



# Improving the Quality of Patient Engagement by Centering the Advocate

- Summary** ■ The patient-centric shift in the healthcare industry is creating opportunities for new relationships with patients, but the quality of patient engagement efforts is inconsistent.
- A deeper understanding of and sensitivity to the patient-advocate's stance can help foster authentic relationships and more gratifying patient engagement experiences.
  - The Whole Advocate model provides a framework for centering the advocate in relationships and improving the quality of engagement.

# “Life itself assigns us our causes.”

This observation by author and psychologist Mary Pipher resonates deeply with persons who become patients due to a disease or other health condition, then come forward to share their lived experience with medical researchers, with developers of new drugs and therapies, and with other patients.

Prior to being diagnosed, most of these individuals never imagined they would be cast in this role. Yet here they are: agreeing, even feeling compelled, to share their lived experiences in order to help improve health outcomes for themselves and others.

For many, this significant act—*going public with personal lived experience in order to make a difference*—redefines their sense of self. No longer “just” patients defined in passive relationship to their disease, they assume an expanded identity, one that is defined by action, agency and purpose.

They are patient-advocates.

And at a time when the healthcare industry is intensifying efforts to “develop and nurture trusted and transparent relationships with patients,”<sup>1</sup> understanding the unique stance of the patient-advocate—not “just” the patient—can help deepen those relationships.

“Every time I share my stories and my experience, I feel a little more empowered. **Like I’m changing the world. And helping create a better future for others.**”

—Tristan Lee,  
sickle cell disease patient-advocate



## Patient-advocate, meet Patient Advocate

The steady call in recent decades for the healthcare industry to become more patient-centric has led to a new role within biopharma and biotech companies. This role is also called patient-advocate.

In this case, however, the term indicates an “advocate for patients” as opposed to a “patient who advocates.” (From now on, to help distinguish between the two, we will use Patient Advocate when referring to the corporate role and patient-advocate when referring to patients sharing lived experience in order to advocate.)<sup>2</sup>

Corporate Patient Advocate teams are typically charged with three key responsibilities:

1. championing patient voices within their companies,
2. serving as the main points of contact with patients and patient-advocacy groups and
3. spearheading a wide range of engagement efforts, including listening sessions, focus groups, patient advisory boards, clinical trial designs, internal speaking opportunities, co-created educational programs, digital platforms and more.

“As a patient-advocate, I fight not just for myself but for the broader illness community. **So I want to know that my efforts and concerns will be met with respect, that they will be valued. I want to know that if I share my personal experience with you or participate in your research study, my involvement will be meaningful.**”

—Melissa Adams VanHouten,  
gastroparesis patient-advocate

While the commitment to and depth of patient engagement varies across the healthcare industry, some claim this broad patient-centric shift marks a sea change in the culture of drug development and patient care, with pharma personnel hearing diverse patient voices more clearly and regularly than ever before.<sup>3, 4</sup>

Nowhere is this truer than for the Patient Advocate teams that are in frequent, even daily, contact with patients. Often, these teams are responsible for interviewing patients and their families about their experiences living with a disease or health condition; listening to patients' struggles in order to understand and identify unmet needs beyond diagnosis and treatment; building ongoing relationships with patients and patient-advocacy groups; and helping patients express, structure and craft their personal stories for internal and external initiatives.

With entire teams of dedicated Patient Advocates now embedded within biopharma/biotech companies, conditions have never been more favorable for the healthcare industry and patients to forge authentic, mutually beneficial relationships.<sup>5</sup>

**“Ultimately, it is not about me. It’s about what my story can do for others. There is no point telling it otherwise.”**  
— Carey Christensen,  
Parkinson’s disease patient-advocate

## The challenge ahead

To reach this increased level of patient engagement, Patient Advocate teams are challenged to hone their interpersonal and relationship-building skills, to operate from a space of deep empathy for the patient’s health journey—and to model that behavior for colleagues.<sup>6, 7</sup> As Jayne Gershkowitz, chief Patient Advocate for Amicus Therapeutics, told *Pharm Exec*, the role of the Patient Advocate is “about being the

conscience of the company, keeping everybody mindful of why we do what we do and who we do it for ... setting the tone for the company culture of commitment and dedication to patients and their families.”<sup>8</sup>

Nonetheless, while patient-advocates and patient-advocacy groups alike welcome companies’ increased engagement, many report that the *quality* of such engagement can be inconsistent. As Tristan Lee, sickle cell disease patient-advocate, notes, “I have been seen and heard by some of the best individuals in those companies. They’ve always been warm, genuine and respectful. Which is a blessing, because I know not every patient-advocate can say the same.”

Patient-advocates have shared with us recent instances in which they:

- received little preparation for the context in which they were asked to share their stories, resulting in them feeling emotional and highly vulnerable;
- were invited to participate in patient forums only to have medical presenters or other pharma representatives leave before they spoke, conveying a disregard for their point of view;
- felt oddly disconnected from the written versions of their health journeys captured and edited by a team of agency interviewers; and
- were uncertain if or how their invited participation would make a difference, leading to frustration and, in some cases, feelings of futility.

What’s missing from these engagements is not an understanding of the value of the patient’s voice. What’s missing is an understanding of—and sensitivity to—the patient as patient-advocate.



## Understanding the patient-advocate's stance

No matter the health issue or how much experience patient-advocates have speaking out, they all have one thing in common: they've chosen to share personal, lived experience publicly in order to improve health outcomes for themselves and for others.

This significant act defines the patient-advocate's stance in two important ways.

First, the choice to disclose personal information—*stepping across the threshold from private to public*—places individuals in a betwixt-and-between state that every advocate experiences differently.<sup>9</sup> Learning to navigate this terrain is part of being a public advocate, and the experience is varied, complex and nuanced—emotionally, physically, socially and psychologically.

Second, sharing personal stories to make a difference positions patient-advocates as agents of change, defined by action and intent. Whether speaking to other patients, the general public, legislators, clinical trial designers and investigators, regulatory agents or pharma professionals, patient-advocates want to know, unequivocally, that somebody will act as a result of hearing their experiences.

“Any engagement imposes costs and burdens that I must carefully evaluate: travel demands, time commitments, possible harm from medications and a whole host of other matters. On top of that, **I must decide whether I am willing to open myself up**, to reveal personal and intimate details of my life, to place myself in the hands of strangers.”

—Melissa Adams VanHouten,  
gastroparesis patient-advocate

Carey Christensen, an advocate for people with Parkinson's disease, puts it simply: “I am looking for people to take action. I am telling my story for a reason. I'm not just telling it for telling's sake, to get a pat on the head or to hear someone say, ‘I'm sorry.’”

Jim Kuhn, patient-advocate for the Foundation for Sarcoidosis Research, identifies the challenge of balancing public disclosure with the focus on goals: “It is hard, mentally and physically, to share our stories—so we want to make sure that there is some benefit at the end.”<sup>10</sup>

“There was this one pharma sales guy who, after I spoke, asked to take a picture with me. I ran into him years later, and **he told me he keeps that picture in his wallet. And that it motivates him every day**—when he goes out to a sales meeting or talks to his customers—to think about the people behind his work.”

—Ivy Elkins,  
lung-cancer research patient-advocate



## Centering the advocate: the Whole Advocate Model

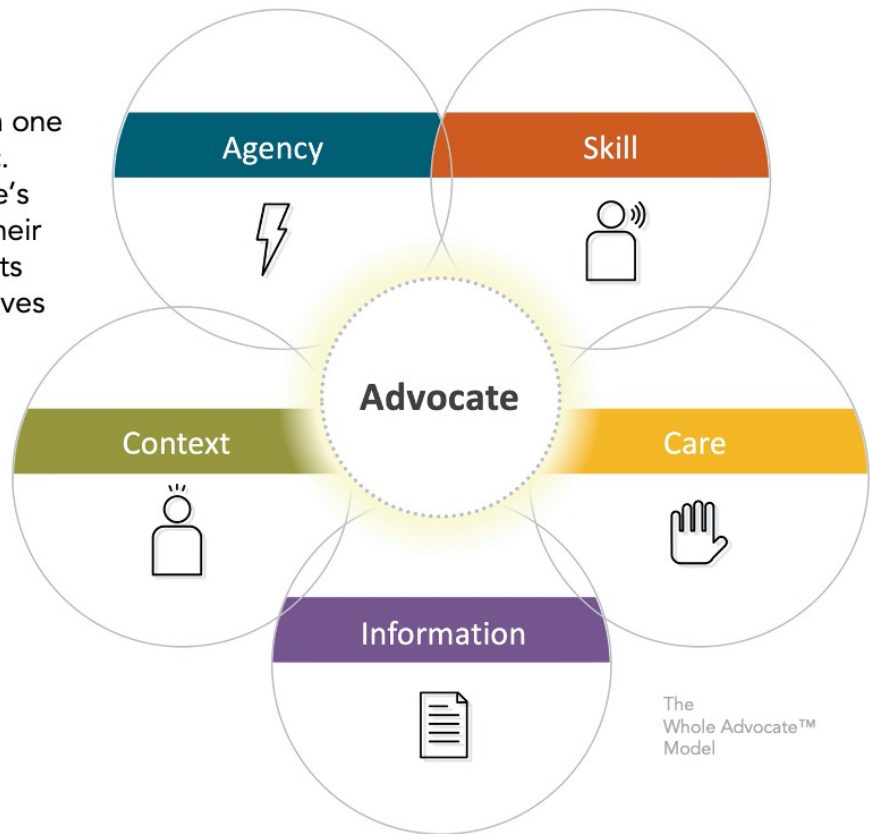
At Living Proof Advocacy, we have the honor of working with and supporting advocates who are addressing today's most pressing issues. They are people impacted by health conditions, of course, but also people sharing their lived experience to combat racism, homelessness, addiction, gun violence and more.

The Whole Advocate Model is the framework we've created to guide our engagement with all advocates, regardless of the cause they are advocating for. We use it to direct all our interactions, to remind us of the values that inform the work we do and to define the quality of our engagements.

The model has also helped other organizations explore their own practices of engaging advocates.

The Whole Advocate Model is similar to patient-centric healthcare models,<sup>11</sup> with one obvious difference: it is advocate-centric. The model revolves around the advocate's identity not as a passive contributor of their story, but as an active agent who warrants support and respect. The model also strives to account for the complexities and nuances of going public with a personal experience. As such, it's a useful overlay to patient-centric models.

The Whole Advocate Model is based upon five principles, each of which has implications for the quality of patient engagement.



## The five principles

**Principle #1: Honor agency.** Empower advocates to claim, assert and preserve their authorship, their voice, their experiences and the use of their stories.

Is there transparency and clarity regarding why advocates are sharing their experiences and how their stories will (or will not) be attributed and shared?

Do advocates understand the control they have over what, how much and how deeply they disclose and what they do not?

Do advocates feel that when their stories are shared by others, their voice and the nuance of their experience is preserved, as opposed to feeling that their stories have been reduced or appropriated?

**Principle #2: Build skills.** Help advocates acquire the skills they need to be successful.

Are advocates provided skill-building opportunities, such as communication, storytelling, advocacy or media skills training/resources?

Is the engagement relational rather than transactional, delivering long-term value to advocates?

Do advocates feel they are being helped to succeed in their goal of making a difference?

**Principle #3: Offer care.** Respect, acknowledge and attend to the significant act of going public with personal lived experience.

Is respect for the advocates' disclosure of lived experience reflected in the engagement communications, environment and follow-up?

Are advocates' emotional, mental and physical health and safety considered as they share their lived experience?

Do advocates feel they have the freedom to express their lived experience broadly (within parameters) vs. what is generally more narrowly considered “the patient journey”?

---

**Principle #4: Share information.** *Arm advocates with the information they need to strengthen their advocacy.*

Have advocates been provided information and/or resources about the topic of their advocacy that can strengthen their work?

Have advocates been provided information and/or resources about advocacy that can strengthen their work?

Are advocates given the opportunity to learn from and about other advocates?

---

**Principle #5: Provide context.** *Ensure advocates understand the contexts of their advocacy (both broad and immediate).*

Do advocates understand and feel prepared for the specific context in which they are asked to share their experiences?

Do advocates understand where they are situated within your company’s broader efforts or initiatives?

Have advocates been provided opportunities to learn about the results of their advocacy?

 **Know the advocate, the patient, the person**

Just as individuals who are managing health conditions do not want to feel they are being seen as “just” patients, so too do patient-advocates. As

a result, increasing empathy and understanding for the patient’s *advocacy* journey—not just the patient’s *medical* journey—can help Patient Advocates excel in their mission to champion patients. Bringing empathy and understanding into patient engagement efforts can help ensure that all engagement is as authentic and respectful as intended, built upon transparency and partnership.

Centering the advocate helps Patient Advocate teams and their companies:

- more clearly articulate the quality of the patient engagement efforts they aim to create
- elevate their company’s patient engagement efforts
- engender trust among patients and patient-advocacy groups by demonstrating an understanding and consideration of the patient-advocate
- identify and strengthen the skills Patient Advocate teams need to engage deeply with patients and
- increase confidence that patient engagement efforts are built upon an authentic, respectful understanding not only of the whole patient, but of the whole advocate.

**“We can never stop being patients. But as patient-advocates, we bring certain skills and abilities to the table.”** <sup>12</sup>

—Jim Kuhn,  
patient-advocate, Foundation for Sarcoidosis Research



## The benefits of true partnership

About six months after her 2013 diagnosis of Epidermal Growth-Factor Receptor (EGFR) positive stage 4 lung cancer, Ivy Elkins began sharing her story via the advocacy group, [LUNGevity](#). Since then, her activities as a patient-advocate have steadily increased, providing her opportunities to speak to employees of some of the world's largest pharmaceutical companies as well as clinical investigators. She is also a founding member of the EGFR Resisters Patient Group through which she advocates for the development of new treatments for the disease.

It's in that arena that Ivy has seen the living proof of her advocacy. "I've been fortunate to be involved in many clinical trial advisory boards at different stages in their development," she says. "And it's so gratifying when we share our stories and hear researchers say, 'Oh, so that's a big deal? We didn't really think about that.'"

For example, once Ivy and two other lung cancer patient-advocates were invited to offer advice to a pharmaceutical company about a new therapeutic solution that was getting ready to go to trial.

"At the meeting, all of us, patients as well as researchers, were very excited," says Ivy. "We learned about the project, and we asked questions. But the thing was they had already developed the delivery method—and all three of us patient-advocates didn't like the solution and didn't feel other lung-cancer patients would use it. There were some significant issues that they just hadn't thought of."

"So we left that meeting wondering what was going to happen now? Are they just going to forget it or contact us again?"

"Well, three months later, they came back. And they had completely reworked their solution into one that met the criteria we were talking about. They had truly listened to us and they really incorporated our feedback."

"We were so pleased knowing our engagement can truly make a difference."

## Strengthen your Patient Advocate team's ability to meaningfully engage patient-advocates

Living Proof Advocacy's **Whole Advocate Workshop** offers Patient Advocate professionals a one-of-a-kind opportunity to explore the empathy and interpersonal skills needed to forge meaningful relationships with patient-advocates, as well as their families and caregivers.

The workshop teaches perspective-shifting skills—by having teams explore their own stories and advocacy—as well as the interpersonal and communication skills needed to help patient-advocates express, structure and craft their personal stories for a variety of communication opportunities.

To learn more about how a **Whole Advocate Workshop** can foster a deeper understanding of and feeling for patient-advocates, contact us at [info@livingproofadvocacy.com](mailto:info@livingproofadvocacy.com).

### About Living Proof Advocacy

We help purpose-driven organizations and individuals harness the power of spoken first-person stories to drive positive change. We do so by providing coaching, consulting and certification services to organizations working on today's most important issues.

[livingproofadvocacy.com](http://livingproofadvocacy.com) • 612.512.1177

“As a patient-advocate, I truly value when I am addressed as such. It’s a badge of honor that I wear with pride. I take it as a sign of respect and value for the years of lived experience, knowledge and insight I provide.”

—Tristan Lee,  
sickle cell disease patient-advocate

<sup>1</sup>Upton, J. (2019, March 20). *Patient Advocacy: The Corporate Mandate*. PharmExec.com. <https://www.pharmexec.com/view/patient-advocacy-corporate-mandate>.

<sup>2</sup>Adding to the confusion is the fact that “patient-advocate” also refers to a healthcare professional who helps patients navigate their healthcare journeys.

<sup>3</sup>Moritz, J. (2017, February 23). *Drug Developers Embrace the Rising Prominence - and Influence - of Patient Advocacy*. Applied Clinical Trials Online. <https://www.appliedclinicaltrialsonline.com/view/drug-developers-embrace-rising-prominence-and-influence-patient-advocacy>.

<sup>4</sup>Upton.

<sup>5</sup>Malki, E. (2020, September 3). *Pharma and the Modern Patient: Creating a Real Connection*. PharmaTimes. [http://www.pharmatimes.com/thought\\_leadership/pharma\\_and\\_the\\_modern\\_patient\\_creating\\_a\\_real\\_connection\\_1347822](http://www.pharmatimes.com/thought_leadership/pharma_and_the_modern_patient_creating_a_real_connection_1347822).

<sup>6</sup>Upton.

<sup>7</sup>Chapman, A. (2018, June 12). *The Power Of Empathy: Reuters Events: Pharma*. The Power Of Empathy | Reuters Events | Pharma. <https://www.reutersevents.com/pharma/patients-and-medical/power-empathy>.

<sup>8</sup>Upton.

<sup>9</sup>This is the state of liminality. Wikimedia Foundation. (2021, May 16). *Liminality*. Wikipedia. <https://en.wikipedia.org/wiki/Liminality>.

<sup>10</sup>Carey Christensen quoted in Capecci, J., & Cage, T. (2019). *Living Proof: Telling Your Story to Make a Difference*. Granville Circle Press.

<sup>11</sup>Sinhasane, S. (2018, November 26). *Patient Centricity FAQs: From What Patient Centricity Is to What It Can Be*. Mobisoft Infotech. <https://mobisoftinfotech.com/resources/blog/patient-centricity-faqs-from-what-it-is-to-what-it-can-be/>.

<sup>12</sup>With gratitude to Ivy Elkins, Jim Kuhn, Tristan Lee and Melissa Adams VanHouten, interviewed, June 2021.