

# Optimizing Use of Electronic Patient-Reported Outcomes (ePROs) to Assess and Improve Disease Management

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## Background

- The value of patient-centric healthcare including use of patient-reported outcomes (PROs) to understand the patient's perspective in disease management is well-recognized<sup>1</sup>
- PROs, which may also be captured electronically (ePROs), are defined as "any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else"<sup>2</sup>
- PROs/ePROs complement clinical measures and can help clinicians understand symptoms and health status (e.g., pain, function, and quality of life) from the patient's perspective overall and in response to changes in treatment
  - Especially relevant for informing the shared decision-making process,<sup>3</sup> as discordance exists between patient and clinician perspectives of disease activity, risk-benefit assessment, information gaps, and clinician-patient communication<sup>4-6</sup>
- Treat-to-target (T2T) is the recommended disease-management strategy for rheumatoid arthritis (RA)<sup>7,8</sup>
  - Proactive strategy in which a specific treatment target is defined and tight disease control (e.g., frequent visits and treatment adjustments) is applied until the target is reached
  - Relies on shared decision-making between clinician and patient that includes use of PROs/ePROs
- As PROs have been typically collected at in-person visits, a gap in determining how to integrate them into clinical practice may have been amplified by recent uptake in telehealth and virtual management of chronic conditions

## Objectives

- To characterize current perspectives, challenges, and solutions for implementation and sustainable use of ePROs using RA as an example that can be extrapolated to patients with other diseases

## Methods

- A targeted literature review was conducted in November and December 2022 for relevant articles published from November 2014 to December 2022 on use of PROs/ePROs in T2T RA care in ambulatory or outpatient settings in the United States
- PubMed and EBSCO/CINAHL databases were searched, abstracts were reviewed, and for those considered of potential relevance, full text articles were obtained for further review
  - From the final set of articles identified as relevant, we extracted emerging concepts and perspectives to develop a discussion guide for a focus group
- A moderated focus group was convened virtually in March 2023 to discuss challenges and solutions for implementing PRO/ePRO-based T2T strategies in clinical settings for RA care
  - The multidisciplinary panel consisted of rheumatologist physician assistant; infusion services director; population health leader; rheumatologist/innovation leader; clinic office manager; clinical informaticist/pharmacist; rheumatologist/immunologist; and subject matter expert (rheumatologist with extensive experience on efficacy, comparative effectiveness, and safety of treatments for RA)
  - The focus group moderator asked questions based on findings from the targeted literature review to stimulate qualitative discussion on challenges and potential solutions for sustainable implementation of T2T and use of PROs/ePROs

## Results

### Targeted Literature Review

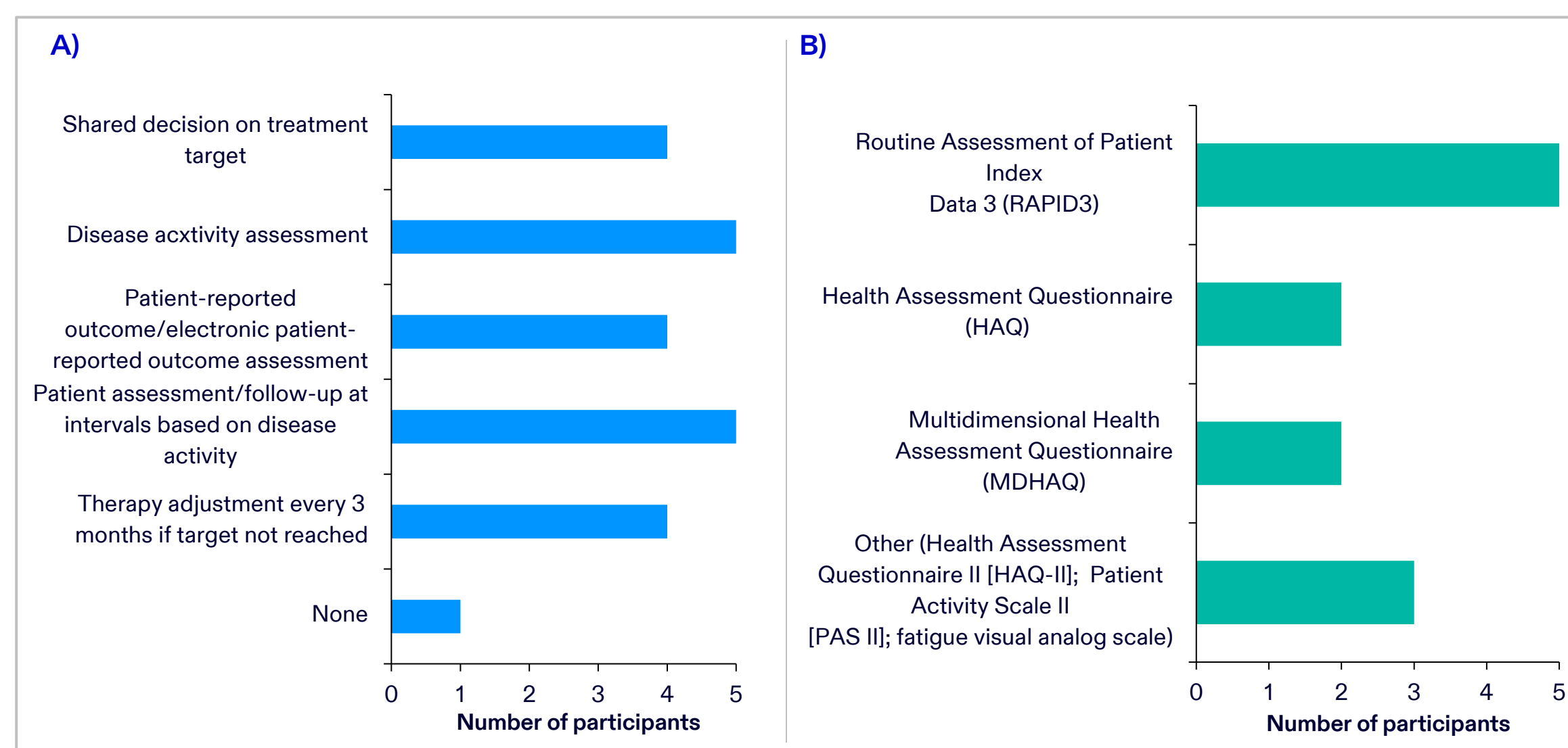
- Twenty articles were identified as relevant for inclusion in the targeted literature review<sup>9-28</sup>
- A major key finding was that while the importance of patient involvement in T2T was recognized, there was poor long-term adherence to T2T strategies in part due to lack of focus on patient-centered care and low patient involvement in decision-making
- Specific challenges to implementation and sustainability of PRO-based T2T included
  - Patient concerns including function, quality of life, and work productivity may not be considered<sup>12,14,18</sup>
  - Time burden associated with data capture and processing<sup>17,18</sup>
  - Need for tools and integrated techniques to improve data capture and processing in clinical practice<sup>12,13,15</sup>
- ePROs may be of potential use in overcoming these challenges, and while multiple mechanisms for collecting ePRO data were identified, a major challenge was low patient and healthcare provider (HCP) commitment to collect and use such data<sup>18</sup>

## Results, cont.

### Focus Group

- Participants noted that while T2T is valued for its benefits for improving patient outcomes and increasing efficiency and productivity of clinic workflows, out-of-office mechanisms (i.e., remote monitoring) to support key elements of T2T strategies are infrequently used
- All focus group participants except one reported using various elements of T2T care including PROs/ePROs (Figure 1A)
  - The most commonly used elements were assessment of clinical disease activity and longitudinal follow-up based on disease activity
  - The Routine Assessment of Patient Index 3 (RAPID3) was the most commonly collected PRO (Figure 1B)

Figure 1. Use of treat-to-target management strategy elements (A) and patient-reported outcome measures (B) for patients with rheumatoid arthritis



- The focus group confirmed and expanded on the challenges for sustainable PRO/ePRO use identified in the targeted literature review, and suggested potential solutions (Table 1)
  - Participants agreed that these challenges contribute to the disincentivization of clinicians, which was considered the main barrier to implementing sustainable PRO-based T2T strategies in clinical settings
  - ePROs, especially if combined with remote therapeutic monitoring, were thought to be useful for visit triage (i.e., to accelerate or postpone already scheduled clinic visits)
  - An essential solution for enhancing systematic use of PROs/ePROs was integrating these measures into electronic health records to reduce manual data entry

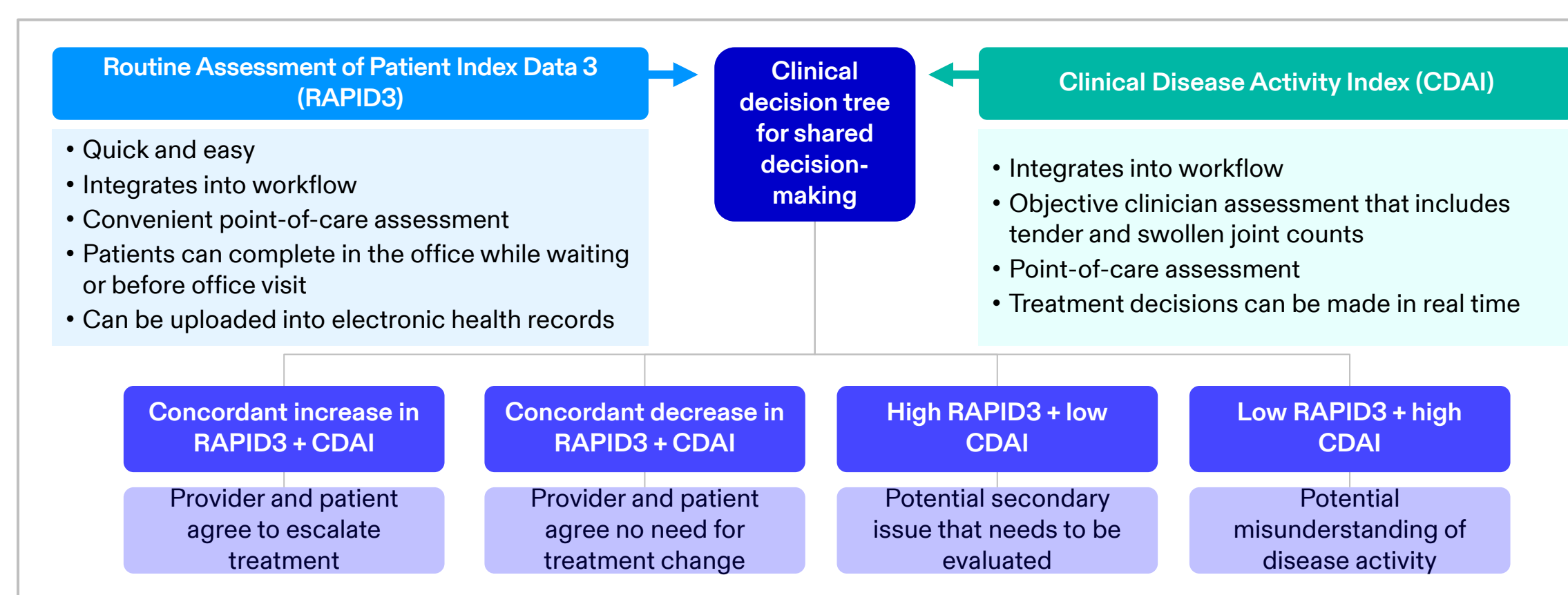
Table 1. Challenges to and potential solutions for sustainable use of patient-reported outcomes (PROs)

KEY CHALLENGES	POTENTIAL SOLUTIONS
<b>Lack of incentive; clinicians may not recognize the value of collecting PRO data or may be unsure how to use such data in clinical decision-making</b>	<ul style="list-style-type: none"> <li>Including PROs in a clinical decision tree can contribute to shared decision-making process</li> <li>Document PRO data collection processes and protocols so that new staff are consistently trained on process, expectations, and commitment to quality</li> <li>Reinforcement of value and benefits of PROs to complement clinical assessment of disease activity</li> </ul>
<b>Uncertainty regarding which PROs to use for comprehensive assessment while limiting clinician workload</b>	<ul style="list-style-type: none"> <li>Generate evidence-based consensus on appropriate PROs                             <ul style="list-style-type: none"> <li>PROs that assess disease activity/impact, e.g., RAPID3 in RA (other PROs as appropriate in other diseases)</li> <li>PROs that assess outcomes considered important by patients (e.g., quality of life, daily function, work productivity)</li> </ul> </li> </ul>
<b>Clinicians and healthcare staff have limited bandwidth to collect and process more patient information</b>	<ul style="list-style-type: none"> <li>Patients complete surveys in electronic health record portal or via touchscreen in office during check-in</li> <li>Patients use remote treatment monitoring to report PROs between visits</li> </ul>
<b>Lack of information technology integration makes collection and documentation of ePROs difficult and inconsistent</b>	<ul style="list-style-type: none"> <li>Integrate ePROs into electronic health records so that clinicians do not have to perform manual data entry</li> <li>Reduce documentation burden of electronic health records, which should center around safety and treatment outcomes rather than billing or medicolegal issues</li> </ul>
<b>Patients may not understand value of completing ePROs</b>	<ul style="list-style-type: none"> <li>Healthcare providers communicate to patients how and why the collected data are being used, and incorporate the collected data into the shared decision-making process</li> <li>Clinical office staff to "champion" ePROs and ensure patients complete questionnaires</li> </ul>

## Results, cont.

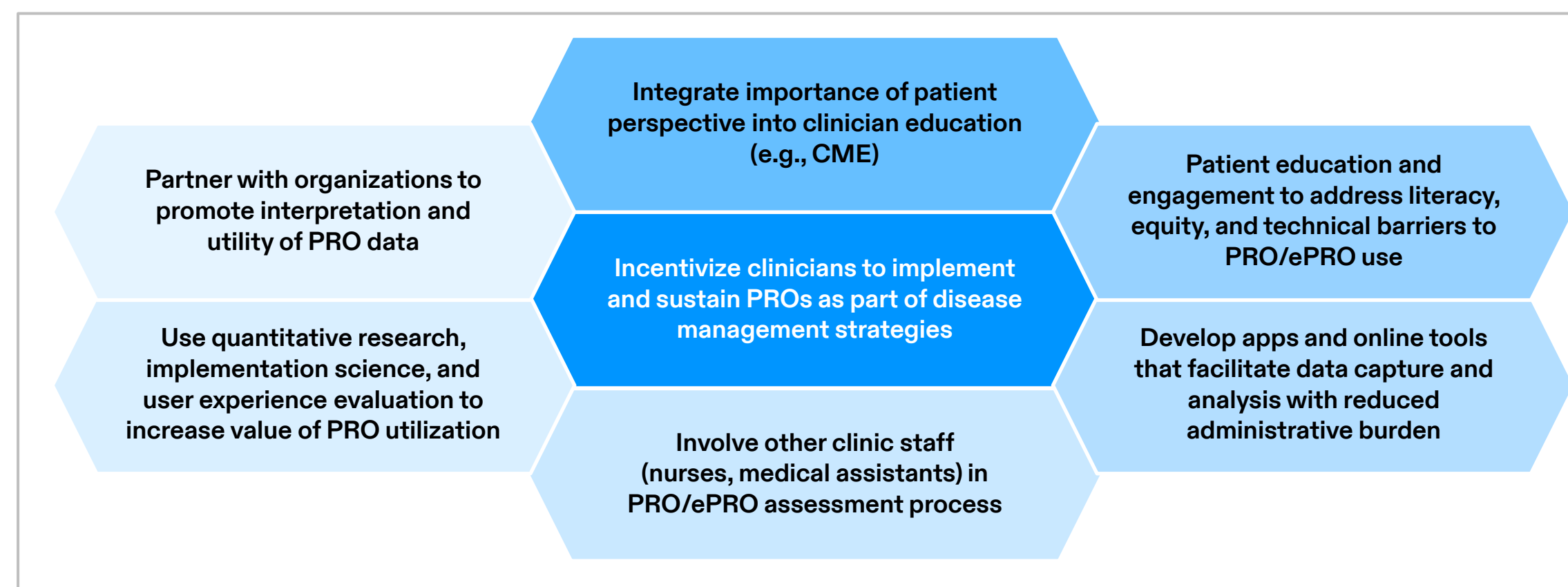
- Clinical decision trees that incorporate concomitant use of a PRO/ePRO and a clinical measure of disease activity were suggested for establishing the value of the patient perspective in the joint decision-making process
- An example of such a decision tree was proposed for RA using the RAPID3, which assesses physical abilities, pain, and overall health<sup>29</sup> as the PRO/ePRO and the CDAI (Clinical Disease Activity Index, which includes tender and swollen joint counts as well as patient and clinician global assessments)<sup>30</sup> as the measure of clinical disease activity (Figure 2)
  - When the PRO and clinical measure are concordant and show poor outcomes, there is agreement for treatment escalation
  - Concordance between the PRO and clinical measure that shows good outcomes indicates that current therapy can be maintained
  - Poor outcomes on the PRO in the presence of a good outcome on the clinical measure likely indicates a secondary process that may need to be identified and resolved
  - A good outcome on the PRO in the presence of a poor outcome on the clinical measure may indicate that the patient doesn't understand that their disease is still active

Figure 2. Example of incorporating a patient-reported outcome (e.g., RAPID3) into a shared decision-making treat-to-target strategy for rheumatoid arthritis.



- With clinician incentivization as the central barrier, actionable solutions could be codified into a proposed inter-related cycle of next steps that would help healthcare providers, patients, and other stakeholders understand the utility of a PRO-based management strategy and more fully engage with it (Figure 3)
  - Top-down and bottom-up steps include emphasizing the importance of the patient perspective in continuing education activities, and involving all clinic staff in gathering and scoring PRO assessments and explaining their utility to patients.
  - Parallel steps, with healthcare provider-focused steps on one side and steps oriented toward enhancing patient-engagement on the other side, would help all stakeholders understand the need for including PROs/ePROs as part of patient care, thereby providing additional support and clinician incentivization

Figure 3. Suggested multistep program with a central goal of incentivizing clinicians for implementing and sustaining patient-reported outcomes in clinical care



CME, continuing medical education; ePRO, electronic patient-reported outcome; PRO, patient-reported outcomes

## Conclusions

- Based on literature review and focus group discussion, challenges for PRO implementation were clinician time restrictions, information technology integration issues, and lack of patient understanding
- Next steps in overcoming these challenges should include
  - Education and incentivization of clinicians and patients to integrate PROs/ePROs into workflows
  - Partnering with professional medical organizations to support use and interpretation of PROs/ePROs
  - Development of apps and online tools that can facilitate data capture while reducing the administrative burden
- The proposed solutions to the identified challenges and the multistep incentivization program have general implications beyond RA, and can be extrapolated for enhancing the patient-centric approach to management of a variety of diseases
- These findings also highlight an opportunity for specialty pharmacies to implement pathways and develop workflows for facilitating widespread adoption of ePROs to improve disease management and patient outcomes

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