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

COLLABORATIVE CHRONIC CARE NETWORK

Peter Margolis, MD, PhD

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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
Network-Based Production

Remission rate
(PGA, Centers >75% registered)

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

79%
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

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

Learning Engine
- Point of Care
- New Knowledge
- Identify Gaps in Care

Patient Outcomes
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

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

### Lower:
Jejunal

### Upper Proximal:
No

### Upper Distal:
Yes

### Perianal Phenotype:
No

### Last Visit:
7/2/2014

### Measurements:
- Wt (kg): 52.70
- Ht (cm): 167.00
- BSA: 1.564

### Other Details:
- Date of last hospitalization: Not Recorded
- Last PPD & Date: Not Recorded
- Last CXR: Not Recorded
- Last Gold Test & Date: Indeterminate 6/26/2013

## Visits

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

*Result date may differ from visit date*

### Lab Ordering Guidelines:
- 5-ASA: q8mo
- 6mp/ASA/MTX: q3-4mo
- Biologics: q2-3mo

### 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>Hx Admission within 3 months</th>
<th>Currently on Corticosteroids</th>
<th>Corticosteroids Last 12 months</th>
<th>Psychosocial Risk Factors</th>
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</thead>
<tbody>
<tr>
<td>0</td>
<td>0-3 (Low)</td>
<td>0 (Quiescent)</td>
<td>0 (Quiescent)</td>
<td>BMI Z-Score &gt;1 or Missing</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>
<td>No</td>
</tr>
</tbody>
</table>

*Result date may differ from visit date*
Automated population management report
<table>
<thead>
<tr>
<th>Measure Group</th>
<th>Sub Group</th>
<th>Measure Title</th>
<th>Network Target</th>
<th>&gt;=75% cohort</th>
<th>Teams’ Performance</th>
<th>Team’s Performance</th>
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</thead>
<tbody>
<tr>
<td>Clinical Measures</td>
<td>Clinical Remission</td>
<td>Percent of patients in remission</td>
<td>80</td>
<td>77</td>
<td>80</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Percent of patients with prednisone-free remission</td>
<td>76</td>
<td>74</td>
<td>75</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Percent of patients with sustained remission</td>
<td>45</td>
<td>47</td>
<td>48</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Percent of patients not taking prednisone</td>
<td>95</td>
<td>93</td>
<td>91</td>
<td></td>
</tr>
<tr>
<td>Adequate Nutrition and Growth</td>
<td></td>
<td>Percent of patients with satisfactory nutritional status</td>
<td>90</td>
<td>90</td>
<td>100</td>
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<tr>
<td></td>
<td></td>
<td>Percent of patients with at risk of nutritional failure</td>
<td>9</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Percent of patients in nutritional failure</td>
<td>2</td>
<td>0</td>
<td></td>
<td></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>
<td></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></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Percent of patients in growth failure</td>
<td>2</td>
<td>0</td>
<td></td>
<td></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>
<td></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>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Percent of patients whose dose of thiopurine is at least the dose</td>
<td>80</td>
<td>67</td>
<td>71</td>
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<tr>
<td></td>
<td></td>
<td>recommended in the ICN Model Care Guidelines</td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Percent of visits where initial dose of anti-TNF therapy is given</td>
<td>95</td>
<td>88</td>
<td></td>
<td>50</td>
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<tr>
<td></td>
<td></td>
<td>that patient had a TB test within the prior 12 months</td>
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<td></td>
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<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>
<td></td>
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<tr>
<td>Data Quality</td>
<td></td>
<td>Percent of population registered AND active in registry</td>
<td>75</td>
<td></td>
<td></td>
<td>98</td>
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<tr>
<td></td>
<td></td>
<td>Percent of actual visits recorded in registry</td>
<td>83</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Percent of visits with all critical data recorded</td>
<td>86</td>
<td>91</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Percent of visits meeting the consistency bundle</td>
<td>85</td>
<td>71</td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Percent of visits entered that were entered within 30 days</td>
<td>98</td>
<td>100</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>of visit date <em><strong>---</strong></em> Data reported on a two month lag</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Percent of active patients in registry with visit recorded in last 13 months</td>
<td>92</td>
<td>98</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Remission rate
(PGA, Centers >75% registered)

79%

71 Care Centers
>19,500 patients
>575 physicians
>35% of all IBD patients
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. JMICR. 2013 29;2:e43
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

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

Awareness → Participation → Contribution → Ownership
Awareness
Knows of ImproveCareNow
Understands they have a role to play

Participation
Signs Consent
Reads Loop
Joins ICNExchange

Contribution
Joins QI Team
Becomes a mentor
Joins PWG, PAC
Posts to Loop

Ownership
Leads Teams
Organizes Events
Trains mentors
Runs QI projects
Creates tools

100%  90%  9%  1%
A contributor
No one asked anyone to make these contributions......
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

Time

Remission Rate

QI and Reliable Care

Clinical Trials
Personalized Medicine

Participation in care
(adherence, shared decision making)

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