Confidentiality, EHRs, & Patient Portals: A New Frontier

Abigail English, JD
Center for Adolescent Health & the Law
english@cahl.org

Webinar
School-Based Health Alliance
January 17, 2017
Overview

- Benefits of EHRs & patient portals
- Confidentiality challenges in EHRs & patient portals
- Federal HIT laws
- Federal confidentiality laws
- State confidentiality laws
- Professional society recommendations
- Evolving practical approaches
- Questions to ask
- Strategies to consider

A. English, Center for Adolescent Health & the Law
Poll Question #1

☐ Has your SBHC or sponsoring organization implemented an EMR or EHR?

☐ Yes

☐ No
Definitions

- EMR (electronic medical record) – digital version of paper chart
- EHR (electronic health record) – record shared among many providers
  - PHR (personal health record) – repository of information from multiple contributors (patient, family, physicians, other health care professionals)
    - PCHR (personally controlled health record) – enables individuals to aggregate, securely store, and access information from multiple sites
- HIE (health information exchange) – organization that provides services to enable sharing of electronic health information

A. English, Center for Adolescent Health & the Law
Benefits of EHRs & Portals

- Improve health care accessibility
  - Appointments
  - Prescriptions
  - Contact with practitioners

- Improve health care effectiveness
  - Increase vaccination rates
  - Increase rates of preventive counseling

- Improve health care safety
  - Reduce unnecessary antibiotic prescribing

- Make population data available to researchers

A. English, Center for Adolescent Health & the Law
Confidentiality Challenges in EHRs & Portals

- Risks for individuals/inadvertent disclosures
  - Automated appointment reminders
  - Problem lists, medications lists in after visit summaries (AVS)
  - Lab test results
  - Patient notes

- Systemic data loss
  - Lost unlocked mobile phone
  - Comprehensive data sharing agreements on HIE
Federal Health IT Laws

- HITECH – Health Information Technology for Economic and Clinical Health Act of 2009, part of American Recovery and Reinvestment Act (ARRA)
- HIPAA – Health Insurance Portability and Accountability Act of 1996
- ACA – Affordable Care Act of 2010
- Adolescent privacy concerns not addressed
HITECH

- 2009 statute
  - HHS authority
  - Improve health care quality, safety, & efficiency through promotion of health IT
    - Electronic health records
    - Health information exchange
  - “Meaningful Use”

- ONC – Office of National Coordinator

- www.HealthIT.gov
Poll Question #2

- Is your sponsoring organization or SBHC implementing meaningful use?
  - Yes
  - No
  - Don’t know
Meaningful Use of EHRs

- Medicare & Medicaid financial incentives
  - Meaningful use of certified EHR technology
    - Recording of patient information as structured data
    - Exchanging summary records
    - Improved outcomes for patients

- Stage 1
  - Electronic capture of clinical data
  - Electronic copies of health information to patients

- Stage 2
  - Continuous quality improvement
  - Exchange of information in most structured format possible
HIPAA & Health IT

- Statute (1996)
- Regulations
  - Office of Civil Rights
  - HIPAA Privacy Rule
    - Use and disclosure of “protected health information” (PHI)
  - HIPAA Security Rule
    - Who is covered by HIPAA Privacy Rule
    - Safeguards to protect electronic PHI

A. English, Center for Adolescent Health & the Law
Federal Confidentiality Laws

- HIPAA Privacy Rule
- Title X Family Planning
- Medicaid
- Drug & alcohol confidentiality regulations
- Ryan White HIV/AIDS program
- Section 330 FQHCs
Rights of individuals
- Control disclosure
- Access records
- Request special confidentiality protections

Parents’ access to information
- Parent as authorized representative
- Minors as individuals
  - Consent for own care
  - Parent accedes to confidentiality
- Deference to state or “other applicable law”
State Confidentiality Laws

- State constitutional right of privacy
- **Minor consent laws**
  - Explicit confidentiality provisions
  - Cross-reference in other laws
- **Medical privacy laws**
  - HIPAA implementation in state law
- Medical records
- Professional licensing
- Evidentiary privileges
- State funding programs
- Education records
State Minor Consent Laws

- All 50 states and DC
  - Minor consent based on status
  - Minor consent based on services
  - Disclosure to parents
- Variability among states & within states
Federal & State Disclosure Laws

- Billing, insurance communications, & EOBs
- Mandatory reporting laws
  - Public health reporting
  - Child abuse reporting
- Patient danger of harm to self or others
- Parental notification requirements

A. English, Center for Adolescent Health & the Law
Poll Question #3

- If your site is using an EMR, EHR, or patient portal, has it been customized to protect adolescent confidentiality?
  - Yes
  - No
  - Don’t know

A. English, Center for Adolescent Health & the Law
Professional Society Recommendations

- **AAP (2012)**
  - Standards for Health Information Technology to Ensure Adolescent Privacy (Policy Statement; endorsed by SAHM)

- **SAHM (2014)**
  - Recommendations for Electronic Health Record Use for Delivery of Adolescent Health Care (Position Paper)
AAP Recommendations (2012)

- Criteria for EHR systems
  - Privacy standards for adolescents
  - Determination of who has access or can control access
  - Recording of authorizations & consents by adolescents
  - Explicit consent by adolescents for release of specific PHI
  - Flexibility to protect specific elements or entire record
  - Privacy standards consistent with state laws
  - Flagging of data for placement in confidential section
  - Protection of aggregate data
  - Billing systems that can suppress billing to parent

A. English, Center for Adolescent Health & the Law
SAHM Recommendations (2014)

- **Vendors/EHR systems**
  - Develop granular privacy controls & robust privacy settings
    - Designation of specific elements & information as confidential & suppressible (e.g. in AVS)
    - Differential access to information (parent & adolescent)
    - Limit sharing of unauthorized information via HIE
    - Default privacy settings that can be overridden

- **Health care systems – commitment & training**
- **Health care providers – know laws & act as champions**
- **Patients & families – use of systems & advocacy for protections**
Special Requirements for Adolescent EMRs

- Confidentiality issues for adolescents at every step
  - Making appointments & related communications
  - Information required by meaningful use
  - Medications, problem lists, behaviors
  - Prescriptions
  - Lab results
  - Posting of bills and AVS

Special Requirements for Electronic Medical Records in Adolescent Medicine (Anoshiravani et al, JAH, 2012)

A. English, Center for Adolescent Health & the Law
EMR Vendor Action Items

- Adolescent privacy default settings
- Granular customizable privacy controls
- Point-of-care privacy controls for physicians
- Clear on-screen labeling of confidential data
- Built-in adolescent privacy-related decision support tools
- Robust patient-adjustable proxy access for portals
- AVS, bill, & post-visit survey suppression capability
- Joint development of adolescent privacy standards with ONC

Special Requirements for Electronic Medical Records in Adolescent Medicine
(Anoshiravani et al, JAH, 2012)

A. English, Center for Adolescent Health & the Law
One Adolescent Patient Portal

- Adolescent patient portal
  - One primary care clinic at academic health center
  - Specifically adapted for adolescent patient needs

- Research study 2012-2015

- Adolescent patient portal models
  - Confidentiality (ages 12-17) – with parent & adolescent agreement
  - Family engagement
  - Parent orientation (ages 0-11)

Meaningful Use of a Confidential Adolescent Patient Portal (Thompson et al, JAH, 2016)

A. English, Center for Adolescent Health & the Law
Adolescent Portal Research Results

- **Users**
  - 963 pediatric portal users / 100% parent as proxy
  - 937 adolescent portal users / 5.9 % parent as proxy

- **Adolescent portal**
  - “Click through” rate varied
    - 37% patient initiated messages
    - 67% lab tests
    - 78% medications
  - Provider messages back to patient
    - 89% of messages received

Meaningful Use of a Confidential Adolescent Patient Portal (Thompson et al, JAH, 2016)

A. English, Center for Adolescent Health & the Law
Questions to Ask | Strategies to Consider

**Questions**
- Have any specific protections been implemented to protect adolescent confidentiality?
- Has the vendor been responsive?
- Is there in-house capacity to customize?

**Strategies**
- Advocate with sponsoring organization to customize EMR, EHR, &/or portal
- Form/participate in internal task force to develop or improve adolescent specific standards

A. English, Center for Adolescent Health & the Law
Resources

Thank you!

- Abigail English, JD
  - english@cahl.org

- Center for Adolescent Health & the Law
  - www.cahl.org