Inappropriate Access to the Adolescent Patient Portal and Low Rates of Proxy Account Creation

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The Final Rule of the 21st Century Cures Act, which took effect in April 2021, implements information-blocking provisions that expand the types of data available to patients within the online patient portal.¹ This expansion of access coincides with patients embracing digital health tools more than ever: nearly 40% of US adults reported accessing their online medical record in 2020, which is up from 28% in 2017.² Digital access to personal health information has been found to provide benefits, including improved patient understanding, stronger therapeutic relationships with health care professionals, and increased quality and safety, while introducing few to no problems.³ Maintaining adolescent privacy is a unique implementation challenge encountered when instituting these portals in a pediatric setting given that both adolescents and legal guardians may have separate, differential access.⁴ This separation becomes more important as these patients age and a therapeutic relationship must be maintained while sensitive topics are increasingly discussed.⁵

Insightfully uncovering a gap in adolescent patient privacy in the context of portal use and implementation, Ip and colleagues⁶ used natural language processing (NLP) to estimate guardian access to an adolescent patient’s portal account. In this multisite study, the authors analyzed portal messages at 3 institutions looking for those initiated by a parent or guardian within an adolescent patient’s account. Ip et al⁶ flagged messages if they contained references to the patient in third person, certain possessive language (eg, my child), or contained the guardian’s name within a salutation. The authors used their NLP algorithm to analyze more than 25,642 messages associated with 3429 adolescent accounts and identified at least 52% to 57% of adolescent accounts that had been accessed by a parent or guardian. After adjusting for NLP sensitivity and specificity (based on manual review of a subset of messages), the authors estimated the prevalence of guardian access is even higher at 64% to 76% of adolescent accounts.

These new findings are striking and highlight the need for thoughtful implementation of patient portals. Private and candid conversations between a health care professional and an adolescent patient concerning mental health, sex, gender identity, and bullying may be compromised if guardians have access to relevant clinic notes. Likewise, guardian access to sensitive testing results, such as sexually transmitted disease or pregnancy testing, obfuscates adolescent privacy, which could lead to hesitancy of seeking health care for this population. Ip and colleagues⁶ findings suggest enabling differential portal access alone may not be adequate to ensure adolescent patient privacy. One approach taken by some institutions is to remove all sensitive information from both patient and guardian portal accounts⁵; this approach may better ensure confidentiality of sensitive information but limits some of the known benefits of the patient portal.

The Society for Adolescent Health and Medicine supports differential portal access for adolescent patients and their proxies⁷; however, as Ip et al⁶ highlight, enabling this feature may not be enough to ensure patient privacy. In this multisite study, proxy accounts for adolescent patients were registered in only 0.3% to 10% of cases. This low rate suggests the need for improved institutional workflows and governance surrounding proxy account creation as well as patient and family education at the beginning of and throughout adolescence. The authors highlight that local quality improvement and enhanced communications are beginning because of these findings, but it is likely that many other institutions could benefit from similar initiatives.
The Final Rule of the 21st Century Cures Act has accelerated the cultural shift of increased health care data transparency introduced by patient portals. Well-defined access policies, easily accessible education, and streamlined patient and proxy portal account creation are needed to support adolescent patients and their families during the transition to adulthood.

ARTICLE INFORMATION
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REFERENCES