CancerCare Manitoba

# The Personal Health Information Act (PHIA)

## Understanding Your Role as a Researcher at CCMB

Leslie Costa
PHI Privacy Officer, CCMB

CancerCare Manitoba

# Objectives of Session

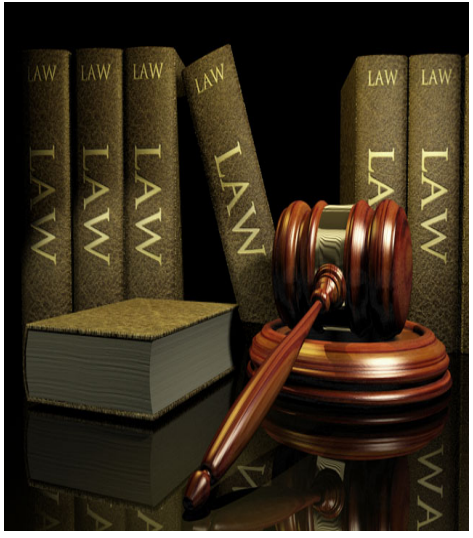
- To inform you about the Personal Health Information Act of Manitoba (PHIA).
- To inform you about your obligations as a Researcher under PHIA.
- Introduction to the Research Resource Impact Committee (RRIC) process.

CancerCare Manitoba

# What is PHIA?

## Manitoba Law

- Provides individuals with the right to access their personal health information, get a copy and request a correction.
- Protects individuals' privacy rights.
- Establishes rules related to how personal health information can be collected, used, disclosed, protected and destroyed and how this applies to health researchers.



CancerCare Manitoba

# Definitions

## What is Personal Health Information?

- **ALL** information recorded in any form that can **IDENTIFY** an individual and that relates to that person's
  - Health or health care history
  - Type of care or treatment provided
  - Payment for health care provided, PHIN, or other identifying numbers or symbols
  - Name, date of birth, home/domestic conditions
  - Occupation, sexual orientation

# Definitions

## Personal Health Information DOES NOT include

- Anonymous or de-identified information that does not permit individuals to be identified. It is now considered to be data.

Note: Cancer Registry works closely with many study researchers and holds the linkage between the PHI and the data

# Definitions

## What and who are Trustees?

- **Trustee** means a
  - Health professional
  - Health care facility
  - Public body (Government, Regional Health Authorities, Educational Institutions)
  - Health services agency (Organizations VON/WeCare)

Who collects or maintains personal health information

CancerCare Manitoba

# Definitions

## Confidentiality

- **Confidentiality** is the obligation of a trustee to protect the personal health information entrusted to it, to maintain the secrecy of the information and not misuse or wrongfully disclose it.

CancerCare Manitoba

# What are a trustee's obligations when Collecting personal health information?

**A trustee has three main obligations when collecting 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.

# Purpose of Collection

- The purpose for collecting personal health information will depend on the function of the particular trustee. 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.

CancerCare Manitoba

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

- The 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.

CancerCare Manitoba

# What is the difference between use and Disclosure?

- **Use** – using PHI within the trustee site
- **Disclosure** – revealing PHI outside the trustee organization/site
  - A disclosure for research, CCMB requires a signed agreement to be in place

CancerCare Manitoba

# 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.

CancerCare Manitoba

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

- If the information is held by a trustee, you apply to the organization's own research review committee such as ethics committee of a hospital or university. **At CCMB it is the RRIC Committee.**

CancerCare Manitoba

# RRIC Approval required for

**Studies that involve:**

a) CCMB data or Cancer Registry data;
b) CCMB patients (including questionnaires or surveys) and/or materials from CCMB patients;
c) CCMB staff (as research subjects);
d) have an impact on CCMB resources.

Research activity, including screening and recruitment, must not begin until written approval has been received from the CCMB RRIC, University of Manitoba Research Ethics Board (REB), and from all other relevant regulatory bodies.

CancerCare Manitoba

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

- Approval of your research project
- A signed agreement with the trustee, stipulating:
  - not to publish identifiable personal health information
  - to use personal health information only for approved project
  - to protect the confidentiality of the personal health information during the project.

CancerCare Manitoba

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

- If your research project will require direct contact with individuals/patients you must first obtain their consent.
- There is one exception to this rule. The trustee does not need the individuals' consent if you just need a random sample of Manitobans and only need the individuals' names and addresses.

CancerCare Manitoba

# How do I obtain consent?

- Send a letter (access to name and address)
- Pamphlets/brochures
- Sign/poster
- Consent Nurse/Coordinator

CancerCare Manitoba

# Resources

- Corporate Share: J drive: Folder: Research Resource Impact Committee
- Internet www.cancercare.mb.ca – link RRIC
- Manitoba Health – The Personal Health Information Act (PHIA) – A Brief Summary for Health Researchers (http://www.gov.mb.ca/health/phia/hr.html)
- The Personal Health Information Act of Manitoba – Article 24: Health Research

CancerCare Manitoba

# QUESTIONS

# ?

Leslie Costa, CCMB PHI Privacy Officer
Phone: 204-787-2727
Email: leslie.costa@cancercare.mb.ca

or

Jacqueline Sholdice, CCMB Medicolegal Correspondent
Phone: 204-787-2266
Email: jacqueline.sholdice@cancercare.mb.ca