A Review of

The Personal Health Information Act

TELL US WHAT YOU THINK

Manitoba

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Message from the Minister

As Minister of Health, it is my pleasure to launch this discussion document on *The Personal Health Information Act* (PHIA). This law touches on issues that are important to all Manitobans. It protects our right to access our own health information and our right to be assured of privacy when public bodies and health care providers collect and store health information about us. By upholding these rights, PHIA contributes to an environment of respect for all citizens who seek public services and health care in this province.

The purpose of this review is to ensure that these rights continue to be applied in the most appropriate manner. The review could not take place without input from the public and from those who operate under the requirements of PHIA on a daily basis. If changes are necessary to balance the interests of patients and protectors of rights, let us know. Your comments will assist us in ensuring that Manitoba's health information legislation continues to serve as a model throughout Canada and the world.

Thank you for your interest and your input.

Dave Chomiak
Minister of Health

Introduction

The Personal Health Information Act (PHIA) became law on December 11, 1997. It protects Manitobans' rights to access their own personal health information and to have that information protected from inappropriate collection, use, disclosure, retention and destruction.

PHIA aims to strike a balance between individual rights and other competing interests and recognizes that this balance may periodically need to be reassessed. The legislation requires that the Minister of Health launch a public review of PHIA to ensure that the act continues to meet its objectives.

This document has been prepared as part of the review process and is intended to stimulate interest and launch public debate. It takes readers through the history of PHIA, the principles upon which the law was founded, its current provisions and some possibilities for 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 feedback on any issue regarding access to, and privacy of personal health information in Manitoba is encouraged.

The government has an ongoing commitment to access and privacy rights. Comments provided by health information trustees and members of the public during this review process will assist in refining the act and ensuring that it continues to serve the interests of the public and the needs of the health system.

Part 1

1.1 Personal Health Information Legislation in Manitoba

Few things are as private and sensitive as information about our health. Recognizing this, the Manitoba government enacted *The Personal Health Information Act* – often referred to as PHIA – in 1997. Based on a set of internationally accepted fair information standards, PHIA was the first Canadian law to apply these standards to health care and personal health information.

PHIA acknowledges that, barring a few 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. 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 *The Freedom of Information and Protection of Privacy Act* (FIPPA) are the key components of Manitoba's access and privacy legislative framework. These two acts were drafted simultaneously to ensure consistency in the application of access and privacy principles across Manitoba. The acts share a similar philosophy, purpose and structure.

PHIA and FIPPA differ from one another mainly in scope. PHIA deals exclusively with access to and privacy of personal health information. FIPPA deals with access to, and privacy of, personal information (other than health information) as well as access to 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 Access and Privacy Legislation in Canada

Both PHIA and FIPPA were developed as part of an international trend towards data protection and individual control of personal information. In 1980, fuelled partly by concerns about the data collection, storage, processing and dissemination capabilities of new information and communication technologies, the Organisation for Economic Co-operation and Development (OECD) adopted a set of fair information principles to regulate the international flow of personal data. The OECD's *Guidelines for the Protection of Privacy and Transborder Flows of Personal Data* have helped guide the development of international legislative approaches over the past two decades. Canada became a signatory to these guidelines in 1984. The Canadian Standards Association (CSA) built on these principles when it drafted its *Model Code for the Protection of Personal Information* in 1996.

CSA Fair Information Principles

1. Accountability
2. Identifying Purposes
3. Consent
4. Limiting Collection
5. Limiting Use, Disclosure and Retention
6. Accuracy
7. Safeguards
8. Openness
9. Individual Access
10. Challenging Compliance

OECD Fair Information Principles

1. Collection Limitation
2. Data Quality
3. Purpose Specification
4. Use Limitation
5. Security Safeguards
6. Openness
7. Individual Participation
8. Accountability

Beginning with the enactment of the federal *Privacy Act* and the *Access to Information Act* in 1983, every jurisdiction in Canada has now drafted some form of public sector access and privacy legislation that acknowledges either the OECD's or the CSA's fair information principles. The way personal information is handled by some private sector organizations is regulated by the federal government's *Personal Information Protection and Electronic Documents Act* (PIPEDA) which came into full effect on January 1, 2004. PIPEDA applies to the collection, use and disclosure of personal information in the course of commercial activities.

Manitoba is one of only a few provinces with access and privacy legislation that acknowledges the unique qualities and sensitivity of personal health information. Manitoba was the first province to enact such a law when PHIA was proclaimed in 1997. Alberta followed suit with its *Health Information Act*, which came into effect in April of 2001. Saskatchewan's *Health Information Protection Act* became law on September 1, 2003. Some other provinces, like British Columbia, have incorporated obligations to protect the privacy of personal health information into their general access to information and protection of privacy laws.

Although the legislative approaches differ somewhat in scope and application, every jurisdiction in Canada now recognizes by law that individuals have a right to access information about themselves and a right to expect that their personal information will be held "in trust" in a way that preserves their privacy.

1.5 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 these principles 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. The government recognizes that PHIA may need to be revised

so that it continues to adequately address health system requirements and citizen expectations.

This document has been prepared to stimulate discussion that will lead to 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:

http://web2.gov.mb.ca/laws/statutes/ccsm/p033-5e.php

The Personal Health Information Regulation is also available free of charge at:

http://web2.gov.mb.ca/laws/regs/pdf/p335-245.97.pdf

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. The first time words described in Appendix A appear, they are in bold font to help readers recognize important phrases and words used in discussions surrounding PHIA.

Information on making a submission to the PHIA Review Steering Committee 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 may not be the only ones. 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 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 persons and organizations regulated by the act (referred to as **trustees**) and the type of information the act applies to (referred to as **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, including organizations that provide health care, such as community or home-based health care; and
- 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 local municipalities.

Over the past five years, it has been suggested that the definition of trustee be amended to include organizations outside the health care and public sectors, such as private sector employers, professional associations, regulatory bodies, private schools and private insurers. Please note that if the province does not impose privacy obligations on additional groups they may be bound by the access and privacy requirements set out in the federal *Personal Information Protection and Electronic Documents Act* (PIPEDA), if they collect, use or disclose personal health information in the course of commercial activities (see Section 1.4 above).

2.1.2 Personal Health Information

PHIA applies only in instances where 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,
- the health care provided to the individual,
- payment for health care provided to the individual.

What do you think?

2.1.1 (a) Do you feel that the legislation should cover persons, organizations or entities other than those already covered? If so, please describe which ones and the rationale for including them.

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

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

It 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 (ex: name, address, date of birth) that is collected in the course of providing or paying for health care.

While definitions of personal health information set out in other jurisdictions' access and privacy laws are similar, they vary somewhat. For instance, the definition of personal health information in PHIA refers only to recorded information. This refers to information documented, recorded or stored in any form, on any storage medium and by any means. This also includes information that is written, photographed and recorded by any graphic, electronic or mechanical means. Some jurisdictions have expanded their definitions of personal health information to include non-recorded information (ex: information overheard or behaviour observed in a hospital hallway). As a result, these laws apply to any information that has come to someone's attention, but has not been documented in any fashion.

Broadening the definition to include non-recorded information could strengthen individual information privacy rights; however, it also poses some regulatory challenges. For instance, under PHIA, individuals have rights of both **access** and **privacy** to their personal health information. It would be difficult to apply a right of access to information that is not documented or recorded in any way. Another option is to create specific confidentiality obligations about non-recorded personal health information in the act.

It should be noted that the **confidentiality** of non-recorded personal health information is currently protected in Manitoba's health care sector by professional practice guidelines and institutional policies and procedures.

Another variation in definitions of personal health information involves separating demographic information (such as name, gender and date of birth) from diagnostic, treatment and care information. PHIA currently applies one set of rules to all personal health information, whether it is demographic or indicative of health status. Modifying the definition of personal health information to distinguish between demographic information and diagnostic, treatment and care acknowledges differing levels of sensitivity. This would allow for the creation of more flexible rules for the disclosure of demographic information without affecting more sensitive personal health information. An amendment like this may support the efficiency of the health system by enabling people to verify a patient's mailing address or check on a person's eligibility for health care coverage.

2.1.3 Non-Application of the Act

PHIA does not apply to certain types of information including anonymous or statistical health information that does not either by itself, or when combined with other available information identify individuals. This section builds on the definition of personal health information and stresses that PHIA applies only where the information can reasonably be linked to a specific person.

Other exemptions to the application of PHIA may deserve consideration. For instance, PHIA does not have a specific timeframe 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 *Health Information Protection Act*, by exempting personal health information about an individual who has been dead for more than 30 years and records that are more than 120 years old. The federal *Personal Information Protection and Electronic Documents Act* (PIPEDA) allows disclosure of personal information if the record is over 100 years old or the individual the information is about has been dead for 20 years, whichever is earlier. This issue is also addressed in Manitoba's *Freedom of Information and Protection of Privacy Act* (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?

2.1.2 (a) Do you feel that the current definition of personal health information is appropriate?

2.1.2 (b) Would you like to see privacy protections expanded to include non-recorded information, or is such information best protected by professional practice guidelines and institutional policies and procedures?

2.1.2 (c) Would you like to see the definition of personal health information changed to note the difference between demographic information and diagnostic, treatment and care information? If so, should PHIA set out separate rules for the two classes of information that recognize the differing levels of sensitivity?

2.1.2 (d) Do you have any other comments on the definition of personal health information?

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 a correction to his or her own recorded personal health information. The act recognizes that individuals may require access to information about themselves to make informed decisions about their health and health care. Access rights also allow individuals to challenge the accuracy of information recorded about themselves.

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

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 2.1.3 (a), what is an appropriate period after which personal health information could be released?

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

personal health information maintained by a trustee. These rights are set out in sections 5 to 9 of the act. Currently in Manitoba, the majority of personal health information is not stored in a central repository of health records or on a provincial health information network. Therefore, individuals must submit requests for access directly to the trustee that maintains the information.

Trustees must help people exercise their rights of access and provide an explanation of any terms, codes or abbreviations used in the records that individuals may not understand. Trustees are required to respond to all requests for access within 30 calendar days.

The general access provisions in PHIA seem to have been fairly well received by both trustees and the public. Questions have been raised about the 30-day time limit. Some members of the public feel that waiting up to 30 days for copies of medical records is unacceptable, particularly when the records are required for a health care purpose. On the other hand, some trustees have expressed difficulty in meeting this deadline and would like the ability to extend it where they can demonstrate just cause. Examples of this might be a situation where the individual has not provided enough details to enable the trustee to identify the records being requested or where the knowledgeable individual responsible for reviewing the record before release, is unavailable for a period of time.

2.2.2 Fees

PHIA allows for reasonable fees to provide individuals with access to their personal health information. These fees may include costs associated with making the information available for viewing or providing copies of the information. These fees can't be more than allowed by the regulations; however, there is currently no regulation limiting the amount trustees may charge. Trustees must be able to justify the fee as reasonable given the costs associated with reproducing and/or preparing the records.

One option that has been proposed is to enact a regulatory provision creating the following maximum fees for requests for access under PHIA:

- an examination cost of $60 or actual cost, whichever is less,
- a copying fee of $0.50 per page for photocopying and computer printouts, and $0.75 per page for microform, or actual cost, whichever is less,
- the actual cost of reproduction for all other media.

2.2.3 Exceptions to Access

PHIA does set out circumstances where a trustee may not allow an individual to examine, or obtain a copy of, his or her personal health information. These exceptions to the right of access are set out in subsection 11 (1) of the act, and include:

- where knowledge of the information could reasonably be expected to endanger the mental or 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 disclosure,
- where providing access could identify a third party, other than another trustee, who supplied information in confidence,

What do you think?

2.2.1 (a) Are the general access provisions set out in sections 5 to 9 of PHIA reasonable?

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

2.2.1 (c) Is the current 30-day time limit for responding to requests for access acceptable? If not, what would be a reasonable time limit?

2.2.1 (d) Should trustees be permitted to extend the time limit under certain defined circumstances? If so, under what circumstances?

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

2.2.1 (f) Do you have any other comments on PHIA's general access provisions?

- 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; or
- where the information was compiled for 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.

What do you think?

2.2.2 (a) Should the Personal Health Information Regulation set out the maximum fees a trustee may charge for granting access to personal health information?

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

2.2.2 (c) Should trustees be required to consider an individual's ability to pay when charging administrative fees for access to personal health information?

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

2.2.4 Correction of Personal Health Information

To ensure the accuracy and completeness of personal health information, PHIA provides the right to request a correction to your recorded personal health information. The trustee must either make the correction, or if the trustee disagrees with the request, attach your statement of disagreement to the file. This provision recognizes that there may be cases where it is inappropriate for the trustee to comply with an individual's request for correction – particularly where the recorded information was based on the professional opinion of a health provider.

The right to request a correction under PHIA has implications for a trustee's duty to ensure the accuracy of information. There may be circumstances where a trustee believes that complying with a request for correction would result in a record of inaccurate information. In these cases, the trustee could attach a statement of disagreement to the record instead of changing the record as requested.

What do you think?

2.2.3 (a) Are the exceptions to access set out in subsection 11 (1) of PHIA reasonable?

2.2.3 (b) If not, how should they be modified?

2.2.3 (c) Should trustees be allowed to refuse access if requests are repetitive or incomprehensible?

2.2.3 (d) Do you have any other comments regarding exceptions to the right of access under PHIA?

What do you think?

2.2.4 (a) Are the rules guiding corrections of records clear and reasonable?

2.2.4 (b) Do you feel that PHIA should more clearly define the circumstances in which a trustee must make a requested correction; and those where, based on professional opinion, the trustee could choose not to? Please explain.

2.2.4 (c) 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 competing 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 (ex: 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, and
- 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 gather and the way information is treated while it is held.

Some jurisdictions have strengthened this limitation by applying what is often referred to as "the reasonable person test" on top of other limitations on collection, use and disclosure. For instance, subsection 5(3) of the federal *Personal Information Protection and Electronic Documents Act* (PIPEDA) requires collections, uses and disclosures to be authorized and limited to *purposes that a reasonable person would consider are appropriate in the circumstances*. This formally acknowledges that

legitimate purposes for the collection, use and disclosure of information are sometimes best defined objectively by the average, reasonable citizen, not subjectively by the trustee. This places a greater onus on trustees to be able to justify their information practices. It should be noted that the reasonable person test could only be applied in cases where collection, use and disclosure is discretionary (not mandatory under law).

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 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 citizens to exercise control over their own information and challenge a trustee's collection practices.

2.3.3 Indirect Collection of Personal Health Information

Section 14 of PHIA requires a trustee to collect information directly from the person the information is about unless:

- the individual has authorized another method of collection,
- collection of the information directly from the individual could reasonably be expected to endanger the mental or physical health or safety of the individual or another person,
- collection of the information is in the individual's interest, and time or circumstances do not permit collection directly from the individual,
- collection of the information directly from the individual could reasonably be expected to result in inaccurate information being collected, and
- another method of collection is authorized or required by a court order or a law of the governments of Manitoba or Canada.

These provisions ensure that individuals remain in control of their own information, where possible, by giving them the ability to choose what information to share and what to withhold. In addition, they assist in preventing accidental and unauthorized disclosures, which can occur when information is collected indirectly from a third party. However, these provisions also recognize that in some circumstances it is appropriate, and in the best interest of the individual, for information to be collected from a third party (for example, if the individual is unable to provide his or her own information due to illness).

The requirement to collect personal health information directly from the individual has raised issues for physicians and other health care professionals who collect information from individuals on their family health histories. The collection of family histories may be necessary to provide health

What do you think?

2.3.1 (a) Do the general limitations in sections 13, 14 and 20 of 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) Should these provisions be amended to require that trustees consider the reasonable person test when determining whether to make a discretionary collection, use or disclosure?

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

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) From a trustee's perspective, 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?

What do you think?

2.3.3 (a) Does the current obligation to collect personal health information directly from the individual, except as otherwise authorized, strike an appropriate balance between an individual's right to privacy and the occasional need for indirect collection?

2.3.3 (b) Should section 14 of PHIA be amended to clarify that trustees are permitted to collect information from a person about his or her family health history without the consent of family members, where necessary to provide health care to that person?

2.3.3 (c) Do you have any other comments on the provisions respecting indirect collection of personal health information?

care, yet it means the indirect collection of personal health information about family members without their knowledge and/or consent. This raises questions about the family members' right to privacy. Saskatchewan has addressed this issue in subsection 25(2) of its *Health Information Protection Act* by expressly authorizing indirect collection of personal health information about a person's family members to gather that person's family health history.

2.3.4 Elements of Consent

PHIA takes the position that personal health information should only be used or disclosed with consent, except in limited circumstances outlined in the act. Individual consent is central to our ability to control information about ourselves.

PHIA does not currently set out the elements of consent. It has been suggested that the elements of an appropriate consent should be outlined in PHIA as follows:

Where consent is obtained in writing, the document will:

- be dated and signed,
- include the trustee's name,
- include the name of the person or organization that will use the information or to whom it will be disclosed,
- include a description of the specific information to be used or disclosed and the purpose for the use or disclosure,
- include the date or event upon which the consent expires, if any, and
- include a statement that consent can be changed or withdrawn at any time before it expires.

Where consent is obtained verbally, the trustee will:

- confirm the identity of the person giving the consent, and
- document the consent in the record that the trustee maintains about that person.

What do you think?

2.3.4 (a) Would the proposed consent requirements assist individuals in exercising control of their personal health information?

2.3.4 (b) Could the proposed consent requirements be improved? If so, how?

2.3.4 (c) From a trustee's perspective, would there be any operational difficulties in complying with the proposed consent requirements?

2.3.4 (d) Do you have any other comments regarding consent to the use and disclosure of personal health information?

2.3.5 Use Without Consent

PHIA allows trustees to use personal health information for the purpose the information was collected. Some additional uses are permitted without consent such as to monitor or evaluate a health service or to plan for future programs that relate to health care delivery. More examples of secondary uses that are allowed without consent are in section 21 of PHIA.

Section 21 acknowledges the need to balance information privacy against other compelling interests, such as safety and health system administration.

2.3.6 Disclosure Without Consent

PHIA outlines when a trustee may disclose personal health information without consent. In some circumstances, it is assumed that the public would not generally object to the disclosure. In others, it is assumed that the benefit of the disclosure clearly outweighs the intrusion into personal privacy.

Some examples of permitted disclosures without consent are:

- to another person providing health care to the individual;

What do you think?

2.3.5 (a) Is it reasonable and appropriate for trustees to use personal health information without consent for the purposes described in section 21 of the act?

2.3.5 (b) Should this section be expanded, restricted or modified in any way?

2.3.5 (c) Do you have any other comments regarding the use of personal health information without consent?

- to obtain payment for publicly funded health care services;
- to lessen or prevent a serious and immediate threat to someone;
- to notify family if someone has been injured;
- to family and close friends when a person is a patient in a health facility, as long as the disclosure is only about care currently being provided and the facility has reason to believe the patient wouldn't object;
- to a person conducting a health research study, if a designated committee has evaluated the study against specific criteria; and
- where the court or another law requires the disclosure, for example, *The Public Health Act* requires reporting of certain diseases, and *The Child and Family Services Act* requires reporting where a minor may be in need of protection.

Please consult the act directly for a complete listing of permitted disclosures without consent. These appear in sections 22, 23, 24, and 25 of PHIA.

What do you think?

2.3.6 (a) Is it reasonable and appropriate for trustees to disclose personal health information without consent for the purposes described in sections 22, 23, 24 and 25 of PHIA? Please explain.

2.3.6 (b) Do you feel that these non-consensual disclosures should be restricted in any way? If so, please describe how.

2.3.6 (c) Do you have any other general comments regarding the disclosure of personal health information without consent?

For example:
Laboratory X has analyzed a sample of tissue taken from a lump in one of hospital Y's patients. The result of the laboratory's analysis indicates that the lump is benign. Surgeons at the hospital later operate on the patient. The laboratory would like confirmation from the hospital that its test produced accurate results (i.e., the lump is indeed benign). Currently, PHIA would require the patient's consent before hospital Y could disclose the information to laboratory X.

2.3.7 Expanding the Disclosure Provisions

Although obtaining consent for disclosures is the preferred option from an information privacy perspective, getting that consent is not always possible. Over the past five years, there have been several suggestions for additions to the list of authorized disclosures without consent. These are explored below.

Disclosure for Quality Assurance

Concerns have been expressed that information necessary to evaluate health services is difficult to obtain under PHIA's current provisions if another trustee maintains that information. Some trustees, that is health care providers and hospitals have suggested that exceptions to non-disclosure be expanded to allow the sharing of information between trustees to monitor, evaluate and ultimately improve the quality of services.

Disclosure to Report Suspected Criminal Activity

Some law enforcement agencies have suggested that measures protecting the privacy of personal health information are overly restrictive and do not adequately permit law enforcement officers to obtain information, in a timely manner, for criminal investigations.

PHIA allows trustees to disclose personal health information to law enforcement agencies with the consent of the individual, 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 the prosecution of an offence.
- The disclosure is made pursuant to a court order, warrant or subpoena.

What do you think?

2.3.7 (a) Should a trustee be permitted to disclose personal health information without consent so that another trustee can evaluate and monitor the quality of its services? If not, why not? If so, why and under what circumstances?

- The officers have been designated as investigators by the Chief Medical Examiner and are seeking information for the purpose of an investigation under *The Fatality Inquiries Act*.
- The disclosure is required by another law of the governments of Manitoba or Canada.

It should be noted that where another law requires a trustee to report suspected abuse of vulnerable persons, such as *The Child and Family Services Act* or *The Vulnerable Persons Living with a Mental Disability Act*, PHIA allows the report to be made without obtaining consent.

Despite the provisions listed above, some law enforcement agencies have asked that PHIA be amended to allow for additional non-consensual disclosures. In particular, they suggest PHIA permit health care providers to disclose personal health information without consent to report suspected criminal activity.

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

What do you think?

2.3.7 (b) Should trustees be permitted to disclose personal health information to law enforcement agencies without consent to assist criminal investigations? If not, why not? If so, why, and under what circumstances?

2.3.7 (c) If you answered yes to 2.3.7 (b), should disclosure without consent or other authority (such as a warrant) be limited to certain kinds of information?

For example:
Ms A arrives at an emergency department with what appears to be a knife wound. Dr. B treats Ms A and is concerned that the wound may have been caused during an assault. She asks Ms A if she can contact the police. Ms A states that the wound is the result of a kitchen accident and 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 Ms 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 Ms A or to someone else.

Disclosure to Family and Close Friends

As discussed in 2.3.6, section 23 of PHIA allows the non-consensual disclosure of some personal health information to family members or other people an individual has a close personal relationship with when the individual is receiving services in a health care facility. However, this does not apply when the individual is receiving services in a community-based setting.

In recent years, health services traditionally provided in hospitals or personal care homes are increasingly being provided within community settings. Some examples are midwifery, home care and palliative care in the home. The availability of these services helps ensure that individuals can remain in their homes while receiving necessary treatment and care. This increased emphasis on community-based services, however, has raised questions about whether section 23 of PHIA should be expanded to allow for the disclosure of some personal health information without consent to family members and other people with close relationships when care is being provided in the community.

It should be noted that where a family member, or other person with a close relationship to the individual, is an authorized representative under section 60 of PHIA (discussed in section 2.5.1 of this document), he or she currently has access to the individual's personal health information, no matter what service or where the service is being provided.

For example:
Mrs. Smith is an elderly woman who receives the services of a home care nurse five times a week. Mrs. Smith sometimes has difficulty understanding the nature and purpose of the treatments she receives. Explaining these to her family is also a challenge. Mrs. Smith's daughter, interested in her mother's well-being, phones the home care case co-ordinator for more information on her mother's care. Currently, the home care case co-ordinator cannot provide Mrs. Smith's daughter with information without Mrs. Smith's consent.

What do you think?

2.3.7 (d) Should trustees be permitted to disclose personal health information, without consent, to family members and other persons with close relationships to individuals receiving health care in the community? If not, why not? If so, why and under what circumstances?

Disclosure of Patient Lists to Clergy and Religious Visitors

Prior to PHIA, it was common for health care facilities to provide patient lists to members of the clergy and religious visitors from various faith communities. These spiritual care providers would scan the lists to identify whether any members of their congregation or faith community had been admitted. If so, they would visit those individuals.

Recently, facilities have begun to re-think the practice of providing complete patient lists without the consent of the individuals on those lists. These lists would reveal personal health information about more individuals than necessary since, in most cases, many of the people on the lists would not be members of the congregation or faith community in question. There is also concern that these lists could include more personal health information about the individuals than is necessary for the clergy member or religious visitor to have. PHIA requires that only the minimum amount of information necessary be disclosed for a specific purpose. Information on specific health care conditions is not necessary to identify members of a particular congregation or faith community.

Most hospitals and personal care homes are in the process of seeking consent from individuals before their personal health information is included on patient lists and disclosed to community clergy and religious visitors. Representatives of congregations and faith communities are also encouraged to seek information directly from their members and members' families, instead of indirectly from facilities. The goal is to ensure patients and residents

can receive support from their faith communities, while remaining in control of their own information and able to exercise their right of information privacy.

Representatives of some faith organizations are concerned that the consent requirement may affect their ability to identify individuals in need of their support or services. They have asked that PHIA be amended to allow facilities to **disclose** patient lists without consent, much as they did prior to the enactment of PHIA.

For example:
Charlotte is a well-respected member of the clergy in a small Manitoba community. The local health centre is not large enough to employ a professional chaplain, so it relies on Charlotte, other clergy members, and religious visitors from the community to provide spiritual care services to the patients in the facility. Prior to the enactment of PHIA, Charlotte would have been provided with a list of all individuals admitted to the facility. She would then have reviewed the list to decide who to visit depending on factors like patient health status and faith association. Individuals were not normally asked if they wished to have a visit from Charlotte. Under PHIA, Charlotte can no longer access complete patient lists without consent. Instead, patients are asked, upon admission, whether they would like to be visited by a member of the community clergy. If they consent, their name and location in the facility are made available to Charlotte or one of her colleagues.

What do you think?

2.3.7 (e) Should trustees be permitted to disclose patient lists to clergy and religious visitors from the community without the consent of the individuals whose information appears on the lists? If not, why not? If so, why and under what circumstances?

2.3.8 Registries of Personal Health Information

In recent years, the accessibility and efficiency of information technology has resulted in more registries of personal health information being created by both trustees and non-trustees. Registries are lists of individuals, often maintained electronically, which generally contain demographic information about people on the list. This demographic information might include name and date of birth, and other registry-specific information, such as a health condition common to everyone on the list. Registries are sometimes referred to as databases.

In many cases, these lists are created to provide health care and/or support health system administration. An example of a registry used for direct patient care is the Manitoba Cervical Cancer Screening Program Registry. It tracks Pap smear tests, facilitating necessary intervention and regular testing. An example of a registry used for health system administration is the Manitoba Health Registration Database, which contains a listing of all persons eligible for coverage under the Manitoba Health Services Insurance Plan. As these registries are established and maintained by trustees, the confidentiality and security of the information within them is protected by PHIA.

In other cases, registries of personal health information are created for other reasons that do not involve direct health care delivery and administration. For example, a researcher may seek to establish a database to support ongoing research initiatives, or a manufacturer of medical implant devices may wish to establish a registry of device recipients and their addresses in case of a product recall. There may be benefits to such registries, but their creation raises issues about health information privacy.

One issue is whether trustees should obtain consent from individuals before disclosing personal health information to third parties establishing registries for purposes other than direct health care delivery and administration. Some feel that consent is essential; others feel it's reasonable for trustees to disclose personal health information without consent to certain classes of registries or registries approved by an authorized review committee, such as the provincial **Health Information Privacy Committee**.

Another issue involves protecting personal health information when registries are created and maintained by non-trustees. In such cases, PHIA may play an indirect role in regulating the collection, use, retention and disclosure of the information maintained in these registries, if the information was obtained from a trustee. For instance, when a trustee discloses personal health information for health research purposes, there must be a written agreement with the researcher setting out limits on retention, use and disclosure. Where the registry involves the collection, use or disclosure of personal health information for a commercial purpose, the privacy rules outlined in the federal *Personal Information Protection and Electronic Documents Act* may apply. Nevertheless, some people feel that additional legislative safeguards should be considered to ensure that lists of personal health information, no matter what their purpose, are created and maintained in a manner that reinforces personal health information privacy.

2.3.9 Protection of Genetic Information

Genetic information is information obtained from DNA, gene product analysis or family histories, used to predict susceptibility to illness, disease, impairment or other mental or physical health disorders. PHIA currently provides the same protections for genetic information as it does for other personal health information. Yet, this information has special characteristics, such as its ability to reveal information about an individual's future health status, and the health status of past, present and future family members. As a result, it has been suggested that PHIA be amended to include stronger provisions to protect the privacy of genetic information.

No health information access and privacy law in Canada provides protection for genetic information over and above the protections applied to personal health information generally. The Province of Ontario had proposed to do so in a draft *Privacy of Personal Information Act*. The draft required express consent for the collection, use and disclosure of genetic information, as opposed to implied consent. It also proposed that consent for the collection, use or disclosure of genetic information, be specific to genetic information and separate from any consent given for the collection, use or disclosure of any other kind of personal health information. Finally, it proposed that organizations keep genetic information separate from all other personal health information, where possible. The draft legislation was never enacted.

Other options for protecting the confidentiality of genetic information could include more limitations on data matching and requiring that information be anonymous in specific circumstances. Other

What do you think?

2.3.8 (a) Should PHIA be amended to specifically address the unique issues raised by the creation and maintenance of non-clinical/administrative registries? If so, how should PHIA address these registries? If not, why not?

2.3.8 (b) Should trustees be permitted to disclose personal health information to non-clinical/administrative registries without consent? If so, under what circumstances? If not, why not?

2.3.8 (c) Do you have any other comments regarding the creation and maintenance of personal health information in registries?

approaches could include setting out unique requirements for disclosure for research and special restrictions on disclosure without consent. It might also be helpful for PHIA to address circumstances where genetic information can be disclosed to descendants of deceased individuals.

2.3.10 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 datasets 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 end up identifying individuals.

As the data processing capabilities of new information technologies continue to evolve, imposing targeted and specific restrictions on data matching may be necessary to maintain an individual's right to privacy. Restrictions will have to consider the benefits of data matching to health care, health research and epidemiological investigation.

What do you think?

2.3.9 (a) Should PHIA include special requirements to protect the confidentiality of genetic information? If so, what requirements would you suggest? If not, why not?

2.3.9 (b) Should PHIA include special rules about consent for the collection, use and disclosure of genetic information? If so, what rules would you suggest? If not, why not?

2.3.9 (c) Do you have any other comments on the protection of genetic information under PHIA?

2.3.11 Privacy Impact Assessments

As threats to information privacy arise, public expectations and legislative requirements continue to evolve. Privacy impact assessments (PIAs) are tools that can help organizations ensure that their programs, services and systems meet the privacy standards expected by the public and required by legislation. PIAs are analytical tools that assist in assessing and understanding the potential impact of a proposed program, service or system on information privacy. They are normally prepared in the planning stages of an initiative to consider privacy concerns early on and avoid costly modifications where privacy standards are not met.

Some jurisdictions have made the use of PIAs mandatory, either by law or policy. Alberta's *Health Information Act*, for example, requires the preparation of PIAs describing how proposed administrative practices and information systems relating to the collection, use and disclosure of personal health information may affect the privacy of that information. The assessment is provided to the province's Information and Privacy Commissioner (similar to Manitoba's Ombudsman) for review and comment before beginning any new practice or system, or changing an existing practice or system. In April 2002, the federal government announced a government-wide PIA policy making

What do you think?

2.3.10 (a) Should trustees be limited in the ability to perform data matching on personal health information without individual consent? If not, why not? If so, why under what circumstances?

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

2.3.10 (c) Do you have any other comments about data matching using personal health information?

What do you think?

2.3.11 (a) Should PHIA require trustees to complete privacy impact assessments?

2.3.11 (b) If you answered yes to 2.3.11 (a), under what circumstances should privacy impact assessments be mandatory?

2.3.11 (c) Do you have any other comments on privacy impact assessments?

it mandatory for federal departments and agencies to document, publish and maintain PIAs for programs and services that may affect information privacy.

PHIA does not require the completion of PIAs, although it is recognized that some trustees require PIAs by policy. Mandatory PIAs could assist in reducing some of the privacy risks associated with certain information practices, such as the development of registries and data matching. However, their benefits must be weighed against their disadvantages, such as the additional administrative burden to trustees.

2.3.12 Retention and Destruction

Section 17 of PHIA states that a trustee shall establish, and comply with, a written policy concerning the retention and destruction of personal health information. These policies must conform with any requirements set out in the regulations.

Retention policies are important in respecting the rights granted under PHIA. These policies 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. Right now there is no regulation setting out retention timeframes. One option is to retain personal health information for a minimum of seven years, or two years after the individual reaches the age of majority, whichever is later. This provision would create a minimum retention period. Trustees would be free to retain information for longer periods, as is often the current practice.

When destroying personal health information, PHIA requires that trustees keep a record of the personal health information that was destroyed, the time period the information relates to, the method of destruction and the person responsible for supervising the destruction. These requirements ensure that someone will be accountable for destroying information in a way that preserves its confidentiality.

There are no regulatory provisions stating the way trustees must 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?

2.3.12 (a) Do you feel that PHIA should further state how and when personal health information is retained and destroyed?

2.3.12 (b) Do you feel that the proposed minimum retention periods for personal health information and required methods of its destruction are reasonable?

2.3.12 (c) Do you have any other comments about the retention and destruction of personal health information?

2.3.13 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 are things like policies, procedures and employee pledges designed to ensure that the practices necessary to protect personal health information are followed. Physical safeguards are physical barriers, such as locked doors and filing cabinets, that prevent unauthorized access to personal health information. Technical safeguards refer to technical interventions that ensure personal health information is protected when stored or transmitted by 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; and
- ensure that those dealing with the information sign a pledge of confidentiality acknowledging that they are bound by the obligations set out in the policies.

Physical safeguards include:

- maintaining personal health information in designated areas, under appropriate safeguards;
- limiting physical access to those areas;
- taking reasonable steps to protect personal health information from fire, theft, vandalism, deterioration, accidental destruction, loss and other hazards; and
- 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 the trustee acquires or designs, are capable of:

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

2.3.14 Emerging Technologies

Recent innovations in information and communication technologies have dramatically changed the ways information is collected, stored and disseminated in the health care sector. Technology can help address many of today's challenges. Health information networks (HINs) – networks of program-based or regional health information systems – provide new ways of assembling and sharing comprehensive and credible information that can be used for decision-making and health system planning. Information co-ordination through HINs helps health care providers make decisions and protects health care consumers by flagging harmful drug interactions and other potentially dangerous situations. Integrated networks facilitate the creation of electronic health records or

What do you think?

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

2.3.13 (b) Do you feel these requirements should be strengthened, relaxed or modified in any other way?

2.3.13 (c) From a trustee's perspective, are there any operational challenges in complying with these security requirements?

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

"paperless" records of health care information from various points of care. Electronic records are one way to respond to challenges of portability, accessibility, consistency and accuracy of clinical information. Tele-medicine, the delivery of medical services from a distance using advanced technologies, presents new opportunities for health care delivery in remote and under-serviced areas. It has been identified as a way to break down barriers to health care accessibility. The increased use of emerging technologies clearly presents possibilities for addressing the needs of patients, providers and governments.

As we continue to integrate new information and communication technologies into the regular delivery of health care, we must be careful to do so in a way that protects information privacy. PHIA restricts the disclosure of information maintained in, or transmitted by these systems, while also ensuring that information can be accessed for legitimate purposes. Despite these current safeguards, questions remain about the best way to protect the privacy of health information in a world fuelled by technology. This review of PHIA presents the opportunity to re-examine the relationship between technology and health information privacy.

What do you think?

2.3.14 (a) Should PHIA be amended to further clarify rules for the collection, storage and disclosure of personal health information via information and communication technologies? Please explain.

2.3.14 (b) Do you have any other comments on the use of ICTs to collect, store and disclose personal health information?

2.3.15 Health Research

Health research has played a significant role in efforts to provide safe and effective health care services. Health research depends largely on information from human subjects. Preserving the right to information privacy and self-determination requires that confidentiality be maintained. These two compelling social interests can be met without conflict. For instance, when a health researcher requires access to personal health information for a study and individuals have consented to the disclosure of their information, both needs are met harmoniously. Issues may arise such as determining the best way to identify and contact potential research subjects, what constitutes an appropriate informed consent, and how to proceed if contacting potential subjects is impractical or impossible.

The issues affecting health research and information privacy are numerous and varied. They are explored throughout this document in other sections including: 2.1.3 Non-application of the Act; 2.3.1 General Limitations on Collection, Use and Disclosure; 2.3.4 Elements of Consent; 2.3.5 Use Without Consent; 2.3.6 Disclosure Without Consent; 2.3.8 Registries of Personal Health Information; 2.3.9 Protection of Genetic Information; and, 2.3.10 Data Matching. Those with a particular interest in the relationship between PHIA and health research are invited to review this document

and respond to the questions about them, as well as the more general questions below.

It should be noted that research involving human subjects and/or personal health information is normally regulated by independent research guidelines and review bodies, in addition to PHIA. Guidelines, including the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans*, have provisions on privacy, confidentiality and consent that are, in most cases, consistent with the current requirements under PHIA. A university-based research ethics board must also review any university-based health study, and the provincial Health Information Privacy Committee must review studies that involve personal health information held by the government.

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 Office of the Ombudsman. The ombudsman is an independent officer of the Manitoba Legislature.

What do you think?

2.3.15 (a) Do the current provisions of PHIA help ensure that the necessary information is available for health research while individuals' rights to information privacy are also protected?

2.3.15 (b) Do you have any other general comments about the relationship between PHIA and health research?

The ombudsman's general powers and duties are to:

- conduct investigations and audits, and make recommendations to monitor and ensure compliance with PHIA;
- inform the public about PHIA;
- receive comments from the public about matters concerning the confidentiality of personal health information or access to that information;
- comment on the implications of proposed legislation, programs or practices of trustees for access to, or confidentiality of, personal health information;
- 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;
- consult with any person with experience or expertise in any matter related to PHIA; and
- 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 *The Manitoba Evidence Act* 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 the investigation under PHIA; and
- converse privately with any officer, employee or agent of a trustee.

In the 2000 annual report, the ombudsman addressed the significance of that office's powers and duties:

Our office is of the view that the most effective way to address legislative compliance is not by responding to complaints under The Personal Health Information Act *but by promoting measures that help avoid breaches from occurring, including education of trustees and the public, and by assisting trustees in assessing and monitoring their own health information policies and practices.*

2.4.2 Complaints and Redress

The Manitoba Ombudsman is the body that receives complaints regarding any trustee's information practices and/or breaches of access and privacy rights. The ombudsman's powers and duties under PHIA assist that office in carrying out this mandate.

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:

- where the individual is refused access to examine or receive a copy of the information;
- where 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.

What do you think?

2.4.1 (a) Do you feel 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 Part 4 of PHIA?

Individuals also 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 on his or her own, where circumstances warrant such action.

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

Although the ombudsman cannot compel a trustee to change its 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.

In 2000, the Office of the Ombudsman considered 38 complaints under PHIA. The ombudsman initiated nine of these. The office reports that most of the 38 complaints concerned privacy issues.

The independent review mechanism outlined above is similar in scope and power to the review mechanisms in Saskatchewan, Nova Scotia, Yukon and the Northwest Territories. Quebec, Ontario, Alberta and British Columbia have all established commissioners or commissions with the authority to issue binding orders to public bodies or health information trustees, as the case may be.

2.5 General Provisions

PHIA outlines general provisions and operational details for the administration of the act. Two provisions have been identified as sections that may require revisions.

2.5.1 Exercising the Rights of Another Person

Currently, a person may exercise the rights granted to another individual under PHIA – that is, the right of access and the right to consent to use and disclosure 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; and
- if the individual is deceased, as his or her personal representative (usually interpreted as the executor or administrator of the deceased's estate).

It may be necessary to expand this list to address situations where individuals are clearly incapable of exercising their own information rights but have no legal representative to exercise their rights for them. There is concern that, where there is no one capable of or authorized to make decisions on a person's behalf, a trustee's ability to provide services may be compromised.

One suggestion is to expand the list of persons authorized to exercise another person's information rights, and include people with power of attorney or people with whom an individual has a close personal relationship, such as spouses, common-law partners or adult children. These persons would be granted the ability to make decisions on another individual's behalf where the individual is clearly incompetent, no other legal representative exists, and the trustee believes the person is acting solely in the best interests of the individual.

What do you think?

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

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

What do you think?

2.5.1 (a) Should PHIA be amended to allow people with power of attorney, or other people with whom an individual has a close personal relationship, to exercise the individual's rights under PHIA? If not, why not? If so, why and under what circumstances?

2.5.1 (b) Should PHIA establish a hierarchy of representatives to address situations where there may be multiple representatives for one individual?

2.5.1 (c) Do you have any other comments about the ability of one person to exercise another individual's informational rights under PHIA?

What do you think?

2.5.2 (a) Are the list of offences set out in subsections 63(1) and 63(3) of PHIA appropriate and adequately extensive to ensure the protection of personal health information?

2.5.2 (b) Is the maximum penalty appropriate to the severity of offences under PHIA?

2.5.2 (c) Do you have any other comments regarding offences and fines under PHIA?

2.5.2 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) and 63(3) of PHIA.

PHIA sends a strong message that any activity that contravenes the act is unacceptable. It also recognizes trustees should not be held liable in cases where they took reasonable steps to ensure compliance. PHIA provides protection from liability and states that no action or proceeding may be brought against the government or a trustee for damages resulting from the use or disclosure of personal health information where the government or trustee reasonably believed that the use or disclosure was authorized under PHIA. The act provides protection from prosecution and states that no trustee or information manager shall be found to have collected, used, sold, disclosed or failed to adequately protect personal health information if the trustee or information manager can show reasonable steps to prevent the contravention.

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 and that the trustee did not take reasonable steps to prevent it, the matter may be referred to the Crown for prosecution. Upon conviction, the maximum penalty for a breach of PHIA is $50,000 for each day the contravention continues.

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 thoughts 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's PHIA Review Web site. **You may submit your comments electronically by visiting that site at www.gov.mb.ca/health/phia/review.html**. Written submissions and questions may be forwarded to the PHIA Review Steering Committee at:

Main Floor, 300 Carlton Street
Winnipeg, MB R3B 3M9
Fax: (204) 945-1020
E-mail: phiareview@gov.mb.ca
Phone: (204) 786-7108 or
toll-free in Manitoba 1-866-366-9443

Please submit your comments and suggestions by no later than **April 2, 2004**.

This will ensure that your feedback can be considered as part of the legislative review process.

Public hearings on PHIA will be held in 2004. For information about the hearings, please call one of the numbers listed above.

You may also contact the steering committee for more information on PHIA or for clarification on any issues outlined in this document. Additional information on PHIA, including brief summaries and frequently asked questions (FAQs), is also available on the Manitoba Health Web site at www.gov.mb.ca/health/phia/index.html.

3.3 Your Confidentiality

The Minister of Health is consulting with the public as part of the legislative review required by *The Personal Health Information Act* (PHIA). Any personal information, and personal health information, you provide as part of this consultation is subject to *The Freedom of Information and Protection of Privacy Act* and *The Personal Health Information Act*. The information you provide will only 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. **Your personal identity (including your name) will not be disclosed without your consent.** However, please be aware that the identity of an organization may be made public in connection with its submission or comments.

You may be contacted by a government representative or the PHIA Review Steering Committee for clarification on your submission, or to provide you with feedback on your comments. Your name will not be placed on any mailing lists that are not related to the review.

If you have any questions about the collection, use or disclosure of your personal information and personal health information, please contact the PHIA Review Steering Committee using the contact information provided in Section 3.2.

Appendices

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. Terms defined in law appear below in italics.

Access - an individual's right to examine or receive a copy of his/her recorded personal health information from a trustee.

The right of access extends only to the individual the information is about or his/her representative. Providing personal health information to any other third party is referred to as a "disclosure" (see below).

Confidentiality - a trustee's obligation to maintain the secrecy of personal health information by protecting it from unauthorized or inappropriate retention, use and disclosure.

Disclosure / Disclose - the act of making personal health information available to a person who is not an employee or agent of the trustee organization.

Information Privacy - See Privacy.

Health Information Privacy Committee - a provincial committee, established under section 59 of PHIA, able to approve disclosures of personal health information for health research purposes, (under section 24 of PHIA) when that information is maintained by a provincial government department or agency.

Additional information on the committee is available at www.gov.mb.ca/health/hipc/index.html.

Personal Health Information - 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.*

This information 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 e-mail 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 - an individual's right to be assured that his/her personal health information will be protected from unauthorized and inappropriate collection, use, retention, disclosure and destruction when maintained by a trustee.

It is often said that the right of privacy drives the duty of confidentiality.

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; and public bodies such as provincial government departments and agencies, regional health authorities, municipalities and educational bodies.

Use - the treatment, handling and/or sharing of personal health information within a trustee organization.

This may include internal analysis, processing, reproduction, transmission or transportation of personal health information.

Appendix B:
List of Abbreviations

CSA: The Canadian Standards Association

FIPPA: *The Freedom of Information and Protection of Privacy Act* (Manitoba)

HIN: Health Information Network

ICT: Information and Communication Technology

PHIA: *The Personal Health Information Act* (Manitoba)

PHIN: The Personal Health Identification Number

PIA: Privacy Impact Assessment

PIPEDA: *The Personal Information Protection and Electronic Documents Act* (Canada)

OECD: The Organisation for Economic Co-operation and Development

Your views are important. Public hearings will be held in Manitoba this year. For information about the public hearings or any other matter related to this review, please contact:

PHIA Review
Telephone: (204) 786-7108
Toll Free: 1-866-366-9443 (MB)

Website: www.gov.mb.ca/health/phia/review.html
E-mail: phiareview@gov.mb.ca