Strangers Helping Strangers to Improve Healthcare: A Virtual Community Commons, *ICN Exchange*

**Dong-Gil Ko,**
Carl H. Lindner College of Business, University of Cincinnati, USA.
E-mail: donggil.ko@uc.edu

**Daniel McLinden,**
Executive in the Learning and Development, Division of General & Community Pediatrics, Cincinnati Children’s Hospital Medical Center, USA.
E-mail: daniel.mclinden@cchmc.org

**Sarah Myers,**
Improvement Director, ImproveCareNow, Senior quality Improvement Consultant, Cincinnati Children’s Hospital Medical Center, USA.
E-mail: sarah.myers2@cchmc.org

**Peter Margolis,**
Director of Research, James M. Anderson Center for Health Systems Excellence, Cincinnati Children’s Hospital Medical Center, USA.
E-mail: peter.margolis@cchmc.org

**Abstract**

Chronic diseases are the leading causes of death and disability especially in the United States. Accordingly, there is an urgent need to improve the quality, cost and management of chronic disease healthcare. To date, all chronic diseases are primarily treated through the use of drugs and/or biological therapies and surgeries. This study examines Inflammatory Bowel Disease (IBD) – a chronic disease that causes chronic inflammation and damage in the gastrointestinal tract. A growing network of medical centers (Improve Care Now) and the use of information technology (ICN Exchange) to improve patient health care without medical or surgical intervention are the focus of this study. Interviews of patients, meeting minutes among administrators, survey data from users of the ICN Exchange, and system metrics are qualitatively examined to gain an appreciation and understanding of knowledge sharing as means to improve patient healthcare. Development of ICN Exchange is discussed as an enabler to improve patient healthcare without medical intervention.
1. Introduction

Chronic diseases are the leading causes of death and disability in the United States (Centers for Disease Control 2010). Approximately 130 million Americans live with at least one chronic illness with inflammatory bowel disease (IBD) accounting for nearly 1.5 million individuals (Centers for Disease Control 2010). Each year, IBD accounts for approximately 100,000 hospitalizations and 700,000 physician visits and results in disability for about 120,000 patients (Centers for Disease Control 2011). There is growing national attention on the urgent need to improve the quality, cost and management of healthcare.

Large gaps exist between recommended care and actual clinical practice. Adults receive only 50%–60% of recommended acute, chronic, and preventive healthcare while children receive only 42% of recommended care (Kerr et al. 2004, Health Union 2016). Childhood IBD is particularly important because it is usually aggressive and children typically experience significant psychosocial impact. Surgical intervention is not uncommon as are therapeutic advances in the treatment of pediatric IBD including immunomodulators and anti-tumor necrosis factor agents. Despite interventions and advances, there has been limited improvement in healthcare outcomes over the last several decades.

Healthcare costs have also seen limited improvements. The vast majority of IBD patients incur an annual direct cost of $5,000 - $18,000 and indirect cost of $5,000 (Crohn’s & Colitis 2014), and hospitalizations, outpatient care, and pharmaceutical claims are each responsible for about one-third of costs (Crandall et al. 2011). With more than 50% of total IBD patient population not receiving recommended care, healthcare costs continue to escalate potentially putting health care out of reach for some patients.

There is also widespread variation in the management of IBD healthcare due to a lack of consensus on best management practices and inadequate care delivery systems (Singh et al. 2017). This variation in management practices includes diagnostic and nutritional interventions, medication procedures, and various screening for colorectal cancer to name a few. Many healthcare stakeholders believe the creation of networks of care centers has been an important avenue to accelerate research in pediatrics; however, they are not without their challenges. Few centers have enough patients to determine if changes in care delivery are making a difference. Network centers are increasingly being used as a means to enable multiple clinical centers to work together to apply quality improvement (QI) strategies to improve care and outcomes.

The most apparent issue involves the patients themselves. IBD affects approximately 80,000 children and adolescents in the US (Crohn’s & Colitis 2014), resulting in symptoms including abdominal pain, diarrhea, bloody stools, weight loss, stunted growth, and fatigue. Children endure emergency department visits, testing, including colonoscopy and x-
rays, and risk hospitalization and surgery. When the disease is active, patients miss school, travel with trepidation, worry about where bathrooms are located, miss out on activities like sleepovers or sports, and become isolated from their peers. When in remission (no symptoms, feeling well, fully active), they can lead normal lives. Prior to the ICN Network, progress in improving outcomes was slow.

Another major issue concerns health care providers. Historically, health care providers worked within single facilities, trying to improve care with little collaboration with those addressing similar issues. They lacked access to tools and systems to compare results, share experiences and know-how. Additionally, clinical care and QI were heavily clinician-centered with little recognition of the knowledge and know-how parents and patients can bring to improving care if provided the same learning opportunities, skills, and tools as clinicians.

Development of an interconnected network of systems for creating new approaches to care, testing them, and translating them into the actual care of patients offers an opportunity to improve overall healthcare outcomes while allowing efficient and effective practices to be shared. At Cincinnati Children’s Hospital Medical Center (CCHMC), development of an IT-based innovative global collaborative knowledge-sharing platform, called the ICN Exchange, provides users a mechanism to “share seamlessly and steal shamelessly” for improving IBD patients’ lives.

2. ImproveCareNow Network

Imagine being a nurse at a small IBD center in rural Virginia who is working with the center’s quality improvement team to create a more proactive pre-visit planning process. The impetus for this is a recent increase in the number of patient visits at which social work or registered dietitian support was needed, but these professionals were unavailable to see the patients as the need was not identified in advance. It is daunting to sit down and build a new process when you are already busy with day-to-day clinical tasks and you don’t know where to start.

Now imagine there is a dynamic repository of information where you can find ideas, tools, and strategies from tens of other centers who have faced this same challenge—a virtual commons. Maybe it’s a video from a team in North Carolina sharing a comprehensive look at their pre-visit planning approach. Maybe it’s a step-by-step document explaining how a center in Oklahoma freed up psychosocial staff to take part in pre-visit planning discussions. Or perhaps it’s a list of issues that parents and patients at a center in Florida hoped would be addressed at every clinic visit.
The ImproveCareNow (ICN)\(^1\) is a sustainable collaborative chronic care network of pediatric gastroenterology practices established in 2007 with the goal of transforming the health, care, and costs for children with inflammatory bowel disease (IBD) – i.e., Crohn disease and ulcerative colitis. The ICN network has partnered with the Collaborative Chronic Care Network (C3N) Project, supported by a National Institutes of Health Transformative Research grant (R01DK085719), to develop and test interventions to become a peer-production learning healthcare system. This system coordinates the creative energies of many people for generating and applying the best evidence for the collaborative healthcare choices of each patient and provider. It would also drive the process of discovery as a natural outgrowth of patient care and ensure innovation, quality, safety, and value in healthcare.

The Network has evolved from a small Improvement Collaborative of eight centers to one having 78 care centers in 36 states and the District of Columbia with two in England (as of August 2015). These 78 centers have 710 pediatric gastroenterologists and 22,000 patients with IBD. The Network enables teams from each center, comprised of clinicians, quality improvement consultants, researchers, patients and parents, to work together, across the globe, in a learning health care system to accelerate the innovation, discovery, and application of new knowledge primarily through sharing of best practices, outcome data, and lessons-learned.

In a large geographically dispersed Network, ensuring that the best improvement methods, tools and ideas are shared equally is a challenge. Traditional collaborative communication and sharing methods such as in-person learning sessions and online webinars are necessary but these high touch strategies do not scale-up to meet the needs of a large network. A technology solution was needed to supplement high touch efforts and cultivate the ”commons” so people can easily find like-minded people, the quality improvement tools they need and the knowledge to implement these tools well. The ICN Exchange\(^2\) was developed to meet this need for pediatric inflammatory bowel disease and was launched in April 2013.

3. Bridging ImproveCareNow Network and ICN Exchange

ICN evolved from a collaborative model of improvement based on the Institute for Healthcare Improvement Breakthrough Series (BTS) to a learning health network that simultaneously conducts QI, research, innovation, and community-building. QI tools are shared widely via the ICN’s online community commons, the ICN Exchange. With funding from the US Agency for Healthcare Quality and Research, ICN created a ‘data-in-once’ registry that enables clinicians to capture data in electronic health records (EHR) and upload it to the multi-site registry. The registry includes process and outcome data for nearly 20,000

\(^1\) [https://improvecarenow.org](https://improvecarenow.org)
\(^2\) [http://icnexchanger.org](http://icnexchanger.org)
patients, provides clinicians with proactive clinical decision-making including automated pre-visit planning tool and an on-demand population management tool. The registry also provides cohort discovery tools to facilitate research, electronic consent management and a centralized Institutional Review Board (IRB) to facilitate research. Accordingly, the Exchange is home to scores of innovations contributed by hundreds of innovators around the world (e.g., technology for N of 1 studies among patients and their clinicians; peer-to-peer mentoring; an on-line forum for patients and parents; crowd-sourced tools and resources).

4. ICN Exchange

The ICN Exchange (simply referred to as the Exchange) is a collaborative knowledge-sharing platform that allows members of an extended learning health system to communicate and innovate across the globe. The various members of the community—from physicians to patients—use it to share seamlessly and steal shamelessly. It provides user-friendly, visually appealing, and adaptable virtual space for the growing number of resources and tools. Importantly, the Exchange enables collaborators to better use the resources and to improve the tools for better patient outcomes. Thus, the Exchange provides a platform for improving knowledge about how to implement an effective and a reliable care delivery system and how to treat and manage pediatric IBD.

4.1 Peer Production Commons

Commons-based peer production describes an “all teach, all learn” model where the creative energies of many individuals are coordinated to facilitate innovation and distribution. It differs from firm production in which production is centrally coordinated. It also differs from market-based production in which production is driven by supply and demand. Wikipedia is one example of a commons-based peer production model.

The Exchange is a commons-based peer production model aimed to produce and distribute information (e.g., best practices for managing pre-planning visits), knowledge (e.g., informal insights and formal research), and know-how (e.g., expertise) to patients, parents, clinicians, researchers, coordinators, QI staffs, and other members participating in the community. The primary goals of the Exchange are to make it easy for people to:

- 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

4.2 Improvements through Data Collection Process

In addition to developing an IT infrastructure that would achieve the goals, setting up processes for managing communities across the globe was equally important. The Exchange team needed to understand how it can benefit the users. Multiple interviews and surveys were
conducted to discover and document successful practices, identify recommendations for revisions to improve its impact, identify facilitators and barriers to using the Exchange. Exhibits 1-4 depict interview questions and field surveys used to gather data.

Exhibit 5 illustrates the Breakthrough Series methods used by the Exchange team for determining what is working and what is not working (Institute for Healthcare Improvement 2003). The method offers a cyclical model for improvement requiring collaborative teams to address three key questions:

- What are we trying to accomplish (aim)? The goal is to determine the specific outcomes they are trying to change through their work.
- How will we know that a change is an improvement (measures)? Team members identify appropriate measures to track their success.
- What changes can we make that will result in improvement (changes)? Teams identify key changes that they will actually implement and test.

4.3 Interviews and Surveys

20 care centers across the United States were interviewed based on their level of Exchange activities: ten most and ten least active care centers were selected. Among the 20, fourteen care centers agreed to participate. There was a wide spectrum of participants whose responsibilities included data entry, reporting, patient consent and management. Participants were typically identified as a primary user, or a point person, of the Exchange. Exhibit 6 depicts the communication network that surfaced from the interviews. It reflects the relationships among all stakeholders participating in the Exchange interview.

The interviews also revealed factors that facilitate the use of the Exchange. They include:

- **Searching for Resources**
  - “I usually go to the Exchange looking for resources that I heard about on a call or during learning session.”
  - “…it’s been helpful for getting up and getting started with the site work and registration”
  - “…looking for other care center resources to avoid recreating the wheel”

- **Required Assignments**
  - “I’m forced to use it. Basically, I use it because I have to.”
  - “I post assignments mostly required stuff. It’s not my first response to go to the Exchange”

- **Email prompts**
  - “Emails from Sarah prompt my use of the Exchange”
  - “Email notifications with a direct link to content are helpful”

- **Learning Session**
Proceedings of the International Conference on Human Capital and Knowledge Management
(IC18Thailand Conference) ISBN: 978-1-943579-70-9

- “It’s helpful that I can find all of the learning session information there”
- “The group visits information from the spring learning session was passed on the psychologist and will be used with the parent advisory group to gauge their interest”

In contrast, there were also barriers to finding resources on the Exchange. They include:

- **Difficult to find an exact resource on the site (search functionality)**
  - “It’s a negative experience to find stuff. It needs a different type of organization”
  - “The search function is not helpful. I start at the homepage and find my way around”
  - “I’m only able to find what's needed 30% of the time”
  - “The search is not helpful. When I conduct a search it often comes back with 0 results, categories tend to work better.”

- **Duplicate images are overwhelming and distracting**
  - “The same pin reoccurring is off-putting. It makes it appear busy and its hard to recognize other pins”
  - “Repeating information/duplicate pins creates a visual burden”

- **Hard to navigate and share documents**
  - “It’s hard to share documents. The special formatting requirements for upload make it difficult.”
  - “I click randomly until I find something”

- **Lack of time**
  - “Use of the exchange is not a priority and falls lower on the priority list when patients are involved. People really don’t have the time to explore the Exchange”
  - “I see the benefits in using the exchange. I would be able to use it better and more if time allowed”

Finally, the interviews offer insight regarding how the Exchange is impacting practice. It highlights the importance and value of accessible resources that can be adapted in a new context.

- **Users have unlimited access to download and adapt resources that support the development of new care processes at their centers.**
  - “The resources on transition I found on the Exchange have been helpful in creating the process at my care center. There was nothing existing before looking on the Exchange”
- I’ve used the IBD mentor handbook from Riley Children's to develop our by-laws
- I have used several of the swim lane templates found on the site. They use them as a starting point for creating our own

- Resources found on the Exchange are adapted and used during patient visits
  - “New diagnosis checklist has been very useful. I downloaded and adapted the document for use with patients. It provides the patient with the tools to coordinate their care”
  - “The “quality of life for patients” not a metric collected by the network but the population management report for patients not seen every 200 days has been very useful at our center.”
  - “I download the E-Circle newsletter form the Exchange, get it approved through the appropriate channels and, hand it out to patients.”
  - “I use the enteral nutrition protocol with patients. I also share it with patients for snack ideas”

The interviews suggest that the Exchange facilitates management of knowledge through the commons offering a virtual medium for storage, dissemination, and integration of knowledge to inform clinical practice by:
- Providing access to tools and resources as needed
- Providing a platform for multi-disciplinary, multi-center collaboration
- Reducing the time that a care center would spend on creating a new resource

Nevertheless, the use of the Exchange such as search, navigation, and how-to-pin remains challenging. The Exchange team sought to address these challenges through a series of routine field surveys.

Another evidence of benefits to the Exchange is testimonials provided by the users. Exhibit 7 highlights varying benefits the Exchange offers to its users. The Exchange serves as a “go-to” resource for bridging and connecting with other, to efficiently share best practices, and to improve quality of healthcare through the use and reuse of templates that are shared.

4.4 System Data-driven Results

A great deal of reports is generated to evaluate the benefits to its users. A Dashboard List highlights multi-perspective reports that capture the use of the Exchange as one metric of its success (see Exhibit 8). Participants are classified as a nonuser, an observer, or a contributor. A nonuser is a registered individual but has not logged in once; an observer is a registered individual who has logged in to the Exchange but has not engaged in a “pin” activity; and a contributor is a registered individual who has performed at least one of the following activities: pin, forum post, comment, or pre-work. Exhibits 9-10 depict a monthly cumulative
count (ending May 2015) of new activities. The cumulative growth indicates continued engagement among all 645 registered users. Moreover, over 40 care centers (over 50%) regularly engage in activities, primarily pin creation, which further demonstrates wide applicability and use of knowledge created in one care center and reused or adapted in another.

4.5 Electronic Health Records

ICN has a longitudinal patient registry with data from nearly 20,000 patients uploaded directly from the EHR—which are analyzed and reported back via an automated, online measurement system. This allows centers and QI coaches to identify successes and gaps in performance and target QI efforts. Key measures include percent of patients in remission, sustained remission, and satisfactory growth and nutritional status (see Exhibit 11). The same system has been used to demonstrate improvement in data quality. The Network tracks the impact of engagement and community-building efforts via monthly surveys to participating centers and numerous metrics describing reach. The percent of patients in remission has increased from 55% in 2007 to 79% and 95% of patients being treated without steroids. Approximately 100 parents are participating on QI teams across 78 participating centers. We have seen the growth of a vibrant, engaged, and proactive community that has created a welcoming and supportive community, and serve as a robust example for networks in other conditions.

Through interviews, surveys, data analyses, testimonials, and EHR data, we were able to determine value arising from use of the Exchange. Our data shows growth in both user base and participation in new activities. This suggests users are gaining immediate access to knowledge that can be readily applied, rather than re-invent the wheel. Reinventing the wheel carries a cost in at least three forms – potential quality control (health care outcome), process delays (financial cost), and mismanagement (best practices). More importantly, the Exchange partially contributed to the 79% remission rate experienced by patients this year.

5. Where Tomorrow?

Presently, the Exchange is comprised of nine members. They are responsible for the day-to-day operation and support of the 78 care centers participating in the Exchange. Exhibit 12 illustrates the Exchange’s overall architecture. Each of the 78 care centers has a set of communities comprised of patient advisory committee, parent working group, physicians, clinical coordinators, researchers, nurses, QI staff, and patients. These communities contribute and access the “community commons” typically through the use of a pin, forum, or search features—a common platform where global community members can share seamlessly and steal shamelessly. The underlying IT architecture is supported by Drupal and MySQL database.
The Exchange has extended our “all teach, all learn” focus beyond what we thought possible. In a large Network, keeping participants connected is daunting, as is ensuring the best tools and ideas are shared equally. Before launching this innovation, tools, ideas, and knowledge generated by individual centers were relegated to e-mail attachments, and file cabinet drawers. Centers connected on monthly webinars and twice yearly in-person meetings, but little asynchronous collaboration and peer mentoring was possible. Our vision for the Exchange is continued evolution toward better curation and organization of health-improving ideas and best practices leading to faster spread across more centers. We have the community of improvers and the will to co-produce using the Exchange, but need to further cultivate the "commons" so people can easily find like-minded people, the tools they need and the knowledge to implement them well. Essentially, place the right maps and guides for their improvement work at their fingertips. And with the aid of Exhibit 13, we strive to achieve out targeted goals.

As the Exchange continues to redesign to better meet the needs of its users, it is developing knowledge management and social network capabilities to better understand what clinical and social factors are contributing to increased remission rates. It is also developing tools to accurately assess direct contribution made to remission rates. Our goal is to continue evolving this peer produced commons for improving healthcare outcomes, costs, and management.

6. Lessons Learned

Data-driven quality improvement, innovation, research, and community building are complementary and necessary strategies for a learning health system. Scaling up as a network grows requires approaches to maximize learning among centers working in similar settings. Building and nurturing an enduring improvement community of improvers takes hard work and creativity, but individual members of dynamic improvement communities will take on leadership roles when given the structure and opportunities and create ideas for improvement that would not have been surfaced by clinicians alone.

Clinician, patients, researchers, and other improvers thrive when given the opportunity and structure for seamless collaboration. People with different talents and expertise will find their niche in a Network that offers many opportunities for participation. The key is creating a system that makes areas for improvement visible, connects like-minded people and centers, and continuously adapts and improves the systems in which they are working together.

References


**Exhibit 1: SCM Interview Protocol**

Hello, my name is _________. I am a part of the Exchange evaluation team. We are conducting interviews with Exchange users to explore how information from the site is used. Your input will help us to determine whether we are successful in meeting our goal of being a learning resource that improves knowledge on how to implement an effective and reliable care delivery system to treat and manage IBD. The interview should not take more than a half hour. Please note that we will not focus on technical feedback during this time. If you are interested in providing technical feedback we can contact you with future opportunities related to site improvement.

1. What are some of your basic job functions?
2. What prompts you to use the Exchange? *(probe-an assignment; looking for a resource; posting useful information)*
3. How often do you visit the exchange?
   a. Daily
   b. 2-3 times a week
   c. Weekly
   d. Bi-weekly
   e. Monthly
   f. Never
4. Thinking of your activity while on the Exchange, what features do you use most often? *(probe-pinning, commenting, downloading, repining)*
5. Is anyone at your care center specifically assigned to use the Exchange by way of job description or specific duties? If so, what is their job role?
6. Is there a specific strategy around use of the Exchange at your care center? If so, can you give me a brief synopsis?
7. Thinking about the Exchange in relation to your quality improvement work…
a. Have you found tools on the Exchange site that you can use to improve care processes at your care center?
   i. [If yes] How easy or hard is it to find the tools?
   ii. [If no] Why not? *(probe* - difficult, lack of trust, lack of QI knowledge)
   iii. Are there any barriers to finding tools/resources on the Exchange?

b. Can you recall specific documents that you’ve shared/ adapted for use with your clinical team to improve care processes? Please share how that process works at your center.

c. Can you recall specific resources that you’ve shared/ adapted for use with patients and families to improve care processes *(probe* - self-management, pre-visit planning) Please share how that process works at your center.

8. Has use of the Exchange impacted progress on your care center goals within ICN? In your larger organization? Please provide specific examples. (i.e.-90 day goals, remission rates, parent engagement efforts etc.)

9. Is there anything that we haven’t covered during this interview regarding the impact of the Exchange on improvement processes at your center?

*Source: ICN Exchange*

**Exhibit 2: Site Evaluation Survey**

1. Please provide your job title.

2. Please provide your role on your ICN QI team.

3. How likely are you to use the following to gather information or resources that can be applied to your clinical or QI work? *(Definitely would- Definitely would not)*
   1. P3K Pinboard site
   2. ICN SharePoint Portal
   3. ICN Listserv
   4. Online information sources (i.e.-CCFA,GIKids.org)
   5. Other (please specify)

4. Please rate your level of satisfaction with the P3K site design in the following areas: *(Very satisfied- Very dissatisfied)*
   1. Ease of use
   2. Visual appeal
   3. Ability to share resources
   4. Usefulness of resources

5. Please indicate the degree to which you agree with the following statements. *(Strongly agree-Strongly disagree)*
1. The P3K Pinboard site is a valuable resource for sharing information with my colleagues.
2. The P3K Pinboard site will accelerate my movement toward high reliability in the core ICN care processes.
3. I would recommend the P3K site to a colleague.

6. What other thoughts or suggestions might you have?

Source: ICN Exchange

Exhibit 3: ImproveCareNow Exchange Survey

Please take a few minutes to complete the survey below. Your feedback will help us accelerate our progress towards making the ImproveCareNow Exchange a useful online resource for the IBD community. For questions about this survey please contact _(phone + email)_.__ Thank you for your time.

1. Please select your ImproveCareNow Care Center
2. Please select your role in the ICN network
3. I have used the ICN Exchange by browsing the contents, adding a comment, participating in a forum discussion, or uploading or downloading content.
   a. Yes
   b. No

If yes (the respondent will not see these questions if they select no)
4. The ImproveCareNow Exchange site is a useful resource for supporting QI activities at my ICN Care Center
   a. Agree
   b. Disagree
5. Please provide specifics examples of how the ICN Exchange has been useful in your work.
6. How can we make the ImproveCareNow Exchange more useful to you? Please give specific examples.

If no
4. If you have not used the ImproveCareNow Exchange, why not? [check all that apply]
   a. I don’t have time
   b. I am not sure how to use the site effectively
   c. I don’t like the layout/format
   d. The content is not relevant to my job
   e. I don’t have a log-in
   f. I was not aware of the ICN Exchange as a resource
   g. I am not able to find the site
   h. Other
   i. If other, please explain.

Please provide additional feedback you would like to share about the ImproveCareNow Exchange.

Source: ICN Exchange
Exhibit 4: ICN ‘How to’ Session Post Event Survey

Please help us improve the ICN Exchange “How To” Sessions by responding to our brief survey below.

Please provide your job title.

Please provide your role on your ICN QI team.

Are you a Pinterest User?
- Yes
- No

How often do you use Pinterest? (Conditional based on response to previous question)
- Often
- Sometimes
- Seldom
- Never

Satisfaction

Please rate your level of satisfaction with the ICN Exchange site design in the following areas:

<table>
<thead>
<tr>
<th></th>
<th>Very satisfied</th>
<th>Very dissatisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>7 6 5 4 3 2 1 N A</td>
<td></td>
</tr>
<tr>
<td>Ease of use</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual appeal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ability to share resources</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Usefulness of resources</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

What other thoughts or suggestions might you have?

Value

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>7 6 5 4 3 2 1 N A</td>
<td></td>
</tr>
<tr>
<td>The ICN Exchange site is a valuable resource for sharing information with my colleagues.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The ICN Exchange site will accelerate my movement toward high reliability in the core ICN care processes.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I would recommend the ICN Exchange site to a colleague.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

What other ‘how to’ sessions would be helpful?

Source: ICN Exchange
Exhibit 5: Breathrough Series Method

Source: National Institute of Health

Exhibit 6: Communication Network among Stakeholders

Communication networks based

Source: ICN Exchange
Exhibit 7: Sample of Exchange Users’ Testimonials

<table>
<thead>
<tr>
<th>Testimonial</th>
</tr>
</thead>
<tbody>
<tr>
<td>“The Exchange has given our community a platform to communicate, collaborate, and locate resources. As an ImproveCareNow coordinator it is a primary responsibility to bring information and tools back to my very busy care team. I am often asked to go to the ICN community to solve problems or ask for input; the forum option gives us the ability to ask questions and get answers from ALL stakeholders. Having the Exchange as the homebase to our community makes bridging and bonding as easy as knocking on your neighbors door.”</td>
</tr>
<tr>
<td>“As an academic children’s hospital, July becomes a transition period. That affects our patients, their families, and the entire care team. As the ImproveCareNow coordinator it is my job to orient new fellows and make the patient transition period to a new provider as seamless as possible. Orienting to ICN and all that the collaborative offers is no small task however, the Exchange makes this easier. I’m able to share with new providers educational tools that they can use, clinical pathways for care, data guides, and multiple other resources. They often reference back to these throughout their training and into their own practices.”</td>
</tr>
<tr>
<td>“The ICN Exchange has provided me with the resources necessary to succeed in my position as Clinical Research Coordinator at MGH/C. Upon starting my new role several months ago, I did not have much of a chance to train with the outgoing coordinator. Instead, I looked towards the Exchange and found the many useful materials that have helped me grow into my position. The ICN Exchange provides flow sheets, checklists, and templates used by research coordinators at other centers, and I was able to view and adapt those to work at MGH/C. One example of this involves a Pre-Visit Planning form uploaded by another hospital; I was able to adapt the form to streamline our PVP process and improve the efficiency of our weekly meetings. Finally, the monthly checklists posted on the exchanged help remind me of the tasks I need to complete and the dates of important events and conference calls. The ICN Exchange is a phenomenal wealth of information that is “shared seamlessly”, which I have definitely “stolen shamelessly”, and I know my ICN center is better off because of it!”</td>
</tr>
<tr>
<td>“The exchange has provided the community with a centralized location to find current documents. Not only documents from the collaborative but from other centers. It’s a central hub where we can share tools and materials. We often post things we are doing with our center there as well as start by looking there when we identify something new we want to develop.”</td>
</tr>
<tr>
<td>“As a parent, the ICN Exchange offers an opportunity to learn, participate, or become actively engaged in the larger community. Initially my experience with ICN was limited to attending Learning Sessions, communicating with other parents, and email communication with a small group of people I knew personally within the network. However, access to the Exchange has broadened my reach substantially. Today, I am able to interact with any number of network professionals!”</td>
</tr>
<tr>
<td>“The Exchange platform has the unique element of transparency whereby patients, parents, and providers interact in a dynamic and accessible environment. As patients, it allows us to communicate directly with parents and providers, as well as being able to see for ourselves what those individuals are posting and sharing. As we released our pediatric ostomy toolkit, we turned to the Exchange so that the notice of its release could be equally shared and that the file could be safely and reliably passed to parents and providers in the network.”</td>
</tr>
</tbody>
</table>

Source: ICN Exchange
### Exhibit 8: Systems Data-driven Reports

<table>
<thead>
<tr>
<th>Report</th>
<th>Chart Type</th>
<th>Reporting Frequency</th>
<th>Process</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Forum Comments by month</td>
<td>Run</td>
<td>Bi-weekly</td>
<td>Auto</td>
</tr>
<tr>
<td>New Activities (cumulative) by month/year</td>
<td>Line</td>
<td>Monthly</td>
<td>Auto</td>
</tr>
<tr>
<td>Activities by Care Center (cumulative) by month/year</td>
<td>Table</td>
<td>Monthly</td>
<td>Auto</td>
</tr>
<tr>
<td>New Activities by Type (monthly) [including ICN staff]</td>
<td>Line</td>
<td>Monthly</td>
<td>Auto</td>
</tr>
<tr>
<td>New Activities by Type (monthly) [excluding ICN staff]</td>
<td>Line</td>
<td>Monthly</td>
<td>Auto</td>
</tr>
<tr>
<td>New Activities by ICN Team Role (cumulative - excluding ICN staff)</td>
<td>Line</td>
<td>Monthly</td>
<td>Auto</td>
</tr>
<tr>
<td>Forum Usage</td>
<td>Line</td>
<td>Monthly</td>
<td>Auto</td>
</tr>
<tr>
<td>User type by team role (monthly) [excluding ICN staff]</td>
<td>Bar</td>
<td>Monthly</td>
<td>Auto</td>
</tr>
<tr>
<td>Site Activity by Care Center Groups</td>
<td>Table</td>
<td>Monthly</td>
<td>Auto</td>
</tr>
<tr>
<td>Care Centers Grouped by Date Entering ICN</td>
<td>Table</td>
<td>Monthly</td>
<td>Auto</td>
</tr>
<tr>
<td>Visits and Visitors to the Exchange</td>
<td>Table</td>
<td>Monthly</td>
<td>Auto</td>
</tr>
</tbody>
</table>

*Source: ICN Exchange*
Exhibit 9: New Activities - Cumulative count over 26 months involving pins, forum topic creation, comments, and pre-work (N=645 registered users)

Source: ICN Exchange
Exhibit 10: New Activities by Type over 26 Months Period (N=645 registered users)

Source: ICN Exchange
Exhibit 11: EHR Outcomes

Source: Improve Care Now Network
Exhibit 12: ICN Exchange’s Architecture

Source: ICN Exchange
Exhibit 13: Short/Long-term Performance Outcomes

Source: ICN Exchange