

Patient and public involvement and engagement in Cambridge universities and NHS Trusts

For Cambridge University Health Partners

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Better
Decisions
Together



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Executive Summary

This report explores the current landscape of Patient and Public Involvement and Engagement (PPIE) in research and innovation across Cambridge University Health Partner (CUHP) members, which include two universities (Anglia Ruskin University and University of Cambridge) and three NHS Foundation Trusts (Cambridge and Peterborough, Cambridge University Hospitals and Royal Papworth).

This project was guided by the National Institute for Health and Care Research (NIHR) PPIE Standards. It was commissioned to understand how PPIE is practiced, where it excels, and where there may be gaps or opportunities for further development.

Key insights

- **Members have shared values, but varied definitions:** While each organisation approaches PPIE differently - reflecting their distinct missions and contexts - there are strong common values of inclusion, partnership, and working 'with' people rather than 'for' them. The NIHR definition of PPIE is the most widely adopted, but there is a variety of definition and strategy, with an awareness that engagement, participation, and involvement often overlap in practice.
- **There is pride in a growing culture of involvement as 'business as usual':** PPIE is increasingly seen as a core part of good research and innovation, rather than a tick-box or funding requirement. There is a strong sense of pride in a shifting cultural paradigm that values lived experience and inclusive approaches to research design and delivery.
- **Strength and innovation are evident in creative, inclusive practice:** Organisations are using flexible, often community-rooted approaches to reach underrepresented groups and embed equity in research. There are tangible impacts across the research and innovation life-cycle - from changes to research design to coproducing new hospital builds - and demonstrate the value of trusting, long-term relationships with both individuals and communities.
- **Challenges and barriers to good PPIE still remain:** Timescales, resources, and system complexity are often barriers to meaningful, sustainable PPIE. Diversity remains a challenge, especially where fast-paced research cycles clash with the time required to build trust in groups and communities. Unclear governance, inconsistent processes, and evaluation challenges were also identified as hurdles. Alongside that, the work is difficult and relentless, and the professionals supporting involvement work need support that recognises the burden of the work.
- **There is promise and potential in building on existing collaborative work:** Collaboration is already happening through peer networks, campaigns, and shared resources, but there is appetite for more cross-partner coordination.

Respondents expressed a need for shared processes, centralised resources, building on joint training, and clearer governance.

“There’s so much amazing work, but we’re not shouting about it!”

Opportunities for CUHP members

- Develop a **shared ambition** for PPIE that reflects collective values and clarifies roles, purpose, and vision. (A draft shared ambition follows this Executive Summary.)
- Support working towards a **coordinated infrastructure** for involvement, including shared contributor pools, communications platforms, and evaluation tools.
- Amplify what is already working by **investing in leadership, learning, and visibility** for PPIE across partners.
- Strengthen **governance, accountability and monitoring** to ensure public voices are embedded not only in research delivery but in strategic decision-making.

PPIE across CUHP members is grounded in values – equity, trust, and collaboration. This report highlights a clear opportunity to align these values with action: by enabling more joined-up, inclusive, and impactful public involvement, CUHP members can lead the way in shaping health research and innovation that truly serves its communities.

Draft CUHP Members' Commitment to PPIE

The commitment below is based on the findings of this project, and commended to the CUHP Board for consideration.

As partners in health, research, and innovation, we believe that **research is better when it is shaped by the people it serves**. Public involvement and engagement are a vital part of designing inclusive, relevant, and impactful research and service transformation.

Ambition

Together, we commit to the following shared ambition:

To build a culture in which patient and public involvement and engagement is visible, valued, and embedded at every level of our organisations - driving equity, excellence, and trust in research and innovation.

Principles

Our shared approach is based on the following principles:

- **With, not for:** Involvement is done with people, not to them or for them. It values lived experience as a form of expertise.
- **Inclusive by design:** Involvement opportunities are accessible, diverse, and actively reach people who are underserved or underrepresented.
- **A core value:** PPIE is part of how we do things. It is embedded in the life cycle of research projects, services, and systems.
- **Supported:** People involved in PPIE receive the support, training, recognition, and feedback they need to take part meaningfully.
- **Collaborative and transparent:** We share learning, evaluate impact, and build trust by being open about how public input shapes outcomes.

Our commitment

To achieve this, we commit to:

- **Investing in infrastructure and leadership** for PPIE, including appropriate support systems and governance.
- **Strengthening diversity and accessibility** by identifying and removing practical, cultural, and systemic barriers to involvement.
- **Creating learning environments** for researchers, staff and contributors, and supporting peer-to-peer knowledge exchange.
- **Working collaboratively** across the CUHP members to share learning, resources, improve how we share impact, and champion good practice.

This ambition is rooted in our shared belief that meaningful involvement makes our research stronger, our services fairer, our communities more connected, and our impact more meaningful.

1. Introduction

1.1 Background

Cambridge University Health Partners brings together two universities and three NHS Foundation Trusts in research collaboration: Anglia Ruskin University, the University of Cambridge, Royal Papworth Hospital NHS FT, Cambridge and Peterborough NHS FT and Cambridge University Hospitals NHS FT.

This work was commissioned to look across all partners to see how members are doing patient and public involvement and engagement (PPIE) in research and innovation, where we are doing it well, and what gaps exist - with a focus on case studies that illustrate the work that is being undertaken.

This project has been structured around the UK Standards for Public Involvement in Research¹ by the National Institute for Health and Care Research (NIHR).

Independent engagement consultants from Better Decisions Together were commissioned to carry out this work.

1.2 Scope

This project did not look at PPIE across all organisational activities, but focused on PPIE in research and innovation. This helps us to look at work that is relevant to NIHR PPIE Standards, but exclude wider public involvement areas, such as the extensive work undertaken by Foundation Trusts with their membership, or ongoing service improvement work.

How we've used the terms engagement, participation and involvement

In health and care research, the terms participation, involvement and engagement can carry distinct meanings depending on the context. However, in this report, we have generally used these terms interchangeably to refer to the public's role in research. We rely on context to clarify the intended meaning in each case.

Throughout the report, we use the abbreviation "PPIE" to stand for Patient and Public Involvement and Engagement, encompassing the various forms of engagement, involvement, and participation.

1.3 Method

We carried out interviews about PPIE with 20 key PPIE professionals and lay contributors across the members. These were in the form of structured conversations. We also distributed a simple questionnaire with key questions to individuals who wanted to contribute or were unable to attend interviews. Six were completed. We spoke to people from all five member organisations plus ancillary bodies.

¹ The UK Standards for Public Involvement in Research can be found at: <https://sites.google.com/nihr.ac.uk/pi-standards/home>

These interviews were analysed and this report summarises the findings.

We have included quotes from these interviews to illustrate the findings. These are largely presented verbatim but may be edited for grammatical coherence, succinctness, or to anonymise contributions.



Highlighted initiatives

Innovative or 'stand-out' initiatives are highlighted with stars.



Case studies

This report features good practice examples in blocks such as this. More details about this good practice can be found in the accompanying Case Studies document.

2. Shared understanding: Values and vision

2.1 What is the shared understanding of PPIE across members?

At the outset, we asked interviewees how they defined PPIE in their organisation. Interviewees used several different definitions of PPIE, as well as referring to coproduction. Some members had their own organisational definitions.

Initiatives or organisations that are funded by NIHR generally adopt the NIHR definition; **the most common definition was that used by the NIHR**. Different definitions were sometimes needed for differently funded workstreams. Some of the definitions mentioned are below.

Source	Definition
NIHR definition	NIHR defines public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. It is an active partnership between patients, carers and members of the public with researchers that influences and shapes research.
National Coordinating Centre for Public Engagement	Public engagement describes the myriad of ways in which the activity and benefits of higher education and research can be shared with the public. Engagement is by definition a two-way process, involving interaction and listening, with the goal of generating mutual benefit.
Wellcome definition	Engaged research means embedding stakeholder perspectives across the research lifecycle - from agenda setting, funding, and research design through to implementation, monitoring, and evaluation.
The Coalition for Personalised Care	(Coproduction) A way of working that involves people who use health and care services, carers and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation.
International Collaboration For Participatory Research	The research process, in its entirety, is a partnership between stakeholders with different backgrounds and perspectives, such as researchers, professionals, community members, policy makers, and others. (Participatory Health Research paradigm)

While not every member organisation has a formal, published definition of PPIE, most reflect core values. There is a strong emphasis on working *with* people, rather than conducting research *on* or *about* people. The language used may differ between

institutions, but the **core values of partnership, inclusion and lived experience** are reflected in understanding of what PPIE means.

2.2 Our shared understanding of PPIE: Take-aways

Members have different definitions according to their own organisation's cultural emphasis on engagement, participation and involvement, and their role in the research ecosystem.

A number of respondents noted that the boundaries between **involvement, engagement, and participation** often blur in day-to-day work. While formal definitions exist, many practitioners use "PPIE" as an umbrella term to describe collaborative work with patients, service users, and the public.

Where definitions are missing, unclear, or not widely understood, there is a risk of misunderstanding or inconsistency. When considering PPIE in the context of CUHP members, the NIHR definition is probably the most appropriate one to use, particularly as this is the main standard used by research funders.

More significantly, there is a real opportunity here to develop an **ambition statement** across CUHP. Such a definition could build on existing frameworks, while reflecting the collaborative, lived experience-led commitment that is already embedded in much of the work. It would also help improve clarity, consistency, and the ability to work across institutional boundaries more effectively, and be a clear commitment from CUHP leadership to progressing PPIE.

Ideas for next steps

Practical next steps could include:

- **Developing and adopting a CUHP-wide ambition statement for PPIE**, building on existing values of inclusion, partnership, and lived experience, and aligning with the NIHR definition. (A draft ambition statement is included in this report.)
- **Co-creating a shared definition or glossary of terms** (e.g. involvement, engagement, participation, co-production) to support clarity and consistency across partners and to help public contributors understand the terms used.
- **Incorporating the shared values and definitions** into induction and training materials for researchers, staff, and contributors to ensure alignment in language and purpose.
- Using the shared understanding as a foundation for **strategic planning**, supporting collaboration across organisational boundaries while respecting local differences in approach. For example, key annual business strategies and dashboards could reference and reflect PPIE as a business priority.

3. Why we do it and where are we going: Mission

Having considered what we mean by PPIE, we considered the question 'Why do we do it?' We explored this through the strategies that members are using to articulate the purpose of their PPIE work.

3.1 Members' engagement strategies

Due to the structures of the different bodies that sit under the governance of the CUHP members, there are a number of different strategies and approaches in the system. (These strategies also have overlapping periods, so not all 'renew' at the same time.)

Some members have **standalone** PPIE Strategies or Patient Engagement Strategies, others have **PPIE included** as part of wider Research and Innovation Strategies, or Research and Development Strategies. Some bodies have joint strategies. Some referred to a **PPIE framework**, rather than a formal strategy.

Some strategies had been developed with patients, for example through lay panels or workshops. Some were also developed with partners.

"Our strategy was coproduced with stakeholders. Towards the end of the drafting we sat down with colleagues [...] and said this is where we think our PPI strategy fits in with yours: could you also show it to your groups and have a discussion?"

In terms of the **standards** used in the strategic approach, most referred to the NIHR Standards, although the Working in Partnership with People and Communities Standards² were also used. Interviewees also mentioned **organisational priorities** of inclusive research and reaching under-served communities.

Each of these strategies varies according to the priorities of the individual organisations and their commissioners or funders, but every organisation was able to identify their PPIE strategic priorities.

3.2 Where are we going? Key take-aways

As each organisation has its own separate priorities, **alignment of strategies wouldn't be realistic or appropriate**: each member's purpose is very different. However, again, a shared commitment could be useful in creating broader strategic alignment across member organisations, which could be used as a structure for considering future PPIE strategic approaches. Some areas, for example, have shared involvement priorities (based on local community need or gaps) that are worked towards on an annual basis.

² Working in partnership with people and communities: statutory guidance (NHS England) at <https://www.england.nhs.uk/publication/working-in-partnership-with-people-and-communities-statutory-guidance/>

The anticipated 10 Year Health Plan or the three shifts (Hospital to Community, Analogue to Digital and Treatment to Prevention) were not mentioned by participants: it is likely that these are being incorporated into the latest strategy revisions but it is worth giving these themes particularly consideration in relation to PPIE approaches.

Ideas for next steps

The suggested next steps already mentioned would help to make the strategic approach more robust across members. Other practical next steps could include:

- **PPIE Forum** to build on current approach, identifying **individual key strengths, priorities** and areas of overlap, potential collaboration, and shared goals.
- **Facilitating regular system updates** on evolving health and research priorities to align PPIE approaches with wider system changes. This could be incorporated as an item on a standing PPIE network agenda and could provide a space to consider, for example, what the 10-Year Health Plan might mean for PPIE work.
- **Supporting partners to understand up-to-date local data** to identify common gaps, for example around underserved communities.

4. What does it look like: Where are we now?

In considering 'Where are we now?' or 'What does our PPIE work look like?', we explored what frameworks are being used to help support PPIE work, what work people are most proud of, the inclusive opportunities that are available, and how public voices are heard in decision-making. This section also explores the current challenges in PPIE work.

4.1 Frameworks used

The framework most often referenced was the **NIHR Standards** (or the 'Involve Standards') which have an established role in setting benchmarks and a structure for PPIE (and are often a prerequisites of funders in the research and innovation space).

Alternative frameworks used include **Working in partnership with people and communities**³ (the standard for NHS Foundation Trusts and ICBs), alongside various **participatory research and coproduction models** that are more commonly used in academic areas. Respondents described how their organisations adapt broader participatory research concepts to ensure that the public not only contributes to shaping research questions and processes but also to evaluating outcomes.

While these standardised frameworks are commonly used as a guide, they are used flexibly to create more inclusive, effective, and context-sensitive PPIE practices.

4.2 What are we proud of?

Interviewees were asked what they were most proud of in the PPIE work that they are doing, to help us understand 'where we are now.'

Several themes emerged, but the main one was that of **a strong sense of pride in the cultural shift** that is taking place around PPIE, and the feeling of a journey that is slowly improving the way PPIE is both perceived and practiced across the research spectrum.

Interviewees felt that PPIE has moved from being seen as an optional add-on (or 'tick box') or merely a funding requirement to **a core value** that is becoming embedded in organisational practice and culture. People felt that they had seen a **mindset shift** among researchers, with increasing numbers initiating PPIE activities not because they are required to, but because they believe it is the right thing to do.

"There's a cultural awakening. Increasingly researchers will come to me and they'll say, 'I'd like to do some PPI' and I'll ask if it is for a funding proposal, and they say, 'No, I'm already funded: I just think it's the right thing to do.'"

³ Working in partnership with people and communities: statutory guidance (NHS England) at <https://www.england.nhs.uk/publication/working-in-partnership-with-people-and-communities-statutory-guidance/>

Structures and processes to support PPIE have been developed, not just in individual organisations but also across members and across the wider health and social care landscape (and beyond!). For example, the ICB's PPIE Network includes health, social care, research, education and even museum professionals whose remit includes public engagement. Linking people and teams was seen as a vital part of making PPIE effective.

Inclusion and representation are also a source of pride for many, and interviewees felt that they had made positive progress in reaching underrepresented groups, including carers, young people, and communities such as Gypsy and Traveller populations. There was a feeling of accomplishment in having had “boots-on-the-ground,” involving direct engagement with communities and the opportunity to build relationships and hear from people with lived experience. There was a clear sense of pride in helping to amplify voices that are often left out of research conversations.

The importance of **relationships and trust-building** was a recurring theme. Contributors spoke about the resources and time it takes to develop meaningful connections with community partners and lay advisers, and the value of those relationships in shaping more inclusive and grounded research.



Patients as Research Ambassadors

Royal Papworth Hospital NHS Foundation Trust has recruited and trained a group of Patient Research Ambassadors who provide real-time public insight into research projects, advising on study design, reviewing materials, and speaking at events to champion public involvement.



Another source of pride was the **impact of PPIE on research and services**. Public involvement has led to changes in study design, improvements in communication materials, and service delivery.

The contributions of **public contributors were described as eye-opening**, often challenging professionals and researchers to think differently and make their work more accessible and meaningful.

Overall, although there was acknowledgement that the work can be hard at times, there was a feeling of pride in being part of a growing momentum that is changing how research is done - and who gets to be part of it.

“We’ve developed a culture that the public voice has to be heard – not only in health related research but wider. A culture of how important our civic commitment is, and enabling members of the public to make research useful and to have an impact.”



Designing with children, not just for them

Cambridge University Hospitals and Cambridgeshire and Peterborough NHS Foundation Trusts worked with local schools and families to involve children directly in designing the new Cambridge Children’s Hospital.

Art packs were distributed to schools and homes, inviting children to express how they wanted the hospital to feel. These creative contributions were combined with feedback from workshops and used by the project team to shape the hospital’s look, atmosphere and integrated care approach. This case shows how creative, early-stage involvement can bring young voices into healthcare design in ways that are both joyful and influential.



4.3 Working to ensuring diverse and accessible participation

Many respondents emphasized the importance of personal, **ongoing relationships** when trying to reach underserved communities. Rather than one-off consultations, some teams are taking a **“boots on the ground” approach** - attending community events, visiting faith groups, and engaging directly with people in familiar, trusted spaces. One example described attending “golden age fairs” and delivering personalised follow-up letters from researchers to people who had expressed an interest in knowing more, which were signed and including photos, to build rapport and trust.



Beyond the research project: Building relationships

One organisation has built a long-term relationship over several years with a local Asian women’s group, continuing to build engagement between formal research projects. This kind of continuity helps bridge the gaps that often emerge when short-term projects end, and makes people feel valued for more than what they can bring to a project.



Many responses reflected the value of **partnering with voluntary, community, and social enterprise (VCSE) groups**, charities, and local councils. These partnerships often serve as 'cultural brokers', opening doors to communities that may otherwise be wary of engaging with research. For example, one contributor described how building a relationship with a Gypsy and Traveller support worker has helped them gain regular insight from a group historically excluded from research. Another example cited using community leaders or influencers to build trust in communities that are cautious about data use or sceptical of health research due to historical exclusion.

"What's needed [to ensure diverse participation] is shoe leather: we've gone out to organisations, faith groups, disability groups, ethnic groups, migrant worker groups - most of whom have never been specifically invited before to talk about access to healthcare. This has led to a huge network of 100 people".

Building trust through faith-placed engagement

Cambridge University Hospitals NHS Foundation Trust worked with the British Islamic Medical Association and Muslim community leaders in Luton and Peterborough to co-design and deliver bowel screening awareness sessions in local mosques. These sessions were adapted to be culturally thoughtful and relevant, and led by local Muslim clinicians, creating a trusted space to talk about health. The project helped increase understanding of screening and demonstrated how partnerships with faith groups can reduce health inequalities and improve awareness for communities that may be underserved by traditional research and public health approaches.



Several teams noted the importance of creating **communications** outreach materials that are relevant and welcoming. This includes using imagery and language that reflect the community's own voice, for example creating bilingual banners or recruiting at local cultural events rather than relying on institutional or NHS branding, which may not necessarily be seen as a 'trusted brand.' Using patients as 'recruiters' through their own networks was also mentioned.

Shaping research around lived experience



Anglia Ruskin University partnered with veterans to co-design focus groups exploring experiences of chronic pain. Veterans shaped the research questions, helped lead the sessions, and ensured the study reflected familiar language and concerns. This involvement helped researchers build trust with a group often underserved in health research, and generated insights that would not have emerged through traditional academic approaches alone.



Innovations in inclusion work

New approaches to inclusion work are happening in large-scale ways as well as more ongoing, embedded work.

Some organisations are using **alternative formats** (such as Easy Read materials or videos) to increase accessibility, especially for people with learning disabilities. Many interviewees noted that public participants tend to skew towards “white, retired, and middle-class”, some organisations are actively working to diversify their panels by recruiting through science fairs, youth groups, housing organisations, and job centres.

In one case, a researcher described working with a South Asian contributor who was “research-naïve” but offered direct, honest feedback that helped improve slides and messaging. These kinds of contributors often bring quick-win perspectives that are missed when panels are homogenous or ‘professionalised’ public contributors.



The Patient Led Research Hub

The Patient Led Research Hub was established in 2015 and is leading research that originates with patients and patient groups, particularly in rare diseases. Patients and families with experience of rare diseases can submit ideas for research studies. Once an idea is put forward, work is done to develop an understanding of the research question and why it is an unmet need. Where there is a new research need, a multi-stakeholder team is put together, matching the patient group with researchers, so that funding can be applied for.

Connecting patients with researchers



The University of Cambridge's Patient Led Research Hub supports patients and charities affected by rare diseases to propose their own research ideas, helping them develop study proposals, partner with researchers, and secure funding - with over 80 ideas supported since it was established.



All organisations have dedicated PPIE roles, and some now have backed up their commitment to inclusion with **dedicated EDI staff roles** with a focus on equality, diversity and inclusion. Other resources include funding for inclusive engagement (e.g. translation services and community outreach costs).

Despite best intentions regarding inclusion, many respondents acknowledged **ongoing challenges**. Time, staffing, funding, and NHS bureaucracy were common barriers. One respondent noted that even when they do reach out to communities (e.g. community champions for a study), by the time relationships are built, the study may already have closed recruitment. Above all, while the intention is there, resource needs to follow.

“Inclusion is really, really important. But the funding and the capacity is absolutely not in place to move from a one-size-fits-all system - where we were struggling anyway with capacity and funding - to what does it even look like to personalise research for everyone.”

Others mentioned that participation often skews to people with the time and privilege to be involved, despite efforts to diversify. Concerns were also expressed about over-reliance on the same contributors, or about contributors joining primarily for financial compensation, leading to questions about authenticity.

4.4 How are we ensuring public voices in decision-making?

There is a lot of thoughtful work being done to bring public voices into the decision-making process, but this varies across organisations. Several contributors acknowledged that while public input is invited, the power to decide still often sits with researchers, institutions or funders. However, the more embedded the involvement is from the start - and the more researchers see its value - the more public voices influence the outcome.

Public input is being embedded into research design

People shared how involving public contributors early in the research process - at the “blank page” stage - enabled shaping the design of research. Public contributors are asked to help shape research questions, influence trial protocols, and co-design patient materials. This not only ensures the research is more relevant and accessible but also helps identify issues that might otherwise be missed by researchers.

“I was reading some patient research information and a professor had written that a risk of this trial was death. I said, as soon as I see that I stopped reading! I said do you want to put that last? And they listened to me.” (Patient)

One respondent shared how their public panel meets regularly to review proposals and provide feedback at early stages, with some members even becoming co-applicants on grant bids. Examples were also given of steering groups and advisory panels who review research at an early stage.



Embedding the public voice in national research oversight

The NIHR BioResource supports a National Participant Advisory Group made up of public contributors who review study proposals and policies, providing input on consent processes, recruitment approaches, and participant experience for research projects that want to use the national BioResource. This model shows how involvement can be embedded in the governance of large-scale research infrastructure.



Participatory Research Support Fund

Innovative early PPIE is also being supported by organisations. For example, the University of Cambridge has established a **Participatory Research Support Fund** to support PPIE at the proposal stage of research.

Standing panels and advisory groups are established

Many organisations have **established regular panels**, public involvement groups and mailing lists, or lay advisory boards that researchers can consult at different points. Some contributors also sit on steering groups and similar governance bodies, where they directly shape the direction of programmes or strategies.

Other examples given included individual project contributors being part of tissue bank meetings, working groups for a new hospital build, or as a core researcher on a project team - spaces that may not have included lay voices.



'We hadn't thought of that!' Patient voices in new hospital design

Cambridge University Hospitals NHS Foundation Trust is involving a Patient Advisory Group in every stage of designing its new Cancer Research Hospital, ensuring that decisions about space, services, and digital tools reflect real patient experience.



A key element of building effective public contributors is consistency: members build relationships with staff and organisations, and get to know the health, social care and research landscape which builds their confidence and skills to enable meaningful contributions over time.

Anglia Ruskin University has an initiative called 'Let's Shape Research Together', a growing panel of public collaborators who work with researchers at the early stages of research design.

"What I personally get out of it is I learn more about the National Health. I learn about how research starts and end. I've learned so much that it empowers me to talk to other people." (Patient ambassador)

Professional ownership of PPIE agenda

In some settings, public input is embedded into formal governance pathways through professional champion roles. For example, one organisation has a management executive group that includes public oversight via a non-executive director who champions PPIE. Having staff 'PPI Champions' embedded into organisations was also highlighted as a good example.



Squeaky wheels: PPIE Staff Champions

The Cambridge Biomedical Research Centre embedded public involvement into its research themes by appointing senior staff as PPI Champions, who raise the profile of involvement through acting as 'squeaky wheels', reminding about involvement at all stages, act as local leads, and meet to drive strategic improvements.



Closing the feedback loop

Several respondents noted the importance of showing contributors how their input was used. In practice, this isn't always done well, but some teams are taking care to build this in, through updates, reflections, or post-project feedback. One organisation described a reflective approach where PPIE staff track public contributions over the life of a project and document what changes resulted, as part of their annual reporting.

4.5 What are the main challenges in PPIE work?

While everyone recognises the value of doing it well, there are systemic, cultural, and practical barriers that persist in ensuring that PPIE is done well. The word 'frustration' was often mentioned.

Time, capacity, and burnout were flagged as a core issue by nearly all PPIE professionals. People spoke of trying to do core PPIE or strategic work while being overwhelmed by admin, meetings, and the sheer volume of projects needing input.

Having to be an **'expert' in almost all key areas** (e.g. finance, HR, safeguarding, corporate structures, admin) on top of PPIE expertise was cited as a cause of stress

and unnecessary sapping of time. The volume of meetings was also cited as a blocker – making it difficult to work collaboratively because other colleagues were unavailable for days at a time.

“If I got a new employee in my team, the organisation wouldn’t expect me to be in charge of HR, finance and legal. And yet in PPI, because it’s always been this really grey world, it just gets left to PPI leads to sort everything out.”

Inconsistent processes and hold-ups were a key area of frustration: several people described difficulties arranging payments for public contributors, both in terms of inconsistent practice and in ensuring that people are paid on time. Even within the same organisation, practice was often variable depending on the project.

One public group left a research project following an 18-month delay in formalising the contract to start the project.

“Even trying to pay people is a headache... vouchers? Payroll? Nobody knows who’s responsible.”

The challenge of ensuring diversity in a time-pressed culture was cited as a barrier to meaningful inclusion: as one person said: “We hear ‘at pace’ all the time.” There’s widespread awareness that current involvement often fails to reflect the full diversity of the communities served. Challenges include engaging people with less time, privilege, or health literacy. There was a consciousness of an over-reliance on the same contributors (often white, middle-class, retired). People were aware of the significant barriers of people around language and digital barriers.

The culture of research that prioritises speed, competition, and outputs doesn’t always align with inclusive, lay-centred work. Short timescales (particularly to satisfy funders) are a barrier to diverse participation—another reason why PPIE needs to be carefully planned with an appropriate lead-in, to enable early conversations with key community groups, rather than repeatedly turning to the same individuals or networks, even if they are experienced and willing.

“By the time we build relationships with communities, the study is already full.”

One gap was that of **involving young people**: this was noted as a particularly tricky group to engage with. However, there are researchers within the membership organisations who are doing some outstanding work in this space: for example, Anglia Ruskin carried out participatory research involving young care leavers, supported by researchers, who helped design research questions and surveys and design and shape the final research report outputs.



Young people as co-researchers

Anglia Ruskin University worked with 25 care leavers as co-researchers to study support during the pandemic, producing a film and flipbook to share their findings and creating a promise for social workers to commit to practice changes based on young people's recommendations.



The challenges of a “tick-box” culture were raised as another issue: despite strides towards culture-change, some researchers still see PPIE as a requirement rather than a valuable process. This creates a risk of superficial involvement and undermines trust. It also affects morale both for contributors who don't get feedback or feel their time was wasted, and for PPIE staff who may undertake a significant amount of relationship-building to lay the foundations for positive diverse contributions.

“Researchers that say: ‘I’m the expert - why would I ask someone on the street what they think?’”

Another frustration was the **failure to close the loop** with public contributors, and to let them know exactly what changed as a result of their input. This not only risks damaging relationships, but also misses the chance to build learning.

“My biggest frustration is when it sits on a shelf: what is the point? The challenge is making sure that something happens as a result of research.”

Evaluating PPIE is messy and difficult and even committed teams struggle to evaluate PPIE meaningfully. There's a desire to show impact, but it's very hard to trace a direct line from involvement to change, and evaluation often gets left until the end - or isn't funded at all.

“We still struggle to explain the ‘so what.’”

Another challenge mentioned was that of **fraudulent or ungentle involvement**. This is a fairly new challenge across the involvement world, and happens where lay people or participants take part in research or involvement activities, usually when a financial incentive is offered, but are not genuine. Particularly where virtual participation is offered, these participants may present themselves as local people with relevant health conditions or experience, but could be ‘dialling in’ from anywhere in the world and using AI to respond to questions with standardised responses. This is a new and developing challenge in involvement and research and there are no simple solutions to the problem.

4.6 Where are we now? Key take-aways

There is clear pride among members in the **cultural shift** that's underway: PPIE is evolving into a more values-driven, embedded part of research and innovation culture. What was once seen as an optional or compliance-driven task is now increasingly recognised as a core principle of good research.

While organisations draw on a **range of frameworks** - most commonly the NIHR Standards - these are being used flexibly, shaped by local needs and organisational priorities.

There's a huge awareness of the importance of inclusion, but a recognition that **genuine diversity** remains elusive in many cases, and that fast-paced research environments often struggle to accommodate the depth of engagement that's needed, because ultimately this is always based on trust and relationships, which take time – and “shoe-leather” - to build.

Involving the public in **decision-making** at different states of the research life-cycle is growing, with some contributors shaping research at the earliest stages or even co-authoring bids. Innovative local grant-funding approaches are supporting this work further, which is enormously positive.

While the commitment to PPIE is clear, so too are the **ongoing challenges**: limited capacity, inconsistent processes, and concerns around ungentle involvement. Nonetheless, the field is evolving, driven by a sense of purpose and a belief that involving people meaningfully is not just good practice, but a core value.

Ideas for next steps

Building on the next steps from previous sections, additional ideas could include:

- **Raising awareness and building on the Cambridgeshire and Peterborough Engagement Insight Library** to improve sharing and showcasing work and frameworks used by members.
- **Taking stock of existing tools for inclusive communication** - such as plain language templates and translated materials - and raising awareness of what's already available (e.g. Easy Read research leaflets) to reduce duplication. The PPIE Network could focus on this topic for a workshop or meeting session, to consider what standards are applicable to each organisation (e.g. Accessible Information Standard for the NHS) and to share learning and resources.
- **Piloting a 'diversity audit' tool** that helps teams review the representativeness of their contributors and adjust outreach strategies accordingly.
- **Creating a peer learning programme** (for example, 'open' PPIE network meetings once a quarter) to help professionals reflect on common challenges like over-reliance on the same contributors, capacity barriers and working 'at pace', and new challenges such as fraudulent contributors.

5. Working together

Collaboration was a big theme across our conversations, and it is clear that there's a strong appetite to work together, the reality is that it's happening in pockets, with plenty of room to grow.

There are many examples of positive partnership working at an organisational levels, and the complex organisational structure of the partners is supporting an extensive network of research collaboratives and initiatives. However, the underlying structures that enable PPIE are not always as well supported.

5.1 How are members working together to progress PPIE?

Networks and peer support are valued

Many involvement professionals are connecting through PPIE peer support networks.

The **PPIE Forum hosted by** CUHP was mentioned as a new space where people valued getting together and sharing good practice. **Involvement can be isolating**, and many noted that the emotional and practical labour of the job makes it even more important to have peer support. People value the chance to “just have a chat” with others doing similar work.

Some organisations run “share the learning” slots in PPIE meetings or regular reflective sessions to swap ideas, discuss ethics, or troubleshoot sticky involvement issues.

The PPIE Network in Cambridgeshire and Peterborough (hosted by the ICB) was mentioned as a space that brings together NHS, university, VCSE, and local authority colleagues to share tools and good practice, avoid duplication, learn from each other.

Other PPIE networks include a **network for cancer**, connecting groups across the University of Cambridge, NHS East of England, and service delivery networks. This created a single entry point for public contributors and is improving consistency around things like payment and communication.

Formal collaboration is developing

However, there was a strong feeling that **more collaboration is needed** and wanted by PPIE staff, to reduce duplication and to understand the current projects and areas of strength for individuals and individual organisations. Some respondents said collaboration happens, but it's not centrally coordinated or is reliant on individual or voluntary efforts.

Collaborative efforts such as the **comms campaign “Love Research” were promising** but overall awareness was poor and a lack of evaluation of follow-up communications meant that it was hard to tell how effective the campaign had really been.

Cross-organisation PPIE weeks and shared campaigns were really valued, and shared presence at events or partnership communications were felt to be enormously helpful and a source of pride.



The Cambridge Festival: celebrating public engagement

At the annual Cambridge Festival, researchers from the University of Cambridge and partner organisations showcase research for the local community, using interactive formats to invite public questions, comments and learning. Public engagement activities include stalls, workshops and open dialogue events that help researchers understand what matters to local communities. This highlights how working together to showcase research can foster meaningful two-way conversations and make research more visible and relevant.



Barriers to collaboration

One challenge that was raised was that the organisations are complex and **lines of management and communication** across PPIE professionals and teams are difficult to navigate. Information cannot be easily disseminated to PPIE people in the same way as other communication messaging, because of this complexity and lack of a 'single point of entry' into PPIE structures. This can be particularly tricky when external networks and organisations want to spread messages or raise awareness of support and funding that is available, but are largely relying on word of mouth.

"I think it would be really good to do projects together. I could drop people a line to say 'I'm going to be doing this – do you want to come with me?' I'm all for making tables longer."

The lack of clear lines of PPIE management (with accompanying subject matter expertise) also results in PPIE professionals having to resolve issues 'between themselves' rather than having a clear management structure in each organisation with expert advisory capabilities. While this may not be unusual in specialist fields, it can lead to key individuals becoming the default point of contact for all PPIE-related enquiries across organisations, increasing their workload and pressure.

Time, capacity, and structure came up again and again as barriers. Without formal roles or funding, much of the collaboration is voluntary or depends on someone going "above and beyond." Research timelines, fragmented systems, the slow pace of NHS progress, and overlapping governance make it hard to coordinate involvement consistently. Some respondents worried about duplication causing

“consultation fatigue” in communities who are approached multiple times by unconnected teams.

“The NHS lack of agility: the complexity of the structures in the NHS are a barrier to getting things done. Small organisations are so nimble, but in the NHS it’s harder to do.”

Shared resources and infrastructure

There's a definite enthusiasm to work more collaboratively - especially to reduce overburdening of contributors, reach underserved groups more effectively, pool skills resources and celebrate and showcase shared impact. But respondents were clear that this needs dedicated leadership, clearer structures, and more resources.

Some contributors made suggestions about shared resources, such as:

- A central pool or “big black book” of PPIE experts who could support projects across multiple organisations.
- A skills bank that showcases the skills or areas of expertise of local PPIE professionals.
- Shared platforms for promoting involvement opportunities.
- Coordinated evaluations or communications strategies.

“We always use the same [lay] people... but other organisation’s panels might have someone who fits better.”

Cambridgeshire and Peterborough Engagement Insight Library

The local Integrated Care Board or ICB is a core partner in research and innovation working with CUHP members, and has a responsibility as a convener for PPIE across the local area. The ICB has its own **network and online resource** that would help progress some of these ambitions, the Cambridgeshire and Peterborough Engagement Insight Library.

The Cambridgeshire and Peterborough Engagement Insight Library is hosted on the NHS Futures Platform and is accessible to PPIE professionals in the local area. It comprises a database, contacts, projects, library and a calendar, including a live project mapping tracker.

The platform is a practical tool that helps coordinate information between a network of around 130 PPIE specialists across the county, including from the NHS, the local authority, research, universities, VCSE and even local museums. **This would be a valuable resource for CUHP members.**

This network meets every six weeks with a theme for each meeting. There are sub-groups that meet to look at specific areas: one is currently looking at developing a reward and recognition approach.

5.2 Working together: What more can be done?

Ad hoc networking and peer learning and peer support/reflective practice are working relatively well - these informal connections are keeping things moving.

We asked respondents what more could be done to improve PPIE across members. All respondents felt that there were areas for improvement. Formal collaborations are starting to happen, but still need more structure, resources, and coordination to really thrive.

To improve collaborative working in involvement across organisations, respondents suggested a mix of practical enablers, structural changes, and cultural shifts.

Define and clarify shared purpose

Many people mentioned uncertainty around what CUHP means in terms of PPIE, who the members are, and what sort of leadership it can provide. To collaborate meaningfully, there needs to be a shared vision and agreed goals. This includes:

- Sharing a joint definition of PPIE.
- Clarifying why collaboration matters and what success looks like.
- Agreeing on principles for working together (e.g. mutual respect, inclusion, shared credit).

Develop shared infrastructure and resources

Collaboration can't just be goodwill - it needs tools, people, and processes. Respondents suggested a central contact directory, a shared calendar of engagement activity and shared templates and reports. These are currently being developed by the ICB on the NHS Futures platform ('Cambridge and Peterborough Engagement Insight Library') and this resource has the potential to meet many of these ambitions.

"Having some kind of pooled resource in terms of marketing, evaluating, reporting, etc. – a pooled resource where we could say 'Can you promote this on our behalf?'."

A centralised pool of both lay advisers and PPIE Professionals who can be matched to projects across partners was also suggested, alongside more coordinated communications support. "Shadowing" or job swaps between PPIE professionals was also suggested.

Build on cross-partner training and development

PPIE staff, researchers, and contributors often work in silos. Shared training helps align language, standards, and expectations. Ideas include joint training sessions for professionals, standardised training for public contributors and working across partners to train both professionals and lay contributors. While training programmes are already happening across members, any ambition to further roll this out should

be accompanied by additional investment to ensure that pressures on existing workloads are not increased.

Consider governance and monitoring

A lack of guidance around frameworks and standards is, in some cases, making evaluation a grey area for some PPIE work. Conversations could be had between PPIE professionals about what frameworks would be helpful in providing a simple structure for evaluating PPIE activity between members. It should be noted that organisations will necessarily be using different frameworks (e.g. People and Communities vs. NIHR Standards) but sharing practice around this may be a useful starting point for measuring impact and developing a collective story of involvement across the region.

This could be done in manageable stages, for example, all members agreeing a 'theme' or themes from a framework for focus in a year. This could also help amplify and coordinate the collective voice of PPIE across member organisations.

“Having a shared criteria or acknowledgement by CUHP that all of our partners are working in line with the NIHR Standards – that would say something.”

Resource ambitions

There was a keen interest in seeing the leadership state PPIE as a strategic priority, and for that to be followed up with resources and accountability. Interviewees clearly felt that lack of time, staff, and funding were blockers to achieving and collaborating more. Staff were very committed to PPIE, and it was clear that many were working above and beyond to keep things on track.

“If we had more funding, we could conquer the world.”

5.3 Working together: Key take-aways

There's a **clear appetite for collaboration**, with people recognising the benefits of working together to share learning, avoid duplication, and strengthen impact – and support each other in what can be tough and lonely roles.

Peer networks and informal connections - such as the CUHP PPIE Forum and local NHS and research networks - have been especially valued for offering spaces to meet and talk. These **relationships are helping to keep momentum going**, even when formal structures are lacking.

Despite this enthusiasm, collaboration is still happening in silos and relies heavily on voluntary effort. Time, funding, and structural complexity - especially within large systems like the NHS - remain significant barriers.

Respondents highlighted the need for shared infrastructure - such as centralised directories, skills banks, and consistent communication platforms - to help reduce

duplication and improve inclusion. Resources like the Cambridge and Peterborough Engagement Insight Library are promising foundations. There was also strong support for joint training, evaluation frameworks, and cross-partner learning opportunities to align standards and amplify collective impact: but to do this, it was felt that clearer leadership was needed, alongside strategic investment.

Ideas for next steps

For this section, our conversations uncovered many suggestions about how working together could be improved. Some of these can be achieved by adopting some of the previous suggested next steps, so these are not repeated here.

Some practical next steps could include:

- **Developing a collaboration framework for PPIE**, clarifying shared goals, principles for working together, and opportunities for joint action across members.
- **Promoting and building on existing platforms**, such as the Cambridgeshire and Peterborough Engagement Insight Library, to coordinate activity and track current projects and contacts. Having a standard item agenda of 'activity in the next quarter' could also be useful for the PPIE Network.
- **Creating a centralised contact directory and skills bank**, enabling teams to connect with public contributors, professionals, and projects more efficiently across organisational boundaries. The Insights Library may work for this purpose.
- **Consider shared communications**, building on successful initiatives like the Cambridge Festival and "Love Research", shared communications may be helpful, for example, to publicise PPIE opportunities. This would also help celebrate shared work more visibly. (The practicalities of this would need to be carefully considered to ensure that no individual's existing workload is increased.)
- **Establishing regular cross-partner reflective spaces**, such as peer learning groups, shadowing opportunities, or joint problem-solving forums to reduce isolation and strengthen practice.
- **Offering shared training opportunities** for researchers, professionals and public contributors, including joint inductions, skills-building workshops, and co-delivered sessions on inclusive involvement.
- **Resourcing collaboration explicitly**, by identifying PPIE as a strategic priority and dedicating funding, time, and leadership capacity to support shared infrastructure, coordination, and innovation.

6. How do we know we are having an impact?

A key element of the NIHR standards is around making an impact, however, **evaluation emerges as a clear challenge** throughout our conversations. PPIE is always very hard (if not impossible!) to measure, and the challenge is increased with different organisations having differing requirements in terms of standards and frameworks. **But this doesn't mean that PPIE is not having an impact**, or that impact is not being recorded where possible.

This section explores how members identify the impact of PPIE and how governance structures help ensure alignment with strategic goals. It also examines the training and upskilling of both staff and contributors, supporting ongoing development and growth.

6.1 Measuring impact

Many teams are using the **NIHR Standards** not just as a guide to best practice, but as a way to reflect on the effectiveness of their involvement work. Rather than treating them as rigid metrics, organisations are using them to structure reviews and discussions.

Some respondents developed their own **checklists** loosely based on these standards. These tools are typically used to track contributor activity (such as reviewing documents, co-designing materials, or attending meetings), as well as to gather feedback from both contributors and researchers. The goal is to capture a rounded picture of involvement - not just whether it happened, or how many people were involved - but how it influenced the project.

"We've converted the NIHR INVOLVE Standards into a bespoke checklist, which is making it a lot easier to embed these best practice methods into our work. I've asked my individual PPIE groups to complete this survey to share their learnings."

Mixed-methods evaluations

Some teams are using mixed-methods evaluations - **combining qualitative and quantitative approaches**. These often include contributor and researcher surveys, reflective interviews or focus groups, and activity tracking (e.g. how many studies involved PPIE, how many documents were reviewed). One example mentioned the use of the [PIRIT Impact Tracker](#) - a tool that documents not only what was done, but what influence was intended, what changes happened, and how significant those changes were.

Case studies as impact evidence

Case studies allow teams to tell the story of how public voices shaped a project, using quotes, reflections, and real-life outcomes. These stories are often more **compelling and accessible** than raw data, and they're particularly powerful when

shared with funders, leadership teams, or new researchers learning about involvement.

Project-level tracking

Embedding PPIE evaluation throughout the project lifecycle was mentioned as an ambition, and flagged as something that **ideally would be included in research funding**. This approach recognises that impact evolves, and that involvement can look different at different stages. However, it was noted that this sort of evaluation approach isn't often planned at an early enough stage to design into funding proposals – but when it is, it can be really powerful.

Evaluation is often informal or under-developed

Despite the interest in evaluation, many respondents admitted that their current approaches are informal, ad hoc, or still in development. Others said they weren't sure what “counts” as meaningful evaluation, or they struggled to measure outcomes when PPIE had been deeply embedded across a wide range of activities. This is a fair reflection of the difficulty of measuring PPIE, which is not a simple task!

The direction of travel

The overall trajectory is positive: organisations are thinking more critically about **how to measure the difference PPIE makes**, and there's a clear appetite to improve evaluation practice – as well as to share this with the public. Teams are starting to look beyond activity counts (such as number of meetings attended, or number of people at a focus group) to focus on outcomes - like how involvement influences research relevance, funding success, or service design.

There's also growing interest in shared tools, cross-partner evaluation frameworks, and case study collections that help make the impact of PPIE more visible and more credible. This is a rich potential area for partners to discuss and progress together.

6.2 Governance: How is our strategic impact monitored?

Governance is particularly important in PPIE to ensure that strategic objectives are met and that the voice of the public is heard at all levels of our organisations. Good governance is not only essential for person-centred research and care but is also a key mechanism for ensuring public accountability.

Governance is variable

Governance and monitoring of PPIE were not major themes in the conversations. Where they were mentioned, **people tended to be unsure of existing arrangements**, or governance was often described in general or informal terms. In some cases, lines of accountability were unclear or tied to outdated structures that were no longer active. This lack of clarity suggests a potential area for improvement across member organisations, particularly in establishing transparent and consistent accountability frameworks.

Where governance was referenced, **it often relied on individual champions** such as a non-executive director (NED) with oversight, or a single staff member informally keeping things on track. While such roles are extremely valuable, relying on individuals limits systemic accountability. In one example, a respondent described how their involvement activity was reviewed by a management executive team every six months. However, examples like this were rare and not reflective of a consistent or embedded approach.

There's **little evidence of strategic governance or organisational accountability** for PPIE across organisations. This suggests that while involvement is happening, it's not always being formally monitored or integrated into institutional decision-making in a systematic way.

Annual reports were occasionally mentioned, but again, the approach appears inconsistent. There's little indication that organisations are using performance metrics or system-wide monitoring tools to track how involvement is being implemented, or to demonstrate accountability to the public and stakeholders.

Monitoring processes, where they exist, tend to be project-specific and **dependent on individual teams or researchers taking the initiative**. In some instances, monitoring is being driven by individual staff members who take it upon themselves to track activities and outcomes. For example, one person described maintaining personal records of involvement activities - like meeting attendance, number of documents reviewed, or informal feedback - so that they can reflect on their work when writing reports or evaluating impact.

Others mentioned **using the NIHR Standards as a framework for this kind of reflective practice**. However, these efforts appear largely self-directed rather than supported by broader organisational policies or approaches. While valuable, such approaches do not guarantee institutional accountability and risk becoming fragmented or inconsistent over time.

6.3 Support and learning

Support and learning embedded within research

A key element of support and learning lies in how it is embedded within the involvement work itself. Several case studies demonstrated that learning can be an intrinsic part of the involvement process, upskilling and empowering participants through access to expert knowledge or training. For example, Citizens' Juries incorporated intensive learning as a central component of their deliberative approach.



Exploring ethical questions through a deliberative approach

The University of Cambridge ran a Citizens' Jury to explore public views on genome editing, bringing together a diverse group of participants who were supported through learning and discussion to reach informed views. This model of deliberative involvement shows how – with the right support – the public can meaningfully contribute to complex ethical debates in science and health, and shape the direction of future policies and research.



How are we ensuring learning opportunities for professionals?

Across the conversations, it's clear that a great deal of PPIE training is available and taking place, and **in some places, being done really well**. However, not everyone knows what is available.



Biomedical Research Centre involvement training series

The **Biomedical Research Centre** runs a well-established and highly-spoken of training programme which includes practical sessions on setting up patient groups, embedding equity, and running co-production activities. There's even a full-day training that brings all these elements together, open to researchers across Cambridge.

"The NIHR BRC Cambridge PPI course series has been really helpful to us in leading a PPI group."

Other organisations described **bespoke training** for their internal teams - focused on understanding the principles of PPIE, managing relationships with public contributors, and working inclusively. However, while these examples highlight good practice, they also show how uneven training provision is across the system. Whether someone receives training often depends on where they work, who they report to, and whether their team has capacity or funding to prioritise learning.

Learning is mostly internal

A key theme that emerges is that learning tends to happen **within organisations**, not always across them. This could potentially create duplication of effort and missed opportunities to learn from others facing similar challenges.

Several contributors highlighted a lack of consistency between partners, and called for shared opportunities to upskill together. People expressed interest in joining forces

on things like training days, contributor development, or building a bank of common resources that everyone can access.

Informal learning and peer exchange are valued

It's important to think beyond formal training, as many respondents emphasized the **value of informal learning spaces** where involvement professionals and contributors can connect, talk honestly, and learn from one another. These include things like “share the learning” slots in PPIE meetings and peer networks and forums.

These spaces are particularly important due to the emotional demands and complex interpersonal dynamics involved in working with patients and carers - who may need support both in sharing personal experiences and in navigating organisational systems. Many people working in this space find comfort and insight in hearing how others have handled similar challenges: being able to reflect and acknowledge the different aspects of what can be significant burdens of the PPIE role.

Training for public contributors

Another interesting area is **onboarding and training for public contributors**. Some felt this was not developed enough to make new contributors feel confident or valued in their role. Some lay contributors have standard organisational induction training for volunteers, which is useful but in itself may feel a bit disjointed and like a “tick box” exercise.

Some organisations offer specific training to prepare lay people for their roles - whether it's reviewing grant applications, co-authoring documents, or sitting on governance boards.

Other induction schemes are also happening which may be more useful and personal, for example, **mentorship or buddying**, where ‘old hands’ are paired up with new recruits, in order to answer questions and encourage from first-hand experience.

Contributors as trainees but also as teachers

The data also shows that learning isn't one-way, and public contributors are both learners and teachers in the PPIE space. Many researchers are learning directly from contributors. For instance, when public members challenge confusing language or unclear visuals, it often leads to better communication and stronger proposals. This everyday, **on-the-ground learning is powerful, but often goes unrecorded**.

“It always surprises me how much [lay advisers] rip stuff apart! Primarily around language and understanding.”



Learning through poetry: our shared experience

The University of Cambridge's Stem Cell Institute ran the 'You, Me, Us' poetry project to bring together patients, carers and researchers in a series of creative workshops exploring experiences of neuroblastoma. Using poetry as a reflective and expressive tool helped participants explore power, emotion, and perspective - creating deeper understanding and empathy across roles, and showing how learning in PPIE can be mutual, emotional and transformative.



6.4 Impact: Key take-aways

Unsurprisingly, evaluating the impact of PPIE remains one of the most persistent challenges facing members. While there is strong agreement that public involvement is making a difference - shaping and improving research and influencing decision-making - **measuring this impact in a systematic way is far from straightforward.**

Organisations are experimenting with tools like checklists, case studies, and mixed-methods evaluations, often adapting the NIHR Standards for reflective practice. However, much of this work remains informal, ad hoc, or dependent on individual effort, rather than being embedded across systems.

Governance structures around PPIE remain uneven, representing a significant and ongoing gap. This underscores the need for stronger strategic leadership and clearer pathways for both oversight and assurance.

Ideas for next steps

Practical next steps could include:

- **Co-developing a shared monitoring framework** to support consistent and transparent evaluation and/or accountability of PPIE activity across members. This could include, for example, identifying a key thematic priority for each year (such as a particular under-served group).
- **Piloting a common evaluation focus or theme each year**, such as inclusion or feedback, to align reflective practice across organisations.
- **Promoting impact stories and case studies**, alongside metrics or checklists, to better capture the qualitative value of involvement. Brief 'elevator pitch'-style case studies could be shared at PPIE Network meetings to increase visibility of current work across partners.

- **Embedding evaluation into project lifecycles from the start**, encouraging teams to plan for impact tracking and reflection early in research design and funding applications.
- **Conducting a full review** of PPIE governance arrangements across partner organisations (or in individual member organisations) to identify good practice, gaps, and inconsistencies. Including a public perspective into this would be ideal.
- **Embedding PPIE into routine reporting**, for example as a regular strand in board reports, through inclusion in corporate dashboards, or incorporating PPIE into Equality Impact Assessments (if these are undertaken for other governance reporting).
- **Involving and mapping public contributors in governance and oversight roles**, not just in project delivery, to ensure accountability and diverse perspectives at strategic levels.

7. Conclusion and next steps

Across Cambridge University Health Partners, it's clear that there is a deeply **values-led approach** to Patient and Public Involvement and Engagement. What comes through powerfully in these conversations is a **collective commitment to equity, inclusion, and partnership in research and innovation** - not just in words, but in practice. People are working in ways that reflect a genuine belief in the value of lived experience, the importance of trust, and the need to shape research and services *with* people, not just *for* them.

This comes through strongly in the **relationships** being built with seldom-heard communities, the creative approaches to inclusion, the **honest reflections** about what's working (and what isn't), and the drive to find creative resolutions to issues that inevitably arise when working in complex, often inflexible systems. Above all, it's clear from the pride people express in **shifting the culture** towards PPIE as 'business as usual', and not an optional 'nice to have.'

However, involvement is built on relationships and **the burden of responsibility for involvement work is high**. Individuals working in this space need support in both words and actions to recognise the intensity of the work they do, and to avoid burn-out.

Some of that support comes through **working collaboratively**, and there is partnership working across CUHP organisations: informal networks of peer support, joint campaigns, shared events, and collective reflection. People are reaching out across organisational boundaries to learn from each other, co-create tools, and support each other in delivering better, more inclusive work. These collaborative efforts may not always be formally structured, but they are already making a difference - and sustain not only the work itself, but also the individuals responsible for delivering it.

There's now an opportunity to build on that foundation. A **shared CUHP ambition** for PPIE could offer clarity of purpose, help amplify and align existing activity, and provide the structure and resourcing needed to deepen impact and demonstrate the value that PPIE brings to both individual member organisations, and to CUHP as a partnership.

This work is grounded in values - and it's those values that offer the greatest opportunity for CUHP. By leading with purpose and supporting this work with care and intention, we can create a joined-up and supportive approach to involvement and engagement that's rooted in trust, inclusion, and the lived realities of the people we serve.



Better
Decisions
Together

This report was compiled by independent consultants
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