NIHR North West London Patient Safety Research Collaboration Patient and Public Involvement and Engagement Strategy

Purpose of the strategy

This document sets out the vision, aims and objectives for Patient and Public Involvement and Engagement (PPIE) at the National Institute of Health and Care Research (NIHR) North West London Patient Safety Research Collaboration (PSRC) for 2023-2027. This strategy is a live document, and it will be revised and updated for 2025-2027 to reflect any changing context or landscape.

Patients and carers bring different lived experience to researchers and healthcare professionals. It is crucial to involve patients and carers meaningfully in all aspects of the PSRC, throughout governance, research themes and individual research projects. Involving patients will help to ensure the PSRC strategic direction addresses areas that are important to patients. It will help to ensure PSRC research projects are ethical, feasible, acceptable, designed appropriately and recruit diverse public partners and participants. It will also ensure that research outputs are relevant to differing patient needs, communicated more widely, and will help to ensure results are translated into policy and practice.

Our Vision

Our vision is to inclusively, meaningfully and appropriately involve public members from diverse backgrounds at a governance-level and project-level, to improve the relevance and impact of our research, whilst ensuring those who we involve have a positive experience.

Our Aims

There is one aim for each of the themes in the <u>UK standards of public involvement in</u> research (seen in brackets below). Appendix 1 sets out the implementation plan of what will be done to help achieve the aims and how success will be measured.

AIM 1 (Governance): To embed the public voice in decision-making and advisory bodies and in co-producing the future strategic direction

Public members should be involved in decision-making around the strategic direction of PSRC and governance of its research projects. Public members should be appropriately supported to meaningfully contribute. We aspire that public members could be involved as equal partners in prioritising areas for future research.

AIM 2 (Support and Learning): To build the capacity of researchers and public members to carry out meaningful PPIE in all research projects

For PPIE to be embedded across all research projects, research staff at all levels need the skills to carry out their own high quality PPIE activities. All researchers/healthcare staff need to be appropriately trained and supported and provided with useful materials and funding to carry out PPIE in their projects. For public members to feel comfortable to share their experiences and views to improve research, we need to foster a culture of empathy, transparency and support. Public members should be appropriately trained and supported, including financially and with access needs. There should be appropriate safeguarding in place. Public members and researchers should all benefit from the experience.

AIM 3 (Inclusive opportunities): To ensure our PPIE opportunities are accessible for a wide variety of people, with a focus on under-represented and under-served groups from our local population

It is important to continue to expand our network of public members, through building and nurturing reciprocal relationships and sharing power with local community groups, with a particular focus on those who are under-represented and under-served. Involving people in developing opportunities and recruitment plans will help to ensure public partners and research participants are from different backgrounds. This will ensure that our research is influenced by and relevant to those who are seldom heard in research.

AIM 4 (Working together): To collaborate with others doing PPIE, to innovate where possible and share approaches

It is important to work together with other organisations, stay on top of evidence and share learnings, to foster new ideas and to avoid duplication of efforts. Work in partnership with community members and, where possible, co-produce projects. Alternatively, learn from different disciplines and use innovative PPIE approaches. Share learnings to add to the evidence base of best practice of PPIE.

AIM 5 (Impact): To capture the impact of PPIE across governance, research projects and people.

It is important to capture the impact of our PPIE activities at these different levels to demonstrate the value of PPIE and to support continuous learning. It will also be crucial to collect feedback from public partners to ensure they are also benefiting from the interaction and to support ongoing learning and improvement of our approaches.

AIM 6 (Communication): To create engaging, inclusive and accessible communications about our PPIE opportunities, during projects and to disseminate our work

The way we communicate about our research and PPIE opportunities will impact who participates, engages with and gets involved in our research. Going to where people are and communicating in different and innovative ways will help to ensure people from different backgrounds hear about our work and how to get involved. Working more closely with accessibility experts and people with different access needs will help ensure our communications are engaging and inclusive. Disseminating our work widely and in different ways will help to raise the profile of PSRC and build communities' trust with research.

Current status of PPIE in Autumn 2023

There are clear PPIE governance structures in place (see Figure 1). The PPIE Advisory Board (initially established in 2017) is made up of PSRC researchers/ clinicians, public partners, the PPIE team and external PPIE leads. Its role is to guide and oversee the implementation and further development of the PPIE strategy and advise the PSRC Executive Board on PPIE matters. It will continue to meet twice a year. The PSRC co-director, Bryony Dean Franklin, continues to co-chair the PPIE Advisory Board alongside a public partner, which helps to ensure PPIE is at the forefront of the collaboration. Since 2017, three theme leads and one researcher from different themes have rotated off the Board after three years of service. This is to improve the diversity of voices on the Board and to help embed PPIE at a theme level.

The PPIE Advisory Board also oversees the ways of working of the Research Partners Group (RPG), a diverse group of nine patients/carers that review PPIE plans and broad patient safety project design. Two researchers present at each RPG meeting and receive feedback. The RPG meets approximately four times a year and carries out ad hoc work over email, such as reviewing a funding application. The PPIE Advisory Board meets prior to the PSRC Executive Board (which also meets twice a year), where the PPIE Advisory Board public partner co-chair and the PPIE lead present on PPIE as a stranding item. The PSRC Management Board meets every 2 months to discuss progress in projects, including PPIE and resourcing.

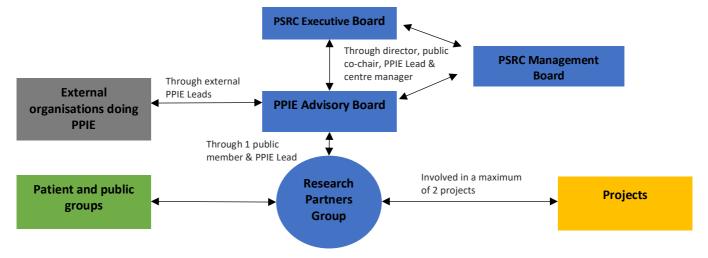


Figure 1: Organogram of PPIE structures and governance

The PPIE lead is accountable for the delivery of the strategy. The PPIE team is made up of the PPIE lead and a part time PPIE officer. Under the guidance of the PPIE Advisory Board, the PPIE team have developed various structures, training and support for researchers to carry out their own PPIE. All staff attend training run by the PPIE lead and are signed posted to resources e.g. the Patient Experience Research Centre (PERC) public involvement resource hub. All researchers are encouraged to have PPIE plans for their research projects and recruit people with relevant experience to their projects. In the previous PSTRC there was some discrepancy between themes, with some themes having PPIE plans for all projects and other themes having fewer PPIE activities. The PPIE team trains researchers in how to capture the impact of PPIE, but previously there has not been a mandatory evaluation process in place.

Equity, Diversity and Inclusivity is core to the PSRC. The PPIE team has been training and supporting researchers to carry out accessible PPIE, as well as leading on some projects focusing on under-represented groups (e.g. those with hearing loss). The PSRC has a Twitter account and is supported by the Institute of Global Health Innovation (IGHI) communications team to produce reports, videos, infographics and blogs of PSRC research and PPIE activities, in order to reach diverse audiences.

The implementation plan builds on the above and focuses on how to ensure our PPIE is inclusive and that we capture impact of our PPIE activities and share our learning.

Appendix 1: Our PPIE implementation plan (2023-2025)

Below is an outline of how we plan to achieve each of the six aims including which quarter and year the task will be completed (Q1 meaning January-March, Q2 April-June, etc.). The implementation plan will be revised for 2025-2028.

Aim 1 (Governance): To embed the public voice in decision-making and advisory bodies and in co-producing the future strategic direction

What we will do?	How we will do it?	How we will measure progress?
The PPIE Advisory Board will have a strong public voice, representing different experiences.	The PPIE Advisory Board will be co-chaired by a public partner and the PSRC co-director. There will be two other public partners on Board, including a member of the Research Partners Group and an external public partner, being mindful of the diversity of the group - linked to our Equity Diversity and Inclusion (EDI) strategy. Every five years, we will recruit a new Research Partners Group member to the PPIE Advisory Board (through an application form shortlisted by the PPIE team and co-chairs) and will rotate-off the current member (in Q1 2024). In order to have some consistency on the Board, the any membership changes will be staggered. (PPIE team/PPIE co-chairs)	Record and review: Review attendance to meetings annually (in Q2 2024) PPIE team to reflect after each meeting if public partners contributes a similar amount to the other members Review annually (in Q2 2024), if suggestions by the public members have been implemented, if not why not Collect feedback from the public members annually (in Q2 2024) and implement any improvements (PPIE team/Public partners)
Greater links between the Research Partners Group and the PPIE Advisory Board.	The PPIE Advisory Board to receive access to the folder of notes from the RPG meetings (in Q2 2024). The RPG member to have a standing item at PPIE Advisory Board meetings to raise any areas of improvement they see,	Record and review: - PPIE Advisory Board and RPG annual survey (in Q2 2024) states a greater understanding of each other's work - Review annually (in Q2 2024) if RPG item remains on agenda and informs future improvements

	through reviewing research projects PPIE plans (in Q1 2024).	(PPIE team/RPG Board member)
The decision and governance boards will include at least one public member and PPIE will be discussed at each meeting.	The public partner co-chair of the PPIE Advisory Board will also sit on the PSRC Executive Board alongside the PPIE lead (ongoing from PSTRC). The public partner co-chair (or the new RPG member to act as alternate) will be invited to the bi-monthly PSRC Management Board meetings, to help ensure PPIE is discussed at each meeting (in Q1 2024). At each Management Board meeting, theme leads will report on PPIE. The PPIE lead will work with the public co-chair to update on general PPIE matters at the Management Board (from Q1 2024).	Record and review: - Review attendance to meetings annually (in Q2 2024) - Review meeting minutes annually to assess if PPIE remained an item and changes suggested were implemented (in Q2 2024) - Collect feedback from the public members of Boards annually (in Q2 2024) and implement any improvements (PPIE team/Public co-chair/RPG Board member)
	(PPIE team/Public co-chair/RPG Board member)	
Have public members review project design and PPIE plans of all PSRC projects.	The PPIE team will train researchers to involve public members (with relevant lived experience) to review their PPIE plans and project design or to present to the RPG (ongoing from PSTRC). PPIE Officer to call out to researchers to present to the RPG a month before each RPG meeting and collect papers (from Q2 2023). The RPG will continue to meet every three months, with two researchers presenting at any stage of their project, preferably as early as possible in the	 Record and review: Review attendance annually of which theme researchers attend RPG meetings (in Q2 2024) Researchers to report sharable details of the public members involved in their research projects via the evaluation form at the end of each project. Researchers to fill out a RPG evaluation form after each RPG meeting to collate changes they are taking on board and any suggested improvements to the RPG, reviewed by the PPIE team annually (in Q2 2024) Every other RPG meeting to be 30 minutes longer for reflection about the workings of the group (or common pitfalls by

	project development (from Q2 2023). (PPIE team/RPG/Researchers)	researchers) and implement any changes to the RPG or the researcher PPIE training - Bring all RPG members together for a reflection/training meeting by Q4 2024 and every 2 years and implement any improvements
		(PPIE team/RPG/Researchers)
Each theme will	We have recruited 3 new	Record and review:
have one	members to the PPIE Advisory	- Review attendance to PPIE
researcher PPIE	Board, through a transparent	Advisory Board meetings
champion, who	process from the other 3	annually (in Q2 2024)
is a member of	themes not previously	- Annual PSRC-wide PPIE survey (in
the PPIE	represented by Bryony Dean	Q2 2024), including monitor
Advisory Board	Franklin (co-chair). New	whether all staff have attended
and champions	members will be trained in their	mandatory PPIE training and any
PPIE in their	roles to champion PPIE, training	common questions the PPIE
theme.	and resources to their	champions are receiving
	colleagues (in Q4 2023).	
		(PPIE team/PPIE Advisory Board/
	(PPIE team/PPIE Advisory Board)	Researchers)

AIM 2 (Support and Learning): To build the capacity of researchers and public members to carry out meaningful PPIE in all research projects

What we will	How we will do it?	How we will measure progress?
do?		
All staff will be trained in PPIE and signposted to training resources.	All staff will attend an interactive 1.5 hour PPIE training session, led by the PPIE lead (including, for example: EDI, safeguarding and capturing impact). All staff will be sent the updated PPIE top tips available on the internal WiKi with downloadable resources application forms, posters and safeguarding advice (in Q1 2024).	Record and review: - Review training attendance and knowledge/use of the resources via the staff annual PPIE survey (in Q2 2024) (PPIE team/Researchers)
	Develop a new PPIE resource (website) in collaboration with researchers, user-centred designers and public members,	

	to support researchers to carry	
	out inclusive PPIE (by Q3 2024).	
	(PPIE team/Researchers)	
The PPIE team to keep updated on evidence/ best practice, and use this to support researchers and public members.	The PPIE team will attend PPIE events, read literature and new guidance and update training appropriately (ongoing from PSTRC). The PPIE team will set up a shared mailbox to support researchers with queries (e.g. meet with them to discuss projects, invite them to observe a workshop etc. (in Q1 2024). Every 3 months the PPIE lead will run a PPIE clinic where researchers can come with PPIE issues and discuss and learn with other colleagues about PPIE (in Q1 2025) The PPIE team will develop some concise, engaging materials to send all new public members to better understand PPIE and how they can add value (in Q1 2025). Through mandatory PPIE training, the PPIE team will train researchers to appropriately train public members getting involved in specific roles.	Record and review: Record attendance of PPIE team to PPIE events/training annually (in Q4 2024) Public members to fill out at least one evaluation form when involved in a project, including about the training/support received, reviewed by PPIE team Annual PSRC-wide PPIE survey, including understanding use of training and resources (in Q2 2024) (PPIE team/Researchers/Public partners)
All rocoarchara	(PPIE team)	Paccard and reviews
All researchers to develop and deliver a PPIE plan for all projects.	The PPIE team, under guidance from PPIE Advisory Board, to develop PPIE planning and evaluation forms for all researchers to use when planning projects (in Q1 2024). (More under aim 6 below).	Record and review: - Researchers to submit PPIE planning to PPIE team at the start of each project - Researchers and public members to submit PPIE evaluation forms at least at the end of projects
		(PPIE team/Researchers)

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	The PPIE team to review	
	evaluation forms received and	
	assess any training needs for	
	researchers (in Q4 2025).	
	(PPIE team/Researchers)	
Develop a user-	As part of the NIHR PSRC	Record and review:
friendly PPIE	Network (SafetyNet), the PPIE	- Annually review clicks and
resource to	team will work with designers,	interactions with the resource (in
support	researchers and public members	Q3 2025)
researchers to	to co-create a PPIE resource,	- Annual PSRC-wide PPIE survey,
do meaningful	which is (different to existing	including knowledge/use of
PPIE.	resources) concise, user-friendly	resource (in Q2 2024)
	and focuses on supporting them	, ,
	to carry out inclusive PPIE and	(PPIE team/Researchers)
	measure impact. It will have a	,
	patient safety focus (e.g. case	
	studies from other national	
	PSRCs), but also be relevant	
	worldwide. This work will be	
	informed by interviews with	
	PSRC researchers (by Q3 2024).	
	i site researchers (by QS 202 i).	
	(PPIE team with collaborators)	
All public	The PPIE team will submit	Record and review:
members to be	payment forms for core PSRC	- Non Pay-roll Fee form tracker to
paid following	public members. Researchers	review if any delays to payments
NIHR guidance,	will submit forms for their	(ongoing)
in a timely	public partners. Public members	, , ,
manner.	will be paid £25 an hour (and £5	(PPIE team/Operations
	working from home expense or	team/Finance team)
	reimbursed for travel) within 8	, , , , , , , , , , , , , , , , , , , ,
	weeks of the interaction. Public	
	members who receive universal	
	credit will be signposted to	
	advice around receiving	
	honoraria (in Q2 2023).	
	PSRC Centre Manager to create	
	Non Pay-roll Fee form tracker	
	and update it (in Q1 2024)	
	(PPIE team/Operations	
	team/Researchers/ Finance	
	team)	
Public members	The PPIE team will source and	Record and review:
will be	produce training for public	
WIII DC	produce training for public	

appropriately trained and supported in their specific roles. members carrying out specific roles (e.g. on qualitative analysis). The PPIE team will support researchers in developing training for public members (ongoing).

The PPIE team will train researchers to always ask for informal feedback at and after training/meetings (ongoing).

- Public partners to fill out an evaluation form at least at the end of the project, including reporting on support/training
- Annual PSRC-wide PPIE survey, including information of the types of roles public partners have done (in Q2 2024)

(PPIE team/Researchers/Public partners)

(PPIE team/Researchers)

Appropriate safeguarding will be in-place for public members and staff.

The PPIE team will train researchers in safeguarding and what extra support/approvals need to be in place for vulnerable groups. This will depend on the context and the PPIE team will work closely with researchers working with specific individuals/groups. The PPIE top tips and future new resource will have useful documents to download e.g. the recent co-production safeguarding statement, list of charities offering free support (by Q3 2024).

Researchers will be encouraged to complete mental health first aid (MHFA) training through Imperial College London (ongoing).

The Institute of Global Health Innovation (IGHI) well-being group will develop a guidance for staff about how to support well-being at work (in Q1 2024).

The IGHI to provide funding to support access to professional support for staff (by Q4 2024).

Record and review:

- Annual PSRC-wide PPIE survey, including asking about if staff have trained in MHFA (in Q2 2024)
- Report any safeguarding incidence appropriately and take appropriate action (ongoing)
- Record improvements in wellbeing survey for IGHI staff, every 2 years (by Q4 2025)

(PPIE team/Researchers/ Well-being group)

The PPIE will train researcher	S
about appropriate approvals	
needed when carrying out PP	PIE .
and co-production (e.g. ethic	al
approval, Licence to Attend,	
data training, Data Barring	
Service) (ongoing).	
(PPIE team/Researchers/ Wel	<i>'</i> I-
being group)	

AIM 3 (Inclusive opportunities): To meaningfully engage and involve a wide variety of people in our work, with a focus on under-represented and under-served groups from our local population

What we will	How we will do it?	How we will measure progress?
do?		
Understand the local population and which groups are under-represented and under-served in research and specifically patient safety research.	The PPIE team will collaborate with other NIHR NWL bodies to carry out desk research about our local population and understand their protected characteristics, in accordance with our EDI strategy (by Q4 2025). Through attending training and reading in the literature, understand more about underserved groups more broadly and those who are often excluded from PPIE e.g. those who have experience with homelessness (ongoing). (PPIE team)	Record and review: - Successful development of a useful document describing the local population, and underrepresented and under-served groups in terms of research and patient safety, shared across PSRC (by Q4 2025) - Record training attended by PPIE team annually (by Q2 2024) (PPIE team)
Understand existing research collaborations with local community groups.	The PPIE team to feed into a NWL dashboard (led by the NWL Clinical Research Network, CRN) to show all the community organisations, their main protected characteristics and if any individual/department or organisation has an existing relationship with them.	Record and review: - Annual click uses of dashboard (by Q2 2025) (PPIE team/NWL Clinical Research Network)

Build new	Continue to work with NWL BRC to reach existing groups including: Community Champions and the Young Person's Advisory Network. (PPIE team/NWL Clinical Research Network) The PPIE team/researchers to	Record and review:
relationships with local community organisations.	take time to build trust with community leaders in order to work with them to understand the best way to interact with the communities they represent. For example, visiting in-person and attending events e.g. Trust's community walking tours (ongoing). Visit new community organisations and use community venues to help nurture the relationships. Continue to be in contact around our work and other opportunities for involvement (ongoing). Reflect on learnings of working with specific communities and write up into case studies for the new PPIE online resource (in Q3 2025). (PPIE team/Researchers/Public partners)	- Annually record the number of new organisations that have led to collaborative work (in Q2 2024) Annual PSRC-wide survey, including researchers recording the number of people involved and new people involved and, when appropriate, their protected characteristics (in Q2 2024) (PPIE team/Researchers/Public partners)
Work in partnership with community groups for mutual benefit.	The PPIE team/researcher to attend community events (e.g. health fairs) and organise one collaborative event per year with community organisations to raise awareness of research/PPIE and to build trust (e.g. People's Research Café or scientific talk). Ensure events are accessible/engaging by Q4 2024).	 Record and review: Annually record the number of community events attended and number of collaborative events and success of events (in Q2 2024) After each event, collect feedback during and after interaction from community members to understand what

Work with community members to ensure our data policies are clear and transparent.	Reflect with community organisations after interactions to understand if they felt the interaction was reciprocal and what could have been improved e.g. through event feedback or discussion with community leader (ongoing). (PPIE team/Researchers/Public partners) Discuss with community members why protected characteristics are being collected as part of our EDI strategy and how it is stored and used. Work with several public members to develop clear Plain English document/infographic about how data is stored/used to help us understand how we are meeting our aims of the EDI strategy (by Q4 2025). Agree with a diverse group of members of the public an appropriate way to collect and use Index of Multiple	could improve have been improved (ongoing) - Annually review sign-ups to PPIE mailing list (in Q2 2024) - Apply for funding for a project with a community group at least every two years (in Q2 2023) - Annual PSRC-wide PPIE survey, including community events researchers have attended (in Q2 2024) (PPIE team/Researchers/Public partners) Record and review: - Annual PSRC-wide PPIE survey, including basic demographics of public partners, if appropriate (in Q2 2024) (PPIE Team/Public partners)
	Deprivation (IMD) e.g. collecting postcode (by Q2 2024). (PPIE Team/Public partners)	
Work to ensure that our opportunities are appealing to people from different backgrounds.	Include guidance in training and PPIE top tips/new resource to suggest our opportunities are in Plain English, eye-catching and clearly advertise what people gain when they get involved with us (e.g. influencing, learning, payments). For example, co-design printed flyers to distribute in the community (in Q1 2024).	Record and review: - Annually review public mailing list sign-up (in Q2 2024) - Annual PSRC-wide PPIE survey, including how many people used interpreters etc. (in Q2 2024) (PPIE Team/Public partners)

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	Linked to our EDI strategy, for each project PPIE team/researchers will ask people for their access needs and have budget allocated to support e.g. translation, dongles etc. (ongoing). (PPIE team/EDI Working	
	Group/Researchers)	
Support the Research Partners Group continued development.	Rotate some members off the RPG and recruit new members to the RPG through a transparent process, to diversify the group every 2-3 years. Include in the RPG terms of reference a maximum length of service. Members who are rotated off will be supported in the transition and sign posted to other opportunities (in Q3 2024).	Record and review: - Every 2-3 years assess the protected characteristics of the RPG and recruit being mindful of diversity (in Q3 2024) - Every 2 years review RPG feedback from reflection meeting (in Q4 2024) - Annually, review feedback from researchers through the RPG evaluation form (in Q4 2024)
	Hold one RPG reflections/training meeting inperson every 2 years (by Q4 2024). (PPIE team/Research Partners	(PPIE team/Research Partners Group/Researchers)
	Group/Researchers)	

AIM 4 (Working together): To collaborate with others doing PPIE, to innovate where possible and share approaches

What we will do?	How we will do it?	How we will measure progress?
Share PPIE	The PPIE lead and PPIE officer	Record and review:
activities and	to attend the "Imperial and	- Annually review number of
learnings with	partners" PPIE leads 6-weekly	collaborative projects across
NWL organisations	meeting, to update on all PPIE	NWL organisations and beyond
and collaborate	activities and learnings, offer	(in Q2 2024)
were possible.	support and identify areas for	- Apply for at least 1 PPIE award
	collaboration and raise the	every 2-3 years (in Q4 2023)
	profile of the PPIE team	
	(ongoing).	(PPIE team/Collaborators)

	The PPIE team to attend other relevant PPIE meetings/ events e.g. NIHR NWL Applied Research Collaboration Exchange Network (ongoing).	
	Collaborate on at least one PPIE project with other NWL organisations per year e.g. the Great Exhibition Road Festival (ongoing).	
	Organise an annual "brunch and learn" session with an external PPIE expert to learn about different ways of working (in Q1 2024).	
	Work closely with the White City community through Imperial's Societal Engagement Team e.g. advertise opportunities through their network (ongoing).	
	(PPIE team/NWL organisations)	
Learn from other disciplines about how to be creative/innovative in PPIE or coproduction and share learnings.	Work on one innovative or coproduced project every 2 years e.g. with the Helix Centre, using PPIE and human-centred design. Share our learnings internally and externally (e.g. blog, academic paper or external talk). (PPIE team/Helix Centre/Public partners)	Record and review: - Record success of apply for at least 1 innovative project every 2 years collaborating across disciplines (in Q4 2023) - Published 1 academic paper every 2 years co-authored with public partners (by Q4 2025) and review impressions - Publish at least 1 blog per year co-authored with public partners and review impressions (by Q4 2024)
Coproduce or innovate with community groups on specific projects.	Apply for funding for collaborative projects with specific under-served communities. Work on at least 1 project every 2-3 years that	(PPIE team/Public partners) Record and review: - Every 2-3 years, assess external funding applied for co-produced/community-led projects and won

is community-led or co- produced (apply by Q4 2023).	- Every 2-3 years review evaluation forms of co-
Develop ways to evaluate if	produced projects (ongoing) - Publish 1 output every 2 years
the project is co-produced well, following the NIHR	from community led/co- produced projects and review
principles of co-production (if community-led/co-produced	impressions
project successful).	(PPIE team/Researchers/Public partners)
(PPIE team/Researchers/Public partners)	,

AIM 5 (Impact): To capture the impact of public involvement across the collaboration and research projects.

What we will do?	How we will do it?	How we will measure progress?
Capture the impact of PPIE at a governance level.	The PPIE team will develop evaluation processes to evaluate PPIE at a governance-level, with input from the PPIE Advisory Board and based on best practice and the UK Standards for Public Involvement in Research. Building on aim 1, the PPEIP team will capture the impact of public members on the PPIE Advisory Board, Research Partners Group, Management Board and Executive Board. We will assess whether PPIE activities and knowledge increase in each theme, with new initiatives e.g. PPIE champions per theme and the new PPIE resource. (PPIE team/PPIE Advisory Board/Researchers)	Record and review: - Annual review of attendance of public partners to decision and advisory boards and review meeting notes (in Q4 2024) - Annual review of RPG notes and evaluation forms (in Q2 2024) - Annual PSRC-wide PPIE survey, to understand PPIE champion impact, researcher knowledge and use of RPG (in Q2 2024) (PPIE team/Researchers)
Researchers and public partners will work together to evaluate the	The PPIE team (under guidance of PPIE Advisory Board) will develop evaluation forms for researchers/public partners to	Record and review: - Planning and evaluation forms completed (by researchers and public members) at start and at

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impact of the PPIE in their projects and on	use at the start/during and the end of projects (in Q3 2023).	least the end of every project and sent to PPIE team (ongoing)
the people involved.	Researchers will be trained in capturing the impact of PPIE, using evaluation forms. The PPIE team will suggest starting each interaction with "you said" and "we did" to show how the public members have been listened to (from Q1 2024). The PPIE team will develop an	(PPIE team/Researchers/Public partners)
	evaluation workshop guidance that all projects will use half way and at the end of their project. This will be reviewed and iterated (by Q4 2025).	
	(PPIE team/Researchers/Public partners)	
Showcase examples of PPIE impact.	Publish at least one output with a PPIE focus per research theme every 2 years, co-authored by public partners (by Q2 2025).	Record and review: - Annual review of number of blogs and papers published with public partners and impressions (in Q2 2024)
	All PSRC publications will describe how public members have been involved or declare why they weren't (ongoing).	- Every 2 years, review number of events highlighting PPIE impact (by Q4 2025)
	Host at least one event every 2 years where PPIE impact is highlighted (by Q4 2025).	(PPIE team/Researchers/Public partners)
	Co-create a designed impact summary poster/report with public members to the impact of PPIE across the collaboration, projects and people (by Q4 2025).	
	(PPIE team/Researchers/Public partners)	
Create a culture of feedback and	Train researchers in the feedback guidance by the Centre for Research in Public	Record and review:

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continuous	Health and Community Care and	Public partners feel listened to
learning.	develop a template for	and supported in evaluation
	researchers and public members	forms
	to give and receive feedback. It	
	will also be suggested to have	(PPIE team/Public partners)
	regularly online/in-person	
	reflection meetings, where the	
	project team will build an	
	environment of open feedback	
	(ongoing).	
	(6.186.1.8)	
	All public partners will be given	
	a key contact from outside of	
	the project in order to give	
	anonymous feedback at any	
	time to the project team	
	(ongoing).	
	(PPIE team/Researchers/Public	
	partners)	

AIM 6 (Communications): To create engaging, inclusive and accessible communications about our PPIE opportunities, our research and impact

What we will	How we will do it?	How we will measure progress?
do?		
Our opportunities will be appealing to people from different backgrounds.	For projects that the PPIE team are leading the PPIE, we will use design programmes or work closely with designers (Helix Centre or external), accessibility experts and public members to develop poster templates that are clear/engaging/accessible to be used by researchers for recruitment. These posters will be printed and used for flyering and distributed through community groups, as well as online distribution (ongoing). The PPIE team will signpost researchers to the societal engagement training (ongoing)	Record and review: - Annual PSRC-wide PPIE survey, including numbers of public members involved (and if appropriate demographics) - Annually, publish at least 1 showcase project (e.g. blog) and details of the demographics of the public members involved, where appropriate (by Q4 2024) - Annually review public mailing list sign-up (in Q2 2024) (PPIE team/Helix Centre designers/Researchers/Public partners)

	(
	(PPIE team/Helix Centre	
	designers/Researchers/Public	
	partners)	
All researchers	The PPIE team to train	Record and review:
will	researchers to ask public	- At least at the end of each
communicate	members their communication	project, public partners to fill out
well and	preferences and ensure there is	an evaluation form
regularly with	a clear two-way line of	
public partners	communication. Public partners	(PPIE team/Public partners)
during projects.	will be given a key	(11 IE team) Tubile partifers)
during projects.	1 ,	
	contact/buddy within each	
	project (ongoing).	
	(PPIE team/Researchers)	
Build trust with	The PPIE team will encourage	Record and review:
community	researchers to disseminate	- Review impressions of the 1
members	their research in engaging ways	published showcased example
through our	(e.g. blogs, plays, podcasts,	(ongoing)
communications.		
communications.	infographics), which will be co-	, , ,
	designed with members of the	mailing list (in Q2 2024)
	public (ongoing).	(DDIE 1 / C 1)
	(0.0)5	(PPIE team/Comms team)
	(PPIE	
	team/Researchers/Comms	
	team/Public partners)	
Be recognised as	PPIE lead to present at at least	Record and review:
PPIE leaders	one PPIE relevant event/	- Every 2 years, assess number of
through sharing	conference every 2 years,	co-presentations with public
our learnings.	preferable with a public partner	partners
	e.g. ADR UK data analytics	- Every 2 years assess PPIE team
	conference 2023 (by Q4 2023).	invites to talk or sit on panels at
		national/international events (in
	PPIE team to train researchers	Q2 2024)
	and public partners to blog	
	about their PPIE experiences	(PPIE team/Researchers/Public
	and impact as a learning tool on	partner)
	the Institute of Global Health	
	Innovation blog and distribute	
	on social media (ongoing).	
	, , ,	
	(PPIE team/Researchers/Public	
	partners)	
	·	
Raise awareness	Annually, host a high profile	Record and review:
about patient	event for World Health	- Reflect on the impact of the
safety and PPIE.	Organization's World Patient	public partners in WPSD event
Jaicty and FFIL.	Safety Day (17 th Sep) where	' '
	Salety Day (17 Seb) where	through reflection workshop and

public partners are involved in co-designing the event and speaking at the event. Develop a "goody bag" of post event materials (in Q3 2023). Blog about the event (in Q2 2024).

Work with the communications team to continue to involve public members/researchers in writing blogs and using PSRC social media accounts to showcase our research, PPIE activities and impact (ongoing).

(PPIE team/Communications team/ICHT/Public partners)

- success of event through attendee feedback (in Q2 2024)
- Record number of attendees to WPSD event and number of views of recording (in Q4 2023)

(PPIE team/Communications team/Public partners)

Leadership and lines of reporting

PSRC has a full time PPIE lead who leads the development and delivery of the strategy. The PPIE lead is also the PSRC EDI lead, to ensure the PPIE and EDI strategies are aligned. An additional PPIE Officer also supports PPIE strategy delivery as part of their role. They make up the PPIE team who act as the secretariat for the PPIE Advisory Board and the Research Partners Group. The PPIE team supports researchers to plan and deliver inclusive PPIE in their research projects and capture impact.

The Research Partners Group is linked to the PPIE Advisory Board through one RPG representative on the Board. The public members of the PPIE Advisory Board member are invited to observe one RPG meeting a year. As mentioned above, additional links between these groups are being put in place (please see Figure 1), to ensure alignment with the overall goals of the PSRC. Each scientific theme is represented in the PPIE Advisory Board through the theme representatives, who will help to ensure the PPIE strategy is aligned with the themes.

Guidance, resources and training

The PPIE team have developed the <u>PPIE Top Tips</u> and signpost to NIHR North West London Biomedical Research Centre core facility Imperial Patient Experience Research Centre's (PERC) <u>online public involvement resource hub</u> to support and guide public involvement including documents, templates, <u>training courses</u> and a PPIE <u>blog</u>. It includes a Massive Open Online Course about co-production and public involvement. The PPIE lead and a public partner are part of the course around co-production - describing a previous project <u>Hearing Birdsong</u>.

Existing public networks

PSRC established the Young Person's Advisory Network with the PERC and Imperial Clinical Trials Unit. PSRC researchers can post youth relevant opportunities to the YPAN through PERC. PSRC also posts opportunities for engagement, involvement and participation on the People in Research website, through PSRC public mailing list and the <u>VOICE platform</u>, which the PSRC have taken over managing.

Funding to support involvement

There is a central PPIE budget to cover core cross-theme activities/posts such as the PPIE lead, the PPIE Advisory Board, Research Partners Group and events such as World Patient Safety Day. Each theme has a separate PPIE budget to pay for public involvement activities for research projects, following the NIHR Payment Guidance for Researchers and Professionals (August 2022). We have also received additional funding from NIHR to lead the PPIE/EDI stream of the PSRC National Network (SafetyNet).

Partnerships and collaborators

We continue to work in partnership with the Imperial Academic Health Science Centre (AHSC). We will continue our collaborations with:

- North West London (NWL) Integrated Care System and Integrated Care Board and its constituent members including, Central and North-West London NHS Foundation Trust and West London NHS Trust
- Local academic and health organisations (<u>Imperial College Health Partners</u>, <u>Imperial College's Institute for Global Health Innovation</u>) and NIHR funded organisations (e.g. other PSRCs, <u>North West London Clinical Research Network (CRN)</u>, <u>Imperial Clinical Trials Unit</u>, <u>North West London Biomedical Research Collaboration (NWL BRC) including PERC</u>, <u>London In Vitro Diagnostics Cooperative (IVD)</u>, <u>North West London Applied Research Collaboration (ARC)</u>)
- 3. Health Data Research UK Alliance
- 4. Third sector and NWL community organisations including charities and groups
- 5. Industry
- 6. Local government

Appendix 2: Background and definitions

Background to this strategy

Our PPIE strategy builds on the NIHR Imperial Patient Safety Translational Research Centre 2017-2022 strategy, Imperial College Healthcare NHS Trust (ICHT) PPIE strategy, NIHR best practice, Going the Extra Mile and the UK standards of public involvement in research. In particular it builds on learnings from the PSRC's PPIE Advisory Board (established May 2017) and Research Partners Group (RPG), established in October 2017 and ICHT's Strategic Lay Forum (SLF), established in November 2015. The SLF's role is to ensure that patients are at the centre of ICHT's care and to support it in becoming user-focused by listening, understanding, and responding to patient and community voices and insights. The key groups who were involved in the development of this strategy were the PSRC PPIE/Equality, Diversity and Inclusion Working group and PPIE Advisory Board, including three public partners.

NIHR Patient Safety Research Collaborations

There are six Patient Safety Research Collaborations across the UK. PSRCs are a partnership between universities and NHS trusts that support patient safety research, funded by the NIHR. PSRCs carry out research to improve patient safety, looking at topics including service delivery, patient safety behaviours, clinical decision making, and transitions between care settings.

NIHR North West London Patient Safety Research Collaboration

The NIHR North West London Patient Safety Research Collaboration (PSRC) is a partnership between Imperial College Healthcare NHS Trust (ICHT) and Imperial College London.

Patient and Public Involvement

NIHR defines patient and public involvement in research as research being carried out 'with' or 'by' patients/carers/members of the public, rather than 'to', 'about' or 'for' them. This includes offering advice from a public perspective and working in partnership with researchers to, for example: come up with research ideas, review research documents, carry out research (e.g. doing interviews or analysing data), and communicate about research to others.

A patient is someone who is currently receiving healthcare or has recently completed an episode of care. Research can benefit from patients' unique experiences of the healthcare system and/or their understanding of their condition. Carers or family members of patients can bring a different perspective, particularly giving insight into the experience of those who do not have capacity to contribute themselves. Members of the public can also become involved in research, for example on populations (e.g. *How to discourage members of the public from expecting antibiotics to be prescribed for colds and sore throats?*). In this document, "public members" describes patients, carers or community member who attend PPIE interactions e.g. a workshop to share their views on a topic.

"Public partner" is a term used to describe patients, carers and members of the public with a specific role in designing or implementing a research study, working in partnership with researchers and healthcare professionals. For example a public partner is a member of a steering group who has significant involvement and influence on a project.

Co-production

Co-production is when a project is co-produced with researchers, healthcare staff and public members or organisations from start to finish. Power is shared equally between stakeholders, there is shared decision-making and everyone benefits from the interaction.

Public Engagement

Public engagement refers to information about research being shared and discussed with patients, carers and members of the public, ideally as a two-way conversation. This includes:

- Talks and discussions about research at <u>events</u> (e.g. conferences, science festivals and meetings);
- A tour of a hospital or research centre;
- The sharing of research findings from a study with the participants of the study, other patients and/or members of the public;

 Media communication (e.g. TV programmes, newspapers, <u>videos</u>, <u>social media</u> and blogs).

Participation

Contrary to involvement or engagement, participation is when research is carried out 'to', 'about' or 'for' people. For example, this includes when a patient is having a new treatment tested on them as part of a clinical trial or when public members are having data about them collected and analysed in a scientific way. This could also be in the form of a survey, interview or focus group, but the data is used to answer a research question rather than to influence the design of a study. For example, being part of a study to see whether listening to music before surgery improves outcomes of the surgery.

Under-served group

The definition is highly context-specific with no single definition; it will depend on the population, the condition(s) or situation being studied and the question being asked by research teams. Some key characteristics common to several under-served groups are:

- Lower inclusion in research than one would expect from population estimates
- High healthcare burden that is not matched by the volume of research designed for the group
- Important differences in how a group responds to or engages with healthcare interventions compared to other groups, with research neglecting to address these factors (NIHR INCLUDE Project).

Appendix 3: PSRC overall goals and research themes

Our PSRC vision is to improve the safety of both patients and healthcare workers by:

- Reducing inequalities in safety outcomes among different patient and staff groups;
- Tackling unresolved challenges in patient safety (differences in provider and patient behaviours, increasing complexity and severity of patient presentations);
- Addressing the challenges and lessons of the pandemic (longer waiting lists, transitioning to new models of care);
- Harnessing transformative technologies to improve care, while addressing its current limitations.

The research themes for the PSRC are:

- Theme 1 Exploring how patient and healthcare worker behaviour can be influenced to optimise safety and minimise risk
- Theme 2 Developing and testing technologies that enhance medication safety
- Theme 3 Using integrated care data to address patient safety challenges
- **Theme 4** Evaluating and integrating patient safety in the design of new service delivery models