Healthier Together: Collaborative Networks of Patients, Clinicians and Researchers Creating Learning Health Systems

Peter Margolis, MD, PhD
Carole Lannon, MD, MPH

James M. Anderson Center for Health Systems Excellence
Cincinnati Children’s Hospital Medical Center

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What if....?

...we could create a vastly better chronic care system by harnessing inherent motivation and collective intelligence of patients and clinicians?
What if....?

... 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

Facebook
Wikipedia
Airbnb
Percent of patients in clinical remission
Crohn’s Disease and Ulcerative Colitis

Centers >75% registered
Percent of patients in clinical remission
Crohn’s Disease and Ulcerative Colitis

95 GI Care Centers
>27,000 patients
>900 physicians
>50% of all patients with IBD

Centers >75% registered
Design principles

1. Focus on outcome (for full population)
2. Build community
3. Effective use of technology
4. Learning system
   - System science, QI, qualitative research, clinical research
“Data in once” - efficient data capture
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“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
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
+ the ostomy toolkit
Awareness → Participation → Contribution → Ownership

Knows of ImproveCareNow
Awareness  
Knows of ImproveCareNow

Participation  
Reads a blog

Contribution  
Signs Consent

Ownership
Awareness → Participation → Contribution → Ownership

- Knows of ImproveCareNow
- Signs Consent
- Reads a blog
- Joins QI Team
- Becomes a mentor
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- Becomes a mentor
- Leads a team
- Creates tools
Awareness

Participation

Contribution

Ownership

100%

90%

9%

1%

Knows of ImproveCareNow

Signs Consent

Joins QI Team

Leads a team

Reads a blog

Becomes a mentor

Creates tools
A “Commons” for sharing

NCH "NG placing party." In 2013, our team had "Enteral Therapy Thursday." We all did enteral therapy PO for a day.

9 views 0 Likes 0 comments
marcijohnson via jsmith onto Nutrition
An Owner
An Owner
Replication of the model
National Pediatric Cardiology Quality Improvement Collaborative

Zoe Madison (Age 6, HLHS)
Reducing variation in growth
Reducing variation in growth
Reducing variation in growth

Identified growth bundle
6 months
Reducing variation in growth

Identified growth bundle
6 months
Reducing variation in growth

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Identified growth bundle
6 months
Improvement in Mortality

46% reduction in inter-stage mortality

“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, Pediatric cardiologist, CHOA

“Learn from one another and get better faster…”

Sarah Vinje, Mom to Cecilia
Ohio Perinatal Quality Collaborative
OPQC = 108 maternity hospitals

75% decrease early elective deliveries
Since 2008, > 61,000 births shifted to term
Births before 32 weeks of gestation to women with prior preterm birth decreased by 20.5% in all hospitals, by 20.3% in African American women, and by 17.1% in women on Medicaid.
Growth of Learning Networks
414 teams, 272 sites, 43 states + DC, 3 countries

# Teams in CCHMC Supported Learning Networks

Number of Sites

Jan 07  Jan 08  Jan 09  Jan 10  Jan 11  Jan 12  Jan 13  Jan 14  Jan 15  Sept 15  Jan 16  May 16  Aug 16  Q4 16
Where do research and innovation ideas come from?

• Top Down - Formal priority setting based on gaps and needs of patients, families, clinicians, researchers, and health system leaders

• Bottom Up - Innovators and researchers inside and outside ICN monitor performance, see problems, understand gaps and work to fix them.
In March 2016, a total of 164 healthcare professionals, parents, and patients ranked these 22 research topics, based on what they believed would result in the greatest improvement in health and well-being for pediatric IBD patients.

<table>
<thead>
<tr>
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<th>Question</th>
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<tbody>
<tr>
<td>1</td>
<td>Do the effects of dual therapy differ for patients who start both treatments at the same time versus those who start biologics then step-up to dual therapy?</td>
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<td>What are the characteristics (i.e. IBD phenotype and patient demographics, treatment course) of children who are unable to achieve remission within the first two years of being diagnosed?</td>
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<td>What are the IBD and patient characteristics that should influence decision-making on the most effective treatments?</td>
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<td>Compare the effectiveness of biologic agents (e.g., Infliximab, adalimumab) vs. enteral feeds to decrease inflammation</td>
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<td>What is the comparative effectiveness of enteral therapy versus medications for treatment of IBD?</td>
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Anti-TNF Monotherapy vs. Combination Therapy with Low Dose Methotrexate in Pediatric Crohn’s disease

Patients with Moderate-Severe Crohn’s Starting on Biologics

Anti-TNF + Low Dose MTX

Anti-TNF + Placebo

Primary
• Maintenance of Remission

Secondary
• PRO
• Antibodies
• Drug levels

Data Collection for 2 Years

IMPROVECARENOW
#14: How effective is a low sugar and/or carbohydrate diet (i.e. SCD) in reducing the symptoms and disease markers of IBD in outcomes?

“One of the most difficult things for me about my child getting a Crohn’s diagnosis was that there seems to be so little attention given in the MD community to how dietary changes might help. I’m not advocating managing Crohn’s with food alone; but I can’t help feel that it is crazy to focus only on giving medication and not worry about what she eats other than ‘no popcorn or seeds’.” Mom on Smart Patients
- The trial was so exclusive that no one was ever randomized.
The ICN SCD N-of-1 Study

- Series of individual N-of-1 trials comparing SCD to a liberalized SCD
- Randomized to SCD or liberalized SCD and alternate between these two conditions for four 8-week treatment periods
- Patients and clinical team will use an app and web portal to facilitate data collection, tracking intervention status, and reviewing individual trial results
- Each individual will have personalized answer about effectiveness of SCD vs. more liberalized SCD in managing their symptoms
- Results of the individual N-of-1 trials aggregated to estimate population level effectiveness
Improving Outcomes with a Learning Health System - Health care delivery, improvement and research together as part of the same system
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- Registry Applications
- EHRs
- Patient-Reported Data
- Biospecimens

- Patients and Families
- Clinicians

- Identify Uncertain Management Practices

- Point of Care
  - Learning Engine

- Standardize Care Process
  - Reduce Variability in Care
  - Customize Care to Patient Needs

- Identify Gaps in Care

- Registry Database
- Registry Applications

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

Patients and Families → Clinicians → Identify Uncertain Management Practices → Identify Gaps in Care → EHRs Patient-Reported Data Biospecimens → Registry Database → Registry Applications → Standardize Care Process Reduce Variability in Care Customize Care to Patient Needs → Patient Outcomes

Identify Uncertain Management Practices → Multi-stakeholder Informed Research → Comparative Effectiveness Research

Learning Engine

Point of Care

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- Learning Engine
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- Patients and Families
- Clinicians

Point of Care
Learning Engine

Standardize Care Process
Reduce Variability in Care
Customize Care to Patient Needs

Patient Outcomes

EHRs
Patient-Reported Data
Biospecimens

Identify Gaps in Care

Identify Uncertain Management Practices

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1. Do the effects of dual therapy differ for patients who start both treatments at the same time versus those who start biologics then step-up to dual therapy?
2. What are the characteristics (i.e. IBD phenotype and patient demographics, treatment course) of children who are unable to achieve remission within the first two years of being diagnosed?
3. What are the IBD and patient characteristics that should influence decision-making on the most effective treatments?
4. Compare the effectiveness of biologic agents (e.g., Infliximab, adalimumab) vs. enteral feeds to decrease inflammation
5. What is the comparative effectiveness of enteral therapy versus medications for treatment of IBD?

Comparative Effectiveness Research

Registry Database

Registry Applications
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What we’ve learned

- Relentless focus on outcomes and transparency
- 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
- Design one system - meet needs and goals of all stakeholder simultaneously
What we have to learn

• Shifting power dynamics
• Education for co-production
• Managing capacity
• How to lead and foster cooperation