Dancing to the same tune?

Are pharma and patients in sync?

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Are pharma and patients in sync?
A few years ago, pharma was besieged by problems – $150bn lost to blockbuster patent cliffs, stalling health budgets, falling engagement with physicians, rising R&D costs, public pressure over high drug prices, and a shift to specialty care, to name but a few.

It was clear to some that the old model, while not yet dead, would not deliver the margins companies (and their shareholders) had become accustomed to. Rising from the ashes like the proverbial phoenix was a new concept, a wonderful, simple idea.

Focus on the patient.

As a transformative concept, patient-centricity has been building steam for years and has now firmly shed the moniker of ‘buzzword’. Patient focus is everywhere; in clinical trial design and recruitment, in relations with patient organizations, in market access. It is here to stay.

Inside these pages, we ask some of the big questions arising from the focus on the patient. In A Defining Moment (p4), we speak to AstraZeneca’s Guy Yeoman about the company’s work to find an answer to the most fundamental question of all – what do patients want?

For many companies, the business case for patient-centricity is clear; in Best of Both Worlds (p8), senior leaders tell us that not only is it possible to deliver both patient value and shareholder value, it is essential. You can’t have one without the other.

In pharma’s increasingly complex multi-stakeholder engagement model, patient advocacy organizations play a crucial role. Yet, as we outline in Dancing to the Same Tune? (p12), care is needed on both sides to maintain and strengthen fair, transparent relationships.

I hope you enjoy Trends in Patient-Centricity.

Paul Simms
Chairman
eyeforpharma
Astrazeneca is going back to basics by publishing a definition of patient-centricity, moving the focus from what a company does to how it does it.
Patient-centricity has been a powerful buzzword in pharma over the last five years, shaking the foundations of the industry and shaping many companies’ approaches to their products and the market. Yet, as with all buzzwords, it runs the risk of losing any real meaning.

In response to calls from patients, AstraZeneca has ‘walked the walk’ and published the first definition of patient centricity, co-created with patients and carers.

For Guy Yeoman, VP Patient Centricity at AstraZeneca, this publication – in the journal BMJ Innovations – is both timely and necessary. “We formed our patient-centricity team internally a couple of years ago with a clear goal to deliver value-added patient engagement across research and development,” he says. However, the team soon realized that its definition of patient-centricity did not exactly match that of patients, prompting what Yeoman admits was a “difficult learning curve”.

“The message from patients was very clear – stop focusing on what you do, it’s how you do it that matters. If you get the ‘how’ bit right, the ‘what’ is much more impactful,” he says.

When AZ sought to validate the resulting definition of patient-centricity and its guiding principles through online patient communities, it was immediately obvious that it had struck a chord, says Yeoman. It was about more than simply delivering medicines that they believe would improve patients’ lives.

“That approach is no longer fit for purpose,” he says. “As patients become increasingly empowered, they want to be able to shape their future, and they want medicines that are meaningful for them, so they can engage with them in ways they haven’t done before.”

The time was right to publish a definition because there are two burning issues for industry right now – getting patients engaged in clinical research and developing medicines with meaning, says Yeoman.

“Right now we struggle to get patients involved in our studies, to stay in our studies, and when they do stay, we struggle to get them to comply with the protocol we have set out,” he says.

“We need patients that want to stay involved in the trials because they understand the scientific validity of what they are doing and the value of it for them. This way we will get faster, more efficient studies, and medicines to them far more quickly than we have done in the past.

Medicines must also have real value for patients. “Instead of putting in endpoints to address regulator concerns we need to find endpoints that are meaningful for patients, and will enable them to understand the value of that medicine. These are medicines that patients are more likely to take.”

“As patients become increasingly empowered, they want to be able to shape their future, and medicines that are meaningful for them.”
The published definition of patient-centricity has led to a more practical framework for working with patients, he says. “Our internal standards for patient interactions are very much based on those principles and we have modelled and developed an infrastructure to allow us to live by that definition and those principles.” This soon-to-be-published framework will show how to implement these defined principles of patient-centricity within the life cycle, says Yeoman.

The benefits of getting patient engagement right are huge. “Once you’ve defined what patient engagement looks like, what the value is, in terms of the value for the patient, the value for the other stakeholders, and the value for the pharma company itself, because I do believe there is a financial return if you get it right,” he says.

Measuring exactly how these solutions impact the patient directly is not something the pharma industry does routinely. “We need to look at the impact from the patient perspective,” says Yeoman. While generic measurements can be taken, he advocates looking specifically at the solution that is being delivered, and working directly with patients to understand the impact.

Along with another company and an online patient community, AZ is now seeking to develop a specific scale to measure how engaged a patient is in a research study. “Once we validate that tool, we will be able to understand what interventions are occurring in a study to help the patient, so that they are more likely to stay in the study and want to comply with the protocol. We need more of these types of measurements that are patient-specific. The industry is finally waking up to this opportunity.”

This work illustrates the need for a fundamental shift in industry attitudes towards working collaboratively to deepen relationships with patients, says Yeoman. AZ is also working with cross-industry organisation TransCelerate to demonstrate that patient engagement in research is showing value. “We are looking at how we can develop a cross-industry score and scale for this. The whole of our industry needs to move in this direction if we are going to fundamentally make a difference,” he says. “In the pre-competitive arena, we all need to move together, sharing our best practice and developing accordingly.”
Long-distance flights can be an ordeal for a healthy traveler but for people with chronic diseases such as Inflammatory Bowel Disease (IBD) sitting in a pressurized metal tube at 35,000 feet for hours on end can present significant challenges.

Even when the condition is stable, aspects of flying that many healthy people take for granted – such as in-flight meals and quick access to toilet facilities – can become very important indeed. And thanks to an award-winning initiative from Takeda, flying with IBD is becoming a much less stressful experience.

FlyWithIBD came out of a wider focus on patient-centricity, says Rob Gallo, Head of Corporate Communications, Europe and Canada. “In Their Shoes is a two-day, fully immersive approach to learning that helps colleagues get into the mindset of our patients. IBD – which includes Crohn’s disease and ulcerative colitis – generally affects people in the early part of their lives, in their 20s and 30s when their lives are taking off, but because they can look healthy, they often have to deal with prejudice and ignorance.”

Soon after, a colleague shared an experience about a mistake with an in-flight meal while travelling and people started talking about how difficult travel is for people with gastroenterological diseases,” says Gallo. “When you have IBD, you book your in-flight meal well ahead because if you can’t eat on a flight or eat the wrong thing when your immune system is already low, it can be a considerable health issue.”

In response, Takeda wrote to the five biggest airlines serving Europe to make four requests, including greater detail about meals at least 48 hours in advance, more meal choice, greater visibility of ingredients, and priority seating near a toilet.

“FlyWithIBD was born out of waiting for a response from the airlines,” says Gallo. “Procurement offered to help by contacting the key account managers at the airlines. In parallel, we developed a Thunderclap in partnership with patient groups to raise awareness of what airlines could do to help people with IBD.”

Within six months, most airlines had responded to two out of four requests and some airlines became highly engaged. “The situation was very complex, with so many different meal types and processes, so we aggregated the results on a website for patients to find out what was available from an airline in their country. We launched the Swiss website first and we’re about to publish the English site.”

There is no commercial dimension for Takeda, says Gallo. “This is not about self-promotion; it’s about making information available to help people living with IBD. We even had national carriers asking to meet the national patient groups directly, which is music to my ears – starting this dialogue is a fantastic outcome.”
Patient-centricity has reshaped pharma. It is front and center in every company’s mission statement, indeed, pretty much every statement, period. In spite of all the rhetoric, however, it would be stretching credulity to say that pharma has universally accepted the concept and is embedding ‘patient value’ in every part of its business.

Can pharma deliver both patient value and shareholder value?
Yet, focusing on patients has clear commercial imperatives; in fact, it has the potential to solve some of the most stubborn challenges facing pharma. Patient engagement can aid and speed trial recruitment, patient advocates can be supremely helpful with regulatory or HTA approval as well as HCP education, all of which have positive financial implications.

Yet, will pharma realize this potential or is patient-centricity destined to remain in the ‘nice to have’ camp? Is it possible to provide real value for both patients and shareholders? The answer is a confident ‘Yes’ for Andy Schmeltz, Senior VP, Patient & Health Impact, at Pfizer. “These two elements are not divergent, they’re fully aligned,” he says. “In fact, companies that can translate a patient-centric approach and patient value into shareholder value are the companies that will be successful.”

A DIFFERENT QUESTION?
The question needs to be reframed, says Julie Gerberding, Chief Patient Officer and Executive Vice President, Strategic Communications, Global Public Policy and Population Health, at Merck. “I don’t think it’s possible to deliver shareholder value without simultaneously delivering value to patients,” she says. “These two vectors are increasingly becoming parallel as we move into an environment where value of care – not so much the volume of care – is the determinant of success.”

Following the logic down its natural path, you reach an important question – what if patients want something that pharma is unable or unwilling to deliver, for example a different trial or endpoint? “I would argue that there might not be an initial saving in terms of study delivery, but you will deliver a medicine that is more meaningful at the end of the day,” says Guy Yeoman, Vice President, Patient Centricity, at AstraZeneca. “If patients are more likely to engage with the medicine, you are more likely to end up with a more successful medicine than if you hadn’t talked to patients at the beginning.”

The voice of the patient leads directly to commercial success in drug development, says Gerberding. “Maybe a better-designed study enrols patients faster, gets the answer quicker, gets the drug approved more readily,” she suggests. “All of these things are operating in an environment where efficiency means better business, better value to shareholders, obviously, but puts us in an environment where we’re much more likely to get that product used – and ultimately results in some commercial value as well.”

TANGIBLE RESULTS
Yeoman points to a lupus study in which patients were taken to an investigator site and asked for their thoughts; 24 recommendations were made, 16 of which were adopted into the study. “An hour was shaved off some of the visit duration for patients and over a million dollars of costs were stripped out as a direct result of a patient simulation – these are immediate and tangible results,” he says. “That study is now delivering in advance of its anticipated recruitment and delivery timelines, so there is clear value from that patient-engaging activity.” AZ’s development team has now mandated that patient insight must be incorporated before a protocol is finalized.

The issue of a drug’s value must be put into the mix as soon as possible, says Kate Knobil, Chief Medical Officer, Pharmaceuticals, at GSK. “How do you bring that value to life, even at earlier stages of development, so that you’re not getting to a registration endpoint and then wondering what to do with this medicine?” she asks. “You’re really bringing the patient insight, the physician insight, the needs of the healthcare systems and the payers in early so you have those
questions early on. That creates a medicine which patients want, which healthcare systems want, and allows you to stop development if it doesn’t meet that expectation.” All of this should be of benefit to shareholders too.

Schmeltz highlights work Pfizer has been doing with the Parkinson’s and Michael J Fox Foundations. “We have relationships with them so that we’re thinking at a higher level about, ‘okay, what are the measurements you need?’,” he explains. “When you get into a specific program and you’re designing a specific study we can link up patients with our clinical leads that are designing the protocols, and kind of have them part of our protocol review process, so it’s not just a token.”

COMMERCIAL SENSE
Going beyond embedding the patient in drug development, Pfizer has made a conscious decision not to develop ‘me-too’ drugs. “We can only be working on medicines that are either novel mechanisms, first in class, that offer a distinct benefit, or something that’s best in class, not with incremental advantages but things that are an order of magnitude differentiated,” says Schmeltz. This approach benefits both patients and the business.

As the head of a business unit that brings together market access, HEOR, payer and market access organisation and the strategy group, Schmeltz’s brief is to “provide meaningful value to patients” and to think about the company’s relationship with payers, providers and regulators. “It doesn’t have to be an antagonistic approach, where we’re pushing our commercial organisation to generate demand and the system is set up to restrict access,” he says. The company has a ‘patients first’ aspiration, which he believes will deliver wins for the patient, healthcare systems, and, ultimately, for the company itself.

ECONOMIC NECESSITY
Producing medicines that deliver value to society – through superior outcomes or reducing overall costs – will become increasingly important in an outcomes-driven healthcare ecosystem, argues Schmeltz. In turn, it provides the rationale for companies to embrace the provision of value for patients as a means for creating value for shareholders. “At the end of the day, the major players are all for-profit entities and we have to operate in a way that makes sense given our scarce resources,” he says.

So, the message from these pharma companies is clear – that their increasing focus on patient value will improve their bottom lines, and not just in the short-term.

“As we start embedding patient engagement practice, we will decrease the number of assumptions we make and get tangible evidence that will translate into a value equation,” says Yeoman.

As Schmeltz puts it: “We don’t claim to have the silver bullet, we’re learning as we go, but we’re getting better.”
Patient case study

Trust me, I’m a pharma company

AbbVie’s Doctor’s YouTube Channel offers patients in Israel educational videos featuring senior clinicians talking about a specific health condition.

“Patients are looking for reliable and objective disease information,” says Doron Obazanek, Public Affairs Manager at AbbVie. “Yet, any information coming from a pharma company is perceived as biased.”

Overcoming this perception was a key challenge in delivering the project. “Nobody believed we could get physicians to volunteer their services to make the videos, and, at first, they were right,” he says. “So, we approached all the major medical centres in Israel and, after more than 500 meeting with physicians, hospital management, legal teams, etc., we found that doctors were happy to volunteer their time. We hoped to recruit 20 experts to make videos but now we’ve made nearly 130.”

The channel, which was recently recognized in the Most Valuable Patient Initiative at the eyeforpharma awards 2017, not only partners with every single major medical center but has become the first social media initiative to be endorsed by the Ministry of Health.

AbbVie had a “very important partner” in this initiative – the Israeli Patient Organization. “They surveyed patient groups to find out what health information people wanted. The most interesting thing we discovered is that the basic questions people ask in every disease area are the same – at least in the early stages,” says Obazanek. AbbVie is also assisted by Google to find out the most common diseases people search for.

One of the basic terms of the project is that no specific treatments are discussed. “The physicians decide what they say, we do not put words into anyone’s mouth. There are clear guidelines that say they can talk about treatment groups only, and that is how we maintain objectivity.”

The channel has now had more than 500,000 views. “When you search for a symptom, a disease or it’s treatment in Hebrew, we appear on the first page, plus patients are taking action and we have seen unprecedented numbers of patients visiting NGO websites, calling patients hotlines and joining support groups.”

The channel is also a major boost for AbbVie, says Obazanek. “In Israel, AbbVie is ranked in the top three companies in terms of awareness, and the increased trust has paved the way for other initiatives and collaborations. [At the start] no one believed a pharma company could follow an objective approach but when they realized it was the only way to create objective and reliable information for patients, they embraced it.” ☀
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.