

DSCN Notice: 15/2004(W)
English DSCN Equivalent: N/A
Date of Issue: 14 May 2004

IRSS Information Requirements and Standards Sub Committee	Subject: New Dataset for the National Community Child Health Database
	Implementation date: 1 st April 2004

DATA SET CHANGE NOTICE

This DSCN gives notification of a new minimum dataset to be used for the National Community Child Health Database and associated 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 Approval Reference No: <i>IRSS 20040304/01</i>
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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 jennifer.evans@hsw.wales.nhs.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 15/2004(W)

Reference: IRSS 20040304/01

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 providers. 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 the Welsh CCH2000 providers. It is envisaged that it will be further developed over time in line with stakeholder and information user requirements.

Implementation Date: 1st April 2004

NCCHD Operational Extracts – Initial and On Going:

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

The first extract will take place at the end of April 2004 to take into account the position as at 31st March 2004. Future extracts will then be planned with the providers.

After each extract, there will be feedback on data quality, with reports being available to the CCH2000 providers.

Derived Items:

To ensure that data is processed legally in the absence of explicit patient consent, certain data items will be derived from data held on CCH2000 and written to NCCHD: -

- **Geographical Ward Code(s)** will be derived from the postcode held on the CCH2000 database at the Trust level, and stored as a data item on the NCCHD database. These Geographical Ward Codes will comprise of the following information:-
 - Electoral Ward
 - Previous Census Ward (i.e. 1998 Wards)
 - Current Census Ward
- **NHS Numbers (Mother's and Child's)** sent by the Trusts, will be converted into encrypted items. The encrypted child's NHS Number will be used as a key to link child's records before storing the child's records on the NCCHD database. Neither of these NHS Numbers will be held on the NCCHD database.

As the NCCHD will not hold patient identifiable data, issues around patient confidentiality should not arise. Therefore, by implication, reporting will not be available from NCCHD on Post Codes, and/or NHS Numbers.

Effect on Data Dictionary:

The data items for the new mandatory dataset for this **NCCHD Operational Extract** and the derived data items for the NCCHD itself will be included in Version 2.4 of the NHS Wales Data Dictionary and are shown in Appendix A (below).

A limited number of Data Terms and Data Items, used in NCCHD, are already in the NHS Wales Data Dictionary (e.g. age, GP Code) and new referencing to NCCHD will be added.

Also, a number of data definitions for new NCCHD data items will be added to the NHS Wales Data Dictionary.

The table in Appendix A shows the NCCHD data definitions being added to the NHS Wales Data Dictionary.

Clearance:

IRSS – who regulate information requirements across the NHS - have commended and approved the introduction of the new National Community Child Health Database dataset following a full appraisal. Appraisal documents, papers and minutes of IRSS meetings are regularly published on HOWIS microsite: -
<http://howis.wales.nhs.uk/microsite/page.cfm?orgid=312&pid=1046>

This follows the work of the Welsh Assembly Child Health Information Requirements Project (Phase 2) also shown on HOWIS microsite:-
<http://howis.wales.nhs.uk/MicroSite/home.cfm?OrgID=302>

The Welsh Assembly have directed that the dataset is a mandated dataset across NHS Wales to populate the NCCHD, in WHC(2003)113, subject to final agreement by the Patient Information Advisory Group (PIAG).

PIAG met on 3rd March 2004 and have formally agreed ⁽¹⁾ that the dataset can be transmitted containing patient identifiers (NHS Number) without the consent of the patient. However, these will only be used in an interim file to ensure correct updating of the child's record. PIAG were informed of the arrangements for encryption and these were endorsed by the group and full details can be obtained from the contact below. Proposals by the CHIRP project to insert a new patient information page in the Health Visitor/Child personal health record to inform the parents of the NCCHD database were welcomed and agreed by PIAG. These have been ordered from printers for insertion (costs borne by the Assembly), following dialogue and communications with the Health Visitor network across NHS Wales.

⁽¹⁾ Copies of the formal letter of agreement from PIAG are available from the contact below at HSW on request

Additional Information:

The CCH2000 providers will be advised of any changes to the data set – subject to clearance – in further DSCNs and regular communications (such as Welsh Health Circulars for information or action).

An NCCHD website is under development on HOWIS, which will contain information for NHS Wales on data capture, information provision and service governance (which will be advised by an Assembly/NHS Expert Group due to meet shortly - details of membership on the new website or from the contact below). It is planned that documents and publications will also be on this site.

For any further queries about implementation or processing of the new dataset, please contact Gill Davison, Head of CCH Systems, on 029 2050 2251 (WHTN: 1790 2251), or via gillian.davison@hsw.wales.nhs.uk

For any further queries relating to this DSCN, please contact: -

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X – Denotes new items to be added to the Data Dictionary

New Item within DD	Date Item	Scope	Data Term	Justification	Timing	Classification or Coding	Mandatory or Optional
	NHS Trust Code	Every Child's Record	Unique Number identifying the Trust	To identify source of information	On registration	Trust Number Format (3 digits) or Powys LHB code	M
X	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). Will be encrypted and used to match child's records. The number will not be stored on NCCHD	M
X	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). Will be encrypted. The number will not be stored on NCCHD	M
	Birth Date (Baby)	All babies born or registered	Date of birth of child	Required to derive child's age for analysis of age related events	On registration	CCYYMMDD	M
	Birth Date (Mother)	All mothers giving birth to live babies	Date of birth of the biological mother.	Required to derive the mother's age at time of birth of child.	On registration of birth or entry of child into UK	CCYYMMDD This date will not be stored on NCCHD.	M
X	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	HHMM	M

New Item within DD	Date Item	Scope	Data Term	Justification	Timing	Classification or Coding	Mandatory or Optional
	Sex of Baby	All babies born or registered	Gender of child	Required to analyse data for differences by sex	On registration	Allowable values:- Male Female N/K	M
X	Geographical Ward Code	All Children Registered	Can be made up of Electoral, and Census (Previous and Current) Ward Codes	Used for geographical analysis at a small area level without compromising patient confidentiality.	At time of extract	2 - 6 alphanumeric field. Database will hold Geographical Ward Code which will be derived from the Postcode.	M
X	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 CCYYMMDD:- 0 = Trust Birth 1 = Transfer In 2 = Transfer Out 3 = Movement In 8 = Living outside, treated inside	M
X	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 CCYYMMDD:- 0 = Trust Birth 1 = Transfer In 2 = Transfer Out 3 = Movement In 4 = Movement Out 5 = Died 7 = Stillbirth 8 = Living outside, treated inside	M

New Item within DD	Date Item	Scope	Data Term	Justification	Timing	Classification or Coding	Mandatory or Optional
	GP Code	Every child's record	The Department of Health code for the GP	Required to ascribe children to GP.	At time of registration	GP code format – 8 digits.	M
X	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	M
	Number of Babies	Every child's record	The number of births resulting from the pregnancy		On registration	Numeric	M
	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	M
	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	M
X	Age of Mother at Birth	All mothers giving birth	Biological mother's age at time of birth		On registration	2 numeric digits denoting years.	M

New Item within DD	Date Item	Scope	Data Term	Justification	Timing	Classification or Coding	Mandatory or Optional
	Ethnic Group	Every child's record	The ethnicity of the person receiving care as defined by the mother.	<p>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.</p> <p>Access and exclusion issues are often key determinants of health outcomes for certain groups.</p> <p>The targeting of specific interventions designed to identify health problems and/or deliver more culturally sensitive care is dependent on such data.</p>	On registration	<p><u>White</u></p> <p>Any White Background A</p> <p><u>Mixed</u></p> <p>White and Black Caribbean D</p> <p>White and Black African E</p> <p>White and Asian F</p> <p>Any other mixed background G</p> <p><u>Asian or Asian British</u></p> <p>Indian H</p> <p>Pakistani J</p> <p>Bangladeshi K</p> <p>Any other Asian background L</p> <p><u>Black or Black British</u></p> <p>Caribbean M</p> <p>African N</p> <p>Any other Black background P</p> <p><u>Other Ethnic Groups</u></p> <p>Chinese R</p> <p>Any other Ethnic Group S</p> <p><u>Not Stated</u></p> <p>Not Stated Z</p>	M

New Item within DD	Date Item	Scope	Data Term	Justification	Timing	Classification or Coding	Mandatory or Optional
	Delivery Method	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 – Other C/S 9 – Other	M
	Labour/Delivery Onset Method	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 – Induced . 3 – Elective C/S. 4 – Emergency C/S 9 - Not Known.	M

New Item within DD	Date Item	Scope	Data Term	Justification	Timing	Classification or Coding	Mandatory or Optional
X	Breast Feeding	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 DH 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). Breast-feeding at four months (recorded with immunisation)	Y or N.	M
X	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	M

New Item within DD	Date Item	Scope	Data Term	Justification	Timing	Classification or Coding	Mandatory or Optional
X	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	M
X	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.	M
X	Apgar Score	All babies born	The total APGAR score for a baby at 1 minute and 5 minutes after birth.		At registration	Positive integer; 0-10 .	M

New Item within DD	Date Item	Scope	Data Term	Justification	Timing	Classification or Coding	Mandatory or Optional
X	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 5 digit national organisational codes or 'DOM' for home birth	M
X	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.	8 digit Date of Test and Outcome values:- Positive Negative Refused	M
X	Neonatal Screening – Hypothyroid	All babies born	Outcome of screening test for Hypothyroid	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.	8 digit Date of Test and Outcome values:- Positive Negative Refused	M

New Item within DD	Date Item	Scope	Data Term	Justification	Timing	Classification or Coding	Mandatory or Optional
X	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.	8 digit Date of Test and Outcome values:- Positive Negative Refused	M
X	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.	8 digit Date of Test and Outcome values:- Positive Negative Refused	M
X	Six-eight Week Pre-School Check	All children in age range 6 - 8 weeks	Child examined 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	Examination details extracted:- Examination Number Date of Exam Height Weight Head Circumference Physical Test Vision Test Audio Test Locomotion Test Manipulation Test Speech Test Behaviour Test	M
X	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	As 'Six-eight Week Pre-school Check'	M

New Item within DD	Date Item	Scope	Data Term	Justification	Timing	Classification or Coding	Mandatory or Optional
X	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	As 'Six-eight Week Pre-school Check'	M
X	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	As 'Six-eight Week Pre-school Check'	M
X	Significant Condition (s)	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	Significant Conditions extracted:- Diagnosis Code (ICD10 Codes. In some instances ICD9 codes still present.) Date of Diagnosis Outcome	M
	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 ICD9 codes still present.	M

New Item within DD	Date Item	Scope	Data Term	Justification	Timing	Classification or Coding	Mandatory or Optional
X	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	Immunisation Status of the following Immunisation:- Primary courses Meningococcal C MMR1 MMR2 Pre school booster School Leaver Booster Hepatitis B BCG Details extracted:- Immunisation Course Immunisation Date (CCYYMMDD) Immunisation Batch ID	M