Users’ Guide for Integrating Patient-Reported Outcomes in Electronic Health Records

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Albert Wu, MD, MPH, Co-Principal Investigator

NIH Collaboratory/PCORNet Grand Rounds
October 13, 2017

Funded by the Patient-Centered Outcomes Research Institute
Multi-Purpose PROs

Assess PROs

Inform Quality Improvement

Evaluate Care Quality

Use in Clinical Practice
Measure once, cut twice—adding patient-reported outcome measures to the electronic health record for comparative effectiveness research

Albert W. Wu*, Hadi Kharrazi, L. Ebony Boulware, Claire F. Snyder

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Accepted 19 April 2013
Multi-Purpose PROs

Assess PROs

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Use in Clinical Practice
Clinician & Patient View Report

Is there one problem in particular you'd like your doctor or nurse to address during your next visit?

I am having trouble doing the things I need to do.

Enter any other comments or questions for your doctor or nurse.

It's helpful answering these questions.

The results for the most recent and four previous surveys are graphed below. Graphs highlighted in yellow represent either a significant worsening or a score that is likely to be a problem. For a summary of the items in each score, click What is this? For an explanation of the scoring, click Score meaning. For suggestions for how to address potential problems, click What can I do?

### Table Chart

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</tr>
</tbody>
</table>
Review of Electronic Patient-Reported Outcomes Systems Used in Cancer Clinical Care

By Roxanne E. Jensen, PhD, Claire F. Snyder, PhD, Amy P. Abernethy, MD, Ethan Basch, MD, Arnold L. Potosky, PhD, Aaron C. Roberts, Deena R. Loeffler, MA, and Bryce B. Reeve, PhD

Lombardi Comprehensive Cancer Center, Georgetown University Medical Center, Washington, DC; The Johns Hopkins University School of Medicine and the Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins, Baltimore, MD; Duke Comprehensive Cancer Center, Duke University Medical Center, Durham; Lineberger Comprehensive Cancer Center, University of North Carolina, Chapel Hill, NC; and Health Outcomes Group, Memorial Sloan-Kettering Cancer Center, New York, NY

Abstract

Purpose: The use of electronic patient-reported outcomes (PRO) systems is increasing in cancer clinical care settings. This review comprehensively identifies existing PRO systems and explores how systems differ in the administration of PRO assessments, the integration of information into the clinic workflow and electronic health record (EHR) systems, and the reporting of PRO information.

Methods: Electronic PRO (e-PRO) systems were identified through a semistructured review of published studies, gray literature, and expert identification. System developers were contacted to provide detailed e-PRO system characteristics and clinical implementation information using a structured review form.

Results: A total of 33 unique systems implemented in cancer clinical practice were identified. Of these, 81% provided detailed information about system characteristics. Two system classifications were established: treatment-centered systems designed for patient monitoring during active cancer treatment (n = 8) and patient-centered systems following patients across treatment and survival periods (n = 19). There was little consensus on administration, integration, or result reporting between these system types. Patient-centered systems were more likely to provide user-friendly features such as at-home assessments, integration into larger electronic system networks (e.g., EHRs), and more robust score reporting options. Well-established systems were more likely to have features that increased assessment flexibility (e.g., location, automated reminders) and better clinical integration.

Conclusion: The number of e-PRO systems has increased. Systems can be programmed to have numerous features that facilitate integration of PRO assessment and routine monitoring into clinical care. Important barriers to system usability and widespread adoption include assessment flexibility, clinical integration, and high-quality data collection and reporting.

Helps clinicians and researchers interested in implementing PRO assessment to aid patient care

Includes
- Considerations
- Options
- Resource requirements
- Relative advantages and disadvantages

Implementing patient-reported outcomes assessment in clinical practice: a review of the options and considerations

Claire F. Snyder · Neil K. Aaronson · Ali K. Choucair · Thomas E. Elliott · Joanne Greenhalgh · Michele Y. Halyard · Rachel Hess · Deborah M. Miller · Bryce B. Reeve · Maria Santana

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Abstract

Purpose While clinical care is frequently directed at making patients “feel better,” patients’ reports on their functioning and well-being (patient-reported outcomes [PROs]) are rarely collected in routine clinical practice. The International Society for Quality of Life Research (ISOQOL) has developed a User’s Guide for Implementing Patient-Reported Outcomes Assessment in Clinical Practice. This paper summarizes the key issues from the User’s Guide.

Methods Using the literature, an ISOQOL team outlined considerations for using PROs in clinical practice; options for designing the intervention; and strengths, weaknesses, and resource requirements associated with each option.

Results Implementing routine PRO assessment involves a number of methodological and practical decisions, including (1) identifying the goals for collecting PROs in clinical practice, (2) selecting the patients, setting, and timing of assessments, (3) determining which questionnaire(s) to use, (4) choosing a mode for administering and scoring the questionnaire, (5) designing processes for reporting results, (6) identifying aids to facilitate score interpretation, (7) developing strategies for responding to issues identified by the questionnaires, and (8) evaluating the impact of the PRO intervention on the practice.

Conclusions Integrating PROs in clinical practice has the potential to enhance patient-centered care. The online version of the User’s Guide will be updated periodically.

This paper is produced on behalf of the International Society for Quality of Life Research (ISOQOL). All authors are members of ISOQOL. All authors participated in writing the paper and reviewing the drafts. The manuscript was reviewed and approved by the ISOQOL Board of Directors as an ISOQOL publication and does not reflect an endorsement of the ISOQOL membership.
Topics Covered

1. Identifying the goals for collecting PROs in clinical practice
2. Selecting the patients, setting, and timing of assessments
3. Determining which questionnaire(s) to use
4. Choosing a mode for administering and scoring the questionnaire
5. Designing processes for reporting results
6. Identifying aids to facilitate score interpretation
7. Developing strategies for responding to issues identified by the questionnaires
8. Evaluating the impact of the PRO intervention on the practice
Multi-Purpose PROs

Assess PROs

Inform Quality Improvement

Evaluate Care Quality

Use in Clinical Practice
Aggregate Data Across Patients

Survey Name: Prostate Cancer Questionnaire

Beth Wilson

A highlighted graph represents either a significant worsening or a score that is likely to be a problem.

Physical Functioning (0 = Bad, 100 = Good)

Mental Functioning (0 = Bad, 100 = Good)

Chris Miller

A highlighted graph represents either a significant worsening or a score that is likely to be a problem.

Physical Functioning (0 = Bad, 100 = Good)

Mental Functioning (0 = Bad, 100 = Good)

Jodi Anderson

A highlighted graph represents either a significant worsening or a score that is likely to be a problem.

Physical Functioning (0 = Bad, 100 = Good)

Mental Functioning (0 = Bad, 100 = Good)
Quality Reporting to Compare Providers

- Worst Pain ≥ 4
- Moderate Nausea

Percentage

Our Practice
Practice A
Practice B
Practice C

Worst Pain ≥ 4
≥ Moderate Nausea
ASCO Pilot-Test of PRO Performance Measures

Patient-Reported Outcome Performance Measures in Oncology

By Ethan Basch, MD, Claire Snyder, PhD, Kristen McNiff, MPH, Rebecca Brown, Suzanne Maddux, RN, Mary Lou Smith, JD, MBA, Thomas M. Atkinson, PhD, Doris Howell, PhD, RN, Anne Chiang, MD, William Wood, MD, MPH, Nathan Levitan, MD, Albert W. Wu, MD, MPH, FACP, and Monika Krzyzanowska, MD

Lineberger Cancer Center, University of North Carolina, Chapel Hill, NC; Johns Hopkins School of Medicine, Baltimore, MD; American Society of Clinical Oncology, Alexandria, VA; Research Advocacy Network, Plano, TX; Memorial Sloan Kettering Cancer Center, New York, NY; Princess Margaret Hospital, Toronto, Ontario, Canada; Yale Cancer Center, New Haven, CT; University Hospitals Seidman Cancer Center, Cleveland, OH; and Dana-Farber/Harvard Cancer Center, Boston, MA

Multi-Purpose PROs

Assess PROs

Inform Quality Improvement

Evaluate Care Quality

Use in Clinical Practice
How do we turn PROMs into remedies?

Slide courtesy of John Browne, PhD, University College – Cork
An interpretable PROM for breast reconstruction? The Breast-Q.
Multi-Purpose PROs

1. Assess PROs
2. Use in Clinical Practice
3. Evaluate Care Quality
4. Inform Quality Improvement
Multi-Purpose PROs

- Assess PROs
- Evaluate Care Quality
- Inform Quality Improvement
- Use in Clinical Practice
Aggregate Data Across Patients

Survey Name: Prostate Cancer Questionnaire

Henry Hamilton

Survey Name: Prostate Cancer Questionnaire

Beth Wilson

Survey Name: Prostate Cancer Questionnaire

Chris Miller

Survey Name: Prostate Cancer Questionnaire

Jodi Anderson

A highlighted graph represents either a significant worsening or a score that is likely to be a problem.
This figure describes the physical function of patients who undergo this procedure on average. Scores of 0 represent poor physical function, and scores of 100 represent good physical function. On average, patients who undergo this surgery have a score of 30 before the procedure. Immediately following the procedure (1 week after surgery), their function has decreased a little to a score of 25. However, physical function then improves over the next 3 months to achieve a score of 50, with a little additional improvement to 55 at the point 6 months after surgery.

The general population of a similar age has a physical function score of 60.

Thus, on average, this procedure improves patients’ physical function substantially, but not quite to the level of the general population.
Advances in the Use of Patient Reported Outcome Measures in

Electronic Health Records

Including Case Studies

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Claire Snyder, PhD
Johns Hopkins University School of Medicine, Baltimore, MD

In support of the PCORI National Workshop to Advance the Use of PRO measures in Electronic Health Records
Atlanta, GA. November 19-20, 2013
<table>
<thead>
<tr>
<th>#</th>
<th>System Affiliation (Name)</th>
<th>Initial Population</th>
<th>Multiple Sites/Clinics</th>
<th>Multiple Populations</th>
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<tr>
<td>1</td>
<td>Epic Systems Corporation (MyChart, EpicCare)</td>
<td>Epic Users</td>
<td>Y</td>
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<td>2</td>
<td>Dartmouth Spine Center</td>
<td>Spine</td>
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<td>Y</td>
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<tr>
<td>3</td>
<td>Cleveland Clinic (Knowledge Program)</td>
<td>Neurological Disorders</td>
<td>Y</td>
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<tr>
<td>4</td>
<td>Group Health Cooperative (Health Profile e-HRA)</td>
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<td>Older Adults</td>
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<td>N</td>
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<td>HIV</td>
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Rationale

• Increasing interest in the topic of PROs in EHRs
  – PCORI-sponsored meeting reviewing the use of PROs in EHRs (November 2013)
  – NIH collaboratory meeting on barriers to routine collection of PROs for EHRs (January 2015)

• Need for:
  – Guidance on the steps involved in integrating PROs in EHRs
  – Opportunity for voluntary consortia to collect PRO-EHR data to enable pooling
Project Phase 1: Planning

- Formed a Steering Group to advise on the overall project plan
- Developed strategy for meeting long-term goals
- Identified questions to be addressed in the PRO-EHR Users’ Guide
- Circulated question list for comment
- Outlined next steps
Steering Group

We appreciate the previous service on the Steering Group of Jamie Skipper, PhD, and Caroline Coy, MPH, from the ONCHIT.
Project Phase 2: Implementation

- Identify Working Group Members
- In-Person Meeting to Discuss Section Outlines
- Develop Draft Sections
- Working/Steering Group Review and Comment on Draft Sections
- Circulate Draft for Comment
- Hold Public Meeting
Special Thanks
Users’ Guide to Integrating Patient-Reported Outcomes in Electronic Health Records

Prepared For PCORI By:
Johns Hopkins University, Baltimore, MD

May 2017

Content

• Considerations involved in integrating PROs in EHRs
• Options offered for each consideration
  – Don’t have to pick just one!
• Relative advantages/disadvantages described for each option
• Case example descriptions (optional)
• Key information gaps/research questions
• Useful references/resources
Topics Covered

1. What strategy will be used for integrating PROs in EHRs?
2. How will the PRO-EHR system be governed?
3. How can users be trained and engaged?
4. Which populations and patients are most suitable for collection and use of PRO data, and how can EHRs support identification of suitable patients?
5. Which outcomes are important to measure for a given population?
6. How should candidate PRO measures be evaluated?
7. How, where, and with what frequency will PROs be administered?
8. How will PRO data be displayed in the EHR?
9. How will PRO data be acted upon?
10. How can PRO data from multiple EHRs be pooled?
11. What are the ethical and legal issues?
Levels of Integration

LOW INTEGRATION
• Secure external web platform
• Patients and providers can only access the PRO functionalities via the external system
• Images of PRO data can be linked with the EHR on the back-end via linkage by patient identification number

HYBRID
• Secure external web platform for PRO data collection
• Interfaces with (bolts on to) an EHR’s clinical test results and patient identification databases
• Providers find patients and assign questionnaires either through a linkage to the external system or directly in the external system
• Patients complete PROs and view results via the external system

FULL INTEGRATION
• Secure, tethered web portal
• Patients can view portions, communicate with providers and complete PRO questionnaires
• PRO measures can employ several core functions of the EHR
Example: Low Integration

**PROVIDERS**
- Order PRO questionnaires via external system; ordering PROs for patients with specific characteristics (e.g., diagnoses) requires entry of this information in the external system
- Can view results in hard copy, or image files within EHR; cannot manipulate PRO data within EHR or plot PROs with other clinical information
- Out of range scores can trigger alerts (+/- advice) via external system

**PATIENTS**
- Complete PROs via external system at home or in clinic
- Can use kiosks/tablets/smart phone/interactive voice response
- Results displayed via external system (+/- advice)

**IT PROFESSIONALS**
- PRO measures programmed in external system
- Programmers must be familiar with external system’s design
- External system programmers control which PRO questionnaires are available

**ANALYSTS/RESEARCHERS**
- PRO and EHR data extracted separately and require linkage on the back-end
**Example: Hybrid Integration**

**PROVIDERS**
- Limited access to PRO data within EHR (visible as blocks of text/image files), broader access via external system
- Can order PRO questionnaires ad hoc or automatically triggered for patients with specific characteristics (e.g., diagnosis)
- Limited manipulation of PRO scores in EHR possible, but can’t be plotted with other clinical data
- Out of range PRO scores can trigger alerts (+/- advice) via external system

**PATIENTS**
- Complete PROs via external system at home or in clinic
- Can use kiosks/tablets/smart phone/interactive voice response
- Results displayed via external system (+/- advice)

**IT PROFESSIONALS**
- PRO measures programmed in external system
- Programmers must be familiar with external system’s design
- Technical interface between PRO and EHR system must be set up and maintained and requires shared patient identifiers for linkage

**ANALYSTS/RESEARCHERS**
- PRO and EHR data extracted separately and require linkage on the back-end
Example: Full Integration

**PROVIDERS**
- Can order PRO questionnaires ad hoc or automatically triggered for patients with specific characteristics (e.g., diagnosis)
- Results displayed within EHR and can be plotted with other clinical data (e.g., laboratory tests)
- Out of range PRO scores can trigger alerts (+/- advice)

**PATIENTS**
- Complete PROs via tethered portal at home or in clinic
- Can use kiosks/tablets/smart phone
- Results displayed within EHR and can be plotted with other clinical data (+/- advice)

**IT PROFESSIONALS**
- Require specific training to work with the EHR
- Some PRO questionnaires built into EHR
- New PRO questionnaires added within EHR constraints

**ANALYSTS/RESEARCHERS**
- Can extract PRO and EHR data for individual patients or groups of patients
# Strategies for Integration: Strengths & Weaknesses

<table>
<thead>
<tr>
<th>LEVEL</th>
<th>STRENGTHS</th>
<th>WEAKNESSES</th>
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<tbody>
<tr>
<td>LOW</td>
<td>- Easier to build a system with limited integration</td>
<td>- No bidirectional exchange between PRO and EHR</td>
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<tr>
<td></td>
<td>- Easier to tailor</td>
<td>- No ability to manipulate PRO data based on EHR data</td>
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<tr>
<td>HYBRID</td>
<td>- User interface designed specifically for PROs</td>
<td>- Requires patients and providers to use system outside of EHR to order/complete PROs</td>
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<tr>
<td></td>
<td>- Greater flexibility in which PROs are included</td>
<td>- Requires upkeep of system separate from EHR</td>
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<tr>
<td></td>
<td>- Can design PRO data display</td>
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<td></td>
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<tr>
<td>HIGH</td>
<td>- PRO data and clinical data collected in the same system in real-time</td>
<td>- Limited flexibility for tailoring questionnaire or report format in system</td>
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<tr>
<td></td>
<td>- Facilitates presentation of PRO data with other clinical data</td>
<td>- Number of PRO measures built in system may be limited</td>
</tr>
<tr>
<td></td>
<td>- Can use clinical data to trigger PROs</td>
<td>- Requires patients be engaged with EHR portal</td>
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</table>
Levels of Governance

**DISTRIBUTED**
- Decisions about implementation, oversight, and PRO use is left to individual or group (e.g., department) users
- Enables tailoring of content to direct clinical needs, as well as small-scale pilots
- Lack of coordination could lead to confusion or duplication, and makes aggregation challenging

**HYBRID**
- Core, central entity provides a set of rules, which are implemented at the user level
- Balances flexibility and need for tailoring
- Could lead to disputes regarding responsibility for final decisions

**CENTRALIZED**
- Appointed individual or group has oversight on implementation and use
- Facilitates coordination, use of best practices, compliance with regulations, and data aggregation
- Could be bureaucratic and use PROs that do not meet specific clinic’s needs
Training & Engaging

Who activates patients?
- Appointment schedulers
- Receptionist
- Nurse/medical assistant/flow staff champion
- Care manager/navigator
- Provider
- Research coordinator
- Automated system

Facilitators
- Easy-to-use technology
- Review and discussion of results with patients
- Patient-friendly reports/data displays
- Self-management decision support
- Enable patient self-initiation

How is value conveyed?
- Scripts
- Patient marketing/information materials
- Review and discussion of results with patients

Training Approaches
- Introduce rationale at department meetings/forums
- Ongoing support to users and training new providers
  - Local champions/super users
  - Qualitative debriefs for individuals/teams
    - Audit and feedback
- Engage stakeholders to design workflows and training
  - Ensure understanding of PRO score meaning
Patients, Outcomes, Measures

EHR CAN HELP SELECT
• All patients for whom a provider/system is accountable
• Defined clinical setting (e.g., primary care)
• Defined condition (e.g., Parkinson’s disease)
• Specific treatment (e.g., knee replacement)

MEASURE EVALUATION CRITERIA
• Availability
• Attributes (e.g., validity, length)
• Standardization
• Ability to pool
• Integration in EHR/stand-alone system
• Stakeholder engagement
• Resources and workflow impact

OUTCOMES
How, Where, When

POSSIBLE EHR ROLES
- Synchronizing questionnaire administration
- Build-in quality/error checks
- Combine PRO data collected across multiple modes
- Meta-data collection (e.g., how PRO was completed and by whom)
- Monitor compliance/alert to missing questionnaires
- Deploying questionnaires in clinic or remotely
CONSIDERATIONS

- Target audience (patients, clinicians, administrators, researchers, others)
- Format (numeric, visual)
- Type of scores (longitudinal, cross-sectional, change)
- Level (individual, population)
- Complexity (simple, complex)
Acting on PRO Data in the EHR

WHEN SHOULD THERE BE PRO COMPLETION NOTIFICATION
• Never
• Always
• Only for certain scores (with or without requirement to “close the loop”)

WHO SHOULD BE NOTIFIED
• Primary care provider
• “Ordering” provider
• Provider with upcoming appointment
• Navigator or administrator
• Patient or designee
• Patient choice

HOW SHOULD NOTIFICATIONS BE SENT
• Email
• Clinical message within EHR
• Text message/secure text message/page

DECISION SUPPORT
• Useful when there is consensus on what to do for which patients
• Evidence base for decision support is increasing
Pooling PRO Data Across EHRs

**CENTRALIZED**

**DISTRIBUTED**

**BOTH REQUIRE**
- Common data model
- Mapping to common values/shared reference standard
# Levels of Consent: Collection & Use

<table>
<thead>
<tr>
<th><strong>NONE</strong></th>
<th><strong>GENERAL DISCLOSURE/OPT-OUT</strong></th>
<th><strong>SPECIFIC DISCLOSURE/OPT-OUT</strong></th>
<th><strong>ROBUST SPECIFIC DISCLOSURE/OPT-IN</strong></th>
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</table>
| • No specific consent  
• Easy to implement and consistent with other clinical data  
• Does not emphasize patient autonomy  
• May not comply with laws, depending on the purpose of collection and use | • Explains PRO collection and use in general, with ability to opt-out  
• Relatively efficient but still allows opt-out  
• Have to track opt-outs and participation rates may be lower  
• May not be sufficient depending on the purpose of collection and use | • Explains collection and use of specific PRO  
• Provides patients with clearest understanding of PRO purpose and allows opt-out; could be written to enable multiple data uses  
• May be burdensome  
• Have to track opt-outs and participation rates may be lower | • Most robust informed consent  
• Provides the greatest amount of information and is consistent with most data uses  
• Could be burdensome and lead to lower participation rates |


Key Steps for Moving Forward

• Create and use open source data standards (e.g., put PROs in Consolidated Clinical Document Architecture [CCDA]; Logical Observation Identifiers Names and Codes [LOINC])
• Develop guidelines for interpretation and action for patients and clinicians
• Identify stakeholders and develop marketing plan with value proposition for each
• Produce evaluation framework to address cost, burden, efficiency, quality, transparency, care, and patient outcomes
• Establish rules of engagement for a central data repository and network of sites
• Provide crosswalk across PRO instruments and meta-data for deep learning
• Implement policies to give more access/control to patients and reimbursement/incentives for patients
A PRO-cision Medicine Toolkit to Address the Challenges of Personalizing Cancer Care Using Patient-Reported Outcomes

- Identify and evaluate approaches to aid interpretation of PRO scores
- Identify and evaluate methods to develop guidance for acting on PRO issues
Discussion