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Health 2.0: Patients as Partners

Social networks like PatientsLikeMe let people take charge of their own care-changing the nature of drug research and the practice of medicine

By [Catherine Arnst](#)

CBS-BusinessWeek Collaboration

The CBS Evening News with Katie Couric has investigated how patients can find reliable medical advice online and looked at the emergence of medical social networks, in a series called [Second Opinion: Medicine Online](#). You can view these reports at cbsnews.com.

Medicine has always been a top-down affair. Doctors, drug companies, regulators, and researchers are the expert gate-keepers, telling patients what they need to know. Even their own medical records are locked away to protect their privacy. So what would happen if critically ill patients joined together, obtained their personal information, and made it public?

Just such a real-world experiment is under way at a Web-based social network started by the company PatientsLikeMe. The two-year-old venture has already signed up 23,000 participants in five chronic-illness categories—amyotrophic lateral sclerosis (ALS), Parkinson's disease, HIV/AIDS, multiple sclerosis, and mood disorders.

On the company's Web site, PatientsLikeMe members are charting their medical histories in minute detail, sharing their most private information with one another and the world at large, often with photos and real names attached. To make money, the company aggregates these records, stripped of identifiers, and sells the information to drug, device, and insurance companies, all with the consent of its patient-members. The buyers can mine a rich vein of data on a variety of chronic illnesses that is simply not available anywhere else. In return, patients get the hope that they are furthering progress toward cures.

This new patients-as-partners model is often called Health 2.0. PatientsLikeMe and a proliferation of similar startups are building a new business predicated on the belief that the wisdom of crowds of patients will bring insights, solace, and most of all, power.

Power because, as it turns out, patients talking among themselves on a global scale with complete transparency produces all kinds of unexpected results. Drug side effects can be reported to regulators by the patients experiencing them, without waiting for the manufacturers to come forward. Pharmaceutical companies can use social networks to recruit subjects quickly for clinical trials, speeding up the pace of research. For that matter, patients can simply band together and run their own clinical trials, leaving drug companies and physicians out of the loop.

NO TIME TO LOSE

In a development that has caught the worried attention of the medical Establishment, some 250 members of

Patients- LikeMe with ALS are testing lithium, a generic drug used to treat mood disorders, with no corporate or academic imprimatur. The patient-run trial was instigated by Humberto Macedo, a 42-year-old systems analyst in Brasilia City, Brazil, diagnosed in March 2007 with ALS, an incurable neurodegenerative disease.

Macedo was confined to a wheelchair, barely able to speak, soon after he was diagnosed. He could still use a computer, though, and he quickly joined the ALS group on PatientsLikeMe. Researching his condition on the Internet, Macedo discovered a report on a small Italian study in which lithium appeared to slow progression of ALS. No company would be willing to finance a confirming trial of a drug that went off patent decades ago, against a disease that strikes only 4 to 8 people per 100,000. So Macedo stepped up, proposing to fellow PatientsLikeMe members that they test it themselves.

In December 2007 he posted a spreadsheet for recording symptoms and vital signs; ALS patients started taking lithium daily and documenting their results. The number of participants in the test quickly reached 250, more than five times as many as in the Italian study. Few doctors are willing to accept the results, nor would any medical journal publish them, since the trial does not meet rigorous scientific standards. "But we can't count on medical experts to get interested in ALS, and we don't have any time to lose," Macedo says via e-mail. "At least we have tried something to help ourselves."

In any event, it looks as though lithium does not slow ALS, and Macedo says he is all right with that. He and his cohort would have always wondered about its efficacy if they hadn't tested the drug. Even the prestigious journal *Nature Biotechnology*, though skeptical about the value of the user-generated trial, treated the experiment respectfully in an October editorial: "For patients with limited life expectancy, the ability to participate in a very rough, low-level clinical study on a new treatment is far more appealing and timely than waiting for clinical data to be published in peer reviewed literature."

The desire, and ability, of patients to participate in their own care isn't new. A January 2008 survey by market researcher iCrossing found that 59% of U.S. adults search the Internet for health information. More surprisingly, the study showed that 34% of the searchers visited emerging social media such as patient blogs, message boards, and forums.

For the chronically ill, social networks mean not having to wait idly in between doctor's appointments. Patients can reach out daily to fellow sufferers to find out what treatments work, or don't, what symptoms to worry about, what actions to take. "The health-care system has traditionally delivered care for acute events only," says Matthew Holt, a health-care consultant with Professional Services Solutions. "But illness is lived in long, ongoing periods."

Critics worry that bad information will flourish in such forums, even though participants insist they won't fall for quackery. "There is enough information that I can always check out any medicine if someone says it works," says PatientsLikeMe member Leonata Good, a 62-year-old Texan with Parkinson's. Holt acknowledges the dangers, but he also points out that bad information is rife in brick-and-mortar medical settings. In any case "the cat's out of the bag," he says. "This is happening, and the world has to deal with it."

Some of the first patient networks emerged from the nonprofit world, but the newest are commercial, and venture capitalists are willing to finance them. There's sure to be some consolidation, but right now patients have a big buffet to choose from. The options range from networks that encompass scores of diseases, like Trusera, launched in July, to one-disease wonders such as SugarStats, a year-old resource for diabetics.

PatientsLikeMe saw the business possibilities of Health 2.0 early on, in part because the company's founders, brothers James (Jamie) and Ben Heywood, are acutely sensitive to the shortcomings of the current medical system. Their middle brother, Stephen, was diagnosed with ALS in 1998 at age 29.

Jamie, the elder of the three and a computer scientist, quit his job the next year and started the nonprofit ALS Therapy Development Institute in hopes of finding a cure. Progress was achingly slow, however, and by 2004 he decided that a commercial venture would be able to scale up much faster.

He recruited his brother Ben and a mutual friend, Jeff Cole, all engineering graduates of the Massachusetts Institute of Technology. The three went to work creating a forum that would allow legions of patients in the ALS community to investigate new treatments together, using matching software loosely modeled after online dating sites.

The idea wasn't the easiest sell, says Ben, now president, but the three managed to get \$750,000 in combined seed money from CommerceNet, an e-commerce incubator, and from eBay ([EBAY](#)) founder Pierre M. Omidyar's investment group. In February 2007 the company raised \$5 million more from venture capital firms.

The network launched in March 2006, supporting just one disease, ALS. Stephen Heywood was its charter member, but he died that November when his ventilator accidentally disconnected. "I think if [PatientsLikeMe] had been around earlier, it wouldn't have happened," says Jamie, the chairman, because other patients would have put Stephen on guard against this not-uncommon danger.

Membership is now growing by 35% a month, and Jamie expects the total to hit one million by 2012. At that point, he predicts, the network will encompass 200 different diseases. "We already have 5% of all ALS patients in the U.S. on our site," he says. That's a larger data set on the disease than exists anywhere else.

The site gets patients to participate by offering them free tools for tracking their medications, symptoms, and health outcomes, and storing the data in easy-to-read charts. A sophisticated search engine allows members to find others whose medical profiles most closely match their own, making note-sharing that much easier.

Several pharmaceutical companies, universities, and research labs have purchased data from PatientsLikeMe, and the founders believe the business will turn a profit in the next 12 to 24 months. Drug companies are also paying fees to recruit participants for clinical trials. Novartis ([NVS](#)) was one of the first to sign on, in May 2008, in order to speed up the start of a 1,200-patient study of a new medicine for multiple sclerosis. "We were in a real crunch in terms of finding eligible patients," says Trevor Mundel, head of development for Novartis. "We saw an immediate uptick in interest once we partnered with them," accelerating the trial by a few months.

PRIVACY ISSUES

All these deals are part of the Heywoods' overarching mission, to speed research by encouraging collaboration between patients and researchers. Such partnerships are usually difficult to pull off because of the Health Insurance Portability & Accountability Act of 1996 (HIPAA), which strictly limits the flow of patient records to insurers, employers, and other third parties. But HIPAA doesn't muzzle the patients themselves. And that opens up a regulatory escape clause.

The PatientsLikeMe Web site explains to members as soon as they sign on that aggregated information will be sold commercially, and that personal records are visible to others—including, inevitably, staff of drug and insurance companies. The fact that so many patients agree to these terms stuns health-care experts. "I am

constantly amazed at what patients will put out there," says Jennifer Texada, director for new media at M.D. Anderson Cancer Center in Houston.

And no matter how often participants say they don't care who knows of their illnesses, there is always the risk that patients will be harmed when personal information is exposed. "Discrimination in health care, housing, and employment is a fact of life. The consequences of disclosure can be very serious," warns Susan M. Dooha, executive director for the Center for Independence of the Disabled in New York.

Many patients find all this talk of consequences and concerns immaterial and patronizing. "I welcome partnerships with pharma," says PatientsLikeMe member Ryan Rollinson, a 22-year-old Minneapolis resident who is HIV positive. "That's how we can speed up progress." Steven Saling, a 40-year-old ALS patient in Boston, describes a sense of liberation through PatientsLikeMe. "Current HIPAA regulations, while well intentioned, keep researchers from connecting the dots to understand what causes ALS," he says.

The privacy issue could become more fraught as medical networks grow. "It only takes one patient with a bad experience to change the culture," says Texada. Yet even when privacy violations occur, as they surely will, patients who have embraced Health 2.0 are unlikely to give up their freedom to network. As Novartis' Mundel acknowledges, "Patients will keep pressuring all of us in the direction of more openness."

BUSINESS EXCHANGE: READ, SAVE, AND ADD CONTENT ON BW'S NEW WEB 2.0 TOPIC NETWORK

The Implications of Patient Power

Health economist Jane Sarasohn-Kahn's sweeping April 2008 survey of medical social networks for the California HealthCare Foundation spotlights many ramifications, including the emergence of new rating systems for doctors and hospitals. For example, a startup called Vitals combines consumer and peer reviews with empirical data.

To read Sarasohn-Kahn's report, go to <http://bx.businessweek.com/health-20/reference/>

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