NDRS
NATIONAL DISEASE REGISTRATION SERVICE

NHS England

Cancer Outcomes and Services Data set (COSD)

User Guide v10.2.12 Final

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

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NATIONAL DISEASE REGISTRATION SERVICE

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

NHS England

For queries relating to this document, please contact:
NDRSenquiries@nhs.net

Contents

Version Control

Version	Date	Brief Summary of Change	Editors
Version 10.0.1 Final	08 September 2023	– new draft user guide to support COSD v10.0.1 (DAPB1521 Amd 89/2022)	Andrew Murphy
Version 10.2.0 Final	20 March 2024	– corrected Topography ICD-O-3 guidance on decimal point (pg68) – updated, Haematological - Cancer care plan – Choices 4, 6 + 7 (pg197) – updated Lung - Cancer Care Plan - Bronchoscopy Performed Type (pg233-234)	Andrew Murphy
Version 10.2.1 Final	13 June 2024	– Minor updates and corrections across user guide	Andrew Murphy
Version 10.2.2 Final	22 July 2024	– Addition important notes covering borderline tumours of the ovary (pg187)	Andrew Murphy
Version 10.2.3 Final	09 August 2024	– Minor updates and corrections across user guide	Andrew Murphy
Version 10.2.4 Final	17 September 2024	– Additional registrable conditions & Appendix H ‘scenario 5’ updated	Andrew Murphy
Version 10.2.5 Final	08 October 2024	– Update to advice around defined sarcoma tables SA11000 (pg241) and SA11080 (pg243)	Andrew Murphy
Version 10.2.6 Final	31 January 2025	– Updated advice for recording CNS contact for Breast patients (pg155)	Andrew Murphy
Version 10.2.7 Final	12 February 2025	– Added new online calculator for Binet stage for CLL (pg201)	Andrew Murphy

Version 10.2.8 Final	20 March 2025	– Updated advice around recording COSD records, where clinically a disease progresses, but requires a new 'primary cancer' record to be recorded within COSD (pg13-14)	Andrew Murphy
Version 10.2.9 Final	30 July 2025	– Updated advice when a Trust uses Bronchoscopy using robotic assistance (procedure), SNOMED CT code (pg236) – Updated Appendix A-E + I URLs (pg297-308)	Andrew Murphy
Version 10.2.10 Final	10 November 2025	– Updated 'Date First Seen (Cancer Specialist)', advice on when to use this data item and new validations being applied on the NDRS API upload portal (pg51-52)	Andrew Murphy
Version 10.2.11 Final	02 June 2026	– Updated CNS guidance (pg87) – Updated Physical Activity (Current) guidance (pg90-92) – Updated HNA and PCSP guidance (pg93-102)	Andrew Murphy
Version 10.2.12 Final	02 July 2026	– Update to CancerStats2 closing and the new NDRS data quality and insight hub (pg297)	Andrew Murphy

Executive summary

This User Guide is one of a suite of documents to aid users in implementing the COSD Information Standard (DAPB1521 Amd 89/2022). It includes all the data items in COSD, together with definitions, formats, codes and values and additional guidance on collection and implementation. Find more COSD documents in the data sets section on our website.

This User Guide is aligned with and should be read in conjunction with version 10.2.1 Final of the data set, published in the data sets section of our website.

The main aim of this revision was to reduce the burden of data collection wherever possible on frontline staff. This in turn has allowed us to remove 77 data items, with a net reduction of 15%. These regular reviews are having a huge effect on the 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 is something we need to be proud of, but there is still more work needed in v11 to maintain COSD as the leading data collection of cancer data in England.

This revised version of the data set also incorporates amendments to the data set itself and a revision of the current schema specification, in-order-to continue to meet the business objectives of the standard. It accompanies a change notice for the standard (Amd 89/2022) which has been accepted by the Data Alliance Partnership Board (DAPB).

Implementation of the Standard is carried out by the National Disease Registration Service (NDRS) and queries regarding implementation should initially be raised with the Data Liaison staff at your local NDRS office.

A COSD Advisory Board including Trust level representation continues to help manage change and reports directly to the COSD Governance Board. The purpose and remit of the COSD Advisory Board, is to review and assess proposed changes to COSD, and make recommendations to the COSD Governance Board for further discussion and consideration before approval or rejection of any change request is made.

The COSD Advisory Board ‘s role is to understand and balance the effect of any changes to the data sets within NHS Trust organisations collecting, quality assuring and reporting high quality cancer data, but also the impact of change on the NDRS functions, and other users of the data.

The COSD Governance Board is made up of an independent chair, the COSD data set Senior Responsible Officer, the COSD data set development sponsor and senior managers from NDRS and from Cancer Alliances. In addition, the NHSE National Clinical Director for Cancer is an advisor to the Governance Board and kept informed by attending meetings or receiving official board minutes and consults on relevant topics.

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 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 was then 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 National Disease Registration Service and NHS Digital transferred to NHS England on 01 February 2023.

The impact on COSD

We would like to confirm that the changes to NHS Digital, will have no impact on the COSD data sets. Submissions of your monthly data will remain unchanged, and we will keep you updated on any developments going forward.

All Trusts should be running the latest version of COSD by 01 July 2024.

Please contact your Regional Liaison Manager if you're having difficulties.

Collecting and submitting COSD data

What is COSD?

The Cancer Outcomes and Services Data set (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 COSD data sets relate to all cancer patients, both adult and paediatric, in acute inpatient and outpatient settings delivered or commissioned by the NHS.

Providers of cancer services have been required to provide a monthly return on all cancer patients diagnosed from 01 January 2013 using this data set. Data are processed via the National Cancer Registration and Analysis Service (NCRAS) local offices, and formal mechanisms for transmission of data from Providers to NCRAS have been extended to carry the COSD data set.

More information can be found on the change specification, requirements specification and implementation guidance on the NHS England website.

Find out more on COSD on the data set pages of the NDRS website.

Why is it needed?

Periodically we needed 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.

What is included in the COSD data collection?

The COSD specifies the data items that need to be recorded for all cancer patients by the NHS in England. This includes all the items that Providers should submit monthly via direct electronic feeds to the NDRS.

These items can be submitted from different systems such as Cancer Management Information System software, Patient Administration Systems (PAS) and Pathology Laboratory Information Management Systems (LIMS).

Whilst some of these items are generic, there are also several site-specific items that are required to record and analyse services and outcomes. These items are also required locally by service providers for patient management and clinical care.

This guide provides a description of the data items, the tumour sites or disease types to which they apply, and any further information needed to collect them.

Some items in the COSD can be submitted through other standard NHS routes, such as Cancer Waiting Times. However, key items such as treatment details, need to be submitted for both.

Data from all sources, whether direct Provider submissions from other national collections or derived from other sources, are linked by the NCRAS at patient and tumour level using NHS Number to complete the full data set.

Read more about COSD data collection in the COSD Technical Guidance.

Which diagnoses does COSD apply to?

For the purposes of COSD the term ‘cancer’ relates to all conditions defined as registerable by the UK and Ireland Association of Cancer Registries (UKIACR) and these are listed in Appendix B.

These are in addition to Appendix A – Cancer Waiting Times ICD10 Codes and Tumour Groups for Primary Diagnoses. COSD requires that all new diagnoses and secondary/metastatic cancers are recorded.

Throughout COSD, we ask for a variety of tumours to be recorded. Cancer Waits (with the exclusion of Breast Cancer) excludes these from their collection, however we ask for many non-invasive cancers, you may have heard these described as ‘in-situ’, ‘benign’ or ‘Neoplasms of unknown or uncertain behaviour’.

For COSD, it’s important to distinguish that the collection of registerable conditions is not about the management of the patient, but how data is collected and analysed. When a

patient is managed clinically within the Trust, we accept that clinically 'pTa' to 'pT1' (non-invasive to invasive) bladder tumour, for example, is a progression of the disease.

However, for COSD, progression is specifically related to progression of cancers. pTis and pTa tumours are not malignant tumours (as defined by the WHO Classification of Tumours), so the progression fields do not apply. Therefore, where this happens, we would expect a new 'Primary Cancer' record to be created for the invasive disease.

It must also be noted that if new episodes were not submitted for pT1 tumours following a previous pTa (or pTis) tumour in the bladder, the number of urological malignancies recorded at the Trust would be underestimated and not included in national statistics.

The same assumptions and process must also be followed for any 'in-situ' or 'non-invasive' cancer for any disease type or group when recording data within COSD.

All recurrences diagnosed at each Trust must now also be included, using the non primary cancer pathway route.

What data items should be completed?

All registerable conditions should be reported as defined in Appendices A and B. This includes submitting all pathology reports for these cases.

For Non-Melanoma Skin Cancer's (NMSC) that do not require discussion at MDT, only pathology reports are required to be included in the submitting organisation's monthly pathology feed to the NCRAS. No other information needs to be submitted for COSD.

Note:

- please refer to the 'Skin' section for more information and definition of tumours that fall under the NMSC header

For all other new cases (as a minimum) the core data set should be completed, including all applicable data items. In addition to the core data set, most cases will also require a site-specific data set to be completed.

For under 25's, there may be 2 'site-specific' data sets completed (CTYA and disease specific), depending on the nature of the disease and where the patient is treated. Please see the 'CTYA' section of this Guide for further details. Wherever possible the burden of data collection has been reduced by assigning CTYA data items to their parent 'Site Specific Tumour Group'.

How is pathology collected?

There is a separate data set and schema for reporting pathology data items. These data should be reported by the pathologist, directly from their Laboratory Information

Management Systems (LIMS) and sent monthly to the NCRAS (from the pathology department) in structured COSD XML.

It is not expected therefore that MDT Coordinators or other non-clinical staff, should attempt to read and transcribe these reports and information into COSD. To support this commitment in reducing the burden of data collection, all pathology data items were removed from COSD v9 and only available in the COSD Pathology data set.

The reduction in their workload by removing this duplication was estimated to be up-to 30%, this in addition to the 15% reduction in v10 has almost halved the burden of data collection on the cancer services teams. This time should be used to ensure full compliance for data collection across all other data-items. This workload reduction has been evidenced in the Burden Advice and Assessment Service submissions as part of the data set review process.

When should data be submitted?

The deadline for first submitting a record is 25 working days after the end of month of diagnosis. All available relevant data items should be included and additional information or updates not available at the time should be uploaded with ensuing monthly submissions. Treatments not submitted with the initial record should also be submitted within 25 working days of the end of month of the Treatment Start Date.

It is important to note that COSD and CWT are no longer being reported on the same day. CWT have reduced the reporting time following the end of each month, whereas (due to the size and complexity of the data), COSD will continue to use the full 25 working days.

The reporting submission dates can be found on the data sets section of this website.

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

Notes:

- currently this is only available for the COSD Patient Pathway xml files
- please contact your local Data Liaison Manager if you have queries regarding the submission process of other cancer data sets

How to record recurrence, progression, and transformations

What is a recurrence?

Cancer recurrence can be defined as the return of cancer after treatment and after a period during which the cancer cannot be detected. The length of time is not clearly defined; however, the patient would have previously been informed that they are free of the disease or that the disease is not detectable. The same cancer may come back where it first started or somewhere else in the body. For haematological malignancies, recurrence may be more commonly referred to as a relapse.

What are the types of recurrence?

The distinction between the types of recurrence of a previously treated tumour requires clinical interpretation. There are different types of cancer recurrence, for example:

- local recurrence - meaning that the cancer has come back in the same place it first started
- regional recurrence - meaning that the cancer has come back in the lymph nodes near the place it started
- distant recurrence - meaning the cancer has come back in another part of the body, some distance from where it started (often the lungs, liver, bone marrow, or brain)

What is progression?

When cancer spreads (increased growth speed) or gets worse it is called progression. Sometimes it is hard to tell the difference between recurrence and progression. A recurrence is where a patient has previously been informed that they are free of the disease or that the disease is not detectable. Progression of a disease is where this has not happened and may be during the initial treatment phase.

What is metastatic/secondary tumour?

Metastasis or metastatic disease is the spread of cancer from one part of the body to another.

Distant metastases are tumour cells that have spread from the primary tumour and formed as distant growth in a different organ.

Notes:

- patients can present with metastatic disease with either a new primary, progression, or recurrence

- patients should be recorded as a new primary, recurrence or progression with the distant metastatic type/site identified

Can someone have a metastatic tumour without having a primary cancer?

No. A metastatic tumour is always caused by cancer cells from another part of the body. In most cases, when a metastatic tumour is found first, the primary cancer can also be found.

However, in some patients, a metastatic tumour is diagnosed but the primary tumour cannot be found. These cases are referred to as unknown primaries or occult (hidden) cancers, and the patient is said to have a cancer of unknown primary origin (CUP).

Such cases should not be recorded as a recurrence, but as a primary cancer of an unknown origin with metastatic type and site at diagnosis recorded. For the recording of unknown primary cancer, please refer to NICE guidance using this link.

What is a transformation?

A transformation is recorded where there is a change in the cancer type (morphology). This could be during initial diagnosis or treatment or can occur after an undefined period following initial diagnosis.

If a disease transforms from an in-situ cancer or non-invasive lesion (including non-invasive urothelial carcinoma) to a new primary invasive lesion, this must be recorded as a new primary diagnosis of cancer and not a transformation.

What is remission?

A remission is a term that is given when the disease cannot be detected in the body after first treatment is given. A remission can be temporary or permanent and does not need to be recorded within COSD.

Haematological recurrence (relapse)

Haematological cancers do not spread the same way as solid tumours and therefore the collection of metastatic type and metastatic site is not required. In addition, the term ‘relapse’ is often used to describe patients who have worsening disease. It is for the clinical teams locally to decide which is the most appropriate category to use for their haematological patients, such as recurrence, progression, or transformation.

Head and neck cancer

For head and neck cancer, there are incidences of second primary cancers that develop at the primary site due to mucosal field change. The distinction between a recurrence of

a previously treated tumour and a second primary requires clinical interpretation in making this distinction.

A referral flow chart/decision tree on 'How to determine what pathway to record', has been developed and displayed below to help support MDT Coordinators and cancer services teams.

Pathway flows for new primary, recurrences, progressions, or transformations

Data can be recorded in COSD using one of 2 distinct pathways, as per the patient flow diagram 1 below. Depending on the data type, you would record these in either:

- the 'Primary Cancer Pathway'
- the 'Non-Primary Cancer Pathway'

Option 1:

- new primary diagnosis
- progression
- transformation

Option 2:

- recurrence
- progression
- transformation

A decision can either be recorded on a 'Primary Cancer Pathway' or a 'Non Primary Cancer Pathway' as follows:

- all 'New Primary Cancer' diagnoses – create a new record on a Primary Cancer Pathway
- all 'Recurrence' diagnoses – create a record on a Non-Primary Cancer Pathway

'Progression' and 'Transformation' diagnoses, either:

- record the information on the existing 'Primary Cancer Pathway' (where the original diagnosis is already on the system)
- create a new record on a 'Non-Primary Cancer Pathway' (if you do not have an existing cancer record on your system, but the patient was diagnosed with cancer at another hospital)

Option 1

For all 'New Primary Cancer' diagnoses, create a new record on a Primary Cancer Pathway and include:

- the 'Primary ICD10'
- the 'Tumour Laterality'

- the ‘Primary Diagnosis Date’

Then continue by adding as much detail to the record as possible, using the ‘Core’ and/or ‘Site Specific’ data items.

For all 'Progression' diagnosis, add progression details on the existing ‘original’ diagnosis including:

- the ‘Date of Progression’
- the ‘Metastatic Type (local, regional or distant)’
- the ‘Metastatic Site’

For all 'Transformation' diagnosis, add transformation details on the existing ‘original’ diagnosis including the ‘Date of Transformation’.

Note:

- additional 'site-specific items' may also be required as applicable to the tumour diagnosed; these are required only for the primary pathway

Option 2

For the Non-Primary Pathway, there is a choice of 3 options – recurrence, progression, or transformation, but only one should be used for each pathway/record submission.

For all 'Recurrence' diagnosis, create a new record for recurrence and include:

- the date of the non-primary diagnosis (note: this is the diagnosis date of the recurrence)
- the original ‘Primary ICD10’ diagnosis
- the ‘Metastatic Type’ (local, regional or distant)
- the ‘Metastatic Site’
- the ‘Palliative Care Specialist Seen Indicator (Cancer Recurrence)’
- Relapse - Method Of Detection

For all 'Progression' diagnosis. create a new record for progression and include:

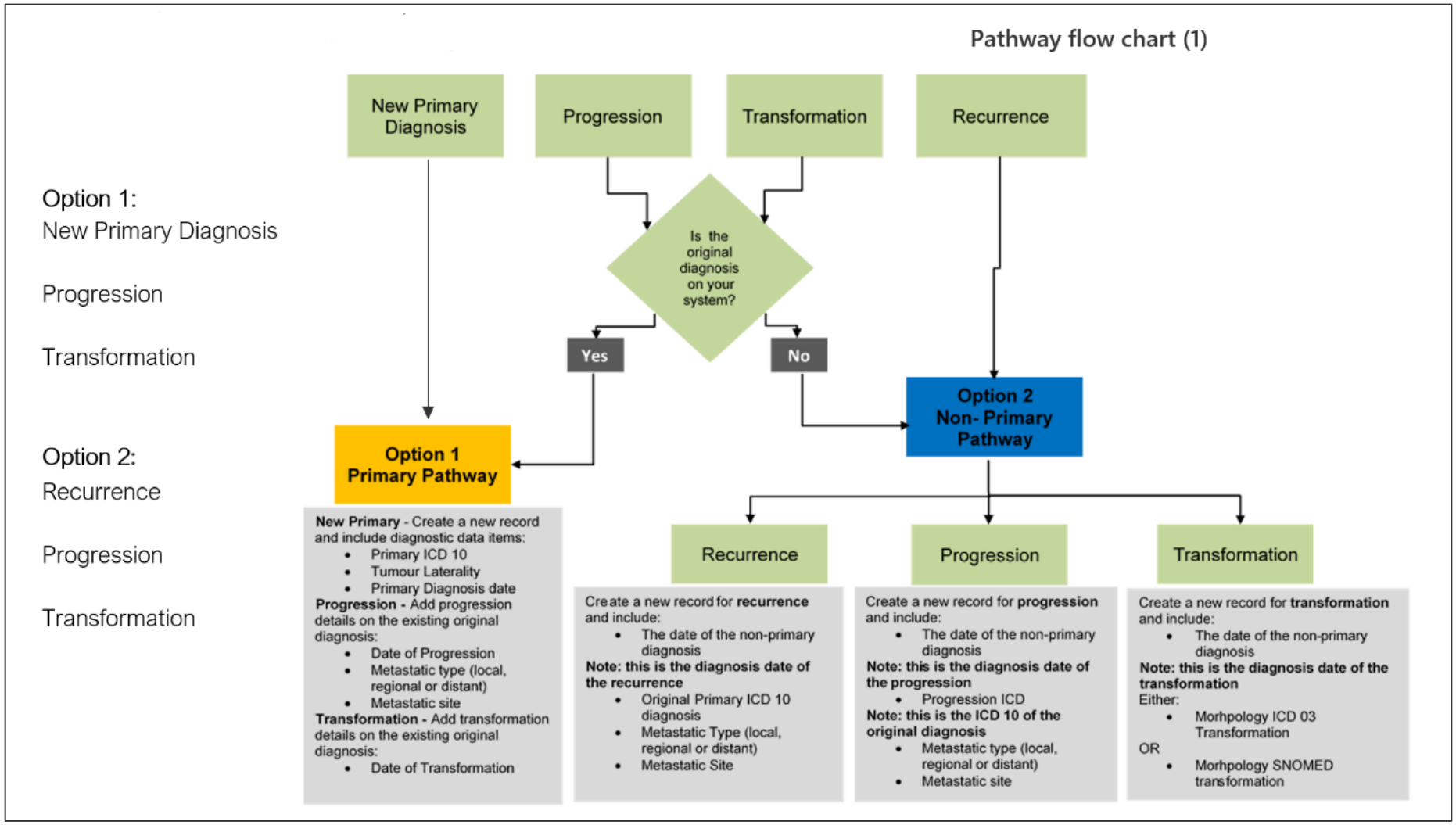
- the date of the non-primary diagnosis (note: that this is the diagnosis date of the progression)
- the ‘Progression ICD’ diagnosis (the ICD10 of the original diagnosis)
- the ‘Metastatic Type’ (local, regional, or distant)
- the ‘Metastatic Site’

For all 'Transformation' diagnosis, create a new record for transformation and include the date of the non-primary diagnosis (note: this is the diagnosis date of the transformation), plus (if known), either:

- the ‘Original Morphology ICD-O-3’ of the transformation
- or the ‘Original Morphology SNOMED’ of the transformation

Pathway flow chart 1

The image below shows the pathway flows for new primary, recurrences, progressions, or transformations. The text in the flowchart is also published in the body text of this page.



Pathway data flow

The flow of data required for each pathway is highlighted below, including the primary, non primary and shared patient pathway data items. There may also be additional data required through the site-specific sections.

Important notes:

- although there are shared sections, it is not expected that all data are submitted for every case
- only those that are applicable to each patient and their pathway (at that time) should be submitted
- all items in each group would be expected on pathways submitted through COSD (if applicable to the patient, their tumour and designated local pathway)

Primary Pathway

- Core – Diagnostic – Primary Cancer Pathway Details
- Core – Referrals and First Stage of Patient Pathway
- Core – Diagnosis
    - Diagnosis Additional items
    - Diagnosis Progression
    - Diagnosis – Transformation
- Core – Staging (where applicable)
- Core – Site Specific Staging (where applicable)
- Any site specific data items that are applicable to the patient, their diagnosis and/or treatment pathway

Non Primary Pathway

- Core – Diagnostic - Non Primary Cancer Pathway Details - Choice
    - Recurrence
    - Transformation
    - Progression
- Core – Diagnostic - Non Primary Cancer Pathway - Referral

Shared Sections

- XML Headers
- Record Identifier
- Core – Patient Identity Details
- Core – Demographics
- Core – Imaging
- Core – Diagnostic Procedures
- Core – Person Observations
- Core – Clinical Nurse Specialist + Risk Factor Assessment

- Core – Clinical Nurse Specialist - Holistic Needs Assessment and Personalised Care and Support Planning
- Core – Multidisciplinary Team Meetings
- Core - Cancer Care Plan
- Core – Treatment
    - Treatment – Surgery
- Core – Acute Oncology
- Core – Laboratory Results
    - Laboratory Results – General
- Any site specific data items that are applicable to the patient, their diagnosis and/or treatment pathway

Key to data tables and ICD-10 codes

Key to data tables

All data items are listed as follows:

Data Item Number	The reference number for the COSD data item
Data Item Section	The section in which the data item appears
Data Item Name	The name of the data item. Please refer to the data set and/or schema for the data dictionary names
Format	Format required for submission of the data item
Schema specification (M/R/O/P)	The detailed schema for submission of the data is included in the Technical Guidance. This column identifies whether items are required for the extract to pass validation rules when submitted in XML format. M – Mandatory R – Required, but is not required to validate the submitted record O – Optional P – Pilot Notes: • items in the 'Core Linkage' section are Mandatory and must be included for the record to pass validation • all applicable data should be submitted as soon as possible
Moved data items	All data items that have moved within the data set since the last version will be indicated using bullet points following each data item description.

Schema specification

Mandatory

The 'Core – Linkage' items are mandatory and must be submitted for all records. It is vital that these are always available so that the correct information can be linked to the right patient and the correct tumour. A record will not be able to be submitted if any mandatory data item is missing. These records should not be added to the main file otherwise the whole file will fail the schema.

In some cases, certain data items have been made mandatory within sections to improve the quality of the data submitted. In these cases, no data within that section can be

submitted without these mandatory data items being completed. The sections however are required; therefore, a missing section will not affect the submission of all other data.

Required

Most other data-items are set as 'Required'. This means that if they are applicable to the reported tumour or patient pathway, they must be completed and treated as a mandatory item. Not every data-item however will be applicable to every patient, tumour, or treatment pathway. By using 'Required', this allows for a more accurate and inclusive collection of data. Therefore, all applicable data in each section marked as 'required' must be submitted for each record as soon as available.

Pilot

In some cases, new data-items maybe piloted by a small group of Trusts. These data do not have to be completed by any other Trust unless you are part of the pilot. If you want to submit these data, please speak with your regional NDRS liaison team(s). All pilot data-items are under review and may change in future version controls of COSD.

Note:

- there is only 1 new data-items being piloted by Trusts in v10

Optional

Optional data items can be submitted by any Trust, but there is no requirement to enforce this data collection at this point. All optional data-items are under review and may change in future version controls of COSD.

Note:

- there are no optional data-items in v10

Meaning of 'Not known' value

'Not known' includes both 'not recorded' and for example 'test not done'. This is usually coded 9 or 99 (depending on the data item format).

ICD10 codes

The core data items should be collected for all cancers and other registerable conditions where applicable. See Appendices A to C for links to the full lists of ICD10 codes.

For diagnoses not included in the site-specific data sets, the core items only should be completed. For some registerable conditions only, pathology reports will be available at presentation – for example, BCC.

D04.0-D04.9 (Carcinoma In-Situ of the Skin) are not required to be collected and submitted through COSD as they are not registerable conditions.

Notes:

- ICD-11 will not be included in this version change for COSD
- however, it is under advisement and will be included in later versions, under the guidance from NHS England

List of Registerable Diseases

The ICD10 disease code lists for all registerable conditions (C & D codes) are provided in Appendices A and B. The Haematological ICD-O-3 codes list can be found within the Haematology section ICD codes and WHO disease groups.

Core - Linkage

Data linkage

These items are mandatory for every record, to enable NCRAS to accurately link patient records. To ensure that records submitted can be linked appropriately, key data fields must be completed for each record submitted.

There will be one linkage section completed each time the record is submitted.

Primary identity details

Must be one occurrence per record (1..1).

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR0010	NHS Number	n10	M*
CR0020	Local Patient Identifier	min an1 max an20	M*
CR1350	NHS Number Status Indicator Code	an2	M
CR0100	Person Birth Date	an10 ccyy-mm-dd	M
CR0030	Organisation Identifier (Code of Provider)	min an3 max an5	M

* A combination of either 'NHS Number' and/or 'Local Patient Identifier' are mandatory for the schema. Both can be submitted, but a record cannot be submitted without at least one of these data items.

NHS Number

The 'NHS Number' is a unique identifier for a patient within the NHS in England and Wales. This will not vary between any organisations of which a person is a patient.

Notes:

- almost all patients should have an NHS Number, and this should always be included where available
- for those who do not have an NHS Number, the hospital number (Local Patient Identifier) must be provided

Local Patient Identifier

For linkage purposes, 'NHS Number' and/or 'Local Patient Identifier' are required. This is a number used to identify a patient uniquely within a health care provider. It may be different from the patient's case note number and may be assigned automatically by the computer system.

NHS Number Status Indicator Code

The NHS Number or Status Indicator Code indicates the verification status of the NHS number provided.

National Code	National Code Definition
01	Number present and verified
02	Number present but not traced
03	Trace required
04	Trace attempted - No match or multiple match found
05	Trace needs to be resolved (NHS number or patient details conflict)
06	Trace in progress
07	Number not present and trace not required
08	Trace postponed (baby under 6 weeks old)

Person Birth Date

The date on which a person was born or is officially deemed to have been born. This should be automatically linked via your local PAS or EPR system when you create a record for the first time.

Organisation Identifier (Code of Provider)

The ‘Organisation Identifier’ of the organisation acting as a health care provider (an6 not applicable to COSD). This is the 3 or 5-digit code of the organisation submitting the demographic details. This will therefore normally be either the organisation where the referral is received or the treating organisation.

Notes:

- there is a new code structure (ANANA) for new organisation identifiers allocated by ODS from 01 September 2020 onwards
- codes issued prior to this date will not be converted
- details of changes to ODR codes can be found on the ODS Portal

Pathway choice

One of the following Cancer Pathway sections must be provided per submission.

Must be one of the following choices per record (1..1)
Pathway Choice - choice 1..1

Pathway Choice – Choice 1 (Primary Pathway)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR0370	Primary Diagnosis (ICD)	min an4 max an6	M
CR0380	Tumour Laterality	an1	M
CR2030	Date of Primary Diagnosis (Clinically Agreed)	an10 ccyy-mm-dd	M

End of Pathway Choice – Choice 1 (Primary Pathway)

Pathway Choice – Choice 2 (Non Primary Pathway)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR6500	Date of Non Primary Cancer Diagnosis (Clinically Agreed)	an10 ccyy-mm-dd	M

End of Pathway Choice – Choice 2 (Primary Pathway)
End of Pathway Choice

Primary Cancer Pathway

This is a linkage section (using a choice) to help improve the ascertainment and data quality of the primary cancer pathway data.

Notes:

- you can only create either a ‘Primary’ or ‘Non Primary’ cancer pathway within each record
- all items in this section are mandatory

Choice 1

Primary Diagnosis (ICD)

See diagnostic coding for details on coding and 'Primary Diagnoses' for the standardised definition of primary diagnosis. The primary diagnosis is normally agreed at the MDT meeting where the patient is discussed.

ICD10 is the International Statistical Classification of Diseases and Related Health Problems (ICD) and is a comprehensive classification of causes of morbidity and mortality. The primary diagnosis is the main condition treated or investigated during the relevant episode of healthcare.

Notes:

- where the ICD10 code only has 3 characters, for example C01, please add "X" as a 'packing digit' to meet the validation rules (such as C01.X, C07.X, C73.X)
- in addition, the reporting format excludes the decimal CXX.X or DXX.X, all xml reports must be recorded as CXXX or DXXX

Tumour Laterality

Identifies the side of the body for a tumour relating to paired organs within a patient (this refers to the side of the body on which the cancer originates). For the Central Nervous System, the definition for bilateral is 'evidence that the tumour is crossing the midline'.

National Code	National Code Definition
L	Left
R	Right
M	Midline
B	Bilateral
8	Not applicable
9	Not known

Notes:

- bilateral Wilms' tumour of the kidneys, ovarian tumours of the same histology and mesothelioma of pleura are treated as a single tumour

- all other bilateral tumours arising in paired organs should be treated as separate primary tumours and separate COSD records submitted for each
    - for example, one record with laterality 'left' and one record with laterality 'right'

Date of Primary Diagnosis (Clinically Agreed)

This data item is mandatory for all new primary cancers as it is required for record linkage. Record the date where Cancer was first confirmed, or diagnosis agreed.

Date of Diagnosis can usually be determined by one of the following 4 methods. You must use the date from the method which provides the earliest confirmation of a diagnosis. This will normally be one of the following.

Pathology report:

- this would normally be the date of the biopsy or procedure that first diagnosed the cancer was performed
- in some cases, the date of the authorised pathology report confirming a cancer diagnosis could be used

Diagnosis confirmed at MDT:

- if the cancer is confirmed clinically (clinical decision or clinical investigation or pathology not yet authorised)
- then the date used should be that of the Multidisciplinary Team Meeting when the diagnosis was agreed by the clinical team treating the patient

Excision:

- for cases where the diagnosing investigation and treatment occurred within the same process (such as where an excision confirms and removes or partially treats a cancer), record the date of the excision as the date of diagnosis and date of first treatment
- all other treatments post this point would be classified as 'Subsequent Treatments'

Other:

- for all other cases, record the date in which the clinical investigation took place
- or clinical agreement that confirms the diagnosis of cancer

Notes:

- this date must always be agreed by the clinical team if any confusion or uncertainty is present
- it is important that the Trust continues to submit their agreed 'Date of Diagnosis' based on the earliest clinically agreed date within the above framework

The NCRAS uses an internationally set of agreed algorithms to assign the 'Date of Diagnosis'. As these dates are used for international benchmarking, they can be different from the agreed and submitted 'Date of Diagnosis' of the reporting Trust.

These use the reported histological date (if present) as the gold standard, and this could supersede a clinical 'Date of Diagnosis' if reported within a given period.

Non Primary Cancer Pathway

This is a linkage section (using a choice), to help improve the ascertainment and data quality of the non primary cancer pathway data.

Notes:

- you can only create either a 'Primary' or 'Non Primary' cancer pathway within each record
- and all items in this section are mandatory

Choice 2

Date of Non Primary Cancer Diagnosis (Clinically Agreed)

This applies to recurrence, progression, or transformation (on the non primary cancer pathway) only. Record the date where the non primary cancer diagnosis was confirmed or agreed. This will normally be one of the following three methods.

Pathology report:

- this would normally be the date when the authorised pathology report confirms a non-primary cancer diagnosis
- the date of the procedure can also be used if positive

Diagnosis confirmed at MDT:

- if the non primary cancer diagnosis is confirmed clinically (clinical decision or clinical investigation or pathology not yet authorised)
- then the date used should be that of the Multidisciplinary Team Meeting when the diagnosis was agreed

Other:

- for all other cases
- record the date in which the clinical investigation took place
- or clinical agreement that confirms the diagnosis of cancer

Non Primary Cancer Pathway Details

If a non primary route is being recorded, you now have a choice to make as to which pathway the patient is on. This would be agreed with the clinical team treating the patient (if unsure please check).

It would be one of the following:

- Non Primary Cancer Pathway - Choice 1 - Recurrence

- Non Primary Cancer Pathway - Choice 2 - Progression
- Non Primary Cancer Pathway - Choice 3 - Transformation

It is expected that for each additional recurrence, progression, or transformation the patient is diagnosed with, a new record would be recorded.

Choice 1 - Non Primary Cancer Pathway Route – Recurrence

Additional details are required for every non primary cancer diagnosis record to ensure that the correct pathway route can be identified, and information can be correctly linked.

The following is specifically for recurrences (choice 1).

Must be up to one occurrence per Non Primary Cancer Pathway if selected as choice (1..1).

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR7100	Original Primary Diagnosis (ICD)	min an4 max an6	R

Start of repeating section - Metastatic Type and Site
May be multiple occurrences per CORE - Diagnostic - Non Primary Cancer Pathway Details (Recurrence) (0..*)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR6520	Metastatic Type	an2	M
CR1590	Metastatic Site	an2	M

End of repeating section - Metastatic Type and Site

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR1550	Palliative Care Specialist Seen Indicator (Cancer Recurrence)	an1	R

Start of repeating item - Relapse - Method of Detection

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR9000	Relapse - Method of Detection	an1	R*

End of repeating item - Relapse - Method of Detection

Original Primary Diagnosis (ICD)

This data item requires the original primary diagnosis to be recorded (if known). This allows for accurate alignment of a recurrence. This is particularly important where a patient has more than one primary diagnosis of cancer recorded.

Metastatic Type

Indicate the type of recurrence or metastatic disease diagnosed by the clinical team.

National Code	National Code Definition
01	Local
02	Regional
03	Distant

Metastatic Site

The site of the metastatic disease, if any, at diagnosis.

National Code	National Code Definition
02	Brain
03	Liver
04	Lung
07	Unknown metastatic site
08	Skin

National Code	National Code Definition
09	Distant lymph nodes
10	Bone (excluding marrow)
11	Bone marrow
12	Regional lymph nodes
97	Not applicable
98	Other metastatic site

Notes:

- both Metastatic Type and Site within a multiple selection group, and both fields are mandatory within the group
- if there is more than one metastatic region, all can now be recorded correctly
- these do not apply to haematological malignancies

It is possible that legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the current requirements and improve/enrich their data submissions or not upload the legacy data items in the new record (if that data is not available).

Palliative Care Specialist Seen Indicator (Cancer Recurrence)

Record whether a palliative care specialist saw the patient. This would be a member of the specialist palliative care team led by a consultant in palliative medicine for a recurrence of cancer.

National Code	National Code Definition
Y	Yes
N	No
9	Not known

Relapse - Method of Detection

Indicate the method of detection for the patient's relapse, more than one method can be recorded. The clinical value in the data item is around the early detection of recurrence.

National Code	National Code Definition
1	Morphology
2	Flow
3	Molecular
4	Clinical examination
9	Other

Notes:

- this data item has a new data item number from v10, to align with other CORE data
- the schema specification has been updated to Required 0..*
  - therefore, more than one selection is now possible

Choice 2 - Non Primary Cancer Pathway Route – Progression

Additional details are required for every non primary cancer diagnosis record to ensure that the correct pathway route can be identified, and information can be correctly linked.

The following is specifically for progressions (choice 2).
Must be up to one occurrence per Non Primary Cancer Pathway if selected as choice (1..1).

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR6900	Progression (ICD)	min an4 max an6	M

Start of repeating section - Metastatic Type and Site
May be multiple occurrences per CORE - Diagnostic - Non Primary Cancer Pathway Details (0..*)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR6520	Metastatic Type	an2	M
CR1590	Metastatic Site	an2	M

End of repeating section - Metastatic Type and Site

Progression (ICD)

This is a mandatory data item. Where a cancer has progressed, record the ICD10 code of the original diagnosis. This will normally be agreed at the MDT by the clinical team.

Metastatic Type

Indicate the type of recurrence or metastatic disease diagnosed by the clinical team.

National Code	National Code Definition
01	Local
02	Regional
03	Distant

Metastatic Site

The site of the metastatic disease, if any, at diagnosis.

National Code	National Code Definition
02	Brain
03	Liver
04	Lung
07	Unknown metastatic site
08	Skin

National Code	National Code Definition
09	Distant lymph nodes
10	Bone (excluding marrow)
11	Bone marrow
12	Regional lymph nodes
97	Not applicable
98	Other metastatic site

Notes:

- both Metastatic Type and Site within a multiple selection group, and both fields are mandatory within the group
- if there is more than one metastatic region, all can now be recorded correctly
- these do not apply to haematological malignancies

It is possible that legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the current requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

Choice 3 - Non Primary Cancer Pathway Route – Transformation

Additional details are required for every non primary cancer diagnosis record to ensure that the correct pathway route can be identified, and information correctly linked.

The following is specifically for transformation (choice 3). There is also a multi-choice (current morphology) section within this group as highlighted below.

Must be up to one occurrence per Non Primary Cancer Pathway if selected as choice (1..1).

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR7200	Original Morphology (ICD-O-3)	min an5 max an7	R
CR7210	Original Morphology (SNOMED)	min an6 max an18	R

Current morphology choice 1..2
Choice 1 - Current morphology

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR7010	Morphology (ICD-O-3) Transformation	min an5 max an7	M

End of Choice 1 - Current morphology

Choice 2 - current morphology
Start of section - current morphology
May be one occurrence per transformation

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR7000	Morphology (SNOMED) Transformation	min an6 max an18	M
CR7030	SNOMED Version Current (Transformation)	an2	M

End of repeating section - metastatic type and site
End of choice 1 - current morphology
End of current morphology

Original Morphology (ICD-O-3)

Record the morphology ICD-O-3 code of the original diagnosis (if known). This will normally be agreed at the MDT by the clinical team.

Original Morphology (SNOMED)

Record the morphology code of the original diagnosis (if known). This will normally be agreed at the MDT by the clinical team.

Important note:

- the next three data items form a 2-choice menu and at least one of the following choices must be provided per Transformation (1..2)

Choice 1

Morphology (ICD-O-3) Transformation:

The morphology code for the transformation of the cancer as defined by ICD-O-3. This can be recorded as well as or instead of 'Morphology (SNOMED) Transformation'.

Note:

- this is a mandatory data item

Choice 2

Morphology (SNOMED) Transformation:

This is the transformation diagnosis using the SNOMED International / SNOMED CT code for the cell type of the tumour recorded as part of a Cancer Care Spell. This can be recorded as well as or instead of 'Morphology (ICD-O-3) Transformation'.

SNOMED Version Current (Transformation)

The version of SNOMED used to encode 'Morphology (SNOMED) Pathology' and 'Topography (SNOMED) Pathology', there may be one occurrence per transformation.

National Code	National Code Definition
01	SNOMED II
02	SNOMED 3
03	SNOMED 3.5
04	SNOMED RT
05	SNOMED CT
99	Not known

Note:

- both 'Morphology (SNOMED) Transformation' and 'SNOMED Version Current (Transformation)' are now a multiple selection group, and both data items are mandatory within the group

Core - Demographics

Demographic details are required for every record to ensure that the correct patient can be identified, and information can be correctly linked.

The Demographics section should be completed by every Provider the first time a record is submitted.

There will only be one Demographics section completed for each record. Demographic linkage items will be required each time the record is submitted.

It is anticipated that some demographic data items listed below will be collected by every provider with which the patient has contact. Where this information is exchanged, the appropriate data item name should be used.

May be up to one occurrence per record (0..1).

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR0050	Person Family Name	max an35	R
CR0060	Person Given Name	max an35	R
CR0070	Patient Usual Address (at Diagnosis)	an175 (5 lines each an35)	R
CR0080	Postcode of Usual Address (at Diagnosis)	max an8	R
CR3170	Person Stated Gender Code	an1	R
CR6840	Person Sexual Orientation Code (at Diagnosis)	an1	R
CR0110	General Medical Practitioner (Specified)	an8	R
CR0120	General Medical Practice (Patient Registration)	min an6 max an8	R

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR0140	Person Family Name (at Birth)	max an35	R
CR0150	Ethnic Category	max an2	R
CR9060	Ethnic Category 2021	max an3	R

Person Family Name
That part of a person's name which is used to describe family, clan, tribal group, or marital association.

Person Given Name
The forename(s) or given name(s) of a person.

Patient Usual Address (at Diagnosis)
The 'Patient Usual Address' of the patient at the time of 'Patient Diagnosis'.

Postcode of Usual Address (at Diagnosis)
The 'Postcode of Usual Address' of the patient at the time of 'Patient Diagnosis'.

Person Stated Gender Code
Person's gender as self-declared (or inferred by observation for those unable to declare their 'Person Stated Gender'.

National Code	National Code Definition
1	Male
2	Female
9	Indeterminate (Unable to be classified as either male or female)
X	Not known ('Person Stated Gender Code' not recorded)

Person Sexual Orientation Code (at Diagnosis)

Person's sexual orientation as self-declared at the time of the 'Patient Diagnosis'. This complies with the information standard DCB2094.

National Code	National Code Definition
1	Heterosexual or Straight
2	Gay or Lesbian
3	Bisexual
4	Other sexual orientation not listed
U	Person asked and does not know or is not sure
Z	Not Stated (person asked but declined to provide a response)
9	Not Known (Not Recorded)

General Medical Practitioner (Specified)

This is the 'PPD Code' of the 'General Medical Practitioner' specified by the patient. The 'General Medical Practitioner' works within the 'General Medical Practitioner Practice' with which the patient is registered.

Default codes:

- G9999998 – General Medical Practitioner PPD Code not known
- G9999981 – General Medical Practitioner PPD Code not applicable

Note:

- this data item is not affected by the other changes to consultant codes throughout the data set

General Medical Practice (Patient Registration)

This is the code of the GP Practice that the patient is registered with.

Default codes:

- V81997 – No Registered GP Practice
- V81998 – GP Practice Code not applicable
- V81999 – GP Practice Code not known

Notes:

- ‘code’ has been removed from the name, on the request of the NHS Data Model and Dictionary Service
- the format of the data item has changed to ‘min an6 max an8’ to allow for any future changes to the national code structure

Person Family Name (at Birth)

The patient's surname at birth.

Ethnic Category

The ethnicity of a person, as specified by the person. The 16+1 ethnic data categories defined in the 2001 census is the national mandatory standard for the collection and analysis of ethnicity.

National Code	National Code Definition
White	
A	(White) British
B	(White) Irish
C	Any other White background
Mixed	
D	White and Black Caribbean
E	White and Black African
F	White and Asian
G	Any other mixed background
Asian or Asian British	
H	Indian
J	Pakistani
K	Bangladeshi

National Code	National Code Definition
L	Any other Asian background
Black or Black British	
M	Caribbean
N	African
P	Any other Black background
Other Ethnic Group	
R	Chinese
S	Any other ethnic group
Z	Not stated
99	Not known

Notes:

- the default option for this item is 99 - Not known
- the Office for National Statistics has developed a further breakdown of the group from that given, which may be used locally

Ethnic Category 2021

The addition of ETHNIC CATEGORY 2021, is to allow capture of expected new census values

There is a requirement to prepare COSD for recording ETHNIC CATEGORY 2021, the classification used in the 2021 census to record the ethnicity of a PERSON, as specified by the PERSON.

This change adds a (spare) field for ETHNIC CATEGORY 2021 in anticipation of introduction of a new value set, replacing the current ETHNIC CATEGORY data item (which uses 2001 census values). No enumeration is currently defined for this data item.

The functionality to allow future landing of the new data in COSD can be 'activated' without a change to the data set through DAPB.

Aims:
As this item forms part of the Unified Information Standard for Protected Characteristics (UISPC), which has not yet been approved by DAPB, the aim at this stage is to provide advance notice to data providers and system suppliers of the intention to report this item at a later date. This item should not be submitted until the wider NHS adopts ETHNIC CATEGORY 2021 and further development by NHS England has been undertaken.

Benefits:
Introducing this data item will future proof COSD allowing data to be submitted in conformance with the latest census values, as opposed to the now-outdated 2001 census values currently in use. The updated 2021 census values allow greater granularity through the introduction of new national codes, allowing the monitoring of health inequalities across more granular, low-level ethnic groups such as gypsies and travellers.

It will also reduce the burden resulting from the procedural requirements (such as a full interim standard release) that would otherwise be needed to update COSD to add this data item at a later stage.

Core - Referrals and first stage of patient pathway

This section includes details from referral up to the first appointment (for the primary diagnosis) and is therefore to be recorded once for each new primary cancer diagnosis. This is essential to support analysis for outcomes and work on presentation and routes to diagnosis. Further guidance on how various scenarios should be recorded is included in Appendix H.

There will only be one 'Referral' section completed for each record. These details include information relating to the first stage of the 'Patient Pathway'.

Notes:

- this section will only be completed for 'primary cancer diagnoses'
- for 'recurrent cancers', the section labelled ‘Core – Non Primary Cancer Pathway’ will be completed instead

May be up to one occurrence as per primary pathway (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR1600	Source Of Referral For Out-Patients	an2	R
CR0230	Date First Seen	an10 ccyy-mm-dd	R

Start of section - Consultant (First Seen) Section 0..1

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR7300	Professional Registration Issuer Code - Consultant (First Seen)	an2	M
CR7310	Professional Registration Entry Identifier - Consultant (First Seen)	min an1 max an32	M

End of section - Consultant (First Seen)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR1410	Organisation Site Identifier (Provider First Seen)	min an5 max an9	R
CR1360	Date First Seen (Cancer Specialist)	an10 ccyy-mm-dd	R
CR1400	Organisation Site Identifier (Provider First Cancer Specialist)	min an5 max an9	R

The following data item has been moved to CTYA - Referral from v10:

- CR2000 - Cancer Symptoms First Noted Date

Source of Referral for Out-Patients

This identifies the source of referral of each 'Consultant Out-Patient Episode'. This is essential for every cancer diagnosis to identify emergency presentations. Please note that where patients first present as an emergency, codes 01, 10 or 04 are applicable.

National Code	National Code Definition
Initiated by the 'Consultant' responsible for the 'Consultant Out-Patient Episode'	
01	following an emergency admission
02	following a domiciliary consultation
10	following an Emergency Care Attendance (including Minor Injuries, Walk In Centres and Urgent Treatment Centres)
11	Other (not listed)
Not initiated by the 'Consultant' responsible for the 'Consultant Out-Patient Episode'	
03	referral from a ‘General Medical Practitioner’
92	referral from a ‘General Dental Practitioner’

National Code	National Code Definition
12	referral from a General Practitioner with an Extended Role (GPwER) or Dentist with Enhanced Skills (DES)
04	referral from an Emergency Care Department (including Minor Injuries Units, Walk In Centres and Urgent Treatment Centres)
05	referral from a CONSULTANT, other than in an Emergency Care Department
06	self-referral
07	referral from a 'Prosthetist'
13	referral from a ‘Specialist Nurse (Secondary Care)’
14	referral from an ‘Allied Health Professional’
15	referral from an ‘Optometrist’
16	referral from an 'Orthoptist'
17	referral from a ‘National Screening Programme’
93	referral from a ‘Community Dental Service’
97	referral: Other (not listed)

Notes:

- the national code definitions for 10, 11, 12, 04, 05 and 97, have been corrected to meet changes to the data dictionary
- for screening events, follow the instructions in the CWT guidance

Date First Seen

This is the date that the 'Patient' is first seen in the 'Provider' that receives the first referral which leads to the cancer diagnosis. It is the date first seen in secondary care for this diagnosis.

Important notes:

- the next two data items are within a multiple selection group and are mandatory within the group
- there may be one occurrence per 'Core - Referrals' section.

Professional Registration Issuer Code – Consultant (First Seen)

This is the code which identifies the 'Professional Registration Body' for the consultant or health care professional who first sees the patient following the initial referral which leads to the cancer diagnosis.

National Code	National Code Definition
02	General Dental Council
03	General Medical Council
04	General Optical Council
08	Health and Care Professions Council
09	Nursing and Midwifery Council

Professional Registration Entry Identifier - Consultant (First Seen)

This is the registration identifier allocated by an organisation for the consultant or health care professional who first sees the patient following the initial referral which leads to the cancer diagnosis.

Organisation Site Identifier (Provider First Seen)

The 'Organisation Identifier' of the 'Organisation Site of the Health Care Provider' at the first contact with the patient.

That is the 'Health Care Provider' at the first 'Out-Patient Attendance Consultant', 'Imaging' or 'Radiodiagnostic Event', 'Clinical Intervention', 'Hospital Provider Spell', 'Emergency Care Attendance' or 'Screening Test' whichever is the earlier service related to the initial referral request. It is the date first seen in secondary care for this diagnosis.

Date First Seen (Cancer Specialist)

This is the date that the patient is first seen by the appropriate specialist for cancer care within a 'Cancer Care Spell'. This is the person or persons who are most able to progress the diagnosis of the primary tumour. If patient's first appointment is with the appropriate cancer specialist, this will be the same as 'Date First Seen'.

It would never be expected that this date would be before the 'Date First Seen'. Equally as this is looking at a referral to a cancer specialist, this would be expected to be used only for that initial referral/diagnosis, for example:

- within Skin cancer, where the patient is required to be seen by and potentially treated by a plastic surgeon, due to the location of the tumour, rather than the dermatologist, who might have been the original referral from the GP
- within gynaecology, where the initial referral is thought to be a tumour in the gynaecological region, but after initial assessment it is thought to be a Lower GI cancer instead (or visa-versa)
    - these patients would then be expected to be transferred to a lower GI MDT and specialist (or visa-versa)

These are just two examples, but all these referrals would be before the first treatment and after or part of the initial diagnosis confirmation. We would not expect this to be a referral to a specialist, longer than 6 months following the initial referral from general practice.

As a result, there will be validations on the NDRS API upload portal, where:

- the 'Date First Seen (Cancer Specialist)' is not before the 'Date First Seen'
- the 'Date First Seen (Cancer Specialist)' is not after 6 months following the 'Date First Seen'

Organisation Site Identifier (Provider First Cancer Specialist)

The 'Organisation Identifier' of the 'Organisation Site' where the patient is first seen by an appropriate cancer specialist on the 'Date First Seen (Cancer Specialist)'. If patient's first appointment is with the appropriate cancer specialist this will be the same as 'Organisation Code (Provider First Seen)'.

Core - Non primary cancer pathway - Referral

This section records the source of referral for a non primary cancer diagnosis pathway.

May be up to one occurrence per 'Non Primary Cancer Pathway' (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR0300	Source Of Referral for Non Primary Cancer Pathway	an2	R
CR7400	Date First Seen - Non Primary Cancer Pathway	an10 ccyy-mm-dd	R
CR7410	Organisation Site Identifier (Provider First Seen - Non Primary Cancer Pathway)	min an5 max an9	R

Source of Referral for Non Primary Cancer Pathway

Non Primary Cancer Pathway only. This identifies the source of referral for a non-primary cancer pathway.

National Code	National Code Definition
Initiated by the 'Consultant' responsible for the 'Consultant Out-Patient Episode'	
01	following an emergency admission
02	following a domiciliary consultation
10	following an Emergency Care Attendance (including Minor Injuries, Walk In Centres and Urgent Treatment Centres)
11	Other (not listed)

National Code	National Code Definition
Not initiated by the 'Consultant' responsible for the 'Consultant Out-Patient Episode'	
03	referral from a ‘General Medical Practitioner’
92	referral from a ‘General Dental Practitioner’
12	referral from a General Practitioner with an Extended Role (GPwER) or Dentist with Enhanced Skills (DES)
04	referral from an Emergency Care Department (including Minor Injuries Units, Walk In Centres and Urgent Treatment Centres)
05	referral from a CONSULTANT, other than in an Emergency Care Department
06	self-referral
07	referral from a 'Prosthetist'
13	referral from a ‘Specialist Nurse (Secondary Care)’
14	referral from an ‘Allied Health Professional’
15	referral from an ‘Optometrist’
16	referral from an 'Orthoptist'
17	referral from a ‘National Screening Programme’
93	referral from a ‘Community Dental Service’
97	referral: Other (not listed)

Notes:

- the national code definitions for 10, 11, 12, 04, 05 and 97, have been corrected to meet changes to the data dictionary
- for screening events, follow the instructions in the CWT guidance

Date First Seen - Non Primary Cancer Pathway

This is the date that the patient is first seen by the appropriate specialist for cancer care within a 'Non Primary Cancer Pathway Care Spell'. This is the person or persons who are most able to progress the diagnosis of the non primary tumour.

Organisation Site Identifier (Provider First Seen - Non Primary Cancer Pathway)

This is the 'Organisation Identifier' of the 'Organisation Site' where the patient is first seen by an appropriate cancer specialist on the 'Date First Seen - Non Primary Cancer Pathway'.

Core - Imaging

Imaging procedures conducted to diagnose or stage the cancer are included in this section. Generic (Core) imaging data may be provided through alternative methods and should be discussed with the local NDRS office.

Details of specific imaging procedures and outcomes required for specific disease groups are included in the appropriate site-specific sections and must be included in monthly submissions.

There are three choices to make when adding data within this section as explained below. This is because not all data are required, if the NICIP or SNOMED CT data items are completed.

Note:

- if Trust A performs the imaging but due to capacity it is reported in another Trust (Trust B), or is sent there for a second opinion, it is the responsibility of Trust A to report this through COSD and not Trust B

May be multiple occurrences per record (0..*)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR0310	Organisation Site Identifier (of Imaging)	min an5 max n9	M
CR0320	Procedure Date (Cancer Imaging)	an10 ccyy-mm-dd	M
CR6780	Imaging Outcome	an2	R

Imaging Location Choice - Choice 1..3
Imaging Location Choice 1

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR1610	Imaging Code (NICIP)	max an6	M

End of Imaging Location - Choice 1

Imaging Location Choice 2

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR3110	Imaging Code (SNOMED CT)	min n6 max n18	M

End of Imaging Location - Choice 2

Image Location Choice 3
Start of section - Imaging Location Group
May one occurrences per CORE - Imaging (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR0330	Cancer Imaging Modality	an4	M
CR0340	Imaging Anatomical Site	max an5	R
CR3000	Anatomical Side (Imaging)	an1	R

End of repeating section - Imaging Location Group
End of Imaging Location - Choice 3
End of Imaging Location Choice

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR0160	Imaging Report Text	max an270000	R

The following data item has been retired from v10:

- CR0350 - Lesion Size (Radiological)

Note:

- image guided procedures (such as breast wire guided biopsies) should be recorded under the ‘Diagnostic Procedures’ section - using OPCS code B32.3

Organisation Site Identifier (of Imaging)

This is a mandatory data item, required to improve data quality. This is the 'Organisation Identifier' of the organisation site where the imaging took place.

Procedure Date (Cancer Imaging)

This is a mandatory data item, required to improve data quality. The date the cancer imaging was conducted.

Imaging Outcome

Record the outcome for the imaging event as agreed with the radiologist or clinical team.

National Code	National Code Definition
01	Abnormal
02	Normal
03	Benign
04	Non-Diagnostic
05	Inadequate
09	Not Known

Note:

- the next five data items form a three choice menu as follows

Choice 1:

- neither choice 2 nor choice 3 are required if this is completed

Imaging Code (NICIP)

If this choice is selected, this becomes a mandatory data item, required to improve data quality. This is the National Interim Clinical Imaging Procedure Code Set code which is used to identify both the test modality and body site of the test. More information on NICIP can be found on the NHS England website.

Choice 2:

- neither choice 1 nor choice 3 are required if this is completed.

Imaging Code (SNOMED CT)

If this choice is selected, this becomes a mandatory data item, required to improve data quality. Imaging Code (SNOMED-CT) is the SNOMED CT concept ID which is used to identify both the test modality and body site of the test.

Choice 3

- this covers all the next three data items; these are grouped and only one occurrence can be recorded against each imaging event
- this is only required if either choice 1 or choice 2 are not completed (however you can return these data as well as choice 1 and choice 2 if preferred)

Cancer Imaging Modality

If this choice is selected, this becomes a mandatory data item, required to improve data quality. The type of imaging procedure used during an Imaging or Radiodiagnostic Event for a cancer care spell.

National Code	National Code Definition
C01X	Standard radiography
C01M	Mammogram
C02X	CT Scan
C02C	Virtual colonoscopy
C03X	MRI Scan
C04X	PET Scan
C05X	Ultrasound Scan
C06X	Nuclear Medicine imaging
C08A	Angiography
C08B	Barium
C08U	Urography (IV and retrograde)

National Code	National Code Definition
C09X	Intervention radiography
CXXX	Other

Imaging Anatomical Site

A classification of the part of the body that is the subject of an Imaging or Radiodiagnostic Event. The coding frame used is the OPCS-4 'Z' coding, plus 2 additional local codes:

- Whole body CZ001
- Multiple sites CZ002

For the purposes of recording Imaging Site for COSD the following high-level codes are sufficient, although more detailed codes can be used if preferred:

National Code	National Code Definition
Z921	Head NEC
Z923	Neck NEC
Z924	Chest NEC
Z925	Back NEC
Z926	Abdomen NEC
Z927	Trunk NEC
Z899	Arm NEC
Z909	Leg NEC
Z019	Brain NEC
Z069	Spine NEC
Z929	Other

Anatomical Side (Imaging)

The side of the body that is the subject of an Imaging or Radiodiagnostic Event.

National Code	National Code Definition
L	Left
R	Right
M	Midline
B	Bilateral
8	Not applicable
9	Not Known

Imaging Report Text

This is the full text provided in the imaging report, this is required by registries to derive final stage and potentially the diagnosis date for registration.

Core - Diagnostic procedures

These data allow for all diagnostic procedures to be correctly recorded within the data set. The organisation code and date are mandatory, however either OPCS or SNOMED CT can be used to record the diagnostic procedure, but if selected are mandatory.

There will be linked 'child groups' throughout the data set to 'CORE - Diagnostic Procedures'. This is to allow greater depth of data collection, whilst maintaining accuracy and ensuring that both the organisation and date are recorded.

May be multiple occurrences per record (0..*)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR7500	Organisation Site Identifier (Diagnostic Procedure)	min an5 max an9	M
CR7510	Diagnostic Procedure Date	an10 ccyy-mm-dd	M

Diagnostic Procedures Choice - Choice 1..2
Diagnostic Procedures - Choice 1
Start of Repeating Item - Diagnostic Procedure (OPCS)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR7520	Diagnostic Procedure (OPCS)	an4	M*

End of Repeating Item - Diagnostic Procedure (OPCS)
End of Diagnostic Procedures - Choice 1

Diagnostic Procedures - Choice 2
Start of Repeating Item - Diagnostic Procedure (SNOMED CT)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR7530	Diagnostic Procedure (SNOMED CT)	min n6 max n18	M*

End of Repeating Item - Diagnostic Procedure (SNOMED CT)
End of Diagnostic Procedures - Choice 2
End of Diagnostic Procedures Choice

Organisation Site Identifier (Diagnostic Procedure)
This is the 'Organisation Identifier' of the organisation site where the diagnostic procedure took place.

Diagnostic Procedure Date
Record the date the diagnostic procedure was conducted.

Note:

- the next two data items form a choice menu and at least one of the following must be provided per submission (1..2)

Choice 1: Diagnostic Procedure (OPCS)
Record the diagnostic procedure(s) conducted during the diagnostic event using OPCS. There may be more than one available, where multiple procedures are classified as a single event.

Choice 2: Diagnostic Procedure (SNOMED CT)
Record the diagnostic procedure(s) conducted during the diagnostic event using SNOMED CT. There may be more than one available, where multiple procedures are classified as a single event.

Sentinel node biopsy

This is a child of 'CORE – Diagnostic Procedures' group.

Must be at least one of the following choices per 'CORE – Diagnostic Procedures' (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR7540	Sentinel Node Biopsy Outcome	an1	R

Sentinel Node Biopsy Outcome
Record the outcome of the 'Sentinel Node Biopsy'.

National Code	National Code Definition
P	Malignant
N	No Malignancy

Notes:

- by adding the diagnostic procedures section both sentinel node biopsy (OPCS code T91.1) and Lymph node dissection (T85) can be easily recorded
- the SNOMED CT procedure code for ‘Sentinel Node Biopsy’ is: 396487001
- these codes are for guidance only
  - it is possible that these codes change over time
  - it is the responsibility of the reporting Trust to ensure correct codes are used

Core - Diagnosis

Diagnosis details in the linkage section are required for every record to ensure that the correct record can be identified, and information can be correctly linked. The full diagnosis details section enables the disease to be correctly registered. All registerable conditions should be recorded – see Appendix B.

Recording an applicable diagnosis (including a 'Date of Diagnosis'), triggers inclusion of the record in the submission. This information will normally be confirmed by the Multidisciplinary Team at their MDT Meeting.

Both ICD10 codes and morphology (SNOMED and/or ICD-O-3) should be completed for all cases, however morphology ICD-O-3 must be provided for all haematological, sarcoma and CTYA malignancies.

ICD-O-3 Topography Codes are only required to be submitted for CTYA cancers. In all other cases the ICD-O-3 Topography codes do not need to be completed by providers and will be recorded by the NCRAS. The ICD-O-3 codes can be accessed on the International Agency for Research on Cancer (IARC) website.

There will only be one diagnosis section completed for each record. Diagnosis linkage items are required each time the record is submitted.

Note:

- the ICD10 codes for secondary cancer should only be used when the primary diagnosis is not known

This section will be agreed by the Multidisciplinary Team (MDT) responsible for the patient and will be completed at the time the patient is discussed at the MDT meeting. The details may be different from those which appear in the Pathology data items.

May be up to one occurrence as per primary cancer pathway (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR6230	Organisation Site Identifier (of Diagnosis)	min an5 max an9	R
CR0390	Basis of Diagnosis (Cancer)	max an3	R

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR0180	Morphology (ICD-O-3)	min an5 max an7	R

Start of section - Current methodology section 0..1

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR6400	Morphology (SNOMED) Diagnosis	min an6 max an18	M
CR6490	SNOMED Version (Diagnosis)	an2	M

End of section - Current methodology

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR0480	Topography (ICD-O-3)	min an4 max an7	R
CR9010	Ki67	an3	P
CR0410	Grade Of Differentiation (at Diagnosis)	an2	R
CR0510	Performance Status (Adult)	an1	R
CR6830	Diagnosis Code (SNOMED CT)	min n6 max n18	R

Start of repeating section - 'Metastatic type' and 'Metastatic Site' section 0..*

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR6960	Metastatic Type	an2	M
CR6970	Metastatic Site	an2	M

End of repeating section - 'Metastatic type' and 'Metastatic Site'

Organisation Site Identifier (of Diagnosis)

The 'Organisation Identifier' of the organisation site where the patient diagnosis took place. The Trust who was responsible for the diagnosis of the patient should be entered here, using their 5 digit hospital code. It is important to take advice from the clinical teams if unsure before completing this field.

Other scenarios around diagnoses could be (but not limited to):

Scenario 1

If a patient was diagnosed at Trust A, but referred to Trust B for treatment, then Trust A is the diagnosing Trust.

Scenario 2

If the definitive test that determines cancer is confirmed at Trust A, but the pathology was reported at Trust B, we would expect Trust A to be reported as the diagnosing Trust.

Pathology reporting may be part of a pathology partnership, Trust A may no longer have a pathology department, Trust B therefore may report all pathology reports for more than one Trust, this does not mean they are the diagnosing Trust.

Scenario 3

If a request for a second opinion at Trust B is made to support the decision at Trust A, Trust A would be expected to be reported as the diagnosing Trust.

Scenario 4

If the management of the patient was done at Trust A, but specific tests were required to support the diagnosis at Trust B (and Trust B has no further part in the diagnostic/treatment process), we would expect Trust A to be reported as the diagnosing Trust.

For example, a lung patient is sent to a specialist centre for specialist diagnostic testing which helps with the diagnosis but is part of Trust A's diagnostic process, then Trust A is still the diagnosing Trust.

Scenario 5

In most cases a histological diagnosis would trump a clinical diagnosis (providing this is prior to treatment commencing), however:

- if a patient was clinically diagnosed with cancer at Trust A, and treatment starts without a histological diagnosis, then the clinical diagnosis should be used as the date of diagnosis and Trust A as the diagnosing Trust

- if a surgical treatment is then performed at a later date by any Trust, which resulted in a histologically confirmed diagnosis, we would expect the clinical diagnosis provided by Trust A to be reported as the date of diagnosis and Trust A as the diagnosing Trust
- these can be complex decisions and clinical advice from the consultants should be sought if there is confusion
- these decisions will help the NCRAS accurately map all diagnoses and future analyses

Scenario 6

If the patient is referred to Trust A as a suspected cancer and then referred to another Trust (without a confirmed diagnosis of cancer) for diagnostics, treatment, and managed by Trust B, we would expect Trust B to be reported as the diagnosing Trust.

Basis of Diagnosis (Cancer)

This is the method used to confirm the cancer.

National Code	National Code Definition
Non-microscopic	
0	Death certificate only (DCO): Information provided is from a death certificate
1	Clinical: Diagnosis made before death, but without any of the following (codes 2-8)
2	Clinical Investigation: All diagnostic techniques, including X-ray, endoscopy, imaging, ultrasound, exploratory surgery (such as laparotomy), and autopsy, without a tissue diagnosis
4	Specific tumour markers: Includes biochemical and/or immunological markers which are specific for a tumour site
Microscopic	
5	Cytology: Examination of cells from a primary or secondary site, including fluids aspirated by endoscopy or needle; also includes the microscopic examination of peripheral blood and bone marrow aspirates, immunophenotyping by flow cytometry and a liquid biopsy in the absence of pathology

National Code	National Code Definition
7.1	Histology of the primary tumour: Histologic examination of tissue from the primary tumour, however obtained, including all cutting techniques and bone marrow biopsies
7.2	Histology of a metastasis: No histology of the primary tumour
7.3	Histology at autopsy: No histology before autopsy
8	Cytogenetic and/or molecular testing: Detection of tumour-specific genetic abnormalities or genetic changes in the tumour, including techniques such as karyotyping, FISH (fluorescent in situ hybridization), PCR (polymerase chain reaction), DNA sequencing
9	Unknown: No information on how the diagnosis has been made (for example PAS or HISS record only)

Notes:

- a liquid biopsy is a sample of blood or another body fluid (liquor, etc.) for the detection of cancer cells or DNA-fragments of these tumour cells
- 0, 1, 2 and 5 have new descriptions from v10
- 6 and 7 have been retired and 7.1, 7.2, 7.3 and 8 are new attributes from v10
- the format has changed to ‘max an3’ to accommodate the above changes

The aim of the basis of diagnosis is to provide a level of certainty of the diagnosis of cancer. This is particularly relevant in the absence of pathological confirmation of the cancer. The proportion of clinical diagnoses (basis of diagnosis 1-4) is an indicator for the quality of the data. While a high proportion of clinical diagnoses in a cancer registry may well reflect the situation regarding clinical and pathological investigations in the registry area, especially in developing countries, it may also indicate an overestimation of the cancer incidence. On the other hand, in registries with a very low proportion of clinical diagnoses there may be an underestimation of the cancer incidence.

More information about the ne w Basis of Diagnosis coding, can be found via the European Network of Cancer Registries (ENCR).

Morphology (ICD-O-3)

The morphology code for the diagnosed cancer as defined by ICD-O-3. This data item must be completed for all Haematological, Sarcoma and CTYA diagnoses.

Important notes:

- the next two data items are within a multiple selection group and if this choice is selected, this becomes a mandatory data item, required to improve data quality
- there may be one occurrence per 'CORE – Diagnosis' section (0..1)

Morphology (SNOMED) Diagnosis

This is the patient's diagnosis using the SNOMED International / SNOMED CT code for the cell type of the malignant disease recorded as part of a Cancer Care Spell. This can be recorded as well as or instead of 'MORPHOLOGY (ICD-O-3)'.

SNOMED Version (Diagnosis)

The version of SNOMED used to encode 'Morphology (SNOMED) Pathology' and 'Topography (SNOMED) Pathology'.

National Code	National Code Definition
01	SNOMED II
02	SNOMED 3
03	SNOMED 3.5
04	SNOMED RT
05	SNOMED CT
99	Not Known

Topography (ICD-O-3)

The topographical site code for the tumour as defined by ICD-O-3. For all cases except CTYA, the NCRAS will derive this. For CTYA cases this is mandatory and should be included in the submission by NHS Providers. This Must Not be submitted using a decimal point for example C509.

Note:

- this has a new format ‘min an4 max an7’ to improve data quality and ascertainment

Ki67

This is a new pilot data item in v10 and only required by Trusts who host a neuroendocrine MDT and has a range of 0-100. This will be provided at the MDT by a clinician, please consult your MDT lead for clarification of this data item, if not discussed at the meeting.

Grade of Differentiation (at Diagnosis):

This is the definitive grade of the tumour at the time of patient diagnosis.

National Code	National Code Definition
GX	Grade of differentiation is not appropriate or cannot be assessed
G1	Well differentiated
G2	Moderately differentiated
G3	Poorly differentiated
G4	Undifferentiated / anaplastic

Notes:

- the default labels for these fields (“well differentiated”, “moderately differentiated” and “poorly differentiated”)
- these are nationally assigned ‘general’ descriptions used within COSD, the correct grade will be applied by the NCRAS upon processing the data
- not required for prostate or testicular cancer or haematological diagnoses

The following mapping table can be used to map other (site-specific) invasive grades, into the main ‘Grade of Differentiation (At Diagnosis)’ field

Grade	GX	G1	G2	G3	G4
Invasive Grade Breast	n/a	Grade 1	Grade 2	Grade 3	n/a

Grade	GX	G1	G2	G3	G4
Colorectal	n/a	Well/Moderately differentiated	n/a	Poorly differentiated	n/a
CNS	n/a	I	II	III	IV
Fallopian Tube, Ovary, Peritoneal	n/a	Low	Intermediate	High	n/a
Neuroendocrine (NET) Tumours	Grade of differentiation is not appropriate or cannot be assessed	Grade 1 NET	Grade 2 NET	Grade 3 NET or Grade 3 NEC	Not used
Salivary Tumour Grade	n/a	Low	n/a	High	n/a
Sarcoma Histological Tumour Grade	n/a	Low	Intermediate	High	n/a

Performance Status (Adult)

A World Health Organisation classification indicating a person's status relating to activity or disability. Although most patients have their performance status assessed before each treatment, within COSD we need a single point to measure all patients and this item can only be recorded once. Performance status is therefore requested to be recorded as close to the point of diagnosis as possible.

National Code	National Code Definition
0	Able to carry out all normal activity without restriction
1	Restricted in strenuous activity but ambulatory and able to carry out light work

National Code	National Code Definition
2	Ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours
3	Symptomatic and in a chair or in bed for greater than 50% of the day but not bedridden
4	Completely disabled; cannot carry out any self-care; totally confined to bed or chair
9	Not recorded

Notes:

- this data item is not applicable for Paediatric patients or Skin diagnoses, except for melanoma stage 4
- if a patient is on high dose steroid therapy (for example, dexamethasone), which is clinically considered to have artificially and temporarily improved the patient's performance status, the performance status assessed prior to commencing on steroids should be recorded

Diagnosis Code (SNOMED CT)

'Diagnosis Code (SNOMED CT)' is the SNOMED CT concept ID which is used to identify the clinical diagnosis given to the patient.

Note:

- please refer to the 'how to find a SNOMED CT diagnosis' for support

Metastatic Type

Indicate the type of metastatic disease diagnosed by the clinical team.

National Code	National Code Definition
01	Local
02	Regional
03	Distant

Metastatic Site
The site of the metastatic disease, if any, at diagnosis.

National Code	National Code Definition
02	Brain
03	Liver
04	Lung
07	Unknown metastatic site
08	Skin
09	Distant lymph nodes
10	Bone (excluding Bone Marrow)
11	Bone marrow
12	Regional lymph nodes
97	Not Applicable
98	Other metastatic site

Notes:

- both Metastatic Type and Site are within a multiple selection group and both fields are mandatory within the group
- if there are more than one metastatic region, all can now be recorded correctly. This is not applicable for most Haematological diagnoses

Diagnosis - Additional items

This is a child group of 'CORE – Diagnosis'.
May be up to one occurrence per Core - Diagnosis (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR7600	Primary Diagnosis Subsidiary Comment	max an50	R

Start of repeating item - 'Secondary Diagnosis (ICD10)'

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR7610	Secondary Diagnosis (ICD10)	min an4 max an6	R*

End of repeating item - 'Secondary Diagnosis (ICD10)'

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR7620	Other Significant Diagnosis Subsidiary Comment	max an50	R
CR7630	Familial Cancer Syndrome	an1	R
CR7640	Familial Cancer Syndrome Subsidiary Comment	max an50	R
CR9020	Functional Syndrome Classification Indicator	an1	R

Start of repeating item - Functional Syndrome Classification Type

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR9030	Functional Syndrome Classification Type	an2	R*

End of repeating item - Functional Syndrome Classification Type

Start of repeating section - Functional Syndrome Classification Type Unknown

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR9030	Functional Syndrome Classification Type	an2	M
CR9040	Other Functional Syndrome Classification Type	max an50	R

End of repeating section - Functional Syndrome Classification Type Unknown

Primary Diagnosis Subsidiary Comment

Additional comments on diagnosis where coding is difficult or imprecise. (Examples of this would be: "papillary glioneuronal tumour" or "angiocentric glioma" to specify recently described diagnoses which do not have ICD10 or ICD-O-3 coding. "Anaplastic ependymoma" or "ependymoblastoma" to distinguish between these 2 diagnoses which may have different treatment decisions or outcomes, but which cannot be distinguished in ICD10 or ICD-O-3 coding.)".

Secondary Diagnosis (ICD)

This is a multiple repeating data item. Record the types (ICD10 codes) of other significant conditions (for example Down Syndrome, NF1, Fanconi anaemia) which may predispose to cancer or influence treatment. This information should be available for the MDT discussion but will only apply to a small number of cases. See Appendix D for more information.

Other Significant Diagnosis Subsidiary Comment

Additional comments on other significant conditions where coding is difficult or imprecise. (For example, “NF1” or “NF2” to distinguish between these 2 distinct conditions which may have different treatment decisions or outcomes but cannot be coded separately.) This information should be available for the MDT discussion but will only apply to a small number of cases.

Familial Cancer Syndrome

Indicate whether there is a possible or confirmed familial cancer syndrome. This information should be available for the MDT discussion but will only apply to a small number of cases.

National Code	National Code Definition
Y	Yes
N	No
P	Possible
9	Not Known

Familial Cancer Syndrome Subsidiary Comment

Where ‘Familial Cancer Syndrome’ is coded as ‘Yes’ or ‘Possible’, this field can be used to provide further details. For example, ‘Li-Fraumeni’, ‘Rhabdoid tumour predisposition syndrome’ or ‘Biallelic PMS2 mutation’ to identify distinct syndromes which may have different treatment decisions or outcomes but cannot be coded separately.

Functional Syndrome Classification Indicator

This is a new data item for v10. Indicate whether there is a possible or confirmed Functional syndrome classification

National Code	National Code Definition
Y	Yes
N	No
9	Not Known

Functional Syndrome Classification Type
This is a new data item for v10. Specify the type of functional syndrome classification the patient is diagnosed with.

More than one is possible if applicable and this item is for Neuroendocrine tumours (NET) only.

National Code	National Code Definition
01	Carcinoid syndrome
02	Insulinoma
03	Glucagonoma
04	VIPoma
05	Gastrinoma/ Zollinger Ell. Syndrome
06	Somatostatinoma
07	CRH/ACTH secreting tumour
08	GHRH secreting tumour
09	PTHrp secreting tumour

Note:
- the following forms a repeating section

Functional Syndrome Classification Type
This is a new data item for v10. Specify 'Other functional syndrome' if none of the above are applicable. This is mandatory if section selected.

National Code	National Code Definition
98	Other functional syndrome

Other Functional Syndrome Classification Type
This is a new data item for v10. If 98 selected above, specify the other functional syndrome classification type.

Diagnosis - Progression

This is a child group of 'Core – Diagnosis'. This allows for where a patient's disease has progressed whilst on their original primary pathway to be recorded. All these data items are mandatory and must be submitted per submission (where applicable), more than one submission is permitted per diagnosis.

May be multiple occurrences per CORE - Diagnosis (0..*)

Start of repeating section - 'Metastatic type' and 'Metastatic Site'
May be multiple occurrences per Core - Diagnosis - Progression (0..*)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR6960	Metastatic Type	an2	M
CR6970	Metastatic Site	an2	M

End of repeating section - 'Metastatic type' and 'Metastatic Site'

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR6910	Progression Date (Primary Pathway)	an10 ccyy-mm-dd	M

Metastatic Type
Indicate the type of metastatic disease diagnosed by the clinical team.

National Code	National Code Definition
01	Local
02	Regional

National Code	National Code Definition
03	Distant

Metastatic Site

The site of the metastatic disease, if any, at diagnosis.

National Code	National Code Definition
02	Brain
03	Liver
04	Lung
07	Unknown metastatic site
08	Skin
09	Distant lymph nodes
10	Bone (excluding Bone Marrow)
11	Bone marrow
12	Regional lymph nodes
97	Not Applicable
98	Other metastatic site

Additional notes:

- both Metastatic Type and Site are within a multiple selection group, both fields are mandatory within the group
- if there is more than one metastatic region, all can be recorded correctly

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and

improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

Progression Date (Primary Pathway)
The date the progression was agreed by the clinical team. This allows for the date of progression (that happens during the initial cancer primary diagnostic or treatment phase) to be recorded.

Diagnosis - Transformation

This is a child group of 'CORE – Diagnosis'. This allows for where a patient's disease has transformed whilst on their original primary pathway to be recorded and more than one submission is permitted per diagnosis.

May be multiple occurrences per Core - Diagnosis (0..*)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR7020	Transformation Date (Primary Pathway)	an10 ccyy-mm-dd	M

Diagnosis transformation morphology choice - Choice 1..2
Diagnosis transformation morphology - Choice 1

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR7010	Morphology (ICD-O-3) Transformation	min an5 max an7	M

End of diagnosis transformation morphology - Choice 1

Diagnosis transformation morphology - Choice 2
Start of section - Current morphology

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR7000	Morphology (SNOMED) Transformation	min an6 max an18	M
CR7030	SNOMED Version (Transformation)	an2	M

End of repeating section - Metastatic type and site
End of diagnosis transformation morphology - Choice 2
End of diagnosis transformation morphology choice

Transformation Date (Primary Pathway)
This is a mandatory data item and is the date the disease transforms. This will normally be agreed at the MDT by the clinical team.

Note:

- the next three data items form a 2-choice menu and at least one of the following must be provided per Transformation (1..2).

Choice 1 -Morphology (ICD-O-3) Transformation
If this choice is selected, this becomes a mandatory data item, required to improve data quality. The morphology code for the transformation of the cancer as defined by ICD-O-3. This can be recorded as well as or instead of 'Morphology (SNOMED) Transformation'.

Choice 2 -Morphology (SNOMED) Transformation
This is the transformation diagnosis using the SNOMED International / SNOMED CT code for the cell type of the tumour recorded as part of a cancer care spell. This can be recorded as well as or instead of 'Morphology (ICD-O-3) Transformation'.

SNOMED Version Current (Transformation)
The version of SNOMED used to encode 'Morphology (SNOMED) Pathology' and 'Topography (SNOMED) Pathology'.

National Code	National Code Definition
01	SNOMED II
02	SNOMED 3
03	SNOMED 3.5
04	SNOMED RT
05	SNOMED CT
99	Not Known

Notes:

- both ‘Morphology (SNOMED) Transformation’ and ‘SNOMED Version Current (Transformation)’ are within a multiple selection group and both data items are mandatory within the group
- there may be one occurrence per transformation

Banked tissue

Notes:

- ‘Banked Tissue at Diagnosis’ has moved to CTYA – Diagnosis – Banked Tissue
- ‘Type of Tissue Banked at Diagnosis’ has been retired from v10

Core - Person Observation

These are measurements that can be done at multiple points in the patient's pathway, to support their clinical management.

May be multiple occurrences per record (0..*)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR6430	Person Observation Height in Metres	n1.max n2	R
CR6440	Person Observation (Weight)	max n3.max n3	R
CR6450	Body Mass Index	n2.n1	R
CR6460	Date Observation Measured	an10 ccyy-mm-dd	M

Person Observation Height in Metres
Height of the patient, in metres to 2 decimal places (n.nn).

Person Observation (Weight)
Weight of the patient, in kilograms with up to 3 decimal places (nnn.nnn).

Body Mass Index
Estimate of a patient's Body Mass Index (BMI) at diagnosis. The Body Mass Index (BMI) can be derived by a calculation using the patient's height and weight. This data item would be obtained at presentation either in the outpatient clinic or on the ward.

Date Observation Measured
Date the patient's weight was measured. This is a mandatory field and enables these data to be used for specific parts of the pathway.

Core - Clinical Nurse Specialist + Risk Factor Assessment

This section contains important data, which will help improve our understanding of the causative risk factors across all tumour sites.

May be up to one occurrence per record (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR2050	Clinical Nurse Specialist Indication Code	an2	R
CR7800	Tobacco Smoking Status	an1	R
CR7810	Tobacco Smoking Cessation	an1	R
CR6760	History of Alcohol (Current)	an1	R
CR6770	History of Alcohol (Past)	an1	R
CR9070	Diabetes Mellitus Type 1 and Type 2 Indicator	an1	R
CR7830	Menopausal Status	an1	R
CR7840	Physical Activity (Current)	an1	R

Note:

- 'CR7820 Diabetes Mellitus Indicator' has been retired in v10 and replaced with 'CR9070 Diabetes Mellitus Type 1 and Type 2 Indicator'

Clinical Nurse Specialist Indication Code

Record when the patient saw an appropriate site-specific clinical nurse specialist. Please read all options to select the most appropriate code.

National Code	National Code Definition
Y1	Yes - Clinical Nurse Specialist present when patient given diagnosis
Y3	Yes - Clinical Nurse Specialist not present when patient given diagnosis but saw patient during same Consultant Clinic Session
Y4	Yes - Clinical Nurse Specialist not present during Consultant Clinic Session when patient given diagnosis but saw patient at other time
Y5	Yes - Clinical Nurse Specialist not present when patient given diagnosis, but the patient was seen by a trained member of the Clinical Nurse Specialist team
NI	No - patient not seen at all by Clinical Nurse Specialist but Clinical Nurse Specialist informed of diagnosis
NN	No - patient not seen at all by Clinical Nurse Specialist and Clinical Nurse Specialist not informed of diagnosis
99	Not known (not recorded)

Notes:

- Y1 could be when either the patient was given the diagnosis of cancer by a consultant (with the Nurse Present) or by the clinical nurse specialist themselves (without a consultant)
    - clinical nurse specialist practice is becoming more independent and in some tumour sites, it will be the clinical nurse specialist that breaks the bad news to the patient
- Y5 was requested by many clinical nurse specialist teams as their workload is more diverse than originally accounted for, which is required to meet the rising demand for their services to help you assign the correct code - the following 3 expanded explanations have been provided:
    - cancer care coordinators are band 3/4 staff who have been employed to work within clinical nurse specialist teams to undertake several duties which do not need to be performed by a clinical nurse specialist including:
        - telephone triage
        - pathway management

        - in some cases, acting as key worker to patients with non-complex disease requiring straight forward management
    - where care coordinators are acting as key workers they have undergone appropriate communication skills training and have developed specific competencies to ensure they have the skills and knowledge to undertake this role which may include the support of patients at diagnosis
    - cancer care coordinators are recognised members of the multi-disciplinary team and are working under the supervision of the senior clinical nurse specialist, and with the approval of the MDT Lead
- NI should be used where a CNS does not actually see the patient, but was informed of the diagnosis
    - this includes where the CNS had a telephone call with the patient, but never actually saw them face-to-face

Tobacco Smoking Status

This is specifically looking at tobacco smoking only. Specify the current tobacco smoking status of the patient. This data item could be collected at presentation either in outpatients or on the ward.

National Code	National Code Definition
1	Current smoker
2	Ex smoker
4	Never smoked
9	Unknown

Tobacco Smoking Cessation

This is specifically looking at tobacco smoking treatments. Specify the tobacco smoking cessation treatment status of the patient. This data item could be collected at presentation either in outpatients or on the ward.

National Code	National Code Definition
1	Patient treated

National Code	National Code Definition
2	Patient not treated
3	Patient offered treatment but declined
8	Not Applicable (Not current tobacco user)
9	Not Known (Not recorded)

History of Alcohol (Current)

Specify the current history of alcohol consumption for the patient (≤3 months) from date of diagnosis.

National Code	National Code Definition
1	Heavy (>14 Units per week)
2	Light (≤14 Units per week)
3	None in this period
Z	Not Stated (patient asked but declined to provide a response)
9	Not Known (Not recorded)

History of Alcohol (Past)

Specify the past history of alcohol consumption for the patient (>3 months) from date of diagnosis.

National Code	National Code Definition
1	Heavy (>14 Units per week)
2	Light (≤14 Units per week)
3	None in this period

National Code	National Code Definition
Z	Not Stated (patient asked but declined to provide a response)
9	Not Known (Not recorded)

Note:

- these are based on the UK Chief Medical Officers' Alcohol Guideline Review (Jan 2016)

Diabetes Mellitus Type 1 and Type 2 Indicator

This is a new data item in v10, and these are risk factors for many cancers. Record if the patient has a diagnosis of type 1 or type 2 diabetes mellitus? This information will normally be available in the patient record.

National Code	National Code Definition
1	Type 1 diabetes mellitus
2	Type 2 diabetes mellitus
3	Other diabetes mellitus not categorised as type 1 or type 2
4	No patient diagnosis of diabetes mellitus has been made
9	Not known

Notes:

- the presence of diabetes is an independent risk factor of development of HCC and many other cancers
- in v10 (on the request of clinician's) we have extended this to allow for the accurate recording of 'Type 1' or 'Type 2' diabetes

Menopausal Status

This data item is a risk factor for many female cancers.

National Code	National Code Definition
1	Premenopausal
2	Perimenopausal
3	Postmenopausal
9	Not Known

Numerous current treatment options are different according to the menopausal status of a patient (particularly but not exclusively those presenting with breast cancer).

Physical Activity (Current)

This is to specify the current physical activity level of the patient.

National Code	National Code Definition
1	Achieves guidance level of physical activity
2	Does not achieve guidance level of physical activity
Z	Not Stated (PATIENT asked but declined to provide a response)
9	Not Known (Not recorded)

The reason for collecting this information is to help prompt the support given to individual patients around their physical activity level, and to provide data that allows analysis of cancer patients' levels of physical activity. Physical Activity is a proven intervention that supports cancer survival (CHALLENGE trial 2025) and cancer treatment side effects.

The activity assessment is based on the Physical Activity Vital Sign (PAVS) form, which has been recommended for its utility in clinical practice.

You can also use the online 'quick activity calculator' version, which is part of the 'More Minute Conversation' resource for health professionals on the Moving Medicine website. (select 'Cancer' then 'More Minutes' on this website).

This 'quick activity calculator' could be incorporated into a local patient administration system or EPR.

If you identify someone not achieving the guidance level of physical activity (150 minutes moderate intensity physical activity per week or 75 minutes vigorous intensity physical activity per week), then it is recommended to advise them to increase physical activity even if only by a small amount, by using a brief behaviour change intervention:

- 'Moving Medicine' has consultation guides on how to have good quality conversations with people affected by cancer about their physical activity
  - there are guides for 3 lengths of conversation: 1 minute, 5 minutes and More Minutes
- NICE Guidance also provides advice:
  - Physical activity: brief advice for adults in primary care (PH44 2013)

People affected by cancer can be signposted to resources such as:

- Moving Medicine website patient facing resources
- Macmillan Cancer Support's resources:
  - Physical Activity before treatment webpage
  - Physical Activity after treatment webpage
  - Physical Activity and Cancer booklet
- Cancer Care Map's directory of cancer support services – search by postcode with the keyword 'Physical Activity'
- We Are Undefeatable website supporting people to get active whilst living with a health condition (not cancer specific)
- Maggie's
- Move Against Cancer
- South East London Cancer Alliance
- Further patient resources and charities are listed on FutureNHS

For staff there are free resources for implementing physical activity interventions across a cancer service, with many listed on FutureNHS including:

- South East London Cancer Alliance's Top Tips for Professionals on physical activity and cancer
- Macmillan Cancer Support resources for professionals:
  - Physical Activity and Cancer: The under-rated wonder drug (2020)
  - Integrating physical activity into cancer care (2020)
  - Physical activity for people with metastatic bone disease (2020)
  - Physical Activity and Cancer: Ten Top Tips (2022)
  - Prehabilitation resources
- BMJ Learning's online course:

    - The health benefits of physical activity: Cancer (2022), which is part of a 10-part course on physical activity
- E-Learning for Health's:
    - PRosPer online learning programme on prehabilitation and rehabilitation for people living with cancer which includes exercise
- E-learning for Health's:
    - Physical Activity and Health learning resource (not cancer specific)

Note:

- NHS England is not responsible for the content of external websites. All weblinks are current as of 30 April 2026.

Core - Clinical Nurse Specialist - Holistic Needs Assessment and Personalised Care and Support Planning

This section covers Holistic Needs Assessment and Personalised Care and Support Planning, has been renamed for COSD version 10. Notes on implementation, can be found at the end of this section.

Please read through this whole section as there have been changes to and within data items and coding options compared to COSD version 9. However, the fundamental requirements are still the same as in version 9. For example, to capture whether personalised care and support planning (PCSP) and holistic needs assessments (HNA) are being offered/completed, at which point in the cancer pathway and by which staff group.

Some of the changes were requested by the NHS Cancer Programme and Macmillan Cancer Support to affirm the importance of completing and recording that personalised care and support planning is happening after a holistic needs assessment.

These Holistic Needs Assessment and Personalised Care and Support Planning data items are marked as 'R – Required' - while not 'mandatory', this means the data items (where applicable) should be submitted as soon as possible but is not required to validate the submitted record.

The COSD dataset is not designed to capture all PCSP and HNA activity for patients. Therefore, please note that, while activity may be carried out in any healthcare, social care or community setting, the focus for COSD data capture is only for those occurring along cancer pathways in a secondary care setting.

May be multiple occurrences per record (0..*)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR7900	Assessment Offered	an2	R
CR7920	Assessment/Care Plan Status	an2	R
CR7930	Assessment/Care Plan Date	an10 ccyy-mm-dd	R

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR7940	Assessment/Care Plan Point of Pathway	an2	R
HNA/PCSP Staff Role Staff Role - Choice 1			Choice 1..1
CR7950	Staff Role Offering the Assessment	an2	M
End of Staff Role - Choice 1 Staff Role - Choice 2			
CR7960	Staff Role Offering the Planning	an2	M
End of Staff Role - Choice 2 End of HNA/PCSP Staff Role Choice			

Both the staff role offering the Holistic Needs Assessment (CR7950) and the staff role offering the planning CR7960' should be collected as these activities may be conducted by different staff members.

The following data items have been retired in v10:

- CR1340 Assessment Completed Date
- CR3150 Assessment Point of Pathway
- CR7910 Staff Role Carrying Out the Assessment
- CR8030 Staff Role Carrying Out the Planning

Assessment Offered

Record whether a PATIENT has been offered an Holistic Needs Assessment (HNA)

National Code	National Code Definition
01	Offered and Undecided
02	Offered and Declined
03	Offered and Accepted

National Code	National Code Definition
04	Not Offered
05	Offered but Patient Unable to Complete

This data item CR7900 'Assessment Offered' indicates whether the PATIENT:

- was undecided about whether to have an HNA (code 01)
- declined the offer of an HNA (code 02)
- accepted the offer of having an HNA and completed it (code 03)
- was not offered a HNA for clinical reasons (code 04)
  - for example, where they would not normally be expected to undergo HNA and PCSP due to being on a clinical pathway that deliberately does not include it (for example because the patient will be referred on to another provider who will offer the HNA and PCSP), or
- was offered an HNA but was unable to complete it (code 05)
  - for example, due to cognitive difficulties, imminent end of life, or where they have died after the offer of the assessment but without having the opportunity to complete it

Rationale:

- it is important to capture the offer of personalised care, whether the HNA occurs or not
- there will always be some people for whom it is correct to make the clinical decision to not offer an HNA to, or who, having been offered an HNA, will be unable to complete it
  - for example, being close to end of life, or being referred to another provider
  - this decision will have been made that as part of an individual's care and it is important to capture this as part of understanding what has happened
- where there is a proper clinical decision to 'not offer' HNA, then this gives Trusts the place to record that entirely appropriate decision
- this coding also ensures when the ratio of HNAs to PCSPs is reviewed nationally, there is a more accurate picture

Additional notes to support data recording of CR7900 'Assessment Offered':

- there is currently no formal national definition of what constitutes the 'offer' of an HNA
- however, it should be a 'proactive' offer, so that the patient's response is known and can be recorded

- HNAs and PCSPs should be regarded as an opt-out part of care, not opt-in
  - for example, sending a standardised letter or text message that requires the patient to request to have an HNA, should not be recorded as an 'offer' of an HNA
- local teams should have an agreed policy and procedure for conducting HNAs and PCSPs and how these are recorded consistently and accurately for patient record and in accordance with the COSD data specification and this document
- HNAs and PCSPs may be requested at any time by the patient:
  - on these occasions, please use the 'Offered and Accepted' code (03)
- if the offer of an HNA is not accepted or completed or it is not offered:
  - the data item CR7930 'Assessment/Care Plan Date' must still be completed with the date the assessment was offered for the non-acceptance or non-completion or non-offer of the HNA to have a time stamp and thus be correctly featured in aggregate data reports
  - the data item CR7920 'Assessment/Care Plan Status' does not apply
  - the data item CR7940 'Assessment/Care Plan Point of Pathway' does still apply
  - the data item CR7950 'Staff Role Offering the Assessment Pathway' does still apply
  - the data item CR7960 'Staff Role Offering the Planning' does not apply

Assessment/Care Plan Status

This is a new data item for v10. This data item provides an indication of whether a PATIENT has been offered a Holistic Needs Assessment (HNA) and /or Personalised Care and Support Plan (PCSP) and whether these have been completed.

National Code	National Code Definition
01	Assessment completed and care plan not offered
02	Assessment completed and care plan offered
03	Assessment completed and care plan completed
04	Assessment completed and care plan declined

National Code	National Code Definition
05	Assessment completed and care plan unable to be completed
06	Assessment completed and care plan not required (no concerns from HNA)

This data item CR7920 'Assessment/Care Plan Status' captures what happens as part of the HNA and PCSP process once the initial offer of the HNA has been accepted and the assessment completed. If the offer of an assessment is not accepted, or the assessment is not completed, this data item will not apply.

The values in this field will indicate, once the PATIENT has completed the assessment (HNA), that:

- a care plan was not offered (code 01)
- a care plan was offered, but at the time of recording it may not be clear whether the patient will take up the offer of a care plan, for example if they are undecided (code 02)
- a care plan was offered and has been completed (code 03)
- a care plan was offered but the patient has declined a care planning conversation (code 04)
- a care planning conversation could not be completed with the patient (code 05)
    - for example, if the patient has lost capacity, has transferred to another care provider, or has died between the completion of the assessment and the offer of a care plan, or
- a care plan has not been offered on the basis that the individual identified no concerns in completing the assessment (HNA) (code 06).

Note that in some instances the patient may identify no concerns in the HNA, but in further discussion may raise issues which are resolved in a Personalised Care and Support Plan. These should be coded as 03, to indicate that a care plan has been completed.

ASSESSMENT/CARE PLAN DATE

This is a new data item in v10. Record the date if:

- a Holistic Needs Assessment or Personalised Care and Support Plan is offered, or
- the date when a decision was made not to offer an assessment for valid clinical reasons as described above
    - if the decision is to not offer an assessment, then data item CR7900 'Assessment Offered' should be coded 'Not Offered'

This date should correspond to the Assessment/Care plan Point of Pathway and Staff role data items.

Rationale:

- having a single, easily recorded, and consistent date allows for more accurate recording of the data and allows for the identification and removal of duplicate records
- it is as important to record that a decision has been taken 'not to offer an assessment' as it can be to record that the offer has been made

Assessment/Care Plan Point of Pathway

This is a new data item for v10. Record the point of the pathway where:

- the offer of a Holistic Needs Assessment or Personalised Care and Support Planning is made, or
- a decision it taken to not offer these

This point of the pathway should correspond to the CR7930 Assessment/Care Plan Date.

National Code	National Code Definition
01	Initial cancer diagnosis
02	Start of treatment
03	During treatment
04	End of treatment
05	Diagnosis of recurrence
06	Transition to palliative care
07	Prehabilitation
08	In palliative or end of life care
97	Other

Additional notes to help with data recording of CR7940 'Assessment/Care Plan Point of Pathway':

- the HNA pathway time points are not defined in terms of a number of days or weeks from diagnosis or from start/end of treatment that the HNA happens within
- there is no national target timescale for HNA and PCSP to happen after diagnosis or after end of treatment
- however, local standards or protocols may be agreed as to where in each cancer type pathway the HNAs and PCSPs should be carried out as a minimum
    - for example, a team may agree a local protocol which includes the offer of HNA and PCSP prior to treatment, after the end of treatment and (if required) on transition to further treatment or to palliative care
- HNA and PCSP activity are part of the National Cancer Plan 2026 and will carry forward previous commitments that these are offered at least at diagnosis/start of treatment and again around/after the end of treatment, although for some cancers, diagnosis and completion of treatment may happen on the same day
    - for example, early skin cancer
- HNAs and PCSPs may be requested at any time by the patient
    - please use the nearest appropriate point in pathway code
- if a patient is undergoing further treatments following primary treatment, then the timepoint of pathway should be Start of/During/End of Treatment, as appropriate
    - for example, treatment for recurrence or metastatic disease

Staff Role Offering the Assessment (Choice 1)

This is a new mandatory data item for v10, allowing for the recording of the role of the staff member who offered the Holistic Needs Assessment (CR7950).

The staff member offering the care planning is recorded separately in CR7960 ‘Staff Role Offering the Planning’ . It is important that both should be recorded as the PCSP may be completed by a different staff member undertaking the HNA.

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National Code	National Code Definition
01	Cancer Nurse Specialist
02	Other nurse
03	Allied Health Professional

National Code	National Code Definition
04	Support worker/Care Navigator (band 3 or 4)
05	Mental health care professional
06	Consultant/Associate Specialist/Junior Doctor
08	Other
09	Not known

Additional notes to help with data recording of CR7950 'Staff Role Offering the Assessment':

- HNAs are carried out by any health or social care professional and by support workers/care navigators, volunteers or by the person themselves from home
  - hence, this data item is capturing the staff member offering the HNA rather than how the assessment is carried out
- a staff role is needed to support workforce planning of who and how HNAs are being offered

Staff Role Offering the Planning (Choice 2)

This is a new mandatory data item for v10, allowing for the recording of the role of the staff member who offered the care planning (CR7960).

The staff member offering the HNA is recorded separately in CR7950 'Staff Role Offering the Assessment. It is important that both should be recorded as the care plan (PCSP) may be completed by a different staff member undertaking the HNA.

National Code	National Code Definition
01	Cancer Nurse Specialist
02	Other nurse
03	Allied health Professional
04	Support worker/Care Navigator (band 3 or 4)

National Code	National Code Definition
05	Mental health care professional
06	Consultant/Associate Specialist/Junior Doctor
08	Other
09	Not Known

Additional notes to help with data recording of CR7960 Staff Role Offering the Planning:

- personalised care and support planning is usually offered by a health or social care professional
- a staff role is needed to support workforce planning of and the workforce offering PCSP activities

Information to support implementation of Holistic Needs Assessment or Personalised Care and Support Planning:

- the ACCEND career frameworks for different staff groups cover competencies on personalised care and end of treatment summaries
- Macmillan Cancer Support provide comprehensive resources including:
  - Personalised Care guide for professionals
  - educational resources via their learning and development platform and a Personalised Care Community of Practice (requires login)
  - a wide range of resources for people affected by cancer including a booklet on holistic needs assessment
- Guy's Cancer Academy's online:
  - learning package on Personalised Care and Support Planning
- E-Learning for Health's:
  - PRosPer module on supporting people with cancer in personalised care and support planning, prehabilitation and rehabilitation
- Some Cancer Alliances have Cancer Academies that offer training modules that may include personalised care
- Personalised Care Institute (not cancer specific):
  - provides a range of resources to equip health and care professionals with the knowledge, skills, and confidence to help patients get more involved in decisions about their care

Note:

- NHS England is not responsible for the content of external websites. All weblinks are current as of 30 April 2026

Core - Clinical Nurse Specialist - Personalised Care and Support Planning

This section has been retired in v10; this includes the following data items:

- CR8000 - Care Planning Offered
- CR8010 - Care Planning Completed Date
- CR8020 - Point of Pathway

These have been replaced by the version 10 schema described above, which consists of:

- CR7900 - Assessment Offered
- CR7920 - Assessment/Care Plan Status
- CR7930 - Assessment/Care Plan Date
- CR7940 - Assessment/Care Plan Point of Pathway
- CR7950 - Staff Role Offering the Assessment
- CR7960 - Staff Role Offering the Planning

Core - Multidisciplinary Team Meetings (MDT)

This section was redesigned in v9 to accommodate the new Guidance for Streamlining Multi-Disciplinary Team meetings (MDTM) that includes bringing some patients onto pre-defined Standards of Care (SOCs).

Local SOCs must be introduced with the support of the full MDT.

All patients must be listed at the full MDTM. No patient should be removed from oversight of the MDTM or responsibility of the MDTM.

Implementation of the streamlining guidance is optional. Where streamlining is introduced, patients will be stratified to the MDTM, to either:

- patient on a SOC (no discussion)
- patient requires discussion for any given reason

Find out more about the Streamlining Multi-Disciplinary Team Meetings on the NHS England website. Questions relating to the guidance document can be directed to england.cancerpolicy@nhs.net.

For locally agreed Standards of Care MDTM, contact your relevant Cancer Alliance - details can be found on the NHS England website.

Record all MDTM's, where the patient was discussed. A new MDT section should be added if a patient was discussed at another Trust, therefore multiple MDTs can be submitted depending on the patient pathway.

There is a choice at the start to indicate if a patient was not discussed at the MDTM or this was unknown (choice 1), or if the patient was discussed (including minuting) for 'patients on predefined standard of care reviewed outside MDTM' (choice 2).

May be multiple occurrences per record (0..*)
'Multidisciplinary Team Meetings' choice - Choice 1..1
'Multidisciplinary Team Meetings' - Choice 1

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR8100	Multidisciplinary Team Meeting Discussion	an1	M

End of 'Multidisciplinary Team Meetings' - Choice 1

'Multidisciplinary Team Meetings' - Choice 2
Start of section - 'Multidisciplinary Team Meetings' detail

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR8110	Multidisciplinary Team Meeting Discussion Type	an1	M
CR3080	Multidisciplinary Team Meeting Date	an10 ccyy-mm-dd	M
CR3090	Organisation Site Identifier of Multidisciplinary Team Meeting	min an5 max an9	M
CR3190	Multidisciplinary Team Meeting Type	an4	M
CR3160	Multidisciplinary Meeting Type Comment	max an60	R

End of section -'Multidisciplinary Team Meetings' detail
End of 'Multidisciplinary Team Meetings' - Choice 2
End of 'Multidisciplinary Team Meetings' choice

Note:

- the following data items form a 2-choice menu and one of the following choices must be provided per CORE - MDT submission (1..1)

Choice 1: Multidisciplinary Team Meeting Discussion

This is a mandatory data item, which identifies if the patient was no discussed at the MDT or if the discussion status was not known at that point.

National Code	National Code Definition
1	Not discussed at all
2	Discussion Status Not Known

Choice 2: Multidisciplinary Team Meeting Discussion Type

This is a mandatory data item, which identifies what MDT the patient was discussed at or if the Patient was on a 'predefined Standard of Care reviewed outside MDTM'. This is an initiative from NHS England to help reduce the number of patients being discussed at an MDT.

National Code	National Code Definition
1	Discussed within Trust MDTM
2	Patient on predefined Standard of Care
3	Discussed at MDTM at another Trust

Multidisciplinary Team Meeting Date

This is a mandatory data item. Record the date of each Multidisciplinary Team meeting where the patient was discussed. This will include but will not be limited to the date when a treatment planning decision was made which is covered specifically under Multidisciplinary Team Discussion Date in the Cancer Care Plan Section.

Note:

- if a patient is on a 'Predefined Standard of Care reviewed outside MDTM', use the date of discussion where this was minuted

Organisation Site Identifier of Multidisciplinary Team Meeting

This is a mandatory data item. The 'Organisation Identifier' of the organisation site where the multidisciplinary team meeting took place. (For joint MDT meetings which cover more than one hospital record a new MDT record for each discussion).

Notes:

- this item is important to assign patients to the appropriate MDT at different points in the pathway

- it should be set up in the reference data for the MDT and can then be automatically included for each MDT meeting where the patient is discussed

Multidisciplinary Team Meeting Type

This is a mandatory data item. Record the type of MDT meeting at which the patient was discussed. Please provide the most detailed level of information that is possible.

Notes:

- the codes at the high level (shown with 2 trailing zeros) are Tumour groups and the items below each high-level code are Multidisciplinary Teams
- organisations should only use the high-level code if the multidisciplinary team type is not adequately listed.
- if this high-level code is used please make sure that the 'Multidisciplinary Meeting Type Comment' field below is also completed

National Code	National Code Definition
0100	Breast
0101	Breast MDT
0102	Metastatic Breast MDT
0200	Brain/Central Nervous System
0201	Brain Central Nervous System (CNS)/Neuroscience MDT
0202	Rehabilitation and Non-Surgical (Network) MDT
0203	Pituitary MDT
0204	Skull base MDT
0205	Spinal cord MDT
0206	Low grade glioma MDT

National Code	National Code Definition
0207	Metastasis to brain MDT
0208	Stereotactic Radiosurgery (SRS) MDT
0209	Genetic subtypes MDT
0300	Colorectal
0301	Colorectal MDT
0302	Anal MDT
0400	CTYA
0401	Paediatric Combined Diagnostic and Treatment MDT
0402	Paediatric Haematology only MDT
0403	Paediatric non-CNS solid tumours only MDT
0404	Paediatric CNS malignancy only MDT
0405	Paediatric Late Effects MDT
0406	Paediatric (POSCU) MDT
0407	Teenage and Young Adult MDT
0408	Teenage and Young Adult Late Effects MDT
0500	Gynaecology
0501	Gynaecology local MDT
0502	Gynaecology Specialist MDT
0600	Haematology

National Code	National Code Definition
0601	Haematology MDT
0602	Lymphoma MDT
0603	Plasma Cell MDT
0604	Myeloid MDT
0605	Bone marrow transplant MDT
0700	Head and Neck (including Thyroid)
0701	Upper Aerodigestive Tract (UAT) only MDT
0702	Upper Aerodigestive Tract (UAT) and Thyroid MDT
0703	Thyroid Only MDT
0800	Lung
0801	Lung MDT
0802	Mesothelioma Specialist MDT
0900	Sarcoma
0901	Bone and Soft tissue MDT
0902	Bone MDT
0903	Soft tissue MDT
1000	Skin
1001	Skin Local MDT
1002	Skin Specialist MDT

National Code	National Code Definition
1003	Melanoma MDT
1004	Supra T-Cell Lymphoma MDT
1100	Upper GI
1101	Upper GI Local MDT
1102	Oesophago-Gastric Specialist MDT
1103	Hepatobiliary and Pancreatic (HPB) Specialist MDT
1104	Pancreatic/Biliary (PB) Specialist MDT
1105	Hepatic Specialist MDT
1200	Urology
1201	Urology Local MDT
1202	Urology Specialist MDT
1203	Testicular Supranetwork MDT
1204	Penile Supranetwork MDT
1300	Other
1301	CUP MDT
1302	Neuroendocrine MDT
1303	Palliative Care MDT
1304	Enhanced Supportive Care MDT
1305	Stereotactic Radiotherapy (SRT) only (all sites)

National Code	National Code Definition
1306	Adrenal MDT

Note:

- 0102 Metastatic Breast MDT, 1305 - Stereotactic Radiotherapy (SRT) only (all sites) and 1306 Adrenal MDT are new MDTs added in v10

Multidisciplinary Meeting Type Comment

This data item provides additional information on the MDT Meeting type, if not covered in the list provided.

Core - Cancer Care Plan

This section includes details applicable to care planning, including performance status, prognostic factors and treatment options which are normally discussed at the MDT meeting. Many of the site-specific data items will be recorded at this point in the patient pathway. See site-specific sections for further details.

The 'Cancer Care Plan Date' will be the MDT after all the investigations have been completed and the treatment plan is agreed. At this point all the information will be available to record the Final pre-treatment TNM and Stage Grouping too.

Important notes 'Cancer Care Plan':

- there will only be one cancer care plan section completed for each record
- most of the data items in this section will normally be available at the meeting at which the first definitive treatment was discussed
- after treatment starts, the treatment plan may change due to medical reasons, this does not create a new cancer care plan, merely changes the treatment plan

Important notes 'Predefined Standard of Care reviewed outside MDTM':

- for patients on a 'Predefined Standard of Care reviewed outside MDTM', the 'Cancer Care Plan Date' will be the MDT after all the investigations have been completed and the treatment plan is agreed, that the patient was minuted at (as per the MDT Section)
- the additional information would be obtained by the MDT Coordinator, liaising with the clinical team responsible for the patients care pathway

Some of the data items in the Care Plan sections of the site-specific data sets will only be available after the initial treatment has been completed or at a subsequent MDT discussion. The items in this section will not therefore necessarily relate to the date of the MDT recorded as 'Multidisciplinary Team Discussion Date (Cancer)'.

Additional notes:

- if a patient is treated prior to the MDT, they should be added to the next MDT for discussion
- this can be classed as discussed at MDT at the point of treatment, for the cancer care plan episode
- therefore, if a patient has a treatment prior to the MDT and is subsequently added to the next MDT, the care plan can be documented as care plan agreed (this often happens for skin)

May be up to one occurrence per Record (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR0430	Multidisciplinary Team Discussion Date (Cancer)	an10 ccyy-mm-dd	R
CR0460	Cancer Care Plan Intent	an1	R

Start of repeating item - 'Planned Cancer Treatment Type'

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR0470	Planned Cancer Treatment Type	an2	R*

End of repeating item - 'Planned Cancer Treatment Type'

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR0490	No Cancer Treatment Reason	an2	R

The following data items have been retired from v10:

- CR8200 - Professional Registration Issuer Code – Consultant Multidisciplinary Team Lead)
- CR8210 - Professional Registration Entry Identifier - Consultant (Multidisciplinary Team Lead)
- CR2060 - Adult Comorbidity Evaluation - 27 Score

Multidisciplinary Team Discussion Date (Cancer)

This is the date when a treatment planning decision was made.

Cancer Care Plan Intent

The intention of a Cancer Care Plan developed within a Cancer Care Spell.

National Code	National Code Definition
C	Curative
Z	Non Curative
X	No active treatment
9	Not known

Note:

- this only needs to be recorded when the care plan is agreed and for Haematology, it is understood that for most cases this would be [Z-Non Curative]

Planned Cancer Treatment Type

This is the clinically proposed treatment, usually agreed at a Multidisciplinary Team Meeting, and may not be the same as the treatment which is subsequently agreed with the patient.

More than one planned treatment type may be recorded, and these may either be alternative or sequential treatments. This only needs to be recorded when the first treatment planning decision is made.

National Code	National Code Definition
01	Surgery
02	External Beam Radiotherapy (excluding Proton Therapy)
03	Chemotherapy
04	Hormone therapy
05	Specialist palliative care
06	Brachytherapy therapy
07	Biological therapy

National Code	National Code Definition
10	Other Active Treatment
11	No active treatment
12	Bisphosphonates
13	Anti-Cancer Drug - Other
14	Radiotherapy - Other
99	Not known

Notes:

- 02 – Teletherapy has been updated to External Beam Radiotherapy (excluding Proton Therapy) to mirror current clinical terminology
- 12 – Biphosphonates has been corrected to Bisphosphonates

No Cancer Treatment Reason

The main reason why no active cancer treatment is specified within a Cancer Care Plan.

National Code	National Code Definition
01	Patient declined treatment
02	Unfit: poor performance status
03	Unfit: significant co-morbidity
04	Unfit: advanced stage cancer
05	Unknown primary site
06	Died before treatment
07	No active treatment available
08	Other

National Code	National Code Definition
10	Monitoring only
99	Not known

Core - Molecular and Biomarkers - Germline Testing for Cancer Predisposition

Notes:

- this complete section has been removed on the advice of the COSD Governance Board, following a thorough 6-month clinical review
  - all data items within this section have been retired from v10, as we now have more accurately collection direct from Genomic Laboratories

Core - Molecular and Biomarkers - Somatic Testing for Targeted Therapy and Personalised Medicine

Notes:

- this complete section has been removed on the advice of the COSD Governance Board, following a thorough 6-month clinical review
  - all data items within this section have been retired from v10, as we now have more accurately collection direct from Genomic Laboratories

Core - Clinical Trials

Notes:

- CR1290 - Patient Trial Status (Cancer) and CR6700 - Clinical Trial Decision Date (Patient) have moved to CTYA - Clinical Trials
- CR6710 - Date Clinical Trial Started and CR1260 - Cancer Clinical Trial Treatment Type have been retired from v10

Core - Staging

The 'TNM Coding Edition' and 'Version Numbers' are mandatory data items; this will help improve the data quality of stage being submitted from Trusts.

The stage of a cancer is a description of how far the cancer has spread. The Union for International Cancer Control (UICC) TNM stage is the most widely used system for staging cancers. The American Joint Committee on Cancer (AJCC), and ENETS (European Neuroendocrine Tumour Society) coding systems can also be recorded throughout these fields. The TNM coding edition field allows for accurate allocation especially where editions change over time.

For COSD the stage may be recorded at 3 points in the patient pathway.

Pre-treatment:

- a clinical TNM (cTNM) stage based on assessment before treatment
- this is derived by the clinical team, based on a combination of physical examination, imaging, endoscopy, biopsy, surgical exploration, and any other relevant clinical assessment
- usually assessed at the MDT meeting where the treatment options are agreed

Pathological stage:

- a pathology TNM (pTNM) stage is based on evidence acquired from a histopathology report from the surgical resection or excision biopsy
- recorded in the 'COSD Pathology' data set only

Integrated stage:

- this is the stage derived by the clinical team
- it is determined from the integration of the pathology stage (pTNM) following surgical resection as the first definitive treatment and the basis of any other clinical assessment such as metastasis (cM) or final review of the case

For most cancers TNM staging is used, however please see the site-specific sections for other staging systems.

In addition:

- the core staging section is not applicable to most Haematological and Gynaecological diagnoses – however, relevant site-specific stage should be recorded
- there will only be one Staging section completed for each record
- general guidance on the recommended staging system by tumour type is included in Appendix E

Use of MX and M0:

- the Union for International Control Cancer (UICC) and American Joint Committee on Cancer (AJCC) TNM version 8 edition states that M0 should be used if there is no positive evidence of distant metastases
- the Union for International Control Cancer (UICC) and American Joint Committee on Cancer (AJCC) TNM version 8 edition removed the not assessed category (x)
- the MX category is considered to be inappropriate as clinical assessment of metastasis can be based on physical examination alone
- the use of MX may result in exclusion from staging

Neuroendocrine Tumours

These are currently staged using the European Neuroendocrine Tumour Society TNM Staging System (ENETS). Where this staging system is used, the values should be recorded in the generic TNM stage fields in the core data set. In addition:

- the 'TNM Coding Edition' should be recorded as "3"
- the 'TNM Version Number (Staging)' should be recorded as "E"

Two values provided for the stage

Clinical teams may on occasion's record 2 values for a stage field if there is a degree of uncertainty. If the patient has no further investigations to confirm the precise value then the lower value should be recorded for COSD.

For example, T1 / T2 would be recorded as T1. In these cases, it is vitally important that stage is confirmed with the clinician to ensure that the most up-to-date clinical decision is being recorded.

Neoadjuvant therapy

For Neoadjuvant patients only record the Clinical stage and the Pathology stage.

Note:

- if the patient has had neoadjuvant therapy (for example, Chemotherapy or Radiotherapy before surgical treatment) the integrated stage may be the same as the pre-treatment stage

May be up to one occurrence as per Primary Cancer Pathway (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR0520	T Category (Final Pretreatment)	max an15	R

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR0540	N Category (Final Pretreatment)	max an15	R
CR0560	M Category (Final Pretreatment)	max an15	R
CR0580	TNM Stage Grouping (Final Pretreatment)	max an15	R
CR6800	Organisation Site Identifier (Reported Pretreatment TNM Stage)	min an5 max an9	R
CR3120	Stage Date (Final Pretreatment Stage)	an10 ccyy-mm-dd	R
CR0620	T Category (Integrated Stage)	max an15	R
CR0630	N Category (Integrated Stage)	max an15	R
CR0640	M Category (Integrated Stage)	max an15	R
CR0610	TNM Stage Grouping (Integrated)	max an15	R
CR6810	Organisation Site Identifier (Reported Integrated TNM Stage)	min an5 max an9	R
CR3130	Stage Date (Integrated Stage)	an10 ccyy-mm-dd	R
CR6980	TNM Coding Edition	an1	M
CR2070	TNM Version Number (Staging)	max an2	M

T Category (Final Pretreatment)

'T Category (Final Pretreatment)' is the code which classifies the size and extent of the primary tumour before treatment.

N Category (Final Pretreatment)

'N Category (Final Pretreatment)' is the code which classifies the absence or presence and extent of regional lymph node metastases before treatment.

M Category (Final Pretreatment)

'M Category (Final Pretreatment)' is the code which classifies the absence or presence of distant metastases pre-treatment.

TNM Stage Grouping (Final Pre-Treatment)

Record the overall clinical TNM stage grouping of the tumour, derived from each T, N and M component prior to treatment. This classification is based on all the evidence available to the clinician(s) with responsibility for assessing the patient and for the patient's treatment plan. Such evidence arises from physical examination, imaging, endoscopy, biopsy, surgical exploration and other relevant examinations. The overall pre-treatment TNM stage grouping indicates the tumour stage at the time the treatment plan was devised.

Organisation Site Identifier (Reported Pretreatment TNM Stage)

This is the 'Organisation Identifier' of the organisation site where the diagnosing MDT agreed the Final Pre-treatment TNM Stage.

Stage Date (Final Pretreatment Stage)

The date of the 'TNM Stage Grouping (Final Pre-Treatment)'.

T Category (Integrated Stage)

'T Category (Integrated)' is the code which classifies the size and extent of the primary tumour after treatment and/or after all available evidence has been collected.

N Category (Integrated Stage)

'N Category (Integrated)' is the code which classifies the absence or presence and extent of regional lymph node metastases after treatment and/or after all available evidence has been collected.

M Category (Integrated Stage)

'M Category (Integrated)' is the code classifies the absence or presence of distant metastases after treatment and/or after all available evidence has been collected.

TNM Stage Grouping (Integrated)

Record the overall TNM stage grouping of the tumour, derived from each T, N and M component after treatment. This classification is based on all the evidence available to the clinician(s) with responsibility for assessing the patient. It will be determined on the basis of all the clinical, imaging and pathological data available following the first surgical procedure(s), such as this is the integration of the pathological staging with the clinical staging. The overall integrated TNM stage grouping indicates the tumour stage after treatment and/or after all available evidence has been collected.

Organisation Site Identifier (Reported Integrated TNM Stage)
This is the 'Organisation Identifier' of the organisation site where the treating MDT post-surgery (where surgery was the first treatment) agreed the Integrated TNM Stage.

Stage Date (Integrated Stage)
The date of the 'TNM Stage Grouping (Integrated)'.

TNM Coding Edition
The TNM Coding edition in use. This is a mandatory data item.

National Code	National Code Definition
1	UICC (Union for International Cancer Control)
2	AJCC (American Joint Committee on Cancer)
3	ENETS (European Neuroendocrine Tumour Society)

TNM Version Number (Staging)
The AJCC or UICC or ENETS version number used for Tumour, Node and Metastasis (TNM) staging for cancer diagnosis. This is a mandatory data item.

Notes:

- the TNM Coding Edition and TNM Version Number (Staging) must be specified for all staging data submitted and has been made mandatory within the schema
- for ENETS, record 'E' as the version

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions or not upload the legacy data items in the new record (if that data is not available).

Core - Site Specific Staging

These are required to record and improve the tumour specific 'site specific stage'. Whilst the date is mandatory, the organisational code has been dropped to required, however it would still be expected to be submitted where known.

These data items would only be reported if there is a linked site specific stage also reported. Please refer to the individual tumour specific sections where there is a site specific stage.

For example:

- Central Nervous System (CTYA)
  - Chang Staging System Stage
- Children Teenage and Young Adults (CTYA)
  - Wilms Tumour Stage
  - International Neuroblastoma Risk Group (INRG) Staging System
  - Pretext Staging System Stage
  - Pretext Annotation Factors
  - International Staging System for Retinoblastoma
- Gynaecological
  - Figo Stage
- Haematological
  - Ann Arbor Stage
  - Binet Stage
  - R-ISS Stage for Myeloma
- Haematological (CTYA)
  - Murphy (St Jude) Stage
  - Children's Oncology Group (Cog) Staging System Stage
  - Central Nervous System Involvement
- Liver
  - Barcelona Clinic Liver Cancer (BCLC) Stage
- Urological (Testicular)
  - Stage Grouping (Testicular)

May be multiple occurrences per primary cancer pathway (0..*)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR8300	Organisation Site Identifier (Site Specific Stage)	min an5 max an9	R

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR8310	Stage Date (Site Specific Stage)	an10 ccyy-mm-dd	M

Organisation Site Identifier (Site Specific Stage)
This is the ORGANISATION IDENTIFIER of the ORGANISATION SITE who carried out the site specific stage.

Notes:

- this data item has reverted to 'Required', to support data collection where the reporting Trust does not know the organisation or MDT that confirmed the site specific stage
- in most cases it would be the MDT that provides all the details to make a site specific stage, as it may require a combination of clinical, radiological, and sometimes pathological input
    - therefore, use the organisation that hosted the MDT

Stage Date (Site Specific Stage)
The date of the sample or MDT that provided a positive stage result. This is mandatory; therefore, the section cannot be submitted without this field completed.

Notes:

- in most cases it would be the MDT that provides all the details to make a site specific stage, as it may require a combination of clinical, radiological, and sometimes pathological input
    - in these cases, use the date of the MDT that reported the stage
- if only a pathological sample resulted in the positive stage result
    - in these cases, use the date the sample was reported
- if in doubt, always consult the MDT lead or clinical champion for more details

Core - Treatment

The initial record is completed up to the first treatment, but all subsequent treatments are also required. Treatments are also reported for cases covered by Cancer Waiting Times although some additional details are included in COSD in both generic core and site specific sections.

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

May be multiple occurrences per record (0..*)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR6540	Adjunctive Therapy	an1	R
CR0680	Cancer Treatment Intent	an2	R
CR1370	Treatment Start Date (Cancer)	an10 ccyy-mm-dd	M
CR2040	Cancer Treatment Modality (Registration)	an2	M
CR1450	Organisation Site Identifier (of Provider Cancer Treatment Start Date)	min an5 max an9	M

Start of Section - Consultant (treatment)
May one occurrences per Core - Treatment (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR8400	Professional Registration Issuer Code - Consultant (Treatment)	an2	M

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR8410	Professional Registration Entry Identifier - Consultant (Treatment)	min an1 max an32	M

End of section - Consultant (treatment)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR8420	End of Treatment Summary Date	an10 ccyy-mm-dd	R
CR0740	Discharge Date (Hospital Provider Spell)	an10 ccyy-mm-dd	R
CR9080	Destination of Discharge (Hospital Provider Spell)	an2	R

The following data item has been retired in v10 and replaced with CR9080:

- CR0750 Discharge Destination (Hospital Provider Spell), due to a change in the data dictionary

Adjunctive Therapy

Adjunctive therapy is therapy given in addition to the main therapy to maximize its effectiveness. This field allows for the accurate recording of these to determine if adjunctive therapy was adjuvant (after the main therapy) or neo-adjuvant (before the main therapy) or not applicable.

National Code	National Code Definition
1	Adjuvant
2	Neoadjuvant
3	Not Applicable (Primary Treatment)
9	Not Known

Cancer Treatment Intent

The original intention of the cancer treatment provided during a Cancer Care Spell.

National Code	National Code Definition
01	Curative
02	Palliative
03	Disease Modification
04	Diagnostic
05	Staging
06	Uncertain of Treatment Intent
09	Not Known
98	Other

Notes:

- 'Disease Modification' is drug specific
- 'Diagnostic' and 'Staging' are surgery specific

Important note:

- the next 3 data items are mandatory and will improve the data quality and ascertainment of treatment records submitted

Treatment Start Date (Cancer)

This is a mandatory data item. This is the Start Date of the first, second or subsequent cancer treatment given to a patient who is receiving care for a cancer condition. Applicable to all registered cases.

Cancer Treatment Modality (Registration)

This is a mandatory data item. Applicable for active and non-active treatments, and to record where a patient declines treatment. Applies to all treatments at all stages in the patient pathway, including both primary cancer and non primary pathways.

National Code	National Code Definition
01	Surgery
02	Anti-cancer drug regimen (Cytotoxic Chemotherapy)
03	Anti-cancer drug regimen (Hormone Therapy)
04	Chemoradiotherapy
05	External Beam Radiotherapy (excluding Proton Therapy)
06	Brachytherapy
07	Specialist palliative care
08	Active Monitoring (excluding non-specialist Palliative Care)
09	Non-specialist Palliative Care (excluding Active Monitoring)
10	Radio Frequency Ablation (RFA)
11	High Intensity Focussed Ultrasound (HIFU)
12	Cryotherapy
13	Proton therapy
14	Anti-cancer drug regimen (other)
15	Anti-cancer drug regimen (Immunotherapy)
16	Light therapy (including Photodynamic Therapy and Psoralen and Ultra Violet A (PUVA) therapy)
17	Hyperbaric oxygen therapy
19	Radioisotope therapy (including Radioiodine)

National Code	National Code Definition
20	Laser treatment (including Argon Beam therapy)
21	Biological therapies (excluding Immunotherapy)
22	Radiosurgery
97	Other treatment
98	All treatment declined

Note:

- 05 – Teletherapy (Beam Radiation excluding Proton Therapy) has been updated to External Beam Radiotherapy (excluding Proton Therapy) to mirror current clinical terminology

Organisation Site Identifier (of Provider Cancer Treatment Start Date)

This is a mandatory data. This is the 'Organisation Identifier' of the organisation site where the treatment took place.

Important notes:

- the next 2 data items are within a multiple selection group and are mandatory within the group
- there may be one occurrence per Core – Treatment Section

Professional Registration Issuer Code – Consultant (Treatment)

This is the 'Consultant Core (Treatment)' and is a code which identifies the professional registration body for the consultant or health care professional responsible for the treatment of the patient.

National Code	National Code Definition
02	General Dental Council
03	General Medical Council
04	General Optical Council

National Code	National Code Definition
08	Health and Care Professions Council
09	Nursing and Midwifery Council

Professional Registration Entry Identifier – Consultant (Treatment)

This is the registration identifier allocated by an organisation for the consultant or health care professional who is responsible for the treatment of the patient.

End of Treatment Summary Date

Record the date the End of Treatment Summary (EOTS) was completed at the end of each phase of acute (secondary care) treatment(s) or at the end of a sequence of treatments and sent to the patient and/or the GP. It is for local determination when in the pathway to provide the End of Treatment Summary(s). Locally, teams may prefer to call these documents 'Treatment Summary' as they may also be given during ongoing treatment.

Notes:

- this is no longer a multiple repeating data item, only one EOTS date is required per treatment record
- this is now a 'required' data item, previously 'optional'
- if the EOTS field is left blank for an earlier treatment, the EOTS date for a later treatment may be auto populated into this blank field within some cancer management systems and then reported to NDRS, within the current COSD record
    - it is advised therefore to always fill in an EOTS date for each treatment, to prevent any reporting data anomalies

Additional notes to help with data recording:

- the End of Treatment Summary is 'complete' when it has been shared with the person and/or their GP
- include the dates of End of Treatment Summaries where:
    - a patient is offered but doesn't want a copy, but it is sent to their GP
    - a patient has a copy, but they requested that it is not sent to their GP
- there should be at least one End of Treatment Summary date relating to primary treatment

- the End of Treatment Summary is different from a discharge summary due to the incorporation of specific information and advice for the patient and GP (see below)
- it should be produced promptly after the treatment
- due to many patients having multiple treatments, it may be preferable to label the document as 'Treatment Summary' or 'Radiotherapy Treatment Summary' to avoid confusion for patients
- the document has to be named 'End of Treatment Summary' in COSD to avoid confusion with other documents such as the Treatment Plan
- check your cancer system requirements regarding data entry, as you may need to record the End of Treatment Summary in more than one place to ensure data is submitted to COSD.

Information to support implementation of End of Treatment Summaries:

- the ACCEND career frameworks for different staff groups cover competencies on personalised care and end of treatment summaries
- Macmillan Cancer Support provide educational resources via their learning and development platform requires login
- an End of Treatment Summary plan is a quality standard in the NICE guidance for Haematological Cancers
- the content of an End of Treatment Summary will normally follow a locally agreed template, incorporating key items that will support self-management, as well as guiding GP practices. Contents include:
  - a summary of diagnosis and treatment
  - schedule of surveillance scans and tests
  - potential markers of recurrence/secondary cancers and information on what to do in these circumstances
  - information on likely side-effects of treatment and how best to manage these, including those that might appear after some months/years
  - key contact point for rapid re-entry if recurrence markers are experienced or if serious side effects become apparent
  - referrals made to other services, for example rehabilitation, mental health care
  - prompts for GP actions
  - lifestyle advice and self-management guidance that the person has been given or signposted to, including details of local support groups and psychosocial support, such as complementary therapies, physical activity, financial support and employment advice

Note:

- NHS England is not responsible for the content of external websites, all weblinks are current as of 30 April 2026

Discharge Date (Hospital Provider Spell)

The date a patient was discharged from a hospital provider spell.

Destination of Discharge (Hospital Provider Spell)

This is a new data item in v10. This records the destination of a patient on completion of the hospital provider spell. It can also indicate that the patient died.

National Code	National Code Definition
19	Usual place of residence unless listed below, for example, a private dwelling whether owner occupied or owned by Local Authority, housing association or other landlord. This includes wardened accommodation but not residential accommodation where health care is provided. It also includes PATIENTS with no fixed abode.
29	Temporary place of residence when usually resident elsewhere (includes hotel, residential educational establishment)
30	Repatriation from high security psychiatric accommodation in an NHS Hospital Provider (NHS Trust or NHS Foundation Trust)
37	Court
40	Penal establishment
42	Police Station / Police Custody Suite
48	High Security Psychiatric Hospital, Scotland
49	NHS other hospital provider - high security psychiatric accommodation dation
50	NHS other hospital provider - medium secure unit
51	NHS other hospital provider - ward for general PATIENTS or the younger physically disabled

National Code	National Code Definition
52	NHS other hospital provider - ward for maternity PATIENTS or neonates
53	NHS other hospital provider - ward for PATIENTS who are mentally ill or have learning disabilities
55	Care Home With Nursing
56	Care Home Without Nursing
66	Local Authority foster care
79	PATIENT died or still birth
84	Independent Sector Healthcare Provider run hospital - medium secure unit
87	Independent Sector Healthcare Provider run hospital - excluding medium secure unit
88	Hospice
89	ORGANISATION responsible for forced repatriation
Default Codes	
98	Not applicable - Hospital Provider Spell not finished at episode end (i.e. not discharged) or current episode unfinished
99	DESTINATION OF DISCHARGE not known

Treatment - Surgery

This section is a child of 'Core – Treatment and only contains surgery details.

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

May be up to one occurrence per Core - Treatment (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR0710	Procedure Date	an10 ccyy-mm-dd	M
CR8500	Surgical Admission Type	an1	R

Start of repeating section - 'Consultant Code (Surgeon)' (0..*)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR8510	Professional Registration Issuer Code - Consultant (Surgeon)	an2	M
CR8520	Professional Registration Entry Identifier - Consultant (Surgeon)	min an1 max an32	M

End of repeating section - 'Consultant Code (Surgeon)'

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR0720	Primary Procedure (OPCS)	an4	R
CR3040	Primary Procedure (SNOMED CT)	min n6 max n18	R

Start of repeating item - 'Procedure (OPCS)'

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR0730	Procedure (OPCS)	an4	R*

End of repeating item - 'Procedure (OPCS)'

Start of repeating item - 'Procedure (SNOMED CT)'

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR3050	Procedure (SNOMED CT)	min n6 max n18	R*

End of repeating item - 'Procedure (SNOMED CT)'

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR6480	Unplanned Return to Theatre Indicator	an1	R
CR6010	ASA Score	an1	R
CR6310	Surgical Access Type	an1	R

Procedure Date

This is a mandatory data item and records the date the surgical procedure was carried out.

Surgical Admission Type

This records the type of surgical admission.

National Code	National Code Definition
1	Elective
2	Emergency
9	Not Known

Important notes:

- the next 2 data items are within a multiple selection group and are mandatory within the group
- there may be multiple occurrences per ‘CORE - Treatment - Surgery’

Professional Registration Issuer Code – Consultant (Surgeon)

This is a code which identifies the professional registration body for the consultant or health care professional who is part of the surgical procedure. If he/she is part of a surgical team, record all consultant surgeons responsible for the procedure.

National Code	National Code Definition
02	General Dental Council
03	General Medical Council
04	General Optical Council
08	Health and Care Professions Council
09	Nursing and Midwifery Council

Professional Registration Entry Identifier - Consultant (Surgeon)

This is the registration identifier allocated by an organisation for the consultant or health care professional who is part of the surgical procedure. If he/she is part of a surgical team, add all consultant surgeons responsible for the procedure.

Primary Procedure (OPCS)

This is the OPCS Classification of Interventions and Procedures code which is used to identify the primary procedure carried out.

Primary Procedure (SNOMED CT)

The primary procedure is the main procedure carried out using SNOMED CT. This may be recorded in addition to 'Primary Procedure (OPCS)'.

Notes:

- any Trust who can submit data in SNOMED CT, must now do so
- refer to the 'how to find a SNOMED CT procedure' section

Procedure (OPCS)

This is a procedure(s) other than the 'Primary Procedure (OPCS)', carried out and recorded for CDS or Hospital Episode Statistics purposes (more than one code can be recorded).

Procedure (SNOMED CT)

This is a procedure(s) other than the 'Primary Procedure', carried out and recorded for CDS or Hospital Episode Statistics purposes (more than one code can be recorded). This may be recorded in addition to 'Procedure (OPCS)'.

Note:

- any Trust who can submit data in SNOMED CT, must now do so
- refer to the 'how to find a SNOMED CT procedure' section

Unplanned Return to Theatre Indicator

Whether or not the patient required a second (unplanned) operation during the same admission as the primary procedure.

National Code	National Code Definition
Y	Yes
N	No
9	Not known

The proposed collection of this data item is:

- if it is a planned primary procedure, select N (as this is not an unplanned return to theatre)
- if this is an unplanned return to theatre (within the same admission/discharge period), create a completely new surgery treatment record for this and then select Y
- the admission and discharge dates for both however would be the same
- the procedure date, OPCS procedures and possibly surgeon(s) may be different

ASA Score

The ASA physical status classification system is a system for assessing the fitness of patients before surgery. You would expect to find this information in the pre-operative notes or the Anaesthetist review section.

National Code	National Code Definition
1	A normal healthy patient.
2	A patient with mild systemic disease
3	A patient with severe systemic disease
4	A patient with severe systemic disease that is a constant threat to life
5	A moribund patient who is not expected to survive without the operation
6	A declared brain-dead patient whose organs are being removed for donor purposes

Surgical Access Type

Approach to surgery (laparoscopic, thoracoscopic, open, robotic, or converted). Record the access used to perform the operation. Recording the surgical access is standard clinical practice and should be obtained from the operational notes.

National Code	National Code Definition
1	Open Surgery
2	Laparoscopic/Thoracoscopic with planned conversion to open surgery
3	Laparoscopic/Thoracoscopic with unplanned conversion to open surgery
4	Laparoscopic/Thoracoscopic completed
5	Robotic Surgery
Z	Not applicable

Stem Cell Transplantation

Note:

- this complete section has been removed on the advice of the COSD Governance Board, following a thorough 6-month clinical review

Core - Acute Oncology

This section is designed to capture Acute Oncology (AO) episodes within a Trust.

The purpose of these items is to capture the unplanned care cancer patients receive in an acute care environment. These data are only for collection by those Hospitals with an Acute Oncology Service (AOS) in place.

Key Objectives for collecting AO data within COSD:

- gather data on the unplanned care provided to cancer patients
- use the data to generate benchmarks and report against metrics
- identify new standards of care for cancer patients requiring emergency care or specialised support

To support the local, regional, and national reporting against these key objectives, the below data items have been identified:

May be multiple occurrences per record (0..*)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR8700	Acute Oncology Assessment Date	an10 ccyy-mm-dd	R
CR8710	Organisation Site Identifier (Acute Oncology)	an5	R
CR8720	Assessment Location	an2	R

Start of repeating item - Patient type

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR8730	Patient Type	an2	R*

End of repeating item - Patient type

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR8740	Outcome	an2	R

This information has been selected specifically because it is commonly collected by AO teams and the collation of these few data items with other nationally collected datasets such as Hospital Episode Statistics (HES), Emergency Care Data Set (ECDS), Systemic Anti-Cancer Therapy (SACT) will provide a view of the unplanned care provided to cancer patients.

Please note the rules have changed for COSD v10, and the assessments can be telephone or face to face and carried out by the AOS or staff trained by the AOS to provide appropriate levels of care and decision making.

Each assessment that takes place during a patient's AO episode should be reported as an individual record, even if the assessments share the same date and Outcome; it is important all data is completed for each assessment to capture all the activity for each episode.

Details about the individual data items and their value lists follow below.

Acute Oncology Assessment Date
This is the date the oncology assessment was carried out.

Additional supporting information includes:

- if more than one assessment has taken place during the AO episode, supply the date of each assessment, along with all the additional data items laid out below, including the Outcome
- include AO assessments carried out by AOS and other medical staff trained to provide AO care (who may not be members of the AOS)

Organisation Site Identifier (Acute Oncology)
This is the 'Organisation Identifier' of the organisation acting as a Health Care Provider.

Additional supporting information includes:

- this data item will identify the location of the hospital or cancer treatment centre in which the patient was assessed
- the 5-digit hospital-specific code of where the assessment took place must be recorded rather than the 3-digit Trust level code

Assessment Location

This is the location where the Acute Oncology (AO) assessment was performed within the health care provider.

National Code	National Code Definition
01	Emergency Care Department
02	Medical Assessment Unit
03	Same Day Emergency Care Service
04	Ward
05	Out-Patient Clinic
06	Dedicated Acute Oncology Bed/Chair
07	Day Case Unit
08	Chemotherapy Unit
09	Health Care Provider Telephone Assessment
10	Radiotherapy Department
97	Other

Notes:

- '98 – Other' has been replaced with '97 – Other', as per Data Dictionary guidelines
- 09 and 10 are new choices in v10

The assessment location will generally be one of the above, or similarly named – select the closest match or 'Other' if none of them fit.

Additional supporting information includes the following:

01 - Emergency Care Department:

- this would be selected if the patient was in an emergency care department chair or bed, admitted or not, when the AOS assessment was carried out

02 - Medical Assessment Unit:
- this would be selected if the patient was in a Medical Assessment Unit chair or bed, admitted or not, when the AOS assessment was carried out

03 - Emergency Ambulatory Care Unit:
- this would be selected if the patient was assessed in an Ambulatory Care unit when the AOS assessment was carried out

04 - Ward:
- this would be selected if it was the most appropriate selection given the other options available for where the AOS assessment was carried out

05 - Out-Patient Clinic:
- this would be selected if it was the most appropriate selection given the other options available for where the AOS assessment was carried out

06 - Dedicated Acute Oncology Bed/Chair:
- this would be selected if the patient was assessed whilst in a dedicated AO bed or chair – admitted or not, when the AOS assessment was carried out

07 - Day Case Unit:
- this would be selected if it was the most appropriate selection given the other options available for where the AOS assessment was carried out

08 - Chemotherapy Unit:
- this would be selected if it was the most appropriate selection to make given the other options available for where the AOS assessment was carried out, inpatient or not

09 - Health Care Provider Telephone Assessment:
- this would be selected for telephone assessments carried out as part of the AOS patient management, regardless of whether the patient is asked to attend for a face-to-face assessment or not
  - for example, the whole episode may be handled via telephone
- however, if preferred, the assessments included in the COSD submission could be limited to only those telephone assessments carried out prior to advising a patient to come in for a face-to-face assessment or as part of the follow-up calls prior to discharging a patient from the AOS
  - the choice will be up to each AOS based on what makes most sense to their service set up, who handles the telephone assessments and where the data is recorded

10 - Radiotherapy Department:
- this would be selected if it was the most appropriate selection to make

98 - Other:

- this would be selected if none of the other options were appropriate

Patient Type

Record the 'type' each patient presentation is grouped within.

National Code	National Code Definition
01	New Presentation
02	Treatment Complication
03	Suspected or Confirmed Neutropenic Sepsis
04	Cancer Complication
08	Suspected or Confirmed Metastatic Spinal Cord Compression (MSCC)
09	Comorbidity Complications
98	Other

Notes:

- '05', '06' and '07' have been deleted as the Information can be more accurately linked by analysts using the whole COSD record
- multiple selections can be made if more than one option fits

Use the below Guidance on how to record Patient Types to support your choices. We acknowledge it is not always clear whether a patient is presenting with treatment or cancer related complications, and we appreciate that it is unlikely the initial choice(s) made will be updated retrospectively.

The above list of options can be mapped to the below Patient Groups, which may be more familiar to you:

- Type I - all patients in whom a first diagnosis of cancer is suspected in the emergency setting
- Type II - patient with known cancer who present as an emergency with acute complications of non-surgical treatment, including Systemic Anti-Cancer Therapy (SACT) or radiotherapy
- Type IIIa - patients with known cancer and are acutely ill because of the disease itself; this group represent the largest proportion of

emergency patients and often present with complex issues including comorbidity, progressive cancer, and end of life care (EOL) needs
- Type IIIb - patient with known cancer and are acutely ill because of comorbidity

See below table for mapping between the data item values and the Type I, II and III patient groups.

Patient group	Acute Oncology patient type
Type I	• New presentation • Suspected or Confirmed MSCC (choose this instead of New Presentation if MSCC is thought to be the primary cause of the AOS episode)
Type II	• Treatment Complication • Suspected or Confirmed Neutropenic Sepsis (choose this instead of Treatment Complication if NS is thought to be the primary cause of the AOS episode)
Type IIIa	• Cancer Complication • Suspected or Confirmed MSCC (choose this instead of Cancer Complication if MSCC has been previously diagnosed and is thought to be the primary cause of the AOS episode)
Type IIIb	Comorbidity
N/A	Other

The Comorbidity Complication and Other patients will help establish the volume of patients who are assessed by AOS but do not actually have a specific cancer related issue at that time.

Interpretation

01 - New Presentation (Type I):
- this option is relevant for patients who have never had a cancer diagnosis before and who are diagnosed for the first time after an emergency attendance
- because these patients will not have an existing cancer record, an eligible cancer record will need to be created to enable the reporting of the AO data items

- we acknowledge there will be some AOS activity that cannot be reported via the COSD because the patient is confirmed with a non-cancer diagnosis

02 - Treatment Complication (Type II):

- this option is relevant for patients who have received or are receiving cancer treatment and consequently, have become poorly
- this could include patients who have an acute or chronic response to treatment, for example, patients who have an AO episode for acute SACT or Radiotherapy reactions or have a chronic condition caused by historic cancer treatment which has left them with directly related health complications

03 - Suspected or Confirmed Neutropenic Sepsis (Type II)

- although this could come under Treatment Complication it has been split out to capture any patients with an AO episode that started off as a suspected or concluded as a confirmed case of Neutropenic Sepsis/Febrile Neutropenia
- these data are intended to establish a national picture of the number of suspected NS cases in England

04 - Cancer Complication (Type IIIa)

- this option is relevant for patients who have become poorly because of their cancer rather than because of the treatment they are receiving
- these patients could have a current diagnosed cancer and are on active treatment or monitoring or patients who have an historic diagnosis

08 - Suspected or Confirmed MSCC (could be Type I or Type IIIa)

- this option is for patients who are suspected of having Metastatic Spinal Cord Compression (MSCC) and should be recorded as such regardless of whether the diagnosis is confirmed
- MSCC patients could also be New Diagnosis, or Cancer Complication but it has been separated out so analysis can be carried out on the number of MSCC patients in England

09 - Comorbidity Complications (Type IIIb)

- this option is for patients who present with comorbidity complications for example, heart disease or diabetes, and receive an AOS assessment
- it is important to gather data on these patients to assess the volume of AOS activity

98 – Other

- this option covers patients who have an emergency presentation for a reason unrelated to their diagnosed cancer, treatment, or comorbidity, for example, a broken bone - this data is not essential but would again help identify the volume of AOS activity

Outcome

Record the outcome of the acute oncology episode.

National Code	National Code Definition
10	Not Admitted
11	Admitted
12	Remained Admitted
13	Discharged from hospital
14	Patient Died
15	Advised to attend for assessment
16	Discharged from acute oncology service (AOS)
17	Discharged to specialist centre
18	Telephone Assessment
98	Other

Notes:

- '8 – Other' has been replaced with '98 – Other', as per Data Dictionary guidelines
- all National Codes have been updated to improve the accuracy of data collection
- 13 has been renamed 'Discharged from hospital'
- 15, 16, 17 and 18 are new choices in v10
- a new format 'an2' has been added to accommodate above changes

This information will generally be captured in the local PAS or Emergency Department system or dedicated AOS system.

These data will help with admission avoidance and length of stay calculations and focus on the outcome of the interaction, rather than the outcome on the patient's overall condition. Patient Died has been included to cover all potential outcomes.

Interpretation

Not Admitted:

- this option would be selected if the patient was not admitted to hospital and was sent to their usual place of residence or other location after being assessed by the AOS
  - this data will be used in the SDEC calculations
- this option is also relevant if the patient was assessed by an AOS who then referred the patient to another Organisation's AOS
  - the second AOS may record their own assessment record(s) for their encounter with the patient

11 - Admitted:

- this option would be selected if the patient was assessed by AOS and admitted either on their recommendation or in consultation with relevant Acute Medicine staff

12 - Remained Admitted:

- this option would be selected if the patient was already an admitted patient before their AOS assessment and continued as an admitted patient after assessment with no recommendation by AOS to be discharged

13 - Discharged from hospital:

- this option would be selected if the patient was already an admitted patient before their AOS assessment and AOS recommended the patient was discharged after assessment
- if this data is not routinely collected by AOS, it will be available in the Hospital Episodes submissions (HES) dataset once the COSD data is curated at national level. This data is used in Length of Stay calculations

14 - Patient Died:

- this option would be selected if the patient died during their AO episode whilst onsite at the Hospital, regardless of whether they had been an admitted patient or not
- if this information is not routinely collected by AOS, it will be available in the ONS dataset once the COSD data is curated at national level

15 - Advised to attend for assessment

- this option would be selected if the patient had a telephone assessment and was advised to come into the Hospital for assessment by a member of the AOS or appropriately trained Medical Staff

16 - Discharged from acute oncology service (AOS)

- this option would be selected if the patient had a telephone or face to face assessment and it was agreed with the appropriate service or patient that AOS involvement was no longer necessary

17 - Discharged to specialist centre

- this option would be selected if the patient had been admitted to hospital and then discharged to a specialist centre
- an AOS at this new specialist centre may also assess the patient and record their own assessment record(s) for their encounter with the patient

18 - Telephone Assessment

- this option would be selected if a Telephone Assessment was planned as a follow up to either a face to face or telephone assessment, for example, the Outcome is to hold another Telephone Assessment with the patient, prior to discharging the patient from the AOS

98 - Other:

- this option has changed from '97 – Other' to '98 – Other' and no longer covers 'Discharged from hospital', 'Advised to attend for assessment', 'Discharged from acute oncology service (AOS)', 'Discharged to specialist centre' or 'Telephone Assessment' as these are now choices
- this option covers all outcomes not listed in the above

Examples of AO assessment pathways

Triage Line Assessment and Advised to Attend Emergency Department

In this example, the patient is assessed via the telephone and advised to come into hospital for assessment. The AOS advise an overnight stay with continued AOS involvement. AOS advise the Ward team the patient can be discharged from hospital with AOS follow up via the telephone until discharged from the AOS.

Day in pathway	Assessment Location	Outcome
Day One	Health Care Provider Telephone Assessment	Advised to Attend for Assessment
Day One	Emergency Care Department	Admitted
Day Two	Ward	Remained Admitted
Day Three	Ward	Discharged from Hospital
Day Five	Health Care Provider Telephone Assessment	Telephone Assessment
Day Six	Health Care Provider Telephone Assessment	Discharged from AOS

Same Day Emergency Care (SDEC)

In this example a patient attends Hospital without prior contact with an AOS, is assessed by an AOS on the same day and AOS advise patient returns to their usual place of residence and managed via telephone with, for example, a fast-tracked outpatient appointment in place.

Day in pathway	Assessment Location	Outcome
Day One	e.g., Emergency Care Department, Ambulatory Care Unit	Not Admitted
Day One	Health Care Provider Telephone Assessment	Telephone Assessment
Day Two	Health Care Provider Telephone Assessment	Discharged from AOS

Discharged to a Specialist Centre

In this example, the patient attends an ED without previous contact with an AOS telephone line and the ED assess, admit, and alerts AOS, who assess the patient and advise they remain admitted but need to be transferred to a specialist centre for ongoing care. Using the Discharge to Specialist Centre infers the patient is discharged from hospital and AOS. The AOS at the specialist centre may record their own encounter with the patient.

Day in pathway	Assessment Location	Outcome
Day One	Emergency Care Department	Admitted
Day One	Ward	Remained Admitted
Day Two	Ward	Discharge to Specialist Centre

Inpatient Assessment

In this example a patient is an inpatient prior to referral to the AOS and remains admitted throughout the AOS encounter.

Day in pathway	Assessment Location	Outcome
Day One	Ward	Admitted
Day One	Ward	Remained Admitted
Day Two	Ward	Remained Admitted
Day Three	Ward	Discharge from AOS

Guidance on Who Should Submit the Data

The following flow chart helps identify which Organisation is responsible for submitting the AOS data to the Registry. This acknowledges that AOS see patients whose cancer care is or has been provided by other Health Care Providers in the region or country.

For AOS data to be included in a COSD submission, it needs to be linked to an eligible cancer record, for example, a registerable cancer condition.

If your Organisation has, is or will be the Health Care Provider for the patient, the AOS data you collect can be included in the monthly submission your Organisation sends to the Registry.

If you would like your AOS encounter data to be submitted to the registry, but your Organisation does/will not have an eligible cancer record to link the AOS data to, you can send the data to the Health Care Provider responsible for submitting the patient's COSD file and they can link the data to their cancer record and submit it on your behalf; this will build the picture of overall AOS activity across your region and nationally.

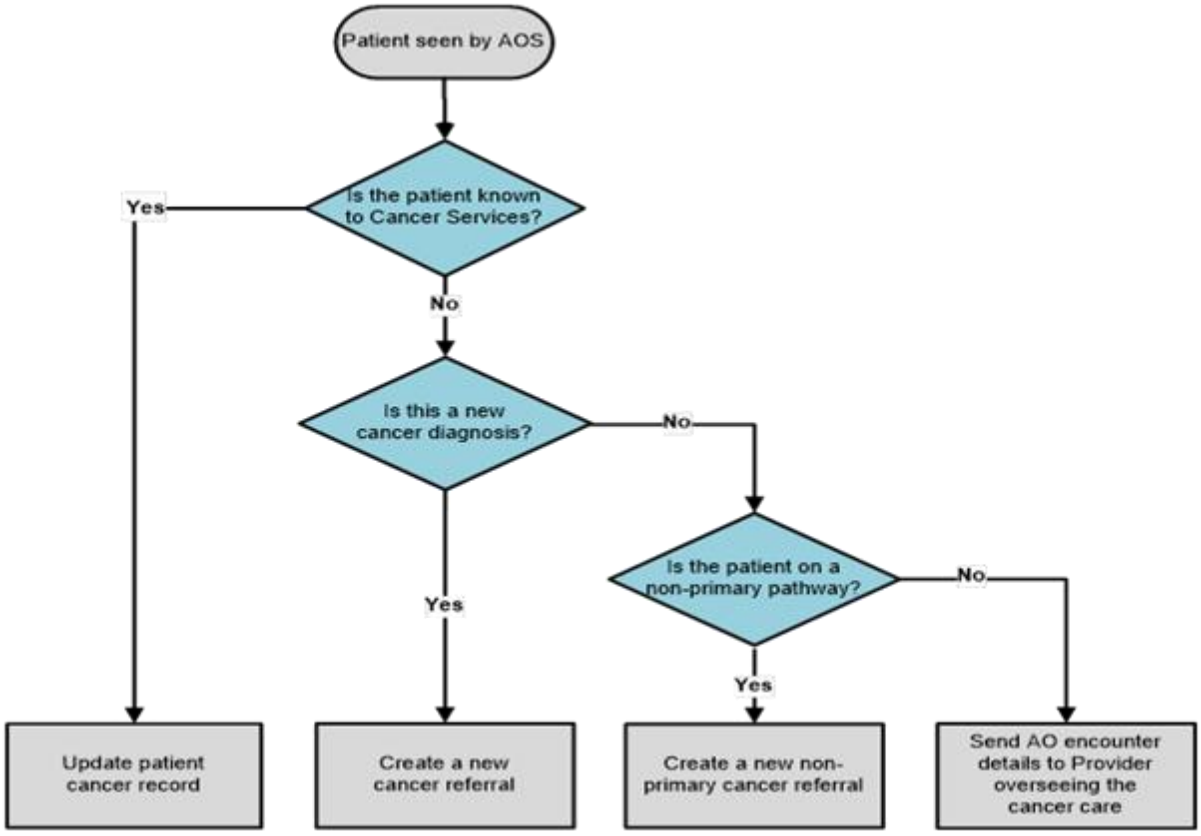
It does not matter whether the patient's cancer care is historic, current, or planned – the AOS encounter data should stimulate the submission of the patient's original COSD file to the Registry, with the AOS and any other new data included.

AOS Patient and Data Flow

The flow chart (below) starts with an assumption that the AOS Organisation will provide the patient's cancer care (Health Care Provider) - if the patient is referred to another Organisation for management, they will be responsible for creating records and submitting the AOS data.

The final two steps in the flow chart indicate if a patient should be on a non-primary patient pathway (see non-Primary pathway details in this User Guide) and whether the AO data items will form part of a cancer record your Organisation is responsible for submitting or if you need to send it to another Health Care Provider so they can submit it on your behalf.

The text from the flowchart follows the image.



Step 1: the patient is seen by AOS.

- is the patient known to Cancer Services?
- if yes: update patient cancer record.
- if no…

Step 2: is this a new cancer diagnosis?

- if yes: create a new cancer referral.
- if no…

Step 3: is the patient on a non-primary pathway?

- if yes: create a new non-primary cancer referral.
- if no…

Send AO encounter details to Provider overseeing the cancer care.

Core - Laboratory Results

This is section is designed to enforce all laboratory results to be reported with both the date and organisation where the test was done. This will be the parent group to many child sections across the data set and site specific data sets.

May be multiple occurrences per record (0..*)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR8800	Laboratory Result Date	an10 ccyy-mm-dd	M
CR8810	Organisation Identifier (Laboratory Result)	min an3 max an5	M

Laboratory Result Date
The date on which an investigation was concluded, for example the date the result was authorised.

Organisation Identifier (Laboratory Result)
The 'Organisation Identifier' of the organisation site acting as a Health Care Provider, which processed the sample.

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

Laboratory results - General

This group is a child of 'CORE - Laboratory Results', and will mandate:

- the date the sample was reported
- the organisation who processed the sample

May be up to one occurrence per Core - Laboratory Results (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CR8900	LDH Value	max n6	R
CR8910	Beta Human Chorionic Gonadotropin (Serum)	max n8	R
CR8920	Alpha Fetoprotein (Serum)	max n8	R

LDH Value

This is the peak LDH (Lactate Dehydrogenase Level) at diagnosis.

Beta Human Chorionic Gonadotropin (Serum)

Maximum Serum level of HCG at diagnosis in IU/l (measured only for CNS germ cell tumours). It is expected that this would be valid and required for the following tumour types:

- Germ Cell CNS
- Germ Cell Non CNS Tumours

Alpha Fetoprotein (Serum)

Maximum Serum level of alpha feto protein at diagnosis. AFP units recorded in kU/l (values > 100,000 are recorded). It is expected that this would be valid and required for the following tumour types:

- Germ Cell CNS
- Germ Cell Non CNS Tumours
- Hepatoblastoma
- Hepatocellular Carcinoma

Site Specific - Breast

ICD-10 CODES

Note:

- please refer to Appendix A and B for site specific registerable ICD codes for Breast Cancer patients

The following data item has been retired from v10:

- BR4120 – NPI Score

With the formation of the new National Cancer Audit Collaborating Centre (NATCAN), all previously independent cancer audits have been brought into one organisation. Part of the rationale for this is to reduce the burden of data collection and reporting across the NHS.

As a result, all data moving forward will be from existing data sources. It is important therefore for Trusts to collect all the site specific data items within COSD, as these will form a large part of future analysis by both the National Audit of Primary Breast Cancer (NAoPri) and the National Audit of Metastatic Breast Cancer (NAoMe).

More information about NATCAN can be found via their official website using this link.

For patients with breast cancer who have been diagnosed with recurrence of their cancer, it is important they have a named CNS (whose job plan includes the care of patients with recurrent/metastatic breast cancer) assigned to them and available for support around the time when the recurrence was identified.

The NAoMe would like all MDT coordinators to ensure the corresponding data item on CNS contact is recorded when completing the COSD record for a non-primary cancer pathway.

The CNS data item should be completed using the options available in [CR2050 - Clinical Nurse Specialist Indication Code], which can be found in the 'CORE - Clinical Nurse Specialist + Risk Factor Assessment' section.

Triple diagnostic assessment

This data item was recommended by the Breast Expert Advisory Group and continues to be important data within COSD and will be used by the new NAoPri cancer audit.

May be up to one occurrence per record (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
BR4400	Triple Diagnostic Assessment	an1	M

Triple Diagnostic Assessment
If a triple diagnostic assessment was completed, indicate if this was completed for the patient in a single visit, following the initial referral?

National Code	National Code Definition
Y	Yes
N	No
9	Not Known

Clinical Nurse Specialist – Risk Factor Assessment

This is a child of Core - Clinical Nurse Specialist + Risk Factor Assessment. This group of data items are only required for patients aged 70 years and over at diagnosis and will be used by the two new breast cancer audits.

Notes:

- these data only pertain to the risk factors below and not the CNS contact itself
- the CNS contact should be collected within the 'Core' (using CR2050)
    - this requires completion, irrespective if there has been contact made, for all patients, regardless of age

May be up to one occurrence per Clinical Nurse Specialist - Risk Factor Assessment (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
BR4500	Fitness Assessment Indicator	an1	R
BR4510	Fitness Assessment Date	an10 ccyy-mm-dd	R
BR4520	Clinical Frailty Scale	an1	R
BR4530	Abbreviated Mental Test Score	max n2	R
BR4540	Cardiorespiratory Disease	an1	R
BR4550	Other Non Breast Locally Advanced/Metastatic Malignancy	an1	R
BR4560	Dementia Diagnosis	an1	R

Fitness Assessment Indicator

Indicate if there was a Fitness Assessment carried out on the patient.

National Code	National Code Definition
Y	Yes
N	No

Note:

- If yes, please complete the following 6 data items

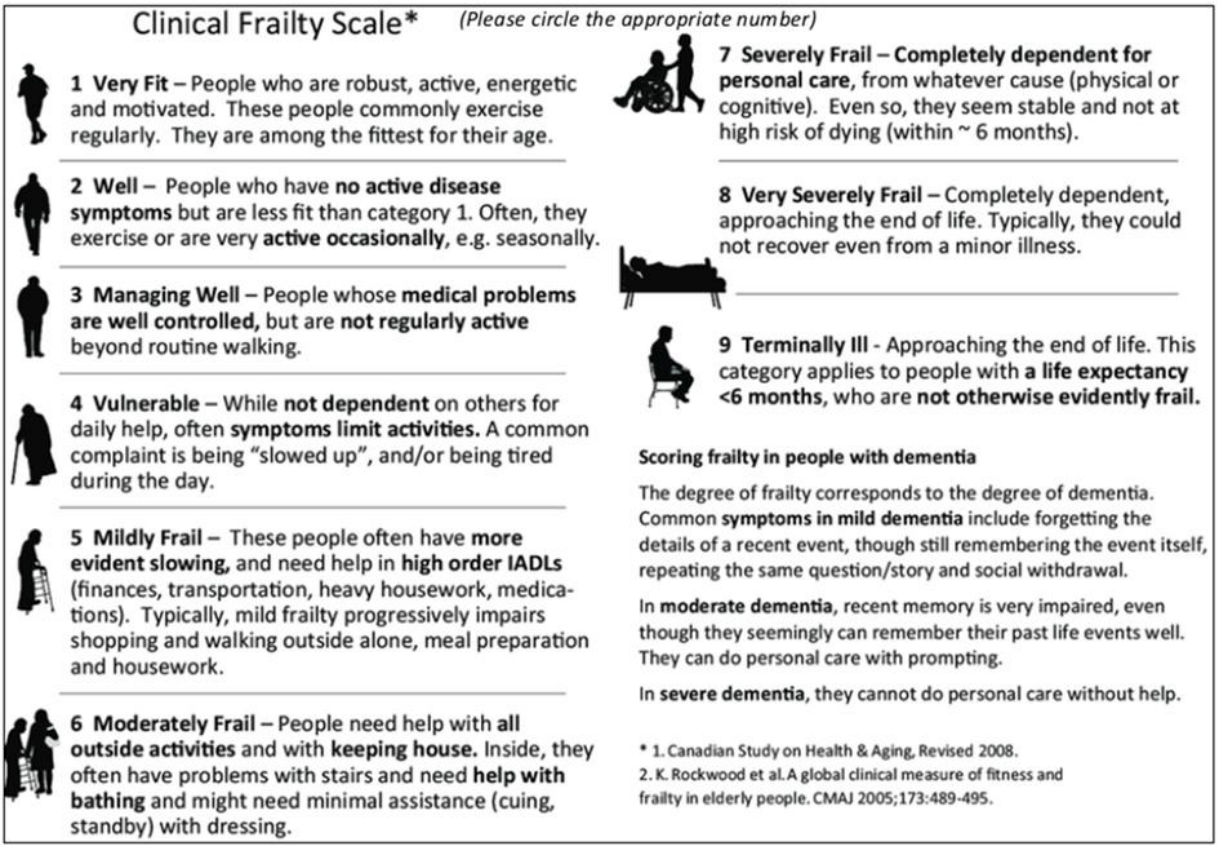
Fitness Assessment Date

Record the date the fitness assessment was completed.

Clinical Frailty Scale

Record the point on the Clinical Frailty Scale, as assigned by the appropriate clinician after discussion with the patient.

National Code	National Code Definition
1	Very fit
2	Well
3	Managing well
4	Vulnerable
5	Mildly frail
6	Moderately frail
7	Severely frail
8	Very severely frail
9	Terminally ill



Clinical Frailty Scale* *(Please circle the appropriate number)*

1 Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 Well – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.

3 Managing Well – People whose **medical problems are well controlled,** but are **not regularly active** beyond routine walking.

4 Vulnerable – While **not dependent** on others for daily help, often **symptoms limit activities.** A common complaint is being "slowed up", and/or being tired during the day.

5 Mildly Frail – These people often have **more evident slowing,** and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 Moderately Frail – People need help with **all outside activities** and with **keeping house.** Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.

7 Severely Frail – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9 Terminally Ill - Approaching the end of life. This category applies to people with **a life expectancy <6 months**, who are **not otherwise evidently frail.**

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

Sources:

Clinical frailty scale from Canadian Study on health and ageing, revised 2008. K. Rockwood et al. A global measure of fitness and frailty in elderly people. CMAJ 2005; 173:489-495.

The chart above explains each frailty measure, using the Clinical Frailty Scale. A text description of the image is below.

Text description of the Clinical Frailty Scale

1. Very fit - people who are robust, active, energetic, and motivated. These people commonly exercise regularly. They are among the fittest for their age.
2. Well - people who have no active disease symptoms but are less fit than category 1. Often they exercise or are very active occasionally, for example seasonally.
3. Managing well - people whose medical problems are well controlled but are not regularly active beyond routine walking.
4. Vulnerable - while not dependent on others for daily help, often symptoms limit activities. A common complaint is being "slowed up", and/or being tired during the day.
5. Mildly frail - these people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.
6. Moderately frail - people need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.
7. Severely frail - completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within 6 months).
8. Very severely frail - completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.
9. Terminally ill - approaching the end of life. This category applies to people with a life expectancy of less than 6 months, who are not otherwise evidently frail.

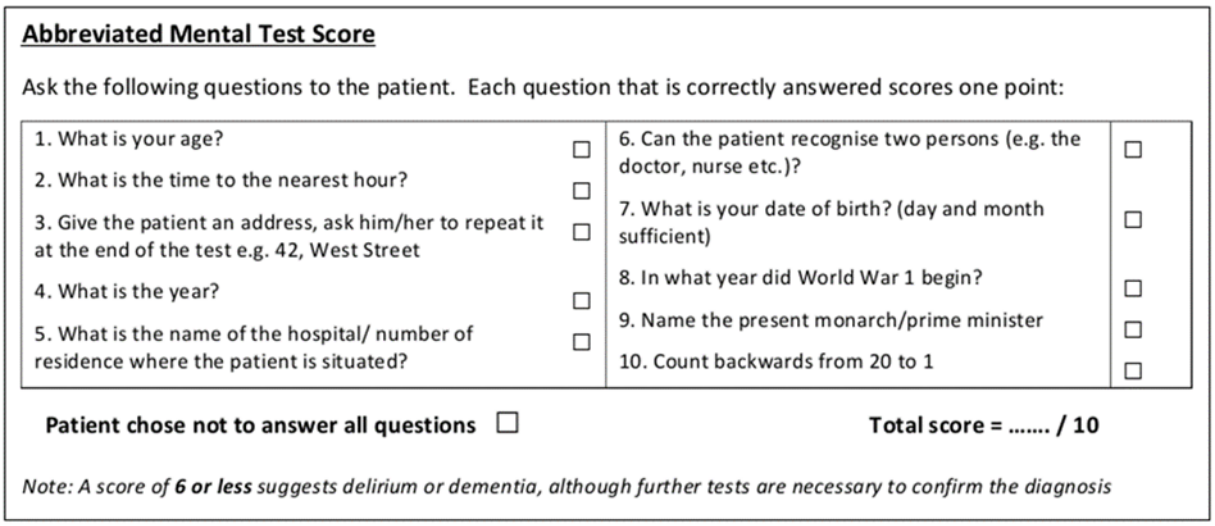
Scoring frailty in people with dementia:

The degree of frailty corresponds to the degree of dementia. Common symptoms:

- in mild dementia include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal
- in moderate dementia, recent memory is very impaired, even though they seemingly can remember their past life events well, they can do personal care with prompting
- in severe dementia, they cannot do personal care without help

Abbreviated Mental Test Score

Record the total Abbreviated Mental Test Score, this should be a score from 0 to 10. A text description of the image follows it.



Abbreviated Mental Test Score

Ask the following questions to the patient. Each question that is correctly answered scores one point:

1. What is your age?	☐	6. Can the patient recognise two persons (e.g. the doctor, nurse etc.)?	☐
2. What is the time to the nearest hour?	☐	7. What is your date of birth? (day and month sufficient)	☐
3. Give the patient an address, ask him/her to repeat it at the end of the test e.g. 42, West Street	☐	8. In what year did World War 1 begin?	☐
4. What is the year?	☐	9. Name the present monarch/prime minister	☐
5. What is the name of the hospital/ number of residence where the patient is situated?	☐	10. Count backwards from 20 to 1	☐

Patient chose not to answer all questions ☐ **Total score = ……. / 10**

*Note: A score of **6 or less** suggests delirium or dementia, although further tests are necessary to confirm the diagnosis*

Text description of the Abbreviated Mental Test Score

Ask the following questions to the patient. Each question that is correctly answered scores one point:

1. What is your age?
2. What is the time to the nearest hour?
3. Give the patient an address, ask him/her to repeat it at the end of the test, for example 42 West Street.
4. What is the year?
5. What is the name of the hospital/number of residence where the patient is situated?
6. Can the patient recognise 2 persons (for example the doctor or nurse)?
7. What is your date of birth (day and month sufficient)?
8. In what year did World War 1 begin?
9. Name the present monarch/prime minister.
10. Count backwards from 20 to 1.

Total score out of 10.

Note:

- a score of 6 or less suggests delirium or dementia, although further tests are necessary to confirm the diagnosis

Cardiorespiratory Disease

Does the patient have severe cardiorespiratory disease?

National Code	National Code Definition
Y	Yes
N	No

Note:

- severe = less than ordinary physical activity or rest causes tiredness, palpitations, or shortness of breath

Other Non-Breast Locally Advanced/Metastatic Malignancy

Does the patient have any other Non-Breast Locally Advanced/Metastatic Malignancy?

National Code	National Code Definition
Y	Yes
N	No

Dementia Diagnosis

This is a new data item for v10. Does the patient already have a known diagnosis of dementia?

National Code	National Code Definition
Y	Yes
N	No

Site Specific - Central Nervous System

Overview

For the COSD, benign brain cancers are included in the Central Nervous System Data set, although they are excluded from Cancer Waits.

ICD-10 codes C47 and C69 are grouped under Brain/Central Nervous System for Cancer Waits but are excluded from the COSD Central Nervous System data set. For diseases coded under C47 (peripheral nerves and autonomic nervous system) or C69 (eye and adnexa) only the CORE data set needs to be completed.

CNS and CTYA CNS have been separated within this group to form 2 sub sections. It is hoped that this will help make data collection easier and improve ascertainment.

ICD-10 CODES

Note:

- please refer to Appendix A and B for site specific registerable ICD codes for CNS Cancer patients

The following data items have been retired from v10:

- BA3000 – Lesion Location (Radiological)
- BA3020 – Number of Lesions (Radiological)
- BA3030 – Lesion Size (Radiological)
- BA3050 – Principle Diagnostic Imaging Type
- CT7030 – Visual Acuity at Presentation
- CT7400 – Visual Fields at Presentation

Cancer care plan

May be up to one occurrence per CORE - Cancer Care Plan (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
BA3080	MDT Provisional Diagnosis (ICD)	min an4 max an6	R

MDT Provisional Diagnosis (ICD)

Working diagnosis as defined at MDT where the first definitive treatment is agreed. This is the clinical opinion which may also be informed by biopsy, radiological and/or other investigations.

Treatment

Treatment - Surgery

This section is a child of 'CORE - Treatment and will mandate:

- the date the treatment started
- the treatment modality
- the organisation that provided the treatment

May be up to one occurrence per CORE - Treatment - Surgery (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
BA3100	Lesion Location (Surgical)	an2	R
BA3200	Biopsy Type	an1	R
BA3210	Excision or Procedure Type	an1	R

Lesion Location (Surgical)

Surgically determined anatomical location of lesion(s) or where centred.

National code	National code definition	National code	National code definition
01	Frontal lobe	02	Temporal lobe
03	Parietal lobe	04	Occipital lobe
05	Pineal region	06	Hypothalamic
07	Basal ganglia/thalamic	08	Cerebellar
09	Midbrain	10	Pons
11	Medulla	12	Fourth ventricle
13	Third ventricle	14	Lateral ventricle
15	Parasagittal/parafalcine dura	16	Posterior fossa convexity dura
17	Convexity dura	18	Petrous temporal bone
19	Orbital roof	20	Skull vault
21	Scalp	22	Anterior cranial fossa
23	Middle cranial fossa	25	Infratemporal fossa
26	Pterygopalatine fossa	27	Anterior clinoid dura

National code	National code definition	National code	National code definition
28	Sphenoid wing dura	29	Subfrontal dura
30	Suprasellar dura	31	Clival dura
32	Cavernous sinus	33	Cerebellopontine angle
34	Jugular bulb	35	Venous angle dura
36	Foramen magnum	37	Cervical intramedullary
38	Cervical intradural	39	Cervical extradural
40	Cervical bony	41	Thoracic intramedullary
42	Thoracic intradural	43	Thoracic extradural
44	Thoracic bony	45	Lumbar intramedullary
46	Lumbar intradural	47	Lumbar extradural
48	Lumbar bony	98	Other

Note:

- this data item was renamed on the advice of the NHS Data Model and Dictionary Service, previously 'Tumour Location (Surgical)'

Biopsy Type

Identify type of biopsy (where performed)

National Code	National Code Definition
1	Frame-based stereotactic biopsy
2	Frameless stereotactic biopsy
3	Open biopsy
4	Percutaneous biopsy
5	Endoscopic biopsy
6	Other Biopsy
9	Not Known

Excision or Procedure Type

Identify type of excision or procedure (where performed)

National Code	National Code Definition
1	Limited (<50%)
2	Partial (50-69%)
3	Subtotal (70-95%)
4	Total Macroscopic
5	Extent Uncertain
6	CSF Division Procedure
9	Not Known

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

Laboratory results - Germ cell CNS tumour

This group is for recording germ cell data for CNS tumours, and is a child of CORE - Laboratory Results, and will mandate:

- the date the sample was reported
- the organisation who processed the sample

May be up to one occurrence per CORE - Laboratory Results (0..1)
CNS - Laboratory results - Germ Cell CNS tumours choice - Choice 1..1
CNS - Laboratory results - Germ Cell CNS tumours - Choice 1

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
BA4000	Alpha Fetoprotein (Cerebrospinal Fluid)	max n8	M

End of CNS - Laboratory results - Germ Cell CNS tumours - Choice 1

CNS - Laboratory results - Germ Cell CNS tumours - Choice 2

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
BA4010	Beta Human Chorionic Gonadotropin (Cerebrospinal Fluid)	max n8	M

End of CNS - Laboratory results - Germ Cell CNS tumours - Choice 2
End of CNS - Laboratory results - Germ Cell CNS tumours choice

Note:

- the following data items form a 2-choice menu, if selected at least one of the following choices must be provided (and are mandatory) per 'CNS - Laboratory Results - Germ Cell CNS Tumours (1..1)'

Choice 1: Alpha Fetoprotein (Cerebrospinal Fluid)
Maximum level of alpha feto protein in the Cerebrospinal Fluid at diagnosis. AFP units recorded in kU/l (values > 100,000 are recorded. (Measured only for CNS germ cell tumours).

Note:

- this has a new data item number in v10, previously CT6530

Choice 2: Beta Human Chorionic Gonadotropin (Cerebrospinal Fluid)
Maximum CSF level of HCG at diagnosis in IU/l. (Measured only for CNS germ cell tumours).

Notes:

- this has a new data item number in v10, previously CT6550

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

Treatment - Surgery - CTYA

This section is a child of 'Core – Treatment', and will mandate:

- the date the treatment started
- the treatment modality
- the organisation that provided the treatment

May be up to one occurrence per Core – Treatment – Surgery (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT7390	Resection Status	an1	R

Resection Status
The Resection Status of the tumour. This is determined at MDT by a combination of surgical history and postop imaging.

National Code	National Code Definition
1	Complete resection
2	Incomplete resection (< 1.5 cm^2 remaining)
3	Incomplete resection (≥ 1.5 cm^2 remaining)
4	Not Applicable, Biopsy only

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

Site Specific Staging

It is important that 'where applicable' all stageable cancers are staged for every case. All site specific staging fields are mandatory and a child of 'CORE – Site Specific Staging' Section, and together mandates the collection of:

- the date the sample was taken which provided a positive site specific stage outcome or the MDT where the stage was agreed
- the organisation who carried out the stage
  - this is a 'required' data item from v10, but important to collect if known
- the stage itself

The Chang stage is a combination of Cerebrospinal fluid (CSF) and imaging findings and can only be done taking both findings into account. As a result, the section name has been updated in v10.

May be up to one occurrence per Core Site - Specific Staging (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT6560	Chang Staging System Stage	an2	M

Chang Staging System Stage

This is a mandatory data item. Chang staging is now a standard staging procedure for Medulloblastoma, CNS PNET, ATRT, ependymoma and CNS germ cell tumours.

National Code	National Code Definition
M0	no evidence of metastatic disease
M1	microscopic tumour cells found in CSF
M2	gross nodular seeding in cerebellum, cerebral subarachnoid space, or in the third or fourth ventricles
M3	gross nodular seeding in spinal subarachnoid space
M4	metastasis outside cerebrospinal axis

Site Specific - Colorectal

ICD-10 CODES

Note:

- please refer to Appendix A and B for site specific registerable ICD codes for Colorectal Cancer patients

Future contracting of NBOCA

The contract for the National Gastrointestinal Cancer Audit Programme (GICAP) at the Royal College of Surgeons of England, which is made up of NBOCA and the National Oesophago-Gastric Cancer Audit (NOGCA), comes to an end on 31 May 2023. From 1 June 2023 both NBOCA and NOGCA will move into the National Cancer Audit Collaborating Centre (NATCAN) at the Clinical Effectiveness Unit (CEU) of the Royal College of Surgeons of England (RCS England).

Part of the rationale for this is to reduce the burden of data collection and reporting across the NHS. As a result, all data moving forward will be from existing data sources. It is important therefore for Trusts to collect all the site specific data items within COSD, as these will form a large part of future analysis by NBOCA.

More information about NATCAN can be found via their official website using this link

Diagnosis

May be up to one occurrence per - CORE Diagnosis (0..1)

Start of repeating item - 'Synchronous Tumour Indicator'

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CO5400	Synchronous Tumour Indicator	an2	R

End of repeating item - 'Synchronous Tumour Indicator'

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CO5160	Tumour Height Above Anal Verge	max n2	R

Synchronous Tumour Indicator

Record any synchronous tumours in the Colon as identified by the clinician at presentation. Synchronous tumours are defined as discrete tumours apparently not in continuity with other primary cancers originating in the same site or tissue, multiple synchronous tumours can be reported.

National Code	National Code Definition
01	Caecum
02	Appendix
03	Ascending Colon
04	Hepatic Flexure
05	Transverse Colon
06	Splenic Flexure
07	Descending Colon
08	Sigmoid Colon
09	Rectosigmoid
10	Rectum

Tumour Height Above Anal Verge

Record the approximate height in centimetres of the lower limit of the tumour above anal verge as measured by rigid sigmoidoscopy or MRI only.

Note:

- this is for rectal cancer only and is supported by the NBOCA, which only allows for HAAV for IDC10 and major site C20 (Malignant neoplasm of rectum)

Clinical Nurse Specialist (CNS)

This section is required to carry details of Clinical Nurse Specialist type (specific to Colorectal Cancers).

May be multiple occurrences as per Core - Clinical Nurse Specialist + Risk Factor (0..*)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CO5180	Clinical Nurse Specialist Type	an1	R

Clinical Nurse Specialist Type

Record the type of Clinical Nurse Specialist assigned to the patient during their treatment pathway.

National Code	National Code Definition
1	Clinical Nurse Specialist
2	Stoma Nurse Specialist
8	Other
9	Not Known

Treatment - Surgery

This is a new section in v10 and is required to carry details of the surgical urgency type specific for Colorectal Cancers.

May be up to one occurrence per - Core Treatment - Surgery (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CO6000	Surgical Urgency Type	an1	R

Surgical Urgency Type

This is a new data item for v10. Record the type of surgical urgency assigned to the patient during their treatment pathway.

National Code	National Code Definition
1	Immediate
2	Urgent
3	Expedited
4	Elective

This data item was requested to support the National Bowel Cancer Audit.

Additional supporting notes:

- IMMEDIATE – Immediate life, limb, or organ-saving intervention – resuscitation simultaneous with intervention
  - normally within minutes of decision to operate
  - life-saving
    - other; for example, limb or organ saving
- URGENT – Intervention for acute onset or clinical deterioration of potentially life-threatening conditions, for those conditions that may threaten the survival of limb or organ, for fixation of many fractures and for relief of pain or other distressing symptoms
  - normally within hours of decision to operate
- EXPEDITED – Patient requiring early treatment where the condition is not an immediate threat to life, limb, or organ survival
  - normally within days of decision to operate
- ELECTIVE – Intervention planned or booked in advance of routine admission to hospital
  - timing to suit patient, hospital, and staff

Whilst it is recognised that additional categories or sub-categories could be defined it is important that the classification remains as simple as possible to use. Please refer to the National Confidential Enquiry into Patient Outcome and Death website for more information.

Site Specific - CTYA

ICD-10 CODES

Note:

- please refer to Appendix A and B for site specific registerable ICD codes for CTYA patients, where the patient is under 25 at the time of diagnosis

The following data items have been retired from v10:

- CT7000 - Treated According to CCLG Guidelines
- CT7010 - CCLG Guideline Name
- CT7090 - Urine VMA / Creatinine Ratio
- CT6160 - Specialty Sub Code (Chemotherapy Consultant)

Overview

The following age groupings are used for COSD:

- paediatric = under 16 years at time of diagnosis
- teenage = 16 - 18 years (under 19) at time of diagnosis
- young adult = 19 - 24 at time of diagnosis

The following guidelines are intended to support the decision on which data sets should be submitted.

Where the patient is discussed by an age specific (paediatric or TYA) MDT at a designated paediatric or TYA Principal Treatment Centre (PTC), the responsibility for completing the CTYA data set rests with the PTC. For patients (of any age) who are also discussed at a site specific MDT, or where the disease is not specified in the CTYA data set, (for example the diagnosis of a colorectal carcinoma), the appropriate site specific data set should also be completed by the relevant MDT.

National guidance offers patients (aged 19 to 24 years) the option of referral to a TYA PTC, although the guidance also indicates that all such patients should be discussed at a TYA MDT even if they are not referred to the PTC for treatment. If, despite this, the patient is only discussed by a site specific MDT, that team should complete the appropriate site specific data set and the relevant additional (non-disease-specific) items in the CTYA data set.

Where a disease is covered by both the CTYA and a site specific data set (such as some haematological diseases), only one set of disease specific items needs to be completed (either CTYA or site specific according to the speciality of the treating team). The non-

disease-specific items in the CTYA data set should however be completed as per the preceding paragraphs.

Disease specific data items

A table has been created and uploaded to the NDRS website, which shows which data items are applicable to each specific diagnosis. It is important to note that some of these have now moved to other sections within COSD to help improve ascertainment, however the disease specific groupings have not changed.

Note:

- use this link to download the CTYA disease specific data item list

Referral

May be up to one occurrence per CORE – Referrals and First Stage of Patient Pathway (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT6050	Specialty (Referrer to Specialist)	an3	R
CT2000	Cancer Symptoms First Noted Date	max an10 ccyy-mm-dd	R

Specialty (Referrer to Specialist)

The specialty of the person referring to the patients Principal Treatment Centre or age specific Specialist TYA MDT.

Cancer Symptoms First Noted Date

Record the time when the symptoms were first noted related to this diagnosis as agreed between the consultant and the patient. This will normally be recorded by the consultant first seeing the patient in secondary care.

Depending on the length of time this should normally include at least the month and year. The day should also be included if known. If symptoms have been present for a long time then it may only be possible to record the year. In these various circumstances the Format/Length will be:

- date: (including year, month and day): CCYY-MM-DD
- year and month: YYYY-MM
- year only: YYYY

Notes:

- this has been moved from CORE to CTYA and is 'ONLY' required for CTYA cases
- this data item has a new data item number in v10, previously CR2000

Diagnosis

May be up to one occurrence per CORE – Diagnosis (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT6030	Consultant Specialty (at Diagnosis)	an3	R
CT6040	Consultant Age Specialty (at Diagnosis)	an1	R

Consultant Specialty (at Diagnosis)

The specialty of the consultant responsible for the patient at the time of diagnosis.

Consultant Age Specialty (at Diagnosis)

The age group specialty of the consultant responsible for the patient at the time of diagnosis. This will be defined by the MDT.

National Code	National Code Definition
P	Paediatric
T	Teenage and young adult
A	Adult

Diagnosis – Banked Tissue

May be up to one occurrence per CORE – Diagnosis (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT6990	Banked Tissue at Diagnosis	an1	R

Banked Tissue at Diagnosis

To carry Banked Tissue details for CTYA patients

National Code	National Code Definition
1	PATIENT approached, consented
2	PATIENT approached, but declined
3	PATIENT not approached

After discussions with Subject Matter Experts, this data item has moved from 'CORE – Diagnosis – Banked Tissue' and is 'ONLY' required for CTYA cases from v10.

Notes:

- this data item has a new data item number in v10, previously CR7700
- '9 – Not Known (Not Recorded)' has been retired in v10

Diagnosis - Neuroblastoma

May be up to one occurrence per CORE - Diagnosis (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT7070	Life Threatening Symptoms at Presentation	an1	R

Life Threatening Symptoms at Presentation

Record if there were any life threatening symptoms at presentation.

National Code	National Code Definition
Y	Yes
N	No

Clinical Trials

May be multiple occurrences per record (0..*)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT7900	Patient Trial Status (Cancer)	an2	M
CT7910	Clinical Trial Decision Date (Patient)	an10 ccyy-mm-dd	R

Note:

- the following two data items have moved from CORE to CTYA and are 'ONLY' required for CTYA cases

Patient Trial Status (Cancer)

This is now a mandatory data item from v10. An indication of whether a patient who is eligible for a cancer clinical trial is taking part in it. These attributes have been updated so that they better reflect the CTYA clinical trial process.

National Code	National Code Definition
01	PATIENT approached, consented to and entered clinical trial
02	PATIENT approached, but declined clinical trial
04	PATIENT not approached, but clinical trial available
05	PATIENT not approached, no clinical trial available

Notes:

- this data item has a new data item number in v10, previously CR1290
- attributes 03 and 09 have been retired from v10
- Attributes 04 and 05 are new from v10

Clinical Trial Decision Date (Patient)

Record the patient's decision date for each clinical trial, provided it is related to the recorded diagnosis.

Note:

- this data item has a new data item number in v10, previously CR6700

Site Specific Staging

It is important that all CTYA stageable cancers are staged for every case. All site specific staging fields are mandatory and a child of 'CORE – Site Specific Staging' Section, and together mandates the collection of:

- the date the sample was taken which provided a positive site specific stage outcome or the MDT where the stage was agreed
- the organisation who carried out the stage
  - this is a 'required' data item from v10, but important to collect if known
- the stage itself

Note, additional CTYA staging is required in the following areas of COSD:

- for CTYA sarcomas, carcinomas, melanomas and extracranial germ cell tumours the TNM staging system MUST be provided per submission (see relevant site-specific section)
- for CTYA Hodgkin and non-Hodgkin lymphomas the Ann Arbor and/or Murphy (St Jude) stage MUST be provided per submission (see Haematological section)
- For CTYA ALL and AML, to comply with the Toronto Cancer Staging benchmarking project, Children's Oncology Group (COG) Staging System Stage and/or Central Nervous System Involvement are required (see Haematological section)
- for CTYA medulloblastomas, other embryonal CNS tumours, ependymomas and intracranial germ cell tumours the Chang staging system MUST be provided per submission (see CNS section)
- for CTYA leukaemia's and other CTYA CNS tumours are unstageable

The following data items are specific to paediatric Wilms tumour, neuroblastomas, paediatric liver tumours (including adult hepatoblastoma), and retinoblastomas.

If applicable, one of the following Site Specific Staging Sections MUST be provided per record.

May be one occurrence per Core - Site Specific Staging (0..1)
CTYA - Site specific staging choice - Choice 1 - Renal Tumours (1..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT6330	Wilms Tumour Stage	an1	M

End of CTYA - Site specific staging choice - Choice 1

CTYA - Site specific staging choice - Choice 2 – Neuroblastoma (1..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT7050	International Neuroblastoma Risk Group (INRG) Staging System	max an2	M

End of CTYA - Site specific staging choice - Choice 2

CTYA - Site specific staging choice - Choice 3 – Hepatoblastoma (1..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT6500	Pretext Staging System Stage	an1	M

Start of repeating item - 'Pretext Annotation Factors'

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT7500	Pretext Annotation Factors	an1	M*

End of repeating item - 'Pretext Annotation Factors'
End of CTYA - Site specific staging choice - Choice 3

CTYA - Site specific staging choice - Choice 4 – Retinoblastoma (1..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT6800	International Staging System for Retinoblastoma	an1	M

End of CTYA - Site specific staging choice - Choice 4
End of CTYA - Site specific staging choice

Choice 1 - Wilms Tumour Stage

National Code	National Code Definition
1	Stage 1
2	Stage 2
3	Stage 3
4	Stage 4
5	Stage 5

Stage is determined by the results of the imaging studies and both the surgical and pathologic findings at nephrectomy. It is essential to record the stage for this group of patients and this information should be available to the MDT following treatment.

Stage 1: the tumour is only affecting the kidney
- the tumour has not spread, and it was completely removed during surgery

Stage 2: the tumour has spread beyond the kidney to the nearby structures
- there are no cancer cells in distant organs, such as the lungs
- it was completely removed during surgery

Stage 3: the tumour has either:
- not been completely removed during surgery
- spread to the lymph nodes in the tummy area (abdomen)
- burst, before or during, the surgery

Stage 4: the tumour has spread to a distant part of the body
- this is most commonly the lungs, but might be the liver, bone, brain or lymph nodes in an area outside the tummy (abdominal) or pelvic area

Stage 5: there are tumours in both kidneys
- this is called bilateral Wilms' tumour
- doctors' stage each of the tumours separately

Choice 2 - International Neuroblastoma Risk Group (INRG) Staging System

The International Neuroblastoma Risk Group Staging System (INRGSS) was designed for the International Neuroblastoma Risk Group (INRG) pre-treatment classification system.

Unlike the INSS, the INRGSS uses only the results of imaging tests taken before surgery. It does not include surgical results or spread to lymph nodes to determine the stage.

Knowledge regarding the presence or absence of image defined risk factors (IDRF) are required for this staging system.

Find out more from the INRGSS in an article from the Journal of Clinical Oncology.

National Code	National Code Definition
L1	Localised tumour not involving vital structures as defined by the list of image-defined risk factors and confined to one body compartment
L2	Locoregional tumour with presence of one or more image-defined risk factors
M	Distant metastatic disease (except stage MS)
MS	Metastatic disease in children younger than 12 months with metastases confined to skin, liver, and/or bone marrow or other sites except bone, lung or CNS

Note:

- the descriptions have been updated on the advice of CTYA clinical leads

Stage L1:

- tumours are localised tumours that do not involve vital structures as defined by the list of IDRFs (Table 1)
- the tumour must be confined within one body compartment, neck, chest, abdomen, or pelvis
- the isolated finding of intraspinal tumour extension that does not fulfil the criteria for an IDRF (Table 1) is consistent with stage L1

Stage L2:

- tumours are locoregional tumours with one or more IDRFs
- the tumour may be ipsilaterally continuous within body compartments (such as, a left-sided abdominal tumour with left-sided chest involvement should be considered stage L2)
- however, a clearly left-sided abdominal tumour with right-sided chest (or vice versa) involvement is defined as metastatic disease

Stage M:

- is defined as distant metastatic disease (such as, not contiguous with the primary tumour) except as defined for MS nonregional (distant) lymph node involvement is metastatic disease

- however, an upper abdominal tumour with enlarged lower mediastinal nodes or a pelvic tumour with inguinal lymph node involvement is considered locoregional disease
- ascites and a pleural effusion, even with malignant cells, do not constitute metastatic disease unless they are remote from the body compartment of the primary tumour

Stage MS:

- is metastatic disease in patients younger than 12 months (365 days) with metastases confined to skin, liver, and/or bone marrow and other sites, but not Bone, Lung or CNS
- MIBG scintigraphy must be negative in bone and bone marrow, provided there is MIBG uptake in the primary tumour, bone scans are not required
- the primary tumour can be L1 or L2 and there is no restriction regarding crossing or infiltration of the midline

Choice 3 - Pretext Staging System Stage

Pretext 1 - 4 refers to sectors of liver involved.

National Code	National Code Definition
1	Stage 1: tumour involves only 1 quadrant
2	Stage 2: tumour involves 2 adjoining quadrants; 2 adjoining sections free
3	Stage 3: tumour involves 3 adjoining quadrants; only 1 quadrant free or 2 non-adjoining quadrants free
4	Stage 4: tumour involves all 4 quadrants
9	Not known

Pretext Annotation Factors

This is a multiple repeating data item. Record any additional ‘Pretext Annotation Factors’ used to support Pretext Staging.

National Code	National Code Definition
V	"extension" into the vena cava and/or all 3 hepatic veins

National Code	National Code Definition
P	"extension" into the main and/or both left and right branches of the portal vein
E	extra-hepatic disease
M	presence of distant metastases
C	Caudate lode
F	Multiple tumour nodules
N	Lymph node involvement
R	Rupture
Z	None

Choice 4 - International Staging System for Retinoblastoma

The international staging system stage for intraocular and extraocular retinoblastoma.

National Code	National Code Definition
0	Stage 0 - Patients treated conservatively, grouped according to intraocular classification
1	Stage 1- Eye enucleated, completely resected histologically
2	Stage 2 - Eye enucleated, microscopic residual tumour
3	Stage 3 Regional extension: a) Overt orbital disease b) Pre-auricular or cervical lymph node extension
4	Stage 4 - Metastatic disease a) Haematogenous metastasis 1. Single lesion 2. Multiple lesions b) CNS extension 1. Prechiasmatic lesion 2. CNS mass 3. Leptomeningeal disease

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

Treatment - Principal Treatment Centre (PTC)

This section is a child of 'Core – Treatment' and will mandate:

- the date the treatment started
- the treatment modality
- the organisation that provided the treatment

Must be one occurrence per CORE - Treatment (1..2)
CTYA - Treatment - Principal Treatment Centre choice - Choice 1..2

CTYA - Treatment - Principal Treatment Centre - Choice 1
Start of repeating item - Principal Treatment Centre - Children's PTC

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT7600	Childhood Principal Treatment Centre	min an3 - max an5	M*

End of repeating item - Principal Treatment Centre - Children's PTC
End of CTYA - Treatment - Principal Treatment Centre - Choice 1

Start of CTYA - Treatment - Principal Treatment Centre - Choice 2
Start of repeating item - Principal Treatment Centre - Teenage Young Adult (TYA) PTC

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT7610	Teenage Young Adult (TYA) Principal Treatment Centre	min an3 - max an5	M*

End of repeating item - Principal Treatment Centre - Teenage Young Adult (TYA) PTC
End of CTYA - Treatment - Principal Treatment Centre - Choice 2
End of CTYA - Treatment - Principal Treatment Centre choice

Childhood or TYA Principal Treatment Centre

Record the patient's nominated childhood or TYA principal treatment centre (PTC), where they have chosen to have treatment. More than one centre can be selected.

There is no longer a pre-defined list of centres as these change over time. Instead from v10, record only the Trust or Hospital code of the principal treatment centre as defined by the Organisational Data Service (ODS).

Renal tumours

May be one occurrence per record (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT6680	Risk Classification (Pathological) after Immediate Nephrectomy	an1	R
CT6340	Risk Classification (Pathological) after Preoperative Chemotherapy	an1	R

Risk Classification (Pathological) after Immediate Nephrectomy

Classification and timing of surgery determine histological risk. This information should be available for the MDT discussion following treatment but will only apply to a small number of cases.

National Code	National Code Definition
F	Favourable
U	Unfavourable

The following definitions are used:

- favourable histology
  - non-anaplastic Wilms tumour (all subtypes); cystic partially differentiated nephroblastoma; mesoblastic nephroma; diffuse nephroblastomatosis
- unfavourable histology
  - anaplastic Wilms tumour (focal and diffuse); malignant rhabdoid tumour of kidney; clear cell sarcoma of the kidney; renal cell carcinoma

Risk Classification (Pathological) after Preoperative Chemotherapy

Classification after preoperative chemotherapy determines histological risk. This information should be available for the MDT discussion following treatment but will only apply to a small number of cases.

National Code	National Code Definition
L	Low
I	Intermediate
H	High

The following definitions are used:

- low risk:
  - cystic partially differentiated nephroblastoma; completely necrotic nephroblastoma; mesoblastic nephroma; diffuse nephroblastomatosis
- intermediate risk:
  - nephroblastoma type - epithelial; stromal; mixed; regressive; focal anaplasia
- high risk:
  - nephroblastoma blastemal type; nephroblastoma with anaplasia; malignant rhabdoid tumour of the kidney; clear cell sarcoma of the kidney; renal cell carcinoma

Retinoblastoma

All cases of Retinoblastoma are referred to the national specialist centres who are requested to record this section in addition to TNM staging.

For many years the Rees-Ellsworth intraocular classification system was used to stage patients according to their likelihood of successful treatment with external beam radiotherapy. As treatment approaches have evolved and chemotherapy has replaced radiotherapy as the mainstay of conservative management, a new intraocular classification has been introduced and has been received with widespread approval from the international community.

The staging of extra-ocular disease is less well established although recently a panel of international experts have proposed a system which is gaining acceptance in published literature.

May be multiple occurrences per record (0..*)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT6780	Retinoblastoma Assessment Laterality	an1	R
CT6790	International Classification for Intraocular Retinoblastoma	an1	R

Retinoblastoma Assessment Laterality

The laterality for which the retinoblastoma details were recorded.

National Code	National Code Definition
L	Left eye
R	Right eye

International Classification for Intraocular Retinoblastoma

The intraocular classification for retinoblastoma as approved by the international community.

National Code	National Code Definition
A	Group A Small tumours away from the foveola and disc: • tumours less than 3mm in greatest dimension confined to the retina and • located at least 3mm from the foveola and 1.5mm from the optic disc
B	Group B All remaining tumours confined to the retina: • all tumours confined to the retina not in group A • subretinal fluid (without subretinal seeding) less than 3mm from the base of the tumour

National Code	National Code Definition
C	Group C Local subretinal fluid or seeding • subretinal fluid alone greater than 3mm to less than 6mm from the tumour • vitreous seeding or subretinal seeding less than 3mm from tumour
D	Group D Diffuse subretinal fluid or seeding • subretinal fluid alone greater than 6mm from the tumour • vitreous seeding or subretinal seeding greater than 3 mm from tumour
E	Group E Presence of one or more of these poor prognosis features: • greater than 2/3 globe filled with tumour • tumour in anterior segment • tumour in or on the ciliary body • iris neovascularisation • neovascular glaucoma • opaque media from haemorrhage • tumour necrosis with septic orbital cellulitis • pthisis bulbi

Site Specific - Gynaecological

ICD-10 CODES

Note:

- please refer to Appendix A and B for site specific registerable ICD codes for Gynaecological cancer patients

Addition important notes covering borderline tumours of the ovary

Borderline tumours of the ovary, consist of abnormal cells which develop in the epithelial tissue covering the ovary. They are slow growing and can spread to other organs of the body.

The two main types of borderline tumours are:

- Serous borderline ovarian tumour – M8442/1
- Mucinous borderline ovarian tumour – M8472/1

Originally, gynaecological morphologies of uncertain behaviour are not 'C' coded within ICD10 and do not require a COSD record. However, serous and mucinous ovarian borderline tumours must be recorded as an invasive 'C56' cancer in your cancer data management system

The following data item has been retired from v10:

- GY7000 – Surgeon Grade

With the formation of the new National Cancer Audit Collaborating Centre (NATCAN), all previously independent cancer audits have been brought into on organisation. Part of the rationale for this is to reduce the burden of data collection and reporting across the NHS.

As a result, all data moving forward will be from existing data sources. It is important therefore for Trusts to collect all the site specific data items within COSD, as these will form a large part of future analysis for the new ovarian audit.

More information about NATCAN can be found via their official website using this link

Site specific staging

It is important that all stageable cancers are staged for every case. All site specific staging fields are mandatory and a child of 'CORE – Site Specific Staging' Section, and together mandates the collection of:

- the date the sample was taken which provided a positive site specific stage outcome or the MDT where the stage was agreed

- the organisation who carried out the stage
  - this is a 'required' data item from v10, but important to collect if known
- the stage itself

Final Figo Stage

May be up to one occurrence per CORE - Site Specific Staging (1..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
GY7010	Final FIGO Stage	max an7	M

This is a mandatory data item. The FIGO stage is generally confirmed at pathology review in MDT meetings following surgery for uterine and vulval malignancies and for ovarian malignancies undergoing primary surgery.

For ovarian malignancies planned to undergo neoadjuvant chemotherapy and for cases of cervical cancer (which is staged clinically), the final FIGO stage is determined at the time of review of clinical findings, imaging, cytology and biopsy histology at the MDT meeting.

Treatment - Surgery

This section is a child of 'Core – Treatment' and will mandate:

- the date the treatment started
- the treatment modality
- the organisation that provided the treatment

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

May be up to one occurrence per CORE - Treatment - Surgery (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
GY7460	Residual Disease	an1	R

Residual Disease

The estimated size of the residual disease (tumour) left after the surgery, as documented by the surgeon at the completion of the procedure and would be captured by the MDT. This data item would apply to ovarian, fallopian tube and peritoneal cancers managed surgically.

National Code	National Code Definition
1	0cm
2	>0 and <1cm
3	=>1cm

Note:

- it is important to work with your clinicians to collect this data at MDT following surgery, as this will be used within the new Ovarian Cancer Audit

Site Specific - Haematological

Overview

To ensure that all the data items can be collected it is essential to discuss the process with clinicians responsible for treating the patients.

Note:

- for all haematological patients it is essential to record the ICD-O-3 Morphology Code (see Core Data set)

ICD codes and WHO disease groups

Please refer to:

- appendix A, B and C for site specific registerable ICD codes for Haematological cancer patients
- appendix C contains the full list of ICD10 codes which are applicable for Haematological diagnoses mapped against the relevant ICD-O-3 codes, as well as the data set which should be completed for each disease and the WHO Disease Group
  - 9591/1 Monoclonal B-cell lymphocytosis (CLL Type) is a new addition and can be mapped to D72.8

The following data items have been retired from v10:

- Cancer Care Plan:
  - HA8210 - Splenomegaly Indicator (CLL)
  - HA8320 - Number of Abnormal Nodal Areas (Follicular)
  - HA8320 - Number of Abnormal Nodal Areas (DLBCL)
  - HA8330 - Primary Extranodal Site (Hodgkin Lymphoma)
  - HA8270 - Extramedullary Disease (ALL)
- Laboratory Results:
  - HA9200 - European Leukaemia Net (ELN) Genetic Risk (AML)
- Diagnosis:
  - CT7160 - FAB Classification
- Molecular and Biomarker:
  - CT6260 - ALK FUSION STATUS FOR ALCL

Stage/prognostic indicators

TNM Staging is not collected for Haematological cancers. However, the following staging data items are required for all relevant cases:

- CLL – Binet stage
- Myeloma – R-ISS Stage

- All Lymphomas – Ann Arbor Stage
  - Including if known [Ann Arbor Symptoms, Ann Arbor Extranodality, Ann Arbor Bulk and Ann Arbor Splenic Involvement]

The following three data items are CTYA Only, to help complete the 'Toronto Childhood Staging System' international benchmarking project:

- Non Hodgkin Lymphoma – Murphy (St Jude) Stage
- Acute Lymphoblastic Leukaemia – Children's Oncology Group (COG) Staging System Stage
- Acute Myeloid Leukaemia – Central Nervous System Involvement

Additionally, the following prognostic indicators are also required:

- CML – Sokal Index
- Myelodysplasia: IPSS-R
- Follicular lymphoma: FLIPI2 Index
- DLBCL – (R)IPI Index Score
- Nodal T-Cell Lymphoma – IPI Index Score
- Mantel Cell – MIPI Index Score
- Hodgkin Lymphoma – Hasenclever Index (Only applicable to advanced Stage 3 and 4 disease)

Lymphoblastic Leukaemia/Lymphoblastic Lymphoma coding

Lymphoblastic lymphoma and lymphoblastic leukaemia are now known to be the same entity. This is reflected in the latest ICD-O-3 coding update which assigns the same morphology code to both and uses the combined term 'lymphoblastic leukaemia/lymphoma'.

Historically different codes were assigned to lymphoblastic lymphoma and leukaemia and ICD10 coding still distinguishes between these 2 groups. The coding list below therefore retains the separate ICD10 codes (C83.5 and C91.0) but assigns the same ICD-O-3 codes to each pair of diseases. (Further detail can be provided if required).

Recording amyloidosis for COSD

The aim is to register patients presenting with symptoms referable to an underlying diagnosis of amyloidosis in the absence of a known, registerable plasma cell or lymphoid neoplasm.

Amyloidosis may be associated with plasma cell neoplasms such as multiple myeloma, other B cell neoplasms (such as lymphoplasmacytic lymphoma), or with paraproteinaemias (which are not associated with identified myeloma or lymphoma (for example MGUS).

If amyloidosis is identified in association with a registerable condition (such as multiple myeloma, plasmacytoma, lymphoplasmacytic lymphoma, Waldenstroms macroglobulinaemia), only the data for the associated registerable condition should be submitted through COSD and this will be registered as a new diagnosis by the cancer registries. Amyloidosis should not be submitted for COSD in these circumstances.

Amyloid deposition associated with chronic infection, medullary carcinoma of the thyroid, insulinoma, prolactinoma, Alzheimer disease, prion diseases and other non-AL types of amyloid, is considered to be secondary amyloidosis and should not be submitted for COSD.

If amyloidosis is identified in the absence of a registerable condition or before the identification of a registerable condition, then data for Primary Amyloidosis* should be submitted for COSD and this will be registered as a new diagnosis by the cancer registries.

Note:

- for the purpose of COSD, MGUS (monoclonal gammopathy of unknown significance) is not a registerable disease and therefore amyloidosis associated with a paraprotein/MGUS should be submitted for COSD and will be registered as a new diagnosis

Amyloidosis as identified above should be recorded for COSD and coded as follows:

- ICD10 codes: E85.9 (Amyloidosis unspecified)
- ICD-O-3 morphology code: M9769/1

Primary Amyloidosis is composed of abnormal immunoglobulin light chains (or rarely heavy chains) which deposit (either intact or in fragments) in various tissues. These form B-pleated sheets (AL amyloid) that bind Congo Red dye with characteristic birefringence.

Clinical data sets and applicable data items

In Appendix I, you will find a proforma that shows which of the site specific data items are applicable to each haematological diagnosis group.

This can be used as a tool (by the clinical team) during MDT, to ensure capture of all relevant data items and to help the MDT coordinator input the clinically agreed data.

This proforma in PDF format, as well as an associated guidance document, is available for download from the Appendix section of this user guide.

Notes:

- this data set has been separated into 2 sub sections ‘Haematology’ and ‘CTYA’
- this will make allocating and recording data on both subgroups easier

Cancer care plan

This section contains all the data items that would be expected to be available at the MDT, where the care plan was agreed. This is a child of Core – Cancer Care Plan.

Cautionary note:

- the choice order and selections within each choice may have changed between v9 to v10

Haematological - Cancer care plan choice Choice 0..1

Haematological - Cancer care plan choice - Choice 1

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
HA8010	Sokal Index (Chronic Myeloid Leukaemia)	n1.n1	M

End of haematological - Cancer care plan choice - Choice 1

Haematological - Cancer care plan choice - Choice 2

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
HA9000	IPSS-R (Myelodysplasia)	n2.n1	M

End of haematological - Cancer care plan choice - Choice 2

Haematological - Cancer care plan choice - Choice 3

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
HA8360	FLIPI 2 Index Score	n1	M

End of haematological - Cancer care plan choice - Choice 3

Haematological - Cancer care plan choice - Choice 4

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
HA8330	Primary Extranodal Site	an2	R
HA8420	Number of Extranodal Sites Code	an1	R
HA8450	(R)IPI Index Score	n1	R

End of haematological - Cancer care plan choice - Choice 4

Haematological - Cancer care plan choice - Choice 5

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
HA8320	Number of Abnormal Nodal Areas	max n2	R
HA8670	Hasenclever Index	n1	R

End of haematological - Cancer care plan choice - Choice 5

Haematological - Cancer care plan choice - Choice 6

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
HA9500	IPI Index Score	n1	R

End of haematological - Cancer care plan choice - Choice 6

Haematological - Cancer care plan choice - Choice 7

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
HA9510	MIPI Index Score	n1	R

End of haematological - Cancer care plan choice - Choice 7
End of Haematological - Cancer Care Plan Choice

Choice 1:

Sokal Index (Chronic Myeloid Leukaemia)

Where applicable, this is a mandatory data item Index derived from age, spleen size, platelet count, myeloblasts %.

Note:

- you can use an online version of the Sokal Index Calculator

Choice 2:

IPSS-R (Myelodysplasia)

Where applicable, this is a mandatory data item. The Revised International Prognostic Scoring System (IPSS-R) for Myelodysplastic Syndromes Risk Assessment Calculator is derived from Haemoglobin, Absolute Neutrophil Count, Platelets and Bone Marrow Blasts as:

- Haemoglobin (g/dL) [4-20] – A possible conversion for Hb values:
  10 g/dL= 6.2 mmol/L, 8 g/dL= 5.0 mmol/L
- Absolute Neutrophil Count (x109/L) [0-15]
- Platelets (x109/L) [0-2000]
- Bone Marrow Blasts (percent) [0-30]
- Cytogenetic Category

Notes:

- you can use an online version of the IPSS-R scoring system
- the format has changed from n1.n1 to n2.n1 in v10

Choice 3:

FLIPI 2 Index Score

Where applicable, this is now a mandatory data item in v10. Follicular Lymphoma International Prognostic Index 2 Score (FLIPI2), derived from age, Serum beta 2 microglobulin, bone marrow involvement, longest diameter of largest involved node and Haemoglobin.

Note:

- you can use an online version of the Follicular Lymphoma Prognostic Index 2 Score (FLIPI2) calculator

Choice 4:

Primary Extranodal Site

Site of origin of lymphoma if believed to be outside lymph nodes as agreed by MDT based on clinical and radiological findings. This is only required for DLBCL.

National Code	National Code Definition
01	Blood
02	Bone
03	CNS
04	GIT
05	GU
06	Liver
07	Marrow
08	Muscle
09	Orbit
10	Pericardium
11	Pulmonary
12	Salivary gland
13	Skin
14	Thyroid
15	Other

Number Of Extranodal Sites Code

Number of sites with Lymphoma outside lymph nodes (clinical assessment).

National Code	National Code Definition
0	0

National Code	National Code Definition
1	1
2	More than 1

(R)IPI Index Score

Revised International Prognostic Index Score, derived from Age, performance status (0-1 v 2-4), LDH, extranodal sites, Ann Arbor Stage.

Notes:

- you can use an online version of the (R)IPI Index for DLBCL Score calculator
- this data item has moved to form a new choice section for all the international prognostic score index data items
- updated data item name, previously '(R)IPI Index for DLBCL Score'

Choice 5:

Number of Abnormal Nodal Areas

Number of abnormal nodal areas detected clinically and radiologically; this is only required for early stage Hodgkin Lymphoma.

Hasenclever Index

Hasenclever Index is only required for lymphomas with Ann Arbor Stage 3 or 4.
Index derived from age, gender, Hb, Albumin, white blood count, Lymphocyte count, Ann Arbor.

Note:

- you can use an online version of the Hasenclever Index calculator

Choice 6:

IPI Index Score

This is a new data item for v10. The International Prognostic Index Score (IPI) for nodal T-cell lymphoma (PTCL-NOS, angioimmunoblastic and anaplastic large cell lymphoma [both ALK+ and ALK-) derived from Age, performance status (0-2 v 3-4), LDH, extranodal sites, Ann Arbor Stage.

Note:

- you can use an online version of the IPI Index calculator

Choice 7:

MIPI Index Score

This is a new data item for v10. The Mantle Cell International Prognostic Index Score (MIPI), derived from Age, ECOG performance status, LDH, and total white cell count.

Note:

- you can use an online version of the MIPI Index Score calculator

Site-Specific Staging

This section contains site specific stage data items that would be expected to be available at the MDT. All site specific staging fields are mandatory and a child of 'CORE – Site Specific Staging' section, and together mandates the collection of:

- the date the sample was taken which provided a positive site specific stage outcome or the MDT where the stage was agreed
- the organisation who carried out the stage
  - this is a 'required' data item from v10, and important to collect
- the stage itself

Cautionary notes:

- the choice order and selections within each choice have changed between v9 to v10
- the following data items form a 6-choice menu and if applicable, one of the following 'Site Specific Staging' Sections MUST be provided per submission

Haematological - Site Specific Staging Choice Choice 1..1

Haematological - Site Specific Staging - Choice 1

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
HA8280	Ann Arbor Stage	an1	M

End of Haematological - Site Specific Staging - Choice 1

Haematological - Site Specific Staging - Choice 2

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
HA8240	Binet Stage	an1	M

End of Haematological - Site Specific Staging - Choice 2

Haematological - Site Specific Staging - Choice 3

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
HA9100	R-ISS Stage for Myeloma	an1	M

End of Haematological - Site Specific Staging - Choice 3

Haematological - Site Specific Staging - Choice 4

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT6250	Murphy (St Jude) Stage	an1	M

End of Haematological - Site Specific Staging - Choice 4

Haematological - Site Specific Staging - Choice 5

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT8270	Children's Oncology Group (COG) Staging System Stage	an1	M

End of Haematological - Site Specific Staging - Choice 5

Haematological - Site Specific Staging - Choice 6

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT8280	Central Nervous System Involvement	an1	M

End of Haematological - Site Specific Staging - Choice 6
End of Haematological - Site Specific Staging Choice

Choice 1:

Ann Arbor Stage

Where applicable, this is a mandatory data item. Staging is based on location of detected disease.

National Code	National Code Definition
1	I = One region of lymph nodes, or spleen or thymus or Waldeyer's ring enlarged
2	II = 2 regions of lymph nodes enlarged on same side of diaphragm
3	III = lymph nodes enlarged on both sides of diaphragm
4	IV = disease outside lymph nodes for example liver, bone marrow

Choice 2:

Binet Stage

Where applicable, this is a mandatory data item. Applicable to Chronic Lymphocytic Leukaemia (CLL). Prognostic index derived from platelet count, Hb, lymphadenopathy, hepatomegaly, and splenomegaly. Note that immune cytopenias are not included when calculating the Stage (such as if Platelet count is below 100 and/or Haemoglobin levels are below 110 as a result of immune cytopenia). Also, please see note on calculations below.*

Binet Stage "solely rely on physical examination and standard laboratory tests, and do not require ultrasound, computed tomography, or magnetic resonance imaging."

National Code	National Code Definition
A	Stage A: if Platelet count >99 and Hb>99 and 0, 1or 2 areas of organ enlargement (number of lymph node groups plus score 1 for hepatomegaly, 1 for splenomegaly)
B	Stage B: if Platelet count >99 and Hb>99 and 3, 4 or 5 areas of organ enlargement
C	Stage C: if Hb<100 or platelet count <100

Notes on Binet Stage calculations:

- platelet count >99 is more fully described as Platelet count >99x109/l
- Hb >99 is more fully described as Hb>99 g/L
- you can use the online version of the BINET calculator for CLL

Choice 3:

R-ISS Stage for Myeloma

Where applicable, this is a mandatory data item. The Revised International Staging System (R-ISS) includes variables included in the original ISS (serum beta-2 microglobulin and serum albumin), while also including the additional prognostic information obtained from serum LDH and high-risk chromosomal abnormalities detected by interphase fluorescent in situ hybridization (iFISH) after CD138 plasma cell purification.

The revised (R-ISS for Myeloma) stages are as follows:

National Code	National Code Definition
1	Stage I: ISS stage I and standard-risk CA by iFISH and normal LDH
2	Stage II: Not R-ISS stage I or III
3	Stage III: ISS stage III and either high-risk CA by iFISH or high LDH

Note:

- you can use an online version of the R-ISS calculator

Choice 4:

Murphy (St Jude) Stage

Where applicable, this is a mandatory data item. The St. Jude Children's Research Hospital model (Murphy Staging), which separates patients on the basis of limited versus extensive disease. More details are available on the National Cancer Institute website.

It is essential to record the disease specific stage for this group of patients. This information should be available to the MDT.

National Code	National Code Definition
1	Stage 1
2	Stage 2
3	Stage 3
4	Stage 4

The following definitions are used:
Stage 1: disease is limited to a single tumour or to one lymph node group (for example, neck, axilla, groin) outside of the abdomen or mediastinum.

Stage 2: disease is limited to one tumour with local lymph node involvement, to 2 or more tumours or lymph node groups on the same side of the diaphragm, or to a completely resected primary tumour of the gastrointestinal tract with/without involvement of local lymph nodes

Stage 3: disease includes tumours or lymph node groups involved on both sides of the diaphragm, any primary intrathoracic tumour (mediastinal, pleural or thymic disease), or extensive NHL within the abdomen; or any paraspinal or epidural tumours.

Stage 4: disease involves the bone marrow and / or central nervous system (CNS), with/without other sites of involvement. Bone marrow involvement in NHL is defined as >5% - <25% malignant cells in an otherwise normal bone marrow. (> 25% malignant cells in the bone marrow is defined as leukaemia).

Choice 5:
Children's Oncology Group (COG) staging system stage
This is a new data item for v10. Where applicable, this is a mandatory data item and has been included in COSD to help complete the 'Toronto Childhood Staging System' international benchmarking project.

National Code	National Code Definition
1	CNS1
2	CNS2
3	CNS3

Additional national code definition notes:

- CNS1:
  - no clinical signs of CNS involvement and no blasts in CSF
- CNS2:
  - no clinical signs of CNS involvement and blasts in CSF and either: WBC <5/µL CSF or WBC ≥5/µL CSF and RBC ≥10/µL CSF and WBC/RBC in CSF ≤2x WBC/RBC in blood

- CNS3:
    - clinical signs of CNS involvement or Blasts in CSF and WBC ≥5/µL CSF and either: RBC <10/µL CSF or RBC ≥10/µL CSF and WBC/RBC in CSF >2x WBC/RBC in blood

Explanatory abbreviation notes:

- CNS Central Nervous System
- CSF Cerebrospinal fluid
- WBC White Blood Cells
- RBC Red Blood Cells

Choice 6:

Central Nervous System Involvement

This is a new data item for v10. Where applicable, this is a mandatory data item and has been included in COSD to help complete the 'Toronto Childhood Staging System' international benchmarking project.

National Code	National Code Definition
1	CNS Negative
2	CNS Positive

Additional national code definition notes:

- CNS Negative
    - lumbar puncture nontraumatic and no blasts in CSF and no clinical signs of CNS involvement
- CNS Positive
    - lumbar puncture traumatic or lumbar puncture nontraumatic and blasts in CSF or clinical signs of CNS involvement

Ann Arbor - Extensions

These data are expected to be collected to support Ann Arbor Stage, although maybe submitted independently of the stage itself.

May be up to one occurrence per Primary Cancer Pathway (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
HA8290	Ann Arbor Symptoms	an1	R
HA8300	Ann Arbor Extranodality	an1	R
HA8310	Ann Arbor Bulk	an1	R
HA8680	Ann Arbor Splenic Involvement	an1	R

Ann Arbor Symptoms

Additional stage designation based on presence or absence of specific symptoms.

National Code	National Code Definition
A	No Symptoms
B	Presence of any of the following: unexplained persistent or recurrent fever (greater than 38°C / 101.5°F), drenching night sweats, unexplained weight loss of 10% or more within the last 6 months

Ann Arbor Extranodality

Additional staging designation based on extranodal involvement.

National Code	National Code Definition
E	Extranodal involvement
0	No Extranodal involvement

Additional notes:

- for Primary Nodal lymphoma, code "E" if there is involvement of a single extranodal site by contiguous spread (i.e. directly adjoining) from the known nodal group
- for Primary Extranodal lymphoma, code “E” if there is a single extranodal lesion with or without lymphatic involvement in the draining

area (for example, a thyroid lymphoma with draining cervical lymph node involvement = “IIE”)
- the designation of Stage 4 for nodal disease implies disseminated disease involving (distant) extranodal sites
- multiple extranodal deposits should be considered Stage IV and “E” should not be used - however, by convention, involvement of the bone marrow, liver, lung, pleura and CSF are always considered Stage 4 even if the disease is isolated to that organ

Ann Arbor Bulk

Additional staging designation based on presence of bulky disease for DLBCL and Hodgkin disease only.

National Code	National Code Definition
X	Bulky disease present
0	No bulky disease present

Notes:
- DLBCL code X - if there are 1 or more lymph node masses >7.5cm
- Hodgkin lymphoma code “X” - if there is presence of bulky disease, that is, a nodal mass whose greatest dimension is more than 10 centimetres in size, and/or a widening of the mediastinum (middle chest) by more than one-third
- Speech marks “ ” have been removed from the description on the request of the NHS England, Data Model and Dictionary Service

Ann Arbor Splenic Involvement

Additional staging designation based on splenomegaly or normal spleen size with confirmed disease involvement. Use code "S" if either is true.

National Code	National Code Definition
S	Spleen involvement or splenomegaly
0	No spleen involvement or splenomegaly

CTYA (sub section)

All data sets for Acute Lymphoblastic Leukaemia (ALL) now become age agnostic - you can duplicate them in a CTYA section. Adult and paediatric colleagues have agreed this collaboratively.

Laboratory results

This section contains laboratory results data items that would be expected to be available at the MDT. This group is a child of CORE – Laboratory Results, and will mandate:

- the date the sample was reported
- the organisation who processed the sample

Cautionary note:

- the choice order and selections within each choice have changed between v9 to v10
- the following data items form a 4-choice menu and if applicable, one of the following sections MUST be provided per submission

Haematological - Laboratory Results Choice Choice 0..1

Haematological - Laboratory Results - Choice 1

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT7330	Bone Marrow Blasts	max n3	R
CT6240	Cytogenetics Subsidiary Comment	max an50	R

End of Haematological - Laboratory Results - Choice 1

Haematological - Laboratory Results - Choice 2

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT7340	Cellularity	max n3	R
CT7350	DEB Test	an1	R
CT7360	Dysplastic Haemopoiesis	an1	R

End of Haematological - Laboratory Results - Choice 2

Haematological - Laboratory Results - Choice 3

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT7800	White Blood Cell Count (Highest Pre Treatment)	max n3.n1	R

End of Haematological - Laboratory Results - Choice 3

Haematological - Laboratory Results - Choice 4

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT7700	Post Induction MRD	an1	M

End of Haematological - Laboratory Results - Choice 4
End of Haematological - Laboratory Results Choice

Choice 1:

Bone Marrow Blasts

Blast cells in bone marrow aspirate as percentage of all nucleated cells. Normally taken from laboratory report on diagnostic bone marrow. (%) Range 0 - 100

Cytogenetics Subsidiary Comment

Description of cytogenetic findings.

Choice 2:

Cellularity

Percentage value of Cellularity, (%) Range 0 to 100.

DEB Test

Record the outcome of DEB Test.

National Code	National Code Definition
P	Positive
N	Negative

National Code	National Code Definition
9	Not Known

Dysplastic Haemopoiesis

Record if the bone marrow produced (Haemopoiesis) is Unilineage, Bilineage or Trilineages dysplastic.

National Code	National Code Definition
1	Unilineage
2	Bilineage
3	Trilineage

Choice 3:

White Blood Cell Count (Highest Pretreatment)

Highest White blood cell count pre-treatment ($x10^9$ per litre). Normally provided by Haematological labs before transfusion/treatment.

Notes:

- range 0.0 to 999.9 (to 1dp)
- this has moved into new choice and has a new data item number as only required now for CTYA cases

Choice 4:

Post Induction MRD

Where applicable, this is a mandatory data item. Percentage of leukaemic cells present at the end of Minimal Residual Disease (MRD) induction.

National Code	National Code Definition
1	0%
2	>0% <0.01%
3	>=0.01% <0.1%

National Code	National Code Definition
4	>=0.1% <1%
5	>=1% <5%
6	>=5%
9	Unknown

Note:

- a range has been added to the national code definitions of 2, 3, 4 and 5, to improve data quality and accuracy of reported data

Diagnosis

These group of data items are specific to the CTYA diagnosis and should be available through the MDT, although the advice is to get clinical clarification and support if unsure.

Must be one occurrence if chosen per CORE - Diagnosis (1..1)
Haematological - Diagnosis – Choice Choice 0..1
Haematological - Diagnosis - Choice 1
Start of Repeating Item - Mixed Phenotype Symptoms (At Diagnosis)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT7200	Mixed Phenotype Symptoms (at Diagnosis)	an1	R*

End of repeating item - Mixed Phenotype Symptoms (at Diagnosis)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT7240	EGIL Score	an1	R

End of Haematological - Diagnosis - Choice 1

Haematological - Diagnosis - Choice 2

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT7170	Paediatric Cytogenetic / Molecular Genetic Risk Group	an1	R
CT7180	AML Risk Factors	an1	R

End of Haematological - Diagnosis - Choice 2

Haematological - Diagnosis - Choice 3
Start of Repeating Item - Paediatric Myelodysplasia

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT7260	Paediatric Myelodysplasia	an1	R*

End of Repeating Item - Paediatric Myelodysplasia

Start of Repeating Item - Underlying Disease Associated with MDS

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT7270	Underlying Disease Associated With MDS	an1	R*

End of Repeating Item - Underlying Disease Associated With MDS

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT7380	Congenital Anomalies	max an300	R

Start of Repeating Item - Myelodysplasia Symptoms at Diagnosis

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT7310	Myelodysplasia Symptoms at Diagnosis	an1	R*

End of Repeating Item - Myelodysplasia Symptoms at Diagnosis
End of Haematological - Diagnosis - Choice 3
End of Haematological - Diagnosis - Choice

Choice 1:

Mixed Phenotype Symptoms (at Diagnosis)

Record if any of the associated symptoms were present at Diagnosis, multiple symptoms can be submitted.

National Code	National Code Definition
1	Hepatomegaly
2	Splenomegaly
3	Lymphadenopathy
4	Mediastinal Mass

EGIL Score

The EGIL Score (European Group for the Immunological Classification of Leukaemia) assigns score points to major antigens to determine if certain lineage is present.

National Code	National Code Definition
1	2 - Points
2	1 - Point
3	0.5 - Point

Choice 2:

Paediatric Cytogenetic / Molecular Genetic Risk Group

Risk groups for ages 0 to 18 – cytogenetic and molecular genetic abnormalities.

National Code	National Code Definition
1	Good Risk
2	Intermediate Risk
3	Poor Risk
9	Not Known

AML Risk Factors

Record if any of these risk factors are present in a patient at diagnosis.

National Code	National Code Definition
1	Denovo
2	High Risk MDS
3	Secondary AML

Choice 3:

Paediatric Myelodysplasia

Record the Paediatric Myelodysplasia clinical findings at Diagnosis, multiple findings can be submitted.

National Code	National Code Definition
1	De Novo MDS
2	Refractory Cytopenia
3	Refractory Cytopenia with Ringed Sideroblasts

National Code	National Code Definition
4	Refractory Cytopenia with Excess Blasts
5	RAEB in Transformation

Underlying Disease Associated with MDS

Record any underlying disease associated with MDS present at diagnosis, multiple underlying diseases can be submitted.

National Code	National Code Definition
1	IBFMS
2	Previous Malignancy
3	Radiation
4	Toxic Insult
5	Mitochondrial Disorder
6	Other Systematic Disorder
7	Congenital Anomalies
9	No underlying disease

Congenital Anomalies

Record any Congenital Anomalies associated with the MDS at Diagnosis, multiple congenital anomalies can be submitted.

Myelodysplasia Symptoms at Diagnosis

Record any other Myelodysplasia symptoms present at diagnosis, multiple symptoms can be submitted.

National Code	National Code Definition
1	Consanguinity
2	Organomegaly at Diagnosis
3	Lymphadenopathy at Diagnosis
4	Severe Infections Prior to Diagnosis
5	Immunodeficiency at Diagnosis

Acute Leukaemias

May be up to one occurrence per Record (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT7110	Primary Induction Failure	an1	R

Primary Induction Failure

Did the patient fail to achieve morphological remission after induction chemotherapy? This is a Haematological CYTA required data item.

National Code	National Code Definition
Y	Yes
N	No
9	Not Known

Site Specific - Head and Neck

ICD-10 CODES

Note:

- please refer to Appendix A and B for site specific registerable ICD codes for Head and Neck cancer patients

Head and Neck cancer details can all be collected within either the Core section of COSD v10.0 or within COSD Pathology v5.0 data sets.

As none of the site-specific data items previously in this section were used for either cancer registration or for any analytical work currently being conducted by NDRS or for any of our partner organisations, it was recommended that these should be removed from COSD to help reduce the burden on front line staff.

Therefore, the following data item has been retired from v10:

- NH9300 – Surgical Access Type
- HN9310 – Other Surgical Access Type
- HN9060 – Cancer Dental Assessment Date
- HN9050 – Care Contact Date (Dietitian Initial)
- HN9200 – Care Contact Date (SLT Initial)
- HN9000 – Clinical Status Assessment Date (Cancer)
- HN9010 – Primary Tumour Status
- HN9020 – Nodal Status
- HN9030 – Metastatic Status
- HN9080 – Speech & Language Assessment Date

Site Specific - Liver and Cholangiocarcinoma

ICD-10 CODES

Note:

- please refer to Appendix A and B for site specific registerable ICD codes for Liver and Cholangiocarcinoma cancer patients

Overview

This data set includes both the collection of Liver and Cholangiocarcinoma data items. Some data will continue to be part of the Cancer Waiting Times (Site Specific Group of Upper GI), but for COSD, they will now be reported within the Liver data set.

It is important that MDT Coordinators understand through specific training (if required), that all data within the Liver section of COSD are applicable to Cholangiocarcinoma. The only exception is LV16100 (Barcelona Clinic Liver Cancer (BCLC) Stage), which cannot be collected for Cholangiocarcinoma.

Notes:

- data item LV16400 (Cholangiocarcinoma Category) must be completed for all cholangiocarcinoma diagnoses, this will help accurately identify the precise Cholangiocarcinoma diagnosed (Intrahepatic, Perihilar or Extrahepatic)
- if in doubt, please discuss this with your specialist consultant within the MDT

You can view and download a HCC staging calculator, by clicking this link.

Diagnosis

This is a child of CORE – Diagnosis group

May be up to one occurrence per CORE – Diagnosis (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
LV16000	Liver Surveillance Scans	an1	R

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
LV16010	Liver Cirrhosis Type	an1	R

Start of Repeating Item - Cause of Liver Cirrhosis

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
LV16020	Cause of Liver Cirrhosis	an2	R*

End of Repeating Item - Cause of Liver Cirrhosis

Liver Surveillance Scans

Has the patient had regular 6 monthly liver ultrasound scans for the purpose of early detection of HCC?

National Code	National Code Definition
Y	Yes
N	No
9	Not Known

Additional information:

- this information will normally be available in the patient record

Rationale for inclusion:

- individuals with cirrhosis are at increased risk of developing HCC (the annual incidence of HCC is approximately 3% in cirrhotic patients)
- detection by ultrasound surveillance is associated with improved outcomes in patients diagnosed with HCC

Liver Cirrhosis Type

Record the type of liver cirrhosis.

National Code	National Code Definition
1	Compensated
2	Decompensated
8	Patient does not have cirrhosis of the liver
9	Not known

Additional information:

- presence of cirrhosis can be defined by previous clinical assessments, current imaging findings, or histopathology before/after treatment
- if cirrhosis is present, it can be compensated or decompensated
- decompensation describes the inability of the liver to carry out its usual functions and is marked by the presence of ascites, hepatic encephalopathy, or variceal bleeding this information will normally be available in the patient record
- if cirrhosis is not decompensated, it is compensated

Rationale for inclusion:

- approximately 80% of HCC occurs in individuals with cirrhosis and cirrhosis is also a risk factor for cholangiocarcinoma
- HCC-related outcomes are different for individuals with and without cirrhosis

When decompensation is present treatment options for HCC are limited. The presence of advanced liver disease has a strong influence on prognosis in addition to that of the cancer.

Cause of Liver Cirrhosis

Record if the patient's liver cirrhosis is caused by known risk factors for liver disease. Select all that apply. This is a multiple repeating data item.

National Code	National Code Definition
01	Alcohol excess
02	Hepatitis B virus infection

National Code	National Code Definition
03	Hepatitis C virus infection
04	Non alcohol related fatty liver disease
05	Hereditary haemochromatosis
06	Autoimmune hepatitis
07	Primary sclerosing cholangitis
10	Primary biliary cholangitis
98	Other
99	Not Known

Additional information:

- this information will normally be available in the patient record

These additional core items should also be completed:

- alcohol use
- smoking
- body mass index

Rationale for inclusion:

- the cause of cirrhosis is associated with different levels of risk for HCC and also with different rates of progression in the underlying liver disease
- these factors are important for determining overall treatment and prognosis. Multiple causes can be selected

Diagnosis - Cholangiocarcinoma

This section is a child of 'CORE – Diagnosis

May be up to one occurrence per CORE - Diagnosis (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
LV16400	Cholangiocarcinoma Category	an1	M

Start of Repeating Item - Cholangiocarcinoma Risk Factors Type

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
LV16500	Cholangiocarcinoma Risk Factors Type	an2	R*

End of Repeating Item - Cholangiocarcinoma Risk Factors Type

Cholangiocarcinoma Category

Where applicable, this is a mandatory data item. This is to help identify the individual components of Cholangiocarcinoma. State where the Cholangiocarcinoma is present, using the designated categories.

Note:

- any cholangiocarcinoma which involves the anatomical hilum of the liver must be classified as perihilar

National Code	National Code Definition
1	Intrahepatic
2	Perihilar
3	Extrahepatic

Additional information:

- Intrahepatic cholangiocarcinoma's are those arising above the second order bile ducts
- Extrahepatic are those arising below the cystic duct
- Perihilar are those arising in-between

Cholangiocarcinoma Risk Factors Type

This is a new data item for v10. Record any additional risk factors that are associated with the cholangiocarcinoma diagnosis

National Code	National Code Definition
01	Primary sclerosing cholangitis
02	Inflammatory Bowel Disease
03	Cirrhosis
04	Caroli's disease
05	Choledochal cysts
06	Hepatolithiasis
07	Choledocholithiasis
08	Cholelithiasis
09	Hepatitis B virus infection
10	Hepatitis C virus infection
11	Alcohol Excess
12	Non alcohol related fatty liver disease
13	Type 2 Diabetes
14	Obesity
15	Hereditary haemochromatosis
16	Pancreatitis
17	Autoimmune hepatitis

National Code	National Code Definition
18	Primary biliary cholangitis
19	Smoking
20	Parasitic Infection/Liver Flukes
98	Other
99	Not Known

Site Specific Staging

It is important that all stageable cancers are staged for every case. All site specific staging fields are mandatory and a child of 'CORE – Site Specific Staging' Section, and together mandates the collection of:

- the date the sample was taken which provided a positive site specific stage outcome or the MDT where the stage was agreed
- the organisation who carried out the stage
  - this is a 'required' data item from v10, but important to collect if known
- the stage itself

A calculator designed to help with completion of the following items can be found here.

May be up to one occurrence per CORE - Site Specific Staging (1..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
LV16100	Barcelona Clinic Liver Cancer (BCLC) Stage	an1	M

Barcelona Clinic Liver Cancer (BCLC) Stage

Where applicable, this is a mandatory data item. The Barcelona Clinic Liver Cancer (BCLC) Stage includes both anatomic and non-anatomic factors and is widely used worldwide to predict prognosis and determine treatment.

This item should only be completed for hepatocellular carcinomas (C220).

National Code	National Code Definition
0	Very early
A	Early
B	Intermediate
C	Advanced
D	Terminal

Additional information:

- the stage calculated closest to diagnosis should be recorded, three separate pieces of clinical information are required
- ECOG Performance Status, this is a measure of the persons functional status from 0 (fully active) to 4 (completely disabled)
- severity of underlying liver diseases measured by the Child-Pugh score that includes both blood test (bilirubin, albumin and INR) and clinical parameters (ascites and encephalopathy)
- cancer burden, the definition of cancer burden here is different to that described by the TNM staging system
- information normally available in the patient record and on review of imaging at MDT

An online calculator is available here for each of these parameters that will also calculate the BCLC stage.

Rationale for inclusion:

- the BCLC staging system integrates information on performance status, liver function, and cancer burden to identify likely treatment options and to guide prognosis
- this information is different to that contained in the TNM staging system and, for persons with HCC, BCLC is more predictive of outcome

It is important that core TNM staging information (CR0520, CR0540, CR0560, CR0580, CR3120 & CR0620, CR0630, CR0640, CR0610, CR3130) are also completed.

The Alpha-fetoprotein (AFP) should also be provided, if known (item no. CR8920).

Treatment and Prognostic Indicators

May be up to one occurrence per record (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
LV16120	Portal Invasion	an1	R
LV16130	UKELD Score	max n2	R
LV16140	Child-Pugh Score	an1	R

Note:

- these indicators should be collected only once and as close to the point of diagnosis as possible

Portal Invasion

Record whether there is tumour present in the main portal vein, or if there is tumour present in a branch of the portal vein or if there is no tumour present in the portal vein.

National Code	National Code Definition
1	Present in Branch
2	Present in Main
3	Not present
9	Not known

Additional information:

- this information is available from imaging review
- '1' and '2' have a new national code definitions – previously 'Branch' and 'Main'

Rationale for inclusion:

- tumour's invasion of large vessels (macrovascular invasion) occurs in different locations

- treatment options may vary by the location of vascular invasion

UKELD Score

Record the UKELD score (range 0-99). The UKELD score is calculated using bilirubin, INR, creatinine and sodium. The UKELD score predicts the risk of mortality due to liver cirrhosis and is used to assess need for liver transplantation.

UKELD calculation is included in the calculator available in the following website https://www.basl.org.uk/index.cfm/content/page/cid/34.

Rationale for inclusion:

- UKELD is a score that indicates prognosis for persons with cirrhosis. It provides an assessment of predicted mortality from liver disease over the following year

Child-Pugh Score

Record the overall Child-Pugh score. This is the level of disease of the liver.

National Code	National Code Definition
A	Child-Pugh A
B	Child-Pugh B
C	Child-Pugh C

Treatment

This section is a child of 'CORE – Treatment and will mandate:

- the date the treatment started
- the treatment modality
- the organisation that provided the treatment

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

May be up to one occurrence per Core - Treatment (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
LV16300	Ablative Therapy Type	an1	R
LV16320	Embolisation Modality	an1	R

Ablative Therapy Type

Describe type of ablative (such as locally destructive treatment) therapy used if any.

National Code	National Code Definition
R	Radiofrequency ablation
M	Microwave ablation
S	Stereotactic ablative radiotherapy (SABR)
7	Other ablative therapy
9	Not known

Notes:

- ‘S – Stereotactic ablative radiotherapy (SABR)’, is new in v10
- ‘8 - Other ablative treatment’ has been retired from v10 and replaced with ‘7 - Other ablative therapy’

Rationale for inclusion:

- ablation treatment is used with curative intent for persons with early stage disease (BCLC-0/A)
- the option chosen will depend on the size of the cancer being treated, how close the cancer is to other structures, and local experience and expertise
- for each ablative therapy treatment, there should be a corresponding treatment record created in CORE - Treatment, with the correct treatment modality, date of treatment and organisation code recorded

Embolisation Modality

What modality of the 'Liver Trans Arterial Embolisation' was used?

National Code	National Code Definition
1	TAE/BLAND
3	DEB-TACE
4	RO DEB-TACE
5	SIRT/TARE/Radioembolisation
6	TACE
9	Not Known

Notes:

- '2 – C-TACE' has a been retired in v10 and replaced with '6 – TACE'
- '5' has a new national code definition – previously 'SIRT'

This refers to the type of material injected into the hepatic artery:

- TAE/BLAND - Transarterial Embolism, Embolic agents such as coils or foam only
- DEB-TACE - drug eluting beads coated with chemotherapy
- RO DEB-TACE - radiopaque drug eluting beads loaded with chemotherapy
- SIRT/TARE/Radioembolisation - Transarterial radioembolization or Selective internal radiation therapy (Y90 radio-embolisation)
- TACE - Transarterial chemo-embolisation, chemotherapy plus embolic agents such as coils or foam

Embolisation can be done in 3 ways:

- without chemotherapy or radiotherapy - so called "Bland" embolisation or TAE
- with chemotherapy – TACE
- with local radiotherapy – so called selective internal radiotherapy (SIRT) or transarterial radioembolization (TARE)

If chemoembolisation is done, the following methods can be used:

- standard chemotherapy – "TACE"
- drug eluting beads – "DEB-TACE"

- radio-opaque drug eluting beads – “RO DEB-TACE”

Information normally available in the patient record within the radiology reports of the procedure.

For each embolisation delivered, there should be a corresponding treatment record created in CORE-Treatment, with the correct treatment modality, date of treatment and organisation code recorded.

Rationale for inclusion:

- there are different types of embolisation that are used in different circumstances and according to local expertise and practices

Treatment – Surgery

This section is a child of ‘CORE – Treatment’, and will mandate:

- the date the treatment started
- the treatment modality
- the organisation that provided the treatment

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

May be up to one occurrence per CORE – Treatment – Surgery (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
LV16210	Surgery Type	an1	R

Surgery Type

What type of liver surgery was performed?

National Code	National Code Definition
1	Liver Resection
2	Liver Transplantation

Additional information:

- was it either a liver resection (where a part of the liver is removed) or a liver transplant?
- this information is available from imaging review

Rationale for inclusion:

- liver resection is treatment with curative intent for persons with early stage disease (BCLC-0/A)

For each surgery type, there should be a corresponding treatment record created in CORE-Treatment, with the correct treatment modality, date of treatment and organisation code recorded.

Transplantation

May be to one occurrence per record (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
LV16200	Liver Transplantation	an1	R

Liver Transplantation

Was the patient listed for transplantation?

National Code	National Code Definition
Y	Yes
N	No
9	Not Known

Additional information:

- this information is normally available in the patient record

Rationale for inclusion:

- liver transplantation is suitable for persons with early stage disease (BCLC-0/A) and offers the greatest chance of cure of HCC

- not all persons who are listed for liver transplantation receive a transplant

Cholangiocarcinoma is a contraindication for transplant, but patients may receive a transplant due to a misdiagnosis. It is important to record this.

Site Specific - Lung

ICD-10 CODES

Note:

- please refer to Appendix A and B for site specific registerable ICD codes for Lung cancer patients

Overview

Some items in the Lung site specific data set may not be available until sometime after the initial record has been uploaded. For surgery patients, treatment record and pathology details may be completed by a different Provider from the First Seen Provider.

With the formation of the new National Cancer Audit Collaborating Centre (NATCAN), all previously independent cancer audits have been brought into one organisation. Part of the rationale for this is to reduce the burden of data collection and reporting across the NHS.

As a result, all data moving forward will be from existing data sources. It is important therefore for Trusts to collect all the site specific data items within COSD, as these will form a large part of future analysis by the National Lung Cancer Audit (NLCA).

More information about NATCAN can be found via their official website using this link.

The following data items have been retired from v10:

- LU10350 – Transthoracic Echocardiogram Result
- LU10420 – Cardiopulmonary Test Type
- LU10370 – Cardiopulmonary Exercise Test Result (NLCA)
- LU10090 – Epidermal Growth Factor Receptor Mutational Status
- LU10500 – ALK Fusion Status
- LU10510 – ROS1 Fusion Status
- LU10520 – PD-L1 Expression

Diagnostic Procedures

This is a child of CORE – Diagnostic Procedures. This mandates the collection of the following data items alongside each choice:

- Organisation Site Identifier (Diagnostic Procedure)
- Diagnostic Procedure Date
- Diagnostic Procedure (OPCS)
- Diagnostic Procedure (SNOMED CT)

The OPCS and SNOMED CT can be either supplied individually or together but you cannot submit a record without one or the other.

Lung - Diagnostic Procedures Choice Choice 0..1
Lung - Diagnostic Procedures Choice 1

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
LU10310	Diffusion Capacity (DLCO or TLCO) Result	max n3	M

End of Lung - Diagnostic Procedures Choice 1

Lung - Diagnostic Procedures Choice 2

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
LU10040	FEV1 Percentage	max n3	R
LU10050	FEV1 Absolute Value	n1.n2	R

End of Lung - Diagnostic Procedures Choice 2

Lung - Diagnostic Procedures Choice 3

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
LU10400	Bronchoscopy Performed Type	an1	M

End of Lung - Diagnostic Procedures Choice 3
End of Lung - Diagnostic Procedures Choice

Cautionary notes:

- the choice order and selections within each choice may have changed between v9 to v10
- the following data items form a 3-choice menu and if applicable, can be one occurrence per 'CORE – Diagnostic Procedure group (0..1)', additional information is supplied below each choice to support this linkage

Choice 1:

Diffusion Capacity (DLCO Or TLCO) Result

Where applicable, this is a mandatory data item. The 'Diffusion Capacity (DLCO)' or Transfer factor of the lungs for carbon monoxide (TLCO) result (% predicted range 0 to 200).

Additional Information:

- OPCS code –
- SNOMED CT code – 23426006

Note:

- it is possible that these codes change over time, it is the responsibility of the reporting Trust to ensure correct codes are used

Choice 2:

FEV1 Percentage

The Forced Expiratory Volume in the first second as a percentage of the predicted value.

Must be an integer in the range of 1 to 200

FEV1 Absolute Value

The absolute value of the patient's Forced Expiratory Volume in the first second in litres.

Must be numeric in the range of 0.10 to 9.99.

Additional information:

- OPCS code - E93.4
- SNOMED CT code - 313223002

Note:

- it is possible that these codes change over time, it is the responsibility of the reporting Trust to ensure correct codes are used

Choice 3:

Bronchoscopy Performed Type

Where applicable, this is a mandatory data item. What type of bronchoscopy performed on the patient?

National Code	National Code Definition
1	Flexible Bronchoscopy

National Code	National Code Definition
2	Rigid Bronchoscopy
3	Endobronchial Ultrasound (EBUS) - Diagnostic
4	Endobronchial Ultrasound (EBUS) - Staging

Additional Information:

- OPCS code (Flexible Bronchoscopy) - E49
- OPCS code (Rigid Bronchoscopy) - E51/E51.8/E51.9
- SNOMED CT code (Bronchoscopy) - 10847001
- SNOMED CT code (Endobronchial Ultrasound) - 439939004
- SNOMED CT code (Bronchoscopy using robotic assistance (procedure)) - 1254743005

Notes:

- '5 – Bronchoscopy not performed' is a new selection in v10
- it is possible that these codes change over time, it is the responsibility of the reporting Trust to ensure correct codes are used
- for Bronchoscopy Type, you can use only the SNOMED CT code (in the 'Diagnostic Procedures' section), and then specify the type using this field
- to accurately collect 'Bronchoscopy not performed' and 'Not known' from the 'Bronchoscopy Performed Type' field, we have separated these out and unlinked them from the 'Core - Diagnostic Procedures' section in the schema

Diagnostic Procedures – Bronchoscopy

To accurately collect 'Bronchoscopy not performed' and 'Not known' from the 'Bronchoscopy Performed Type' field, we have separated these out and unlinked them from the 'Core - Diagnostic Procedures' section in the schema

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
LU10400	Bronchoscopy Performed Type	an1	R

Bronchoscopy Performed Type

May be up to one occurrence per record (0..1)

National Code	National Code Definition
5	Bronchoscopy not performed
9	Not known

Mediastinal Sampling

May be up to one occurrence per record (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
LU10060	Mediastinal Sampling Indicator	an1	R

Mediastinal Sampling Indicator

Record if the patient had a mediastinoscopy, mediastinotomy, open mediastinal sampling or other type of mediastinal biopsy (for example, Endobronchial ultrasound or transbronchial needle aspiration biopsy). This data item will be recorded by the specialist centres.

National Code	National Code Definition
Y	Yes
N	No
9	Not known

Treatment – Surgery – LCCOP

This is a child of 'CORE – Treatment' and will mandate:

- the date the treatment started
- the treatment modality
- the organisation that provided the treatment

May be up to one occurrence per CORE - Treatment - Surgery (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
LU10390	Regional Anaesthetic Technique	an1	R

Regional Anaesthetic Technique

Record the regional anaesthetic technique used on the patient.

National Code	National Code Definition
1	Epidural
2	Paravertebral Catheter
3	Other Technique
4	No Regional Anaesthesia
9	Not Known

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

Lung – Health Check

May be up to one occurrence (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
LU10600	Lung Health Check Indication	an1	R

Lung Health Check Indication

Record if the patient attended a Targeted Lung Health Check (TLHC) appointment.

National Code	National Code Definition
1	Patient attended a lung health check appointment resulting in a referral for a Low Dose CT scan
2	Patient attended a lung health check appointment but not referred for a Low Dose CT scan
3	Patient did not attend / not invited for a lung health check appointment
9	Not known

Site Specific - Sarcoma

ICD-10 CODES

Note:

- please refer to Appendix A and B for site specific registerable ICD codes for Sarcoma cancer patients

Overview

Sarcomas can arise within any site of the body and should have the ICD 10 and ICD-O-3 site code and the morphology code stated for each reportable Sarcoma.

The Cancer Waiting Times and COSD data sets have consistent inclusion criteria for sarcomas, although the COSD also includes C78.6 ("Secondary malignant neoplasm of retroperitoneum and peritoneum").

For tumours coded under the C46 ICD-10 codes only the CORE data set needs to be completed.

The following data items have been retired from v10:

- SA11010 – Sarcoma Tumour Subsite (Bone)
- SA11090 – Sarcoma Tumour Subsite (Soft Tissue)
- SA11025 – Multifocal or Synchronous Tumour Indicator
- CT6360 – Cytogenetics for Alveolar Rhabdomyosarcoma
- CT6460 – Cytogenetics for Ewings Sarcoma

Diagnosis

This section is a child of Core-Diagnosis.

May be up to one occurrence per CORE - Diagnosis (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
SA11000	Sarcoma Tumour Site (Bone)	an4	R
SA11080	Sarcoma Tumour Site (Soft Tissue)	an4	R

Sarcoma Tumour Site (Bone)

Location of the bone sarcoma within the body as defined by OPCS4 code. This is (more specific than ICD10/ICDO3 sites).

National Code	National Code Definition
Z639	Cranium
Z649	Face
Z659	Jaw
Z663	Cervical Spine
Z664	Thoracic Spine
Z665	Lumbar Spine
Z681	Clavicle
Z684	Glenoid
Z685	Scapula
Z699	Humerus
Z709	Radius
Z719	Ulna
Z724	Carpal
Z732	Metacarpal
Z733	Thumb
Z734	Finger
Z742	Sternum

National Code	National Code Definition
Z746	Rib
Z751	Sacrum
Z753	Ileum
Z754	Ischium
Z755	Pubis
Z756	Acetabulum
Z757	Coccyx
Z769	Femur
Z779	Tibia
Z786	Fibula
Z787	Patella
Z799	Tarsus
Z802	Metatarsus
Z803	Great toe
Z804	Toe
Z928	Multiple

Notes:

- use Cranium (Z639) for instances of Sarcoma of the Skull
- only use codes specified within this list; if new codes are required, please request these for v11 using the 'Submit Change Request' form

Sarcoma Tumour Site (Soft Tissue)

Location of the soft tissue sarcoma within the body as defined by OPCS4 code. This is (more specific than ICD10/ICDO3 sites).

National Code	National Code Definition
Z272	Stomach
Z301	Liver
Z459	Uterus
Z533	Peritoneum
Z891	Shoulder
Z892	Upper Arm
Z893	Forearm
Z894	Hand
Z898	Specified Arm Region (to include wrist and elbow)
Z901	Buttock
Z903	Upper Leg (to include thigh)
Z904	Lower Leg (to include calf)
Z905	Foot
Z908	Specified leg region (to include groin, knee, ankle)
Z921	Head
Z923	Neck
Z924	Chest (to include Intrathoracic)

National Code	National Code Definition
Z927	Trunk (to include upper and lower)
Z928	Multiple
Z929	Unknown

Note:

- only use codes specified within this list; if new codes are required, please request these for v11 using the 'Submit Change Request' form

This next section forms a choice of 2 CTYA disease groups and associated data items.

Diagnosis - Rhabdomyosarcoma and Other Soft Tissue Sarcomas

Sarcoma - Diagnosis – Choice Choice 0..1
Sarcoma - Diagnosis - Choice 1

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT6350	IRS Post Surgical Group	an1	R
CT6750	IRS Post Surgical Group Date	an10 ccyy-mm-dd	R
CT6370	Rhabdomyosarcoma Site Prognosis Code	an1	R

End of Sarcoma - Diagnosis - Choice 1

Diagnosis – Ewings

Sarcoma - Diagnosis - Choice 2

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
CT6450	Tumour Volume at Diagnosis	an1	M

End of Sarcoma - Diagnosis - Choice 2
End of Sarcoma - Diagnosis - Choice

Choice 1 (Rhabdomyosarcoma and Other Soft Tissue Sarcomas):

IRS Post Surgical Group

IRS group defines the post-surgical disease status at diagnosis. This information should be available for the MDT discussion following treatment but will only apply to a small number of cases.

National Code	National Code Definition
1	Group 1
2	Group 2
3	Group 3
4	Group 4

The following definitions are used:

- group 1 - primary complete resection
- group 2 - microscopic residual disease or primary complete resection with (completely resected) lymph node involvement
- group 3 - macroscopic residual disease
- group 4 - distant metastases

IRS Post Surgical Group Date

The date on which the IRS Post Surgical Group was recorded.

Rhabdomyosarcoma Site Prognosis Code

Grouping of anatomical sites which imply prognostic significance. This information should be available for the MDT discussion but will only apply to a small number of cases.

National Code	National Code Definition
F	Favourable
U	Unfavourable

The following definitions are used:

- favourable sites: Orbit, genitourinary Non Bladder Prostate, Non-Parameningeal Head and Neck
- unfavourable sites: all other sites of disease

Choice 2 (Ewings):

Tumour Volume at Diagnosis

Radiologically calculated estimate of tumour volume at diagnosis which has value in determining treatment.

National Code	National Code Definition
L	Less than 200ml
M	200ml or greater

Site Specific - Skin

ICD-10 CODES

Note:

- please refer to Appendix A and B for site specific registerable ICD codes for Skin cancer patients

Malignant neoplasm of the anus should be coded as:

- margin (C43.5, C44.5)
- skin (C43.5, C44.5)
- perianal skin (C43.5, C44.5)

Overview

All skin cancers diagnosed from January 2018 should be staged using UICC TNM v8, and the stage fields (which are in the 'Core' data set), should be used where applicable:

- for Melanomas the full Core and Site Specific data sets must be submitted
- for SCCs and BCCs which require MDT discussion, the full Core and Site Specific data sets must be submitted
- for other non-melanoma* cases which require MDT discussion, only the Core data set should be submitted
- where stage is applicable for these cases (for example Merkel Cell tumours and Adnexal carcinomas) please use the CORE Staging fields, using UICC TNM 8
- for all skin cancers that do not require MDT discussion, the minimum requirement is for the pathology report to be submitted
- for skin cancers that do require MDT discussion it is acceptable for the pathology stage to be taken to be the integrated stage when submitting COSD
- providers are encouraged to submit complete data sets if possible

Grade of Differentiation is not applicable for skin cancers other than SCC and therefore 'Grade of Differentiation (at Diagnosis)' is not applicable for Melanoma, BCCs or Merkel Cell tumours.

Non-melanoma skin cancers include:

- BCC
- SCC
- Merkel Cell tumours
- Adnexal (primary malignant adnexal carcinomas of eccrine, apocrine, follicular and sebaceous subtypes)

- other NMSC

Cancer Care Plan

Data within this section would be expected to be available at the MDT, where the care plan was agreed. This is a child of Core – Cancer Care Plan.

May be up to one occurrence per Core - Cancer Care Plan (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
SK13000	Immunosuppressed Status	an1	R

Immunosuppressed Status
This is a new data item for v10. Record the patient's immunosuppressed status.

National Code	National Code Definition
Y	Immunosuppressed
N	Not immunosuppressed
9	Not Known

Examples of immune suppression includes:

- organ transplant recipients
- immunosuppressive medication
- haematological malignancy
- HIV/hepatitis B or C

Treatment - Surgery - BCC, SCC & MM

This section includes surgery details for Basal Cell Carcinoma, Squamous Cell Carcinoma, and Malignant Melanoma. This is a child of Core – Treatment – Surgery, and will mandate:

- the date the treatment started
- the treatment modality
- the organisation that provided the treatment

May be up to one occurrence per Core - Treatment - Surgery (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
SK12010	Grade of Clinician/Surgeon Operating	max an3	R
SK12700	Member of Specialist MDT	an1	R

Grade of Clinician/Surgeon Operating

This is the level of training reached of the actual operating Clinician or Surgeon, and not necessarily the responsible Clinician.

National Code	National Code Definition
NU	Nurse
TS	Trainee Specialist Doctor
CS	Consultant Surgeon (other than Plastic Surgeon)
CD	Consultant Dermatologist
CPS	Consultant Plastic Surgeon
HP	Hospital Practitioner
SAS	Specialty And Associate Specialist
SI	GP with an Extended Role (GPwER)
GP	General Practitioner
98	Other Care Professional

Notes:

- 'SAS - Specialty and Associate Specialist' is a new selection from v10
- 'SI - GP with an Extended Role (GPwER)' national code definition has been updated to meet new Data Dictionary terminology

- OO has been retired and replaced with 98, on the advice of the NHS Data Model and Dictionary Service

Member of Specialist MDT

Is the actual operating Clinician or Surgeon a member of the Specialist MDT?

National Code	National Code Definition
Y	Yes
N	No
9	Not Known

Site Specific – Upper GI

ICD-10 CODES

Note:

- please refer to Appendix A and B for site specific registerable ICD codes for Upper GI cancer patients

Future contracting of NOGCA

The contract for the National Gastrointestinal Cancer Audit Programme (GICAP) at the Royal College of Surgeons of England, which is made up of NBOCA and the National Oesophago-Gastric Cancer Audit (NOGCA), comes to an end on 31 May 2023. From 1 June 2023 both NBOCA and NOGCA will move into the National Cancer Audit Collaborating Centre (NATCAN) at the Clinical Effectiveness Unit (CEU) of the Royal College of Surgeons of England (RCS England).

Part of the rationale for this is to reduce the burden of data collection and reporting across the NHS. As a result, all data moving forward will be from existing data sources. It is important therefore for Trusts to collect all the site specific data items within COSD, as these will form a large part of future analysis by NOGCA.

More information about NATCAN can be found via their official website using this link

Overview

It is important to note that all 'Liver and Cholangiocarcinoma' cancers are now to be reported within the 'Liver' section of COSD.

All staging should now be recorded using the 'CORE – Staging' section, using UICC TNM v8.

Treatment – Surgery – General

This is a child of 'CORE – Treatment – Surgery', and will mandate:

- the date the treatment started
- the treatment modality
- the organisation that provided the treatment

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

May be up to one occurrence per Core - Treatment - Surgery (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UG13810	Non Curative Intent Reason (Upper GI)	an1	M

Non Curative Intent Reason (Upper GI)

Record the reason why the patient was taken to theatre for curative intent, but intraoperative findings prevent surgery.

National Code	National Code Definition
1	Extensive intrahepatic disease
2	Widespread disease
3	Both extensive intrahepatic and widespread disease
7	Metastatic disease (either liver or peritoneal)
8	Locally advanced disease

Notes:

- 4, 5 and 6 have been retired
- 7 and 8 are new selections from v10

Treatment – Surgery – O-G

This is a child of 'CORE – Treatment – Surgery', and will mandate:

- the date the treatment started
- the treatment modality
- the organisation that provided the treatment

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

May be up to one occurrence per Core - Treatment - Surgery (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UG14230	Post Operative Tumour Site (Upper GI)	an2	M

Post Operative Tumour Site (Upper GI)

The main cancer site for which the patient is receiving care, as established in the resected specimen. Please note that "Cardia" should no longer be used to describe adenocarcinomas located at the gastro-oesophageal junction. Instead, these tumours should be described by the appropriate Siewert type.

National Code	National Code Definition
01	Oesophagus upper third
02	Oesophagus middle third
03	Oesophagus lower third
04	Siewert 1
05	Siewert 2
06	Siewert 3
07	Fundus
08	Body of stomach
09	Antrum
10	Pylorus

Treatment – Surgery – ESODATA

This is to carry surgical complication details for 'Upper GI – Esophageal Database (ESODATA)' as specified. This is a child of 'CORE – Treatment – Surgery', and will mandate:

- the date the treatment started
- the treatment modality
- the organisation that provided the treatment

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

May be up to one occurrence per Core - Treatment - Surgery (0..1)
Start of Repeating Item - Surgical Complications - International Esophageal Database (ESODATA)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UG15010	Surgical Complications - International Esophageal Database (ESODATA)	an4	R*

End of Repeating Item - Surgical Complications - International Esophageal Database (ESODATA)

Start of Section - Surgical Complications Leak Severity Type (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UG15010	Surgical Complications - International Esophageal Database (ESODATA)	an4	M
UG15020	Leak Severity Type	an1	M

End of Section - Surgical Complications Leak Severity Type

Start of Section - Surgical Complications Conduit Necrosis/Failure Type (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UG15010	Surgical Complications - International Esophageal Database (ESODATA)	an4	M

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UG15030	Conduit Necrosis/Failure Type	an1	M

End of Section - Surgical Complications Conduit Necrosis/Failure Type

Start of Section - Surgical Complications Recurrent Laryngeal Nerve Injury Involvement Type (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UG15010	Surgical Complications - International Esophageal Database (ESODATA)	an4	M
UG15040	Recurrent Laryngeal Nerve Injury Involvement Type	an1	M

End of Section - Surgical Complications Recurrent Laryngeal Nerve Injury Involvement Type

Start of Section - Surgical Complications Chyle Leak Severity Type (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UG15010	Surgical Complications - International Esophageal Database (ESODATA)	an4	M
UG15050	Chyle Leak Severity Type	an1	M

End of Section - Surgical Complications Chyle Leak Severity Type

Start of Repeating Section - Surgical Complications Additional Complications (0..*)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UG15010	Surgical Complications - International Esophageal Database (ESODATA)	an4	M

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UG15070	Additional Complications	max an150	M

End of Repeating Section - Surgical Complications Additional Complications

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UG15060	Clavien-Dindo Classification of Surgical Classifications	an1	R

Surgical Complications – International Esophageal Database (ESODATA)

The types of complications as defined in the International Esophageal Database (ESODATA).

This list has been compiled by the Esophageal Complications Consensus Group (ECCG)

National Code	National Code Definition
0100	Gastrointestinal
0101	No post-operative complications
0104	Ileus defined as small bowel dysfunction preventing or delaying enteral feeding
0105	Small bowel obstruction
0106	Feeding J-tube complication
0107	Pyloromyotomy/Pyloroplasty complication
0108	Clostridium Difficile infection
0109	GI bleeding requiring intervention or transfusion
0110	Pancreatitis

National Code	National Code Definition
0111	Liver dysfunction
0112	Delayed conduit emptying requiring intervention or delaying discharge or requiring maintenance of ng drainage >7 days post-op
0113	Bowel ischaemia
0199	None
0200	Pulmonary
0201	Pneumonia
0202	Pleural effusion requiring additional drainage procedure
0203	Pneumothorax requiring intervention
0204	Atelectasis mucous plugging requiring bronchoscopy
0205	Respiratory failure requiring intubation
0206	Acute respiratory distress syndrome
0207	Acute aspiration
0208	Tracheobronchial injury
0209	Chest drain requirement for air leak for >10 days post-op
0299	None
0300	Cardiac
0301	Cardiac arrest requiring CPR
0302	Myocardial infarction

National Code	National Code Definition
0303	Dysrhythmia atrial requiring intervention
0304	Dysrhythmia ventricular requiring intervention
0305	Congestive heart failure requiring intervention
0306	Pericarditis requiring intervention
0399	None
0400	Thromboembolic
0401	DVT (Deep Venous Thrombosis)
0402	PE (Pulmonary Embolus)
0403	Stroke (CVA)
0404	Peripheral thrombophlebitis
0499	None
0500	Urologic
0501	Acute renal insufficiency (defined as: doubling of baseline creatinine)
0502	Acute renal failure requiring dialysis
0503	Urinary tract infection
0504	Urinary retention requiring reinsertion of urinary catheter, delaying discharge, or discharge with urinary catheter
0599	None
0600	Infection

National Code	National Code Definition
0601	Wound infection requiring opening wound or antibiotics
0602	Central IV line infection requiring removal or antibiotics
0603	Intrathoracic/Intra-abdominal abscess
0604	Generalised sepsis
0605	Other infections requiring antibiotics
0699	None
0700	Neurologic/Psychiatric
0702	Other neurologic injury
0703	Acute delirium
0704	Delirium tremens
0799	None
0800	Wound/Diaphragm
0801	Thoracic wound dehiscence
0802	Acute abdominal wall dehiscence/hernia
0803	Acute diaphragmatic hernia
0899	None
0900	Other
0901	Chyle leak
0903	Reoperation for thoracic bleeding

National Code	National Code Definition
0904	Reoperation for abdominal bleeding
0905	Reoperation for reasons other than bleeding, anastomotic leak or conduit necrosis
0906	Multiple organ dysfunction syndrome
0999	None

Notes:

- the following is the start of a repeating section – 'Surgical Complications Leak Severity Type'
- this will link both the complication and the type
- these data items are mandatory within the section, therefore you cannot submit this section without all data being reported

Surgical Complications – International Esophageal Database (ESODATA)

The specified type of complication as defined in the International Esophageal Database (ESODATA).

National Code	National Code Definition
0102	Oesophagoenteric leak from anastomosis, staple line, or localised conduit necrosis

Leak Severity Type

Record the severity of the leak

National Code	National Code Definition
1	Type I
2	Type II
3	Type III

National Code	National Code Definition
9	Not Known (not recorded)

Notes:

- the following is the start of a repeating section – 'Surgical Complications Conduit Necrosis/Failure Type'
- this will link both the complication and the type
- these data items are mandatory within the section, therefore you cannot submit this section without all data being reported

Surgical Complications – International Esophageal Database (ESODATA)

The specified type of complication as defined in the International Esophageal Database (ESODATA).

National Code	National Code Definition
0103	Conduit necrosis/failure requiring surgery

Conduit Necrosis/Failure Type

Record the conduit necrosis/failure type

National Code	National Code Definition
1	Type I
2	Type II
3	Type III
9	Not Known (not recorded)

Notes:

- the following is the start of a repeating section – 'Surgical Complications Recurrent Laryngeal Nerve Injury Involvement Type'
- this will link both the complication and the type
- these data items are mandatory within the section, therefore you cannot submit this section without all data being reported

Surgical Complications – International Esophageal Database (ESODATA)
The specified type of complication as defined in the International Esophageal Database (ESODATA).

National Code	National Code Definition
0701	Recurrent nerve injury

Recurrent Laryngeal Nerve Injury Involvement Type
Record any recurrent laryngeal nerve injury involvement type

National Code	National Code Definition
1	Type Ia
2	Type Ib
3	Type IIa
4	Type IIb
5	Type IIIa
6	Type IIIb
9	Not Known (not recorded)

Notes:

- the following is the start of a repeating section – 'Surgical Complications Chyle Leak Severity Type'
- this will link both the complication and the type
- these data items are mandatory within the section, therefore you cannot submit this section without all data being reported

Surgical Complications – International Esophageal Database (ESODATA)
The specified type of complication as defined in the International Esophageal Database (ESODATA).

National Code	National Code Definition
0902	Chyle leak severity/type

Chyle Leak Severity Type

Record any Chyle leak severity type

National Code	National Code Definition
1	Type Ia
2	Type Ib
3	Type IIa
4	Type IIb
5	Type IIIa
6	Type IIIb
9	Not Known (not recorded)

Notes:

- the following is the start of a repeating section – 'Surgical Complications Additional Complications'
- this will allow for any additional complications to be recorded
- these data items are mandatory within the section, therefore you cannot submit this section without all data being reported

Surgical Complications – International Esophageal Database (ESODATA)

The specified type of complication as defined in the International Esophageal Database (ESODATA).

National Code	National Code Definition
1001	The patient had other complications

Additional Complications

If 'other complications' selected, state any complications that is not in the ECCG recommended complications list above?

Clavien-Dindo Classification of Surgical Classifications

Record the overall grade as per the Clavien-Dindo Classification of Surgical Classifications.

National Code	National Code Definition
1	Grade I
2	Grade II
3	Grade IIIa
4	Grade IIIb
5	Grade Iva
6	Grade Ivb
7	Grade V
9	Not Known (not recorded)

Note:

- it was noted that the name is misspelt in v9. this has been corrected in v10, previously 'Calvien-Dindo Classification of Surgical Classifications'

Treatment – Surgery – Outcome Measures

This is to carry surgery outcome measures for 'Upper GI – Esophageal Database (ESODATA)' as specified. This is a child of 'CORE – Treatment – Surgery', and will mandate:

- the date the treatment started
- the treatment modality
- the organisation that provided the treatment

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and

improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

May be up to one occurrence per CORE – Treatment - Surgery (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UG15110	Change in Level of Care	an1	R
UG15120	Blood Product Utilisation	an1	R
UG15130	Number of Units Transfused	an1	R

Change in Level of Care

Record if there was any change in the level of care required for the patient?

National Code	National Code Definition
1	No escalation in level of care required
2	Required escalation in level of care (ICU, ITU / HDU)
9	Not Known (not recorded)

Blood Product Utilisation

Record if there were any blood products required?

National Code	National Code Definition
1	Intra-operative transfusions
2	Post-operative transfusions
3	Intra and post-operative transfusions
8	Not Applicable (None - No transfusions)
9	Not Known (not recorded)

Number of Units Transfused

Record the number of units of blood transfused.

National Code	National Code Definition
1	1-2 units
2	3-4 units
3	5 or more units
9	Not Known (not recorded)

Treatment – Surgery – Oesophagectomy

This is to carry surgery procedure details, for 'Upper GI – Oesophagectomy' as specified. This is a child of 'CORE – Treatment – Surgery', and will mandate:

- the date the treatment started
- the treatment modality
- the organisation that provided the treatment

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

May be up to one occurrence per CORE – Treatment – Surgery (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UG15200	Surgical Approach Type	an1	R
UG15210	Open Approach Type	an1	R
UG15220	Minimally Invasive Approach Type	an1	R
UG15230	Anastomosis Type	an1	R

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UG15240	Oesophageal Conduit Type	an1	R
UG15250	Neck Dissection	an1	R

Surgical Approach Type

Record the type of surgical approach used during the Oesophagectomy.

National Code	National Code Definition
1	Open Oesophagectomy
2	Minimally Invasive Oesophagectomy
9	Not Known (not recorded)

Open Approach Type

Record the type of open surgical approach used during the Oesophagectomy.

National Code	National Code Definition
1	Trans Thoracic Oesophagectomy
2	Trans Hiatal Oesophagectomy

Minimally Invasive Approach Type

Record the type of minimally invasive approach used during the Oesophagectomy.

National Code	National Code Definition
1	Total Minimally Invasive
2	Abdominal part minimally invasive

National Code	National Code Definition
3	Chest part minimally invasive

Anastomosis Type

Record the type of anastomosis used during the Oesophagectomy.

National Code	National Code Definition
1	Neck anastomosis
2	Chest anastomosis
3	None
8	Other
9	Not Known (not recorded)

Oesophageal Conduit Type

Record the type of oesophageal conduit used during the Oesophagectomy.

National Code	National Code Definition
1	Stomach
2	Small bowel
3	Colon
4	None
8	Other
9	Not Known (not recorded)

Neck Dissection

Record if there was any neck dissection during the Oesophagectomy.

National Code	National Code Definition
Y	Neck dissection
N	No neck dissection
9	Not Known (not recorded)

Treatment – Surgery – Liver Cholangiocarcinoma and Pancreatic

This is to carry surgery details for Upper GI, as specified. This is a child of 'CORE – Treatment – Surgery', and will mandate:

- the date the treatment started
- the treatment modality
- the organisation that provided the treatment

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

May be up to one occurrence per CORE - Treatment - Surgery (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UG13240	Surgical Palliation Type	an1	M

Surgical Palliation Type

This is a mandatory data item. Record the type of surgical palliation performed if any, for example Hepaticojejunostomy.

National Code	National Code Definition
0	None

National Code	National Code Definition
1	gastric bypass
2	biliary bypass
3	gastric/biliary bypass
4	celiac plexus block
9	Not known

Treatment – Surgery – Endoscopic or Radiological Procedures – Pancreatic and O-G

This is to carry surgery details for Endoscopic and Radiological procedures for Upper GI, as specified. This is a child of 'CORE – Treatment – Surgery', and will mandate:

- the date the treatment started
- the treatment modality
- the organisation that provided the treatment

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

May be up to one occurrence per CORE - Treatment - Surgery (0..1)
Start of Repeating Item - Endoscopic Procedure Type

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UG14290	Endoscopic Procedure Type	an1	M*

End of Repeating Item - Endoscopic Procedure Type

Endoscopic Procedure Type
This is a mandatory data item. The main endoscopic procedures carried out. More than one procedure can be entered. This is a repeating data item.

National Code	National Code Definition
1	Stent insertion
2	Laser therapy
3	Argon plasma coagulation
4	Photodynamic therapy
5	Gastrostomy
6	Brachytherapy
7	Dilation
8	Other

Treatment – Surgery – Endoscopic or Radiological Procedures – Main

This is to carry surgery details for Endoscopic and Radiological procedures for Upper GI, as specified. This is a child of 'CORE – Treatment – Surgery', and will mandate:

- the date the treatment started
- the treatment modality
- the organisation that provided the treatment

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

May be up to one occurrence per CORE – Treatment – Surgery (0..1)
Start of Repeating Item - Endoscopic or Radiological Complication Type

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UG13090	Endoscopic or Radiological Complication Type	an2	M*

End of Repeating Item - Endoscopic or Radiological Complication Type

Endoscopic or Radiological Type Complication

This is a mandatory data item. The types of complications that the patient experiences during the admission for the endoscopic procedure. More than one option can be selected.

National Code	National Code Definition
00	No complications
02	Perforation
03	Haemorrhage
09	Pancreatitis
10	Cholangitis
88	Other

Site Specific – Urology

ICD-10 CODES

Note:

- please refer to Appendix A and B for site specific registerable ICD codes for Urological cancer patients

Overview

The site-specific Urological data set applies additionally to in situ Bladder cancers and pTa Bladder cancers, although these are excluded from Cancer Waits. Please refer to the training guides for more information about coding these tumours for COSD.

With the formation of the new National Cancer Audit Collaborating Centre (NATCAN), all previously independent cancer audits have been brought into one organisation. Part of the rationale for this is to reduce the burden of data collection and reporting across the NHS.

As a result, all data moving forward will be from existing data sources. It is important therefore for Trusts to collect all the site specific data items within COSD, as these will form a large part of future analysis by the National Prostate Cancer Audit (NPCA).

More information about NATCAN can be found via their official website using this link.

Watchful Waiting and Active Surveillance

A treatment (Cancer Treatment Modality) of “Active Monitoring” should be recorded for all patients who are largely asymptomatic and may progress to active treatment if the status of the disease progresses, (this covers all patients who are being monitored only and will include “watchful waiting” as used clinically).

For symptomatic patients who are not receiving active treatment, the selected treatment type (Cancer Treatment Modality) will be either “Specialist Palliative Care” or “Non specialist Palliative Care” depending on whether the patient is under the care of a specialist in palliative medicine.

For tumours in unusual sites where there is overlap between a data set based on anatomy and another based on the disease description it is recommended that both data sets are completed. For example, for a melanoma of the penis both the penile and the melanoma data set should be completed.

The following data items have been retired from v10:

- UR15320 – Extranodal Metastases
- UR15330 – Lung Metastases Sub-Stage Grouping
- UR15040 – S-Category AFP
- UR15050 – S-Category HCG
- UR15060 – S-Category LDH
- UR15020 – Normal LDH

Diagnostic Procedures – Prostate

This is a child of 'CORE – Diagnostic Procedures'. This mandates the collection of the following data items alongside each choice:

- Organisation Site Identifier (Diagnostic Procedure)
- Diagnostic Procedure Date
- Diagnostic Procedure (OPCS)
- Diagnostic Procedure (SNOMED CT)

The OPCS and SNOMED CT can be either supplied individually or together but you cannot submit a record without one or the other.

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

May be up to one occurrence per CORE - Diagnostic Procedures (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UR15410	Prostate Biopsy Technique	an2	M
UR15440	Biopsy Anaesthetic	an1	M

Prostate Biopsy Technique

This is a mandatory data item within this section. Record the type of prostate biopsy technique performed before treatment. This is part of the National Prostate Cancer Audit (NPCA) and the attributes have been changed to make understanding the type of biopsy technique used easier.

National Code	National Code Definition
10	TRUS guided biopsy (standard)
11	TRUS guided biopsy (targeted)
12	TRUS guided biopsy (targeted and standard)
13	Transperineal biopsy (systematic)
14	Transperineal biopsy (targeted)
15	Transperineal biopsy (targeted and systematic)
99	Not Known

Additional Information

TRUS guided biopsy:

- OPCS code - M70.3
- SNOMED CT code - 431605004
- SNOMED CT code - 241487002

Transperineal biopsy:

- OPCS code - M70.2
- SNOMED CT code - 265593007

Notes:

- it is possible that these codes change over time, it is the responsibility of the reporting Trust to ensure correct codes are used
- for TRUS Guided Biopsy and Transperineal Biopsy, you can use only the SNOMED CT or OPCS code (in the 'Diagnostic Procedures' section), and then specify the type using this field

Biopsy Anaesthetic

This is a mandatory data item within this section. Record the type of anaesthetic used during the biopsy. This is part of the National Prostate Cancer Audit (NPCA).

National Code	National Code Definition
1	Local
2	Sedation
3	General
9	Not Known

Diagnosis – Prostate

May be up to one occurrence per CORE - Diagnosis (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UR15500	mpMRI Pre-Biopsy	an1	R
UR15510	MRI/Fusion Biopsy	an1	R
UR15070	PSA (Diagnosis)	max n5.n1	R

mpMRI Pre-Biopsy
Indicate if a multiparametric mpMRI performed on the patient before the biopsy? It is important for the NPCA audit to know if the MRI was not a multiparametric as if it was, please ensure this is recorded accurately.

National Code	National Code Definition
Y	Yes
N	No
9	Not Known

MRI/Fusion Biopsy

Indicate if a MRI/Fusion Biopsy was performed on the patient? It is important for the NPCA audit to know if a MRI/Fusion Biopsy was not performed as if it was, please ensure this is recorded accurately.

National Code	National Code Definition
Y	Yes
N	No
9	Not Known

PSA (Diagnosis)

'Prostate Only'. Prostate Specific Antigen blood level in ng/ml, measured at time of diagnosis (positive values only).

Cancer Care Plan

May be up to one occurrence per CORE – Cancer Care Plan (0..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UR15000	Estimated Glomerular Filtration Rate	max n2	R
UR15010	Hydronephrosis	an1	R
UR15030	Preoperative S-Category	an2	R
UR15600	Postoperative (NADIR) S-Category	an2	R

Estimated Glomerular Filtration Rate

'Renal Only'. This is the estimated Glomerular Filtration Rate. It is a measurement of kidney function in mls/min/1.73m^2. This is to be collected once at diagnosis. Note that this should be recorded as part of standard renal function test. Positive values. Numerical value to be recorded (categories can be derived from this at a later stage) (0-99).

Hydronephrosis

'Bladder Only'. Consequence of reduced outflow of urine from Kidney. May be present in one or both kidneys.

National Code	National Code Definition
0	None
L	Left
R	Right
B	Bilateral
8	Not Applicable (No Kidneys)
9	Not known

Preoperative S-Category

'Testicular Only'. The preoperative S-Category at diagnosis, based on serum tumour markers AFP, HCG and LDH. For Testicular Cancer, preoperative S category is an additional prognostic factor.

See below for further details of values to be recorded:

National Code	National Code Definition
SX	LDH - Marker studies not available or not performed; HCG - Marker studies not available or not performed; AFP - Marker studies not available or not performed
S0	LDH - Normal; HCG - Normal; AFP - Normal
S1	LDH - Less than 1.5 x normal; HCG - Less than 5,000; AFP - Less than 1,000
S2	LDH - 1.5-10 x normal; HCG - 5,000-50,000 AFP - 1,000-10,000

National Code	National Code Definition
S3	LDH - Greater than 10 x normal; HCG - Greater than 50,000; AFP - Greater than 10,000

Note:

- this has a new name in v10, to allow for the separation of preoperative and postoperative S-Category being recorded
- the description and data definitions have been updated in v10

Postoperative (NADIR) S-Category

This is a new data item in v10. 'Testicular Only'. The postoperative (NADIR) S-Category, based on serum tumour markers AFP, HCG and LDH. For Testicular Cancer postoperative S category is an additional prognostic factor.

See below for further details of values to be recorded:

National Code	National Code Definition
SX	LDH - Marker studies not available or not performed; HCG - Marker studies not available or not performed; AFP - Marker studies not available or not performed
S0	LDH - Normal; HCG - Normal; AFP - Normal
S1	LDH - Less than 1.5 x normal; HCG - Less than 5,000; AFP - Less than 1,000
S2	LDH - 1.5-10 x normal; HCG - 5,000-50,000 AFP - 1,000-10,000
S3	LDH - Greater than 10 x normal; HCG - Greater than 50,000; AFP - Greater than 10,000

Laboratory Results

This section and all its content have been retired from v10.

Site Specific Staging

It is important that all stageable cancers are staged for every case. All site specific staging fields are mandatory and a child of 'CORE – Site Specific Staging' Section, and together mandates the collection of:

- the date the sample was taken which provided a positive site specific stage outcome or the MDT where the stage was agreed
- the organisation who carried out the stage
  - this is a 'required' data item from v10, but important to collect if known
- the stage itself

Testicular

For testicular cancer, it is important that the TNM stage components should both be collected as follows:

- UICC stage groupings should now be used for testicular cancer in the CORE – Staging section (Pre-treatment TNM Stage components are optional)
- S category (the IGCCCG classification for testicular cancer) should be collected separately
- first CT scan performed (usually after orchidectomy) prior to chemotherapy/radiotherapy should be reported in the Core Imaging section

Notes:

- after many discussions with SME's, it has been agreed to keep the Royal Marsden staging classification for testicular cancer for v10
- this will be reviewed again during the v11 review
- TNM staging as described above should still be collected in addition to the RMH anatomical groupings

May be up to one occurrence per CORE – Site Specific Staging (1..1)

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UR15300	Stage Grouping (Testicular)	max an2	M

Stage Grouping (Testicular)
'Testicular Only'. Nationally agreed anatomical stage groupings as defined by The Royal Marsden Hospital (RMH).

National Code	National Code Definition
1	Stage 1
1S	Stage 1S
1M	Stage 1M
2A	Stage 2A
2B	Stage 2B
2C	Stage 2C
3A	Stage 3A
3B	Stage 3B
3C	Stage 3C
4A	Stage 4A
4B	Stage 4B
4C	Stage 4C

Note:

- this is now a mandatory data item if applicable

Additional staging advice

Stage 1:

- Confined to testis

Stage 1S:

- (Not used)

Stage 1M:

- Rising post orchidectomy markers only

Stage 2A:

- Abdominal lymphadenopathy < 2cm

Stage 2B:

- Abdominal lymphadenopathy 2cm - 5cm

Stage 2C:
- Abdominal lymphadenopathy > 5cm

Stage 3A:
- Supradiaphragmatic lymphadenopathy with abdominal lymphadenopathy < 2cm

Stage 3B:
- Supradiaphragmatic lymphadenopathy with abdominal lymphadenopathy 2cm - 5cm

Stage 3C:
- Supradiaphragmatic lymphadenopathy with abdominal lymphadenopathy > 5cm

Stage 4A:
- Extralymphatic metastases with abdominal lymphadenopathy < 2cm

Stage 4B:
- Extralymphatic metastases with abdominal lymphadenopathy 2cm - 5cm

Stage 4C:
- Extralymphatic metastases with abdominal lymphadenopathy > 5cm

Treatment 'Choice'

This is a child of 'CORE – Treatment', and will mandate:
- the date the treatment started
- the treatment modality
- the organisation that provided the treatment

It is possible that some legacy data may not have all the required mandatory fields. The recommendation is for Trusts to update their data to meet the new requirements and improve/enrich their data submissions, or not upload the legacy data items in the new record (if that data is not available).

Must be one occurrence if chosen per CORE - Treatment (1..1)

Treatment - Choice Choice 0..1
Treatment - Choice 1

Treatment - Intravesical Indicator Choice Choice 1..1
Treatment - Intravesical Indicator - Choice 1

c	Data Item Name	Format	Schema Specification (M/R/O/P)
UR15100	Intravesical Chemotherapy Received Indicator	an1	M

End of Treatment - Intravesical Indicator – Choice 1

Treatment - Intravesical Indicator - Choice 2

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UR15110	Intravesical Immunotherapy Received Indicator	an1	M

End of Treatment - Intravesical Indicator – Choice 2
End of Treatment - Intravesical Indicator Choice
End of Treatment - Choice 1

Treatment - Choice 2

Data Item Number	Data Item Name	Format	Schema Specification (M/R/O/P)
UR15420	Procedure - Nerve Sparing	an1	R
UR15430	Radical Prostatectomy Margin Status	an1	R

End of Treatment – Choice 2
End of Treatment - Choice

Treatment Choice 1 (Intravesical Indicator – Choice 1):

Intravesical Chemotherapy Received Indicator

'Bladder Only'. If selected, this is a mandatory data item. (Only required for patients having chemotherapy). Record as YES for patients having intravesical chemotherapy to distinguish from intravenous. This data item requires clinical involvement to ensure completeness.

National Code	National Code Definition
Y	Yes
N	No
9	Not Known

Treatment Choice 1 (Intravesical Indicator – Choice 2):

Intravesical Immunotherapy Received Indicator

'Bladder Only'. If selected, this is a mandatory data item. (Only required for patients having immunotherapy). Record as YES for patients having immunotherapy to distinguish from systemic. This data item requires clinical involvement to ensure completeness.

National Code	National Code Definition
Y	Yes
N	No
9	Not Known

Notes:

- either 'Intravesical Chemotherapy Received Indicator' or 'Intravesical Immunotherapy Received Indicator' is required for patients having anti-cancer therapy treatment to distinguish between modes of delivery
- only one will be applicable for each treatment, as specified by the 2 'Intravesical Indicator' choices above

Treatment Choice 2

Procedure – Nerve Sparing

Extent of surgical nerve sparing. This part of the National Prostate Cancer Audit (NPCA).

National Code	National Code Definition
1	Bilateral
2	Unilateral

National Code	National Code Definition
3	None
9	Not Known

Radical Prostatectomy Margin Status

The surgical margin status following radical prostatectomy. This is also part of the National Prostate Cancer Audit (NPCA).

National Code	National Code Definition
1	Negative Margins
2	Positive Margins <3mm in length
3	Positive Margins ≥3mm in length
4	Positive Margins, length unknown
9	Not Known

Key changes since version 9.0.2

This updated version of the User Guide includes new data-items, re-alignment of data structure, amendments and contains corrections, for example where there were errors in previous versions and updates where clinical coding or staging values changed from COSD Data set v9.0.2 and should be used to help data collection.

Throughout the data set there are now 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

This provides a net reduction in the v10 data set of 54 data items.

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

All the changes are available to view in the COSD workbook, within the yellow 'Change Log' tab. This will provide you with the following information:

- change ID
- data item number

- data item name
- data item section
- change type
- previous
- new
- change reason
- approved
- data set version (where change actioned)

Corrected schema to allow Cancer Care Plan to be recorded for all pathways, not just a Primary Pathway.

Clinical terminology integration within COSD

Why are we integrating clinical terminologies within COSD?

The data set can benefit significantly from implementing clinical terminologies within the data model:

- using SNOMED CT to capture outcome measures can reduce the need for individual tables for each measure
- a single table can capture multiple measures using a common structure
- the data set can respond more quickly to changes in clinical practice and information requirements
- terminology is updated at regular intervals and the data set automatically can capture the latest terms without the need for changing the data set through the DAPB process
- all NHS healthcare providers in England must now use SNOMED CT for capturing clinical terms within electronic patient record systems
- the use of SNOMED CT simplifies exchanging clinical information between systems

It is important to note that there is limited use of SNOMED CT within COSD, however this will be reviewed and may capture more clinical terminology within future versions.

What is SNOMED CT

SNOMED CT is the standard clinical terminology for the NHS to support recording of clinical information, in a way that supports data management and analysis to support patient care, while enabling data extraction and data exchange.

SNOMED CT provides a comprehensive set of clinical phrases or terms; this is called a terminology. SNOMED CT is much more than just a set of clinical phrases, for example it also includes groups with relationships between terms. It is the most comprehensive international terminology currently available and can be used across all care settings and all clinical domains.

SNOMED CT is managed and maintained internationally by SNOMED International and in the UK by the UK National Release Centre (part of NHS England).

Find out more about the UK National Release Centre on the NHS England website.

SNOMED CT is specified as the single terminology to be used across the health system. Find out more about SNOMED CT and the Personalised Health and Care 2020 policy paper on GOV.UK.

Benefits of using SNOMED CT

As the NHS moves to paperless, and the aspiration to exchange data electronically across the NHS, it is critical that all systems share the same clinical vocabulary. If every system uses its own vocabulary then interoperability is reduced to simply moving readable documents around the system and clinicians having to repeatedly transcribe data they need to be within their system, thus introducing errors.

The use of an international terminology enables system suppliers to design their system to a common terminology that can be implemented with less country specialisation across a number of countries. The last few years has seen a shift by suppliers from developing country specific solutions to global solutions with local configuration.

Further resources on SNOMED CT

More information about SNOMED CT can be found on the NHS England website - this includes information about the following.

Licensing:

- the UK is a SNOMED International member country
- use of SNOMED CT in the UK is free; however, the use of SNOMED CT does require a license
- SNOMED CT licencing enquiries can be sent to snomed.implementation@nhs.net

Training:

- NHS England offer a range of ways for individuals to learn more about SNOMED CT and its uses
- NHS England provide a number of training and education resources about SNOMED CT, including an overview of SNOMED CT, pre-recorded webinars, case studies, brochures and technical guidance
- for system suppliers, you may also be interested in the more technical guidance provided through the recorded webinars

Searching for concepts within SNOMED CT

NHS England have developed a SNOMED CT Browser that can be accessed online.

The NHS England SNOMED CT Browser provides ways to browser and search the SNOMED CT UK Edition. The SNOMED CT UK Edition is currently released twice per year and consists of the International Edition plus the UK-specific content provided within

the UK Clinical Extension and UK Drug Extension including maps to ICD-10 and OPCS-4.

This is for use in the UK only.

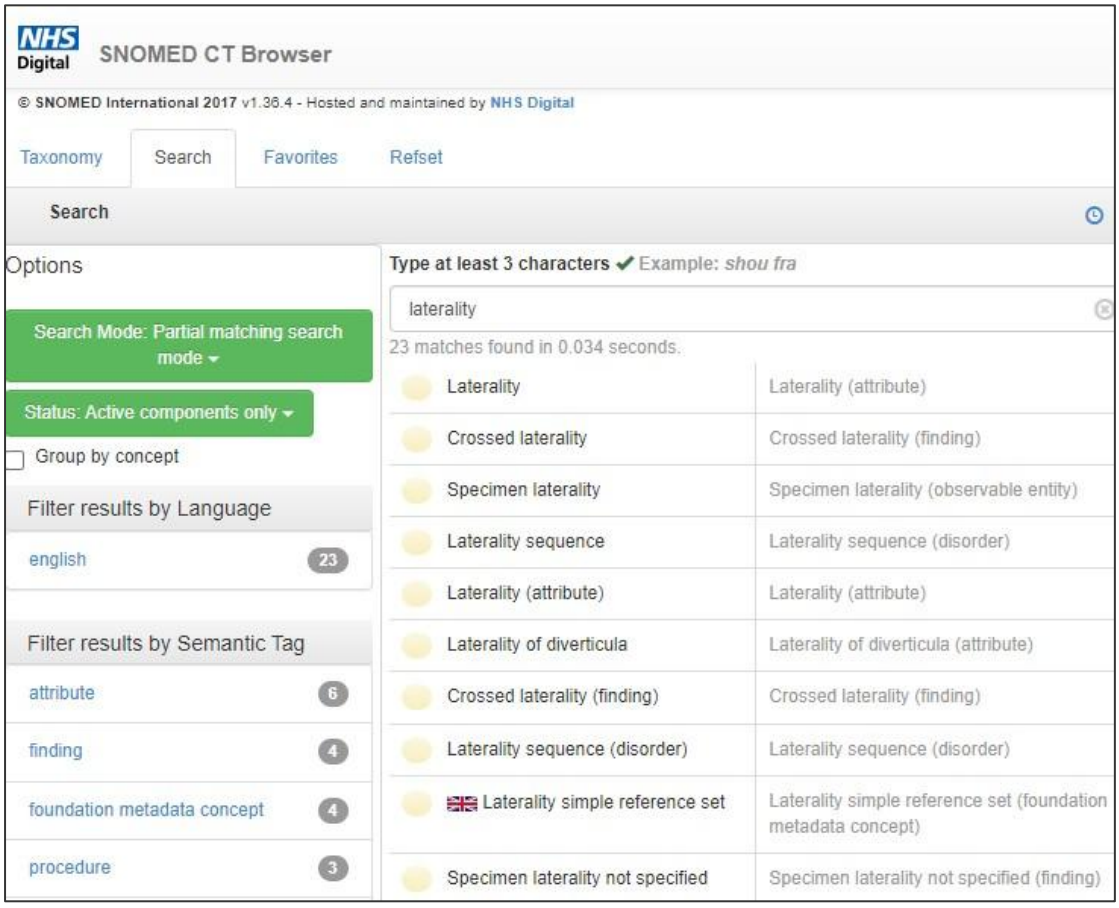
A list of the SNOMED CT releases contained in the browser is maintained and can be viewed on the NHS England website.

The Browser is provided by NHS England to anyone for reference purposes. The interface and REST APIs are not to be used as part of production systems in health care settings.

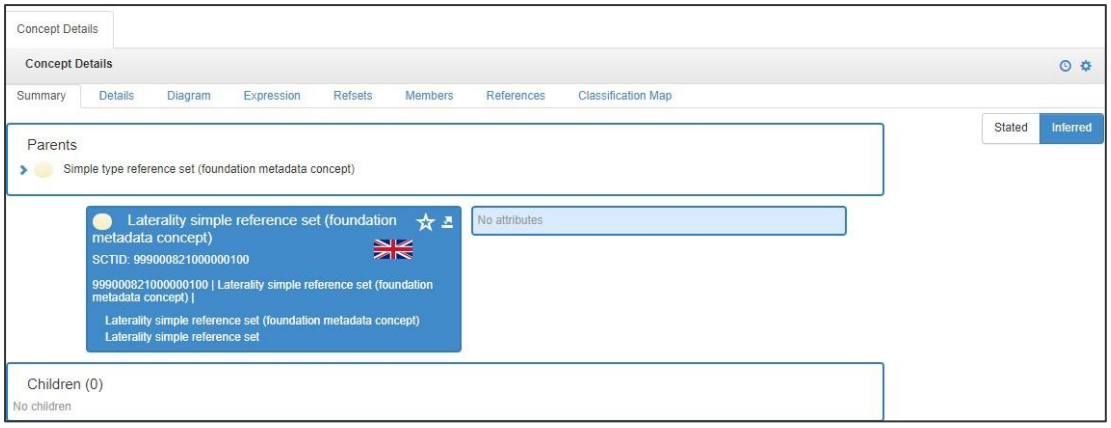
How to use termbrowser

The following provides a useful guide on how to use termbrowser, when searching for SNOMED CT codes:

- go to the termbrowser website
- click the 'Go Browsing' button
- click 'Search'
- enter the known ID or start typing the term required and all available concepts and reference sets will appear below



- select one of the search results - on the right will be the concept ID and information for the item you have selected

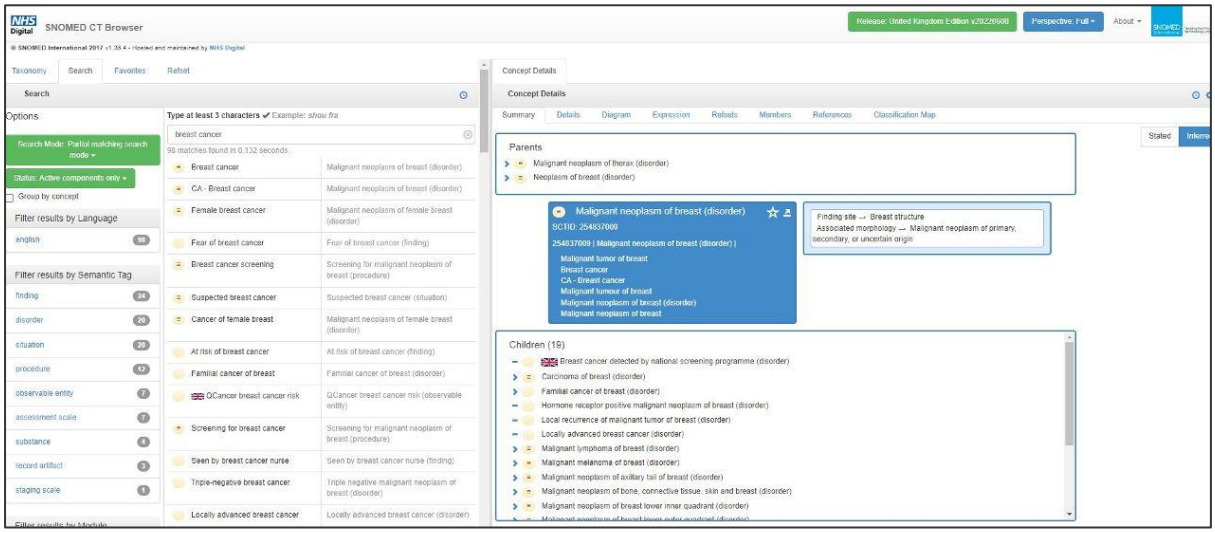


- if this is a reference set - select the members tab from the right-hand window to view all member concepts and their ID's

How to find a diagnosis

When searching for a diagnosis, ensure that you use the (disorder) hierarchy, which will be in brackets at the end of the 'Fully Specified Name' field.

For example, if you search for ‘Breast Cancer’ a long list of available types of breast cancer diagnoses will appear for you to choose as follows:



You can select the more granular level from the children list (on the right) and then cross reference your diagnosis by using the ‘Classification Map’ to ICD10.

For example, if you select ‘Malignant neoplasm of breast (disorder)’ the classification map will show three ICD10 codes:

Concept Details

Concept Details

Summary | Details | Diagram | Expression | Refsets | Members | References | Classification Map

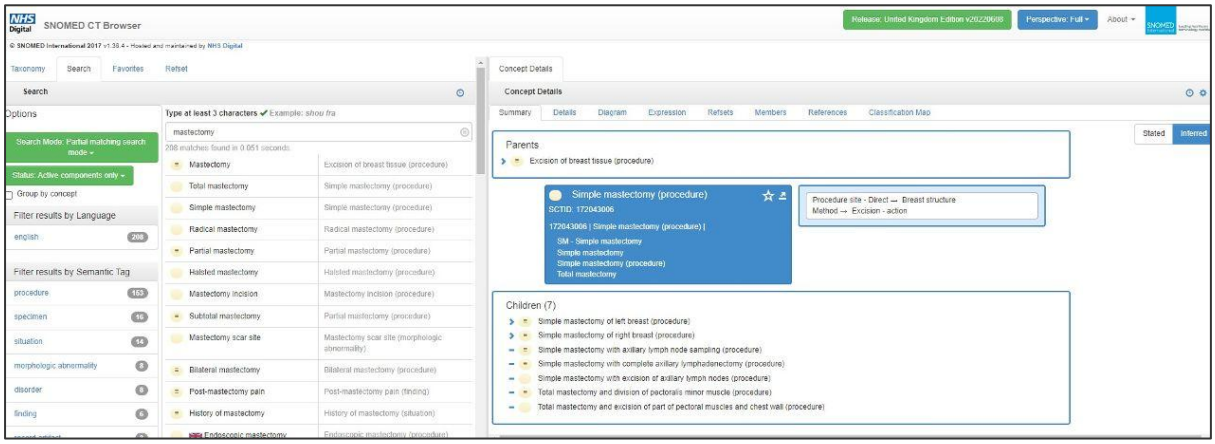
Malignant tumor of breast (disorder)
254837009
ICD10

Map Entries		Rule	Advice
1/1/1	C44.5 Malignant neoplasm: Skin of trunk	ALTERNATIVE	ADDITIONAL CODE POSSIBLE
1/1/2	C50.0 Malignant neoplasm: Nipple and areola	ALTERNATIVE	ADDITIONAL CODE POSSIBLE
1/1/3	C50.9 Malignant neoplasm: Breast, unspecified	TRUE	ADDITIONAL CODE POSSIBLE

How to find a procedure

When searching for procedures, it is important that you only use the (procedure) hierarchy, which will be in brackets at the end of the 'Fully Specified Name' field.

For example, you could search for mastectomy and a long list of available types of mastectomies will appear for you to choose as follows:



You can select the more granular level from the children list (on the right) and then cross reference your diagnosis by using the 'Classification Map' to OPCS.

For example, if you select 'Simple mastectomy of left breast (procedure)' the classification map will show all associated OPCS codes as follows:

Concept Details

Concept Details

Summary | Details | Diagram | Expression | Refsets | Members | References | Classification Map

Simple mastectomy (procedure)
172043006
OPCS4.9

Map Entries		Rule	Advice
1/1/1	B27.3 Total mastectomy and excision of pectoralis minor muscle	ALTERNATIVE	ADDITIONAL CODE POSSIBLE
1/1/2	B27.2 Total mastectomy and excision of both pectoral muscles NEC	ALTERNATIVE	ADDITIONAL CODE POSSIBLE
1/1/3	B27.8 Other specified	ALTERNATIVE	ADDITIONAL CODE POSSIBLE
1/1/4	B27.5 Subcutaneous mastectomy	ALTERNATIVE	ADDITIONAL CODE POSSIBLE
1/1/5	B27.1 Total mastectomy and excision of both pectoral muscles and part of chest wall	ALTERNATIVE	ADDITIONAL CODE POSSIBLE
1/1/6	B27.4 Total mastectomy NEC	TRUE	ADDITIONAL CODE POSSIBLE

Feedback and queries

This User Guide provides additional information to support the COSD Specification and should also be used in conjunction with the COSD Data set v10.0.2, Implementation and Technical Guidance documents.

Feedback and questions relating to the COSD are welcomed and should be emailed to nhsdigital.COSDenquiries@nhs.net. In addition, there is an online change request form.

Queries regarding the Standard itself should be addressed in the first instance to nhsdigital.COSDenquiries@nhs.net.

You can also contact your local NDRS Liaison Manager - find out more on the NDRS Data Liaison team on the COSD page of our website, in the Help and Feedback section.

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.

CancerStats2 website replacement

CancerStats2 has now been closed. You can access all your Trust reports via the new NDRS 'data quality and insight hub' (NHS Health and Social Care Network [HSCN] connections only, (This link opens in a new window)

Reports are being added over time, so it may be that the reports you use to find are not currently available. If you cannot find the reports you need, please contact you regional Data Liaison Manager, who will help you access these during the transition.

Please note that this platform requires an N3/HSCN secure network connection. To ensure the best user experience, we encourage the use of modern web browsers such as Google Chrome, Mozilla Firefox, or Microsoft Edge to access the platform. A small number of platform users have reported issues when opening reports using Internet Explorer.

Acknowledgements

We would like to express thanks to all those who have participated and continue to provide support and guidance in the development of this information standard. Specific thanks go to the COSD Advisory and Governance boards, the Royal College of

Pathologists and Expert Advisory Group (EAG) members, for helping to guide COSD and continue to ensure all data is clinically relevant and not out-of-date.

Particular thanks must be given to the NDRS Liaison Managers, who work tirelessly around the country supporting their local Trusts with data quality, ascertainment and cancer data set issues and queries. Together they provide a huge resource, and their work often goes unnoticed, but by a few.

Appendix A:

Cancer waiting times ICD10 codes and tumour groups for primary diagnoses

Please refer to the downloadable documents on our website for full details of the ICD-10 codes used within COSD

These are registerable conditions for the purposes of Cancer Waiting Times and used within Cancer Registration, such as NCRAS mandatory fields.

Notes:

- the table lists all the registerable diseases by ICD10 code, together with the expected data set to be completed and the potential stage
- this table provides general guidelines only as not all permutations can be covered and there will always be exceptions, local clinical input is essential to identify and complete the appropriate stage
- further guidance is available from your local cancer registration service office

Appendix B:

Mandatory registerable conditions

Please refer to the downloadable documents on our website for full details of the ICD-10 codes used within COSD

Further details to be provided regarding applicable data fields for each disease. These are additional Cancer Registration, for example, NCRAS mandatory registerable conditions.

Notes:

- the following table lists all the registerable diseases by ICD10 code, together with the expected data set to be completed and the potential stage
- this table provides general guidelines only as not all permutations can be covered and there will always be exceptions, local clinical input is essential to identify and complete the appropriate stage
- further guidance is available from your local cancer registration service office
- 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 some cases
- whilst we await the WHO disease classification being updated to reflect this fact, it's inclusion as a registerable condition requiring collection via the COSD has been agreed with the National Disease Registration Service

Appendix C:

WHO classification of tumours of haematopoietic and lymphoid Tissue

Please refer to the downloadable documents on our website for full details of the codes and groupings

Group numbers have been assigned for ease of reference as used in ICD Codes and WHO Disease Groups in the Haematological section of the User Guide. (WHO Classification does not distinguish Groups 7 and 8 as separate disease groups).

Notes:

- where a suffix has been added, this should be used consistently as shown to ensure that diseases with the same ICD-O-3 code can be correctly distinguished
- to ensure that consistent coding continues to be applied nationally, please advise the COSD team if you identify potential changes or additional coding requirements
- for visual clarity, the ICD-O-3 codes in the table are formatted differently from the specification, records should be submitted according to the format in the specification, either “MXXXXX”, or “MXXXXXX” with suffix
- where marked as “CORE ONLY” there is no disease specific data set so only the core data set will be completed. Please also note that every record must include the relevant ICD-O-3 code

Appendix D:

CTYA – associated conditions

Please refer to the downloadable documents on our website for full details of the associated conditions

Associated conditions to be recorded in Childhood Cancers. The associated conditions in the patient should include any medical condition that could be related to aetiology of the child's cancer or could affect treatment or outcome.

The list provided on the downloads page is not meant to be exhaustive. Where examples are given, these are simply the most frequent or important conditions within a given category. The overriding rule should be that, if it is believed that a condition might be relevant to aetiology, produce significant comorbidity, or otherwise affect treatment or prognosis, and then it should be recorded.

In particular, it is suggested that any heritable condition included in Online Mendelian Inheritance in Man (OMIM), should be recorded.

Appendix E:

Recommended staging to be collected by cancer registries

Please refer to the downloadable documents on our website for full details of the recommended stage for each specific tumour type

The National Staging Panel for Cancer Registration recommends that the staging systems recorded by the cancer registries follow the guidance issued by the Royal College of Pathologists and the Cancer Outcomes Services Dataset.

It is also important to note that both UICC and AJCC coding systems have updated to v8, please refer directly to the TNM Staging Books, for the most recent and accurate stage groupings /combination.

Notes:

- FIGO 2021 for vulvar cancer takes effect from 1 January 2022
- FIGO 2018 for cervical cancer takes effect from 1 January 2020
- head and neck sites changed from TNM7 to TNM8 from 1 January 2019
- TNM 7 changed to TNM 8 (except head and neck) from 1 January 2018
- Lower GI changed from TNM5 to TNM8 from 1 January 2018

Additional notes:

- the use of preferred staging systems (which should be used), is under frequent review and may change in the future
  - the list was accurate at the time of publication
- ENETS - European Neuroendocrine Tumour Society TNM, can now be recorded in the 'CORE – Staging' section, along with all other TNM stage (where applicable)

Site specific stage items to be submitted:

CNS – CTYA	• Chang Staging System Stage
CTYA	• International Staging System for Retinoblastoma • International Neuroblastoma Risk Group (INGR) Staging System • Pretext Staging System Stage • Wilms Tumour Stage • TNM Stage Grouping for Non CNS Germ Cell Tumours
Gynaecological	• Final Figo Stage
Haematological	• Ann Arbor Stage

	• Binet Stage • R-ISS Stage for Myeloma
Haem – CTYA	• Ann Arbor Stage • Murphy (St Jude) Stage • Children's Oncology Group (COG) Staging System • Central Nervous System Involvement
Liver	• Barcelona Clinic Liver Cancer (BCLC) Stage
Urological	• Stage Grouping (Testicular), as defined by The Royal Marsden Hospital (RMH)

Appendix F:

Skin data set – staging additional information

AJCC recording for the Skin data set has been reviewed and the following is the advice from the Royal College of Pathologists. From 1 January 2018, UICC TNM 8 only will used for staging all skin cancers to include:

- cutaneous basal cell carcinoma
- cutaneous squamous cell carcinoma and regional lymph nodes
- cutaneous adnexal carcinoma and regional lymph nodes
- cutaneous malignant melanoma and regional lymph nodes
- cutaneous merkel cell carcinoma and regional lymph nodes
- cutaneous lymphomas

Appendix G:

Timetable for implementation of v10.0

Submissions are accepted as follows for Version 9.0 and/or v10.0

Diagnosis month	data set	schema	Accepted MDT system submission format	Accepted Pathology submission format
January 2024	v9.0	v9.0	XML only	XML only
February 2024	v9.0	v9.0	XML only	XML only
March 2024	v9.0	v9.0	XML only	XML only
April 2024	v9.0 or v10.0	v9.0 or v10.0	XML only	XML only
May 2024	v9.0 or v10.0	v9.0 or v10.0	XML only	XML only
June 2024	v9.0 or v10.0	v9.0 or v10.0	XML only	XML only
July 2024	V10.0	V10.0	XML only	XML only
August 2024	V10.0	V10.0	XML only	XML only
September 2024	V10.0	V10.0	XML only	XML only
October 2024	V10.0	V10.0	XML only	XML only
November 2024	V10.0	V10.0	XML only	XML only
December 2024	V10.0	V10.0	XML only	XML only
January 2025	V10.0	V10.0	XML only	XML only

Notes:

- it is important to remember that there is a 25 working day period (post the end of each diagnosis month) before data should be reported, therefore:
  - April's data would be reported June
  - May's data would be reported in July
  - June's data would be reported in August
- both v9.0 and v10.0 can be submitted during this period, until the Trust updates its cancer information system
- all Trusts must be submitting v10 from September 2024 onwards (July's data)

Appendix H:

Referral scenarios

Referral information is required once for each cancer diagnosis and is completed by the Provider which diagnosed the cancer. This should therefore be recorded from the beginning of the referral pathway within the Provider which led to the cancer diagnosis. It will normally begin at the referral to outpatients from primary care, from emergency services or from another Provider.

Cancer Waiting Times only requires this information for 2ww and screening referrals but for COSD it is essential that details of the referral section of the pathway are recorded for all cases.

Data items from referral to first seen date

The following data items should be completed according to the scenarios following:

- Priority Type Code
- Source of Referral for Out-Patients
- Date First Seen
- Consultant Code
- Organisation Code (Provider First Seen)
- Scenarios

Scenario 1:

'2 Week Wait and Screening Cases':

- details as covered by Cancer Waiting Times guidance

Scenario 2:

'Patients Initially Referred To Out-Patients':

- 'Source of Referral for Out-Patients' will normally be

National Code	National code definition
03	Referral from a general medical practitioner
92	Referral from a general dental practitioner
12	Referral from a general practitioner with special interest

- if referred from another hospital

National Code	National code definition
05	referral from a consultant, other than in an accident and emergency department

Scenario 3:

'Patients Initially Seen as Emergencies but then referred to another consultant':

- 'Source of Referral for Out-Patients' will be either:

National Code	National code definition
01	following an emergency admission
10	following an accident and emergency attendance (including minor injuries units and walk in centres)
04	referral from an accident and emergency department (including minor injuries units and walk in centres)

Date First Seen':

- will be the first out-patient appointment following the emergency presentation or the first consultation with the specialist if patient remained as an inpatient

'Consultant Code':

- relates to 'Date First Seen' so will be the consultant who the patient was referred to following the emergency presentation

'Organisation Code (Provider First Seen)':

- relates to the 'Date First Seen' so will be the organisation the patient was referred to following the emergency presentation

Scenario 4:

Where a patient's cancer was initially diagnosed and first treated as an emergency:

'Source of Referral for Out-Patients':

- will normally be one of the emergency codes above

'Date First Seen':

- will be the date of the emergency first treatment

'Consultant Code':

- relates to 'Date First Seen' so will be the consultant carrying out the first treatment

'Organisation Code (Provider First Seen)':

- relates to the 'Date First Seen' so will be the organisation carrying out the first treatment

Scenario 5:

Where a patient's cancer was an incidental finding of another treatment or process.

- 'Source of Referral for Out-Patients' will be

National Code	National code definition
11	Other - initiated by the consultant responsible for the 'Consultant Out-Patient Episode'

- 'Date First Seen' will be the date of the incidental finding
- 'Consultant Code' relates to Date First Seen, so will be the consultant who made the incidental findings during another treatment or process
- 'Organisation Code (Provider First Seen)' relates to the Date First Seen, so will be the organisation where the incidental findings were made

Data items for cancer specialist

The following data items should be completed according to the scenarios following:

- 'First Seen by Specialist Date (Cancer)'
- 'Organisation Code (Provider First Cancer Specialist)'

Scenario 1:

Patient was first seen by the appropriate cancer specialist. Use same details as 'Date First Seen' and 'Organisation Code (Provider First Seen)'.

Scenario 2:

Initial referral was not to the appropriate cancer specialist. Record details for the first appointment with the appropriate cancer specialist to progress this cancer diagnosis.

Appendix I:

Haematology proforma and collection guidance document

Please refer to the downloadable documents on our website for both the haematology proforma and guidance document

The proforma shows which of the site specific data items are applicable to each haematological diagnosis group.

This can be used as a tool (by the clinical team) during MDT, to ensure capture of all relevant data items and to help the MDT coordinator input the clinically agreed data.