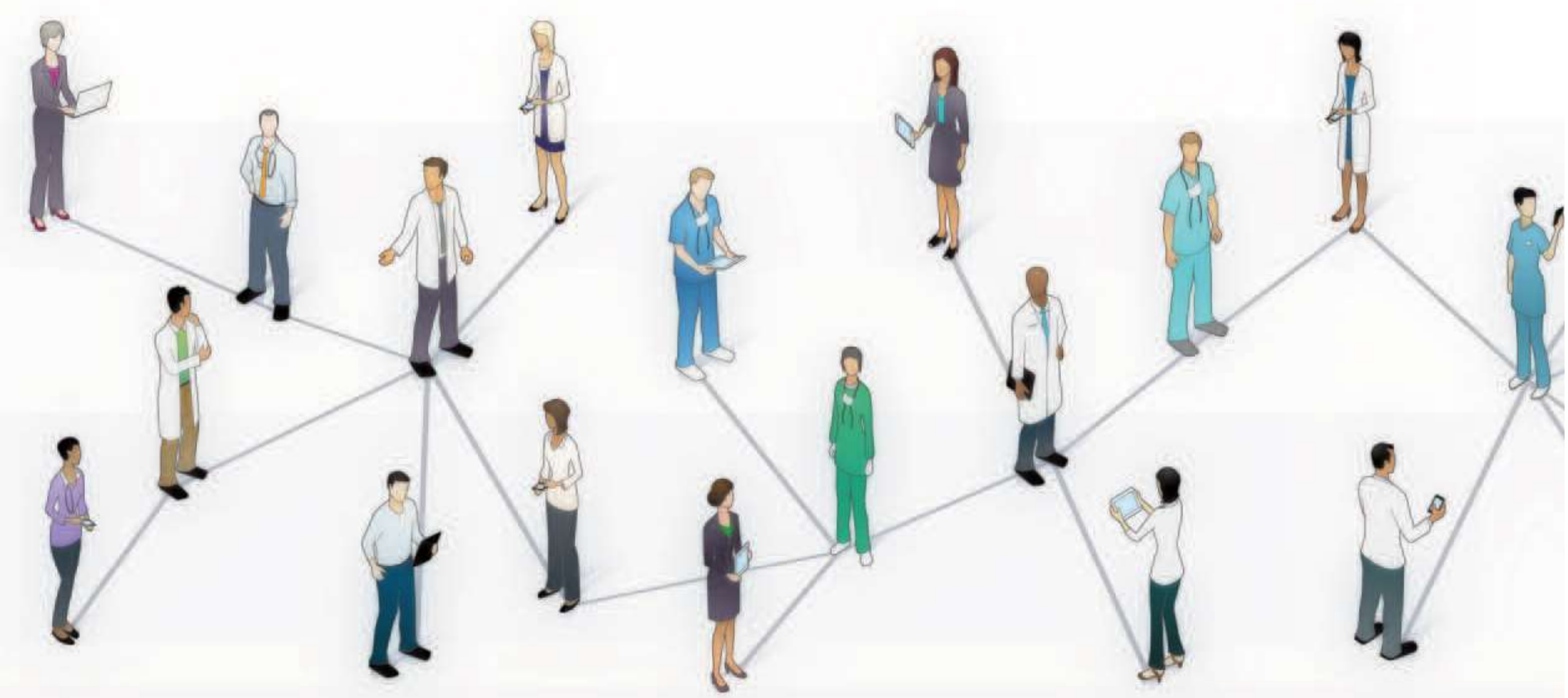
How Crowdsourcing Is Changing Medicine

One physician. One patient. That's the model that has historically governed the doctor-patient relationship. But the iconic image of a doctor caring for a patient is shifting as more and more virtual entities crowd into the exam room. With the advent and ongoing evolution of crowdsourcing, there may be hundreds of other patients involved in one patient's care. Likewise, there may be dozens of healthcare providers weighing in to help a patient receive the care he or she needs. How is crowdsourcing informing the doctor-patient relationship, and how can healthcare providers be prepared for the ways in which crowdsourcing is changing the dynamics in medicine?



By Dana Martin

Crowdsourcing, a term first coined by Jeff Howe, a contributor to *Wired* magazine,[1] is most often associated with marketing and social media. A company might crowdsource its customers to decide on a new product launch, or a Twitter user might poll his or her followers for the best answer to a question. But crowdsourcing has other applications as well. The approach of widely canvassing a group in order to solve a problem or gain new insights is gaining popularity in the medical community. Crowdsourcing is making a name for itself in medicine beyond the more traditional forms such as expert panels, case conferences, medical databases and polls in medical journals. Emerging technologies are making it easier than ever for patients to communicate with one another online and to participate in research, as well as for physicians to come together in virtual spaces with the shared goal of diagnosing and addressing difficult medical cases.

Peer Support

Peer support has existed in many real-world incarnations and predates the use of the term crowdsourcing. Patients who share the same diagnosis or who are all dealing with similar, often life-altering, symptoms may reach out to one another for the support and encouragement that only their peers can provide. These groups exist in communities across the country, and many are hosted and supported by local hospitals, churches, community centers and other local entities. Studies show that peer support is effective for patients with kidney disease, cancer, diabetes, heart disease, depression, HIV/AIDS, multiple sclerosis, brain injury, burns, amputation and numerous other health conditions.[2]

More and more, these peer support groups also exist online, where the number of participants is often much larger than it would be in a local support group, especially where rare diseases are concerned. With larger groups, more information can be shared and solicited, which makes crowdsourcing possible in ways that might not have been feasible in the past. These days, even a patient with a rare disease can poll thousands of other patients with the same condition. This is an important shift. That same patient might not have another person in his or her community to share information with and request information from. Online peer support groups can confer many of the same benefits as in-person groups. One study whose objective was to test whether engaging in an online patient community improves self-management and self-efficacy in veterans with epilepsy concluded that such an intervention increased epilepsy self-management and self-efficacy scores, with the greatest improvement occurring in information management behaviors.[3]

Peer support groups, especially those that include a large number of members, are an important consideration for those providing healthcare to patients. Members of peer support groups are often well-informed about their conditions and treatment options. “Dealing with a patient who is informed allows for more open communication between the doctor and the patient,” says Rick Kellerman, MD, FAAFP, a family physician in Wichita, Kan. “The doctor can speak with the patient on a different level because he knows that the patient does have a body of information to draw from in relation to his own health.”[4]

At the same time, patients might be getting information from the group that counters their own physicians’ chosen courses of treatment. Informed and engaged patients require a different approach than those who learn about their conditions only from their healthcare providers. These patients will often ask more questions and demand more from their providers. In turn, providers need to be prepared to field questions, address proposed treatment options, explain why the given course of treatment has been chosen, and address any potential misinformation that has been gathered from fellow members of the support group. Such misinformation can arise because most online peer support groups are not mediated by healthcare professionals.[5]

Peer Support That Facilitates Research

An extension of peer support, patient-centered sharing networks such as Patients Like Me not only connect patients with one another in the ways that traditional support networks do, they also use the data they collect from patients to improve patient care, change the way the medical industry conducts research, and transform the way patients manage their conditions. The large amounts of data that Patients Like Me collects are aggregated and analyzed in order to give patients a collective voice that makes them the center of healthcare research and initiatives. One area in which Patients Like Me is leveraging this collective data is pharmaceutical research and evaluation. The data sets the company creates have been used to inform drug research. The company also wants patients to collaborate on developing outcome measures that evaluate the efficacy of new drugs. These measures would include elements that matter to those taking the medications. About a dozen pharmaceutical groups have already collaborated with Patients Like Me, including Merck and Novartis.[6]

In June, Patients Like Me announced another patient-centric initiative in the area of drug research. The company has signed a research collaboration agreement with the U.S. Food and Drug Administration (FDA) to determine how patient-reported data can give new insights into drug safety. The company and FDA will explore the potential of patient-generated data to inform regulatory review activities related to risk assessment and management. “Most clinical trials only represent the experience of several hundred or at most several thousand patients, making it impossible to anticipate all the potential side effects of drugs in the real world,” says Ben Heywood, co-founder and president. “Patient-generated data give a more complete picture about a drug’s safety by providing a window into patients' lives and healthcare experiences over time. We're very encouraged by the FDA's action to evaluate newer sources of data to help identify benefits and risks earlier."[7]

Doctor Crowdsourcing by Patients

Another kind of crowdsourcing involves patients talking with a pool of doctors as opposed to their peers. CrowdMed, the first site of its kind, gives patients access to a team of medical professionals, including doctors, researchers and acupuncturists. Jared Heyman, the company's founder and CEO, created the CrowdMed website after his sister spent three years suffering from a chronic, undiagnosed medical condition. He says the average patient on CrowdMed has been ill for eight years and has already incurred $60,000 in medical bills trying to reach a diagnosis by the time they reach the site. The site is not a replacement for visiting a physician. Rather, it is a tool that can help solve medical mysteries, according to Heyman. "We are definitely trying to shorten that path, from when a patient recognizes they have some type of illness that doesn't have a clear diagnosis, and to when they actually have the right answer," he says.[8]

SERMO, a crowdsourcing site for physicians, recently made news when a primary care doctor in Utah saved a boy's life after posting about his symptoms on the site.

One success story directly tied to the use of CrowdMed is that of Catherine Tan, who had a bicycle accident when she was a teenager. The resulting head injury left her with headaches and vision issues, but no effective treatment plan, even after $250,000 had been spent on medical bills. Her mother shared Tan's story on CrowdMed, along with a $400 award for an accurate diagnosis. The group of medical investigators on the site, whom Tan's mother describes as a community of young medical professionals who are reading and thinking in much more creative ways than the traditional medical establishment, determined that Tan did not have a concussion as a result of her accident but did have some brain damage. She is now being treated at Cleveland Clinic. In relation to this success story, Heyman adds that the average case on CrowdMed is solved in just 75 days. One of Heyman's means for getting these speedy diagnoses is casting a bigger net than simply using the typical roster of medical doctors. Medical students, nurses, chiropractors and nutritionists can all weigh in, alongside physicians, in getting to the bottom of patients' difficult medical issues.[9]

While promising, models such as CrowdMed and those that may spring up in its wake are not without their drawbacks, chief among them concerns about privacy and medical errors.[10] In addition, according to Darshak Sanghavi, a pediatric cardiologist and fellow of the Brookings Institution, some patients may not feel comfortable receiving a diagnosis by way of majority vote. This approach can feel impersonal. A better model, he notes, is having designated subspecialists review the information from those providing input.[11] CrowdMed's solution for providing context and limiting the flow of incoming information is to use a patented prediction market technology that collects and filters feedback from those who participate in the case, then provides a report with the best suggestions for further discussion with the patient's doctor. This isn't a doctor's distillation, but it is an innovative form of intelligent analysis that can be shared with the patient's doctor — as long as that doctor is open to reading and incorporating such feedback.

There's also the issue of additional costs associated with these sites, which may be prohibitive for some patients. Many have, however, already spent tens if not hundreds of thousands of dollars trying to get an accurate diagnosis and treatment plan, so the additional fees or monetary incentives are minuscule by comparison. Finally, there's the issue of platform. Those without access to the Internet or who are not Internet-savvy may not make use of online crowdsourcing tools. This includes nondigital natives such as older adults, who otherwise might be perfect candidates for such services.

Physician Crowdsourcing

SERMO, a crowdsourcing site for physicians, recently made news when a primary care doctor in Utah saved a boy's life after posting about his symptoms on the site.[12] The child, who had a persistent cough, coughed up a branchlike mass. Within two days, 231 doctors from the United States and the United Kingdom had responded with 16 possible diagnoses. One of those doctors made the right diagnosis, which was seconded by another SERMO user. The boy had an extremely rare respiratory condition and needed to be seen by a specialist immediately.

SERMO differs from CrowdMed because it's a resource for physicians to crowdsource other physicians, not for patients to make such inquiries. In this way, it functions more like an online extension of the more established forms of sharing and collaborative problem-solving that exist in medicine. SERMO is designed to do what Dr. Sanghavi says is necessary for crowdsourcing to be at its most effective, which is getting the consensus of about 1,000 highly trained specialists.[11,13] Under these conditions, even though many doctors will have the wrong answer, the plurality, Dr. Sanghavi points out, will hit the mark. "Debunking the myth of the lone maverick, health researchers suggest that groups of doctors outperform individuals not only in diagnosing problems but also in treating them," he says.

One issue with sites such as SERMO is the overall lack of training in collaborative technologies on the part of physicians.[14] Doctors receive little training in the use of social media sites such as Facebook and Twitter, and they don't tend to spend a lot of time on these networks.[14,15] Physician crowdsourcing sites have many of the same elements as public-facing social media outlets and may, therefore, encounter similar resistance with regard to their use. A 2012 article published in the *Journal of the American Medical Association* notes that the foundational values associated with the practice of medicine reinforce the independent, rather than the collaborative, model of care, even with regard to real-world social networking among physicians.[16] It also takes time, including time away from other patients and from practice management, to incorporate crowdsourcing into one's routine on a regular basis.

Making Room for Crowdsourcing

All the physician- and patient-led sources of information out there won't help the physician who doesn't allow the collaborative mindset into his or her work, the one who still wants to operate a solo practice in relative isolation and without the input of patients, other physicians or the wider healthcare community. A paradigm shift is required to incorporate any of these tools.

Dr. Sanghavi points out that even when new guidelines are agreed to through the most rigorous forms of physician-driven crowdsourcing — collective efforts that are published, widely distributed and nationally endorsed — they aren't always followed. "Some doctors may honestly think the crowd is wrong, but more likely, they're unaware of the fact that guidelines exist or they're wedded to outmoded practices," he says. According to the *New England Journal of Medicine*, guidelines for practice may predispose physicians to consider changing their behavior, but rapid change in actual practice may be unlikely unless disincentives are removed or there are other incentives for adopting the guidelines.[11,13] By extension, emerging forms of online crowdsourcing, which aren't published and don't result in changes to policy guidelines, and also may carry no intrinsic incentives or barriers to disincentives, might be even more difficult to translate into changes in physician behavior. In addition, many of these forms of crowdsourcing are for rare or difficult-to-diagnose conditions, ones that may be less likely to apply to a physician's broader patient base.

Even given the obstacles crowdsourcing faces, results such as those seen with Catherine Tan and the boy with the rare respiratory condition can't be ignored, nor can the fact that we are living in an increasingly connected culture in which asking a larger group for advice on everything is the norm, even in medicine. Perhaps in the future, one-to-many relationships between patients and doctors will be as common, if not more common, than the one-to-one relationships that dominate today's medical landscape. ❖

DANA MARTIN *is a writer and editor in the Midwest who specializes in science, medicine and health.*

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