

<b>Section</b>	Privacy Policies, Procedures and Practices			
<b>Name</b>	<b>Privacy Policy in Respect of POGO's Status as a Prescribed Entity ("Privacy Policy"), formerly the <i>POGO Privacy and Data Security Code</i></b>			
<b>Authority</b>	Senior Leadership Team			
<b>Owner</b>	Privacy Officer			
<b>Levels of Access</b>	Level 0, Level 1, Level 2, Level 3, Level 4			
<b>Number</b>	<b>Created</b>	<b>Frequency of Ongoing Review</b>	<b>Last Ongoing Review</b>	<b>Next Ongoing Review</b>
1.01	7/10/2025	Triennially	n/a	~8/1/2027

## Definitions

Please refer to [Appendix A](#) for definitions of acronyms and terms.

## Background

### About POGO

Founded in 1983, Pediatric Oncology Group of Ontario (POGO) works to ensure that everyone affected by childhood cancer has access to the best care and support. We partner to ensure an excellent childhood cancer care system for children and youth with cancer, survivors of childhood cancer and their families and healthcare teams, in Ontario and beyond. POGO champions childhood cancer care and, as the collective voice of this community, is the official advisor to Ontario's Ministry of Health on children's cancer control and treatment. POGO is a non-profit organization with charitable status incorporated in 1997 under the laws of Ontario, here for kids with cancer, for now, for life.

### POGO's Status under the *Personal Health Information Protection Act*

In 2004, POGO was designated as a Prescribed Entity under section 18(1) of the Regulations to the Personal Health Information Protection Act, 2004 (PHIPA) for the purposes described in section 45 of PHIPA. This designation legally permits POGO to collect and use Personal Health Information (PHI) disclosed by Health Information Custodians (HICs) for analyzing or compiling statistical information related to the management, evaluation, monitoring, resource allocation or planning of any part of the health system, including service delivery.

POGO is committed to adhering to PHIPA, its Regulations and the *Manual for the Review and Approval of Prescribed Persons and Prescribed Entities* ("the Manual") from the Information and Privacy Commissioner of Ontario (IPC). It has established a Privacy and Information Security program with policies, procedures and practices to protect the privacy of individuals whose PHI is received and maintain the confidentiality of that information, which are reviewed and approved by the IPC every three years.

## Related Policies, Procedures and Practices

Please refer to [Appendix C](#) for a list of POGO policies, procedures and practices related to the 10 Fair Information Principles.

## Purpose

This policy, procedures and practices sets out POGO's compliance with:

- The 10 Fair Information Principles of the Canadian Standards Association (CSA) *Model Code for the Protection of Personal Information* (1996) integrated into the *Personal Information Protection and Electronic Documents Act*, 2000 (PIPEDA)
- PHIPA and its Regulations in respect of POGO's status as a Prescribed Entity and
- The Manual of the IPC.

## Scope

This policy, procedures and practices applies to:

- All POGO Agents handling PHI and Personal Information (PI) on behalf of POGO and
- All PHI and PI collected, used, disclosed, retained, transferred and/or disposed of by POGO under either its statutory authority as a Prescribed Entity or the authority of express consent.

## 10 Fair Information Principles

### Principle 1 – Accountability

POGO is responsible for Personal Health Information and Personal Information under its control. The Chief Executive Officer is accountable for its compliance and has delegated their authority to different members within POGO.

The *POGO Privacy and Information Security Governance and Accountability Framework* outlines POGO's governance structure for ensuring compliance with PHIPA and its Regulations and the Manual.

The Chief Executive Officer (CEO) of POGO is ultimately accountable to the POGO Board of Directors, the IPC and Ontario's Ministry of Health, as applicable, for ensuring POGO complies with:

- The 10 Fair Information Principles outlined in this policy, procedures and practices
- PHIPA and its Regulations regarding POGO's status as a Prescribed Entity and
- POGO's Privacy and Information Security policies, procedures, and practices.

The CEO delegates their authority to other individuals within POGO, who are responsible for developing and managing POGO's Privacy and Information Security programs. Each of these individuals reports directly to the CEO, and their specific duties and responsibilities are detailed in [Appendix B](#). The roles and their key activities are as follows:

- **Privacy Officer:** This role has the authority to manage POGO's day-to-day Privacy program and oversee compliance with the Privacy and Information Security programs. The Privacy Officer's key responsibilities include developing, implementing and ensuring awareness of and compliance with POGO's policies, procedures and practices related to Privacy, Information

Security, Human Resources and Organizational matters pertaining to PHIPA, its Regulations and the Manual. The Privacy Officer also leads the triennial review process.

- **Director, Finance and Administration:** This role has the authority to manage POGO's day-to-day Information Security program. The Director, Finance and Administration's key responsibilities include developing and implementing the organizational Information Security, Corporate Risk Management and Business Continuity and Disaster Recovery (BCDR) programs, as well as overseeing compliance for Corporate Risk Management and the BCDR Plan.
- **Manager, Data Holdings and Operations:** This role has the authority to manage POGO's Data Holdings containing PHI and PI. The Manager, Data Holdings and Operations' key responsibilities include developing and implementing data governance standards, implementing information security standards and overseeing compliance for data governance.

The CEO has also delegated authority to several operational committees within POGO to gather feedback on operational approaches to comply with POGO's Privacy and Information Security policies, procedures and practices. These committees include the Operations Group, the POGO Data Operations Committee and cross-functional teams (CFTs) focused on Data Holdings. All Terms of Reference for these committees are available upon request by contacting the Privacy Officer using the contact information provided in [Principle 10 – Challenging Compliance](#).

## Principle 2 – Identifying Purposes

POGO identifies the purposes for which the Personal Health Information or Personal Information is collected, used and disclosed under its Prescribed Entity statutory authority or consent provisions.

POGO creates a statement of purpose for each POGO Data Holding to describe the purposes for collection, use and disclosure.

POGO clearly identifies the purposes for which it collects and uses PHI or PI before gathering or utilizing such data. POGO ensures each purpose for collecting or using PHI, under its authority as a Prescribed Entity, aligns with the collections permitted by PHIPA and its Regulations. Additionally, these purposes are necessary for POGO to fulfill its mandate.

POGO's Data Holding managers and CFTs seek consultation with external pediatric oncology agents, where applicable, when identifying, reviewing and amending Data Holding statements of purpose and/or any of the purposes for collection of PHI or PI.

POGO collects PHI under its statutory authority as a Prescribed Entity to:

- Maintain the POGO Networked Information System (POGONIS), which is POGO's active registry and Database of all childhood cancer cases diagnosed and/or treated at specialized childhood cancer programs in Ontario since 1985
- Maintain Data Holdings that enable POGO to administer programs and services, including the POGO Provincial Pediatric Oncology AfterCare Clinic, Interlink Nursing and Satellite Clinic Programs
- Coordinate the allocation of funding across the provincial childhood cancer care system
- Fulfill POGO's contractual obligations to Ontario's Ministry of Health and the Public Health Agency of Canada (PHAC) regarding reporting on childhood cancer in Ontario

- Support the planning, monitoring, evaluation and improvement of the childhood cancer care system and its programs through various projects and initiatives POGO may undertake from time to time and
- Provide information to policymakers, government entities and community stakeholders to guide decision-making that reflects the needs of children and youth with cancer, survivors of childhood cancer and their families and healthcare teams, while also assessing how POGO continues to address those needs.

POGO also collects PI under the authority of express consent to:

- Administer service delivery programs to children and youth with cancer, survivors of childhood cancer and their families
- Inform our community stakeholders and
- Facilitate additional analysis and potential research endeavors through Linkages with POGONIS.

### Principle 3 – Consent

POGO obtains consent from individuals for the collection, use or disclosure of Personal Health Information or Personal Information for any activity outside its Prescribed Entity authority.

POGO is legally authorized to collect, use and disclose PHI without individual consent under its authority as a Prescribed Entity, following PHIPA and its Regulations.

When POGO uses or discloses PHI collected under its statutory authority as a Prescribed Entity for research purposes, it complies with sections 37(1)(j) and (3), 39(1)(c) and 44(2)-(4) and (6)(a)-(f) of PHIPA as well as section 18(3) of its Regulations, where applicable. If the research ethics board (REB) requires informed consent from the individuals whose PHI is being used, POGO ensures the researcher obtains this consent before proceeding with the use or disclosure.

POGO obtains express consent from the patient/client and family, if applicable, prior to its collection, use and disclosure of PI.

### Principle 4 – Limiting Collection

POGO will only collect Personal Health Information or Personal Information if other information will not serve the purpose and will not collect more Personal Health Information or Personal Information than is reasonably necessary to serve the purpose.

### Types of Personal Health Information and Personal Information Collected by POGO

POGO collects pediatric oncology-related PHI and PI such as:

- Demographic, diagnosis, treatment and outcome information for children and youth with cancer diagnosed and/or treated at a specialized childhood cancer program in Ontario
- Administrative information derived from POGO programs and service delivery to children and youth with cancer, survivors of childhood cancer and their families and healthcare teams and
- Time-limited data sets to inform and facilitate specific analyses, projects and initiatives to meet the strategic goals and objectives of POGO's *Childhood Cancer Care Plan*.

## Sources of Personal Health Information Collected by POGO

POGO as a Prescribed Entity collects PHI from:

- HICs in Ontario that operate specialized childhood cancer programs and the POGO AfterCare Clinic, Interlink Nursing and Satellite Clinic Programs and
- Other Prescribed Entities, Prescribed Persons and Prescribed Organizations for Linkage purposes.

POGO also collects PI from children and youth with cancer, survivors of childhood cancer and their families with consent.

## POGO Data Holdings Containing Personal Health Information and Personal Information

### POGO Prescribed Entity Data Holdings

POGO maintains the following Data Holdings containing PHI under its statutory authority as a Prescribed Entity:

- POGONIS
- POGO AfterCare Clinic Program Database
- POGO Interlink Nursing Program Database
- POGO Satellite Clinic Program Database

### POGO Consent-Based Service Delivery Program Data Holdings

POGO maintains the following Data Holdings containing PI under the authority of express consent:

- POGO Financial Assistance Program Database
- POGO School and Work Transitions Program Database

Individuals may obtain further information in relation to the purposes, elements and sources of each Data Holding containing PHI or PI on the POGO website at [POGO Databases](#) or by contacting the Privacy Officer using the contact information provided in [Principle 10 – Challenging Compliance](#).

## Principle 5 – Limiting Use, Disclosure and Retention

POGO commits to:

- Minimize the use of Personal Health Information or Personal Information by only using it when necessary and opting for alternative information whenever possible
- Use only the least identifiable and minimum amount of Personal Health Information or Personal Information or opt for De-Identified and/or Aggregate information when appropriate
- Not disclose Personal Health Information or Personal Information if other information can fulfill the purpose
- Not disclose more Personal Health Information or Personal Information than is reasonably necessary to achieve the purpose
- Publish only Aggregated data and
- Only keep Personal Health Information or Personal Information as long as required to serve POGO's mandate or contractual obligations.

## Uses of Personal Health Information and Personal Information by POGO

POGO uses PHI and PI:

- For the purposes for which POGO collected the PHI under its statutory authority as a Prescribed Entity or under express consent or in our statements of purpose set out in [Principle 2 – Identifying Purposes](#)
- To conduct research on childhood cancer in accordance with sections 37(1)(j) and (3), 39(1)(c) and 44(2)-(4) and (6)(a)-(f) of PHIPA and section 18(3) of its Regulations or under the authority of express consent where aligned with the four pillars of the POGO Research Unit (PRU):
  - Epidemiology
  - Health services research
  - Health economics and
  - Status of survivors/quality of life
- To perform data Linkages with other Prescribed Entities, Prescribed Persons and Prescribed Organizations, in accordance with sections 13(1) and 18(1) of the Regulations to PHIPA, when consistent with the purposes outlined in section 45(1) of PHIPA and its Regulations and
- With the express consent of the individual to whom the PHI or PI relates.

POGO analyzes data in both Aggregate and individual record-level forms in accordance with section 45(1) of PHIPA. POGO only uses the minimum amount of PHI or PI necessary to achieve its purposes, ensuring the information is either De-Identified or Aggregated whenever possible. Access to PHI or PI is restricted to authorized POGO Agents on a “need-to-know” basis, meaning POGO Agents only access the information necessary to perform their duties. POGO remains responsible for all PHI and PI accessed by POGO Agents.

POGO ensures any use of PHI it collected as a Prescribed Entity complies with the permitted uses outlined by PHIPA and its Regulations, as detailed in POGO’s statements of purpose.

### **Disclosures of Personal Health Information and Personal Information by POGO**

POGO discloses PHI and PI:

- For the purposes for which POGO collected the PHI under its statutory authority as a Prescribed Entity or under the authority of express consent set out in [Principle 2 – Identifying Purposes](#)
- To the HIC that originally provided the information to POGO, provided it does not include any additional identifying details, in accordance with section 18(5) of the Regulations to PHIPA
- To facilitate research on childhood cancer, in accordance with sections 37(1)(j), 39(1)(c) and 44(2)-(4) and (6)(a)-(f) of PHIPA or under the authority of express consent
- With the express consent of the individual to whom the PHI or PI relates or
- As required by PHIPA and its accompanying Regulations.

POGO reviews De-Identified and/or Aggregate information prior to disclosure to ensure the patient/client cannot be identified and it is reasonably foreseeable in the circumstances that the information cannot be utilized, either alone or with other information, to identify the patient/client.

### **Disclosures of Personal Health Information and De-Identified and/or Aggregate Information for Purposes Other Than Research**

POGO executes a Data Sharing Agreement (DSA) with the person or organization specifying the purpose for which the disclosure of PHI is being requested.

POGO may disclose De-Identified and/or Aggregate information to HICs in Ontario, Ontario’s Ministry of Health, PHAC and other persons and organizations in the childhood cancer community. Prior to such



disclosures, POGO first receives a POGO Data Request Form from and/or executes a written agreement with the person or organization specifying the purpose for which the disclosure of De-Identified and/or Aggregate information is being requested.

### **Disclosures of Personal Health Information and De-Identified and/or Aggregate Information for Research Purposes**

POGO discloses both PHI and De-Identified and/or Aggregate information to researchers studying childhood cancer, provided their research aligns with the four pillars of the PRU mentioned in [Uses of Personal Health Information by POGO](#).

Before any disclosures occur, researchers must submit a POGO Data Request Form, a Research Plan, a copy of the REB approval for the Research Plan and any other necessary documentation related to the research project. If the REB determines informed consent is required from the individuals whose PHI is involved, the researcher must obtain this informed consent.

After these steps, POGO will execute a Research Agreement with the researcher, which clearly outlines the purpose for requesting the disclosure of PHI or De-Identified and/or Aggregate information.

### **Secure Retention, Transfer and Disposal of Records of Personal Health Information and Personal Information**

POGO has established guidelines and implemented procedures for the secure retention of PHI and PI.

POGO securely retains all records of PHI and PI in electronic format indefinitely, or as specified by the HIC in the DSA or per the individual's express consent.

When POGO uses records of PHI or PI for purposes other than research, it retains the identifiable records as long as necessary to fulfill the purposes for which the PHI or PI was collected or as outlined in the DSA or express consent. For research purposes, POGO retains identifiable records of PHI for the duration specified in the Research Plan approved by the REB. POGO securely disposes of or De-Identifies and/or Aggregates records of PHI or PI that are no longer needed to meet the identified purposes.

POGO transfers all PHI and PI through a secure channel.

### **Principle 6 – Accuracy**

POGO verifies Personal Health Information and Personal Information remains accurate, complete and up-to-date as possible in order to properly satisfy the purposes for which it is to be used.

POGO has implemented standard operating procedures (SOPs) to continuously monitor, evaluate and improve the accuracy, timeliness and other quality dimensions of PHI and PI. POGO specifies any limitations in the accuracy, completeness or timeliness of PHI, PI or De-Identified and/or Aggregate information it uses or discloses.

## Principle 7 – Safeguards

POGO protects all data, including Personal Health Information and Personal Information, within its custody or control by applying appropriate administrative, technical and physical safeguards.

POGO considers all Personal Health Information and Personal Information to be highly sensitive.

POGO has implemented administrative, technical and physical safeguards to:

- Protect the privacy of individuals whose PHI or PI is received and maintain the confidentiality of that information
- Protect PHI and PI against theft, loss and unauthorized collection, use or disclosure and
- Protect records of PHI and PI against unauthorized copying, modification or disposal.

### Administrative Safeguards

- POGO Agents commit to following POGO's Code of Conduct, execute Confidentiality Agreements and complete initial privacy and information security training upon commencement of their employment, contractual or other relationship with POGO.
- POGO Agents granted approval to access and use PHI or PI re-execute Confidentiality Agreements and complete ongoing privacy and information security training on an annual basis.
- POGO conducts and routinely reviews privacy impact assessments (PIAs) for its programs and services with Data Holdings containing PHI or PI and manages any findings, risks and recommendations arising.
- POGO has implemented policies, procedures and practices for granting access to and use of PHI or PI and Confidential Information (CI), secure transfer and disposal of records of PHI or PI to prevent unauthorized parties from gaining access to the PHI or PI, acceptable use of technology and BCDR.

### Technical Safeguards

- Firewalls, virtual private networks (VPNs), separate networks, password requirements and encryption.
- Logging of system audits and data modifications.
- Back-up and recovery systems and a secure file transfer process.

### Physical Safeguards

- Locked facility with tracked card access, locked filing cabinets, restricted access to offices and internal/external video monitoring.

## Principle 8 – Openness

POGO commits to making detailed information about its policies, procedures and practices relating to the management of Personal Health Information and Personal Information publicly and readily available.

POGO publishes this policy, procedures and practices, Data Holding statements of purpose and Frequently Asked Questions (FAQs) on its external website.



Individuals may obtain further information in relation to the Privacy policies, procedures and practices of POGO:

- On the POGO website at [Frequently Asked Questions \(FAQs\)](#) or
- By contacting the Privacy Officer directly by mail, email or telephone using the mailing address and contact information set out in [Principle 10 – Challenging Compliance](#).

## Principle 9 – Individual Access

POGO will, upon request by an individual, inform the individual of the existence, use and disclosure of their Personal Health Information or Personal Information.

POGO will provide access to Personal Information collected through its consent-based service delivery programs. Individuals can challenge the accuracy and completeness of the information and have it amended as appropriate.

Individuals may request information about the existence, use and disclosure of their PHI or PI by:

- Contacting the Privacy Officer directly by mail, email or telephone using the mailing address and contact information set out in [Principle 10 – Challenging Compliance](#) or
- Completing a request form available through the POGO website at [Privacy Concerns, Complaints and Inquiries](#) for submission to the Privacy Officer.

Subject to verification of identity, POGO informs the individual of the existence, use and disclosure of their PHI or PI to the best of its ability. Where POGO collected the individual's PHI under its statutory authority as a Prescribed Entity, POGO redirects any access and correction requests to the HIC(s) that originally disclosed the individual's PHI to POGO and amends the individual's PHI as directed by the HIC(s). Where POGO collected the individual's PI under the authority of express consent, POGO addresses any access and correction requests itself.

## Principle 10 – Challenging Compliance

An individual can challenge POGO's compliance with the above principles. Their challenge should be addressed to the person accountable for the organization's compliance, usually through POGO's Privacy Officer.

Individuals may direct inquiries, concerns or complaints related to POGO's compliance with the 10 Fair Information Principles set out in this policy, procedures and practices, PHIPA and its Regulations or the Privacy policies, procedures and practices implemented by POGO by:

- Contacting the Privacy Officer directly by mail, email or telephone using the mailing address and contact information listed below or
- Completing the POGO Privacy Concern, Complaint or Inquiry Form available through the POGO website at [Privacy Concerns, Complaints and Inquiries](#) for submission to the Privacy Officer.

Privacy Officer  
Pediatric Oncology Group of Ontario  
480 University Avenue, Suite 1014  
Toronto, ON M5G 1V2  
[privacy@pogo.ca](mailto:privacy@pogo.ca)

416-592-1232 ext. 298

Individuals may direct complaints regarding POGO's compliance with PHIPA and its Regulations to the IPC using the mailing address and contact information listed below.

Information and Privacy Commissioner of Ontario  
2 Bloor Street East, Suite 1400  
Toronto, ON M4W 1A8  
[info@ipc.on.ca](mailto:info@ipc.on.ca)  
Toronto Area: 416-326-3333  
Long Distance: 1-800-387-0073  
TDD/TTY: 416-325-7539

## Compliance, Audit and Enforcement

- POGO Agents are required to comply with this policy, procedures and practices.
- POGO Agents are required to notify the Privacy Officer at the first reasonable opportunity, in accordance with the *Policy, Procedures and Practices for Privacy Breach Management*, if a POGO Agent breaches or believes there may have been a breach of this policy, procedures or practices.
- The Privacy Officer is responsible for ensuring compliance with this policy, procedures and practices.
- The Chief Executive Officer enforces compliance, and the consequences of breach, in accordance with the *Policy, Procedures and Practices for Discipline and Corrective Action*.
- Compliance is audited by the Privacy Officer in accordance with the *Policy, Procedures and Practices for Privacy Audits*.

## Record of Updates

Date (Year/Month)	Description	Approval Authority
2025 July	Revised the <i>POGO Privacy and Data Security Code</i> to be titled <i>Privacy Policy in Respect of POGO's Status as a Prescribed Entity ("Privacy Policy")</i> . Incorporated contents from <i>POGO Privacy and Data Security Procedures and Policy 9.1.01 Process for 44 and 45 Projects</i> .	Privacy Officer

## Appendix A: Glossary of Terms

Term	Definition
<b>Confidential information (CI)</b>	Means any and all data and information, written or oral, which relates in any way to POGO, past, present or future, including any and all proprietary information of any nature or kind, in POGO's custody or control, fundraising plans, practices or strategies, technical data, trade secrets or know-how, research of POGO and/or any third party, business plans, project plans, products, services, formulas, technology, designs, marketing, finances or other business information, notes and memoranda as well as any other data or information provided to the POGO Agent by POGO or generated by the POGO Agent in the course of fulfilling the purposes for which it was provided to the POGO Agent.
<b>Data holding</b>	An entity or system to store, manage or retain data, either structured or unstructured, ranging from individual files on a computer or in paper format to large databases maintained by organizations or institutions. Includes the applications, files, policies, procedures and practices and standard operating procedures (SOPs) developed and implemented to govern the data and its management.
<b>Data Sharing Agreement (DSA)</b>	An agreement that is executed between POGO and another party in accordance with Policy 1.10 <i>Execution of Data Sharing Agreements</i> and the <i>Template Data Sharing Agreement</i> .
<b>Database</b>	A structured collection of data organized and stored to allow for efficient retrieval, updating and management, typically consisting of one or more tables containing rows and columns of data.
<b>De-identified and/or aggregate information</b>	In relation to the PHI of an individual, means to remove any information that identifies the individual or for which it is reasonably foreseeable in the circumstances that it could be utilized, either alone or with other information, to identify the individual, and "de-identification" has a corresponding meaning.
<b>Health information custodian/custodian</b>	A "health information custodian" within the meaning of PHIPA and its regulations.
<b>Identifying information</b>	Includes information that identifies an individual or for which it is reasonably foreseeable that it could be used, either alone or with other information, to identify an individual.
<b>Information environment</b>	The network, information systems, technologies, applications, software, servers, components and configurations of POGO, including those that enable the collection, use and disclosure of PHI in the custody or control of POGO and work to keep the PHI secure.

Term	Definition
<b>Information security breach</b>	An occurrence or event that, at a minimum, actually or imminently jeopardizes the confidentiality, integrity or availability of information or the information environment.
<b>Information security incident</b>	Includes, at a minimum: <ul style="list-style-type: none"> <li>• A contravention or imminent threat of contravention of the Information Security and Organizational policies, procedures and practices implemented by POGO or Policy 3.02 <i>Information Security Training and Awareness</i>, related to the requirements of the Manual, or</li> <li>• A contravention or imminent threat of contravention of PHIPA or its regulations, the terms of any written agreements or other legal obligations or any other occurrence or event that potentially jeopardizes the confidentiality, integrity or availability of information or the information environment.</li> </ul>
<b>IPC</b>	The Information and Privacy Commissioner of Ontario.
<b>Linkage</b>	The bringing together of two or more records of PHI or pseudonymized data to form a composite record for a specific individual.
<b>Manual</b>	<i>The Manual for the Review and Approval of Prescribed Persons and Prescribed Entities</i>
<b>Personal health information (PHI)</b>	Means identifying information about an individual in oral or recorded form if the information: <ol style="list-style-type: none"> <li>Relates to the physical or mental health of the individual, including information that consists of the health history of the individual's family</li> <li>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</li> <li>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</li> <li>Relates to payments or eligibility for health care, or eligibility for coverage for health care, in respect of the individual</li> <li>Relates to the donation by the individual 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</li> <li>Is the individual's health number or</li> <li>Identifies an individual's substitute decision-maker. PHIPA, s.4(1).</li> </ol>
<b>Personal information (PI)</b>	Recorded information about an identifiable individual including and not limited to age, identifying number, address and telephone number.
<b>PHIPA</b>	Personal Health Information Protection Act, 2004

Term	Definition
<b>PIPEDA</b>	Personal Information Protection and Electronic Documents Act, 2000
<b>POGO Agent</b>	Means a person that, with the authorization of POGO, acts for or on behalf of POGO in respect of PHI for the purposes of POGO, and not the POGO Agent's own purposes, whether or not the POGO Agent has the authority to bind POGO, whether or not the POGO Agent is employed by POGO and whether or not the POGO Agent is being remunerated.
<b>POGO Agent Confidentiality Agreement</b>	An agreement that is executed between POGO and each of its POGO Agents as required by the IPC Manual and in accordance with Policy 3.04 <i>Execution of Confidentiality Agreements by Agents</i> and the <i>Template Confidentiality Agreement with Agents</i> .
<b>Prescribed Entity (PE)</b>	Entity prescribed for the purposes of subsection 45(1) of PHIPA and that is prescribed in subsection 18(1) of PHIPA's regulations.
<b>Prescribed Organization (PO)</b>	Organization prescribed for the purposes of Part V.1 of PHIPA and that is prescribed in subsection 18(1) of PHIPA's regulations.
<b>Prescribed Person (PP)</b>	Person prescribed for the purposes of clause 39(1)(c) of PHIPA and that is prescribed in subsection 13(1) of PHIPA's regulations.
<b>Privacy breach</b>	<p>An occurrence that, at a minimum, includes:</p> <ul style="list-style-type: none"> <li>• A collection, use and disclosure of PHI that is not in compliance with PHIPA and its regulations</li> <li>• A contravention of the Privacy, Human Resources* and Organizational policies, procedures or practices implemented by POGO, related to the requirements of the Manual</li> <li>• A contravention of written acknowledgments, DSAs or other legally binding written agreements, Research Agreements, Confidentiality Agreements and TPSP Agreements, related to the requirements of the Manual, and</li> <li>• Circumstances where PHI is stolen, lost or collected, used or disclosed without authority or where records of PHI are subject to unauthorized copying, modification, or disposal.</li> </ul> <p>*With the exception of Policy 3.02 <i>Information Security Training and Awareness</i>, a contravention of which is an information security incident.</p>
<b>Privacy complaint</b>	At a minimum, includes concerns or complaints relating to the Privacy policies, procedures and practices implemented by POGO and related to the compliance of POGO with PHIPA and its regulations.
<b>Regulations</b>	Regulation 329/04 to PHIPA as well as any other regulations that may be enacted under PHIPA from time to time.
<b>Research Agreement</b>	An agreement between POGO and researchers to whom PHI will be disclosed that is executed prior to the disclosure of PHI.



Term	Definition
<b>Research plan</b>	<p>A research plan sets out in writing the intentions of a researcher in conducting planned research and, in accordance with PHIPA and its regulations, the research plan must, at a minimum, set out:</p> <ul style="list-style-type: none"> <li>• The affiliation of each person involved in the research</li> <li>• The nature and objectives of the research and the public or scientific benefit of the research that the researcher anticipates and</li> <li>• All other prescribed matters related to the research.</li> </ul> <p>A research plan must be approved by a research ethics board (REB) and is subject to a number of additional requirements set out under PHIPA and its regulations.</p>
<b>Suspected privacy breach</b>	Any occurrence where reasonable grounds exist to indicate a privacy breach.
<b>Third-party service provider (TPSP)</b>	A third-party service provider (TPSP) contracted or otherwise engaged to provide services to or for POGO in respect of PHI.
<b>TPSP Agreement</b>	An agreement executed between POGO and a TPSP in accordance with Policy 1.11 <i>Executing Agreements with Third-Party Service Providers in Respect of Personal Health Information</i> and the <i>Template Agreement for Third-Party Service Providers</i> .

## Appendix B: Duties and Responsibilities

### Privacy Officer

- Overseeing the management of the day-to-day Privacy Program
- Developing, implementing, reviewing and amending Privacy and Information Security policies, procedures and practices and ensuring compliance with and the transparency of the same
- Facilitating compliance with PHIPA and its Regulations and ensuring POGO Agents are aware of their duties thereunder
- Ensuring POGO Agents are aware of the Privacy and Information Security policies, procedures and practices implemented by POGO and are appropriately informed of their duties and obligations thereunder
- Directing, delivering or ensuring the delivery of the initial and ongoing privacy and information security training and fostering a culture of privacy and information security awareness
- Conducting, reviewing and approving PIAs
- Supporting the development of DSAs, Research Agreements and Third-Party Service Provider (TPSP) Agreements
- Receiving, documenting, tracking, remediating and responding to privacy complaints
- Receiving and responding to privacy inquiries and consultation requests
- Receiving, documenting, tracking, investigating and remediating Privacy Breaches, Information Security Breaches, Suspected Privacy Breaches or Information Security Incidents
- Developing the privacy and information security audit schedules and conducting privacy audits
- Monitoring evolving industry privacy and information security standards and best practices
- Preparing and delivering the annual privacy and information security report to the POGO Board of Directors and
- Preparing and leading POGO through the triennial review by the IPC.

### Director, Finance and Administration

- Overseeing the management of the day-to-day Information Security Program
- Developing, implementing and ensuring compliance with the *Corporate Risk Management Framework* and BCDR Plan
- Participating in developing, implementing, reviewing and amending Information Security policies, procedures and practices
- Ensuring the logging, monitoring and auditing of privacy and information security events
- Overseeing the conduct of information security audits
- Participating in the development and delivery of the annual privacy and information security report to the POGO Board of Directors and
- Supporting the Privacy Officer through the triennial review by the IPC.

## Appendix C: Related Policies, Procedures and Practices

- Policy 1.03 *Transparency of Privacy Policies, Procedures and Practices*
- Policy 1.04 *Collection of Personal Health Information*
- Policy 1.05 *Maintaining Statements of Purpose for Data Holdings Containing Personal Health Information*
- Policy 1.06 *Limiting Agent Access to and Use of Personal Health Information*
- Policy 1.11 *Executing Agreements with Third-Party Service Providers in Respect of Personal Health Information*
- Policy 1.15 *Privacy Audits*
- Policy 1.16 *Privacy Breach Management*
- Policy 1.17 *Privacy Complaints*
- Policy 1.18 *Privacy Inquiries*
- Policy 3.01 *Privacy Training and Awareness*
- Policy 3.02 *Information Security Training and Awareness*
- Policy 9.1.07 *Use of Personal Health Information for Research*
- Policy 9.1.08 *Disclosure of Personal Health Information for Purposes Other Than Research*
- Policy 9.1.09 *Disclosure of Personal Health Information for Research Purposes and the Execution of Research Agreements*
- Policy 9.1.10 *Execution of Data Sharing Agreements*
- Policy 9.1.12 *Linkage of Records of Personal Health Information*
- Policy 9.1.13 *De-Identifying Personal Health Information*
- Policy 9.1.14 *Privacy Impact Assessment*
- Policy 9.1.18 *Access to Records by the Public*
- Policy 9.1.19 *Ethics Review Process for POGO*
- Policy 9.2.06 *Retention, Return and Destruction of Data*
- Policy 9.2.07 *Secure Transfer of Records of Personal Health Information*
- Policy 9.2.27 *Small Cell*
- Policy 9.2.29 *Re-Identification Risk Assessment*
- Policy 9.3.02 *Confidentiality and Non-Disclosure Agreement*
- Policy 9.3.06 *Disciplinary Action – Privacy Breach*