Imperial College London

Chelsea and Westminster Hospital NHS
NHS Foundation Trust

The National Neonatal Research Database

Information for parents of babies admitted to NHS neonatal units

Your baby's data

While your baby is receiving NHS neonatal care, staff enter data in an electronic record, just like information written in paper case notes. Staff use these data to help care for your baby. In addition, some of these data (called the Neonatal Data Set) are stored in a National Neonatal Research Database and used to improve healthcare and services for newborn babies.

This leaflet explains how data in the National Neonatal Research Database are used. You can also find out more about how patient data are used to improve care at the website "Understanding Patient Data" (https://understandingpatientdata.org.uk/why).

What is the National Neonatal Research Database?

The National Neonatal Research Database is a national resource of information on babies admitted to NHS neonatal units, used under UK data protection and research legislation for a variety of purposes to improve newborn care and health services. Chelsea and Westminster Hospital and Imperial College London are jointly responsible for the National Neonatal Research Database.

The purposes for which the National Neonatal Research Database is used include evaluation of outcomes, whether care is delivered in accordance with national standards, and research to improve services and prevent, diagnose and treat disease. Organisations that use the National Neonatal Research Database include the Department of Health, NHS, and medical Royal Colleges.

You can find out more about the National Neonatal Research Database at https://www.imperial.ac.uk/neonatal-data-analysis-unit.

How is information about my baby kept secure?

After neonatal unit staff enter information about your baby onto the electronic record a defined set of data, the Neonatal Data Set, which is an approved NHS information standard, is sent electronically through the NHS net, to the Imperial College London Neonatal Data Analysis Unit at Chelsea and Westminster NHS Foundation Trust Hospital. This includes the NHS number of baby and mother, and information about diagnoses and care received. Patient names are not sent to the Neonatal Data Analysis Unit.

At the Neonatal Data Analysis Unit, NHS numbers are removed and stored separately on the secure NHS server of Chelsea and Westminster NHS Foundation Trust. Only de-identified data are stored in the National Neonatal Research Database at Imperial College London. "De-identified" means that information that can identify a baby directly has been removed. The NHS numbers are only used in accordance with special regulatory permission to link information in the National Neonatal Research Database with other information held by health organisations in order to make maximum use of the information to improve care and services.

Information in the National Neonatal Research Database is stored permanently as a national resource and held securely in accordance with relevant legislation. Information is only used in accordance with all required regulatory permissions.

Why has the National Neonatal Research Database been established?

The National Neonatal Research Database has been established to support audit, evaluation and research to improve newborn care and health services. All NHS organisations are expected to participate and support health and care audit, evaluation and research. The Health Research Authority and government departments in Northern Ireland, Scotland and Wales set standards for NHS organisations to make sure they protect patient privacy and comply with the law. National Research Ethics Committees review studies to make sure that research uses of data are in the public interest and meet ethical standards. A variety of organisations, such as NHS organisations, universities, companies developing new medicines or medical devices, and medical research charities, sponsor studies. These organisations have to show that the studies are in the public interest, in this case, improvement of newborn care and health services.

Can I refuse to have my baby's data included in the National Neonatal Research Database?

You are free to opt out of having your baby's data included in the National Neonatal Research Database. If you do not wish to have your baby's data included in the National Neonatal Research Database, please inform a member of staff on the neonatal unit where your baby is receiving care. Ask them to inform the Electronic Patient Record supplier not to send your baby's data to the Neonatal Data Analysis Unit. Alternatively, you may use the national opt out service.

Opting out will mean that your baby's data will not contribute to any of the purposes for which the National Neonatal Research Database is used. Data on all babies admitted to an NHS neonatal unit are included routinely in the National Neonatal Research Database unless a parent opts out.

Including information on every baby helps maximise benefits by ensuring all audits, evaluations and research studies are properly representative of NHS neonatal care in the UK. As there are around 100,000 babies admitted to NHS neonatal units each year it would be burdensome to parents and impracticable for staff to seek permission every time the National Neonatal Research Database is used for a new purpose.

What are my other rights?

You are entitled to request a copy of your baby's information held in the National Neonatal Research Database or ask for this to be deleted. Please ask a member of staff on the neonatal unit where your baby is receiving care. They will contact the Neonatal Data Analysis Unit on your behalf.

Only de-identified information in the National Neonatal Research Database is used for audit, evaluation and research without asking you for additional permission. The only exceptions are studies that fall under the support for the NNRD under 'section 251' from the Health Research Authority following advice from the Confidentiality Advisory Group regarding the use of confidential patient information for research purposes without explicit consent, and outside the direct care team.

If the National Neonatal Research Database is used for studies that require additional information or involve extra procedures, you will be asked for extra separate approval.

Who should I contact for more information?

We hope you have found this information helpful. If you have any questions about the National Neonatal Research Database, please go to www.imperial.ac.uk/ndau or contact ndau@imperial.ac.uk.

If you wish to lodge a complaint about the way your baby's data are being handled, please contact the Information Commissioner's Office at casework@ico.org.uk