



PEDIATRIC ONCOLOGY GROUP OF ONTARIO

Healthcare innovation
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Population data
Policy development
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Privacy Update Winter/Spring 2010

**Co-Privacy Officers:
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*Zippering up for security:
Committed to ensuring
privacy and security of
personal health information*

As outlined in Ontario's privacy legislation, POGO (as a 45.1 entity) may collect, use, and disclose personal health information without consent for the purpose of "analysis or compiling statistical information with respect to the management, 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).

As Co-Privacy Officers, we are responsible for the administration and maintenance of POGO's privacy policies and procedures and continue to create and fine-tune POGO's privacy program.

Here are a few of the latest updates!

▪ **New IPC Review Process**
Every three years, organizations are reviewed by the Information and Privacy Commissioner (IPC) of Ontario. The reviews include the submission of new privacy documents and materials along with an on-site review meeting every three years. The IPC recently announced a new review process whereby organizations are now responsible for submitting a detailed report to the IPC highlighting privacy, security, human resources, and organizational security measures, along with privacy indicators set out by the IPC, and a sworn affidavit that ensures privacy requirements have been met. While the three-year approval remains 2011, the report is due November 2010 and provides the IPC with one year to review the submitted documents.

During the last review in July 2008, the IPC review panel was very pleased with POGO's privacy program and security practices although they did make several recommendations to further enhance our security practices. The implementation of these recommendations will be reported to the IPC in the November 2010 report.

▪ **IPC Orders**
In our last newsletter we highlighted the IPC's concerns regarding the high incidence of lost or stolen mobile devices, such as laptop computers, personal digital assistants (PDAs), and flash drives. Health Information Custodians were

strongly urged to ensure that personal health information stored on these devices was encrypted. Subsequently, in 2007, the IPC produced a fact sheet and Health Order-004 outlining encryption standards and providing encryption software solutions.

http://www.ipc.on.ca/images/Resources/up-fact_12e.pdf

Despite this required IPC health order in 2007, in December 2009, a USB memory stick containing personal health information (that was not encrypted) was lost by a public health nurse on her way to a flu immunization clinic. After a lengthy investigation by the IPC, it was determined that it was a serious breach that was avoidable and a new Health Order (HO-007) was created. **We again encourage you to take a moment to review the following health order to ensure your mobile devices are properly secured.**

<http://www.ipc.on.ca/images/Findings/ho-007.pdf>

▪ **Small Cell Data**
As POGO continues its analyses in preparation for the production of a Pediatric Oncology Atlas, several chapter authors have identified the need to view and analyze data in cells with five or less occurrences. While our practice has been 'not to report' these cells, POGO has recently determined that where the small cell information is of clinical importance and valuable for the scientific community, or when the size would be difficult to suppress without also suppressing other, more significant information, it may be permissible to include the information within a small cell. In this event, researchers are required to notify the POGO Co-Privacy Officers and work

through the POGO Small Cell Policy. The authors/researchers must sign a release that identifies the data required and how it will be used, secured, and destroyed. Please speak with Bruna DiMonte, Senior Database Administrator, for more details.

New for 2010

- **The New POGONIS Platform**
Over the past year, POGO has worked very closely with Artificial Intelligence in Medicine Inc. (AIM), the software company that designed the POGO Networked Information System (POGONIS) in 1997, to upgrade the POGONIS platform. POGO staff have completed the final testing stages of the new platform, POGONIS 2.0, and are now importing data into the new platform. Most POGO Data Managers and staff have been trained on the new platform.

- **New Consent Form**
A new consent form to be signed by patients and families has been developed that allows POGO and those working on its behalf to use and publish patient and family pictures, names, voices, videos, and narratives for advertising, promoting, and publicizing POGO programs and services.

- **Agreements**
Author Confidentiality Agreement
A new confidentiality agreement has been created for authors who may be working with small cells. This agreement confirms the basis upon which POGO will allow authors to access, use, disclose, and manage small cell information.

- **Cancer Care Ontario Agreement**
In March 2010, POGO and CCO signed a new data sharing agreement that will allow POGO to import additional mortality

data into POGONIS. This will further POGO's health system planning and management role, as outlined in PHIPA, 2004 to monitor and report incidence, outcomes, and health service utilization among children with cancer in Ontario.

- **PHAC agreement**
In April 2010, POGO signed a data sharing agreement with the Public Health Agency of Canada whereby POGO will share a sample of de-identified cases from POGONIS to assist the software developers who are creating a national childhood cancer surveillance database.

- **Privacy Officer Presentation**
At the ICES/CIHI/MOHLTC Health Care 2010 Symposium (February 1, 2010), the POGO Co-Privacy Officers, along with other 45.1 entities, shared their perspectives on the evolution of PHIPA, 2004 in a panel discussion entitled "Untangling the Personal Health Information Protection Act Five Years Later". This well attended session elicited pertinent questions and discussion from multidisciplinary stakeholders engaged in privacy issues at various levels.

Staff Training

The Co-Privacy Officers continue to train staff, researchers, and research personnel on the privacy and confidentiality of personal health information in accordance with the PHIPA legislation. If you and your team require privacy training, please do not hesitate to contact us.

Contact

If you have any comments, questions, or suggestions, please contact POGO's Co-Privacy Officers:

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Visit POGO online at www.pogo.ca

POGO gratefully acknowledges the support of the Ontario Ministry of Health and Long-Term Care



Commitment to Privacy

POGO's Privacy Code is based on the ten principles of the Canadian Standards Association Model Privacy Code for the Protection of Personal Information found in Canada's federal privacy legislation.

Among these principles is our commitment to:

- **Identifying Purposes:**
POGO identifies the purposes for which its Scientists and staff use personal health information before the information is collected or used.

- **Consent:** Is only required if researchers are using record-level data and there is an REB ruling that requires the researcher to seek individual consent. The onus is on the researcher to ensure consent is obtained.

- **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.