

By Robin Robinson

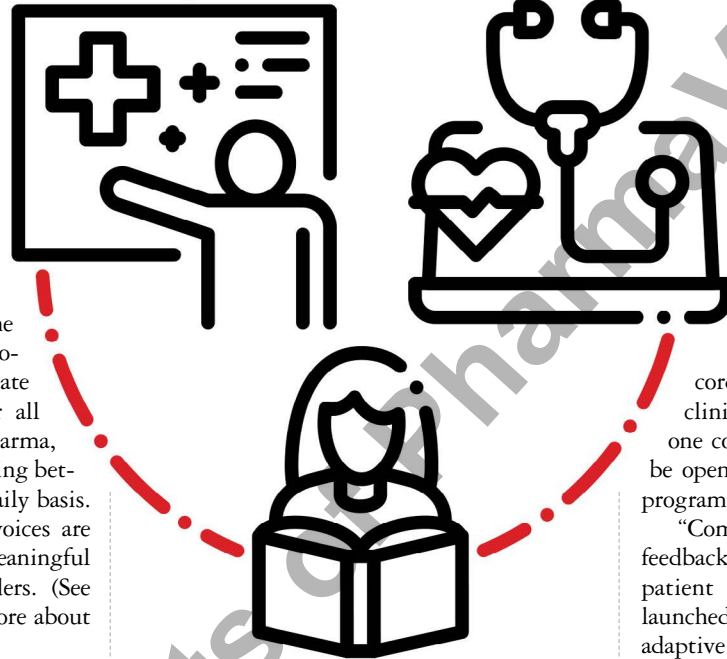
The Patient Knows Best

S hantana Hazel, Wayne Eskridge, and Lisa Lurie are just three of thousands of patient activists who have used their own patient journey and experiences to create informational and support tools for others. Through their own experience, they are able to fill in the information or service gaps and provide or guide the tools needed to create better educational opportunities for all stakeholders. Their advocacy with pharma, physicians, and other patients is creating better patient outcomes and care on a daily basis. These three have made sure their voices are heard, and they have set the bar for meaningful collaboration between all stakeholders. (See the Patient Voices sidebar to read more about their inspiring stories.)

“It is critical for the pharmaceutical industry to co-create patient solutions with patients, to go beyond advisory boards and panels to bring patients around the table, understand their unmet needs and perspectives, and design the solutions with them,” says Anne Najjar, global head of patient experience at AbbVie.

Pharma need to start with the basics and develop a deep understanding of the patient journey and the patient’s unmet needs, by understanding them as people living with an illness, but surrounded by all other aspects of life. “When thinking about patient education and support, it is more than just giving information and pushing it through pretty websites, apps and brochures,” Ms. Najjar says. “It’s the understanding of what information is needed, when is it needed, in what form and how will it be used by the patient to achieve the best possible outcomes.”

It’s important to note that this process is not linear, but iterative, she adds. So it is also critical for pharma companies to continue to engage with patients as their unmet needs evolve, the landscape changes, and the solutions continue to evolve to meet these changing needs.



The patient voice is crucial throughout the entire healthcare process, but especially relevant in creating spot-on patient education.

“This iterative and continuous co-creation will ensure that our patients can easily find what they are looking for, they understand what they find, and they can use what they find to meet their needs and achieve the best possible outcomes with their therapy,” Ms. Najjar says.

Involving patients and/or patient advocates directly and early in the process so that their voices can guide the development of educational tools and materials is ideal, says Lina Eliasson, Ph.D., partner at Sprout Health Solutions. This ensures that their unmet needs and wants can inform the objectives and the strategy, and that they can provide feedback on whether what has been created meets those needs and wants. “When it is not possible to involve patients or advocates directly, there are

other methods to bridge the gap, including reviewing available literature or patient-focused research reports and online social listening,” she says.

Making sure there is a mechanism for continual feedback once a program has been initiated is also crucial and often a missing factor in patient education programs, according to Rebecca Love, RN, principal, clinical innovation, at OptimizeRx. Anyone communicating with patients needs to be open to receiving feedback and adjusting programs accordingly.

“Companies need to be open to constant feedback,” Ms. Love says. “Several of the patient engagement programs that we’ve launched ask for feedback. It’s important to be adaptive in these programs to get feedback to improve initiatives. By creating the ability for people to provide feedback, this increases not only the credibility of the program, but the trust in the program.”

Health Disparity No. 1 Problem with Patient Education

One element that is most commonly missing in today’s patient education efforts, our experts say, is accommodations for health equity and health literacy. Speaking with the appropriate patient groups about their needs and what would ring true to them is key to solving this disparity in diverse cultures. (See related article — Bringing Health Equity to all Patients — in this issue for more information about health equity.)

“One very prominent issue would be the lack of true cultural representation within education materials,” says Andrew Thorn, executive VP, head of planning at Ogilvy Health. “Are the materials available in alternate languages? How many websites have built dynamic translations into their user interface? How many pharma sites have embraced VUI — voice-user interface — like

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REBECCA LOVE
OptimizeRx



Alexa? And how many ads truly integrate multicultural considerations into their campaigns? Are companies embracing the core principles of Health-Learning Design in the way we talk about medicine and treatments, or proactively involving the patient in a shared decision-making model of care?”

The answers to all these questions, he says, is most frequently no.

According to Steve Smith, president, patient advocacy at WCG, patient education needs to become more targeted to the languages, cultures, education levels, and medical literacy of the patient. This need is more acute as the impact of severe health disparities and endemic lack of participation in healthcare and clinical research by minority communities widens the health equity gap. “Experts in minority health advise us all to make education and information available in languages people understand, and be sure education is delivered in culturally competent ways,” he says. “There is evidence shown by those who do this, that it works to engage people to make healthier communities.”

Health advocate Ms. Hazel agrees wholeheartedly with this observation, as she has experienced it herself. As a patient advocate, she is working to address the gaps to create equal healthcare across the board.

“The biggest element that I see that has been lacking for a long time is health equity; especially, as a black woman, I deal with it on a regular basis, living with endometriosis and rheumatoid arthritis,” she says. “We all need to work at teaching patients how to advocate for themselves, as well as holding pharma accountable and holding physicians accountable and getting everyone to recognize that this responsibility belongs to all of us.”

According to Ms. Najjar, the goal of patient education has changed since the shift in



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LEAH CARLISLE
Fishawack

the healthcare system that put more responsibility on the patient to be empowered to make good decisions. “In the current healthcare system, the patient is considered a partner in his or her own care, not only a ‘recipient’ of care. The goal of patient education has shifted accordingly from directing patients on the best action to take, to now supporting patients in learning about their healthcare to improve their own health,” she says. “This means that we must empower patients with information that is reliable and simple to understand. To enable them to communicate effectively with their healthcare providers, so together, they can make the best decision for the patient’s overall health and well-being. This, simply put, is a focus on improving patients’ overall health literacy so they can take control of their own well-being, make informed healthcare decisions and improve their communication with their healthcare providers.”

However, there are challenges to gaining the trust of those who may need the patient information the most, Mr. Thorn says. This includes distrust of pharma and physicians in some cases.

“We are living in an age of disinformation and trust is low,” he says. “Hispanic men, for example, are less likely to have a regular doctor, have cultural barriers to discussing health and may not have access to educational materials in their preferred language.”

Another challenge is how the pandemic has



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ANNE NAJJAR
AbbVie

What Do Patients Want and Is Pharma Delivering?

A BCG June 2020 survey highlighted key agenda items for any pharma company’s patient-centricity efforts:

- ▶ Create a clear corporate identity and develop a cross-geography approach that emphasizes direct engagement with patients.
- ▶ Focus the approach on the attributes that matter most and/or where the company is performing worse.
- ▶ Ensure consistent execution in each local market and across functions, from R&D to commercial, to deliver consistent patient-centric outcomes.
- ▶ Engage key members of the healthcare ecosystem, especially nurses, to understand patients’ needs and what is and isn’t working.
- ▶ Act on the tremendous patient centricity opportunity in large private-pay markets.

According to the survey, patients, HCPs, and patient advisory groups reported the three top actions they want most from pharma are:

- ▶ Commitment to affordable access
- ▶ Trials to reflect real world and outcomes that matter to patients
- ▶ Transparent information



diminished the patient-doctor relationship, he adds. As telehealth, loss of insurance, and general fear reduce the routine conversations a patient has with a doctor, the relationship suffers and relatedly, so does trust. While many factors contribute to the erosion of trust, experts blame a lack of time with patients more than anything else. Trust tends to build over time and through repeated interactions, which can be difficult to provide — especially during a pandemic. Additionally, as people take to the Internet for self-diagnosis and treatment they often encounter distorted truths and false information, which leads to poor outcomes.

“We need to find ways — through telehealth and other means — to better facilitate earlier and more frequent conversations between doctors and patients if we want to effect change,” he says.

Patients as Part of the Solution

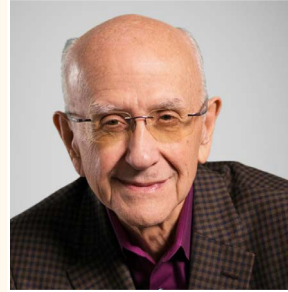
Patients and caregivers want to be part of the solution — they have passion and purpose, and together, these are two powerful forces, says Jennifer Reilly, VP, account director at Cross & Wild.

As we referenced earlier with our three patient advocates, if a community wasn't available when they were diagnosed, patients are apt to help build a place for others to go so they don't experience the same overwhelming feeling of loneliness at diagnosis. While patients or caregivers live through their own challenges and grief, they rally more than ever



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STEVE SMITH
WCG



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WAYNE ESKRIDGE
Fatty Liver Foundation



If people don't recognize themselves in the patient education materials, if they don't feel represented, they won't be engaged.

ANDREW THORN
Ogilvy Health

to make sure others feel the support around them.

Other ways for patients to contribute is through advocacy organizations, joining online patient communities, and signing up to market research panels, Dr. Eliasson says. “All of us working in the patient education space need to ensure we are creating opportunities for patients to be involved in a meaningful way and where they feel empowered to share their views,” she says. “From the industry perspective, we need to work with our medical, legal and regulatory colleagues to reduce the barriers to patients being part of the solution of creating more effective educational materials.”

Agencies can form advisory boards of people from the communities they are trying to reach with their messages. These community advisory boards or patient advisory boards should be engaged early enough to review plans in advance so that their advice can be acted upon, Mr. Smith says. “They should also be consulted again as the materials are being used to give feedback as to reception of

the material by the communities in question,” he says. “Images on materials, instructors, speakers, or other educators such as nurses and physicians should mirror the communities patients come from to the extent possible.”

“Everything that is created for patients should be created with patients,” Ms. Carlisle

says. In doing this, engaging with expert patients such as those leading patient advocacy groups can be extremely valuable, as they balance a deep understanding of what patients experience and need with a more robust understanding of a therapy area and key educational topics. Expert patients, however, should not be the only ones engaged. From insight to implementation, it's important that companies engage closely with a diverse group of patients and caregivers who truly represent the populations that they want to reach.

“Engage with patients and caregivers early on through deep qualitative means, for example through ethnographies, to truly understand what educational resources they need,” she says. “And continue to engage with them as materials are developed to ensure the content, design, and user experience are clear and meaningful. Co-creation can be powerful; allowing patients and caregivers themselves to build content and materials as part of the process rather than solely feeding back on materials that are created can make a significant difference. Taking this approach enables companies to infuse real patient voices and stories into the materials.”

Once she became a patient advocate Ms. Hazel found her patient voice, and she learned quickly to use it, not just for her own good, but for other patients as well.

“I didn't realize my voice was so important until I started asking questions and I started being a part of my care plan and showing up for myself as a woman, as a person, and as a patient,” she says. “It's important for patients to know their voices matter because no one knows us the way we know ourselves; we know



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SHANTANA HAZEL
Sister Girl Foundation

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our bodies better than anyone.”

Patients need to voice their concerns, advocate for themselves, and demand better of their healthcare professionals, who in turn should demand more of the education materials being provided to them, Mr. Thorn says.

“With all things, particularly so with patient education, if people don’t recognize themselves in the materials, if they don’t feel represented, they won’t be engaged,” he says. “So patients across all ethnicities, ages, and disease states need to step up and say: ‘This doesn’t work for me... You’re not speaking to me and you’re not speaking with me.’”

At AbbVie, Ms. Najjar says the company is well aware that listening to patients and learning about their experiences can dramatically improve drug development, delivery, and accessibility, as well as patient support. “In order to do that, we must ensure the patient voice within pharma is consistently informing key strategies and decisions,” she says. “Starting with informing key development milestones such as clinical trial endpoints and clinical trial design and continuing throughout the commercialization journey.”

Mr. Eskridge of the Fatty Liver Foundation has partnered many times with pharma companies and other organizations. “We’ve been working with the pharmaceutical companies since we started,” he says. “Basically, we have probably received grants from all the big ones anyway and a number of smaller ones. For instance, Fatty Liver Foundation and Madrigal Pharmaceuticals teamed up for a Web conference series for NAFLD/NASH education.”

The four-part webinar series hosted by Mr. Eskridge delivers the latest research and medical information, including lifestyle/diet, testing and treatment, to people living with non-alcoholic fatty liver disease (NAFLD) and non-alcoholic steatohepatitis (NASH) and their medical providers. The organization is also currently working with Bristol Myers Squibb on a pilot peer-to-peer network that connects to a database and to wellness navigators and to health coaches that can help people navigate this lifestyle change, he says. “Our goal is to recruit 10,000 wellness navigators who will be given the information to be taught, instructed on the nutritional information, health information, and be helped to engage the local community in various ways with that information,” he says.

Ms. Lurie has not yet partnered with a pharma company, but she would like to. “I



Patients are the end users of medicines and healthcare, and their voices should guide everything pharma does.

DR. LINA ELIASSON
Sprout Health
Solutions



Working directly with patients and caregivers and giving them a voice to not only advise on what information they need, but also understand how they will best receive it, leads to the development of the most effective educational materials.

JENNIFER REILLY
Cross & Wild

would welcome pharmaceutical companies supporting survivor-created companies such as Cancer Be Glammed,” she says. “There are communities of patients working every day for other people and I think it would be a terrific marriage, because we have the community, we have a voice, we have a platform, we have access to patients — and patient care is at the heart of what we do.”

Ms. Love from OptimizeRx agrees. “I think life-science companies feel that education is outside of their scope,” she says. “I fundamentally believe that life-science companies must own the patient engagement and the patient experience related to their medications.”

The reason, she says, is simple: providers are too busy and patients who have the disease, who on top of their regular lives are trying to manage a complex disease that is disrupting

How To Ensure Patient Education Is Helpful And Relevant To Patients

- ▶ Meet patients where they are. Don’t assume they will land on your website or that they always want to hear directly from a pharma company (although building trust in your organization and brand is critical). Understand where your patients are going for information and support — online or offline — and at which points in their journey, as this will help you provide relevant education at that point of need.
- ▶ Personalize your materials as much as possible. Understand your patient segments — what makes them different, and what do they have in common? Develop cohesive materials to address core patient insights and then create variations that are tuned to the needs of each patient segment. Proactively consider the data you want to generate to enable this personalization to continue and grow on an ongoing basis.
- ▶ Optimize materials for every health literacy level. It’s also important to tailor materials for expert or more engaged patients alongside materials for patients who are just beginning to learn about their disease and/or are less engaged in education. Finally, give experts and those interested the ability to drill down deeper into topics they are interested in by developing a content journey filled with opportunities to “double click” into the details, new touchpoints, and omnichannel engagement.
- ▶ Ensure your education is not a one-way street. In addition to co-creating resources and solutions, provide opportunities for patients to give feedback on what has been valuable and relevant to them, and what could have been better. Additionally, facilitate educational conversations with other patients and caregivers, as well as with their physicians.

Source: Leah Carlisle, Fishawack Health

and potentially threatening their lives, don't have the bandwidth.

"The one player in that triangular relationship is the life-sciences company; the company is the expert on that medication, understands the side effects and the adverse effects, and can

create programming that not only supports the provider, but the patient who can continue on with the treatment with less disruption," she says.

Ms. Hazel has worked with several pharmaceutical companies and has had a positive

experience. "It's more than an experience for me; this is life, and it's helping paint a picture for people who are on the outside," she says. "It's been rewarding because our involvement has created programs that benefit others. I've worked with Lilly on several projects around

Voices of the Patients

COMMUNITY BUILDER



SHANTANA HAZEL, who lives with endometriosis and rheumatoid arthritis, has spent more than 10 years providing a community of women

with advocacy, education, and support during their endometriosis, breast, and ovarian cancer journeys. She has won multiple patient advocacy awards for her commitment. She co-created an app called ArthritisPower, with CreakyJoints, where she also served as Patient Governor co-chair. A support, education, advocacy, and research organization for people living with arthritis and rheumatic disease. The app is the 1st patient-centered registry where you can keep track of your symptoms, share with your family and help in advancing research. She founded The Sister Girl Foundation, a nonprofit organization geared toward providing awareness, education, support, and advocacy for women with endometriosis, breast, and ovarian cancers, and has written several books that teach others how to become empowered patients.

A target of racial bias and healthcare disparity in her long healthcare journey, Ms. Hazel is determined to help others so they do not suffer the many difficulties — such as a 14-year delay in diagnosis and 16 endo-related surgeries — she has experienced. "I am committed to helping women who are suffering in silence find their voices and advocate for their own healthcare," she says.

CREATING A NATIONAL VOICE

As a patient educator, **WAYNE ESKRIDGE**



has a lot to offer from his experiences with the relatively unknown disease, nonalcoholic steatohepatitis or NASH. Few patients are able to improve their health after a NASH diagnosis, but

Mr. Eskridge did, (currently, both FibroScans and biopsies identify his disease as "idle") and now he does not miss any opportunity to educate others from his learnings. His experience led him to create the Fatty Liver Foundation in January 2017 to provide much-needed information for folks diagnosed with NASH.

He says education is a "complete necessity" for a disease that not many know about. Unlike cancer or MS, for example, NASH is little known to not only patients, but caregivers and physicians as well. "When somebody talks about NASH, most people have no context," he says. "Even if people are telling us important information, we don't have an easy connection to make to that information and so, it passes us by."

This makes it difficult to successfully manage the patient journey or to even know what you don't know. "The information that's out there in the world for NASH is just awful," Mr. Eskridge says. "Education needs to create a teachable moment, when a person is engaged enough to say, 'this is important, this might mean something to me.'"

When Mr. Eskridge first started the foundation, he says it was the only national voice focused strictly on NASH. Since then many more patient resources have been added; however, the general population is still unaware of the disease, Mr. Eskridge says. "There's been progress made and the disease is more visible, but we are not at the point where people read a headline about NASH and understand its importance."

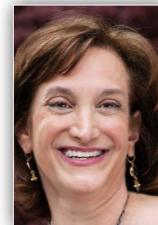
To help with that awareness, the Fatty

Liver Foundation has partnered with several organizations, including several pharma companies, on patient education. One point of focus is to create awareness for the need of early screening, identification, and intervention for people at risk of developing nonalcoholic steatohepatitis.

"One of our missions is to convince the American healthcare system that it needs to be proactive about identifying the disease earlier," Mr. Eskridge says. "The standard guidance from the American Association for the Study of Liver Diseases is that we don't screen for asymptomatic liver disease."

More often, patients will not be diagnosed until they develop identifiable symptoms. "It is a very frequent complaint of NASH patients that once they've been diagnosed with cirrhosis they find out that in their medical history the doctor noted that they have fatty liver but they were never told. If they had known, maybe they would have been able to make behavior changes to avoid becoming cirrhotic," he says.

A HOLISTIC VIEW OF HEALING



For breast cancer survivor **LISA LURIE**, her patient experience taught her how important it is to take a holistic view of healing. After her double mastectomy surgery and her cancer treatment 11 years

ago, she was left scarred, both physically and emotionally, and there were no resources for her to turn to, not even to find a comfortable shirt to wear post-op. "I had fantastic medical care, but very little support in trying to deal with my new body image issues, my self-esteem, and my identity," Ms. Lurie says. "I felt bereft. I felt alone. I felt I was no longer enough. From that moment,

awareness, advocacy, and patient-centered care, which has been instrumental to a lot of patients being heard, being listened to, being seen, and, ultimately, creating change.”

One of things that has changed, Ms. Hazel says, is how some pharma companies are adver-

tising their products by using actual patients instead of actors and using messaging and dramatizations that resonate with real patients.

“For example, I worked on this one project and it was all based on showing hope,” she adds. “Yes, we have rheumatoid arthritis, but

we still have a life. Just because we have this disease doesn’t take our lives away. We’re still able to do things. We may have to alter them a little bit, but there’s still hope, there are still brighter days. Instead of seeing actors in these spots, actual patients were depicted in these commercials.”

Ms. Hazel’s end goal is to get both physicians and pharma companies to pay more attention to patients. “We do know what we’re talking about,” she says. “We may not have a medical degree, but we know what we’re talking about — invite us to be a part of the research, to be a part of the programs being created.”

At the end of the day, she says, pharma companies will have more patients who trust them and are willing to talk with them. **PV**

I became determined to help women cope with cancer-created lifestyle concerns and to develop a dynamic community of survivors sharing their hard-won wisdom to ensure that their experiences would be different than mine.”

Just a year after her diagnosis in 2008, Ms. Lurie and a friend started Cancer Be Glammed, with the intention to provide women with lifestyle support, real solutions, and to encourage them to take charge of their recovery and give them the education, empowerment and tools to do that.

“I have been involved in patient education for many years, and it is critical to heal the whole person and that includes addressing his or her psychosocial issues,” she says. “I know that it’s a big challenge in the healthcare community, and I decided to make it my purpose.”

For most breast cancer patients, the No. 1 source of lifestyle education comes from their oncologist, staff in the oncology practice, and especially oncology nurses, navigators, and social workers. It is important that these resources are aware of the need and availability of psychosocial support, such as Cancer Be Glammed. Although designed for the patient, the company also has the mission of being an asset to advance patient education for oncologists and the healthcare community.

“I think it’s important that doctors recognize that they have to address the mental health impact of cancer on patients in conjunction with caring for their physical health,” she says. “Part of my advocacy is to educate them about that. We are making presentations at hospitals, healthcare organizations, and to physicians to help them understand that this is a key part of someone’s recovery.”

In addition to their website Cancerbeglammed.com, the group has created

a digital guidebook called Cancer Be Glammed: The Guide that they are making available to hospitals and oncology centers. It features cancer survivors as models and provides quick actionable tips for dealing with appearance-related challenges like hair loss, skin problems, and body-altering surgeries, including mastectomies and oostomies. It’s written from all these wonderful women’s perspectives so that it’s relevant and authentic. The guide was designed in a digital format so it can be customized for hospitals, oncology practices, and cancer centers.

While there are many surveys about the medical and healthcare challenges of cancer, Ms. Lurie discovered there were very few focused on identifying the lifestyle and appearance-related needs of women struggling with body-image and self-esteem issues from surgery and treatment. These include disfigurement, hair loss, limited mobility, weight changes, skin and nail problems, and intimacy issues.

In partnership with Wrapped in Love, an online recovery clothing company for cancer patients, Cancer Be Glammed conducted a Cancer Recovery Life & Style Survey with 876 women participating. The results included data on the lifestyle needs and wants of women in terms of physical products, information, and where they want to access their information.

The Cancer Recovery survey aimed to accomplish three things: One, to better understand and serve the women in our cancer communities; two, to provide valuable, lifestyle recovery information to oncology doctors, nurses, navigators, and social workers who provide psychosocial support for their patients, and three, to advocate for inclusion and visibility for women with cancer in the worlds of beauty, fashion, and lifestyle.



I have been involved in patient education for years, and it is so critical to heal the whole person and that includes addressing his or her psychosocial issues.

LISA LURIE
Cancer Be Glammed