

## Project Summary/Abstract

### 1. The challenge and potential impact

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 clinical collaborative care network (C3N).

Our C3N is modeled after collaborative innovation networks (COINs),<sup>1,2</sup> cybert 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.<sup>3</sup>

Joining patients (patients and 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. Our proposed C3N challenges 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.

Our **Specific Aim** is to design, prototype, optimize, and evaluate a patient-provider C3N to improve clinical practice, patient self-management, and disease outcomes of pediatric inflammatory bowel disease (IBD). Our **central hypothesis** is that it is possible to design a shared patient-provider C3N by reducing transactional costs and using the COIN framework; that planned experimentation and collective collaboration will result in a C3N that will optimize participation, engagement, and social networking; and that a functional C3N will serve as a structure for facilitating behavior change in clinical care and self-management, dramatically changing the system of chronic illness care and, in turn, improving health outcomes. **Testing this hypothesis is important** because changes *within the current system* are likely to lead to only incremental improvement. Harnessing the nascent power of social networking technology to join patients and providers in a shared collaborative to *create a new system* for clinical and self-management behavior change can transform clinical practice and the way that new clinical knowledge is generated. A successful example of such a network could have vast impact: If we are successful, C3Ns have the potential to transform chronic illness care across the US, saving hundreds of thousands of lives and billions of dollars.

Imagine a 16 year-old girl with IBD on thiopurines, a disease-modifying but potentially toxic therapy, struggling with diet restrictions as she attempts to deal with all the other challenges of adolescence. She logs on to the secure C3N site and uses an intuitive interface to find adolescent patients like her, uses the survey tool to ask how others manage these situations, and develops a close support system with girls from across the US. Imagine a "Yes we can" video for patients – yes we can know our therapeutic drug level, ask for more information, etc – and a video of a model clinical encounter. Parents could push this video to their provider, might even bring a video camera to their next visit, and might post this video, with privacy features, on the C3N. Imagine a family logging on and finding that their physician is not on the network. They identify all the patients seeing this provider and urge them to ask her to join. The physician, confronted with this coordinated campaign, finally does log on and finds classmates from her subspecialty fellowship, other clinicians near her, and practical tips, tools, and videos for improving office systems for chronic care. She also finds her patients online, one of whom is a member of that 16-year-old girl's support system and has missed her last two appointments. And imagine the world's most comprehensive database of de-identified data from children with IBD, easily available to allow academics, clinicians, parents, and patients to generate new knowledge to improve outcomes.

## 2. The Approach

### Overview

Our approach will consist of three phases: 1) design of the C3N, 2) prototyping the C3N and optimizing its function, and 3) evaluation of impact and potential for spread. The first phase will knit together the infrastructure for the C3N and the second phase will result in a functioning C3N. The third phase will describe the way the C3N is used and innovations that arise from the C3N, and will determine how the C3N contributes to the implementation of evidence-based care, the spread of innovations, and change in health outcomes. We will use Rogers's<sup>4</sup> and Bass's theories of the diffusion of innovation in that we will initially engage innovators and early adopters and, when possible, design the innovations so that they are more likely to diffuse. **Our approach differs significantly from current behavioral or health services research** because we are not seeking to implement a particular intervention, but rather to create a system that will develop and spread new innovations in facilitating human behavior change with respect to chronic illness care.

**Phase 1, Design: What are the design characteristics and tools needed for a C3N spanning patients and clinicians; and how can transactional costs of collaboration be reduced or eliminated?** The design phase will apply the COIN framework<sup>1, 5</sup> to the organizational management structure of the C3N. We will use our expertise in systems engineering and patient-centered design to create tools and structures for motivating participation and engagement. This work will be informed by the Chronic Care Model,<sup>3</sup> which posits a care system<sup>6</sup> producing effective interactions between patients and clinicians, resulting in behaviors that improve outcomes. Transactional costs are barriers to collaboration (time, effort, money) arising from issues such as intellectual property, privacy, research ethics, and academic incentives. We will apply principles and tools from the Science Commons to create an ethical/legal framework for enabling C3N participants to share data more freely.<sup>7</sup> This phase will result in a refined model and specific tools to create a working prototype of the C3N.

**Phase 2, Prototype and Optimization: How can the C3N be optimized, as measured by numbers and engagement of participants, and development and use of tools?** We will use targeted outreach based on social networks and iterative, multi-factorial experiments commonly used in systems-engineering<sup>8</sup> to optimize the C3N. We will also engage a broad collaborative of innovators by publishing the Lybba Application Programming Interface (API), allowing third-party and native applications to be developed and shared. By the end of the first two phases, we expect to have a functioning C3N that includes of patients, clinicians, health IT developers, and academics collaborating to improve care and self-management for pediatric IBD.

**Phase 3, Evaluation: How is the C3N used, how does it change the system of care, and what are the effects on behavior change and outcomes?** In this phase, we will describe how participants interact with the C3N and the changes in chronic care delivery resulting from the C3N, and will model the relationship between network characteristics and evidence-based care and adherence and clinical outcomes, after accounting for covariates (e.g., sociodemographics, case mix, practice/provider type, patient severity of illness). By the end of this phase, we expect to have a clear understanding of how and the degree to which a C3N changes the delivery of chronic illness care and clinical outcomes, as well as proof of concept knowledge for expanding C3Ns to other populations and diseases.

### Infrastructure

This project will take advantage of an existing research and improvement network (PIBDNet) and a technology platform designed to support a social network of patients with chronic illness (Lybba). It is important to note that while these two entities currently exist, the proposed project is not merely a continuation of existing research; it represents a discontinuous leap, both methodologically and conceptually. As yet, there has been no attempt to combine these two and there is little, if any, precedent to guide the integration of physicians and patients on a single network. Further, we expect the combination of the two to represent a self-developing system capable of producing a qualitatively-different system of care, as opposed to just incremental change.

IBD is an exemplary condition for a C3N for several reasons. Its low prevalence means that patients are unlikely to have access to a large peer group and that clinicians and researchers must collaborate across treatment centers to accrue sufficient samples for study. IBD affects children in early adolescence, a group especially likely to engage a web-enabled innovation. Finally, there are few financial incentives for the pharmaceutical industry to conduct studies in this group. It is not surprising, therefore, that the outcomes of care have not improved in the last 30 years.<sup>9</sup>

**PIBDNet** (the Pediatric Inflammatory Bowel Disease Network for Research and Improvement; see letter of support) is a well-developed practice network formed with support of the American Board of Pediatrics (ABP)<sup>10</sup> and the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN). PIBDNet's purpose is to enable all pediatric gastroenterologists in the US to collaborate to

improve the care and outcomes of children with IBD. The 15 sites in PIBDNet comprise 5%-10% of the pediatric gastroenterologists in the US and share a comprehensive population-based registry of 2000 of the estimated 100,000 children with IBD. Over a 12-month period, PIBDNet sites have worked together to achieve improvements in care delivery, including diagnosis and disease classification and management of nutrition and growth, and have spread these changes to all practitioners within each site.<sup>11</sup> The network was expanded in July 2008 and new sites have demonstrated a faster rate of improvement compared to original sites, implying that active peer-to-peer communication has been effective in accelerating the pace of change. Although this effort has reduced variations in some care processes, variation in performance and outcomes remains.

**Lybba** (see letter of support) is a California 501(c)(3) non-profit public benefit corporation whose mission is to educate and empower people to lead healthy lives. Recognizing the importance of story telling in motivating health and social change, Lybba was created by Wes Hill, a social anthropologist and writer, and Jesse Dylan, an internationally-acclaimed cinematographer and expert in developing compelling visual and narrative experiences. Dylan's video 'Yes We can'<sup>12</sup> in support of the Obama presidential campaign spread to over 30 million people through YouTube over a several-week period. Most individuals with such skills are found in industries such as entertainment, marketing, and politics; few are devoting their expertise to health care.

Lybba uses advanced social networking, communication and content management to organize patient-relevant content, allowing users to share experiences, opinions, comments, questions. It provides the ability to tag and organize research conducted on the web into a coherent summary that can be easily shared with the physician for informed discussion. Social networking features include blogging, picture/video, secure message, and IM chat, and the ability to incorporate other open-source applications and data collection tools for health and symptom monitoring. It offers the ability to share this information securely with clinicians, expanding the opportunity for more continuous communication. Lybba is currently developing an advanced, semantic search tool that will help patients identify others like them and will help push related content that they may not even know exists onto their screen, increasing awareness and educational opportunities. The Lybba platform was built using open-source technology, primarily the LAMP model - Linux OS, Apache Server, MySQL Server, and Perl, with a specific focus on the creation of a flexible abstract database architecture to allow for easy customization to meet the special content requirements of specific diseases. Lybba is currently open only to a small group of patients and developers, which makes it ideal for prototyping and experimentation.

### **Phase 1, Design: What are the design characteristics and necessary conditions for a C3N?**

**Introduction:** There is evidence that organized networks for care delivery and research, such as the children's oncology group, can advance knowledge and improve the adoption and implementation of evidence, resulting in improved disease outcomes.<sup>13, 14</sup> A network incorporating both patients and clinicians on a shared platform would enable complex interactions among and between patients and physicians, greater access to evidence and expertise at a much more specific level of detail, and new ways for patients to interact with care teams. No such network currently exists. The objective of Phase 1 is to understand the design characteristics, conditions, and tools to optimize the first such combined network.

**Approach:** We will use an iterative approach applicable to creating knowledge in complex systems that draws on our expertise in system design and has been applied successfully in many industries, including medical care.<sup>8, 15</sup> The goal of the design process is to create a framework for a collaborative network involving patients, clinicians and care sites that improves the outcomes of pediatric IBD. The structured design process will take place during three 2-day in-person meetings during Year 1 by patients, providers, and a panel of internationally-recognized experts in complex system design, quality improvement, psychology and adherence, open source intellectual property arrangements, social networks, economics, collaborative and user-driven innovation, communications, and viral marketing. It will include an interpretive component<sup>16</sup> to enable experts from different disciplines to generate ideas for integrating network technology and principles into chronic illness care, as well as an analytic planning phase to develop measures and applications of network-based approaches. It will take place within and across three areas: 1) C3N framework; 2) technical design, including tools and measures; and 3) design for motivation and engagement. When possible, designs for behavior change will be parallel across patient self-management and clinical care.

**C3N framework.** We propose to nurture growth of the C3N by applying the COIN framework,<sup>1</sup> which posits a developmental process based on intrinsically motivated participants, fluid leadership, and progression of members from across different levels of participation. The framework suggests stages of growth from the initial leaders, to creation of a COIN, to learning networks and beyond to users. The strategy is to provide support to develop the network into a growing and supportive ecosystem of learning networks of patients and practices. Design activities will take advantage of existing health care delivery system laboratories that have been

created by the investigators: Cincinnati Children's Chronic Care Innovation Laboratory and pediatric IBD quality initiative, and vanguard sites participating in PIBDNet. These will also form the test bed for the new ideas developed by the COIN, as well as a source of new COIN members. We will also incorporate an Open Science framework, which suggests that transactional costs involved in research and communication (money, time, effort) hamper learning and collaboration. Design activities will, thus, also focus on ways to reduce or eliminate the transactional costs of collaboration, especially in terms of incentives for collaboration for patients, practices and researchers; incentives for early and transparent sharing of findings; and risks of medical liability, privacy and HIPPA, and research ethics and IRB that arise when patients and physicians have greater access to data. For example, Science Commons has developed standard Materials Transfer Agreements (<http://sciencecommons.org/projects/licensing/>) to reduce the transactional costs of sharing physical biological samples and standard agreements that allow owners of intellectual property to share their work (<http://creativecommons.org/licenses/by-nc-sa/3.0/us/>). The power of open innovation to transform entire industries and how we solve complex problems is evident from the impact of the Linux and other open source software. It is also demonstrated by the massive cultural and scientific collaboration enabled by the Creative Commons licenses, which has made an enormous impact on the sharing of Web content, from Wikipedia and Flickr to open access scientific journals. Experts in anthropology, economics, psychology, and law will develop a cultural and ethical framework to enhance trust and commitment to shared goals.

**Technical design: tools and measures.** We will enumerate and prioritize enhancements to existing IT applications, including ways to allow data to be used to guide improvement and promote communication within and across participants (patient to patient, patient to doctor, researcher to researcher). For example, online tools, based on statistical process control methods, could allow individuals to explore data to make comparisons across care sites and to identify sites that are achieving unusually high levels of performance (i.e., successful innovators), convey information to specific individuals based on their disease characteristics (e.g., site of IBD disease, medication), and examine de-identified data from the registry and information about care sites to conduct epidemiologic outcome studies. This phase will also identify measures and analytic applications to describe the evolution of the network in real time using the Condor application to perform dynamic social network analysis (dSNA).<sup>17</sup> Using Condor as a dSNA-based community-health dashboard will permit us to monitor, measure, and optimize progress of the C3N as soon as it is operational. This approach can also identify emergent COINs while they are in the process of being created, at the beginning of phase 2.

Measures of clinical care delivery (for example, diagnosis and disease classification and management of nutrition and growth) exist within PIBDNet. These will be used, with modifications as necessary. We will also develop measures of treatment regimen adherence derived from parent- and self-report estimates of missed doses, self-reported adherence tracking logs, electronic medication container monitoring systems, and pharmacy refill data. These and other measures to be selected will provide a multi-method and dynamic assessment of patient adherence that can be used for research and patient care.

**Design for motivating participation and engagement.** This design process will involve extensive, substantive input from patients and families, as well as clinicians, using methods refined in the Chronic Care Innovation Laboratory. The Lab has expertise in user-centered design, an ethnographic approach<sup>18</sup> rarely used in health care. For example, the group worked with adolescents who used photography and storytelling to inform development of a method to classify adolescents according to their motivational type to better tailor self-management support. We will also apply our expertise in computer usability testing<sup>19</sup> to design elements of the user interface of web-based applications.

The design will focus on using social networking to: 1) facilitate self-management and clinical care behavior change, 2) activate and empower patients, and 3) tailor interventions to improve participation.

The C3N will allow large-scale implementation of proven efficacious interventions to promote behavior change. Beyond this, social networking among patients and providers may allow new behavioral norms and expectations to evolve, opportunities for observational learning, and social and motivational support, all of which could potentiate the effects of behavioral change interventions. The products of this design phase will include educational content (e.g., self-management education); tools for behavioral planning, tracking status and symptoms; and socially-engineered approaches (contests, games) for behavior change.

Patients must be able to communicate across the power differential between clinicians and themselves. We will develop tools to help patients to ask questions about their disease and to motivate physicians to provide evidence-based care. For example, we will develop messages for patients that educate, empower, and activate them to talk to clinicians about what they expect from good chronic illness care (e.g., use of a chronic disease registry to facilitate pre-visit planning) in a way that can motivate clinicians to adopt and implement

such care processes. As well, patients on specific medications could receive information about how to ask questions related to their own specific therapy (e.g., What should we do about my low 6-TGN level? Should I be on a higher dose?). The design phase will result in content and tools for refining and pushing such messages to those needing them (e.g., via social support, blog, videos etc).

To increase physician participation, we will identify current incentives for physician behavior and design ways of maximizing them. We will characterize the social networks among all pediatric IBD physicians (those in PIBDNet and those who are not) to develop tailored outreach interventions and communications. We will map the current social networks of pediatric gastroenterologists using well-tested instruments developed by Burt<sup>20</sup> and analyzed using Pajek1.24.<sup>21</sup> Network partitions by participant characteristics will be generated and specific outreach strategies developed, based on network characteristics.

**Expected Outcomes for Phase 1.** 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 and participation, and 5) options for reducing transactional costs related to medical-legal issues of intellectual property and patient privacy, and lessons for enhancing trust and shared commitment.

**Phase 2, Prototype and optimization: How can the C3N be optimized, as measured by 1) numbers and engagement of participants and 2) development and use of tools?**

**Introduction.** A valid design is a necessary, but not sufficient, basis for a functional C3N. While examples exist for the natural evolution of such COINs, there are certain attributes of a C3N that make it necessary to intentionally and systematically develop its potential. In a C3N, patients and providers will interact in ways they have never done before and some residual transactional costs are likely. As well, while COINs are often made up of technical experts, a C3N will include individuals without technical expertise (both patients and physicians). The objective of phase 2 is to systematically optimize the C3N.

**Approach.** We will use several approaches. We will find the optimal strategy for recruiting new physicians using the results of the social network analysis, information on their individual characteristics, and their structural position within the overall network of pediatric gastroenterologists. Our approach will be a hybrid of targeted recruitment and “word-of-mouth” (WOM) referral marketing strategy in which we use this information to target those physicians who: 1) are most likely to join based on individual characteristics and exposure to peer influence; and 2) have greatest potential to influence non-participants and raise the propensity to join among prospective members in subsequent recruitment waves. Engagement depends on a host of factors, including, for example, frequency of communication from colleagues and friends, the nature of communication (how specific and actionable information is) and the design characteristics of the C3N technical application (e.g., ease of navigation, features of tools available, and user characteristics). To optimize engagement, we will use multi-factorial experiments, a method to study and improve multiple components of a system at once<sup>8</sup> that is common in other industries but has seen limited use in clinical research. For example, an initial experiment to understand the factors of frequency, content, and target of communication might use a  $2^{3-1}$  fractional factorial design to simultaneously test more or less frequent communications of differing content to physicians who are either “high-likelihood responders” or “low-likelihood responders”. Patient recruitment will include tests of “viral marketing” approaches patterned on Jesse Dylan’s previous successful campaigns.

We will test the technical platform prototype by providing access to a limited number of patients, physicians and care teams, and use rapid cycles of feedback to study usability, quality of information content, etc. Once the prototype appears to be successful on a limited basis, we will introduce it more broadly. We will continue to monitor patient engagement and social network characteristics and will further refine the design to maximize engagement using ongoing experimentation. We will use dynamic network analysis methods<sup>22</sup> to study the structural evolution of the C3N and to examine how innovations or interventions may affect the formation of ties among members. This is of particular potential importance given the literature on status differences thought to contribute to disparities in health access and outcomes. Natural patterns of structural evolution may segregate cliques of patients and providers, rather than integrate interactive communities, as we hope to achieve.

We anticipate that innovators (patients and physicians) will identify new ways to use the C3N and will need customization and adaptation tools that might not currently exist. Lybba plans to publish its Application Programming Interface (API) so that third parties, including health IT professionals, can develop applications for the C3N, much like the many applications developed by third parties for the iPhone. The extent to which third-party application developers will be incorporated into the C3N will depend on protocols for ensuring patient privacy. To further optimize development, technical and subject experts operating as a core resource

will interact with users (patients and physicians) to co-develop these tools. For example, if users identified a need to query C3N data in a specific way, the core will work with these users to develop an intuitive interface to allow those with limited quantitative skills to extract the knowledge they need. Open source principles suggest that laboratories, such as PIBDNet sites or the Chronic Care Innovation Laboratory, will make themselves available for prototype testing. We will also approach tool diffusion systematically, using statistical process control methods to identify highly effective tool users (for example, using the care planning tool effectively), qualitative methods to understand how and why they are effective, and the results of the dSNA to push that information to other users throughout the network.

**Expected Outcomes for Phase 2.** This work will result in a functional C3N. We expect to have participation by all PIBDNet practices and the majority of patients within those practices, as well as additional practices and patients from outside PIBDNet. We expect to have a robust collaborative learning network and community of third-party developers. We expect that our systematic approach will result in broad and deep engagement in which clinicians and patients will contribute data, have a means to aggregate collective knowledge, and make explicit the tacit knowledge emerging from innovations about how to change behavior. The C3N will provide an opportunity for patients and caregivers to be privy to collective knowledge from the other end of the examination table. For example, in an open system that includes both patients and providers, patients would be able to query emerging physician trends and access data from multiple health care systems with which they would never have interacted. The ability for patients and providers to learn from and influence one another within one social network system that is structured specifically to support improved outcomes makes previously-untapped knowledge accessible and actionable.

**Phase 3, Evaluation: How is the C3N used, how does it change the system of care, and what are the effects on behavior change and outcomes?**

**Introduction.** Relatively little is known about the ways patients and providers will interact with a C3N, what kinds of changes in the chronic care system this will create, or how these changes will affect behavior change and health outcomes. The objective of phase 3 is to describe the functioning of the C3N, changes to the care system that emerge from the C3N, and its effects on behavior and outcomes.

**Approach:** A key concept is that the C3N is a system for changing the way care is delivered; it provides a means for innovations in behavior change to emerge. This implies that it will not be possible to predict the way the C3N will function nor specific changes in care delivery. It will, however, be possible, using the data-capture tools and building on the open source framework, as well as tools developed by the core resource team, to accurately describe the functioning and effects of the network.

To describe the use of the C3N, we will use both dynamic social network analysis (dSNA) and qualitative methods. Using dSNA, we will describe the social network characteristics (e.g., betweenness centrality, density, contribution index, and degree) of participants (e.g., patient/family, clinician, clinical practice) and of the overall network, over time. We will determine use patterns and the connections among and between individual patients and physicians, and the extent to which these vary by participant characteristics. We will also use case studies to describe examples in greater depth.

To describe changes in the chronic illness system, we will identify patterns of interaction among and between patients and physicians that differ from traditional one-to-one episodic care. Some of these patterns will be described using C3N data, and some will be described using participant surveys. We will be alert to opportunities and instances of policy change (e.g. reimbursement for e-visits; email contact) in the broader marketplace and how these might effect or be affected by the C3N.

To understand the effects of the C3N on behavior and outcomes, we will use methods outlined above to model the relationship between network characteristics and interaction patterns and 1) implementation of evidence-based clinical care and adherence, 2) the uptake of new innovations, and 3) clinical outcomes, after accounting for covariates (e.g., sociodemographics, case mix, practice/provider type, patient severity of illness). Network partitions by clinical performance and patient outcomes will also be constructed to examine whether there are observable clusters of physicians with convergent/similar practice patterns or patient outcomes. We will examine the extent to which physician peer performance predicts a physician's own performance and whether and how patient involvement in the network affects physician patterns of care and their own self-management, through information retrieval and social support.

**Expected Outcomes for Phase 3.** We expect to document that patients and physicians will engage the C3N and each other in novel ways, that new ways of delivering care will emerge and that these patterns of engagement and care innovations will result in improved self-management and clinical care, as well as better outcomes. As well, we expect to have proof-of-concept and knowledge to develop C3Ns in other conditions.

### **3. Appropriateness of the T-R01 mechanism**

The present application proposes the creation of a new network-based approach to chronic illness care, the design and study of which are uniquely suited to the stated goals of the T-R01 initiative. The C3N outlined in this application will challenge the current clinical and scientific paradigms by creating a system that will develop and spread new innovations in facilitating human behavior change with respect to chronic illness care. This is a creative response to a fundamental problem in that the C3N will harness the inherent motivation and collective intelligence of patients and physicians to improve the chronic illness care system. The C3N will promote radical change in the delivery of chronic illness care and its study, but could also impact other scientific areas such as collective intelligence, behavioral science, organizational management, comparative effectiveness, and clinical decision making.

The proposed research is substantially different from the mainstream of health care delivery and behavioral science in several ways. First, while existing disease-specific research networks have been successful in improving care and outcomes and generating new knowledge, these networks often exclude important stakeholders in the process of designing and implementing chronic care research. The proposed C3N is quite different from these in that it is a structure for patient-physician collective collaboration. The C3N responds to the limited access that patients and practicing physicians have in shaping and advancing existing chronic care research by giving them the tools and connections to innovate. Unlike mainstream science, the C3N is user driven and inclusive of individuals regardless of geography (e.g., rural practices can participate), affiliation (e.g., non-academic practices and individuals can participate), or means (i.e., participants can develop research questions and access data without accruing significant transactional costs). Patients and practicing physicians have a voice in designing research questions, which will result in increased innovation, generalizability, speed of dissemination, and impact of findings, and they can participate in generating knowledge and interact on more equal footing with health care providers, which could lead to improved self-efficacy and increased influence on practice and care.

The proposed approach also differs from existing research in its attempt to understand the inherently-complex nature of human behavior and the potential for emergent phenomena in a social network. Unlike traditional research, which often tests specific standardized interventions, the C3N we propose is a system designed to generate multiple innovations to change the delivery of chronic illness care. This is a radical and necessary shift from present chronic care science that is focused on individual interventions and the often-erroneous assumption that behavior change is a linear event. The T-R01 vehicle is the only mechanism that could support the present proposal to develop a network within which to study the complexity of behavior change in patients, physicians, and practices. In addition, no other mechanism exists to assemble the appropriate team for such a task, which will include leading minds from such varied areas as systems engineering, behavioral medicine, collective intelligence, anthropology, the arts, intellectual property, and health services research.

The research proposed here also differs significantly from current approaches to translation of research into practice, which are associated with delays of up to 17 years in moving from efficacy research to effectiveness studies, translation and dissemination into clinical care. Currently-available methods to translate new knowledge into practice are slow, have limited reach and are uni-directional. Our C3N model addresses this problem by providing a system of care that increases the sample size, diversity of sub-groups, and capacity for experimentation to systematically make changes and study their impact. The accelerating pace of discovery in the laboratory and the need to transition to more personalized care will not be possible without more effective and rapid means of influencing the behavior of health care practitioners and patients.

If successful, this C3N model will lead to vast improvements in the collaborative nature of health services research, by including non-academic health care providers and connecting practices and empowering patients to participate in the process. It will bring down boundaries that presently exist in academia by making data collection, aggregation and the generation of new knowledge into an open process. It will also lead to a significant change in the expected speed with which the generation of new knowledge is translated and disseminated into practice.

#### 4. Timeline

Our 3-phased approach is expected to occur over five years. We intend to complete the design phase by the end of the Year 1. At the end of Year 1, we expect to have the framework, design principles, and specifications for the C3N, new technical and self-management tools, an understanding of the conditions necessary for the C3N to grow in size and participation, and ways to reduce the transactional costs related to medico-legal issues of intellectual property and patient privacy, and lessons for enhancing trust and shared commitment.

Prototyping and optimization will be completed in Years 2 and 3. By the end of Year 3, we expect to have a functional C3N, encompassing all or nearly all current PIBDNet practices, the majority of patients in those practices, and a substantial number of practices and patients beyond the original PIBDNet membership. We expect to be able to demonstrate patient and physician engagement, to have designed and deployed additional tools for patients and physicians to interact with the C3N, and to have a functional core resource to continue to develop new tools and capabilities.

Years 4 and 5 will be devoted to the evaluation phase. By the end of Year 4, we expect to have initial results regarding the use of the C3N and to be able to describe changes in the ways that physicians and patients interact. By the end of Year 5, we expect to have published evidence for all of the above and for the links between social network characteristics and behavior change and clinical outcomes.

Given the inherent risks in this highly innovative proposal, we will continually reassess our approaches based on our results. If necessary, we will pursue alternative paths. If, in our design phase, we are unable to reduce or eliminate the transactional costs associated with incentives to participate or medico-legal obstacles, we will design a more limited C3N within the limits we encounter, while simultaneously working to reduce these obstacles. If, in the prototype and optimization phase, we are unable to increase the number and engagement of participants or to develop and deploy additional tools, we will explore other ways of recruiting physicians and patients and developing tools. It should be noted that we will be able to monitor the C3N in real time and will be able to respond quickly to obstacles. It is possible, in the evaluation phase, that we will encounter methodological and analytic obstacles. In some cases, our sample may be biased, in that only participants with certain characteristics will engage with the C3N and provide data. Even if this were so, our project would still be successful as 'proof of concept,' with future research undertaken to explore ways to minimize bias and engage a broader sample of potential participants. As well, there may be differential dropout, in that patients who are more severely ill may be more likely to engage. As they improve, they may drop out of the C3N and their improvement would be censored. We will monitor this phenomenon and, if necessary, use participating practice sites to survey patients who drop out. Additional threats include the potential for the C3N to generate 'bad' advice and for the C3N to exacerbate the digital divide. In both cases, we intend to understand these risks in a controlled environment and develop ways to mitigate these risks.