

# **Health and Privacy:**

## *The Experience of a Regulator*

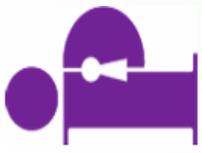
**Ken Anderson**

**Assistant Commissioner (Privacy)**

**Information and Privacy Commissioner/Ontario**

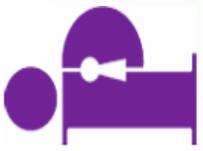
Edinburgh Privacy and Technology Workshop  
Edinburgh, Scotland

*September 6, 2005*

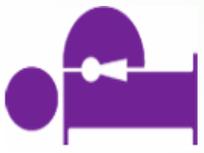


# What This Talk is About

- I. Health Information**
- II. Choice of Privacy Protection**
- III. Regulation**
- IV. How the Regulator Chooses to Implement**
- V. Examples**
  - i. Short Notices**
  - ii. Registries and Entities**
  - iii. Tribunal Services**
- VI. Summary**



# *Health Information*



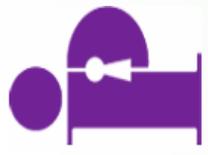
# Unique Characteristics of Personal Health Information (PHI)

- Highly sensitive and personal in nature;
- Must be shared immediately and accurately among a range of health care providers for the benefit of the individual; and
- Widely used and disclosed for secondary purposes that are seen to be in the public interest (e.g., research, planning, fraud investigation, quality assurance).



# Why Privacy in Health is Critical in the 21<sup>st</sup> Century

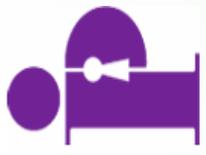
- Patchwork of rules across the health sector, with some areas unregulated;
- Growing emphasis on improved use of technology, including computerized patient records;
- Increasing electronic exchanges of health information;
- Multiple providers involved in health care of an individual – need to integrate services; and
- Development of health networks.



# Federal Recognition of Privacy for Personal Health Information

## Krever Commission – 1980

*“ ...our society values privacy for health information, creating a need for the observance of, or respect for, confidentiality...we do not favour free and uninhibited disclosure of everyone’s health information.”*



# A Stable Health System Requires Information Sharing

## **Romanow Commission – 2002**

*“If we are to build a better health system,  
we need a better information sharing  
system so that all governments and all  
providers can be accountable to  
Canadians.”*



# *Choice of Privacy Protection*



# Canadian Charter of Rights and Freedoms

- The right to privacy is not explicitly protected in the Canadian Charter of Rights and Freedoms (Charter) but implicitly so and the right has its genesis in section 8, which provides:

*The right to be free from unreasonable searches  
and seizures.*

- The analysis of section 8 of the Charter by the courts in the search and seizure cases has resulted in a limited protection of the right to privacy.

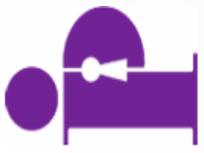


# The Limited Constitutional Right to Privacy

- The judgments of the Supreme Court of Canada relating to section 8 of the Charter have concluded that when the state conducts a search of an individual or his property without prior judicial authorization;  
(a) in circumstances where the individual had a reasonable expectation of privacy, and (b) the search was an unreasonable intrusion on that right; then that search is a violation of section 8 of the Charter.

# **i** Constitutional Compromise in a Criminal Law Context

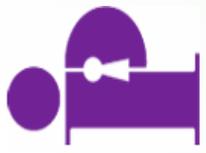
- In most of the cases regarding section 8, these rules form a constitutional compromise between the right to be free from search by the state and the need to permit investigations in criminal matters. Every assessment of whether there is a *reasonable expectation of privacy* takes into account the context of the case.



# Privacy is Now a Constitutional Expectation

In British Columbia, a complaint had been lodged with the Human Rights Commission by eight women on behalf of female members of a Mormon sect practicing polygamy. The complaint alleges that the B.C. government failed to protect the women involved in the sect from an oppressive culture. The female members of the group came forward and stated that it is not the government that has violated their rights but the complainants who have violated their “constitutionally guaranteed rights of religion, association, privacy and peaceful assembly.”

— *Globe and Mail*, Oct 12, 2004



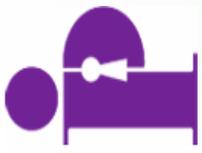
# Privacy, the Charter and Personal Health Information

- *R v Mills, [1999] 3 SCR 668* the majority recognized that “The values protected by privacy rights will be most directly at stake where the confidential information contained in a record concerns aspects of one’s individual identity or where the maintenance of confidentiality is crucial to a therapeutic, or trust like relationship.”



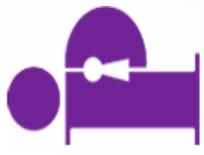
# Privacy, the Charter and Health Information

- The Supreme Court of Canada has recently recognized “that there is the highest level of personal and private information contained in an individual’s DNA”. *R. v. S. A. B., [2003] 2 SCR 678*



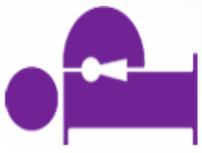
# Common Law

“In short, patients should have access to their medical records in all but a small number of circumstances. In the ordinary case, these records should be disclosed upon the request of the patient unless there is a significant likelihood of a substantial adverse effect on the physical, mental or emotional health of the patient or harm to a third party.” *McInerney v. MacDonald* [1992] 2 S.C.R. 138.



# Call for Legislation in Ontario

- The IPC had been calling for legislation to protect Ontarians health information since its inception in 1987;
- Numerous attempts made over the years to get a bill introduced and passed, but have never succeeded:
  - *Personal Health Information Privacy Act, 2000*
  - *Privacy of Personal Information Act, 2002*



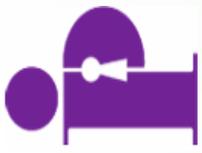
# Lessig's Four Modalities of Regulation

- Law or Legislation – enforced by government;
- Social Norms – enforced by a community;
- Markets – regulates by price;
- Architecture – shapes behaviour.
- *“These four modalities regulate together. The net regulation of any particular policy is the sum of the four modalities together.”*

— Lawrence Lessig, Professor of Law at Stanford Law School,  
*The Law of the Horse: What Cyberspace Might Teach*,  
Berkman Center for Internet and Society, December 1999, pp. 506-508



# *Regulation*



# Viewpoints on Legislation

*“For values like privacy, bottom-up regulation is unlikely to change an architecture — here, the architecture of commerce that so significantly benefits a particular powerful class of users. The challenge is to layer onto this bottom-up design structures and incentives that will enable some collective choice other than the unorganized cumulative effect of individually expressed preferences.”*

— Lawrence Lessig, Professor of Law at Stanford Law School,  
*The Law of the Horse: What Cyberlaw Might Teach*,  
Berkman Center for Internet and Society, December 1999, p. 542.

# Viewpoints on Legislation (Cont'd)

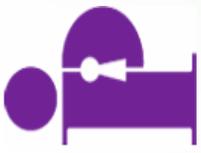
*“... if we were to start regulating privacy in the online environment today, we probably would not start from here, with a legal instrument, the origins of which were entirely pre Internet and designed for a pre-globalisation commercial world..., where information was a relatively scarce and static commodity that relatively few non-state actors collected and processed in relatively unthreatening ways.”*

— **Lilian Edwards**, *The Problem with Privacy: A Modest Proposal*,  
International Review of Law Computers and Technology,  
November 2004, p. 315.

# Viewpoints on Legislation (Cont'd)

*“Reactive strategies appear too enforcement oriented and therefore rely too heavily on the use of state authority. Helping people comply up front is less adversarial and more economical with respect to the use of authority and therefore ought, as a matter of policy, to be preferred.”*

— **Malcolm Sparrow**, *The Regulatory Craft*,  
The Brookings Institute, 2000, p.182.



# Conformity Options

- Industry Standards/Ethics
- Government Policy Statements
- Publicity
- Technology Solutions (eg. PET)
- Education
- Contracts
- Audit
- Regulation
- Ordinary Legislation
- Enforcement
- Quasi- constitutional and constitutional
- International

— Oscapeella, Eugene, *A Review and Analysis of the Policy and Legislative Options Developed by the Department of Justice to Protect Genetic Information and Privacy.*

October 1, 2003



# Privacy Legislation Across Canada

## **Canada**

- *Privacy Act*
- *Personal Information Protection and Electronic Documents Act*

## **Prince Edward Island**

- *Freedom of Information and Protection of Privacy Act*

## **Newfoundland & Labrador**

- *Access to Information and Protection of Privacy Act*

## **Nova Scotia**

- *Freedom of Information and Protection of Privacy Act*
- *Part XX of the Municipal Government Act*

## **New Brunswick**

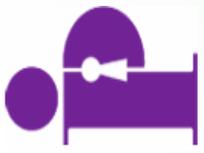
- *Right to Information Act*
- *Protection of Personal Information Act*

## **Quebec**

- *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*

## **Ontario**

- *Freedom of Information and Protection of Privacy Act*
- *Municipal Freedom of Information and Protection of Privacy Act*
- *Personal Health Information Protection Act*



# Privacy Legislation Across Canada (Cont'd)

## **Manitoba**

- *Freedom of Information and Protection of Privacy Act*
- *Personal Health Information Act*

## **Saskatchewan**

- *Freedom of Information and Protection of Privacy Act*
- *Local Authority Freedom of Information and Protection of Privacy Act*
- *Health Information Protection Act*

## **Alberta**

- *Personal Information Protection Act*
- *Freedom of Information and Protection of Privacy Act*
- *Health Information Act*

## **British Columbia**

- *Freedom of Information and Protection of Privacy Act*
- *Personal Information Protection Act*

## **Nunavut [Territory]**

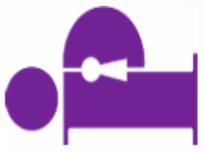
- *Access to Information and Protection of Privacy Act*

## **Northwest Territories**

- *Access to Information and Protection of Privacy Act*

## **Yukon Territory**

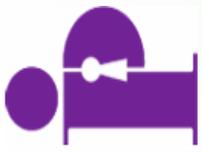
- *Access to Information and Protection of Privacy Act*



# PHIPA

## *Personal Health Information Protection Act*

- Came into effect November 1, 2004.
- Schedule A – the *Personal Health Information Protection Act (PHIPA)*.
- Schedule B – the *Quality of Care Information Protection Act (QOCIPA)*.

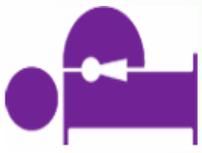


# Mandate of the Legislation

- Require consent for the collection, use and disclosure of personal health information, with necessary but limited exceptions;
- Require that health information custodians treat all personal health information as confidential and keep it secure;
- Codify an individual's right to access his/her personal health information, as well as the right to correct errors;
- Give a patient the right to instruct health information custodians not to share any part of his/her personal health information with other health care providers;
- Establish clear rules for the use of personal health information for fundraising or marketing purposes;
- Set guidelines for the use and disclosure of personal health information for research purposes;
- Ensure accountability by granting an individual the right to complain to the IPC about the practices of a health information custodian; and
- Establish remedies for breaches of the legislation.



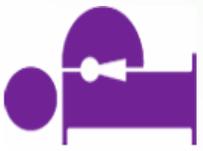
# *How the Regulator Chooses to Implement*



# Role of the Regulatory Agency

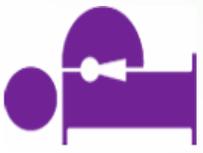
“Regulatory agencies, by their conduct, can take reasonable law and produce oppressive regimes.”

— Malcolm Sparrow, *The Regulatory Craft*, 2000



## Stressing the 3 C's

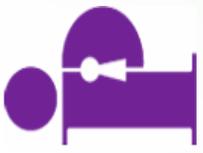
- **Consultation:**
  - Opening lines of communication with health community;
- **Collaboration:**
  - Working together to find solutions;
- **Co-operation:**
  - Rather than confrontation in resolving complaints.



# IPC under PHIPA

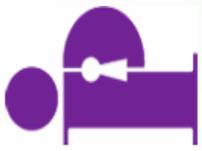
## *Three Key Roles*

- 1. Research and provide advice on proposed legislation and policy;**
- 2. Promote education;**
- 3. Ensure that government organizations comply with access and privacy laws;**
  - RD/AD;
  - Mediation;
  - Adjudication.



# Public Education

- Since September, 2004 we have received over 3,000 telephone requests from health care professionals and the public re PHIPA;
- On-going meetings with regulated health professions to discuss PHIPA and to answer specific questions about its application to unique environments;
- Conduct speeches/presentations/workshop.



# Tools and Resources

- **IPC Publications:**
  - Frequently Asked Questions: Personal Health Information Protection Act;
  - Frequently Asked Questions: Regulations under the Health Information Protection Act;
  - Frequently Asked Questions: Health Cards and Health Numbers;
  - A Guide to the Personal Health Information Protection Act;
  - The Personal Health Information Act and Your Privacy.
- **IPC brochures:**
  - The Personal Health Information Protection Act and Your Privacy;
  - Access/Correction Complaints;
  - Collection, Use, Disclosure and Other Complaints;

# Tools and Resources (cont'd)

## **IPC Focus Papers:**

- Safeguarding Your Personal Health Information;
- Fundraising Under PHIPA;
- Consent Form 14;
- Reporting Requests Under PHIPA;
- Ontario Regional Poison Control Centres and the “Circle of Care”;
- Disclosure of Information in Emergency and Other Urgent Circumstances.

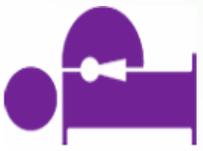
## **Joint Publications:**

- OHA/OMA Toolkit;
- Your Health Information: Your Rights;
- Physician Privacy Toolkit.



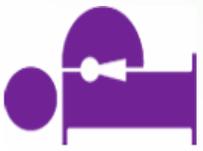
# Examples

- I. Short Notices
- II. Registries and Entities
- III. Tribunal Services



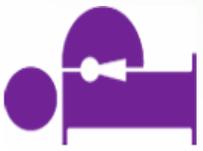
# *I. Short Notices*

## *(Multi-Layered Notices)*



# Introduction to Short Notices Movement

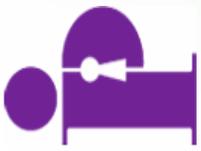
- When dealing with the law of consent, adequate notice is usually a required feature;
- Often, lengthy notices have been used to comply with the requirement but this has resulted in failure due to being lengthy, over-detailed and written in abstruse or obscure language;
- From the above, the “short notices movement” was born to address these inadequacies.



# Short Notices

## *Movement Adopted*

- 2003 - the movement to establish a global short privacy notice was officially recognized at the International Conference of Data Protection Commissioners in Sydney, Australia;
- 2004 - in Berlin, a working group of Commissioners, business leaders, lawyers and privacy practitioners met and prepared a memorandum recognizing that a new architecture was needed for privacy notices;



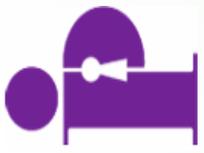
# Berlin Memorandum

- Effective privacy notices should be delivered within a *framework* with the following core concepts:
- **Multi-layered** – Privacy information should not be conveyed solely in a single document
- **Comprehension and Plain Language** – All layers should use language that is easy to understand
- **Compliance** – The total notices framework (all the layers taken together) should be compliant with relevant law
- **Format and Consistency** – Consistent format and layout will facilitate comprehension and comparison
- **Brevity** – The length of a privacy notice makes a difference (*maximum of seven categories*)
- **Public Sector** – These concepts have equal applicability to government collection and use of personal information.



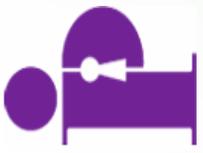
# European Union

- In a report titled *WP100*, the EU Article 29 Working Group agreed that notices compliant with Article 10 can be provided in a “layered” approach, and that individuals can be provided with “short notices” as long as other more detailed notices are readily available.
- *Article 10, deals with the information organizations need to provide to individuals when processing their personal information.*
- *The Article 29 Working Group also differentiated between the three types of notices:*
  - **Short layer** — a brief statement posted where space is limited;
  - **Condensed layer** — a longer summary of highlight points of the entire privacy policy;
  - **Full layer** — complete privacy policy, which could be a multi-page, exhaustive description of a company's privacy practices.



## Goal of the Short Notice

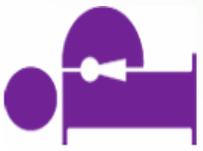
- The goal of the short notice is to provide all individuals with essential information about their access and privacy rights in an easily readable and comparable format.



# Benefit of Short Notices to Individuals

## *Short notices:*

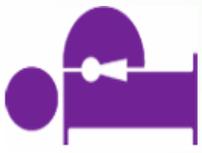
- Provide an easier way for people to become well informed about what an organization does with their personal information; and
- allow people to become empowered with a choice over their personal information;
- Provide a consistent look and feel for these messages in different contexts, (i.e. health, business, government).



# Benefit of Short Notices to Organizations

While individuals are the main beneficiaries of improved communication of information about an organization's privacy practices, there are also benefits for organizations:

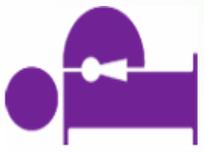
- Able to communicate more effectively with the public allowing for the growth of a relationship based on trust, *through simple understanding*;
- A standardized format could be used globally by an organization to provide for economies of scale;
- Able to effectively comply with legislation.



# Short Notices Under PHIPA

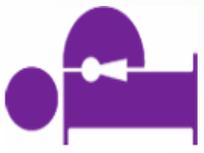
## *Role of the IPC*

- In Ontario, the IPC has taken a leadership role in promoting the use of short notices in the health sector;
- The IPC wanted to ensure that patients are well informed of their rights and have the knowledge to exercise those rights;
- Additionally, the IPC also wanted to help Health Information Custodians communicate more effectively with the public about their information practices and how patients may exercise their rights.



# 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.



# Approach to the Health Information Short Notice

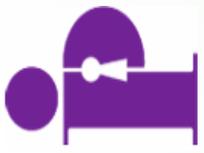
- In line with the Berlin Memorandum, the PHIPA short notices group has adopted a multi-layered approach, with an emphasis on developing separate short notices for each of the following health care groups:
  - Primary care providers
  - Hospitals and facilities
  - Long-term care facilities
- Primary Care Notices are not profession-specific, but should apply to all primary health care providers.
- The working group will continue to make efforts in developing additional layers of information to supplement the notices.



# Design of the Health Information Short Notice – *Posters*

- Capable of being used as a wall poster or in hand out paper format;
- Capable of being used online as well as in hard copy;
- Include IPC logo, logo of OBA and possibly logo of limited number of distributing organizations – health Colleges and major health professional associations;
- Have space for individual practitioner/hospital or facility to include contact information.





# Design of the Health Information Short Notice – *Brochures*

- Vary in length, depending on whether for primary care or for hospital use;
- Are useable online as well as in hard copy;
- Provide detail for issues raised in the notices.



# Reaction to the Short Notices

- As of mid-August over 2,000 Short Notices documents have been downloaded from the IPC Website.

## Requests for Paper Materials:

- Packages sent out as of mid-August 2005:
  - **Total: 267,179**
    - Brochures: 175,835
    - Posters: 91,344
- Brochures and Posters sent out to specific entities:
  - Hospitals – 12,987
  - Facilities – 32,283
  - Private Practices – 221,909



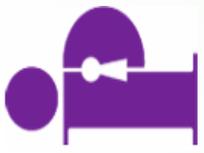
# Testimonial From Health Care Community

*"The notice and brochure developed by the Information and Privacy Commissioner/Ontario are tools we will use in our Public Health department. They will enable us to easily communicate with our clients about the purpose for which their personal health information is being collected, while at the same time helping us to fulfill our obligations under the Personal Health Information Protection Act, 2004."*

— Anne Schlorff,  
Director of Administrative Services for Region of Waterloo Public Health



## *II. Registries and Entities*



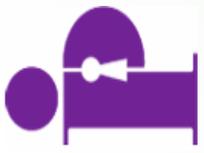
# PHIPA and the Use and Disclosure of PHI

- PHIPA recognizes the need for the disclosure and use of PHI for the management, evaluation, monitoring and planning for the health system;
- PHIPA facilitates and permits the disclosure and use of PHI without consent to certain prescribed registries and entities for these purposes.



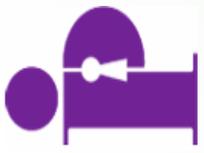
# Regulated Automatic Disclosures

- **Registries:**
  - Health Information Custodians (HICs) are permitted to disclose Personal Health Information (PHI) to a person who maintains a registry for the purpose of improving the provision of health care; and
  - Registries are also permitted to use or disclose PHI for research purposes with a research plan approved by a research ethics board.
- **Entities:**
  - HICs are permitted to disclose PHI to prescribed entities for purposes related to the planning and management of the health care system; and
  - Entities are also permitted to use or disclose PHI for research purposes with a research plan approved by a research ethics board.



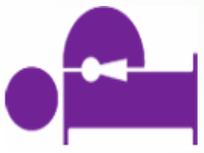
# Prescribed Registries under s. 13(1) of the Regulations

- **Prescribed registries for the purpose of s. 39(1) include:**
  - Cardiac Care Network ;
  - INSCYTE in respect of its Cytobase registry;
  - London Health Sciences Centre in respect of its Joint Replacement Registry;
  - Canadian Stroke Network in respect of the Canadian Stroke Registry.



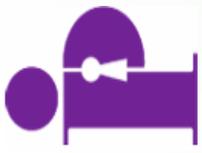
# Prescribed Entities under s. 18(1) of the Regulations

- **Prescribed entities for the purpose of s. 45(1) include:**
  - Cancer Care Ontario (CCO);
  - Canadian Institute for Health Information (CIHI);
  - Institute for Clinical Evaluative Sciences (ICES);
  - Pediatric Oncology Group of Ontario (POGO).



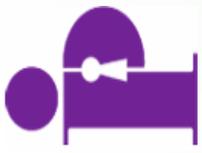
# IPC Review of Practices and Procedures

- The prescribed registry/entity must have in place practices and procedures to protect the privacy and confidentiality of the PHI it receives; and
- The IPC shall review the practices/procedures of prescribed registries/entities every 3 years: s. 45(4).



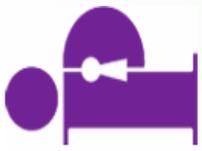
# Background: Registries

- **Cardiac Care Network:** co-ordinates the provision of advanced cardiac services for adults province-wide, with the aid of a computerized patient registry; database is used to facilitate/monitor access to services by patients and their physicians.
- **Cytobase:** centralized interactive database of cervical cytology (Pap) reports; this system automatically registers some 60,000 reports monthly, which are submitted electronically from geographically diverse sources; patient histories are provided on-line to authorized pathologists to support ongoing diagnoses.



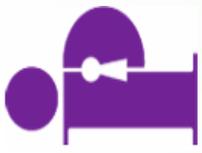
## Background: Registries (cont'd)

- **Joint Replacement Registry:** follows the 23,000 total hip and knee replacements performed annually in Ontario; goal is to collect information at the time of surgery to allow medical community to monitor the effectiveness of various techniques/technologies, reducing the revision rate.
- **Canadian Stroke Registry:** database of stroke patients; collect clinical data to formulate recommendations for best practice in stroke management for stroke care and research.



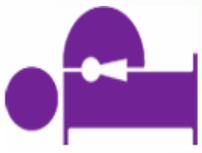
## Background: Entities

- **CCO:** is the government's principal adviser on cancer issues; manages the Ontario Breast Screening Program, the Ontario Cervical Screening Program, the Ontario Cancer Registry and the New Drug Funding Program, and runs a multifaceted program in cancer research.
- **CIHI:** pan-Canadian organization dedicated to health policy and research; goals are to identify and promote national health indicators; coordinate and promote the development and maintenance of national health information standards; develop and manage health databases and registries; conduct analysis and special studies.



## Background: Entities (cont'd)

- **ICES:** conducts research by using population-based health information; provides evidence to support health policy development and changes to the organization and delivery of health care services.
- **POGO:** organization of five specialty pediatric oncology programs: The Hospital for Sick Children (Toronto), McMaster Children's Hospital (Hamilton), Children's Hospital of Western Ontario (London), Kingston General Hospital and Children's Hospital of Eastern Ontario (Ottawa) who champion childhood cancer care and control.



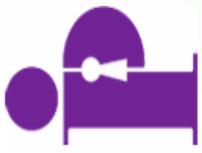
# Where Are We Now?

## **Registries:**

- The IPC has reviewed the documentation provided by, and conducted site visits of two of the four **prescribed registries.**

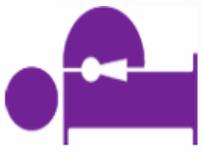
## **Entities:**

- The IPC has reviewed the documentation provided by, and conducted site visits of, two of the **prescribed entities.**



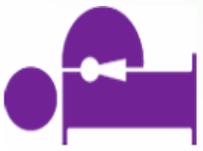
# Community Perspectives

- **Prescribed registries and entities:**
  - Willing to partner with the IPC;
  - Willing to ensure transparency;
  - Recognize obligation of accountability to the public.
- **The “privacy community”:**
  - Where disclosures are permitted without consent, there is a heightened need for transparency and notice.

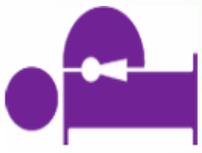


# Where Are We Going?

- IPC anticipates meeting the deadline of November 1, 2005;
- IPC has experienced a significant level of co-operation, collaboration and transparency;
- IPC has gained insight into the important work of registries and entities in improving health outcomes and also into the concerns of those who supply their personal health information.



# III. *Tribunal Services*



# Oversight and Enforcement

- Information and Privacy Commissioner is the oversight body.
- IPC may investigate where:
  - A complaint has been received
  - Commissioner has reasonable grounds to believe that a person has contravened or is about to contravene the Act
- In the absence of a complaint, the *Commissioner* also has the power to conduct a self-initiated review.



# Tribunal

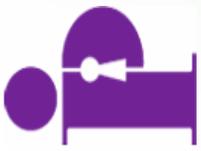
**Tribunal Services consists of three sections:**

1. Registrar, Intake, and Tribunal Support;
2. Mediation; and
3. Adjudication.



# Goals

- **Use of mediation and alternate dispute resolution always stressed – *IPC* publishes quarterly newsletter designed to promote mediation to privacy and access professionals.**
- **Order-making power used as a last resort.**
- **Conducting public and stakeholder education programs: education is key.**
- **Comment on an organization's information practices.**



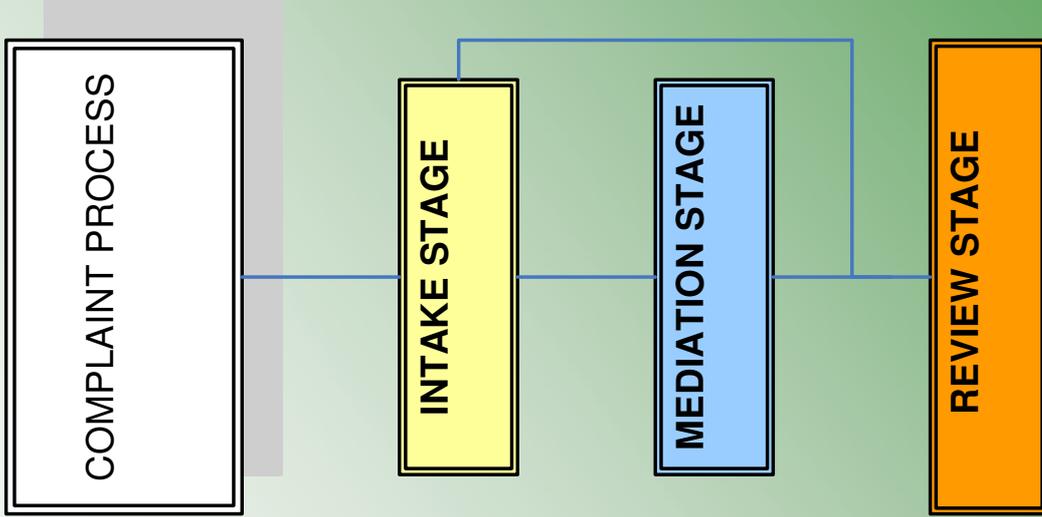
# Complaints

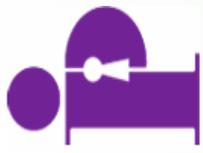
## **Complaint Process:**

- Complaint can be filed based on the access/correction decision of a HIC;
- Complaint can be filed if person believes the HIC has or is about to contravene the *Act* or its regulations; and
- Complaint will usually relate to the collection, use or disclosure of personal health information.

## **Mediation:**

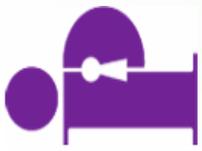
- Use of mediation and alternate dispute resolution always stressed; and
- Order-making power used as a last resort.





# Alternatives to Investigation

- Prior to investigating a complaint, the Commissioner may:
  - Inquire as to other means used by individual to resolve complaint.
  - Require the individual to explore a settlement.
  - Authorize a mediator to review the complaint and try to settle the issue(s).



# Commissioner's Review

If a complaint cannot be settled informally, the Commissioner may conduct a review of the complaint. It is the Commissioner's decision whether or not to conduct a review;

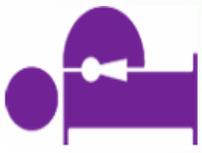
- in conducting a review, the *Commissioner* may: enter any premises associated with the review;
- inspect or copy any records, documents, and other material relevant to the review;
- summons the appearance of *persons* before the *Commissioner* and require them to provide evidence under oath; and
- inquire into *records of personal health information*, under specified circumstances; and issue binding orders.



# Powers of the Commissioner

Under *PHIPA*, the Commissioner may,

- *Make an order directing any person whose activities the Commissioner reviewed;*
- to grant an individual access to a requested record, or to make a requested correction, if a review relates to a complaint into a request by an individual for access to, or correction of, a record;
- to perform a duty imposed by this Act or its regulations;
- to cease collecting, using or disclosing personal health information;
- to dispose of records of personal health information but only if the disposal of the records is not reasonably expected to adversely affect the provision of health care to an individual;
- to change, cease or not commence an information practice;
- to implement an information practice if the information practice is reasonably necessary in order to achieve compliance with this Act and its regulations;
- to refrain from, or to take, action if it is necessary to make the order against the agent to ensure that the custodian will comply with the order made against the custodian; or
- to make comments and recommendations on the privacy implications of any matter that is the subject of the review. 2004, c. 3, Sched. A, s. 61 (1).
- **Orders, other than for access or correction, may be appealed on questions of law.**



## Keeping the Public Informed

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



# Status of Cases

As of mid-August, 2005, we have received **103** complaints:

- **45 Access/Correction Complaints**
  - (11 at Intake, 4 at Mediation; 30 Resolved)
- **31 Collection/Use/Disclosure Complaints**
  - (11 at Intake, 4 at Mediation, 16 Resolved)
- **27 HIC-Reported Breaches**
  - ( 16 at Review; 11 Resolved)

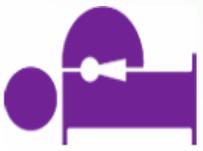
**Total (103): 46 Files Open; 57 Files Closed**



# Mediation Stories

## *A Private Lab*

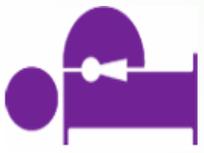
- A computer containing patients' PHI was stolen from a private laboratory during an after-hours break-in;
- As a solution, it was decided that the IPC would work with the laboratory to develop a notification program which included the following response:
  - a) area physicians were sent a Public Notice of the theft and asked to post it and provide a copy to affected patients;
  - b) the laboratory was asked to post a Public Notice; and
  - c) a press release for local media outlets was issued.



# Mediation Stories

## *A Hospital*

- 396 patient diagnostic reports went missing from patients' charts in the course of routine clerical work;
- In this case, there were special circumstances that led the IPC to recommend that notice of the breach should be given in person by the health care provider and posted in the patient's files. It was agreed that patients would be notified of the breach at their next appointment with their health care provider.



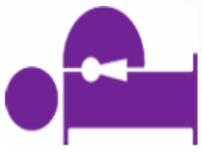
# Mediation Stories

## *A Records Storage Company*

- A mother who was seeking both her own and her daughter's health records from a record storage company was faced with a fee that she claimed was excessive and would impose a personal hardship.
- The IPC intervened to facilitate a reduced fee.
- The company agreed to reduce its fee if the complainant could provide information to support her statement that the fee would in fact impose a hardship. The information was provided through the mediator and the fee was reduced to an agreeable amount.
- The complainant was satisfied and the file was closed.



# *IV. Summary*



# Feedback from Health Professionals

- *“PHIPA has been a call to action of the system which is really positive.”*
- *“PHIPA is enabling us to provide better quality health care and ensure that patient health information is treated with respect.”*

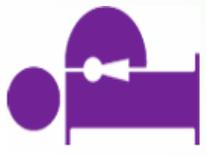
— Peggy Taillon, Vice President Advocacy,  
Community Engagement and Privacy Officer,  
Ottawa Hospital.



# Feedback from Health Research Professionals

*“Generally, privacy legislation was written in an attempt to correct past wrongs, most of which were perpetrated in sectors other than health. It is now time for the legitimate health research community to begin partnering with privacy experts and advocates to look in a positive way at how personal health data can and should be used to better life for our population.”*

— Pam Slaughter, *A National Strategy for Waiting-Times Research?*,  
CMAJ, May 10, 2005, p. 1283.



# A Matrix of Policy Responses in One Instrument?

*“Problems come in complex matrixes, and  
policy responses usually consist of a  
matrix of instruments.”*

— Les Pal, “There Ought to be a Law!” *Instrument Choice*:

*An Overview of the Issues,*” Department of Justice Strategic Issues Series



# Looking Ahead

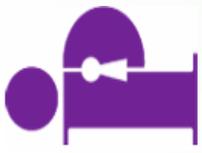
*“If Canadians cannot be confident that the privacy of their health information will be protected, they may withhold vital information from their health care providers or avoid seeking treatment altogether. The potential consequences of this sort of protective behaviour would be staggering-for ourselves as individuals, for the health care system, and for society as a whole.”*

— George Radwanski, Privacy Commissioner of Canada  
June 27, 2002



*Any  
Questions?*





# How to Contact Us

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