

Research Governance
and Integrity Team**PARENT INFORMATION SHEET**

Chief Investigator: Dr Annemarie Lodder

Study Title eParental Insights: Using digital technologies to acquire and incorporate parent-reported experiences into the UK National Neonatal Research Database

We are inviting you to help us obtain information about your thoughts about your baby's stay at our Neonatal Intensive Care Unit (NICU)

We are approaching you because you are the parent/carer of a baby who is currently in NICU or has spent time at NICU and is about to be discharged from our neonatal unit.

Background

Doctors and health care professionals work hard to provide the best care and treatments for babies in NICU. We know that this is a stressful time for parents and that the NICU environment can be daunting. Parent reported experiences of their baby's time at NICU are not routinely collected but are an important part of understanding the impact of having a sick or preterm baby. These assessments are also important for research studies that aim to improve the care we provide to preterm and sick newborn babies.

The current situation

There is currently no national, systematic approach for capturing parent reported experiences of their baby's stay at NICU. At present, some parents are asked to complete questionnaires, but not all. Another issue is that these questionnaires are traditionally completed by a health care professional or researchers using pen and paper. This is time consuming, inefficient and a waste of resources.

Our proposed approach

A team at the Neonatal Data Analysis Unit at Chelsea and Westminster Hospital/Imperial College London have developed a new process to enable parents to complete the Parental Stressor Scale: NICU (PSS:NICU) securely online, on a computer, mobile phone, or other device, and to store the results securely so that they can be shared with other authorised users, including your baby's NHS team.

We are inviting you to participate in a study to help the team at the Neonatal Data Analysis Unit test how well this new process works. We will ask you to complete the questionnaire online, and a researcher may contact you afterwards to ask you about your thoughts on this approach so that we can determine if this method is acceptable for parents.

What will this mean for me and my baby?

With your permission, we will share your contact details and your baby's NHS number/date of birth with the Neonatal Data Analysis Unit at Chelsea and Westminster Hospital/Imperial College London for the specified purposes listed below; we will record your decision

Research Governance and Integrity Team

electronically. The Neonatal Data Analysis Unit will only use your contact details for the following reasons and will not release them to any person or organisation.

Once you agree to take part, the Neonatal Data Analysis Unit will send you:

- A notification and a link to authenticate your identity and complete the PSS: NICU
- If not completed, we may send you a follow up reminder a week later to ask to complete the PSS:NICU.
- A member of the research team may contact you to ask if you are willing to provide feedback on completing the questionnaire
- Without-obligation notifications about studies and links to information that might be of interest or of importance to you and your baby

What will happen to the PSS:NICU questionnaire results?

- We will store a copy of the results with your baby's record in the National Neonatal Research Database at the Neonatal Data Analysis Unit where it will be available anonymously for authorised uses. The National Neonatal Research Database supports a large number of studies to improve the care of babies admitted to neonatal units. You should have received information about the National Neonatal Research Database from your neonatal unit, and you can also find a copy [here](#).

Will my details and my baby's details be kept confidential?

Your details and your baby's will be stored confidentially. Only your baby's NHS healthcare providers and authorised members of the research team will be able to access identifiable data

What if I change my mind?

You are free to change your mind at any time and withdraw your permission for the Neonatal Data Analysis Unit to store your contact details and baby's NHS number/date of birth at any time without having to give a reason. If you notify the Neonatal Data Analysis Unit that you have withdrawn your consent, your details and your baby's details will be deleted. If you have already submitted the questionnaire this will not be deleted but will be stored anonymously.

What happens if something goes wrong?

It is extremely unlikely that anything will go wrong but we are required by Imperial College to inform you as follows: *"Imperial College London holds insurance policies which apply to this study. If you experience harm or injury as a result of taking part in this study, you will be eligible to claim compensation without having to prove that Imperial College is at fault. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for a legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should immediately inform the Local Lead Investigator named below. The normal National Health Service mechanisms are also available to you. If you are still not satisfied with the response, you may contact the Imperial College Joint Research Compliance Office".*

Research Governance
and Integrity Team**What will happen to the results of the study?**

We will write up our findings in a report and aim to publish this at the end of the project. No identifiable information will be used.

Who is organising and funding this study?

This study is funded and organised by Imperial's Biomedical Research Centre. You can find out more about how Imperial College London uses personally-identifiable information to conduct research to improve health, care and services in the Neonatal Data Analysis Unit [Privacy Notice](#).

Who has reviewed this study?

The NNRD is a Research Ethics Committee approved database. The study has submitted a Data Asset Registration Tool registration for the PSS:NICU.

Thank you for reading this information sheet**Contact for further information**

[Name and contact details of local investigator]