

NNRD Privacy Notice

This notice is provided in compliance with the General Data Protection Regulation 2018. It relates to the use of information in the context of research conducted by the Neonatal Data Analysis Unit (the NDAU) and sponsored by Imperial College London.

Background

The Neonatal Data Analysis Unit (the NDAU) is a research unit in the Section of Neonatal Medicine, Department of Medicine, Imperial College London; based at the Chelsea and Westminster Hospital campus of Imperial College London. The NDAU was established to improve the quality of operational clinical data captured at the point of clinical care and promote their best use to support neonatal services and facilitate research. The NDAU is supported by a multi-professional Steering Board that includes parent and patient representatives. The work of the NDAU is conducted with NHS Trust, and Research Ethics approval as required. The NDAU complies with the National Statistics Practice and Protocol on Data Access and Confidentiality.

The NDAU oversees data held in the National Neonatal Research Database (NNRD). The NNRD is formed from clinical data about you and your baby that are extracted from routinely recorded NHS care records. These clinical data are recorded by neonatal unit staff using a commercial electronic medical record system (a form of electronic medical notes) as part of routine clinical care. Data recorded on this electronic medical record systems are securely transferred to servers based within the Chelsea and Westminster NHS Foundation trust. Following receipt of these data, any personal information (for example NHS numbers) are removed. No identifying information are included in the NNRD.

Who is responsible for the data we collect?

Under the General Data Protection Regulation, the 'data controller' is responsible for what happens to data which is collected. Imperial College London is the data controller for this study.

Imperial College London will collect information about you and your baby in the National Neonatal Research Database (NNRD). The NNRD will not provide any identifying information about you or your baby to Imperial College London. We will use this information to better understand neonatal conditions and treatments, and to improve neonatal clinical care.

Imperial College London will keep primary research data for 25 years after the study has completed in line with Medical Research Council guidance for clinical studies; these data will not contain any identifying information about you or your baby.

Your rights

Your usual statutory rights to access, change or move your information are limited, because of exceptions applicable to some types of research, and also because we need to manage your information in specific, lawful ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you and your baby that we have already obtained. To safeguard your rights, we will not use any identifying information about you or your baby.

Legal basis

As a university we use information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use information from people for research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

Sharing your information with others

We may share your personal data with other Imperial College employees, agents, contractors and service providers (e.g. suppliers of printing and mailing services, email communication services or web services, or suppliers who help us carry out any of the activities necessary for this project). Any third party service providers are required to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies.

Contact us

If you wish to raise a complaint on how we have handled your personal data or if you want to find out more about how we use your information, please contact Imperial College London's Data Protection Officer via email at dpo@imperial.ac.uk, via telephone on 020 7594 3502 and via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO). The ICO does recommend that you seek to resolve matters with the data controller (us) first before involving the regulator.