



# Shaping the Future of Public and Patient Engagement in KHP Neurosciences

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# “Strengthening neuroscience engagement through trusted collaboration”

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## One page summary

# Partnering for meaningful collaboration in Neurosciences

### *Key message*

Charities in Neurology are driving PPEI, grounded in lived experience, often without recognition or funding. They shape peer support, research priorities, and governance, and are eager to collaborate - calling for ethical, well-resourced partnerships that respect their capacity and expertise. Meaningful change relies on trust, mutual respect, and shared leadership, principles King's Health Partners (KHP) Neurosciences is well placed to champion. With strong appetite for sustained collaboration and charities ready to lead, this is an opportunity to unite patient, charity, and academic leadership to transform neuroscience engagement.

### *What we've done together*

KHP Neurosciences is committed to sustained collaboration with patients, families, carers, and community partners. Through conversations with 19 charities across neurological, rare, and neurodiverse conditions, we explored current PPEI practice and ways to strengthen it. These charities identified improvement opportunities, a further 18 organisations then prioritised these opportunities.

### *Key insights from across the organisations*

- Equity gaps persist – especially for digitally excluded and minoritised communities.
- Research partnerships often fall short – lacking co-design, feedback, and accessibility.
- Charities hold rich, underused data – from helplines, surveys, and peer networks.
- Mistrust of extractive models – driven by one-off, transactional engagements.

### *What charities need*

- Early involvement in research design and dissemination.
- Accessible, co-produced outputs e.g. lay summaries, webinars.
- Training for researchers and clinicians on ethical engagement.
- Compensation and infrastructure to support sustained involvement.

### *Charities proposed the following improvement opportunities*

Priority 1. Public and peer education projects - *for clinicians, researchers, and peer leaders*

Priority 2. Joint policy advocacy - *unified voice for policy change creating visibility, access, and equity*

Priority 3. Underrepresented groups focused outreach campaigns - *reaching beyond digital-first models*

Priority 4. Collaborate on rare & overlapping conditions - *pain, fatigue, mental health, cognition, pathways*

Priority 5. Shared central hub for PPI Support - *templates, ethics guidance, accessible communication.*

Priority 6. Early-career researcher engagement - *work directly with lived experience groups*

Priority 7. Shared ambassador & peer support - *shared training, peer mentorship, and leadership*

### *What next*

Delivering these priorities will expand patient access, close equity gaps, and fast-track research partnerships. With charities ready to lead, the next steps focus on turning this momentum into lasting collaboration:

1. Co-produce a proposal, plan and budget to apply for funding to progress the opportunities – co-facilitated by KHP Neurosciences team, working with the nominated charity leads
2. Submit a proposal to secure funding across different industries –facilitated by nominated charity leads
3. Establish a core team with those who shown interest in leading, once funding is secured



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## Section 1. Overview

*“We have a responsibility to make research feel safe, visible and relevant to the people it’s about.”*

### - Tourette’s Action

KHP Neurosciences Patient & Public Engagement and Involvement (PPEI) extends beyond information-sharing; it empowers diverse stakeholders to co-design services and research, ensuring high-quality care that genuinely reflects the needs of people living with neurological conditions. We held one-to-one discussions and conducted a survey with charities to understand their PPEI models and collaboration opportunities and priorities.

We spoke with 19 charities and surveyed 17 organisations supporting people with neurological, rare, and neurodiverse conditions. This overview shares the key strengths, challenges, opportunities, and priorities for building shared approaches to research, support and collective voice. These insights will guide our next steps, help align resources, and connect with existing expertise.

### 1. The voices from the charities

*“We don’t want to be token voices. We want to shape the conversation from the start.”*

#### - FND Hope

Lived experience plays a central role in governance across the organisations, shaping strategy, peer support initiatives, and influencing the makeup of research funding panels. While charities are leading the way in PPEI work, they often do so without formal recognition or dedicated funding. Despite these challenges, organisations have an appetite to collaborate with KHP. To make this partnership meaningful, charities are calling for clear pathways to early involvement, constructive feedback, and appropriate resourcing.

Across the organisations it was highlighted that charities:

- **Are leaders in engagement:** teams, boards and support services are founded on lived experience. These include ambassador programmes, community research and peer-support innovations. They have a deep understanding of the human impact of gaps in diagnosis, care and inclusion, particularly for rare and frequently misdiagnosed conditions.
- **Wish to collaborate** but, with clarity, fairness and respect for their capacity. Charities have experienced extractive partnerships and are calling for ethical models that value peer support, leadership and trust.
- **Hold invaluable insights into what matters:** to patients, carers and communities - especially around service gaps, stigma and misdiagnosis.
- **Value co-production:** but they need practical tools, training and partnerships that do not rely on unpaid labour.

### 2. From insight to action

*“We’re approached when funding applications are due, but not when research questions are being formed.”*

#### - Progressive Supranuclear Palsy Association

There are opportunities for KHP and the Charities to build deeper, ethical and mutually beneficial collaboration.

#### *Insights*

1. **Equity gaps are evident:** many organisations struggle to reach non-English speakers, minoritised groups and digitally excluded people.
2. **Clinical research often misses opportunities:** for co-design, accessibility, feedback on real-world impact.



3. **Underutilised rich data and insight:** Charities collect a lot of data through helplines, ambassador programmes and community surveys—yet this remains largely inaccessible to formal research systems.
4. **Mistrust of extractive research approaches:** drop-in/drop-out partnerships and a lack of feedback loops are key pain points that will need to be addressed.

#### Action

*“We have the networks. What we need is structured, funded partnership to use them well.”*

#### - Charity

KHP can add value and lead by example in neuroscience engagement - by building long-term partnerships rooted in trust, equity and shared learning. Organisations suggested actions we collectively can take:

1. **Amplify joint working** on access, diagnosis and community trust advocacy
2. **Embed charities at the beginning** in study design, recruitment, lay review, research prioritisation and dissemination.
3. **Produce accessible outputs**, this means simplifying and humanising language by co-producing outputs, lay summaries, webinars, lived-experience panels
4. **Partner on delivering training** for researchers, clinicians, students, principal investigators in how to engage ethically and effectively.
5. **Invest in sustained relationships** rather than transactional engagements by supporting compensated engagement that help charities to budget for participation and build sustainable models.
6. **Establish ongoing infrastructure** rather than one-off consultations- advisory boards and engagement forums.

### 3. Shaping what comes next, together

*“None of us is as smart as all of us.”* - Brain Trust

Let charities together with KHP, shape the next steps as a network, not in isolation. The charities suggested to prioritise and start with:

Priority 1. Public and peer education projects - *for clinicians, researchers, and peer leaders*

Priority 2. Joint policy advocacy - *unified voice for policy change creating visibility, access, and equity*

Priority 3. Underrepresented groups focused outreach campaigns - *reaching beyond digital-first models*

Priority 4. Collaborate on rare & overlapping conditions - *pain, fatigue, mental health, cognition, pathways*

Priority 5. Shared central hub for PPI Support - *templates, ethics guidance, accessible communication.*

Priority 6. Early-career researcher engagement - *work directly with lived experience groups*

Priority 7. Shared ambassador & peer support - *shared training, peer mentorship, and leadership*

The organisations expressed willingness to be part of a collaborative network and to nominate leads for PPEI engagement. This shows a strong appetite for partnership and shared leadership in shaping future patient and public involvement.

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## Section 2. From insight to action: benefits for Charities and KHP

This section presents a thematic analysis of 19 interview summaries from organisations involved in patient, public, and expert involvement in neurosciences. The interviews were semi-structured under seven themes and co-written with KHP Neurosciences’ Patient & Carer Advisory Group. The analysis identified key patterns, insights, and opportunities to inform strategy, partnership, and programme development. Potential benefits for each identified opportunity for the Charities together with KHP over time.



#### Indicative timelines for implementation: 6-12 months

**A. Shared online central hub for PPI support** - Co-develop an online central hub for training, ethics, and compensation guidance across neurological charities and research teams, designing inclusive, accessible research processes and recruitment pathways. This will complement existing Charity and KHP resources i.e. SIA and Brain Trust already tested offer peer-led training, offers provided by King's Academic Training Office, NIHR [Resources and training for public involvement in research](#).

##### *Benefits:*

- Robust frameworks for PPI – clear ethics, training, and compensation structures
- Accessible education – co-created resources embedded in an online hub
- Innovative pipelines – lays a foundation for scalable PPI approaches

**B. Early-career researcher engagement** - Promote placements, mentoring, review pathways for early-career researchers to work directly with lived experience groups.

##### *Benefits:*

- Stronger career pathways – placements and mentorship for new researchers
- Representative research – early exposure to diverse patient insights
- Innovation – fresh ideas and talent in the research ecosystem support charity in funding applications

#### Indicative timelines for implementation: 12-24 months

**C. Joint underrepresented groups-focused outreach campaigns** - Partner on awareness campaigns reach and identification of underrepresented or misdiagnosed groups.

##### *Benefits:*

- Focused campaigns – targeted public engagement for hard-to-reach groups
- Representative research – improved reach into underserved populations
- Strengthened grassroots network – support for inclusive participation

**D. Co-author a joint policy advocacy** - Align on key system gaps (e.g. neuro-rehab, post-diagnosis care, pain services) for shared policy action.

##### *Benefits:*

- Shared advocacy, power in numbers - a bigger unified voice for policy change, aligned messaging on systemic gaps
- Strengthened grassroots network - more influence at policy level

#### Indicative timelines for implementation: Over 24 months

**E. Collaborate on rare & overlapping conditions** - Convene cross-condition learning groups around overlapping issues, like pain, fatigue, mental health and cognition, diagnosis pathways. A learning set or roundtable could begin this process.

##### *Benefits:*

- Representative research – insight from cross-condition lived experience
- Innovation – solutions to shared, complex challenges, wider peer collaboration



**F. Public and peer education projects** - Co-create public education tools to bridge the gap between specialist knowledge and lived experience.

*Benefits:*

- Accessible education – co-created learning tools for public and clinical audiences
- Focused campaigns – better understanding of rare and misunderstood conditions
- Robust frameworks for PPI – knowledge translation embedded in involvement models

**G. Develop shared ambassador & peer support** - Build a cross-organisation network of lived experience ambassadors with shared training, peer mentorship, and leadership development.

*Benefits:*

- Strengthened grassroots network – cross-organisational connection and leadership
- Stronger career pathways – progression for lived experience contributors
- Robust frameworks for PPI – formal roles for ambassadors and peer leaders

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## Section 3. Shaping what comes next, together

We shared the interim findings and benefits of the priorities with 19 organisations for further input. After making revisions, we sent a survey to 55 organisations to rank these priorities. Eighteen responded. Section 4 provides more detail.

This is what the charities prioritised we need to do together next:

### 1. Public and peer education projects

**Opportunity:** Increase co-created public education tools to bridge the gap between specialist knowledge and lived experience. Work together across organisations to co-produce tools based on existing expertise.

For example:

- SIA and Brain Trust already tested peer-led training models
- Polio Survivors Network and Royal Hospital for Neuro-disability highlight rare, neglected topics
- Organisations could deliver webinars, podcasts, or storyboards co-produced by clinical and community members cross-condition public learning tools

### Survey results:

**Public and peer education projects** - Co-create public education tools to bridge the gap between specialist knowledge and lived experience. **Importance:** how critical this is for your charity (1 = Not at all, 5 = Very)



## 2. Joint policy advocacy

**Opportunity:** Align on key system gaps (e.g. neuro-rehab, post-diagnosis care, pain services) for shared policy action. A shared policy paper or briefing could amplify the charity voices collectively, challenges they flagged for example:

- Decline of neuro-rehab and hydrotherapy access (TMS, Polio Network)
- Need for care advisors and service continuity (MD Campaign, SIA)
- Recognition of "invisible" conditions (e.g. FND, TM, PSPA)

### Survey results:

**Co-author a joint policy advocacy** - Align on key system gaps (e.g. neuro-rehab, post-diagnosis care, pain services) for shared policy action. **Importance:** how critical this is for your charity (1 = Not at all, 5 = Very)



## 3. Underrepresented groups focused outreach campaigns

**Opportunity:** Partner on awareness campaigns that reach underrepresented or misdiagnosed groups. Frequent barriers raised were digital exclusion, misdiagnosis, cultural stigma. Organisations are open to:

- Joint campaigns (e.g. Tourette's Action, Ouch UK, BDFA)
- Joint staff, GP education and training (e.g. Encephalitis International, PSPA).
- KHP could coordinate, co-fund and disseminate accessible educational materials.

### Survey results:

**Joint underrepresented groups-focused outreach campaigns** - Partner on awareness campaigns reach and identification of underrepresented or misdiagnosed groups.

**Importance:** how critical this is for your charity (1 = Not at all, 5 = Very)



## 4. Collaborate on rare & overlapping conditions

**Opportunity:** Convene cross-condition learning groups around overlapping issues, like: Pain, Fatigue, Mental health and cognition, Diagnosis pathways, and a learning set or roundtable format could begin this process. TSA, TMS, BDFA, Encephalitis International, and others raised these overlapping needs across rare and co-morbid conditions.



### Survey results:

**Collaborate on rare & overlapping conditions** - Convene cross-condition learning groups around overlapping issues, like pain, fatigue, mental health and cognition, diagnosis pathways, and a learning set or roundtable format could begin this process. **Importance:** how critical this is for your charity (1 = Not at all, 5 = Very)



### 5. Shared central hub for PPI Support

**Opportunity:** Co-develop a central hub for training, ethics, and compensation guidance across neurological charities and research teams. Collaborate on designing inclusive, accessible research processes and recruitment pathways. A common concern is that researchers often approach organisations late, with inaccessible language or unclear benefit. The solution might be to create joint “researcher readiness toolkit” with patient group, organisations expressed the need for shared tools:

- MSA UK, BDFA and Brain & Spine Foundation requested early-stage involvement
- TSA and TMS highlighted ethical guidance gaps
- FND Hope, PSPA, TSA, Pernicious Anaemia Society need shared tools to train lived experience contributors, and to review research proposals.

This opportunity could be co-led between the Charities and KHP, tapping into existing resources for support with co-branded resources.

### Survey results:

**Shared online central hub for PPI support:** Co-develop an online central hub for training, ethics, and compensation guidance across neurological charities and research teams, designing inclusive, accessible research processes and recruitment pathways.

**Importance:** how critical this is for your charity (1 = Not at all, 5 = Very)



### 6. Shared ambassador & peer support development

**Opportunity:** Build a cross-organisation network of lived experience ambassadors with shared training, peer mentorship, and leadership development.

KHP could help unify and amplify efforts, especially across rare disease networks, for example:



- Brain & Spine Foundation, GAIN, and FND Hope already have strong ambassador programmes
- BDFA and TSA want to scale peer engagement but lack infrastructure

**Survey results:**

**Develop shared ambassador & peer support** Build a cross-organisation network of lived experience ambassadors with shared training, peer mentorship, and leadership development. **Importance:** how critical this is for your charity (1 = Not at all, 5 = Very)



**7. Early-career researcher engagement**

**Opportunity:** Support the development of placements, mentoring, review pathways for early-career researchers to work directly with lived experience groups. Brain Trust, FND Hope, and PSA expressed specific interest in this, this could be tied to:

- PPI placements or internships
- Joint studentship proposals with KHP and voluntary sector hosts

**Survey results:**

**Early-career researcher engagement:** Promote placements, mentoring, review pathways for early-career researchers to work directly with lived experience groups. **Importance:** how critical this is for your charity (1 = Not at all, 5 = Very)



## Section 4. The details: what we learned from the charities

**Who we worked with and how**

This detailed section has been placed last. It forms the foundation upon which earlier report sections were built. It offers a deeper understanding of patient and public engagement across neurological, neurodevelopmental, and neurodiverse conditions, through our conversations with the 19 organisations and the additional survey received from 18/55(33%) organisations.



The data identifies patterns and priorities among respondent charities. We acknowledge that the results may not represent the population of UK neurological charities, especially those that did not or could not respond, and therefore there may be the potential for non-response bias in our interpretation. However, the range of responses, and consistency with qualitative input, strengthen confidence in the themes identified.

### *About the participating charities*

The 29 charities involved represent a broad mix of neurological condition support organisations, each focusing on a distinct disorder or group of related conditions.

Table 1. Participating organisations

1. Batten Disease Family Association	16. Myaware
2. Brain and Spinal Injury Chairty	17. Nerve Tumours UK
3. Brain and Spine Foundation	18. Ouch UK
4. Brain Trust	19. Pernicious Anaemia Society
5. Brain Tumour Support	20. Polio Survivors Network
6. Cavernoma Alliance UK	21. Progressive Supranuclear Palsy Association
7. Different Strokes Peer Support Group	22. PSP Association
8. Dystonia Society	23. Restless Leg Syndrome UK
9. Encephalitis International	24. Royal Hospital for Neuro-disability
10. Facial Pain Association	25. Spinal Injury Association
11. FND Hope UK	26. Spinal Research
12. Inflammatory Neuropathies UK	27. Tourette’s Action
13. Multiple Sclerosis Trust	28. Transverse Myelitis Society
14. Multiple System Atrophy Trust	29. Tuberous Sclerosis Association
15. Muscular Dystrophy Campaign	

Table 2. Primary neurological conditions supported

<ul style="list-style-type: none"> <li>• Autoimmune pernicious anaemia with or without neurological symptoms</li> <li>• Batten disease</li> <li>• Brain tumours</li> <li>• Dystonia</li> <li>• Encephalitis</li> <li>• Functional neurological disorders</li> <li>• Multiple sclerosis</li> </ul>	<ul style="list-style-type: none"> <li>• Myasthenia gravis and related syndromes</li> <li>• Headaches</li> <li>• Neurofibromatosis</li> <li>• Neuropathic facial pain (e.g., trigeminal neuralgia)</li> <li>• Polio</li> <li>• Restless Legs Syndrome (Willis Ekbom Disease)</li> <li>• Spinal cord injury</li> <li>• Stroke</li> <li>• Tourette’s</li> </ul>
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### *The approach we used*

We first mapped a list of about 100 organisations through online data and internal staff recommendations. We excluded commonly supported conditions and charities i.e. Alzheimer’s, dementia and epilepsy to ensure those who are underserved were the focus. 75 organisations were approached, 19 responded. We designed a methodology to explore the depth and diversity of engagement practices, guided by a thematic framework and questions aligned with the goals of KHP PPEI. The questions were co-written with KHP Neurosciences’ Patient & Carer Advisory Group. Seven common themes were identified, and 133 responses analysed across these themes, identifying recurring patterns, emerging insights, and opportunities for shared learning – as explored in the earlier sections of this report. The conversation notes and the interim report results were reviewed and edited by participants.

Using the reviewed results, a survey invited 55 organisations to prioritise the importance of the opportunities on a scale from 1 (not important) to 5 (very important). Additionally, participants could further provide descriptive information on priorities, suggest events or conferences for researchers to attend, and add comments, questions, suggestions, and research questions. Lastly participants were asked whether they



wanted to lead the collaboration. 18 responded.

Finally, the survey quantitative and qualitative data key themes and patterns across responses were identified and triangulated with the interview results.

## Results of the conversations and survey

Our process for analysing the information consisted of four steps:

1. Familiarisation: we first identify patterns under the seven themes across the 19 organisations
2. Initial coding: The information then summarised key points or recurring ideas within each theme.
3. Theming: We grouped similar themes into sub- and main (meta)themes
4. Summarised output: then explained each theme and provided information with example quotes.

### *Results of conversations with the 19 organisations*

The analysis mapped the current state of PPI and revealed common challenges and collective aspirations. The findings informed the potential for working together and mutual benefits that could strengthen the future of engagement across the neurosciences sector.

#### **Theme 1. Introduction**

The 19 organisations reflected a rich experience, rooted in lived experience. Many were founded in response to gaps in NHS provision and have since evolved into expert allies and advocates for their communities. A strong drive exists to raise the profile and legitimacy of neurological conditions - particularly those that are frequently underdiagnosed or misdiagnosed. The introduction of the charities highlighted a crucial backdrop for engagement: *the importance of trust, the persistence of unmet needs, and the ongoing challenges people face in navigating the health system.*

Meta-Themes	Sub-Themes
<ul style="list-style-type: none"> <li>• Condition-specific advocacy e.g. FND, Batten, MSA, PSPA</li> <li>• Peer-led or hybrid models (volunteer-run, clinician-supported)</li> <li>• Lack of recognition in mainstream care (especially for rare/complex conditions)</li> <li>• Research and care gaps</li> </ul>	<ul style="list-style-type: none"> <li>• Dual professional/lived experience roles</li> <li>• Multidisciplinary support structures</li> </ul>

#### **Theme 2. Understanding existing engagement networks**

Approaches to engagement varied considerably - from structured ambassador programmes to more informal peer support groups. Reaching patients often depends heavily on trusted relationships with specialist clinicians, who act as vital connectors. While online networks are widely used, many organisations consistently raise concerns about digital exclusion and the barriers it creates. As a result, there is a clear call for more equitable, inclusive, and proactive outreach strategies that ensure *“no one is left behind”*.

Meta-Themes	Sub-Themes
<ul style="list-style-type: none"> <li>• Digital-first communities e.g. newsletters, webinars, social media</li> <li>• Clinician-led referrals into community</li> <li>• Hidden populations e.g. post-polio, advanced conditions</li> </ul>	<ul style="list-style-type: none"> <li>• Fragmented vs. formal networks</li> <li>• Importance of caregiver-led forums</li> <li>• Challenges in reaching underserved groups e.g. language, digital literacy</li> </ul>

#### **Theme 3. Exploring opportunities for collaboration and shared learning**

Organisations expressed a strong willingness to collaborate, though many highlighted limitations in capacity. While shared learning is widely valued, it needs to be well-structured, purposeful, and avoid duplication of



effort. Several organisations have already developed innovative, scalable approaches that could benefit others - provided they receive the right support and resourcing to share and sustain them.

Meta-Themes	Sub-Themes
<ul style="list-style-type: none"> <li>• Willingness to collaborate tempered by capacity issues</li> <li>• Avoiding duplication is a shared concern</li> <li>• Open to researcher collaboration, especially on real-world topics</li> </ul>	<ul style="list-style-type: none"> <li>• Peer-led insight as research driver</li> <li>• Demand for shared infrastructure e.g. ethics, training</li> <li>• Unequal access to research or funding</li> </ul>

#### Theme 4. Strengthening PPI in Neurosciences

PPI practice varies widely across organisations. Some have established structured models, such as peer leadership roles and advisory panels, while others rely more on informal feedback mechanisms. There is a growing momentum to professionalise lived experience roles and ensure contributors are fairly compensated. However, limited funding and capacity continue to pose significant barriers to making this a reality.

Meta-Themes	Sub-Themes
<ul style="list-style-type: none"> <li>• PPI ranges from organic to formalised</li> <li>• Barriers include lack of funding, digital exclusion, carer burnout</li> <li>• Appetite for co-production, especially with appropriate compensation</li> </ul>	<ul style="list-style-type: none"> <li>• Peer ambassador and review roles</li> <li>• Community panels and feedback loops</li> <li>• Challenges in engaging progressive/advanced condition groups</li> </ul>

#### Theme 5. Governance and advisory groups

Governance models are evolving. While lived experience is becoming more integrated into governance structures, many boards are still predominantly led by professionals. Organisations are keen to strengthen feedback loops, broaden representation, and make the impact of engagement more visible and meaningful.

Meta-Themes	Sub-Themes
<ul style="list-style-type: none"> <li>• Lived experience in governance is increasingly standard</li> <li>• Variation in formality (trustee boards, review panels, service forums)</li> <li>• Transparency and feedback loops still evolving</li> </ul>	<ul style="list-style-type: none"> <li>• Strategic advisory boards</li> <li>• Research prioritisation via patient voice</li> <li>• Efforts to diversify governance</li> </ul>

#### Theme 6. Alignment with KHP PPEI initiatives

Most organisations were initially unaware of KHP as an organisation, and its PPEI initiative, but once introduced, they recognised strong potential for alignment. While there are some concerns about duplicating existing efforts, there is clear enthusiasm for developing shared infrastructure, co-producing initiatives and creating opportunities for joint dissemination.

Meta-Themes	Sub-Themes
<ul style="list-style-type: none"> <li>• Most organisations were not initially aware of KHP PPEI</li> <li>• Once explained, alignment was strongly welcomed</li> <li>• Desire to avoid duplication, amplify voices, and co-develop training/tools</li> </ul>	<ul style="list-style-type: none"> <li>• Practical offers: co-design, review, access to networks</li> <li>• Critiques of extractive relationships in past academic partnerships</li> <li>• Need for mutual benefit and sustainable partnership models</li> </ul>



## Theme 7. Looking ahead

Looking ahead, organisations aspire to develop ethical models of co-production, expand peer-led involvement, and ensure research reaches underserved and marginalised communities. Many highlighted the need for stronger data, better training, and greater alignment with policy to support this work. There is a shared ambition to shift from reactive forms of engagement towards proactive, system-level change.

Meta-Themes	Sub-Themes
<ul style="list-style-type: none"> <li>• Ambition to scale meaningful PPI</li> <li>• Focus on access, compensation, and policy change</li> <li>• Clear need for shared learning and joint visibility</li> </ul>	<ul style="list-style-type: none"> <li>• Digital inclusion and training access</li> <li>• Multilingual resources</li> <li>• Ethical co-production models, especially in rare disease and neurodiversity</li> </ul>

### Survey - quantitative results

The results showed that across the 18 participating charities, priorities for education, policy, and inclusion were most important. Priorities such as shared infrastructure, early-career engagement, and peer support, while also valued, may be more important to specific charities or might require tailored implementation.

In table 3. the variation (standard deviation) in responses, highlighted where customisation or different approaches may be necessary to meet the needs of all participating organisations. The standard deviation tells how much responses vary: a high value (as in 'outreach', 1.51) means charities are more divided in their opinions, some see this as vital, others less so. A lower standard deviation (as in 'joint policy advocacy', 0.87) means, there is greater consensus. The 25% and 75% values show that the 'central half' of responses typically sits between 3 and 4 (or 3 and 5 for top-rated priorities), confirming that most indicators are seen as important, but not always top priority for all.

### The collective next steps

The next steps should focus energy and resourcing in the top prioritised areas for the broadest impact:

1. *Public and peer education projects* were the most important, with most seeing this a top priority (75% scored 5). This signals a strong need for collaborative knowledge-sharing to bridge specialist and lived experience.
2. *Joint policy advocacy* and 3. *Outreach to underrepresented groups* were highly valued, emphasising a collective appetite for influencing change, and for reaching marginalised populations.
4. *Collaboration on rare & overlapping conditions* sits closely behind, although slightly more variable in importance across charities.
5. *Shared online hubs*, 6. *Early-career engagement*, and 7. *Ambassador/peer support network* received moderate ratings, but some wide variance: many rated these as important (3 or 4), few see them as less priority (1 or 2), hence the wider spread and lower standard deviations.

Table 3. Key statistics for priorities n=18

Priority of the opportunities (in order of importance top to bottom)	Mean	Std. Dev.	Min	25%	Median	75%	Max
1. Public and peer education projects	4.41	0.96	2	4.0	5.0	5.0	5
2. Joint policy advocacy (system gaps)	4.06	0.87	3	3.0	4.0	5.0	5
3. Underrepresented groups-focused outreach campaigns	3.89	1.51	1	3.0	5.0	5.0	5
4. Collaborate on rare & overlapping conditions	3.83	1.25	1	3.0	4.0	5.0	5
5. Shared online central hub for PPI support	3.56	1.01	1	3.0	4.0	4.0	5
6. Shared ambassador & peer support network	3.39	0.98	1	3.0	3.0	4.0	5
7. Early-career researcher engagement	3.28	0.92	2	3.0	3.0	4.0	5



### Survey - qualitative data responses

To summarise the qualitative data meaningfully, we identified themes and patterns across responses across four fields:

#### 1. Descriptive information about collaboration priorities and needs

- Early involvement in research design and ongoing, ethical collaboration is importance.
- Key areas highlighted: policy advocacy on neuro-rehab and post-diagnosis care, and establishing a shared support infrastructure, tailored training for researchers and healthcare professionals to engage more effectively with lived experience groups.

#### 2. Suggested events and conferences for researchers to attend

- Disease-specific conferences: MS Trust Annual Conference, Encephalitis Conference, Dystonia Matters Live.
- Networks and expert partnerships: Brain Tumour Society meetings, World Orphan Drug Conference.
- Community-oriented forums and patient-led events to better connect with stakeholders.

#### 3. Additional comments and requests

- More funding and recognition for charities' role in research involvement.
- Accessible communication methods that consider disabilities
- Concerns about extractive research practices, build relationship based on mutual respect and value.
- Specific clinical and policy issues e.g. greater education on certain conditions, emphasis on non-pharmacological interventions, and improving medical training.

#### 4. Willingness to participate and lead

Many organisations expressed willingness to be part of a collaborative network and to nominate leads for PPEI engagement. This shows a strong appetite for partnership and shared leadership in shaping future patient and public involvement.

### Combining survey's qualitative data and interview results

Table 4. synthesises the survey priorities, needs, and cautions descriptive information, the one-to-one conversations and survey quantitative results. A clear triangulation means, the approach was robust.

Table 4. Results synthesis table

Theme	One-to-One conversation n=19	Survey data n=18
1. Early involvement/ co-production	Explicit	Repeatedly mentioned in priorities
2. Shared tools/hubs/training	Detailed suggestions	Cited/shared resource need, e.g. joint training
3. Equity/access/inclusive outreach	Highlighted as a gap	Stressed by multiple organisations
4. Recognition/ compensation/ capacity	Emphasized as barrier	Cited as barrier, calls for formalisation
5. Lived experience in governance	Stated as growing	Peer/ambassador roles reported/ desirable
6. Policy advocacy, rare cond. focus	Key next step	Identified as a high-impact strategy
7. Caution re: extractive practice	Key critique	Echoed in comments/ suggestions
8. Appetite for collaboration/lead	Assumed need	Confirmed "yes" to participation

----- THANKS FOR READING, THIS IS THE END OF REPORT! -----

