Improvement and Innovation Networks
The Intersection between Research and Quality Improvement

Lloyd Provost
Associates in Process Improvement
lprovost@apiweb.org
The Collaborative Knowledge Networks

COINs are embedded into a multidimensional network of communities.
Effective networks for improvement

Developing and managing effective networks to support quality improvement in healthcare

The Health Foundation
Inspiring Improvement

Learning report
March 2014

http://www.health.org.uk/publications/effective-networks-for-improvement/
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
Components of a network-based Learning Health System*

- Focus on outcome
- Build community
- Effective use of technology
- Learning system
  
  System science, quality improvement, qualitative research, clinical research
ImproveCareNow is an Example of an Improvement Network

Purpose of ImproveCareNow (ICN):
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, first organized in 2005

Richard Colletti, MD and Peter Margolis, MD, PhD. Supported by: NIH NIDDK R01DK085719, AHRQ R01HS020024, AHRQ U18HS016957, PCORI PPRN-1306-01754, ImproveCareNow Network Care Centers, CCHMC Learning Networks Program
The ImproveCareNow Story

• ImproveCareNow has *improved care and outcomes* for children *without new medications*.

• **Patients partnered** with researchers and providers to **innovate** within this Learning Health System.

• The network works continuously to **build a community** to motivate and support providers, researchers, and patients.

• Through a quality improvement network, ICN has **changed patients lives**.
Number of centers in ICN
(Thru the 3rd quarter of 2013)
Geographic Reach of ImproveCareNow Network, 2014
Aggregate Improvement in Outcomes

Percent of patients in remission

Month


API - 2014

ImproveCareNow, 2014
Learning from Variation among Centers

Funnel Plot (P Chart) of Remission Rates in June 2012

Remission Rate %

40% 50% 60% 70% 80% 90% 100%

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z aa bb cc dd

ImproveCareNow Centers

74.7%

UCL

LCL

ImproveCareNow, 2014
Some ICN Publications

ImproveCareNow: The Development of a Pediatric Inflammatory Bowel Disease Improvement Network

Wallace Crandall, MD,1 Michael D. Kappelman, MD, MPH,2 Richard B. Colletti, MD,3 Ian Leibowitz, MD,4 John E. Grunow, MD,5 Sabina Ali, MD,6 Howard I. Baron, MD,7 James H. Berman, MD,8 Brendan Boyle, MD,1 Stanley Cohen, MD,9 Fernando del Rosario, MD,10 Lee A. Denson, MD,11 Lynn Duffy, MD,4 Mark J. Integlia, MD,12 Sandra C. Kim, MD,2 David Milov, MD,10 Ashish S. Patel, MD,13 Bess T. Schoen, MD,9 Dorota Walkiewicz, MD,14 and Peter Margolis, MD, PhD15

Inflamm Bowel Dis • Volume 17, Number 1, January 2011

Improved Outcomes in a Quality Improvement Collaborative for Pediatric Inflammatory Bowel Disease

Wallace V. Crandall, Peter A. Margolis, Michael D. Kappelman, Eileen C. King, Jesse M. Pratt, Brendan M. Boyle, Lynn F. Duffy, John E. Grunow, Sandra C. Kim, Ian Leibowitz, Bess T. Schoen, Richard B. Colletti and for the ImproveCareNow Collaborative

Pediatrics 2012;129:e1030; originally published online March 12, 2012;

Collaborative Chronic Care Networks (C3Ns) to Transform Chronic Illness Care

Peter A. Margolis, Laura E. Peterson and Michael Seid

Pediatrics 2013;131:S219
DOI: 10.1542/peds.2012-3786J
Improving Outcomes with a Learning Health System

- Patients and Families
- Clinicians
- Identify Uncertain Management Practices
  - Multi-stakeholder Informed Research
  - Comparative Effectiveness Research
- Point of Care Learning Engine
  - EHRs
  - Patient-Reported Data Biospecimens
  - New Knowledge
  - Standardize Care Process
  - Reduce Variability in Care
  - Customize Care to Patient Needs
  - Identify Gaps in Care
- Registry Database
- Registry Applications
- Learn Outcomes
The ICN2 Registry Technology for real-time learning

data on 14000 patients and 80000 patient visits. populated by EHR

ImproveCareNow, 2014
The ICN2 Registry

Data are entered in real time or close to real time during the visit and in many centers are being uploaded right from the electronic record. Visit records contain 80 variables describing that patient and their care.
Registry: Management of Patient Population

ICN - Population Management Report
Data as of 11/26/2013

Nationwide Children’s Hospital
DX: Crohn’s Disease, Indeterminate Colitis, Ulcerative Colitis

Care Stratification Score

12 Month Disease Activity - CSS

<table>
<thead>
<tr>
<th>Measure Group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 (Quiescent)</td>
<td>82%</td>
</tr>
<tr>
<td>1 (Mild)</td>
<td>8%</td>
</tr>
<tr>
<td>2 (Moderate or Severe)</td>
<td>10%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>12 Month Disease Activity - CSS (n and %)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 (Quiescent)</td>
</tr>
<tr>
<td>1 (Mild)</td>
</tr>
<tr>
<td>2 (Moderate or Severe)</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>

Care Stratification Score

<table>
<thead>
<tr>
<th>Measure Group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-3 (Low)</td>
<td>82%</td>
</tr>
<tr>
<td>4-9 (High)</td>
<td>17%</td>
</tr>
<tr>
<td>&gt;=10 (Critical)</td>
<td>1%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Care Stratification Score (n and %)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-3 (Low)</td>
</tr>
<tr>
<td>4-9 (High)</td>
</tr>
<tr>
<td>&gt;=10 (Critical)</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>
Learning for Improvement (QI)
Care Center Performance Report

- Percent of visits with a complete bundle (≥75%, [%])
- Cumulative Number of Patients - (≥75%, [n])
- Percent of visits where TPMT has been measured when treatment with thiopurine is started, (≥75%, [%])
- Percent of visits meeting the consistency bundle (≥75%, [%])
- Percent of active patients in registry with visit recorded in last 13 months (≥75%, [%])
- Percent of visits entered that were entered within 30 days of visit date *** - *** Data reported on a two month lag (≥75%, [%])
“Research Grade Data”

Growth status
- satisfactory
- at risk
- in failure
- not assessed

Adherence assessment
- satisfactory

Drop in height by 2 isobars; OR height below 3rd percentile for age; OR height velocity below 3rd percentile

Assessments

Physician's global assessment of current disease status
- quiescent
- mild
- moderate
- severe
- unknown

Nutritional status
- satisfactory
- at risk

Moderate pain; moderate diarrhea, including nighttime and/or bloody stools; significant fatigue; active fistula; significant weight loss and/or abdominal tenderness; non-toxic; significant lab abnormalities
What kind of data does the Learning Health System have on Kyle?

Kyle’s Biospecimen Data

Kyle’s Other CCHMC Clinical Data

Kyle’s Patient Reported Outcomes

Meet Kyle

Kyle is a 15 yo M h/o Crohn’s Disease, penetrating phenotype x 5 years currently complaining of severe nausea.

Utilization Data

Registry data From Kyle’s GI specialist

Meet Kyle

Kyle is a 15 yo M h/o Crohn’s Disease, penetrating phenotype x 5 years currently complaining of severe nausea.

ImproveCareNow, 2014

API - 2014
### Care Center Level Studies

<table>
<thead>
<tr>
<th>Treatment Combination</th>
<th>Pre-visit Planning</th>
<th>Population Management</th>
<th>Self-Management Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site 1</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Site 2</td>
<td>+</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Site 3</td>
<td>-</td>
<td>+</td>
<td>-</td>
</tr>
<tr>
<td>Site 4</td>
<td>-</td>
<td>-</td>
<td>+</td>
</tr>
<tr>
<td>Site 5</td>
<td>+</td>
<td>-</td>
<td>+</td>
</tr>
<tr>
<td>Site 6</td>
<td>-</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Site 7</td>
<td>+</td>
<td>+</td>
<td>-</td>
</tr>
<tr>
<td>Site 8</td>
<td>+</td>
<td>+</td>
<td>+</td>
</tr>
</tbody>
</table>

#### % in Remission

Run Order Plot for: Aug RR

---

ImproveCareNow, 2014
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

Nocturnal (I chart)
PT sick, took amoxicillin 12/9-12/16
PT sick, took Augmentin 1/25 - 2/1

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

ImproveCareNow, 2014
Methods
In this randomized, double-blind trial, we evaluated the efficacy of infliximab monotherapy, azathioprine monotherapy, and the two drugs combined in 508 adults with moderate-to-severe Crohn’s disease who had not undergone previous immunosuppressive or biologic therapy.
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

ImproveCareNow, 2014
This study provides evidence that anti-TNFα therapy given to pediatric patients who have moderate to severe CD in real-world settings is effective at achieving remission at rates comparable to single-group, open-label clinical trials, such as REACH,4 with pediatric patients and comparative controlled studies done with adults, such as SONIC.6
Applying REACH selection criteria to the ICN sample yielded an average of 75 initiator trials across the 100 replicates.

The approach we used in this study to examine observational registry data as a sequence of nonrandomized trials is a promising methodology that can be extended to other clinical questions.

The method allows generalization of likely benefits to patients as it avoids overly strict selection criteria that characterize explanatory clinical trials, which test efficacy and are not representative of real-world practice.
Improving Outcomes with a Learning Health System

- **Patients and Families**
- **Clinicians**
- **Identify Uncertain Management Practices**
- **Multi-stakeholder Informed Research**
- **Comparative Effectiveness Research**
- **Point of Care**
  - Learning Engine
  - EHRs
    - Patient-Reported Data
    - Biospecimens
- **Identify Gaps in Care**
- **Registry Database**
- **Registry Applications**
- **Standardize Care Process**
  - Reduce Variability in Care
  - Customize Care to Patient Needs
- **Patient Outcomes**

**ImproveCareNow, 2014**