Towards a Learning Health System: Incorporating Research into Clinical Care Using the EHR Patient Portal for Research Data Collection

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Abstract

Patient portal use has increased as has the functionality available within these portals. The ability to collect patient reported information is key to efficient health care and can be a key tool for research data capture. This project describes the transition from using REDCap to using the EHR patient portal for an autism center that conducts clinical intake and research screening via a questionnaire.

Introduction

Use of the patient portal for research recruitment and data capture is on the rise and health care organizations have embraced it as a bi-directional communication tool between patient and provider¹. However, uptake by patients has been mixed and found to be dependent upon user comfort-level with technology and the design of the portal². The University of Kansas’ Center for Child Health and Development (CCHD) maintains a research registry and database captured within RedCap. Data includes assessment results and diagnosis following interdisciplinary evaluations as well as information collected via survey prior to patient visits. The CCHD provides family centered care and conducts research regarding child development so the initial intake process for families must be easy to use and support both missions. The intake requires collection of a detailed patient family and medical history in order to inform the potential diagnosis of autism. The Patient Intake Form (PIF) was built as a survey and data collected via REDCap. When a patient contacted registration to schedule an appointment the registration staff triaged and if the patient qualified, an email was sent to the patient or guardian with a link to the REDCap survey. Having this rich set of data in REDCap streamlined research workflows but required clinicians to navigate both RedCap and the EHR during patient visits. Therefore the PIF survey was transitioned to a questionnaire in the EHR for ease of access.

Methods

The REDCap survey was reviewed and questions pruned so as to not duplicate current EHR fields. The data capture form was built as a flowsheet in the EHR then as a questionnaire in the patient portal. Where possible, data was mapped from the questionnaire to the appropriate existing fields in the EHR such as family history, medical history so that data was not duplicated in the chart. A decision tree was also built in the EHR for registration staff to automatically generate the questionnaire and register the patient/guardian for portal access if needed.

Results

The new portal questionnaire and associated workflows were deployed in July 2019. The new workflow utilizes a registration decision tree in the EHR to determine whether the patient qualifies and should be provisioned with portal access and the questionnaire sent. The questionnaire results are now visible to providers to use for patient care.

Conclusion

Utilizing the EHR patient portal for patient-reported research data collection is an opportunity to incorporate research into clinical care workflows and provide detailed information to the clinicians. Mapping questionnaire data to existing data fields in the EHR was time consuming as was the governance process to approve the build. Challenges remain with acceptance of research information being part of the medical record. Future work includes implementing the REDCap FHIR API in the EHR to send these data to the REDCap database.

References