

“Unspoken Questions”: A Qualitative Study of Rheumatologists’ Perspectives on the Clinical Implementation of Patient-reported Outcome Measures

Shanthini Kasturi¹ , John B. Wong², Lisa A. Mandl³ , Timothy E. McAlindon¹ , and Amy LeClair⁴

ABSTRACT. *Objective.* To identify rheumatologists’ views on perceived barriers and facilitators to the clinical implementation of patient-reported outcome measures (PROM).

Methods. Semistructured interviews were conducted with academically affiliated clinical rheumatologists. Interviews were audio-recorded and transcribed. Deidentified transcripts were independently coded and analyzed for themes.

Results. Fifteen attending rheumatologists, 8 women (53%) and 7 men (47%) with a mean of 17.3 years in practice (range 5–43) at 2 urban academic medical centers, participated in interviews. Rheumatologists identified several barriers to integrating PROM in clinical care, highlighting physician buy-in and culture change as significant challenges beyond logistical considerations. They further underscored the lack of effective interventions and resources for addressing the domains of most interest to patients. Physicians also recognized significant benefits of PROM in clinical care, including contributing to the clinical impression by providing the patient perspective, and promoting agenda setting by uncovering “unspoken questions.” They additionally noted that PROM could support treatment planning, build patient-physician relationships, and facilitate patient engagement. Participants suggested that technology, physician education, and team-based care could facilitate the effective implementation of PROM.

Conclusion. Rheumatologists identified multiple mechanisms through which PROM could augment clinical care, but also noted several obstacles to implementation, questioning the added value of PROM and the limited availability of interventions to improve patient-centered outcomes. Programs seeking to successfully integrate PROM to enhance patient-centered care and meet quality benchmarks should prioritize physician buy-in and training, and provide resources to address the outcomes that are measured.

Key Indexing Terms: patient-centered care, patient-reported outcome measures, qualitative research, rheumatologists

Although patient-reported outcome measures (PROM) have long been used in clinical research, they have only recently gained momentum as powerful tools to advance clinical care¹. PROM are instruments that assess the status of health conditions directly

This study was funded in part by the National Center for Advancing Translational Sciences, National Institutes of Health (NIH), Award Number 1KL2TR002545, the Michael D. Lockshin Fellowship of the Barbara Volcker Center for Women and Rheumatic Disease at the Hospital for Special Surgery, and the Tupper Research Fund. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

¹S. Kasturi, MD, MS, T.E. McAlindon, MD, MPH, Division of Rheumatology, Allergy & Immunology/Department of Medicine, Tufts Medical Center, Boston, Massachusetts; ²J.B. Wong, MD, Division of Clinical Decision Making, Tufts Medical Center, Boston, Massachusetts; ³L.A. Mandl, MD, MPH, Division of Rheumatology/Department of Medicine, Hospital for Special Surgery and Weill Cornell Medicine, New York, New York; ⁴A. LeClair, PhD, Institute for Clinical Research and Health Policy Studies, Tufts Medical Center, Boston, Massachusetts, USA.

Address correspondence to Dr. S. Kasturi, MD, MS, Division of Rheumatology, Allergy, & Immunology, Tufts Medical Center, 800 Washington Street, Box 406, Boston, MA 02111, USA.

Email: skasturi@tuftsmedicalcenter.org

Accepted for publication June 12, 2020.

from patient reports without interpretation by a clinician or anyone else². A growing literature supports the benefit of PROM in improving patient-centeredness, including patient-physician communication, symptom detection, tracking and treatment, and patient satisfaction^{3,4}. Healthcare quality metrics increasingly emphasize patient-reported outcomes (PRO) in recognition of their value in capturing the patient experience of illness. PROM comprise over 20 of the performance measures endorsed by the National Quality Forum and are part of the Centers for Medicare and Medicaid Services value-based healthcare initiatives in orthopedics and oncology^{5,6,7}.

In rheumatology, the annual measurement of functional status, which is a patient-reported outcome, is an American College of Rheumatology rheumatoid arthritis (RA) quality measure and a requirement of the Merit-based Incentive Payment System, 1 of 2 value-based payment models in Medicare’s Quality Payment Program^{8,9}. Despite these mandates, the measurement of functional status in clinical rheumatology is far from routine. Only 50% of patients with RA in a national electronic health record-enabled registry had a documented functional status score, with the rate of clinicians utilizing this information likely even lower¹⁰. This statistic is particularly notable given the pioneering role of

rheumatologists in promoting PRO as a critical mechanism of assessing chronic disease in research and clinical settings^{11,12}.

With the growing interest of patients and payers in utilizing PROM to improve clinical care, understanding the obstacles to their integration in routine practice is essential. While theoretical difficulties of implementing PROM in clinical care including logistical and technological concerns have been described, there has been little systematic evaluation of the perspectives of clinician end-users, including those of rheumatologists^{13,14,15,16,17,18}. Acquiring knowledge of the theoretical as well as pragmatic challenges encountered by rheumatologists therefore becomes critical to informing the design of effective systems and pathways for integrating PROM in the care of patients who suffer from chronic systemic conditions with persistent effects on quality of life (QOL). The objective of this study was to elicit rheumatologists' views on perceived challenges and potential facilitators to the clinical implementation of PROM.

MATERIALS AND METHODS

Study design and participants. Semistructured interviews were conducted with practicing rheumatologists affiliated with 2 urban academic medical centers, Tufts Medical Center in Boston, and the Hospital for Special Surgery in New York. All practicing rheumatologists at Tufts Medical Center who were not investigators in this study were invited to participate in interviews. Rheumatologists at the Hospital for Special Surgery were contacted using purposeful sampling to include practitioners with and without a specific clinical interest in lupus. An interview guide was developed focused on exploring perspectives on the barriers to implementing PROM in clinical care, particularly on use in patients with systemic lupus erythematosus (Supplementary Data, available with the online version of this article). The interview guide also probed possible benefits and potential facilitators of the use of PROM in clinical care.

Data collection. Participants provided verbal consent after reviewing a study information sheet. Demographic information including sex, race, ethnicity, and number of years in practice were queried. Interviews took place in-person or over the telephone, and were audio recorded, then professionally transcribed verbatim. Interviews were conducted until thematic saturation was achieved. Transcripts were uploaded into Dedoose software for coding and analysis. All study procedures were approved by the Tufts Health Sciences Institutional Review Board (IRB# 13047).

Analysis. To develop the codebook, 2 independent coders (SK, AL) reviewed a subset of 3 interviews, then met to review code definitions and applications. They reviewed additional transcripts, adding and editing codes, until a final codebook was developed. All transcripts were then rereviewed using a comparison and consensus approach to verify that the codes were applied consistently. A thematic analysis was performed employing an iterative inductive process, and codes were organized into themes and subthemes to identify the main barriers to, and benefits and facilitators of, implementing PROM in clinical care¹⁹.

RESULTS

A total of 15 attending rheumatologists were invited to participate in the study, and all consented to be interviewed (Table 1), falling within the recommended number of participants to attain maximal response variation²⁰. Interviews ranged from 20 to 43 (mean 33, median 28) minutes, with 8 conducted in person and 7 by telephone. Five rheumatologists practiced at Tufts Medical

Table 1. Characteristics of study participants.

	Rheumatologists, N = 15
Years in practice, mean (SD), range	17.3 (10.1), 5–43
Female	8 (53.3)
Race	
White	10 (66.7)
Asian	4 (26.7)
Biracial	1 (6.7)
Ethnicity	
Hispanic/Latino	2 (13.3)
Collection of PROM at point of care	13 (86.7)
Use of PROM in clinical care	11 (73.3)

Values are expressed in n (%) unless otherwise specified. PROM: patient-reported outcome measures.

Center, and 10 at Hospital for Special Surgery. Most participants reported collecting and using PROM at the point of care for clinical and quality reporting purposes but noted that workflows were not always reliably followed. The Multidimensional Health Assessment Questionnaire and the Routine Assessment of Patient Index Data 3 were the PROM most commonly collected by participants.

Thematic analysis

A. Challenges of implementing PROM in clinical care.

Participants identified a number of barriers to using PROM in routine clinical care (Table 2), which were categorized into challenges at either the physician level or healthcare system level. Physician-level barriers pertained to prevalent beliefs and attitudes related to PROM, inertia around practice change, and lack of adequate skills or training around PROM. Systems-level challenges related to limitations imposed by current practice conditions, including availability and access to interventions and logistical issues.

1. Physician-level barriers

Theme 1: Perception of no added value of PROM. Several participants were quick to question the utility of PROM, pointing out that it was not evident that the standardized surveys to which they had been exposed provided any additional information over a history taken by a skilled physician, or even better delineated the general question of how the patient was doing. One rheumatologist felt that the Health Assessment Questionnaire (HAQ) was outdated and not meaningful to patients: "I don't think my patients are interested in filling them out.... Everybody filled out an HAQ and they were like, 'Why do I have to fill this out? It's not relevant to me.'" [R9] Some noted that the lack of added value could be related to the limited precision and responsiveness to change of the measures they used: "Some of the things that are scored either don't change very much or they change very widely from visit to visit." [R5] Others acknowledged that the surveys could provide additional information, but this was unlikely to change their clinical impression or management plan.

Table 2. Challenges of implementing patient-reported outcome measures (PROM) in clinical care.

No added value	<p>“After 20 years of experience, you kind of know what’s going on in 5 minutes... like, many times we get the picture, and we don’t ask all the questions that we really need to ask if you are a resident.” [R3]</p> <p>“I think I get to the same questions without doing it in a formal way... I think I get to the point, the questions that I need to ask for patient care, and I think of [PROM] more as for studies.” [R15]</p> <p>“I don’t feel like it adds to what I’m going to do for the patient beyond the things that I do.” [R10]</p> <p>“I’m not always sure that it adds more to just asking people how they’re doing and whether things are good or bad, or what their problems are. So I’m not always convinced there’s an additive effect there.” [R6]</p>
Practice inertia	<p>“It’s very difficult to change their culture or how physicians practice, or before practicing, just to bring something new to patient care.” [R3]</p> <p>“I think the doctor has to be a believer as well, because a lot of doctors may walk in the room thinking they know what to do, but they may not... Some doctors may not think it’s really that important and others may think, oh, this is really going to change what I offer the patient today.” [R13]</p>
Time constraints/competing priorities	<p>“It doesn’t mean that you don’t think it’s important, but you have to focus on what you think is medically the most important. I think that’s why these other things, they just don’t get addressed because of lack of time, lack of resources.” [R2]</p> <p>“The doctor feels like they just barely have enough time to address all the other important issues, which the patient may not think that’s important at the time. It’s always the main issue here.” [R14]</p>
Score interpretation	<p>“I see it in the chart there in front of me. I have no clue what that means for a patient. So, to me, asking them ‘How are you doing?’ is so much more than what those numbers say. And I have people that check 9 every time... well, for 10 years they’ve been checking 9, and it’s fibromyalgia.” [R10]</p> <p>“Unfortunately it’s the people with lupus that’s kind of not severe that you most want a score like this, where it works the least well because they’re the people who you’re like, ‘Eh, is it all fibro-y stuff going on here?’” [R6]</p> <p>“[Without] context, there’s no kind of anchoring for it. It can be very high in that different people give very disparate answers based on, I don’t know, all kinds of reasons.” [R5]</p>
Lack of effective interventions	<p>“Measuring fatigue for me is not satisfying because if I’m... asking them ‘How’s your fatigue?’ and they’re like, ‘Oh, it’s like still terrible,’ then they’re going to get mad at me for asking this. Like giving them a questionnaire about it, and then they’re like, ‘See? It’s so bad.’ And I’m like, ‘Oh, sorry, that’s unfortunate for you.’” [R9]</p> <p>“The things that we’ve talked about that are of most concern to the patients are the things that we have the least ability to help them with. Sleep: Wouldn’t it be nice if there were a sleep person at the sleep center who worked with lupus patients and who would see them in a prompt way? Cognition: I tell patients what I think about it. I tell them that it’s probably related to the lupus, and it does tend to fluctuate, and we don’t have a good treatment for it.” [R2]</p> <p>“Not having a lot to offer for things like cognitive stuff: that I think is big. So you know that the patient has cognitive issues, but then being confronted with that 3 or 4 times a year can be depressing—not depressing but, you know, discouraging for the physician and for patients.” [R14]</p> <p>“I guess the main barrier, as I see it, is that relatively few of those things are kind of actionable or immediately correctable in a way that’s separate from the overall lupus disease activity. And a lot of the treatments that we would add can potentially worsen those things rather than help them. And so I think that calling attention to something that just cannot be directly remedied is hard.” [R5]</p>
Limited resources for interventions	<p>“We’ve had patients who have expressed anxiety and depression, and it’s nearly impossible to get them to see a psychiatrist or a therapist, and even if we have a social worker, I’m not sure how much of an impact that makes to get them into cognitive behavioral therapy.” [R15]</p> <p>“I think the more that you sort of query mental health, the more it’s important to have resources to give people. So just in the same way that if you’re going to screen for something, you should have an intervention that can follow.” [R5]</p>

[R]: rheumatologist.

Many participants expressed their personal belief in the value of PROM, but recognized prevailing attitudes of uncertainty or distrust: “I think sometimes [physicians] who are a little skeptical about PRO think that the people who promulgate them are suggesting that they don’t know how to talk to patients. They don’t know how to get the right information, and therefore, this is fixing you not being a very good doctor.” [R7] One rheumatologist suggested the PROM could result in information overload:

“If it’s too much information, I think it makes things difficult. If you have too many things to review... then maybe important things are left behind.” [R4] Another expressed fear of unintended consequences: “Something like this can lead to an oversight body taking numbers and means, and potentially using it in ways that I would disagree with, or could be held against you” [R10], implying that not only do these measures not add value, but they could potentially cause more harm to physicians.

Theme 2: Practice inertia. Rheumatologists agreed that “buy-in” was critical to facilitating the implementation of PROM in clinical care, but that physician culture is challenging to change. “The problem is that everyone has a very different style of practicing, and people get at some of these issues and questions, either not at all or in different ways than others.... You’re trying to standardize a certain practice.... It’s hard to do that.” [R15] They noted that even small modifications to expectations around care could be met with significant inertia, particularly in the setting of time constraints and competing priorities, unless there was substantial motivation to change. Participants acknowledged this was not unique to PROM, but could apply to any practice change, no matter how beneficial in the long run.

Theme 3: Challenges in score interpretation. Participants noted that appropriate training was essential for accurate score interpretation, particularly in the context of noninflammatory comorbidities such as fibromyalgia. They suggested interpretation guidelines for individual patients, by type of condition, and in relation to the general population. Several rheumatologists emphasized the importance of understanding clinically significant score changes and thresholds for action.

2. Systems-level barriers

Theme 1: Lack of effective interventions. A critical recurring challenge emerging in the interviews was the lack of efficacious treatments for many of the domains measured by PROM. Participants lamented their inability to offer remedies for fatigue and cognitive difficulties in particular, noting that often there were few avenues for action beyond treating disease activity. While many interviewees emphasized that the discussion of PRO could validate and engage patients, thus serving as an intervention itself, a few questioned the benefit of raising issues without clear solutions. They suggested that patients may resent such conversations and noted that it was difficult for them personally to discuss problems that they could not fix as physicians.

Theme 2: Limited resources for interventions. Participants pointed out that even when proven treatments exist, they are often not easily accessible or readily available. Several rheumatologists cited long waits for specialists in mental health such as psychotherapists or psychiatrists, and difficulties connecting patients with neuropsychiatrists for cognitive assessments and sleep specialists to evaluate secondary causes of fatigue. Some noted the additional complexity of navigating access to care based on patients’ insurance status.

Theme 3: Administrative burden. Nearly every interviewee raised the challenge of the additional administrative burden imposed by PROM, anticipating various logistical difficulties. Customization of surveys by disease and language, practicalities of administration and scoring, and data capture from patients who do not readily complete PROM (due to illness, survey fatigue, privacy concerns, etc.) were practical barriers to assessment that rheumatologists identified. Logistics related to technology, including data management and visualization, specifically electronic medical record (EMR) integration, were a

recurring concern. Competing priorities and the time constraints of clinical encounters were highlighted by several rheumatologists, who pointed out that clinical matters took precedence, leaving limited time to cover QOL issues. While many noted that PROM could potentially save time by setting the agenda for a visit, 1 participant expressed concern that they may unnecessarily prolong encounters.

B. Uses and benefits of implementing PROM in clinical care

As many of the respondents were already routinely collecting PROM in their practice, they noted the benefits of the additional information and how they employed them in the care of their patients. Five themes relating to the utility of PROM in clinical care emerged in the interviews (Table 3).

Theme 1: Contribute to clinical impression. Participants felt that PROM were an additional piece of information that contributed to their overall clinical impression, particularly in patients whose disease was not obviously flaring, by more objective criteria such as the physical examination or laboratory results. They noted that PROM could help identify red flags, especially if there were acute changes in scores or discrepancies with clinical data. Several used PROM to glean a global sense of patients’ well-being, including the effect of treatments on physical, emotional, and social health. All interviewees noted that the surveys bridge a disconnect in clinical care by shedding light on patients’ experience of illness, which is otherwise not captured by conventional measures of disease activity. Some even noted that the symptoms identified by PROM not picked up by other measures may correlate with an underlying biomarker of disease activity that has yet to be uncovered: “There may be some specific thing that heralds a disease flare in ways that are not captured by the tests that we [currently] do.” [R5]

Theme 2: Set the agenda. Several physicians noted that having the PROM helped set the agenda for the conversation with the patient. Some even argued that these measures helped them save time because they allowed the physicians to hone in more quickly on specific issues of importance to the patient. Others pointed out that by drawing attention to QOL concerns, PROM could convey that the doctors “get it,” and as a result, reduce time spent in discussion.

Theme 3: Inform treatment. Rheumatologists saw value in using PROM to develop a treatment plan. “I feel like the more information you have, the better chance you have of putting it all together to come up with a plan that’s going to be helpful.” [R2] Many observed that PROM could be tracked longitudinally to understand how treatments affect overall outcomes, including the unintended adverse effects of medications. They also pointed out that longitudinal tracking of PRO could be used to provide patients with feedback about the progression of their disease. Participants noted that PROM could shed light on avenues for intervention beyond traditional antiinflammatory treatments and increase the overall impact of rheumatologists on their patients. A couple of interviewees identified PROM as a key facilitator of asynchronous clinical care (i.e., managing patients

Table 3. Uses and benefits of patient-reported outcome measures (PROM) in clinical care.

Contribute to clinical impression	<p>“I use that to fill in the important pieces as to how they’re doing. Pain score, functional score: All of those are really important.” [R8]</p> <p>“I use it to get a general sense of the patient’s overall status. I also use it when from time to time patients, when there are subtle changes, they can sometimes have trouble expressing qualitatively whether they feel better or not. So it’s an adjunctive piece of objective information for that.” [R7]</p> <p>“I use the information in combination with my clinical observation and impression of the patient because sometimes there are discrepancies.” [R4]</p> <p>“You have to put it in the clinical context, for sure, but I think it’s just another way to fill that out. And I think it’s just when somebody’s really sick, it’s obvious. Quality of life is poor and all that stuff. Like that’s a no-brainer. But I think that maybe is only, like, 10–15 % of the patients, and the rest of the patients, are a continuum of doing okay. Like doing okay, well, and actually not doing so well. And sometimes, depending on people’s coping mechanisms, you might have a misguided sense of really what their quality of life is.” [R1]</p>
Identify patient perspective	<p>“There are patients who have mild connective tissue disease or lupus but who really are suffering much more than other patients. I think that it’s important to know that. That is some of the information that you get.” [R2]</p> <p>“The other role it could play would be in a situation where you think the disease isn’t that active, and then there’s enough things that are legitimately inflammatory that you realize you’re just wrong about it. Because I think when a patient is upbeat and cheerful, they sometimes don’t seem that sick. But when you realize they’re very fatigued—they can’t get out of bed for 2 hours, they can’t do this, that, or the other thing—you’re like, ‘Hmm, maybe I’m not right about that or maybe they’re not right about that.’” [R1]</p> <p>“People don’t necessarily feel their nephritis or their interstitial lung disease or what-have-you. Yeah, but I care about function. I care about people being able to work or do the things that they want to do to not have pain.” [R5]</p>
Identify red flags	<p>“If I saw an outline or a number suddenly that was much lower or much higher, I’d probably ask them about it. So it would be a prompt for me to check into it.” [R10]</p> <p>“I will glance at it when I go in. If I see something that I find surprising, I will raise it with a patient.” [R2]</p>
“Biomarker”	<p>“In some patients, if you see a trend where some of these more subjective features tend to happen when their disease is more active, you can perhaps understand that in that patient, that could be an actual marker of impending flare.” [R12]</p> <p>“I think all of these things are useful in context. So if there is an idea that a particular measure reflects disease activity in some kind of measurable standard way, then yeah, it would be really helpful to have some measure of that.” [R5]</p>
Set the agenda	<p>“It helps you focus because every patient’s different. So when you go in the room, you’re focusing on the things the patients care about because I think you don’t always know what that is. And it’s obvious sometimes when the patient still looks unhappy that you haven’t hit on the right thing. So this way, you can just get to the important stuff.” [R1]</p> <p>“To have the information gathered for you, it just allows you to hone in on what seems to be most important for that particular patient.” [R2]</p> <p>“It allows you to zero in on things if you see that there’s something unusual or something that’s changed for that patient.” [R2]</p>
Save time	<p>“It would actually help you save time, because it would show you some things that otherwise maybe wouldn’t come out until the end of the visit.” [R10]</p> <p>“I think that this kind of thing can save a little bit of time because we’re all so constrained in terms of the amount of time we have for our encounters with patients. It provides you with an at-a-glance idea of how the patient perceives themselves to be doing.” [R2]</p>
Inform treatment	<p>“I think overall quality of life is maybe the only thing that matters at the end of the day. And, in particular, the quality-of-life part is important because it can also incorporate the effect or potential side effects of treatment also. So someone’s pain might be better, but they’re having terrible side effects from the treatment we’re giving them. Then their quality of life still won’t improve or may not improve as much if they weren’t having those side effects.” [R7]</p> <p>“I really think it helps to understand all these little things that are happening in their life. And then you know why things are happening before you just jump to raise the medication dosage, then you want to help them to sort that out; otherwise you can’t just keep immunosuppressing people for the stress in their life. It won’t work.” [R13]</p> <p>“I feel like many times what happens is your treatment is sort of sabotaged, right? So that you think you need to use more medication when you don’t. Is a person not getting up in the morning because they’re stiff, or is it because they’re not sleeping well because you gave them too many steroids? You have to kind of delve into that.” [R1]</p>
Identify avenues for intervention	<p>“I actually find that when people don’t seem as active, I probably delve into it more because then I feel like, ‘What else is going on?’ And so it’s more of a discriminator as to maybe there are other things affecting quality of life or other things affecting sleep. Or could it be depression? Could it be fibromyalgia? So it’s discriminative in a way as to disease when the disease isn’t active, maybe.” [R1]</p> <p>“I think we sometimes miss opportunities to improve our patients’ lives because we don’t address those issues. We think of ourselves as inflammation and joint doctors. But those can be really big components. And, in fact, in some cases, maybe their disease is such that you can’t do anything about their arthritis, but you help them sleep better or you help them have better mental health; they actually improve significantly.” [R7]</p>
Population management and asynchronous care	<p>“What I’m after is population management. So, if a patient is stable on treatment, and their patient-reported outcomes are rock stable, and we know that ahead of time, maybe that patient doesn’t need to come in very often. Maybe a check-in with a nurse or the physician assistant could substitute for a provider visit.” [R7]</p>

Table 3. Continued.

	“I think patients are under a tremendous amount of anxiety in the midst of a visit. I think they forget a lot of things... so, if you can separate the visit and what you gain from that, vital signs and things like that, versus what’s really going on in their life, that would be tremendously helpful.” [R8]
Provide patient feedback	“Are there therapies that can be offered to change what the patient’s perception is of how they’re doing but also kind of giving patients feedback about where they started, where they’re at now?” [R14] “It’s very helpful. It also helps them to realize how much better they’ve gotten.” [R13]
Build patient-physician relationships	“For some of these measures, there may not be an intervention. You’re not intervening. For example, cognition, the levels, I’m not sure if it will change a lot with any treatments we do—maybe in some situations, but most of the time they will not change so much. It’s good to know. At least that gives you a sense that you and the patient know each other well. There’s no miscommunication. You’re on the same page. I think that’s important to have the trust that I understand exactly where you are and the other way around. I think that’s the main value of this, that people would trust that they have a good relationship with the physician.” [R4] “I think it also strengthens the relationship when they get that you need to get [who] they are as people.” [R8] “I think it’s an important topic because... it’s the other side of the coin in terms of making patients well. This is one reason that patients go from doctor to doctor sometimes. I saw a patient not long ago who said to me, ‘I just don’t feel well.’ Her labs are great, but she doesn’t feel well. Every time she went to her doctor, her doctor just said, ‘You are doing great,’ and didn’t listen to the fact that she didn’t feel good. I think it’s really important.” [R2] “I think that we have better relationships and better overall outcomes with our patients when we are addressing the issues that they’re concerned with.... It doesn’t really help the patient feel better when you say, ‘Congratulations! Your complements are back in the normal range’ if they still can’t pick up their grandkid or go to work and be productive and earn a living. So I would say that the patient-reported outcomes help us focus on things that are particularly important to patients.” [R7]
Engage patients	“It’s a way to validate the patient and make them feel like they’re more involved and that you’re listening, which is one of those things, even without hard data, it’s hard to imagine that’s bad.” [R6] “I think that, particularly if people saw their numbers over time and saw how they were doing, they could—it would be empowering to reinforce things like lifestyle changes that might impact those numbers and allow patients to make more concrete steps towards improving their symptoms.” [R5] “I believe that lupus patients are so scared shitless about the medicines we use that they probably understate what’s going on with them so as not to be given steroids, Cytoxan, things like that. And so the patient never really gives us a full understanding. The thing that helps me most is... every 3 or 4 weeks, I want them to email me how they’re doing... it’s a snapshot, some of which is orchestrated by them to either appear better; maybe to appear worse. But they can’t deliver all that they feel.” [R8] “I think a lot of success in lupus care has to do with adherence. And so, if people – identifying those things that people care about and trying to address them. The more that people like you are trying to help them do what they want, the more they will do what you want.” [R5]

[R]: rheumatologist.

between clinical visits) and could help detect changes in disease activity and triage patient care.

Theme 4: Build patient-physician relationships. Several participants observed that the “main value” of PROM extended beyond contributing to discrete medical decisions, to building therapeutic relationships between patients and physicians. Rheumatologists noted that by focusing on the topics of importance to patients, PROM could facilitate trust and understanding. Strong relationships, in turn, could translate into better patient outcomes through a variety of mechanisms, including increased buy-in for treatment plans, which could potentially decrease healthcare utilization down the road.

Theme 5: Engage patients. Similarly, rheumatologists highlighted PROM as a valuable tool for engaging and empowering patients. Several interviewees suggested that PROM could provide validation for patients by drawing attention to symptoms and priorities patients deemed relevant. By enabling longitudinal tracking, PROM could also empower patients to reinforce disease management strategies, including medication adherence. In addition, participants noted that the surveys could improve

communication and uncover the “unspoken questions that people are very afraid of” [R2] by lowering the threshold to discuss concerns.

C. Facilitators of the use of PROM in clinical care

Participants identified many mechanisms to facilitate the use of PROM in routine practice, emphasizing that a user-friendly approach minimizing the burden on providers was critical to successful implementation.

Theme 1: Technology. Nearly every interviewee mentioned leveraging technology when describing the ideal implementation of PROM in clinical care. This ranged from remote capture of PROM through electronic patient portals or tablets in the waiting room, to complete integration of PROM with the EMR. Rheumatologists envisioned a digital “inbox” similar to one in which they receive laboratory and imaging results, and a dashboard where PROM scores would be automatically calculated and graphed longitudinally alongside medications and other clinical data. They suggested built-in reference ranges, clinical decision support, and automated notifications for values of concern.

Theme 2: Physician engagement and training. Participants emphasized the importance of adequate physician education and “buy in” to the successful implementation of PROM. As 1 rheumatologist noted, the “doctor has to be a believer.” [R13] Another explained, “You have to have an interest, an investment by the people using this stuff... There would be a sort of upfront effort needed to be done to show that these are useful measures and actually make a difference.” [R15] Several noted that training on score interpretation and management, including available resources to address QOL concerns, was critical.

Theme 3: Team-based care. Several rheumatologists pointed out that a nonphysician provider, such as a nurse, nurse practitioner, physician assistant, or even trained medical assistant, could play a critical role in reviewing and triaging PROM. They envisioned a system in which PROM could be assessed between visits, reviewed by a physician extender with escalation of concerning issues to the physician when needed. As 1 participant explained, “I think the secret to the most effective treatment and best outcomes is multimodal team-based care with frequent assessments and touch points. And, I think, PRO may hold the key to being able to conduct more frequent touches outside of the traditional care settings in ways that we’re not taking advantage of right now.” [R7] Participants also suggested that the management of PROM requires multidisciplinary teams, comprising various medical specialties, allied health professionals, complementary and integrative health specialists, and peer support programs.

DISCUSSION

In this sample of practicing academic rheumatologists, a majority of whom were already collecting PROM, we found several barriers to the effective clinical implementation of PROM, both at the level of individual physicians (the perception of no added value, practice inertia, and difficulties with score interpretation) and at the healthcare system level (a lack of effective interventions, inadequate resources for accessing existing remedies, and significant administrative burden). However, rheumatologists also recognized the value of PROM in enhancing patient-centered care and identified several facilitators for their clinical integration. By identifying rheumatologists’ perceived challenges and potential facilitators of using PRO in clinical care, our findings can help inform the development of effective strategies for implementation (Figure 1). This is of particular importance as payers and regulatory agencies continue to encourage and perhaps ultimately mandate the collection of PRO as part of value-based patient-centered healthcare initiatives in rheumatology.

Of the barriers emerging in our study, the most significant may be attitudinal, specifically physicians’ perception that PROM do not add value to clinical care. Although similar to findings reported in oncology, primary, and palliative care¹⁷, these views are somewhat surprising in rheumatology, given the hundreds of such measures already developed for use in rheumatology by rheumatologists, and rheumatologists’ vocal advocacy of the use of self-report questionnaires in clinical practice

since the 1990s^{12,21,22}. Combating these views requires the selection of PROM that physicians see as valid (i.e., relevant and responsive to change), and then convincing physicians of the value of their use. While the benefits of implementing PROM on processes and outcomes of care, including communication, symptom detection, QOL, hospitalization, and patient satisfaction have been established in oncology^{23, 24, 25}, similar evidence is limited in rheumatology²⁶. Demonstration of the benefits of PROM in rheumatology, which differs from oncology in many ways including the chronicity of conditions, is a necessary investment towards convincing clinicians that these surveys are a worthwhile time commitment. Further research is also needed to establish general and disease-specific population norms and score thresholds for clinical concern, and to develop clinical pathways guiding the use of PROM. Such supporting data will enable educational and training initiatives similar to those that have been described in large-scale efforts to implement PROM in oncology, orthopedics, and pediatrics^{27,28,29,30}.

The most challenging barrier that emerged in the interviews may be the insight that there are few effective interventions to address certain outcomes prioritized by patients. While fatigue, for example, can improve with the treatment of inflammatory disease, it is complex, multifactorial in etiology, and often refractory to pharmacotherapy. The development, testing, and dissemination of novel therapeutic strategies for these patient-centered concerns remain a critical need. However, as several participants observed, there may also be inherent value in the discussion of these topics during clinical visits. This is consistent with the views of patients, who cite increased engagement and validation when completing and reviewing PROM with their physicians^{31,32}.

Other barriers encountered by physicians, such as practice inertia, the administrative burden of PROM, or the inaccessibility of effective interventions, require deliberate institutional prioritization and investment. Incentives, whether financial/regulatory (such as those contained in value-based payment initiatives) or cultural (in the form of strong leadership), can play an important role in facilitating the restructuring of institutional priorities to invest in technology and practice redesign, including team-based care.

Our study has many strengths, including its systematic approach, but may be limited in its generalizability. We interviewed rheumatologists practicing in tertiary care academic medical centers, whose perspectives may not be representative of the physicians practicing in private offices or smaller medical centers who comprise the majority of rheumatologists in the United States. In addition, most of the rheumatologists in this study were already collecting PROM in their practice setting, which could present a selection bias. However, the decision to collect PROM was made at the practice level, not by the individuals interviewed, and it is likely that the exposure made them more informed participants in the study. Finally, as our study was limited to physicians, our findings may not be applicable to other healthcare providers involved in the collection and management of PROM. Future studies should examine their views as well as

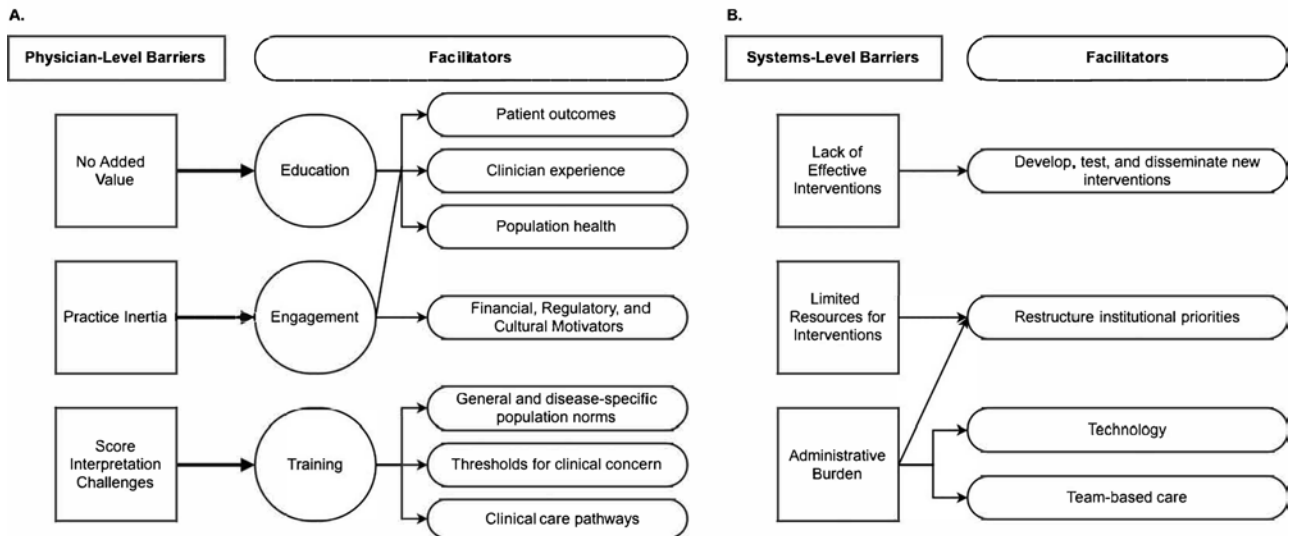


Figure 1. Implementing patient-reported outcome measures in clinical care.

those of rheumatology patients, who have expressed enthusiasm for the inclusion of PROM in their clinical care^{26,32}.

Overall, our study highlights rheumatologists' views of PROM as a potentially powerful clinical tool, while identifying several actionable areas for effective implementation. Though rheumatologists acknowledged the possible limitations of PROM, they were largely positive about the ability of these instruments to enhance care. Our findings suggest that surmounting the barriers to the clinical integration of PROM requires physician buy-in and training, but perhaps more importantly, necessitates institutional and societal investment in managing the downstream consequences of measurement.

ACKNOWLEDGMENT

We would like to thank Shreya Shetty for technical assistance.

ONLINE SUPPLEMENT

Supplementary material accompanies the online version of this article.

REFERENCES

1. Lavallee DC, Chenok KE, Love RM, Petersen C, Holve E, Segal CD, et al. Incorporating patient-reported outcomes into health care to engage patients and enhance care. *Health Aff* 2016;35:575-82.
2. U.S. Department of Health and Human Services, Food and Drug Administration. Patient-reported outcome measures: use in medical product development to support labeling claims. [Internet. Accessed September 3, 2020.] Available from: www.fda.gov/downloads/drugs/guidancecomplianceregulatoryinformation/guidances/ucm193282.pdf
3. Valderas JM, Kotzeva A, Espallargues M, Guyatt G, Ferrans CE, Halyard MY, et al. The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature. *Qual Life Res* 2008;17:179-93.
4. Howell D, Molloy S, Wilkinson K, Green E, Orchard K, Wang K, et al. Patient-reported outcomes in routine cancer clinical practice: a scoping review of use, impact on health outcomes, and implementation factors. *Ann Oncol* 2015;26:1846-58.
5. National Quality Forum. Measures, reports & tools: quality positioning system [Internet. Accessed September 3, 2020]. Available from www.qualityforum.org/Measures_Reports_Tools.aspx
6. Centers for Medicare and Medicaid Services. Comprehensive care for joint replacement model: quality measures, voluntary data, public reporting processes for preview reports. [Internet. Accessed September 3, 2020.]. Available from: innovation.cms.gov/innovation-models/cjr
7. Oncology Care Model. Centers for Medicare and Medicaid Services. [Internet. Accessed September 3, 2020.] Available from: innovation.cms.gov/initiatives/Oncology-Care
8. Yazdany J, Robbins M, Schmajuk G, Desai S, Laccaille D, Neogi T, et al. Development of the American College of Rheumatology's rheumatoid arthritis electronic clinical quality measures. *Arthritis Care Res* 2016;68:1579-90.
9. U.S Centers for Medicare & Medicaid Services. Quality Payment Program. Quality measures. [Internet. Accessed September 3, 2020.] Available from: qpp.cms.gov/mips/quality-measures
10. Yazdany J, Bansback N, Clowse M, Collier D, Law K, Liao KP, et al. Rheumatology informatics system for effectiveness: a national informatics-enabled registry for quality improvement. *Arthritis Care Res* 2016;68:1866-73.
11. Callahan LF. The History of Patient-Reported Outcomes in Rheumatology. *Rheum Dis Clin North Am* 2016;42:205-17.
12. Wolfe F, Pincus T. Standard self-report questionnaires in routine clinical and research practice-- an opportunity for patients and rheumatologists. *J Rheumatol* 1991;18:643-4.
13. Fung CH, Hays RD. Prospects and challenges in using patient-reported outcomes in clinical practice. *Qual Life Res* 2008;17:1297-302.
14. Snyder CF, Aaronson NK. Use of patient-reported outcomes in clinical practice. *Lancet* 2009;374:369-70.
15. Lohr KN, Zebrack BJ. Using patient-reported outcomes in clinical practice: challenges and opportunities. *Qual Life Res* 2009; 18:99-107.
16. Greenhalgh J. The applications of PROs in clinical practice: What are they, do they work, and why? *Qual Life Res* 2009;18:115-23.
17. Boyce MB, Browne JP, Greenhalgh J. The experiences of professionals with using information from patient-reported outcome

- measures to improve the quality of healthcare: a systematic review of qualitative research. *BMJ Qual Saf* 2014;23:508-18.
18. Rose M, Bezjak A. Logistics of collecting patient-reported outcomes (PROs) in clinical practice: an overview and practical examples. *Qual Life Res* 2009;18:125-36.
 19. Bradley E, Curry LA, Devers KJ. Qualitative data analysis for health services research: developing taxonomy, themes, and theory. *Health Serv Res* 2007;42:1758-72.
 20. Kuzel AJ. Sampling in qualitative inquiry. In: Crabtree BF, Miller WL, editors. *Doing qualitative research*. Second ed. Thousand Oaks: Sage Publications; 1999: 33-45.
 21. Pincus T. Why should rheumatologists collect patient self-report questionnaires in routine rheumatologic care? *Rheum Dis Clin North Am* 1995;21:271-319.
 22. Katz PP. Introduction to special issue: patient outcomes in rheumatology, 2011. *Arthritis Care Res* 2011;63:S1-3.
 23. Velikova G, Booth L, Smith AB, Brown PM, Lynch P, Brown JM, et al. Measuring quality of life in routine oncology practice improves communication and patient well-being: a randomized controlled trial. *J Clin Oncol* 2004;22:714-24.
 24. Kotronoulas G, Kearney N, Maguire R, Harrow A, Di Domenico D, Croy S, et al. What is the value of the routine use of patient-reported outcome measures toward improvement of patient outcomes, processes of care, and health service outcomes in cancer care? A systematic review of controlled trials. *J Clin Oncol* 2014; 32:1480-501.
 25. Basch E, Deal AM, Kris MG, Scher HI, Hudis CA, Sabbatini P, et al. Symptom monitoring with patient-reported outcomes during routine cancer treatment: a randomized controlled trial. *J Clin Oncol* 2016;34:557-65.
 26. Bartlett SJ, De Leon E, Orbai A-M, Haque UJ, Manno RL, Ruffing V, et al. Patient-reported outcomes in RA care improve patient communication, decision-making, satisfaction and confidence: qualitative results. *Rheumatology* 2019 Oct 30 (E-pub ahead of print).
 27. Papuga MO, Dasilva C, McIntyre A, Mitten D, Kates S, Baumhauer JF. Large-scale clinical implementation of PROMIS computer adaptive testing with direct incorporation into the electronic medical record. *Health Syst* 2017;7:1-12.
 28. Gerhardt WE, Mara CA, Kudel I, Morgan EM, Schoettker PJ, Napora J, et al. Systemwide implementation of patient-reported outcomes in routine clinical care at a children's hospital. *Jt Comm J Qual Patient Saf* 2018;44:441-53.
 29. Santana MJ, Haverman L, Absolom K, Takeuchi E, Feeny D, Grootenhuys M, et al. Training clinicians in how to use patient-reported outcome measures in routine clinical practice. *Qual Life Res* 2015;24:1707-18.
 30. Dubenske LL, Gustafson DH, Shaw BR, Cleary JF. Web-Based cancer communication and decision making systems: connecting patients, caregivers, and clinicians for improved health outcomes. *Med Decis Mak* 2010;30:732-44.
 31. Kasturi S, Burket JC, Berman JR, Kirou KA, Levine AB, Sammaritano LR, et al. Feasibility of Patient-Reported Outcomes Measurement Information System (PROMIS) computerized adaptive tests in systemic lupus erythematosus outpatients. *Lupus* 2018;27:1591-9.
 32. Kasturi S, Epsten M, Batterman A, Horton R, Kleinman J, Rose J, et al. Relevance and Utility of Patient Reported Outcomes Measurement Information System (PROMIS®) Instruments in SLE: A Qualitative Study [abstract]. *Arthritis Rheumatol* 2017;69 Suppl 10.