NIHR | Yorkshire and Humber Patient Safety Research Collaboration

Patient and Public Involvement and Engagement Strategy (2023-2028)

Yorkshire & Humber Patient Safety Research Collaboration

(version 1.0 October 2023)

Patient & Public Involvement and Engagement (PPIE) Strategy

Purpose and aims

The overarching vision of the NIHR Yorkshire and Humber PSRC is to co-produce innovative solutions to make care safer for patients and their families. Key to this is ensuring that these solutions reflect and meet the needs of our diverse communities. This can be achieved by working with and for patients, families, and health and social care staff, grounding our research in their daily realities and the evolving system within which care is delivered. Our PPIE strategy offers the mechanisms by which we can deliver on this, recognising that respectful and trusting relationships are the cornerstones to making effective change. Thus, a second key element of our PPIE strategy is to strive to narrow the gap between the diverse worlds of research and patients, families, and staff through training (across the whole research journey) to enhance transparency, knowledge, skills and confidence. In these ways, our strategy aligns closely with the goals and objectives of our PSRC.

Strategy development and objectives

Our strategy was developed with our Lay Leaders and through consultation with our wider PPIE members including members of the Safety In Numbers Group (SING) https://safety-in-numbers.co.uk/ . They told us that they wanted their emotional, physical, and intellectual needs to be met and that they wanted to be respected, valued and listened to without judgement. They made a series of additional suggestions which have been captured in our programme of activities.

Our four strategic objectives are underpinned by and reflect the UK Standards for Public Involvement in Research. Equity, diversity and inclusion (EDI) as represented in our EDI strategy is central to each objective, and involvement and participation inform our work from priority setting to implementation and dissemination. Our objectives align with the UK standards for public involvement set out by NIHR https://sites.google.com/nihr.ac.uk/pi-

standards/standards and these are represented in our measures of success.

Objective 1. Building a sense of ownership
We will build a sense of patient and public ownership of PSRC research through partnership working and designing meaningful, inclusive PPIE opportunities for researchers, patients and the public. In developing this objective, our Lay Leaders emphasised how PPIE activities should be fully inclusive of our communities and also targeted, where appropriate, to focus on patient groups of priority to our local integrated care boards (ICBs).

Objective 2. Working with and into our communities
We will collaborate with community groups and Voluntary Care Sector Organisations (VCSOs) to design innovative ways to develop and deliver our research, champion diversity and co-produce accessible research outputs. To deliver this objective we will continue to work with PPIE networks across our wider research infrastructure to involve and engage diverse communities.

Objective 3. Growing skills and confidence
Through co-designed training and targeted support, we will develop our researcher PPIE capability and provide opportunities for patients and members of the public to develop PPIE skills, and knowledge and understanding of research.

Objective 4. Generating impact and learning
We will monitor and evaluate PPIE activities to improve approaches to and experiences of PPIE, reflect on the difference PPIE has made, learning from what didn't go well as well as what did, from both the perspective of researchers and the public.

Ongoing work to support the delivery of our strategy

Our experienced Lay Leaders are key to the delivery of our PPIE strategy. Lay leaders are named as such because they are both members of the Yorkshire and Humber communities we serve and volunteer or work in a leadership capacity within health, social care or voluntary sector organisations (see our Yorkshire and Humber PSRC website for information on our Lya leaders https://yhpsrc.org/our-lay-leaders/). Over the past five years they have ensured that the patient voice is represented at all levels and over the research continuum and they have supported with engagement at local, regional and national levels. We continue to grow this group (ensuring it is diverse) with current work ongoing to expand membership to a minimum of 10 Lay Leaders, all of whom will receive training to support their integration into the themes and the research team and research processes.

Our Safety In Numbers Group of members of the public and healthcare professionals have been active contributors in our research including supporting the work of our PhD students. This group of local members of the public, patients and healthcare professionals get involved in research activity in a number of ways: supporting co-design activities, advising on project

design and ethics, acting as participants, helping to involve other patient groups etc. We have reviewed our work with the Group over the last five years and are currently consulting with members on how to make improvements including how to grow the group. Over the past five years we have formed a strong strategic partnership with Care Opinion. Care Opinion are a non-profit organisation that offers an online platform for patients, service users and carers to provide honest feedback, through sharing their stories of care experiences. The stories are publicly available. We work with Care Opinion in a range of different ways, but in the field of PPIE, our approach is twofold.

1. During project development, we work with Care Opinion to search the existing database of stories to better understand a safety issue from a patient perspective. For example, in our early work on psychological safety in mental health inpatient settings and in work on discharge from hospital to home for mental health service users, this information was invaluable to help inform our research questions.

2. We have established a Care Opinion research community of 1500 members. We have worked with Care Opinion to develop the processes for recruiting these members and involving them in our research. We will grow this membership and also develop processes for monitoring the diversity of research community members.

We are astutely aware that those people who write stories on Care Opinion and want to get involved in research in this way, although able to provide information of value, may not represent the diversity of experiences of our local communities, particularly as they relate to poorer levels of education and social deprivation. Thus, through our SING group and other community activities we will ensure that we include the voices of diverse groups.

Our Quality and Safety patient panel has been critical to the work of the wider Yorkshire Quality and Safety Research group (within which our PSRC is hosted) since 2009. This panel has a particular role in providing input into project design at a very early stage, offering guidance and support about how we present the idea, the specific considerations from a PPIE perspective and how we can access wider support. The primary role of this group is early consultation.

Integral to our work is the involvement of health and social care staff, in particular to research themes that, for example, focus on de-implementation and safety culture. Their contribution to our research requires us to adhere to the same principles of PPIE and EDI as for patients and families. Therefore, we must ensure that our approaches are inclusive that their experiences are heard and valued for future patient benefit. This will include providing training in research and creating opportunities for skills development through our Academic Capacity Development Strategy. For such research themes, our approach will be to set up staff advisory groups. We have involved such groups, alongside patient and public input, in past studies and have found them to be invaluable.

We acknowledge that there is much work to be done across with the general public to increase interest and trust in research and to improve awareness of patient safety research. We have started to engage with local ICB Research Communities of Practice to share the learning,

looking to join forces and tapping into existing relationships to create much broader reach using more creative approaches. We will explore other opportunities for wider engagement through local venues such as art galleries and town halls particularly where events are upcoming.

Action plan

Programme of activities		Monitoring & Milestones
Objective 1. Building a sense of ownership		
	We will grow our group of lay leaders to ten, growing the diversity of this group and continue to work with them. Two lay leaders will be embedded in each theme and two will support the delivery of our of the PPIE strategy with support from our PPIE and EDI lead, guide our PPIE activities and support the PSRC governance.	Ten lay leaders recruited by March 2024. Attendance at all executive and advisory board meetings.
	With support from our lay leaders, we will **grow our** SING community https://safety-in-numbers.co.uk to be representative of our communities. We will monitor diversity through our EDI strategy action plan. We will engage with and offer opportunities to the public and researchers that will, through understanding people's experiences, guide theme research and deliver safety solutions.	Starting in year 1 we aim to have reached a membership of 200 with 50% having contributed to our research projects by the end of year 4 (**part of Milestone 2**).
	We will establish a staff advisory group within the PSRC, starting within the De-cluttering safety theme. This will be a multi-disciplinary group and will include nurses, doctors, pharmacists, AHPs. In later years the group will be expanded to include those in supporting roles.	By April 2024 establish a staff advisory group (N=8-10) to support de-cluttering theme. Offer training and/or secondment opportunities to this group of staff by December 2024 Active involvement in research by December 2024.
	Our SING group, supported by our Lay Leaders, will advise on **targeted guides to the safe use of the health and social care system** aimed at different groups and output in different languages and formats.	The learning gathered within the PSRC and training in dissemination will inform development of these guides. Two guides to have been disseminated by the end of year 4.
	Theme-led project-based PPIE workshops will be developed	Starting in year 3 with

	and delivered through different media to design, advise on, and disseminate PSRC research.	completion in year 5. This coincides with completion of many of the theme objectives outlined in our business plan.
	We will further develop our Care Opinion research community to 4,000 members who are active partners in designing research and a targetable cohort of participants.	**Milestone 2** – to be complete by the end of year 4.
	We will host an annual awards ceremony to recognise PPIE contributions to PSRC research, celebrating their achievements and those of our researchers.	Starting in year 2 with completion in year 5
	As part of building PPIE into the early stages of the research continuum we will continue to involve patient representatives and lay leaders in our early planning and in writing funding bids. We will monitor involvement in successful bids as part of monitoring impact.	Continuous throughout the 5 year period.
Measure of success for Objective 1: All projects and themes with the PSRC to have included PPIE across the research continuum with researchers and members of the public rating their inputs as meaningful, valued and inclusive by PPIE researcher, patients and the public.		

Objective 2. Working with and into our communities		
	We will train up to **ten <u>further</u> community-based researchers*** to work with our researchers to encourage wider participation and reduce barriers to participation. Community researchers and theme researchers will be buddied to promote mutual skills development. This will be informed by work undertaken by the EDI working group to explore current approaches to PPIE and through engagement with local communities.	**Milestone 1.** Ten community-based researchers to be trained by the end of year 2 and collecting data within year 3.
	In partnership with current SING members, we **will run targeted campaigns with VCSOs**, working with our Lay Leaders and their extensive regional networks, to improve inclusivity of membership resulting in a wider community of people.	Starting in year 1 campaigns will run periodically and be complete by year 4 with the aim of reaching our stated target for SING membership of 200. This also feeds into Milestone 2.
	To disseminate project outputs and promote knowledge of	Starting in year 2. By year 3

	patient safety and research, we will work together with patients and specialist groups to develop creative ways of disseminating findings e.g. comic style, infographics, short videos. We will also, where appropriate, create easy-read versions and translate project information and/or findings into the most common written and spoken languages and British Sign Language.	we aim to have generated outputs of this nature from every theme. Some of this work will inform our targeted guides on safe use of health and social care.
	We will work with a group of VCSOs to identify opportunities for joint working between community organisations and our research themes, and to gain insights into patient experiences.	Starting in year 1 and continuing through the duration of the PSRC.
	We will involve patients and the public in celebrating World Patient Safety Day (as we did in September 2023) and seek other opportunities to engage with the citizens of Yorkshire and Humber to promote understanding of patient safety and patient safety research (e.g. City of Culture event).	Annual celebration of World Patient Safety Day involving our various lay groups,
Measure of success for Objective 2: To have created and maintained a diverse network of at least 5 community organisations where their members are willing, able and motivated to contribute to research activity on an ongoing basis.		

Objective 3. Growing skills and confidence		
	With our Lay Leaders, we will identify or co-develop suitable support and training for SING members, focussing on reducing barriers to involvement. This training will also be offered to our Community Researchers, adapting for the different roles they will take on.	Starting in year 2 following on from the EDI working group assessment of current practices. Will deliver this as a training package over subsequent years as the SING group grows finishing in year 5.
	To build skills and confidence in PPIE, we will deliver and evaluate training informed by our cross-centre research about PPIE capability, informed by the UK Standards for Public Involvement. Training will be offered to researchers in each PSRC.	From year 2 to be completed by end of year 3.
	Researchers and patients will be further supported through two additional groups. First, our EDI Working Group will assess our approach to PPIE and participant recruitment and advise on removing barriers to involvement and	EDI working group assessment will take place at the end of year 1 with development plans

	participation. Second, our **Quality and Safety Patient Panel**, which has 11 members with increased diversity of age, gender, ethnicity, and representation from people with learning disabilities, will support researchers and members of the public in developing PPIE plans.	happening over year 2.
Measure of success for Objective 3: For all researchers to be confident, knowledgeable and skilled in delivering PPIE and for all SING members to be confident and knowledgeable about participating in the research process.		

Objective 4. Generating impact and learning		
	A PPIE Impact Group will continue to capture examples from our themes of best practice in research design, delivery and dissemination. The group will be co-led by two Lay Leaders with theme researchers as members. Using a bespoke framework, the group will identify and share the impact PPIE makes to PSRC research. Best practice will inform our PPIE training.	Development of evaluation framework by end of year 1 and leading into PPIE training starting in year 2.
	We will work closely with NIHR PSRC for North West London who lead PPIE for the PSRC network to share learning and resources and to deliver joint projects.	Objective monitored via PSRC Network reporting
Measure of success for Objective 4: Researchers and members of the public reporting that PPIE made a difference to research and that PPIE is done well.		

Partnerships & collaborations

We will continue to work with regional PPIE groups, e.g. the Born in Bradford community team, to broaden diversity and reach. Our Lay Leaders bring extensive existing partnerships, for example the Planned Care Alliance, Bradford and District Citizens Advice, and the Northwest Regional Stakeholder Network (Cabinet Office Disability Unit). We will work with the local ICBs that are covered by our PSRC linking into their Research Communities of Practice Groups capitalising on the learning and sharing links into local communities. At a national level we have established strong links with the Harmed Patients' Alliance; Action Against Medical Accidents; and Patient Safety Learning.

Resources

A PPIE Lead will project manage our PPIE activities and, with the support of a research administrator, the Programme Manager, theme leads and research staff. Lay Leaders will direct PPIE at theme level and with two specifically dedicated to focusing on community

engagement, training and impact. Covid-19 has altered how people wish to engage with us and we will continue to develop a mix of digital and face-to-face opportunities. We will invest in the SING website functionality and remote engagement technology. We will engage specialist online event co-ordinators to facilitate this. We will commit budget to support appropriate remuneration according to INVOLVE guidelines and ensure that these are clear from the outset.

Leadership and lines of reporting

Our PPIE Lead (supported by the Programme Manager) and Lay Leaders will report on PPIE activities at Theme, Executive, and Advisory Board meetings. Our PPIE Lead and lay leaders will advise on our PPIE strategy and the Programme Manager will champion PPIE at executive level.

Monitoring, review & reporting

Our Lay leaders meet on a regular basis with meetings facilitated by the PPIE lead, Programme Manager. Our PPIE Impact Group will report into the Lay Leader meetings and to the Executive Board via Lay Leader representation. We will develop a reporting template based on the above programme of activities with planned scheduling of anticipated completion times, milestones and approaches to capturing our measures of success.