

## **Information for parents**

### **What is eNewborn?**

eNewborn is a collection of information (a database) on babies from neonatal units around the world. All the information in eNewborn is “de-identified”; this means it is impossible to find out about individual babies from the database. The headquarters of eNewborn is at Imperial College London, one of the top ten universities in the world.

eNewborn is approved by the UK National Research Ethics Service (reference 20/LO/1046) for use under data protection and research legislation to improve newborn care. eNewborn is also approved by the local/national authority of each contributing neonatal unit or network. Imperial College London is the data controller for eNewborn and is responsible for looking after the information in the database and using it properly. Everyone involved at Imperial College London will keep your baby’s data safe and secure and follow privacy rules. We provide more information below about eNewborn.

### **Why are we collecting data for eNewborn?**

The purpose of eNewborn is to improve patient care. The Chief Investigators and other members of the International Investigator Group use eNewborn to conduct studies. Other individuals and organisations can apply to the International Investigator Group for permission to use eNewborn. If the application is considered in the interests of babies and likely to benefit the care they receive, and if the applicants have obtained all necessary regulatory approvals to ensure that the use of data is in the public interest, and meets ethical standards, the International Investigator Group will normally give permission. Approved researchers’ are granted access to conduct data analyses within a secure virtual environment. There is no transfer of any data; only the results of analyses may be transferred out of Imperial College London.

### **Your baby’s health data**

The care your baby receives on the neonatal unit depends on the clinical information that the nurses and doctors record in paper and electronic records. This information includes mother’s details such as type of delivery, and diagnoses, care received and outcomes for the baby. These data can improve newborn care in many other ways such as helping neonatal units to improve their work and testing new and improved ways to care for babies and support families. One way in which care is improved is by participating in the international collaboration, eNewborn. Below, we explain how we use your baby’s data to improve care for babies through eNewborn.

### **What is the purpose of eNewborn?**

We use eNewborn to check whether neonatal care does what we want it to do (audit), to describe and compare care across many countries and units (evaluation and benchmarking), and to develop new and improved ways to care for babies (research).

### **How do we keep data secure?**

The local lead within each hospital or network sends data electronically using a secure system to Imperial College London, where eNewborn is located. No patient names are included, nor any

information like date of birth, address, or dates, that might identify you or your baby. The local hospital lead ensures there can be no identification of any individual baby.

### **Can I refuse to have my baby's data included in eNewborn?**

Under General Data Protection Regulations, you are free to refuse to have your baby's data included in eNewborn. This will mean that your baby's data will not contribute to any of the purposes for which eNewborn is used. Data on all babies admitted to neonatal units participating in eNewborn are included routinely unless a parent refuses. Including information on every baby helps maximise benefits by ensuring all audits, evaluations and research studies are properly representative of neonatal care. If you do not wish to have your baby's data included in eNewborn, please inform a member of staff on the neonatal unit where your baby is receiving care. They will make sure your baby's data are not included in eNewborn.

### **What are my choices about eNewborn?**

You can request a copy of the information on your baby that your neonatal unit sends to eNewborn. Please ask a member of staff on the neonatal unit where your baby is receiving care. You can stop your neonatal unit sending your baby's data to eNewborn at any time, without giving a reason, and without affecting your baby's care. We will retain any information that is already in eNewborn.

### **Legal basis of eNewborn**

Imperial College London is a university and in this capacity, uses personal information to conduct research to improve health, care and services. As a publicly funded organisation, Imperial College London has to ensure that it is in the public interest when personal information is used. Health and care research should serve the public interest. This is done by following the [UK Policy Framework for Health and Social Care Research](#), and by complying with the law, and the recommendations and guidance from the UK Information Commissioners Office.

### **International data transfer**

The UK is outside the European Economic Area so data transfer to Imperial College London is in accordance with local neonatal unit/country data protection legislation. If required, a data sharing agreement with Imperial College London that incorporates European Commission approved standard contractual clauses, safeguard how your data are processed.

### **What should I do if I wish to make a complaint?**

If you wish to raise a complaint against Imperial College London on how they have handled personal data, please contact the Imperial College London Data Protection Officer by email ([dpo@imperial.ac.uk](mailto:dpo@imperial.ac.uk)), telephone (+44 (0) 20 7594 3502) or post (Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ).

If you are not satisfied with the response or believe Imperial College is processing your personal data in a way that is not lawful, you can complain to the Information Commissioner's Office (ICO). The ICO recommends that you first try to resolve matters with the data controller (Imperial College London) before involving them.

If you wish to make a complaint against your baby's neonatal unit, please contact the local lead.

**Whom should I contact for more information?**

We hope you have found this information helpful. If you would like to know more about eNewborn please email [enewborn@imperial.ac.uk](mailto:enewborn@imperial.ac.uk). If you have any questions please ask a member of staff at your baby's neonatal unit.