

# Evaluating *PHIPA*: Is it a Good Thing?

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Implementing the Personal Health Information Protection Act Best Practices for Securing PHI Protection

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### What This Talk Is About

- Life before PHIPA
- Value of PHIPA
- Impact on health information custodians
- Public education
- Health information short notices
- Privacy impact assessments
- Implementation issues e.g. fees, lock-box, notification of security breaches
- Results
- Next Steps



### Without PHIPA:

- Patchwork of rules across health sector
  - barrier to integration of services from multiple health care providers
  - barrier to implementation of new technology such as health infoways and EHRs
- Parts of health sector subject to PIPEDA and parts unregulated
- Duties of custodians and individuals' rights not clearly defined
- As of January 1, 2004, Health Information Custodians (HICs) in private practice covered by PIPEDA



### Why is it a good thing?

- PHIPA drafted with the needs of the health sector in mind
- Provides a consistent set of rules for the collection, use and disclosure of personal health information across the health care sector
- Obligations of custodians and rights of individuals are clearly defined
- Because PHIPA is substantially similar to PIPEDA, custodians are exempt from the application of the federal rules with respect to the collection, use and disclosure of personal information occurring within Ontario. Other jurisdictions with health sector privacy legislation, custodians have to deal with multiple layers of legislation



### What remains the same?

Many things remain essentially the same, with some variations in the details. Some examples are:

- The obligation to safeguard personal health information (PHI);
- The obligation not to disclose PHI except in limited circumstances or on consent;
- The ability to disclose PHI to reduce risk of serious harm; and
- The obligation to provide access to PHI.



### PHIPA adds clarity

- PHIPA conflict provisions (s.7 of the Act and s.1(5) and s.5 of O. Reg. 329/04)
- In the event of a conflict PHIPA prevails (s.7(2))
- There is no conflict unless it is not possible to comply with both PHIPA and its regulations and any other Act or its regulations.



# Does it strike the right balance?

- Designed to allow personal health information to flow among health care providers, but at the same time protect the privacy of individuals
- In the health care context, consent can be implied for the collection, use and disclosure of personal health information
- Outside the health care context, express consent usually required



# Was implementation onerous?

- Only 6 months from the time the legislation was passed until it came into force
- Nonetheless, implementation was a surprisingly smooth process – it is business as usual in the health care sector
- 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.



# Is it an undue burden on custodians?

#### **New obligations**

- Requires much more transparency –written statement of information practices available to the public; posting of notices when implying consent, etc.
- Appointment of contact person
- Privacy training and education
- Responding to lock-box requests
- Individuals must be notified when security breached
- Dealing with an oversight body



# How does PHIPA alleviate burden on custodians?

- Since substantially similar designation, most custodians that were subject to PIPEDA are no longer
- If PHIPA were not here, PIPEDA would apply in a patchwork (nonsensical except to the constitutional lawyer) fashion
- More guidance in PHIPA as to what is a custodian than there is for PIPEDA's commercial activity concept!



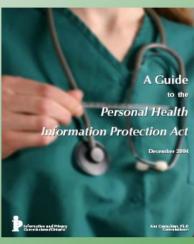
### How does PHIPA alleviate burden on custodians... continued

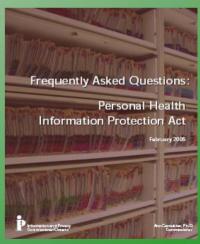
- Clearly no requirement for express consent in the context of providing care between health information custodians
- Specified custodians may assume implied consent when providing health care
- Provides clear authority to collect, use and disclose personal health information without consent in a range of appropriate circumstances
- PHIPA is consistent with most existing standards of practice
- Variety of tools developed by the IPC to assist custodians with implementation



### **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.







### 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
- Ongoing 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



### PHIPA: Fact Sheets

- Health Information Custodians Working for Non-Health Information Custodians
- Secure Destruction of Personal Information
- Lock-box
- Disclosure of Information Permitted in Emergency or other urgent circumstances
- 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



#### Lock-box Fact Sheet

#### What does the term 'lock-box' mean?

The Personal Health Information Protection Act (PHIPA) is a consent-based statute, meaning that ig itsee Ontarians control over the collection, use and disclosure of their personal health information by stipulating that health information custodians can only collect, use and disclose an individual's personal health information with the experson implied consent of that individual, subject to limited exceptions.

Integral to the concept of consent is the notion that individuals have the ability to withhold or withdraw their consent to the collection, use or disclosure of their personal health information for a particular purpose, including for the provision of health care. Section 20(2) of PHDPA makes it clear that individuals may withhold or withdraw their consent to the collection, use or disclosure of their personal health information by health information custodians for the purposes of providing or dassisting in providing health care, assisting in providing health care.

Further, under PHIPA, individuals may provide express instructions to health information custodians not to use or disclose their personal health information for health care purposes withour consent in the circumstances set out in sections 37(1)(a), 38(1)(a) and 50(1)(c) of PHIPA.

These provisions have come to be referred to as the "lock-box" provisions, although lock-box is not a defined term in PHIPA.

#### What information can individuals 'lock,' and from whom can they lock it?

The withholding or withdrawal of consent or the express instructions cited above may take various forms, including communications from individuals to health information custodians:

- not to collect, use or disclose a particular item of information contained in their record of personal health information (for example, a particular diagnosis);
- not to collect, use or disclose the contents of their entire record of personal health information;
- not to disclose their personal health information to a particular health information custodian, a particular agent of a health information custodian or a class of health information custodians or agents (e.g. physicians,



### 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

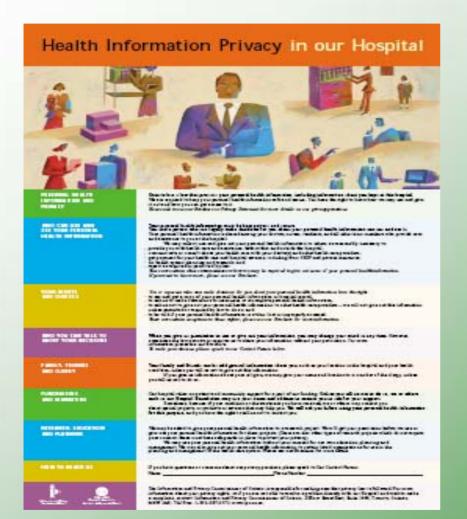


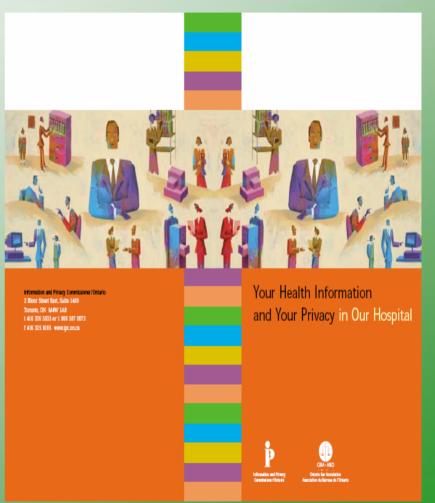
# Health Information Short Notices Working Group

- Information and Privacy Commissioner/ Ontario
- Ontario Bar Association's 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



### **Short Notices Products**







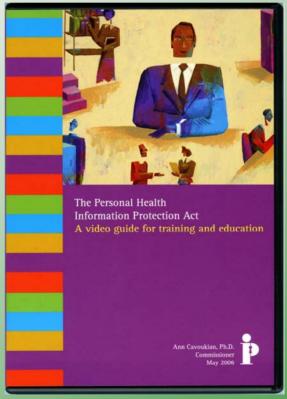
### Privacy Impact Assessments (PIAs)

- Self-assessment tool developed to assist health information custodians in reviewing the impact of a proposed information system, technology or program on privacy
- Goal is to identify and mitigate privacy risks
- PIAs are not required under PHIPA, but are rapidly becoming a best privacy practice



### **Other Resources**

PHIPA Training Video – available upon request





# Ongoing implementation issues

Fees

Lock-box

Notification of Security Breaches



### **Fees**

 IPC received complaints and inquiries about fees for access to records of personal health information

- Inconsistent interpretation of a reasonable cost recovery = varied cost structure
- The IPC proposed the idea of fee regulation
- Many different stakeholders consulted



#### Lock-Box

- A consent system necessarily implies the ability to withhold or withdraw consent
- PHIPA allows an individual to expressly withhold or withdraw consent or expressly instruct a custodian not to use or disclose personal health information without consent for the purpose of providing health care in circumstances set out in section 37(1)(a), 38(1)(a) and 50(1)(e)
- Withdrawal of consent critical for substantial similarity designation
- Documentation Conditions placed on an individual's consent cannot prohibit or restrict the recording of information that is required by law, established professional practice, or institutional practice Section 19(2)
- Some systems capable of locking information at the encounter or record level
- Required level of granularity is an issue PHIPA does not put any limits on what the individual may request in terms of locking



#### Checks on the Lock-Box

- **Notification** if a custodian is prevented from disclosing personal health information under *Section 38(1)(a)* that the custodian believes is reasonably necessary for the provision of health care due to an express instruction of the individual, the custodian must notify the recipient of that fact under *Section 38(2)*. Proposed regulations will also require the same notification of agents of a health information custodian
- Override subject to certain exceptions, a custodian may use or disclose (regardless of Lock-Box) if PHIPA permits the collection, use or disclosure to be made without consent, for example if necessary to eliminate or reduce a significant risk of serious bodily harm to a person or a group of persons (Section 40)



# Further Limits on the Lock-Box

 Presents challenges for large Legacy
 IT systems which were not designed to accommodate consent preferences



### **IPC Position on Lock-Box**

- Lock-box provisions came into full force as of November 1, 2005
- Fact sheet available on IPC website
- Compliance with the lock-box provisions of PHIPA may be achieved by health information custodians through:
  - Policies, procedures or manual processes;
  - Electronic or technological means;
  - A combination of policies, procedures or manual processes and technological means
- Custodian may choose method of compliance
- IPC expects custodians may need to develop creative solutions to respond to individual requests



### **Notification**

 Section 12(1) requires custodians to notify the individual at the first reasonable opportunity if personal health information is stolen, lost or accessed by unauthorized persons



### **Notification Challenges**

- Sometimes the identities of individuals are not known (e.g., no backup for lost laptop)
- Sometimes there are a large number of individuals involved and individual notification may not be practical or possible
- Sometimes it is not known what has happened to the information (e.g., custodian doesn't know if there was any unauthorized use or disclosure of lost information) so custodian may not know what to tell the individual about the breach
- Notification may cause unnecessary stress for individuals who may already be facing life-threatening illness



### **Notification Solutions**

- IPC is working with custodians to develop creative solutions to notification requirement
- Posting general notices in newspapers, physician's offices, health care facilities and other places where it is likely to come to the attention of affected individuals
- Notification in person at next scheduled appointment rather than by letter



### It's a Revolution - NOT!

 PHIPA was never intended to revolutionize the health sector – it is business as usual

 It merely codifies, in one place, a lot of requirements that had always been the responsibility of those we now call health information custodians (HICs)



# Has PHIPA Achieved Its Promise?

- As of April 24, 2006 279 files opened
- 111 complaints about access/correction
- 73 complaints about collection, use and disclosure
- 67 self-reported breaches by custodians
- 28 complaints initiated by IPC
- Only one order issued
- Most complaints resolved at an early stages through mediation



### Other Changes Needed?

- Working well to date
- Opportunity to make changes through broad regulation-making authority
- Open regulation-making process working well
- Before Nov. 2/07, a comprehensive review of this Act will commence
- Let us know your comments on what you feel can be improved!



### **How to Contact Us**

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