



Ontario — *Leading the Way in Health Information Privacy*

Ann Cavoukian, Ph.D.

**Information and Privacy Commissioner
Ontario**

Ontario Occupational Health Nurses Association

Toronto, Ontario

May 31, 2006



Personal Health Information Protection Act (PHIPA)

- Came into force on November 1, 2004;
- Applies to organizations and individuals involved in the delivery of health care services (including the Ministry of Health and Long-Term Care);
- The only health sector privacy legislation in Canada based on consent: implied consent within the “circle of care,” otherwise, express consent;
- The only health sector privacy legislation that was declared substantially similar to the federal legislation in 2005.



Mandate of the Legislation

- Requires consent for the collection, use and disclosure of PHI, with necessary but limited exceptions;
- Requires that health information custodians treat all PHI as confidential and keep it secure;
- Codifies an individual's right to access and request correction of his/her own PHI;
- Gives a patient the right to instruct health information custodians not to share any part of his/her PHI with other health care providers;
- Establishes clear rules for the use and disclosure of personal health information for secondary purposes including fundraising, marketing and research;
- Ensures accountability by granting an individual the right to complain to the IPC about the practices of a health information custodian; and
- Establishes remedies for breaches of the legislation.



Health Care Defined

- Any observation, examination, assessment, care, service or procedure that is done for a health-related purpose and that:
 - Is carried out or provided to diagnose, treat or maintain an individual's physical or mental condition;
 - Is carried out or provided to prevent disease or injury or to promote health.



Who's Covered

Health Information Custodians:

- Health care practitioner;
- Hospitals and independent health facilities;
- Homes for the aged and nursing homes;
- Pharmacies;
- Laboratories;
- Home for special care;
- A centre, program or service for community health or mental health.



Occupational Health Nurses

- When working for a health information custodian (e.g., rehab clinic) and providing health care, Occupational Health Nurses (OHNs) will be considered to be **agents** of a health information custodian;
- When working for a non-health information custodian (e.g., a manufacturing company) and providing health care, OHNs will be considered to be **health information custodians**.



General Rules for Custodians

- Must take reasonable steps to ensure accuracy and security of personal health information (e.g., locked file cabinets and offices);
- Must have a contact person to ensure compliance with the legislation and to respond to access/correction requests, inquiries and complaints from public – in a small office, the nurse may perform these duties;
- Must have written information practices that comply with PHIPA and are available to the public – see IPC’s short notices products for examples;
- Must obtain consent before PHI is collected, used or disclosed, unless permitted without consent – in most cases consent can be implied;
- Must be responsible for actions of agents – to train and educate all staff on privacy and security.



HICs Working for Non-HICs

- In many cases, occupational health nurses (HICs) will be working for a person/organization that is not a health information custodian (e.g., nurse working for a manufacturing company);
- There are many special considerations that are outlined in our Fact Sheet *Health Information Custodians Working for Non-Health Information Custodians*. For example, special considerations for HICs working for non-HIC employers:
 - Required not to share personal health information with non-HIC employers, except with the consent of the individual, or as permitted by law;
 - May need to store health information records in a place that is not within their own direct custody and control (e.g., nurses working for school boards may be required to keep records in a central location in the school accessible to other health care providers).

www.ipc.on.ca/docs/fact-11-e.pdf



Agents of HICs Working for Non-HICs

- Agents (e.g., a file clerk) of a custodian (i.e., the occupational health nurse) may include persons working for a non-HIC employer (e.g., manufacturing company);
- Example: an occupational health nurse (OHN) working for a manufacturing company may use the services of a staff person employed by the company to schedule appointments, manage records and perform filing; would be considered an agent of the OHN, thus also falling under *PHIPA*.



Disclosures to Non-HIC Employers

- A Health Information Custodian (OHN) cannot disclose personal health information to a non-HIC employer (e.g. factory) unless:
 - The individual patient consents (e.g., where information is needed by the employer to accommodate a worker's medical condition);
 - The disclosure is permitted or required by PHIPA (e.g., to prevent harm; for the purpose of contacting next of kin in circumstances where the individual is unable to consent, in the event of an injury or illness);
 - The disclosure is permitted or required by another law (e.g., nurse must report to superintendent of correctional facility if an inmate is seriously ill).



Record Storage

- Normally, custodians keep records in a location under their direct custody and control (i.e., locked filing cabinet in the OHN's office);
- S. 14(2) of PHIPA permits records to be kept in a location other than a place in the nurse's control (e.g., central file room) if:
 - The record is kept in a reasonable manner (files kept locked); and
 - **The individual consents** (consent may be implied).



General Rules for OHNs as Agents

- Only permitted to collect, use, disclose, retain or dispose of PHI on custodian's behalf (e.g. rehab. centre) if:
 - the custodian is permitted to do so; and
 - it is in the course of the agent's duties.
- Must notify the custodian at the first reasonable opportunity if PHI is stolen, lost or accessed by unauthorized persons;
- Must comply with custodians information policies and practices.



PHIPA:
First Year at the
Commissioner's Office



PHIPA Implementation

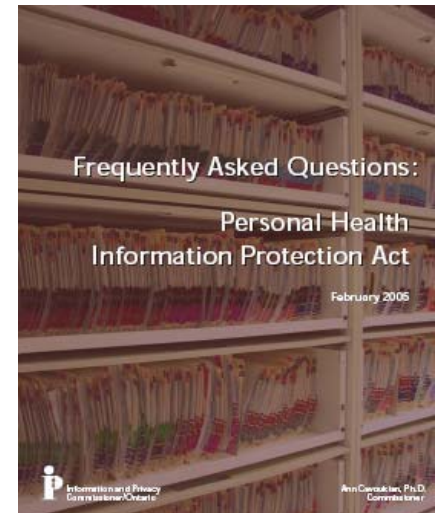
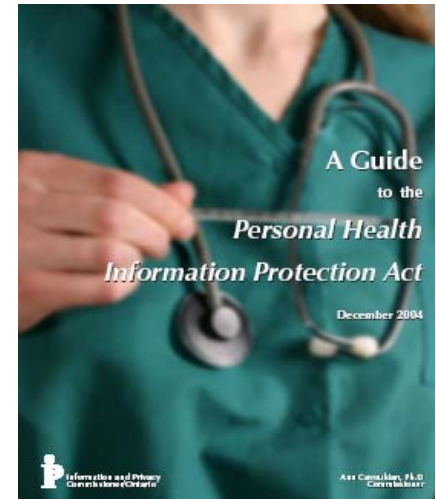
- The implementation has been a surprisingly smooth process;
- Custodians have done an excellent job, with a high level of cooperation with IPC in resolving issues;
- Relatively few complaints to the IPC – most complaints are being handled effectively by the custodians themselves.



IPC Publications

Public Education Program

- Frequently Asked Questions and Answers available on IPC website (including hard copies);
- User Guide for Health Information Custodians available on IPC website (including hard copies);
- IPC PHIPA publications distributed to Colleges and Associations of the Regulated Health Professions;
- IPC/MOH brochure for the general public:
 - may be placed in reception areas;
 - to be distributed to patients.





IPC Publications

Public Education Program (Cont'd)

- OHA Toolkit – IPC participated in its development;
- IPC/OBA “short notices” working group:
 - Developing concise, user-friendly notices and consent forms to serve as effective communication tools;
- On-going meetings with Regulated Health Professions, the Federation of Health Regulatory Colleges and Associations;
- IPC PHIPA awareness article distributed to Colleges and Associations for inclusion in their members’ Magazines and Newsletters;
- IPC Training Video (recently released);
- *PHIPA* Conference hosted by the IPC to celebrate the 1st anniversary of the *Act*.



IPC PHIPA Fact Sheets

- Health Information Custodians Working for Non-Health Information Custodians;
- Secure Destruction of Personal Information;
- Long-term Care Homes: Consent and Access under the Personal Health Information Protection Act, 2004;
- Lockbox;
- Disclosure of Information Permitted in Emergency or other Urgent Circumstances;
- Reporting Requests under *PHIPA*;
- Consent and Form 14;
- Fundraising under *PHIPA*;
- Ontario Regional Poison Information Centres and the Circle of Care;
- Your Health Information: Your Access and Correction Rights;
- Safeguarding Personal Health Information.



Health Information Short Notices

- The goal is to develop easy to read items containing the necessary elements regarding the collection, use and disclosure of personal health information, but not to overwhelm individuals with so much information that they will **not** read them;
- The language of the notices must be accessible and easily understood — *plain language is key*.



Health Information Short Notices Working Group

- Information and Privacy Commissioner/ Ontario;
- Ont Bar Assoc Privacy and Health Law sections;
- Ministry of Health and Long-Term Care;
- Ontario Dental Association;
- *One of only several projects around the world focusing on short notices in the health sector:*
- The IPC looks forward to engaging members of the health and legal profession in further improving the multi-layered approach in communicating with the public.



IPC
Complaints
and
Investigations



Stages of Complaints

- **Intake:**
 - Matter may be resolved by informal resolution;
- **Mediation:**
 - Matter may be resolved by a mutually agreed upon resolution between a complainant and the custodian; or
 - Matter may be resolved when IPC is satisfied with the actions taken by the custodian;
- **Adjudication:**
 - Matter is fully investigated and a formal determination is made on the issues.



Outcomes of Complaints

- **Intake:**
 - The outcome of an informal resolution is a letter to both parties confirming the resolution;
- **Mediation:**
 - When the resolution is between an individual and a custodian, a letter is sent to both parties confirming the resolution;
 - When the IPC is satisfied with the actions taken to resolve a HIC–reported breach, or an IPC Initiated Complaint, a Report is issued;
- **Adjudication:**
 - The outcome at adjudication can be a Report or an Order (only one order issued to date).



Status of *PHIPA* Complaints

- Total number of *PHIPA* complaints = 307;
- 222 are closed (72%); 85 are open (28%);

PHIPA complaints by category (open and closed):

TOTAL PHIPA COMPLAINTS (OPEN+CLOSED)	No.	%
Access/Correction	118	39%
Collection/Use/Disclosure	80	26%
HIC Reported Breach	78	25%
IPC Initiated Complaint	31	10%
Total Complaints	307	100%

- As of May 31, 2006



Mediation Stories



Mediation Stories

Nurse's Briefcase Stolen

- Public health nurse reported that her briefcase, containing personal health information on a USB storage device, had been stolen from her home;
- Nurse was involved in a stop smoking program involving local high schools – storage device included information about students in the program;
- Notification was an issue because parents may not have known student was smoking and custodian was unsure if addresses were current;
- Lesson – personal health information should not be stored on unprotected storage medium for prolonged periods of time.



Mediation Stories

Records Found on Public Transit

- A health care professional found hospital records (including directions to patient's homes) while traveling on public transit and contacted the IPC;
- IPC contacted the patient who reported that a nurse had recently visited her home;
- The nurse had taken the information from the hospital to facilitate the patient's ongoing participation in a research study;
- Both the hospital and nurse apologized;
- Hospital incorporated clearer guidance on the safe transport of personal health information and what to do in the event of a privacy breach, into its existing policies and procedures.



Mediation Stories

Nurse Posted Pictures

- A nurse working at a health care facility posted photographs taken within the facility on a personal website;
- Photographs were primarily of staff, but also inadvertently included personal health information of some patients (e.g., names on white boards, names posted on patients' bed, etc.);
- In conjunction with IPC, it was decided to notify the five affected individuals in person at their next visit with their health care provider rather than in writing.



Mediation Stories

Nursing Services Company

- A computer belonging to a small company specializing in nursing services could not be found following a break-in;
- Company notified both the police and the IPC;
- IPC assisted in developing a multi-pronged approach to notification;
 - Local physicians, long-term care facilities, local hospitals and other agencies were asked to post notices; and
 - Physicians with ongoing relationships with patients who received services from the company were asked to inform these patients directly; and
 - Current clients of the company were informed directly;



Mediation Stories

Nursing Services Company (cont'd)

- Company enhanced physical security – changed all locks and installed alarm system;
- **Patient identifiers were separated from the clinical data in the database – *introducing an enormous safeguard;***
- Other safeguards – implemented document security travel bags, fax on demand, new privacy and security policies and enhanced staff training.



Ontario's PHIPA:

Requirement for Breach Notification

Section 12 (2) – Notice of Loss:

A health information custodian that has custody or control of personal health information about an individual shall notify the individual at the first reasonable opportunity if the information is stolen, lost, or accessed by unauthorized persons.

www.e-laws.gov.on.ca/DBLaws/Statutes/English/04p03_e.htm



Notifying Affected Parties of Privacy Breach

- Common issue in custodian reported breaches is how to notify individuals who may have been affected by breach;
- Custodian sometimes unsure of what happened to patients' personal health information;
- Patients to be notified may have life threatening illnesses – don't want to inflict any additional stress;
- IPC has taken a flexible approach to notification – in some cases, far preferable for the physician to notify in person at next visit rather than immediately, in writing.



The Incident



“The Incident”

October 1, 2005

- I was contacted by a newspaper reporter from the Toronto Star who advised me that patient health records were being blown around the streets of downtown Toronto;
- The records were being used as props on the location for a film shoot about the September 11, 2001 terrorist attacks on New York’s World Trade Center;
- The seriousness of such an incident, coupled with the potential devastating impact on patient privacy, prompted the need for immediate action.



“The Incident”

October 1, 2005 (Cont'd)

- I conducted an immediate site visit and personally attended at the film location;
- When I arrived, the medical records had been retrieved, as the reporter indicated might be the case;
- While I found no evidence of patient health records on the streets, I did retrieve a one page memo that, while containing no personal health information, involved some sensitive information;
- I immediately alerted the Executive members of my office and initiated an investigation pursuant to s.58(1) of the *Personal Health Information Protection Act (PHIPA)*.



“The Incident”

October 2, 2005

- The Toronto Star ran a story describing the incident, along with a picture of the film set littered with what would appear to be patient records;

Film shoot uses real medical records

Privacy official has plans to investigate

RAJU MUDHAR

STAR REPORTER

A TV miniseries filming in downtown Toronto may have to answer to Ontario's privacy commissioner after it was discovered that “fake garbage” used in the movie actually consisted of patients' medical records from a Barhurst St. clinic.

The paper littered the sidewalk on Wellington St. W., near York St., yesterday for filming of *The Untold History Project*, a Touchstone Television production about the Sept. 11, 2001, terrorist attacks on the United States that will air on ABC. Toronto is filming in for New York City, and fire trucks, police cruisers and strewn garbage are being used to recreate the scene. But much of the garbage yesterday was actually medical documents — mostly information about X-rays bearing the address of a Barhurst St. clinic. The material, noticed by someone on the movie set, included information about ultrasounds, chest X-rays and even dismos-



Mounds of medical records strewn along Wellington St. W. yesterday during filming of a TV miniseries on the 9/11 attacks. Below, an ultrasound report picked from the pile.

- A close-up of one patient health record from an X-ray and ultrasound clinic also appeared with the story;
- The patient's name had thankfully been removed from the photograph of the actual health record.



The Investigation



The Investigation: *First Steps*

- My office's "privacy breach protocol" was immediately implemented;
- On the first day of the review, two IPC investigation teams attended the relevant sites to recover all personal health information and to start the process of determining how this incident could have occurred;
- The teams were in regular contact with my office throughout the day, and with one another, as they undertook the first step of containment and began the investigation.



Commissioner's Investigation

- The investigation determined that the health records originated with a Toronto X-ray and ultrasound clinic;
- Boxes containing the records were removed, without notice, from a locked storage area by the Toronto Clinic's landlord and placed near the building's common parking area;
- A Toronto Clinic staff member, realizing that the records were not secure, placed them in her vehicle and drove them to a Richmond Hill clinic owned by the same corporation;



Commissioner's Investigation

(Cont'd)

- From there, the boxes were picked up by the Paper Disposal Company that provided shredding services for both clinics;
- Because of a misunderstanding on the part of an employee of the Paper Disposal Company, some of the boxes were marked for recycling, not shredding;
- These boxes were passed on to a recycling company who subsequently sold the records – intact – to a film company for use on its set.



Privacy Breach Protocol

Alert Your Incident Response Team

- **Containment:** *Identify the scope of the potential breach and take steps to contain it;*
- **Notification:** *Identify those individuals whose privacy was breached and, barring exceptional circumstances, notify those individuals accordingly;*
- **Investigation:** *Conduct an internal investigation into the matter, linked to the IPC's investigation and with law enforcement if so required;*
- **Remediation:** *Address the situation on a systemic basis where program or institution-wide procedures warrant review.*



The Order



Impact of the Order

*“This Order will establish the practice to be followed by all health information custodians **and their agents** in Ontario, with respect to the Commissioner’s expectations for the secure disposal of health information records under Ontario’s new Health Information Privacy Law.”*

— Order HO-001, October 2005



Keeping HICs Informed

- Summaries of all mediated cases and reports are available on our website;
- Orders are public documents and available on our Web site;
- Relevant data are regularly made available to the public and to health professionals (*number of complaints, examples of successful mediations, common issues, etc.*).



How to Contact Us

Ann Cavoukian, Ph.D.

Information & Privacy Commissioner of Ontario

2 Bloor Street East, Suite 1400

Toronto, Ontario, Canada

M4W 1A8

Phone: (416) 326-3333 / 1-800-387-0073

Web: www.ipc.on.ca

E-mail: info@ipc.on.ca