Openness, Not Privacy: Web Site Promotes Sharing Disease Successes, Hardships

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by Chris Dimick

While most PHR services strive to keep user information private, one Web site encourages users to make personal information like HIV status and medication lists open on the Internet. In fact, PatientsLikeMe.com thrives on the openness of patients sharing their health information.

Launched in 2006, PatientsLikeMe is a social networking site that allows people with life-threatening illnesses to connect to others with similar conditions. Users upload personal medical information such as medication lists and symptoms into their profiles and then allow the general community to track their progress.

"What is really different about our communities is that they are data-centric communities where patients can share their experiences, find patients like themselves, and learn from others," says Ben Heywood, cofounder and president of PatientsLikeMe. "The site is structured in a way in which we capture patients' disease progression and outcomes, treatments, and symptoms over time, in a way that makes it very easy to use that information in understanding and treating your own disease."

Patients Sharing Symptoms, Medication Histories

The site was inspired after Ben Heywood's brother, Stephen, was diagnosed with ALS in 1998. The Heywood family wanted to find the best health information for Stephen, and they soon realized patient-to-patient sharing of information could benefit treatment. Ben Heywood and his brother James linked up with Jeff Cole, a former classmate of Ben Heywood's at the Massachusetts Institute of Technology, and created PatientsLikeMe.

About 7,500 people use the free site, while more than 10,000 regularly use and view the profiles. The site is organized by disease, with patients being able to join communities for ALS, HIV/AIDS, MS, mood disorders, and Parkinson's disease. The power of thousands of patients sharing disease information is limitless, Heywood says.

Heywood tells the story of a PatientsLikeMe user with MS who had been receiving 10 mg of a drug to treat a symptom. Ten years earlier a doctor told the user that taking more than 10 mg could cause physical harm. Once on the PatientsLikeMe site, the MS patient found that others with MS were using much higher doses of the drug, up to 110 mg. This gave the patient information that he took to his doctor, who increased the dosage. That increased dosage ultimately relieved the symptom.

Though not meant to be a personal health record, PatientsLikeMe does allow people to track disease progression, and therefore it can provide helpful medical information for physicians, Heywood says. Users have an option to print the information and take it to their physicians.

Accepting an “Openness Philosophy”

Information is entered into the site in a very structured way, so users can search by any basic trait such as age, symptom, and medication. The structured data also serves as the foundation of the site’s business model. PatientsLikeMe allows researchers and healthcare products and services companies access to deidentified patient data, both individual and aggregated, for advancing medications and other health products and services.

Patients must agree to this use of their data before joining the site. However, patients ultimately choose what information they enter into the site. This includes personal information such as name or location that can identify them.

But the entire site is founded on openness and sharing personal information. Users must accept to the site’s “Openness Philosophy,” Heywood says, in order to get the full benefits of networking and figuring out better health outcomes. The site turns traditional privacy concerns on its head.

“This is breaking down all the barriers that privacy erected in healthcare,” Heywood says. There are pros and cons to this openness, he acknowledges, and some patient risk. But the means justifies the ends, which is better healthcare.

“We believe that openly sharing information is the only way to improve medical care,” he says. “And you make a decision about the risks and rewards. But I think our members really buy into the value of sharing in this environment.

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