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**HEALTH**  
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Research 2.0: How drug companies are using social networks to recruit patients for clinical research.

By [Sarah Kliff](#) | Newsweek Web Exclusive  
Mar 10, 2009

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Like most social-networking sites, Inspire.com is a place where users talk about the most intimate details of their lives. They want advice on coping with stage III [cancer](#) or to offer encouragement to a mother deciding about life support for her premature baby. But Inspire's nearly 100,000 users aren't just sharing with each other (and the 62 nonprofits who partner with the site), they're also receiving targeted information from pharmaceutical companies who use the site as a recruiting tool for drug studies. Opening this door between patients and drugmakers has some obvious benefits but also raises a host of ethical and

medical dilemmas.

On the plus side, those grappling with serious or chronic diseases get to hear about clinical studies and new treatments that they might not otherwise know about. Pharmaceutical companies get easy online access to highly engaged populations with specific medical conditions. "One day we come to you and say, 'There's a clinical trial going on, here's some information, now it's your decision.' It lets the patients raise their hand and say, 'I want to participate,'" says Inspire's founder, [Brian Loew](#). Social networks not only allow pharmaceutical companies to hone in on extremely specific populations, but also enable them to reach patients who live far from major medical centers and typically never hear about studies.

Recruitment has long been a bottleneck in medical research. Of the approximately 50,000 [clinical trials](#) currently underway in the United States, 80 percent are delayed at least a month because of low enrollment. One problem: potential trial participants are often skeptical and worried about safety. "There's an increasing wariness about the pharmaceutical industry and the clinical trial process," says Ken Kaitlin, director of the Center for the Study of Drug Development at Tufts University in Boston. "It's not uncommon to hear about drugs taken off the market because of major safety problems ... that makes the public a little more concerned." Pharmaceuticals hope they can overcome such fears by building partnerships with social networks that they can mine for potential volunteers.

Loew launched Inspire in 2005, and spent the first three years building up members in partnership with nonprofits, including The Lung Cancer



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Alliance and National Organization for Rare Disorders. Now, with a core group of users on the site, two major pharmaceuticals have begun recruiting for clinical trials, one in the lung-cancer community and one in arthritis. Inspire has partnerships with two other major pharmaceuticals in the works. The drug companies pay Inspire a flat fee for the recruiting service; the Web site's compensation does not hinge on meeting a particular recruiting goal.

Three of the four pharmaceuticals working with Inspire declined to discuss their interest in social networks, or even reveal their names. The fourth, Merck, declined multiple requests for an interview but did issue a brief statement on their commitment to "rapid and effective enrollment of appropriate patients into trials" as to allow for "timely development of innovative medicines."

[Novartis](#), one of the first drugmakers to engage research participants through a social network, partnered with PatientsLikeMe.com to recruit clinical-trial subjects for a multiple-sclerosis drug in 2008. "[Social networking] hadn't been applied to clinical trials," says Trevor Mundel, head of exploratory clinical development at Novartis. "At the time, we were having a lot of difficulty enrolling patients."

In May 2008, the site sent out a message to the 8,000 members of their multiple-sclerosis community, alerting them to the Novartis trial. From that e-mail, nearly 1,500 members visited the Novartis Web site. After recruiting through PatientsLikeMe.com, Novartis saw a boost in registrations for the study, although they did not track which or how many individuals enrolled because of the campaign—due to patient privacy concerns. "The registration did start to pick up," says Mundel. "We don't have the tracking, but I've got to believe some of it was generated by the e-mails."

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