

# Your baby's information and the National Neonatal Audit Programme

## Privacy Notice – Isle of Man

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. The National Neonatal Audit Programme (NNAP) uses this information to improve care and outcomes for other babies in the future.

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, the Welsh Government and Manx Care (Isle of Man).

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, Scotland and the Isle of Man 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, System C, 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 and Isle

of Man GDPR and LED Implementing Regulations 2018. 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 Isle of Man patient data?**

The NNAP data sharing has been approved by the Isle of Man Department of Health and Social Care and the Isle of Man Information Commissioner.

Processing is permitted under the Isle of Man GDPR and LED Regulations 2018 on the following legal bases:

- **Applied GDPR 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, inter alia, Manx Care.*
- **Applied GDPR Article 9(2)(h)** *processing is necessary for the purposes of ... the management of health or social care systems and services on the basis of Union law (as applied to the Island by or under the authority of an Act of Tynwald) or Manx law... and under **Schedule 2, Regulation 12, Part 2(2)(f)** the management of health care systems or services or social care systems or services...of the **GDPR and LED Implementing Regulations 2018** to fulfil the statutory obligation placed upon Manx Care, prescribed under **Section 23 of the Manx Care Act 2021** namely, as to improvement in quality of services.*
- **Public interest** under the common law duty of confidentiality, reinforced by the Manx Care Act and the NHS Act 2001 which mandate Manx Care to provide the function around improvement of health and social care on behalf of the Isle of Man Dept. of Health and Social Care.

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

Manx Care will share your personal data with the NNAP audit which is based in the UK. As the UK is deemed adequate by the EU, they are also deemed adequate by the Isle of Man, so no further steps are required to ensure the transfer of your data from the Isle of Man to the UK. This is because the UK is considered to have equivalent data protection legislation in place which will provide the same level of protection to your data as it would receive in the Isle of Man.

Data will only ever be further 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 HQIP's guidance to applicants.

Once NNAP receive your data, 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 sole 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 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 for your baby's information not to be used for any purpose other than routine healthcare. To opt out, please contact the Isle of Man Government by emailing [fps@gov.im](mailto:fps@gov.im).** You can also speak to the NNAP team to find out how to opt out by contacting [nnap@rcpch.ac.uk](mailto:nnap@rcpch.ac.uk) or calling us on 0203 861 1910.

## 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 Manx Care 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 contact [fps@gov.im](mailto:fps@gov.im) 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 Manx Care as data controller. If we receive any requests, we will forward these to them.
- **Right to restriction:** Any requests for restriction of processing should be sent to Manx Care and they will inform us where applicable.

To action any of these rights or if you have any queries related to your privacy, please contact the Manx Care Data Protection Officer at: [DPO-ManxCare@gov.im](mailto:DPO-ManxCare@gov.im).

## 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](http://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](mailto:nnap@rcpch.ac.uk) or visit our website [www.rcpch.ac.uk/nnap](http://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](mailto:information.governance@rcpch.ac.uk)

The Healthcare Quality Improvement Partnership (HQIP) is the data controller of the NNAP 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](mailto:communications@hqip.org.uk).

Your NHS Trust or Health Board is the data controller of your baby's record. Please contact the Manx Care Data Protection Officer if you have any questions about your baby's medical record at: [DPO-ManxCare@gov.im](mailto:DPO-ManxCare@gov.im).

You do have the right to lodge a complaint with the UK Information Commissioner's Office (ICO) at [casework@ico.org.uk](mailto:casework@ico.org.uk) if you have concerns about the way your baby's personal data are being handled.

You can also lodge a complaint with the Isle of Man Information Commissioner's Office (ICO). For more information, please see their website: <https://www.inforights.im/complaint-handling/how-to-make-a-complaint-to-the-information-commissioner/data-protection-complaints/>.

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](http://www.bliss.org.uk).

