ImproveCareNow
A Learning Health System Built on Partnership and Collaboration

Richard Colletti, Annette Kulzer, Amy Quinn, Sarah Myers, Marc Tsou
ImproveCareNow: A Learning Health System to Transform the Health, Care and Cost of IBD

Richard B. Colletti, MD
President and Executive Network Director, ImproveCareNow
Professor and Vice Chair for Clinical and Research Affairs, UVM
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
Aim

- Describe a Learning Health System
- Give an overview of ImproveCareNow as a Learning Health System
A Learning Health System

*Concept of the Institute of Medicine*

- Network of clinicians, researchers, patients and families
- Focus on improving outcomes
- Innovative technology
- Safe, evidence-based patient-centered care
- Integrating clinical care, improvement and research
Why do we need a Learning Health System?

- Clinical data isn’t shared—a missed opportunity for learning
- Pediatric research is expensive and difficult
- Systems providing clinical care are unreliable with suboptimal patient outcomes
What is the reliability of medical care?

- **Patients receive** only 60% of recommended care
- **Patients take** only 60% of recommended medications
- There is a *gap* between recommended care and the care actually carried out
- If medical care and patient self-management were more reliable, would outcomes be better?
Remission rate
(Physician Global Assessment, Centers >75% registered)
How we improve care and outcomes

1. **Establish Aims and Measures**
   - What are we trying to accomplish?
   - How would we know if a change is an improvement?

2. **Measure performance**

3. **Identify gaps** between standard and actual performance

4. **Make changes** to close the gaps using tools to increase reliability
73 centers

20,500 IBD patients

600 Ped GI

45% Of cared for by pediatric gastroenterologists
How many patients in the registry?

18,000 registered

A gold mine of data for learning

Largest and fastest growing in the world

105,000 visits
Data collection and entry

- Register every patient with inflammatory bowel disease
  - Enter data for every outpatient visit
- 50 to 75 data elements each visit
- Manual web-based data entry into registry
  
  OR
  
  Electronic data extraction and transfer
Patient visit

1. Data recorded
2. Manually extracted

3. Data entry

Data storage

ICN
1. Complete diagnostic and initial evaluation (100%, 90%, n=1)

2. Disease phenotype and extent of disease are documented (100%, 90%, n=29)

3. Disease severity is documented (100%, 90%, n=29)

4. Height, weight and BMI are plotted (96%, 90%, n=25)

5. Satisfactory nutritional status (97%, 89%, n=89)

6. Nutritional status is classified (100%, 90%, n=29)

7. Satisfactory growth status (99%, 88%, n=89)

8. Growth status is classified (100%, 90%, n=29)

Number of patients enrolled in Clinipace (cumulative)

9. Appropriate doses of Sulfasalazine and/or Mesalamine (83%, 85%, n=6)

10. Started on a 6MP or azathioprine... pre-tested for TPMT level (100%, 90%, n=3)

11. Plan and carry out changes

12. Study

13. Do

14. Act

Plan

Do Study

Act

Clinical care

Automated data analysis

Electronic extraction

Electronic transfer

Data-in-One

ICN

ICN Research datasets

QI analysis

Real time reporting to sites

Research datasets
6 interventions to improve care

1. Training in quality & systems improvement
2. Registry with high quality data
3. Model IBD Care guideline
4. Population management
   • Care stratification
5. Pre-visit planning
6. Self-management support
### Clinical Measures

<table>
<thead>
<tr>
<th>Measure Group</th>
<th>Sub Group</th>
<th>Measure Title</th>
<th>Network Target</th>
<th>&gt;=75% cohort performance</th>
<th>Team’s Performance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Remission</td>
<td></td>
<td>Percent of patients in remission</td>
<td>80</td>
<td>77</td>
<td>80</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Percent of patients with prednisone-free remission</td>
<td>76</td>
<td>74</td>
<td>75</td>
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<tr>
<td></td>
<td></td>
<td>Percent of patients with sustained remission</td>
<td>45</td>
<td>47</td>
<td>48</td>
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<tr>
<td></td>
<td></td>
<td>Percent of patients not taking prednisone</td>
<td>95</td>
<td>93</td>
<td>91</td>
</tr>
<tr>
<td>Adequate Nutrition</td>
<td></td>
<td>Percent of patients with satisfactory nutritional status</td>
<td>90</td>
<td>90</td>
<td>100</td>
</tr>
<tr>
<td>and Growth</td>
<td></td>
<td>Percent of patients with at risk of nutritional failure</td>
<td>9</td>
<td>0</td>
<td>0</td>
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<tr>
<td></td>
<td></td>
<td>Percent of patients in nutritional failure</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Percent of patients with satisfactory growth status</td>
<td>90</td>
<td>92</td>
<td>98</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Percent of patients with at risk of growth failure</td>
<td>6</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Percent of patients in growth failure</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Model Classification</td>
<td></td>
<td>Percent of visits with a complete bundle</td>
<td>95</td>
<td>85</td>
<td>91</td>
</tr>
<tr>
<td>Model Treatment</td>
<td></td>
<td>Percent of patients with a documented visit within the last 200 days</td>
<td>80</td>
<td>76</td>
<td>83</td>
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<tr>
<td></td>
<td></td>
<td>Percent of patients whose dose of thiopurine is at least the dose recommended in the ICN Model Care Guidelines</td>
<td>80</td>
<td>67</td>
<td>71</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Percent of visits where initial dose of anti-TNF therapy is given that patient had a TB test within the prior 12 months</td>
<td>95</td>
<td>88</td>
<td>50</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Percent of Patients where the dose of infliximab is at least 4.5 mg/kg</td>
<td>95</td>
<td>95</td>
<td>92</td>
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</table>

### Data Quality

<table>
<thead>
<tr>
<th>Measure</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent of population registered AND active in registry</td>
<td>75</td>
</tr>
<tr>
<td>Percent of actual visits recorded in registry</td>
<td>83</td>
</tr>
<tr>
<td>Percent of visits with all critical data recorded</td>
<td>88</td>
</tr>
<tr>
<td>Percent of visits meeting the consistency bundle</td>
<td>85</td>
</tr>
<tr>
<td>Percent of visits entered that were entered within 30 days of visit date <em><strong>-</strong></em> Data reported on a two month lag</td>
<td>98</td>
</tr>
<tr>
<td>Percent of active patients in registry with visit recorded in last 13 months</td>
<td>92</td>
</tr>
<tr>
<td>Data Quality Performance</td>
<td>98</td>
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</tbody>
</table>
Automated population management report

- **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 Remission
  - Prednisone Usage

- **Diagnosis at the last visit**
  - Crohn's Disease: 24%
  - Ulcerative Colitis: 73%
  - Indeterminate Colitis: 3%

- **Remission Status**
  - Quiescent: 77%
  - Mild: 21%
  - Moderate: 1%
  - Severe: 1%
Automated population management report

**Medication Use**

<table>
<thead>
<tr>
<th>Measure Group</th>
<th>Yes</th>
<th>No</th>
<th>Don't Know</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>71%</td>
<td>29%</td>
<td></td>
</tr>
</tbody>
</table>

**Thiopurine is at least the dose recommended in the Model Care Guideline (n and %)**

<table>
<thead>
<tr>
<th>Status</th>
<th>Count</th>
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</thead>
<tbody>
<tr>
<td>No</td>
<td>5</td>
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<tr>
<td>Yes</td>
<td>12</td>
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<tr>
<td>Don't Know</td>
<td>65</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>82</strong></td>
</tr>
</tbody>
</table>

**Infliximab Dose is at least 4.5 mg/kg (n and %)**

<table>
<thead>
<tr>
<th>Status</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>3</td>
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<tr>
<td>Yes</td>
<td>35</td>
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<tr>
<td>Don't Know</td>
<td>44</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>82</strong></td>
</tr>
<tr>
<td>Azathioprine Dose at Last Visit</td>
<td>Dose of Azathioprine (mg/kg/day)</td>
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<tr>
<td>--------------------------------</td>
<td>---------------------------------</td>
</tr>
<tr>
<td>200</td>
<td>3.8</td>
</tr>
<tr>
<td>150</td>
<td>3.33</td>
</tr>
<tr>
<td>150</td>
<td>3.09</td>
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<tr>
<td>125</td>
<td>3.03</td>
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<tr>
<td>200</td>
<td>3.02</td>
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<tr>
<td>250</td>
<td>2.69</td>
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<tr>
<td>150</td>
<td>2.51</td>
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<td>100</td>
<td>2.45</td>
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<tr>
<td>150</td>
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<td>150</td>
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<td>125</td>
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<td>225</td>
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<td>100</td>
<td>2.25</td>
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<td>75</td>
<td>2.21</td>
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<td>150</td>
<td>2.19</td>
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<td>150</td>
<td>2.12</td>
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<td>125</td>
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<td>175</td>
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<td>100</td>
<td>1.74</td>
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<td>125</td>
<td>1.7</td>
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<tr>
<td>100</td>
<td>1.68</td>
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<tr>
<td>100</td>
<td>1.61</td>
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<tr>
<td>31</td>
<td>1.29</td>
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<tr>
<td>125</td>
<td>1.28</td>
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<tr>
<td>100</td>
<td>0.94</td>
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</tbody>
</table>
# Automated pre-visit planning report

**Patient Name**: [PatientName] [MRN Basic Report]

**Patient Num**: 16

**Primary Provider**: 260

**Secondary Provider**: 

**Diagnosis**: Crohn’s Disease - 09/15/2003

**Phenotype**: Inflammatory, non-penetrating, non-stricturing

**Extent**: 

**Lower**: Colonic only

**Upper proximal**: Not Assessed

**Upper distal**: No

**Last visit**: 10/24/2012

**Wt (kg)**: 37.80

**Ht (cm)**: 158.90

**BSA**: 1.292

**Last PPD**: 

**PPD Date**: 

**Last CXR**: 

**Date of last hospitalization**: 10/24/2012

**CXR Date**: Don’t Know

## Visits

<table>
<thead>
<tr>
<th>Date</th>
<th>PGA</th>
<th>Nutritional Status</th>
<th>Growth Status</th>
<th>Albumin</th>
<th>CRP</th>
<th>ESR</th>
<th>Hematocrit</th>
</tr>
</thead>
<tbody>
<tr>
<td>09/16/2009</td>
<td>Quiescent</td>
<td>In failure</td>
<td>Satisfactory</td>
<td>4.7</td>
<td>2.70</td>
<td>25.0</td>
<td>45.7</td>
</tr>
<tr>
<td>12/01/2009</td>
<td>Quiescent</td>
<td>At risk</td>
<td>Satisfactory</td>
<td>4.8</td>
<td>1.28</td>
<td>9.0</td>
<td>45.5</td>
</tr>
<tr>
<td>12/21/2010</td>
<td>Quiescent</td>
<td>In failure</td>
<td>At risk</td>
<td>4.9</td>
<td>0.53</td>
<td>9.0</td>
<td>44.4</td>
</tr>
<tr>
<td>02/11/2011</td>
<td>Quiescent</td>
<td>In failure</td>
<td>At risk</td>
<td>5.0</td>
<td>0.50</td>
<td>6.0</td>
<td>45.2</td>
</tr>
<tr>
<td>12/21/2011</td>
<td>Mild</td>
<td>In failure</td>
<td>In failure</td>
<td>4.6</td>
<td>0.31</td>
<td>9.0</td>
<td>43.0</td>
</tr>
<tr>
<td>04/18/2012</td>
<td>Mild</td>
<td>In failure</td>
<td>In failure</td>
<td>4.8</td>
<td>0.65</td>
<td>9.0</td>
<td>45.5</td>
</tr>
<tr>
<td>06/20/2012</td>
<td>Quiescent</td>
<td>In failure</td>
<td>In failure</td>
<td>4.7</td>
<td>0.30*</td>
<td>6.0</td>
<td>43.3</td>
</tr>
<tr>
<td>10/24/2012</td>
<td>Quiescent</td>
<td>In failure</td>
<td>- Missing</td>
<td>4.8</td>
<td>0.30*</td>
<td>6.0</td>
<td>46.0*</td>
</tr>
</tbody>
</table>

* Result date may differ from visit date.
  
  # See below for ordering recommendation.

<table>
<thead>
<tr>
<th>Lab Guidelines</th>
<th>5-ASA: q6mc</th>
<th>6mp/AZA/MTX: q3-4mo</th>
<th>Biologics: q2-3mo</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>

## Care Stratification

<table>
<thead>
<tr>
<th>CS Score</th>
<th>CSS Group</th>
<th>Current Disease Activity</th>
<th>12 Month Disease Activity</th>
<th>BMI Z-score</th>
<th>Ht Velocity</th>
<th>Hosp Adm within 3 months</th>
<th>Currently on Cortico</th>
<th>Cortico last 12 months</th>
<th>Psychosocial Risk Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>0-3 (Low)</td>
<td>0 (Quiescent)</td>
<td>0 (Quiescent)</td>
<td>3 (BMI&lt;2)</td>
<td>0 (&lt;Velocity&lt;1)</td>
<td>0 (No or Unknown)</td>
<td>0 (No or Unknown)</td>
<td>0 (No or Unknown)</td>
<td>0 (No or Unknown)</td>
</tr>
<tr>
<td>Treatment</td>
<td>Dose (mg)</td>
<td>Dose (mg/kg)</td>
<td>Guideline</td>
<td></td>
<td></td>
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<td>---------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>5-ASA</td>
<td>Asacol</td>
<td>Active: 80 (60-100) mg/kg/day up to 4.8 g/day; Quiescent/Inactive: 40 (30-100) mg/kg/day up to 4.8 g/day; If &gt; 4800 mg/day, then 4800 mg/day.</td>
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<tr>
<td></td>
<td>Pentasa</td>
<td>Adult: 0.375 mg tabs 4 tabs q day (1.5 g/day)</td>
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<tr>
<td></td>
<td>Apriso</td>
<td>Adult: 1.2 g tabs 2-4 tabs q day (2.4-4.8 g/day)</td>
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<tr>
<td></td>
<td>Lialda</td>
<td>Adult: (750 mg tabs) 3 tabs TID PO</td>
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<tr>
<td></td>
<td>Sulfasalazine</td>
<td>30 mg/kg/day divided qid (25-80 mg/kg/day max 4 g/day)</td>
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<tr>
<td>Immunomodulators</td>
<td></td>
<td>Consider 6 TGN levels</td>
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<tr>
<td></td>
<td>Thiopurines</td>
<td>Consideration: If active dz, consider 6 TGN levels q 90</td>
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<tr>
<td></td>
<td>Azathioprine</td>
<td>1.0-1.5 mg/kg/day PO intermediate TPMT activity; 2.0-3.0 mg/kg/day PO normal-to-high TPMT activity</td>
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<tr>
<td></td>
<td>6MP</td>
<td>0.5-0.75 mg/kg/day PO intermediate TPMT activity; 1.0-1.5 mg/kg/day PO normal-to-high TPMT activity</td>
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<tr>
<td></td>
<td>Methotrexate</td>
<td>12.5 - 15 mg/m2 up to a maximum of 25 mg PO/SQ/IM; Maintenance for adult 15-25 mg</td>
<td></td>
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<tr>
<td>Biologics</td>
<td>Remicade/Infliximab</td>
<td>Consideration: If active (moderate/severe) dz, consider trough/HACA at least q 180 days</td>
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<td>Intermeta</td>
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<td></td>
<td>Adalimumab/Humira</td>
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<tr>
<td></td>
<td>Certolizumab/Cimzia</td>
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<tr>
<td>Varicella immunization status (not updated automatically):</td>
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<td></td>
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<tr>
<td>Steroids</td>
<td>Prednisone</td>
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</tr>
<tr>
<td></td>
<td>Budesonide</td>
<td>Steroid Dependent: Yes No Consider corticosteroid sparing agents</td>
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</tbody>
</table>
Collaboration

- “We all teach, we all learn”
- “Steal shamelessly, share seamlessly”
- “To go fast, work alone
  To go far, work together”
Using data for research as well as QI: Simulated trial

**Outcomes**
ImproveCareNow n=96; REACH n=112

<table>
<thead>
<tr>
<th></th>
<th>REACH</th>
<th>ICN-REACH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Response</td>
<td>88%</td>
<td>82%</td>
</tr>
<tr>
<td>Remission</td>
<td>59%</td>
<td>48%</td>
</tr>
</tbody>
</table>

NS
Simulated trial with control group

Clinical Remission

Steroid-free Remission

Number of Weeks

Probability

Number of Weeks

Probability
8 ways that a Learning Health System can facilitate drug research and implementation

1. Measure **real-world and long-term effectiveness** of drugs
2. Use data for **comparative effectiveness research**
3. **Optimize medication use** by clinicians and patients
4. Engage **clinicians and patients to prioritize** and design studies
5. **Identify research subjects** to facilitate study design and recruitment
6. Conduct **prospective drug efficacy** studies
7. Conduct **post-marketing surveillance** for adverse events
8. Serve as a laboratory to **test innovations** in medication delivery and drug level monitoring
The value equation

Value = outcomes - cost

$28,000 PPPY

$350 PPPY

“The Triple Aim—Improve health, care and cost”

“Best Care at Lower Cost”
What if ImproveCareNow were a new drug?

**Improve-imab©**

- **Directions**: apply daily to delivery system
- **Adverse effects**: none known
- **Benefits**: 25% better chance of remission
- **Annual Cost**: the same as a 6-week course of mesalamine
6 ways ImproveCareNow can make your CEO happy

1. **USNWR** (US News & World Report) gives credit in rating the best children’s hospitals
2. **ABP** (American Board of Pediatrics) gives full credit for part 4 of Maintenance of Certification
3. **OPPE** (JCAHO Ongoing Professional Practice Evaluation) criteria for QI can be met
4. **CME/CNE** (Continuing Education) credits given for attendance at Learning Sessions
5. **P4P** (Pay for Performance) criteria can be met
6. **ACO** (Accountable Care Organization) focus on best care at lower cost is the focus of ImproveCareNow
A Learning Health System

- Community
- Focus on the outcome
- Safe, evidence-based patient-centered care
- Best care at lower cost
- Research is a natural outgrowth of clinical care
- New knowledge is generated easier, faster, better and cheaper
ImproveCareNow: Our Approach to QI and Collaboration

Sarah Myers
From Improvement Collaborative to Enduring Improvement Network

- Select Topic (develop mission)
  - Expert Meeting
  - Develop Framework & Changes Planning Group
- Participants (10-100 teams)
  - Prework
- LS 1 → AP1
- LS 2 → AP2
- LS 3 → AP3*

Dissemination (Publications, Congress, etc.)

Holding the Gains

Supports:
- Email (listserv)
- Phone Conferences
- Visits
- Monthly Team Reports

LS - Learning Session
AP - Action Period

*AP3 - Continue reporting data as needed to document success
The Model for Improvement

Fig 2. The Model for Improvement

What are we trying to accomplish?
How will we know that a change is an improvement?
What change can we make that will result in improvement?

Act
Plan
Study
Do

Participating in the ICN Network

• “All teach, all learn”
   (share seamlessly, steal shamelessly)

• Transparent Sharing of Aggregate Data

• Sharing Results of PDSAs

• Learning from Successes AND Failures

• PARTICIPATION IS KEY!
Supporting and Nurturing Improvement Learning and Leadership

- Onboarding via the QI Fundamentals Series, including an applied learning opportunity
- Quality improvement coaches’ feedback on reports, data, and progress
- Feedback from peers and Learning Lab
- ICN Exchange knowledge commons
- Peer communities: Physician Leadership Group, Parent Working Group, Patient Advisory Council, Improvement Coordinators, Registered Nurses, Registered Dietitians, Psychologists/Social Woers
# Staying Connected and Accountable

## Overview of the Annual ImproveCareNow Calendar and Operations

<table>
<thead>
<tr>
<th>90 Day Goal Period</th>
<th>October</th>
<th>November</th>
<th>December</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Period 1</strong></td>
<td>Set annual aims 2 Webinar</td>
<td>Learning Lab Webinar</td>
<td>2 Webinars</td>
</tr>
<tr>
<td><strong>Period 2</strong></td>
<td>Learning Lab Webinar (90 minutes!)</td>
<td>February 2 Webinars Pre-work for Spring LS</td>
<td>March ICN Spring LS</td>
</tr>
<tr>
<td><strong>Period 3</strong></td>
<td>April Learning Lab Webinar</td>
<td>May 2 Webinars</td>
<td>June Learning Lab Webinar</td>
</tr>
<tr>
<td><strong>Period 4</strong></td>
<td>July Webinars (90 minutes!)</td>
<td>August Learning Lab Webinar</td>
<td>September Pre-work for Fall LS 2 Webinars</td>
</tr>
</tbody>
</table>
Please report your progress on your **October-December 2014** (current goals) goals and share your new goals for **January to March 2015** (new goals).

Take a look at what other teams are working on and connect with those with similar goals! To enter your information, select your team from your Learning Lab’s drop down menu, select the appropriate intervention tab, and click on each box to access a text entry form.

To get you started, **Take a quick video tour of how to use the Goal Tracking Tool.**

*Note: Recommended browsers are IE10, Safari, Chrome and Firefox. Older browsers may not display this application correctly.*

<table>
<thead>
<tr>
<th>Registration</th>
<th>Data Quality</th>
<th>Population Mgmt</th>
<th>PVP</th>
<th>SMS</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning Labs</td>
<td>Care Center</td>
<td>Current 90-Day Goal</td>
<td>Progress toward goal</td>
<td>New 90-Day Goal</td>
<td>Note</td>
</tr>
</tbody>
</table>

1. **Learning Labs: White Learning Lab** (9 items)

2. **Learning Labs: Green Giant Learning Lab** (10 items)

| Green Giant... | Children's Hospital at Montefiore | Enroll 85% of our p... |
| Green Giant... | UCSF Benioff Children's Hospital | Consent and regist... |
Going to Scale and staying CONNECTED in a Growing Network
Learning Labs: Maintaining Community as We Grow

**RED LEARNING LAB**
- Arnold Palmer Hospital for Children
- Cincinnati Children’s Hospital Medical Center
- Levine Children’s Hospital
- Nationwide Children’s Hospital
- Oklahoma University Medical Center
- Pediatric Specialists of Virginia
- University of North Carolina at Chapel Hill

**BLUE LEARNING LAB**
- Children's Hospital Colorado
- Great Ormond Street Hospital
- Nemours | Alfred I. duPont Hospital for Children
- Penn State Health Children’s Hospital
- Providence Sacred Heart Children’s Hospital
- Rainbow Babies & Children’s Hospital
- Riley Hospital for Children
- Texas Children’s Hospital
- University of Michigan | CG Mott Children’s Hospital

**ORANGE LEARNING LAB**
- Advocate Children’s Hospital, Oak Lawn
- Advocate Children’s Hospital, Park Ridge
- Baystate Medical Center
- Children’s Clinic
- Children’s Hospital of the King’s Daughters
- CHKD—Children’s at Scottish Rite
- GI Care for Kids
- New Hampshire’s Hospital for Children
- NW Pediatric Gastroenterology & Nutrition Associates
- Rand’s Children’s Hospital

**PURPLE LEARNING LAB**
- Arkansas Children’s Hospital
- Boys Town National Research Hospital
- Children’s Medical Center of Ohio
- Children’s
- Dell Children’s Medical Center of Central Texas
- Helen DeVos Children’s Hospital
- Mayo Clinic
- University of Minnesota
- St. Louis Children’s Hospital | Washington University
- UT Southwestern | Children’s Medical Center Dallas

**YELLOW LEARNING LAB**
- Boston Children’s Hospital
- Children’s Hospital at Dartmouth
- Children’s Hospital of Philadelphia
- Children’s Hospital of Wisconsin
- Children’s Mercy Hospital
- Lucile Packard Children’s Hospital at Stanford
- Massachusetts General Hospital for Children
- Mount Sinai Kravis Children’s Hospital
- OHSU Doernbecher Children’s Hospital
- Seattle Children’s Hospital
- University of Iowa Children’s Hospital

**WHITE LEARNING LAB**
- Bon Secours St. Mary’s Children’s Hospital
- Cardinal Glennon Children’s Medical Center
- Children’s Hospital of Illinois, Peoria
- Children’s of Alabama
- Floating Hospital for Children at Tufts Medical Center
- La Bonheur Children’s Hospital
- Monroe Carell Jr. Children’s Hospital at Vanderbilt
- Nemours Children’s Clinic, Jacksonville
- Phoenix Children’s Hospital

**GREEN LEARNING LAB**
- Barbara Bush Children’s Hospital at Maine Medical Center
The Big Picture: The Layers of Community

- Network
- Committees/Initiatives
- Learning Labs
- Centers
The Big Picture: How Ideas are Tested and Spread

A testable idea

Center | Learning Lab | Network

Committee/Initiative | Centers | Network

Network | Learning Lab | Centers
We Have the Community

How do we maintain the commons so people can:

• Find other like-minded people
• Find activities they want and tips for doing a better job at them
• Have shared goals and accountability
• Have the right maps and guides
ICN Exchange: Enhancing Knowledge Sharing
Patients as Partners and Leaders
People: Driven by Generosity, Experience, and Collaboration
Parent Working Group: Professional Experience

- Mechanical engineer
- Sales rep
- Managed care medical director
- Camp director
- Meeting and events coordinator
- Physician
- Statistician
- VP of new technology
- Business development manager
- Electrical engineer
- Information systems consultant
- IT project manager
- Nurse
- Writer and editor
- Director of sales
- Operations specialist
- Childbirth educator
- Product manager
- Respiratory therapist
- Realtor
- Clinical researcher
- Foundation director
- Healthcare consultant
- Media consultant
STRUCTURE: Parent Working Group

Lead Parent Partner

Parent Leadership Council
- Assistant Lead Parent
- 4 Subcommittee Chairs
- 2 members at large
- Meets monthly

Parent Working Group
- One parent from each care center
- Meets quarterly

Subcommittees
- Membership: acquisition, onboarding & mentoring
- Communications
- Learning Session Planning
- Research

Other ICN Parents
- Other parents who are part of ICN but not ready for a network leadership role; may be active in care center mentoring, online discussion, etc. Kept abreast of PWG activities via newsletter or email.
Patient and Family Engagement at the “Front Lines” of our Network

Being part of the distributed learning health system to produce information, knowledge, and know-how for improving the health care system and personal health.

100% 100% 1%

Awareness Participation Contribution Ownership
Awareness

CUMULATIVE SHOWS OF SUPPORT

Week of Campaign

SHOWS OF SUPPORT

22-Jul  29-Jul  5-Aug  12-Aug  19-Aug  26-Aug  2-Sep  9-Sep  15-Sep
35      61      117     217     320     366     465     554     1032
Participation
Contribution
ImproveCareNow: A Learning Health System Built on Partnership and Collaboration

Annette Kulzer
Amy E. Quinn
V. Marc Tsou, MD
CHKD – Norfolk, Virginia
Our hospital

- The Children’s Hospital of The King’s Daughters (CHKD) is a 206 bed, free-standing children’s hospital located in Norfolk, VA

- It is the pediatric teaching hospital for the Eastern Virginia Medical School (EVMS)

- The Department of Pediatrics is the largest of EVMS with 350 faculty members
The GI Practice

- 5 practice locations (main hospital and 4 satellite locations; 2 of which are ASCs)

- Each practitioner is paired with a LPN as a team

- The team travels together and have their own set of patients
Why did we want to join ICN?

- We wanted to improve our care
- Our beliefs versus the facts
- Quality is measureable
- Knowledge – Skills - Tools
What would it show us?

- Variation in care
- Gaps and deficiencies
- How to design and test solutions (PDSA cycles)
- **How to change our culture**
- Safer, leaner care
Early challenges

- Funding $
- Time
- All at once or piecemeal?
- Who’s on first?
Early solutions

- Funding → hospital
- Time – always an issue
- Piecemeal
- Janice Karr to the rescue
Starting out

- We identified our core team

- Dr. Tsou and his nurse Terri Cross were the test team

- We learned from the other centers and benefitted from the collective wisdom
"to share seamlessly and steal shamelessly"
Network-Based Production

Yochai Benkler, “The Wealth of Networks”
Our Wish List - Then

- Research Coordinator (RC)
- Parent Involvement
- Social Worker
- Dietitian
- Psychologist
Our Wish List - Now

- RC
- Parent Involvement
- Social Worker
- Dietitian
- Psychologist

IMPROVE CARE NOW
Early focus

- Enroll, enroll, enroll
- Swim lanes
- Understanding the data
Team meetings – spreading the Gospel

- On boarding the teams one-by-one
- Monthly team meetings
  - Time limitations
- Culture change
The Journey – 4 years in

- Very rewarding
- QI geeks
- Applying what we have learned
- Lean Methodology
Progress report

- Secure funding
- Parent program
- Grand Rounds
- Group appointments
  - Multidisciplinary programs
Progress report – cont.

- Deeper ICN involvement
  - SW, RC, MD, Parent
  - Engagement, PROMIS, PWG
- “Teach Nights”
  - Local CCFA chapter
  - Build our IBD community
A Month in the Life of an ICN Center

What does it take to make it work?
Data, data, and more data!

QI tools:
- Pre-visit planning
- Population management
- Data quality and enrollment
- Self-management support
- PDSAs
Reporting
  - Monthly, quarterly, annually

Communication
  - Exchange
  - Learning lab calls
  - Team meetings
  - Role-specific group calls

Ongoing learning opportunities
  - Network-wide webinars

Research
Parent Working Group

Annette Kulzer
Children’s Hospital of the King’s Daughters
PWG: Our Mission

- Numerous years caring for children with IBD
- Bowel resections
- Colonoscopies
- FLARES
- Tube feedings
- Group visits
- Years of experience with Remicade
- Hospitalizations
- C. diff
- 6-MP
- CT enterography
- Upper endoscopy
- Azulfidine
- ERYTHEMA NODOSUM
- Drug allergies
- Methotrexate
- Prednisone
- Cimzia
- PIC line
- Humira
- PROBIOTICS
Roles of Parents

- Assist the Network
- Provide the Voice of Caregivers
- Work with our Local Care Teams
- Spreading Information and Support
PWG: Our Professional Experience

Nurse
Sales rep
Managed care medical director
Camp director
Meeting and events coordinator
Physician
Statistician
Business development manager
VP of new technology
Mechanical engineer

ELECTRICAL ENGINEER
Childbirth educator
Product manager
Information systems consultant
Realтор
Respiratory therapist
IT project manager
Dental Hygienist
Clinical researcher

WRITER AND EDITOR
Foundation director
Director of sales

OPERATIONS SPECIALIST
Hedge fund manager
Healthcare consultant
Media consultant
PWG: ICN and Community Experience

- Fundraising
- CCFA walks
- Waitign room redesign
- GI resource room
- Support groups
- Crohn’s walks
- QI team member
- EMPOWERED BY KIDS
- Rise and Conquer Foundation board
- In-hospital patient support
- TAKE STEPS FOR LIFE
- Parent mentoring program
- Parent mentoring binder
- Monthly QI meetings

88 Learning Sessions
IBD DIGMA Days
Newsletters
Monthly Emails to Support Group
IBD Teach Nights
Inpatient Visits
Participate in QI Teams Meetings
Newly Diagnosed IBD Binder
“You have not lived today until you have done something for someone who can never repay you.”

- John Bunyan