Learning from Networks to Improve Health Outcomes

Carole Lannon
Stacey Lihn
Shannon Provost

Presenters have nothing to disclose.

December 8, 2015
Session A6  9:30 – 10:45 am
Session B6  11:15 am – 12:30 pm

Introductions

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Stacey Lihn
stacey@sistersbyheart.org
After this session, you should be able to:

- Recognize network-based theories and methods from the social sciences that are beginning to impact health care improvement paradigms.
- Identify key drivers and barriers around using networks as the foundation of learning health care systems.
- Describe network strategies for collaborating with patient and family partners and getting results at different levels of scale.

Why networks?
Why now?

“IOM: Schematic of a learning health care system

“These complex conditions are beyond the skills of any one scientist or single institution to solve. **We need to harness the collective intelligence of large communities of researchers, entrepreneurs, clinicians, and patients.**” - Peter Margolis, MD, PhD
Collaborative networks have emerged in health care systems as a primary means to translate evidence into practice and to support quality improvement and research.
Practical steps for cultivating successful networks:

- Articulating a clear common purpose
- Developing a cooperative structure
- Building critical mass
- Maximising the benefit of collective intelligence
- Building a meaningful sense of community

Do networks impact quality improvement?

Traditional performance measures may overlook outcomes such as relationship development, trust building and changes in values and attitudes. Network impact must be measured on multiple levels: individual, organisation, network and community.

*Evidence demonstrating the impact of networks is scarce.* It is difficult to identify precisely a network’s effect on clinical outcomes independent of other factors – which is true of many health improvement initiatives, given their intangible nature.
D-Day: December 9, 2009

D-Day: Diagnosis Day

D-Day: [Noun]

The day on which any large-scale operation is planned to begin

HYPOPLASTIC LEFT HEART SYNDROME (HLHS) “Half a Heart”

- A rare congenital heart defect
- Significant mortality and morbidity
- Three staged heart reconstruction

- Most expensive birth defect in the first year of life
- Long hospitalizations
- High complexity outpatient care
9 children born to families feeling scared and alone.

9 moms connecting to support each other and bond as Sisters.

Through their determination and vision, a concept evolved...
Hypoplastic Left Heart Syndrome (HLHS)

HLHS is a severe congenital heart defect in which the left side of the heart is underdeveloped. The heart's left side has the job of pumping oxygenated blood into the aorta, the large artery that carries blood to the body. In a child with HLHS,
Linked by Heart (LBH) is divided amongst six regions within the United States. Each region is represented by 2 Regional Coordinators, HLHS moms from across the nation helping families connect with each other (locally and those sharing the same hospital for care and treatment).

12 Regional Coordinators

Complications of Registered HLHSers

<table>
<thead>
<tr>
<th>Complication</th>
<th>Frequency</th>
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</thead>
<tbody>
<tr>
<td>Prolonged Hospital Stay</td>
<td>100</td>
</tr>
<tr>
<td>Collaterals</td>
<td>62</td>
</tr>
<tr>
<td>Blood Clots Following Intervention</td>
<td>61</td>
</tr>
<tr>
<td>Tricuspid Regurgitation</td>
<td>53</td>
</tr>
<tr>
<td>Arrhythmia</td>
<td>44</td>
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<tr>
<td>Vocal Cord Paralysis</td>
<td>43</td>
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<tr>
<td>Seizure</td>
<td>32</td>
</tr>
<tr>
<td>Chylous Effusions</td>
<td>33</td>
</tr>
<tr>
<td>Other</td>
<td>35</td>
</tr>
<tr>
<td>Diaphragm Paralysis</td>
<td>25</td>
</tr>
<tr>
<td>Pulmonary Hypertension</td>
<td>27</td>
</tr>
<tr>
<td>Depressed Heart Function</td>
<td>27</td>
</tr>
<tr>
<td>Stroke</td>
<td>24</td>
</tr>
<tr>
<td>Intact or Restricted Septum</td>
<td>24</td>
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<tr>
<td>Sternal Infection</td>
<td>19</td>
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<tr>
<td>Hospital Acquired MRSA</td>
<td>11</td>
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<tr>
<td>Protein Losing Enteropathy</td>
<td>7</td>
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<tr>
<td>Chromosomal Disorder</td>
<td>9</td>
</tr>
<tr>
<td>Blood Disorder</td>
<td>6</td>
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<tr>
<td>Plastic Bronchitis</td>
<td>3</td>
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Sisters by Heart by the Numbers

Growth in Participation, 2010 - 2015

Families registered in Linked by Heart Regional Facebook Groups

Families registered in Linked by Heart Database

Care packages sent
**Sisters by Heart by the Numbers**

**Growth in Awareness, 2011 – 2015**

- **Facebook page ‘likes’**
- **Blog hits**

New in 2015: 694 Twitter followers

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**Not the Parents of Yesterday**

*Sunday, September 11, 2011*

**The Practitioner’s Perspective: How to Choose a Congenital Heart Center**

We’re so excited to start a new series of guest blog postings from various practitioners who deal with our special kids on a regular basis. First up is **10 ways to get your child the best heart surgeon**

By Elizabeth Cohen, Senior Medical Correspondent

Updated 10:49 AM EDT, Sun August 4, 2013

**Hypoplastic Left Heart Syndrome (HLHS) Information Page**

Important Questions to Ask
Zoe Madison (age 5, HLHS)

Co-Production: Working Together to Improve Care and Outcomes

www.jcchdqi.org
Why Partner with NPC-QIC?

Variation in care
Variation in outcomes
Improvements generalizable to other defects
Nationwide collaboration – melding data and experiences
Provide a voice for infants and children
Build bridges and close gaps

Sisters by Heart empowers HLHS families to work with practitioners to transform the practice of pediatric cardiac medicine.

58 Participating Care Centers and Growing
Improved outcomes: Identified a growth bundle and now 80% of infants have satisfactory weight gain.
NPC QIC Organizational Structure

Co-governing with parents
- Governance Council
- Steering Committee
- Leadership group
- Business Advisory Committee

Work Groups
- Transparency
- Mortality
- Feeding
- Readmissions
- Research & Publications Committee
- Phase II Design

Transparency Work

- Important Questions
- Benefitting Parents/Providers
- Fostering Teamwork
Research Explained

Research articles identified by parents
- New articles published about HLHS
- Significant past articles published about HLHS

Members of the Research and Publication Committee review the article and work with the original author to create a one page review piece: Research Explained

Research Explained posted/published using Social Media

NPC-QIC: Promoting Local Co-Production

Parents and Practitioners involved with NPCQIC and SBH are:
- Creating and Developing Cardiac FACs
- Pushing for Transparency
- Recommending QI Workgroups
- Advocating and Implementing CCHD Screening
- Improving Overall Patient-Centered Care
Expanding Our Reach to Further Improve Outcomes

“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
“What if”

A short video, produced by SBH for a collaborative meeting with NPCQIC

https://www.youtube.com/watch?v=4cjMXpYwhuo

What if….?

we could create a vastly better 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?

NIH Transformative Research Award to CCHMC
The network business model is well established in other industries

Shared Purpose + Community + Technology/Connectivity + Shared Common Resources

= Faster Learning and Impact

Learning Networks

Accelerating Health Impact, Discovery, and Innovation
Improving Outcomes with a Learning Health System:
Health care delivery, improvement, and research together as part of the same system

Anderson Center Learning Networks Core supports five networks

- 3 national chronic care networks (inflammatory bowel disease, juvenile idiopathic arthritis, and complex congenital heart disease)
- 1 national safety network
- 1 regional perinatal network

- Involve collaborations among patients/families, clinicians, and researchers
- Serve as collaborative laboratories
- Use data for both improvement and research
- All have achieved improved outcomes
Nurturing new networks (design phase)

- Autism
- Community/public health
- Cystic Fibrosis
- Healthy Weight
- Renal Transplant
- Sickle Cell
- Type-1-Diabetes

350 teams, 244 Sites, 45 states and DC, 3 countries, 55 CTSAs

# Teams in CCHMC Supported Learning Networks
Creating transformative Learning Health Networks

1. Focus on outcome
2. Build community
3. Effective use of technology
4. Learning systems
   - System science, QI, qualitative research, clinical research

Our Methods

IHI Breakthrough Series

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

Select Topic
- Expert Meetings
- Planning Group

Prework
- Develop Key Driver Diagram

Action Periods
- LS 1
- LS 2
- LS 3

Support Structures
- E-mail
- Website
- Phone
- Assessments
- PI Expertise
- Monthly Action Period Webinars
- Monthly Team Reports
Program Model

select a high-impact topic that resonates with caregivers and focus on patient outcomes

Slide adapted from
Amy Billett, MD

The network model delivers results

83 GI Care Centers
>25,000 patients
>30 procedures
>30% of all patients with IBD

90 hospitals
>$79M saved
3,699 children spared harm

All 120 Ohio birth hospitals
>50,000 births shifted to term
>$36M savings over 4 years

40% decrease in inter-stage mortality
55 care centers
>$95M of all patients
Network results are making a real difference

Safer hospitals

Reduced mortality

Fewer pre-term births

Improved quality of life

Networks enable better, faster and cheaper clinical research

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
Simulated Clinical Trial Results Using Registry Data

Clinical Remission

Steroid-free Remission

Rate Ratio: 1.53

Rate Ratio: 1.74

Networks = “Collaborative Laboratories”

(Patients, families, clinicians, researchers) + data
Patients & Families as Partners

Network co-production

Hierarchical production: Central decision making

Peer production: Coordination of creative energy of large numbers of people
What we’ve learned

We go faster and further when we partner with patients and families.

Senior leadership support is essential.

Relentless focus on outcomes that matter to patients and that address needs of all participants (patients, families, clinicians, and researchers) drives progress.

Processes, tools and structures enable sharing and collaboration.
Learning Networks Draft ROI

Centers receive:

• QI training and tools
• Regular reports:
  • Patient status
  • Center performance
  • Population management
  • Pre-visit planning
  • Data quality
• Model guidelines
• Research opportunities
• Testing and using innovations
• Education, CME, MOC, USNWR
• More reliable pro-active care
• Better patient outcomes

Centers contribute:

• (Annual participation fee)
• Physician, nurse, coordinator, staff time
• Travel to twice-yearly Learning Sessions/Community Conferences
• Standardized data
• Collaboration
• Leadership and governance

Network Challenges

• Data burden for front-line teams

• Varying needs of network teams (e.g. early adopters vs. majority, new teams vs. veterans)

• Growth (as network goes to scale)
  • Keeping the growing number of teams connected
  • Managing a growing number of projects

• Funding
Building Reusable Network Infrastructure

Infrastructure to facilitate ‘reusable’ data (for clinical care, QI, research)
Compendium of tools to design and support networks
Training and coaching to build QI capability
Support to develop along the Maturity Model

Many colleagues contribute to this work.
Networks represent interaction structures among sets of connected units.

Knowledge and social networks include the stock exchange and currency markets.

Economic networks may be modelled as networks. Human and other living beings are organic networks.

A number of biological systems may be modelled as networks. Human and other living beings are organic networks.

Network Analysis in the Social Sciences

Stephane P. Borgatti, Ajay Mehra, Daniel J. Brass, Giuseppe Labianca

13 FEBRUARY 2009 VOL 323 SCIENCE

A field is emerging that leverages the capacity to collect and analyze data at a scale that may reveal patterns of individual and group behaviors.

Computational Social Science

David Lazer,1 Alex Pentland,2 Lada Adamic,2 Sinno Labroso,1 Albert-Laszlo Barabasi,1 Dean做起2, Nicholas Christakis,1 Nicholas E. Goul,2 Joseph A. Banks,1 Myron Eshmatov,1 Terence Johanssen,1 Gary King,1 Michael Lacy,1 Zhe Yao,2 Marshall Van Alstyne,1

SCIENCE VOL 323 6 FEBRUARY 2009

Networks represent interaction structures among sets of connected units.
Network Graphs and Components

- **An undirected network**
- **A directed and weighted network**

**Social Networks**

Social networks consist of actors connected by one or more types of interdependency:
- *e.g. friendship, kinship, acquaintance, common interest, shared experience, beliefs, prestige, advice, or knowledge.*

**Network ties** establish the nature of linkage between a pair of actors
- Four types of ties: proximities, relations, interactions, flows
- Tie strength may be determined by the duration, intensity, intimacy, exchange, and/or reciprocity that define a relationship
Mechanisms of Network Growth

- Homophily
- Triadic closure
- Focal closure
- Affiliation
- Preferential attachment

Social Network Analysis

- Linking the statistical properties of a formal network graph with actual behaviors and relationships

- Development of measures to capture structural elements in ways that help us make sense of the network

- Data collection for SNA
  - Survey-based
  - Digital traces
Network Interventions

Thomas W. Valente

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<td>Use network structure; word of mouth, snowball, matching</td>
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Network interventions are purposeful efforts to use social networks or social network data to generate social influence, accelerate behavior change, improve performance, and/or achieve desirable outcomes among individuals, communities, organizations, or populations.

Thomas Valente, PhD
Keck School of Medicine
University of Southern California

Identification

Who are the most influential actors?

An organizational chart offers limited insight...

Nominal leaders may lack social influence.
Opinion Leaders

Network data can identify regional and local leaders who may drive others’ decisions to try something new

Effect of Local Medical Opinion Leaders on Quality of Care for Acute Myocardial Infarction
A Randomized Controlled Trial
JAMA, May 6, 1998—Vol 279, No. 17

Identification of potential opinion leaders in child health promotion in Sweden using network analysis

From Theory to Practice: 56 MANAGED CARE / JULY 2000
Identifying Authentic Opinion Leaders to Improve Care
Beverly A. Collins, M.D., M.B.A., M.S., John W. Harvey, Robert Davis, Poole D.P.

More Identification opportunities

Bridging nodes: important for diffusion across groups
  • Possibly less burdened than leaders; may also be more amenable to change

Isolates or Peripherals: these nodes may receive information late or not at all...
  • Health care costs are often monopolized by isolates

Low-threshold adopters: the “low-hanging fruit” for change adoption
  • These individuals are typically quick to adopt and may be inclined to persuade others
Network Interventions

Scientific American

Network Segmentation

- Network intervention is directed toward or includes a group, expected to adopt an innovation at the same time
- Groups can reinforce (or inhibit) the behavior change process
- Positions may indicate hierarchy or clustering at the same time

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Network Segmentation

Use social network analysis:

• to identify components or cliques

• for evaluation of network-based improvement initiatives

• to define similar positions in different groups

An evolving Collaborative Chronic Care Network
Network Interventions

Thomas W. Valente

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Slow Ideas

Some innovations spread fast. How do you speed the ones that don’t?

BY ATUL GAWANDE

e.g., anesthesiology

e.g., hand washing

We yearn for frictionless, technological solutions. But people talking to people is still the way that norms and standards change.

Three clusters of influence associated with rates of diffusion:

- Attributes of the innovation
- Characteristics of adopters (and those who fail to adopt)
- Contextual and managerial factors

Disseminating Innovations in Health Care

Donald M. Berwick, MD, MPP

JAMA, April 16, 2003—Vol 289, No. 15 1969
Spreading changes that result in improvement

Diffusion of innovations theory explains how new ideas and practices spread within and between communities. But it is limited with regards to explicit guidance on catalyzing or controlling change...

**Social network data can inform design and management of improvement initiatives.**

Network actors have different thresholds indicating their likelihood to adopt a change and different network positions indicating their potential to influence others.

**We can quantify adoption thresholds and potential for influence with SNA.**

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**A Framework for Spread**

*From Local Improvements to System-Wide Change*

**Leadership**
- Topic is a key strategic initiative
- Goals and incentives aligned
- Executive sponsor assigned
- Day-to-day managers identified

**Set-up**
- Target population
- Adopter audiences
- Successful sites
- Key partners
- Initial spread plan

**Social System**
- Key messengers
- Communities
- Technical support
- Transition issues

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**This is a network!**
Network Interventions

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Network Design (Alteration)

How to understand social sources of QI information in care teams?

How to best organize the teams (or networks) of clinicians who deliver care to IBD patients?

Gavin W. Hougham, PhD, University of Chicago Medical Center
Ron Burt, PhD, University of Chicago Booth School of Business
David Meltzer, MD, PhD, University of Chicago Medical Center

IMPROVE CARE NOW
Three guiding principles for Network Interventions

1. **Program goals matter**
   In some cases you want to increase cohesion; in other cases you want to increase fragmentation.

2. **A well-articulated theory of behavior change is essential**
   What is driving the community of interest? Understand motivations for and barriers against behavior change.

3. **Learn as well as induce...**
   Be prepared to learn from your community just as you are trying to influence it.

Thank you. What questions are there?
Visit the Learning Networks Core website

http://www.cincinnatichildrens.org/service/j/anderson-center/learning-networks/default/

• With links to individual networks:
  • Solutions for Patient Safety
  • ImproveCareNow
  • National Pediatric Cardiology Quality Improvement Collaborative
  • Pediatric Rheumatology Care and Outcomes Improvement Network
  • Ohio Perinatal Quality Collaborative
Social Network Analysis resources

- UCINET Software: [https://sites.google.com/site/ucinetsoftware/home](https://sites.google.com/site/ucinetsoftware/home)
- SNA basics video tutorial: [https://www.youtube.com/watch?v=ei3YEn8xUnI](https://www.youtube.com/watch?v=ei3YEn8xUnI)
- Manuel Lima and The Power of Networks: [https://www.youtube.com/watch?v=nJmGrNdJ5Gw](https://www.youtube.com/watch?v=nJmGrNdJ5Gw)
- For an in-depth introduction to SNA see Lada Adamic’s MOOC on Coursera: [https://www.youtube.com/playlist?list=PL2rR6Wa-StjYOW7v6I8_npcK6ED0KEbCN](https://www.youtube.com/playlist?list=PL2rR6Wa-StjYOW7v6I8_npcK6ED0KEbCN)
- LinkedIn Network Visualization and Analysis: [http://socilab.com/](http://socilab.com/)