Social Networking by the Numbers

Previous incarnations of online patient communities have amounted to little more than disjointed, out-of-date message threads initiated by people asking questions their doctors should already have answered. PatientsLikeMe.com aims to do better. It's a unique social-networking forum for those with diseases and conditions ranging from posttraumatic stress disorder to Parkinson's. The site's concept is easy to sum up: "Show me the numbers." If a sign, symptom, laboratory value, population, treatment, outcome, or patient demographic can be quantified, PatientsLikeMe will quantify it.

The resulting cache of data is worth its weight in nanochips to pharmaceutical corporations, insurance companies, device manufacturers, and other interested parties. In lieu of advertising, the site's owners gather and peddle patients' de-identified (anonymous) medical information, supposedly in an effort to "democratize patient data and accelerate research like never before." Because the site is not a so-called covered entity, it is not subject to HIPAA regulations. Privacy advocates have expressed concern about the group's casual trafficking of patients' personal information.

The idea for PatientsLikeMe was conceived one day as Jamie Heywood, the brother of an ALS patient, perused the online dating site Match.com. Combing through the detailed personal profiles—age, body type, family background, and so on—he was struck by the idea of pairing the concept of the online singles ad with the data in a typical medical chart. Eureka! PatientsLikeMe was born.

Take, for instance, the site's multiple sclerosis (MS) community. Its home page tells us that as of this writing, it has 11,093 members, 424 of whom have joined just this week. Each member is asked periodically to complete a set of questionnaires that, when submitted, map the individual patient's outcomes, treatments, and symptoms. The collective results are then tallied and summarized in tidy charts and lists like those shown below [image omitted from this writing sample]. In fact, the numbers are crunched six ways to Sunday and presented in searchable alphabetical lists, pie charts, timelines, percentile grids, scatterplot graphs, and other visuals for the site's resourceful users. Members can even create maps on which each pin represents a specific community member in a given city. Users post advice and comments, often forging enduring bonds with other members.

Perhaps the site's most innovative and controversial feature is its organization of informal clinical trials. Winning FDA approval to market a new prescription drug in the United States is a tough slog. Once researchers have identified a promising substance among thousands tested, it takes an average of 14.7 years to conduct a multiphase clinical trial. The process is a bit speedier when an approved drug is investigated to determine its safety and efficacy for a new indication—that is, for a new use—but it's still a protracted affair.

PatientsLikeMe has found a workaround. Unfettered by governmental or institutional rules, members can organize a clinical trial, of sorts, in just days. Admittedly, they're also unburdened by the rigors of scientific protocol, since research findings are based on self-report. (Even when patients supply objective data, such as the results of their laboratory tests, they're offering a self-report of that data, with no external verification of its accuracy.) It’s unlikely that such a loosey-goosey methodology for a quantitative research study could survive the peer-review process of any academic journal.

Still, the findings are good enough for the members of PatientsLikeMe. Since December 2007, the group has been reporting the ongoing results of its study of the effects of lithium on patients with amyotrophic lateral sclerosis (ALS, or Lou Gehrig’s disease). Peer review, schmeer review—the research may lack *gravitas,* but its conclusions can’t be dismissed. Summarized in a series of straightforward, color-coded bar graphs, the study’s findings compare a population of ALS patients taking lithium with a control group of ALS patients who do not take the drug. The data are further categorized by dose and type of lithium, severity of symptoms, age and sex of the patient, and other factors. Researchers may not be able to accept the study’s conclusions as indisputable fact, but they’re likely to be intrigued enough to duplicate the investigation under more conventional conditions.

Qualitative research based on data drawn from PatientsLikeMe carries inherently more credibility, since such research relies on interviews, questionnaires, and other subjective methods of data collection. In fact, the *European Journal of Neurology* recently published the results of an online survey of ALS community members.

Pharmaceutical companies like Novartis are capitalizing on this ready population of willing study participants by using the site to recruit subjects for clinical trials. Researchers poring over the data on the site are unearthing surprising trends, such as previously unrecognized symptoms among particular patient populations. It remains to be seen what other useful insights will arise from this innovative social network. You can be sure, though, that its members will continue to prove there’s courage in numbers.

Sources Consulted

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