

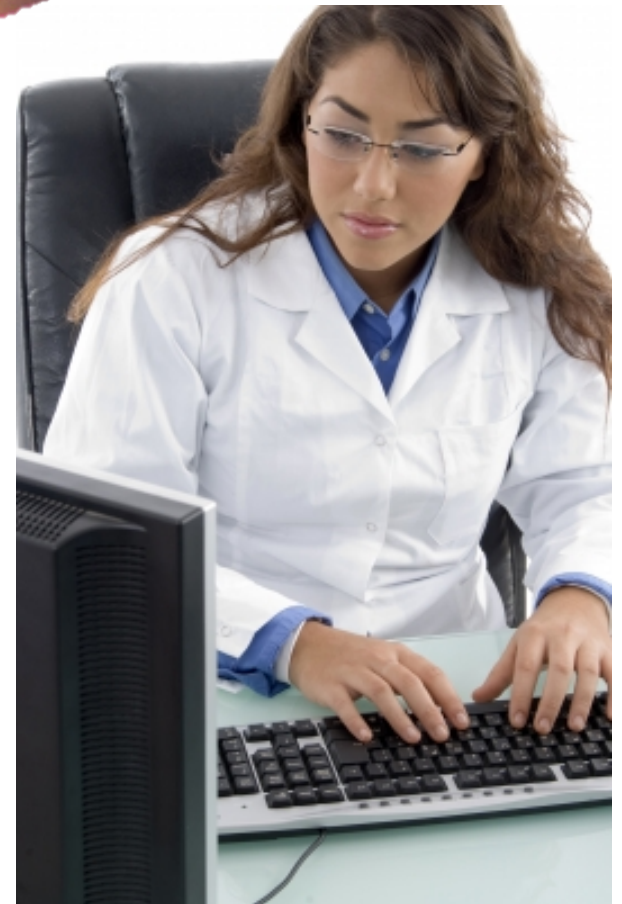
Healthier Together: Collaborative Networks of Patients, Clinicians and Researchers to Transform Chronic Illness Care



COLLABORATIVE CHRONIC CARE NETWORK

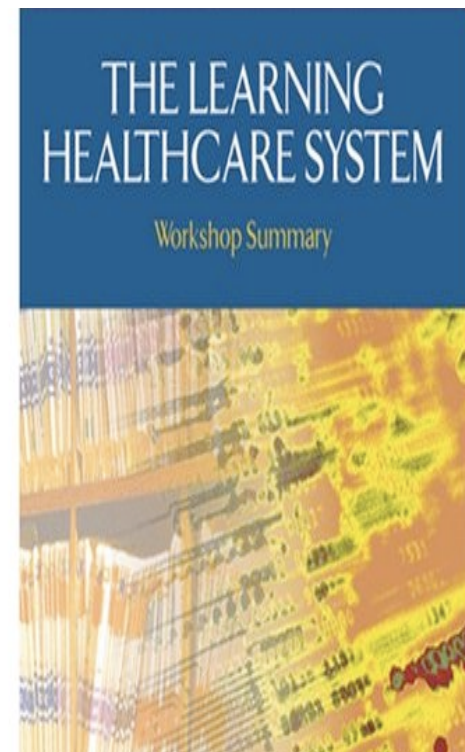
Peter Margolis, MD, PhD
Jennie David

Supported by: NIH NIDDK R01DK085719, AHRQ R01HS020024, AHRQ U18HS016957, PCORI PPRN-1306-01754, ImproveCareNow Network Care Centers, CCHMC Learning Networks Program

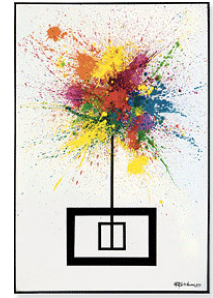


Learning Healthcare System

- Patients and providers work together to choose care based on best evidence
- Drive discovery as natural outgrowth of patient care
- Ensure innovation, quality, safety and value
- All in real-time



What if....?



- ...we could create a vastly better chronic care system by harnessing inherent motivation and collective intelligence of patients and clinicians?
- ... this system allowed patients and physicians to share information, collaborate to solve problems, use their collective creativity and expertise to act in ways that improve health?

Networks





Yochai Benkler
Harvard Law



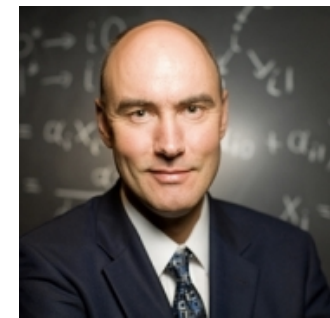
Elinor Ostrom 1933-2012
Economist
Nobel Laureate 2009

Relevant Biologic and Social Science

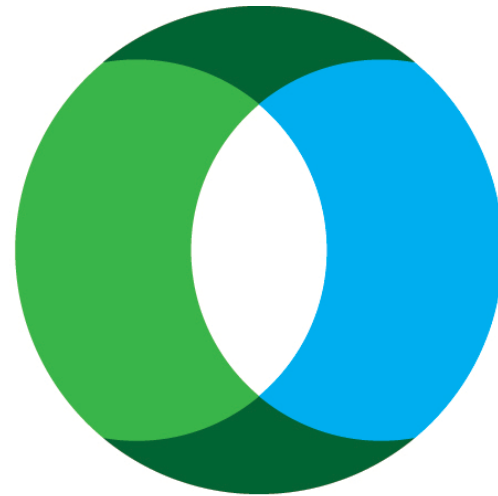
- Non-market/commons-based production
- Actor-oriented network organizational architecture
- Evolutionary mechanisms of cooperation



Oystein Fjeldstad
Norwegian Business School
Chair, Dept of Strategy

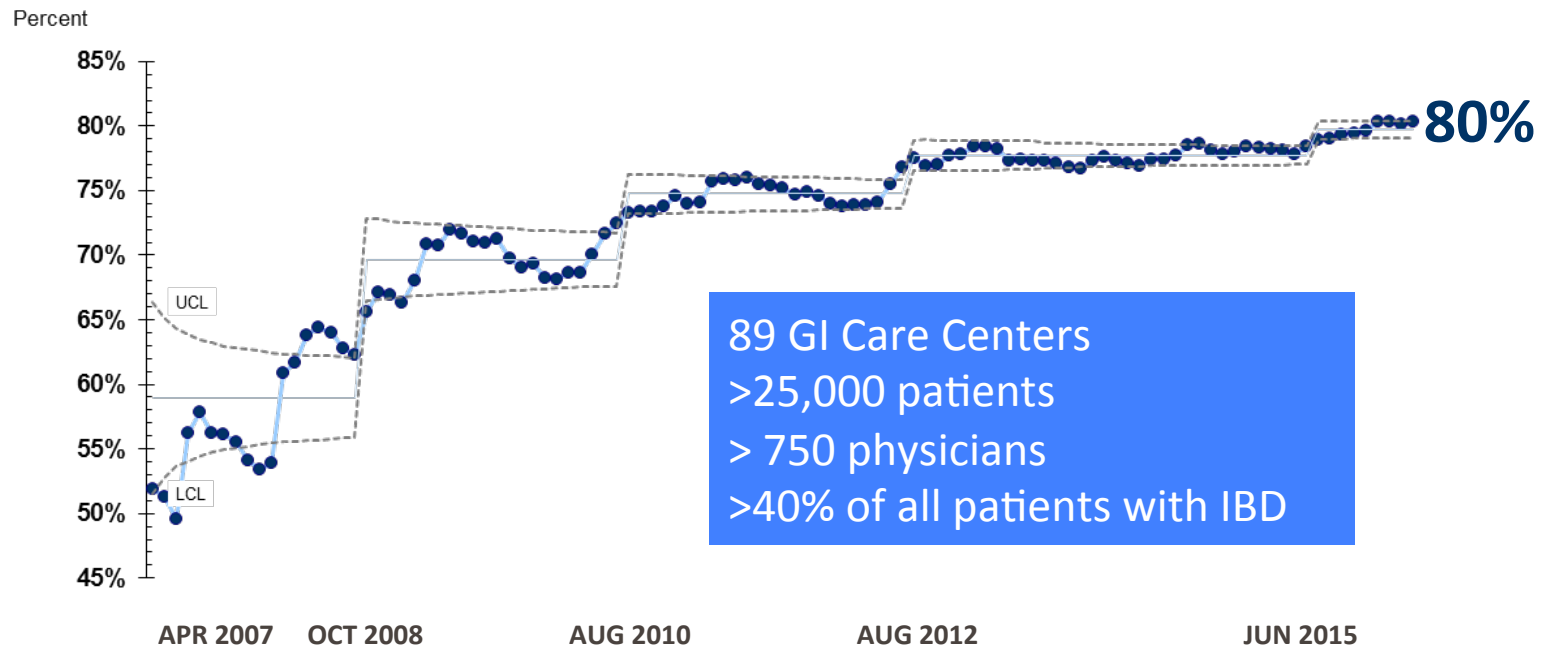


Martin Nowak
Program on Evolutionary Dynamics
Harvard



IMPROVE**CARE**NOW

% of patients in clinical remission Crohn's and Ulcerative Colitis



Centers >75% registered

[Improved Outcomes in a Quality Improvement Collaborative for Pediatric Inflammatory Bowel Disease.](#) Pediatrics. 2012;129:1030-41

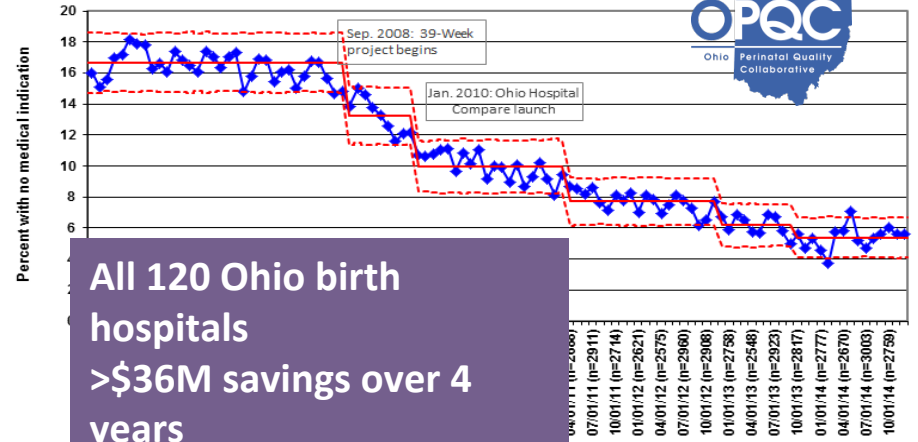
**Children's Hospitals' Solutions for Patient Safety
Serious Safety Event Rate (SSER)**

SSER is Expressed as a Rolling 12 Month Average per 10,000 Adjusted Patient (APD)



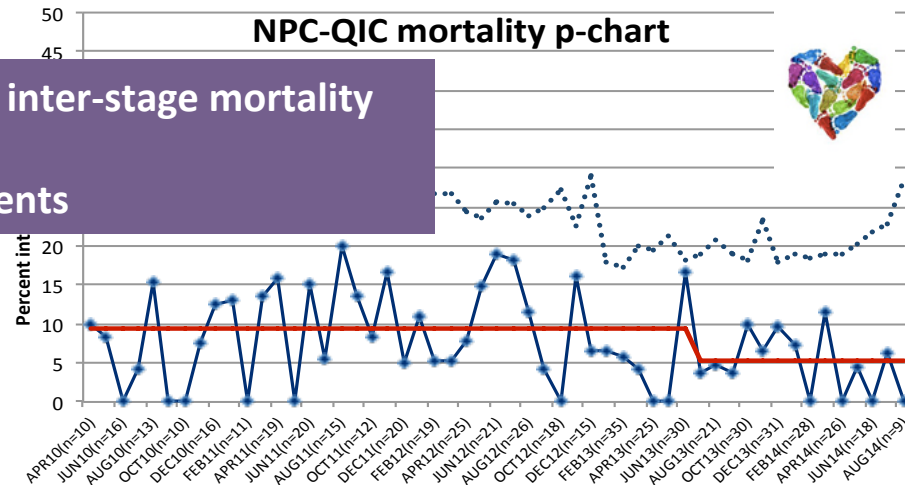
Solutions for Patient Safety
90 hospitals
>\$79,000,000 saved
3,699 children spared harm

**Births induced at 37-38 weeks with no apparent medical indication for early delivery,
by month, 2006-2014
Aggregate of Ohio maternity hospitals**



All 120 Ohio birth hospitals
>\$36M savings over 4 years

NPC-QIC mortality p-chart



40% decrease in inter-stage mortality
55 care centers
>80% of all patients

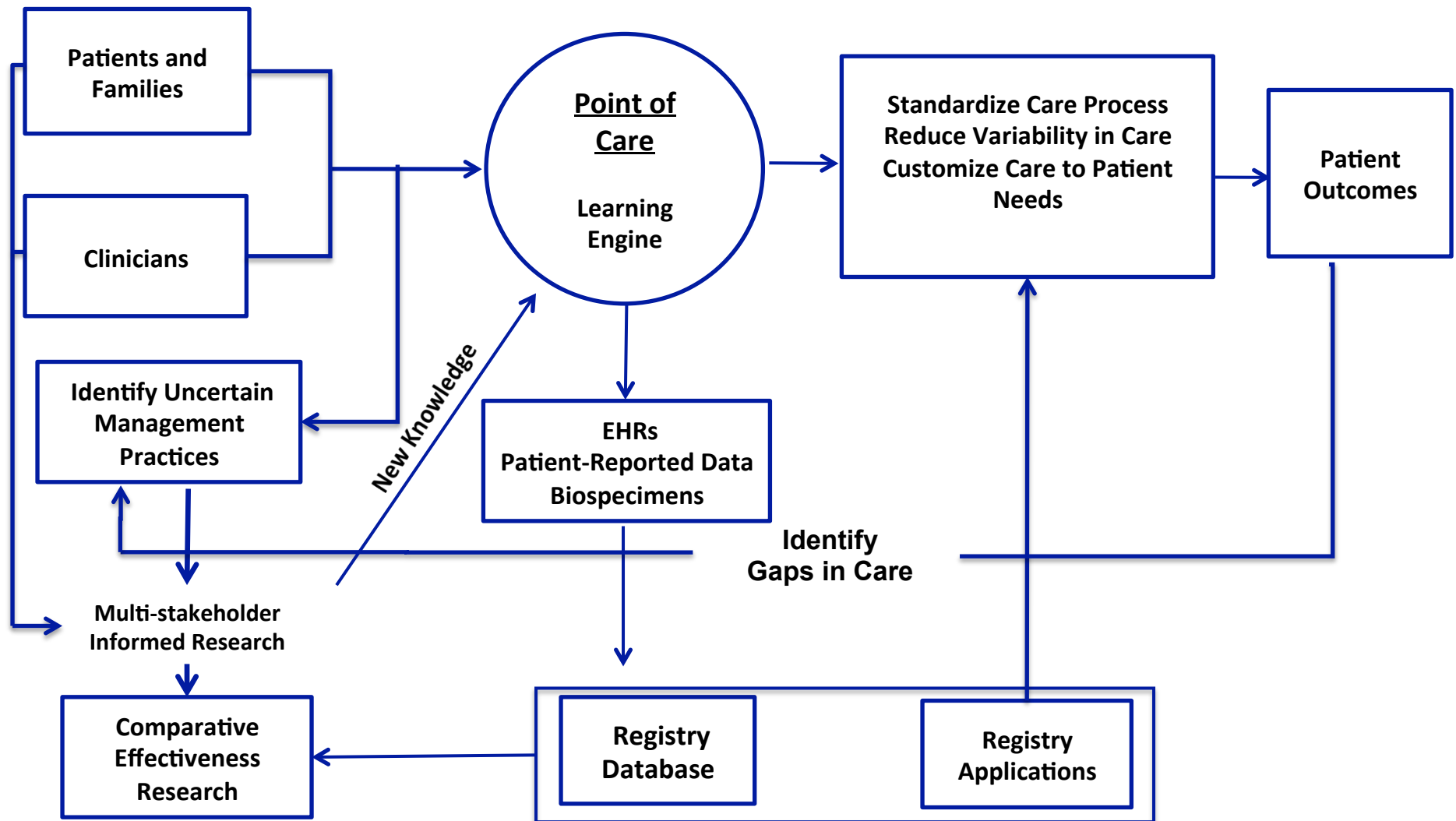
Components of a network-based Learning Health System*

1. Focus on outcome
2. Build community
3. Effective use of technology
4. Learning system
 - System science, QI, qualitative research, clinical research

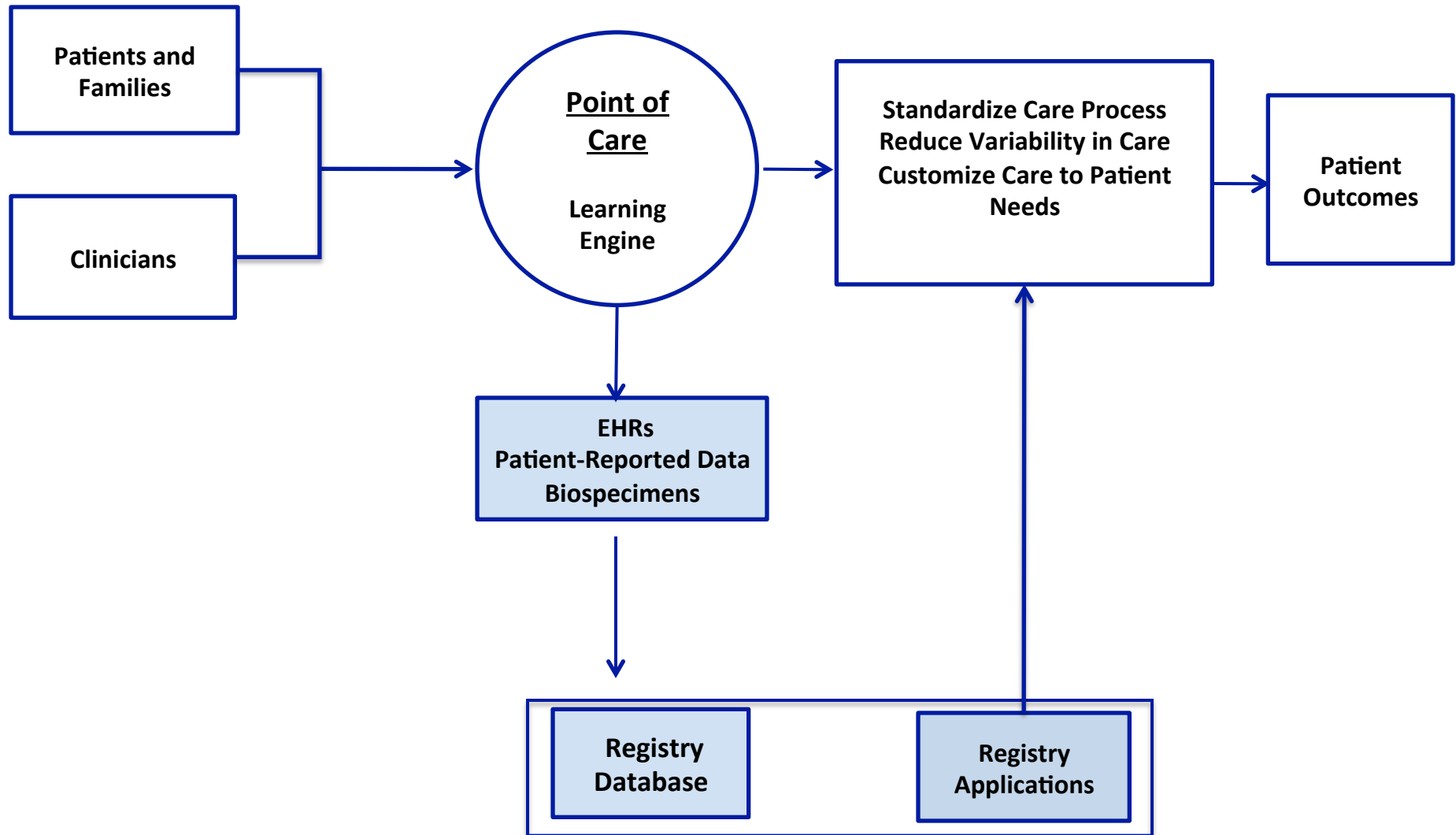


*Collective creativity (Swarm Creativity; Peter Gloor)
Lead User innovation (Democratizing Innovation; Eric von Hippel)
New economic models (The Wealth of Networks; Yochai Benkler)
Actor-oriented organizational architecture (Configuring value for competitive advantage; Charles Stabell and Oystein Fjelstad)

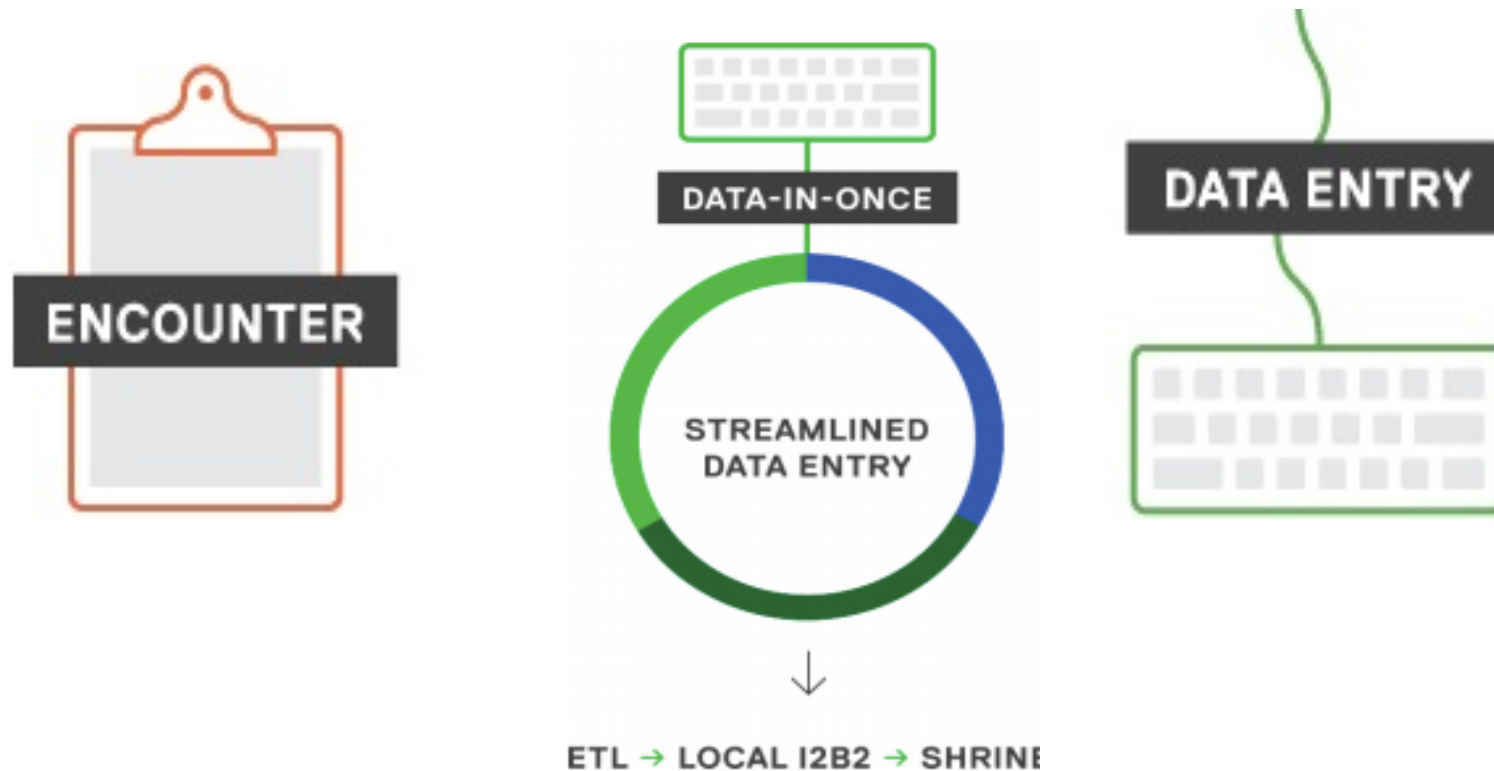
Improving Outcomes with a Learning Health System - Health care delivery, improvement and research *together as part of the same system*



Improving Outcomes with a Learning Health System



“Data in once” - Technology for efficient data capture



Marsolo K, Margolis PA, Forrest CB, Colletti RB, Hutton JJ. A digital architecture for a network-based learning health system – integrating chronic care management, quality improvement, and research. eGEMS. 3:2015

Data-in-once (at clinical visit)

IST - EP4 PEDI GASTRO - RICHARD B COLLETTI

Epic - In Basket Chart Schedule Patient Lists Pre-Proc Encounters Referrals Charting Tools

Crohnsjr, Richard

Crohnsjr, Richard MRN: 0028007623 PCP: LARRABEE, JERRY G Allergies: Unknown; Not on File
13 y.o., Male DOB: 01/21/1998 Visit#: 590160 Infection: None

11/16/2011 visit with Colletti, Richard, MD for FOLLOW UP RETURN - test

Images References Print AYS Other Note Types Anti-Coag Enc

Snapshot

Chart Review Charting

Flowsheets Chief Complaint Vital Signs Extended Vitals Problem List History Social History Allergies Medications Immun. Rpt Hearing/Vision SmartSets Progress Notes Dx and Orders

Synopsis

History

Allergies

Problem List

Medications

Immunizations

Demographics **IBD Registry** Disease Measurement

Letters Disease Mgmt

Doc Flowsheets Medications Verify Rx Benefits Reconcile Dispens... Disclaimer

Order Entry

MAR Discharge Pt. Instructions LOS & Follow-up Charge Capture After Visit Summary Close Encounter

Visit Navigator

IBD Registry

Background Information

Current diagnosis

Crohn's disease ulcerative colitis indeterminate colitis

Has the patient had a complete colectomy? (If correct information appears in the sidebar, it is okay to leave this response blank.) Yes No unknown

Does the patient currently have an ileostomy or colostomy? Yes No unknown

Current symptoms

Describe the IBD symptoms on the WORST day in the last 7 days:

General well-being

normal fair poor unknown

Limitations in daily activities

no limitations occasional frequent unknown

Abdominal pain

none mild moderate to severe unknown

Stool characteristics

Describe the stools on the WORST day in the last 7 days:

Total number of stools not available/assessed

Most stools were formed partially formed watery unknown

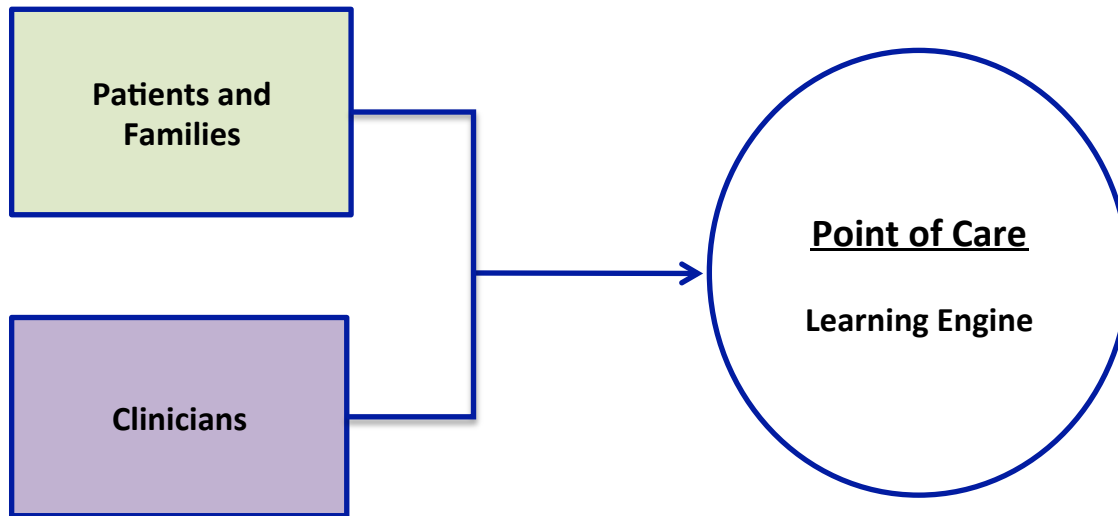
Number of liquid/watery stools per day (0 if none) not available/assessed

Did the patient report bloody stools? Yes No unknown



An “Enhanced” Registry uses data for clinical care, QI and research

- Automated chronic care process reports
 - Pre-visit planning
 - Population management
- Transparent performance data and QI Reports
- Data quality reports - ‘Research Grade’ Data
- Data and technology for research
 - Observational and comparative effectiveness
 - Clinical trials
 - N of 1
 - Consent management



Bianca Simmons, Age 20



“What does not kill you makes you stronger.”

Bianca's Goals

- Keep symptoms at bay
- Be a leader in the IBD community

Engagement

Being part of the distributed learning health system,

- to produce information, knowledge, and know-how
- for improving
 - personal health and
 - the health care system

Includes patients, families, clinicians and health system leaders

Stages of Engagement

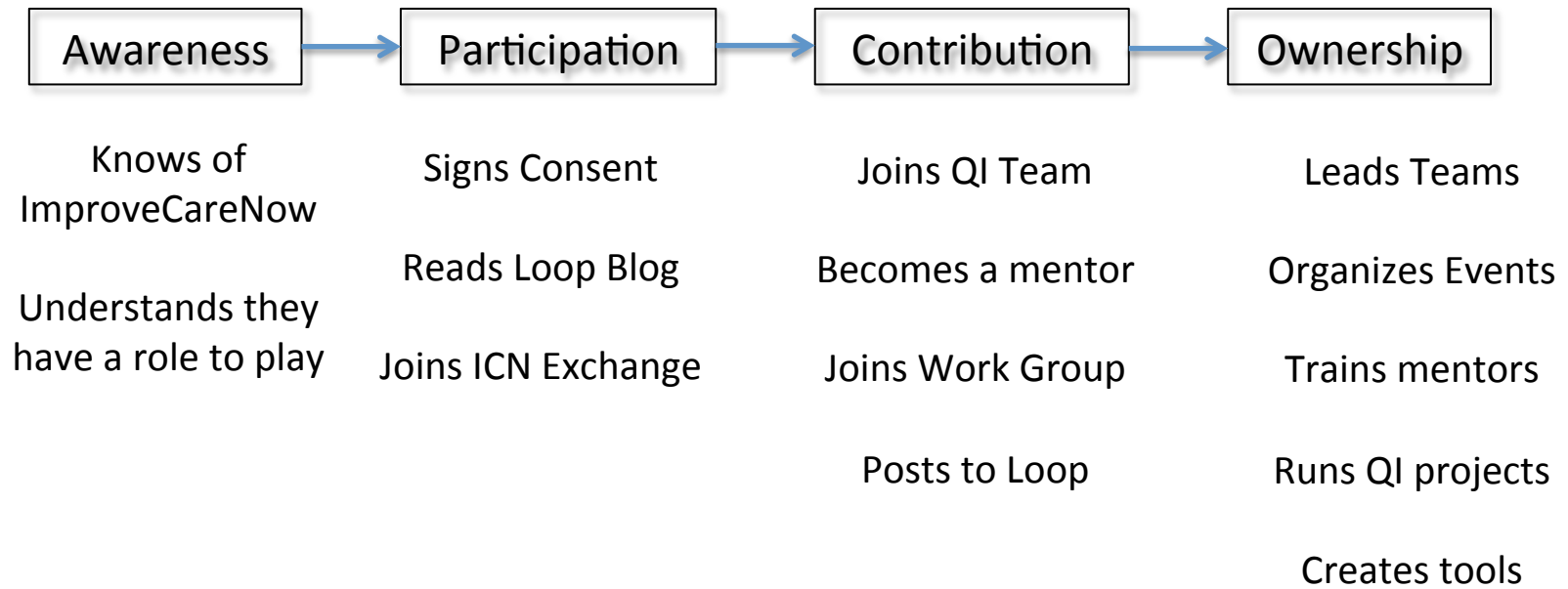


100%

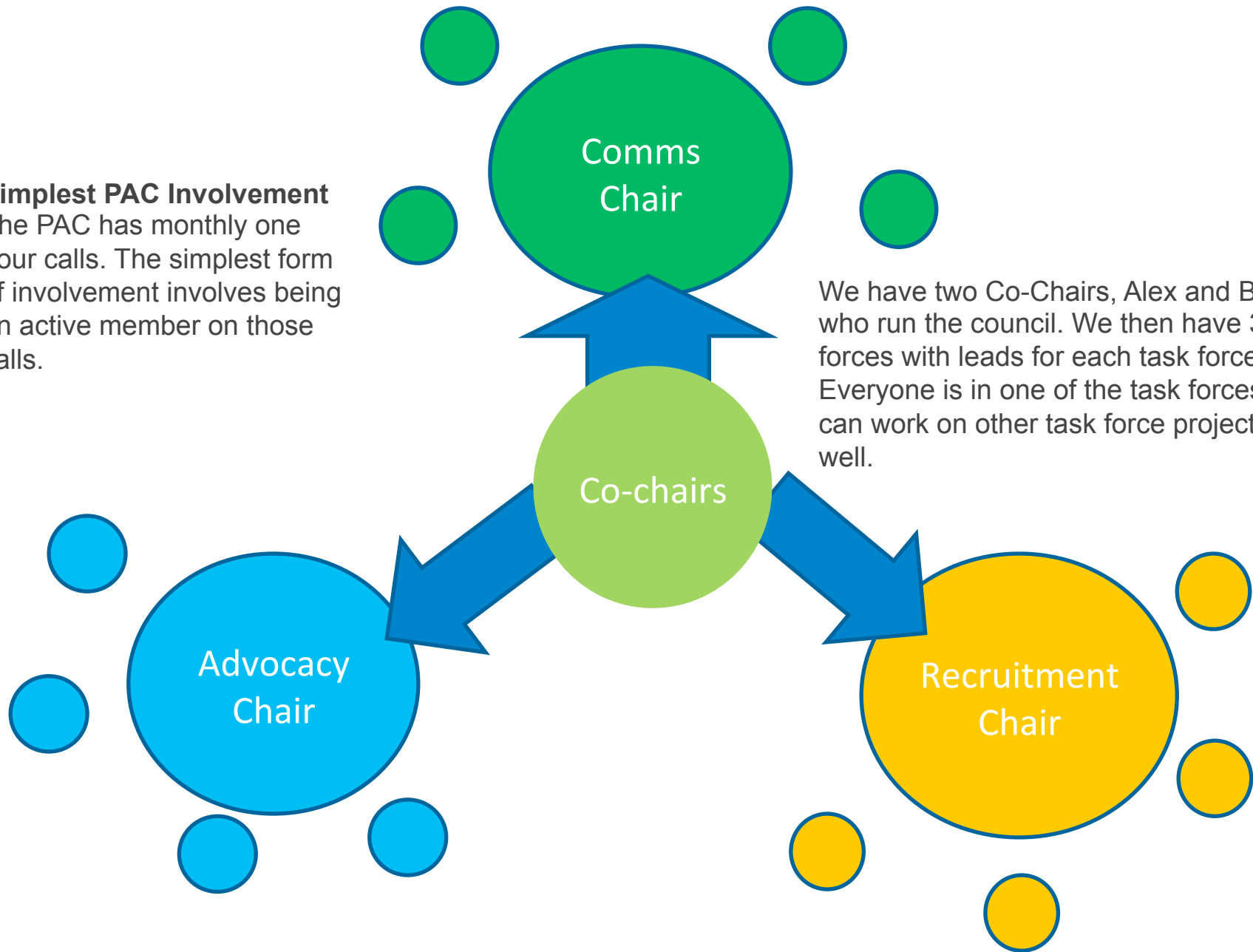
90%

9%

1%



Simplest PAC Involvement
The PAC has monthly one hour calls. The simplest form of involvement involves being an active member on those calls.



We have two Co-Chairs, Alex and Bianca, who run the council. We then have 3 task forces with leads for each task force. Everyone is in one of the task forces but can work on other task force projects as well.

+

the ostomy toolkit

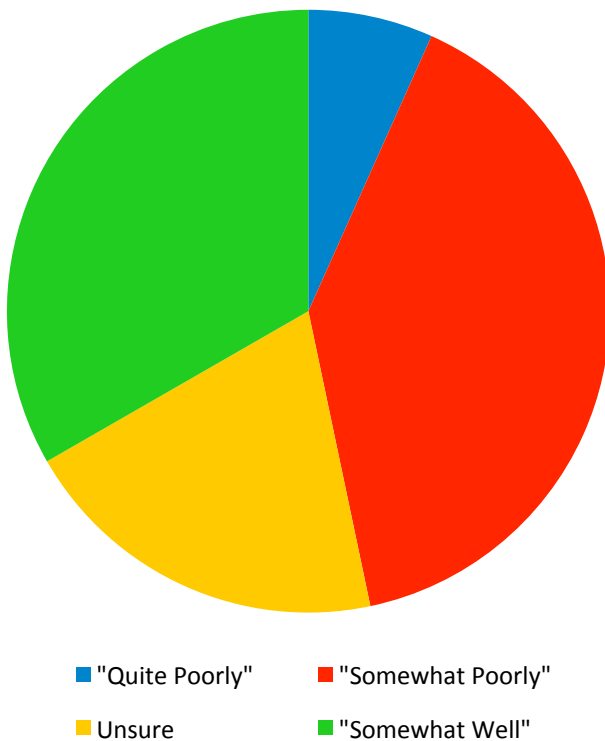


Ostomy Toolkit Data

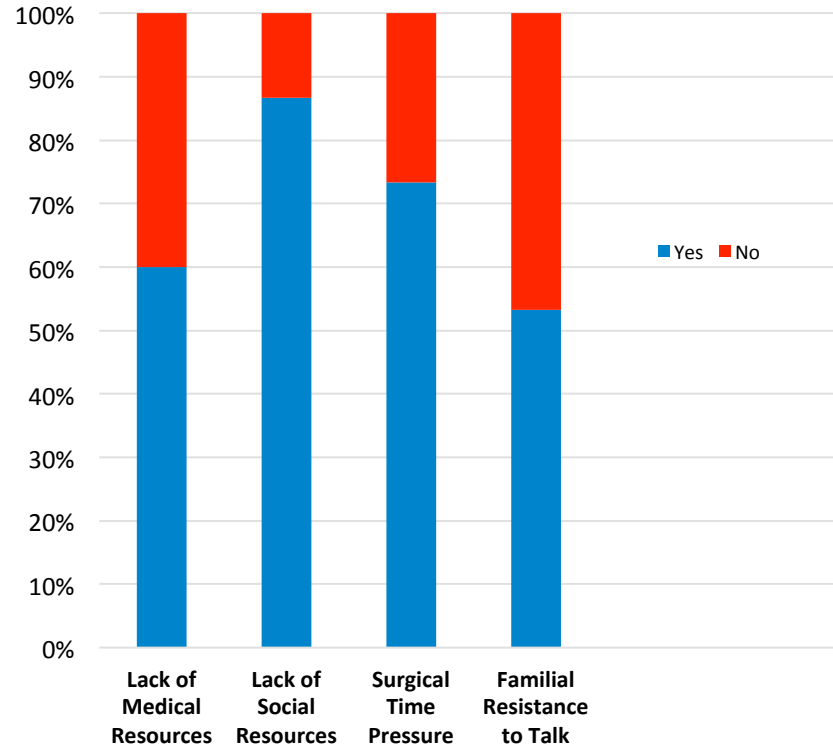


IMPROVECARENOW

Clinician Perspectives on Center's Level of Preparation for Youth Undergoing Ostomy Surgery



Clinician-Reported Barriers to Patient Preparation



(David, Seid, Mongiat, Jofriet, & Daly, 2016)

A “Commons” for sharing

[You Follow](#)
[My account](#)
[Log out](#)

[Home](#)
[How To](#)
[About ICN Exchange](#)
[FAQ](#)

+ Add

[Category](#)
[Video](#)
[Most Viewed](#)
[Forums](#)
[Recent Content](#)

For National Healthcare Quality Week along with many activities the hospital hosts an internal poster session. Teams from around the hospital share their work.

7 views 0 likes 0 comments

sricks onto Network Performance

Updated FAA analysis

5 views 0 likes 0 comments

TTodd onto Nationwide documents

Visit/Population Tracking

Instructions for entering visit tracker data into ICN2- available October 11, 2013

22 views 0 likes 2 comments

DJeffers onto Data collection tools

fdelrosario Is this available already today? I can't find the button on the Home screen.

ImproveCARENow Case Report Form

Updated, condensed version of the ICN2 registry from- updated 11Oct2013

23 views 0 likes 0 comments

DJeffers onto Data collection tools

NUMBER OF URGENT BOWEL MOVEMENTS

A Personalized Learning System for Improving Patient-Physician Collaboration - Heather C. Kaplan, Jeremy Adler, Shehzad A. Saeed, Ian Eslick, and Peter A. Margolis - Harvard Business Review

20 views 2 likes 3 comments

Thursday Evening Reception + Innovation Fair

Innovation overview, goals, activities & progress, impacts & insights, next steps & how to get involved.

We look forward to seeing you there!

SCOPE

Qualifying ICN physicians can get up to 60 credits towards Maintenance of Certification for the American Board of Pediatrics. Pin includes link to forms & instructions online.

13 views 0 likes 0 comments

snocito onto About ICN

Power point presentation on how we assure use of the Paris Criteria

24 views 1 likes 0 comments

tjackson onto Data Quality and Registration Tools

Submit a Research Proposal

ImproveCareNow is continuously strengthening its scientific infrastructure to support the learning necessary to improve health outcomes of children and adolescents with IBD.

Follow the steps below to complete an application and submit your research proposal

1. Determine if the [ICN2 Database](#) has the data available to answer your research questions
2. Review the [ICN policies](#) regarding data sharing and authorship
3. Download and follow the instructions on the [Research Proposal Request Form](#)
4. Send the following documents to [Kendra Wiegand](#):
 - Completed [Research Proposal Request Form](#) with Bio-sketch and Proposal
 - Signed [Data Sharing Expectations Form](#)

Once
a con
Rese!

RESEARCH PROPOSAL REQUEST FORM

Improving lives through collaborative medicine

Complete the Research Proposal Request documents and return to Kendra Wiegand at k.wiegand@cchmc.org

Completed proposal request includes the following:

1. Completed Research Proposal Request Form
2. Signed Data Sharing Expectations form
3. Principle Investigator Bio Sketch
4. Mentor Letter of Support (if applicable)



ImproveCareNow Data Authorship and Acknowledgement Policy

A primary goal of ImproveCareNow (ICN) is to create a community of patients, families, clinicians, and researchers working together to improve the health and lives for children with Inflammatory Bowel Disease (IBD). Patients make a major contribution towards this vision by

ImproveCareNow Data Sharing Expectations

A primary goal of ImproveCareNow is to create a community of patients, families, clinicians, and researchers working together to maximize the likelihood of finding treatments and cures for children with Inflammatory Bowel Disease. Fundamental to reaching this goal is establishing an open approach to sharing data, a strategy advocated, and often required, by many funding agencies. A more open approach to data sharing facilitates the flow of information and knowledge to all community members by reducing the cost, time, and effort required to learn from the data patients have invested. This in turn accelerates the application of discoveries made to improving patient care and outcomes. Achieving ImproveCareNow's goal requires that we outline the norms and expectations that will guide the process of data sharing within and outside the ImproveCareNow Network and allow us to evolve into an open-source database in the future.

the ostomy toolkit

Long distance bag high five

the ostomy toolkit: a guide to gutsy living

written and prepared by the patient advisory council for the ImproveCareNow Network
for pediatric ostomies, from pediatric ostomies

Tools for Parents

Below are links to tools that were created by parents of children with IBD or that may be relevant to them. Follow the direct links to access the tools on the ICN Exchange.

- Parent Working Group - general**
ICN Parent Working Group Subcommittees: <http://improvecarenowexchange.org/node/1298>
- ICN Parent Working Group Mission: <http://improvecarenowexchange.org/node/1300>
- Self-Management Support (SMS)**
ImproveCareNow Self Management Support Handbook: <http://improvecarenowexchange.org/node/1456>
- Children's Mercy An Educational Guide for IBD: <http://improvecarenowexchange.org/node/1345>

- Mentoring**
Nationwide Children's Volunteer/Visitor Handbook: <http://improvecarenowexchange.org/node/1218>
- Riley Parent Mentor Group Mission Statement: <http://improvecarenowexchange.org/node/907>
- Riley Parent Mentor Group Binder: <http://improvecarenowexchange.org/node/1018>
- UNC Draft Welcome Letter: <http://improvecarenowexchange.org/node/289>
- Empowered by Kids Book of Hope: <http://improvecarenowexchange.org/node/1330>

School Resources
Letter to Request Specialized College Housing: <http://improvecarenowexchange.org/node/848>

APRISO, ASACIO MU, Delzico, Lialda, Pentasa	Yes	Yes	Oral
Cansasa		Yes	Suppository
Rowasa		Yes	Enema
Budesonide, Entocort EC, Uceris	Yes	Yes	Oral

Selected Commonly Used Medications in IBD

(Note: this is a partial list of drugs and brand name approved for use in children with IBD)

Medication Class	Generic Name
Aminosalicylates (5-ASA) & Mesalamines	Sulfasalazine
	Balsalazide
	Olsalazine
Corticosteroids	Mesalamines
	Budesonide
	Prednisone Prednisolone

PAC - Patient Advocates & Patients

The Patient Advisory Council ("PAC") for ImproveCareNow and CSN is a working group, made up of diverse teenagers and young adults (14+), diagnosed with IBD in childhood or adolescence, from all over the country. The PAC works with the clinical specialists of ImproveCareNow and the research specialists of CSN with the shared mission of remission and feeling better today for kids with IBD. As representatives of the children and adolescents in the ImproveCareNow network of care centers, PAC members volunteer on task forces to collaborate with clinicians, researchers, parents, and other network partners on the development of projects within the areas of **Communications, Advocacy, & Recruitment**.

We have referred to our incredible PAC members as "patient advocates," and are often are asked, "What's the difference between a patient advocate and a patient?" Here are our thoughts regarding the similarities and differences between patient advocates and patients:

Patient Advocate	Patient
Pediatric patient	Pediatric patient
An expressed interest in advocating for other patients	May have an interest in but has not expressed the desire to advocate for other patients
The interest in sharing one's story (e.g., blog posts)	May be considering sharing one's story but has not decided if it is of comfort to him/her
Seeks and participates in advocacy activities (e.g., PAC member)	May passively follow advocacy activities (e.g., read LODP posts)
Consistently dedicates time to advocacy activities	Currently dedicates time to other activities in higher life but not to advocacy activities

Inflammatory Bowel Disease New Diagnosis Checklist for Patients & Families

Checklist for _____ Date: _____

Who has been diagnosed with Crohn's disease, Indeterminate or

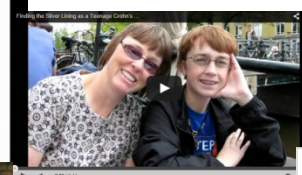
- I have been given a copy of the Children's Mercy IBD Education book.
- I have been given a copy of the Children's Mercy "How to Prepare for your Visit" Form.
- My blood sample has been taken to run necessary blood tests.
- My email address (name@improvecarenowexchange.org) has been added to the IMPROVECARENOW network.

Group Visits: An Interactive Demonstration



Using the Care Stratification Report In Your Population Management Meeting

This tutorial was made by the Nationwide Children's Hospital IBD team for ImproveCareNow.



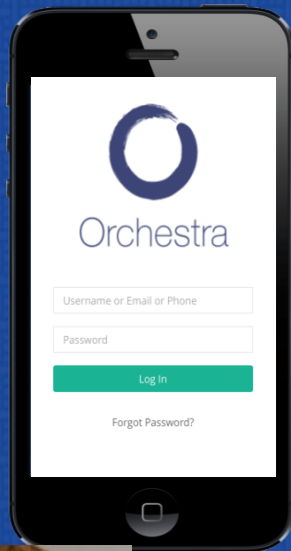
Opening Up About Your Disease Makes the Suffering Easier



Transition: getting ready to move to adult services



mHealth Enabled Personal Engagement



Mobile App

Web App

SMS

Desktop



- Scalable, consumer grade
- Behavioral design
- Engagement & collaboration
- Symptom observation & monitoring
- Personalized learning & experimentation

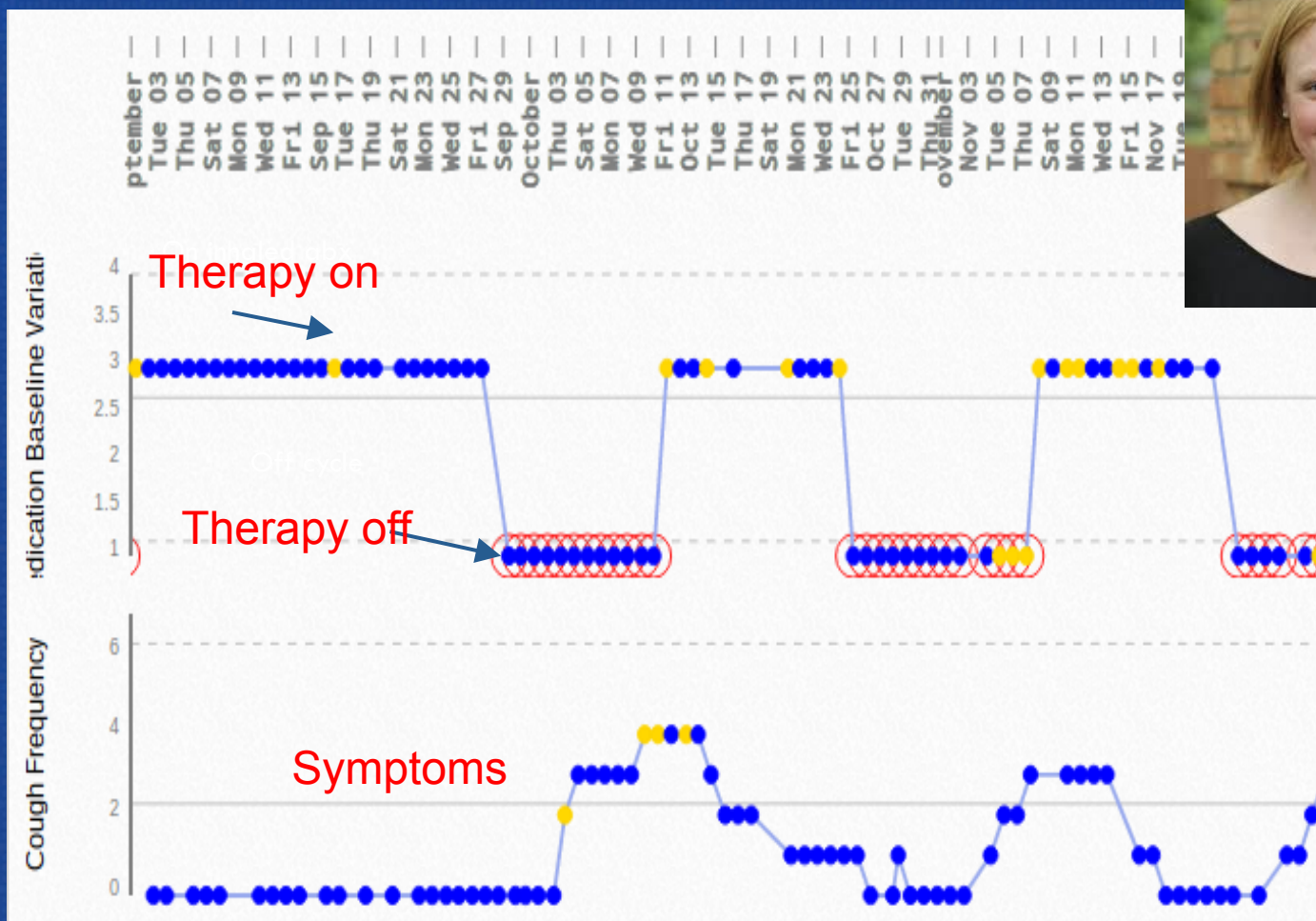
"A Personalized Learning System for Improving Patient-Physician Collaboration"
Harvard Business Review, HBR Blog Network, 2013 Oct.
<http://blogs.hbr.org/2013/10/a-personalized-learning-system-for-improving-patient-physician-collaboration/>

Data used to determine treatment plan

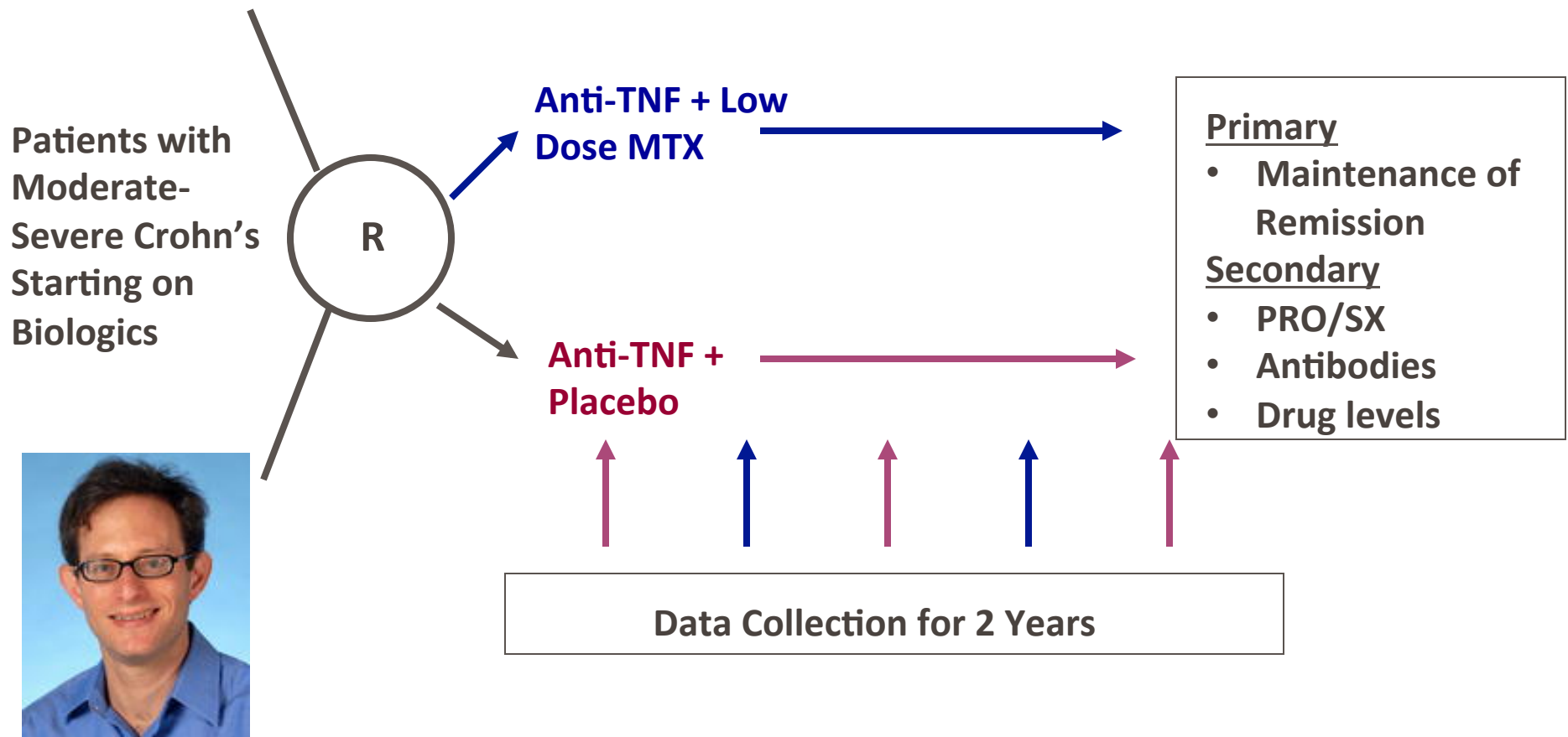
4 year old with CF

14 day on/off inhaled antibiotic cycles to manage multi drug resistant bacteria

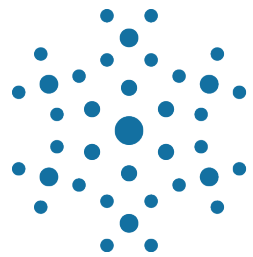
- “on” cycles keep cough to a baseline of no cough
- “off” cycles increased cough frequency



Anti-TNF Monotherapy vs. Combination Therapy with Low Dose Methotrexate in Pediatric Crohn's disease



Building Distributed Leadership



270STRATEGIES



Steal shamelessly, share seamlessly

Common Purpose
Generosity and Contribution
Mastery
Continuous Improvement
Learning
Trust
Friendship
Solidarity
Respect
Hope
Gratitude

What we've learned

- Relentless focus on outcomes
- Design for synergy - meet needs and goals of all stakeholder simultaneously
- Increase number of participants
- Variety of ways to accumulate and share resources (a 'commons')
- Structures and processes make it easier to collaborate
- Cooperative behaviors emerge

What we have to learn

- Addressing shifting power dynamics
- Education for co-production
- Managing capacity as contribution increases
- How to lead and foster conditions for cooperation