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PharmaTimes



HOW TO BUILD FUTURE-PROOF PATIENT PARTNERSHIPS

INSIGHTS PAPER

www.patientpartnershipindex.co.uk

Listen up!

As the Patient Partnership Index moved into its second year, the impacts of the COVID-19 pandemic dominated not only the health sector, but almost every aspect of daily life. A recurring theme of this year's best entries were how pharmaceutical companies and their patient group partners have come together to overcome and address the challenges through truly co-created and impactful partnerships.

The best companies took the time to listen to the patient groups they work with to hear how best to serve their patient communities at a time of tremendous demand and uncertainty. We were inspired by the excellence demonstrated across industry, as well as the deep commitment to working more closely with patient groups to better understand how partnerships could innovate to meet the real needs of patients.

Reflecting on the changes we want to preserve and the improvements we need to make following the pandemic, OVID Health's Patient Partnership Index 2021 Insights Paper looks at ***what patient advocacy, communications and engagement best practice means for the future of these partnerships. And most importantly, how do we get there?***



Index 2026

Pharmaceutical companies patient partnerships in five years' time

To understand how to best work together in the coming years, we asked: ***what do the entries to the Patient Partnership Index 2021 tell us about the future of best practice and what insights did our judging panel share?*** Here are the answers:

1

Deep and meaningful engagement

Communications and trust are core to any successful partnerships, as well as engaging as equal partners in the collaboration. Partnerships that establish and build on a foundation of shared purpose go on to achieve the best results.

An excellent example of this is from **Pfizer's** GOLD entry. Their partnership with **Breast Cancer Now** went beyond the boundaries of a bilateral partnership, collaborating with health services to identify and deliver improvements for patients on the front line. Deep involvement with local patient communities to understand their experiences of services widened and deepened the partnerships involved.

Jenny Ousbey, OVID Health Managing Director and Chair of Index Judges for 2021, reflected on her own experience on designing and delivering a multilateral project with the NHS and a newly-created cancer charity: *"As our health service recovers from the pandemic, patient partnerships can play their part in helping to restore it. When multiple partners are involved, especially those operating on thin resources, the partnerships need to establish early on the shared goal and the roadmap to delivering it, so each player knows what they must consider and do to overcome the challenges in the healthcare system they seek to improve."*

2

Hearing an authentic voice

The stand-out entries to the Patient Partnership Index 2021 were ones tackling health inequalities, stigma, or underrepresentation in disease communities. Industry and patient groups want to be authentic when they advocate for patients.

The GOLD entry from **Gilead Sciences** is a best practice exemplar in challenging assumptions with the **National Rheumatoid Arthritis Society**. By prioritising diversity, they were able to identify the real life impact on people with arthritis stemming from a lack of diverse representation within the patient population with a condition many associate with the elderly.

Associate Director at OVID Health and diversity champion in healthcare communications Rachel Gonzaga says: *"A campaign that represents people of all backgrounds and ages affected by a disease area, one that shares their stories and raises awareness of the diversity of experience in the patient community, truly puts patients at the heart. To deliver this we seek commitment from all partners to build time into projects to develop patient insight through a range of audience research tools."*

Gilead Sciences Ltd &

National Rheumatoid Arthritis Society (GOLD)

In partnership with the National Rheumatoid Arthritis Society (NRAS), Gilead Sciences launched the joint 'We R.A. Priority' awareness campaign. This campaign sought to challenge longstanding misperceptions and stigma surrounding rheumatoid arthritis (RA), a condition depicted by many in the media as a disease reserved for the frail and elderly, and as such a low priority for health systems to address.

"What we wanted to do from the very get-go was engage with NRAS and say 'what's actually happening with the community? What's the priority for the community? What are they looking at?'" The theme of the campaign was decided based on proactive and inclusive conversations with NRAS and other patient organisations in RA, alongside an audit of existing and previous campaigns to understand where Gilead and NRAS could contribute. This research illustrated the lack of diversity in communications in RA, particularly regarding the age and ethnic diversity of people living with the condition.

Gilead created patient videos to share voices from across the patient community. Launching online, the campaign encouraged patients to share their stories over social media, and secured coverage in media such as This Morning, Women's Hour, and National Talk Radio to reach more than 5.4 million people.

3

Finding the sweet spot

Pharmaceutical companies have responded to the COVID-19 pandemic on multiple fronts: vaccines, treatments, adapting existing modalities of treatment delivery to secure continuity, and even volunteering their clinical skills and training on the front line. The Patient Partnership Index 2021 celebrated the ways in which companies supported their patient partners to continue to make an impact.

The GOLD entry from **LEO Pharma**, working with the **Psoriasis Association**, was co-created pre-pandemic to run as focus groups. Pivoting to a virtual format straight out of people's homes, they were able to hear patients' lived experiences with the condition. Being able to adapt identified a new avenue to contribute real value to patient lives that was until that point uncharted.

OVID Director Roudie Shafie says: *"Developing projects that meet real and genuine need means being nimble and prepared to start without necessarily having the answer. We can stay accountable to the company and funders by having a clear objective from the partnership which is measurable. There is a pattern emerging in patient partnership best practice in how success metrics are set and measured. These are about strategic goals rather than mapping out a year's worth of outputs right at the start."*

LEO Pharma & the Psoriasis Association (GOLD)

LEO Pharma's collaboration with long-standing partner the Psoriasis Association sought to develop a deep understanding of the patient community via a survey of over 500 people living with psoriasis. They found two thirds of people with scalp psoriasis had deliberately avoided appointments with their barber or hairdresser. So, together the partners reached out to the Lions Barber Collective, a charity training barbers to raise awareness around mental wellbeing and collaborated on a social media campaign to share practical tips with hairdressers, health professionals and people with psoriasis on having better conversations about the condition.

"We made a choice to go unscripted and it really created raw but very authentic insights that helped us bring the campaign to life". Social media impressions for the Heads Up to Psoriasis campaign were more than 3.3 million over the first four weeks, and most importantly drove behaviour change – 74% of almost 2,000 respondents online who engaged with the campaign indicated they would visit their doctor to discuss scalp psoriasis in the next six months.

4

The future is now

Social media is increasingly a forum for patient communities. They are powerful means to create a sense of shared community, which is particularly important in conditions which some groups may feel are taboo, rare or leave people feeling isolated. Both patient advocacy groups and pharmaceutical companies are adapting at pace to continue to engage and communicate in a compliant way using digital platforms and forums.

While some patient advocacy groups face resource challenges with adapting to changes in the way patient communities engage, companies can also come up against their own challenges too, such as internal policies and the reality, as well as the perception, of the ABPI Code of Conduct. This combination means initiatives that need to work innovatively and creatively to deliver impact require cross-functional teams internally and senior leadership buy-in.

Amicus Therapeutics, a SILVER entry in this year's Index, brought together internal stakeholders at both country and global level to deliver an advocacy campaign with the **Fabry International Network** to connect leaders from country-level patient advocacy groups and communities in this rare disease. Together this group from multiple countries created actionable recommendations for policymakers.

Amicus Therapeutics & the Fabry International Network (SILVER)

Fabry is a rare inherited disease causing life-threatening, multi-systemic signs and symptoms, most seriously affecting the heart, kidneys and central nervous system. Working with the Fabry International Network (FIN), a global umbrella organisation representing over 62 patient associations in this space, Amicus Therapeutics' Patient & Professional Advocacy team engaged in a series of discussions on the COVID-19 pandemic. *"The first thing we really wanted to do was listen and hear exactly what was going on at a country level, and also to see if there were best practice examples that we could pull across the different patient organisations."*

Amicus and FIN together organised the Global Fabry Patient Leader roundtable, to share learnings between national leaders on the impact of COVID-19 on people living with Fabry disease and identify solutions to engage healthcare providers and decision makers. This unprecedented roundtable brought together patient group leaders from more than 16 countries, including the UK, USA, Australia, Canada, Germany, Denmark, and Spain. Out of the roundtable, FIN sent an open letter, co-signed by the patient community leaders, to all clinical expert centres in their countries to share the urgent need of Fabry patients for continuous access to care throughout the pandemic and beyond.

5

A whole company approach

The key thread running through all the Index's metrics and fuelling all of the very best partnerships is genuine commitment throughout the company to making these projects a success. In practice, this makes internal communications a key activity for teams working with patient groups. By siloing patient partnerships, companies can become detached from the impact their contribution has. Internal communications is the key instrument to energise companies around this goal and ensure they work with purpose and urgency.

OVID Associate Director Rachel Gonzaga says: *"To bring the rest of your company with you on your patient partnerships, you have to bring patients to life for everyone. There are several practical methods for achieving this, ranging from bringing patient advocates to speak to staff and share their experience, feeding back the impacts of patient partnerships projects across the company at 'town hall' events, and ensuring leaders within the company are closely engaged with the patient groups and the patient community they are working to support."*

Pfizer Ltd & Breast Cancer Now (GOLD)

Pfizer's UK Oncology Patient Experience team and Breast Cancer Now wanted to work together to improve services for breast cancer patients. They found a shared goal in scaling up Breast Cancer Now's work in the Service Pledge programme in Trusts to Cancer Alliance level. The Pledge aims to ensure all breast cancer patients have a voice in service delivery, ensuring they receive personalised and high-quality care.

The partnership worked with the East of England Cancer Alliance and individual hospitals in the area to identify disparities and inform action plans to address them. They reached out to local patient groups seeking feedback from patient experience to build into the project. Pfizer were able to provide additional financial support and practical assistance to Breast Cancer Now via colleague volunteering programmes when the project was challenged by the pandemic.

The collaboration resulted in Breast Cancer Now working with eight primary and secondary breast cancer services to help identify potential improvements and efficiencies for patients. Across all services over 40 improvements were identified, including the submission of a business case for a dedicated secondary breast cancer multi-disciplinary team meeting. As a result, all HCPs involved reported improved understanding of patients' perspectives.

Making change happen

The Patient Partnership Index judges considered entries based on a metrics framework developed by OVID Health in partnership with patient groups, pharmaceutical companies, and independent experts and academics.

Developing a future-proof, best practice partnership with patient groups with this framework in mind will help you lead the way for the rest of the industry:

1

Engagement

Embed your patient partnership across the company, from CEO or MD level down, and regularly ask how the needs of your patients are being met.

2

Co-creation

Fully co-create collaborations with patient organisations, from concept to delivery. Set the parameters of the concept to be compliant.

3

Transparency

Be transparent and share knowledge and expertise relevant to the patient organisation you're working with, internally and externally.

4

Empowerment

Show genuine commitment to supporting your patient organisation partners to grow and thrive to serve their community.

5

Innovation

Always be innovating in your partnerships to increase impact.

6

Impact

Measure the impact of your patient organisation activities regularly and make sure they are evidenced clearly.

About the Patient Partnership Index 2021

The Patient Partnership Index 2021 is the UK's leading initiative in patient-centric communications and advocacy. Created by health communications and public affairs agency OVID Health and media partner PharmaTimes, the Index offers pharmaceutical and biotech companies an opportunity to showcase, benchmark and evaluate the quality of their communications and advocacy with patient groups.

If you are looking to develop your patient partnership activities and want to draw on the expert insights behind the Index, the award-winning team at OVID Health are happy to discuss this with you.

OVID Managing Director Jenny Ousbey says: *“The power of storytelling isn’t going to change in five years’ time, or ever. The mediums by which we tell stories, though, will.*

We’ve recently worked on projects involving patient advocates using Instagram to tell their stories – something no one would have expected ten years ago. The next big platform is likely something completely different that none of us have heard of yet. But though the platforms might change, what makes a compelling story is timeless and the ability to reach new and diverse audiences is something we should all be excited and energised for.”



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