
Health Care and Social Networks: Creating an Online Patient Community



By [Matt Golosinski](#), Contributing Writer

Can an online medical data-sharing platform accelerate research, improve treatment and create a powerful forum for those with life-changing diseases? Thousands are reaching out to PatientsLikeMe.

When **Jamie Heywood** co-founded PatientsLikeMe in 2004, he was focused on the ultimate bottom line: trying to save his brother's life.

That mission began in 1998, when Stephen Heywood, then 29, was diagnosed with amyotrophic lateral sclerosis (ALS), the mysterious and always-fatal degenerative neuromuscular illness dubbed “Lou Gehrig’s disease” in the USA when it felled one of that country’s most prominent baseball players. Jamie, an MIT-trained mechanical engineer, quit his day job in technology development at the San Diego-based Neurosciences Institute to found the ALS Therapy Development Institute, a biotechnology foundation aimed at improving the lives of people like Stephen.

As one of the keynote speakers at the fourth INSEAD Healthcare Alumni Summit in London this autumn, Heywood told INSEAD Knowledge on the side lines of the event, “I was always very frustrated at how expensive it was to do clinical research and wondered why we couldn’t try things more quickly and more effectively,” says Heywood, who conveys an empiricist’s passion for piecing together data to solve big problems. “Our medical system could be better in so many ways. What we do as a business is measure whether things work in the real world, and our customers—today, mostly pharmaceutical firms—care about what works in the real world, because they have to prove that things work to sell their products.”

From 1999-2007, Heywood served as the ALS Therapy Development Institute’s CEO, overseeing a team of more than a dozen full-time scientists and conducting disease research and management through partnerships with several health-related firms. During this time, his efforts are credited with bringing two drugs to clinical trial.

Stephen Heywood lost his battle with ALS in November 2006 after 11 years, far exceeding the average life expectancy of three years for those diagnosed with the disease. His story inspired a book (*His Brother’s Keeper*) and a film (*So Much, So Fast*), and eventually inspired Jamie Heywood, his second brother Benjamin and friend Jeff Cole—fellow MIT engineering alums—to create PatientsLikeMe, a business venture that combined the power of digital communications and data aggregation to combat disease.

“The most important thing we wanted to do was build a way for patients to share rigorous outcome measures so that they could compare themselves to each other,” Heywood recalls. “Once we built these tools that allowed patients to measure their conditions against other people who had wheelchairs or who were on ventilators or who had different issues with their disease, then we built a forum to allow members to interact directly. But the primary goal was to enable these people to share their deep clinical data and provide answers to the question ‘Given my status, what is the best outcome I can hope to achieve, and how do I get there?’”



patientslikeme®

Not Just a Disease Registry

The company operates like a disease registry—a familiar framework for collecting patient information—but with a key difference: It’s open to anyone, providing a community for seriously ill people—and some practitioners and researchers—to connect with one another.

“That’s why we build PatientsLikeMe, to lower the cost of discovering new treatments and to measure and understand disease,” Heywood says. “Together, this community can help reduce the time to determine what works.”

Heywood himself has learned a lot from the online interactions. “As soon as we launched, I was learning something everyday when I logged on and saw what people were talking about,” he says. “I think that’s been our amazing experience, how much the crowd knows, how much value they can add. Typical disease registries are silos and only belong to the one or two doctors or researchers who own them,” Heywood adds. “They are the only ones who can use the data or publish from it. Here you have everyone who is a patient and everyone who is connected with the disease looking at the data and maximising the shared value of the learning. I think that’s a much more powerful way of thinking about the value of a registry in medicine.”

This approach has garnered PatientsLikeMe considerable press, including recognition in 2007 by Business 2.0 and CNN Money as one of the “15 Companies that Will Change the World.” The firm also ranked 23 on Fast Company’s 2010 list of “Most Innovative Companies” and was featured on

CBS News and in The New York Times.

Today, PatientsLikeMe continues to provide data-driven insights for patients and clinicians trying to create better treatment outcomes across a range of diseases—from ALS, Parkinson’s and multiple sclerosis to AIDS, anxiety and mood disorders. In fact, Heywood says that PatientsLikeMe now serves more than 165,000 people and includes data and resources to address some 2,000 diseases, although he acknowledges the site targets about 50 core afflictions.

“We started building a strong ALS community in 2005 and then extended that gradually over the next six years to include other diseases and conditions,” Heywood notes, adding that the company formally expanded its website and invited all patients with any condition to join in April 2011. “This strategic expansion was something we’d always planned.”

Still, he considers the social interactions facilitated by the company to be a secondary benefit. The real advantages he sees derive from patients sharing real-time data about their disease, symptoms, treatment, hospitalisation, side effects and quality of life. That data is permitting PatientsLikeMe to make an even bigger difference. Last year, Heywood says, he and his colleagues published a paper in the journal *Nature Biotechnology* that refuted a clinical trial for the drug Lithium as a potential ALS treatment.

“We watched the drug being used by the PatientsLikeMe population and we demonstrated that it had no impact on patients’ outcomes,” he says. “We demonstrated this before any of the clinical trials were done to prove that it didn’t work.” Those trials, which did proceed, confirmed what the PatientsLikeMe data indicated. “There were four large-scale follow-up studies that cost tens of millions of dollars, and they all failed. We were able to analyse the data so quickly and effectively that we showed that the drug didn’t work even before anyone enrolled in the follow-up studies,” Heywood says.

Selling privacy by the pound?

These results come at a price, Heywood knows. They are only possible thanks to the openness of the PatientsLikeMe community, whose members are willing to trade off some of their privacy to gain potential treatment boons. Managing patient privacy is also at the heart of the company’s business model.

PatientsLikeMe calls itself a “for-profit with a not-just-for-profit attitude”.

Membership is free and the company currently accepts no advertising. But something has to bring in the funds to pay the bills. And that “something” is selling de-identified patient data from the site to pharmaceutical, insurance, and medical device companies. It’s a policy clearly stated on the company’s website, and is framed as being integral to seeking ways to improve patient outcomes. Given the continuing participation of patients, concerns about this data exchange seem to be eclipsed by the benefits of insights and solace gained from fellow sufferers online.

“The people who use our site are mostly those who wake up in the morning and illness is part of their life and they want to make it better,” Heywood says. “These are data-seekers or people trying to take responsibility for their health in a new way. Almost everyone who uses our site has had some negative experience with healthcare in some way. They have some story where they were frustrated with trust or felt uncomfortable with an answer they got [from their doctor] and so they want to learn on their own.”

Heywood says that concerns about aggregating data are “legitimate” and, in part, derive from the treatment of prisoners during World War II. He says PatientsLikeMe believes strongly in transparency and that the company has contracts that prevent its partners from “re-identifying” data and matching medical details to specific patients.

However, he believes that public conceptions about privacy are shifting, especially among younger people, and that sharing medical data judiciously holds the promise of significant treatment advances. In addition, Heywood says that people are “more comfortable about having data used to advance the public good.” He also thinks that privacy laws have sometimes overstepped their usefulness, becoming so stringent that they impede medical progress.

“Privacy went too far,” he opines. “Privacy advocates began to sort of prevent people from doing effective research.”

If privacy frameworks continue to shift, Heywood’s commitment to finding new and better options to advance medicine remain steadfast, galvanised by his brother’s disease and death.

Regardless, he sees his company's data-driven social media platform playing a positive role in patient empowerment, and he says that even the medical establishment seems more receptive to what his company is doing.

"Since we've launched, I haven't heard a single objection from any of the clinicians that are treating a patient with one of our major conditions. They've all told me that they learned something that they really value," Heywood says. "There's this bias against patient empowerment; people think that patients can't input or share data accurately. But when you look at the data and what you can learn from a patient—I haven't seen anyone who didn't think it was valuable."

But his main focus remains enhancing research and patient outcomes. "I built this company to measure and understand disease, and to reduce the time to determine what works. If we can do those things, we can discover new treatments that hopefully make our platform less necessary."

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