

The Emerging Role of Patient COMMUNITIES

Social media serves up patient information to marketers.

Michael Dornan, a psoriasis sufferer for more than 17 years, started psoriasis-social.org in an effort to share his self-earned knowledge and experiences about the disease with other sufferers. On his site, Mr. Dornan explains how he uses the Internet to research treatments and possible prevention strategies and requests a dialogue about the topic with others.

“Mr. Dornan is just one example of the growing role of social communities in patients’ lives and treatment, as well as a good example of how valuable patient communities can be to pharmaceutical marketers,” says Kurt Mueller, chief digital and science officer at Roska Healthcare Advertising.

Mr. Dornan operates his own community, provides patients and caregivers with great resources and the ability to connect with one another, and serves on the board of directors for social-medicine.org.

“Imagine as a brand marketer, being able to connect and be supported by 20 advocates like Michael,” Mr. Mueller says. “This is extremely powerful. Companies should be taking advantage of all the information that is available through patient communities by creating outreach programs that cultivate and activate mentors like Mr. Dornan. Peer mentors are the most powerful resource marketers have.”

Jeffrey Lee Simons, director of social media at Drug Market Info, agrees. Mr. Simons says that companies should partner in any way they can — at the national level or at a grassroots level — with patient advocacy groups. For example, some companies are establishing patient advocate roles that interact closely with patients to help with access and information on therapy.

Mr. Simons’ colleague, Mary Beth Cicero, principal of Drug Market Info, says companies

can participate in local walks and fund-raisers and have company personnel talk with patients directly on a local level.

Marketers will find that patient communities are generally open, honest forums that provide a wealth of information about patients’ concerns and behaviors.

“People are surprisingly candid in social media settings,” Mr. Simons says. “This allows for a level of true communication, if the company is willing to listen and engage honestly.”

If a company acts as, and is therefore seen as, an honest participant, it can earn trust, build brand loyalty, and forge a larger number of one-to-one communication relationships than it ever could through other means, Mr. Simons adds.

He predicts that social media will become the strongest customer relationship management tool ever invented, affording strong channels for increased patient compliance, problem resolution, knowledge sharing, drug interaction information, and recall or alert dissemination.

Digging into the Patient Space

Initiating a crowdsourcing experiment is a simple way to test the value of social media, Mr. Mueller says. He suggests asking community members to create the best customer support program possible for the brand.

“Engaging the patient as a drug development partner can effect immediate, significant, and positive change.”

DR. JEFFREY HANDE
Medidata Solutions



“Patient communities will become the strongest customer relationship management tool ever invented.”

JEFFREY SIMONS / Drug Market Info

“If marketers actually task the social universe with solving a problem, they’ll be surprised by the results,” he says. “When the social networks go to work on a solution, marketers will find consumers come up with many ideas they never even considered.”

While all solutions may not be 100% viable, gaining insights from actual patients and caregivers will be invaluable in shaping the campaign.

“And all of this costs zero dollars,” Mr. Mueller says.

Nick Colucci, president and CEO of Publicis Healthcare Communications Group, also believes marketers can collect a wealth of knowledge from patient communities.

“Patient communities often stem from personal experiences where they see room for improvement or the need for information,” he says. “Interacting with these communities before campaigns are developed will provide insights that bring value back to that community and the marketer.”

This type of feedback from patient advocacy groups can really help companies understand how patients view their therapy and what their needs are, Ms. Cicero says.

“A good course of action is to gather as much information on patients as possible, before doing formal primary research,” Ms. Cicero says. “Companies developing products should interview patients to provide necessary treatment insights when assessing markets and market potential. In this way unmet needs are uncovered and the disease state as a whole is evaluated, not just the product.”

Another benefit to mining information from patient communities will be the data to prove better health outcomes, says William Crown, Ph.D., president, commercialization, OptumInsight Life Sciences.

“With 133 million people in the United States today suffering from chronic diseases that significantly impact the quality of their lives, there is ever-increasing pressure on the healthcare system to provide better outcomes at controlled or reduced costs,” he says. “As the healthcare landscape transforms to improve access and emphasize collaboration, patients increasingly are at the forefront of changes. These include a trend toward real-world data, especially patient-reported outcomes in post-marketing studies as regulators and payers demand to see real-world effectiveness. This raises the importance for life-sciences companies, providers, and payers to listen to patient needs in support of healthy behaviors, such as prevention services, and to address adherence issues to medication protocols that are critical to patient wellness.”

No stakeholder group is better situated to impact drug development in the 21st century than empowered patients, says Jeffrey Handen, Ph.D., VP, clinical solutions, Medidata Solutions Worldwide.

“Patients will ultimately define the acceptable risks and side effects in the risk/benefit



“ Patient communities will provide the data to prove better health outcomes. ”

DR. WILLIAM CROWN
OptumInsight Life Sciences

value equation of drug development,” Dr. Handen says. “Right now, patients, can operationally impact the single biggest challenge to clinical development: recruitment. By re-engaging the patient through patient advocacy organizations and other mechanisms, not as a consumer, but as a drug development partner, the industry and the regulators can effect immediate, significant, and positive change in getting meaningful therapeutics to market in a sustainable model.”

Rules Of Engagement

However, before a company decides to engage with patients online, it must first make a commitment in doing so. According to Brian Loew, co-founder and CEO of Inspire, marketers should not solicit patient involvement if they are not ready to accept a volume of feedback, both good and bad.

“Companies need to decide first whether they really want to talk to patients and listen to them,” Mr. Loew says. “If companies don’t want to listen, that’s okay, but if they do, they should first ask for permission from the group organizer. Next, they need to clearly identify themselves within the community. Finally, they need to be open and honest with patients about what they want to know, why they want to know it, what they are going to do with the information, and what’s in it for the patients.”

Marketers need to throw away the traditional rules of marketing when developing a patient engagement campaign and create new, more relevant strategies, says Gene Guselli, president and CEO of InfoMedics.

“I believe the key to breakthrough thinking on patient engagement is to not get intellectually locked into current models,” he says. “Beyond DTC marketing, the industry is still in its infancy relative to patient en-



“ Patient communities can be used to gather as much information on patients as possible, even before primary research. ”

MARY BETH CICERO / Drug Market Info

Physicians Perceive Value in Patient Communities

Physicians believe that online physician and patient communities have promise for improving patient care, but they are struggling with the associated challenges, according to a 4,033-clinician study conducted by QuantiaMD and Care Continuum Alliance.

Almost 90% of physicians surveyed use at least one social media site for personal use, while more than 65% have used at least one to support their professional practice. Only 11% of study participants were familiar with online patient communities, but of those with a familiarity, two-thirds believe these communities have a positive effect on patients. Almost 40% of these physicians say they already recommend these communities to their patients and another 40% would consider recommending them.

According to the study, physicians believe online patient communities are especially beneficial for:

- » Rare diseases
- » Cancer
- » Chronic illness
- » Maternal and infant care
- » Wellness and prevention
- » Weight management
- » Depression

Source: QuantiaMD. For more information, visit quantiamd.com.



“The key to patient engagement is to avoid getting intellectually locked into current marketing models.”

GENE GUSELLI / InfoMedics



“Companies need to be consistent and authentic, because if they are not, patients will detect the misconnection right away.”

BRIAN LOEW / Inspire

gagement. As such, the industry has a significant opportunity to create patient engagement models that include state-of-the-art methodologies that are technology driven and

outcomes based.”

The first place to start is to offer disease — not product-oriented — patient valued information to instill credibility. Once trust is established, the industry will be able to longitudinally build meaningful relationships with patients.

“As patient participation rates increase, a valuable patient experience data asset will emerge, enabling the industry to influence its key stakeholders,” Mr. Guselli says. “But the creation of these patient data assets must adhere to scientifically accepted outcomes methodologies and be truly unbiased.”

Credibility is key when engaging with patients, as is respect, says Mr. Loew. Marketers should strive to provide information at multiple educational levels, not just the product-insert level.

“The biggest hurdle for the industry is to remember that patient communities are not a place for one-way, broadcast relationships, but rather honest, two-way conversations,” he says. “And patients are very adept at sniffing out phonies. Pharmaceutical



“Peer mentors are the most powerful resource marketers have.”

KURT MUELLER

Roska Healthcare Advertising

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