



By Taren Grom

# Patients' Voices

This special issue explores the influence of patients as opinion leaders, advocates, and consumers across a multitude of intersections in the healthcare journey.

**P**harmaVOICE editors have been writing about patient-centricity and all this topic encompasses for what seems like a decade. Some say the term has lost meaning because of its ubiquitous use. We contend that patients are leading the way and influencing how businesses operate today. For sure, there is still a long way to go, but progress is palpable.

And, while not a bold projection, we expect patient influence will continue to change how the industry looks at its most important stakeholder. This was the premise for this special issue — Patients — to address a multitude of areas: clinical trials, apps and digital tools, health literacy, advocacy groups, storytelling, and business strategies.

This patient-based issue wouldn't be complete without insights from patients themselves. Through each of the articles we have included their feedback on the subject at hand, including their challenges and where they see opportunities for improvement.

We also asked our thought leaders a provocative question: What if the word "patient" were removed from the equation? This question is based on the premise that the term

patient no longer represents the journey we all take as consumers of healthcare.

We kick off this special issue with insights into the impact and influence patient opinion leaders are having on their communities, companies, and each other. Enjoy!

## Patient Opinion Leaders

Howard Chang has lived with severe psoriasis and eczema for almost 40 years, since childhood. He is a National Psoriasis Foundation Psocial Ambassador and Advocacy Action Network volunteer for the western region. He recently celebrated a decade of writing his psoriasis column, *The Itch to Beat Psoriasis*, on *Everyday Health*. He also blogs for *PsoSTRONG.com* on well-being and on his own website, *PsoHoward.com*. He has served on psoriasis patient panels and advisory groups sponsored by pharmaceutical companies. He is a patient opinion leader.

Patient opinion leaders (POLs) are indi-



Patient opinion leaders represent and give voice to the patient.

**HOWARD CHANG**  
National Psoriasis Foundation Psocial Ambassador  
Psoriasis Patient  
@hchang316

viduals who are well versed in a disease either as sufferers or caretakers of individuals with chronic disorders and who share their knowledge on the particular disease with others. With the advent of social media, their influence is becoming more important than ever.

"Patient opinion leaders represent and give voice to the patient," Mr. Chang says. "As patients, they feel the weight and burden of living with a particular condition. Nothing can replace the perspectives that emerge from the day-to-day battle with a health challenge.

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## Patients' Voices: Clinical Trials

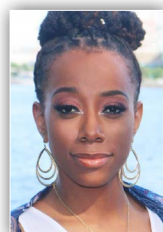
### CLINICAL TRIAL CHALLENGES

PharmaVOICE asked patients to identify the challenges they encounter with current clinical trial processes. For more information, please turn to Technology and Patient-Centric Trials.



**STARLA ESPINOZA**  
MS Patient Leader  
Multiple Sclerosis Patient  
facebook.com/curemsnow

Technology use for trials could really bridge the gap in geographical location for valuable patient participation. Pharma should do everything it can to address this issue.



**DIMA HENDRICKS**  
Sickle Cell Anemia Patient  
@DimaHendricks

Clinical trials are no longer just about designing study protocols and procedures. There needs to be a sense of patient-centricity. Today, more researchers and pharmaceutical companies are not only involving patients, but they are also investing time in understanding the lifestyle of the patient population.



**BARBY INGLE**  
President of International Pain Foundation (iPain)  
Central Pain Syndrome Patient  
@BarbyIngle

A patient-centric clinical trial is one where the researchers running the trial put themselves in the shoes of the patient. Trial staff members have patient advisors involved with each aspect of the clinical trial, from goal setting, creation, to how to run it, marketing it, and sharing the final outcomes. It involves regular interaction with the patients to understand their needs and development of the new product or trial. This is so important because as we know engaged patients are healthier patients.



**CANDACE LERMAN**  
Health Policy Consultant  
Immune Thrombocytopenia Patient  
@RareCandace

Patient-centric clinical trials are trials designed to work with patients, collect RWE data, and provide support to caregivers and family. In a way, CROs and companies have 24/7 access to patients and their families with social media. Formulating a plan is critical. Many patients I talk to feel a little uneasy approaching anyone other than their doctor. I believe we need a round table with members of Congress, HHS, the DOJ, patient representatives, and industry to address the future of the use of technology, specifically social media, for the future of clinical trials.



**CHRISTEL OERUM**  
Diabetes Strong  
Diabetes Patient  
@TheRealFitBlog

Today, the term patient-centric clinical trial unfortunately means very little as patients seem to be included very late in the development phase. By not including the patients until the feasibility studies, companies miss out on guidance on what the patients actually need in order to manage their disease optimally. The issue is to a large extent that quality-of-life measures won't necessarily lead to an increased premium for the industry when the product comes to market, making a focus on clinical outcomes the primary focus. From a patient perspective, this is a big issue for conditions like diabetes where the patient has to manage the condition 24/7. An earlier inclusion of the patient could help with clinical outcomes, and although the industry might not receive an upfront monetary reward from the insurance companies, they will have a higher chance of converting patients into long-term users making it worthwhile in the long run.

**WHITNEY PETIT**  
Epilepsy Patient Leader  
Epilepsy Patient  
@cfepilepsy



Patient-centric clinical trials means that the patient is more than a test subject in the clinical trial. The patients are essentially stakeholders and now a part of the process even before it hits production. The patient is the center of it all. I believe pharmaceutical companies could be on the right track. As the pharmaceutical industry continues to turn to patients for insight, the right technologies will continue to evolve when it comes to patient engagement and clinical trials. I'm sure measures will need to be in place to protect the patient, the research, and outcomes. Pharma companies have to find a way to also build the trust of patients when it comes to clinical trials. Patients are no longer just test subjects. We want to be treated as an individual first.



**LILLY STAIRS**  
Head of Patient Advocacy, Clara Health  
Autoimmune Disease Patient  
@LillyStairs

Truly patient-centric clinical trials mean that patients are involved in the trial design from day one. Working with patients from inception results in clinical trials that enroll faster and retain participants because they have thought through every angle of the patient experience. Often patient-centric trials incorporate free care, concierge services, and reduced hospital visits when possible.



**MARIA THOMAS**  
Hyperhidrosis Trailblazer and Patient Advocate  
@MyLifeAsAPuddle

Trials need to actually take the patient into consideration. Companies need to ask several questions, such as do the protocols make sense for the disease state? For the patient to qualify, can they achieve the measurables within a reasonable range, or is the range too high?

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## Patients' Voices: Apps

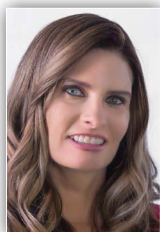
### APPS AND DIGITAL TOOLS

PharmaVOICE asked patients to identify what pharma needs to do better when creating patient-based apps and digital tools. For more information, please turn to Patient-Centered Apps.



**STARLA ESPINOZA**  
MS Patient Leader  
Multiple Sclerosis Patient  
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curemsnow

The most crucial element is variety of information from all angles and level of interaction for the patients within the app.



**BARBY INGLE**  
President of  
International Pain  
Foundation (iPain)  
Central Pain Syndrome Patient  
@BarbyIngle

Digital tools are going to become a major factor in getting patients engaged and participating in their healthcare between provider appointments. With all of the surgeries and chronic conditions I live with, I am hyperaware of changes in my body. There will be a time where I won't have to head to the ER first; I will use my available at-home tools to assess the situation and possibly talk to a provider through telemedicine and get the care I need, call in prescriptions to the pharmacist, or order an X-ray. My smartphone will be able to do an ECG and upload the data to my providers on call. They will be able to monitor my vitals and make arrangements for the care I need. With the added ability to be monitored in emergency situations and telemedical available, my care will only improve, leading my overall health to also improve.



**ILANA JACQUELINE**  
Patient Advocate,  
Author, Speaker  
Primary Immune  
Deficiency Disease Patient  
@IlanaJacqueline

The single biggest mistake is underestimating the large amount of data patients with chronic illness must keep track of to survive and achieve a high quality of life. More research with patient groups, especially those with complex conditions can help take an app from helpful to life-altering. Updated use of biometric tracking technologies, digital imaging, AI diagnostic capabilities, and most importantly, the future, is based on better communication between patients and healthcare providers. More involved, better educated patients who feel they are working as a team with their providers will create better overall outcomes.



**CHRISTEL OERUM**  
Diabetes Strong  
Diabetes Patient  
@TheRealFitBlog

Too often, the pharma industry forgets the personal aspect of living with a condition and only focuses on medical outcomes. Apps seem to be developed without insights from the actual users and often don't allow for integration with other health apps, such as MyFitnessPal, activity trackers, etc. leaving the patients emotionally disengaged and juggling way too many apps. I've found that the most successful patient-centered apps are those that engage the user and provide actionable information. Including a fun, more lighthearted aspect (such as the MySugr interactive "monster") makes the app more engaging and can distract a little from the daily management of a disease like diabetes.



**WHITNEY PETIT**  
Epilepsy Patient Leader  
Epilepsy Patient  
@cfepilepsy

Pharma tends to forget the actual patient aspect of patient-based apps. The most crucial element for a successful patient-centered app goes back to the biggest mistake. It is crucial to have patients be a part of the process from the start. A patient advisory board would help in this area. This way, the voice of the patient can be used to drive the direction of the app and digital tools.

## Patients' Voices: Health Literacy

### PATIENT LITERACY

PharmaVOICE asked patients to identify how low healthcare literacy impacts patient initiatives. For more information, please turn to Patients and Health Literacy.

**DIANA CLEVELAND**  
CoEhlers-Danlos New England/  
Massachusetts Support Group  
Ehlers-Danlos Patient  
@OriaBlue

Low health literacy, particularly in the areas of rare, chronic, and/or orphan diseases, too often has an unnecessary, deleterious impact on patient/providers and health systems. In particular, some healthcare organizations' practices of prioritizing simple, less expensive, and faster solutions to complex problems seen in patients whose cases are poorly understood can lead to marginalization, endangerment, and higher cost, whereas the prioritization of education, advocacy, and empathy can lead to shorter hospital stays, better patient outcomes, and less cost to the healthcare organization. For example, learning about how many patients with Ehlers-Danlos present with gastrointestinal issues (as connective tissue/collagen defects can impact 80% of the body), can help guide hospitalists, nurses, and insurance companies to anticipate the needs of this population, and stop leaping to judgment that a patient's complaints are "all in the head."



**GRACE CORDOVANO**  
Enlightening Results  
Cancer Patient  
Advocate  
@GraceCodovano

About 12% of U.S. English speaking adults have the health literacy required to make informed decisions about their care. Low health literacy is associated with negative patient outcomes. How can a nation with such poor health literacy possibly design, develop, coordinate, and run a robust, seamless, safe, cost-effective, transparent healthcare system? We can't and we don't.



## MT Pharmacy Outreach Toolkit



The Center for Information and Study on Clinical Research Participation (CISCRP), a nonprofit organization, has released a new educational video called the MT Pharmacy. Sponsored by Sanofi US, the digital public service announcement is designed to increase awareness of the important role that clinical research participants and clinical trials play in advancing public health.

“The goal of the MT Pharmacy is to demonstrate what modern medicine would look like without clinical trials and study volunteers,” says Ken Getz, founder and board chair of CISCRP. The MT Pharmacy is a novel approach to both engage the local community and to educate the public through the words of real people.”

While there are thousands of experimental drugs currently in development, with the potential to ease symptoms or even cure various diseases, none of these treatments will become available to patients without

clinical trials and clinical trial volunteers. In a global study conducted by CISCRP in 2017, close to 70% of the public has never or rarely considered clinical trials as an option when discussing treatment options with their doctor or health provider. And only 6% of people who suffer from severe and chronic diseases participate in clinical trials each year. Low participation rates delay and limit the development of new medical therapies.

“Sanofi is proud to collaborate with CISCRP on the MT Pharmacy initiative to raise awareness of the importance of clinical trial participation,” says Peter Lalli, head of Sanofi North America corporate social responsibility. “Clinical trials are essential for gaining access to new therapies and helping to ensure medicines are safe and effective across all patient populations.”

To view the MT Pharmacy video, visit: <https://youtu.be/w90COWBW03g>

That intense personal experience becomes an authentic part of a person that connects deeply with others who share in a similar experience.”

Because not everyone in a patient community feels the freedom to advocate or speak publicly about their and the community’s needs, Mr. Chang says patient leaders can articulate and effectively communicate those needs and experiences to healthcare providers, lawmakers and administrators, pharmaceutical industry representatives, and insurance policy providers. In this way POLs provide a vital link from the patient world to others, who impact their ability to receive care and support needed to live as well as they desire to.

“Patient leaders also inspire and empower other patients and providers,” Mr. Chang says. “Some days just getting through basic routines living with nagging and chronic conditions feels like a massive wall to climb. As a patient living with severe psoriasis since childhood, I have traveled through dark valleys with inflamed skin covering most of my body. Other patients who shared their stories encouraged me to seek help and keep going. As a blogger, advocate, and volunteer for the National Psoriasis Foundation, I seek to do the same for others who find themselves struggling to make it through a difficult season with their health.”

Lilly Stairs, an autoimmune patient and

the head of patient advocacy at Clara Health, also believes POLs are essential not only to the patient ecosystem, but the healthcare ecosystem as a whole. “POLs represent the collective voice of their communities and are well equipped to share those insight with pharma, insurance, and digital health companies,” Ms. Stairs explains. The communication loop comes full circle as POLs then share their experiences working with pharma back with their engaged communities, helping to foster a greater understanding of up and coming treatment options and resources available to the broader patient population.

“POLs can wield their influence via countless avenues — social media is a booming platform for advocates to share their story and support fellow patients,” she says. “We’re increasingly seeing POLs asked to work alongside pharma and digital health companies to design trials and provide product input. On the very cutting-edge are the companies that have begun to hire POLs as decision-making leaders, and that is a very exciting step in the right direction.”

Jen Horonjeff is a Ph.D. by training, but a patient advocate by birthright. She is committed to using both her professional and personal experience to develop and establish best practices, services, and products through patient-centered models. As founder and CEO of Savvy Cooperative, she believes patient opinion leaders can help serve as liaisons of information between multiple professional stakeholders and their patient community.

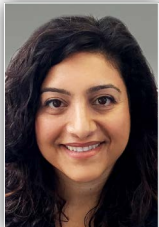
“This helps professionals across academia, health systems, pharma, policy, payers, digital health, and others hear directly from those with lived experiences in the condition of interest,” she says. “This is critical so that professionals can learn about real unmet needs and patient priorities, which may or may not validate the original hypotheses they had about patients’ behavior, barriers, and priorities. POLs are in positions where they can disseminate information back to their patient communities. They can share resources and opportunities with their peers in culturally sensitive ways, which professionals are unlikely to achieve on their own. These leaders become trusted sources of information, and many patients may value the knowledge and perspective they share just as much as their clinicians.”

Dr. Horonjeff says with the advent and access to technology, the evolution of the empowered patient is now turning into a revolution. Patients now have access to information from a variety of sources, including clinical studies, peer communities, and price transparency data. “More patients are motivated to get involved,” she says. “They have important roles guiding regulatory agencies, policy mak-

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## What if the word “patient” was removed from the conversation?



**VIOLET ALDAIA**  
President,  
Daggerwing Health

Removing the word “patient” from the conversation is imperative — it allows us to see the whole person in context of his or her life, and what we call the “Total Lived Experience.” This approach allows us to better understand daily life influences in order to identify unique and influential barriers and opportunities for behavioral change and ultimately better disease management outcomes.



**JEN BRISELLI**  
Managing Director of  
Experience Strategy &  
Design, Mad\*Pow

In his book *Design for Care*, Peter H. Jones makes a compelling case against words like patient, consumer, and user in favor of health seeker. I believe his rationale is one of the more mature perspectives out there, and it aligns well with the stance we’ve long held at Mad\*Pow. We are most innovative and successful when we design for people. Words hold a lot of power, and the how we refer to those we serve through the products, services, and experiences we provide can significantly influence the way individuals and entire organizations orient toward their customers in the delivery of those experiences. Terms like patient reduce people to a one-dimensional caricature framed by illness and lack of agency — a current state default condition from which we can only make incremental improvements, rather than an aspirational state of wellness toward which we can close ever shrinking gaps. What’s more, we know from our extensive work

in healthcare experience design that people don’t generally view themselves as patients — the patient role is episodic, not continuous, and those intervals between health service encounters, where people do not consciously identify as “patients,” represent some of the most significant, yet overlooked, opportunities for pharma and the broader health ecosystem to proactively deliver value through improved healthcare experiences.



**JONCA BULL, M.D.**  
VP, PPD Consulting

For medical product development, this would mean silence. Patients are at the heart of clinical research and essential to all conversation. Why? In the past, clinicians served as surrogates for the patient voice. Key opinion leaders and advisory boards were the primary informers for addressing unmet medical need. The AIDS crisis and the founding of NORD (the National Organization of Rare Diseases) were watershed moments for patient advocacy and engagement. This has only grown in scope and significance. Not including patients in the conversation? No way, not today! Patients are central to the conversation and essential to effective recruitment and retention.



**GRACE CORDOVANO**  
Enlightening Results

The word “patient” is a general term that’s taken for granted. Replace the word patient with “person or human with a diagnosis” and you profoundly change the definition. There is a distinct difference between the person who visits an urgent care clinic for pink eye vs. the person with advanced cancer who is told that they no longer respond to treatment. There is a clear

distinction between the person who goes to the ER in need of stitches vs. the person who lives with multiple chronic diseases on a daily basis. Both patients? Yes, but explicitly unique in their experiences, preferences, values, and needs. It’s critical to use the correct lens to understand the person, the human, with the diagnosis instead of falling habit to generalizations. It’s essential to tailor treatment and care to the whole person vs. narrowly focusing on only an individual diagnosis of the patient.



**DEBBIE DRELL**  
Director of Membership,  
NORD

While the industry adoption of terms such as patient-centricity and patient engagement helps to keep patients at the forefront of discussions, this does present an interesting juxtaposition about defining patients by their disease state, rather than as whole citizens or individuals. Interestingly enough, we have a long way to go in moving toward the rhetoric of a complete person, a “citizen” and not the “patient” identity.



**JENNIFER FILLMAN**  
VP/General Manager,  
Specialty Services,  
Cardinal Health  
Specialty Solutions

If the word patient were removed, it would be only science, not healthcare. The “care” part of healthcare dictates that the patient must be involved in the conversation. As science advances, we are finding many nuances of diseases that are individualized. As each patient has a different set of internal and external factors affecting their disease, an individualized approach to patient care is required.

ers, and innovators, so that together they can accelerate the co-creation of better solutions.”

The paternalistic healthcare system of the past is being replaced with patient-centricity and prioritizing the patient experience. And Dr. Horonjeff believes that as more and more professionals turn to patient leaders this can help them understand this cultural shift and explore tangible ways to improve the experiences of the patient.

“While this sounds nice, it also carries with it a business case and competitive advantage,” she says. “Those who work with patients will create solutions that impact the patient’s life, keep them engaged in their care, and achieve better outcomes. What may have started years ago as a tokenistic platitude to the patient community is now an earnest desire to work with patients to benefit from their vast and rich expertise that was previously overlooked.”

Dr. Horonjeff’s belief is that in the future, no company will dream of creating a solution that will impact patients without working with them early and often throughout the development process.

“When we think about the scale of patient-facing solutions, the opportunities for patient involvement is massive,” she says. “This will put today’s patient leaders in positions to help empower new leaders and to work



**ROSLYN SCHNEIDER, M.D.**  
Global Patient Affairs  
Lead, Pfizer

I believe the word patient sometimes connotes a hierarchy of power, which can be problematic. However, saying “person” alone doesn’t necessarily honor or respect the experience that people have when living with, or trying to prevent, an illness.

We in the patient and medical community want to capture that special experience, but that’s too long to say so we need a word more specific than “people at large.”

I often use a disclaimer when I say patient. I mean a person who is living with or trying to prevent a diagnosis, but I also include the other people who are living with that illness — the family members, care partners, and other members of their support community. They also have a really important role and have insights that we need to understand when we’re trying to serve the patient community.



**CHARLES “CHAS” SCHULTZ**  
Executive Director,  
Corporate  
Communications  
and Patient Advocacy,  
Lexicon Pharmaceuticals

There is absolutely no doubt, the “patient” remains at the center of the healthcare ecosystem. Some argue that only those who lay hands on the person should refer to him or her as the patient, but I for one think that is a distracting debate.

There are two important points that need to be made. First is that patients have the tools and capacity to participate in their care decision making and that they can ask the right questions and under-

stand what they are being told by the healthcare provider. Helping patients gain these skills is everyone’s responsibility. We all need to prevent visits to the physician office becoming visits to The Tower of Babel.

stand what they are being told by the healthcare provider. Helping patients gain these skills is everyone’s responsibility. We all need to prevent visits to the physician office becoming visits to The Tower of Babel.

The second important point is that simply focusing on “the patient” is not nearly enough. Yes, the patient is at the center of this ecosystem, but others participate as well. As Paul Kalanithi wrote in “When Breath Becomes Air,” any major illness transforms a patient — really the entire family’s life.”

We need to expand the conversation circle — and cycle — to provide opportunities for input from everyone with a stake in the patient’s illness journey: family members, trusted friends, and the integrated team of healthcare players.

As the late Steve Jobs said, “It’s not the tools you have faith in. Tools are just tools — they work or they don’t work. It’s the people you have faith in or not.”



**JENNIFER SIGAUD**  
Managing Director,  
Atlantis Healthcare

People are much more than their diagnosis. In most situations, we prefer to talk about “people or individuals living with a long-term condition” rather than use the label of “patient.”

This acknowledges that a person is more than the condition that he or she has been diagnosed with and more than the treatment he or she has been prescribed. Additionally, this underscores the notion that people want to fit their condition and its management around their life, not make it their life.

enough power to be statistically significant, so too will be the case with patient leaders. The same research projects will require patient involvement from the beginning to make sure the clinical study is not only feasible, but also gets a step closer to improving the outcomes patients care about, which, it’s worth stating, are not always the same as what clinicians, researchers and industry professionals care about.” **PV**

## Patient-Based Business Strategies



**JILL DONAHUE**  
Co-Founder,  
The Aurora Project,  
Excellerate

### Patient-focused Missions

When asked how important is it that pharma deliver on its patient-focused missions/visions, 90% of pharma associates scored it an 8 or higher on a 10-point scale. When asked how confident they are that pharma could deliver on those mission/visions, only 25% scored their confidence as an 8 or higher on a 10-point scale.

### Leadership

62% of pharma associates agreed that their CEO demonstrates through actions — not just words — that he/she believes focusing on patients is the right thing to do, 58% agree that their country head does the same, while 64% said their manager does.

### Pride in Pharma

Pharma associates are proud of what they and their companies do — 76% say they are confident that they are making their world a better place; 79% say helping patients is their primary motivation for working in this industry; 67% of pharma associates believe that patients would trust them more if they could secretly observe their meetings.

“Pharma is committed to its patient-focused missions and visions, but still struggles with the how,” says Jill Donahue, co-founder of The Aurora Project. “The low confidence that we see in the 2018 survey, suggests that pharma is still exploring how to integrate patient-centricity into its core value proposition.” She also notes that this year’s survey confirms that a majority of pharma leaders are walking the talk, and that leadership is key to creating patient-centric culture change.

“Pharma’s patient-centric evolution is great for patients but it’s also great for pharma,” Ms. Donahue concludes. “Patient-centricity drives engagement and pride in our work, which builds trust with our stakeholders.”

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