# WHAT IS THE ○ C3N

The **Collaborative Chronic Care Network**  grew out of a realization that the system for chronic illness care isn't really working: It's *not* working for patients who suffer more than they have to, it's *not* working for their parents who aren't able to participate in their care as part of the care team, it's *not* working for their doctors who practice based on minimized clinical trials that unfortunately can't tell us what is best for individual patients, and it's *not* working for researchers who are interested in making a difference but needed access to data and organized systems.  The  C3N Project, as it's more informally known, has the potential to transform care of chronic disease, which includes saving lives and doing so in a cost-effective way.

## Foundation for the Future

The C3N Project is working to lay the foundation for a new kind of chronic illness healthcare system, that encourages the buy-in and active participation of people around the world.  Since our beginning in January 2010, the C3N Project has:

- Assembled a diverse team of experts from medicine, public health, psychology, computer science, film, design, law, sociology, communications & economics
- Built up a dynamic group of patients, who volunteer their time as team members on C3N innovations
- Created an initial innovation network of more than 100 patients, clinicians & researchers—all contributing actively to the C3N for IBD as co-designers
- Designed & put into prototype testing 20 innovations
- Won a $12 million grant from the U.S. Agency for Healthcare Research and Quality to build the data & informatics infrastructure for the C3N data network
- Put into practice policies for overcoming barriers, such as intellectual property, data sharing and privacy and medicolegal liability
- Designed the architecture and specifications for the communication and technology platform necessary for patients, families, clinicians and researchers to collaborate
- Partner with many organizations, including MIT & ImproveCareNow: c3nproject.org/people

### CONTACT

| Customer Service | Principal Investigators |
| --- | --- |
| *Molly McKean* | *Peter Margolis, MD, PhD* |
| press@c3nproject.org | *Michael Seid, PhD* |

## Funding & Location

The C3N Project is funded by a Transformative R01 (TR01) grant awarded by the National Institute of Health.  For the official summary please visit  http://c3nproject.org/about.

The C3N Project is housed at the James M. Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital Medical Center.

## Recent Press & Contact

The C3N Project has had the privilege to be represented in a variety of publications, some of which include:

- **The Wall Street Journal: "**Heart Gadgets Test Privacy-Law Limits" (*Published November 28, 2012*)
- **The Huffington Post:** "The Good Doctor" (*Posted November 9, 2012*)
- **The New York Times:** "Apps Alert the Doctor When Trouble Looms" (*Published October 8, 2012*)
- **The Cincinnati Enquirer:** "Children's Research Could Save Your Life" (Published August 10, 2012)
- **The Wall Street Journal:** "Patients as Partners" (*Published April 16, 2012*)
- **BusinessWeek**: "The Nurse in Your Pocket" (Published January 5, 2012)

**Want to interview us?** *please allow 2 business days*
**Contact** press@c3nproject.org

# FREQUENTLY ASKED QUESTIONS

## Who is actually using the C3N?

The C3N is working with ImproveCareNow—an established, effective results-oriented network that is implementing quality improvement (QI) methodology and tools across a clinical setting in over 52 care centers, and with 450 gastroenterologists and 15,600 IBD patients. The clinicians of ImproveCareNow are currently testing C3N innovations at their care centers, and with their own patients.

## What is ImproveCareNow?

The ImproveCareNow Network is an established network of gastroenterological care centers and professionals nationwide, specializing in pediatric Crohn's disease and ulcerative colitis. They work to get more kids into remission and feeling better, today: www.improvecarenow.org

## Is the C3N model being used for any other disease or conditions? Do you plan to expand the focus?

The C3N model is not being tested in any other diseases or conditions, currently. However, we intend for the C3N to be a model that we will spread to other chronic conditions, like CF.

## I would love to see a C3N in a *specific population/disease*—how does one get started?

We are currently in the second phase of the project, which involves testing a patient-provider C3N to improve clinical practice, self-management and disease outcomes of pediatric IBD. By the end of the third phase—the implementation—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. We will also have proof of concept knowledge for expanding C3N to other populations and diseases, again like CF.

**C3N** http://c3nproject.org

## What results/outcomes have you achieved?

The C3N Project has engaged in developing and testing over 20 innovations. Here's some examples of what has been accomplished so far:
- Developed both a Patient Advisory Council and a Parent Working Group, which has matched patients with innovation teams and parents with ImproveCareNow QI teams
- Partnered on the development of an in-clinic iPad game, currently being tested at Oklahoma University and Mayo Clinic
- Developed a Facebook application that matches kids with other patients with IBD based on similar interests
- Pilot testing at ImproveCareNow care centers for self management support tools, as part of a large-scale factorial study
- Using smartphones to passively collect data
- Designing N-of-1 trials, and developing a multi-user web platform to manage these experiments

## How can I learn more?

The C3N Project hosts quarterly webcast, where we feature key collaborators and the innovations they are work with us on. During this live, virtual events, attendees will have an opportunity to speak directly with our Principal Investigators and with the collaborators. Webcast information will be posted to our web site, and promoted through our social media.

## How can I participate in this research?

Contact us at research@c3nproject.org and please include your CV, specific research interests and effort you could contribute. We encourage all to attend a webcast first, to learn more and get a few questions answered directly by our lead experts. After you participate in the webcast and/or contact us, a member of the project will follow up with you accordingly.

# GLOSSARY

C3N | Collaborative Chronic Care Network, an innovation lab where patients, clinicians and researchers work together as co-designers that aims to transform the health system of chronic illness care for IBD

ICN | ImproveCareNow, an nationwide network improving the care and outcomes for kids and adolescents with Crohn's disease and ulcerative colitis [http://www.improvecarenow.org]

ER | Enhanced Registry, is a grant designed to focus on: learning as a collaboration among patients, clinicians and researchers; advancing health-related data about individuals and populations; and a governance model that promotes diverse leadership.  ER  can be viewed more simply as the data that C3N disseminates—it's modular, versatile and scalable, and converts the data into smart information that is useful and actionable

CCHMC | Cincinnati Children's Hospital Medical Center, home to the James M. Anderson Center for Health Systems Excellence where C3N is located [http://cincinnatichildrens.org]

BMI | Biomedical Informatics, a research division at Cincinnati Children's where the Enhanced Registry is housed and managed

i2b2 | Informatics for Integrating Biology & the Bedside, an NIH-supported National Center for Biomedical Computing that is developing a scalable informatics framework designed for translation research [https://i2b2.cchmc.org]

EMR | Electronic Medical Record, linked to i2b2 data warehouse

TR01 | Transformative Research Award, was specifically created to support exceptionally innovation high risk, original and/or unconventional research projects that have potential to create or overturn fundamental paradigms [http://commonfund.nih.gov/TRA/index.aspx]

Federated IRB | An initiative towards centralized review to maintain standards and remove duplicative effort

Innovation | A project or program designed, prototyped, piloted and implemented by the C3N Project

COINs | Collaborative Innovation Networks from the interaction of like-minded, self-motivated individuals who share the same vision [http://www.ickn.org/innovation.html]

Learning Health System | Patients & providers  work together to choose care based on best evidence, drive discovery as natural outgrowth of patient care, ensure innovation, quality, safety and value—all in real time

PAC | Patient Advisory council, a group of patients supported by ImproveCareNow and the C3N Project

***Didn't find what you're looking for? Email us at info@c3nproject.org.***