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*ALL
RIGHTS
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Privacy Issues, Valid Consent, And Release of Personal Data



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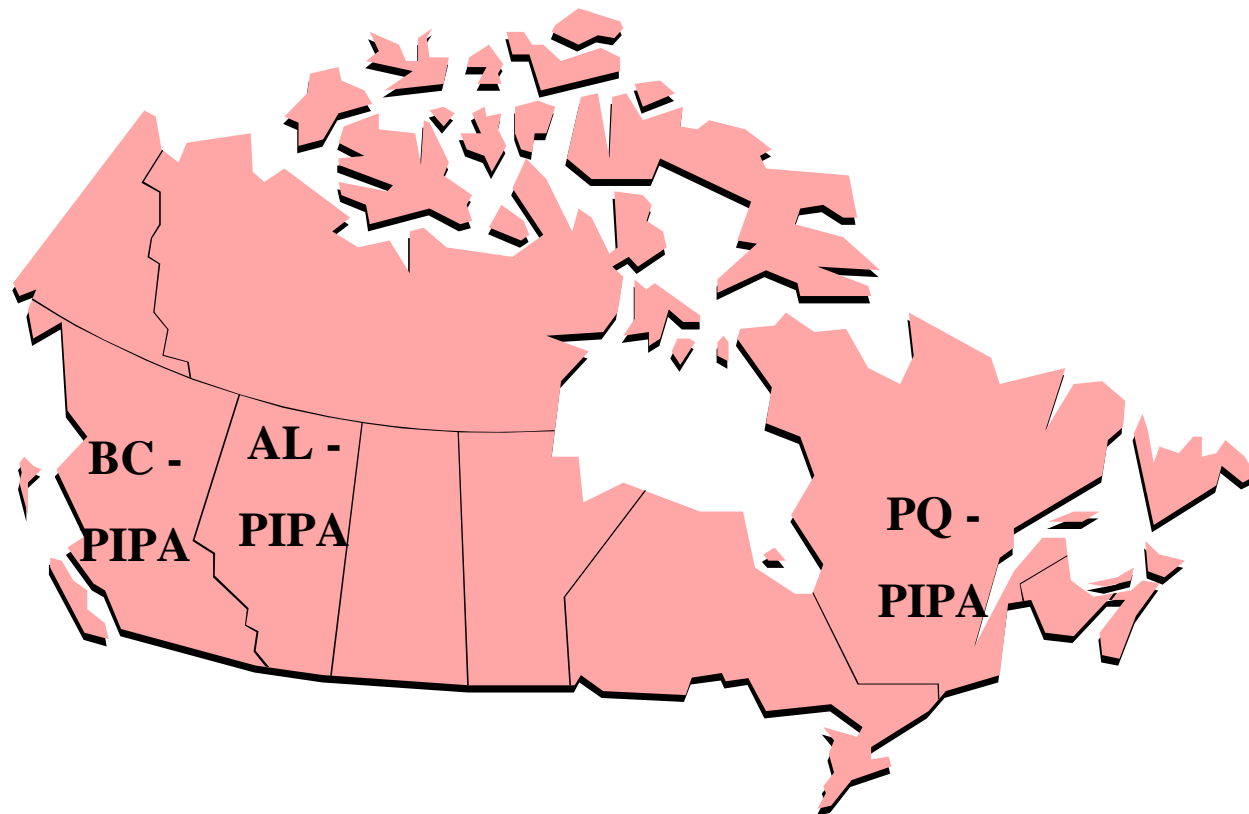
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Canada – Federal: PIPEDA

Personal Information Protection and Electronic Documents Act
(in effect since January 1, 2004)

Covers trans-border data flow

PROVINCIAL: PIPA
(The Personal Information Protection Act)



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Ontario PHIPA (Bill 31)

Personal Health Information Protection Act (Nov 2004)

- “An Act to enact and amend various Acts with respect to the protection of health information”.
- Health information custodians (HICs) that collect, use and disclose personal health information (PHI).
- Non-health information custodians where they receive personal health information from a health information custodian (use and disclosure provisions).

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Commissioner's Role

The commissioner may:

- Act upon receipt of a complaint, or upon her own initiative, where it is believed that the Act has been contravened, or is about to be contravened.
- Enter and inspect premises (non-dwellings) without a warrant or court order, and may demand production of information and access to computers.
- Make copies or records, and may remove records that are not required for the immediate care of a patient in order to review or copy them.
- Generally, the commissioner will seek the consent of the individual(s) whose personal health information she is seeking, before taking action with respect to a record that contains PHI.



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Definitions

- Key People:
 - Individual, Person, or
 - Substitute Decision Maker (also Guardian of the person)
 - Spouse, Partner, Parent, Relative
 - Attorney, Personal Care or Property
 - Guardian, Property
 - Health Information Custodian (person or organization)
 - Agent
 - Health Care Practitioner
 - Service Provider
 - Researcher

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Health Information Custodian (HIC)

- includes:
 - Health care practitioner
 - Hospitals and independent health facilities
 - Homes for the aged and nursing homes
 - Pharmacies
 - Laboratories
 - Home for special care
 - A centre, program or service for community health or mental health



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“Personal Information” - PIPEDA

“Factual information, recorded or not
about an identifiable individual”

- Factual information
- Recorded or not
- About an identifiable individual

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“Personal Information” - PIPEDA

Includes:

- Age, Name, ID numbers, Income, Ethnic origin, or Blood type;
- Opinions, Evaluations, Comments, Social status, Disciplinary actions;
- Employee Files, credit records, loan records, medical records, dispute between consumer & merchant, intentions (i.e., change jobs);
- Personal health information (physical or mental) collected as part of or incidental to treatment;

Does NOT include business contact information:

- Name, title, address, telephone
- NOT e-mail or fax!

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“Personal Health Information”

Identifying information about an individual

- Oral or recorded form;
- Physical or mental health;
- Includes health history of the individual's family.

Relates to the providing of health care to the individual including:

- The identification of a person as a provider of health care to the individual,
- An individual's plan of service (*Long-Term Care Act, 1994*)
- Payments or eligibility for health care;
- Donation of any body part or bodily substance of the individual or is derived from the testing or examination of any such body part or bodily substance,
- Is the individual's health number, or
- Identifies an individual's substitute decision-maker.



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Ontario
PHIPA

Definitions

- Key Information
 - Personal Health Information (PHI)
 - Identifying information
 - Record
 - Mixed Records

- Key Actions
 - Use
 - Disclosure (also “permissive”)
 - Information Practices

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10 PIPEDA Principles

Code for the protection of personal information developed under the auspices of the Canadian Standards Association (CSA).

1. Accountability
2. Identifying Purposes
3. Consent
4. Limiting Collection
5. Limiting use, disclosure and retention
6. Accuracy
7. Safeguards
8. Openness
9. Individual Access
10. Provide Recourse

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3. Knowledgeable Consent

- Consent must be based on knowledge of what & why (purpose)
- Voluntary agreement with what is being done or proposed.
- Consent can be either express or implied.
- Express consent is given explicitly, either orally, or in writing.
- Implicit consent arises where consent may be reasonably inferred from the action or inaction of the individual.”
- Consent can be withdrawn.

Consent

Personal Health Information (PHI) may be

- Disclosed to another health-care provider without express consent if the information is required for health care and it is not reasonable to obtain a timely consent. Disclosure is not permitted where there has been an express instruction to the contrary.
- There are a variety of other discretionary disclosures listed, including:
 - Audit;
 - Legal proceedings;
 - Disclosure to a potential successor to evaluate the operations of the HIC;
 - Planning and management; and
 - Disclosures related to risk.



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Mandatory Disclosure

Under specific circumstances, disclosure must and can be made without consent. The circumstances of disclosure vary depending on the act that give them the authority:

- Aviation medical Advisor, **Chief medical officer or medical health officer**, **Children's Aid Society**, College of regulated health care professionals, College of Physicians and Surgeons, Minister of Health and Long term Care, OHIP, Coroner, Designated police officer, by order.
- Writ or summons of Ont. Court, Registrar General, Registrar of Motor Vehicles, Trillium Gift of Life, Workplace Safety and Insurance Board, **Ambulance Services**, Cancer Care Ontario, Deputy minister of Veteran's Affairs, College of RHPA, College of Pharmacists Investigator, **Public Guardian and Trustee**, Minister Inspector



Lock Box

- **PHIPA permits an individual to place restrictions on the *use* or *disclosure* of his or her PHI by either *expressly withdrawing* or *withholding* consent for its collection, use or disclosure.**
- **These rights are colloquially referred to as the lock box provisions. Note that the term lock box is not defined in PHIPA; rather it is a term of art used within the health community in relation to sections**



Lock Box Limits

- **Notification** – if the custodian who discloses believes that all information necessary for the provision of health care has not been disclosed, the custodian must notify the recipient.
- **Override** – the custodian may disclose if disclosure is necessary to eliminate or reduce a significant risk of serious bodily harm to a person or a group of persons.



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Circle of Care concept

- **Describes HICs and their authorized agents who are permitted to rely on an individual's implied consent when collecting, using, disclosing or handling personal health information for the purpose of providing direct health care.**
- **Though it has value in the descriptive process, it does not hold weight in any legal way. It was initially used in discussion of concepts in the legislation, but does not in fact exist with in PHIPA legislation.**

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Circle of Care

In a hospital setting, concept of the circle of care includes:

- **The attending physician(s)**
 - **The health care team:**
 - **Residents,**
 - **Nurses,**
 - **Technicians,**
 - **Clinical clerks**
 - **Other employees assigned to the patient who have direct responsibilities of providing care to the individual**

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Need To Know vs. Ability to Know

- Who has an ability to know PI or PHI in any specific situation?
- Who has a need to know? Those health care professionals who are directly or indirectly involved in a particular patient's care.

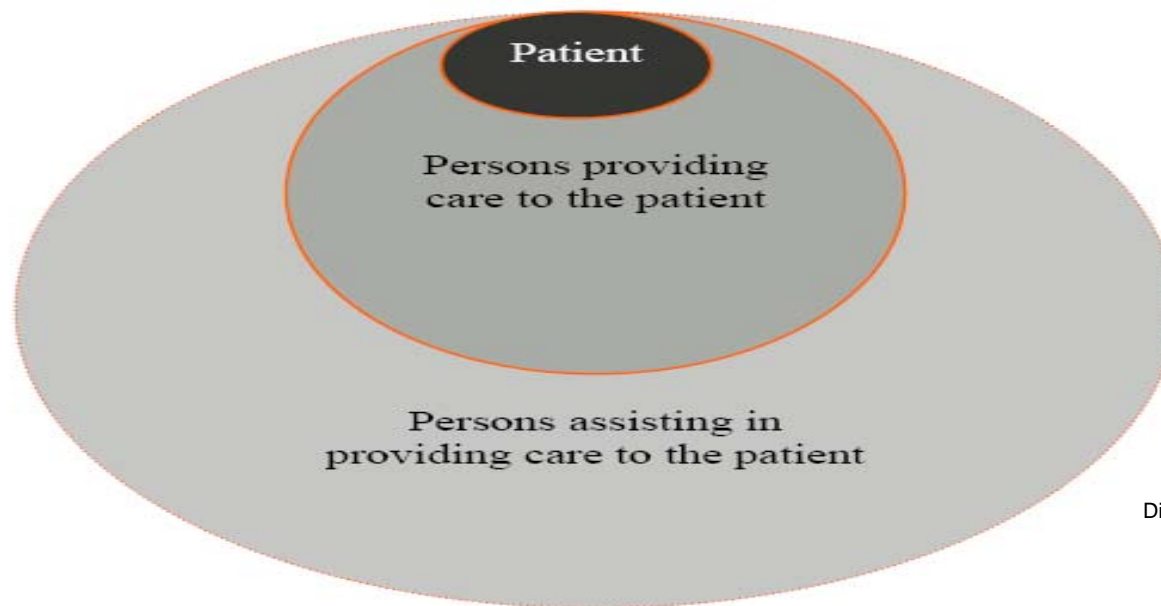


Diagram from OHA Privacy Toolkit

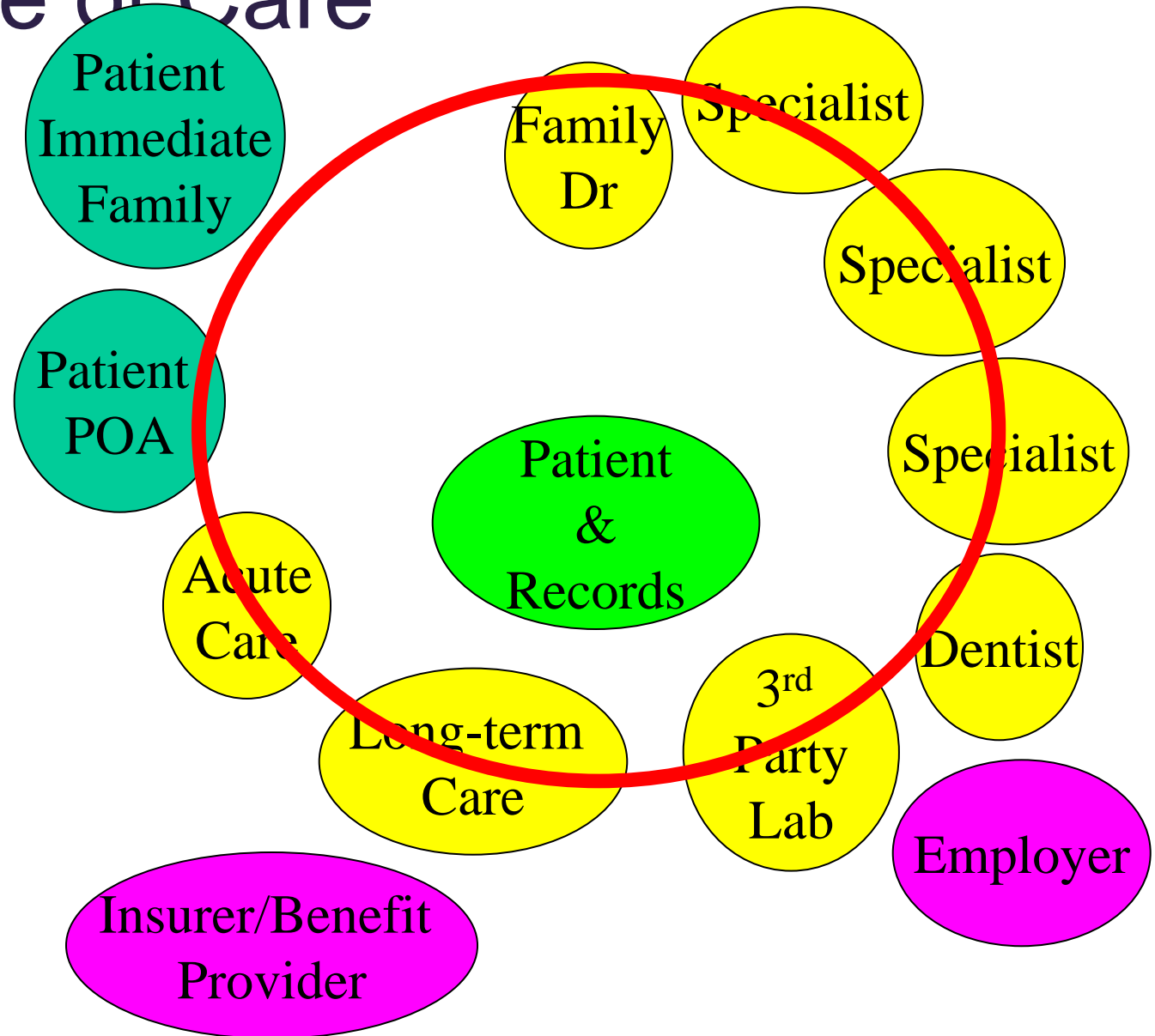
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Circle of Care



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Family Health Teams

- Introduced April, 2005
- Ontario's McGuinty government introduced "Family Health Teams" (FHTs)
 - An interdisciplinary team of physicians and other providers such as nurse practitioners, nurses, social workers and dieticians. as "a key component of the government's health care plan"

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Family Health Teams

- “Joining” a FHT requires a patient to sign a multi-page form that gives consent to share the individual’s health data with all of the health practitioners in the FHT, **and** to the Ministry of Long-term Health.

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Consent to Release Personal Information

- I understand that my family doctor will be able to offer better medical care if I permit my family doctor and the ministry to share appropriate and relevant information relating to my health.
- I agree to allow my family doctor, other family doctors in the Patient Enrolment Model (if applicable) and the ministry to exchange the information in this form related to my enrolment.
- I agree that my family doctor and the ministry can exchange information about my name, address, and telephone number.

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Why Sign THIS Consent?

- HICs may rely on express or implied consent (HIPA), and
- Assumed implied consent
- So, isn't this express consent unnecessary duplication?

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More Consent to Release PI

- I agree to allow the ministry to release the following specific information to my family doctor:
 - Dates of immunizations (flu shots, etc)
 - Dates of preventive care screening devices (pap tests, mammograms, etc)
 - Dates of service, fees paid and fee codes of primary health care services provided to me by a family doctor outside my family doctor's Patient Enrolment Model.

- I understand that this consent to release personal information ends when:
 - My enrolment with my family doctor ends, or
 - I cancel my consent by writing or telephoning the Ministry of Health and Long-term Care.

However I understand that the information already released to my family doctor will remain in my medical file.



Cancellation Conditions

Enrolment with my family doctor and my consent to release personal health information will end when:

- I cancel my enrolment by writing my family doctor or by writing or telephoning the ministry;
- I no longer qualify for health care services under the Health Insurance Act (Ontario);
- The Patient Enrolment Model to which my doctor belongs no longer exists;
- My family doctor chooses to discontinue acting as my family doctor in accordance with the College of Physicians and Surgeons of Ontario guidelines;
- I enroll with another family doctor; or,
- The ministry grants me an extended absence.



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More Cancellation Conditions

My enrollment with my family doctor and my consent to release personal health information may end when:

- I consistently fail to meet the obligations to which I have agreed in the Patient Commitment;
- My family doctor leaves the Patient Enrolment Model;
- I become a resident of a nursing home or chronic care facility;
- I am imprisoned in a Provincial or Federal correctional institution; or,
- I move outside the geographic area where the Patient Enrolment Model to which my family doctor belongs regularly provides services.

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Privacy laws are a maze that all Canadian organizations must negotiate now and forever.



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Thanks for listening!

14845-6 Yonge Street, Ste.211

Aurora (Toronto), Ontario

Canada L4G 6H8

Toll-free: 1-866-865-1967

Toronto: 416-410-3877

iturnbull@canadianprivacyinstitute.ca

www.canadianprivacyinstitute.ca

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