

Dancing to the same tune?

Patient advocacy groups and pharma companies have the same ultimate goal – better health outcomes – but managing these relationships needs care on both sides



Patient advocacy groups represent a direct route for pharma to understand what patients actually think about their medicines – and what patients want from them. However, as with any collaboration, there are a few golden rules.

“You need to have respect and there needs to be a true spirit of partnership,” says Nisith Kumar, Director, Global Patient Affairs, Pfizer. “We’re in a highly-regulated industry and we didn’t always have this [level of patient] access, so one of the challenges has been a cultural shift.”



Meet our contributors



Nisith Kumar
Director, Global Patient Affairs
Pfizer



Ann Kwong
Founder and CEO
TREK Therapeutics



Lynn Bartnicki
Patient advocate
Living Beyond Breast Cancer

“Some drug companies are really focused on patients, and some don’t have a clue.”

LYNN BARTNICKI, PATIENT ADVOCATE

When pharma interacts with patient groups, it must have a long-term view of the relationship, says Kumar. “The relationship shouldn’t be viewed as transactional; it must be a long-term strategic approach with the patient group as a valued partner.”

Setting expectations is crucial for both industry and patient groups, especially an understanding that, while patient input is very valuable for a pharma company, all of it may not necessarily be actionable. “Patients might share really good insights but we might not be able to integrate them for a variety of possible reasons. However, once the feedback is provided there should be a follow-up communication to talk about what can be incorporated and what can’t – and why.”

An area of potential disagreement is the real-time sharing of results. “A patient organization might want certain results delivered there and then, and we have to explain that this could jeopardize the integrity of the trial,” says Kumar.

This illustrates the benefits of communication, as patients understand the rationale behind a pharma company’s decision and, in turn, pharma addresses patient need. “Twenty-five years ago, a patient in a trial might never know whether they were active or placebo. That is changing.”

The level of detail on the protocol that can be shared is another potential cause of tension. “Not every team will want to share each part of a draft protocol with a patient group, such as details on the mechanism of action,” says Kumar.

THE COST FLASHPOINT

Managing expectations is an essential part of a long-term relationship and is particularly useful when discussing the

cost of treatment. “Discussion over pricing is a big point of tension,” says Ann Kwong, Founder and CEO of TREK Therapeutics, which aims to launch a cure for hepatitis C virus (HCV) in 2022. “Pricing is the major place where expectations don’t match. We can get it as low as possible and it’s never quite going to be sufficient. That’s partly a function of human nature.”

Explaining the complexity of costs to patient groups is difficult, she says. “There are other players involved, like pharmacy benefit managers, and there’s also the rebate issue, so it’s complex.”

Yet cost is a huge issue for patients, says Lynn Bartnicki, a patient advocate for Living Beyond Breast Cancer. “The prices of drugs are outrageous; we want to get them at an affordable amount of money. Drug companies and insurance companies need to work together.”

As a public benefit corporation, TREK can make a profit but it does not have a legal duty to maximize financial returns for shareholders – this puts it into a different philosophical and fiduciary bracket to many pharma companies. “With patients and their need for lower-cost, accessible drugs on the one hand and pharma for-profit organizations on the other, we’re looking to shift the balance back to the patient,” says Kwong.

“Most people at the Discovery level never talk to a patient,” she says. “Patient groups are not brought in early to share their issues and what companies should take into consideration. Having more rounded input would be useful.”

Bartnicki agrees, saying that her impression from last year’s eyeforpharma Philadelphia conference was that “some drug companies are really focused on their patients and some don’t have a clue.”





BRAINSTORMING TOGETHER

In HCV, one of the most important considerations is the duration of treatment, particularly in the US, where a 12-week course of a drug might only be approved monthly by insurers, says Kwong. This leaves medical care providers having to spend a day phoning their patient's insurance company. "It's a huge drain on time. If we could get treatment down to six weeks, could we get a six-week approval?"

Most people with HCV do not even know they are infected, she adds. "This is an area where it is important to get patient stories out there. It will help to bring other patients out, chipping away at the stigma of the disease, which is an important component in getting treated. It is important for companies to brainstorm with patient groups in order to work out whether we can do this better."

If companies manage these relationships sensitively, what does pharma get out of such collaborations? "Insight, things we hadn't even thought of, because we're not the patient," says Kumar. "We have the scientific knowledge but we don't have the practical and often personal day-to-day knowledge of the disease."

Along with many other big pharma companies, Pfizer is part of the non-profit TransCelerate BioPharma, aimed at simplifying and accelerating R&D of innovative new therapies. "We have patient advocates who provide input on a huge range of areas, including trying to identify a clinical trial online through ClinicalTrials.gov, which is not as easy as it could be," he says. "We are also trying to enhance the patient experience through e-consent and the eLabel initiative, under the TransCelerate umbrella."

CONTACT AND SUPPORT

As a cancer survivor, Bartnicki has a better understanding than most of what patients require from their interactions with pharma. For her, contact and support are important.

For example, when on a course of Herceptin, she had access to a support line where she could talk to specialists about the drug's side effects, such as mouth dryness, for which she was given useful advice. "There was also an app for the phone so you could contact them in so many ways," she says.

It was important that someone was available to listen to her, not least because the drug costed "thousands and thousands each month". Cost is rarely far from patients' thoughts.

Patient groups are not all the same, says Kwong. "Each patient group occupies a different niche." She predicts that more patient groups will develop along similar lines to the Michael J. Fox Foundation for Parkinson's Research or the cystic fibrosis advocacy group. "Ivacaftor would not have been developed without support from the Cystic Fibrosis Association," she says. "They can have an effect."

Patient groups being active partners in – and helping to pay for – research into new treatments is the way forward, she adds. "It comes down to funding – without money we can't run clinical trials."

SEAMLESS PROCESSES

Kumar believes patient engagement at Pfizer will be almost seamless ten years from now. "It'll be embedded in systems and processes, and will happen at the beginning of the drug development process, which we've already started seeing. My hope is for standing agreements with patient advocacy groups so that we collaborate more and more. With each engagement, there are opportunities to learn but it's going to take a leap of faith for some companies."

Yet networks such as PatientsLikeMe are not waiting for pharma to approach them, they are sharing information among themselves. Companies need to be on the front foot in managing these relationships.

Lynn Bartnicki is clear about what she wants from pharma. "We are looking for a cure or, at the very least, make metastatic breast cancer a chronic disease instead of a terminal one. Pharma has done it in other areas."

When it comes to pharma's interaction with patients it is, then, as simple – and as complex – as that. 

