

All grown up: Patient engagement comes of age

Patient engagement has evolved from something nice to do to an essential part of the pharma marketer's toolbox.

Sara Mahoney reviews the important milestones in the era of patient engagement and reports on the steps pharma has taken along the pathway to embrace the people it serves

While the idea of tapping the power of patients has been kicking around for decades, the rise of social media in the past five years has turned it into a medical juggernaut. The healthcare industry's embrace of the people it serves has been long in coming and key stakeholders are still struggling to grasp patients' sprawling influence. For pharma, that means an awareness of patients as advocates, helping them sell more products and gain market share. But there is also wariness: Patients can also be powerful adversaries, creating millions of dollars in damages with an ill-timed tweet.

Key patient leaders, with diagnoses that range from cancer to lupus to diabetes to infertility, offer the newly diagnosed a rich ecosystem of content, from blogs to social media to meet-ups. A crop of agencies has

emerged to help bridge the gap between these patients and healthcare companies, training armies of "patient ambassadors" while still other companies have evolved to build online patient networks.

The most visible shift has been how quickly patient-engagement efforts have morphed from a nice thing to do to an essential part of the marketing mix, says Jack Barrette, CEO and founder of WEGO Health, a company that uses mobile technology to activate hundreds of thousands of patients. "These patient activists are more visible all the time, fueling this 'give me my damn data' movement, for example. They no longer say, 'Why aren't there patients at this event' or 'Why isn't there a patient advisory board?' They're not asking. They're demanding."

And there are tens of millions of them. "Nearly two-thirds of US consumers are leveraging social media for their health," says Rory Stanton, an analyst at Manhattan Research. "Over one-third of them are influenced by the other patients they've interacted with online. And we know patients are interested in hearing from pharmaceutical companies via patient activists on social media."

But there are still a lot of questions. Plenty of evidence shows that engaged patients get better faster, get better care and have lower costs, but how long do they stay engaged? And what about the unengaged? Do these rank-and-file patients feel the benefit? Does engagement actually create new problems, such as widening the already-gargantuan gap between America's haves and have-nots?

The Power of Dave

While Dave deBronkart, best known as "e-Patient Dave," takes no credit for starting the patient-engagement trend—that's an honor he lays at the feet of pioneers dating back to the 1970s—he certainly became the first public face of the phenomenon. Building from his experience as a kidney-cancer patient, his TED Talk, Let Patients Help, has garnered nearly half a million views. He's gained so much credibility for patient involvement that he was even tapped by the Mayo Clinic as visiting professor in internal medicine.

But he's certainly not alone. There's Kerri Sparling's SixUntilMe and Manny Hernandez's Ask Manny, both covering diabetes. Matthew Zachary's StupidCancer addresses many cancers, while Donna Cryer's DCPatient looks at liver disease as well as broader engagement efforts. And with each post that's shared, more patients are chiming in themselves, generating hundreds of millions of impressions.

It's undeniable that these legions of patients feel better and are more able to act on their own behalf. And there's growing evidence that the benefits of engagement are long lasting: A new study from the University of Oregon shows that the advantages persist over four years.

But for the most part these patients are leery of the pharmaceutical industry, says Barrette. A new WEGO study finds that the majority—55%—say pharma isn't working collaboratively with patients. About 45% say the industry doesn't understand their real needs. But 46% take their criticism even further, saying pharma does understand—it just doesn't do enough to address those needs. (Only 9% of the total sample feel pharmaceutical companies are doing all they can to help.)

Smart medical marketers get it and are realizing that patient engagement has to mean more than simply creating portals or throwing up a Facebook page or two. "Social-media engagement shouldn't be a passive experience where you wait for patients to reach out to you," says Trish Nettleship, director of social media and influence for UCB, the biopharmaceutical company. "It's an opportunity to add value through dialogue. Our patients don't view pharma companies differently than any other. When you post a tweet about your airline experience, you expect a response within minutes, not hours and days—and the idea that you may not receive a response at all is inconceivable. It's past time for us to join the conversation."

In many ways, says Steve Simcox, CEO of Health Talker, a big part of pharma's take on patient engagement is this new understanding that it has so much in common with other industries. "Finance, automobiles, airlines—they all know who their best customers are and treat them like their best customers. And the idea is to continually delight those customers."

His agency, which uses the power of word of mouth to connect like-minded patients, "provides them with educational tools to fuel those conversations." The business potential is vast, since word of mouth propels more spending than any other form of marketing. But even more vast, he says, is the potential to evangelize patients. "They agree to spread the word, and what we hear from them, over and over, is that the healthcare journey is not a straight line. And when we ask why they do this work, there is a strong pay-it-forward mentality. They say, 'If only I'd known then what I know now, things would be different,' and they want to share it."

And it is working. Stanton points to success stories like Apple's ResearchKit and the Asthma Health App

1969 Whole Earth Catalogue first published, emphasizing DIY approach to health

1973 Simon & Schuster publishes *Our Bodies, Ourselves* urging women to take charge of their own health

1979 EPIC, now the leading EHR company, is founded

1987 250 members stage the first ACT-UP protest, taking to Wall Street to demand greater access to experimental AIDS drugs

1992 *SELF* magazine and Estée Lauder launch pink-ribbon campaign for breast-cancer awareness

2004 In his State of the Union address, Pres. George W. Bush vows to wire the healthcare industry

2008 Congress's stimulus bill includes \$30 billion for digital health initiatives

2009 Kaiser Permanente announces that its My Health Manager already has 3 million users

2010 Veterans Affairs launches Blue Button Connector, designed to give patients their data

2011 Dave deBronkart, best known as e-Patient Dave, gives influential TED Talk • A large 11-country survey demonstrates that more-engaged patients get higher-quality care with fewer errors

2012 Meaningful Use Phase 2 rules include reqs that at least 5% of patients communicate electronically • IT consultant Leonard Kish dubs patient engagement "the blockbuster drug of the century"

2013 HHS Secretary Kathleen Sebelius says EHR adoption has reached the tipping point, exceeding its goal for 50% of doctors' offices and 80% of eligible hospitals

2014 Deadline for attesting to MU Phase 2

2015 HHS announces intention to roll back the 5% rule, sparking an uproar among patient advocates

as examples of how willing people are to share data and participate in research, as well as the success of Novartis's "Take That, MS" campaign for Gilenya and Merck's customizable patient-engagement apps.

Moving forward, Nettleship predicts an organizational restructuring within pharma companies, "a key shift to centering around our patients, rather than our own internal functions. Patients are swiftly becoming drivers of their own healthcare and we need to accommodate them so that we can be effective partners."

And deBronkart forecasts even more upheaval as consumers gain control of all the data their health generates. "Access to our medical records will initially shock us," he says, "and then open our eyes and let us be actively involved in what's going on."

Recently, for example, he learned he was prediabetic and got serious about lifestyle changes, even beyond simple diet and exercise tracking. He paid closer attention to his sleep, enrolled in a diabetes-prevention program and lost 27 pounds in four months. "There is data that now lives all around me, data that I am using to manage my life. We are going to see much more personal awareness, linked by wearable devices and multiple platforms."

Assessing the risks of engagement

While the advantages of engagement are becoming clearer, there are concerns about who may be left behind. A recent study from Northwestern University reports that online patient portals, for example, potentially widen the gap in health disparities and that patients with less education, low health literacy and who are African American are significantly less likely to use them. White patients are 2.5 times more likely to be registered to use portals, and patients with good health literacy skills are 3.5 times more likely to be registered with the portal than those with weaker skills.

And even when people with fewer skills do sign up, says coauthor Sam Smith, a psychologist and cancer researcher now at Queen Mary University of London, it's surprising how reluctant they are to use the portals, even for such functions as refill requests, e-mailing their doctors or viewing test results. Those findings challenge the widely held view that even a little engagement begets more engagement.

"Even after the widespread disparities in registering for a patient portal, we still see inequalities in its subsequent use," he says, indicating that "there is no one single barrier to leveraging these kinds of technologies. And the fear is that the lower use of these functions may contribute to existing disparities in care."

Others worry more about what's happening on the other end of the spectrum, the engagement elite, such as those behind the fast-growing #DIYPS, using open-source software and algorithms to help those with diabetes fine-tune their own care. Such hacks are not only spearheading true breakthroughs and gaining tremendous followings but also getting increased scrutiny.

And many fear shoddy science. All it takes is a quick look at the average American's Facebook newsfeed to realize the very real risk of flimsy research. Be it the anti-vaccination movement, information about genetically modified organisms, Ebola risks or detox diets, there's no shortage of stupid when it comes to social media.

"There's so much power in knowing you're not alone, and that's the great thing about social media," says Brenda Snow, founder of the Snow Companies and an early pioneer on the engagement scene. "But people need to learn to ask questions before they share. Is it sourced? Is it reputable? Is the person credible? Just because someone has a blog doesn't make them an expert. If they're passing on information about a pharmaceutical product, has it been vetted?"

Most of all she worries about patients passing along information that "sets up unrealistic expectations and false hope. It's the most damaging thing you can do," Snow says.

But as far as deBronkart sees it, the more sharing of information the better, as patient activists get savvier all the time. "All the way back to the Reformation, if you want to increase the public's ability to sniff out BS on their own, they need to have access," he says. "I believe that over time things will get better. People will become more capable. If companies do something shady, like knowingly suppress research data, there ought to be the strongest consequences."

SixUntilMe's Sparling thinks that while there is still way too much finger-pointing in every corner of the engagement ring, pharma could do itself a big favor by just listening more intently. "Pharma keeps trying to jam itself into the conversation," she says. "The problem is often they look at the target audience as patients or consumers. We call ourselves 'people' and we want these companies to listen."

And pharma shouldn't expect patients to be patient. She points to the growing movement of diabetes hackers—a circle of people who, at least theoretically, are bypassing both providers and pharma—as a prime example. Sure, she concedes, that frightens certain stakeholders. But not patients. "Living with a disease that is chronic? That's scary. But people taking their lives and data into their own

PATIENT POINTS*

84%

of people say their doctors provide a patient portal

78%

of those who have wearable devices and fitness trackers say it would be helpful if doctors could access their data

64%

would sometimes choose telehealth options instead of in-person visits, if offered

27%

would always/often choose telehealth

67%

of doctors say they have noticed change in conversations with their patients since portals, health apps and wearable devices have become available

46%

of healthcare professionals plan to introduce mobile apps in the next five years

86%

of healthcare professionals think apps increase their knowledge of patients' conditions

72%

of healthcare professionals say health apps will encourage patients to take more health responsibility

hands? That's not scary. That is brave and brilliant."

As long as companies intensify their patient engagement efforts with transparency, authenticity and compassion, engaged patients will want to work with companies, these experts say. Engaged patients will even forgive the occasional misstep. What they won't forgive, though, is not talking to them at all. "When a patient community is struggling with these issues, life can be very dark," says Snow, who entered the industry following her own experiences as an MS patient. "During these hard times, these people need to be lifted up. All patients deserve that hope. If you don't have choices, life looks bleak."

Transformative healthcare takes patient-experience rethink

Consumer goods companies meet their customers where they live and create business and communications strategies that work with or around audience needs. Not so healthcare.

Creating more of a seamless experience will be the key to transforming how patients engage with the healthcare industry and how the healthcare industry will be able to effectively communicate with patients, said speakers at the inaugural *MM&M* Transforming Healthcare conference in New York City on April 30.

Michele Polz, Biogen's head of patient insights, said that unlike consumer companies that seek to fit into a buyer's life, the healthcare industry tends to create what it considers tools and health solutions that require patients to make an effort to tack them to their routines and everyday life, as if health were a distinct and separate part of their day.

She said the shortfall exists because patients are managing their own lives as well as their disease. Tools that hew to pharma's linear concept "fail to connect to the life of the patient."

To erase the distinction between illness and everyday life, drugmakers, insurers and healthcare providers need to look at health and health-related interactions through the patient's lens.

—Deborah Weinstein

*Sources: eClinicalWorks poll, conducted online by Harris Pol, April 2015; Research Now, March 2015