Needs
Most of these are available in electronic form, re-arranged by me in chronological order, They are ready to go on the website when a better way of classifying them has been devised.

Datasets relevant to Maternity & Neonatal Care

A list of all datasets so far collected ready to be accessed via the website (plus a list of main maternity casenotes and other sources also used)

Amongst many others, the EEPD project is indebted to all those who worked on any of the following datasets or contributed in any way to current standards of national documentation. Whenever possible the names of individuals who were members of the relevant working groups are documented.

Although several of these datasets are obsolete or were only proposals, they are still worth documenting since otherwise many good forms of wording or useful ideas would be lost.

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Edited by
Rupert Fawdry, FRCS (Ed), FRCOG, Consultant Obstetrician & Gynaecologist
General Editor: Electronic Encyclopaedia of Perinatal Data (EEPD) Web site: www.fawdry.info
31, St Mary's Way, Leighton Buzzard, LU7 2RX, United Kingdom
Home: 01525 37 01 37 Fax: 01525 38 24 53 Mobile: 077 68 97 44 13
E-mail: eepd@fawdry.demon.co.uk web site: www.fawdry.info or www.perinataldata.info
or
C/o The Perinatal Institute, Crystal Court,
Aston Cross (off Rocky Lane), Birmingham B6 5RQ
Tel: 0121 687 3400 www.perinatal.nhs.uk

Any Comments, Criticisms, Corrections or Suggestions for Improvement very welcome
The EEPD Volume III. Maternity & Neonatal Data Resource Document

is gradually attempting to take full account of all of the following:

A. Data Sets related to Maternity Care as defined by some relevant body.
Total U.K. Data Sets so far identified: 5+4+1+3+3+3+10+18+2+12+5+2+3+1 = 74

The U.K. tax-payer is ultimately required to provide funding for the data entry work of the majority of these different datasets!
Yet almost all of them are virtually independent in their data selection and definitions and therefore required fresh data entry on any computer system!

INDIVIDUAL RETURNS
Every Birth (B)
Birth Certificate (United Kingdom) Registrar of Births, Deaths and Marriages
Birth Notifications / Child Health Registers (including NHS Number project & New Birth Notification)
(More than 20 partially different versions have been in use in the past)
Maternity data required for filling in the parent-held Child Health Record
(Oxford Region Version with any known additions required by other regions)
NPEU & ORHA Recommendations (Paediatric)
Disability and Perinatal Care: Measurement of Health Status at Two Years.
Working Groups convened by the National Perinatal Epidemiology Unit and the Oxford Regional Health Authority
“Birthrate Plus” Data needed for each Birth Event in order for later analysis.
Using clinical indicators to assess case mix, workload outcomes and staffing needs in intrapartum care and for predicting postnatal beds needs.
Canadian Birth Certificate (1997)
Canadian Toronto Consensus Perinatal Database (1994)

SCOTTISH (S)
Scottish Acute Hospital Discharges (SMR 01)
Scottish Maternity Discharge (SMR 02)
Scottish Neonatal Discharge (SMR 11)

KORNER (K)
Full Korner Document
Korner Maternity Compulsory Minimum Maternity Data Set
Korner Maternity Clinical Options
Korner Maternity Paediatric Options
Korner Maternity Anaesthetic Alternative Options
Settatree’s proposals for a Revised Korner Maternity” (>300 items)
Draft RCOG Audit Committee Sub-Group proposals
for a “Revised Maternity Tail” / Revised Korner Maternity”

ANAESTHESIA (A)

HOSPITAL MANAGEMENT
H1  H.E.S. - Hospital / Consultant Episode ( - currrent)
H2  H.E.S. Maternity Tail
H3  Contract / Commissioning Minimum Data Set Proposals
LARGE ELECTRONIC DATABASES

Oxford Record Linkage Initiative
Cardiff Births Survey - Maternity (19?? - present?)
Cardiff Births Survey - Neonatal (19?? - present?)
Maternity Care Data Project Data Dictionary proposals (450 questions)
Perinatal Institute - MANNERS Maternity
Perinatal Institute - MANNERS Neonatal
Perinatal Institute - MANNERS Special Care

Dutch (1977) Van Hemel Dataset

ELECTRONIC PATIENT RECORDS COMPUTER SYSTEMS (MATERNITY)
CCL/Circona/St.Mary’s
Euroking
Protos (Now Evolution as a temporary part of iSoft)
Terranova
Care Records

Some Births only

MOTHER
M1 Risk Management/Adverse Patient Outcomes
M2 Hydatidiform Mole Registration
M3 Anti-Epileptic Drugs in Pregnancy
M4 Rare Diseases in Pregnancy
M5 National Sentinel Caesarean Section Audit (SENTINAL)
M6 Abortion Certificate Notification
M7 Abortion Notification (including new 2002 revised version)
M8 Notifiable Diseases
M9 Maternal Death United Kingdom Confidential Enquiry into Maternal deaths (2002 Version)
M10 Rubella and Rubella Vaccination in Pregnancy

NEONATE
N1 Stillbirth Certificate
N2 Neonatal Death Certificate
N3 CESDI (1996 Version)
N4
N5 BAPM Neonatal Data Set (1997)
N6 Adoption pro formas (2001)
N13 Cytogenetics Feed-Back
N14 Cardiac Scan Feed-back
N15 Cranio-Facial Abnormalities Register
N16 Oxford Record Linkage Project (No longer active but had useful ideas)
N17 Health Status at Two Years Proposals

X. CONGENITAL ANOMALIES
X1. National Congenital Anomalies System
X2 National Down Syndrome Cytogenetic Register
X3 Early Childhood Impairments (Oxford)
X4 Mersey Region Register
X5 Scottish Register of Motor Deficit
X6 North of England (NECCPS)
X7 Northern Ireland (NICPR)
COLLECTIVE RETURNS

RETURNS (Annually)
R1 Royal College of Obstetricians and Gynaecologists (RCOG Annual) Returns
R2 English National Board Annual Returns (ENB Annual) - For Midwifery Practice
(The ENB has now been superseded but the data items previously required by the ENB are still of relevance)
R3 Modernising Maternity Care
A Commissioning Toolkit for Primary Care Trusts in England (November 2001)

WORKLOAD
W2 Forecast of future workload

GOVERNANCE / Audit / Benchmarking
G1 Required by Purchasers in the past
G2 Changing Childbirth Indicators for Success
G3 Clinical Negligence Scheme for Trusts
G4 Clinical Outcome Indicators
G5 Towards Safer Childbirth.
G6 National Benchmarking Company proposals
G7 Clinical Governance
G8 Standard Primipara
G9 Robson Caesarean Section Audit
G10 ASQUAM Project.
G11 Procedures Suitable for Audit.
G12 North & South Thames Project

QUESTIONNAIRES
Q1 Reproductive Health (Wendy Graham)
Q2 Output/Quality Review System (OQRS) Questionnaire from St.Thomas’ & Guy’s
Q3 Changing Childbirth Information Survey. NPEU
Q4 Audit Commission Value for Money (MK Pilot Birmingham Heartlands & Ipswich)

PAYROLL / Personnel
P1 Payroll / Personnel StandardDataset (if it exists yet)
B. Casenotes
Far too many for them all (over 200) to be listed here but the following four records are of special importance
C1 Milton Kenes and the West Midlands (1984) (“Green Notes”)
C2 National Maternity Records Project (“Your Personal Pregnancy Record”)
C3 West Midlands Maternity Records Project (“Pregnancy Notes”)
C4 West Midlands Perinatal Institute (wmpi) G.R.O.W. Charts
C5 USA (1977) Hollister Maternal/Newborn Record System
C6 Scottish National Maternity Record

C. Triggers

Action Suggestion Triggers
T1 Basis for providing Triggers for “Risks Identified” and “Action Suggestions”
T2 Basis for offering to display or print Care Guidelines or Protocols
T3 Basis for suggesting the supply of Patient Information Leaflets
T4 Basis for suggesting the inclusion of this patient in a current Research project

Communication Triggers
T5 Memos or Letters or Discharge Summaries etc
T6 Investigations Request Proformas

Letters used so far: Anaesthesia, Birth, Casenotes, Databases, EPRs, Governance, Hospital Management, Korner, Large, Mother, Neonate, Overseas, Personnel/Payroll, Questionnaires, Returns, Scottish, Triggers, Workload, X = Congential Anomalies

Remaining Letters: FIJUVYZ

NOTE

“Risk Factors” are confusingly used in three related but different ways

a. Pregnancy (Hand held) Paper Records
   As factors to be printed in paper records at the initial assessment or during pregnancy
e.g. WHO Records, or Sighthill Records

b. In Electronic Patient Records
   As “Triggers Items” for “Action Suggestions” in complex Electronic Maternity Dataset Records.
   See EEPD Volume 4. SIGNPOSTS

c. Audit
   As triggers for retrospective audit of past events
e.g. Prolonged second stage, Undiagnosed Breech etc.