

PARENT INFORMATION LEAFLET

Study title

Systematic electronic capture of parent reported cognitive and language development in children aged two-years (ePARCA-R)

The study

We are carrying out a study to improve services for infants admitted to NHS neonatal units by obtaining information about their development at the age of two-years through an electronic parent questionnaire. The study will initially involve all neonatal units in West London hospitals. The study is supported by the British Association of Perinatal Medicine, British Association of Neonatal and Neurodevelopmental Follow-Up and the charity for preterm and sick babies, Bliss.

We are inviting you to help us with this study. We are approaching you either because your baby is about to be discharged from our neonatal unit, or because your child is attending his or her two-year clinic visit. Please read this, and ask about anything that is unclear.

Background

Assessing development at two years of age is an important part of the care of babies who were born very preterm or sick, as this can help identify those who might benefit from additional support. These assessments are also important in 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 assessing the development of all two-year old children who received neonatal care. At present, some children receive tests or their parents are asked to complete questionnaires, but not all.

A further difficulty is that if an assessment is done, there are no processes for sharing this information securely with other health professionals or authorised people. Without the ability to share such information safely, families are often called upon to complete multiple assessments by health professionals and researchers. This is burdensome to families, inefficient and a waste of resources.

Our proposed approach

The National Institute of Health and Clinical Excellence (NICE) has recommended the use of the PARCA-R questionnaire to assess a child's thinking skills and language development when they are 2 years of age, so that support can be provided if needed. The PARCA-R questionnaire is completed by parents. It is quick and easy to do, and is used by health professionals and researchers throughout the world.

To try and solve the problem that there is currently no national, systematic approach for assessing the development of all two-year old children who received neonatal care, 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 PARCA-R 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 child's NHS team.

We are inviting you to participate in a study to help test how well this new process works.

What will this mean for me and my child?

With your permission we will share your contact details and your infant'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 electronically. The Neonatal Data Analysis Unit will only use your contact details for the following purposes and will not release them to any person or organisation.

If your baby is on the neonatal unit, the Neonatal Data Analysis Unit will send you:

- Notifications by email when your child is aged 6 months, 12 months, and 18 months from birth, by text or email, to remind you to inform them of any change in your contact details or circumstances
- Without-obligation notifications about studies and links to information that might be of interest to you or of importance to your child
- When your child is approaching the age of two-years corrected for prematurity, a notification and a link to authenticate your identity and complete the ePARCA-R; you will also be able to save and print a copy of the ePARCA-R for yourself

If you are the parent of a child who will be due to attend a two-year follow-up clinic, the Neonatal Data Analysis Unit will send you:

- Without-obligation notifications about studies and links to information that might be of interest to you or of importance to your child
- A notification and a link to authenticate your identity and complete the ePARCA-R; you will also be able to save and print a copy of the ePARCA-R for yourself

What will happen to the ePARCA-R questionnaire result?

- We will store a copy of the results with your child'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](#).
- We will also send a copy to be stored with your child's west London NHS Whole Systems Integrated Care Record so that this is available to your child's NHS healthcare providers

- You will be able to save or print a copy of the completed questionnaire and your child's results for yourself

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

Your details and your child's will be stored confidentially. Only your child'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 and withdraw your permission for the Neonatal Data Analysis Unit to store your contact details and infant 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 infant's details will be deleted. If you have already submitted the ePARCA-R this will not be deleted but will be stored anonymously.

Who is organising and funding this study?

This study is funded and organised by Imperial College London. 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](#).

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

Chief Investigator: Professor Neena Modi, Imperial College London (n.modi@imperial.ac.uk)

West London Hospital Leads:

- Hillingdon Hospitals NHS Foundation Trust: Dr Elizabeth Lek, Consultant Neonatologist (elizabeth.lek@nhs.net)
- Imperial NHS Trust (Queen Charlotte's and Chelsea Hospital; St Mary's Hospital): Dr Sunit Godambe, Consultant Neonatologist (sunit.godambe@nhs.net)
- Northwick Park Hospital: Dr Edit Fukari-Irvine, Consultant Neonatologist (edit.fukari-irvine@nhs.net)
- Chelsea and Westminster NHS Foundation Trust: Dr Nora Tusor Consultant Neonatologist (nora.tusor@nhs.net) and Dr Enitan Ogundipe Consultant Neonatologist (enitan.ogundipe@nhs.net)
- West Middlesex Hospital: Dr Elizabeth Eyre, Consultant Neonatologist (eeyre@nhs.net)