Public Health England

Protecting and improving the nation's health

Cancer Outcome and Services Data set

Implementation guide

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Published September 2019
PHE publications
gateway number: GW-621

PHE supports the UN
Sustainable Development Goals

Data Coordination Board

This information standard (DCB1521) has been approved for publication by the Department of Health and Social Care 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 13/2019) 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: 12 September 2019.

Contents

Amendment history

Version(s)	Date	Amendment History
COSD v9.0 & Pathology v4.0	24 April 2019	Draft document sent to DCB for initial review
COSD v9.0 & Pathology v4.0	8 July 2019	Final amended document sent to DCB for board review
COSD v9.0 & Pathology v4.0	2 August 2019	Final amended document for publication

Executive summary

The purpose of this document is to provide guidance intended to support providers of Cancer Services and developers (both in-house and commercial system suppliers), to prepare for the implementation of the Cancer Outcomes and Services Data set, (COSD v9.0 and v4.0 for Pathology) from April 2020.

All documents (or links to them) can be found on either the COSD[1] or NHS Digital[2] websites unless otherwise stated. These provide assurances that the proposed approach meets the business requirements identified in the requirements specification for DCB1521 Amd 13/2019 have been adequately researched and can be delivered.

This is an update to an existing information standard DCB1521 Amd 74/2016 and is required to ensure that the data still meets the business objectives, scope and content of the standard and continues to be clinically accurate and relevant.

In order to maintain the clinical accuracy, it is important to regularly review COSD with clinical experts from across the NHS, including analysts and NHS England.

Occasionally other information standards have specific data items which interact with COSD. Where this happens, it is important to liaise with the developers of those standards to ensure all data items remain accurate and are updated where necessary.

Although in the most part all changes are described as COSD, there is a separate pathology data set, which requires a different schema pack due to the different linkage required. This will be referred to within this document as COSD Pathology data set v4.0.

It is important to note that pathology is at v4.0 due to this being the fourth schema required for this data set, and that pathology was first mandated as a separate data set in 2016. All pathology data items have now been removed from the main COSD v9.0 data set and can only be submitted via the pathology data set and set of schemas.

[1] http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd
[2] http://www.digital.nhs.uk/isce/publication/dcb1521

Introduction

Background

The COSD is the national standard for reporting cancer for the NHS in England. The National Cancer Registration and Analysis Service (NCRAS) are responsible for ongoing maintenance, development and implementation. The data sets relate to all cancer patients, both adult and paediatric, in acute inpatient and outpatient settings, but does not include private patients or primary care.

Overtime clinical data items may have changed or been amended by internationally recognised bodies, for example Royal College of Pathologists or international staging systems (revised international prognostic scoring system for myelodysplasia). These must be acknowledged, and amendments made.

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 recognise, 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.

Implementation approach

The implementation of COSD is managed by the 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.

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 via the CancerStats website[3]

[3] https://cancerstats.ndrs.nhs.uk/guidance/DI_team

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

Summary of changes

All changes made in COSD v9.0 and Pathology v4.0 are clearly outlined in the requirement specification and change request documents published on the DCB1521 website[4].

This revision allowed the data sets 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 April 2020 onwards.

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 13/2019.

Following acceptance by DCB and confirmation of authority to publish by the Department of Health and Social Care, the official Information Standards Notice (ISN) and related documents were published on the 6 September 2019.

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 (for example, the data sets, user guides and technical guides), will be available to download via the NCIN website[5], where a new page for COSD downloads will be created.

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.

[4] http://digital.nhs.uk/isce/publication/dcb1521
[5] http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd

Implementation process

The documents listed in steps one to 4 and step 10, 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 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 6 September 2019 and will provide an implementation period of six-and-a-half 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 specification

This provides a more detailed description of the Information Standard and was 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 sets and processes
- clinical and information governance
- technical architecture

Step 3: read the change request

For new users all documents should be reviewed to understand the requirements of COSD v9.0 and Pathology v4.0, for existing users this document is important as the change request provides a summary of the changes to the data sets.

Step 4: read the data set and user guide (COSD v9.0 or Pathology v4.0)

Additional supporting documents are published via the COSD downloads page[6]. These are separate to those published by NHS Digital above, as follows:

- the data sets
- the user guides
- the technical guides

Details of how to download the new schema packs are available from the Technology Reference data Update Distribution website (TRUD)[7] – if you do not have an account it is easy to create one from the TRUD 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.

These provide the detailed information and explanation about the data items in the data set, including 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.

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.

The COSD v9.0 and/or Pathology v4.0 User Guides should be read in conjunction with the data sets for additional information/guidance and are included within the overall suite of documentation.

[6] http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd
[7] https://isd.digital.nhs.uk/trud3/user/guest/group/0/login/form

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 (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 6 September 2019 and 31 March 2020 (six-and-a-half months). Please refer to the table in step 7 for the phased Implementation to full conformance timeframe.

Between April to June 2020, both COSD v8.1 or v9.0 and Pathology v3.0 or v4.0 can be submitted. From July 2020 only the new COSD v9.0 or Pathology v4.0 will be accepted.

Not all the data will need to be submitted immediately due to patients differing treatment plans, however you need to be sure you have considered all the issues.

Step 7: check your current state of readiness

Review your systems (software):

- as many of the new or amended data items in COSD will already be recorded electronically within your Trust or organisation
- checking what changes are required to meet the amendments or new items

Review your processes, checking:

- if there are any changes to process required?
- If there are additional training needs?
- If there is additional clinical system access required?
- to ensure that clear mapping documents have been set up with your IT/system supplier

Review your data collection to:

- check for 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
- check for 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

Review your quality assurance (QA) and submission processes, as:

- it is essential that clinical teams are confident in the data being submitted for their patients
- doing so ensures 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[8], which is called CancerStats. Access and registration are 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 team 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.

[8] https://cancerstats.ndrs.nhs.uk/

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 SLA.

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 3-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 3 phased timetable below. The revised data sets COSD v9.0 or Pathology v4.0 are expected to be submitted using the following timetable:

Phase	Dates	Action
Phase 1: implementation period	6 Septermber 2019 to 31 March 2020	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	1 April 2020 to 30 June 2020	allows for a 3-month period where data can be submitted in accordance with either COSD v8.1 or v9.0 and/or Pathology v3.0 or v4.0 schema formats
Phase 3: full conformance	1 July 2020 onwards	requires full conformance, using only COSD v9.0 and/or Pathology v4.0 schema formats

Step 10: read the technical guide

The technical guides have been updated for both COSD v9.0 and Pathology v4.0 data sets and are available on the NCIN website from 7 September 2017.

Step 11: attend your regional roadshow

The NCRAS are planning to run a series of 8 regional roadshows (between January and February 2020) across England.

Details will be communicated towards the end of 2019 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)[9]
- NCRAS liaison managers, outlining good practice in your region
- acute oncology representatives

Step 12: check for updates

The NCIN website will continue to publish additional information and updates on the COSD webpages[10].

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.

You can sign up to NHS Digital's Data Standards Assurance Service distribution list, by emailing: standards.assurance@nhs.net.

[9] http://digital.nhs.uk/isce/publication/dcb0147
[10] http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd

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 2019 to 2020 with system suppliers and IT departments across the NHS in England to help and support development, implementation, and testing prior to 'Full Conformance' from 1 July 2020.

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 their regional NCRAS office by the end of December 2019, outlining their compliance readiness and timescales for deployment to their clients. This will be coordinated by the regional NCRAS liaison managers.

These reports will be assessed by the COSD Advisory Board at a meeting in January 2020, 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 3-month phased implementation period for deployment of the new data set upgrades has been written into the implementation programme from 1 April 2020 to 30 June 2020. This will help with roll-out where, for instance, suppliers have multiple clients and when 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 COSD v8.0 and/or Pathology v3.0, until the serious issue (which caused the stop/go process) is resolved and an acceptable solution agreed.

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.