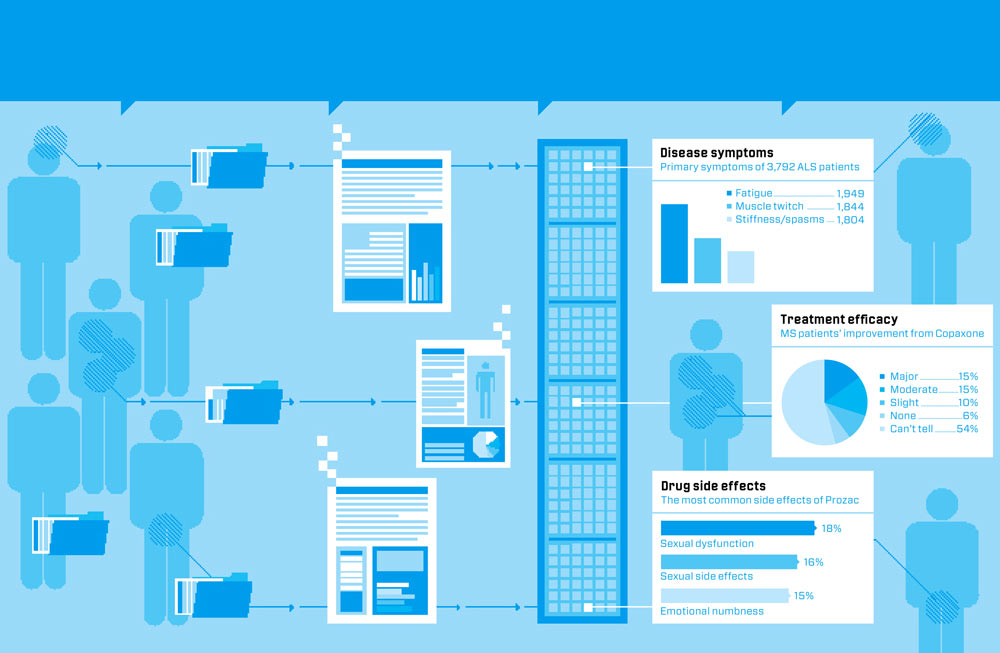
**Jamie Heywood: Forget Medical Privacy**

By Brendan I. Koerner [Email](http://www.wired.com/services/feedback/letterstoeditor)09.21.09

[](http://www.wired.com/techbiz/people/magazine/17-10/ff_smartlist_heywood)

Click to enlarge image.  *Infographic: Data provided by PatientsLikeMe*

*Wired*'s Smart List 2009

[[http://www.wired.com/images/article/magazine/1710/ff_smartlist_t.jpg](http://www.wired.com/techbiz/people/magazine/17-10/ff_smartlist)12 Shocking Ideas That Could Change the World](http://www.wired.com/techbiz/people/magazine/17-10/ff_smartlist)

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**Want to put your doctor's** stethoscope in a twist? Ask them to hand over a complete copy of your medical records. Then watch as they nervously demur, citing state laws, cost, and fuzzy hospital policies.

[Jamie Heywood](http://www.patientslikeme.com/members/view/71) wants those obstacles legislated out of existence so we can access our own health data almost as easily as ordering a pizza. And he hopes consumers will in turn share that data with one another via online communities such as PatientsLikeMe, which he cofounded in 2004.

"Privacy has been used as an excuse by those who have a vested interest in hoarding this information," Heywood says. He believes that the real reason hospitals jealously guard medical records is they don't want to open themselves up to second-guessing from patients—or patients' lawyers. And that lack of openness, Heywood argues, is making us sicker: With data scarce, there's no clear way for physicians to know what treatments are working for other practitioners.

PatientsLikeMe allows people with chronic diseases to create public profiles listing their symptoms, medications, and other details long deemed too sensitive to share. Users can then see how fellow travelers are faring and get leads on promising treatments. The company, meanwhile, anonymizes the data and sells it to medical researchers and drug developers.

PatientsLikeMe obviously has its own vested interest in making medical records more accessible. In addition to testifying before Congress, Heywood is a driving force behind the Declaration of Health Data Rights, a four-point manifesto that supporters can publicly endorse through HealthDataRights .org. The declaration's third tenet, in particular, is bound to vex secretive doctors and hospitals: "We the people have the right to take possession of a complete copy of our individual health data, without delay, at minimal or no cost."

Heywood admits that there may be pitfalls—the prospect, for example, that employers could weed out workers with rare diseases. But by his estimate, tens of thousands of lives are lost each year because health data doesn't flow freely. "You're talking an entire Vietnam War annually," he says, "versus a couple of lost jobs."