Your baby's information and the National Neonatal Audit Programme

Privacy Notice – England and Wales

While your baby is in the neonatal unit, staff record information in an electronic record. They use this to care for your baby, and to help the health service run well. he National Neonatal Audit Programme uses this information to improve care and outcomes for other babies in the future.

The National Data Opt Out (which allows patients in England to opt out of their information being used for purposes beyond their direct care) does not apply to the National Neonatal Audit Programme. This is because applying the National Data Opt Out would introduce biases to the data and jeopardise patient safety. You can still choose for your baby's information to not be used for the purpose of the NNAP, more details on how you can do this are provided below in the ***Do you ask my permission to use my baby's information?*** section.

For more information about the NNAP, and how and why we use your baby's information, please click on the headers below. You can also download a full version of the privacy notice at the end of this page.

What is the National Neonatal Audit Programme (NNAP)?

The National Neonatal Audit Programme (NNAP) is run by the Royal College of Paediatrics and Child Health (RCPCH). We are commissioned by the Healthcare Quality Improvement Partnership (HQIP) and funded by NHS England, the Scottish Government and the Welsh Government.

The NNAP helps neonatal units to improve the care they provide to babies who need specialist treatment. We use information about your baby's care to help neonatal units in England, Wales and Scotland to improve the care and outcomes for other babies.

We look at whether babies receive consistent, high-quality care, whether babies have recommended health checks to reduce the risk of complications and monitor how well babies are doing following this care.

What information does the NNAP use?

Neonatal unit staff enter your baby's information onto a secure electronic record system named BadgerNet. All neonatal units share information from these electronic records with the NNAP project team within the RCPCH, via another processor, Clevermed Ltd, who manage the BadgerNet system used by neonatal units to record clinical data. This includes

identifiable and special category personal data, including NHS or CHI Number (Baby and Mother), Date and time of admission to neonatal care (Baby), Date and time of discharge from neonatal care (Baby), Date and time of birth (Baby), Date of death (Baby), Date of birth (Mother), Ethnicity (Mother), Gender (Baby), Postcode of usual address (Mother), information about the care that mum and baby received and any related health conditions. The NNAP project team only uses the information for the purpose of the National Neonatal Audit Programme to monitor and try to improve standards of patient care.

Information is stored securely and used in accordance with UK Data Protection legislation. The NNAP only conducts analysis of NNAP data once all identifiable information has been removed.

The RCPCH and its partners feel it is in the best interests of babies and families to process this information to improve the care babies receive. Our partners include parents and parent representative organisations, such as Bliss, the charity which champions the right for every baby born premature or sick to receive the best care by supporting families, campaigning for changes, supporting professionals, and enabling life-changing research.

What is the legal basis for processing patient data?

The NNAP has section 251 approval to collect patient identifiable data in England and Wales without explicit patient consent as its aims are in the public interest since the audit will help improve standards of neonatal care, ensuring that high standards and quality of neonatal care continue. To find out more about section 251 approval, visit the Health Research Authority website.

Processing is permitted under the General Data Protection Regulation (GDPR) on the following legal bases:

- Article 6 (1) (e) processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller. This is justified through commissioning arrangements which link back to NHS England and the Welsh Government.
- Article 9 (2) (i) processing is necessary for reasons of public interest in the area of public health. This is justified as the NNAP aims to ensure high standards of quality and safety of health care.

We also protect your privacy rights by providing you with the option to opt out of being included in the audit.

Will my **baby's personal** data be shared?

Data will only ever be shared with the approval of HQIP. For HQIP to approve the request, the requestor must be able to demonstrate compliance with stringent data protection policies and arrangements and the aims of the research must be approved, as per

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HQIP's guidance to applicants.

Personal data shall not be transferred to a country or territory outside the UK unless that country or territory ensures an adequate level of protection for the rights and freedoms of data subjects in relation to the processing of personal data. No individual babies are identified in any of our reports.

How long are the data held for?

The NNAP team at the RCPCH acts as the data processor on behalf of the Healthcare Quality Improvement Partnership (HQIP), who are data controllers for the NNAP data. HQIP are joint data controllers with NHS England for English NNAP data and with Digital Health and Care Wales (DHCW) for Welsh NNAP data. The RCPCH will hold the NNAP data for as long as it is commissioned to deliver the NNAP project by HQIP. All data will be deleted or transferred back to HQIP within two weeks of the end of our contract. If HQIP commissions the RCPCH to deliver the NNAP under a new or extended contract, then the data will be retained for the period of the new contract.

Do you ask my permission to use my **baby's** information?

Information about all babies admitted to an NHS neonatal unit is routinely included in the NNAP. It is important that we include information on every baby treated by a neonatal unit so that the NNAP is properly representative of neonatal care in the UK. Because of the large number of babies involved, it is impractical to seek consent from each family. You can choose to opt out of having your baby's information submitted to the audit. You can choose for your baby's information to not be used for the purpose of the NNAP. If you would like to make that choice then please tell the staff on the neonatal unit where your baby is receiving care. They will make sure your baby's information is not included in the NNAP. You can also speak to the NNAP team to find out how to opt out by contacting nnap@rcpch.ac.uk or calling us on 0203 861 1910.

Does the National Data Opt-Out apply to the NNAP?

In England, the National Data Opt-Out service allows patients aged 13 or over (or those with parental responsibility for patients under 13) to opt out of their information being used for purposes beyond their direct care. For more information, please visit: https://digital.nhs.uk/services/national-data-opt-out.

The Secretary of State for Health and Social Care, having considered the advice from the Health Research Authority Confidentiality Advisory Group, has decided that the National Data Opt-Out should not be applied to this audit. This is because applying the National Opt-Out would introduce biases to the data and make it difficult to monitor care safety and quality, jeopardising patient safety. However, if any personal data is used for any other

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purposes, such as further research in the future, the National Data Opt-Out will be applied.

What are my rights?

We explain a bit more about your rights below:

- Right of access: The personal data we hold about you is provided by your unit. We can let you know which categories of data we collect but you will need to contact your unit directly for a copy of the information as they are data controllers of your patient record.

- Right to Erasure and Right to Object: The right of erasure does not apply to this audit because your data is being processed for the purposes of performing a task in the public interest, which in this case is for ensuring high standards of quality and safety health care. However, if you want to opt out of future audit rounds, please let your unit know and they will remove you from the submission so that we don't receive the data.

- Right to rectification of inaccurate data: Any requests to amend or update your personal data should be sent to your unit as data controller. If we receive any requests, we will forward these to the unit.

- Right to restriction: Any requests for restriction of processing should be sent to your Trust and they will inform us where applicable.

Will I have access to the audit reports?

Yes, each year, the NNAP produces a parent and carer guide to the audit, called Your **baby's** care. The guide is available in English and Welsh. We also produce a poster of results that neonatal units can display on the wall. You can also view the full NNAP national annual report and information about each hospital on NNAP Online at www.nnap.rcpch.ac.uk.

Who should I contact for more information?

To find out more about the audit and how your baby's information is used, please talk to the staff in your neonatal unit. You can also contact the project team at nnap@rcpch.ac.uk or visit our website www.rcpch.ac.uk/nnap. You can also contact the College's Data Protection Officer if you have queries about how the college processes personal data: information.governance@rcpch.ac.uk

The Healthcare Quality Improvement Partnership (HQIP) is the data controller of the NNAP (jointly with NHS England for English data and Digital Health and Care Wales for Welsh data) and can also be contacted if you have any questions about how your information is being used for the audit.

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Please direct any queries for the Healthcare Quality Improvement Partnership Data Protection Officer to: communications@hqip.org.uk.

Your NHS Trust or Health Board is the data controller of your baby's record, so please contact them directly if you have any questions about your baby's medical record.
You do also have the right to lodge a complaint with the Information Commissioner's Office (ICO) at casework@ico.org.uk if you have concerns about the way your baby's personal data are being handled.

Bliss is the UK charity working to ensure that every baby born premature or sick in the UK has the best chance of survival and quality of life. Bliss fully supports the National Neonatal Audit Programme. For more information about Bliss please visit www.bliss.org.uk.

NNAP
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RCPCH
Royal College of Paediatrics and Child Health
Leading the way in Children's Health

HQIP
Healthcare Quality Improvement Partnership

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