

Neonatal Data Set v2.0 Change Specification

Data Alliance Partnership Board

The Data Alliance Partnership Board (DAPB), which holds delegated authority from the Secretary of State for Health and Social Care, has approved a change to an existing information standard for publication under [section 250 of the Health and Social Care Act 2012](#).

Assurance that this information standard meets the requirements of the Act and is appropriate for the use specified in the specification document has been provided by the Data Standards Assurance Service (DSAS) and endorsed by the Data Alliance Partnership Sub Board (DAPSB).

This information standard comprises the following documents:

- Change Specification
- Implementation Guidance
- Requirements Specification.

An Information Standards Notice (DAPB1595 Amd 30/2022) has been issued as a notification of use and implementation timescales. Please read this alongside the documents for the standard.

The controlled copies of these documents can be found on the [NHS Digital website](#). Any copies held outside of that area, in whatever format (e.g. paper, email attachment), are considered to have passed out of control and should be checked for currency and validity.

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1 Background

1.1 Summary

The purpose of this document is to outline updates to the existing Neonatal Data Set (NDS) that introduce amendments and new data items.

Regular review of the NDS is key to ensuring data are relevant to current clinical practice and reflect the needs of diverse stakeholders.

This release of the NDS (v2.0) represents a change to the NDS and includes several new data items following wide clinical, management, commissioner, providers, system supplier and parent consultation.

This document should be read in conjunction with the key and supporting documents in Section 1.2 below.

1.2 Key and supporting documents

Ref #	Title
Key documents	
1	NDS Data Specification – Episodic Daily
2	NDS Data Specification – Two year Follow up
3	NDS Implementation Guidance
4	NDS Requirements Specification
Supporting documents	
5	Data Quality Assessment

1.3 Glossary of abbreviations

See Requirements Specification.

2 Change specification

2.1 Reason for release

Inclusion of additional items to the NDS enables the capture of greater detail of antenatal care, labour and maternal health and wellbeing that are known to affect perinatal outcomes (i.e. maternal drug use, both illicit and prescription). Details around the birth plan have also been included to capture water births. Including these items supports current research projects and increases the scope of use of the NDS.

Items pertaining to neonatal death and palliative care are currently limited in the NDS. The expansion of NDS items surrounding early death and end of life pathways is important for both clinical and community teams, and auditing will identify needs and inform resources nationally.

Items within the two year follow up section of the NDS have been completely reformed in line with the formation of the British Association for Neonatal Neurodevelopmental Follow-up (BANNFU, formerly Thames Regional Perinatal Group (TRPG)). These changes include introduction of SNOMED CT codes.

The following sections outline in detail the changes proposed for this release.

2.2 New items added

Full details of all the new items (listed below) are provided in the NDS Data Specification v2.0. Each sub-heading in bold refers to the Category tab within the NDS specification where the item is placed.

Antenatal items

- Maternal alcohol abuse
- Maternal drug abuse (illicit and prescribed)
- Source of estimated date of delivery
- Chorionicity of baby
- Zygosity of baby
- Amnionicity of baby
- Magnesium Sulphate given to mother pre-partum
 - The reason why Magnesium Sulphate was not given
- Hepatitis B status of the mother during pregnancy
- Syphilis status of the mother during pregnancy as tested using VDRL test
- Hepatitis C status of the mother during pregnancy
- HIV status of the mother during pregnancy
- Maternal Coronavirus at birth

Labour and delivery items

- Baby planned to be delivered in water
 - Baby delivered in water
- Age in minutes from birth at time of first surfactant dose

Admission details items

- Principal clinical reason for admission

Discharge details items

- Death certificate for babies who die within 28 days
- Death certificate for babies who die after 28 days
- Location of death
- Coroners referral
- Coroners post-mortem

- If discharged on oxygen, how much oxygen was prescribed
- Baby sent home on Parenteral Nutrition
- Diagnosed with necrotising enterocolitis (NEC) in this period of Neonatal Critical Care
 - Clinical and radiological signs used to decide whether a baby is diagnosed with NEC
- MRI scan performed in this period of Neonatal Critical Care
 - Day of care the latest MRI scan was done on
 - MRI scan during this admission which detected a brain injury
- Discharged with neonatal palliative care plan in place

A new category of data '**Neurology**' has been added to accommodate the following items:

- Date and time therapeutic cooling achieved (33-34oC)
- Reflexes on day 1
- Cerebral Function Monitoring (CFM) on day 1

Daily summary

- Additional oxygen given today
- Pneumothorax today
- Extracorporeal membrane oxygenation (ECMO) today
- Gastroschisis silo in situ today
- Treatment for Neonatal Abstinence Syndrome (NAS)
- Surgery for ventricular-peritoneal shunt performed on this day of care
- Active cooling today
- Passive cooling today
- Epidural catheter today
- Ventricular tap today
- External Ventricular drain today
- Retinopathy of prematurity (ROP) Surgery today
- Maximum bilirubin level today
- Treated hypoglycaemia today
 - How was hypoglycaemia treated
 - Lowest level of glucose
- Trans-anastomotic tube
- Urinary catheter

Two year follow up

- Two year neonatal outcomes assessment timestamp
- Person death timestamp (post discharge from neonatal critical care)
- Coded assessment tool type (SNOMED CT)
- Person score
- Assessment tool completion timestamp
- Number of minutes (birth to event)
- Assessment tool completion year and month
- Coded observation (SNOMED CT)
- Observation value
- UCUM unit of measurement
- Coded observation timestamp

- Number of minutes (birth to event)
- Observation year and month

2.3 Removal of items

Some items within the NDS will no longer be collected for v2.0.

The following pilot items are dropped from the NDS:

- Mother antenatally booked indicator
- Infection culture test indicator (blood)
- Infection culture test indicator (cerebrospinal fluid)
- Infection culture test indicator (urine)
- Abdominal x-ray performed indicator
- Newborn hearing screening performed indicator

The following pseudo-anonymisation items are dropped from the NDS (they are duplications of admission month and year):

- Parents seen by senior staff member year and month
- Observation year and month (temperature)

All previous TRPG two year follow up items have been removed and replaced with the two year follow up items listed in the section above.

2.4 Amendment of items

Some items have been amended from their original format or definition.

- Qualification attainment level mother (National Neonatal Data Set)
 - To be replaced with the highest level of education enrolment of the mother, either part-time or full-time
- Organisation site identifier (of actual place of delivery)
 - Default codes aligned with the Maternity Services Data Set
- Organisation site identifier (of planned delivery)
 - Default codes aligned with the Maternity Services Data Set
- Person phenotypic sex
 - Changed national code for not known to 'X' to align with other data sets
- Person genotypic sex
 - Data dictionary item status updated to 'Required'
- Ethnic category 2021 (mother) & ethnic category 2021 (father)
 - Categories aligned with 2021 definition
- Mode of delivery
 - Data dictionary item status updated to 'Required'
- Birth order (Maternity services)
 - Aligned with the Maternity Services Data Set
- Number of fetuses (Maternity episode)
 - Aligned with Maternity Services Data Set
- Neonatal resuscitation method (National Neonatal Data Set)

- Addition of more resuscitation methods
- Umbilical cord clamped immediately after birth indicator
 - Data dictionary item status updated to 'Required'

- Ward type discharged to (National Neonatal Data Set)
 - Replaced 'Neonatal Intensive Care Unit' to 'Other neonatal unit'. Clarification of 'Transitional care' to 'Transitional Ward'
- Location of highest level of care
 - Options here have been simplified to neonatal unit versus non-neonatal unit. Details of how to fill this item out to be provided in Guidance
- Number of rectal washouts today
 - Change to item name (inclusion of the word TODAY) and meaning. Now counting number of washouts, rather than whether they had more than 3 washouts
- Surfactant given indicator (during resuscitation)
 - Change of item name and description to Surfactant given indicator (during initial management). This is a more accurate reflection of when and why surfactant is given. Surfactant is often given for stabilisation rather than resuscitation as in the case of babies born premature

Other minor amendments have been made to ensure alignment with the NHS Data Model and Dictionary. Updates to the NHS Data Model and Dictionary routinely occur whenever an information standard is changed. This means that some data items that were accurate at the time of the Neonatal Data Set version 1 Information Standards Notice publication now need updating for consistency with related information standards.