

# Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN) Charter

*Revised November 2016*

## **PR-COIN: A Learning Network to Improve Patient Care in Rheumatology**

The public, medical insurers, and other agencies turn to the American Board of Pediatrics (ABP) to certify whether a pediatrician is equipped to delivery quality care. As part of the “Maintenance of Certification (MOC)” process, pediatric rheumatologists must address an area called “Performance in Practice” by participating in quality improvement (QI) projects to improve patient care. In 2008, the ABP invited pediatric rheumatologists to a multispecialty meeting to encourage development of a collaborative QI network to support the charge to improve care delivery. Thus began development of The Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN). PR-COIN is a QI learning network dedicated to improve the way we deliver care to children with chronic, often complex, medical conditions in rheumatology, with initial focus on improving patient outcomes in juvenile idiopathic arthritis.

## **The Challenge**

PR-COIN initially addresses Juvenile idiopathic arthritis (JIA) and will expand to other rheumatic conditions as these are developed.

JIA encompasses a group of incurable conditions characterized by autoimmune inflammatory arthritis. Impacting about 1 in 1000 children, JIA can cause lasting damage. JIA often persists into adulthood and may result in joint destruction, vision loss due to inflammation in the eye (uveitis), and permanent disability. JIA often requires chronic treatment with immunosuppressive medications including biologic therapeutics.

Despite a number of randomized controlled trials of therapeutics in JIA, until recently, there have not been evidence-based protocols to guide treatment. There is currently substantial variation in many aspects of treatment of patients including: timing of initiation of disease modifying anti-rheumatic drugs (DMARDs), dosing and route of administration (e.g., methotrexate), use of steroids – oral, intravenous or intra-articular, decisions about whether, when and how to discontinue medications once disease is controlled, monitoring for drug safety, and compliance with uveitis screening guidelines [1,2]. Wide differences in treatment approach mean not all patients are achieving the best possible outcomes.

In 2011, the American College of Rheumatology (ACR) published treatment guidelines for JIA, and proposed quality measures of process of care for treatment of JIA were published [3,4]. Additionally, the Childhood Arthritis and Rheumatology Research Alliance (CARRA) endeavors to develop consensus-based treatment plans [1]. These efforts present an opportunity for standardizing treatment, yet adoption of and adherence to available guidelines by physicians and patients is unknown. Frustratingly, there are numerous examples in healthcare of slow adoption of, or failure to routinely follow, published recommendations [5].

Implementing QI initiatives can successfully bridge the gap between treatment guidelines and clinical practice. Currently, information on how care is delivered, i.e., compliance with treatment and process of care guidelines, and the consequences of such care represented by clinical outcomes data are not systematically and routinely collected, measured, or tracked in many pediatric rheumatology centers. Thus, valuable information that could improve the quality of care delivery is not available.



### PR-COIN Learning Network Overview

The Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN) is a “learning network”, a multi-center clinical network that uses data for QI and research. Learning networks involve collaborations among multidisciplinary teams of clinicians and staff, patients and families, and researchers. Networks harness the collective will, intelligence, and experience of patients and practices [6]. Combining learning and data is particularly important because of the small numbers of patients with rheumatic conditions and resource constraints at any one site. By sharing data and aligning practices, such networks: 1) reduce unwanted variations in care delivery by identifying, testing and applying successful approaches; 2) enhance learning about how to effectively scale up improvement, understand what tools work for spread in what settings, and effectively integrate research with improvement; and 3) provide infrastructure for patient-centered outcomes research, especially with respect to understanding the comparative effectiveness of healthcare interventions. Benchmarking becomes possible through analysis of the data submitted by participating practices. Shared information can facilitate quick improvement of the processes in collaborating centers. PR-COIN was formed to fill the role of such a multicenter learning network in pediatric rheumatology.

### An Approach to Improving Care and Outcomes

Strong evidence exists to guide improved chronic illness care. The “Improving Chronic Illness Care Model” [7] is a well-established evidence-based framework that has been widely documented to improve the outcomes across numerous chronic illnesses. The model is designed as a roadmap to improving patient-clinician interaction by identifying processes that produce prepared, proactive practice teams and an informed, activated patient. When implemented, this model results in reliable processes to ensure that guidelines for care are visible and used. Care teams have clearly defined roles; clinical information systems and patient registries support the use of data for pre-visit planning and population management; and patient and family education and self-management are supported.

Improvement in how we deliver care serves the goals of improved patient outcomes as well as efficient and value-based care. The structure of PR-COIN employs proven QI methods, paired with proven interventions described in the Improving Chronic Illness Care framework. Key interventions include auditing performance and outcomes of care in a transparent fashion, use of a population management tool, pre-visit planning, self-management and patient engagement, and treatment guidelines [see Figure, page 9, which shows the PR-COIN Key Driver Diagram]. Fundamental to effective application of these interventions is leveraging a population registry. There are limited resources to serve children with arthritis with a shortage of pediatric rheumatologists who see patients in relatively few centers. Since fairly small numbers of patients are seen at each center, sharing data is important. By systematically recording and tracking how patients are being treated, pooling data, and at the same time studying patient outcomes, pediatric rheumatologists will be able to better understand which treatment approaches are optimal. Ultimately, a single unified comprehensive registry across pediatric networks and hospitals would reduce duplication of work and provide a uniform data collection system. In order to achieve improved processes of care and patient outcomes over time, it is imperative that such registry enables quality improvement initiatives at each practice.

### Support and Benefits for PR-COIN Teams



The PR-COIN is guided by a Steering Committee comprised of rheumatologists and parents, with QI advice and coordination from the James M. Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital Medical Center. In addition to the advantages of participation in a learning network as described, PR-COIN provides to participant teams, aggregate network and team specific monthly data reports, ongoing training in Improvement Science methodology and tools, population management and pre-visit planning tools, sharing of data, documents, clinical tools, processes and best practices between teams, individual coaching for team improvement, plus credit for physicians towards Maintenance of Certification of the American Board of Pediatrics (for eligible physicians).

### **Mission**

The mission of the Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN) is to improve dramatically, the outcomes of care for all children with rheumatic conditions.

PR-COIN is developing into a vibrant, cooperative community of providers, patients and families working towards the shared goal of more children with JIA (and other rheumatic conditions as these are developed) who have inactive disease, who live without chronic pain, and are confident and competent in their self-care.

### **Success Measures**

The ACR sponsored Quality Measures Work Group [4], which included PR-COIN Steering Committee members, recommended process quality measures (i.e., measurement of how processes of care are delivered) to achieve to improve care of children with JIA. These process quality measures were developed based upon surveys (including of rheumatologists, patients, nurses), a literature guided consensus process, and their experience and practice. PR-COIN members selected initial process measures for improvement and additionally identified important clinical outcome measures. These quality measures are listed in the Table (page 6).

As other rheumatic conditions are developed within PR-COIN the Data Subcommittee will develop similar measures for quality care delivery.

### **PR-COIN Interventions**

PR-COIN uses Key Driver Diagrams (see example on page 9) to highlight recommended interventions which PR-COIN teams test to determine their effect on outcomes. Details, results, and data reflecting of teams' interventions are shared during conferences and monthly Action Period Calls, and are posted to the member only website so that all may benefit from one another's experience, tools, documents and learning. Below is an overview of PR-COIN activities and plans.

### **PR-COIN History and Phases**

*Pilot Phase* – Implementing the registry and collecting data

Between July – December 2010, pilot sites created and tested a web-based data capture system, the Rheumatology Clinical Registry of the American College of Rheumatology (RCR) from which monthly aggregate and site specific feedback reports are generated.

*Phase I* – Launch and preliminary activities

In January 2011 twelve teams across North America formally launched PR-COIN to share knowledge gained through regularly scheduled Learning Network activities based upon the Institute for Healthcare



Improvement's Breakthrough Series approach. Early activities established baseline data while teams received training in performance improvement methodology prior to testing change strategies outlined in the Key Driver Diagram at their sites. Team members convened at face-to-face Improvement Learning Sessions to present their work and receive intensive training and coaching from quality improvement coaches and content experts. Between Learning Sessions, teams submit data regarding their performance on a monthly basis along with summaries of changes being tested. All information is posted on a secure, members' only website to promote information exchange across the Learning Network. Teams develop and evaluate process improvements related to the care of children with JIA and determine how best to reliably incorporate these strategies into clinical practice. Aggregate and site specific monthly feedback reports enable teams to assess their progress. Team participation in monthly webinars and conference calls facilitates shared learning on challenges and successes in improving the process and outcome of care delivery.

#### *Phase II – Addition of new teams and maturation of infrastructure*

As new teams join all have full participant status with access to PR-COIN members' only website, data, webinars and conferences plus are oriented to the PR-COIN Learning Network, and receive training in Improvement Science methodology plus guidance with legal and regulatory requirements.

In addition to facilitating team development and achievement of measurable improvement in processes of care, PR-COIN acts to support team participation through innovative information technology resources that reduce data entry burden and enhance data reporting, and aspires to establish research guidelines and implement network wide planned experimentation. Teams can effectively manage and plan care for their patients in the protected registry by accessing PR-COIN's private, secure Population Management Tool, organized by clinical aspects such as functional ability, pain level, diagnosis etc. as well as by measures of quality of care. Clinicians can identify which of their own patients fall below ideal control of disease and symptoms and assess their population as a whole for gaps in care. This allows for targeted interventions to better manage all patients, including those at highest risk.

#### *Phase III – Engagement of Parents in Network and Team Improvement Activities*

Our Key Driver Diagram acknowledges the crucial role families play in clinical outcomes. To this end in the fall of 2013 PR-COIN hired a Parent Engagement Consultant to create and accelerate strategies for participation and engagement of families at both individual member team and PR-COIN network levels. Parent input and integration is accomplished through a variety of mechanisms not limited to: participation and presentations at Learning Sessions and Action Period Calls, a Family Advisory Group (comprised of interested parents and patients), and formal incorporation into PR-COIN's governing Steering Committee. Furthermore the Parent Engagement Consultant acts to support individual teams in establishing mechanisms and processes to incorporate families into local improvement efforts.

#### *Current Phase – Technologic Support and Improved Outcomes*

As PR-COIN continues to accept new member teams, technological support mechanisms become an especially valuable benefit. PR-COIN launched a web-based Pre-Visit Planning Report that compiles database elements into a printable report teams can easily review, print or share with teammates so all are aware of care gaps and opportunities to provide evidence based care.



Other advances in informatics include creation of a SmartForm for JIA and Consent Management system. Applicable initially to EPIC users, this SmartForm allows uniform storage and eventual transmission of PR-COIN registry data. Teams using Epic individually program their SmartForm data to be electronically transmitted to PR-COIN for registry use, omitting data entry to the registry.

Data from member site patients with JIA may be entered into the registry. The most frequent use of registry data is for QI purposes via the Population Management Tool, Pre-Visit Planning Report, and monthly performance reports. However when PR-COIN registry data is provided for approved research purposes, patient consent is required. The Consent Management System assures researchers only receive data from consented patients.

PR-COIN focuses efforts on increasing remission from Clinic Active Disease and physical function, plus reducing pain levels. We work to standardize scoring of Provider Global Assessment and initiate more meaningful measures of disease level.

#### *Future Phases*

PR-COIN further matures into a sustainable network supporting more teams to continually improve and innovate how health care is delivered to member rheumatology patients. An expanding focus will be remediation strategies for patients experiencing unsatisfactory levels of pain, physical disability, and quality of life; and towards reducing barriers to patients accessing care. PR-COIN efforts are expected to increase the value of health care delivered through spreading efficient delivery of care and improved outcomes, to enable comparative studies of clinical effectiveness, and eventually facilitate validation of new guidelines for treatment of JIA and other rheumatic conditions.

PR-COIN is exploring the potential for adding Lupus as a condition linked to PR-COINs Collaborative Learning Network model of care.

#### **Learning Network Expectations**

Form a site PR-COIN Improvement Team to test and implement improvement strategies and tools, participate in monthly Action Period Webinars and conferences, and submit data. Team members might include rheumatologists, nurses, clinic staff, research coordinator, and other disciplines involved in your care processes.

#### *Participating organizations and teams:*

- Secure senior leader support for the improvement team's work in the Learning Network
- Provide financial, staff and other resources in support of the practice team (including member fees, support to attend Learning Sessions, time for data entry and devoted to testing and implementing changes in the center, and active senior leadership involvement)
- Support the physician champion to be an active participant
- Send a representative team to Learning Sessions, preferably including the physician champion
- Use the Learning Network population registry to systematically enter data on patients with JIA (and other rheumatic conditions as these are developed)
- Set 90 Day Goals, perform tests of change that lead to improvements in outcomes, and share findings with PR-COIN



- Participate in all activities including orientation, Learning Sessions, Action Period calls and the listserv to share with and learn from others
- Obtain human subjects research regulatory approval (e.g., IRB, REB, etc.), consent patients
- Gain institutional agreement for the legal documents required for participation
- Submit Monthly Team Progress Reports

*The PR-COIN Learning Network Coordinating Team:*

- Provide evidence-based information on JIA (and other rheumatic conditions as these are developed) and the Quality Measures Work Group identified quality measures
- Provide training in Improvement Science methods, tools and approaches, including applying the Model for Improvement, and offer coaching to PR-COIN member teams
- Support information sharing structures such as Learning Sessions, monthly webinars, the website and community message board.
- Provide aggregate and team specific monthly feedback reports based upon data submitted by each site
- Maintain secure member only website for posting of teams' charts, monthly reports, aggregate information, and tools, plus references, presentations and training materials
- Offer Maintenance of Certification credit for the American Board of Pediatrics to eligible Rheumatologists



## References

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Table. PR-COIN Quality Measures of Clinical Outcomes and Processes of Care for Patients with JIA.  
 Data is collected on the Quality Measures and performance is displayed in monthly QI reports (run charts)

<p><u>Clinical Outcomes Measures</u></p>	<ul style="list-style-type: none"> <li>• Proportion of patients with clinical inactive disease</li> <li>• Proportion of patients with clinical inactive disease on medications</li> <li>• Proportion of patients with clinical inactive disease not on medications</li> <li>• Proportion of patients with optimal physical functioning</li> <li>• Proportion of patients with pain score &lt;3</li> </ul>
<p><u>Process Improvement Measures</u></p>	<ul style="list-style-type: none"> <li>• Proportion of patient visits where arthritis related pain was measured</li> <li>• Proportion of patient visits where physician's global assessment was performed</li> <li>• Proportion of patients who had visits in the month with completed joint count in past 180 days</li> <li>• Proportion of patients with visits in the month who had functional ability measured in the last 180 days</li> <li>• Proportion of patients with visits in the month who had HRQOL measured in the last 180 days</li> <li>• Proportion patients who had visits in the month who received uveitis (slit lamp eye exam) screen per Heiligenhaus Guidelines</li> <li>• Percent of patients newly prescribed DMARDS who had baseline toxicity labs documented</li> <li>• Proportion of patients newly prescribed DMARDS who had medication counseling</li> </ul>





# Pediatric Rheumatology – Care and Outcomes Improvement Network Inactive Disease Key Driver Diagram

Outcomes ←

Key Drivers ←

Change Concepts and Interventions

**Global AIM:**  
The PR-COIN Collaborative will build a sustainable network to improve the outcomes of care for children with juvenile idiopathic arthritis (JIA)

**Project AIM:**  
By June 30, 2015 PR-COIN patients with clinical inactive disease will increase from 34% to 36%

**Recognition of Active Disease**

**Active Joint Control**

**Evidence Based Management**

**Prepared, Proactive Practice Team**

**Informed, Activated and Engaged Patients and Families**

**POPULATION MANAGEMENT (PM)**

- Identify patients at risk for uveitis, active joints, morning stiffness, and abnormal lab values (Population Management Report)

**CONSISTENT, RELIABLE CARE**

- At each visit perform disease activity monitoring according to ACR JIA Quality Measures e.g. Physician Global Assessment, Patient Reported Outcomes (pain, stiffness, functional ability)
- Monitor for treatment complications (labs, uveitis and TB screening)
- Vigilant management per ACR and CARRA treatment guidelines

**PRE-VISIT PLANNING (PVP)**

- See PVP KDD interventions

**SELF-MANAGEMENT SUPPORT**

- Address Self Management (SM) per team and patient roles and responsibilities
- Collaboratively set patient goals, priorities, preferences, and treatment plans (Shared Decision Making)
- Teams confirm patient understanding and competency (e.g. teach back)
- Between and at each visit, monitor, document and discuss progress toward SM goals with patient
- Families comply with medications, screenings, lab tests, activity per Self Management (SM) plan

