

Time to take patient engagement to the next level

Patient engagement in pharma is evolving, with some companies doing it better than others. Envision Pharma Group's Dawn Lobban and Sarah Avent discuss the need to engage with patients at every level for holistic inclusion of the patient voice in order for pharma to become truly patient-centric.



The Covid pandemic has sparked people's interest in science and medicine and empowered the public to make important health choices. It's also shone a light on the need to provide accurate and timely information and to engage the public at every point in the medicine development lifecycle.

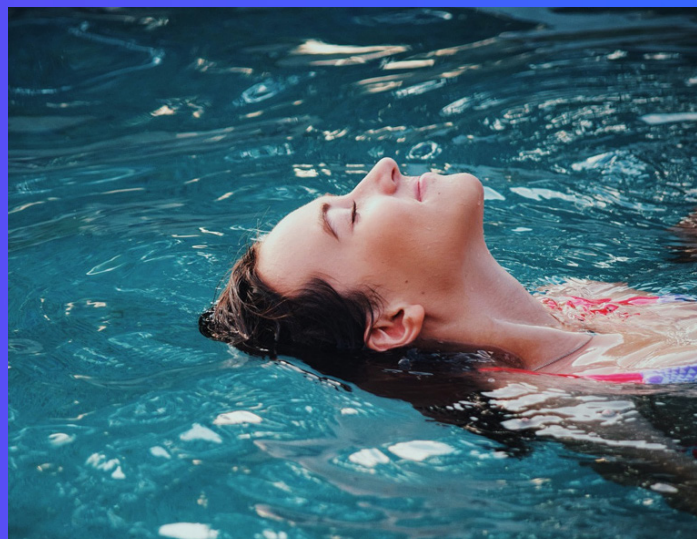
More than anything, however, it highlights the importance of patient-engagement more generally in medicine development, a concept the pharmaceutical industry has been talking about for years. Says Dawn Lobban: "We know that clearly patients are experts at living with the disease, and if we want to understand what it's like to live with a disease, then they are the people who can provide those insights."

Indeed, there is growing recognition of the importance and value of patient engagement in medicine development. Not only can it benefit patients by better addressing unmet needs and improving outcomes, but it makes financial sense. For instance, a 2017 study by a team, including researchers from Janssen, Duke University and the Tufts Center for the Study of Drug Development, among others, found that compared with an investment of \$100,000 in patient engagement, the increases in net present value and expected net present value (ENPV) could exceed 500-fold the investment, with the ENPV increase equivalent to accelerating a pre-phase 2 product launch by two and a half years¹.



Regulatory changes are also shifting the needle, with companies needing to demonstrate they are addressing the real unmet needs of patients. Meanwhile, various initiatives are pushing the cause, such as the not-for-profit Patient Focused Medicines Development (PFMD), which brings stakeholders together and provides processes and toolkits to support pharma. Training courses for patient advocates, like EUPATI and cancer network WECAN, have also played a role.

For these reasons, Sarah Avent says the industry is in the process of a massive sea change where the patient voice is becoming prioritised. Many companies have gone beyond talking and there are now numerous examples of effective patient engagement initiatives. But some companies are engaging better than others, she adds, and those that do it well look across all levels, from a cultural level through to an operational and patient-engagement level. "Everyone's got a willingness to put patients at the heart of what they're doing, and seeing others do this through the publication of their experiences is really going to help internal learning and drive best practice across the industry."



This is just the start of the sea change. Now it's time for the whole industry to really embrace patient-centricity and patient engagement at all levels, and make medicines development really work for all stakeholders. Many companies recognise the value of patient engagement, says Lobban. "Now they're asking themselves more questions about the how."

Engagement at a cultural level

The first step is a cultural shift. That is, developing a patient-centric culture embedded within the fabric of the organisation, driven from the top down and bottom up. And that means leadership buy-in to a patient-centric approach. Avent says more pharma leaders are putting patient-centricity at the heart of the company. "We're hearing from some pharma that patient engagement and voice is within their corporate strategic priorities for the year coming up... People have talked about it a lot but now we're really seeing people walking the talk."



But Avent warns, this is not a tick-box exercise nor is it about developing materials internally and then getting them rubber stamped by a patient group. “People need to be doing this for the right reasons. It’s not just one individual’s responsibility to be more patient-centric, it’s everybody’s.”

And that means having the resources, the processes, infrastructure and internal communication in place. “It’s making sure you’ve got your advocates at the top,” explains Avent, who works with pharma using 90TEN’s EMBED model which combines the agency’s Feel-Think-Do™ behavioural science approach with organisational change principles from experts such as Dr John Kotter. “Then you make sure you’ve got champions throughout the organisation understanding what it is that people want to be moving towards and measuring it and then not just seeing it as a one-off initiative but an approach that is integral to the fabric of the organisation.”

It’s also about ensuring people within the company feel confident they can engage with patients compliantly, she adds. That might involve training and learning from other companies that are doing patient-engagement well. It’s entirely possible, she says, but the support needs to come from the top down across the whole organisation.

This change-management-style approach results in new ways of operating that intrinsically have the patient in mind. For instance, inviting compliance teams to meetings with patients to hear first-hand the patient voice, finance teams making sure patients and patient groups get paid quickly, HR including value-based questions around patient-centricity in recruitment packs, manufacturing teams understanding how to put patient information leaflets together, and annual reports that balance commercial drivers with patient access to medicines and how many lives have been changed.



“For too long, patient engagement has sat in a silo in pharma companies driven by a separate team,” says Lobban. “When we think about true patient engagement throughout the medicine lifecycle, this actually needs to be an integral part of every function and every person’s role within that function. The best way to make this happen is combining a top-down and bottom-up approach – both leadership and followership are critical to success”.



Engagement at an operational level

Furthermore, a patient-centric culture is about treating patients as partners over the long-term, Lobban says. “It needs to be a partnership based on mutual goals and mutual benefits. There needs to be tools and guidance developed both for patients to get involved but also for pharma in terms of how to involve patients.” PFMD, EUPATI and WECAN are already spearheading this, she adds.



The strategy for long-term patient engagement and partnership, Lobban believes, is to tap into the patient voice early in medicine development. “Too often we see pharma companies thinking about the patient as they get towards launch and thinking about patients more like an audience than a partner.”

That said, there are companies already involving patients in various elements such as how to make clinical trial protocols more patient friendly or how to improve recruitment. But Lobban says getting patients involved even earlier than this, during the designing of the research question ahead of developing the medicine, is a relatively untapped area for pharma. Doing this can more likely lead to meeting a real need, an important consideration for drug approval and market access. Although, she adds, it’s imperative patients are then involved as partners all the way through the development process.

Another untapped area of patient engagement is within scientific literature and publications. “For too long, the patient voice has just not been heard in the published peer-reviewed literature,” says Lobban. “We see a lot of market research, qualitative research, focus groups, but then too often those insights are taken and actually published by scientists and healthcare professionals and that patient voice, which was obviously present in the insight, is lost in the publication.”

Encouraging patients to author publications ensures the patient perspective is accurately reflected in the scientific literature, unmet needs are prioritised in research, and publications are more relevant for and accessible to a patient audience. Given the public's growing interest in their own health and in science since the pandemic, having a patient voice in publications can bridge the gap between scientific literature and the public, Lobban explains. "The more we can bring the two together, the better to empower people to take responsibility and to encourage shared decision making."

More patient authorship can be achieved through education and training – highlighting what it means to be an author and how to get published – and encouraging more patients to become authors, as well as ensuring the opportunity exists for them. The interest is there and Lobban says Envision is advocating tracking of the patient author to follow the increase of this trend.



She dismisses the compliance objection, saying there is no compliance reason why patients shouldn't be authors if they, like healthcare professionals, fulfil the authorship criteria. "I think there also needs to be education within pharma companies around the fact that patients can and should be authors where it's appropriate... The more this happens, the more it will happen because people will see other colleagues doing it."

Another way to bridge the gap between scientific literature and the public is the introduction of plain language summaries, which makes the complex scientific literature understandable and accessible to the broader lay audience, Lobban says. Most pharma companies are keen to develop these for their publications and various recommendations and guidelines are in development, which will help address the 'how's of doing this. It's an important move forward, she adds, as this will help empower patients and the public to become part of the conversation.



Engagement at the patient level

Indeed, incorporating patients into the conversation and tapping into the patient voice is key for better communications. When patients are engaged and their insights are fed into the development lifecycle and materials are co-created, it won't be just the medicines that are better but the resulting communications will also resonate better with patients.



But it's important the right patients – that is, the target audience – are engaged and listened to, and that companies are objective, says Avent. "It's making sure that even if people have got different views to you, or different values, or different belief systems, that they are all listened to and respected. Then we work with these communities to co-create a programme that's going to resonate and address their specific needs."

But for true patient-centricity it is also recognising that there is no one-size-fits all, she adds. Consider the differences between older people and the younger generation, for instance. The former will be more of the mindset that the doctor knows best while the latter are more proactive with their own health, more information seeking, and want that information at their fingertips. These two audiences are going to engage in different ways.

It's therefore important, says Avent, that pharma engages with a wide range of different audiences, including different ages, religions, cultures, disabilities, and socio-economic situations. "Diversity of patient voice is really important – just making sure we're engaging with real patients and finding them in different ways and making sure there's a lot of diversity in the views and opinions that are being brought into the organisation."

Ultimately, engaging patients means that patients are more engaged with their own health. Avent gives the example of HIV. Thirty years ago, an appointment with a GP would be a discussion about viral load and CD4 count and treatments. "Whereas now, because you can live a very long and normal and healthy life with HIV, the appointment now should be less focused on these things and more on how HIV might impact your long-term health, mental health, co-morbidities, side effects of HIV or the treatments."



She says Envision's Hep C, Ki? campaign with Gilead is a case in point and is a good example of shared decision making. Here it's not just about a tool, handout, or resource but about encouraging patients and healthcare professionals to have the right conversations in a language and way that resonates with the patients. "This is about pharma making sure they are supporting people to have these better conversations."

Engaging patients for better healthcare

Pharma knows it can't design a product for patients without involving them. But moving forward, how pharma engages with patients and incorporates the patient voice needs to be richer and deeper.



It's about engaging with patients in a way where they are central to the medicines-development process so that patient needs are met and outcomes improved. It's about empowering patients, making them proactive participants in their healthcare, from the early stage of drug development right through to the healthcare appointment in the doctor's office.

Many companies are making headway, focusing on engagement across the cultural, operational and patient levels. But a more holistic approach across the industry, and learning from each other, will transform healthcare and its delivery and make pharma truly patient-centric.

This is where healthcare is moving to and it's a job that shouldn't just be left to patient groups and healthcare providers, says Avent. "I do think there is a role to play with everyone together collectively supporting patients."

For pharma moving forward, full patient engagement is everything. Pharma has the power and potential to help drive this change and, if harnessed in the right way, the industry can bring much to the future of patient health.

About the interviewees



Dawn Lobban, global lead, Patient Partnerships, Envision the Patient Part of the Envision Pharma Group. With a strong background in medical affairs, Dawn is particularly interested in optimal patient involvement in medicine development. Through active participation in key working groups, including ISMPP (International Society for Medical Publication Professionals) and PFMD (Patients Focused Medicine development), Dawn works hard to explore effective ways to ensure effective patient engagement. Her research and opinions are published in a number of abstracts and articles.



Sarah Avent, associate director at 90TEN, part of the Envision Pharma Group. Sarah has more than 15 years' experience working in healthcare communications across the NHS and within communications agencies. 90TEN's patient engagement lead, Sarah has extensive experience in managing patient organisation relations and communication to patient audiences. Having led award-winning campaigns co-created with community group organisations, healthcare professionals, and pharma, she is passionate about integrating the patient voice into industry work wherever feasibly possible and always puts the needs of patients first.

About the company



Founded in 2001, Envision Pharma Group is a global, innovative technology and scientific communications company serving pharmaceutical, biotechnology, and medical device companies. Envision is a leading provider of evidence-based communication services and industry-leading technology solutions (iEnvision) that have applicability across many areas of medical affairs and related functional responsibility. Envision Pharma Group provides services and technology solutions to more than 90 companies, including all of the top 20 pharmaceutical companies.

Envision has 20 offices: six in the United Kingdom – Bishop's Stortford, Glasgow, Horsham, London, Wilmslow, and Alderley Edge; one in Serbia – Subotica; one in Hungary – Szeged; one in Coimbra, Portugal, nine in the United States – Fairfield and Glastonbury, CT, Philadelphia and Wyomissing, PA, Warren, NJ, Boston and Melrose, MA, Powell, OH, Pasadena, CA; and two in the Asia-Pacific region – Tokyo and Sydney. The company employs 1100+ team members, including over 250 highly qualified and experienced in-house medical writers, and 200 technology solutions team members who provide software development and customer support. To find out more, visit www.envisionpharmagroup.com.

