

Patient Communities: Getting to Know You

The industry is tapping into the wealth of market research available through patient communities.

In 2010, UCB and PatientsLikeMe launched a patient community designed as an online forum for epilepsy patients to share their experiences in order to, hopefully, improve their own personal disease management. UCB has used the site as a market research tool to better understand its patients, their lives, and treatment experiences through the collection of outcomes data and market research on what patients need. That was the beginning, and as other companies follow suit, patient communities are emerging as the new platform for market research.

“We have experienced the benefits of collecting patient reported outcomes from the online epilepsy community that we sponsored with PatientsLikeMe,” says Sue Curro, VP, senior global project leader, patient solutions, UCB.

Ms. Curro says UCB is taking the research a step further and is analyzing the data to determine if there are additional endpoints or markers that should be looked at in the trials.

“In the same way, we see the opportunity to query a group of engaged patients as a way to better understand the patient/physician dialogue to identify areas of unmet need that can be addressed by a comprehensive, focused patient support and marketing strategy,” she says.

(For more information on the UCB patient community for patients with epilepsy, visit patientslikeme.com/conditions/3-epilepsy.)

Patient communities such as UCB’s turn up the volume on patient voices and this is beneficial to both the patients and the companies that are willing to listen, says Ben Heywood, president and co-founder of PatientsLikeMe.

“Any time a company engages with patients directly and understands their needs more concretely, it has the opportunity to deliver better value,” he says.

Pat Choumitsky, senior product manager, immunology, UCB, says her experience has

proven that patient communities are invaluable to the development of marketing strategies.

“We’ve created a private online patient community through Communispace that allows us to listen to patients passively, while actively engaging them in market research activities in an iterative way,” she says.

Two basic types of market research surveys are emerging in this new channel — active and passive. According to Daniel Ghinn, CEO, director of digital engagement, Creation Healthcare, passive listening is the observation of conversations taking place and analyzing patient experiences from these conversations; and active listening is a form of primary research that involves deliberately participating in a community, openly prompting discussion, and asking questions of its patient members.

Despite its direct access to patients, market research of patient communities cannot stand alone, but should be used as a supplement to more traditional methods. Data collected from the patient communities should be combined with the results of other efforts to create a comprehensive impression of the patient.

“Patient communities provide only one component of a market research study,” Mr. Ghinn says. “For example, we carried out a patient study for a pharmaceutical company across 16 European countries in multiple languages, but we aligned patient responses from each country with what we already knew about cultural trends across the region to build a complete picture that was then used as the basis for developing a major European digital engagement strategy.”

One of the major benefits in using patient communities includes providing valuable information about consumers. Another is that it also provides an opportunity for developing relationships with them.

“As a marketer, I believe that a genuine give-and-take relationship with a customer leads to a true understanding of each other’s



needs,” says Jim Dayton, senior director, emerging media of Intouch Solutions. “Pharma companies need to engage the online patient communities to gain this level of understanding about their customers.”

The first step to achieving a meaningful level of engagement is working with the patient communities to listen, or monitor, some of the conversations going on and see if pharma can add value to those conversations, he adds.

Patient communities can also open doors to patients that have otherwise been hard to research. For example, traditional market research companies have historically struggled to find cancer patients, to the extent that some oncology research is simply not conducted due to feasibility.

Patient engagement company Inspire part-

ners with national patient organizations, including several cancer organizations, to provide community platforms for patients and relevant market research opportunities for life-sciences companies.

According to Brian Loew, co-founder and CEO, Inspire, two recent research projects involved providing patient information to two major pharmaceutical companies derived from two of Inspire’s cancer support groups. Inspire conducted a detailed survey for Stage IV lung cancer patients that provided relevant perspectives of several hundred lung cancer patients and caregivers, a larger study than what had ever been previously conducted around this issue, Inspire reports.

“The client company was able to understand seriously ill patients’ attitudes about en-

rolling in clinical trials that would treat symptoms of the disease, but not the cancer itself,” Mr. Loew says.

Another large pharmaceutical company requested a large study with Inspire’s bladder cancer patients and discovered that patients had been experiencing unnecessary and severe pain during the administration of a therapeutic that has been on the market for years.

“This was news to our client and led to plans to re-educate physicians about administration of the drug,” Mr. Loew says.

These projects were successful because the companies had the opportunity to hear from large and engaged oncology patient communities in a way that was not available just a few years ago.

“This is new ground for many, but the companies we are working with are finding insights that would not have been available in as timely a manner elsewhere,” Mr. Ghinn says. “For example, outside of pharma, when we developed a digital strategy for the World Health Organiza-



“ Companies are finding insights from patient communities that would not have been available so quickly before. ”

DANIEL GHINN / Creation Healthcare



“ A genuine give-and-take relationship with a customer leads to a true understanding of each other’s needs. ”

JIM DAYTON / Intouch Solutions

tion's awareness initiative around antimicrobial resistance, we were able to use research carried out via patient communities to prioritize the most effective topics and social media channels."

The explosion of social media channels and outlets has made it easier for marketers to find patient communities, be it a formal advocacy group or independent patients who are simply

asking for information regarding a specific disease or possible treatments.

"Patient communities have always been an important stakeholder in healthcare marketing and I would suggest they are one of the most important stakeholders in the industry," says Michael Parisi, managing partner, Ogilvy CommonHealth Worldwide. "Companies

need to see the increasing value of these patient communities, engage them, and supply them with the answers they seek."

Patients who engage in patient communities provide authentic feedback, which is another benefit to marketers.

"Active patients engage two to three times a week and their motivation is to share their ex-

SOUND BITES FROM THE FIELD ▶▶

Being able to really get to know the target patient is the major benefit of using patient communities for market research, but there are also many other advantages.



MICHAEL J. KONOWICZ is Executive VP, Innovations, Communications Media Inc., a promotion planning and buying

organization concentrating on the pharmaceutical industry. For more information, visit cmimedia.com.

“Tapping into the thoughts of online communities is a great way to get into the true psyche of the patient. In focus groups and other forms of market research, we know the observer effect is alive and well, in that the act of observing will influence the phenomenon of being observed. But in patient communities, those who are struggling with or are overcoming the battle with their health concerns are usually open, honest, and unfiltered. By observing that naked dialogue, we're able to enhance our research with those additional insights for messaging or a media plan strategy.”



SADRON LAMPERT is VP, Copy, Snow Companies, a boutique agency specializing in direct-to-patient and word-of-mouth

communications for the pharmaceutical and healthcare industries. For more information, visit snow-companies.com.

“We believe that the only risk in using patient communities for market research is being unprepared to hear what patients have to say. The benefits, though, are far greater, particularly in the case of smaller, underserved patient populations. Patients are going to react to marketing messages through the prism of their own daily challenges and, in some cases, stigmas that they face. To craft messages and communications that resonate with these communities, it's critical to understand what they need to hear.”



PETER H. NALEN is President and CEO of Compass Healthcare Marketers, an interactive and marketing services agency focused on the patient

experience, especially those with rare and orphan conditions. For more information, visit compasshc.com.

“Patient communities come in many shapes and sizes. In general, diseases and conditions that are serious, chronic, and rare are the most likely to have robust and active patient communities that are highly engaged in social media. Usually, the smaller the patient population, the more influential — and well-organized — the patient community is. That's because small patient populations depend heavily on each other for information and advice, and they rely on social media and organized patient communities, including advocacy groups, to share their experiences and knowledge. Small patient communities are tight-knit, and can be difficult to integrate. Working with them requires demonstrating an understanding of the patient experience and an intention of providing some kind of assistance in the form of resources, information, therapy, materials, etc. One of the major risks is that if you don't do your homework, or don't come off the right way, you can easily disenfranchise yourself from the influential people in the community who may share their discontent throughout social media. On the other hand, if you do the right things, you can harness the good will of the community and access the patients you need for market research. The benefit of working with patient communities goes far beyond the market research. You can also create valuable and lasting relationships with brand advocates who have the power to influence many other potential patients in the community.”



PATRICK O'SHEA is Partner/Account Service Lead for FingerPaint Marketing, an integrated marketing and advertising firm. For more information, visit fingerpaintmarketing.com.

“With the advent of social communities, we now have a wonderful opportunity to view our patient audience in a more open and trusting peer-based environment that actually encourages information and emotive sharing. This allows us to identify who truly influences their behaviors and how they interact with like patients; determine how much or little medical information will influence, create, or drive behaviors toward a better outcome; and most importantly, listen in on the collective dialogue to better understand where the opportunities exist to advance the brand. In this way, community settings enable researchers to cut through all the superficial features/benefits clutter and engage with patients and other stakeholders on a much deeper level. For companies striving to add value to the brand experience, a more comfortable format for research can be invaluable.”



MICHAEL YOUNG is VP, Alliance Management Group at PPD, a CRO providing drug discovery, development, and life-cycle

management services. For more information, visit ppdi.com.

“Pharmaceutical and diagnostic market research conducted within patient communities can provide unique insights into therapy adoption rates, clinical trial participation, and whether benefit messages are resonating with target demographics. As former president of the board of directors of the Cutaneous Lymphoma Foundation, I have encouraged more market research with organized patient communities to truly understand both clinical and treatment access issues as well as concerted efforts to collect patient-reported outcomes per recent FDA guidance. Some of the most valuable market research for the industry is of the patients, ultimately, for the patients.”

periences so they can improve the lives of others,” Ms. Choumitsky says.

These patients are open and honest about their needs, wants, likes, and dislikes.

“This authenticity allows marketers to develop creative imaging and messaging, and test these concepts to narrow the best choices and make the modifications and tweaks before going into rounds of qualitative and quantitative testing, resulting in stronger, more reliable, motivational, and breakthrough results,” Ms. Choumitsky says. “It is always less expensive to get creative right the first time.”

Mr. Parisi agrees and encourages marketers to listen to the authentic tone and language of these communities to better understand the physical, psychological, and emotional barriers that surround a disease or treatment category.

“Pharma companies can work collectively with patient groups to build journey maps or engagement models that look at the impact a disease or treatment may have on one’s day-to-day life and help develop support programs and tools to drive better outcomes,” he says.

UCB’s market research success with patient communities has been so great that it encourages others in the industry to use it.

“We highly endorse the online patient community as one of many channels for input for



“ Companies are able to understand seriously ill patients’ attitudes about enrolling in clinical trials through patient community research. ”

BRIAN LOEW / Inspire

market strategy,” Ms. Curro says. “Patients are on a journey in their disease experience. When a company can ask patients who are at various



“ Patient communities are invaluable to the development of marketing strategies. ”

PAT CHOUMITSKY / UCB

stages and trajectories in the management of their conditions directly what they need, what they already find useful, and where the gaps are, then it can truly develop materials and programs that will fill these gaps.”

Ms. Curro says a perfect example of this is the UCB survey conducted within the product life-cycle management on mobile applications for epilepsy management.

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“Patient communities have always been an important stakeholder in healthcare marketing.”

MICHAEL PARISI / Ogilvy CommonHealth Worldwide

“We received very clear and valuable feedback relative to what patients said they would actually use and what would not add any value, which saves time and money.”

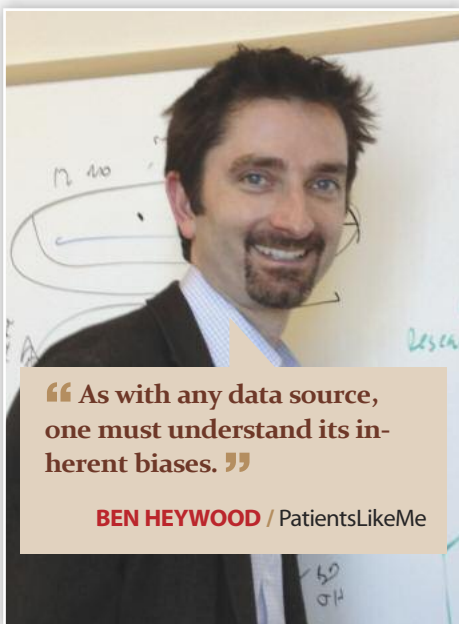
“Traditional market research is often limited to a point in time, requiring marketers to make decisions at the conclusion of the research without the ability to go back and clarify,” Ms. Choumitsky says. “In a patient community, marketers have the ability to continuously ask for clarification with deeper, richer insights. And, it helps marketers communicate in the language that patients use to describe themselves, their situations, their relationships, etc.”

The proof is in the postings. After launching a DTC TV marketing initiative based on input from patients in its research community, UCB observed a blog comment posted by someone outside of its patient community that gave kudos to the company for really knowing its patients.

According to Ms. Choumitsky, the post read: “I have to give them one thing. I thought their commercial was pretty spot on, or at least it was leaps ahead of what I’m used to seeing. Someone’s been doing good research and listening to all of us. Not sure if they consulted with anyone, but I wouldn’t be surprised. What was surprising was seeing something like this on TV.”

“It’s unusual to get such an authentic response to a TV commercial and to hear from a patient directly that we listened, understood, and provided something of value,” Ms. Choumitsky says. “This is what motivates me and lets me know that what we do makes a difference in the lives of patients.”

It may take a while for pharma to become comfortable with patient communities and interacting with patients on their own turf, Mr. Dayton says. However, pharmaceutical companies need to swallow that fear to gain the benefit of listening to the patients. Companies then need to act on what they hear.



“As with any data source, one must understand its inherent biases.”

BEN HEYWOOD / PatientsLikeMe

“The interaction with the communities can provide the driving insights for a solid marketing strategy,” Mr. Dayton says. “Many companies have already approached patient communities and formed partnerships to gain insights from the conversations going on. In many ways, patient communities are an amazing resource for marketers. If approached appropriately, members will help companies because many feel like they can be brutally honest.”

Mitigating the Risks

There are risks with using patient communities for market research, but they are no greater than the inherent risks in any market research efforts, and most often, the benefits far outweigh the risks, our experts say. As long as communication is open and transparent, there are no serious regulatory risks for the industry, although some caution that the information collected in this manner could be slanted.

“As with any data source, one must understand its inherent biases,” Mr. Heywood says. “Pharmaceutical companies must be careful to follow the regulatory and ethical rules around engaging with patients and their data. While there is some risk, some of it is real and some of it is perceived.”

Ms. Choumitsky says she has heard that some marketers don’t trust research done in patient communities, because they believe it is not well-controlled and adds a bias over time, but she has experienced the opposite.

“I believe it is critical to engage with a patient community that is vested in helping others with their condition and with individuals who are committed to providing feedback from the patient perspective and not the pharma company perspective,” she says.

While attention does need to be given to the credibility of individual participants’ re-



“There are opportunities to query a group of engaged patients to better understand the patient/physician dialogue to identify areas of unmet need that can be addressed by a comprehensive, focused patient support and marketing strategy.”

SUE CURRO / UCB

sponses, as well as the context of the responses, Mr. Ghinn says transparency and ethics are the keys to success in this arena.

“We are always open with the communities in which we participate about what we are doing and why,” he says. “Above all else, ethics and transparency are key in developing trusting relationships.”

Mr. Dayton of Intouch Solutions names misinformation, sample size, and poor methodology as the three biggest risks of using patient communities for market research. However, this type of research amply supplements other research efforts and can be an easy way to collect data in between research cycles.

“If engaged appropriately, a patient community can be an always-on stream of market data,” he says. “Of course, this takes a commitment of resources and time to have ongoing monitoring and conversations with the patient community to fully understand and act upon their needs.”


Mr. Loew’s opinion is if there is any risk, then it may be that the self-selected segment of the patient population that engages in patient communities is not the average patient.

“In our own observation, this patient population is more engaged and educated about health conditions than the average patient. So these patients are not broadly representative of the entire population,” he says. “This is neither good nor bad, but the nature of the sample must be recognized, just as with any research project.”

The risks of these data are the same as with any resource, Ms. Curro agrees.

“When surveying online communities, responses usually come from patients who may

be more engaged than the general patient population for that disease, may be younger than the average patient who is being treated, and a higher percentage of females,” she says. “How-

ever, we do not see this as a negative since we segment our patient populations and know best where the online data will be a match.” 

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EXPERTS 



PAT CHOUMITSKY. Senior Product Manager, Immunology, UCB, a global biopharmaceutical company focused on the discovery and development of innovative medicines and solutions to transform the lives of people living with severe diseases of the immune system or of the central nervous system. For more information, visit ucb-usa.com.



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JIM DAYTON. Senior Director, Emerging Media, Intouch Solutions Inc., a digital marketing agency servicing the pharmaceutical industry. For more information, visit intouchsol.com.



DANIEL GHINN. CEO, Director of Digital Engagement, Creation Healthcare, an engagement strategy consultancy specializing in the healthcare and pharmaceutical industries. For more information, visit creationhealthcare.com.

BEN HEYWOOD. President and Co-Founder, PatientsLikeMe, a privately funded company dedicated to making a difference in the lives



of patients diagnosed with life-changing diseases. For more information, visit patientslikeme.com.



BRIAN LOEW. Co-Founder and CEO, Inspire, which builds online communities for patients and caregivers and helps life-sciences organizations connect with them. For more information, visit corp.inspire.com.



MICHAEL PARISI. Managing Partner, Ogilvy CommonHealth Worldwide, a WPP company, represents creative talent in the world of healthcare communications with 65 offices across 36 countries. For more information visit ogilvychww.com.

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Market research leaders share best practices on how to effectively survey patients in community patient groups.



PAT CHOUMITSKY is Senior Product Manager, Immunology, UCB, a global biopharmaceutical company focused on the discovery and development of innovative medicines and

solutions to transform the lives of people living with severe diseases of the immune system or of the central nervous system. For more information, visit ucb-usa.com.

“While it is important to actively engage patients, it is just as important to listen to their interactions passively. Allow the dialogue to be open and flow freely and then just listen for those pearls. We find that some of the best ideas come directly from our patients, not our marketing colleagues.”



SUE CURRO is VP, Senior Global Project Leader, Patient Solutions, at UCB, a global biopharmaceutical company focused on the discovery and development of innovative

medicines and solutions to transform the lives of people living with severe diseases of the immune system or of the central nervous system. For more information, visit ucb-usa.com.

“It is imperative to understand the demographics of the community. Beside the obvious basics, it’s also important to understand the dynamics within the community. Are there patient KOLs in the group who influence other patients? How is

the community growing? Are the demographics changing? It is also important to balance the online patient feedback with face-to-face discussions with patients, their caregivers, and patient advocacy organizations for the most complete picture.”



JIM DAYTON is Senior Director, Emerging Media, Intouch Solutions Inc., a digital marketing agency servicing the pharmaceutical industry. For more information, visit intouchsol.com.

“Keep the community aware of the fact you are listening, even if you are working with a patient community. The last thing any company needs is its target audience thinking that it is doing something unethical or violating their privacy. At this point in social media’s evolution, it is pretty easy to avoid this situation. Reputable communities will help companies get involved with full disclosure to their members. In some cases, they will facilitate conversations between members and partner companies. However, there are conversations going on in some communities that are private and the members want pharma to stay out. Any company that doesn’t respect patients’ privacy will see a wave of negative sentiment. Also, any company not using patient communities these days for market research is woefully behind the times, and losing competitive ground with every patient post. We are heading toward a future where patient value will drive the market value of products and services, so companies need to build the infrastructure to quickly and deeply understand the needs of patients using their products.”



BEN HEYWOOD is President and Co-Founder of PatientsLikeMe, a privately funded company dedicated to making a difference in the lives of patients diagnosed with life-changing diseases. For more information, visit patientslikeme.com.

“In our experience doing clinical and market research with our patients and pharma, we have found that to engage responsibly, one best practice for companies to follow is to be open and transparent about the work, the motives, and the method of engaging. Companies really need to understand and respect the rules of engagement for each specific community.”



BRIAN LOEW is Co-Founder and CEO of Inspire, which builds online communities for patients and caregivers and helps life-sciences organizations connect with them.

For more information, visit corp.inspire.com.

“Many market research studies recruit participants based on their desire to earn money by sharing their opinions. We don’t believe paying patients is bad. But when compensation is the primary motivation for participation, that approach increases risk of inauthentic participation and lowers research quality. A better way is talking to patients who have already demonstrated engagement in their medical conditions by participation in patient communities, and who happen to be willing to participate in market research as well.”

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