Health Privacy in the Information Age

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Creating Healthy Connections
Canada – the context

2003 Population: 31,629,700
Governance: Shared Accountability

- Federal Government
  - Sets and administers national principles
- 13 Provincial/Territorial Governments
  - Plan, finance, manage, evaluate health services
- 100+ Health Regions
  - Coordinate care delivery over a set geographical area
- 900+ Hospitals
  - Manage care
- Approximately 60,000 doctors, 300,000 nurses, 26,000 pharmacists
  - Deliver care
Last Year, In Canada

- 35 million Diagnostic Images
- 440 million Laboratory Tests
- 2.8 million Inpatient hospitalizations
- 382 million Prescriptions filled
- 3.4 million Vioxx Prescriptions in 2003 for patients that had to be contacted in 2004
- 322 million office-based physicians visits - 94% resulting in handwritten paper records
- 60,000 physicians faced 1.8 million new medical papers in 20,000 journals and 300,000 clinical trials

Information is the Lifeblood of our Healthcare System!

About 2,000 health care transactions per minute, many quite complex, and all requiring documentation and information flow.
In spite of spectacular advances in medicine, the foundation of healthcare delivery is still primarily 

**paper-based**
## Impact on quality of care
Lack of Patient Data affects access, safety & quality, productivity

<table>
<thead>
<tr>
<th>For Every ....</th>
<th>.... in Canada</th>
</tr>
</thead>
<tbody>
<tr>
<td>1000 hospital admissions</td>
<td>75 people suffer an <strong>adverse event</strong></td>
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<tr>
<td>1000 patients discharged from hospital</td>
<td>90 suffer a <strong>serious problem</strong> with drugs received on discharge</td>
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<tr>
<td>1000 laboratory &amp; radiology tests</td>
<td>Up to 150 are unnecessary <strong>duplicates</strong></td>
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<tr>
<td>1000 women at risk of cervical cancer</td>
<td>300-400 are <strong>not screened</strong></td>
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<tr>
<td>1000 patient visits with a Specialist</td>
<td>680 Specialists received <strong>no patient info</strong></td>
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<tr>
<td>1000 post-heart attack patients</td>
<td>370-460 <strong>don’t receive</strong> recommended Beta-blocker therapy</td>
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In study of 168 traditional medical records 81% did not have the information required to make patient care decisions.

CIHI estimates up to 24,000 deaths each year result from preventable adverse events in hospitals, in large part due to incomplete information.
Calls for Accelerated EHRs

- **Electronic health records and telehealth are key to health system renewal**
  - First Ministers 10-Year Health Accord, Sept 2004
- **First Ministers continue to recognize the necessity of EHRs in their “10-Year Plan to Strengthen Health Care”**
  - Accelerate development and implementation of the electronic health record, including e-prescribing.
  - Recommended a National Pharmaceuticals Strategy to “broaden the practice of e-prescribing through accelerated deployment of the Electronic Health Record”
- **2005 - Health Council of Canada report recommends an “immediate broadening of the use of IT”**
  - “Electronic patient records will pay huge health dividends in improved patient safety and lives saved”.
  - “Canada can and should achieve this goal for all Canadians in five years – not fifteen”.
- **2006 - Health Council of Canada report urges an acceleration of electronic health records, telehealth and wait time management information systems.**
  - “If we don’t modernize the management of patient information, all other activities for health care renewal will stall.”
Canada Health Infoway

- Infoway was launched 2003 as an independent, not-for-profit corporation, equally accountable to 14 F/P/T governments. It’s members are Canada’s 14 Deputy Ministers of Health.

Infoway’s Mission
- To foster and accelerate 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. To build on existing initiatives and pursue collaborative relationships in pursuit of its mission.

Infoway’s Goal
- To have an interoperable electronic health record in place across 50 percent of Canada (by population) by the end of 2009.
Nine Strategic Investment Programs

A 3-year joint technology and investment plan was developed with each jurisdiction that provides a long-term roadmap as to how these EHR components will rollout.
The View of Canadians

• 80% of Canadians rate EHRs as a strong improvement over paper records in terms of the effectiveness for all those involved in the health care system and for the system overall.*

• 84% agree that timely and easy access to personal health information is integral to the provision of quality health care.**

• The most frequent reasons for supporting the EHR are:
  – increased access to and availability of health records
  – a faster, more efficient health system
  – cost-effectiveness

• **BUT** Canadians want access to and use of the information to be appropriately limited*. 

• **AND** they want clear assurances that privacy is being protected and respected.*

*EKOS survey of 2000 Canadians, 2003  
**EKOS survey of 2500 Canadians, 2004
72% of Canadians want to be able to find out who accessed their health records and when

66% of Canadians want it to be a serious criminal offence for anyone to access the record without proper authorization
57% of Canadians want to be able to access, verify and report corrections to their record at any time.
The view of Canadians

• 59% of Canadians want there to be a clear and accessible privacy policy

• 57% feel it is important that the system is supported by their doctor

• End users (patients, physicians, health facilities) must have confidence and trust that privacy and security are being adequately addressed.

• ‘Getting privacy right’ is key to the success of the EHR.
Example: Drug Information Systems
14 projects in 8 jurisdictions

- **Alberta**: Province-wide DIS with e-prescribing, drug profile, adverse-reaction alerts
- **Ontario**: Ontario’s Drug Program information, initially Emergency room access
- **Saskatchewan**: Province-wide DIS for 95% of meds prescribed
- Developing clinical drug messaging standards. Drug claims message standards already developed

- ... When VIOXX was pulled from the market, it took our practice just one hour to produce a report on patients who had been prescribed the medication, allowing us to contact every one of them the same day.”

  Dr. Sue MacLean, Founding Partner, Markham Family Physicians; Infoway’s Senior Medical Advisor (formerly)

Expect $3.6 billion annual savings, Canada wide, avoiding adverse drug reactions and drug compliance issues
Privacy Legislation in Canada

The legislative landscape

- Federal privacy legislation
  - The *Privacy Act* - applies to the public sector
  - *Personal Information Protection and Electronic Documents Act (PIPEDA)*
    - applies to personal information (including personal health information) used in the course of commercial transactions (private sector)
    - **applies in a jurisdiction if there isn’t substantially similar legislation**
  - Other federal legislation applies to the forces, the RCMP, federal prisons

- Provincial legislation
  - Public sector general privacy legislation - all provinces & the territories
  - Private sector general privacy legislation – Quebec, British Columbia & Alberta
  - *(PIPEDA applies to the provincial private sector in provinces that don’t have legislation found to be ‘substantially similar’ to PIPEDA.)*
  - Specific health information legislation – Alberta, Saskatchewan, Manitoba & Ontario
  - Other relevant legislation – Public Hospitals Acts, Mental Health Acts, Public Health Administration Acts, etc.
Privacy Legislation in Canada

- Canadian privacy laws reflect many of the 10 principles set out in the Canadian Standards Association’s Model Code for the Protection of Personal Information (CAN/CSA-Q830-96), which are:
  - Accountability
  - Identifying Purposes
  - Consent
  - Limiting Collection
  - Limiting Use, Disclosure and Retention
  - Accuracy
  - Safeguards
  - Openness
  - Individual Access
  - Challenge Compliance

- Other key component:
  - Oversight provisions
Privacy Legislation in Canada

Generally the health information privacy legislation:

- provides authority for the collection, use and disclosure of personal health information within the circle of care, for care and treatment, on the basis of implied or deemed consent
- requires express consent for other uses and disclosures, unless authorized by law. The list of authorized uses and disclosures generally includes:
  - determining eligibility and processing payments,
  - quality assurance activities,
  - managing and planning the health system,
  - research that complies with set requirements,
  - other laws
- sets out the obligations of custodians and others

NOTE: the approach to consent varies in each jurisdiction
Infoway’s Privacy Mandate

As set out in its formation documents Infoway is required to:

• “incorporate the protection of personal health information in its activities in accordance with applicable laws and privacy principles.”

Even though:

• Infoway does not create the systems
• Infoway does not manage the systems
• Infoway does not hold data or manage repositories of data
Meeting Infoway’s Privacy and Security mandate

- Infoway ensures that privacy and security are addressed in the projects it funds by
  - Requiring Privacy Impact Assessments
  - Sharing / leveraging best practices
  - Encouraging use of the Privacy and Security Architecture

“Privacy by Design: Don’t Make Privacy An Afterthought – Build It In”

Ann Cavoukian, Ph.D.
Information & Privacy Commissioner/Ontario
What is the Privacy and Security Architecture?

The Privacy and Security architecture:

• provides an inventory of privacy and security services that need to be considered when building and managing a system, for example:
  – User identity management
  – User authentication
  – Access control
  – Information consent management
  – Identity protection
  – Anonymization services
  – Encryption services
  – Digital signature services
  – Secure audit services
  – General security services
Infoway’s privacy mandate – looking ahead - governance

- Statement of accountabilities (roles and responsibilities)
- Rules respecting:
  - Organizational & cross-organizational administration
  - iEHR operations
    - System configuration, administration,
    - operations & interoperation

TRUST

End User Acceptance & Use

iEHR SUCCESS

Effective functioning within and between systems and jurisdictions
Governance in the iEHR context

- Funding and operations of governance entities
- Community Care Centers
- Accreditation, conformance, dispute resolution, liability
- Specialist Clinic
- Hospital Emergency
- Home Care
- Emergency Services
- Laboratory
- Statement of Accountabilities & privacy & security standards
- Risk management framework PIA.s, TRA.s, VAs

Sharing of phi via iEHR
An Example
Diagnostic Imaging Systems

- 25 active systems in 10 jurisdictions
- Reduces patient transfers & waiting for results
- Improves interpretation of diagnostic results
- Cut travel to view film; increase remote readings
- 20% productivity radiologists, 10% specialists
- Productivity adds capacity of 5-10 M exams
- “Shared Service” = economies of scale
- Avoids $350 M yr duplicates, film, handling
- $1 Billion in total annual savings estimated

“With the system up and running, I have become a better diagnostic radiologist. I don’t think there’s any doubt”
Dr. K Wong, Radiologist, Fraser Valley

Better results at less cost
Infoway Toolkits capture all phases of the projects to reduce cost and risks for other jurisdictions
The Opportunities

- Reduced Wait Times
- Better Prescribing Practices
- Improved access to care in rural and remote communities
- Complete and accurate clinical information to diagnose and treat
- Less administrative burden, More time for patients
The Opportunities

- Less adverse drug events
- Healthier lifestyles
- Better therapeutic outcomes
- Well managed chronic illness
- Increased patient participation in care
Recognizing the Need for Electronic Health Records

EHRs are key to a modern 21st century health system.

They will drive significant improvements in

ACCESS

PRODUCTIVITY

QUALITY

Getting privacy ‘right’ is key.
Information on Infoway, on projects underway across Canada, and resource materials, are available on the Infoway website

www.infoway-inforoute.ca

Thank you.