



by Taren Grom

Driving Patient Engagement

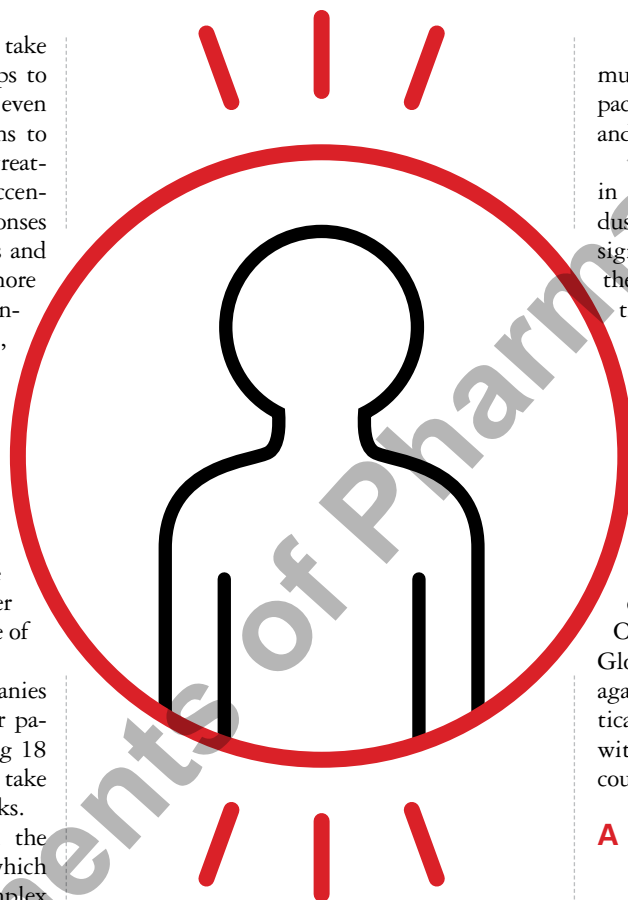
Pharmaceutical companies should take a cue from patient advocacy groups to drive patient engagement, and even partner with those advocacy organizations to create better patient experiences with treatment, according to a new survey from Accenture. The survey, which included responses from 4,000 patients in the United States and Europe, revealed that patients need more from pharmaceutical companies. Respondents, who had either migraine issues, rheumatoid arthritis, or chronic lymphocytic leukemia, stated that the pharmaceutical companies that sell medications to manage their diseases are falling short on patient engagement. Seventy-six percent of respondents agreed that pharmaceutical companies have a responsibility to provide engagement services that coincide with their medication offerings, but fewer than one in five patients are actually aware of any of these services.

With 85% of pharmaceutical companies stating they have plans to ramp up their patient engagement strategies in the coming 18 months, patients are saying they should take a page out of advocacy organizations' books.

"These findings makes sense, given the more targeted nature of new science — which is more personalized and often more complex in its treatment approach — and that delivering real impact requires a deeper understanding of the patient," says Eva Wiedenhöft, a managing director in Accenture's Life Sciences practice. "In this regard, a stronger collaboration between pharma and patient organizations can provide benefits for both parties."

The industry has come a long way in a relatively short amount of time as it relates to becoming more patient-focused across the spectrum of discovery to commercial, says Andy Pyfer, partner, Fingerpaint. "Companies are engaging patients earlier and more often in the process, well before clinical trials are ever a thought," he says. "Taking the time to intimately understand their pain points, as well as how a condition holistically impacts a patient's life, allows a company to develop a more focused strategy."

Mr. Pyfer believes success is not so much about one specific leader or department but



A cultural shift throughout pharma is putting patients squarely in the middle of strategic decision-making.

more about ingraining, and consistently reinforcing, the importance of the patient and their needs into every part of the company's culture. "The patient should influence everyone from bench scientists and the human resources team to the finance department and the engineers designing the product's packaging," he says. "For example, companies in the rare disease space are doing a commendable job of positively engaging patients. They view them as a gold mine of information and are consistently tapping them to help guide their decisions."

As the industry evolves, all companies must actively understand how a disease impacts the patient and their caregivers as people and develop solutions to address those needs.

In January 2020, more than 230 leaders in the biotechnology and pharmaceutical industries, academia, and life-science investors, signed a letter of commitment to patients and the public toward this goal. They note that the industry is at a pivotal point in history, and that the dawn of a golden age of medicine has arrived, with companies having the ability to treat and cure diseases that have long been untreatable and incurable. The co-authors of the pledge include: John Crowley, J.D., chairman and CEO, Amicus Therapeutics; Paul Hastings, CEO, Nkarta Therapeutics; Rachel King, CEO, GlycoMimetics; Jeremy Levin, D.Phil., chairman and CEO, Ovid Therapeutics; Ted Love, M.D., CEO, Global Blood Therapeutics; and John Marganore, Ph.D., CEO, Alnylam Pharmaceuticals. According to the statement released with the pledge, their mission is to change the course of each individual's life for the better.

A Patient Focus

"Patient-centricity certainly seems to be focused across the entire industry as a needed area of advancement and improvement, at least in words if not actions," says Michael Keens, chief operating officer, Firma Clinical. "From our work in helping align pharmaceutical companies with advocacy groups, as a benefit to patients, we have seen faster and more expansive adoption within distinct segments within the industry. Outside of companies focused in rare/orphan disease, which by their very limited nature and availability of the patient population tend to be the most forward-thinking and acting in patient focus, real world evidence and commercial teams seem to be more focused on implementing a patient-centric approach to their work. This may be as a direct means to differentiate their research from other competitors or for further post-approval research, or because they feel more comfortable given explicit FDA guidance and support. Regardless, it's likely



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ANDY PYFER
Fingerpaint



most patients will feel the industry is truly patient-focused only once these improvements and engagements are deeply integrated in the R&D aspect of drug development.”

The industry is moving from “patient-centric” to “patient experience” by deeply understanding unmet psycho-social, financial, and everyday logistical needs, says Usama Malik, chief business officer and chief financial officer at Immunomedics. “These comprehensive patient journey maps enable pharma companies to design novel products and services that aid patients and their caregivers throughout the care continuum, including but not limited to: transportation, financial assistance and patient access programs, nurse navigators, social and digital tools, communities, etc. At Immunomedics, we have spent countless hours with patients, caregivers, and advocacy groups to understand the needs of triple-negative breast cancer patients, raise awareness, design services, and co-create new programs that make it easier for patients and caregivers to navigate a complex and debilitating disease.”

JD Cassidy, executive VP, client engagement strategy, Publicis Health, notes that his agency increasingly is partnering with clients in early-stage development to more fully understand a patient’s emotions and decisions as they consider and participate in clinical trials. “Tracking patient experiences that early provides rich insights for the development of future patient engagement plans,” he says. “It’s exciting to hear stories of better outcomes from patients as a result of physicians and researchers partnering with them earlier in the development process.”

He also notes it’s important to remember that companies should be in the treatment business, not the prescription business. “How patients respond and the resulting health outcomes come not just from the benefits of the product but the larger treatment plan supporting the patient,” he says. “Email reminders aren’t enough; rather, optimizing the psycho-social environment around the patient is what enhances outcomes. Finally, we need to continue to understand, test, and learn the role

that data and technology can provide to support patients and caregivers in their journey.”

Mr. Malik says what were once transactional relationships with advocacy groups have grown to be collaborative relationships, squarely centered on supporting the patient experience and journey in meaningful, authentic ways. “Today, the industry partners early and often with advocacy groups, not just to inform commercial launch approaches that take patient needs into account, but also to identify and invest in products and services beyond the pill, to reduce the friction in a patient’s journey. “At Immunomedics, we have been able to connect with triple-negative breast cancer patients and advocacy organizations in a meaningful way, and their insights have helped us to identify opportunities to support the whole person. For example, we established Humanly, a digital community platform that offers a trusted space for people living with cancer to be themselves – to find comfort, strength and optimism through shared experiences. As we plan for our commercial launch, the voice of patients and advocacy groups are critical to informing the design of our programs and services to address the critical needs of patients.”

Serving Patients on a New Level

David Goldsmith, chief strategy officer at WEGO Health, says there are several ways in which pharmaceutical companies can create better patient partnerships. “They can commit to patient collaboration; they can build it into the DNA of the company, and reward teams for making it a key pillar of their work, from drug discovery to patient support. Even the most well-intentioned companies will struggle to better serve patients without a deeper, 360-degree view into their needs, aspirations, and most formidable health challenges.”

He notes that focus groups, ethnographic research, and human-centered design practices are all key opportunities to collaborate, but brands can go a step further. “They can build diverse patient advisory boards that serve as an ongoing source of feedback and guidance,”

Patients’ Voices



YOLANDA BRUNSON-SARRABO
Multiple Myeloma
@madaboutmyeloma

I definitely believe that there is a better way for pharma companies to meet and serve patients. Everyone is aware of the complexities of approaching patients directly, but I believe the options and choices should be made by the patients rather than the doctors blocking that relationship. I think if pharma sees the people they help recover and those who are struggling they can work harder in doing what it is they do.



MARIA DE LEON
Parkinson’s and migraine
@DrmariaDe

Pharma has done a great job in developing patient-focused advisory teams to bring their unique perspective to salient research issues to the community in question, but also they have done tremendous strides toward taking into account the patient’s experience with disease as to how they market and provide information, educational programs, and try to fill gaps in knowledge and understanding of language used by physicians. For instance in Parkinson’s, several pharmaceutical companies have gathered patient as well as physician input to better define “on and off” phenomena and given patients tools to use when discussing with their physicians.

I believe pharma companies can invite minorities, such as, Hispanics to have a seat at the table of these salient conversations between patients, doctors, researchers, and themselves. Companies need to reach out to communities that don’t generally have access to centers of excellence and do educational programs there. They need to let them know there are programs of assistance in their own language. Finally, for all patients, companies need to provide education, materials, and support for all stages of a disease. Often I find there is a great deal of information about early stages but sparse information for those who are battling with issues past their fifth, tenth, fifteenth year of a disease when most patients need reassurance that there is still something to be done, new developments, etc.



CHRISTINE FROST
Menopause
@Shahrazad1001

There is a lot of fear and frustration right now about cost, accessibility, and coverage. People are watching policies change on a national level that have a severe impact on their lives and patients feel helpless to address potentially not being covered for medications they need, losing coverage, being switched to lower quality brands, and being nickel-and-dimed for hidden costs that aren’t made clear. I’d love to see more corporate compassion

Patients' Voices

and an effort to help people navigate the complex bureaucratic world of healthcare. Companies tend to spend a lot of money on reps to encourage doctors to write prescriptions, but I don't think enough effort is put into understanding the patient burden and quality of life issues.



KRISTAL KENT
Patient Advocate
Fibromyalgia, Chronic Pain, and
Military Veteran's Medical Needs

Unfortunately, gaps continue to exist within pay scales for patient and advocates alike. While industry leaders often times will pay "experts," these same entities try to illicit patient involvement in projects, yet do not offer payment for the patients' time, skill set, and expert opinion. The downfall of this is the message sent to the patient is while we want your involvement on this project, you are not seen as an equal team player, thus you will not be paid for your time, skill set, and expertise.

I believe a step to better serve patients would be every pharmaceutical company should create a "patient panel." Many organizations within healthcare are incorporating this concept to move toward more patient-driven objectives and initiatives, based on the patient panel's input and recommendations.

I have had a few opportunities to work with pharma-centric departments. My role was to provide input on patient-centered research and the best practices to incorporate the patient voice. I also served on patient-driven advisory panels, in which I provided input on how to promote patient inclusivity in research and media-marketing, along with how to build positive relationships and collaborations with leading patient experts.



CANDACE LERMAN
Attorney/Patient Advocate
Rare diseases
@rarecandace

I am a part of a variety of pharma projects, everything from clinical trial design/recruitment to patient-support services. In my experience as both a lawyer and rare disease patient, I am able to give unique insights to guide projects strategically. We save time, money, manpower, and deliver great products to patients.



EMILY LEVY
CEO, and Co-Founder
Mighty Well
Vascular disease, Lyme disease
@MightyWell

Throughout my journey as a patient living with vascular access for all of my adult life — three PICCs, 100s of IVs, and now a chest port — I have become passionate about vascular access education for patients, caregivers, and clinicians. The desire to increase education and



The patient-centricity paradigm in pharma/ biotech has continued to evolve substantially over the last two decades.

USAMA MALIK
Immunomedics

Mr. Goldsmith says. "Just as medical advisory boards bring their collective clinical experience to bear on drug development and treatment protocols, patient advisory boards bring their collective patient experience to bear on all aspects of the patient journey."

The right mix of patient leaders, particularly those with deep reach into patient communities, can pick up signals that even the best social listening platforms will miss. "Pharma companies that work with patient leaders in this capacity will be better positioned to learn what they can do to strengthen and improve virtually every touchpoint they have with the patient population," Mr. Goldsmith says.

Rosamund Round, VP, Patient Innovation Center at Parexel, says the one thing that will really move the needle is improving consistency. "If we involve patients strategically in business planning, across the drug development lifecycle, and on every study, then we will truly be successful," she says. "Making the patient central to how we do business each and every time will have a much greater impact on how we can serve patients."

Mr. Malik says dealing with a disease can add significant psychological, emotional, financial, and physical burdens in the lives of patients and their caregivers. "Pharma/ biotech can do more to understand the barriers, bottlenecks, and hurdles patients face, and contribute to easing some of the barriers to ensure access to therapy," he says. "There are many opportunities for closer and stronger partner-



Having a designated leader that can advocate for patients and provide patient insights to various areas of the business is invaluable.

JD CASSIDY
Publicis Health

ships between patients, caregivers, advocacy groups, and pharma/ biotechs; for example, lowering barriers to medical research and clinical trials, or leveraging patient advisory groups to provide input into trial design and patient reported outcomes, or designing products and services beyond the pill that enable patients to play an active role in care delivery and care consumption."

Lyn Falconio, chief marketing officer, at Publicis Health, says better outcomes start with understanding patients, not just their disease, and the agency is making the shift from thinking about "which disease does the patient have" to "which patient does the disease have." "It's about expanding what we do beyond product manufacturing and R&D and into supporting the total patient experience," she says. "I think this is where the idiom 'the little things add up' is useful to remember. Often when we pause to understand patient pain points, we're able to make small shifts that have a big impact on outcomes. For example, one of the biggest patient hurdles to clinical trial participation is transportation. Think about that — you have patients willing to participate in your trial, but lack of public transit or the expense of taking a car gets in the way of consistent trial participation. By understanding the patient beyond the exam room, we can stretch our imagination and identify opportunities that meet them wherever they are."

As the pharma/biotech industry continues to evolve to better serve patients in a meaningful way, having a designated patient function has become table stakes in any healthcare organization. "The investment in building and deploying such a team demonstrates a level of dedication to becoming a patient-focused



organization — both to the community that we serve and current and future employees,” Mr. Malik says. “To be successful, a team needs to serve as a conduit between patients and the company, bringing patient perspective into any discussion around business planning and translating it into program development, trial design, product and services design, etc. to provide an optimal experience. We believe that ingraining patient focus into our DNA requires deep connections with the patient and caregiver communities. We have built programs that provide a space for employees to share their personal stories, from living with cancer as a patient and/or caregiver to building their own advocacy organization. We also collaborate with our advocacy partners to educate

our employees and the broader care needs of our patients.”

Mr. Cassidy says too often opportunities for development or enrichment of patient insights fall through the cracks created by the hectic day-to-day demands of the business. “Having a designated leader who can advocate for patients and provide patient insights to various areas of the business is invaluable,” Mr. Cassidy says. “These leaders also have the responsibility of establishing patient best practices for their organizations. Finally, these leaders should reaffirm the critical role patient advocacy organizations can play in the lives of patients and caregivers and reinforce the partnerships industry should have with these organizations.” **PV**

Patients’ Voices

care for this patient population has led me to partner with Voices of Vascular, sponsored by Becton Dickinson. Through this, we have been able to share the stories of the Mighty Well patient community, which has allowed me to be a voice for the thousands of patients in our brand’s network to reach clinicians and develop thought leadership and building stronger patient and clinician relationships to further clinical outcomes.

Mighty Well has seen healthcare as a whole truly starting to become more patient-centric, but there is still a long way to go to make sure the patient is truly at the center of all aspects of healthcare. I would suggest bringing in patients who have lived through experiences be involved in all elements of pharma product research, design, and launch. I think healthcare sometimes forgets that at the end of the day, patients are the consumers.

Patients have the right to choose the products in and on their bodies. By including patients in all aspects of R&D and launch, pharma companies can better connect with patients who are now taking their healthcare journeys online, as we have seen with Mighty Well and Voices of Vascular.



TERESA WRIGHT-JOHNSON
A Heart That Matters
Heart Survivor, MS Warrior,
Inspirational Speaker, Patient
Leader and Advocate, Community

Activist

@ReesiesAllHeart

The key improvement that I have seen in the industry’s transformation to become more patient focused is employing patient engagement. The industry appears to recognize the importance of the patient voice and the effect that their individual experience has in advancing the work in research, technology, drug development, and marketing strategies through patient connection.

In becoming more patient focused, pharmaceutical companies are engaging patients as consultants, realizing they have a plethora of information about living with illness, quality of life issues, and addressing the unmet needs of the communities they market to. Also, in becoming more patient focused, companies are developing steering committees, made up of patients, industry, and other stakeholders. These committees engage patients and develop a module of important priorities, concerns, and desired outcomes. Steering committees endeavor to include, expand, and execute patient priorities and organizational development.

There are still gaps in minority participation in research and clinical trials. Lack of representation affects patient report outcomes and reduces effective treatment options. To better serve patients, pharmaceutical companies have to be transparent with their intentions. They must be diverse and inclusive, which are not one and the same.

An Industry Commitment

More than 250 industry leaders make a pledge to patients, acknowledging that they have a moral obligation to develop the best medicines and ensure that every person who may benefit has access to them. To do this, they state that the industry needs to act with the highest integrity and corporate responsibility — always putting the interests of patients first. To fulfill their obligations to patients and to renew trust and confidence in how their deliver on the mission, each of the signees affirms this “New Commitment to Patients,” informed by the following core principles and actions:

ENSURE ACCESS

- ▶ The pricing of our medicines at launch will reflect innovation and value to patients, and we commit to achieve broad patient access.
- ▶ We believe in growing our businesses with sustainable innovation, and any price increases on our medicines must be reasonable and guided by the need for uninterrupted patient access.
- ▶ To achieve the goal of patient access, we will collaborate with policymakers, pharmacy benefit managers, payers, and providers to find ways to limit or eliminate copays and deductibles for all patients.
- ▶ We will support generic and biosimilar approvals of safe and effective medicines

after legitimate patent and regulatory protections expire.

- ▶ We will seek to collaborate with all key parties in the healthcare system, including all biopharmaceutical companies, pharmacy benefit managers, payers, hospitals, pharmacies, distributors, and policymakers, to ensure that all patients get access to the medicines they need.

ACT WITH INTEGRITY AND RESPONSIBILITY

- ▶ We support only ethical business practices that drive innovation, competition, and patient choice.
- ▶ We will invest only in novel therapies that address unmet patient needs.
- ▶ We commit to patient advocacy in how we build and operate our companies, and to connecting directly with patients and their families.
- ▶ We will speak out about and not tolerate companies and other stakeholders who abuse this commitment to patients, and who abuse policies aimed at fairly rewarding innovation.

By supporting this New Commitment to Patients, they express their conviction to develop medicines with patients as their primary concern. They believe in doing so it will best serve the interests of patients, their caregivers, and healthcare providers, as well as those of shareholders and society at large.