



PEDIATRIC
RHEUMATOLOGY

PR-COIN

CARE & OUTCOMES
IMPROVEMENT
NETWORK

A Learning Network to Deliver High
Quality Health Care and Bring Research
Discoveries to Patients Faster



Mission

The mission of PR-COIN is to build a **thriving and inclusive community** of patients, families, clinical teams and researchers that uses quality improvement science to **identify and close gaps in care** for children with rheumatic diseases and to bring research discovery to patients faster.

Vision

Children with rheumatic diseases will have **excellent health outcomes** under the care of **highly effective** pediatric rheumatology **teams**.

Our Core Values

PR-COIN commits to the following core values on our improvement journey

- Patient Centeredness
- Respect
- Collaboration
- Openness
- Innovation
- Never Give Up

Why what we do is important

There are gaps in quality of care in rheumatology!



Gaps in Systems of Care

- Lack of effective systems to support rheumatology to do the best for their patients
- **Clinics** do not measure how well they perform on recommended care processes
- **Hospital information systems** do not:
 - Enable Population Management to stratify and identify the most vulnerable patients
 - Allow for Pre-Visit Planning to support patient care

Gaps in Process & Outcomes

Juvenile idiopathic arthritis (JIA) patients:

- Not reliably receiving the best care possible according to recommended guidelines
 - <50% with toxicity labs per guidelines
 - No reliable measurement of pain, function, well-being
 - No systematic counseling on medication use
 - Not following treatment algorithms
- Not achieving desired outcomes
 - <50% in remission on medications

Gaps in Self-management Support

Many patients and families do not receive all the information they need to:

- understand their condition
- make decisions about treatments
- effectively care for their child at home
- be partners in shared decision making (SDM) with their doctors and care teams

Gaps in Research into Practice

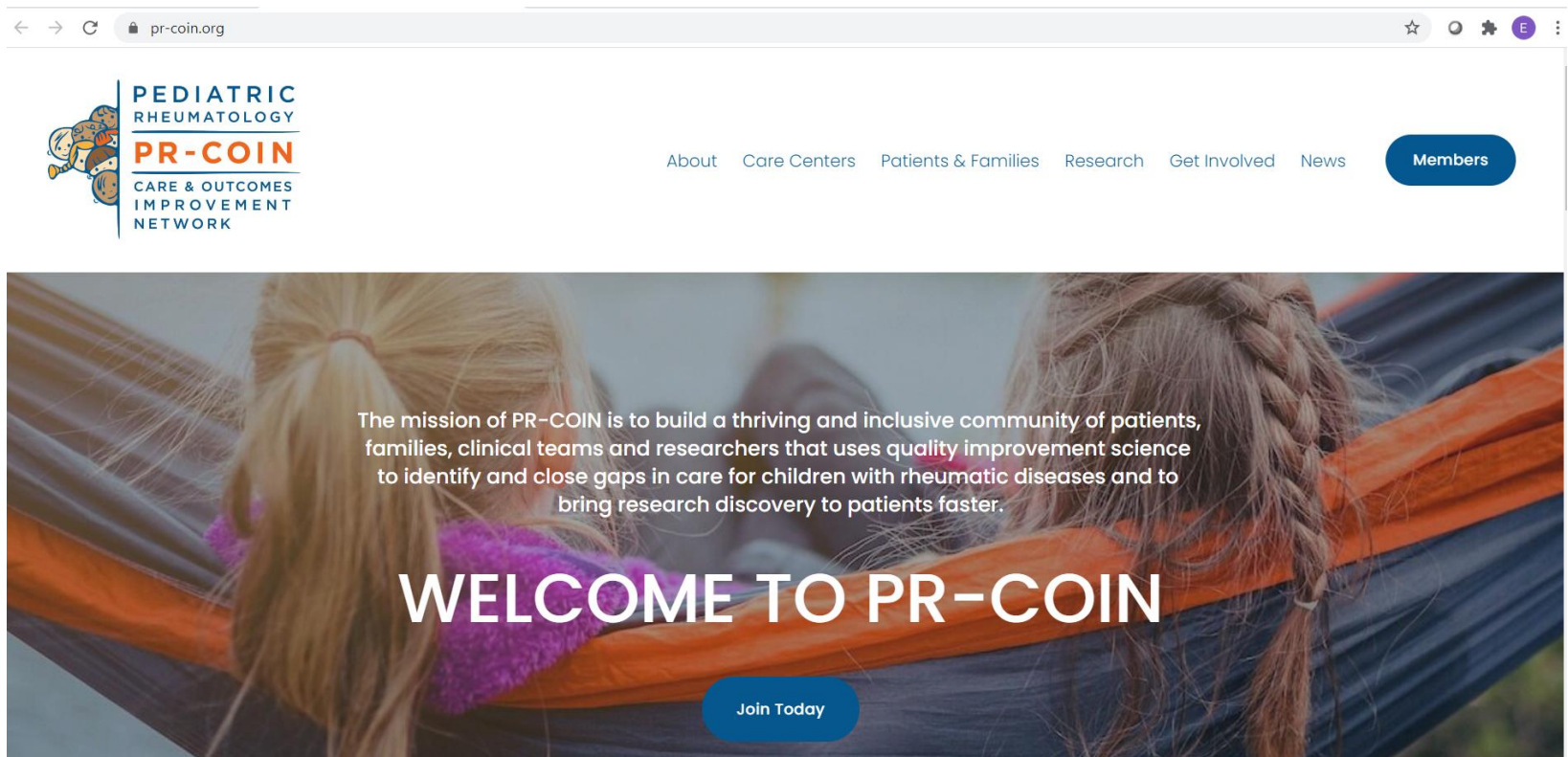
There is up to a 17-year lag for research findings to reliably make it to the bedside.

Doctor must:

- Be aware of study result
- Accept the finding
- Recognize the patient is like those in study
- Remember to share the result with the patient
- Patient must:
 - Agree with recommendation
 - Adhere to the recommendation

Even if all those steps happen, <25% of recommended interventions reach the patient

How we address these gaps

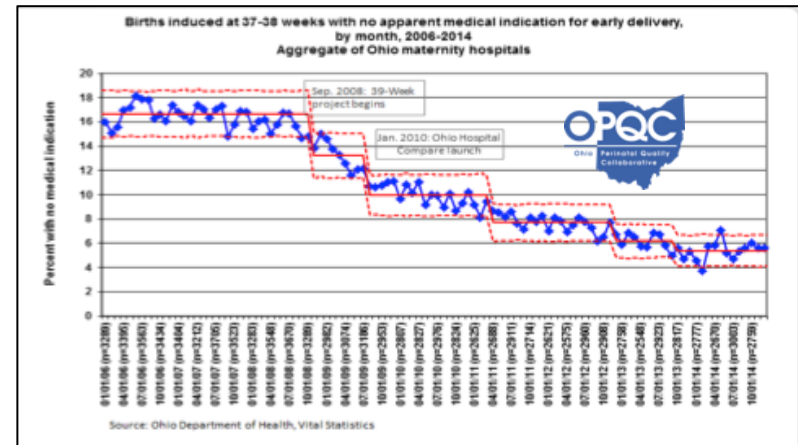
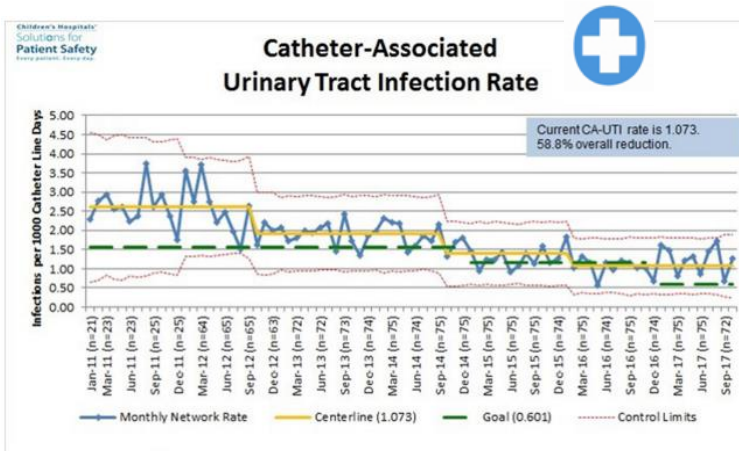
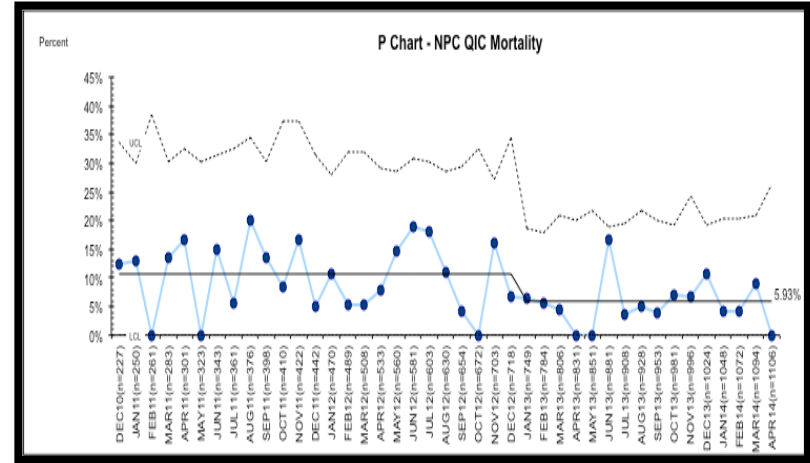
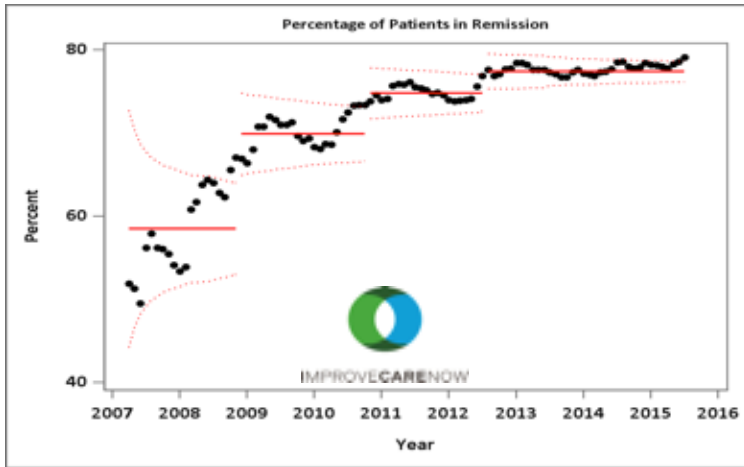


PR-COIN was established in 2011 for the pediatric rheumatology community to collaborate with patients and families on quality improvement initiatives to improve delivery of care and outcomes of JIA treatment

PR-COIN is a Learning Health System



The Power of Learning Health Systems



Learning Health System Approach

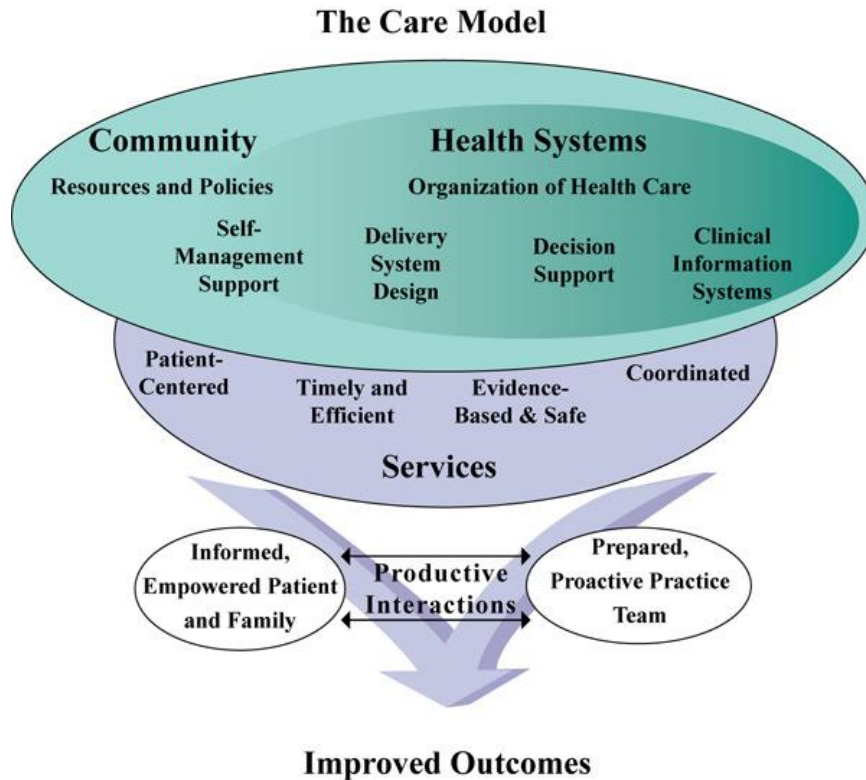
- Collaborate as a peer community to develop successful and novel approaches to improve care
- Use QI methodology & tools to drive improvements
- Use a shared registry of patient data to
 - Measure performance
 - Identify gaps in care
 - Develop focused improvement strategies
- Empower and co-produce with patients and families
- Encourage, enable, and publicize research discovery

Learning Health System Approach

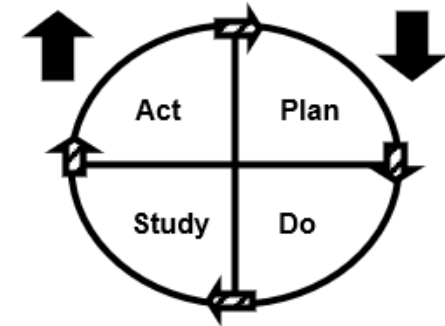
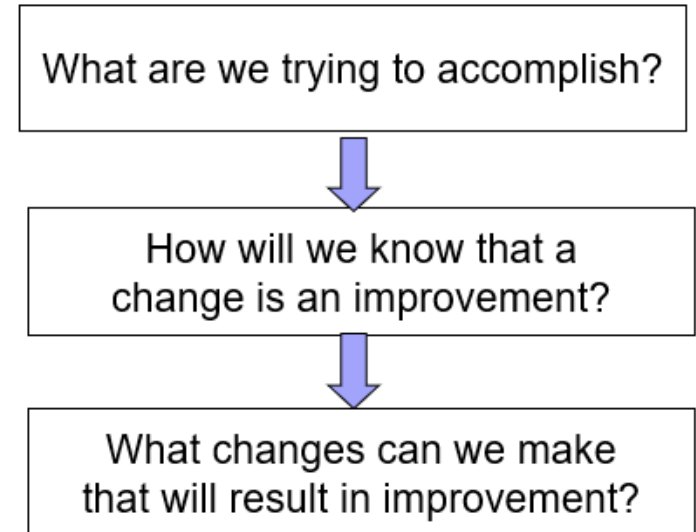
Using the Registry:

- Assess overall performance using quality measures
 - Compared to the overall network
 - Compared to leading centers in the Canada and USA
- Evaluate the impact of improvements at all levels
 - Clinic
 - Providers
 - Patients
- Analyze and learn from a growing database using a shared registry (>5,000 patients and 30,000 office visits)

Using Proven Methodologies



Developed by The MaColl Institute



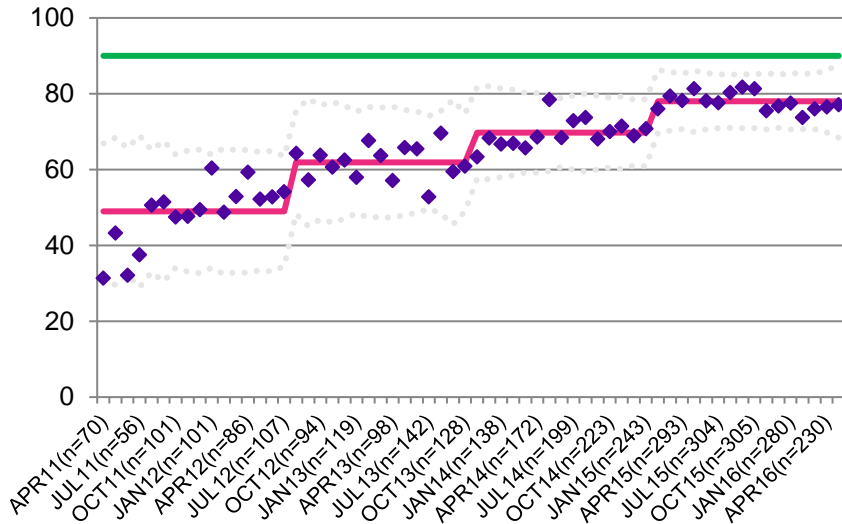
Developed by Associates in Process Improvement and adopted by the Institute for Healthcare Improvement (IHI)

The Chronic Care Model

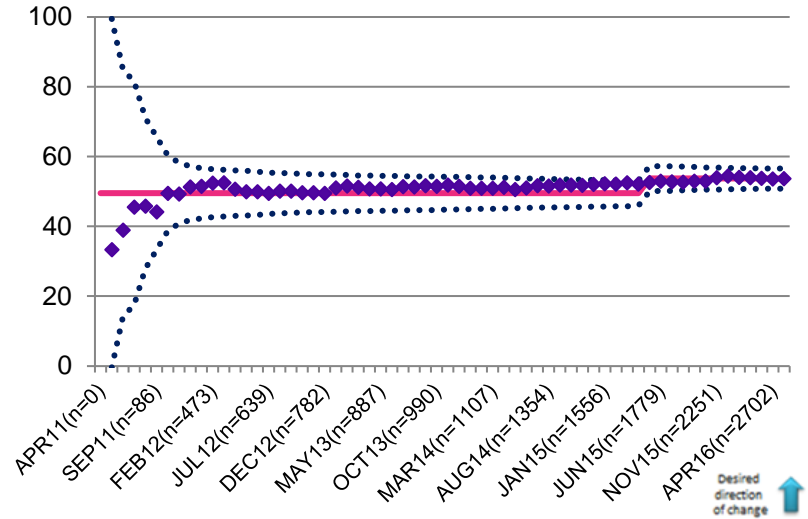
<http://www.improvingchroniccare.org/>

PR-COIN's Improvements

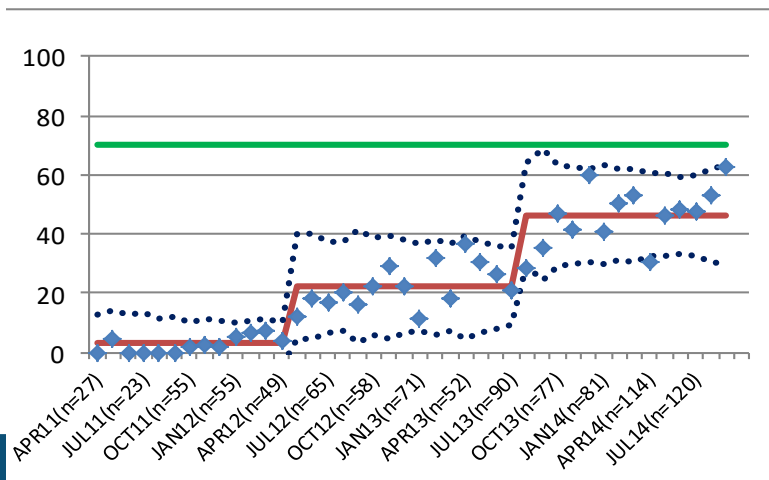
Percent of patients on non-biologic DMARDs who Had visits in the month and had toxicity labs performed



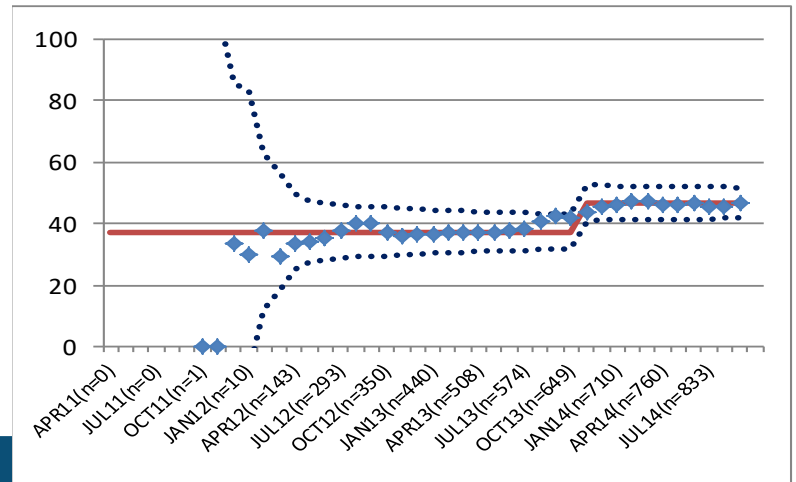
Percent of patients with oligoarthritis or polyarthritis with either inactive or low disease activity by JADAS.



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



Percent of patients in remission on medications for 6 months



Shared Decision Tool to describe disease activity and set treatment target with families

Disease Activity?

This chart will help you describe how you are doing.

Depending on how you are doing today, you can set a target goal in a different category.

You and your provider will discuss together what treatment steps to take to help you reach your target.

Pick another topic

| | | Joints with Active Arthritis | Provider's Score | Patient/Family's Score |
|---------------------------|---|------------------------------|---|---|
| Inactive Disease | In the past week, the patient has had no JIA symptoms | Zero joints | The provider has given the patient an active disease score of 1 or lower | No negative impact currently |
| Low (Mild) Disease | In the past week, the patient has had very few JIA symptoms | Maybe one or more joints | The provider has given the patient an active disease score of more than 1 | Maybe a slight impact on daily life currently |
| Moderate Disease | In the past week, the patient has had a few or more JIA symptoms | One or more joints | The provider has given the patient an active disease score of usually more than 2.5 | Some impact on daily life currently |
| Severe Disease | In the past week, the patient has had quite a bit of JIA symptoms | Typically several joints | The provider has given the patient an active disease score of usually more than 6.5 | Significant impact on daily life currently |

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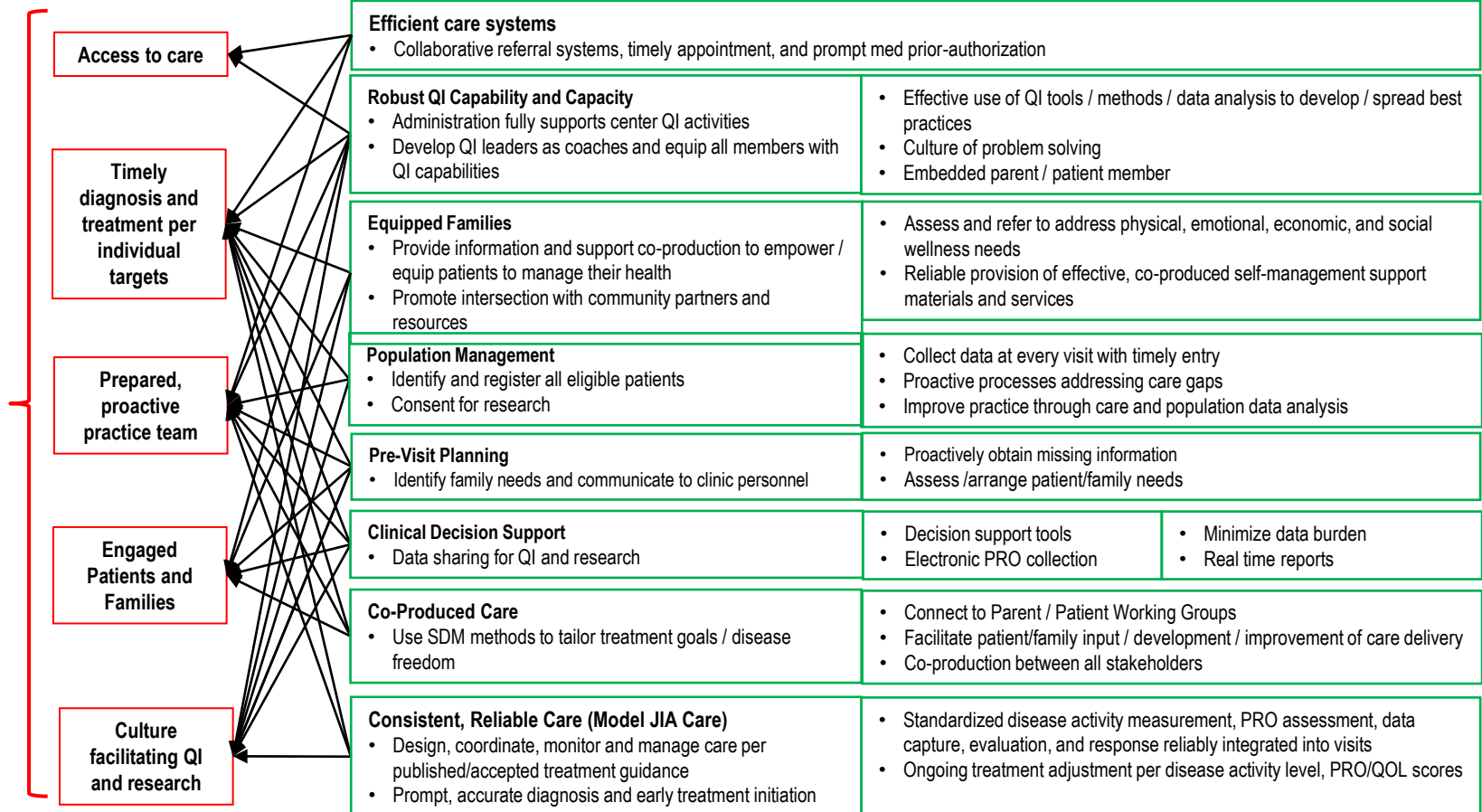
PR-COIN's Key Driver Diagram

Focusing the work

Last updated:
8/2020

KEY DRIVERS

CHANGES and INTERVENTIONS



PR-COIN's Measures

Outcome Measures

- Mean Disease Activity (cJADAS10)
- Inactive or low disease activity by cJADAS10
- Clinical inactive disease (Excludes ESR/CRP)
- Clinical inactive disease (Includes ESR/CRP)
- Mean Joint Count
- % Pt/Parent w/ PGA \leq 2
- Optimal Physical Function
- Mean PGA of Well-Being
- No Pain/Mild Pain
- Pain Interference
- Ever achieve low disease or inactive by 6mo
- Achieve low disease or inactive by 6mo

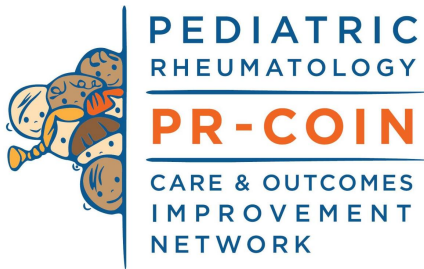
Process Measures

- Treatment Target Set
- Provider attestation of disease activity for T2T
- Self-Management Support given
- Medication Safety Monitored
- Infection (Balancing)
- Use of Care Algorithm/Clinical Decision Support

Data Quality

- Eligible pts enrolled in PR-COIN
- Critical data elements captured
- Active pts with visit recorded in last 13 mo.
- Pts enrolled within 120 days of diagnosis

PR-COIN Infrastructure





Texas Children's Hospital



HEALTH

University of Minnesota
Masonic Children's Hospital



Children's of Alabama

SickKids



PHOENIX CHILDREN'S Hospital



Atrium Health
Levine Children's



THE UNIVERSITY OF MISSISSIPPI
MEDICAL CENTER



PennState Health
Children's Hospital



Hackensack Meridian
Hackensack University
Medical Center

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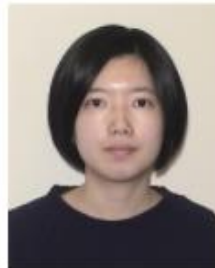
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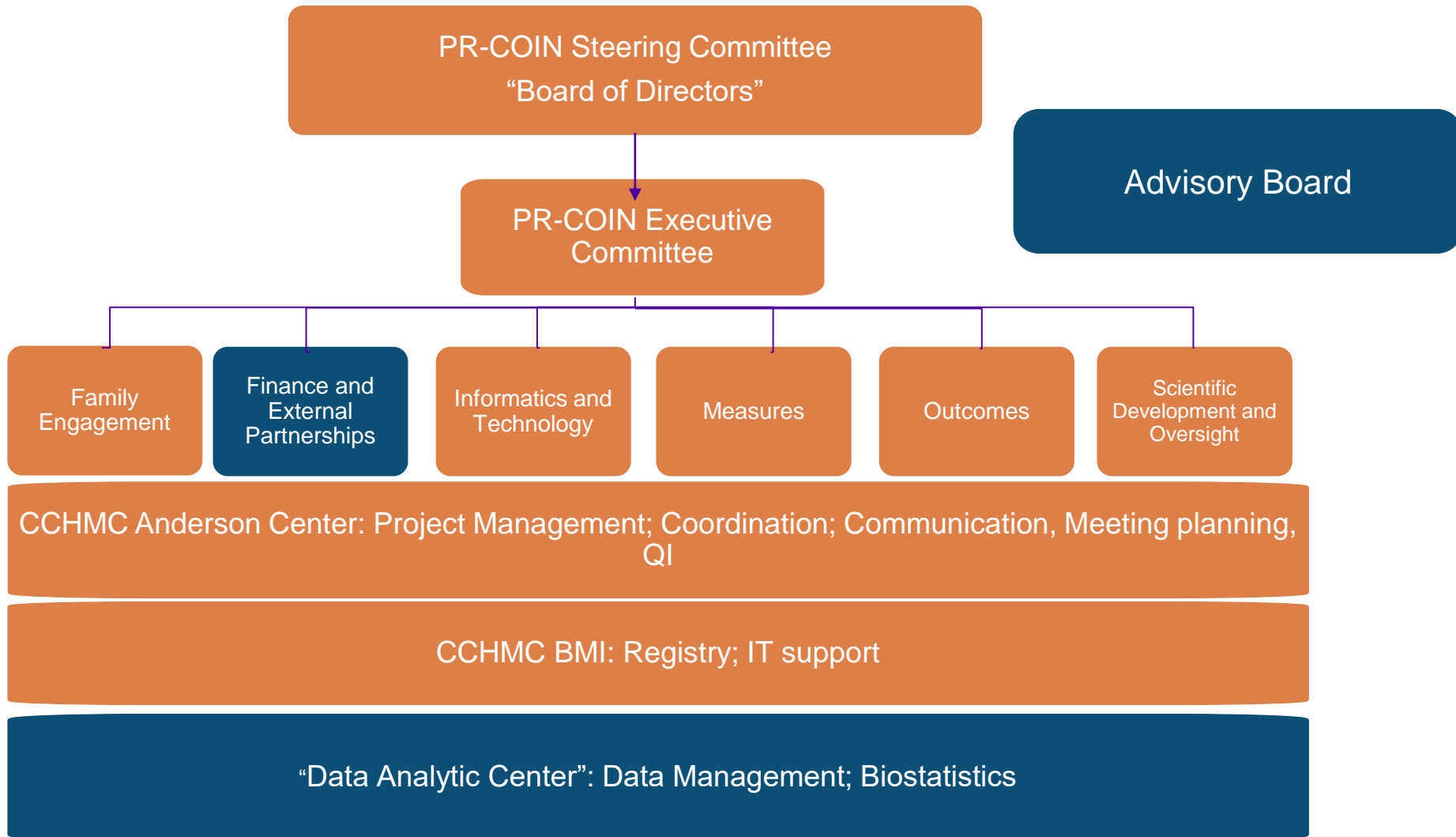


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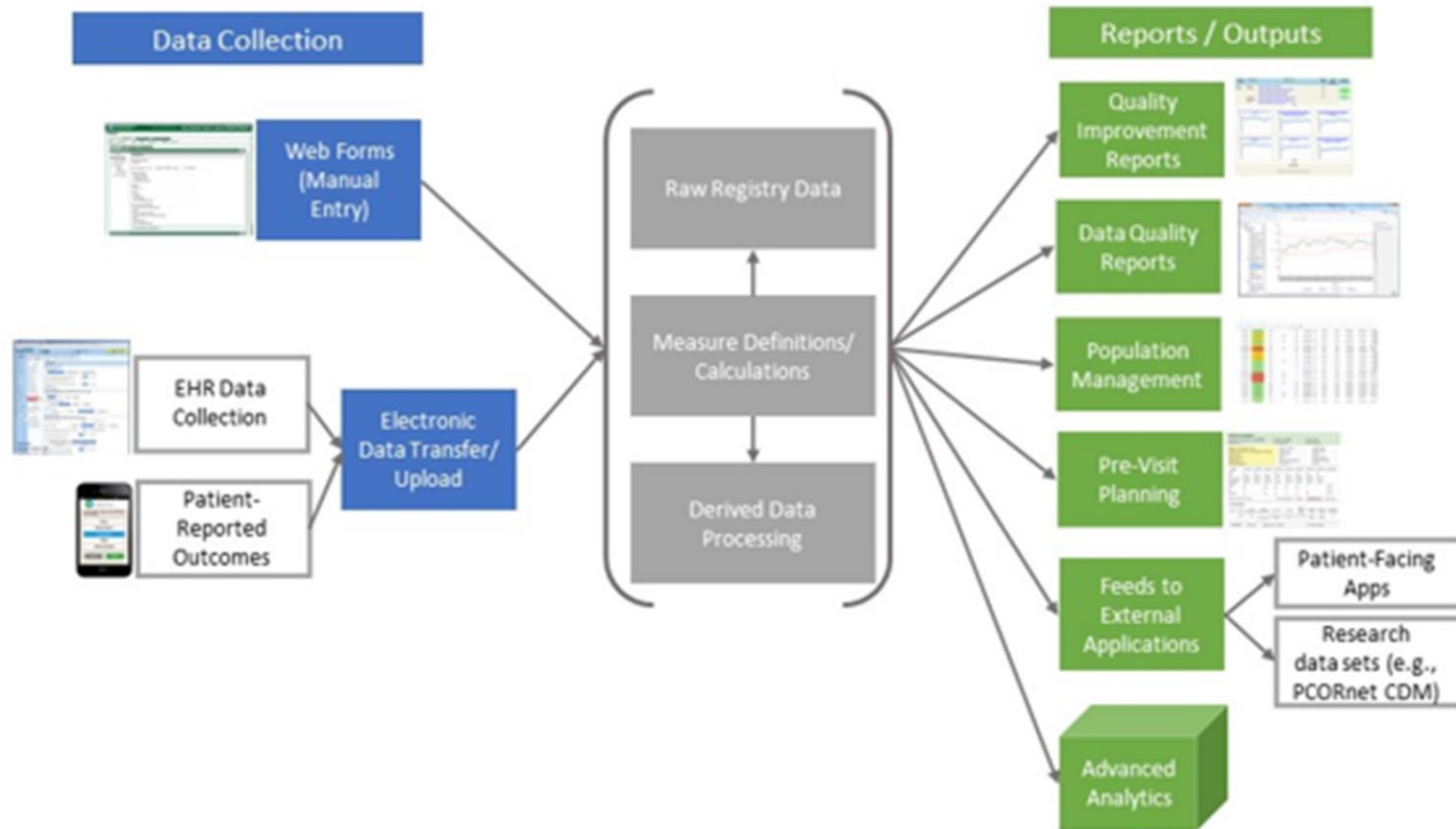
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Data Manager
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PR-COIN Organizational Structure



PR-COINs State of the Art Registry Supports Improvement and Research

PCORI LHS Registry System Diagram

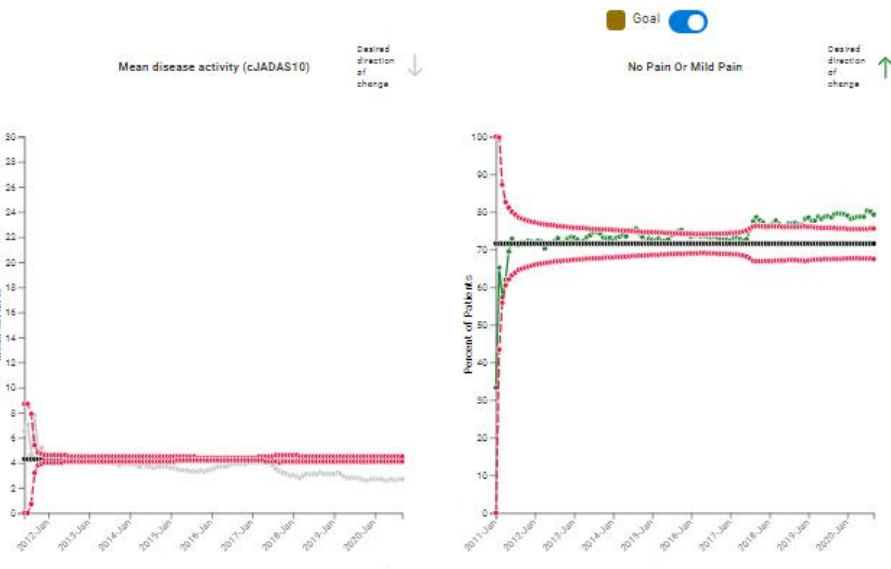
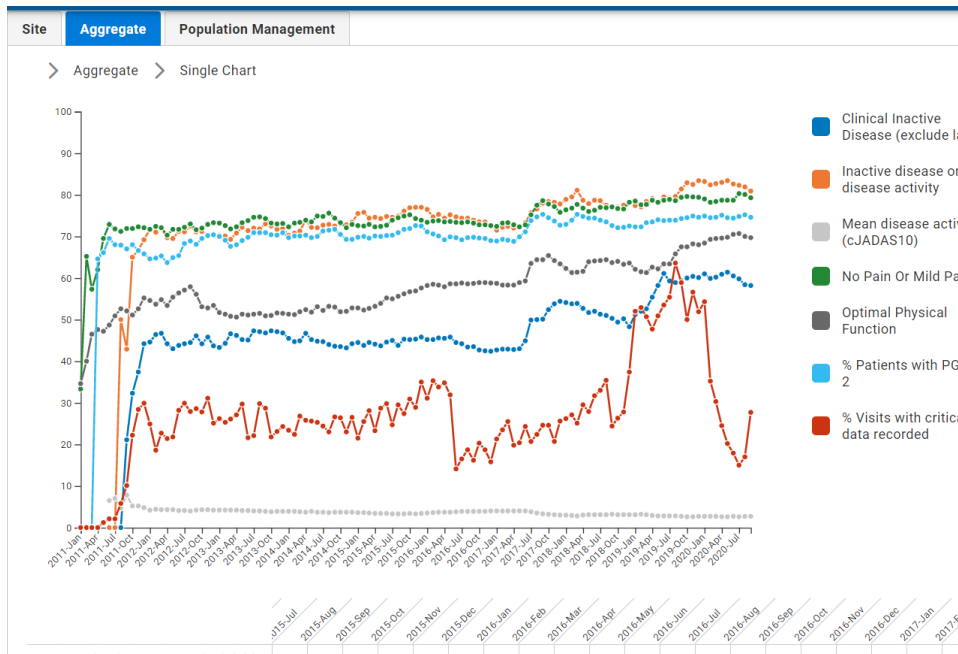


Aggregate and center level quality performance reports

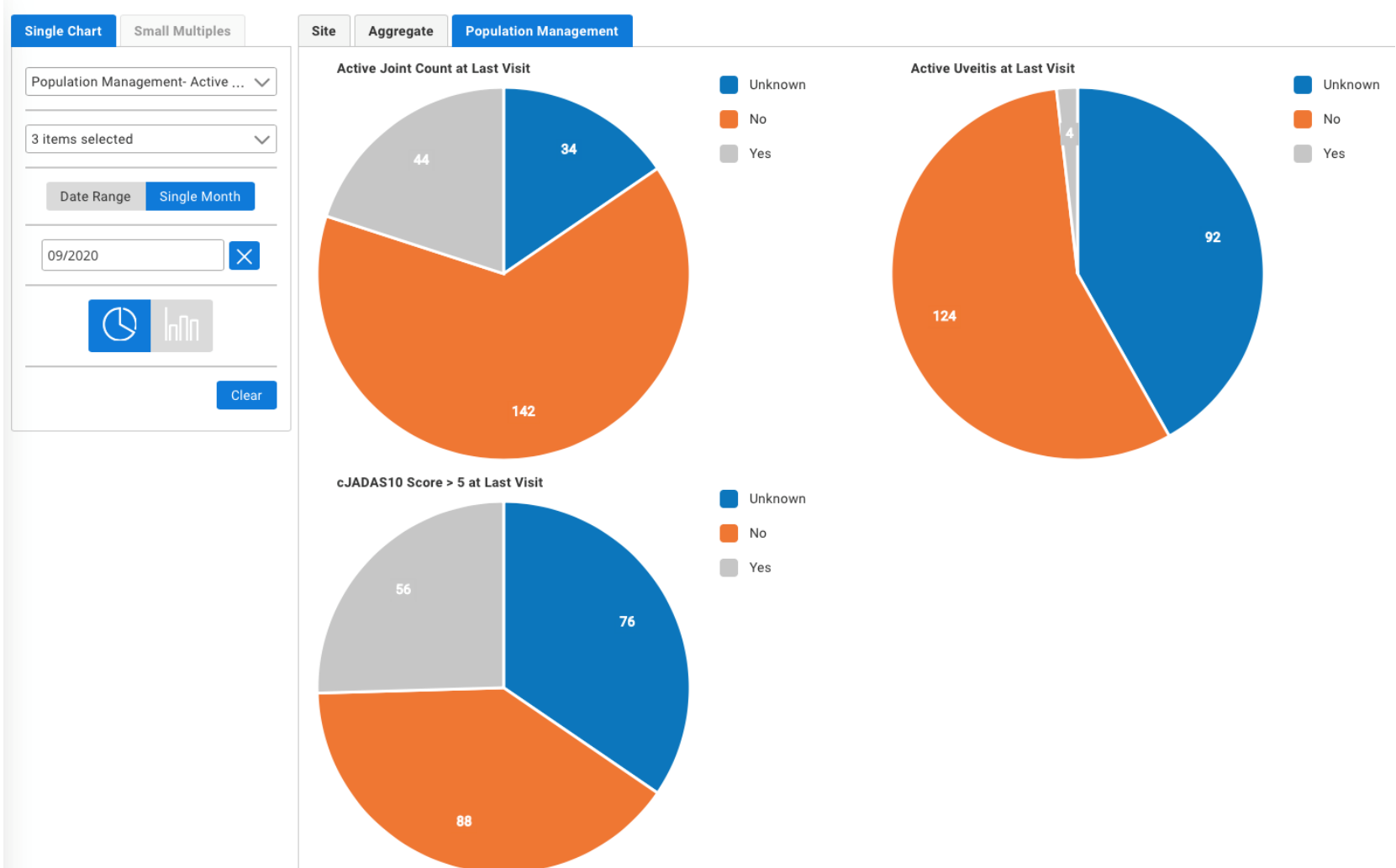
← → ↻ 🔒 pr-coin.lhsregistry.org/reporting/index.xhtml

PR-COIN

Home Single Chart **Small Multiples** Site **Aggregate** Population Management



Population management graphs allow to drill down and identify patients at risk



Electronic Data Transfer (EDT) Considerations

Electronic Data Capture

- PR-COIN registry accepts structured, standard data elements from electronic medical records (EMR) and registries (e.g., REDCap)
- Extracting data for upload from structured data fields in EMRs results in
 - Increased data entry efficiency
 - Less need for research coordinator time
 - Increased data completeness (less 'unknowns')
 - Improved data capture and accuracy at clinic visits

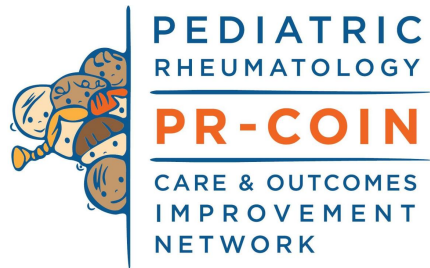
Epic Customer Option for PR-COIN Smartform

- PR-COIN registry accepts structured, standard data elements from Epic electronic medical record
- A JIA Smartform is available in Epic Foundation system
- Use of Smartform allows for “data-in-once”
 - Providers enter data for clinic visit in the EHR system which populates the registry

Epic customers may learn more about the Smartform on UserWeb

- Here's a link to "Research Toolkit: Capturing Clinical Data to Advance Research on Juvenile Idiopathic Arthritis (JIA)" in Galaxy:
<https://galaxy.epic.com/?#Browse/page=1!68!50!100029643>
- Here's a link to "Juvenile Idiopathic Arthritis (JIA) Toolkit Setup and Support Guide" in Galaxy:
<https://galaxy.epic.com/?#Browse/page=1!68!50!100029628>

Membership Benefits



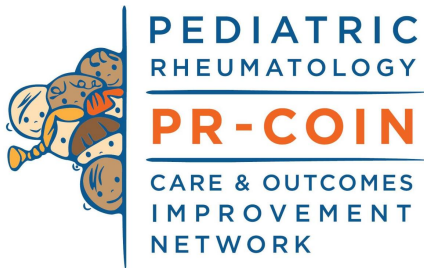
PR-COIN Benefits

- Collaborate with other centers at Network-wide webinar calls and face-to-face conferences with rheumatologists, parents, patients, and QI experts
- On-demand Registry reports and tools
 - QI Reports
 - Pre-Visit Planning
 - Population Management
- Maintenance of Certification Part IV (active and eligible providers) and Continuing Medical Education credit
- Access to the PR-COIN registry for research studies

PR-COIN Benefits

- Access document repository via members-only website
- Be a part of identifying and implementing best practices
- Participate on PR-COIN Committees
- Ongoing training and personalized coaching in Improvement Science methodology and tools
- Be recognized as a leader in improving health care

Thank You!



Contact PR-COIN at pr-coin@cchmc.org with questions or to learn more