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Trends

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in Patient Centricity

Adherence: through the eyes of the patient

Medicine adherence:
Are pharma and patients speaking the same language?

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When two worlds converge

The lack of alignment between pharma and patients. Is it real?

Adherence: Through the eyes of pharma.

Tackling healthcare's most intractable problem

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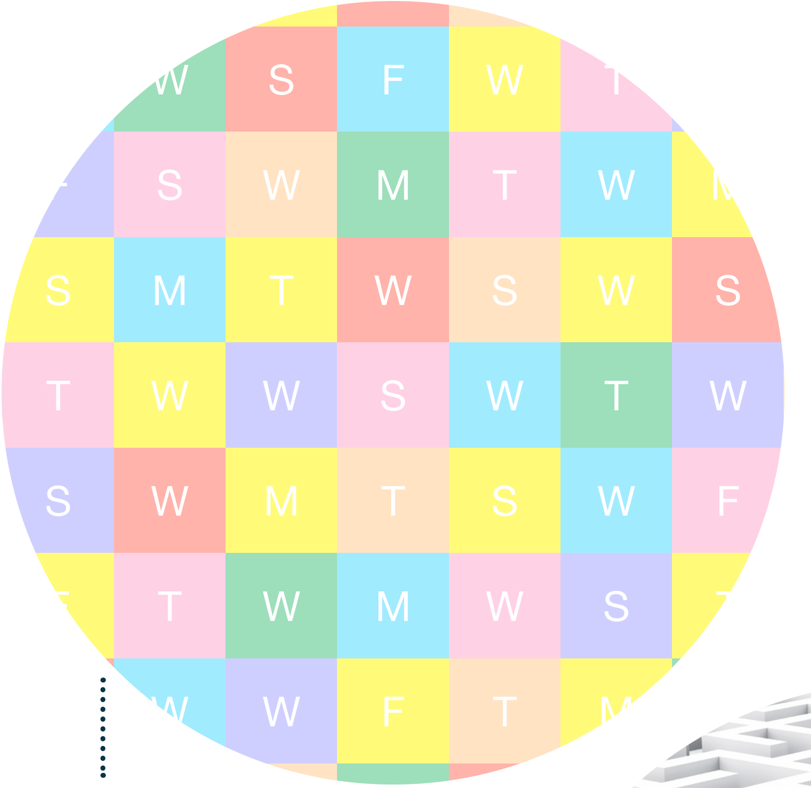

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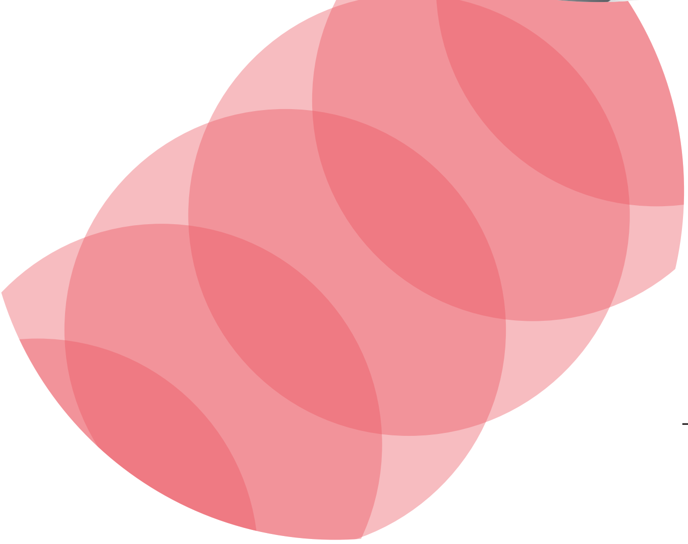

Welcome

Who knows best, the patient or the pharma company?

For years we've grappled with this question. There are scientists who deride the idea that patients understand what's best for them, with little grasp of the complex biological and chemical processes within the human body. And there are scientists who have had their opinions turned around by exposure to patients, realising the great wisdom of someone who lives their life with a disease.

So when it comes to adherence, should we enforce the expert view? Or is the patient the real expert?

I believe there is only one right answer, and it is that answer is: neither. The detached scientist and the uninformed patient are both wrong.

But there is a solution. The solution is education. Only through education can the patient become the expert, and the scientist can become more empathetic and informed. It should be pharma's mission not just to listen to patients, but to educate them.

As Martin Luther King said: 'Intelligence plus character - that is the goal of true education'. I have been astounded at how well-educated some motivated patients have become in their own disease and the health industry around them. In these very pages we explore patients who work at pharma companies. Let's help continue this trend: if we care about our health, we can learn to look after it.

Paul Simms

Paul Simms
Chairman
eyeforpharma

Adherence: Through the eyes of the patient

Are pharma and patients speaking the same language when it comes to medication adherence?

WRITTEN BY DANIELLE BARRON

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It has been well-documented that medication non-adherence is the Achilles heel of the pharma industry. Otherwise efficacious drugs are not having the expected impact on patient outcomes, because patients simply aren't taking them. Addressing the issue is a major challenge for organisations who have spent millions of pounds devising potential solutions to this perennial problem, with varying results.

But what is the patient perspective on adherence? Do they even use this term? And how do they think pharma can help patients take their medication safely and effectively?

Two patient advocates who recently spoke to us say the reasons patients don't take their medication are many and complex, and not always understood by industry.

Patient advocate Matt Eagles has Parkinson's disease and is an active member of eyeforpharma's unique Im-patient steering committee. Eagles has been taking medication almost all of his life for various medical issues and he sees a fundamental disconnect between how pharma perceives adherence and how patients do.

According to Eagles, discourse around adherence evokes the "paternalistic view that pharma has of patients" and conjures up feelings of guilt in patients.

"It's like pharma telling off a child who has been naughty – 'you haven't taken all your medication today'."

According to Eagles, what pharma forgets is that one size does not always fit all – he says patients know their own bodies better than anyone else.

"You know if you if you are not feeling well with a headache, for example, you take an aspirin or a paracetamol. Admittedly they are not a prescription drug, but you don't feel guilty not taking one whereas with prescription meds, there is that feeling of guilt."

Elly Aylwin-Foster is another patient advocate, who has lived all her life with cystic fibrosis. She is also a member of the Im-patient committee.

While she is well aware of adherence as an issue, she says this is largely due to her work within the healthcare industry as opposed to her personal experience as a patient. She also asserts that patients simply do not use the term in real life.

"I might use the term adherence or compliance if I am speaking to my own doctor or other people within the healthcare industry, but I don't think I have ever used it outside the healthcare industry. In conversations I have with other patients in real life or those I see online, no one uses that word to describe their actions, of course they don't.

"Patients and pharma are speaking a different language."

Many of the solutions pharma has devised for addressing non-adherence are based on the idea that patients simply forget to take their scheduled dose of medication. Eagles maintains that it is far more nuanced than that; although many patients might forget, there are also myriad reasons as to why a patient may simply decide not to take it. He also believes that patients must see tangible benefits of a drug in order to persist with it.

"If a medicine works and helps them, they will take it – in my view there has to be a tangible benefit."

Aylwin-Foster agrees. "I would describe myself as a very adherent patient, I'm happy to take medication and doing

> “Sometimes a non-adherent attitude can come from a place of lack of trust but also a fear of whether taking a medication is the right thing for them.”
>
> ELLY AYLWIN-FOSTER

everything I can to keep myself healthy. But there are always times when I won’t take a certain medication I have prescribed for a particular reason, and those could be for days, weeks, or even months.”

Aylwin-Foster echoes Eagles’ comments when she says that many patients are simply choosing not to take a certain medication because of how it makes them feel – there must be a real benefit, and the side effect profile cannot undermine their quality of life.

“Many people with cystic fibrosis may have to take ciprofloxacin, a high strength antibiotic used to treat resistant or difficult bacterial infections. But it’s a medication with a lot of side effects so there are a lot of people who just swear off it and say they will never take it again.

“Most patients acknowledge that side effects are sometimes just a fact of life, and if the treatment is working and the side effects are bearable then that’s ok. Sometimes a non-adherent attitude can come from a place of lack of trust but also a fear of whether taking a medication is the right thing for them.”

Eagles adds that the same dosage can cause different reactions in different people.

“In Parkinson’s if you get too much dopamine in your system the side effects can be worse than the actual Parkinson’s, with the twitching and dyskinesia, so if you are adhering to your tablet regime as given to you by your doctor you could feel awful. Whereas if you know it is time for a dose but you feel fine and think you should delay it, then you will feel better.”

Other, more practical issues can also impact adherence, and this is where the patient’s view is so valuable; Eagles explains his problems with tablets that must be cut in half to obtain the correct dose.

“They don’t always break exactly in half, and sometimes they degrade so you lose a lot of the medication. Air can also cause tablets to degrade. Pharma needs to think about how they package, dispense, and dose medicines.”

Eagles’ solution to this is a branded pill box, made specifically for a certain type of medication.

“Having a pill box that is suitable for the medication, not just one size fits all, would make a huge difference. Why don’t they produce branded pill boxes with instructions on the box?

Meet our contributors

Elly Aylwin-Foster
Patient Advocate

Matt Eagles
Patient Advocate

Medicines come in generic glass bottles or plastic pots, but you need a pill box for out and about. People don't want to be taking pills if they don't have to so why not make it as easy as possible? It's a no-brainer for pharma in terms of encouraging adherence."

Both Eagles and Aylwin-Foster are adamant that there is a lack of clear information provided by pharma for patients when it comes to taking their medication properly.

Attempting to learn more about a medication online can open a can of worms; Aylwin-Foster believes it is incumbent on pharma to provide accurate and accessible information on its medications for its real customers – the patients – as well as combatting the misinformation that can be found by searching Dr Google.

"There is a lot of easily accessible information online which can be valuable for patients but there is a negative side, such as conspiracy theories that come up around various types of medication. Pharma has no idea how entrenched the fear can be from reading this kind of stuff and I don't think the industry has any response to it. I personally can find that quite frustrating when I actually want quite detailed and specific information on a drug, I can't always find that and I certainly can't find it from the manufacturer," she admits.

Pharma's apparent misunderstanding of the adherence issue could be solved by true dialogue between industry and patients, agree both patients.

"There are many different types of patients. If pharma could look more on social channels, they could join the dots and not see patients in isolation," says Eagles.

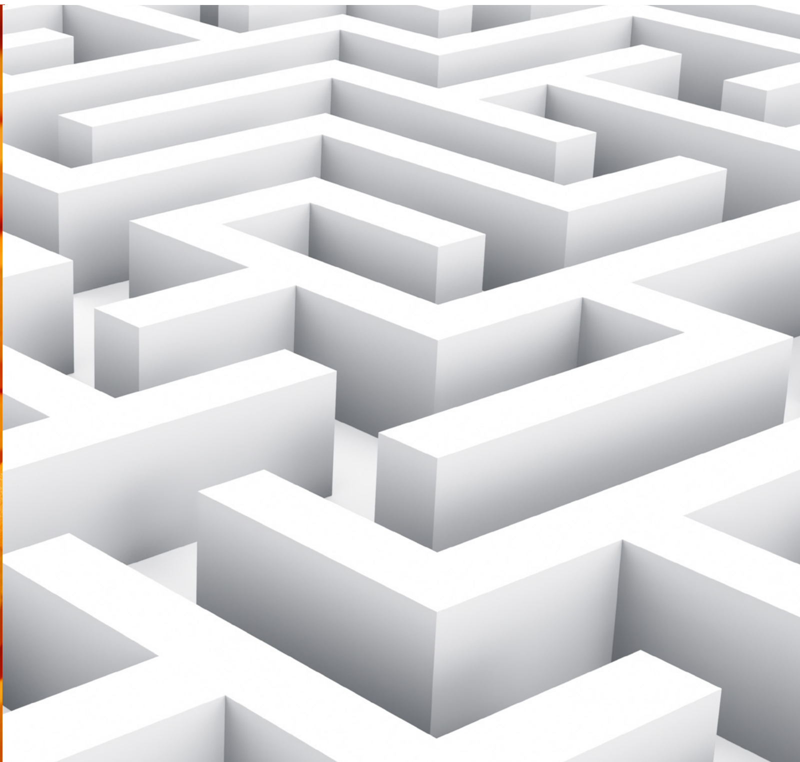
> "Both sides are on the defensive – they need to meet in the middle"
>
> MATT EAGLES

According to Aylwin-Foster, pharma has got it all wrong by focusing their adherence solutions on reminders or notifications in the form of texts and apps. "Pharma seem to think patients mostly don't take their medication because they've forgotten – they don't understand that perhaps a patient might want more information or more of a dialogue round how and why they take their medication," says Aylwin-Foster.

"Direct communication between pharma and patients is still quite rare and relatively new. It's not that it is distrust per se, but there hasn't been an opportunity for a relationship to form between pharma and curious patients searching for more information."

"Both sides are on the defensive - they need to meet in the middle, there needs to be a compromise. Pharma has to have empathy, because if you can get empathy then you can get solutions," Eagles asserts.

"Pharma needs to move beyond seeing it as a disease state and think of the patient as a person. The origin of the word patient comes from the Latin verb pati 'to suffer', but there is no need for patients to suffer unnecessarily."



ADHERENCE: THROUGH THE EYES OF PHARMA

What progress has been made to tackle healthcare's most intractable problem?

WRITTEN BY LUCY FULFORD

Across the healthcare industry, large numbers of patients still fail to take medications as prescribed. Once outside of the supervision of the doctor's office or clinical setting, it's up to the patient to stick to their treatment regimen, making non-adherence a healthcare headache. Pharma is increasingly seeking to tackle this head-on, recognising the widespread benefits that even small improvements in adherence bring.

It is in pharma's interests to do so. Failure to adhere to medication is an unmitigated disaster on all fronts. If patients do not reap the benefits of a medication, the time and energy poured into a product is rendered pointless; negatively impacting health outcomes and impairing pharma's ability to demonstrate the real-world effectiveness of its products.

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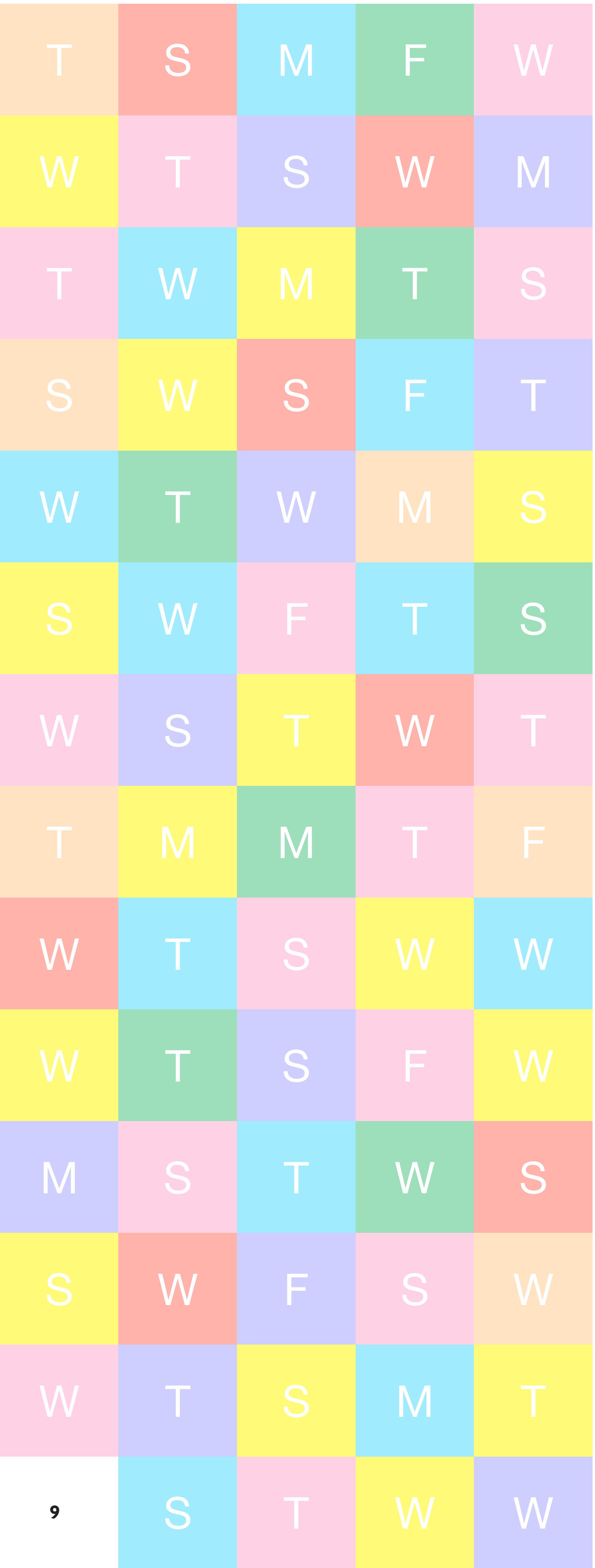

"PHARMA CAN START TO THINK, IN CONJUNCTION WITH THE PAYER, ABOUT CRAFTING A CARE PLAN FOR THOSE PATIENTS"

JOHN PAGLIUCA

GETTING TO THE NUB

Where a failure to correctly take medication may once have been presumed to be due to a basic lack of understanding, to be remedied with enhanced medical education, new approaches to non-adherence recognise the nuances of the issues affecting adherence, which vary by disease, circumstance and product.

People who have intermittent symptoms have different patterns of adherence than people who have no symptoms, people with multiple chronic conditions taking multiple medications behave differently to people with one condition, and anxiety and depression also affect adherence.

Pharma companies are now taking a more holistic view of patients and their behaviour in order to understand, rather than assume, the root causes of non-adherence. These can range from the more obvious, like barriers to cost, through to complex socio-economic factors, such as baby boomers caring for elderly parents and neglecting their own health in the process, says John Pagliuca, Vice President Global Life Sciences, SCIO Health Analytics, an EXL Company.

"Once we start to see these different reasons behind non-adherence, pharma can start to think, in conjunction with the payer, about crafting a care plan for those patients, asking what the appropriate messages and touch points are that will help facilitate better overall care and health."

This more involved approach aligns with the industry-wide effort to understand the minutiae of the patient experience. Metrics should be based on a patient's personal motivations for taking medication. Such granular insight will help pharma to better allocate resources and provide support where it counts.

This feeds into the field of behavioural science, which is commonplace in the consumer market, but in its infancy in the health space. The thinking is clear: if you can modify people's beliefs — the psychological relationship they have with their medication — you can potentially modify their behaviour. It isn't immediately apparent how pharma will turn this thinking into actionable steps, but it could change the face of educational programs.

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PLUMBING THE DEPTHS

Taking steps to remedy non-adherence begins with a deeper understanding of the issues at play. Data-driven explorations are providing a better understanding of the different components of adherence — measuring them and then looking at why there are adherence problems at each stage is one of the things that's going on in the methodology in the field, including the academic ventures.

The recently published medication adherence reporting guidelines (EMERGE) from the European Society for Patient Adherence, COMpliance, and Persistence (ESPACOMP), defines adherence in three distinct stages to address – initiation, implementation and persistence.

In terms of initiation, while a lot of effort has been going into education around how to take a product, increasing work is being done on healthcare provider communication. Anywhere from 15 to 30 percent of prescriptions are never filled — a stark statistic — partly from patients choosing not to, often because there's a lack of agreement between healthcare providers and patients about their options. Shared decision-making is shown to improve adherence. This is a major push for pharma.

For the second phase, the implementation, some products are harder to take because of scheduling, or because they're injectables, and with persistence, attention is being spent on how to help people take their medicines as prescribed for the duration. So a lot of effort goes into educational messages and training materials to support people or patient support programs.

Two metrics provided by SCIO Health Analytics to their clients – a patient risk score and a patient impactability score – also offer pharma advanced ways to assess compliance among patient populations. By creating an algorithm showing how patients consume healthcare around a specific condition, a concurrent year baseline is established. Incorporating associated costs of hospital visits, lab work and medications means a dollar value can be put on a patient, in terms of their total annual cost of care.

"We can say that there are 10 million patients who approach care the same, scattered across the US," says Pagliuca. "We can segment those patients based on demographics, clinical attributes, comorbid conditions, and then predict the next 12 months, asking if they continue doing the same things, what does that mean for their wellbeing and the overall out- of-pocket and cost against the healthcare system?"

Such deep dives offer pharma unprecedented insights into non-adherence, he says, from identifying the patients struggling with the costs of multiple conditions not covered by their health plans, who may, for example, prioritise paying for chronic obstructive pulmonary disease (COPD) drugs over those for their diabetes, because they feel the effects of the COPD more pressingly on a day-to-day basis, through to establishing that co-pay assistance schemes and, in focused care programs established by their payer partners, would better serve populations if they took into account regional differences when assigning resources.

Meet our contributors

John Pagliuca
Vice President,
Global Life Sciences
SCIO Health Analytics

> **“WHAT WE BRING TO THE TABLE AND WHAT MAKES IT A LOT MORE POWERFUL IS WE’RE USING CLINICAL DATA IN ADDITION TO THE SOCIO-ECONOMIC DATA”**
>
> JOHN PAGLIUCA

TAILORING APPROACHES

Such deeper data is enabling pharma to take a lead from the consumer world and split patient populations into groups to receive more targeted messaging, such as 2-3 ‘segment types’ per condition, based on how they approach care.

“Brands generally do a very good job of promoting based on the demographics of their consumers, so they may have the same overarching messaging, but they may have different versions of that message geared toward a particular consumer population,” says Pagliuca. “Pharma is finding the same thing, but through their partnership with the payers they can use those nuanced segments to help drive better care for those patients, which in turn helps drive up adherence.

“What we bring to the table and what makes it a lot more powerful is we’re using clinical data in addition to the socio-economic data, and we marry both together. You can say with a high degree of certainty that there’s real world clinical reasons for this to be happening, in conjunction two socio-economic reasons, using the data to get into the mind-set of the patient.”

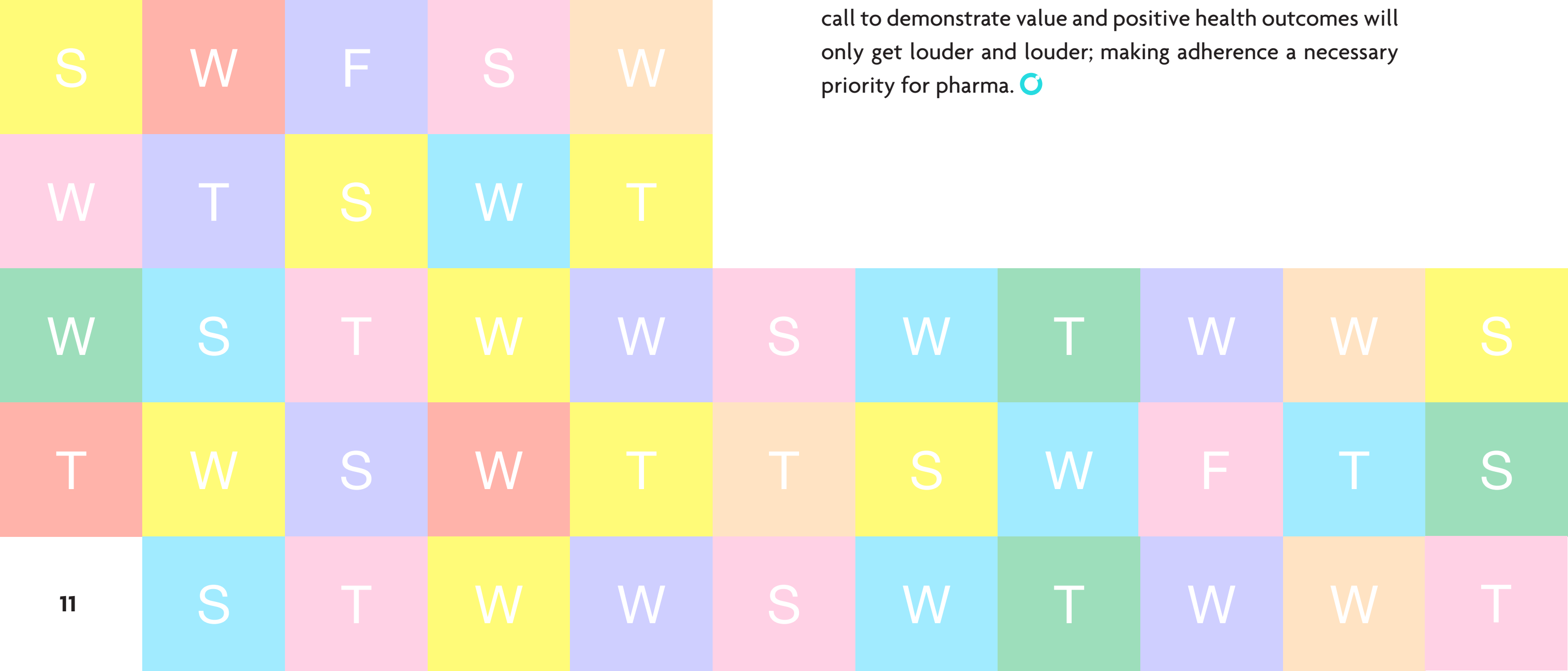
DIGITAL DYNAMISM

Investment is also being seen in digital innovations seeking to drive up adherence rates. Pharma companies are rolling out interactive apps that provide medical education, ongoing monitoring of conditions and tools to support self-management.

As data science takes shape with the advent of machine learning and greater sophistication of statistical-based models, connected healthcare ecosystem devices are proving to be an exciting realm in adding clinical insight, says Pagliuca, with their very nature of monitoring and interaction challenging non-adherence. “Several products and drugs in development around diabetes care will wirelessly send real time information to the cloud, where those data will be crunched to provide insight to both the provider, manufacturer and payer about how the patient is using that product and about their overall condition.”

As for concrete progress, Pagliuca says it’s too early to say, but recognises improvements in getting “the right message to the right type of patients via the right healthcare professional or provider.” There’s more work to be done yet, he adds. “These models are there, now getting everybody always aligned is a whole other story. Payers sometimes manage to financials and not to patients due to lack of resources.”

Adherence is a topic that is here to stay, however. The call to demonstrate value and positive health outcomes will only get louder and louder; making adherence a necessary priority for pharma.



When Two Worlds Converge

We often shake our heads in frustration at the lack of alignment between pharma and patients. But is it real?

WRITTEN BY ANDREW STONE

Surely, nobody better to ask than patients who work at pharma companies. They inhabit both worlds. What are their personal motivations, and what wisdom have they accrued from being on both the inside and outside? It was this train of thought that culminated in the creation of the 'Patients in Pharma Series": a diverse range of voices, each painting a unique portrait of what it means to both work in pharma and be a patient. Here are some recent highlights (you will find more in-depth articles on each person at www.eyeforpharma.com)

JORDAN RANKIN

For Jordan Rankin, the patient perspective has always come naturally. After joining Janssen six years ago straight from university, he found himself gravitating towards patient work in his spare time while working in sales. Now, patient engagement has become his day job, with his work directly informed by his own medical experiences.

"I've got ulcerative colitis, and this experience led me to making the jump into the patient engagement team. I can understand why it's so important to have that voice heard within a business like Janssen: I am driven by helping other patient voices from outside the company be heard and help shape some of the decisions we make to drive the best results."

Jordan was diagnosed with the digestive disorder aged 19, halfway through his first year of university in York. "It was a pretty awful time to get hit with something like ulcerative colitis," he says. "For a start, it can be quite an embarrassing disease – the symptoms are essentially that you're running to the toilet 15 to 25 times a day. That's a bit of a shock, especially when you're away from home and living in halls, with shared bathrooms. It's not something you can immediately talk to people about."

He has found the pharma industry to be sympathetic, however. "Working in pharma has been a very positive experience for me, because everyone is very understanding of what it's like to be a patient and people are typically more educated about different conditions," he says. "J&J have the credence of 'patients first,' and such a focus on patient wellbeing, that everyone really does understand if you need a bit of flexibility – managers have been great with me working from home or leaving a bit earlier."

Meet our contributors

Jordan Rankin
Patient Advocate and Patient Engagement and Advocacy Manager
Janssen

Rocco Falchetto
Director, NIBR Analytical Sciences & Imaging
Novartis

Breda Daly
Executive Account Manager
Janssen

After a year in market research, one in marketing, and three as an account manager, Jordan joined the patient engagement team, and now works as a Patient Engagement and Advocacy Manager to develop the relationships between Janssen and patient advocacy groups and charities. "It's how we can work in partnership to deliver the best outcomes for patients – partnering with patient groups and charities to make sure that patient voice is integral to what we do as a company and really shapes every stage from R&D through to licensed products. Being a patient myself, and knowing how I've navigated the system, is an interesting perspective to go into it with."

In turn, his work with pharma has empowered his ongoing engagement with healthcare services. "If I'm honest, if I didn't work in pharma, I'd probably take the attitude of sticking my head in the sand sometimes and be quite passive as a patient – go, get told and then leave the consultation. Being that bit more informed allows me to probe the doctors a little bit about why they are making those decisions." He's also begun engaging with an irritable bowel disease helpline at his hospital. "The difference that you get in treatment, because you've not waited until it's got awful, makes a massive difference."

Knowing what he's gone through himself means that Jordan often has a natural rapport with fellow patients he meets through his work. "It helps in terms of being empathetic towards conditions. For example, if we're asking a patient to travel to a meeting, I'm aware that it's not as easy for all people as just getting in a car. You have to consider whatever the condition or disease is that they have and be sympathetic and empathetic to that.

"It sometimes helps in reverse. If I open up to patient groups, they can see I'm not just a nameless person from J&J, but a person and a patient as well, so I think that helps make a bit of a bond at times as well, which can be really positive. I think the sharing of stories is always a good thing."

> "If I'm honest, if I didn't work in pharma, I'd probably take the attitude of sticking my head in the sand sometimes"
>
> JORDAN RANKIN

ROCCO FALCHETTO

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

Rocco, a Director in NIBR Analytical Sciences & Imaging at Novartis, is just one of the 10,000 people worldwide 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 he shaped his life around EPP, Rocco gravitated towards science, studying biochemistry and then moving into the pharmaceutical industry, joining Novartis 23 years ago.

Despite working in research, he chose not to focus in his own disease as it simply felt too personal, however, he has spent some of his spare time looking for new treatment options.

“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 us 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.”

> **“It’s very important to bring us back to our purpose by hearing human stories.”**
>
> ROCCO FALCHETTO

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 and of the efficacy of the compound, and much was based on real-world patient-reported outcomes, which however made it difficult to convince the authorities that this compound was efficacious in patients.”

Rocco 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. “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.”

“I decided life was short and you need to look after yourself.”

BREDA DALY

BREDA DALY

By her own admission, in her 30s, Breda Daly, an executive account manager at Janssen, wasn’t living the healthiest of lifestyles. But when her mother was tragically killed by a drunk driver, she was prompted to overhaul her lifestyle, transforming herself from an inactive smoker into a champion triathlete.

“It was just one of those life-changing moments,” she says. “I decided life was short and you need to look after yourself. About six months later I gave up cigarettes. I took up sports and started doing triathlons, and as I got quite good at that I started looking after my own health a lot.”

Going from strength to strength, in 2016 she qualified for a major international Half Ironman and was set to take part in the 2017 Ironman 70.3 World Championship in Tennessee the following year. However, it was at this peak of her physical fitness, aged 44, that she was dealt a second blow.

“Two days before Christmas, I was in the shower and felt a tiny lump in my breast. I thought it couldn’t be cancer because I was feeling so good – I had got a personal best two weeks’ beforehand.”

But a month later she was diagnosed with breast cancer. After undergoing surgery and commencing six months of chemo, Breda was warned she’d have to put her life on hold for a year. But her existing athleticism, combined with decades in pharma and psychiatry, left her determined to remain as active and healthy as she could through treatment.

Getting a group of people together, Breda walked every day, something she found helpful for both body and mind. “I got through the chemo really, really well, walking, doing some run races and cycling 80km. I actually did a Half Ironman a week after I finished my chemo. It was great for people to be able to see that I was able to do so much on chemo.” As well as remaining active, Breda improved her diet an extra “five to ten per cent” by cutting out all sugar and eating organic, as well as using organic skincare products.

She found herself leaning on lessons she’d learnt during her 18 years at Janssen. “At Janssen they promote a lot of health and wellbeing for yourself. We had done mindfulness and, I found that when I got cancer, the mind element was bigger than the physical – everything you hear is very negative and you have to try and filter that. I found that when I woke up at night, I was able to use the different techniques we did at work to focus on breathing and try not to worry.”

Her proactivity was well-received by her treatment team, who enjoyed watching her progress. “For me, I was determined to fight this disease with the right treatment all the while remaining as physically active as I was before my diagnosis. The oncology doctors had never seen someone go through cancer and chemo and be able to do as much physically as I’ve done. On the day I finished treatment, my consultant told me I was the one of the most positive and proactive patients he’d ever met. He’s now encouraging his patients to do a lot more than he would have done before – to walk, to try to run.” They are now writing an academic paper about Breda and her results.

Testing positive for the BRCA1 gene and having an 80 per cent risk of further breast cancer and a 60 per cent risk of ovarian cancer, Breda had precautionary surgery. Never one to do things by halves, she was the first person in Ireland to have both breasts and ovaries removed in one operation, and four weeks later won a cross country race.

On returning to her work in dermatology and rheumatology, Breda found her professional practice enhanced by her experiences. “Being a patient has definitely changed the way I do my job,” she says. “I’m much clearer around patients, I have more empathy and I can understand the expense of having an illness, which I wouldn’t have known before.”