

# Pandora's Box is Open



## Minors' Access to their Information

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## Presentation Objectives

- Share an overview of a legal / privacy framework review
- Discuss the findings from an environmental scan, pan-Canadian survey and focus groups
- Share insights and approaches related to mature minors' access to their personal digital health information

Joan Roch

# LEGAL / PRIVACY REVIEW

# Ensuring a common understanding

- What is a minor?
  - 19 – BC, NB, NS, NL, NU, NT, YK
  - 18 – AB, AK, MB, ON, QC, PEI
- What about 'mature' minors?
- What about health information laws?
  - Generally include the individual's right to access their information
  - How does that right apply to children?

# Minors' access, consent, use & disclosure of PHI

## Minors' Access

- Outside of Quebec, there is no minimum age in statutes for access to own PHI
- Quebec – person must be 14 to access his/her information

## Minors' consent to collect, use & disclose (CUD)

- Outside of Quebec, there is no minimum age for consent to collect, use & / or disclose one's PHI
- **Knowledgeable / informed consent may be required; may require capacity**
- Note: Quebec does not use CUD terms – parent/tutor acts on behalf of person under 14.

# Consent to treatment

- Consenting to healthcare treatment is more complex than health information management, for example it can involve consideration of:
  - Nature of the medical decision – life or death vs basic care
  - Decision by care provider that the minor understands the nature and consequences, benefits and risks of the treatment

# Minors' information, consultation & consent rights - social services statutes

High level generalizations:

- Information
  - Statutes require children 12 and older to be given information about matters that affect, e.g., reports about whether the child is in need of protection.
- Consent for adoption
  - Statutes in all jurisdictions require a minor (generally 12) to consent to adoption (ON – 7; QC 10)
- Right to make application under acts, refuse protection, be a party to proceedings
  - Generally 16 ( sometimes 14)

## The bottom line

- It is reasonable to expect minors wanting access to their personal health information
- Health information laws ensure the individual's right of access
  - Outside of Quebec chronological age limits are not stated
- Other statutes and the mature minor doctrine civil code provisions provide guidance



Fraser Ratchford

# PAN-CANADIAN PERSPECTIVES

# Understanding adolescent access to digital health information

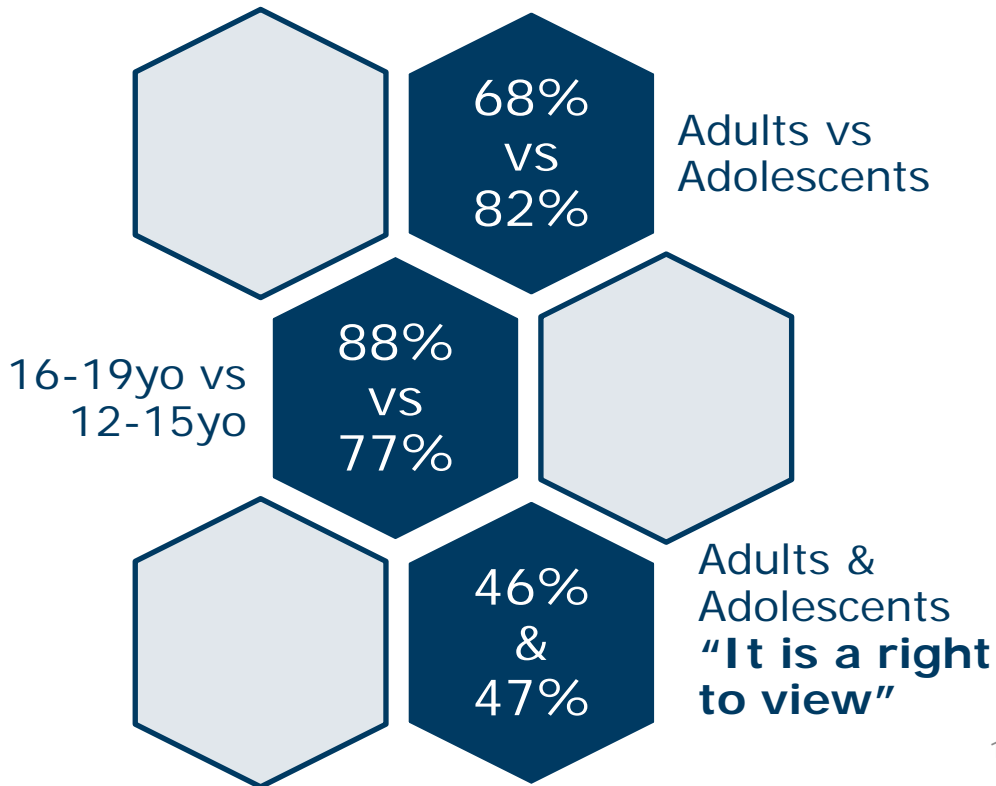
Research: December 2015 to March 2016:

- Environmental scan & literature review
- Pan-Canadian Survey and Focus Groups
  - Online survey (n=2011)
  - Focus Groups (9 in total)
- Legal / privacy framework review



# Allowing adolescents to access their information

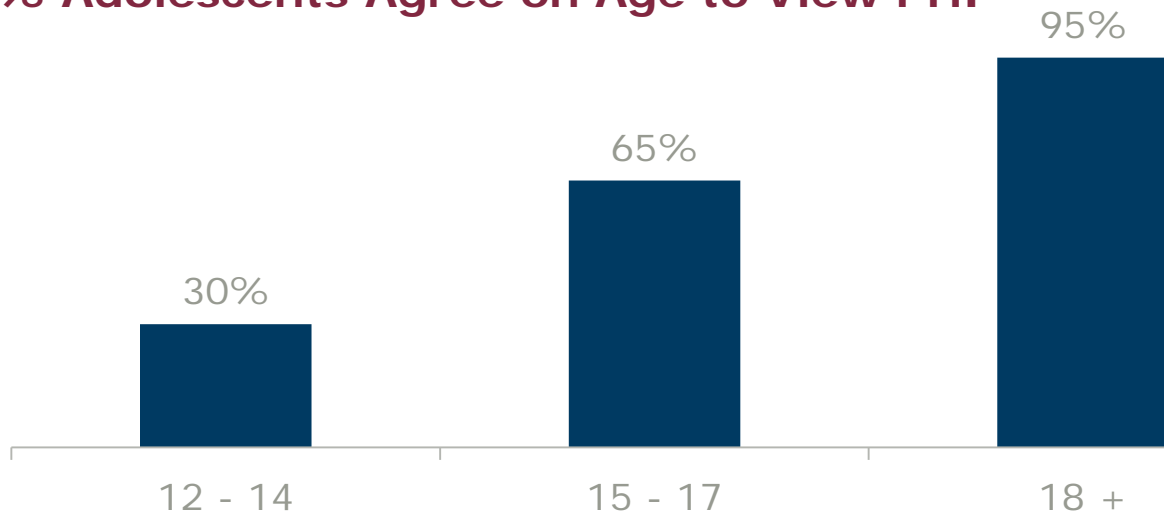
Generally, both adults and adolescents support the idea that adolescents should be able to view their personal health information online.



## Adolescent perceptions of an appropriate age to view

Adolescents agreed that as they age, they should be allowed to see their personal health information

### % Adolescents Agree on Age to View PHI



**While some adolescents felt that they may not understand the information shown, they still feel the decision to view it, should be made on their own.**

## Adolescent likelihood to check PHI online

### Reasons for checking PHI

- Check test results
- When sick
- When filling out forms

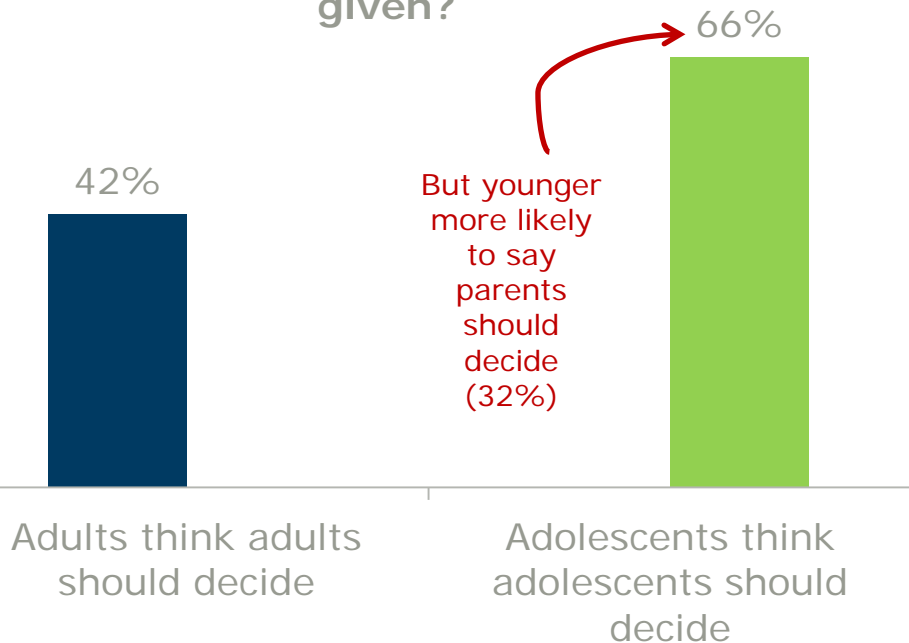
### What they would check

- Lab results
- Prescriptions
- Immunizations
- Past & future appointments
- X-rays

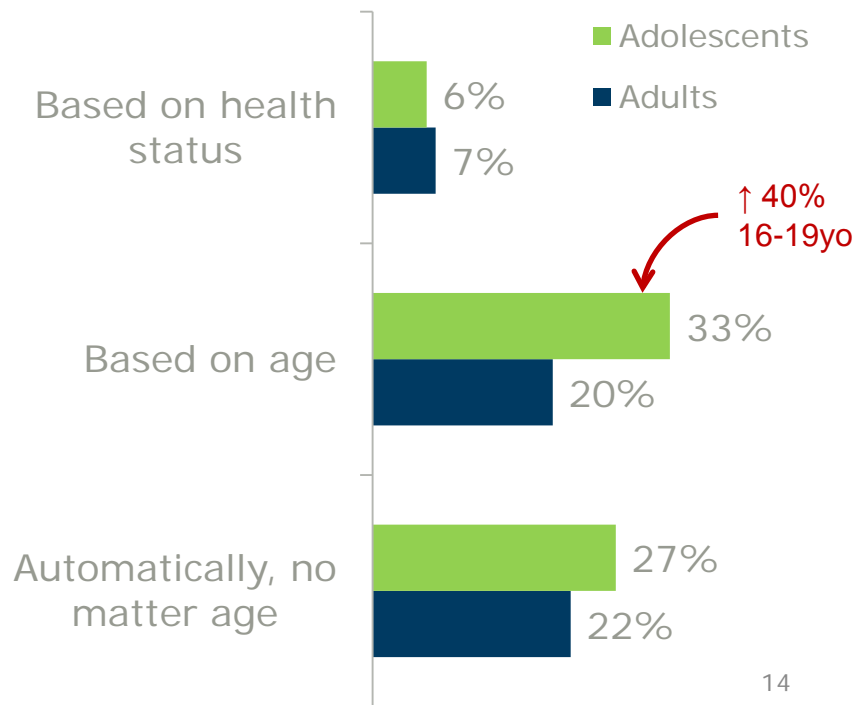
- Reasons for checking PHI online would be largely situational and to fulfill a specific information need
- Few adolescents would check without prompting from someone to a specific information need
- Adolescents would check more services than adults think they would

# Determining who should decide adolescent access & how

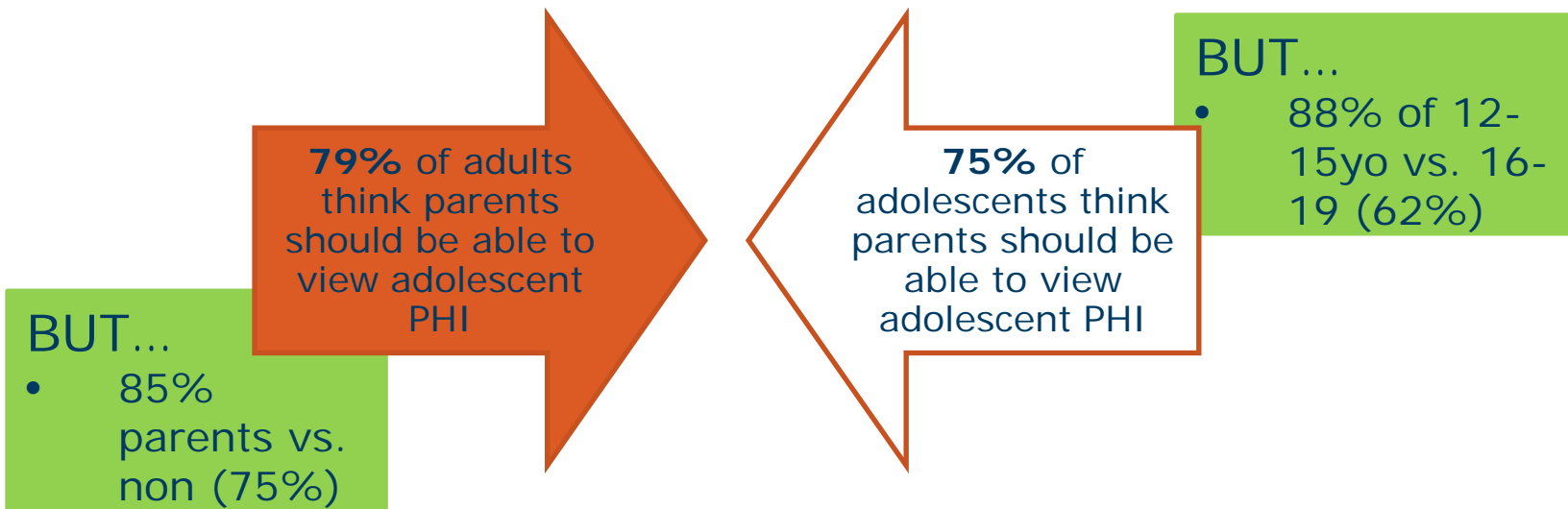
Who decides access should be given?



What triggers access?



## Should parents be able to view?



Older adolescents are less likely to want parents to automatically have access to their health information

## Views on confidentiality & sharing

- Both adults and adolescents view PHI as confidential:
  - adolescents more than adults (85% vs. 81%)
  - 16-19 years more likely to say their PHI is confidential
- 77% of adolescents are comfortable with parents viewing their PHI
  - 75% adolescents & 80% adults expect parents to view until adulthood
- 84% of adolescents would not share their PHI with friends or others
  - Consistent across all age groups
- 83% of adolescents believe THEY should control who can see their PHI, no matter their age
  - vs. 43% of adults





## Decision-making, empowerment and access

IF AN ADOLESCENT CAN MAKE A DECISION ABOUT TREATMENT, THEY CAN ALSO EXPECT CONFIDENTIAL ACCESS TO THEIR HEALTH CARE INFORMATION

- Capacity to consent is sometimes determined by age – e.g.:
  - In Quebec: 14 years of age
  - New Brunswick: 16 years of age
  - Manitoba: 16 years of age

“The disclosure of information follows the consent to treatment: how can you have capacity to consent to treatment but not have capacity to have that information?”  
(Interviewee)

# Access in the context of life

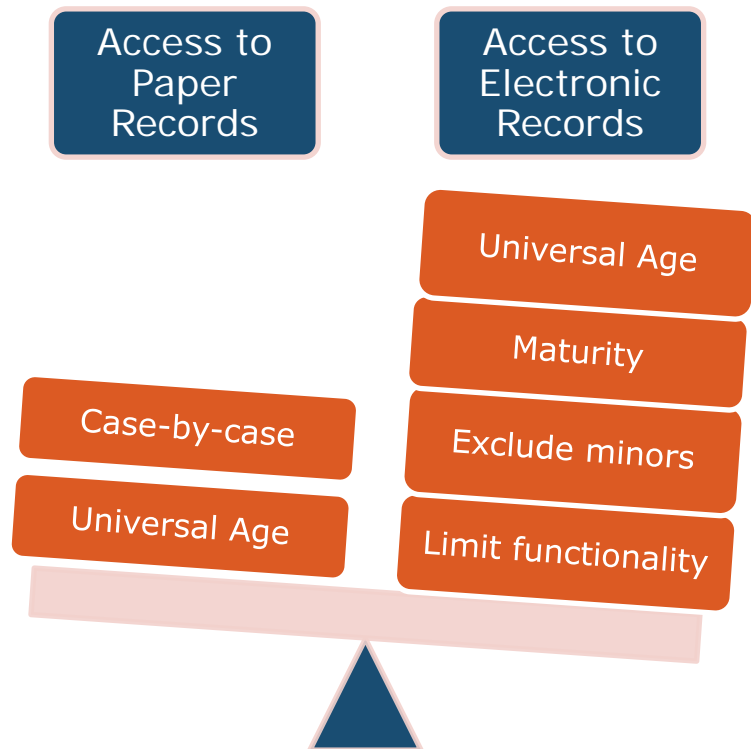


## Considerations for Assessing Mature Minor

- Age
- Relationships
- Maturity
- Independence
- Capacity
- Legislation
- Provider perception



# Policies to Access Health Information for Adolescents



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How do you enable confidentiality?

- Segmented data
- Remove / withhold sensitive information
- Distinct medical records

Jennifer Gillert, CHEO

# ON THE GROUND EXPERIENCE

# Protecting Privacy in Pediatrics

*A practical perspective  
in Consumer Health*



The screenshot shows the CHEO MyChart patient portal. At the top, it features the CHEO logo and the text "The secure health portal of the Children's Hospital of Eastern Ontario" and "Le portail de santé sécurisé du Centre hospitalier pour enfants de l'est de l'Ontario". Below this is a large image of a young girl in a polka-dot dress standing on a hula hoop. To the right of the main image is a grid of smaller photos showing various children and families. On the far right, there is a login section with fields for "MyChart Username" and "Password", a "Sign In" button, and links for "Forgot MyChart Username?" and "Forgot Password?". Below the login section are buttons for "New User? Sign Up Now" and "Learn More..." with links for "FAQs", "Privacy Policy", and "Terms and Conditions". At the bottom right, there is a small text: "MyChart® licensed from Epic Systems Corporation, © 1999 - 2012. Patents pending."

# Children's Hospital of Eastern Ontario

- 167 bed tertiary care hospital
- Referral Base: ~ 2 million
  - *194,000 outpatient visits to 63 specialty clinics*
  - *Pediatric Care to Eastern Nunavut*
- Academic institution, affiliated with U of Ottawa
- Regional trauma center
- Level III NICU





## MyChart @ CHEO

- Tethered patient portal
- Features live today:
  - *Future & past visit information*
    - Reminders and After visit summaries
  - *Health information including:*
    - Test Results (lab, imaging)
    - Allergies, Medications, Health Issues
    - Updates to health information
  - *Growth Charts*
  - *Secure two-way messaging*







## Enrollment Process

- Access Request Form
  - *Patient & Proxy signature (as applicable)*
- Manual proxy access checks completed by Health Records
  - *Patient Alerts*
  - *Legal Guardianship*
  - *Unique patient populations (e.g. Eating Disorders)*
- Activation email sent to patient, proxy (as applicable)



## Age Categories for Proxy Access

- **Ages 0-11:** The proxy can be granted full access to the MyChart record upon approval of application. The patient will have access only with permission of the parent/legal guardian.
- **Ages 12-15:** The proxy can be granted full access to a patient's MyChart record unless the patient advises CHEO that he/she doesn't want a parent or guardian to have access to the MyChart record.
- **Age 16 or older:** The proxy will only have access to a patient's MyChart record if the patient gives permission by proxy by filling out the request form.



## Proxy Access Safeguards

- “Check-points” built in place to deactivate proxy accounts at transition ages
  - *12, 16, 19*
- Re-enrollment at transition ages
- Unique user account per proxy or patient (not shared)
  - *Including unique email addresses for each account*

## MyChart Deactivation

- Processes to consider:
  - *Inappropriate Use*
  - *Request for Deactivation by Patient*
  - *Legal Update*
  
- Methods of Proxy Deactivation
  - *Patient from within MyChart*
  - *Privacy officer as per legal updates*
  - *Written deactivation request*
  - *Automatic, at specified ages*





## Key Feature Supporting Privacy requirements

- Unique accounts for each user (patient, proxies)
- Expiry notification in advance of transition age deactivation
- Password changes at any time
- Deactivation of proxy by the patient
- Option for confidential messaging between patient & provider
- Restricting sensitive results release



## Lessons Learned

- Manual review of Access Requests in Pediatrics to validate legal guardianship
- Electronic processes highlight existing challenges in paper processes
- Age of Consent
- Patient portal privacy education
  - *Patients & families*
  - *Clinicians*





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## To sum-up...

- Adolescents have a right to their personal health information
- There are no privacy or legislative barriers concerning adolescent access
- Policy development needs to respect the interests and wishes of adolescents while creating a balance that reflects evolving capacity and maturity with age
- Education and training are needed – for all – parents, adolescents, care providers
- Technology solutions need to be enhanced to support ‘business requirements’ related to access and minimize risk of inadvertent disclosure



## Available Resources

Add in links for each document once available from Kate

- Research outputs are available on Inforoute
  - Environmental Scan: Processes to Enable Adolescent Access to Personal Health Records
  - Environmental Scan: Statutory Provisions Relating to Rights of Minors
  - Environmental Scan: Statutory Provisions Relating to Rights of Minors – Summary Table
  - Provisions Relating To Minors in Provincial and Territorial Health Information Privacy and Health Care Consent Statutes
  - Adolescent e-Access Research Final Report



# DISCUSSION



Canada Inforoute  
Health Santé  
Infoway du Canada

Thank you