

NIHR Policy Research Unit for Maternal and Neonatal Health and Care (PRU-MNHC)

Parent, Patient, Public Involvement and Engagement
(PPPIE) Strategy 2024 to 2028



Introduction

The NIHR Policy Research Unit in Maternal and Neonatal Health and Care (PRU-MNHC) focuses on providing robust research evidence to support policy and practice to optimise the health of women, their babies, partners and families. This document sets out the Parent, Patient and Public Involvement and Engagement (PPPIE) Strategy for this work to ensure that the voices of [women, their partners and families](#) from diverse backgrounds and experiences are at the heart of all our research. The strategy has been co-developed by our PPPIE Task Group, led by our PPPIE lay co-leads. This plan will be monitored and reviewed annually by the PPPIE Task Group.

Background

The National Perinatal Epidemiology Unit (NPEU) has conducted policy research in maternal and neonatal health and care as part of its core programme of research since its foundation in 1978. Involving women, parents and the organisations that represent them in this research has always played a central role in our work.

Our goal is to build on what has been achieved so far, by setting out a clear strategy for improving and expanding parent, patient and public involvement and engagement (PPPIE) in the research undertaken by the PRU-MNHC. This strategy document sets out our vision, aims and objectives for the PRU-MNHC for the next five years, how we will achieve them and how our progress, and any impact from what we do, will be measured.

The first iteration of this strategy was developed for the 2019-2024 PRU-MNHC. During that period we also secured funding to run a project we called [The Listening Series](#). This was a project to hear from women and families who are underrepresented in research about what researchers need to do to make it easier for them to get involved. Five key themes emerged from this work:

- building relationships and trust
- involving stakeholders from the outset of projects
- showing the impact our research has for diverse individuals, groups and communities
- communicating clearly in formats that are appropriate to the needs of different audiences
- continually imagining life in the shoes of the people we are aiming to hear from/reach/include.

Our vision aims and objectives have been adjusted to ensure these themes are embedded in our work.

As some of our work involves the analysis of routinely collected health data, we are also mindful of our contribution to maintaining the social contract which ensures public

acceptance of the use of personal data for research purposes. PPPIE is particularly important to bridge the gap between data scientists and the people to whom the data relates. The principles developed for the Consensus Statement on Public Involvement and Engagement with Data-Intensive Health Research, published in the International Journal of Population Data Science, also underpin our work.

The PRU-MNHC's research programme sits under 5 key themes:

- **Supporting healthy behaviours pre-conception, during pregnancy and postnatally**
- **Pregnancy loss and perinatal morbidity and mortality**
- **Maternal mortality, morbidity and experience of care**
- **Neonatal care**
- **Workforce and maternity/neonatal care systems**

We use a variety of methods to answer research questions for projects in each theme. For instance, we collect information from parents and health professionals through surveys and interviews, and use anonymous information from routinely collected health records. Sometimes we gather all previous research on a topic and combine the data from each study. This gives us a more accurate picture of what we know so far about a particular aspect of maternal or newborn health, than a single study. Many of our studies use epidemiological analysis where we study how often health-related events happen in a population, and whether they affect some groups or communities more or less than others.

Our research has two cross-cutting themes:

- **Improving equity and equality** – to improve clinical outcomes and experiences of care for women and babies most likely to have the poorest outcomes
- **Big data and analytics** – to support informed choice and decision-making and improve cost-effectiveness of care.

New topics for research under each theme will evolve from our ongoing discussions with people in government working in maternity and newborn policy, as well as with the co-investigator group and following broad consultation with our PPPIE stakeholders. The resulting research questions will be incorporated into the programme of work with the agreement of the PRU-MNHC Oversight Group. This group comprises policy and practice representatives from the Department of Health and Social Care, NHS England, the Office for Health Improvement and Disparities and others, and oversees the work of the PRU-MNHC.

Definitions

We work to the [NIHR](#) definition of patient and public involvement and engagement¹ as well as recognising and celebrating the unique characteristics of the population we research. PPPIE for the PRU-MNHC is defined as **parent, patient and public involvement and engagement**.

It encompasses women, mothers, fathers, partners and other family members as well those individuals who are not yet pregnant, but who may in the future be impacted by reproductive health policies in England. Where appropriate it may include adults affected by maternal pregnancy complications in their own early lives, as well as children affected by the experience of a sibling dying before, during or shortly after birth.

Our PPPIE also includes organisations that represent, work with, support or advocate for these populations, and may support us in involving them. We refer to all these individuals, groups and organisations as our '**PPPIE partners**'. When we talk about our '**stakeholders**', we are referring to our PPPIE partners as well as all the co-investigators, our researchers, and our Oversight Group, as well as policy makers, service providers and clinicians.

We also work to the [NIHR](#) definition of public involvement and engagement activities:

- Participation considers parents, patients or the public who allow their data to be used in a particular project.
- Involvement refers to parents, patients or the public being involved in the prioritisation, design or execution of research.
- Engagement includes researchers and our PPPIE partners providing and sharing information and knowledge about the research with the wider world, both public and professional.

Vision

Our vision is for PPPIE to be at the heart of all PRU-MNHC research. Insights from our PPPIE partners will contribute to study design, development of research, as well as execution, interpretation and dissemination. Their involvement will result in research which influences policy and improvements in care, making a positive difference to the lives of women, their babies and families in England. While it will specifically influence policy in England, our research has potential for international relevance and we will disseminate it widely through our international networks. Our PPPIE will be built on the principle of 'no research about us without us'.

This will ensure that our research is responsive to developments in family life, society and changing health services and remains relevant

¹ 'When using the word 'public' we mean patients, potential patients, carers and people who use health and social care services and well as people from organisations that represent people who use services'
www.involve.org.uk

We will achieve our vision by creating a research culture which empowers and benefits all our stakeholders and aims to be a model of best practice within the scope of each research methodology we use. We will apply learning from The Listening Series.

We will consult our PPPIE partners on what is working and what is not working in our strategy and share any learning with other Policy Research Units through meetings, publications and conferences.

Figure 1. The research process and what involvement and engagement means (adapted from NIHR 2018)



Aim and objectives

Our key aim is to empower PPPIE partners from across the ethnic, social and demographic spectrum, as well as researchers, to join together in shared decision making to shape

different stages and aspects of the research, dependent on the methodology. Our strategy sets out how we will achieve this aim through objectives which reflect our values, developed from the NIHR's National Standards for Public Involvement in Research². We will achieve these objectives through a regular programme of activities developed and agreed by our PPPIE Task Group, a multi-disciplinary group of academic and lay contributors who are responsible for the delivery of our strategy.

Delivering our aims and objectives

Delivering the strategy will be monitored and reviewed by the PRU-MNHC PPPIE Task Group. The Task Group is made up of up to four researchers, two lay co-leads and four other lay members, with backgrounds and experiences which reflect those of families who are under-represented in health research but most likely to experience the poorest outcomes. These include families from Black and Asian ethnic backgrounds, women with disabilities and younger parents. This new and expanded Task Group, an innovation since the PRU-MHHC 2019-2023 (see infographic below) will ensure that achieving inclusivity and addressing health inequalities is central to delivering all our PPPIE objectives.

² National Standards for Public Involvement in Research [invo.org.uk](https://www.invo.org.uk)



Figure: Putting PPIE at the heart of the PRU

Objective 1

We will be inclusive and diverse, actively involving our PPIE partners in our research, and inviting PPIE from a range of ethnic and socio-demographic groups and including, where possible, a variety of genders, ages, ethnicities, cultures, abilities and experiences, ensuring all views and experiences are heard and valued.

We will do this by:

- Continuing to map our existing PPIE against the representative population and filling the gaps in our PPIE partner network.
- Working to expand and deepen our connections with a range of local and other community organisations working with pregnant women and new families.
- Building on what we have learnt from work in 2019-2023, specifically the Listening Series, we will explore new research approaches which reach and address the needs of under-represented individuals and communities to ensure their voices are heard.

Objective 2

We will build capacity by supporting our PPPIE partners and researchers to engage, through mentoring, training, sensitively-designed opportunities and events as well as clear communications.

We will achieve this by:

- Upskilling researchers by providing them with opportunities for PPPIE induction, through internal or external training. Helping them build knowledge, skills and resilience in reaching, listening and responding to PPPIE, in particular those most affected by poor outcomes but least represented in research.
- Supporting researchers to identify training needs for newly recruited PPPIE panels associated with individual studies and addressing those needs.
- Identifying the gaps in information needs for our PPPIE partners and developing resources to support them in engaging with research.
- Ensuring all our external communications platforms are up to date, accessible and engaging to our audiences, and identifying the gaps in information needs for our PPPIE partners and developing resources to support them in engaging with research.
- Where funds allow, innovating new ways of sharing information such as podcasts, animations and films.

Objective 3

We will consult and co-produce with our PPPIE partners at every relevant stage of our work, ensuring our work is always communicated in a way that is clear, concise, sensitive and appropriate for each audience.

We will achieve this by:

- Setting up PPPIE topic-specific panels where appropriate.
- Triaging individual studies with PPPIE lay co-leads and lay Task Group members using our methodology-specific Guidance Tool (see example in Appendix A).
- Developing PPPIE plans and role descriptions for each project.
- Ensuring that rapid response projects, have, at a minimum, PPPIE support from our lay Task Group members.
- Working with our researchers and our PPPIE partners to co-produce dissemination plans for individual research projects that will reach all appropriate audiences.
- Exploring potential work with other organisations and their PPPIE panels, such as the Clinical Networks, Royal College of Obstetricians and Gynaecologists and the Royal College of Paediatrics and Child Health.

Objective 4

We will monitor and evaluate our PPPIE progress for individual studies, as well as the impact of our research on our stakeholders.

We will achieve this by:

- Monitoring and evaluating the progress of PPPIE for each study using a tool we have developed called the '8 Rs' (Appendix B).
- We will report the involvement of PPPIE in all our studies using GRIPP2-SF (short form checklist), the first international, evidence-based tool for reporting PPPIE in research (Appendix C) and review our work in the light of reporting.
- Conducting an informal evaluation of the impact of research on maternity and newborn policy through existing contacts within the Department of Health and Social Care and with other ALBs as changes to policy emerge.

Objective 5

We will bring about innovation and learning by adding to the evidence-base for how to achieve effective PPPIE in a policy research unit.

We will achieve this by:

- Reflecting on what we've achieved and learned, and continually reviewing and improving the effectiveness of our PPPIE Task Group.
- Reflecting on what we've achieved and learned, and continually reviewing and improving how we involve and engage our PPPIE partners.
- Sharing our learning via our annual report, bi-annual mailings to our PPPIE partners and our PPPIE partner stakeholder days.
- Aiming to publish key elements of the development and progress of our strategy in journals such as *Research Involvement and Engagement*.
- Presenting aspects of our PPPIE at relevant conferences such as ENGAGE, which is organised by the [National Co-ordinating Centre for Public Engagement](#).

Objective 6

We will focus on the future by growing sustainable PPPIE.

We will achieve this by:

- Training and supporting our lay PPPIE Task Group members.
- Discussing the use of health data and data linkage with our PPPIE Partners, and exploring the responses of different groups and demographics to increased data sharing.
- Involving and engaging a wider network of women, family members, parents, and their representatives as needed.
- Ensuring recent service users are represented among our PPPIE partners

- Ensuring that our PPPIE relationships are strong and reflect a principle of ‘reciprocity’, so that being involved benefits our PPPIE partners as well as our researchers.

Implementation

Programme of activities and milestones

To achieve our aim and objectives, we will deliver a programme of activities each year of the PRU-MNHC. Some of these will be regular activities covered by our current budget, such as our annual PPPIE stakeholder meetings; communication and training activities; support for individual studies, and our dissemination and engagement plans.

We will also set milestones in our strategy for innovating new work for PPPIE. We will try, wherever possible, to ensure this work is cost-neutral but some innovations may require further funding beyond our existing budget; our PPPIE Task Group will horizon scan for funding opportunities. Innovative projects beyond our regular activities will inevitably be impacted by our ability to secure these extra funds.

Resources

The PRU-MNHC has budgeted for two PPPIE lay co-leads (Plachcinski and Bevan) to support the delivery of its PPPIE strategic objectives with the support of the PPPIE Task Group.

The PPPIE Task Group will comprise a PPPIE co-ordinator, at least two researchers and at least four lay PPPIE representatives, reflecting broad sociodemographic and birth/parenting experiences. The PPPIE co-ordinator will be responsible for the day-to-day delivery of the strategy, and co-ordinate PPPIE and communication activities.

There are additional resources within the NPEU including graphic design expertise. Where appropriate, PPPIE activities will also be supported by the Public Engagement Officer in the Nuffield Department of Population Health, University of Oxford. Where there is no resource available for a new piece of work, our PPPIE Task Group will seek extra funding opportunities.

Governance, leadership, reporting and reviewing

PPPIE in the PRU-MNHC will be led and overseen by Associate Professor Rachel Rowe, the two PPPIE co-leads, and the PPPIE Task Group. This group, which reflects a broad range of PPPIE expertise, lived experience and research expertise, has developed this strategy and is responsible for monitoring and reviewing its effective implementation, arranging training to ensure both researchers and our PPPIE partners can collaborate confidently and competently, and supporting PPPIE activities. This group will meet every three months and report to the Programme Management Group (see Appendix D).

Payment and recognition for PPPIE

We will offer fees and expenses to PPPIE partners to ensure that:

- All our PPPIE partners feel that their work is recognised and valued
- No one is left out of pocket as a result of working with us

Our PPPIE partners will be recompensed in line with the [NIHR](#)'s public contributor payment policy, based on a day rate of £150. Fees will be offered when we ask a partner to undertake a specific task, such as attending a meeting or reviewing documents. All fees are honorarium payments and do not mean individuals have a contract of employment with PRU-MNHC. No one is obliged to accept a fee that is offered and we will remain flexible in our approach, exploring with our PPPIE partners whether there are alternative preferred ways of recognising their contribution to our work.

We will cover or reimburse all reasonable expenses associated with requested involvement, such as travel, childcare and telephone costs. We will offer to pay directly for expenses, where possible. Claims for expenditure must include original receipts and will be processed as quickly as possible. We will continue to review payment policies based on departmental and NIHR guidance.

Contact us:

Any queries about parent, patient and public involvement at the PRU-MNHC can be sent to Nisha Shah, Research Facilitator at npeuppi@npeu.ox.ac.uk.

Appendix A

Guidance for Researchers to deliver PPIE for secondary analysis

If you have to apply for the data you are researching, then having PPIE as part of your application is important. Researcher **Victoria Coathup** explains how this worked for her study looking at maternal BMI and childhood infection through routinely collected data.

“To apply for the Scottish data we had to evidence that we had consulted with a PPIE group as part of the process. Through the PRU-MNHC’s PPIE co-lead, Rachel, we got in touch with an organisation called Big Births, who provide support and information for pregnant women who have BMIs over 30. We eventually had both a representative from the charity itself, as well as nine other women who had responded to the recruitment Birth Births had helped us with via social media. These were women who gave birth in Scotland during the study period, and therefore were likely to be in the dataset we were applying for.”

Victoria Coathup

Whether PPIE are named on your data application or not, engaging PPIE **early** as part of the study may help you look at what findings/outcomes haven’t yet been more deeply explored and may benefit from secondary analysis. Their experience of services may shed valuable light on gaps in the evidence base and therefore maybe influence decisions about priorities/gaps in secondary data analysis or indeed how to approach the study. See case studies below:

“The PPIE group helped us think about how breastfeeding would be categorised as there are big differences between exclusive, mixed and those who breastfeed for a few days and then swap to formula.”

Victoria Coathup

“For the [Birth after previous C-section](#) project, getting the data on pelvic floor was really complex and messy, but our PPIE group said it was important so we persevered. They also highlighted that perinatal mental health was key and this become another outcome we measured.”

Kate Fitzpatrick

“For TIGAR [how being born early might affect a child's health and their progress at school] we looked at hospital admissions and school results. We struggled to get data on school results initially but we pursued this, and included this in the case for an extension to the funder, because this was really important to parents on our PPPIE group.”

Maria Quigley

“For a responsive project exploring the pre-conception advice provided to women by their GP, we discussed our plans with a PPPIE group that Rachel helped us recruit. The group helped us to think about what might be driving the patterns we see in the data, such as the groups of women most likely to seek pre-conception advice from their GP, and what they go to the GP to talk about. This helped us to think more broadly about the codes that are part of general health promotion prior to pregnancy, as well as those more clearly linked to pregnancy planning such as discussions about folic acid.”

Claire Carson



When the research findings are concluded, PPIE can...



- comment on key findings from the secondary analysis, once it's conducted
- help write lay summaries of findings including infographics, website material, tweetable summaries. It may be they can suggest ways of summarising the work to make it more accessible (such as animation) and help you with/lead application for further grants for these types of comms
- support dissemination through their own communications, community/group meetings, social platforms, networks and conferences
- translate reports into different languages for their communities to improve your reach
- talk at conferences provide quotes or contextual narrative, and speak to the media giving first-hand experiences which will bring the study 'to life'.

"For [TIGAR](#) a lead from a support organisation said the lay summary was nice but too long so then we designed a short version....But it's important to know even if you think you've got it right, and we had several people on our groups, you still may receive unexpected responses from the public. One mum of a baby who was premature emailed to say she felt the signposting for support should have been clearer. I then worked with Charlotte, the PRU-MNHC PPIE co-lead, to review the information and let the mum know we'd done this."

Maria Quigley

"We could not have produced lay summaries coherently for the [Birth after previous C-section](#) study without the group's feedback. One member felt the lay summary was too long and had too much detail so we produced a one-page summary.

Our PPIE also highlighted it was important to empower women to make informed choices which impacted their care. Since research showed that third and four degree tears only occur in those planning VBAC, rather than highlight that negative findings, we commented on what they could do to prevent that happening."

Kate Fitzpatrick

Who, how & what: Identifying which PPPIE partners are relevant to the research

- individuals with lived experience of a particular condition or from a social demographic that's relevant to the research. For instance: TIGAR included not only mothers who had children born prematurely, but organisations who support families as well as adults born premature themselves and aware of the impact being premature had on their medical and educational needs.
- organisations that support people, work with people or represent them
- small organisations (both single issue charities and those run by individuals) or big, national organisations – the former may have capacity issues but strong views, the latter may be more broadly representative

The PRU-MHHC has a PPPIE network of more than 100 organisations and individuals we have worked with over the years and which we are aiming to make more inclusive with the help of lay members of our PPPIE Task Group. Call Rachel and Charlotte and we can help you identify organisations/individuals both on it, and possibly not on it we may need to include.

“For TIGAR we managed to recruit a really diverse group of people from mothers of premature babies to those working in the area of Special Educational Needs. We involved charities as well as adults who were born premature and therefore had important insights into the impact being premature had had on their lives.”

Charlotte Bevan

When you're inviting PPPIE partners it can be:

- by inviting them to be on a Steering Group or Advisory Group
- through regular meetings
- through one-off focus groups/workshops/consensus meetings

Consider what your PPPIE will need in order to engage. It may be:

- information that's clear and summarises, free of jargon, the research, its aims, what you expect from PPPIE, and what happens next, including Terms of Reference if appropriate.
- information in other languages and sensitive to people's educational and physical needs
- training in understanding the research methodology and how PPPIE partners might meaningfully contribute
- Information about frequency and length of meetings, location if face-to-face, and the likely or expected scope of their involvement
- financial support – expenses for transport, childcare, a half or full day's PPPIE payment. NIHR INVOLVE budget calculator for PPPIE is available here: *[provide hyperlink]*
- technical support – if you are aiming to communicate via conference calls/emails etc.

- emotional support – if the topic is likely to be sensitive, do you have the expertise available to support them if this is the case?
- sensitivity to the physical environment: is the location of meetings appropriate and sensitive to the group and topic you're discussing. Are there access issues? Will your PPPI partners need food and drinks and have you asked them in advance what their preferences are?

What to be aware of when identifying your PPPIE

- do you need to reach out beyond existing PPPIE partners at the NPEU and can the PPPIE Task Group help?
- how representative is the organisation/individual likely to be?
- if your PPPIE is single-issue driven, does that matter, or does your PPPIE need to represent a spectrum of views and experiences?
- are there any likely negative impacts for your PPPIE partners in being involved and have you reflected and prepared for this in advance? Might a negative impact occur after the research is complete?
- do you need people with expertise in supporting your particular PPPIE partners but who may not act as PPPIE themselves?
-

Consider what you might 'give back' to benefit your PPPIE which may have nothing to do with the project itself

- ask them if there is anything you can do for them that might benefit them in return for their support and within the limits of your resource and expertise
- if they don't identify anything because they are unsure, make suggestions or think of ways in which their involvement might lead to greater health literacy or help them return to education or training, and factor that into your relationship with them.

Adding an extra E - broader public Engagement

Engagement is about sharing the work more publicly. You will be able to do this with the help of your PPPIE partners or at other public engagement activities the university is associated with.

Knowing when you are getting it right

Monitor your PPPIE throughout against the '8 Rs' [[hyperlink](#)] and keep a log of all meetings, papers and discussions so you can measure the impact PPPIE has had at every relevant stage – whether it's positive or negative. Look at the GRIPP2-SF early on and use this log or 'diary' so that you can respond to the various GRIPP2 questions and evaluate and report the impact

of PPPIE at the end of the study. If you aim to write a paper focusing on your PPPIE it will be important to use the GRIPP2-LF [hyperlink] in the planning stages of your study and equally keep a log of all relevant papers, meetings and discussions throughout.

Contact [Rachel](#) and [Charlotte](#) who will be able to help you decide all of the above, alternatively email npeuppi@npeu.ox.ac.uk.

Appendix B

Monitoring, evaluating and reporting PPPIE for individual studies

The '8 Rs'³ - PPPIE Evaluation to inform Gripp2-SF reporting

- **Reach**

Have you reached the groups and people who matter to the research, and asked them relevant questions about the research, its focus, methodology, outcomes and dissemination?

- **Relevance**

Is your research relevant to the group(s) most affected by it? What was missing in previous research that could be improved upon?

- **Refinement & improvement**

Have you found PPPIE partners who can refine the questions you're asking, the methodology, the plain English information, its reach and relevance? Have you improved the research in the process?

- **Relationships**

How does your relationship with your PPPIE partners work? Do they or you need more training to make this more effective? How do you stay in touch with them, ensure communication has really taken place, and that people feel genuinely empowered to engage?

- **Reciprocity**

Have you ensured that your relationship with your PPPIE partners benefits them as well as you? Even well-established charities and third sector groups have limited funds and smaller organisations will have even less resource; it may be that you have the expertise to support them with another of their own aims and objectives not directly linked to the research. Ask them.

- **Record**

Have you kept a diary or record of your PPPIE, who you involved, how you involved them, what their experiences were and what the outcomes were for your research – both positive and negative?

- **Reflection**

Using your record or diary of your PPPIE interactions have you reflected on how these might be improved?

- **Response**

Ensure you respond to your PPPIE partners to let them know what has happened to the research, where it's been published and what the policy response and impact has been so far. Have you asked them about their own involvement, and how the published research may have impacted their work?

³ Innovated from recommendations in the NIHR's Going the Extra Miles <https://www.nihr.ac.uk/documents/about-us/our-contribution-to-research/how-we-involve-patients-carers-and-the-public/Going-the-Extra-Mile.pdf>

Appendix C

GRIPP2-SF (a short-form checklist for studies where PPIE is a secondary or tertiary focus) ⁴

Section and topic	Item	Reported on page
Aim	Report the aim of PPI in the study	
Methods	Provide a clear description of the methods used for PPI in the study	
Study results	Outcomes – report the results of PPI in the study including both positive and negative outcomes	
Discussion and conclusion	Outcomes – comment on the extent to which PPI influenced the study overall. Describe positive and negative effects.	
Reflections/ critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience.	

⁴ GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research
S Staniszewska et al, The British Medical Journal 2017; 358:j3453

Appendix D

Figure 1: Organisation Structure and Governance

