
PEDIATRIC ONCOLOGY GROUP OF ONTARIO NETWORKED INFORMATION SYSTEM (POGONIS)

History

In 1983, POGO identified the need to develop a childhood cancer registry given that there was no provincial standardized pediatric oncology registry. This has evolved into what is now known as the Pediatric Oncology Group of Ontario Networked Information System (POGONIS). Since 1985, POGO and the five specialized pediatric cancer centres have used a common system for the classification and mutual definition of childhood cancer and regularly input data into POGONIS. The data captured by POGONIS includes demographic information (name, date of birth, age, postal code, gender, etc.) and diagnosis (primary site, stage code, etc.) since 1985, and key treatment information (chemotherapy, radiation, cancer surgery, etc.) and patient outcomes (relapse, death, etc.) since 1995 for all cases of childhood cancer in Ontario. Using POGONIS, the five centres can track vital statistics regarding patients and service output. The database was later expanded to accommodate the tracking of late effects and AfterCare (long-term follow-up) services through the POGO AfterCare Clinics.

Value

The only database of its kind in Canada, POGONIS has become a valuable tool for Ontario that is used across Canada and abroad. The richness of POGONIS data supports POGO and its partners in planning for childhood cancer control in Ontario and is an integral resource for the work of the POGO Research Unit.

POGONIS is designed to monitor:

- The incidence and prevalence of childhood cancer
- The demand for care and workload of pediatric oncology programs
- The nature and specifics of treatment
- Patient outcomes
- Long-term effects of childhood cancer and its treatment.

Purpose

POGONIS provides reliable and validated data that are used to:

- Report on the incidence of childhood cancer in Ontario
- Make projections of the number of children to be treated in the future
- Plan new programs in response to incidence, projections, and research findings
- Conduct population-based research and support other research related projects
- Analyze and report on the utilization of AfterCare services in the province
- Analyze and report where children live in relation to where they are

treated in order to facilitate the strategic location of treatment facilities.

- Forecast future staffing requirements

Partners

- Children's Hospital of Eastern Ontario/Ottawa Regional Cancer Centre, Ottawa
- Children's Hospital, London Health Sciences Centre, London
- Kingston General Hospital/Kingston Regional Cancer Centre, Kingston
- McMaster Children's Hospital, Hamilton Health Sciences, Hamilton
- Princess Margaret Hospital, Toronto
- The Hospital for Sick Children, Toronto

News

On November 1, 2005, POGO received a provincial designation as a 45.1 entity within the Personal Health Information Protection Act (PHIPA). This designation allows for the collection, use and disclosure of personal health information for the purposes of planning statistical information analysis, the evaluation of resource allocation, and health system planning, including the delivery of services. This designation now enables POGO and POGONIS to link with other databases within the province, greatly augmenting POGO's analysis and research capacity.

In 2009, POGO upgraded the POGONIS platform with the assistance of Artificial Intelligence in Medicine (AIM), the software company that designed the POGONIS database in 1997. The new system is based on an event-oriented model in which data is organized according to a timeline of events for each patient. Each event corresponds to a milestone in a child's journey through the cancer care continuum. The upgrade ensures better workflow management, provides enhanced query capabilities, enhances security and privacy standards, and enhances data export capabilities.

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