



COLLABORATIVE CHRONIC CARE NETWORK

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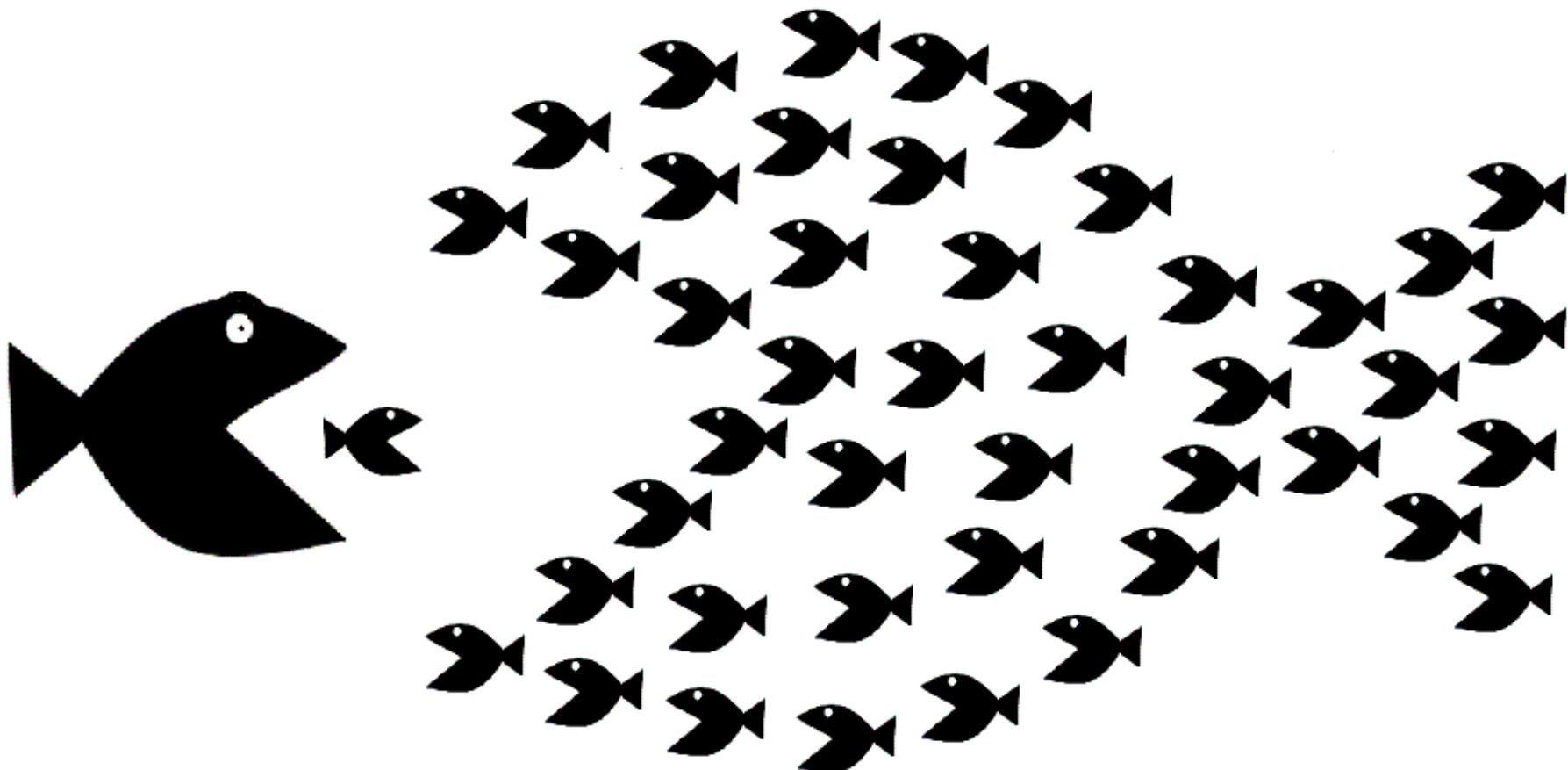
Learning Health Systems

- 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

Institute of Medicine



Network-Based Production



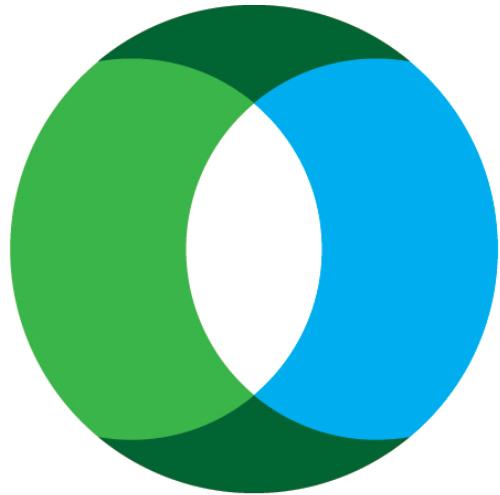
Yochai Benkler, "The Wealth of Networks"

A C3N is
a network-based
production system
for health improvement



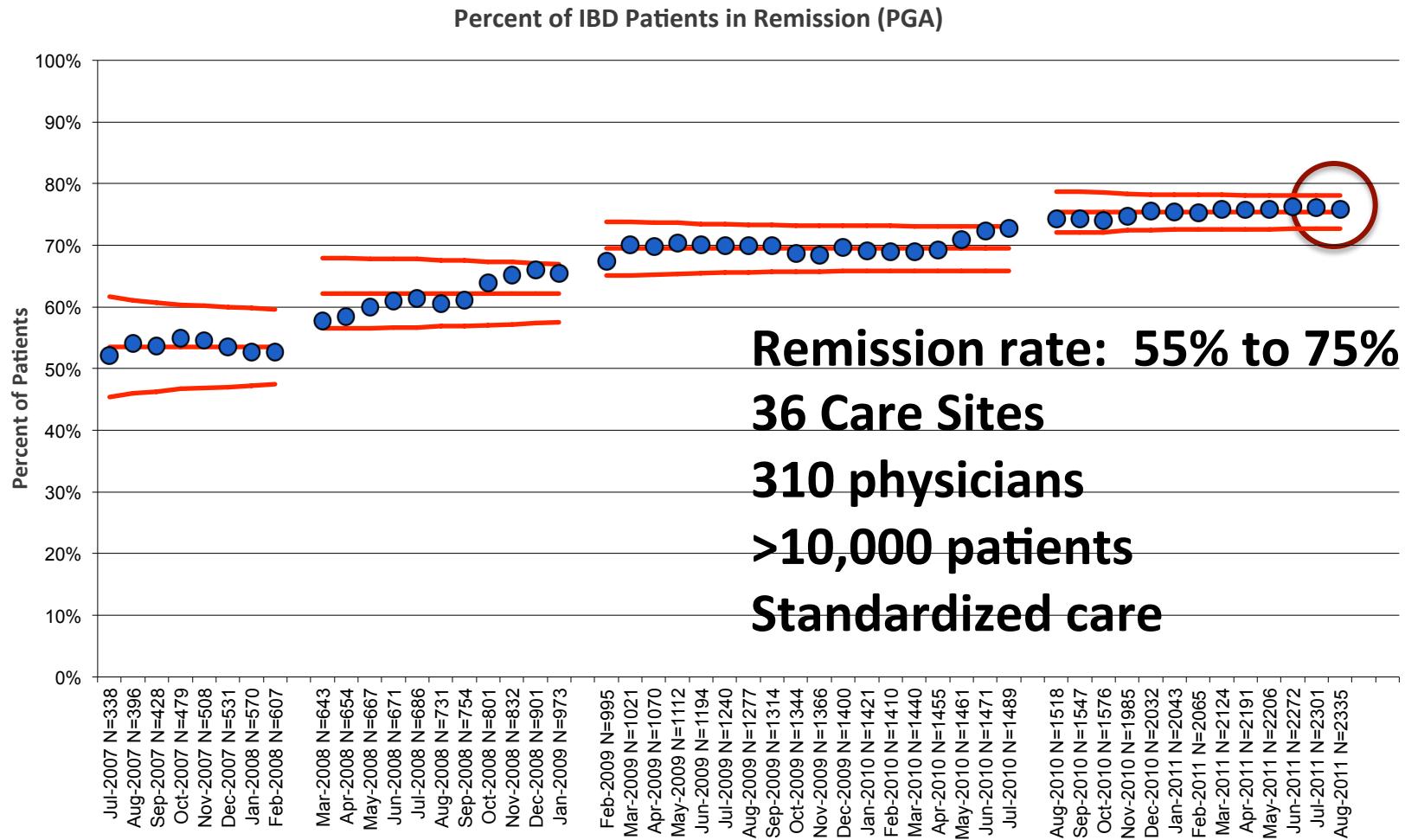
C3N





IMPROVE**CARE**NOW

Percent of Patients in Remission

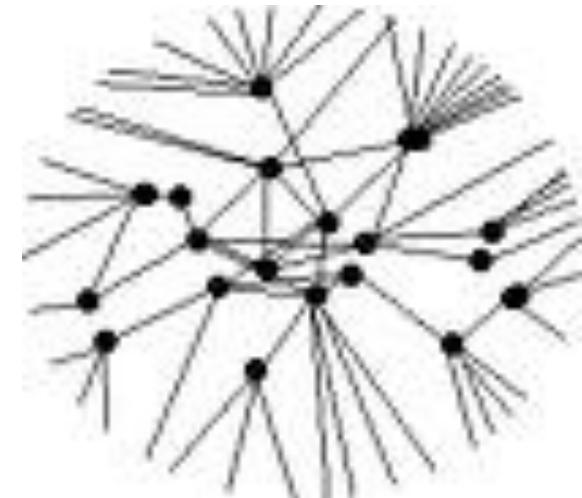


Crandall, Margolis, Colletti et al
Pediatrics 2012;129:1030



How do you create a network–based production system for health and health care?

1. Build Community – Social Operating System
2. Develop Technical Operating System
3. Enable Learning, Innovation and Discovery – Scientific Operating System



Building Community

- Compelling purpose
- Core leadership – patients, clinicians, researchers
- Sharing stories
- Many ways to contribute



Building community

- Sharing stories
- Patient and parent advisory councils
- Parents on QI teams
- Patients on staff
- Parents and patients at network meetings
- Lots of places to communicate (care centers, education days, integrated website, newsletters, social media)

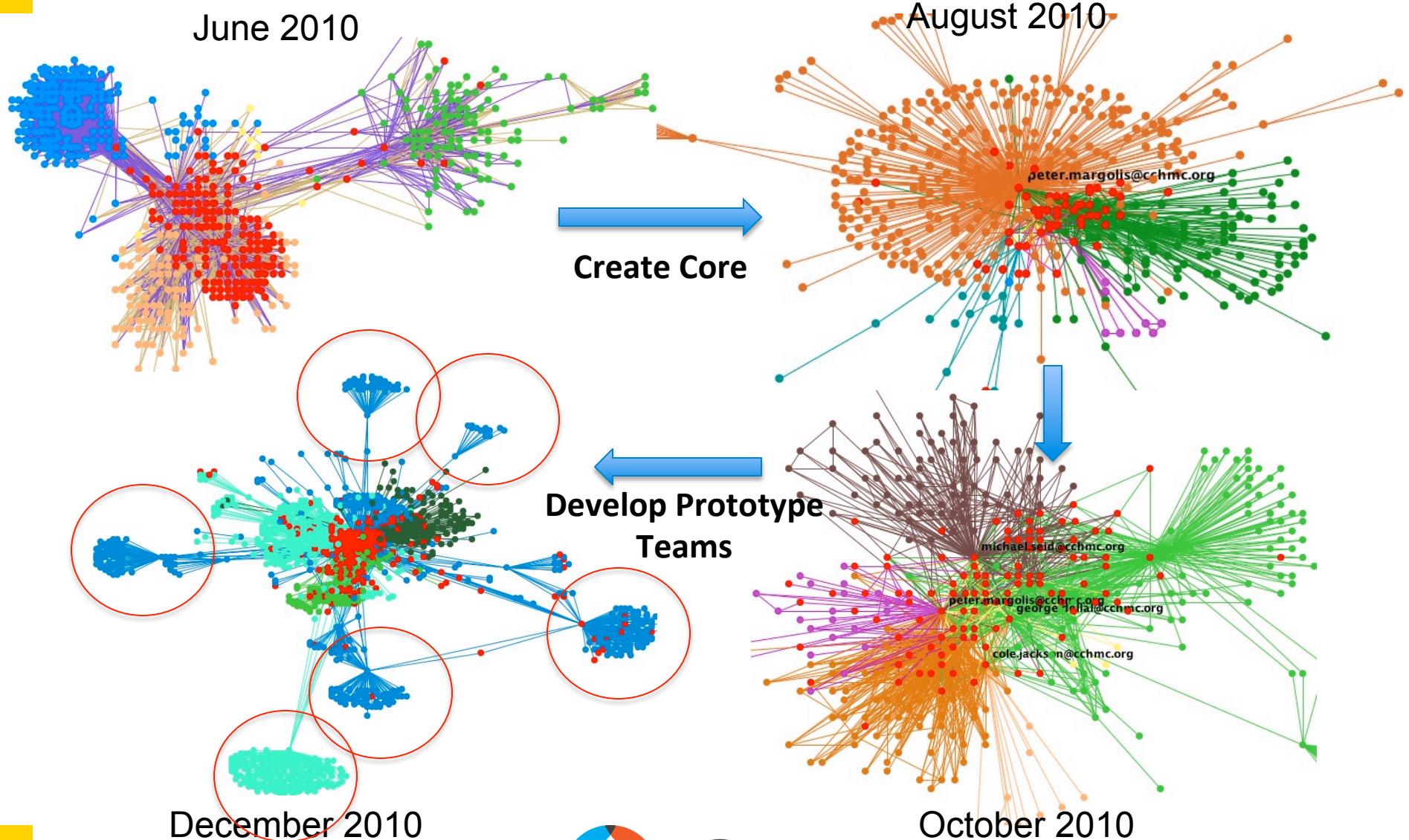
Jill Plevinsky

Eden D'Ambrosio

Lisa Vaughn etc .



Evaluating Leadership Behavior During Design Phase



Peter Gloor, PhD. MIT Center for
Collective Intelligence



C3N



Reducing Transactional Costs

Technical Operating System



Example: Data Collection

TST - EP4 PEDI GASTRO - RICHARD B COLLETTI

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

Crohnsjr, Richard

MRN: 0028007623 PCP: LARRABEE, JERRY G
DOB: 01/21/1998 Visit#: 590180 Allergies: Unknown: Not on File
Infection: None

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

Images References Print AVS Other Note Types Anti-Coag Enc

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: 3.0 not available/assessed

Most stools were: formed, partially formed, watery, unknown

Number of liquid/watery stools per day (0 if none): 1.0 not available/assessed

Did the patient report bloody stools? Yes No unknown

The typical amount of blood was: small amount in <50% of stools, small amount in >=50% of stools, large amount, unknown

Did the patient report nocturnal diarrhea? Yes No unknown

Extraintestinal manifestations (current)

Fever >38.5 C for 3 of the last 7 days? Yes No unknown

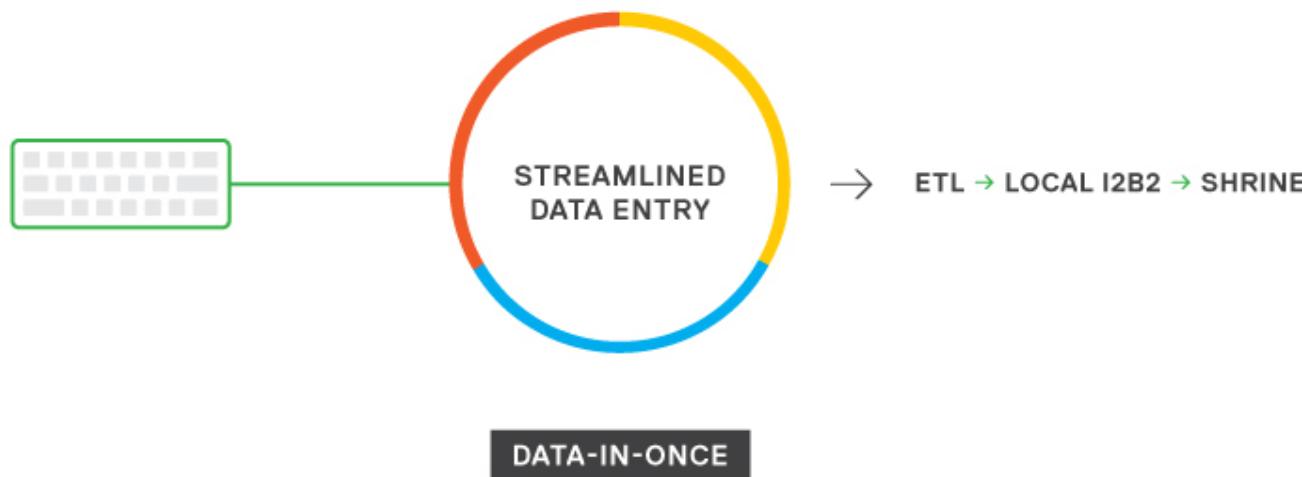
Definite arthritis? Yes No unknown

More Activities

Courtesy
Richard Colletti, MD
Keith Marsolo, PhD

“Enhanced” Registry

- CER using distributed registry (>10,000 patients)
- Chronic care processes
- QI reports
- Data Quality
- Support for experiments



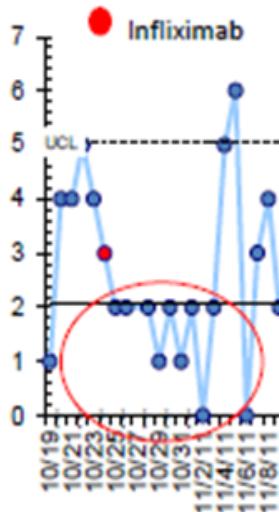
John Hutton, MD; Keith Marsolo, PhD; Charles Bailey, MD; Christopher Forrest, MD, PhD; Marshall Joffe, MD, PhD; Wallace Crandall, MD; Mike Kappleman, MD, MPH; Eileen King, PhD

Testing Multiple Interventions Simultaneously

2^3 Full Factorial Design with 3 Replications

Treatment Combination	Pre-visit Planning	Population Management	Self-Management Support
Site 1	-	-	-
Site 2	+	-	-
Site 3	-	+	-
Site 4	-	-	+
Site 5	+	-	+
Site 6	-	+	+
Site 7	+	+	-
Site 8	+	+	+

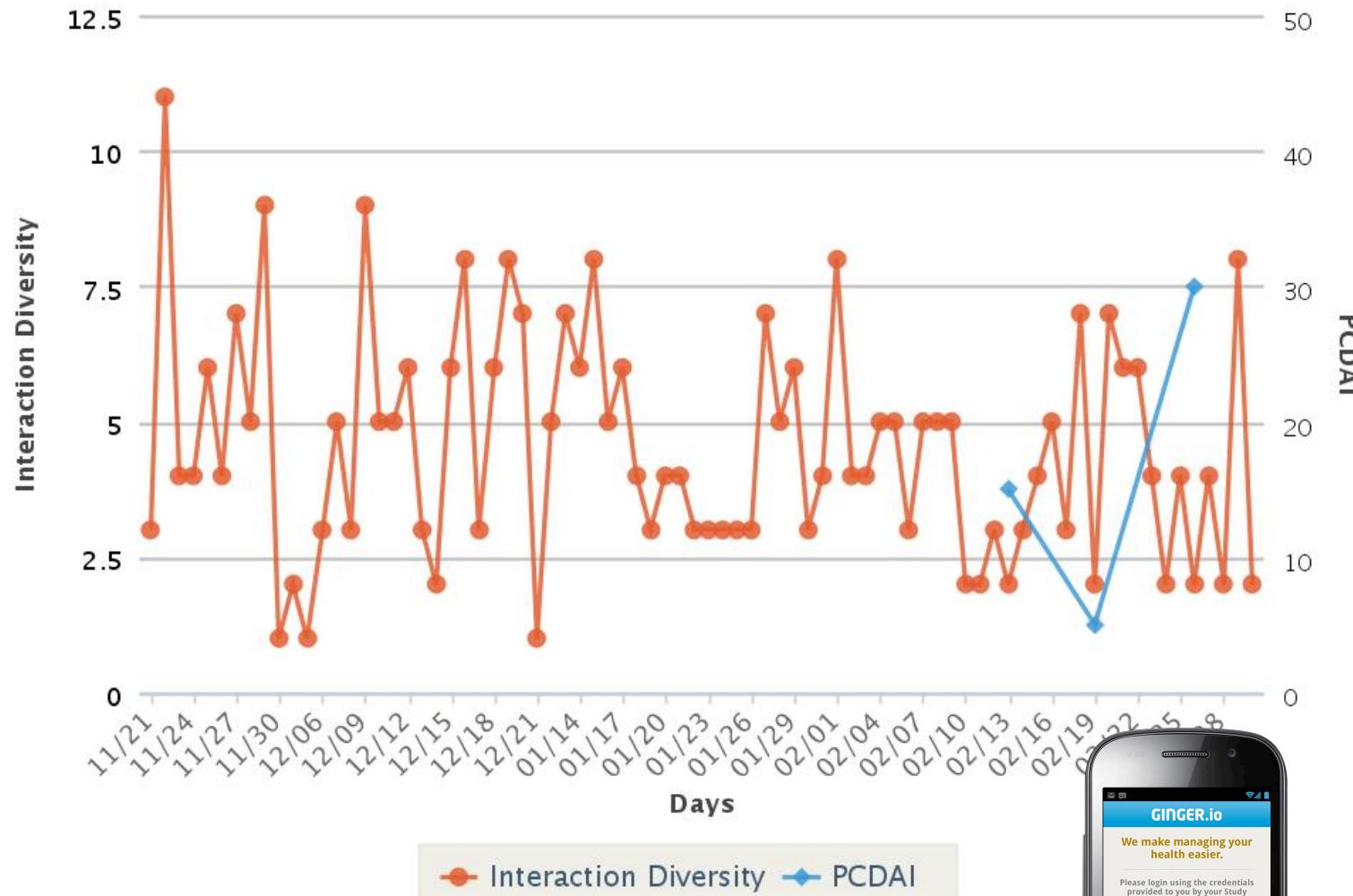
Molly's Story



Nocturnal Stools (I chart)

Heather Kaplan, MD, MSc
Jeremy Adler, MD, MPH
Ian Eslick, MS

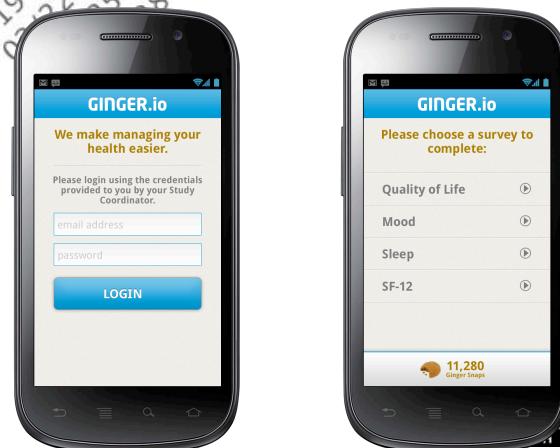
Reducing Burden of Data Collection



Anmol Madan, PhD
Ginger.io



C3N



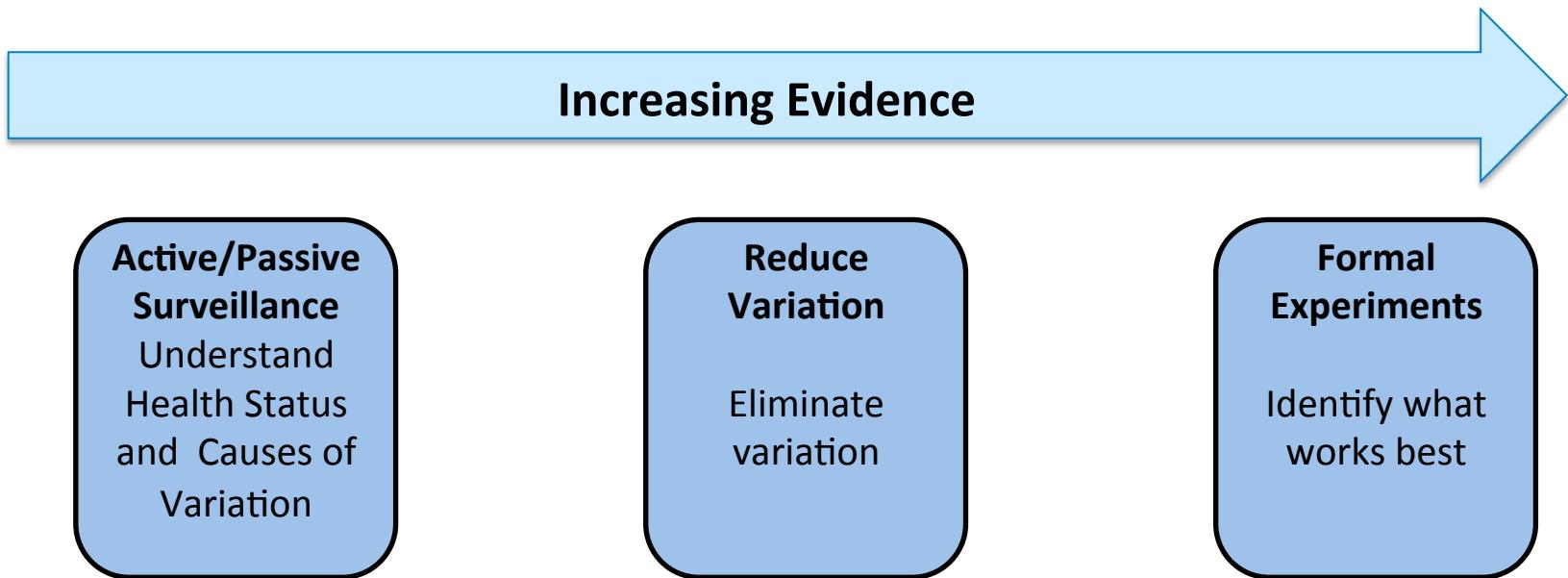
How can PCORI build on the C3N model?

- Expand to all care centers and all children with IBD (50-75,000)
- Build additional communities to work together to co-create learning health systems
- Support research at whole system level
 - Support design and prototype to see how to fit pieces together
- Data sharing linked to action



COLLABORATIVE CHRONIC CARE NETWORK

Collaborative Learning System for Patients, Clinicians and Researchers



Increased Confidence in Finding the Right Treatment
Improved Outcomes
Increased Knowledge of Disease

Initial Collaborators

- ImproveCareNow
 - 36 care centers
 - >10,000 patients
- Patients
- Lybba Design and Communications
- Associates in Process Improvement
- U of Chicago Booth School of Business
- Creative Commons
- MIT Media Lab
- MIT Center for Collective Intelligence
- UCLA Center for Healthier Families and Children

