

Trends

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in Patient-Centricity

Growing Pains

How companies are scaling patient-centricity



Made to Measure

Measuring patient-centricity



Patients in Pharma

The remarkable story of Novartis' Rocco Falchetto



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welcome

At eyeforpharma, we have been interested in the patient-centricity movement from its very beginnings.

Our Chairman, Paul Simms, ran our first Patient Summits 15 years ago as a fresh-faced conference organizer, and we have always strived to involve patients as much as possible in our events. This ethos reached a milestone last month with the first-ever 'im-patient conferences' at our recent Patient Summits in both London and Philadelphia, events entirely created and run by patients.

Patient engagement and involvement is now widely seen as a fundamental element in the success of our industry. The idea of creating anything – a medicine, an app, a service – without the involvement of its ultimate 'end user' has thankfully been consigned to history. We are also now moving beyond engaging patients to spreading a patient-focused mindset throughout our organizations. Patient-centricity means much more than simply patient engagement and involvement.

However, the patient-centricity project is far from complete. In considering the content for this edition of *Trends in Patient-Centricity*, two issues arose in nearly every conversation we had with those working at the coalface.

The first is *measuring* patient-centricity. Many companies ventured into this brave new world without much thought to how they might measure success, but how can we prove the value of our efforts if we do not measure their impact? We discuss this issue with senior pharma execs in *Made to Measure* (page 4).

The second issue is *scaling* patient-centricity. As we realize the value of a patient-first mindset, how do we move from pilots and centers of excellence to full-scale rollout? In *Growing Pains* (page 10), we talk to four very different companies to find out how they are approaching the issue.

In the final pages of this 'mini magazine' we publish an article from an editorial series that is very close to our hearts. Each *Patients in Pharma* article interviews a patient who also works at a pharma company, asking how those two experiences have shaped their lives and opinions. In *The Discovery That Changed My Life* (page 16), Novartis scientist Rocco Falchetto tells his remarkable story.

I hope you enjoy this edition of *Trends in Patient-Centricity*.

Giselle Quartin

Head, International

+44 (0) 207 375 7176

gquartin@eyeforpharma.com

Josh Bramwell

Head of Product

+44 (0) 207 375 7203

jbramwell@eyeforpharma.com





Made to measure

After many years of patient-centric efforts, pharma is finally starting to measure its impact.

“If you can’t measure it, you can’t improve it.”

Often attributed to management guru Peter Drucker but perhaps coined first by 19th century scientist William Thompson, Lord Kelvin, there is more to this famous quotation than first meets the eye.

On the one hand, it is common sense – you do, you measure, you improve. But, on the other hand, can your activity be measured? Do the tools and metrics even exist? And, are you measuring the right things? Measuring can be a tricky business.

Patient-centricity has transformed pharma, yet few companies effectively measure the impact of their patient engagement activities let alone track the shift in their people towards a patients-first mindset.

So, how can we improve unless we measure? Where does this vacuum leave the patient-centric champions scattered across pharma? Does the next iteration of patient-centricity need metrics, or can the industry move forward without them?

In the most recent annual benchmarking survey carried out by the Aurora Project, 42% of respondents said their company measured their patient-centric efforts.

“I expected that number to be far lower,” says author, speaker and Aurora Project founder, Jill Donahue, who is “on a mission to lift pharma”. In her conversations with executives right across the industry, the consensus is that no one had yet worked out all the kinks.

“People tell me that measurement of patient-centricity is the Holy Grail. So, I’m left wondering what the 42% are measuring. Is it enterprise-wide or small-scale?”

Janssen is perhaps typical among forward-looking companies, and is tracking a shift in behavior. “We’re looking to systematize patient engagement across the whole company; disease strategy

through post-marketing, we want patient input in all key decision moments,” says Daniel De Schryver, Patient Engagement and Advocacy Lead, EMEA.

Two years ago, at the global level, Janssen implemented a dashboard to measure patient engagement in disease and compound strategies and clinical plans, which has proven to be “an effective approach for driving change.” However, De Schryver admits that it was not easy to develop such full-spectrum measurement, stressing the need for unbiased metrics that are valid for all stakeholders.

WHAT DO PATIENTS WANT?

“There are so many aspects of pharma’s operations that would be interesting to look at,” says Mathieu Boudes, PARADIGM Coordinator at the European Patients’ Forum. “Historically, the HIV groups have developed an ecosystem where industry and patient can work efficiently together so, after years of advocacy, the field is almost ready. Now, we need a big effort to nail the final cultural shift, and this will happen by measuring the impact of patient engagement in medicines R&D.”

In fact, pharmaceutical companies owe it to patients to act. “Efficient patient engagement in the development of medicines brings better health outcomes while de-risking their development. But the resource of patients is not endless; we need to focus on how and when patient involvement delivers the greatest impact,” he says.

However, Boudes acknowledges the barriers to overcome. “If we want patient engagement to go mainstream, we need to measure it – but the criteria have not yet been developed. We don’t have the key indicators yet. To bring in the patient perspective at the right moment and at the right level, will need both qualitative and quantitative metrics, but that’s difficult.”

In some ways, measurement of the value of patient engagement is the \$64,000 question, says Paul Robinson, European Lead, Patient Innovation, at MSD (known as Merck in the US and Canada). “Industry is very evidence-based so there are a lot of people who say, I’m not going to change my process unless you’ve got evidence to show it is valuable. Of course, there is an alternative view, that involving patients is the right thing to do because they are the ultimate consumers and their perspective is highly likely to be relevant. What we don’t know yet is whether a combination of gut feeling and commonsense will win, or whether hard, tangible metrics will be necessary. I suspect it will be a combination of both.”

Meet our contributors



Mathieu Boudes
PARADIGM Coordinator
European Patients' Forum



Daniel De Schryver
Patient Engagement and Advocacy Lead, EMEA
Janssen



Jill Donahue
Author, speaker and co-founder
Aurora Project



Jay Graves
VP
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Head of Global Patient Advocacy
Novartis



Pooja Merchant
Head of External Medical Affairs
Bayer



Paul Robinson
European Lead, Patient Innovation
MSD

Novartis has been committed to patient engagement even before its much-reported Patient Declaration in 2015. "Patient engagement is as much an art as a science," says Laura McKeaveney, Head of the company's Global Patient Advocacy. "Following the medicine's lifecycle, that's the science part of it. The art is to superimpose the patient pathway over the medicine life cycle."

She imagines it as a double helix like DNA, where one strand is the medicine lifecycle and the other the patient pathway. "We have to clearly identify the critical points of intersection and make those points matter, if we are to further improve patient outcomes," she says.

What McKeaveney and her colleagues have discovered is that it's not easy. "It isn't easy because you're talking about measuring impacts over many years, at least 4 or 5 years on. What we're playing with now is to look at which key activities lead to long-term impacts, then working out how to build milestones to monitor progress to ensure that we're on the right path."

IT'S ALL ABOUT OUTCOMES

While all agree that patient outcomes must be the ultimate endpoint, intermediate measures are essential. "The real metric is the long one – better usage of a solution means less waste, more sustainable healthcare and better patient outcomes," says Janssen's De Schryver. "But, with such a long time between developing a solution and seeing the outcome in the patient population, all the other measurements will be short term."

However, the reality is that few companies are even measuring such short-term metrics. "We use our dashboard to measure progress and establish accountability, but we measure whether we engaged with patients; we do not measure outcomes of the engagement yet. Our current approach for measuring the impact of patient engagement is through case examples. As more teams engage directly with patients, the more value they are seeing."

At Roche Diabetes Care in the US, they measure a number of factors, says Jay Graves, VP of Sales. "Unfortunately, it's not so much quantitative as qualitative measures. I have a document that guides us through the year and there are places on it specific to the patient, where we see high levels of customer service, responsiveness, advocacy. These are some things that we do measure."

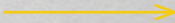
An external measure for patient engagement could be company reputation, he adds. "A good way to get strong quantifiable numbers would using patient surveys or patient interviews around brand awareness. It's fairly easy to tack on a question such as "Do you think this organization has the patient in mind?", and score that. If you come in low then we have to ask, What does our brand mean to people? Are we just another medical company? It would be good to have something that translates your corporate culture to the rep on the ground."

When it started on the patient-centricity journey, Bayer measured nothing, says Pooja Merchant, Head of External Medical Affairs at Bayer. “We decided not to measure anything yet because the whole purpose was just to do – to get teams to take action. Until we did that, we would never know what worked.”

Now, Merchant is keen to find the right path for Bayer. “I tell people to forget what they hear from the external world – we need to learn by doing it ourselves. With the support of Patient Insights & Engagement (PIE), a cross-functional network, our focus for the last two years has been activation, activation, activation, and supporting teams when they do take action. Now we’re at a stage where we have some good examples that we are proud of, where we’ve partnered and co-created, so we’re trying to capture our learnings.”

WHAT TO MEASURE?

What kind of metrics are they focusing on? “We’re not yet there where we can say because we engaged we increased recruitment or because we engaged we improved patient outcomes. I honestly don’t think anyone is there. It’s such a multifactorial process and so based on building genuine relationships that you cannot directly correlate one action to one outcome. Right now, we’re working on a project basis, where a debrief gets conducted after every project to get feedback on how it went, and what it changed. We’re not there yet where we have standard metrics incorporated in all our processes and we get reports on a monthly basis.”



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Pooja Merchant, Bayer

The picture grows more complex when the entire enterprise may not be the best approach. “The metrics are different for every department,” says Donahue. “For example, in Commercial we need to help sales reps be more focused on patients – what is preventing them from helping more patients and how can we train on that?”

Donahue believes it is helpful to look outside our industry. She points to US-based online shoe and clothing retailer Zappos. “How did they get to be so customer-focused? One way was through changing their incentives,” she says.

When the company’s CEO Tony Hsieh noticed that call center workers were measured by the number of calls they handled per hour, he realized it was at odds with the group’s purpose – to deliver happiness. “He recognized that this reward system was driving haste and brevity instead of connection and joy, so he banished the metric and replaced it with Personal Emotional Connections (PECs), which meant creating a bond outside the conversation about the product,” says Donahue. “Why don’t we, in pharma, replace number of calls per day and sales-based bonus systems with Patient-focused Connections (PFCs)?”

However, any metrics need to encompass multiple perspectives, adds Robinson. “My suspicion is that industry will focus on fewer protocol amendments, better design, faster recruitment, fewer dropouts, faster time to a yes/no decision – these are what industry values but they are also relatively easy to measure. However, including what patient organizations value will be harder – how do you measure a sense of involvement and the value of your input?”

So what metrics do patients value? “I won’t say,” says the EPF’s Boudes. “I will leave that to the 34 members of the PARADIGM consortium. What I can say is that we need quantitative and qualitative measures; you need to touch both the brain and the heart. You change the heart with anecdotes, with stories, with people’s satisfaction, but, at the end of the day, business decisions

are made in dollars and euros, so you need harder metrics. Humanizing the numbers behind the KPIs is key to making patient engagement a greater reality and ensuring that the needle moves from ‘engaging with patients is the right thing to do’ to ‘it is the right thing to do for the pharma business.’” *For more information on the IMI PARADIGM initiative, see box (right).*

Bayer’s Merchant agrees. “It cannot be just hard metrics, although part of me wishes it could be. I don’t think this can only be measured by how many amendments have been mitigated, because of the emotional component of connecting people and empathy-building and motivation. Usually with metrics, there’s a single number or a simple graph but this is not a topic that you can apply a similar concept to. That’s why it’s been so hard to figure out how to measure and what to measure.

“Every person like me in every company who is driving this is genuinely keen to get some way of being able to communicate the value because it will only help expedite and create more activation and get more teams to do it,” she adds.

It is clear that the task of working out how to measure patient-centric efforts has many in pharma and beyond scratching their heads right now. In fact, the nut may be so tough to crack that it ushers in a new era of cross-industry collaboration, as we’re seeing with the IMI PARADIGM project in Europe.

However, considering the difficulty of measuring this activity that has taken over pharma and adding to that the truth that patient engagement activities are relatively inexpensive, perhaps all this effort is ultimately unnecessary.

“Maybe we’re making it too complicated by insisting on hard deliverable metrics, maybe they’re not obtainable,” says MSD’s Robinson.

Sometimes, perhaps, common sense is the best guide in business after all. ☺

“We need quantitative and qualitative measures; you need to touch both the brain and the heart.”

Mathieu Boudes, European Patients’ Forum.





Changing the PARADIGM together

As with patient engagement itself, collaboration is the order of the day when it comes to measuring its impact.

“There are papers now published about how much money can be saved by engaging with patients, the net value of patient engagement, and many academics are working on it,” says Mathieu Boudes of the European Patients’ Forum. “We also have the DIA and the Clinical Trials Transformation Initiative (CTTI) working on it. Together, we drift towards intelligence.”

In fact, the task of working out how to measure the value of patient-centric projects is not one that pharma should undertake alone.

“No single company should tackle this alone” says Novartis’ McKeaveney. “We need more multi-stakeholder approaches to the overall subject and in particular on measurements and impact. Including patient insights at key decision-making points has to become part of the industry’s understanding of how to optimize outcomes – for the patient, company and other stakeholders. We are pleased to be part of several multi-stakeholder alliances, including Patient Focused Medicines Development (PFMD) and we’re very active in the IMI project PARADIGM, where a critical deliverable will be an agreed-upon set of meaningful measurements on patient engagement.”

PARADIGM – Patients Active in Research And Dialogues for an Improved Generation of Medicines – is a public-private partnership co-led by the European Patients’ Forum and the European Federation of Pharmaceutical Industry Associations, EFPIA. It receives funding from the Innovative Medicines Initiative, which itself receives support from the European Union’s Horizon 2020 research and innovation program, and EFPIA.

Its mission is “to provide a unique framework that enables structured, effective, meaningful, ethical, innovative, and sustainable patient engagement (PE) and demonstrates the ‘return on the engagement’ for all players.” However, a key objective of the initiative is to produce a set of metrics to measure the impact of patient engagement.

Many companies are actively involved, including Janssen “We are looking at measurement, but we don’t want to sit on an island,” says

De Schryver. “I really believe that the many brains in PARADIGM can come up with far better approaches than we could alone.”

However, he acknowledges this approach will be slower. “We’re not going to see anything concrete before the end of 2019, longer before anything is published. But because it is a collaborative approach rather than a single group of scientists sitting in a room, it will be broadly based and so widely accepted.”

Work has already begun, says MSD’s Robinson. “At the moment we’re gathering information on what people value then we will try to come up with a set of metrics to measure what they value. We’ll then apply those metrics to a set of cases – we have quite a few examples now where companies have done patient engagement in studies and we know how they went, we know recruitment rates, the number of protocol amendments, dropout rate, etc. That work is going on, but it is early days.”

PARADIGM is indicative of a new era of collaboration, according to McKeaveney. “We haven’t seen this kind of collaboration before – between departments, between companies, between multiple stakeholders in the healthcare ecosystem, and, importantly, with an international liaison group to enable global thinking and participation. Everyone is trying to figure it all out but the deeper you get into this, the more you realize you have no expertise, that there are so many questions. This is an opportunity for us to improve together and create the ‘paradigm’ shift needed.”

Bayer’s Merchant agrees. “PARADIGM is an opportunity to catalyze progress in patient engagement. The more stakeholders we involve and the more we build upon and connect to existing efforts, the faster we can define a framework that brings value to all stakeholders. Although such cross-sectoral exchange is not easy, it is essential.”

Yet, pharma needs to resist the urge to compete, says Mathieu Boudes. “We’re not going to do it alone but as a community; we see the ability to measure patient engagement as a pre-competitive tool that everybody can use. How you operationalize patient engagement is the responsibility of each organization, but measuring it is something everybody can work on together.”



Growing pains

How companies are scaling up their patient-centric efforts



Meet our contributors



Jill Donahue
Author, speaker and co-founder
Aurora Project



Jay Graves
VP, Sales
Roche Diabetes Care



Laura McKeaveney
Head of Global Patient Advocacy
Novartis



Pooja Merchant
Head of External Medical Affairs
Bayer



Paul Robinson
European Lead, Patient Innovation
MSD

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here is no one-size-fits-all model for pharma companies seeking input from patients. There was no blueprint when companies took their first tentative steps a few years ago and there is none now as they enter the next era – scaling up patient-centric efforts to become business as usual.

“When I talk to patient organizations, many times they ask, Why does wanting better patient outcomes require a culture shift in pharma?” says Laura McKeaveney, Head of Global Patient Advocacy at Novartis. “But that’s not what requires the culture shift.”

People who work in pharma want better patient outcomes, she says, “but if you look at our models, for 150 years we’ve had the healthcare professionals at the center of our universe, then the regulator and the payer community entered into the healthcare ecosystem. Now, with the rise of the patient movement in the 1980s and 1990s, we have a new stakeholder group. This is an evolution and we ought not to be too hard on ourselves.”

Yet, with the plethora of patient-led research that is “driving very deep insights” into how pharma would have looked if patient insights had been included from the beginning, the time for action is now, she says. “It shouldn’t be a choice anymore; if you want to optimize value in the system then you’ve got to make patient engagement fundamental to your business.

“These trends are irreversible; the patient movement isn’t going to go backwards, the regulators are increasingly providing guidance to bring patient insights into decision making, and payers are becoming more interested because they want drugs to deliver outcomes that matter to patients and clinicians. None of that is going to change, if anything it’s going to get stronger,” says McKeaveney.

As with many aspects of the patient-centric transformation of pharma, from the outside, scaling up efforts seems like a no-brainer. The evidence of the benefit to all parts of the health ecosystem is swelling, external pressure is building, internal experience is growing, so what’s holding companies back?

A fundamental barrier is a lack of understanding around what patient-centricity is, says Jill Donahue, author, speaker and co-founder of the Aurora Project. “Many think it is programs, and expensive programs at that, which belong to one department.”



This results in them seeing it as a “granola issue”, she says. “When everything is going well, we can do patient-centric initiatives, but when things get tough, budgets dry up. I wish everyone knew about the incredible research proving that purpose-driven/patient-driven people, brands and organizations are far more successful. Patient-centricity and profitability are not incompatible; they are inseparable.”

Patient-centricity is far more than just patient-engagement programs, she adds. “It is a cultural shift. It is about connecting each person in the organization to the difference they can make for patients. When we instill the power of purpose, it’s like releasing the hounds.”

With champions spread throughout most pharma organizations, is it the case that the pressure is bottom-up rather than top-down?

“If you sit in front of a senior leader and say, We need to think about the patient. They will say, Sure! But I don’t think they would ask the question, How? There are still some old-school folks out there,” says Jay Graves, VP Sales at Roche Diabetes Care Inc. “However, at Roche, our CEO talks about the patient a lot. He’s been instrumental in making smart moves with our businesses where there always needs to be a reason why we bring something to the patient. If we build a device, it needs to support the drug in a specific way, increasing adherence or safety or another patient benefit.”

When speaking with senior leaders, Pooja Merchant, Head of External Medical Affairs at Bayer, prefers to use different language. “The [expression] patient engagement is not always clearly understood by senior management since patients have always been a fundamental motivator for the industry, so we approach it by saying that we’re bringing design thinking to science. I rarely say patient engagement, rather I say partnering with patients to design around user needs.

“Design thinking aligns teams towards a goal and promotes a faster pace of work, reduces development time, builds relationships directly with patients, improves product outcomes and lessens the risk of costly failures. When you show value via such an established methodology, it’s more effective than using loaded terminology.”


While efforts are underway to measure the impact of patient input into pharmaceutical operations (see Made to Measure), metrics are only one side of the coin when selling a patient-centric approach with colleagues.

“We drive the projects then we ask the teams to come and share what they learned,” says Merchant. “We have them present at town halls, create a report, make a video, anything to create a snapshot of what they learned, what inspired them, what changed in the way they started to approach their project. When someone in your group shares how they did it, it shows that it is possible, and more teams start thinking about it. You can also share it widely across functions and therapeutic areas.”

“For me,” says Graves, “it is about keeping the patient front of mind – that’s how it permeates through an organization. For example, at the office, instead of a sales area and a marketing area, we have areas named after patients with diabetes who we know personally. So, as you walk through the building you see the stories of these patients – you’re literally surrounded by patients. It is far more effective than someone standing on their chair once a month to say to remember the patient. It helps it become ingrained.”

Paul Robinson, European Lead, Patient Innovation at MSD (known as Merck in the US and Canada), quotes long-time chief patient officer Lode





“When someone in your group shares how they did [engagement], it shows that it is possible – and more teams start thinking.”

Pooja Merchant, Bayer

Dewulf. “He says it’s like being a parent – you can learn what’s it’s like in theory and you can watch your friends doing it, but it’s not until you become a parent yourself that you understand all the nuances, joys and tribulations. It’s the same with this – you can subscribe to it in theory, you can see your colleagues doing it, but sooner or later you have to give it a go yourself, you have to sit down with a bunch of patients and find out their perspectives. Once you’ve done it yourself, you become one of the advocates.”

DIFFERENT APPROACHES

Creating a wave of patient-centricity that ripples through an organization converting all it touches is not an easy task. How a company goes about creating the culture shift depends on both how the company approached the patient-centricity project in the first place and what it has learned along the way.

“In 2015, Novartis launched what was called at the time the Patient Declaration,” says McKeaveney. “However, a key piece of feedback from the patient community was, We loved it but what’s happened as a result? This started us thinking and, in 2017, Vas Narasimhan – now our CEO but then Head of Global Drug Development – asked me to bring the Patient Declaration to the next level, to make it more relevant and meaningful for where we were as a company. The first thing we did was engage with the global patient community (which we did not do with the original declaration) to get additional insights and to co-create Our Commitment to Patients and Caregivers.”

Through dialogue with the patient community, the new Commitment sets out what the community could expect from Novartis across four pillars; respecting and understanding the patient community perspective, expanding access to our medicines, conducting responsible clinical trials, and recognizing the importance of transparency and reporting.

Previously focused on patient activation and disease awareness, more recently Novartis has increased its focus on early research and clinical trials. “The reality of involving patients with early research is that there is a difficult point – the go/no-go decision that is frequently encountered. However, our teams realized that if we made building sustainable, long-term relationships with the patient community one of our key measurements, then your ‘exit strategy’ – for want of a better expression – with the patient community at the go/no-go is part of that very respectful, trusting relationship,” she says.

In order for such a relationship to start, however, “deep discussions” are required for every clinical program to ensure it has a robust, clearly articulated patient engagement strategy before going into clinical program launch, adds McKeaveney.

Contrasting with Novartis’ visionary approach, Bayer’s strategy has focused on fostering support among rank-and-file colleagues. “Our journey has been slightly different from others because we did not nominate a chief patient officer or establish a specialized function but rather we took a grass roots approach,” says Merchant.



A cross-functional network called Patient Insights and Engagement (PIE) puts champions in every function from early research to marketing. “We call it a movement because it’s not an initiative or a function – it gets everyone, no matter where you are in the company, thinking about what they can do directly to bring in the patient perspective.”

She admits that it takes longer but they have now reached the point where the vision is built and there are teams in place to drive it in their functions. “Now we’re at the stage of building more training tools, more capacity, and just doing more. I believe that you can only learn what works and what doesn’t work by doing it.”

The company rolled out a framework earlier this year along with actionable tools – checklists, questionnaires, etc. – and case studies to enable colleagues to run their own patient advisory boards. “It’s not about investment that will disrupt, it’s about changing behavior, and I don’t think you can do that without connecting to what drives people. That’s how you build critical mass. It has been really fulfilling to see what happens when you bring people together with a common purpose and passion. It’s really powerful.

“We’re at the stage where we’ve designed directly with patients several times and people want to do more, so we are focused now on becoming more strategic and identifying the touchpoints in our decision making where we know we should not proceed without having a dialogue with patients,” says Merchant.

At MSD, Robinson is one of four regional champions. “We are making huge efforts to engage with patients in our development processes, and part of that is the creation of a small patient

engagement team to drive the change in culture and behavior. I have colleagues in our other three regions – Latin America, Asia Pacific and the US – because you really need champions to bang the drum and to hold colleagues’ hand while they do it for the first time. Ultimately, the hope is that you won’t need people like me and it becomes business as usual because everyone believes it’s the right thing to do and does it automatically.”

The signs are positive, he adds. “I am encouraged by the number of clinical teams that are dipping a toe in the water – we’ve done patient input in cancer, with a vaccine, in Alzheimer’s, as well as in HIV where we’ve always done it. The people who have dipped a toe in have found it to be extremely helpful and enlightening – in many cases it resulted to changes in their plans.”

And now the pace of adoption is increasing. “We’re beginning to see it pick up speed – snowballing would be too strong a word but we’re seeing more clinical development teams asking us to help them sit down with patients. I don’t think we’re out in the lead, as a company, and we’re not all the way there yet, but demand is increasing and we’re working on how we can satisfy that demand.”

While most companies are focusing their efforts in the clinical sphere, patient-centric practices are needed throughout organizations. A key area for the entire industry is ensuring patients get access to its innovative medicines as quickly and efficiently as possible.

“I’ve seen patient testimony at HTA meetings that have a huge impact on the outcome,” says Robinson. “However, we need to ensure we are aligned with what patients value.”

“I’ve seen patient testimony at HTA meetings that have a huge impact on the outcome... however, we need to ensure we are aligned with what patients value.”

Paul Robinson, MSD

He states an ideal scenario where a company outlines its drug's actions (A, B & C), the clinical expert says A & B are important and the patient says that it is B & C that keeps them up at night.

"When the committee hears a consistent story, it makes their job easy – the decision might be 'no', of course. However, if the patient says it's X & Y that keeps them up at night, and there's no data on how the drug affects X & Y, it introduces uncertainty, and uncertainty makes it much easier for a committee to say they're not sure. Aligning our development with what patients need and value is highly likely to improve the product we develop and so improve the chances it will be paid for, as long as it's sensibly priced."

In many ways, the true test of the patient-centricity project is whether it filters through to customer-facing commercial functions – a long way from the roots of the movement in clinical.


Patient contact is very important for sales reps, says Roche's Graves. "In sales, you're out there on your own; you're on your own island, day in and day out, and you might only see one another once or twice a year. Ever since I started down this path, I have strived to get reps close to patients. Many of our reps have been around diabetes for so long they are as knowledgeable as some physicians, but it is good if they can relate patient stories back to clinicians, especially those who don't see many diabetics."

Graves encourages reps – as well as HQ staff – to spend time at diabetes summer camps. "If a diabetes rep wants to go to a diabetes camp, I support it and I won't charge them vacation time. There's also a camp very close to our headquarters. It's amazing to see the

kids playing in the pool or running around like any other kid or sitting out by the campfire while also wired up to devices. It allows you to understand what is meaningful in their lives and that what you're selling is important, that without it they may not have been able to go down to the lake that day. It's those kinds of things that keep the patient very much alive for us."

Focusing on patients can result in highly productive customer (or rather, partner) engagement, says Donahue. "A KAM told us that adopting a patient-focused mindset totally changed her results. She described a formulary meeting where normally the committee sits with their arms crossed and gives you 10 minutes to present your data. Because she decided to share her 'purpose story', she gained their trust. The meeting went on for an hour and they booked another meeting for the next day."

At the end of the process the treatment option was placed on the formulary (bringing \$2m into the company) and patients were better served. "Sharing examples internally helps people 'get it.'"

Celebrating internal success is important but sometimes the most powerful validation comes from patients themselves. "Recently, a patient with diabetic kidney disease blogged about her experience of speaking at Bayer on what it was like to be a clinical trial patient," says Merchant. "It was totally unexpected but when we read the blog we were so excited. If patients are talking about it, then they genuinely value and care about our collaboration. It is the appreciation and recognition by external partners that really gets the teams most excited and motivated to do more." 



THE Discovery That Changed My Life



For Rocco Falchetto, stepping into the sun was extremely painful. Then one day, everything changed.

When Rocco Falchetto was a child, he developed a fear of sunlight – and for good reason. Diagnosed with an ultra-rare disease that causes extreme light sensitivity, when his skin was exposed to the sun's rays, he would be left in agonizing pain.

Rocco, who is a Director in NIBR Analytical Sciences & Imaging at Novartis, is one of the about 10,000 people living with erythropoietic protoporphyria (EPP), a rare metabolic disorder which results in phototoxic reactions being triggered by certain kinds of artificial light and sunlight, for which sunscreens are ineffective.

"As a patient it is very life-limiting," he says. "You have to work your life around the light conditions to try and protect yourself. It impacts everything – your professional life, social life, family life – and everything around you also has to adapt to your condition."

An invisible disease, EPP is often misdiagnosed as an allergy or a mental health issue, causing patients trauma as they spend springtime and summers covered in protective clothing, gloves, hats and sometimes even face masks, rather than shorts and T-shirts.

Increasingly, Rocco avoided being outside, hiding from both the glare of the sun and judgmental looks of others.

As he shaped his life around EPP, he gravitated towards science, studying biochemistry and then moving into the pharmaceutical industry, joining Novartis 23 years ago.



“Everything I did was influenced by the disease. As a kid you ask yourself, ‘Why me? What causes this?’ I developed a thirst for scientific knowledge, as it is the domain of answers.”

Despite working in research, he chose not to focus in his own disease as it simply felt too personal, however, he spent some of his spare time searching the internet for answers.

“I was always on the lookout for treatments – I tried all kinds of remedies and nothing ever worked. Then, one day I saw that an Australian pharmaceutical company was making a product for another condition, and I immediately wondered if it could help EPP patients.”

At that time, all Rocco knew about the compound was that it stimulated the natural pigmentation of the skin.

“When you go into the sun, you develop a tan – it’s the natural mechanism to protect us from the harmful effects of light. This company had modified the hormone that triggers the pigmentation so that it was in pharmaceutical form.”

After speaking to his doctor, a porphyria specialist in Switzerland, things started to snowball. Within just a few months she had organized the first clinical trials and Rocco was enrolled as one the first five EPP patients to receive the medicine.

The results were immediate. “What I experienced was nothing short of amazing – it was a miracle. When I finally gathered my courage and exposed myself to the sun, I realized the treatment was working.

The effect on his life was equally remarkable. “It changed everything; finding out at the age of 41 that the sun doesn’t only mean pain but can be warm and pleasant. It was mind-blowing. I suddenly realized that my life could be different, that it could be free of the pain.”

His incredible journey didn’t end there; the phase II clinical trial was so successful that it was halted early to move straight onto phase III trials across Europe and the US, leading to a marketing authorization application.

“That’s where I started learning about the challenges in drug access,” says Rocco. “EPP is very difficult to measure – there were no objective measures of the severity of the symptoms or the efficacy of the compound. Much was based on real-world patient-reported outcomes, which made it difficult to convince the authorities that the compound was efficacious.”


He started advocating for EPP patients, and a year later helped facilitate the invitation of patient representatives to speak to the European Medicines Agency (EMA) in London.

“We were the first patient community in the history of the EMA to be invited to the formal meeting where they were voting on whether or not to grant recommendation for marketing authorization. Thanks to our testimonies as patients, the drug was finally approved under exceptional circumstances. That’s something I’m very proud of.”

As he continues his work, Rocco draws from his EPP journey. “To experience the process as a person and a researcher – to see how an experimental drug can change a person’s life – was incredible. Being a subject gives you a totally different perspective, you realize how important the work is that we do behind the bench.

“It’s a privilege to work to discover and develop drugs. If you’re successful, you’re going to change people’s lives. I recently told my story to our ethics, risk and compliance group, who are not even directly involved in research, to help them see that each one of us is contributing to helping patients gain a better quality of life. It’s very important to bring us back to our purpose by hearing human stories.”

Thinking back over the scale of his achievements, Rocco will always remember 21 January 2006 – the day he showed his doctor a printout of his internet search. “A lot of people were involved in bringing this medicine to patients, but I am very proud that I was the catalyst for the first clinical trial.”

Twelve years on, “It’s almost like I don’t have the disease anymore,” he says. “It is truly life-changing.” 

Patients in Pharma