NCVHS Committee on Privacy, Confidentiality, and Security
AAP Response to Committee Questions

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

In general, information around custody, adoption, abuse/neglect, sexuality/reproductive health and psychiatric/behavioral/substance abuse concerns.

HIPAA Privacy Rule and its regulations defer to individual state laws and other applicable laws on the issue of adolescent privacy; thus *state law governs disclosures* to parents but also *privacy protections* afforded to adolescents.

Problems may arise where *state law is silent or unclear*, thus any regulation should preserve state law and the professional practice by *permitting a health care provider to use discretion* to provide or deny a parent access to such records as long as that decision is consistent with state or other law.

HIPAA also allows the minor to exercise control over protected health information when the parent had agreed to the minor obtaining confidential treatment; also if the provider is concerned about abuse or harm to the child, HIPAA has indicated the provider may decide to "not treat a parent as a personal representative" of the minor or in the inverse situation, if the provider feels the minor poses a threat to themselves or others, may disclose "protected" information to the parent/guardian.

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

The entire Medical Record does not receive the same level of protection. Certainly the record of immunizations, history of allergies would need to be accessible. Perhaps the first initiative should be to include details of a history that should be universally available.

As pointed out by others, protection of privacy of information for sensitive health concerns are not limited to adolescent who are minors; older teens (≥18 years) as well as adults both young and old have concerns about privacy of sensitive health concerns including but not limited to sexually transmitted infections, pregnancy, mental health, victims of violence, and substance abuse.

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 in the event that the patient comes for treatment regarding another issue?

EHR systems should support privacy policies that vary by age and according to presenting problem and diagnosis and BE FLEXIBLE enough to handle the policies of individual practices consistent with applicable law in the jurisdiction. Confidentiality of visits for reproductive

health care, diagnosis, and treatment of sexually transmitted infections, as well as substance abuse and certain mental health issues must reflect the laws of each state's health and safety code for adolescent confidentiality.

Also the system would need to allow the referring provider the ability to control information that is communicated to other subspecialists, particularly if protected information may be inadvertently shared because privacy issues are not routinely considered (ex: referral to sports medicine of teen confidentially on contraceptives).

If it is a personal health record, the PHR should have the functionality to allow the adolescent to control access. For an institution or practice based record, the systems/privileges of that entity would control access and monitor appropriate use. As an example, the software should be configurable to "hide" psychiatric notes based on user level access or require a second level active access control when a provider looks at certain types of information.

3. Should mental health or reproductive health records go back to the primary care provider? If so, does this provide parental access to records that might not be shared with parents by the original treating provider?

Again it would depend on age. A six year old in psychiatric care should have the notes go back to the provider, but a 17 year old should not unless requested by the teen. Instead the provider may be sent a summary with less detail or have controlled access in another manner. If such records go back to the provider, there must be protection of such records until cleared by the teen as information that may be or may not be shared with parent/guardian.

An example where some teens may not elect to share even with primary care provider (PCP) is teen's obtaining contraception in outside facility as school based clinic, title X family planning program. *The reason is that in current environment, the PCP cannot provide/guarantee confidential care for sensitive issues.*

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

The HIPAA rules are pretty specific and the same criteria should be applied as would apply to an adult record (data can be shared for billing, etc)

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

Parents should not have access to records of adolescents that are protected by privacy controls and should not have access to the remainder of the record without the adolescent patient's permission.

6. 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?

Currently Kaiser Permanente in California has a system in which either an entire visit or part of a visit may be kept confidential including as an example screening tests for sexually transmitted infections as well as the results and medications prescribed. Parents can view their adolescent's medical record from Kaiser, whether paper or electronic, but in this situation, all information recorded in the confidential section is manually removed prior to the viewing.

I have also been told that information may be shared among health care providers of Kaiser but that visits and notations made in the Department of Psychiatry/Mental Health and CDRP (Chemical Dependence Recovery Programs) have a "firewall" isolating this information from other health care providers. For example, if a 16 year old patient assigned to a primary care provider is being seen in Psychiatry, the only access provided is the medication list.

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

Minors cannot legally consent to allowing or disqualifying their health information to be included in PHRs, PCRHs, and HIEs because current technologies only allow parents to provide informed consent. Current health information technologies [e.g., Electronic Health Records (EHRs), Personal Health Records (PHRs), Personally Controlled Health Records (PCHRs) and Health Information Exchanges (HIEs)] do not have the technical capacity to maintain the protection of confidential health information that is consistent with laws of their local jurisdiction and with desires of patients and families.

Future EHRs need to be able to provide these privacy protections by granting teens' rights to consent, disqualify health information that is protected.

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

This is very complex issue as even when a child/teen is placed in foster care, the "licensed" foster parent may consent to routine medical and dental treatment either granted by the court or provided by voluntary consent by person with legal custody. Parents may have rights to access of medical records and be involved with health care decisions unless their parental rights have been terminated.   Thus it is assumed that the non custodial parent would have no access without the permission of the custodial parent or the teen patient if able to give consent.

EHRs systems need to manage consent for treatment and information access and need to be able to record and respond to these details. EHR systems need to be able to support the record keeping of difference between guarantor and guardian.

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

EHRs need to be able to support the recording of consent and assent for treatment. As an example, EHRs should be flexible to allow for the emergency treatment of minors in which the parent or legal guardian may be absent (ex: trauma) or and the usual procedures for consent change (ex: teen presents in the ER for evaluation for STI).