CHALLENGES TO MAINTAINING CONFIDENTIALITY IN THE ELECTRONIC HEALTH RECORDS FOR ADOLESCENT PATIENTS

By

Anna Pooranie Nadhan

A Dissertation

Presented by the Department of Medical Informatics and Clinical Epidemiology
and the Oregon Health & Science University School of Medicine
in partial fulfillment of
the requirements for the degree of

Doctor of Master of Science

June 2022

School of Medicine

Oregon Health & Science University

CERTIFICATE OF APPROVAL

This is to certify that the Master's Capstone Project of

A. Nadhan

"Challenges to Maintaining Confidentiality in the Electronic Health Record for Adolescent Patients"

Has been approved

Capstone Advisor
Dr. Paul Gorman

TABLE OF CONTENTS

Acknowledgements

I would like to acknowledge and give my thanks to my capstone OHSU faculty advisor, Dr. Paul Gorman. His guidance through every step of this project was invaluable; to Dr. Sharath Kharidi, my clinical informatics fellowship program director at ChristianaCare for his constant support and encouragement; to Dr. Terri Steinberg for choosing me to be ChristianaCare's first clinical informatics fellow; Dr. David Driban, assistant CMIO of ambulatory medicine at Christiana Care, who guided me through the complex meetings held for the school based wellness project; to Jolanda R Arter-Chance who allowed me to shadow her when gathering current state information; to the ChristianaCare Privacy officers who provided education on optimal patient privacy for consent forms; and to the ChristianaCare Healthcare Information and Management Systems Society (HIMSS) team who kept the team informed of Delaware and federal laws pertaining to adolescent healthcare.

Special thank you to my family and friends, who supported me through my fellowship. I would like to especially thank my husband, Ajith, whose patience, understanding, and encouragement allowed me to successfully complete my master's degree.

Lastly, I would like to thank ChristianaCare and Medecision for funding my clinical informatics fellowship at ChristianaCare and allowing me to earn a master's degree in Biomedical Informatics from OHSU.

Abstract

Since the migration from paper health records to electronic health records (EHR) began, there have been many confidentiality problems which have arisen and been addressed; however, the implementation of adolescent confidentiality in the EHR has yet to be successfully executed. We sought to identify issues and best practices during the conversion of health records from paper to an electronic health record (EHR) in school-based wellness clinics because of an ongoing conversion project in the ChristianaCare, a private not-for-profit regional healthcare system in Delaware. This paper will explore the legal and societal challenges of adolescent medicine, how an EHR may augment these challenges, and the unique obstacles personally encountered during the implementation of an EHR in a school-based wellness clinic serving adolescent patients.

Background

Adolescence is a transition period between childhood and adulthood presenting unique challenges for providing effective healthcare for adolescents and maintaining confidentiality of this care in the electronic health record. When a patient is less than twelve years old, parents assume sole responsibilities for all health-related decisions for the child, and in most states when the patient reaches eighteen years old, they are no longer considered minors and in most cases are able to make all decisions regarding their health. Though there may be state by state variations in the age at which adolescents become solely responsible for making healthcare decisions, typically the time frame between twelve years old and eighteen it becomes less clear which party is responsible for the patient's health. Legally, the patient is still a minor, however, depending on the individual, they may be old enough to have some understanding of their treatment options and the impact of making health-related decisions. In order to provide effective healthcare to an adolescent patient during this time of growth, a strong physician-patient relationship must be built. This relationship depends on mutual respect and trust.

In addition to seeing a primary care provider at an outpatient office, some students in the United States have the option of seeing a healthcare provider at a school-based health center. Most often these centers are on school grounds and aim to increase access to primary care, especially to those children who are underserved, at risk, and stressed.[1] Usually health information is not shared with the teachers or other staff working at the school, and the school-based health center works separately from the school's health clinic. Restricting health information from educators is one layer of confidentiality given to the students. School-based health clinics also offer children the opportunity to build a relationship with their healthcare providers. The advantage of this relationship has been highlighted among adolescent boys, who sought care at a school-based health center more frequently than from a traditional healthcare office.[2] A few reasons cited for this increased use in services from a school-based health center include convenience and an

increased sense of confidentiality. As more and more school-based health centers move from paper to electronic records, maintaining the confidentiality their patients value will need to be carefully considered and implemented thoughtfully. We sought to identify issues and best practices during the conversion of health records from paper to an electronic health record (EHR) in school-based wellness clinics because of an ongoing conversion project in the ChristianaCare, a private not-for-profit regional healthcare system in Delaware.

This paper will explore the legal and societal challenges of adolescent medicine, how an EHR may augment these challenges, and the unique obstacles encountered during the implementation of an EHR in a school-based wellness clinic serving adolescent patients.

Methods and Literature

Literature was gathered from academic databases. These databases were Google Scholar, PubMed, and Embase. Key words used in searches included "Electronic Medical Record", "EMR", "Electronic Health Record", "EHR", "School-based health center", "Adolescent medicine and Confidentiality", "Patient portals and adolescents." Most of the literature found consisted of case studies, editorial articles, and textbooks on EHR implementation and government websites regarding federal and state laws. There was one survey study looking at patient and parent attitudes towards patient portals and one survey study evaluating CMIO thoughts regarding adolescent privacy policies.

Challenges of Adolescent Medicine

The legal foundation of confidentiality in healthcare has been established by the Health Insurance Portability and Accountability Act (HIPAA).[3] HIPAA states parents can access their child's records as long as they are under the age of 18, except in three specific cases: a minor's care is directed by the court, the parent agrees that the clinician and minor have a confidential relationship, and when a parent's consent is not required for treatment as dictated by state or other applicable laws. Another federal law to consider in school-based well centers is the Family

Education and Privacy Act (FERPA); the law allows parents to access the minor's educational records, except in instances where health records are kept as part of a school-based health center separate from their school records. Though HIPAA and FERPA have established a foundation for providing adolescents with confidential healthcare, they do not address the challenges of variable state laws, lack of provider understanding of confidentiality laws, and electronic health records.

Minor consent laws vary from state to state and largely depend on the status of the minor and the type of healthcare services sought by the minor. The status of the minor include mature minors and emancipated minors and are defined by state laws. States also determine which services should be confidential, such as those involving sexual health, reproductive services, mental health, and emergency care. The age of consent also differs from state to state. Despite the variability in confidentiality laws, all states allow breach of confidentiality when the patient is a danger to themselves or others. Additionally, all healthcare providers have a federal obligation to report suspected abuse of any form and neglect to their state per the Federal Child Abuse Prevention and Treatment Act (CAPTA).

In addition to navigating the variability of state laws, healthcare providers also must practice using their own code of ethics and judgement, adding another layer of difficulty when maintaining adolescent confidentiality. Additionally, providers are not always provided adequate and routine training when it comes to maintaining adolescent confidentiality. Providers often learn federal laws surrounding confidentiality but may not be required to learn about local laws and recommended practices.

Variability in laws regarding minors and their rights in medical decision making are complicated even further by an inability to adequately define the maturity and competence of minors. It is well known as children grow older they become more independent than their parents, but what is less clear is when a minor is mature and competent enough to make medical decisions. During adolescence, the minor may have the ability to understand the situation they are in, but often lack

the judgement and experience to understand the consequences of their decisions.[4] They may also perceive short-term outcomes more valuable and ignore long-term consequences. It is important to gauge the maturity of a minor by assessing their understanding of the purpose and risks of their treatments, availability of alternative treatments, and consequences and benefits of their decision.

Maintaining Confidentiality in the Electronic Health Record

The Health Information Technology for Economic and Clinical Health (HITECH) Act encouraged the use of health information technology as a way to advance healthcare.[5] Due to the passing of the HITECH Act, many healthcare organizations have shifted to using electronic medical records and are still in the process of converting their entire organization from paper charts to electronic. The conversion to electronic records promotes sharing of information among a patient's entire healthcare team, facilitates coordination of care between healthcare facilities, and increases communication of health-related information to patients.[6 - 8] In a school-based health clinic, the conversion of records from paper to electronic would help providers share a patient's records with another clinic or facility in the area. This would allow the patient's record to be complete and comprehensive as they move between the school-based health record, hospitals, and traditional outpatient clinics. Ultimately this results in safer, higher quality, cost effective care. Although there are many barriers to implementing electronic records, the perceived benefits outweigh the burden of implementation. [9 -12] Additionally, there are no clear standards or regulations around how to effectively use EHR and patient portal privacy features to provide the privacy adolescents require. [13]

Electronic health records (EHR) and patient portals are two common applications used to create, read, and transmit a patient's health information. Despite their advantages, EHRs and patient portals add yet another layer of complexity to maintaining adolescent confidentiality. Providers worry about the ability to document an adolescent visit effectively, while maintaining respect for an adolescent's right to privacy.[14] With the recent passing of the Open Notes law requiring most

notes to be freely available to patients, healthcare organizations have struggled to maintain an adolescent patient's right to confidentiality while complying with the law.[15] In order to reconcile this issue, steps should be taken by organizations implementing EHRs and patient portals to ensure they understand the privacy features and how to optimize these features to balance the adolescent's right to confidentiality with the parent's right to their child's healthcare information.[4, 16]

Paper charts allowed information to be confidential by having a separate page or section for sensitive parts of the healthcare encounter. Additionally, some services would be provided for free to avoid insurance claims and certain labs would only be sent to the ordering provider. Now, with electronic health records and portals, information is more accessible to the patient. This accessibility benefits the patient but comes at the cost of decreased discretion.[17, 18] The patient's other providers who have access to the patient's chart can also see this information, even though the patient did not specifically disclose this information to those providers. For adolescents, it may be helpful if their healthcare providers have access to sensitive health information such as sexual transmitted infections or contraceptive methods, however the electronic health record doesn't clearly identify if this information has been shared with the adolescent's parent. In order to protect the adolescent's right to privacy and disclosure of this sensitive information, it is imperative for the healthcare organization to identify six key features of an EHR (Table 1). [17, 19]

Table 1. Key features in an EHR to protect adolescent confidentiality

1. Functionality to mark as 'confidential' notes, portions of notes, labs, medications, diagnoses, and correspondence
2. Functionality to suppress 'confidential' items from the After Visit Summary that is given to the patient or sent to the health portal
3. The ability to exclude 'confidential' items from medical records release to parents and caregivers without the adolescent's consent
4. Role-based access to patient records based on professional role in the healthcare setting (e.g., a physician may be able to see all records, whereas scheduling staff can only see demographics and insurance information)
5. The ability to put alerts on specific patient records (e.g., those who are dependents of employees that have EHR access)

6. Functionality to allow for billing of services to different payors (e.g., well child care billed to primary insurance, family planning services from the same visit billed through Title X)

The patient portal is another source of potential inappropriate disclosure of sensitive health information and even many providers have concerns about the confidentiality of a patient portal for adolescents.[20] Depending on the institution, adolescents may or may not have access to their own health portals. In addition, parents may have limited access to their adolescent's information through the portal. When setting up a patient portal for adolescent patients, it is important to establish three key features of the portal (Table 2).[17]

Table 2: Key features in an electronic patient portal to protect adolescent confidentiality

1. The type of access that is available for the patient vs. the parent (a) Single-access type, meaning that the parent and/or the adolescent see the same information (b) Patient and proxy access, allowing differentiation between what the patient can see (e.g., confidential lab tests) and what the designated proxy can see (e.g., immunizations and bill payment)
2. The ability to suppress 'confidential' items from portal view or from proxy view
3. Functionality for secure confidential messaging between the patient and the healthcare team.

In addition to the technical aspects to maintaining adolescent confidentiality in an EHR and patient portal, it is important to implement best practices by engaging and educating key stakeholders. Two of the most important stakeholders to engage are parents and adolescent patients. Though parents and patients may not have a strong opinion about the EHR because they are not end users, the patient portal is something with which they interact directly. A 2008 study evaluated adolescent patient and parental attitudes towards the patient portal and found mixed attitude towards the use of a portal.[21] Both parents and adolescents felt the portal would improve access to care, facilitate communication with providers, and be useful for scheduling visits. However, despite the potential benefits, parents were worried they wouldn't be informed about their child's major health issues, while adolescents were concerned the information exchanged on the portal would not truly be kept confidential. What was clear from the study was the need for

primary care providers to explain the benefit of adolescent portal access for adolescents, tools of the portal, types of portal access available. In addition to the parents and patients, the healthcare team uploading information and interacting with the EHR and portal is another important stakeholder.[17] This team includes front desk staff, primary care providers, clinical staff, and administrators. Involving these key stakeholders in the design, implementation, and maintenance of EHR components and patient portals will ensure the most effective use of technology.

Unique Consent Challenges in the School-based Wellness Setting

ChristianaCare has implemented a unique school-based wellness program to make providing care to adolescents more convenient. The program builds clinics on high school campuses throughout Delaware and employs ChristianaCare employees to run the clinics. Parents who consent to have their child seen at the wellness center agree to have their child pulled from class during the school day to receive healthcare services from the clinic. When implementing an electronic health record in this setting, we found the difficulties mentioned above with maintaining confidentiality, but additional challenges came in the from school district restrictions, consent forms, and Delaware minor consent laws.

The school-based wellness centers associated with ChristianaCare operate in several different school districts in the state of Delaware. Though previous studies have shown key stakeholders believe reproductive health services provided at a school-based wellness clinic have a positive impact on adolescents, each district has the authority to approve certain sensitive services such as provision of contraception and testing for sexually transmitted infections.[22] When the decision was made to convert the well centers to an electronic health record, it was imperative to create a consent form with these restrictions in mind.

Another obstacle faced when planning the conversion from paper charts to the EHR was documenting the adolescent consent for services not requiring parental consent. Currently, there has not been agreed upon process for documenting a separate approved consent form and is an issue the organization is actively working on to resolve.

Lastly, the organization is trying to establish a patient portal allowing adolescents exclusive access to sensitive notes, educational materials, lab results, and communication with their provider. This has proven difficult due to federal laws around child online protection privacy conflicting with the accepted age at which minors can consent to certain services without parental oversight. According to Delaware law, minors over the age of 12 have the right to consent to reproductive health services without their parents' knowledge.[23] These services include sexually transmitted infection lab testing which may require private communication with the adolescent patient regarding results and further treatment. However, per the Federal Trade Commission's Children's Online Privacy Protection Rule (COPPA), personal information, including online contact information such as an email, should not be collected from any minor below the age of 13.[24] This law is in direct conflict with the Delaware age of consent, and prevents any 12-year-old adolescent patient from confidentially receiving information regarding reproductive health services via a patient portal. A solution for this discrepancy has not been agreed upon by the organization, but likely the policy will conform to the COPPA law and make a confidential adolescent portal accessible to patients 13 years and older. The same age will be used for any communication done via text message or telephone.

Conclusion

After going through the literature review and starting the conversion process, we have three key recommendations to navigating the complicated intersection of adolescent medicine and electronic medical records, local and federal laws, privacy features of the EHR compared to patient and parent expectations, and patient and parent rights. The first recommendation is to

thoroughly research the local state laws as well as federal laws pertaining to adolescent medicine, and communication with adolescents. Regular meetings with the organization's legal department will ensure compliance with state and federal laws. The second is to understand the EHR's privacy settings and capabilities. Once the options are understood, it is essential to survey patients and parents to understand their expectations of confidentiality in the EHR. Matching expectations to the reality of EHR confidentiality will help adolescents continue to feel comfortable using the school-based health center for sensitive health needs. Lastly, the electronic record and patient portal settings should reflect both parental and adolescent rights, a task which has been difficult to achieve. One recommendation to accomplish the goal of respecting patient and parental rights is transparency. Explaining the laws, importance of adolescents taking a leading role in their healthcare, and the electronic capabilities will help parent and patients better understand the organization's confidentiality rules. The conversion of medical records from paper to electronic has proven providing quality care to adolescent patients faces many legal, societal, and technologic difficulties. These difficulties should be addressed with research, and increased regulations and guidelines in order to give adolescents the care they deserve and set them up for success once they gain the legal right to make healthcare decisions for themselves.

References

1. Kjolhede C, Lee AC, Duncan De Pinto C, O'Leary SC, Baum M, Savio Beers N, Moran Bode S, Gibson EJ, Gorski P, Jacob V, Larkin M. School-based health centers and pediatric practice. Pediatrics. 2021 Oct 1;148(4).
2. Juszczak L, Ammerman A. Reaching adolescent males through school-based health centers. Journal of Adolescent Health. 2011 Jun 1;48(6):538-9.
3. Pathak PR, Chou A. Confidential care for adolescents in the US Health Care System. Journal of patient-centered research and reviews. 2019;6(1):46.

4. Hickey K. Minors' rights in medical decision making. JONA'S healthcare law, ethics and regulation. 2007 Jul 1;9(3):100-4.
5. Interoperability [Internet]. HealthIT.gov. 2021 [cited 2022Apr24]. Available from: https://www.healthit.gov/topic/interoperability
6. Menachemi N, Collum TH. Benefits and drawbacks of electronic health record systems. Risk management and healthcare policy. 2011;4:47.
7. Aguirre RR, Suarez O, Fuentes M, Sanchez-Gonzalez MA. Electronic health record implementation: a review of resources and tools. Cureus. 2019 Sep 13;11(9).
8. Nguyen L, Bellucci E, Nguyen LT. Electronic health records implementation: an evaluation of information system impact and contingency factors. International journal of medical informatics. 2014 Nov 1;83(11):779-96.
9. Kruse CS, Kothman K, Anerobi K, Abanaka L. Adoption factors of the electronic health record: a systematic review. JMIR medical informatics. 2016 Jun 1;4(2):e5525.
10. Kruse CS, Kristof C, Jones B, Mitchell E, Martinez A. Barriers to electronic health record adoption: a systematic literature review. Journal of medical systems. 2016 Dec;40(12):1-7.
11. Tsai CH, Eghdam A, Davoody N, Wright G, Flowerday S, Koch S. Effects of electronic health record implementation and barriers to adoption and use: a scoping review and qualitative analysis of the content. Life. 2020 Dec;10(12):327.
12. Entzeridou E, Markopoulou E, Mollaki V. Public and physician's expectations and ethical concerns about electronic health record: Benefits outweigh risks except for information security. International journal of medical informatics. 2018 Feb 1;110:98-107.
13. Wilcox L, Sharko M, Hong M, Hollberg J, Ancker JS. The need for guidance and consistency in adolescent privacy policies: a survey of CMIOs. InAMIA Annual Symposium Proceedings 2018 (Vol. 2018, p. 1084). American Medical Informatics Association.
14. Stablein T, Loud KJ, DiCapua C, Anthony DL. The catch to confidentiality: the use of electronic health records in adolescent health care. Journal of Adolescent Health. 2018 May 1;62(5):577-82.

15. Federal Rules Mandating Open Notes [Internet]. [cited 2022 Apr 24]. Available from: https://www.opennotes.org/onc-federal-rule/
16. Bayer R, Santelli J, Klitzman R. New challenges for electronic health records: confidentiality and access to sensitive health information about parents and adolescents. Jama. 2015 Jan 6;313(1):29-30.
17. Williams RL, Taylor JF. Four steps to preserving adolescent confidentiality in an electronic health environment. Current Opinion in Obstetrics and Gynecology. 2016 Oct 1;28(5):393-8.
18. Zandieh SO, Yoon-Flannery K, Kuperman GJ, Langsam DJ, Hyman D, Kaushal R. Challenges to EHR implementation in electronic-versus paper-based office practices. Journal of general internal medicine. 2008 Jun;23(6):755-61.
19. Anoshiravani A, Gaskin GL, Groshek MR, Kuelbs C, Longhurst CA. Special requirements for electronic medical records in adolescent medicine. Journal of adolescent health. 2012 Nov 1;51(5):409-14.
20. Goldstein RL, Anoshiravani A, Svetaz MV, Carlson JL. Providers' perspectives on adolescent confidentiality and the electronic health record: A state of transition. Journal of Adolescent Health. 2020 Mar 1;66(3):296-300.
21. Bergman DA, Brown NL, Wilson S. Teen use of a patient portal: a qualitative study of parent and teen attitudes. Perspectives in Health Information Management/AHIMA, American Health Information Management Association. 2008;5.
22. Herrman JW. Stakeholder perceptions of the provision of reproductive health services by school-based health centers as they may inform public policy. Policy, Politics, & Nursing Practice. 2015 Feb;16(1-2):51-62.
23. Delaware Code Online [Internet]. [cited 2022 Apr 24]. Available from: https://delcode.delaware.gov/title13/c007/sc01/index.html
24. 16 CFR Part 312 -- Children's Online Privacy Protection Rule [Internet]. [cited 2022 Apr 24]. Available from: https://www.ecfr.gov/current/title-16/chapter-I/subchapter-C/part-312