










The Development of the Rheumatology Informatics System for Effectiveness Learning Collaborative for Improving Patient-Reported Outcome Collection and Patient-Centered Communication in Adult Rheumatology

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Objective. Patient-reported outcomes (PROs) are an integral part of treat-to-target approaches in managing rheumatoid arthritis (RA). In clinical practice, however, routine collection, documentation, and discussion of PROs with patients are highly variable. The RISE LC (Rheumatology Informatics System for Effectiveness Learning Collaborative) was established to develop and share best practices in PRO collection and use across adult rheumatology practices in the United States

Methods. The goals of the RISE LC were developed through site surveys and in-person meetings. Participants completed a baseline survey on PRO collection and use in their practices. RISE LC learning sessions focused on improving communication around PROs with patients and enhancing shared decision-making in treatment plans. During the coronavirus disease 2019 (COVID-19) pandemic, the RISE LC pivoted to adapt PRO tools for telehealth.

Results. At baseline, all responding sites (n = 15) had established workflows for collecting PROs. Most sites used paper forms alone. PRO documentation in electronic health records was variable, with only half of the sites using structured data fields. To standardize and improve the use of PROs, participants iteratively developed a Clinical Disease Activity Index–based RA Disease Activity Communication Tool to solicit treatment goals and improve shared decision-making across sites. The COVID-19 pandemic necessitated developing a tool to gauge PROs via telehealth.

Conclusion. The RISE LC is a continuous, structured method for implementing strategies to improve PRO collection and use in rheumatological care, initially adapting from the Learning Collaborative model and extending to include features of a learning network. Future directions include measuring the impact of standardized PRO collection and discussion on shared decision-making and RA outcomes.

INTRODUCTION

The collection and use of patient-reported outcomes (PROs) as part of a treat-to-target approach in managing rheumatoid arthritis (RA) is recommended as an integral part of treatment

guidelines (1,2). However, the collection use of outcome measures to guide management is variable in routine clinical practice (3,4). The collection of PROs has become a major focus of recent quality improvement (QI) initiatives in individual adult rheumatology practices (5), but there is currently no structured method for

The views expressed here are those of the authors and not necessarily those of the Agency for Healthcare Research and Quality or the National Institutes of Health/National Institute of Arthritis and Musculoskeletal and Skin Diseases.

This work was supported by the Agency for Healthcare Research and Quality under grant R18 HS025638. Dr. Yazdany is supported by the Alice Betts Chair in Arthritis Research and the National Institutes of Health/National Institute of Arthritis and Musculoskeletal and Skin Diseases (K24 AR074534).

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No potential conflicts of interest relevant to this article were reported.

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Submitted for publication February 13, 2021; accepted June 21, 2021.

sharing and coordinating best practices that arise through these initiatives.

The Learning Collaborative (LC) is a structured method that was developed by the Institute for Healthcare Improvement (IHI) to accelerate change by bringing together QI teams to share best practices and use rapid tests of change (ie, plan-do-study-act cycles) to improve care (6). The LC method has been used to improve the quality of care in both pediatric and adult rheumatology practices. In adult rheumatology, the TRACTION (Treat-to-Target in RA: Collaboration to Improve Adoption and Adherence) trial randomized sites to LC or usual care and demonstrated significant improvement in treat-to-target adherence after just 9 months of LC participation, with sustained response 9 months after the initial intervention (7,8).

Although the traditional LC is limited to 12 to 18 months, the Institute of Medicine recognizes that health care systems should continuously seek to improve care. The concept of the learning health care system is to apply the structure of the LC to a longer-term improvement effort. The learning health care system should continuously “generate and apply the best evidence for the collaborative healthcare choices of each patient and provider; to drive the process of discovery as a natural outgrowth of patient care” (9). In pediatrics, learning health care systems have been shown to demonstrate sustained improvement in rates of remission in patients with inflammatory bowel disease, to reduce infant mortality in congenital heart disease, and to reduce catheter-associated urinary tract infections (10). The PR-COIN (Pediatric Rheumatology Care and Outcome Improvement Network) was launched in 2011 as an international learning health care system that develops tools and processes to improve shared decision-making and patient outcomes in juvenile idiopathic arthritis (11,12). PR-COIN has demonstrated improvement in treat-to-target adherence in the treatment of juvenile idiopathic arthritis and improves shared decision-making through the development of medication choice cards (13–15).

The RISE LC (Rheumatology Informatics System for Effectiveness LC) was established in March 2019 as a method of exchanging QI ideas, tools, and innovations among organizationally diverse institutions across the United States. The RISE

LC was developed as a learning network in which the structure of the traditional LC was expanded to an ongoing, long-term QI effort, much like PR-COIN.

Herein, we outline the methods for the development of the RISE LC, describe initial QI efforts centered around the collection and use of PROs in routine clinical practice, and present initial data on the implementation of these practices for the collection and use of PROs for both in-person and telehealth visits.

PATIENTS AND METHODS

Development of the RISE LC. *RISE LC approach.* The structure of the RISE LC was based on the IHI’s Breakthrough Series (Figure 1), particularly the development of learning networks (6). The RISE LC adapted the rapid test of change and regular learning sessions from the traditional IHI LC model. Like many learning health systems, the purpose of the RISE LC was to address the practical challenges of collecting PROs, which is an evidence-based practice in treat-to-target algorithms in rheumatology. The strategies used by the RISE LC included working collaboratively to develop new approaches and tools that would support the collection of PROs in a sustainable and clinically meaningful way. LC faculty and participants met regularly to exchange QI ideas through learning sessions. The participants then implemented changes at their local institutions during action periods, using plan-do-study-act (PDSA) cycles.

Recruitment of participants into the LC. RISE LC participants were recruited through individual outreach and oriented at an information session at the American College of Rheumatology’s Annual Meeting in November 2018. The RISE LC allowed rolling enrollment, as one center expressed interest in joining after the initial enrollment date, thus deviating from the traditional LC structure. This site was integrated into PDSA cycle discussions. Centers that enrolled earlier in the history of the RISE LC shared data on their tests of change based on the implementation of new tools so as to inform the new site and not impact the workflow of the LC.

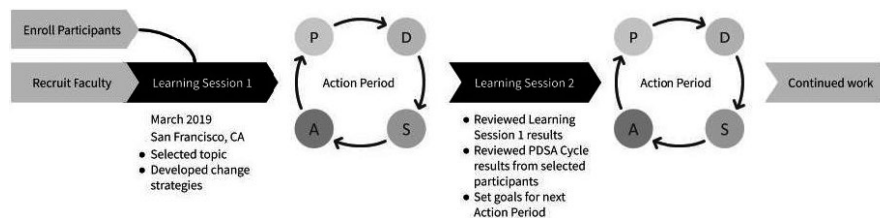


Figure 1. Structure of the RISE LC (Rheumatology Informatics System for Effectiveness Learning Collaborative). The structure of the RISE LC was adapted from the Institute for Healthcare Improvement Breakthrough Series incorporating features of the learning network. Faculty and participants met in person and selected topics and developed change strategies during Learning Session One. Participants then return to home institutions to test out change through a series of plan-do-study-act (PDSA) cycles during the action period. Subsequent learning sessions were webinars structured to review results of previous PDSA cycles and set test of change for the next action period.

Learning sessions of the LC. Learning sessions began in March 2019 with an in-person meeting followed by hour-long webinars every 1 to 2 months. As a learning network, topics for discussion were selected by faculty with input from participants. During the initial meeting, RISE LC participants discussed the most relevant topics in QI affecting adult rheumatology. Participants came to a consensus to focus on QI efforts that are patient-centric and would more meaningfully impact communication rather than meet an institutional metric for QI success. The final QI topic selected was to improve PRO collection and communication in RA through the development and implementation of a communication tool.

Webinars were recorded and made available to participating centers. The structure for a webinar learning session included a review of the previous learning session's proceedings, a PDSA cycle review from one or more of the participating institutions, and a targeted discussion of the project goals during the next implementation period. Participants were expected to attend learning sessions. Two to three sites were selected to report on the results of their PDSA cycles during each learning session. Participants were encouraged to give feedback through facilitated discussions and learn from the PDSA cycles. With each learning session and implementation (action) period, additional resources and best practices for QI are shared among participants.

The project was approved by the University of California, San Francisco, Institutional Review Board.

Initial focus of the LC. The first learning session was devoted to creating consensus on the purpose of the RISE LC. Activities included a short online survey to identify perceived gaps in care and in-person discussion. Areas for potential improvement were ranked in order of priority by each participating site.

Assessment of baseline PRO collection workflows. In the traditional LC model, prework is done to assess the baseline performance of participating institutions. To gauge baseline clinical workflows for PROs at participating institutions, a PRO workflow survey was collaboratively designed and disseminated to participants as prework for the RISE LC. The survey addressed key domains relating to center characteristics, electronic health record (EHR) systems, PRO collection methods, PRO structured data entry capability into the EHR, and baseline practices surrounding using and sharing PROs with patients. The survey was administered electronically during the first quarter of 2020 prior to significant workflow changes caused by the COVID-19 pandemic.

Development and assessment of the RA Disease Activity Communication Tool. In pursuit of improved communication with patients around PROs, an RA Disease Activity Communication Tool was iteratively developed to help facilitate the clinician-patient conversation regarding PROs and treatment goals (see detailed description below).

Several process measures and outcome measures were planned to evaluate communication around RA after the development and implementation of the RA Disease Activity Communication Tool. Process outcomes included 1) the percentage of patients with RA for whom the RA Disease Activity Communication Tool was used and 2) the percentage of patients with RA for whom treatment goals were documented. Outcome measures included 1) the percentage of patients with RA and low disease activity or remission and 2) patient-reported shared decision-making based on the CollaboRATE survey – a three-item patient-reported measure (16).

Adaptation to telehealth during the COVID-19 pandemic. With the onset of the COVID-19 pandemic, the RISE LC quickly pivoted to address the challenges of collecting PROs during telehealth visits with rapidly evolving clinical workflows and varied staff support. Existing measures for PRO collection were adapted for ease of administration in telehealth settings without relying on local changes to EHR builds.

RESULTS

Participants. The RISE LC comprises a network of 15 United States medical centers from 10 states. Two centers were associated with Veterans Affairs hospitals, with the remaining associated with an academic medical center or a county health system. Of the 14 centers that enrolled initially in November 2018, all continue to actively participate, and one new center enrolled in July 2020. Many institutions have a team consisting of attending rheumatologists and fellows.

Initial focus of the LC. The RISE LC's initial topic was selected through an LC participant survey and discussion at the first learning session. The RISE LC participants identified patient communication regarding PROs to be a major gap in care. Most centers have been consistently collecting PROs and were using disease activity scores such as the Clinical Disease Activity Index (CDAI) and Routine Assessment of Patient Index Data 3 (RAPID3) in a treat-to-target approach with their patients with RA but reported that patients were often not aware of their scores or the meaning of the scores. Participants expressed a desire to meaningfully use PROs to establish patient-centered treatment goals and enhance shared decision-making. They were also interested in improving shared decision-making through eliciting and incorporating patient treatment goals to generate a more personalized approach to the treat-to-target strategy.

Results of baseline PRO collection workflow survey. As prework before the learning sessions began, 12 of 15 centers completed an initial workflow survey; two were Veterans Affairs sites, and 10 were clinics associated with an academic medical center (10 clinics) or a county health system (three clinics). The

results of the survey are summarized in Figure 2. EPIC Systems was the most commonly reported EHR, followed by NextGen and Computerized Patient Record System. For PRO collection, 10 of 15 sites used solely paper forms to collect PROs from patients in waiting rooms or examination rooms, whereas one site used tablets alone. One site used paper forms, tablets, and an online patient portal for collection. Frequently cited challenges for PRO collection included inconsistent staffing, busy workflows for medical assistants, and language and literacy barriers for patients.

For PRO documentation in the EHR, six sites relied on structured data fields in the EHR, whereas the remaining sites required providers to type PROs in the free-text portion of clinical notes. The sites that captured PROs in structured fields reported EHR capacity to review prior PRO scores longitudinally. Nine centers reported that clinicians regularly shared PROs with each patient during clinical visits. Only one site had the capacity for patients to view PRO results between clinical encounters. Four of six sites that recorded PROs in structured EHR fields reported regularly sharing PROs with patients either during or after a clinical encounter.

Development of the RA Disease Activity Communication Tool. During the next several learning sessions, the RISE LC collaboratively combined several existing tools to create a new RA Disease Activity Communication Tool. Based on visualizations

used in a patient-facing dashboard developed to display RA disease activity during a clinic visit, the LC created a paper handout for patients that displayed a thermometer depicting the CDAI, illustrating high disease activity as “hot” and remission/low disease activity as “cool” (Figure 3A) (17,18). A color scale and facial depiction of pain enhanced the graphical representation of “hot” and “cool” disease activity. Two checkboxes next to the thermometer were added to assist rheumatologists in explaining whether high disease activity was attributed to active RA or to other chronic conditions.

After several PDSA cycles, LC members expressed a desire to solicit information about patient goals because this was important for putting PROs into context. Therefore, in the second iteration, a section titled “My RA treatment goals” was added to the paper form on the basis of additional qualitative work performed with patients with RA (19,20). The goal setting diagram explicitly elicits a patient’s treatment goals for that day’s visit (Figure 3B). LC participants also added a section to the form to note any therapy change or other recommended interventions by clinicians. The layout of the tool was designed to encourage clinicians and patients to review RA disease activity using the thermometer and treatment goals and then come to an agreement about treatment through shared decision-making.

After multiple cycles of PDSA testing, LC participants further concluded that, although depicting RA outcomes and goal setting

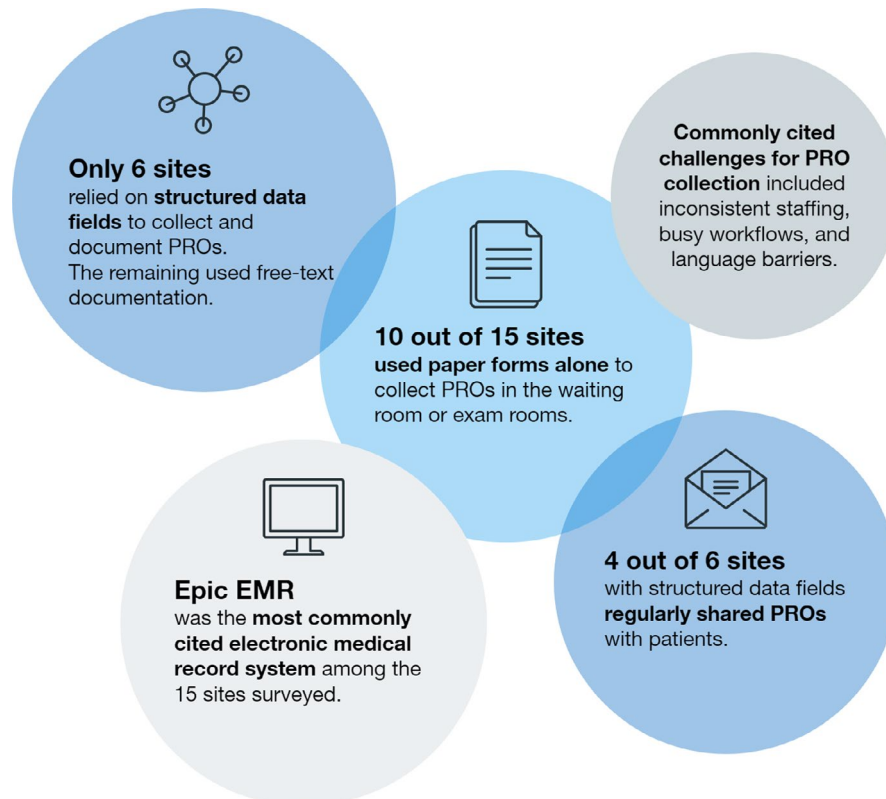


Figure 2. Patient-reported outcome workflow survey results from 15 RISE LC (Rheumatology Informatics System for Effectiveness Learning Collaborative) centers. A baseline survey was distributed to all RISE LC participants from March 2020 to May 2020 to better gauge participating center characteristics and existing practices in patient-reported outcome (PRO) collection, PRO entry into the electronic health record, and PRO access and sharing. EMR, Electronic Medical Record.

(A)
TREATMENT PROGRESS WORKSHEET

Name _____ DoB _____ Visit date _____

My CDAI today (Clinical Disease Activity Index)

2.8 Normal
10
22
76 Severe

My Rheumatoid Arthritis treatment goals

What I want to be able to do:

CDAI by next visit: _____

Notes

My treatment plan _____

Next visit _____

(B)
TREATMENT PROGRESS WORKSHEET

Patient: please complete before visit

Name _____ DoB _____ Visit date _____

What's on my mind for today's visit:

Please take a moment to write down any thoughts you've had regarding your health. Feel free to include your plan of care, your medications, your test results, or any worries you've had. Your notes help guide your provider's discussion with you.

My treatment goals:

Check your **3 most important goals** for today's visit:

Check your 3 most important goals

My treatment plan:

We'll continue the current therapy. We're going to make the following changes to your therapy:

Notes:

VISIT SUMMARY

Provider: please complete during visit

Your CDAI today (Clinical Disease Activity Index)

2.8
10
22
76

Notes:

You're experiencing active Rheumatoid Arthritis

You're experiencing pain from other conditions

Your treatment plan:

We'll continue the current therapy. We're going to make the following changes to your therapy:

Notes:

Next visit _____

Name _____ DoB _____ Visit date _____

Figure 3. Evolution of the rheumatoid arthritis (RA) disease activity communication tool. **A**, Elements of the initial prototype derived based on feedback from previous patient focus group on communication regarding disease activity. **B**, Final prototype-incorporated questions to elicit patient treatment goal. The front page of the worksheet is completed by the patient. The back of the worksheet includes a visit summary where the physician reviews disease activity with patients and document any treatment changes. CDAI, Clinical Disease Activity Index; RAPID3, Routine Assessment of Patient Index Data 3.

were critical to enabling meaningful use of PROs, it was also important to help patients with agenda-setting to further facilitate shared decision-making during the clinic visit. Therefore, the third iteration of the tool included the following agenda-setting question that had been developed and implemented by two participating sites: “What’s on Your Mind for Today’s Visit?” (21). This question was incorporated in the second iteration of the tool (Figure 3B). Templates of both versions of the tool were provided to LC participants to be adopted to local clinical practice and workflow.

With agreement on the content of the final communication tool, LC participants completed several PDSA cycles to assess its feasibility and usefulness. Participants uniformly conveyed that the tool was practical to use, taking less than 5 minutes for patients to complete their portion and less than 1 minute for clinicians to complete the CDAI figure. PDSA cycles also revealed that the tool was easy for patients to understand. Clinicians generally felt that the tool facilitated discussion of RA goals and outcomes during encounters.

Measuring progress. Given the success of tool implementation after initial PDSA cycles across the LC, data collection to assess the impact of the tool on quality measures and RA outcomes was planned. However, data collection had to be halted because of disruptions to in-person clinical visits and rapid shifts to remote video or telephone encounters during the COVID-19 pandemic. The process measures that had been planned to evaluate communication around RA outcomes included 1) the percentage of patients with RA for whom the RA Disease Activity Communication Tool was used and 2) the percentage of patients

with RA for whom the treatment goal was documented. The outcome measures developed included 1) the percentage of patients with RA and low disease activity or remission and 2) the use of CollaboRATE, a brief patient survey measuring shared decision-making (16), to assess whether the use of the RA Disease Activity Communication Tool improves shared decision-making.

Adaptation to telehealth during the COVID-19 pandemic. The COVID-19 pandemic and the rapid shift to telehealth visits created new challenges in the collection and discussion of PROs. LC participants endorsed newfound difficulties in collecting the RAPID3 during video or telephone visits because of several barriers, as summarized in Figure 4. Common reasons included lack of physician or staff time to administer questions, inability to electronically administer the survey in the previsit setting given the lack of universal patient access to the EHR patient portal, and language and health literacy barriers (16). Only 1 of 15 sites was able to collect the RAPID3 consistently for telehealth visits.

The RISE LC identified the need for a shorter PRO measure that would be able to be administered by the clinicians alone during telehealth visits, with minimal staff and technologic support. Collaborating during learning sessions, LC participants developed a brief survey tool that combined single items for pain, function, and fatigue from the Multidimensional Health Assessment Questionnaire and the “What’s on Your Mind for Today’s Visit?” question (Figure 5). Piloting revealed that these simpler questions took approximately 1 to 3 minutes for physicians to verbally administer themselves during a telephone or video visit. Some LC participants noted that the questions helped them triage telehealth visits

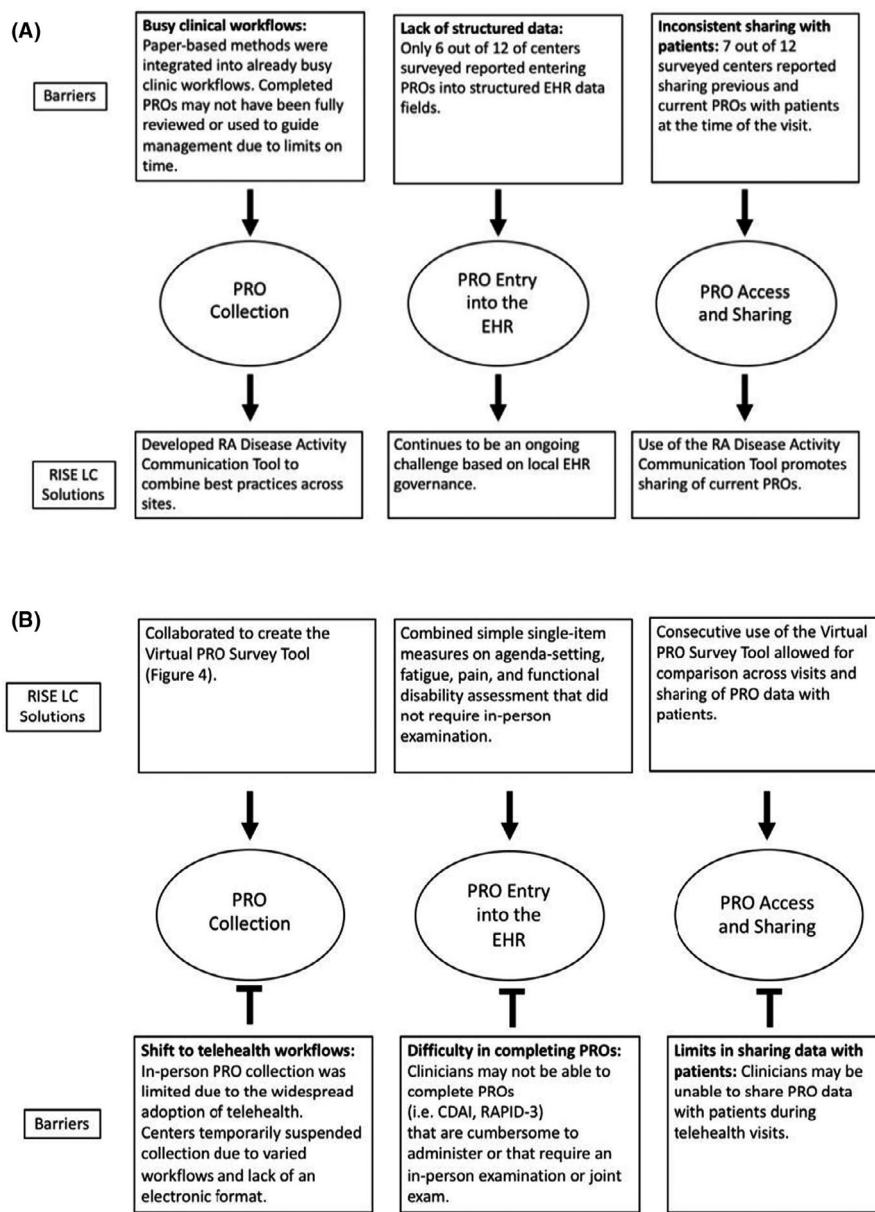


Figure 4. Common barriers to patient-reported outcome (PRO) collection before and after the coronavirus disease 2019 pandemic and RISE LC (Rheumatology Informatics System for Effectiveness Learning Collaborative) solutions to address barriers. **A**, Baseline challenges to PRO collection in clinic. **B**, Emerging challenges to PRO collection during telehealth visits. CDAI, Clinical Disease Activity Index; EHR, electronic health record; RAPID3, Routine Assessment of Patient Index Data 3.

to determine who needed an in-person appointment for their next encounter.

DISCUSSION

The RISE LC represents the first continuous and ongoing learning network for adult rheumatologists to work collaboratively to generate and implement QI tools to address key challenges in practice. This paper describes the initial LC work, which focused on the meaningful use of PROs and shared decision-making in adult rheumatology clinics in the United States. The project has developed a practical tool for using PROs in clinical practice and

has built a community of rheumatologists who are committed to creating a patient-centered, meaningful approach to QI.

Rather than working on QI initiatives in silos, LC participants have worked together to increase PRO collection and improve patient-physician communication regarding RA outcomes and shared decision-making. Participants applied innovations that were initially developed at different institutions to enhance shared decision-making and create a communication tool to help encourage discussion of PROs with patients. Through iterations of PDSA cycles and learning sessions, the LC developed best practices for streamlining clinic workflows to incorporate this tool. The RA Disease Activity Communication Tool developed by the LC was



Virtual PRO Survey

Please submit one survey per patient encounter. This survey link is reusable for additional patient encounters.

What's on my mind for today's visit?

Select which category applies to your patient's response:

- Symptoms
- Medication-Related
- Non-Medical
- Other

Select your patient's score for the following three questions:

	0- None	1	2	3	4	5	6	7	8	9	10- Severe/Extremely Affected
Pain: How much pain have you had because of your arthritis in the past week?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Functional disability assessment: How much does your condition affect your ability to function in daily life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fatigue: How much of a problem has fatigue or tiredness been for you over the past week?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Powered by Qualtrics

Figure 5. RISE LC (Rheumatology Informatics System for Effectiveness Learning Collaborative) virtual patient-reported outcome (PRO) survey tool. A shorter PRO measure was developed from combining the “What’s on Your Mind for Today’s Visit?” question and deriving elements from the Multidimensional Health Assessment Questionnaire. Rheumatologists were encouraged to use the survey tool at the start of telehealth encounters (telephone or video visits) to gauge patient symptoms and set agendas for the appointment.

easy to implement and efficient to use. Participants felt that it allowed them to move from collecting PROs without a standardized workflow to discuss results with patients, to a simple system that meaningfully uses PROs to facilitate shared decision-making. Furthermore, as a continuous learning system, the RISE LC has

been able to adapt to new challenges, such as creating new tools and workflows for telehealth visits with the onset of the COVID-19 pandemic.

There are several limitations to the generalizability of the tools created by the RISE LC. The majority of the sites enrolled were

academic centers with dedicated QI faculty and clinical staff who could likely more easily integrate the use of these tools into their clinical workflow. Additionally, the COVID-19 pandemic severely restricted the LC's ability to collect preintervention and postintervention data on the use of the RA Disease Activity Communication Tool once visits became largely virtual. Furthermore, the tools created mainly benefitted literate, English-speaking populations and may need to be tailored for diverse clinical settings.

Several lessons were highlighted during the development of the RISE LC. Despite having competing priorities, many LC participants were very willing to try small tests of change through the rapid PDSA cycle format facilitated by the webinars and action periods. Furthermore, participants remained engaged in these efforts by working to adapt workflows and QI tools to their specific institutions. The RISE LC served as a source for brainstorming and rapid, iterative development of implementation tools for practice. Subsequently, each participant could test and evaluate new tools in his or her home institution and maintain ownership over specific changes. During webinars following action periods with rapid PDSA cycles, participants could share their assessments of new tools or workflows in a low-stakes environment, highlight the strengths of their institution in adapting these items, and learn from the experiences of others.

In many ways, the COVID-19 pandemic created a "stress test" for the RISE LC. Faced with a rapid conversion to telehealth visits, participants were unable to use the collaboratively developed tool in its original format to collect RA PROs. Through collective discussion and PDSA cycles, the RISE LC shifted focus to developing tools and PRO collection workflows that were suitable for virtual care during the COVID-19 pandemic. Thus, strengths of the LC model are its adaptability to the realities of a changing clinical care environment and its ability to support diverse sites and providers through change. The RISE LC also provided a sense of community and support during an unprecedented stressful period.

As the RISE LC matures, a next step will involve developing pragmatic and randomized study designs to test the tools developed by the group in improving treat-to-target and shared decision-making in rheumatology care and to gauge the usefulness and generalizability of these interventions. Data collection across multiple institutions with varied EHRs remains an ongoing issue in reporting on measures from the participants as a whole. Connectivity with RISE, the American College of Rheumatology's Qualified Clinical Data Registry, may address this in the future if there is continued uptake of the registry by rheumatology practices across the United States.

The strengths of the RISE LC are its support of collaboratively created tools for clinical use, application to multiple types of rheumatology practices independent of location or resources, and continuous adaptability. The current RISE LC, which has been designed to serve as a continuous learning network, has been operating for approximately 2 years, with long-term participation

bolstered by the fact that the rheumatologists have found the work meaningful and useful to their clinical practices. Despite challenges posed by the pandemic, the RISE LC continues to gain traction, with many future projects on the horizon. Participants will continue to compile best practices and tools for adult rheumatology that can be assembled into a library for future use and dissemination. As the RISE LC matures, younger generations of rheumatologists are joining the learning network, thereby forging a pipeline for the next generation of QI champions in adult rheumatology.

The RISE LC represents a practical departure from the traditional LC model, with a focus on developing a learning network that generates implementation strategies for QI and the use of PROs in adult rheumatology clinics in the United States. The learning network promotes the sharing of best practices to improve patient-physician communication and shared decision-making. These solutions have been adapted to the challenges of transitioning to virtual care during the COVID-19 pandemic. Future directions will include implementing these tools across sites and measuring the impact on treat-to-target adherence and shared decision-making for patients and clinicians in adult rheumatology clinics.

AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be published. Drs. Subash, Liu, and Yazdany had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. Subash, Liu, Bajaj, Barton, Bartels, Bermas, Schmajuk, Yazdany

Acquisition of data. Subash, Liu, DeQuattro, Choden, Jacobsohn, Bajaj, Barton, Bartels, Bermas, Danila, Downey, Ferguson, Reiter, Wahl, Weinstein, Zell, Yazdany

Analysis and interpretation of data. Subash, Liu, Dequattro, Katz, Bajaj, Barton, Bartels, Bermas, Danila, Schmajuk, Yazdany.

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