

National Neonatal Audit Programme

Privacy Notice - Scotland

Using your baby's information in the National Neonatal Audit Programme

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. All neonatal units use electronic records. Partners outside the hospital use this information to improve neonatal services through audit and research; this includes the National Neonatal Audit Programme.

What is the National Neonatal Audit Programme?

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 National Neonatal Audit Programme 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, Scotland and Wales 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 National Neonatal Audit Programme 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 National Neonatal Audit Programme (NNAP) project team within the RCPCH, via another processor, System C, who manage the BadgerNet system used by neonatal units to record clinical data. This includes sensitive 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 National Neonatal Audit Programme only conducts analysis of NNAP data once all identifiable information has been removed.

The Royal College of Paediatrics and Child Health 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 change, supporting professionals, and enabling life-changing research.

What is the legal basis for processing patient data?

The NNAP has approval from the Public Benefit and Privacy Panel for Health and Social Care (HSC-PBPP) to process patient identifiable data 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 Public Benefit and Privacy Panel for Health and Social Care approval, visit the [HSC-PBPP website](#).

Processing is permitted under the UK General Data Protection Regulation (UK 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.
- Article 9 (2) (i) processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices, on the basis of Union or Member State law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy. This is justified as the NNAP aims to drive improvements in the quality and safety of care and to improve outcomes for patients.

We also protect your privacy rights by providing you with the ability to choose for your data to not be included in the audit.

Will my baby's personal data be shared?

The NNAP published data in anonymised, aggregated form. No individual babies are

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The Royal College of Paediatrics and Child Health (RCPCH) is a registered charity in England and Wales (1057744) and in Scotland (SC03829)

identified in any of our reports. The NNAP does not share identifiable or pseudonymised data from Scottish services with others.

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.

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, who have contracted us to carry out this audit, and are data controllers for the NNAP data. The RCPCH will hold the NNAP data for as long as it is commissioned to deliver the NNAP project by HQIP. All patient identifiable data will be deleted at the end of our contract with HQIP. If HQIP commissions the RCPCH to deliver the NNAP under a new or extended contract, then the data will be retained by the RCPCH 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 National Neonatal Audit Programme. It is important that we include information on every baby treated by a neonatal unit so that the National Neonatal Audit Programme 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 for your baby's information not to 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 National Neonatal Audit Programme.

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 in health care. However, if you do not want your personal data to be used for future rounds of the NNAP, please let your neonatal unit know and they

will remove you from the submission so that we don't receive the data. The Health Board providing your neonatal care will still retain your overall healthcare 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 NHS Health Board and they will inform us where applicable.

Will I have access to the audit reports?

Yes, each year, the National Neonatal Audit Programme 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 National Neonatal Audit Programme 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 National Neonatal Audit Programme and can also be contacted if you have any questions about how your information is being used for the audit. Please direct any queries for the Healthcare Quality Improvement Partnership Data Protection Officer to: communications@hqip.org.uk.

You do also have the right to lodge a complaint with the Information Commissioner's Office (ICO) – Scotland at Scotland@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.

