

PPIE Mapping short report: Executive summary & next steps

For Cambridge University Health Partners

JUNE 2025



Summary

This is a short version of the full report [*Patient and Public Involvement and Engagement in Cambridge Universities and NHS Trusts*](#) for Cambridge University Health Partners (June 2025).

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. The themes below cut across all NIHR Standards, and consider the findings from a strategic point of view, considering members' shared vision and values, mission, working together, and governance and impact.

This short report comprises a draft ambition statement, a snapshot of the main findings, and a practical list of suggested next steps to help build on the foundation of excellent practice that is evident across members. It also contains case studies (including the two below) to illustrate some of the good practice that is happening across CUHP members. For the detail behind this report, please see the [full report](#).



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.



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.



Draft CUHP Members' Commitment to PPIE

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.

Executive Summary

This project 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).

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.



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.



Opportunities for CUHP members

- Develop a **shared ambition** for PPIE that reflects collective values and clarifies roles, purpose, and vision.
- 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.

Next steps ideas by theme

1. Shared understanding: Values and vision

- 1.1 **Developing a CUHP-wide ambition statement for PPIE**, building on existing values of inclusion, partnership, and lived experience, and aligning with the NIHR definition.
- 1.2 **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.
- 1.3 **Incorporating the shared values and definitions** into induction and training materials for researchers, staff, and contributors to ensure alignment in language and purpose.
- 1.4 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.



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.



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

- 2.1 **The PPIE Network** could discuss their **individual key strengths and priorities** identify areas of overlap, potential collaboration, and shared goals.
- 2.2 **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.
- 2.3 **Supporting partners to understand up-to-date local data** to identify common gaps, for example around underserved communities.



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.



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

- 3.1 **Raising awareness and building on the Cambridgeshire and Peterborough Engagement Insight Library** to improve sharing and showcasing work and frameworks used by members.
- 3.2 **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.
- 3.3 **Piloting a 'diversity audit' tool** that helps teams review the representativeness of their contributors and adjust outreach strategies accordingly.
- 3.4 **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.



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.



4. Working together

- 4.1 **Developing a collaboration framework for PPIE**, clarifying shared goals, principles for working together, and opportunities for joint action across members.
- 4.2 **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.
- 4.3 **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.
- 4.4 **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.)
- 4.5 **Establishing regular cross-partner reflective spaces**, such as peer learning groups, shadowing opportunities, or joint problem-solving forums to reduce isolation and strengthen practice.
- 4.6 **Offering shared training opportunities** for researchers, professionals and public contributors, including joint inductions, skills-building workshops, and co-delivered sessions on inclusive involvement.
- 4.7 **Resourcing collaboration explicitly**, by identifying PPIE as a strategic priority and dedicating funding, time, and leadership capacity to support shared infrastructure, coordination, and innovation.



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.



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

- 5.1 **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).

- 5.2 Piloting a common evaluation focus or theme each year**, such as inclusion or feedback, to align reflective practice across organisations.
- 5.3 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.
- 5.4 Embedding evaluation into project lifecycles from the start**, encouraging teams to plan for impact tracking and reflection early in research design and funding applications.
- 5.5 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.
- 5.6 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).
- 5.7 Involving and mapping public contributors in governance and oversight roles**, not just in project delivery, to ensure accountability and diverse perspectives at strategic levels.



'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.



These next steps offer a practical starting point for CUHP members to strengthen and align PPIE efforts across the system. Building on shared values, this work can help ensure public involvement remains embedded, inclusive, and impactful.



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This summary report was compiled by independent consultants
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