

PPIE Strategy

Developed: June 2023 – live document

List of Abbreviations

MLTC	Multiple long-term conditions
NIHR	National Institute for Health and Care Research
NU	Newcastle University
PPIE	Patient and public involvement and engagement
PSRC	Patient Safety Research Collaborative

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1.0: Background to the Newcastle NIHR Patient Safety Research Collaborative

1.1: Context

Led by Professor Andrew Husband, the Newcastle NIHR Patient Safety Research Collaborative (PSRC) is focused on delivering visible research that results in real-world, transformative change for patient safety and health outcomes for those with multiple long-term conditions. Specifically, the work will be focused on the use of medicines, polypharmacy and the transfer of care between different healthcare environments.

There are four themes of focus making up the NIHR Newcastle PSRC:

1. Artificial intelligence and data science in multiple long-term conditions
2. Safer management of polypharmacy in multiple long-term conditions
3. Safer integrated health and social care environments
4. Safer management of multiple long-term conditions in disadvantaged communities

As reflected in our aims (discussed in Section 1.4 below), the NIHR Newcastle PSRC will ensure everyone can get involved with the research and work we do – including our staff, patients, and members of the public, regardless of protected characteristics, career stage or profession.

1.2: Executive summary

Patient and public involvement, engagement and participation (PPIE) is central to our PSRC, which will ensure that research is co-produced with those most at risk of multiple long-term conditions (MLTCs). PPIE is embedded in all the themes, so that our PSRC addresses the needs of patients, carers and the wider community, thus enabling our research to be accessible and relevant, and leading to improved health and care. We have drawn upon engagement with patients/public to underpin the initial plans of our PSRC. We will build on existing, and create further, strong PPIE partnerships with local and regional public, community and patient groups.

We will embed PPIE in the development and delivery of our PSRC through its governance, influencing all stages of research activities and subsequent dissemination, thereby maximising impact. This PPIE strategy is a working document, which will be co-developed with further input from PPIE members as the work of the PSRC progresses. Our PPIE approach and plans are informed by the UK Standards for Public Involvement in research. These are reflected in our **strategic objectives for PPIE for the PSRC, which are to:**

1. Co-produce and co-develop research in partnership with patients/public/communities.

2. Engage with communities and populations, under-represented in research and most affected by MLTCs.
3. Include public representation in the governance of our PSRC through visible involvement in leadership, research management, dissemination and knowledge mobilisation.
4. Equip, enable and empower researchers and patient/public members to build a vibrant, skilled and sustainable PPIE community.
5. Undertake continuous learning by assessing the difference that PPIE makes to research and share learning with research and practice communities in health and social care.

1.3: Our team

The NIHR Newcastle PSRC team, all of whom are committed to equality, equity, diversity and inclusion, are listed below:

Director: Professor Andy Husband

CEO: Dame Jackie Daniel, Newcastle upon Tyne Hospitals NHS Foundation Trust

Operational Support

Operations Manager: Gwen Forster

Operations Administrator: Pippa Wood

Theme 1: Artificial Intelligence and Data Science in multiple long-term conditions

Professor Nick Reynolds - Theme co-lead

Professor Mike Barnes - Theme co-lead

Theme 2: Safer management of polypharmacy in multiple long-term conditions

Professor Adam Todd - Theme co-lead

Professor Barbara Hanratty - Theme co-lead

Theme 3: Safer integrated health & social care environments

Dr Hamde Nazar - Theme co-lead

Professor Neil Watson - Theme co-lead

Theme 4: Disadvantaged Communities

Professor Linda Sharp - Theme co-lead

Professor Clare Bamba - Theme co-lead

Patient & Public Involvement and Engagement (PPIE)

Professor Sheena Ramsay - Co-lead

Olivia Grant - Co-lead

Education & Training

Dr Niina Kolehmainen - Co-lead

Professor Annette Hand - Co-lead

1.4: Partnership approach to plans for PPIE in NIHR Newcastle PSRC

To achieve our aims and ensure our responsiveness, we will establish a patient/public advisory group (PPAG) group. Following consultation with other PPIE networks and members, we are taking a considered and deliberate approach to bringing this group together. We are starting initially with a small group of PPIE members who have had some contact with our PSRC, and thereafter, increasing the membership in a targeted way to reflect the diverse communities who are affected by the conditions our research will benefit. Given the strong emphasis of our PSRC on inequalities and engagement, we will have inclusive representation from the public and community groups, who are typically under-served by research, for example people excluded by ethnicity, socioeconomic status, deprivation, disability or geography. This group will be chaired by our PPIE co-lead, Olivia Grant. The process for establishing this group has started. The group will meet regularly, the timings and frequency of the meetings will be decided by the groups collectively, and will be guided by the needs of PSRC research. Feedback and input from the group will be reported back to the PSRC Management Group and in turn to the Scientific Advisory Group. This will support the further development of the PPIE strategy and plans, which will be revisited continually. This channel of reporting will ensure appropriate external public representation into the governance structures of our PSRC.

The PPAG group will inform the PSRC by providing input into our research, for example, by helping to prioritise research for Themes. They will be a constant source of advice and scrutiny on planning research activities, dissemination, recommendations and impact of research findings.

1.5: Programme of activities below describe our plans to engage with and reach out to marginalised populations

A key feature of our PPIE strategy is to provide training, development and support for PPIE both to researchers and to public/community groups, particularly those who are under-represented in research. The goal is to help both PPIE members and researchers build confidence, communication and practical skills in PPIE. By supporting community groups/voluntary sector to build capacity in engaging with research; we will build on our existing models of reciprocal partnerships with voluntary sector organisations, where training and development is provided to PPIE members. We will plan regular workshops and training events for PPIE members.

We plan to create innovative PPIE activities such as videos and blogs as part of our PPIE strategy for making research accessible, and for wider dissemination. To ensure inclusive and wider access, we plan on co-creating videos and providing infographics in different languages. We have budgeted these essential PPIE activities, which range from participating

in governance and management structures, planning research activities, training, developing accessible resources, and dissemination.

For building meaningful engagement with under-represented groups, we will undertake proactive outreach activities, with existing voluntary sector groups so that we take our research to communities and listen and learn from them. To implement this, we plan an 'embedded peer-researcher or PPIE' model, where members in the community/voluntary sector are supported to facilitate engagement and reach into communities, as well as to upskill PPIE researchers in voluntary sector. In collaboration with our regional voluntary, community sector and social enterprise (VCSE) support network (VONNE), the embedded peer-researcher will help reach out to and engage with community/voluntary groups (*e.g.*, minority ethnic groups, deprived regions, rural communities), and provide input and insights on our research from the perspective those with the greatest needs. This role will enable upskilling and training members of community organisations or the voluntary sector. This approach will help create a reciprocal and sustainable model of PPIE. There is a successful pilot scheme of such a model in our region, which is supported by a collective of NIHR and other research networks. We have started discussions to join this collective effort to support a 'peer researcher' who will also link in with our PSRC.

Our strong collaborations at local, regional and national level provide key leverage for our PPIE strategy. An important aspect of our approach to PPIE is to collaborate with and learn from other PPIE networks in our region, particularly with NIHR networks. We have taken time to listen to and build relationships with these different networks. 'Creating Connections' is a network in our region, which brings together PPIE across NIHR North East North Cumbria Applied Research Collaboration (NENC ARC), Fuse Centre for Translational Public Health Research (NIHR School for Public Health Research), and the NIHR Biomedical Research Centre (BRC), and VOICE. VOICE (<https://www.voice-global.org/>) is a global PPIE platform hosted at the National Innovation Centre for Ageing at Newcastle. The regional 'Creating Connections' Group co-ordinated by the NIHR Research Support Service (RSS) bring together public involvement networks across NIHR infrastructure, NHS organisations and Universities. We will also seek to extend our links with other relevant networks, such as the Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (CNTW) PPIE group. We will work with these collaborations to share ideas and learning, plan our dissemination, training, and knowledge mobilisation activities.

1.6: Learning and evaluation

Learning from undertaking PPIE in research is fundamental to our PPIE plans. Our PSRC research will be evaluated to assess the impact that PPIE is having on research, wider PPIE community, and on the impact our research is having on people affected by multiple long-term conditions (MLTCs). Building capacity and skills amongst PPIE contributors, including enhancing professional and personal skills, confidence and self-esteem are important outcomes our PPIE strategy seeks to achieve. Similarly, up-skilling our researchers to have the confidence and skills to undertake meaningful PPIE are impacts we will look to evaluate. We will also understand and seek input from our PPIE members about what they find to be important to measure the impact of PPIE.

A continuous learning process will be adopted whereby feedback on PPIE activities will be sought, using 'plan-do-study-act' approaches. In addition, formal evaluations of PPIE will be undertaken using frameworks such as the public involvement impact assessment framework to ensure that we are undertaking and developing evidence-based PPIE. The learning from PPIE activities will be shared widely with the research and PPIE community and the public locally and regionally to maximise the impact of PPIE.

2.0: The programme(s) of activities or plans to deliver the strategic objectives

The programme(s) of activities or plans to deliver the strategic objectives are described below:

PPIE strategic objectives and programme of activities	Activities	Themes	Milestones
Co-produce and co-develop research in partnership with patients/public/communities.	PPAG group of PPIE members: advice and scrutiny on planning research activities, dissemination, recommendations and impact of research findings.	Central PPIE Support All Themes	Review and establish in year 1
	Develop strong partnerships with regional PPIE networks, such as ‘Creating Connections’, which includes NIHR ARC NENC, BRC, Voice, Fuse Centre for Translational Public Health – to share learning and best practice, plan and coordinate dissemination, training, and other PPIE activities.	Central PPIE support	Starting in Year 1 and ongoing
	Monitor PPIE resources against committed budget.	Central PPIE support	Ongoing
	PPIE Researcher to support, lead and coordinate PPIE activities and strategy development	Central PPIE support	Start in Year 1
	Data science strategy linked to a fully integrated PPIE strategy – for example, involving patients and public in the design and development of trusted research environments (TREs)	Data and AI related theme	Years 1 and 2
	Develop and agree protocol for longitudinal qualitative study alongside PPIE input.	Polypharmacy	Year 1

PPIE strategic objectives and programme of activities	Activities	Themes	Milestones
	Develop protocols for the scoping and realist reviews for the evidence synthesis projects alongside PPIE input. Publication of finalised protocols for each in online open access repository eg. PROSPERO	Polypharmacy	Year 1
	Consult on and develop research proposals on behavioural and digital systems mapping in partnership with PPIE.	Integrated Health & Social Care	Year 1 and beyond
	Develop protocols for initial theme projects with PPIE involvement.	Disadvantaged Communities	Year 1
	NIHR Newcastle PSRC PPAG will work closely with AI-MULTIPLY PAG and also reach out to patients and carers associated with the care pathways in dermatology and ophthalmology. Theme study aims and outcomes will reflect patient and public priorities. Form and integrate PPIE groups within and across themes. Form and integrate with other NIHR infrastructure PPIE groups reaching out to patients and carers associated with the care pathways in dermatology and ophthalmology. Recording actionable feedback. Influencing study design through a 'you said, we did' approach.	Data and AI	Years 1 to 5

PPIE strategic objectives and programme of activities	Activities	Themes	Milestones
Engage with communities and populations, under-represented in research and most affected by multiple long-term conditions (MLTC).	Ensure inclusive representation on PPAG group, especially from groups typically under-served in research, for example people excluded by ethnicity, socioeconomic status, deprivation, or geography	Central PPIE Support All Themes	Start in Year 1 and review every year
	Plan innovative PPIE activities such as creating videos and blogs for making research accessible, and for wider dissemination. To ensure inclusive and wider access, plan co-creating videos and infographics in different languages.	All themes	Years 2 to 5
	Undertake proactive, outreach activities to take our research to communities and listen and learn from them.	All themes	Years 1 to 5
	‘Embedded peer-researcher’: co-fund peer researcher with ‘Creating Connections’ network – PPIE member(s) in the community/voluntary sector to help reach out to and engage with community/voluntary groups	Core support	Year 1

PPIE strategic objectives and programme of activities	Activities	Themes	Milestones
	<p>Working with AI Multiply PAG to ensure NLTC-PP study aims and outcomes reflect patient and public priorities:</p> <ul style="list-style-type: none"> <li data-bbox="524 485 1379 655">i) Applying innovative explainable AI-methodology and insights gained from AI-MULTIPLY to identify risk and improve safety for patients with MLTC-PP. Develop clinical risk scores and identify tipping points, that can be tested and implement innovative solutions that will impact care. <li data-bbox="524 699 1379 836">ii) Develop novel, explainable and innovative interventions to a) prioritise high-risk patients and b) optimise clinical audit, care pathway development and staffing requirements in out-patient specialities. 	Data and AI related theme	Years 1 to 5

PPIE strategic objectives and programme of activities	Activities	Themes	Milestones
	<p>Develop and implement novel ways of involving, engaging and facilitating participation for patients and the public in the research outputs of the PSRC: Our PPIE strategy is focused on involving, engaging and encouraging participation in our research from a range of communities.</p> <p>We will undertake research in the area of PPIE, to understand what impact these activities have on the research process, on how we disseminate our work and what impact the work has.</p> <p>We will focus on communication of the outcomes of research and how we reach disadvantaged communities with the outputs of the PSRC.</p> <p>Research findings will be accessible and understandable throughout the communities we serve.</p>	Core All Themes	Years 2- 5
Include public representation in the governance of PSRC through visible involvement in leadership, research management, and dissemination and knowledge mobilisation.	PPAG with PPIE members Steering Committee Representation	Central PPIE Support	Years 1 to 5
	PPIE input in development of research plans and dissemination	All themes	Years 1 to 5

PPIE strategic objectives and programme of activities	Activities	Themes	Milestones
Equip, enable & empower researchers and patient/public members to build a vibrant, skilled and sustainable PPIE community.	Provide training, development and support for PPIE to PSRC researchers	Central PPIE Support All Themes	Years 1 to 5
	Training for PPIE members, public/community groups, particularly those who are under-represented in research	Central PPIE support	Years 1 to 5
	Support 'embedded researchers' through training and involvement in research.	Central PPIE support	Years 1 to 5
	Recruit a diverse and multi-professional cohort of interns, MSc and PhD students and postdoctoral fellows: The PSRC will create an actively inclusive recruitment process, in partnership with our PPAG and PPIE Theme Leads to attract the best talent into the collaborative	Core E&T	1-2 years
Undertake continuous learning by assessing the	Learn from & evaluate PPIE to assess impact that PPIE is having on research.	Central PPIE Support All Themes	Years 1 to 5

PPIE strategic objectives and programme of activities	Activities	Themes	Milestones
difference that PPIE makes to research and share the learning widely with research & practice communities in health, social care and voluntary sector.	Evaluate impact of PPIE on building capacity and skills amongst PPIE contributors, including enhancing personal skills, confidence and self-esteem.	Central PPIE Support All Themes	Years 2 to 5
	Impact on up-skilling PSRC researchers to have the confidence and skills to undertake meaningful PPIE.	Central PPIE Support All Themes	Years 2 to 5
	A continuous learning process to be adopted for feedback on PPIE activities using plan-do-study-act approaches.	Central PPIE Support All Themes	Years 1 to 5