The 21st Century Cures Act and Adolescent Health: Managing Electronic Health Information for the Digital Generation

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Image Credit:
https://www.washingtonpost.com/sf/style/2017/01/04/generation-z-landing-page/?utm_term=.dfefcb20e027
A few notes about today’s Grand Rounds

• All lines are muted throughout the presentation.
• Please use the Q&A to ask questions or make comments.
• We will be recording the session.
• Today’s recording and materials will be posted to the PHN website 3 business days following the presentation:
  https://pediatrichealthnetwork.org/
Speakers

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Disclosures: None
Disclosures

• No conflicts of interest or commercial affiliations to report
• This presentation’s content includes no off-label use of drugs or devices
Learning Objectives for Today’s Talk

• Describe the role of confidentiality in adolescent health care and how access to and privacy of certain health services is protected by law

• Explain the basics of the 21st Century Cures Act (21CCA) Final Rule and how it impacts sharing of pediatric health information

• Understand the complexity and benefits of health information sharing with adolescents and young adults

• Discuss practical aspects of managing confidentiality as a precursor to information sharing
Overview

Adolescent Confidentiality 101
- The role of confidentiality in adolescent health care
- What laws matter?

Parents, Privacy & Patient Portals
- Adolescents & Patient Portals
- 21st Century Cures Act: What is the Final Rule?
- The CNH Approach

Adolescent Confidentiality 201
- Practice-level considerations
- Practice example – Woodbridge Pediatrics
Adolescent Confidentiality 101
Why is confidentiality important in Adolescent health care?

• Promotes accurate, comprehensive care
• Ensures access to certain health services when parental disclosure might be a barrier to seeking care
• Facilitates developmentally appropriate care – supported, independent interactions with health care providers is needed for health independence
• Aligns with regulations protecting minors’ right to consent for certain types of health care
• Not about keeping secrets or undermining the role of the parent
Minor Consent & Confidentiality: Which laws matter?

• State-specific/local laws regarding minors/parents
  • Minor consent, privacy, and mandatory reporting
  • Family law explicitly detailing parents’ rights/responsibilities

• Laws/regulations governing specific types of health services
  • Mental Health, Substance Abuse
  • Reproductive Health Services (eg Title X services)

• Federal Laws & regulations about health information
  • HIPAA Privacy Rule
  • 21st Century Cures Act
Minor Consent & Confidentiality

Health concerns for which minors can independently seek care:

- Sexual health (HIV & other STIs)
- Reproductive Health (Contraception, Prenatal Care, Abortion Services)
- Mental Health
- Substance Abuse

What are the rules in the DMV?
Here in the DMV:

Minors’ Ability to Independently Consent to Health Services

<table>
<thead>
<tr>
<th></th>
<th>CONTRACEPTIVE SERVICES</th>
<th>STI SERVICES</th>
<th>PREGNATAL CARE</th>
<th>ADOPTION</th>
<th>MEDICAL CARE FOR MINOR’S CHILD</th>
<th>ABORTION SERVICES</th>
<th>SUBSTANCE ABUSE SERVICES</th>
<th>OUTPATIENT MENTAL HEALTH CARE</th>
</tr>
</thead>
<tbody>
<tr>
<td>District of Columbia</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All**</td>
</tr>
<tr>
<td>Maryland</td>
<td>All*</td>
<td>All*</td>
<td>All*</td>
<td>All</td>
<td>All</td>
<td>Parental Notice</td>
<td>All</td>
<td>Allψ</td>
</tr>
<tr>
<td>Virginia</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>All</td>
<td>Parental Consent and Notice</td>
<td>All</td>
<td>All</td>
</tr>
</tbody>
</table>

*Providers may but are not required to notify parents
**90 day service limit, can consent to medications at 16+ in emergency conditions
ψMust be at least 16yo to consent to medications

https://www.guttmacher.org/policy-resources/adolescents
Here in the DMV: When can providers break confidentiality?

The health professional may, but shall not be obligated to, inform the parent, parents, or legal guardian of the minor of any treatment given or needed when, in the judgment of the health professional, the following situations exist: Severe complications are present or anticipated; Major surgery or prolonged hospitalization is needed; Failure to inform the parents or legal guardian would seriously jeopardize the safety and health of the minor patient; and To inform them would benefit the minor's physical and mental health and family harmony. § 602.5

Without the consent of or over the express objection of a minor, the health care provider may, but need not, give a parent, guardian, or custodian of the minor or the spouse of the parent information about treatment needed by the minor or provided to the minor [Md. Code Ann., Health-Gen. II § 20-102(f)]

A minor shall also be deemed an adult for the purpose of accessing medical records related to subdivisions 1 through 4 above; §54.1-2969. However, Virginia law also states that parents may not be denied access to the health records of their minor child, except when the minor’s treating physician deems such disclosure would cause substantial harm to the minor or another person. § 20-124.6
Minor Confidentiality & HIPAA Privacy Rule

• Parents/guardians are considered the “authorized representative” of a minor child under HIPAA, with three exceptions:
  • Someone other than the parent is authorized to and has provided consent (e.g., a court-appointed decision maker)
  • State or other law determines a minor can consent to a health service and the minor provides consent
  • When the parent/guardian agrees to a confidential relationship between the minor and a health care provider

When a minor may lawfully obtain health care without the consent of a parent or guardian, a parent or other personal representative may not be authorized access to the minor’s records, without the minor’s consent.
ONC 21st Century Cures Act, Final Rule* Basics

• Requires that patients be able to access their electronic health information (EHI) at no cost
• The intent is interoperability and health care transparency to improve safety and quality of health care
• Failure to provide access to EHI ("Information Blocking") can result in penalties
• Mandate is to share EHI on request – many systems are complying by pushing EHI through a patient portal

*Published May 1, 2020

Organizations must meet the new EHI access mandate, while protecting minors’ rights to confidential health information
Parents, Privacy & Patient Portals

NOT KNOWING EVERYTHING your kid does online is a GOOD THING.

Words by: @BeHeroes/ APPropriate Podcast  Art: @LindsayBravan
Poll Questions

Does your practice have a confidentiality policy that is provided to AYA patients and their parents/guardians?
   a. Yes
   b. Partially/In Progress
   c. No

Does your practice provide educational materials on confidentiality to AYA patients and their parents/guardians?
   a. Yes
   b. Partially/In Progress
   c. No
The Open Notes Movement:
Transparent Communication in Health Care

“Transparent notes will require transparent doctoring.” - Dr. Sigall Bell

OpenNotes is the international movement promoting and studying transparent communication in healthcare. We help patients and clinicians share meaningful notes in medical records. We call these open notes.

Patients who read notes report that they:
- have improved understanding of their health and medical conditions
- recall their care plan more accurately
- are better prepared for visits
- feel more in control of their care
- take better care of themselves
- take their medications as prescribed more frequently
- have more successful conversations and stronger relationships with their doctors

And keep in mind: Reminding patients that notes are available and providing clearly marked patient portals are both important for engaging patients in a practice that is new to them, as well as to most clinicians.

https://www.opennotes.org/
Medical documentation arose as individual case reports written for teaching purposes. Documentation for patient care later occurred in physicians’ personal daybooks and only evolved into the individual patient record in the early 20th century. Dr. Lawrence Weed improved the utility of the patient record by introducing a problem-oriented/subject-object-assessment-plan structure and he and other innovators transformed the patient record into electronic form. Pediatricians built on these innovations to create a child health electronic health record (EHR) for primary care. An American Academy of Pediatrics task force formally specified the child-specific needs of the EHR, but much work remains to integrate the EHR into the pediatric primary care of the future.

Who uses the Pediatric Patient Portal?


- Data extracted from EHR of a large academic medical center from 9/12-7/20
- Patients with activated accounts were more likely to be AYA patients; female, white, non-Hispanic, privately insured, and have low socioeconomic vulnerability index

<table>
<thead>
<tr>
<th>Patient Age Group (years)</th>
<th>% Activated Accounts</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-11</td>
<td>36%</td>
</tr>
<tr>
<td>12-17</td>
<td>41%</td>
</tr>
<tr>
<td>18-21</td>
<td>62%</td>
</tr>
<tr>
<td>All ages</td>
<td>39%</td>
</tr>
</tbody>
</table>

n= 52,713 unique patients
Who uses the Pediatric Patient Portal?


<table>
<thead>
<tr>
<th>Functionality</th>
<th>Younger children 0–11 years</th>
<th>Adolescents 12–17 years</th>
<th>Young adults 18–21 years</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Records access and management</td>
<td>10 291 (74.0%)</td>
<td>3525 (81.4%)</td>
<td>1942 (92.3%)</td>
<td>15 758 (77.5%)</td>
</tr>
<tr>
<td>Appointment management</td>
<td>8993 (64.7%)</td>
<td>3083 (71.2%)</td>
<td>1850 (87.9%)</td>
<td>13 926 (68.5%)</td>
</tr>
<tr>
<td>Messaging</td>
<td>8409 (60.5%)</td>
<td>2357 (54.4%)</td>
<td>1621 (77.0%)</td>
<td>12 387 (60.9%)</td>
</tr>
<tr>
<td>Visit/admission summaries</td>
<td>3909 (28.1%)</td>
<td>1228 (28.4%)</td>
<td>1047 (49.8%)</td>
<td>6184 (30.4%)</td>
</tr>
<tr>
<td>Interactive feature use</td>
<td>9738 (70.0%)</td>
<td>2998 (69.3%)</td>
<td>4039 (93.3%)</td>
<td></td>
</tr>
<tr>
<td>Any feature use</td>
<td>12 243 (88.1%)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Defined as use of any of the four features studied.

 Teens were more likely to use the portal for accessing health records and managing appointments.
AYA and Patient Portals: Youth Centered Implementation


Patient portals for the adolescent and young adult population: Benefits, risks and guidance for use

Jennifer A. Lee\( ^{a,b,c,d,\ast} \) and, Cynthia Holland-Hall\( ^{c,e} \)

Patient portals are the primary means by which electronic health information (EHI) is shared with patients and families. The use of patient portals increased during the COVID-19 pandemic and may continue to rise with the implementation and enforcement of the 21st Century Cures Act that encourages facilitation of access to EHI and prohibits information blocking. Research on the use of patient portals by adolescents and their families is limited. Potential benefits of portal use to adolescents include increased engagement in their own health care, direct communication with their health care clinicians, and facilitation of transition of care to new clinicians in adulthood. Clinicians need to educate adolescents on the functions available through the portal, appropriate use and expectations for messaging through the portal, and the pros and cons of viewing EHI such as test results independently. Parental proxy access to the adolescent’s portal should be carefully and thoughtfully implemented, because it poses a potential breach to confidential care via disclosure of sensitive or protected information. Adolescents who choose to deny their parents proxy access to the portal should be supported in that decision. It is important that all clinicians understand portal functionality and have strategies to optimize use within their practice. This paper provides the reader considerations and tips for portal use within this population.

Curr Probl Pediatr Adolesc Health Care 2021; 000:101101
AYA and Patient Portals

• Potential benefits
  • Enhanced communication, patient engagement and experience
  • Facilitates confidential communication
  • Tool for developing health literacy and health independence

• Potential risks
  • Breaches of confidentiality
  • Appropriate messaging/communication
  • Anxiety about health information (e.g., if abnormal results viewed without appropriate support)
AYA and Patient Portals

• Unique barriers to implementation
  • Verification of user identity for enrollment
  • Concerns about breaches in confidentiality
  • Emerging health independence and health literacy
  • Proxy access for caregivers

• And what about...?
  • Disparities in access augmenting healthcare disparities
  • Youth with developmental or cognitive disabilities
  • Youth with complex or chronic health conditions
AYA and Patient Portals: Youth Centered Implementation

• Real time enrollment
• Developmentally appropriate education for youth
  • Confidentiality and limits to confidentiality
  • Portal functionality and use
  • Appropriate use of portal versus other communication options
• Caregiver Education
  • Confidentiality and limits to confidentiality
  • Proxy portal functionality
Sample documents: CNPA Foggy Bottom

After you turn 13, appointment reminders by phone can go to you or to your parent (see “Teen Patient Portal Access” form).

After you turn 13, you may sign up for our “Patient Portal” to view your chart, vaccine record, lab results, etc. online. Only you will have access to this Portal, but you can share access with a parent/guardian upon your consent.

Your doctor or nurse practitioner will discuss how you want to handle your Portal Access on a regular basis.

An informed teen is a healthy teen.
Implementing the ONC 21\textsuperscript{st} Century Cures Act

- The Interoperability Final Rule applies to all clinicians, practices and health systems that maintain electronic health information (EHI)
- EHI must be shared in a timely manner on request
  - Patients cannot be charged
  - Must be transmitted securely if shared electronically
  - Is not required to be pushed through a portal
- Facilitates access to health information to which individuals already have legal access
- Defers to existing local, state, and federal laws as to WHAT health information can be accessed by individuals, including caregivers
ONC 21st Century Cures Act, More on the Final Rule

- 21CCA includes 8 Information Blocking Exceptions detailing “reasonable and necessary” practices in which electronic health information (EHI) might be withheld
  - **Privacy Exception** – Disclosure of EHI should not violate state or federal privacy laws (includes laws protecting minor confidentiality)
  - **Preventing Harm Exception** – EHI can be withheld if access poses a substantial risk of harm
  - **Infeasibility Exception** – Practical challenges may limit organizations’ ability to grant full access to EHI (e.g., technology limitations)
21st Century CURES Act:
The Children’s National Hospital Approach

ACKNOWLEDGMENTS:

Jessica Herstek, MD
Chief Medical Informatics Officer

Tova Ronis, MD
Medical Director of Informatics - Ambulatory
21st Century CURES Act: The CNH Approach

Major Guiding Principles

• Provide secure access to electronic health records to which parents/patients already have legal access, while also being compliant with laws governing health information privacy

• “Open Notes” is the default standard - healthcare transparency and meaningful communication improve patient-provider collaboration and thus quality and safety

• Everything is shared EXCEPT those elements of EHI flagged as confidential
21st Century CURES Act: The CNH Approach

• EHI is shared through a secure patient portal, which required modifications for compliance with the Final Rule

• CNH’s Cerner-based portal includes inpatient records, outpatient specialty records, ER records, CNH diagnostic studies (laboratory, radiology)

• EHI is accessible (“always shared”) through the portal unless flagged as “confidential”
  • “Never Shared” – certain categories of clinical documentation (e.g., HIV services, CAPC, social work) or diagnostic data protected by minor confidentiality law (e.g. STI labs, substance abuse testing)
  • “Sometimes Shared” – Providers can switch to a confidential note type if confidential information is disclosed, or provide documentation/results securely through the portal on the portal user’s request
21st Century CURES Act: The CNH Approach

- Provider Outreach & Education
- Changes to the Patient Portal
  - Parent account deactivated at 18 (instead of 13)
  - Enrollment <18yo is by invitation, self enrollment for 18+ (instead of all self enrollment)
  - Parent users cannot see confidential information at any age
- Teen portal:
  - Can enroll without parent consent
  - Do not have access to confidential information (yet) but can request information securely
  - Can securely message medical team
Adolescent Confidentiality

Adolescents must be supported as independent users of care at all points of contact
Protecting Confidentiality: Practice-Level Considerations

• Consider confidentiality in all workflow processes where information is shared internally or externally
• Educate staff, providers, patients and parents about confidentiality laws and practice policies
• Set clear roles, rules and expectations, including limits to confidentiality
• A specific confidentiality policy is useful for educating staff, patients and their families

Templates for a practice confidentiality policy and patient/parent education materials will be available through PHN!
Role of the Provider (and other Health Care Staff)

• Offer a private space to identify confidential concerns, and to collect an accurate and comprehensive history
• Be non-judgmental, honest, and guarantee privacy with clearly stated expectations
• Support adolescent growth and development, including transition to adulthood and health independence
• Partner with caregivers to support adolescent patients

Confidential notes will require confidential doctoring
Role of the Adolescent

• Begin to take ownership of their healthcare
• Learn to express their concerns
• Learn and express their own and their family’s medical history
• Learn to navigate the health care system independently
• Develop as medical decision makers using appropriate resources and supports
Role of the Parent/Adult Caregiver

• Still a central member of the healthcare team
• Remain a critical support in their teen’s life
• Recognize the value of privacy in helping their teen share and reflect on their behaviors
• Agree that information disclosed in a healthcare setting should be met with strategies for safety, not punishment
Protecting Confidentiality: Practice-Level Considerations

Appointment Management
• Can minors make appointments independently and confidentially?
• Are automated reminders sent? Can they be turned off?
• Are post-visit surveys sent?

Telephone Services
• Are staff providing telephone services aware of the confidentiality policy?
• Is there a clear process for internally communicating adolescent’s consent to share sensitive information with others?
Protecting Confidentiality: Practice-Level Considerations

At the Visit

- Does the check-in process support adolescent patients’ confidentiality and right to present for confidential care?
- How are adolescent patients screened for confidential concerns?
- Is there a separate area for parents/guardians to facilitate independent time with the adolescent patient?
- How are confidential lab collection and specimen handling managed?
Protecting Confidentiality: Practice-Level Considerations

Medication Reconciliation
• What is the process and how are confidential medications reconciled?

Lab and Referral Tracking
• How are confidential lab results reported?
• How are referrals for confidential health issues managed?

Billing Processes
• Are EOBs sent which would potentially compromise confidentiality?
• Are alternate payment schemes available to support confidential care?
Protecting Confidentiality: Practice-Level Considerations

The EHR

• Is contact information for the adolescent patient recorded to enable confidential communications?
• Do after-visit summaries include confidential information on the problem list, order set, or medication list?

Patient Portals

• Are potentially confidential information types included?
• Do different access levels exist that would limit guardians’ access to confidential information?
• If only one access level exists, is it possible to redact confidential information?
Limits of Confidentiality

Confidentiality is necessarily limited in cases of:

• Risk of harm to self or others
• Child abuse or sexual assault
• Reportable disease

Are limits to confidentiality clear?

• To patients and their families
• To all staff

The intent of confidentiality is to remove access barriers and facilitate care. If maintaining confidentiality becomes a barrier to patient health and safety, consider involving a parent or trusted adult.
Confidentiality in Practice:
Woodbridge Pediatrics
Dr. Kathleen Bekhit
Confidentiality in Practice

- If a teenager has a confidential concern, how do you manage and document that concern?
  - ....during a well visit?
  - ....during a sick visit (for another complaint?)
Identifying confidential information in the record – Flagging information as confidential is a necessary step for keeping it confidential, through electronic or other means.

For well visits, the HEADSS exam is part of the template. For sick visits, the confidential risk assessment can be merged into the sick visit template (“Other Notes” for free text.)
Confidentiality in Practice

• How do you keep medications confidential?
  • Prescribing and picking up medication?
  • On medication lists or for medication reconciliation?
  • Addressing possible breaches of confidentiality if risk is high?

• How do you keep labs confidential?
  • ....collecting labs? What about blood specimens?
  • ....reporting results?
Confidential Labs – Can indicate in individual results screen “Don’t publish to Web Portal”
Confidential Labs – Use internal notes to indicate confidentiality and results handling
Confidentiality in Practice

- Any tips for how to support other office staff in maintaining a youth-friendly environment, and confidentiality of care?
- What are the most important steps a practice can take?
Summary

• The 21st Century Cures Act guarantees patients access to their electronic health information (EHI)
• This poses significant challenges for critical aspects adolescent health care, that depend on confidentiality of care and health information.
• Implementing 21CCA requires a careful look at how confidential care is handled at all points of workflow
• We can use patient portals to improve care deliberately support youth to become responsible, independent managers of their own health need
• Information sharing can be a tool for improving quality and safety in health communications, and may require a culture change in how we document care
Further Reading & Resources
Resources: CNH Clinical Informatics

Clinical Informatics Resources

21st Century Cures Act
A new federal law in effect as of spring 2021 gives our patients greater access to their health data.

- Cures Act Overview
- Frequently Asked Questions
- Videos (less than 5 minutes)
  - Confidential Note - what is it?
  - Confidential Note - how to use it

Clinical Informatics Updates
- Spring 2021
- December 2020
- August 2020

Quick Bytes
1-5 minute videos taught by the Clinical Informatics team. Offering tips, tricks and strategies to optimize use of medical record and related technologies. View the series here or within Cerner eCoach.

Some of the topics covered include:
- AutoText tips
- Introduction to First Dose STAT feature
- Using confidential note types
Resources: www.OpenNotes.org
What Pediatricians Need to Know About the 21st Century Cures Act Interoperability Final Rule

The information below highlights what pediatricians need to know about the 21st Century Cures Act Interoperability Final Rule.
AAP Reporting Tool: Information Sharing Consequences in Pediatric Care

Information Sharing Consequences in Pediatric Care

AAP is collecting stories of real-world scenarios involving your organization or patients/families that may demonstrate unintended consequences of information sharing and/or the 21st Century Cures Act Interoperability Final Rule.

Please note that this is an information-collecting tool. This is not intended as a technical assistance/guidance request. Any follow-up from AAP will be for the purposes of clarification. If you need assistance in implementing the Cures Act Final Rule, please email your questions to CHIC@aap.org.

OK

Pediatric Health Network
Children's National
Position paper
Confidentiality Protections for Adolescents and Young Adults in the Health Care Billing and Insurance Claims Process

The Society for Adolescent Health and Medicine and the American Academy of Pediatrics

https://www.adolescenthealth.org/SAHM_Main/media/Advocacy/Positions/Confidentiality-Position-Statement.pdf
Position paper

Recommendations for Electronic Health Record Use for Delivery of Adolescent Health Care

The Society for Adolescent Health and Medicine

https://www.jahonline.org/article/S1054-139X(14)00053-6/fulltext
SAHM: Policy & Position Statements

NASPAG/SAHM Statement: The 21st Century Cures Act and Adolescent Confidentiality

In 2020, the Office of the National Coordinator for Health Information Technology (ONC) issued a Final Rule to implement specific requirements of the 21st Century Cures Act. The goal of the Final Rule is to increase access, use, and exchange of electronic health information. The North American Society for Pediatric and Adolescent Gynecology (NASPAG) and the Society for Adolescent Health and Medicine (SAHM) agree that sharing health information with patients and families allows for improved medical care. We believe it is equally important to recognize the right of adolescent minors to access confidential care, which is protected to some degree in every U.S. state. As experts in the care of adolescents, NASPAG and SAHM are in a unique position to inform institutional policies around the release of information for this population.

Adolescent Confidentiality Background

The confidentiality of adolescents' health information is protected by a combination of state and federal laws. Although laws vary by state, in each state, adolescent minors have the right to consent to some health care services; also, some adolescent minors are allowed to consent for all or most of their own care. For example, with regard to sexual and reproductive health care, all states allow minors to have access to screening and treatment for sexually transmitted infections.

State Specific Resources

DC

Maryland
https://www.peoples-law.org/youth-health-law

Virginia
Thank you for caring for youth.

https://www.instagram.com/covid_and_beyond/

pkapunan@childrensnational.org
CME must be claimed within 90 days of event!
Coming up at PHN...

Next month’s Grand Rounds will provide an important update on newly published STD guidelines.

In March, PHN will launch an MOC-eligible learning collaborative focusing on Adolescent Care in the Medical Home. In conjunction, we have complied a Resource Library that will be posted along with this webinar on our website. Resources include:

- a template for your office’s confidentiality policy
- educational materials about confidentiality for patients and parents/guardians
Thank you

PHN@childrensnational.org