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Patients as Partners

An online network for sufferers of inflammatory bowel disease provides some clues to the power of collaboration

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By [AMY DOCKSER MARCUS](#)

Doctors around the country have enlisted some new helpers in the fight against chronic disease—their patients.

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A few years ago, a far-flung group of pediatric gastroenterologists set up an online network where they could share data and treatment strategies for children and adolescents with inflammatory bowel disease, in hopes of improving outcomes. It worked—up to a point. The remission rate jumped to 75% from 50% at some of the centers, but then hit a ceiling.

Some of the doctors raised a provocative question: Could they get even better results by bringing patients and parents into the effort?

Patients would experiment with new treatments and closely monitor how the regimens affected them day to day, then feed the data into the online network through computers or smartphones for doctors to examine. The patients could also use the network for things like social support, finding other patients who shared similar interests or lived near them.



Fabrizio Costantini for The Wall Street Journal

WORKING TOGETHER Emily Brandt and her doctor, Jeremy Adler, meet every two weeks to assess her health and sometimes adjust her treatment.

"We were very focused on improving outcomes, but we were doing it without the families," says Richard B. Colletti of the University of Vermont College of Medicine, director of the doctor-founded network. "Until parents and patients are true partners, you can't get the best outcomes."

A Work in Progress

The new project, called the Collaborative Chronic Care Network, currently includes

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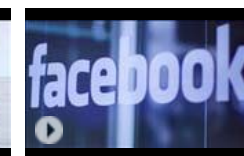
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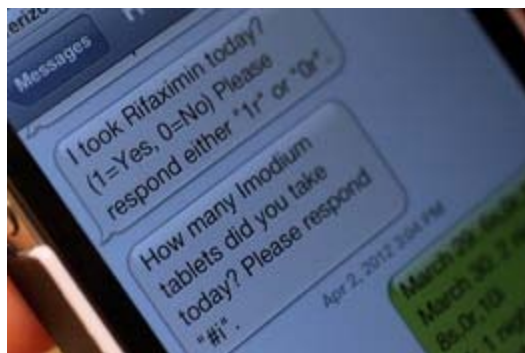
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33 participating centers testing 22

different projects. The registry has enrolled 6,800 patients, and organizers expect the number to reach 10,000 by the end of the year.

It's still a work in progress. Doctors need to figure out how to take promising pilot studies involving five or 10 patients and introduce them on a larger scale. The researchers wrestle with how to protect patients' privacy while still making it possible to extract useful information from the registry.



Fabriziano Constantini The Wall Street Journal

DATA DRIVEN Emily Brandt's meetings with her doctor include a review of data from her answers to four text messages daily.

illnesses are rising in children for reasons that are not fully understood, says Neal Halfon, director of the UCLA Center for Healthier Children, Families & Communities and a collaborator on the project.

Then there's the reluctance of certain patients. One doctor reported that when he showed the results of one unsuccessful mini-trial to the patient, the patient refused to accept that something he thought was working really wasn't. "It may be hard to change some people's behavior," says Jeremy Adler, a pediatric gastroenterologist, "even with clear data."

The effort comes at a time when doctors are trying new ways to treat chronic conditions and when the rates of those

It's particularly tough to get data on inflammatory bowel disease, a group of debilitating and painful conditions of the colon and intestines of which the main forms are Crohn's disease and ulcerative colitis. The problem affects around 50,000 children, and that relatively small number makes it difficult to get drug companies interested in running trials. Even the biggest centers may see only 500 patients, "not enough to tell whether any approach is making a difference," says Peter A. Margolis of Cincinnati Children's Hospital

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The Network Effect

The Collaborative Chronic Care Network hopes to raise remission rates by allowing patients to collaborate with doctors in collecting data and suggesting ideas for treating their condition

6,800

Patients in the network's registry

33

Care centers participating

300-plus

Pediatric gastroenterologists in the network—about 25% of all pediatric GI physicians in the U.S.

22

Pilot projects being conducted

94%

Response rate of patients to daily messages in personalized trials over 360 days

16

Members of patient advisory council

Source: Collaborative Chronic Care Network
The Wall Street Journal

Medical Center, who is one of the developers of the network project.

Eager Volunteers

The new network may have an advantage, though: These are patients who are especially comfortable with the technology involved in monitoring and reporting on their condition. Susannah Fox, an associate director of the Pew Internet Project, says their research found that smartphone owners are more likely to contribute and track health data online; so are people who have a chronic condition. The very group targeted by the network is part of the "culture that is nurturing" a new approach, Ms. Fox says.

The idea was to go from a system that focused on clinicians and what they were prescribing to one where patients could contribute new ideas on how to treat their disease as readily as a scientist. "We want the doctors and patients to do experiments together," says Michael Seid of Cincinnati Children's, a developer of the network.

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One of the participants is Emily Brandt, a 20-year-old student at the University of Michigan with ulcerative colitis. As part of one pilot, she gets four text messages every day asking her different questions, including whether she took her medicine and how many times she woke up in the middle of the night. Her doctor, Dr. Adler, gets the results in graph form, which he and Ms. Brandt analyze together every two weeks.

Both say they have learned new things. Dr. Adler says he was thinking about changing her medications but wanted more information before making a decision. Using the graph, he saw that Ms. Brandt's symptoms appeared to improve for the first 10 days after an intravenous infusion she receives every eight weeks. Neither of them had been aware of the pattern, and they continue to follow the data to see if it holds. "When you have chronic symptoms, every day blurs," Dr. Adler says. "So many times, we are fooled into thinking something works or doesn't work."

Ms. Brandt says she was diagnosed with inflammatory bowel disease at the age of 6. At one point, she underwent surgery to remove her large intestine in an effort to stop her symptoms. "It didn't fix it," she says.

Growing up, she didn't always tell her doctors when she was in pain because she feared they would suggest another surgery. When she got involved in the network, she finally opened up. She says one of the aspects that persuaded her to participate was when they asked her what she wanted to see studied. She shared that she often ate large numbers of granola bars because she believed they helped control her symptoms. One of their first mini-trials was testing whether that was true. (It wasn't.)

Ms. Brandt appreciates the flexibility of the network, too. She asked for short trials that more easily fit into the hectic life of a college student. No surgery, she added. "They are giving me options that are a lot more realistic for me to try," Ms. Brandt says.

After the project began, Ms. Brandt got a sinus infection and was prescribed a short course of antibiotics. She told Dr. Adler that she went to the bathroom less often and didn't wake up as frequently at night. When she stopped taking the antibiotics, her symptoms returned. They both wondered, "was this real or a coincidence?" Dr. Adler says. So he put Ms. Brandt on an antibiotic for two weeks followed by a two-week washout period, and is collecting more results. "The early data look promising, but I am afraid to draw conclusions yet," he says.

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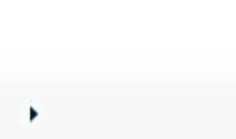
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