Collaborative Chronic Care Network (C3N)

USA

Elina Farmanova, PhD (candidate)
Former Improvement Lead
Canadian Foundation for Healthcare Improvement
Ottawa, ON

Maria Judd, BScPT, MSc
Senior Director
Canadian Foundation for Healthcare Improvement
Ottawa, ON

Peter Margolis, MD, PhD
Co-Principal Investigator
Collaborative Chronic Care Network
Cincinnati, OH

Justin Vandergrift, BA
Co-Lead, Strategy Council, ImproveCareNow
President, Chadwick Investment Group
President, Empowered by Kids
Charlotte, NC

Michael Seid, PhD
Co-Principal Investigator
Collaborative Chronic Care Network
Cincinnati, OH

Background

Described as a platform for bringing together patients, clinicians and researchers to work together to co-design better ways to manage health and healthcare, the Collaborative Chronic Care Network (C3N) Project is a prototype of the Institute of Medicine's (IOM) (Fore et al. 2013) vision of a learning health system for chronic care management based on a collaborative, actor-oriented architecture (Authors 2015). Dr. Peter Margolis, one of the C3N Project's leading physicians and co-principal investigator, played a key part in its creation. In his words, "The C3N concept grew out of the realization that the system for chronic illness care wasn't working – for patients who were suffering more than they had to, for parents who weren't able to participate as part of the care team, for physicians who practised based on limited clinical trial data [and] for researchers who wanted to make a difference but needed access to data" (C3N 2013).

Funded by a grant from the National Institutes of Health in the US, the C3N Project was established in 2010 and has become an innovation lab that transforms the system of chronic illness care for children and their families via improved communication, extensive information systems and sound experimentation. The C3N Project focuses on innovative approaches to the social, technical and scientific components of its architecture. The social component is facilitated by community building, engaging all stakeholders and their expertise, and by providing multiple ways to participate and contribute (Margolis et al. 2012). Information technology infrastructure facilitates data capture and knowledge sharing aimed at generating the data needed to reduce unwanted variation in care and to adopt advances more rapidly. A structured approach to innovation design provides a scientific component or "laboratory" for testing innovative approaches to care.

The C3N Project is housed within Cincinnati Children's Hospital Medical Center in Cincinnati, Ohio, and has focused on transforming care for children with Crohn's disease and ulcerative colitis (also known as inflammatory bowel disease [IBD]). (See the Cincinnati Children's case study in this collection; p. 57.) Using quality improvement (QI) methodology and tools, the C3N Project has been working with multiple industry partners – notably, the Massachusetts Institute of Technology; the University of California, Los Angeles; and the ImproveCareNow Network for IBD – to create patient and parent workgroups, develop apps and technologies and create a community through interactions and social media across 86 national care centres, more than 500 gastroenterologists and about 40–50% of all IBD patients and their parents in the US. According to Justin Vandergrift, a volunteer and a parent co-lead with the C3N Project, "the C3N represents healthcare that is looking to reach out to the consumer … and is creating faster and better [healthcare], at a reduced cost."

The IBD network is growing beyond the US (currently expanding to the UK), and a C3N Project for cystic fibrosis is in development. According to the physician leaders, creators of the C3N Project and parents involved in the network, the C3N Project model can be adopted to improve the delivery of care and self-management of other chronic diseases and patient groups.

Patient Engagement

The unique feature of the C3N Project is its emphasis on creating a large-scale "wrap around" network of care that connects patients, parents, caregivers, clinicians and researchers to partner and co-design improvements. Patient Engagement/Community is one of four C3N Project innovation clusters (the others are QI Chronic Illness and Care Support; Registry Development and Sustainability; and Patient Self-Tracking/ Continuous Care) (C3N n.d. a). It incorporates eight C3N Project innovations: Emma App, E^3 Healthcare Study, IBD Volunteers, Building Community Leadership, Patient Advisory Council (PAC), Self-Management Support, YouMeIBD and Communications (C3N n.d. b). These innovations – from mobile apps to portable medical records, from community events to educational strategies – connect patients and parents with others like them and the larger care team. Overall, Patient Engagement/Community improves learning through the collaboration of teams beyond traditional meetings and enables an increased exchange of ideas and QI.

With respect to the organizational strategies fostering greater and more meaningful patient engagement, the PAC, the Parent Working Group and an electronic health records (EHR)-linked enhanced registry (ICN2), are of particular interest. The PAC for IBD grew out of the C3N Project's design process. Its purpose is to help sick children move into remission. The PAC includes diverse patients with IBD from across the US and offers a variety of levels of engagement. The commitment level is up to each member; every patient contributes as much or as little as they want. Among the many activities in which they engage, patients provide insight to research studies; contribute meaningfully to the development of C3N Project innovations; gain valuable experience interacting with clinicians, researchers and other health professionals; and share experiences through social media and blogging.

The national Parent Working Group works with parents to provide support and assure best possible care for sick children at home. Like the PAC, the group includes parents of patients with IBD from across the US and offers a variety of levels of engagement. Every parent contributes as much or as little as they want. The group is the place to share, spread and build on others' successes. Parents contribute to the care process by improving the availability and quality of health information circulated within and beyond the network.

The ICN2 Enhanced Registry provides a large scale model of linking and sharing EHR data for chronic diseases. The registry captures data directly from EHRs using a "data-in-once" process that records clinical data during a patient encounter (C3N n.d. a). Data are collected during routine clinical workflows and can be accessed and shared among multiple users. These data are reused for multiple purposes, such as pre-visit planning, QI and research. Because data are available instantly, variations in care delivery are picked up without delay and each child can receive optimal care based on the best available evidence at every visit. The registry enables the one-time collection of data used to improve clinical chronic illness care delivery, drive QI and inform comparative effectiveness research. It eliminates the need to collect data by chart abstraction and double data entry, thus increasing efficiency and reducing costs.

Key Strategies to Support Patient Engagement

The C3N Project's patient engagement strategy is anchored in valuing the patient voice and experience and understanding the importance of collaboration. Pediatric patients and their parents are the co-designers of care, involved in every step of the process, from consultations to partnerships and shared leadership. In this way, patients, providers and researchers are involved in co-designing healthcare services, a fundamental design principle ensuring appropriateness and value to patients and optimum cost to the health system (Batalden et al. 2015). C3N Project physician leaders attribute much of the project's success to the patient engagement strategy and the following key actions:

- **Developing organizational structures that support patient engagement.** The C3N Project developed both a national PAC and a national Parent Working Group, which matched patients with innovation teams and parents with ImproveCareNow QI teams. The structures were embedded in an organizational chart and included a job description.
- **Creating a horizontal leadership structure across the organization.** As Sami Kennedy, a C3N Project PAC member, noted, in the network "patients aren't below any clinician or researcher, or parent" (C3N n.d. c).
- **Building partnerships.** Patients volunteer their feedback and participate as team members alongside clinicians and researchers. At the same time, the C3N Project builds partnerships with other organizations, such as ImproveCareNow, universities, innovative companies and others, to support the large-scale network and services offered to patients and their families.
- **Applying a network-based approach.** Patients can share their stories through the network, test new ideas and/or contribute their data.
- **Providing tools to support patient engagement in direct care.** The C3N Project offers a wide range of supports for patients – from mobile apps to portable medical records – to enable effective self-management of IBD and other chronic conditions.

Impact

In only five years, the C3N Project developed and tested more than 20 innovations. Below are examples of the project's accomplishments to date:

- Developed both a national PAC and a national Parent Working Group, and is also in the process of implementing distributed leadership teams that match patients with innovation teams and parents with ImproveCareNow QI teams

- Developed a Facebook application that matches children who have IBD with other patients who have the condition, based on similar interests
- Pilot testing multiple self-management support tools at ImproveCareNow care centres
- Using smartphones to collect data passively
- Designing *N*-of-1 trials (a single case study) and developing a multi-user web platform to manage these experiments

Early evaluation results are positive. They show that the C3N Project's goal-directed design can influence patients' behaviours to meet treatment goals by supporting them with online and in-person healthcare interventions that are aligned with their motivations (Fore et al. 2013). In addition, the C3N Project appears to complement QI methods by combining clinical and research aims with the goals of disease management. Simplified treatment regimens developed as part of the project have led to improved medication adherence and a reduction in medication dosages. Personalized learning systems and social support show promising improvements in increased patient satisfaction, overall happiness and remission level (the latter has risen from 55% to 77%) (C3N n.d. d).

Summary

The C3N Project is a network-based co-design system that harnesses the collective intelligence of patients, parents, clinicians and researchers. It distributes knowledge, information and innovations across the network and beyond, dramatically accelerating the discovery and application process. The project is an example of an innovative initiative that improves patient experience, encourages patient and family engagement and enhances patient-centredness. Leveraging goal-oriented network architecture, co-design and the effective use of technology, the C3N Project enables patients to engage in and direct their care, while also improving the healthcare system via improved policies, structures and processes at the organizational level.

This case study was researched and written in 2014 and 2015 as part of research commissioned by the Federal Advisory Panel for Healthcare Innovation to inform their report: *Unleashing Innovation: Excellent Healthcare for Canada* (http://www.healthycanadians.gc.ca/publications/health-system-systeme-sante/report-healthcare-innovation-rapport-soins/index-eng.php).

References

Authors. 2015. "Health Care System Architecture: A Value Creation Perspective." *California Management Review* (Under revision).

Batalden, M., P. Batalden, P. Margolis, M. Seid, G. Armstrong, L. Opipari-Arrigan and H. Hartung. 2015. "Coproduction of Healthcare Service." *BMJ Quality & Safety* doi:10.1136/bmjqs-2015-004315. Retrieved April 10, 2016. <http://qualitysafety.bmj.com/content/early/2015/09/16/bmjqs-2015-004315.full>.

Collaborative Chronic Care Network (C3N). n.d. a. “Innovations.” Retrieved February 20, 2015. <http://c3nproject.org/innovations>.

Collaborative Chronic Care Network (C3N). n.d. b. “Patient Engagement/Community.” Retrieved February 25, 2015. <http://c3nproject.org/innovations/patient-engagement-community>.

Collaborative Chronic Care Network (C3N). n.d. c. “Patients as Co-Designers.” Retrieved February 25, 2015. <http://c3nproject.org/patients>.

Collaborative Chronic Care Network (C3N). n.d. d. “The C3N Project | A Year Since Inventing Breakthroughs Day.” Retrieved March 8, 2016. <https://www.youtube.com/watch?v=mn613fIB00I>.

Collaborative Chronic Care Network (C3N). 2013. *What Is the C3N?* Retrieved June 14, 2016. <http://c3nproject.org/sites/bmidrupal7pc3n.chmcres.cchmc.org/files/documents/C3N%20Press%20Kit_20130926.pdf>.

Fore, D., L.M. Goldenhar, P.A. Margolis and M. Seid. 2013. “Using Goal-Directed Design to Create a Novel System for Improving Chronic Illness Care.” *JMIR Research Protocols* 2(3): e43. Retrieved March 8, 2016. <http://www.researchprotocols.org/2013/2/e43/>.

Margolis, P., L.E. Peterson and S.E. Seid. 2012. “Collaborative Chronic Care Networks (C3Ns) to Transform Chronic Illness Care.” *JAMA Pediatrics* 131(Suppl 4): S219–23. doi:peds.2012-3786J.