

PATIENT STORIES



By Robin Robinson

As the industry continues to embrace a more patient-centric business model, patient views have shifted to the forefront of several strategies, including using patient advisory boards for drug development and clinical trial protocols, and patient stories and communities to guide marketing and other commercial initiatives. Patient stories have a profound effect on the impact of a message, whether that message is for another patient, a physician, or a researcher.

One of the drivers behind this evolution is the U.S. healthcare industry's transformation from volume to value, which has created more incentives to bend the cost curve.

"With a greater emphasis on increased patient outcomes for less cost, patient stories are being used as a way to communicate the value of a particular drug, therapy, or treatment through the eyes of the patient," says Sandy Robinson, managing director at Manatt Health. "The most compelling stories are typically told by the patients themselves or their caregivers. These stories give insights into the burden of a particular disease and touch the heartstrings of others who hear them."

According to Dave Taylor, senior director of research at Inspire, patient-centricity has evolved rapidly within the past several years from a concept to being implemented by many companies within the industry.

"Companies are investing in and formally organizing around patient-centricity," Mr.

The power of the patient voice is stronger than ever across marketing, clinical trials, and drug development.

Taylor says. "We've seen senior-level pharmaceutical executives dedicated to bringing in patient input and driving the organizations toward patient-centricity."

The benefit, he says, is the messages become more tangible, accessible, relatable, and personal.

"The change is that companies are talking with patients, rather than talking to them," he says.

Take, for instance, the story of Crohn's patient Robert Hill who has climbed seven world peaks, including Everest, with an ostomy. Through this endeavor he raised not only disease awareness, but also funding for Crohn's research and showed other Crohn's patients what they can aspire to. And there's the story of 42-year-old Dan Doherty who suffers from severe epilepsy and who for years couldn't be left alone or experience any stress for fear it would set off a seizure. He has since found a treatment that allows him to function at a higher level. He has embraced public speaking and, through the group Toastmasters, has

learned how to talk with conviction to a roomful of strangers. This achievement has enabled him to work with the Epilepsy Foundation and to speak about his disease.

What do these, and many other, patient stories have in common? Hope. And hope is where the value is to other patients.

"The value of patient stories is that they can inspire patients with the same condition to aspire to a higher level of health and happiness," says Jim Curtis, president of advertising, strategy and operations, Remedy Health Media.

Patients with chronic conditions often settle into survival mode, dealing with the day-to-day issues of their disease until it becomes their new normal. However, if they see others with the same condition accomplishing better health, they become inspired.

According to research conducted by Remedy Health, 90% of patients who heard an inspirational story about another patient said they became more hopeful, which spurred them to taken action, such as trying a new treatment, going to a doctor, exercising or eating healthier. Hope creates action, Mr. Curtis says.

"There is no greater partner we can look for in healthcare than the patient," says Cheryl Lubbert, president and CEO, Health Perspectives Group. "By incorporating the patient's voice early and often, we can expect better health literacy, more connectedness, better

adherence, and ultimately, better health outcomes.”

Specifically, those working in drug discovery can extract a deeper understanding of what patients are facing and the barriers they live with while battling their disease to identify innovations that are meaningful, impacting side effects, efficacy, comorbidities, and convenience.

Those working on clinical trials can design a trial informed by patients’ issues and barriers, resulting in faster trial recruitment, improved retention, and fewer protocol amendments — potentially reducing time and cost to complete the trial. There is also an opportunity to provide results in a patient-friendly format to improve health literacy for consumers.

Those working in marketing can expect communication and messages that are impactful, compassionate, better received, and delivered in the way most consumers prefer.

“We recently published results from a survey of more than 500 consumers, and three of the top eight communication methods — advertising, online, print — that ranked highest included real patient stories, confirming that people want to hear from others like them,” Ms. Lubbert says.

Keep It Real

The advent of social media has helped spread the stories of patients, as well as increased the expectation of consumers with regard to the information they are demanding.

Technology and the online culture of today have converged to make real stories one of the most desirable communication methods to reach consumers, Ms. Lubbert says.

“Real stories are what are captivating people now,” she says. “These stories create emotion, which helps people learn, remember, and, ultimately, connect to the information being delivered.”

At the same time, the industry must be careful not to manufacture patient stories, because today’s consumers will see right through them.

“Marketers need to recognize that they can’t fake it on social media,” says Wendy White, founder, Wendy White Consulting, and former senior VP, rare disease at Dohmen Life Sciences, and a rare disease expert. “These real life stories force pharma marketers to be more authentic because they don’t want to have a gap between what’s happening on social media and what is being said in an advertising message, or they will end up with people on social media closing that gap in a way that might not be positive.”

Gone are the days of staging a story and using actors to portray patients. That method



Whether it’s for marketing or a clinical trial, industry is now aware that it must listen to the voice of the patient to instill authenticity.

DAVE TAYLOR
Inspire



Across the board, patients can provide valuable insight into the business process.

PUNIT DHILLON
OncoSec Medical



Instead of using KOLs, now manufacturers must tap into the patient voice via patient advisory boards and patient opinion leaders.

WENDY WHITE
Wendy White Consulting

no longer flies in today’s real-time social media world. Patients want authenticity, and with that credibility, pharma companies can begin to gain trust and cultivate meaningful relationships with customers.

“While a patient story can provide insight on what lies ahead and a hopefulness in overcoming setbacks, the key is to stay realistic,” says Kate Perry, Psych.D., director, behavioral science, Atlantis Healthcare.

“The best patient stories I’ve seen are positive and inspirational, but they also tackle a problem or set of issues,” she says. “The biggest challenge is to resist the temptation to only share happy stories, which could pose the risk of distancing other patients. When patient stories include trials and challenges, they automatically help normalize the experience.”

“The patient sitting in a chair with the camera focused right on their face giving a testimonial is no longer a story that works, because people want more reality in the storytelling,” Mr. Curtis adds. “There has to be a real story. It’s no longer actors who are relating stories or testimonials on a pharmaceutical website. Stories take place in real life, and they need to be reflected on online and in social areas from someone who is authentic.”

Using patient stories is not only about hearing patients’ voices, but also

making sure these voices are being reflected in the design, the content, and overall user experience of a support intervention.

“Throughout the marketing cycle, there are many ways the patient voice can and should be applied,” Dr. Perry says. “There’s the literal approach, where patient stories are transcribed and shared on a website or in a magazine as part of supportive resources available to other patients. There’s also the critical step of using patient feedback to refine a program, over time, to ensure it continues to

The real key is to create a great story that people are emotionally connected to, can trust, and can relate to.

JIM CURTIS
Remedy Health Media





Patient stories can be a powerful tool to resonate within any marketing outreach or self-management solution.

DR. KATE PERRY
Atlantis Healthcare

as if she is suffering from the disease.”

Not only do things have to look right, they also have to sound right to real patients. Mr. Taylor adds that the industry has begun to pay more attention to the language patients use in describing their experiences and using the same language in its messaging.

“The industry is now listening to the voice of the patient,” he says. “Whether the communication is for marketing or clinical trial messaging,

the industry is now aware that it must get the language right to instill authenticity.

For example, messages must use the same types of words that patients with diabetic nerve pain use to actually describe their symptoms, or how patients with psoriasis talk about plaque and scales. Also, it is important to match the tone that patients take when they talk about their disease. These are all elements that today’s pharma marketers are investing in.

“The greatest advantage of using patient stories is credibility,” says Dian Griesel, Ph.D., president, DGI Comm. “These are priceless third-party endorsements by real people who are telling the world about their personal needs or experience for, or with, a particular issue or product.”

Listening to the patient voice can help determine real needs, issues, values, concerns,

challenges, and other important feedback that can be incorporated into overall marketing messages and planning. “Online feedback is a new form of an ongoing focus group,” Dr. Griesel says. “The biggest challenge: the same platforms that give the cheerleaders a voice give the naysayers equal airtime.”

Another challenge with story telling is telling a good story that people respond to, relate to, and are emotionally connected with. To post a story that no one has an emotional connection to or that seems contrived or is too testimonial or even has an inkling of bias because it’s delivered by a pharmaceutical company won’t be shared, won’t be viewed, won’t be acted upon as much, Mr. Curtis says.

“The real key is to create a great story that people are emotionally connected to, can trust, can relate to, and therefore, can be inspired and then take an action,” he says.

“The greatest advantage of using patient stories to carry a brand message is that the voice of the patient can really be heard and resonate with others,” Ms. Robinson says. “It puts a face to the disease burden and creates a personal connection. The biggest challenge is patient privacy — unmasking the disease state particularly when the disease is sensitive in nature.”

The Patient Voice in R&D

According to Pfizer, patient involvement in its R&D process is a fundamental strategy at the company, and it will continue to involve patients earlier and more systematically in the drug development lifecycle. To Pfizer,

meet the needs of all participants.”

Inspire reports that feedback from patients shows that pharma companies still struggle with creating marketing messages that are authentic.

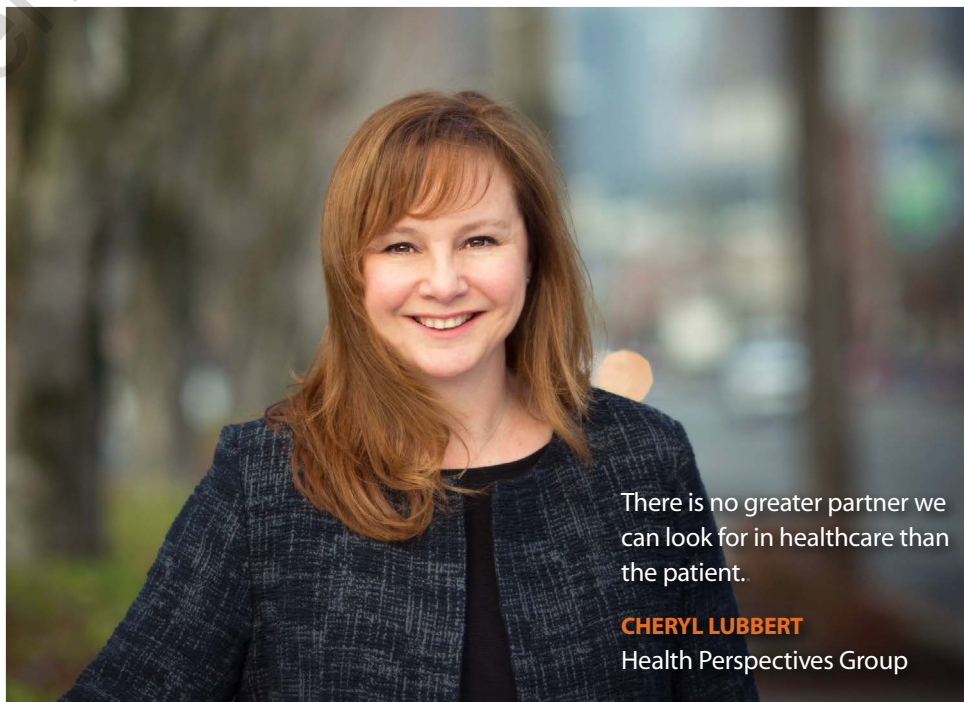
“For example, the concern is that in some promotional materials, especially in cancer, the person looks too happy or too healthy to be real, to be authentic,” Mr. Taylor says. “People would rather hear a story from a real patient, such as Jessica Stone who had breast cancer and was treated with Afinitor, which reduced her tumor and who is now in remission, than see an actor with a head scarf to make her look

Patient Engagement

A drug development guide to meeting patients’ needs and preferences

- ▶ Engagement between organizations encourages the sharing of capabilities and is based upon achieving mutual objectives and goals.
- ▶ Engagement can build stronger alliances and more diverse representation in clinical research.
- ▶ Patient-relevant research findings can be communicated to all stakeholders to optimize treatment plans.
- ▶ More representative participants in clinical trials can potentially influence health equity and broaden market access to therapies.
- ▶ Therapies that better address patient needs may foster drug adherence and reduce associated morbidities and costs.

Source: Pfizer



There is no greater partner we can look for in healthcare than the patient.

CHERYL LUBBERT
Health Perspectives Group

patient involvement in R&D means building a patient-centered culture both internally and externally; it means potentially faster, more efficient development of meaningful therapies; it means greater potential for regulatory success, and greater chance at broader access of its medicines.

Pfizer has an initiative called Patients in Development, which involves internal meetings that involves bringing in groups of patients, as well as study coordinators and investigators as part of the process.

The power of patient stories humanizes the challenges that need to be addressed in drug development. When patients share stories about their personal experiences, talk about the current leading research in the field and how their experience has been as a patient or a caregiver, this provides an individualized discussion around a clinical study or drug by people who are affected or hold direct knowledge, says Punit Dhillon, co-founder and CEO, OncoSec Medical.

“There are many positive examples of forums and communities for different diseases; one that I am a fan of is [becancerpositive.com](#), which shares stories of people who have experienced or are still living with cancer and inspiring others to maintain a positive state of mind and healthy state of being, and a richer quality of life together as a community,” he says.

Ms. White believes it is also time for a cultural shift in how industry views the development process.

“The change needs to go beyond manufacturers thinking they just make a therapy and then sell it through a value chain,” she says. “Companies have to take into account how what they are producing is going to help patients and therefore they have to think bigger and they have to hear the voices of the patients and caregivers because they are the ones on the front line.”

Ms. White calls these patients POLs, or patient opinion leaders. “Instead of KOLs, now and especially in the rare disease space, companies need to ask the opinion of patients,” she says.

For example, at a recent patient advisory meeting, Ms. White observed how listening to patients helped to refine a trial protocol to provide better outcomes.

Pfizer, which has had a focus on patient interaction in the rare disease and oncology space for some time, is bringing this practice to the entire portfolio. The company has embedded a protocol review committee into every protocol. Teams are charged with bringing back feedback they obtained from patients during the development of that protocol. In addition, there will be a consistency in the approach across the board.

Ms. White says companies of all sizes are putting together patient boards, and several are identifying specific roles just for that purpose, such as chief patient officer. Large companies, such as Merck and Sanofi, and smaller biotech companies like Amicus Therapeutics are filling these positions to increase the role patients play in their business models.

“Small biotech companies quite effectively pull together patient advisory boards to help them with all the different stages of development,” Ms. White says. “Companies are finding patient opinion leaders and advisory boards to be extremely helpful.”

“Being able to access individual data in the overall healthcare ecosystem would bring forth a lot of benefits for all sides of the drug development equation, and I believe there is more pressure for quick implementation by healthcare providers,” Mr. Dhillon says. “The foreseeable downside to this could be the possibility for crowds to agree on incorrect ideas or facts. However, with the regulatory checks and balances in place for clinical trials and drug development, opening up a patient-directed forum to inform this process is not unrealistic; after all, the patient is the key component before, during, and after a treatment of a particular disease.”

Connecting with patients and listening to their personal stories should inform all of pharma’s decisions and push the healthcare conversation to a two-way dialogue, Ms. Lubbert says.

Every time a patient is asked his or her opinion, for example during an advisory coun-



The greatest advantage of using patient stories is credibility.

DR. DIAN GRIESEL

Dian Griesel International

cil, he or she sees first-hand the passion and dedication of people working at that biopharmaceutical company have for developing new treatments to change and save lives. There is real value in making these connections with patients — each one helps to influence the image and perception of the industry.

Internally, focusing on patient experiences also can engage employees and connect them to their work in new ways, reminding them of the good things they are doing inspiring and encouraging their efforts.

“If pharmaceutical and biopharmaceutical companies continue to incorporate patient stories early and often, it will create downstream benefits, from shaping clinical trial design to better informed patient-support programs at and after launch,” Ms. Robinson says. “It shows up in more tailored educational tools and patient-assistance programs. When patients share their stories, it can really make a difference for someone who struggles with the same disease. It is hard to put a value on something that can be a true multiplier and make the difference in the life of a patient.” **PV**



The greatest advantage of using patient stories to carry a brand message is that the voice of the patient can really be heard.

SANDY ROBINSON

Manatt Health