



by Taren Grom

The Power of Patients

Patient engagement is permeating all spheres of the healthcare ecosystem.



On the cover...

This month's cover image is a self-portrait painted by Casey Ford, age 19, who has a rare connective tissue disorder, which is characterized by under-developed, absent, or misplaced/misaligned kneecaps in newborns. Today, Casey is a freshman studying computer science at Lafayette College and is a rare disease activist, having participated in a rare disease march in 2019. Throughout life, Casey has made great strides in managing the chronic pain associated with this disease and has gone from using a cane to rock climbing and weightlifting regularly.

Welcome to the third annual special Patient Voice issue. This issue was born out of the desire to bring the authentic voices of patients — representing dozens of different conditions — to the forefront. In this special issue, patients as well as dozens of industry experts tackle some of the biggest issues impacting their care, from



corporate culture to clinical trials and R&D to marketing and education to advocacy to the physician/payer dynamic. We want to thank our patient warriors for being honest, transparent, and at times, vulnerable in sharing their individual stories, struggles, and successes.

Patient Engagement

As patients are increasingly engaged in their own healthcare, and as their needs are evolving, pharmaceutical companies now have the ambition and the need to achieve greater patient centricity, says Gbenga Olatunji, director, Strategy&. Companies that operate in specialty care therapy areas, such as oncology, have a history of working closely with patients and patient groups, often as part of market access initiatives or to provide disease and treatment information. In the past decade, that engagement has also expanded to include patient services, patient advisory boards, and collaboration on a broader agenda including product development.

Experts across the board agree there is potential for greater collaboration between all stakeholder groups. This includes how patient insights can become a key part of the brand

planning process for pharma companies. Mr. Olatunji believes companies should develop a full understanding of the patient's journey. The patient's experience of their disease will often commence long before they ever need to take a pill or undergo any treatment. Many illnesses will have started well before any symptoms manifest and in some cases, those symptoms may initially be missed, ignored, or misinterpreted.

Gretchen Goller, global head, patient recruitment and retention solutions at ICON, agrees that there is a need in the industry to continually evolve and to increase patient centricity from discovery to commercialization.

"One of the ways we can do that is by making the patient voice an integral part of the process," she says. "We need to find out what will motivate patients to participate in a trial and when they have taken that step, ensure we make it easier for them to participate fully for better outcomes. By taking the time to listen and understand the patient perspective and the challenges of the diseases, we are able to design trials focused on effective treatments. Reducing patient burden is a key focus and one area that pharma is looking at more seriously is using the decentralized or hybrid trial models

which can increase flexibility for the patient and avoid disruption to daily life."

One of the ways the industry is working to engage more with patients, says Mila Woodfield, associate director, patient strategy, at Eversana Engage is through storytelling. "We're seeing campaigns featuring real patients sharing their authentic experiences in compelling testimonial videos throughout digital, social, and popular media, as well as the development of patient mentorship and ambassador programs," she says. "Marketers know that the power of well-told patient stories can carry more influence for patients, physicians, and payers than data alone. This inherent value is driving more and more companies to focus on telling patient stories."

It's clear as an industry that we need to ensure that authentic patients are embedded throughout the process from discovery to market and beyond. "Patient engagement needs to be championed across the industry — from CEOs to healthcare providers — and we all must commit to being patient minded," Ms. Woodfield says. "It is incumbent on all of us to ensure that the patient is present in everything we do so we can provide meaningful value to the treatment journey."

Put physicians in the driver's seat.

Introducing Swittons "Virtual Rep" for Pharma to empower Physicians.

- Pharma provides Swittons to Physicians
- Physicians CLICK when they have a need
- Pharma takes action
- Everyone is happy



Swittons

Better Everything.



With so many companies in healthcare talking about the importance of patient-centricity it's exciting to see those patient-centric values brought to life in the role of the chief patient officer. "Healthcare is no longer transactional, and our industry understands better outcomes are not the result of medicine alone," says Lyn Falconio, chief marketing

officer, Publicis Health. "As we reframe our approach to build everything through the lens of consumer experience, we need leaders with in-depth knowledge of the patient, their journey, their experience, and their expectations both in and out of their condition."

However, the challenge of an emerging role like the chief patient officer is that they are

often not given the budget, resources, or teams they need to pull things through or move at the pace of change.

"We believe chief patient officers are a vital new role, which is why Publicis Health is proud to have appointed our own chief patient officer to collaborate with clients and our agencies," Ms. Falconio says. ^{PV}

Patients' Voices: RULES OF ENGAGEMENT



LAUREN FREEDMAN
Invisible and Chronic Illness
@uninvisiblepod

Patients should be compensated as paid consultants. If their work saves a company on expenses and increases gains, they're a part of that growth. In addition, as a patient leader this is my work: if I'm giving my time, I should be compensated accordingly.



CHRISTINE FROST
Menopause
@Shahrazad1001

I know Facebook is a big avenue for story sharing, but I believe in branching out and doing in-depth social listening to see where people are and what they talk about. Conversations on Facebook tend to be more personal and private, whereas Twitter is good for advocacy and newsy/conference engagement. Inviting patients to be featured either on panels at conferences or in patient story videos would be a good starting point if I were to advise a company on a plan.



DANIEL GARZA
HIV Advocate
@LilMesican

Do some homework, know that not all groups are similar. Know that there are other factors that influence a person; cultural, religion, etc. To try to lump it up is a huge mistake. Simplify things; if you try to use all the \$10 words you will lose folks. Think about diversity.



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

My rules would be, as the patient sharing my story, the pharmaceutical company would have to have my final approval on the marketing message to ensure my story is presented fully. Another rule I would have is that the pharmaceutical company present my message

to help promote a greater understanding of my medical condition within their marketing messages.



EMILY LEVY
CEO and Co-Founder of Mighty Well
@MightyWell

My tips would be: include patient influencers from day one on any new initiative; create content that feels authentic and that is in touch with a modern patient's experience; include diverse voices and faces because that is the reality of America; create a way to include new patient voices once the campaign has launched to continually be innovating on initiatives; and fairly compensate patients for their time. Many times, pharma companies undervalue the time and effort of patients' involvement. Patients have a unique set of circumstances that often require two to three times more physical effort and prep time due to our conditions. Understand that and compensate them accordingly.

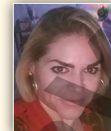
MICHELE NADEEM
Patient Influencer
Chronic Lymphocytic Leukemia (CLL)
@globalcorpcomms

My rules would be that pharma companies keep patients' stories authentic and to use more patients in their marketing. I would suggest that pharma also brings in patients during their marketing campaign message development. I myself have headed communications for multi-billion-dollar corporations and can speak from experience that internally what a company perceives as the right message can be incorrect and difficult to change if the proverbial train has already left the station. Often patients are not brought in until most of the marketing plans are about to launch.



DAKOTA ROSENFELT, PHARM.D.
Bleeding Disorders
@DRosenfelt, @HemoTool

Pharmaceutical companies should not tweak the patient story to fit their narrative, or patients just completely lost their power.



BRISA SIMENTAL
Patient
Fibromyalgia

Don't make our illness "happy." We are in pain, be honest.

Help get our story across to other people who suffer from the same thing. The more we, as patients, know about our illness and each other, the better we will understand the medications that we are given.



SIMON STONES
Patient Advocate and Consultant
Musculoskeletal Diseases, Inflammatory Bowel Disease, Pancreatic Cancer
@SimonRStones

There's no one-size-fits-all approach, and that's a good thing. Patients aren't one group of people who all act in the same way — contrary to the picture that is often painted. There are also different levels of patient advocates, ranging from those who have become patient experts interested in research and advocacy activities, to those who are engaged in less committed activities, and then those who choose not to, or don't have access to advocacy opportunities. Every voice is important though, and that involves using multiple methods to engage the patient community, ranging from forums, committees, and one-off events, to advocates involved as consultants.



MELISSA ADAMS VANHOUTEN
AGMD Public Policy & Outreach Director
Gastroparesis

@MelissaRVH

Reach out to us rather than forcing us to find you. Make the process simple. And above all else, appreciate the effort it takes for us to share, the mental toll it takes to open up about our personal lives, and do your best to truly hear us and act in our best interests.