

AHRQ National Webinar on Integrating Patient-Reported Outcomes into Practice: Benefits, Challenges, and Recommendations for Action

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[Rheumatology Informatics System for Effectiveness Patient-Reported Outcome \(RISE PRO\) Dissemination Project](#)

QUESTION: How did you adapt your survey instruments for patients with vision loss, limited English proficiency, or health literacy limitations?

ANSWER: In our research talking to rheumatology practices around the country, they had different methods for addressing this issue. Some acknowledged that they did not have the resources to administer patient-reported outcomes (PROs) when patients were not able to complete them due to language or literacy issues. On the other end of the spectrum, there were practices that had medical assistants read the information to patients or had family members helping patients fill out these PROs. We found that there was a lot of heterogeneity and that for the most part, people were not using technology that facilitated more innovative ways of reaching the patient population. For example, technologies that might read questions aloud, or that might assign questionnaires in languages beyond Spanish, for example. There is still a lot of work to be done in this area.

QUESTION: What method(s) are best for collecting PROs, such as emailing a survey, giving the patient a device with the survey loaded, providing a QR code and the patient uses their own device, or any others?

ANSWER: The most important thing that we learned in our qualitative studies was that there was definitely not a one-size-fits-all approach. We mainly talked to single specialist or multi-specialty community rheumatology practices, and they did not have the IT infrastructure to develop elaborate electronic health record (EHR) integrations. Most people were using simple, low-tech workflows. The most common thing was to collect the information on paper, have the medical assistant score the sheet and enter data into the EHR. There were people who were using iPads that were not necessarily integrated with the EHR but would at least automate the calculation. Of course, there were people that were doing more advanced things, like using digital applications (apps) and the patient portal, and there is a lot of room for innovation in this area. The advice I would give for people that are just starting out is to be realistic about the resources that are available in the healthcare setting and to start small, even if that means starting on paper or with a simple iPad survey and then building from there. It takes time to make more sophisticated integrations, especially with digital apps and the EHR.

QUESTION: What features would ideal supportive EHR software include to overcome the incompleteness of the patient-reported outcomes data collection and extraction that you mentioned?

ANSWER: One of the things that we need to overcome is that rheumatologists currently have no easy way of entering structured data regarding rheumatoid arthritis (RA) PROs, and the EHR impedes their workflow. Also, the ability to track the information in some kind of visualization over time and to be able to share that with patients in a way that facilitates shared decision making. They have devised creative workarounds, such as entering PRO values as a vital sign or a lab result or in a nursing flow sheet and that is problematic. What we really want is an EHR that is designed to support chronic disease management and that includes some of these RA PROs as part of its foundation software. Especially because these are nationally endorsed quality measures, and we have evidence that using these measures to treat-to-target results in better patient outcomes. So, for me, the EHR would have structured data that is in a very intuitive place. It might connect to a digital app easily and then have nice visualizations or dashboards that the doctors can use to share with their patients. Also, importantly there should be access for the patient to be able to also track their outcomes. They are filling out all this information and it would be wonderful for there to be an easy way for them to track their own progress over time.

QUESTION: You mentioned large language models. Are you now experimenting with them to extract data?

ANSWER: We are, and a computer scientist artificial intelligence (AI) post-doctoral fellow is working with me. We are in the process of using the RISE registry clinical notes and trying to organize and extract EHR data, including PROs, using some of the newer large language models. We have done some early experiments just with data at the University of California, San Francisco and it is interesting that the newer large language models, like Generative Pre-trained Transformer (GPT), really outperform some of the older tools that we were using. They are very powerful, even with very little tuning and training in the healthcare setting and I think there is a lot more to come in this area. EHR clinical notes are currently in sort of a locked box and these large language models are going to open up many new areas of research, so it's a really exciting time.

QUESTION: For those who used digital data collection, how did you accommodate the limitations and the "digital divide" for some patients with limited broadband connectivity, inadequate devices, limited digital health literacy?

ANSWER: In our qualitative work, rheumatology clinics that collected data digitally, for example with patient portal survey pushes, often had a back-up workflow for those who were not able to complete surveys on-line. Most often this "back-up" workflow involved handing the patient a paper survey during in-person appointments. To ensure that patients with low literacy could respond to the survey, medical assistants were trained to ask, "Can I offer assistance in completing this survey?" Since the RA PRO surveys are relatively short, survey items take <5 minutes to administer verbally. Unfortunately, this workflow only helps in situations where there is language concordance between patients and medical assistants. There is room for innovation in this area; some are exploring devices that are able to provide voice administration.

QUESTION: Do any of the presenters have data on toolkit utilization? This is wonderful work, and I am curious if there is any feedback on how useful the developed toolkits have been for users.

ANSWER: We are monitoring use of the RA Toolkit with web analytics as well as a feedback survey embedded in the Toolkit itself. In terms of web analytics, the toolkit had been opened by 1000 unique IP addresses by February 2024. For reference, there are about 3000 clinical rheumatologists in the United States, and we assume that mostly rheumatologists are using the Toolkit. Initial survey feedback data has been positive with some suggestions for improvement. For example, one respondent requested CME credit for interacting with the Toolkit. We are partnering with the American College of Rheumatology to further publicize and disseminate the Toolkit and will continue to monitor usage and feedback over time.

Margie E. Snyder, Pharm.D., M.P.H., FCCP, FAPhA
Purdue University College of Pharmacy

[An Evaluation of the Spread and Scale of PatientToc™ from Primary Care to Community Pharmacy Practice for the Collection of Patient-Reported Outcomes](#)

QUESTION: How did you adapt your survey instruments for patients with vision loss, limited English proficiency, or health literacy limitations?

ANSWER: PatientToc™ is designed to optimize the use of the technology for patients that have some of those considerations. For example, the responses as selected light up so that the patient can tell what response they are on. In addition to that, there is a speak-aloud function. If a patient has any challenges with vision or literacy, we provided the pharmacies with individual on-earbuds that patients could use to have questions and responses read to them.

QUESTION: What method(s) are best for collecting PROs, such as emailing a survey, giving the patient a device with the survey loaded, providing a QR code and the patient uses their own device, or any others?

ANSWER: We really observed in our work a need for flexibility. For many patients and pharmacies, the kiosk model, or the Android tablet model of having the patient complete the PROs in the pharmacy as they waited for prescriptions was fine. However, we did hear loud and clear that many patients, as well as pharmacies, particularly the younger generation would have preferred to have been able to download the app themselves to their own mobile device and complete the PROs electronically that way. We also heard that this would have been easier on paper. Even in terms of workflow, part of that is dependent on systems that the pharmacy already has in place. For example, in our scale phase, one of the pharmacies already routinely uses an iPad for checking patients out, including through the drive-through. This meant that patients in the drive-through were used to having a tablet handed to them in the car and they would answer a few things then hand it back. That pharmacy was very comfortable in their patient population. Overall, flexibility is key.

QUESTION: What features would ideal supportive EHR software include to overcome the incompleteness of the patient-reported outcomes data collection and extraction that you mentioned?

ANSWER: Any time there is an opportunity, I love the idea of the patient being able to track their own PROs. Also, to make it easy with visual tools and other things for the clinician to track, and decision support to help guide when the data is coming in. In some ways that would

have been useful if we could have added some guidance for the pharmacists. We had training modules but not built-in or integrated decisions support.

QUESTION: If you could have done one thing differently in your project, what would it have been?

ANSWER: It would have been having more intentional discussions with PatientToc™ at the beginning to make sure we really understood the scope of work; as the project unfolded, it became more clear that we were not on the same page. What did we mean when we said, “integrated with the pharmacy dispensing system,” exactly? We wanted information to pre-populate to reduce the patient burden and having to type in any information, particularly with medications. Patients really struggle with the names of their medications and how to spell them, so that would have been much simpler. Having those conversations more in-depth on the front end, this is a key lesson learned by me.

QUESTION: What type of community pharmacies were involved in your project (chains, independents, specialty)?

ANSWER: In the pilot phase, one pharmacy was an outpatient health-system pharmacy and two were independent pharmacies. In the scaled phase, eight pharmacies were part of small chains (defined as four+ locations) and four were independent pharmacies.

QUESTION: Do any of the presenters have data on toolkit utilization? This is wonderful work, and I am curious if there is any feedback on how useful the developed toolkits have been for users.

ANSWER: We did track toolkit resource utilization. You are welcome to email me for more information: snyderme@purdue.edu

**Steven P. Dehmer, Ph.D., on behalf of PI Leif Solberg, M.D.
HealthPartners Institute**

[Optimizing the Value of Patient-Reported Outcome Measures in Improving Care Delivery through Health Information Technology](#)

QUESTION: How did you adapt your survey instruments for patients with vision loss, limited English proficiency, or health literacy limitations?

ANSWER: For our surveys we often have phone options with multiple languages. The more interesting question is in terms of collecting the patient-reported outcomes in orthopedic care, especially as that is expanding. I am not familiar with all the strategies that they use for patients within our care system, but among them is having an iPad available in the waiting room or at the clinic where the patients can fill out and potentially get help with the survey at the time. There will be a need for other strategies as well if the surveys are to be used more broadly for millions of patients.

QUESTION: What method(s) are best for collecting PROs, such as emailing a survey, giving the patient a device with the survey loaded, providing a quick response (QR) code and the patient uses their own device, or any others?

ANSWER: Multimodal is certainly helpful, I do not know if there is any one best method. It is helpful when asking patients to complete surveys if they get something back from it, as it increases the intrinsic motivation to do it in the first place. When you are using the PROs in a way that the patient's value, that will enhance interest in taking the time to complete it by whatever mode is used.

QUESTION: What features would ideal supportive EHR software include to overcome the incompleteness of the patient-reported outcomes data collection and extraction that you mentioned?

ANSWER: Integration and enhancing utility are really key features.

QUESTION: Where can we learn more about the PROMOTE study?

ANSWER: There are citations at the bottom of the slides where you can find more on what I talked about. If you go to the [DHR website](#) and search for [Dr. Leif Solberg](#), you will see the [study](#), the final report and links to the nine publications thus far (we have three more in the works that should be coming soon).

QUESTION: Why can't patients receive their patient-reported outcome measures (PROM) score with an explanation of what it means, or at minimum a scale showing worst to best score, so they see where they are?

ANSWER: Part of the challenge is that the PROM scores do not have inherent meaning. I agree that there could be ways to share with patients that are meaningful to them.

QUESTION: In Estonia hip and knee replacement PROM will become compulsory for providers. How do you comment - will it help the patients and/or health care system in general?

ANSWER: Without speaking to this specific situation, in general, yes, collecting PROMS for hip and knee replacement procedures can be beneficial to both patients and care systems. PROMS reporting can support quality measurement and quality improvement and may be used to support improvement of the overall value with these procedures. Moreover, incorporation of PROMs into clinical care and shared decision making can yield meaningful benefits as well. But we have more to learn to realize this full potential, and the real costs to patients and health care systems associated with collecting PROMs is an important factor to be considered as well.

QUESTION: For those who used digital data collection, how did you accommodate the limitations and the "digital divide" for some patients with limited broadband connectivity, inadequate devices, limited digital health literacy?

ANSWER: Strategies we have used to address such "digital divide" issues included providing patients the opportunity to complete the PRO survey on an iPad or with a paper copy during clinic visits. These opportunities included any visit in orthopedics, not just when a patient was scheduled to see their surgeon.