Cancer Outcomes and Services Data set (COSD)

Specification

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
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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

Title	COSD Specification		
DAPB Reference	DAPB1521 Amd 89/2022		
Sponsor	Dr Brian Rous	**Status**	Draft
Senior Responsible Officer	Sarah Stevens	**Versions**	COSD v10.0 & COSD Pathology v5.0
Developer	Andrew Murphy		
Author(s)	Andrew Murphy	**Version Date**	11 September 2023

Amendment History:

Version(s)	Date	Amendment History
COSD v10.0 & COSD Pathology v5.0	23 May 2023	Draft document sent to DAPB for initial review
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 either the National Disease Registration Service (NDRS) COSD pages or NHS England websites unless otherwise stated. These provide assurances that the proposed approach meets the business requirements identified in the requirements specification for DAPB1521 Amd 89/2022 and have been adequately researched and can be delivered.

This is an update to an existing information standard DCB1521 Amd 13/2019. This is required to ensure that the data sets still meet the business objectives, scope, and content of the standard and continue 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. Occasionally other information standards have specific data items which interact with COSD. Where this happens, the Head of Cancer Datasets has liaised with the developers of those standards, to ensure all data items remain accurate and are updated.

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.

Finally, extensive reviews have been held with both the NHS Data Model and Dictionary Service and the Data Design Authority, as well as experts within the classification and terminology teams in NHS England. These reviews have ensured that all data items now meet the national standards and expectations for effective data set design within the NHS.

Introduction

Background

The Cancer Outcomes and Services Data set (COSD) is the national standard for reporting cancer for the NHS in England. The National Disease Registration Service (NDRS) are responsible for ongoing maintenance, development, and implementation.

COSD is a compiled data set, which provides the standard for secondary uses information required to support national cancer registration and associated analysis (at local, regional, national, and international level), as well as other national cancer audit programmes.

COSD provides the standard for secondary uses and consists of:

- a set of individual data items, with their definitions
- the assemblage of these data items into tumour specific discrete data sets
- the means of flowing the data items
- compilation of the data items into two reconciled data sets
    - Patient Pathway
    - Pathology

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, these must be acknowledged, and amendments made within COSD.

In addition, other information standards are supported. For example, DCB2094 Sexual Orientation Monitoring; DCB0147 National Cancer Waiting Times Monitoring Data Set, and SCCI0034 SNOMED CT.

COSD Pathology continues to be an important part of the standard and has its own data set and schema. Consultation has continued with both Laboratory Information Management System (LIMS) suppliers, and the Royal College of Pathologists (RC Path), to ensure all data requested meets the RC Path core data set specifications.

COSD meets Information Governance and GDPR requirements and is supported by a National Disease Registries Directions 2021, which is written on behalf of the Secretary of State for Health and Social Care.

Why is it needed?

Periodically we need to revise the COSD to ensure that we meet the current information requirements for the NHS.

The 'NHS Long Term Plan' aims to save thousands of lives each year by dramatically improving how we diagnose and treat cancer. The ambition is that by 2028, an extra 55,000 people each year will survive for five years or more following their cancer diagnosis.

The need to have strong cancer data collection, empowers NHS England to enforce this through the mandate of data collections. These data will be the base for cancer analysis and research for the next 5 years.

Who does COSD apply to:

COSD applies to the following key groups and organisations:

- cancer centres, cancer units and all other providers of NHS commissioned cancer services
- developers and suppliers of electronic systems for use in NHS commissioned cancer centres and NHS provider services
- organisations purchasing electronic systems for use in NHS commissioned cancer centres and NHS provider services
- users of secondary data about cancer at both national and local levels, including:
    - at a national level:
        - Department of Health and Social Care (DHSC)
        - National Disease Registration Service (NDRS)
        - National Cancer Registration and Analysis Service (NCRAS)
        - NHS England (NHSE)
    - at a local level:
        - cancer alliances
        - commissioners and providers

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 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.

Key changes since version 9.0.2

These updated versions of the data set include new data-items, re-alignment of data structure, amendments and contains corrections, for example where there were errors in previous versions or updates to clinical coding or staging values.

Throughout the data sets there are a series of choices which will make collecting and reporting data easier to understand and will be supported by the new schemas. In addition, there are some key new sections to link potentially orphaned data items throughout the data set.

The proposed changes can be divided into the five key areas:

- deleted data items
- new data items
- data items with amended attributes
- moved data items
- schema specification changes

Note:

- in some cases, the same data item is used in different sections of the data set, in these circumstances they are only counted once

The following are the major changes to COSD v10.0:

Key Change	Numbers
Deleted Data Items	76
New Data Items	22
Data Items with Amended Attributes	13
Moved Data Items	10
Schema Specification Change	12

The following are the major changes to COSD Pathology v5.0:

Key Change	Numbers
Deleted Data Items	28
New Data Items	42
Data Items with Amended Attributes	13
Moved Data Items	4
Schema Specification Change	1

Ongoing linkage with the Royal College of Pathologists (RC Path) ‘Core’ data sets is vital and continues to be a priority to ensure clinical accuracy. This data set was reviewed by the chair of the Royal College of Pathologists Working Group on Cancer Services.

Working closely with the college is vital to ensure that COSD maps exactly to their specified data items and names. This will ensure that there is no burden on the histopathologists in recording these data, as they are mandated to collect these via the RCPath. In addition, it also reduces the burden on reporting for system suppliers to an absolute minimum, as they can map directly from their main tables to the export reports required for COSD.

Detailed notes for all the changes are available to view in the COSD workbook, within the yellow 'Change Log' and summary tabs.

Burden of data collection

These changes have continued the work done in previous reviews and has had a huge effect on the future formulation of COSD.

The removal of the pathology data items into their own specific data set in v9, resulted in a reduction on burden of data collection for MDT Coordinators of up to 30%. In v10 there is a further 15% reduction, resulting in an overall burden reduction of up to 45% in 3 years.

This shows we are responding to concerns from Trusts about the size and complexity of COSD. It is important to remember though that there is still more work needed in v11 to maintain COSD as the leading data collection of cancer data in England.

Clinical review

COSD has been through a rigorous clinical review/assessment, this has involved talking to:

- Royal Colleges
- specialist tumour site specific groups
- leading consultants, across all disease types:
    - in total over 60 subject matter experts (SMEs)
- cross referencing other data sources to reduce burden
- getting additional expert advice from:
    - National Disease Registration Service (NDRS)
    - NHS England (NHSE), including the former NHS Digital
    - NHS Wales
- all proposed changes were reviewed by the COSD Advisory Board
- all recommendations were approved by the overarching COSD Governance Board

Altogether, this clinical review helped define the draft data sets.

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

The data sets 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 need to collect
- 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 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 each data set and the user guides.

Implementation start and full conformance timeline

The following timeframe will be used to support the implementation, data collection and outline the full conformance dates:

- implementation is between 11 September 2023 to 31 March 2024 (6 months)
- data collection will start from 01 April 2024 (with a three month roll-out period between 01 April 2024 to 30 June 2024)
- full conformance from 01 July 2024 (reported in the July batch, within the September upload)

Supporting documents

All the documents referred to in this specification document were submitted to the Data Standards Assurance Service (DSAS) for review under DAPB1521 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 Specification 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.

Related Standards

The following standards should also be read in conjunction with this information standard, links to each website are imbedded within each bullet points below:

- DCB0147 National Cancer Waiting Times Monitoring Data Set
- DAPB0111 Radiotherapy Data Set
- DCB1533 Systemic Anti-Cancer Therapy Data Set
- SCCI1577 Diagnostic Imaging Data set
- SCCI0021 International Classification of Diseases
- SCCI0034 SNOMED CT
- DCB2094 Sexual Orientation Monitoring
- Royal College of Pathologists Standards and Data sets for Histopathology Reporting on Cancers and Tissue Pathways

Contacts

The following are a list of key contacts responsible for the development and management of the data sets:

- senior responsible officer – Sarah Stevens (Director for National Disease Registration)
- sponsor - Dr Brian Rous (Director of Tumour Classification)
- developer - Andrew Murphy (Head of Cancer Datasets)
- implementation manager - Andrew Murphy (Head of Cancer Datasets)
- maintenance manager - Andrew Murphy (Head of Cancer Datasets)

COSD has a specific email address as follows:

- nhsdigital.cosdenquiries@nhs.net

Health and Care Organisations

Requirements

The following are a series of requirements which all health care organisations must read:

- NHS Providers of cancer services (hereinafter referred to as NHS Providers) MUST read the Specification and Change Request in conjunction with the Implementation Guidance to identify how the standard is applicable to them
- NHS Providers MUST review their system compatibility against this standard to identify any changes required to current practice to ensure that all data items in COSD v10.0 or COSD Pathology v5.0 can be flowed electronically by the dates specified in this document
- if there are compatibility gaps, then further development is required to meet the standard
- NHS Providers MUST submit the data using the XML format for extracts from MDT cancer information management systems
- NHS Providers MUST submit the data using the XML format for extracts from pathology systems
- NHS Providers SHOULD NOT utilise this data set primarily to support their clinical and operational data capture

It is important that where a Trust originally records a patient as having cancer and a record is sent during routine data uploads, but this diagnosis changes to a non-registerable condition, that NDRS is immediately informed of this decision. Due to the complex way cancer information systems are designed, this change of status will not be sent automatically within the next available upload of data.

Conformance Criteria

The following are a series of conformance requirements which all health care organisations must read:

- data items submitted are as specified in the COSD v10.0 or COSD Pathology v5.0 data sets and submitted within the defined reporting period and in the format specified
- all specified linkage items are required (at record level) to enable linkage of the relevant cancer registration records
- there is a 25 working day reporting period following the month end, to submit the agreed data items following diagnosis date
- there is a 25 working day reporting period following the month end, to submit the agreed data items following treatment start date

- there is a 25 working day reporting period following the month end, to submit any additional or amendments to the data items
- an agreed method of submission with the NDRS is required, for all items not flowed as part of the standard extract (for example, imaging data)
- Trusts MUST notify the NDRS (as soon as possible after discovery) of any known reasons for significant variation in the number of new cases submitted monthly in comparison to previous months
- all data extracted from Trust MDT cancer information management systems is to be reported in XML
- all data extracted from Trust pathology systems are to be reported in XML, or agreed method of reporting whilst Trusts migrate to new systems capable of reporting in XML

Conformance is now measured in real-time, using the new COSD Monthly reports which are sent to senior Trust managers, including the Cancer Services Manager by the regional NDRS Data Liaison Manager.

The expectation is that Trusts should be reporting ascertainment at 100% and that this is monitored within the new COSD monthly feedback reports. To achieve this, the COSD data submitted by Trusts are linked to CWT and HES to get a true picture of the total number of cancers diagnosed per Trust.

These reports are intended to allow stakeholders to make a swift appraisal of COSD conformance over the previous 12 months. The overall ranking is derived from the data shown in the key metric visualisation (section 2.2 of these reports), and all scores and rankings shown are intended to provide national context to the Trust specific percentages.

Additional reporting is available on the CancerStats2 portal, and includes:

- NHS England staging dashboard
- early stage cancer
- level 3 curated data
- living with and beyond cancer reports

Cancer incidence and mortality, survival, prevalence, routes to diagnosis and other key reports are now available on the publicly facing CancerData website.

Regular reports are provided to the COSD Governance Board to monitor and manage compliance to the Information Standard.

IT Systems

It would be expected that all Trusts have a service level agreement (SLA), with their system supplier to ensure future development needs are sufficient to meet changes to the standard.

Requirements

Trusts MUST ensure that cancer IT and pathology systems change in accordance with their local contractual arrangements, to enable all specified data items in COSD v10.0 and COSD Pathology v5.0 to be captured and extracted in compliance with the Specification and Implementation Guidance.

There will be amendments to, and new schemas issued, for both COSD v10.0 and COSD Pathology v5.0 to support this process.

Conformance Criteria

The requirement above MUST be met.

NHS Providers MUST submit the agreed data items within 25 working days of the month end following diagnosis or treatment date. The DAPB standard provides all the documentation to support this process, including:

- implementation guide
- change request
- specification document
- COSD data set v10.0
- COSD pathology data set v5.0
- schema(s)
- data set user guides
- technical guides

Each regional NDRS office has a nominated Cancer Improvement lead who will help and support any Trust struggling to meet the standard.

COSD upload portal

This is used by Trusts to submit their monthly COSD data submissions. The portal has been designed to improve:

- the accuracy of data received, by providing validations at the point of upload
- the security of data transfer, by removing the need for Trusts to email submissions

- stage completion, by returning a patient level report back to Trusts

Once the submission process is complete via the ‘Submit to registry’ function, all uploaded data is encrypted. The only data that can be seen is the error report and this can only be seen by other people with permission to access your Trust’s data.

Support, training, and testing is available for new users via their regional NDRS Data Liaison Manager, and they can provide you with an in-depth user guidance document for the COSD Upload Portal.

The COSD upload portal can be accessed online, however:

- the submission portal is only available via a N3/HSCN connection
- a portal login is required using a username and password
- all accounts must be created for an individual user rather than any shared account usage

Note:

- currently this is only available for the COSD Patient Pathway xml files

The deadline for submitting a pathology report/record is 25 working days after the end of each month and should only be submitted once the pathologist has finished assessing each sample and authorises the report.

It is acceptable for pathology records to be submitted quicker than 25 working days, and in some cases are submitted in real-time as the pathologist authorises each report using the direct submission method through the NDRS API portal.

Notes:

- find the reporting submission schedule on the COSD data set pages, on the NDRS website
- please contact your local Data Liaison Manager if you have queries regarding the submission process of the data sets

Scope

This is a change to the standard which introduces new data items, removes data items, makes amendments to and re-aligning of data within the current data sets and a revision of the current schema specifications to continue to meet the business objectives of the standard (DAPB1521 Amd 89/2022).

The data set relates to all cancer patients, both adult and paediatric, in acute inpatient and outpatient settings. The trigger for data collection is when a diagnosis, or suspected diagnosis of cancer is confirmed. Primarily this diagnosis takes place within secondary care.

The standard covers neoplasms coded within ICD-10 diagnosis codes range C00 - C97, D00 - D48 and E85.9.

All changes can be found within the published Change Request document.

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 need to collect
- 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 both data sets has been removed and full explanations of how to collect these data within the new structure are provided within the change logs of each data set and accompanying user guides.

Finally, wherever possible, where there were data that are no longer part of a linked Royal College of Pathologists (tumour specific 'Core' data set), these have also been removed from COSD Pathology v5.0.

Implementation and Use

Guidance

This standard, together with the data sets, define the complete set of secondary uses cancer data for reporting and specifies the items which need to be returned directly by NHS Providers.

Provider submissions:

COSD patient pathway data items comprise the subset of the COSD to which the remainder of this specification refers unless otherwise stated. These are the items which are included in the COSD XML schema and are expected to be flowed directly from NHS Providers to the NDRS API.

Pathology:

COSD pathology data items are expected to be collected directly from the pathology department and are identified separately within their own data set. These are items which are essential to compile the full data set but are covered by their own schema and data flow.

Model data flow diagram

The following diagram demonstrates how the full COSD data set will be compiled centrally by local NDRS offices from data flowing from several systems and sources.

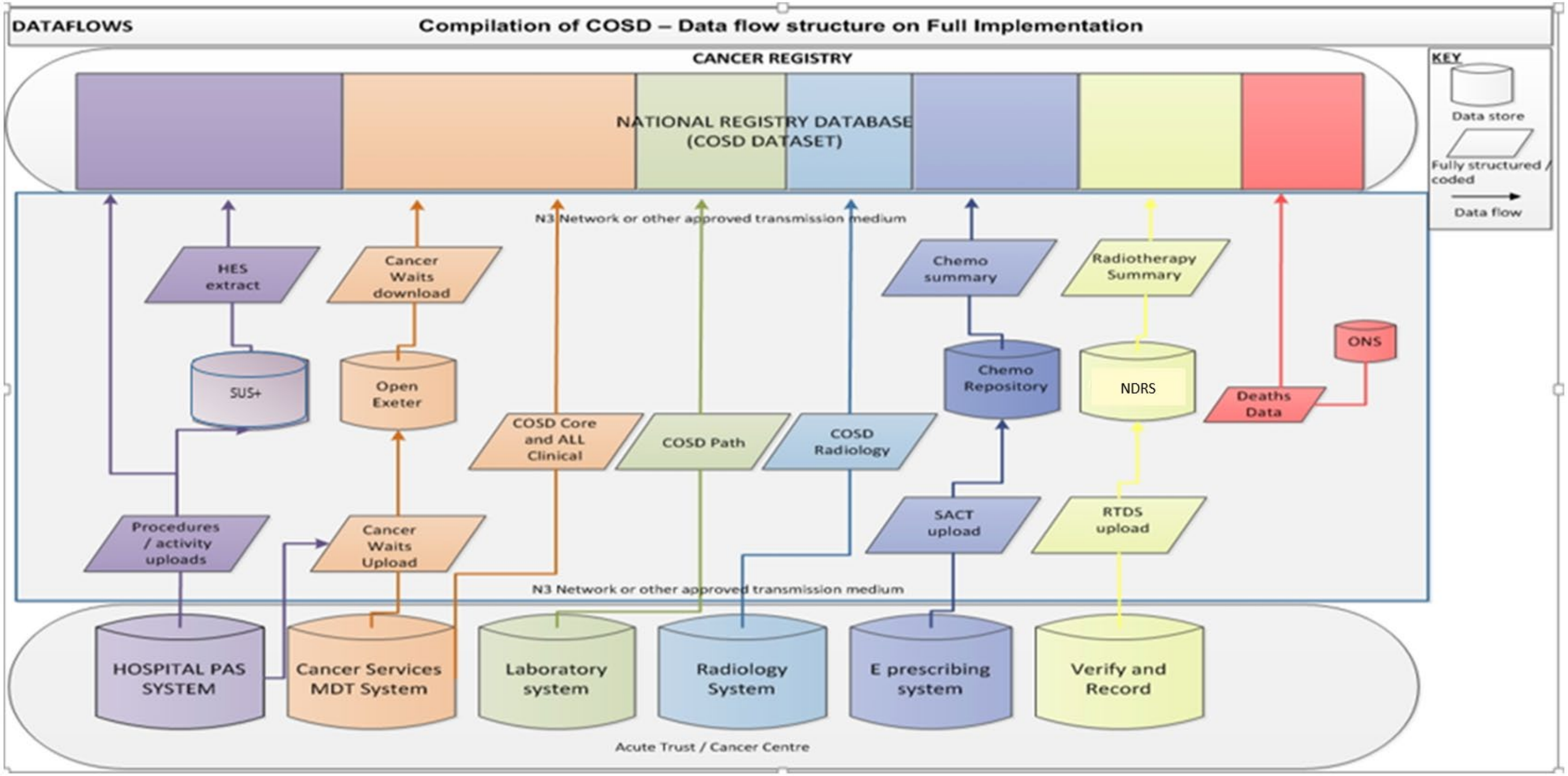

Fig 1: COSD compilation - Data flow structure on full implementation

Structure of data set - Provider Submissions

There is a core data set, of which most data items are applicable to all cancers recorded, and an additional set of site specific data sets, one for each of the thirteen identified tumour groups (as per fig 2). Some of these site specific data sets contain further subsets applicable to individual diseases.

Each recorded case will therefore have a core and usually a site specific data set completed. This would be the same for pathology, where you have a Core and then twelve site specific pathology data sets (as per fig 3).

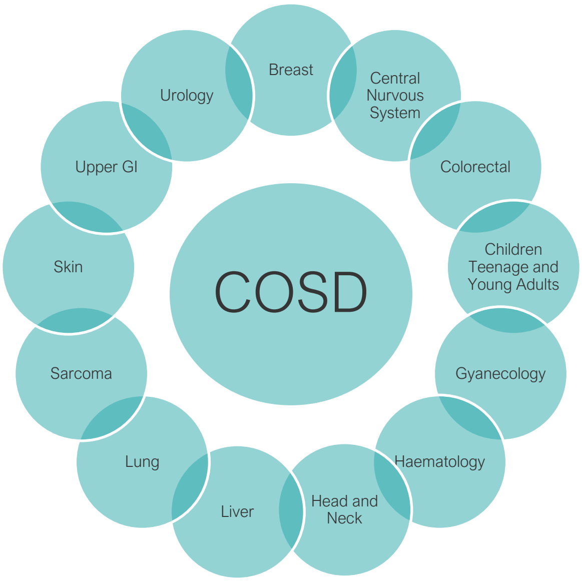

Fig 2: Structure of COSD

Fig 3: Structure of COSD

Data set subsections

Within each of the core and site specific data sets, the data items are further grouped according to their stage along the patient pathway. In both data sets, choices have been introduced to define decisions better and improve data quality. Several data items are mandatory, to improve data quality and prevent records being submitted without enough information to be useful for cancer registration.

The user guides (available as separate documents), provide a clear explanation on data flows for a primary cancer and non-primary cancer pathway. This includes explanations on what is a recurrence, transformation and progression and supporting flow diagrams.

Pathology data items are only able to be reported via the pathology data set and associated schema packs. This is to reduce duplication and errors being reported through the transcription of complex clinical reports into secondary systems.

Governance

Transition to NHSD and NHSE

NDRS transition to NHS Digital (NHSD)

On 01 October 2021 responsibility for the National Disease Registration Service transferred to NHS Digital (NHSD) from Public Health England (PHE). This transfer was part of the government's reforms to the public health system announced in March 2021 and meant that NHS Digital became the data controller for data collected by NDRS under data protection law.

Bringing together NDRS' and NHS Digital' data and technical expertise provided significant benefits for patients, clinicians, and the wider health and social care system.

NHSD transition to NHS England (NHSE)

Building on the huge progress made on digital transformation during the pandemic, NHSD and NHSX have merged into NHS England.

The decision by the Secretary of State for Health and Social Care to accept the recommendations of Laura Wade-Gery, Chair of NHS Digital and a non-executive director at NHS England, was announced on Monday 22 November 2021. Find out more about the Laura-Wade Gery report on GOV.UK.

Responsibility for the NDRS and NHS Digital transferred to NHS England on 01 February 2023.

The impact on COSD

It is important to recognise that the changes to NHS Digital, will have no impact on the COSD data sets. The mandated requirement to submit monthly data remains unchanged.

Information Governance, 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. Consequently, a Clinical Safety Case Report is not required to support the standard.

NDRS is part of NHS England which is an executive agency of the Department of Health and Social Care. The function of NDRS is to fulfil the Secretary of State for Health's statutory responsibilities to protect and improve public health and reduce health inequalities. Running national data collections on a range of diseases, including cancer, is a vital part of this work.

National Disease Registries Directions 2021

The ‘National Disease Registries Directions 2021’ was issued on the 30 September 2021.

This was written on behalf of the Secretary of State for Health and Social Care (the Secretary of State) to provide Directions to the Health and Social Care Information Centre, known as and hereafter referred to in these Directions as NHS Digital, now NHS England.

These Directions are given in exercise of the powers conferred by sections 254(1) and (6), section 260(2)(d), section 261(2)(e) and section 304(9), (10) and (12) of the Health and Social Care Act 2012 (the 2012 Act) and Regulation 32 of the National Institute for Health and Care Excellence (Constitution and Functions) and the Health and Social Care Information Centre (Functions) Regulations 2013 (the Regulations).

The purpose of these Directions (Purpose) is to support the transfer of responsibility for the operation and maintenance of the National Disease Registration Service, which comprises the National Cancer Registration and Analysis Service (NCRAS) and the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS), collectively the National Disease Registries, from Public Health England to NHS Digital as part of the closure of Public Health England and transfer of its functions.

Full details of the Direction can be found on the NHS England’s ‘directions and data provision notices/secretary of state directions’ webpage

Data Provision Notice (DPN)

In addition, the NDRS have a published Data Provision Notice, which covers the following key areas:

- Purpose of collection
- Benefits of collection
- Legal basis for the collection, analysis, publication, and dissemination
- Persons consulted
- Scope of the collection
- Form, Manner, and Timing
- Burden of the collection

This data provision notice covers all the work NDRS does, not just COSD, however provides in-depth advice and information around the legal framework to which the organisation works.

Full details of the DPN can be found on the NHS England’s ‘data provision notices’ webpage.

General Data Protection Regulation (GDPR)

Under General Data Protection Regulation (GDPR) the lawful basis upon which the registry will process personal data is

- UK GDPR Article 6(1)(c) - processing is necessary for compliance with a legal obligation to which the controller is subject (the Directions)

The lawful basis for processing (disseminating) personal data is:

- UK GDPR Article 6(1)(e) - processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller

The conditions which apply to processing (collecting, analysing or disseminating) of special categories of personal data are:

- UK GDPR Article 9(2)(g) - processing is necessary for reasons of substantial public interest, on the basis of domestic law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject, supplemented by:
    - Data Protection Act 2018 Schedule 1, Part 2, paragraph 6: Statutory etc and government purposes
- UK GDPR Article 9(2)(h) - processing is necessary for the… management of health or social care systems and services, supplemented by:
    - Data Protection Act 2018 Schedule 1, Part 1, paragraph 2: Health or social care purposes
- UK GDPR Article 9(2)(i) - processing is necessary for reasons of public interest in the area of public health, supplemented by:
    - Data Protection Act 2018 Schedule 1, Part 1, paragraph 3: Public interest purposes
- UK GDPR Article 9(2)(j) - processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1), supplemented by:
    - Data Protection Act 2018 Schedule 1, Part 1, paragraph 4: *Research etc purposes*

Full details of NHS England's GDPR guidance, can be found on the 'keeping data safe and benefiting the public/gdpr webpage.

NHS Providers

Each Provider is responsible for ensuring the data submitted to the NDRS or submitted through other standard NHS routes is of the highest quality and completeness possible, and accurately represents the service provided.

The NDRS provides a dynamic feedback process from the cancer registration system to Providers. This will allow data quality assurance at a field level - with clinical teams given secure access to the data (via the CancerStats2 portal) that their organisation has submitted.

Technical Architecture

Implementation overview

The COSD standard was reviewed and modified the requirements on NHS Providers to submit monthly cancer data returns to the NDRS by approved NHS secure methods. Providers should therefore have reviewed and revised their previous arrangements to submit monthly returns to their local NDRS office in relation to the timeframe, content, and format of those returns in order to conform to this Specification.

It is recognised that the data items may be recorded in different electronic systems, however it is recommended to send an integrated record of all data items in one file using the xml schemas. This provides the rules for identifying and linking records to enable the data to be processed effectively by the NDRS.

Cancer data returns to the NDRS cover a revised core data set and includes thirteen site specific data sets consisting of data items. These have been identified by Expert Advisory Groups (EAGs) throughout the NHS, as essential for the analysis of outcomes and services of the relevant tumour sites.

Pathology data is no longer reported in the main COSD data set. Instead, these data items form the COSD Pathology v5.0 data set and have been reviewed by the Royal College of Pathologists and mapped to their ‘Core’ data set items.

For COSD v10 and COSD Pathology v5.0, schema packs have been developed within NDRS and are provided via the TRUD website, maintaining consistency.

There is a 6 month implementation period to amend local systems to comply with the new standard (DAPB1521 Amd 89/2022). The full data sets should be submitted using XML format for all new primary, recurrent, metastatic, and secondary cancers.

Providers are therefore expected to update their data extraction processes as per the defined standard. All new extracts should be developed using the XML schema provided as part of the standard. All extracts from MDT management and pathology systems should be submitted in XML.

It is recognised that some changes to pre-existing working practices may be required.

The collection of pathology data direct from the pathology labs, has reduced the burden of data collection on the MDT, thus providing more time to collect the non-pathological data items.

Actions required

NHS Providers will need to:

- identify items in COSD which were previously collected electronically and those that require changes to systems to collect them
- identify electronic source for all data items, this may include (but not limited to): Patient Administration Systems (PAS), Electronic Patient Records (EPR), MDT software systems, pathology, and imaging systems
- identify the items that can be extracted in XML format and submitted by the current NHS compliant methods to the NDRS
- identify data items which are not recorded in XML format but could be submitted in other formats until appropriate electronic software is available
    - this is likely to be pathology data items, which are included in the separate pathology data set

A range of supporting documents are available from the COSD pages on the NDRS website. Additional support is available to Providers from the NDRS Data Liaison Teams.

Data Sources

Data may be recorded in a variety of systems such as MDT software, PAS or EPR's, however it is expected that only a single consolidated record will be submitted using the xml schema.

Submission of Data

Providers will submit the data to the NDRS monthly in XML format, using the current NHS approved standards of submission (see Implementation Guidance for further details).

Format for Submissions

All Trusts are required to submit data from MDT 'Cancer Information Management Systems' and Pathology 'Laboratory Information Management Systems (LIMS)' in the prescribed XML format.

Phased approach to implementation for both data sets

The revised data sets COSD v10.0 and COSD Pathology v5.0 will have a 6 month implementation period for Trusts and suppliers to make and test the changes required throughout the new standard.

Full compliance of the standard must commence by July 2024 at the latest with a phased roll-out from April 2024 (for start of data collection). This is to make allowance for the varied timescales of different software suppliers and in-house developers.

During this three month period, data can be submitted in accordance with either data set as follows:

- COSD v9.0 (schema COSD v9.0.1) or v10.0 (schema COSD v10.0)
- COSD Pathology v4.0 (schema COSD Pathology v4.1.1) or COSD Pathology v5.0 (schema COSD Pathology v5.0)

Data extracts from pathology systems should be submitted in XML and below is a table of compliance for the COSD data sets.

By Date	All Providers
11 Sept 2023	DAPB1521 Amd 89/2022 ISN Publication
11 Sept 2023	Implementation period starts (6 months)
Oct to Dec 2023	Supplier system testing (phase 2)
Jan to Feb 2024	Trust system testing (phase 3)
31 March 2024	Implementation period ends (6 months)
01 Apr 2024	Start of data collection of the COSD data sets
Apr to Jun 2024	Three month roll-out period, to support system developers
01 Jul 2024	Full Compliance of the COSD data sets. July 2024 data would be uploaded in the September 2024 data submission

Working Practices

The implications of the data standard to data providers are as follows:

- all NHS Providers and system suppliers need to include the new and changed data items in their electronic systems
- these organisations may need to amend their transmission methods to enable the new and changed data items to flow and be centrally collated by the NDRS
- there may be training implications for staff given changes to data item definitions or the implementation of new data items
- provider multi-disciplinary teams may need to adjust their previous processes for capturing data, to include all the data items in the monthly extracts and ensure accuracy of clinical items

Implementation Guidance

Implementation guidance has been developed to support users, organisations, and systems suppliers to implement the standard. Versions of the documentation are available on the NHS England standards website.

New COSD user guides have been developed to support the publication of the latest version changes and are available on the COSD pages of the NDRS website.

Contact Details

Information, including the COSD data sets, technical guides and user guides are available on the NDRS website.

Queries regarding this document should be addressed to:

- nhsdigital.cosdenquiries@nhs.net

Queries regarding submissions should be discussed with the NDRS Regional Liaison Managers. Contact emails and telephone numbers are available on the NDRS website.

Appendix A - Glossary of Terms

The following is a glossary of terms which relate to and are referenced within this specification document. The term is followed (in brackets) by the acronym, then below is the definition, in some cases there are hyperlinks to websites for additional information:

Burden

The Data Standard Assurance Service (DSAS) team within NHS England, assess the burden on the NHS of all data collections as per the Health and Social Care Act 2012. Anyone who collects data on a national scale from the service, needs to go through the burden process to gain approval to collect the data.

Cancer

For the purposes of this standard the term ‘cancer’ is used throughout the standard and related documents to cover all conditions defined by the World Health Organization (WHO) and International Agency for Research on Cancer (IARC) Classification of Tumours.

Cancer Centres

Organisations which help people to live with, through and beyond cancer by bringing together specialist clinical and professional staff and communities of support.

Cancer Outcomes and Services Data set (COSD)

COSD is the national standard for reporting cancer in the NHS in England. It replaced the previous National Cancer Data set and includes the former Cancer Registration data set and additional site specific data items relevant to the different tumour types.

Cancer Registries

Organisations which exist internationally to collect, process, analyse and disseminate data on cancer patients in their local regions.

Cancer Stats Portal

Online resource that allows Trusts to review specific cancer data.

Care Quality Commission (CQC)

One of the independent regulators of health and social care in England.

Commissioners

Organisations that plan, purchase, and monitor services to meet the health needs of their local population.

Diagnostic Imaging Data set (DIDS)

Data set containing diagnostic imaging test activity across the NHS, taken from Radiology Information Systems. (See SCCI Standard 1577).

Expert Advisory Groups (EAGs)

A group of experts (at tumour site level) who advise NDRS on what data needs to be collected and what analyses conducted.

Extensible Markup Language (XML)

Extensible Markup Language (XML) is a set of rules for encoding documents in machine-readable form.

Information Standard Notice (ISN)

A document containing standards that relate to the processing of information.

International Statistical Classification of Diseases and Related Health Problems (ICD)

A medical classification list for the coding of diseases, signs and symptoms, abnormal findings, complaints, social circumstances and external causes of injury or diseases, as maintained by the World Health Organization (WHO). The title is followed by the revision number. For example, ICD10 is the tenth revision.

International Classification of Diseases for Oncology (ICD-O)

An extension of the ICD coding system used principally in tumour or cancer registries for coding the site (topography) and the histology (morphology) of neoplasms. The title is followed by the revision number. For example, ICD-O-3 is the third revision.

MDT Coordinator

The Multi-Disciplinary Team (MDT) coordinator is the person(s) responsible for facilitating the MDT meeting. They also have additional duties for collecting and recording information on patients as they pass through the Provider Trust, whilst on a cancer pathway. Sometimes known as a Patient Pathway Coordinator.

National Cancer Registration and Analysis Service (NCRAS)

The NCRAS is responsible for collecting cancer data from all NHS Providers of cancer care in England. The NCRAS is a function within the National Disease Registration Service within NHS England.

National Cancer Waiting Times Monitoring Data set (NCWTMDS)

The Information Standard (DCB0147) used to monitor the time that patients with suspected and diagnosed cancer have wait for appointments, tests, and treatments. This is generally referred to as CWT.

National Disease Registration Service (NDRS)

The NDRS is part of NHS England which comprises the National Cancer Registration and Analysis Service (NCRAS) and the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS).

NHS Digital (NHSD)

NHS Digital has now merged with NHS England.

NHS England (NHSE)

NHS England is an executive non-departmental public body (NDPB) of the department of Health and Social Care. NHS England provides national leadership for the NHS. they promote high quality health and care for all, and support NHS organisations to work in partnership to deliver better outcomes for patients and communities, at the best possible value for taxpayers and to continuously improve the NHS.

Office of National Statistics (ONS)

The UK's largest independent producer of official statistics and the recognised national statistical institute of the UK.

Providers

Organisations that provide health services.

Radiotherapy Data Set (RTDS)

A standard data set covering every patient treated with radiotherapy in the NHS in England.

Systemic Anti-Cancer Therapy Data Set (SACT)

The national collection of all cancer systemic anti-cancer therapy data in the NHS in England, which covers all solid tumour and haematological malignancies.

The Royal College of Pathologists (RC Path)

A professional membership organisation committed to setting and maintaining professional standards and to promoting excellence in the practice of pathology.

XML schema

The documentation, definitions and descriptions required to enable the production and transmission of data for a specific XML.

Appendix B - Mandatory Registerable Conditions

ICD 10	Description of neoplasm
C00 - C97	All malignant neoplasms
D00 - D09 (excluding D04)	All carcinoma in-situ (excluding all D04 in-situ skin cancers)
D32 - D33 D35.2 & D35.3 D35.4	Benign neoplasms of brain & other parts of nervous system Benign neoplasms of pituitary gland & craniopharyngeal duct Benign neoplasms of pineal gland
D37 - D48 (excluding D47.2)	All neoplasms of uncertain behaviour Neoplasms of unspecified nature of bladder Neoplasm of unspecified nature of brain Neoplasm of unspecified nature of other parts of nervous system & pituitary gland only (Excluding D47.2 Monoclonal gammopathy of undetermined significance (MGUS))
E85.9	Primary Amyloidosis

Notes:

- although Primary amyloidosis (E85.9) is listed as an E ICD code in the World Health Organisation (WHO) disease classification, amongst clinicians it is widely acknowledged and subsequently treated as a cancer, receiving Chemotherapy in cases
- COSD User Guide has a full list of Mandatory Registerable Conditions, this can be accessed via the NDRS website

Appendix C - 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 4:
- NDRS, COSD webpage - https://digital.nhs.uk/ndrs/data/data-sets/cosd
- ISN publications - http://digital.nhs.uk/isce/publication/dapb1521

Page 6:
- Long Term Plan - https://www.longtermplan.nhs.uk/

Page 9 (Supporting documents):
- ISN publications - http://digital.nhs.uk/isce/publication/dapb1521

Page 10 (Supporting documents):
- 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 10 (Related Standards):
- Cancer Waits - https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/dcb0147-national-cancer-waiting-times-monitoring-data-set
- RTDS - https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/dapb0111-radiotherapy-data-set
- SACT - https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/dcb1533-systemic-anti-cancer-therapy-data-set
- Diagnostic Imaging - https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/scci1577-diagnostic-imaging-data-set
- ICD - https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-

collections/scci0021-international-statistical-classification-of-diseases-and-health-related-problems-icd-10-5th-edition

- SNOMED CT - https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/scci0034-snomed-ct
- Sexual Orientation Monitoring - https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/dcb2094-sexual-orientation-monitoring
- RCPath - https://www.rcpath.org/profession/guidelines/cancer-datasets-and-tissue-pathways.html

Page 12:

- CancerStats2 portal - https://cancerstats.ndrs.nhs.uk/
- Cancer Data - https://www.cancerdata.nhs.uk/

Page 14:

- COSD upload portal - http://nww.api.encore.nhs.uk/
- Submission schedule - https://digital.nhs.uk/ndrs/data/data-sets/cosd#submission-schedule

Page 15:

- Change Request document - http://digital.nhs.uk/isce/publication/dapb1521

Page 19:

- Laura-Wade Grey report - http://www.gov.uk/government/news/major-reforms-to-nhs-workforce-planning-and-tech-agenda
- 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 20:

- NDRS Directions - https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notices/secretary-of-state-directions
- DPN - https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notices/data-provision-notices-dpns

Page 21:

- GDPR guidance - https://digital.nhs.uk/data-and-information/keeping-data-safe-and-benefitting-the-public/gdpr

Page 24:

- COSD supporting documents - https://digital.nhs.uk/ndrs/data/data-sets/cosd

Page 25:

- Implementation Guidance - http://digital.nhs.uk/isce/publication/dapb1521

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- COSD User Guides - https://digital.nhs.uk/ndrs/data/data-sets/cosd

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- COSD supporting documents - https://digital.nhs.uk/ndrs/data/data-sets/cosd
- COSD contact details - https://digital.nhs.uk/ndrs/data/data-sets/cosd

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- WHO - https://whobluebooks.iarc.fr/
- CQC - https://www.qcs.co.uk/

Page 29:

- Diagnostic Imaging - https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/scci1577-diagnostic-imaging-data-set

Page 30:

- Cancer Waits - https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/dcb0147-national-cancer-waiting-times-monitoring-data-set
- NHS England - https://www.england.nhs.uk/
- RTDS - https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/dapb0111-radiotherapy-data-set

- SACT - https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/dcb1533-systemic-anti-cancer-therapy-data-set

Page 32

- Mandatory Conditions - https://digital.nhs.uk/ndrs/data/data-sets/cosd#downloads