Maternity - regional data collection
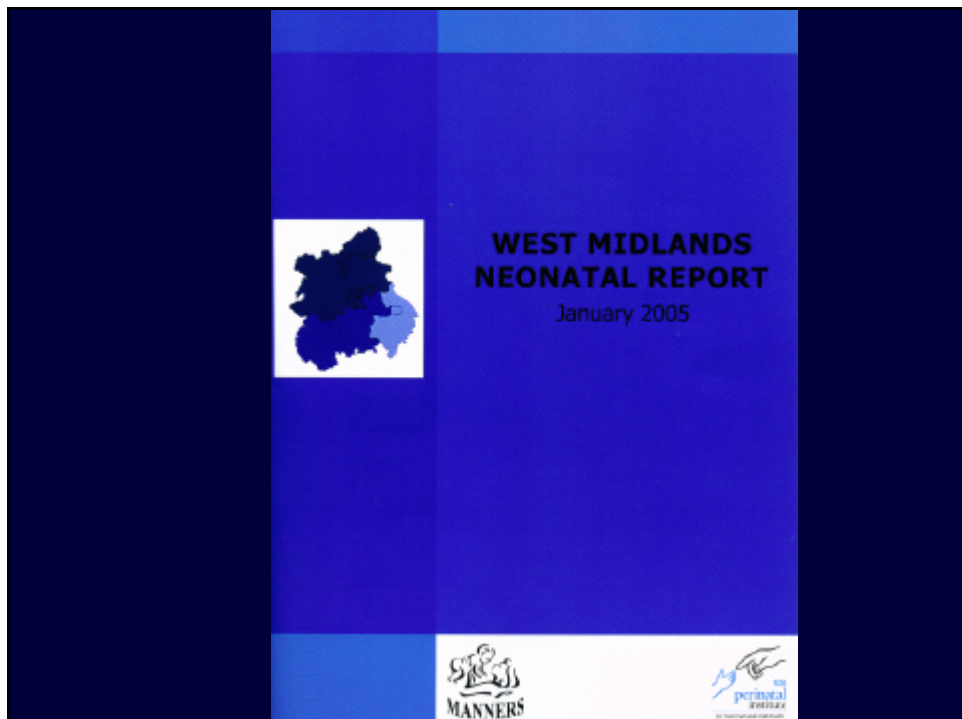
- Perinatal mortality (RRFs)
- Confidential Enquiries
- Antenatal Screening
- Congenital Anomalies
→ • Neonatal Care

- Specialised Services Commissioning
- Neonatal Care Networks

- Neonatal Forum
- Commissioners
- Clinical Networks
- Neonatal Professional Advisory Group
- Dataset subgroup

Neonatal Core Data Index

perinatal institute
for maternal and child health

Data Item, Basis, Explanation, Values and Origin

Version 4.1: March 2005
Data Items: 78

Crystal Court
Aston Cross
Birmingham
B6 5RQ

For further information contact:
Nicola Beamish
Tel: 0121 687 3434
Email: nicola.beamish@perinatal.nhs.uk

SCREENING DETAILS

DATA ITEM	Retinopathy of prematurity screening
BASIS	The examination of the level for retinopathy of prematurity
EXPLANATION	To measure compliance with national recommendations
INPUT OPTIONS	Maturely conclusive
	Screened prior to leaving
	Discharged before screening (screening to be managed)
	Not completed (did not meet criteria)
DATA ORIGIN	BAPM, N-PAG

DATA ITEM	Retinopathy of prematurity staging
BASIS	a record of worst stage of ROP in either eye
EXPLANATION	ROP is a significant neurological disease
INPUT OPTIONS	Maturely conclusive
	No ROP
	Stage 1
	Stage 2
	Stage 3
	Stage 4
	Stage 5
DATA ORIGIN	BAPM, N-PAG

DATA ITEM	Retinopathy of prematurity therapy
BASIS	a record of laser therapy given to treat ROP
EXPLANATION	The need for therapy for ROP is an indicator of severity of disease
INPUT OPTIONS	Maturely conclusive
	No therapy given
	Therapy given
DATA ORIGIN	BAPM, N-PAG

DATA ITEM	Date of Neonatal Bloodspot Test
BASIS	Record of when the test was performed
EXPLANATION	To make sure in correct age of test and result of process
INPUT OPTIONS	DD/MM/YYYY
DATA ORIGIN	M-PAG, N-PAG, NSC

DATA ITEM	Universal Neonatal Hearing screen
BASIS	Record of test or has been performed
EXPLANATION	Facilitates and that analysis calculations to variables.
INPUT OPTIONS	No screen required
	No screen
	No follow up required
	Follow up required
DATA ORIGIN	BAPM, M-PAG, N-PAG, NSC

Benefits of a regional record

- Central server and data management
- Specialised team incl. programmers
- Standardised dataset
- Standardised data security
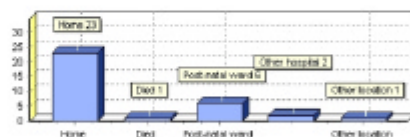- High ascertainment
- Central analysis of data

**WEST MIDLANDS
NEONATAL REPORT**
January 2005

MANNERS

perinatal
institute

Neonatal Unit Monthly Summary: November 2001

Admissions from

- Delivery Suite 22 (red)
- Home 1 (green)
- Other hospital 6 (yellow)
- Ward 3 (blue)

Discharges

Home 23
Died 1
Post-natal ward 6
Other hospital 2
Other location 1

Birth weight	Discharged Alive	Died
0 - 999	0	0	0
1000 - 1499	0	0	0
1500 - 1999	0	0	0
2000 - 2499	0	0	0
2500 - 2999	0	0	0
3000 - 3499	0	0	0
3500+	0	0	0

Care Levels

Intensive Care 1	Days	45
	Daily average	1.5
Intensive Care 2	Days	12
	Daily average	0.4
Special Care	Days	78

NIC

All Neonates

Event

Antenatal Screening Audit	CESDI PNM stats	C/S Sentinel Audit	CESDI 27/28	Laming 2003
				Social services
'Screen +ve'	Stillbirths	CS rates		Acute admissions
Diagnostic tests – CVS, Echo	Referrals to Fetomat . unit	Intrapartum complications	Neonatal Unit	PHDU

Conception   *NN4B*   **Kindergarten**

ALL BOOKINGS	ALL PREGNANCIES	ALL BIRTHS	ALL NEONATES	ALL CHILDREN
'Offer' of screening	SGA Detection	Length of stay	NN screening	Immunisation
	Smoking cessation	Breastfeeding	Immunisation	Developmental milestones

Denominator

Maternity Core Data Index

Data Item, Basis, Explanation and Values

Version 5: April 2005
Data items: 233

Crystal Court
Aston Cross
Birmingham
B6 5RQ

For further information contact:
Nicola Beamish
Tel: 0121 687 3434
Email : nicola.beamish@perinatal.nhs.uk

REFERENCE DATASETS

ANSAG	Antenatal Screening Advisory Group
BAPM	British Association of Perinatal Medicine
BNDS	Birth Notification Data Set
CAR	WM Congenital Anomalies Register
CDS	Commissioning Data Set
CEMACH	Confidential Enquiry into Maternal and Child Health
DOH	Department of Health
ENN	EuroNeoNet
GROW	Gestation Related Optimal Weight
HES	Hospital Episode Statistics
HOI	Health Outcome Indicators – Normal Pregnancy and Childbirth
M-PAG	Maternity Professional Advisory Group – West Midlands
N-PAG	Neonatal Professional Advisory Group – West Midlands
NICE	National Institute for Clinical Excellence
NSC	National Screening Committee
ONS	Office for National Statistics
RCOG	Royal College of Obstetricians and Gynaecologists
RCPCH	Royal College of Paediatrics and Child Health
RCR	Royal College of Radiologists
RUG	Regional Ultrasound Group
SS	SureStart

DATA ITEM	Care plan at the start of labour
BASIS	To identify lead professional responsible for care at start of labour
EXPLANATION	To facilitate audit of elements of care in labour
INPUT OPTIONS	Midwife in GP shared care
	Midwife, obstetrician & GP shared care
	Midwife only
	Midwife & obstetrician only
	Obstetrician only
DATA ORIGIN	CDS, HES, H MG

DATA ITEM	Reason for change of care
BASIS	Record of reason for change of intended plan of care at any time during pregnancy and/or labour
EXPLANATION	Facilitates tracking of care and audit of best practice
INPUT OPTIONS	No change necessary
	Clinical reasons during pregnancy
	Other reasons during pregnancy
	Clinical reasons during labour
	Other reasons during labour
DATA ORIGIN	CDS, CEMACH HES, M MG

DATA ITEM	Labour onset
BASIS	The manner in which labour was spontaneous
EXPLANATION	To record any intervention in process of labour
INPUT OPTIONS	No labour evident
	Spontaneous
	Induced artificially
	Caesarean before labour
	TOP – Medical / surgical
DATA ORIGIN	CDS, HES, H MG

DATA ITEM	Method of induction
BASIS	To record any intervention in process of labour
EXPLANATION	To facilitate audit of standard of care in labour
INPUT OPTIONS	Not previously in register
	Membrane sweep
	Prostaglandin E2
	Gemeprost
	ARM
	Oxytocin
DATA ORIGIN	HES, MMMG

Pregnancy Notes

Name _____

Address _____

Postcode _____ Date of birth ___ / ___ / ___

Unit No. _____ NHS No. _____

These notes should be carried by the expectant mother at all times during her pregnancy

CONFIDENTIAL

If found, please return the notes immediately to the owner, or her midwife or maternity unit

NHS number barcode

EDD ___ / ___ / ___

Plan of care

Date recorded	Planned place of birth	Lead professional	Reason, if plan changed
/ /			
/ /			
/ /			
/ /			

Primary care

Centre _____ GP (= own) _____

Address _____ Midwife _____

_____ Health visitor _____

Interpreter _____

Maternity Unit

Hospital _____ Switch _____ Delivery suite _____

Address _____ Day unit _____ Antenatal clinic _____

Ward _____ Ambulance _____

Next of Kin

Name _____

Address _____

Relation _____

Emergency Contact

Name _____

Address _____

page 1

The Pregnancy Notes

These are your Pregnancy Notes. They aim to fulfil two main functions. Firstly, they are a guide to your options during pregnancy, and are intended to help you to make informed choices. This is to promote care which is safe and personalised to you and your baby. However, the explanations in these notes are a general guide only, and not everything will be relevant to you. Please feel free to ask if you have any questions. Additional information is also available on a special website, www.preg.info, or in leaflets which you may be given as and when needed.

Secondly, these notes are an important record of your pregnancy, so please keep them safe and with you at all times. The booking details should be completed jointly with your midwife or doctor. All information you provide will be considered as confidential. However, anything you do not wish to be written in these notes can be recorded elsewhere instead.

Information about your pregnancy is also recorded electronically for audit and statistical reports, in the quest to maintain high standards of care in the health service. If you are being looked after in a maternity unit outside the West Midlands, please ask your care provider for further details about this. In the West Midlands, electronic information is kept on a secure database at the Perinatal Institute. The details collected are all relevant to the care of you and your baby, but your name and address is removed before anyone other than your personal carers can see your data. If you would like to know more, or have any concerns about information being held about your pregnancy, please contact the Perinatal Institute (see details on bottom of page 22).

Data collection and record keeping discussed ☐ Date ☐ / / ☐ Signed* Care Provider ☐

Consent Protocol for Secondary Use of Perinatal Data

June 2004

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

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:

   The details which are included are relevant to the care of you and your baby. Some of this information is shared with other staff within the NHS, to maintain safety and high quality standards of care. Some details will also be assessed for audits and statistical reports. However your name and address will be removed before anyone other than your personal carers see any of the information. If you would like to know more, or have any concerns about information being held about you or your baby, please contact the Perinatal Institute (see details on bottom of page 22).

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 Pregnancy Notes.

3. At booking, the midwife or other caregiver should sign in the notes that information concerning data collection / purpose of use etc has 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 entering data onto MANNERS will be asked by the programme to confirm 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 the MANNERS support team should be notified, by the mother directly: Phone 0121 687 3434 or Email: manners@perinate.org

7. The unique identifier (NHS Number) will be used to ensure that the mother's or her baby's data is blocked from extraction for secondary analysis.

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

NSF – Standard 11

Routine Data Collection and Analysis

11.2 The Government recognises that data from NHS maternity care providers is important as it provides a measure, not only of the health of pregnant women, but also of their babies. Data on the mother's health plays an important part in the child's health record, so maternal and child health should be linked. Such information, on processes and outcomes, also informs continuous improvement in local maternity services to best address local needs.

Primary Care Trusts and NHS Trusts ensure that maternity data is collected and made available in accordance with recognised best practice, and agreed national datasets once published.

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education and skills

DH Department of Health

Children's & Maternity Services Information Strategy

Supporting the Children's, Young People and Maternity Services National Service Framework

Part of the agenda for "Every child matters: Change for children"

Information for Secondary Purposes

Supporting Information for 'Access to Approved Data Items for Secondary Analysis'

3.1 Approved data items used to record and describe the care and management of children, young people and mothers/mothers-to-be will appear on the Spine Record. The National Programme for IT (NPfIT) through the LSP will ensure that stakeholders for secondary purposes information can gain access to this data, subject to security and confidentiality considerations, either locally or through the services of national organisations established for this purpose such as the National Analytical Service.

There are at present many datasets in use throughout the field of children's and maternity services. Few, if any, of these datasets are approved by the NHS Information Standards Board (ISB) and there is little coordination.

National Action 1.3 envisages a programme, under the auspices of the NPfIT, which will identify the data items that are needed to record and describe the care and management of children, young people and mothers/mothers-to-be and arrange for them to be approved by the ISB and therefore to appear on the Spine Record as they are used.

This will make such items available also for secondary analysis purposes through extraction and analysis from the Spine Record. Such extraction and analysis could be performed locally or through the services of national organisations established for this purpose such as the National Analytical Service. See National Action 2.3.

There are many stakeholders for secondary purposes information and the National Programme for IT (NPfIT) will need to ensure, through working with the appropriate partners, that the necessary hardware, software and procedures are in place to enable such organisations to extract the data they require.

One example that it may be useful for the NPfIT and the LSP to refer to as part of the implementation of this action is that of the MANNERS (Maternal and Neonatal Electronic Recording System) project of the Perinatal Institute. The MANNERS software uses a core dataset based largely on data that has already been defined. Fine-tuning is done through an iterative process of multidisciplinary consultation and field-testing in maternal and neonatal units. The Perinatal Institute's IT unit programs the software and updates and amends the data fields as required. As the software runs on the Institute's central server, all units use the most up to date version. The project is paid for by the West Midlands Specialist Services Agency, which recognises the need for data for events / outcomes as well as for denominators, i.e. all pregnancies and all babies/children.

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A full list of the current functionality of MANNERS to date is listed below:

MATERNITY
- Customised Growth Charts
- Calculated EDD by scan
- Maternal label with NHS No. barcode
- A/N Screening Report
- Calculated time of ROM to birth
- Calculated gestation at delivery
- LW summary
- Birth Congenital Anomaly Notification
- Delivery report & graphs
- BMI
- Calculated gestation at each A/N scan

- A/N Congenital Anomaly Notification
- Calculated length of 1st, 2nd & 3rd stage of labour
- Calculated birth centile minutes
- Maternal transfer summary
- Baby transfer summary
- Neonatal label with NHS No. barcode
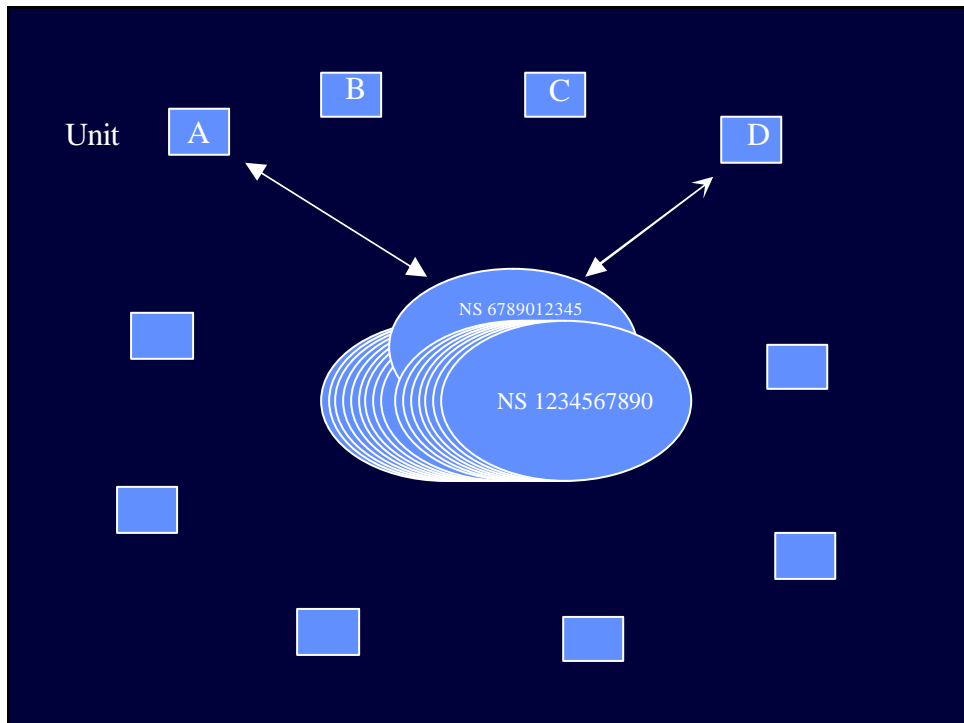- Admissions report & graphs

NEONATAL
- Calculated Apgars @ 1, 5 & 10 minutes
- Death notification
- Neonatal Congenital Anomaly Notification

- Discharge report & graphs
- Discharge notification
- Neonatal summary
- Admission report & graphs

The following is a list of possible stakeholders for secondary purposes information.

Maternal and Neo-Natal Electronic Recording System *(MANNERS)*

- patient based
- multi-user access, secure, web-based system
- agreed core datasets
- facilitating local reports and regional analysis

www.perinatal.nhs.uk/manners

MANNERS

- NHSnet
- NHS number as unique identifier
- Confidentiality & Consent policies in place
- Password protected
- User access levels
- Supports HL7 messaging
- Dataset agreed by WM users
- Support, teaching & helpdesk function