



Position paper

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

 The Society for Adolescent Health and Medicine

Executive Summary

Adolescents stand to benefit greatly from improved electronic access to reliable health information and health care. Use of electronic health records (EHRs) can potentially improve health care accessibility, effectiveness, and safety but can create challenges for the ongoing protection of patient confidentiality and privacy. Protection of adolescent confidentiality as dictated by applicable laws is a responsibility shared by EHR vendors, hospital and clinic administrators, clinicians, patients, and families.

Based on a systematic review of the literature and consultation with thought leaders, the Society for Adolescent Health and Medicine adopts the following positions:

- The design, implementation, and use of EHRs need to take into account the special needs of adolescents for access to health information and the vigorous protection of confidentiality.
- EHR vendors need to ensure development of systems that meet regulatory requirements and address the privacy needs of all patients, including adolescents, by building robust, flexible, granular privacy settings into all aspects of their products.
- Health care systems implementing EHRs must train their employees in techniques to protect adolescents' confidential information, in accordance with national and state/provincial laws, as well as institutional policies.
- Health care providers working with adolescents should advocate for specific adolescent privacy protections in the implementation of EHRs used within their clinics or institutions, as well as communicate their needs to EHR vendors.
- Health care providers should educate adolescents and their families on how to use an EHR, what information can be considered confidential and ways to protect patient and family confidentiality when using or accessing EHRs.

Background

Definitions

For the purpose of this position article, an electronic medical record (EMR) is a digital version of a paper chart, a longitudinal

electronic record of patient visits to one particular office, practice, or health care system that includes information such as demographics, vital signs, problem list, medication list, and allergies. In contrast, an electronic health record (EHR) is a record shared among many health care providers, of which all or part may also be accessed and used by the patient. A type of EHR known as a personal health record (PHR) is "a repository of information from multiple contributors (e.g., patient, family, guardians, physicians, and other health care professionals) regarding the health of an individual." A personally controlled health record is a subset of a PHR and is a system that "enable[s] individuals to aggregate, securely store, and access electronic health information from multiple sites of care, and to share that information with care providers and others" [1]. Many health care providers use the terms EMR, EHR, PHR, and personally controlled health record interchangeably, which suggests that discussions around this topic need to clarify who has access to both input and access health information. A patient portal is an online application that allows a patient and/or a patient's proxy to contact a health care provider and access his or her information in an EHR. A health information exchange (HIE) is "an organization that provides services to enable the electronic sharing of health-related information," such as between hospital systems [2].

Prevalence of electronic health record use

It is difficult to obtain international data about EHR adoption and implementation especially in developing countries. In 2010, the American consulting firm Accenture surveyed health care information companies and estimated the global EHR market at US\$19.7 billion dollars. Of note, they excluded two of the largest potential markets, China and India, from this analysis due to insufficient data. More than two thirds of respondents indicated that government incentives, such as the 2009 American Recovery and Reinvestment Act in the U.S. and the Australian government's \$450 million investment in health information technology, are the biggest drivers of EMR adoption [3]. In 2011, almost 60% of American children's hospitals were using an EMR [4]. In 2012, a Commonwealth Fund study of nearly 8,500 primary care physicians in 10 developed countries including Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway,

Position paper approved by the Society for Adolescent Health and Medicine's Board of Directors, January 2014.

Switzerland, the United Kingdom, and the United States showed EMR adoption rates ranging from 41% in Switzerland to 98% in the Netherlands and Norway. In that survey, 69% of U.S. primary care physicians indicated that they were using an EMR [5]. The development of open-source EHRs such as openMRS promises to extend the potential benefits of medical informatics to developing countries [6].

Benefits of electronic health record use for adolescents

There is a growing literature on the potential benefits of EHR use for children and adolescents. EHR-based clinical decision support systems have been shown to improve care for adolescents with Attention Deficit Hyperactivity Disorder, increase human papillomavirus (HPV) vaccination rates, and reduce unnecessary antibiotic prescribing [7–9]. Prescription fulfillment data accessed electronically may improve care for adolescent depression [10]. EHRs promise to make large amounts of population data available for adolescent health researchers as well as to make secure, individual contact with health practitioners possible, even across great distances. In the United States, 95% of adolescents have access to a computer, but in the developing world, cell phones and smart phones may be more accessible, so mobile app-friendly technologies will be crucial in extending EHR use globally [11,12].

“Meaningful use” regulations in the United States

In the United States, the 2009 American Recovery and Reinvestment Act included the Health Information Technology for Economic and Clinical Health Act, which offers physicians' and health care systems' incentive payments totaling \$27 billion over 10 years through Medicare and Medicaid to promote adoption and “meaningful use” of EHRs. The “meaningful use” regulations outline core objectives required for payment not only comprising basic EMR functions including collecting patient demographics, vital signs, problem lists, medication lists, allergies, and smoking status but also extending to providing written after-visit summaries (AVSs) and discharge summaries to a certain percentage of patients and reporting quality information electronically to the Centers for Medicare and Medicaid Services. There is also a menu list of objectives that include items such as providing patients' access to their health information (i.e., providing a patient portal), generating lists of patients by condition for quality improvement or reduction of disparities, providing a summary of care for purpose of referrals, or reporting certain surveillance data to public health authorities [13]. The incentive payments put hospital and clinical systems and EHR vendors under considerable pressure to conform to requirements to qualify for payments. However, in the case of adolescent minor patients, it is not clear whether the patient, parent, or both should be included when offering patient access to electronic health information. American privacy laws, which give individual states jurisdiction over what information may remain confidential for minors, further complicate this issue.

Adolescent confidentiality

In all 50 U.S. states, testing and treatment for sexually transmitted infections are protected by law as confidential for adolescents in most situations. For an adolescent seeking care for a

sexually transmitted infection, this protected information may be inadvertently disclosed to a parent via an automated appointment reminder (e.g., an appointment the parent did not make), a problem list or medication list that can be imported to other parts of the health record and printed out by others in an AVS, test results that are sent home or visible via a patient portal, billing information (explanation of benefits) mailed to the family, or a patient note visible on a portal where the parent has full access. Electronic documentation of protected health information also carries the risk of data loss ranging from losing an unlocked mobile phone to large-scale inappropriate data use due to comprehensive data sharing agreements on HIE.

The American Academy of Pediatrics has recently described the lack of current EHR standards to protect adolescent health information in their position statement (endorsed by the Society for Adolescent Health and Medicine) [14]. The Society for Adolescent Health and Medicine has previously affirmed that “confidentiality protection is an essential component of adolescent health care” [15]. Privacy is good care and a right for all patients. Adolescents may forgo health care if they do not perceive that health care providers will keep their private information private, especially for reproductive health, mental health, and substance abuse concerns. The desire for increased transparency and electronic access to health information should be counterbalanced by privacy protections to ensure access to appropriate confidential care for all patients, especially vulnerable adolescents.

In certain states and in many other parts of the world, confidentiality extends more widely than Sexually Transmitted Infection (STI) care to potentially include all aspects of clinical care as long as the young person is considered to be a mature minor and is not at major risk of harm [16]. Countries that have ratified the UN Convention on the Rights of the Child must also uphold international law in this regard.

Recommendations

Protecting adolescent confidentiality is a shared responsibility and requires ongoing vigilance.

Recommendations for vendors/electronic health record system requirements

EHR systems have largely been designed to facilitate sharing of information within a clinical system and not usually to restrict the flow of that information. In the current regulatory environment, vendors do not necessarily have an incentive to develop the product settings necessary to provide granular privacy controls unless they perceive that these features will improve their market share. Regulatory requirements for “meaningful use” in the United States need to be re-examined from the perspective of confidentiality for adolescents and inclusive of all ages. Explicit recognition of adolescent privacy protections would encourage vendors to make needed changes.

Adolescent care providers need to help educate vendors and purchasing institutions about existing adolescent confidentiality laws and the desirability of robust privacy settings. Several large EHR vendors have both annual meetings and online forums where such feedback can be provided.

For a detailed description of specific recommendations for protecting adolescent confidentiality in an EHR, we direct readers to the excellent summary provided by Anoshiravani and

colleagues [17]. We summarize and provide additional recommendations here.

1. EHRs should have the functionality to designate problems, medications, visit notes, laboratory and radiology results, genetic testing, and social and family history as confidential, so that these can be easily suppressed from an AVS, discharge summary, or other printed material generated after a visit, as well as shielded from those who should not have access to such information.
2. EHRs should have flexible functionality to provide differential access to information (e.g., via a patient portal) for parents and adolescents, in such a way that is transparent to the adolescent patient. Options include (1) permitting access to nonconfidential information only to both parents and adolescents (information parity); (2) permitting full access only to the 13- to 17-year-old adolescents, with parents able to receive only nonconfidential information—an approach that requires actively blocking access to certain information by the parent and requires vigilance and ongoing effort to maintain, but which in our view is the ideal; and (3) permitting full parental access for unusual or complicated situations (e.g., intellectual disability or cancer), ideally customized by the adolescent; or (4) turning off portal access for all patients aged 13–17 years [1]. Of note, we also believe that parents should also be able to restrict certain family information from the child's record (e.g., family history of Huntington's disease, HIV, consanguinity, or substance abuse).
3. EHRs should employ the same privacy protections for adolescents (and all patients) when transmitting health information through a HIE.
4. EHRs should have functionality to ensure that confidential information is not shared with other unauthorized health care providers using the same system or through HIE.
5. Most importantly, all the above functionalities should be included in special default privacy settings, which could be easily turned on or off in health care venues that require these confidentiality protections. These default settings could then be overridden by providers at the point of care or by patients to modify access to specific information (e.g., patient might allow differential access to a psychologist, school nurse, teacher, or camp counselor). The availability of default, modifiable privacy settings will ultimately benefit all patients in any sort of health care proxy situation.

Recommendations for health care systems

Protection of confidentiality is an ongoing, daily process. Just as health care employees must understand and implement national patient privacy laws (such as the Health Insurance Portability and Accountability Act in the United States), so they must also understand and implement local adolescent confidentiality laws. We recommend that providers well versed in adolescent health care be part of any system-wide IT initiative within a health care system. Devising systems that protect adolescent confidentiality may also improve care for other patient populations who may not want to share all their information with their families—such as geriatric patients with adult children, patients who feel they have a stigmatizing condition such as HIV or a mental health disorder, or patients in intimate partner violence situations. Employees must also be trained in face-to-face interactions (such as appointment scheduling,

billing, and medication reconciliation) with adolescents and their caregivers to avoid disclosure of protected information. In addition, both vendors and health care systems must use caution and plan for foreseeable data losses associated with the use of less secure means of communication, including printed AVSs as well as popular and easy to lose electronic devices such as smart phones and tablet computers.

Recommendations for health care providers

Adolescent health care providers should be champions of confidentiality protections within EHR systems while promoting their effective use and implementation. They must be familiar with national and local laws that define adolescent consent and confidentiality, and they should serve on institutional committees to design and implement EHRs in a way that is sensitive to providing confidential adolescent care. Given that many EHR systems in use do not currently have default privacy settings for adolescents, health care providers need to educate patients and their families about what personal health information is available online. They need to advocate for their patients' protected health information to be selectively suppressed or moved when it is accessed inappropriately, and they need to empower patients and families to do the same. They should look for opportunities to work with vendors to adapt the EHR to adolescents' needs. They also need to educate patients and families about how they can use their own EHRs, including how to access a patient portal and what kind of communication is timely and appropriate. Written orientation to the EHR may be helpful. Adolescent health care providers also need to advocate on their patients' behalf both with state policy makers who may view adolescent privacy protections as a barrier to EHR access for constituents and researchers who may overlook the need for privacy in the interest of access to large amounts of data.

Recommendations for patients and families

In an ideally designed health care system, adolescent patients and families would not need to advocate for safeguards of their own protected health information. Given the inadequate privacy protections presently in use in most EHRs, however, it is a necessity. Widespread EHR use offers the potential to advance care of adolescents and reduce health disparities and problems of health care access. But more research is needed about what adolescents and their families think should be confidential and what should be accessible online. In a survey done prior to widespread EHR use, less than 50% of U.S. adolescents believed that health care providers would keep their private information private [18]. Lack of access to computers or Internet service or adolescents' lack of willingness to use EHRs due to confidentiality concerns has the potential to create or worsen health disparities, especially in resource-limited settings and for more vulnerable adolescents. Health care providers need to advocate to extend access to all patients and to provide alternate methods of communication to those without computer or Internet access or to those with particular confidentiality concerns. More research is needed about adolescents and their families' experiences with EHR use, especially how their perception of the confidentiality of the information affects their decisions to seek care.

Adolescent patients, like all patients, have a right to have their protected health information kept confidential in EHR systems, as dictated by applicable laws. EHRs were designed to facilitate sharing of information, which ideally facilitates coordinated health care. Use of EHRs poses myriad opportunities for inadvertent disclosure of confidential health information, however. EHR vendors, health care systems, health care providers, and families must work together and take proactive steps to protect adolescent patient confidentiality to sustain the trust our patients hold in us. By protecting all patients' right to privacy, we will best be able to harness the power of EHRs to improve the health of individuals and populations.

Acknowledgments

The authors thank Dr. S. Jean Emans for her helpful comments.

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