

Information Standards Notice – Change

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

You must comply with the change to this standard by the full conformance date specified below.

Standard details	
DAPB unique identifier	DAPB1595 Amd 30/2022
Name	Neonatal Data Set, Version 2.0
Approval date	26 May 2022
Publication date	13 June 2022
Standard definition	
Description	<p>The Neonatal Data Set (NDS) is a secondary uses, patient-level, data set that captures key information recorded for the purposes of direct care at each stage of the neonatal critical care pathway including:</p> <ul style="list-style-type: none"> • demographics • diagnoses • daily interventions and treatments • care processes • outcomes • follow up health status at age 2 years. <p>Data are currently captured for all babies admitted to NHS-funded neonatal units, primarily in respect of:</p> <ul style="list-style-type: none"> • mothers of babies admitted • babies admitted. <p>Data is submitted to the Neonatal Data Analysis Unit at Imperial College London on a quarterly basis. Following receipt, any personal information is removed before adding to the National Neonatal Research Database (NNRD).</p> <p>The data supports national audits, national policy development, national quality improvement, and approved research studies.</p>
About this change	Version 2.0 of this information standard has been updated to enable the capture of greater detail as well as to align with

	<p>current clinical practice. In addition this release introduces SNOMED CT®.</p> <p>Changes to data items include:</p> <ul style="list-style-type: none"> • addition of data items, e.g. in relation to: <ul style="list-style-type: none"> ○ magnesium sulphate administration ○ maternal coronavirus ○ water births ○ neurology • amendment of data items, e.g. in relation to: <ul style="list-style-type: none"> ○ early death and end of life pathways ○ maternal characteristics ○ methods of resuscitation ○ two year follow up ○ ODS codes ○ alignment with the national Maternity Services Data Set ○ alignment with NHS Data Model and Dictionary • removal of data items, e.g.. in relation to: <ul style="list-style-type: none"> ○ previously defined as pilot items.
Scope (Health and Social Care Act 2012)	NHS Services
Applies to	This information standard applies to all organisations providing NHS-funded neonatal services.
Impacts upon	Implementation of this information standard impacts all health IT systems suppliers providing systems to the above providers; suppliers should work with their customers to determine necessary changes.
Legal authority	<p>This information standard is published under section 250 of the Health and Social Care Act 2012.</p> <p>All those in scope of this information standard must ensure that patient transparency information is brought to the attention of patients. The national data opt-out policy must be applied before data is submitted to the Neonatal Data Analysis Unit (NDAU). The NDAU has approval to receive patient identifiable data from the Confidentiality Advisory Group (reference: ECC 8-05(f)/2010).</p>

Link to further documentation	The Change Specification, Requirements Specification and Implementation Guidance are available on the NHS Digital website: www.digital.nhs.uk/isce/publication/dapb1595 Further guidance is published by the Neonatal Data Analysis Unit: https://www.imperial.ac.uk/neonatal-data-analysis-unit/neonatal-data-analysis-unit/
Contacts	
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Dates	
Implementation and conformance dates	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 from 1 November 2022. Full conformance to this update is due by 16 January 2023. In line with the January 2023 quarterly extraction.
Post Implementation Review date	30 November 2023

The controlled version of this Information Standards Notice is published on the NHS Digital website: www.digital.nhs.uk/isce/publication/isns