Public Health
England

Protecting and improving the nation's health

Cancer Outcomes and Services Dataset (COSD)

Version 8.0

Implementation Guide

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health, and are a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

Public Health England
Wellington House
133-155 Waterloo Road
London SE1 8UG
Tel: 020 7654 8000
www.gov.uk/phe
Twitter: @PHE_uk
Facebook: www.facebook.com/PublicHealthEngland

© Crown copyright 2017
You may re-use this information (excluding logos) free of charge in any format or medium, under the terms of the Open Government Licence v3.0. To view this licence, visit OGL or email psi@nationalarchives.gsi.gov.uk. Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

Published: September 2017
PHE publications
gateway number: 2017376

PHE supports the UN
Sustainable Development Goals

Corporate member of
Plain English Campaign
Committed to clearer
communication
339

SUSTAINABLE
DEVELOPMENT GOALS

Data Coordination Board

This information standard (DCB1521) 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 Data Coordination Board (DCB), a sub-group of the Digital Delivery Board.

This information standard comprises the following documents:

- Specification
- Implementation Guide
- Change Request.

An Information Standards Notice (DCB1521 Amd 74/2016) 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. 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.

Date of publication: 28 September 2017.

Contents

Amendment History

Version	Date	Amendment History
8.0	31-05-2017	Updated for COSD v8.0 changes (pre-publication)
8.1	15-06-2017	Updated version with changes following review and recommendations
8.2	21-07-2017	Updated version with changes following review and recommendations
8.3	11-08-2017	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) v8.0 from April 2018. All documents (or links to them) can be found on the NCIN website - COSD pages[1] unless otherwise stated.

Although in the most part all changes are described as COSD v8.0, there is a separate pathology data set (which is a sub set of COSD), but requires a different schema pack due to the different linkage required. This will be referred to within this document as COSD v8.0 Pathology data set v3.0. It is important to note that pathology is at v3.0 due to this being the third schema required for this subset, and that pathology was first mandated as a separate data set in 2016.

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 has been re-branded to reflect these changes and will continue to publish additional information and updates on the COSD pages.

All Providers are already submitting the current version of COSD and this guidance is intended to support identification and implementation of the changes in v8.0. This document and all supporting documentation will be available from the COSD downloads webpage, a new v8.0 section will be created to prevent confusion between different versions of the standard.

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 multi-disciplinary teams (MDT) 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 set team at COSDenquiries@phe.gov.uk.

---

[1] http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd

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)[2]. The COSD replaced the previous National Cancer Data set and the Cancer Registration Data set.

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.

> Note: It is important to note however, 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

Version 8.0 (COSD) completes the required changes started in v7.0 (COSD). These additional changes were required in order to make the data set clinically accurate and also meeting the recommendations within the Achieving World-Class Cancer Outcomes, A Strategy for England 2015-2020 (Cancer Taskforce Report)[3].

This required a change to the standard which includes:

- a new ‘Non Primary Cancer Pathway’ to improve ascertainment and data quality
- some movement of items within the data set
- the re-aligning of data into more logical groups, especially within children, teenage and young adults (CTYA)
- a revision of the current schema specification, in order to continue to meet the business objectives of the standard

New data items have been added after an extensive (6 month) consultation was conducted with 47 key stakeholder groups and clinical experts:

- 13 site specific clinical reference groups (SSCRGs)
- experts from within the National Cancer Registration and Analysis Service (NCRAS)

---

[2] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213785/dh_123394.pdf

[3] http://www.cancerresearchuk.org/about-us/cancer-strategy-in-england

- clinical support and advice from the chair of the Royal College of Pathologists Working Group on Cancer Services
- cancer charities (Cancer Research UK, Breast Cancer Care and Living Beyond Cancer)
- patient groups and individuals through ‘Use My Data’ and SSCRGs
- national cancer audits
- cancer and pathology system suppliers
- NHS England
- cancer waiting times (CWT)
- quality surveillance
- cancer taskforce transformation board

The COSD v7.0 revision allowed the data set to be clinically reviewed, validated and updated by experts in all fields of Cancer, and provides a clinically sound set of data to be collected from 2017 onwards. However, it was recognised that there were still further improvements and new pathways required, to ensure that it complied with the cancer taskforce report recommendations.

The cancer taskforce report produced a series of recommendations, of which 7 directly impacted upon COSD. The strategy pointed out the need for changes, which have been interpreted and applied to the data set, new data items were included within both v7.0 and now v8.0 to support these recommendations.

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

- ‘Non-Primary Cancer’ diagnoses and pathways
- the ability to record transformation, progression and metastatic disease during the ‘Primary Diagnosis’ pathway
- improved cancer treatment intent
- improved clinical trials data
- new section to accurately record Liver tumours

Some data have been re-aligned across the data set to improve ascertainment and data quality, and where clinical staging or coding systems have changed, these have been reflected within this release.

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 is mandated across all Trusts that supply these data in COSD XML directly from their pathology departments
    - this is different from the patient pathway sub 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

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 logs of the data set.

Finally, where there were data that are no longer part of a linked national data set (e.g. Royal College of Pathologists), these have also been removed from v8.0 of the COSD.

1.4. Status of documents

All the documents referred to in this guidance were submitted to the Data Standards Assurance Service (DSAS) for review under DCB1521 amendment Amd 74/2016. Following acceptance by Data Coordination Board (DCB) and confirmation of authority to publish by the Department of Health, the official Information Standards Notice (ISN) and related documents were published on the 28th September 2017.

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 DCB as an approved standard and additional documents (e.g. the Data Sets, User Guides and Technical Guides), will be available to download via the NCIN Website[4], where a new page for v8.0 downloads will be created.

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 reviewed the standard application for v7.0 and made the following observations:

"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[5]. 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

---

[4] http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd

[5] SCCI0129 Clinical Risk Management: its Application in the Manufacture of Health IT Systems: http://content.digital.nhs.uk/isce/publication/scci0129

such modification must be considered by the manufacturer and all other parties involved under SCCI0129 and the health organisation under SCCI0160[6]."

After discussion with NHS Digital, because the IG requirements within COSD have not changed within the scope of v8.0, there was no requirement to re-submit a Privacy Impact Assessment or file a new clinical safety report. However local decisions on these matters should be agreed to ensure Trusts' PIAs and SLA's are all up-to-date.

2. Implementation process

The following documents have all been published by either NCRAS or NHS Digital, unless otherwise stated. Please note that all deadlines unless otherwise stated relate to the month of diagnosis, not the month of submission.

The following is 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.

It is important to read all the steps first as depending on your current readiness, if you are a new user/system supplier and creating a new cancer information system for the first time, you may require a different implementation approach, which could be different to the published order below:

Step 1: Read the Information Standards Notice (ISN)

This is the official notification of the Information Standard, published by the Data Coordination Board (DCB). It provides an outline of the approved standard and timeframe for compliance. Compliance with ISNs will normally be included in contracts between NHS Providers and their system suppliers.

This was available to download from the 28th September 2017, and will provide an implementation period of 6 months (please refer to table in Step 7). To receive Notifications about standards activity please email standards.assurance@nhs.net

Step 2: Read the COSD v8.0 Specification

This provides a more detailed description of the Information Standard and will be published at the same time as the ISN. This provides information about all the requirements and conformance, new and existing users must comply with, including information about:

- the data set process
- clinical and information governance
- technical architecture

---

[6] SCCI0160 Clinical Risk Management: its Application in the Deployment and Use of Health IT Systems: http://content.digital.nhs.uk/isce/publication/SCCI0160

Step 3: Read the Change Request

This provides a summary of the changes to the data set since the last version, including the schema and timescales for delivery. If you are a new user/system supplier, please go directly to step 4.

Step 4: Read the Data Set and User Guides (COSD v8.0) or (Pathology data set v3.0)

These provide the detailed information and explanation about the data items in the data set, definitions, formats 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 COSD data sets should be reviewed to understand the requirements of current versions. For new users, this is important as the change request document will only give details of items which have changed since the previous versions.

Each data set has many worksheets (or tabs) at the bottom of each document. 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** - changes that are only applicable to schema and do not affect the data items within the data set

The COSD v8.0 and/or Pathology data set v3.0 User Guides should be read in conjunction with the data sets for additional information/guidance and are included within the overall suite of documentation.

The Information Standards Notice (ISN) and all related documents were published on 28th September 2017, via the NHS Digital website[7].

Additional supporting documents e.g. the User Guides, Data Sets, Technical Guides etc., were published via the COSD downloads page[8], on the 28th September 2017. These are separate to those published by NHS Digital above.

Details of how to download the new schema packs are available from the Technology Reference data Update Distribution (TRUD)[9] website, if you do not have

---

[7] http://content.digital.nhs.uk/isce/publication/scci1521
[8] http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd_downloads_v7
[9] https://isd.digital.nhs.uk/trud3/user/guest/group/0/login/form

an account, it is easy to create one from their login page. TRUD allows you to securely download all reference files from NHS Digital and once downloaded, any update or correction to these files will create an automatic message to all registered venders.

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 (multi-disciplinary teams)
- multi-disciplinary team (MDT) coordinators
- cancer services manager
- cancer data manager
- informatics/IT departments
- software suppliers
- strategic clinical network team
    - vanguards or cancer alliances
- commissioners
- your local (NCRAS) office
    - data loaders
    - liaison managers

If you are developing an in-house system, you need to understand how the data are collected to improve existing collection systems. Where an off-the-shelf system is used, this is less important as the system supplier should have done this through client engagement or a service level agreement (SLA).

Step 6: Plan how you will implement

Implementation of the new version of the standard will be between 28th September 2017 and 31st March 2018 (6 months). Please refer to the table in step 7 for the phased Implementation to full conformance timeframe.

Between Apr-Jun 2018, both versions of the data set can be submitted. From July 2018 only the amended v8.0 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

Systems (Software):

- many of the new or amended data items in COSD will already be recorded electronically in your Trust

- check what changes are required to meet the amendments or new items

Processes:

- are there any changes to process required:
    - additional training needs
    - additional clinical system access
    - clearer mapping documents with your IT/system supplier

Collection:

- new/amendments - there will be new and amended data which will be required to be collected differently
    - identify who will collect these data and at what stage in the pathway
- deletions/corrections - data has been grouped into more logical pathways or in some cases deleted to prevent duplication
    - identify where these data are and collect appropriately

Quality Assurance and submission:

- it is essential that clinical teams are confident in the data being submitted for their patients
- review processes to ensure quality assurance of the data is performed before submission to NCRAS
- if necessary, review audit tools with software suppliers to meet new requirements

Feedback on current submissions is available from the COSD Conformance portal[10], 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.

Step 8: Put COSD on the agenda

Make sure that clinical colleagues are aware of COSD by raising it at any local or network meetings. This could include strategic clinical network, vanguard or cancer alliance meetings, or any other relevant clinical network or Trust event.

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).

---

[10] https://nww.cancerstats.nhs.uk/

Similarly Trusts must talk with their software suppliers to agree dates for roll-out of their systems and local updates. Based on previous experience, we have allowed a three month window to allow for this.

If Trusts use an in-house system, they need to start discussions early to ensure all changes can be incorporated within the three phased timetable below.

The revised data sets COSD v8.0 or Pathology data set v3.0 are expected to be submitted using the following timetable:

Phase	**Dates**	**Action**
Phase 1 - Implementation Period	29-09-2017 to 31-03-2018	the development lead times of software suppliers and in-house developers to make changes to systems to reflect requirements and align with conformance criteria
Phase 2 - Data Collection Period	01-04-2018 to 30-06-2018	allows for a three month period where data can be submitted in accordance with either COSD v7.0 or v8.0 and/or Pathology data set v2.0 or v3.0 formats
Phase 3 - Full Conformance	01-07-2018 onwards	requires full conformance, using only COSD v8.0 and/or Pathology data set v3.0 formats

Step 10: Read the Technical Guide

The Technical Guides have been updated for data set COSD v8.0 and Pathology data set v3.0 and are available on the NCIN website from 29th September 2017.

Step 11: Attend your regional roadshow

The National Cancer Registration and Analysis Service (NCRAS) are planning to run a series of 8 regional roadshows (between January and February 2018) across England.

Details will be communicated towards the end of 2017 via newsletter and NCRAS will work with each Trust to arrange placements for these events.

These workshops will cover:

- cancer data collection
- quality assurance
- an update on implementation
- will inform stakeholders of all new changes

We aim to target particularly those who may have been less involved to date, including:

- cancer managers
- deputy or clinical leads

- information managers
- 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.

Other important cancer data set developers or clinical audits will also be invited to present at these meetings such as:

- cancer waiting times (CWT)[11]
- systemic anti-cancer therapy (SACT)[12] data set
- radiotherapy data set (RTDS)[13]
- other national (HQIP)[14] audits

Step 12: Check for updates

The NCIN website has been re-branded to reflect these changes and will continue to publish additional information and updates on the COSD webpages[15].

Editions of the COSD Newsletter will be published periodically to provide advice for users, of any updates or key milestones. 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 2017/18 with system suppliers and IT departments across the NHS in England to help and support development, implementation, and testing prior to ‘Full Conformance’ from 1st July 2018.

A series of meetings will be held with the major software suppliers and Trust 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 2017, outlining their compliance readiness and timescales for deployment to their clients. This will be coordinated by the regional NCRAS liaison managers.

---

[11] https://digital.nhs.uk/cancer-waiting-times
[12] http://www.chemodataset.nhs.uk/home
[13] http://www.natcansat.nhs.uk/rt/rtds.aspx
[14] http://www.hqip.org.uk/national-programmes/a-z-of-nca/
[15] http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd

These reports will be assessed by the COSD Advisory Board at a meeting in January 2018, with recommendations submitted to the COSD Governance Board for discussion later in that month. These meetings are held quarterly and a second review can be undertaken in April (if required).

A three month phased implementation period for deployment of the new data set upgrades has been written into the implementation programme from 1st April 2018 to 30th June 2018. This will help with roll-out where, for instance, 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. Should this occur, it will be widely communicated through:

- NCRAS liaison managers
- newsletters
- the Data Coordination Board

In this eventuality, Trusts will be able to revert back to v7.0, 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 the roll-out and any lessons learnt will be documented and used to improve the next version.