

The Personal Health Information Act

A Brief Summary for

HEALTH RESEARCHERS

INTRODUCTION

The Personal Health Information Act (PHIA) regulates the collection, use, disclosure, security and destruction of “personal health information” by “trustees.” It has important implications for health researchers.

This brief summary is intended to give you as a health researcher some idea of your responsibilities under the Act. It is not comprehensive. For a better understanding, you should review the actual legislation and its regulations. Copies are available from Statutory Publications, 200 Vaughan St., Winnipeg, MB R3C 1T5, phone 945-3101. To help you, this summary refers to specific sections in the Act.

What is “personal health information”?

Personal health information is any information that:

- is recorded in any form;
- can be linked to an identifiable individual; and
- relates to an individual’s health, health history, genetic makeup, health care, personal health identification number (PHIN) or other identifying information collected in the course of providing health care. *See s. 1(1) of the Act.*

It is important for researchers to note that PHIA only applies to health information that can be connected to a particular individual either on its

own or when combined with other available information. The Act does not apply to health information that is about anonymous individuals who cannot be identified.

What is a “trustee”?

The Act identifies four categories of trustees:

- health care facilities
- some health professionals
- health services agencies (organizations that provide health care under an agreement with another trustee—the Victorian Order of Nurses and We Care are two examples)
- public bodies (such as provincial government departments and agencies, municipal governments, educational institutions and regional health authorities) *See s. 1(1) of the Act.*

Some of these categories are defined more fully in the regulations.

What are the obligations of a trustee?

A trustee’s obligations fall into two main categories.

1. A duty to assist individuals in gaining access to their own personal health information.
2. A duty to protect the privacy of individuals in the collection, use, disclosure, security, retention and destruction of their personal health information.



ACCESS

What does “access” mean?

The Act puts in statutory form the common law right of an individual to access his or her own personal health information. There are three elements to this right:

1. A right to examine personal health information.
2. A right to obtain a copy of personal health information.
3. A right to seek a correction of personal health information.

PROTECTION OF PRIVACY

What are a trustee’s obligations concerning the protection of an individual’s privacy with respect to personal health information?

The obligations of a trustee as set out in the Act affect the:

- collection
- use
- disclosure
- security
- retention and
- destruction

of personal health information.

What are a trustee’s obligations when collecting personal health information?

A trustee has three main duties when collecting personal health information.

1. To notify the individual of the purpose for the collection of personal health information.
2. To collect only necessary personal health information.
3. To collect personal health information from the individual whenever possible.

How is the purpose for the collection of personal health information determined?

Determining the purpose for collecting personal health information is a critical requirement of the Act. Not only does the Act impose a requirement on trustees to notify the individual of this purpose at the time the information is collected, but the identified purpose for the collection will help determine what information can be collected and how it can later be used.

The purpose for collecting personal health information will depend on the function of the particular trustee as well as the circumstances in which the collection takes place. For example, a psychiatric facility is likely to collect personal health information for a different purpose than the emergency ward of a hospital. The personal health information needed when an individual comes to a clinic for an inoculation will likely be different from what is needed when someone enters a personal care home. If the trustee is a teaching hospital, one of the stated purposes of collection of personal health information may be research by staff within the facility.

Why should trustees have to notify the individual of the purpose for the collection of personal health information?

This requirement is based on the principle that an individual has a right to make decisions about his or her own health care. Informing the individual as fully as possible about the reasons for collecting personal health information will allow him or her to make an informed decision about providing personal health information.

This principle is so important that the Act requires that, when personal health information is collected by someone who is not a health professional, he or she must advise the individual about someone who can be contacted to gain more information about the purposes for collecting the information.

See s. 15(1) of the Act.

In what situations does the Act prohibit the collection of personal health information?

Stressing the need to respect individual privacy, the Act generally permits the collection from individuals of only as much information as is needed for specific purposes. What a trustee needs to know will largely depend on his or her purpose in collecting personal health information. The Act prohibits the collection of personal health information for illegal purposes, purposes unrelated to the function or activity of the trustee, and purposes other than those disclosed to the individual as the reasons for the collection of the personal health information. *See s. 13 of the Act.*

What is the difference between use and disclosure?

For the purposes of PHIA, “use” refers to what is done with the personal health information within the trustee organization. If research is being done within the trustee organization by its staff, it is a “use.”

For example, PHIA says a public body or a health care facility can use personal health information for research and planning that relates to the provision of health care or payment for health care by those trustees. *See s. 21(d)(ii) of the Act.*

“Disclosure” involves revealing personal health information outside the trustee organization to other trustees, the individual’s friends and family, or to other individuals.

For example, if a trustee is requested to reveal personal health information to a university student for his or her thesis, it would be a disclosure.

A trustee is permitted to disclose personal health information without the consent of the individual it is about for the purpose of research related to the provision of health care or payment for health care where the researcher is performing the research for the trustee on a contract basis. *See s. 22(2)(g)(ii) of the Act.*

Both use and disclosure involve revealing personal health information to someone. This may be done by permitting others to read it, sending it to them by mail, fax, e-mail, or by revealing the information orally.

What obligations are placed on a trustee by the Act when using or disclosing personal health information?

The general rule concerning use and disclosure of personal health information is that no use or disclosure of the information may be made except:

- to the extent that it is necessary to accomplish the purpose for which the personal health information was collected, or
- with the informed consent of the individual it is about. *See s. 21, 22 of the Act.*

Therefore, if the individual was informed that one of the purposes of the collection of the information was for internal research, then the trustee is permitted to use it for such research.

Otherwise, the trustee must get the individual’s consent for use of the information for research.

The specific rules governing disclosure for research purposes are addressed in *s. 24 of the Act.*

What are the Act’s goals with regard to health research?

While PHIA is designed to protect and safeguard personal health information, it recognizes that such information may sometimes be needed by health researchers. So researchers may be given access to personal health information as long as they follow rules required for approval of their research projects and safeguard its confidentiality.

As a researcher, how do I get the personal health information I need for my project?

If the information is held by government, you apply to the health information privacy committee to be established under the regulations.

If the information is held by a trustee other than government, you apply to the organization’s own research review committee (defined in *s. 1(1) of the Act*) such as the ethics committee of a hospital or university, for example. *See s. 24(2) of the Act.*

What are the minimum requirements for approval of any research project that uses personal health information?

- the research has to be important enough to outweigh any invasion of privacy involved
- the research cannot be done without using identifiable personal health care information
- it is impossible or impractical to get consent from the people the personal health information is about
- the project ensures the security of the personal health information and its destruction when finished.

See s. 24(3) of the Act.

What do I have to do to get personal health information from a trustee?

If your research project is approved by one of the committees referred to above, you have to sign an agreement with the trustee:

- not to publish identifiable personal health information
- to use personal health information only for the approved project
- to protect adequately the confidentiality of the personal health information during the project. *See s. 24(4) of the Act.*

What if I need to contact the individuals the personal health information is about?

If your project will require direct contact with individuals, the trustee your agreement is with must get the individuals' consent before disclosing the personal health information to you.

There is one exception to this rule. The trustee doesn't need the individuals' consent if you just need a random sample of Manitobans and only need the individuals' names and addresses.

See s. 24(5) of the Act.

What security precautions must be taken with respect to personal health information?

The Act requires trustees to store personal health information in such a way that only those who need to obtain the information will have access to it. Personal health information should not be disclosed outside the trustee organization unless such a disclosure has been assessed to determine whether it is permitted by the Act. Personal health information must not even be accessed by people within the trustee organization unless it is determined that they need to have that access.

See s. 20(3) of the Act.

All trustees must establish administrative, technical and physical safeguards to ensure the confidentiality and accuracy of personal health information.

Among other things, these safeguards must include procedures to limit access to the information to authorized people and ensure that the electronic transmission of personal health information is not intercepted. For more information about security safeguards, *see s. 18 of the Act and Regulation 245/97.*

What are the rules concerning destruction of personal health information?

Personal health information must be destroyed in a manner that preserves its confidentiality.

See s. 17(2), (3) of the Act.

All trustees must establish a written policy concerning the destruction of personal health information and must comply with it. *See s. 17(1) of the Act.*

Trustees must also keep a record of the destruction of personal health information, noting:

- the individual whose personal health information was destroyed
- the time period to which the information relates
- the method of destruction used and the person responsible for supervising the destruction. *See s. 17(4) of the Act.*

OTHER GENERAL PROVISIONS

Is it permissible to disclose personal health information to information managers?

The Act defines an information manager as a person or body that:

- processes, stores or destroys personal health information;
- provides information management; or
- provides information technology services

for or to a trustee. ***See s. 1(1) of the Act.***

The Act recognizes that, in order to perform their functions, information managers require access to personal health information. If you are a trustee, you may disclose personal health information to an information manager only after the information manager has a written agreement with you that ensures the personal health information is

adequately protected. And, as the trustee, you remain responsible for any use an information manager makes of personal health information. ***See s. 25 of the Act.***

What is the role of the Ombudsman in enforcing the Act?

The Ombudsman's role can be divided into two broad categories:

- supervising compliance with the Act generally. ***See Part 4 of the Act.***
- dealing with complaints about specific violations of the Act. ***See Part 5 of the Act.***

For further information about PHIA, you may also be interested in the brief summaries prepared for Health Care Facilities and Health Professionals.