

Teenager, Parent, and Clinician Perspectives on the Electronic Health Record

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Management of adolescent confidentiality and sensitive services has always posed challenges to medical clinicians. State and federal laws, as well as institutional policies, may dictate what information can or cannot be shared by a clinician with a parent or guardian of an adolescent. Clinicians concerned about diagnosis disclosure via insurance notifications may limit their testing or prescription, refer sensitive services to more specialized reproductive health clinics, or appeal to noninsurance funders to cover sensitive testing and confidential prescriptions. All factors may be burdensome to patients, families, and/or clinicians.

With the advent of electronic health records (EHRs), clinicians face additional challenges for preserving adolescent confidentiality.¹ Clinicians are frequently in the difficult situation of balancing their patient's need for confidentiality with creating an accurate and complete medical record that enhances coordination of care with families and other clinicians.² Current EHR systems are often extremely limited in their ability to ensure confidentiality of items such as medications or problem lists across the many interfaces in which these items could be disclosed (such as after-visit summaries, shared or open notes, problem and medication lists within the portal system).³ Whereas some institutions have a practice of using confidential note types or confidential encounters for sensitive information,

this practice relies on clinicians to consistently document the appropriate information in the appropriate location. Institutions have also used custom-built functionality for excluding specific laboratory values or medications from being shared within the portal, but this is a labor-intensive undertaking that requires constant upkeep for ever-changing diagnostic codes, medication, and laboratory orders. Because of these challenges, and as a way to protect adolescent confidentiality, many institutions have defaulted to portal systems that share limited information with patients and families by blocking access to medications, laboratory values, notes, and/or problem lists.^{4,5} Unfortunately, this has resulted in the limitation of meaningful use of the EHR for these users.⁶

Our institution has been fortunate to have an active Family Advisory Council with whom we have worked closely in development of our adolescent functionality and protocols. It is important to realize that the development of these protocols is often a push and pull between 3 distinct forces: the adolescent patient, the parent or guardian, and the clinician and/or institution. Although these factors are often aligned, each may also have demands or needs that are contrary to those of the other 2 partners. In this article, we aim to give a voice to the different stakeholders involved in and affected by these policies in hopes of better understanding the needs going

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Drs Carlson and Goldstein conceptualized the manuscript, drafted the initial manuscript, and reviewed and revised the manuscript; Mr Buhr and Ms Buhr helped to draft the initial manuscript and reviewed and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

DOI: <https://doi.org/10.1542/peds.2019-0193>

Accepted for publication Oct 7, 2019

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: No external funding.

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

To cite: Carlson JL, Goldstein R, Buhr T, et al. Teenager, Parent, and Clinician Perspectives on the Electronic Health Record. *Pediatrics*. 2020; 145(3):e20190193

forward. The following commentary was provided by adolescent medicine physicians and a parent-adolescent dyad from our Family Advisory Council. Tyler and Nancy Buhr's experiences with the medical system have been in the context of managing Tyler's diagnosis of hemophilia since the time of his birth. Tyler is currently a senior in high school.

HOPES FOR THE PORTAL

Parent

We did not get a patient portal account until my son was 15 years old, so we were already in the teenager "black-out" years ("black-out" referring to the often limited information available to teenagers and their proxies through the portal once a patient turns 12 years of age). I had been told about the limited access I would have as a parent of a teenager, so my expectations were low. I had hoped it would allow for more streamlined communication with his doctors and medical teams and easier access to his health history and would ultimately mean less need for phone calls to his care team (which is not always easy to do).

I was initially confused by the layout of the portal. As a parent with proxy access, was I supposed to have the same functionality as my son? My portal was basically useless, so without using his access (by signing in as him), I would not have used the portal myself.

Teenager

I did not really understand how I would use the patient portal. My mom had been managing my health record until that point. It is hard for kids to manage everything.

Clinician

With the portal, we hoped to improve the flow of information between clinicians and patients and parents. Removing the barriers of "phone-call-tag" and concern of voicemail

security, the portal could provide an easy way to communicate laboratory results or simple instructions. Rather than patients and parents having to navigate a complex phone tree to leave me a message, they could contact me directly via messaging. Ideally, the portal would allow easier navigation of appointments and coordination of care between clinicians, an essential need for our patients with more complex health needs, which could result in a more complete and accurate EHR.

REALITY OF THE PORTAL

Parent

I was shocked at how little I could do with my proxy access account. Paying his bills was about it! It did allow me to message with his care team, which was helpful (for me!). It was also helpful to be able to request refills during this time because my son is on a medication that needs to be called in by his doctor each month (versus auto refill), so this meant less phone calls to his doctor's office. I also used the billing function quite often to view our statements, to make payments, and to communicate with billing when I had questions.

Teenager

I had not had the need to have access to my health information, so I did not use the portal; my mom did. Recently, I have needed to find my immunization history for college, so now I am seeing that having access to this information online will be helpful. I think I will use it more when I am on my own at college.

Clinician

The main benefit we have noted thus far has been the ability to communicate nonsensitive information with patients and families (as long as they are actually signed up to use the portal and make use of it). Because of issues around confidentiality for teenagers, along

with technical limitations that have yet to be sorted out (such as the ability to show medication lists to allow for refill requests), patient and family access to information through the portal has not been fully realized. This sets up a conundrum in that with limited portal functionality, there is little incentive for patients and families to use the portal. If there is low use, there may be less motivation on the part of the clinicians and/or institution to invest the time and resources to address this complicated issue.

PORTAL USE AND CONSIDERATIONS FOR TRANSITION

Parent

Because my son has hemophilia, transition to adult care is a big focus of our education with his team. There are many things my son will have to learn and "own" as he approaches 18 and manages his own care. It would be great to include owning his electronic health record as part of it. For example, Hemophilia Clinic has a transition readiness tool that includes knowledge about the diagnosis, medication management, who to call for what, how to make appointments, and understanding insurance. A section on patient portals should be included. It would also be beneficial for his doctors and nurses to talk to him about the portal, show it to him at visits, explain how they use it, and encourage his usage. The more his team embraces the portal and advocates for its use, the more likely it is that we will too.

Teenager

I do not care if my mom helps manage my care and has access to my records. It could be something that we manage together as I transition and learn to manage everything on my own. I trust my parents and am pretty open with them, so I do not have concerns, but some teenagers will. It should be made really clear to teenagers who is

seeing their account and e-mail messages. There should be a private messaging system even if parents have access. If there is a particular e-mail you do not want parents to see, it would be good to have a “make private” option. I would want my doctor to let me know that our communication can be private and not shared with my parents.

Having the mobile app is convenient and good for teenagers. Text appointment reminders would be good, and making communication available via text is important. Having an area on the app that stores your most used areas (such as refill prescriptions or e-mailing your doctor) would make it quicker to get to where you want to go. For example, I would use a mobile app that allowed me to easily enter data of my bleeding history.

Clinician

The EHR has many key features that could enhance the transition of care, often needed most by our complex patients. Adopting functionality that allows their parents to continue involvement as their child(ren) are transitioning to the adult health care system is essential. However, we need to know that when patients disclose their concerns to us, we will be able to protect them as we are legally bound to do. At the same time, we want to involve parents and guardians in the care of their teenagers as much as possible because we know that is associated with improved health outcomes. Vendor-built systems that allow for more nuanced access to information for both adolescents and proxies is needed. However, it seems as if EHRs are still struggling with how to create and implement such a system. It is messy.

SHARED DECISION-MAKING AND THE EHR

Patients, parents, and clinicians view the portal as an opportunity to

streamline communication between team members and see the EHR as an important advancement for improving care. To maximize this functionality, we encourage institutions to actively sign up teenagers and proxies for an account and encourage clinicians to familiarize themselves with this workflow, which, ultimately, may improve efficiency. Specific training for patients and families on how to use the portal or other EHR-compatible functions will be an essential educational tool to improve familiarity with the technology. Improved clarity on what can and cannot be seen during the adolescent years would be helpful for setting expectations for all team members. Possible sites for disseminating patient-facing materials include waiting rooms, clinic rooms, and inpatient facilities, as well as online.

Although institutions hope that teenagers will be active users of the portals, many teenagers are also interested in an app-based interface to interact with their health care team because they may be more likely to access information through their phone.⁷ Vendors and institutions should consider this technology preference and work to incorporate it into the current EHR functionality if we are hoping to improve teenager engagement and management in their care. In addition, teenagers are wanting reassurance that sensitive information or e-mails will remain confidential, generally a common theme for adolescent care.^{8,9} Clarifying this ability within the portal may be helpful for reassuring teenagers and encouraging portal use.

Although clinicians constantly worry about the worst-case scenario for confidentiality breaches of patients (having confidential information erroneously released that leads to emotional or physical harm to a patient), many teenagers are wanting and appreciative of having their parents involved in their care.

Likewise, parents do not want to hamper the transition efforts of their children but want to remain involved in and supportive of the transition process. Efforts to make the portal and EHR as open and transparent as possible for teenagers and their families will be a valuable step to making the EHR an effective tool for this age group. Although confidentiality practices need to be in place, perhaps they can be more graded than the current state. For example, if confidentiality is deemed to be a concern, filters can be implemented that exclude sensitive appointment types, laboratory values, or medications from being shown. If a patient and clinician do not identify any confidentiality concerns, filters can be electively removed, thus allowing for more information to be shared with parents. This will require thoughtful discussions at the institution and vendor level but is critical for improving functionality.

CONCLUSIONS

The opportunity for the EHR to improve communication, patient safety, and patient engagement is significant.¹⁰ However, without addressing the challenges around adolescent confidentiality in the EHR, we will never be able to fully realize this potential. These are not insurmountable problems; empowering stakeholders (teenagers, families, clinicians, and institutions) to be the drivers of change will be a critical step in developing a useful and used EHR.

ABBREVIATION

EHR: electronic health record

REFERENCES

1. Anoshiravani A, Gaskin GL, Groshek MR, Kuelbs C, Longhurst CA. Special requirements for electronic medical

- records in adolescent medicine. *J Adolesc Health*. 2012;51(5):409–414
2. Stablein T, Loud KJ, DiCapua C, Anthony DL. The catch to confidentiality: the use of electronic health records in adolescent health care. *J Adolesc Health*. 2018;62(5):577–582
 3. Bourgeois FC, Nigrin DJ, Harper MB. Preserving patient privacy and confidentiality in the era of personal health records. *Pediatrics*. 2015;135(5). Available at: www.pediatrics.org/cgi/content/full/135/5/e1125
 4. Sharko M, Wilcox L, Hong MK, Ancker JS. Variability in adolescent portal privacy features: how the unique privacy needs of the adolescent patient create a complex decision-making process. *J Am Med Inform Assoc*. 2018;25(8): 1008–1017
 5. Webber EC, Brick D, Scibilia JP, Dehnel P; Council on Clinical Information Technology; Committee on Medical Liability and Risk Management; Section on Telehealth Care. Electronic communication of the health record and information with pediatric patients and their guardians. *Pediatrics*. 2019; 144(1):e20191359
 6. Ancker JS, Sharko M, Hong M, Mitchell H, Wilcox L. Should parents see their teen's medical record? Asking about the effect on adolescent-doctor communication changes attitudes. *J Am Med Inform Assoc*. 2018;25(12): 1593–1599
 7. Miklin DJ, Vangara SS, Delamater AM, Goodman KW. Understanding of and barriers to electronic health record patient portal access in a culturally diverse pediatric population. *JMIR Med Inform*. 2019;7(2):e11570
 8. Gilbert AL, Rickert VI, Aalsma MC. Clinical conversations about health: the impact of confidentiality in preventive adolescent care. *J Adolesc Health*. 2014; 55(5):672–677
 9. Coker TR, Sareen HG, Chung PJ, Kennedy DP, Weidmer BA, Schuster MA. Improving access to and utilization of adolescent preventive health care: the perspectives of adolescents and parents. *J Adolesc Health*. 2010;47(2): 133–142
 10. Goldzweig CL, Orshansky G, Paige NM, et al. Electronic patient portals: evidence on health outcomes, satisfaction, efficiency, and attitudes: a systematic review. *Ann Intern Med*. 2013;159(10):677–687

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Pediatrics 2020;145;

DOI: 10.1542/peds.2019-0193 originally published online February 5, 2020;

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DOI: 10.1542/peds.2019-0193 originally published online February 5, 2020;

The online version of this article, along with updated information and services, is located on the World Wide Web at:

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