Public Health
England

Protecting and improving the nation's health

Cancer Outcomes and Services Data set (COSD) Version 7.0

Implementation Guide

SCCI Standardisation Committee for Care Information

This information standard (SCCI1521) has been approved for publication by the Department of Health 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:

- Specification
- Change Request
- Implementation Guide.

An Information Standards Notice (SCCI1521 Amd 1/2016) has been issued as a notification of use and implementation timescales. Please read this alongside the documents for the standard.

The controlled versions of these documents can be found on the NHS Digital website.

Date of publication 17 August 2016.

Contents

Amendment History

Version	Date	Amendment History
6.0	18/12/12	Updated for COSD v6.0 changes (pre-publication)
7.0	18/03/16	Updated for COSD v7.0 changes (pre-publication)
7.1	10-06-2016	Final version with changes following ISAS review and recommendations
7.2	24-06-2016	Final version with changes following 2nd quality review and recommendations
7.3	25-07-2016	Final for publication
7.4	08-08-2016	Final for Publication (post editorial comments)

1. Introduction

The following guidance is intended to support providers of Cancer Services and developers (both in-house and system suppliers), to prepare for the implementation of the Cancer Outcomes and Services Data set (COSD) v7.0 from April 2017. All documents (or links to them) can be found on the NCIN website - COSD pages[1] unless otherwise stated.

The National Cancer Intelligence Network (NCIN) has now become part of the National Cancer Registration and Analysis Service (NCRAS), which is part of Public Health England (PHE). The NCIN website will be re-branded shortly to reflect these changes but will continue to publish additional information and updates on the COSD webpages[2].

All Providers are already submitting the current version of COSD and this guidance is intended to support identification and implementation of the changes proposed in v7.0. This document and all supporting documentation will be available from the COSD downloads webpage[3].

1.1. Implementation approach

The implementation of COSD is managed by the National Cancer Registration and Analysis Service (NCRAS) directly with its data providers. The principal approach is to work in partnership with clinicians and their information, management and multidisciplinary teams to implement the standard successfully.

Trusts should contact their local NCRAS office to discuss any issues. If you are unsure who your local NCRAS Liaison Manager is, you can find out by sending an email to COSDenquiries@phe.gov.uk.

Any issues regarding the standard itself or change requests should continue to be sent to the COSD data sets team at COSDenquiries@phe.gov.uk.

1.2. Background

The Cancer Outcomes and Services Data set (COSD) provides a standard for secondary uses information, initially required to support the implementation and monitoring of *Improving Outcomes: a strategy for cancer* (IOSC)[4]. The COSD replaced the previous National Cancer Data set and the Cancer Registration Data set.

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[1] http://www.ncin.org.uk/collecting_and_using_data/
[2] http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd
[3] http://www.ncin.org.uk/collecting_and_using_data/data_collection/cancer_outcomes_and_services_data set_cosd_latest_downloads
[4] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213785/dh_123394.pdf

The Standard supports national statistics, allowing local and national comparisons of performance and service activity. Additionally, the output supports commissioning and service development through the provision of relevant information on service delivery and outcomes.

As COSD is for Secondary Care uses, there is no intention for this to be used by Primary Care or Private Hospitals.

> ** It is important to note that if a patient is on a NHS pathway, but the treatment is carried out in a private hospital (due to capacity issues or at the request of the NHS Trust), these data must be collected and reported (within COSD) by the NHS Trust, as if the treatment was carried out by them.

1.3. Summary of changes

This is a change to the standard which includes some movement of items within the data set, re-aligning data into more logical groups and a revision of the current schema specification (and the creation of a new Pathology Schema), in order to continue to meet the business objectives of the standard.

New data items have been added after extensive consultation was conducted with all the Site Specific Clinical Reference Groups (SSCRGs), experts from within the National Cancer Registration and Analysis Service (NCRAS), as well as clinical support and advice from the chair of the Royal College of Pathologists Working Group on Cancer Services.

As many of the data within COSD were originally agreed in 2012, this process allowed the data set to be clinically reviewed, validated and updated by experts in all fields of Cancer and provide a clinically sound set of data to be collected from 2017 onwards.

The Achieving World-Class Cancer Outcomes, A Strategy for England 2015-2020 (Cancer Taskforce Report)[5], produced a series of recommendations which directly impacted upon COSD. The strategy pointed out the need for changes – which have been interpreted and applied to the data set and new data items have been included within v7.0 to support the recommendations.

In addition there are new data to help identify and analyse:

- An unplanned return to theatre
- The surgeon (or surgeons) who were responsible for each surgical episode
- Molecular and biomarker testing.

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[5] https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf

Many data have been re-aligned across the data set into the correct higher level groupings.

The data set can now be easily maintained within each Trust, by using one of two subsets (depending on the department responsible for each data collection process):

- Pathology - This was part of the last version of the standard and is now mandated across all Trusts to supply these data in COSD XML directly from their pathology departments.
    - This is different from the main COSD data set as there are unique linkages for pathology and therefore requires its own unique schema.
- Patient Pathway – This is the data excluding Pathology, which the Cancer Services Teams need to collect. By removing the pathology data from their workload, it reduces their burden of data collection by up-to 30% across the whole data set.
    - Pathology consists of 151 data items which is 30% of the data set. As these data are now collected and submitted by the pathology departments directly, it is a huge burden of duplication if we therefore ask the Cancer Services (non-clinical) teams to transcribe the same data into COSD via a Trusts Cancer Information Systems.

Wherever possible duplication across the data set has now been removed and full explanations of how to collect these data within the new structure are provided within the change log of the data set.

Finally, where there were data that are no longer part of a linked national data set (eg Royal College of Pathologists), these have also been removed from the data set.

1.4. Status of documents

All the documents referred to in this guidance have been submitted to the Standardisation Committee for Care Information (SCCI) for acceptance under SCCI1521 amendment Amd 1/2016. Subject to acceptance by SCCI and following confirmation of authority to publish by the Department of Health, the official Information Standards Notice (ISN) and related documents will be published 17th August 2016.

These documents are intended to support providers and developers who wish to identify and plan changes to their systems. The standard will be formally issued via SCCI as an approved standard and additional documents (eg the Data Sets, User Guides and Technical Guides) will be available to download via the NCIN Website[6]

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[6] http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd_downloads_v7

1.5. Changes to systems

Please note that COSD specifies the data which Providers are required to submit to the NCRAS for secondary uses and does not define record level data to be used in the delivery of care. The data for COSD should be derived from patient identifiable data which are already recorded for the purpose of care management.

1.6. Clinical Safety

The NHS Digital Clinical Safety Team has reviewed the standard application and would like to have the following noted:

"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[7]. Consequently, a Clinical Safety Case Report is not required to support the **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 modification must be considered by the manufacturer and all other parties involved under SCCI0129 and the health organisation under SCCI0160[8]."

2. Implementation process

The following documents are all prepublication unless otherwise stated but the process will be the same following approval and publication. Please note that all deadlines unless otherwise stated relate to the month of diagnosis, not the month of submission.

The following are a sequence of steps, set-out to help you understand the implementation process and support you in asking the right questions and engaging the right people within your organisation:

Step 1: Read the Change Request

This provides a summary of the changes to the data set, schema and timescales for delivery. If you are a new user/supplier and creating a new cancer information system for the first time, please go directly to **Step 2**.

Step 2: Read the Information Standards Notice (ISN)

This is the official notification that the Information Standard has been published by the Standardisation Committee for Care Information (SCCI). It provides an outline of the approved standard and timeframe for compliance. Compliance with ISNs will

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[7] SCCI0129 Clinical Risk Management: its Application in the Manufacture of Health IT Systems (accessible at: http://digital.nhs.uk/isce/publication/scci0129)

[8] SCCI0160 Clinical Risk Management: its Application in the Deployment and Use of Health IT Systems (accessible at: http://digital.nhs.uk/isce/publication/scci0160)

normally be included in contracts between NHS Providers and their system suppliers.

This is expected to be available to download from the 17th August 2016, this will provide an implementation period of 7½ months (please refer to table in Step 7).

Step 3: Read the COSD v7.0 Specification

This provides a more detailed description of the Information Standard and will be published at the same time as the ISN.

Step 4: Read the data set and User Guide v7.0

These provide the detailed information and explanation about the data items in the data set, definitions and values which can be recorded. These are divided by tumour group and will give you an idea of what will need to be submitted for different types of cancers. The User Guide also includes further details to support this and is included within the overall suite of documentation, this should be read in conjunction with the data set.

COSD Version 7.0 data set should be reviewed to identify changes to the current submissions.

All changes are highlighted in the relevant worksheets and specified in the change control log.

There are also three additional worksheets which list the changes as either:

- **Substantial -** significant changes to the data set such as additional items or values which require changes to systems and possibly to processes.
- **Cosmetic** – minor modifications such as format restrictions which are unlikely to require changes to processes and only minimal changes to systems.
- **Schema mandation only** – removal of previous mandation for all but linkage data in the XML extracts. As this ‘relaxed’ was already being trialled this is unlikely to require changes to either systems or processes.

The COSD v7.0 User Guide should be read in conjunction with the Data Set for additional information and guidance. Subject to acceptance by the SCCI Committee, the official Information Standards Notice (ISN), and all related documents will be published on 17 August 2016, on the NHS Digital website[9].

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[9] http://digital.nhs.uk/isce/publication/scci1521

Additional supporting documents eg the User Guide, Data Sets, Technical Guides, will be published via the COSD downloads page[10], on 18 August 2016.

Details of how to download the new schema packs are available from the TRUD[11] website, if you do not have an account, it is easy to create one from their login page.

Step 5: Identify and discuss with stakeholders

It is essential to engage with those who are involved in recording, checking, submitting and using the data in/or for your organisation. This will probably include (but is not restricted to) some or all of the following (names may vary):

- Clinical teams (Multidisciplinary Teams)
- MDT Coordinators
- Cancer Services Manager
- Cancer Data Manager
- Informatics/IT Dept
- Software suppliers
- Strategic Clinical Network team
- Commissioners
- Your local (NCRAS) office.

If you are developing an in-house system, you need to understand how the data is collected to improve existing collection systems. Where an off-the-shelf system is used, this is less important as the system supplier would have done this through client engagement.

Step 6: Plan how you will implement

Implementation of the new version of the standard will be between 18 August 2016 and 31 March 2017 (7½ months). Please refer to the table in step 7 for the phased Implementation to Full Conformance timeframe.

During phase 2 both versions of the data set can be submitted. From July 2017 only the amended version will be accepted.

Not all the data will need to be submitted immediately, but you need to be sure you have considered all the issues.

Step 7: Check your current state of readiness

The two main issues to be considered are systems capability (can the data items be collected electronically) and completion and collection (are the data items collected).

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[10] http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd_downloads_v7
[11] https://isd.hscic.gov.uk/trud3/user/guest/group/0/login/form

Systems (Software): Many of the new or amended data items in COSD will already be recorded electronically in your Trust. Check what system changes are needed to meet the amendments

Processes: Are any changes to process required?

Collection: You will also need to check if the new data fields which are already on the systems are being completed and if not, identify who will collect them and at what stage in the patient pathway. Data has been grouped into patient pathway points to help identify where and when they should be collected.

QA and submission: It is essential that clinical teams are confident in the data being submitted for their patients. You should already have processes in place to assure the data but may need to check that these are still applicable. Changes in process or data collection need to be coordinated with the Cancer Services Team locally, and/or (if necessary) software suppliers.

Step 8: Put COSD on the agenda

Make sure that clinical colleagues are aware of COSD by raising it at any network meetings. This could include Network Site Specific Groups (NSSG) Meetings (if these are still running in your area) or any other relevant clinical network or Trust events.

Step 9: Talk to your software supplier/customers

If you have a commercial system, you will need to speak with your supplier to confirm the timescale for any necessary changes to the cancer management system you use. In most cases these changes will be part of your Service Level Agreement (SLA). (See the following steps if you have an in-house system).

Similarly software suppliers will need to talk with their customers to agree dates for roll-out of systems. Based on previous experience, we have allowed a three month window to allow for this.

The revised data set v7.0 is expected to be submitted using the following timetable:

Phase	**Dates**	**Action**
Phase 1 – Implementation Period	18/08/2016 to 31/03/2017	providers and suppliers making changes
Phase 2 – Data Collection Period	01/04/2017 to 30/06/2017	data flow in either v6 or v7 format
Phase 3 - Full Conformance	01/07/2017	only using v7 format – All data backdated to 01/04/2017

- Phase 1 is to make allowance for the development lead times of software suppliers and in-house developers. ISN publication date is 17/08/2016 and the documentation will be available from 18/08/2016.
- Phase 2 allows for a three month period where data can be submitted in accordance with either data set v6.0 (schema v6.0) or data set v7.0 (schema v7.0) and both will be accepted by the validation processes.
- Phase 3 requires full conformance in v7.0 and all data to be backdated to 1 April 2017.

Step 10: Read the Technical Guide

The Technical Guide has been updated and a prepublication version for data set v7.0 will be available on the NCIN website from August 2016. This includes details of who to contact for ad hoc support.

Step 11: Sign up to the XML workshop

The NCRAS, with the support of NHS Digital, is planning to run a workshop early in 2017. This will be aimed at representatives from all Trusts who would like assistance in developing XML feeds from their cancer information management systems in order to submit data in XML format.

All Trusts are already submitting COSD and COSD Pathology in XML, so this workshop will be aimed at technical teams and Trusts who will be developing submission files for the first time and new members of staff.

An example here would be in the event (however unlikely) that a new hospital Trust is created that has never previously submitted COSD, and they use an in-house system, (they would be developing for the first time). Equally some Trusts may have new staff who have not yet developed in XML but will be required to make changes to in-house systems.

Step 12: Attend your regional roadshow

The National Cancer Registration and Analysis Service (NCRAS) are planning to run a series of roadshows between January and February 2017, in Birmingham, Bristol, Leeds and London.

These workshops will cover cancer data collection, quality assurance, an update on implementation and will inform stakeholders of the changes. We aim to target particularly those who may have been less involved to date, including Cancer Managers, Deputy or Clinical Leads, Information Managers and Pathology Managers.

These roadshows will also provide an opportunity for developers to see the standard in context and will cover both the organisational and technical aspects as well as issues regarding process.
The roadshows are expected to take a full day and will be an opportunity for both central teams and clinical teams to find out more, discuss issues and ask questions.

Step 13: Check for updates

NCIN has now become part of the National Cancer Registration and Analysis Service (NCRAS), which is part of Public Health England (PHE). The NCIN website will be re-branded shortly to reflect these changes but will continue to publish additional information and updates in the COSD webpages[12].

Feedback on current submissions is available from the COSD Conformance portal[13], which is called CancerStats. Access and registration is available to all authorised NHS staff, and it is recommended that each MDT has a clinical member responsible for reviewing their data submitted monthly to the NCRAS (clinical champion). These data are submitted by the Cancer Services teams at the start of each month and are available for review by the end of the same calendar month.

Editions of the COSD Newsletter will be published periodically to advise of updates. If you would like to be added to the circulation list please contact COSDenquiries@phe.gov.uk.

3. End To End Testing

It was not possible to complete end-to-end testing with system suppliers prior to the standard being issued. Extensive consultation will continue throughout 2016/17 with system suppliers and IT departments across the NHS in England to help and support development, implementation, and testing prior to ‘Full Compliance’.

A series of meetings will be held with the major software suppliers and IT departments to assess their readiness/compliance. It is expected that all organisations/suppliers provide a written report to the Head of Cancer Datasets by the end of December 2016, outlining their compliance readiness and timescales for deployment to their clients.

These reports will be assessed by both the COSD Advisory Board at a meeting on 12 January, with recommendations submitted to the COSD Governance Board for discussion on 26 January 2017. These meetings are held quarterly and a second review can be undertaken in April (if required).

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[12] http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd
[13] https://nww.cancerstats.nhs.uk/

There has already been a three month window for deployment of the new data set upgrades, written into the implementation programme from 1 April to 30 June 2017. This will help with roll-out where suppliers have multiple clients and simultaneous upgrades are not possible.

The COSD Governance Board will also have the ability to insert a stop/go on the implementation process, if there are serious concerns that implementation cannot be safely achieved.

In this eventuality, Trusts will be able to revert back to v6.0, until the serious issue (which caused the stop/go process), is resolved and an acceptable solution agreed.

4. Lessons Learned

Throughout the implementation process the Head of Cancer Datasets will monitor roll-out and the Implementation Guide will be updated to reflect these. A new updated guidance document will be published on the COSD downloads (v7.0) webpage, once it is ready.

This updated document will be available via the NHS Digital website.[14]

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[14] http://digital.nhs.uk/isce/publication/scci1521