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Incorporating longitudinal pediatric patient-centered outcome measurement into the clinical workflow using a commercial electronic health record: a step toward increasing value for the patient

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ABSTRACT

Patient-centered outcomes measurement provides healthcare organizations with crucial information for increasing value for patients; however, organizations have struggled to obtain outcomes data from electronic health record (EHR) systems. This study describes how Texas Children's Hospital customized a commercial EHR system and assembled a cross-functional team to capture outcomes data using existing functionality. Prior to its installation and customization, no surgical subspecialties besides the congenital heart and transplant surgery groups conducted prospective, patient outcomes measurement, but by 2015, the outcomes of over 1300 unique patients with supracondylar fractures, cleft lip and/or palate, or voiding dysfunction had been tracked. Key factors for integrating outcomes measurement into the clinical workflow include ongoing communication between cross-functional teams composed of clinicians and technical professionals, an iterative design process, organizational commitment, and prioritizing measurement as early as possible during EHR optimization.

Keywords: Epic, electronic health records, outcomes, value, patient-centered outcomes measurement

CASE REPORT

INTRODUCTION

As first championed by Michael Porter and Elizabeth Teisberg, a fundamental goal of healthcare should be to maximize value for patients, where value is defined as the health outcomes achieved per dollar spent to deliver them.[1] Unfortunately, it is widely recognized that health outcomes in America are heterogeneous, often inadequate, and lack patient-centeredness.[2] Outcomes are typically measured narrowly and intermittently, and those that matter most to patients, such as functional status and quality of life, remain largely unknown.[3,4] Outside of organ transplantation and in vitro fertilization, which require providers to measure and report certain outcomes for every single patient, most providers collect few, if any, patient outcomes on a continuous basis. Even fewer providers report them publically.[5,6] For providers with paper or antiquated electronic health record (EHR) systems, the greatest barriers to measurement historically were time, cost, and workflow disruption.[7] Advanced EHRs have been heralded by researchers and policy-makers alike as a key solution.[8] A tenet of the Patient Protection and Affordable Care Act, for instance, proclaimed that EHRs would reduce administrative burdens, cut costs, reduce medical errors and most importantly, improve the quality of care.[9] With this supposition, the American Recovery and Reinvestment Act's 2009 Meaningful Use statute granted payments to providers for transitioning to qualified EHRs, a measure that will cost tax payers an estimated $27 billion by 2017.[10] In addition to the Meaningful Use incentive program, numerous programs by both private and public insurers have motivated hospitals to report an increasing number of measures. Massachusetts General Hospital and the Massachusetts General Physicians Organization, for instance, report over 120 measures to different external entities at a cost of over one percent of net patient service revenue, even though institution-wide performance measures have been shown to only predict small differences in patient outcomes.[11,12]

Ideally, EHRs should enable the capture and reporting of data on patient health outcomes. In fact, future iterations of Meaningful Use will require it.[13] However, many organizations, including Texas Children's Hospital, have found it challenging to abstract information beyond measures of the care delivery process and clinical guideline compliance. Further complicating electronic measurement in the pediatric population are special requirements in terms of privacy controls, proxy access, and health information exchange.[14] Across all patient groups, there remains a paucity of information in the literature about optimizing EHRs for patient-centered outcomes measurement. This study describes the evolving experience at Texas Children's Hospital with prospectively capturing, evaluating, and reporting pediatric patient-centered outcome information using a commercially available EHR system.

METHODS

Prior to the installation of a system-wide EHR at Texas Children's Hospital, the inpatient hospital documentation system was paper-based. For outpatient care, a free-text electronic record was used. In 2006, Texas Children's purchased the Epic Systems EHR (Epic Systems, Verona, WI, USA) and began a staged implementation of the various modules (revenue cycle, ambulatory, inpatient, etc.). The outpatient clinical go-live occurred in 2008, and the hospital's began in 2010. Measurement and extraction of patient-centered outcomes was not prioritized during the implementation phase, but was addressed in future optimization cycles. Upon completion of the deployment,

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clinicians from multiple departments began requesting the ability to better measure meaningful patient outcomes, something the Congenital Heart Surgery Service at Texas Children's Hospital Heart Center was already doing with a homegrown software tool. Modeled after this experience, a team of clinical data specialists, statisticians, data analysts, and systems analysts was assembled in December 2011 and charged with incorporating patient-centered outcome measurement into the clinical workflow to enable meaningful measurement of every patient, beginning with selected conditions in orthopedic surgery, plastic surgery, and urology. By December 2013, the outcome measurement team included a dedicated vendor-trained analyst to build custom forms and to ensure that data captured throughout the care cycle (inpatient, outpatient, patient portal) could be aggregated and analyzed cumulatively.

The decisions regarding which specialties were prioritized were made at the level of the department of Surgery, and its subsidiary, the Outcomes & Impact Service. A key factor in prioritizing which departments would develop the tools first was an assessment of divisional readiness and the identification of a physician-champion. Custom tools that collected discrete and mineable data were first created for supracondylar fracture patients. Prior to their development, providers could only track supracondylar fracture patients using claims data, which aggregated multiple types of fracture patterns together (type I, II, and III) that have highly variable treatments and outcomes. A structured and mineable spreadsheet for documenting patient care was developed to measure critical aspects of the patient presentation in the emergency center, such as mechanism of injury, hand color, and skin condition (Figure 1a). Similar but separate spreadsheets were used to document the patient's preoperative condition (Figure 1b), operative experience (Figure 1c), and condition upon discharge (Figure 1d). Clinicians used the forms at the point of care to document the patient assessment longitudinally. The development of each spreadsheet required structured dialogues regarding the timing and mode of data capture among the orthopedic surgeons and the vendor-trained analyst building the spreadsheet.

Following the development of supracondylar fracture patient spreadsheets, a more sophisticated data collection form was developed to capture outcomes for patients with voiding dysfunction that allowed for discrete data capture, prose note generation, image incorporation, and the potential for clinical decision support.[15] The form was designed to assess and aggregate patient burden of disease through patient-reported responses to assessments of both bladder and bowel function, pain, and quality of life using a validated tool (Figure 2).[16] Midlevel practitioners used the form as part of their initial patient intake and for ongoing assessment of disease burden, as the form automatically calculated and reported a disease-burden score at each encounter. Clinicians and patients together referenced the scores from prior visits and used the functional assessment information to guide interventions and escalations of care, such as initiation of antibiotic prophylaxis, biofeedback exercise, or behavioral therapy.

In plastic and reconstructive surgery, structured spreadsheets were initially created to capture patients' functional and aesthetic

CASE REPORT

Figure 1: Emergency department history and physical documentation flowsheet: supracondylar fracture patient (image printed with permissions from Texas Children's Hospital). (A) Fields from the initial evaluation portion of the flowsheet. (B) Fields from the preoperative evaluation portion of the flowsheet. (C) Fields from the operative experience portion of the flowsheet. (D) Fields from the condition at discharge portion of the flowsheet.

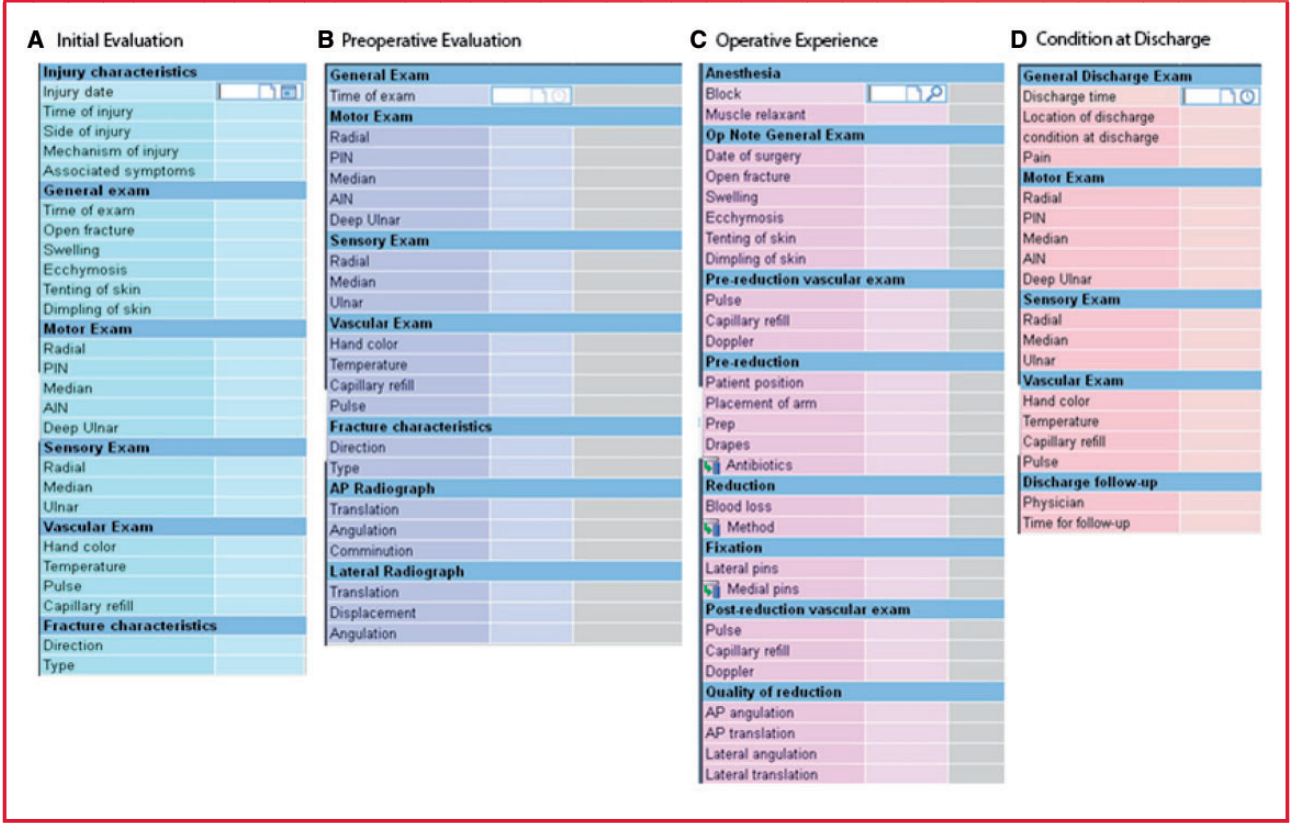
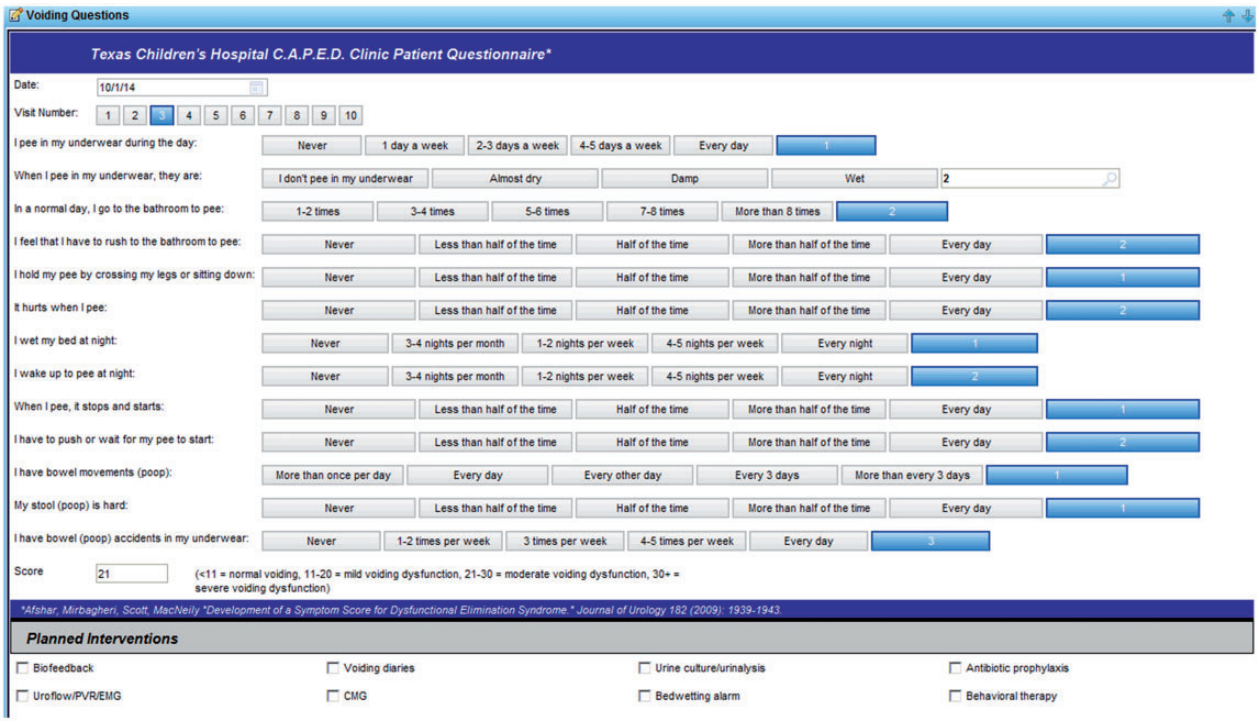


Figure 2: Form for evaluation of patient with voiding dysfunction (image printed with permissions from Texas Children's Hospital.).



outcomes after cleft, lip, and palate repair. In the first 20 months, only 23 patients were tracked, at which time the spreadsheet was converted to a more structured form with accompanying "hard stops," which required providers to fully complete the outcomes documentation prior to finalizing the visit note (Figure 3a). Although hard stops are typically not recommended by EHR vendors due to possible workflow disruption and end-user dissatisfaction, [17,18] this particular request was made by the clinicians to ensure form completion. Over the ensuing 5 months, 214 patients were tracked. During the same period, outpatient note templates were created that contained predefined lists of choices bound to structured, mineable data elements that speech pathologists used to track characteristics of speech for cleft lip and palate patients, such as minimal, moderate, or severe hypernasality (Figure 3b). The drop-down list was bound to the structured data elements, ensuring the data would be mineable, which was not the default functionality. As of January 2015, patients with brachial plexus injury were being followed with both visualizations of the operative repair (when indicated) (Figure 3c) and their subsequent functional outcome (Figure 3d), measured with discrete, mineable, and reportable elements.

RESULTS

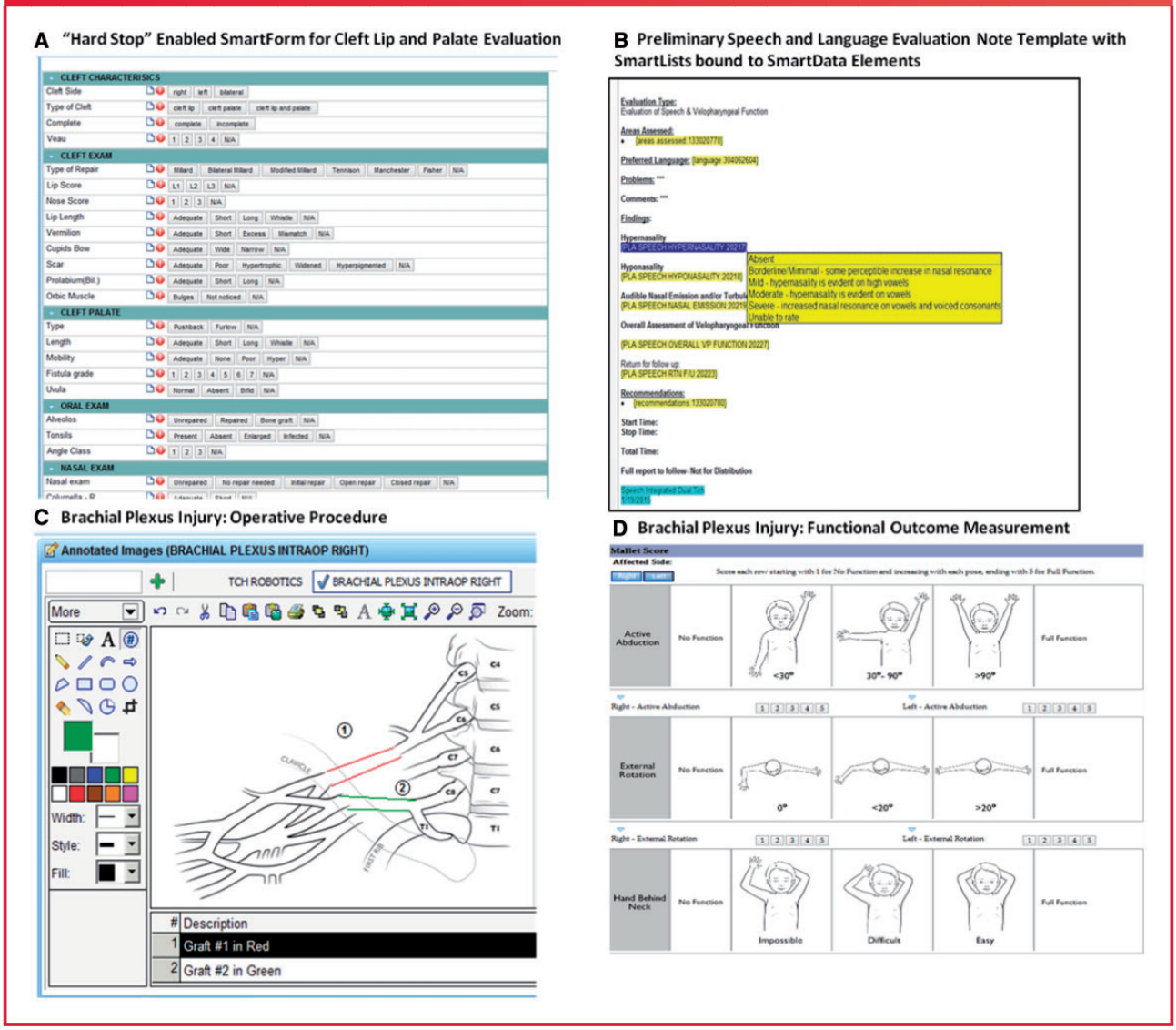
Prior to the installation and optimization of the EHR, manual chart abstraction was the only means of measuring and reporting patient-centered outcomes. Other than the congenital heart surgery groups, which used dedicated, separate data capturing systems, no specialties conducted prospective, continuous measurement of patient outcomes. By 2014, more than two dozen mineable measures including pain, functionality, appearance, and burden of disease were being collected on an ongoing basis in a structured format for three conditions: supracondylar fractures, cleft lip and palate, and voiding dysfunction (Table 1). While these conditions represented only a portion of each department's total annual volume, over 1300 unique patients had been tracked as of January 1, 2015. Data was being gathered in operating room, ambulatory, and Emergency Center settings.

DISCUSSION

To truly improve the quality of care and ultimately deliver value to the patient, patient outcomes must be routinely measured and reported at the level of the medical condition. Increasingly, this entails use of an electronic health record. There are limited reports in the literature about how to integrate patient-centered outcomes measurement into the EHR.[19,20] This is the first study to systematically describe several successful approaches to incorporating pediatric patient-centered outcome measurement into a pre-existing commercially available electronic health record system leveraging existing functionality.[21]

At the department level, incorporating patient-centered measurement tools such as structured forms and spreadsheets into the clinical workflow is an iterative process and requires a clinician-focused strategy and cross-functional teams consisting of front-line clinicians, vendor-trained analysts, data architects, and data specialists. Clinician engagement is critical since providers directly interface with patients and understand outcome measurement priorities and workflow limitations. Including a systems analyst early in the process is also important as clinicians typically do not appreciate the specific functionalities of each software tool. Ongoing collaboration between these teams is essential and helps to ensure that the design allows for effective outcome measurement while minimizing negative impact on care efficiency.

Figure 3: Plastic and reconstructive surgery measurement form (image printed with permissions from Texas Children's Hospital. Mallet drawing courtesy of the Department of Physiotherapy, Royal Children's Hospital Melbourne). (A) "Hard Stop" enabled SmartForm used for initial cleft lip and palate evaluation. (B) Speech and language evaluation note template showing SmartLists bound to SmartData elements to enable future data mining. (C) Annotated image note with mineable fields used in the operating room to document key parts of the operative repair for brachial plexus injury. (D) A functional outcome scale incorporated into the EHR using a SmartForm to track functional outcomes following brachial plexus repair.



At the organizational level, incorporating patient outcomes measurement into the EHR requires significant commitment as the process can be resource-intensive. Engagement of the institution-wide team responsible for information technology is critical to ensure that individual projects do not cause unintended downstream effects. For instance, during the development of the structured form for the Voiding Dysfunction Clinic, it was discovered that the same questionnaire being built for the vendor's integrated patient portal was not being designed to ensure compatibility with data collected during the patient encounter.[14] Essentially, there would have been two separate data repositories for the same type of information on the same patients. Only close collaboration among the patient portal and ambulatory teams allowed the patient forms to be linked to a single data repository.

Technical teams rely on weekly user feedback, as well as quantitative assessments of engagement, as measured by the portion of patients tracked through clinical sources compared to patients identified in administrative systems.

Through this multi-year, multi-specialty experience, it is clear that incorporating outcome measurement into the EHR and the clinical workflow requires a dedicated, cross-functional team of clinical and technical experts, which add considerable cost to the care delivery structure. Each tool previously described carries both advantages and disadvantages in terms of cost, customizability, and functionality. Ultimately, organizations will need to determine which strategy works best for optimizing their EHR for patient-centered outcomes measurement and reporting while simultaneously developing mechanisms to demonstrate the return on investment.

Table 1: Patient Outcome Measurement at Texas Children's Hospital by Condition.

Medical Condition	Mineable Measures (pre-EHR, 2009)	Mineable Measures within EHR (2014 – present)	Unique Patients Tracked/Year	Total Department Visits/Year
Voiding dysfunction	Outpatient encounters (claims data)	Volume of patients with voiding dysfunction	470 (604 visits)	13 745
	Diagnosis (claims or scheduling data)	Patient responses and scores to voiding dysfunction survey		
		Changes in scores over time in response to interventions		
		Outcomes for voiding dysfunction		
Cleft lip/cleft palate	Outpatient encounters (claims data)	Cleft lip characteristics (e.g., side, type)	513[a]	6564
	Diagnosis (claims or scheduling data)	Key elements of cleft lip and palate exam (e.g., lip length, scar, etc.)		
	Procedural Volume (claims data)	Cleft palate characteristics (e.g., type, length, mobility)		
		Key features of the oral exam as it relates to outcomes measurement		
		Key features of the nasal exam as it relates to outcomes measurement		
Supracondylar fractures	Outpatient encounters (claims data)	Volume by type of supracondylar fracture (I, II, or III)	622 (477 operative patients)	29 317
	Diagnosis (claims or scheduling data)	Key elements of history and physical during initial presentation		
	Procedural Volume	Key elements of preoperative exam—motor, sensory, vascular, fracture characteristics, findings from radiograph		
		Key elements from operation		
		Key elements from post-operative exam		
		Key elements of discharge exam		

[a]Projected based on 5-month experience.

Organizations considering transitioning to a new EHR should discuss priorities for outcome measurement early in the process with the end goal in mind. Seemingly innocuous post hoc requests such as having patient-reported outcomes built into the EHR may have difficulty getting prioritized in a myriad of optimization requests. Institutions in the post-implementation "optimization" phase should opt for a dedicated outcome measurement team to collaborate with the multiple implementation teams, which are typically structured by clinical application or specialty service. Development of outcomes measurement tools must involve clinicians to ensure that they are as user-friendly and clinically relevant as possible. Ultimately, however, providers and policy-makers alike will need to advocate and provide incentives for improved patient-centered outcome measurement and reporting capabilities for all EHR vendors.

This study has several limitations. It only captures the in-depth experience of a single institution, Texas Children's Hospital. Second, commercial EHR capabilities can vary by vendor and software version. Also, although this EHR vendor's software has the capability to do this at any institution, organizational readiness, local resources, and governance structures to support significant configuration can vary substantially by site.

Additionally, outcome measurement using the EHR at Texas Children's has been implemented rather recently, and only in a few areas, given the barriers previously described. There remains limited data on adoption, user satisfaction, costs, or patient impact over time. Follow-up studies are needed to evaluate the differences among developing outcome measurement tools, and to evaluate the tools' impact on patient outcomes, physician satisfaction, and the cost of delivering care.

Despite these limitations, this study demonstrates that robust, longitudinal, patient-centered outcome measurement is feasible using currently available information technology, despite workflow and time constraints.

CONTRIBUTORS

K.C. and C.F. were engaged in every aspect of the study from the detection of the problem through the creation of the solution, design of the study, analysis of the data, and writing of the paper. Z.L., M.X., and T.F. were involved in the design of the study, the analysis of the results, and the writing of the paper.

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