Technical Note

Using a Web-Based Data Collection Platform to Implement an Effective Electronic Patient-Reported Outcome Registry

Vincent A. Lizzio, M.D., Caleb M. Gulledge, B.S., Fabien Meta, M.D.,
Sreten Franovic, B.S., M.S., and Eric C. Makhni, M.D., M.B.A.

Abstract: Modern health care places significant emphasis on patient-centered care. As a result, many orthopaedic providers are incorporating routine patient-reported outcome measure (PROM) collection into their practice. However, routine PROM collection often disrupts clinical workflow and can place a burden on both the patient and the provider. Electronic PROM collection systems, if implemented deliberately to maximize convenience and efficiency, have the potential to mitigate these obstacles. This technique guide presents an overview of designing and implementing a PROM-based clinical registry for the ambulatory orthopaedic clinic using Research Electronic Data Capture (REDCap; Vanderbilt University, Nashville, TN). We outline the basic steps of creating a simple but effective patient registry using this accessible data collection platform.

Modern health care places significant emphasis on patient-centered care. Because of this, many orthopaedic providers are incorporating routine patient-reported outcome measure (PROM) collection into their practice. Unfortunately, routine PROM collection places a burden on both the patient and the provider, often resulting in disruptions in clinical workflow.[1]

Electronic PROM (EPROM) collection systems have the potential to mitigate many of the aforementioned obstacles; however, great care must be taken to design and implement these collection systems in a logical and deliberate manner. These systems must be designed with patient privacy and information protection foremost in mind, followed by a need for patient and provider convenience and efficiency.

In this technique guide, we review our method of designing, building, and implementing a PROM-based clinical registry for the ambulatory orthopaedic clinic. We outline the basic steps of creating a simple but effective patient registry using an accessible data collection platform.

Technique

We use Research Electronic Data Capture (REDCap; Vanderbilt University, Nashville, TN) to routinely collect EPROMs on all patients coming into our ambulatory sports medicine clinic.[2] REDCap is a noncommercial, web-based platform developed by Vanderbilt University. This platform functions on the local institutional server; however, it also communicates with Vanderbilt University's server for specialized auto-scoring and computerized adaptive testing (CAT) functionality. The requirements for installing REDCap include a web server with PHP (Personal Home Page, a scripting language for web development), a MySQL (My Structured Query Language) database server, an SMTP (Simple Mail Transfer Protocol) e-mail server, and a file server. At our institution, we have a dedicated team in the public health sciences department that manages these servers.

With REDCap, users can create custom questionnaires or download existing EPROMs from a shared online library. Our EPROM collection system is based on a few basic principles displayed in Table 1. A detailed

Table 1. Basic Principles of EPROM Collection

Principle	Strategies
Minimize patient burden	Reduce overall number of questions
	Reduce overall time to completion
	Avoid asking patients to respond to questions that can be easily found in the chart
Minimize provider burden	Reduce time to completion
	Administer PROM remotely
	Avoid clinical delays
Reduce decision making	Use single standardized forms for all patients and avoid custom questionnaires
	Use branching logic
Optimize for clinical research and quality reporting	Perform automatic calculated scoring of PROM
	Use consistent variable names and coding
	Catalog patients by diagnosis and/or procedure

EPROM, electronic patient-reported outcome measure; PROM, patient-reported outcome measure.

description of registry implementation and EPROM administration is provided in Video 1.

Project Setup

The project is enabled for longitudinal collection with survey administration. Because of variability in the frequency and timing of clinical encounters among different patients, events are loosely defined as "clinic visit 1," "clinic visit 2," and so on (individual users can choose terminology most relevant to their practice). Aside from some unique demographic questionnaires in the initial clinic encounter, every event is identical.

Every clinical encounter begins with a short survey that asks the patient to explain which provider he or she is seeing and the reason for his or her clinic visit. The purpose for the clinic visit is based on the anatomic location of injury and formatted as a "check box"–style question, with each response prompting a follow-up

question to specify laterality. This method accommodates for multiple injuries or concerns, if necessary.

We collect National Institutes of Health Patient-Reported Outcomes Measurement Information System (PROMIS) questionnaires from every patient at every clinical encounter. Specifically, we collect the PROMIS Physical Function CAT (for patients with lower-extremity injury), PROMIS Physical Function–Upper Extremity CAT (for patients with upper-extremity injury), PROMIS Pain Interference CAT, and PROMIS Depression CAT for all patients.[1] These forms are downloaded from the REDCap Shared Library and added to each event (Fig 1).

Clinic visit 1 is unique in that it includes surveys that obtain identifying and demographic information including name, medical record number, ethnicity, and so on. This encounter also contains a custom data entry form (not a patient survey) that can be routinely

Fig 1. The Research Electronic Data Capture Shared Library has thousands of prebuilt questionnaires for common patient-reported outcome measures. These forms may contain unique functionality that would otherwise not be possible with standard survey construction, such as computerized adaptive testing and auto-scoring. (PROMIS, Patient-Reported Outcomes Measurement Information System; SF, short form.)

A

B

Fig 2. (A) A patient's first clinic visit prompts a custom demographic information form. (B) The diagnosis and procedure form allows grouping of patients for targeted data extraction. (CPT, current procedural terminology; ID, identification; Post Op, postoperatively.)

updated to catalog diagnoses, procedures, or research enrollment (Fig 2). Although this requires maintenance, it allows the provider to conveniently extract data for specific groups of patients during data export. Massive extraction of patient procedure and diagnosis information from the electronic medical record (EMR) and insertion into REDCap can expedite maintenance of these forms.

Optimizing Patient Compliance and Quality of Data

The survey workflow is designed to minimize patient effort and decision making. For our purposes, the use of branching logic and survey queues automates the vast majority of survey administration. This prevents incomplete responses or incorrect administration of EPROMs.

Although the PROMIS Pain Interference and PROMIS Depression forms are distributed to all patients, the type of PROMIS Physical Function form that is given to a patient is dependent on his or her specific area of injury. If an upper-extremity injury is selected, the PROMIS Physical Function–Upper Extremity questionnaire is added to the survey queue whereas the generic PROMIS Physical Function questionnaire is not.

Once a specific physical function form is prompted for administration, it is programmed to be administered for every subsequent patient encounter. This is for purposes of tracking long-term outcomes of patients. For example, a patient who was seen a year ago for shoulder pain and is now returning for knee pain will receive both PROMIS

Physical Function and PROMIS Physical Function–Upper Extremity forms even if he or she only selects "knee" as the anatomic location of injury.

Within the custom demographic questionnaires, we use branching logic to hide questions that are not relevant to the patient. For example, follow-up questions regarding duration and amount of smoking will only be visible if patients affirm that they have a smoking history.

Finally, when a patient submits his or her responses to 1 survey, the subsequent survey is automatically started (enabled in "survey settings"). Thus, the patient only sees a continuous series of questions and does not need to put forth the effort of selecting each survey individually.

Workflow

After patient check-in on the day of the clinical encounter, a research assistant searches for an existing patient in REDCap (if returning) or adds a patient to the registry. The first questionnaire of the next available event is selected and opened as a survey onto an iPad (Apple, Cupertino, CA) (Fig 3). The patient is given the tablet computer and directed to return it when he or she is finished. A large stop sign is illustrated to clearly depict completion of the survey. Once the survey is completed, the research assistant communicates to the medical assistant that the patient is ready to be taken back to the examination room and begin the clinical encounter.
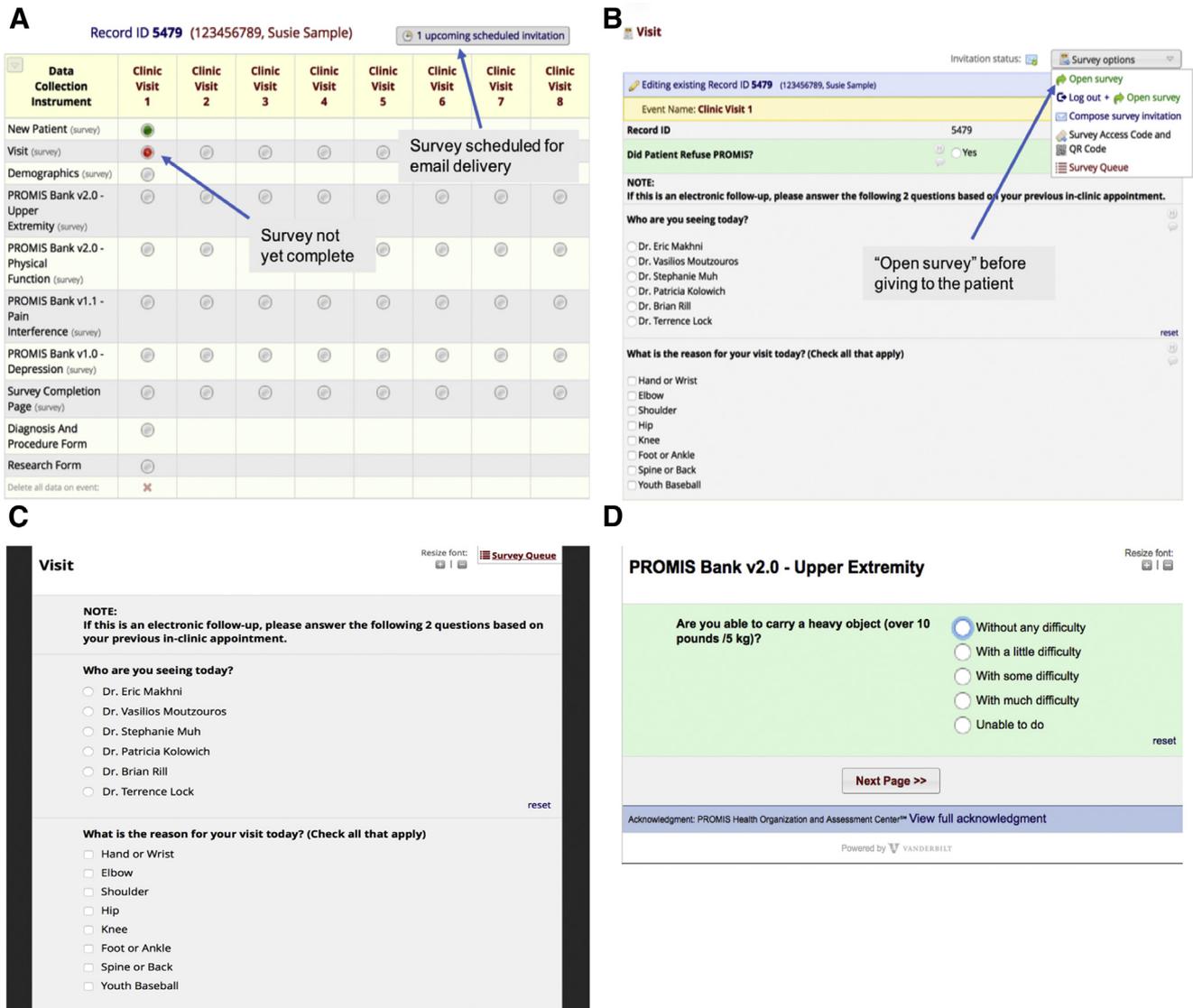
Fig 3. (A) Survey status and secure electronic invitations are easily managed at the record identification (ID) homepage. (B) A research assistant navigates to the appropriate survey form and opens the survey for the patient. (C) The patient survey entry form is simple and easy to navigate for the patient. (D) Computerized adaptive testing forms are automatically prompted based on the anatomic location of injury. (PROMIS, Patient-Reported Outcomes Measurement Information System.)

EPROMs are also remotely distributed to patients before their scheduled clinic visits. This is performed through REDCap's e-mailing capabilities and Mosio's integrated text messaging service (Mosio, Seattle, WA). A research assistant or clinical assistant reviews the schedule and sends an e-mail containing a link to the REDCap survey 1 week before each patient's scheduled clinic visit. These links are also sent by text through the Mosio service so that patients can complete their surveys by mobile phone. This gives patients the opportunity to complete EPROMs remotely and avoid the slight inconvenience of in-clinic participation.

Cataloging of patient diagnoses, procedures, surgical procedures, and research enrollment can be performed retrospectively. This maintenance is performed at the end of every clinical workday to keep the registry up to date.

Discussion

Developing a system of routine survey administration that has high patient compliance while avoiding delays in clinical workflow can be extremely difficult. Our method of using REDCap to administer PROMIS CAT questionnaires makes data collection efficient and effective. PROMIS is an ideal PROM because it allows for the use of CAT forms, which exhibit superior psychometric qualities compared with traditional paper-and-pencil forms, including fewer questions,
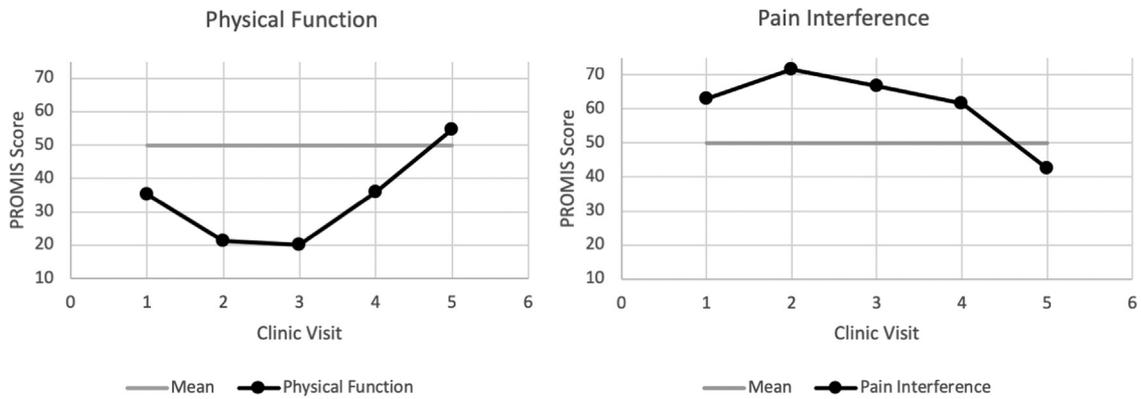
Fig 4. Data output for Patient-Reported Outcomes Measurement Information System (PROMIS) computerized adaptive testing score review. (DOS, date of surgery; Pre Op, preoperatively.)

decreased time to completion, lower floor and ceiling effects, and improved reliability.[3,4] CAT forms use item-response theory, which allows each questionnaire to evaluate previous responses to determine optimal subsequent questions.[4] By predominantly using CAT forms, time to completion is significantly reduced and clinical delays are often prevented.[5]

Previous studies have evaluated the feasibility and compliance of our system. On average, patients take 3.29 minutes to complete the entire survey set[5] and only have to answer 15.3 PROMIS questions in total.[6] Patient compliance for in-clinic survey administration is over 90%,[6] with remote e-mail compliance approaching 70% (unpublished data, P. Borowsky, November 2018).

Currently, REDCap is limited by the inability to interface with EMRs. Because of this, reviewing scores in real time (and comparison with previous scores) remains somewhat cumbersome and requires manual entry to generate trended data output (Fig 4). Future integration of REDCap with common EMRs would significantly improve clinical utility. Ultimately, our method of designing and implementing REDCap for PROMIS collection overcomes many of the challenges associated with high-volume PROM collection in a busy orthopaedic practice.

References

1. Brodke DJ, Saltzman CL, Brodke DS. PROMIS for orthopaedic outcomes measurement. *J Am Acad Orthop Surg* 2016;24:744-749.
2. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—A metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform* 2009;42:377-381.
3. Fidai MS, Saltzman BM, Meta F, et al. Patient-Reported Outcomes Measurement Information System and legacy patient-reported outcome measures in the field of orthopaedics: A systematic review. *Arthroscopy* 2018;34:605-614.
4. Hung M, Stuart AR, Higgins TF, Saltzman CL, Kubiak EN. Computerized adaptive testing using the PROMIS physical function item bank reduces test burden with less ceiling effects compared with the short Musculoskeletal Function Assessment in orthopaedic trauma patients. *J Orthop Trauma* 2014;28:439-443.
5. Kadri O, Jildeh TR, Meldau JE, et al. How long does it take for patients to complete PROMIS scores?: An assessment of PROMIS CAT questionnaires administered at an ambulatory sports medicine clinic. *Orthop J Sports Med* 2018;6. 2325967118791180.
6. Lizzio VA, Blanchett J, Borowsky P, et al. Feasibility of PROMIS collection in the ambulatory sports medicine clinic with respect to cost and patient compliance: A single surgeon experience. *Orthop J Sports Med* 2019;7:2325967.