Neonatal Critical Care Minimum Data Set: Implementation Guidance

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SCCI Standardisation Committee for Care Information

This information standard (SCCI0075) has been approved for publication by NHS England 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 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.

An Information Standards Notice (SCCI0075 Amd 112/2015) 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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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	SCCI0075 – NCCMDS – Requirements Specification
2	Neonatal Critical Care Minimum Data Set: Change Specification	SCCI0075 – NCCMDS – Change Specification
3	Standards for Hospitals Providing Neonatal Intensive and High Dependency Care (Second Edition)	http://www.bapm.org/publications/documents/guidelines/hosp_standards.pdf

Contents

1 Introduction

1.1 Purpose

1.1.1 Purpose of this document

The purpose of this Implementation Guidance is to provide guidance to all impacted users on how to implement and use the Neonatal Critical Care Minimum Data Set Standard, and implement any changes resulting from its release. It should be read in conjunction with the Requirements Specification (or Change Specification, for existing users) for the Information Standard.

1.1.2 Purpose of the Information Standard

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.

1.2 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, and is the responsibility of NHS Digital.

The standards and definitions of care used in the data set are based on the British Association of Perinatal Medicine (BAPM) Categories of Care 2011 which have been in use for a number of years by the service and are used in other similar data sets, such as the Neonatal Data Set. The data items within the NCCMDS can be derived from data that are recorded and used as part of the clinical management of a patient.

The NCCMDS Standard requires all providers of NHS neonatal critical care to collect and flow the specified data. The NCCMDS is a requirement for all NHS Trusts and NHS Foundation Trusts that provide neonatal critical care in England. This includes all Trusts that have a Neonatal Intensive Care Unit (NICU) and those that have Maternity or Neonatal Transitional Care Wards that deliver the critical care interventions (identified by Critical Care Activity Codes; CCACs) specified in the Data Set Specification provided in the Requirements Specification.

There are two versions of the NCCMDS:

- Version 1.0 (2007 Release), which is de facto the Standard first mandated by DSCN 14/2006 and includes 26 CCACs
- Version 2.0 (2016 Release), which is based on Version 1.0, but includes 14 additional (making a total of 40) CCACs.

Version 2.0 of the NCCMDS is collected by NHS providers of care in England and Version 1.0 is sent directly from them to the Secondary Uses Service (SUS) at NHS Digital, as a part of the Commissioning Data Set messages, as per Information Standards Board (ISB) 0092. SUS is the single, comprehensive repository for healthcare data in England, and is the mechanism by which the NTPS is implemented in England.

2 Implementation Plan

2.1 Overview

The implementation plan sets out the activities and timescales for the adoption of the NCCMDS Information Standard. Version 1.0 of the NCCMDS was implemented in April 2007. Providers may implement Version 2.0 (whilst maintaining the ability to produce Version 1.0) at any time from 7 September 2016. All providers must implement Version 2.0 (whilst maintaining the ability to produce Version 1.0) by 1 December 2016. NHS Digital will monitor conformance with the Standard.

This guidance has been written so that it is applicable both to those organisations that already capture the NCCMDS and need to update their systems, and also to those organisations that do not currently capture the NCCMDS. Frequently asked questions 3 and 4 are included to explain the different actions required of both types of organisation.

2.2 Impacted Users

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

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

  These individuals are required to work with system suppliers to ensure that the data required for Version 2.0 of the NCCMDS can be captured and stored locally, and that Version 1.0 (2007 Release) of the NCCMDS is 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.

- 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 data items for both Version 1.0 and Version 2.0 of the NCCMDS, and ensure that they are used appropriately, in accordance with the British Association of Perinatal Medicine Categories of Care 2011 standard.

- 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 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.

2.3 Additional Support

Additional support for implementing the Standard is available from the National Casemix Office at NHS Digital, via enquiries@nhsdigital.nhs.uk.

3 Guidance for Healthcare Organisations

3.1 End User Implementation Actions

3.1.1 For those with responsibility for data capture solutions and IT solutions

These individuals will need to take actions including:

- Determining the most appropriate means of data capture in local circumstances. Considerations will include whether:
  - Data should be captured electronically, at source, or captured in notes and made electronic at a later date
  - Data capture should be based on recording of the NCCMDS per se, or whether the NCCMDS can be derived from data items already recorded in the local record, or extra items can be added to the local record requirements in order that the NCCMDS can be derived from the local record.
- Development and testing of new or additional data capture solutions with those staff involved in the capture and recording of data.
- Determining which data items are to be used to link the NCCMDS to the CDS, and whether any additional data should be captured to support this or other purposes (subject to a sound legal basis for data capture).
- Ensuring that all data that is captured, in whatever format, can be translated to the NCCMDS, and can be held securely on IT systems.
- Liaising with IT systems suppliers to agree system requirements that support local needs as well as the delivery on the NCCMDS.
- Ensuring sufficient testing and/or piloting of new or updated systems prior to release.
- Understanding interoperability requirements with other systems and/or data sets, e.g. CDS, Neonatal Data Set.

The primary purpose of the Standard is for secondary uses only and will therefore have no direct impact on Clinical Safety and as such is not in scope of SCCI0129[1]. Consequently, a Clinical Safety Case Report is not required to support this Standard. However, implementation of this Standard may require modification to the health IT system from which the collection/extraction is made. The safety implications of any such modifications must be considered by the manufacturer and all other parties involved under SCCI0129[1] and the health organisation under SCCI0160[2].

[1] Clinical Risk Management: its Application in the Manufacture of Health IT Systems: http://digital.nhs.uk/isce/publication/scci0129

[2] Clinical Risk Management: its Application in the Deployment and Use of Health IT Systems: http://digital.nhs.uk/isce/publication/scci0160

3.1.2 For those with responsibility for the day-to-day data capture required to deliver the NCCMDS

These individuals will need to take actions including:

- Familiarisation with the new NCCMDS Standard and the BAPM Standard on which it is based.
- Active participation in the development and testing of new or updated data capture forms or methods.
- Attendance on any training that may be provided to support implementation of the Standard.
- Achieving a high-level understanding of the NTPS and the importance/impact of NCCMDS data quality.
- Ensuring that any data captured is complete, accurate, timely, and if handwritten, clearly legible.
- Considering whether privacy notices in respect of the NCCMDS need to be updated.

The primary purpose of the Standard is for secondary uses only and will therefore have no direct impact on Clinical Safety and as such is not in scope of SCCI0129[1]. Consequently, a Clinical Safety Case Report is not required to support this Standard. However, implementation of this Standard may require modification to the health IT system from which the collection/extraction is made. The safety implications of any such modifications must be considered by the manufacturer and all other parties involved under SCCI0129[1] and the health organisation under SCCI0160[2].

3.1.3 For those with responsibility for onward transmission and other uses of the data

These individuals will need to take actions to fully understand the uses of each version of the NCCMDS and ensure that all processing is subject to fair processing agreements that comply with national information governance requirements and any local policies.

3.2 End User Guidance on Completing the Data Set

3.2.1 Overview

There are two parts to the NCCMDS:

a) Data which applies to the whole period of critical care.

b) Data related to each day of critical care.

The first set of data need only be recorded once and may be updated as the episode develops to discharge from critical care.

Daily data needs to be completed each day within the critical care period. A day is regarded as a calendar day midnight to midnight. Daily events should be recorded if they occur at any point in the 24 hour period. It is for units to decide when to collect the data, however, since periods are midnight to midnight, as close to midnight as feasible would be ideal. A single critical care period may contain up to 999 daily records; each daily record may contain up to 20 CCACs and up to 20 OCPS codes for High Cost Drugs.

A period of critical care is not the same as a consultant episode.

a) In a NICU environment the period of critical care will be from admission to discharge from the NICU.

b) On a Maternity ward or Neonatal Transitional Care ward, the critical care period runs from the first to the last day of a continuous period of neonatal critical care.

The definition of a critical care episode is available at: http://www.datadictionary.nhs.uk/data_dictionary/classes/c/critical_care_period_de.asp?shownav=1.

The full scope and specification for the NCCMDS, including detailed guidance, is provided in the Requirements Specification.

3.2.2 Frequently Asked Questions

	Question	Answer
1	What is an Information Standard?	Information Standards are products which assist the collection, management and sharing of health and social care information to support an individual's care. Putting an information standard into place means that for those organisations which use them, there is a clear and common way of sending and receiving agreed information in a structured format. They may be used by hospitals, GP practices, local authorities and care homes for example. NHS Digital develops Information Standards for use across England. Before an Information Standard can be agreed for use nationally, it must go through an assurance process to ensure that it is fit for purpose. The Standardisation Committee for Care Information (SCCI) has delegated authority from the National Information Board to accept Information Standards for health and social care. This review process is the formal means to gain approval from the Secretary of State and NHS England for publication under section 250 of the Health and Social Care Act 2012.
2	When should NCCMDS be collected?	NCCMDS should be captured daily. A data item should be recorded as "Yes" if the criterion was met that calendar day. For this reason, data capture will be most straightforward if it takes place close to or slightly after midnight each day. Three examples to illustrate: 1. If a patient received nCPAP during part of the day then this should be recorded as "yes" even if the patient is not on nCPAP at midnight, when the data capture takes place. 2. If a patient is put onto nCPAP at 23:50 in the evening then this should also be recorded as "yes" even though it has only taken place 10 minutes before midnight. 3. If a patient receives critical care during the day then any activity should be recorded even if the patient is no longer there when the data capture takes place.

	Question	Answer
3	We've been collecting the NCCMDS since 2007: what do we need to do now?	You'll need to read the Change Specification and take the following actions: 1. Existing systems and processes (including training on data recording) must be updated in order to facilitate local recording of NCCMDS Version 2.0 (2016 Release), i.e. update systems to allow the capture and recording of the additional CCACs. 2. Existing systems and processes must be 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, so that the new CCACs (80-93) do not form part of the data set for transmission to SUS. This can be achieved by following the guidance in Section 2.4 of the Change Specification. 3. Ensure that each version of the NCCMDS is used for the purposes described in Section 2.1 of the Change Specification.
4	We've never collected the NCCMDS before: what do we need to do?	You'll need to read the Requirements Specification and take the following actions: 1. Establish systems and processes (including training on data recording) in order to facilitate local recording of NCCMDS Version 2.0 (2016 Release), i.e. create systems to allow the capture and recording of all CCACs. 2. Systems and processes must be configured in order to allow Version 2.0 (2016 Release) of the NCCMDS to be translated into Version 1.0 (2007 Release) of the NCCMDS, so that the CCACs 80-93 do not form part of the data set for transmission to SUS. This can be achieved by following the guidance in Appendix 2 of the Requirements Specification. 3. Ensure that each version of the NCCMDS is used for the purposes described in Section 1.3 of the Requirements Specification.
5	How should NCCMDS be collected for babies discharged and readmitted on the same day?	If a baby receives two episodes of critical care in one day which relate to two consultant episodes then you should capture NCCMDS for both episodes separately. This is only required where a consultant discharge and readmission is involved. This situation is most likely to occur where a baby is transferred to another Trust for surgery and returned to your hospital the same day.
6	Capturing data outside of NICU	Data related to critical care activity on Maternity and Neonatal Transitional Care Wards may be collected by ward or NICU staff. The advantage in NICU staff collecting this data may be: • Greater familiarity with NCCMDS • Ready access and familiarity with the IT system used to record NCCMDS data.

	Question	Answer
7	We still need to comply with ISB 0092: How can the NCCMDS data be merged with the Commissioning Data Set data?	Version 1.0 of the NCCMDS is part of CDS. However, it is anticipated that the majority of Trusts will collect NCCMDS on a standalone IT system. Combining data with CDS may be done by: a) Importing NCCMDS data into the Patient Administration System (PAS), if the PAS supports this. This is expected to be the exception rather than the rule as it will involve a fairly sophisticated interface to be developed. b) Merging the CDS produced by PAS and NCCMDS after the CDS has been processed into a standardised XML message but before it is submitted to SUS. c) Merging the CDS produced by PAS and NCCMDS in a data warehouse or database before being processed into a standardised XML message and submitted to SUS. This is expected to be the principal method chosen, with some local variation to suit local IT. These methods are suggestions only and do not limit Trusts in any way. It is for Trusts to decide how the requirement is delivered in their own organisations and add any fields necessary to the NCCMDS data capture which may be required to provide the data keys to enable reliable merging of the data files.
8	How can I test whether my Version 1.0 extract will meet SUS requirements?	Guidance on producing Version 1.0 of the NCCMDS is provided in Appendix 2.0 of the Requirements Specification. Simple checks may include ensuring that no instances of the CCACs 80-93 appear in the data to be transmitted to SUS. You may wish to make use of the current Casemix HRG Local Payment Grouper software in order to check conformance. Outputs from the Grouper will highlight any errors associated with the inclusion on invalid codes.
9	Does the Standard dictate how the notices should be recorded?	No. It is up to individual providers to decide how they wish to record the data; particularly whether they wish to record the data directly, or derive the NCCMDS data items from more granular data already captured on local clinical systems.
10	If a baby reached 28 days should we stop collecting NCCMDS and start collecting the Paediatric Critical Care Minimum Data Set (PCCMDS)?	No. NCCMDS should be collected for all babies in NICU and for all babies receiving critical care (special care) on Maternity and Neonatal Transitional Care Wards regardless of age. PCCMDS would be collected if the baby was transferred to PICU or a Children's Ward.

	Question	Answer
11	If a baby <28 days is admitted to PICU should we collect NCCMDS?	No. PCCMDS should be collected for all babies on PICU or a ward for Children and Young Adults.
12	If a mother is admitted to hospital herself should we record CCAC 21 Carer Resident - Caring for Baby as yes? Do rooming mothers count as CCAC 21 Carer Resident - Caring for Baby?	This will depend on whether the mother is actively caring for the baby. If the mother (or other external carer) is caring for the baby and reducing the nursing workload compared to if the mother (or other external carer) was not present, then yes. If the mother (or other external carer) is present but not caring for the baby to the point where nursing effort is significantly reduced, then no. In general, it is expected that this field will be recorded as yes for babies on Maternity and Neonatal Transitional Care Wards and no for babies on NICU.
13	What is an External Carer?	This will generally be the baby's mother but may be any other carer who is not part of the hospital paid staff.
14	What happens if we don't record all of the critical care activity?	Version 2.0 NCCMDS data will be required to complete the Reference Costs submission and used to determine a neonatal critical care tariff. If data is not recorded then a future tariff may be incorrectly set. Version 1.0 NCCMDS data is used to produce the HRGs that are a mandated NTPS tariff. If data are not submitted then providers may not receive appropriate reimbursement for care provided.
15	How does NCCMDS fit in with the BAPM data set and regional data sets?	NCCMDS is an NHS mandated data set. All of the data items within NCCMDS can also be found within the BAPM data set. Many regional data sets are similar to NCCMDS but may differ to a varying degree. NCCMDS has been mandatory since April 2007 and used for reimbursement since April 2008. Regional and BAPM data sets may be collected post if networks wish to do this for local / regional purposes, subject to appropriate information governance arrangements being in place. However, the data set which drives the reimbursement regime is the NCCMDS.

	Question	Answer
16	How does NCCMDS fit with the National Neonatal Data Set (ISB 1595)?	The NCCMDS is a mandated national data set created in 2007 that flows from English providers to NHS Digital, Version 1.0 of which is sent as a subset in the following Commissioning Data Set messages: CDS V6-2 Type 120 - Admitted Patient Care - Finished Birth Episode Commissioning Data Set CDS V6-2 Type 130 - Admitted Patient Care - Finished General Episode Commissioning Data Set CDS V6-2 Type 180 - Admitted Patient Care - Unfinished Birth Episode Commissioning Data Set CDS V6-2 Type 190 - Admitted Patient Care - Unfinished General Episode Commissioning Data Set The National Neonatal Data Set created in 2014 consists of a defined list of data items that are extracted from electronic clinical records created by clinical staff relating to all neonatal critical care delivered in England and Wales. The Neonatal Data Analysis Unit has established a database, the National Neonatal Research Database (NNRD) to hold data comprising the National Neonatal Data Set, as a national resource.
17	How does NCCMDS fit with SNOMED CT?	In the longer term it is envisaged that NCCMDS data will be derived directly from the clinical record and SNOMED Clinical Terms. Direct derivation from the clinical record will only be feasible once an electronic clinical record has been implemented so is not expected to be an option available for most units immediately.
18	How does NCCMDS fit with OPCS coding?	NCCMDS uses OPCS for recording High Cost Drugs. OPCS and High Cost Drugs are defined outside NCCMDS and trusts will need to take account of periodic changes to OPCS and High Cost Drugs when collecting NCCMDS.
19	How is NCCMDS used in assigning NCC HRGs?	Each item within NCCMDS is used either singly or in combination with other items to assign a patient to a HRG. The HRGs are closely related to BAPM care levels. For example: 01 (Respiratory support via a tracheal tube) maps to HRG = Intensive Care 09 (Oxygen Therapy) in combination with PERSON WEIGHT < 1,500g maps to HRG = High Dependency
20	What are the considerations in terms of confidentiality and consent?	The same rules will apply to the NCCMDS as are in place for CDS. The Local Information Governance Manager can refer to the Confidentiality and Data Protection Assurance- Acute Trusts Knowledge base guidance.

	Question	Answer
21	How do I find out more?	More information on NCCMDS and HRGs can be obtained from NHS Digital's SCCI submission. This can be obtained from the SCCI web pages: http://www.digital.nhs.uk/isce/publication/scci0075

4 Considerations for IT Suppliers

The IT systems requirements and conformance criteria associated with the NCCMDS are provided in the Requirements Specification, along with a full Data Set Specification, and guidance on the relationship between versions 1.0 and 2.0 of the data set. How suppliers go about satisfying these requirements, and any other requirements that may originate locally, is for the supplier and the healthcare provider to agree upon. However, in considering system configurations it is worth keeping in mind that interoperability may be required with other existing systems or data sets including the CDS and the Neonatal Data Set.

5 Conformance Criteria Monitoring

5.1 Healthcare Organisations

NHS Digital will take overall responsibility for monitoring conformance with the Standard. Initially, conformance monitoring will be through:

- Assessment of compliance with Reference Costs reporting and analysis of Reference Costs submissions
- Assessment of compliance with NCCMDS CDS submission requirements.

Further options to monitor compliance will be explored should any concerns about compliance be raised by or to NHS Digital.

5.2 IT Systems

NHS Digital has no direct relationship with system suppliers. Conformance with IT system requirements will therefore be up to healthcare providers. It is recognised that if IT system conformance is not achieved, healthcare providers will not be able to comply with the Standard as a whole, and this would be identified through the conformance monitoring of healthcare providers.