

ZIPPING UP FOR SECURITY

# Pediatric Oncology Group of Ontario Privacy & Data Security Code



Where caring is the best medicine  
for kids with cancer.

Highlighting POGO's personal health information policies and procedures as they pertain to the ten principles of the Canadian Standards Association.

## **Table of Contents**

### **1.14 Privacy & Data Security Code**

Page 2	Foreword
Page 3	Introduction, The Principles
Page 4	Principle 1 – Accountability
Page 5	Principle 2 - Identifying Purposes
Page 6	Principle 3 – Consent
Page 6	Principle 4 – Limiting Collection,
Page 6	Principle 5 – Limiting Use, Disclosure, and Retention
Page 8	Principle 6 – Accuracy,
Page 8	Principle 7 – Safeguards
Page 9	Principle 8 – Openness
Page 10	Principle 9 – Individual Access
Page 10	Principle 10 – Challenging Compliance
Page 12	Appendix A – POGO History, Organization, Programs, Research Agenda
Page 14	Appendix B – POGO Data Holdings
Page 16	Appendix C – Privacy Commitment
Page 17	Appendix D – POGO Glossary of Terms

## Foreword

The Pediatric Oncology Group of Ontario (POGO) is a not-for-profit corporation established in 1983 to improve the circumstances of Ontario's children with cancer, their families and caregivers, through the development and implementation of an accessible, well integrated provincial childhood cancer system. POGO plans for provincial pediatric oncology needs, coordinates the allocation of funding across the province, maintains the provincial pediatric oncology database (POGONIS), conducts research focusing on childhood cancer in accordance with all applicable legislation, including Ontario's *Personal Health Information Protection Act, 2004* and its regulation, provides clinical leadership, and develops evidence-based standards and guidelines for childhood cancer care.

POGO is a multi-disciplinary, multi-centre collaboration of health professionals representing the Pediatric programs that treat children with cancer across the province of Ontario. The founding partner organizations of POGO are all of Ontario's specialized childhood cancer programs, which are located within academic teaching hospitals at Children's Hospital, London Health Science Centre; Children's Hospital of Eastern Ontario, Ottawa; Children's Hospital, Hamilton Health Sciences, Hamilton; Kingston General Hospital; and The Hospital for Sick Children, Toronto.

In 1995, POGO became the principal advisor to the Ontario Ministry of Health and Long-Term Care (MOHLTC) on matters relating to childhood cancer care and control in Ontario.

In 2004, POGO was designated as a prescribed entity pursuant to section 45 of the *Personal Health Information Protection Act, 2004*. As a result, POGO is permitted to collect and use personal health information, without consent, for the purpose of analysis and compiling statistical information with respect to the management of, evaluation or monitoring of, the allocation of resources to or planning for all or part of the health system. POGO is further permitted to use and disclose personal health information, without consent, where permitted by the *Personal Health Information Protection Act, 2004*.

As a prescribed entity, POGO is required to have in place practices and procedures to protect the privacy of individuals whose personal health information it receives and to maintain the confidentiality of that information and these practices and procedures must be reviewed and approved by the Information and Privacy Commissioner/Ontario every three years.

This document highlights POGO's practices and procedures with respect to personal health information and is based on the ten principles of the Canadian Standards Association Fair Information Practices, which now form part of Canada's federal privacy law, the *Personal Information Protection and Electronic Documents Act*.

## Introduction

The principles articulated in this document are based on the ten principles found in the Canadian Standards Association Fair Information Practices, which now form part of Canada's federal privacy law, the *Personal Information Protection and Electronic Documents Act*.

## The Principles

POGO's Privacy Principles are as follows:

Accountability  
Identifying Purposes  
Consent  
Limiting Collection  
Limited Use, Disclosure, and Retention  
Accuracy  
Safeguards  
Openness  
Individual Access  
Challenging Compliance

This document discusses each of these principles individually as they apply to personal health information (PHI) in the custody or control of POGO. As a prescribed entity pursuant to section 45 of the *Personal Health Information Act, 2004* (PHIPA), POGO collects and uses PHI for the purposes of analysis or compiling statistical information with respect to the management of, evaluation or monitoring of, the allocation of resources to or planning for all or part of the health system, namely the childhood cancer system. In particular, POGO uses PHI for the following purposes:

- Analyzing the demographics and epidemiology of cancer in children
- Identifying trends and outcomes related to childhood cancer treatment
- Identifying gaps in the delivery of cancer care services
- Developing, implementing and evaluating new treatment programs, and determining the optimal location of such programs

In addition to the above, POGO uses PHI for facilitating and conducting research in accordance with all applicable legislation, including PHIPA and its regulation. POGO's key areas of research include the following:

- Epidemiology
- Health services research
- Health economics, and
- Status of survivors and quality of life

## **Principle 1 – Accountability**

Principles and procedures for ensuring confidentiality and security of PHI are strictly enforced in order to ensure the privacy of individuals with respect to their PHI, in order to maintain the confidentiality of the PHI and in order to protect PHI against theft, loss, unauthorized use, disclosure, copying, modification or disposal. POGO is responsible for all data, including PHI, in its custody or control and designates individuals who are accountable for its compliance with the following principles.

- 1.1 a) POGO's Executive Director is ultimately accountable for POGO's compliance with these principles, for ensuring that all of POGO's activities as defined within its role as a prescribed entity pursuant to section 45(1) of PHIPA are complied with and for ensuring that the principles of privacy, confidentiality and security are adhered to.
  - b) The Executive Director is accountable to POGO's Board of Directors, the Ontario Ministry of Health and Long-Term Care (MOHLTC), and the Information and Privacy Commissioner/Ontario regarding these matters.
  - c) The Executive Director delegates his/her authority to other individuals within POGO who are responsible for developing and managing POGO's Privacy Program.
  - d) The Executive Director has designated staff to act as the Privacy Officer(s) who oversee POGO's compliance with these principles and who oversee POGO's compliance with PHIPA and its regulation.
- 1.2 Other individuals may be responsible for the day-to-day collection and processing of PHI. These individuals are required to abide by the practices and procedures implemented by POGO to protect the privacy of individuals whose PHI it receives and to maintain the confidentiality of that PHI.
- 1.3 POGO is responsible for PHI in its custody or control, including PHI that has been transferred to a third party for processing purposes. POGO uses contractual agreements and other means (confidentiality agreements, data sharing agreements and researcher agreements) to ensure its protection while the PHI is being processed by a third party.
- 1.4 POGO has policies and procedures in place for:
  - protection of PHI;
  - orientation and training of new staff regarding POGO's policies, procedures and practices, as well as reinforcing staff sensitivities to privacy protection on a regular basis;
  - receiving and responding to complaints and inquiries;
  - developing and disseminating information about its privacy policies, procedures and practices.

## **Principle 2 – Identifying Purposes**

POGO identifies the purposes for which it uses PHI before the information is collected or used.

POGO uses PHI for the purposes of analysis or compiling statistical information with respect to the management of, evaluation or monitoring of, the allocation of resources to or planning for all or part of the health system, namely the childhood cancer system, in accordance with section 45 of PHIPA and its regulation.

POGO also uses PHI for facilitating and conducting research into childhood cancer in accordance with PHIPA and its regulation.

- 2.1 As part of its mandate and consistent with its partnership agreement with the MOHLTC, POGO collects, uses and discloses PHI in compliance with PHIPA and its regulation to plan for provincial pediatric oncology needs, coordinate the allocation of funding across the province, maintain the provincial pediatric oncology database (POGONIS), conduct research focusing on childhood cancer, provide clinical leadership, and develop evidence-based standards and guidelines for childhood cancer care.
- 2.3 2.2 Identifying the purposes for which POGO collects and uses PHI before collection, allows careful determination of the information needed to fulfill these purposes. PHI is transferred from each responsible health information custodian to POGO with a chain of accountability for data protection. Where PHI is collected, the purposes of such collection are identified to the organization or individual from whom PHI is sought before it is collected. Depending upon the way in which the information is collected, this may be done verbally (i.e., by telephone) or in writing.
- 2.4 If a new purpose is subsequently identified, the new purpose must be permitted or required by law, before PHI can be used for that new purpose.
- 2.5 When research is being conducted with the consent of the individual to whom the PHI relates, the POGO researchers collecting PHI must fully explain to individuals the purposes for which the information is being collected as part of the consent process in accordance with all applicable legislation, including PHIPA and its regulation.

## **Principle 3 – Consent**

- 3.1 For the purposes of its role as a prescribed entity pursuant to section 45(1) of PHIPA, consent is not required prior to the collection and use of PHI by POGO for the purpose of analysis or compiling statistical information with respect to the management of, evaluation or monitoring of, the allocation of resources to, or planning for all or part of the health system, including the delivery of services. Consent is also not required to use or disclose PHI in accordance with, and subject to the statutory conditions contained within, PHIPA and its regulation. For example, POGO may use PHI without consent for research purposes provided it prepares a research plan in accordance with the requirements of PHIPA and its regulation and obtains research ethics board (REB) approval of the research plan.
- 3.2 If researchers request PHI held within POGONIS, the researchers must also submit to POGO a research proposal prepared in accordance with PHIPA and its regulation and a copy of the decision of the REB approving the research plan. The researchers must also enter into an agreement with POGO imposing conditions and restrictions respecting the use, security, disclosure, return or disposal of the PHI.
- 3.3 If the REB determines that the consent of the individual is required prior to the collection or use of the PHI, the informed consent of the individual must be obtained.

## **Principle 4 – Limiting Collection**

POGO limits the collection of PHI to that which is necessary for its identified purposes.

- 4.1 The amount and the type of PHI collected is limited to that which is necessary to fulfill its purposes as a prescribed entity pursuant to section 45 of PHIPA.
- 4.2 POGO will not collect PHI for purposes other than section 45 of PHIPA unless it obtains consent of the individual to whom the PHI relates or unless the collection is otherwise permitted or required by law.

## **Principle 5 – Limiting Use, Disclosure, and Retention**

As a prescribed entity pursuant to section 45 of PHIPA, POGO is permitted to collect and use PHI without consent for the purpose of analysis or compiling statistical information with respect to the management of, evaluation or monitoring of, the allocation of resources to or planning for all or part of the health system, including the delivery of services. POGO is further permitted to use and disclose PHI, without consent, where permitted by PHIPA and its regulation.

PHI in the custody or control of POGO is not used for purposes other than those for which it was collected, as outlined in the Introduction Section, and is not disclosed except with the consent of the individual or as permitted or required by law, including PHIPA and its regulation. POGO only retains PHI for as long as necessary to satisfy the purposes for which it collected the PHI.

***Use:***

- 5.1 PHI collected pursuant to its function as a prescribed entity pursuant to section 45(1) of PHIPA is not used by POGO for purposes other than those for which it was collected except where permitted by PHIPA and its regulation (see Principle 2, subparagraph 2.1).
- 5.2 POGO only undertakes data linkage (the bringing together of two or more records of PHI to form a composite record) when consistent with the purposes of section 45(1) of PHIPA.
- 5.3 POGO analyzes data in both aggregated and record-level fashion for purposes pursuant to section 45(1) of PHIPA.
- 5.4 POGO allows only authorized staff to use specific POGO data holdings of PHI on a “need to know” basis, that is, when required to perform their duties.

***Disclosure:***

- 5.6 POGO only publishes aggregated data. To protect against inadvertent disclosure of PHI, no information is disclosed with less than five observations per cell. Where observations are less than five per cell, patient or substitute decision maker consent must be obtained.
- 5.7 POGO only discloses PHI as permitted by PHIPA and its regulation.
- 5.8 POGO discloses PHI to researchers provided the researchers submit a research plan prepared in accordance with PHIPA and its regulation, the researchers submit a copy of the decision of the REB approving the research plan and the researchers enter into an agreement with POGO imposing conditions and restrictions respecting the use, security, disclosure, return or disposal of the PHI.
- 5.9 POGO also discloses PHI to other entities prescribed pursuant to section 45 of PHIPA and its regulation for purposes of analysis or compiling statistical information with respect to the management of, evaluation or monitoring of, the allocation of resources to or planning for all or part of the health system.
- 5.10 If POGO receives a concern or complaint by any person, that a recipient of PHI has made false or misleading statements in the request for PHI or has violated one or more conditions of the research plan approved by the research ethics board or the terms or conditions of an agreement entered into with POGO, POGO investigates. If the concern or complaint is substantiated, POGO imposes sanctions, which may include:
  - a) A written complaint to the recipient/research organization;
  - b) Recovery of data disclosed by POGO;
  - c) Report to the relevant REB;
  - d) Refusal of future access to data;
  - e) Legal action, or
  - f) A complaint to the Information and Privacy Commissioner/Ontario.

### **Retention:**

- 5.9 POGO has developed guidelines and implemented procedures with respect to the secure retention of PHI.
- 5.10 For purposes of fulfilling its mandate as a prescribed entity pursuant to section 45 of PHIPA, POGO securely retains PHI in electronic format for as long as necessary to meet the purposes of long-term analysis and reporting.
- 5.11 POGO retains all paper records of PHI as long as is necessary to input the PHI into POGONIS.
- 5.12 For the purposes of research, POGO securely retains the PHI for the length of time set out in the research plan approved by the REB board.
- 5.13 PHI that is no longer required to fulfill the identified purposes is anonymized or securely destroyed. POGO has developed guidelines and implements procedures to govern the anonymization of PHI. POGO has developed guidelines and implemented procedures to govern the secure destruction of PHI.

### **Principle 6 – Accuracy**

PHI shall be as accurate, complete, and up-to-date as is necessary for the purposes for which it is to be used.

- 6.1 Health information custodians that transfer PHI to POGO are responsible for ensuring the PHI is accurate, complete and up-to-date for the purpose specified.
- 6.2 POGO uses educational programs, data quality programs, data coding standards and data edits to ensure the quality of PHI in its custody for the intended purposes is accurate, complete and up-to-date.
- 6.3 POGO ensures that PHI used on an ongoing basis, including information that is disclosed to third parties, is accurate and up-to-date. POGO specifies if limits exist on the accuracy/availability of source data.
- 6.4 Data within POGONIS is not intended for the purpose of directing patient care at any time.

### **Principle 7 – Safeguards**

POGO protects all data, including PHI, within its custody or control. POGO considers all PHI to be highly sensitive. Thus information protection is paramount and accomplished with security safeguards appropriate to the sensitivity of the information.

- 7.1 *Without exception*, all PHI is considered to be sensitive.
- 7.2 Security safeguards protect PHI against loss or theft, as well as unauthorized access, disclosure, copying, use, modification and disposal. POGO protects PHI regardless of the format in which it is held. POGO has procedures in place for the secure transfer and delivery of data, including PHI.

- 7.3 The safeguards in place include:
- (a) physical measures; e.g. locked facility with tracked card access, locked filing cabinets and restricted access to offices, internal/external video monitoring of POGO.
  - (b) organizational measures; e.g., employee confidentiality agreements (with the potential for immediate dismissal where applicable) and limiting access on a “need-to-use” basis.
  - (c) technological measures; e.g., the use of firewalls, VPN, separation of networks, passwords, encryption, audit logs, data modification logs, backup and recovery systems.
  - (d) anonymization of PHI; PHI disclosed may be further anonymized by removing data fields e.g. name, health card number, date of birth etc.
- 7.4 POGO requires a signed confidentiality agreement from all staff, including POGO scientists/researchers/associates, fellows and students, and from all external agents who may have access to data, including PHI. On an ongoing basis, POGO trains and makes all staff aware of the importance of maintaining the confidentiality of PHI.
- 7.5 POGO has put in place policies, procedures and practices pertaining to the secure disposal or secure destruction of PHI to prevent unauthorized parties from gaining access to the information.
- 7.6 POGO prepares and routinely carries out privacy impact assessments for its data holdings, both existing and proposed.

## **Principle 8 – Openness**

POGO makes information about its policies, procedures and practices relating to the management and protection of PHI readily available upon request. This information is available in printed form and on its website – [www.pogo.ca](http://www.pogo.ca).

- 8.1 The information made available includes this Privacy and Data Security Code as well as:
- (a) The name or title and address of the person who is accountable for POGO’s policies, procedures and practices and to whom complaints or inquiries can be forwarded.
  - (b) The means of gaining access to PHI held by POGO.
  - (c) A description of the types of PHI held by POGO, including a general account of its use.
  - (d) A copy of brochures or other information that explain POGO’s policies, procedures and practices.

## **Principle 9 – Individual Access**

Upon request, an individual or substitute decision-maker shall be informed of the existence, use and disclosure of the PHI of the individual. Individuals or their substitute decision-makers who request access to their records of PHI, will be referred to the responsible physician or institution who provided the PHI to POGO.

- 9.1 Upon request, POGO shall inform an individual or their substitute decision-maker whether or not POGO holds PHI about the individual, and what kind of information (i.e. the data elements). Subject to proof of identity, POGO indicates the source of the PHI. POGO shall facilitate individual access to PHI by referring them to the source for the PHI. POGO shall provide an account of the use that has been made of, or is being made of the PHI, and an account of the third parties to whom it has been disclosed.
- 9.2 An individual or their substitute decision-maker is required to provide sufficient information to permit POGO to provide an account of the existence, use, and disclosure of PHI. The information provided shall only be used for this purpose.
- 9.3 In providing an account of third parties to which it has disclosed PHI about an individual, POGO attempts to be as specific as possible. When it is not possible to provide a list of the organizations to which it has actually disclosed PHI about an individual, POGO shall provide a list of organizations/researchers to which it may have disclosed PHI about the individual.
- 9.4 POGO responds to an individual or their substitute decision-maker's request within a reasonable timeframe and at minimal or no cost to the individual subject to the exceptions noted above. The requested information shall be provided or made available in a form that is generally understandable.
- 9.5 When the providing health information custodian notifies POGO that the individual has successfully demonstrated the inaccuracy or incompleteness of PHI, POGO amends the PHI as required. Depending upon the nature of the PHI challenged, an amendment involves the correction, deletion or addition of information. Where appropriate, POGO transmits the amended PHI to third parties having access to the information in question.
- 9.6 When a providing health information custodian notifies POGO of an unresolved challenge to the accuracy and completeness of the PHI, POGO records the unresolved challenge in the record of PHI. When appropriate, the existence of the unresolved challenge is transmitted to third parties having access to the PHI.

## **Principle 10 – Challenging Compliance**

An individual is able to address a challenge concerning compliance with the above principles to the designated individuals accountable for POGO's compliance. These individuals include: the Executive Director, Medical Director and the Privacy Officer(s) or their designates.

- 10.1 POGO has procedures in place that are accessible and easy to use when receiving and responding to complaints or inquiries about its policies and practices relating to the handling of PHI.

- 10.2 POGO informs individuals who make inquiries or lodge complaints of the existence of relevant compliant procedures.
- 10.3 POGO investigates all complaints. If a complaint is found to be justified, POGO takes appropriate measures including, if necessary, amending its policies, procedures and practices.

To address a challenge concerning POGO's compliance with its privacy policies, practices and procedures or to address a challenge concerning POGO's compliance with PHIPA and its regulation, please contact:

Madeline Riehl or Bruna DiMonte  
Co-Privacy Officers  
Pediatric Oncology Group of Ontario  
480 University Avenue, Suite 1014  
Toronto Ontario M5G 1V2  
Tel. 416-592-1232

In addition, an individual may address a challenge concerning POGO's compliance with PHIPA and its regulation by contacting the Information and Privacy Commissioner/Ontario at:

Information and Privacy Commissioner/Ontario  
2 Bloor Street East Suite 1400  
Toronto Ontario M4W 1A8  
Tel. 416 326-8809

## **Appendix A**

### **POGO History, Organization, Programs, Research Agenda**

---

- Charitable status was obtained in December 2003.
- POGO began as a grass-roots, multi-disciplinary, multi-centre alliance of professionals representing the pediatric programs that treat children with cancer. The five founding and primary partners of POGO are:
  - Children’s Hospital of Western Ontario, London
  - Children’s Hospital of Eastern Ontario, Ottawa
  - Children’s Hospital, Hamilton Health Sciences Centre
  - Kingston General Hospital; and
  - The Hospital for Sick Children, Toronto.
- POGO’s mission is to improve the circumstances of all children who are afflicted with cancer and those of their families and caregivers. A high priority is placed on building consensus within the childhood cancer community regarding: directions for growth and standards of care; on educating the public, patients, families and caregivers about preventing, treating and coping with childhood cancer and its possible late effects; and providing accurate data for research.
- POGO brings together all groups involved in childhood cancer – pediatric oncologists, nurses, psychologists, social workers, pharmacists, nutritionists, child life specialists, technicians, data managers, parents, survivors, community caregivers and voluntary sector organizations.
- The above noted individuals also serve as a meeting ground for professionals to develop an evolving consensus on approaches to the delivery of a “gold standard” of care during the acute and post-treatment phases of the disease.
- POGO ’s Board of Directors comprises representation from all major pediatric oncology programs in Ontario. (see Board members. Section 1.6 of Privacy Binder).
- POGO Standing Committees include: POGO Advisory, Clinical Oncology, Research Committee, Psycho-Social Services, and the Pediatric Oncology Nursing and Successful Academic and Vocational Transition Initiative (SAVTI).
- The organization has built a reputation for recommendations that are based on solid provincial data, scientific evidence and significant clinical experience.
- In 1988 and 1994, POGO generated comprehensive reports outlining strategic plans for pediatric cancer control in Ontario. In 1995, following the submission of the 1994 report to government, POGO received the official mandate to advise the Ontario Ministry of Health [MOHLTC] regarding childhood cancer care and control. The areas identified as problematic in the 1994 report led to immediate action:
  - increased staffing, which at that time fell far short of minimum requirements;
  - implementation of an integrated, comprehensive and provincial system of care;
  - development and funding of a system of long-term follow-up care for survivors;
  - development of a proposal for the management of effective, expensive supportive care drugs and chemotherapeutic agents;

- a childhood cancer database, focused on service planning, and the cornerstone of an integrative body;
  - the promotion of inter-disciplinary research and development of support for clinical trials;
  - formal recognition of a provincial pediatric oncology coordinating body; and
  - protection of the funding for childhood cancer, which is vulnerable.
- Today, POGO has vastly expanded its mandate to identify and address gaps in service, develop new programs, and co-ordinate and improve care for children with cancer and their families throughout Ontario. Examples of such programs include:
    - satellite sites at 5 centres across the province to provide active treatment closer to home;
    - AfterCare clinics to provide long-term follow-up to cancer survivors at the five tertiary hospitals and an expanded POGONIS to include the AfterCare data;
    - POFAP – the Pediatric Oncology Financial Assistance Program to off-set out-of-pocket costs faced by families of children with cancer;
    - expanded activities and development of the in-house component of the POGO Research Unit;
    - SAVTI- the Successful Academic and Vocational Transition Initiative to assist survivors with cognitive effects of their disease and treatment to transfer into post-secondary learning or work environments; and
    - an active internal and external network of individuals who participate in various standing committees and who plan professional multi-disciplinary educational opportunities.
  - By 2000, the campaign to raise \$4M for the POGO Chair in Childhood Cancer Control began, and with the help of dedicated POGO staff, achieved their target by mid 2003. Staff continue to raise funds for educational activities, POFAP and PRU efforts.
  - POGO has created a province-wide database (POGONIS) that receives data from the five pediatric oncology programs and produces virtually all the information required for planning pediatric cancer care across the province. It is one of the few childhood cancer databases in the world that captures standardized and wide-ranging information on an entire patient population of children and the critical dimensions of their care. (see Section 2.1 of Privacy Binder for description of POGONIS)
  - The pediatric cancer care and control model that POGO has created has worked so well that other jurisdictions throughout the world have sought POGO's advice on setting up similar programs for their population.

## **Appendix B**

### **POGO Data Holdings**

---

#### **1) POGO Networked Information System (POGONIS)**

POGO began collecting data on childhood cancer cases in 1985 as part of the vision for building a provincial strategy for childhood cancer. The database was built on the following principles:

- The need for a lean dataset
- A standardized data collection system for the province
- Data to support strategic planning and excellent subject identification

Since 1985, the five tertiary pediatric programs have operated with a common system for the classification of childhood malignant disease and a mutual definition of the critical dataset to be collected on the patient population within their respective programs. As a result, there is an agreement between the five programs with regard to: disease classification; the definition of a child; key descriptors of the patient; description of patient treatment status; categories of service rendered, etc.

The scope and utility of the POGO database grew significantly between 1987 and 1994. As a result, an expanded database known as POGONIS (POGO's Networked Information System) was created. The POGONIS database:

- secured the first ten years of provincial data accumulated (1985 – 1994) on cases of childhood cancer treated in POGO programs;
- was expanded to contain carefully selected standardized medical/biologic, psychosocial, treatment, late effects and outcome information; and
- greatly increased the access of POGO programs, the POGO provincial operation, the Ontario MOHLTC and researchers to data for purposes of planning, evaluation, quality control, costing and clinical investigation.

POGONIS is unique and valuable in its ability to estimate the incidence of childhood cancer in the province in terms of determining population projections, service surveillance, outcome measures, survival information, program evaluation potential and in assembling cohorts for investigation in multiple research projects.

This dataset contains detailed information on all aspects of cancer in children, including demographics, diagnosis, treatment and death. It also contains data on children who are seen in the POGO Satellite and POGO AfterCare Programs (refer to Section 1.3 Privacy Binder for descriptions of these programs). The collected data is active and longitudinal, i.e., data items are collected and added to the database over time.

The database contains the following information for each child diagnosed with cancer in Ontario since 1985:

- Demographic information (e.g., full name, address, postal code, age, sex, date of birth, health card number, etc.)
- Diagnosis information (e.g., cancer type, date of diagnosis, histology information, etc.)
- Treatment information (e.g., type of treatment, dose, date, place, etc.)

- Death information (e.g., date of death, cause, location, etc.)

POGONIS is also used to produce a Passport to Health for survivors that contains vital diagnostic, treatment and outcome information needed for their ongoing care. The Passport to Health was created in 2000 and is managed by the POGO Data Managers. It is given to the patients at the time of entering the AfterCare clinics by the clinic staff. It is designed to be a wallet-sized document carried by the survivors.

The operating costs of the POGONIS database are supported by the Ontario MOHLTC. These funds support a POGONIS Database Administrator who:

- oversees the operation of the database (its integrity and structure);
- maintains the system's data dictionary and architecture;
- is responsible for the training and educational support of the POGO Data Managers/Clinical Research Associates;
- is responsible for receiving, coordinating and responding to all data requests forwarded to the POGO Office;
- is responsible for ensuring the quality of the data;
- assists in the analysis and reporting of trends in the number of childhood cancer cases and service delivery; and
- with the POGO Medical Director, conducts annual reviews of the data dictionary, architecture and classification system to ensure it complies with international classification systems for childhood cancers.

MOHLTC funds also support the POGO Data Managers/Clinical Research Associates at each of the five tertiary pediatric institutions in Ontario. The Data Managers are responsible for the registration of all pediatric oncology patients diagnosed at their local institutions according to the standard POGO Diagnostic Nomenclature and Classification System and patient chart review and data entry into POGONIS. Each Data Manager receives detailed on-going training regarding the technical operation of the POGONIS database, the dictionary and architecture, the reporting feature, and how to produce a Passport to Health. Each Data Manager signs a Confidentiality Agreement with POGO.

## **2) HHR – Health Human Resource Annual Staffing Information**

This database contains full-time (FTE) staffing information regarding funded and filled positions from the core disciplines (physicians, nurses, allied health professionals and support staff) employed within the oncology divisions at the five pediatric tertiary institutions within Ontario.

## **3) POFAP Data – (see 1.3 (Fact Sheets) of Privacy Binder for description of POFAP)**

This database contains registration information on families who are funded within the POGO Financial Assistance Program.

## **4) Interlink Community Cancer Nurses Databases**

The patient database contains information on patients and their families who have accessed Interlink Community Cancer nursing services. Information collected includes patient demographics, diagnostic, physician information, service delivery and frequency of visits, and discharge and re-admission information. This information is available per patient by Interlink nurse and by region.

## **APPENDIX C**

### **Privacy Commitment**

---

POGO's mandate to plan and coordinate childhood cancer services within Ontario and advise the Ministry of Health and Long-Term Care on childhood cancer control is complemented by its promise to respect personal privacy, safeguard the confidentiality of PHI and provide a secure environment for the databases under its management.

POGO meets this commitment by ensuring:

- data confidentiality;
- principles and policies that protect PHI;
- strict policies that limit access to data;
- security measures: organizational, technological and physical;
- processes for review of privacy and security policies and procedures by the Data Security Committee on an ongoing basis;
- mandatory staff training;
- a strict approval process for all research proposals/data requests in accordance with all applicable legislation, including PHIPA and its regulation;
- requirements that ALL staff and third parties sign a pledge of confidentiality; and
- regular review of policies to ensure they are compatible with current PHI legislation and protection practices.

## **APPENDIX D**

### **POGO Glossary of Terms**

---

**AfterCare data** – A database that contains historical diagnostic and treatment information on pediatric patients followed at POGO AfterCare Clinics. This database contains annual follow-up information related to monitoring and health promotion of survivors.

**Aggregated data** – Summed and/or categorized anonymous data is analyzed and placed in a format that precludes further analyses (for example, in tables or graphs) to prevent the chance of revealing an individual's identity (individual records cannot be reconstructed).

**Associate Researcher** – an academic/scientist /researcher who is either located at a POGO centre or University or at a Canadian University other than one within the POGO network, who carries out POGO relevant research and/or associated activities.

**Consent** – Is permission granted by an individual to collect, use or disclose their PHI that has been obtained in accordance with the requirements for informed consent in PHIPA.

**Data** – A generic term used for all information that is collected by POGO for POGO purposes.

**Database Administrator** – A POGO staff member responsible for all data/database management and research activities, as well as ensuring POGO's compliance with privacy under.

**Data Agreements** – Formal legal document between POGO and a health information custodian (example: POGO partner hospitals, researchers). These agreements are signed when data is exchanged between parties.

**Data Managers** – Designated Data Managers/Clinical Research Associates located at the five POGO centers responsible for the accurate collection and transmission of patients' PHI to POGO.

**Data linkage** – Data that is linked from various databases via a unique number for a specific individual. (see record linkage definition)

**Encrypted data** – Data that is scrambled using specific software, just prior to transmission or as it is being entered into a database.

**Health Human Resources (HHR)** – Individuals located in a health care setting and designated as full-time or part-time equivalents. POGO conducts an annual review of partner hospital staffing information.

**Health Information Custodian** – means a person or organization who has custody or control of personal health information as a result of, or in connection with performing the persons or organizations powers or duties or the work as outlined in section 3(1) of PHIPA and its regulation.

**Interlink Community Cancer Nurses** – Hospital employed, POGO funded community cancer nurses who provide services to childhood cancer patients and families in the community

**Knowledge Transfer** – The exchange, synthesis and ethically sound application of findings among and between knowledge users.

**LAN** – Local Area Network.

**Linkage System** – Is the secure standalone system used to house and link administrative databases.

**Moated Data** – data held on computers with no external connections in order to ensure data cannot be accessed from the outside.

**MOHLTC** – Ontario Ministry of Health and Long-Term Care.

**Personal Health Information (PHI)**– Refers to information about an individual in oral or recorded form, if the information (a) relates to the physical or mental health of the individual, including information that consists of the health history of the individual's family; (b) 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; (c) is a plan of service within the meaning of the Long-Term Care Act, 1994 for the individual; (d) relates to payments or eligibility for health care in respect of the individual; (e) relates to the donation by the individual of any body part or any bodily substance of the individual or information derived from the testing or examination of a body part or bodily substance of the individual or (f) is the individual's health care number; (g) identifies an individual's substitute decision-maker .

**Personal Identifiers** – Data that characterize persons such as full name, address (including postal code), date of birth.

**POFAP Data** – Data collected on families when they are registered/apply for POGO Financial Assistance.

**Primary Data** – Data that is collected to answer specific research questions. Such data may be obtained from subjects by interviews, chart abstractions or reviews, questionnaires or through observation and intervention studies by POGO scientists.

**POGO ID** - A combined alphabetic and numeric identification assigned to each individual at the time of registration. An individual could have more than one POGO ID if he/she has multiple cancer diagnoses.

**POGONIS** – Pediatric Oncology Group of Ontario Networked Information System.

**Privacy Officer** – Oversees the development and implementation of organization-wide privacy principles, policies and practices.

**45(1) Prescribed Entity** – an organization prescribed pursuant to section 45 of PHIPA that has the authority to collect and use PHI for the purposes of analysis or compiling statistical information with respect to the management of, evaluation or

monitoring of, the allocation of resources to or planning for all or part of the health system.

**REB** – Research Ethics Board as defined in PHIPA.

**Record linkage** – Using a unique number that joins information together on an individual found in different databases to give a “picture” of the care continuum (see also data linkage).

**Research** – a systematic investigation designed to develop or establish principles, facts or generalizable knowledge, or any combination of them, and includes the development, testing and evaluation of research.

**Satellite Database** – A database that contains information on children who receive cancer services at formalized POGO satellites.

**Study ID** – The unique number assigned to each patient as they enter a research study.

**Survey Data** – Data collected from surveying a specific population.

**Third Parties** – for the purposes of collecting, using and disclosing PHI, third parties include: other prescribed entities pursuant to section 45(1) of PHIPA, prescribed persons that compile or maintain registries pursuant to section 39(1)(c) of PHIPA; researchers; health information custodians; governmental institutions of Canada or Ontario as deemed applicable; or individuals for the purposes of passport to health.