

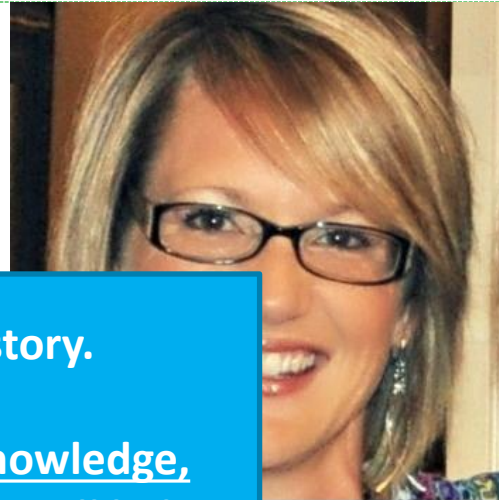
Building Co-Production into the Woodwork: Lessons from ImproveCareNow

PR-COIN Spring Learning Session
Sarah Myers
May 8, 2015

By the end of this talk:

- ▶ You will know what I mean when I say co-production
- ▶ You will be able to share at least one example of how centers in another collaborative quality improvement network got started with co-production
- ▶ You will have food for thought for your discussion about co-production tomorrow.

Cliff Notes Version of the ImproveCareNow Story



They all have a story.

AND they all have knowledge,
ideas, and talents that will help
improve care.



Spring 2007





PARENT WORKING GROUP



“Co-production.” Is that more QI jargon?



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Article [Talk](#)

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- This article may be [confusing or unclear](#) to readers. *(March 2012)*
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- This article is [written like a personal reflection or opinion essay](#) that states the Wikipedia editor's particular [feelings](#) about a topic, rather than [presenting the facts](#). *(January 2014)*
- This article includes a [list of references](#), but its [sources remain unclear](#) because it has [insufficient inline citations](#). *(January 2014)*

The **co-production of public services** has been defined in a variety of ways - e.g. "Co-production means delivering public services in an equal and reciprocal relationship between professionals and citizens" (new economics foundation) or "the public sector and citizens making better use of each other's assets and resources to achieve better outcomes and improved efficiency" (Government of the Netherlands)

Experiments on co-production on public services have been launched in many countries, from Denmark to Malaysia, the UK and the US.^[1]

Contents [\[hide\]](#)

1 Emergence of co-production

2 Definition

Maintaining community aesthetics and health



Working to improve schools together

National Standards for Family-School Partnerships



[PTA.org/excellence](https://pta.org/excellence)

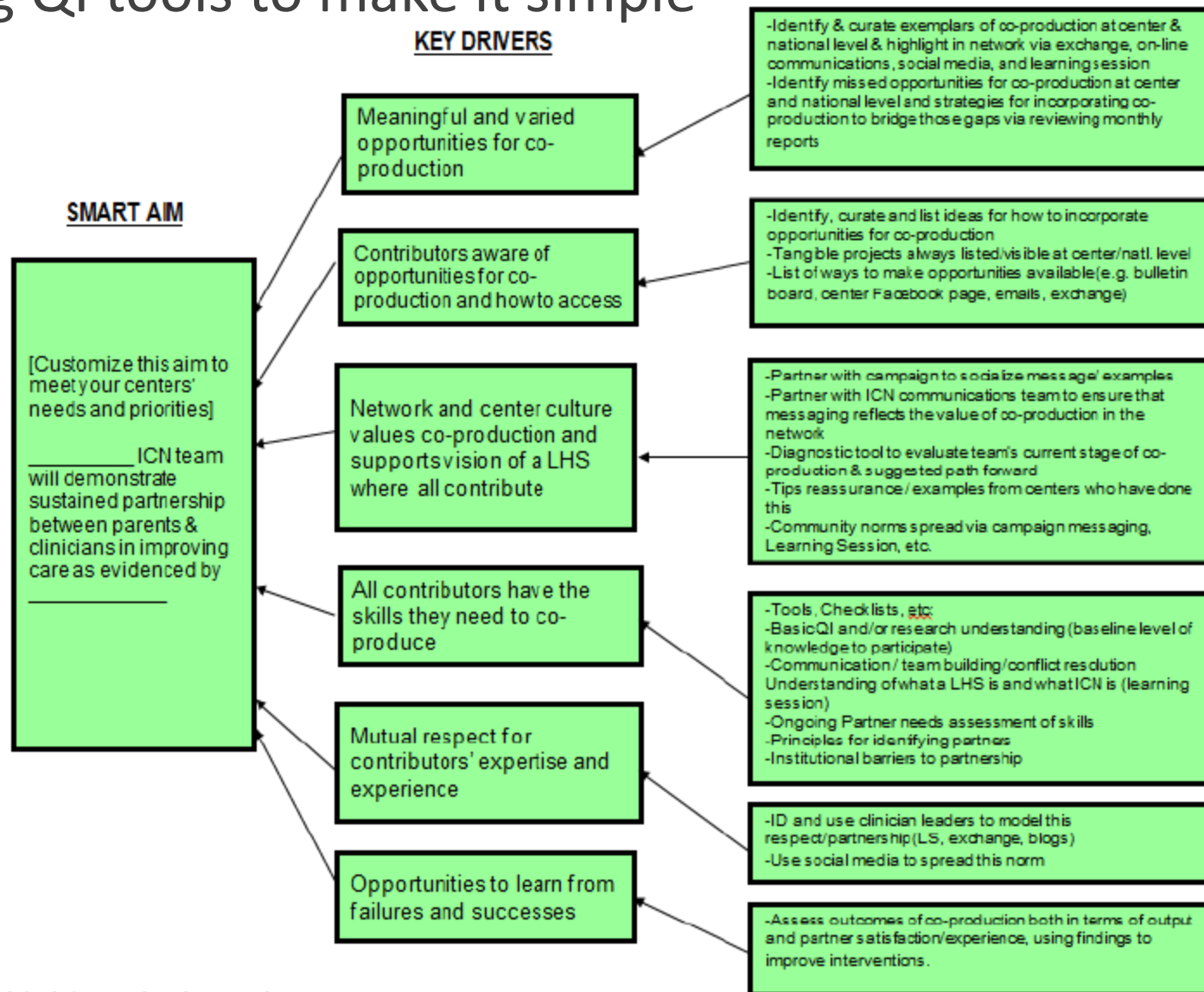
Other Examples?

It's really pretty simple:

- ▶ It's producing things—in this case improvements in care and outcomes—together.

Co-production is patients, families, clinicians, and researchers collaborating as equal and reciprocal contributors to produce **information** (e.g., clinical data, patient reported outcomes), **knowledge** (informal insights and formal research), and **know-how** (expertise) to improve healthcare and health outcomes.

Using QI tools to make it simple



CO-PRODUCTION AT THE NETWORK LEVEL

Patient and Family Engagement at the “Front Lines” of our Network

Being part of the distributed learning health system to produce information, knowledge, and know-how for improving the health care system and personal health.

100%

90%

9%

1%

Awareness



Participation



Contribution



Ownership



People + Structure + Trust =

Engagement and coproduction
that we previously thought
impossible!

People: Driven by Generosity, Experience, and Collaboration



Parent Working Group: Professional Experience

Mechanical engineer

ELECTRICAL ENGINEER

Childbirth educator

Product manager

Sales rep

Managed care medical director

Information systems consultant

Respiratory therapist

Camp director

IT project manager

Realtor

Clinical researcher

Nurse

WRITER AND EDITOR

Foundation director

Meeting and events coordinator

Director of sales

Physician

VP of new technology

OPERATIONS SPECIALIST

Statistician

Business development manager

Hedge fund manager

Healthcare consultant

Media consultant

STRUCTURE: Parent Working Group

Lead Parent Partner

Parent Leadership Council

Assistant Lead Parent

4 Subcommittee Chairs

2 members at large

Meets monthly

Subcommittees

- ✓ Membership: acquisition, onboarding & mentoring
- ✓ Communications
- ✓ Learning Session Planning
- ✓ Research

Parent Working Group

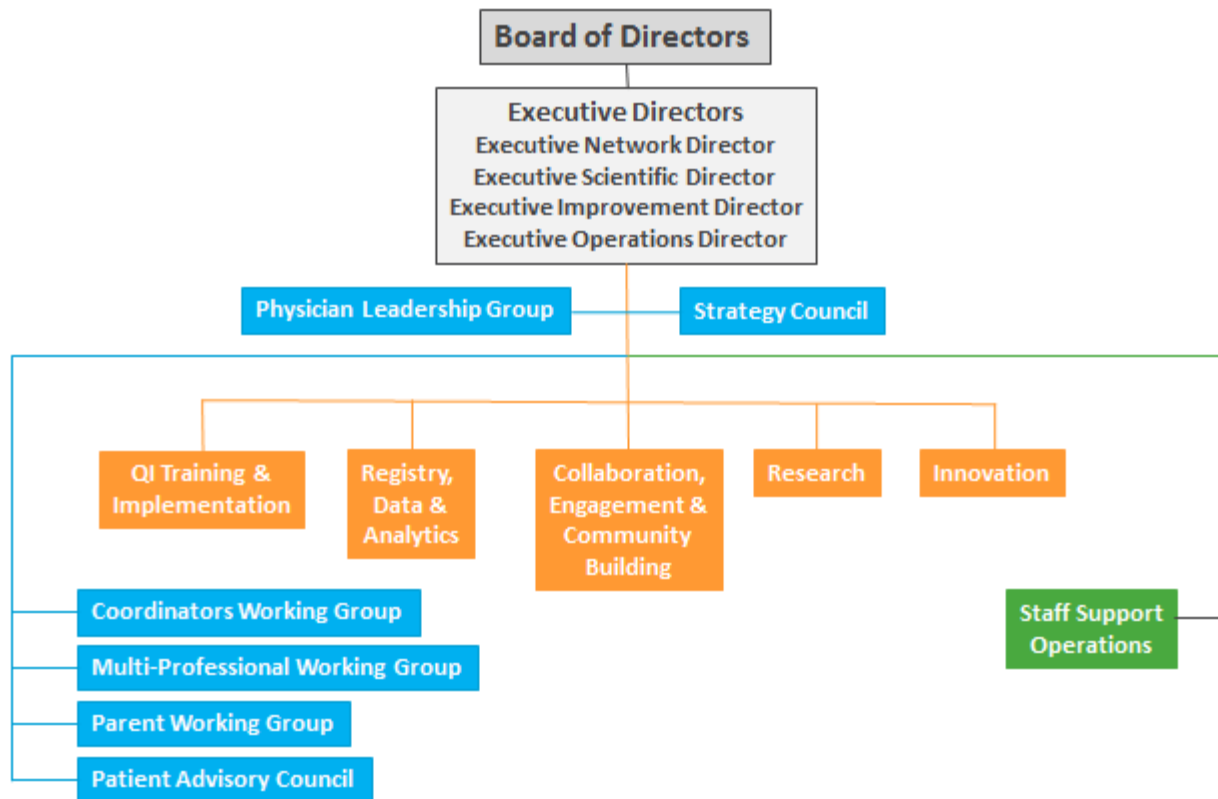
One parent from each care center

Meets quarterly

Other ICN Parents

Other parents who are part of ICN but not ready for a network leadership role; may be active in care center mentoring, online discussion, etc. Kept abreast of PWG activities via newsletter or email.

Patients and Parents as Part of Network leadership



Trust

- ▶ Families need to *trust* that they are seen as full partners
- ▶ We need to *trust* that we are still needed
- ▶ We need to be able to give and take feedback and be honest if one side is pushing too far too fast
- ▶ Get to know each other as people in order to establish this *trust*, just as one would any *co-worker*

Parent Working Group | Profile

Name

Title | Parent Rep

ICN Center | Nationwide Children's Hospital

Child's Age, Diagnoses | 18, Crohn's Disease (diagnosed at age 9)

Profession | Sales Rep, Stay at home mom

Volunteer Activities | Nationwide Children's Hospital Volunteer, ICN Volunteer, CCFA Take Steps Committee, CCFA Board Member
Central Ohio, School Volunteer, Empowered By Kids volunteer


IBD Journey | Our 9 year IBD journey has been a roller coaster ride. This disease has taught us to become advocates for everyone impacted by these diseases. We realize the impact it has on the entire family. As a mom, I wish I could trade places with my son and take away his Crohn's Disease. My goal is to help as many families as I can because I still remember the day of diagnosis like it was yesterday.

Tell us one thing no one knows about you | When I was in grade school, I was in the KISS fan club!





A Week of Learning from Patient Partners!

by  Sarah Myers 7 minutes ago 3 Views



IMPROVE**CARE**NOW

Remistart Patient Rebate Program Helpful Hints

1. Request a copy of your enrollment form from GI department
2. Make a copy of your enrollment form for your records and mail or fax a copy to:
Remistart
14001 Weston Parkway
Suite 103 Cary, NC 27513
Phone: (888) 222-3771
Fax: (877) 234-3048
www.remistart.com
3. One week after mailing/faxing your enrollment form, call Remistart at (888) 222-3771 to confirm they received your application

...the Learning from Patients and Parents pre-work activity and your experience, work at your table to answer the questions below in a rapid and focused way. All should contribute, be open to ideas, and think big, including parent partners! Your ideas will help us improve care for more kids with IBD!

Goal): Access and Communication
 Accurate Diagnosis, Disease Classification
 Optimal Nutritional Intake
 Optimal SMS/Adherence

Proactive, Timely, Reliable Care
 Appropriate Drug Selection and Dosage
 Optimal Psychosocial Health

or:

Presented at your table:

RN, Nurse Practitioner, Coordinator, ^{Parent} & Consultant

Question	Response
Describe what [focus area] means to you; what the ideal look like from your perspective?	<ul style="list-style-type: none"> - Know how & when / multiple formats, - Parent/guardian reach someone 24/7 & will be responded - Transparency among providers about plan - Better access patient portal - Comfort levels to talk about issues
Challenges in this	<ul style="list-style-type: none"> - Difficult to use patient portal - limited access - Big gap on portal system of parents - Large volume ; parent frustration of not knowing

Unit coord
with 100% x1

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(step) → fastest path.
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possible - need cross
medical records
ent families

ICN Exchange: Enhancing Knowledge Sharing

Join one of two optional focus groups in May!

Details here


This invitation for a voluntary activity is being sent on behalf of the ICN PCORI project team.

37 views 2 likes 0 comments

smyers on PCORI

Learning Sessions

Smart Patients: Patient-Patient Interaction and Empowerment



Smart Patients

0 | 0

Inflammatory Bowel Disease

Conversations

conversations 14
not read

tags

3
inflammatory bowel... 14
use all tags


Clinical trials

resources

isary
trial

my conversations

START A CONVERSATION




Siblings

Heather D replied, last reply about 13 hours ago

Another good topic, Beth. I feel for you Jen! What a difficult balancing act you have on your hands. Sounds like you're doing a great job. Liz, my story is similar to yours... [continue reading](#)

3 unread replies by Heather D, Beth N

tags: [inflammatory bowel disease](#) [mark read](#)



Yoga and meditation


Started by Beth N, last reply about 17 hours ago

Have any of you tried yoga or meditation in your children with IBD? There's an interesting conversation going on in another thread about this.

See... [continue reading](#)

4 unread replies by Lisa P, Beth N

tags: [inflammatory bowel disease](#) [mark read](#)



Welcome to our ICN-Partners community

Transplant Tracy replied, last reply about 19 hours ago

Hi I'm Tracy. I am currently on UNOS waiting list for an intestinal

Video Tutorial

Find your way around Smart Patients with our video tutorial.

Share Feedback

If you have any comments or suggestions on how we can improve Smart Patients click on the 'site feedback' tag and start a conversation.

[site feedback](#)

Interested?

Tags represent topics for conversation. Hover your mouse over a tag to find out more.

[crossing disease boundaries](#)
[ulcerative colitis](#)
[crohns disease](#)

If you follow a tag, conversations with that tag will appear on your home

QI Cheat Sheet for ImproveCareNow Parent Partners

Version 1.0

April 2015

Our basic Model for Improvement:

1. What do we want to accomplish (our aim)
2. How will we know if a change is an improvement (our measures)
3. What changes can we make that will result in improvement? (our changes)

About AIMS:

- In ImproveCareNow, centers develop annual aims, 90-day goals, and specific aims for short-term improvement projects that will help them reach their larger goals.
- Keep it **SMART**: Specific, measureable, actionable, realistic, time-bound
Not this: We will help more patients get pre-visit planning.
This: 60% of scheduled IBD patient visits will have pre-visit planning by June 30, 2015
- Develop your aim **as a team** so all are aligned around what you are trying to accomplish

About Changes:

Working Together to ImproveCareNow



IMPROVE**CARE**NOW

**Co-Production Change Package
Version 2.1: Catalyzing Community Input
May 5, 2015**

CO-PRODUCTION AT THE INDIVIDUAL CENTER LEVEL



Levine Children's Hospital: Guidance for the IBD Journey

Levine Children's Hospital Educational Videos

Social Work



IBD and Surgery



IBD and the Flu



Camp Victory Junction



Riley Children's Hospital: Easing the Financial Burden

Buzzy: A small tool to help in a big way

Three years ago my son started on Humira in an attempt to get his Ulcerative Colitis into remission. Although it quickly became apparent that Humira was controlling his UC, my husband and I were struggling to successfully administer the drug. Our process consisted of 30 to 40 minutes of negotiation along with bribes and other unsuccessful attempts at minimizing the injection pain. We tried our best to allow our son to have some control over the situation by waiting for him to tell us when he was ready. In the end, we were just getting frustrated. That is when we found Buzzy.

Buzzy was developed by a physician and pain researcher (www.buzzy4shots.com). It works on the Gate Control Theory of Pain. Its design confuses the nerves with both temperature and vibration. The theory is that this distracts from the injection pain and interrupts the neural pain pathways. Using Buzzy has reduced our shot time to 2-3 minutes and has greatly reduced the family stress and anxiety associated with this experience. I knew that we needed to make Buzzy accessible to all of our patients who receive injections or infusions to help with injection pain and needle phobia. With a price tag of \$40, our care team recognized that this purchase could be a burden on families already dealing with high medical costs.

Our Parent Mentoring Group at Riley Hospital for Children did research using the ICN database to determine the number of our patients that were using injections and infusions as their primary therapy. We collected data from the infusion nurses and Child Life specialists that had been successfully using Buzzy in the hospital. Armed with this data and personal experience, we prepared a grant that we submitted to the Women for Riley, a philanthropic group of women that support the Riley Hospital and

Northwest Pediatric GI: Raising Awareness & Building Bridges

Page 2

ImproveCareNow

Who me? Get involved?

By Jennifer Erickson

My name is Jennifer Erickson and I am a parent of an IBD patient, and the Parent Advisory Liaison for NWPG and Improve Care Now. I hope to become a familiar face in the community and clinic, a comforting voice as we discover new ways to best support our families, and a bridge for increased communication between our patients and physicians.

*Please LIKE our
KwCCpdx Facebook
page at
<https://www.facebook.com/KwCCpdx>.*

There is an established support group for adults through the CCFA headed up by Mark McNamara markjmcnamara@gmail.com that meets up at OHSU on a monthly basis. We hope to add to the good they do through our own group, KwCC, geared for Kids with Crohn's and Colitis. Our kids, and us parents, are bound by a common diagnosis and similar stories. Commiseration and humor can play a great role in healing the spirit. Our

Nationwide: Leveraging Professional Experience

To whom it may concern:

I am writing this letter to support the implementation of a 504 school plan for (insert name). As you may know, (name) has been diagnosed with an inflammatory condition of the intestinal tract known as (insert diagnosis), also known as Inflammatory Bowel Disease (IBD). The disease tends to wax and wane and is often characterized by recurrent flares of symptoms. Primary symptoms (due to inflammation of the intestinal lining) during flare-ups include abdominal pain, diarrhea (often with blood and mucus), fevers, and can even progress to intestinal obstruction and perforation if not monitored and treated closely.

While the specific cause of Inflammatory Bowel Disease is not yet known, we do know that the underlying inflammation is driven by a dysregulated immune system response. Although we can help decrease the inflammation and maintain remission by utilizing powerful chemotherapeutic-type agents, there is currently no cure for this disease. Inflammatory Bowel Disease is one of the most difficult gastrointestinal disorders to treat, and children and adolescents with this disease have complex medical needs which require management by pediatric gastroenterologists, a very specialized medical subspecialty. This management requires a great deal of effort and vigilance for associated symptoms and potential complications, as well as the side effects of the medications used. Because IBD affects the intestines, patients often have additional symptoms including poor growth, anemia, and osteoporosis. Therefore, adequate and supplemental nutrition in the form of Ensure or Boost supplements is sometimes required.

Because of the reasons outlined above, the following points should be included in the school plan:

- Have adequate time to make up any work missed due to absences because of the disease. Furthermore, additional time for tests and assignments may be needed in the future, particularly when her disease is flaring.
- Have unlimited restroom privileges.
- Be allowed to carry a water bottle and/or nutritional supplements at all times.
- Be able to go to the nurses office at any time for medications or ANY signs of a flare.
- Be allowed to tote books on a cart with wheels if a backpack is too difficult to carry.
- Will require frequent visits to the hospital for check-ups, medications and possible in-patient admissions. Such visits should be allowed and time to make up missed work provided.
- During flares, may need to be excused from physical activities such as PE; however, when in remission, there are no restrictions regarding sports or other physical activities.

Children's Mercy: Defining the Role

RESPONSIBILITIES:

1. Attend Quality Improvement meetings on a quarterly basis (via in-person, SKYPE, or teleconference).
2. Be available to speak with parents and families that need support and advice; especially those newly diagnosed.
3. Be available to attend clinic meetings (via in-person, SKYPE, or teleconference).
4. Serve as an advocate for IBD patients at Children's Mercy Hospital and their parents/guardians.
5. Provide feedback and suggestions regarding quality improvement initiatives to the IBD Quality Improvement Team.
6. Attend one learning session in Chicago annually – expenses will be paid through the ImproveCareNow collaborative or through the CMH GI budget.

**“BUT THEY MUST HAVE A LOT OF
RESOURCES. WE ARE SO BUSY.”**

Co-Production is **not** a Change to Test

- ▶ Co-production is not a new QI intervention. It's a way of doing work that helps you move further, faster, and in ways that are more meaningful to families.
- ▶ Co-production does not equal more work in the long run but you have to put thought into working in this way
- ▶ When it becomes part of the way you do QI, it helps get projects done

Common “fears”

- ▶ It will take more time that we don't have
- ▶ We will air our “dirty laundry”
- ▶ Parents will want to focus on their own child's care
- ▶ My ideas won't be needed or heard anymore

Examples of 90-Day Goals: Small to ambitious

- ▶ Mercy: “Host advocacy event-education/resource fair for IBD patients and families.”
- ▶ Greenville: “Identify and engage 2-3 volunteers demonstrating commitment as parent leaders.”
- ▶ Iowa: “Identify at least 5 parents who are willing to provide support to new diagnosis patients.”

Changes to Test: Getting Started

- ▶ Talk as an improvement team about what co-productions **means to you** and your improvement work. Talk about your concerns and fears.
- ▶ Identify **a champion** who “gets” what parents and partners bring to the table...someone who will make this way of thinking prominent in all conversations
- ▶ Think about **a few parents** that might have good input into a small-scale project—start small, start this week (start with a list of 4-5 parents who are likely to want to contribute)
- ▶ Start communicating with patient community via social media



Follow @UMkidsIBD on Twitter for:



Information on Crohn's disease and ulcerative colitis (IBD) management
 Updates on your C.S. Mott pediatric IBD program's activities & outcomes
 IBD education & research information
 Letters & blogs by patients, families, & your pediatric IBD care team
 Updates from IBD conference and meetings

The screenshot shows the Facebook profile of 'The Schubert-Martin IBD Center at Cincinnati Children's Hospital'. The cover photo features the Cincinnati Children's logo and a close-up of a child's face. The page includes a 'Timeline' tab, a 'Like' button, and a 'Following' status. A post from yesterday at 10:49am is visible, discussing the center's role in improving care for inflammatory bowel disease (IBD) through the ImproveCareNow program.

Feeling ready to start?

- ▶ Invite a parent to attend your next QI meeting
- ▶ Invite a parent to review an educational tool that you haven't updated in a while
- ▶ Ask a newer parent for feedback on the new diagnosis process and one thing they would improve

Bottom line: Just starting talking and connecting as people.

What are the 3 things you like most about your visit to our clinic?	
If you could change 3 things about the care you receive for your IBD what would they be?	
What do we wish the clinic team knew about your life with IBD before every visit with you?	
What are the key challenges you face in your day-to-day life with IBD?	
How might we as your care team better support you in dealing with these challenges when you are at home between clinic visits?	
What are the 3 things you most dislike about	

Questions?