Accessing Information & Conducting Research Under Ontario's Privacy Laws

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GRAND COUNCIL TREATY #3 DRUG TASK FORCE



Agenda

- Privacy Law in Ontario
- About the Office of the Information and Privacy Commissioner of Ontario
- FIPPA Freedom of Information and Protection of Privacy Act
- MFIPPA Municipal Freedom of Information and Protection of Privacy Act
- PHIPA Personal Health Information Protection Act
- CYFSA The Child, Youth, and Family Services Act
- ARA Anti-Racism Act
- Coroners Act
- Summary



Privacy Law in Ontario

Privacy Law in Ontario

	Federal Public Sector	Private Sector	Ontario Public Sector	Ontario Health Sector
Applicable to	 Government of Canada E.g. federal ministries, agencies, crown corporations 	Private Sector businesses	 Government in Ontario E.g. ministries, agencies, hospitals, universities, cities, police, schools 	 Health Care Sector individuals, custodians (e.g. hospitals, clinics, pharmacies, etc.)
Laws	Privacy Act	 Personal Information Protection and Electronic Documents Act (PIPEDA) 	 Freedom of Information and Protection of Privacy Act (FIPPA) Municipal Freedom of Information and Protection of Privacy Act (MFIPPA) 	 Personal Health Information Protection Act (PHIPA)
Oversight	Privacy Commissioner of Canada	Privacy Commissioner of Canada	Information and Privacy Commissioner of Ontario	Information and Privacy Commissioner of Ontario



The Office of the Information and Privacy Commissioner of Ontario

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 Role and 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 ...



Freedom of Information and Protection of Privacy Act (FIPPA)

Application of FIPPA

- The Freedom of Information and Protection of Privacy Act (FIPPA) applies to public institutions in Ontario.
- This includes provincial ministries, most provincial agencies, boards and commissions, as well as community colleges, universities, and hospitals.

Protection of Privacy

- FIPPA requires that the government protect the privacy of an individual's personal information existing in government records.
 - Record: means a record of information in any recorded form.

Right of Access

- FIPPA also gives individuals the right to request access to government-held information, including general records and records containing their own personal information.
 - Personal information: means recorded information about an identifiable individual.



Right of Access

- Every person has a right of access to a record in the custody/control of a FIPPA institution, with limited exceptions.
- Any person can:
 - Ask for their own information
 - Ask for general records
- Any type of record can be requested
 - Paper records, emails, videos, photos, electronic information

Right of Access: Records of Personal Information Held by FIPPA Institutions

- If you want access to records of personal information under FIPPA, first ensure that the entity holding the records is a FIPPA institution, then contact the department or agency that has the information you are seeking.
- The Ontario government makes available a Directory of Institutions on its website that includes the contact information for each FIPPA institution.
- The Ontario government also makes available an online Directory of Records, which describes the types of records maintained by government.

Right of Access: Exemptions

- FIPPA sets out mandatory exemptions that require an institution to refuse to disclose a record, including:
 - Cabinet records;
 - Third party information if supplied in confidence and where disclosure could prejudice the interests of a third party;
 - Personal information about individuals other than the requester where disclosure would constitute an unjustified invasion of personal privacy.
- FIPPA also sets out discretionary exemptions which allow institutions to decide whether to disclose the requested record(s), including:
 - Information about inter-governmental relations, if the information was received in confidence;
 - Advice or recommendations within the institution;
 - Law enforcement;
 - Defense;
 - Information which could prejudice the financial or other specified interests of the institution;
 - Solicitor-client privilege;
 - Information which could endanger the health or safety of an individual;
 - information already available to the public or soon to be published.

Right of Access: Fees

- FIPPA establishes a system under which individuals seeking access to government records are required to bear some of the administrative costs involved in handling their requests, with certain limited exceptions.
- A person who makes a request for access to records must pay a \$5 application fee. The institution may also charge fees for:
 - Manually searching for a record
 - Preparing the record for disclosure
 - Computer and other costs incurred in locating, retrieving, processing and copying a record
 - Shipping costs
 - Photocopies and computer printouts
 - Records provided on CD-ROMs
 - Other costs incurred in responding to a request, as may be set by regulation
- The IPC has published guidance regarding Fees, Fee Estimates and Fee Waivers

Right of Access: Appeals

- Requesters may appeal any decision of a FIPPA institution, including denial of access and the fee estimate.
- A third party may appeal the institution's decision to disclose information that affects their interests.
- The IPC may investigate privacy complaints and report on them publicly.
- The IPC may order institutions to cease and destroy an improper collection of personal information.
- The IPC may make recommendations to safeguard privacy.

Research

- FIPPA permits the disclosure of personal information for research purposes if:
 - The disclosure is consistent with the conditions or reasonable expectations of disclosure under which the personal information was provided, collected or obtained,
 - The research purpose for which the disclosure is to be made cannot be reasonably accomplished unless the information is provided in individually identifiable form, and
 - The person who is to receive the record has agreed to comply with the conditions relating to security and confidentiality prescribed by the regulations; or
 - If the disclosure does not constitute an unjustified invasion of personal privacy.
- The conditions in the regulations to FIPPA include the requirement to set out the terms and conditions relating to security and confidentiality in a research agreement (in addition to other requirements).

Data Integration

- FIPPA includes provisions that enable prescribed data integration units, if certain conditions are met, to collect personal information for linking to create and enable access to de-identified datasets for the purpose of analysis in relation to:
 - The management or allocation of resources;
 - The planning for the delivery of programs and services provided or funded by the Government of Ontario; and
 - The evaluation of those programs and services.
- To ensure transparency, accountability and the protection of privacy, FIPPA provides a set of rules and safeguards that regulate the manner in which data integration units collect, link, use, disclose, de-identify, retain, transfer and dispose of personal information.
- This includes the requirement for the development of data standards approved by the IPC as well as the review and approval of the practices and procedures of data integration units by the IPC.
- Researchers are permitted to collect personal information from data integration units if certain conditions are met.



Summary

- FIPPA applies to provincial government bodies referred to as "institutions."
- Anyone can submit a "freedom of information" (FOI) request to a FIPPA institution to access:
 - Records of their own personal information
 - General records
- The government of Ontario makes available an online Directory of Institutions and a Directory of Records.
- There may be mandatory or discretionary exemptions that prevent you from being able to gain access to the records you are requesting.
- Every FOI request has a \$5 application fee and there are likely to be additional fees related to the provision of access to the records.
- A requester may appeal an access decision or fees to the IPC.
- FIPPA permits institutions to disclose personal information for research, with conditions.
- FIPPA permits the disclosure of personal information to data integration units, under certain conditions.
- Data integration units are permitted to disclose personal information to researchers under certain conditions.

Municipal Freedom of Information and Protection of Privacy Act (MFIPPA)

Application of MFIPPA

- The Municipal Freedom of Information and Protection of Privacy Act (MFIPPA) applies to municipal organizations in Ontario.
- This includes all municipal corporations including a metropolitan, district, or regional municipality, local boards and commissions.
- As with FIPPA, institutions under MFIPPA must protect the privacy of an individual's personal information existing in government records.
- MFIPPA also provides individuals with the right to request access to municipal government information, including most general records and records containing their own personal information.

Examples of MFIPPA Institutions

- Local Housing Corporations
- Municipalities
- Municipally operated long-term care homes
- Municipally operated ambulance/paramedic services
- Police Services Boards
- Public Health Units
- School boards



Summary

- MFIPPA applies to municipal government bodies referred to as "institutions."
- Anyone can submit a "freedom of information" (FOI) request to an MFIPPA institution to access:
 - Records of their own personal information
 - General records
- As with FIPPA, the government of Ontario makes available an online Directory of Institutions and a Directory of Records.
- There may be mandatory or discretionary exemptions that prevent you from being able to gain access to the records you are requesting.
- Every FOI request has a \$5 application fee and there are likely to be additional fees related to the provision of access to the records.
- A requester may appeal an access decision or fees to the IPC.

Personal Health Information Protection Act (PHIPA)

Application of PHIPA

- The majority of PHIPA governs personal health information in the custody or control of:
 - Health Information Custodians or
 - Agents of custodians

Application of PHIPA: 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
 - Is a plan that sets out the home and community care services for the individual to be provided by a health service provider or Ontario Health Team pursuant to funding under section 21 of the *Connecting Care Act, 2019*
 - 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
- Identifying information: when the information identifies an individual or when it is reasonably foreseeable in the circumstances that it could be utilized, either alone or with other information, to identify the individual.

Application of PHIPA: Custodians and Agents

- Health information custodians include:
 - Health care practitioners who provides health care
 - Group practices of health care practitioners who provide health care
 - 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 are persons that, with the authorization of a custodian, act for or on behalf of the custodian in respect of PHI.

Collection, Use and Disclosure

- Health information custodians are not permitted to collect, use or disclose personal health information <u>unless</u>:
 - the individual consents, or
 - the collection, use or disclosure is permitted or required by PHIPA to be made without consent
- PHIPA's "limiting principles" also prohibit custodians from:
 - Collecting, using or disclosing personal health information if other information will serve the purpose
 - Collecting, using or disclosing more personal health information than is reasonably necessary to serve the purpose

Uses and Disclosures Without Consent

- Custodians are permitted (or required, as the case may be) to use or disclose personal health information without consent, in certain circumstances.
- Some permitted <u>uses</u> without consent include:
 - Planning or delivering programs or services that the custodian provides or funds or for allocating resources to, evaluating, or monitoring the programs or services
 - Educating agents to provide health care
 - Research in compliance with PHIPA
- Some permitted <u>disclosures</u> without consent include:
 - Contacting a relative, friend or substitute decision-maker if the individual is injured, incapacitated or ill and unable to give consent
 - Determining or verifying the eligibility of an individual to receive publicly funded health care
 - To public health authorities for a purpose in the Health Protection and Promotion Act
 - Eliminating or reducing a significant risk of serious bodily harm
 - Research in compliance with section 44 of PHIPA



Right of Access: Records of Personal Health Information Held by Custodians

- In general, individuals have a right of access to records of personal health information about themselves that are in the custody or control of a health information custodian, with some exceptions such as:
 - The record is subject to legal privilege that restricts disclosure of the record
 - Another Act, an Act of Canada, or a court order prohibits disclosure of the record
 - Granting the access could reasonably be expected to result in a risk of serious harm to the treatment or recovery of the individual or a risk of serious bodily harm to the individual or another person

Right of Access: Fees

- Custodians may charge a reasonable fee for providing access to an individual's records of personal health information.
- PHIPA also permits a custodian to waive all or part of the fee associated with an access request.
- In charging a fee, PHIPA requires custodians to first provide the individual with a fee estimate.
- The fee amount must not exceed the prescribed amount set out in the regulations, if any, or the amount of reasonable cost recovery; however, there is currently no regulation prescribing the fee for providing access to an individual's records of personal health information.

Complaints Under PHIPA

- A person who believes that another person has contravened, or is about to contravene PHIPA, has the right to submit a written complaint to the IPC.
- For example, a person may complain about:
 - A custodian's information practices
 - A refusal to grant access to personal health information
 - A refusal to correct or amend personal health information
 - The fee estimate provided by a custodian in responding to a request to access records of personal health information

Research under Section 44 of PHIPA

- Custodians are permitted to disclose personal health information to a researcher for research purposes if the conditions of section 44 of PHIPA are met.
- For example, researchers must submit a detailed research plan to a Research Ethics Board (REB) for approval.
- When deciding whether to approve a research plan involving the use or disclosure of personal health information without consent, a REB must consider:
 - Whether the research can be reasonably accomplished without using the personal health information;
 - The public interest in conducting the research and in protecting privacy;
 - Whether obtaining consent is impractical; and
 - Whether adequate safeguards will be in place to protect the privacy of individuals and the confidentiality of their personal health information.
- In addition, the custodian must enter into an agreement with the researcher that may impose further restrictions, including the manner in which the researcher may use and disclose the personal health information.

Prescribed Entities and Prescribed Persons

- Custodians are also permitted to disclose personal health information to:
 - <u>Prescribed entities</u> for the purposes of planning, management and analysis of the health system (if certain conditions under PHIPA are met).
 - <u>Prescribed persons</u> who compile and maintain registries of personal health information for the purpose of facilitating or improving the provision of health care or that relates to the storage or donation of bodily parts or substances (if certain conditions under PHIPA are met).
- Prescribed entities and prescribed persons under PHIPA are permitted to disclose personal health information to researchers if the conditions of section 44 of PHIPA are met.

Summary

- PHIPA primarily applies to personal health information in the custody or control of health information custodians.
- PHIPA does not provide a right to access general records.
- Anyone can request access to records of their own personal health information.
- Disclosure of personal health information for purposes other than the provision of health care to the individual is typically only permitted with the express consent of the person to whom the information relates.
- Custodians are permitted (or required, as the case may be) to disclose personal health information without consent, in certain circumstances.
- For example, this includes research in compliance with s. 44 of PHIPA.
- Prescribed entities and prescribed persons may also disclose PHI to researchers in compliance with section 44 of PHIPA.
- PHIPA does not permit an application fee for requesting access to records of your own PHI, but there are likely to be additional fees related to the provision of access to the records.
- Anyone may make a complaint to the IPC who believes that another person has contravened, or is about to contravene PHIPA.

The Child, Youth, and Family Services Act (CYFSA)

Overview of the CYFSA

- The primary purpose of the Child, Youth, and Family Services Act (CYFSA) is to promote the best interests, protection and well-being of children.
- The CYFSA governs certain programs and services for children, youth, and families, including:
 - Child welfare
 - Residential care
 - Adoption
 - Youth justice
 - Children's mental health
 - First Nations child and family services
 - Inuit child and family services
 - Métis child and family services



Part X of the CYFSA

- The CYFSA is divided into parts, and the Information and Privacy Commissioner is the oversight body for Part X of the CYFSA.
- Part X of the CYFSA sets out rules for service providers regarding privacy and access to personal information.
 - Service provider: includes persons or entities that provide services funded under the CYFSA, or under the authority of a license under the CYFSA (e.g. children's aid societies).
- With limited exceptions, service providers must have consent to collect, use or disclose personal information.
- Service providers must give individuals access to records of their own personal information on request, subject to limited exceptions, and must respond to requests for correction of inaccurate or incomplete records.

Part X of the CYFSA: Disclosures Without Consent

- Service providers are permitted (or required, as the case may be) to use or disclose personal information without consent, in certain circumstances, including:
 - Everyone must report to a children's aid society if they reasonably suspect a child may be in need of protection
 - Children's aid societies are required to consult with a representative chosen by each of a child's bands and First Nation, Métis or Inuit communities whenever proposing to provide certain services to the child (e.g. safety plan)
 - If there are reasonable grounds to believe that the disclosure is necessary to assess, reduce or eliminate a risk of serious harm to a person or group
 - To contact a relative, friend or potential substitute decision-maker in certain instances, such as where the individual is injured or incapacitated
 - For purposes such as planning services, managing services, and research
- IPC guidance: <u>Part X of the Child, Youth and Family Services Act: A Guide to Access and Privacy for Service Providers</u>

Part X of the CYFSA: Access to Personal Information Held by a Service Provider

- Individuals have a right under Part X to access their records of personal information from service providers, subject to limited exceptions.
- There are some exceptions to the right of access such as:
 - The record being subject to legal privilege restricting its disclosure
 - Another law or court order prohibits the disclosure
 - If granting access could reasonably be expected to:
 - Result in a risk of serious harm to any individual
 - Lead to the identification of an individual who was required by law to provide information in the record to the service provider
 - Lead to the identification of an individual who provided the information in confidence

Part X of the CYFSA: Fees

- Service providers are <u>not permitted to charge fees</u> for providing access to a record of personal information.
- This rule applies to all of the activities associated with processing an access request.

Research

- Service providers are permitted to disclose personal information for purposes such as planning services, managing services, and research.
- Service providers may disclose personal information to:
 - The Minister of Children, Community and Social Services for certain purposes, including determining compliance with the CYFSA, and improving the quality of services.
 - <u>Prescribed entities</u> for analysis or compiling statistics for planning, managing and evaluating services, the allocation of resources to those services (including their delivery) if certain conditions are met.
 - A First Nations, Inuit or Métis person or entity, for analysis or compiling statistics for planning, managing and evaluating services, the allocation of resources to those services (including their delivery), if certain conditions are met.
- Prescribed entities under Part X of the CYFSA are permitted to disclose personal information to a researcher if certain conditions are met (e.g. research plan approved by a research ethics board)

First Nations, Inuit or Métis "Person or Entity"

- A service provider may only disclose personal information to a First Nations, Inuit or Métis person or entity if:
 - The person or entity identifies as a First Nations, Inuit or Métis person or entity
 - The information relates to First Nations, Inuit or Métis individuals
 - The service provider and the person or entity have entered into an agreement with respect to the use, security, disclosure, return or disposal of the information that requires the person or entity to notify the service provider in the case of a privacy breach
 - The service provider has received written acknowledgement from each of the bands or First Nations, Inuit or Métis communities whose member's personal information will be disclosed, indicating approval of the person or entity to receive the personal information
 - The service provider has received written acknowledgement from each of the bands or First Nations, Inuit or Métis communities with which an individual whose personal information will be disclosed identifies, indicating approval of the person or entity to receive the personal information



CYFSA Summary

- Part X of the CYFSA sets out rules for service providers regarding privacy and access to personal information.
- Part X of the CYFSA does not provide a right to access general records.
- Anyone can request access to records of their own personal information.
- Disclosure of personal information is typically only permitted with the consent of the person to whom the information relates.
- Service providers are permitted (or required, as the case may be) to use or disclose personal information without consent, in certain circumstances.
- For example, this includes purposes such as planning services, managing services, and research.
- Prescribed entities under Part X of the CYFSA are permitted to disclose personal information to a researcher if certain conditions are met (e.g. research plan approved by a research ethics board).
- Part X of the CYFSA puts in place provisions for disclosing personal information to a First Nations, Inuit or Métis person or entity that does not need to be prescribed by regulation but must meet certain conditions.
- Part X of the CYFSA does not permit an application fee for requesting access to records of your own personal information and, in fact, service providers are not permitted to charge any fees at all for providing this access.
- A requester may appeal an access decision to the IPC.

Anti-Racism Act (ARA)

Anti-Racism Act

- The Anti-Racism Act (ARA) authorizes or requires public sector organizations (PSOs) listed under the regulations to collect and use personal information for the purpose of eliminating systemic racism and advancing racial equity.
- The ARA sets out privacy obligations to protect that personal information.
- The regulation requires PSOs in child welfare, education, and justice to collect personal information (for example, Indigenous identity, race, religion, and ethnic origin information.
- The IPC is the oversight body with respect to the personal information rules and may:
 - Order PSOs to discontinue, change, or implement a practice, and destroy personal information collected
 - Comment and make recommendations on privacy implications of any matter related to the act, regulations, or data standards



Disclosure of Personal Information

- PSOs may disclose personal information only if:
 - The person to whom the information relates consents to the disclosure;
 - The disclosure is required by law;
 - The disclosure is for the purpose of a proceeding;
 - The disclosure is for a research purpose in accordance with section 8; or
 - The disclosure is to the IPC.
- However, these permitted disclosures do not apply to personal information held by the PSO if it was lawfully collected for another purpose in addition to the purpose under the ARA.

Anti-Racism Data Standards

- The <u>Data Standards for the Identification and Monitoring of Systemic Racism</u>, also known as Ontario's <u>Anti-Racism Data Standards</u> or "The Data Standards," were established for the collection, use and management of information, including personal information, to identify and monitor systemic racism and racial disparities for the purpose of eliminating systemic racism and advancing racial equity.
- The Standards have been made by the Minister Responsible for Anti-Racism and have been established by approval of the Lieutenant Governor in Council.
- The Information and Privacy Commissioner (IPC) and the Ontario Human Rights Commission (OHRC) were consulted in their development.
- Anti-Racism Data Standards Order in Council 897/2018

Summary

- The ARA authorizes or requires PSOs to collect and use personal information for the purpose of eliminating systemic racism and advancing racial equity.
- The ARA Data Standards require certain de-identified information to be reported publicly.
- The ARA Data Standards require PSOs to provide individuals with access to records of their own personal information.
- Disclosure of personal information is typically only permitted with the consent of the person to whom the information relates.
- PSOs are permitted (or required, as the case may be) to use or disclose personal information without consent, in certain circumstances.
- However, these permitted disclosures do not apply to personal information held by the PSO if it was lawfully collected for another purpose in addition to the purpose under the ARA.

The Coroners Act

Coroners Act: Prescribed Entities

- Under the Coroners Act, the Chief Coroner is permitted to disclose personal information to prescribed entities for the purpose of research, analysis, or the compilation of statistics related to the health or safety of the public, or any segment of the public.
- <u>Prescribed entities</u> under the Coroners Act are permitted to disclose personal information to researchers if certain conditions are met (e.g. research plan approved by a research ethics board).
- The IPC reviews and approves the practices and procedures of prescribed entities under the Coroners Act every three years.

PHIPA and Coroners

- Coroners are <u>not</u> health information custodians under PHIPA.
- However, PHIPA includes specific provisions related to coroners, including:
 - Ontario Health may provide coroners with personal health information that is accessible by means of the electronic health record (EHR) if the provision is related to an investigation conducted under the Coroners Act (subject to requirements set out under the regulations to PHIPA).
 - If personal health information is collected without authority by a coroner by means of the EHR, the coroner must:
 - Notify the individual at the first reasonable opportunity
 - Notify the Commissioner at the first reasonable opportunity



Summary

- Under the Coroners Act, prescribed entities may collect personal information from the Chief Coroner, without the consent of the individuals to whom the information relates, and use it for the purpose of research, analysis, or the compilation of statistics related to the health or safety of the public, or any segment of the public.
- Prescribed entities under the Coroners Act are permitted to disclose personal information to researchers if certain conditions are met (e.g. research plan approved by a research ethics board).

Summary

Obtaining Information under Ontario's Privacy Laws

	M/FIPPA	PHIPA	Part X CYFSA	ARA	Coroners Act
Generally, individuals may obtain:	Their own personal informationGeneral records	Their own personal health information	 Their own personal information 	Their own personal informationPublic reports	• N/A
Generally, researchers may obtain:	 General records Personal information from institutions if conditions are met Personal information from data integration units, if conditions are met 	 Personal health information from custodians if s44 conditions are met Personal health information from prescribed entities or prescribed persons if s44 conditions are met 	 Personal information from a prescribed entity if conditions are met 	 Public reports General records Personal information, if conditions are met 	 Personal information from prescribed entities if certain conditions are met

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