Privacy Statement

May 2018
**Personal Data we collect**

The Northern Neonatal Network is an NHS organisation whose primary aim is “to provide a safe, high quality service for neonatal care workloads across the Network region, and seek to improve outcomes for all babies born and cared for within it”. The Network region is the North-east and North Cumbria. In order to fulfil our aim, we process data relating to the clinical care of these babies and their mothers. These data are primarily held on the national Badger neonatal system which records a large number of items of clinical data and which in some hospitals functions as an electronic health record. The data held on Badger are used for direct clinical care and for local audit.

For mothers, the Badger system holds limited data about the pregnancy which is restricted to aspects that have a direct bearing on the health of their babies, except in those hospitals where the Badger maternity information system is used for collecting all maternity data.

After discharge from neonatal care we collect and analyse data on the outcome for babies at high risk of developmental problems.

For babies who die we additionally collect any relevant information that subsequently becomes available (for example from blood tests or post-mortem results) so that we can maintain an accurate local audit of babies who die under a year of age; such deaths commonly relate to diseases or complications that originate in the fetal or neonatal period. These data are held on a database that is separate from the Badger system; the Network Infant Mortality Audit.

As with other NHS data, the lawful basis for our holding these data in compliance with the General Data Protection Regulation (2018) is 'Public Task'.

The NHS Trusts responsible for the hospitals in which the babies are cared for are the Data Controllers. The Northern Neonatal Network is a Data Processor.

**How we use Personal Data**

We use the data to audit the process and quality of neonatal care across the Northern Neonatal Network and to support collective arrangements such as the Northern Neonatal Transport Service (NNeTS).

We make regular quarterly reports, available on the Northern Neonatal Network website, of various measures of care, and we make important measures of overall outcome available for public scrutiny. These data always relate to groups of cases (aggregate data); no individuals are identifiable.

We do not undertake national audits. There are separate mechanisms for this, which are the National Neonatal Audit Programme (NNAP), and Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries in the UK (MBRRACE-UK) which monitors stillbirths and neonatal deaths (but not infant deaths). Both of these are covered by Section 251 of the NHS Act 2006.
Sharing Personal Data

The Northern Neonatal Network does not share any individual personal data with other parties. The Badgernet system facilitates data sharing between hospitals when a baby is transferred from one hospital to another to ensure clinical safety.

Subject access to data

Parents may request data access on their babies from the hospitals in which they are looked after; the Northern Neonatal Network holds no data that are not separately available from the NHS Trusts who are the Data Controllers.

Where there is a lawful basis for an agency or an individual other than parents to request personal health information on a baby, such a request is made to the hospital(s) where that baby received care.

Data retention

Long term monitoring of neonatal outcomes is recognised to be of great importance, as is the measurement of changes in outcomes over time. The NHS sets minimum requirements for the retention of medical records and other data with which we comply with. The Network (via the Network Data Manager) retains all anonymous material. Where the Network holds individual records (for example in the Network Infant Mortality Audit), these records are 'de-personalised' after 5 years which means that identifiers are removed or replaced with non-specific ones. For example, we remove names and addresses, replace the exact date of birth with year of birth, and modify the postcode by removal of the last 3 characters.

How Personal Data are protected

City Hospitals Sunderland NHS Foundation Trust (CHSFT) is the host organisation for the Northern Neonatal Network. All Network data are held securely on the CHSFT computer systems, in line with Trust information governance procedures.

There is also highly restricted physical access to machines capable of accessing Northern Neonatal Network data within CHSFT.