

# Consent Protocol for Secondary Use of Paediatric Data

September 2004



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

1. All parents/guardians should be given the leaflet as soon as possible following admission of their child to the Unit.
2. The caregiver should complete the stamp in the child 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 parent/guardian does not have sufficient understanding of the English language, an interpreter (rather than family member) should be made available.
5. If the parent/guardian decides, at any time, that they do not want any details about their child to be used for secondary analysis, this information should be recorded in the child's notes and the MANNERS support team should be notified, by the mother directly: Phone 0121 687 3434 or Email: [manners@perinatal.nhs.uk](mailto:manners@perinatal.nhs.uk)
6. The MANNERS team will ensure that an 'opt-out' form is sent to the parent/guardian for completion and the unique identifier (NHS Number) will be used to ensure that their child's data is blocked from extraction for secondary analysis.