

Necrotising Enterocolitis (NEC)

This hospital is taking part in a study to help improve the **quality of acute care** provided to **babies born at <32 weeks gestation** who develop **Necrotising Enterocolitis (NEC)**. The organisation collecting the data is called **NCEPOD**.

NCEPOD is a national organisation that uses data to help **improve the quality of care for future patients** in the UK. We do this by collecting data on patients from hospitals and other locations where they may be cared for.

For more than 35 years, NCEPOD has run studies across the UK, and these have led to changes in how healthcare is provided.

How can I find out more?



For more information, please contact us by post, phone, or email:
nec@ncepod.org.uk

How your
data might
be used,
and how
you can say
NO!

If you had a **baby who developed NEC and was discharged from hospital, or who died, between 1 January 2024 and 31 December 2025**, their healthcare data may be included in this study. We will keep their data safe until the end of the study, when it will be deleted.

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 you do NOT want your baby's data to be used, please get in touch with Marisa Mason by post, phone, or email: mmason@ncepod.org.uk

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 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**. Our Privacy Notice can be accessed [here](#).



@ncepod



NCEPOD is a registered charity in England and Wales: **1075588**
and a company limited by guarantee: **301938**

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