Patient and Public Involvement and Engagement Strategy 2022-2025

Published February 2022
Table of contents

*Introduction* ................................................................................................................................. 2

*Definitions* .................................................................................................................................. 2

*Our vision* ...................................................................................................................................... 3

  Why? ........................................................................................................................................... 3

  The key principles .......................................................................................................................... 3

*Our Strategy themes* ...................................................................................................................... 4

  Theme 1: Involvement and inclusive opportunities ................................................................. 5

  Theme 2: Governance ................................................................................................................... 6

  Theme 3: Supporting and learning ............................................................................................... 6

  Theme 4: Working together ........................................................................................................ 8

  Theme 5: Communications .......................................................................................................... 9

  Theme 6: Impact .......................................................................................................................... 10

*What comes next?* ......................................................................................................................... 11
Introduction

Health and care research and innovation must be designed in partnership with the people who will ultimately benefit from developments in health and care: patients, carers and the public. Evidence demonstrates that patient and public involvement and engagement (PPIE) is critical to designing research questions that matter to patients and the public and ensuring the successful spread of innovation. PPIE also positively influences the methods and outcomes of innovation and research. As well as all these benefits, UCLPartners believes that it is the right thing to do.

PPIE is already being embedded across areas of health and social care in England. The NHS Long Term Plan calls for people to be empowered in their health and social care. NHS England and Improvement has stated its commitment to involving patients and the public in NHS services. The National Institute for Health Research (NIHR) has for a long time advocated for PPIE in research, and many health research funders have followed suit (e.g. Wellcome Trust, Cancer Research UK).

This strategy presents our approach to PPIE at UCLPartners, setting out how we will ensure that our activities are robustly informed by a diverse range of patient, carer and public insights, and be responsive to their needs.

The strategy has been informed by a development session held with patient partners in June 2021, and from feedback from our patient partners, UCLPartners staff, the UCLPartners Academic Health Science Centre (AHSC) Executive group, and the UCLPartners PPIE Committee (which brings together colleagues across the six research and innovation functions within UCLPartners).

Definitions

Throughout this document, we use the following definitions for our work:

**Patient involvement** can be described as recognising patients as “protagonists of their care journey” honouring their lived experiences of both physical and mental health conditions, and proactively creating and developing opportunities for patients to have a say in how their health care is designed and delivered. This also applies to research and innovation: where patients ought to be given opportunities to contribute to health research and innovation as *experts by experience*. Patients should have opportunities at every stage of the research cycle from identifying research questions to implementing research findings.

**Public involvement** acknowledges the need to give carers, families, and wider public groups a platform for influencing change in physical and mental healthcare services delivery and research.

**Patient and public engagement** refers more broadly to the concept of, and active working toward, keeping up an ongoing dialogue with patients and the public about the work of UCLPartners, as equal stakeholders in our processes and outcomes.

Throughout this strategy, we use the word ‘patients’ as a shorthand to describe individuals who have accessed health and social care services, and ‘public’ constitutes wider public groups, carers, families, residents, citizens and communities.
Our vision

At UCLPartners, our vision is that all physical and mental health and care research and innovation across our partnership is informed and enriched by involvement and engagement that is proactive, responsive, and designed and delivered with our diverse population.

Why?

There are several benefits from PPIE for our staff, our work, and patients, carers and general public. These include:

**Valuing expertise** – There is a vast wealth of knowledge and experience held by ‘experts by experience’ or people with lived experience that, without PPIE, would be inaccessible to traditional researchers, innovators, educators and those developing health and care services.

**Equity** – Research and innovation in health and care shouldn't be developed without the participation of patients, following the concept of "nothing about us without us". We see PPIE as the right thing to do, whilst ensuring the work we do has a societal impact. Ethical scrutiny is also key when spending public money.

**Pragmatism** – Involving patients and public in research and innovation leads to less wastage in research and better uptake of innovations in health and care and improved value for money

**Necessity** – PPIE is often a requirement for receiving funding, ethics approval, etc.

Ultimately, we believe PPIE improves services and outcomes for people using health and social care services, which drives us to continually improve our PPIE.

The key principles

The following principles will guide our work with patients and the public. We will:

- **Work collaboratively** with and **actively engage** patients, carers, families and communities in our region and ensure that **their insights** inform our work

- Recruit patient and public partners **transparently**, and **remunerate** patients appropriately in line with national best practice guidance

- **Support** patients and the public to engage with our work, including offering training to empower PPIE members in discussions, decision-making, governance, co-design and co-production

- **Collaborate** across the different research and innovation functions within UCLPartners and with a range partners across our geography and nationally, and **share** best practice widely

- **Embed PPIE** as a core part of our project development and delivery, and support UCLPartners staff to actively design and deliver meaningful PPIE

- Ensure we are **accountable** for responding to patient insights and input, and continuously **document, monitor** and **evaluate** our PPIE work

- Ensure that our PPIE work represents the **diversity** of our population
Our strategy themes

The objectives and activities within our strategy are centred around the six themes in the UK Standards for Public Involvement. These standards were developed over three years through a joint four-nation partnership between the NIHR, the Chief Scientist Office (Scotland), Health and Care Research Wales and the Public Health Agency (Northern Ireland). The Standards are a comprehensive framework of what good public involvement looks like and are designed to support self-reflection and learning.

Over the next three years, we will advance our work in patient and public involvement and engagement at UCLPartners, using these themes to guide our work:

**Inclusive opportunities:** We will ensure our patient, carer and public partners represent the broad diversity of the communities we serve and that we are inclusive in how we involve patients

**Governance:** We will establish governance processes in UCLPartners to ensure patient, carer and public partners are effectively involved in decision-making and ensure these insights inform our strategy and operations

**Supporting and learning:** We will provide support and training for our patient, carer and public partners; and support our staff and partner organisations to involve patients, carers and the public in their work

**Working together:** We will collaborate to create more opportunities for patient, carer and public partners to influence and inform research, innovation, higher education and health care delivery from prioritisation through to delivery phases. We will collaborate locally and nationally with PPIE teams to address pressing health challenges such as health inequalities

**Communications:** We will ensure clarity and transparency of our communications with patients, and increase the visibility of our patient and public involvement and engagement work, giving patient views and voices prominence in our internal and external communications

**Impact:** We will capture and disseminate the results and impact of our patient engagement and embed learning for constant improvement
Theme 1: Inclusive opportunities

We will ensure our patient, carer and public partners represent the broad diversity of the communities we serve and that we are inclusive in how we involve patients.

We will achieve this by:

- Identifying areas of under representation in our current PPIE work through mapping techniques, including identifying community groups that we currently engage with, and actively working to build new relationships to help us draw upon diverse experiences of health and care.

- Championing equality, diversity, inclusion and respect in our work through ensuring our PPIE is flexible and accessible, removing existing barriers to participation and using a range of inclusive methods and technologies to increase public engagement in our research and remunerating contributors.

- Strategically increasing our community engagement by working together with partner organisations, integrated care systems (ICSSs), charities and community groups to reach out to under-represented people to invite them to be involved in our work. This will require us to proactively go to where people are, rather than expecting them to come to us, to ensure our work is relevant to the different communities in our region.

- Drawing upon our existing networks, and building new ones, and considering our renewed community engagement work, we will ensure we increase the representation of individuals from the protected characteristics in our PPIE work.
Theme 2: Governance

We will establish governance processes in UCLPartners to ensure patient, carer and public partners are effectively involved in decision-making and ensure these insights inform our strategy and operations.

We will do this by:

- Formalising input and decision-making from patients by developing a UCLPartners ‘PPIE panel’ that will advise on projects, our organisational strategy and our plans and approach to PPIE.

- Ensuring patient partners take an active role in our governance following the UCLPartners strategy and governance review in 2022.

- Including patients/carers on recruitment interview panels for senior roles and patient-facing roles at UCLPartners

- Setting expectations through UCLPartners business planning that PPIE will be a core part of project design and delivery, across all teams
Theme 3: Supporting and learning

We will provide support and training for our patient, carer and public partners; we will support our staff and partner organisations to involve patients, carers and the public in their work.

We will do this by:

- Working across the different research and innovation functions within UCLPartners through our PPIE Committee* to provide a new introduction to PPIE for patients looking to join PPIE work
- Supporting UCLPartners staff and partners to include PPIE as a standard process in the set up and delivery phases of all new and ongoing projects, including through induction, one-to-one support and resources provided in our staff intranet
- Supporting UCLPartners staff to develop their knowledge and skills in PPIE through formal and informal learning opportunities, including through training programmes and learning networks
- Training patients, carers and members of the public in evaluation methods, and integrating them with the new Evaluation function at UCLPartners
- Developing a PPIE support model for clinical and commercial innovators, to support them to meaningfully involve patients and the public

*Membership of the PPIE Committee consists of members of staff working in patient experience roles in our partner hospitals, public engagement roles in our universities, and patient and public involvement and engagement specialists in our research partners, plus two patients.
Theme 4: Working together

We will collaborate to create more opportunities for patient, carer and public partners to influence and inform research, innovation, higher education and health care delivery from prioritisation through to delivery. We will collaborate locally and nationally with PPIE teams to address pressing health challenges such as health inequalities.

We will do this by:

- Working with our PPIE Committee to design and deliver collaborative projects to enhance our PPIE capacity and practice (e.g. support for people new to PPIE, and joint work to increase diversity of our patient, carer and public members group)

- Sharing training opportunities for patients to be involved widely across our partnership

- Playing a proactive part in national PPIE networks and discussions, such as the national Academic Health Science Network (AHSN) PPIE group, NHS England and Improvement staff network, and NIHR networks, and the ongoing discussions to address health inequalities

- Working with charities, integrated care systems (ICSs) and others to reach out to specific groups of patients and carers, rather than creating our own stand-alone networks

- Ensuring that patients who are involved in our work routinely receive feedback on their input and the impact of their contributions, building an open dialogue of feedback and transparency
Theme 5: Communications

We will ensure clarity and transparency of our communications with patients and increase the visibility of our patient and public involvement and engagement work, giving patient views and voices prominence in our internal and external communications.

We will do this by:

• Setting – and meeting – targets for including more patient voices in our external communications (e.g. patient blogs, videos), ensuring that diverse voices have the opportunity to share their experiences and perspectives

• Publishing this strategy on our website and clearly articulating through our communications channels how patients feed into our strategy and different work programmes

• Working with PPIE and communication leads in partner organisations to create engaging impact stories about patient involvement and share widely

• Increasing the internal visibility of PPIE, e.g. sessions regularly at staff meetings, PPIE included in new staff induction, development of PPIE resources for internal communication channels

• Regularly reviewing with our patient panel the language we use in our communications to ensure inclusivity and accessibility

• Creating a plain-English introduction to who UCLPartners are, what PPIE is and how patients can get involved
Theme 6: Impact

We will capture and disseminate the results and impact of our patient involvement and engagement and embed learning for constant improvement.

We will do this by:

- Ensuring all our PPIE activities have clear objectives and Key Performance Indicators (KPIs)
- Developing a repository of PPIE impact assessments and provide reports on this to the UCLPartners senior management team and Board
- Requiring programme and project leads to regularly report on PPIE activities carried out as part of their programmes and describe the changes that have happened as a result of these activities
- Developing a feedback mechanism for our staff, patients, carers and public members to comment on PPIE activity
- Sharing and celebrating examples of PPIE best practice in research, innovation and education from across our partnership
- Reviewing the impact of our PPIE work annually with our patients, carers and members of the public and our senior management team
What comes next?

After launching our strategy in February 2022, we will establish our ‘PPIE Panel’ to work alongside the UCLPartners PPIE team to refine and develop our action plan and hold us to account throughout the strategy lifespan.

Together we will annually review our strategy for fidelity, and track our progress towards achieving our vision of all health and care research and innovation across our partnership being informed and enriched by involvement and engagement.

If you have any queries about this strategy, or the PPIE work at UCLPartners, please contact the Patient and Public Involvement and Engagement team at PPIE@uclpartners.com