

**Rheumatology Informatics System for Effectiveness Patient-Reported Outcome (RISE-PRO)
Dissemination Project**

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Abstract

Purpose: The overarching aim of the RISE Patient-Reported Outcome (RISE PRO) project was to scale and spread the use of rheumatoid arthritis PRO measures across rheumatology practices nationally.

Scope: In this project, an interdisciplinary team of rheumatologists, epidemiologists, clinical informaticists and qualitative researchers worked with the American College of Rheumatology to advance PRO measurement in rheumatology practices. The technology platform for the project was the RISE registry, an electronic health record (EHR) based Qualified Clinical Data Registry that includes over 3 million people with rheumatic diseases.

Methods: The project established an evidence-based clinical learning network to support the participation of rheumatology practices in PRO measurement and improvement efforts (Aim 1). In addition, to scale PRO extraction from the clinical notes of EHRs of rheumatology practices, a natural language processing (NLP) pipeline was developed, validated, and disseminated (Aim 2). We sought to evaluate the impact of PRO collection efforts across rheumatology practices using both qualitative and quantitative research methods (Aim 3). Finally, the findings from this project are being incorporated into a ToolKit that includes resources for successful PRO implementation for national dissemination.

Results: The project generated a new learning network focused on collecting PROs and improving outcomes for people with rheumatic diseases (Aim 1). An NLP algorithm to reliably extract PROs from the EHRs of over 300 rheumatology practices using over 40 different EHR systems was developed and validated across the RISE registry. The NLP algorithm is publicly posted on github for national dissemination (Aim 2). We extracted and analyzed PROs from EHRs nationally, including from over 80,000 people with rheumatoid arthritis, to demonstrate that RISE registry participation improved PRO measure collection. Moreover, we catalogued the workflows and innovations of practices with successful PRO collection efforts using qualitative methods (Aim 3). A ToolKit that includes trainings and tools for successful PRO implementation is being developed to facilitate the efficient and effective collection of PROs across rheumatology practices. In summary, the RISE-PRO project has enabled one of the largest systematic PRO collection efforts in the United States.

Key Words: patient-reported outcomes, rheumatology, natural language processing

I. PURPOSE

Although there is significant interest in the scale and spread of patient-reported outcomes (PROs) to guide clinical care across a range of conditions, uptake has been slow and inconsistent in the U.S. health care system. Using rheumatoid arthritis (RA) as the target condition, we undertook the RISE PRO project to scale and spread the use of PROs across rheumatology practices nationally.

PROs are important in RA, a condition that affects 1.3 million Americans and is a leading cause of disability in the U.S. Among chronic conditions, RA has robust scientific evidence for the validity of functional status PROs. Functional status assessments have been important outcome measures in RA clinical trials, are responsive to therapy changes, and are strong predictors of future disability and mortality. Moreover, PROs have been successfully used to inform evidence-based treatment decisions, and to facilitate shared decision-making and patient engagement in RA. Measuring functional status PROs during routine clinical care is recommended in national RA guidelines and is a National Quality Forum-endorsed quality measure.

In 2014, the American College of Rheumatology (ACR) launched the Rheumatology Informatics System for Effectiveness (RISE) registry to facilitate quality improvement on a national scale. The registry passively extracts electronic health record (EHR) data from rheumatology practices, aggregates and analyzes these data centrally, and feeds performance on quality measures and outcomes back to clinicians using a web-based dashboard. RISE captures the collection of PROs across rheumatology practices nationally, provides benchmarking on PRO measure performance, and generates data for comparative effectiveness studies. However, a significant challenge in PRO capture is that many clinicians record PRO results in clinical notes rather than as structured EHR data, limiting retrieval of this information for patient longitudinal monitoring, quality reporting and performance benchmarking. The overarching goal of the RISE-PRO project was to address some of the barriers to PRO collection and to further scale and spread the use of PROs through RISE. The specific aims included:

Aim 1: To create an evidence-based clinical learning network to support the participation of public hospital systems in PRO measurement and improvement efforts through RISE.

Aim 2: To develop and scale a natural language processing (NLP) system to extract PRO measures from clinical notes in the EHRs of RISE registry practices.

Aim 3: To analyze the impact of the RISE PRO learning network on quality of care and health outcomes in RA.

II. SCOPE

A. Background

PROs are considered core outcomes in RA. RA is the most common inflammatory arthritis, affecting up to 1% of U.S. adults and causing significant disability, excess mortality and economic burden. The disease is characterized by pain and swelling in the joints, fatigue, and profound joint stiffness. Over time, inflammation can cause joint deformities and impaired physical functioning. Although inflammation can be measured using blood tests such as the ESR (erythrocyte sedimentation rate) or CRP (C-reactive protein), the nature of RA makes PROs critical to understanding disease activity and its functional consequences.

Among chronic diseases, RA has many decades of robust scientific evidence supporting the role of PROs in predicting health outcomes and in informing clinical care. This legacy dates back to the Health Assessment Questionnaire (HAQ), which was among the first instruments to measure patient-centered dimensions of health. As new treatments, including biologic and non-biologic disease modifying drugs, have radically reduced the disability caused by RA, new versions of the HAQ have been developed that capture higher levels of functioning (e.g., HAQ II and MDHAQ). In addition, several studies have validated the use of Patient-Reported Outcome Measurement System (PROMIS®) physical function scales in RA. Another core PRO in RA is the

patient's global assessment of RA disease activity, typically measured on a visual analog scale. The patient global assessment is used as a component of composite disease activity measures such as the Clinical Disease Activity Index (CDAI), which is used to track disease activity. Adjusting treatment to target a better disease activity score is associated with improved health outcomes, including less disability ("treat-to-target"). Given the strong evidence supporting PRO use in RA, as well as the availability of valid, reliable PRO measures, we chose RA as the target condition to scale and spread the use of PROs using health IT.

Measuring and using PROs to guide RA management is central to providing high quality care and is recommended by national guidelines and quality measures. Routine measurement and monitoring of physical function PROs helps clinicians and patients determine if a key treatment goal, maintaining functional capacity, is being achieved. Research has also demonstrated that RA patients managed with treat-to-target approaches, including the use of PROs, have a higher likelihood of achieving remission, less joint damage, and better quality of life. Guideline recommendations by the ACR and other organizations suggest using PROs to monitor RA disease activity and functional status routinely. In addition, in 2014, our research group led efforts to achieve endorsement from the National Quality Forum on two measures recommending the use of RA PROs in clinical practice (NQF 2523: RA Assessment of Disease Activity and NQF 2524 RA Functional Status Assessment). High performance on these measures is important for rheumatologists to succeed under payment reform, including the Merit-based Incentive Payment System (MIPS).

Despite the evidence base supporting the use of PROs and the introduction of PRO-based quality measures into national reporting programs such as MIPS, the collection and use of PROs in RA has been inconsistent. Barriers include inadequate clinician knowledge on the use of PROs, workflow and technology barriers to collecting PROs, and lack of tools to effectively communicate PRO results with patients to guide shared decision-making and clinical care. Our goal was to address some of these barriers to enable the successful scale and spread the use of PROs across rheumatology practices using health IT.

B. Context

PRO use has been uneven across rheumatology practices. Some rheumatology practices are using PROs to guide chronic care management, to monitor symptoms, to engage RA patients in disease tracking and shared decision-making, and for national quality reporting and benchmarking. However, using PROs remains uneven, with some practices not collecting these outcomes at all, and others collecting them inconsistently or as unstructured data in clinical notes. Data from the RISE registry at the start of this project suggested that among the 178,931 individuals with RA, just over half have a functional status PRO score or RA disease activity score recorded. Rates of PRO implementation in non-RISE practices are similar or lower. Although RISE has represented one of the largest systematic PRO measurement efforts nationally, we observed substantial room for improvement in spreading the use of PROs in rheumatology practice.

Methods to scale and spread PRO measures need to accommodate the diversity of health IT infrastructure and other resources in rheumatology practices. Rheumatology practices in the United States are diverse. Ranging from solo rural practices with minimal health IT infrastructure to single specialty groups or academic health systems with more IT resources, practices have varying human and technology resources to devote to PRO collection. Any solution to scale and spread the use of PROs across practices nationally needs to recognize and address this diversity. For example, many practices use EHR systems that do not have functionality for administering PROs through applications or patient-portals. Further, many EHRs do not include structured data fields to record PRO results. These health IT barriers are particularly relevant in smaller community practices that often have EHR software that is challenging to customize. As a result, many U.S. rheumatologists record PRO results in clinical notes rather than in structured fields. This makes the information difficult to retrieve for quality reporting, patient monitoring over time, or population-health management. Unfortunately, EHR technology vendors have been slow to develop foundation software that makes PRO collection and use in clinical care less cumbersome for rheumatologists. Given these realities, scalable solutions, such as developing natural language processing (NLP) systems to extract PROs from clinical notes is needed and was a key focus of this project.

The RISE registry provides a novel technology platform to track use of PROs across rheumatology practices nationally. While barriers to PRO collection at the practice level are significant, national registries hold promise in making PRO data more usable for clinicians and in aggregating this information for quality reporting and for research. In rheumatology, a national EHR-enabled Qualified Clinical Data Registry (QCDR) has been developed by the ACR to improve the quality of care for rheumatic conditions. The registry passively collects data from the EHRs of participating practices, aggregates and analyzes data centrally, and continuously feeds back performance on quality measures and outcomes to practices via a web-based dashboard. Because of federal QCDR permissions, data on all patients seen by participating rheumatologists is uploaded to the registry, thereby avoiding selection bias. This novel informatics infrastructure has allowed us to rapidly scale and spread RISE since 2014; the registry now includes data from the practices of approximately 30% of U.S. rheumatologists. RISE is an ideal data repository for studying the scale and spread of PROs across rheumatology practices since both structured data and clinical notes are available for analysis on all patients seen by participating clinicians.

With consideration of these contextual factors, the RISE PRO project used a combination of learning networks and technology development (i.e., NLP pipelines) to scale and spread the use of PROs across rheumatology practices.

C. Settings

This project was conducted at the University of California, San Francisco (UCSF) and at Stanford University. The project relied on the technology infrastructure of the ACR's RISE registry, described below.

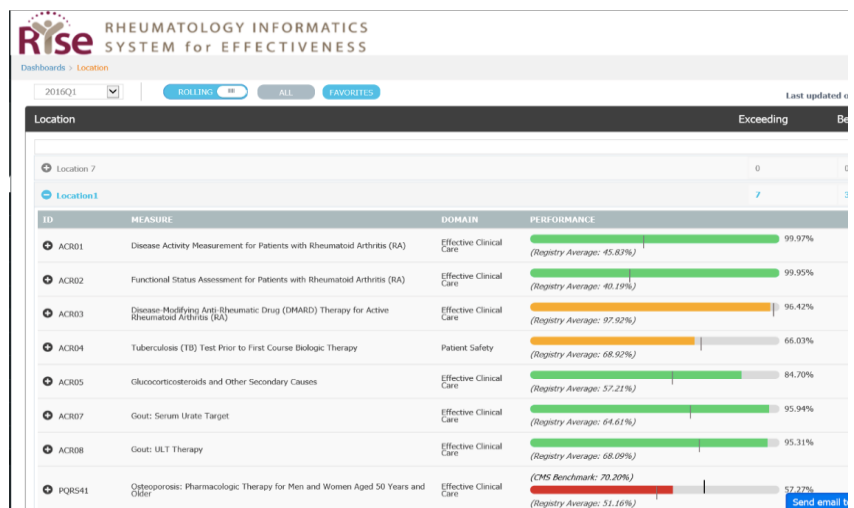
RISE practices are distributed across the United States. The registry currently includes data from over 300 rheumatology practices and 3 million distinct patients. UCSF is the lead data analytic center for the RISE registry.

RISE is constructed to minimize impact on practice workflow by collecting data that is entered during the course of routine care into the EHR. RISE can connect to most certified EHR systems; currently, the registry maps to >40 different EHRs. Practices interact with RISE through a user-friendly web-based dashboard (see **Figure 1**). The dashboard includes clinician and practice-level performance on measures and outcomes and provides national benchmarking. Several quality measures relying on PROs are in the RISE dashboard: 1) documentation of RA functional status using a validated measure, 2) documentation of RA disease activity using a validated measure, and 3) achievement of low or moderate RA disease activity based on a validated measure. Practices can run a query to examine the performance of PRO measures in their patients with RA to optimize MIPS reporting, to facilitate population health management, and to guide quality improvement efforts.

D. Participants

For Aim 1, participants were rheumatologists participating in the learning network. Recruitment of learning network members is discussed below.

Figure 1. RISE dashboard, showing performance on quality measures.



For Aims 2 and 3, data derive from the RISE registry and participants therefore included patients seen in rheumatology practices that are connected to the registry.

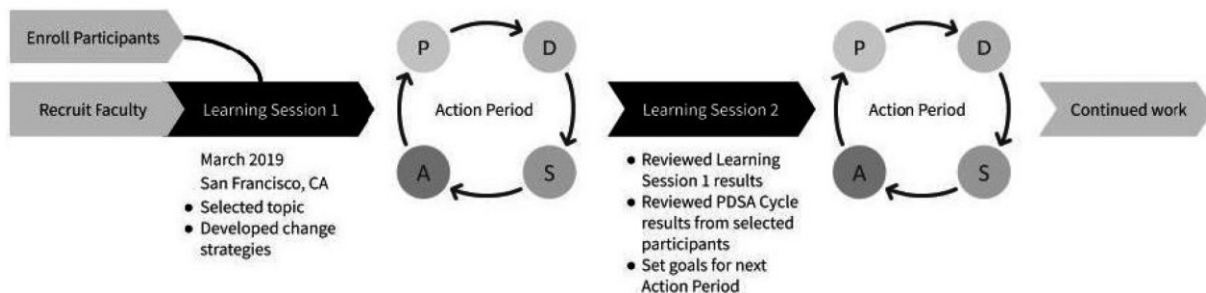
III. METHODS

Study Design

For Aim 1, our goal was to create a Learning Collaborative (LC) based on the Institute for Healthcare Improvement's (IHI) Model, establishing a network of clinics that work to incorporate PROs into clinical care.

Overview. We based the structure of the RISE-PRO Learning Network on the IHI's Breakthrough Series (**Figure 2**), particularly the development of learning collaboratives. Using rapid tests of change and learning sessions, we aimed to address the practical challenges of collecting and using PROs in clinical practice to guide RA care.

Figure 2. Structure of the RISE-PRO Learning Network.



Setting up the learning network using the IHI Model. Our team attended the IHI Breakthrough Series College in October 2018, a professional development program that provided training in establishing a Learning Collaborative health care model. Materials from these trainings helped our team develop a strategic plan for launching the RISE PRO Network. An IHI Improvement Learning Consultant and project investigators led meetings, and attendees worked together to define the specific objectives of the learning network around the use of PROs.

Recruiting sites to participate in the Learning Network. Recruitment occurred by networking through the ACR, and 12 sites agreed to participate and completed enrollment agreements. We aimed to mostly include public hospitals and several safety net health systems. Sites included Zuckerberg San Francisco General Hospital (ZSFG), Highland Hospital in Alameda County, Veterans Affairs Hospital Albuquerque, Veterans Affairs Hospital San Francisco, University of Texas Southwestern, Veterans Affairs Hospital Oregon Health Sciences, Denver Health, University of Colorado Health System, University of Alabama at Birmingham, University of Wisconsin, Loma Linda Health System, VA Puget Sound Healthcare System/University of Washington. Rheumatologists from these sites worked together to define shared goals around the use of PROs to improve healthcare for individuals with RA. Three face-to-face meetings were conducted among network members; the remaining meetings occurred virtually because of the pandemic.

Defining the Network's shared goals and objectives. Learning sessions began in March 2019 followed by hour-long webinars every 1 to 2 months; over 20 learning sessions were completed. As a learning network, topics for discussion were selected by faculty with input from participants. 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 Plan-Do-Study-Act 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. Through a series of surveys and meetings, the primary issue that the network decided to tackle (mutually agreed upon in early learning sessions) was the following: *How can PROs be collected and used in a patient-centered way to improve outcomes for rheumatoid arthritis (RA) at every clinical encounter?*

Assessment of baseline PRO collection workflows. We administered a survey to RISE PRO Learning Network participants to assess their PROs workflows, including their PRO collection methods, PRO structured data entry capability into the EHR, and technologies or methods used to share PROs with patients.

Carrying out learning sessions to create health IT workflows to collect PROs and to facilitate discussing PRO results with patients at every RA encounter. Multiple learning sessions were used to optimize workflows for using health IT to collect the PROs and record them in the EHR. We learned that a few clinics used iPads to collect PROs, some used questionnaires administered through the EHR patient portal, and others collected PROs on paper and then had nursing staff enter results into flowsheets or as lab results in the EHR. Given the diversity of approaches and health IT resources, the network decided to develop a practical tool that could be used across sites to share PRO results with patients during the RA encounter. This tool was iteratively developed to facilitate the clinician-patient conversation regarding PROs and treatment goals (see more detailed description below). Given diverse patients seen across the network, the tool was also translated and piloted in Spanish and Chinese.

Investigating the impact of the learning network on PRO collection and use. With the onset of the COVID-19 pandemic, the group's work was heavily impacted. We were in the process of collecting data on the effectiveness of our learning network and PRO implementation tools when there was a sudden and overnight shift to telehealth. Data collection was halted since all measures relied on collection and use of PROs during face-to-face encounters.

At the July 2020 webinar, Learning Network participants decided to explore different workflows for collecting PROs during telehealth visits during the pandemic. Webinars for collaborators continued to build a consensus strategy for using PROs during virtual care. Through a series of learning cycles, we piloted different approaches to collecting this important information and settled on a brief physician or nurse/staff administered survey from a commonly used PRO measure for RA called the multidimensional health assessment questionnaire (MDHAQ). Unfortunately, administering survey items over the phone was infeasible for most practices who were dealing with pandemic-related staffing shortages and busy clinics. Network members ultimately settled on two approaches: 1) Collecting PROs using health IT such as EHR patient portal surveys; this was feasible for only a minority of sites since most did not have capacity to push PROs to patients at the start of the pandemic; 2) Using simpler one-item PRO surveys for pain, physical and function that were administered by the physician during telehealth encounters. The network summarized the methods regarding RA PRO collection during in-person and telehealth encounters in a research paper, described below (*Subash M, Liu LH, DeQuattro K, Choden S, Jacobsohn L, Katz P, Bajaj P, Barton JL, Bartels C, Bermas B, Danila MI, Downey C, Ferguson S, Reiter K, Wahl E, Weinstein E, Zell J, Schmajuk G, Yazdany J. The Development of the Rheumatology Informatics System for Effectiveness Learning Collaborative for Improving Patient-Reported Outcome Collection and Patient-Centered Communication in Adult Rheumatology. ACR Open Rheumatol. 2021 Oct;3(10):690-698. PMID: 34288595*).

For Aim 2, our goal was to develop and scale a natural language processing (NLP) system to extract PRO measures from clinical notes in the EHR across hundreds of RISE registry practices. This phase of the project was performed as a collaboration between our investigative group at UCSF and computer scientists at Stanford University, we used a multi-step process (**Figure 3**), summarized below, to develop the NLP system. Our methods were ambitious and represent one of the first efforts to develop and validate an NLP pipeline across over 100 practices nationally that were using >20 different EHR software systems.

Note aggregation and IRB procedures. We developed infrastructure to extract 34 million notes from 854,628 patients, 158 practices and 24 different EHR systems that transmitted data to the RISE registry. Clinical notes have protected health information (PHI), including names, addresses, dates, and other features. To use a large clinical note corpus for research, we needed to obtain privacy permissions from two separate entities. First, we worked with the ACR and a national Institutional Review Board (IRB), Western IRB, to obtain permissions to analyze a note corpus with redacted PHI. We also obtained permission from the UCSF IRB to use notes for research purposes. Although our intention was to fully de-identify clinical notes, currently, no available software is 100% reliable, necessitating the UCSF IRB approval.

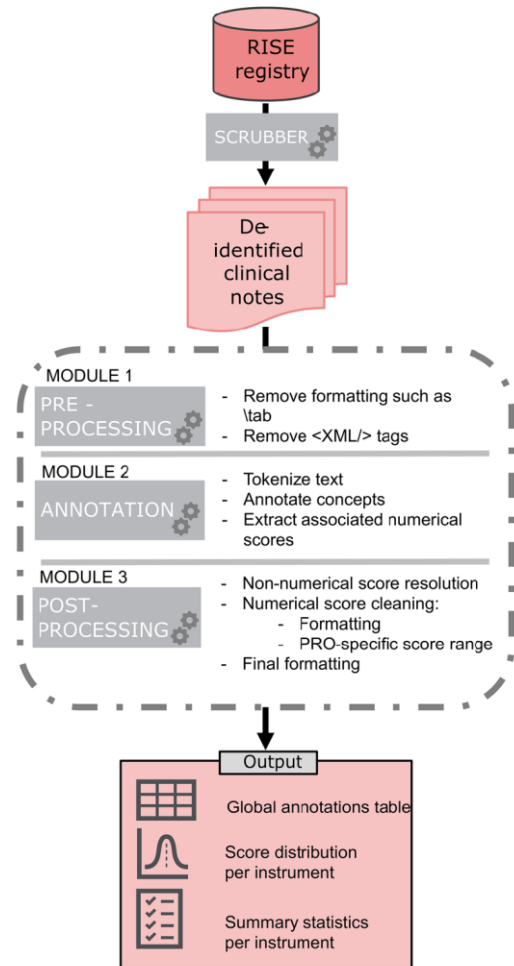
Note de-identification procedures. Next, we explored algorithms to remove PHI from clinical notes. There is currently no gold standard for the removal of PHI from notes. We explored several different options, and ultimately chose to use the National Library of Medicine (NLM) Scrubber after testing multiple systems.

Developing RA PRO terminologies. We developed a PRO terminology dictionary for use in our NLP algorithms. Our machine annotation tool was based on a dictionary customized to the ACR quality measures for the assessment of two PROs (RA disease activity and RA functional status). For each PRO, the current quality measure permits the use of several measurement tools. For example, for functional status assessment, the Patient Reported Outcome Measurement Information System (PROMIS) tools, Health Assessment Questionnaire II (HAQ II), Routine Assessment of Patient ID 3 (RAPID-3) are all acceptable measures and were therefore captured in our dictionary.

Note corpus preparation. Notes between January 1, 2018, and December 31, 2018, were included. A multi-step process consisting of 3 modules was used to process and annotate clinical notes (see **Figure 3**). In the first module, we pre-processed raw text to harmonize the notes and remove text that included XML code or other formatting. The second module was developed using subject matter expert-curated terminology for pattern recognition, a Spacy pipeline for the core text processing step, and rules to identify numerical scores associated with the outcome measure mentions identified by the pattern recognition. Finally, RA PRO measures and associated scores were cleaned, yielding global annotation tables.

Assessment of NLP pipeline performance. We randomly selected 100 notes; 182 RA outcome measure mentions were detected and manually chart reviewed. A subject matter expert determined if a score was available and whether the score was correctly extracted by the NLP tool. Sensitivity, positive predictive value and F1 scores were derived comparing the manually extracted versus NLP derived scores. We additionally compared the NLP pipeline to RA outcome measures that were available in structured data fields in a subset of patients. We used two strategies to determine the agreement between the NLP pipeline and these structured data: exact matching performed on numerical scores and fuzzy matching to determine whether the scores mapped to the same categories (i.e., RA remission, low/moderate/ or high disease activity).

Figure 3. Methods for developing NLP pipeline for PRO extraction from RISE registry clinical notes.



External validation of the pipeline. As a final step, we further evaluated the performance of the NLP pipeline in a large academic health system that does not participate in the RISE registry.

For Aim 3, our goal was to analyze the impact of the RISE PRO learning network on quality of care and health outcomes in RA.

Although our initial Aim was to evaluate the impact of the RISE PRO learning network on PRO collection and RA outcomes, the COVID-19 pandemic had a negative impact on the work of the learning network. Specifically, between 2018 and early 2020, the learning network developed a series of procedures and materials to scale and spread the use of PROs across rheumatology practices. All these workflows and materials assumed that rheumatology patient care would occur during face-to-face encounters. In March 2020, all learning network participants shifted to telehealth. Because these practices care for immunocompromised patients, use of telehealth was prolonged and continues to this day in many of the sites.

Given that we were unable to evaluate the impact of learning network materials on PRO collection and use, our investigative team shifted our Aim. Our experience with the learning network made it clear that to further scale and spread the use of PROs, rheumatologists and their practices needed a variety of resources. We therefore decided to develop a ToolKit to facilitate the scale and spread of RA PROs across practices. We pivoted to this strategy because there are currently no national resources available for rheumatologists that guide the effective implementation, collection and use of PROs for people with RA. Moreover, in conversations with both the ACR and RISE PRO Learning Network members, colleagues were highly enthusiastic about the development of such a ToolKit, and the ACR offered to host the ToolKit on its website and maintain it after this project ends.

To inform the content of the ToolKit we performed a series of qualitative studies with rheumatology practices, including those participating in the RISE registry. Our overarching aim was to interview health care professionals from diverse rheumatology practices (solo practices, multi-specialty practices, single-specialty practices, academic health systems) to understand how practices currently collect PROs, what technologies they employ, and the factors associated with high performance on PRO-based quality measures.

Selection of practices for participation. We used purposive sampling to identify 136 RISE practices with a high proportion of patients with documented RA outcome measures (≥ 30 patients). Because academic medical centers (AMCs) are under-represented in the RISE registry, we reached out to 5 high-performing AMCs to participate in the study, out of which two were RISE practices. A rheumatologist and key staff from each practice involved in RA measure collection, including health IT personnel, practice managers, Medical Assistants (MAs) or nurses/ nurse practitioners (NPs) were invited to participate in virtual semi-structured interviews.

Qualitative methods and use of the Consolidated Framework for Implementation Research (CFIR). A semi-structured interview guide was developed using the core concepts of CFIR to explore key elements of the process, characteristics of individuals, intervention, inner and outer setting. It was pilot tested with team members and rheumatologists and edited accordingly. Interviewers collected information on participants' sociodemographic characteristics, practice resources and characteristics including number of RA patients seen per week, experiences with collecting RA PROs, including the challenges they face, successes, and suggestions for improvement. While data saturation for high performing practices was reached before completing all interviews, we continued virtual data collection with all practices that meet eligibility criteria to cover the collection and use of RA PROs across the different practice settings and EHR software systems. Interviews lasted between 30 to 80 min and were audio recorded and transcribed verbatim.

Analysis of qualitative data. We conducted a thematic analysis of responses to open-ended questions, using both deductive and inductive techniques to identify key themes. First, we reviewed the data to apply a set of deductive codes and create a preliminary set of inductive codes to capture emergent ideas within and across interviews. Codes were discussed, revised, and organized into a structured codebook. Codes were applied to

each interview which was then transformed onto a separate matrix to read through and identify key themes within and across codes. Using an iterative consensus process, we organized themes and sub-themes into components within CFIR domains and identified exemplary quotes for each component illustrating how each key factor served as a success or barriers to collecting RA PROs.

Finally, we used the data from qualitative analyses as well as the experiences of the Learning Network to develop the RA PRO ToolKit content. We are working with ACR web developers to publish the ToolKit in early 2023.

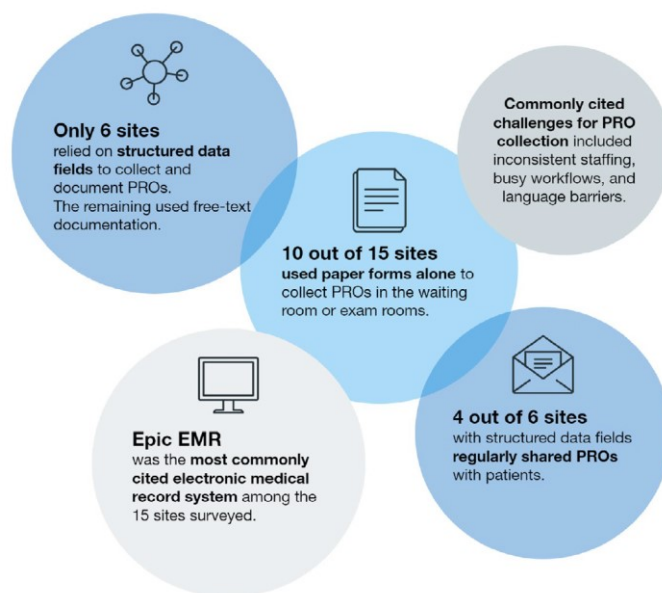
IV. RESULTS

A. Principal Findings for Aim 1: Establishment of the RISE-PRO Learning Network.

We successfully developed the RISE PRO Learning Network and conducted over 20 learning sessions between 2019 and 2022. Sites in the network (listed above) represent diverse health systems across the United States. Most sites are publicly funded health systems. Although the AHRQ grant period has ended, the Learning Network continues to meet on a regular basis with the support of the ACR. Below we outline key data and findings generated from the network's activities.

Results of the baseline PRO collection workflow survey. Participating sites completed a survey regarding their PRO collection workflows. The results of the survey are summarized in **Figure 4**. Key findings included that 10 of 15 sites used solely paper forms to collect PROs from patients in waiting or examination rooms; the remaining sites used combinations of paper forms, tablets, or on-line PRO collection through EHR patient portals. 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 (all requiring staff to type PRO results into the fields), whereas the remaining sites had providers type PRO results 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 sites 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.

Figure 4. Patient-reported outcome workflow survey results from RISE PRO Learning Network Sites.



Development of the RA PRO tool for use in RISE PRO Learning Network rheumatology practices. During a series of learning sessions, the network developed a schema to display RA outcomes to patients during a clinic visit. Multiple PDSA cycles across network clinics led to the final version of the tool, which is depicted in **Figure 5**. The tool incorporates elements of human-centered design work that has been performed with extensive provider and patient input through previous projects by network investigators. The left side of the tool is completed by RA patients in the clinic waiting room before their encounter to capture their goals for both their clinical encounter and their disease overall. Patients are asked to respond to “What’s on my mind for today’s visit” and then to document their specific treatment goals. The right side of the form is used by the provider to indicate the patient’s RA disease activity, which is collected through a PRO form such as the Routine Assessment of Patient Index Data 3 (RAPID 3), or through a composite measure with a PRO component such as the Clinical Disease Activity Index (CDAI).

As noted above, the network was getting ready to formally assess the impact of its activities as well as implementation of the RA tool above on PRO collection and RA outcomes, the pandemic unfortunately halted activities. Learning network participants noted that collection of PROs over phone or virtual visits was extremely challenging because of lack of physician or staff time to administer questions, inability to electronically administer PROs before visits given lack of universal access to the EHR patient portal, and lack of health IT support to build systems to push PRO surveys to patients outside the EHR and then to integrate the information back into the EHR. One site had developed an application to administer PROs to patients but noted that there were frequent integration challenges with the EHR. Many sites also reported language and literacy barriers to PRO administration via electronic surveys. Nevertheless, 1 site was able to successfully collect PROs via telehealth during the pandemic; that site had dedicated medical assistants that would work with patients one-on-one to complete surveys electronically via an EHR portal prior to appointments.

Figure 5. RA PRO tool developed by the Learning Network for implementation across clinical sites.

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:

- Improve My Mood
- Have Less Pain
- Work Regularly
- Feel Less Tired
- Check your 3 most important goals
- Do Daily Activities
- Improve My Sleep
- Avoid Side Effects
- Other

VISIT SUMMARY
 Provider: please complete during visit
 Your CDAM today: (Clinical Disease Activity Index)

Remission/Low
 Your disease is well controlled and symptoms are manageable. 2.8

Moderate
 Your disease is active and symptoms are often disruptive. 10

High
 Your disease is very active and symptoms are constant or severe. 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 _____

The details of the Learning Network's accomplishments on PRO collection, including a discussion of PRO collection during telehealth encounters, was published in a paper: *Subash M, Liu LH, DeQuattro K, Choden S, Jacobsohn L, Katz P, Bajaj P, Barton JL, Bartels C, Bermas B, Danila MI, Downey C, Ferguson S, Reiter K, Wahl E, Weinstein E, Zell J, Schmajuk G, Yazdany J. The Development of the Rheumatology Informatics System for Effectiveness Learning Collaborative for Improving Patient-Reported Outcome Collection and Patient-Centered Communication in Adult Rheumatology. ACR Open Rheumatol. 2021 Jul 20.*

Additional foundational work to facilitate the scale and spread of PROs. While developing the RISE-PRO Learning Network, we worked on several foundational projects relevant to the scale and spread of PROs across rheumatology practices nationally. These are summarized below:

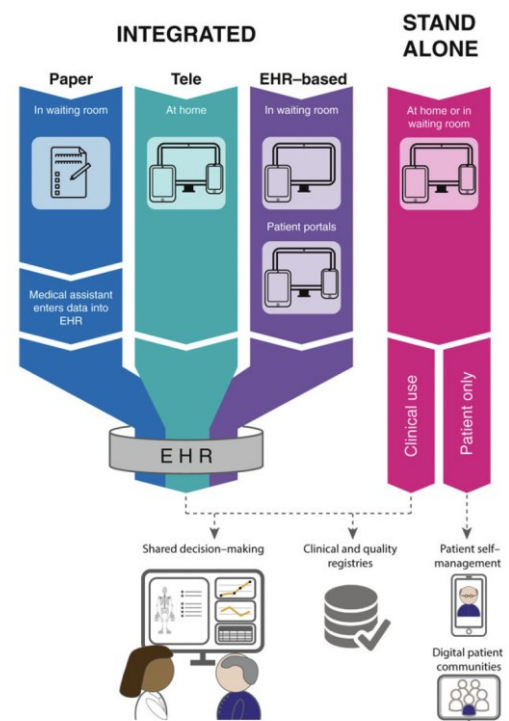
Developing recommendations for which PROs should be used in RA clinical care. For this project, which was done in collaboration with the ACR, we used the CONsensus-based Standards for the selection of health Measurement INSTRUMENTS (COSMIN) to evaluate functional status PROs in RA, defined measures that fulfilled pre-defined minimum standards, and then conducted a modified Delphi process to select preferred functional status PROs for use in RA care. Three measures were ultimately recommended, including the Patient-Reported Outcomes Measurement Information System physical function 10a form (PROMIS PF10a; www.nihpromis.org), Health Assessment Questionnaire-II (HAQ-II; <https://rheuminfo.com/docs/physician-tools/HAQ-II1.pdf>), and the Multidimensional Health Assessment Questionnaire (MD-HAQ; https://rheuminfo.com/docs/physician-tools/Multidimensional_HAQ.pdf). These measures form the basis for a RA PRO functional status quality measure in rheumatology that is used in national pay-for-performance programs and that is implemented in the RISE registry. The work was published: *Barber CEH, Zell J, Yazdany J, Davis AM, Cappelli L, Ehrlich-Jones L, Everix D, Thorne JC, Bohm V, Suter L, Limanni A, Michaud K. 2019 American College of Rheumatology Recommended Patient-Reported Functional Status Assessment Measures*

in Rheumatoid Arthritis. Arthritis Care Res (Hoboken). 2019 Dec;71(12):1531-1539. PMID: 31709771; PMCID: PMC6884654).

Examining uptake of RA PROs through an EHR patient portal. In this UCSF study, we examined the implementation of an online PRO questionnaire for assessing RA functional status that was sent to patients via the EHR patient portal prior to their arrival in clinic. We found a small but steady increase in PRO collection through the portal (from 10% of RA patients at the start of implementation to 19% of patients over the first year of implementation). Compared to White patients, both African American and Latino patients were less likely to have active online EHR portal accounts, and among those with accounts, these groups were less likely to complete PROs. No significant differences were found across age and gender. These findings highlight that attention to inclusion of vulnerable populations when implementing health IT systems for PRO collection is important; if certain populations are less likely to use portals, there is a risk of systematic exclusion in PRO collection efforts. Findings are summarized in this manuscript: *Li J, Yazdany J, Trupin L, Izadi Z, Gianfrancesco M, Goglin S, Schmajuk G. Capturing a Patient-Reported Measure of Physical Function Through an Online Electronic Health Record Patient Portal in an Ambulatory Clinic: Implementation Study. JMIR Med Inform. 2018 May 9;6(2):e31. PMID: 29743158; PMCID: PMC5966655.*

Performing a structured literature review of the use of health IT to support use of PROs in rheumatology. We conducted a review to identify published reports on the use of health IT tools to collect PROs in clinical rheumatology settings. Reports of both EHR-enabled tools and stand-alone applications were included. Special attention was paid to the design process, adoption and integration into routine care, patient and physician satisfaction with use, and evaluation of patient outcomes after implementation. Ten health IT tools were identified and discussed; the current health IT landscape for PRO collection is characterized in **Figure 6**. This work was published: *Gandrup J, Yazdany J. Using Health IT to Support Use of Patient Reported Outcomes in Rheumatology. Rheum Dis Clinic North Am. 2019 May; 45 (2): 257-273.*

Figure 6. Methods for PRO collection across rheumatology practices.



1. Principal Findings for Aim 2: Development of an NLP pipeline to extract PROs from clinical notes.

RISE-PRO investigators successfully developed, implemented and published an NLP algorithm to extract RA PROs from the EHRs. This NLP pipeline is the first to extract RA outcomes from free text notes across multiple EHRs (e.g., different EHR software vendors) and practices nationally.

Using notes from the RISE registry, we found that an NLP approach successfully extracted mentions of RA outcome measures and scores from 92 practices and 20 EHR brands. Compared to manual chart review, the NLP pipeline had a sensitivity, positive predictive value (PPV), and F1 score of 95%, 87%, and 91%, respectively. Substantial agreement was observed between scores extracted from RISE notes and scores derived from structured data ($\kappa = 0.43-0.68$ among DA and $0.86-0.98$ among functional status measures). In the external validation in a large, academic health system not in the RISE registry, we found a sensitivity, PPV, and F1 score of 92%, 69%, and 79%, respectively.

The work was presented at several conferences and published in a journal: *Humbert-Droz M, Izadi Z, Schmajuk G, Gianfrancesco M, Baker MC, Yazdany J*, Tamang S* (co-senior). Development of a Natural*

Language Processing System for Extracting Rheumatoid Arthritis Outcomes from Clinical Notes Using the National Rheumatology Informatics System for Effectiveness Registry. Arthritis Care Res (Hoboken). 2022 Feb 14. PMID: 35157365.

The NLP algorithm was also made publicly available: https://github.com/mhdroz/RISE_PROS. The pipeline was constructed so that investigators working in different domain areas can adapt the tool to their different content areas.

Additional foundational work to facilitate use of NLP for extraction of PROs and other health outcomes.

While developing the RISE-PRO NLP pipeline, we worked on two other projects that advanced foundational methods relevant to advancing the use of NLP for extraction of clinical information such as PROs from free text clinical notes in the EHR. These are summarized below:

Developing a checklist for investigators considering the use of NLP in EHR data. During the RISE-PRO project,

we learned multiple important lessons about applying NLP to clinical notes and developed a paper to disseminate these lessons to the wider community. The paper included a discussion of items for investigators to consider before embarking on an NLP project and includes a github repository resource. The github site includes several sections, including:

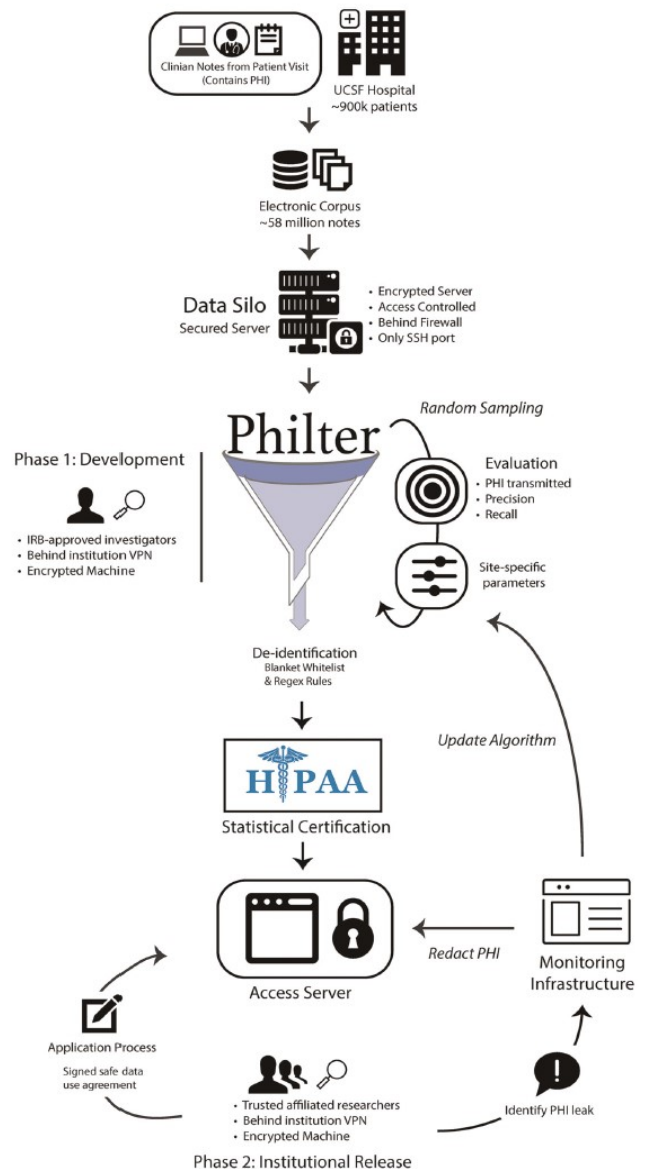
- A New Project Checklist
- A Data Readiness Assessment
- Clinical NLP Resources

This paper is in press: *Tamang S, Humbert-Droz M, Gianfrancesco M, Izadi Z, Yazdany J. Practical Considerations for Developing Clinical Natural Language Processing Systems for Population Health Management and Measurement. JMIR (in press 2022).* The accompanying github site is available at: <https://github.com/suzytamang/practical-considerations-for-healthcare-natural-language-processing-systems>.

Developing improved systems to de-identify clinical notes for NLP projects and clinical research. In the process of evaluating numerous solutions for de-identification of clinical notes for this project, we noted that currently available systems have significant weaknesses because they have been trained on only a small number of note corpora. Using a privacy-centric approach to remove PHI, we developed a novel pipeline that uses several state-of-the-art tools, including pattern matching, statistical modeling, blacklists, and whitelists. The new system had a recall of 99.5% and an F2 of 94.4% for removing PHI on the note corpus of the University of California, San Francisco, and outperformed two commonly used note-identification tools. We called the program Philter (Protected Health Information filter; see **Figure 7**).

We have made the tool open-source tool on github: <https://github.com/BCHSI/philter-ucsf>. The work has been published: *Norgeot B, Muenzen K, Peterson TA,*

Figure 7. Protected Health Information Filter (Philter).



Fan X, Glicksberg BS, Schenk G, Rutenberg E, Oskotsky B, Sirota M, Yazdany J, Schmajuk G, Ludwig D, Goldstein T, Butte AJ. Protected Health Information filter (Philter): accurately and securely de-identifying free-text clinical notes. NPJ Digit Med. 2020 Apr 14;3:57. PMID: 32337372.

2. Principal findings for Aim 3: Using the Consolidated Framework for Implementation Research (CFIR) to Investigate PRO use across rheumatology practices and to develop a ToolKit for national dissemination.

We conducted 19 interviews across 16 RISE community practices and 5 academic medical centers involving a total of 35 participants. Participants were sampled to include the interprofessional team involved in implementing and using PROs in rheumatology practice, and included 19 rheumatologists, 8 medical assistants, 5 practice managers, 1 nurse practitioner, and 1 health IT specialist. Common themes in successful implementation of RA measure collection discussed by participants within the CFIR domains were summarized using qualitative methods, as described in more detail below.

The Process. Practices reported using a small group of PROs, most commonly the Routine Assessment of Patient Index Data 3 (RAPID3) and the patient-global assessment for the Clinical Disease Activity Index (CDAI). Workflows have been developed to suit the needs of the individual clinic, revolving around things like simplicity and efficiency for both large and small practices. Often, the foundation and maintenance of the PRO collection workflow either revolve around a central clinic PRO champion (smaller practices) or by quality reporting needs of the clinic overall (in larger practices). Technical difficulties and data transmission, such as cumbersome EHR workflows to enter PROs into structured fields, were major process challenges faced by almost all practices. A minority of practices had more advanced health IT systems for PRO collection. For example, only one practice employed iPads in the waiting room for RA measure collection; however, even this practice faced challenges and reported that the information from the iPad did not upload automatically into the EHR, so the practice workflow still required that medical assistants or nurses check the iPad for the scored measures and document them manually. Another practice used the EHR patient portal for PRO collection, but not all patients used their portal regularly, necessitating that PRO surveys continue to be administered by paper. One practice reported using a “magic pen” – a device that the patient uses to complete paper PRO forms that automatically scans their responses and can be docked for uploading into the EHR.

Intervention Characteristics. In most cases, PRO collection workflows began with a staff member giving paper forms to the patient upon arrival at the clinic. In fewer cases, forms are given to the patient electronically, either by an online portal or a device provided by the clinic, such as an iPad. Either physicians or an automated function in the EHR are responsible for scoring the PRO measure, with most practices reporting manual entry of scores into the EHR. Almost all study participants expressed frustration about the lack of EHR vendor support to collect PROs; only one EHR (NextGen) had software to facilitate entry and longitudinal tracking of PROs specifically for RA; even larger vendors such as Epic required some degree of local customization for PRO entry and tracking. Few practices reported successful collection of PROs via telehealth encounters, requiring the patient to (either periodically or completely) schedule an in-person encounter to collect the PRO measures. Lack of automatic calculation of scores and inability of the EHR to capture structured data from scanned forms and uploaded pdf files were challenges faced by some practices when transmitting RA outcome measures electronically to the RISE registry.

Individual Characteristics. Nearly all interview participants emphasized the importance of clinic culture around quality improvement for the success of their current PRO collection workflows. The idea of “checks and balances,” or ensuring multiple staff members are responsible for ensuring collection of PRO measures, was a common reason for success. Physicians and staff both reported the importance of proper training in the methods and reasons behind the collection of PROs, with additional emphasis placed on educating patients about why the PROs were important and how they would be used. Most of the practices reported that patient survey fatigue was the main barrier faced when collecting RA PROs. In fact, participants reported that patients often did not want to complete the same questionnaires at every visit, which limited their ability to collect this information longitudinally.

Inner Setting. The capacity for continuous quality improvement of workflows was common for practices with high rates of PRO collection and use, with many reporting the ability to respond to internal feedback and suggestions for improvement as necessary. Often clinic leadership was proactive in allocating financial resources, health IT support, and other resources to improve workflows. Conversely, some practices reported financial limitations in their ability to optimize PRO collection and use workflows, noting that switching to a new EHR system was needed, but not financially viable.

Outer Setting. Influences on the decision to collect PRO measures are consistent with ongoing internal and external sources including quality improvement programs, professional opinions on the value of PRO measures, performance measure reporting, and requirements set by insurance companies for medication prior authorizations. In terms of outer setting challenges faced, several practices described inconsistencies in the RISE registry dashboard that displays PRO measure performance for national quality reporting. Often, this reflected the inability of the registry to capture PROs recorded as free text in clinical notes.

These results were presented at the ACR meeting (*Jacobsohn L, Nasrallah C, Young C, Schmajuk G, Yazdany J. Application of the Consolidated Framework for Implementation Research (CFIR) to Study Top-Performing Practices in the RISE Registry [abstract]. Arthritis Rheumatol. 2022; 74 (suppl 9). <https://acrabstracts.org/abstract/application-of-the-consolidated-framework-for-implementation-research-cfir-to-study-top-performing-practices-in-the-rise-registry/>) and a manuscript is in preparation. Moreover, the findings from the high-performing practices in this study have informed the development of a ToolKit for PRO collection and use in RA; we anticipate that the ACR will publish the ToolKit developed through this project in 2023 on its website.*

Additional foundational work on the impact of health IT on PRO collection and health outcomes.

Evaluating if participation in a national registry, RISE, improves the collection of PROs for RA. We evaluated data from 59,986 patients seen in 54 rheumatology practices. Practices participating in the registry had significant improvements in quality measures related to measuring RA functional status PROs over time (8.4% increase per year, $p < 0.001$). Single-specialty group practices had the fastest rates of improvement over time. By the end of the study period, functional status PROs were available to almost 80% of patients with RA. This work was published: *Izadi Z, Schmajuk G, Gianfrancesco M, Subash M, Evans M, Trupin L, Yazdany J. Rheumatology Informatics System for Effectiveness (RISE) Practices See Significant Gains in Rheumatoid Arthritis Quality Measures. Arthritis Care Res (Hoboken). 2020 Sep 16. PMID: 32937026.*

Investigating the relationship between EHR systems and performance on PRO-based quality measures. Over the course of the RISE-PRO project, it became clear that which EHR software system a rheumatologist used profoundly influenced their ability to collect and track PROs over time. Some EHRs, such as NextGen, had rheumatology specific software modules that allowed the entry of PRO scores as structured data, and had sophisticated dashboards for tracking PROs over time. To quantify this phenomenon, we performed a study involving 220 RISE practices caring for 314,793 patients with RA. We used multivariable linear regression and zero-inflated negative binomial models to examine the independent effect of the EHR system used on practice-level PRO quality measure performance, adjusting for practice characteristics and patient case-mix. Even after adjustment, NextGen practices performed significantly better than other practices using EHRs such as eClinicalWorks and eMDs on the RA functional status PROs. This work was published: *Hammam N, Izadi Z, Li J, Evans M, Kay J, Shiboski S, Schmajuk G, Yazdany J. The Relationship Between Electronic Health Record System and Performance on Quality Measures in the American College of Rheumatology's RISE Registry: Observational Study JMIR Med Inform 2021;9(11):e31186.*

Examining socioeconomic disparities in functional status PROs in a national sample of patients with RA. Using the RISE registry, we performed a cohort study to evaluate functional status PROs, with area deprivation index (ADI) serving as the primary independent variable. Among 83,965 individuals with RA, functional status was

statistically significantly worse across each successively lower quintile of socioeconomic status (SES). In addition, the probability of functional decline over the study period was statistically significantly higher in individuals with low SES (18.9% in the lowest SES quintile) compared with individuals with high SES (14.1% in the highest SES quintile). Therefore, worse functional status PROs and faster declines in functioning over time were observed in patients with lower SES. This paper illustrates how the scale and spread of PROs across rheumatology practices and the central aggregation of this data in the RISE registry can provide a framework for monitoring disparities in RA and for generating evidence to spur action toward achieving health equity. *Izadi Z, Li J, Evans M, Hammam N, Katz P, Ogdie A, Suter LG, Yazdany J,* Schmajuk G* (co-last authors). Socioeconomic Disparities in Functional Status in a National Sample of Patients With Rheumatoid Arthritis. JAMA Netw Open. 2021 Aug 2;4(8):e2119400. PMID: 34347058.*

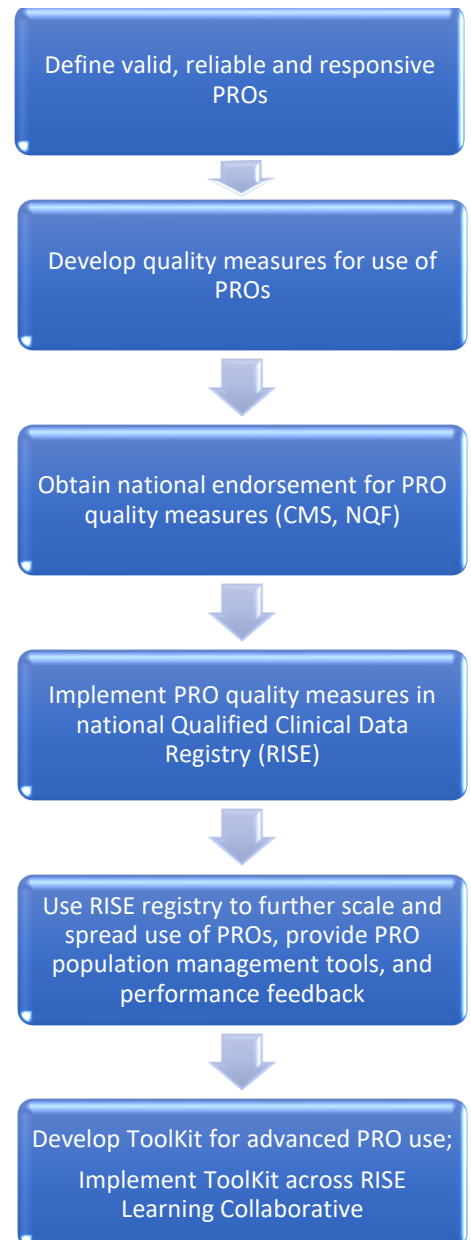
V. DISCUSSION

The RISE PRO project has allowed us advance methods and infrastructure to support the scale and spread of the use of PROs across rheumatology practices nationally. The work presented above is part of a comprehensive national strategy that our team has spearheaded over many years to increase the use of PROs in rheumatology, pictured in **Figure 8**. Below we discuss some of the opportunities and challenges that our investigative team has encountered during this project and what we see as critical future directions.

Valid, reliable, responsive and feasible PROs are needed to facilitate national use. It is important that PRO measures used in clinical practice have undergone rigorous testing in diverse populations. The evidence-base for measures is still underdeveloped in many areas, but is robust in RA, making it an ideal condition for the scale and spread of PROs. Measuring and using PROs to guide RA management is central to providing high quality care and is recommended in national guidelines. In collaboration with the ACR, we were able to use systematic literature reviews and consensus processes to further specify the “best of set” RA functional status PROs for use in clinical practice. This has led to clear recommendations for clinicians, who now rely on a small set of vetted PROs for use in their practices.

Development and implementation of national quality measures that address the use of PROs in clinical practice can standardize use. Our group has worked over many years with the ACR to achieve National Quality Forum (NQF) and Centers for Medicare and Medicaid Services (CMS) endorsement for the use of RA PROs in clinical practice (NQF 2523: RA Assessment of Disease Activity and NQF 2524 RA Functional Status Assessment). During the course of the RISE-PRO project, we continued to collaborate with the ACR to maintain these measures in national quality measurement and reporting programs. High performance on these PRO measures is important for rheumatologists to succeed under payment reform, including the Medicare-based Incentive Payment System. Developing and maintaining this national quality measurement infrastructure around PROs has been key to facilitating more rapid national uptake by practicing rheumatologists.

Figure 8. National Strategy for the Scale and Spread of PROs for RA.



The innovative technology infrastructure of the RISE registry has allowed tracking of PRO measures and tools for population health management. The RISE registry includes a dashboard that allows clinicians to view their performance on PRO-based quality measures and to compare their performance to that of peers. Moreover, the dashboard has tools for population health management, such as being able to generate a list of patients who are missing PROs or those with low PRO scores. The infrastructure of the RISE registry has allowed us to track the use of PROs over time in rheumatology practices and to demonstrate that use of PROs in RISE practices is increasing over time. Importantly, with a majority of patients in the registry having functional status PROs, we have been able to set up a national measurement framework for monitor disparities in RA. Qualified Clinical Data Registry technology infrastructure has therefore been critical to the scale and spread of PROs in rheumatology.

Many rheumatology practices still face barriers to PRO collection and use. Through the use of a Learning Network and detailed qualitative work with RISE practices in this project, we have been able to document the challenges that rheumatology practices face in collecting and using PROs. Almost all rheumatologists we interviewed felt strongly that collecting PROs was important for providing high quality care for RA and were motivated to do so. Despite high motivation to collect PROs, the most frequently cited barrier to their efficient collection and use was the lack of EHR system functionality to support documentation and tracking of PROs. We found that practices with EHRs that had software content that made it easy for rheumatologists to record PROs and track their results over time had the highest rates of PRO collection and use. Other frequently cited barriers included high staff turnover during the pandemic (e.g., new staff were unfamiliar with PRO collection workflows), time constraints, and patient survey fatigue. Next steps to address these barriers are to work directly with EHR vendors to increase functionality around collection and use of PROs and to develop a ToolKit that outlines best practices for different practice settings, patient populations, and EHR systems (as described below).

Use of NLP systems to extract PROs from clinical notes is possible, but this solution requires significant financial investment and upkeep. Given that many EHRs lack structured data fields for collection of PROs, and that most rheumatologists still document PROs in clinical notes, we undertook an ambitious project to develop an NLP pipeline for use across national RISE practices, which use 40 different EHR systems. Most NLP pipelines to date have been developed and implemented in health systems or networks using the same EHR software. Despite many challenges in the areas of IRB approvals, data transmissions, ontology creation, and data standardization, we were successful in developing, publishing, and making publicly available, an NLP pipeline for extraction of RA PROs. The pipeline performed well across RISE practices and was further validated in a non-RISE health system. This proof-of-concept study demonstrates that it is possible to develop an NLP pipeline across practices nationally, but that considerable resources are needed. We conclude that although NLP can be used for PRO extraction from clinical notes in the EHR, working with EHR vendors to facilitate easy to use structured data fields as well as language and literacy appropriate patient-facing interfaces for PRO collection that communicate with the EHR would be preferable. Alternatively, sidecar applications for PRO collection which interface with the EHR, which we are exploring through another AHRQ grant (R01HS025405), are promising, but also very resource intensive.

A ToolKit that incorporates the lessons learned by the RISE PRO Learning Network and the qualitative work done with rheumatology practices will disseminate the findings of this project. The RISE PRO project allowed us to successfully establish a Learning Network that continues to meet and is now run collaboratively with the ACR. This network of practices has established successful workflows for PRO collection and use and has worked with our team to develop a ToolKit that incorporates best practices around RA PROs. The ToolKit contains chapters on 1) how to choose which RA PROs to use in clinical practice; 2) tips for using PROs to succeed in federal quality reporting programs like MIPS; 3) how to develop efficient workflows for collecting RA measures (e.g., building a team, PRO collection for in-person vs. telehealth, EHR customization, use of apps and other technologies); 4) considerations for PRO collection in diverse populations, including non-English speaking populations; 5) case studies of high-performing practices; 6) using the RISE registry to benchmark performance on PRO quality measures; and 7) a staff training guide about effective collection of PROs in practice. The ToolKit is scheduled for publication on the ACR website in 2023.

In summary, the RISE-PRO project has enabled one of the largest systematic PRO collection efforts in the United States. Data from the RISE registry has allowed us to demonstrate that when RA patients are seen by a rheumatologist anywhere in the country, a majority are asked to report their functional status and disease activity using standardized PROs. We have learned that rheumatologists have built diverse workflows that are customized to their practice settings, resources, patient-populations and EHR systems to collect these PROs. This project has allowed us to build a Learning Network to advance the use of PROs in rheumatology and to construct an NLP pipeline to extract PROs from the clinical notes in an EHR. Next steps will include dissemination of the RA PRO ToolKit across rheumatology practices, and further enrollment of practices in the RISE Learning Network to implement the ToolKit.

LIST OF PUBLICATIONS RELATED TO PROJECT

1. Katz P, Yazdany J, Trupin L, Rush S, Helmick CG, Murphy LB, Lanata C, Criswell LA, Dall'Era M. Psychometric evaluation of the NIH Patient-Reported Outcomes Measurement Information System (PROMIS®) in a multi-racial, multi-ethnic systemic lupus erythematosus (SLE) cohort. *Arthritis Care Res (Hoboken)*. 2018 Oct 24.
2. Ragouzeos D, Gandrup J, Berrean B, Li J, Murphy M, Trupin L, Yazdany J, Schmajuk G. "Am I OK?" using human centered design to empower rheumatoid arthritis patients through patient reported outcomes. *Patient Educ Couns*. 2019 Mar;102(3):503-510. 2018 Oct 28.
3. Kulhawy-Wibe SC, Zell J, Michaud K, Yazdany J, Davis AM, Ehrlich-Jones L, Thorne JC, Everix D, Cappelli LC, Suter LG, Limanni A, Barber CEH. A Systematic Review and Appraisal of the Cross-Cultural Validity of Functional Status Assessments Measures in Rheumatoid Arthritis. *Arthritis Care Res (Hoboken)*. 2019 Apr 12.
4. Norgeot B, Glicksberg BS, Trupin L, Lituiev D, Gianfrancesco M, Oskotsky B, Schmajuk G, Yazdany J, Butte AJ. Assessment of a Deep Learning Model Based on Electronic Health Record Data to Forecast Clinical Outcomes in Patients With Rheumatoid Arthritis. *JAMA Netw Open*. 2019 Mar 1;2(3):e190606.
5. Gandrup J, Yazdany J. Using Health Information Technology to Support Use of Patient-Reported Outcomes in Rheumatology. *Rheum Dis Clin North Am*. 2019 May;45(2):257-273.
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7. Barber CEH, Zell J, Yazdany J, et al. 2019 American College of Rheumatology Recommended Patient-Reported Functional Status Assessment Measures in Rheumatoid Arthritis. *Arthritis Care Res (Hoboken)*. 2019;71(12):1531–1539. PMID 31709771
8. Izadi Z, Schmajuk G, Gianfrancesco M, Subash M, Evans M, Trupin L, Yazdany J. Rheumatology Informatics System for Effectiveness (RISE) Practices See Significant Gains in Rheumatoid Arthritis Quality Measures. *Arthritis Care Res (Hoboken)*. 2020 Sep 16. PMID: 32937026
9. Katz P, Pedro S, Alemao E, Yazdany J, Dall'Era M, Trupin L, Rush S, Michaud K. Estimates of Responsiveness, Minimally Important Differences, and Patient Acceptable Symptom State in Five Patient-Reported Outcomes Measurement Information System Short Forms in Systemic Lupus Erythematosus. *ACR Open Rheumatol*. 2020;2(1):53–60. PMID 31943975
10. Norgeot B, Muenzen K, Peterson TA, Fan X, Glicksberg BS, Schenk G, Rutenberg E, Oskotsky B, Sirota M, Yazdany J, Schmajuk G, Ludwig D, Goldstein T, Butte AJ. Protected Health Information filter (Philter): accurately and securely de-identifying free-text clinical notes. *NPJ Digit Med*. 2020 Apr 14;3:57. PMID: 32337372
11. Liu LH, Garrett SB, Li J, Ragouzeos D, Berrean B, Dohan D, Katz PP, Barton JL, Yazdany J, Schmajuk G. Patient and clinician perspectives on a patient-facing dashboard that visualizes patient reported outcomes in rheumatoid arthritis. *Health Expect*. 2020 Apr 9. PMID: 32270591

12. Aguirre A, Trupin L, Margaretten M, Goglin S, Noh JH, Yazdany J. Using process improvement and systems redesign to improve rheumatology care quality in a safety net clinic. *J Rheumatol*. 2020 Feb 15;jrheum.190472. PMID: 32062597
13. Katz P, Dall'Era M, Trupin L, Rush S, Murphy LB, Lanata C, Criswell LA, Yazdany J. The impact of limited health literacy on patient-reported outcomes in systemic lupus erythematosus. *Arthritis Care Res (Hoboken)*. 2020 Aug 2. PMID: 32741118
14. Subash M, Liu LH, DeQuattro K, Choden S, Jacobsohn L, Katz P, Bajaj P, Barton JL, Bartels C, Bermas B, Danila MI, Downey C, Ferguson S, Reiter K, Wahl E, Weinstein E, Zell J, Schmajuk G, Yazdany J. The Development of the Rheumatology Informatics System for Effectiveness Learning Collaborative for Improving Patient-Reported Outcome Collection and Patient-Centered Communication in Adult Rheumatology. *ACR Open Rheumatol*. 2021 Jul 20. PMID: 34288595.
15. Hammam N, Izadi Z, Li J, Evans M, Kay J, Shiboski S, Schmajuk G, Yazdany J. The Relationship Between Electronic Health Record System and Performance on Quality Measures in the American College of Rheumatology's Rheumatology Informatics System for Effectiveness (RISE) Registry: Observational Study. *JMIR Med Inform*. 2021 Nov 12;9(11):e31186. PMID: 34766910; PMCID: PMC8727049.
16. Humbert-Droz M, Izadi Z, Schmajuk G, Gianfrancesco M, Baker MC, Yazdany J, Tamang S. Development of a natural language processing system for extracting rheumatoid arthritis outcomes from clinical notes using the national RISE registry. *Arthritis Care Res (Hoboken)*. 2022 Feb 14. PMID: 35157365

PUBLICLY AVAILABLE GITHUB RESOURCES FOR THIS PROJECT

<https://github.com/BCHSI/philter-ucsf>

<https://github.com/suzytamang/practicalConsiderationsCNLP/wiki/Practical-Considerations-for-Healthcare-Natural-Language-Processing-Systems>