

# Neonatal Critical Care Minimum Data Set: Change Specification

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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 Standardisation Committee for Care Information (SCCI), a sub-group of the National Information Board.

This information standard comprises the following documents:

- Requirements Specification
- Change Specification
- Implementation Guidance.

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## Glossary of Terms

A full glossary of terms is provided in the Requirements Specification (see Related Documents).

## Related Documents

Reference	Document Title	Document Filename
1	Neonatal Critical Care Minimum Data Set: Requirements Specification	<a href="#">SCCI0075 – NCCMDS – Requirements Specification</a>
2	Neonatal Critical Care Minimum Data Set: Implementation Guidance	<a href="#">SCCI0075 – NCCMDS – Implementation Guidance</a>
3	Paediatric Critical Care Minimum Data Set: Change Specification	<a href="#">SCCI0076 – PCCMDS – Change Specification</a>



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# 1 Overview

## 1.1 Background

The Neonatal Critical Care Minimum Data Set (NCCMDS) provides a record of what happens to a patient when they receive neonatal critical care in a Neonatal Intensive Care Unit (NICU), Maternity Ward, or Neonatal Transitional Care Ward. It was first introduced by Data Set Change Notice (DSCN) 14/2006.

The primary purpose of the NCCMDS is to allow the operation of the National Tariff Payment System (NTPS) within neonatal critical care. NCCMDS supports the NTPS by capturing the data needed to generate a Healthcare Resource Group (HRG) for each calendar day (or part thereof) of a period of neonatal critical care. The NCCMDS is transmitted into the Secondary Uses Service (SUS) as a part of the Commissioning Data Sets (CDS), as per Information Standards Board 0092 (Amd 16/2010 Version 6.2). SUS groups the data set into neonatal critical care HRGs, which are a mandated currency under the NTPS (i.e. providers are paid for their activity based on HRGs, with prices negotiated between the provider and the commissioner). These HRGs are also used in the Department of Health's annual mandated costing exercise, Reference Costs.

Key to the NCCMDS are Critical Care Activity Codes (CCACs), which provide a record of both the observations made about a patient during receipt of critical care services, and the clinical care provided to them. The CCAC data element, which is shared with the Paediatric Critical Care Minimum Data Set (PCCMDS), currently has 50 codes, 26 of which are relevant to the NCCMDS. A subset of CCACs is also used to determine which patients are covered by the NCCMDS: whilst all patients receiving critical care on a NICU are in scope, those on a Maternity Ward or Neonatal Transitional Care Ward are only in scope if one of 23 CCACs is applicable for more than four hours. CCACs are also critical to the grouping algorithm that produces HRGs from NCCMDS data.

## 1.2 Description of Change

This change introduces two versions of the NCCMDS:

1. The existing NCCMDS, previously mandated by DSCN 14/2006, is uplifted to a Standardisation Committee for Care Information (SCCI) Standard, as NCCMDS Version 1.0 (2007 Release). This version must continue be used for transmission of the NCCMDS to SUS.
2. A new version of the NCCMDS, with additional CCACs, is introduced. This version, Version 2.0 (2016 Release), is intended for local (direct care, clinical audit) and aggregate (e.g. Reference Costs) uses only. In total, 18 new CCACs are introduced, 14 of which are relevant to the NCCMDS (the other four are relevant to the PCCMDS only, whilst two are relevant to both data sets). The 14 new CCACs are added to the list of criteria for inclusion in the data set for those receiving neonatal critical care outside of a NICU. The new CCACs are detailed in [Section 2.2](#).

Version 1.0 (2007 Release) is effectively a subset of Version 2.0 (2016 Release). Further information about the intended uses of each version of the NCCMDS is provided in [Section 2.1](#). Information about how to produce Version 1.0 of the NCCMDS from Version 2.0 is provided in [Section 2.4](#).

As part of the change, the field Discharge Method (Hospital Provider Spell) is replaced with Discharge Method Code (Hospital Provider Spell), in order to bring the data set in line with the Commissioning Data Sets. This is simply a label change.

## 1.3 Rationale for Change

The NCCMDS has not been significantly amended since its implementation in April 2007; including development time, it is now effectively ten years old. The standards and definitions of care used in the data set are based on the 2001 British Association of Perinatal Medicine (BAPM) Standards for Hospitals Providing Neonatal Intensive and High Dependency Care, which have since been superseded by the BAPM Categories of Care 2011; the latter have been in use by the Service for a number of years and are used in other similar data sets, such as the Neonatal Data Set.

Clinical and Service feedback has highlighted that the changes described in this document (and those described in the Change Specification for SCCI0076 Paediatric Critical Care Minimum Data Set, with which it shares the Critical Care Activity Codes that record patient status and interventions on a daily basis) are needed to ensure that the NCCMDS continues to reflect current clinical practice, including innovations in healthcare that have emerged over the last decade. Updates to these codes are needed to enable the evolution of the HRGs that are derived from the NCCMDS data.

The new CCACs cannot simply be introduced into the existing NCCMDS. Firstly, it is not possible for the new codes to be transmitted to SUS until there is an update to the CDS that will allow the new codes to pass through the XML Schema. Secondly, the revised NCCMDS and uplifted HRG design will need to be implemented, tested, and costed in such a way that the current data and HRGs used for reimbursement are not affected. Therefore it is necessary to maintain two versions of the NCCMDS: one for local use and costing, and one for national flow and reimbursement. This allows new data to be collected locally without affecting the data flows used to facilitate reimbursement at local levels.

The additions to the Critical Care Activity Codes have been agreed by a task group comprising the Casemix Expert Working Group, NHS England's Clinical Reference Group, representatives from BAPM, and NHS England's pricing and specialised commissioning teams.

## 1.4 Impacted Users

Users who need to act to conform to the updated Standard are:

1. Those with responsibility for data capture solutions and IT solutions.

These individuals are required to work with system suppliers to ensure that the new CCACs can be captured and stored locally (in accordance with Version 2.0 (2016 Release)), and that Version 1.0 (2007 Release) of the NCCMDS continues to be available for its mandated collection as part of the CDS. The ability to produce Version 1.0 of the data set from Version 2.0 must be tested and proven before any actual recording of Version 2.0 data.

2. Those with responsibility for the day-to-day data capture required to deliver the NCCMDS.

This group will include clinical and administrative staff, who need to be aware of the availability of the new CCACs, and ensure that they are used appropriately, in accordance with the British Association of Perinatal Medicine Categories of Care 2011 standard.

3. Those with responsibility for onward transmission and other uses of the data.

This will include those informatics and other staff with responsibility for transmission of the CDS data, those who have a role in producing Reference Costs data, and any other

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local users of the data. These individuals will need to be aware of the permitted uses of each version of the data set and ensure that any use or transmission of the data complies with appropriate fair processing arrangements that are consistent with national and local information governance criteria and guidelines.

### 1.5 Implementation

Providers may implement this change immediately. All providers must implement this change by the full implementation date of 1 December 2016. The requirements and conformance criteria associated with this change are provided in [Sections 3.1.1](#) and [3.1.2](#).

## 2 Change Requirement

### 2.1 Introduction of Multiple Versions of the NCCMDS

In order to allow the new CCACs to be recorded and used locally (including use to inform the aggregate nationally mandated Reference Costs collection), and to maintain the current flow of data into SUS, two versions of the NCCMDS are created:

1. The existing NCCMDS, previously mandated by DSCN 14/2006, is uplifted to a Standardisation Committee for Care Information (SCCI) Standard, as NCCMDS Version 1.0 (2007 Release). This version must continue to be used for transmission of the NCCMDS to SUS.
2. A new version of the NCCMDS, with additional CCACs, is introduced. This version, Version 2.0 (2016 Release), is intended for local (direct care, clinical audit) and aggregate (e.g. Reference Costs) uses only. In total, 18 new CCACs are introduced, 14 of which are relevant to the NCCMDS (the other four are relevant to the PCCMDS only, whilst two are relevant to both data sets). The 14 new CCACs are added to the list of criteria for inclusion in the data set for those receiving neonatal critical care outside of a NICU. The new CCACs are detailed in [Section 2.2](#).

Maintaining two versions of the NCCMDS allows data to be collected locally without affecting the data flows currently used to facilitate reimbursement at local levels. It is intended that the next time that there is a major update to the CDS, NHS Digital will submit a proposal to effect a change to the CDS such that Version 2.0 (2016 Release) of the NCCMDS flows to SUS in full and is used in the NTPS.

The version of the NCCMDS to be used for the following purposes is:

Purpose	Pre-change	Post-change	In future*
Local recording in systems; direct care	Version 1.0 (2007 Release)	Version 2.0 (2016 Release)	Version 2.0 (2016 Release)
Local managerial and clinical audit	Version 1.0 (2007 Release)	Version 2.0 (2016 Release)	Version 2.0 (2016 Release)
Submitted with the CDS for NTPS	Version 1.0 (2007 Release)	Version 1.0 (2007 Release)	Version 2.0 (2016 Release)
Aggregate activity and costing data submitted with Reference Costs	Version 1.0 (2007 Release)	Version 2.0 (2016 Release)	Version 2.0 (2016 Release)

\*Subject to SCCI acceptance and successful implementation of changes to the CDS.

Version 1.0 (2007 Release) is effectively a subset of Version 2.0 (2016 Release). Information about how to produce Version 1.0 of the NCCMDS from Version 2.0 is provided in [Section 2.4](#).

## 2.2 New Critical Care Activity Codes

Version 2.0 (2016 Release) of the NCCMDS introduces 14 new codes onto the CCAC list:

Code	Definition
80	Patient receiving heated humidified high flow therapy (HHHFT)
81	Presence of an umbilical venous line
82	Patient receiving a continuous infusion of insulin
83	Patient receiving therapeutic hypothermia
84	Patient has a Replogle tube in situ
85	Patient has an epidural catheter in situ
86	Patient has an abdominal silo
87	Administration of IV blood products
88	Patient has a central venous or long line (PICC line) in situ
89	Patient has an indwelling urinary or suprapubic catheter in situ
90	Patient has a trans-anastomotic tube in situ following oesophageal atresia repair
91	Patient has confirmed clinical seizure(s) today and/or continuous CFM monitoring
92	Patient has a ventricular tap via needle or reservoir today
93	Patient has a stoma

Codes 80 and 85 are shared with the PCCMDS. A further four codes, relevant only to the PCCMDS, are also added to the CCAC data element. This results in a maximum CCAC list of 68 codes, although neither the NCCMDS nor the PCCMDS fully utilises all available codes in either HRG design or Data Dictionary definition.

## 2.3 Impact on NCCMDS Coverage

The NCCMDS must be collected for all patients on a NICU, regardless of the care being delivered. It must also be collected for patients (excluding mothers) on a Maternity Ward or Neonatal Transitional Care Ward to whom one or more CCACs (excluding codes 03 and 21, and those applicable to the PCCMDS only) applies for a period greater than four hours. The coverage of NCCMDS Version 2.0 (2016 Release) is therefore increased by the introduction of the new CCACs.

## 2.4 Maintaining Data Flows in Conformance with Multiple Versions of the NCCMDS

In order to conform to both versions of the current Standard, and maintain the flow of CDS data, it will be necessary to remove the new codes from the data extract that is produced for SUS or any other external flow of data where Version 2.0 items are not covered by appropriate fair processing arrangements (see [Section 3.1.1](#)). This will mean:

1. Identifying and removing any instance of a new CCAC from the CCAC field for each day of the critical care period.
2. Checking whether (1) has led to the CCAC field being blank for any day of the critical care period.
3. Ensuring blank fields identified in (2) are populated with the default CCAC: 99 'No Defined Critical Care Activity' (this is necessary as SUS will not accept a null field).
4. Checking whether (3) has led to any of the critical care periods with a Critical Care Unit Function Code of 13 being made up exclusively of days where the only recorded CCAC is 99.
5. Checking whether (3) has led to any of the critical care periods with a Critical Care Unit Function Code of either 14 or 15 being made up exclusively of days where the only recorded CCAC is 03, 21, or 99.
6. Removing any critical care periods identified in (4) or (5).

## 3 Revisions to Published Documentation

### 3.1 SCCI Documentation Suite

Full SCCI documentation has been produced for the NCCMDS for the first time. This is available at <http://www.digital.nhs.uk/isce/publication/scci0075>

These Requirements are included in the Requirements Specification; they are replicated here for ease of reference.

#### 3.1.1 Requirements for IT Systems

The following Requirements for IT systems are introduced:

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##### Requirements

- 1 IT systems and processes **MUST** be established or updated in order to facilitate local recording of NCCMDS Version 2.0 (2016 Release).
- 2 IT systems **MUST** be configured in such a way that NCCMDS data can be linked to the Commissioning Data Set messages within which Version 1.0 NCCMDS data are transmitted, as per the requirements of ISB 0092.
- 3 IT systems and processes **MUST** be established or updated in order to allow Version 2.0 (2016 Release) of the NCCMDS to be translated into Version 1.0 (2007 Release) of the NCCMDS.
- 4 The ability to produce Version 1.0 (2007 Release) from Version 2.0 (2016 Release) **MUST** be tested and proven prior to actual recording of Version 2.0 (2016 Release) data.

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##### 3.1.1.1 Conformance Criteria for IT Systems

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##### Conformance Criteria

- 1 It **MUST** be possible to enter all Version 1.0 and Version 2.0 data items into the local record **OR** it **MUST** be possible to derive all Version 1.0 and Version 2.0 data items from the local record. This **MUST** be achieved by 1 December 2016.
  - 2 It **MUST** be possible to produce Version 1.0 (2007 Release) of the NCCMDS from the Version 2.0 (2016 Release) data recorded. The ability to achieve this **MUST** be tested and proven prior to recording of Version 2.0 data and **MUST** be implemented once Version 2.0 data recording commences, which is no later than 1 December 2016.
  - 3 Version 1.0 (2007 Release) data **MUST** be able to pass through the SUS XML Schema without error. This has been a requirement since April 2007 and **MUST** continue after the introduction of Version 2.0.
  - 4 It **MUST** be possible to link each NCCMDS record (each record representing a period of neonatal critical care) with the Commissioning Data Set Consultant Episode data for the patient receiving care. This has been a requirement since April 2007 and **MUST** continue after the introduction of Version 2.0.
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### 3.1.2 Requirements for Healthcare Providers

The following Requirements for data capture are introduced:

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#### Requirements

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- 1 Data capture forms and processes (including training on data recording) **MUST** be created or updated in order to facilitate local recording of NCCMDS Version 2.0 (2016 Release).
- 2 Clinicians and other Healthcare professionals **MUST** inform senior management if their software application(s) has not been created or updated to include all critical care activity codes.
- 3 Data from NCCMDS Version 2.0 (2016 Release) **MUST** be used to inform the reporting of Reference Costs from 2016/17 onwards. Data from Version 2.0 **MAY** be used for local purposes including clinical audit. Data from Version 2.0 **MUST NOT** be shared with any other party or organisation unless appropriate fair processing arrangements that comply with national and local information governance policies are in place.
- 4 Data from NCCMDS Version 1.0 (2007 Release) **MUST** continue to be used as the basis of the data transmitted to SUS via the CDS. Data from Version 1.0 **MAY** continue to be shared with other parties under existing fair processing arrangements that comply with national and local information governance policies. Data from Version 1.0 **MUST NOT** be shared with any other party or organisation unless appropriate fair processing arrangements that comply with national and local information governance policies are in place.

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#### 3.1.2.1 Conformance Criteria for Healthcare Providers

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##### Conformance Criteria

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- 1 It **MUST** be possible to capture the new data items on any data capture forms, no later than 1 December 2016.
- 2 Staff with responsibility for data capture **MUST** be aware of the introduction of both Version 1.0 and Version 2.0 data items and their definitions.
- 3 Reference Costs submissions from 2016/17 onwards **MUST** be based on Version 2.0 of the NCCMDS.
- 4 Version 1.0 of the NCCMDS **MUST** continue to flow to SUS as part of the CDS transmission.

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## 3.2 Data Dictionary

This update effects a number of changes to the Data Dictionary. These are documented in full at <http://www.digital.nhs.uk/isce/publication/scci0075>.