

Privacy and EHR Information Flows in Canada

EHIL Webinar Series

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Outline

1. Background
2. *Infoway's* privacy mandate and work
3. The Common Understandings Paper
4. Looking Ahead

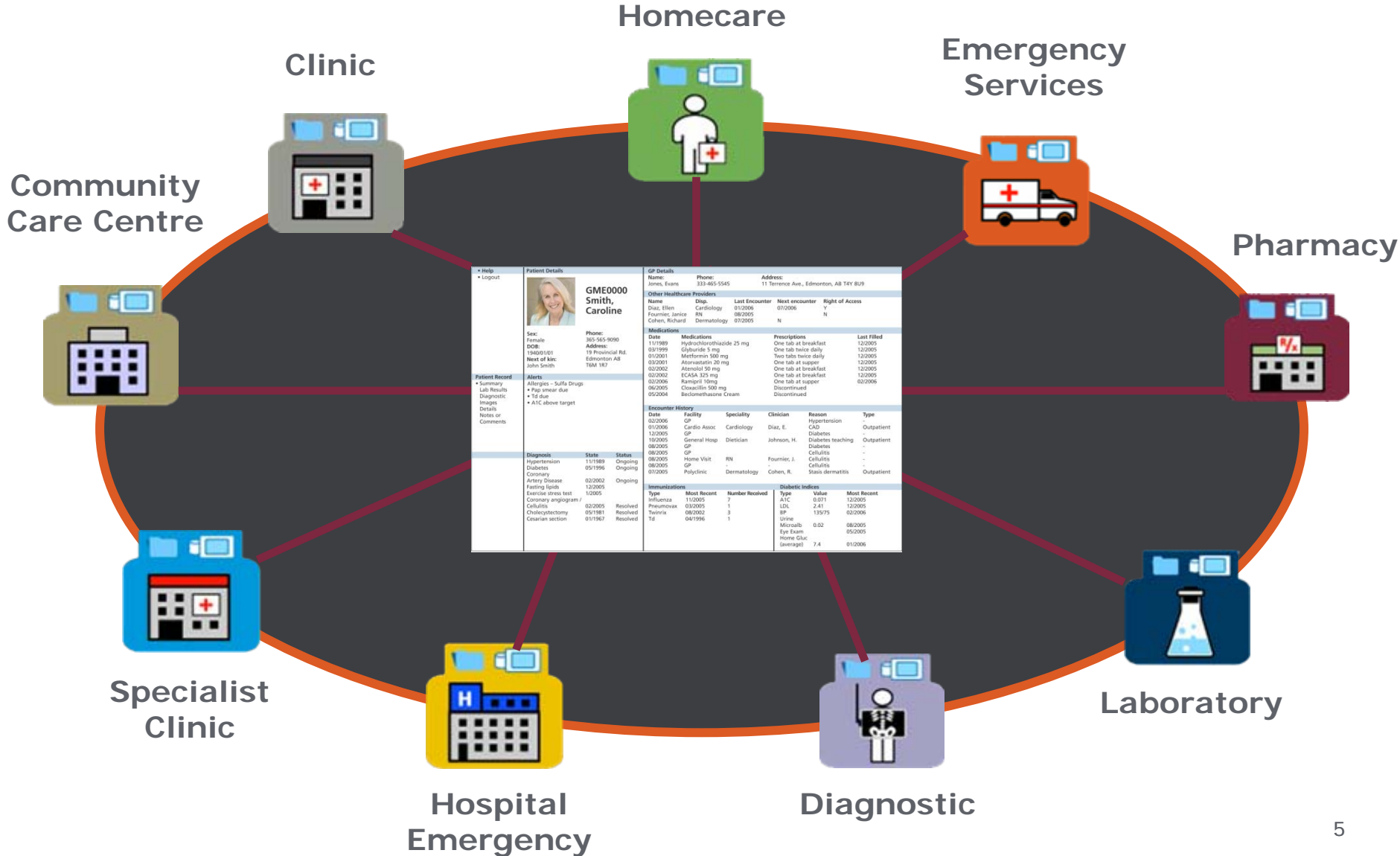
Canada Health Infoway

- Created in 2001
- \$2.1 billion in federal funding
- Independent, not-for-profit corporation
- Accountable to 14 federal/provincial/territorial governments

Mission:

Fostering and accelerating the development and adoption of electronic health information systems with compatible standards and communications technologies on a pan-Canadian basis with tangible benefits to Canadians. *Infoway* will build on existing initiatives and pursue collaborative relationships in pursuit of its mission.

Points of care



Examples of Recent Progress

- Diagnostic imaging network in southwest Ontario
- Sault Ste. Marie EMRxtra
 - improved medication coordination and identification of drug related problems

Drug Information systems report

- An estimated \$436million in cost savings and efficiencies in 2010 alone

For more information on progress go to:

Knowingisbetter.ca

Strong support for the EHR

- 2007 public opinion survey shows:
 - An increase in the public's support for and comfort with the EHR:
 - 2003 - 85 per cent support EHR
 - 2007 - 90 per cent support EHR
 - Concerns decreased since 2003 but expectations that privacy and security will be addressed, increased
 - E.g., Audit trails – privacy policies – sanctions
 - Acceptance towards some secondary uses

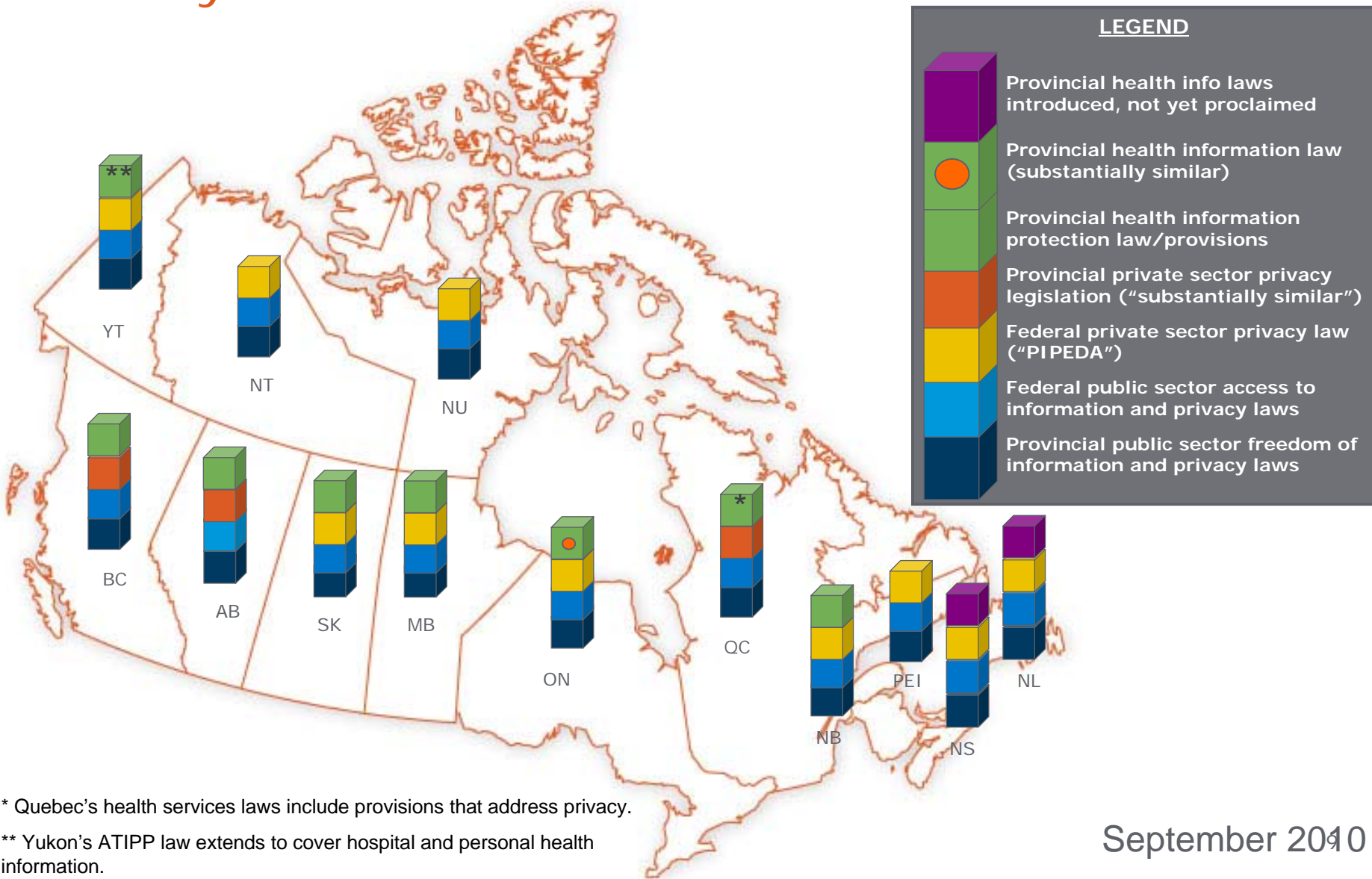


Infoway's Privacy Mandate



- achieve objectives in compliance with applicable privacy laws and include privacy impact assessments

Privacy and health information laws



* Quebec's health services laws include provisions that address privacy.

** Yukon's ATIPP law extends to cover hospital and personal health information.



Privacy at *Infoway*

- Infoway has taken a 'Privacy by Design' approach
- Elements include:
 - the privacy and security architecture
 - a Privacy Impact Assessment policy
 - contributing to legislative and policy initiatives
 - Involvement in external activities
 - Projects e.g.,
 - the Inter-jurisdictional data flow project
 - The consent directives project



Privacy at *Infoway*

- Preparing papers and reports on EHR privacy issues, e.g.,
 - The Privacy Impact Assessment of the Electronic Health Record Blueprint
 - **The White Paper on Information Governance**
 - **The Common Understandings Paper**

- Hosting forums e.g.,
 - **The pan-Canadian Privacy Forum**
 - **The Health Information Privacy Group**
 - The HIAL implementers group,
 - Standards Collaborative Working Group 8

Privacy by Design at Infoway

- 2005
 - the Privacy and Security Conceptual Architecture
- 2007
 - *White Paper on Information Governance of the Interoperable EHR*
 - Objectives:
 - discuss information governance in the EHR context
 - » The concept of a shared health record
 - » 'Access' based vs. 'disclosure' based
 - » Increases the visibility of actions (e.g., audit trails)
 - » Increase in trans-jurisdictional data flows
 - share lessons learned from other sectors
 - stimulate action

Key messages in the White Paper

- Information governance is not new; we need to look at it in the EHR context
- Each jurisdiction's approach will be informed by its legislation and health delivery mechanisms.
- Existing mechanisms can be leveraged.
- Addressing information governance is a process.

The Privacy Forum

- Created November 2007
 - All jurisdictions supported the initiative.
- Unique composition:
 - A representative from each Health Ministry and each Privacy Commissioner/Ombudsman's Office.
- Its objectives:
 - To enhance the group's understanding of the EHR
 - To share experience and expertise
 - To consider information governance/privacy issues raised in the White Paper (and the EHR PIA) and common solutions that support the interoperable EHR.

The Health Information Privacy Group

- Created December 2008
 - Result of Privacy Forum deliberations
- Composition:
 - The Ministry representatives of the Privacy Forum.
- Its objectives:
 - To discuss the information governance issues raised in the White Paper (and the EHR PIA)
 - To work towards the development of common solutions that support the interoperable EHR.

The Common Understandings paper

- The paper represents the consensus of the HIP group
- The paper:
 - builds on the existing legislative landscape
 - emphasizes jurisdictional responsibility
 - promotes consistency in approach
 - supports appropriate trans-jurisdictional flow of information
- Scope:
 - In – information for care and treatment, some secondary uses,
 - Out - public health surveillance, first nations

The common understandings

Relate to:

1. foundational understandings
2. trans-jurisdictional collection and disclosure of EHR information
3. patient control of their EHR information
 - patient notification
4. trans-jurisdictional disclosures of EHR information for secondary use
5. accountability for information governance of the iEHR

1. Foundational common understandings

- Set the stage for trans-jurisdictional disclosures of PHI in a multi-jurisdictional EHR context, e.g.:
 - Jurisdictional support for appropriate and privacy-protective trans-jurisdictional disclosures
 - Recognition that jurisdictions make EHR system choices that meet their legislative requirements, while striving for pan-Canadian interoperability
 - EHR disclosures take place in compliance with legislative or other authorities

2. Trans-jurisdictional disclosure and collection

- Basic principles underpinning the collection and disclosure of EHR information across jurisdictions, within Canada, e.g.,:
 - Clarifies that ‘sharing’, ‘flowing’, ‘movement’ of PHI from one jurisdiction to another is a ‘disclosure’ from one jurisdiction and an (indirect) ‘collection’ by the other.

2. Trans-jurisdictional disclosure and collection (cont)

- Disclosing jurisdiction follows its legislation/policies respecting disclosure and the jurisdiction that is (indirectly) collecting the information follows its legislation/policies for collection.
- Information disclosed to a second jurisdiction becomes subject to the legislation and policies of the second jurisdiction.

3. Patient control and notices

- Principles about patient control of their EHR PHI & key messages for patient notices about EHRs, e.g.:
 - The control a patient has exercised over his or her information in the home jurisdiction should be respected in another jurisdiction to the extent possible given the second jurisdiction's legal framework and EHR system choices

3. Patient control and notices (cont)

- For jurisdictions whose EHR systems allow for patient control of their information, patient notices should include messages about:
 - Situations in which their information can be unmasked without their consent
 - Other provisions that can override personal masking requests
 - The fact that if they seek care in another jurisdiction, the information collected in that 'other' jurisdiction will be subject to the 'other' jurisdiction's masking policies.

4. Trans-jurisdictional disclosures for secondary use

- Context
 - Current legislative framework authorizes secondary use
 - Part of recognized value of EHR is potential to use information for secondary use
 - EHR environment needs to continue to allow for appropriate and privacy-protective secondary use

Secondary Use (cont)

In scope	Out of scope
Trans-jurisdictional disclosures	Uses and disclosures within a jurisdiction
Disclosures without consent	Disclosures for which consent is required or sought
EHR information	Information from source systems
Information that is identifiable or potentially re-identifiable – PHI or potential PHI	Anonymous or aggregated information
Clinical program management, health system administration and research	Population health surveillance Secondary uses unrelated to health

Secondary Use (cont)

- HIP Group's focus:
 - de-identification of personal health information
 - review and assessment processes
 - patient notification
 - governance

Secondary Use (cont)

- De-identification:
 - call for disclosure of aggregate or de-identified information as norm; but recognize authority for disclosures of identifiable
 - need for entities to have knowledge of de-identification techniques and how to apply them
 - recognize that de-identification alone is not enough, that other practices also required to minimize privacy risks

Secondary Use (cont)

- Review and assessment processes:
 - jurisdictions need review and assessment processes for trans-jurisdictional disclosures of EHR data for secondary uses
 - particularly for identifiable or potentially re-identifiable information
 - the review should be commensurate with the potential risk level of the disclosure

Secondary Use (cont)

- Patient notification:
 - need for patient information on trans-jurisdictional disclosures for secondary uses
 - need to be able to inform patients on request of trans-jurisdictional disclosures of their identifiable information for secondary uses

Secondary Use (cont)

- Governance
 - foundational principles apply to disclosures for secondary use
 - call for information sharing agreements for additional protection and clarity

5. Accountability for information governance of the iEHR

- Accountability at three levels
 - Jurisdictional
 - Organizational
 - Pan-Canadian

5. Accountability for information governance of the iEHR

- Jurisdictional level:
 - jurisdictions are accountable
 - assumes jurisdictional governance structures in place & stresses importance that structures:
 - include a privacy and information governance component
 - be accountable to the Minister
 - be clear where accountability resides
- Organization level
 - need for organizations to revisit their privacy responsibilities in EHR environment and their compliance with privacy obligations.

5. Accountability for information governance of the iEHR

- Pan-Canadian level
 - calls for a pan-Canadian coordinating structure to discuss, address and coordinate common privacy and security related information governance issues, IT issues and standards.
 - Suggests continuation of the f/p/t HIP group to continue work on the privacy elements.

Moving forward

- Paper is posted.
- Being shared broadly through print and presentations.
- Positive reactions to date.
- Value to jurisdictions
- Considerable interest from organizations and programs facing inter-jurisdictional movement of information.

Questions??

www.infoway-inforoute.ca

Click on **Resources** for access to:

- **Privacy and EHR Information Flows in Canada:** *Common understandings of Pan-Canadian Health Information Privacy Group*
- - *includes links to other key documents and resources*

*Thank
you!*