Networked Healthcare Communities

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Senior Quality Advisor
American Board of Pediatrics

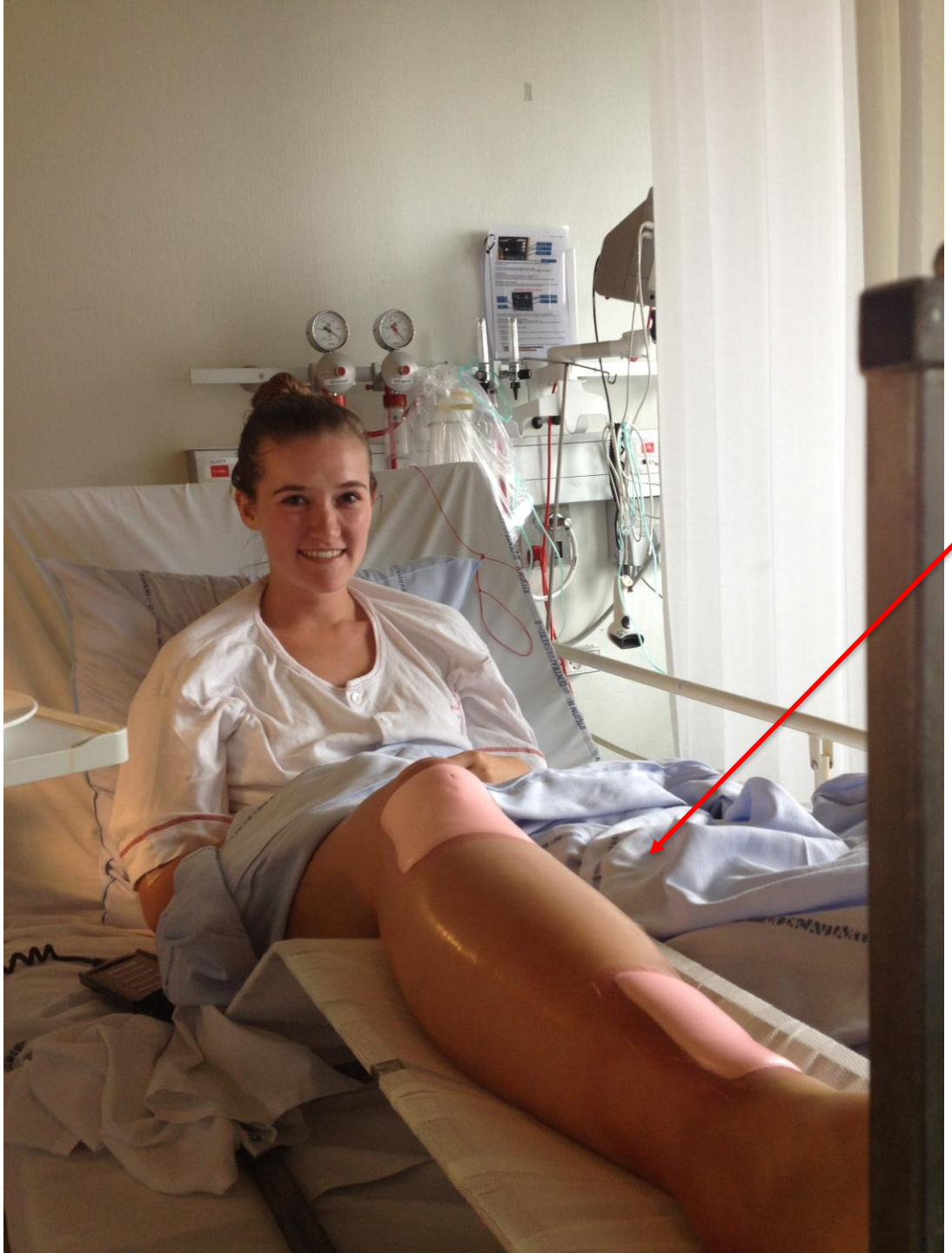
rkkp

regionernes kliniske kvalitetsudviklingsprogram

- Denmark
  - Recognized for its registries and exemplar research
  - Doing terrific work laying foundation for networked health communities using patient registries for improvement
- Cincinnati Children's
  - Honored and humbled to share our journey

BUTTERS,SUSANNAH LEE
1901913672
022Y F
21-09-2013
03:17:33
21-09-2013
03:17:33
ACC: 36460000
Rigshospitalet
Crus
SE: 1
IM: 1
W: 4095, C: 2047
MAG: 19%
LOSSLESS

2013



2013: Surgery #1

2014: Surgery #2

2017
Half-marathon

Overview of Today's Presentation

- What *is* a Learning Network?
- Do Learning Networks *work*?
- How did we start?
- How do we work?
- What did we learn?

What is a Learning Network?

Community of patients, families, clinicians, and scientists across multiple sites who use data for clinical care, improvement, discovery (research), and innovation

Why networks?

1. Reliable improvement in population outcomes at scale
2. Culture of collaboration that engages all stakeholders
3. Useful laboratories
4. Provide a robust infrastructure to produce new knowledge and innovative care models

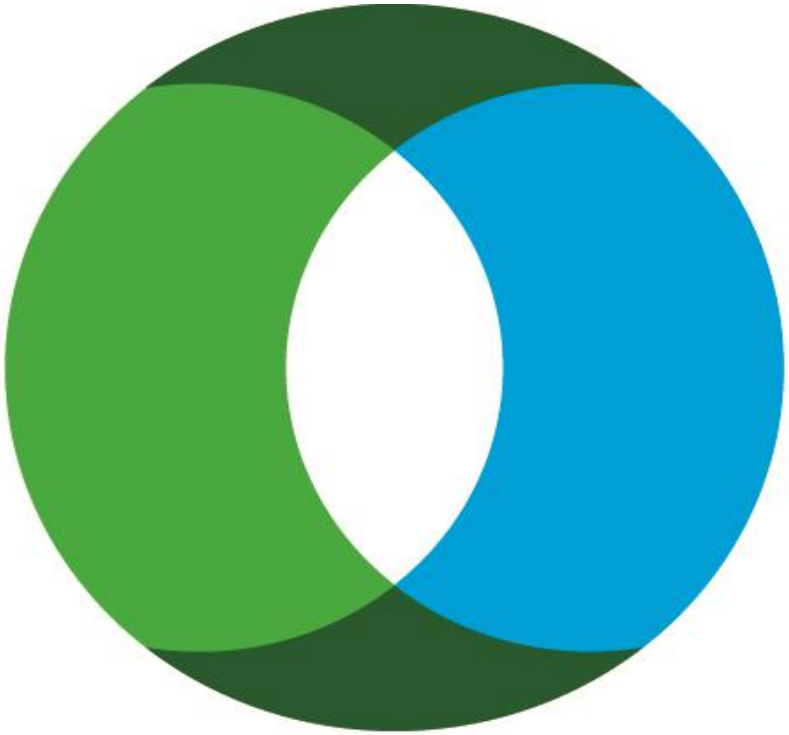
“The Heart of the Matter”

National Pediatric Cardiology Quality Improvement Collaborative

and *Sisters by Heart*

Overview of Presentation

- What *is* a Learning Network?
- **Do Learning Networks *work*?**
- How did we start?
- How do we work?
- What did we learn?

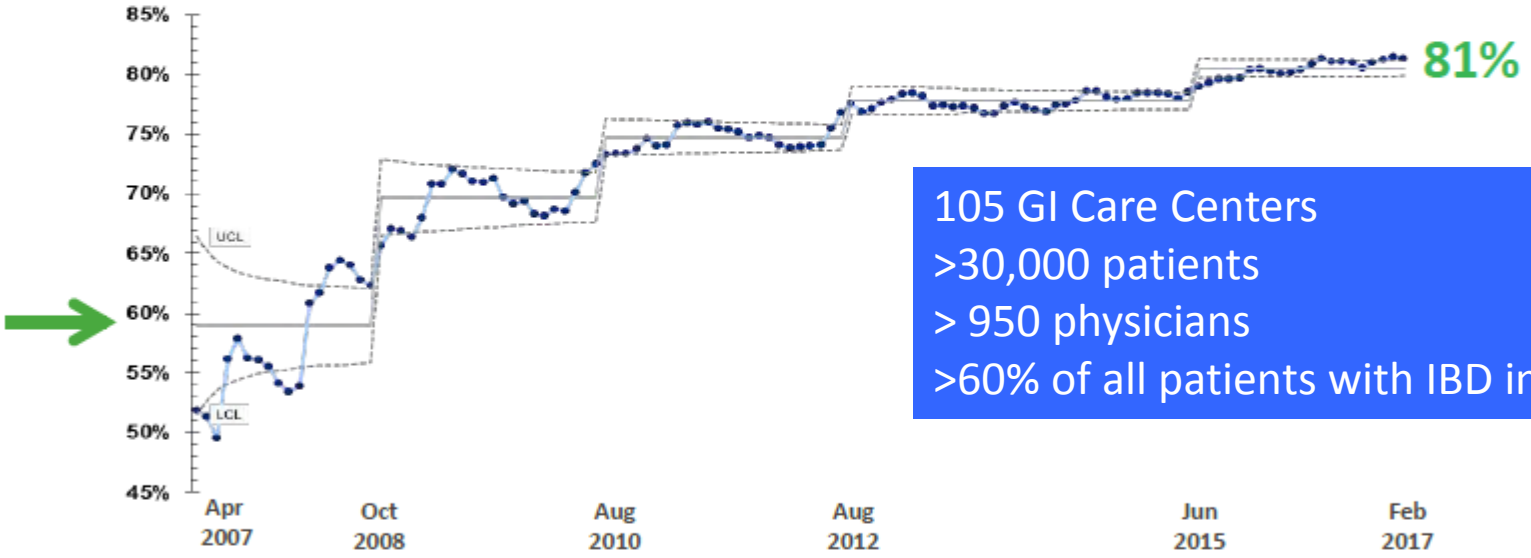


IMPROVECARENOW

Learning Network for children and adolescents with Inflammatory Bowel Disease
Began with 6 clinical sites in 2007

Clinical remission rate in CD and UC

PGA = Inactive (Physician Global Assessment)



105 GI Care Centers
>30,000 patients
> 950 physicians
>60% of all patients with IBD in US

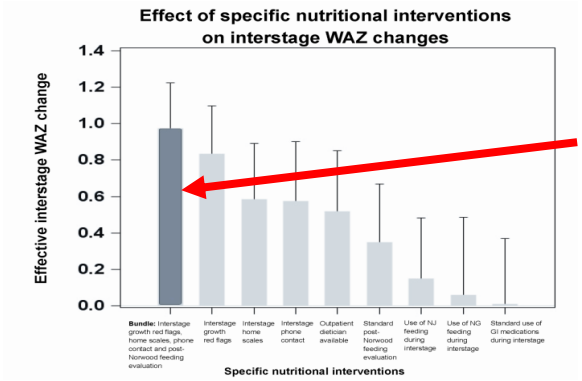
Rates of remission improved from 55% to 81% over 10 years, without a new treatment

REPLICATION OF THE MODEL

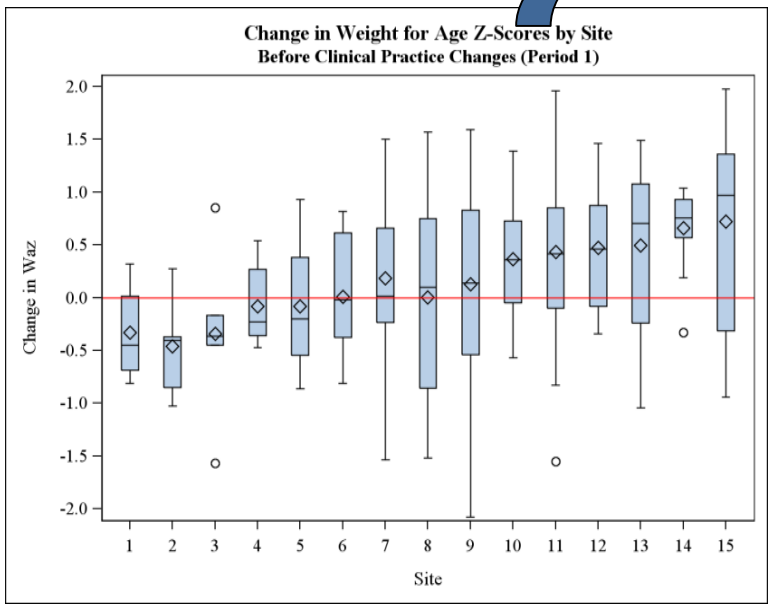
National Pediatric Cardiology Quality Improvement Collaborative
Infants with hypoplastic left heart syndrome (“half-a-heart”)

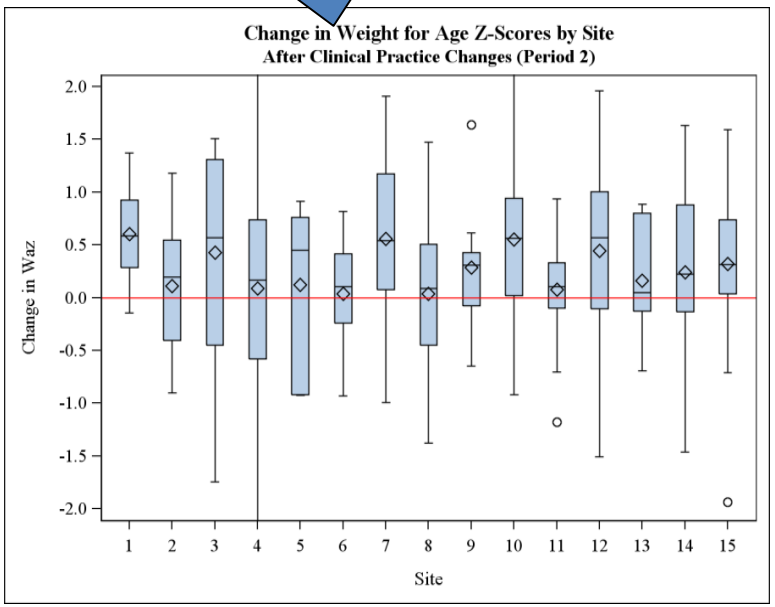
Two initial aims: 1)improve growth of infants and 2) reduce mortality

Reducing variation in growth

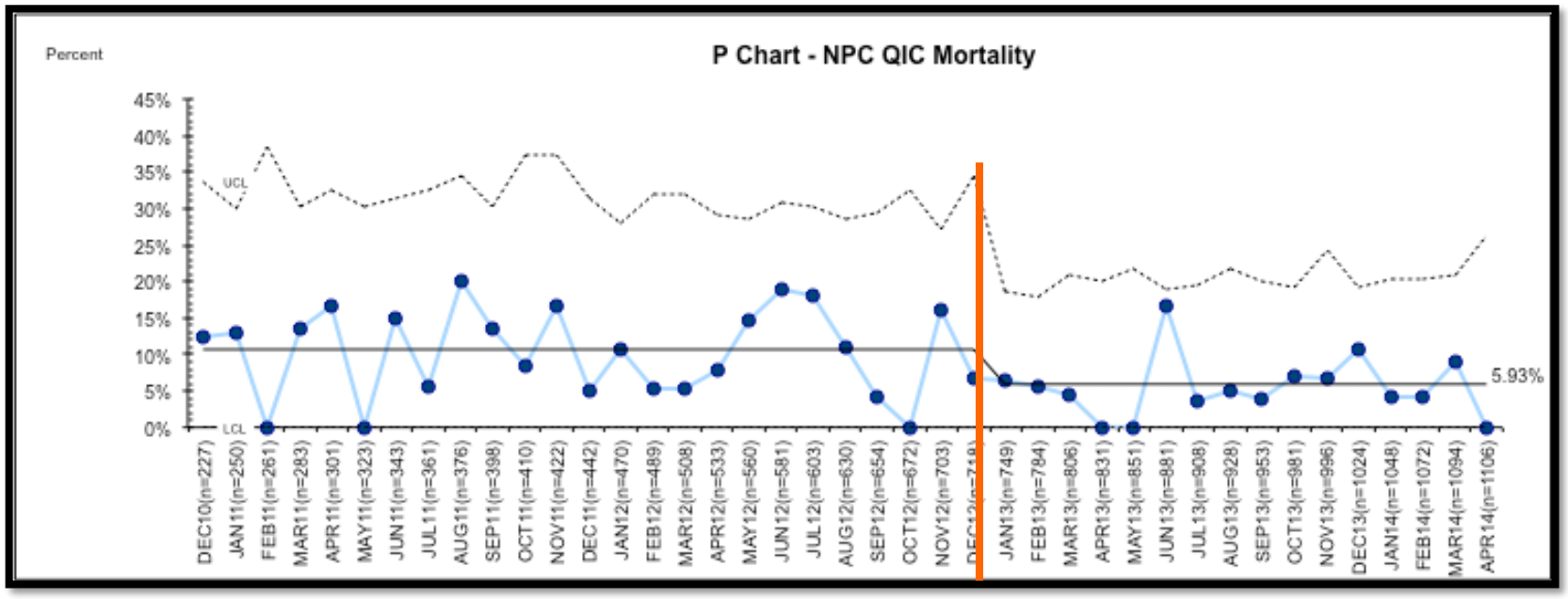


Identified growth bundle
In 6 months





Improvement in Mortality



46% reduction in inter-stage mortality

Anderson et al. *Circ Qual and Outcomes*. 2015;8:428-436

"I've learned more about the needs of patients and parents during the few years of the collaborative than in my previous 18 years of clinical practice."

Martha Clabby, MD, Pediatric cardiologist

Childrens Hospital of Atlanta

"Learn from one another and get better faster…"

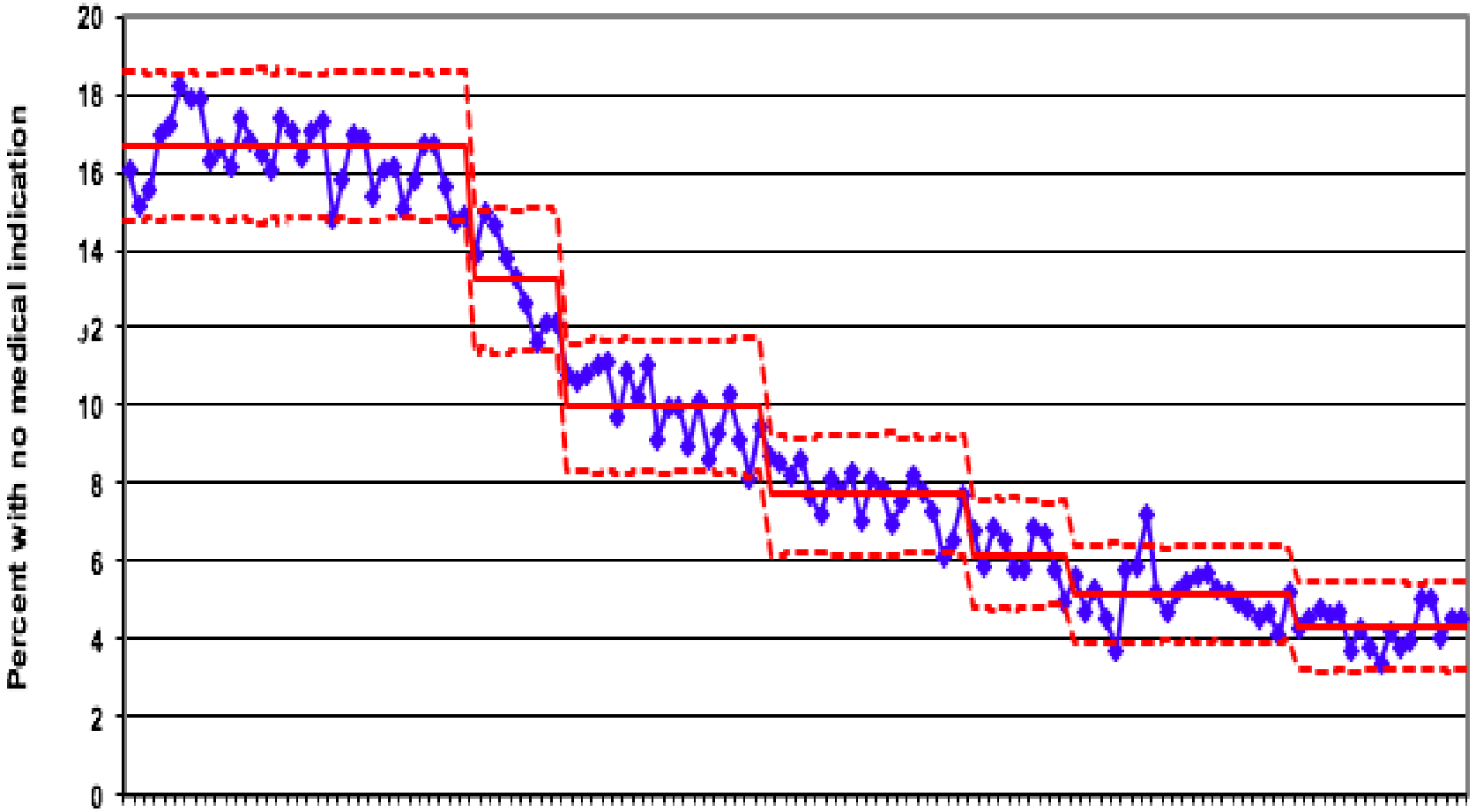
Sarah Vinje, Mom to Cecilia

Ohio Perinatal Quality Collaborative

108 maternity hospitals in Ohio

75% decrease in early elective deliveries

since 2008, >67,000 births shifted to term



Solutions for Patient Safety

MISSION:

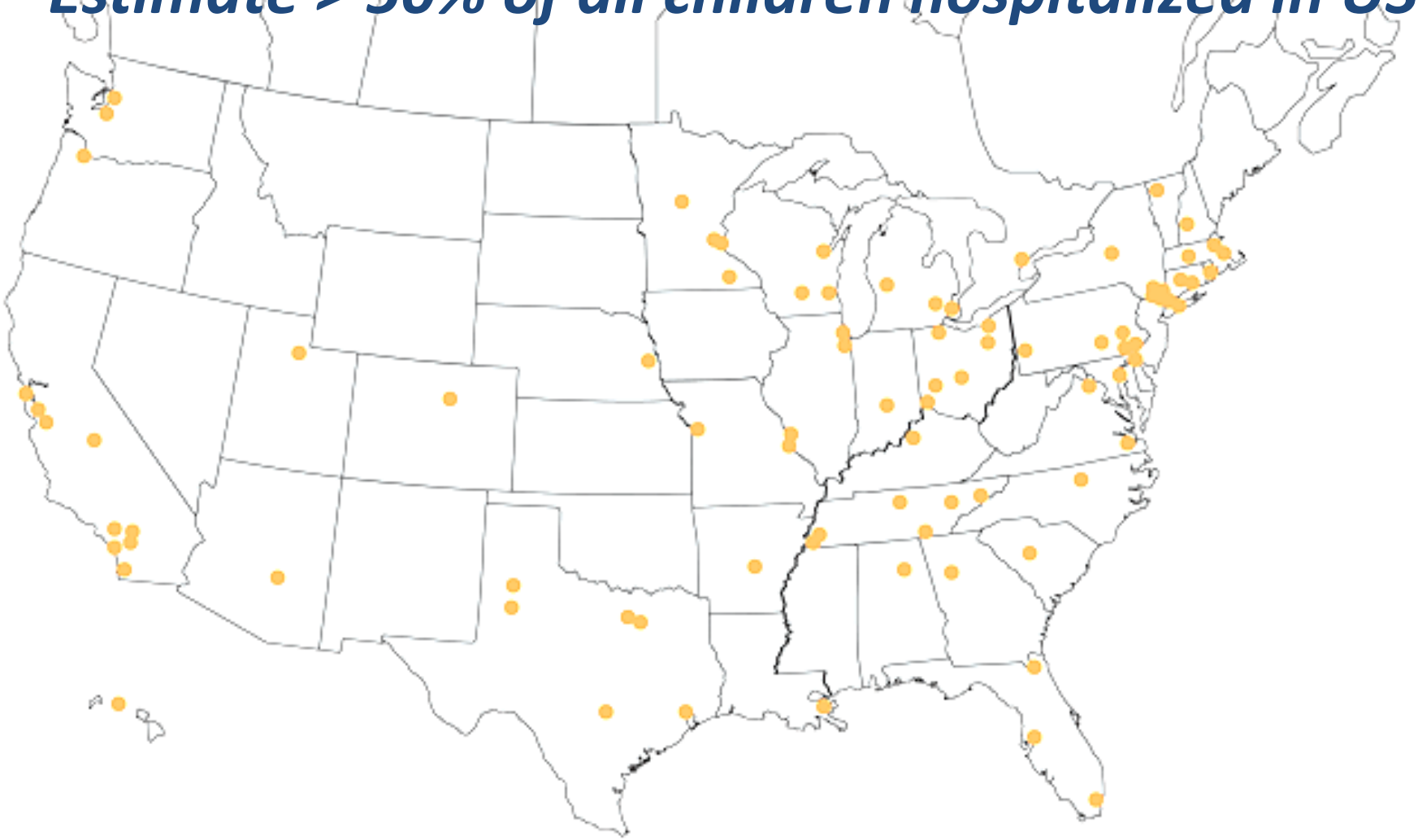
Working together
to eliminate serious harm across all children's hospitals

VISION:

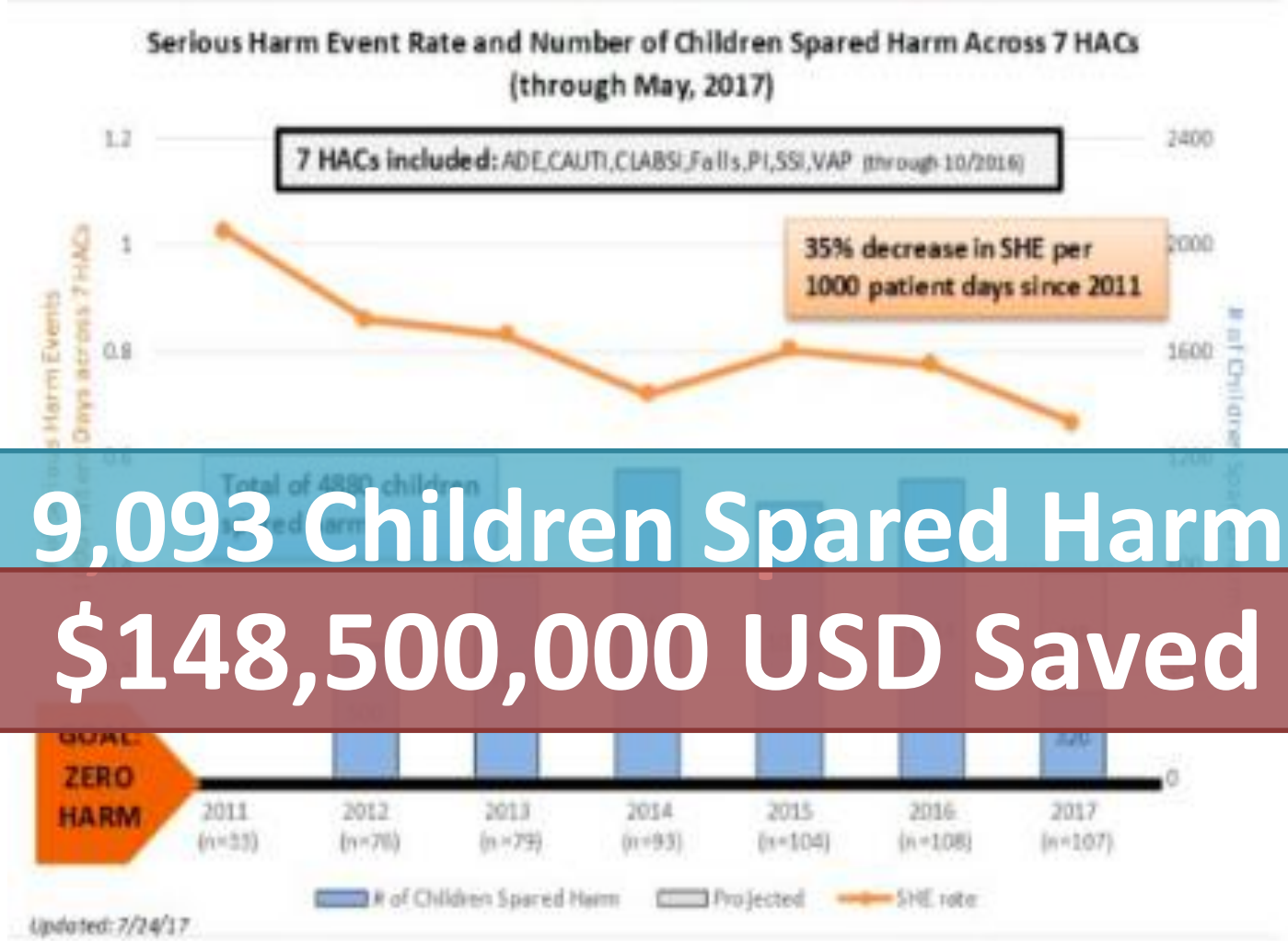
All Kids, All Hospitals, All Safe

Solutions for Patient Safety

- **100+ Children's Hospitals**
- ***Estimate > 50% of all children hospitalized in US***



Addressing hospital-acquired conditions (HACs)



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Proof of concept of model

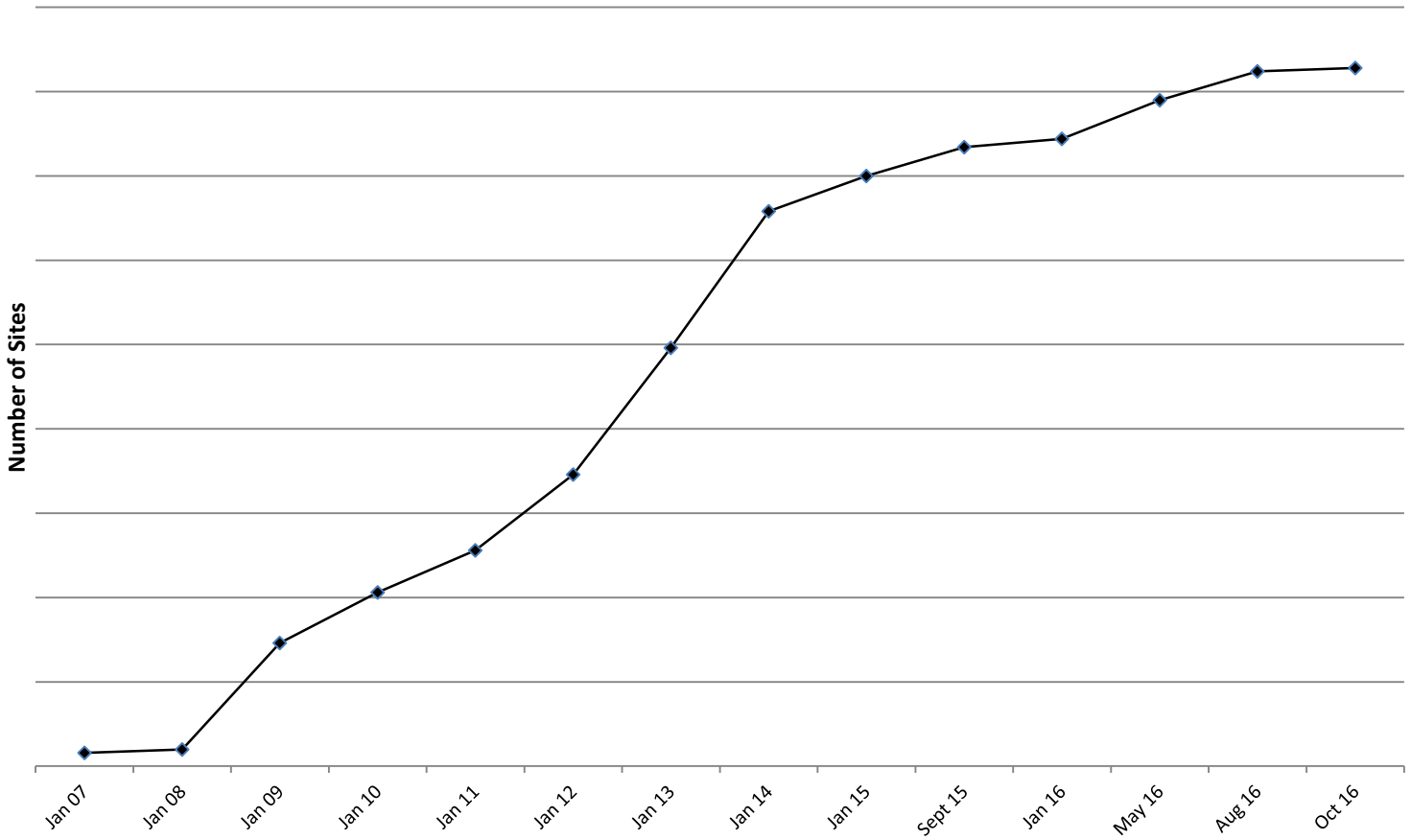
- Chronic diseases
  - “common” (inflammatory bowel disease)
  - rare (half-a-heart)
- Perinatal @ population level
- Hospital-based Safety

Growth of Learning Networks

558 teams at 286 sites

43 states and 5 countries (the US, UK, Canada, Belgium and Qatar)

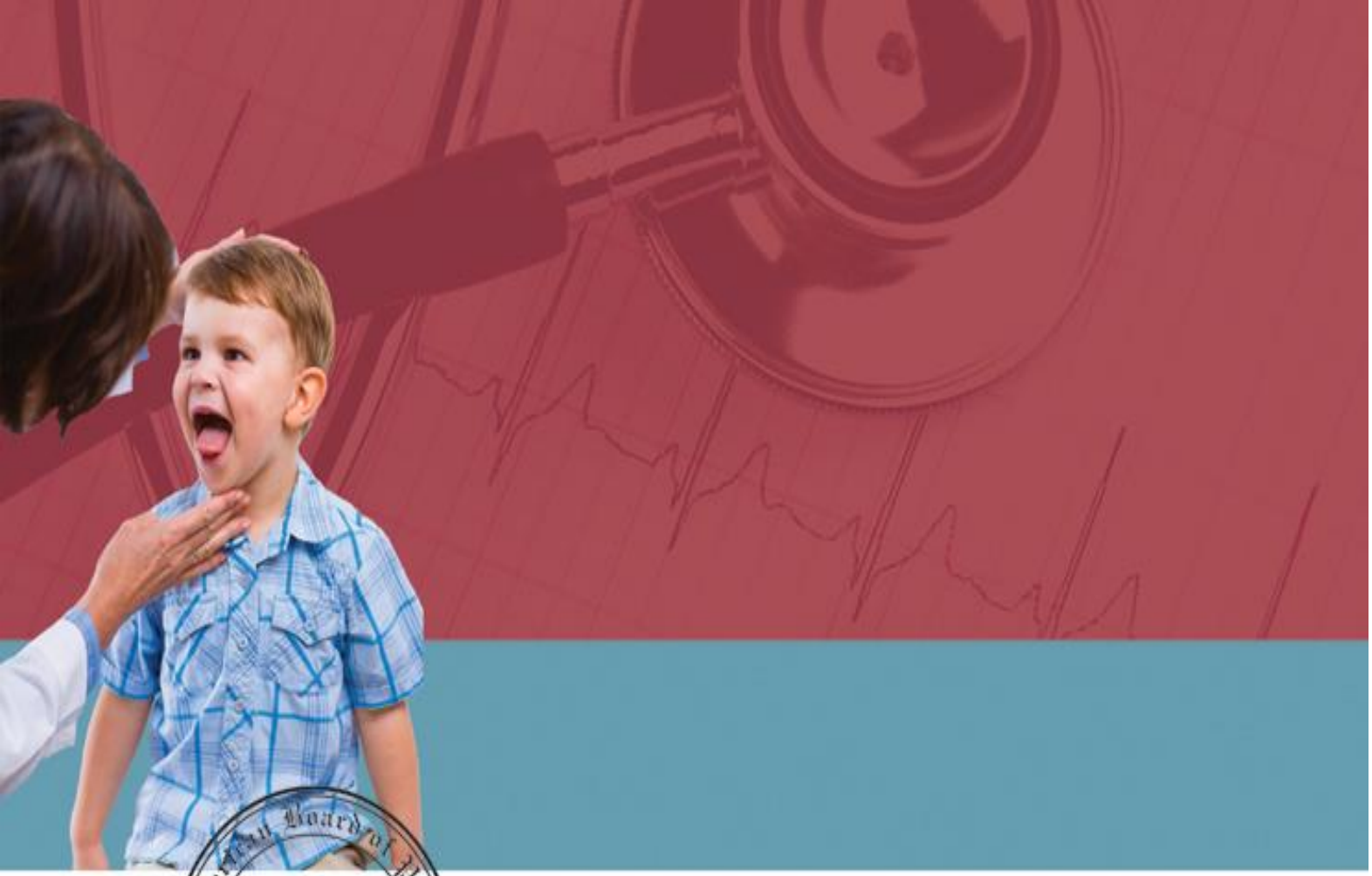
8 networks



Overview of Presentation

- What *is* a Learning Network?
- Do Learning Networks *work*?
- **How did we start?**
- How do we work?
- What did we learn?

We began with a focus on improvement and translating research into practice.

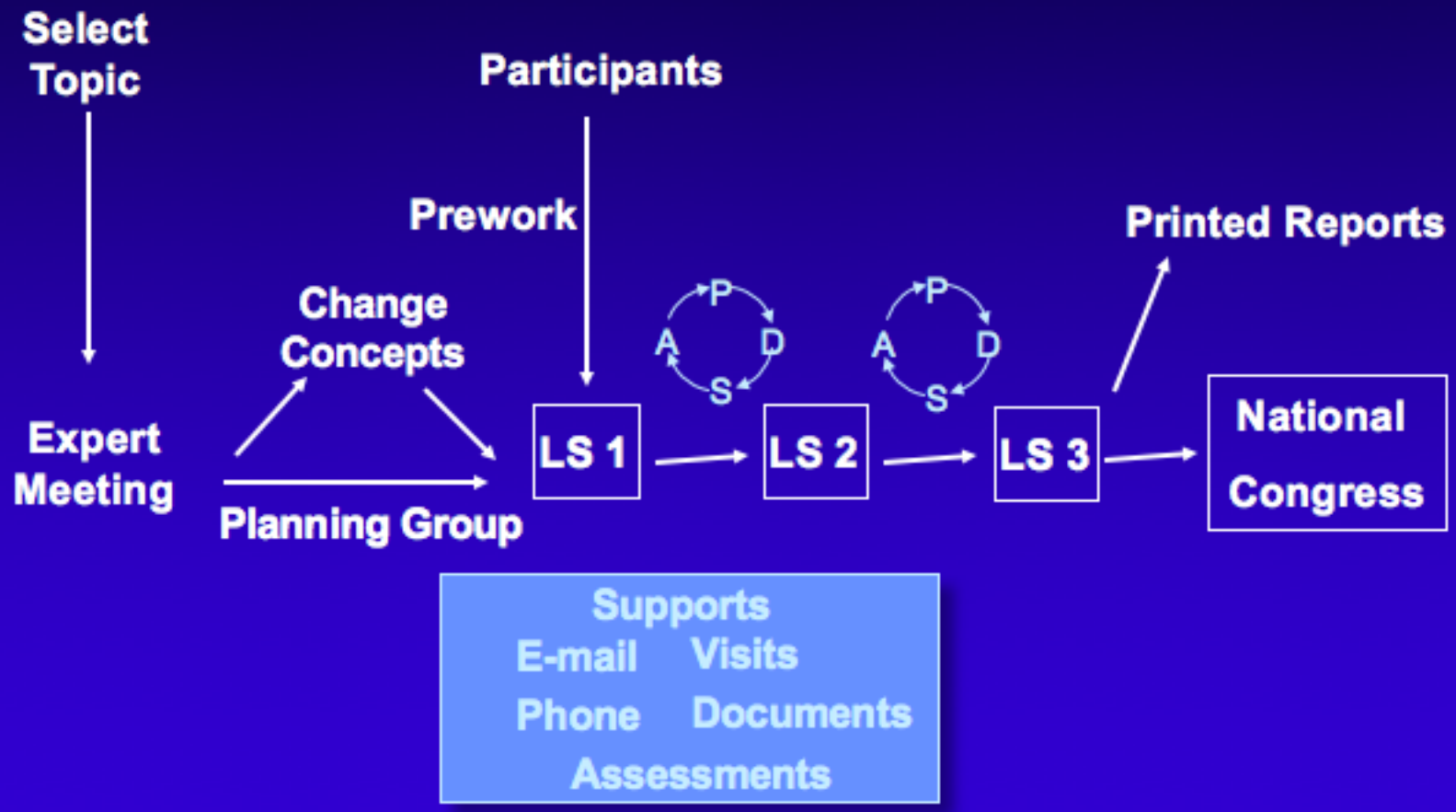


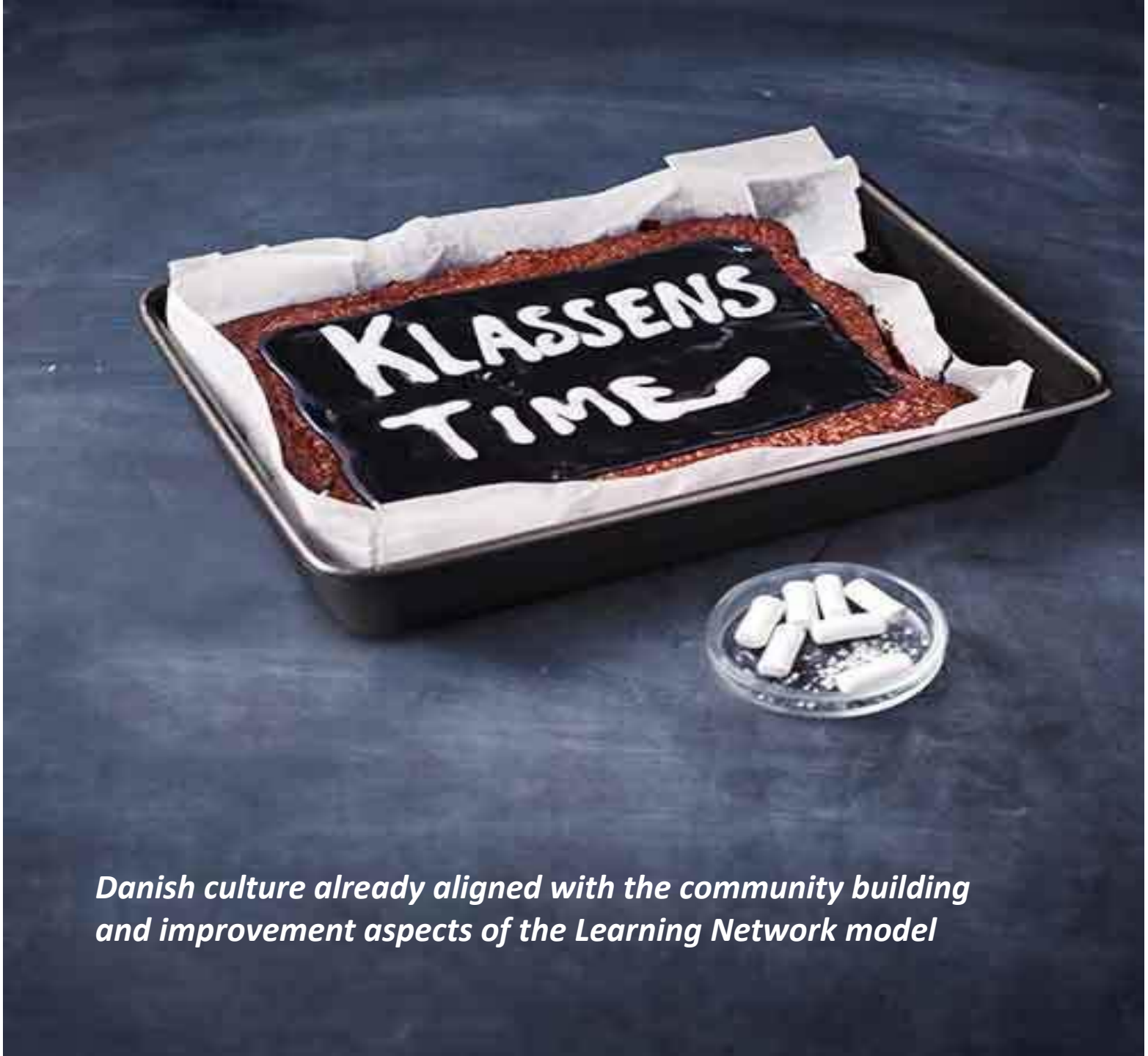
2003:
American Board of Pediatrics:
Development & Promotion of Collaborative Network Model

Initial focus

- Data
- QI methods
  - Shared goals
  - Regular performance feedback (e.g. monthly)
  - Testing changes to standardize care
- Methods to facilitate collaboration and sharing of knowledge : “All teach, all learn”
  - (face-to-face team meetings, monthly webinars, listserv, visits)

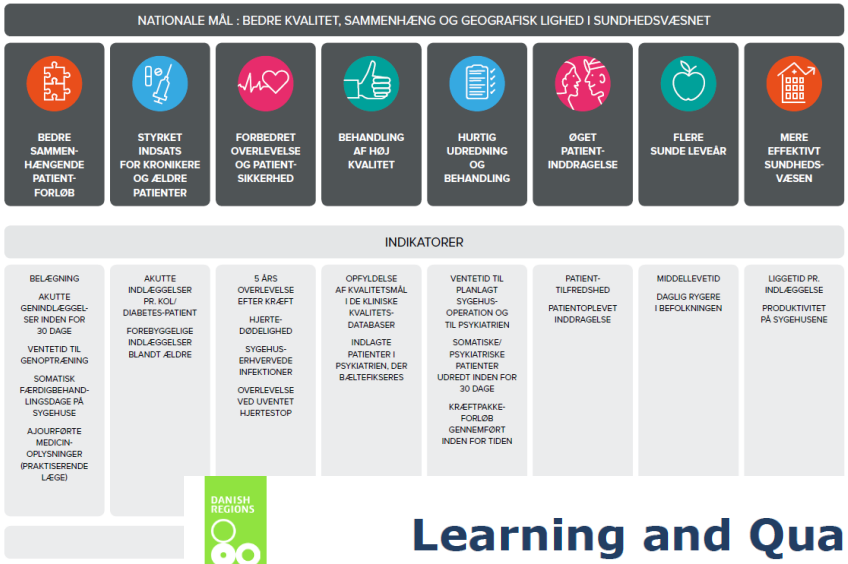
The Breakthrough Series





Danish culture already aligned with the community building and improvement aspects of the Learning Network model

Danish National Quality Program goals



Denmark laying foundation for quality and collaborative learning networks

Learning and Quality Teams established

1) Specialised paliative treatment (in cooperation with clinical register for palliative treatment)

2) Stroke (in cooperation with clinical register for Stroke)

3) Rational antibiotic theraphy in hospitals (reducin use of antibiotics)

Duration: 6-8 month of preparation. 2 years collaborativ work.

The next Learning and Quality Teams

The first LQTs focused om quality issues within hospital setting. Next LQT in colaboration with primary care for better cross sector care and cohesion:

1) +65 years old patients with hip fracture (pre and post operative, rehabilitation)
2) ADHD (visitation, diagnoses, medication, primary care services)
3) Perioperative treatment of acute high risk abdominal surgery
4) Type 1 diabetes in children and youth

All in cooperation with relevant clinical registries.

Researcher

Mom

Clinicians

“My belly hurts”

To improve care and outcomes, we need to connect patients & families, clinicians and researchers

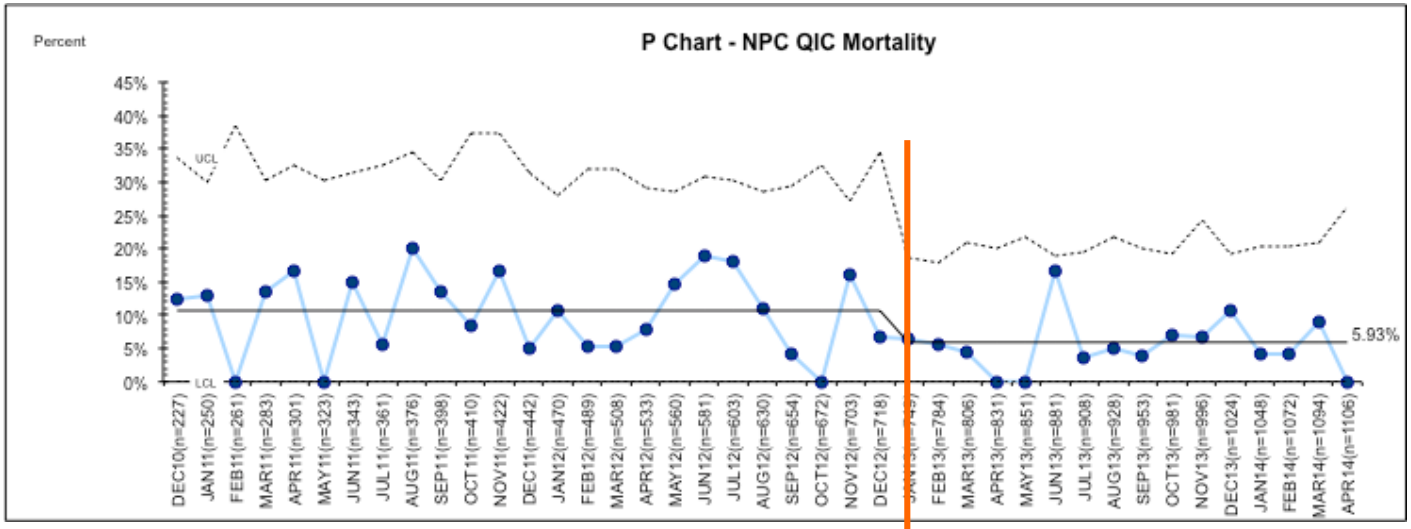
The Network Journey

- Clinician-focused → All participants
- Time-bounded → Enduring Networks
- QI → QI + Research

- Now, Learning Networks are doing research that makes a difference
  - Linking biomarkers to patient remission
  - Shared decision-making
  - Identifying effective clinical bundles
  - Comparative effectiveness studies
  - Pragmatic trials of biologics, pharmaceuticals
  - Patient reported outcomes
  - Social network analyses
  - Dissemination and implementation studies

Diffusion of results within the network

Pediatric cardiology network
Sustained improvement in mortality



Reduction in interstage mortality by >40% and now stable at ~5%

Anderson et al. *Circ Qual and Outcomes*. 2015;8:428-436

We had worked very hard to standardize care processes.
We asked: Any other reasons why mortality decreased?

Study from our Network:
Digoxin Use Associated with Decreased Mortality

ORIGINAL RESEARCH

American Heart Association | American Stroke Association

Digoxin Use Is Associated With Reduced Interstage Mortality in Patients With No History of Arrhythmia After Stage I Palliation for Single Ventricle Heart Disease

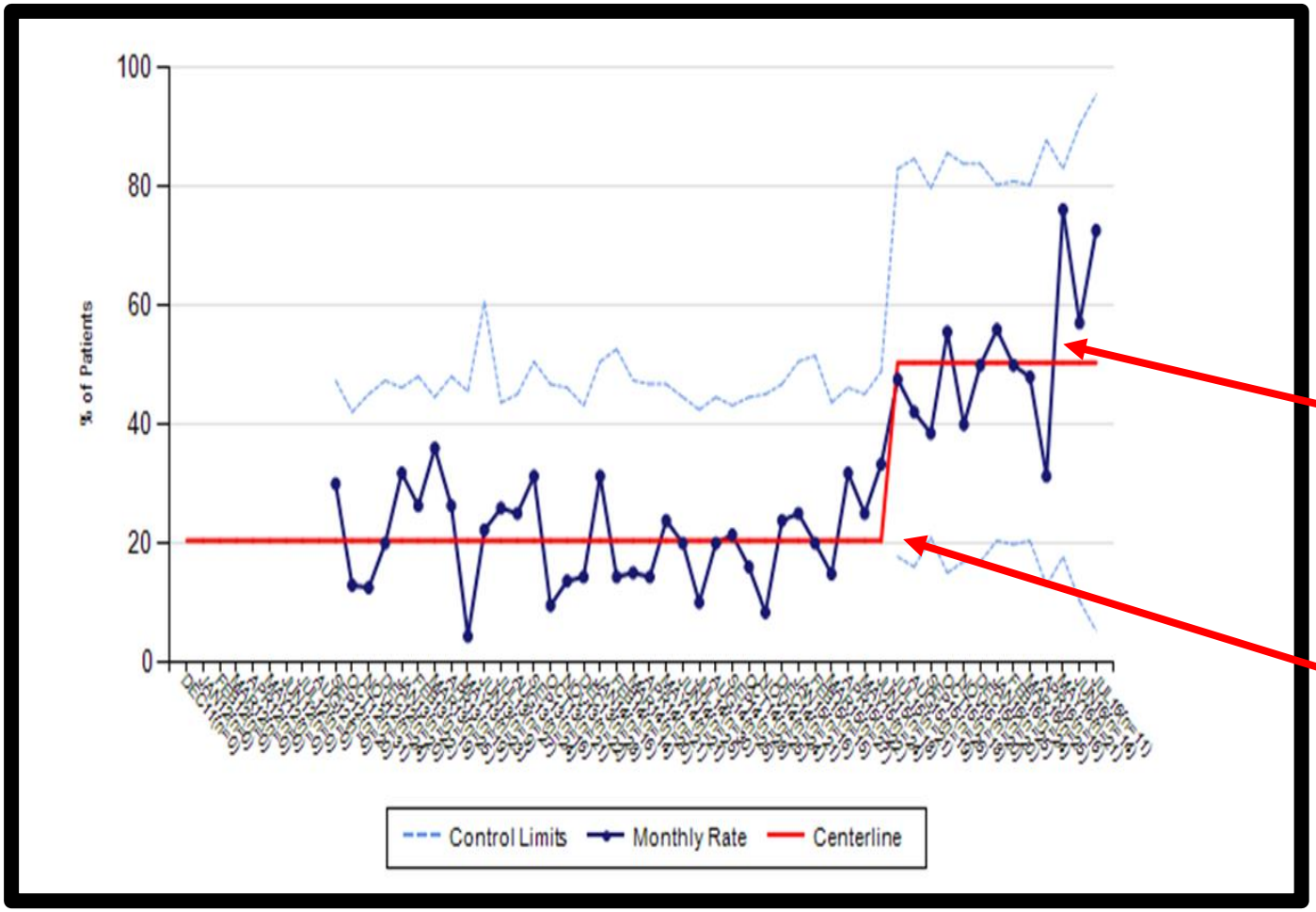
David W. Brown, MD; Colleen Mangeot, MS; Jeffrey B. Anderson, MD; Laura E. Peterson, BSN, SM; Eileen C. King, PhD; Stacey L. Lihn, BA; Steven R. Neish, MD; Craig Fleishman, MD; Christina Phelps, MD; Samuel Hanke, MD; Robert H. Beekman III, MD; Carole M. Lannon, MD, MPH; on behalf of the National Pediatric Cardiology Quality Improvement Collaborative

Background—Interstage mortality (IM) remains significant after stage 1 palliation (S1P) for single-ventricle heart disease (SVD), with many deaths sudden and unexpected. We sought to determine whether digoxin use post-S1P is associated with reduced IM, utilizing the multicenter database of the National Pediatric Cardiology Quality Improvement Collaborative (NPCQIC).

Methods and Results—From June 2008 to July 2013, 816 infants discharged after S1P from 50 surgical sites completed the interstage to stage II palliation, transplant, or IM. Arrhythmia during S1P hospitalization or discharge on antiarrhythmic medications were exclusions (n=270); 2 patients were lost to follow-up. Two analyses were performed: (1) propensity-score adjusted logistic regression with IM as outcome and (2) retrospective cohort analysis for patients discharged on digoxin versus not, matched for surgical site and other established IM risk factors. Of 544 study patients, 119 (21.9%) were discharged on digoxin. Logistic regression analysis with propensity score, site-size group, and digoxin use as predictor variables showed an increased risk of IM in those not discharged on digoxin (odds ratio, 8.6; lower confidence limit, 1.9; upper confidence limit, 38.3; $P<0.01$). The retrospective cohort analysis for 60 patients on digoxin (matched for site of care, type of S1P, post-S1P ECMO use, genetic syndrome, discharge feeding route, ventricular function, tricuspid regurgitation, and aortic arch gradient) showed 0% IM in the digoxin at discharge group and an estimated IM difference between the 2 groups of 9% ($P=0.04$).

Conclusions—Among SVD infants in the NPCQIC database discharged post-S1P with no history of arrhythmia, use of digoxin at discharge was associated with reduced IM. **(*J Am Heart Assoc*. 2016;5:e002376 doi: 10.1161/JAHA.115.002376)**

Spread of the Use of Digoxin in the Network



Publication of results

Discussion of results at network meeting

Ohio Perinatal Quality Collaborative

through the collaborative use of improvement science, to reduce preterm births and improve maternal and birth outcomes across Ohio as quickly as possible

Ohio Colleges of Medicine Government Resource Center

Ohio Department of Health

Ohio Department of Medicaid
John R. Kasich, Governor
Barbara R. Sears, Director

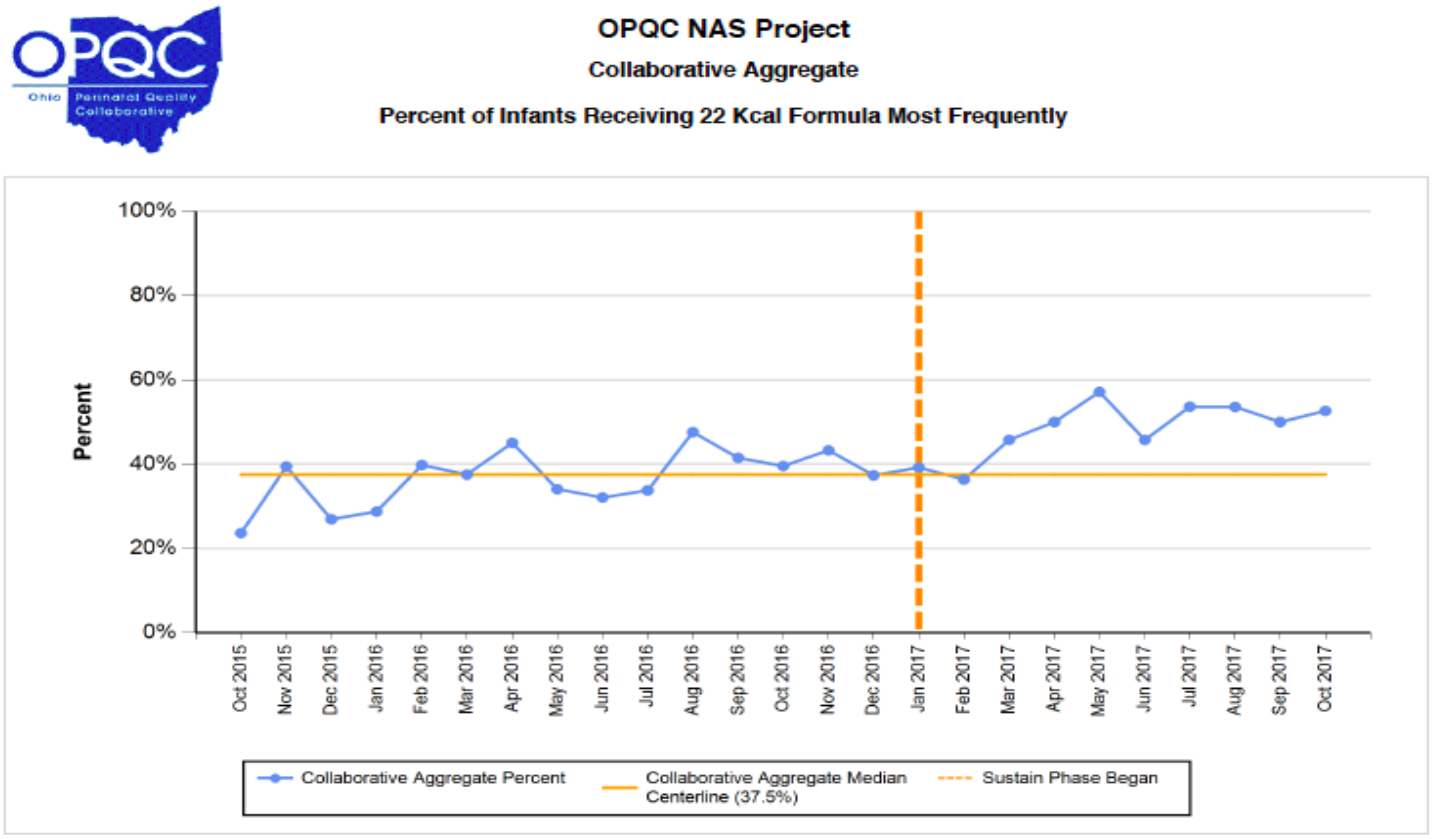
MedTAPP
Medicaid Technical Assistance and Policy Program

Neonatal Abstinence Syndrome (NAS) Project
Orchestrated Testing at 52 Neonatal Units

Question: Is there a certain formula that is best for non-breastfeeding infants with NAS?

22-calorie formula is better

Diffusion of 22-calorie formula through the neonatal network



Example of a natural experiment within a network

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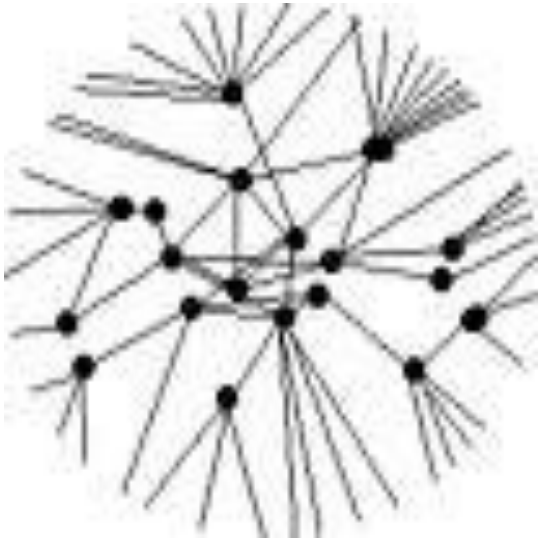
Design Principles



1. Focus on outcome
2. Build community
3. Use technology effectively
4. Develop and continuously improve the system

Networks

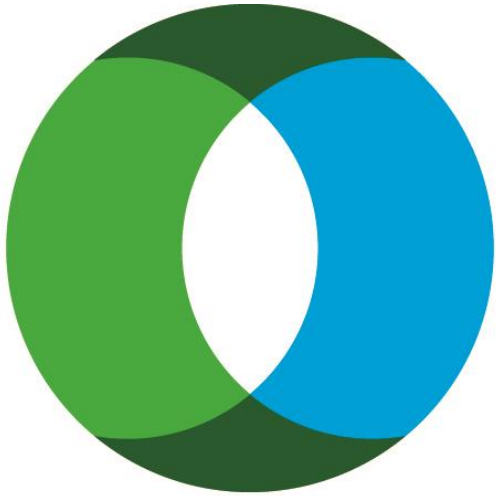
WIKIPEDIA

The Free Encyclopedia

What if….?

- …we could create a vastly better chronic care system by harnessing inherent motivation and collective intelligence of **patients** and clinicians?

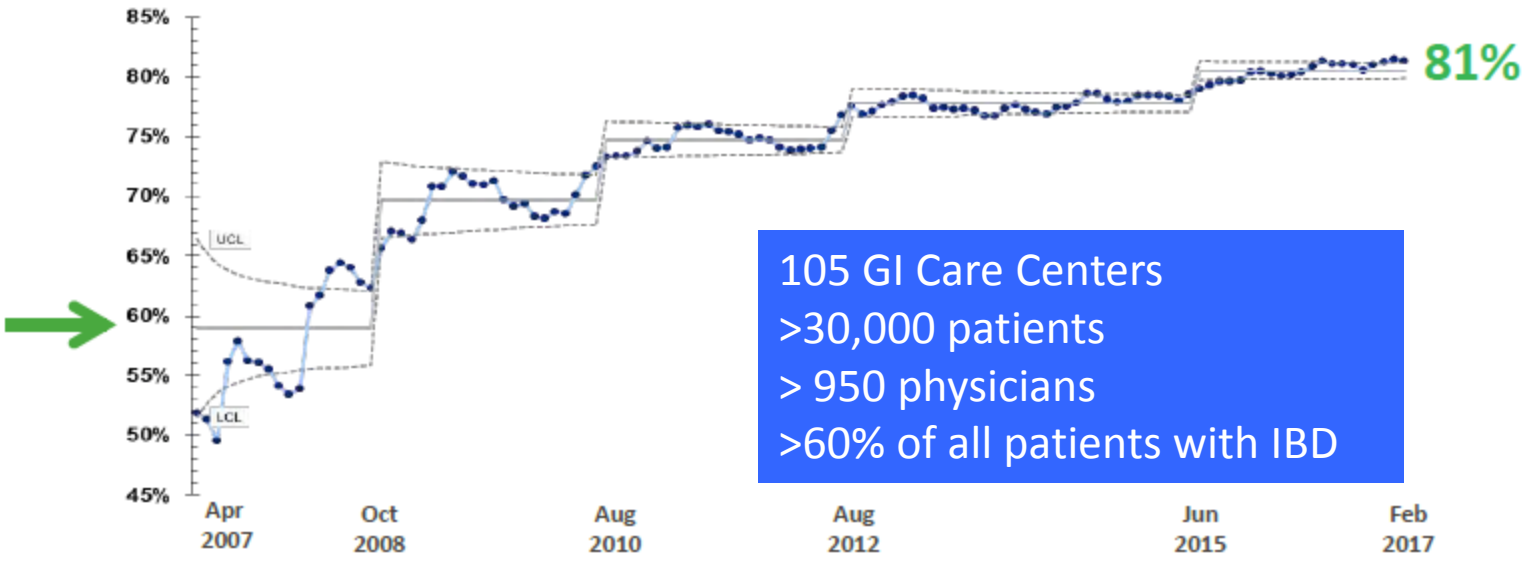
- … this system allowed **patients** and physicians to share information, collaborate to solve problems, use their collective creativity and expertise to act in ways that improve health?



IMPROVE**CARE**NOW

Clinical remission rate in CD and UC

PGA = Inactive (Physician Global Assessment)



105 GI Care Centers
>30,000 patients
> 950 physicians
>60% of all patients with IBD

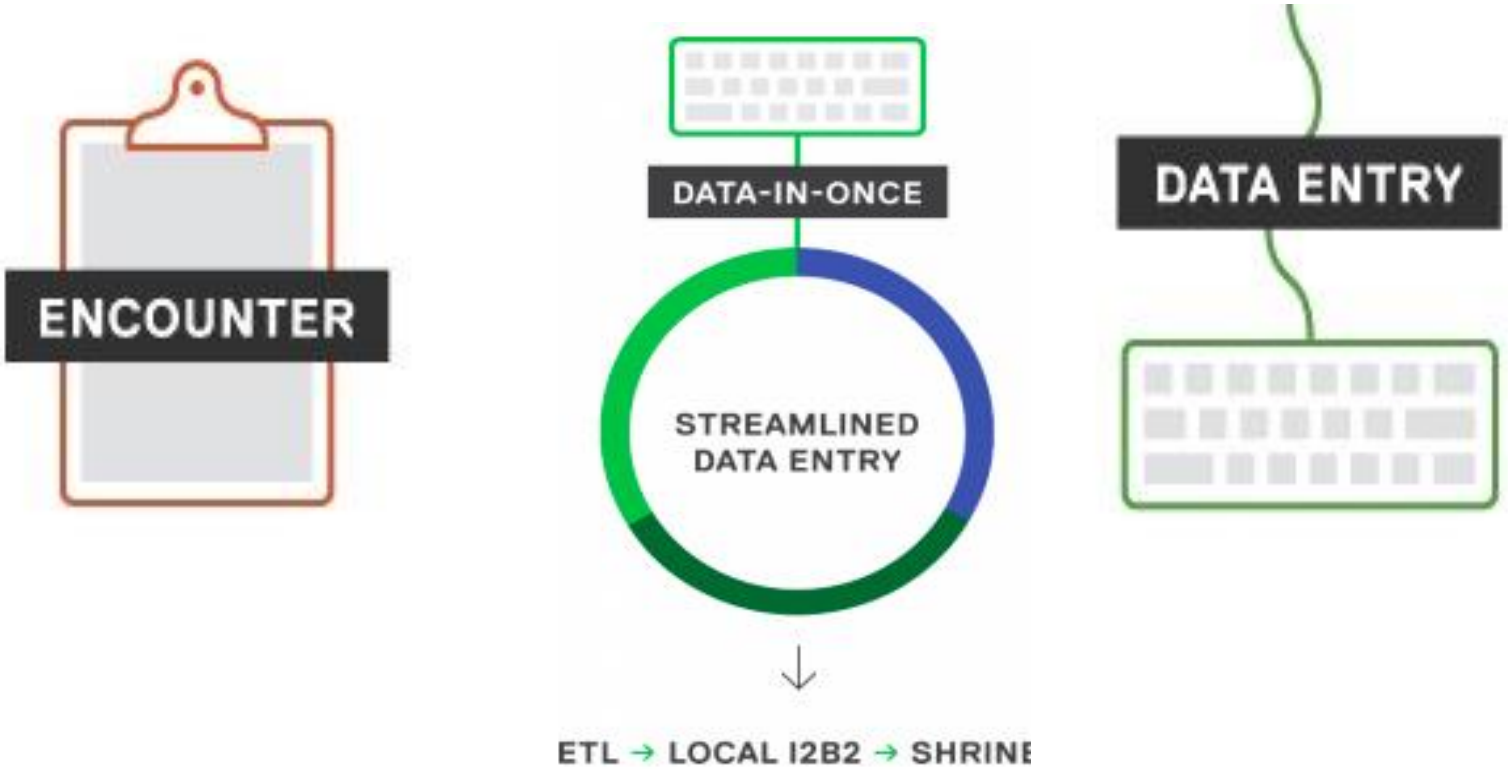
Creating a culture of generosity and contribution (with all stakeholders)

+

the ostomy toolkit

An Educator

“Data in once”
Technology for efficient data capture

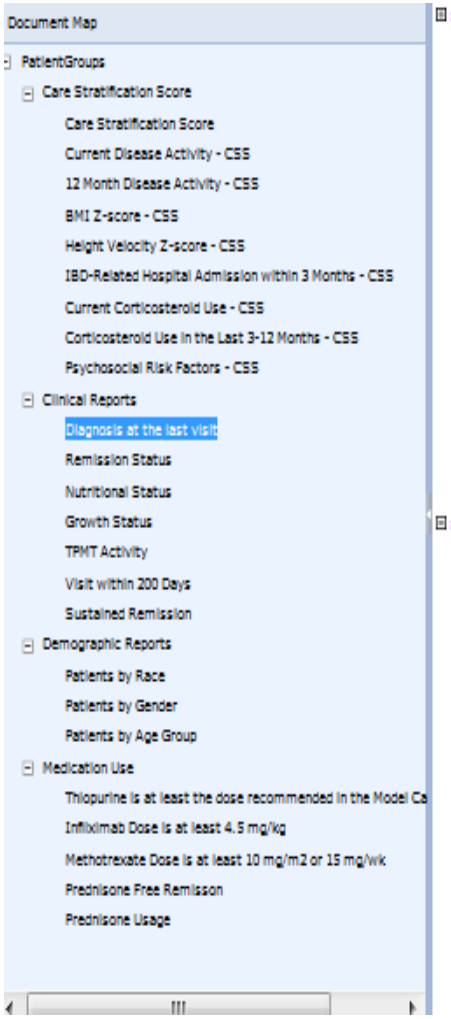


Marsolo K, Margolis PA, Forrest CB, Colletti RB, Hutton JJ. A digital architecture for a network-based learning heath system – integrating chronic care management, quality improvement, and research. eGEMS. 3:2015

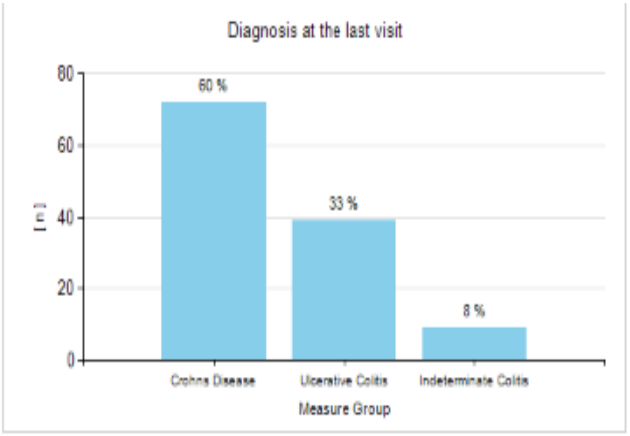
“Enhanced” Registry

- Automated chronic care reports
- QI Reports
- Transparent performance data
- Data quality reports
- Data (and technology) for research
  - Comparative effectiveness
  - Clinical trials
  - N of 1

Automated population management

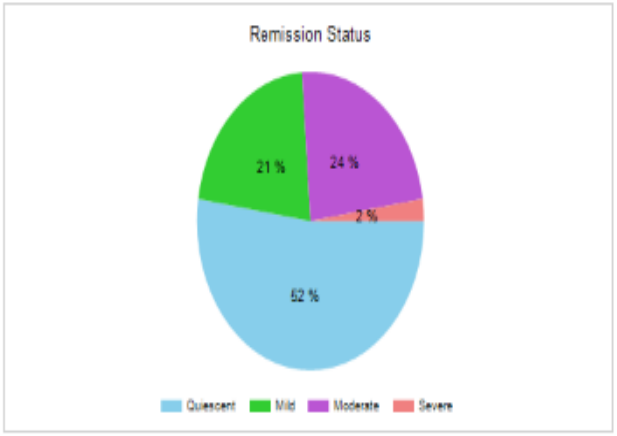


Switch



	Diagnosis at the last visit (n and %)
Crohns Disease	72
Ulcerative Colitis	39
Indeterminate Colitis	9
Total	120

Switch



	Remission Status (n and %)
[redacted]	78
Quiescent	22
Mild	9
Moderate	10
Severe	1
Total	120

Automated pre-visit planning

IBD PRE-VISIT ASSESSMENT

Patient Name: Huxtable,Rudy /MRN:6005603 | Birth Date: 7/16/2002 | Primary Provider:
Patient Num: 5 | Current Age: 12.0 | Secondary Provider:

Diagnosis: Crohn's Disease - 3/2010	Last Visit: 3/7/2014	Last PPD & Date:
Phenotype: Inflammatory, non-penetrating, non-stricturing	Wt (kg): 20.41	Negative 9/7/2012
Lower: Ileal only	Ht (cm): 91.44	Last CXR:
Upper Proximal: No	BSA: .72	Negative 9/10/2010
Upper Distal: No	Date of last hospitalization:	Last Gold Test & Date:
Perianal Phenotype: No	Not Recorded	Not Done

>> Visits:	01/15/2013	01/23/2013	02/26/2013	04/09/2013	05/21/2013	07/09/2013	08/19/2013	03/07/2014	Age of Result
sPCDAI	0	20	0	10	0	10	25	50	
PGA	Quiescent	Quiescent	Quiescent	Quiescent	Quiescent	Quiescent	Quiescent	Mild	
Nutritional Status	Satisfactory	Satisfactory	Satisfactory	At risk	Satisfactory	Satisfactory	Satisfactory	Satisfactory	
Growth Status	Satisfactory	Satisfactory	Satisfactory	Satisfactory	Satisfactory	Satisfactory	Satisfactory	Satisfactory	
Albumin	4.5		4.3	4.5	4.3	4.4	4.3		12 mo ⓘ
CRP	0.00		0.00	0.00	0.50	0.00			13 mo ⓘ
ESR							7.0		12 mo ⓘ
Hematocrit	36.0		36.1	38.7	35.7	35.5	34.8		12 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
5	4-9 (High)	1 (Mild)	1 (Mild/Moderate/Severe)	0 (BMIZscore >=-1 or Missing)	3 (HtVelocityZscore <-2)	0 (No or Unknown)	0 (No or Unknown)	0 (No or Unknown)	No

>> Treatments	Dose (mg)	mg/kg (last wt)	Guideline	ⓘ Attention Needed
Immunomodulators				
Thiopurines TPMT date / result	Not done		Consideration: If active dz, consider 6TGN levels q 90	ⓘ Consider 6 TGN levels
Other				
Enteral Therapy	Supplemental therapy		Dietary consult	

Other Labs	Levels	Dates	Levels	Dates	Notes
6MP Patients	6-TGN: 192.0	12/23/2011	6MMPN: 779.0	12/23/2011	

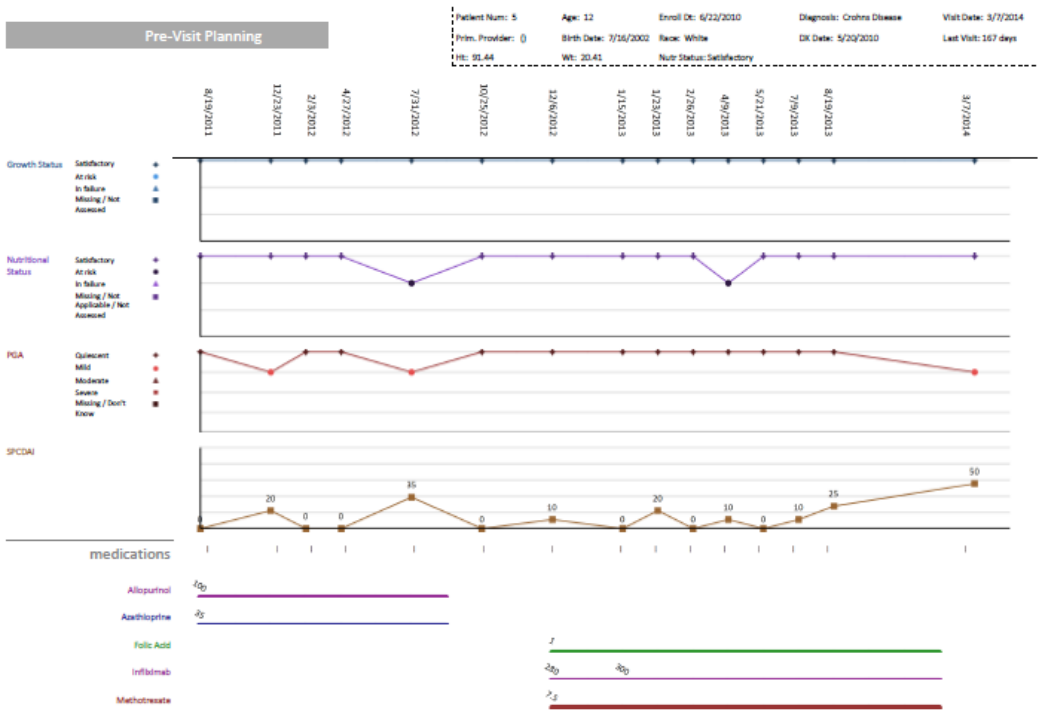
Considerations: The following are general items for your consideration as you establish a plan for your patient. They are not applicable to all patients. Similarly, evaluation and testing beyond those noted below may be indicated. These considerations should not be used in place of your clinical judgement.

Thiopurines: Consider 6 TGN levels

Additional considerations for patients with suspected MILD disease:

Maximize current therapy

• Confirm adherence to medication and dosage



Overview of Presentation

- What *is* a Learning Network?
- Do Learning Networks *work*?
- How did we start?
- How do we work?
- **What did we learn?**

Learning Network Components

- Systems of Leadership
  - Including leadership team: Faculty/Content Lead, Improvement/Collaborative Science Lead, Patient/Family(s))
- Network Coordinating Center
  - Governance & Management
- Quality Improvement support & capability
- Research/science support
- Data & Analytics / Data Coordinating Center
  - Data collection/management/registry, and analytics
- Community
  - Improvement Teams at network sites / centers, including patients and families

What we've learned

- Go faster and further when we partner with patients and families
- Building participation by everyone develops more capacity
- Relentless focus on outcomes drives progress
- Structures and processes make it easier to collaborate

What we are still learning

- Becoming more efficient and developing a shared infrastructure
- The better we get, the problems may become more complex
- Balancing priorities: improvement, research, innovation

In a networked world, value comes from who you are connected to, how you are connected, and the ability to share and contribute

Taking advantage of a network requires new ways to lead and practice to facilitate sharing, generosity, trust, connectivity and cooperation.