



EMPOWERING TOMORROW'S PATIENTS

INSIGHTS PAPER

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The Patient Partnership Index is the UK's leading initiative in patient-centric communications and advocacy. Created by health communications agency OVID Health, 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.

Introduction



In the three years since we launched the Patient Partnership Index, its impact has led to huge changes in the way pharmaceutical companies and patient organisations have approached these types of partnerships. The standard has improved, and the partnerships have become more sophisticated, collaborative and impactful. We are so proud of the collective effort and passion that made this happen.

As the Patient Partnership Index moved into 2022, the impacts of the COVID-19 pandemic dominated not only the health sector, but almost every aspect of daily life. Unsurprisingly the recurring theme of entries this year was therefore how pharmaceutical companies and patient group partners came together to overcome and address the challenges highlighted by the pandemic through truly co-created and impactful partnerships.

Importantly, many entries brought patients back together after the lonely and isolating experience of the pandemic. Some also used a touch of humour to get messages across following a period when people have been bombarded with vital health messages on vaccinations and mask-wearing.

The best companies took the time to listen to the patient groups they work with and to understand how to support these 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 amplify local projects or to understand how to embed the patient voice into innovative partnerships.

In summary, we know patient organisations view the most patient centric companies as those willing to commit to long term partnerships, with matching objectives to further the patient voice by sharing skills and expertise beyond just financial contributions.

Creating Strong and impactful partnerships



1

A Long-Term Partnership

Long term partnerships lead to stronger communication and trust, which are core to any successful project. It is clear that if a company invests in their relationships with a patient group over time, they can learn from mistakes, and implement these learnings to create trust and ultimately deliver more impact for the patients they serve. It also allows for more strategic planning of resource allocation by both the company and the patient group.

Partnerships that establish and build on a foundation of shared purpose go on to achieve the best results. This can mean building on an existing piece of work, and adding value to this, rather than trying to start from scratch and duplicating effort.

Novo Nordisk & Diabetes UK (GOLD)

In the 2022 GOLD entry Novo Nordisk described the partnership between them and Diabetes UK. This has existed since 2014 when it was brokered with Ashridge Business School. It aims to capitalise on the specialist knowledge of frontline diabetes clinicians by empowering them to accelerate change and become strong advocates for diabetes. A grass roots approach was taken to early development through collective programme creation by all partners and the first cohort of Clinical Champions.

Since the programme began, over 140 clinicians from across the UK and across the diabetes care pathway have been recruited to become Clinical Champions and the partnership has achieved tangible improvements in the NHS, positively impacting people with diabetes. An innovative pathway change in Northern Ireland facilitated provision of a specialist diabetes clinic that offers retinopathy screening and podiatry occurring during dialysis sessions, ensuring quality care was received by those patients most in need who can also be the hardest to reach. Another project spanning central England introduced a new insulin chart which resulted in an 18.3% reduction in insulin errors, as well as introducing a condensed diabetes ketoacidosis (DKA) protocol. The protocol reduced the average time from patient admission to DKA diagnosis, cut patient treatment times, as well as reducing the average length of stay in hospital by 3.2 days.

2

Tackling Deep-Rooted Challenges

Health inequalities, stigma, or underrepresentation in disease communities are all issues that both patient organisations and industry agree need to be tackled and they can have an impact when working in partnership to tackle. This collective knowledge and experience enables real practical solutions to be explored. In 2022 more and more entries placed inequalities at their core, and this focus shows no sign of abating after the pandemic shone a spotlight on this deep-rooted issue.

Gilead Sciences Ltd, Find your Four (GOLD)

In the 2022 GOLD entry Gilead UK & Ireland discussed their *Find your Four* campaign. When *Find Your Four* was developed no individual organisation was prioritised in the co-creation of the campaign. Each organisation was recognised as representing the unique needs of specific HIV communities.

Materials were developed for communities with additional health literacy needs – specifically UK ethnic minority groups that are disproportionately impacted by health inequalities. Africa Advocacy Foundation, and Aymara Social Enterprise, were engaged (among others) in the co-creation of the simple and engaging Rights and Routes guides to HIV care and translated into appropriate languages, Portuguese, French and Spanish.

Ambassadors representing black, gay/bisexual, female and transgender HIV communities were engaged to co-create, feature in, and share social media content. While these ambassadors are all people living with HIV, they were not engaged on the basis that they represent individual patient organisations, but as cultural influencers.

The campaign will continue into 2022 and 2023 and has so far reached 5.4m reach via traditional media; more than 300,000 via social media; more than 25,000 views of video content and more than 6,000 interactions of content via social media.

3

Co-creation



If partners are completely aligned to the same strategic direction and objectives, then it will lead to better outcomes for both partners, as well as for patients. When it is not appropriate to start a project from scratch, which may be the case if an existing project has already been set up and a partner is brought in to add value, you must be able to demonstrate clearly aligned values and why the project will grow in strength by adding new perspectives. Transparency as to why you have co-created in the way you have is vital for forging a long-term and successful partnership.

Roche & The Eyes Have It Partnership (GOLD)

The 2022 GOLD entry from Roche for The Eyes Have It Partnership demonstrated that patient groups can be the most valuable partners. They were involved in every stage, from determining strategy through to delivery, and their importance is demonstrated by their logos sitting side by side on all content. Collateral to drive engagement has been developed with input from all.

The focal point of the programme in 2021 was the delivery of the inaugural Westminster Eye Health Day which aimed to push eye health up the political agenda, and was attended by key clinicians, patient representatives and over 50 parliamentarians. The event resulted in dozens of parliamentary questions, a Westminster Hall debate, and a meeting with the Minister. This engagement led to an announcement from NHS England that they would appoint the first National Clinical Director for Eye Care, ensuring system change called for by 'The Eyes Have It' will be driven forward - helping up to 2.5 million people with sight loss in the UK.

Patient groups were shown to have benefitted from working alongside experienced professionals in policy and communications to drive engagement and awareness, achieving a greater reach collectively than might have been possible alone. The benefit for Roche as a new entrant to this space was to reflect a true patient perspective in their work.

4

Impact!

The single biggest outcome all parties want to see from partnership working is impact. This should be clear from the start of the project, including how it will be measured. Impact sometimes takes time though and sometimes cannot be achieved in a single year. If that is the case then it should be clear what signposting impact can be demonstrated initially (for example media reach), before moving on to the ultimate goal in the longer term. And don't forget, reach (e.g pieces of media coverage for a campaign) is no substitute for real-world behaviour or policy change. Work hard at the start of your partnership to really consider how you can move the dial in a meaningful way. And be strict on your KPIs so you do not create 'mission drift' mid-partnership.

Galapagos & National Rheumatoid Arthritis Society (NRAS) (GOLD)

The Galapagos GOLD entry from 2022 highlighted a collaborative partnership with leading rheumatoid arthritis charity – National Rheumatoid Arthritis Society (NRAS) which involved obtaining first-hand insight and ensuring any campaign created was innovative, unique, and added value to the community. Existing campaigns were unrelatable, undiversified and did not have a digital focus.

Ultimately the We R.A Priority awareness campaign reached over 10 million people, and over 50% of the RA patient population. In addition, many champions have become long term advocates for NRAS, and one patient champion has been nominated for a British Diversity Award for their contribution.

Making change happen



The Patient Partnership Index judges consider entries based on a framework developed by OVID Health in partnership with patient groups, pharmaceutical companies, and independent experts and academics. If you are about to embark upon developing or exploring a future-proof, effective partnership with patient groups – then this framework will help you to develop a truly best-practice partnership:

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.

We Are OVID Health

An award-winning independent agency specialising in healthcare public affairs, patient advocacy and communications.



At OVID Health We.....

-  Advise pharmaceutical companies on strategies to embed the patient voice across their organisation.
-  Design and deliver impactful patient-facing materials and campaigns.
-  Implement large or small-scale patient and public involvement programmes.
-  Manage national or global above-brand patient advocacy programmes.
-  Create and deliver impactful policy and PR campaigns in partnership with pharmaceutical companies and patient advocacy groups.



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