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

COLLABORATIVE CHRONIC CARE NETWORK

Peter Margolis, MD, PhD
Jennie David

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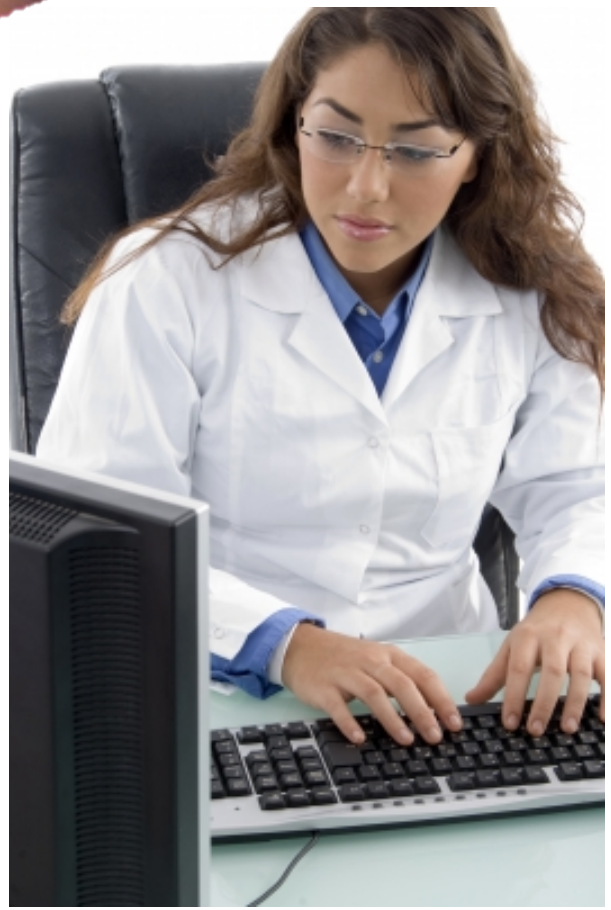
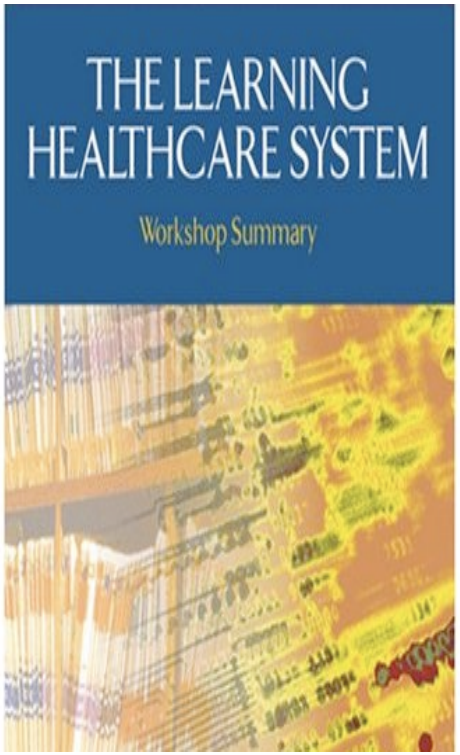


Learning Healthcare System

- 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

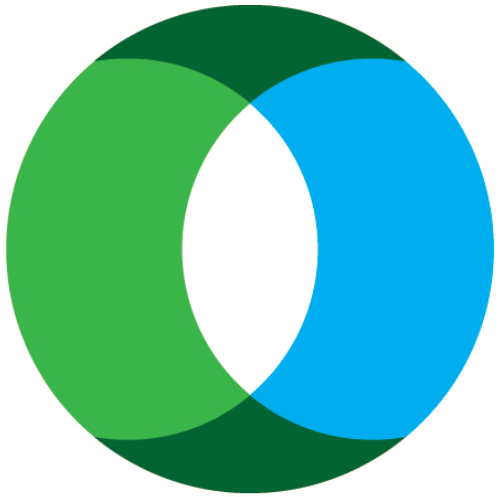
Elinor Ostrom 1933-2012
Economist
Nobel Laureate 2009

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

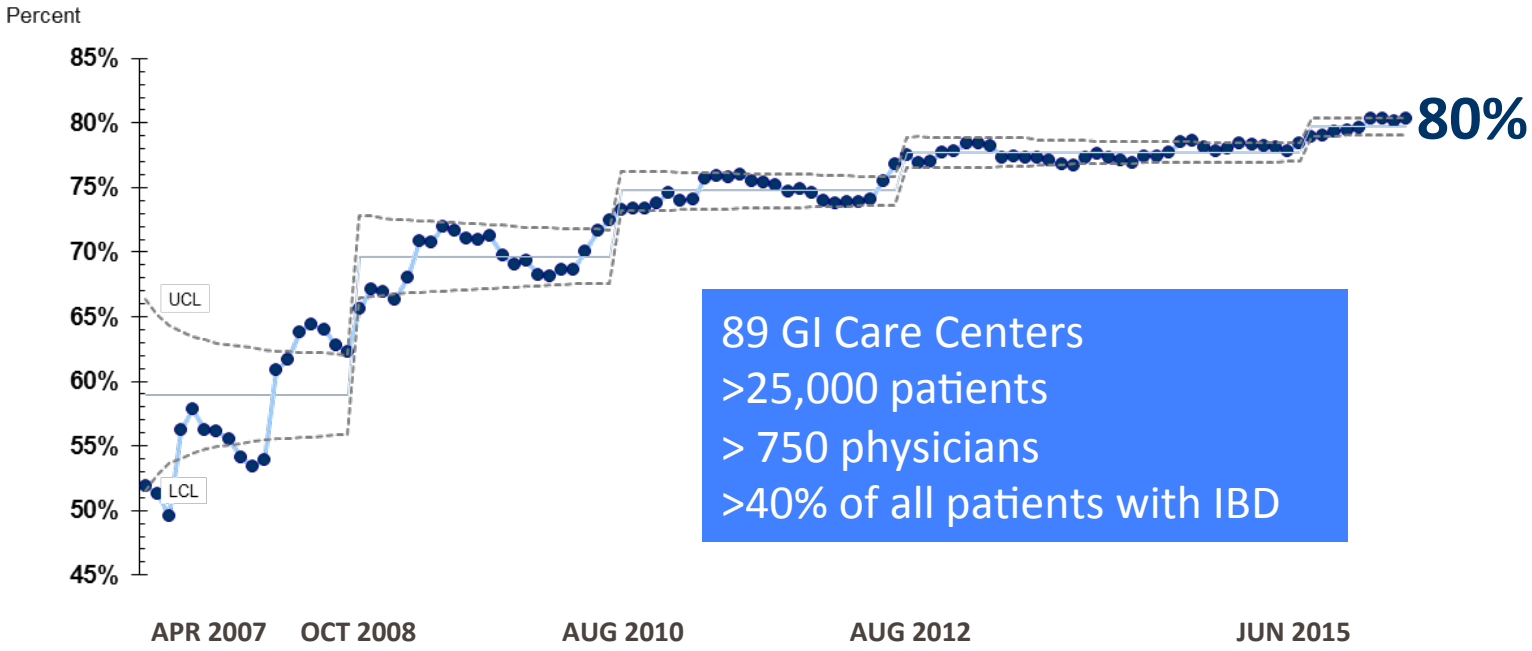
Martin Nowak
Program on Evolutionary Dynamics
Harvard



IMPROVE**CARE**NOW

% of patients in clinical remission

Crohn's and Ulcerative Collitis

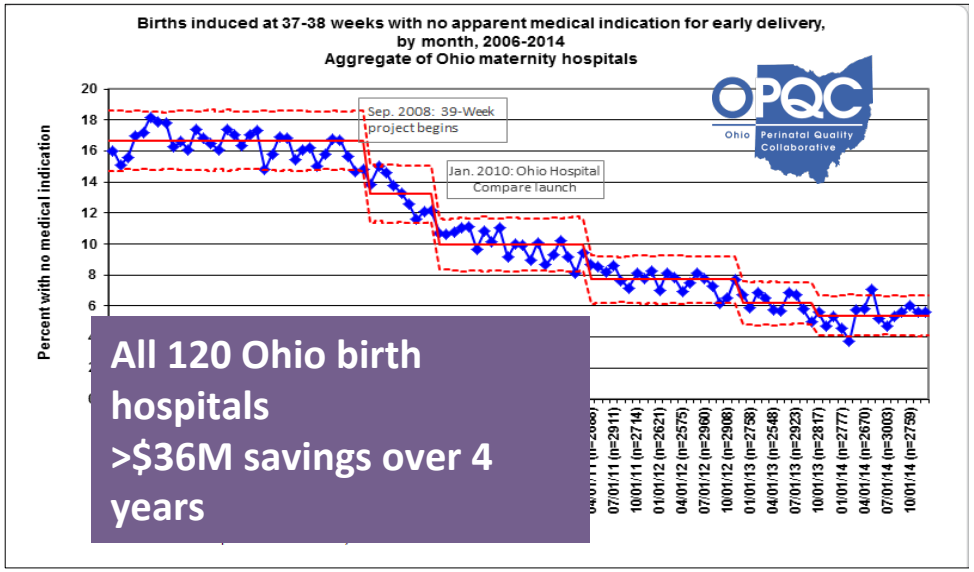


89 GI Care Centers
>25,000 patients
> 750 physicians
>40% of all patients with IBD

Centers >75% registered

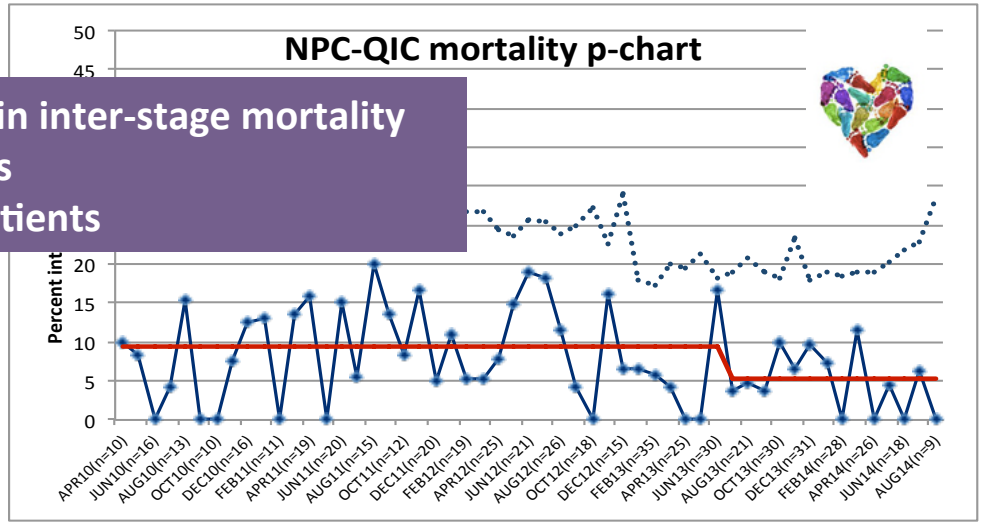
Improved Outcomes in a Quality Improvement Collaborative for Pediatric Inflammatory Bowel Disease. Pediatrics. 2012;129:1030-41

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



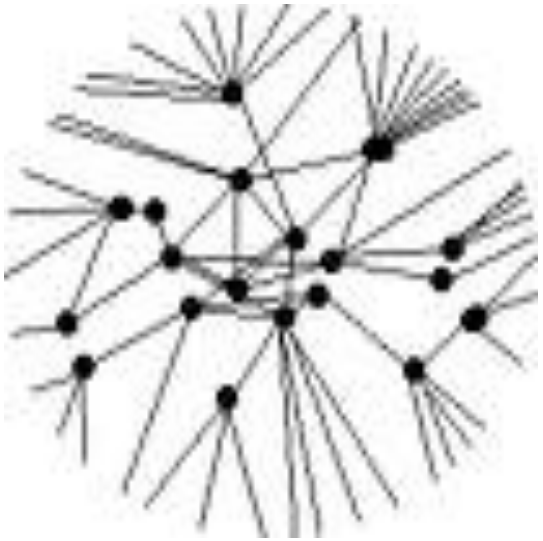
All 120 Ohio birth hospitals
>$36M savings over 4 years

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



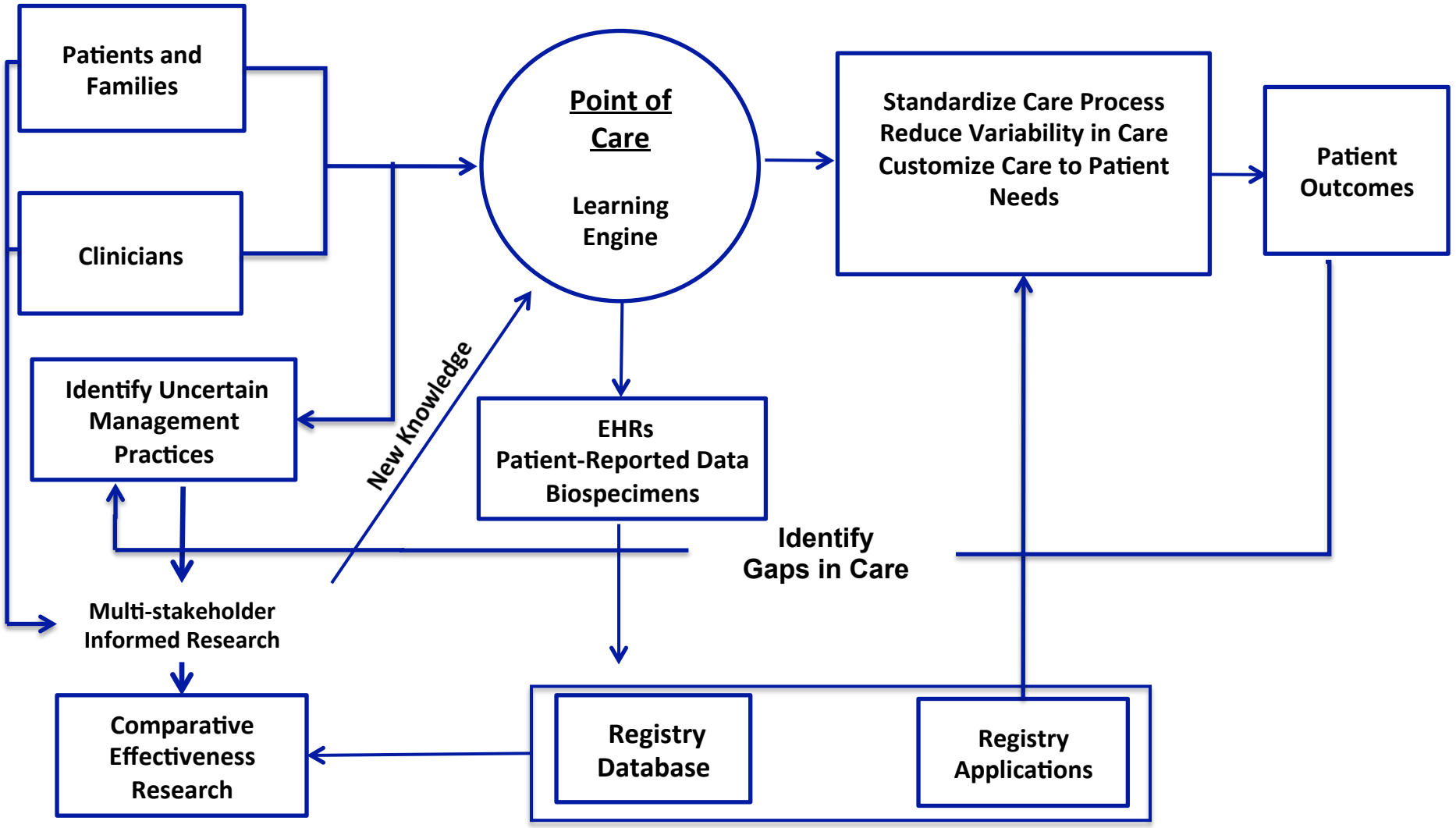
Components of a network-based Learning Health System*

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

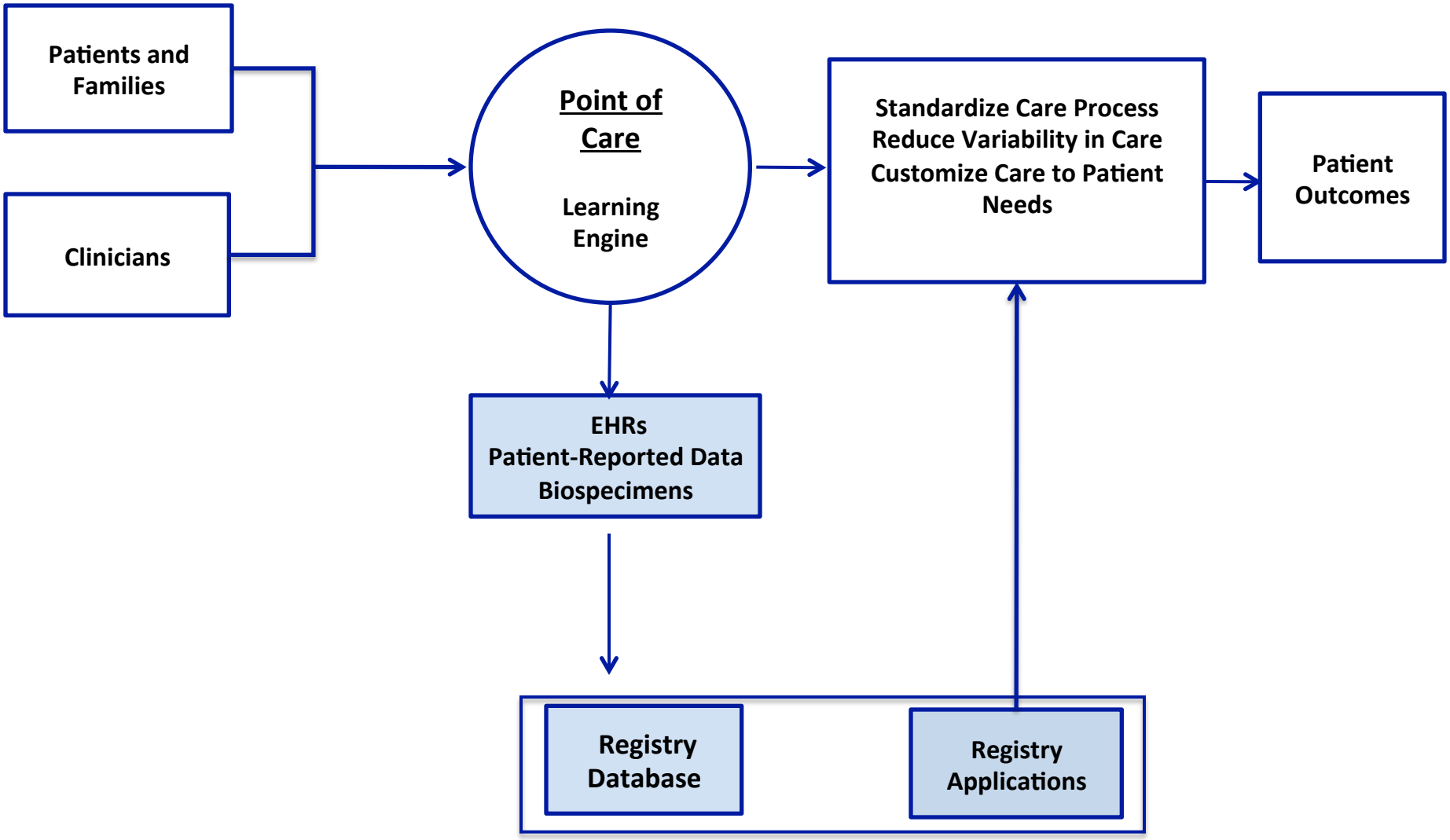


*Collective creativity (Swarm Creativity; Peter Gloor)
Lead User innovation (Democratizing Innovation; Eric von Hippel)
New economic models (The Wealth of Networks; Yochai Benkler)
Actor-oriented organizational architecture (Configuring value for competitive advantage; Charles Stabell and Oystein Fjelstad

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

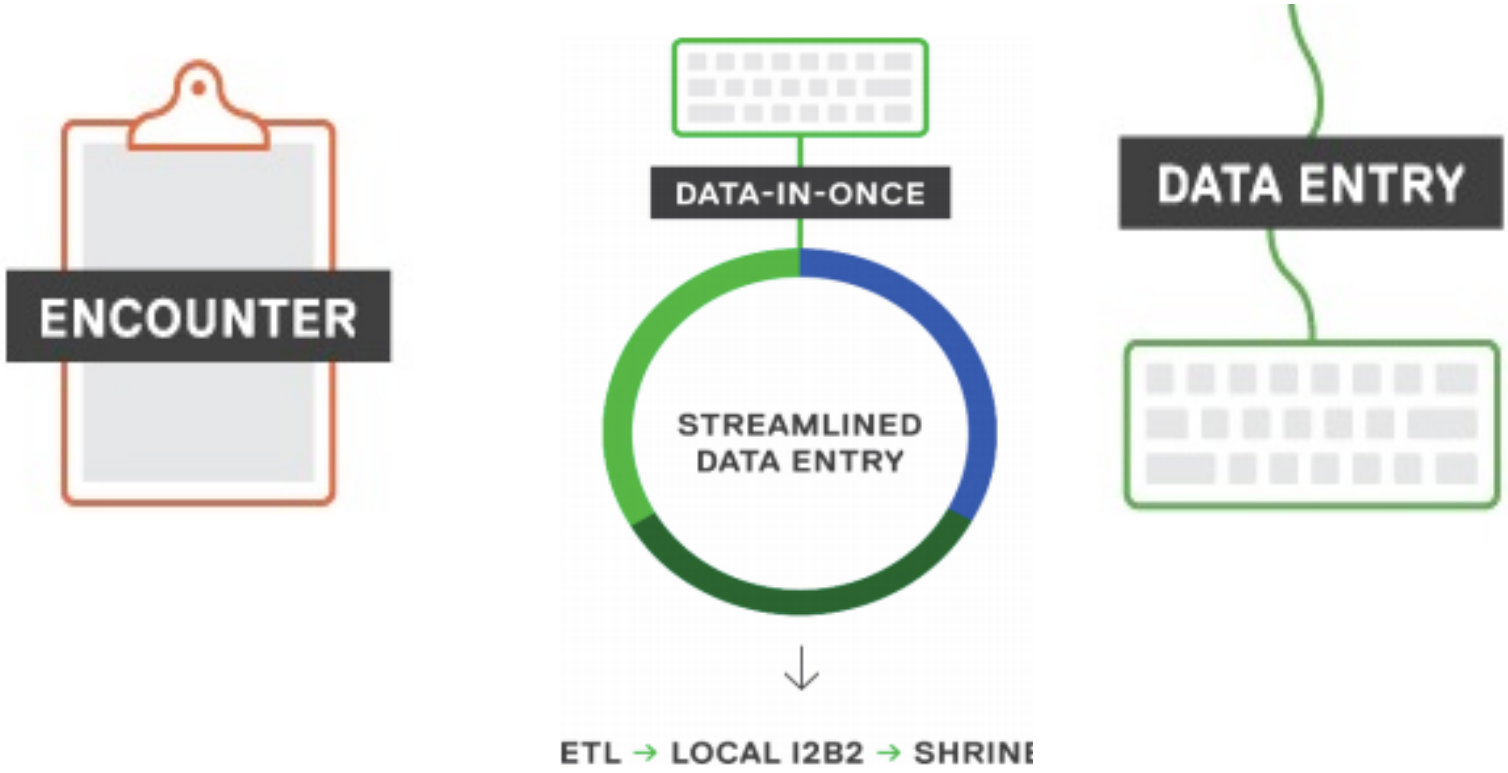


Improving Outcomes with a Learning Health System



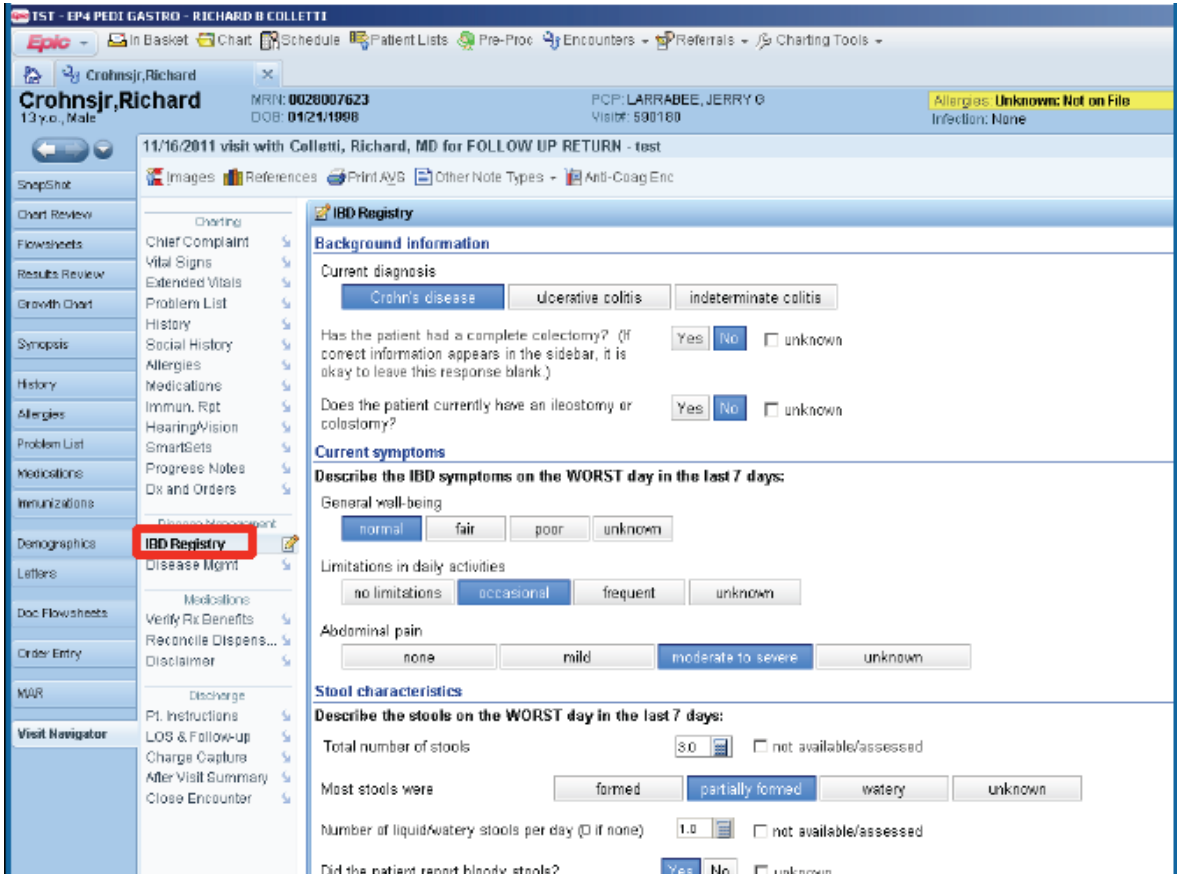
Source: Marsolo et al. *Forthcoming*

“Data in once” - Technology for efficient data capture



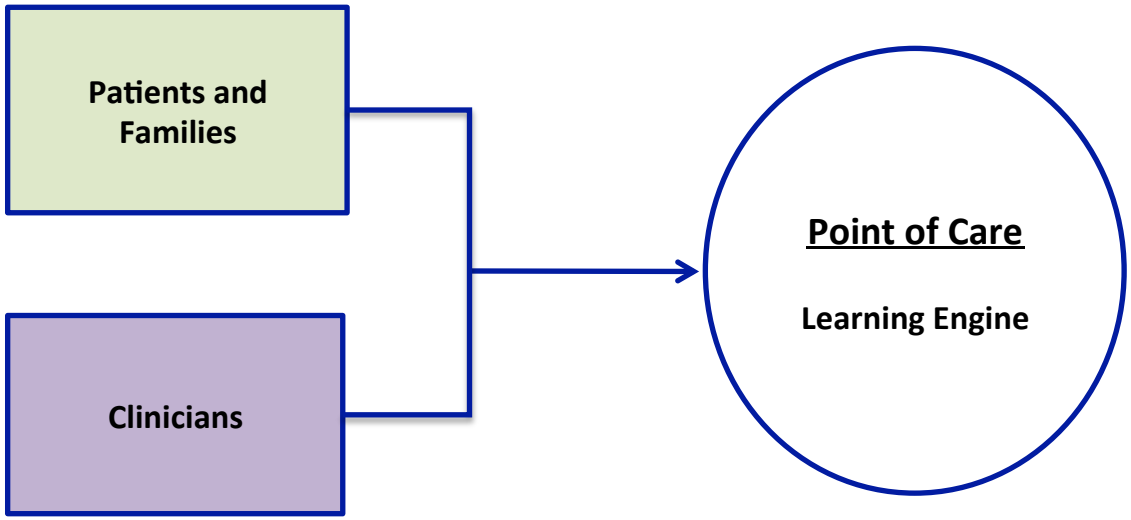
Marsolo K, Margolis PA, Forrest CB, Colletti RB, Hutton JJ. A digital architecture for a network-based learning heath system – integrating chronic care management, quality improvement, and research. eGEMS. 3:2015

Data-in-once (at clinical visit)

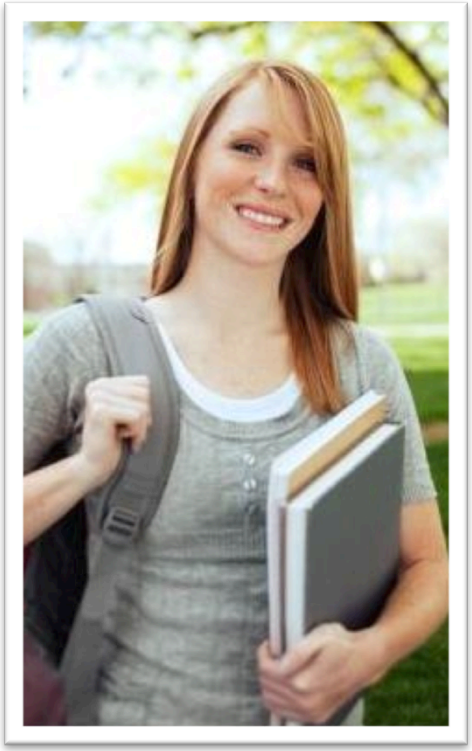


An “Enhanced” Registry uses data for clinical care, QI and research

- 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


Patients and Families
Clinicians
Point of Care
Learning Engine

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

Fore D, Goldenhar LM, Seid, M, Margolis PA. Using goal-directed design to create a novel system for improving chronic illness care. JMIR. 2013 29;2:e43

Engagement

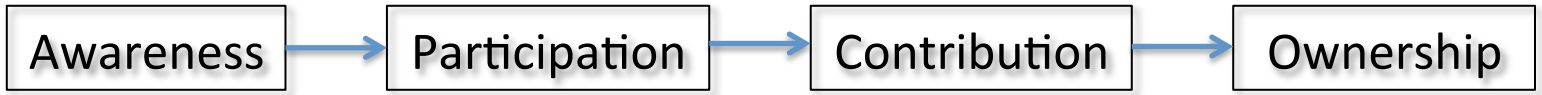
Being part of the distributed learning health system,

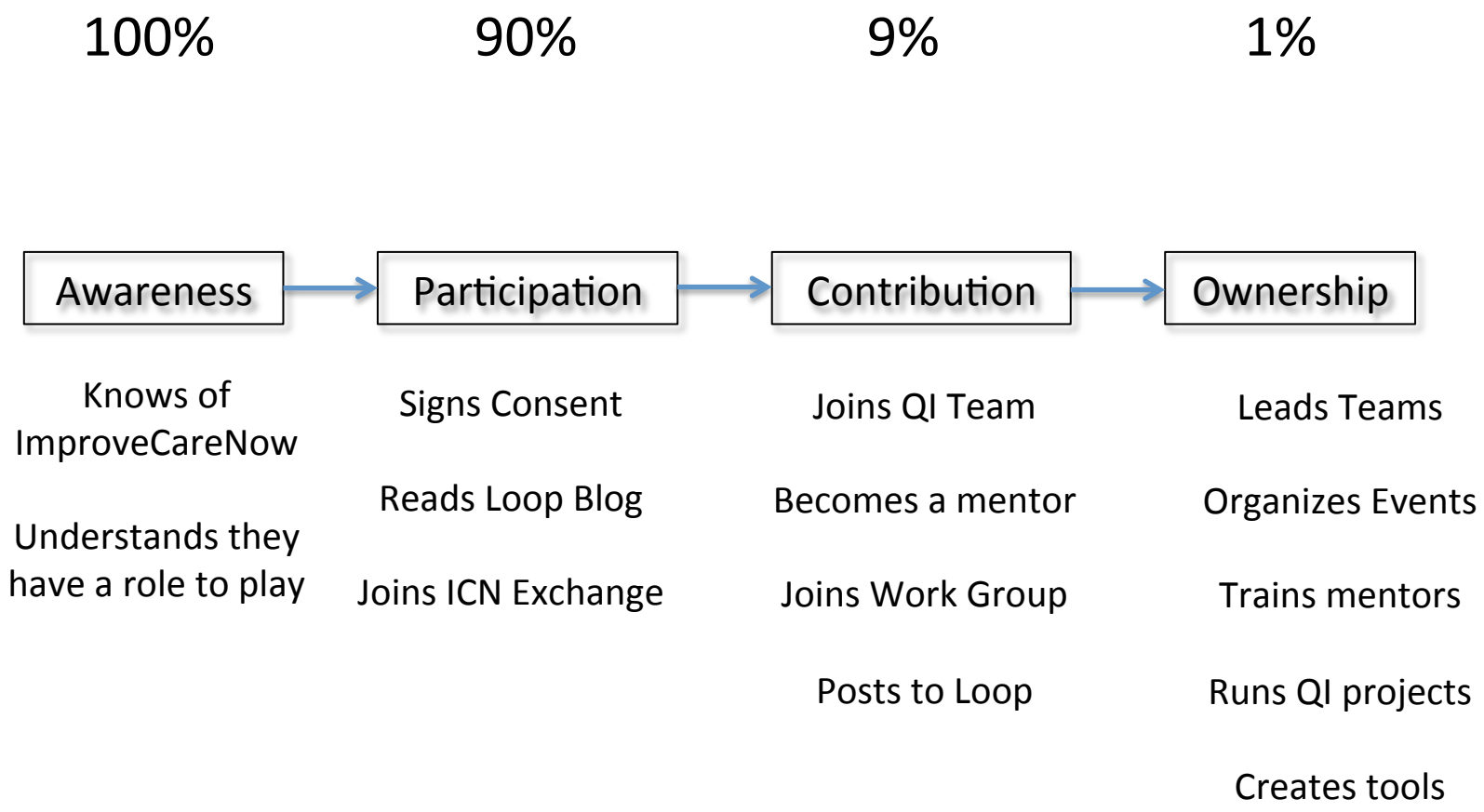
- to produce information, knowledge, and know-how
- for improving
  - personal health and
  - the health care system

Includes patients, families, clinicians and health system leaders

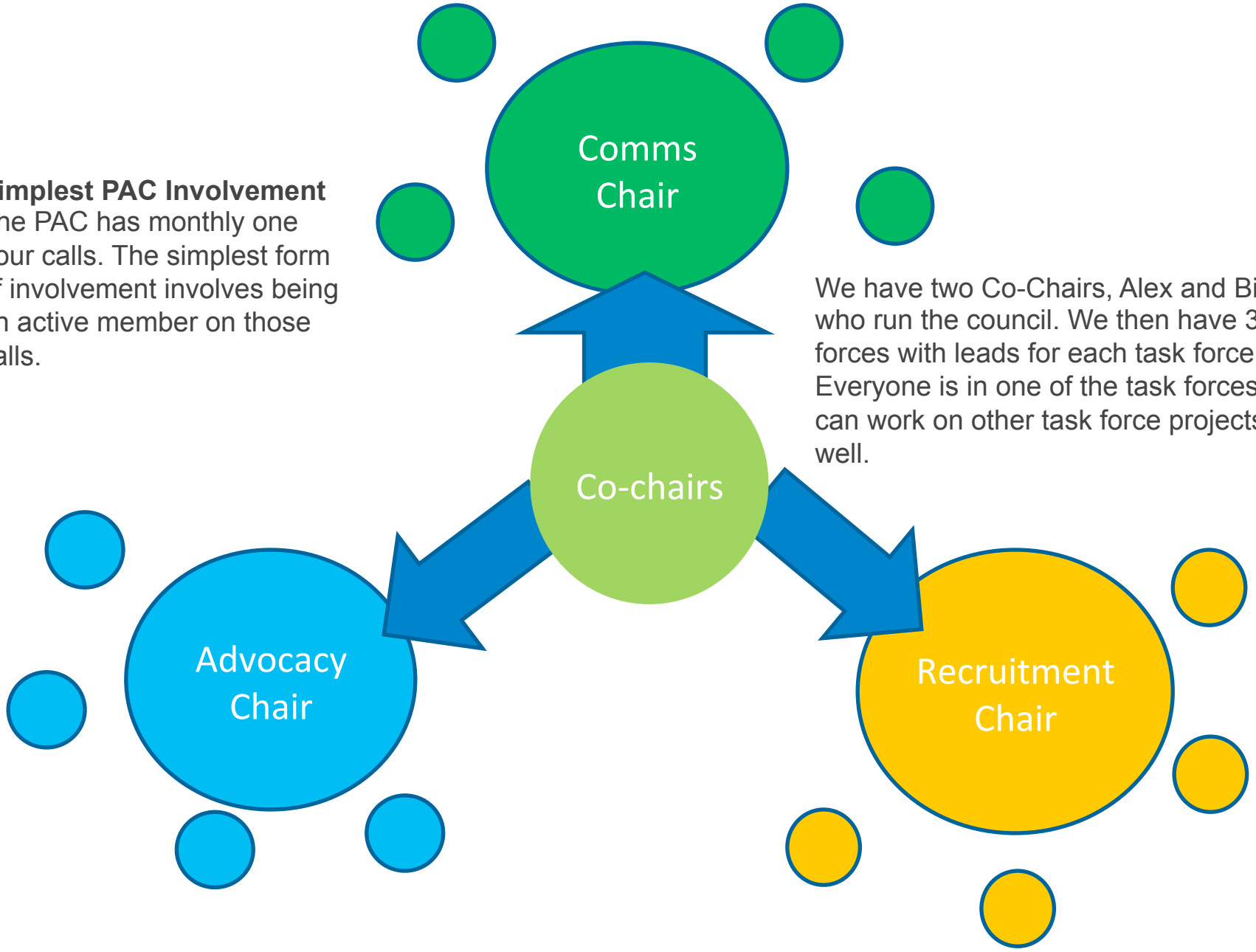
Seid M, Margolis PA, Opipari-Arrigan L. Engagement, Peer Production, and the Learning Healthcare System. JAMA Pediatrics. 2014;168:201-2

Stages of Engagement




100%
90%
9%
1%
Awareness
Participation
Contribution
Ownership
Knows of ImproveCareNow
Understands they have a role to play
Signs Consent
Reads Loop Blog
Joins ICN Exchange
Joins QI Team
Becomes a mentor
Joins Work Group
Posts to Loop
Leads Teams
Organizes Events
Trains mentors
Runs QI projects
Creates tools

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



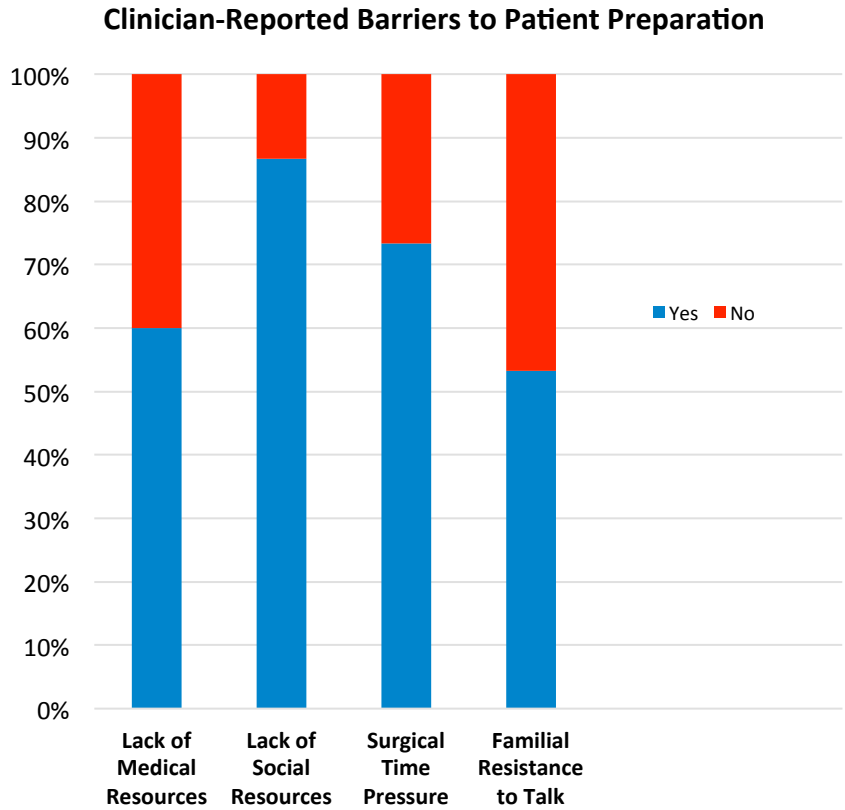
We have two Co-Chairs, Alex and Bianca, who run the council. We then have 3 task forces with leads for each task force. Everyone is in one of the task forces but can work on other task force projects as well.

+

the ostomy toolkit

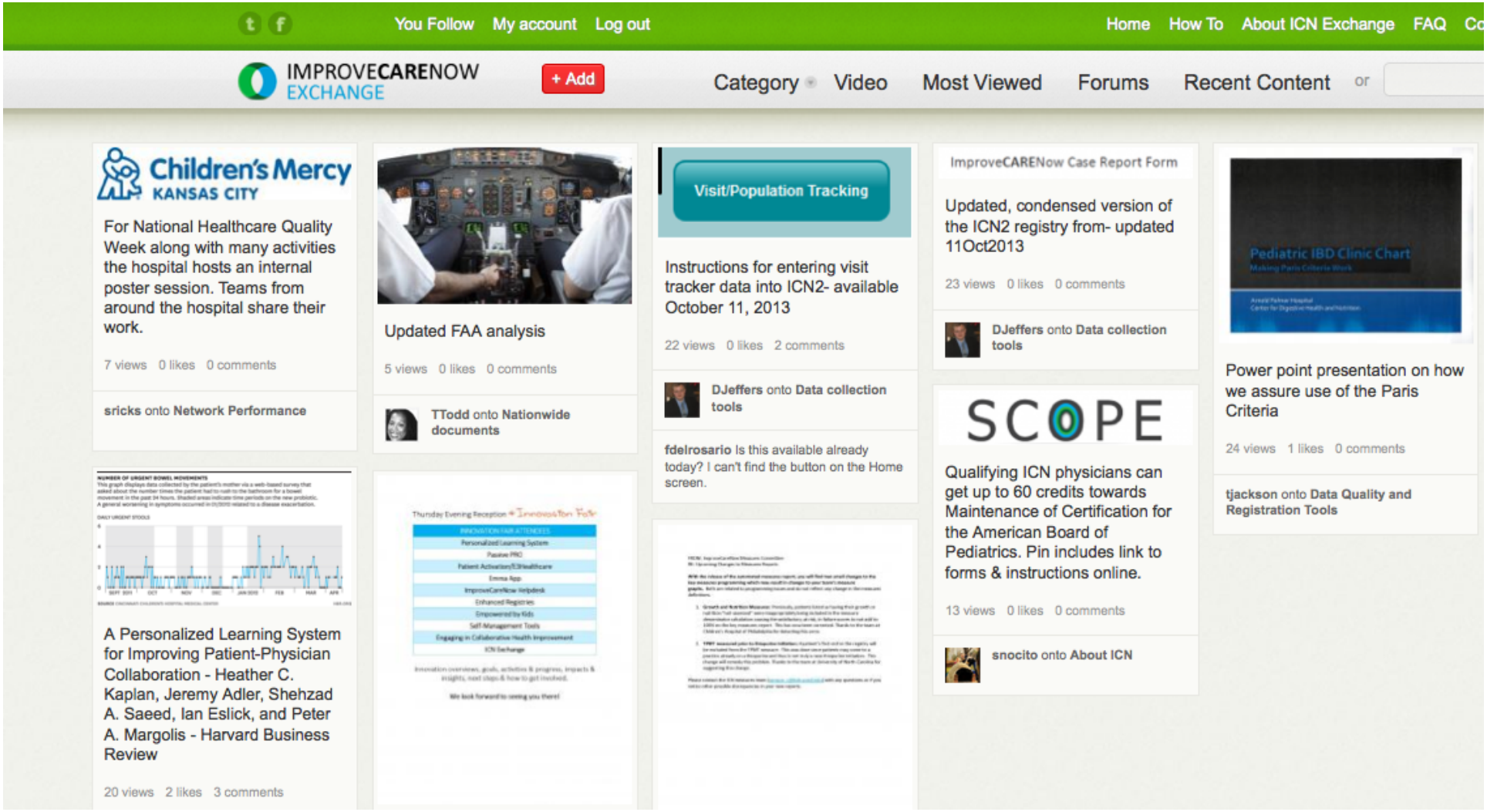
Ostomy Toolkit Data

IMPROVECARENOW



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

A “Commons” for sharing



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 submitted, you will receive a con
Resea

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improving lives through collaborative medicine

Research Proposal Request Form

ctions
e complete the Research Proposal Request documents and return to Kendra Wiegand at
ra.Wiegand@cchmc.org.
mpleted 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)

degree(s)

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

ICN
ir
out their

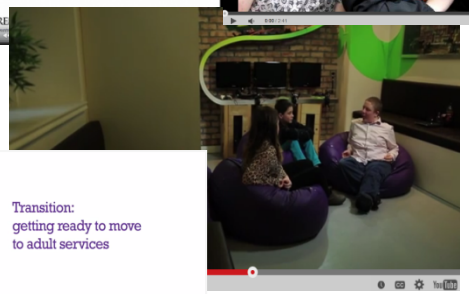
ImproveCareNow Data Sharing Expectations

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.

Using The
Care Stratification Report
In Your
opulation Management Meeting

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

NATIONWIDE CHILDRE



Transition:
getting ready to move
to adult services

Selected Commonly Used Medications in
(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			
	Mesalamines			
	Apriso, Asacol HD, Delzicol, Lialda, Pentasa	Yes	Yes	Oral
	Cansasa		Yes	Suppository
	Rowasa		Yes	Enema
Corticosteroids	Budesonide	Yes	Yes	Oral
	Prednisone			
	Prednisolone			
	Methylprednisolone			

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/1768
ICN Parent Working Group Mission: http://improvecarenowexchange.org/node/1800

Self-Management Support (SMS)
ImproveCareNow Self Management Support Handbook: http://improvecarenowexchange.org/node/1496
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/1024
UNC Draft Welcome Letter: http://improvecarenowexchange.org/node/849
Empowered By Kids Book of Hope: http://improvecarenowexchange.org/node/1330

School Resources
Levine Letter to Request Special College Housing: http://improvecarenowexchange.org/node/848

Patient Advocates & Patients

The Patient Advisory Council ("PAC") for ImproveCareNow and C3N 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 C3N 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 LOOP posts)
Consistently dedicates time to advocacy activities	Currently dedicates time to other activities in his/her life but not to advocacy activities

Children's Mercy

Inflammatory Bowel Dis

New Diagnosis Checklist
for Patients & Families

Checklist for _____ Date: _____

Who has been diagnosed with Crohn's disease, Indeterminant 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.

all together now

mHealth Enabled Personal Engagement

Mobile App

Web App

SMS

Desktop

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

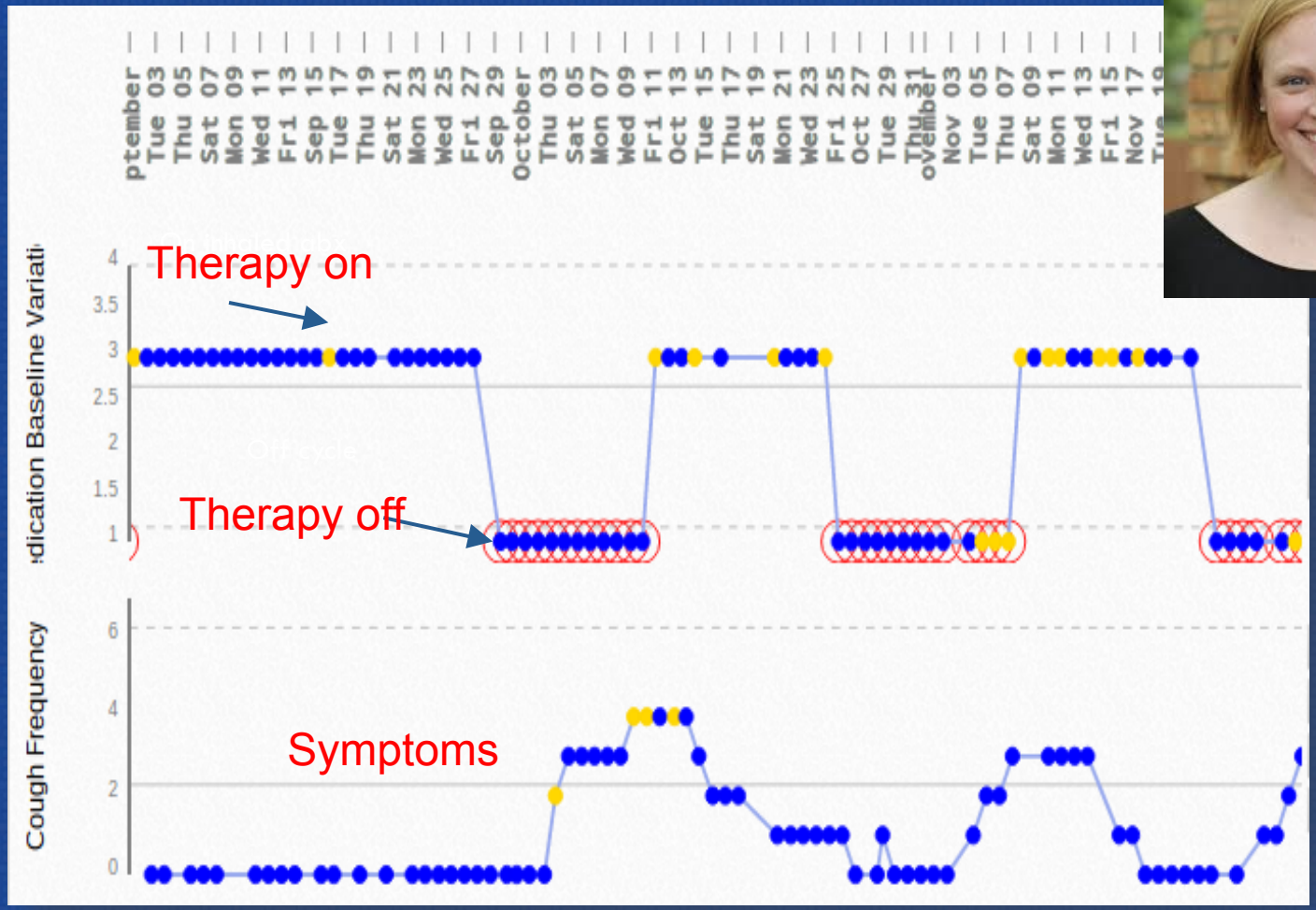
A Personalized Learning System for Improving Patient-Physician Collaboration" Harvard Business Review, HBR Blog Network, 2013 Oct. http://blogs.hbr.org/2013/10/a-personalized-learning-system-for-improving-patient-physician-collaboration/

Data used to determine treatment plan

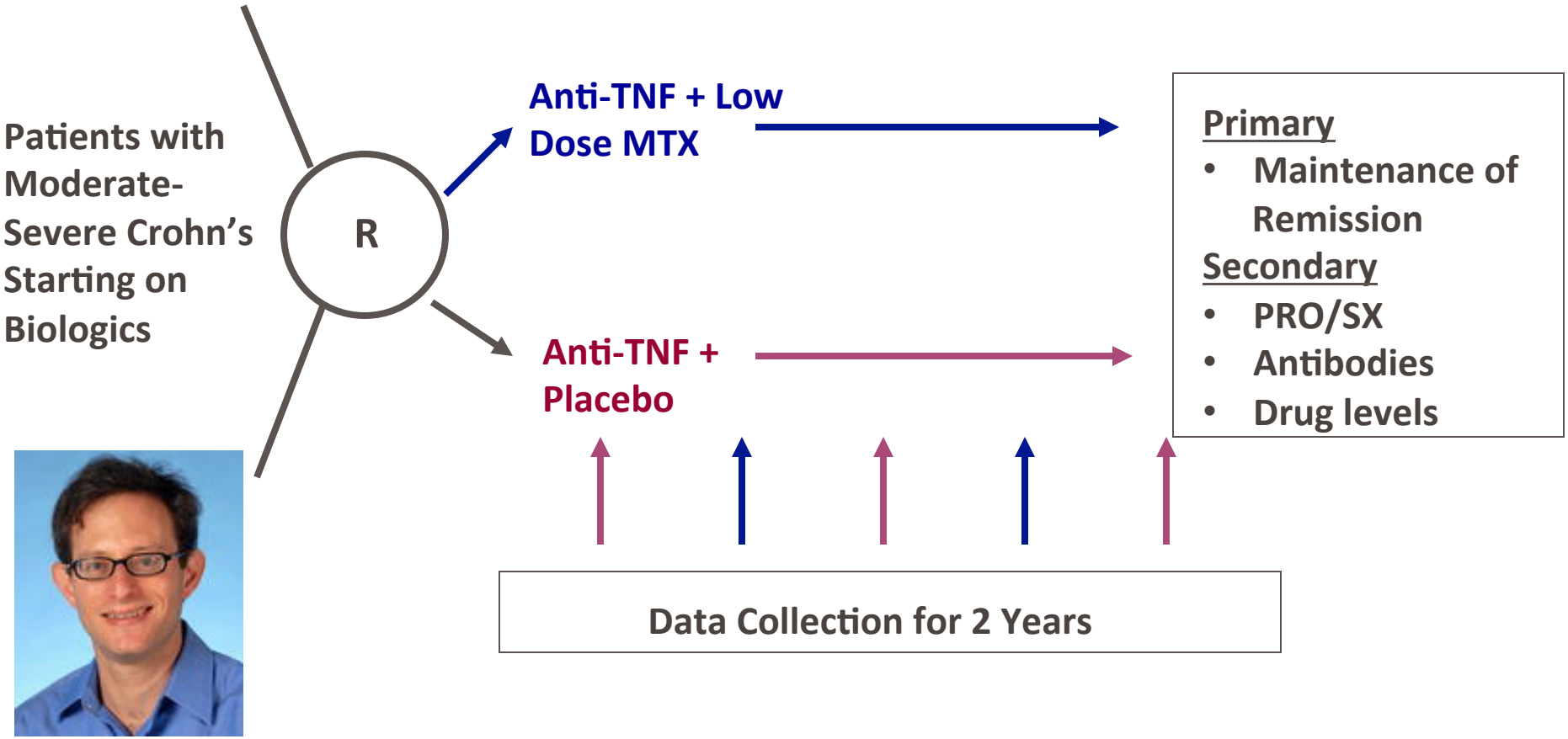
4 year old with CF

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

Steal shamelessly, share seamlessly

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

C3N

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

C3N

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