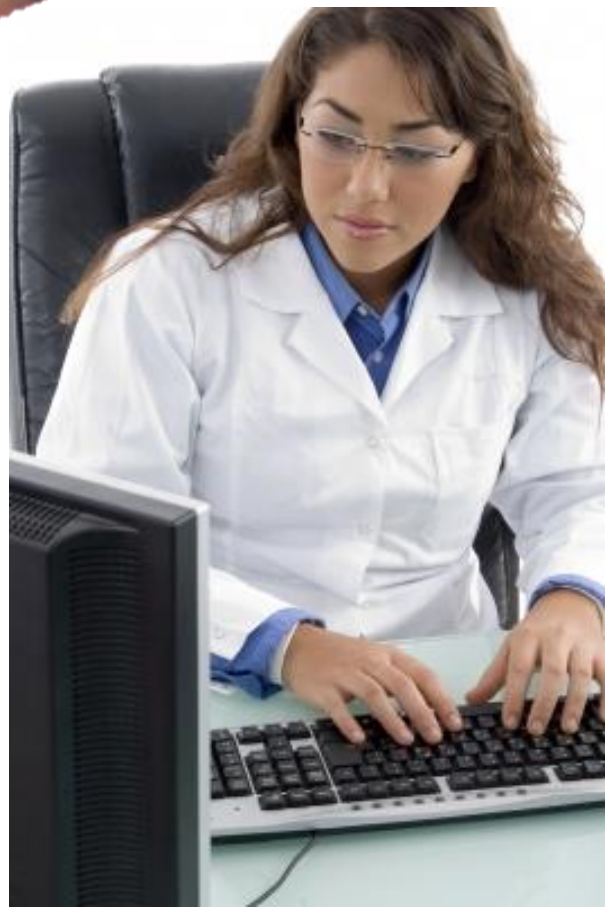
Healthier Together: Collaborative Networks of Patients, Clinicians and Researchers to Transform Chronic Illness Care

COLLABORATIVE CHRONIC CARE NETWORK

Peter Margolis, MD, PhD

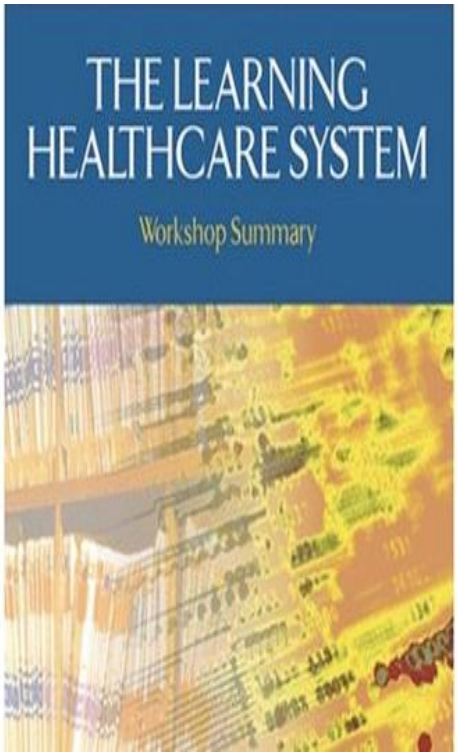
December 4, 2014

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



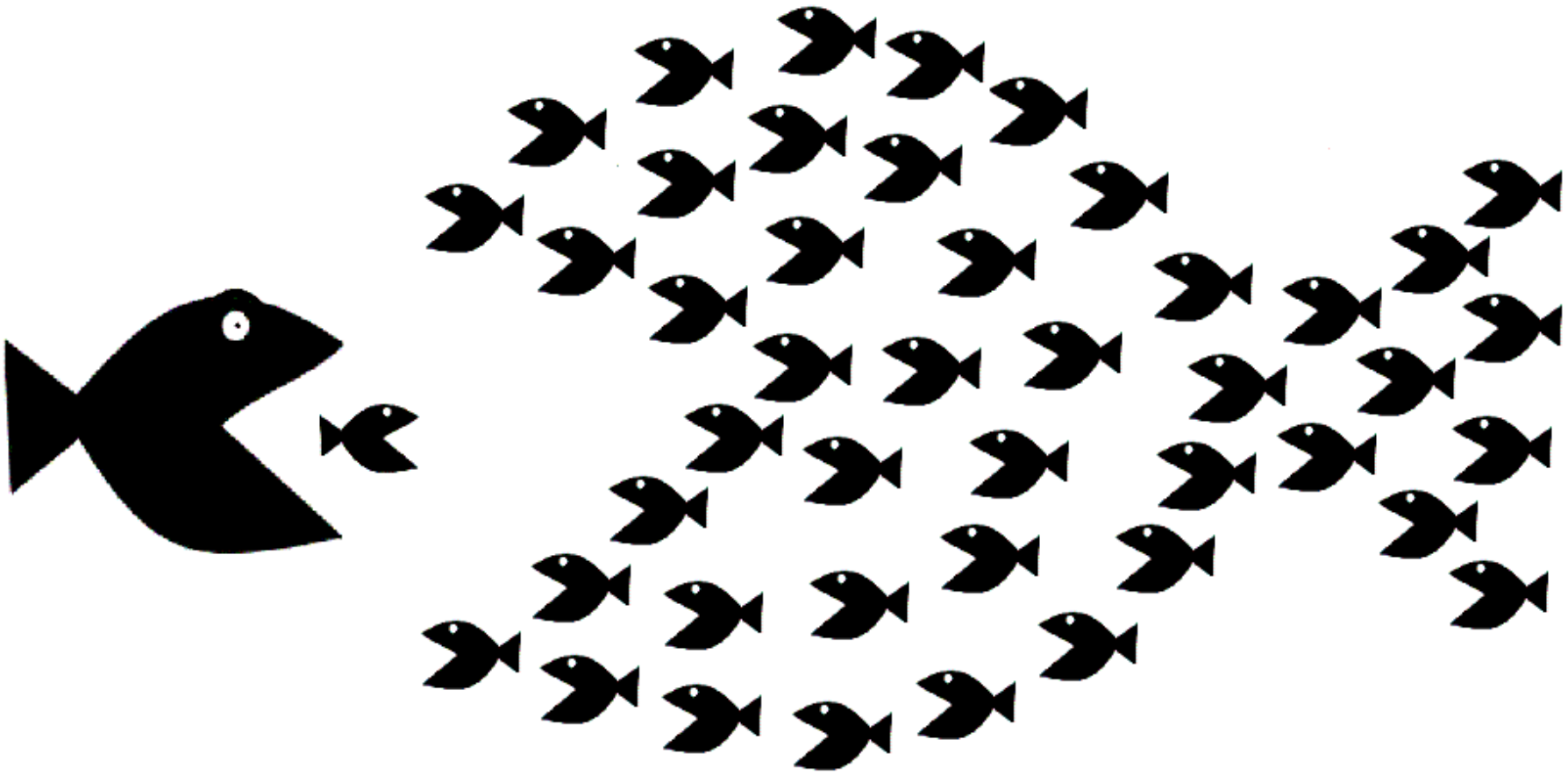
Learning Healthcare System

- 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

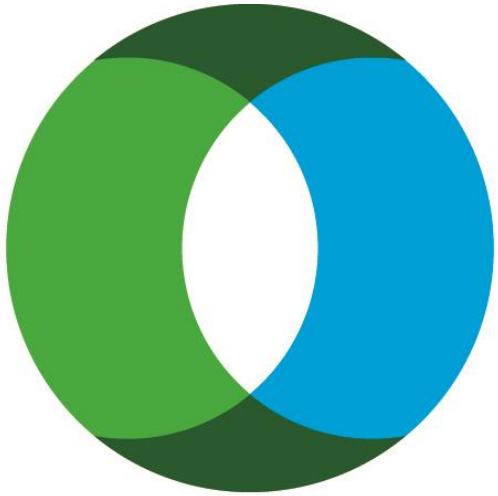


C3N

Network-Based Production



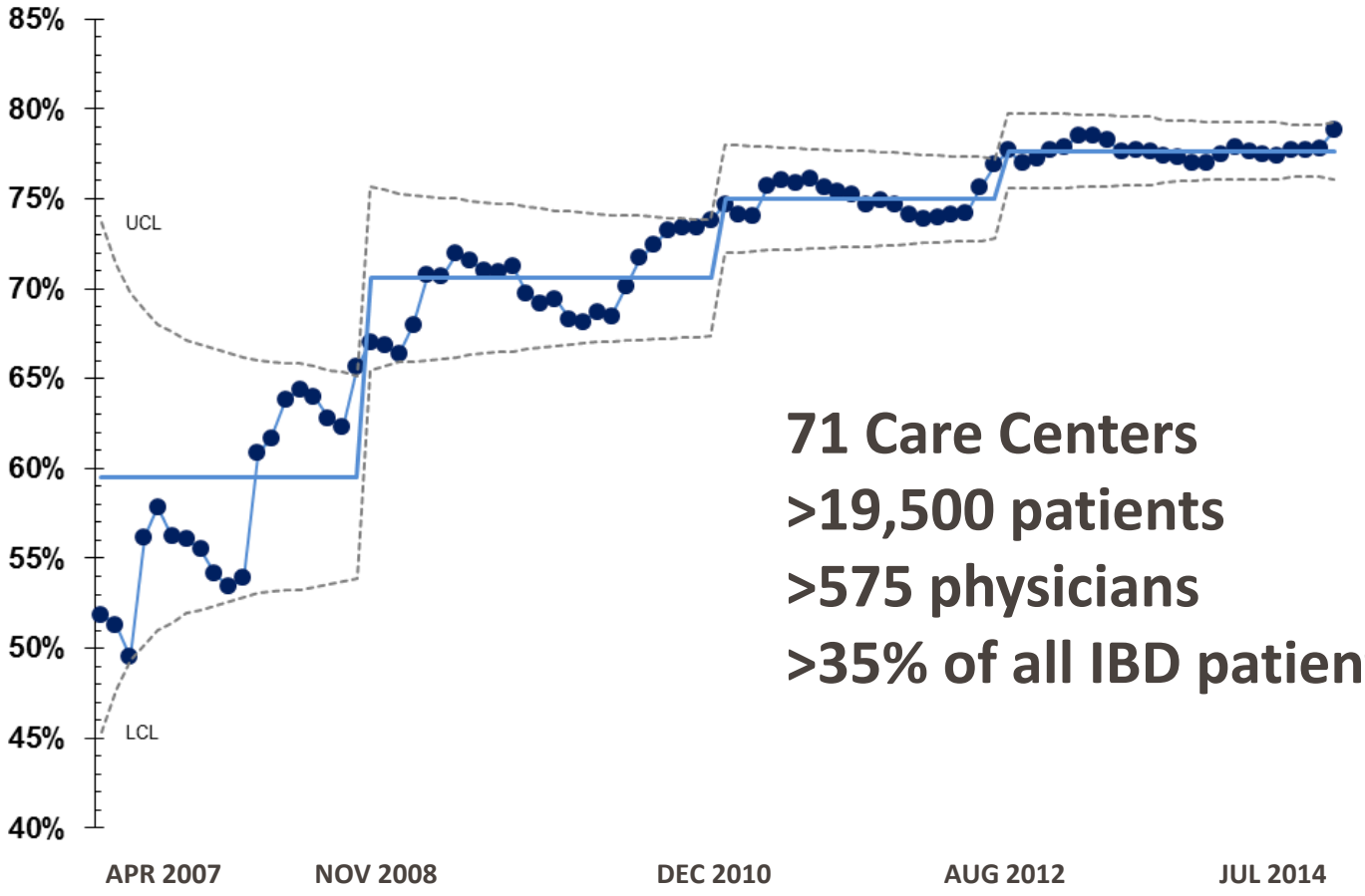
Benkler, Y. (2011). *The Penguin and the Leviathan: The triumph of cooperation over self-interest*. New York: Crown Business.



IMPROVE**CARE**NOW

Remission rate

(PGA, Centers >75% registered)



79%

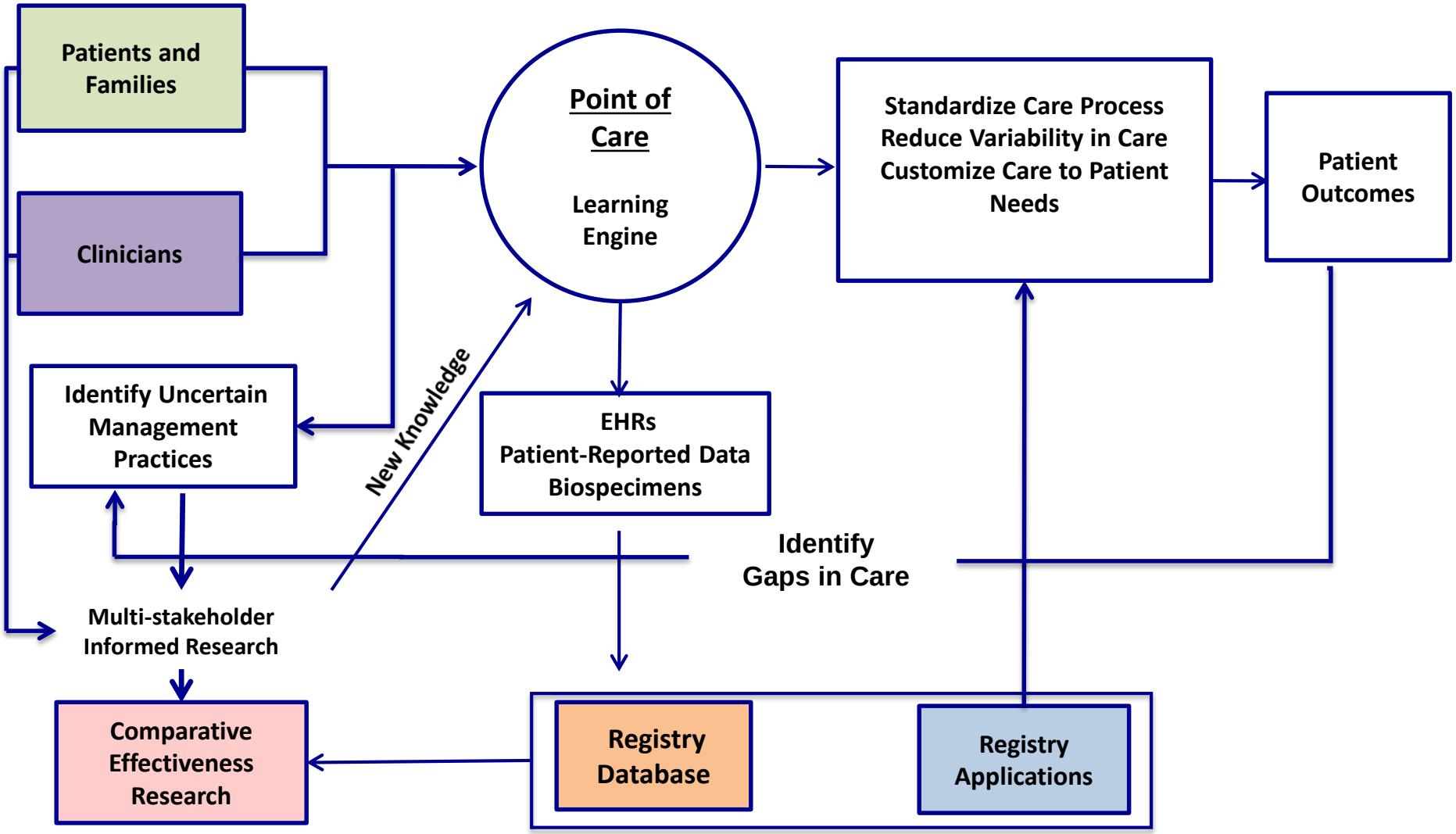
71 Care Centers
>19,500 patients
>575 physicians
>35% of all IBD patients

Components of a network-based Learning Health System*

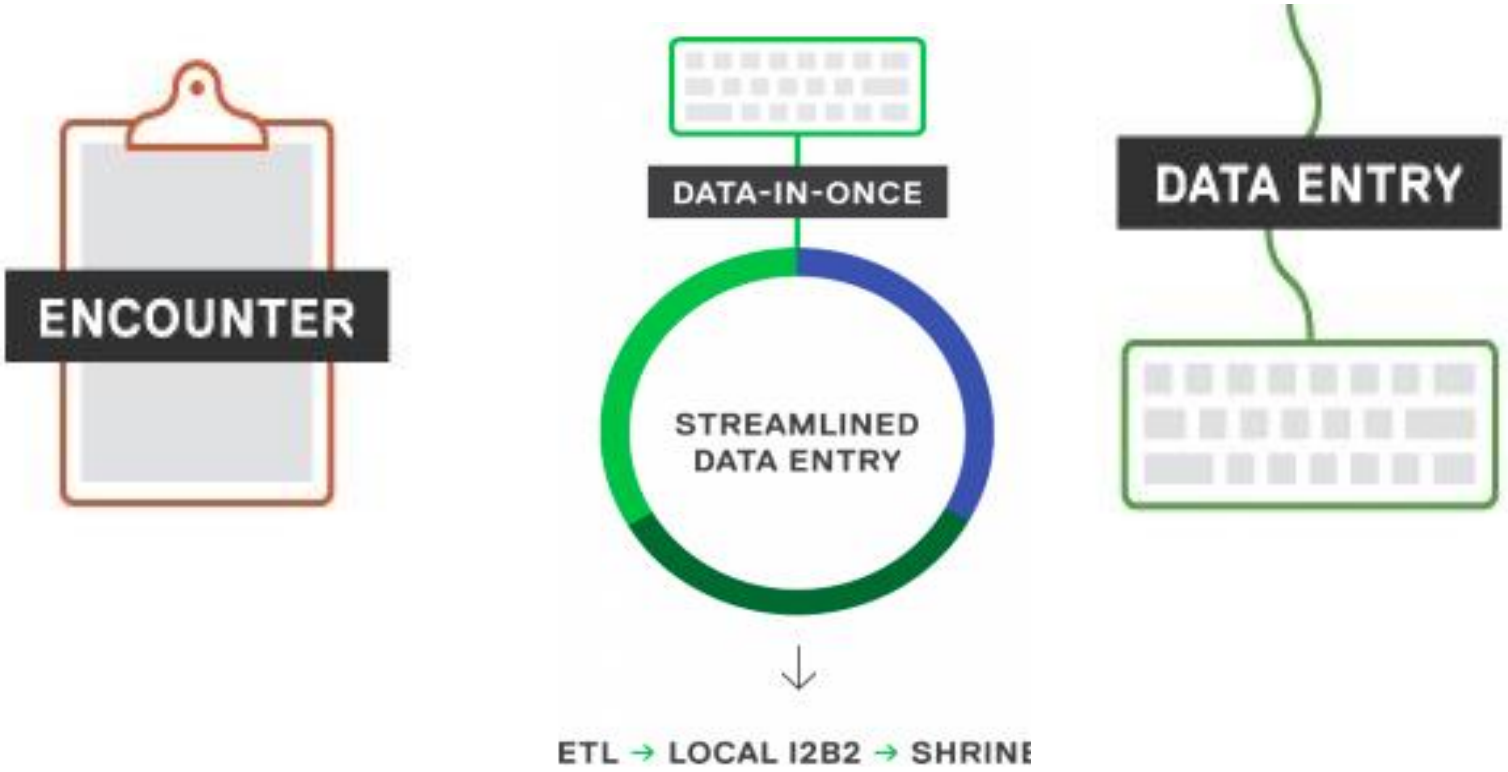
1. Focus on outcome
2. Build community and culture of sharing (a ‘commons’)
3. Effective use of technology
4. Learning system sciences
   - Systems science, QI, qualitative research, health services research, biostatistics, epidemiology

*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

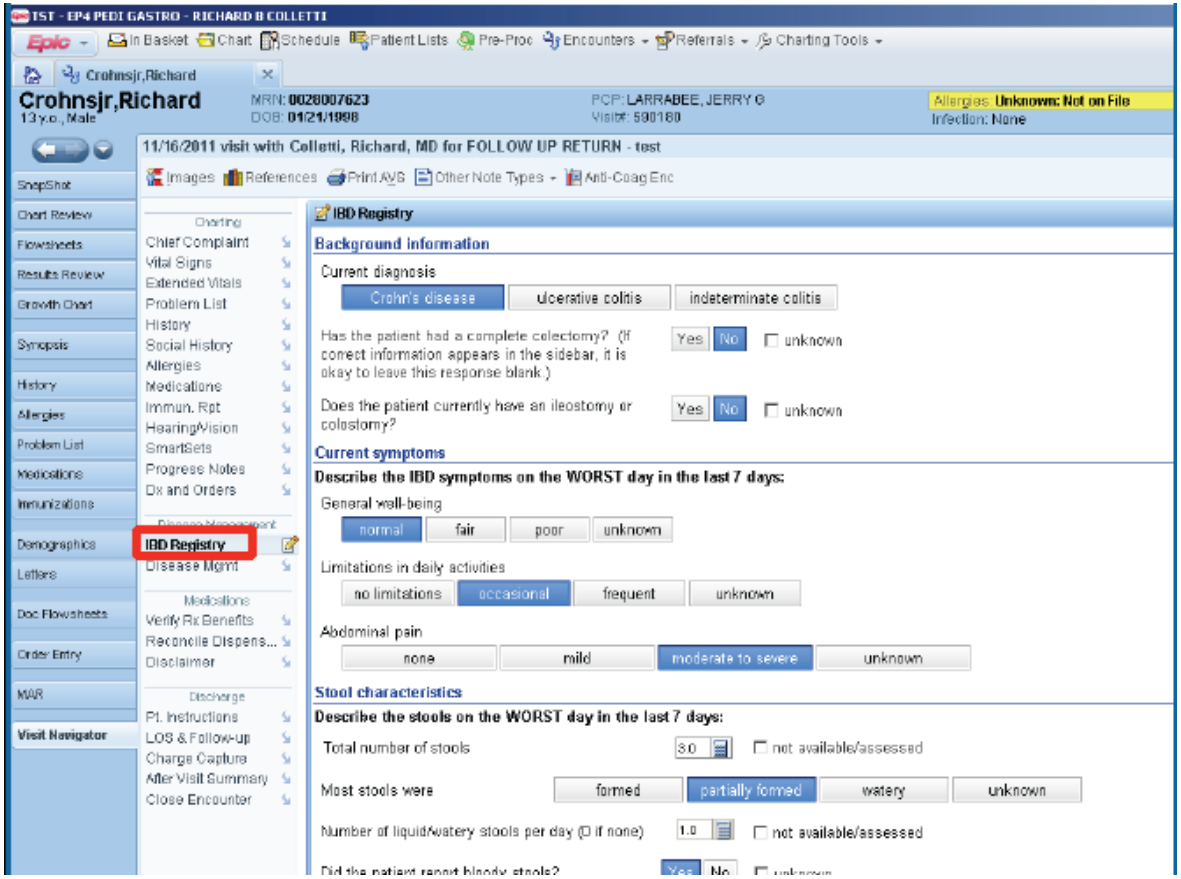


Effective use of technology to reduce costs of data collection



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

Data-in-once (at clinical visit)



New enhanced automated pre-visit planning report

Diagnosis: Crohn's Disease - 2/2008	Last Visit: 7/2/2014	Last PPD & Date:
Phenotype: Inflammatory, non-penetrating, non-stricturing	Wt (kg): 52.70	Not Recorded
Lower: Ileocolonic	Ht (cm): 167.00	Last CXR:
Upper Proximal: No	BSA: 1.564	Not Recorded
Upper Distal: Yes	Date of last hospitalization:	Last Gold Test & Date:
Perianal Phenotype: No	Not Recorded	Indeterminate 6/26/2013

>> Visits:	05/01/2013	06/26/2013	07/10/2013	08/06/2013	01/15/2014	03/19/2014	05/07/2014	07/02/2014	Age of Result
sPCDAI	*10*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	
PGA	*Mild*	*Mild*	*Mild*	*Quiescent*	*Quiescent*	*Quiescent*	*Quiescent*	*Quiescent*	
Nutritional Status	*Satisfactory*	*Satisfactory*	*Satisfactory*	*Satisfactory*	*Satisfactory*	*Satisfactory*	*Satisfactory*	*Satisfactory*	
Growth Status	*At risk*	*At risk*	*At risk*	*Satisfactory*	*Satisfactory*	*Satisfactory*	*Satisfactory*	*Satisfactory*	
Albumin		*4.1*	*4.5*	*4.2*	*4.4*	*4.2*	*4.5*	*4.2*	*1 mo*
CRP		*0.00*	*0.00*	*0.00*	*0.00*	*0.00*	*0.00*	*0.00*	*1 mo*
ESR		*25.0*		*11.0*	*40.5*	*8.0*	*9.0*	*3.0*	*1 mo*
Hematocrit		*37.5*	*38.8*	*39.4*		*39.0*	*41.2*	*40.5*	*1 mo*

*Result date may differ from visit date

Lab ordering guidelines: 5-ASA:q6mo 6mp/ASA/MTX:q3-4mo Biologics:q2-3mo

Care Stratification

CS Score	CSS Group	Current Disease Activity	12 Month Disease Activity	BMI Z-Score	Ht Velocity	Hosp Adm within 3 months	Currently on Cortico	Cortico last 12 months	Psychosocial Risk Factors
0	0-3 (Low)	0 (Quiescent)	0 (Quiescent)	0 (BMIZscore >=-1 or Missing)	0 (HtVelocityZscore >=-1 or Missing or N/A)	0 (No or Unknown)	0 (No or Unknown)	0 (No or Unknown)	No

Automated population management report

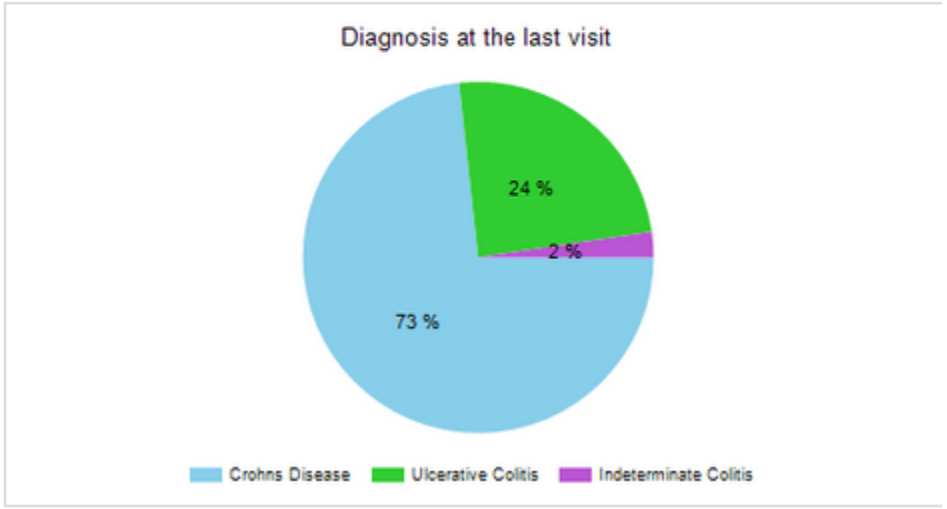
ImproveCareNow > Data > SSRS_Data

Actions | 3 of 7 | Find Next |

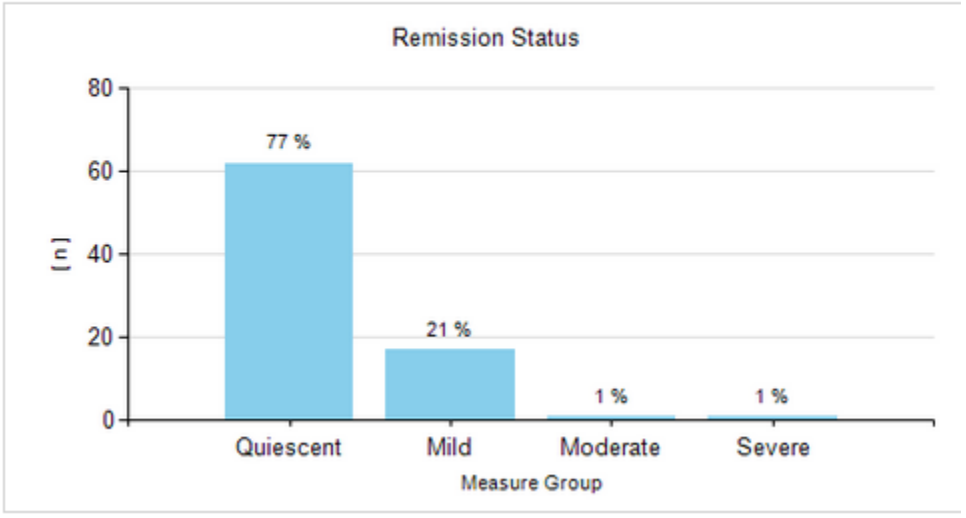
Document Map

- PatientGroups
  - Care Stratification Score
    - Care Stratification Score
    - Current Disease Activity - CSS
    - 12 Month Disease Activity - CSS
    - BMI Z-score - CSS
    - Height Velocity Z-score - CSS
    - IBD-Related Hospital Admission within 3 Months - CSS
    - Current Corticosteroid Use - CSS
    - Corticosteroid Use in the Last 3-12 Months - CSS
    - Psychosocial Risk Factors - CSS
  - Clinical Reports
    - Diagnosis at the last visit
    - Remission Status
    - Nutritional Status
    - Growth Status
    - TPMT Activity
    - Visit within 200 Days
    - Sustained Remission
  - Demographic Reports
    - Patients by Race
    - Patients by Gender
    - Patients by Age Group
  - Medication Use
    - Thiopurine is at least the dose recommended in the Model Care Guideline
    - Infliximab Dose is at least 4.5 mg/kg
    - Methotrexate Dose is at least 10 mg/m2 or 15 mg/wk
    - Prednisone Free Remisson
    - Prednisone Usage

Switch



Switch



Data as of 12/10/2013 Reporting Month: 2013-11 Reporting Center: Vermont Children's Hospital

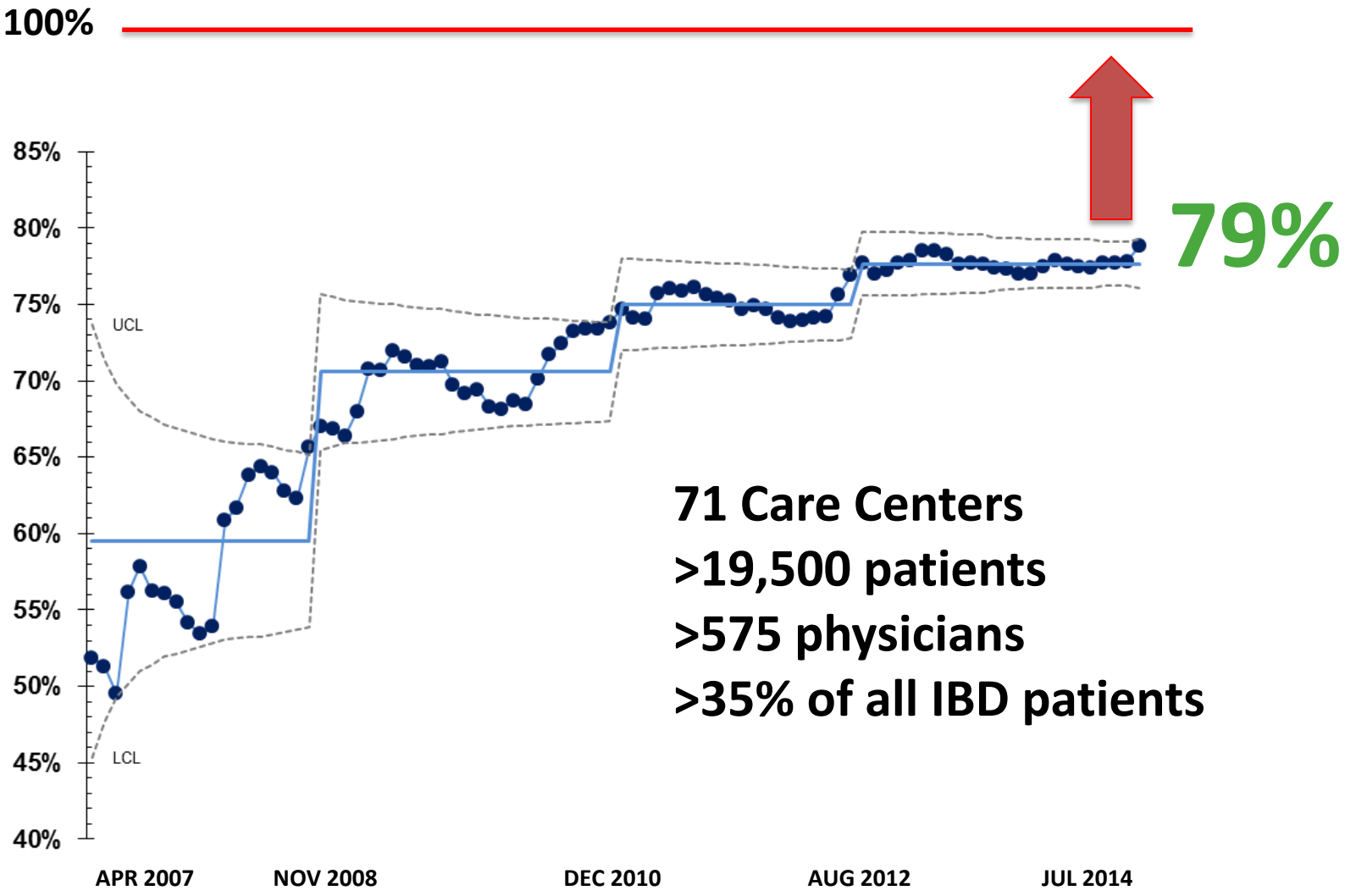
Export Center Data To Excel | All Center Measures - Small Multiples Graphs | All Centers Performance Report | All Graphs Per Center Report

Dashboard With Sparkline | All Measures Per Center - Small Multiples Graphs | Gap Analysis Report

Measure Group	Sub Group	Measure Title	Network Target	>=75% cohort Teams' Performance	Team's Performance
Clinical Measures	Clinical Remission	Percent of patients in remission	80	77	80
		Percent of patients with prednisone-free remission	76	74	75
		Percent of patients with sustained remission	45	47	48
		Percent of patients not taking prednisone	95	93	91
	Adequate Nutrition and Growth	Percent of patients with satisfactory nutritional status	90	90	100
		Percent of patients with at risk of nutritional failure		9	0
		Percent of patients in nutritional failure		2	0
		Percent of patients with satisfactory growth status	90	92	98
		Percent of patients with at risk of growth failure		6	2
		Percent of patients in growth failure		2	0
	Model Classification	Percent of visits with a complete bundle	95	85	91
	Model Treatment	Percent of patients with a documented visit within the last 200 days	80	76	83
		Percent of patients whose dose of thiopurine is at least the dose recommended in the ICN Model Care Guidelines	80	67	71
		Percent of visits where initial dose of anti-TNF therapy is given that patient had a TB test within the prior 12 months	95	86	50
		Percent of Patients where the dose of infliximab is at least 4.5 mg/kg	95	95	92
Data Quality		Percent of population registered AND active in registry		75	98
		Percent of actual visits recorded in registry		83	100
		Percent of visits with all critical data recorded		86	91
		Percent of visits meeting the consistency bundle		85	71
		Percent of visits entered that were entered within 30 days of visit date ***-*** Data reported on a two month lag		98	100
		Percent of active patients in registry with visit recorded in last 13 months		92	98

Remission rate

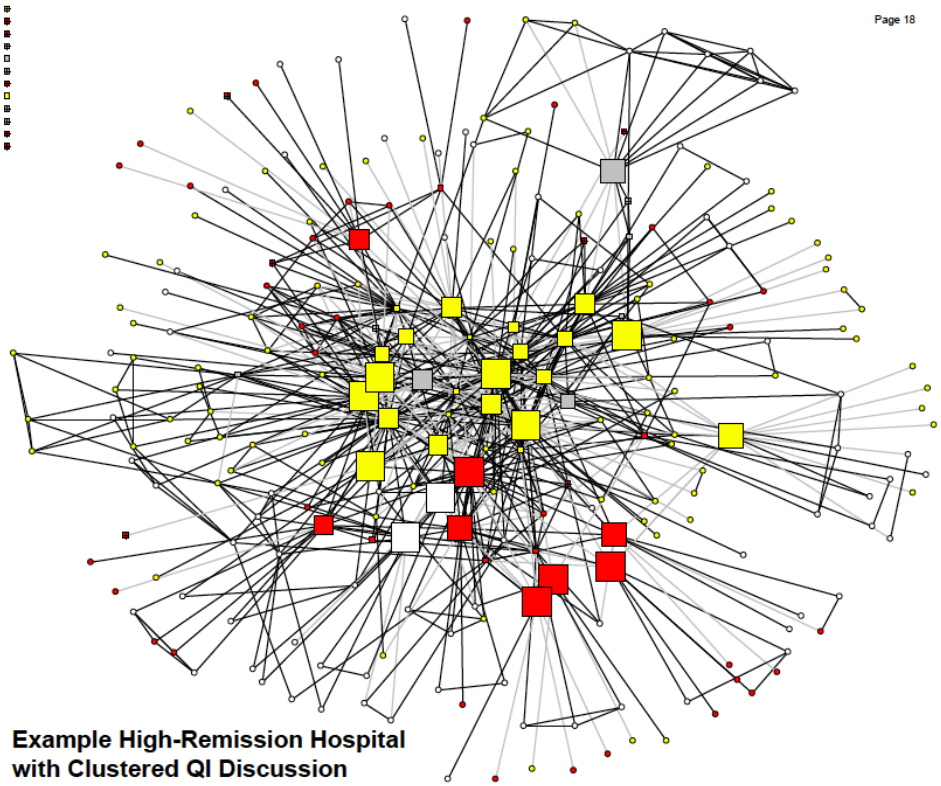
(PGA, Centers >75% registered)



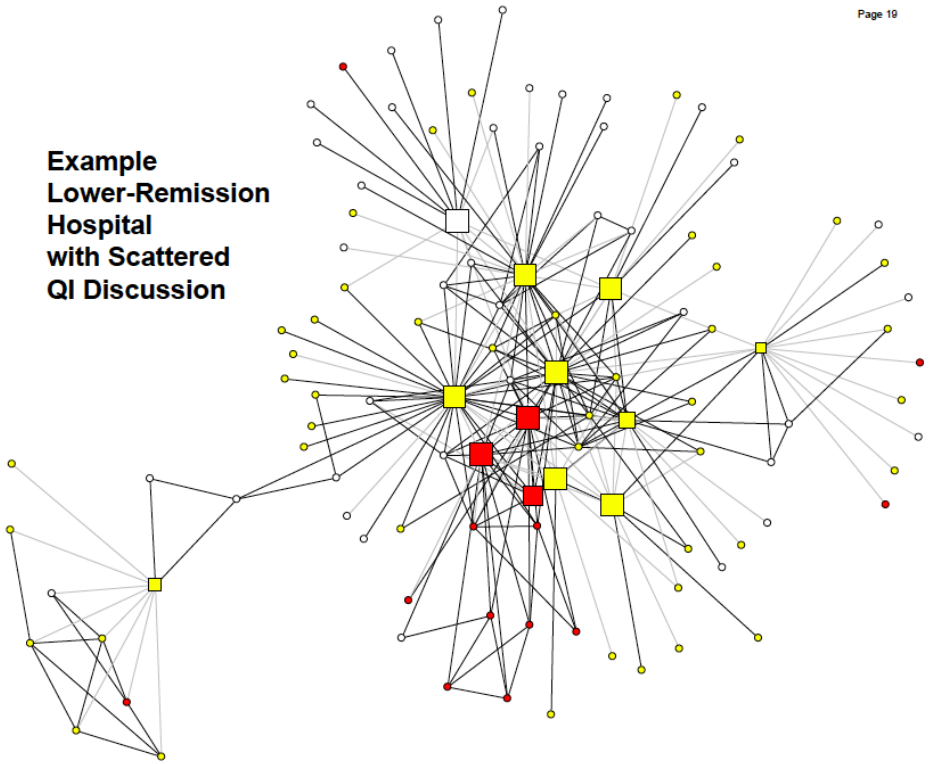
Two Types of Research

- Research on Networks
  - What motivates people to participate and contribute and improve?
  - Who are the users of the system? What are their goals and needs?
- Research using the network for clinical research
  - What treatments work best for whom?

Social Network Analysis



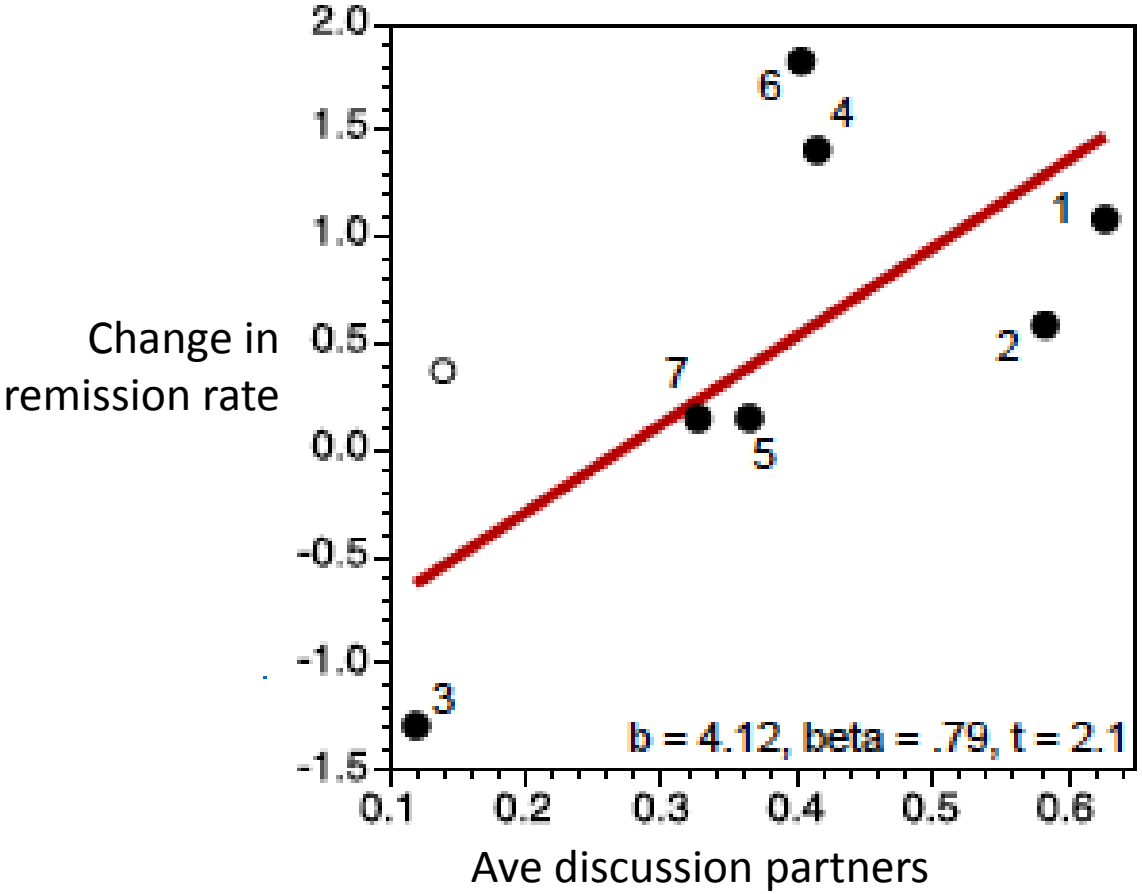
Example High-Remission Hospital with Clustered QI Discussion



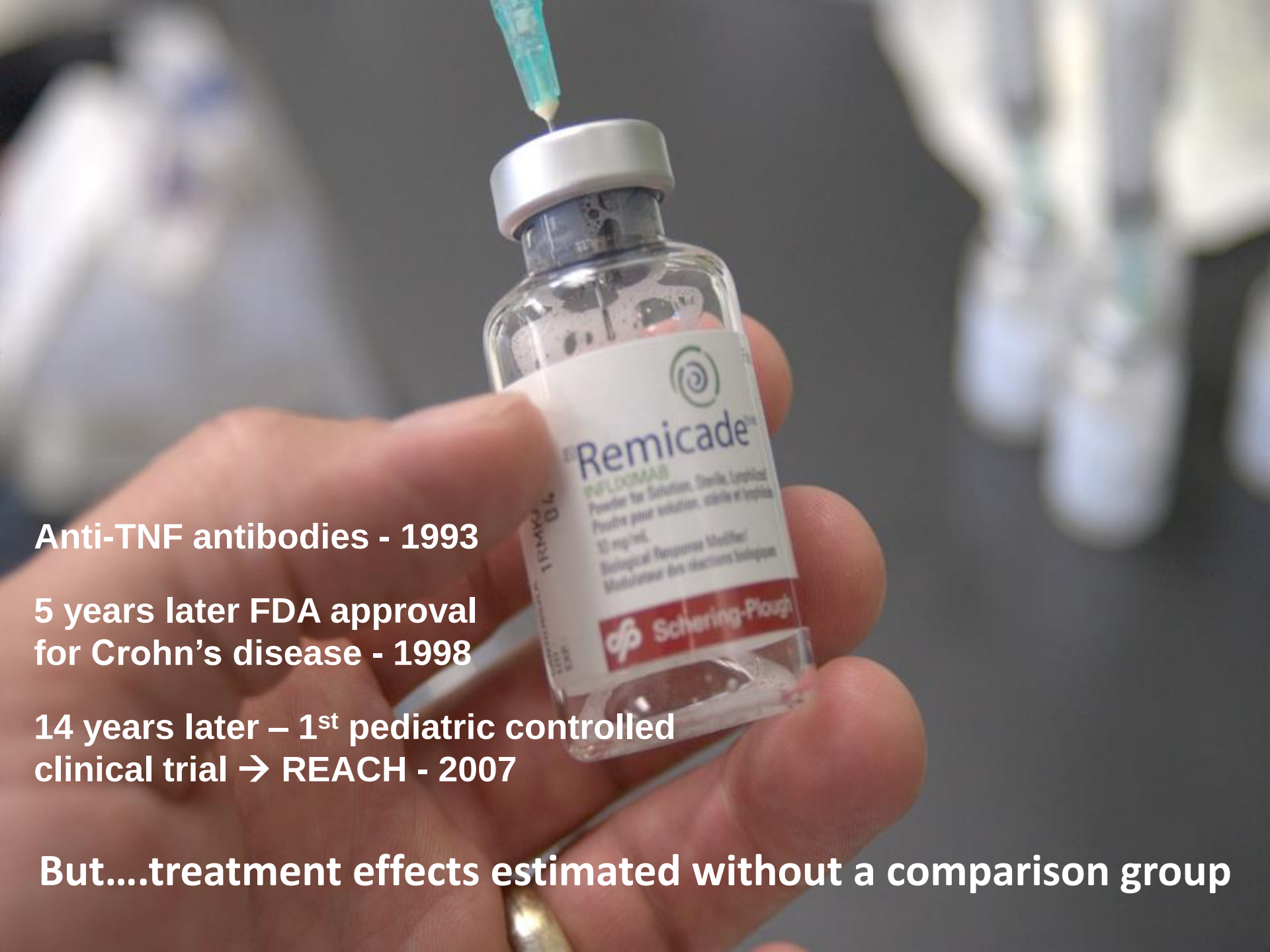
Example Lower-Remission Hospital with Scattered QI Discussion

Ron Burt, PhD, David Meltzer, MD, PhD, Gavin Hougham, PhD

Social norms drive coordination and better outcomes



Social norm = people have many colleagues with whom they discuss QI AND colleagues also have many people with whom they discuss QI



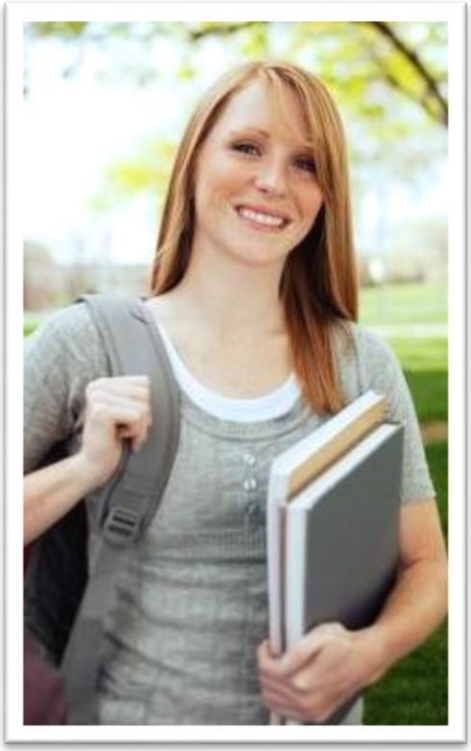
Anti-TNF antibodies - 1993

5 years later FDA approval for Crohn's disease - 1998

14 years later – 1st pediatric controlled clinical trial → REACH - 2007

But….treatment effects estimated without a comparison group

Bianca Simmons, Age 20



"What does not kill you makes you stronger."

Bianca's Goals

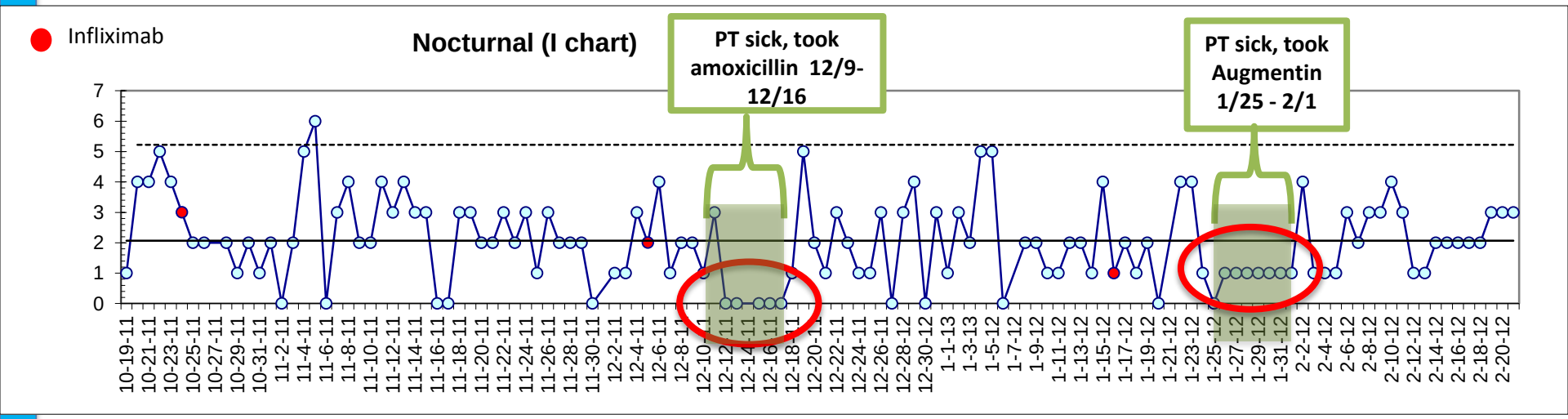
- Keep symptoms at bay
- Be a leader in the IBD community

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

C3N

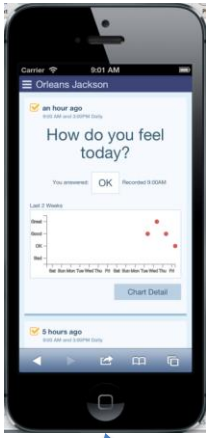
Personalized Learning

19 yr. old with Crohn's colitis
Colectomy with ileo-anal anastomosis (10 yrs)
Chronic diarrhea, nocturnal stools, fatigue, poor quality of life
Current medications: Infliximab & PRN imodium



Heather Kaplan, MD, MPH, Jeremy Adler, MD, MPH, Shehzad Saeed, MD, Ian Eslick, MS, Lloyd Provost, MS, Tom Nolan, PhD, Peter Margolis, MD, PhD

Platform Components



Mobile App/Web App: Families/Patients

- Tracking Symptoms
- Patient Notes
- Visualize Data
- Health Reports
- Survey delivery

Desktop/Web: Providers and Families

- Population review
- Patient data review
- Note review and response
- User setup and administration
- Study administration

Cloud-Based Data Service

- Wearable device integration
- SMS / Email / Mobile integration
- EMR interoperability
- User engagement analytics
- Rapid multi-site deployment

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/

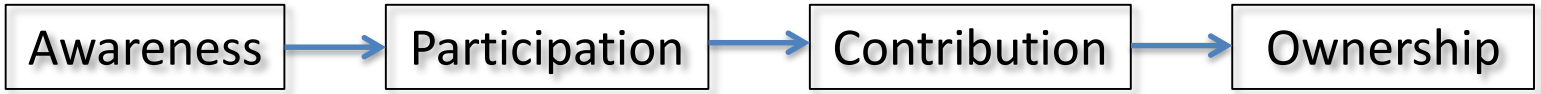
Engagement

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


Awareness
Participation
Contribution
Ownership

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

A contributor

No one asked anyone to make these contributions…….


a note
to say
thanks...


Thank You
Thank You
Thank You
Thank You
Thank You
Thank You


Thanks

Thank you cards….

- “Thank you for believing in us and giving us the opportunity to work with ICN”
- “It was amazing to craft my own scope of work and run with it.”
- “I know I don’t need to say thanks, and I know action is needed….but I want to (say thanks). ICN has changed my life more than IBD. Isn’t that an amazing thing?”

Steal shamelessly, share seamlessly

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

ImproveCareNow Network is becoming a *system* for health and productivity

Personal satisfaction, engagement and meaning

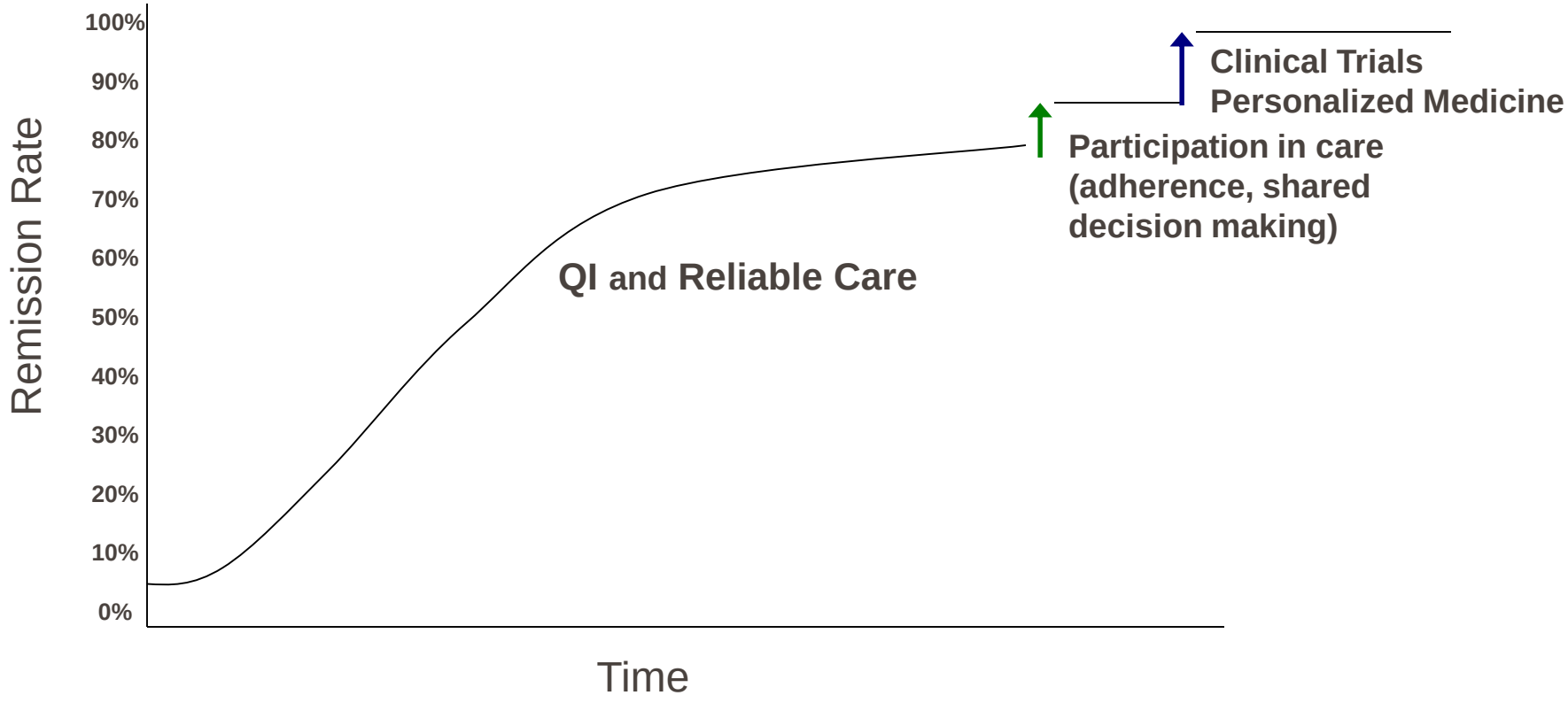
A C3N is a Distributed Learning Health System

- **Engages all stakeholders** (patients, clinicians, researchers) in advancing health of children and co-developing the system
- **Measurable impact** on health of participating children
- Reduces **time from knowledge generation to patient impact from years to months**
- **A lab** to prototype and test innovations and respond to priorities for research and outcomes data
- Generate **new evidence - faster, cheaper, and with higher quality** than conventional scientific models

Questions

- In what sequence should the components of a learning health system be created?
- What system redesigns are needed to unleash the interdependent work among patients, clinicians and researchers? In the clinic? In the research setting?
- How will the hazards of new options be recognized and prevented?
- What are the financial implications of significant co-contribution and networked research?
- How will training have to change for co-produced care and collaborative research?

Trajectory Towards Improved Remission Rates



Thanks to Ted Denson, MD

Our mission is simple….

“ to engage and empower patients/parents to have a voice for those impacted by

A Platform for Network Production

- Social process engender trust and collaboration
  - Transparency of results data
  - Processes for patients, families, clinicians, researchers to interact and contribute
  - Competency-based training
- Technology
  - Interoperable data model and data sharing for CER
  - Longitudinal PRO
  - Fully linked biorepository
  - Registry based trial recruitment
- Scientific
  - Multi-stakeholder informed research agenda
  - Multiple large CER studies
  - Registry based trials
  - Aggregated “N of 1” data
  - “Data mining”
- Policy
  - Central IRB
  - Data sharing, privacy and ethics policies
  - IP Commons

Purpose of ImproveCareNow

Transform the **health, care and costs** for **all** children and adolescents with Crohn's disease and ulcerative colitis by building a sustainable **collaborative chronic care network**, enabling patients, families, clinicians and researchers to work together in a **learning health care system** to **accelerate innovation, discovery and the application of new knowledge**.

September 2012