

Newsletter

Issue 1

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WHAT IS A POLICY RESEARCH UNIT?

Hello and welcome to our first newsletter

We are Rachel Plachcinski and Charlotte Bevan, lay co-leads on parent, patient and public involvement and engagement (PPPPIE) for the PRU-MNHC, and we will be sending out this newsletter twice a year to keep people up to date on what we are doing, how we are doing it and what all the acronyms mean.

First off, the PRU-MNHC is the Policy Research Unit in Maternal and Neonatal Health and Care. The aim of the unit is to inform government policies around the health and care of women, before, during and after pregnancy, as well as the health and care of their newborn babies. Much of the work of the PRU is planned well in advance but we also have to be able to react quickly to new situations, such as the coronavirus outbreak in the UK. There's more on this on page 2.

The PRU-MNHC is led by the National Perinatal Epidemiology Unit (NPEU) at the University of Oxford, in collaboration with researchers from the Universities of Birmingham, Leicester, Manchester and Cardiff, as well as Imperial College and University College, London. NPEU is funded to do this until 2023.



Our vision is for the views and experiences of women, their partners and families to be at the heart of the work of the PRU-MNHC, in support of the principle of 'no research about us without us'. Our key aim is to empower parent, patient and public involvement and engagement (PPPPIE) partners from a variety of backgrounds to join with researchers in shared decision making to shape different stages and aspects of research projects. We will summarise our work in an annual report and aim to continuously improve our communications so that our research can be understood by everyone. Our strategy for PPPPIE at the PRU-MNHC will be added to **our website** in the next few weeks.

Thank you to all those PPPPIE partners who have already helped us with its development. It aims to be a 'live' document and we will continue to consult with you throughout the PRU-MNHC programme on its development and evaluation.

OUR RESEARCH PROGRAMME

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 and practice. This includes the vision for maternity care which is set out in the Better Births report of the National Maternity Review, and the national ambition to halve the rates of stillbirth, newborn 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 maternity and newborn care

Two to five projects under each theme have already been agreed for 2019 and 2020 with the Department of Health and Social Care. The views of women, fathers, partners, as well as the charities and organisations which represent and support them, help us to identify what is important to research in the health and care of mothers and newborns. You can read more about the projects on our website. We aim to share messages from our research in a variety of ways, from academic papers to infographics and on social media.

CORONAVIRUS ALERT

PRU-MNHC researchers are helping to fill some of the gaps in our knowledge about coronavirus with a new rapid response study looking at the impact of the virus on newborn babies.

The **Neonatal Complications of Coronavirus Disease (COVID-19)** study aims to find out:

- How many babies develop coronavirus infection in the first month after birth, how many babies born to pregnant women who develop coronavirus around the time of birth need neonatal care, and any long term impact for these babies.
- Which groups of babies are more likely to develop COVID-19 infection and what symptoms or signs they have.
- How COVID-19 in babies is identified and treated across the UK.

The study is being run through the British Paediatric Surveillance Unit (BPSU) which looks at the impact of rare health conditions in children. Research colleagues at NPEU are also running studies through the **UK Obstetric Surveillance System (UKOSS)** and **MBRRACE-UK** to help us develop a full picture of the impact on both mothers and their babies.

We hope to have some results to share with you by the end of this year.

HOW WE DO RESEARCH



Much of the research we do in the PRU-MNHC involves using routinely collected information such as that held in GP or hospital records. We also run studies to collect new information, and, for other projects we run a new analysis on information collected for a previous project (this is called secondary analysis).

We conduct interviews with women and their families (qualitative research) and we carry out systematic reviews, gathering together all the research which has been done on a particular topic to draw out the main findings and identify any unanswered questions.

NEW MATERNITY SURVEY: YOU AND YOUR BABY

This week saw the publication of the 'You and Your Baby' survey which explores the health and wellbeing of women who gave birth in England and was carried out in 2018.

This is the first national maternity survey in England to ask women about their health and wellbeing six months after childbirth. It's also the first time we have asked women about vaping around the time of pregnancy and childbirth.

Looking at trends over time, more women are initiating breastfeeding and continuing to breastfeed for longer, and they are waiting longer before introducing solid foods to their baby. Fewer women smoked during pregnancy, and more women are taking their full entitlement for maternity leave.

One significant challenge highlighted by the survey is the ongoing need to address mothers' mental health problems and to offer women the support they need.

Sian Harrison and Maria Quigley, lead researchers on the survey, thanked all the women who took part: "We really appreciate you taking the time to share your views and experiences with us."

A report of the findings from the 'You and Your Baby' survey and an infographic summary of the key findings are available from our [website](#).



MOTHER'S COUNTRY OF BIRTH AND OUTCOMES FOR UK-BORN BABIES

One of our research projects has tried to find out why babies born in the UK, with one or both parents from a minority ethnic background, are more likely to be born premature than white British babies. The reasons are complex and the higher risk does not apply to all babies with a minority ethnic heritage. For example, it does not apply to all degrees of prematurity and it isn't associated with all causes of death.

Our findings have been published in a series of papers. In our final paper, we explored whether the risk of death or prematurity was different in babies whose mother was born outside the UK rather than in the UK. We found that in babies with a minority ethnic heritage, the baby's risk of death or prematurity was lower if the mother had been born outside the UK, rather than in the UK. You can read more on our [website](#).

SETTING PRIORITIES FOR RESEARCH INTO POSTNATAL CARE

In 2019 we ran our annual Away Day for parents, patients and the public in May. Our thanks to everyone who attended and contributed to developing ideas for questions that still need addressing in research around postnatal care. The issues you raised have been shared with NPEU researchers and will inform our ongoing discussions with the Department of Health and Social Care.

The gaps in research you felt should be a priority in postnatal care in hospital before discharge were:

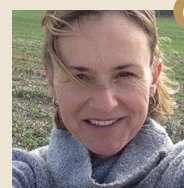
- What different family structures are there, and how does the health service meet their needs?
- What information are women receiving, both in pregnancy and straight after birth, and is it contributing to poor mental health especially after difficult births?
- How do high risk pregnancies affect partners and families, as well as women?

When addressing future research questions around community-based post-natal care, important issues were:

- Engaging fathers and non-binary families, especially with regards to mental health
- Infant feeding in the transition to home
- Continuity of postnatal care – how should midwives, GPs and health visitors work together, and how should families be supported following complex or traumatic births.

WORKING WITH CHARITIES TO CO-DESIGN RESEARCH - PPPIE IN ACTION

Charlotte Bevan, our PPPIE lay co-lead, and Senior Research and Prevention Advisor for Sands, the stillbirth and neonatal charity, and Dr Rachel Rowe, Senior Health Services Researcher at the NPEU, talk about the Listening to Parents survey, the first national survey of parents whose baby had died around the time of birth, undertaken in England in 2014 and funded by the previous PRU in Maternal Health and Care.



Charlotte



Rachel

C 'Sands has been supporting bereaved families for more than 40 years. We felt there was a gap in understanding the experiences and needs of parents in the devastating situation of losing their baby before, during or shortly after birth. A key theme that emerged from a survey of parents we'd run in 2010 was that bereaved parents didn't feel listened to – either during their experiences of pregnancy and labour or indeed after the tragedy of their baby's death. Their voices were those experiences that were never heard, except within the confines of their own support groups.'

R 'The PRU had run several national maternity surveys on behalf of the Department of Health, but had not included bereaved parents because it didn't feel appropriate to try and address their experiences in the same survey. We were also concerned about the ethical challenges of asking parents whose baby had died about their experiences of care, and were uncertain whether we would be able to get ethics approval to carry out such a survey.'

C 'Sands approached the NPEU and asked if researchers could help us analyse the open-ended questions in our Sands survey of bereaved parents. After discussing this further at a PPPIE Partner Away Day, the NPEU proposed designing a new national survey of bereaved parents' experiences that was likely to be more representative.'

R 'The PRU gained agreement from the Department of Health to prioritise a survey. The fact that the need for this survey had been identified by Sands and Bliss certainly helped with this. We asked both Sands and Bliss to be on our advisory group for the survey. We felt they had the authenticity and strength to represent parents' voices – and their involvement helped demonstrate, in our application for ethics approval, that we could carry out the survey in a way which was ethically sound.'

'Over many discussions we drafted a sensitive invitation letter and Sands and Bliss advised on changes to some of the questions. In particular, they highlighted that some questions from the previous surveys were irrelevant given bereaved parents' devastating experience, and that others should be included, such as how long it took to get post mortem results. With their help we found parents to help us pilot the survey.'

C 'We had to be really sensitive and mindful of the impact the whole project was going to have, and not just on parents, but on the researchers too. The NPEU team was disappointed with the 30% response rate but we weren't because the survey represented the views of 720 parents who we knew would have found it incredibly difficult to fill out the questionnaire but whose views were vital to developing health services.'

R 'We published the survey as a report and illustrated it with pictures parents agreed to share with us of them and their babies. When we launched it, a parent came to talk about their own personal experience, and chief executives from Sands and Bliss gave their response to the survey findings. It helped put the report in context.'

C 'The survey results, and the secondary analysis of its findings around post mortem, highlighted things we knew profoundly affected parents, but which we couldn't evidence. That was really useful. The National Bereavement Care Pathway has referenced the results of the report in every page of its guidance.'

R 'Without lobbying from charities like Sands, I don't think this piece of work would have ever been undertaken. It certainly brought home to me the value of asking difficult questions. I can't envisage doing a piece of work like this without the involvement of parents and charities who represent them. It would just be impossible.'

KEEPING IN TOUCH

We are exploring the options for our next PPPIE Partner Away Day, in the light of government guidance about coronavirus and social isolation. We really look forward to connecting with you to talk about the work of the PRU-MNHC and hear about the questions arising from your work with parents, so are looking at online alternatives.

In the meantime, if you want to find out more about our parent, patient and public involvement and engagement work, contact the team at:

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