

# Cancer Outcomes and Services Data set (COSD)

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## Implementation Guide

## About the NDRS

The National Disease Registration Service (NDRS) is part of NHS England. Its purpose is to collect, collate and analyse data on patients with cancer, congenital anomalies, and rare diseases. It provides robust surveillance to monitor and detect changes in health and disease in the population. NDRS is a vital resource that helps researchers, healthcare professionals and policy makers make decisions about NHS services and the treatments people receive.

The NDRS includes:

- the National Cancer Registration and Analysis Service (NCRAS) and
- the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)

Healthcare professionals, researchers and policy makers use data to better understand population health and disease. The data is provided by patients and collected by the NHS as part of their care and support. The NDRS uses the data to help:

- understand cancer, rare diseases, and congenital anomalies
- improve diagnosis
- plan NHS services
- improve treatment
- evaluate policy
- improve genetic counselling



National Disease Registration Service  
The Leeds Government Hub  
7&8 Wellington Place  
Leeds  
LS1 4AP



For queries relating to this document, please contact:  
[NDRSenquiries@nhs.net](mailto:NDRSenquiries@nhs.net)

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# Data Alliance Partnership Board

The Data Alliance Partnership Board (DAPB), which holds delegated authority from the Secretary of State for Health and Social Care, has approved a change to an existing information standard for publication 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 Standards Assurance Service (DSAS) and endorsed by the Data Alliance Partnership Sub Board (DAPSB).

This information standard comprises the following documents:

- Change Specification
- Data Set Specification
- Implementation Guidance
- Requirements Specification

An Information Standards Notice (DAPB1521 Amd 89/2022) 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 England 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: 11 September 2023

# Contents

Executive Summary	4
Implementation approach	5
Summary of changes	5
Status of documents	6
Changes to systems	7
Clinical Safety and Data Protection	7
Implementation process	8
Step 1: Read all available documentation	8
Information Standards Notice (ISN)	8
COSD Specification	8
Change Request	8
Data Set and User Guide (COSD v10.0 or COSD Pathology v5.0)	9
Technical Guide	9
Step 2: Download and read the Schema documents	9
Step 3: Talk to your software supplier/IT teams	9
Step 4: Identify and discuss with stakeholders	10
Step 5: Plan how you will implement	11
Step 6: Check your current state of readiness	11
Step 7: Put COSD on the agenda	12
Step 8: Attend your regional roadshow	12
Step 9: Check for updates and newsletter sign-up	13
End to End Testing	14
Lessons Learned	15
Appendix A - Uniform Resource Locator (URL) Glossary	16

## Amendment history

Version(s)	Date	Amendment History
COSD v10.0 & COSD Pathology v5.0	11 May 2023	Draft to support v10 and Pathology v5.0, sent to DSAS
COSD v10.0 COSD Pathology v5.0	21 June 2023	Updated draft document sent to DSAS for editorial review
COSD v10.0 & COSD Pathology v5.0	25 July 2023	Minor editorial changes by DSAS

## 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 v10.0 and COSD Pathology v5.0) from April 2024.

All documents (or links to them) can be found on the [National Disease Registration Service \(NDRS\) website - COSD pages unless otherwise stated](#). These provide assurances that the proposed approach meets the business requirements identified in the requirements specification for DAPB1521 Amd 89/2022 have been adequately researched and can be delivered.

This is an update to an existing information standard DCB1521 Amd 13/2019 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.

To maintain the clinical accuracy, it is important to regularly review COSD with clinical experts from across the NHS, including analysts (within NDRS) and NHS England.

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 v5.0.

# Implementation approach

The implementation of COSD is managed by the NDRS 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 NDRS office to discuss any issues regarding the standard itself. If you are unsure who your local NDRS Liaison Manager is, you can find out by sending an email to [nhsdigital.cosdenquiries@nhs.net](mailto:nhsdigital.cosdenquiries@nhs.net).

## Summary of changes

There are two versions of COSD (v10.0 and COSD pathology v5.0). Changes were required to make the data sets clinically accurate, fully align with the Royal College of Pathologists (RC Path) Core data sets and to meet Information Governance and GDPR requirements. COSD is supported by a National Disease Registries Directions 2021, which is written on behalf of the Secretary of State for Health and Social Care.

COSD has been through a 6-month clinical review, including SMEs from all tumour groups, cancer audits, Royal Colleges, as well as experts within the NDRS registration and analytical teams. In addition, SMEs from NHS England (NHSE), the former NHS Digital (NHSD) and NHS Wales were also consulted upon.

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 2024 onwards.

New data items have been added, but more importantly for this review many data items were removed, to reduce the burden of data collection. Importantly, only data that is being used for cancer registration or for analysis (including NDRS data partners) are requested.

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

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

- COSD v10.0 - this is the data excluding Pathology, which the cancer services teams must collect
  - in some cases, clinician's using Electronic Patient Records (EPRs) will record the data direct into local systems

- COSD Pathology v5.0 - this is mandated across all Trusts that supply these data in COSD XML, directly from their pathology departments

Wherever possible, duplication across the data sets has now been removed and full explanations of how to collect these data within the new structure are provided within the user guides of each data set.

Finally, where there were data that are no longer part of a linked national data set (for example, Royal College of Pathologists), these have also been removed from v5.0 of the COSD Pathology data set.

## Status of documents

All the documents referred to in this guidance were submitted to the Data Standards Assurance Service (DSAS) for review under DAPB1521 amendment Amd 89/2022.

Following acceptance by Data Alliance Partnership Board (DAPB) 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 11 September 2023.

This Implementation Guide should be read in conjunction with the following documents, websites are imbedded within each bullet point header below:

### [NHS England - DAPB1521 COSD:](#)

- [specification](#)
- [change request](#)
- [implementation guide](#)
- [information standard notice](#)

### [NDRS - COSD pages:](#)

- [COSD data set v10.0](#)
- [COSD v10.0 user guide](#)
- [COSD v10.0 technical guide](#)
- [COSD pathology data set v5.0](#)
- [COSD pathology v5.0 user guide](#)
- [COSD pathology v5.0 technical guide](#)

### [Technology Reference Update Distribution \(TRUD\) website:](#)

- [COSD data set v10.0 schema pack](#)
- [COSD pathology data set v5.0 schema pack](#)

These documents are intended to support providers and developers who wish to identify and plan changes to their systems.

## Changes to systems

Please note that COSD specifies the data which Providers are required to submit to the NDRS for secondary uses but 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.

## Clinical Safety and Data Protection

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 DCB0129 and DCB0160](#). Consequently, a Clinical Safety Case Report is not required to support the standard.

Full Information Governance, Clinical Safety and Data Protection information, along with the Data Provision Notice (DPN), National Disease Registries Directions 2021 and General Data Protection Regulations (GDPR) as explained in full within the Specification document.

# Implementation process

The following documents have all been published by either the NDRS or NHS England, and there are hyperlinks to each website in the 'status of documents' section above.

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 all available documentation

All documentation will be available to download from the 11 September 2023 and will provide an implementation period of 6½ months (please refer to table in Step 3). To receive notifications about standards activity email [standards.assurance@nhs.net](mailto:standards.assurance@nhs.net).

### Information Standards Notice (ISN)

This is the official notification of the Information Standard, published by the DAPB. It provides an outline of the approved standard and timeframe for compliance.

Compliance with Information Standard Notices (ISNs) are part of the NHS Contract (section 28.2.2) and will normally be included in contracts between NHS Providers and their system suppliers.

### COSD Specification

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

### Change Request

This provides a summary of the changes to the data sets since the last version, including the schema and timescales for delivery.

## **Data Set and User Guide (COSD v10.0 or COSD Pathology v5.0)**

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 distinct 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 specified in the change control log.

The COSD v10.0 or COSD Pathology v5.0 User Guides, should be read in conjunction with the data sets for additional information/guidance and are included within the overall suite of documentation and can be downloaded from the NDRS website.

## **Technical Guide**

The technical guides have been updated for both COSD v10.0 and COSD Pathology v5.0 data sets and can be downloaded from the NDRS website.

These technical guides are essential for system suppliers or IT teams, where COSD is being built for the very first time. These provide extended advice around reporting of complex data using Extensible Markup Language (XML), as well as the process around submitting data files.

## **Step 2: Download and read the Schema documents**

Details of how to download the new schema packs are available from the [Technology Reference data Update Distribution website \(TRUD\)](#). If you do not have an account, it is easy to create one from their login page.

TRUD allows you to securely download all reference files from NHS England and once downloaded, any update or correction to these files will create an automatic message to all registered vendors.

## **Step 3: Talk to your software supplier/IT teams**

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).

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 v10.0 or COSD Pathology v5.0 are expected to be submitted using the following timetable:

Phase	Dates	Action
Phase 1 - Implementation Period	11 September 2023 to 31 March 2024	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 April 2024 to 30 June 2024	Allows for a three month period where data can be submitted in accordance with either: <ul style="list-style-type: none"> <li>• COSD v9.0.2 and/or v10.0</li> <li>• COSD Pathology v4.0.2 and/or v5.0 schema formats.</li> </ul>
Phase 3 - Full Conformance	01 July 2024 onwards	Requires full conformance, using only COSD v10.0 or COSD Pathology v5.0 schema formats.

## Step 4: 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 include (but is not restricted to) some or all the following (names may vary):

- clinician's and clinical teams (multi-disciplinary teams)
  - multi-disciplinary team (MDT) coordinators
  - cancer services manager
  - cancer data manager
- informatics/IT departments
  - software suppliers
- vanguards or cancer alliances
  - strategic clinical networks
  - commissioners
- your local (NDRS) office
  - liaison managers
  - data loaders

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 5: Plan how you will implement

Implementation of the updated version of the standard will be between 11 September 2023 to 31 March 2024 (6½ months). Please refer to the table in step 3 for the phased Implementation to full conformance timeframe.

Between Apr to Jun 2024, both versions of the data set can be submitted. From July 2024 only COSD v10.0 or COSD Pathology v5.0 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 6: Check your current state of readiness

Review your systems (software):

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

Review your processes:

- are there any changes to process required?
- are there additional training needs?
- is there additional clinical system access required?
- ensure you have clear mapping documents with your IT/system supplier

Review your data 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

Review your quality assurance (QA) and submission processes:

- 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 NDRS, using the API portal
- if necessary, review audit tools with software suppliers to meet new requirements

Feedback on current submissions is available from the [CancerStats2 portal](#). 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 NDRS (a clinical champion).

These data are submitted by the cancer services team by the 25th working day of each month and are available for review by the end of the same calendar month. In addition, there are new monthly COSD reports sent to senior Trust managers, outlining key conformance metrics, including Stage, Performance Status and CNS contact.

## **Step 7: 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 8: Attend your regional roadshow**

The NDRS are planning to run a series of 8 regional roadshows (between January to February 2024) across England.

Details will be communicated towards the end of 2023 via newsletters and NDRS 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

The following group of people are key to these meetings:

- cancer managers
- 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, details of these will follow.

## **Step 9: Check for updates and newsletter sign-up**

The NDRS website will continue to publish additional information and updates on the COSD webpages. These will include HTML versions of all documents as well as printable pdf versions too. This ensures we comply with strict new accessibility standards and makes our documentation accessible to all.

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 complete the form using this link.](#)

## End to End Testing

As with previous versions, it was not possible to complete end-to-end testing with system suppliers prior to the standard being issued. Extensive consultation will continue throughout 2023/24 with system suppliers and IT departments across the NHS in England to help and support development, implementation, and testing prior to 'Full Conformance' from 01 July 2024.

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 NDRS office by the end of December 2023, outlining their compliance readiness and timescales for deployment to their clients. This will be coordinated by the regional NDRS liaison managers.

These reports will be assessed by the COSD Advisory Board at a meeting in January 2024, 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 01 April 2024 to 30 June 2024. This will help with roll-out where, for instance, suppliers have multiple clients and when simultaneous upgrades are not possible.

The COSD Governance Board can 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:

- DAPB within NHS England
- NDRS liaison managers
- newsletters

In this eventuality, Trusts will be able to revert to COSD v9.0.2 and COSD Pathology v4.0.2, 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.

## Appendix A - Uniform Resource Locator (URL) Glossary

This section provides the full URL address, to help and support sight impaired users access all links throughout the document.

Page 3:

- NDRS, COSD webpage - <https://digital.nhs.uk/ndrs/data/data-sets/cosd>

Page 5 (Supporting documents):

- ISN publications - <http://digital.nhs.uk/isce/publication/dapb1521>
- NDRS, COSD webpage - <https://digital.nhs.uk/ndrs/data/data-sets/cosd>
- TRUD - <https://isd.digital.nhs.uk/trud3/user/guest/group/0/home>

Page 6:

- Clinical risk - <https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/dcb0129-clinical-risk-management-its-application-in-the-manufacture-of-health-it-systems>

Page 8:

- TRUD - <https://isd.digital.nhs.uk/trud3/user/guest/group/0/home>

Page 11:

- CancerStats2 portal - <https://cancerstats.ndrs.nhs.uk/welcome>

Page 12:

- COSD newsletter sign-up - <https://visitor.r20.constantcontact.com/manage/optin?v=001Ay5KKtyAO-278pB6C3Dd5cW5OrSMtlpw>