



FOR KIDS WITH CANCER
FOR NOW, FOR LIFE.

Pediatric Oncology Group of Ontario

Privacy and Data Security Code

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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 CHEO, Ottawa, Children's Hospital, London Health Sciences Centre (CH, LHSC), London, The Hospital for Sick Children (SickKids), Toronto, Kingston Health Sciences Centre, Kingston General Hospital Site (KHSC, KGH), Kingston and McMaster Children's Hospital, Hamilton Health Sciences (MCH, HHS), Hamilton.

In 1995, POGO became the official source of advice to the Ontario Ministry of Health (MOH) 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 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 delivery of services" (PHIPA, 2004). 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. These practices and procedures must be reviewed and approved by the Information and Privacy Commissioner of 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 forms 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 in the custody or control of POGO. As a prescribed entity pursuant to section 45 of the *Personal Health Information Act, 2004* (PHIPA) and its Regulation 329/04, POGO collects and uses personal health information (PHI) 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," namely the childhood cancer system (PHIPA, 2004). In particular, this document has regard for Policy 9.1.1 *Process for 44 and 45 projects*, Policy 9.1.7 *Use of PHI for Research*, Policy 9.1.8 *Disclosure of PHI for Purposes Other Than Research*, and Policy 9.1.9 *Disclosure of PHI for Research Purposes and the Execution of Research Agreements*.

POGO also collects personal health information pursuant to patient/client consent for the following POGO Data Holdings:

- the POGO School and Work Transitions Program,
- the POGO Financial Assistance Program and
- the POGO Interlink Nursing Program.

POGO uses personal health information 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;
- Delivery of service for the POGO School and Work Transitions Program, the POGO Financial Assistance Program and the POGO Interlink Nursing Program.

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

- Epidemiology;
- Health services research;
- Health economics; and
- Status of survivors/quality of life.

Principle 1 – Accountability

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

1.1

- a. POGO's Chief Executive Officer 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 and its regulation are complied with, and for ensuring that the principles of privacy, confidentiality, and security are adhered to.
- b. The Chief Executive Officer is accountable to POGO's Board of Directors, the Ontario Ministry of Health (MOH), and the Information and Privacy Commissioner of Ontario regarding these matters.
- c. The Chief Executive Officer delegates his/her authority to other individuals within POGO who are responsible for developing and managing POGO's Privacy Program.
- d. The Chief Executive Officer has designated staff to act as the Privacy Officer and the Director of Information Technology, Data and Analytics 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 personal health information. These individuals are required to abide by the practices and procedures implemented by POGO to protect the privacy of individuals whose personal health information it receives and to maintain the confidentiality of that personal health information.

1.3 POGO is responsible for the personal health information in its custody or control, including personal health information that has been transferred to an agent, custodian or to a third-party service provider. POGO uses contractual agreements and other means (confidentiality agreements, data sharing agreements and researcher agreements) to ensure its protection while the personal health information is being utilized, disclosed or destroyed by an agent or third party service provider.

1.4 POGO has policies and procedures in place for:

- Protection of personal health information;
- Orientation and training of new POGO agents regarding POGO’s policies, procedures, and practices, as well as reinforcing individual sensitivities to privacy protection on a regular basis;
- Receiving and responding to complaints and inquiries; and
- Developing and disseminating information about its privacy policies, procedures and practices.

Principle 2 – Identifying Purposes

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

POGO uses personal health information 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,” namely the childhood cancer system, in accordance with section 45 of PHIPA and its regulation (PHIPA, 2004) and uses personal health information for the delivery of services for the consent-based programs, the POGO School and Work Transitions Program, the POGO Financial Assistance Program and the POGO Interlink Nursing Program.

POGO also uses personal health information 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 MOH, POGO collects, uses and discloses personal health information 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) and other data holdings, conduct research focusing on childhood cancer, provide clinical leadership, and develop evidence-based standards and guidelines for childhood cancer care.

2.2 Identifying the purposes for which POGO collects and uses personal health information before collection allows careful determination of the information needed to fulfill these purposes. POGO’s senior management and its data holding program managers seek consultation with external pediatric oncology agents, where applicable, when identifying, reviewing, and amending the statement of purpose of its data holdings. Personal health information is transferred from each responsible health information custodian to POGO with a chain of accountability for data protection. Where personal health information is collected, the purposes of such collection are identified to the organization or individual from whom personal health information is sought before it is collected.

- 2.3 If a new purpose is subsequently identified, the new purpose must be permitted or required by law before personal health information can be used for that new purpose.
- 2.4 When research is being conducted with the consent of the individual to whom the personal health information relates, the POGO researchers collecting personal health information 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, and its regulation, consent is not required prior to the collection and use of personal health information 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” (PHIPA, 2004). Consent is also not required to use or disclose personal health information in accordance with, and subject to the statutory conditions contained within, PHIPA and its regulation.
- 3.2 For the purposes of providing services for the POGO School and Work Transitions Program, the POGO Financial Assistance Program and the POGO Interlink Nursing Program, POGO obtains consent from the patients/clients or parents prior to the collection of personal health information.
- 3.3 If researchers request personal health information held within any POGO Data Holding for 44 research purposes, the researchers must obtain research ethics board approval of their research plan. The researchers must submit the research ethics board (REB) approval along with other required documents to POGO as per PHIPA and its regulation.
- 3.4 The research ethics board determines if consent of the individual is required. If it is determined that consent is required, the informed consent of the individual must be obtained, prior to the collection or use of the personal health information, and prior to the disclosure of personal health information by POGO.
- 3.5 Should an individual wish to have their consent withdrawn from a research dataset, the researcher notifies the POGO Privacy Office of the patient’s request to withdraw.

Principle 4 – Limiting Collection

- 4.1 POGO only collects personal health information that is required for its stated purposes, i.e., POGO’s mandate.
- 4.2 The amount and the type of personal health information collected is limited to that which is necessary to fulfill its purposes as a prescribed entity pursuant to section 45 of PHIPA and its regulation, i.e., POGO does not collect more personal health information than is necessary to meet the stated purposes.
- 4.3 POGO will not collect personal health information for purposes other than section 45 of PHIPA unless it obtains REB approval and consent of the individual to whom the personal health information 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, use, and disclose personal health information 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” provided it is in compliance with PHIPA 2004 section 45, and subsections 18(4), (5), (6) and (8) of PHIPA Regulation 329/04.

POGO is permitted to use and disclose personal health information in its custody for 44 purposes as outlined in section 37(1) (j), 37(3) and 44 (2) to (4) and 44(6) (a) to (f) of PHIPA and subsection 18(3) of the regulation. POGO permits this use and disclosure if the research purposes fall within one of the four research pillars of the POGO Research Unit: Epidemiology, Health Services Utilization, Health Economics, and Quality of Life/ Survivor Status. Prior to the approval, use and disclosure of personal health information for research purposes, the requirements noted in section 44 of the Act and its regulation must be met.

Personal health information 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 of this document, and is not disclosed except with the consent of the individual or as ruled by the research ethics board or as permitted or required by law, including PHIPA (2004) and its regulation 329/04.

POGO only retains personal health information for as long as necessary to satisfy the purposes for which it collected the personal health information.

Use

- 5.1 Personal health information 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).

Personal health information collected pursuant to the delivery of services for the POGO School and Work Transitions Program, the POGO Financial Assistance Program and the POGO Interlink Nursing Program is used solely to provide the services of these consent-based service delivery programs.

45 Internal Uses

- 5.2 As part of its mandate and consistent with its partnership agreement with the Ministry of Health (MOH), POGO uses personal health information 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) and its other data holdings (Satellite, AfterCare and ACTS), conduct research focusing on childhood cancer, provide clinical leadership, health analytic team purposes, quality indicators, therapeutics, health technologies, and develop evidence-based standards and guidelines for childhood cancer care.

POGO analyzes data in both aggregate and record-level form for purposes pursuant to section 45(1) of PHIPA.

POGO allows only authorized POGO agents to use specific POGO data holdings of personal health information on a “need-to-know” basis, that is, when required to perform their duties.

45 External Uses

- 5.3 External agents may request and use aggregate POGO data for 45 purposes. POGO uses personal health information to undertake data linkages (the bringing together of two or more records of personal health information to form a composite record) with the other 45 entities, when consistent with the purposes of section 45(1) of PHIPA and its regulations.

44 Uses

- 5.4 POGO uses personal health information for research purposes if the research falls within one of the four research pillars of the POGO Research Unit: Epidemiology, Health Services Utilization, Health Economics, and Quality of Life/Survivor status and meets the requirements as set out in section 37(1) (j), 37(3) and 44 of the Act and 18(3) of the Regulations.

Disclosure

- 5.5 POGO only discloses personal health information as permitted by PHIPA (2004) and its regulation 329/04 or otherwise authorized by law or the disclosure is required by law.

45 Disclosures

- 5.6 POGO data disclosures are made at the highest degree of anonymity. This means that, whenever possible, data are aggregated. Where disclosures of personal health information or de-identified data are made for 45 purposes, POGO ensures all legislative requirements are compliant with PHIPA and its regulation. POGO only publishes aggregated data. To protect against inadvertent disclosures of personal health information, no information is disclosed with five observations or less per cell. Where analyses using observations equal to or less than five cases per cell, POGO's Small Cell Policy is followed (see Policy 9.2.27). When publishing observations equal to or less than five, POGO follows the criteria set out in its "Privacy Considerations at POGO – Working with Small Cells."
- 5.7 POGO also discloses personal health information to health information custodians and other prescribed entities and registries 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" (PHIPA, 2004).
- 5.8 POGO enters into Data Sharing Agreements with health information custodians and other prescribed entities and registries. POGO's Privacy and Data Security Manual, Section 3.5 (Data Sharing Agreements) describes the process that must be followed including the documentation that must be completed, provided or executed, who is responsible for same, the content of the documentation, and to whom it must be provided.

44 Disclosures

- 5.9 POGO discloses personal health information to researchers provided the researchers meet all of the requirements as per PHIPA including the submission of the research plan, a copy of the decision of the research ethics board approving the research plan, the completion of a privacy impact assessment, and the researchers entering into an agreement with POGO imposing conditions and restrictions respecting the use, security, disclosure, return or disposal of the personal health information.

- 5.10 If POGO receives an inquiry, concern or complaint from any person indicating that an agent or custodian requesting personal health information has made false or misleading statements 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 the question or concern. If a concern or complaint is substantiated, POGO imposes sanctions, which may include:
- a. A written complaint to the agent/research organization;
 - b. Recovery of data disclosed by POGO;
 - c. Report to the relevant research ethics board;
 - d. Refusal of future access to data;
 - e. Legal action; or
 - f. A complaint to the Information and Privacy Commissioner of Ontario.

Retention

45 Purposes

- 5.11 POGO has developed guidelines and implemented procedures with respect to the secure retention of personal health information.
- 5.12 For purposes of fulfilling its mandate as a prescribed entity pursuant to section 45 of PHIPA, POGO securely retains personal health information in electronic format for as long as necessary to meet the purposes of long-term analysis and reporting.
- 5.13 POGO retains all paper records of personal health information as long as is necessary to input the personal health information into POGONIS.
- 5.14 Personal health information 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 personal health information. POGO has developed guidelines and implemented procedures to govern the secure destruction of personal health information.

44 Purposes

- 5.15 For the purposes of research, POGO securely retains the personal health information for the length of time set out in the research plan approved by the research ethics board.

- 5.16 Personal health information that is no longer required to fulfill the identified purposes of the research project is anonymized or securely destroyed as stated in the research plan and approved Privacy Impact Assessment. POGO has developed guidelines and implements procedures to govern the anonymization of personal health information. POGO has also developed guidelines and implemented procedures to govern the secure destruction of personal health information for research projects.

Principle 6 – Accuracy

Personal health information 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 personal health information to POGO are responsible for ensuring the personal health information 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 that the quality of personal health information in its custody for the intended purposes is accurate, complete, and up-to-date.

- 6.3 POGO ensures that personal health information used on an ongoing basis, including information that is disclosed to custodians or agents, is accurate and up-to-date. POGO specifies if limits exist on the accuracy or availability of source data.

- 6.4 Data within POGONIS is not intended for the purpose of directing clinical patient care at any time.

Principle 7 – Safeguards

POGO protects all data, including personal health information, within its custody or control. POGO considers all personal health information 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 personal health information is considered to be sensitive.

- 7.2 Security safeguards protect personal health information against loss or theft, as well as unauthorized access, disclosure, copying, use, modification, threat and risk, and disposal.

POGO protects personal health information regardless of the format in which it is held. POGO has procedures in place for the secure transfer and delivery of data, including personal health information.

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. signed employee Confidentiality Agreements (with the potential for immediate dismissal where applicable), formal agreement with users of PHI detailing acceptable use of data and IT resources, robust exit interview of existing staff, auditing of agent computers (use of applications and access privileges), encrypted USB key/s (Iron Key/s), personal laptop review and sign-off (attestation) at the end of employment or contractual relationship, privacy training within 2 weeks of employment or contractual relationship, Code of Conduct, limiting access on a “need-to-use” basis, and Business Continuity and Disaster Recovery.
- c. Technological measures: e.g. the use of firewalls, VPN, separation of networks, passwords, encrypted USB key/s (Iron key/s), encryption, audit logs, data modification logs, backup and recovery systems, and secure file transfer process; disabling home computer access from POGO Remote Desktop; disabling the use of external ports of PHI users to prevent transferring/storage of PHI; only allowing POGO staff to connect to Dropbox via the web browser, and strong security measures regarding the use of mobile devices.
- d. Anonymization of personal health information: personal health information disclosed may be further anonymized by removing data fields, e.g. name, health card number, date of birth, postal code, etc.

7.4 POGO requires a signed Confidentiality Agreement from all internal and external agents i.e., staff, scientists, fellows, students, Board members, volunteers, seconded staff, POGO Data Managers, POGO Interlink Nurses, etc., on an annual basis who may have access to Confidential Information, including personal health information. On an ongoing basis, POGO trains and makes all agents aware of the importance of maintaining the confidentiality of personal health information.

7.5 POGO has put in place policies, procedures, and practices pertaining to the secure disposal or secure destruction of personal health information to prevent unauthorized parties from gaining access to the information.

7.6 POGO prepares and routinely carries out privacy impact assessments for its programs and 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 personal health information readily available upon request. This information is available in printed form and on its website: 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 Data Request Form detailing the process for gaining access to personal health information held by POGO;
 - c. A description of the types of personal health information held by POGO, including a general account of its use; and
 - d. A copy of brochures or other information that explain POGO’s policies, procedures, and practices.

Principle 9 – Individual Access

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

- 9.1 Upon request, POGO shall inform an individual or their substitute decision-maker whether or not POGO holds personal health information about the individual, and what kind of information (i.e. the data elements). Subject to proof of identity, POGO indicates the source of the personal health information. POGO shall facilitate individual access to personal health information by referring them to the source for the personal health information. POGO shall provide an account of the use that has been or is being made of the personal health information, and an account of the agents 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 personal health information. The information provided shall only be used for this purpose.
- 9.3 In providing an account of agents to whom POGO has disclosed personal health information regarding an individual, POGO attempts to be as specific as possible. When it is not possible to provide a list of the organizations to whom it has actually disclosed personal health information about an individual, POGO shall provide a list of

organizations/researchers to whom it may have disclosed personal health information 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 health information custodian who provides data to POGO notifies POGO that the individual has successfully demonstrated the inaccuracy or incompleteness of personal health information, POGO amends the personal health information as required. Depending upon the nature of the personal health information challenged, an amendment may involve the correction, deletion, or addition of information. Where appropriate, POGO transmits the amended personal health information to agents who have access to the information in question.
- 9.6 When a health information custodian who provides data to POGO notifies POGO of an unresolved challenge to the accuracy and completeness of the personal health information, POGO records the unresolved challenge in the record of personal health information. When appropriate, the existence of the unresolved challenge is transmitted to other agents who have access to the personal health information.

Principle 10 – Privacy Inquiries and Challenging Compliance

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

- 10.1 POGO has procedures in place that are accessible (<http://www.pogo.ca/about-us/privacy/privacy-inquiries-challenges/>) and easy to use when receiving and responding to complaints or inquiries about its policies and practices relating to the handling of personal health information.
- 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 an inquiry or 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:

Privacy Officer
Pediatric Oncology Group of Ontario
480 University Avenue, Suite 1014
Toronto Ontario M5G 1V2
privacy@pogo.ca

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

Information and Privacy Commissioner of Ontario
2 Bloor Street East Suite 1400
Toronto Ontario M4W 1A8
Tel. 416-326-3333
Long Distance: 1-800-387-0073
TDD/TTY: 416-325-7539
Email: info@ipc.on.ca

Appendix A: 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;
- Case identification; and
- Data to support strategic planning.

Since 1985, the five specialized childhood cancer 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 delivered, etc.

The scope and utility of the POGO database grew significantly between 1987 and 1994. As a result, in 1997, an expanded database known as POGONIS (POGO Networked Information System) was created in collaboration with Artificial Intelligence in Medicine, Inc. (AIM), now known as Inspirata Canada Inc.

POGONIS:

- 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/biological, treatment, late effects, and outcome information; and
- Greatly increased the access of POGO programs, the POGO provincial operation, the Ontario MOH, and researchers to data for purposes of planning, evaluation, quality control, costing, and clinical investigation.

POGONIS is unique. Its purpose and value is 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 report on system quality indicators 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, outcomes, and death. It also contains data on children who are seen in the POGO Satellite and POGO AfterCare Programs. Specific data

from Ontario Health (Cancer Care Ontario's) Ontario Cancer Registry is linked with POGONIS. 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 and morphology information, etc.);
- Treatment information (e.g. type of treatment, dose, date, location, etc.);
- Outcomes; and
- Death information (e.g. date of death, cause, location, etc.).

POGONIS is also used to produce a Passport to Health for survivors that contains key diagnostic, treatment, and outcome information to meet survivors' needs for rapidly accessible portable information relevant to their understanding of their history.

The Passport to Health was created in 2000 and is managed by POGO Data Managers. It is designed to be a wallet-sized document carried by survivors. In 2015, POGO and the AfterCare Clinics launched After Cancer Treatment Summaries (ACTS) to be distributed to childhood cancer survivors. These summaries contain the diagnostic, treatment and outcome data generated from POGONIS.

The operating costs of POGONIS are supported by the Ontario MOH. These funds support POGO Database Administrators, Analysts and Programmers who:

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

The MOH funds also support the POGONIS Data Managers/Clinical Research Associates at each of the five specialized childhood cancer programs 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 conduct patient chart review and enter data into POGONIS. Each Data Manager receives detailed on-going training regarding the technical operation of POGONIS, the data dictionary and architecture, standard operating procedures, the reporting feature, and how to produce a Passport to Health. Each Data Manager signs a Confidentiality Agreement with POGO.

In 2008, POGO and AIM, Inc. (now Inspirata Canada Inc.) collaborated again to upgrade POGONIS to a new software platform that implements a patient event model. The new system incorporates advances in cancer registry data management models and practices, as well as evolving software standards.

Legislative Authority

In 2004, POGO was designated a 45.1 entity under Ontario's new *Personal Health Information Protection Act, 2004*, S.O. 2004, c. 3, Sched. A ("PHIPA") listed in s. 18(1) of its attendant regulation, O.Reg. 329/04 (the "PHIPA Regulation").

This legislative status allows POGO to collect, use and disclose pediatric oncology personal health information ("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, including delivery of services."

Data Sharing Agreements are in place with all of POGO's data partners.

2) POGO Financial Assistance Program Database

The POGO Financial Assistance Program is a reimbursement fund for families with children in active cancer treatment largely funded through charitable donations. POGO Financial Assistance Program provides over \$800,000 a year to families in Ontario to offset some of the out-of-pocket costs they incur when a child is in treatment and connects families to low- or no-cost hotel stays with partner hotels.

Families face tremendous out-of-pocket costs when a child is in cancer treatment. These include accommodation, food and child care for siblings. It is not uncommon for one parent to leave work to care for the sick child, resulting in a loss of family income. POGO studies show that this can consume a third of the average family's after-tax income and costs Ontario families a total of \$8 million a year. Presently over 900 families per year rely on support from POGO Financial Assistance Program.

POGO Financial Assistance Program is administered by POGO through Ontario's five specialty pediatric oncology programs located at:

- CHEO
- Children’s Hospital, London Health Sciences Centre
- Kingston Health Sciences Centre, Kingston General Hospital
- McMaster Children’s Hospital, Hamilton Health Sciences
- The Hospital for Sick Children

A front-line employee at the child’s treatment centre, such as a nurse, resource navigator, or social worker, will orient the family to the POGO Financial Assistance Program and help the family complete a registration form which is sent to POGO for processing. POGO will send an information letter to the family containing their POGO Financial Assistance Program identification number, which must be included on all POGO Financial Assistance Program claim forms.

In addition to collecting and using PHI to deliver services, the Program collects and analyzes data to monitor its impact and plan future services.

Legislative Authority

POGO relies upon a consent for its authority to collect, use and disclose personal health information for the POGO Financial Assistance Program purposes.

3) POGO Interlink Nursing Program Database

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

The purpose of this database is for reporting the nursing workload per activity and the number of patients assisted by the POGO Interlink Nurses to the MOH.

Legislative Authority

POGO relies upon a consent for its authority to collect, use and disclose personal health information for the POGO Interlink Nursing Program purposes.

4) The POGO School and Work Transitions Program

The POGO School and Work Transitions Program database contains demographic information on survivors who need assistance in transitioning to post-secondary education or the workforce. The survivor’s name; date of birth; diagnosis; date of diagnosis and treatment; and general, educational attainment and vocational goals are maintained in the database.

The purpose of this database is for reporting academic or vocational outcomes to the Ministry of Education. The data collection will be used for evaluation purposes – retrospective study and longitudinal study in the future.

The POGO School and Work Transitions Program provides guidance, advocacy and empowerment for survivors of childhood cancer and brain tumours. More than 60% of childhood cancer survivors will experience health and wellness concerns as a direct result of their disease or treatment. These include neurocognitive and psychosocial challenges that can result in poor working memory, increased forgetfulness, persistent fatigue, low self-esteem, depression, and/or poor social skills. These challenges can lead to serious disruptions in survivors’ personal, educational, and professional development. The POGO Transition Counselors facilitate a smoother transition from high school to appropriate school and work opportunities.

The participating specialized childhood cancer programs work cooperatively and collaboratively, jointly committing to the ongoing successful implementation of the POGO Transitions Program.

The program involves consultation with and counselling of survivors of brain tumours and cancer diagnosed as a child or youth to address transitions related to school and/or volunteer or paid work. The program also supports POGO’s Survivor to Survivor (S2S) Network which provides the opportunity for survivors to build skills through planning and carrying out informational events for fellow survivors in conjunction with a volunteer topic expert.

In addition to collecting and using PHI to deliver services, the program collects and analyzes data to monitor its impact and plan future services.

Legislative Authority

POGO relies upon a consent for its authority to collect, use and disclose personal health information for the POGO School and Work Transitions Program purposes.

5) **After Cancer Treatment Summary (ACTS) Database**

The Dana-Farber Cancer Institute (DFCI) employs a state-of-the-art software (ACTS) program which uses complex algorithms to generate risks and recommendations tailored to individual survivors based on their treatment history. Since 2015, POGO utilizes the DFCI ACTS Care Plan software to enable clinicians to distribute to young adult survivors in POGO AfterCare Clinics a Survivor Care Plan Package, housed in a binder with information tailored to the needs of each individual survivor. Components of the POGO Survivor Care Plan Package are:

- The Passport to Health, produced by POGONIS
- Document generated from POGONIS/DFCI software, individualized for each survivor:
 - Treatment Summary
 - Summary of Risks and Recommendations
 - Follow-up Plan
 - Individual Health Links from the Children’s Oncology Group as currently distributed
- A “Web Links” booklet outlining relevant online resources for survivors and identifying which websites offering Canadian content, an online network, and/or a peer support program

The updated Passport to Health and Survivor Care Plan Package have tremendous potential to improve survivor knowledge about treatment history and potential late effects from treatment. POGO has collaborated with survivor representatives and healthcare provider representatives from each centre to launch the POGO Survivor Care Plan Package across the Ontario’s Provincial AfterCare Program network.

Legislative Authority

In 2004, POGO was designated a 45.1 entity under Ontario’s new *Personal Health Information Protection Act, 2004*, S.O. 2004, c. 3, Sched. A (“PHIPA”) listed in s. 18(1) of its attendant regulation, O.Reg. 329/04 (the “PHIPA Regulation”).

This legislative status allows POGO to collect, use and disclose pediatric oncology personal health information (“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, including delivery of services.”

6) **POGO Satellite Program Database**

The Pediatric Oncology Group of Ontario (POGO) Provincial Pediatric Oncology Satellite Program is a collaboration between select tertiary pediatric programs and carefully selected community hospitals that enables childhood cancer patients to receive appropriate components of their cancer care, in well-prepared POGO Satellite Clinic sites closer to home. The POGO Satellite Program has been demonstrably successful from 1998 to today, diverting thousands of outpatient visits from the specialized childhood cancer programs each year and enabling hundreds of inpatient admissions and days to community hospitals located closer to the homes of childhood cancer patients and families.

The POGO Satellite Program Database is a SQL server database which is aligned to [The Childhood Cancer Care Plan - A Roadmap for Ontario 2018-2023](#) and its strategic goal of data-driven quality improvement, ensuring availability of the right data to measure health service delivery for children with cancer treated in the POGO Satellite Program.

The POGO Satellite Program Database supports administrative database users to review data quality, analyze and maintain data integrity and audit when data was entered and by whom as well as when and what data entries were changed and by whom. The POGO Satellite Program Database aims to improve availability, utility and access to standardized quality data to enhance program planning, evaluation and reporting.

Legislative Authority

In 2004, POGO was designated a 45.1 entity under Ontario's new *Personal Health Information Protection Act, 2004*, S.O. 2004, c. 3, Sched. A ("PHIPA") listed in s. 18(1) of its attendant regulation, O.Reg. 329/04 (the "PHIPA Regulation").

This legislative status allows POGO to collect, use and disclose pediatric oncology personal health information ("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, including delivery of services."

7) **POGO AfterCare Program Web Application**

The Provincial Pediatric Oncology AfterCare Program is a project of the Pediatric Oncology Group of Ontario (POGO). It is a long-term follow-up program designed to provide survivors of childhood cancer with: systematic and proactive health surveillance for late effects of the disease and its treatment in areas of identified risk; early detection and rapid intervention; and comprehensive collection of data on late effects to improve the care of future generations of children with cancer. Since 2001, formal POGO AfterCare Clinics have

been launched in five tertiary pediatric oncology programs and in two adult survivor sites. Through POGO, healthcare providers affiliated with cancer programs in these sites work together to protect the health of survivors of childhood cancer.

POGO initiated a project to re-envision the POGO AfterCare Program Database with a focus on data elements and features necessary for a robust survivor-surveillance system, aligned to [The Childhood Cancer Care Plan - A Roadmap for Ontario 2018-2023](#) and its strategic goal of data-driven quality improvement, ensuring the right data are available and being used to drive an effective childhood cancer system.

Following consultations conducted over 2019 with survivors, POGO AfterCare Program clinicians, clinic staff and data managers, POGO undertook to revise the existing POGO AfterCare Program Database. Consultations provided POGO current-state information and insight into how information needs have changed over time across programs. POGO AfterCare Program Database revisions aim to improve utility and quality of data and collection processes to enhance program planning and reporting.

In 2021, POGO amended Data Sharing Agreements with the five tertiary pediatric institutions and select adult institutions that provide survivor care to pediatric and adult survivors of childhood cancer patients to include reference to the updated POGO AfterCare Program Database. The POGO AfterCare Program Database web application was implemented in all POGO AfterCare Clinic program sites in 2021.

Legislative Authority

In 2004, POGO was designated a 45.1 entity under Ontario's new *Personal Health Information Protection Act, 2004*, S.O. 2004, c. 3, Sched. A ("PHIPA") listed in s. 18(1) of its attendant regulation, O.Reg. 329/04 (the "PHIPA Regulation").

This legislative status allows POGO to collect, use and disclose pediatric oncology personal health information ("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, including delivery of services."

Appendix B: Privacy Commitment

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

POGO meets this commitment by ensuring:

- Data confidentiality and security;
- Principles and policies that protect personal health information;
- 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 POGO Privacy and Data Security Committee on an ongoing basis;
- Mandatory training for POGO agents during orientation, as well as ongoing training based on updates to privacy policy, protocol, and/or procedures;
- A strict approval process for all research proposals/data requests in accordance with all applicable legislation, including PHIPA and its regulation;
- Requirements that all POGO agents and third parties sign a Confidentiality Agreement; and
- Regular review of policies to ensure that they are compatible with current personal health information legislation and protection practices.

Appendix C: POGO Glossary of Terms

45(1) Prescribed Entity – an organization prescribed pursuant to section 45 of PHIPA that has the authority to collect and use personal health information 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” (PHIPA, 2004).

After Cancer Treatment Summary (ACTS) - database generates a list of potential late effects based on treatment exposures for any given patient. Appropriate preventative and screening recommendations are attached to each potential late effect.

Agent (Internal or External) – Individuals who act for, or on behalf of, POGO and who may or may not be employees of POGO. Agents include POGO staff, the POGO Board, researchers, volunteers, or those who are seconded employees to POGO.

Aggregate Data – Summed and/or categorized anonymous data is analyzed and placed in a format that precludes further analyses (e.g. in tables or graphs) to prevent the chance of revealing an individual’s identity (individual records cannot be reconstructed).

Consent – Is permission granted by an individual to collect, use, or disclose their personal health information 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.

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

Data Managers – Designated POGO Data Managers/Clinical Research Associates located at the five POGO specialized childhood cancer programs responsible for the accurate collection and transmission of patients’ personal health information to POGO.

Data Sharing Agreement – A formal legal document between POGO and a health information custodian (e.g. POGO partner hospitals, researchers). These agreements are signed when data is exchanged between parties.

Database Administrators/Data Analysts – POGO staff who report to the Senior Database Administrator and who are responsible for maintaining, updating, and supporting, auditing and analyzing data in POGO data holdings.

De-identified Data – Data that is rendered unidentifiable through the use of unique identifiers that ensure the data cannot be traced back to a particular person without the use of a legend to re-assemble the information.

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

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

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

MOH –Ministry of Health (Ontario).

Personal Health Information – 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; (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), and date of birth.

POGO AfterCare Program Web Application – 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. This follow-up data is routinely imported into the patient’s file in POGONIS.

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

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 had multiple cancer diagnoses.

POGO Interlink Nurses (Interlink) – Hospital-employed, POGO-funded community cancer nurses who provide services to childhood cancer patients and families in the community.

POGO Interlink Nursing Program Database - Contains information on patients and their families who have accessed POGO Interlink Nursing Program services. The database is used for reporting

the nursing workload per activity and the number of patients assisted by the POGO Interlink Nurses to the MOH.

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

POGONIS – Pediatric Oncology Group of Ontario Networked Information System.

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

Privacy Officer – An individual who oversees the development and implementation of organization-wide privacy principles, policies, and practices.

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 (also see 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.

Senior Database Administrator – A POGO staff member responsible for all data and database management, research data requests and ensuring POGO’s compliance with privacy under PHIPA as a Privacy Officer.

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

Survey Data – Data collected from surveying a specific population.

The POGO School and Work Transitions Program Database - contains demographic information on survivors who need assistance in transitioning to post-secondary education or to the workforce.

Third-Party Service Providers – A privacy company that provides a service to POGO, i.e., Iron Mountain Shredding.