

Collaborative Chronic Care Networks (C3Ns) to Transform Chronic Illness Care

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KEY WORDS

chronic illness, chronic care network, quality improvement

ABBREVIATIONS

C3N—Collaborative Chronic Care Network

IBD—inflammatory bowel disease

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abstract



Despite significant gains by pediatric collaborative improvement networks, the overall US system of chronic illness care does not work well. A new paradigm is needed: a Collaborative Chronic Care Network (C3N). A C3N is a network-based production system that harnesses the collective intelligence of patients, clinicians, and researchers and distributes the production of knowledge, information, and know-how over large groups of people, dramatically accelerating the discovery process. A C3N is a platform of “operating systems” on which interconnected processes and interventions are designed, tested, and implemented. The social operating system is facilitated by community building, engaging all stakeholders and their expertise, and providing multiple ways to participate. Standard progress measures and a robust information technology infrastructure enable the technical operating system to reduce unwanted variation and adopt advances more rapidly. A structured approach to innovation design provides a scientific operating system or “laboratory” for what works and how to make it work. Data support testing and research on multiple levels: comparative effectiveness research for populations, evaluating care delivery processes at the care center level, and N-of-1 trials and other methods to select the best treatment of individual patient circumstances. Methods to reduce transactional costs to participate include a Federated IRB Model in which centers rely on a protocol approved at 1 central institutional review board and a “commons framework” for organizational copyright and intellectual property concerns. A fully realized C3N represents a discontinuous leap to a self-developing learning health system capable of producing a qualitatively different approach to improving health. *Pediatrics* 2013;131:S219–S223

Pediatric collaborative improvement networks such as described in this supplement have made significant gains in care processes and outcomes for children, moving toward the vision outlined by the Institute of Medicine for learning health care systems.¹ However, the overall system of chronic illness care in the United States typically delivers health services to relatively passive patients in clinician-mediated encounters by using knowledge produced by researchers and clinical experts. Patients do not always receive optimal treatment, and the model does not facilitate patient and family participation in the delivery and improvement of care. Clinicians may have a variety of treatment options from which to choose, but evidence from randomized controlled trials does not always apply, is unavailable, or cannot provide evidence on what will work best for a particular individual. Researchers trying to develop knowledge for and affect specific groups of patients are faced with small, unrepresentative data sets and a lack of easy ways to share data and increase the reach and impact of their research. As noted by Batalden, “every system is perfectly designed to get the results it gets.”² The current chronic care delivery system does not work well. Patients receive 50% of indicated care³ and adhere to 50% of what is recommended.⁴ A new paradigm is needed for chronic care: a Collaborative Chronic Care Network (C3N). This article provides a description of the attributes of a C3N, and of a prototype C3N Project.

COLLABORATIVE CHRONIC CARE NETWORKS

All participants in health care (patients and families, caregivers, clinicians, and researchers) care deeply about improving health. What is missing is a system to harness this motivation and

focus participants’ collective intelligence toward transforming care and outcomes. What if we could harness the collective intelligence of patients, clinicians, and researchers to create such a system? Wikipedia (the Web-based, collaborative encyclopedia project), Linux (the open-source computer software operating system), and the open, rapid sharing of data that occurred in advance of publication in the human genome project are just 3 examples of how the production of knowledge, information, and know-how can be distributed over large groups of people, dramatically accelerating the discovery process. These models are transforming how individuals connect, exchange information, and produce knowledge, enabling previously unimaginably large groups of people to join together to make real their shared vision of the future. These models have rapidly achieved unprecedented innovation and performance, in part because they have built systems that allow inherent motivation of like-minded individuals to flourish through a culture of cooperation.⁴ This form of production has been termed network-based or “social” production.⁵

Network-based production is particularly suited to complex systems such as health care, precisely because the knowledge, skills, and tools necessary to develop and implement real change are often beyond the capacity of 1 place, person, or organization because the stakeholders in the process (in this case, patients, clinicians, and researchers) are motivated and have skills that can be devoted to the task, and finally because the scientific questions about how to accomplish improvements in health and health care require a multidisciplinary complex systems science perspective. A C3N is a network-based production system for health and health care.

A PROTOTYPE C3N

With proper design, leadership, measurement, and engineering, we assert it is possible to create such C3Ns. With support from the National Institute of Diabetes and Digestive and Kidney Diseases⁶ and the Agency for Healthcare Quality and Research,⁷ the C3N Project (<http://c3nproject.org/>) is building the first prototype C3N, working to transform the ImproveCareNow Network of pediatric gastroenterologists⁸ into a C3N in which clinicians, researchers, and patients and families with Crohn’s disease and ulcerative colitis collaborate to improve care and outcomes.

A C3N is not a single intervention. It is a platform, comprising social, scientific, and technical “operating systems” on which to design, test, and implement an array of interconnected processes and interventions to improve health, care, and appropriate use of resources. In the subsections that follow, we describe each of the 3 operating systems, with illustrations from the main activities being undertaken in the C3N Project to accomplish each goal.

BUILDING COMMUNITY: THE SOCIAL OPERATING SYSTEM

Networks are social constructs. Issues of governance, communication, decision-making, and standardization are much harder than the technical problems, and if the social processes do not work, all else is for naught. Developing an effective social operating system for a C3N involves a number of cultural shifts: viewing health care as shared work, not as a transaction or commodity; seeking out and using all stakeholders’ expertise; creating a sense of solidarity; and promoting the idea that individuals can make a difference. Health reform efforts have focused on pushing change via payment and regulation. Aligning

patient, clinician, and researcher motivations and increasing expectations for performance deliberately stimulates a pull for solutions.

Building community starts with communicating a compelling vision; for the C3N Project, it is improving the health of all patients affected by a chronic illness. The project's core leadership team of patients, clinicians, and researchers share responsibility for defining this vision and purpose, communicating it, and creating strategies for implementation. Sharing stories is a powerful way to motivate action. A short film about ImproveCareNow's work was created by renowned filmmaker Jesse Dylan, and a diverse group of participants, supporters, and collaborators (including ImproveCareNow clinicians and staff, patients and family members, researchers, quality improvement experts, and health care innovators) post their personal stories regularly on LOOP, the official blog of ImproveCareNow (<http://improvecarenowblog.org/>).

The C3N Project is also learning to use distributed leadership principles to engage and connect all its stakeholder groups and align the participants' self-interest and goals while recognizing their diverse motivations for cooperative behavior (eg, personal fulfillment, recognition, financial rewards).⁹ Last year, a team of patients, clinicians, and researchers completed a community organizing course given by Marshall Ganz, an organizer from Cesar Chavez's United Farm Workers movement. Because small, local communities are also important to the social functioning of network-based production systems, they are now using this training to develop prototype distributed leadership teams at a number of ImproveCareNow care centers.

Additional efforts to engage patients and families in the transformation of

ImproveCareNow to a realized C3N have included the development of both a Patient and a Family Advisory Council, efforts to embed a patient or family representative on each ImproveCareNow care center's quality improvement team, and a peer-mentoring program to link more-experienced to less-experienced patients. Finally, the C3N Project is deliberately providing multiple ways that patients, families, clinicians, and researchers can contribute. "Chunking" the work into small components and distributing it among a large community of people willing to offer their talents allows those with limited time to contribute.⁵

DEVELOPING A TECHNICAL OPERATING SYSTEM TO INTEGRATE DATA

Information technology infrastructure barriers to efficient and timely data collection, entry, and reporting are an example of technical challenges that limit the use of data in collaborative improvement networks. The monthly ImproveCareNow Network performance reports have been automated to accelerate the quality improvement process. Cooperation among clinicians has resulted in agreement on standard measures of process and outcomes and transparent performance metrics across participating clinical centers. This action enables a community of peers to engage in continuous peer review and learn from variation, so that advances can be spotted and adopted more rapidly. The resulting standardization of care processes reduces unwarranted variation in care delivery, improving clinical outcomes¹⁰ and increasing the signal-to-noise ratio for more efficient research.

Medical record data in the ImproveCareNow registry had been handled 3 times: during the clinical encounter; when the data are viewed in or printed from the electronic health record and

abstracted onto a data collection form; and finally when re-entered into an online clinical registry. With the Agency for Healthcare Quality and Research funding, we are leveraging an open source data warehouse called i2b2¹¹ to build a "data in once" system that will draw data directly from the electronic health record to the registry. The resulting "enhanced" registry will allow automation of effective chronic care processes (eg, previsit planning for the clinic encounter), population management, and patient activation activities (eg, previsit prompts to stimulate them to come with questions about their concerns).

Inclusion of patient-reported outcomes is a national research priority of the Patient-Centered Research Outcomes Institute.¹² Passive patient-reported outcomes, such as data collected from a mobile phone app that passively monitors the number of phone calls and text messages per day, as well as the user's global positioning system location, may allow study of outcomes that are important to patients while reducing data collection burden. ImproveCareNow clinicians and collaborators are testing data gathering through the phone coupled with automated user surveys administered by e-mail or text message to see if an app could help adolescent patients predict flares of their IBD and eventually avert future symptoms.

ENABLING LEARNING, INNOVATION AND DISCOVERY: THE SCIENTIFIC OPERATING SYSTEM

Improving the health system requires a laboratory for discovery not only for what works but also how to make it work. A C3N enables a structured approach to the design, development, and experimental testing of innovations in care delivery. Data collected at the point of care and aggregated from the individual to the population can support

TABLE 1 Matrix of Chronic Care Processes Being Tested in the ImproveCareNow Factorial Study

Enrollment and Data Quality	Previsit Planning	Population Management	Self-Management Support	No. of Care Centers
+	–	–	–	3
+	+	–	–	5
+	–	+	–	4
+	–	–	+	2
+	+	–	+	4
+	–	+	+	3
+	+	+	–	6
+	+	+	+	3

+ connotes care centers working on that chronic care process.

testing and research on multiple levels: comparative effectiveness research at a population-wide level, evaluation of care delivery systems and processes at the care center level, and N-of-1 trials and other methods for patients and their clinicians to select the best treatment of individual patient circumstances.

At the population level, the ImproveCareNow Network is using data from its registry to compare the effectiveness of alternative treatment strategies for pediatric patients with Crohn's disease, with a special focus on the timing of biologic agents. Thirty-six of the participating care centers are participating in a factorial study to test the effect of multiple care delivery options on IBD remission rates, with each center allocated to 1 of 8 combinations of chronic care delivery processes (Table 1).

Several ImproveCareNow care centers are also prototyping a model for conducting N-of-1 trials, experiments designed jointly by a patient and clinician to determine how that individual patient responds to specific treatments or interventions. In 1 case, a college student with ulcerative colitis regularly

ate large quantities of granola bars, believing they helped control her symptoms. Together with her gastroenterologist, they devised a minitrial in which she tracked nocturnal awakening for stooling, determining that the granola was not effective. Together, they are now studying the effect of adding an antibiotic medication to her treatment regimen.

POLICY IMPLICATIONS

A number of policy and organizational constraints impose potentially significant transactional costs of time, money, and effort that can hinder the ability of individuals or care centers to participate in a C3N. The C3N Project is testing new approaches to mitigate these costs. Review for research and ethics considerations has typically been undertaken by each individual practice site participating in a network. ImproveCareNow has implemented a Federated IRB Model, so that participating care centers can rely on a protocol approved at 1 central institutional review board. This method is consistent with proposals for more effective application of the Common Rule.¹³

Over time, participants in a C3N may develop enhanced trust in each another and a commitment to shared goals, fostering sharing of knowledge and data. However, academic norms (such as the need to publish for career advancement) and organizational copyright and intellectual property concerns may limit even desired knowledge sharing. The C3N Project is developing a “commons framework” to make sharing systematic, strategic, safe, and informed. Standard agreements are being developed that allow owners of intellectual property to share their work. These tilt toward nonexclusive broad licenses as a default, with an opportunity to opt out when there is an invention, tool, or other knowledge product of high value that needs exclusive licensing. Finally, data sharing is facilitated through the creation of federated databases in which data are housed at the participating institutions and queried to create de-identified data sets.

CONCLUSIONS

A C3N has the potential to become an active, collaborative innovation network in which patients, families, clinicians, and researchers collaborate semi-autonomously on a broad range of innovations. Fully realized, a C3N comprises a platform upon which improvement, innovation, and discovery can occur. The C3N model thus represents a discontinuous leap, methodologically and conceptually, to a self-developing learning health system capable of producing a qualitatively different approach to improving health, care, and costs.

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