

 <p>Winnipeg Regional Health Authority Office régional de la santé de Winnipeg Caring for Health À l'écoute de notre santé</p> <p>POLICY</p>	<p>REGIONAL</p> <p>Applicable to all WRHA governed sites and facilities (including hospitals and personal care homes), and all funded hospitals and personal care homes. All other funded entities are excluded unless set out within a particular Service Purchase Agreement.</p>		Level: 1
	Policy Name: Disclosure of Personal Health Information for Health Research	Policy Number: 10.40.144	Page 1 of 6
	Approval Signature: <i>Original signed by A. Wilgosh</i>	Section: GENERAL ADMINISTRATION	
	Date: April 2010	Supercedes: New	

1.0 **PURPOSE:**

- 1.1 To ensure that the Individuals' right to Privacy of their Personal Health Information including Demographic Information is protected during Disclosure for health research as set out under *The Personal Health Information Act* ("PHIA").
- 1.2 To detail the conditions and restrictions on the Trustee's ability to Disclose Personal Health Information for health research.

2.0 **DEFINITIONS:**

- 2.1 **Access:** The right of an Individual, or a Person Permitted to Exercise the Rights of an Individual, to examine (view) and receive a copy of the Individual's Personal Health Information Maintained by the Trustee.
- 2.2 **Confidentiality:** 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.
- 2.3 **Demographic Information:** An Individual's name, address, telephone number, and email address.
- 2.4 **Disclosure of Personal Health Information:** Revealing the Personal Health Information outside the Trustee, i.e. to other Trustees, to family and friends of the Individual, or to other persons legally entitled to have Personal Health Information released to them.
- 2.5 **Express Consent:** Consent given directly by an Individual in oral, written or electronic form. For example, completion of a consent form by an Individual that authorizes the Disclosure of the Individual's own Personal Health Information is a form of Express Consent.
- 2.6 **Health Care:** Any care, service or procedure provided to diagnose, treat or maintain an Individual's health; provided to prevent disease or injury or promote Health Care; or that affects the structure or a function of the body and includes the sale or dispensing of a drug, device, equipment or other item pursuant to a prescription.
- 2.7 **Health Care Facility:** A hospital, personal care home, Psychiatric Facility, medical clinic, laboratory, CancerCare Manitoba and community health centre or other

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facility in which Health Care is provided and that is designated in the PHIA regulation.

- 2.8 Health Professional: A person who is licensed or registered to provide Health Care under an Act of the Legislature or who is a member of a class of persons designated as Health Professionals in the PHIA regulation.
- 2.9 Health Services Agency: An organization that provides Health Care such as community or home-based Health Care pursuant to an agreement with the Trustee.
- 2.10 Individual: A patient, client or resident receiving Health Care services within the WRHA/ Health Care Facility. For the purpose of Access, correction, Use and Disclosure of Personal Health Information includes Persons Permitted to Exercise the Rights of an Individual.
- 2.11 Institutional Research Review Committee: A committee formally established by a Health Care Facility, university or similar body. Within the WRHA this includes the University of Manitoba Research Ethics Boards whose function is:
- to review the efficacy and scientific and ethical value of a research proposal involving human subjects or involving the review of Records containing Personal Health Information; and
 - to ensure that the person proposing the research has adequate safeguards in place to protect the Confidentiality of Personal Health Information.
- 2.12 Integrity of Personal Health Information: The preservation of its content throughout storage, Use, transfer, and retrieval so that there is confidence that the information has not been tampered with or modified other than as authorized.
- 2.13 Maintain: In relation to Personal Health Information, to have custody or control of the information.
- 2.14 Personal Health Information: 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; or
 - payment for Health Care provided to the Individual;
- and includes:
- the PHIN (personal health identification number) and any other identification number, symbol or particular assigned to an Individual; and
 - 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;
- and for further clarity includes:
- personal information such as financial position, home conditions, domestic difficulties or any other private matters relating to the Individual which have been Disclosed to the Trustee;
- and for the purpose of the Confidentiality policy:

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- any Personal Health Information exchanged verbally about an identifiable Individual.

2.15 Personal Representative includes any of the following:

- an Executor/Executrix or joint Executor/Executrix named in a deceased Individual's will; or
- a court appointed Administrator or joint Administrator of a person's estate.

2.16 Persons Permitted to Exercise the Rights of an Individual means:

- 2.16.1 (a) any person with written authorization from the Individual to act on the Individual's behalf;
- (b) a proxy appointed by the Individual under *The Health Care Directives Act*;
- (c) 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;
- (d) a substitute decision maker for personal care appointed for the Individual under *The Vulnerable Persons Living with a Mental Disability Act* if the exercise of the right relates to the powers and duties of the substitute decision maker;
- (e) the parent or guardian of an Individual who is a minor, if the minor does not have the capacity to make Health Care decisions;
- (f) if the Individual is deceased, his or her Personal Representative.

2.16.2 If it is reasonable to believe that no person listed in 2.16.1 exists or is available, the adult person listed first in the following who is readily available and willing to act may exercise the rights of an Individual who lacks the capacity to do so:

- (a) the Individual's spouse, or common-law partner, with whom the Individual is cohabiting;
- (b) a son or daughter;
- (c) a parent, if the Individual is an adult;
- (d) a brother or sister;
- (e) a person with whom the Individual is known to have a close personal relationship;
- (f) a grandparent;
- (g) a grandchild;
- (h) an aunt or uncle;
- (i) a nephew or niece.

Ranking: The older or oldest of two or more relatives described in 2.16.2 is to be preferred to another of those relatives.

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

2.18 PHIN: The personal health identification number assigned to an Individual by the minister to uniquely identify the Individual for Health Care purposes.

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- 2.19 Prescribed Health Research Organization includes:
- Manitoba Centre for Health Policy at the University of Manitoba; and
 - Canadian Institute for Health Information.
- 2.20 Privacy: The fundamental right of an Individual to control the collection, Use and Disclosure of their Personal Health Information.
- 2.21 Privacy Officer: An employee designated by the WRHA or the Health Care Facility whose responsibilities include dealing with requests from Individuals who wish to examine, receive a copy or make a correction to Personal Health Information Maintained by the Trustee and facilitating the Trustee's compliance with PHIA. The definition is intended to mean the Privacy Officer and/or their delegate.
- 2.22 Psychiatric Facility: A place designated in the regulation of *The Mental Health Act* as a facility for the observation, assessment, diagnosis and treatment of persons who suffer from mental disorders.
- 2.23 Record or Recorded Information: 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.
- 2.24 Security: The process of protecting the Personal Health Information by assessing threats and risks to information and taking steps to mitigate these threats and risks. The result is the consistent application of standards and controls to protect the Integrity and Privacy of the information during all aspects of its use, processing, disclosure, transmittal, transport, storage, retention including conversion to a different medium and destruction.
- 2.25 Site: A Health Care Facility, community health centre, community office within the WRHA.
- 2.26 Trustee: A Health Professional, Health Care Facility, public body or Health Services Agency that collects or Maintains Personal Health Information. For clarity, the WRHA as a public body is the Trustee of the Personal Health Information collected and Maintained within Health Care Facilities and Sites owned and/or operated by the WRHA and includes Community Health Services. The other hospitals and personal care homes within the region are Trustees of the Personal Health Information collected and Maintained at each Health Care Facility.
- 2.27 Use: Involves revealing Personal Health Information to someone within the Trustee's own organization who needs to know the information to do their job. Use includes processing, reproduction, transmission and transportation of Personal Health Information.

3.0 POLICY:

- 3.1 The Trustee may Disclose Personal Health Information for health research in accordance with PHIA.

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- 3.2 If the Personal Health Information was Recorded in a designated Psychiatric Facility or unit, the information is subject to the provisions on Disclosure of information contained in *The Mental Health Act*.
- 3.3 The Trustee may Disclose Personal Health Information to a person conducting health research only if an Institutional Research Review Committee has approved the research and it has been determined that:
- the research is of sufficient importance to outweigh the intrusion into Privacy that would result from the Disclosure of Personal Health Information;
 - the research purpose cannot reasonably be accomplished unless the personal information is provided in a form that identifies or may identify Individuals;
 - it is unreasonable or impractical for the person proposing the research to obtain consent from the Individuals the Personal Health Information is about; and
 - the research project contains:
 - i) reasonable safeguards to protect the Confidentiality and Security of the Personal Health Information; and
 - ii) procedures to destroy the information or remove all identifying information at the earliest opportunity consistent with the purposes of the project.
- 3.4 When it is determined that consent is required to Disclose Personal Health Information and/or the research project requires direct contact with the Individual, the Trustee shall obtain written Express Consent from the Individual.
- 3.5 The Trustee need not obtain consent if the information consists only of the Individuals' names and addresses.
- 3.6 An approval is conditional on the person proposing the research project entering into an agreement with the Trustee, in accordance with the regulation, in which the person agrees to:
- not to publish the Personal Health Information requested in a form that could reasonably be expected to identify the Individuals concerned;
 - to Use the Personal Health Information requested solely for the purposes of the approved research project; and
 - to ensure that the research project complies with the required safeguards and procedures, specifically the project shall contain:
 - reasonable safeguards to protect the Confidentiality and Security of the Personal Health Information; and
 - procedures to destroy or remove, at the earliest opportunity consistent with the purposes of the research, any information that, either by itself or when combined with other information available to the holder, allows Individuals to be readily identified.
- 3.7 The Trustee may Disclose Personal Health Information to a Prescribed Health Research Organization without consent from the Individual, for any of the following purposes:

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- Analyzing the health status of the population;
- Identifying and describing patterns of illness;
- Describing and analyzing how health services are Used;
- Analyzing the availability and adequacy of human resources required to provide health services;
- Measuring health system performance;
- Health system planning.

3.8 Before Disclosing Personal Health Information to a Prescribed Health Research Organization, the Trustee must enter into an agreement with the organization that includes:

- The purposes for which the health research organization may Use the Personal Health Information;
- Prohibit Disclosure of Personal Health Information except with the Trustee's prior written consent;
- Require the health research organization to implement and Maintain adequate safeguards for the protection, retention and destruction of Personal Health Information satisfactory to the Trustee;
- Allow the Trustee to monitor compliance with the terms of the agreement; and
- Include remedies to address any failure by the health research organization to comply with the terms of the agreement.

4.0 **PROCEDURE:**

4.1 Disclosure Of Personal Health Information

4.1.2 All requests for Disclosure of Personal Health Information should be coordinated with the Health Care Facility, health information services department and/or Site Privacy Officer.

4.1.3 Where feasible, a Record should be kept of Personal Health Information Disclosed to the researcher (e.g. a list of chart numbers).

5.0 **REFERENCES:**

- 5.1 *The Mental Health Act.*
- 5.2 *The Personal Health Information Act (Manitoba).*
- 5.3 *The Personal Health Information Regulations.*

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