



PEDIATRIC
RHEUMATOLOGY

PR-COIN

CARE & OUTCOMES
IMPROVEMENT
NETWORK

Quality Improvement Collaborative

APPLICATION PACKET





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Anonymous donors
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LETTER OF INTRODUCTION

Dear Colleague,

We are delighted about your interest in becoming a participating center in the Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN). **The overall mission** of PR-COIN is to dramatically improve the outcomes of care for children with rheumatic conditions. PR-COIN partners with rheumatology patients and their parents to achieve inactive disease, improve quality of life and support families in managing their child's condition. Our strategy is to harness the inherent motivation and unique expertise of all stakeholders including patients and caregivers, clinicians, researchers, and community partners, and apply structured quality improvement methods, advanced information technology systems, and sharing of best practices to track and continuously improve health outcomes for children with JIA nationally. The initial focus of PR-COIN is on children with JIA, but in the future we plan to expand to other rheumatic conditions.

We believe PR-COIN will provide great value to your center and patients as current PR-COIN participants have learned important QI skills, their patients have benefitted access to materials co-produced by PR-COIN with parents, and centers have adopted best practices for care delivery through collaboration within PR-COIN.

PR-COIN launched in 2011, using a model developed and refined through the launch of several successful chronic care networks at Cincinnati Children's Hospital. Leveraging a PCORI grant, PR-COIN is enhancing its registry, strengthening its QI training infrastructure and developing a set of tools and strategies to better guide patients, families, clinicians, and researchers to improve care.

How the Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN) works

With guidance from experts in quality improvement and chronic care delivery, participating centers collect and share clinical data, and identify and share best practices across the network. Centers test specific changes in their local care processes to determine how to incorporate improvements into daily practice, which may include redesigning how care is delivered to achieve better outcomes. Each center assembles a local QI team responsible for center improvement activities, data capture, and attendance at PR-COIN learning sessions with other centers. An annual participation fee is paid by each center. The PR-COIN Coordinating Center provides QI training and arrange mentorship for participating centers, conduct semi-annual in-person learning sessions and monthly webinars, and supports a registry that provides data reports to centers to facilitate improved care for patients.

At each participating center, data about patients, disease status, and care provided is captured from every clinical visit. Initially, teams enter data into the PR-COIN registry using web forms. For Epic EHR users, we have developed a Smartform that facilitates a "data-in-once" strategy. The goal is to work with information services at each center and other EHR vendors to capture most clinical data during clinic visits to allow direct upload into the PR-COIN registry. Data from current and previous months are analyzed and summary reports and graphic displays provided back to centers to facilitate and improve the care they provide. Specific reports available to centers include: provider level, center level and network level performance on key clinical process and outcome measures over time, a population management report with patient-level detail regarding patient outcomes and care, a data quality report, and a pre-visit planning report with individual patient data and decision support to help teams prepare for upcoming visits.

Each center can review data reports to identify gaps in care and outcomes and perform Plan-Do-Study-Act cycles to close the gaps while collecting data to determine the effectiveness of changes they make. With this iterative process of continuous quality improvement, changes are made in the way care is delivered at your center, resulting in improvements in the care and outcomes.

PR-COIN already provides group QI training and individualized coaching to support the teams in local QI activities. During monthly webinars and in person bi-annual learning sessions, effective interventions are shared with all participating centers, enabling each center to benefit from the work of others. Centers are both learners and teachers. To facilitate communication among the centers, there is a member only PR-COIN website containing tools and reports that centers can download. In addition, there is a newsletter and social media platform for our network to stay connected.

The goals of the Pediatric Rheumatology Care and Outcomes Improvement Network are to enable providers at each center to:

- Learn and apply principles of the Model for Improvement and the Chronic Care Model to improve care and outcomes for their patients
- Partner with patients and families to co-produce health through better systems of care
- Establish systems for measuring and tracking performance
- Work together to establish best practices
- Collaborate and share tools and materials with other centers that aid improved care delivery
- Design and participate in research
- Receive credit for continuing education at learning sessions and webinars
- Meet requirements for maintenance of certification, Part IV (MOC) by the American Board of Pediatrics

The Pediatric Rheumatology Care and Outcomes Improvement Network agrees to:

- Support the network to achieve these goals
- Organize and present monthly conference calls and semi-annual learning sessions for all of the centers
- Coach centers in applying a systems framework to patient care, including systematically implementing and evaluating changes in care
- Develop and implement a structured QI framework for testing changes in care delivery across all participating centers
- Provide best-practice information on care and tools, forms, and other aids to help with implementation of changes
- Coordinate communication across all centers to provide participants with analyses regarding the effectiveness of changes and work of their colleagues
- Develop measures for tracking network performance and a repository of interventions for application and testing
- Provide secure HIPAA-compliant data management, including electronic data entry, data storage, and data analysis
- Work with centers to develop systems of efficient data capture with the goal to achieve “data-in-once” with automated upload of clinical data into the PR-COIN registry
- Partner with existing networks in pediatric rheumatology to complement their missions, in part by developing efficient capture and sharing of clinical data
- Facilitate comparative effectiveness research across centers and the network
- Work with the care centers to create effective and equitable access to the data to advance knowledge regarding care and outcomes for children with rheumatic disease

Each center agrees to:

- Obtain the support of the administrative leadership at the center for multi-year participation in PR-COIN
- Have a QI team (e.g., a physician, a nurse, and one other staff member for data entry and to oversee improvement), including a physician leader that will organize, lead and advocate for improvement efforts at the center
- Enter relevant clinical data about all JIA patients receiving care at the center into the PR-COIN Registry

- Provide access to local IT support to configure the EHR to support automatic upload of clinical data (Epic users, ~20-40 hrs.)
- Enable team members, including the physician leader, to attend all learning sessions, providing support for their travel and accommodations
- Provide resources and support to the center team, including time to devote to testing and implementing changes
- Perform pre-work activities to prepare for learning sessions
- Link the goals of the Network to the goals of the center
- Implement changes in one or more of the target areas of rheumatology care and perform tests of changes
- Communicate in a timely fashion, including electronically, with the Network organizers
- Participate in conference calls, webinars, and other activities to communicate, share and learn with other centers.
- Make defined measurements at least monthly and share the results with PR-COIN and other participating centers
- Pay an annual participation fee of \$20,000 (if join in FY19 fee is \$10,000 for FY19 and FY20; fee increased to \$20,000 after FY2020)

Partnership with existing networks

Through a PCORI grant, we are presently partnering with the Arthritis Foundation and the Childhood Arthritis and Rheumatology Research Alliance (CARRA) to create a network-based learning health system called PARTNERS Learning Health System (LHS). In a Learning Health System, clinical findings emulate research discoveries, which are then implemented in clinics more quickly and effectively using QI methodology. The PARTNERS LHS has the potential to propel the improvements accomplished by PR-COIN and help grow and sustain the network, while leveraging access to the Arthritis Community and the pediatric research community. This new collaboration will help spread best practices to more patients and implement research more efficiently in clinics.

How Pediatric Rheumatology Care and Outcomes Improvement Network will be funded

A large portion of the network's revenues comes from annual participation fees, which help defray the cost of maintaining the registry and delivering the QI tools and trainings. Other sources of funds include a) foundation and other grants, b) philanthropic support, and c) industry sponsorship.

Projected timeline

- February 2018 – march 2019: New registry built and new initiatives developed (Treat to Target and Self-Management Change Packages created)
- March 2019-onward: Data Entry into registry, QI reports available
- January 17-18, 2019: Kick off Learning Session in Atlanta, GA
- March 2019 onward: Pre-Visit planning and Population Management Reports created

We are thrilled with your interest in joining this exciting collaborative effort that will transform care and improve outcomes for children with rheumatic disease. We look forward to speaking with you soon. In the meantime, please feel free to contact us should you have any questions.

Sincerely,

Esi Morgan, MD, MSCE, C. April Bingham, MD, MS, Beth Gottlieb, MD, MS
 Executive Committee, on behalf of the Pediatric Rheumatology Care and Outcomes Improvement Network
 (<https://PR-COIN.org>)
pr-coin@cchmc.org

APPLICATION CHECKLIST FOR TEAMS

This application packet serves the purpose of enrollment in PR-COIN, and thereby participation in the PARTNERS Learning Health System (LHS). By joining PR-COIN, you agree to implement QI principles at your centers, and work alongside PR-COIN member centers, as well as the Arthritis Foundation and CARRA, to include patients and caregivers in your research and/or quality improvement initiatives, and support the spread of best practices to all patients and families served, and self-management support materials to the community reached by the AF. Please make sure to return the application to the PR-COIN Coordinating Center once this application is fully completed with signatures (pr-coin@cchmc.org). The PR-COIN Coordinating Center is responsible for on-boarding centers into PR-COIN, and introduction to the PARTNERS LHS.

PARTNERS LHS - Quality Improvement Collaborative/PR-COIN:

PARTNERS LHS includes PR-COIN, a network (“collaborative”) of rheumatology care teams that conduct quality improvement projects and share data and best practices to help deliver better clinical care, so as to improve outcomes. PR-COIN (the QI Collaborative) works as a testing ground for research findings, trying to move research findings on new or better treatments more quickly to everyday use.

PR-COIN is directing this project with quality improvement support and project coordination from the James M. Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital Medical Center (CCHMC) in Cincinnati, Ohio, USA.

This application packet is to guide you in understanding our network and to facilitate preliminary activities to become an active PR-COIN team. PLEASE NOTE –an important factor for success is the support of a senior or executive leader in assuring your team has the resources and time to engage in improvement activities and realize the full benefit of PR-COIN membership. **We strongly recommend your site form an improvement team that is representative of your clinic such, with members such as care providers (MD/DO/NPs), nurses, PT/OT, SW, clinic staff, as well as coordinators (consent, data entry), and incorporate parent and/or patient advisors.**

- Please review this packet and the accompanying PR-COIN Charter that describes our Learning Health System with respect to the collaboration between the AF, CARRA and PR-COIN, as well as our goals, benefits, and requirements.

- Submit the following to join PR-COIN:
 - ✓ Intent to Apply Form (page)
 - ✓ Site Application Form (page) within one month of submitting your intent including:
 - Senior Leader Agreement
 - Site Team Information

You will be notified via email of your application status.

Upon approval and admittance to PR-COIN, representatives will support your team in completing these remaining required activities:

- Submission of human subjects’ research protection regulatory documents (hereafter referred to as IRB - . Institutional Review Board) as required by your local hospital or clinic. To support your IRB application, teams will receive PR-COINs IRB protocol templates plus recommended verbiage for parent consent and patient assent forms.

- Submission of two data sharing legal agreements. PR-COIN will use a QI registry hosted at Cincinnati Children’s Hospital to produce its performance reports and QI tools (ex: Pre-Visit Planning and Population Management tools). Accordingly, two legal agreements are required to enable data submission and analysis:

1) The “Participation Data Use Agreement” (PDUA) with CCHMC, permits the transfer of your team data to the PR-COIN registry for analysis.

2) The Business Associate Agreement with CCHMC permits the later to act as a business associate and complete the QI services stated in the PDUA

Data collection cannot begin until both legal agreements and your IRB’s approval are finalized, so start this process early by introducing your legal and IRB experts to PR-COIN Coordinating Center (pr-coin@cchmc.org). The PR-COIN Coordinating Center is responsible for on-boarding centers into PARTNERS LHS.

Note: network and team level performance are depicted graphically and shared within the network. Teams enrolling > 50% of the JA population may publicly display specified performance measures.

Participation Fee:

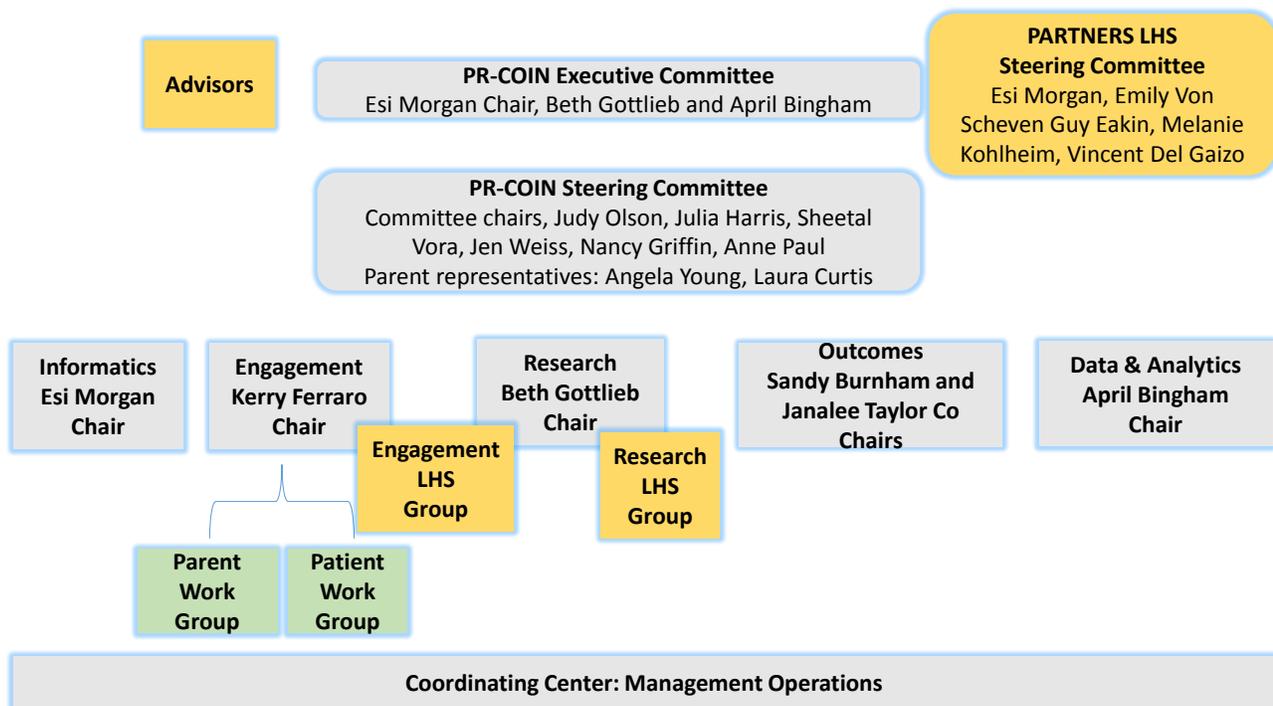
Please be advised that PR-COIN’s annual membership fee is \$10,000 for centers that decide to join any time between now and June 2019. While the membership fee will remain at \$10,000 for the next fiscal year (FY2020) for those FY19 members, it will increase to \$20,000/year for all other centers who commit to join after the 2019 year. Starting in FY21 (July 2020) the annual membership fee will be \$20,000/year for all members, regardless of duration in the network.

Please direct all questions and correspondence to pr-coin@cchmc.org

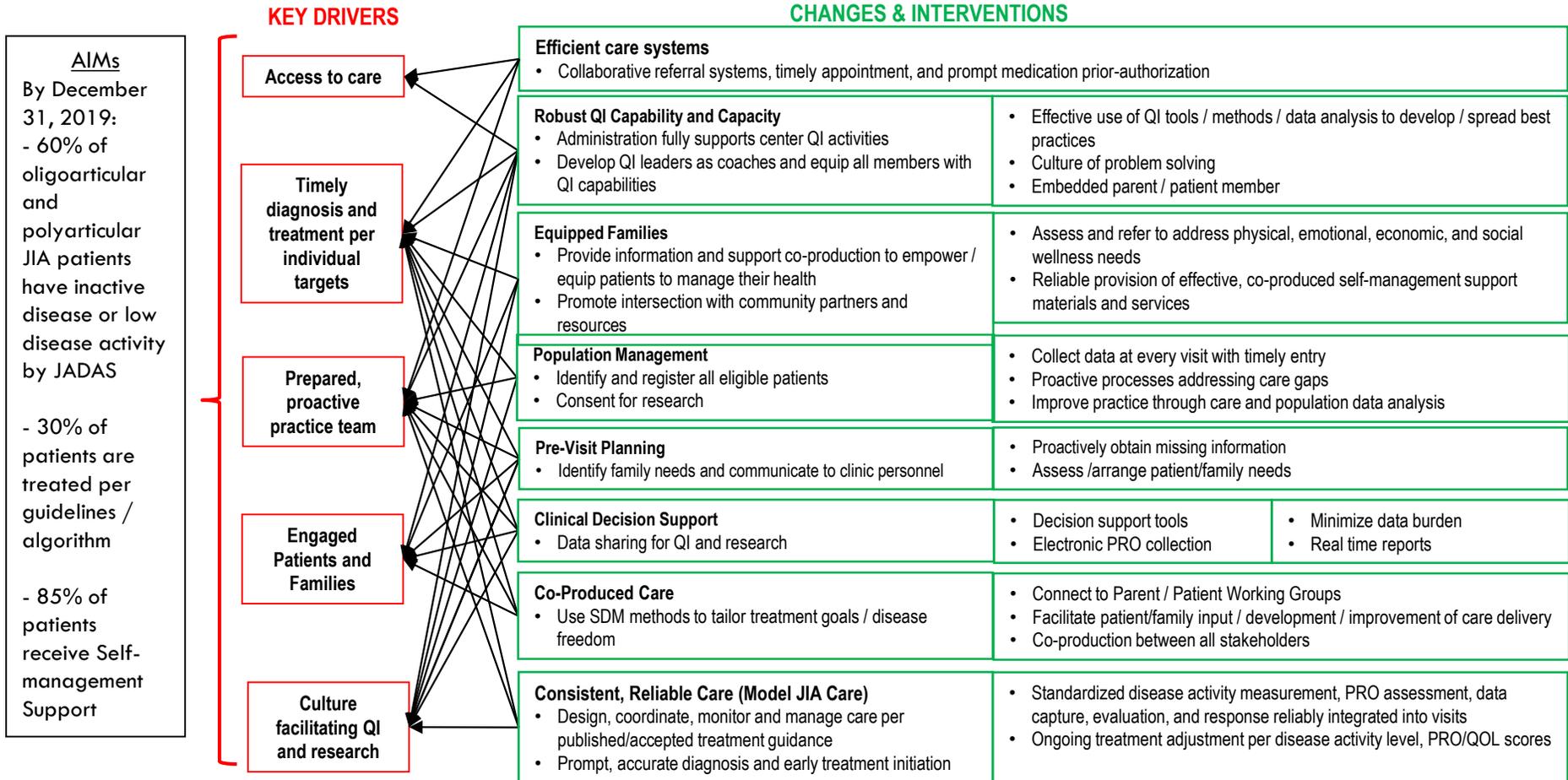
PR-COIN AND PARTNERS LHS LEADERSHIP AND COORDINATION CENTER

PR-COIN’s Organizational Structure is composed of a leadership team which includes an Executive Committee and a larger Steering Committee with broad representation of the network. Committees work in teams to address functional areas within the network, including Data and Registry, Outcomes Improvement, Research, Community Engagement and Informatics. In parallel to the PR-COIN’s structure is a PARTNERS Learning Health System (LHS) Steering Committee that gathers PR-COIN, CARRA and the Arthritis Foundation’s representatives, as well as parent advocates. Engagement LHS and Research LHS committees are launching with the goal to develop synergistic interventions across the three organizations. The PR-COIN Coordinating Center provides management support to both PR-COIN collaborative and the PARTNERS LHS infrastructure.

For more information about our organizational structure, please contact us at pr-coin@cchmc.org; <https://pr-coin.org>; Fax 513-636-0171 Attention: PR-COIN



PR-COIN/PARTNERS LHS KEY DRIVER DIAGRAM



**PEDIATRIC RHEUMATOLOGY
CARE AND OUTCOMES IMPROVEMENT NETWORK
INTENT TO APPLY**

Please complete this brief Intent to Apply Form and email to pr-coin@cchmc.org

Organization Name: _____ **Date:** _____

Lead Physician Name: _____

Title: _____

Address: _____

City: _____ **State:** _____ **Zip/Postal Code:** _____

Phone: _____ **Email:** _____

Key Contact Person (for typical correspondence): _____

Phone: _____ **Email:** _____

IRB Contact: _____

Phone: _____ **Email:** _____

Legal Contact: _____

Phone: _____ **Email:** _____

Hospital QI Director: _____

Phone: _____ **Email:** _____

By submitting this intent to apply, we agree to submit the full application within one month.

PEDIATRIC RHEUMATOLOGY

CARE AND OUTCOMES IMPROVEMENT NETWORK

SITE APPLICATION

Interested sites should please complete the information below and return your completed application to pr-coin@cchmc.org

Site Name: _____

Site Address: _____

Name of person completing this application: _____

Title: _____

Email: _____

Phone number: _____

1. Briefly describe the aspects of your hospital/clinic/organization that relate to care of the child with a rheumatologic condition (clinic size, providers e.g. doctors, physician assistant, nurse practitioners, number of nurses) hospital based or outreach clinics, location (specify; urban, rural, suburban), social worker in clinic.

2. Please estimate the number of children your site sees each year with *newly diagnosed JIA*: _____

3. At routine clinic appointments, are any of the following data collected:
 - a. Pain Scores Yes No
 - b. HRQOL (health related quality of life) Measure Yes No
(Indicate which one) _____
 - c. Physical Function Measure Yes No
(Indicate which one) _____
 - d. Physician Global Assessment of Disease Activity Yes No
 - e. Parent Assessment of Overall Well-being Yes No

4. Does your pediatric rheumatology team utilize an electronic health record (EHR)? Please describe (name/vendor, version, how long have you been using this EHR).

- a. If not currently on an EHR, any plans to adopt an EHR in future? Vendor selected?
 - b. If currently on an EHR, any plans to switch vendors?
5. Does your pediatric rheumatology team utilize a physical therapist and/or occupational therapist as part of your outpatient clinical team on a regular basis? Please describe resources available to you for rehabilitation support.
6. Briefly describe any experience that you or others have in initiating successful improvement activities, participating in a learning network or any experience with measurement of quality outcomes. In what topic area(s)? Do you have quality improvement support within the unit structure or from the hospital? Examples of this support would be: data collection, team facilitation, meeting documentation and planning for improvement activities aimed at helping you accomplish your goals.
7. Briefly describe what your organization wants to accomplish as a participant in PR-COIN:
8. Please add any additional information about your setting that may be relevant to this project.

Site Team

A site core team typically consists of a physician or nurse practitioner lead, a member of the ancillary nursing staff, administrative or clerical staff members, and others as meets your needs. PR-COIN advocates the inclusion of patients / family members interested in improving team processes and outcomes.

Please submit contact information for ALL Team Members

Team Member – Key Contact

The Key Contact serves as a day to day liaison to disseminate information between your team and PR-COIN and coordinate team activities including parent outreach, regular improvement team meetings, managing improvement responsibilities and ensuring reports and/or data are collected and reported. It is best that the Key Contact not be a physician.

Name: _____ Title: _____

Direct Phone: _____ Email: _____

Team Member

Name: _____ Title: _____

Direct Phone: _____ Email: _____

Team Member

Name: _____ Title: _____

Direct Phone: _____ Email: _____

Team Member

Name: _____ Title: _____

Direct Phone: _____ Email: _____

Team Member

Name: _____ Title: _____

Direct Phone: _____ Email: _____

Team Member

Name: _____ Title: _____

Direct Phone: _____ Email: _____

Also be thinking of prospective “Family Team Members” who might participate in team activities!

SENIOR LEADER/ADMINISTRATOR AGREEMENT

The Senior Leadership are persons outside the improvement team with administrative oversight for the clinical area who can materially and politically support the improvement team in this endeavor, including removing barriers to improvement.

Name: _____

Title: _____

Direct Phone: _____ Direct Fax: _____

Email: _____

As Senior Leaders, we understand the project's objectives and expectations, and pledge to support our team in their data collection and improvement work by reducing barriers and providing resources necessary to achieve PR-COIN quality improvement goals and greater integration with the research and patient community. Example activities include team meetings, conduct of Plan-Do-Study-Act tests, data collection and entry, participation in PR-COIN and PARTNERS meetings and conferences. Furthermore I agree our center will remit \$10,000 participation fee annually to join the network before July 2020 (effective FY2019, and FY2020). After that date, I agree to the annual membership fee of \$20,000/year. I understand full payment of the annual participation fee is required to receive full privileges of PR-COIN membership.

Rheumatology Division Senior Leader Signature

Rheumatology Clinic Director/Manager Signature

Rheumatology Nursing Senior Leader Signature

This signature page must be received with your application in order for your application to be considered.
Please email to pr-coin@cchmc.org.