

# Neonatal Data Set v2.0 Requirements 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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## Executive summary

The purpose of this document is to provide guidance to support providers of Neonatal Services to undertake the implementation of the Neonatal Data set (NDS) update v2.0, including any amendments to local contractual arrangements to allow the required system changes to be actioned.

This is an update to an existing information standard ISB 1595, comprising data set changes. This update is necessary to ensure the standard continues to be clinically relevant and accurate.

Overlaps with other information standards, such as the Maternity Services Data Set, have been considered to minimise burden and ensure all data items remain accurate and consistent across data sets.

## 1 Background

The NDS is a patient-level data set that captures key information at each stage of the neonatal critical care pathway including demographics, diagnoses, daily treatments, care processes and outcomes. The NDS is a secondary uses data set extracted from clinical data recorded for the primary purposes of direct patient care. It defines the data items, definitions and associated value sets extracted from local electronic patient record systems.

The standard is applicable only in England but data are currently collected across the UK. The standard primarily, but not exclusively, aims to capture information on two data subjects:

- Mothers of babies admitted to NHS neonatal units
- Babies admitted to NHS neonatal units.

Limited information about the father of admitted babies is captured.

The standard supports national audits, national policy development, national quality improvement, and approved research studies.

### 1.1 Key and supporting products

This document should be read in conjunction with the following:

Ref #	Title
<b>Key documents</b>	
1	NDS Data Specification – Episodic Daily
2	NDS Data Specification – Two Year Follow Up
3	NDS Implementation Guidance

4	NDS Change Specification
<b>Supporting documents</b>	
5	Data Quality Assessment

## 1.2 Glossary of abbreviations

NDS	Neonatal Data Set
NHS	National Health Service
TRPG	Thames Regional Perinatal Group
SLA	Service Level Agreement
GDPR	General Data Protection Regulation
IT	Information Technology
NDAU	Neonatal Data Analysis Unit

## 1.3 Related standards

Reference	Title
DCB1513	<a href="#">DCB1513: Maternity Services Data Set - NHS Digital</a>
SCCI0075	<a href="#">Neonatal Critical Care Minimum Dataset</a>

## 2 Scope

The NDS applies to all organisations providing NHS funded neonatal services within England. Other related services (preceding and following neonatal care) to which the standard may be relevant are:

- Maternity
- Fetal Medicine
- Ambulance services
- In-patient paediatrics
- Community maternity and paediatrics services such as health visitors, occupational therapy, physiotherapy, educational psychology

The standard primarily, but not exclusively, applies to the following professionals:

- Commissioners
- Maternity and neonatal services administrative personnel.
- Obstetricians
- Midwives
- Neonatologists

- Neonatal nurses
- Advanced nurse practitioner
- Community and hospital paediatricians
- Dietitians
- Physiotherapists
- Other specialist groups such as ophthalmologists, surgeons and palliative care teams
- Information and IT professionals

### 3 Summary of changes

This release of the NDS (v2.0) represents a change to the NDS following wide clinical, management, commissioner, provider, system suppliers and parent consultation. The consultation period was conducted over a 6 week period (opened 04/07/2019, closed 15/08/2019) and was then repeated for Specialised Commissioning and the British Association of Perinatal Medicine at their request, over the last quarter of 2021 and first quarter of 2022.

The new release of the NDS (v2.0) contains the following changes:

- Addition of data items such as, magnesium sulphate administration and maternal coronavirus, to capture current clinical practice ensuring the data set remains clinically relevant
- Removal of data items surplus to requirements. These items include all previous TRPG two year follow up items
- Amendment of existing items to enable better capture of data by either reducing the number options for items such as maternal education level or improving the detail provided by items such as methods of resuscitation; clarification of these kinds of items will make them easier to record

Details of these changes can be found within the Change Specification (see 1.1 supporting products).

## 4 Requirements and conformance

### 4.1 Health care organisations

The following are a series of requirements which all health care organisations providing NHS funded neonatal services must follow:

- NHS Providers of neonatal services (hereinafter referred to as NHS Providers), whether new or existing users, **MUST** read the Data Specification and Change Specification in conjunction with the Implementation Guidance to identify how the standard is applicable to them
- NHS Providers **MUST** review their system compatibility against this standard to identify any changes required to current practice to ensure that all data items in NDS

v2.0 can be captured and flowed electronically by the dates specified in this section. If there are compatibility gaps, then further development is required to meet the standard

- NHS Providers **SHOULD** have a service level agreement (SLA), with their system supplier to ensure all specified data items in the NDS v2.0 are captured and submitted by the supplier in compliance with the Specification and Implementation Guidance on a quarterly basis (16<sup>th</sup> January, April, July and October) and future development needs are met to reflect the changes to the standard
- This standard **SHOULD** only be used to define the extract from the electronic patient records system. It is not a specification for a clinical system. NHS Providers **SHOULD NOT** use this data set to define their clinical and operational data capture
- NHS Providers **SHOULD** review or amend any data items that do not meet the data quality minimum standard within the quarter as part of the data custodian's quality assurance checks. Details of these data quality checks can be found within the Data Quality Assessment (see section 1.1 supporting products)

The following is a conformance requirement which all health care organisations providing NHS funded neonatal services **MUST** read:

- Data items are submitted by the system supplier at quarterly intervals (16<sup>th</sup> January, April, July and October), as specified in the NDS v2.0

## 4.2 IT systems

All NHS Providers **SHOULD** have a service level agreement (SLA), with their system supplier to ensure this and future development needs are sufficient to meet changes to the standard.

IT systems suppliers **MUST** submit the defined data items on a quarterly basis (16<sup>th</sup> January, April, July and October).

## 4.3 Legal position and governance

Data collected by NHS Providers is subject to the principles of the General Data Protection Regulation (GDPR).

NHS Providers are considered Data Controllers under GDPR and **MUST** ensure the following principles are adhered to:

- NHS Providers (Data controllers) **MUST** ensure they properly inform parents on the possibility that they and their babies clinical care data (please see Data Specification for more details on these items) could be used for research and audit purposes. This may

include linkage to other data sources. Support for this entire process **SHOULD** be provided both verbally and through privacy information leaflets for parents and/or posters on neonatal units, such as those provided to units by the Neonatal Data Analysis Unit ([Information for patients and carers | Faculty of Medicine | Imperial College London](#)). Should parents choose to opt their babies out of secondary uses, NHS Providers **MUST** ensure this is possible through the National Data Opt Out ([National data opt-out - NHS Digital](#)) and within the IT systems themselves.

- NHS Providers **MUST** ensure the local data systems and data warehouses comply with Data Security and Protection Toolkit standard ([DAPB0086: Data Security and Protection Toolkit - NHS Digital](#)).
- Information on this is available from NHS Digital's 'Keeping patient data safe' webpage ([Keeping patient data safe - NHS Digital](#)). In addition, Data Privacy Impact Assessments **SHOULD** be undertaken to further support this process

## 5 Implementation timeline

Implementation of the changes laid out in this document will take place over a 6 month period starting June 2022.

- ISN publication June 2022
- IT Systems **MUST** be fully conformant by 31 October 2022
- NHS Providers **MUST** be able to collect the information as defined in the Data Specification by 1 November 2022
  
- Full conformance to this update is due by 16 January 2023. In line with the January 2023 quarterly extraction
  
- First submissions of data that conforms to the NDS v2 Data Specification will flow with the January 2023 extraction. Followed by subsequent quarterly submissions (April, July, October and January).