

# If You're Not Sure, Just Ask: Everything You Need to Know About Express Consent

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Information and Privacy  
Commissioner of Ontario

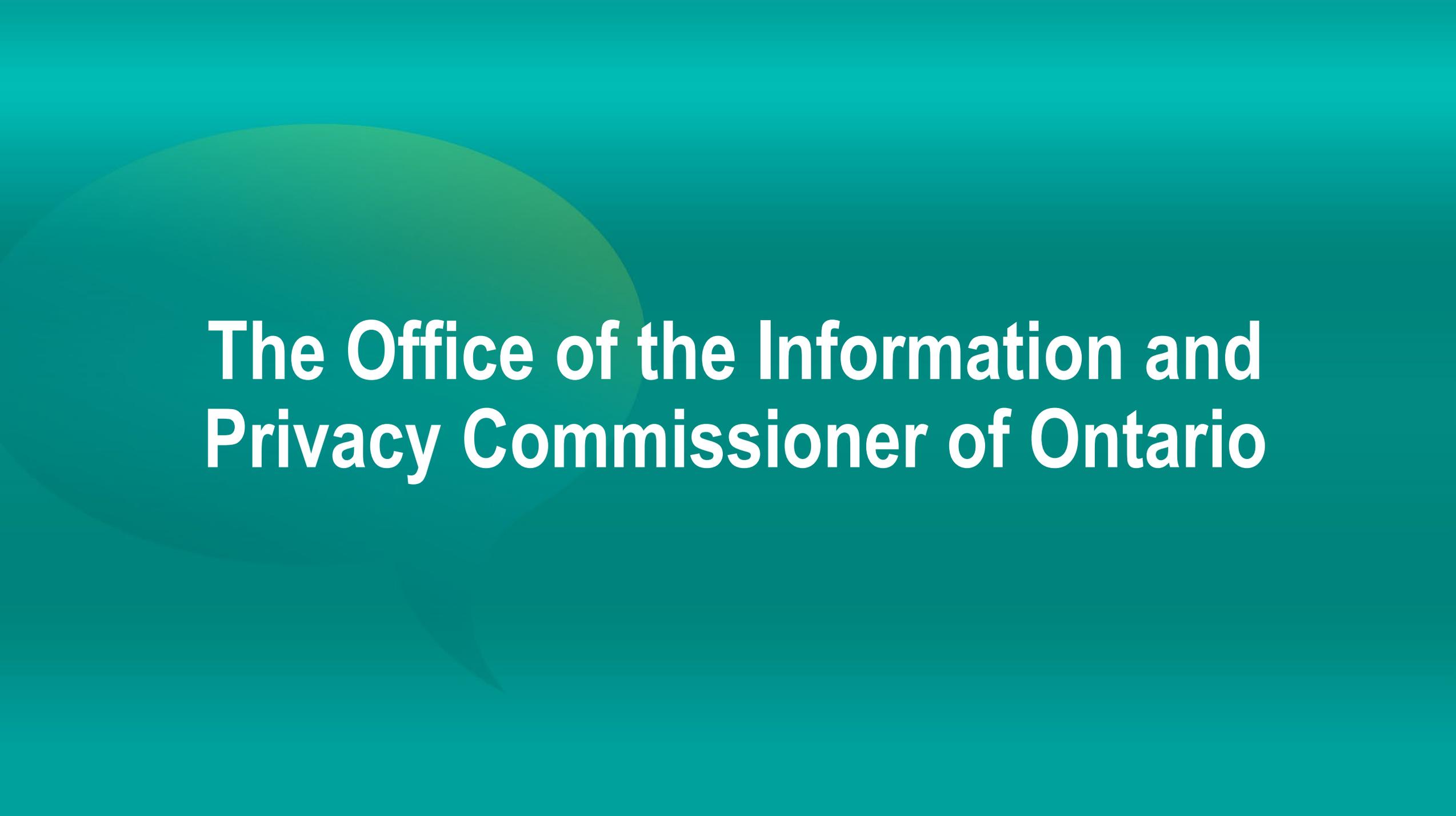
Commissaire à l'information et à la  
protection de la vie privée de l'Ontario

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# Overview

- About the IPC
- Application of PHIPA
- Consent under PHIPA
- Capacity and Substitute Decision Making
- Withholding and Withdrawing Consent
- PHIPA's Limiting Principles
- Additional Resources



# **The Office of the Information and Privacy Commissioner of Ontario**

# Privacy Law in Ontario

	Federal Public Sector	Private Sector	Ontario Public Sector	Ontario Health Sector
Generally applicable to	Government of Canada <ul style="list-style-type: none"> <li>E.g. federal ministries, agencies, crown corporations</li> </ul>	Private sector businesses in Canada	Public sector in Ontario <ul style="list-style-type: none"> <li>E.g. government, ministries, agencies, hospitals, universities, cities, police, schools</li> </ul>	Health care sector in Ontario <ul style="list-style-type: none"> <li>individuals, custodians (e.g. hospitals, clinics, pharmacies, etc.)</li> </ul>
Laws (non-exhaustive)	<ul style="list-style-type: none"> <li><a href="#">Privacy Act</a></li> <li><a href="#">Access to Information Act</a></li> </ul>	<ul style="list-style-type: none"> <li>Personal Information Protection and Electronic Documents Act (<a href="#">PIPEDA</a>)</li> <li>Canada's Anti-Spam Legislation (<a href="#">CASL</a>)</li> </ul>	<ul style="list-style-type: none"> <li>Freedom of Information and Protection of Privacy Act (<a href="#">FIPPA</a>)</li> <li>Municipal Freedom of Information and Protection of Privacy Act (<a href="#">MFIPPA</a>)</li> </ul>	<ul style="list-style-type: none"> <li>Personal Health Information Protection Act (<a href="#">PHIPA</a>)</li> </ul>
Oversight	<ul style="list-style-type: none"> <li><a href="#">Privacy Commissioner of Canada</a></li> <li><a href="#">Information Commissioner of Canada</a></li> </ul>	<ul style="list-style-type: none"> <li><a href="#">Privacy Commissioner of Canada</a></li> </ul>	<ul style="list-style-type: none"> <li><a href="#">Information and Privacy Commissioner of Ontario</a></li> </ul>	<ul style="list-style-type: none"> <li><a href="#">Information and Privacy Commissioner of Ontario</a></li> </ul>

# Information and Privacy Commissioner of Ontario



Patricia Kosseim

- Ontario's Information and Privacy Commissioner is an officer of the legislature
  - Appointed by and reports to the Legislative Assembly of Ontario
  - Independent of the government of the day
- The IPC has authority under the following laws:
  - *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)*
  - *Child, Youth and Family Services Act, 2017 (CYFSA)*
  - *Anti-Racism Act, 2017 (ARA)*
  - *Coroners Act*

# IPC's Overall Role & Mandate

In addition to overseeing provincial access and privacy laws, the office of the IPC also serves the government, public institutions and the public through its mandate to:

- Resolve appeals when access to information is refused
- Investigate privacy complaints related to personal information
- Ensure compliance with the province's access and privacy laws
- Review privacy policies and information management practices
- Conduct research on access and privacy issues and provide comment on proposed legislation and government programs
- Educate the public, media and other stakeholders about Ontario's access and privacy laws and current issues affecting access and privacy

## IPC'S VISION

Enhance Ontarians' trust that their access and privacy rights will be respected by ...





# Application of PHIPA

# Application of PHIPA

- Ontario's *Personal Health Information Protection Act, 2004* (PHIPA) sets out rules for the collection, use and disclosure of personal health information (PHI) by health information custodians.

# Personal Health Information

- Personal health information (PHI) 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
  - Is a plan that sets out the home and community care services to be provided by a funded health service provider or Ontario Health Team
  - Relates to payments or eligibility for health care
  - Relates to the donation of body parts or bodily substances
  - Is the individual's health number
  - Identifies an individual's substitute decision-maker

# Health Information Custodians

- Health information custodians (custodians) include:
  - Health care practitioners who provides health care
  - Group practices of health care practitioners who provide health care
  - Health service providers that are part of an Ontario Health Team and that provide a funded home and community care service
  - Hospitals, psychiatric facilities and independent health facilities
  - Long-term care homes, retirement homes and homes for special care
  - Pharmacies, ambulance services, labs and specimen collection centres
  - Centres, programs, or services for community health or mental health whose primary purpose is the provision of health care
  - Medical Officers of Health of a board of health (*public health units*)
  - Minister/Ministry of Health

# Agents

- A person that, with the authorization of a custodian, acts for or on behalf of the custodian in respect of PHI.
- Agents do not have to be paid by the custodian to be considered an agent.
- Custodians remain responsible for any PHI that is collected, used, disclosed, retained or disposed of by their agents.



# Consent under PHIPA

# Consent under PHIPA

- Custodians shall not collect, use or disclose PHI unless:
  - Consent of the individual has been obtained; or
  - Collection, use or disclosure is permitted or required to be made without consent.
- There are three types of consent under the PHIPA:
  - Express;
  - Implied; and
  - Assumed implied

# Valid Consent

- For consent to be valid, the consent must be:
  - Given by the individual (or their substitute decision-maker),
  - Knowledgeable,
    - It must be reasonable to believe that the individual knows:
      - The purpose of the collection, use or disclosure, and
      - That they may give or withhold consent.
  - Related to the information, and
  - Given voluntarily (not be obtained by deception or coercion).

# Valid Consent

- PHIPA does not specify how long consent is valid.
- In determining whether consent continues to remain valid, custodians must consider the elements of valid consent and should reflect on whether there has been a significant change to the nature of:
  - The information
  - The individual's relationship with the custodian disclosing the PHI
  - The individual's relationship with the custodian collecting the PHI

# Express Consent

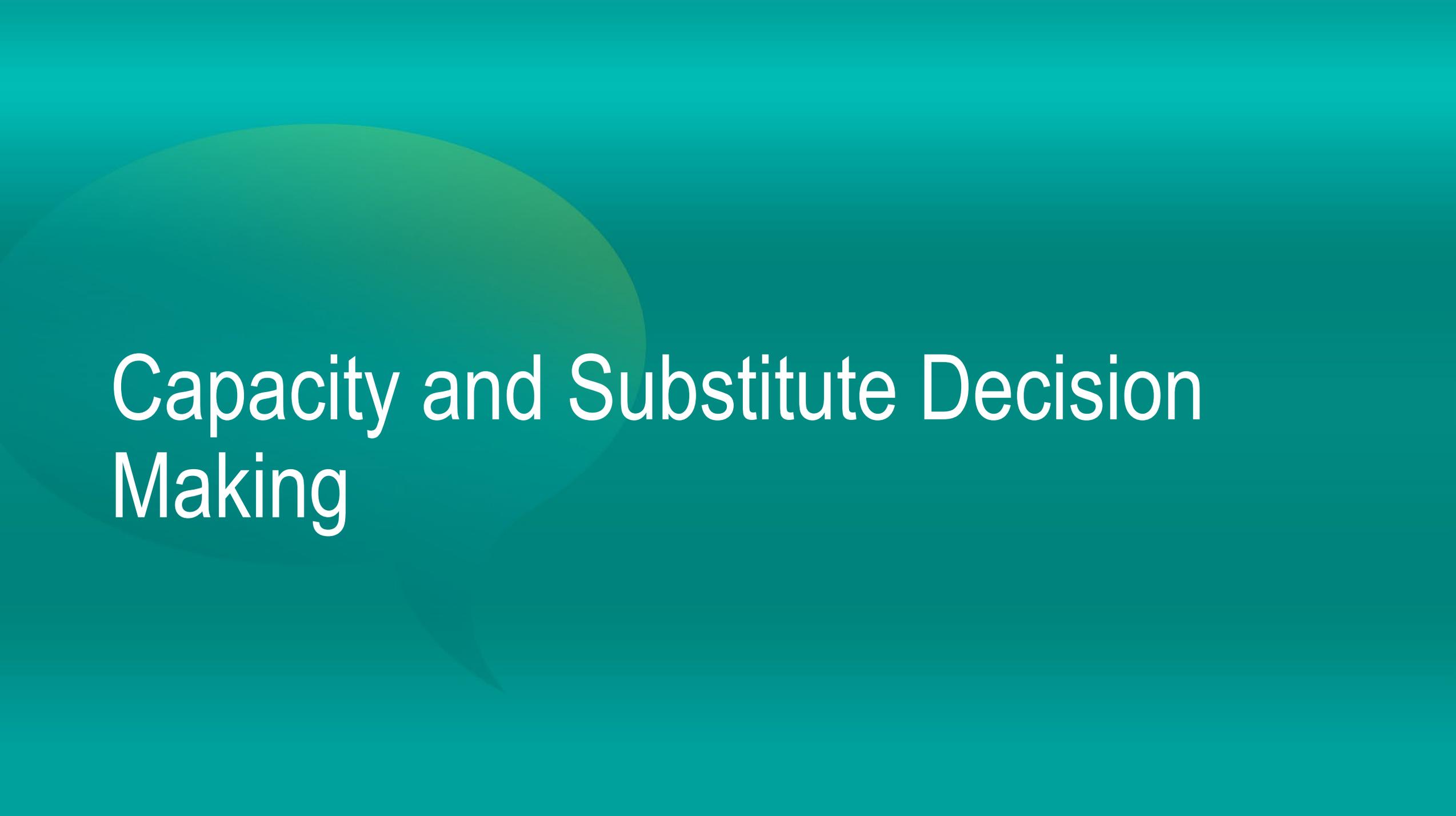
- Express consent is not a defined term in PHIPA.
- It is commonly understood as consent that has been clearly and unmistakably given in writing or orally.
- Although express consent is not required by PHIPA to be provided in writing, obtaining express consent in writing may help avoid ambiguity.
- When consent is provided orally, it is recommended that the custodian document the consent in the individual's health record.
- Express consent is required in the following situations:
  - When a custodian discloses PHI to a non-custodian (with some exceptions)
  - When a custodian discloses PHI to another custodian for a purpose other than for the provision of health care
  - When collecting, using or disclosing PHI for marketing or fundraising (with some exceptions)

# Express Consent: Disclosing PHI to a Non-Custodian

- The following are examples of recipients to whom disclosures of PHI are likely to require express consent:
  - Insurance companies
  - Community support service providers who are not providing health care (e.g. volunteer transportation or meal services)
  - Religious groups
  - Family members (unless a substitute decision maker)
  - Friends
  - Neighbours

# Express Consent: Marketing and Fundraising

- Marketing does not include:
  - Communication by a custodian who provides insured services to inform individuals that they may receive ancillary uninsured services for a block fee
  - Communication by the Canadian Blood Services for the purpose of recruiting donors
- Custodians may use the name and address for fundraising if:
  - The purpose is for a charitable or philanthropic purpose related to the custodian's operations
  - The custodian posts a public notice that:
    - Informs individuals that their name and address may be used and disclosed for fundraising purposes unless the individual opts-out, and
    - Provides information on how individuals can easily opt-out.
  - The custodian provides individuals with an easy way to opt-out of receiving future solicitations
  - Any communication from the custodian or person conducting fundraising on its behalf must not include any information about the individual's health care or health status.



# Capacity and Substitute Decision Making

# Capacity to Consent

- An individual is capable of consenting to the collection, use or disclosure of their PHI if they:
  - Understand the relevant information, and
  - Appreciate the reasonably foreseeable consequences of giving or not giving consent.
- A custodian may presume an individual is capable unless there are reasonable grounds to believe the individual is incapable of consenting.
- An individual may be capable of consenting to the collection, use, or disclosure of some parts of their PHI, but incapable of consenting with respect to other parts.
- An individual may be incapable of consent at one time, but capable at another.

# Substitute Decision Making

- If the individual is determined to be incapable, the following persons may act on their behalf (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
- PHIPA sets out conditions for substitute decision makers, including that they must be available and willing to assume the responsibility of making consent decisions.

# Power of Attorney in the News

<https://www.cbc.ca/radio/whitecoat/power-of-attorney-canada-1.7086725>

White Coat Black Art

## Life can change overnight. 2 families share what people should know about power of attorney

Mary Jarratt was thrown into action as power of attorney when her brother had a life-changing stroke



Brandie Weikle · CBC Radio · Posted: Jan 22, 2024 4:00 AM EST | Last Updated: January 22



When Dr. Mary Jarratt's brother, Billy Jarratt, left, had a debilitating stroke at 58, she was thrown into the role of power of attorney. She had to make tough decisions about his care, the care of his teenaged son and whether to sell the family home. (Brian Goldman/CBC)





# Withholding & Withdrawing Consent

# Withholding and Withdrawing Consent

- In general, individuals have the right to expressly withhold or withdraw their consent to the collection, use or disclosure of their PHI for any purpose, including for health care purposes.



# Disclosures Related to Risks

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- A custodian may disclose PHI, 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.



# PHIPA's Limiting Principles

# PHIPA's "Limiting Principles"

- In general, custodians may not:
  - Collect, use or disclose PHI if other information will serve the purpose
  - Collect, use or disclose more PHI than is reasonably necessary to meet the purpose



# Additional Resources

## Additional Resources

- [The Personal Health Information Protection Act, 2004](#)
- [A Guide to the Personal Health Information Protection Act](#)
- [Frequently Asked Questions: Personal Health Information Protection Act](#)
- [Circle of Care: Sharing Personal Health Information for Health-Care Purposes](#)
- [Yes, You Can. Dispelling the Myths About Sharing Information with Children's Aid Societies](#)
- [Lock-Box Fact Sheet](#)
- [Fundraising Under PHIPA](#)

# Contact Us

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