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THE SPARK GLOBAL
Shaping the future of patient-centred healthcare

> “If everyone is moving forward together, then success takes care of itself.”
>
> **Henry Ford**

Brought to you by Precision AQ, in partnership with our contributors

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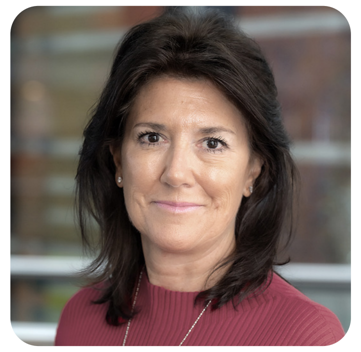

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FOREWORD

Patient engagement is becoming ever more present in the pharmaceutical and medical devices world. Understanding patient experiences, listening to the patient voice and incorporating learnings is becoming intrinsic to planning and decision making throughout the lifecycle of a medicine or product.

In this second edition of our Guide, we explore how vital partnerships between industry and patient organisations/independent patient advocates play out in practice, and we reflect on areas for consideration and improvement. It is our hope that the Guide will stimulate thinking and dialogue that may serve to continue to advance the patient-centric approach to these partnerships, highlight the value of the patient voice and, ultimately, benefit patients.

The content and reflections we present have arisen from numerous conversations with our contributors as part of an annual insight-gathering and listening exercise. Some themes continue from last year's Guide and remain a focus, and some evolve the conversation offering fresh thinking for this year. What sits at the forefront of my mind when thinking about the myriad of insights we gained is that the dedication and commitment from industry to embrace patient centricity is high in theory, but in reality, effective implementation of this mission varies by many degrees.

So, what have we learnt? What has stood out?

- The true value and impact that the patient experience and perspective can offer is not always fully recognised in contrast to the intrinsic recognition of the value and impact assigned to the healthcare professional perspective
- Embedding a truly patient-centric mission in thought and practice throughout an organisation and for the lifecycle of a product/medicine is one of the biggest challenges
- Budget restraints and longevity of funding commitments to patient associations can cause frustration and limit patient centricity
- Hesitancy exists around allowing broader access to patients and their experience beyond patient advocacy team members in order to gain insights and improve understanding
- There is a continued need to simplify processes to enable patient partnerships

We explore this in more depth in our Guide and offer best practice food for thought alongside practical ideas and approaches to inspire change. This year, we have contributions not only from patient associations but also from individual patient advocates as well as from the industry.

We want to say a huge thank you to our contributors without whom we couldn't have developed this Guide. We hope you enjoy the read.

Claire Paling
SENIOR DIRECTOR, PATIENT INSIGHTS & SUPPORT

IS IT TIME TO RECOGNISE THE ‘POL – PATIENT OPINION LEADER’ AND THE VALUE OF PATIENT EXPERIENCE?

Historically, the culture and mindset of the industry tended to focus on developing new devices and medicines for patients with scientists and healthcare professionals. Healthcare professionals have always been thought of and referred to as key opinion leaders (KOLs) or external experts, and are highly valued and remunerated for the scientific expertise and guidance they can provide to the industry, and rightly so. However, this is not always the case for patient experts who are important opinion leaders too.

A patient opinion leader (whether an individual with lived experience of a condition, an independent advocate for patients, or a patient association) is a relatively new term, as is the consideration of working with patients – listening, co-creating, collaborating with, valuing and remunerating their expertise. There has been progress in trying to support a fair market value approach to engaging and working with patient advocacy experts. However, there is still work to be done to ensure industry, across the board, recognises the significant worth and impact patient experience and perspective can have.

> “The culture is changing – some companies are starting to stratify patients and refer to patient thought leaders within the patient community, however, more could be done.”

Trishna Bharadia MFPM(hon)
PATIENT ENGAGEMENT CONSULTANT AND HEALTH ADVOCATE

> “In rare disease, patient groups are very close to the community which is very tight knit. This makes a difference to partnerships as patient groups can make things happen very quickly and the value of this needs to be appreciated. This is especially true when it comes to playing a part in regulatory decisions and being able to share lived experience to humanise the real need for a medicine.”

Luke Langlands
CHIEF EXECUTIVE OFFICER,
TUBEROUS SCLEROSIS ASSOCIATION

> “Industry is starting to see the value brought by patient groups who have a much closer idea of what matters to patients and can share this.”

Debra Montague
FOUNDER AND CHAIR,
ALK POSITIVE

> “Patient insights are critical to Astellas having the whole picture and using that picture to develop medicines that meet the needs of patients. We can’t just push ahead based on what’s scientifically possible, we must go in eyes wide open as to what’s meaningful to patients and their caregivers.”

Doug Noland
HEAD OF PATIENT PARTNERSHIPS,
PATIENT CENTRICITY DIVISION, ASTELLAS

INSPIRATION

Patient council approach

- This is a multi-patient group akin to a steering committee that meets regularly throughout the year, year-on-year, to harness the patient voice and ideate to act on insights
- It can be extremely effective, especially when established early with consistency and long-term commitment

Establishing regular touchpoints

- Invest time for regular exploration meetings beyond specific projects and around future plans, current challenges and latest news
- This demonstrates recognition of the value of patient insights and partnerships, strengthens relationships, and enables the uncovering of synergies that might otherwise have been missed

Patient group/patient advocate accreditation

- Could a healthcare regulatory organisation accredit charities or individuals to demonstrate the quality of their work, resources and services and instil confidence within the industry when identifying who could be valuable to partner with?

HOW DO YOU SPREAD THE TENTACLES OF PATIENT CENTRICITY THROUGHOUT AN ORGANISATION?

Understandably, there are challenges to be faced when it comes to embedding a patient-first mindset in every part of an organisation and ensuring the patient experience is not just understood and considered, but acted upon and incorporated throughout: from research and development, medical and government affairs, brand and marketing, procurement processes, manufacturing and, ultimately, products/treatments to improve patient outcomes. Moving from the concept of a meaningful mission to reality takes time, commitment and consistency.

> “A patient-centred company is not filled with lots of people and just a few are focused on patient engagement. It needs to be a company that instils a responsibility in every employee and every department to think about how they/their role can be mindful of patient needs.”

Trishna Bharadia MFPM(hon)
PATIENT ENGAGEMENT CONSULTANT AND HEALTH ADVOCATE

> “Meaningful mission starts and ends with patients. Considering what something means for a person with a condition, or family member/carer/friend, should be central to everything we think, and more than that, to everything we do. It must involve an open mind with no hidden agenda.”

Anja Strootker
PUBLIC AFFAIRS AND COMMUNICATIONS CONSULTANT, MEDTRONIC

> “A patient-first mindset requires constant and consistent internal messaging and initiatives to ensure it becomes central to an organisation’s culture.”

Merce Duran-Sindreu
PATIENT STRATEGIC ALLIANCES MANAGER, MEDTRONIC

> “Beyond our Patient Partnerships Team, we believe that patient engagement is everyone’s responsibility at Astellas.”

Stephen Head
SENIOR DIRECTOR, PATIENT PARTNERSHIPS, ASTELLAS

> “Understanding the patient experience can be very valuable. Patient councils are a great way to ensure continuous and proactive input and feedback on all steps of the drug development life cycle and initiatives from the Patient Community.”

Mark Sterckel
PATIENT ENGAGEMENT EXPERT

INSPIRATION

Commitment to embedding a patient-first culture

- Host patient mission ceremonies and employee holiday events to champion the patient experience
- Invite patients to factories/manufacturing plants as well as headquarters to ensure widespread exposure to the patient experience
- Make patient-first-mindset training mandatory for all employees annually to keep it front of mind

Establish a robust and dedicated patient partnership team

- Define patient engagement key values to:
  - guide behaviour and define a consistent approach to building trusted partnerships with patient communities worldwide
  - motivate employees to help to ensure that patient community insights are appropriately acted upon and filtered into the organisation
- Develop and publicise a commitment/pledge to patient engagement

TIME FOR A DIFFERENT APPROACH TO FUNDING MODELS?

Budget constraints across all stakeholders and a continuing turbulent economic environment have impacted investment in patient partnership activities. Patient-focused activities and patient-group engagement can often be the first to be pulled in the face of restricted budgets, highlighting the disparity between intention and practice when it comes to patient centricity. We identified a disconnect between industry funding practice and the functional needs of patient organisations. Funding is usually linked to a specific project or event and is therefore short to medium term. Patient groups understand the need for this, and transparency around funding. However, this creates challenges for long-term financial planning and securing the ongoing running costs of a patient organisation – finding the funding for 'day-to-day' running costs can be a significant burden. There is also a tendency for funding to end as product/medicine patents come to an end. This change in priorities can be understood, but once a drug comes to market, shouldn't the responsibility for long-term disease awareness and education remain? The question arises, could funding be approached differently?

> “The TSA has experienced situations where funding stops once a medicine has generic counterparts. It would send a clear message about the importance of patient community work if funding continued.”

Luke Langlands
CHIEF EXECUTIVE OFFICER,
TUBEROUS SCLEROSIS ASSOCIATION

> “There is such a variety in the way pharma works when it comes to fair and equitable remuneration for the third sector. It needs to be transparent and respectful, there should be SOPs and rules of engagement when it comes to the financial side of partnerships. Funding models need to change and allow for support of a service not just sponsorship of an event or initiative. Grant applications need to give space to explain the rationale behind a request.”

Catherine Bouvier
CHIEF EXECUTIVE OFFICER & CO-FOUNDER,
NEUROENDOCRINE CANCER UK

> “In 2023, Heart Valve Voice (HVV) saw a 40% reduction in funding pretty much overnight due to the economic situation. Funding is always a challenge and as they can’t fund staff or ongoing running costs of patient associations, capacity building is tricky. Funding is always tied to project work, and this can be limiting and make it hard to plan and future proof.”

Wil Woan
EXECUTIVE DIRECTOR,
HEART VALVE VOICE

> “Longevity and commitment should go beyond the lifecycle of the patent.”

Trudie Lobban MBE
FOUNDER AND TRUSTEE,
ARRHYTHMIA ALLIANCE

INSPIRATION

Agree different funding models

- Consider initiating 3-year funding plans that are project based in the main but long term with regular payments throughout the year
- It might involve meeting various requirements and working closely with multiple people to gain approval, but discussing a long-term approach can be successful

European Government fund

- Create a European Government-held fund, paid into by industry, to support patient associations and patient advocates with the work they do, including conference attendance and long-term running costs
- Careful consideration would be needed to ensure:
  - it was accessible without too much red tape and available to those who most need it, i.e., small patient groups and individual patient advocates
  - clinical need didn't influence funding decisions inappropriately

Profit allocation

- Encourage industry to set aside a percentage of company profit to financially support patient community education and awareness programmes to ensure the commitment to patient partnerships lives on beyond the lifecycle of a patent
- The funding could be assigned to campaigns that would support multiple patient groups across multiple conditions
  - An example initiative for which financial support would be helpful: Arrhythmia Alliance is working on a patient advocacy toolkit to empower patients to advocate no matter what the disease area, i.e., to approach and work with hospitals, trusts, politicians, the media and regulatory agencies

IS RISK AVERSION LIMITING ACCESS TO PATIENT INSIGHT?

Patient partnerships are often driven by a particular individual or team within an organisation and there is little opportunity for networking or to share the patient experience with wider teams, in particular, commercial teams. This is a continued theme from our 2023 Guide. What came to light this year is that this can be due to hesitancy and industry being risk adverse around commercial teams accessing the patient experience/having contact with patient experts or advocates. As a result, these teams avoid the patients all together. In addition, these teams may think that, because they are in contact with healthcare professionals and clinicians, they understand the patient journey and, therefore, don't need to learn more from patients. However, only a patient living with a condition can truly know the lived experience, and in sharing this, may shed light on an unrealised area of need that a healthcare professional is unable to.

> “Whilst I understand the importance of compliance, industry can often be quite risk averse and there is fear over allowing me to talk to anyone who isn't clearly patient 'compliant' although that intelligence can often help us leverage the patient voice.”

Wil Woan
EXECUTIVE DIRECTOR,
HEART VALVE VOICE

> “Pharma can be quite insular and siloed, and it doesn’t always come naturally to connect the dots. There can be great benefit to linking patient groups to a range of team members to improve understanding of the lived patient experience and to cut through any assumptions. This is especially true in the rare disease space.”

Luke Langlands
CHIEF EXECUTIVE OFFICER,
TUBEROUS SCLEROSIS ASSOCIATION

> “Industry talks about putting patients at the heart of everything and striving to improve patients’ lives, and there is nothing better to help this than hearing the patient experience from the horse’s mouth.”

Debra Montague
FOUNDER AND CHAIR,
ALK POSITIVE

INSPIRATION

Highlight influence to open doors to conversation

- As a patient group/patient advocate, highlight how you have influenced disease treatment guidelines, or have reach and contact with regulatory bodies to demonstrate your influence on policy. This can lead to industry patient-engagement contacts connecting you with other areas of the business

Patient community engagement across teams without agenda

- Consider open and collaborative meetings between the patient community and multiple teams – market access, research and development, medical affairs, patient advocacy and marketing to gather insights and share learnings about a disease area with no barriers to dialogue
- Approach it with respect and inquisitiveness, and without it being specific to a treatment/product or initiative. Early exploratory conversations can lead to great partnerships

CAN MORE BE DONE TO SIMPLIFY PROCESSES FOR PATIENT PARTNERSHIPS?

Complex and lengthy processes, especially when it comes to contracting, were a pain point for many of our contributors. This is a theme that is carried over from our 2023 Guide and one that continues to need consideration. Complicated terminology and language are used in contracts, and there tends to be little flexibility for tailored or bespoke contracts. With time and resources stretched for many patient groups and patient advocates, understanding and navigating the contracting process can be a challenge, as too can be the time lag between finalising an agreement and receiving funding.

> “There is still work to be done around industry recognising that independent patient advocates exist and are not part of a patient group. That they have a unique role as they are independent and require a unique contract, one that doesn’t include IT security policies, or anti-slavery policies, for example, because an individual wouldn’t necessarily have these written policies.”

Trishna Bharadia MFPM(hon)
PATIENT ENGAGEMENT CONSULTANT AND HEALTH ADVOCATE

> “In our experience, the lag between signed agreements and actually getting agreed funds varies massively between groups – with some it’s fairly quick, with others it’s extremely slow. These funds can be significant for annual or multi-year planning and project implementation. It is important that patient groups receive clear communications about industry’s expectations for an agreement, and realistic timelines for when money will be received.”

Luke Langlands
CHIEF EXECUTIVE OFFICER,
TUBEROUS SCLEROSIS ASSOCIATION

INSPIRATION

Discuss alternative processes

- Work with industry legal teams on simplifying processes and explaining why this is important for the patient community
- They will likely be open to meeting patients' needs; for example, consider shortening payment terms for specific agreements

Communicate clearly

- Ensure there is clarity around project agreement and payment terms and timings, and that all parties are aligned

CLOSE

The path to a widespread meaningful mission and active implementation of excellent patient engagement is long and winding. We are on a journey, and while industry may be at different stages (with some organisations already there or very close), it is committed to reaching the destination – one in which the value of the patient voice is truly recognised and acted upon by all from bench to bed.

We hope you'll join us in smoothing the path. If you want to partner with us on the journey or are interested in exploring any of the ideas shared further within your own organisation, please reach out to mh.patientsupport@precisionaq.com. We'd love to hear more about your particular goals and work with you to realise them.

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