



PATIENT PARTNERSHIP INDEX 2020

*Reinventing partnerships between
pharmaceutical companies and
patient groups*

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The Index will provide a valuable platform for spreading best practice in meaningful patient centricity, while celebrating the companies that stand out with regard to their communications, engagement and advocacy with patient groups.

Selina McKee

Editor
Pharmatimes Magazine

At the ABPI, we strongly believe that working with patients and patient organisations can bring significant public health benefits. At a time when pharma companies and patient organisations alike are working flat out to improve public health, the Index will help share best practice and foster positive, compliant collaborations in the interests of patients.

Jill Percy

Director of Code Engagement
The ABPI





Jenny Ousbey
Managing Director
OVID Health

FOREWORD

Pharmaceutical companies – large and small – entered the Index in 2020. What the entries all had in common was a passion for working with others to help patients. None were purely transactional – each partner had a clear role to play in achieving a joint mission. And both sides were honest and clear on what they were gaining from the partnership and how the project would help patients as well as their own organisations.

Our consultants have worked in patient advocacy and integrated campaigning for decades. In that time, we’ve seen partnerships move from project-based activities to longer-

term shared missions. For us, this is the key measure of a successful partnership that changes patients’ lives.

Combining our insights from the entries to the Index, hints and tips shared by leaders in patient advocacy at our Patient Partnership Index Conference and our years of experience working for pharmaceutical companies and charities, we’ve curated this report on how to achieve ‘Gold standard’ patient partnerships in advocacy and communications. Together we are reinventing healthcare communications.

INTRODUCTION

With the far-reaching impact of a global pandemic still emerging, partnerships between pharmaceutical companies and patient communities are more vital than ever. Patients’ treatment and care has been disrupted, charity finances are under huge pressure and the life sciences industry is tackling its most pressing medicine and vaccine development challenge to date. We are seeing health inequalities grow and access to treatments and care being stretched.

At OVID Health, we set up the Patient Partnership Index because we share your commitment to putting patients first. We want to support and inspire companies and patient organisations to partner together to deliver meaningful and powerful change for patients. To

achieve this, the Patient Partnership Index – a first-of-its-kind benchmark for the industry – aims to share best practice and raise the bar. This report summarises what we learnt from the entries we received to the Index in its first year, combined with our expert advice on how to apply GOLD standard practices to your partnerships in the future.



WHAT IS THE PATIENT PARTNERSHIP INDEX?

The Index is a ground-breaking initiative from leading industry publication Pharma Times magazine and specialist health communications agency OVID Health.

Launched in May 2020, the Index offers pharmaceutical and biotech companies an opportunity to showcase and evaluate the quality of their communications and advocacy with patient groups. The aim is to celebrate the companies that meet the mark, so we can raise the bar across the industry.

The Index evaluated the highest standards, based on a bespoke metric, of partnerships in communications and advocacy between pharmaceutical, biotech and patient communities.

OUR METRIC

Across six key themes, our bespoke metric was designed to provide a robust framework to award **GOLD**, **SILVER** and **FINALIST** standard to deserving entries.

Gold standard entries showed:



Engagement

Patient partnerships are embedded across the company from CEO or MD level down, where they regularly ask how patient needs are being met

Empowerment

The company wants the patient organisations to grow and thrive to serve its community

Innovation

The company is constantly innovating in its partnerships to increase impact

Co-creation

Fully co-created collaborations, from concept to delivery. Company can set parameters of concept (to be compliant) and then co-creates with patient organisations

Transparency

The company is transparent and shares knowledge and expertise relevant to the patient organisation, internally and externally

Impact

The company is measuring the impact of its patient organisation activities regularly and they are evidenced clearly

Co-creation is really key. A true pharma-patient partnership can't be transactional, it must be about sharing expertise and ideas as much as sharing resource or financially supporting the patient charity.

Richard Davidson

Index Judge and CEO of Sarcoma UK



INGREDIENTS FOR A SUCCESSFUL PATIENT PARTNERSHIP

Embed Patient Partnerships at All Levels of The Company

Achieving senior level buy-in within a company in patient-centred advocacy and communications is essential. Having an Executive Board member or a General Manager who takes an active role in listening to patients helps the company to take a longer-term view, which in turn fosters partnerships that achieve more for patients and companies.

OVID's framework for engaging senior leaders in patient advocacy includes:

1. Through a full understanding of the Association of the British Pharmaceutical Industry (ABPI) Code, clearly and compliantly set out the intended advocacy impact of the patient partnership programmes – making a strong case for engaging.
2. Share case studies of previous examples of impactful partnerships, where patients, patient organisations and companies have benefited.
3. Demonstrate the impact a high-quality patient partnership can have on reputation.

Relentlessly tell the human story – bring patient stories into the most corporate of settings.

OVID's top tips for embedding patient engagement at

all levels of an organisation are:

1. Make it easy for everyone to hear the voice of patients! Make hearing a patient story something you don't have to carve out time in your day to do. For example, start your internal town hall meetings with a video from a patient.
2. Make employees feel like ambassadors for your patients. Roll out an internal ambassador programme, providing patient stories alongside your corporate story, so employees can tell the full story about what your company does.
3. Conduct audits with patient groups and share the results internally. This way, all employees understand their perspective.

How OVID can help companies:

- Internal audits and capacity building programmes – working across business functions to make a “patient promise” plan of action on how to embed patient-centricity.
- Strategy workshops for helping patient

advocacy teams plan their year ahead and get the most out of new and existing relationships at a global/national level.

- Internal engagement programmes on patient advocacy.
- Internal and external corporate ambassador programmes.

Pfizer UK (Index GOLD standard)

Pfizer's framework for engaging with patient communities is a collaborative approach that is thoughtful and benefits patients and strengthens the company itself. Alongside board-level representation through a Global Chief Patients Officer, Pfizer has embedded patient voices throughout the organisation to create a company culture with a rigorous focus on patient engagement.

Pfizer also demonstrates a commitment to their ongoing relationship with patient groups, involving them across projects and throughout the processes of creation, implementation and reflection.



Measure Your Impact

It's crucial both partners are honest and clear on what they want to achieve and, importantly, how they are going to measure the benefits to patients as well as to their business. Whether a partnership is trying to create policy change, behaviour change or inform healthcare professionals, we can demonstrate real value. This loops back to leadership – demonstrating value internally is important in getting patient engagement buy-in at the most senior levels of a company.

OVID's framework for measuring the success of an advocacy partnership project includes:

1. The stories of change. Tell stories that describe what you have evaluated in a clear and engaging way. They can set out the mechanisms and pathways by which the partnership was able to influence a particular change, or equally importantly, describe how an intervention failed and analyse the possible reasons why.
2. The progress markers. These are the steps we take towards our

impact. We agree them collectively between partners at the start of the project and progress monitored throughout. When used systematically, Progress Markers can help the gauge whether partnerships are having the desired effect in the long-term.

3. The impact assessment. At OVID we use the “Bellwether method”, a tool developed by Harvard Family Research Project for the Blair Foundation. It is a qualitative survey tool that determines what “influencers” know and think about a particular policy issue before and after an advocacy programme. By interviewing bellwethers, it also gives analytical information of what type of messaging and approaches make the best impressions.

OVID's top tips for measuring impact in patient partnerships are:

1. Link KPIs compliantly to business strategies.
2. Choose a fuss-free way to collect monitoring and evaluation data with patient organisation partners.
3. Don't forget to measure impact internally too. Patient partnership can bring benefits for the business by motivating colleagues and teams.

How OVID can help companies:

- Build monitoring and evaluation frameworks for partnership projects and programmes.
- Implement our three-pillar measurement framework to partnership agreements.
- Advising on compliant KPIs that are linked to commercial strategies.
- Track the impact of your projects by implementing the Bellwether method with policy and change makers we recommend you engage with.

Sanofi UK (Index GOLD standard)

Sanofi regularly assesses the impact of their work with patient groups. They conduct an annual survey to identify areas where patient groups would like support upskilling, and then they evaluate the success of upskilling workshops. 24 organisations attended workshops in 2018, and 100% of attendees found value in attending.

In 2018, Sanofi partnered with the MS Trust on the ‘Missing Pieces’ project, where measuring impact was carefully considered. Sanofi UK developed a survey to better understand the quality of service provision in the UK and Ireland. The results highlighted a significant difference in the quality of service and treatment rate compared to what could be expected from NHS service specifications. These were summarised in a report and an awareness campaign was launched. The report reached more than six million people (via the media and MS Trust channels) and the findings were used to redesign the endpoints of a Sanofi Genzyme study to better reflect patient preferences. Further insights from the MS community informed the development of a patient-led animation to empower and support patients in discussions with their healthcare team through education on what services are available to them.



Be Adaptive and Nimble

The pharmaceutical industry's response to supporting patients through the COVID-19 pandemic has shown how nimble and agile companies can be.

Patients unexpectedly needed to urgently access information and services across many disease areas. In response, companies created new emergency funds and updated agreements so existing grants could be repurposed to address this immediate need. And we've seen amazing results where companies and charities quickly understood what issues their patients were facing and put simple measures in place to fix them.

OVID's framework for forming adaptive patient partnerships:

1. Simplify your processes at the start of a partnership and build in scope to be agile.
2. Be clear on who the decision maker is on each project, and who has the authority to quickly change course if needed.
3. Have regular review points in a project to proactively introduce the possibility of adapting if unexpected barriers occur. Make sure the patient voice is represented at these review points.

OVID's top tips for creating nimble and agile companies:

1. Where long standard operating procedures (SOPs) are necessary for engaging with patient groups, create simple guiding principles to make the SOPs accessible to all.
2. Be ABPI Code trained and think about the spirit of the code. If your intentions are compliant and you are confident your objectives are in the spirit of the Code, your actions are likely to be compliant too.
3. Have a clear separation between processes where grants and donations are involved vs processes where co-creation happens, including separate compliance guidance documents and contracts.
4. As always, centre around what you are trying to change for patients and your business. By being clear on this overarching objective, it will be easier to quickly agree specific tactics.

How OVID can help:

- Translating complicated SOPs into simple how-to guides
- Workshops to identify and simplify compliance processes that are barriers to agility
- Equality impact assessments of existing relationship and recommendations on reaching diverse groups of patients.

Gilead Sciences Ltd (Index GOLD standard)

On 16th March the premises of many HIV patient groups were closed to their members due to the COVID-19 pandemic, so services had to adapt. Gilead agreed existing grants received by patient groups in 2020 could be repurposed to address immediate need and additional emergency funding was provided via a swift virtual Grants Review.

Two key initiatives were developed with patient groups to respond to the COVID-19 crisis and its challenges for people living with HIV. Content capsules were created to support the broader HIV community with reliable information about COVID-19, and a Pulse Survey was carried out to capture the perspective and challenges of patient groups during COVID-19 as a means to reshaping services and generating future funding.



Creativity is a necessity if you want your message to get noticed

Be brave! Innovation – both in form and format – can lead to outstanding impacts in patient partnerships. Health communications is a crowded space. To get cut-through, everything from design to delivery has to stand out from the crowd. After all, as OVID's namesake famously wrote, Fortune and Love Favour the Brave.

This extends beyond your message, essential though it is: it's also how you are trying to be noticed, and by whom. Creating campaigns with patient groups requires inclusivity, ensuring experiences and voices from within patient communities are understood and reflected to craft an authentic message that reaches the right people.

Intercept (Index SILVER standard)

In 2019, Intercept partnered with the PBC Foundation on the 'Know Your Numbers' campaign, which aimed to provide PBC (Primary Biliary Cholangitis) patients with an understanding of results of their regular blood tests. Primary Biliary Cholangitis (PBC) is a chronic and progressive condition with few or no visible symptoms, and patients may sometimes feel disconnected from their disease and treatment. Intercept and the PBC Foundation worked together on a creative multi-channel campaign to communicate scientific and medical terms in a way that is engaging and easy to understand.

The campaign was well-received by patients. As PBC is a rare disease, if a patient doesn't live near to a liver hub, the healthcare professional treating them may not have seen many people with this condition before. So arming patients with an understanding of their liver test results is extremely important so they can actively manage their condition. Patients said they were having more meaningful conversations with their healthcare professionals as a result of the campaign.

OVID's framework for creative partnerships includes:

1. Understand your audience. We spend time analysing and getting to really know your patient community and their day-to-day perspective. It inspires us to create something that connects with them they haven't seen before.
2. Emotional resonance. This is a technique used by pollsters to assess the likely political success of a new policy. It's not about whether people agree with your message, but whether they feel it enough to act. Companies and patient organisations can together reach the right audiences, but then they must bring them along.
3. Co-creation is key. Be inspired by ideas from your patient group partner. Use their insight to co-create content – involve them from the start of planning, in choosing a creative agency partner and be inspired by what can be achieved.

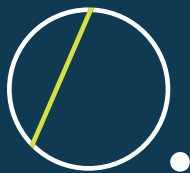
OVID's top tips for embedding creativity in your communications and advocacy:

1. Compliance is not a barrier to creativity.
2. Don't lose focus on the objective, even the most creative ideas that get you noticed can fail if they don't deliver impact.
3. There's so much noise, don't be afraid to use creativity to 'package' up messages to get them noticed by your target stakeholders.
4. Even just being creative with how you visually present something, or how you deliver a message, is what can make your programme stand out from the crowd.

How OVID can help:

- Award-winning creative ideas for partnership campaigns.
- Strategic advice and stress-testing creative ideas to ensure they are compliant but creative enough to generate an impact.
- Facilitating co-creation workshops.





OVID
HEALTH



OVID Health's Call to Action

Embedding patient advocacy at all levels of a company and being agile are goals that companies will need to work on over the long-term, and OVID Health is here to help make it a reality, faster.

Through strong planning processes at the start of each partnership, we should make sure our projects are measurable and creative.

Once a partnership has been created, ask yourself these additional questions to help steer yourselves towards a successful outcome for patients and your company.

We have an opportunity to reinvent partnerships and a clear framework through which we can improve the way partnerships are valued and perceived. By working together, we can truly make transactional partnerships a thing of the past and make equal and impactful partnerships the key to success for every healthcare company in the future.

5. Do we have a transparent relationship founded in trust with the patient organisation we hope to partner with?
4. Do we have buy-in across the company?
3. How are we going to measure success?
2. Are we planning on doing something authentic to who we are as a company?
1. Are we addressing a genuine need for patients?



OVID Health Client Services in Patient Advocacy

1. Independent audits of existing relationships (including patient group interviews).
2. Internal audits and capacity building programmes – working across business functions to make “patient promise” plan of action on how to embed patient centricity. This can be therapy area specific or company-wide.
3. Bringing together patient groups and a company (e.g. creating ideas both want to be involved in).
4. A model for bringing patient groups together; creating a multilateral project or relationships rather than bilateral relations with lots of small organisations.
5. Empowering patient groups to communicate with healthcare professionals.
6. A framework for setting up and running patient advocacy councils.
7. Supporting internal patient advocacy teams to design and deliver campaigns in partnerships with patient groups.
8. Strategy workshops for helping patient advocacy teams plan their year ahead and how to get the most out of new and existing relationships at a global/national level.



Jess Mills, Founder, ACT for Cancer and the Tessa Jowell Foundation:

“OVID was a totally invaluable part of the team! Couldn’t recommend their services more highly, we feel very lucky to have found them.”

Athena Lamnisos, Chief Executive, The Eve Appeal:

“Amazing. I would recommend OVID to anyone. Clear, strategic, very informed advice and a pleasure to work with. OVID really did make it possible to run an impactful campaign and kept us on track, focused and without panic.”

Christine Hancock, Director, C3 Collaborating for Health said:

“OVID's insightful analysis of our messaging and helpful process guiding us to think more strategically and clearly about the way we communicate was invaluable.”

Dr Ben Pearce, Director, Paintings in Hospitals said:

“OVID took the time to understand the essence of our message and the communications challenges we face. OVID has been instrumental in helping us create an effective campaign strategy to raise our profile in the health sector and their expert opinion and advice has been key to making our 60th anniversary event a resounding success.”

Sue Wixley, Director of Marketing & Communications, Future Care Capital said:

“We really liked OVID’s approach to our brief – they hit the ground running and were strategic in their approach to internal and external stakeholders. Most crucially they delivered brilliant media coverage and really helped us to maximise our impact with the audience we wanted to reach.”

OUR WORK WITH PATIENT GROUPS

PATIENT PARTNERSHIP INDEX 2020

To find out more, or to partner with us on your next project, please contact us on:

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To pre-register for entry to the Patient Partnership Index 2021 please go to:
<https://patientpartnershipindex.co.uk/enter/>

To find out more about our work in public affairs, PR and campaigns go to:
<http://www.ovidhealth.co.uk>

