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Meaningful Use of a Confidential Adolescent Patient Portal

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A B S T R A C T

Purpose: To design and evaluate the usage of an adolescent patient portal specifically adapted for adolescent health care needs that also satisfied institutional meaningful use guidelines regarding electronic health records.
Methods: Key stakeholders at one academic health care center adopted an online portal and opted to designate a patient portal specifically for adolescents to maximize confidentiality in compliance with state privacy laws. This study analyzed aggregate electronic health record data of adolescents' (ages 12–17.9 years) uptake, usage, and functionality of this portal and compared it to parent portal usage for younger children (ages 0–11 years). Differences in means were calculated using paired *t* tests.
Results: The portal was used similarly between parents of young children and adolescents, with almost 1,000 enrollees in each group from September 1, 2012 to March 31, 2015. There were no gender differences in enrollment. Adolescents were less likely than parents of younger children to review appointments (73% vs. 85%), laboratory tests (67% vs. 79%), problem lists (40% vs. 78%), or allergies (45% vs. 77%, all p values $<.001$). Parents of younger children more frequently messaged providers (3,297 messages) although adolescents sent 1,397 confidential messages.
Conclusions: Institutional decisions for implementing meaningful use requirements can align with goals of adolescent health. Patient portals can enhance adolescent health care quality and adolescents readily use a confidential portal. Implementation of meaningful use requirements should be checked against adolescent health care needs to maximize confidentiality and promote health communication.

IMPLICATIONS AND CONTRIBUTION

Patient portals can fulfill meaningful use requirements but little is known regarding adolescent use of patient portals when confidentiality is prioritized. Adolescents used the portal similarly to parents of younger children, accessing it for sensitive adolescent health issues including asking questions to providers and seeking laboratory results.

Providers of adolescent health, in support of guidelines and recommendations for confidential care, have advocated for use of an electronic health record (EHR) to promote adolescent health while preserving patient confidentiality [1–4]. This call to action both coincides with and reacts to the federal legislative actions to support EHR use, starting with the initial 1996 Health Insurance Portability and Accountability Act that had a secondary aim of allowing efficient transfer of health information electronically, continuing with the 2003 Institute of Medicine comment on EHRs and culminating in the 2009 Health Information Technology for Economic and Clinical Health Act (HITECH) with its

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meaningful use (MU) program in 2010. Stating that the goal of EHR is not "adoption alone but *meaningful use* of EHRs," [5] the MU program incentivizes clinicians to demonstrate a set of government-established criteria as indicators of quality EHR use. Yet in the push to meet MU standards, little is known about how these requirements impact adolescent health. (For more information about MU requirements, see Table 3, Appendix). Broader use of the EHR, driven by MU incentives, is causing practitioners and health care systems to make explicit choices about difficult issues related to adolescent confidentiality, sometimes without consideration of state-specific privacy laws pertaining to adolescents or careful clinical consideration of adolescent health and well-being.

Traditionally, providers have used telephone, letters, and face-to-face interactions to communicate with adolescents about sensitive health information, although confidentiality breaches can easily occur. One of the many required MU criteria is to "provide patients with an electronic copy of their health information," [6] such as can be delivered through an online EHR patient portal. In 2007, only 1% of the adult population had access to an Internet-based personal health record [7], yet by 2012, another report cited that up to 20% of physician offices have patient portals available [8]. Although EHR portals allow for secure information exchange between patients and providers, offering a unique solution to existing challenges in adolescent confidential communication, establishment of adolescent portals has lagged significantly behind national trends and advances in adult medicine [1,9]. Adolescent use of patient portals has many potential benefits [10], yet there are well-recognized challenges to the adoption of adolescent online health services [11]. Institutional concerns about confidentiality, individual state laws and fears regarding privacy breaches remain the prominent barriers to improving adolescent access to online health services [11,12].

Health care institutions, in their efforts to satisfy MU and/or to improve adolescent confidentiality, can choose to adopt one of three models to implement an adolescent health portal [13]. The models either prioritize adolescent confidentiality, family (parent and adolescent together) engagement or, in contrast, parental needs only. Conceptually, aligned with guidelines for quality adolescent care and most state laws [1,14], institutions that aim to maximize adolescent confidentiality in their portal would allow adolescents to privately communicate with their physician without parental oversight. Adolescents would be able to request appointments, ask questions, view medications, and receive laboratory results via the portal. Providers would consequently play a significant role in teaching adolescents how to care for themselves as they transition into adulthood. In this model, parents are given limited or no access, although individual adolescents could opt to share their information with a parent. The other two models do not allow for confidential communication about sensitive information between providers and adolescents. In fact, it would be illegal if confidential information (such as sexually transmitted infection results, which are confidential in all 50 states and Washington DC) is sent to a patient portal and a parent is able to gain access to it. Despite this, institutions have and may still opt for these models of implementation that do not prioritize adolescent confidentiality.

Once an institution adopts an adolescent portal, research is lacking on how adolescents may use it, especially those specifically designed to maximize adolescent issues of confidentiality. This study aims to ascertain how frequently adolescents will use a patient portal that prioritizes adolescent confidentiality. Additionally, we aim to measure if adolescents readily enroll and use the portal's broad functionality for communication of routine and sensitive information.

Methods

Portal design via stakeholder engagement

We describe usage of an adolescent portal after engaging key stakeholders to convene, discuss, and adopt a policy toward the design of adolescent portals. Using methods of participatory research, this stakeholder committee had representation from legal guidance, administration, information technology, nursing, and pediatric and adolescent medicine. They convened over 9 months to design a patient portal to meet the needs for adolescents at one academic medical center. This patient portal was already available to adult patients as part of the EHR system, EPIC, within the health care system, but it had been withheld from use by adolescents. Key decisions considered by the committee regarding complex legal considerations and available functionality within EPIC are highlighted in Table 1 [1].

The committee opted for a portal model which maximizes adolescent confidentiality by following recommendations from adolescent policy groups [15]. The family engagement and parent-oriented models did not follow state law by allowing for confidential information exchange and so were not adopted by the committee. Specifically, the key stakeholders felt that although the family engagement approach would be ideal with every teen having an involved parent to guide them, we wanted the portal to be a novel access point where adolescent health care providers could provide confidential care and advice directly to adolescents. The parent-oriented approach did not align with the goals of confidential exchange, health education, or existing laws. In either the family engagement model or parent-oriented model, inadvertent release of confidential information to the parent would be illegal, furthering our decision.

In the adolescent confidentiality portal model, adolescents who are 12 years of age to those just before their 18th birthday, and their parent, must both agree to a confidential relationship between the health care provider and minor. This model allows for confidential communication about complex situations that may arise such as those surrounding family planning, sexually transmitted infections, and pregnancy. It also provides a confidential venue to convey educational materials, or answer questions that adolescents may have. Parents in this confidentiality model can choose to enroll in a proxy access, where they can view limited information such as their child's immunization list; they cannot view the problem list, medications, allergies, appointment review for upcoming appointments or released laboratory tests.

Adolescents create their own login with a private password; once they have entered the portal they can click through to view all aspects of the patient portal. (See Figure 1 for screenshots of a sample adolescent portal.) Importantly, they can receive confidential notifications of laboratory tests, many of which are automated. By design, sensitive laboratory tests, such as HIV, cannot be directly transmitted in the adolescent portal. The adolescent must call to receive the result personally. For other laboratories, a clinician can choose to release the result, then program a notification should the patient not retrieve it, or they can use alternate methods, such as the phone, to reach the adolescent.

Nonetheless, the stakeholder committee had concerns about the implementation of the adolescent portal. They hypothesized