

Pediatric Oncology Group of Ontario

Privacy Update Spring/Summer 2009

Privacy Officers:
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&
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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 personal health information (PHI) 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 privacy officers, we are responsible for the administration and maintenance of POGO's privacy policies and procedures.

We continue to create and fine-tune POGO's privacy program. Here are a few of the latest updates!

▪ Data Sharing Agreements

Since we last reported that POGO had signed data sharing agreements with all five tertiary partner hospitals, we have signed data sharing agreements with the Institute for Clinical and Evaluative Sciences (ICES) and Cancer Care Ontario (CCO) - two of our three 45.1 entity partners. Generally, data sharing agreements define how and when Personal Health Information (PHI) may be used and disclosed. Such agreements also enable POGO to realize its data linkage capabilities.

The ICES agreement will allow POGO to obtain aggregate information on health services utilization to be included in the POGO Pediatric Oncology Atlas (now under development).

The agreement with CCO and subsequent data linkage will allow POGO to obtain additional death information on patients registered in POGO's database (POGONIS) from 1985 to present. Our 45.1 entity status provides the ability to have full names and health card numbers in POGONIS, thus enabling the linkage with CCO to obtain this valuable death information. This information will also be used in POGO's Atlas.

POGO hopes to finalize data sharing agreements with the POGO Satellite and Adult AfterCare Centres during the current fiscal year (2009/10).

▪ Visit by the Information and Privacy Commissioner (IPC) of Ontario

POGO underwent a rigorous review by the IPC in July 2008. While the IPC review panel was very pleased with POGO's privacy program and security practices, they did make several recommendations to further enhance our security practices. The implementation of these recommendations will be reviewed at POGO's next IPC visit in 2011.

▪ Risk and Threat Assessment by Emergis Inc.

As recommended by the IPC, POGO engaged the services of Emergis Inc., a Telus company, in May 2008 to conduct an internal and external threat assessment. While several recommendations were made to enhance POGO security systems, POGO was pleased to learn that the overall risk to the integrity of our environment was very low.

▪ IPC Encryption Guidelines

We have all read much of late regarding the high incidence of loss or theft of mobile devices, such as laptop computers, personal digital assistants (PDAs) or flash drives. Health Information Custodians (HICs) need to ensure that PHI stored on these devices is encrypted. The IPC has produced a fact sheet that outlines encryption standards and provides encryption software solutions: http://www.ipc.on.ca/images/Resources/up-fact_12e.pdf.

POGO continues to address the issue of encryption by ensuring the security of personal health information on laptops, USB keys, and server drives. POGO also employs encryption

software when transferring personal health information.

New for 2009

■ A 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 POGONIS database in 1997, to upgrade the POGONIS platform. POGO Staff are in the final stages of testing the new platform - POGONIS 2.0. Once testing is complete, final importation of data will occur, after which all Data Managers and POGO staff will receive formal training from AIM.

■ Confidentiality Agreement

It is advantageous to renew confidentiality agreements on an annual basis, affording an opportunity to remind all individuals associated with POGO of their obligations to protect the confidentiality of information. As such, the privacy officers have renewed POGO's Confidentiality Agreements with all staff, board members, data managers, researchers, and third parties for 2009.

Staff Training

The co-privacy officers continue to train staff, researchers, and research personnel on the privacy and confidentiality of PHI in accordance with the PHIPA legislation. If you and your team require privacy training, please do not hesitate to contact us.

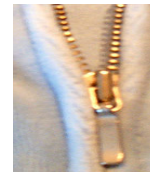
If you have any comments, questions, or suggestions, please contact POGO's Co-Privacy Officers:

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



Our 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 health information found in Canada's federal privacy legislation.

Among these principles is our commitment to:

■ **Accountability:** POGO is responsible for all data held in its possession or custody and designates individuals who are accountable for compliance with specific principles.

■ **Openness:** Information regarding our privacy policies and practices is available in both printed format and on our website: www.pogo.ca.

■ **Limiting Collection:** POGO limits the collection of PHI to that which is necessary for its identified purposes.

■ **Safeguards:** POGO protects all PHI within its custody and considers it to be highly sensitive. The safeguards POGO has put in place include physical, organizational, and technological measures.

■ **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 that provided the PHI to POGO.