

In This Issue

- Protection of Personal Health Information
 - KHSC Policies related to PHI
 - CITI Canada Privacy Course



Protection of Personal Health Information

Privacy regulations that pertain to clinical research include the federal *Personal Information Protection and Electronic Documents Act (PIPEDA)* and the provincial *Personal Health Information Protection Act (PHIPA)* of Ontario. PIPEDA applies to the private sector, setting out privacy requirements for organizations that collect, use or disclose personal information in the course of commercial activities. PHIPA governs the collection, use, and disclosure of personal health information. PHIPA is particularly relevant for the health sector and clinical researchers in Ontario. Under PHIPA, persons or organizations that provide health care are collectively known as health information “custodians”. To learn more about PIPEDA and PHIPA, please see the links below:

PIPEDA: <https://www.priv.gc.ca/en/privacy-topics/privacy-laws-in-canada/the-personal-information-protection-and-electronic-documents-act-pipeda/>

PHIPA: <https://www.ontario.ca/laws/statute/04p03>

Personal health information (PHI) includes oral or written information with respect to an individual (living or deceased) that relates to:

- their physical or mental health, including the health history of the individual’s family;
- the provision of any health care or services provided to the individual, including the persons providing the care or services;
- a plan of service for an individual requiring long-term care;
- payment or eligibility of an individual for health care or services;

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- the donation by the individual of any body parts or any bodily substances or information derived from the testing or examination of such body parts or bodily substances;
- an individual's health number;
- the identity of an individual's substitute decision-maker.

Compliance with PHIPA is mandatory for all research in Ontario that uses PHI. PHIPA spells out the rights of individuals and the obligations of trustees/custodians in the health care system (physicians, regional health authorities, health professionals, etc.) with respect to PHI. Section 4 of PHIPA pertains to use and disclosure of personal health information for research.

Researchers must make every reasonable effort to protect research participants' privacy and maintain confidentiality. Researchers must safeguard the information entrusted to them and not misuse or wrongfully disclose it. There are a number of guidance documents available for researchers, including the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2)* which covers topics such as privacy, confidentiality, and informed consent in research.

To learn more about the TCPS2, please check out this link: [Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2 \(2022\) \(ethics.gc.ca\)](https://www.ethics.gc.ca/eng/3/0/2/0/20220127).

Privacy (as defined in the TCPS2) refers to an individual's right to be free from intrusion or interference by others. An individual's right to privacy is respected if they have an opportunity to exercise control over their own bodies, personal information (includes personal health information), expressed thoughts and opinions, personal communications with others, and the space that they occupy. An important aspect of privacy is the right of an individual to exercise control regarding their consent to or withholding of consent for, the collection, use or disclosure of their information. An individual's right to refuse inclusion in research must be respected in accordance with PHIPA.

Confidentiality (as defined in the TCPS2) refers to the obligation to safeguard entrusted information. Researchers must put in place appropriate security measures, including physical, administrative and technical safeguards, to protect information from unauthorized access, use, disclosure, modification, loss or theft. Physical safeguards include the use of locked filing cabinets and locating computers containing research data away from public areas. Administrative safeguards include the development and enforcement of organizational rules about who has access to personal information about research participants. Technical safeguards include use of computer passwords, firewalls, anti-virus software, encryption and other measures that protect data from unauthorized access, loss or modification.

For more information about accessing PHI for research, please check out "[Research Roadmap: Accessing Patient Data for Research](#)".

KHSC Policies related to PHI

The following KHSC policies cover various topics related to PHI:

- 01-046 Email Usage
- 01-151 Social Media
- 01-222 Use of Cell Phones, Cameras and Recording Devices
- 06-120 Medical Photography: Photographs/Audio Visual Recording
- 09-050 Disclosure of Personal Health Information
- 09-055 Personal Health Information Protection
- 09-130 Patient Information for Research, Teaching Utilization
- 09-140 Access to, Correction and Use of Personal Health Information
- 09-150 Duplication of Personal Health Information (photocopying, facsimile)

The most up-to date versions of KHSC's policies can be found on KHSC's Intranet.

CITI Canada Privacy Course

The Network of Canada (N2) and CITI Canada launched in 2017 the "*Introductory Course on Privacy and Security for Personal Health Information in the Canadian Health Research Environment*". This course was developed in order to provide researchers, research staff, students and trainees with a basic understanding of privacy and security requirements for health research with human participants.

The online course provides important information, based on accepted privacy and security standards and regulatory requirements, for the appropriate collection, use, dissemination, retention and destruction of PHI within the health research environment. The materials address requirements set out in guidance documents such as the TCPS2 as well as federal, provincial and territorial legislation including PIPEDA. Although the main focus of this course is on PHI as opposed to *all personal information* (PI), since PHI is a subset of PI, the same principles apply to both categories of information and PI is mentioned frequently throughout the course. This means that the course can have applicability to all types of research conducted with human participants.

To access the online privacy course through CITI Canada if you do not already have a username or password, please reach out to Lisa McAvoy (Lisa.McAvoy@kingstonhsc.ca or KHSC-KGH Site ext. 3344). Researchers, research staff, students and trainees who already have a CITI Canada account can add this course to their curriculum.