

The Patient Experience: Keeping *It Real*

A deep understanding of the patient is crucial in today's marketplace.

The secret to providing a positive patient experience is not much of a secret: you just have to fully understand the patient. Don't guess what they might want and need, but through thorough market research, know without a doubt the patient, and use that knowledge to present the product in a realistic manner.

To achieve this goal, the industry is slowly bringing the point of view of the patient into the entire commercialization process. Companies are at different stages of uptake — from cutting edge to not at all — and some are addressing patients as early as the clinical stages while others are waiting until product approval. Experts say the industry needs to focus on the end users of its products at all stages of the patient journey from clinical development through to launch and beyond.

While a patient-centric evolution is taking place, Mat Hesser, director of patient center of excellence for MS, at Biogen Idec, believes the industry has not come far enough.

"Too many companies continue to view the world as physician-centric, and do not recognize the growing influence of the patient in treatment decisions," Mr. Hesser says. "The evolution toward a fully integrated commercialization approach centering on the patient experience will continue to crystalize over the next five to 10 years."

Jim Hickey, senior director of client services at Verilogue, predicts that within a few years the industry will universally have one goal that supports the patient experience, as there is a tremendous amount of attention being put on the patient today.

"In the next few years, if a company is not thinking about the patient early on in the process, it will be left behind," he says.

Companies such as Biogen Idec, Verastem, and Takeda have taken steps to study their patient-consumers so that they can appropriately plan tools, services, and messages that will enrich the patient experience.

"We focus on identifying the needs of the patient, and work back from there," Mr. Hesser says. "Telling patients what they need, without asking them, leads to unsatisfactory relationships. We want to build holistic connections, grounded in patient insights that can also enhance the relationships we have with physicians, nurses, and other key stakeholders."

Focusing on patients has always been a significant part of the corporate philosophy at Millennium, but the goal has recently intensified, gaining traction on both the patient advocacy and the commercialization side, says Kathy Gram, senior director, patient advocacy, Millennium: The Takeda Oncology Company.

Ms. Gram's patient advocacy efforts have increased greatly in the past few years, as the company adds more and more programs in an effort to achieve its goal of keeping patients compliant to improve health outcomes.

"Four years ago just trying to get one program off the ground was challenging, and now we have a whole portfolio of initiatives," she says. "I have been able to increase the number of programs among various topics and along different touch points throughout the patient experience. We help patients manage side effects and their disease, which helps them remain compliant and achieve results that are consistent with our clinical trials."

Although she is not involved in the commercial side, Ms. Gram

has noticed that the patient is moving to the forefront of almost every discussion on that end as well. At the most recent national sales meeting, almost every piece of every presentation contained something about the patient experience, she says.

To maintain the focus, Millennium also features real patient photos throughout its campus and has a patient portal presenting real patient stories that employees can read. Patients attend sales meeting to specifically address the sales reps. Both reps and patients gain from this exchange, Ms. Gram says.

"Everybody says hearing the patient stories is always the most impactful part of the national sales meeting and they never get tired of it," she says. "They say patients are what get them up in morning and keep them going to the last call of the day."

Ms. Gram also notes that the patients often





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KATHY GRAM / Millennium



“Because everybody learns differently, materials need to resonate appropriately for each patient type and depend on the disease state, the age of the individual, and where he or she is on the patient journey.”

MARC SIROCKMAN / Artcraft Health

thank her for allowing them to share their stories.

Verastem also actively engages in discourse with advocacy groups to learn about patient motivations and beliefs.

“It is important to ensure that a measured approach is taken early on in the development process so that we can appropriately proceed through the stages of listen, learn, and eventually begin to educate,” says Brian Sullivan, director, corporate development at Verastem. “It is important to start before commercialization so that we can bring forward a product that appropriately addresses unmet needs present in a disease area.”

A 15-year-veteran of pharma marketing research, Mr. Hickey at Verilogue says he has observed a big change in the focus of market research in just the past five or six years.

“The physician was the traditional focus for market research and more frequently the patient is becoming an equal and sometimes greater focus for certain brands,” he says. “Before joining Verilogue six years ago, I could count on one hand the number of studies I executed that focused solely on patients. But now from a market research standpoint, I see more budget dollars going toward understanding the patient and more objectives and more business questions are being generated from the focus on the patient.”

Keeping It Real

There are two parts to this emerging patient-centric trend: getting to know the patient and then proving that knowledge to de-

liver pertinent and realistic products and services.

In the pharma marketing arena, patient expectation will drive the movement forward. For example, the industry is slowly graduating from using dramatizations and actors in ads with broad messaging, and instead is beginning to use real patients and their individual stories to connect with other patients.

“Pharma is starting to realize that gone are the days of finding a pretty model to be the face of the brand,” says Nadine McGowan, executive VP at Snow Companies. “Patients are starting to expect to hear from real people who are living with the disease and who are potentially taking the same product for treatment.”

Real patients can spot a fake patient immediately, and the messaging then loses credibility, Ms. McGowan says.

“We have talked with patients who have rheumatoid arthritis and they said they can tell right away if a person featured in an ad has RA or not — they can tell by the way the model’s hands look,” she says. “Real patients are looking to identify and relate to somebody who is experiencing similar situations and if there is an actor in the place of a real patient, that creates a level of immediate distrust.”

Keeping it real stems from adequate and accurate market research that enables a company to get to know patients on an almost personal level. Using market research — from traditional to social media — early on in the commercialization process is more crucial in today’s patient-driven marketplace.

In terms of market research, trends are also

shifting to a more personal experience. Instead of gathering focus groups behind the one-way glass with pharma listening, today there are more transparent ways to create relationships with the patient community.

“Today, people are sitting down around a table in an advisory format, creating relationships with pharma that are more analogous with relationships pharma has with healthcare professional speakers,” Ms. McGowan says. “We believe using the same approach on the patient side fills a need to form a relationship and continue the dialogue with the patients that the drug company is serving.”

Ms. McGowan believes the industry will start partnering with patient communities in order to mine information that will enable it to provide real patient experiences in a compliant and safe way.

“Real patients can discuss side effects using real-life experiences and offer tips that help other patients manage the disease and stay on product, an important goal for all stakeholders,” she says.

Due to group dynamics, personal interviews with patients can derive much more rich and meaningful data, and the open dialogue also allows relationships to be maintained over time.

“We don’t use a lot of focus groups because there are often dominant personalities that take over a conversation; a meek person within a

The Pharmaceutical Industry Needs Emotional Insights

Marketers in the pharmaceutical industry have a tremendous need for emotional insights about the experiences of patients, whose suffering, especially emotional distress, is a prime target of treatment. The positive emotional side effects of a drug whose putative treatment target is a physical malady are often not understood as a benefit of the drug by the patient who experiences them. Drug makers who understand and appreciate the patients' emotional distress are in a better position to describe the emotional benefits that may accompany the targeted physiological benefit, and thus enhance the patient's appreciation of the salutary emotional effects of a drug therapy.

But emotional insights from patients are not easy to obtain. Patients have a hard time revealing their emotions, where the intimate details of suffering, especially emotional suffering, are often felt to be deeply private matters.

Psychologists and neuroscientists have also taught us that there are many dimensions of emotional experience that individuals simply can't talk about. These emotional forces lie in the unconscious or pre-conscious regions of the brain, where they are inaccessible to rational reflection.

A new emotional learning tool called MindSight uses emotionally evocative images in a rapid-exposure/rapid-response exercise that gets under the radar of conscious thought to reveal authentic emotional insights about patients' suffering experiences. This tool takes advantage of an "emotional discovery window" defined by neuroscientists as the time period in which a subject is having a totally emotional response after viewing an image, before the subject begins to "think" rationally about that image.

MindSight links the emotional aspirations and frustrations of doctors and patients to a model of nine core motives — security, empowerment, belonging, identity, engagement, nurturance, mastery, achievement, and esteem — that drive human behavior, each of which can be frustrated by disease and suffering, and fulfilled by treatment and recovery.

Source: Forbes Consulting. For more information, visit forbesconsulting.com.



“Too many companies continue to view the world as physician-centric and do not recognize the growing influence of the patient in treatment decisions.”

MAT HESSER / Biogen Idec

group may have a great opinion but he or she doesn't share it," says Chris Evans, director of innovation at West Pharmaceutical Services. "We conduct personal interviews in an open dialogue format within the environment of use. For example, when doing a very large diabetes study, we visited between 20 or 30 patients and did hour-long interviews in their homes, asking them to walk us around the house to show us their day-to-day routine — where they tested glucose level, where they stored insulin, etc. We required our designers to take part in those interviews as well so they could get a real perspective on each patient's life."

West's research analysts were able to develop four personas from those interview results, and everyone from the group fell into at least one of the categories. The four personas include stage one, the victim, who has recently been diagnosed; stage two, the resentful newcomer, a patient who has taken ownership of his or her disease; stage three, the auto pilot, who has achieved basic competence for care, he or she might use informational materials such as books or a chart index, and follows physician instructions; and the stage four — and only one or two people ever reach this stage — is referred to as the director of operations, the patient who has everything in control and has complete oversight into his or her health.

"When designing for the patient journey, we consider each stage from first diagnosis to getting the disease under control, and that knowledge gives us the ability to design a product that addresses all four of those needs," Mr. Evans says.

Another wealth of patient information lives within patient advocacy and ambassador programs. At Snow Companies, founder Brenda Snow, who is also a patient living with MS, developed a proprietary ambassador program of real patients managing real diseases that share their stories to help other patients cope with the disease, as well as provide information to help



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NADINE MCGOWAN
Snow Companies

the life-sciences industry better understand the patients it serves. While Snow may have been the first company in the industry to establish such a program, others are following suit.

According to Ms. Gram, Millennium currently has 45 ambassadors who discuss their medical experience with patients and core groups, and, to date, they have reached 32,000 patients in four years of the program.

"It's important that patients truly believe that we do care about them and that our messages is not just corporate values on a plaque hung up on a wall, but that we are actually listening to the patient and incorporating the things they feel are important into our products and our programs," Ms. Gram says.

Ms. McGowan agrees that reaching and resonating with patients is the most important part of a relationship.

"The patients who we talk to want to know that the company making the drugs they are taking cares about them and has their best interest in mind," she says. "The research conducted around patient focus can harness the voices of these patients and use the power of

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“When designing for the patient journey, we consider each stage from first diagnosis to getting the disease under control.”

CHRIS EVANS / West Pharmaceutical Services

storytelling to bridge the divide between pharma and patient communities to provide real patient experiences.”

The same type of deep knowledge needs to be present in effective patient education solutions, says Marc Sirockman, executive VP and general manager at Artcraft Health.

“We focus on understanding the literacy, social, and emotional barriers that patients



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BRIAN SULLIVAN / Verastem

Personal Connected Health Alliance



The Personal Connected Health Alliance (PCHA) is a collaboration between the Continua Health Alliance, HIMSS, and the mHealth Summit. PCHA's mission is to establish a business model and

support practical implementation of plug-and-play interoperable personal health solutions. PCHA is focused on consumers engaging with their health via interoperable health solutions to meet their lifestyle needs, and will generate a new knowledge base for advancing education and awareness for personal connected health technologies.

According to Richard Scarfo, VP of events for PCHA, patient engagement comes at an evolving time in healthcare when personal connected devices are making access to information easier and more commonplace.

“PCHA supports technology that enables personal health solutions that foster independence and empower people to better manage their health and wellness from anywhere and at any time,” he says.



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“In the next few years if a company is not thinking about the patient early on in the process it is going to be left behind.”

JIM HICKEY / Verilogue

materials need to resonate appropriately for each patient type and depend on the disease state, the age of the individual, and where he or she is on the patient journey,” he says. “Each tactic of an educational strategy needs to resonate appropriately for each patient learning style.”

At Millennium, the patient is involved across the whole continuum of drug development, and just recently the company has brought patients onboard to help in clinical trial designs.

“We have patient advocates who will look at our clinical trial protocols and give input,” Ms. Gram says. “We also have a CRO component to every clinical trial where we get feedback from patients about their experience from clinical trials, and we use that information to make the process more patient friendly. This is new for us and demonstrates that patient involvement is receiving an even higher priority throughout the whole organization.”

If the industry is going to survive the new patient-driven healthcare system that is emerging on the horizon, it must be prepared to proactively reach out to patients during the development process.

“Creating a comprehensive commercialization process that takes into account the basic human need for understanding and compassion while providing a treatment option firmly rooted in the science is paramount,” Mr. Sullivan says. “A basic mantra that we use in our development is listen first, continuously learn, and only then educate on our potential solutions.” **PV**

may be experiencing as they manage their health outcomes, and on the gaps as they work toward empowering themselves to manage their condition,” he says. “When patients go online, what do they search for? When they talk to their healthcare provider, what are they asking? At what point do they question whether they should get the script filled? And how do we create reinforcements to help nudge them along?”

The patient-centric approach changes several elements in patient education. One is that the healthcare provider is no longer the single source of information.

“Not too long ago, pharmaceutical sales reps would just give the three-point message to the physician and let them market the brand and educate on the disease state,” Mr. Sirockman says. “Today, we need to develop and design fully integrated communication and educational campaigns targeted to patients that empower them to make informed decisions and take control of their treatment and their lives.”

An important element to remember when designing educational material is the learning style of each patient.

“Because everybody learns differently, ma-



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Market Research: Early *and* Often

Identifying patient needs requires multiple avenues of research early in the development process.

There should be no guesswork in identifying the patient and his or her needs. Our experts suggest using all types of market research as early in the process as possible to provide a successful patient experience.

According to Brian Sullivan, director, corporate development at Verastem, there are multiple phases to creating an integrated commercialization approach that addresses the concerns of patients, physicians, and caregivers. Some experts encourage an early start to bringing the patient into the mix, but Mr. Sullivan thinks companies need to have made a firm commitment to the development before involving patients for feedback.

"I think it is appropriate to actively engage patient advocacy organizations once it has been determined that an agent has a favorable safety profile and the work being done in an identified disease area has both the potential to make a meaningful difference for patients and one that the company is willing to commit to an advanced development program," he says. "To be properly integrated, a pharmaceutical company needs to be in alignment with all stakeholders, it needs to be confident that it will pursue a development path before fully engaging with the patient community, and needs to begin an education campaign for stakeholders on the potential of the product it is bringing forward."

And it is important to involve the patient as early as possible once the commitment to develop the product has been made, Mr. Sullivan adds.

"If a company waits until the commercialization phase it will be trying to shape a product that is already mostly baked and difficult to mold and tailor to the people who need new options," he says.

There are multiple approaches and channels to use for market research, and at Verilogue, the focus is on observational research of the conversations between physicians and patients. Even though the patient spends more time outside the doctor's office, says Jim Hickey, senior director of client services at Verilogue, the crucial moments occur in front of the doctor.



"Our patient advisors' input is very valuable."

KATHY GRAM
Millennium: The Takeda
Oncology Company



"Companies today start early on creating patient relationships, which is indicative that patients are not an afterthought."

NADINE MCGOWAN / Snow Companies

"Every experience patients have outside of the office comes to bear when they are inside the doctor's office, making decisions," he says. "Using video diaries for patients to describe their experiences can reveal more insights into a single patient experience. This research allows us to look at reality, so if one patient is experiencing something, then others may be experiencing it as well."

According to Chris Evans, director of innovation at West Pharmaceutical Services, "when" may be more crucial than "how" market research is conducted.

"We tell designers or developers who will listen, no matter who is doing the research, be sure to do it early enough in the discovery phase to be able to understand what users like and dislike," Mr. Evans says. "The more relevant information received from stakeholders, the better chance of developing a better product."

At Snow Companies, industry clients are beginning to reach out to patient advisory boards even before FDA approval, and according to Nadine McGowan, executive VP at Snow Companies, this is a sign that companies are thinking about the patient journey far in advance.

"We definitely have seen an increase in the number of companies that want to start early to create patient relationships, which is encourag-



"Every experience patients have outside of the office comes to bear when they are inside the doctor's office, making decisions."

JIM HICKEY / Verilogue

ing and indicative that patients are not an afterthought, this is a really positive shift," she says.

Millennium uses quantitative market research along with a half dozen focus groups or advisory board discussions every year, and the company participates in a continual dialogue with its patient ambassadors.

"Our patient ambassadors are the pulse of what's going on in patient communities," says Kathy Gram, senior director, patient advocacy, Millennium: The Takeda Oncology Company. "When we create any campaign or messaging, we convene patient advisors to help us so we make sure we are sending the right message that is easily understood and has an effective outcome. Their input is very valuable." **PV**

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