Charter

The Collaborative Chronic Care Network (C3N) Project: Phase I – Design of a System to Improve the Outcomes of Patients with Chronic Illness

Background

Chronic illness kills too many and costs too much. Reducing this burden is possible, yet within our current health care system, Americans receive about 50% of indicated care and patients follow doctors' orders about as often. What if there was a way to create a vastly better chronic illness care system by harnessing the inherent motivation and collective intelligence of patients and clinicians? What if this system allowed patients and physicians to share information freely, collaborate to solve important problems, and use their collective creativity and expertise to act in ways that improve health? A system for transforming chronic care is possible – we intend to build it by designing, prototyping, optimizing, and evaluating a collaborative clinical care network (C3N).

The C3N is modeled after collaborative innovation networks (COINs), virtual teams of self-motivated individuals with a collective vision, enabled by the Web to achieve a common goal by sharing ideas, information, and work. COINs are not new - collective intelligence has existed at least since humans learned to hunt in groups. The internet, though, has allowed COINs to deliver their full potential, with Wikipedia, Linux, and the World Wide Web Consortium itself as prominent examples. COINs are, however, new to chronic illness care and, while many doctors and patients use the Web to search for and find health information, existing health-related social networks separate patients from providers, despite the fact that patient-provider interaction is key to chronic illness care.

Joining patients, parents and providers (physicians and other clinicians) in a shared collaborative network is a radically innovative approach in health care. It challenges the dominant chronic illness care system or paradigm, which views patients as objects on which to intervene, structures care around episodic one-to-one patient-physician interactions, and assumes an inherent power differential based on knowledge. The C3N will challenge the paradigm by engaging patients as co-equals; by making interaction continuous through asynchronous one-to-one and one-to-many communication; and by leveling the knowledge gradient. Moreover, while many social learning theories yield simple mechanistic formulas for behavior change, a C3N acknowledges the inherently complex nature of human behavior and provides the means to describe and understand emergent behaviors.

Purpose and Aim

The aim of the one-year Design Phase is to create the design for a patient-provider C3N that will improve clinical practice, patient self-management, and disease outcomes of pediatric inflammatory bowel disease (IBD). The C3N will provide a system platform with components that will:

1. Facilitate practice and provider behavior change by supporting the existing improvement collaborative (ImproveCareNow) to deliver highly reliable IBD care.
2. Facilitate patient behavior change by developing and supplying self-management tools, informing, empowering, and activating patients, and providing support via a social network and more continuous communication
3. Increase interaction among users, and innovation, and dissemination both within and across user types, about topics such as chronic illness care, self-management, adherence, and research using a range of technologies (e.g., phone, face-to-face, Internet, social networking tools).
4. Ensure high-quality patient self-report data and practice data submission.

5. Co-develop new tools, resources and information, based on user needs, that makes the C3N easier to use and more effective at generating new knowledge and improving outcomes and experience of care.
6. Promote the use of data for research, clinical care, and self-management by:
    a. reducing barriers to research resources including C3N data and staff
    b. developing, testing and implementing easier access to the data
    c. creating data visualization tools and customizable data queries.
7. Translate existing evidence to provide up-to-date, useful, accurate, evidence-based information for patients and families.

The purpose of the Design Phase is to identify how these components can work together and to design prototypes and tests that will be conducted to ensure that the design yields a system capable of transforming chronic illness care across a variety of practice sites and large populations of patients.

Preliminary measures of system performance include:

- Increased participation, engagement, and interaction among all types of users
- Improved health outcomes (e.g., steroid free remission, improved quality of life)
- Improvements in the reliability and effectiveness of chronic illness care (e.g., more appropriate use of medications and monitoring of disease activity)
- Improved self-management
- Increased production of new knowledge and discoveries
- Reduced transactional costs for research and increased planned experimentation

Methods

The C3N is conceptualized as a *system* of inter-related activities capable of continuous improvement (See system Diagram). In this phase, we will generate a design for the C3N including: a description of the needs the system will fulfill for participants, measures to evaluate the system, specific components to be tested, and a plan for developing the system. We will use an "idealized" design process based on an approach developed by Associates in Process Improvement. The process will be organized around three face-to-face Design Meetings involving project co-investigators, experts, and patients and parents.

Timeline

The Design Phase will be action oriented where possible to take advantage of opportunities to test new concepts on a small scale when possible. Specific deadlines for the Design Phase include:

- First face-to-face Design Meeting January 25-26, 2010
- Finalize Design Charter by February 1, 2010.
- Completion of: 1) an assessment of existing systems, 2) IBD network analysis, and 3) user and stakeholder interviews by May 31, 2010
- Second Design Meeting with completion of a list of quality characteristics and measures of program success mid-June 2010
- Documentation of a preliminary proposed C3N design by September 7, 2010.
- Third Design Meeting early-mid September 2010
- Finalization of the proposed design plan and associated plans for testing by September 30, 2010.

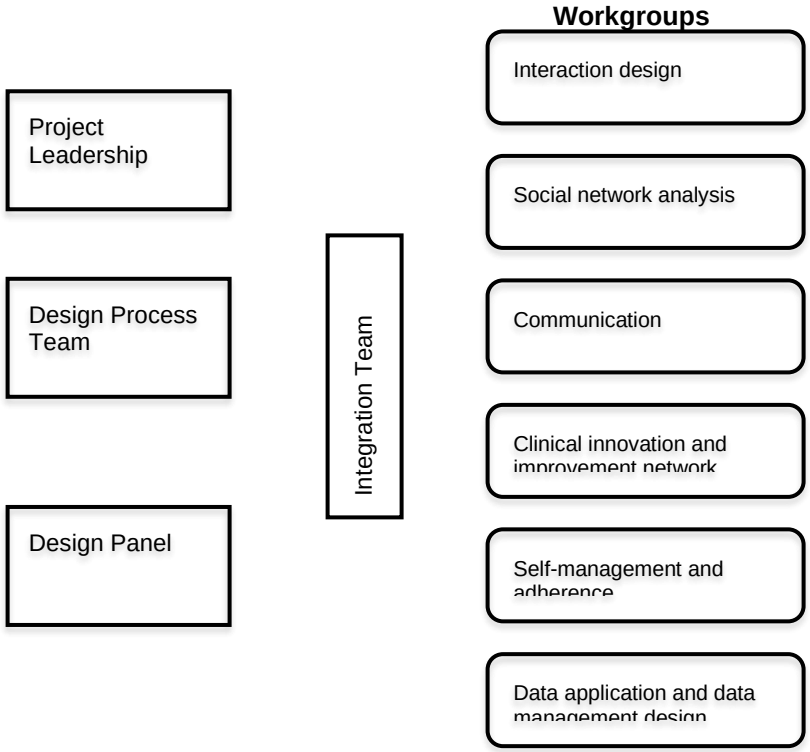
Organizational structure

Overall leadership including decisions about governance, finance and stakeholder communication will be the responsibility of the Co-PIs. A Design Process Team will develop the charter for the design process, and manage and organize and lead three meetings of a "Design Panel" comprised of co-

investigators and other contributors. The Design Process Team will also establish the charge for each work group focused on each of the C3N components, as well as specific design activities.

Design activities will be carried out by work groups. During the design phase, work groups will include interaction design, social network analysis, collaborative innovation and improvement network, self-management and adherence, data application and data management design, and communication. Individuals from each work group will be responsible for carrying out data collection and synthesis in support of the final design. An Integration Team, comprised of the team leads from each work group, will lead the integration and coordination of the workgroups' design activities, make decisions about priorities and allocate resources. A central function of the Integration Team is ensuring that the work groups align their questions and think about how the components will work together. A project Advisory Panel will provide input twice a year.

A simplified organizational framework for the C3N design process demonstrates the relationship of the project teams and workgroups.



Prior to the first design meeting, the teams will review the expectations of the project and the design charter and system diagram. Following the initial design meeting, we will begin a user-centered, "interaction" design process undertaken through direct observation, focus groups or individual interviews with a range of potential C3N users (e.g., patients, families, clinicians who are part of networks, researchers). Observations gathered during this process will inform all work groups.

Each work group will also evaluate currently available and emerging systems related to the C3N and explore models developed by others within and outside of health care. (e.g., Slashdot.com) In doing so, the work group can identify where the current systems are meeting the needs of users and where new products need to be developed or linked. Ultimately, we will compare current systems to the design measures that are developed.

After collecting informant data, the design panel will come together for their second meeting and define measures of performance and define targets for the measures. As outlined below, the design measures will reflect the needs of the users including patients, families, participating physicians and care teams, and researchers.

Based on this information, the work groups will develop preliminary designs for integration and production of the final design and a plan for development and testing to be reviewed at a third design panel meeting.

Preliminary team members and work groups include (Bold indicates lead/member Integration Team):

Design Process Team	**Clinical innovation and improvement network**
<Lead Name >	**<Lead Name >**
< Member Name >	< Member Name >
< Member Name >	< Member Name >
< Member Name >	< Member Name >
< Member Name >	<Parent Name>
Social network analysis	Another ICN MD
<Lead Name >	**Patient behavior change: Self-management and adherence**
< Member Name >	**<Lead Name >**
< Member Name >	< Member Name >
< Member Name >	< Member Name >
< Member Name >	< Member Name >
< Member Name >	TBD parent/patient
Communications	TBD GI Doc
<Lead Name >	Project Specialist
< Member Name >	**Data application &data management design**
C3N Project coordinator/webmaster	**<Lead Name >**
Representative from ImproveCareNow	< Member Name >
Advisors:	< Member Name >
< Advisor Name >	< Member Name >
< Advisor Name >	< Member Name >
< Advisor Name >	**Interaction design**
< Advisor Name >	**<Lead Name >**
Social network applications design and development	< Member Name >
Begins after Design Meeting 1	< Member Name >
	< Member Name >

Summary of the design process for workgroups

Key concepts applicable to the C3N design task include:

1. Identify what is currently known about key components of the C3N system including: data applications, social networking applications and social networking sites for patients and parents, and physicians. How well do they work under the current conditions? What problems have been encountered in implementation of each?

2. Identify needs and expectations of user groups: patients, parents, care providers, researchers. Identify the strengths and weaknesses of current systems and factors that encourage/ discourage participation in the systems that are analogous to C3N components.

   The initial work of the work groups will be to define the list of users to be interviewed and sites to be observed. For example, within the physician user group, we will need to explore the needs of participants from academic and non-academic practices and potentially adult GI practitioners. The C3N should enable participants from a range of practice settings to participate.

   Prior to performing the interviews, the Design Panel will predict what the end users will say about their needs. This process will help to identify where the new information differs from the Design Panels preconceived notions and serve as a way of determining when the interaction design process is revealing new information.

   We will obtain information using four possible formats:
   a. Direct observation
   b. Group interviews/Focus Groups
   c. Personal interviews
   d. Online survey

   Some of this work has been completed by participating organizations. Review of what has already been collected will be undertaken as step number 1 in order to focus additional data collection efforts.

3. Defining measures ("quality characteristics") as a means to describe numerically, the needs identified during the interaction design process. These measures will be used to assess the ability of the C3N system to achieve its purpose and the extent to which design objectives have been met during the testing phase. For researchers, users may say that it should be easy to access de-identified data, identify other researchers with similar interests, communicate asynchronously, and learn about observations being made. For patients, users may say that it is easy to find relevant information about IBD, identify other patients who are experiencing similar problems, that participation involves limited time commitment. For sub-specialty practices, users might say that it is easy to find ideas and strategies for practice changes and seek assistance from peers about how to implement them. The design measures might become empowerment, self-efficacy and knowledge about IBD, number of ideas tested for practice change, and new collaborators for research. Measures will be:
   a. Continuous variables, if possible
   b. Measurable
   c. Sufficient to define quality of the system
   d. Specific enough to guide the design

4. Setting targets for the design measures based on interaction and user-centered research; "What does the user need?" An example of a target is a patient activation score of X.

5. Assess existing current systems within the C3N components such as Patients Like Me, and the Institute for Healthcare Improvement Open School. Compare existing systems to the targets to establish the effectiveness of programs already available.

6. Identifying potential ways that the components of the system can be integrated to achieve the desired outcomes (design measures) and the potential for synergy between components. This may lead to design questions to be tested in the implementation of C3N.

7. Designing the services and processes that are close to the targets under a wide range of conditions. This will lead to a plan for testing specific components of the overall C3N system.

Advisory Panel

An Advisory Panel comprised of systems design experts, parents, patients, and institutional representatives will meet twice a year to review the progress of the initiative and identify issues and themes that need to be addressed. For example, institutional representatives from Cincinnati Children's Hospital will identify legal and privacy issues related to participation in such a system.

Key C3N System Requirements

The program design requirements include:

1. Defining a communication strategy that increases trust and commitment
2. Defining how to best incorporate patient education, self-management and adherence support into the C3N system
3. Defining a plan for sharing data and other resources
4. Reducing transactional costs of network participation and research
5. Defining a strategy for prototype tests involving GI practices, patients, networks
6. Integrating the components and understanding the potential for synergy between the components
7. Development of measures of disease outcome and process
8. Utilizing data from actual patient care
9. Integrating the program into the work that GI physicians (and primary care physicians) do
10. Integrating the network into the day-to-day activities of patients and families
11. Identify links to stakeholder groups (e.g., patients, professional organizations, health care systems)
12. Identifying linkages to learn from other similar sub-specialty research and improvement networks

Final Product

The final product for the Design Phase is the design of the prototype patient-provider C3N and associated testing plans. This work will result in: 1) a framework and design principles for constructing the C3N, 2) specifications for the system as a whole, targets for the performance in each specific area, and measures to be used during the evaluation, 3) new technical and self-management tools, 4) an understanding of the conditions necessary for such a network to grow in membership size, participation and impact and communications strategies to accomplish this, and 5) options for reducing transactional costs related to medical-legal issues of intellectual property and patient privacy.