Consent Protocol for the Use of the South East Neonatal Data (SEND) System

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 within neonatal units using the South England Neonatal Database (SEND)

1. All mothers should be given the parent leaflet as soon as possible following admission of their baby to the Unit.

2. 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.

3. If the mother does not have sufficient understanding of the English language, an interpreter should be made available.

4. If the mother decides, at any time, that she does not want any details about her baby to transferred to another neonatal unit should the need arise or anonymised data used for secondary analysis, the mother should be given an information sheet and opt out consent form.

5. The signed opt-out consent form should be copied: the original should be kept on file and a copy given to the mother for her information.

6. A member of the nursing team should ensure that all neonatal unit staff is made aware of this. The unique identifier (NHS Number) will be used to ensure that her baby’s data is blocked from extraction for secondary analysis and/or transfer.

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