

# National Neonatal Audit Programme

## Your baby's information

### 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, 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 National Neonatal Audit Programme use?

Neonatal unit staff enter your baby's information onto a secure electronic record system. All neonatal units share information from these electronic records with the Neonatal Data Analysis Unit at Chelsea and Westminster NHS Foundation Trust and Imperial College London. This includes sensitive personal data, including NHS number (CHI number in Scotland), information about the care mum and baby received and any health conditions. However, no names are included in this information transfer. The Neonatal Data Analysis Unit uses the information for the National Neonatal Audit Programme and for other research purposes.

Information is stored securely and used in accordance with the General Data Protection Regulations and other relevant legislation. The National Neonatal Audit Programme only uses 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, and the Neonatal Data Analysis Unit.

The legal basis for using this information is that it allows us to carry out a task that is in the public interest. In respect of the National Neonatal Audit Programme the public interest is protected through ensuring that high standards and quality of neonatal care continue.<sup>1</sup> We also protect your privacy rights by providing you with the option to opt out.

The National Neonatal Audit Programme team at the Royal College of Paediatrics and Child Health does not have access to any information that could identify individual babies and no babies are identified in our reports. The Royal College of Paediatrics and Child Health does not share any personal information or transfer any data outside of the United Kingdom.

### **How long are the data held for?**

The National Neonatal Audit Programme data is fully anonymised and held separately from any identifiable data sources. The Royal College of Paediatrics and Child Health does not hold any personal data and anonymised and summarised data needed to support the programme will be held indefinitely on behalf of the Healthcare Quality Improvement Partnership.

### **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 to opt out of having your baby's information submitted to the audit.

If you do not want your baby's information to be used, 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. This will not affect your baby's care in any way. For further information on how to opt out please contact [nnap@rcpch.ac.uk](mailto:nnap@rcpch.ac.uk).

### **What are my rights?**

Under General Data Protection Regulations, you have certain rights with regard to your personal data and that of your baby held by the Neonatal Data Analysis Unit. Under certain circumstances, you can ask for your baby's data to be deleted (although this does not apply to an individual's health record or where it is used for public interest purposes) or have

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<sup>1</sup> In this case, the legal bases for processing under GDPR are Article 6 (1) (e) and Article 9 (2) (i).

inaccuracies changed, request that the data is only stored and not further processed or ask for the processing of the data to be stopped altogether. You are also entitled to request a copy of the information held about you or your baby. If you want to make any of these requests, please contact a member of staff on the neonatal unit.

## Will I have access to the audit reports?

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 view the full National Neonatal Audit Programme 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).

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](mailto:communications@hqip.org.uk).

You do also have the right to lodge a complaint with the 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.

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).

You can find out more about the Neonatal Data Analysis Unit by visiting their website <https://www.imperial.ac.uk/neonatal-data-analysis-unit>.



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