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Editorial

The Quality Chasm Widened by the Impact of the Cures Act on Adolescent Confidentiality



Redesign of the health information system was a key element in the agenda presented in 2001 by the Institute of Medicine's call to arms to improve the U.S. health-care system, "Crossing the Quality Chasm" [1]. This report suggested that a primary goal of electronic health record (EHR) systems should be to improve the quality and efficiency in the delivery of health care. EHR systems should facilitate interinstitutional connections and provide patients with access to their health information through patient portals. The implementation of the Cures Act in April of 2021 represents the culmination of this effort to promote transparency, prohibiting information blocking and requiring institutions to provide patients with access to all their electronic health information (with some exceptions). Unfortunately, in the process of leaping across the chasm to enhance information exchange, some of the progress made to provide confidential health care to adolescents has been reversed.

The article by Xie et al. in this issue shines a spotlight on the risks of oversharing in the era of comprehensive health information exchange [2]. The authors share a quality-improvement framework used to identify and rectify adolescent patient portal accounts that were incorrectly registered to guardian email accounts instead of adolescent email accounts. The effort was motivated by a confidentiality breach that occurred at their institution when a parent/guardian received notification of an adolescent patient's confidential appointment. As part of the initiative's baseline assessment, Xie et al. used a variety of methodologies to establish that as many as two-third of their institution's adolescent patient portals were inappropriately associated with guardian email addresses and therefore presented risk for confidentiality breaches and disclosure of protected health information.

The concept of confidentiality is recognized as a cornerstone of adolescent health-care delivery, with multiple studies demonstrating that adolescents will forgo health care or withhold important health-related information if confidentiality is not assured [2–7]. In addition to preventing undue harm to

adolescents, confidentiality facilitates autonomy and decision-making, key developmental tasks required to become independent, functional adults [8]. The Society for Adolescent Health and Medicine, American Academy of Pediatrics, American College of Obstetrics and Gynecology, and other professional organizations provide guidelines that support adolescent consent and confidentiality and go further to describe actions that can preserve this key component of adolescent care with implementation of EHR systems [9–11].

More recent studies exploring adolescents' and guardians' perception of care have reaffirmed the importance of confidentiality in the delivery of high-quality adolescent health care. Adolescents and their guardians generally express an expectation that private time for confidential discussions be part of adolescent visits [12,13]. In addition, adolescents express more confidence in their care provider when the provider discusses confidential topics, such as difficulties at home, contraception use, or substance use [14]. Most importantly, those at the highest social and medical risk appear to be the most affected by non-assurance of confidentiality. For example, adolescents with suicidal ideation and suicide attempts, as well as those who report unprotected sex and substance use, appear to be less likely to seek care when confidentiality is not assured [15].

Most U.S. states' laws allow adolescents to consent independently to some services related to sexual and/or reproductive health, mental health, and substance use. The health information collected as part of these services is protected that only the adolescent patient have access to it unless the adolescent has expressly consented to sharing this information with others [16]. After the announcement that the Cures Act would mandate open notes, professional organizations and adolescent-focused health information experts sounded the alarm expressing concern about the dichotomous challenge of meeting both the transparency and confidentiality legal requirements and proposed potential interventions to prevent confidentiality breaches while still fulfilling the open notes mandate [17–21].

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Many proposed solutions rely on providers to create separate notes or flag notes that contain confidential information [17,20]. These provider-driven solutions may help, but automated and fail-safe solutions are needed for multiple reasons. First, while some providers see confidentiality as ubiquitous in the routine of the adolescent visit, other providers do not routinely incorporate confidential time in their visits with adolescents and thus may not be fully aware of which information in the adolescent's medical record should be protected [22]. In addition, care providers have reported limited exposure to training in EHR-related strategies to preserve confidentiality and wide variations in approaches to adolescent portal access [23]. Finally, placing the onus on health-care providers adds to the already burgeoning administrative workload contributing to burnout and diminishing workforce in health care.

The institution-level approach described by Xie et al. is innovative and noteworthy. It uses both labor-intensive manual review of accounts and portal content and staff education in portal registration, as well as sophisticated IT strategies including the Levenshtein edit distance technique to detect guardian emails registered for adolescent accounts and natural language processing to analyze portal messages. This 2-year initiative validates many of the concerns raised before the implementation of open notes. Their intervention flagged more than 2,000 adolescent patient portals that were incorrectly registered with guardian email accounts, with the highest number occurring with portal registration over the phone (Xie 2021). Rapid registration for patient portals was necessary for implementation of telemedicine during COVID-19, and it is highly likely that other institutions have similar adolescent patient portal concerns [24]. The ongoing effort to rectify errors in portal access described at this institution, however, is one that requires resources and manpower that other institutions may not be able to garner to mitigate this legal and ethical dilemma.

The strong commitment to protecting adolescent health-care information confidentiality demonstrated by Xie et al. needs to be mirrored on a national level by our EHR vendors and health-care regulators, perhaps even legislators. EHR vendors need to, or perhaps should be mandated or legally required to, develop systems that allow care providers and patients to control the flow of health information in a way that is transparent to both them and the parties legally entitled to receive it. These features will be of benefit to all patients who care about their privacy and also to those who might want to share some information with other family members or proxies. Adolescents deserve to reap the benefits of patient portals and open notes while also continuing to receive high-quality care centered around their need for confidentiality, emerging autonomy, and trajectory toward independence.

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