



Privacy in the Patient and Family Centered Practice

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Session objectives

- Identify shared values
- Sample Canadian laws that govern the disclosure of health information to patients and families
- Explore requirements for patient/family access under Alberta's *Health Information Act*
- Summarize how Canadian health privacy law impact the provision of patient and family centered care
- Outline the current state of information technology projects in Alberta that facilitate the direct sharing of information with patients and families
- Identify key privacy and security considerations for organizations moving forward with these information systems



Shared values

Health privacy laws and patient and family centered care:

- Recognize patient control and autonomy
- Seek to equalize the inequalities that have historically existed in the provision of care (power, knowledge, program design)
- Understand that information must be shared in order to allow patients and their families to participate in care but do so in a way that allows the patient to maintain dignity and respect
- Remove the barrier of secrecy from the treatment relationship and enhance trust



- eHealth is experiencing massive growth in Canada.
- As of June 30, 2008, Canada Health Infoway (CHI) had invested \$1.5 billion in 260+ projects across Canada to facilitate the exchange of electronic health information.
- Many of the information systems currently being developed have the capability to share more and better information with patients and families.
- CHI has funded several custom designed patient portal projects (MyCare Source in Grand River Hospital for cancer patients, UHN's Chronic Kidney Disease Patient Portal)
- Discussions are taking place with Microsoft and Google to better understand their EPR offerings and their potential place in the eHealth architecture



eHealth and patient access

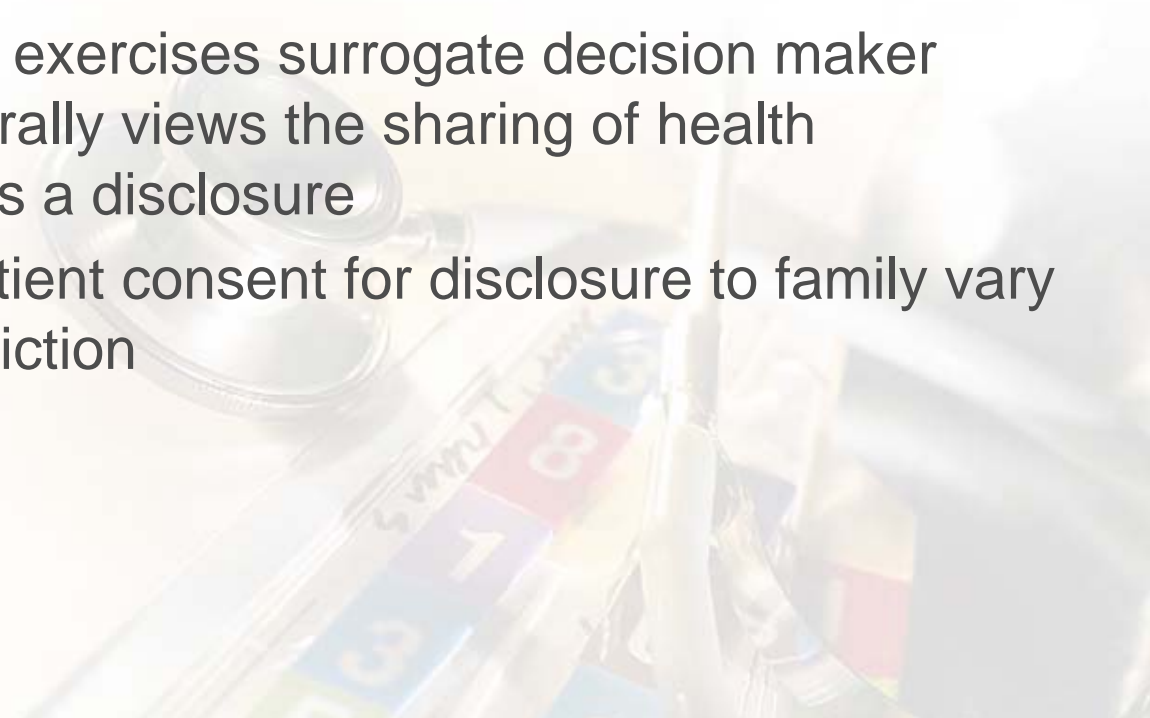
Considerable diversity exists in patient portal systems, and privacy risks remain largely unassessed

- Developed by “vendors” (Microsoft/Google) and controlled by the patient
- Developed and operated by doctors in primary care settings, contributed to by patients and providers, but controlled by the doctor
- Developed and operated by institutions or provincial departments of health, with limited capacity for patient contributions

Regardless of the format these systems take, they have potential to enhance the reliability, portability, legibility and accessibility of the patient record.



Common features of health privacy laws

- Patients have a right of access to their health information
 - Health services providers retain the ability to provide “informal access” to health information to patients
 - If informal access cannot/will not be given, formal access rights exist under a variety of statutes
 - Unless a family member exercises surrogate decision maker powers, legislation generally views the sharing of health information with family as a disclosure
 - The requirements for patient consent for disclosure to family vary from jurisdiction to jurisdiction
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Ontario's *Personal Health Information Protection Act* (PHIPA) is a consent-based statute

- General information about a patient's status (inpatient), health condition (critical, poor, satisfactory, etc.) and location within the facility can be shared with family without consent
- "A custodian's ongoing disclosure of personal health information to a relative or friend requires the patient's express consent..."

Guide to Ontario's Personal Health Information Act p. 351

- Express consent can be written or oral but it must be explicit and positive
- PHIPA contains a lock-box provision which requires a custodian to stop using or disclosing health information where the individual has withdrawn consent

Manitoba's *Personal Health Information Act* (PHIA) allows health information to be disclosed with patient consent, but also recognizes that it can be shared with family or others with whom the patient has a close personal relationship if:

- The disclosure is about health care currently being provided
- The disclosure is made in accordance with good medical or other professional practices; and
- The trustee reasonably believes the disclosure to be acceptable to the individual...

(PHIA s. 23(1))



Alberta's *Health Information Act*

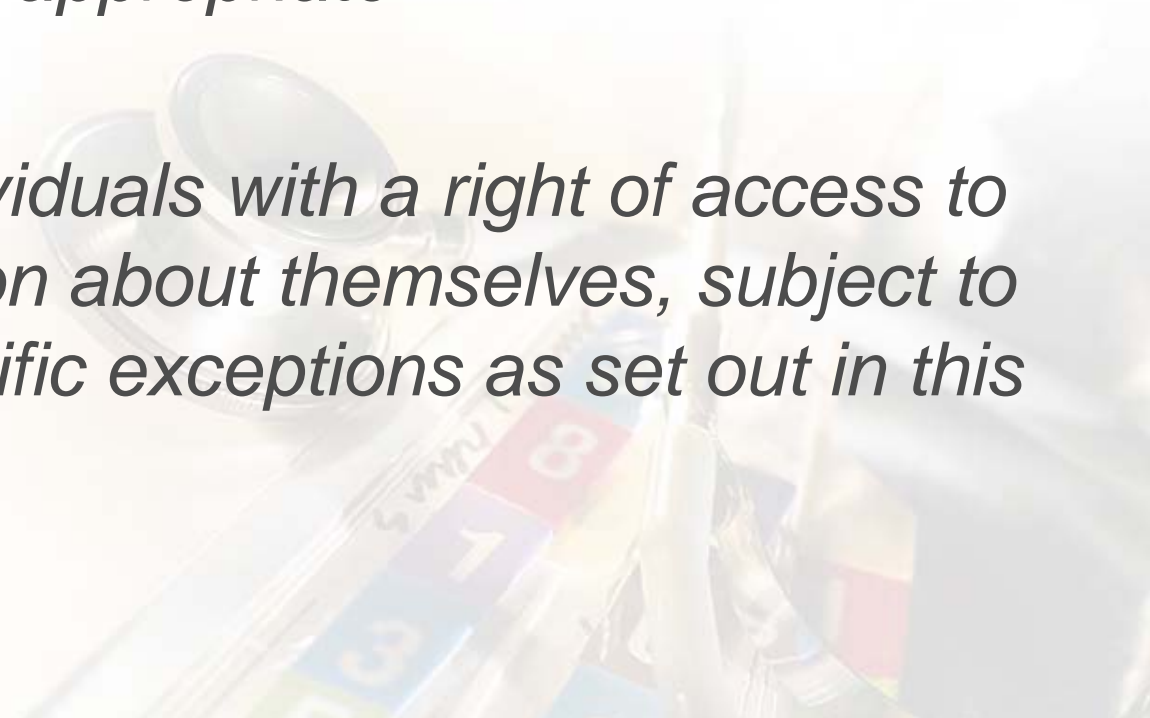
2 *The purposes of this Act are*

...

(b) to enable health information to be shared and accessed where appropriate

...

(d) to provide individuals with a right of access to health information about themselves, subject to limited and specific exceptions as set out in this Act





Informal patient access to information

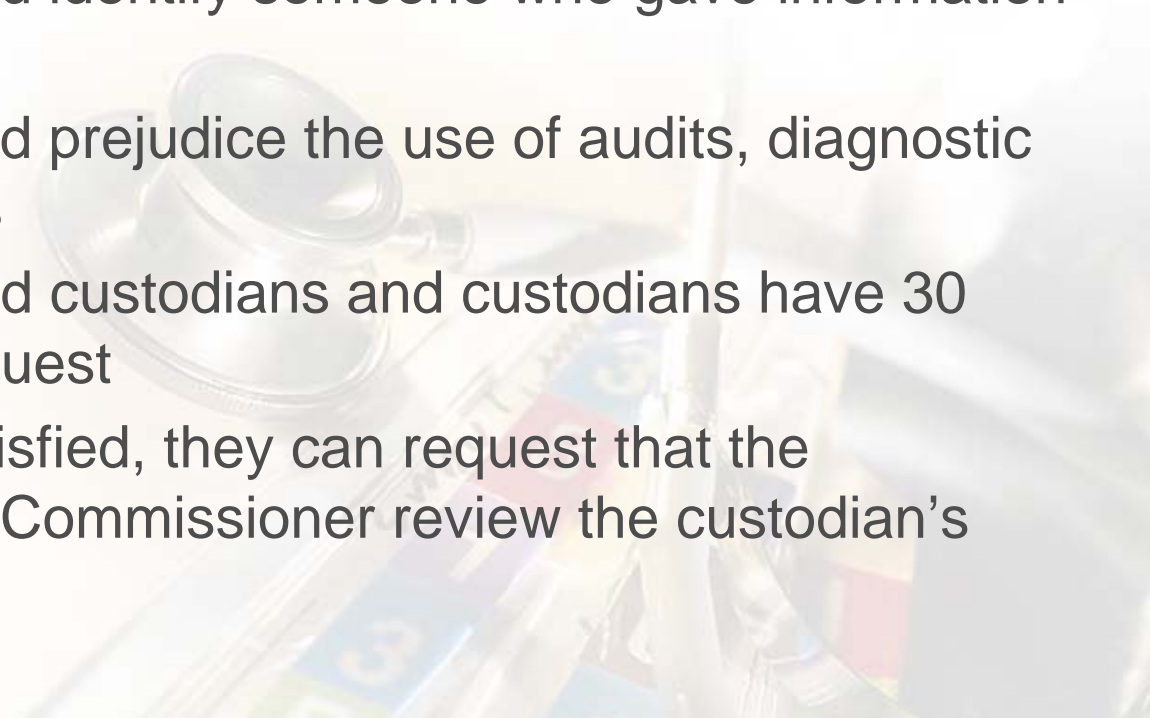
A custodian can disclose health information to the individual who is the subject of the information or to the individual's authorized representative

(HIA s. 33)





Formal access requests under the HIA

- The HIA extends the right to request access to health information
 - A custodian must grant access unless the Act allows them to withhold this information
 - If the disclosure could reasonably be expected to cause harm
 - If the disclosure would identify someone who gave information in confidence
 - If the disclosure would prejudice the use of audits, diagnostic tests or assessments
 - Fees can be charged and custodians and custodians have 30 days to respond to a request
 - If an individual is not satisfied, they can request that the Information and Privacy Commissioner review the custodian's decisions.
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Disclosure to family

- The HIA contemplates the disclosure of health information to family in the following circumstances
 - With the patient's consent (*HIA s. 34*)
 - To a person who is responsible for providing continuing care and treatment (*HIA s. 35(1)(b)*)
 - To family members or others with a close personal relationship where the information relates to the presence, location, condition, diagnosis, progress and prognosis of the individual provided the individual has not expressly refused (*HIA s. 35(1)(d)*)
 - To minimize an imminent danger (*HIA s. 35(1)(m)*)
 - Where an individual lacks the capacity to consent and disclosure is in the best interests of the patient (*HIA s. 35(1)(n)*)



Principles related to limitation

All disclosure of health information under the HIA must take place with the following principles in mind

- Custodians must disclose the most limited amount of information to fulfill the intended purpose (*HIA s. 58(1)*)
- Custodians have an obligation to take steps to ensure that information is disclosed to the authorized, intended recipient (*HIA s. 45*)
- Custodians must consider, as an important factor, the wishes of the individual related to the disclosure of their health information prior to disclosing information (*HIA s. 58(2)*)

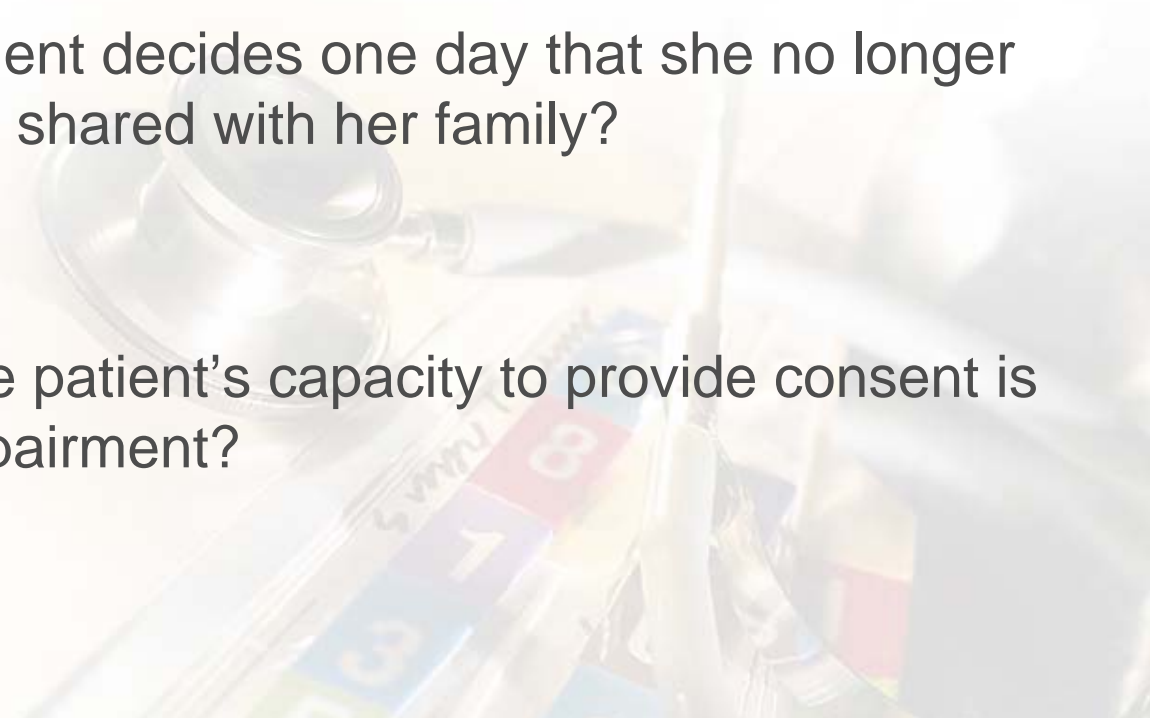


Case study

An 82 year old woman is a resident in an Alberta long term care centre. Her family is active in her care. What are the parameters for the release of information to the patient? To the family?

Does this change if the patient decides one day that she no longer wishes information to be shared with her family?

How does this change if the patient's capacity to provide consent is affected by cognitive impairment?





Guidance to providers of patient and family centered care

- Discuss any information sharing with your patients and address their concerns
- Consider the wishes of your patient related to the disclosure of their information
- The legislative “high water mark” is to obtain written consent for the disclosure of health information to families, although various jurisdictions do not require written consent
- Remember that the patient exercises a legal right of access to your clinical records, and that information provided by others must be considered for disclosure



Patient and family access to electronic health information

- Access to timely and accurate information is required to provide patient and family centered care
- Access to information is also a cornerstone of privacy laws
- Direct patient/family access to EPR/EMR/EHR systems support both these goals

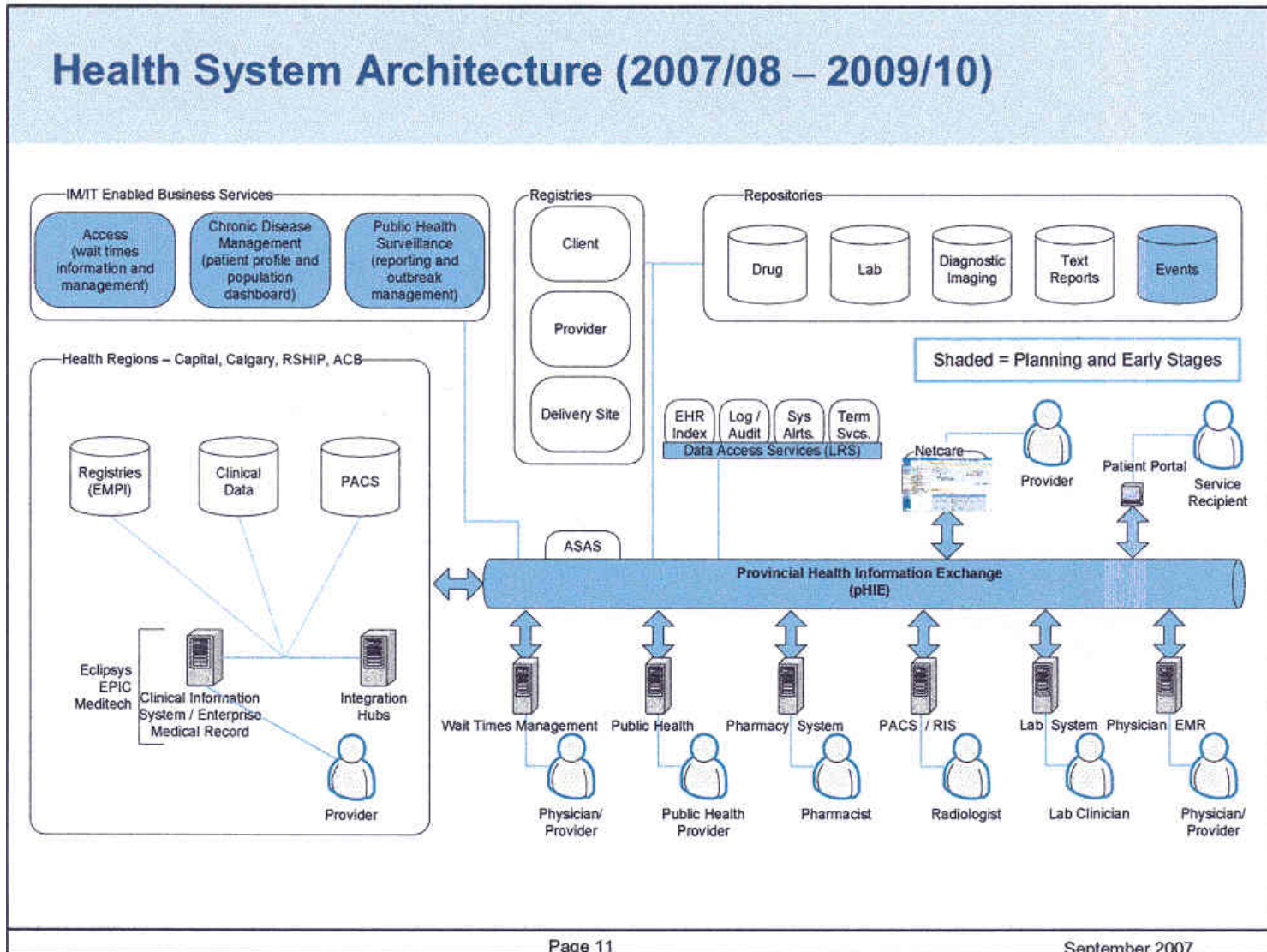
But...

- Immediate electronic access may not be appropriate in every setting or in the best interests for every patient
- Some clinicians report a “chilling effect” as the level of access to clinical notes increases



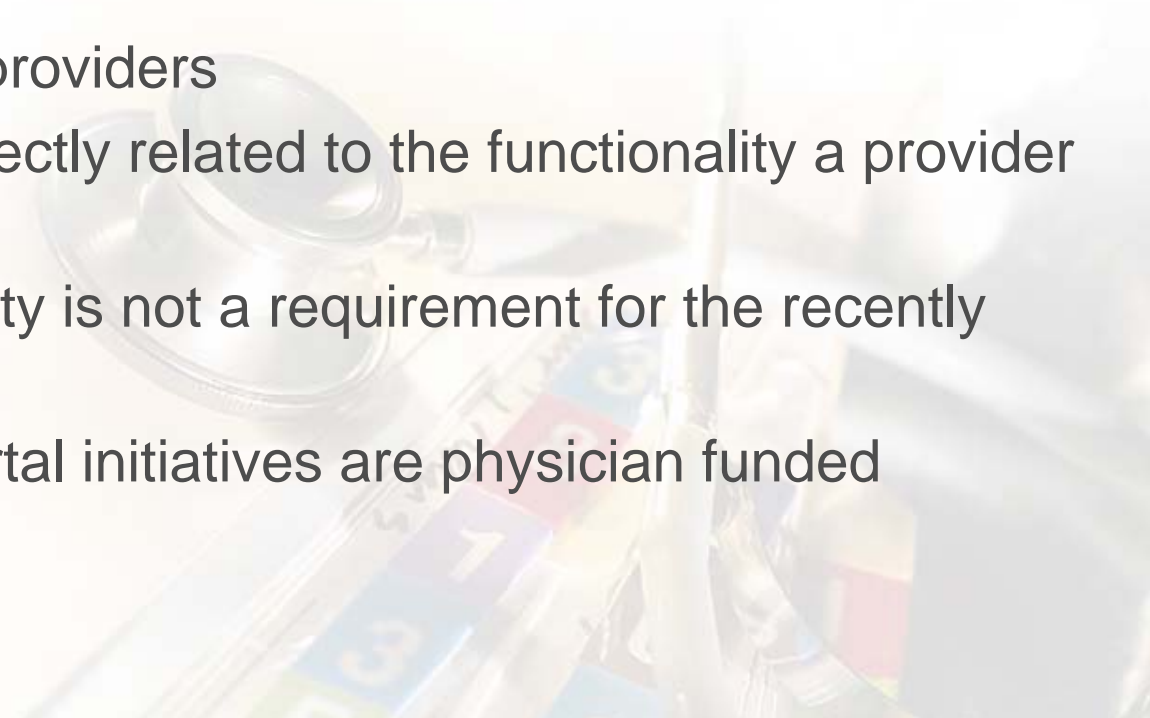


Where can/should access take place?





The Alberta solution – primary care

- Less than 1% of physicians in Alberta had advised us that they are using patient portal technology for their EMR systems
 - Those that are do not use portals the same way
 - Contact information
 - Online scheduling
 - Ability to email care providers
 - The privacy risks are directly related to the functionality a provider chooses
 - Patient Portal functionality is not a requirement for the recently issued POSP EMR RFP
 - Current EMR patient portal initiatives are physician funded
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The Alberta solution – Alberta Netcare Patient Portal

- Phase 1 – Educating (18 months)
 - Trusted content
 - Health system navigation
 - Personalized health management tools and alerts
 - Feedback
- Phase 2 – Empowering (3 years)
 - Presentation of identifiable health information
 - Scheduling and referrals
 - Immunizations and allergies
 - Medication list and prescription renewals
 - Results review
 - Donor registration
 - Medical assessments
 - Contextual health explanations and standards of care



The Alberta solution – Alberta Netcare Patient Portal

- Phase 3 – Enabling (5 years)
 - Online consultations
 - Interactive treatment plans
 - Provider notes
 - Second opinions
 - Patient journals
 - Health system usage reports
 - Symptom tracking
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Guidance for those developing IT systems

- Patients state their # 1 concern about EHR systems is privacy and security – patient portals may make this concern more real for the patient
- Provide means for password change, education and support
- Remember the limitation principles – should family have the same access rights as patients? Should they have the same data entry abilities? Do you need to build a lockbox or masking functionality?
- Every user within the system must be uniquely identified
- The patient has a right to know who has accessed their information – be sure to build adequate auditing capabilities
- Privacy impact assessments are required under Alberta law



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