

DSCN Notice: 73/2002 English DSCN Equivalents: N/A Date of Issue: December 2003

IRSS Information Requirements and Standards Sub Committee

Subject: New Dataset for the National Community Child Health Database

Implementation date: 31st January 2004

DATA SET CHANGE CONTROL PROCEDURE

This DSCN gives notification of changes to be included in Version 2.4 of the NHS Wales Data Dictionary.

Summary of change:

Implementation of a new mandatory data set for the new National Community Child Health Database (NCCHD).

Change Proposal Reference No: IRSS/09/03/01

The Information Requirements and Standards Sub Committee (IRSS), is responsible for approving information standards.

Please address enquiry's about this DSCN to Jennifer Evans, Data Standards and Information Quality Team, HSW, Brunel House, 2 Fitzalan Road, Cardiff CF24 0HA Tel: 029 20502539 or E_Mail iennifer.evans@bsw.wales.nbs.uk

Data Set Change Notices are available via the Intranet Service HOWIS http://howis.wales.nhs.uk/ or by contacting the above address.

DSCN numbering format = sequence number/year of issue, (W) for Welsh DSCN's.

DATA SET CHANGE NOTICE 73/2002

Reference: IRSS/09/03/01

Subject: New Dataset to support the new NCCHD

Type of Change:

Implementation of a new mandatory minimum data set (MDS) for the new National Community Child Health Database (NCCHD).

Background:

The Child Health System in Wales is already the source of key public health monitoring data such as vaccination, immunisation and perinatal mortality data, but has the potential to supply much more. Existing and potential users of the data, at both the national and local level, were consulted during the Child Health Information Requirements Project (CHIRP) and have expressed a desire to see the potential of the Child Health System fully realised.

Following the introduction of the new Oracle based (Community) Child Health System CCH2000, which has been implemented locally in all Trusts in Wales, it has now become extremely difficult to obtain all-Wales data. This has affected all users of all-Wales information and was recognised by CHIRP as a significant added risk to the availability of all-Wales data.

Phase 2 of the CHIRP project has concluded that the preferred method of ensuring the future of all-Wales data is to set up a new national database created by pulling together selected information from the locally managed CCH2000 databases. This will be known as the National Community Child Health Database (NCCHD), and will be the source of very valuable information for Wales, critical to the delivery of a high quality and effective child health service.

The NCCHD will be populated by a mds, which has been developed and approved by the CHIRP project, and will be transmitted from all Trusts in Wales. It is envisaged that it will be further developed over time in line with stakeholder and information user requirements.

Additional information can be found in the document WHC (2003) 113.

Implementation Date: 31 st January 2004

Action

Prior to the first collection at 31st January 2004, Trusts should take the following actions to ensure compliance with the requirements of the mds, particularly in the use of National Data Standards:

- Registered GP and GP Practice Codes (WMD 10) Adopt the use of the National codes within Trust CCH2000 systems; assistance in moving from the use of 'local' codes can be provided by HSW.
- <u>Ethnic Group</u> (WMD 17) Adopt the use of the National codes for this data item; assistance in moving from the use of 'local' codes can be provided by HSW.
- <u>Postcoding</u> (WMD 7) Ensure that all data held in Trust CCH2000 Databases (for 'year of birth' 1988 onwards) has a valid Postcode wherever feasible; facilities to obtain 'missing' postcodes are available in CCH2000.
- NHS Number of child (WMD 2) Ensure that the records of all children held on Trust Databases (for 'year of birth' 1988 onwards) contain a valid new NHS Number wherever feasible. Missing NHS Numbers can be obtained from the NHS Administrative Register (NHSAR) or the National Strategic Tracing Service (NSTS). Facilities to assist this process are available in the CCH2000 software, and advice can be obtained from HSW.
- **Place of Birth** (WMD 29) Adopt the use of the National codes for this data item; assistance in moving from the use of 'local' codes can be provided by HSW.
- **Breastfeeding Indicators** (WMD 21) —It is intended that standardised and consistent breastfeeding data will in future be collected across the countries of the UK. This will entail expanding the data collected on breastfeeding to clarify initiation/intention to breastfeed at birth and extend the types of feeding reported on and the ages at which they are reported. Until these issues are finalised, and Trusts are advised otherwise, each Trust should comply with the recording of the key breastfeeding indicators as outlined in WHC (2001) 024.

The Community Child Health Systems team at HSW will issue details of the implementation process. For any further queries, please contact Gill Davison, Head of CCH Systems, on 029 2050 2251 (WHTN: 1790 2551), or via gillian.davison@hsw.wales.nhs.uk

The data extracts from each individual trust will be automated on a quarterly basis, and controlled by HSW.

After each extract, there will be feedback on data quality, with reports being available to all Trusts.

Effect on Data Dictionary:

The data definitions for the new NCCHD mds will be included in Version 2.4 of the NHS Wales Data Dictionary and are shown in Appendix A (below).

Clearance:

IRSS have approved the introduction of the new National Community Child Health Database dataset.

Additional Information:

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WMD	Name	Scope	Definition	Justification	Timing	Classification or Coding
1	Trust Number	Every Child's Record	Unique Number identifying the Trust	To identify source of information	On registration	Trust Number Format (3 digits).
2	NHS Number of Child	All babies born and eligible children entering the country	Child's Unique NHS Number	Best unique identifier both for use at local level, and linking children receiving care/treatment in any part of the NHS system	Issued at birth.	NHS Number format. (10 digits)
3	NHS Number of biological mother	All mothers giving birth to live babies	Biological mother's unique NHS Number	Enable linkage of child's record to biological mother's record to access details of antenatal, delivery, and postnatal events	On registration of birth or entry of child into UK	NHS Number format (10 digits)
4	Date of Birth	All babies born or registered	Date of birth of child	Required to derive child's age for analysis of age related events	On registration	DD/MM/YYYY.
5	Time of Birth	All babies born or registered	Time of birth of child	Infants born during the night are thought to have a greater risk of infant & early neonatal mortality related to asphyxia	On registration	ННММ
6	Sex	All babies born or registered	Gender of child	Required to analyse data for differences by sex	On registration	Allowable values:- Male Female N/K

WMD	Name	Scope	Definition	Justification	Timing	Classification or Coding
7	Post Code	All children registered	Valid postcode for known place of residence of child	Used to derive the geographical distribution of children with certain characteristics.	On registration and at change of address	8 digit field
8	Initial Status	All children	The reason why the record was initially created and the date of creation.	To record the level of trust births, transfers in, and movements in.	On registration or movement in	Numeric code and date in format DD/MM/YYYY:- 0 = Trust Birth 1 = Transfer In 2 = Transfer Out 3 = Movement In
9	Current Status	All children	The reason why the child has reached its current status and the date of status.	To record the level of transfer in and out, movement in and out, and deaths.	At time of receipt of information	Numeric code and date in format DD/MM/YYYY:- 0 = Trust Birth 1 = Transfer In 2 = Transfer Out 3 = Movement In 4 = Movement Out 5 = Died 7 = Stillbirth 8 = Living outside, treated inside
10	GP Practice Code	Every child's record	Each GP practice has a unique code issued and maintained by the Prescription & pricing Authority	Required to ascribe children to GP practice caseloads. Can be linked with the LHB via the same code table to derive data by LHB	At time of registration	Practice code format – 6 digits. Consistent with Organisational Code service.

Appendix A

National Community Child Health Dataset

WMD	Name	Scope	Definition	Justification	Timing	Classification or Coding
11	HV/School Nurse Code	Every child's record	Each HV/School Nurse requires an unique code	Required to ascribe children to HV/School Nurse caseload.	At time of registration; amended whenever a change occurs	4 alpha numeric code; locally managed
12	Number Born	Every child's record	The number of births resulting from the pregnancy		On registration	Numeric
13	Birth Order	Every child's record	The order of the birth where more than one birth resulted from pregnancy	Multiple pregnancy increases the risk of perinatal/neonatal morbidity and mortality	On registration	Numeric
14	Birth Weight	Every child's record	First weight of the baby following delivery, preferably in the first hour of birth	Birth weight is a major risk factor for neonatal mortality and morbidity, and is required to analyse the outcomes of antenatal and perinatal care.	On registration	In grams – 4 digits
16	Age of Mother at Birth	All mothers giving birth	Biological mother's age at time of birth	•	On registration	2 numeric digits denoting years.

WMD	Name	Scope	Definition	Justification	Timing	Classification or Coding	
17	Ethnic Group	Every child's record	Ethnic group of child as determined by the mother (& father where reliable)	It is important to be able to respond appropriately, not only in the means of delivering services and care, but in the understanding of the different health requirements of the many different ethnic and cultural groups. Access and exclusion issues are often key determinants of health outcomes for certain groups. The targeting of specific interventions designed to identify health problems and/or deliver more culturally sensitive care is dependent on such data.	On registration	White Any White Background Mixed White and Black Caribbean White and Black African White and Asian Any other mixed background Asian or Asian British Indian Pakistani Bangladeshi Any other Asian background Black or Black British Caribbean African Any other Black background Other Ethnic Groups Chinese Any other Ethnic Group Not Stated Not Stated	H J K L M N

WMD	Name	Scope	Definition	Justification	Timing	Classification or Coding
19	Mode of Delivery	All babies born	The procedure by which a woman is delivered of a baby		On receipt of Neonatal Discharge form, within 14 days of birth	0 - SVD(Normal Vertex) 1 - Other Spontaneous (Cephalic) 2 - Forceps (Low) 3 - Forceps (Other) 4 - Ventouse 5 - Breech Delivery 6 - Breech Extraction 7 - Elective C/S 8 - Emergency C/S 9 - Other
20	Onset of Labour	All babies born	The method by which the process of labour began		On receipt of Neonatal Discharge form, within 14 days of birth	 1 - Spontaneous 2 - Any caesarian section carried out. 3 - Surgical Induction; by amniotomy. 4 - Medical induction 5 - Combination of surgical and medical induction 9 - Not Known

WMD	Name	Scope	Definition	Justification	Timing	Classification or Coding
21	Breast Feeding (Data item as defined by CHIRP2 and Community Nurse Performance indicators)	All mothers giving birth	Baby being breast fed (either wholly or partially). Include any breast feeding or giving of breast milk to infants.	Health promotion indicator. Breast-feeding is acknowledged as optimal nutrition for children. Better health outcomes later in life, particularly with regard to the prevention of heart disease and strokes have been reported. The Department of Health has consistently sought to promote breast-feeding. Will enable the monitoring of coverage and the outcome of interventions designed to increase coverage	Breastfeeding intention recorded at birth. Breast feeding at six-eight weeks (with six-eight week check). Breastfeeding at four months (recorded with immunisation)	Y or N.
22	Mother's Smoking History	Every child's record	The history of the cigarette smoking habit of the mother		On receipt of Neonatal Discharge form, within 14 days of birth	0 – Non-smoker 1 – Gave up in pregnancy 2 – 0-9 a day 3 – 10 or more a day 9 – Not Known

WMD	Name	Scope	Definition	Justification	Timing	Classification or Coding
23	Type of Maternal care	All babies born	Type of Maternal Care		On receipt of Neonatal Discharge form, within 14 days of birth	0 - Booked and delivered consultant led care 1 - Booked Community Hospital 2 - Booked and delivered midwife led care 3 - Booked MLC (transferred antenatally) 4 - Booked MLC (transferred in labour) 5 - Booked MLC (transferred postnatally in maternal interest) 6 - Booked MLC (transferred postnatally in infant interest) 9 - Not Known
25	Gestational Age	Every child's record	Best estimate of gestation at the time of delivery in completed weeks, normally based on the postmenstrual age, but may be modified on the basis of ante natal ultrasound scan. Where gestation is unknown, it is based on the postnatal estimate of maturity.	Gestational age is an important determinate of outcome; a major risk factor for neonatal mortality and morbidity, and is required to analyse the outcomes of antenatal and perinatal care. It should also be taken into account when assessing growth and weight gain.	At registration	2 digit number representing the number of completed weeks

WMD	Name	Scope	Definition	Justification	Timing	Classification or Coding
28	Apgar Score	All babies born	The total apgar score for a baby at 1/5 minutes		At registration	Positive integer; 0-10
29	Place of Birth	Every child's record	Actual place of child's birth, i.e. hospital number or home (as applicable)	Place of birth is an important factor associated with outcome.	At registration	Standardised 6 digit national organisational codes
31	Neonatal Screening - PKU	All babies born	Outcome of Guthrie (screening) test for Phenylketonuria	The identification of infants with Phenylketonuria is a national screening programme aimed at reducing the incidence of brain damage to nil. If the condition is discovered before the age of eight weeks and treatment initiated, the child should suffer no serious sequelae. Coverage figures will be derived from this	Recorded as soon as data received from lab.	Outcome values:- Positive Negative Not Done.

WMD	Name	Scope	Definition	Justification	Timing	Classification or Coding
32	Neonatal Screening - Hypothyroid	All babies born	Outcome of screening test for Hypothryiod	The identification of infants with Hypothyroidism is a national screening programme aimed at reducing the incidence of brain damage to nil. If the condition is discovered before the age of eight weeks and treatment initiated the child will suffer no serious sequelae. Coverage figures will be derived from this	Recorded as soon as data received from lab.	Outcome values:- Positive Negative Not Done.
35	Neonatal Screening – Cystic Fibrosis	All babies born	Outcome of screening test for Cystic Fibrosis	Identification of infants with Cystic Fibrosis is a national screening programme aimed at reducing the incidence of the disease to nil. Coverage figures will be derived from this	Recorded as soon as data received from lab.	Outcome values:- Positive Negative Not Done.
36	Neonatal Screening – Duchenne Muscular Dystrophy	All boys born	Outcome of screening test for Duchenne Muscular Dystrophy	The identification of infants with Muscular Dystrophy is a national screening programme aimed at reducing the incidence of the condition to nil. Coverage figures will be derived from this information	Recorded as soon as data received from lab.	Outcome values:- Positive Negative Not Done.
39	Six-eight Week Pre-School Check	All children in age range 6 - 8 weeks	Child reviewed as per Recommendations of 4 th edition of 'Health for all Children'	Parent education and resource planning, Children's NSF, see Health for all Children (Edition 4) Protocol	At time of check	Values 'Done', 'Not Done'.

WMD	Name	Scope	Definition	Justification	Timing	Classification or Coding
40	Eight Month Pre-School Check	Await recommendations of 4th edition of 'Health for all Children'	Outcome of 6 to 8 month assessment	Parent education and resource planning, Children's NSF, see Health for all Children (Edition 4) Protocol	At time of check	Values 'Done', 'Not Done'.
41	Two Year Pre- School Review	All children	Review of child's health development progress to two years	Parent education and resource planning, Children's NSF, Look after/Quality Protects/ Child Protection/Part 8 reviews.	At time of check	Values 'Done', 'Not Done'.
42	Primary School Entry Review	All children about age four	Review of child's health development progress at 4 years plus	Looked after/Quality Protects/Child protection/Part 8 reviews. Parental reassurance. Outcomes assessment for earlier interventions. Audit of pre- school programme. Research and development	Within 6 months of school entry	Values 'Done', 'Not Done'.
45	Significant Condition	All children	Disease, illness, behavioural health associated conditions causing child, family or health professional significant concern.	It would be important that those conditions that are significant to the promotion of the health of the child, its future learning potential and its future care/treatment were recorded for all who need to know as well as for purposes of selecting samples for audit and research purposes	At all HFA4 reviews for 0 – 19 years	ICD10 Codes. In some instances ICD09 codes still present.
46	Cause of Death	All live-born children who die up till 19 years	The diagnosis as recorded on post mortem or, in its absence, on the certificate of death	Outcome measures of interventions or risk factors. For research purposes	On receipt of post mortem or death certificate	ICD10 Codes. In some instances ICD09 codes still present.

Appendix A

National Community Child Health Dataset

WMD	Name	Scope	Definition	Justification	Timing	Classification or Coding
47	Immunisation Status	All children	The giving of a vaccine or group of vaccines aimed at developing antibodies within the individual such that they are protected from the disease as part of a national programme	To monitor the up take and coverage of immunisation to ascertain the level of protection against the disease in the population The data can also be used to follow up defaulters and to provide sample frames for follow up research and audit on outcomes and inadvertent sequelae	At time of giving immunisation	Date when each immunisation antigen received. Primary courses Meninggococcal C MMR1 MMR2 Pre school booster School Leaver Booster Hepatitis B BCG Format of DD/MM/YYYY

- WMD = Welsh Minimum Dataset
- Please note that there are gaps in the WMD numbering sequence; this is due to a second phase of data requirements and will be addressed in due course, by a Stakeholder group.