

# 2009 Progress in Comprehensive Care for Rare Blood Disorders Conference

Health Informatics Primer

# Topics

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1. Background
2. Health Informatics
3. EHR, EMR, PHR...
4. Connecting patient registries with the pan-Canadian EHR

# Background

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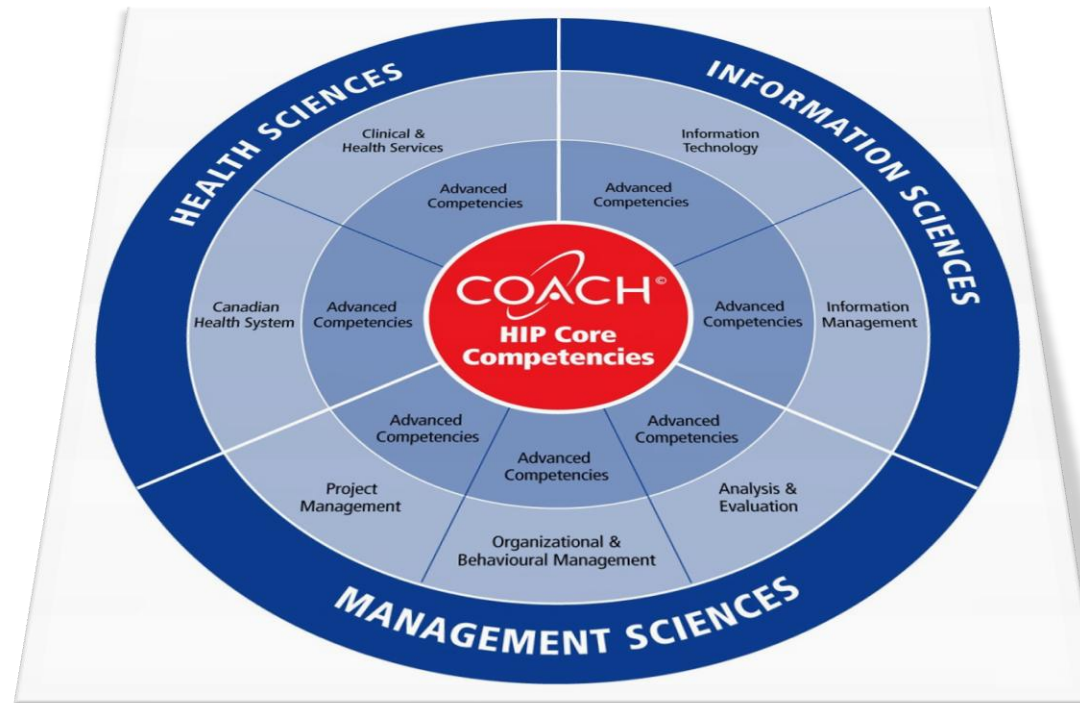
- Gavin Tong, B.Sc., MBA
- Director, Gordon Point Informatics Ltd.
- Formerly:
  - COACH Board of Directors
  - VP, Interoperability & Standards, ITAC Health
  - Manager, Standards Development Coordination, Canadian Institute for Health Information (CIHI)

# Health Informatics

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*“Health informatics is the intersection of clinical, IM/IT, and management practices to achieve better health” - COACH*

# Health Informatics: A multi-disciplinary Challenge



*Three core bodies of knowledge:*

Management Sciences    Information Sciences    Health Sciences

# ...Information for Better Health

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- Primary Use:
  - Information used directly in the provision of care
    - Specialty clinics, GP offices, hospitals
- Secondary Use (Health System Use)
  - Information used to administer and/or improve the delivery of care
    - Researchers, governments, advocacy groups

# COACH

## *Taking Health Informatics Mainstream*

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- Promotion & advocacy
- Professionalism
  - Code of ethics, certification, and recognition of excellence
- Conferences, education, & publications

ASSOCIATION CANADIENNE  
D'INFORMATIQUE DE LA SANTÉ

**COACH**

CANADA'S HEALTH  
INFORMATICS ASSOCIATION

# EHR...EMR...EPR...PHR?

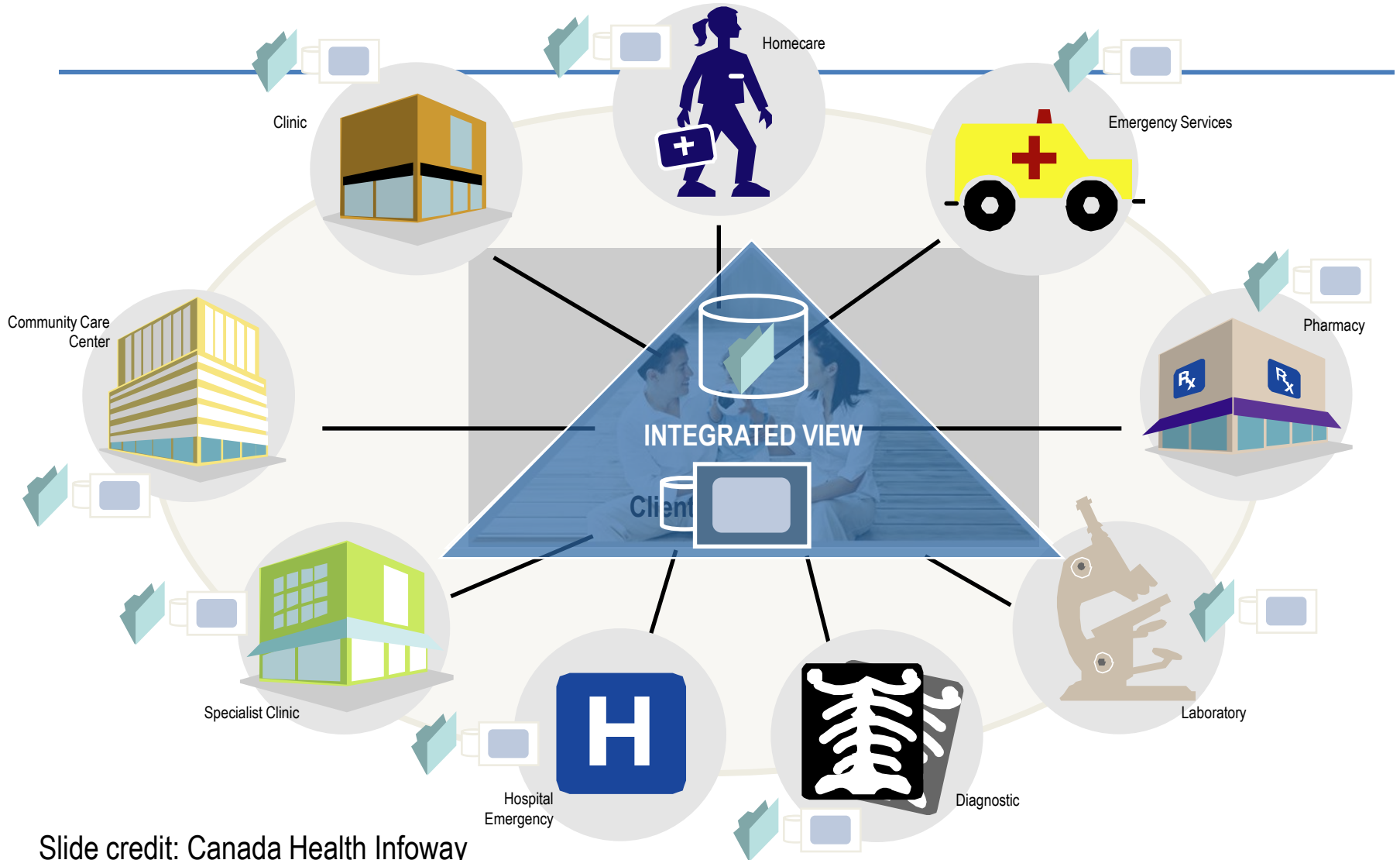
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## Common characteristics:

- Life-time, complete, up-to-date health information
  - physician visits & hospital stays
  - diagnostic images & reports
  - laboratory test results
  - prescribed drugs and immunizations
  - ..etc.



# Integrated Shared View of Client / Patient Data



Slide credit: Canada Health Infoway

# EHR...EMR...EPR...PHR?

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- Electronic Health Record
  - Pan-Canadian approach to creating a network of interoperable systems.
- Electronic Medical Record or Electronic Patient Record:
  - Often localized to Physician Offices or Hospitals
- Personal Health Record
  - Typically a health record that is initiated and maintained by an individual (Paper, Software, Web Enabled)

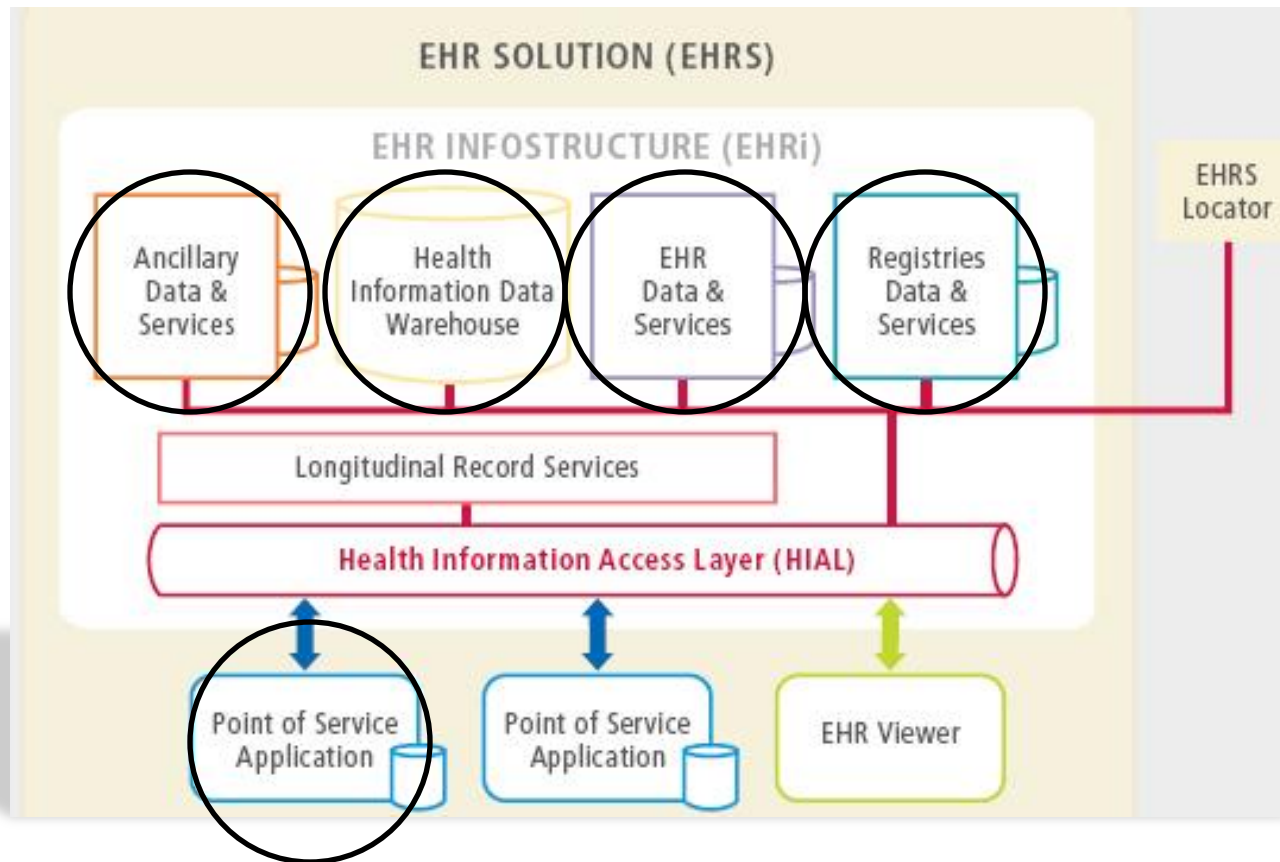
# Canada Health Infoway

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- Strategically working in partnership with the country's federal, provincial, and territorial governments to create and implement electronic health record (EHR) systems
- Strategic investors **not** the builders

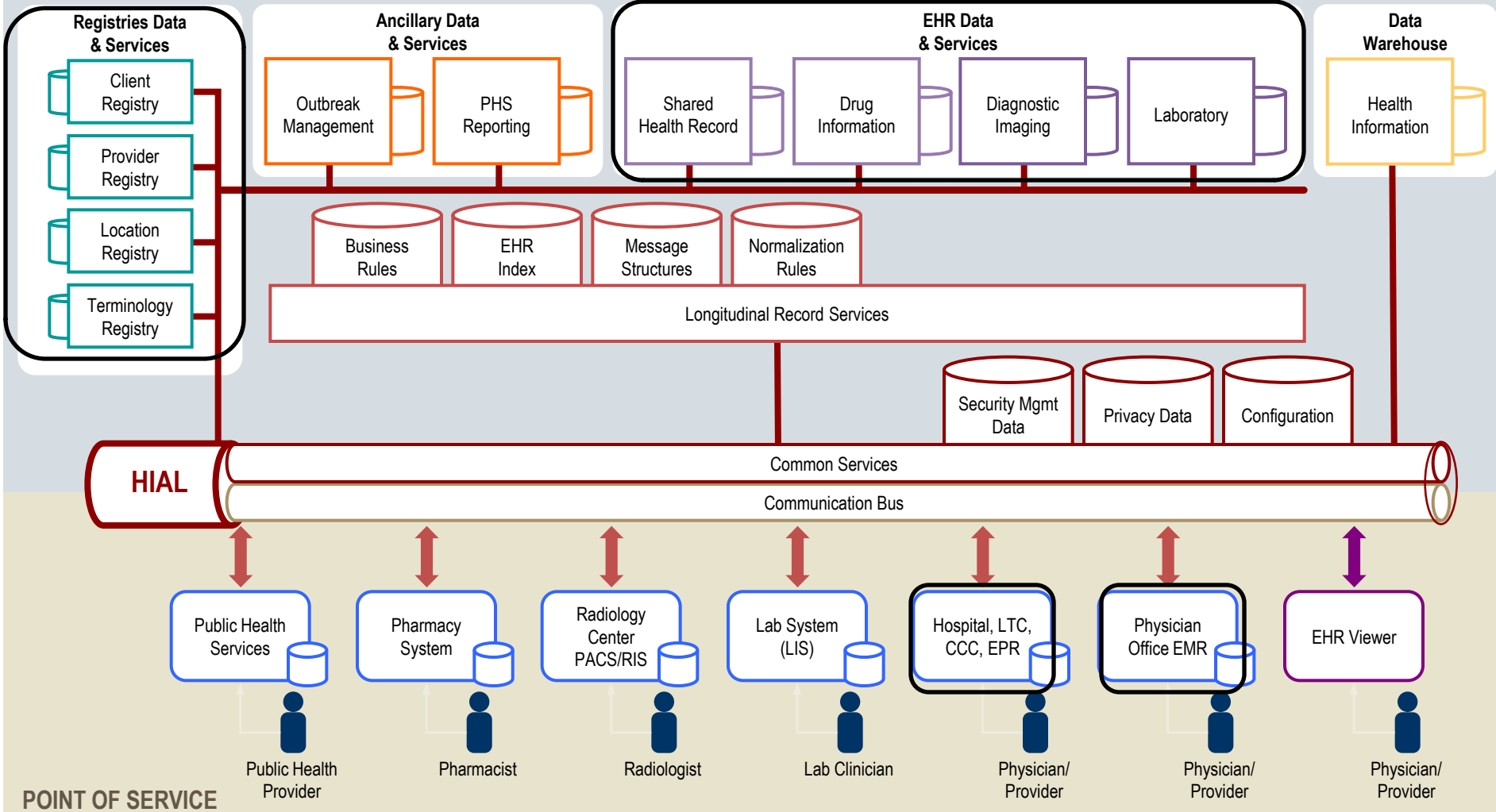
# Pan-Canadian EHR Blueprint



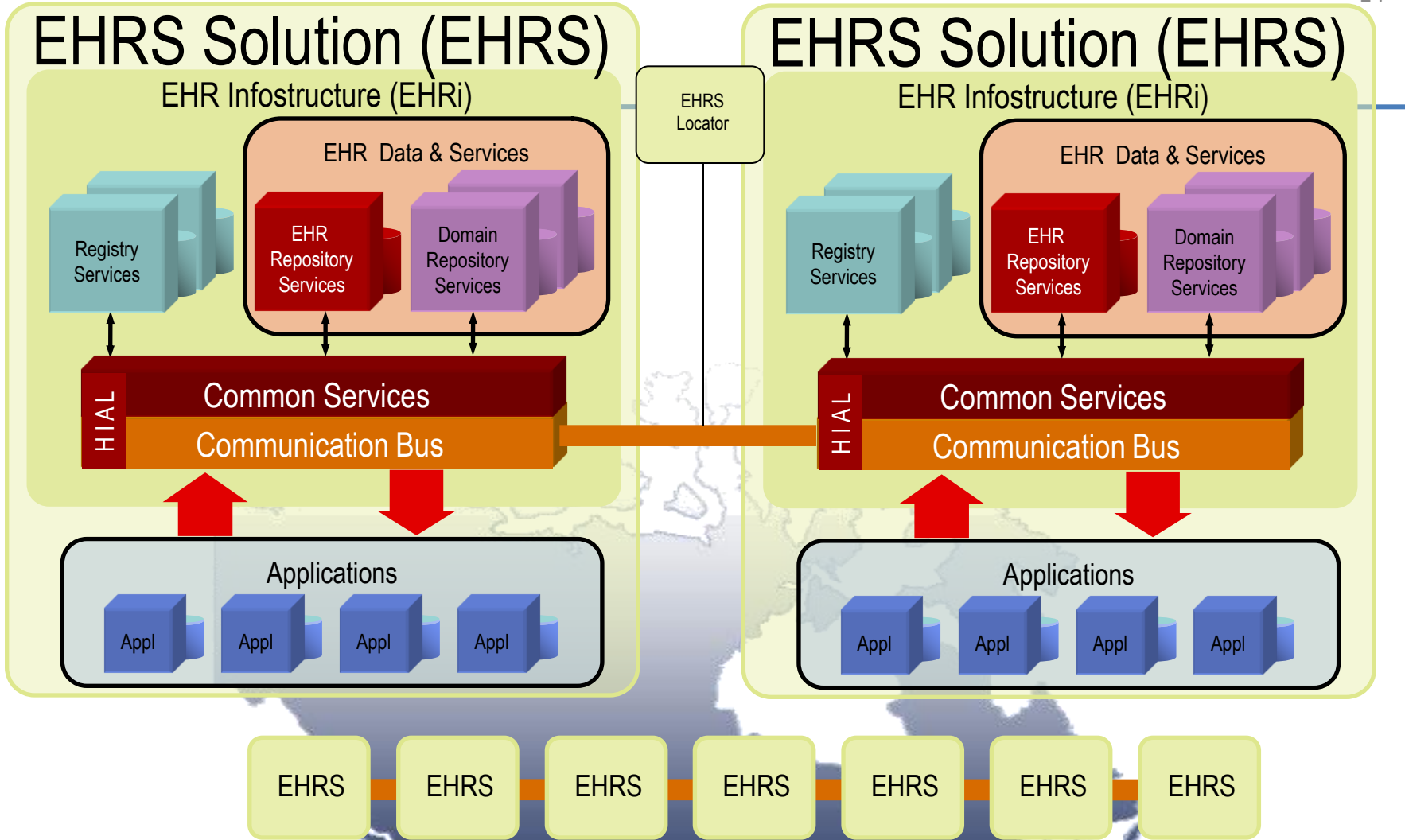
Slide credit: Canada Health Infoway

# EHR Infostructure: Conceptual

## JURISDICTIONAL INFOSTRUCTURE



Slide credit: Canada Health Infoway



Slide credit: Canada Health Infoway

# EHR Activity In Canada



Slide credit: Canada Health Infoway

# RBDO Context

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- When you arrive in the ER
- When you need access to quality care

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*“Estimated 70,000 preventable adverse events occur annually in hospitals, resulting in 9,250 to 23,750 deaths”*

Slide credit: Canadian Adverse Events Study, 2004

# Arrival in the ER

		Client Registry	Decision Support & Alerts
<p><b>Remember...</b> <b>FactorFirst</b></p> <p><b>PROMPT INFUSION</b> will halt bleeding, minimize long-term complications and can save life. If bleeding persists, follow the guidelines for life or limb-threatening bleeds and call the:</p>	<p><b>Delay in the restoration of hemostasis to the patient with hemophilia or von Willebrand disease may be life or limb-threatening.</b></p> <ul style="list-style-type: none"> <li><b>PROMPT TRIAGE AND ASSESSMENT.</b> <ul style="list-style-type: none"> <li>Determine the severity of the bleed.</li> <li>Recognize that bleeding in the head, spine, abdomen or pelvis may initially be occult and potentially life-threatening.</li> </ul> </li> <li><b>TREAT FIRST AND INVESTIGATE LATER – “FACTOR FIRST”.</b> <ul style="list-style-type: none"> <li>Avoid invasive procedures such as arterial punctures unless the patient has factor replacement.</li> <li><b>NO</b> IM injections and <b>NO</b> ASA.</li> <li>The patient or guardian may be your most important resource, so do ask about specific treatment protocols.</li> <li>Contact the patient’s Hemophilia Treatment Centre where a hematologist is always on call.</li> <li>Provide clear discharge instructions and arrange a follow-up plan or admit to hospital if necessary.</li> </ul> </li> </ul>	<p><b>Patient Information:</b></p> <p>Name: _____</p> <p>Date of Birth: _____</p>	<p><b>Recommended Treatment:</b></p> <p>Product and Dose/kg for Life or Limb-threatening Bleeds:</p> <p>_____</p> <p>_____</p>
<p><b>Hemophilia Treatment Centre</b></p> <p>Physician: _____</p> <p>Nurse: _____</p> <p>Day Phone: _____</p> <p>Night Phone: _____</p>		<p>Diagnosis: _____</p> <p>Severity: _____ Level: _____</p> <p>Response to desmopressin (DDAVP): <input type="checkbox"/> no <input type="checkbox"/> yes to _____ %</p> <p>Inhibitors: <input type="checkbox"/> no <input type="checkbox"/> yes</p> <p>Other Medical Information: _____</p> <p>_____</p> <p><b>Shared Health Record</b></p> <p>_____</p> <p>_____</p>	<p>Product and Dose/kg for Moderate/Minor Bleeds:</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>
<p>Organization Registry Provider Registry</p>	<p><b>Use Universal Precautions</b></p> <p>Decision Support &amp; Alerts</p>	<p>Date of Recommendation: ____/____/____</p> <p>Signature of Physician _____</p>	

# Access To Quality Care

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- Provider and Organization Registries:
  - Primary use examples:
    - Allows GPs to find specialists and comprehensive treatment centres by geography or shortest wait
  - Secondary use examples:
    - How many haematologists are in each Province/Territory?
    - Which regions are underserved?
    - Is the number of specialists keeping pace with changes in geography and populations of people with rare blood disorders?



# CHS Strategic Goals (Abridged)

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EHR Data

Primary  
Use

- Care and Treatment
- Safe, Secure Blood Supply

Secondary  
Use

- Research
- Advocacy
- Public Awareness

# Connecting EHR Data with Patient Registries

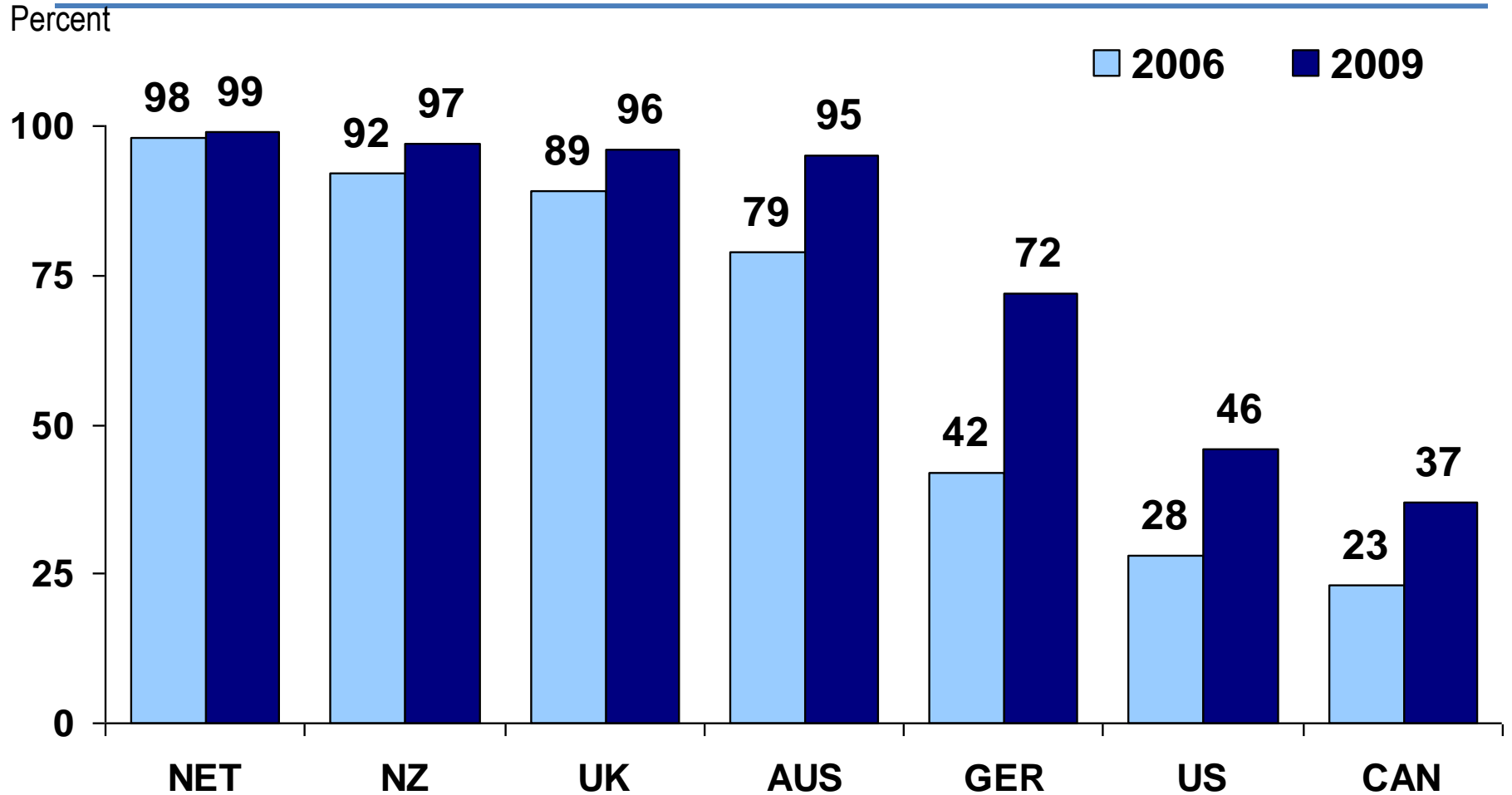
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## Strategic Challenges

1. Funding
2. Governance
3. Timeliness



# Doctors Use OF EMRs, 2006 and 2009\*



\* 2006: "Do you currently use electronic patient medical records in your practice?"

\* 2009: "Do you use electronic patient medical records in your practice (not including billing systems)?"

# Connecting EHR Data with Patient Registries

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## Tactical Challenges

1. Data not in the EHR
2. Primary use vs. secondary use
3. Privacy, confidentiality & security



# Overcoming Challenges

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- Aligning messages with the key trends influencing care
  - Rising costs of health care
  - Chronic disease prevention and management
  - Moving from acute to community care
  - Physician shortages
  - Rising patient consumerism

# Targeting Your Message

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Organization	Role
Ministries of Health	Fund the delivery of care and build the EHRs
Canada Health Infoway	Strategically working in partnership with the country's federal, provincial, and territorial governments to create and implement electronic health record (EHR) systems  Strategic investors NOT the builder
Canadian Institute for Health Information	Independent, not-for-profit organization that provides essential data and analysis on Canada's health system and the health of Canadians

# Rising to the Challenge

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*“Knowledge is Power”*

Francis Bacon, 1561-1626



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*“Knowledge is a commodity.  
Imagination is power!”*

# Thanks and Questions

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Thank you for your time!



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