

6.3.1 PHIPA, Privacy and Research

POGO has a designation under the [Ontario Personal Health Information Protection Act \(PHIPA, 2004\)](#) as a 45 prescribed entity status. This designation enables POGO to collect statistical information, utilization data and identifiable data for analysis and evaluation.

Strict rules and guidelines have been put into place to protect the privacy of personal health information (PHI) in accordance with PHIPA regulations. POGO’s [childhood cancer database POGONIS](#) has additional layers of security: Record-level data is accessible by authorized personnel using two layers of security, user accounts and passwords, secured on a POGO server in a locked office with video surveillance.

POGO has signed data sharing agreements with tertiary hospital partners as required by PHIPA regulations. Authorized users also sign confidentiality and non-disclosure agreements with POGO. Similar agreements will be negotiated with POGO Satellite Clinics.

Specifically, POGO uses PHI for the following purposes:

- Analyzing the demographics and epidemiology of cancer in children.
- Identifying trends and outcomes, and facilitating and conducting research 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.

From time to time, research proposals involving the use of POGONIS data for research purposes are submitted to POGO as a 45 prescribed entity, which allows POGO to conduct research (Section 44 of PHIPA) and comply with 44 regulations. Such research proposals must be scientifically feasible and relevant, approved by a recognized Research Ethics Board (REB), and approved by senior medical staff at POGO before data is released.

Disclaimer: Source Accuracy

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Record of Updates

Version Number	Date of Effect	Summary of Revisions
1	6/28/2021	<ul style="list-style-type: none"> • Original version posted.

