

## Patient-based site tracks drug responses

In the wake of safety concerns about medications such as Vioxx and Avandia, regulators and consumers alike are paying more attention to the potential adverse reactions people might have to drugs on the market. A new online portal launched in August by the website PatientsLikeMe.com now tracks such responses to drug treatment through reports from its members.

"We're launching a real-world drug monitoring system because there isn't one that looks at what actually happens to patients—from medication start to stop—including the frequency and the severity of each complication or side effect," says Jamie Heywood, cofounder and head of research at the Cambridge, Massachusetts-based PatientsLikeMe. But the site doesn't only aggregate patient reports of negative drug reactions; it also collects reports of efficacy. Starting in 2009, Heywood hopes to contribute data from the site through the Sentinel System to the national drug monitoring program of the US Food and Drug Administration (FDA), which works through voluntary reports submitted by doctors, patients and hospitals.

According to Saul Weingart, coauthor of a recent study that compared adverse events detected by hospital chart review with patient reports (*Ann Intern Med.* 149, 100–108; 2008), the current reporting system has room for improvement. "There are a lot of adverse events that don't go into a patient's chart, some of which are serious and preventable, that clinicians are either unaware of or fail to document," says Weingart.

The web-based tracking system at PatientsLikeMe.com attempts to overcome this limitation by appealing to patients directly with the look and feel of a social

networking site like Facebook or MySpace. There are similar websites that provide ratings systems for drugs, such as iGuard.org and DailyStrength.org, where users review treatments, and the sites generate data about treatment success rates. For example, at DailyStrength.org, hundreds of users reviewed the multiple sclerosis drug Copaxone and gave it a 75% success rate.

PatientsLikeMe.com's ambitions are unique, because other patient support sites do not track and report adverse events, although most provide links to the FDA's self-reporting page. But not all diseases or their related treatments are covered. The website recently added four diseases, bringing the total covered to just 15, such as multiple sclerosis and depression. Heywood and his team decide which diseases to include on the basis of a number of factors, including user suggestions.

Since the site's initial launch in March 2006, the number of users has grown to over 22,000 members. PatientsLikeMe developed the treatment evaluation system after noticing that people on the website's forum often discussed adverse reactions.

"I don't think these websites are infringing on our job," says Paul Seligman, associate director of Safety Policy and Communication at the FDA's Center for Drug Evaluation and Research. According to Seligman, it's always been known that the number of adverse events that actually occur is much higher than what gets reported to the regulatory and public health agencies. "The degree to which some of these sites can help promote the importance of reporting is extremely valuable," he adds.

But according to Weingart, the problem with collecting adverse event data through websites like PatientsLikeMe.com is that participants tend to be the most informed and tech-savvy patients, thereby limiting one's ability to generalize on the basis of the responses. There is also a discrepancy between side effects that patients find annoying and side effects defined as a reportable adverse event. Another problem is that various sites don't collect information in a consistent way. "Patient reports are very reliable and credible," explains Weingart, "but without a clinician looking them over in the context of an individual's medical history, this information is difficult to interpret and may not be helpful for solving quality-of-care problems."

*Genevive Bjorn, Maui, Hawaii*

## Condom ringtone catches on

Imagine a spirited a cappella song that lasts just a few seconds and consists only of the word condom—repeated almost 50 times. It's not exactly what one would expect to become a popular ringtone among India's estimated 270 million cell phone users, who typically download films or

religious songs. But, in this country where sex education is still taboo in many areas, the ringtone was downloaded about 300,000 times in the first month since its launch in August.

The BBC World Service Trust, a charity organization run by the media giant, launched the condom ringtone in India to spread awareness about HIV prevention. The BBC Trust hopes that the tune will portray condoms as acceptable among smart, upwardly mobile youth and remove the image of promiscuity that condoms conjure in India.

But the true impact of such campaigns is debated. The latest national family health survey covering 2005–2006 found that 70% of men knew about condoms, but only 40% of unmarried men who engage in high-risk sex had used one the last time they had intercourse.

Experts also emphasize that such ringtone campaigns should go hand-in-hand with information about condom availability. "The message needs to be backed up with accessible services. The message is about technology, but it needs more information on where condoms are available and who is to use them," points out public health researcher Ritu Priya of the Jawaharlal Nehru University in New Delhi.

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**A click away:** Online networks rate drugs