Leading Quality Improvements in Pediatric Rheumatology Care

A Learning Network Approach
Overview of PR-COIN and Learning Networks
Are all children with JIA receiving the best care possible according to recommended guidelines?

Are pediatric rheumatologists working in systems that allow us to do the best by our patients?

Are patients and families getting all the information they need to understand JIA, make decisions about treatments, and effectively care for their child at home?
PR-COIN Wants to Improve Care

International, quality improvement Learning Network working to improve care for children with Juvenile Idiopathic Arthritis

- Launched in 2011 as sustainable collaborative of pediatric rheumatologists with focus on quality improvement initiatives
- 13 Sites - 1 Canada, 10 in US, and growing
- Over 1,300 unique patients registered in database and growing monthly

As of May 2014
Value of a Learning Network

**Healthcare Improvement Needs a QI System**

- In current U.S healthcare system, patients often receive less than half of clinically indicated standard of care (IoM Report).
  

- Improvement research requires a large base of data and instances to test improvement tools.

- Limitations - small numbers of pediatric patients at each clinic site.

**Learning Networks Movement**

- Multi-site, practice-based clinical networks.

- Combine engaged patients and families, multidisciplinary clinicians and staff, researchers and communities.

- By combining patients and practices across a Learning Network, improvement is enhanced and accelerated.*

- Provides foundation for QI research, testing and implementation.

**Learning Network Acclaim**

- American Board of Pediatrics
- Agency Healthcare Research and Quality
- Patient-Centered Outcomes Research Institute (PCORI)

- Acclaimed for engaging patients and clinicians to improve health outcomes.

- PR-COIN is 1 of 5 Learning Networks coordinated by the Anderson Center of Health Systems Excellence at Cincinnati Children’s Hospital Medical Center.

* ![Image](http://www.cincinnatichildrens.org/service/j/anderson-center/learning-networks/default/)
**Need for JIA Learning Network**

**JIA:**
- Chronic childhood painful, inflammatory joint condition
- Affects 1:1000 children
- Can lead to long term disability, pain and reduced quality of life
- Associated eye inflammation (uveitis) can cause vision loss
- Early diagnosis and proper treatment improves long term outcomes

**Challenge: Variation**
- **Variation** exists in treatment patterns by provider, medical center and location
- **Challenge:** Patients are not reaching optimal outcomes (inactive disease, low pain score)

**Opportunity: PR-COIN**
- Network of experts
- Developed tools and successful processes
- Learning from peers and share best practices
- Maintenance of Certification

**Outcomes:**
- Improve care
- Increase family engagement in process
Learning Networks are Successful – ImproveCareNow example
Learning Network Success in Other Chronic Diseases

Purpose: To build a sustainable collaborative network where all pediatric gastroenterologists can work together in a compelling process of continuous quality improvement, innovation and discovery that will over the next decade dramatically reduce the morbidity and improve the health and well being of children and adolescents with Inflammatory Bowel Disease.

Figure 1

Percent of IBD Patients in Remission

Remission rate: 60% to 77%

66 Care Sites
>500 physicians
>15,000 patients
Standardized care
PR-COIN Structure, Approach and Achievements
Process Improvements and Goals

PR COIN is seeking to improve clinical processes in the delivery of care in order to improve safe use of therapeutics and Best Practice Care.
PR COIN Approach for Transforming Care Delivery in JIA Population

- Performance tracking of team and network outcome and process measures
- Proven QI methodology
- Growing data repository
- 10 sites submitting data into Registry
- 1,253 unique patients in database as of March 2014

IHI Breakthrough Series Model
- Share best practices to reduce cost & time
- QI tools to test small changes to improve clinic processes

Shared Tools
- Shared Decision Making
- Population Management
- Pre-Visit Planning

Improved Care, Processes and Outcomes

Improved Care, Processes and Outcomes
PR-COIN Achievements: Examples of Statistically Significant Progress

Percent of patients in remission on medications for at least 6 months

Percent of patients on DMARDs who had medication counseling within the last 12 months
Parent Engagement

- PR-COIN has developed a strong Parent Working Group composed of 8 active families receiving care at PR-COIN centers

- The role of the Parent Working Group is to raise awareness about PR-COIN, advise and participate in QI activities, and collaborate with local care teams by sharing insight about patient and family needs
PR-COIN and partners were recently awarded the $1M PCORnet grant funded by PCORI (partners include the Arthritis Foundation, CARRA, Friends of CARRA and the Lupus Foundation).
Membership Benefits and Participation Expectations
Membership Benefits

- Maintenance of Certification credit (upon meeting requirements)
- Monthly team and aggregate data reports
- Access to PR-COIN aggregate data for approved research projects (teams have access to their specific data)
- Training in Quality Improvement methods and tools
- Quality Improvement consultation
- Participation in twice yearly Learning Sessions and monthly webinars
- Support with IRB and legal processes
- Access to Member Only websites including use of the Population Management Tool
- PR-COIN materials, documents, presentations, and tools
- Citation on public website
- Web-based data submission
Benefits at Every Institutional Level

Benefits to Pediatrics Department
- Exemplar for other divisional QI efforts
  - Join a growing international network of recognized institutions
  - Receive QI initiative support aligned with organizational priorities

Benefits to Rheumatology Division
- Become a leader in improving health care
- Increase visibility and branding potential as members of international collaborative for outcomes excellence

Benefits to Our Entire Organization
- Improve patient outcomes and engagement
- Access to QI tools and broad network of peers
- Maintenance of Certification Part IV
- Learn best practices
- Exemplar for other divisional QI efforts
- Join a growing international network of recognized institutions
- Receive QI initiative support aligned with organizational priorities
Participation Expectations

- Attendance at two Learning Sessions/year
- Consenting patients, and timely collection and submission of process and outcome data via secure website
- Engagement in improvement coaching through conference calls, webinars and listserv
- Application of relevant materials and tools supporting improved clinic processes and care
- Active conduct of local improvement activities focused on care delivery
- IRB approval and execution of two data sharing agreements
PR COIN Participation Costs

Team Responsibilities

- Annual site participation fee fiscal year (July – June)
- Resources managing data entry and human subjects requirements (IRB, patient consent and legal agreements)
- Travel and lodging at two Learning Sessions per year

Cost relative to Actual Operations

- The average annual cost for running Learning Network is $325,000*
- Fee is small compared to membership in similar successful Learning Networks (ImproveCareNow, and IHI Impact Collaborative)

* includes: Data management and statistical analysis (electronic data capture and upgrades, quality control, statistician, reporting), electronic population management reports, quality improvement consultant, learning sessions, project management, IT, monthly webinars, public and member only websites, and more
PR-COIN SPONSORS (all)

Cincinnati Children’s
change the outcome®

Learning Networks

CERTs
Centers for Education & Research on Therapeutics

CCRF Place Outcomes Award

American College of Rheumatology
EDUCATION • TREATMENT • RESEARCH

An Anonymous Family Foundation

STUDY ENDORSED BY

Arthritis Foundation
Take Control. We Can Help.™

CARRA

pcori
Patient-Centered Outcomes Research Institute
Find out how your team can improve outcomes for your patients with JIA.

Join PR-COIN today!

Contact PR-COIN coordinating center for further information at pr-coin@cchmc.org