AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

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

Presented by:	**Moderated by:**
Jinoos Yazdany, M.D., M.P.H.	Chris Dymek, Ed.D.
Margie E. Snyder, Pharm.D., M.P.H.	Agency for Healthcare Research and Quality
Steven P. Dehmer, Ph.D.	

February 27, 2024

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Agenda

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

Note: You will be notified by email once the slides and recording are available.

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Presenter and Moderator Disclosures

Jinoos Yazdany, M.D., M.P.H.
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Steven P. Dehmer, Ph.D.
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 - Consultant: Pfizer, UCB, ImmPACT Bio

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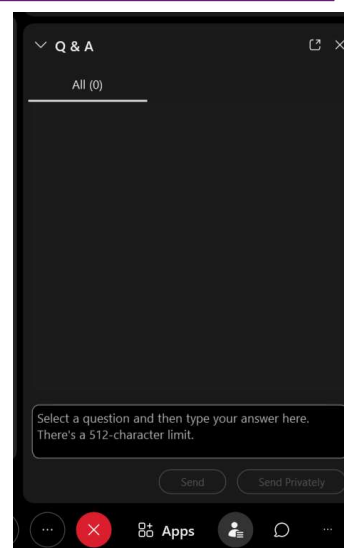
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Learning Objectives

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.

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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

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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?
  - 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?

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Rheumatoid Arthritis Patient-Reported Outcomes

- 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

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Rheumatoid Arthritis Patient-Reported Outcomes

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
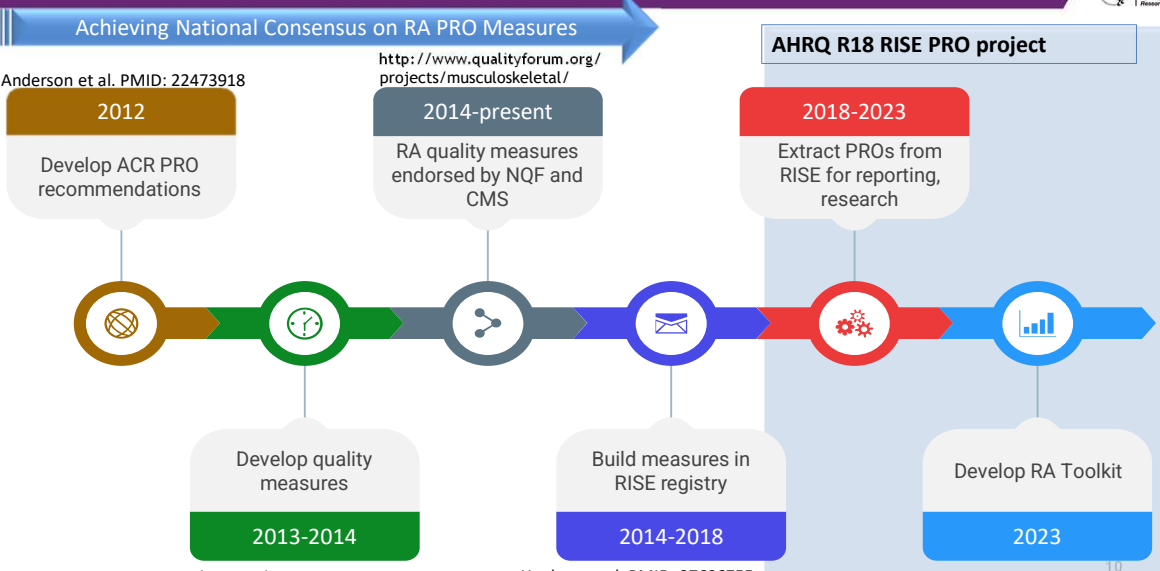
TREAT TO TARGET

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#1 Can We Scale and Spread RA PROs Across U.S. Rheumatology Practices?

Achieving National Consensus on RA PRO Measures

http://www.qualityforum.org/projects/musculoskeletal/

AHRQ R18 RISE PRO project

DECADES OF PRO DEVELOPMENT

Anderson et al. PMID: 22473918

2012	2014-present	2018-2023
Develop ACR PRO recommendations	RA quality measures endorsed by NQF and CMS	Extract PROs from RISE for reporting, research

Develop quality measures	Build measures in RISE registry	Develop RA Toolkit
2013-2014	2014-2018	2023

Yazdany et al. PMID: 27564778   Yazdany et al. PMID: 27696755
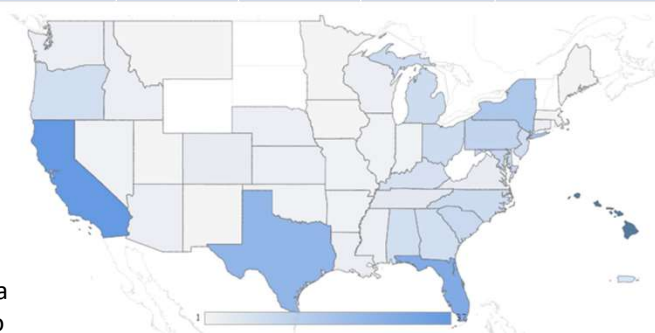
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Establishing Digital Infrastructure for Monitoring PROs as Quality Measures

Active Practices	Active Providers	Active Locations	Collective Patients	Collective Patient Visits
282	1,073	831	3,250,844	34,289,482

Yazdany et al. PMID 27696755

- 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

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Performance on RA Disease Activity Quality Measure Improving

- 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
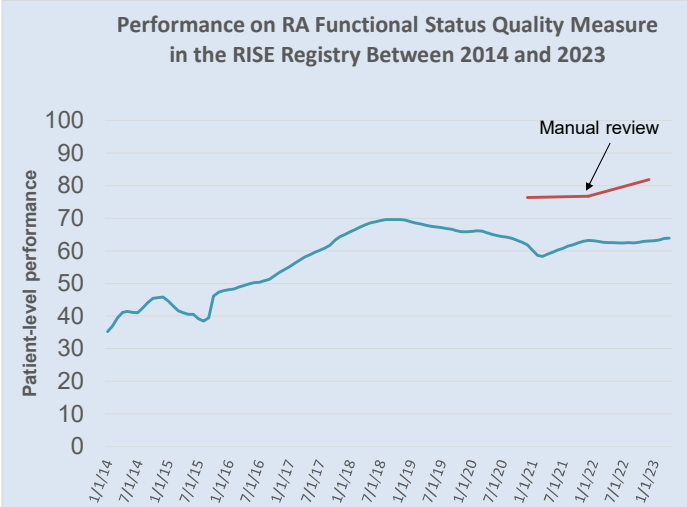
We do not see major differences in performance by age, sex, race, ethnicity, or socioeconomic status (ADI)

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

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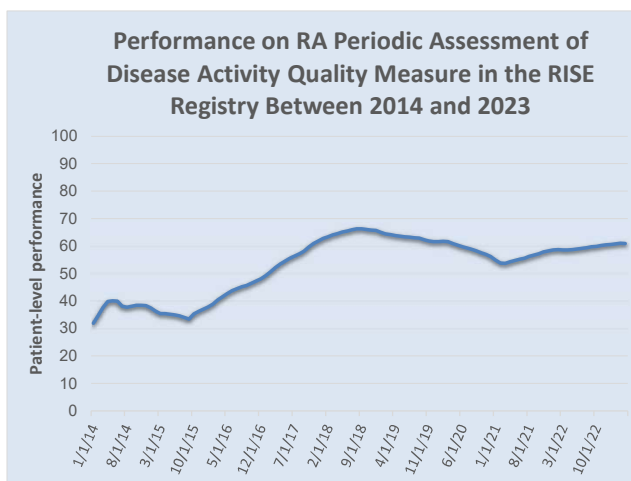
Performance on RA Functional Status PRO Quality Measure Improving

- QPP178: Rheumatoid Arthritis Yearly Functional Status PRO Assessment
  - Many rheumatologists are measuring functional status with a version of the Health Assessment Questionnaire (HAQ)
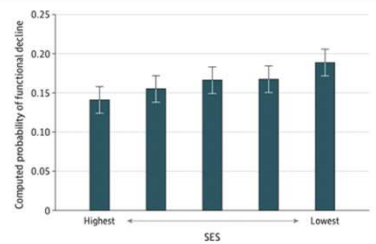
Performance on RA Functional Status Quality Measure in the RISE Registry Between 2014 and 2023

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Consensus-Based PROs and RISE Registry Enable a National System to Monitor Health Disparities

JAMA Network Open.

Original Investigation | Health Policy
Socioeconomic Disparities in Functional Status in a National Sample of Patients With Rheumatoid Arthritis

Zara Izadi, MPharm, MAS; Jing Li, MPH; Michael Evans, MS; Nevin Hammam, MD; Patricia Katz, PhD; Alexis Ogdie, MD, MSCE; Lisa G. Suter, MD; Jinoos Yazdany, MD, MPH; Gabriela Schmajuk, MD, MSc

Figure 2. Computed Probabilities of Functional Decline Across Quintiles of Area Deprivation Index in the Longitudinal Analysis

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

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Summary

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!
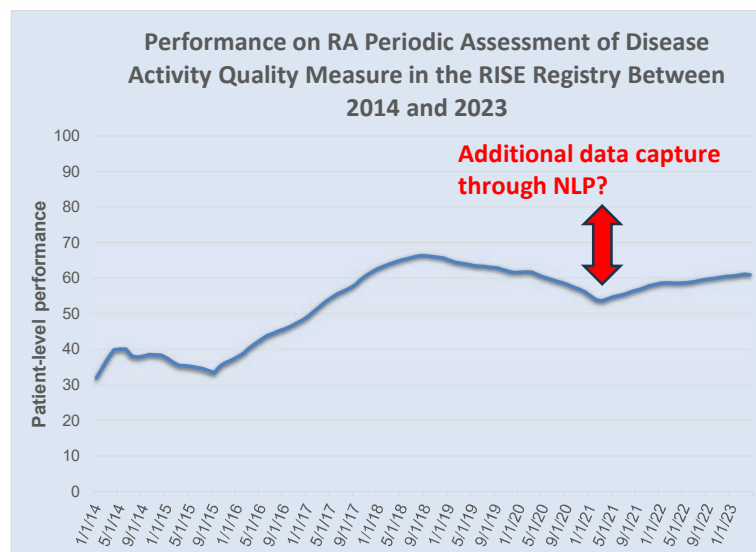
Key Lessons Learned

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

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#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?

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NLP Pipeline for Extracting RA Outcome Measures

AMERICAN COLLEGE of RHEUMATOLOGY
Empowering Rheumatology Professionals

Arthritis Care & Research
Vol. 75, No. 3, March 2023, pp 608–615
DOI 10.1002/acr.24869
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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 Tamang[4]

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

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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

A [...] - - - - DAS 28 - 1 - - Current MDHAQ Function Index 0.7 [PERSONALNAME] Patient self-report joint score - RAPID 3 Score 7.7 RAPID4 Score - CDAI Score 11 CDAI Interpretation 10.1 - 22.0: ModerateActivity[ALPHANUMERICID] Interpretation - [ALPHANUMERICID] Interpretation - Rheumatoid Arthritis Prognosis good \\sscharaux11 [...]

B [...] Stable with current treatment. She rates herSDAI 7/10, but that is [...]

C CDAI: 1 sw 9 tj 9 pga 7 ega = 34 high diseaseactivity She as near normal inflammatory markers [...]

D [...] His review of systems sheet is reviewed and scanned into the chart. Rapid 3. Form given to patientforcomp. [...]

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

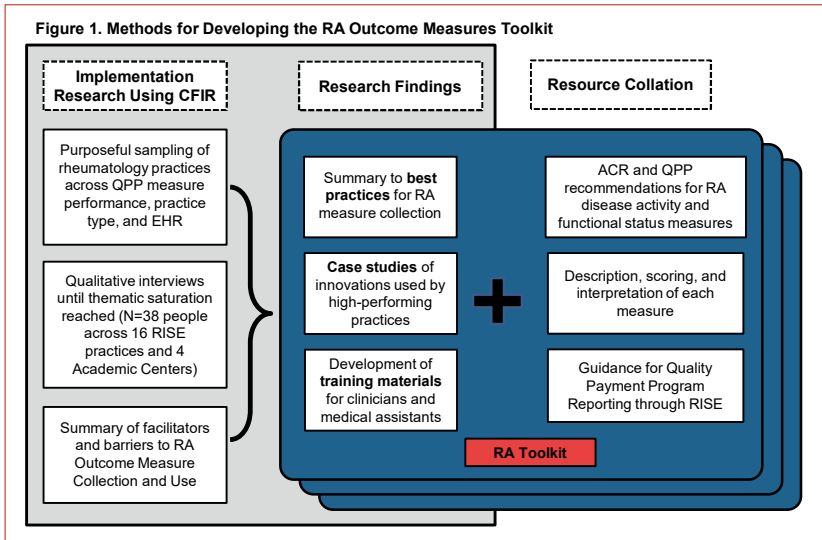| RA outcome measure	No. of scores compared	Exact matching based on numerical scores	Fuzzy matching based on score categories
CDAI score	234,400	0.43 ± 0.38	0.87
RAPID3 score	140,680	0.68 ± 0.36	0.69
RAPID3 score (range 0–10)	6,218	0.91	0.94
RAPID3 score (range 0–30)	134,462	0.66	0.68
MDHAQ score	37,874	0.98 ± 0.46	NA
HAQ score	1,313	0.86 ± 0.37	NA

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Summary

#2 Can NLP enhance PRO information extraction?

Opportunities	Challenges
PRO extraction via NLP was feasible and had reasonable accuracy in RISE registry	Data aggregation and cleaning across multiple sites to develop and maintain NLP pipelines is resource intensive
For practices lacking IT infrastructure to collect structured data, NLP adds value in capturing PRO data	Privacy and security concerns for assembling large note datasets across many sites
Large Language Models will improve accuracy	PRO documentation lacks standardization; addressing copy/paste data is difficult

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#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

https://ratoolkit.kotobee.com/

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RA Toolkit: Primer on RA Outcome Measures

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RA Toolkit: Workflows for Collecting RA PROs

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RA Toolkit: Resources
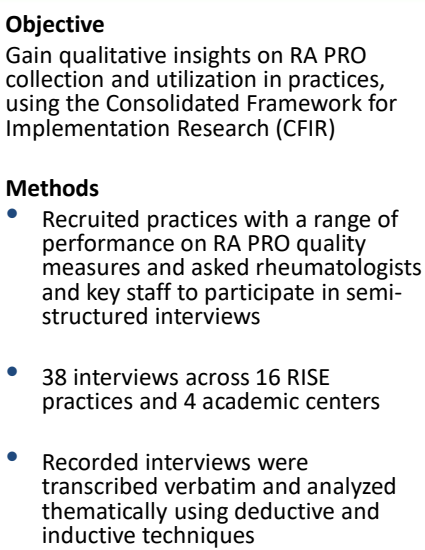
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Qualitative Study: Understanding Facilitators and Barriers to PRO Collection and Use

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

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

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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"*

The Electronic Health Record Problem

https://www.commonwealthfund.org/blog/2018/electronic-health-record-problem

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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.

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Future Directions

2012	2014-present	2018-2023	2024 and Beyond
Develop ACR PRO recommendations	RA quality measures endorsed by NQF and CMS	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

Develop quality measures	Build measures in RISE registry	Develop RA Toolkit
2013-2014	2014-2018	2023

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Research Impact

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.

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Thank You

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Alicia Hamblin

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

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Learning Objective

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

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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.

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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.

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PatientToc™

- 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

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

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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.

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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: PatientToc™, pharmacy records, researcher records in REDCap, interviews

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Phase 1 Findings: Expected Barriers

1. Lack of <u>existing integrations among technology vendors</u> and/or concerns about the feasibility/effectiveness of future integrations of existing technology with PatientToc™.

2. Some <u>sub-groups of patients</u> (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™.

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Phase 1 Findings: Expected Barriers

3. PatientToc™ could be difficult to incorporate into <u>pharmacy workflow</u> 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. <u>Data security</u> 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.

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Phase 1 Findings: Expected Facilitators

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

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

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Phase 1 Findings: Expected Facilitators

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

4. Most stakeholders (pharmacists, pharmacy staff, and patients) felt PatientToc™ was <u>easy to use, felt training requirements would be minimal, and offered limited suggestions</u> for improvement.

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Recommendations & Resulting Toolkit

- 14 recommendations were identified

- Resulting toolkit for pilot implementation
  - PatientToc™ mission statement template
  - Kickoff meeting agenda template
  - Audit & Feedback report
  - Training modules
  - SDOH CE modules
  - Posters, pamphlets, bag stuffers, digital media templates
  - Scripted language
  - Sample workflows
  - Referrals "cheat sheet"

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PatientToc™ in Community Pharmacies
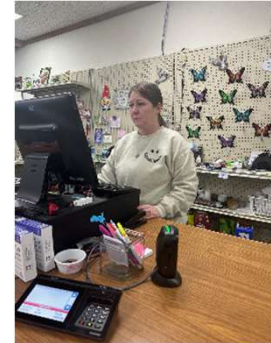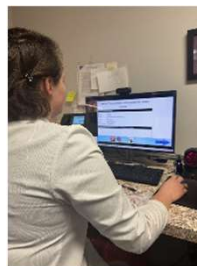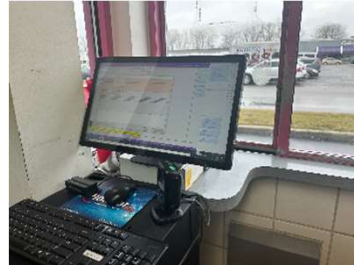
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Phase 2 Pilot Key Findings
n= 3 pharmacies

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.

Accepted for poster presentation at the 2024 American Pharmacists Association Meeting

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Phase 2 Pilot Key Findings

Acceptability

- Patients overall <u>spent about 6 minutes on the app, which aligns with the goal</u> from the pre-implementation work (target was 2-10 minutes).
- Many <u>patients start the app but are stopping before entering their name</u> and contact information.
- There is a <u>need for improved pharmacist and staff introduction of PatientToc</u> 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).

Accepted for poster presentation at the 2024 American Pharmacists Association Meeting

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Phase 2 Pilot Key Findings

Appropriateness

- The app is viewed as <u>overall appropriate for a community pharmacy environment but might be less appropriate for some specific contexts</u> (e.g., grocery setting, drive through).

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Phase 2 Pilot Key Findings

Fidelity

- Overall, <u>pharmacies used PT as planned in their workflow but fewer follow-on surveys than encounters were logged</u> in our database.
  - 21-100% of encounters.
- Observations and interviews point to three potential reasons:
  - Did not wish to take clinical action so just did not complete documentation.
  - Technical issues impacting completion and/or data transfer.
  - Limited familiarity and buy-in to the purpose of having patients use PT.

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Phase 2 Pilot Key Findings

Feasibility

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

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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.

Accepted for poster presentation at the 2024 American Pharmacists Association Meeting

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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
  - 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

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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

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Challenges & Lessons Learned

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

- Clear scope of work with vendor is essential
  - While intent was for integrated app, vendor was unable to deliver in a timely/cost-effective manner
  - 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
  - Minimal staff adoption beyond pharmacist champions
  - Challenging context in pharmacies post-pandemic; ask to do "one more thing"
  - Multi-PBRN collaboration without prior pilot work to explore team dynamics and impacts on facilitation

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Summary: Research Impact

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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Optimizing Use of Patient-Reported Outcomes in Orthopedic Care

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Background

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 year1
- ► Surgery rates could double by 20302

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

[1] Fingar et al. 2014. Most Frequent Operating Room Procedures Performed in U.S. Hospitals, 2003-2012. PMID: 25695123.
[2] Sloan et al. 2018. Projected Volume of Primary Total Joint Arthroplasty in the U.S., 2014 to 2030. PMID: 30180053.

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Orthopedic PROMs

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

	Oxford Hip Score	HOOS JR	Oxford Knee Score	KOOS JR
No. of Questions	12	6	12	7
Domains	Pain, limping, daily functions, sleep	Pain, daily functions	Pain, limping, daily functions, sleep	Stiffness, pain, daily functions

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PROMs in Practice

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

[1] American Academy of Orthopaedic Surgeons American Joint Replacement Registry. Annual Report 2022: The Ninth Annual Report of the AJRR on Hip and Knee Arthroplasty. Rosemont, IL. 2022.
[2] Hospital-Level, Risk Standardized Patient-Reported Outcomes (NQF #3559). 87 FR 49246-49257.

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Challenges with PROMs in Orthopedics

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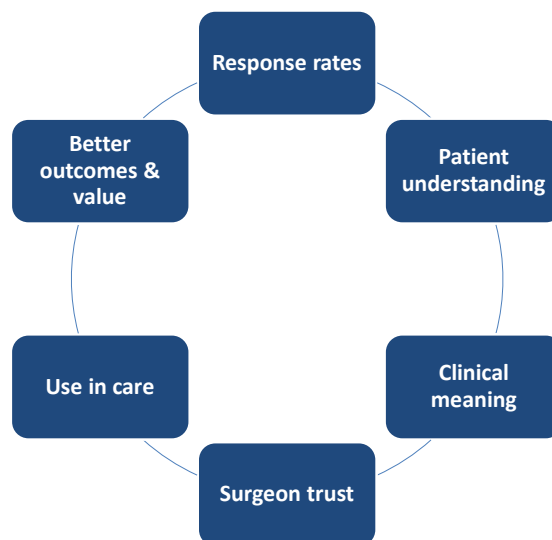
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The PROMOTE Study

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

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PROMOTE Study Aims

Identify patient-preferred outcomes

Aim1

Aim 2

Test text reminders to improve PROM survey response rates

Test making PROMs available in EHR

Aim 3

Aim 4

Test sharing surgeon peer comparisons on PROMs and costs

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PROMs Completion Rates

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.

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Patient Preferred Outcomes

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%

Whitebird et al. 2021. Personalized outcomes for hip and knee replacement: the patients point of view. PMID: 34735662.

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Personalized PROMs

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.

Solberg et al. 2023. Is There Room for Individual Patient-Specified Preferences in the Patient-Reported Outcome Measurement Revolution? PMID: 38046995.

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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%

Whitebird et al. 2021. Personalized outcomes for hip and knee replacement: the patients point of view. PMID: 34735662.
Ziegenfuss et al. 2022. Is the Promise of PROMs Being Realized? PMID: 36314931.

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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.

Logistical barriers

Too many clicks required
Display is not meaningful/helpful
Time is too short

Perceptual barriers

Patients do not understand scores
Comparisons needed to give meaning
Surgeons unsure of reliability/meaning

Whitebird et al. 2022. What Do Orthopaedists Believe is Needed for Incorporating Patient-reported Outcome Measures into Clinical Care? A Qualitative Study. PMID: 34846308. 67

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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.

Patient Pre-Operative Factors Considered

Age, sex, race
BMI, number of medications
Medicaid status
Baseline function, mental, and physical PROMs

Surgeon Factors Considered

Procedure volume
Years of experience

Solberg et al. 2022. Adjusting for Variation in Patient-Reported Outcome Measures Is Needed to Improve Care After Total Knee Arthroplasty. PMID: 34520430. Dehmer et al. Which Matters Most in Predicting Quality and Costs for Hip and Knee. In Process. 68

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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.
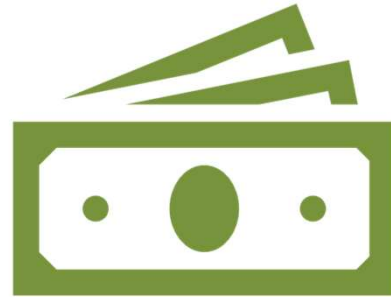
Dehmer et al. Which Matters Most in Predicting Quality and Costs for Hip and Knee Arthroplasty. In Process.

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Surgeon Performance Feedback

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.

Asche et al. The Effect of Individualized Surgeon Comparative Feedback on Arthroplasty Outcomes: An Interrupted Time Series Analysis. In Process.

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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

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Research Impact of PROMOTE Study

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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