Paediatric Critical Care Minimum Data Set: Implementation Guidance

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SCCI Standardisation Committee for Care Information

This information standard (SCCI0076) 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 (SCCI0076 Amd 113/2015) 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	Paediatric Critical Care Minimum Data Set: Requirements Specification	SCCI0076 – PCCMDS – Requirements Specification
2	Paediatric Critical Care Minimum Data Set: Change Specification	SCCI0076 – PCCMDS – Change Specification

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 Paediatric 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 PCCMDS is to allow the operation of the National Tariff Payment System (NTPS) within paediatric critical care. PCCMDS 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 paediatric critical care.

1.2 Background

The Paediatric Critical Care Minimum Data Set (PCCMDS) provides a record of what happens to a patient when they receive paediatric critical care in a Paediatric Intensive Care Unit (PICU) or other critical care setting suitable for children. It was first introduced by Data Set Change Notice (DSCN) 01/2007, and is the responsibility of NHS Digital. The data items within the PCCMDS can be derived from data that are recorded and used as part of the clinical management of a patient.

The PCCMDS Standard requires all providers of NHS paediatric critical care to collect and flow the specified data. The PCCMDS is a requirement for all NHS Trusts and NHS Foundation Trusts that provide paediatric critical care in England. This includes all Trusts that have a Paediatric Intensive Care Unit (PICU) and those that have other 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 PCCMDS:

- Version 1.0 (2007 Release), which is de facto the Standard first mandated by DSCN 01/2007 and includes 31 CCACs
- Version 2.0 (2016 Release), which is based on Version 1.0, but includes six additional (making a total of 37) CCACs.

Version 2.0 of the PCCMDS 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 PCCMDS Information Standard. Version 1.0 of the PCCMDS 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 PCCMDS and need to update their systems, and also to those organisations that do not currently capture the PCCMDS. 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 PCCMDS can be captured and stored locally, and that Version 1.0 (2007 Release) of the PCCMDS 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 PCCMDS.

  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 PCCMDS, and ensure that they are used appropriately.

- 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 PCCMDS per se, or whether the PCCMDS 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 PCCMDS 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 PCCMDS 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 PCCMDS, 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 PCCMDS.
- 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.

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 PCCMDS

These individuals will need to take actions including:

- Familiarisation with the new PCCMDS Standard.
- 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 PCCMDS data quality.
- Ensuring that any data captured is complete, accurate, timely, and if handwritten, clearly legible.
- Considering whether privacy notices in respect of the PCCMDS 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 PCCMDS 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 PCCMDS:

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 PICU environment the period of critical care will be from admission to discharge from the PICU.

b) In other settings, the critical care period runs from the first to the last day of a continuous period of paediatric 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 PCCMDS, 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 PCCMDS be collected?	PCCMDS 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.
3	We've been collecting the PCCMDS 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 PCCMDS 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 PCCMDS to be translated into Version 1.0 (2007 Release) of the PCCMDS, so that the new CCACs (80, 85, 94-97) 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 PCCMDS is used for the purposes described in Section 2.1 of the Change Specification.

	Question	Answer
4	We've never collected the PCCMDS 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 PCCMDS 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 PCCMDS to be translated into Version 1.0 (2007 Release) of the PCCMDS, so that the CCACs 80, 85, and 94-97 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 PCCMDS is used for the purposes described in Section 1.3 of the Requirements Specification.
5	How should PCCMDS be collected for children discharged and readmitted on the same day?	If a child receives two episodes of critical care in one day which relate to two consultant episodes then you should capture PCCMDS 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 child is transferred to another Trust for surgery and returned to your hospital the same day.
6	Capturing data outside of PICU	Data related to critical care activity on non-PICU wards may be collected by ward or PICU staff. The advantage in PICU staff collecting this data may be: • Greater familiarity with PCCMDS • Ready access and familiarity with the IT system used to record PCCMDS data.

	Question	Answer
7	We still need to comply with ISB 0092: How can the PCCMDS data be merged with the Commissioning Data Set data?	Version 1.0 of the PCCMDS is part of CDS. However, it is anticipated that the majority of Trusts will collect PCCMDS on a standalone IT system. Combining data with CDS may be done by: a) Importing PCCMDS 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 PCCMDS 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 PCCMDS 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 PCCMDS 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 PCCMDS is provided in Appendix 2.0 of the Requirements Specification. Simple checks may include ensuring that no instances of the CCACs 80, 85, or 94-97 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 PCCMDS data items from more granular data already captured on local clinical systems.
10	If a baby younger than 28 days is admitted to PICU should we collect the Neonatal Critical Care Minimum Data Set (NCCMDS)?	No. The Paediatric Critical Care Minimum Data Set (PCCMDS) should be collected for all patients on PICU or a ward for Children and Young Adults.

	Question	Answer
11	If a child older than 28 days is admitted to NICU should we collect PCCMDS?	No. NCCMDS should be collected for all patients on NICU, Neonatal Transitional Care Wards and Maternity Wards.
12	If a patient reached 19 years old should we stop collecting PCCMDS and start collecting Critical Care Minimum Data Set (CCMDS)?	No. The Paediatric Critical Care Minimum Data Set (PCCMDS) should be collected for all patients on PICU or a ward for Children and Young Adults.
13	What happens if we don't record all of the critical care activity?	Version 2.0 PCCMDS data will be required to complete the Reference Costs submission and used to determine a paediatric critical care tariff. If data is not recorded then a future tariff may be incorrectly set. Version 1.0 PCCMDS 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.
14	How does PCCMDS fit with TISS?	The Therapeutic Intervention Scoring System (TISS) is used by some but not all PICUs. PCCMDS is a mandatory collection but it does not prevent trusts collecting TISS or any other data that they wish to collect locally. Trusts who wish to collect other data which is similar to PCCMDS, may wish (at their discretion) to combine the data collections by adding the additional data to their PCCMDS collections. This additional data cannot flow via SUS in the same way as PCCMDS but combining the data collection should make the process more efficient.
15	How does PCCMDS fit with PICANet?	The Paediatric Intensive Care Audit Network (PICANet) is a clinical audit collection covering PICUs. PCCMDS is a mandatory collection; PICANet is a voluntary collection that all PICUs participate in. PICANet is not modified in any way by PCCMDS. There are very few data items shared by PICANet and PCCMDS. However, as with other data collections, Trusts may wish (at their discretion) to combine the data collections by adding the various data items together to make collection more efficient. Submission arrangements for PICANet are different to PCCMDS and are unaffected by the introduction of PCCMDS.

	Question	Answer
16	How does PCCMDS fit with SNOMED CT?	In the longer term it is envisaged that PCCMDS 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.
17	How does PCCMDS fit with OPCS coding?	PCCMDS uses OPCS for recording High Cost Drugs. OPCS and High Cost Drugs are defined outside PCCMDS and trusts will need to take account of periodic changes to OPCS and High Cost Drugs when collecting PCCMDS.
18	How is PCCMDS used in assigning PCC HRGs?	Each item within PCCMDS is used either singly or in combination with other items to assign a patient to a HRG. Further information for each HRG design is available at www.digital.nhs.uk/casemix.
19	What are the considerations in terms of confidentiality and consent?	The same rules will apply to the PCCMDS 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.
20	How do I find out more?	More information on PCCMDS and HRGs can be obtained from the NHS Digital's SCCI submission. This can be obtained from the SCCI webpages: http://www.digital.nhs.uk/isce/publication/scci0076

4 Considerations for IT Suppliers

The IT systems requirements and conformance criteria associated with the PCCMDS 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.

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 PCCMDS 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.