Patient and Family Access to Electronic Health Records: A Key Ingredient for a Pediatric Learning Health System

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In the United States (US) health care system, the evolution of the Electronic Health Record (EHR) is at a unique crossroad. Federal regulations requiring "meaningful use" are incentivizing providers to use electronic portals for secure communication and ensuring that patients have increasing access to their own medical records [1]. Based on the number of times an EHR is accessed per week, some health systems now have more patients accessing the EHR than physicians. It is important to encourage patients to access their EHR so that their engagement can contribute to the clinical care as well as to clinical research. The Institute of Medicine has charged the nation to increase patient involvement in the EHR by creating learning health systems (LHS: defined as a health system that applies evidence-based medicine in a collaborative effort between patient and provider) [2]. The authors believe patients' access to their own EHRs could encourage them to better co-manage their disease as well as to contribute to ongoing clinical research.

Meaningful use of the EHR has its roots in creating a more value-based care model, which seeks to reward providers and health systems for improving care coordination. The EHR has been identified as one solution to converge care teams and link distinct pieces of a fragmented system. In an effort by Health and Human Services in 2010 to encourage EHR adoption, incentive payments under their "meaningful use" criteria were outlined. Since then, there has been an unprecedented surge in EHR use. In addition, there has been a mountainous upswing in the launch of mobile health or "mHealth" technologies, which promise more flexibility and convergence of conversations about one's health. This effort to collect and analyze personal health data has been described as the "self-tracking movement." In its ideals, the self-tracking movement represents a patient-generated, grass-roots initiative to exchange health data and patients' unique experiences in a more open, transparent way.

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However, physician access through HIPAA-secure linkage of self-tracking data with the EHR has been missing.

This is where a patient portal tethered to the EHR can fill an important niche in a pediatric LHS. Electronic communication and patient-reported outcome (PRO) measures collected within EHR portals can help young patients and parents engage with their physicians and become activated in self-management of their health. In 2004, the National Institutes of Health began standardizing PRO measurements for clinical research into the Patient Reported Outcomes Measurement Information System, or PROMIS, a set of rigorously validated instruments addressing broad areas of function. The FDA also recognized the future impact of PROs and the need to standardize how PROs are collected for drug development and approval, publishing guidelines in 2006 for use in drug labeling [3].

For patients and physicians, longitudinally collected PROs could inform clinical practice for patients with a common diagnosis and personalize care for individual patients using real-time data. For example, insulin-dependent diabetic patients can track and report fasting and pre-prandial glucose levels to their endocrinologist through their EHR if they are piloting a new insulin regimen, or provide real-time feedback on the user friendliness of a new insulin pump that is being tested. Systematically collected PROs could generate key health outcomes data for a particular disease of interest. When PROs are collected in such a fashion through a secure patient portal, more comprehensive clinical data could be more easily accessed to guide clinical decision-making at the point-of-care. For example, a "green button" could be employed within the EHR which would display aggregate data about a cohort of patients similar to the current patient receiving care. Especially in the absence of robust published evidence, this added functionality could allow the clinician to use this practice-based evidence to help guide clinical decision-making [4].

In pediatrics, adolescents who actively participate in their health care online represent re-engagement of a vulnerable patient group that has tended to disengage from the health care system. Engagement through electronic portals is a familiar method of daily communication for adolescents, particularly on mobile devices. The average US teenager has internet access on their personal smart phones, and more importantly, they appear interested in communicating with their physicians about their health through mobile phones [5]. Effective mobile EHR or personal health record platforms can become a unique portal for teenagers to engage the health care system and generate important PROs. To achieve this, particular attention must be paid to the special privacy and confidentiality considerations of patient portal use by adolescents. Building a set of health care proxy options into EHRs is one way to ensure that health systems can use these tools effectively while still complying with privacy laws [6].

The EHR should evolve to a patient-inclusive technology, facilitating patient empowerment through ease of data access, HIPPA-secure and encrypted data sharing, and improved communication with all health care team members. At Stanford Children's Health today, health information exchange allows a community pediatrician, an academic pediatric gastroenterologist, a registered dietician, and a private practice psychiatrist to better care for a teenager with Crohn's disease and depression on multiple medications. Through our

patient portal, the teenager (and her parents) can communicate with one or all of her providers and review her own test results. In the near future, we will use standard EHR vendor functionality to ensure that if this patient were to enroll in a study, she will be able to report PROs directly from her mobile application when prompted by an automated text message. We also hope to make the medical record more transparent by allowing families – after obtaining necessary consent and assent – full access to physician notes, consistent with the OpenNotes movement. When the same patient is ready to transition from pediatric to adult care, the critical hand-off of information is relayed more easily between patient-preferred providers and care team members.

Patient-centered technology can support high-value, "whole-person" care. Such care coordination within a LHS empowers patients and families to be more activated and informed about disease self-management [7]. Researchers may more efficiently access PROs across various platforms as PROs become increasingly important to point-of-care, clinical trials, and drug development. As users of health technology become more interconnected with technology that reflects and supports convergence around the patient, the EHR could reach the goal it aspired to from the beginning — a portal that connects real people and adds meaning for every user.

Acknowledgments

Abbreviations

US	United States
EHR	electronic health records
LHS	learning health system
PRO	patient-reported outcome

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