

Health Privacy: Hidden Issues to Help Navigate the System

December 5, 2022

Brendan Gray, Health Law Counsel

THE LEGAL GUIDE TO CONSENT, CAPACITY
AND SUBSTITUTE DECISION-MAKING,
December 5, 2022

DISCLAIMER

THIS PRESENTATION IS:

- PROVIDED FOR INFORMATIONAL PURPOSES,
- NOT LEGAL ADVICE, AND
- NOT BINDING ON THE IPC.

Topics

1. Intro to the IPC
2. *PHIPA*
3. Electronic health privacy developments

What is the IPC?

Information and Privacy Commissioner of Ontario (IPC)

- The IPC is an officer of the legislative assembly
- Until very recently, the IPC only had authority under three acts:
 - *Freedom of Information and Protection of Privacy Act (FIPPA)*
 - *Municipal Freedom of Information and Protection of Privacy Act (MFIPPA)*
 - *Personal Health Information Protection Act, 2004 (PHIPA or the Act)*

Information and Privacy Commissioner of Ontario (cont')

- But now there are more with an oversight role for the IPC, such as:
 - *Child, Youth and Family Services Act, 2017*
 - *Anti-Racism Act, 2017*

PHIPA

Application of PHIPA

- *PHIPA* came into force on November 1, 2004
- The majority of *PHIPA* governs “personal health information” in the custody or control of:
 - “Health Information Custodians,” or
 - “Agents” of health information custodians
- However, *PHIPA* also has broader application
 - For example it contains restrictions on the use and disclosure of personal health information by non-health information custodians that receive personal health information from health information custodians

Duties Imposed on Health Information Custodians and their Agents

- A number of duties are imposed on health information custodians and their agents under *PHIPA*
- These duties generally fall into four categories:
 - Collection, use and disclosure of personal health information
 - Security of personal health information
 - Responding to requests for access to and correction of records of personal health information
 - Transparency of information practices

Collection, Use and Disclosure

- Not permitted to collect, use or disclose personal health information UNLESS:
 - The individual consents; or
 - The collection, use or disclosure is permitted or required without consent
- There are three types of consent under *PHIPA*:
 - Express
 - Implied
 - Assumed implied

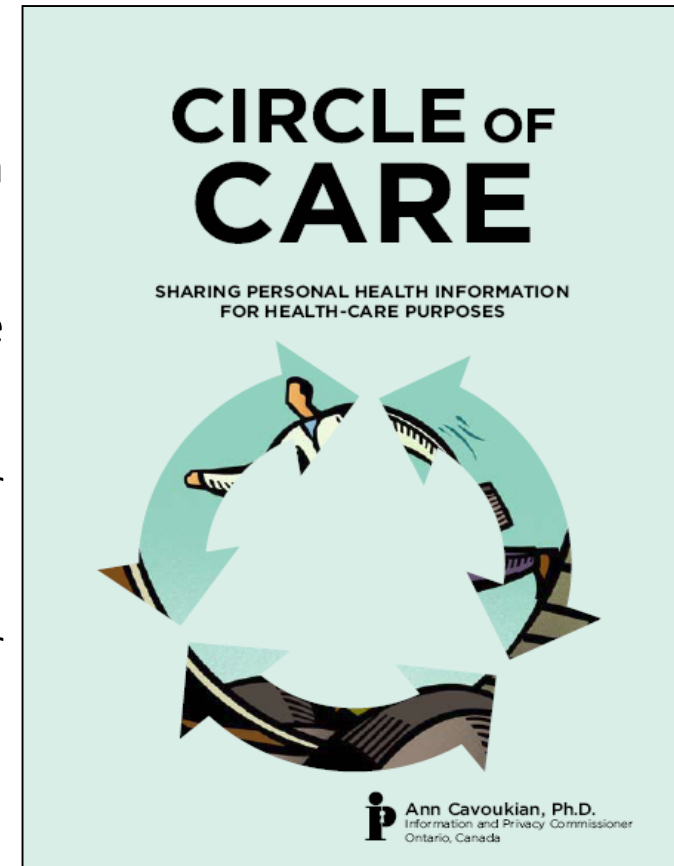
Express vs Implied Consent

- In general, express consent is required to:
 - Disclose personal health information to a non-health information custodian
 - Disclose personal health information to another custodian for a purpose other than health care
 - Collect, use or disclose personal health information for marketing or fundraising
- In all other circumstances, consent may be implied
- For example, consent may be implied:
 - To collect or use personal health information for any purpose, subject to certain exceptions
 - To disclose personal health information to another custodian for a health care purpose

Assumed Implied Consent

Custodians *may* assume implied consent provided all six conditions are satisfied:

1. The custodian falls within a category of custodians that are entitled to rely on assumed implied consent
2. The personal health information must have been received from the individual, his or her substitute decision-maker or another custodian
3. The personal health information must have been received for providing or assisting in providing health care to the individual
4. The purpose of the collection, use or disclosure must be for providing or assisting in providing health care to the individual
5. In the context of a disclosure, the disclosure must be to another custodian
6. The custodian must not be aware the individual expressly withheld or withdrew consent



Elements for Valid Consent

Consent must:

1. Be the consent of the individual or their substitute decision-maker (if applicable)
2. Be knowledgeable, meaning, it must be reasonable to believe that the individual knows:
 - The purpose of the collection, use or disclosure; and
 - That the individual may give or withhold consent
3. Relate to the information
4. Not be obtained by deception or coercion.

Capacity Generally

- Custodians are required to presume that an individual is capable of consenting to the collection, use or disclosure of their personal health information, unless there are reasonable grounds to believe the individual is incapable.
- An individual is capable of consenting to the collection, use or disclosure of personal health information if the individual is able to:
 - Understand information relevant to the decision of whether to consent; and
 - Appreciate the reasonably foreseeable consequences of giving, not giving, withholding or withdrawing consent.
- Individuals may be capable of consenting to the collection, use or disclosure of some parts of their personal health information and incapable with respect to others, and may be capable of consenting at one time but incapable at another.

Capable Individuals

- Consent in relation to a capable individual may be provided by:
 - the capable individual, or
 - if the individual is at least 16 years of age, any capable person sixteen years of age or older authorized in writing by the individual to provide the consent on their behalf.

Where there is an *HCCA* Substitute Decision-Maker

- Individuals may be found to be incapable and have substitute decision-makers for specific health care decisions under the *Health Care Consent Act, 1996 (HCCA)*:
 - treatment within the meaning of section 9 of the *HCCA*;
 - admission to a long-term care home, within the meaning of section 39 of the *HCCA*; or
 - a personal assistance service within the meaning of section 56 of the *HCCA* (e.g. assistance with hygiene, washing, dressing, grooming, eating, drinking).
- Where an individual has a substitute decision-maker under the *HCCA*, that substitute decision-maker can also give, withhold, or withdraw consent under *PHIPA* for all decisions about the individual's personal health information that are necessary for, or ancillary to, the decision under the *HCCA*.

Incapacity under *PHIPA*

- Where an individual has been determined to be incapable under *PHIPA*, the following persons (in the following order of priority) may give, withhold or withdraw consent on their behalf:
 - The individual's guardian of the person or guardian of property, if the consent relates to the guardian's authority to make a decision on behalf of the individual
 - The individual's attorney for personal care or attorney for property, if the consent relates to the attorney's authority to make a decision on behalf of the individual
 - The individual's representative appointed by the Consent and Capacity Board, if the representative has authority to give the consent
 - The individual's spouse or partner
 - A child or parent of the individual, or a children's aid society or other person who is lawfully entitled to give or refuse consent in the place of the parent.
 - A parent of the individual with only a right of access
 - A sibling of the individual
 - Any other relative of the individual

Requirements for Substitute Decision-Makers

- A substitute decision-maker is only able to make a decision on behalf of an incapable individual where the substitute decision-maker is:
 - capable of consenting to the collection, use or disclosure;
 - at least sixteen years of age or is the parent of the individual to whom the personal health information relates;
 - not prohibited by court order or separation agreement from having access to the individual or from giving or refusing consent on the individual's behalf;
 - available (meaning that it is possible to communicate with the substitute decision-maker and obtain consent within a reasonable time); and
 - willing to assume responsibility for making the decision.

Requirements for Substitute Decision-Makers

- A person may only consent on behalf of an incapable individual where there is no higher ranked person who meets the above requirements. Unless the person believes that:
 - no other higher or equally ranked persons exists; or
 - any higher ranked person would not object to them making the decision - But only if the higher ranked person is not the guardian of the person or guardian of property, attorney for personal care or attorney for property, or representative appointed by the Consent and Capacity Board.

If no one meets the above requirements, or if the two highest and equally ranked persons disagree, the Public Guardian and Trustee may make the decision on behalf of the incapable individual.

Requirements for Substitute Decision-Makers (cont'd)

- A substitute decision-maker who gives, withholds or withdraws a consent (or provides an express instruction), must take into consideration:
 - (a) the wishes, values and beliefs that,
 - (i) if the individual is capable, the person knows the individual holds and believes the individual would want reflected in decisions made concerning the individual's personal health information, or
 - (ii) if the individual is incapable or deceased, the person knows the individual held when capable or alive and believes the individual would have wanted reflected in decisions made concerning the individual's personal health information;
 - (b) whether the benefits that the person expects from the collection, use or disclosure of the information outweigh the risk of negative consequences occurring as a result of the collection, use or disclosure;
 - (c) whether the purpose for which the collection, use or disclosure is sought can be accomplished without the collection, use or disclosure; and
 - (d) whether the collection, use or disclosure is necessary to satisfy any legal obligation.

Children under 16

- Children can give, withhold or withdraw consent where they are capable and are presumed to be capable, unless there are reasonable grounds to believe they are incapable
- If the child is less than 16 years old, a parent of the child or a children's aid society or other person who is lawfully entitled to give or refuse consent in the place of the parent may also give, withhold or withdraw consent.
 - This does not apply to information that relates to treatment within the meaning of the *HCCA* about which the child made their own decision, or counselling in which child participated on their own under the *Child, Youth and Family Services Act*.
 - A parent does not include a parent who has only a right of access to the child.
- If there is a conflict between a capable child who is less than 16 years old, and the parent of the child or a children's aid society or other person who is lawfully entitled to give or refuse consent in the place of the parent, the decision of the capable child prevails.

Deceased Individuals and other Acts

- If the individual is deceased, the deceased's estate trustee or the person who has assumed responsibility for the administration of the deceased's estate, if the estate does not have an estate trustee, may give, withhold or withdraw consent.
- A consent may also be given, withheld or withdrawn by person whom an Act of Ontario or Canada authorizes or requires to act on behalf of the individual.

Requests for Access, etc.

- Where *PHIPA* permits or requires an individual to make a request, give an instruction or take a step and a substitute decision-maker is authorized to consent on behalf of the individual to the collection, use or disclosure of personal health information about the individual, the substitute decision-maker may make the request, give the instruction or take the step on behalf of the individual.

Electronic health privacy developments

Access to records in electronic format

- With the increase in electronic forms of communication, there was a concern that an individual's right of access under *PHIPA* would become outdated
- Individuals are also increasingly taking steps to manage their own PHI through patient portals and health apps
- In light of these changes, two amendments were made to *PHIPA*:
 - to expressly give individuals the right to access their records of PHI in an electronic format, provided the format meets prescribed requirements or is an electronic format specified by Ontario Health in accordance with the regulations
 - amended *PHIPA* to regulate a new class of persons called “consumer electronic service providers” (CESPs)

Access to records in electronic format, cont'd

- Regarding the right to access records in an electronic format that meets the prescribed requirements, regulations are now in force
- The regulations provide individuals with a right of access to records in PDF format, or any other format agreed to by the individual and the custodian (including a secure online portal).
- No regulations have been made relating to how Ontario Health can specify access formats.
- The Ministry of Health recently proposed regulatory amendments to further change this provision and also allow Ontario Health to begin specifying access formats
- The IPC has made several submissions on this issue that are available on our website.

Access to records in electronic format, cont'd

- CESP's are defined as persons who provide electronic services to individuals at their request, primarily for the purpose of allowing those individuals to access, use, disclose, modify, maintain or otherwise manage their records of PHI, or for such other purposes as may be prescribed (e.g. apps used by individuals to access copies of physician reports and prescriptions)
- Many of the specific requirements relating to CESP's are left to be prescribed in regulation
- The CESP provisions are not yet in force and no regulations have been made

Consent Directives in the Provincial Electronic Health Record (EHR)

- Individuals cannot opt out of having their PHI included in the provincial EHR
- Once included, however, individuals will have the right to implement consent directives
- A consent directive withholds or withdraws the consent of an individual to the collection, use or disclosure of his or her PHI for health care purposes
- Regulations have been made specifying the data elements that may not be subject to a directive
- The regulations provide that you cannot impose a consent directive on basic demographic information

Consent Directives in the EHR, cont'd

- Regulations under *PHIPA* further limit the PHI that may be blocked by a consent directive. Individuals only have the right to block the entirety of their health record – unless a more granular block is “reasonably possible”
- Note that this aspect of the regulation does not apply to consent directives previously made in the systems that have become the EHR (and where no new directive has been made)

Consent Overrides in the EHR

- A custodian will be permitted to override a directive:
 - with the express consent of the individual; or
 - where there are reasonable grounds to believe it is necessary to eliminate or reduce a significant risk of serious bodily harm to the individual or another person or group but, if the risk is to the individual, it must not be reasonably possible to get timely consent
- A custodian that collects PHI subject to a directive may only use it for the purpose for which it was collected
- For example, where PHI is collected with express consent, it may only be used in accordance with the individual's consent

Notice of Consent Overrides in the EHR

- Where a directive is overridden, the prescribed organization (Ontario Health) is immediately required to provide written notice to the custodian that collected the PHI
- Upon receipt of the notice, the custodian is required to:
 - notify the individual to whom the PHI relates at the first reasonable opportunity; and
 - where the PHI is collected to eliminate or reduce a significant risk of serious bodily harm to another person or group, provide additional written notice to the Commissioner
- Regulations to *PHIPA* specify the content of these notices

Access to records in the EHR

- On March 31, 2023, provisions of *PHIPA* come into force allowing access requests:
 - to be made to the prescribed organization (Ontario Health) as if it was a custodian with respect to records in the EHR; and
 - to be made to custodians with respect to records in the EHR viewed, handled or otherwise dealt with by the custodian.
- This is subject to exceptions and additional requirements to the right of access to the EHR set out in regulation, including:
 - That Ontario Health is only required to respond to requests for access, and provide access, through a digital means of access specified by the Agency.

QUESTIONS?

CONTACT US

Information and Privacy Commissioner of Ontario

2 Bloor Street East, Suite 1400
Toronto, Ontario, Canada M4W 1A8
Phone: (416) 326-3333 / 1-800-387-0073
TDD/TTY: 416-325-7539
Web: www.ipc.on.ca

E-mail: info@ipc.on.ca

Media: media@ipc.on.ca / 416-326-3965