An Enterprise Approach to Designing Patient-Reported Outcomes (PROs) Systems: Diverse Perspectives Across a Large Healthcare Organization

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Introduction

Patient-reported outcomes (PROs) represent the patient's voice within clinical systems and provide important information directly from patients about how they experience health and healthcare. PROs continue to expand into the mainstay of clinical care and are utilized more frequently to document care processes and outcomes for clinical decision making, quality improvement, population health monitoring, and payment modeling. Yet, PROs systems are often implemented and evaluated in very siloed applications and settings. It is imperative that PROs systems are developed with a broader perspective on how they can be best leveraged and used across multiple settings in healthcare systems by distinct patients, providers, and administrators. Not only must PROs systems adapt to the needs and constraints of large healthcare organizations to remain sustainable, they must be designed with the flexibility to facilitate effective PRO data collection and review across the patient care continuum. Such an approach will ensure that clinicians "hear" their patients' voice to promote mutual understanding, shared decision making, and use of PRO data to support quality of care. In response to changing healthcare and policy environments, University of Washington (UW) Medicine, a large healthcare system in the Seattle area and coordinating organization for the regional Accountable Care Network (ACN), has prioritized the capture and presentation of PRO data as part of a larger goal to use health information technology to transform healthcare and improve patient and population health. To efficiently support an enterprise approach to PROs at UW Medicine, we undertook an effort to understand and address diverse perspectives through a system-wide lens on the development and integration of PROs systems into clinical care.

Methods

We engaged a multidisciplinary team representing diverse areas of expertise (e.g., health services research, human-centered design, information systems, systems engineering, health informatics, implementation science, health system leadership) to assess perspectives and recommendations for PRO systems design including identifying and reconciling requirements to meet stakeholder needs, data visualization and reporting, workflow and implementation, and systems integration. We then organized their expert opinion as well as evidence from the field into a set of formal design principles that are critical to consider when designing, developing, and implementing PROs systems within complex healthcare delivery systems.

Results

Design principles were organized into four development approaches that can address the complexity of building PROs systems for the diverse user base of a large healthcare system:

1) ***Establishing PRO design requirements that align with diverse stakeholder needs:*** Meaningful PROs systems start with an approach to establish design requirements for PRO capture and use that address the information needs of all systems users. When designing PRO systems for large healthcare systems, this process is further complicated as the information needs of users diversify across multiple clinical specialties, care settings, and stakeholder roles (e.g., patients, providers, administrators). Not only is the assessment of stakeholder needs a critical step for system design, health systems must also establishing preliminary organizing frameworks that help ensure decisions are consistent with overarching system goals.

2) ***Designing enterprise strategies for PRO reporting:*** Given requirements for PROs capture and use, PRO systems must consider how to display PROs for a variety of audiences and purposes, including individual patient care and decision-making, clinical quality improvement, and population health. Expectations for how PROs should be visually and functionally reported will vary by clinical specialty and user, even for the same

PRO data points. Additional considerations are necessary regarding the integration of PRO data with electronic health record data to provide optimal visualizations to support patient care.

3) ***Incorporating characteristics of diverse clinical environments into PROs workflow models:*** Workflow design for the capture and use of PROs by clinical staff is as integral to PROs system success as the technology itself. However, healthcare organizations must also consider standards for resource allocation, security, clinical care policies and procedures, and approaches to patient portal use. A systems engineering approach is recommended for modeling and evaluating clinical workflow and integration of standardized PRO capture across diverse clinical settings.

4) ***Enhancing PROs data and interface integration across healthcare delivery systems:*** At the point of care, PROs provide an invaluable opportunity to better understand and track patient outcomes and inform clinical decision-making. However, at the enterprise level, the collection of PROs data also invites the potential for duplication, inefficiencies, fragmentation, and inappropriate data use. Healthcare organizations must consider the diversity of PROs data collection tools that organically develop in any large system and how to best integrate these tools to balance the needs of PROs functionality, the interface experiences of healthcare system users, and the efficiencies needed to support scalability across health systems.

Discussion:

In the era of accountable care, PROs are an increasingly important measure of care and care quality. While this provides a critical opportunity to connect patients' experiences with clinical decision-making, PRO data use continues to develop in siloed clinical settings. In order to leverage the capacity of PROs to truly facilitate patient-centered care, it necessary to establish a more strategic approach that guides HIT enabled practice models across healthcare systems, supporting the needs of stakeholders at all levels of the system and ensuring alignment with broader goals for patient care. The design principles detailed from this work highlight the importance of clearly documenting the capabilities, constraints, and needs of the healthcare environment in which PROs will be implemented prior to formalizing the design approach, and thoroughly defining how data will be used across all system stakeholders to inform both the technical requirements and workflow design. The framework provided by these design principles can guide the development of effective HIT systems that aim to integrate patient reported data into clinical care.