

Mining for *Gold* in Patient Communities

Companies find market research value from both public and private patient communities.

During a recent social media summit with patient community members who live with diabetes, Roche discovered a vital piece of information that changed its marketing and improved its credibility within the patient community.

According to Mike Lawson, head of experience at the Diabetes Hands Foundation and a diabetes patient who attended the summit, Roche was demonstrating its glucose meter to the assembled group of community patients when one patient mentioned that the meters in the ads featured unrealistic glucose readings. Heeding the patient's feedback, Roche changed the numbers in the ads to better represent a number a diabetic could relate to.

"Open dialogue like this can never be wrong and pharma companies don't do it enough," Mr. Lawson says. "Roche is an innovator in social media. Usually, big companies tend to be leery of talking openly with patients because they can't control what is said."

For the past four years, Roche has hosted an annual social media summit, inviting 30 or so diabetes patient bloggers and Facebook and Twitter users to have an open dialogue about the disease, its treatments, patient behavior, and concerns. Roche uses these conversations to determine what it could be doing better.

This example goes to the core of the value that patient communities — whether public or private — can bring to bear for market research.

Creating interactive relationships with consumers benefits both the company and patients by identifying unmet needs and correcting misperceptions, while providing patient education, support, and information about access to therapies.

"The industry needs to build relationships based on dialogues with patients rather than monologues directed at patients," says Tom Sellers, senior director of patient advocacy at Millennium: The Takeda Oncology Company. "It's a two-way street; we learn a lot from patients and we can provide patients with information to help our medicines be more effective."

Millennium actively engages with up to 25 organizations in the cancer community, exchanging information with patients within those communities. And, in some cases, the company provides financial support for organizations such as mylifeline.org, a nonprofit that encourages cancer patients and caregivers to create free, customized websites.

This year, Millennium is launching a new initiative

called the Cancer Advocacy Council. The group will be made up of thought leaders in the cancer community. The ongoing conversations will revolve around real issues facing cancer patients. According to Mr. Sellers, a cancer patient, caregiver, and survivor himself, the current paradigm in the industry is to assemble patient advisory boards around a specific drug or disease for one day or a few days. Millennium's goal for the Cancer Advocacy Council, however, is to have a forum for continuing relationships of a strategic nature with thought leaders in the cancer community for as long as it can be sustained.

Patient Private and Public Communities

The pharmaceutical industry's interaction with online patient communities has increased over the past few years.

"Many pharma companies are paying attention to online patient communities and other social tools, such as blogs and videos, to better understand their target audience," says Frieda Hernandez, VP of strategic initiatives at Siren Interactive, a relationship marketing agency focused on understanding the behaviors of patients and physicians dealing with chronic rare diseases.

"If a pharma company can fill an unmet need and add value to the community, this can lead to a relationship with patients and, over time, build trust. This is especially true in rare disease communities, where social media has provided the means for widely dispersed patients and caregivers to become hyper-connected and amplify their voices."

New tools now make it possible to quickly tap into the wealth of relevant information on a particular disease



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TOM SELLERS

Millennium: The Takeda Oncology Company



“ New tools now make it possible to quickly tap into the wealth of relevant information within patient communities. ”

ROBERT CARMIGNANI / eHealthcare Solutions
@E_HS

state, product, or consumer discussion virtually in real time. With the advent of market research tools that can easily mine these insights from patient posts online, marketers can identify unmet needs and collect knowledge about patient community behavior by monitoring public patient communities.

“These tools are an enormous advancement for marketers to access and leverage online patient communities and the critical information they provide,” says Robert Carmignani, executive VP, sales and marketing, eHealthcare Solutions. “Until now, the vastness and fragmented nature of the Internet has made it particularly difficult to efficiently access relevant information from social media channels.”

On the other hand, private patient advisory boards — both virtual and in person — are also extremely valuable, Ms. Hernandez says.

“The benefit of a private group is that patients and their caregivers can be asked about specific initiatives and can help cocreate projects,” she explains. “Private communities also effectively navigate around the 1-9-90 rule, or participation inequality, which theorizes that

small groups of people — or 1% — are the principal content creators of the community; 9% interact through comments, and 90% lurk. In private communities, participation is spread more equally across all members.”

According to Julie Schlack, VP of innovation at Communispace, which provides privately recruited online communities for market research, the membership of a private community can be much more targeted toward the types of patients marketers need to hear from. Another benefit is increased participation. As opposed to the 1-9-90 rule of public social media participation, in private communities, the average participation rate can be as high as 64% to 85%.

“Although private community members may be incentivized through a modest sum, the ROI is often higher compared with public forums, because their participation rates are so much higher and they will directly answer the questions posed to them,” she says.

Ms. Schlack adds that people in a private community setting will speak much more freely and honestly than in a public social media forum, and private communities are actively facilitated by community managers.

“For example, our managers are visible in the community every single day and actively demonstrate that we are listening, and this is hugely motivating and easier to do in the construct of a private patient community,” she adds.

MYTH BUSTERS

Experts poke holes in commonly held misperceptions about working with patient communities.



JACK BARRETTE

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There is a misunderstanding that patient communities do not want to hear about pharmaceutical products from pharmaceutical companies. The misperception is that info is only useful if it's general, disease-specific, and unbranded. But communities are interested in good content that goes beyond the disease to brand-specific data that dive deep into how drugs work, side effects, dosing, etc.

The industry believes that consumers only want to hear about lifestyle aspects of a drug, but in fact we hear the opposite. Patients report that they would like to have more information about the science. Patients actually want to talk about a nausea side effect or a dosing issue. It's a win-win; sponsors can be much more explicit and specific in questioning the panels, and, in turn, the communities would prefer to help patients understand what the limitations of a product or treatment are, instead of having vague conversations.

JULIE SCHLACK

VP, Innovation
Communispace

There are two myths I'd like to bust. The first is that companies can scrape the Web for minimal cost rather than paying to create online patient communities and achieve the same results. While Web mining can be used for monitoring trends, if companies just rely on public social media content they are only getting a fraction of relevant content and may get a less representative or relevant sampling of people, who know less of who they are and where they are coming from.

The second is pharma companies don't dare talk to patients. That is not true. Whether on Twitter or brand pages or private communities, in this day and age, companies don't dare not talk to patients.

When GlaxoSmithKline launched its weight-loss drug Alli in 2005, it was one of the first pharma companies to provide an online community for discussion about the benefits and potential treatment effects of taking the drug.

“GSK was definitely a pioneer in the whole social space, particularly in using an online community,” Ms. Schlack says.

She says in 2010 social communities started to gain some real traction, and she attributes the relatively slow rate of adoption to many factors, but the primary hurdle is the industry's legal and regulatory concerns. Because



“ Patient communities want to interact with the companies that make the treatments for their members. ”

JACK BARRETTE / WEGO Health
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it is easier to handle regulatory risks within a private community, they are being more rapidly adopted by pharma than public groups.

“The industry feels safer being able to proactively address regulatory concerns around adverse events, off label usage, and HIPAA in the private setting,” Ms. Schlack says.

At WEGO Health, a social network built to support health bloggers, Tweeters, and patient community leaders, pharma companies can interact privately with health activist leaders who have vast experience with their disease and its treatments. These leaders offer insight on how best to educate and motivate the patient community as a whole.

“The value of talking with community leaders is their ability to interpret the social monitoring noise and drill down to what really matters to the community,” says Jack Barrette, CEO of WEGO. “Information gathered from leaders can help companies stay ahead of the patient curve. To keep up with a patient community, the industry needs to talk to the people who are creating the content, not those who are commenting on it after the fact.”

Leaders will be able to provide powerful and actionable insights that regular members of the community may not have, however, marketers must not forget that these leaders are not representative of typical patients.

“Social media is so pervasive that it may seem that bloggers are like everyone else, but they are not,” Mr. Barrette says. “They are more motivated, more passionate, and more likely to take action. We must not interpret their actions as typical.”

Mr. Barrette says more pharma companies are taking the lead in providing and support-



“ Pharma companies are paying attention to online patient communities to better understand these target audiences. ”

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ing patient communities, and according to reported patient feedback, the communities are very receptive. In partnership with the Digital Health Coalition, WEGO conducted an industry survey and the results showed that the number of companies involved in online patient communities has increased since 2009, and more pharma companies are participating with patient communities than hospitals and insurers. The survey asked health activists to name companies that are actively participating in social media and both Sanofi and Novartis were recognized.

In 2010, Sanofi US created the discussdiabetes.com blog as well as established Facebook and Twitter accounts. Laura Kolodjeski, Sanofi’s diabetes community manager, is the face of the blog, and she interacts directly with members.

“According to our survey, the diabetes community said Sanofi’s efforts around diabetes care is what it has been looking for all along, and they questioned why more companies aren’t doing this,” Mr. Barrette says.

Novartis has maintained a community — cmlearth.com — for patients with chronic myeloid leukemia (CML) since 2008. The social network is designed to connect the CML community, including patients, patient groups, and healthcare professionals from around the world.

“Here is a big pharmaceutical company that is very conservative but doing what it should be doing,” Mr. Barrette says. “The online oncology and hematology consumer community has commented that Novartis is always there to answer questions and give educational material, and has questioned where are the other companies.”

While digital capabilities have certainly enhanced opportunities for engagement by providing an alternative to face-to-face focus groups and interviews, Mr. Sellers cautions that the industry must not ignore the other channels that are available for patient communication.

“It is important to talk about patient com-



“ A number of companies are tapping online communities to consult with caregivers, patients, and healthcare providers. ”

JULIE SCHLACK / Communispace
jwschlack

munities in a broader sense than just online or virtual communities,” Mr. Sellers says. “Patients engage in different ways and there are certainly a lot of really good solid online communities that provide places for patients to interact, but a lot of those are often augmented by face-to-face support groups that are equally important to patients. Being able to hear from patients in all types of settings provided by any platform will provide valuable information about patients and help us identify unmet needs.”

Marketers must find ways to access and harness the strength of this market research information with regulatory guidance and support, Mr. Carmignani says. There is a tremendous amount of relevant, insightful, and timely market research information readily available online, and marketers need to identify effective, approved ways to access the power of that information. The historically expensive, cumbersome, and time-consuming focus group approach will remain effective for some engagements, but in many instances, it will yield to the immediacy and depth of social media-based market research, where patients, caregivers, and other healthcare consumers often speak more freely and openly about products, patient experiences, and outcomes.” **PV**



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Patient Communities

Industry leaders share best practices on interacting and sustaining online patient communities.

Tom Sellers brings a unique perspective to his role as senior director of patient advocacy at Millennium, The Takeda Oncology Company.

For many years, Mr. Sellers has been on the patient advocacy side of the table — as a cancer survivor, as a former CEO of the National Coalition for Cancer Survivorship, and as a former chief financial officer of the American Cancer Society in New England. He has a tremendous amount of insight on what it means to be a patient and what resonates and what doesn't.

For example, he says there is a right way and a wrong way to have a dialogue with patients; connections need to be truly two-way, and pharma companies need to listen as much as they "tell."

"Historically, some company presentations were the standard dog-and-pony show when they bring patient groups together," Mr. Sellers says. "The discussions centered around the company's products and what is coming down the pipeline. Five or 10 years ago, these meetings were happening without much real two-way dialogue. Today, there is a lot more dialogue and a lot more venues and mechanisms for having that dialogue, and this is where the benefit of social media and a Web-based presence can support the type of work we are doing."

Another person who brings a vast amount of patient experience to his position is Mike Lawson, head of experience at the Diabetes Hands Foundation. He finds it frustrating to constantly be sold to by the industry. He encourages the industry to provide valuable, meaningful information, along with the hard sell.

"As a person with diabetes, I get pitched

Creating online dialogues with consumers benefits both companies and patients.

products 24/7," he says. "I get junk mail in email, snail mail, Facebook ads. I understand it's the industry's job to sell its products, but these are great opportunities to create genuine relationships going to waste."

Mr. Lawson suggests the industry should strive to create a relationship with patients first by providing suggestions, research, and pertinent articles on an ongoing basis.

"Then when companies want to sell their products, I will be more apt to listen, but I'm not going to click on a link just because a company wants to sell me something today," Mr. Lawson says. "First, companies need to establish a genuine, long-term relationship that goes beyond selling products or the next newest thing."

Part of the challenge, Mr. Sellers says, is to keep the objective of the communication in mind at all times.

"We need to keep in mind how the interaction is going to be mutually beneficial; relationships can't be one way and they must be broader than financial support," he says. "It is about working together for what's best for patients."

Mr. Lawson also believes making sure everyone feels comfortable within the community is key to success.

TuDiabetes welcomes members through an application approval process, and this

membership application process helps ensure a robust community that is very diverse. Moderators monitor posts to guard against people using vulgarities or inappropriate posts, and if someone's comments are not constructive or are not furthering the conversation, they will be removed. Another rule is that pharmaceutical companies are not allowed to become members.

"Membership application helps with success of any patient community and we do have policies about who can be a member and what exactly can or can't be discussed on the site," Mr. Lawson says.

Maintenance and facilitation of the community is very important, as is setting expectations of engagement to keep everyone on the same page.

"We work hard to make sure we all understand what the objectives are," Mr. Sellers says. "Our staff spends a lot of time in face-to-face opportunities with patient groups and leaders to keep a relationship going, and we lay out an annual plan for how often we are going to work together and what types of communications we are going to have."

For example, Millennium conducts a monthly conference call with key leaders and a quarterly face-to-face meeting with many of the leaders of the organizations it has relationships with.

"Millennium develops and supports programs that are beneficial to patients and educates them about treatments and therapies and how to access them," Mr. Sellers says. "We see our role as a convener, both within the company to bring together those who can benefit from hearing from the patient groups directly and to convene patient groups that can help each other."

PATIENT COMMUNITY CASE STUDIES ▶▶

Experts offer insights on successful social media community engagement.

Diabetes Hand Foundation Provides Worldwide Support

MIKE LAWSON

Head of Experience, Diabetes Hand Foundation

In its fifth year, the patient community TudiaDetes, sponsored by Diabetes Hand Foundation, has reached a milestone of 25,000 members, becoming the biggest online community for diabetes. The community is not only large, but very active, with videos, speaker events, and discussions on a daily basis. Diabetes Hand Foundation also sponsors the Big Blue Test, a program that encourages people with diabetes to test their blood sugar, exercise for 14-20 minutes, test again, and share their experience on BigBlueTest.org. The mission of the program is to raise awareness about the importance of exercise in connection with diabetes management.

For every test conducted, people with diabetes in need receive life-saving supplies through Big Blue Test grants that are awarded to humanitarian diabetes charities in the United States and around the world. Roche Diabetes Care sponsors the Big Blue Test. The test has evolved greatly since its start in 2009, each year gaining participants and subsequently larger donations. In 2012, there were 20,000 entries collected in one month, which resulted in a donation of \$100,000 from Roche Diabetes Care. These funds will be granted to charities in Haiti and the Dominican Republic and parts of the U.S.

Millennium and Hurricane Sandy



TOM SELLERS

Senior Director of Patient Advocacy, Millennium: The Takeda Oncology Company

If the industry becomes more structured and comprehensive in listening to the patient voice through whatever means and acting on what it hears, it will have a bigger impact on patients and its own reputation.

For example, when Hurricane Sandy hit, many of the hospitals in New York were devastated and many patients who were scheduled to start a round of chemotherapy that week couldn't get in touch with their doctors or the hospitals.

One multiple myeloma patient called the International Myeloma Foundation (IMF) about the dilemma.

"The IMF called Millennium, and our staff was able to help get that person to treatment and that is exactly why we do what we do," says Tom Sellers, senior director of patient advocacy, Millennium: The Takeda Oncology Company. "An important reason to listen to the patient voice is to help us understand why we do what we do. When we bring the patient voice right into the company, everyone sees the reason why they are doing their job, and that reason is someone out there needs our therapy."

Siren Increases Disease Awareness



FRIEDA HERNANDEZ

VP, Strategic Initiatives
Siren Interactive

Siren Interactive was engaged to increase targeted patient visits to an unbranded disease education website.

"We performed online intelligence and learned that patients were not identifying with the general disease term but with specific subtypes of the disease," Frieda Hernandez, VP, strategic initiatives, Siren Interactive. "Using this insight, we optimized the existing site content

around keywords and created new content on the disease subtypes. It's important to listen to what patients are saying online."

As a result, there was a 200% lift in traffic to the site with a 30% increase in registrations for email updates.

UCB and Rheumatoid Arthritis



JULIE SCHLACK

VP, Innovation, Communispace

In an effort to help people suffering from severe central nervous system or immunological disorders to lead normal, everyday lives UCB listened to rheumatoid arthritis patients to create a specialized fitness program that strives to offer patients both innovative new medicines and groundbreaking solutions that go beyond drugs.

Building on this platform of dedication to holistic patient care, UCB sought to develop a fitness program for rheumatoid arthritis (RA) sufferers. While medication can help to slow joint damage, a healthy balance of rest and exercise, in combination with patient education and support programs, is a vital component to patient relief and quality of life. UCB saw a void in effective fitness education and materials for RA patients.

"Armed with this knowledge, company representatives talked with RA sufferers to identify their fitness needs and in partnership with The Cooper Institute, we came up with a solution that can be customized by each patient, called the RA Fit Kit," says Julie Schlack, VP, innovation, Communispace. "This is an example of how a patient community had a material impact on a client's business."

▼ For more information, visit rafitkit.com.