Real-World Implementation of Patient-Reported Outcomes (PRO) into Electronic Health Record (EHR) Systems

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Abstract

Advancement in clinical research and decision support is hindered by limited inclusion of patient reported outcomes (PRO) data in electronic health records (EHRs) and other health IT solutions, preventing the availability of patients’ perspective in their own care. Although there are some EHRs that capture PRO, such as the National Institutes of Health (NIH)-funded Patient Reported Outcomes Measurement Information System (PROMIS) instruments, collecting this data at the point of care is not common practice. Digital tools to streamline the collection of PRO are not widely adopted due to challenges in workflow integration and lack of standards. Patient perspective and autonomy remains a powerful tool to ensuring healthcare decisions are informed by patients and used to impact prevention, diagnosis, treatment and long-term care. This panels presents findings from a project that aims to address gaps in the availability of PRO data by standardizing the integration of PRO with EHRs and other health IT systems.

Introduction

Patient-reported outcomes (PRO) consist of “any information providing the status of a patient’s health outcome which comes directly from the patient without interpretation of that patient’s response by a clinician or anyone else”.1 Although evidence shows that PRO can improve health outcomes, are relevant to clinical care and research, and offer insights into health status, symptom burdens, treatment adherence, and quality of life, PRO data is not routinely available in electronic form. Limited access, lack of standards, and complicated data applications threaten the opportunity of advancement for researchers who want to analyze PRO across practices or health systems. These researchers can benefit from a more standardized approach to data collection.

A vital goal for collecting PRO data is to enhance clinical decision-making and focus on data-driven care. Successful incorporation of PRO measures within this context requires continuous collection of accurate, valid, accessible, and reusable data in real time to support patient care, clinical research, quality improvement, and effectiveness treatment options.2,3

Patient Reported Outcomes

This project aims to standardize the integration of unstructured PRO in electronic health record (EHR) and other health IT systems and accomplish semantically consistent common data elements (CDE). The standardization of PRO data across health IT products can be achieved by using semantically consistent CDEs for data capture and using standard ways to exchange the data across health IT systems. The project implemented workflow and administrative processes to support testing of the technical specification. Common data element and data capture standards allow for PRO assessments to be conducted and easily shared regardless of the EHR or health IT solution being used. The project involves three models (Figure 1) for patient reported outcome measure (PROM) administration and incorporation of external PROM instruments: (1) using EHRs or other health IT systems, (2) using an external application or the Assessment Center’s application programming interface (API), or (3) using an EHR to launch a SMART on FHIR app.
Panel Objectives and Presenters

This panel will bring together the federal funder that oversees the pilots Office of the National Coordinator for Health IT (ONC) and leadership from pilot sites. Expert panelists will provide an in-depth review of how the inclusion of PRO is shaping patient’s treatment plans and can significantly improve health outcomes. This discussion will provide the audience with an understanding of patient reported outcomes, describe methods for measuring them, highlight successes and challenges experienced at pilot sites, and discuss implications for clinical research.

Ms. Stephanie Garcia, program manager of ONC’s patient-centered outcomes research (PCOR) initiatives within ONC’s Chief Scientist Division will introduce and moderate the session. Ms. Garcia supports the Assistant Secretary for Planning and Evaluation (ASPE) portfolio of intradepartmental projects that are funded through the Patient-Centered Outcomes Research Trust Fund to support the development of a robust data infrastructure that enables the incorporation of patient responses into research.

Dr. Daniella Meeker, Director of Clinical Research Informatics at the University of Southern California, will discuss the EHR-based PRO capture and exchange implementation of the HL7 Fast Healthcare Interoperability Resources (FHIR) PRO Implementation Guide (IG) with the EASIPRO system that includes 150 validated PRO measures at the pSCANNER (patient-centered scalable national network for effectiveness research) network. pSCANNER integrates data from three existing networks covering over 24 million patients. Dr. Meeker will discuss experiences in integrating external PROM instruments with EHRs and SMART-on-FHIR sandboxes.

Kyle Bradford, Associate Director of Informatics at Louisiana Public Health Institute will discuss experiences from the Research Action for Health Network (REACHnet) pilot site. REACHnet is a clinical data research network of health systems in Louisiana and Texas covering 7 million patients. Mr. Bradford will discuss REACHnet’s Health in Our Hands tablet-based collection of PRO data from patients and implementation of the HL7 FHIR PRO IG to map patient questionnaire data to a FHIR resource and stored in a FHIR server to support PRO data capture and exchange. Mr. Bradford will highlight experiences in collection of Physical Function PRO data and discuss applications to clinical research, patient recruitment, and identification of patients for clinical interventions.

Panel Discussion Questions
What key decisions must be made by organizations considering administering PROMs to patients?

How do organizational differences, vendor variations, and other factors affect the ability to standardize PRO?

What are the advantages, disadvantages, and other considerations when evaluating different PRO administration models (i.e., EHR, external PRO system, app/API integration)?

How should organizations work with their EHR vendor to deploy PRO? What EHR configuration or localization is needed?

Panel Learning Objectives

- Participants will learn about different types of patient reported outcomes and models for integrating them within health IT systems.
- Participants will have an improved understanding of the technical areas for standardization and critical integration of patient reported measures.
- Participants will learn about the technical specifications and workflows for implementing different PROM models and understand the implications of real-world workflows for PROM administration.
- Participants will learn about experiences from pilot sites implementing various PROM models and understand how to use the technical specifications and implementation guide in their own implementations.

Conclusion

While the focus of this project is to develop research infrastructure for PCOR, it simultaneously provides data needed to improve care delivery, patient experience, and decision support. This project and standards development effort supports development of a learning health system where research routinely enables and contributes to improved patient-centered outcomes. PRO standards development and implementations that support multiple models for capture and interoperable exchange of patient-reported data can offer flexibility and the opportunity to leverage established external instrument repositories, integrated EHR PROMIS instruments, and external PRO databases. Understanding the available options and lessons learned from standards development and pilot sites can foster increased adoption of PRO standards and development of best practices for the industry.

Statement of Participation

Each of the panelists and the moderator have confirmed that they will participate if this submission is accepted, at the assigned timeslot during the Informatics Summit.

References


