Integrating Patient-Reported Outcomes into Practice: Benefits, Challenges, and Recommendations for Action

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Margie E. Snyder, Pharm.D., M.P.H.
Steven P. Dehmer, Ph.D.

Moderated by: Chris Dymek, Ed.D.
Agency for Healthcare Research and Quality

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Agenda

• Welcome and Introductions
• Presentations
• Q&A Session With Presenters
• Instructions for Obtaining CME Credits

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- Doctors Margie E. Snyder and Steven P. Dehmer, have no relevant financial relationships to disclose.
- Dr. Jinoos Yazdany has the following relevant financial relationships to disclose:
  - Independent Research Grant: Gilead, Aurinia, BMS Foundation
  - Site in a clinical trial: Astra Zeneca
  - Consultant: Pfizer, UCB, ImmPACT Bio
How to Submit a Question

• At any time during the presentation, type your question into the “Q&A” section of your WebEx Q&A panel.

• Please address your questions to “All Panelists” in the drop-down menu.

• Please include the presenter’s name or their presentation order number (first, second, or third) with your question.

• Select “Send” to submit your question to the moderator.

• Questions will be read aloud by the moderator.
Learning Objectives

At the conclusion of this webinar, participants should be able to:

1. Explore the process of spreading and implementing patient-reported outcomes across rheumatology practices nationwide, shedding light on the practical aspects of this journey.

2. Explain the benefits and challenges of using a mobile application to collect PRO data on medication adherence in pharmacies.

3. Discuss patient preferences in how PRO measures are collected and used in orthopedic care and how they may be used to enhance shared decision making and improve outcomes.
Advancing Rheumatoid Arthritis Care: Scaling Up and Disseminating Patient-Reported Outcomes

Jinoos Yazdany, M.D., M.P.H.
Professor of Medicine, University of California, San Francisco
Chief of Rheumatology, San Francisco General Hospital
Objectives

Key Questions Our Research Has Tried to Answer:

• Can we scale and spread the use of rheumatoid arthritis (RA) PROs across U.S. rheumatology practices?

• Can we extract PRO data from structured EHR data?
  o Can natural language processing (NLP) of clinical notes enhance information extraction?

• Can we develop implementation tools to help practices collect and effectively use RA PROs to improve care?
RA is an autoimmune disease that can destroy joints and lead to disability if untreated.

RA impacts ~1% of Americans.

The main goals of RA treatment are to reduce disease activity and preserve function.

- Disease activity is assessed using a measure with physician and patient (PRO) components.
- Physical function is measured using PROs.

Barber et al. PMID 31709771; England et al. PMID 31709779
The use of PROs in rheumatology for assessing functional status started decades ago, notably with the 1980 introduction of the Health Assessment Questionnaire (HAQ).

- Evidence supports that using RA disease activity measures to treat-to-target leads to better patient outcomes (less joint damage, less disability).

- Functional status PROs aid in detection of functional decline and enrich shared decision-making by capturing symptom experience.
#1 Can We Scale and Spread RA PROs Across U.S. Rheumatology Practices?

Achieving National Consensus on RA PRO Measures

- Anderson et al. PMID: 22473918 2012
  - Develop ACR PRO recommendations

- Yazdany et al. PMID: 27564778 2014-present
  - RA quality measures endorsed by NQF and CMS

AHRQ R18 RISE PRO project

- Yazdany et al. PMID: 27696755 2018-2023
  - Extract PROs from RISE for reporting, research

- Develop RA Toolkit 2023

DECADES OF PRO DEVELOPMENT

10
Establishing Digital Infrastructure for Monitoring PROs as Quality Measures

- American College of Rheumatology’s EHR-enabled registry
- **Data**: Mostly community practices (over 20 different EHR systems)
  - Collect all structured data and clinical notes
- **Dashboard**: Practices access quality measures via a dashboard and can use the registry to report to CMS
- **Research**: Data is aggregated at UCSF for research

<table>
<thead>
<tr>
<th>Active Practices</th>
<th>Active Providers</th>
<th>Active Locations</th>
<th>Collective Patients</th>
<th>Collective Patient Visits</th>
</tr>
</thead>
<tbody>
<tr>
<td>282</td>
<td>1,073</td>
<td>831</td>
<td>3,250,844</td>
<td>34,289,482</td>
</tr>
</tbody>
</table>

Yazdany et al. PMID 27696755
QPP177: Rheumatoid Arthritis Periodic Assessment of Disease Activity (>50% of visits)

- Most rheumatologists are measuring the Clinical Disease Activity Index (CDAI) or Routine Assessment of Patient Index Data-3 (RAPID-3) in routine care.

We do not see major differences in performance by age, sex, race, ethnicity, or socioeconomic status (ADI).
• QPP178: Rheumatoid Arthritis Yearly Functional Status PRO Assessment
  - Many rheumatologists are measuring functional status with a version of the Health Assessment Questionnaire (HAQ)
Consensus-Based PROs and RISE Registry Enable a National System to
Monitor Health Disparities

Objective: Examine association between socioeconomic status (SES) and physical function over time in RA

Data: RISE registry (2016-2018) data from 83,965 people with RA

Key Findings:
- Lower SES is associated with worse physical function
- Functional decline is more significant in lower SES groups, even after adjusting for demographics, baseline function, medications, and other factors

Conclusions:
- Disparities in functional outcomes related to SES
- PROs in RISE facilitate a system to monitor and test interventions targeting these disparities
Can we scale and spread the use of RA PROs across U.S. rheumatology practices?

YES, people with RA now have PROs measured at a majority of U.S. rheumatology visits!

Key Lessons Learned

1. Professional consensus on which measures are valid, reliable, and feasible in clinical practice facilitated a cohesive national PRO collection strategy

2. Development and endorsement of quality measures incentivized participation by rheumatologists

3. Technology infrastructure of the RISE registry facilitated performance feedback, research and quality improvement
#2 Can We Extract PRO Data From Structured EHR data (and Will NLP Increase Yield)?

Performance on RA Periodic Assessment of Disease Activity Quality Measure in the RISE Registry Between 2014 and 2023

Additional data capture through NLP?
Development of a Natural Language Processing System for Extracting Rheumatoid Arthritis Outcomes From Clinical Notes Using the National Rheumatology Informatics System for Effectiveness Registry

Marie Humbert-Droz,1 Zara Izadi,2 Gabriela Schmajuk,3 Milena Gianfrancesco,2 Matthew C. Baker,4 Jinoos Yazdany,2 and Suzanne Tannanγ4

Objective
Development and evaluation of an NLP pipeline (we used expert-curated terms and Spacy text processing tool to identify patterns and numerical scores linked to outcome measures) to extract RA outcomes from clinical notes

Methods
• Inclusion of all patients in RISE (2015–2018)
• NLP pipeline extracted 8 RA disease activity and functional status measures
• Performance evaluated through chart review, structured data comparison, and external validation
NLP Pipeline for Extracting RA Outcome Measures

Results

• Processed 34 million notes from 854,628 patients across 158 practices and 24 EHR systems
• **Internal Validation**: High sensitivity (95%), PPV (87%), and F1 score (91%) comparing NLP to available structured data
• **Added Value**: Compared to notes, structured data had sensitivity of only 39% and F1 score of 51%, *indicating that a significant amount of data would be missed without notes*
• **External validation**: pipeline showed sensitivity (92%), PPV (69%), and F1 score (79%) in a large health system

Conclusions

• NLP pipeline demonstrated good internal and external validity for extracting RA outcomes from notes across 158 practices in a national registry
• Notes contain more PRO scores than structured data
• Pipeline is publicly available at: https://github.com/mhdroz/RISE_PROS

Table 1. Kappa scores denoting inter-rater agreement between natural language processing extractions and structured data for rheumatoid arthritis (RA) outcomes

<table>
<thead>
<tr>
<th>RA outcome measure</th>
<th>No. of scores compared</th>
<th>Exact matching based on numerical scores</th>
<th>Fuzzy matching based on score categories</th>
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<tr>
<td>CDAI score</td>
<td>234,400</td>
<td>0.43 ± 0.38</td>
<td>0.87</td>
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<tr>
<td>RAPID3 score</td>
<td>140,680</td>
<td>0.68 ± 0.36</td>
<td>0.69</td>
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<tr>
<td>RAPID4 score</td>
<td>6,218</td>
<td>0.91</td>
<td>0.94</td>
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<tr>
<td>RAPID4 score (range 0-10)</td>
<td>134,462</td>
<td>0.66</td>
<td>0.68</td>
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<tr>
<td>RAPID4 score (range 0-30)</td>
<td>37,874</td>
<td>0.38 ± 0.46</td>
<td>NA</td>
</tr>
<tr>
<td>MDHAQ score</td>
<td>3,131</td>
<td>0.85 ± 0.37</td>
<td>NA</td>
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</tbody>
</table>
## #2 Can NLP enhance PRO information extraction?

<table>
<thead>
<tr>
<th>Opportunities</th>
<th>Challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td>PRO extraction via NLP was feasible and had reasonable accuracy in RISE registry</td>
<td>Data aggregation and cleaning across multiple sites to develop and maintain NLP pipelines is resource intensive</td>
</tr>
<tr>
<td>For practices lacking IT infrastructure to collect structured data, NLP adds value in capturing PRO data</td>
<td>Privacy and security concerns for assembling large note datasets across many sites</td>
</tr>
<tr>
<td>Large Language Models will improve accuracy</td>
<td>PRO documentation lacks standardization; addressing copy/paste data is difficult</td>
</tr>
</tbody>
</table>
#3 Can We Develop an Implementation Toolkit to Help Practices Collect and Effectively Use RA PROs?

Figure 1. Methods for Developing the RA Outcome Measures Toolkit

- **Implementation Research Using CFIR**
  - Purposeful sampling of rheumatology practices across QPP measure performance, practice type, and EHR
  - Qualitative interviews until thematic saturation reached (N=38 people across 16 RISE practices and 4 Academic Centers)
  - Summary of facilitators and barriers to RA Outcome Measure Collection and Use

- **Research Findings**
  - Summary to best practices for RA measure collection
  - Case studies of innovations used by high-performing practices
  - Development of training materials for clinicians and medical assistants

- **Resource Collation**
  - ACR and QPP recommendations for RA disease activity and functional status measures
  - Description, scoring, and interpretation of each measure
  - Guidance for Quality Payment Program Reporting through RISE

[https://ratoolkit.kotobee.com/](https://ratoolkit.kotobee.com/)
Chapter 2: RA Measures

Choosing RA measures to use in your practice

Both disease activity and functional status measures should ideally be tracked over time in people with RA, as they provide valuable longitudinal data to inform treatment decisions. Studies have consistently shown that treating to a target of low disease activity or remission in RA improves outcomes; this treatment approach requires the use of standardized measures to define the treatment target (see Figure). Moreover, by monitoring changes in disease activity and functional status, you can tailor interventions, adjust treatment plans through shared decision-making, and take measures to prevent
Chapter 4: Workflows for RA Measures

How to Develop Efficient Workflows for RA Measures

In this section of the toolkit, we provide practical tips on developing efficient and effective workflows for implementing RA outcome measures in your practice. To gather this knowledge, we conducted interviews with numerous high-performing rheumatology practices, delving into their strategies and innovations. We have compiled their invaluable experiences and innovations to share with you, empowering you to enhance the collection of RA outcomes in your own practice.

RA Outcome Measure Collection Workflow (Telehealth Visits)

[Diagram showing workflow steps involving patient, EHR system, front desk, medical staff, and clinician]

RA Outcome Measure Collection Workflow (In-Person Visits with Electronic Forms)

[Diagram showing workflow steps involving patient, EHR system, front desk, medical staff, and clinician]
Download translated RA PRO forms in Spanish and Chinese below.

- **Patient Global Assessment**: Spanish
- **Patient Global Assessment**: Chinese
- **HAQ II**: Spanish
- **RAPID3/MDHAQ**: Spanish
- **PROMIS-PF**: Spanish
- **PROMIS-PF**: Chinese

**Training Guides**

Download medical staff training guides/infographics for RA outcome measure collection below.

- **Rheumatoid Arthritis Outcome Measures Collection: MA Training Guide**
- **Rheumatoid Arthritis Outcome Measures Knowledge Test**
Qualitative Study: Understanding Facilitators and Barriers to PRO Collection and Use

**Objective**
Gain qualitative insights on RA PRO collection and utilization in practices, using the Consolidated Framework for Implementation Research (CFIR)

**Methods**
- Recruited practices with a range of performance on RA PRO quality measures and asked rheumatologists and key staff to participate in semi-structured interviews
- 38 interviews across 16 RISE practices and 4 academic centers
- Recorded interviews were transcribed verbatim and analyzed thematically using deductive and inductive techniques

<table>
<thead>
<tr>
<th>CFIR domain</th>
<th>Challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outer Setting</td>
<td>Incomplete capture of RA measure performance in RISE registry</td>
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<tr>
<td></td>
<td>Expensive to purchase EHR systems that have rheumatology specific software</td>
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<tr>
<td>Inner Setting</td>
<td>Developing reliable workflows to administer PROs to RA patients</td>
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<tr>
<td></td>
<td>Time constraints with high patient volumes</td>
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<td></td>
<td>Inadequate training for medical staff (high staff turnover)</td>
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<tr>
<td>Individuals</td>
<td>Patient survey fatigue</td>
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<td></td>
<td>Language barriers and low health literacy</td>
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<tr>
<td>Implementation</td>
<td>Difficulty collecting RA outcome measures during telehealth visits</td>
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<td></td>
<td>Inconsistent collection of PROs, especially for in-person visits</td>
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<tr>
<td>Innovation</td>
<td>Difficulty collecting RA outcomes in structured data fields in the EHR</td>
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Illustrative Quotes Regarding Facilitators and Barriers: CFIR Inner Setting

**Facilitators** included rheumatologist support & a culture of continuous improvement

- “[Rheumatologists] like to measure how the patients are doing so that they can see their progress”
- “…we review the data monthly. All the faculty and advanced practice providers are involved and they either give feedback verbally or send emails with questions, concerns, or ideas”

**Barriers related to the EHR were common**

- “It was a lot of customization when we initially built it. I think EPIC came out with the joint exam module. But even that required customization”
- “The EMR does not have the ability to capture the structured data... So, I will input those data manually so that my EMR can capture it for MIPS reporting and the RISE registry”
- “I looked into a different EMR, I think the TSI, they have a pretty good incorporation of these data, but the cost is prohibitive, and then the switching EMR is a painful process”

Lessons Learned in RA PRO Program

**Standardization through Guidelines:** National RA guidelines have played a crucial role in standardizing use of RA PROs in clinical practice.

**RISE Registry's Tech Role:** RISE's technology enables effective PRO tracking for patient care and research.

**EHR Challenges:** Extraction of PROs from structured EHR data is possible but incomplete; development of supportive EHR software is needed.

**NLP and Resource Intensity:** NLP can extract PROs from clinical notes but requires significant resources.

**Education and Mentorship Needs:** Education on use of PROs and peer-to-peer mentorship are needed on an ongoing basis for effective implementation in clinical practice.
Future Directions

2012
Develop ACR PRO recommendations

2014-present
Develop quality measures endorsed by NQF and CMS

2018-2023
Extract PROs from RISE for reporting, research

2024 and Beyond

1. Enhance EHR systems to facilitate PRO collection and use in RA
2. Study pros/cons and costs of structured data collection versus NLP systems
3. Research impact and value for patients
This research program implemented rheumatoid arthritis PROs nationally by developing quality measures, partnering with federal quality programs, and using a national EHR-based registry to extract PROs and provide performance feedback and training to rheumatologists.
Thank You

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U.S. rheumatology professionals
Patients

https://quil.ucsf.edu/
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Adapting and Implementing a Mobile Application for Medication Adherence Patient-Reported Outcomes in Community Pharmacies

Margie E. Snyder, Pharm.D., M.P.H., FCCP, FAPhA

Professor of Pharmacy Practice,
Purdue University College of Pharmacy
Learning Objective

• Explain the benefits and challenges of using a mobile application to collect patient-reported outcome (PRO) data on medication adherence in pharmacies.
Medication Adherence and Community Pharmacies

- Medication non-adherence is highly prevalent and costly for the United States
- CMS Star Ratings program measures emphasize the importance of medication adherence to payers/policy makers
- Community pharmacies are incentivized to promote adherence

Res Social Adm Pharm. 2021;17:466-74.
Medication Adherence PROs

- Multiple measures available

- No sustained models for community pharmacists’ systematic collection and use of PROs for improving medication adherence

*Res Social Adm Pharm.* 2021;17:466-74.
Mobile application created out of the LA Net practice-based research network
- Patient-facing version collects a variety of health assessments/PROs
- Provider-facing version enables review and response to PROs
Project Goals

• Pre-Implementation (Phase 1)
  1. Conduct a pre-implementation developmental formative evaluation to identify potential barriers, facilitators, and recommendations to PatientToc™ implementation and create a draft implementation toolkit.

• Implementation (Phase 2)
  2. Conduct two plan-do-study-act cycles to refine an implementation toolkit for spreading and scaling PatientToc™ in community pharmacies.
  3. Conduct a comprehensive, theory-driven, evaluation of the quality of care, implementation, and patient health outcomes of spreading and scaling PatientToc™ to community pharmacies.

Res Social Adm Pharm. 2021;17:466-74.
Methods

Phase 1
- Guided by the Consolidated Framework for Implementation Research
- Site visits and interviews at both LA Net clinics and community pharmacies

Phase 2
- Implementation outcomes as defined by Proctor; PROs were Brief Medication Questionnaire (BMQ, primary) and Merck Adherence Estimator
- Scope of implementation chosen by participating pharmacies; request for 50 patients in pilot
- Pilot focused on patients aged 50+ (expanded to 18+ in scaled implementation) using oral medications for diabetes, hypertension, and/or lipids
- Facilitation plan and toolkit informed by Phase 1 findings
- Data sources: PatientToctm, pharmacy records, researcher records in REDCap, interviews

Res Social Adm Pharm. 2021;17:466-74.
1. Lack of existing integrations among technology vendors and/or concerns about the feasibility/effectiveness of future integrations of existing technology with PatientToc™.

2. Some sub-groups of patients (e.g., older adults, those with arthritis, those who don’t physically come in to the pharmacy, those who prefer paper over technology) might be challenged and/or uneasy/unwilling to use PatientToc™.
Phase 1 Findings: Expected Barriers

3. PatientToc™ could be difficult to incorporate into pharmacy workflow due to space (e.g., small waiting areas, shared space) or staffing (e.g., time required, possible need for additional staff, staff turnover, competing demands) constraints and/or communication gaps among staff.

4. Data security concerns (e.g., privacy of information provided in PatientToc™ by patients, mistrust of technology, uncertainty regarding where the information is sent) could limit uptake of PatientToc™ by patients and pharmacy staff.

Phase 1 Findings: Expected Facilitators

1. Pharmacy teams are generally willing to try new things, like PatientToc™, if it will help advance their number one goal of improving patient care.

2. Pharmacy leadership is respected and generally strong communication across team members is present, which would support PatientToc™ implementation.

3. Measures of importance to pharmacy teams (e.g., STAR ratings, CPESN metrics, patient satisfaction, medication adherence, ROI) align with those expected to be impacted by PatientToc™ and measured by the research team.

4. Most stakeholders (pharmacists, pharmacy staff, and patients) felt PatientToc™ was easy to use, felt training requirements would be minimal, and offered limited suggestions for improvement.
Recommendations & Resulting Toolkit

• 14 recommendations were identified

• Resulting toolkit for pilot implementation
  o PatientToc™ mission statement template
  o Kickoff meeting agenda template
  o Audit & Feedback report
  o Training modules
  o SDOH CE modules
  o Posters, pamphlets, bag stuffers, digital media templates
  o Scripted language
  o Sample workflows
  o Referrals “cheat sheet”
PatientToc™ in Community Pharmacies
Phase 2 Pilot Key Findings
n= 3 pharmacies

Adoption

- Adoption by staff (i.e., asking patients to use PT) was lower than expected.
  - 11-37 patients vs. 50
- Adoption was better among patients waiting for their medications.
- Staff were generally satisfied with toolkit items but did not consistently use them.
- Drivers of patient adoption included using the app for a newly prescribed medication, having medication concerns at baseline, and having a strong existing relationship with pharmacy staff.
- Low staff adoption likely make it hard to fully assess other outcomes.
Phase 2 Pilot Key Findings

Acceptability

• Patients overall spent about 6 minutes on the app, which aligns with the goal from the pre-implementation work (target was 2-10 minutes).
• Many patients start the app but are stopping before entering their name and contact information.
• There is a need for improved pharmacist and staff introduction of PatientToc to patients to “level-set” expectations to enhance satisfaction and promote further use (e.g., why patient name and contact information are being collected, how information will be used to improve patient care, and that it will take about 5 minutes to complete so patients should plan on that).
Appropriateness

- The app is viewed as overall appropriate for a community pharmacy environment but might be less appropriate for some specific contexts (e.g., grocery setting, drive through).
Phase 2 Pilot Key Findings

Fidelity

• Overall, pharmacies used PT as planned in their workflow but fewer follow-on surveys than encounters were logged in our database.
  o 21-100% of encounters.

• Observations and interviews point to three potential reasons:
  o Did not wish to take clinical action so just did not complete documentation.
  o Technical issues impacting completion and/or data transfer.
  o Limited familiarity and buy-in to the purpose of having patients use PT.
Phase 2 Pilot Key Findings

Feasibility

- Staff exhibited some misunderstanding of where patient data goes and there was sometimes a disconnect in timing the collection and review of patient data and completion of follow on surveys in the pharmacy workflow.
- Pharmacy workflow was not heavily impacted, but this could be due to overall low adoption pharmacies or timing of PROs review.
- Use in some contexts (e.g., waiting patients) was more feasible than in other (e.g., drive throughs).
- Unscheduled contacts with PFs decreased over time but sometimes associated with less adoption over time.

Accepted for poster presentation at the 2024 American Pharmacists Association Meeting
Toolkit/Facilitation Revisions for Scaling

- Decrease patient age threshold to 18 years+ and change 30-day fill requirement to any medication to encourage use with more patients.
- Provide pharmacies with a brief data summary (e.g., average time required by patients to complete PatientToc™) to promote staff adoption.
- Increase from one launch visit to three in the first week and add weekly or twice weekly webinars for the first month to help with adoption and feasibility.
  - Ensure more time for start-up tasks to occur prior to the first launch visit.
- Consider requiring use of the Android emulator for completion of follow-on surveys to reduce costs.
Alignment Between Phase 1 and Phase 2 Pilot

• All expected barriers identified in Phase 1 aligned with what we observed in the Phase 2 pilot

• Three of the four expected facilitators aligned
  o Star ratings considerations did not appear to influence adoption by pharmacy teams

• Unable to implement half of the recommendations

Accepted for poster presentation at the 2024 American Pharmacists Association Meeting
Next Steps

• Scaled implementation phase is wrapping up this month
  ○ Findings appear similar to pilot phase with several challenges with adoption still noted
  ○ 7 of 12 pharmacies dropped out early, after 1 to 4 months of implementation

• Data analyses and synthesis

• Pilot tests of app integrated with pharmacy management system
Challenges & Lessons Learned

• Importance of pre-implementation phase
  o Experiences in pilot aligned with findings of formative research
  o Need to better mitigate expected barriers and fully implement recommendations

• Clear scope of work with vendor is essential
  o While intent was for integrated app, vendor was unable to deliver in a timely/cost-effective manner
  o Non-integrated app requires text write-in that was not observed in formative phase and has challenges in the display impacting acceptability; need for formal usability testing

• Increased resources/pilot testing of facilitation to improve adoption
  o Minimal staff adoption beyond pharmacist champions
  o Challenging context in pharmacies post-pandemic; ask to do “one more thing”
  o Multi-PBRN collaboration without prior pilot work to explore team dynamics and impacts on facilitation
Implementing a mobile application in community pharmacies for the purposes of identifying and resolving medication non-adherence is challenging and requires extensive pre-implementation work to mitigate barriers and promote adoption by pharmacy teams and patients.
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PBRNs/study sites: LA Net, Rx-SafeNet, MPPBRN

Funding: Agency for Healthcare Research and Quality (R18 HS925043)

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PURDUE
COLLEGE OF PHARMACY
Optimizing Use of Patient-Reported Outcomes in Orthopedic Care

Steven P. Dehmer, Ph.D.
Senior Research Investigator and Health Economist
HealthPartners Institute - Minneapolis, MN
Total hip and knee replacement procedures are among the most common elective surgeries in the United States

- About 400 thousand hip and 700 thousand knee procedures per year\(^1\)
- Surgery rates could double by 2030\(^2\)

**Clinical challenge:** how is success measured?

- Objective clinical measures such as strength, gait, and range of motion may miss a holistic assessment of patient perceptions and function
- Patient-Reported Outcome Measures (PROMs) seek valid and reliable assessments direct from patients

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Multiple PROMs have been validated and standardized for hip and knee

- Common for Hip: Oxford Hip Score, HOOS JR
- Common for Knee: Oxford Knee Score, KOOS JR

<table>
<thead>
<tr>
<th></th>
<th>Oxford Hip Score</th>
<th>HOOS JR</th>
<th>Oxford Knee Score</th>
<th>KOOS JR</th>
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<td>6</td>
<td>12</td>
<td>7</td>
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<tr>
<td>Domains</td>
<td>Pain, limping, daily functions, sleep</td>
<td>Pain, daily functions</td>
<td>Pain, limping, daily functions, sleep</td>
<td>Stiffness, pain, daily functions</td>
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</tbody>
</table>
Since 2012, the American Academy of Orthopaedic Surgeons has collected PROMs for its American Joint Replacement Registry.\(^1\)

- As of 2021, 2.8 million hip and knee procedures for 2.6 million patients
- PROMs reported from 1,251 clinical sites in all 50 states

Starting in 2025, the Centers for Medicare & Medicaid Services will require reporting of PROMs for hip and knee arthroplasty.\(^2\)

- Data will be publicly reported in 2027
- Hospitals reporting PROMs on <50% of procedures will face financial penalties

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Challenges with PROMs in Orthopedics

- Response rates
- Better outcomes & value
- Patient understanding
- Use in care
- Clinical meaning
- Surgeon trust

Better outcomes & value

- Use in care
- Clinical meaning
- Surgeon trust
- Patient understanding

60
**The PROMOTE Study**

**Partnership:** A care delivery and research collaboration from the start

**Goal:** To assess opportunities to enhance the use of PROMs in orthopedic care

**Vision:** To innovate the use of PROMs to achieve the triple aim

**Design:** Mixed methods, randomized and non-randomized interventions
**PROMOTE Study Aims**

**Aim 1**
Identify patient-preferred outcomes

**Aim 2**
Test text reminders to improve PROM survey response rates

**Aim 3**
Test making PROMs available in EHR

**Aim 4**
Test sharing surgeon peer comparisons on PROMs and costs
Key finding #1:

Text messaging can improve response rates to PROMs surveys.

- Among 3700 patients sent PROMs surveys, 1707 did not respond by Day 7.
- We randomized the 1707 patients to receive a text reminder on Days 7 and 12 vs. no text reminder.
- By end of collection, 51% responded in texting arm vs. 35% in no-text arm (aOR = 1.93, p<0.001).
- Text messages can be automated and low cost.

Ziegenfuss et al. 2024. The Impact of text messaging to promote Patient Reported Outcome Measures (PROMs) completion in orthopedic practice: Findings from a randomized controlled study. In process, American Journal of Medical Quality.
Key finding #2:

Patients prefer personalized PROMs over standardized orthopedic PROMs to track progress.

- 54% of 226 survey respondents preferred tracking improvement in post-surgery with their own outcomes.
- 63% of patients wanted to surgeons to know their personal outcomes.
- It is feasible - we started collecting and tracking personalized PROMs.

Most common personalized outcomes:

- Ability to walk without pain/discomfort – 57%
- Pain relief – 51%
- Ability to return to an active lifestyle – 36%
- Ability to return to leisure activities – 23%
- Ability to use stairs without pain – 21%
- Ability to sleep through the night – 15%
- Ability to work around home – 15%
- Ability to care for self – 13%
- Increased strength – 10%
- Improved flexibility – 9%
- Ability to return to sport – 9%
- Ability to return to work – 9%

Key finding #3:

Personalized PROMs are better collected by open-ended questions and change over time.

- Questions were added to PROMs surveys collected over 6 months for 1481 patients.
- 91% of patients responding to pre-surgical surveys provided an open-ended PROM goal.
- 3 months after surgery, 54% mostly or completely achieved their PROM goal and 86% identified a new personal outcome goal.
- 83% of open-ended PROMs would have lost some or a large amount of meaning if categorized into 17 most common PROMs.

Using PROMs for Shared Decision Making

Key finding #4:
Patients want to engage in shared decision making with their surgeons, but making PROMs available in electronic health records does mean they will be used at the point of care.

► 79% of 226 patients surveyed wanted to engage in shared decision making after surgery.

► Patients identified a wide range of issues affecting them post-surgery.

► When PROMs were integrated into the electronic medical record, we found they were accessed at <1% of orthopedic encounters.

Most common issues post-surgery
- Stairs inside home – 62%
- Stairs outside home – 43%
- Concerned about infections – 31%
- Home not handicapped accessible – 28%
- Concerned about pain medications – 25%
- Live alone – 20%
- Have pets to care for – 20%
- Family/friends not available to help – 10%
- Nausea from anesthesia – 10%
- Stairs needed to use bathroom – 9%
- Affordability of follow-up care – 8%
- Primary caregiver for someone else – 4%

Barriers to using PROMs in Clinical Care

Key finding #5:
Surgeons see multiple barriers to using PROMs during visits with patients.

- Interviews with 11 surgeons revealed perceptions that PROMs were more useful in aggregate than for individual patient care.
- Logistical issues impede use of PROMs at the point of care.
- Surgeons worry about patient perceptual barriers and the validity/reliability of scores.
- Suggestions for enhance utility included introducing PROMs earlier, making scores more accessible, and developing graphical displays to facilitate patient engagement in their outcomes.

白bear et al. 2022. What Do Orthopaedists Believe is Needed for Incorporating Patient-reported Outcome Measures into Clinical Care? A Qualitative Study. PMID: 34846308.
Factors Influencing PROMs Improvement

Key finding #6:

Patient factors are more strongly associated than surgeon factors in predicting PROMs improvement.

- Substantial (40-50%) of variation in PROMs improvement can be explained by pre-operative patient factors.

- After accounting for patient factors, very little (<1%) of variation in PROMs improvement can be attributed to the surgeon.

Factors Influencing Costs

Key finding #7:

Variation in surgical implant costs and procedure time is more associated with the surgeon than the patient.

- Moderate (5-35%) variation in implant costs was associated with the surgeon.
- Substantial (65-70%) variation in procedure times as associated with the surgeon.
- Minimal (<5%) of variation in these outcomes was associated with patient factors.

Key finding #8:

Surgeon reports on their performance with PROMs and cost outcomes did not improve these outcomes.

- An intervention that distributed quarterly reports comparing PROMs improvement and cost-related outcomes unblinded to peers did not result in outcomes improvement.

- Distrust in data and a relatively weak intervention were likely contributing factors.

Final Thoughts and Future Directions

Collection of PROMs in orthopedics will be accelerated by CMS policies

Standardized PROMs have a role for aggregate reporting and comparisons, but patients are more focused on their personal outcomes

There is strong interest and opportunity in using PROMs to enhance individual care and shared decision making
By forming a real partnership between a care system and researchers and by listening to both patients and surgeons, it is possible to learn how to improve the approach, collection, and use of patient-reported outcome measures to improve care.
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