

Open innovation networks are one key to improved care

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Fostering innovation to speed the improvement of health care is the goal of an \$8.3 million grant to researchers at Cincinnati Children's Hospital Medical Center.

"The system of providing care for the chronically ill is broken," says Peter Margolis, MD, PhD, co-Principal Investigator of the project.

"What we aim to do, building on our previous successes, is to create a totally new system of providing care through widespread collaboration."

This ambitious undertaking, dubbed a "collaborative clinical care network," is modeled after collaborative innovation networks, cyberteams 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 greater potential, with Wikipedia, Linux, and the World Wide Web Consortium itself prominent examples.

Collaborative innovation networks are, however, new to chronic illness care. 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.

"Everyone wants better health for kids, and everyone involved has stories about road blocks to better care," said Michael Seid, PhD, the other co-PI on the project funded by the National Institutes of Health. "We aim to harness doctors,' nurses,' and patients' inherent motivation to improve and the collective intelligence represented by all parties."

"We are building a way to bring patients and providers together and give them the tools they need to collaborate to improve care and outcomes."

The \$8.3 million grant from the National Institutes of Health is part of \$348 million awarded Sept. 24, 2009 to "encourage investigators to explore bold ideas that have the potential to catapult fields forward and speed the translation of research into improved health," according to the NIH.

"Although all ... programs encourage new approaches to tough research problems, the appeal of ... (these) programs is that investigators are encouraged to define the challenges to be addressed and to think out of the box while being given substantial resources to test their ideas," said NIH Director Francis S. Collins, MD, PhD.

Collaborating with the Cincinnati Children's researchers are doctors and hospitals from ImproveCareNow, a collaborative improvement network focusing on Crohn's disease and ulcerative colitis, as well researchers at the University of Chicago, the University of California - Los Angeles, University of Vermont, Massachusetts Institute of Technology, Science Commons, Lybba and Ursa Logic Corporation.

The research will focus on Crohn's disease and ulcerative colitis, which affect about 100,000 young people in the United States.

These were chosen because they have so much to gain from the collaborative: rare enough that patients do not have access to a large peer

group and clinicians must collaborate across treatment centers to achieve the numbers they require for study; they primarily affect children in early adolescence, a perfect age to engage in Web-enabled innovation; and because they are uncommon, there are few financial incentives for the pharmaceutical industry to conduct studies with the group.

Success already seen

Margolis and Seid already have achieved strong initial success through their involvement in the ImproveCareNow network. ImproveCareNow is one example of a highly successful collaborative network.

ImproveCareNow, which focuses on Crohn's disease and ulcerative colitis, is a collaboration of 16 hospitals across the country and about 2,500 patients. Using a model for systematically collecting data and sharing it openly, care has improved quickly and doctors have seen a dramatic, rapid increase in the number of patients in remission.

Translate the success to the entire population and it means 10,000 new children in remission, without new drugs and without spending huge amounts of money (and lots of time) on research and development, according to the researchers.

Networked collaboration offers opportunities for patients and care providers to share their experiences, but these stories will be complemented by real data on care and outcomes. The researchers say combining and sites' performance data will allow providers and patients to see not only what others are doing, but how care is improving.

"Right now, it is painfully slow to get medical information and new discoveries into practice," said Margolis. The reason, he says, is because doctors and patients may operate in virtual silos which hide their information. Networked collaboration allows participants to share more

easily so that others can see, learn, and get healthier.

Social media infrastructure

The new research will take advantage of a social media platform being developed by Lybba, a California-based non-profit whose mission is to educate and empower people to lead healthy lives. Lybba is headed by Jesse Dylan, a cinematographer who created, among other things, the "Yes We Can" video in support of Barack Obama that was seen by 30 million people through YouTube in just a few weeks during the 2008 presidential campaign.

Lybba uses social media to allow users to share experiences, opinions, comments and questions. The networking will include blogging, photography, video, secure messaging and instant messaging.

Social networks are not new to health care populations. Today, many support groups for patients and/or parents exist on the Internet. But this will not be simply peer-to-peer networking as exists now. (Previous research by Cincinnati Children's examined potential problems of teens sharing health information, or misinformation, among themselves.) Health care professionals will be a part of the process, and the solution.

Participation and privacy are concerns

It will not be easy. The researchers know one of the stumbling blocks likely will be ensuring participation by already-busy doctors. During the design phase, they will study ways to encourage doctors to become more engaged with their patients and with fellow physicians. They hope parents and patients will encourage doctors to get involved, and by connecting colleagues, doctors will view the social networks as a means to collaborate and improve the care they are naturally motivated to

provide.

Another issue for the researchers to address is patient confidentiality and federal privacy laws. The software platform on which the network will operate will be designed to protect privacy and confidentiality, but also allow and encourage the sharing of information.

Part of NIH's bold initiative for transformative research

The Cincinnati Children's researchers are especially excited about receiving the grant from a special NIH fund set aside for highly creative and highly innovative projects. The so-called "transformative RO1 grants" are for projects "proposing exceptionally innovative, high-risk, original and/or unconventional research with the potential to create or overturn fundamental paradigms," according to the NIH.

The five-year grant will also allow testing of ways to make care more continuous, communication more seamless, and to enhance patients' and families' ability to perform necessary self-care for the conditions.

Another advantage of the social networks is that it will improve the relationship between the doctors and patients. Today, there is not a lot of time for pre-visit preparation. Often a doctor glances at a chart just seconds before walking into a patient's room. The patient may be feeling better at that point in time and not mention some previous episodes that might help the doctor provide better care.

"The networks will help us move toward more continuous interactions with patients," Margolis said. "It will improve communication. It will improve relationships and it will improve care."

He and his partners at centers across the country know their vision is a bold one.

"This is radically different from what we have done in the past," Seid said. "We are not trying to make one change at a time; we are creating a system that makes it possible for [patients](#) and doctors to make many changes - quickly and efficiently - to improve health. This has the potential to change the way all chronic care is provided."

Source: Cincinnati Children's [Hospital](#) Medical Center ([news](#) : [web](#))

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