How we use data to improve the quality of care provided to premature babies who develop Necrotising Enterocolitis (NEC): parent carer information

Please read this leaflet carefully. It explains who we are, what we are doing, and how we keep data confidential and anonymous.

This hospital is taking part in a confidential enquiry to see where care can be improved for premature babies who develop **Necrotising Enterocolitis (NEC)**.

What is NCEPOD?

NCEPOD is a national organisation that runs confidential enquiries to improve the quality of care for future patients in the UK. NCEPOD looks at areas of care that we think could be improved by reviewing the care that patients have received. For over 35 years, NCEPOD have run studies in different areas of healthcare that have had a real impact on how healthcare is now delivered.

What is this study about?

This study will involve us collecting data from all hospitals that provide acute care to premature babies who develop NEC. For example, we may ask a hospital where they were seen for information about the care they received.

What information about your baby will be collected?

At the start, we will collect your baby's NHS/Hospital number, date of birth, sex and mother's postcode. To make sure we include the right babies, we will use data from the **National Neonatal Audit Programme (NNAP)**. The NNAP collects information about babies who are born early or become unwell and need care in a neonatal unit. It already collects information about babies with NEC, which will help us identify the babies who can be included in this study.

If your baby's data is randomly chosen for inclusion in the study, we will go to the clinicians involved in your baby's care to ask them to complete a questionnaire and return copies of parts of their case notes so that we can ask other clinicians to review where they think care could have been improved. At this point, all data that would identify your baby (such as name, address, date of birth, etc.) will have been removed, so the clinicians will not know who they are.

We will also invite all healthcare professionals who were involved in your baby's care to share their views in a survey on what went well and what could have been improved from their perspective.

Why haven't I been asked for permission to use my information?

To carry out this work in England and Wales, we have been given **Section 251** support to collect and use this information under very strict conditions of confidentiality and data security by the **Secretary of State for Health and Social Care**, on advice from the **Confidentiality Advisory Group (CAG)**. In Northern Ireland, the work has been supported by the **Privacy Advisory Committee**. Access to this information is strictly limited to those who need to process it, and all information in the final report is anonymous. Once the study is complete, all data will be securely destroyed. More information is available here.

In addition, in England, the **National Data Opt-Out (NDOO)** is a process that allows individuals to opt-out of their confidential patient information being used for purposes other than medical care. To ensure that NCEPOD recommendations are not affected by reported variations in who is opting out, we will not be

excluding the data of individuals who have opted out via the NDOO. We have been granted this exemption by the Secretary of State for Health and Social Care, on advice from the **CAG**.

However, individuals still have the right to contact NCEPOD and ask for their data to be removed and permanently erased.

Is their information secure?

Yes, your baby's information is secure. All data sent electronically to us will be secured with a password. Access to the information we collect is limited to the small NCEPOD team. All personal information in the case notes we collect will be removed. All data is kept in a secure, alarmed office, either in locked cabinets or on secure computers.

What will happen to their information?

- We will **never** share information that can identify your baby with any other organisations for any reason other than for linking your care with approved partners (e.g. if your baby was transferred from one hospital to another, we may request data from both hospitals).
- All patient data, including case notes, will be securely **disposed of at the end of the study**.
- Your baby's name will **never appear** in any project publication. It will be **impossible** for you to be recognised from the analysis as we will combine your data with that of other patients.

Can I ask for their data not to be used?

Yes, you can ask us to delete your baby's data at **any time** without it affecting the level of care you or your baby receive, or you can tell us more generally that you don't want your baby's data used, just in case it is selected.

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Who is commissioning and funding the work?

NCEPOD's work is commissioned by the **Healthcare Quality Improvement Partnership (HQIP)** on behalf of the funding bodies listed below and additional funding by independent sector hospitals:

- **NHS England | Welsh Government | Department of Health, Northern Ireland |Bailiwick of Jersey**

What do I do if I think the data has not been used correctly?

If you have concerns about the way your baby's personal data is being handled, please contact Marisa Mason by post, phone, or email.

If you feel it is serious enough, you also have the right to contact the Information Commissioner's Office, the authority in the UK responsible for data protection law. They can be contacted by telephone on: 03031231113 or via their website: https://ico.org.uk/concerns/