



**POWER TO
THE PEOPLE**

In an era where elections, referenda and public opinion polls have become ten-a-penny, it's no surprise that pharma has, like the rest of modern business, decided to ask the audience. Patient engagement - the art of involving patients in the design and delivery of products and services by securing an authentic understanding of their needs, experiences and behaviours - is gaining traction.

Pharma companies are increasingly seeking the opinions of patients in the development of new innovations and, as the healthcare 'swingometer' lurches from old-school paternalism towards co-creation and collaboration, the approach is bringing power to the people. But unlike politics, where elections are (normally) decided by the weight of the popular vote, patient engagement is not an exercise in quantitative research. To create a winning manifesto, companies need to think beyond the 'safe seat' of numbers-based research and instead allow more qualitative insight to inform decision-making. In the democratisation of healthcare, effective engagement is not about relying on broad-brush opinion polls, it's about being brave enough to identify, listen to and be shaped by the most important constituents of all: real patients living in the real world of their diseases.

Marginal gains

The pharma industry is finally making strides with patient engagement, as part of a wider narrative that's empowering patients to play a greater role in decisions about their care. According to RnRMarketResearch, the global patient engagement solutions market is forecast to reach \$13.7bn by 2019, with governments, health systems, industry and patients recognising co-creation as the best means of improving outcomes and delivering value. But while healthcare tech and digital solutions providers are queuing up to offer tools that support patient communications, pharma is also using engagement techniques to help develop innovations to improve health outcomes. The industry is making marginal gains as it slowly learns how deep patient insights can provide a mandate to change patient behaviour. "Pharma companies are beginning

to understand patient engagement and how it can add huge commercial insight and value to what they do," says Richard Jones, patient services director, The Earthworks. "Patient engagement is integral from drug discovery and design, right through to launch and keeping patients on treatment. Fundamentally - and at long last - the term itself is absolutely the correct language. For the past decade or so, the industry has danced around different terminology that's mostly been focused on telling patients what to do; adherence, persistence and concordance are all hierarchical terms that give instructions to patients. Patient engagement is about partnership - it's about creating an equal relationship between patients, healthcare professionals and industry. Evidence increasingly shows that if we begin from that start-point, we've a better chance of succeeding. "The goal is to focus on genuinely wanting to solve a problem from the patient's perspective - and that means ensuring that they're not only engaged in their treatment, but they're also engaged in their disease understanding and in the healthcare system that supports them. The most effective patient engagement works across these three pillars and recognises the skills, motivations and behaviours that influence the patient experience. It's a more holistic approach - and by adopting it, pharmaceutical companies are beginning to secure a better understanding of patients' problems and developing innovations that help address them."

New manifesto

So what does that innovation look like? Well thankfully it's moved beyond digital tools to support medicines adherence and transitioned towards leveraging patient insights to inform innovations in drug design, care pathways and patient journeys. "Companies have progressed from an insular focus on 'beyond the pill' solutions for launch products and are beginning to consider what patients really need far earlier in the clinical development process," says Meike Wenzel, partner at Executive Insight. "Similarly, we're seeing a number of companies trying to set themselves up differently internally - for example, in some companies there

are now functions within clinical development that are responsible for patient engagement. It's not happening across the board, but there are encouraging signs that companies are moving away from retrospective methods of capturing patient insight at launch and are instead looking more broadly across the value chain to secure understanding far earlier. Some of the most proactive companies have sought a patient view of what 'value' might look like as early as preclinical development - although this is the exception rather than the rule. It is, however, sensible to have a good understanding of patient needs as early as Phase II. Ultimately, the best approach is to try to involve patients throughout the development and brand life cycle, rather than just before launch."

'Patient engagement is about partnership - an equal relationship between patients, HCPs and industry'

Don't trust the opinion polls

The industry's pledge to be 'patient-led' has been in pharma's manifesto for years, although some critics argue it's a policy designed to win votes. Despite the cynicism, it remains a well-intentioned and, in fact, essential ambition in an increasingly scrutinised environment. "Patient-centricity has been a huge mantra for pharma as it grapples the challenges of gaining public trust and demonstrating value," says Jennie Talman, CEO, Havas Just. "Centring everything around the needs of patient has therefore become a key part of the narrative. However, patient-centricity is often derided as rhetoric that companies use with very little to back it up. →



This is perhaps unfair. Industry now partners much more effectively with patient advocacy groups, government bodies and other health experts who provide independent input into pharma's commercial strategies - and companies have become much better at listening in order to reflect the value they bring to patients. But there's still much work to be done. Patient engagement, which is fundamentally about gaining an intimate understanding of patients' needs and motivations, is a hard thing to do in a highly regulated industry where it's difficult to even talk to a patient. To progress, pharma needs to think differently about how it conducts patient research and to understand the nuance between research and insight. Too often, market research that's done among patients is not conducted optimally. "Most companies commission quantitative patient research to generate insights that can be fed into a commercial or disease strategy. But it's all about the

numbers. Classically, studies are carried out via traditional market research agencies that research predetermined types of patients - and there's an inherent bias in the results. Evidence shows that it's far more effective to conduct qualitative or ethnographic research among smaller groups of target patients. Ethnographic research engages real patients in their own environment, allowing companies to understand patients as 'whole people' rather than simply asking them questions about their disease. Such research, which typically takes place in patients' homes and requires a more psychology-based approach, uncovers the 'lived experience' of patients. Real patients in their real world. We're seeing more companies adopting this approach. However, compared to traditional market research, it's expensive and can only be done with smaller numbers. This creates a challenge for industry; once you've done good, authentic research, you've got to be brave

enough to act on what you hear because you won't have the numbers to back you up. Marketers therefore need to be bold, back their instincts and listen to the voices that emerge from

qualitative research - because although they might be telling you something new and unfamiliar, they could provide the key to creating more effective patient journeys in your disease area."

Proportional representation

Meike Wenzel agrees, arguing that companies who conduct deep and detailed research and have the courage of their convictions to act on it will ultimately prevail. "It's important to secure a good depth of involvement with patients," she says. "The most ineffective approaches are where companies treat patient engagement as a tick-box exercise; they conduct superficial research or ask doctors what they think their patients need, avoiding direct engagement altogether. Optimal patient engagement takes the conversation to a deeper level; when patients can see that their contribution and insight has become an input to decision-making, it's proven to have a demonstrable impact. "This 'deep dive' into patients' perspectives does require pharma to shift from its traditional approach to capturing customer insight. Companies must resist the temptation to impose an agenda. Patient workshops need to be open, empowering participants to talk freely about what it's like to live with their disease rather than respond to predefined questioning. Uncovering needs or hidden needs is never easy - so unless you create a trusting atmosphere that makes patients feel comfortable enough to share personal stories, you won't get very far. The prospect of running workshops without a strict agenda is anathema for many within pharma - and it can undoubtedly cause nervousness around regulations. However, bringing compliance officers into the process early as part of a cross-functional team can help companies allay fears, mitigate risk and overcome perceived barriers. Moreover, this collaborative and transparent approach can help companies unlock the significant benefits of patient engagement in the development of their products and services."

A mandate for change

So how best should companies proceed? In the era of self-proclaimed patient-centricity, it's

surprising how many companies still think brand-first rather than patient-first. This needs to change. "One of the biggest challenges is that pharmaceutical companies have traditionally centred around brand and brand communications strategies," says Richard Jones. "As a result, they're often searching for messages that they can wrap around a brand to make it more palatable, positive or suitable for patients. This inevitably leads to a degree of reverse engineering where they align what they hear with what they want to say or do. However, happily, brands and businesses are growing up. There are some really innovative companies, such as ViiV Healthcare and some of the larger multinationals, who are genuinely listening to their patients and having better conversations that breed better understanding. Those companies are putting patients at the heart of what they do by applying analytical rigour to develop deep understanding of patients' challenges. They're using social listening tools to understand the real-world conversations around diseases and therapeutics that are taking place. And they're capturing the voice of the patient and dialling it up so they can hear and act on it properly. It's no surprise that these proactive companies are beginning to see the benefits of true patient engagement."

Power to the people

At a global scale, the much-vaunted democratisation of healthcare is giving patients a greater say in decisions about their care. Pharma's efforts to bolster its real-world understanding of disease through greater - and more targeted - patient engagement can only help improve health outcomes and accelerate the delivery of high-quality, high-value care. Despite this, investment in qualitative research and tools to better understand the needs of patients across the value chain often fall short of the levels required to secure meaningful change. It's a missed opportunity. There are plenty of political elections across the EU in 2017 - but if you get just one vote to make a difference this year, vote for a renewed focus on patient engagement. And give power to the people.

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