



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

Parent, Patient, Public Involvement and Engagement
(PPPIE) Strategy, 2019 to 2024



UNIVERSITY OF
BIRMINGHAM

CARDIFF
UNIVERSITY



UNIVERSITY OF
LEICESTER

MANCHESTER
1824
The University of Manchester

PRIFYSGOL
CAERDYD

UCL

Imperial College
London

FUNDED BY

NIHR

National Institute
for Health Research

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 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, with input from PRU-MNHC researchers, the PRU-MNHC Oversight Committee and our PPPIE partners. This plan will be monitored and reviewed annually by the PPPIE Task Group. Our plain language summary of the PRU-MNHC's work and our PPPIE strategy is included in this document (**Appendix A**).

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 all the research of 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 PRU-MNHC's research programme sits under 5 key themes:

- Health before pregnancy starts and optimising health throughout pregnancy
- Understanding pregnancy loss, why babies become sick or die and how to support bereaved parents
- Women's experiences of care during pregnancy, labour and afterwards and its impact on their health
- The care of newborn babies
- How health services are organised and deliver care.

Two to five projects are undertaken under each theme every two years. Our research methodologies encompass systematic reviews, epidemiological data analysis, qualitative research, secondary analysis, and surveys of parents and patients' experience. Tackling inequalities in maternal and neonatal health and care, as well as mental health and social care, feature as cross-cutting themes across the programme. New topics for research under each theme will evolve from the discussions with policy colleagues/customers and the co-investigator group, and following broad consultation with our stakeholders. New topics will be incorporated into the programme of work in agreement with the PRU Oversight Group.

Definitions

We work to the INVOLVE 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 pregnancy complications in their own early lives, as well as children affected by the death of a sibling due to their mother's perinatal loss.

Our PPPIE also includes organisations that represent, work with, support or advocate for these populations, and may support us in reaching them. We refer to all these individuals, groups and organisations as our '**PPPIE partners**'. A list of our current PPPIE partners can be found in **Appendix B**. 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 INVOLVE 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 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 social demographic spectrum and 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 as well as new and more innovative projects.

Objective 1

We will be inclusive and diverse, actively involving our PPPIE partners in our research, and inviting PPPIE from a range of socio-demographic groups and including, where possible, a variety of genders, ages, ethnicities, cultures, abilities and experiences, including same sex parents, adoptive parents, and parents who live separately, ensuring all views and experiences are heard and valued.

We will do this by:

- Mapping our existing PPPIE against the representative population and filling the gaps in our PPPIE partner network.
- Exploring new research approaches which reach and address the needs of seldom heard communities (See **Appendix C** for the Listening Series we conducted with representatives of under-represented groups, and subsequent resources developed).

Objective 2

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

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 including seldom heard groups.
- Identifying the gaps in training and information needs for our PPPIE partners and developing resources to support them in engaging with research.
- Exploring potential work with other organisations and their PPPIE panels, such as the Clinical Research Networks, Royal College of Obstetricians and Gynaecologists and the Royal College of Paediatrics and Child Health.

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 and sensitive.

We will achieve this by:

² https://www.invo.org.uk/wp-content/uploads/2019/02/71110_A4_Public_Involvement_Standards_v4_WEB.pdf

- Setting up PPPIE topic-specific panels where appropriate.
- Triaging individual studies with PPPIE Lay Co-leads using our methodology-specific Guidance Tool (see example in **Appendix D**).
- Co-producing clear, concise and appropriately targeted information about the whole programme of work with our researchers and PPPIE partners.
- Working with our researchers and our PPPIE stakeholders to co-produce dissemination plans for individual research projects that will reach all appropriate audiences.
- Where funds allow, innovating new ways of sharing information such as podcasts, animations and films.

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 E**).
- 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 E) and review our work in the light of reporting.
- Conducting an informal evaluation of the impact of research on maternity and newborn healthcare 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 way 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 Away Day.
- 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, and the NIHR's INVOLVE conference.

Objective 6

We will focus on the future by growing sustainable PPPIE.

We will achieve this by:

- Involving and engaging a wider network of women, family members, parents, including adoptive and foster 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.

In order to understand what progress we are making in achieving the objectives outlined above, we will conduct a baseline survey among our PPPIE partners, plus other internal and external stakeholders, using a questionnaire based on the NIHR National Standards for Public Involvement. We will repeat the survey in year 4 of our work programme.

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 Partner Away Day; 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. In the table below we have highlighted our proposed PPPIE activity, identified key milestones of these activities and examples of measures of success. **We have highlighted in bold the measures of success that have been achieved in the first year.**

PPPIE activity	Milestone	Measures of success
<p>Expand PPPIE partner network:</p> <p>a) understand gaps b) approach new partners</p> <p><i>This will support our objectives: inclusive and diverse, build capacity, focus on the future</i></p>	<p>Established 2019</p> <p>Monitor annually, Jan-April</p>	<ul style="list-style-type: none"> ➤ Recruited PPPIE Lay Co-leads ➤ Existing PPPIE for current studies added to master database ➤ Compare demographic data of PPPIE partners with population level birth data ➤ Gap analysis of existing PPPIE ➤ Where gaps exist identify and approach new PPPIE partners

<p>Improve access to PPPIE opportunities:</p> <p>a) create topic-specific panels</p> <p>b) specific outreach to BAME and seldom heard groups</p> <p><i>This will support our objectives: inclusive and diverse, consult and co-produce, focus on the future</i></p>	<p>Establish panels in 2020</p> <p>Review BAME involvement and communication annually</p>	<ul style="list-style-type: none"> ➤ Budget arrangements for PPPIE reviewed ➤ Consulted on PPPIE strategy with PPPIE partners and other stakeholders ➤ Set up neonatal panel ➤ Set up pregnancy and baby loss panel ➤ Explore potential for virtual network ➤ Explore potential routes for reaching BAME and seldom heard groups ➤ Review PPPIE payment policies to ensure they are timely and responsive to individual circumstances
<p>Improve communications to all PPPIE audiences</p> <p><i>This will support our objectives: build capacity, consult and co-produce</i></p>	<p>Established autumn 2019</p> <p>Monitor annually</p>	<ul style="list-style-type: none"> ➤ PPPIE partner Away Day led and facilitated by Lay Co-leads ➤ Communications survey undertaken with PPPIE partners ➤ Plain English website information about the PRU-MNHC's work updated on website ➤ Profiles of PPPIE Lay Co-leads updated on website ➤ Continue to develop bi-annual newsletter ➤ Continue to improve plain English communications and explore platforms for dissemination to lay audiences
<p>Develop PPPIE plans for individual studies</p> <p><i>This will support our objectives monitor and Evaluate, Innovation and Learning, Build Capacity</i></p>	<p>Established autumn 2019</p> <p>Monitor annually</p>	<ul style="list-style-type: none"> ➤ PPPIE column added to PRU-MNHC GANTT chart ➤ Methodology-specific guidance tool for PPPIE developed ➤ Each study triaged and proportionate PPPIE plan developed
<p>Training for PPPIE partners</p>	<p>To be included in annual review of 2020</p>	<ul style="list-style-type: none"> ➤ Existing NPEU podcasts reviewed ➤ Schedule created for new content (4 x year)

<p><i>This will support our objectives Monitor and Evaluate, Innovation and Learning, Focus on the Future</i></p>		<ul style="list-style-type: none"> ➤ First podcast shared with PPPIE partners online ➤ Gap analysis of training needs of PPPIE partners performed ➤ List compiled of free training available for PPPIE partners and shared
<p>Training for researchers in value of PPPIE and approach</p> <p><i>This will support our objectives Build Capacity, Monitor and Evaluate, Innovation and Learning and Focus on the Future</i></p>	<p>Established 2019</p> <p>To be included in annual review of 2020</p>	<ul style="list-style-type: none"> ➤ PPPIE Lay Co-leads presentation on value of PPPIE to PRU-MNHC meeting ➤ '8 Rs' document for achieving proportionate PPPIE developed and used in each project ➤ Sandwich seminar from Patient and Public Involvement (PPI) officer for the Oxford branch of the RDS-SC attended by PRU researchers ➤ PPPIE training needs, opportunities and costs scoped ➤ Method developed for recording PPPIE skills development in staff annual performance and development review
<p>Nurturing sustainable PPPIE relationships</p> <p><i>This will support our objectives Inclusive and Diverse, Build Capacity, Consult and Co-produce, Focus on the Future</i></p>	<p>Established 2019 and ongoing</p> <p>Monitor annually</p>	<ul style="list-style-type: none"> ➤ PPPIE survey feedback from Away Day ➤ Principles of relationship-building and reciprocity built into PPPIE '8 Rs' monitoring tool ➤ Feedback fed into organisation of subsequent Away Day ➤ Principle of place-based PPPIE written into Guidance Tool
<p>Monitoring and evaluating PPPIE</p> <p><i>This will support our objectives Innovation and Learning, Monitor and Evaluate, Consult and Co-produce, and Focus on the Future</i></p>	<p>Tool developed autumn 2019</p> <p>Monitoring and evaluation ongoing</p> <p>End of 2020</p>	<ul style="list-style-type: none"> ➤ Developed '8 Rs' tool for monitoring and evaluating whether researchers are achieving meaningful PPPIE ➤ GRIPP2-SF to be used in reporting and embedded in PPPIE plan as part of evaluation ➤ Learning points from GRIPP2-SF reporting to be reviewed.

		<ul style="list-style-type: none"> ➤ Develop feedback loop once research is published, back to PPPIE partners and to gather their response (the 8th R) ➤ Draft paper on implementation and impact of '8 Rs' on PRU-MNHC projects and researchers
<p>Reporting</p> <p><i>This will support our objectives Monitor and Evaluate, Innovation and Learning, Build Capacity and Focus on the Future</i></p>	<p>Established 2019 and ongoing</p> <p>Monitor annually</p>	<ul style="list-style-type: none"> ➤ PPPIE Task Group to report to PRU-MNHC researcher meetings (4-6 times a year) ➤ PPPIE Task Group to report to investigators meeting (2 times a year) ➤ Newsletter to PPPIE partners (2 times a year) ➤ Annual report sent to stakeholders ➤ Annual report sent to NIHR
<p>Partnership Building</p> <p><i>This will support our objectives Innovation and Learning, Building Capacity, Consult and Co-produce, and Focus on the Future</i></p>	<p>Established events, to be monitored and evaluated annually</p>	<ul style="list-style-type: none"> ➤ PPPIE Task Group attended PRU-MNHC strategy development event hosted by NIHR ➤ Meeting with Public Engagement Lead for Nuffield Department of Population Health, University of Oxford ➤ Annual PPPIE partner Away Day ➤ Facilitating consultation teleconferences between researchers and PPPIE partners ➤ PPPIE Lay Co-leads to attend relevant conferences and clinical research network events ➤ Develop a programme of researcher attendance at parent-led groups for place-based learning.

Resources

The PRU-MNHC has budgeted for two PPPIE Lay Co-leads to each work an average of three days per month during the course of the programme to support the delivery of its PPPIE strategic objectives. There are additional resources within the NPEU including administration, communication and 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 our deputy director, Alderdice, and the PPPIE Task Group (Alderdice, Bevan, Plachcinski, Rowe, and McLeish). This group, which reflects a broad range of PPPIE 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.

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 INVOLVE standards, 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.

Contact us:

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

Appendix A

The Policy Research Unit for Maternal and Child Health and Care's work and our public involvement strategy

The aim of a policy research unit is to provide research evidence to inform government policy decisions about how best to deliver health and social care.

There are policy research units for various areas of health, such as older people, public health, mental health and obesity. You can see the whole list here: <https://www.nihr.ac.uk/explore-nihr/funding-programmes/policy-research.htm>.

The NPEU hosts the Policy Research Unit in Maternal and Neonatal Health and Care (PRU-MNHC). The goal of the PRU-MNHC is to carry out research to support policy and clinical care to optimise the health of women, their babies, partners and families. The PRU-MNHC is funded for 5 years, until December 2024.

Who decides what research is conducted?

The five themes of the PRU-MNHC research programme have been agreed with the Department of Health and Social Care. The research is focused on supporting current maternity policy which includes the vision for maternity care set out in the report of the National Maternity Review, "Better Births", and to meet the national ambition to halve the rates of stillbirth, neonatal and maternal death and brain injury in newborn babies by 2025. The themes are:

- Health before pregnancy, and optimising health throughout pregnancy
- Understanding pregnancy loss, why babies become sick or die, and supporting bereaved parents
- Women's experiences of care during pregnancy, labour and afterwards, and its impact on their health
- The care of newborn babies
- How health services are organised and deliver care

Over 2019-2020 between two and five projects are being carried out under each theme. The views of women, fathers, partners, as well as the charities and organisations which represent and support them, help us develop our research ideas based on their priorities for what is important to research in the health and care of mothers and newborn babies. You can read more about the projects on our website: <https://www.npeu.ox.ac.uk/pru-mnhc>.

What does your research entail?

We carry out many different types of studies in the PRU-MNHC. Some of the research we do involves using routinely collected information such as that held in GP or hospital records across the UK. We also run surveys to collect new information, and for other projects we run a new analysis on data collected for a previous project (this is called secondary analysis). We conduct interview studies with women and their families (qualitative research) and we carry out systematic reviews, where we gather together all the research which has been done on a particular topic to draw out the main findings and identify where there are gaps in the evidence base.

Our strategy for including you in our research

We have set out our vision and plans for including women, fathers, their partners and families in our research in our parent patient, public involvement and engagement (PPPIE) strategy. We call this group our PPPIE partners.

We want PPPIE to be at the heart of all the research we conduct, making sure it is responsive to developments in family life, society and changing health services. We have developed six objectives and a programme of activities to support this aim. The objectives are:

1. We will be inclusive and diverse, actively involving our PPPIE partners from a range of backgrounds, ensuring all views and experiences are heard and valued.
2. We will build capacity by supporting our PPPIE partners and our researchers to work together through mentoring, training and events.
3. We will consult and co-produce with our PPPIE partners at every relevant stage of our work in a way which is clear, concise and sensitive.
4. We will monitor and evaluate our PPPIE progress, both for individual studies and for the impact it has on our work with midwives, doctors, NHS commissioners and government bodies.
5. We will bring about innovation and learning by sharing our work with other research groups.
6. We will focus on the future by encouraging and supporting more women, fathers, their partners and families to be involved in our work.

You can read more about the strategy on our website <https://www.npeu.ox.ac.uk/pru-mnhc/pru-mnhc-public-involvement>

Keep in touch

We will be sending out two newsletters a year and summarising our work in an annual report. We aim to continuously improve our website and communications so that our research can be understood by everyone. We will also review our PPPIE strategy each year and adapt it as necessary to meet our goals.

If you would like to be added to our mailing list, or have any questions about the work of the PRU-MNHC, email NPEUPPI@npeu.ox.ac.uk.

Appendix B

Our PPPIE partners

Acacia Family Support
Action Against Medical Accidents (AvMA)
Action on Pre-eclampsia (APEC)
Association for Improvements in Maternity Services (AIMS)
Antenatal Results and Choices (ARC)
Auntie Pam's (Pregnancy peer support service, based in Dewsbury, West Yorkshire)
Baby Lifeline
Best Beginnings
Big Births
Birth Companions
Birth Trauma Association (BTA)
Birthrights
Black Mums Upfront
BLISS
Bradford Doula Project
Breastfeeding Network
British Pregnancy Advisory Service (BPAS)
Caesarean Birth
Campaign for Safer Births
Child Accident Prevention Trust (CAPT)
Child Bereavement UK (CBUK)
City of Sanctuary Maternity Stream, Leeds
CMV Action
Dads In Mind
Disability, Pregnancy and Parenthood
Dope Black Mums
Doula UK
Elizabeth Bryan Multiple Births Centre (EBMBC)
Ectopic Pregnancy Trust
Fatherhood Institute
Fertility Foundation UK
Fertility Network UK
FiveXMore
Future Men
Gemma Goodyear, BAME, LGBTQ+ and IVF pregnancies
General Anaesthetic Caesarean Support Group
Gestational Diabetes UK
Group B Strep Support (GBSS)

Grace in Action
Haamla Leeds Doula Project
Happy MOMents
Harriet Williams, Young Parent consultant
Hull Goodwin Doula Project
Intraheptic Cholestasis of Pregnancy Support (ICP Support)
International Stillbirth Alliance
Jewish Bereavement Counselling Service
Laura Centre, Leicester
LGBT Mummies
Lullaby Trust
Make Birth Better
MAMA Academy
Mars Lord, doula and birth activist
MASIC
Maternal Mental Health Alliance
Maternal OCD
Miscarriage Association
Mothers4Mothers
Multiple Births Foundation
Mummy's Star
Mums Like Us
Muslim Bereavement Support
National Maternity Voices
NCT
Parent Infant Partnership
Parenting Science Gang
Parents 1st
Parents4parents
Pelvic Partnership
Positive Birth Movement
Pregnancy and Baby Charities Network - CMV Action
Pregnancy Choices
Pregnancy Sickness Support
Pyramid of Antenatal Change
RCOG Women's Voices Panel
Sands, the stillbirth and neonatal death charity
Shoreditch Trust
SSNAP – Supporting Sick Newborns and their Parents
St Michael's Fellowship
Survivors of Bereavement by Suicide
The Breastfeeding Network
The Motherhood Group

Tiny Life
Tommy's
Twins Trust (formerly TAMBA)
Willow's Rainbow Box
Winston's Wish
Working Together with Parents Network
Music, Football and Fatherhood

Appendix C

Engaging and involving diverse individuals, groups and communities in research – the Listening Series

Involving and consulting parents and families has been an important part of NPEU's work for many years. We want to involve and engage people from as many different backgrounds as possible when we are planning research studies, designing the projects and sharing the results, but we know that we don't always get it quite right. It's vital that we do better, partly for fairness and equity, but also making sure that we ask research questions that matter to women, parents and families and that our research findings are meaningful and accessible to those people whom they concern. We know that the people we hear from less often are also the ones who are most likely to experience poor health and complications in pregnancy, birth and postnatally.

In 2020 we ran a series of listening groups to find out what more we could do to support people to influence, take part in and use our research. Twenty people took up our invitation to join these groups, speaking on behalf of fathers, parents of Black and South Asian ethnicity, parents with physical disabilities, teenage parents, those experiencing social and economic deprivation and parents with learning disabilities.

We got some amazing insights into how the general public respond to research and what we need to do so that they feel they can get involved in planning research, take part in the research, or just be aware of what we do. This might include simply knowing about it (attending a science fair, reading a blog or news article, listening to a podcast or online talk - what we call engagement); becoming involved in it (influencing what we research and how we do it), or participating in it (actually taking part).

Five things really stood out from the conversations:

- Build trust - Relationships are at the heart of all good public involvement and engagement. This is even more important for people who are less likely to be involved in research, who may distrust anything they perceive as being part of the establishment, or who may simply not see the relevance of research to them and their lives.
- Involve people from the beginning - Our contributors told us that they sometimes felt exploited, and that they were only being 'brought out' or contacted when it was convenient to researchers. Early involvement in a project is a key part of building trust.
- Show impact - People have busy lives and a lot to cope with, but they do want to see change. People told us that they wanted to know how health research might contribute to changing policies and care locally, for their friends, families and communities. This was critical to catching their interest and getting them engaged with research.
- Use simple communications - Many people feel bombarded by information in their everyday lives. We need to be more thoughtful and innovative in how we communicate, whether it's using animations, infographics or much simpler language to describe things.
- Imagine life in our shoes - People told us that we need to think about the pressures on their lives and make engagement, involvement and participation as easy as possible for them. That means thinking about the particular community groups they are involved with, or social

media platforms they use, and approaching them with invitations that mention their particular circumstances, such as having a disability.

We've produced a film outlining the themes, and written guidance giving more practical tips on how to implement them in your research. You can view and download this from the OxPop TV website: <https://tv.ndph.ox.ac.uk/ppie/>

A huge thank you to everyone who took part, and to the University of Oxford's Departmental Public Engagement with Research Seed Fund, who funded this project.

Auntie Pam's pregnancy peer support – Lisa Akester

Maternity Voices Partnership – Agnes Agyepong

Birth Companions – Kate Chivers

Black Mums Upfront - Nana-Adwoa Mbeutcha

Dads in Mind – Adrian Pell

Fatherhood Institute – Kathy Jones

Fathers Reaching Out – Mark Williams

Future Men – Chris Stein

Happy MOMents – Sumayya Mulla

Motherhood Group – Sandra Igwe

Mums Like Us – Sally Darby

Muslim Bereavement Support Services – Sabina Patel

National Maternity Voices – Mo Ade

NDPH Public Involvement Panel – Scott Williams

Parents1st UK – Celia Suppiah

St Michael's Fellowship – Sue Pettigrew

Shoreditch Trust – Jacqui Roberts

Willow's Rainbow Box – Amneet Graham

Young parents advocate – Harriet Williams

Appendix D

Guidance for Researchers to deliver PPPIE

PPPIE will be influenced by the nature of specific methodologies. Secondary analysis of existing routine data, for example, will require a different level of PPPIE compared to a novel qualitative study. We have developed a guidance tool for each methodology the PRU currently uses which is a set of trigger questions when making PPPIE plans. The following is an example of PPPIE Guidance and reflective questions for systematic reviews.

PPPIE Guidance for Researchers undertaking Systematic Reviews

Systematic reviews may have limited scope for PPPIE compared to other types of research but there are still many ways to ensure the parent, patient and public voice is reflected in the research at all stages of the design, execution and dissemination.

Think about why you need PPPIE?

- to refine the parameters of the review – what to include, what not to include? You may have defined it already but your PPPIE partners may have views that are relevant and change your perspective
- to review results, commenting and identifying key themes
- to edit and improve draft papers
- to co-author papers
- to help summarise and disseminate findings.

All research, regardless of methodology, needs PPPIE for dissemination

Your PPPIE may be able to:

- help write lay summaries of findings, develop infographics, animations, website material, tweetable summaries
- support dissemination through their own means of communication, community/group meetings, social platforms and networks
- translate reports into different languages for their communities to improve your reach
- speak at conferences, provide quotes or contextual narrative, and speak to the media giving first-hand experiences which will bring the review ‘to life’.

Identifying which PPPIE partners are relevant to the review topic

- individuals with lived experience
- organisations that support people
- organisation that work with people
- organisations that represent people
- small organisations (both single issue charities and those run by individuals) or big, national organisations.

When you're thinking of engaging PPPIE partners ask yourself how you will reflect their views?

- 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 review, its aims, what you expect from PPPIE, and what happens next, including Terms of Reference
- information in other languages and sensitive to people's educational and physical needs
- training in understanding the research methodology and how PPPI 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, child care, a half or full day's PPPIE payment. NIHR INVOLVE budget calculator for PPPIE is available here: <https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/>
- 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?

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

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 PPPI Task Group help?
- how representative is the organisation/individual likely to be?
- if your PPPI is single-issue driven, does that matter, or does your PPPI 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?

Adding the E - broader public Engagement

- Where can you share the work more publically? 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 against the '8 R's and use these to evaluate and report on the outcomes of your PPPIE via the GRIPP2-SF. Don't leave filling out the GRIPP2-SF to the end of your study but fill out the checklist as you go along.

Appendix E

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 Mile <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>

GRIPP2-SF (a short-form checklist for studies where PPPiE 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