

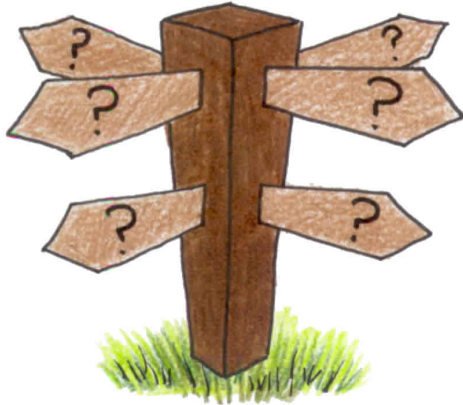
## How to Begin?

Many of our parents and providers have asked, “How do we begin?” The best way for a provider to begin is to determine which parents or patients might be receptive, open, and interested in engaging, and call or email them directly. No parent would be offended to receive an email or phone call asking for help in taking better care of our kids. Some may say they do not have time or are not interested, but it never hurts to ask. Be clear with the type of activities in which you plan to engage them and what projects are coming up, so they understand what the time commitment will be.

For parents/patients, this is a little trickier. Providers can be very difficult to reach sometimes, especially if they have long clinic hours. If your site has provided contact info for an “Engagement Champion,” use that contact person to make your first phone call or email. Let them know that you are interested in helping in any way they see fit and give some of the examples of things you are excited about. If you do not have a contact person via PR-COIN, then go to your child’s provider first. They should be able to connect you with the right person, or they can be your contact for engagement. Be sure to stress that the idea of engagement is not narrowly-scoped: you are looking to help the entire site with all of their patients and the care they receive, not focusing on your child and changing just their care by developing this engagement relationship.

If anyone has any further questions, ideas, or examples, please feel free to reach out to:

**PR-COIN’s Parent Working Group at**  
[prcoinparents@gmail.com](mailto:prcoinparents@gmail.com)



## Engaging Patients & Families



*Prepared by the Parent Working Group of PR-COIN to outline ways to engage parents and patients at their local sites and within the greater PR-COIN network. Effective engagement of parents and patients leads to true co-production of materials, efforts, and projects, and can help drive the work of our network to be more patient/parent-focused and more productive.*

**pr-coin.org**  
**pr-coin@ccmhc.org**



# Engagement Examples



= Amount of time commitment

## Via e-mail only:

- Send examples of consent forms, new brochures/flyers, and patient handouts prior to implementation in the clinic setting for parent/patient feedback.
- Help to develop surveys as needed for patients/parents in clinic.
- Act as a sounding board for any ideas providers have regarding parent/patient interaction.



## Face-to-face quarterly (or more):

- Form a rheumatology parent advisory board/council and meet to discuss current successes and shortcomings of the department.
- Attend rheumatology department meetings and give an update of PR-COIN activities, projects, goals, and parent involvement.



## Face-to-face monthly (or more):

- Develop task groups for focus areas for improvement within the department and invite parents to sit on each group.
- Participate in a PR-COIN network project and invite parents to participate as part of your site's team.



## As Needed/Frequent

- Participate in a mentorship program (called "Connecting Families" at Nationwide Children's) to help mentor newly diagnosed families
- Present information about PR-COIN at Arthritis Foundation events (JA Family Day, Family Camps, Advocacy Day, etc.)
- Assist with assembling new-diagnosis packets, making copies, etc. when appropriate.
- Develop a local Facebook group for your site (Columbus, Ohio; Philadelphia, PA; Hershey, PA all have them) so providers have a place to go to ask for survey participation, brainstorming, and feedback on AF/site events.

