
- to comment on the implications of proposed legislation, programs or practices of trustees for access to, or confidentiality of, personal health information
- to comment on the implications for the confidentiality of personal health information when:
  - using or disclosing personal health information for record linkage
  - using information technology in the collection, storage, use or transfer of personal health information
- to consult with any person with experience or expertise in any matter related to PHIA
- to engage in or commission research into any matter related to the purposes of PHIA

The ombudsman also has all the powers and protections of a commissioner under <u>The Manitoba Evidence Act</u> and may:

- require the production of any record maintained by a trustee that is relevant to an investigation under PHIA
- enter into any premises of a trustee, where necessary, for an investigation under PHIA
- converse privately with any officer, employee or agent of a trustee

#### What do you think?

**2.4.1 (a)** Do you think that the general powers and duties of the ombudsman, outlined in Part 4 of PHIA, assist that office in encouraging compliance with PHIA?

**2.4.1 (b)** Do you have any other comments on the powers and duties of the Manitoba Ombudsman under PHIA?

#### 2.4.2 General Role of the Information and Privacy Adjudicator

Effective January 1, 2011, amendments to PHIA relating to Manitoba's first Information and Privacy Adjudicator came into force. Although the adjudicator is appointed under <u>The</u> <u>Freedom of Information and Protection of Privacy Act</u> (FIPPA), the adjudicator has a similar role under PHIA.

The ombudsman model works very well at protecting the access and privacy rights of Manitobans. In the majority of cases, the ombudsman is successful at resolving access and privacy complaints. However, in the few cases that the ombudsman is unable to resolve, the ombudsman has the ability to ask for a review by the Information and Privacy Adjudicator.

The adjudicator is able to make binding orders that trustees must comply with. Among other things, the adjudicator's orders may apply to:

- access to personal health information
- fees charged for access to personal health information
- · corrections to personal health information
- changing or putting a stop to the way personal health information is collected, used, disclosed or destroyed

#### What do you think?

**2.4.2 (a)** Do you think that the general powers and duties of the Information and Privacy Adjudicator assist in encouraging compliance with PHIA?

**2.4.2 (b)** Do you have any other comments on the powers and duties of the Information and Privacy Adjudicator under PHIA?

#### 2.4.3 Complaints and Redress

Individuals may direct any complaints about any trustee's information practices or breaches of access and privacy rights to the <u>Manitoba Ombudsman</u>. PHIA empowers the ombudsman to handle such complaints.

Individuals who have requested access to personal health information have the right to make a complaint to the ombudsman on any matter relating to the request, including:

- when the individual is refused access to examine or receive a copy of the information
- when a correction to an individual's personal health information is not made
- an unreasonable delay by the trustee in responding to the request
- an unreasonable or unauthorized fee charged by the trustee

Individuals have the right to make a complaint to the ombudsman if they believe their personal information:

- has been collected, used or disclosed contrary to the act
- has not been protected in a secure manner as required by the act

After receiving a complaint, the ombudsman must investigate unless:

- the length of time that has elapsed since the date the subject matter of the complaint arose makes an investigation no longer practical or desirable
- the subject matter of the complaint is trivial or the complaint is not made in good faith, or is frivolous or vexatious
- the circumstances of the complaint do not require investigation

The ombudsman may initiate investigations independently where circumstances warrant.

Following the completion of an investigation, if the ombudsman supports the position of the complainant, the ombudsman may make recommendations for changes to policy or practice. Complaints regarding a denial of access under PHIA can also be appealed to the Court of Queen's Bench.

PHIA does not permit a family member to file a complaint with the ombudsman regarding:

- a decision of a trustee to refuse to disclose to them the personal health information of their relative who is a patient or resident in a health care facility, or is receiving health care services from a trustee at home, or failure of a trustee to disclose the information to them in the time required by PHIA
- (ii) a decision of a trustee to refuse to disclose to them the personal health information of a relative who is deceased

Although the ombudsman cannot compel a trustee to change practices, the ombudsman can comment publicly on any issue related to access and privacy rights in Manitoba. As a result, the recommendations of the ombudsman carry considerable weight. Where a trustee refuses to accept or implement the recommendations of the ombudsman, the ombudsman has the power to refer the case to the Information and Privacy Adjudicator, who has the power to make binding decisions.

#### What do you think?

**2.4.3 (a)** Does the independent review mechanism established under Part 5 of PHIA provide an adequate and effective process for redress?

**2.4.3 (b)** Should a family member be able to file a complaint about the refusal of a trustee to disclose to them the personal health information of their relative who is a patient or resident in a health care facility, or is receiving health care services from a trustee at home, or a failure to disclose the information in the time required in PHIA? Please explain.

**2.4.3 (c)** Should a family member be able to file a complaint about the refusal of a trustee to disclose to them the personal health information of their relative who is deceased? Please explain.

**2.4.3 (d)** Do you have any other comments on the complaint and investigation process established under Part 5 of PHIA?

### **2.5 General Provisions**

PHIA outlines general provisions and operational details for the administration of the act.

#### 2.5.1 Offences

PHIA sets out the offences that a person or trustee can be charged with and, if found guilty by the courts, fined. These quasi-criminal sanctions contribute to health information privacy by imposing legal sanctions for activities that pose a threat to this right. A list of offences appears in subsections 63(1) to 63(3) of PHIA.

Very seldom do contraventions of PHIA end in prosecution in Manitoba. This may be the result of a climate that encourages re-education and policy improvement in response to minor breaches. Nevertheless, if, following an investigation, the ombudsman believes that a significant breach has occurred, the matter may be referred to the Crown for prosecution. Upon conviction, the maximum penalty for a breach of PHIA is \$50,000. Other provinces have implemented higher maximum penalties and different fine levels for individuals and corporations. For example, Ontario recently doubled its maximum fines for offences under its <u>Personal Health Information Protection Act</u> to make them \$100,000 for individuals and \$500,000 for organizations.

Amendments to PHIA in 2013 made it an offense for an employee of a trustee to use, gain access to or attempt to gain access to another person's personal health information without authorization. This amendment was intended to enable prosecution when an employee of a trustee accesses an individual's personal health information not for the purposes of providing health care or services, but rather to snoop into the individual's health record. Previous to this amendment, prosecution could only take place if the employee accessed the information without authorization and then shared it outside of their organization.

It has been suggested that the offence provisions in PHIA relating to an employee of a trustee for snooping into an individual's health record or wilfully disclosing personal health information, where such disclosure is not authorized under PHIA, should also apply to former employees of a trustee.

It has also been suggested that additional offence provisions should be considered. For example, if there is an amendment which would require mandatory breach notification to an individual, the ombudsman or both, PHIA should further be amended to make it an offence to fail to notify the individual or ombudsman, as required.

Finally, PHIA currently provides that the prosecution of an offence under PHIA must be started no later than two years after the commission of the alleged offence. However, an offence such as unauthorized access to or use of information by an employee of a trustee (snooping) may not be discovered until more than two years after the snooping took place, making prosecution impossible. Consideration should be given to setting a time limit for prosecution based on the discovery of the offence. For example, Saskatchewan's <u>Health Information</u> <u>Privacy Act</u> provides that a prosecution must be started not more than two years after the date of the discovery of the alleged offence.

### What do you think?

**2.5.1 (a)** Should the list of offences under PHIA be expanded? If so, in what way?

**2.5.1 (b)** Should the offence provisions respecting employees of trustees be expanded to include former employees?

**2.5.1 (c)** *Is the amendment added in 2013 appropriate and adequate to deter potential snooping? Please explain.* 

**2.5.1 (d)** Should the time period for starting the prosecution of an offence begin upon discovery of an alleged offence? Please explain.

2.5.1 (e) Do you have any other comments regarding offences and fines under PHIA?

# Part 3

# **3.1 Conclusion**

Thank you for your attention to the issues outlined in this document and for your interest in The Personal Health Information Act. We hope this document will serve to launch public debate and help ensure that PHIA continues to reflect the government's strong commitment to the access and privacy rights of its citizens.

# **3.2 Submitting Your Comments**

Please provide us with your comments on PHIA. We invite you to comment on some, or all of the matters outlined in this document, as well as any other issues that concern you and fall within the scope of PHIA. Your comments and suggestions will help us ensure that PHIA continues to serve the interests of the public and meet the needs of the health care system.

The questions posed in Part 2 of this document are set out on Manitoba Health, Seniors and Active Living's PHIA Review webpage. You may submit your comments electronically by visiting that site at <u>www.gov.mb.ca/health/phia/review.html</u>. Written submissions and questions may be forwarded to:

PHIA Review Legislative Unit Manitoba Health, Seniors and Active Living Main Floor, 300 Carlton Street Winnipeg, MB R3B 3M9

Fax: 204-945-1020 Email: PHIAreview@gov.mb.ca Phone: 204-788-6612

Please submit your comments and suggestions by no later than May 31, 2017. This will ensure they will be considered as part of the legislative review process. Individual responses to submissions will not be provided by the department to anyone submitting feedback in the review process.

You may also contact the Legislative Unit for more information on PHIA or for clarification on any issues outlined in this document. More information on PHIA, brief summaries and a frequently asked questions section (FAQ) are available on the Manitoba Health, Seniors and Active Living web page at <a href="http://www.gov.mb.ca/health/phia/index.html">http://www.gov.mb.ca/health/phia/index.html</a>.

# 3.3 Your Confidentiality

The Minister of Health, Seniors and Active Living is consulting with the public as part of the legislative review required by The Personal Health Information Act. Any personal information, including health information, you provide as part of this consultation is collected in accordance with and subject to The Freedom of Information and Protection of Privacy Act and The Personal Health Information Act.

Any information you provide will be used to assist in carrying out the review, evaluating The Personal Health Information Act and developing possible amendments. This may involve disclosing your comments to other review participants, institutions and interested parties, during and after the review process, through various means, including written reports and the Internet. In addition, following the completion of the review, copies of all submissions received for the purpose of the review will be made available to the public at the Legislative Library.

If you submit any information for the purposes of this review as a private citizen, your identifying information will be removed from your submission before it is made public in the Legislative Library. In addition, your personal identity (including your name) will not be shared without your consent with other review participants, institutions and interested parties during or after the review, though you may be contacted by a government representative for clarification on your submission.

However, please be aware that the identity of an organization, and the name of any individual that submits any information for the purposes of this review on behalf of an organization, will be made public at the Legislative Library and may be disclosed to other review participants, institutions and interested parties during and after the review process.

If you have any questions about the collection, use or disclosure of your personal information and personal health information, please contact the Legislative Unit using the contact information provided in section 3.2.

# **Appendix A: Concepts and Terminology**

This appendix has been developed to help readers understand concepts and terms that appear in PHIA and throughout this document.

**ACCESS** – an individual's right to examine, receive a copy of or request a correction to recorded personal health information maintained by a trustee.

The right of access extends only to the person the information is about or that person's representative. Providing personal health information to any other third party is considered a disclosure (see below).

**CONFIDENTIALITY** – a trustee's obligation to maintain the confidentiality of personal health information by protecting it from unauthorized retention, use and disclosure.

**DISCLOSURE/DISCLOSE** – the act of making personal health information available to any person, other than the person the information is about, who is not an employee or agent of the trustee organization.

#### **INFORMATION PRIVACY**

See Privacy.

**PERSONAL HEALTH INFORMATION** – according to PHIA, this means recorded information about an identifiable individual that relates to:

- the individual's health, or health care history, including genetic information about the individual
- the provision of health care to the individual

 payment for health care provided to the individual and includes

- the Personal Health Identification Number (PHIN) or any other identifying number, symbol or particular assigned to an individual
- 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

This definition includes even potentially identifiable information – for example, information that may appear unidentifiable, but that may lead to the identification of an individual when combined with other available information.

#### **PERSONAL INFORMATION**

Personal information is defined in FIPPA as recorded information about an identifiable individual, including:

- the individual's name
- the individual's home address, or home telephone, facsimile or email number
- information about the individual's age, sex, sexual orientation, marital or family status
- information about the individual's ancestry, race, colour, nationality, or national or ethnic origin
- information about the individual's religion or creed, or religious belief, association or activity

- personal health information about the individual
- the individual's blood type, fingerprints or other hereditary characteristics
- information about the individual's political belief, association or activity
- information about the individual's education, employment or occupation, or educational, employment or occupational history
- information about the individual's source of income or financial circumstances, activities or history
- information about the individual's criminal history, including regulatory offences
- the individual's own personal views or opinions, except if they are about another person
- the views or opinions expressed about the individual by another person
- an identifying number, symbol or other particular assigned to the individual

**PRIVACY** – the right of individuals to be assured their personal health information will be protected from unauthorized collection, use, retention, disclosure and destruction when maintained by a trustee.

**RECORD/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 or any mechanism that produces records.

**TRUSTEE** – means a health professional, health care facility, public body or health services agency that collects or maintains personal health information.

This definition includes:

- health professionals licensed or registered under a provincial act or designated in the Personal Health Information Regulation
- health facilities such as hospitals, medical clinics, personal care homes and laboratories
- health services agencies that provide health care, such as community or home-based health care, pursuant to an agreement with another trustee
- public bodies such as provincial government departments and agencies, regional health authorities, municipalities and educational bodies

**USE** – treatment, handling and sharing of personal health information within a trustee organization. This may include internal analysis, processing, reproduction, transmission and transportation of personal health information.