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Patient portals for the adolescent and young adult population: Benefits, risks and guidance for use

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Patient portals are the primary means by which electronic health information (EHI) is shared with patients and families. The use of patient portals increased during the COVID-19 pandemic and may continue to rise with the implementation and enforcement of the 21st Century Cures Act that encourages facilitation of access to EHI and prohibits information blocking. Research on the use of patient portals by adolescents and their families is limited. Potential benefits of portal use to adolescents include increased engagement in their own health care, direct communication with their health care clinicians, and facilitation of transition of care to new clinicians in adulthood. Clinicians need to educate adolescents on the functions available through the portal, appropriate use and expectations for messaging through the portal, and the pros and cons of viewing EHI such as test results independently. Parental proxy access to the adolescent’s portal should be carefully and thoughtfully implemented, because it poses a potential breach to confidential care via disclosure of sensitive or protected information. Adolescents who choose to deny their parents proxy access to the portal should be supported in that decision. It is important that all clinicians understand portal functionality and have strategies to optimize use within their practice. This paper provides the reader considerations and tips for portal use within this population.

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Introduction

As the use of electronic health records (EHRs) is now widespread, optimal use of the patient portal is an increasingly important consideration for pediatricians. In addition to driving almost universal adoption of EHRs, the Health Information Technology for Economic and Clinical Health (HITECH) act of 2009 also incentivized the use of patient portals through promotion of increased access to patient electronic health information (EHI). On April 5, 2021, the information blocking provisions of the 21st Century Cures Act went into effect in the United States. Patients now have almost immediate access to several elements of their EHI, typically accessed through the patient portal. Although most studies related to patient portal use are in the adult population, the use and study of patient portals care of the pediatric and adolescent and young adult populations is increasing. Clinicians must be aware of the functionality as well as the limitations of their system’s patient portals. In particular, they must be cognizant of the risk of confidentiality breaches when providing health care to adolescents and young adults.

While adolescents and young adults express enthusiasm and interest in using patient portals, research describing the use of portals in this population is limited. This review describes the potential impact of the patient portal specific to adolescent and young adult health care with special consideration of the technical, privacy, and workload aspects. This paper provides guidance for clinicians to incorporate effective use of the patient portal into their practice.

Patient portal: what is it?

A patient portal is a secure internet-based website that enables digital communication and sharing of EHI between a clinician and his/her patients. Patients
or their proxies can access patient portals through the internet or by downloading a separate application. Patient portals are typically designed for general patient use, but disease-specific patient portals have been developed for diabetes, sickle cell disease, congenital heart disease, and cancer. Some portals are specific to ambulatory care or inpatient care. A patient portal may be provided by the EHR vendor or it may be run by an independent company or application developer. Understanding the functionality of your individual portal is critical to improving its use.

**Patient portal: can AYA can access it?**

Individual health systems define different types of portal access. This varies in terms of what information and features are available. Table 1 describes common access types. Initial activation of the patient portal often requires in-person verification of identity and documentation of legal custody. In some cases, health systems may offer provisional (limited) access to patient accounts pending in-person verification. In response to the COVID-19 pandemic, some organizations developed processes for enrollment without in-person verification.

The age at which adolescent patients first have personal access to their patient portal may vary but is typically 12-14 years. With activation of adolescent patient portals, there is often an additional step that entails the adolescent providing assent for proxy access by the parent. This may be a barrier to activation. Pediatric practices accustomed to offering portal access only to parents may be less likely to initiate the discussion with adolescents unless they have explicitly developed an approach to enrolling this population. Many portals offer an option to provide temporary access. Adolescents and young adults can temporarily share the information in their portals with family members or other clinicians rather than granting full proxy access.

### Patient portal: are adolescents and young adults using it?

The use of pediatric patient portals has increased over time but continues to vary across practices. Adolescents may use the portal by themselves, but caregivers and proxies of adolescent patients commonly log in for adolescent patients; in one study, 83% of logins for adolescent patients were conducted by surrogate users. Despite studies that show that a majority of adolescents find the patient portal easy to use, adolescent age is an independent factor of reduced portal enrollment and use. In a survey of adolescents age 13 to 18 in a general pediatrics clinic, 94% had heard the term EHR but only 55% were familiar with patient portals. Strategies such as dedicated staff to educate adolescent and young adults have been shown to improve enrollment especially when activation is completed when the patient is still in the clinic.

| Patient Age | Patient Access | Parent/Guardian Access |
|-------------|----------------|------------------------|
| Young Child | None           | Full                   |
| Adolescent (< 18 yr) | Full or Limited** | Full or Limited proxy access** |
| Adult (> 18 yr) | Full           | None                   |
| Adult (> 18 yr) | Full           | Full or Limited proxy access** |

*Age for AYA determination is typically age 12-14 years, but varies
**Variable access is determined by organizational setup. Additionally, clinicians can make determination to block certain elements from release on a case by case basis.

Impact of COVID-19 on patient portal use

The COVID-19 pandemic increased the adoption and use of health information technology for patient care. This enabled patients to access some elements of health care while adhering to regional stay-at-home orders. With the rapid transition to telemedicine, there was a rapid expansion of portal use. Many healthcare systems adopted the patient portal as the primary means through which health care is provided. This has led to upwards of a 10 fold increase in overall pediatric patient portal enrollment rate per week from mean 152 new enrollments per week to 1582 at a large academic medical center. Enrollment site (inpatient versus outpatient) was not described.
Benefits of using patient portals

Enhanced patient communication

Adolescents and young adults want to use patient portals to ask questions outside of visits, share data, and build rapport with their clinician. Electronic messages for care delivery are being used in primary care pediatrics, medical specialties, and surgical specialties. Perceptions of portals as a communication tool vary by patient characteristics, including diagnoses. Parents of chronically ill children report that portals are helpful to facilitate communication with their child’s clinician. Adolescents and young adults with sickle cell disease who were trained on use of a patient portal demonstrated improved communication with their clinicians as evidence by the Talking with Providers subscale of the Transition Readiness Assessment Questionnaire.

Clinicians view patient communication of health issues and requests for medication refills as the greatest portal benefit. In a study of pediatricians practicing in a large medical facility, 43% believed the portal increased their workload overall, but 80% found it led to a reduction in telephone calls and valued the ability to send messages to patients any time of day/night. In addition, clinicians believe written instructions may be easier to interpret and remember than oral instructions. Patient portals may further be used to improve communication regarding care goals and indications for hospitalizations.

Patient engagement

Use of the patient portal may increase patients’ engagement in their own health care. In a study of adult patients with multiple complex chronic illnesses, access to a portal was associated with more office visits and fewer emergency room visits. Another study of adults in a primary care setting reported improved adherence to appointments and reduced no-show rates among users of the patient portal. Adult use of a portal to document family history was associated with feelings of patient empowerment. However, participants in this qualitative study also expressed concerns about validity and privacy with use of the portal. In a survey of parents of hospitalized pediatric patients, 8% of parents identified incorrect information on their child’s medication list through the portal. Parents of children with chronic health conditions expressed a desire for easy ability to correct inaccurate information.

Patient satisfaction

While some patients have difficulties utilizing complex portal interfaces, others find them easy to use. A survey of parents of hospitalized patients age younger than 12 years found that 90% were satisfied with portal use, stating that it improved care and gave them access to information that helped them understand and make decisions regarding their child’s care. Adolescent patients and their parents were not included in that study. Parents of children with chronic health conditions report that information in the portal is useful, accurate, and timely and they want additional medical information to be accessible through the portal.

Risks of portal use

Threats to adolescent confidentiality

Verbal breaches of adolescent confidentiality are common in pediatric hospitals with family centered rounds, and it is reasonable to assume that the risk of such breaches will increase with increased sharing of EHI through patient portals. In some instances, most notably when seeking certain types of reproductive health care, mental health care, and substance abuse treatment, adolescents are legally permitted to receive care without parental consent. Specific legislation regarding the types of care protected varies by state, and in many states these rights are accompanied by the expectation that these visits remain confidential.
Adolescent patients may not be aware of their rights in this regard, and may therefore hesitate to activate the patient portal. More concerning, of course, is the risk that they may forego necessary care altogether if they fear their parent will have access to documentation or orders placed during such an encounter. Several prior studies have demonstrated that adolescents would delay or avoid certain elements of reproductive or other sensitive health care if their confidentiality was not ensured. When questioned about use of patient portals related to STI testing, most college students stated they would be willing to utilize the portal, but also expressed concerns about privacy breaches, cost, and clinician patient relationship. Participants expressed concern that “if you are handling everything through technology, there is no personal connection.”

The American Academy of Pediatrics, The Society for Adolescent Health and Medicine, and other societies invested in the health of adolescents have issued position statements calling for improved technical functionality for protecting adolescent confidentiality. However, EHRs were not designed to prevent accidental disclosure of confidential information and cannot be relied upon to identify and protect sensitive content. While some health systems may have measures in place to prevent release of information, in general, clinicians are expected to manually review and annotate information that should not be shared in the patient portal.

It is not only the adolescent patient’s confidentiality that is at risk. There is also a risk of inadvertent release of information obtained from a parent that should not be released to the adolescent. Examples include an adolescent’s adoption status or other circumstances surrounding their birth that have not been shared with them yet, or parental histories of mental health or substance abuse diagnoses that parents wish to keep confidential. A parent providing history during a health encounter with their infant or young child may not consider whether they want that information to be visible in the portal when their child reaches adolescence. When surveyed about portal use to document family histories, adults expressed concerns about family member privacy and indicated that they may be hesitant to provide names of relatives. Financial information such as outstanding balances may also be available to the adolescent through the portal.

Clinicians should know with whom they are communicating when sending and responding to portal messages, especially when confidential adolescent content is being discussed. In prior studies of adult patient messages, proxies sent messages frequently using the patient account (rather than their own proxy account) but only identify themselves about half of the time.

**Inappropriate message types**

Patients may be uncertain about appropriate use of patient portal messaging. Studies have shown that adult patients may send messages that may be urgent including concerns for suicidality. Patients may expect immediate response to patient portal messages, but clinicians may have policies in place that give them up to 2 days to respond. Patients must also understand a practice’s approach to message workflow; for example, a message that they send to their physician may first be read and possibly completely managed by a nurse or administrator. If such discrepant expectations are not acknowledged and addressed, patients may become impatient and frustrated with the lack of the anticipated response.

**Anxiety about information and results seen**

The ability to see test results through the portal as soon as they are available carries both benefits and risks. Although patients have a right to timely access to their EHI, there may be times when this poses a psychological risk. Anxious patients may be relieved to see normal test results. For certain diagnosis, like new diagnosis of cancer, some patients may prefer a discussion with their clinician to reviewing results online while others may prefer learning about rare diagnosis in the privacy of their own home. The misinterpretation of test results, such as incidental findings on imaging studies and clinically insignificant laboratory values that flag as “abnormal” may cause significant distress to the patient until the issue can be discussed with the clinician. In a qualitative analysis of adult oncology patients, more than half (19/35) reviewed test or scan...
reports before speaking with a clinician. Truly abnormal results, such as a positive test for a sexually transmitted infection (STI), may be even more difficult to process when viewed before the clinician can contact the patient to discuss them, provide education, and develop a management plan. For less mature patients, such as younger adolescents, having to process results without necessarily even having the support of a caregiver when results are viewed may cause great distress. Furthermore, adolescents may be “triggered” by viewing certain other elements of their EHR, such as a patient with an eating disorder seeing her growth chart, or a patient with a trauma history reading a description of his trauma.

### Healthcare disparities

Requiring use of the patient portal and may contribute to health disparities. Sociodemographic disparities, language differences, and geographical factors all affect enrollment and activation of the portal. Parents who activate the portal may be more likely to have access to a home computer and be more engaged in their child’s healthcare. Practices that come to rely on the patient portal for care delivery should remain aware that many families, even after they are enrolled, have significant barriers to use such as lack of access to devices or high speed internet services, and this must not be perceived as lack of interest or engagement.

### Practice implications

#### Optimizing patient portal use for adolescent patients

The patient portal has great potential for use in adolescent and young adult health care. Adolescents and young adults in North America are generally skilled and comfortable navigating new technologies and using electronic communication. The vast majority of households in the United States have smartphones through which they can access a portal. This means of connecting directly with their healthcare clinicians may increase adolescents’ engagement in their own health care and access to confidential healthcare services. Table 2 describes common patient portal functionality with specific examples of potential use by adolescents.

The patient portal may serve as a useful teaching tool as well, allowing adolescents not only to access reliable health information, but also to practice mature communication with their health professionals. They may also, through use of the portal, learn skills required for successful health care transition, such as making appointments, requesting medication refills, accessing their own insurance information, and sharing information with new clinicians. Clinical encounters with adolescents may be enhanced by the administration of screening tools and data collection questionnaires through the portal, saving time in the clinic.

There are several challenges that are helpful to address before the patient portal can be used safely and effectively by adolescents. Although most adolescents have smartphones, cost is a cited limitation. Service may be interrupted (and portal access thereby limited) during times of financial hardship, or when phones are damaged, lost, or stolen. Though they are generally tech-savvy, adolescents still may require explicit, concrete instruction on the functionality of the portal and how they may use it to access care. They should be made aware that messaging through the portal is more analogous to emailing than texting. It is also important to teach when a phone call for an urgent need is more appropriate. These challenges are all heightened when language barriers exist. As described above, threats to confidentiality are perhaps the greatest concern. Even when parental access to the portal is automatically limited at a certain age and the adolescent is offered confidential access, it can be extremely challenging for them to negotiate or deny proxy access to a parent who requests it. Pediatric clinicians are therefore faced with the challenge of encouraging the use of the patient portal to take advantage of its great potential and to comply with federal mandates while protecting the interests of adolescent patients. Understanding a portal’s functionality, and how you can adapt it to meet a primary care practice’s needs, is of critical importance. If a clinician is a member of a larger institution and have limited control over portal functionality, you may be in a position to advocate for adolescent-friendly use and features. Guidelines to help clinicians appropriate this process are found in Table 3.
### TABLE 2. Functionality of patient portals for adolescent patients.

| Function                        | Examples of Use by Adolescents                                                                 |
|---------------------------------|-----------------------------------------------------------------------------------------------|
| Appointment scheduling          | • Schedule routine appointments                                                                |
|                                 | • Securely schedule appointments for confidential care                                          |
| Telehealth                      | • Access telehealth appointments (routine or confidential)                                      |
|                                 | • Access health care when transportation is unavailable                                         |
| View and Manage Care Team       | • Keep track of all care team members and clinicians                                            |
|                                 | • Facilitate transition of health care to new clinicians                                        |
| Secure Messaging                | • Send and receive secure messages                                                              |
|                                 | • Ask questions about care plan or medications                                                  |
|                                 | • Enquire about options for confidential care services                                           |
| Photos and Videos               | • Send photos or videos to clinicians                                                           |
|                                 | • Enhance telehealth visits by providing quality clinical images                                 |
| Letters and Forms               | • Print school and work excuses                                                                 |
|                                 | • Print sports physical clearance forms                                                         |
|                                 | • Submit work permits for completion                                                           |
| Medical Record                  | • View historical information (personal and family medical history, immunization records, allergies)   |
|                                 | • View current medical information (medications, test results, clinical notes, upcoming appointments) |
|                                 | • View patient education materials                                                              |
| Screening Questionnaires        | • Complete screening tools and other data collection forms online prior to visit                |
|                                 | • Complete screening assessments that communicate with larger EHR (eg, import into clinical notes, flow sheets) |
| Insurance Information           | • View insurance information                                                                   |
|                                 | • Access necessary information for completion of forms, etc., when physical insurance card is not available |
| Sharing of Records              | • Share view of patient portal with family members                                               |
|                                 | • Provide access to “outside” healthcare clinicians                                              |
|                                 | • Manage proxy access                                                                           |
| Account Settings                | • Update photo                                                                                   |
|                                 | • Provide personal mobile phone number                                                           |
|                                 | • Select communication preferences (eg, email, text, phone)                                       |
| Resource Links                  | • Access reputable medical information, recommended by the healthcare organizations               |
|                                 | • Access links to confidential care (eg, STI clinics, substance abuse treatment centers)          |
| Medication Management           | • Ask questions about medications                                                                |
|                                 | • Request medication refills                                                                     |
| Immunizations                   | • Print out immunization records for school, work                                                |

### TABLE 3. What clinicians need to know.

| Preparing your office to offer portal access | • Develop scripts or handouts for educating adolescent patients on their rights regarding confidential access and explaining the proxy process. Respect and support the decision of adolescents who choose not to grant proxy access. |
| Preparing your patients to sign up for the portal | • Support “real time” enrollment while in office                                                |
|                                                | • Provide patient education on portal use- Technical use of portal functionality                 |
|                                                |   ○ Appropriate use of portal (example: when phone call is preferred)                          |
|                                                |   ○ Expected timeframe for response to messages                                                  |
|                                                |   ○ Discuss pros and cons of immediately accessing laboratory/imaging results                  |
|                                                |   ○ Information on types of care that may be kept confidential and not accessible through the portal |
| Providing Confidential Care through the Portal | • Encourage parents to use their proxy access, rather than using the patient’s login information and password, when they access the portal |
|                                                | • Ensure patients and families who cannot or prefer not to use the portal (eg, due to language or technology barriers) that other means of communication and patient support will remain in place |
|                                                | • Understand your state’s minor consent laws and when adolescent confidentiality should be maintained. Relevant legislation for every state may be found at [www.cahl.org](http://www.cahl.org). |
|                                                | • Decide which elements, if any, you wish to block from portal access (eg, STI test results and treatments, clinic notes containing sensitive content) while minimizing information blocking |
|                                                | • Determine patient’s preferred means of communication (eg, portal, text, mobile phone) and document consistently so that office staff can find it |
|                                                | • Periodically (at least yearly) revisit and update patient’s preferences regarding proxy access, as preferences may change with advancing age |
Conclusion

Patient portals are the primary means by which EHI is shared with patients. The use of patient portals has increased with the COVID-19 pandemic and may continue to increase with the 21st Century Cures Act Information Blocking regulation. Use of the patient portal can lead to benefits such as improved patient satisfaction, engagement, and communication as well as risks such as inappropriate use of messaging, confidentiality breaches, and widening the internet access divide. It is important that all clinicians understand portal functionality and have strategies to optimize use within their practice. It is critical that clinicians understand the adolescent confidentiality considerations with increased sharing of EHI through a patient portal. Ultimately, studies have shown use of patient portals can lead to improved healthcare for adolescents and young adults.

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