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Privacy, Medical Records, and Adolescent Health

The widespread adoption of electronic medical records (EMRs) has major implications for the availability of confidential services, privacy, and the optimal delivery of health care services to adolescents. While adolescents are generally thought of as healthy, preventable causes of morbidity and mortality keep adolescents and young adults from achieving their potential of becoming productive, healthy adults. Some of these health problems and risk factors include substance use, depression and other mental health disorders, chronic illness, unintended pregnancies, sexually transmitted diseases (STIs), HIV, obesity, asthma, and intentional and unintentional injuries. Models that integrate services to keep adolescents healthy rather than being episodic and fragmented offer new paradigms for changing our health care delivery systems. Adolescents deserve comprehensive, developmentally appropriate, adolescent-friendly health care that recognizes and fosters positive family relationships as well as independence and encourages active participation in their own health promotion and life planning. Adolescents need access to high quality preventive and subspecialty care, but the availability of confidential health services is essential for adolescents to actually use and trust in the system and obtain treatment to address health problems.

The transition from paper to electronic medical records has further complicated the potential privacy concerns of adolescents and others. While paper records made documentation of and separation of records of such services easier than EMRs, a number of problems occurred even in the pre-EMR days that breached privacy including billing of confidential visits that disclosed the reason for the visit, confidential information embedded within comprehensive care visits that was inadvertently copied, and varying state laws about age of consent, status of mature minors and emancipated minors, and categories of diagnosis and treatment covered. However, in both paper and electronic records, the asthma action plans and immunization history may be interspersed or embedded among visits for contraceptive care, pregnancy diagnosis, or STI treatment. The medication list may contain oral contraceptives and antibiotics for Chlamydia infection in addition to asthma controller medications. These issues have been compounded by the individual institutional EMRs which can easily be copied without regard to the content of the document and privacy could be lost with unfiltered access of parents to all clinical encounters. Easy access to clinical notes as opposed to brief summaries in electronic format poses additional challenges. Although the majority of encounters may have non-confidential medical information, neither parent nor adolescent may have a good concept of confidential services. They may also not have the health literacy skills to be able to interpret the medical language and reviews of systems, etc

found in clinical notes. In a recently presented study, Nordt et al [1] found that HIV positive adolescents and young adults receiving care in our clinics were unaware of confidentiality policies and many expressed discomfort at the level of detail recorded in a mock medical note shown to them as part of the study. Most participants wanted full control of their personally controlled health record (PCHR) and felt they needed more knowledge about what the provider was writing in their note with a discussion at each visit of what elements were confidential. However, they saw the ability to view and comprehend medical information as a way to motivate improved self care. The study reinforced the importance of providers incorporating the concepts of the PCHR, confidentiality, and the usefulness for care of details documented in the medical record during the visit.

The development of the personally controlled health record (PCHR) which pulls in data from multiple sources has increased the complexity of the issues for adolescents. While the previously identified issues of sequestration of parts of the record related to *provider* access is important for adolescent and adult health care, a more pressing need is acknowledging the need for differential access of adolescent patients and their parents/guardians to sensitive and confidential health information. The AAP Council on Clinical Information Technology [2] endorsed Personal Health Records (PHR) and stated “PHRs are owned and controlled by the patient or patient’s parent/guardian” and “Adolescents have the right to exclude parents from their PHRs when law dictates that they may be treated without parental consent... Specific health information such as information about sexually transmitted disease/HIV status... may require special protections.” However, the paper did not indicate the degree of complexity involved in actual implementation of these principles with EMRs or PHRs. Few health systems have truly grappled with developing methodology to translate the principles related to optimal adolescent health care. A review of 6 health care systems [3] found that in 5 systems parents had access to their child’s health record only to age 13 years (12 years in one system) and that adolescents either had no access until age 18 or in one case access to medications, allergies, and clinic visit summaries. Only one health system provided access by both parents and adolescent after age 14 to parts of the record including medication list, allergies and clinic visit summaries. Diagnoses or treatments that would be part of confidential visits were not specifically mentioned.

Children’s Hospital Boston has been an early pioneer in grappling with some of these issues as they develop the elements of both a patient portal for CHB records but also a PCHR (Indivo) [4]. In 2007, a group of adolescent medicine, IT, and legal faculty began to examine the issues related to design and implementation of this modality and to address issues of special interest to adolescent health including reproductive health services, STIs, psychiatric services, substance abuse, and genetic testing [5]. Although the easiest solution would be to give access to both adolescents and parents, clearly protected private information would be released to both parents and adolescents jeopardizing care and making it less likely that teens would receive needed services. While the individual institution can make sure that their policies allow release of records with these issues in mind, building a useful PCHR system requires the ability to be to gather data from multiple institutions in states with varying laws. We thus considered

options including: a central authority that oversees all records; each institution develops its own mechanism and releases records with that in mind (high burden on individual providers and institutions to protect privacy of patients); establishment of categorical policies for institutional subscriptions that replicate the access policies that adolescent patients and families sign. Institutions would then need to be able to identify and label protected health information with checkbox; tag information by being attached to parent, adolescent, or both; and/or release in accordance with uniform access policies.

In addition, the PCHR needs to have a system in which authentication takes place with signatures/agreements at age 13 with a change in access policies at age 18. Even if the parent does not provide consent to PCHR access when the patient becomes 13, the patient would still be able to create an account and access certain sensitive medical information. We developed tables of access by age, information and sensitive test results as a way to define the standards for developing this new modality [5].

Tables 1-3 (from reference 5)

Table 1 ■ Access Control Policies for a PCHR Based on Patient's Age

Patient's Age	Parent/Guardian Access	Patient Access	Registration
< 13 yrs	All medical information	None	Registration/Consent of parents; Screening by PCHR administrator.
13-<18 yrs	Most information, except sensitive/confidential patient data*	Most information except sensitive parent and other 3 rd party data*	Re-registration at age 13; consent by parent for access of information by teen; agreement by teen; confidentiality and sensitive test rules in place.
≥ 18 yrs	None, unless access rights to others granted by patient, law or court order	All medical information	Re-registration by adolescent to be sole owner of PCHR.

PCHR = personally controlled health records.

*Examples of sensitive data are shown in Table 3.

Table 2 ■ Pediatric PCHR Access Controls

	Age		
	<13 Years	13-<18 Years#	≥ 18 Years*
Indivo/Portal General Access	C- P+	C+ P+	C+
Problem List	C- P+	C+ P+ except	C+
Sensitive Dx that parent cannot access†		C+ P-	
Sensitive Dx that patient cannot access‡		C- P+	
Procedure List	C- P+	C+ P+ except	C+
Sensitive Proc. that parent cannot access†		C+ P-	
Medication	C- P+	C+ P+ except	C+
Sensitive Meds that parent cannot access†		C+ P-	
Allergies	C- P+	C+ P+	C+
Immunizations	C- P+	C+ P+	C+
Clinic Notes	C- P+	C+ P+ except	C+
Sensitive info that parent cannot access†		C+ P-	
Sensitive info that patient cannot access‡		C- P+	
Laboratory Results	C- P+	C+ P+ except	C+
Sensitive tests that parent cannot access†		C+ P-	
Sensitive tests that child cannot access‡		C- P+	
Genetics		C- P+	
Radiology Results	C- P+	C+ P+ except	C+
Sensitive tests that parent cannot access†		C+ P-	
Sensitive tests that patient cannot access‡		C- P+	
Pathology Results	C- P+	C+ P+ except	C+
Sensitive result that parent cannot access†		C+ P-	
Sensitive result that patient cannot access‡		C- P+	

C = Child/Adolescent Patient; P = Parent/Guardian; PCHR = personally controlled health record; + = access allowed; - = access not allowed.

*Access allowed to parent/guardian only if patient allows or if parent has been legally declared medical guardian for adolescents ≥18. It is also recognized that age of consent is higher in several states.

†Without agreement of patient.

‡Without agreement of parent.

#General access to medical information granted to minor adolescent patient provided the parent/guardian consents. Access to patient's sensitive information granted regardless of parental consent.

Table 3 ■ Examples of Sensitive Results Requiring Special Consideration

Laboratory Results
Infectious Disease
Chlamydia Trachomatis
Neisseria Gonorrhoeae
Hepatitis B Virus
Hepatitis C Virus
HIV ELISA/Western Blot
HIV Viral Loads
HIV Phenotype
CD4 count
Human Papilloma Virus
Herpes Simplex Virus
Rapid Plasma Reagin
Trichomonas
Toxicology
Amphetamine
Barbiturates
Benzodiazepine
Cannabinoid
Cocaine
Ethyl alcohol
Methamphetamine
Opiate
Phencyclidine
Genetics
All genetic test results
Reproductive Health
Pregnancy test (HCG)
Alpha-Fetoprotein
Immunology
Human Leukocyte Antigen typing
Radiology Results
Pelvic Ultrasound related to Pregnancy
Pathology Results
Products of conception
Pap Test

Questions from the Panel:

1. Are there certain types of information in children and adolescents' health records that are particularly sensitive?

For adolescents, particularly sensitive areas are sexual activity, contraception, pregnancy, STIs, HIV/AIDS, substance abuse, gender identity, psychiatric treatment, social worker/client privilege, genetic testing. See Tables 2 and 3.

2. Should everything in the record receive the same level of protection?

Medical records are private but for adolescents there are multiple levels of privacy needed so that information needs to be segregated for parents and adolescents, but also sensitive issues such as psychotherapy may need similar access controls as have been defined for adults.

3. Are there particular treatment considerations for the use and disclosure of information from the record? For example, what information should be made available from an adolescent's reproductive health record or mental health record in the event that the patient comes for treatment regarding another issue?

Yes, for most adolescent issues, the record should be available to the treating provider. If there are confidential services not relevant to the problem, there needs to be segregation of data. Most treating providers benefit from access to the total record. If there is a specific purpose such as emergency treatment for a comatose patient, then there needs to be a mechanism such as "breaking the glass" by the medical provider directly involved in care to obtain the full record. The issues of access by parents and adolescents are described above.

4. What are appropriate sequestration and access policies related the use and disclosure of information for non-treatment related purposes?

See above for our formulation of adolescent patient and family access to health information in the PCHR. For providers, if one is presuming the need to treat the whole patients versus an isolated minor complaint would yield similar sequestration but variable access. For the provider accessing the record, these methodology should be non-burdensome in both documentation and availability of information and might be targeted mostly at psychiatric treatment notes (as opposed to a clinical summary of the diagnosis and medications)

5. What would implementing such controls mean for patient care as a whole?

It would be very important to balance confidentiality with clinical need to know. The process should be non-burdensome for both documentation and access.

6. What limits, if any, would you recommend on the patient's or parent's control?

See above.

7. What entities are now implementing these kinds of controls, and what kinds of policies or procedures have they adopted? Are there particular problems these entities have encountered?

Children's Hospital Boston is in the midst of developing an innovative PCHR which will integrate issues relevant to adolescent care. These issues seem to have been ignored by other PCHRs to date. The most challenging will be the clinic notes that have embedded material. Test results and dedicated family planning visits will be easier to segregate. However, with increasing efforts to develop robust PCHRs, it will be critical to have uniform standards of segregation to allow access for parents and adolescents. Without a robust system with segregation, the only two options are 1) no one has access when the patient is 13-17; or 2) the parent has access to immunizations, asthma plans, and allergies, but the remainder of the PCHR is under control of the adolescent. A third (and unacceptable) option is to give access only to parents which would breach confidentiality and privacy and significantly undermine adolescent health care services. Other than Indivo (in the near future), PCHRs at this time do not allow for the differential access policies and most patient portals allow access to a single user only, which has forced clinics to either terminate parental access and give access to the adolescent or terminate access altogether once a patient turns a certain age (anywhere from 10-15 yrs, depending on the clinic/institution). A few vendors allow or will soon allow proxy access, but this seems to be geared to allowing full, and not differential, access to another individual. These systems were clearly not developed with adolescents in mind.

Our CHB team continues to endorse the option that would create the differential access and categorical protection in our paper: access is granted based on age-based rules on the PCHR side (<13yrs, 13-17yrs, >17yrs), and patient data is categorically tagged on the institutional side based on established/standardized confidentiality/privacy rules. This would require institutions to appropriately categorize/tag the data (and agree to the categories even if individual providers may disagree) and PCHR vendors to agree to implement differential age-based access rules. The approach and implementation are being planned in a stage-wise process over time and will require funding and commitment.

8. How is parental access to adolescents' records handled?

Our medical records department reviews the record, redacts text that is confidential, and provides notice to the adolescent that record is being shared and to the parent that it is incomplete. This is labor intensive and a new system will be much preferable.

9. How is access to records by non-custodial parents handled?

Generally same access as other parent unless there are issues related to abuse, neglect etc.

10. Would a policy permitting sequestration of some or all of the information in children and adolescents' health records have other important considerations?

Considerations include emergencies, duty to warn or protect, statutory mandates to disclose such as child abuse. The clinician treating the patient needs the option to be able to "break the glass" if the adolescent is at significant risk. In these cases, the physician would likely also share the relevant, medical information with the family in order to optimize care. The most important segregation is for PCHR, not for provider access to records.

References

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