

Consent Protocol for Secondary Use of Neonatal Data

December 2005



This protocol is built around the Parent Information Leaflet - "A guide to recording information on your baby's care in the Neonatal Unit" - which is in standard use in the West Midlands.

1. All mothers should be given the parent leaflet as soon as possible following admission of their baby to the Unit.
2. The caregiver should complete the stamp in the baby notes that information concerning data collection / purpose of use etc has been explained.
3. Details should be given about where further information can be obtained, including local contacts and details of the Perinatal Institute, as detailed on the back page of the leaflet.
4. If the mother does not have sufficient understanding of the English language, an interpreter should be made available.
5. If the mother decides, at any time, that she does not want any details about her baby to be used for secondary analysis, this information should be recorded in the baby notes and the MANNERS support team should be notified by Phone 0121 687 3434 or Email: manners@pi.nhs.uk
6. The MANNERS team will ensure that an 'opt-out' form is sent to the mother for completion or the Clinical Lead in the Unit should email the Clinical Informatics Manager. The unique identifier (NHS Number) will be used to ensure that her baby's data is excluded from extraction for secondary analysis.