

THE GOOD
PATIENT
PARTNERSHIP
GUIDE 2023



*“Partnership is not a posture
but a process – a continuous
process that grows stronger
each year as we devote
ourselves to common tasks.”*

John F Kennedy



How are patient group partnerships commonly viewed and handled by the pharmaceutical and medical devices industry?

As imperative to informing the work of industry?

As vital partnerships to be nurtured?

As the cornerstone of patient centricity?

We explore this and more through in-depth interviews with leading patient organisations as we seek to uncover how critical partnerships between industry and the third sector can be enhanced for the good of patients.

Foreword



Diana Evans

Executive Director Patient Education, Makara Health

Makara Health initiated this project to demonstrate commitment to insight led patient engagement and support. To continue to help our clients and the organisations we work with to explore how these critical relationships can be improved and deepened. We have invested in a powerful listening exercise with patient organisations and identified some interesting areas of focus. As I reflect on the conversations we have undertaken over the last few months with our generous contributors to this report – leading patient organisations in their fields – I am struck by how consistently the main themes came through across all interviews. From the more straightforward process driven ‘tweaks’ that should be realistic for industry to address (and I urge them to do so) to some of the broader issues worthy of greater consideration and debate.

80% of the top pharmaceutical companies cite some iteration of a patient centred approach as a core value to their organisation, rightly so. If the pharmaceutical industry wants to be truly patient centric then surely that starts with how we interact in every way with the groups that represent those patients? We have explored these interactions to uncover the perspective of the patient groups and have aimed to provide concise insights and tangible recommendations within this short report – quality over quantity and minimal naval gazing! You will find clear recommendations for industry professionals striving to initiate or improve engagement policy and process and for those already doing great work, looking to up their game in this space, guidance on what ‘great’ looks like with our ‘stellar’ recommendations.

We have made suggestions across five key themes: Building long-term partnerships, adding value beyond financial support, speeding up and simplifying processes, the power of post covid collaboration and delivering patient insight across businesses.

My own career has varied from starting out working within a UK patient organisation and more recently taking on a voluntary role with a new healthcare charity, to working within industry roles charged with building relationships with such groups. I see the world from all perspectives and I am passionate about leading a team at Makara that can really be a catalyst for change... starting with this report.

Long-term partnerships

It came as no surprise that our interviewees valued the partnerships they hold with the pharmaceutical and devices industry. Yet, they urged patient organisations and industry to always strive for long-term relationships built on deep foundations supported by mutual areas of interest for patient benefit. Greater investment by industry in advocacy driven roles has helped to support this drive.

Patient groups are keen to embark upon truly collaborative projects that meet both their needs and

the needs of industry. They see value in setting out on a journey together, with shared and agreed goals, and building a lasting mutually beneficial partnership that achieves a vision that ultimately meets the needs of patients.

It is important to consider exactly how relationships and projects are handled over time, in particular in the case of patient groups and industry personnel changes. Relationships between patient groups and industry should be viewed as key organisational partnerships

supporting ambitions for patients, therefore worthy of careful consideration, open and clear communication, and some consistency process wise.

Planning for longevity to support patient groups doesn't have to mean endless funding but it is prudent to consider transitional approaches to funding. If patient-centricity is a central tenet of any organisation, then ongoing interest and relationship management with engaged patient groups should be attended to, even if funding reduces or stops.



GOOD PARTNERSHIPS

Take time to co-collaborate on strategy and policy before thinking about specific projects – this might take the form of a strategy workshop or the initiation of a cross-functional working group (including medical counterparts, social media content creators, communications, PR, patient information)



STELLAR PARTNERSHIPS

Plan a path of travel and a long-term relationship encompassing multiple projects and a shared vision/goal with a patient organisation. Build a relationship that includes transparency and planning around clear communication as well as long-term funding and, if necessary, suitable exit plans for projects



Philippe Halbout
Chief Executive, International
Osteoporosis Foundation

“Identifying a common strategic interest makes a big difference. We want partnership and collaboration with industry that is much more than just a shopping list.”

When we as a Foundation shake hands to agree on a project with our partners, we do so in trust that the collaboration reflects mutual interests, and that it is 100% aligned with the needs of the patients we both serve.”



Catherine Bouvier
CEO & Co-Founder,
Neuroendocrine Cancer UK

“It can be challenging when there are constant people changes.

That’s quite frustrating when you’ve just started on a project and you are really trying to see something through and you’re hoping that there’s been a good enough handover, sometimes the new person will come in and see it differently and want to change the course of the whole project.

I have actually ended up pulling the project before because an interim person was more focused on a different aspect and it didn’t fit with what I was trying to do.”

Adding value beyond financial support

We know industry provides a vital financial lifeline to patient organisations – a lifeline that should be transparent and documented appropriately. Those we spoke to highlighted that industry does a great job offering value beyond financial support and we found numerous examples of this in our interviews. Sometimes, however, large,

well-networked, cross-functional organisations and industry can lose sight of what these attributes can also offer patient groups, particularly smaller or newer, less established organisations. When working within industry, it can be easy to take for granted the number of touchpoints available within NHS, HCP or policy audiences.



GOOD PARTNERSHIPS

Build opportunities for patient group contacts to understand and get to know the industry, different functions, conferences, events and personnel where appropriate. The relationship can be managed by a single point of contact but exposure to the wider organisation can help deepen the relationship and spot opportunities. There may be infrastructure or activities that can further patient group goals without a need for funding



STELLAR PARTNERSHIPS

Take the time to understand the profile and networking needs of the patient organisations the industry is engaged with. This can be a huge stepping stone to support the patient organisation's profile amongst key stakeholders and ultimately improve support and advocacy for the patients they represent



Catherine Bouvier
CEO & Co-Founder,
Neuroendocrine Cancer UK

"I'm not sure I see us as 'patient advocates' more like community organisations working collaboratively with the NHS, really.

That's how we should be viewed."



Debra Montague
Founder and Chairwoman,
ALK Positive UK

“Industry have tentacles far and wide, and they could use these to talk more about the patient groups they are engaged with – of course it’s important to ensure necessary checks and balances to this but it would be a big help if industry could do more to make key stakeholders aware of them, particularly healthcare professionals.”





Trudie Lobban MBE
Founder and Trustee,
Arrhythmia Alliance

A stellar case study

At the beginning of the pandemic, when we went into lockdown and they were shutting clinics, I called one of our supportive clinicians and said, "right, what can we do to help patients?" and they said, "we're going to have to close our pacemaker clinics so we need to get more remote monitors out to patients". I phoned my key industry network and said, "if the doctors get the patients' permission, would you be able to send the monitors direct to patients?" - which until this moment was basically unheard of, and I said

"If I send you our information, would you put our information in the packs, so patients then know about us?"

We went back to the clinicians, they thought it was a fantastic idea. The doctors got permission and the GDPR element covered, industry shipped the remote monitors to the patients.

We provided education and support, industry provided the technical support and of course, the doctors provided the medical support.

There was no money attached to the project, it was just about our collective effort to make sure patients were monitored and didn't have to go into the hospital unless it was absolute emergency.

A truly patient outcome focused collaboration – that we could all be proud of.



Speeding up and simplifying processes

It was a common theme across the board, and sadly a common frustration, that industry is still getting too caught up in red tape and process. There is a very clear understanding of the needs regarding compliance and code requirements. However, one of the biggest frustrations was one that requires swift review across the sector – payment terms and speed of payment.

There was also frustration with a lack of understanding of the burden of process on patient groups.



GOOD PARTNERSHIPS

Discuss the patient group's preferences and take the time to work together, in unison with your finance team, to find a solution and ensure charitable organisations aren't waiting anxiously for funds



STELLAR PARTNERSHIPS

Work with internal stakeholders to review payment terms and processes for patient organisations and, if necessary, work out a bespoke SOP – this will set you apart as a company that has listened



Philippe Halbout
Chief Executive, International
Osteoporosis Foundation

“To set up an agreement with industry is incredibly challenging. There is an imbalance in the workloads relating to this too, because industry has the manpower to manage the paperwork needed.

Our staff resources are more limited and we naturally have less time to dedicate to the discussion and negotiation of terms. As well, funding can be slow coming through, which for a small charity can be an issue. It can be quite some months – and that is challenging to say the least as we have financial commitments which must be met.”

COVID – The catalyst for collaboration

Industry response during Covid seems to have been somewhat of a litmus test to ascertain those true to a patient-centric purpose. There seems to have been a spectrum of responses - those companies that immediately battened down the hatches and were introspective versus those who saw the big picture and immediately recognised the challenges facing the charitable sector they were engaged with. Introspection and a focus on dealing with an

unprecedented global situation was understandable. However, it provided a stark contrast to those companies that took an outward looking approach. We heard incredible heart-warming stories of actions and reactions by industry in this time of crisis and others that frankly would not have passed the red face test. We all know, you are only as good as your last performance and a reputation can be built and destroyed in times of crisis. On the whole, what we

saw was incredible collaboration, between companies, with academia and Government.

This was a fact highlighted in our discussions and a sincere hope that this would be a new era in collaboration across the board for industry. A hope that some good has come from Covid when it comes to how industry collaborate with each other and collaborate beyond/outside their own industry.



GOOD PARTNERSHIPS

Have contingency plans for times of crisis, including how to work with and continue to support patient groups. Will make sure these relationships are still front of mind and given due consideration at a time when it is all too easy to become introspective and adopt a short-term mindset



STELLAR COLLABORATIONS

Recognise there's greater scope for cross-industry collaboration and also know that it can sometimes prove a small world in the world of this industry. Recognise there's more scope to tap into the network of like-minded individuals from other commercial organisations or third party groups to create a greater sense of common purpose to support all patients in a relevant disease area or perhaps across the NHS, particularly during the ongoing crisis within the NHS





Trudie Lobban MBE
Founder and Trustee,
Arrhythmia Alliance

"I will never forget the companies that helped and the ones that went quiet during Covid. One organisation immediately set up an emergency fund for patient organisations, enabling access to funding within a week. I cried when they told me."





Debra Montague
Founder and Chairwoman,
ALK Positive UK

“I think industry can make it incredibly difficult to collaborate with other companies in the industry. I know of examples where the legal department have held up an initiative and non-promotional initiative for 18 months, because the two legal teams spent the time throwing out certain words in the contract, and another group would throw another law out or would add one.

COVID has shown us what's possible. And it's changed what is possible”



Insight where it matters – a missed opportunity?

A particularly interesting area uncovered in our interviews was around the brick wall put up between patient organisations and commercial teams within industry. We know this has its roots in creating a very clear dividing line in terms of reducing any risk of

brand promotion to public, perceived or otherwise. However, in our discussions it became clear that this was potentially doing a disservice to the patients these medicines are ultimately for.



GOOD PARTNERSHIPS

Consider whether there is greater opportunity to expose commercial teams and sales teams to more patient insight and experience. The vast majority of this exposure comes from the HCPs they interact with – is that enough to truly understand the patient experience?



STELLAR INSIGHT DRIVEN COMMERCIAL TEAMS

Consider the sensitivity around contact between patient organisations and commercial teams, alongside a recognition of the amount that could be learnt from talking to patient organisations combined with the fact that the ABPI code doesn't ban contact. They, therefore, also consider reducing existing barriers to allow contact, with clear checks and balances in place to ensure appropriate communication and engagement





Debra Montague
Founder and Chairwoman,
ALK Positive UK

"I do think there's a disconnect between who in industry can interact with patient groups and who can't. I think something gets lost by not being able to speak to patients openly.

You know, to develop real insights into what the needs of patients are."



Summary

This in-depth listening project has uncovered a wealth of insights, delivering some key tangible actions alongside, perhaps, some more reflective findings.

We hope it encourages action and change, where possible, and greater cross-functional discussions within relevant companies to consider how they can improve existing relationships, nurture new ones and be true to a patient-centred approach.

If you have any comments or feedback on this report, we'd love to hear from you.

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