

West Midlands Consent Protocol for Secondary Use of Perinatal Data

June 2005



The protocol is built around the Pregnancy Notes, which are in standard use. *

1. All mothers should be informed at booking that information is collected for secondary use, with reasons given. Explanatory text is as provided on page 2 of the Pregnancy Notes
2. Details should be given about where further information can be obtained, including the website of the Perinatal Institute (www.perinatal.nhs.uk) where many results of secondary analysis are presented.
3. At booking, the midwife or other caregiver should sign in the notes that information has been given and data collection / purpose of use etc have been explained.
4. Where the mother does not understand English sufficiently, an interpreter should be made available to provide the same information.
5. All staff submitting data to the Perinatal Institute are required to confirm and record that the relevant section on page 2 of the Notes is ticked and signed by the care provider.
6. If the expectant mother decides, at booking or at any time during her pregnancy, that she does not want any details about her or her baby to be used for secondary analysis, this information should be recorded in her Notes and her primary care provider will supply her with the opt-out form which the mother can then send to the Perinatal Institute.
7. The Perinatal Institute will use the unique identifier (NHS Number) to ensure that the mother's or her child's data is not held for secondary analysis.

* The unit which is currently still using its own Notes will be asked to make similar provisions.