

Consent and Sharing PHI with Families

A presentation to Champlains Pathways to
Better Care, June 16th, 2016

Nicole Minutti, Health Privacy Policy Analyst



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Agenda

- Application of PHIPA
- Consent Under PHIPA
- Capacity and Substitute Decision Making
- Withholding and Withdrawing Consent
- Disclosures Related to Risk
- Sharing PHI with Families



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APPLICATION OF PHIPA



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Application of PHIPA

- Ontario's *Personal Health Information Protection Act* (PHIPA) sets out rules for the collection, use and disclosure of personal health information by health information custodians
- PHIPA applies to **personal health information** in the custody or control of:
 - **Health information custodians** and
 - **Agents** of health information custodians



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Personal Health Information

- Personal health information is identifying information about an individual in oral or recorded form that:
 - Relates to an individual's physical or mental health
 - Relates to the provision of health care to the individual
 - Relates to payments or eligibility for health care
 - Identifies an individual's substitute decision-maker
 - Is the individual's health number
 - Is a plan of service under the *Home Care and Community Services Act, 1994*
 - Relates to the donation of body parts or bodily substances



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Health Information Custodians

- Health information custodians include:
 - A health care practitioner who provides health care
 - A person who operates a group practice of health care practitioners who provide health care
 - A service provider within the meaning of the *Home Care and Community Services Act, 1994* who provides a community service to which that Act applies
 - A hospital, psychiatric facility and independent health facility
 - A pharmacy, ambulance service, lab or specimen collection centre
 - A long-term care home, care home or home for special care
 - A community care access corporation
 - Minister/Ministry of Health and Long-Term Care



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Agents

- An agent is a person that, with the authorization of a health information custodian, acts for or on behalf of the custodian in respect of personal health information
- It is irrelevant whether or not the agent:
 - Is employed by the health information custodian
 - Is remunerated by the health information custodian
 - Has the authority to bind the health information custodian
- A health information custodian remains responsible for personal health information collected, used, disclosed and retained or disposed of by an agent
- Agents may be subject to further conditions or restrictions imposed by the custodian



CONSENT UNDER PHIPA



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Consent under PHIPA

- A health information custodian shall not collect, use or disclose personal health information unless:
 - Consent of the individual has been obtained; or
 - The collection, use or disclosure is permitted or required to be made without consent by the *Personal Health Information Protection Act, 2004* (“the Act”)
- The *Act* sets out the requirements for the consent to be considered valid



Valid Consent

- For consent to be valid, the consent must:
 - Be the consent of the individual or his or her substitute decision-maker (where applicable)
 - Be knowledgeable
 - It must be reasonable to believe that the individual knows the purpose of the collection, use or disclosure and that he or she may give or withhold consent
 - Relate to the information, and
 - Not be obtained by deception or coercion



Types of Consent

- There are three types of consent under the *Act*:
 - Express;
 - Implied; and
 - Assumed implied



Express Consent

- Consent may be express or implied, except when the *Act* specifies that consent must be express
- Express consent is required in the following situations (with some exceptions):
 - When a HIC discloses PHI to a non-HIC
 - When a HIC discloses PHI to another HIC for a purpose other than for the provision of health care
 - When collecting, using or disclosing PHI for marketing purposes
 - When collecting, using or disclosing PHI for fundraising purposes (if collecting, using or disclosing more than the name and address of the individual)



Implied Consent

- In all other circumstances where consent is required prior to the collection, use or disclosure of PHI about an individual, HICs may rely on implied consent
- Consent may be implied to:
 - Collect or use PHI for most purposes, with some exceptions
 - Disclose PHI to another HIC for the purpose of providing or assisting in providing health care
- Although the Act permits HICs to rely on implied consent, they are not required to rely on implied consent



Assumed Implied Consent

- In order to rely on assumed implied consent with regard to the collection, use and disclosure of personal health information, all of the following six conditions must be met.
 1. The health information custodian must fall within the category of custodians entitled to rely upon assumed implied consent
 2. The personal health information in question must have been received from the individual to whom the information pertains, his/her substitute decision-maker, or another custodian;
 3. The personal health information must have been received for the provision of health care to the individual;
 4. The purpose of the collection, use, or disclosure must be for the purpose of providing health care to the individual to whom the information relates;
 5. In the context of a disclosure, the disclosure must be to another health information custodian; and
 6. The health information custodian that receives personal health information must not be aware that the individual has expressly withheld or withdrawn consent



Persons Who May Consent

- If an individual is capable of consenting to the collection, use, or disclosure of the personal health information, consent may be given by the individual, or
 - If the individual is at least 16 years of age, any natural person who is also at least 16 years of age, capable of consent, and whom the individual has authorized in writing to act on his or her behalf
 - If the individual is a child who is less than 16 years of age, 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 *unless the information relates to treatment about or counselling in which the child has made a decision on his or her own*



Persons Who May Consent (*cont'd*)

- If the individual is incapable of consenting to the collection, use of disclosure of the information, a person who is authorized under subsection 5(2), (3), or (4) or section 26
- 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.
- A person whom an Act of Ontario or Canada authorizes or requires to act on behalf of the individual.



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CAPACITY AND SUBSTITUTE DECISION MAKING



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Capacity to Consent

- An individual is capable of consenting to the collection, use or disclosure of their personal health information if they are able to:
 - Understand the information that is relevant to deciding whether to consent to the collection, use, or disclosure, as the case may be; and
 - Appreciate the reasonably foreseeable consequences of giving, not giving, withholding, or withdrawing the consent.
- An individual may be capable of consenting to the collection, use, or disclosure of some parts of their personal health information, but incapable of consenting with respect to other parts.
- Likewise, an individual may be capable of consenting at one time, but incapable of consenting at another time.



Substitute Decision Making

- If the individual is determined to be incapable, the following persons may act on his/her behalf (ranked in the following order):
 - The individual's guardian of the person or guardian of property
 - The individual's attorney for personal care or attorney for property
 - The individual's representative appointed by the Consent and Capacity Board
 - The individual's spouse or partner
 - A child or parent of the individual
 - A parent of the individual with only a right of access
 - A brother or sister; or
 - Any other relative



WITHHOLDING & WITHDRAWING CONSENT



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Withholding & Withdrawing Consent

- In general, individuals have the right to expressly withhold or withdraw consent to the collection, use or disclosure of their personal health information for any purpose (including health care purposes)
- Individuals also have the right to provide express instructions to health information custodians not to use or disclose personal health information for health care purposes without their express consent in certain circumstances



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DISCLOSURES RELATED TO RISKS



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Disclosures Related to Risks

- A health information custodian may disclose personal health information without consent, where the custodian believes on reasonable grounds that that the disclosure is necessary to eliminate or reduce a significant risk of bodily harm to one or more persons



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SHARING PERSONAL HEALTH INFORMATION WITH FAMILIES



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HALIFAX – It's a quandry for health care professionals that has caught the attention of experts across the country: should family members and loved ones be told about a patient's struggle with mental health issues?

Nova Scotia is reviewing the rules around the disclosure of information under its health privacy laws after a grieving mother appeared at the legislature last month.

Frustration over health disclosure doesn't trump privacy protection: experts

NATIONAL ([HTTP://WWW.680NEWS.COM/CATEGORY/NATIONAL/](http://www.680news.com/category/national/))

by KEITH DOUCETTE, THE CANADIAN PRESS

Posted Jun 13, 2016 9:00 am EDT Last Updated Jun 13, 2016 at 10:00 am EDT



Carolyn Fox addresses a news conference at the Nova Scotia legislature in Halifax on Tuesday, May 17, 2016. THE CANADIAN PRESS/Andrew Vaughan

Former Ontario privacy commissioner Ann Cavoukian was a fierce defender of individual privacy rights, but also didn't hesitate to set public institutions straight when she felt they weren't forthcoming enough with information.

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In 2008, she issued a joint statement with her B.C. counterpart clarifying that privacy rules allow health information to be disclosed in emergency situations. It came after the family of an 18-year-old Carleton University student blamed the Ottawa school for failing to inform them of her depression or prevent her suicide.

In an interview, Cavoukian was adamant that with mental health in particular, privacy laws must protect the confidentiality of the patient – but emphasized the provisions that allow for exceptions.

to families, especially in the case of young adults.

Nova Scotia's laws are similar to those in provinces such as Ontario and British Columbia, where disclosure can occur when it's determined there is an imminent threat to the health or the safety of any person, including the patient.

Family members can be told on the day of treatment about the presence, location and condition of a patient as long as the patient doesn't object to the information's release.

Catherine Tully, Nova Scotia's privacy commissioner, said she has concerns about whether officials and employees of government bodies know enough about what can and can't be disclosed.

"It is absolutely a training issue," said Tully. "I have travelled around the province and talked to hundreds of people responsible for administering our privacy laws and training is a very key issue and one that requires constant work."

Dr. Linda Courey, senior director of mental health and addictions for the Nova Scotia Health Authority, said clinicians are acutely aware of the "complicated balance" between an individual's right to privacy and understanding that families often have a need to know.

Courey said the mental health and addictions system in Halifax area hospitals has worked over the years to ensure that patients' wishes are paramount.

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"..the patient's wishes are paramount and their privacy must always come first. ... that cuts off a source of support in some cases, but that decision does not rest with the health care professional. It rests with the patient."

Sharing PHI with Families

- In most circumstances, **express** consent of the individual is required to disclose personal health information to relatives
- Custodians must consider whether the consent is **valid**
- Custodians are not permitted to disclose PHI if an individual is capable and has **withheld or withdrawn consent** to disclose PHI to one or more family members
- If an individual has been determined **not capable** to consent, a substitute decision maker will consent on his/her behalf
- If a custodian determines it necessary, on reasonable grounds, PHIPA permits the disclose of PHI **without consent** in order to eliminate or reduce a significant risk of bodily harm to one or more persons



Questions?

Nicole Minutti, MHSc

Health Privacy Policy Analyst

Office of the Information and Privacy Commissioner of Ontario

Nicole.minutti@ipc.on.ca



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