



PUT A RING ON IT

According to a WEGO Health survey of patient influencers, the pharma business needs to take engagement far more seriously than it has in the past. At the same time, there are signs that it is finally acting with more urgency—even more transparency—than ever before. **Jaimy Lee** unpacks the results

Patients want drugmakers to stop viewing them as sales targets and profit drivers. Some want to see the end of direct-to-consumer advertising, while others wish pharmaceutical companies would use real patients and tell real stories in ads and education materials.

Those were just some of the revelations from a survey conducted in May by WEGO Health. About 58% of the respondents identified themselves as patients and 23% as both patients and caregivers. The remaining respondents were either caregivers or health-care professionals.

About half of the 113 patient influencers who responded to the survey said they expect pharma's patient engagement to increase in effectiveness within a year—which represents a notable upward shift in optimism. For years pharma-patient engagement was considered limited, characterized as one-way communication under the best of circumstances. But social media and increasingly demanding and engaged patient populations have prodded drugmakers to begin changing the way they engage with patients. And now it seems the gap between what patients expect from the companies that make the medications they take and what drugmakers are willing to do to meet those demands given their legal, regulatory and financial constraints is finally shrinking.

"This is moving in the right direction," says WEGO Health CEO Jack Barrette. "There has been a shift and it may have been very gradual, but [the results] would not have been as good a year ago."

Still, pharma has work to do to improve perceptions of its engagement efforts with patients. Roughly 34% of surveyed patients said they agree that pharma companies are working collaboratively with patients and patient leaders to improve patient engagement. But nearly 45% of respondents said that pharma-patient engagement is at a standstill and that company efforts have remained the same over the past year.

THUMBS-UP, THUMBS-DOWN

In terms of the types of initiatives that resonate best with patients, 59% of survey participants said patient leader advisory boards offer effective, authentic engagement, while 48% view the use of materials using real patients rather than models or actors as the most effective way to engage with patients. Patients are less impressed with drugmakers collecting feedback on promotional campaigns, dedicated employee bloggers and sponsored community members.

When asked to anonymously suggest one change to how pharmaceutical companies might engage with patients, advertising was one topic brought up repeatedly by respondents, with one opining that there should be "less sexual innuendo in ads" and that pharma companies should "lessen [the] number of commercials on television, as they create false expectations of the drug."

Another participant suggested doing away with DTC advertising. "Stop direct-to-patient advertising!" the respondent wrote. "Laypeople have neither the education nor the clinical judgment to make medication decisions on their own. It puts physicians in a precarious position."

A third criticism related to the structures and objectives of patient advisory boards. A patient influencer suggested that drugmakers should endeavor to develop "visible and noticeable use of non-token patient advisory boards."

Patient-engagement experts noted, however, that some companies are considered more effective engagers than others. Novartis's branded website for Gilenya, its multiple-sclerosis drug, was cited as one example. Pfizer's work rewriting fair-balance information—the company used less jargon and more everyday language than in the past—was singled out for its effectiveness, as were Sanofi's engagement efforts with diabetes patients.

"BROADER ISSUES"

But broader issues affecting the industry as a whole are contributing to the demand and willingness among drugmakers to better engage and communicate with patients. This includes the increasing focus by pharma in developing drugs that treat rare diseases, which traditionally have more engaged patient populations, and the July passage by the House of Representatives of the 21st Century Cures Act, a bill that seeks to involve patients in the drug-development process (rather than engaging them only after a drug comes to market). Two other contributing factors are tied directly to healthcare costs: the rise in high-deductible health plans, which require more cost-sharing from patients, and the growing impetus to solve billion-dollar problems like medication adherence.

"There's a much better understanding of what the problems are," says Stephen Smith, a patient advocate and senior director of patient value for Medidata Solutions, which consults with drugmakers on clinical trials. "But they have long a way to go toward actually solving those problems."

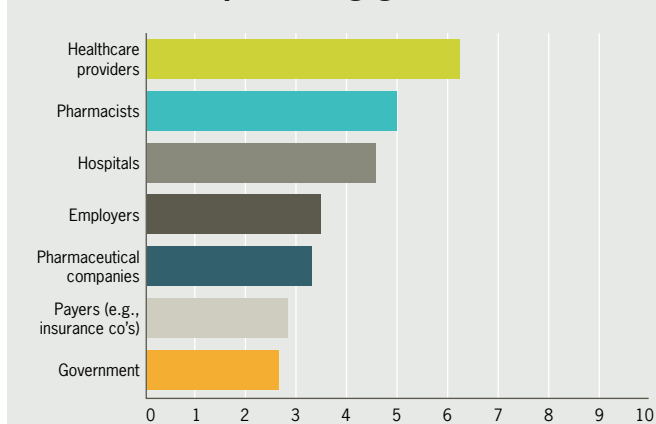
Smith, who wasn't involved with the survey, believes most pharma companies are ramping up patient-engagement efforts and patient-engagement efforts are not just limited to the drugmakers that produce therapies to treat rare diseases. Barrette agrees, adding, "We're seeing a perfect storm of market forces that are driving patient engagement."

That storm includes patient demands. Few patient participants (2%) said they were completely satisfied with how pharma companies identify risks associated with their therapies, with about 32% saying they are generally satisfied with risk identification. What patients want is "more transparency with the risk of taking their drugs" as well as more effort by drugmakers to "put all ingredients and possible allergy sources on the label," according to two respondents.

A slightly higher percentage of survey participants were more satisfied with pharma's financial assistance and support. Forty-four percent of patient influencers said they were "somewhat," "mostly" or "completely" satisfied with financial-assistance initiatives. Still, one patient said drugmakers should make financial-assistance programs easier, in part because "docs hate paperwork."

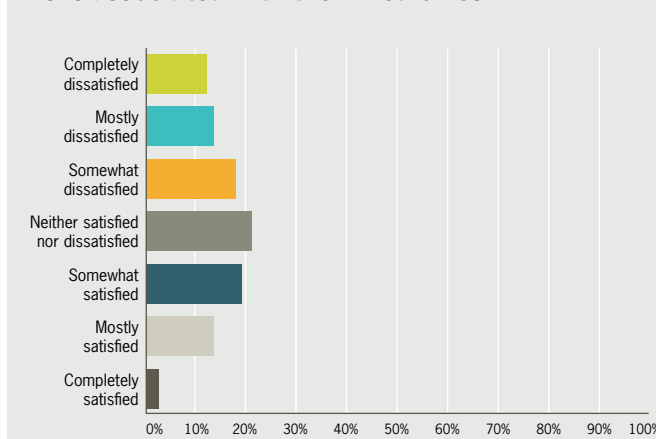
Almost half of the patient influencers (46% of respondents) believe that pharma companies understand the needs of the patients who take their therapies but do not do enough to address those needs. About the same percentage of respondents—45%—said they were troubled by pharma's lack of understanding and they don't believe that drugmakers understand the needs of real patients.

Healthcare stakeholders ranked in order of commitment to patient engagement



Source: WEGO Health Patient Engagement Study—Pharma Edition, 2015

Satisfaction with how pharmaceutical companies support patients' engagement by identifying the risks associated with their medicines



Source: WEGO Health Patient Engagement Study—Pharma Edition, 2015

A number of patient influencers were fairly up front in their critiques of the industry. "They should actually talk to us instead of relying on theory and profit," wrote one respondent. Another suggested that pharma companies should stop marketing treatments as miracle drugs because patients are devastated "when [a product] does not work at all or even close to what the advertisements claim. The true figures of efficacy should be more prominent."

Nonetheless, Barrette believes that the survey's findings are valuable to drugmakers because they show that patients want to engage with pharma companies and that they have an expectation that companies will increase their engagement. "There is a strong sense these companies aren't doing enough," he notes. "At the same time, they're about to and are starting to do more. We're at a point of change."

The survey is the first in a series of patient-engagement scorecards that WEGO plans to field. ■