



Health Information Privacy and Electronic Health Records: *The Ontario Perspective*

Ann Cavoukian, Ph.D.

Information & Privacy Commissioner/Ontario

Mexican Delegation

Ottawa

May 2, 2006



Outline of Presentation

- 1. Importance of health privacy*
- 2. Health information privacy laws in Canada*
- 3. Ontario's Personal Health Information Protection Act, (PHIPA)*
- 4. Electronic Health Records*
- 5. Conclusion*



Health Privacy is Critical

- The need for privacy has never been greater:
 - Extreme sensitivity of personal health information;
 - Patchwork of rules across the health sector; with some areas currently unregulated;
 - Increasing electronic exchanges of health information;
 - Multiple providers involved in health care of an individual – need to integrate services;
 - Development of health networks;
 - Growing emphasis on improved use of technology, including computerized patient records.



Provincial Health Privacy Laws in Canada

Alberta

- *Health Information Act*

Manitoba

- *Personal Health Information Act*

Québec

- *Act respecting access to documents held by public bodies and the protection of personal information;*
- *Act respecting the protection of personal information in the private sector.*

Saskatchewan

- *Health Information Protection Act*

Ontario

- *Personal Health Information Protection Act*



Ontario's Personal Health Information Protection Act (PHIPA)

- Came into effect November 1, 2004
- Based on Canada's Fair Information Practices*:
 - Accountability
 - Identifying Purposes
 - Consent
 - Limiting Collection
 - Limiting Use, Disclosure, Retention
 - Accuracy
 - Safeguards
 - Openness
 - Individual Access
 - Challenging Compliance

*CSA Standard CAN/CSA-Q830, *Model Code for the Protection of Personal Information*; PHIPA has been deemed to be substantially similar to PIPEDA.



Scope of PHIPA

- Health information custodians (HICs) that collect, use and disclose personal health information (PHI);
- Non-health information custodians that receive personal health information from a health information custodian (use and disclosure provisions);
- “Agents” acting on behalf of health information custodians.



Health Information Custodians

- **Definition includes:**
 - 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.



PHIPA Consent

- Consent is required for the collection, use, disclosure of PHI, subject to specific exceptions;
- Consent must:
 - be a consent of the individual;
 - be knowledgeable;
 - relate to the information;
 - not be obtained through deception or coercion;
- Consent may be express or implied.



Implied Consent

- Custodians may imply consent when disclosing personal health information to other custodians for the purpose of providing health care to the individual;
- Exception – if the individual expressly withholds or withdraws consent (lock box).



Status of *PHIPA* Complaints

- Total number of *PHIPA* complaints = 288;
- 195 are closed (68%); 92 are open (32%);

PHIPA complaints by category (open and closed):

TOTAL PHIPA COMPLAINTS (OPEN+CLOSED)	No.	%
Access/Correction	115	40%
Collection/Use/Disclosure	75	26%
HIC Reported Breach	70	24%
IPC Initiated Complaint	28	10%
Total Complaints	288	100%

- As of May 1, 2006



Electronic Health Records (EHR)

Advantages:

- Improve quality and lower cost of health care;
- Quick access to wide range of data;
- Better security through more effective access controls and audit trails;
- Improved privacy protection by limiting access to need-to-know;
- Better data for health system management, enhancing quality of care, and research.



More about EHRs...

Challenges:

- Facilitate data linkages and data sharing;
- Unauthorized access is more catastrophic due to volume of records and quantity and quality of data;
- Multiple users and multiple access points raise accountability issues and increase vulnerability.



Key Questions About EHRs

- What data should be entered on EHR?
- Is data centralized or stored at point of generation?
- How do you manage consent, particularly when integrating legacy systems not designed with consent in mind?
- What level of security constitutes “reasonable steps”?
- Who has access to what information and for what purposes?
- Who checks for privacy breaches and notifies individuals of breaches?
- If data centralized, who has custody and control of EHR? Who is accountable? What is legal status of central archive?
- Under what legislative authority can a custodian transfer custody and control of personal health information a central archive?



Canada Health Infoway (CHI)

- CHI is a national organization involving Canada's 14 federal, provincial and territorial Deputy Ministers of Health;
- CHI's mission is to foster and accelerate the development and adoption of electronic health information systems with compatible standards and communications technologies on a pan-Canadian basis;
- CHI was launched in 2001; CHI and its public sector partners have over 100 EHR projects either completed or underway;
- CHI has developed a privacy and security architecture for EHRs.



EHRs in Ontario

- The Ontario Health Quality Council reported that each year 32,000 Ontario patients were made worse because of errors caused by the **lack** of electronic health records;
- Errors could be prevented (including adverse drug reactions) “if all doctors had online access to patient files;”
- The Council’s concerns echo an investigation last year that found government efforts to bring computerized patient records to all Ontarians riddled with delays.

*Ray Hession, Chair,
Ontario Health Quality Council, April 27, 2006.*



EHR Incentives in the U.S.

"By computerizing health records, we can avoid dangerous medical mistakes, reduce costs, and improve care."

President George W. Bush, State of the Union Address, January 20, 2004

- In 2004, President Bush launched an initiative to make electronic health records available to most Americans within the next 10 years;
- Under his Health IT Plan, all federal agencies (e.g., Medicare, Medicaid and the Veterans Administration) were ordered to review programs and propose ways to incorporate electronic health initiatives into their medical support systems.



Conclusion

- Ontario's PHIPA facilitates the development of EHRs;
- The steady growth of EHRs throughout Canada and the United States can be expected to continue and increase;
- We, in the privacy community, must ensure that privacy gets build into the architecture and design of EHRs, right from the outset.



How to Contact Us

Ann Cavoukian, Ph.D.

Information & Privacy Commissioner/Ontario

2 Bloor Street East, Suite 1400

Toronto, Ontario M4W 1A8

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

Web: www.ipc.on.ca

E-mail: info@ipc.on.ca