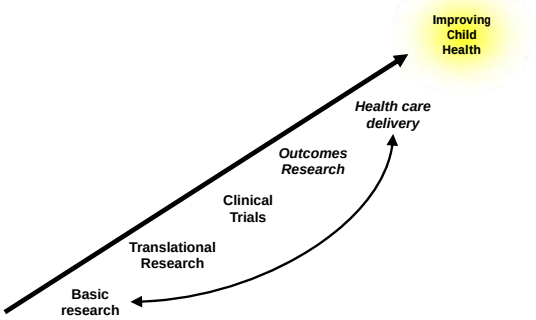
Michael Seid, PhD
Pulmonary Medicine
James M Anderson Center
Cincinnati Children's Hospital Medical Center

If I Only Had a Voice:

Engaging Patients and Families as Collaborators in Designing and Testing Interventions



John Bucuvalas, MD
Cincinnati Children's

C3N

COLLABORATIVE CHRONIC CARE NETWORK

Supported by
NIH NIDDK R01DK085719
AHRQ R01HS020024
AHRQ U18HS016957

.5 x .5 = .25

C3N

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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?
- … 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?

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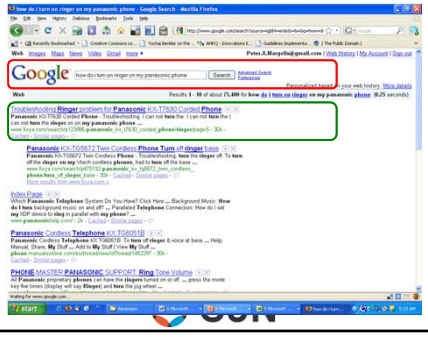
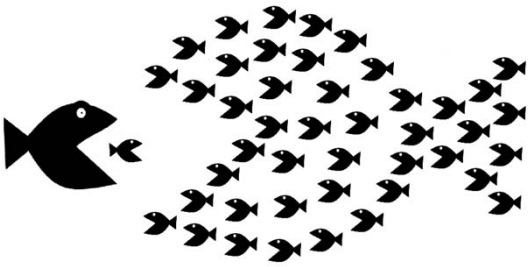
What if….?



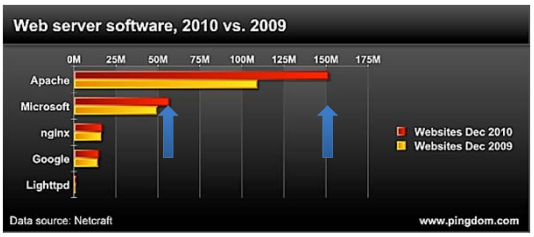


C3N Project

- Collaborative Chronic Care Network
  - A social, technical and scientific platform to enable collaboration among all stakeholders to improve health
  - A distributed production system for creating data, knowledge, and know-how.

http://www.c3nproject.org C3N

Apache Web Server Market Share



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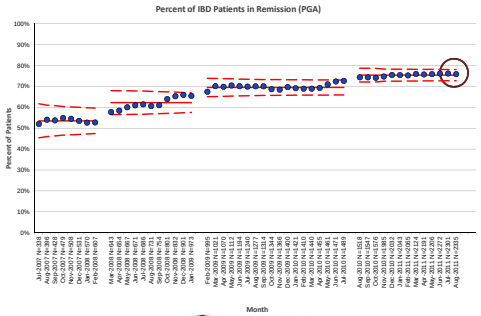
Open Sharing in Science

IMPROVECARENOW

IMPROVECARENOW

Percent of Patients in Remission



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NIH Roadmap Transformative Research Program

"projects that have the potential to transform a field of science"

Dominant chronic illness care paradigm

- Structures care around episodic, 1:1, synchronous interactions
- Limited ways for patients to participate
- Inherent power difference based on knowledge

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C3N challenges this by

- Making interactions continuous and asynchronous
- Empowering patients and providers to affect discovery and knowledge production
- Using technology to enable people to gracefully change behavior in course of daily life

C3N

Creating Conditions for a C3N

1. Align motivation around common vision
2. Make it easy to contribute
   - design, system engineering and technology
3. Enable better communication
4. Decrease time, effort and money to participate

C3N

Building a C3N

- Compelling purpose
- Culture
- All stakeholders– patients, clinicians, researchers
- Sharing stories, creating narratives.

C3N

Patients = Collaborators

- Creator ➔ COIN ➔ CLN ➔ CIN

Slashdot
News for Nerds. Stuff that matters.

debian

Swarm Creativity: Competitive Advantage Through Collaborative Innovation
By Peter A. Gloor

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Identify User Goals

- Ethnographic Research
- Create "Personas"

Bianca Simmons, age 20

Goals

- Keep symptoms at bay
- Be a leader in the IBD community

- *"What does not kill you makes you stronger"*
- With her ostomy bag discretely tucked into her jeans, Bianca makes her way around the Clearstone University campus in style.
- She's been on and off all of the steroids and other medications because either they weren't working or, like Humira and the elemental diet, they simply didn't suit her lifestyle.
- So, when she had surgery, it was a big relief. She thinks she will have the bag for a while especially since her boyfriend doesn't seem to mind it.
- She's a CCFA camp counselor in the summers, keeps in touch with her campers throughout the year, and participates in CCFA events whenever she can. Last month, she and a friend raised nearly a thousand dollars for CCFA camp scholarships.

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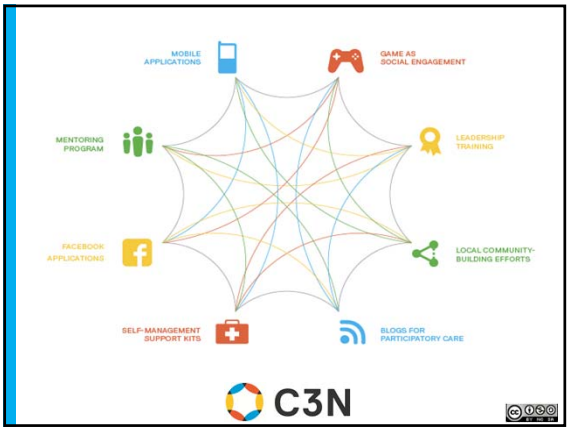

Processes for communication and collaboration

- Patient and parent advisory councils
- Parents on QI teams
- Patients on staff
- Parents and patients at network meetings
- Multiple communication channels (clinical sites, education days, integrated website, newsletters, social media)

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Scientific

- Learning in the face of complexity
- Nomothetic and idiographic
- 'Reagent grade' clinic – reduce variation
- Industrial design/engineering process
- Common transparent measurement
- Continuous peer review
- What and How

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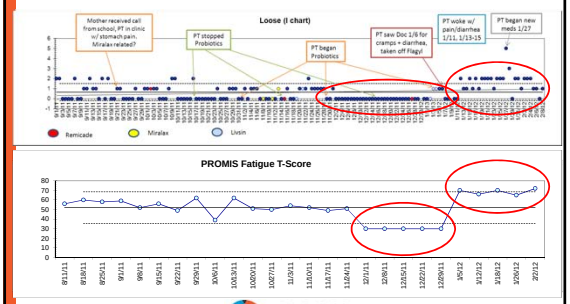
N-of-1 Trials + Patient Reported Outcomes



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Contribute to the transformation

Patients and families can:

- Participate in the Patient Advisory Council
- Participate in an intervention
- Ask your physician about ImproveCareNow
- "Like" us on Facebook
- Subscribe to our newsletter, The HIVE

C3N

You can make a difference.

Researchers can:

- Participate in an intervention
- Follow us on Twitter @C3NProject
- Join the discussion on Twitter #whatifHC
- Subscribe to our newsletter, The HIVE

C3N

You can make a difference.

Clinicians can:

- Join the Improve**Care**Now network
- Follow C3NProject and Improve**Care**Now on Twitter
- Join the discussion on Twitter #whatifHC
- Subscribe to our newsletter, The HIVE

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Join the transformation today.

"Emily's story has already been rewritten: She's not only a patient but a participant in her own health." – *Stanford X Medicine blog*

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Get involved

Join the movement www.c3nproject.org

info@c3nproject.org

C3N | Collaborative Chronic Care Network

@C3NProject

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