Public Health England

Protecting and improving the nation's health

Cancer Outcome and Services Data set

User guide

Version 9.0.7

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Published August 2020
PHE publications
gateway number: GW-621

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Note: additional 'site-specific items' may also be required as applicable to the tumour diagnosed. These are required only for the primary pathway.

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Version control

Version	Date	Brief Summary of Change	Editors
Version 9.0 Final	28 June 2019	New User Guide to support the COSD data set v9.0 (DCB1521 Amd 13/2019)	Andrew Murphy
Version 9.0 Final	30 August 2019	Final amended document for publication	Andrew Murphy
Version 9.0.1 Final	10 October 2019	Corrected number error in 'Breast Cancer' section pg97	Andrew Murphy
Version 9.0.2 Final	5 November 2019	Update to pathway flow chart (1) pg14, Primary Diagnosis ICD reporting pg19 and Appendix E pg283	Andrew Murphy
Version 9.0.3 Final	16 January 2020	Update to Core – Multidisciplinary Team Meetings pg58, CR8100 pg60 and error in field format for CR8030 pg56	Andrew Murphy
Version 9.0.4 Final	31 March 2020	Correction from ISS to R-ISS pg138, Updated advice on recording Brain/CNS imaging fields (BA3000, BA3020, BA3030 & BA3050) pg106	Andrew Murphy
Version 9.0.5 Final	14 May 2020	Updated advice on Grade Of Differentiation (At Diagnosis) pg42-43	Andrew Murphy
Version 9.0.6 Final	24 July 2020	Updated Haematology section pg147 and Appendix G pg286; Removed the abbreviation of 'CNS' for Clinical Nurse Specialist, so now only used to describe 'Central Nervious System'. Added new Appendix I (haematology site-specific data collection proforma). Amended reporting advice for IPSS-R (Myelodysplasia) pg150	Andrew Murphy
Version 9.0.7 Final	8 October 2020	Reworked the pathway flow chart section pg13-pg15 to comply with new accessibility standards. Added information about the new ODS (ANANA) coding structure and weblink pg19. Updated the disease specific data item table for CTYA pg118-pg119	Andrew Murphy

Executive summary

Cancer Outcomes and Services Data set – Version 9.0 release (April 2020)

This User Guide is one of a suite of documents to aid Users in implementing the COSD Information Standard (DCB1521 Amd 13/2019)[1]. It includes all the data items in COSD, together with definitions, formats, codes and values and additional guidance on collection and implementation.

This User Guide is aligned with and should be read in conjunction with version 9.0 of the data set which is available to download on the NCIN website[2]. Other guidance and supporting documents are also available on the NCIN website and we are continuing to explore an online version of the Guide.

This revised version of the User Guide incorporates some amendments to the data set, an extension of scope 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 13/2019) which has been accepted by the Data Coordination Board (DCB), see the section "What's changed" for a summary of changes.

Implementation of the Standard is carried out by the National Cancer Registration and Analysis Service (NCRAS) and queries regarding implementation should initially be raised with the Data Liaison staff at the local offices of the NCRAS.

Queries regarding the Standard itself should be addressed in the first instance to: COSDenquiries@phe.gov.uk or your local NCRAS Liaison Manager (their details can be obtained from the CancerStats portal).

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 NCRAS 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.

All Providers have access to their current monthly position via CancerStats[3] (NHS N3 connections only) which has been established by the NCRAS. This provides feedback

[1] http://content.digital.nhs.uk/isce/publication/scci1521
[2] http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd
[3] https://cancerstats.ndrs.nhs.uk/

on files submitted (Level 1) and completion for some key data items (Level 2), where the files are submitted in the prescribed XML format. It also now includes the next level of reports (Level 3), which covers data that has been processed and quality assured by the NCRAS.

In addition, there are now reporting tools for the National Lung Cancer Audit (NLCA) and the National Prostate Cancer Audit (NPCA) as well as access to population level Incidence, Mortality and Survival data. In 2017, additional reporting of the National Radiotherapy data set (RTDS) and Clinical Headline Indicators (CHI) was made available too.

I would like to take this opportunity to thank all those who have been involved in the development and implementation of the Standard and encourage you to continue to send us your comments which help to identify necessary amendments and improvements. A COSD Advisory Board including Trust level representation has been created to help manage change and reports directly to the COSD Governance Board.

Andrew Murphy,
Head of Cancer Datasets
National Cancer Registration and Analysis Service (NCRAS),
Public Health England (PHE)

How to record recurrences, progressions and transformations

What is a recurrent cancer?

Cancer recurrence can be defined as the return of cancer after treatment and after a period of time 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 include:

- local recurrence means that the cancer has come back in the same place it first started
- regional recurrence means that the cancer has come back in the lymph nodes near the place it started
- distant recurrence means 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 a 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.

Please note: 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) cancer, and the patient is said to have ‘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.

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 of time 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 cancers

For head and neck cancer there is an incidence 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 new 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 flow diagram 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

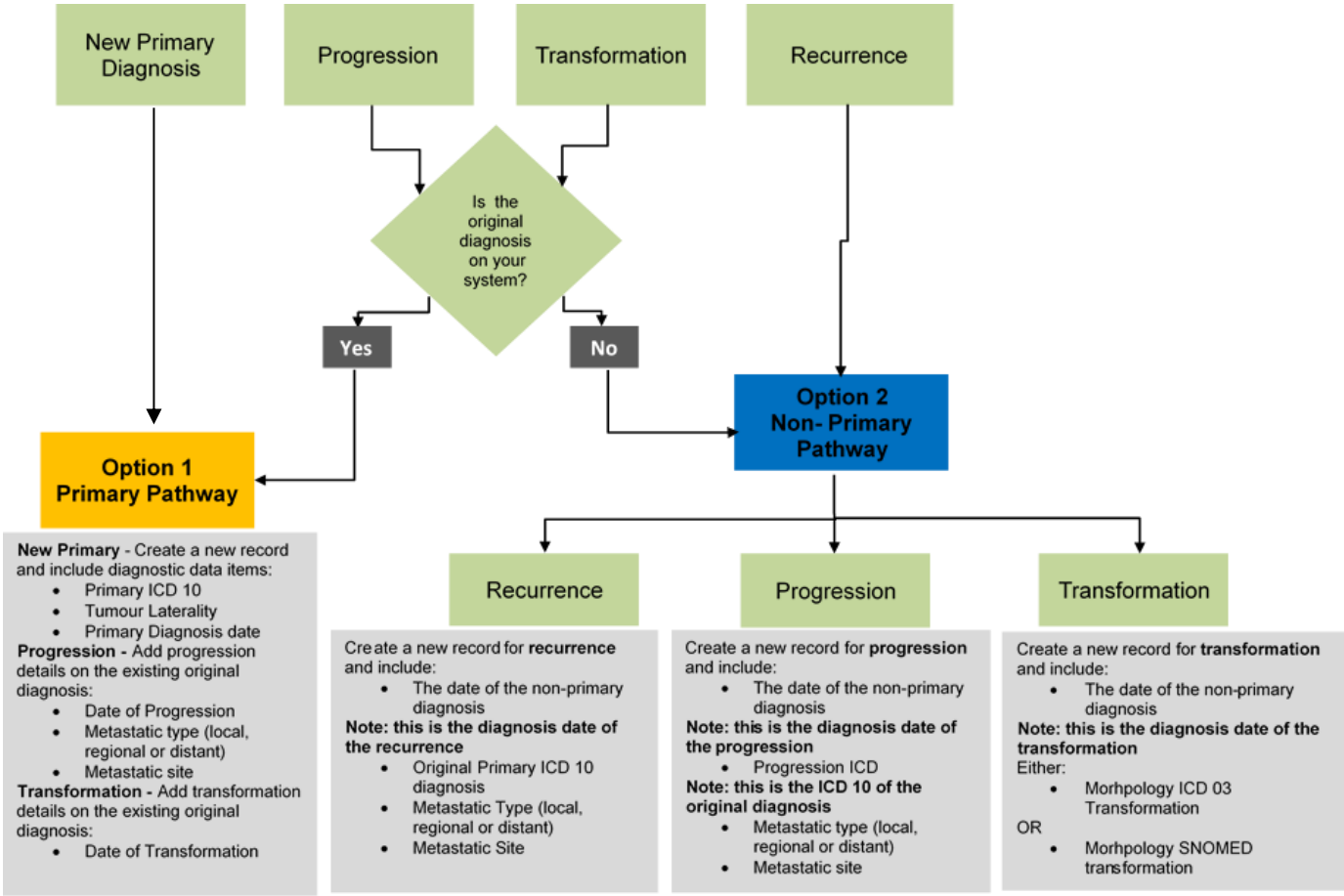
Option 2:

Recurrence

Progression

Transformation

Pathway flow chart (1)



Note: additional 'site-specific items' may also be required as applicable to the tumour diagnosed. These are required only for the primary pathway.

Pathway flows for new primary, recurrences, progressions or transformations

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

New Primary Diagnosis

- 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
- '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'
- 'Transformation' diagnosis:
  - add transformation details on the existing 'original' diagnosis including:
    - the 'Date of Transformation'

Back to (Option 1) Pathway flow chart (1)

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, one therefore has a choice of 3 options – recurrence, progression or transformation, but only one should be used for each pathway/record submission.

- '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'
- '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
    - *note: this is the ICD10 of the original diagnosis*
  - the 'Metastatic Type (local, regional or distant)'
  - the 'Metastatic Site'
- '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

Back to (Option 2) Pathway flow chart (1)

The pathway flow chart

The pathway flow chart (2) on pg16, identifies the additional expected COSD – Core sections that would be applicable to each pathway type.

Please note that 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.

The items highlighted in **Orange Bold**, would be expected on all pathways submitted through COSD (if applicable).

Pathway flow chart (2)

Primary pathway

Unique sections

Core - Diagnostic - Primary Cancer Pathway Details
Core - Referrals and First Stage of Patient Pathway
Core - Diagnosis
Core - Diagnosis - Additional Items
Core - Diagnosis - Progression
Core - Diagnosis - Transformation
Core - Banked Tissue
Core - Cancer Care Plan
Core - Staging
Core - Site Specific Staging

Shared sections

XML Headers
Record Identifier
Core - Patient Identity Details
Core - Demographics
Core - Imaging
Core - Diagnostic Procedures
Core - Person Observation
Core - Clinical Nurse Specialist + Risk Factor Assessment
Core - Clinical Nurse Specialist - Holistic Needs Assessment
Core - Clinical Nurse Specialist - Personalised Care and Support Plan
Core - Multidisciplinary Team Meetings
Core - Molecular and Biomarkers - Germline Testing for Cancer Predisposition
Core - Molecular and Biomarkers - Somatic Testing for Targeted Therapy and Personalised Medicine
Core - Clinical Trials
Core - Treatment
Core - Surgery
Core - Treatment - Stem Cell Transplantation
Core - Acute Oncology
Core - Laboratory Results
Core - Laboratory Results - General

Non-primary pathway

Unique sections

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

Core - Non Primary Cancer Pathway - Referral

Note: additional 'site-specific items' may also be required as applicable to the tumour diagnosed. These are required only for the primary pathway.

CORE

Key to Data Item Tables

All data items are listed as follows:

Data item No.	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. This is followed by the [DATA DICTIONARY ITEM NAME] if different in purple
Format	Format required for submission of the data item
Schema specification (M/R/O/X/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. (Note that all applicable data should be submitted as soon as possible). M = Mandatory: A section cannot be included in the record submitted unless it contains completed Mandatory items in that section. If there is other data in a section and the Mandatory items are not completed the record will not pass validation tests. **Please note: items in the CORE LINKAGE section are Mandatory and must be included for the record to pass validation** R = Required: This data item (where applicable) should be submitted as soon as possible but is not required to validate the submitted record. O = Optional: This item may be submitted at the discretion of the Provider. It is either not currently required nationally or it will be obtained/derived by the National Cancer Registration Service from other sources. P = For use in a pilot project only. X = Not applicable for schema: This data item should not be included in the submission. (It will be obtained/derived by the National Cancer Registration Service from other sources).
	Items marked with a yellow highlight, denote items which have been moved within the data set
	Items marked with a green highlight, denote either a new data items for v9, or a new description/attribute in an existing data item. In some data items this may also indicate a change in the data item number, format or schema specification.

ICD-10 CODES

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

Note: additional 'site-specific items' may also be required as applicable to the tumour diagnosed. These are required only for the primary pathway.

Note: 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 present – 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.

CORE – LINKAGE

These items are Mandatory for every record in order to link patient records. In order to ensure that records submitted can be linked appropriately some key data fields must be completed for each record submitted. These are shown in the Core Linkage section.

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

CORE – PATIENT IDENTITY DETAILS

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR0010	CORE - PATIENT IDENTITY DETAILS	**NHS NUMBER**	n10	M[4]
CR0020	CORE - PATIENT IDENTITY DETAILS	**LOCAL PATIENT IDENTIFIER** *[LOCAL PATIENT IDENTIFIER (EXTENDED)]*	min an1 max an20	M[4]
CR1350	CORE - PATIENT IDENTITY DETAILS	**NHS NUMBER STATUS INDICATOR CODE**	an2	M
CR0100	CORE - PATIENT IDENTITY DETAILS	**PERSON BIRTH DATE**	an10 ccyy-mm-dd	M
CR0030	CORE - PATIENT IDENTITY DETAILS	**ORGANISATION IDENTIFIER (CODE OF PROVIDER)**	min an3 max an5	M

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.

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.

[4] A combination of either **NHS NUMBER** and/or **LOCAL PATIENT IDENTIFIER** is Mandatory for the schema. Both can be submitted, but a record cannot be submitted without at least one of these data items.

NHS NUMBER STATUS INDICATOR CODE: The NHS NUMBER STATUS INDICATOR CODE indicates the verification status of the NHS number provided.

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 detail conflict)
06	Trace in progress
07	Number not present and trace not required
08	Trace postponed (baby under 6 weeks old)

PERSON BIRTH DATE: This is now a mandatory data item from v9.0. 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 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.

Note: There is a new code structure (ANANA) for new organisation identifiers allocated by ODS from 1 September 2020 onwards - codes issued prior to this date will not be converted[5].

PATHWAY CHOICE

This is a new choice within v9 and one of the following Cancer Pathway sections MUST be provided per submission.

Must be one of the following choices per record (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
PATHWAY CHOICE				Choice 1..1
PATHWAY CHOICE (Primary Pathway) - CHOICE 1				
CR0370	CORE - DIAGNOSTIC - PRIMARY CANCER PATHWAY DETAILS	**PRIMARY DIAGNOSIS (ICD)**	min an4 max an6	M
CR0380	CORE - DIAGNOSTIC - PRIMARY CANCER PATHWAY DETAILS	**TUMOUR LATERALITY**	an1	M

[5] https://digital.nhs.uk/services/organisation-data-service/guidance-for-developers/new-care-models-case-study

CR2030	CORE - DIAGNOSTIC - PRIMARY CANCER PATHWAY DETAILS	**DATE OF PRIMARY DIAGNOSIS (CLINICALLY AGREED)** *[DATE OF PRIMARY CANCER DIAGNOSIS (CLINICALLY AGREED)]*	an10 ccyy-mm-dd	M
END OF PATHWAY CHOICE (Primary Pathway) - CHOICE 1				
PATHWAY CHOICE (Non Primary Pathway) - CHOICE 2				
CR6500	CORE - DIAGNOSTIC - NON PRIMARY CANCER PATHWAY DETAILS	**DATE OF NON PRIMARY CANCER DIAGNOSIS (CLINICALLY AGREED)** *[DATE OF NON PRIMARY CANCER DIAGNOSIS (CLINICALLY AGREED)]*	an10 ccyy-mm-dd	M
END OF PATHWAY CHOICE (Non Primary Pathway) - CHOICE 2				
END OFPATHWAY CHOICE				

CORE – DIAGNOSTIC – PRIMARY CANCER PATHWAY DETAILS:

This is a new linkage section (through choice) in v9, to help improve the ascertainment and data quality of the primary cancer pathway data.
Note: You can only create either a ‘Primary’ or ‘Non Primary’ cancer pathway within each record, and all items in this section are mandatory.

Choice 1

Must be up to one occurrence per record if selected as choice (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR0370	CORE - DIAGNOSTIC - PRIMARY CANCER PATHWAY DETAILS	**PRIMARY DIAGNOSIS (ICD)**	min an4 max an6	M
CR0380	CORE - DIAGNOSTIC - PRIMARY CANCER PATHWAY DETAILS	**TUMOUR LATERALITY**	an1	M
CR2030	CORE - DIAGNOSTIC - PRIMARY CANCER PATHWAY DETAILS	**DATE OF PRIMARY DIAGNOSIS (CLINICALLY AGREED)** *[DATE OF PRIMARY CANCER DIAGNOSIS (CLINICALLY AGREED)]*	an10 ccyy-mm-dd	M

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.

Note: 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 (CWT): 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'.

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

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 3 methods. You must use the date from the method which provides the earliest confirmation of a diagnosis.

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.

Note:

- 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 National Cancer Registration and Analysis Service (NCRAS) use 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 of time
- the National Lung Cancer Audit (NLCA) use the final reported cancer registration 'Date of Diagnosis' for their annual reporting

CORE – DIAGNOSTIC – NON PRIMARY CANCER PATHWAY DETAILS:

This is a new linkage section (through choice) in v9, to help improve the ascertainment and data quality of the non primary cancer pathway data.

Note: 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

Must be up to one occurrence per record if selected as choice (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR6500	CORE – DIAGNOSTIC – NON PRIMARY CANCER PATHWAY DETAILS	**DATE OF NON PRIMARY CANCER DIAGNOSIS (CLINICALLY AGREED)** *[DATE OF NON PRIMARY CANCER DIAGNOSIS (CLINICALLY AGREED)]*	an10 ccyy-mm-dd	M

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 3 methods:

1. Pathology report**.** This would normally be the date when the authorised pathology report confirms a non-primary cancer diagnosis, although the date of the procedure can also be used if positive
2. 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
3. Other. For all other cases, record the date in which the clinical investigation took place or clinical agreement that confirms the diagnosis of cancer

CORE – NON PRIMARY CANCER PATHWAY ROUTE

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), and would be one of the following.

1. NON PRIMARY CANCER PATHWAY - CHOICE 1 - Recurrence
2. NON PRIMARY CANCER PATHWAY - CHOICE 2 - Progression
3. 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.

CORE – NON PRIMARY CANCER PATHWAY ROUTE – RECURRENCE

Additional details are required for every non-primary cancer diagnosis record in order to ensure that the correct pathway route can be identified, and information can be correctly linked. The following is a new section for v9.0, specifically for recurrences (choice 1).

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR7100	CORE - DIAGNOSTIC - NON PRIMARY CANCER PATHWAY DETAILS (RECURRENCE)	**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..*)				
CR6520	CORE - DIAGNOSTIC - NON PRIMARY CANCER PATHWAY DETAILS (RECURRENCE)	**METASTATIC TYPE** *[CANCER METASTATIC DISEASE TYPE]*	an2	M
CR1590	CORE - DIAGNOSTIC - NON PRIMARY CANCER PATHWAY DETAILS (RECURRENCE)	**METASTATIC SITE** *[METASTATIC SITE (AT DIAGNOSIS)]*	an2	M
End of repeating section - Metastatic Type and Site				
CR1550	CORE - DIAGNOSTIC - NON PRIMARY CANCER PATHWAY DETAILS (RECURRENCE)	**PALLIATIVE CARE SPECIALIST SEEN INDICATOR (CANCER RECURRENCE)**	an1	R
Start of repeating item - Relapse - Method of Detection				
CT7190	CORE - DIAGNOSTIC - NON PRIMARY CANCER PATHWAY DETAILS (RECURRENCE)	**RELAPSE - METHOD OF DETECTION** *[RELAPSE METHOD DETECTION TYPE]*	an1	R
End of repeating item - Relapse - Method of Detection				

ORIGINAL PRIMARY DIAGNOSIS (ICD): This is a new data item for v9 and 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.

01	Local
02	Regional
03	Distant

METASTATIC SITE: The site of the metastatic disease, if any, at diagnosis. More than one site can be recorded.

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

Note: both Metastatic Type and Site are now a multiple selection group, 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 some legacy data may not have all the required mandatory fields for v9. 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).

PALLIATIVE CARE SPECIALIST SEEN INDICATOR (CANCER RECURRENCE): Record whether the patient was seen by a palliative care specialist. This would be a member of the specialist palliative care team led by a consultant in palliative medicine for a recurrence of cancer.

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.

1	Morphology
2	Flow
3	Molecular
4	Clinical Examination
9	Other

Note: this field should be collected if appropriate for any cancer, but especially for CTYA - ALL/AML/MPAL diagnoses.

CORE – NON PRIMARY CANCER PATHWAY ROUTE – PROGRESSION

Additional details are required for every non-primary cancer diagnosis record in order to ensure that the correct pathway route can be identified, and information can be correctly linked. The following is a new section for v9.0, specifically for progressions (choice 2).

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR6900	CORE - DIAGNOSTIC - NON PRIMARY CANCER PATHWAY DETAILS (PROGRESSION)	**PROGRESSION (ICD)** *[CANCER 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 (Recurrence) (0..*)				
CR6520	CORE - DIAGNOSTIC - NON PRIMARY CANCER PATHWAY DETAILS (PROGRESSION)	**METASTATIC TYPE** *[CANCER METASTATIC DISEASE TYPE]*	an2	M
CR1590	CORE - DIAGNOSTIC - NON PRIMARY CANCER PATHWAY DETAILS (PROGRESSION)	**METASTATIC SITE** *[METASTATIC SITE (AT DIAGNOSIS)]*	an2	M
End of repeating section - Metastatic Type and Site				

PROGRESSION (ICD): This is now a mandatory data item from v9. 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.

01	Local
02	Regional
03	Distant

METASTATIC SITE: The site of the metastatic disease, if any, at diagnosis. More than one site can be recorded.

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

Note: both Metastatic Type and Site are now 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.

It is possible that some legacy data may not have all the required mandatory fields for v9. 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 – NON PRIMARY CANCER PATHWAY ROUTE – TRANSFORMATION

Additional details are required for every non-primary cancer diagnosis record in order to ensure that the correct pathway route can be identified, and information correctly linked. The following is a new section for v9.0, 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR7200	CORE - DIAGNOSTIC - NON PRIMARY CANCER PATHWAY DETAILS (TRANSFORMATION)	**ORIGINAL MORPHOLOGY (ICD-O-3)** *[MORPHOLOGY (ICD-O CANCER TRANSFORMATION ORIGINAL]*	min an5 max an7	R
CR7210	CORE - DIAGNOSTIC - NON PRIMARY CANCER PATHWAY DETAILS (TRANSFORMATION)	**ORIGINAL MORPHOLOGY (SNOMED)** *[MORPHOLOGY (SNOMED CANCER TRANSFORMATION ORIGINAL)]*	min an6 max an18	R
CURRENT MORPHOLOGY CHOICE				Choice 1..2
CHOICE 1 - CURRENT MORPHOLOGY				
CR7010	CORE - DIAGNOSTIC - NON PRIMARY CANCER PATHWAY DETAILS (TRANSFORMATION)	**MORPHOLOGY (ICD-O-3) TRANSFORMATION** *[MORPHOLOGY (ICD-O CANCER 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				
CR7000	CORE - DIAGNOSTIC - NON PRIMARY CANCER PATHWAY DETAILS (TRANSFORMATION)	**MORPHOLOGY (SNOMED) TRANSFORMATION** *[MORPHOLOGY (SNOMED CANCER TRANSFORMATION)]*	min an6 max an18	M
CR7030	CORE - DIAGNOSTIC - NON PRIMARY CANCER PATHWAY DETAILS (TRANSFORMATION)	**SNOMED VERSION CURRENT (TRANSFORMATION)** *[SNOMED VERSION (CANCER TRANSFORMATION)]*	an2	M
End of repeating section - Metastatic Type and Site				
END OF CHOICE 2 - CURRENT MORPHOLOGY				
END OF CURRENT MORPHOLOGY CHOICE				

ORIGINAL MORPHOLOGY (ICD-O-3): This is a new data item for COSD v9. 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): This is a new data item for COSD v9. Record the morphology code of the original diagnosis (if known). This will normally be agreed at the MDT by the clinical team.

Note: The next 3 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.

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.

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. There may be one occurrence per Transformation.

CORE – DEMOGRAPHIC DETAILS

Demographics

Demographic details are required for every record in order 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. 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.

It is anticipated that some of the 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR0050	CORE - DEMOGRAPHICS	**PERSON FAMILY NAME**	max an35	R
CR0060	CORE - DEMOGRAPHICS	**PERSON GIVEN NAME**	max an35	R
CR0070	CORE - DEMOGRAPHICS	**PATIENT USUAL ADDRESS (AT DIAGNOSIS)**	an175 (5 lines each an35)	R
CR0080	CORE - DEMOGRAPHICS	**POSTCODE OF USUAL ADDRESS (AT DIAGNOSIS)**	max an8	R
CR3170	CORE - DEMOGRAPHICS	**PERSON STATED GENDER CODE**	an1	R
CR6840	CORE - DEMOGRAPHICS	**PERSON SEXUAL ORIENTATION CODE (AT DIAGNOSIS)**	an1	R
CR0110	CORE - DEMOGRAPHICS	**GENERAL MEDICAL PRACTITIONER (SPECIFIED)**	an8	R
CR0120	CORE - DEMOGRAPHICS	**GENERAL MEDICAL PRACTICE CODE (PATIENT REGISTRATION)**	an6	R
CR0140	CORE - DEMOGRAPHICS	**PERSON FAMILY NAME (AT BIRTH)**	max an35	R
CR0150	CORE - DEMOGRAPHICS	**ETHNIC CATEGORY**	max an2	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).

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 is a now a 'Required' data item and complies with the information standard DCB2094.

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.

Note: this data item is not affected by the other changes to consultant codes throughout the dataset and has been agreed upon with NHS Digital.

GENERAL MEDICAL PRACTICE CODE (PATIENT REGISTRATION): This is the code of the GP Practice that the PATIENT is registered with.

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.

(The Office for National Statistics has developed a further breakdown of the group from that given, which may be used locally).

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
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

Note: the default option for this item is 99 “Not known”

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.

Note: 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR1600	CORE - REFERRALS AND FIRST STAGE OF PATIENT PATHWAY	**SOURCE OF REFERRAL FOR OUT-PATIENTS**	an2	R
CR0230	CORE - REFERRALS AND FIRST STAGE OF PATIENT PATHWAY	**DATE FIRST SEEN**	an10 ccyy-mm-dd	R
Start of SECTION - Consultant (First Seen)				Section 0..1
CR7300	CORE - REFERRALS AND FIRST STAGE OF PATIENT PATHWAY	**PROFESSIONAL REGISTRATION ISSUER CODE - CONSULTANT (FIRST SEEN)** *[PROFESSIONAL REGISTRATION ISSUER CODE (CANCER FIRST SEEN)]*	an2	M
CR7310	CORE - REFERRALS AND FIRST STAGE OF PATIENT PATHWAY	**PROFESSIONAL REGISTRATION ENTRY IDENTIFIER - CONSULTANT (FIRST SEEN)** *[PROFESSIONAL REGISTRATION ENTRY IDENTIFIER (CANCER FIRST SEEN)]*	min an1 max an32	M
End of repeating section - Consultant (First Seen)				
CR1410	CORE - REFERRALS AND FIRST STAGE OF PATIENT PATHWAY	**ORGANISATION SITE IDENTIFIER (PROVIDER FIRST SEEN)** *[ORGANISATION SITE IDENTIFIER (OF PROVIDER FIRST SEEN)]*	min an5 max an9	R
CR1360	CORE - REFERRALS AND FIRST STAGE OF PATIENT PATHWAY	**DATE FIRST SEEN (CANCER SPECIALIST)**	an10 ccyy-mm-dd	R

CR1400	CORE - REFERRALS AND FIRST STAGE OF PATIENT PATHWAY	**ORGANISATION SITE IDENTIFIER (PROVIDER FIRST CANCER SPECIALIST)** *[ORGANISATION SITE IDENTIFIER (OF PROVIDER FIRST CANCER SPECIALIST)]*	min an5 max an9	R
CR2000	CORE - REFERRALS AND FIRST STAGE OF PATIENT PATHWAY	**CANCER SYMPTOMS FIRST NOTED DATE**	max an10 ccyy-mm-dd	R/O[6]

Note: the following data item has been retired from v9.0:

- CONSULTANT CODE (FIRST SEEN)
- CANCER OR SYMPTOMATIC BREAST REFERRAL PATIENT STATUS (PRIMARY)

SOURCE OF REFERRAL FOR OUT-PATIENTS (CWT): This identifies the source of referral of each Consultant Out-Patient Episode. This is essential for every cancer diagnosis in order to identify emergency presentations. Please note that where patients first present as an emergency, codes 01, 10 or 04 are applicable.

Initiated by the CONSULTANT responsible for the Consultant Out-Patient Episode	
01	following an emergency admission
02	following a Domiciliary Consultation
10	following an Accident And Emergency Attendance (including Minor Injuries Units and Walk In Centres)
11	other - initiated by the CONSULTANT responsible for the Consultant Out-Patient Episode
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 a Special Interest (GPwSI) or dentist with a Special Interest (DwSI)
04	referral from an Accident And Emergency Department (including Minor Injuries Units and Walk In Centres)
05	referral from a CONSULTANT, other than in an Accident And Emergency 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	other - not initiated by the CONSULTANT responsible for the Consultant Out-Patient Episode

DATE FIRST SEEN (CWT): 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.

Note: The next 2 data items are now a multiple selection group and are mandatory within the group. There may be one occurrence per CORE - Referrals section.

[6] Required for CTYA, Optional for all others

PROFESSIONAL REGISTRATION ISSUER CODE – CONSULTANT (FIRST SEEN): This is a new data item in v9 replacing the 'Consultant Code (First Seen)' and is a 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.

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 a new data item in v9 replacing the 'Consultant Code (First Seen)' and 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) (CWT): 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, Accident and Emergency 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.

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).

CANCER SYMPTOMS FIRST NOTED DATE (required for CTYA – optional for all others): 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

Note: Required for CTYA cancers, but optional for all others.

CORE – NON PRIMARY CANCER PATHWAY – REFERRAL

This is a revised section to record 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR0300	CORE - NON PRIMARY CANCER PATHWAY - REFERRAL	**SOURCE OF REFERRAL FOR NON PRIMARY CANCER PATHWAY** *[SOURCE OF REFERRAL FOR OUT-PATIENTS (NON PRIMARY CANCER PATHWAY)]*	an2	R
CR7400	CORE - NON PRIMARY CANCER PATHWAY - REFERRAL	**DATE FIRST SEEN - NON PRIMARY CANCER PATHWAY** *[DATE FIRST SEEN (NON CANCER PRIMARY PATHWAY)]*	an10 ccyy-mm-dd	R
CR7410	CORE - NON PRIMARY CANCER PATHWAY - REFERRAL	**ORGANISATION SITE IDENTIFIER (PROVIDER FIRST SEEN - NON PRIMARY CANCER PATHWAY)** *[ORGANISATION SITE IDENTIFIER (OF 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.

Initiated by the CONSULTANT responsible for the Consultant Out-Patient Episode	
01	following an emergency admission
02	following a Domiciliary Consultation
10	following an Accident And Emergency Attendance (including Minor Injuries Units and Walk In Centres)
11	other - initiated by the CONSULTANT responsible for the Consultant Out-Patient Episode
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 a Special Interest (GPwSI) or dentist with a Special Interest (DwSI)

04	referral from an Accident And Emergency Department (including Minor Injuries Units and Walk In Centres)
05	referral from a CONSULTANT, other than in an Accident And Emergency 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	other - not initiated by the CONSULTANT responsible for the Consultant Out-Patient Episode

DATE FIRST SEEN - NON PRIMARY CANCER PATHWAY: This is a new data item in v9 and 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 a new data item in v9 and 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 carried out 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 NCRAS 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 now 3 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR0310	CORE - IMAGING	**ORGANISATION SITE IDENTIFIER (OF IMAGING)**	min an5 max n9	M
CR0320	CORE - IMAGING	**PROCEDURE DATE (CANCER IMAGING)**	an10 ccyy-mm-dd	M
CR6780	CORE - IMAGING	**IMAGING OUTCOME** *[CANCER IMAGING OUTCOME]*	an2	R
IMAGING LOCATION CHOICE				Choice 1..3
IMAGING LOCATION CHOICE 1				
CR1610	CORE - IMAGING	**IMAGING CODE (NICIP)**	max an6	M
END OF IMAGING LOCATION - CHOICE 1				
IMAGING LOCATION CHOICE 2				
CR3110	CORE - IMAGING	**IMAGING CODE (SNOMED CT)**	min n6 max n18	M
END OF IMAGING LOCATION - CHOICE 2				
IMAGING LOCATION CHOICE 3				
Start of SECTION - Imaging location group May one occurrences per CORE - Imaging (0..1)				
CR0330	CORE - IMAGING	**CANCER IMAGING MODALITY**	an4	M
CR0340	CORE - IMAGING	**IMAGING ANATOMICAL SITE**	max an5	R
CR3000	CORE - IMAGING	**ANATOMICAL SIDE (IMAGING)**	an1	R
End of repeating section - Imaging location group				
END OF IMAGING LOCATION - CHOICE 3				
END OF IMAGING LOCATION CHOICE				
CR0160	CORE - IMAGING	**IMAGING REPORT TEXT**	max an270000	R
CR0350	CORE - IMAGING	**LESION SIZE (RADIOLOGICAL)**	max n3. max n2	R

Note: Image guided procedures (such as Breast wire guided biopsies) should be recorded under the new 'Diagnostic Procedures' section - using OPCS code B32.3.

It is possible that some legacy data may not have all the required mandatory fields for v9. 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).

ORGANISATION SITE IDENTIFIER (OF IMAGING): This is a mandatory data item from v9, 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 from v9, required to improve data quality. The DATE the Cancer Imaging was carried out.

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

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

Note: The next 5 data items form a 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 from v9, 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 at the following link: https://digital.nhs.uk/services/terminology-and-classifications/national-interim-clinical-imaging-procedure-nicip-code-set

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 from v9, 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 of the next 3 data items, these are grouped and only once 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 from v9, required to improve data quality. The type of imaging procedure used during an Imaging or Radiodiagnostic Event for a Cancer Care Spell.

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)
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:

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.

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 diagnosis date for registration.

LESION SIZE (RADIOLOGICAL): The size in millimetres of the maximum diameter of the primary lesion, largest if more than one.

CORE – DIAGNOSTIC PROCEDURES

This is a new section for v9 and allows 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR7500	CORE - DIAGNOSTIC PROCEDURES	**ORGANISATION SITE IDENTIFIER (DIAGNOSTIC PROCEDURE)** *[ORGANISATION SITE IDENTIFIER (OF DIAGNOSTIC PROCEDURE)]*	min an5 max an9	M
CR7510	CORE - DIAGNOSTIC PROCEDURES	**DIAGNOSTIC PROCEDURE DATE** *[PROCEDURE DATE (DIAGNOSTIC PROCEDURE)]*	an10 ccyy-mm-dd	M
DIAGNOSTIC PROCEDURES CHOICE				Choice 1..2
DIAGNOSTIC PROCEDURES - CHOICE 1				
Start of repeating item - Diagnostic Procedure (OPCS)				
CR7520	CORE - DIAGNOSTIC PROCEDURES	**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)				
CR7530	CORE - DIAGNOSTIC PROCEDURES	**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: The DATE the diagnostic procedure was carried out.

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

DIAGNOSTIC PROCEDURE (OPCS): Record the diagnostic procedure(s) carried out during the diagnostic event using OPCS. There may be more than one available, where multiple procedures are classified as a single event.

DIAGNOSTIC PROCEDURE (SNOMED CT): Record the diagnostic procedure(s) carried out during the diagnostic event using SNOMED CT. There may be more than one available, where multiple procedures are classified as a single event.

CORE – DIAGNOSTIC PROCEDURES – SENTINEL NODE BIOPSY

This is a new section for v9 and is a child of CORE – Diagnostic Procedures Group. Must be at least one of the following choices per Core – Diagnostic Procedures (1..2)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR7540	CORE - DIAGNOSTIC PROCEDURES - SENTINEL NODE BIOPSY	**SENTINEL NODE BIOPSY OUTCOME** *[SENTINEL LYMPH NODE BIOPSY OUTCOME]*	an1	R

SENTINEL NODE BIOPSY OUTCOME: Record the outcome of the Sentinel Node Biopsy. This has been moved from the skin section in v9.0.

P	Malignant
N	No Malignancy

Note: 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.

CORE – DIAGNOSIS

Diagnosis details in the linkage section are required for every record in order 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. Please refer to site-specific sections for applicable ICD10 and/or ICD-O-3 codes. 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 and CTYA malignancies in v9.

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.

ICD-O-3 codes can be found on the International Agency for Research on Cancer (IARC) website[7].

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 responsible for the patient and will probably 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR6230	CORE - DIAGNOSIS	**ORGANISATION SITE IDENTIFIER (OF DIAGNOSIS)**	min an5 max an9	R
CR0390	CORE - DIAGNOSIS	**BASIS OF DIAGNOSIS (CANCER)**	an1	R
CR0180	CORE - DIAGNOSIS	**MORPHOLOGY (ICD-O-3)** *[MORPHOLOGY (ICD-O DIAGNOSIS)]*	min an5 max an7	R
Start of SECTION - Current Morphology			Section 0..1	
CR6400	CORE - DIAGNOSIS	**MORPHOLOGY (SNOMED) DIAGNOSIS**	min n6 max n18	M
CR6490	CORE - DIAGNOSIS	**SNOMED VERSION (DIAGNOSIS)**	an2	M
End of SECTION - Current Morphology				
CR0480	CORE - DIAGNOSIS	**TOPOGRAPHY (ICD-O-3)** *[TOPOGRAPHY (ICD-O)]*	min an5 max an7	R
CR0410	CORE - DIAGNOSIS	**GRADE OF DIFFERENTIATION (AT DIAGNOSIS)**	an2	R
CR0510	CORE - DIAGNOSIS	**PERFORMANCE STATUS (ADULT)**	an1	R
CR6830	CORE - DIAGNOSIS	**DIAGNOSIS CODE (SNOMED CT)** *[DIAGNOSIS (SNOMED CT)]*	min n6 max n18	R
Start of repeating item - Metastatic Type and Site			Section 0..*	
CR6960	CORE - DIAGNOSIS	**METASTATIC TYPE** *[CANCER METASTATIC DISEASE TYPE]*	an2	M
CR6970	CORE - DIAGNOSIS	**METASTATIC SITE** *[METASTATIC SITE (AT DIAGNOSIS)]*	an2	M
End of repeating item - Metastatic Type and Site				

[7] http://codes.iarc.fr/home

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 several Trusts, 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:

- 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 difficult 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 was 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.

Non-microscopic	
0	Death Certificate: The only information available is from a death certificate
1	Clinical: Diagnosis made before death but without the benefit of any of the following (2-7)
2	Clinical Investigation: Includes all diagnostic techniques (for example X-rays, endoscopy, imaging, ultrasound, exploratory surgery 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 whether from a primary or secondary site, including fluids aspirated using endoscopes or needles. Also including microscopic examination of peripheral blood films and trephine bone marrow aspirates
6	Histology of a metastasis: Histological examination of tissues from a metastasis, including autopsy specimens
7	Histology of a primary tumour: Histological examination of tissue from the primary tumour, however obtained, including all cutting and bone marrow biopsies. Also includes autopsy specimens of a primary tumour
9	Unknown: No information on how the diagnosis has been made (for example PAS or HISS record only)

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 and CTYA diagnoses.

Note: The next 2 data items are now a multiple selection group and If this choice is selected, this becomes a mandatory data item from v9, required to improve data quality. There may be one occurrence per CORE – Diagnosis section (0..1).

MORPHOLOGY (SNOMED) DIAGNOSIS: This is the PATIENT 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.

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

TOPOGRAPHY (ICD-O-3): (MANDATORY for CTYA cases, OPTIONAL for others). The topographical site code for the tumour as defined by ICD-O-3. For all cases except CTYA this will be derived by the National Cancer Registration Service. For CTYA cases this should be included in the submission by NHS Providers. This MUST be submitted using a decimal point for example C50.9.

GRADE OF DIFFERENTIATION (AT DIAGNOSIS): is the definitive grade of the Tumour at the time of PATIENT DIAGNOSIS.

Note: Not required for prostate cancer, testicular cancer or haematological diagnoses.

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

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**
General Description	Grade of differentiation is not appropriate or cannot be assessed	Well differentiated	Moderately differentiated	Poorly differentiated	Undifferentiated / anaplastic
Invasive Grade Breast	n/a	Grade 1	Grade 2	Grade 3	n/a
Colorectal	n/a	Well / Moderately differentiated	n/a	Poorly differentiated	n/a
CNS	n/a	I	II	III	IV
Salivary Tumour Grade	n/a	Low	n/a	High	n/a
Sarcoma - Histological Tumour Grade	n/a	Low	Intermediate	High	n/a
Fallopian Tube, Ovary, Peritoneal	n/a	Low	Intermediate	High	n/a

PERFORMANCE STATUS (ADULT): A World Health Organisation classification indicating a PERSON's status relating to activity / 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.

Note: this data item is not applicable for Paediatric patients or Skin diagnoses, except for melanoma stage 4.

Note: 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.

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

Note: the attribute descriptions have changed in v9, to match those prescribed by The World Health Organization (WHO).

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: this is a required data item in v9.0.

METASTATIC TYPE: Indicate the type of metastatic disease diagnosed by the clinical team. More than one type can be recorded in v9.

01	Local
02	Regional
03	Distant

METASTATIC SITE: The site of the metastatic disease, if any, at diagnosis. Multiple occurrences of this item are permitted.

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

Note: both Metastatic Type and Site are now 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.

It is possible that some legacy data may not have all the required mandatory fields for v9. 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 – DIAGNOSIS – ADDITIONAL ITEMS

This is a child group of Core - Diagnosis. Although the data items within this group are required for CTYA cases, it was felt that they would also be valid for some adult cases (where applicable), and hopefully improve ascertainment.

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR7600	CORE - DIAGNOSIS - ADDITIONAL ITEMS	**PRIMARY DIAGNOSIS SUBSIDIARY COMMENT** *[PRIMARY DIAGNOSIS (CANCER COMMENT)]*	max an50	**R**
Start of repeating item - SECONDARY DIAGNOSIS (ICD)				
CR7610	CORE - DIAGNOSIS - ADDITIONAL ITEMS	**SECONDARY DIAGNOSIS (ICD)**	min an4 max an6	**R***
End of repeating item - SECONDARY DIAGNOSIS (ICD)				
CR7620	CORE - DIAGNOSIS - ADDITIONAL ITEMS	**OTHER SIGNIFICANT DIAGNOSIS SUBSIDIARY COMMENT** *[SECONDARY DIAGNOSIS (CANCER COMMENT)]*	max an50	**R**
CR7630	CORE - DIAGNOSIS - ADDITIONAL ITEMS	**FAMILIAL CANCER SYNDROME** *[FAMILIAL CANCER SYNDROME INDICATOR]*	an1	**R**
CR7640	CORE - DIAGNOSIS - ADDITIONAL ITEMS	**FAMILIAL CANCER SYNDROME SUBSIDIARY COMMENT** *[FAMILIAL CANCER SYNDROME COMMENT]*	max an50	**R**

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): Types (ICD10 codes) of other significant conditions (for example Down Syndrome, NF1, Fanconi anaemia) which may predispose to cancer or influence treatment. Possible multiple entries. This information should be available for the MDT discussion but will only apply to a small number of cases. See Appendix D for list of Associated Conditions to be recorded on Childhood Cancer Registration Forms.

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. The following definitions are used:

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.

CORE – DIAGNOSIS – PROGRESSION

This is a new group for COSD v9 and 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 now mandatory and must be submitted per submission, more than one submission is permitted per diagnosis.

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
Start of repeating item - Metastatic Type and Site May be multiple occurrences per CORE - Diagnosis - Progression (0..*)				
CR6960	CORE - DIAGNOSIS - PROGRESSION	**METASTATIC TYPE** *[CANCER METASTATIC DISEASE TYPE]*	an2	M
CR6970	CORE - DIAGNOSIS - PROGRESSION	**METASTATIC SITE** *[METASTATIC SITE (AT DIAGNOSIS)]*	an2	M
End of repeating item - Metastatic Type and Site				
CR6910	CORE - DIAGNOSIS - PROGRESSION	**PROGRESSION DATE (PRIMARY PATHWAY)** *[CANCER PROGRESSION AGREED DATE (PRIMARY CANCER PATHWAY)]*	an10 ccyy-mm-dd	M

METASTATIC TYPE: Indicate the type of metastatic disease diagnosed by the clinical team. More than one type can be recorded in v9. This is an existing data item used in a new (grouped way) for v9 and is mandatory within this grouped section.

01	Local
02	Regional
03	Distant

METASTATIC SITE: The site of the metastatic disease, if any, at diagnosis. Multiple occurrences of this item are permitted. This is an existing data item used in a new (grouped way) for v9 and is mandatory within this grouped section.

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

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.

CORE – DIAGNOSIS – TRANSFORMATION

This is a new group for COSD v9 and 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR7020	CORE - DIAGNOSIS - TRANSFORMATION	**TRANSFORMATION DATE (PRIMARY PATHWAY)** *[CANCER TRANSFORMATION AGREED DATE (PRIMARY CANCER PATHWAY)]*	an10 ccyy-mm-dd	M
DIAGNOSIS TRANSFORMATION MORPHOLOGY CHOICE				Choice 1..2
DIAGNOSIS TRANSFORMATION MORPHOLOGY - CHOICE 1				
CR7010	CORE - DIAGNOSIS - TRANSFORMATION	**MORPHOLOGY (ICD-O-3) TRANSFORMATION** *[MORPHOLOGY (ICD-O CANCER TRANSFORMATION)]*	min an5 max an7	M
END OF DIAGNOSIS TRANSFORMATION MORPHOLOGY - CHOICE 1				
DIAGNOSIS TRANSFORMATION MORPHOLOGY - CHOICE 2				
Start of SECTION - Current Morphology				
CR7000	CORE - DIAGNOSIS - TRANSFORMATION	**MORPHOLOGY (SNOMED) TRANSFORMATION** *[MORPHOLOGY (SNOMED CANCER TRANSFORMATION)]*	min an6 max an18	M
CR7030	CORE - DIAGNOSIS - TRANSFORMATION)	**SNOMED VERSION (TRANSFORMATION)** *[SNOMED VERSION (CANCER 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 in v9. This is the date the disease transforms. This will normally be agreed at the MDT by the clinical team and is now a mandatory data item in v9.

Note: The next 3 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 from v9, 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.

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. There may be one occurrence per Transformation.

CORE – DIAGNOSIS – BANKED TISSUE

This is a new section for v9 and are required for CTYA but optional for all other tumours (where applicable).

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR7700	CORE - DIAGNOSIS - BANKED TISSUE	**BANKED TISSUE AT DIAGNOSIS** *[PATIENT CONSENT FOR TISSUE BANKED AT DIAGNOSIS INDICATION CODE]*	an1	R
Start of repeating item - Type of Tissue Banked at Diagnosis				
CR7710	CORE - DIAGNOSIS - BANKED TISSUE	**TYPE OF TISSUE BANKED AT DIAGNOSIS** *[TISSUE TYPE BANKED AT DIAGNOSIS (CANCER)]*	an1	R*
End of repeating item - Type of Tissue Banked at Diagnosis				

BANKED TISSUE AT DIAGNOSIS: Indicate whether any tissue was banked at diagnosis. This field has been updated since v8 to be more in line with clinical practice.

~~Y~~	~~Yes~~
~~N~~	~~No~~
1	PATIENT approached, consented
2	PATIENT approached, but declined
3	PATIENT not approached
9	Not Known (Not Recorded)

TYPE OF TISSUE BANKED AT DIAGNOSIS: Indicate what tissue was banked at diagnosis, more than one can be selected.

1	Tumour
2	Blood
3	CSF
4	Bone Marrow
5	Urine

CORE – PERSON OBSERVATION

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR6430	CORE - PERSON OBSERVATION	**PERSON OBSERVATION HEIGHT IN METRES** *[PERSON HEIGHT IN METRES]*	n1.max n2	**R**
CR6440	CORE - PERSON OBSERVATION	**PERSON OBSERVATION (WEIGHT)** *[PERSON WEIGHT]*	max n3.max n3	**R**
CR6450	CORE - PERSON OBSERVATION	**BODY MASS INDEX**	n2.n1	**R**
CR6460	CORE - PERSON OBSERVATION	**DATE OBSERVATION MEASURED** *[OBSERVATION DATE]*	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 has been updated with additional risk factors, which will help improve our understanding of causative risk factors across all tumour sites.

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR2050	CORE - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT	**CLINICAL NURSE SPECIALIST INDICATION CODE**	an2	**R**
CR7800	CORE - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT	**TOBACCO SMOKING STATUS** *[SMOKING STATUS (CANCER)]*	an1	**R**
CR7810	CORE - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT	**TOBACCO SMOKING CESSATION** *[TOBACCO SMOKING CESSATION TREATMENT INDICATION CODE]*	an1	**R**
CR6760	CORE - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT	**HISTORY OF ALCOHOL (CURRENT)** *[ALCOHOL HISTORY (CANCER IN LAST 3 MONTHS)]*	an1	**R**
CR6770	CORE - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT	**HISTORY OF ALCOHOL (PAST)** *[ALCOHOL HISTORY (CANCER BEFORE LAST 3 MONTHS)]*	an1	**R**
CR7820	CORE - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT	**DIABETES MELLITUS INDICATOR** *[PATIENT DIAGNOSIS INDICATOR (DIABETES)]*	an1	**R**
CR7830	CORE - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT	**MENOPAUSAL STATUS** *[MENOPAUSAL STATUS (AT DIAGNOSIS)*	an1	**R**
CR7840	CORE - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT	**PHYSICAL ACTIVITY (CURRENT)** *[PHYSICAL ACTIVITY VITAL SIGN LEVEL (CURRENT)]*	an1	**R**

Note: the following data item has been retired from v9.0:

- SMOKING STATUS

CLINICAL NURSE SPECIALIST INDICATION CODE: Record if and when the patient saw an appropriate site-specific clinical nurse specialist. Please therefore read all options in order to select the most appropriate code.

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)

Note: 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. As a result, and to help you assign the correct code, the following 3 expanded explanations have been provided.

1. Cancer care coordinators are band 3/4 staff who have been employed to work within clinical nurse specialist teams to undertake a number of duties which do not need to be performed by a clinical nurse specialist including telephone triage, pathway management and in some cases acting as key worker to patients with non-complex disease requiring straight forward management.

2. 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.

3. They 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.

TOBACCO SMOKING STATUS: This is a new data item, 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.

1	Current smoker
2	Ex smoker
4	Never smoked
9	Unknown

TOBACCO SMOKING CESSATION: This is a new data item, 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.

1	Patient treated
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.

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

HISTORY OF ALCOHOL (PAST): Specify the current history of alcohol consumption for the patient (>3 months) from date of diagnosis.

1	Heavy (>14 Units per week)
2	Light (≤14 Units per week)
3	None ever
Z	Not Stated (PERSON 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 INDICATOR: This data item has been moved from Liver to CORE and renamed, as it is a risk factor for many cancers. Record if the patient does have a diagnosis of diabetes?

Y	Yes
N	No
9	Not known

Note: The presence of diabetes is an independent risk factor of development of HCC and many other cancers.

Does the patient have a diagnosis of diabetes?

This information will normally be available in the patient record.

MENOPAUSAL STATUS: This data item has been moved from Breast to CORE, as it is a risk factor for many cancers.

1	Premenopausal
2	Perimenopausal
3	Postmenopausal
9	Not Known

Numerous current treatment options are different according to the menopausal status of a patient (particularly those presenting with breast cancer). In particular endocrine therapy choices for clinical trial entry are often dictated by menopausal status.

PHYSICAL ACTIVITY (CURRENT): This is a new data item for v9 to specify the current physical activity level of the patient.

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

The activity assessment is based on The Physical Activity Vital Sign (PAVS), which has been recommended for its utility in clinical practice compared to other measures such as International Physical Activity Questionnaires (IPAQ) and the General Practice Physical Activity Questionnaire (GPPAQ).

Please see:
http://www.exerciseismedicine.org/assets/page_documents/The%20Physical%20Activity%20Vital%20Sign%20without%20Strength_2015_07_09_PDF.pdf

or Online quick 'Activity calculator' format:

https://movingmedicine.ac.uk/disease/cancer/?current_page=the-more-minutes-consultation&subpage=ask

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 intervention such as in:

- physical activity: brief advice for adults in primary care (NICE Guidance PH44 2016)
- Macmillan Cancer Support's Move More resources
- resources for health professionals: https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/physical-activity
- online learning module Understanding physical activity and cancer: https://learnzone.org.uk/courses/course.php?id=297
- resources for people affected by cancer: macmillan.org.uk/beactive
- moving Medicine cancer resource: https://movingmedicine.ac.uk/disease/cancer/#start

CORE – CLINICAL NURSE SPECIALIST – HOLISTIC NEEDS ASSESSMENT

This section has been updated with additional assessments linked to the HNA. The Personalised Care and Support Planning is recorded in its own new section.

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR7900	CORE - CLINICAL NURSE SPECIALIST - HOLISTIC NEEDS ASSESSMENT	**ASSESSMENT OFFERED** *[OFFER STATUS (HOLISTIC NEEDS ASSESSMENT)]*	an2	R
CR3140	CORE - CLINICAL NURSE SPECIALIST - HOLISTIC NEEDS ASSESSMENT	**ASSESSMENT COMPLETED DATE** *[HOLISTIC NEEDS ASSESSMENT COMPLETED DATE]*	an10 ccyy-mm-dd	R
CR3150	CORE - CLINICAL NURSE SPECIALIST - HOLISTIC NEEDS ASSESSMENT	**ASSESSMENT POINT OF PATHWAY** *[HOLISTIC NEEDS ASSESSMENT POINT OF PATHWAY (CANCER)]*	an2	R
CR7910	CORE - CLINICAL NURSE SPECIALIST - HOLISTIC NEEDS ASSESSMENT	**STAFF ROLE CARRYING OUT THE ASSESSMENT** *[STAFF ROLE CARRYING OUT HOLISTIC NEEDS ASSESSMENT]*	an2	R

HOLISTIC NEEDS ASSESSMENT OFFERED: This is a new data item for v9 and an indication of whether a PATIENT has been offered a Holistic Needs Assessment (HNA).

01	Offered and Undecided
02	Offered and Declined
03	Offered and Accepted
04	Not Offered
05	Offered but Patient Unable to Complete

This data item captures the first time the patient is offered an HNA and whether they:

- were undecided whether or not to have an HNA
- declined having an HNA
- accepted having an HNA, or
- were unable to complete, for example due to cognitive difficulties

The category ‘Not Offered’ covers patients who would not normally be expected to undergo HNA due to being on a clinical pathway that deliberately does not include it (for example some skin cancer patients or because the patient has been referred on to another provider who will offer the HNA).

HOLISTIC NEEDS ASSESSMENT COMPLETED DATE: The date a Holistic Needs Assessment (HNA) is completed. Every HNA should be recorded.

Additional notes to help with data recording:

- the date of the HNA is either the date of offer of HNA or the date of completion if completed
- HNAs are carried out in all healthcare, social care and community settings (for example, libraries), however it will not be possible to capture all these for the purposes of COSD - this is particularly true for HNAs carried out as part of long term follow up
- therefore, the focus for COSD data should be on recording HNAs carried out before, during and shortly after treatment, and only those that are carried out in a secondary care environment will be required for the purposes of COSD

HOLISTIC NEEDS ASSESSMENT POINT OF PATHWAY: The point in the patient pathway when a Holistic Needs Assessment (HNA) is completed.

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
97	Other
~~98~~	~~Other~~

Additional notes to help with data recording:

- 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
- locally, standards may be set around certain timescales, and/or local agreement on where in each cancer type pathway the HNAs should be carried out as a minimum
- the focus of HNA activity for purposes of meeting NHS England policy commitments on the personalisation of care is around:
  (1) diagnosis/start of treatment
  (2) around/after the end of treatment
- however, it is important that HNA is also done at transition points such as diagnosis of recurrence and transition to palliative care. HNAs may also be requested at any time by the patient
- if a patient is undergoing further treatments following primary treatment (for example treatment for recurrence or metastatic disease) then the timepoint of pathway should be Start of/During/End of Treatment, as appropriate

STAFF ROLE CARRYING OUT THE HOLISTIC NEEDS ASSESSMENT: This is a new data item for v9. Record the role of the individual carrying out the Holistic Needs Assessment.

01	Cancer Nurse Specialist
02	Other nurse
03	Allied health Professional
04	Support worker/Care Navigator (band 3 or 4)
05	Psychologist or other mental health professional
06	Consultant/Medical Team
08	Other
09	Not Known

Additional notes to help with data recording:

- HNAs are carried out by any health or social care professional and also by support workers/care navigators, volunteers or by the person themselves from home
- staff role is needed in order to support workforce planning of who and how HNA and Personalised Care and Support Planning activities are being carried out

CORE – CLINICAL NURSE SPECIALIST – PERSONALISED CARE AND SUPPORT PLAN

This section is new section for v9 and is a child of 'Core - Clinical Nurse Specialist'. The Personalised Care and Support Plan (PCSP) details are recorded in this section.

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR8000	CORE - CLINICAL NURSE SPECIALIST - PERSONALISED CARE AND SUPPORT PLANNING	**CARE PLANNING OFFERED** *[OFFER STATUS (PERSONALISED CARE AND SUPPORT PLANNING)]*	an2	R
CR8010	CORE - CLINICAL NURSE SPECIALIST - PERSONALISED CARE AND SUPPORT PLANNING	**CARE PLANNING COMPLETED DATE** *[PERSONALISED CARE AND SUPPORT PLANNING COMPLETED DATE]*	an10 ccyy-mm-dd	R
CR8020	CORE - CLINICAL NURSE SPECIALIST - PERSONALISED CARE AND SUPPORT PLANNING	**POINT OF PATHWAY** *[PERSONALISED CARE AND SUPPORT PLANNING POINT OF CANCER PATHWAY]*	an2	R
CR8030	CORE - CLINICAL NURSE SPECIALIST - PERSONALISED CARE AND SUPPORT PLANNING	**STAFF ROLE CARRYING OUT PLANNING** *[STAFF ROLE CARRYING OUT PERSONALISED CARE AND SUPPORT PLANNING]*	an2	R

PERSONALISED CARE AND SUPPORT PLAN OFFERED: This is a new data item for v9 and an indication of whether a PATIENT has been offered a Personalised Care and Support Plan (PCSP).

01	Offered and Undecided
02	Offered and Declined
03	Offered and Accepted
04	Not Offered

05	Offered but Patient Unable to Complete
06	Not required (no concerns from HNA)

Additional notes to help with data recording include:

- a Personalised Care and Support Plan (PCSP) is what has previously been termed a Care Plan (resulting from a Holistic Needs Assessment)
- guidance on Personalised Care and Support Planning is available from NHS England[8]
- this data item captures the first time the patient is offered the opportunity to create a PCSP (normally following an HNA) and whether they:
  - were undecided whether or not to have a PCSP
  - declined having a PCSP
  - accepted having a PCSP
  - were unable to complete, due to cognitive difficulties for example.
- the category 'Not Offered' covers patients who would not normally be expected to have personalised care and support planning due to being on a clinical pathway that deliberately does not include it (such as some skin cancer patients or because the patient has been referred on to another provider who will offer the PCSP)
- evidence indicates that around 20% of people who complete an HNA will not go on to have an agreed PCSP because there was a shared decision with their health and social care professional that they had no concerns from their HNA that needed a PCSP to be drawn up for – this should be recorded as Offered and Declined

PERSONALISED CARE AND SUPPORT PLAN COMPLETED DATE: This is a new data item for v9. The date a Personalised Care and Support Plant is completed.

Additional notes to help with data recording:

- the date of the PCSP is either the date of offer of PCSP or the date of completion if completed
- personalised care and support planning are carried out in all healthcare, social care and community settings (for example, libraries) but it will not be possible to capture all these for the purposes of COSD - this is particularly true for personalised care and support planning that is carried out as part of long term follow up
- therefore, the focus should be on recording personalised care and support planning that is carried out before, during and shortly after treatment, and only those that are carried out in a secondary care environment will be required for the purposes of COSD
- actions carried out as a result of a PCSP (for example, a referral to counselling) are not required to be captured for COSD purposes in this iteration (v9) but may to be part of v10

[8] https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/

PERSONALISED CARE AND SUPPORT PLAN POINT OF PATHWAY: This is a new data item for v9. The point of the pathway where a Personalised Care and Support Plan is completed.

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
98	Other

Additional notes to help with data recording:

- the pathway time points for PCSPs are not defined in terms of a number of days or weeks from diagnosis or from end of treatment that the PCSP happens within
- locally, standards may be set around these timescales, and/or local agreement on where in each cancer type pathway the PSCP should be carried out as a minimum
- the focus of PCSP activity for purposes of meeting NHS England policy commitments on the personalisation of care is around:
  (1) diagnosis/start of treatment
  (2) around/after the end of treatment
- however, it is important that PCSP is also done at transition points such as diagnosis of recurrence and transition to palliative care. PCSP may be requested at any time by the patient
- if a patient is undergoing further treatments following primary treatment (for example, treatment for recurrence or metastatic disease) then the timepoint of pathway should be Start of/During/End of Treatment, as appropriate

STAFF ROLE CARRYING OUT THE PERSONALISED CARE AND SUPPORT PLAN: This is a new data item for v9. Record the role of the individual carrying out the Personalised Care and Support Plan assessment.

01	Cancer Nurse Specialist
02	Other nurse
03	Allied health Professional
04	Support worker/Care Navigator (band 3 or 4)
05	Psychologist or other mental health professional
06	Consultant/Medical Team
08	Other
09	Not Known

Additional notes to help with data recording:

- personalised care and support planning are usually carried out by a health or social care professional
- staff role is needed in order to support workforce planning of who and how HNA and PCSP activities are being carried out

CORE – MULTIDISCIPLINARY TEAM MEETINGS

This section has been redesigned 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); or
- Patient requires discussion for any given reason

Guidance for MDTM streamlining can be found 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 teams can contact their relevant Cancer Alliance[9].

Record ALL MDTM's, where the patient was discussed.

There is now 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).

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.

[9] https://www.england.nhs.uk/cancer/improve/cancer-alliances-improving-care-locally/cancer-alliance-contacts/

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
MULTIDISCIPLINARY TEAM MEETINGS CHOICE				Choice 1..2
MULTIDISCIPLINARY TEAM MEETINGS - CHOICE 1				
CR8100	CORE - MULTIDISCIPLINARY TEAM MEETINGS	**MULTIDISCIPLINARY TEAM MEETING DISCUSSION** *[MULTIDISCIPLINARY TEAM MEETING CANCER CARE PLAN NOT DISCUSSED INDICATION CODE]*	an1	M
END OF MULTIDISCIPLINARY TEAM MEETINGS - CHOICE 1				
MULTIDISCIPLINARY TEAM MEETINGS - CHOICE 2				
Start of SECTION - Multidisciplinary Team Meeting Detail				Section 1..1
CR8110	CORE - MULTIDISCIPLINARY TEAM MEETINGS	**MULTIDISCIPLINARY TEAM MEETING DISCUSSION TYPE** *[MULTIDISCIPLINARY TEAM MEETING CANCER CARE PLAN DISCUSSION TYPE]*	an1	M
CR3080	CORE - MULTIDISCIPLINARY TEAM MEETINGS	**MULTIDISCIPLINARY TEAM MEETING DATE** *[MULTIDISCIPLINARY TEAM MEETING DATE (CANCER)]*	an10 ccyy-mm-dd	M
CR3090	CORE - MULTIDISCIPLINARY TEAM MEETINGS	**ORGANISATION SITE IDENTIFIER OF MULTIDISCIPLINARY TEAM MEETING** *[ORGANISATION SITE IDENTIFIER (OF MULTIDISCIPLINARY TEAM MEETING)]*	min an5 max an9	M
CR3190	CORE - MULTIDISCIPLINARY TEAM MEETINGS	**MULTIDISCIPLINARY TEAM MEETING TYPE** *[MULTIDISCIPLINARY TEAM MEETING TYPE (CANCER)]*	an4	M
CR3160	CORE - MULTIDISCIPLINARY TEAM MEETINGS	**MULTIDISCIPLINARY MEETING TYPE COMMENT** *[MULTIDISCIPLINARY TEAM MEETING TYPE COMMENT (CANCER)]*	max an60	R
End of SECTION - Multidisciplinary Team Meeting 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 at least one of the following choices must be provided per CORE - MDT submission (1..2).

Choice 1

MULTIDISCIPLINARY TEAM MEETING DISCUSSION: This is a new mandatory data item in v9, which identifies if the patient **was not** discussed at the MDT or if the discussion status was not known at that point.

1	Not discussed at all
2	Discussion Status Not Known

Choice 2

MULTIDISCIPLINARY TEAM MEETING DISCUSSION TYPE: This is a new mandatory data item in v9, 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 a new initiative from NHS England to help reduce the number of patients being discussed at an MDT.

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 now a mandatory data item in v9. 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: this data item will be removed from the CWT data set collection from 2020.
- 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 now a mandatory field in v9. 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). Note: this item is important in order 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 now a mandatory field in v9. Record the type of MDT meeting at which the patient was discussed. Please provide the most detailed level of information that is possible.

Note: the codes at the high level (shown in bold, 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.

0100	**Breast**
0101	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
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**
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
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

MULTIDISCIPLINARY MEETING TYPE COMMENT: This is an optional data item to provide 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:

- should a patient be treated prior to MDT and they are 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 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 Primary Cancer Pathway (0..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR0430	CORE - CANCER CARE PLAN	**MULTIDISCIPLINARY TEAM DISCUSSION DATE (CANCER)**	an10 ccyy-mm-dd	R
Start of SECTION - Consultant (Multidisciplinary Team Lead)			Section 0..1	
CR8200	CORE - CANCER CARE PLAN	**PROFESSIONAL REGISTRATION ISSUER CODE - CONSULTANT (MULTIDISCIPLINARY TEAM LEAD)** *[PROFESSIONAL REGISTRATION ISSUER CODE (MULTIDISCIPLINARY TEAM LEAD)]*	an2	M
CR8210	CORE - CANCER CARE PLAN	**PROFESSIONAL REGISTRATION ENTRY IDENTIFIER - CONSULTANT (MULTIDISCIPLINARY TEAM LEAD)** *[PROFESSIONAL REGISTRATION ENTRY IDENTIFIER (MULTIDISCIPLINARY TEAM LEAD)]*	min an1 max an32	M
End of repeating section - Consultant (Multidisciplinary Team Lead)				
CR0460	CORE - CANCER CARE PLAN	**CANCER CARE PLAN INTENT**	an1	R
Start of repeating item - Planned Cancer Treatment Type				
CR0470	CORE - CANCER CARE PLAN	**PLANNED CANCER TREATMENT TYPE**	an2	R
End of repeating item - Planned Cancer Treatment Type				
CR0490	CORE - CANCER CARE PLAN	**NO CANCER TREATMENT REASON**	an2	R
CR2060	CORE - CANCER CARE PLAN	**ADULT COMORBIDITY EVALUATION - 27 SCORE**	an1	O

Note: The following data items have been retired from v9.0:

- CONSULTANT CODE (MULTIDISCIPLINARY TEAM LEAD)

MULTIDISCIPLINARY TEAM DISCUSSION DATE (CANCER): This is the date when a treatment planning decision was made.

Note: this data item has now been removed from the CWT data set collection from 2020.

Note: the next 2 data items are now a multiple selection group and are mandatory within the group. There may be one occurrence per CORE - Cancer Care Plan Section.

PROFESSIONAL REGISTRATION ISSUER CODE - CONSULTANT (MULTIDISCIPLINARY TEAM LEAD): This is a new data item in v9 replacing the 'Consultant Code (Multidisciplinary Team Lead)' and is a code which identifies the PROFESSIONAL REGISTRATION BODY for the Consultant or health care professional who is designated as the MDT Lead.

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 (MULTIDISCIPLINARY TEAM LEAD): This is a new data item in v9 replacing the 'Consultant Code (Multidisciplinary Team Lead)' and is the registration identifier allocated by an Organisation for the Consultant or health care professional who is designated as the MDT Lead.

CANCER CARE PLAN INTENT: The intention of a Cancer Care Plan developed within a Cancer Care Spell.

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 the majority of 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.

01	Surgery
02	Teletherapy
03	Chemotherapy
04	Hormone therapy
05	Specialist palliative care

06	Brachytherapy Therapy
07	Biological Therapy
10	Other Active Treatment
11	No active treatment
12	Biphosphonates
13	Anti-Cancer Drug - Other
14	Radiotherapy - Other
99	Not known

NO CANCER TREATMENT REASON: The main reason why no active cancer treatment is specified within a Cancer Care Plan.

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
10	Monitoring only
99	Not known

ACE – 27 SCORE (ADULT COMORBIDITY EVALUATION 27 SCORE): Overall Comorbidity Score is defined according to the highest ranked single ailment, except in the case where 2 or more Grade 2 ailments occur in different organ systems. In this situation, the overall comorbidity score should be designated Grade 3.

0	None
1	Mild
2	Moderate
3	Severe
9	Not known

Note: ACE 27 scoring relates to co-morbidities and should not therefore include the condition (Cancer) being treated. This is not applicable for Skin diagnoses.

CORE – MOLECULAR AND BIOMARKERS

This was a new section in v7.0, in response to the Achieving World Class Cancer Outcomes, A Strategy for England 2015 to 2020 (Taskforce report), and to ensure that COSD maintains itself at the cutting end of technology in cancer diagnostics and treatments offered to patients.

Whilst the intention is to ultimately get all the molecular and biomarker outcome data direct from the laboratories themselves; until these data feeds are consistent and ascertainment complete, these sections and additional site-specific data items will continue to be collected through COSD.

CORE – MOLECULAR AND BIOMARKERS – GERMLINE TESTING FOR CANCER PREDISPOSITION

To carry Molecular and Biomarkers (Germline Testing for Cancer Predisposition) details for a patient, where these have been offered by the clinical teams.

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR6100	CORE - MOLECULAR AND BIOMARKERS - GERMLINE TESTING FOR CANCER PREDISPOSITION	**GERMLINE GENETIC TESTING OFFERED** *[OFFER STATUS (GERMLINE GENETIC TEST)]*	an2	R
Start of repeating item - GERMLINE GENETIC TESTING OFFERED				
CR6110	CORE - MOLECULAR AND BIOMARKERS - GERMLINE TESTING FOR CANCER PREDISPOSITION	**GERMLINE GENETIC TEST OFFERED** *[GERMLINE GENETIC TEST TYPE OFFERED]*	an2	R*
End of repeating item - GERMLINE GENETIC TESTING OFFERED				
Start of repeating item - OTHER GERMLINE GENETIC TESTING OFFERED				
CR6120	CORE - MOLECULAR AND BIOMARKERS - GERMLINE TESTING FOR CANCER PREDISPOSITION	**OTHER GERMLINE GENETIC TEST OFFERED** *[OTHER GERMLINE GENETIC TEST TYPE OFFERED COMMENT]*	max an30	R*
End of repeating item - OTHER GERMLINE GENETIC TESTING OFFERED				
CR6130	CORE - MOLECULAR AND BIOMARKERS - GERMLINE TESTING FOR CANCER PREDISPOSITION	**GERMLINE ANALYSIS OFFERED DATE** *[ACTIVITY OFFER DATE (GERMLINE GENETIC TEST)]*	an10 ccyy-mm-dd	R
CR6140	CORE - MOLECULAR AND BIOMARKERS - GERMLINE TESTING FOR CANCER PREDISPOSITION	**ORGANISATION IDENTIFIER OF REPORTING REGIONAL GENETICS LABORATORY** *[ORGANISATION IDENTIFIER (REPORTING LABORATORY)]*	an3 or an5	R
CR6150	CORE - MOLECULAR AND BIOMARKERS - GERMLINE TESTING FOR CANCER PREDISPOSITION	**REFERRAL TO CLINICAL GENETICIST OFFERED** *[OFFER STATUS (REFERRAL TO REGIONAL CLINICAL GENETICS SERVICE)]*	an2	R

GERMLINE GENETIC TESTING OFFERED: An indication of whether a PATIENT has been offered a germline genetic test.

01	Offered and Undecided
02	Offered and Declined
03	Offered and Accepted
04	Not Offered

GERMLINE GENETIC TEST OFFERED: Record the germline / genetic test offered to the Patient. More than one of these can be selected.

01	Hereditary Breast and Ovarian Cancer (BRCA1 / BRCA2 / NGS Panel)
02	Lynch Syndrome / HNPCC (MLH1 / MSH2 / MSH6 / PMS2 / EPCAM / NGS Panel)
03	Myeloid Neoplasms (CEBPA / DDX41 / RUNX1 / ANKRD26 / ETV6 / GATA2)

97	Other
~~98~~	~~Other~~

Note: the addition of NGS Panel has been added to 01 and 02, to ensure alignment with the testing that will be performed in 2020.
The following are the classification for the new Myeloid Neoplasms attribute:

Myeloid neoplasms with germline predisposition without a pre-existing disorder or organ dysfunction:

- acute myeloid leukaemia with germline CEBPA mutation
- myeloid neoplasms with germline DDX41 mutation[a]

Myeloid neoplasms with germline predisposition and pre-existing platelet disorder:

- myeloid neoplasms with germline RUNX1 mutation[a]
- myeloid neoplasms with germline ANKRD26 mutation[a]
- myeloid neoplasms with germline ETV6 mutation[a]

Myeloid neoplasms with germline predisposition and other organ dysfunction:

- myeloid neoplasms with germline GATA2 mutation
- myeloid neoplasms associated with bone marrow failure syndromes[b]
- myeloid neoplasms associated with telomere biology disorders[b]
- juvenile myelomonocytic leukaemia associated with neurofibromatosis, Noonan syndrome, or Noonan syndrome-like disorders[c]
- myeloid neoplasms associated with Down syndrome[a,d]

[a] Lymphoid neoplasms have been reported
[b] See table 7.03 p127 (WHO blue book) for specific genes
[c] See Juvenile myelomonocytic leukaemia, p89 (WHO blue book)
[d] See Myeloid proliferations associated with Downs syndrome, 1699 (WHO blue book)

OTHER GERMLINE GENETIC TEST OFFERED: If [97-Other] is selected in the field CR6110 'Germline Genetic Test Offered' Specify the Gene or Syndrome that was offered.

GERMLINE ANALYSIS OFFERED DATE: Record the date on which the germline genetic test was offered.

ORGANISATION IDENTIFIER OF REPORTING REGIONAL GENETICS LABORATORY: This is the ORGANISATION IDENTIFIER of the Organisation where the reporting laboratory is based.

REFERRAL TO CLINICAL GENETICIST OFFERED: Indicate whether the patient has been offered a referral to a Regional Clinical Genetics Service.

01	Offered and Undecided
02	Offered and Declined
03	Offered and Accepted
04	Not Offered

MOLECULAR AND BIOMARKERS – SOMATIC TESTING FOR TARGETED THERAPY AND PERSONALISED MEDICINE

To carry Molecular and Biomarkers (Somatic Testing for Targeted Therapy and Personalised Medicine) details for a patient, where these have been performed by the clinical teams. The date and lab details are now mandatory to improve data quality.

It is possible that some legacy data may not have all the required mandatory fields for v9. 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
Start of repeating item - GENE OR STRATIFICATION BIOMARKER ANALYSED				
CR6170	CORE - MOLECULAR AND BIOMARKERS - SOMATIC TESTING FOR TARGETED THERAPY AND PERSONALISED MEDICINE	**GENE OR STRATIFICATION BIOMARKER ANALYSED** *[GENE OR STRATIFICATION BIOMARKER TYPE ANALYSED]*	an2	R*
End of repeating item - GENE OR STRATIFICATION BIOMARKER ANALYSED				
Start of repeating item - OTHER GENE OR STRATIFICATION BIOMARKER ANALYSED				
CR6180	CORE - MOLECULAR AND BIOMARKERS - SOMATIC TESTING FOR TARGETED THERAPY AND PERSONALISED MEDICINE	**OTHER GENE OR STRATIFICATION BIOMARKER ANALYSED** *[OTHER GENE OR STRATIFICATION BIOMARKER TYPE ANALYSED COMMENT]*	max an30	R*
End of repeating item - OTHER GENE OR STRATIFICATION BIOMARKER ANALYSED				
CR6190	CORE - MOLECULAR AND BIOMARKERS - SOMATIC TESTING FOR TARGETED THERAPY AND PERSONALISED MEDICINE	**DATE GENE OR STRATIFICATION BIOMARKER REPORTED** *[GENE OR STRATIFICATION BIOMARKER REPORTED DATE]*	an10 ccyy-mm-dd	M
CR6200	CORE - MOLECULAR AND BIOMARKERS - SOMATIC TESTING FOR TARGETED THERAPY AND PERSONALISED MEDICINE	**ORGANISATION IDENTIFIER OF REPORTING LABORATORY** *[ORGANISATION IDENTIFIER (REPORTING LABORATORY)]*	min an3 max an5	M

Note: the following data items have been retired from v9.0:

- STRATIFIED MOLECULAR TEST PERFORMED

GENE OR STRATIFICATION BIOMARKER ANALYSED: Record the specific Gene or Stratification Biomarker analysed for the Patient, regardless of test outcome. More than one of these can be selected.

01	ALK Fusions
02	BCR-ABL Fusion
03	BRAF Mutation
04	BRCA1 Mutation
05	BRCA2 Mutation
06	EGFR Mutation
07	ERBB2 (HER2/neu) Amplification / Overexpression
08	JAK2
09	KIT (CD117) Mutation
10	KRAS Mutation
11	Microsatellite Instability (MSI) / Mismatch Repair Analysis
12	NGS Panel (specify in [CR6180] below)
13	NRAS Mutation
14	Oncotype DX Gene Expression Test
15	PDGFRA Mutation
16	PIK3CA Mutation
17	RET Fusions
18	ROS Fusions
19	PD-L1
97	Other
~~98~~	~~Other~~

OTHER GENE OR STRATIFICATION BIOMARKER ANALYSED: If [97-Other] is selected in the field CR6170 'Gene or Stratification Biomarker Analysed'. Specify the Gene or Stratification Biomarker that was analysed.

DATE GENE OR STRATIFICATION BIOMARKER REPORTED: This is now a mandatory data item for v9, which will improve data quality. Record the date the Gene or Stratification Biomarker was reported.

ORGANISATION IDENTIFIER OF REPORTING LABORATORY: This is now a mandatory data item for v9, which will improve data quality. This is the ORGANISATION IDENTIFIER of the Organisation where the reporting laboratory is based.

CORE – CLINICAL TRIALS

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR1290	CORE - CLINICAL TRIALS	**PATIENT TRIAL STATUS (CANCER)**	an2	R

CR6700	CORE - CLINICAL TRIALS	**CLINICAL TRIAL DECISION DATE (PATIENT)** *[CLINICAL TRIAL DECISION DATE]*	an10 ccyy-mm-dd	R
CR6710	CORE - CLINICAL TRIALS	**DATE CLINICAL TRIAL STARTED** *[CLINICAL TRIAL START DATE]*	an10 ccyy-mm-dd	R
CR1260	CORE - CLINICAL TRIALS	**CANCER CLINICAL TRIAL TREATMENT TYPE**	an1	R

PATIENT TRIAL STATUS (CANCER): 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 clinical trial process.

01	PATIENT approached, consented to and entered clinical trial
02	PATIENT approached, but declined clinical trial
03	PATIENT approached and consented, but failed screening
09	Not Known (Not Recorded)

TRIAL DECISION DATE (PATIENT): Record the Patient's decision date for each Clinical Trial, provided it is related to the recorded diagnosis. This is a mandatory date for 01 and 02 above only and links each Clinical Trial (if more than one entered). If there are more than one entered on the same day, record the FIRST Clinical Trial only.

DATE CLINICAL TRIAL STARTED: Record the start date for each Clinical Trial entered, provided it is related to the recorded diagnosis. This will allow for multiple trials to be recorded if applicable. Each trial has to be part of the primary diagnosis treatment pathway.

CANCER CLINICAL TRIAL TREATMENT TYPE: The type of treatment covered by a cancer CLINICAL TRIAL. This is used to record the type(s) of treatment that are the subject of the cancer CLINICAL TRIAL into which the patient has been entered and does not necessarily mean the treatment that the patient will actually receive (which will be recorded only as part of the clinical trial documentation).

01	Surgery
02	Chemotherapy
03	Hormone therapy
04	Immunotherapy
05	Radiotherapy
06	Combination treatment
07	Observational study
98	Other

Notes: where a trial covers more than one type of treatment, such as chemotherapy compared with radiotherapy, then the option for “combined treatment” should be selected. In addition, where the trial covers a treatment type not specified here, for example biological therapies, ‘Other’ should be selected from the attribute list

CORE – STAGING

The ‘TNM Coding Edition’ and ‘Version Numbers’ are now mandatory from v9, 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 addition of a TNM coding edition field allows for accurate allocation.

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

Pre-treatment

A clinical TNM (cTNM) stage based on evidence acquired before treatment.

It is derived by the clinical team, based on a combination of physical examination, imaging, endoscopy, biopsy, surgical exploration and any other relevant examination.

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’ dataset 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 information collected such as metastasis (cM) or final review of the case.

For most cancers TNM staging is used but see 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 (i.e. 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR0520	CORE - STAGING	**T CATEGORY (FINAL PRETREATMENT)**	max an15	R
CR0540	CORE - STAGING	**N CATEGORY (FINAL PRETREATMENT)**	max an15	R

CR0560	CORE - STAGING	**M CATEGORY (FINAL PRETREATMENT)**	max an15	R
CR0580	CORE - STAGING	**TNM STAGE GROUPING (FINAL PRETREATMENT)**	max an15	R
CR6800	CORE - STAGING	**ORGANISATION SITE IDENTIFIER (REPORTED PRETREATMENT TNM STAGE)** *[ORGANISATION SITE IDENTIFIER (OF TNM STAGE GROUPING FINAL PRETREATMENT)]*	min an5 max an9	R
CR3120	CORE - STAGING	**STAGE DATE (FINAL PRETREATMENT STAGE)** *[TNM STAGE GROUPING DATE (FINAL PRETREATMENT)]*	an10 ccyy-mm-dd	R
CR0620	CORE - STAGING	**T CATEGORY (INTEGRATED STAGE)**	max an15	R
CR0630	CORE - STAGING	**N CATEGORY (INTEGRATED STAGE)**	max an15	R
CR0640	CORE - STAGING	**M CATEGORY (INTEGRATED STAGE)**	max an15	R
CR0610	CORE - STAGING	**TNM STAGE GROUPING (INTEGRATED)**	max an15	R
CR6810	CORE - STAGING	**ORGANISATION SITE IDENTIFIER (REPORTED INTEGRATED TNM STAGE)** *[ORGANISATION SITE IDENTIFIER (OF TNM STAGE GROUPING INTEGRATED)]*	min an5 max an9	R
CR3130	CORE - STAGING	**STAGE DATE (INTEGRATED STAGE)** *[TNM STAGE GROUPING DATE (INTEGRATED)]*	an10 ccyy-mm-dd	R
CR6980	CORE - STAGING	**TNM CODING EDITION**	an1	M
CR2070	CORE - STAGING	**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 PreTreatment 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, from v9 this is now a mandatory data item.

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

Note: for v9 the addition of European Neuroendocrine Tumour Society (ENETS) has been added to this list of TNM coding editions reportable through COSD, to improve data quality.

TNM VERSION NUMBER (STAGING): The AJCC or UICC or ENETS version number used for Tumour, Node and Metastasis (TNM) staging for cancer diagnosis. From v9 this is now a mandatory data item.

Note: 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 number.

It is possible that some legacy data may not have all the required mandatory fields for v9. 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

This is a new group for v9, and will mandate all reported site specific stages to have:

- the date the sample was taken or the MDT (for clinical stage), which provided a positive site specific stage outcome
- the organisation who carried out the stage
- the stage itself

This will improve data quality and will only be required to be collected where there is a site specific stage reported. This will not be applicable to every patient or every tumour and must be linked with the site specific stage fields within the separate site specific data sets.

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR8300	CORE - SITE SPECIFIC STAGING	**ORGANISATION SITE IDENTIFIER (SITE SPECIFIC STAGE)** *[ORGANISATION SITE IDENTIFIER (OF CANCER SITE SPECIFIC STAGE)]*	min an5 max an9	M
CR8310	CORE - SITE SPECIFIC STAGING	**STAGE DATE (SITE SPECIFIC STAGE)** *[STAGE DATE (CANCER SITE SPECIFIC STAGE)]*	an10 ccyy-mm-dd	M

ORGANISATION SITE IDENTIFIER (SITE SPECIFIC STAGE): This is a new data item for v9 and is the ORGANISATION IDENTIFIER of the ORGANISATION SITE who carried out the site specific stage.

STAGE DATE (SITE SPECIFIC STAGE): This is a new data item for v9 and provides the date of the sample/MDT which provided a positive stage outcome. For clinical decisions, the MDT would be where the clinical stage would be agreed based on all the available evidence (if a pathological sample was not possible).

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 for v9. 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR6540	CORE - TREATMENT	**ADJUNCTIVE THERAPY** *[ADJUNCTIVE THERAPY TYPE]*	an1	R
CR0680	CORE - TREATMENT	**CANCER TREATMENT INTENT**	an2	R
CR1370	CORE - TREATMENT	**TREATMENT START DATE (CANCER)**	an10 ccyy-mm-dd	M
CR2040	CORE - TREATMENT	**CANCER TREATMENT MODALITY (REGISTRATION)**	an2	M
CR1450	CORE - TREATMENT	**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)				
CR8400	CORE - TREATMENT	**PROFESSIONAL REGISTRATION ISSUER CODE - CONSULTANT (TREATMENT)** *[PROFESSIONAL REGISTRATION ISSUER CODE (TREATMENT)]*	an2	M
CR8410	CORE - TREATMENT	**PROFESSIONAL REGISTRATION ENTRY IDENTIFIER - CONSULTANT (TREATMENT)** *[PROFESSIONAL REGISTRATION ISSUER CODE (TREATMENT)]*	min an1 max an32	M
End of repeating section - Consultant (Treatment)				
Start of repeating section - Date of Treatment Summary				
CR8420	CORE - TREATMENT	**END OF TREATMENT SUMMARY DATE** *[CANCER END OF TREATMENT SUMMARY PLAN COMPLETION DATE]*	an10 ccyy-mm-dd	O
End of repeating section - Date of Treatment Summary				
CR0740	CORE - TREATMENT	**DISCHARGE DATE (HOSPITAL PROVIDER SPELL)**	an10 ccyy-mm-dd	R
CR0750	CORE - TREATMENT	**DISCHARGE DESTINATION (HOSPITAL PROVIDER SPELL)** *[DISCHARGE DESTINATION CODE (HOSPITAL PROVIDER SPELL)]*	an2	R

Note: The following data item has been retired from v9.0:

- CONSULTANT CODE (TREATMENT)
- CANCER TREATMENT EVENT TYPE

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.

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. The addition of 'Uncertain of Treatment Intent' has been added from v9.

01	Curative
02	Palliative
03	Disease Modification *
04	Diagnostic * *
05	Staging * *
06	Uncertain of Treatment Intent
~~08~~	~~Other~~
09	Not Known
98	Other

* ***Disease Modification is Drug Specific***

** ***Diagnostic and Staging are Surgery Specific***

Note: The next 3 data items are now a mandatory and will improve the data quality and ascertainment of treatment records submitted.

TREATMENT START DATE (CANCER) (CWT): This is now a mandatory data item from v9. 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 but see Cancer Waiting Times for definition.

CANCER TREATMENT MODALITY (REGISTRATION): This is now a mandatory data item from v9. Applicable to all registered cases see Appendix A + B for definitions and values. 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.

01	Surgery
02	Anti-cancer drug regimen (Cytotoxic Chemotherapy)
03	Anti-cancer drug regimen (Hormone Therapy)
04	Chemoradiotherapy
05	Teletherapy (Beam Radiation 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)
20	Laser Treatment (including Argon Beam therapy)
21	Biological Therapies (excluding Immunotherapy)
22	Radiosurgery
97	Other Treatment
98	All treatment declined

ORGANISATION SITE IDENTIFIER (OF PROVIDER CANCER TREATMENT START DATE) (CWT): This is now a mandatory data item from v9.

Note: The next 2 data items are now 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 a new data item in v9 replacing 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.

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 (TREATMENT): This is a new data item in v9 replacing the 'Consultant Core (Treatment)' and 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: This is a new data item in v9. Record the date the treatment summary was completed at the end of each phase of acute (secondary care) treatment(s) and sent to the patient and/or the GP. This is an optional, multiple repeating data item.

Supporting information, include those 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 requested it is not sent to their GP

Additional notes to help with data recording:

- an End of Treatment Summary is recommended but not required at the end of every acute phase of treatment
- there should be at least one End of Treatment Summary relating to primary treatment
- the End of Treatment Summary is 'complete' when it has been shared with the person and/or their GP
- 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)
- guidance from Macmillan is available on the 'Recovery Package' webpage: https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package
- additional information is available at: 'Treatment Summary How To Guide (Macmillan Cancer Support 2016)'

The content of a 'End of Treatment Summary' will normally follow a locally agreed template, incorporating key items that include:

- a summary of diagnosis and treatment
- 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 information and advice that the person has been given or signposted to, including details of local support groups and psychosocial support, such as complementary therapies, physical activity, returning to work advice

Note: The next 2 data items have been moved into the treatment section from v9.

DISCHARGE DATE (HOSPITAL PROVIDER SPELL): the date a PATIENT was discharged from a Hospital Provider Spell.

DISCHARGE DESTINATION (HOSPITAL PROVIDER SPELL): This records the destination of a PATIENT on completion of the Hospital Provider Spell. It can also indicate that the PATIENT died.

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 Provider)
37	Court
38	Penal establishment or police station
48	High Security Psychiatric Hospital, Scotland
49	NHS other hospital provider - high security psychiatric accommodation
50	NHS other hospital provider - medium secure unit
51	NHS other hospital provider - ward for general PATIENTS or the younger physically disabled
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
54	NHS run Care Home
65	Local Authority residential accommodation i.e. where care is provided
66	Local Authority foster care
79	Not applicable - PATIENT died or still birth
84	Non-NHS run hospital - medium secure unit
85	Non-NHS (other than Local Authority) run Care Home
87	Non-NHS run hospital
88	Non-NHS (other than Local Authority) run Hospice
Default Codes	
98	Not applicable - hospital provider spell not finished at episode end (i.e. not discharged, or current episode unfinished)
99	Not known

CORE – TREATMENT – SURGERY

This section is a child of 'Core – Treatment and has changed to carry only the surgery details. This is a change in v9 from Surgery and Other Procedures.

It is possible that some legacy data may not have all the required mandatory fields for v9. 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR0710	CORE - TREATMENT - SURGERY	**PROCEDURE DATE**	an10 ccyy-mm-dd	M
CR8500	CORE - TREATMENT - SURGERY	**SURGICAL ADMISSION TYPE** *[CANCER SURGICAL ADMISSION TYPE]*	an1	R
Start of repeating item - CONSULTANT CODE (SURGEON)				
CR8510	CORE - TREATMENT - SURGERY	**PROFESSIONAL REGISTRATION ISSUER CODE - CONSULTANT (SURGEON)** *[PROFESSIONAL REGISTRATION ISSUER CODE (RESPONSIBLE SURGEON)]*	an2	M

CR8520	CORE - TREATMENT - SURGERY	**PROFESSIONAL REGISTRATION ENTRY IDENTIFIER - CONSULTANT (SURGEON)** *[PROFESSIONAL REGISTRATION ENTRY IDENTIFIER (RESPONSIBLE SURGEON)]*	min an1 max an32	M
End of repeating item - CONSULTANT CODE (SURGEON)				
CR0720	CORE - TREATMENT - SURGERY	**PRIMARY PROCEDURE (OPCS)**	an4	R
CR3040	CORE - TREATMENT - SURGERY	**PRIMARY PROCEDURE (SNOMED CT)**	min n6 max n18	R
Start of repeating item - Procedure (OPCS)				
CR0730	CORE - TREATMENT - SURGERY	**PROCEDURE (OPCS)**	an4	R*
End of repeating item - Procedure (OPCS)				
Start of repeating item - Procedure (SNOMED CT)				
CR3050	CORE - TREATMENT - SURGERY	**PROCEDURE (SNOMED CT)**	min n6 max n18	R*
End of repeating item - Procedure (SNOMED CT)				
CR6480	CORE - TREATMENT - SURGERY	**UNPLANNED RETURN TO THEATRE INDICATOR** *[ADDITIONAL UNPLANNED PROCEDURE REQUIRED INDICATOR]*	an1	R
CR6010	CORE - TREATMENT - SURGERY	**ASA SCORE** *[ASA PHYSICAL STATUS CLASSIFICATION SYSTEM CODE]*	an1	R
CR6310	CORE - TREATMENT - SURGERY	**SURGICAL ACCESS TYPE**	an1	R

Note: The following data items have been retired from v9.0:

- CONSULTANT CODE (SURGEON)

PROCEDURE DATE: This is now a mandatory data item for v9 and records the date the surgical procedure was carried out.

SURGICAL ADMISSION TYPE: This is a new data item for v9.0 and records the type of surgical admission.

1	Elective
2	Emergency
9	Not Known

Note: the next 2 data items are now a multiple selection group and are mandatory within the group. There may be one occurrence per CORE – Surgery Section.

PROFESSIONAL REGISTRATION ISSUER CODE – CONSULTANT (SURGEON): This is a new data item in v9 replacing the 'Consultant Code (Surgeon)' and is a code which identifies the PROFESSIONAL REGISTRATION BODY for the Consultant or health care professional who is responsible for the treatment of the patient. If he/she is part of a surgical team, add all consultant surgeons responsible for the procedure.

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 a new data item in v9 replacing the 'Consultant Code (Surgeon)' and is the registration identifier allocated by an Organisation for the Consultant or health care professional who is responsible for the treatment of the patient. If he/she is part of a surgical team, add all consultant surgeons responsible for the procedure.

PRIMARY PROCEDURE (OPCS): Primary procedure is the main procedure carried out.

PRIMARY PROCEDURE (SNOMED CT): Primary procedure is the main procedure carried out using SNOMED CT. This may be recorded in addition to PRIMARY PROCEDURE (OPCS).

Note: This field has been upgraded to Required, therefore any Trust who can submit data in SNOMED CT, must now do so.

PROCEDURE (OPCS): This is a procedure(s) other than the PRIMARY PROCEDURE (OPCS), carried out and recorded for CDS or Hospital Episode Statistics purposes. (This may occur more than once).

PROCEDURE (SNOMED CT): This is a procedure(s) other than the PRIMARY PROCEDURE, carried out and recorded for CDS or Hospital Episode Statistics purposes (this may occur more than once). This may be recorded in addition to PROCEDURE (OPCS).

Note: This field has been upgraded to Required, therefore any Trust who can submit data in SNOMED CT, must now do so.

UNPLANNED RETURN TO THEATRE INDICATOR: Whether or not the patient required a second (unplanned) operation during the same admission as the primary procedure

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.

1	A normal healthy patient.
2	A patient with mild systemic disease
3	A patient with severe systemic disease that limits function, but is not incapacitating
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.

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

Note: This field has been created so that it can be used for any tumour site to record the surgical access type used by the surgeon. For Head and Neck, an additional field is available which is specific to only this type of surgery.

CORE – TREATMENT – STEM CELL TRANSPLANTATION

This section is a child of 'Core - Treatment and is to carry Stem Cell Transplantation details. Although the data items within this group are required for CTYA cases, it was felt that they would also be valid for some adult cases (where applicable), and hopefully improve ascertainment.

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR8600	CORE - TREATMENT - STEM CELL TRANSPLANTATION	**STEM CELL INFUSION SOURCE** *[STEM CELL INFUSION SOURCE CODE]*	an1	R
CR8610	CORE - TREATMENT - STEM CELL TRANSPLANTATION	**STEM CELL INFUSION DONOR** *[STEM CELL INFUSION DONOR TYPE]*	an1	R
CR8620	CORE - TREATMENT - STEM CELL TRANSPLANTATION	**CONDITIONING REGIMEN** *[STEM CELL TRANSPLANT CONDITIONING REGIMEN]*	an1	R

Note: STEM CELL INFUSION DATE: is recorded as a surgical procedure in Core Treatment Modality [CR2040] 01 - Surgery, then the date would be provided from the CORE section too using [CR0710] Procedure Date. This reduces duplication and improves the quality of the data submitted.

STEM CELL INFUSION SOURCE: Source of stem cells for infusion.

B	Bone Marrow
P	Peripheral Blood
C	Cord
9	Not known

STEM CELL INFUSION DONOR: Donor for stem cell infusion.

1	Autologous
2	Allogeneic - Sibling
3	Allogeneic - Haplo
4	Allogeneic - Unrelated
9	Not Known

CONDITIONING REGIMEN: Record the MDS Stem Cell Transplant Conditioning Regimen.

1	Myeloablative
2	Reduced Intensity
3	Minimal Intensity

CORE – ACUTE ONCOLOGY

This is a new section for COSD v9 and 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.

The data in the following AO section will be focussed on Patients with an emergency attendance or admitted patients (where the patient was in a bed for one or more nights).

Patients to include are those who were:

- assessed and then admitted
- assessed and sent to their usual place of residence
- assessed as an Admitted Patient after an emergency attendance and kept in
- assessed as an Admitted Patient after an emergency attendance and discharged to their usual place of residence

The assessment will have been ‘face to face’ with the patient (rather than by phone) and carried out by Nursing or Medical staff who are contracted members of the local AOS or trained by the AOS to provide appropriate levels of care and decision making on behalf of the AOS.

If more than one assessment takes place during a patient's AO episode, each assessment should be reported as an individual record, even if the assessments share the same date; it is important all data is completed for each assessment to provide the complete picture for each patient.

These data are generally collected by the AOS as part of their day to day activity and are used in the compilation of their Quality Surveillance (peer review) returns for Acute Oncology, Neutropenic Sepsis, CUP and MSCC activity and targets. If not all items are directly collected by your AOS, they can be derived using existing data collected for COSD, HES and by your Emergency Department.

For AO care provided by Nursing or Medical staff trained by the AOS but not actually contracted to the AOS, their activity should also be included in the COSD Acute Oncology submission to ensure all AO type activity is accounted for.

These data have been chosen for collection within COSD, rather than the Systemic Anti-Cancer Therapy (SACT) dataset, due to the points in the pathway not always being directly linked to a systemic anti-therapy treatment.

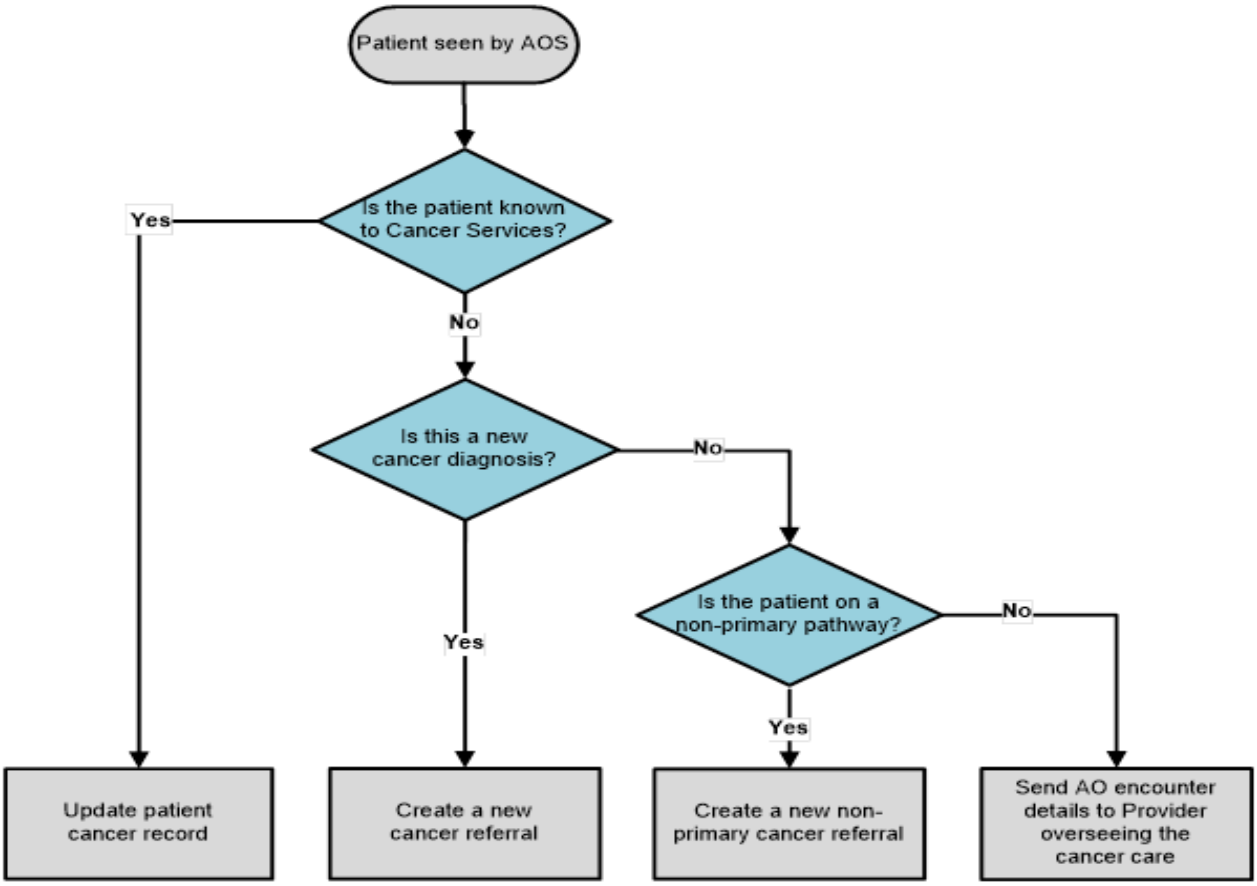
May be multiple occurrences per record (0..*)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR8700	CORE - ACUTE ONCOLOGY	**ACUTE ONCOLOGY ASSESSMENT DATE** *[ACUTE ONCOLOGY ASSESSMENT COMPLETED DATE]*	an10 ccyy-mm-dd	R
CR8710	CORE - ACUTE ONCOLOGY	**ORGANISATION SITE IDENTIFIER (ACUTE ONCOLOGY)** *[ORGANISATION SITE IDENTIFIER (OF ACUTE ONCOLOGY ASSESSMENT)]*	an5	R
CR8720	CORE - ACUTE ONCOLOGY	**ASSESSMENT LOCATION** *[ACUTE ONCOLOGY ASSESSMENT LOCATION]*	an2	R
Start of repeating item - Patient Type				
CR8730	CORE - ACUTE ONCOLOGY	**PATIENT TYPE** *[ACUTE ONCOLOGY ASSESSMENT PATIENT PRESENTATION TYPE]*	an2	R
End of repeating item - Patient Type				
CR8740	CORE - ACUTE ONCOLOGY	**OUTCOME** *[ACUTE ONCOLOGY EPISODE OUTCOME]*	an1	R

AOS Patient and Data Flow

The following flow chart helps identify whether your Trust will be responsible for submitting these data items as part of their COSD submission. The flow assumes your Trust will provide the patient's cancer care - if the patient is referred to another Provider for management, that Trust will be responsible for creating records and a COSD submission.

The final 2 steps in flow chart below help you understand if a patient should be on a non-primary patient pathway (at your Trust) or if the data should be sent to another provider, as the patients cancer care is currently managed by that Trust.



Below is guidance on how to interpret the AO Data Items.

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
- AO assessments carried out by AOS and other medical staff trained to provide AO care (but not actually members of the AOS)

ORGANISATION SITE IDENTIFIER (ACUTE ONCOLOGY): 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 hospital-specific code of where the assessment took place should be recorded rather than the Trust level code

ASSESSMENT LOCATION: The location where the Acute Oncology (AO) assessment was performed within the health care provider.

01	Emergency Care Department
02	Medical Assessment Unit
03	Emergency Ambulatory Care Unit
04	Ward
05	Out-Patient Clinic
06	Dedicated Acute Oncology Bed/Chair
07	Day Case Unit
08	Chemotherapy Unit
98	Other

Additional supporting information includes:

- **Emergency Care Department**. This would be chosen if the patient was in an emergency care department chair or bed, admitted or not, when the AOS assessment was carried out.
- **Medical Assessment Unit**. This would be chosen if the patient was in a Medical Assessment Unit chair or bed, admitted or not, when the AOS assessment was carried out.
- **Emergency Ambulatory Care Unit**. This option would be chosen if the patient was assessed in an Emergency Ambulatory Care Unit when the AOS assessment was carried out. A new term for this activity is Same Day Emergency Care, which represents the activity which would take place in an Emergency Ambulatory Care Unit.
- **Ward**. This would be chosen if it was the most appropriate selection given the other options available for where the AOS assessment was carried out.
- **Out-Patient Clinic**. This would be chosen if it was the most appropriate selection given the other options available for where the AOS assessment was carried out.
- **Dedicated Acute Oncology Bed/Chair**. This would be chosen if the patient was assessed whilst in a dedicated AO bed or chair - admitted or not, when the AOS assessment was carried out.
- **Day Case Unit**. This would be chosen if it was the most appropriate selection given the other options available for where the AOS assessment was carried out.
- **Chemotherapy Unit**. This would be chosen 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.
- **Other**. This option would be chosen if none of the other options were appropriate.

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

PATIENT TYPE: Record the type each patient presentation is grouped within.

01	New Presentation
02	Treatment Complication
03	Suspected or Confirmed Neutropenic Sepsis
04	Cancer Complication
05	Cancer Recurrence/Progression (Local or Regional)
06	Cancer Recurrence/Progression (Distant)
07	Cancer Transformation
08	Suspected or Confirmed Metastatic Spinal Cord Compression (MSCC)
09	Comorbidity Complications
98	Other

Note: Multiple selects can be made if more than one option fits.

The purpose of this data item is to capture the volume of patients being seen by AOS, divided into these Patient groups:

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 items values that the Type I, II and III patient groups.

AO Patient Type and Patient Group Mapping:

Patient Group	AO Patient Type
Type I	New Presentation
Type II	Treatment Complication Suspected or Confirmed Neutropenic Sepsis
Type IIIa	Cancer Complication Suspected or Confirmed MSCC Cancer Recurrence/Progression (Local/Regional) Cancer Recurrence/Progression (Distant) Cancer Transformation
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

- **New Presentation**. 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).

- **Treatment Complication**. This option is relevant for patients who have received or are receiving Cancer treatment and have become poorly as a consequence. 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.

- **Suspected or Confirmed Neutropenic Sepsis**. 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.

- **Cancer Complication**. 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.

Introduction to options 5, 6 and 7 below: recurrences, progressions and transformations

Cancer Complication includes patients who are on a non-Primary Pathway as per the description included in this COSD v9 User Guidance. To enable more comprehensive levels of analysis on the types of patients seen by AOS, see below for details on how to ensure the patient records are created to enable the reporting of the AO data in COSD. If the patient is on:

- a Recurrence Pathway as per the Guidance, and your Cancer Services will be overseeing the care of the patient, a new cancer referral will need to be created to enable the reporting of the AO and other relevant COSD data items
- a Progression Pathway as per the Guidance and your Cancer Services will be overseeing the care of the patient, a new record will need to be created to tie in the AO and other relevant COSD data items
- a Transformation Pathway as per the Guidance and your Cancer Services will be overseeing the care of the patient, a new record will need to be created to tie in the AO and other relevant COSD data items

- any of the above non-Primary Pathways and the patient is being referred on to another Cancer Care Provider for all of their care, the AO episode details should be forwarded onto this Provider for inclusion in their submission to COSD

- **Cancer Recurrence/Progression (Local/Regional)**. This option is relevant for patients who have become poorly because their current or historic cancer has progressed either locally or regionally, for example the cancer has returned in the same location as the original diagnosis or has spread to regional lymph nodes.

- **Cancer Recurrence/Progression (Distant)**. This option is relevant for patients who have become poorly because their current or historic cancer has spread to a distant part of their body, for example the cancer has spread to distant lymph nodes or to the liver.

- **Cancer Transformation**. This option is relevant for patients who have had, for example a known haematological cancer that has transformed into another disease type.

- **Suspected or Confirmed MSCC**. 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 Progression/Recurrence but it has been separated out so national analysis can be carried out on the number of MSCC patients.
- **Comorbidity Complications**. 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 in order to assess the volume of AOS activity.

- **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.

1	Not Admitted
2	Admitted
3	Remained Admitted
4	Discharge
5	Patient Died
8	Other

This information will generally be captured in the local PAS or Emergency Department system (if separate) or maybe in a dedicated AOS system. These data will help with admission avoidance and length of stay calculations and focuses 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

1. **Not Admitted.** This option would be selected if the patient was not admitted to hospital and was sent to their usual place of residence after being assessed by the AOS - this activity would usually be counted as 'Admission Avoidance'.

2. **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.

3. **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.

4. **Discharged**. 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. This activity would generally be used in the Length of Stay calculations.

5. **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.

8. **Other**. This option covers outcomes not listed in the above.

CORE – RADIOTHERAPY

Note: the following data item has been retired from v9.0:

- BRACHYTHERAPY TYPE

Note: this will be added to the Radiotherapy Data Set (RTDS), during its next review (planned 2021/22):

CORE – ACTIVE MONITORING

Note: the following data item has been retired from v9.0:

- MONITORING INTENT

Note: this can be collected by using [CR0680 - Treatment Intent (attributes 01; 02; 09)] and [CR2040 - Treatment Modality (attribute 08)]. The assumption can be inferred for this treatment option that all intents are based on future planned treatment.

CORE – LABORATORY RESULTS

This is a new group for COSD v9, 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR8800	CORE - LABORATORY RESULTS	**LABORATORY RESULT DATE** *[LABORATORY RESULT AUTHORISED DATE]*	an10 ccyy-mm-dd	M
CR8810	CORE - LABORATORY RESULTS	**ORGANISATION IDENTIFIER (LABORATORY RESULT)** *[ORGANISATION IDENTIFIER (OF 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 for v9. 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 – LABORATORY RESULTS – GENERAL

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

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

In addition, these items have moved into a ‘Laboratory General’ group, as it was felt they could be used for more than CTYA cases and hopefully improve ascertainment.

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR8900	CORE - LABORATORY RESULTS - GENERAL	**LDH VALUE** *[LACTATE DEHYDROGENASE LEVEL (PEAK AT DIAGNOSIS)]*	max n6	R
CR8910	CORE - LABORATORY RESULTS - GENERAL	**BETA HUMAN CHORIONIC GONADOTROPIN (SERUM)** *[BETA HUMAN CHORIONIC GONADOTROPIN (MAXIMUM AT DIAGNOSIS)]*	max n8	R
CR8920	CORE - LABORATORY RESULTS - GENERAL	**ALPHA FETOPROTEIN (SERUM)** *[ALPHA FETOPROTEIN (MAXIMUM AT DIAGNOSIS)]*	max n8	R

Note: the following data item has been moved into a new laboratory group in the Urological section from v9.0:

- NORMAL LDH

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 CERCINOMA

Note: both these 2 data items have had their format and range changes to max n8 (range 0.99999999), after careful clinical advice.

BREAST

Key:
() = if applicable
* = different data set from CWT group specified

ICD-10 All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C50.0	Nipple and areola	Breast	•			
C50.1	Central portion of breast	Breast	•			
C50.2	Upper-inner quadrant of breast	Breast	•			
C50.3	Lower-inner quadrant of breast	Breast	•			
C50.4	Upper-outer quadrant of breast	Breast	•			
C50.5	Lower-outer quadrant of breast	Breast	•			
C50.6	Axillary tail of breast	Breast	•			
C50.8	Overlapping lesion of breast	Breast	•			
C50.9	Breast, unspecified	Breast	•			
D05.0	Lobular carcinoma in situ	Breast	•			
D05.1	Intraductal carcinoma in situ	Breast	•			
D05.7	Other carcinoma in situ of breast	Breast	•			
D05.9	Carcinoma in situ of breast, unspecified	Breast	•			
D48.6	Neoplasm of uncertain or unknown behaviour of Breast	Breast			•	

BREAST – TRIPLE DIAGNOSTIC ASSESSMENT

This is a new group for COSD v9 and been consulted with and recommended by the Breast Expert Advisory Group and the National Audit of Breast Cancer in Older Patients.

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
BR4400	BREAST - TRIPLE DIAGNOSTIC ASSESSMENT	**TRIPLE DIAGNOSTIC ASSESSMENT** *[BREAST TRIPLE DIAGNOSTIC ASSESSMENT INDICATOR]*	an1	R

TRIPLE DIAGNOSTIC ASSESSMENT: This is a new data item for v9. If a triple diagnostic assessment was completed, indicate if this was completed for the patient in a single visit, following initial referral?

1	Yes
2	No
9	Not Known

BREAST – PROGNOSTIC INDEX

This data will be recorded once, in Prognostic Index. This replaces the Cancer Care Plan, and although this data may be collected from these meetings, that may not be the case for every patient.

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
BR4120	BREAST - PROGNOSTIC INDEX	**NPI SCORE** *[NOTTINGHAM PROGNOSTIC INDEX SCORE]*	max n2.max n2	R

NPI SCORE: NPI Score should be collected for invasive breast cancers. Nottingham Prognostic Index Score (calculated from invasive tumour size, grade and lymph node involvement).

Where:

- **S** is the maximum diameter of the index lesion in centimetres (invasive carcinoma)
- **N** is the number of axillary lymph nodes involved: 0 nodes = 1, 1-3 nodes = 2, >4 = 3
- **G** is the grade of tumour: Grade 1 = 1, Grade 2 = 2, Grade 3 = 3

The index is calculated using the formula:

$$NPI = [0.2 \times S] + N + G$$

Note: It is important to record all relevant information to ensure that NPI following neoadjuvant therapy can be identified.

BREAST – CLINICAL NURSE SPECIALIST – RISK FACTOR ASSESSMENT – NABCOP

This is a new group for COSD v9 and been consulted with and recommended by the Breast Expert Advisory Group and the National Audit of Breast Cancer in Older Patients and is based on a pilot conducted in 2018.

This group is intended to carry new National Audit of Breast Cancer in Older Patients assessment details for Breast Cancer and is only required for patients aged 70 years and over at diagnosis.

May be up to one occurrence per Clinical Nurse Specialist - Risk Factor Assessment (0..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
BR4500	BREAST - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT - NABCOP	**FITNESS ASSESSMENT INDICATOR** *[FITNESS ASSESSMENT FOR OLDER PATIENTS WITH BREAST CANCER INDICATOR]*	an1	R
BR4510	BREAST - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT - NABCOP	**FITNESS ASSESSMENT DATE** *[FITNESS ASSESSMENT FOR OLDER PATIENTS WITH BREAST CANCER COMPLETED DATE]*	an10 ccyy-mm-dd	R
BR4520	BREAST - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT - NABCOP	**CLINICAL FRAILTY SCALE** *[CLINICAL FRAILTY SCALE POINT]*	an1	R
BR4530	BREAST - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT - NABCOP	**ABBREVIATED MENTAL TEST SCORE** *[ABBREVIATED MENTAL TEST SCORE]*	Max n2	R
BR4540	BREAST - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT - NABCOP	**CARDIORESPIRATORY DISEASE** *[SEVERE CARDIORESPIRATORY DISEASE INDICATOR]*	an1	R
BR4550	BREAST - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT - NABCOP	**OTHER NON BREAST LOCALLY ADVANCED/METASTATIC MALIGNANCY** *[OTHER NON BREAST LOCALLY ADVANCED METASTATIC MALIGNANCY INDICATOR]*	an1	R

FITNESS ASSESSMENT INDICATOR: This is a new data item for v9. Indicate if there was a Fitness Assessment carried out on the patient. If yes please complete the following 5 data items.

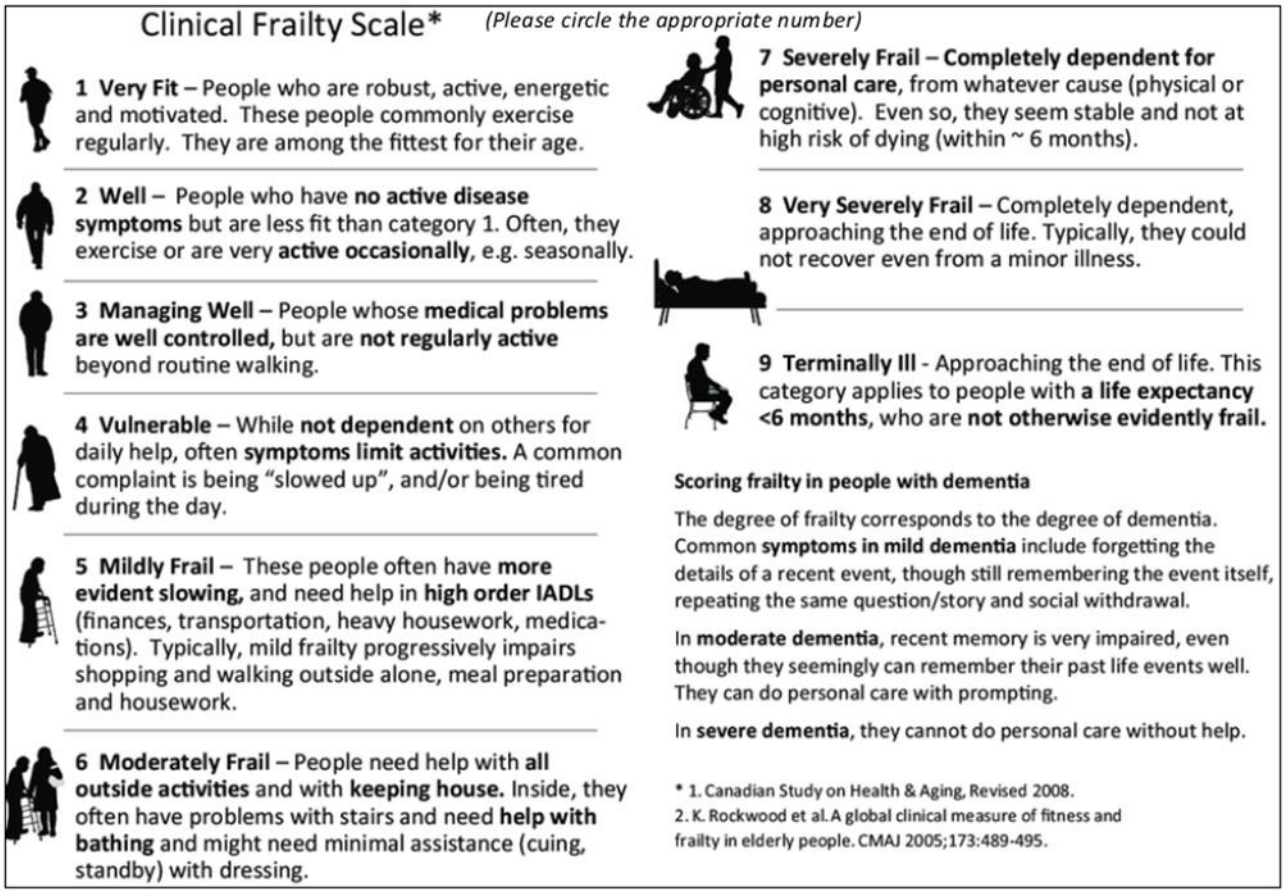
Y	Yes
N	No

FITNESS ASSESSMENT DATE: This is a new data item for v9. Record the date the fitness assessment was completed.

CLINICAL FRAILTY SCALE: This is a new data item for v9. Record the point on the Clinical Frailty Scale, as assigned by the appropriate clinician after discussion with the patient.

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

The chart below explains each frailty measure, using the Clinical Frailty Scale.



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.

ABBREVIATED MENTAL TEST SCORE: This is a new data item for v9. Record the total Abbreviated Mental Test Score, this should be a score from 0 to 10.

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*

CARDIORESPIRATORY DISEASE: This is a new data item for v9. Does the patient have severe cardiorespiratory disease?

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: This is a new data item for v9. Does the patient have any other Non-Breast Locally Advanced/Metastatic Malignancy?

Y	Yes
N	No

Moved (Breast) Data Items

BREAST – DIAGNOSIS (MENOPAUSAL STATUS)

This group has been retired from COSD in v9 and ‘Menopausal Status’ has been moved to Core - Clinical Nurse Specialist - Risk Factor Assessment’.

Retired (Breast) Data Items

BREAST – REFERRALS

This group has been retired from COSD in v9, including the following data items:

- Date of Clinical Assessment
- Organisation Site Identifier (of Clinical Assessment)
- Clinical Assessment Result (Breast)

CENTRAL NERVOUS SYSTEM (CNS)

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: for Central Nervous System, full details are required for benign and uncertain tumours as well as malignant diseases.

Key:
() = if applicable
* = different data set from CWT group specified

ICD-10 All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C47.0	*Peripheral nerves of head, face and neck*	*Brain/Central Nervous System*		•		*Usually treated by Sarcoma MDT.*
C47.1	*Peripheral nerves of upper limb, including shoulder*	*Brain/Central Nervous System*		•		*Usually treated by Sarcoma MDT.*
C47.2	*Peripheral nerves of lower limb, including hip*	*Brain/Central Nervous System*		•		*Usually treated by Sarcoma MDT.*
C47.3	*Peripheral nerves of thorax*	*Brain/Central Nervous System*		•		*Usually treated by Sarcoma MDT.*
C47.4	*Peripheral nerves of abdomen*	*Brain/Central Nervous System*		•		*Usually treated by Sarcoma MDT.*
C47.5	*Peripheral nerves of pelvis*	*Brain/Central Nervous System*		•		*Usually treated by Sarcoma MDT.*
C47.6	*Peripheral nerves of trunk, unspecified*	*Brain/Central Nervous System*		•		*Usually treated by Sarcoma MDT.*

C47.8	*Overlapping lesion of peripheral nerves and autonomic nervous system*	*Brain/Central Nervous System*		•		*Usually treated by Sarcoma MDT.*
C47.9	*Peripheral nerves and autonomic nervous system, unspecified*	*Brain/Central Nervous System*		•		*Usually treated by Sarcoma MDT.*
C69.0	*Conjunctiva*	*Brain/Central Nervous System*		•		*Not normally treated by CNS MDT.*
C69.1	*Cornea*	*Brain/Central Nervous System*		•		*Not normally treated by CNS MDT.*
C69.2	*Retina*	*Brain/Central Nervous System*		•		*Not normally treated by CNS MDT.*
C69.3	*Choroid*	*Brain/Central Nervous System*		•		*Not normally treated by CNS MDT.*
C69.4	*Ciliary body*	*Brain/Central Nervous System*		•		*Not normally treated by CNS MDT.*
C69.5	*Lachrymal gland and duct*	*Brain/Central Nervous System*		•		*Not normally treated by CNS MDT.*
C69.6	*Orbit*	*Brain/Central Nervous System*		•		*Not normally treated by CNS MDT. Maybe treated by Sarcoma MDT.*
C69.8	*Overlapping lesion of eye and adnexa*	*Brain/Central Nervous System*		•		*Not normally treated by CNS MDT.*
C69.9	*Eye, unspecified*	*Brain/Central Nervous System*		•		*Not normally treated by CNS MDT.*
C70.0	Cerebral meninges	Brain/Central Nervous System	•			
C70.1	Spinal meninges	Brain/Central Nervous System	•			
C70.9	Meninges, unspecified	Brain/Central Nervous System	•			
C71.0	Cerebrum, except lobes and ventricles	Brain/Central Nervous System	•			
C71.1	Frontal lobe	Brain/Central Nervous System	•			
C71.2	Temporal lobe	Brain/Central Nervous System	•			
C71.3	Parietal lobe	Brain/Central Nervous System	•			
C71.4	Occipital lobe	Brain/Central Nervous System	•			
C71.5	Cerebral ventricle	Brain/Central Nervous System	•			
C71.6	Cerebellum	Brain/Central Nervous System	(•) (*)			CTYA data set collected for Medulloblastoma patients under 25.
C71.7	Brain stem	Brain/Central Nervous System	•			

C71.8	Overlapping lesion of brain	Brain/Central Nervous System	•			
C71.9	Brain, unspecified	Brain/Central Nervous System	•			
C72.0	Spinal cord	Brain/Central Nervous System	•			
C72.1	Cauda equina	Brain/Central Nervous System	•			
C72.2	Olfactory nerve	Brain/Central Nervous System	•			
C72.3	Optic nerve	Brain/Central Nervous System	•			
C72.4	Acoustic nerve	Brain/Central Nervous System	•			
C72.5	Other and unspecified cranial nerves	Brain/Central Nervous System	•			
C72.8	Overlapping lesion of brain and other parts of central nervous system	Brain/Central Nervous System	•			
C72.9	Central nervous system, unspecified	Brain/Central Nervous System	•			
C75.1	Pituitary gland	Other	*			Usually treated by CNS MDT.
C75.2	Craniopharyngeal duct	Other	*			Usually treated by CNS MDT.
C75.3	Pineal gland	Other	*			Usually treated by CNS MDT.
C79.3	Secondary malignant neoplasm of brain and cerebral meninges	Brain/Central Nervous System		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.4	Secondary malignant neoplasm of other and unspecified parts of nervous system	Brain/Central Nervous System		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
D32.0	Benign neoplasm of cerebral meninges	Brain/Central Nervous System	•			
D32.1	Benign neoplasm of spinal meninges	Brain/Central Nervous System	•			
D32.9	Benign neoplasm of meninges, unspecified	Brain/Central Nervous System	•			
D33.0	Benign neoplasm of brain, supratentorial	Brain/Central Nervous System	•			
D33.1	Benign neoplasm of brain, infratentorial	Brain/Central Nervous System	•			
D33.2	Benign neoplasm of brain, unspecified	Brain/Central Nervous System	•			
D33.3	Benign neoplasm of cranial nerves	Brain/Central Nervous System	•			

D33.4	Benign neoplasm of spinal cord	Brain/Central Nervous System	●			
D33.7	Benign neoplasm of other specified parts of central nervous system	Brain/Central Nervous System	●			
D33.9	Benign neoplasm of central nervous system, unspecified	Brain/Central Nervous System	●			
D35.2	Benign neoplasm of Pituitary gland	Brain/Central Nervous System	●			
D35.3	Benign neoplasm of Craniopharyngeal duct	Other	*			Usually treated by CNS MDT.
D35.4	Benign neoplasm of Pineal gland	Brain/Central Nervous System	●			
D42.0	Neoplasm of uncertain or unknown behaviour of cerebral meninges	Brain/Central Nervous System	●			
D42.1	Neoplasm of uncertain or unknown behaviour of spinal meninges	Brain/Central Nervous System	●			
D42.9	Neoplasm of uncertain or unknown behaviour of meninges, unspecified	Brain/Central Nervous System	●			
D43.0	Neoplasm of uncertain or unknown behaviour of brain, supratentorial	Brain/Central Nervous System	●			
D43.1	Neoplasm of uncertain or unknown behaviour of brain, infratentorial	Brain/Central Nervous System	●			
D43.2	Neoplasm of uncertain or unknown behaviour of brain, unspecified	Brain/Central Nervous System	●			
D43.3	Neoplasm of uncertain or unknown behaviour of cranial nerves	Brain/Central Nervous System	●			
D43.4	Neoplasm of uncertain or unknown behaviour of spinal cord	Brain/Central Nervous System	●			
D43.7	Neoplasm of uncertain or unknown behaviour of other parts of central nervous system	Brain/Central Nervous System	●			
D43.9	Neoplasm of uncertain or unknown behaviour of central nervous system, unspecified	Brain/Central Nervous System	●			
D44.3	Neoplasm of uncertain or unknown behaviour of pituitary gland	Brain/Central Nervous System	●			
D44.4	Neoplasm of uncertain or unknown behaviour of Craniopharyngeal duct	Brain/Central Nervous System	●			
D44 .5	Neoplasm of uncertain or unknown behaviour of pineal gland	Brain/Central Nervous System	●			

CNS (sub section)

CENTRAL NERVOUS SYSTEM – IMAGING

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
BA3000	CENTRAL NERVOUS SYSTEM - IMAGING	**LESION LOCATION (RADIOLOGICAL)**	an2	R
BA3020	CENTRAL NERVOUS SYSTEM - IMAGING	**NUMBER OF LESIONS (RADIOLOGICAL)**	max n2	R
BA3030	CENTRAL NERVOUS SYSTEM - IMAGING	**LESION SIZE (RADIOLOGICAL)**	max n3.max n2	R
BA3050	CENTRAL NERVOUS SYSTEM - IMAGING	**PRINCIPAL DIAGNOSTIC IMAGING TYPE**	an1	R

After consultation with clinical experts and after reviewing the completeness of these data items, it has been agreed at these data are not easily accessible or recorded in a way that can be collected by MDT/Pathway Coordinators.

The evidence is that the quality and completeness is not good enough to use, and therefore we recommend that Trusts no longer collect these specifically through the Brain CNS section.

Trusts can continue to collect imaging data through the use of the CORE Imaging data items

CENTRAL NERVOUS SYSTEM – CANCER CARE PLAN

May be up to one occurrence per Core - Cancer Care Plan (0..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
BA3080	CENTRAL NERVOUS SYSTEM - CANCER CARE PLAN	**MDT PROVISIONAL DIAGNOSIS (ICD)** *[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.

CENTRAL NERVOUS SYSTEM – TREATMENT – SURGERY

This section is a child of 'Core - Treatment. This is a change in v9 from Surgery and Other Procedures, 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
BA3100	CNS - TREATMENT - SURGERY	**TUMOUR LOCATION (SURGICAL)**	an2	R
BA3200	CNS - TREATMENT - SURGERY	**BIOPSY TYPE** *[BIOPSY TYPE (CENTRAL NERVOUS SYSTEM TUMOURS)]*	an1	R
BA3210	CNS - TREATMENT - SURGERY	**EXCISION OR PROCEDURE TYPE** *[EXCISION TYPE (CENTRAL NERVOUS SYSTEM TUMOURS)]*	an1	R

TUMOUR LOCATION (SURGICAL): Surgically determined anatomical location of lesion(s) or where centred.

01	Frontal lobe	26	Pterygopalatine fossa
02	Temporal lobe	27	Anterior clinoid dura
03	Parietal lobe	28	Sphenoid wing dura
04	Occipital lobe	29	Subfrontal dura
05	Pineal region	30	Suprasellar dura
06	Hypothalamic	31	Clival dura
07	Basal ganglia/thalamic	32	Cavernous sinus
08	Cerebellar	33	Cerebellopontine angle
09	Midbrain	34	Jugular bulb
10	Pons	35	Venous angle dura
11	Medulla	36	Foramen magnum
12	Fourth ventricle	37	Cervical intramedullary
13	Third ventricle	38	Cervical intradural
14	Lateral ventricle	39	Cervical extradural
15	Parasagittal/parafalcine dura	40	Cervical bony
16	Posterior fossa convexity dura	41	Thoracic intramedullary
17	Convexity dura	42	Thoracic intradural
18	Petrous temporal bone	43	Thoracic extradural
19	Orbital roof	44	Thoracic bony
20	Skull vault	45	Lumbar intramedullary
21	Scalp	46	Lumbar intradural
22	Anterior cranial fossa	47	Lumbar extradural
23	Middle cranial fossa	48	Lumbar bony
25	Infratemporal fossa	98	Other

BIOPSY TYPE: Identify type of biopsy (where performed)

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)

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 for v9. 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).

CNS CTYA (sub section)

CENTRAL NERVOUS SYSTEM – TREATMENT – SURGERY – CTYA

This section is a child of ‘Core - Treatment. This is a change in v9 from Surgery and Other Procedures, 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT7390	CNS - TREATMENT - SURGERY - CTYA	**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.

1	Complete resection
2	Incomplete resection (< 1.5 cm2 remaining)
3	Incomplete resection (≥ 1.5 cm2 remaining)
9	Not Applicable, Biopsy only

It is possible that some legacy data may not have all the required mandatory fields for v9. 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).

CENTRAL NERVOUS SYSTEM – DIAGNOSIS – LOW GRADE GLIOMA

This section is a child of 'Core - Diagnosis'. Record additional data around Low Grade Glioma Diagnoses.

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
Start of repeating item - Visual Acuity At Presentation				
CT7030	CNS - DIAGNOSIS - LOW GRADE GLIOMA	**VISUAL ACUITY AT PRESENTATION** *[VISUAL ACUITY TEST RESULT (AT DIAGNOSIS)]*	an1	R
End of repeating item - Visual Acuity At Presentation				
Start of repeating item - Visual Fields At Presentation				
CT7400	CNS - DIAGNOSIS - LOW GRADE GLIOMA	**VISUAL FIELDS AT PRESENTATION** *[VISUAL FIELD TEST RESULT (AT DIAGNOSIS)]*	an1	R
End of repeating item - Visual Fields At Presentation				

VISUAL ACUITY AT PRESENTATION: Record the visual acuity at presentation on the patient, this is a repeating data item.

1	Left - Normal
2	Right - Normal
3	Left - Abnormal
4	Right - Abnormal
9	Not Known

VISUAL FIELDS AT PRESENTATION: Record the visual fields at presentation on the patient, this is a repeating data item.

1	Left - Normal
2	Right - Normal
3	Left - Abnormal
4	Right - Abnormal
9	Not Known

CENTRAL NERVOUS SYSTEM – STAGING – CSF (Cerebrospinal Fluid)

This section is a child of 'Core - Site Specific Staging'.

The Chang stage is a combination of Cerebrospinal fluid (CSF) and imaging findings and can only be done taking both findings into account.

May be up to one occurrence per Core Site - Specific Staging (0..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT6560	CTYA - STAGING - CSF (Cerebrospinal Fluid)	**CHANG STAGING SYSTEM STAGE**	an2	M

Note: the following data item has been retired from v9.0

- CHANG STAGING SYSTEM STAGE DATE

CHANG STAGING SYSTEM STAGE: This is now a mandatory data item in v9. Chang staging is now a standard staging procedure for Medulloblastoma, CNS PNET, ATRT, ependymoma and CNS germ cell tumours.

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

CHANG STAGING SYSTEM STAGE DATE: This field is now collected via the 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
- the organisation who carried out the stage
- the stage itself

CENTRAL NERVOUS SYSTEM – LABORATORY RESULTS – GERM CELL CNS TUMOURS

This group is for recording germ cell data for CNS tumours, is now 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CNS - LABORATORY RESULTS - GERM CELL CNS TUMOURS CHOICE				Choice 1..1
CNS - LABORATORY RESULTS - GERM CELL CNS TUMOURS - CHOICE 1				
CT6530	CNS - LABORATORY RESULTS - GERM CELL CNS TUMOURS	**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				
CT6550	CNS - LABORATORY RESULTS - GERM CELL CNS TUMOURS	**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 Cerebro Spinal Fluid at diagnosis. AFP units recorded in kU/l (values > 100,000 are recorded. (Measured only for CNS germ cell tumours.).

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).
Note: both of the format lengths have been increased to max n8 (0-99999999). This is to meet current reporting guidelines and permissible results.

It is possible that some legacy data may not have all the required mandatory fields for v9. 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).

COLORECTAL

ICD-10 CODES

Key:
() = if applicable
* = different data set from CWT group specified

ICD-10 All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C17.0	*Duodenum*	*Colorectal*		•		*Usually treated by Upper GI MDT*
C17.1	*Jejunum*	*Colorectal*		•		*Usually treated by Upper GI MDT*
C17.2	*Ileum*	*Colorectal*		•		*Usually treated by Upper GI MDT*
C17.3	*Meckel's diverticulum*	*Colorectal*		•		*Usually treated by Upper GI MDT*
C17.8	*Overlapping lesion of small intestine*	*Colorectal*		•		*Usually treated by Upper GI MDT*
C17.9	*Small intestine, unspecified*	*Colorectal*		•		*Usually treated by Upper GI MDT*
C18.0	Caecum	Colorectal	•			
C18.1	Appendix	Colorectal		•		
C18.2	Ascending colon	Colorectal	•			
C18.3	Hepatic flexure	Colorectal	•			
C18.4	Transverse colon	Colorectal	•			
C18.5	Splenic flexure	Colorectal	•			
C18.6	Descending colon	Colorectal	•			
C18.7	Sigmoid colon	Colorectal	•			
C18.8	Overlapping lesion of colon	Colorectal	•			
C18.9	Colon, unspecified	Colorectal	•			
C19	Malignant neoplasm of rectosigmoid junction	Colorectal	•			
C20	Malignant neoplasm of rectum	Colorectal	•			
C21.0	Anus, unspecified	Colorectal		•		
C21.1	Anal canal	Colorectal		•		
C21.2	Cloacogenic zone	Colorectal		•		
C21.8	Overlapping lesion of rectum, anus and anal canal	Colorectal		•		

C26.0	Intestinal tract, part unspecified	Colorectal	•			
C26.1	Spleen	Colorectal		•		
C26.8	Overlapping lesion of digestive system	Colorectal		•		
C26.9	Ill-defined sites within the digestive system	Colorectal		•		
C78.4	Secondary malignant neoplasm of small intestine	Colorectal		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C78.5	Secondary malignant neoplasm of large intestine and rectum	Colorectal		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C78.8	Secondary malignant neoplasm of other and unspecified digestive organs	Colorectal		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
D01.0	Carcinoma in situ of Colon	Colorectal			•	
D01.1	Carcinoma in situ of Rectosigmoid junction	Colorectal			•	
D01.2	Carcinoma in situ of Rectum	Colorectal			•	
D01.3	Carcinoma in situ of Anus and anal canal	Colorectal			•	
D01.4	Carcinoma in situ of Anus and anal canal	Colorectal			•	
D01.7	Other specified digestive organs	Colorectal			•	
D01.9	Carcinoma in situ of Digestive organ, unspecified	Colorectal			•	
D37.3	Neoplasm of uncertain or unknown behaviour of Appendix	Colorectal			•	
D37.4	Neoplasm of uncertain or unknown behaviour of Colon	Colorectal			•	
D37.5	Neoplasm of uncertain or unknown behaviour of Rectum	Colorectal			•	
D37.7	Other digestive organs	Colorectal/Upper Gastrointestinal			•	
D37.9	Digestive organ, unspecified	Colorectal/Upper Gastrointestinal			•	

COLORECTAL – DIAGNOSIS

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
Start of repeating item - SYNCHRONOUS TUMOUR INDICATOR				
CO5400	COLORECTAL - DIAGNOSIS	**SYNCHRONOUS TUMOUR INDICATOR** *[SYNCHRONOUS TUMOUR COLON LOCATION (AT DIAGNOSIS)]*	an2	R
End of repeating item - SYNCHRONOUS TUMOUR INDICATOR				
CO5160	COLORECTAL - DIAGNOSIS	**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.

1	CAECUM
2	APPENDIX
3	ASCENDING COLON
4	HEPATIC FLEXURE
5	TRANSVERSE COLON
6	SPLENIC FLEXURE
7	DESCENDING COLON
8	SIGMOID COLON
9	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 data entry system which only allows entries for HAAV for IDC10 and major site C20 (Malignant neoplasm of rectum).

COLORECTAL – CLINICAL NURSE SPECIALIST

This is a new data item in v9 and 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CO5180	COLORECTAL - CLINICAL NURSE SPECIALIST	CLINICAL NURSE SPECIALIST TYPE	an1	R

CLINICAL NURSE SPECIALIST TYPE: This is a new data item for v9. Record the type of Clinical Nurse Specialist assigned to the patient during their treatment pathway.

1	Clinical Nurse Specialist
2	Stoma Nurse Specialist
8	Other
9	Not Known

Retired (Colorectal) Data Items

COLORECTAL – STAGING

This group has been retired from COSD in v9, including the following data items:

- Modified Dukes
- Modified Dukes Stage Date

CHILDREN TEENAGERS AND YOUNG ADULTS

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

For all patients under 25 more than one data set may be required depending on the nature of the disease and the management of the patient, however throughout v8.0 items wherever possible have moved to their parent group to prevent duplication and improve ascertainment. 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.

Please note that CANCER SYMPTOMS FIRST NOTED DATE, which records when symptoms were first noted, is included in the Referral section of the Core data set and should be completed for all under 25s.

ICD-10 CODES

Any applicable ICD10 code where the patient is under 25 at the time of diagnosis (see Appendices A and B).

CTYA – TABLES OF DATA ITEMS TO BE COMPLETED

Data items applicable to all cases (any diagnosis)

√ = to be completed for all cases (√) = to be completed for all cases where applicable

Data item No.	Data Item Name	All cases
CTYA Section		
CT6050	SPECIALTY (REFERRER TO SPECIALIST)	√
CT6030	CONSULTANT SPECIALTY (AT DIAGNOSIS)	√
CT6040	CONSULTANT AGE SPECIALTY (AT DIAGNOSIS)	√
CT6160	SPECIALTY SUB CODE (CHEMOTHERAPY CONSULTANT)	√
CORE - SURGERY AND OTHER PROCEDURES - STEM CELL TRANSPLANTATION		
CR8620	CONDITIONING REGIMEN	(√)
CR8600	STEM CELL INFUSION SOURCE	(√)
CR8610	STEM CELL INFUSION DONOR	(√)

Disease specific data items

The following table (pg117-pg118) 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.

√ = to be completed for all disease specific cases
(√) = to be completed for all disease specific cases if applicable

Note: All site specific staging values are now collected in conjunction with the 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
- the organisation who carried out the stage
- the stage itself

Data item No.	Data Item Name	ALL (Acute lymphoblastic Leukaemia)	AML	NHL	Hodgkin Lymphoma	Neuroblastoma	Renal	Rhabdomyosarcoma and other Soft Tissue Sarcomas	STS excluding Rhabdomyosarcoma	Osteosarcoma	Ewings	Germ Cell CNS	Germ Cell Non CNS	Medulloblastoma	Hepatoblastoma	Retinoblastoma
CTYA Section																
CT6330	WILMS TUMOUR STAGE						√									
CT7050	INTERNATIONAL NEUROBLASTOMA RISK GROUP (INRG) STAGING SYSTEM					√										
CT6500	PRETEXT STAGING SYSTEM STAGE														√	
CT7500	PRETEXT ANNOTATION FACTORS														√	
CT6790	INTERNATIONAL CLASSIFICATION FOR INTRAOCULAR RETINOBLASTOMA															√
CT6680	RISK CLASSIFICATION (PATHOLOGICAL) AFTER IMMEDIATE NEPHRECTOMY						√									
CT6340	RISK CLASSIFICATION (PATHOLOGICAL)AFTER PREOPERATIVE CHEMOTHERAPY						√									
CT6780	RETINOBLASTOMA ASSESSMENT LATERALITY															√
CT6800	INTERNATIONAL CLASSIFICATION FOR INTRAOCULAR RETINOBLASTOMA															√
CNS - CTYA Section																
CT6560	CHANG STAGING SYSTEM STAGE													√		
CT6530	ALPHA FETOPROTEIN (CEREBROSPINAL FLUID)											√				
CT6550	BETA HUMAN CHORIONIC GONADOTROPIN (CEREBROSPINAL FLUID)											√				
Haematology - CTYA Section																
CT6250	MURPHY (ST JUDE) STAGE			√												
CT6240	CYTOGENETICS SUBSIDIARY COMMENT	√	√													
CT6260	ALK FUSION STATUS FOR ALCL			√												
Haematology - Section																
HA8280	ANN ARBOR STAGE				√											
HA8290	ANN ARBOR SYMPTOMS				√											
HA8300	ANN ARBOR EXTRANODALITY				√											
HA8270	EXTRAMEDULLARY DISEASE	√	√													

Data item No.	Data Item Name	ALL (Acute lymphoblastic Leukaemia)	AML	NHL	Hodgkin Lymphoma	Neuroblastoma	Renal	Rhabdomyosarcoma and other Soft Tissue Sarcomas	STS excluding Rhabdomyosarcoma	Osteosarcoma	Ewings	Germ Cell CNS	Germ Cell Non CNS	Medulloblastoma	Hepatoblastoma	Retinoblastoma
Sarcoma - CTYA Section																
CT6350	IRS POST SURGICAL GROUP							√								
CT6750	IRS POST SURGICAL GROUP DATE							√								
CT6370	RHABDOMYOSARCOMA SITE PROGNOSIS CODE							√								
CT6450	TUMOUR VOLUME AT DIAGNOSIS										√					
CT6360	CYTOGENETICS FOR ALVEOLAR RHABDOMYOSARCOMA							√								
CT6460	CYTOGENETICS FOR EWINGS SARCOMA										√					
Sarcoma - Section																
SA11000	SARCOMA TUMOUR SITE (BONE)									√	√					
SA11010	SARCOMA TUMOUR SUBSITE (BONE)									√	√					
SA11080	SARCOMA TUMOUR SITE (SOFT TISSUE OTHER THAN RHABDOMYOSARCOMA)								√							
SA11090	SARCOMA TUMOUR SUBSITE (SOFT TISSUE) OTHER THAN RHABDOMYOSARCOMA								√							
CORE - Section																
CR8910	BETA HUMAN CHORIONIC GONADOTROPIN (SERUM)											√	√			
CR8920	ALPHA FETOPROTEIN (SERUM)											√	√		√	

Note: pathology data items are now only collectable through the COSD Pathology Data set v4.0, to remove duplication in the main COSD data set.

CTYA – REFERRAL (All cases)

May be up to one occurrence per Core – Referrals and First Stage of Patient Pathway (0..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT6050	CTYA - REFERRAL	**SPECIALTY (REFERRER TO SPECIALIST)** *[CARE PROFESSIONAL MAIN SPECIALTY CODE (CANCER REFERRAL)]*	an3	R

SPECIALTY (REFERRER TO SPECIALIST): The specialty of the person referring to the patients Principal Treatment Centre or age specific Specialist TYA MDT.

CTYA – DIAGNOSIS

May be up to one occurrence per Core – Diagnosis (0..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT6030	CTYA - DIAGNOSIS	**CONSULTANT SPECIALTY (AT DIAGNOSIS)** *[CARE PROFESSIONAL MAIN SPECIALTY CODE (DIAGNOSIS)]*	an3	R
CT6040	CTYA - DIAGNOSIS	**CONSULTANT AGE SPECIALTY (AT DIAGNOSIS)** *[CHILDREN TEENAGERS AND YOUNG ADULTS AGE CATEGORY (CONSULTANT 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.

P	Paediatric
T	Teenage and Young Adult
A	Adult

CTYA – DIAGNOSIS – NEUROBLASTOMA

These are New data items, requested after long discussions and consultation with the clinical experts.

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT7070	CTYA - DIAGNOSIS - NEUROBLASTOMA	**LIFE THREATENING SYMPTOMS AT PRESENTATION** *[LIFE THREATENING SYMPTOMS AT DIAGNOSIS INDICATOR (NEUROBLASTOMA)]*	an1	R

LIFE THREATENING SYMPTOMS AT PRESENTATION: Record if there were any life threatening symptoms at presentation.

Y	Yes
N	No

CTYA – STAGING

CTYA – STAGING – RENAL TUMOURS

It is important that all CTYA stageable cancers at staged for every case. From v9, 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
- the organisation who carried out the stage
- the stage itself

Please 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 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 leukaemias and other CTYA CNS tumours are unstageable.

The following data items are specific to paediatric renal tumours, including adult Wilms tumour, neuroblastomas, paediatric liver tumours (including adult hepatoblastoma), and retinoblastomas. These MUST be provided per submission for these tumours.

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CTYA - SITE SPECIFIC STAGING CHOICE				Choice 1..1
CTYA - SITE SPECIFIC STAGING CHOICE - CHOICE 1				
CT6330	CTYA - SITE SPECIFIC STAGING - RENAL TUMOURS	**WILMS TUMOUR STAGE**	an1	M
END OF CTYA - SITE SPECIFIC STAGING CHOICE - CHOICE 1				
CTYA - SITE SPECIFIC STAGING CHOICE - CHOICE 2				
CT7050	CTYA - SITE SPECIFIC STAGING - NEUROBLASTOMA	**INTERNATIONAL NEUROBLASTOMA RISK GROUP (INRG) STAGING SYSTEM** *[INTERNATIONAL NEUROBLASTOMA RISK GROUP STAGING SYSTEM STAGE]*	max an2	M
END OF CTYA - SITE SPECIFIC STAGING CHOICE - CHOICE 2				
CTYA - SITE SPECIFIC STAGING CHOICE - CHOICE 3				
CT6500	CTYA - SITE SPECIFIC STAGING - HEPATOBLASTOMA	**PRETEXT STAGING SYSTEM STAGE**	an1	M
Start of repeating item - Pretext Annotation Factors				

CT7500	CTYA - SITE SPECIFIC STAGING - HEPATOBLASTOMA	**PRETEXT ANNOTATION FACTORS**	an1	M
Start of repeating item - Pretext Annotation Factors				
END OF CTYA - SITE SPECIFIC STAGING CHOICE - CHOICE 3				
CTYA - SITE SPECIFIC STAGING CHOICE - CHOICE 4				
CT6800	CTYA - SITE SPECIFIC STAGING - RETINOBLASTOMA	**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

M Must be one occurrence if chosen per Core - Site Specific Staging (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT6330	CTYA - SITE SPECIFIC STAGING - RENAL TUMOURS	**WILMS TUMOUR STAGE**	an1	M

Note: the following data item has been retired from v9.0.

- WILMS TUMOUR STAGE DATE

WILMS TUMOUR STAGE: This is now a mandatory data item in v9.

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.

1	Stage 1
2	Stage 2
3	Stage 3
4	Stage 4
5	Stage 5

WILMS TUMOUR STAGE DATE: This field is now collected via the 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
- the organisation who carried out the stage
- the stage itself

CTYA – STAGING – NEUROBLASTOMA

Choice 2

Must be one occurrence if chosen per Core - Site Specific Staging (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT7050	CTYA - SITE SPECIFIC STAGING - NEUROBLASTOMA	**INTERNATIONAL NEUROBLASTOMA RISK GROUP (INRG) STAGING SYSTEM** *[INTERNATIONAL NEUROBLASTOMA RISK GROUP STAGING SYSTEM STAGE]*	max an2	M

Note: the following data item has been retired from v9.0.

- INTERNATIONAL NEUROBLASTOMA RISK GROUP (INRG) STAGING SYSTEM DATE

INTERNATIONAL NEUROBLASTOMA RISK GROUP (INRG) STAGING SYSTEM: This is now a mandatory data item in v9.

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, please use this link to review IDRF (Table 1) data (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2650389/).

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 18 months with metastases confined to skin, liver, and/or bone marrow

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 18 months (547 days) with metastases confined to skin, liver, and/or bone marrow. Bone marrow involvement should be limited to less than 10% of total nucleated cells on smears or biopsy. 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.

INTERNATIONAL NEUROBLASTOMA RISK GROUP (INRG) STAGING SYSTEM DATE: This field is now collected via the 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
- the organisation who carried out the stage
- the stage itself

CTYA – STAGING – HEPATOBLASTOMA

Choice 3

Must be one occurrence if chosen per Core – Site Specific Staging (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT6500	CTYA - SITE SPECIFIC STAGING - HEPATOBLASTOMA	**PRETEXT STAGING SYSTEM STAGE**	an1	M
Start of repeating item - Pretext Annotation Factors				
CT7500	CTYA - SITE SPECIFIC STAGING - HEPATOBLASTOMA	**PRETEXT ANNOTATION FACTORS**	an1	M*
Start of repeating item - Pretext Annotation Factors				

Note: the following data item has been retired from v9.0.

- PRETEXT STAGING OUTSIDE LIVER

PRETEXT STAGING SYSTEM STAGE: Pretext 1 - 4 refers to sectors of liver involved.

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 new data item for v9, is a multiple repeating data item and replaces Pretext Staging Outside Liver. Record any additional 'Pretext Annotation Factors' used to support Pretext Staging.

V	"extension" into the vena cava and/or all 3 hepatic veins
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

Pretext Staging System Stage is now a child of Core - Site Specific Staging, and will mandate:

- the date of the sample/MDT which provided a positive stage outcome
- the organisation who carried out the site specific stage

CTYA – STAGING – RETINOBLASTOMA

Choice 4

Must be one occurrence if chosen per Core - Site Specific Staging (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT6800	CTYA - SITE SPECIFIC STAGING - RETINOBLASTOMA	**INTERNATIONAL STAGING SYSTEM FOR RETINOBLASTOMA**	an1	M

Note: the following data item has been retired from v9.0:

- RETINOBLASTOMA ASSESSMENT DATE

INTERNATIONAL STAGING SYSTEM FOR RETINOBLASTOMA: This is now a mandatory data item in v9.

The international staging system stage for intraocular and extraocular retinoblastoma.

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

RETINOBLASTOMA ASSESSMENT DATE: This field is now collected via the 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
- the organisation who carried out the stage
- the stage itself

It is possible that some legacy data may not have all the required mandatory fields for v9. 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).

CTYA – TREATMENT – PRINCIPAL TREATMENT CENTRE

This section is a child of ‘Core – Treatment. This is a change in v9 from Surgery and Other Procedures, and will mandate:

- the date the treatment started
- the treatment modality
- the organisation that provided the treatment

This is a new group for v9, requested after extensive discussions and consultation with the CTYA Expert Advisory Group.

Must be one occurrence per Core - Treatment (1..2)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
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				
CT7600	CTYA - TREATMENT - PRINCIPAL TREATMENT CENTRE	**CHILDHOOD PRINCIPAL TREATMENT CENTRE** *[ORGANISATION IDENTIFIER (CHILDRENS NOMINATED 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				
CTYA - TREATMENT - PRINCIPAL TREATMENT CENTRE - CHOICE 2				
Start of repeating item - Principal Treatment Centre - Teenage Young Adult (TYA) PTC				
CT7610	CTYA - TREATMENT - PRINCIPAL TREATMENT CENTRE	**TEENAGE YOUNG ADULT (TYA) PRINCIPAL TREATMENT CENTRE** *[ORGANISATION IDENTIFIER (TEENAGE YOUNG ADULTS NOMINATED 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: These are new data items for v9. Record the patient’s nominated childhood or TYA principal treatment centre (PTC), whether or not they have chosen to have treatment at the PTC. More than one centre can be selected.

Choice 1 (Children's principal treatment centre (PTC))

ROA03	Manchester University NHS Foundation Trust
RBS01	Alder Hey Children's NHS Foundation Trust
RR8	Leeds Teaching Hospitals NHS Trust
RHQ	Sheffield Children's Hospital NHS Foundation Trust
RQ301	Birmingham Children's Hospital NHS Foundation Trust
RP401	Great Ormond Street Hospital for Children NHS Foundation Trust
RPY	The Royal Marsden NHS Foundation Trust
RA7	University Hospitals Bristol NHS Foundation Trust
RTH	Oxford University Hospitals NHS Foundation Trust
RMH	University Hospital Southampton NHS Foundation Trust
RGT	Cambridge University Hospitals NHS Foundation Trust
RTD	The Newcastle Upon Tyne Hospitals NHS Foundation Trust

RX1	Nottingham University Hospitals NHS Trust

Choice 2 (Teenage Young Adult (TYA) principal treatment centre (PTC))

RGT	Cambridge University Hospitals NHS Foundation Trust
RBS01	Alder Hey Children's NHS Foundation Trust
RTD	The Newcastle Upon Tyne Hospitals NHS Foundation Trust
RTH	Oxford University Hospitals NHS Foundation Trust
RR8	Leeds Teaching Hospitals NHS Trust
RX1	Nottingham University Hospitals NHS Trust
RRK02	University Hospitals Birmingham NHS Foundation Trust
RHQ	Sheffield Teaching Hospitals NHS Foundation Trust
RMH	University Hospital Southampton NHS Foundation Trust
RBV01	The Christie NHS Foundation Trust
REN20	The Clatterbridge Cancer Centre NHS Foundation Trust
RPY	The Royal Marsden NHS Foundation Trust
RRV	University College London Hospitals NHS Foundation Trust
RA7	University Hospitals Bristol NHS Foundation Trust

CTYA - TREATMENT - CCLG

The Children's Cancer and Leukaemia Group (CCLG) is a child of 'Core - Treatment. This is a change in v9 from Surgery and Other Procedures, 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 for v9. 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).

This is required to carry treatment details for Children's Cancer and Leukaemia Group (CCLG) guidelines.

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT7000	CTYA - TREATMENT - CCLG	**TREATED ACCORDING TO CCLG GUIDELINES** *[PATIENT TREATED TO CHILDRENS CANCER AND LEUKAEMIA GROUP GUIDELINES INDICATOR]*	an1	R
CT7010	CTYA - TREATMENT - CCLG	**CCLG GUIDELINE NAME** *[CHILDRENS CANCER AND LEUKAEMIA GROUP GUIDELINE NAME]*	Max an100	R

TREATED ACCORDING TO CCLG GUIDELINES: Record whether a patient was treated according to the Children's Cancer and Leukaemia Group guidelines.

Y	Yes
N	No
9	Not Known

CCLG GUIDELINE NAME: Record the name of the Children's Cancer and Leukaemia Group guideline.

CTYA – LABORATORY RESULTS – NEUROBLASTOMA

This group is now a child of CORE – Laboratory Results, and will mandate:

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

It is possible that some legacy data may not have all the required mandatory fields for v9. 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 one occurrence per Core – Laboratory Results (0..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT7090	CTYA - LABORATORY RESULTS - NEUROBLASTOMA	**URINE VMA / CREATININE RATIO** *[URINEVANILLYLMANDELIC ACID CREATININE RATIO]*	max n2.n1	R

Note: the following data item has been retired from v9.0.

- CYTOGENETIC RISK CLASSIFICATION (NEUROBLASTOMA)
- FERRITIN VALUE

URINE VMA / CREATININE RATIO: Urinary vanillylmandelic acid (VMA) used to evaluate to evaluate catecholamine production, useful in the diagnosis of pheochromocytoma and neuroblastoma and in confirmation of elevated catecholamine levels.

CTYA – RENAL TUMOURS

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT6680	CTYA - RENAL TUMOURS	**RISK CLASSIFICATION (PATHOLOGICAL) AFTER IMMEDIATE NEPHRECTOMY** *[PATHOLOGICAL RISK CLASSIFICATION CODE (AFTER NEPHRECTOMY)]*	an1	R
CT6340	CTYA - RENAL TUMOURS	**RISK CLASSIFICATION (PATHOLOGICAL) AFTER PREOPERATIVE CHEMOTHERAPY** *[PATHOLOGICAL RISK CLASSIFICATION CODE (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.

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.

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

CTYA – 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT6780	CTYA - RETINOBLASTOMA	**RETINOBLASTOMA ASSESSMENT LATERALITY**	an1	R
CT6790	CTYA - RETINOBLASTOMA	**INTERNATIONAL CLASSIFICATION FOR INTRAOCULAR RETINOBLASTOMA**	an1	R

RETINOBLASTOMA ASSESSMENT LATERALITY: The laterality for which the retinoblastoma details were recorded.

L	Left eye
R	Right eye

INTERNATIONAL CLASSIFICATION FOR INTRAOCULAR RETINOBLASTOMA: The intraocular classification for retinoblastoma as approved by the international community.

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

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

CTYA – CHEMOTHERAPY

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT6160	CTYA - CHEMOTHERAPY	**SPECIALTY SUB CODE (CHEMOTHERAPY CONSULTANT)** *[CHILDREN TEENAGERS AND YOUNG ADULTS AGE CATEGORY (CONSULTANT PRESCRIBING CHEMOTHERAPY)]*	an1	R

SPECIALTY SUB CODE (CHEMOTHERAPY CONSULTANT): The age group specialty of the consultant responsible for prescription of chemotherapy.

P	Paediatric
T	Teenage and Young Adult
A	Adult Only

GYNAECOLOGICAL

ICD-10 CODES

Key:
() = if applicable
* = different data set from CWT group specified

ICD-10 All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C48.1	*Specified parts of peritoneum*	*Sarcoma*	● *			** Sarcoma and Gynaecological Data sets to be collected where applicable.*
C48.2	*Peritoneum, unspecified*	*Sarcoma*	● *			** Sarcoma and Gynaecological Data sets to be collected where applicable.*
C51.0	*Labium majus*	*Gynaecological*	● *			**Gynaecological and Skin Data sets to be collected where applicable.*
C51.1	*Labium minus*	*Gynaecological*	● *			**Gynaecological and Skin Data sets to be collected where applicable.*
C51.2	*Clitoris*	*Gynaecological*	● *			**Gynaecological and Skin Data sets to be collected where applicable.*
C51.8	*Overlapping lesion of vulva*	*Gynaecological*	● *			**Gynaecological and Skin Data sets to be collected where applicable.*
C51.9	*Vulva, unspecified*	*Gynaecological*	● *			**Gynaecological and Skin Data sets to be collected where applicable.*
C52	Malignant neoplasm of vagina	Gynaecological	●			
C53.0	Endocervix	Gynaecological	●			
C53.1	Exocervix	Gynaecological	●			
C53.8	Overlapping lesion of cervix uteri	Gynaecological	●			
C53.9	Cervix uteri, unspecified	Gynaecological	●			
C54.0	Isthmus uteri	Gynaecological	●			
C54.1	Endometrium	Gynaecological	●			
C54.2	Myometrium	Gynaecological	●			
C54.3	Fundus uteri	Gynaecological	●			
C54.8	Overlapping lesion of corpus uteri	Gynaecological	●			

C54.9	Corpus uteri, unspecified	Gynaecological	•			
C55	Malignant neoplasm of uterus, part unspecified	Gynaecological	•			
C56	Malignant neoplasm of ovary	Gynaecological	•			
C57.0	Fallopian tube	Gynaecological	•			
C57.1	Broad ligament	Gynaecological	•			
C57.2	Round ligament	Gynaecological	•			
C57.3	Parametrium	Gynaecological	•			
C57.4	Uterine adnexa, unspecified	Gynaecological	•			
C57.7	Other specified female genital organs	Gynaecological	•			
C57.8	Overlapping lesion of female genital organs	Gynaecological	•			
C57.9	Female genital organ, unspecified	Gynaecological	•			
C58	Malignant neoplasm of placenta	Gynaecological	•			
C79.6	Secondary malignant neoplasm of ovary	Gynaecological		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
D06.0	Carcinoma in situ of endocervix	Gynaecological			•	
D06.1	Carcinoma in situ of exocervix	Gynaecological			•	
D06.7	Carcinoma in situ of other parts of cervix	Gynaecological			•	
D06.9	Carcinoma in situ of cervix, unspecified	Gynaecological			•	
D07.0	Carcinoma in situ of endometrium	Gynaecological			•	
D07.1	Carcinoma in situ of vulva	Gynaecological			•	
D07.2	Carcinoma in situ of vagina	Gynaecological			•	
D07.3	Carcinoma in situ of other and unspecified female genital organs	Gynaecological			•	
D39.0	Neoplasm of uncertain or unknown behaviour of Uterus	Gynaecological			•	
D39.1	Neoplasm of uncertain or unknown behaviour of Ovary	Gynaecological			•	
D39.2	Neoplasm of uncertain or unknown behaviour of Placenta	Gynaecological			•	
D39.7	Neoplasm of uncertain or unknown behaviour of Other female genital organs	Gynaecological			•	
D39.9	Neoplasm of uncertain or unknown behaviour of Female genital organ, unspecified	Gynaecological			•	

GYNAECOLOGICAL – SITE SPECIFIC STAGING

In order for us to be able to perform meaningful future analyses of COSD / cancer registration data both nationally and internationally, it is essential that we all move from the old to the new staging systems in a coordinated manner, with consistent staging systems employed for complete calendar years.

Following discussions with NCRAS, the British Association of Gynaecological Pathologists (BAGP) and BGCS Council, we have agreed that we should implement the transition for the purposes of cancer registration data from the 2009 to the 2018 FIGO staging systems for cervical cancer for all cases diagnosed on and beyond 1 January 2020.

This provides adequate time to implement changes to IT system capturing staging data including Infoflex and Somerset, as certain disease stages did not previously exist in the old staging system (for example cervical cancer IIIC1 and IIIC2).

In the meantime, we encourage MDTs to document and capture both the 2009 and 2018 FIGO stages for cervical cancers, and the 2018 system can be utilised for the purposes of clinical management. Please inform your pathologists and MDT coordinators of the change and approach your software providers to request an upgrade of the staging capture system.

Please use the referenced website, for the most recent and accurate FIGO stage groupings/combination[10].

May be up to one occurrence per Core - Site Specific Staging (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
GY7010	GYNAECOLOGICAL - SITE SPECIFIC STAGING	**FINAL FIGO STAGE**	max an7	M

Note: the following data item has been retired from v9.0.

- FINAL FIGO STAGE DATE

FINAL FIGO STAGE: This is now a mandatory data item in v9. 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

[10] https://obgyn.onlinelibrary.wiley.com/toc/18793479/2018/143/S2?elq_mid=30925&elq_cid=555150&

time of review of clinical findings, imaging, cytology and biopsy histology at the MDT meeting.

FINAL FIGO STAGE DATE: This field is now collected via the 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
- the organisation who carried out the stage
- the stage itself

GYNAECOLOGICAL – TREATMENT – SURGERY

This section is a child of 'Core – Treatment. This is a change in v9 from Surgery and Other Procedures, 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 for v9. 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
GY7000	GYNAECOLOGICAL - TREATMENT - SURGERY	**SURGEON GRADE** *[CARE PROFESSIONAL SENIOR OPERATING SURGEON GRADE (CANCER)]*	an1	R
GY7460	GYNAECOLOGICAL - TREATMENT - SURGERY	**RESIDUAL DISEASE** *[RESIDUAL DISEASE SIZE (GYNAECOLOGICAL CANCER)]*	an1	R

SURGEON GRADE: Grade of senior surgeon present at operation.

S	Subspecialist Gynaecological Oncologist
C	Consultant Gynaecologist (not subspecialist)
N	Non-Training Sub-Consultant Grade
T	Trainee including Subspecialty Fellow and ST Trainee
G	General Surgeon / other surgical specialty
Z	Colposcopist NOS

Note: Colposcopist - NOS (not otherwise specified) should be recorded where the procedure is a colposcopy that was carried out by a qualified colposcopist who is not a surgeon and cannot be otherwise classified in this list.

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.

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 an important Ovarian Audit.

HAEMATOLOGICAL

Overview

In order 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).

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 and stage date (including all component data items). This can be derived if components are recorded
- Myeloma – R-ISS and stage date
- All Lymphomas – Ann Arbor Stage and stage date, Ann Arbor Symptoms, Ann Arbor Extranodality, Ann Arbor Bulk and Ann Arbor Splenic Involvement

Additionally, the following prognostic indicators are also required:

- CML – Sokal index (including all component data items). This can be calculated if components are recorded
- Myelodysplasia: IPSS
- Follicular lymphoma: FLIPI2 index
- DLBCL – (R)IPI index
- Hodgkin Lymphoma – Hasenclever index (Only applicable to advanced Stage 3 and 4 disease)

ICD CODES AND WHO DISEASE GROUPS

The following table shows 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. (Please see Appendix C for Description of Disease Groups).

IMPORTANT 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

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 (i.e. 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.

Please note that 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 code: 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.

ICD-O-3	ICD-O-3 WHO Description	ICD-10 (4th Edition)	ICD10 Description	Clinical data set	WHO DISEASE GROUP
9740/1 A	Cutaneous mastocytosis	D47.0	Histiocytic and mast cell tumours of uncertain and unknown behaviour	CORE ONLY	1
9740/1 B	Extracutaneous mastocytoma	D47.0	Histiocytic and mast cell tumours of uncertain and unknown behaviour	CORE ONLY	1
9740/3	Mast Cell Sarcoma	C96.2	Malignant mast cell tumour	CORE ONLY	1
9741/1	Indolent systemic mastocytosis	D47.0	Histiocytic and mast cell tumours of uncertain and unknown behaviour	CORE ONLY	1
9741/3	Systemic mastocytosis (including systemic mastocytosis with AHNMD or aggressive systemic mastocytosis)	C96.2	Malignant mast cell tumour	CORE ONLY	1
9742/3	Mast Cell Leukaemia	C94.3	Mast cell leukaemia	CORE ONLY	1
9875/3	Chronic Myelogenous Leukaemia, BCR-ABL1 positive	C92.1	Chronic myeloid leukaemia [CML], BCR/ABL-positive	CML	1
9875/3 A	Chronic Myelogenous Leukaemia, Accelerated Phase	C92.1	Chronic myeloid leukaemia [CML], BCR/ABL-positive	CML	1
9875/3 B	Chronic Myelogenous Leukaemia, Blastic Phase	C92.1	Chronic myeloid leukaemia [CML], BCR/ABL-positive	CML	1
9875/3 C	Chronic Myelogenous Leukaemia, Chronic Phase	C92.1	Chronic myeloid leukaemia [CML], BCR/ABL-positive	CML	1
9876/3	Atypical chronic myeloid leukaemia, BCR-ABL1 negative	C92.2	Atypical chronic myeloid leukaemia, BCR/ABL-negative	MDS	1
9950/3	Polycythaemia vera*	D45	Polycythaemia vera	CORE ONLY	1

ICD-O-3	ICD-O-3 WHO Description	ICD-10 (4th Edition)	ICD10 Description	Clinical data set	WHO DISEASE GROUP
9961/3	Primary myelofibrosis*	D47.4	Osteomyelofibrosis	CORE ONLY	1
9962/3	Essential Thrombocythaemia*	D47.3	Essential (haemorrhagic) thrombocythaemia	CORE ONLY	1
9963/3	Chronic neutrophilic leukaemia	D47.1	Chronic myeloproliferative disease	CORE ONLY	1
9964/3	Chronic eosinophilic leukaemia, NOS*	D47.5	Chronic eosinophilic leukaemia [hypereosinophilic syndrome]	CORE ONLY	1
9975/3	Myeloproliferative neoplasm, unclassifiable*	D47.1	Chronic myeloproliferative disease	CORE ONLY	1
9965/3	Myeloid and lymphoid neoplasms with PDGFRA re-arrangement	C92.7	Other myeloid leukaemia	CORE ONLY	2
9966/3	Myeloid neoplasms with PDGFRB	C92.7	Other myeloid leukaemia	CORE ONLY	2
9967/3	Myeloid and lymphoid neoplasms with FGFR1 abnormalities	C92.7	Other myeloid leukaemia	CORE ONLY	2
9945/3	Chronic myelomonocytic leukaemia	C93.1	Chronic myelomonocytic leukaemia	MDS	3
9946/3	Juvenile myelomonocytic leukaemia	C93.3	Juvenile myelomonocytic leukaemia	MDS	3
9975/3 A	Myelodysplastic/Myeloproliferative neoplasm, unclassifiable	C94.6	Myelodysplastic and myeloproliferative disease, not elsewhere classified	CORE ONLY	3
9980/3	Refractory anaemia*	D46.4	Refractory anaemia, unspecified	MDS	4
9982/3 A	Refractory anaemia with ring sideroblasts*	D46.1	Refractory anaemia with ringed sideroblasts	MDS	4
9982/3 B	Refractory anaemia with ring sideroblasts associated with marked thrombocytosis*	D46.1	Refractory anaemia with ringed sideroblasts	MDS	4
9983/3	Refractory anaemia with excess blasts*	D46.2	Refractory anaemia with excess of blasts	MDS	4
9985/3	Refractory cytopenia with multilineage dysplasia*	D46.5	Refractory anaemia with multi-lineage dysplasia	MDS	4
9985/3 A	Refractory cytopenia of childhood*	D46.5	Refractory anaemia with multi-lineage dysplasia	MDS	4
9986/3	Myelodysplastic syndrome associated with isolated del(5q)*	D46.6	Myelodysplastic syndrome with isolated del(5q) chromosomal abnormality	MDS	4
9989/3	Myelodysplastic syndrome, unclassifiable*	D46.9	Myelodysplastic syndrome, unspecified	MDS	4
9991/3	Refractory neutropenia*	D46.7	Other Myelodysplastic syndromes	MDS	4
9992/3	Refractory thrombocytopenia*	D46.7	Other Myelodysplastic syndromes	MDS	4
9727/3	Blastic plasmacytoid dendritic cell neoplasm	C86.4	Blastic NK-cell lymphoma	AML	5
9840/3	Acute erythroid leukaemia	C94.0	Acute erythroid leukaemia	AML	5
9861/3 A	AML with mutated CEBPA	C92.0	Acute myeloblastic leukaemia [AML]	AML	5
9861/3 B	AML with mutated NPM1	C92.0	Acute myeloblastic leukaemia [AML]	AML	5
9861/3 C	Acute myeloid leukaemia, NOS	C92.0	Acute myeloblastic leukaemia [AML]	AML	5
9865/3	AML with t(6;9)(p23;q34) DEK-NUP214	C92.0	Acute myeloblastic leukaemia [AML]	AML	5
9866/3	Acute promyelocytic leukaemia with t(15;17)(q22;q12) PML-RARA	C92.4	Acute promyelocytic leukaemia [PML]	AML	5

ICD-O-3	ICD-O-3 WHO Description	ICD-10 (4th Edition)	ICD10 Description	Clinical data set	WHO DISEASE GROUP
9867/3	Acute myelomonocytic leukaemia	C92.5	Acute myelomonocytic leukaemia	AML	5
9869/3	AML with inv(3)(q21q26.2) or t(3;3)(q21;q26.2) RPRN1-EVI1	C92.0	Acute myeloblastic leukaemia [AML]	AML	5
9870/3	Acute basophilic leukaemia	C94.7	Other specified leukaemia	AML	5
9871/3	AML with inv(16)(p13.1;q22) or t(16;16)(p13.1;q22) CBFB-MYH11	C92.5	Acute myelomonocytic leukaemia	AML	5
9872/3	AML with minimal differentiation	C92.0	Acute myeloblastic leukaemia [AML]	AML	5
9873/3	AML without maturation	C92.0	Acute myeloblastic leukaemia [AML]	AML	5
9874/3	AML with maturation	C92.0	Acute myeloblastic leukaemia [AML]	AML	5
9891/3	Acute monoblastic and monocytic leukaemia	C93.0	Acute monoblastic/monocytic leukaemia	AML	5
9895/3	AML with myelodysplasia-related changes	C92.8	Acute myeloid leukaemia with multilineage dysplasia	AML	5
9896/3	AML with t(8;21)(q22;q22) RUNX1-RUNX1T1	C92.0	Acute myeloblastic leukaemia [AML]	AML	5
9897/3	AML with t(9;11)(p22;q23) MLLT3-MLL	C92.6	Acute myeloid leukaemia with 11q23-abnormality	AML	5
9898/1	Transient abnormal myelopoiesis	D47.1	Chronic myeloproliferative disease	CORE ONLY	5
9898/3	Myeloid leukaemia associated with Down syndrome	C92.7	Other myeloid leukaemia	AML	5
9910/3	Acute megakaryoblastic leukaemia	C94.2	Acute megakaryoblastic leukaemia	AML	5
9911/3	AML (megakaryoblastic) with t(1;22)(p13;q13) RBM15-MKL1	C94.2	Acute megakaryoblastic leukaemia	AML	5
9920/3	t-AML	C92.0	Acute myeloblastic leukaemia [AML]	AML	5
9920/3 A	t-MDS/MPN	C94.6	Myelodysplastic and myeloproliferative disease, not elsewhere classified	MDS	5
9920/3 B	t-MDS	D46.7	Other myelodysplastic syndromes	MDS	5
9930/3	Myeloid sarcoma	C92.3	Myeloid sarcoma	CORE ONLY	5
9931/3	Acute panmyelosis with myelofibrosis	C94.4	Acute panmyelosis with myelofibrosis	CORE ONLY	5
9801/3	Acute undifferentiated leukaemia	C95.0	Acute leukaemia of unspecified cell type	AML	6
9805/3	Mixed phenotype acute leukaemia NOS	C95.0	Acute leukaemia of unspecified cell type	AML	6
9806/3	Mixed phenotype acute leukaemia with t(9;22)(q34;q11.2) BCR-ABL1	C95.0	Acute leukaemia of unspecified cell type	AML	6
9807/3	Mixed phenotype acute leukaemia with t(v;11q23) MLL re-arranged	C95.0	Acute leukaemia of unspecified cell type	AML	6
9808/3	Mixed phenotype acute leukaemia, B/myeloid, NOS	C95.0	Acute leukaemia of unspecified cell type	AML	6
9809/3	Mixed phenotype acute leukaemia, T/myeloid, NOS	C95.0	Acute leukaemia of unspecified cell type	AML	6
9811/3 A	B lymphoblastic lymphoma, NOS	C83.5	Lymphoblastic (diffuse) lymphoma	ALL	7

ICD-O-3	ICD-O-3 WHO Description	ICD-10 (4th Edition)	ICD10 Description	Clinical data set	WHO DISEASE GROUP
9811/3 B	B lymphoblastic leukaemia, NOS	C91.0	Acute lymphoblastic leukaemia [ALL]	ALL	7
9812/3 A	B lymphoblastic lymphoma with t(9;22)(q34;q11.2);BCR-ABL1	C83.5	Lymphoblastic (diffuse) lymphoma	ALL	7
9812/3 B	B lymphoblastic leukaemia with t(9;22)(q34;q11.2);BCR-ABL1	C91.0	Acute lymphoblastic leukaemia [ALL]	ALL	7
9813/3 A	B lymphoblastic lymphoma with t(v;11q23);MLL re-arranged	C83.5	Lymphoblastic (diffuse) lymphoma	ALL	7
9813/3 B	B lymphoblastic leukaemia with t(v;11q23);MLL re-arranged	C91.0	Acute lymphoblastic leukaemia [ALL]	ALL	7
9814/3 A	B lymphoblastic lymphoma with t(12;21)p13;q22);ETV6-RUNX1	C83.5	Lymphoblastic (diffuse) lymphoma	ALL	7
9814/3 B	B lymphoblastic leukaemia with t(12;21)p13;q22);ETV6-RUNX1	C91.0	Acute lymphoblastic leukaemia [ALL]	ALL	7
9815/3 A	B lymphoblastic lymphoma with hyperdiploidy	C83.5	Lymphoblastic (diffuse) lymphoma	ALL	7
9815/3 B	B lymphoblastic leukaemia with hyperdiploidy	C91.0	Acute lymphoblastic leukaemia [ALL]	ALL	7
9816/3 A	B lymphoblastic lymphoma with hypodiploidy (hypodiploid ALL)	C83.5	Lymphoblastic (diffuse) lymphoma	ALL	7
9816/3 B	B lymphoblastic leukaemia with hypodiploidy (hypodiploid ALL)	C91.0	Acute lymphoblastic leukaemia [ALL]	ALL	7
9817/3 A	B lymphoblastic lymphoma with t(5;14)(q31;q32);IL3-IGH	C83.5	Lymphoblastic (diffuse) lymphoma	ALL	7
9817/3 B	B lymphoblastic leukaemia with t(5;14)(q31;q32);IL3-IGH	C91.0	Acute lymphoblastic leukaemia [ALL]	ALL	7
9818/3 A	B lymphoblastic lymphoma with t(1;19)(q23;p13.3);TCF3-PBX1	C83.5	Lymphoblastic (diffuse) lymphoma	ALL	7
9818/3 B	B lymphoblastic leukaemia with t(1;19)(q23;p13.3);TCF3-PBX1	C91.0	Acute lymphoblastic leukaemia [ALL]	ALL	7
9729/3	T lymphoblastic lymphoma	C83.5	Lymphoblastic (diffuse) lymphoma	ALL	8
9837/3	T lymphoblastic leukaemia	C91.0	Acute lymphoblastic leukaemia [ALL]	ALL	8
9591/3 A	Hairy cell leukaemia variant	C85.1	B-cell lymphoma, unspecified	Other Lymphomas	9
9591/3 B	Splenic diffuse red pulp small B-cell lymphoma	C85.1	B-cell lymphoma, unspecified	Other Lymphomas	9
9591/3 C	Splenic B-cell lymphoma/leukaemia, unclassifiable	C85.1	B-cell lymphoma, unspecified	Other Lymphomas	9
9591/3 D	B cell lymphoma, NOS	C85.1	B-cell lymphoma, unspecified	Other Lymphomas	9
9596/3	B-cell lymphoma, intermediate between DLBCL/Classical Hodgkins	C85.1	B-cell lymphoma, unspecified	Other Lymphomas	9
9597/3	Primary cutaneous follicle centre lymphoma	C82.6	Cutaneous follicle centre lymphoma	Follicular	9
9671/3	Lymphoplasmacytic lymphoma	C83.0	Diffuse large B-cell lymphoma	Other Lymphomas	9
9673/3	Mantle cell lymphoma	C83.1	Mantle cell lymphoma	Other Lymphomas	9
9678/3	Primary effusion lymphoma	C83.8	Diffuse large B-cell lymphoma	Other Lymphomas	9

ICD-O-3	ICD-O-3 WHO Description	ICD-10 (4th Edition)	ICD10 Description	Clinical data set	WHO DISEASE GROUP
9679/3	Primary mediastinal (thymic) large B-cell lymphoma	C85.2	Mediastinal (thymic)large B-cell lymphoma	Other Lymphomas	9
9680/3	Diffuse large B-cell lymphoma (DLBCL), NOS	C83.3	Diffuse large B-cell lymphoma	DLBCL	9
9680/3 A	Primary DLBCL of the CNS	C83.3	Diffuse large B-cell lymphoma	DLBCL	9
9680/3 B	EBV positive DLBCL of the elderly	C83.3	Diffuse large B-cell lymphoma	DLBCL	9
9680/3 C	B-cell lymphoma, intermediate between DLBCL /Burkitt lymphoma	C83.3	Diffuse large B-cell lymphoma	DLBCL	9
9680/3 D	Primary cutaneous DLBCL, leg type	C83.3	Diffuse large B-cell lymphoma	DLBCL	9
9680/3 E	DLBCL associated with chronic inflammation	C83.3	Diffuse large B-cell lymphoma	DLBCL	9
9687/3	Burkitt lymphoma	C83.7	Burkitt lymphoma	Other Lymphomas	9
9688/3	T-cell/histiocyte rich large B-cell lymphoma	C83.3	Diffuse large B-cell lymphoma	Other Lymphomas	9
9689/3	Splenic marginal zone lymphoma	C83.0	Small cell B-cell lymphoma	Other Lymphomas	9
9690/3	Follicular lymphoma	C82.9	Follicular lymphoma, unspecified	Follicular	9
9691/3	Follicular lymphoma Grade 2	C82.1	Follicular lymphoma grade II	Follicular	9
9695/3	Follicular lymphoma Grade 1	C82.0	Follicular lymphoma grade I	Follicular	9
9698/3	Follicular lymphoma Grade 3	C82.2	Follicular lymphoma grade III, unspecified	Follicular	9
9698/3 A	Follicular lymphoma Grade 3A	C82.3	Follicular lymphoma grade IIIa	Follicular	9
9698/3 B	Follicular lymphoma Grade 3B	C82.4	Follicular lymphoma grade IIIb	Follicular	9
9699/3 A	Extranodal marginal zone lymphoma of mucosa-associated lymphoid tissue (MALT)	C88.4	Extranodal marginal zone B-cell lymphoma of mucosa-associated lymphoid tissue [MALT-lymphoma]	Other Lymphomas	9
9699/3 B	Nodal marginal zone lymphoma	C83.0	Small cell B-cell lymphoma	Other Lymphomas	9
9712/3	Intravascular large B-cell lymphoma	C83.8	Other non-follicular lymphoma	Other Lymphomas	9
9731/3	Solitary plasmacytoma of bone	C90.3	Solitary plasmacytoma	CORE ONLY	9
9732/3	Plasma cell myeloma	C90.0	Multiple myeloma	Myeloma	9
9733/3	Plasma cell leukaemia	C90.1	Plasma cell leukaemia	Myeloma	9
9734/3	Extraosseous plasmacytoma	C90.2	Extramedullary plasmacytoma	CORE ONLY	9
9735/3	Plasmablastic lymphoma	C83.3	Diffuse large B-cell lymphoma	Other Lymphomas	9
9737/3	ALK positive large B-cell lymphoma	C83.3	Diffuse large B-cell lymphoma	Other Lymphomas	9
9738/3	Large B-cell lymphoma arising in HHV8-associated multicentric Castleman disease	C83.3	Diffuse large B-cell lymphoma	Other Lymphomas	9

ICD-O-3	ICD-O-3 WHO Description	ICD-10 (4th Edition)	ICD10 Description	Clinical data set	WHO DISEASE GROUP
9760/3	Immunoproliferative disease, NOS	C88.9	Malignant immunoproliferative disease, unspecified	CORE ONLY	9
9761/3	Waldenström macroglobulinaemia	C88.0	Waldenström macroglobulinaemia	Other Lymphomas	9
9762/3	Heavy chain disease	C88.2	Other heavy chain disease	CORE ONLY	9
9762/3 A	Alpha heavy chain disease	C88.3	Immunoproliferative small intestinal disease	CORE ONLY	9
9762/3 B	Gamma heavy chain disease	C88.2	Other heavy chain disease	CORE ONLY	9
9762/3 C	Mu heavy chain disease	C88.2	Other heavy chain disease	CORE ONLY	9
9764/3	Immunoproliferative small intestinal disease	C88.3	Immunoproliferative small intestinal disease	Other Lymphomas	9
9766/1	Lymphomatoid granulomatosis	C83.8	Other non-follicular lymphoma	CORE ONLY	9
9769/1	Primary Amyloidosis	E85.9	Amyloidosis, unspecified	CORE ONLY	9
9823/3	Chronic lymphocytic leukaemia/small lymphocytic lymphoma	C91.1	Chronic lymphocytic leukaemia of B-cell type	CLL	9
9826/3	Burkitt cell leukaemia	C91.8	Mature B-cell leukaemia Burkitt-type	Other Lymphomas	9
9833/3	B-cell prolymphocytic leukaemia	C91.3	Prolymphocytic leukaemia of B-cell type	CORE ONLY	9
9940/3	Hairy cell leukaemia	C91.4	Hairy-cell leukaemia	CORE ONLY	9
9700/3	Mycosis fungoides	C84.0	Mycosis fungoides	Other Lymphomas	10
9701/3	Sézary syndrome	C84.1	Sézary disease	Other Lymphomas	10
9702/3 A	Peripheral T-cell lymphoma, NOS	C84.4	Peripheral T-cell lymphoma, not elsewhere classified	Other Lymphomas	10
9702/3 B	Anaplastic large cell lymphoma, ALK negative	C84.7	Anaplastic large cell lymphoma, ALK-negative	Other Lymphomas	10
9705/3	Angioimmunoblastic T-cell lymphoma	C86.5	Angioimmunoblastic T-cell lymphoma	Other Lymphomas	10
9708/3	Subcutaneous panniculitis-like T-cell lymphoma	C86.3	Subcutaneous panniculitis-like T-cell lymphoma	Other Lymphomas	10
9709/3 A	Primary cutaneous CD8+ aggressive epidermotropic cytotoxic T-cell lymphoma	C84.8	Cutaneous T-cell lymphoma, unspecified	Other Lymphomas	10
9709/3 B	Primary cutaneous CD4 positive small/medium T-cell lymphoma	C84.8	Cutaneous T-cell lymphoma, unspecified	Other Lymphomas	10
9714/3	Anaplastic large cell lymphoma, ALK positive	C84.6	Anaplastic large cell lymphoma, ALK-positive	Other Lymphomas	10
9716/3	Hepatosplenic T-cell lymphoma	C86.1	Hepatosplenic T-cell lymphoma	Other Lymphomas	10
9717/3	Enteropathy-associated T-cell lymphoma	C86.2	Enteropathy-type (intestinal) T-cell lymphoma	Other Lymphomas	10
9718/3	Primary cutaneous anaplastic large cell lymphoma	C86.6	Primary cutaneous CD30-positive T-cell proliferations	Other Lymphomas	10
9719/3	Extranodal NK/T cell lymphoma, nasal type	C86.0	Extranodal NK/T-cell lymphoma, nasal type	Other Lymphomas	10
9719/3 A	T/NK-cell lymphoma	C84.9	Mature T/NK-cell lymphoma, unspecified	CORE ONLY	10
9724/3	Systemic EBV positive T-cell lymphoproliferative disease of childhood	C84.5	Other mature T/NK-cell lymphomas	Other Lymphomas	10
9725/3	Hydroa vacciniforme-like lymphoma	C84.5	Other mature T/NK-cell lymphomas	Other Lymphomas	10

ICD-O-3	ICD-O-3 WHO Description	ICD-10 (4th Edition)	ICD10 Description	Clinical data set	WHO DISEASE GROUP
9726/3	Primary cutaneous gamma-delta T-cell lymphoma	C84.5	Other mature T/NK-cell lymphomas	Other Lymphomas	10
9827/3	Adult T-cell leukaemia/lymphoma	C91.5	Adult T-cell lymphoma/leukaemia (HTLV-1-associated)	Other Lymphomas	10
9831/3	T-cell large granular lymphocytic leukaemia	C91.7	Other lymphoid leukaemia	CORE ONLY	10
9831/3 A	Chronic lymphoproliferative disorder of NK-cells	C91.7	Other lymphoid leukaemia	CORE ONLY	10
9834/3	T-cell prolymphocytic leukaemia	C91.6	Prolymphocytic leukaemia of T-cell type	CORE ONLY	10
9948/3	Aggressive NK cell leukaemia	C95.0	Acute leukaemia of unspecified cell type	CORE ONLY	10
9650/3	Classical Hodgkin lymphoma	C81.9	Hodgkin lymphoma, unspecified	Hodgkin	11
9651/3	Lymphocyte-rich classical Hodgkin lymphoma	C81.4	Lymphocyte-rich classical Hodgkin lymphoma	Hodgkin	11
9652/3	Mixed cellularity classical Hodgkin lymphoma	C81.2	Mixed cellularity classical Hodgkin lymphoma	Hodgkin	11
9653/3	Lymphocyte-depleted classical Hodgkin lymphoma	C81.3	Lymphocytic depleted classical Hodgkin lymphoma	Hodgkin	11
9659/3	Nodular lymphocyte predominant Hodgkin lymphoma	C81.0	Nodular lymphocyte predominant Hodgkin lymphoma	Hodgkin	11
9663/3	Nodular sclerosis classical Hodgkin lymphoma	C81.1	Nodular sclerosis classical Hodgkin lymphoma	Hodgkin	11
9751/3 A	Multifocal and multisystemic (disseminated) Langerhans-cell histiocytosis [Letterer-Siwe disease]	C96.0	Multifocal and multisystemic (disseminated) Langerhans-cell histiocytosis [Letterer-Siwe disease]	CORE ONLY	12
9751/3 B	Multifocal and unisystemic (disseminated) Langerhans-cell histiocytosis	C96.5	Multifocal and unisystemic Langerhans-cell histiocytosis	CORE ONLY	12
9751/3 C	Unifocal Langerhans-cell histiocytosis	C96.6	Unifocal Langerhans-cell histiocytosis	CORE ONLY	12
9755/3	Histiocytic sarcoma	C96.8	Histiocytic sarcoma	CORE ONLY	12
9756/3	Langerhans cell sarcoma	C96.4	Sarcoma of dendritic cells (accessory cells)	CORE ONLY	12
9757/3	Interdigitating dendritic cell sarcoma	C96.4	Sarcoma of dendritic cells (accessory cells)	CORE ONLY	12
9757/3 A	Dendritic cell tumour, NOS	C96.4	Sarcoma of dendritic cells (accessory cells)	CORE ONLY	12
9758/3	Follicular dendritic cell sarcoma	C96.4	Sarcoma of dendritic cells (accessory cells)	CORE ONLY	12
9759/3	Fibroblastic reticular cell tumour	C96.4	Sarcoma of dendritic cells (accessory cells)	CORE ONLY	12
9971/1 A	Early lesions plasmacytic hyperplasia	D47.7	Other specified neoplasm of uncertain or unknown behaviour of lymphoid, haematopoietic and related tissue	CORE ONLY	13
9971/1 B	Early lesions infectious mononucleosis-like PTLD	D47.7	Other specified neoplasm of uncertain or unknown behaviour of lymphoid, haematopoietic and related tissue	CORE ONLY	13
9971/3 A	Polymorphic PTLD*	D47.7	Other specified neoplasm of uncertain or unknown behaviour of lymphoid, haematopoietic and related tissue	CORE ONLY	13
9971/3 B	Monomorphic PTLD (B- and T/NK-cell types)*	D47.7	Other specified neoplasm of uncertain or unknown behaviour of lymphoid, haematopoietic and related tissue	CORE ONLY	13
9971/3 C	Classical Hodgkin lymphoma type PTLD*	C81.9	Hodgkin lymphoma, unspecified	CORE ONLY	13
9591/3	Malignant lymphoma, non-Hodgkin, NOS	C85.9	Non-Hodgkin lymphoma, unspecified	Other Lymphomas	(No applicable group)
9800/3	Leukaemia, NOS	C95.9	Leukaemia, unspecified	CORE ONLY	

ICD-O-3	ICD-O-3 WHO Description	ICD-10 (4th Edition)	ICD10 Description	Clinical data set	WHO DISEASE GROUP
9860/3	Myeloid leukaemia, NOS	C92.9	Myeloid leukaemia, unspecified	CORE ONLY	
		C81.7	Other classical Hodgkin lymphoma	Redundant (reclassified)**	
		C82.5	Diffuse follicle centre lymphoma	Redundant (reclassified)**	
		C82.7	Other types of follicular lymphoma	Redundant (reclassified)**	
		C83.9	Non-follicular (diffuse) lymphoma, unspecified	Redundant (reclassified)**	
		C88.7	Other malignant immunoproliferative diseases	Redundant (reclassified)**	
		C93.7	Other monocytic leukaemia	Redundant (reclassified)**	
		C93.9	Monocytic leukaemia, unspecified	Redundant (reclassified)**	
		C94.7	Other specified leukaemias	Redundant (reclassified)**	
		C95.1	Chronic leukaemia of unspecified cell type	Redundant (reclassified)**	
		C95.7	Other leukaemia of unspecified cell type	Redundant (reclassified)**	
		C96.7	Other specified malignant neoplasms of lymphoid, haematopoietic and related tissue	Redundant (reclassified)**	
		C96.9	Malignant neoplasms of lymphoid, haematopoietic and related tissue, unspecified	Redundant (reclassified)**	
	not used in ICD-O-3 (D46.4 used instead)	D46.0	Refractory anaemia without ringed sideroblasts, so stated	Redundant (reclassified)**	
		D47.9	Neoplasm of uncertain or unknown behaviour of lymphoid, haematopoietic and related tissue, unspecified	Redundant (reclassified)**	

* There is a behaviour discrepancy between the ICD10 site code and the new ICD-O-3 morphology code - although these diseases are now coded with a behaviour code of 3 they are still recorded with a D code in ICD10.

** Redundant - disease has been reclassified under other codes

HAEMATOLOGICAL – CLINICAL DATA SETS AND APPLICABLE DATA ITEMS

In Appendix I, you will find a new proforma for v9 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 in the guidance section of cancerstats. Please login here https://cancerstats.ndrs.nhs.uk/.

Note: This data set has been separated into 2 sub sections ‘Haematology’ and ‘CTYA’. This will make allocating and recording data on both sub groups easier.

HAEMATOLOGY – (sub section)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
HAEMATOLOGICAL - CANCER CARE PLAN CHOICE				
HAEMATOLOGICAL - CANCER CARE PLAN CHOICE - CHOICE 1				
HA8010	HAEMATOLOGICAL - CANCER CARE PLAN - CML	**SOKAL INDEX (CHRONIC MYELOID LEUKAEMIA)** *[CHRONIC MYELOID LEUKAEMIA INDEX SCORE (SOKAL)]*	n1.n1	M
END OF HAEMATOLOGICAL - CANCER CARE PLAN CHOICE - CHOICE 1				
HAEMATOLOGICAL - CANCER CARE PLAN CHOICE - CHOICE 2				
HA9000	HAEMATOLOGICAL - CANCER CARE PLAN - MYELODYSPLASIA	**IPSS-R (MYELODYSPLASIA)** *[REVISED INTERNATIONAL PROGNOSTIC SCORING SYSTEM SCORE]*	n1.n1	M
END OF HAEMATOLOGICAL - CANCER CARE PLAN CHOICE - CHOICE 2				
HAEMATOLOGICAL - CANCER CARE PLAN CHOICE - CHOICE 3				
HA8210	HAEMTOLOGICAL - CANCER CARE PLAN - CLL	**SPLENOMEGALY INDICATOR**	an1	M
END OF HAEMATOLOGICAL - CANCER CARE PLAN CHOICE - CHOICE 3				
HAEMATOLOGICAL - CANCER CARE PLAN CHOICE - CHOICE 4				
HA8320	HAEMATOLOGICAL - CANCER CARE PLAN - FOLLICULAR LYMPHOMA	**NUMBER OF ABNORMAL NODAL AREAS**	max n2	R
HA8360	HAEMATOLOGICAL - CANCER CARE PLAN - FOLLICULAR LYMPHOMA	**FLIPI 2 INDEX SCORE** *[FOLLICULAR LYMPHOMA INTERNATIONAL PROGNOSTIC INDEX 2 SCORE]*	n1	R
END OF HAEMATOLOGICAL - CANCER CARE PLAN CHOICE - CHOICE 4				
HAEMATOLOGICAL - CANCER CARE PLAN CHOICE - CHOICE 5				
HA8320	HAEMATOLOGICAL - CANCER CARE PLAN - DLBCL	**NUMBER OF ABNORMAL NODAL AREAS**	max n2	R
HA8330	HAEMATOLOGICAL - CANCER CARE PLAN - DLBCL	**PRIMARY EXTRANODAL SITE**	an2	R
HA8420	HAEMATOLOGICAL - CANCER CARE PLAN - DLBCL	**NUMBER OF EXTRANODAL SITES CODE**	an1	R
HA8450	HAEMATOLOGICAL - CANCER CARE PLAN - DLBCL	**(R)IPI INDEX for DLBCL SCORE** *[REVISED INTERNATIONAL PROGNOSTIC INDEX SCORE]*	n1	R
END OF HAEMATOLOGICAL - CANCER CARE PLAN CHOICE - CHOICE 5				
HAEMATOLOGICAL - CANCER CARE PLAN CHOICE - CHOICE 6				
HA8320	HAEMATOLOGICAL - CANCER CARE PLAN - HODGKIN LYMPHOMA	**NUMBER OF ABNORMAL NODAL AREAS**	max n2	R
HA8330	HAEMATOLOGICAL - CANCER CARE PLAN - HODGKIN LYMPHOMA	**PRIMARY EXTRANODAL SITE**	an2	R
HA8670	HAEMATOLOGICAL - CANCER CARE PLAN - HODGKIN LYMPHOMA	**HASENCLEVER INDEX** *[HASENCLEVER INDEX SCORE]*	n1	R
END OF HAEMATOLOGICAL - CANCER CARE PLAN CHOICE - CHOICE 6				
HAEMATOLOGICAL - CANCER CARE PLAN CHOICE - CHOICE 7				
Start of repeating item - Extramedullary Disease				
HA8270	HAEMATOLOGICAL - CANCER CARE PLAN - ACUTE LYMPHOBLASTIC LEUKAEMIA	**EXTRAMEDULLARY DISEASE** *[EXTRAMEDULLARY DISEASE SITE}*	an1	M*
End of repeating item - Extramedullary Disease				
END OF HAEMATOLOGICAL - CANCER CARE PLAN CHOICE - CHOICE 7				
END OF HAEMATOLOGICAL - CANCER CARE PLAN CHOICE				

Note: The following data items form a 7-choice menu and must be one occurrence if chosen per Core – Cancer Care Plan group (1..1)

HAEMATOLOGICAL – CANCER CARE PLAN – CHRONIC MYELOID LEUKAEMIA

Choice 1

Must be one occurrence if chosen per Core - Cancer Care Plan (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
HA8010	HAEMATOLOGICAL - CANCER CARE PLAN - CML	**SOKAL INDEX (CHRONIC MYELOID LEUKAEMIA)** *[CHRONIC MYELOID LEUKAEMIA INDEX SCORE (SOKAL)]*	n1.n1	M

Note: the following data item has been retired from v9.0:

- SPLEEN CM BELOW COSTAL MARGIN

SOKAL INDEX (CHRONIC MYELOID LEUKAEMIA): Index derived from age, spleen size, platelet count, myeloblasts %.

The following websites can be used as a Sokal Index Calculator and have additional supporting data:

- http://bloodref.com/myeloid/cml/sokal-hasford
- http://www.siematologia.it/LG/SOKAL/SOKAL.htm

HAEMATOLOGICAL – CANCER CARE PLAN – MYELODYSPLASIA

Choice 2

Must be one occurrence if chosen per Core – Cancer Care Plan (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
HA9000	HAEMATOLOGICAL - CANCER CARE PLAN - MYELODYSPLASIA	**IPSS-R (MYELODYSPLASIA)** *[REVISED INTERNATIONAL PROGNOSTIC SCORING SYSTEM SCORE]*	n1.n1	M

Note: the following data item has been retired from v9.0:

- IPSS (MYELODYSPLASIA)

IPSS-R (MYELODYSPLASIA): This is a new data item for v9. 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

The following website: https://www.mds-foundation.org/ipss-r-calculator/ is an online calculator for the IPSS- R scoring system.

Note: It has been highlighted that there is a small risk that a 10 can be recorded (less than 10% of cases are >6), however this unfortunately breaks the current schema and data item format. If this is the case, please submit 9.9 and NCRAS will upgrade this to 10 within their system. 9.9 is not a valid IPSS-R score, so there is no risk from this approach. The schema will be corrected in v10.

HAEMATOLOGICAL – CANCER CARE PLAN – CHRONIC LYMPHOCYTIC LEUKAEMIA

Choice 3

Must be one occurrence if chosen per Core - Cancer Care Plan (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
HA8210	HAEMATOLOGICAL - CANCER CARE PLAN - CLL	**SPLENOMEGALY INDICATOR**	an1	M

Note: the following data items have been retired from v9.0:

- HEPATOMEGALY INDICATOR
- NUMBER OF LYMPHADENOPATHY AREAS

SPLENOMEGALY INDICATOR: Spleen enlargement identified from clinical examination.

Y	Yes
N	No

HAEMATOLOGICAL – CANCER CARE PLAN – FOLLICULAR LYMPHOMA

Choice 4

Must be one occurrence if chosen per Core – Cancer Care Plan (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
HA8320	HAEMATOLOGICAL - CANCER CARE PLAN - FOLLICULAR	**NUMBER OF ABNORMAL NODAL AREAS**	max n2	R
HA8360	HAEMATOLOGICAL - CANCER CARE PLAN - FOLLICULAR	**FLIPI 2 INDEX SCORE** *[FOLLICULAR LYMPHOMA INTERNATIONAL PROGNOSTIC INDEX 2 SCORE]*	n1	R

NUMBER OF ABNORMAL NODAL AREAS: Number of abnormal nodal areas detected clinically and radiologically, this is only required for the following 3 types: Follicular, DLBCL and Hodgkin.

FLIPI 2 INDEX SCORE: 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.

The following websites can be used as a Follicular Lymphoma International Prognostic Index 2 (FLIPI2) Calculator and additional supporting data:

- http://www.siematologia.it/LG/FLIPI2/FLIPI2.htm
- http://bloodref.com/lymphoid/lymphoma/flipi2

HAEMATOLOGICAL – CANCER CARE PLAN – DIFFUSE LARGE B CELL LYMPHOMA

Choice 5

Must be one occurrence if chosen per Core - Cancer Care Plan (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
HA8320	HAEMATOLOGICAL - CANCER CARE PLAN - DLBCL	**NUMBER OF ABNORMAL NODAL AREAS**	max n2	R
HA8330	HAEMATOLOGICAL - CANCER CARE PLAN - DLBCL	**PRIMARY EXTRANODAL SITE**	an2	R
HA8420	HAEMATOLOGICAL - CANCER CARE PLAN - DLBCL	**NUMBER OF EXTRANODAL SITES CODE**	an1	R
HA8450	HAEMATOLOGICAL - CANCER CARE PLAN - DLBCL	**(R)IPI INDEX for DLBCL SCORE** *[REVISED INTERNATIONAL PROGNOSTIC INDEX SCORE]*	n1	R

NUMBER OF ABNORMAL NODAL AREAS: Number of abnormal nodal areas detected clinically and radiologically, this is only required for the following 3 types: Follicular, DLBCL and Hodgkin.

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 the following 2 types: DLBCL and Hodgkin.

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).

0	0
1	1
2	More than 1

(R)IPI INDEX for DLBCL SCORE: Revised International Prognostic Index Score, derived from Age, performance status, LDH, extranodal sites, Ann Arbor Stage.

The following websites can be used as a (R)IPI INDEX for DLBCL SCORE Calculator and additional supporting data:

- https://qxmd.com/calculate/calculator_64/diffuse-large-b-cell-lymphoma-prognosis-r-ipi
- http://bloodref.com/lymphoid/lymphoma/revised-ipi

HAEMATOLOGICAL – CANCER CARE PLAN – HODGKIN LYMPHOMA

Choice 6

Must be one occurrence if chosen per Core - Cancer Care Plan (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
HA8320	HAEMATOLOGICAL - CANCER CARE PLAN - HODGKIN	**NUMBER OF ABNORMAL NODAL AREAS**	max n2	R
HA8330	HAEMATOLOGICAL - CANCER CARE PLAN - HODGKIN	**PRIMARY EXTRANODAL SITE**	an2	R
HA8670	HAEMATOLOGICAL - CANCER CARE PLAN - HODGKIN	**HASENCLEVER INDEX** *[HASENCLEVER INDEX SCORE]*	n1	R

NUMBER OF ABNORMAL NODAL AREAS: Number of abnormal nodal areas detected clinically and radiologically, this is only required for the following 3 types: Follicular, DLBCL and Hodgkin.

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 the following 2 types: DLBCL and Hodgkin.

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

HASENCLEVER INDEX: Index derived from age, gender, Hb, Albumin, white blood count, Lymphocyte count, Ann Arbor stage.

Note: Hasenclever Index is only required for lymphomas with Ann Arbor Stage 3 or 4.

The following website can be used as a Hasenclever Index Calculator and additional supporting data: http://bloodref.com/lymphoid/lymphoma/ips-hasenclever

HAEMATOLOGICAL – CANCER CARE PLAN – ACUTE LYMPHOBLASTIC LEUKAEMIA

Choice 7

Must be one occurrence if chosen per Core - Cancer Care Plan (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
Start of repeating item - Extramedullary Disease				
HA8270	HAEMATOLOGICAL - CANCER CARE PLAN - ACUTE LYMPHOBLASTIC LEUKAEMIA	**EXTRAMEDULLARY DISEASE** *[EXTRAMEDULLARY DISEASE SITE]*	an1	M*
End of repeating item - Extramedullary Disease				

EXTRAMEDULLARY DISEASE: Site/s of disease identified outside bone marrow, including presence of blasts within CFS, more than one option can be recorded. Multiple attributes are allowed to be selected.

1	CNS1 (Without Blasts)
2	CNS2 (< 5 WBC in the CSF with blasts)
3	CNS3 (≥5 WBC in the CSF with blasts)
4	Testes
9	Other

HAEMATOLOGICAL – STAGING

Note: the following data items form a 4-choice menu and at One of the following Site Specific Staging Sections MUST be provided per submission

The Ann Arbour Stage group has also been corrected in v9, to isolate the Stage from the extensions, which support the stage decision.

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
HAEMATOLOGICAL - SITE SPECIFIC STAGING CHOICE				
HAEMATOLOGICAL - SITE SPECIFIC STAGING - CHOICE 1				
HA8280	HAEMATOLOGICAL - STAGING - ANN ARBOR - HODGKIN, FOLLICULAR, DLBCL, OTHER LYMPHOMAS	**ANN ARBOR STAGE**	an1	M
END OF HAEMATOLOGICAL - SITE SPECIFIC STAGING - CHOICE 1				
HAEMATOLOGICAL - SITE SPECIFIC STAGING - CHOICE 2				
HA8240	HAEMATOLOGICAL - STAGING - CLL	**BINET STAGE**	an1	M
END OF HAEMATOLOGICAL - SITE SPECIFIC STAGING - CHOICE 2				
HAEMATOLOGICAL - SITE SPECIFIC STAGING - CHOICE 3				
HA9100	HAEMATOLOGICAL - STAGING - MYELOMA	**R-ISS STAGE for MYELOMA** *[REVISED INTERNATIONAL STAGING SYSTEM STAGE FOR MULTIPLE MYELOMA]*	an1	M
END OF HAEMATOLOGICAL - SITE SPECIFIC STAGING - CHOICE 3				
HAEMATOLOGICAL - SITE SPECIFIC STAGING - CHOICE 4				

CT6250	HAEMATOLOGICAL - STAGING -NON HODGKIN LYMPHOMA	**MURPHY (ST JUDE) STAGE**	an1	M
END OF HAEMATOLOGICAL - SITE SPECIFIC STAGING - CHOICE 4				
END OF HAEMATOLOGICAL - SITE SPECIFIC STAGING CHOICE				

HAEMATOLOGICAL – STAGING – ANN ARBOR

Choice 1

Must be one occurrence if chosen per Core - Site Specific Staging (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
HA8280	HAEMATOLOGICAL - STAGING - ANN ARBOR - HODGKIN, FOLLICULAR, DLBCL, OTHER LYMPHOMAS	**ANN ARBOR STAGE**	an1	M

Note: the following data item has been retired from v9.0:

- ANN ARBOR STAGE DATE

ANN ARBOR STAGE: This is now a mandatory field for v9.0. Staging is based on location of detected disease.

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

ANN ARBOR STAGE DATE: This field is now collected via the 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
- the organisation who carried out the stage
- the stage itself

HAEMATOLOGICAL – STAGING – CLL

Choice 2

Must be one occurrence if chosen per Core - Site Specific Staging (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
HA8240	HAEMATOLOGICAL - CANCER CARE PLAN - CLL	**BINET STAGE**	an1	M

Note: the following data item has been retired from v9.0:

- BINET STAGE DATE

BINET STAGE: This is now a mandatory field for v.9. 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."

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 > 99 x 109/L
- Hb >109" is more fully described as "Hb >109 g/L

BINET STAGE DATE: This field is now collected via the 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
- the organisation who carried out the stage
- the stage itself

HAEMATOLOGICAL – STAGING – MYELOMA

Choice 3

Must be one occurrence if chosen per Core - Site Specific Staging (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
HA9100	HAEMATOLOGICAL - CANCER CARE PLAN - MYELOMA	**R-ISS STAGE for MYELOMA** *[REVISED INTERNATIONAL STAGING SYSTEM STAGE FOR MULTIPLE MYELOMA]*	an1	M

Note: the following data item has been retired from v9.0:

- ISS STAGE for MYELOMA DATE
- ISS STAGE for MYELOMA

R-ISS STAGE for MYELOMA

This data item replaces ISS Stage for Myeloma in v9 and is now a mandatory field for v.9.

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:

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

The following is an online calculator for R-ISS:

- https://qxmd.com/calculate/calculator_354/multiple-myeloma-prognosis-r-iss

R-ISS STAGE for MYELOMA DATE: This field is now collected via the 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
- the organisation who carried out the stage
- the stage itself

HAEMATOLOGICAL – STAGING – NON HODGKIN LYMPHOMA

Choice 4

Must be one occurrence if chosen per Core – Site Specific Staging (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT6250	CTYA - NON-HODGKIN LYMPHOMA	**MURPHY (ST JUDE) STAGE**	an1	M

Note: the following data items have been retired from v9.0:

- MURPHY (ST JUDE) STAGE DATE

MURPHY (ST JUDE) STAGE: This is now a mandatory field for v.9. The St. Jude Children's Research Hospital model (Murphy Staging), which separates patients on the basis of limited versus extensive disease. (http://www.cancer.gov/cancertopics/pdq/treatment/child-non-hodgkins/HealthProfessional/page3).

It is essential to record the disease specific stage for this group of patients. This information should be available to the MDT. 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)

1	Stage 1
2	Stage 2
3	Stage 3
4	Stage 4

MURPHY (ST JUDE) STAGE DATE: This field is now collected via the 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
- the organisation who carried out the stage
- the stage itself

HAEMATOLOGICAL – ANN ARBOR – EXTENSIONS

This is a new group for v9 and the 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 record (0..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
HA8290	HAEMATOLOGICAL - STAGING - ANN ARBOR - HODGKIN, FOLLICULAR, DLBCL, OTHER LYMPHOMAS	**ANN ARBOR SYMPTOMS** *[ANN ARBOR SYMPTOMS INDICATION CODE]*	an1	R
HA8300	HAEMATOLOGICAL - STAGING - ANN ARBOR - HODGKIN, FOLLICULAR, DLBCL, OTHER LYMPHOMAS	**ANN ARBOR EXTRANODALITY** *[ANN ARBOR EXTRANODALITY INDICATION CODE]*	an1	R
HA8310	HAEMATOLOGICAL - STAGING - ANN ARBOR - HODGKIN, FOLLICULAR, DLBCL, OTHER LYMPHOMAS	**ANN ARBOR BULK** *[ANN ARBOR BULKY DISEASE INDICATION CODE]*	an1	R
HA8680	HAEMATOLOGICAL - STAGING - ANN ARBOR - HODGKIN, FOLLICULAR, DLBCL, OTHER LYMPHOMAS	**ANN ARBOR SPLENIC INVOLVEMENT** *[ANN ARBOR SPENIC INDICATION CODE]*	an1	R

ANN ARBOR SYMPTOMS: Additional stage designation based on presence or absence of specific symptoms.

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.

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. 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.

X	“Bulky” disease present
0	No “bulky” disease present

ANN ARBOR SPLENIC INVOLVMENT: Additional staging designation based on splenomegaly or normal spleen size with confirmed disease involvement.
Code "S" if either is true.

S	Spleen involvement or spenomegaly
0	No spleen involvement or splenomegaly

HAEMATOLOGICAL – LABORATORY RESULTS

This group is now a child of CORE – Laboratory Results, and will mandate:

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
HAEMATOLOGICAL - LABORATORY RESULTS CHOICE				
HAEMATOLOGICAL - LABORATORY RESULTS - CHOICE 1				
HA9200	HAEMATOLOGICAL - LABORATORY RESULTS - AML	**EUROPEAN LEUKAEMIA NET (ELN) GENETIC RISK (ACUTE MYELOID LEUKAEMIA)** *[EUROPEAN LEUKAEMIA NET GENETIC RISK CODE]*	an1	R
HA8150	HAEMATOLOGICAL - LABORATORY RESULTS - AML and ALL	**WHITE BLOOD CELL COUNT (HIGHEST PRE TREATMENT)**	max n3.n1	R
END OF HAEMATOLOGICAL - LABORATORY RESULTS - CHOICE 1				
HAEMATOLOGICAL - LABORATORY RESULTS - CHOICE 2				
CT7330	HAEMATOLOGICAL - LABORATORY RESULTS - MYELODYSPLASIA	**BONE MARROW BLASTS BONE** *MARROW BLAST CELLS PERCENTAGE*	max n3	R
CT6240	HAEMATOLOGICAL - LABORATORY RESULTS - ALL/AML	**CYTOGENETICS SUBSIDIARY COMMENT** *[CYTOGENETIC FINDINGS COMMENT]*	max an50	R
END OF HAEMATOLOGICAL - LABORATORY RESULTS - CHOICE 2				
HAEMATOLOGICAL - LABORATORY RESULTS - CHOICE 3				
CT7340	HAEMATOLOGICAL - LABORATORY RESULTS - PAEDIATRIC MYELODYSPLASIA	**CELLULARITY** *[CELLULARITY PERCENTAGE]*	max an3	R
CT7350	HAEMATOLOGICAL - LABORATORY RESULTS - PAEDIATRIC MYELODYSPLASIA	**DEB TEST** *[DIEPOXYBUTANE TEST RESULT]*	an1	R
CT7360	HAEMATOLOGICAL - LABORATORY RESULTS - PAEDIATRIC MYELODYSPLASIA	**DYSPLASTIC HAEMOPOIESIS** *[DYSPLASTIC HAEMOPOIESIS TYPE]*	an1	R
END OF HAEMATOLOGICAL - LABORATORY RESULTS - CHOICE 3				
HAEMATOLOGICAL - LABORATORY RESULTS - CHOICE 4				
CT7700	HAEMATOLOGICAL - LABORATORY RESULTS - ACUTE LYMPHOBLASTIC LEUKAEMIA - RESPONSE	**POST INDUCTION MRD** *[LEUKAEMIC CELLS PRESENT POST MINIMAL RESIDUAL DISEASE INDUCTION]*	an1	M
END OF HAEMATOLOGICAL - LABORATORY RESULTS - CHOICE 4				
END OF HAEMATOLOGICAL - LABORATORY RESULTS CHOICE				

Note: the following data items have been retired from v9.0:

- PLATELET COUNT
- BLOOD HAEMOGLOBIN CONCENTRATION (GRAMS PER LITRE)
- BONE MARROW KARYOTYPE
- NEUTROPHIL COUNT
- ALBUMIN LEVEL
- BETA2 MICROGLOBULIN LEVEL
- BLOOD LYMPHOCYTE COUNT
- LACTATE DEHYDROGENASE LEVEL
- BLOOD MYELOBLASTS PERCENTAGE
- BLOOD BASOPHILS PERCENTAGE
- BLOOD EOSINOPHILS PERCENTAGE
- CYTOGENETIC GROUP (ACUTE MYELOID LEUKAEMIA)

HAEMATOLOGICAL – LABORATORY RESULTS – VARIOUS

Choice 1

Must be one occurrence if chosen per Core – Laboratory Results (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
HA9200	HAEMATOLOGICAL - LABORATORY RESULTS - AML	**EUROPEAN LEUKAEMIA NET (ELN) GENETIC RISK (ACUTE MYELOID LEUKAEMIA)** *[EUROPEAN LEUKAEMIA NET GENETIC RISK CODE]*	an1	R
HA8150	HAEMATOLOGICAL - LABORATORY RESULTS - AML and ALL	**WHITE BLOOD CELL COUNT (HIGHEST PRE TREATMENT)**	max n3.n1	R

EUROPEAN LEUKAEMIA NET (ELN) GENETIC RISK (ACUTE MYELOID LEUKAEMIA): This is a new data item for v9.0 and is the cytogenetic and molecular analysis of bone marrow (preferably) or blood.

F	Favourable
I	Intermediate
A	Adverse
N	No result

2017 ELN risk stratification by genetics:

Risk category*	**Genetic abnormality**
Favourable	t(8;21)(q22;q22.1); *RUNX1-RUNX1T1*
	inv(16)(p13.1q22) or t(16;16)(p13.1;q22); *CBFB-MYH11*
	Mutated *NPM1* without *FLT3*-ITD or with *FLT3*-ITD^{low}†
	Biallelic mutated *CEBPA*
Intermediate	Mutated *NPM1* and *FLT3*-ITD^{high}†
	Wild-type *NPM1* without *FLT3*-ITD or with *FLT3*-ITD^{low}† (without adverse-risk genetic lesions)
	t(9;11)(p21.3;q23.3); *MLLT3-KMT2A*‡
	Cytogenetic abnormalities not classified as favourable or adverse
Adverse	t(6;9)(p23;q34.1); *DEK-NUP214*
	t(v;11q23.3); *KMT2A* rearranged
	t(9;22)(q34.1;q11.2); *BCR-ABL1*
	inv(3)(q21.3q26.2) or t(3;3)(q21.3;q26.2); *GATA2,MECOM(EVI1)*

Risk category*	Genetic abnormality
	−5 or del(5q); −7; −17/abn(17p)
	Complex karyotype,§ monosomal karyotype‖
	Wild-type *NPM1* and *FLT3*-ITD^{high}†
	Mutated *RUNX1*¶
	Mutated *ASXL1*¶
	Mutated *TP53*#

The addition of 'no result' is also an option for COSD.

More information can be found at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5291965/

WHITE BLOOD CELL COUNT (HIGHEST PRETREATMENT): Highest White blood cell count pre-treatment (x 10^9 per litre). Normally provided by Haematological labs before transfusion/treatment.

Range 0.0 to 999.9 (to 1dp)

HAEMATOLOGICAL – LABORATORY RESULTS – PAEDIATRIC MYELODYSPLASIA

Choice 2

Must be one occurrence if chosen per Core - Laboratory Results (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT7330	HAEMATOLOGICAL - LABORATORY RESULTS - MYELODYSPLASIA	**BONE MARROW BLASTS [BONE MARROW BLAST CELLS PERCENTAGE]**	max n3	R
CT6240	HAEMATOLOGICAL - LABORATORY RESULTS - ALL/AML	**CYTOGENETICS SUBSIDIARY COMMENT** *[CYTOGENETIC FINDINGS COMMENT]*	max an50	R

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.

HAEMATOLOGICAL - LABORATORY RESULTS - PAEDIATRIC MYELODYSPLASIA

Choice 3

Must be one occurrence if chosen per Core – Laboratory Results (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT7340	HAEMATOLOGICAL - LABORATORY RESULTS - PAEDIATRIC MYELODYSPLASIA	**CELLULARITY** *[CELLULARITY PERCENTAGE]*	an max n3	R
CT7350	HAEMATOLOGICAL - LABORATORY RESULTS - PAEDIATRIC MYELODYSPLASIA	**DEB TEST** *[DIEPOXYBUTANE TEST RESULT]*	an1	R
CT7360	HAEMATOLOGICAL - LABORATORY RESULTS - PAEDIATRIC MYELODYSPLASIA	**DYSPLASTIC HAEMOPOIESIS** *[DYSPLASTIC HAEMOPOIESIS TYPE]*	an1	R

CELLULARITY: Percentage value of Cellularity, (%) Range 0 to 100.

DEB TEST: Record the outcome of DEB Test.

P	POSITIVE
N	NEGATIVE
9	Not Known

DYSPLASTIC HAEMOPOIESIS: Record if the bone marrow produced (HAEMOPOIESIS) is Unilineage, Bilineage or Trilineages dysplastic.

1	Unilineage
2	Bilineage
3	Trilineage

HAEMATOLOGICAL - LABORATORY RESULTS – ACUTE LYMPHOBLASTIC LEUKAEMIA – RESPONSE

Choice 4

Must be one occurrence if chosen per Core - Laboratory Results (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT7700	HAEMATOLOGICAL - LABORATORY RESULTS - ACUTE LYMPHOBLASTIC LEUKAEMIA - RESPONSE	**POST INDUCTION MRD** *[PERCENTAGE OF LEUKAEMIC CELLS PRESENT POST MINIMAL RESIDUAL DISEASE INDUCTION]*	an1	M

Note: the following data items have been retired from v9.0:

- D29 BM
- D29 MRD
- D29 STATUS OF EXTRAMEDULLARY

POST INDUCTION MRD: This is a new data item for v9. Percentage of leukaemic cells present at the end of Minimal Residual Disease (MRD) induction.

1	0%
2	<0.01%
3	<0.1%
4	<1%
5	<5%
6	>=5%
9	Unknown

HAEMATOLOGY – CTYA (sub section)

All datasets for Acute Lymphoblastic Leukaemia (ALL) now become age agnostic - if you wish to duplicate them in a CTYA section then fine. Adult and paediatric colleagues have agreed this collaboratively.

HAEMATOLOGICAL – DIAGNOSIS

Must be one occurrence if chosen per Core - Diagnosis (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
HAEMATOLOGICAL - DIAGNOSIS - CHOICE				
HAEMATOLOGICAL - DIAGNOSIS - CHOICE 1				
Start of repeating item - Mixed Phenotype Symptoms (at Diagnosis)				
CT7200	HAEMATOLOGICAL - DIAGNOSIS - MIXED PHENOTYPE ACUTE LEUKAEMIA	**MIXED PHENOTYPE SYMPTOMS (AT DIAGNOSIS)** *[MIXED PHENOTYPE ACUTE LEUKAEMIA SYMPTOMS (AT DIAGNOSIS)]*	an1	R
End of repeating item - Mixed Phenotype Symptoms (at Diagnosis)				
CT7240	HAEMATOLOGICAL - DIAGNOSIS - MIXED PHENOTYPE ACUTE LEUKAEMIA	**EGIL SCORE** *[EUROPEAN GROUP FOR THE IMMUNOLOGICAL CLASSIFICATION OF LEUKAEMIA SCORING SYSTEM SCORE]*	an1	R
END OF HAEMATOLOGICAL - DIAGNOSIS - CHOICE 1				
HAEMATOLOGICAL - DIAGNOSIS - CHOICE 2				
CT7160	HAEMATOLOGICAL - DIAGNOSIS - ACUTE MYELOID LEUKAEMIA	**FAB CLASSIFICATION** *[FRENCH AMERICAN BRITISH CLASSIFICATION (ACUTE MYELOID LEUKAEMIA)]*	max an5	R
CT7170	HAEMATOLOGICAL - DIAGNOSIS - ACUTE MYELOID LEUKAEMIA	**PAEDIATRIC CYTOGENETIC / MOLECULAR GENETIC RISK GROUP** *[CYTOGENETIC RISK GROUP (PAEDIATRIC MOLECULAR GENETIC ABNORMALITIES)]*	an1	R

CT7180	HAEMATOLOGICAL - DIAGNOSIS - ACUTE MYELOID LEUKAEMIA	**AML RISK FACTORS** *[ACUTE MYELOID LEUKAEMIA RISK FACTORS (AT DIAGNOSIS)]*	an1	R
END OF HAEMATOLOGICAL - DIAGNOSIS - CHOICE 2				
HAEMATOLOGICAL - DIAGNOSIS - CHOICE 3				
Start of repeating item - Paediatric Myelodysplasia				
CT7260	HAEMATOLOGICAL - DIAGNOSIS - PAEDIATRIC MYELODYSPLASIA	**PAEDIATRIC MYELODYSPLASIA** *[PAEDIATRIC MYELODYSPLASIA CLINICAL FINDINGS (AT DIAGNOSIS)]*	an1	R*
End of repeating item - Paediatric Myelodysplasia				
Start of repeating item - Underlying Disease Associated with MDS				
CT7270	HAEMATOLOGICAL - DIAGNOSIS - PAEDIATRIC MYELODYSPLASIA	**UNDERLYING DISEASE ASSOCIATED WITH MDS** *[UNDERLYING DISEASE ASSOCIATED WITH MYELODYSPLASIA (AT DIAGNOSIS)]*	an1	R*
End of repeating item - Underlying Disease Associated with MDS				
CT7380	HAEMATOLOGICAL - DIAGNOSIS - PAEDIATRIC MYELODYSPLASIA	**CONGENITAL ANOMALIES** *[CONGENITAL ANOMALIES COMMENTS]*	max an300	R*
Start of repeating item - Myelodysplasia Symptoms at Diagnosis				
CT7310	HAEMATOLOGICAL - DIAGNOSIS - PAEDIATRIC MYELODYSPLASIA	**MYELODYSPLASIA SYMPTOMS AT DIAGNOSIS** *[OTHER 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				

HAEMATOLOGICAL – DIAGNOSIS – MIXED PHENOTYPE ACUTE LEUKAEMIA

Choice 1

Must be one occurrence if chosen per Core – Diagnosis (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
Start of repeating item - *MIXED PHENOTYPE SYMPTOMS (AT DIAGNOSIS)*				
CT7200	CTYA - DIAGNOSIS - MIXED PHENOTYPE ACUTE LEUKAEMIA	**MIXED PHENOTYPE SYMPTOMS (AT DIAGNOSIS)** *[MIXED PHENOTYPE ACUTE LEUKAEMIA SYMPTOMS (AT DIAGNOSIS)]*	an1	R*
End of repeating item - *MIXED PHENOTYPE SYMPTOMS (AT DIAGNOSIS)*				
CT7240	CTYA - DIAGNOSIS - PAEDIATRIC MYELODYSPLASIA	**EGIL SCORE** *[EUROPEAN GROUP FOR THE IMMUNOLOGICAL CLASSIFICATION OF LEUKAEMIA SCORING SYSTEM SCORE]*	an1	R

MIXED PHENOTYPE SYMPTOMS (AT DIAGNOSIS): Record if any of the associated symptoms were present at Diagnosis, multiple symptoms can be submitted.

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.

1	2 - Points
2	1 - Point
3	0.5 - Point

HAEMATOLOGICAL - DIAGNOSIS - ACUTE MYELOID LEUKAEMIA

Choice 2

Must be one occurrence if chosen per Core – Diagnosis (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT7160	CTYA - DIAGNOSIS - ACUTE MYELOID LEUKAEMIA	**FAB CLASSIFICATION** *[FRENCH AMERICAN BRITISH CLASSIFICATION (ACUTE MYELOID LEUKAEMIA)]*	max an5	R
CT7170	CTYA - DIAGNOSIS - ACUTE MYELOID LEUKAEMIA	**PAEDIATRIC CYTOGENETIC / MOLECULAR GENETIC RISK GROUP** *[CYTOGENETIC RISK GROUP (PAEDIATRIC MOLECULAR GENETIC ABNORMALITIES)]*	an1	R
CT7180	CTYA - DIAGNOSIS - ACUTE MYELOID LEUKAEMIA	**AML RISK FACTORS** *[ACUTE MYELOID LEUKAEMIA RISK FACTORS (AT DIAGNOSIS)]*	an1	R

FAB CLASSIFICATION: FAB classification of AML used during diagnosis of acute myeloid leukaemia (AML).

M0	Undifferentiated acute myeloblastic leukaemia
M1	Acute myeloblastic leukaemia with minimal maturation
M2	Acute myeloblastic leukaemia with maturation
M3	Acute promyelocytic leukaemia
M4	Acute myelomonocytic leukaemia
M4EOS	Acute myelomonocytic leukaemia with eosinophilia
M5	Acute monocytic leukaemia
M6	Acute erythroid leukaemia
M7	Acute megakaryocytic leukaemia

PAEDIATRIC CYTOGENETIC / MOLECULAR GENETIC RISK GROUP: Risk groups for ages 0 to 18 – cytogenetic and molecular genetic abnormalities.

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.

1	Denovo
2	High Risk MDS
3	Secondary AML

HAEMATOLOGICAL – DIAGNOSIS – PAEDIATRIC MYELODYSPLASIA

Choice 3

Must be one occurrence if chosen per Core - Diagnosis (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
Start of repeating item - PAEDIATRIC MYELODYSPLASIA				
CT7260	CTYA - DIAGNOSIS - PAEDIATRIC MYELODYSPLASIA	**PAEDIATRIC MYELODYSPLASIA** *[PAEDIATRIC MYELODYSPLASIA CLINICAL FINDINGS (AT DIAGNOSIS)]*	an1	R*
End of repeating item - PAEDIATRIC MYELODYSPLASIA				
Start of repeating item - UNDERLYING DISEASE ASSOCIATED WITH MDS				
CT7270	CTYA - DIAGNOSIS - PAEDIATRIC MYELODYSPLASIA	**UNDERLYING DISEASE ASSOCIATED WITH MDS** *[UNDERLYING DISEASE ASSOCIATED WITH MYELODYSPLASIA (AT DIAGNOSIS)]*	an1	R*
End of repeating item - UNDERLYING DISEASE ASSOCIATED WITH MDS				
CT7380	CTYA - DIAGNOSIS - PAEDIATRIC MYELODYSPLASIA	**CONGENITAL ANOMALIES** *[CONGENITAL ANOMALIES COMMENTS]*	Max300	R*
Start of repeating item - MYELODYSPLASIA SYMPTOMS AT DIAGNOSIS				
CT7310	CTYA - DIAGNOSIS - PAEDIATRIC MYELODYSPLASIA	**MYELODYSPLASIA SYMPTOMS AT DIAGNOSIS** *[OTHER MYELODYSPLASIA SYMPTOMS AT DIAGNOSIS]*	an1	R*
End of repeating item - MYELODYSPLASIA SYMPTOMS AT DIAGNOSIS				

Note: the following data items have been retired from v9.0:

- RISK GROUP ALLOCATION

PAEDIATRIC MYELODYSPLASIA: Record the Paediatric Myelodysplasia clinical findings at Diagnosis, multiple findings can be submitted.

1	De Novo MDS
2	Refractory Cytopenia
3	Refractory Cytopenia with Ringed Sideroblasts
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.

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.

1	Consanguinity
2	Organomegaly at Diagnosis
3	Lymphadenopathy at Diagnosis
4	Severe Infections Prior to Diagnosis
5	Immunodeficiency at Diagnosis

HAEMATOLOGICAL – ACUTE LEUKAEMIAS

This section is a child of 'Core - Treatment. This is a change in v9 from Surgery and Other Procedures.

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT7110	HAEMATOLOGICAL - TREATMENT - ACUTE LEUKAEMIAS	**PRIMARY INDUCTION FAILURE** *[PRIMARY INDUCTION CHEMOTHERAPY FAILURE INDICATOR]*	an1	R

PRIMARY INDUCTION FAILURE: Did the patient fail to achieve morphological remission after induction chemotherapy? This is a Haematological CYTA required data item.

Y	Yes
N	No
9	Not Known

HAEMATOLOGICAL – MOLECULAR AND BIOMARKERS – SOMATIC TESTING FOR TARGETED THERAPY AND PERSONALISTED THERAPY – NON HODGKIN LYMPHOMA

This group child of Core - Molecular and Biomarker - Somatic Testing for Targeted Therapy and Personalised Medicine group and mandates the date of the test and the organisation details of the lab that processed the sample.

May be up to one occurrence per Core - Molecular and Biomarkers - Somatic Testing for Targeted Therapy and Personalised Medicine (0..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT6260	HAEMATOLOGICAL - MOLECULAR AND BIOMARKERS - SOMATIC TESTING FOR TARGETED THERAPY AND PERSONALISTED THERAPY - NON HODGKIN LYMPHOMA	**ALK FUSION STATUS FOR ALCL** *[ALK GENE FUSION STATUS (ANAPLASTIC LARGE CELL LYMPHOMA)]*	an1	M

ALK FUSION STATUS FOR ALCL: The Anaplastic Lymphoma Kinase (ALK) protein is expressed in a subset of ALCL, due to underlying gene fusion events. Its presence or absence distinguishes prognostically important subsets of this diagnosis.

This should be available for the MDT discussion but will only apply to a small number of cases.

~~P~~	~~ALK - POSITIVE~~
~~N~~	~~ALK - NEGATIVE~~
1	Positive
2	Negative
3	Indeterminate/Test Failed
8	Not Applicable (Not Tested)
9	Not Known

HEAD and NECK

Overview

In the first phase of implementing the COSD, the site specific Head and Neck data items will be collected once pre-treatment and at least once post treatment. The assessment information should be recorded 12 months post diagnosis as a minimum, and annually thereafter, if possible.

ICD-10 CODES

Key:
() = if applicable
* = different data set from CWT group specified

ICD-10 All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C00.0	External upper lip	Head and Neck		•		
C00.1	External lower lip	Head and Neck		•		
C00.2	External lip, unspecified	Head and Neck		•		
C00.3	Upper lip, inner aspect	Head and Neck	•			
C00.4	Lower lip, inner aspect	Head and Neck	•			
C00.5	Lip, unspecified, inner aspect	Head and Neck	•			
C00.6	Commissure of lip	Head and Neck	•			
C00.8	Overlapping lesion of lip	Head and Neck	•			
C00.9	Lip, unspecified	Head and Neck	•			
C01	Malignant neoplasm of base of tongue	Head and Neck	•			
C02.0	Dorsal surface of tongue	Head and Neck	•			
C02.1	Border of tongue	Head and Neck	•			
C02.2	Ventral surface of tongue	Head and Neck	•			
C02.3	Anterior two-thirds of tongue, part unspecified	Head and Neck	•			
C02.4	Lingual tonsil	Head and Neck	•			
C02.8	Overlapping lesion of tongue	Head and Neck	•			

C02.9	Tongue, unspecified	Head and Neck	•			
C03.0	Upper gum	Head and Neck	•			
C03.1	Lower gum	Head and Neck	•			
C03.9	Gum, unspecified	Head and Neck	•			
C04.0	Anterior floor of mouth	Head and Neck	•			
C04.1	Lateral floor of mouth	Head and Neck	•			
C04.8	Overlapping lesion of floor of mouth	Head and Neck	•			
C04.9	Floor of mouth, unspecified	Head and Neck	•			
C05.0	Hard palate	Head and Neck	•			
C05.1	Soft palate	Head and Neck	•			
C05.2	Uvula	Head and Neck	•			
C05.8	Overlapping lesion of palate	Head and Neck	•			
C05.9	Palate, unspecified	Head and Neck	•			
C06.0	Cheek mucosa	Head and Neck	•			
C06.1	Vestibule of mouth	Head and Neck	•			
C06.2	Retromolar area	Head and Neck	•			
C06.8	Overlapping lesion of other and unspecified parts of mouth	Head and Neck	•			
C06.9	Mouth, unspecified	Head and Neck	•			
C07	Malignant neoplasm of parotid gland	Head and Neck	•			
C08.0	Submandibular gland	Head and Neck	•			
C08.1	Sublingual gland	Head and Neck	•			
C08.8	Overlapping lesion of major salivary glands	Head and Neck	•			
C08.9	Major salivary gland, unspecified	Head and Neck	•			
C09.0	Tonsillar fossa	Head and Neck	•			
C09.1	Tonsillar pillar (anterior) (posterior)	Head and Neck	•			
C09.8	Overlapping lesion of tonsil	Head and Neck	•			
C09.9	Tonsil, unspecified	Head and Neck	•			
C10.0	Vallecula	Head and Neck	•			
C10.1	Anterior surface of epiglottis	Head and Neck	•			
C10.2	Lateral wall of oropharynx	Head and Neck	•			
C10.3	Posterior wall of oropharynx	Head and Neck	•			

C10.4	Branchial cleft	Head and Neck	•			
C10.8	Overlapping lesion of oropharynx	Head and Neck	•			
C10.9	Oropharynx, unspecified	Head and Neck	•			
C11.0	Superior wall of nasopharynx	Head and Neck	•			
C11.1	Posterior wall of nasopharynx	Head and Neck	•			
C11.2	Lateral wall of nasopharynx	Head and Neck	•			
C11.3	Anterior wall of nasopharynx	Head and Neck	•			
C11.8	Overlapping lesion of nasopharynx	Head and Neck	•			
C11.9	Nasopharynx, unspecified	Head and Neck	•			
C12	Malignant neoplasm of pyriform sinus	Head and Neck	•			
C13.0	Postcricoid region	Head and Neck	•			
C13.1	Aryepiglottic fold, hypopharyngeal aspect	Head and Neck	•			
C13.2	Posterior wall of hypopharynx	Head and Neck	•			
C13.8	Overlapping lesion of hypopharynx	Head and Neck	•			
C13.9	Hypopharynx, unspecified	Head and Neck	•			
C14.0	Pharynx, unspecified	Head and Neck	•			
C14.2	Waldeyer's ring	Head and Neck	•			
C14.8	Overlapping lesion of lip, oral cavity and pharynx	Head and Neck	•			
C15.0	*Cervical part of oesophagus*	*Upper Gastrointestinal*	*			*Usually treated by Head & Neck MDT.*
C30.0	Nasal cavity	Head and Neck	•			
C30.1	Middle ear	Head and Neck	•			
C31.0	Maxillary sinus	Head and Neck	•			
C31.1	Ethmoidal sinus	Head and Neck	•			
C31.2	Frontal sinus	Head and Neck	•			
C31.3	Sphenoidal sinus	Head and Neck	•			
C31.8	Overlapping lesion of accessory sinuses	Head and Neck	•			
C31.9	Accessory sinus, unspecified	Head and Neck	•			
C32.0	Glottis	Head and Neck	•			
C32.1	Supraglottis	Head and Neck	•			
C32.2	Subglottis	Head and Neck	•			
C32.3	Laryngeal cartilage	Head and Neck	•			
C32.8	Overlapping lesion of larynx	Head and Neck	•			

C32.9	Larynx, unspecified	Head and Neck	•			
C73	Malignant neoplasm of thyroid gland	Head and Neck		•		
C77.0	Lymph nodes of head, face and neck	Head and Neck	•			Secondary - only use if unable to code to specific primary site
D00.0	Carcinoma in situ of Lip, oral cavity and pharynx	Head and Neck			•	
D02.0	Carcinoma in situ of Larynx	Head and Neck			•	
D09.3	Carcinoma in situ of thyroid and other endocrine glands	Head and Neck			•	
D37.0	Neoplasm of uncertain or unknown behaviour of lip, oral cavity and pharynx	Head and Neck			•	
D38.0	Neoplasm of uncertain or unknown behaviour of Larynx	Head and Neck			•	
D44.0	Neoplasm of uncertain or unknown behaviour of thyroid gland	Head and Neck			•	

HEAD AND NECK – TREATMENT – SURGERY

This section is a child of 'Core – Treatment. This is a change in v9 from Surgery and Other Procedures, 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 for v9. 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
HN9300	HEAD AND NECK - TREATMENT - SURGERY	**SURGICAL ACCESS TYPE** *[SURGICAL ACCESS TYPE (HEAD AND NECK CANCER)]*	an1	R
HN9310	HEAD AND NECK - TREATMENT - SURGERY	**OTHER SURGICAL ACCESS TYPE** *[OTHER SURGICAL ACCESS TYPE (HEAD AND NECK CANCER)]*	an60	R

SURGICAL ACCESS TYPE: This is a new data item for v9. Select the appropriate surgical access type used for the patent's operation from the agreed types.

1	Mandibulotomy
2	Lip split and Mandibulotomy
3	Weber Ferguson Approach
4	Drop Through the Neck
8	Other (Specify)
9	Not Known (not recorded)

OTHER SURGICAL ACCESS TYPE: This is a new data item for v9. If [8 - Other (Specify)] is selected in the Head and Neck - Surgical Access Type field, specify what surgical access type was used.

HEAD AND NECK – PRE-TREATMENT ASSESSMENT

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
HN9060	HEAD AND NECK - PRE TREATMENT ASSESSMENT	**CANCER DENTAL ASSESSMENT DATE**	an10 ccyy-mm-dd	R
HN9050	HEAD AND NECK - PRE TREATMENT ASSESSMENT	**CARE CONTACT DATE (DIETICIAN INITIAL)**	an10 ccyy-mm-dd	R
HN9200	HEAD AND NECK - PRE TREATMENT ASSESSMENT	**CARE CONTACT DATE (SLT INITIAL)** *[CARE CONTACT DATE (SPEECH AND LANGUAGE THERAPIST INITIAL)]*	an10 ccyy-mm-dd	R

CANCER DENTAL ASSESSMENT DATE: The date of the first dental assessment by a dentally qualified practitioner, which contributes to preparation for treatment, (this is a person who the Multi-Disciplinary Team considers suitably qualified to carry out the pre-treatment dental assessment of the patient).

CARE CONTACT DATE (DIETICIAN INITIAL): The date that the patient was first assessed by a dietician.

CARE CONTACT DATE (SLT INITIAL): The date that the patient was first assessed by a speech and language therapist.

HEAD AND NECK – POST-TREATMENT ASSESSMENT

The assessment information should be recorded 12 months post diagnosis as a minimum, and annually thereafter, if possible.

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
HN9000	HEAD AND NECK - POST TREATMENT ASSESSMENT	**CLINICAL STATUS ASSESSMENT DATE (CANCER)**	an10 ccyy-mm-dd	R
HN9010	HEAD AND NECK - POST TREATMENT ASSESSMENT	**PRIMARY TUMOUR STATUS**	an1	R
HN9020	HEAD AND NECK - POST TREATMENT ASSESSMENT	**NODAL STATUS**	an1	R
HN9030	HEAD AND NECK - POST TREATMENT ASSESSMENT	**METASTATIC STATUS**	an1	R
HN9080	HEAD AND NECK - POST TREATMENT ASSESSMENT	**SPEECH & LANGUAGE ASSESSMENT DATE** *[SPEECH AND LANGUAGE ASSESSMENT DATE]*	an10 ccyy-mm-dd	R

CLINICAL STATUS ASSESSMENT DATE (CANCER): The date on which a clinical assessment was performed.

PRIMARY TUMOUR STATUS: The status of the primary tumour at this follow-up contact.

1	Residual primary tumour
2	No evidence of primary tumour
3	Recurrent primary tumour
4	Not assessed
5	Uncertain

NODAL STATUS: The status of the regional nodal metastases at this follow-up contact.

1	Residual regional nodal metastases
2	No evidence of regional nodal metastases
3	New regional nodal metastases
4	Not assessed
5	Uncertain

METASTATIC STATUS: The status of the distant metastases at this follow-up contact.

1	Residual distant metastases
2	No evidence of metastases
3	New distant metastases
4	Not assessed
5	Uncertain

SPEECH & LANGUAGE ASSESSMENT DATE: Record the date of contact where assessment swallowing occurs following completion of treatment.

Whilst ideally data is entered at each contact after completion of treatment, key point of recording is at 6 months post cancer care plan agreed date. (Please note: this is not the same data item as First SLT Contact Date, which is included in the DAHNO data set from November 2012).

LIVER and CHOLANGIOCARCINOMA

Overview

This data set has now been expanded to include both the collection of Liver and Cholangiocarcinoma, on the advice of the Expert Advisory Group (EAG). 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.

The addition C22.1 and C24.0 have been added to the ICD table below to be used in conjunction with the new data item LV16400 (CHOLANGIOCARCINOMA CATEGORY). 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.

There is a HCC staging calculator available here.

ICD-10 CODES

Key:
() = if applicable
* = different data set from CWT group specified

ICD-10 All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C22.0	Liver cell carcinoma	Upper Gastrointestinal	•			Liver cell carcinoma is also known as HCC.
C22.1	Intrahepatic bile duct carcinoma	Upper Gastrointestinal	•			BCLC stage and date are not applicable
C22.2	Hepatoblastoma	Upper Gastrointestinal	•			BCLC stage and date are not applicable
C22.3	Angiosarcoma of liver	Upper Gastrointestinal	•			BCLC stage and date are not applicable
C22.4	Other sarcomas of liver	Upper Gastrointestinal	•			BCLC stage and date are not applicable

C22.7	Other specified carcinomas of liver	Upper Gastrointestinal	•			BCLC stage and date are not applicable
C22.9	Liver, unspecified	Upper Gastrointestinal	•			BCLC stage and date are not applicable
C24.0	Extrahepatic bile duct	Upper Gastrointestinal	•			BCLC stage and date are not applicable
C78.7	Secondary malignant neoplasm of liver and intrahepatic bile duct	Upper Gastrointestinal		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
D01.5	Carcinoma in situ of Liver, gallbladder and bile ducts	Upper Gastrointestinal			•	Liver cell carcinoma is also known as HCC.
D37.6	Liver, gallbladder and bile ducts	Upper Gastrointestinal			•	

LIVER – DIAGNOSIS

This is a child of Core – Diagnosis group

May be up to one occurrence per Core – Diagnosis (0..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
LV16000	LIVER - DIAGNOSIS	**LIVER SURVEILLANCE SCANS** *[LIVER CANCER SURVEILLANCE SCAN INDICATOR]*	an1	R
LV16010	LIVER - DIAGNOSIS	**LIVER CIRRHOSIS TYPE**	an1	R
Start of repeating item - Cause of Liver Cirrhosis				
LV16020	LIVER - DIAGNOSIS	**CAUSE OF LIVER CIRRHOSIS** *[LIVER CIRRHOSIS CAUSE TYPE]*	an2	R
End of repeating item - Cause of Liver Cirrhosis				

Note: the following data item has been moved to CORE - Risk Factors from v9.0:

- DIABETES INDICATOR

LIVER SURVEILLANCE SCANS: Has the patient had regular 6 monthly liver ultrasound scans for the purpose of early detection of HCC?

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.

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.

01	Alcohol excess
02	Hepatitis B virus infection
03	Hepatitis C virus infection
04	Non alcohol related fatty liver disease
05	Hereditary haemochromatosis
06	Autoimmune hepatitis
07	Primary sclerosing cholangitis
~~8~~	~~Other~~
~~9~~	~~Not known~~
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.

LIVER – DIAGNOSIS – CHOLANGIOCARCINOMA

This section is a child of ‘Core – Diagnosis and is new for v9:

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
LV16400	LIVER - DIAGNOSIS - CHOLANGIOCARCINOMA	**CHOLANGIOCARCINOMA CATEGORY** *[CHOLANGIOCARCINOMA PRESENCE CATEGORY]*	an1	M

CHOLANGIOCARCINOMA CATEGORY: This is a new section for COSD v9, to help identify the individual components of Cholangiocarcinoma. State where the Cholangiocarcinoma is present, using the designated categories. Any cholangiocarcinoma which involves the anatomical hilum of the liver must be classified as perihilar.

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.

LIVER – STAGING

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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
LV16100	LIVER - SITE SPECIFIC STAGING	**BARCELONA CLINIC LIVER CANCER (BCLC) STAGE** *[BARCELONA CLINIC LIVER CANCER STAGE]*	an1	M

Note: the following data item has been retired from v9.0:

- BARCELONA CLINIC LIVER CANCER (BCLC) STAGE DATE

BARCELONA CLINIC LIVER CANCER (BCLC) STAGE: 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).

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. Additional information about the size of the largest lesion diagnosed as HCC can be provided in the core dataset (item no. CR0350). The Alpha-fetoprotein (AFP) should also be provided, if known (item no. CT6520).

BARCELONA CLINIC LIVER CANCER (BCLC) STAGE DATE: This field is now collected via the 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
- the organisation who carried out the stage
- the stage itself

This item should only be completed for hepatocellular carcinomas (C220).

LIVER – TREATMENT AND PROGNOSTIC INDICATORS

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
LV16120	LIVER - TREATMENT AND PROGNOSTIC INDICATORS	**PORTAL INVASION** *[PORTAL VEIN INVASION INDICATION CODE]*	an1	R

LV16130	LIVER - TREATMENT AND PROGNOSTIC INDICATORS	**UKELD SCORE** *[UNITED KINGDOM MODEL FOR END-STAGE LIVER DISEASE SCORE]*	max n2	R
LV16140	LIVER - TREATMENT AND PROGNOSTIC INDICATORS	**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.

1	Branch
2	Main
3	Not present
9	Not known

Additional information

This information is available from imaging review

Rationale for inclusion

Tumours 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 here.

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: This is a new data item for v9. Record the overall Child-Pugh score. This is the level of disease of the liver.

A	Child-Pugh A
B	Child-Pugh B
C	Child-Pugh C

LIVER – TREATMENT

This section is a child of 'Core - Treatment. This is a change in v9 from Surgery and Other Procedures, 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 for v9. 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
LV16300	LIVER - TREATMENT	**ABLATIVE THERAPY TYPE**	an1	R
LV16320	LIVER - TREATMENT	**EMBOLISATION MODALITY** *[LIVER TRANSARTERIAL EMBOLISATION MATERIAL INJECTION TYPE]*	an1	R

Note: the following data item has been retired from v9.0:

- HCC EMBOLISATION

ABLATIVE THERAPY TYPE: Describe type of ablative (such as locally destructive treatment) therapy used if any.

~~N~~	~~None~~
R	Radiofrequency ablation
M	Microwave ablation
8	Other ablative treatment
9	Not known

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?

1	TAE/BLAND
2	C-TACE
3	DEB-TACE
4	RO DEB-TACE
5	SIRT
9	Not Known

This refers to the type of material injected into the hepatic artery:

- TAE/BLAND - Transarterial Embolism, Embolic agents such as coils or foam only
- C-TACE - standard chemotherapy drug
- DEB-TACE - drug eluting beads coated with chemotherapy
- RO DEB-TACE - radiopaque drug eluting beads loaded with chemotherapy
- SIRT - Y90 radio-embolisation

Additional information

Transarterial (chemo-) embolisation (TA[C]E) is the most frequently used treatment for persons with HCC

Embolisation can be done in 3 ways:

1. Without chemotherapy or radiotherapy - so called “Bland” embolisation or TAE.
2. With chemotherapy – TACE.
3. With local radiotherapy – so called selective internal radiotherapy (SIRT).

If chemoembolisation is done, the following methods can be used:

- standard chemotherapy – “C-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.

LIVER – TRANSPLANTATION

This is a new section and is a change in v9 from Surgery and Other Procedures.

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
LV16200	LIVER - TRANSPLANTATION	**LIVER TRANSPLANTATION** *[LIVER TRANSPLANT WAITING LIST INDICATOR]*	an1	R

LIVER TRANSPLANTATION: Was the patient listed for transplantation?

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.

LIVER – TREATMENT – SURGERY

This section is a child of 'Core - Treatment. This is a change in v9 from Surgery and Other Procedures, 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 for v9. 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
LV16210	LIVER - TREATMENT - SURGERY	**SURGERY TYPE** *[LIVER SURGERY PERFORMED TYPE]*	an1	R

SURGERY TYPE: What type of liver surgery was performed?

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.

LUNG

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.

Site specific data items have been aligned between the COSD and the National Lung Cancer Audit.

ICD-10 CODES

Key:
() = if applicable
* = different data set from CWT group specified

ICD-10 All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C33	Malignant neoplasm of trachea	Lung	•			
C34.0	Main bronchus	Lung	•			
C34.1	Upper lobe, bronchus or lung	Lung	•			
C34.2	Middle lobe, bronchus or lung	Lung	•			
C34.3	Lower lobe, bronchus or lung	Lung	•			
C34.8	Overlapping lesion of bronchus and lung	Lung	•			
C34.9	Bronchus or lung, unspecified	Lung	•			
C37	Malignant neoplasm of thymus	Lung	•			
C38.0	Heart	Lung		•		
C38.1	Anterior mediastinum	Lung		•		
C38.2	Posterior mediastinum	Lung		•		
C38.3	Mediastinum, part unspecified	Lung		•		
C38.4	Pleura	Lung		•		

C38.8	Overlapping lesion of heart, mediastinum and pleura	Lung		•		
C39.0	Upper respiratory tract, part unspecified	Lung		•		
C39.8	Overlapping lesion of respiratory and intrathoracic organs	Lung		•		
C39.9	Ill-defined sites within the respiratory system	Lung		•		
C45.0	Mesothelioma of pleura	Lung		•		
C45.1	Mesothelioma of peritoneum	Lung		•		
C45.2	Mesothelioma of pericardium	Lung		•		
C45.7	Mesothelioma of other sites	Lung		•		
C45.9	Mesothelioma, unspecified	Lung		•		
C78.0	Secondary malignant neoplasm of lung	Lung		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C78.1	Secondary malignant neoplasm of mediastinum	Lung		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C78.2	Secondary malignant neoplasm of pleura	Lung		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C78.3	Secondary malignant neoplasm of other and unspecified respiratory organs	Lung		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
D02.1	Carcinoma in situ of Trachea	Lung			•	
D02.2	Carcinoma in situ of Bronchus and lung	Lung			•	
D02.3	Carcinoma in situ of Other parts of respiratory system	Lung			•	
D02.4	Carcinoma in situ of Respiratory system, unspecified	Lung			•	
D38.1	Neoplasm of uncertain or unknown behaviour of Trachea, bronchus and lung	Lung			•	
D38.2	Neoplasm of uncertain or unknown behaviour of Pleura	Lung			•	

D38.3	Neoplasm of uncertain or unknown behaviour of Mediastinum	Lung			•	
D38.4	Neoplasm of uncertain or unknown behaviour of Thymus	Lung			•	
D38.5	Neoplasm of uncertain or unknown behaviour of Other respiratory organs	Lung			•	
D38.6	Neoplasm of uncertain or unknown behaviour of Respiratory organ, unspecified	Lung			•	

LUNG – DIAGNOSTIC PROCEDURES

This is a new section in v9 and 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.

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
LUNG - DIAGNOSTIC PROCEDURES CHOICE				
LUNG - DIAGNOSTIC PROCEDURES - CHOICE 1				
LU10350	LUNG - DIAGNOSTIC PROCEDURES - TRANSTHORACIC ECHOCARDIOGRAM	**TRANSTHORACIC ECHOCARDIOGRAM RESULT**	max n3	M
END OF LUNG - DIAGNOSTIC PROCEDURES - CHOICE 1				
LUNG - DIAGNOSTIC PROCEDURES - CHOICE 2				
LU10310	LUNG - DIAGNOSTIC PROCEDURES - DIFFUSION CAPACITY	**DIFFUSION CAPACITY (DLCO or TLCO) RESULT** *[DIFFUSION CAPACITY TEST RESULT]*	max n3	M
END OF LUNG - DIAGNOSTIC PROCEDURES - CHOICE 2				
LUNG - DIAGNOSTIC PROCEDURES - CHOICE 3				
LU10040	LUNG - DIAGNOSTIC PROCEDURES - FEV1	**FEV1 PERCENTAGE** *[FORCED EXPIRATORY VOLUME IN 1 SECOND (PERCENTAGE)]*	max n3	R
LU10050	LUNG - DIAGNOSTIC PROCEDURES - FEV1	**FEV1 ABSOLUTE VALUE** *[FORCED EXPIRATORY VOLUME IN 1 SECOND (ABSOLUTE AMOUNT)]*	n1.n2	R
END OF LUNG - DIAGNOSTIC PROCEDURES - CHOICE 3				
LUNG - DIAGNOSTIC PROCEDURES - CHOICE 4				
LU10420	LUNG - DIAGNOSTIC PROCEDURES - CARDIOPULMONARY TEST	**CARDIOPULMONARY TEST TYPE** *[CARDIOPULMONARY EXERCISE TEST TYPE]*	an1	R
LU10370	LUNG - DIAGNOSTIC PROCEDURES - CARDIOPULMONARY TEST	**CARDIOPULMONARY EXERCISE TEST RESULT (NLCA)** *[CARDIOPULMONARY EXERCISE TEST RESULT]*	max n3	R
END OF LUNG - DIAGNOSTIC PROCEDURES - CHOICE 4				
LUNG - DIAGNOSTIC PROCEDURES - CHOICE 5				

LU10400	LUNG - DIAGNOSTIC PROCEDURES - BRONCHOSCOPY	**BRONCHOSCOPY PERFORMED TYPE**	an1	M
END OF LUNG - DIAGNOSTIC PROCEDURES - CHOICE 5				
END OF LUNG - DIAGNOSTIC PROCEDURES CHOICE				

Note: the following data items form a 5-choice menu and Can be one occurrence per Core – Diagnostic Procedure group (0..1), additional information is supplied below each choice to support this linkage.

LUNG – DIAGNOSTIC PROCEDURES – TRANSTHORACIC ECHOCARDIOGRAM

Choice 1

Must be one occurrence if chosen per Core - Diagnostic Procedures (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
LU10350	LUNG - DIAGNOSTIC PROCEDURES - TRANSTHORACIC ECHOCARDIOGRAM	**TRANSTHORACIC ECHOCARDIOGRAM RESULT** *[TRANSTHORACIC ECHOCARDIOGRAM TEST RESULT]*	Max n3	M

Note: the following data items have been retired from v9.0:

- TRANSTHORACIC ECHOCARDIOGRAM DATE

TRANSTHORACIC ECHOCARDIOGRAM RESULT: The Transthoracic Echocardiogram left ventricular ejection fraction result (% range 0-100).

Additional information

- OPCS code - U20.1
- SNOMED CT code - 434158009

Note: it is possible that these codes change over time, it is the responsibility of the reporting Trust to ensure correct codes are used.

LUNG – DIAGNOSTIC PROCEDURES – DIFFUSION CAPACITY

Choice 2

Must be one occurrence if chosen per Core - Diagnostic Procedures (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
LU10310	LUNG - DIAGNOSTIC PROCEDURES - DIFFUSION CAPACITY	**DIFFUSION CAPACITY (DLCO or TLCO) RESULT** *[DIFFUSION CAPACITY TEST RESULT]*	Max n3	M

Note:the following data items have been retired from v9.0:

- DIFFUSION CAPACITY (DLCO or TLCO) DATE

DIFFUSION CAPACITY (DLCO or TLCO) RESULT: 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.

LUNG – DIAGNOSTIC PROCEDURES – FEV1

Choice 3

Must be one occurrence if chosen per Core - Diagnostic Procedures (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
LU10040	LUNG - DIAGNOSTIC PROCEDURES - FEV1	FEV1 PERCENTAGE *[FORCED EXPIRATORY VOLUME IN 1 SECOND (PERCENTAGE)]*	max n3	R
LU10050	LUNG - DIAGNOSTIC PROCEDURES - FEV1	FEV1 ABSOLUTE VALUE *[FORCED EXPIRATORY VOLUME IN 1 SECOND (ABSOLUTE AMOUNT)]*	n1.n2	R

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.

LUNG – DIAGNOSTIC PROCEDURES – CARDIOPULMONARY TEST

Choice 4

Must be one occurrence if chosen per Core - Diagnostic Procedures (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
LU10420	LUNG - DIAGNOSTIC PROCEDURES - CARDIOPULMONARY TEST	**CARDIOPULMONARY TEST TYPE** *[CARDIOPULMONARY EXERCISE TEST TYPE]*	an1	R
LU10370	LUNG - DIAGNOSTIC PROCEDURES - CARDIOPULMONARY TEST	**CARDIOPULMONARY EXERCISE TEST RESULT (NLCA)** *[CARDIOPULMONARY EXERCISE TEST RESULT]*	Max n3	R

Note: The following data items have been retired from v9.0:

- CARDIOPULMONARY EXERCISE TEST DATE

CARDIOPULMONARY TEST TYPE: Indicate which cardiopulmary test was used.

1	Incremental Shuttle Walk Test (ISWT)
2	Oxygen Consumption (VO2)

CARDIOPULMONARY EXERCISE TEST RESULT (NLCA): The Cardiopulmonary Exercise Test result (% predicted range 0-200).

Additional information

- OPCS code - U19.4
- SNOMED CT code - 276341003

Note: it is possible that these codes change over time, it is the responsibility of the reporting Trust to ensure correct codes are used.

LUNG – DIAGNOSTIC PROCEDURES –BRONCHOSCOPY

Choice 5

Must be one occurrence if chosen per Core - Diagnostic Procedures (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
LU10400	LUNG - DIAGNOSTIC PROCEDURES - BRONCHOSCOPY	**BRONCHOSCOPY PERFORMED TYPE**	an1	M

Note: the following data items have been retired from v9.0:

- PROCEDURE DATE BRONCHOSCOPY
- BRONCHOSCOPY PERFORMED INDICATOR

BRONCHOSCOPY PERFORMED TYPE: This is a new data item for v9. What type of bronchoscopy performed on the patient?

1	Flexible Bronchoscopy
2	Rigid Bronchoscopy
3	Endobronchial Ultrasound (EBUS) - Diagnostic
4	Endobronchial Ultrasound (EBUS) - Staging
9	Not known

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

Note: 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.

LUNG – MEDIASTINAL SAMPLING

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
LU10060	LUNG - MEDIASTINAL SAMPLING	**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.

Y	Yes
N	No
9	Not known

LUNG – MOLECULAR AND BIOMARKERS – SOMATIC TESTING FOR TARGETED THERAPY AND PERSONALISED MEDICINE

This is a new section in v9 and replaces Lung - Biomarkers. This is also a child of Core – Molecular And Biomarkers – Somatic Testing For Targeted Therapy And Personalised Medicine.

This mandates the collection of the following data items alongside each data item:

- Organisation Identifier Of Reporting Laboratory
- Date Gene Or Stratification Biomarker Reported

May be up to one occurrence per Core - Molecular and Biomarkers - Somatic Testing for Targeted Therapy and Personalised Medicine (0..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
LU10090	LUNG - MOLECULAR AND BIOMARKERS - SOMATIC TESTING FOR TARGETED THERAPY AND PERSONALISED MEDICINE	**EPIDERMAL GROWTH FACTOR RECEPTOR MUTATIONAL STATUS**	an2	R
LU10500	LUNG - MOLECULAR AND BIOMARKERS - SOMATIC TESTING FOR TARGETED THERAPY AND PERSONALISED MEDICINE	**ALK FUSION STATUS** *[ALK GENE FUSION STATUS (LUNG CANCER]*	an1	R
LU10510	LUNG - MOLECULAR AND BIOMARKERS - SOMATIC TESTING FOR TARGETED THERAPY AND PERSONALISED MEDICINE	**ROS1 FUSION STATUS** *[ROS1 FUSION STATUS]*	an1	R

LU10520	LUNG - MOLECULAR AND BIOMARKERS - SOMATIC TESTING FOR TARGETED THERAPY AND PERSONALISED MEDICINE	**PD-L1 EXPRESSION** *[PD-L1 EXPRESSION PERCENTAGE]*	an1	R

EPIDERMAL GROWTH FACTOR RECEPTOR MUTATIONAL STATUS: Select the recorded outcome for the Epidermal Growth Factor Receptor Mutational Status.

~~3~~	~~Failed analysis~~
~~4~~	~~Not assessed~~
~~5~~	~~Wild type/non-sensitising mutation~~
~~6~~	~~Sensitising/activating mutation~~
07	Wild type
08	Sensitising/activating mutation(s) only
09	Resistance mutation (to 1st gen TKIs) – with or without other mutation
98	Not Applicable (Not Assessed)
99	Not Known (Failed analysis)

ALK FUSION STATUS: This is a new data item for v9. Select the recorded outcome for the Anaplastic Lymphoma Kinase (ALK) Gene Fusion Status.

1	Positive
2	Negative
3	Indeterminate/Test Failed
8	Not Applicable (Not Tested)
9	Not Known

ROS1 FUSION STATUS: This is a new data item for v9. Select the recorded outcome for the ROS1 Gene Fusion Status.

1	Positive
2	Negative
3	Indeterminate/Test Failed
8	Not Applicable (Not Tested)
9	Not Known

PD-L1 EXPRESSION: This is a new data item for v9. Select the recorded outcome for the PD-L1 Expression percentage.

1	Not Tested
2	<1%
3	1% - 50%
4	>50%
5	Indeterminate/Test Failed
9	Not Known

It is possible that some legacy data may not have all the required mandatory fields for v9. 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 – TREATMENT – SURGERY – LCCOP

This is a child of Core - Treatment in v9. This is a change in v9 from Surgery and Other Procedures, 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
LU10390	LUNG - TREATMENT - SURGERY - LCCOP	**REGIONAL ANAESTHETIC TECHNIQUE** *[REGIONAL ANAESTHETIC TECHNIQUE (CANCER)]*	an1	R

REGIONAL ANAESTHETIC TECHNIQUE: Record the regional anaesthetic technique used on the patient.

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 for v9. 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).

SARCOMA

Overview

Sarcomas can arise within any site of the body and should have the ICD 10 site code of that part of the body and the morphology code stated for 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").

As much information as possible is required in order to accurately reflect the sarcoma subsite. For tumours coded under the C46 ICD-10 codes only the CORE data set needs to be completed.

ICD-10 CODES

Key:
() = if applicable
* = different data set from CWT group specified

ICD-10 All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C40.0	Scapula and long bones of upper limb	Sarcoma	•			
C40.1	Short bones of upper limb	Sarcoma	•			
C40.2	Long bones of lower limb	Sarcoma	•			
C40.3	Short bones of lower limb	Sarcoma	•			
C40.8	Overlapping lesion of bone and articular cartilage of limbs	Sarcoma	•			
C40.9	Bone and articular cartilage of limb, unspecified	Sarcoma	•			
C41.0	Bones of skull and face	Sarcoma	•			
C41.1	Mandible	Sarcoma	•			
C41.2	Vertebral column	Sarcoma	•			
C41.3	Ribs, sternum and clavicle	Sarcoma	•			

C41.4	Pelvic bones, sacrum and coccyx	Sarcoma	●			
C41.8	Overlapping lesion of bone and articular cartilage	Sarcoma	●			
C41.9	Bone and articular cartilage, unspecified	Sarcoma	●			
C46.0	Kaposi sarcoma of skin	Sarcoma		●		
C46.1	Kaposi sarcoma of soft tissue	Sarcoma		●		
C46.2	Kaposi sarcoma of palate	Sarcoma		●		
C46.3	Kaposi sarcoma of lymph nodes	Sarcoma		●		
C46.7	Kaposi sarcoma of other sites	Sarcoma		●		
C46.8	Kaposi sarcoma of multiple organs	Sarcoma		●		
C46.9	Kaposi sarcoma, unspecified	Sarcoma		●		
C47.0	Peripheral nerves of head, face and neck	Brain/Central Nervous System		●		Usually treated by Sarcoma MDT.
C47.1	Peripheral nerves of upper limb, including shoulder	Brain/Central Nervous System		●		Usually treated by Sarcoma MDT.
C47.2	Peripheral nerves of lower limb, including hip	Brain/Central Nervous System		●		Usually treated by Sarcoma MDT.
C47.3	Peripheral nerves of thorax	Brain/Central Nervous System		●		Usually treated by Sarcoma MDT.
C47.4	Peripheral nerves of abdomen	Brain/Central Nervous System		●		Usually treated by Sarcoma MDT.
C47.5	Peripheral nerves of pelvis	Brain/Central Nervous System		●		Usually treated by Sarcoma MDT.
C47.6	Peripheral nerves of trunk, unspecified	Brain/Central Nervous System		●		Usually treated by Sarcoma MDT.
C47.8	Overlapping lesion of peripheral nerves and autonomic nervous system	Brain/Central Nervous System		●		Usually treated by Sarcoma MDT.
C47.9	Peripheral nerves and autonomic nervous system, unspecified	Brain/Central Nervous System		●		Usually treated by Sarcoma MDT.
C48.0	Retroperitoneum	Sarcoma	●			Usually treated by Sarcoma MDT.
C48.1	Specified parts of peritoneum	Sarcoma	● *			* Sarcoma and Gynaecological Data sets to be collected where applicable.

C48.2	Peritoneum, unspecified	Sarcoma	● *			* Sarcoma and Gynaecological Data sets to be collected where applicable.
C48.8	Overlapping lesion of retroperitoneum and peritoneum	Sarcoma	●			
C49.0	Connective and soft tissue of head, face and neck	Sarcoma	●			
C49.1	Connective and soft tissue of upper limb, including shoulder	Sarcoma	●			
C49.2	Connective and soft tissue of lower limb, including hip	Sarcoma	●			
C49.3	Connective and soft tissue of thorax	Sarcoma	●			
C49.4	Connective and soft tissue of abdomen	Sarcoma	●			
C49.5	Connective and soft tissue of pelvis	Sarcoma	●			
C49.6	Connective and soft tissue of trunk, unspecified	Sarcoma	●			
C49.8	Overlapping lesion of connective and soft tissue	Sarcoma	●			
C49.9	Connective and soft tissue, unspecified	Sarcoma	●			
C69.6	Orbit	Brain/Central Nervous System		●		Not normally treated by CNS MDT. May be treated by Sarcoma MDT.
C78.6	Secondary malignant neoplasm of retroperitoneum and peritoneum	Sarcoma		●		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.5	Secondary malignant neoplasm of bone and bone marrow	Sarcoma		●		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
D48.0	Neoplasm of uncertain or unknown behaviour of Bone and articular cartilage	Sarcoma			●	
D48.1	Neoplasm of uncertain or unknown behaviour of Connective and other soft tissue	Sarcoma			●	Only applicable for GISTs

SARCOMA – DIAGNOSIS

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
SA11000	SARCOMA - DIAGNOSIS	**SARCOMA TUMOUR SITE (BONE)**	an4	R
SA11010	SARCOMA - DIAGNOSIS	**SARCOMA TUMOUR SUBSITE (BONE)**	an2	R
SA11080	SARCOMA - DIAGNOSIS	**SARCOMA TUMOUR SITE (SOFT TISSUE)**	an4	R
SA11090	SARCOMA - DIAGNOSIS	**SARCOMA TUMOUR SUBSITE (SOFT TISSUE)**	an2	R
SA11025	SARCOMA - DIAGNOSIS	**MULTIFOCAL OR SYNCHRONOUS TUMOUR INDICATOR**	an1	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).

Note: Other Z codes may be used if they are felt more appropriate.

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
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

Note: Use Cranium (Z639) for instances of Sarcoma of the Skull.

SARCOMA TUMOUR SUBSITE (BONE): Sub-location of the bone sarcoma within the tumour site. This gives a more details location of the tumour and should be recorded by specialist centres treating the patient.

PR	Proximal
DS	Distal
DP	Diaphyseal (Middle)
TO	Total
OO	Other
NK	Not known

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).

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)
Z927	Trunk (to include upper and lower)
Z928	Multiple
Z929	Unknown

Note: Other Z codes may be used if they are felt more appropriate.

SARCOMA TUMOUR SUBSITE (SOFT TISSUE): Sub-location of the soft tissue sarcoma within the tumour site. This gives a more details location of the tumour and should be recorded by specialist centres treating the patient.

RP	Retroperitoneal (subsite of Z53.3)
IP	Intraperitoneal (subsite of Z53.3)
WR	Wrist (subsite of Z89.8)
EB	Elbow (subsite of Z89.8)
UT	Upper Trunk (subsite of Z92.7)
LT	Lower Trunk (subsite of Z92.7)
AD	Adductors (subsite of Z90.3 & Z90.4)
AN	Anterior (subsite of Z90.3 & Z90.4)
PO	Posterior (subsite of Z90.3 & Z90.4)
LA	Lateral (subsite of Z90.3 & Z90.4)
NK	Not Known (No record or Test not carried out)
NA	Not Applicable

MULTIFOCAL OR SYNCHRONOUS TUMOUR INDICATOR: An indicator of the presence of tumours at multiple sites arising synchronously/concurrently.

Y	Yes
N	No
9	Not known

SARCOMA – DIAGNOSIS CHOICE

This is a new within v9 and provides a choice of 2 CTYA disease groups and associated data items.

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
SARCOMA - DIAGNOSIS - CHOICE				
SARCOMA - DIAGNOSIS - CHOICE 1				
CT6350	SARCOMA - DIAGNOSIS - RHABDOMYOSARCOMA and OTHER SOFT TISSUE SARCOMAS	**IRS POST SURGICAL GROUP** *[INTERGROUP RHABDOMYOSARCOMA STUDY POST SURGICAL GROUP]*	an1	R
CT6750	SARCOMA - DIAGNOSIS - RHABDOMYOSARCOMA and OTHER SOFT TISSUE SARCOMAS	**IRS POST SURGICAL GROUP DATE** *[INTERGROUP RHABDOMYOSARCOMA STUDY POST SURGICAL GROUP DATE]*	an10 ccyy-mm-dd	R
CT6370	SARCOMA - DIAGNOSIS - RHABDOMYOSARCOMA and OTHER SOFT TISSUE SARCOMAS	**RHABDOMYOSARCOMA SITE PROGNOSIS CODE**	an1	R
END OF SARCOMA - DIAGNOSIS - CHOICE 1				
SARCOMA - DIAGNOSIS - CHOICE 2				
CT6450	SARCOMA - DIAGNOSIS - EWINGS	**TUMOUR VOLUME AT DIAGNOSIS** *[TUMOUR VOLUME AT DIAGNOSIS CODE]*	an1	M
END OF SARCOMA - DIAGNOSIS - CHOICE 2				
END OF SARCOMA - DIAGNOSIS - CHOICE				

SARCOMA – DIAGNOSIS – RHABDOMYOSARCOMA and OTHER SOFT TISSUE SARCOMAS

Choice 1

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT6350	SARCOMA - DIAGNOSIS - RHABDOMYOSARCOMA and OTHER SOFT TISSUE SARCOMAS	**IRS POST SURGICAL GROUP** *[INTERGROUP RHABDOMYOSARCOMA STUDY POST-SURGICAL GROUP]*	an1	R
CT6750	SARCOMA - DIAGNOSIS - RHABDOMYOSARCOMA and OTHER SOFT TISSUE SARCOMAS	**IRS POST SURGICAL GROUP DATE** *[INTERGROUP RHABDOMYOSARCOMA STUDY POST SURGICAL GROUP DATE]*	an10 ccyy-mm-dd	R
CT6370	SARCOMA - DIAGNOSIS - RHABDOMYOSARCOMA and OTHER SOFT TISSUE SARCOMAS	**RHABDOMYOSARCOMA SITE PROGNOSIS CODE**	an1	R

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. 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

1	Group 1
2	Group 2
3	Group 3
4	Group 4

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. The following definitions are used:

- favourable sites: Orbit, genitourinary Non Bladder Prostate, Non-Parameningeal Head and Neck
- unfavourable sites: all other sites of disease

F	Favourable

U	Unfavourable

SARCOMA – DIAGNOSIS – EWINGS

Choice 2

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT6450	SARCOMA - DIAGNOSIS - EWINGS	**TUMOUR VOLUME AT DIAGNOSIS** *[TUMOUR VOLUME AT DIAGNOSIS CODE]*	an1	R

TUMOUR VOLUME AT DIAGNOSIS: Radiologically calculated estimate of tumour volume at diagnosis which has value in determining treatment.

L	Less than 200ml
M	200ml or greater

SARCOMA – LABORATORY RESULTS CHOICE

This is a new within v9 and provides a choice of 2 CTYA disease groups and associated data items.

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

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
SARCOMA - LABORATORY RESULTS - CHOICE				
SARCOMA - LABORATORY RESULTS - CHOICE 1				
CT6360	SARCOMA - LABORATORY RESULTS - RHABDOMYOSARCOMA and OTHER SOFT TISSUE SARCOMAS	**CYTOGENETICS FOR ALVEOLAR RHABDOMYOSARCOMA** *[CYTOGENETIC PRESENCE TYPE (RHABDOMYOSARCOMA)]*	an1	M
END OF SARCOMA - LABORATORY RESULTS - CHOICE 1				
SARCOMA - LABORATORY RESULTS - CHOICE 2				
CT6460	SARCOMA - LABORATORY RESULTS - EWINGS	**CYTOGENETICS FOR EWINGS SARCOMA** *[CYTOGENETIC ANALYSIS CODE]*	an2	M
END OF SARCOMA - LABORATORY RESULTS - CHOICE 2				
END OF SARCOMA - LABORATORY RESULTS - CHOICE				

LABORATORY RESULTS – RHABDOMYOSARCOMA and OTHER SOFT TISSUE SARCOMAS

Choice 1

Must be one occurrence if chosen per Core - Laboratory Results (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT6360	SARCOMA - LABORATORY RESULTS - RHABDOMYOSARCOMA and OTHER SOFT TISSUE SARCOMAS	**CYTOGENETICS FOR ALVEOLAR RHABDOMYOSARCOMA** *[CYTOGENETIC PRESENCE TYPE (RHABDOMYOSARCOMA)]*	an1	M

CYTOGENETICS FOR ALVEOLAR RHABDOMYOSARCOMA: Presence of a specific cytogenetic abnormality. This information should be available for the MDT discussion but will only apply to a small number of cases. The following definitions are used:

P	Fusion positive
N	Fusion negative
X	Non informative
9	Not known (Not available)

LABORATORY RESULTS – EWINGS

Choice 2

Must be one occurrence if chosen per Core - Laboratory Results (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CT6460	SARCOMA - LABORATORY RESULTS - EWINGS	**CYTOGENETICS FOR EWINGS SARCOMA** *[CYTOGENETIC ANALYSIS CODE]*	an2	M

CYTOGENETICS FOR EWINGS SARCOMA: Cytogenetic analysis.

11	t(11;22)
VT	Variant Translocation
NG	Negative
NA	Not Available

It is possible that some legacy data may not have all the required mandatory fields for v9. 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).

SKIN

Overview

All skin cancers diagnosed from January 2018 should be staged using UICC TNM v8, and the stage fields (which are included 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
- or 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 more 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

ICD-10 CODES

Key:
() = if applicable
* = different data set from CWT group specified

ICD-10 All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C43.0	Malignant melanoma of lip	Skin	●			
C43.1	Malignant melanoma of eyelid, including canthus	Skin	●			
C43.2	Malignant melanoma of ear and external auricular canal	Skin	●			
C43.3	Malignant melanoma of other and unspecified parts of face	Skin	●			
C43.4	Malignant melanoma of scalp and neck	Skin	●			
C43.5	Malignant melanoma of trunk	Skin	●			
C43.6	Malignant melanoma of upper limb, including shoulder	Skin	●			
C43.7	Malignant melanoma of lower limb, including hip	Skin	●			
C43.8	Overlapping malignant melanoma of skin	Skin	●			
C43.9	Malignant melanoma of skin, unspecified	Skin	●			
C44.0	Skin of lip	Skin	(●)	(●)	(●)	See the Skin chapter of the COSD User Guide (Overview Section) for further information on the collection of this Skin disease.
C44.1	Skin of eyelid, including canthus	Skin	(●)	(●)	(●)	See the Skin chapter of the COSD User Guide (Overview Section) for further information on the collection of this Skin disease.
C44.2	Skin of ear and external auricular canal	Skin	(●)	(●)	(●)	See the Skin chapter of the COSD User Guide (Overview Section) for further information on the collection of this Skin disease.

C44.3	Skin of other and unspecified parts of face	Skin	(●)	(●)	(●)	See the Skin chapter of the COSD User Guide (Overview Section) for further information on the collection of this Skin disease.
C44.4	Skin of scalp and neck	Skin	(●)	(●)	(●)	See the Skin chapter of the COSD User Guide (Overview Section) for further information on the collection of this Skin disease.
C44.5	Skin of trunk	Skin	(●)	(●)	(●)	See the Skin chapter of the COSD User Guide (Overview Section) for further information on the collection of this Skin disease.
C44.6	Skin of upper limb, including shoulder	Skin	(●)	(●)	(●)	See the Skin chapter of the COSD User Guide (Overview Section) for further information on the collection of this Skin disease.
C44.7	Skin of lower limb, including hip	Skin	(●)	(●)	(●)	See the Skin chapter of the COSD User Guide (Overview Section) for further information on the collection of this Skin disease.
C44.8	Overlapping lesion of skin	Skin	(●)	(●)	(●)	See the Skin chapter of the COSD User Guide (Overview Section) for further information on the collection of this Skin disease.
C44.9	Malignant neoplasm of skin, unspecified	Skin	(●)	(●)	(●)	See the Skin chapter of the COSD User Guide (Overview Section) for further information on the collection of this Skin disease.
C51.0	Labium majus	Gynaecological	● *			*Gynaecological and Skin Data sets to be collected where applicable.
C51.1	Labium minus	Gynaecological	● *			*Gynaecological and Skin Data sets to be collected where applicable.
C51.2	Clitoris	Gynaecological	● *			*Gynaecological and Skin Data sets to be collected where applicable.
C51.8	Overlapping lesion of vulva	Gynaecological	● *			*Gynaecological and Skin Data sets to be collected where applicable.

C51.9	Vulva, unspecified	Gynaecological	• *			*Gynaecological and Skin Data sets to be collected where applicable.
C79.2	Secondary malignant neoplasm of skin	Skin		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
D03.0	Melanoma in situ of lip	Skin		•		
D03.1	Melanoma in situ of eyelid, including canthus	Skin		•		
D03.2	Melanoma in situ, of ear and external auricular canal	Skin		•		
D03.3	Melanoma in situ of other and unspecified parts of face	Skin		•		
D03.4	Melanoma in situ of scalp and neck	Skin		•		
D03.5	Melanoma in situ of trunk	Skin		•		
D03.6	Melanoma in situ of upper limb, including shoulder	Skin		•		
D03.7	Melanoma in situ of lower limb, including hip	Skin		•		
D03.9	Melanoma in situ, unspecified	Skin		•		
D48.5	Neoplasm of uncertain or unknown behaviour of Skin	Skin			•	

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)

Note: the following data item has been moved to CORE - Diagnostic Procedures - Sentinel Node Biopsy from v9.0:

- SENTINEL NODE BIOPSY OUTCOME

Note: the following data items have been retired from v9.0:

- SENTINEL NODE BIOPSY
- SENTINEL NODE BIOPSY DATE
- ORGANISATION IDENTIFIER OF REPORTING LABORATORY

These can all now be collected via the new Core – Diagnostic Procedures section.

Note: the following data items have been retired from v9.0:

- AJCC STAGE GROUP
- AJCC STAGE GROUP DATE

All staging should now be recorded using the CORE – Staging section.

SKIN – TREATMENT – SURGERY – BCC, SCC & MM

This is a child of Core – Treatment in v9. This is a change in v9 from Surgery and Other Procedures, 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
SK12010	SKIN - SURGERY AND OTHER PROCEDURES - BCC, SCC & MM	**GRADE OF CLINICIAN/SURGEON OPERATING** *[CARE PROFESSIONAL OPERATING SURGEON TYPE (CANCER)]*	Max an3	R
SK12700	SKIN - SURGERY AND OTHER PROCEDURES - BCC, SCC & MM	**MEMBER OF SPECIALIST MDT** *[MEMBER OF SPECIALIST MULTIDISCIPLINARY TEAM INDICATOR]*	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.

NU	NURSE
TS	TRAINEE SPECIALIST DOCTOR
CS	CONSULTANT SURGEON (other than Plastic Surgeon)
CD	CONSULTANT DERMATOLOGIST
CPS	CONSULTANT PLASTIC SURGEON
HP	HOSPITAL PRACTITIONER
SI	GP WITH SPECIAL INTEREST
GP	GENERAL PRACTITIONER
OO	OTHER CARE PROFESSIONAL

MEMBER OF SPECIALIST MDT: Is the actual operating Clinician or Surgeon a member of the Specialist MDT?

Y	Yes
N	No
9	Not Known

It is possible that some legacy data may not have all the required mandatory fields for v9. 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).

UPPER GI

Overview

ICD-10 codes C17.1, C17.2, C17.3, C17.8 and C17.9 are grouped under Upper GI for Cancer Waits but are excluded from the COSD Upper GI data set. For diseases coded under C17.1, C17.2, C17.3, C17.8 and C17.9 only the CORE data set needs to be completed.

It is important to note that all Liver and Cholangiocarcinoma cancers are now to be reported within the Liver section of COSD.

ICD-10 CODES

Key:
() = if applicable
* = different data set from CWT group specified

ICD-10 All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C15.0	Cervical part of oesophagus	Upper Gastrointestinal	*			Usually treated by Head and Neck MDT.
C15.1	Thoracic part of oesophagus	Upper Gastrointestinal	•			
C15.2	Abdominal part of oesophagus	Upper Gastrointestinal	•			
C15.3	Upper third of oesophagus	Upper Gastrointestinal	•			
C15.4	Middle third of oesophagus	Upper Gastrointestinal	•			
C15.5	Lower third of oesophagus	Upper Gastrointestinal	•			
C15.8	Overlapping lesion of oesophagus	Upper Gastrointestinal	•			
C15.9	Oesophagus, unspecified	Upper Gastrointestinal	•			
C16.0	Cardia	Upper Gastrointestinal	•			
C16.1	Fundus of stomach	Upper Gastrointestinal	•			
C16.2	Body of stomach	Upper Gastrointestinal	•			
C16.3	Pyloric antrum	Upper Gastrointestinal	•			

C16.4	Pylorus	Upper Gastrointestinal	•			
C16.5	Lesser curvature of stomach, unspecified	Upper Gastrointestinal	•			
C16.6	Greater curvature of stomach, unspecified	Upper Gastrointestinal	•			
C16.8	Overlapping lesion of stomach	Upper Gastrointestinal	•			
C16.9	Stomach, unspecified	Upper Gastrointestinal	•			
C17.0	Duodenum	Colorectal		•		Usually treated by Upper GI MDT
C17.1	Jejunum	Colorectal		•		Usually treated by Upper GI MDT
C17.2	Ileum	Colorectal		•		Usually treated by Upper GI MDT
C17.3	Meckel's diverticulum	Colorectal		•		Usually treated by Upper GI MDT
C17.8	Overlapping lesion of small intestine	Colorectal		•		Usually treated by Upper GI MDT
C17.9	Small intestine, unspecified	Colorectal		•		Usually treated by Upper GI MDT
C23	Malignant neoplasm of gallbladder	Upper Gastrointestinal	•			
C24.1	Ampulla of Vater	Upper Gastrointestinal	•			
C24.8	Overlapping lesion of biliary tract	Upper Gastrointestinal	•			
C24.9	Biliary tract, unspecified	Upper Gastrointestinal	•			
C25.0	Head of pancreas	Upper Gastrointestinal	•			
C25.1	Body of pancreas	Upper Gastrointestinal	•			
C25.2	Tail of pancreas	Upper Gastrointestinal	•			
C25.3	Pancreatic duct	Upper Gastrointestinal	•			
C25.4	Endocrine pancreas	Upper Gastrointestinal	•			
C25.7	Other parts of pancreas	Upper Gastrointestinal	•			
C25.8	Overlapping lesion of pancreas	Upper Gastrointestinal	•			
C25.9	Pancreas, unspecified	Upper Gastrointestinal	•			
C78.7	Secondary malignant neoplasm of liver and intrahepatic bile duct	Upper Gastrointestinal		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
D00.1	Carcinoma in situ of Oesophagus	Upper Gastrointestinal			•	

D00.2	Carcinoma in situ of Stomach	Upper Gastrointestinal			•	
D01.5	Carcinoma in situ of Liver, gallbladder and bile ducts	Upper Gastrointestinal			•	
D37.1	Neoplasm of uncertain or unknown behaviour of Stomach	Upper Gastrointestinal			•	
D37.2	Neoplasm of uncertain or unknown behaviour of Small intestine	Upper Gastrointestinal			•	
D37.6	Liver, gallbladder and bile ducts	Upper Gastrointestinal			•	

Note: The following data items have been retired from v9.0

- CLINICAL STAGE (PANCREATIC CANCER)
- CLINICAL STAGE (PANCREATIC CANCER) DATE

All staging should now be recorded using the CORE – Staging section.

Note: the following data item have been retired from v9.0:

- STAGING LAPAROSCOPY PERFORMED

Note: the following data item have been retired from v9.0:

- SURGICAL COMPLICATIONS

UPPER GI – TREATMENT – SURGERY – GENERAL

This is a child of Core - Treatment in v9. This is a change in v9 from Surgery and Other Procedures, 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 for v9. 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
UG13810	UPPER GI - TREATMENT - SURGERY - GENERAL	**PALLIATIVE TREATMENT REASON (UPPER GI)** *[PALLIATIVE TREATMENT REASON CODE (UPPER GASTROINTESTINAL)]*	an1	M

PALLIATIVE TREATMENT REASON (UPPER GI): Rationale for palliative treatment.

1	Extensive intrahepatic disease
2	Widespread disease
3	Both extensive intrahepatic and widespread disease
4	Biliary obstruction
5	Gastric outlet obstruction
6	Pain

UPPER GI – TREATMENT – SURGERY – O-G

This is a child of Core – Treatment in v9. This is a change in v9 from Surgery and Other Procedures, 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 for v9. 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
UG14230	UPPER GI - TREATMENT - SURGERY - O-G	**POST OPERATIVE TUMOUR SITE (UPPER GI)** *[POST OPERATIVE TUMOUR SITE (UPPER GASTROINTESTINAL)]*	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.

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

UPPER GI – TREATMENT – SURGERY – ESODATA

This is a new section to carry surgical complication details for Upper GI – Esophageal Database (ESODATA) as specified. This is a child of Core – Treatment in v9. This 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 for v9. 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 group (0..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
Start of repeating item - Surgical Complications				
UG15010	UPPER GI - TREATMENT - SURGERY - ESODATA	**SURGICAL COMPLICATIONS - INTERNATIONAL ESOPHAGEAL DATABASE (ESODATA)** *[INTERNATIONAL ESOPHAGEAL DATABASE SURGICAL COMPLICATIONS]*	an4	R*
End of repeating item - Surgical Complications				
UG15020	UPPER GI - TREATMENT - SURGERY - ESODATA	**LEAK SEVERITY TYPE** *[OESOPHAGOENTERIC LEAK SEVERITY TYPE]*	an1	R
UG15030	UPPER GI - TREATMENT - SURGERY - ESODATA	**CONDUIT NECROSIS/FAILURE TYPE** *[OESOPHAGECTOMY OESOPHAGEAL CONDUIT NECROSIS FAILURE TYPE]*	an1	R
UG15040	UPPER GI - TREATMENT - SURGERY - ESODATA	**RECURRENT LARYNGEAL NERVE INJURY INVOLVEMENT TYPE**	an1	R
UG15050	UPPER GI - TREATMENT - SURGERY - ESODATA	**CHYLE LEAK SEVERITY TYPE**	an1	R
UG15060	UPPER GI - TREATMENT - SURGERY - ESODATA	**CALVIEN-DINDO CLASSIFICATION of SURGICAL CLASSIFICATIONS**	an1	R

Start of repeating item - Additional Complications				
UG15070	UPPER GI - TREATMENT - SURGERY - ESODATA	**ADDITIONAL COMPLICATIONS** *[ADDITIONAL INTERNATIONAL ESOPHAGEAL DATABASE SURGICAL COMPLICATIONS]*	max an150	R*
End of repeating item - Additional Complications				

SURGICAL COMPLICATIONS – INTERNATIONAL ESOPHAGEAL DATABASE (ESODATA): This is a new data item for v9. The types of complications as defined in the International Esophageal Database (ESODATA)

This list has been compiled by the Esophageal Complications Consensus Group (ECCG)

0100	**Gastrointestinal**
0101	No post-operative complications
0102	Oesophagoenteric leak from anastomosis, staple line, or localised conduit necrosis
0103	Conduit necrosis/failure requiring surgery
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
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
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**
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**
0701	Recurrent nerve injury
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
0902	Chyle leak severity/type
0903	Reoperation for thoracic bleeding
0904	Reoperation for abdominal bleeding
0905	Reoperation for reasons other than bleeding, anastomotic leak or conduit necrosis
0906	Multiple organ dysfunction syndrome
0999	None
1000	**Additional Complications**
1001	The patient had other complications that is not in the ECCG recommended complications list above?

LEAK SEVERITY TYPE: This is a new data item for v9. Record the severity of the leak

Only required if option [0102 - Oesophagoenteric leak] is selected in data item UG15010

1	Type I
2	Type II
3	Type III
9	Not Known (not recorded)

CONDUIT NECROSIS/FAILURE TYPE: This is a new data item for v9. Record the conduit necrosis/failure type

Only required if option [0103 - Conduit necrosis/failure requiring surgery] is selected in data item UG15010.

1	Type I
2	Type II
3	Type III
9	Not Known (not recorded)

RECURRENT LARYNGEAL NERVE INJURY INVOLVEMENT TYPE: This is a new data item for v9. Record any recurrent laryngeal nerve injury involvement type

Only required if option [0701 – Recurrent nerve injury] is selected in data item UG15010

1	Type Ia
2	Type Ib
3	Type IIa
4	Type IIb
5	Type IIIa
6	Type IIIb
9	Not Known (not recorded)

CHYLE LEAK SEVERITY TYPE: This is a new data item for v9. Record any Chyle leak severity type

Only required if option [0902 - Chyle leak severity/type] is selected in data item UG15010

1	Type Ia
2	Type Ib
3	Type IIa
4	Type IIb
5	Type IIIa
6	Type IIIb
9	Not Known (not recorded)

CALVIEN-DINDO CLASSIFICATION of SURGICAL CLASSIFICATIONS: This is a new data item for v9. Record the overall grade as per the Clavien-Dindo Classification of Surgical Classifications

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)

ADDITIONAL COMPLICATIONS: This is a new data item for v9. Did patient have any complications that is not in the ECCG recommended complications list above?

Only required if option [1001 – The patient had other complications] is selected in data item UG15010. Multiple complications can be recorded

UPPER GI – TREATMENT – SURGERY – OUTCOME MEASURES

This is a new section to carry surgery outcome measures for Upper GI – Esophageal Database (ESODATA) as specified. This is a child of Core – Treatment in v9. This 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 for v9. 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
UG15110	UPPER GI - TREATMENT - SURGERY - OUTCOME MEASURES	**CHANGE IN LEVEL OF CARE** *[ESCALATION IN LEVEL OF PATIENT CARE FOLLOWING OESOPHAGECTOMY INDICATOR]*	an1	R
UG15120	UPPER GI - TREATMENT - SURGERY - OUTCOME MEASURES	**BLOOD PRODUCT UTILISATION** *[BLOOD PRODUCTS REQUIRED FOLLOWING OESOPHAGECTOMY INDICATION CODE]*	an1	R
UG15130	UPPER GI - TREATMENT - SURGERY - OUTCOME MEASURES	**NUMBER OF UNITS TRANSFUSED** *[UNITS OF BLOOD TRANSFUSED FOLLOWING OESOPHAGECTOMY]*	an1	R

CHANGE IN LEVEL OF CARE: This is a new data item for v9. Record if there was any change in the level of care required for the patient?

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: This is a new data item for v9. Record if there were any blood products required?

1	None - No transfusions
2	Intra-operative transfusions
3	Post-operative transfusions
4	Intra and post-operative transfusions
9	Not Known (not recorded)

NUMBER OF UNITS TRANSFUSED: This is a new data item for v9. Record the number of units of blood transfused.

1	1-2 units
2	3-4 units
3	5 or more units
9	Not Known (not recorded)

UPPER GI – TREATMENT – SURGERY – OESOPHAGECTOMY

This is a new section to carry surgery procedure details, for Upper GI - Oesophagectomy as specified. This is a child of Core - Treatment in v9. This 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 for v9. 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
UG15200	UPPER GI - TREATMENT - SURGERY - OESOPHAGECTOMY	**SURGICAL APPROACH TYPE** *[OESOPHAGECTOMY SURGICAL APPROACH TYPE]*	an1	R
UG15210	UPPER GI - TREATMENT - SURGERY - OESOPHAGECTOMY	**OPEN APPROACH TYPE** *[OPEN OESOPHAGECTOMY SURGICAL APPROACH TYPE]*	an1	R
UG15220	UPPER GI - TREATMENT - SURGERY - OESOPHAGECTOMY	**MINIMALLY INVASIVE APPROACH TYPE** *[MINIMALLY INVASIVE OESOPHAGECTOMY SURGICAL APPROACH TYPE]*	an1	R
UG15230	UPPER GI - TREATMENT - SURGERY - OESOPHAGECTOMY	**ANASTOMOSIS TYPE** *[OESOPHAGECTOMY ANASTOMOSIS TYPE]*	an1	R

UG15240	UPPER GI - TREATMENT - SURGERY - OESOPHAGECTOMY	**OESOPHAGEAL CONDUIT TYPE** *[OESOPHAGECTOMY OESOPHAGEAL CONDUIT TYPE]*	an1	R
UG15250	UPPER GI - TREATMENT - SURGERY - OESOPHAGECTOMY	**NECK DISSECTION** *[OESOPHAGECTOMY NECK DISSECTION INDICATOR]*	an1	R

SURGICAL APPROACH TYPE: This is a new data item for v9. Record the type surgical approach used during the Oesophagectomy.

1	Open Oesophagectomy
2	Minimally Invasive Oesophagectomy
9	Not Known (not recorded)

OPEN APPROACH TYPE: This is a new data item for v9. Record the type of open surgical approach used during the Oesophagectomy.

1	Trans Thoracic Oesophagectomy
2	Trans Hiatal Oesophagectomy

MINIMALLY INVASIVE APPROACH TYPE: This is a new data item for v9. Record the type of minimally invasive approach used during the Oesophagectomy.

1	Total Minimally Invasive
2	Abdominal part minimally invasive
3	Chest part minimally invasive

ANASTOMOSIS TYPE: This is a new data item for v9. Record the type of anastomosis used during the Oesophagectomy.

1	Neck anastomosis
2	Chest anastomosis
3	None
8	Other
9	Not Known (not recorded)

OESOPHAGEAL CONDUIT TYPE: This is a new data item for v9. Record the type of oesophageal conduit used during the Oesophagectomy.

1	Stomach
2	Small bowel
3	Colon
4	None
8	Other
9	Not Known (not recorded)

NECK DISSECTION: This is a new data item for v9. Record if there was any neck dissection during the Oesophagectomy.

Y	Neck dissection
N	No neck dissection
9	Not Known (not recorded)

UPPER GI – TREATMENT – SURGERY – LIVER CHOLANGIOCARCINOMA and PANCREATIC

This is a child of Core – Treatment in v9, to carry surgery details for Upper GI, as specified. This is a change in v9 from Surgery and Other Procedures, 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 for v9. 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
UG13240	UPPER GI - TREATMENT - SURGICAL - LIVER CHOLANGIOCARCINOMA and PANCREATIC	**SURGICAL PALLIATION TYPE**	an1	M

SURGICAL PALLIATION TYPE: Record the type of surgical palliation performed if any, for example Hepaticojejunostomy.

0	None
1	gastric bypass
2	biliary bypass
3	gastric/biliary bypass
4	celiac plexus block

UPPER GI – TREATMENT – SURGERY – ENDOSCOPIC OR RADIOLOGICAL PROCEDURES – PANCREATIC and O-G

This is a child of Core – Treatment in v9, to carry surgery details for Endoscopic and Radiological procedures for Upper GI, as specified. This is a change in v9 from Surgery and Other Procedures, 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 for v9. 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
Start of repeating item - Endoscopic Procedure Type				
UG14290	UPPER GI - TREATMENT - SURGERY - ENDOSCOPIC OR RADIOLOGICAL PROCEDURES - PANCREATIC and O-G	**ENDOSCOPIC PROCEDURE TYPE**	an1	M*
End of repeating item - Endoscopic Procedure Type				

ENDOSCOPIC PROCEDURE TYPE: The main endoscopic procedures carried out. More than one procedure can be entered. This is a repeating data item.

1	Stent insertion
2	Laser therapy
3	Argon plasma coagulation
4	Photodynamic therapy
5	Gastrostomy
6	Brachytherapy
7	Dilation
8	Other

UPPER GI – TREATMENT – SURGERY – ENDOSCOPIC OR RADIOLOGICAL PROCEDURES – MAIN

This is a child of Core – Treatment in v9, to carry surgery details for Endoscopic and Radiological procedures for Upper GI, as specified. This is a change in v9 from Surgery and Other Procedures, 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 for v9. 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
Start of repeating item - Endoscopic/Radiological Complications				
UG13090	UPPER GI - TREATMENT - SURGERY - ENDOSCOPIC OR RADIOLOGICAL PROCEDURES - MAIN	**ENDOSCOPIC OR RADIOLOGICAL COMPLICATION TYPE**	an2	M*
End of repeating item - Endoscopic/Radiological Complications				

ENDOSCOPIC OR RADIOLOGICAL TYPE COMPLICATION: The types of complications that the patient experiences during the admission for the endoscopic procedure. More than one option can be selected.

00	No complications
02	Perforation
03	Haemorrhage
09	Pancreatitis
10	Cholangitis
88	Other

UROLOGICAL

Overview

The site-specific Urological data set applies additionally to in situ Bladder cancers (D09.0) and pTa Bladder cancers (D41.4), although these are excluded from Cancer Waits.

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.

ICD-10 CODES

Key:
() = if applicable
* = different data set from CWT group specified

ICD-10 All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	**Core Data set**	**Path Only**	
C60.0	*Prepuce*	*Urological*	● *			** Urological and Skin Data sets to be collected where applicable.*
C60.1	*Glans penis*	*Urological*	● *			** Urological and Skin Data sets to be collected where applicable.*
C60.2	*Body of penis*	*Urological*	● *			** Urological and Skin Data sets to be collected where applicable.*
C60.8	*Overlapping lesion of penis*	*Urological*	● *			** Urological and Skin Data sets to be collected where applicable.*
C60.9	*Penis, unspecified*	*Urological*	● *			** Urological and Skin Data sets to be collected where applicable.*
C61	Malignant neoplasm of prostate	Urological	●			
C62.0	Undescended testis	Urological	●			
C62.1	Descended testis	Urological	●			
C62.9	Testis, unspecified	Urological	●			
C63.0	Epididymis	Urological	●			
C63.1	Spermatic cord	Urological	●			
C63.2	Scrotum	Urological	● *			** Skin Data set to be collected where applicable.*
C63.7	Other specified male genital organs	Urological		●		
C63.8	Overlapping lesion of male genital organs	Urological		●		
C63.9	Male genital organ, unspecified	Urological		●		
C64	Malignant neoplasm of kidney, except renal pelvis	Urological	●			
C65	Malignant neoplasm of renal pelvis	Urological	●			
C66	Malignant neoplasm of ureter	Urological	●			
C67.0	Trigone of bladder	Urological	●			
C67.1	Dome of bladder	Urological	●			
C67.2	Lateral wall of bladder	Urological	●			
C67.3	Anterior wall of bladder	Urological	●			
C67.4	Posterior wall of bladder	Urological	●			

C67.5	Bladder neck	Urological	•			
C67.6	Ureteric orifice	Urological	•			
C67.7	Urachus	Urological	•			
C67.8	Overlapping lesion of bladder	Urological	•			
C67.9	Bladder, unspecified	Urological	•			
C68.0	Urethra	Urological	•			
C68.1	Paraurethral glands	Urological		•		
C68.8	Overlapping lesion of urinary organs	Urological		•		
C68.9	Urinary organ, unspecified	Urological		•		
C79.0	Secondary malignant neoplasm of kidney and renal pelvis	Urological		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.1	Secondary malignant neoplasm of bladder and other and unspecified urinary organs	Urological		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
D07.4	Carcinoma in situ of penis	Urological			•	
D07.5	Carcinoma in situ of prostate	Urological			•	
D07.6	Carcinoma in situ of other and unspecified male genital organs	Urological			•	
D09.0	Carcinoma in situ of Bladder	Urological	•			
D09.1	Carcinoma in situ of other and unspecified urinary organs	Urological			•	
D40.0	Neoplasm of uncertain or unknown behaviour of prostate	Urological			•	
D40.1	Neoplasm of uncertain or unknown behaviour of testis	Urological			•	
D40.7	Neoplasm of uncertain or unknown behaviour of other male genital organs	Urological			•	
D40.9	Neoplasm of uncertain or unknown behaviour of male genital organs, unspecified	Urological			•	
D41.0	Neoplasm of uncertain or unknown behaviour of kidney	Urological			•	

D41.1	Neoplasm of uncertain or unknown behaviour of renal pelvis	Urological	•			
D41.2	Neoplasm of uncertain or unknown behaviour of ureter	Urological	•			
D41.3	Neoplasm of uncertain or unknown behaviour of urethra	Urological	•			
D41.4	Neoplasm of uncertain or unknown behaviour of bladder	Urological	•			
D41.7	Neoplasm of uncertain or unknown behaviour of other urinary organs	Urological			•	
D41.9	Neoplasm of uncertain or unknown behaviour of urinary organs, unspecified	Urological			•	

UROLOGICAL – DIAGNOSTIC PROCEDURES – PROSTATE

This is a new section in v9 and 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 for v9. 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 No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
UR15410	UROLOGICAL - DIAGNOSTIC PROCEDURES - PROSTATE	**PROSTATE BIOPSY TECHNIQUE** *[PRETREATMENT PROSTATE BIOPSY TECHNIQUE TYP]*	an2	M
UR15440	UROLOGICAL - DIAGNOSTIC PROCEDURES - PROSTATE	**BIOPSY ANAESTHETIC** *[BIOPSY ANAESTHETIC TYPE]*	an1	M

PROSTATE BIOPSY TECHNIQUE: This is now a mandatory data item in v9. 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.

~~1~~	~~Transrectal sampling biopsy~~
~~2~~	~~Transrectal saturation biopsy~~
~~3~~	~~Perineal sampling biopsy~~
~~4~~	~~Perineal template mapping biopsy~~
~~7~~	~~Not Applicable (No biopsy done)~~
~~8~~	~~Other~~
~~9~~	~~Not known~~
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

Note: 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 new data item for v9. Record the type of anaesthetic used during the biopsy. This is part of the National Prostate Cancer Audit (NPCA).

1	Local
2	Sedation
3	General
9	Not Known

UROLOGICAL – DIAGNOSIS – PROSTATE

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

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
UR15500	UROLOGICAL - DIAGNOSIS - PROSTATE	**mpMRI PRE-BIOPSY** *[MULTIPARAMETRIC MRI SCAN INDICATOR]*	an1	R
UR15510	UROLOGICAL - DIAGNOSIS - PROSTATE	**MRI/FUSION BIOPSY** *[MRI ULTRASOUND FUSION GUIDED BIOPSY INDICATOR]*	an1	R
UR15070	UROLOGICAL - DIAGNOSIS - PROSTATE	**PSA (DIAGNOSIS)** *[PROSTATE SPECIFIC ANTIGEN (DIAGNOSIS)]*	max n5.n1	R

mpMRI PRE-BIOPSY: This is a new data item for v9. 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.

Y	Yes
N	No
9	Not Known

MRI/FUSION BIOPSY: This is a new data item for v9. 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.

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).

UROLOGICAL – CANCER CARE PLAN

May be up to one occurrence per Core – Cancer Care Plan (0..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
UR15000	UROLOGICAL - CANCER CARE PLAN	**ESTIMATED GLOMERULAR FILTRATION RATE**	max n2	R
UR15010	UROLOGICAL - CANCER CARE PLAN	**HYDRONEPHROSIS** *[HYDRONEPHROSIS CODE]*	an1	R
UR15030	UROLOGICAL - CANCER CARE PLAN	**S-CATEGORY** *[S CATEGORY CODE]*	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/1.73m2. 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 [HYDRONEPHROSIS CODE]: BLADDER ONLY. Consequence of reduced outflow of urine from Kidney. May be present in one or both kidneys.

0	None
L	Left
R	Right
B	Bilateral
8	Not Applicable (No Kidneys)
9	Not Known

S-CATEGORY: TESTICULAR ONLY. This data item has moved from Urological - Cancer Care plan in v9. Based on serum tumour markers AFP, HCG and LDH. For Testicular Cancer S category is an additional prognostic factor.

See below for further details of values to be recorded.

SX	Tumour marker studies not available or not performed
S0	Tumour marker levels within normal limits
S1	LDH < 1.5 X Normal and HCG (mIu/ml) < 5000 and AFP (ug/ml) < 1000
S2	LDH 1.5-10 X Normal or HCG (mIu/ml) 5000-50,000 or AFP (ug/ml) 1000-10,000
S3	LDH > 10 X Normal or HCG (mIu/ml) > 50,000 or AFP (ug/ml) > 10,000

CODE	LDH (UNITS/LITRE)	HCG (MILLIUNITS/MILLILITRE)	AFP (NANOGRAMS/MILLILITRE)
SX	Marker studies not available or not performed	Marker studies not available or not performed	Marker studies not available or not performed
S0	Normal	Normal	Normal
S1	Less than 1.5 x normal	Less than 5,000	Less than 1,000
S2	1.5-10 x normal	5,000-50,000	1,000-10,000
S3	Greater than 10 x normal	Greater than 50,000	Greater than 10,000

UROLOGICAL – LABORATORY RESULTS

This is a new section in v9. This group is now a child of CORE - Laboratory Results, and will mandate:

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

It is possible that some legacy data may not have all the required mandatory fields for v9. 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 one occurrence per Core - Laboratory Results (0..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
UR15040	UROLOGICAL - CANCER CARE PLAN	**S-CATEGORY AFP** *[S CATEGORY (ALPHA FETOPROTEIN)]*	max n6	R
UR15050	UROLOGICAL - CANCER CARE PLAN	**S-CATEGORY HCG** *[S CATEGORY (HUMAN CHORIONIC GONADOTROPIN)]*	max n7	R
UR15060	UROLOGICAL - CANCER CARE PLAN	**S-CATEGORY LDH** *[S CATEGORY (LACTATE DEHYDROGENASE)]*	max n6	R
UR15020	UROLOGICAL - CANCER CARE PLAN	**NORMAL LDH** *[LACTATE DEHYDROGENASE LEVEL (NORMAL UPPER LIMIT)]*	max n6	R

S-CATEGORY AFP: This data item has moved from Urological – Cancer Care Plan. TESTICULAR ONLY. Alpha Feto-Protein (AFP) is a serum tumour marker. Where normal are values recorded, this will be collected once at diagnosis by specialist MDT. If abnormal at diagnosis the lowest measurement prior to chemotherapy or radiotherapy should be recorded. If no chemotherapy or radiotherapy is given, where markers are abnormal record lowest measurement post orchidectomy. Range 0 to 999999.

S-CATEGORY HCG: This data item has moved from Urological – Cancer Care Plan. TESTICULAR ONLY. Human Chorionic Gonadotropin (HCG) is a serum tumour marker. Where normal values are recorded, this will be collected once at diagnosis by specialist MDT. If abnormal at diagnosis the lowest measurement prior to chemotherapy or radiotherapy should be recorded. If no chemotherapy or radiotherapy is given, where markers are abnormal record lowest measurement post orchidectomy. To be collected once at diagnosis by specialist MDT. Range 0 to 999999.

S-CATEGORY LDH: This data item has moved from Urological - Cancer Care Plan. TESTICULAR ONLY. Serum Lactate Dehydrogenase (LDH) is a serum tumour marker. Where normal values are recorded, this will be collected once at diagnosis by specialist MDT. If abnormal at diagnosis the lowest measurement prior to chemotherapy or radiotherapy should be recorded. If no chemotherapy or radiotherapy is given, where markers are abnormal record lowest measurement post orchidectomy. Range 0 to 999999.

NORMAL LDH: This data item has moved from Core – Laboratory Results – General. TESTICULAR ONLY. This is the upper limit of normal for the LDH (Lactate Dehydrogenase Level) assay which is used to calculate S Category. Range 0 to 999999.

UROLOGICAL – STAGING – TESTICULAR

Testicular

For testicular cancer ideally RMH stage grouping and TNM stage components should both be collected as follows:

- UICC stage groupings should not be used as they do not map to RMH stage – 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

Note: Although International Germ Cell Consensus (IGCC) Prognostic Groupings largely supersedes RMH Staging for testicular cancer (except for seminomas), the Urological SSCRG has agreed that RMH Staging should continue to be used for staging testicular cancer for the near future.

When COSD is reviewed, recommendations on how to stage for testicular cancers is clinically considered and consulted upon to ensure accuracy.

May be up to one occurrence per Core – Site Specific Staging (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
UR15300	UROLOGICAL - STAGING - TESTICULAR	**STAGE GROUPING (TESTICULAR)** *[STAGE GROUPING (TESTICULAR CANCER)]*	max an2	R
Start of repeating item - Extra-nodal metastases				
UR15320	UROLOGICAL - STAGING - TESTICULAR	**EXTRANODAL METASTASES** *[EXTENT OF METASATIC SPREAD]*	an1	R
End of repeating item - Extra-nodal metastases				
UR15330	UROLOGICAL - STAGING - TESTICULAR	**LUNG METASTASES SUB-STAGE GROUPING**	an2	R

Note: The following data items have been retired from v9.0:

- TESTICULAR DATE

STAGE GROUPING (TESTICULAR): (TESTICULAR ONLY). Nationally agreed anatomical stage groupings as defined by The Royal Marsden Hospital (RMH).

1	Stage 1	Confined to testis
1S	Stage 1S	(Not used)
1M	Stage 1M	Rising post orchidectomy markers only
2A	Stage 2A	Abdominal lymphadenopathy < 2cm
2B	Stage 2B	Abdominal lymphadenopathy 2cm - 5cm

2C	Stage 2C	Abdominal lymphadenopathy > 5cm
3A	Stage 3A	Supradiaphragmatic lymphadenopathy with abdominal lymphadenopathy < 2cm
3B	Stage 3B	Supradiaphragmatic lymphadenopathy with abdominal lymphadenopathy 2cm - 5cm
3C	Stage 3C	Supradiaphragmatic lymphadenopathy with abdominal lymphadenopathy > 5cm
4A	Stage 4A	Extralymphatic metastases with abdominal lymphadenopathy < 2cm
4B	Stage 4B	Extralymphatic metastases with abdominal lymphadenopathy 2cm - 5cm
4C	Stage 4C	Extralymphatic metastases with abdominal lymphadenopathy > 5cm

TESTICULAR DATE: This field is now collected via the 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
- the organisation who carried out the stage

Note: for Testicular cancer the ‘Stage Group’, ‘Extranodal Metastases’ and ‘Lung Metastases Sub-Stage Grouping’ are required rather than mandatory. This is to allow for the metastatic data to be submitted without the stage (if not known at that point in time).

EXTRANODAL METASTASES: (TESTICULAR STAGE 4 ONLY). Indicate the extent of metastatic spread (multiple items can be selected).

Note: this data item only applies to a small cohort of patients.

L1	Less than or equal to 3 metastases
L2	Greater than 3 metastases
L3	Greater than 3 metastases, one or more greater than or equal to 2cm diameter

Additional staging notes

Urethra:

- most verrucous carcinomas arise from penile skin rather than urethra – readers are referred to the penile data set for clarification
- recording Urethra stage following neoadjuvant therapy
- for cases of bladder or urethral cancer treated by cystectomy, problems will be encountered where neoadjuvant therapy is used
- TNM stage will be dependent on histological examination of the resected specimen together with information obtained, such as from radiological imaging
- wherever possible TNM with the "y" prefix (NEOADJUVANT THERAPY INDICATOR) should be used for pathology stage fields
- for all other cases, where no operation is performed, staging will have to be based on radiological appearances either before or after the neo-adjuvant treatment and an integrated TNM stage decided based on the radiological appearances

Prostate:

- recording prostate stage following neoadjuvant therapy

- for cases of prostate cancer treated by prostatectomy, problems will be encountered where neoadjuvant therapy (usually hormones) is used
- TNM stage will be dependent on histological examination of the resected specimen together with information obtained, such as from radiological imaging
- wherever possible TNM with the "y" prefix (NEOADJUVANT THERAPY INDICATOR) should be used for pathology stage fields
- for all other cases – where no operation is performed – staging will have to be based on radiological appearances either before or after the neo-adjuvant treatment and an integrated TNM stage decided based on the radiological appearances

Kidney:

- recording kidney stage following preoperative drug therapy
- for cases of kidney cancer treated with surgery, problems will be encountered where preoperative drug therapy (usually biological targeted therapy) is used
- TNM stage will be dependent on histological examination of the resected specimen together with information obtained from radiological imaging
- wherever possible TNM with the "y" prefix (NEOADJUVANT THERAPY INDICATOR) should be used for pathology stage fields
- for all other cases, where no operation is performed, staging will have to be based on radiological appearances either before or after preoperative drug therapy and an integrated TNM stage decided based on the radiological appearances

Penis:

- recording penis stage following neoadjuvant therapy
- for cases of penile cancer treated with surgery, problems will be encountered where preoperative chemotherapy is used
- TNM stage will be dependent on histological examination of the resected specimen together with information obtained from radiological imaging
- wherever possible TNM with the "y" prefix (NEOADJUVANT THERAPY INDICATOR) should be used for pathology stage fields
- for all other cases, where no operation is performed, staging will have to be based on radiological appearances either before or after the preoperative chemotherapy and an integrated TNM stage decided based on the radiological appearances

UROLOGICAL – TREATMENT CHOICE

Must be one occurrence if chosen per Core - Treatment (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
UROLOGICAL - TREATMENT - CHOICE				Choice 0..1
UROLOGICAL - TREATMENT - CHOICE 1				
UROLOGICAL - TREATMENT - INTRAVESICAL INDICATOR CHOICE				Choice 1..1
UROLOGICAL - TREATMENT - INTRAVESICAL INDICATOR - CHOICE 1				
UR15100	**UROLOGICAL - TREATMENT - BLADDER**	**INTRAVESICAL CHEMOTHERAPY RECEIVED INDICATOR**	**an1**	M
END OF UROLOGICAL - TREATMENT - INTRAVESICAL INDICATOR - CHOICE 1				
UROLOGICAL - TREATMENT - INTRAVESICAL INDICATOR - CHOICE 2				
UR15110	**UROLOGICAL - TREATMENT - BLADDER**	**INTRAVESICAL IMMUNOTHERAPY RECEIVED INDICATOR**	**an1**	M
END OF UROLOGICAL - TREATMENT - INTRAVESICAL INDICATOR - CHOICE 2				
END OF UROLOGICAL - TREATMENT - INTRAVESICAL INDICATOR CHOICE				
END OF UROLOGICAL - TREATMENT - CHOICE 1				
UROLOGICAL - TREATMENT - CHOICE 2				
UR15420	UROLOGICAL - TREATMENT - PROSTATE	**PROCEDURE - NERVE SPARING** *[PROSTATE NERVE SPARING SURGERY TYPE]*	an1	R
UR15430	UROLOGICAL - TREATMENT - PROSTATE	**RADICAL PROSTATECTOMY MARGIN STATUS**	an1	R
END OF UROLOGICAL - TREATMENT - CHOICE 2				
END OF UROLOGICAL - TREATMENT - CHOICE				

UROLOGICAL – TREATMENT – BLADDER

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 for v9. 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).

Choice 1

Must be one occurrence if chosen per Core - Treatment (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
UR15100	UROLOGICAL - TREATMENT - BLADDER	**INTRAVESICAL CHEMOTHERAPY RECEIVED INDICATOR**	an1	**M**
UR15110	UROLOGICAL - TREATMENT - BLADDER	**INTRAVESICAL IMMUNOTHERAPY RECEIVED INDICATOR**	an1	**M**

Note: either INTRAVESICAL CHEMOTHERAPY RECEIVED INDICATOR or INTRAVESICAL IMMUNOTHERAPY RECEIVED INDICATOR is required for patients having anti-cancer therapy treatment in order to distinguish between modes of delivery. Only one will be applicable for each treatment, as specified by the following 2 'Intravesical Indicator' choices.

Intravesical Indicator – Choice 1:

INTRAVESICAL CHEMOTHERAPY RECEIVED INDICATOR: This is now a mandatory data item in v9. BLADDER ONLY. (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.

Y	Yes
N	No
9	Not known

Intravesical Indicator – Choice 2:

INTRAVESICAL IMMUNOTHERAPY RECEIVED INDICATOR: This is now a mandatory data item in v9. BLADDER ONLY. (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.

Y	Yes
N	No
9	Not known

UROLOGICAL – TREATMENT – PROSTATE

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 for v9. 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).

Choice 2

Must be one occurrence if chosen per Core – Treatment (1..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
UR15420	UROLOGICAL - TREATMENT - PROSTATE	**PROCEDURE - NERVE SPARING** *[PROSTATE NERVE SPARING SURGERY TYPE]*	an1	R
UR15430	UROLOGICAL - TREATMENT - PROSTATE	**RADICAL PROSTATECTOMY MARGIN STATUS**	an1	R

Note: the following data item have been retired from v9.0:

- PSA (PRE-TREATMENT)

PROCEDURE – NERVE SPARING: Extent of surgical nerve sparing. This is also required for the BAUS audit (BAUS Q20) and is part of the National Prostate Cancer Audit (NPCA).

1	Bilateral
2	Unilateral
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).

1	Negative Margins
2	Positive Margins <3mm in length
3	Positive Margins ≥3mm in length
4	Positive Margins, length unknown
9	Not Known

What's changed since user guide 8.0.8?

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 v8.0 and should be used to help data collection.

COSD v9.0, has improved the recording of recurrence, metastatic disease, progression and transformation, making the process easier and more logical. A new non-primary cancer pathway linkage section has been created and 3 new distinct pathways added through a choice system.

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.

There are some key new sections within the CORE section as follows:

- **pathway choice**
  - primary or non primary pathway choice
- **non primary pathway choice**
  - recurrence
  - progression
  - transformation
- **diagnostic procedures**, mandating:
  - this is the organisation identifier of the organisation site where the diagnostic procedure took place
  - the date the diagnostic procedure was carried out
  - the diagnostic procedure(s) carried out using OPCS. This maybe recorded in addition to diagnostic procedure (SNOMED CT)
  - the diagnostic procedure(s) carried out using SNOMED CT. This maybe recorded in addition to diagnostic procedure (OPCS)
- all **imaging** must have (through mandation):
  - the organisation identifier of the organisation site where the imaging took place
  - the date the Cancer Imaging was carried out
  - and one or more of the following (although one must be provided):
    - imaging code (NICIP)
    - imaging code (SNOMED CT)
    - cancer imaging modality
- **diagnosis progression**
  - where the disease progresses whilst the patient is on their primary pathway and they have not been given the all clear

- **diagnosis transformation**
  - where the disease transforms whilst the patient is on their primary pathway and they have not been given the all clear
- **personalised care and support planning**
  - to support the HNA, which has also been updated
- **multi disciplinary team meeting** (MDT) has had an overhaul, to meet the demands of the busy NHS and allowing for patients on predefined standard of care reviewed outside MDTM, to be recorded and monitored
  - MDT is no longer going to be part of cancer waiting times from 2020
- **Site specific staging** now requires through mandation, that every site specific stage must be recorded along with:
  - the organisation identifier of the organisation site who carried out the site specific stage
  - the date of the sample/MDT which provided a positive stage outcome
- all **treatments** must have (through mandation):
  - the start date of the first, second or subsequent cancer treatment given to a patient who is receiving care for a cancer condition
  - the treatment modality – the type of treatment or care which was delivered in a cancer treatment period
  - the organisation identifier of the organisation site where the treatment start date for cancer is recorded
- **surgery and other procedures** have been replaced with **surgery**, and the following data item is mandatory for all reported surgical procedures:
  - the date the procedure was carried out
- **acute oncology**
- **laboratory results** now require that every reported lab result also has (through mandation):
  - the date on which an investigation was concluded, such as the date the result was authorised
  - the organisation identifier of the organisation site acting as a health care provider, which processed the sample

The main changes through the site specific sections were as follows:

Breast:

- new, breast - triple diagnostic assessment section
  - recording if a triple diagnostic assessment completed for the patient in a single visit, following initial referral?
- new, NABCOP section
  - to carry new National Audit of Breast Cancer in Older Patients assessment details for Breast Cancer

Colorectal:

- new, clinical nurse specialist section
    - specifically, to record the type of clinical nurse specialist assigned to the patient during their treatment pathway (including stoma nurse)

CTYA:

- new, choices throughout many sections to improve the quality of the data submitted
- new, principal treatment centre data item
    - to record the patient's nominated children's or TYA principal treatment centre (PTC), whether or not they have chosen to have treatment at the PTC. If the service is integrated between 2 PTCs, record both PTC trusts

Haematological:

- multiple new choice sections, improving the quality of the data collected
- the removal of many of the difficult to collect laboratory result
    - freeing up time to collect the remaining important data items

Head and Neck:

- new, treatment section
    - to carry Surgery details for head and neck cancer

Liver:

- new, cholangiocarcinoma section
    - allows clinical teams to state where the Cholangiocarcinoma is present, using the designated categories

Lung:

- many new choice sections and data moved into the correct sections from v9
- a new section for recording bronchoscopy, linked to the diagnostic procedures section in the core
- new molecular test results required by the lung expert advisory group
    - linked to the core molecular section

Upper GI:

- new sections for recording complications
    - these comply with the esophageal database (ESODATA)

Urology:

- updated sections to support the National Prostate Cancer Audit (NPCA)

It is possible that some legacy data may not have all the required mandatory fields for v9. 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).

Additional supporting information

What is the Cancer Outcomes and Services Data set?

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.

This standard consists of:

- a set of individual data items, with their definitions
- the assemblage of these data items into discrete data sets
- the means of flowing the data items
- compilation of the data items into a single reconciled and verified data set

All patients diagnosed with or receiving cancer treatment in or funded by the NHS in England are covered by the standard. This includes adult and paediatric cancer patients.

Providers of cancer services have been required to provide a monthly return on all cancer patients diagnosed from 1 January 2013 using this data set. Data are collated 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 at the following websites:

- the Change Specification, Requirements Specification and Implementation Guidance are available on the NHS Digital website[11]
- further guidance is published by Public Health England[12]

Why is it needed?

Periodically we needed to revise the Cancer Outcomes and Services Data set to ensure that we meet the current information requirements for the NHS. The Cancer Reform Strategy (2007) identified better information and stronger commissioning as 2 of the key drivers to achieve the goal that cancer services in this country should be amongst the best in the world.

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[11] www.content.digital.nhs.uk/isce/publication/dcb1521
[12] http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd

The Achieving World-Class Cancer Outcomes, A Strategy for England 2015 to 2020 (Taskforce Report) further strengthens the need to have strong cancer data collection and empowers both PHE and NHS England to enforce this through the mandate of data collection. 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 electronically directly to the National Cancer Registration and Analysis Service (NCRAS) on a monthly basis.

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

Whilst some of these items are generic there are also a number of site-specific items which are required in order 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 are submitted through other standard NHS routes such as Cancer Waiting Times and do not need to be submitted directly for COSD (although some 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.

Other guidance documentation

Technical Guidance is provided separately and is available on the NCIN website.

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 cancer are recorded.

All recurrences diagnosed at each Trust must now also be included.

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) which 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[13].

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 25s, 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 CTYA section of this Guide for further details[14]. 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 recorded?

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 have been removed from COSD v9 and only available in the COSD Pathology v4 data set.

The reduction in their workload by removing this duplication is estimated to be up-to 30%, and this time should be used to ensure full compliance for data collection across

[13] Please see section **11. Skin** for more information and definition of tumours that fall under the NMSC header.
[14] There are plans to improve the collection of CTYA data items across the data set to help reduce duplication.

all other data-items. This work load reduction has been evidenced in the Burden Advice and Assessment Service submissions as part of the data set review process.

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.

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 or tumour. 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 NCRAS liaison team(s). All pilot data-items are under review and may change in future version controls of COSD[15].

Optional

There are a few data-items that are optional, any Trust can submit these data, 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.

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).

[15] There are currently no new data-items being piloted by Trusts in v8.

List of Registerable Diseases

The ICD10 disease codes 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.

When should the 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 will no longer be reported on the same day. CWT are planning to reduce 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 dates can be found on the NCIN website[16].

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 v9.0, Implementation and Technical Guidance documents.

Feedback and questions relating to the COSD are welcomed and should be emailed to: COSDenquiries@phe.gov.uk

I would like to express my 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 Group, Royal College of Pathologists and Expert Advisory Group members, for helping to guide COSD and continue to ensure all data is clinically relevant and not out-of-date.

Particular thanks also has to be given to the NCRAS 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.

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

Appendix A: cancer waiting times ICD10 codes and tumour groups for primary diagnoses

(Applicable from April 2012) These are registerable conditions for the purposes of Cancer Waiting Times and used within Cancer Registration, such as NCRAS mandatory fields.

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

Key:
() = if applicable
* = different data set from CWT group specified

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C00.0	External upper lip	Head and Neck		•		
C00.1	External lower lip	Head and Neck		•		
C00.2	External lip, unspecified	Head and Neck		•		
C00.3	Upper lip, inner aspect	Head and Neck	•			
C00.4	Lower lip, inner aspect	Head and Neck	•			
C00.5	Lip, unspecified, inner aspect	Head and Neck	•			
C00.6	Commissure of lip	Head and Neck	•			
C00.8	Overlapping lesion of lip	Head and Neck	•			
C00.9	Lip, unspecified	Head and Neck	•			
C01	Malignant neoplasm of base of tongue	Head and Neck	•			
C02.0	Dorsal surface of tongue	Head and Neck	•			
C02.1	Border of tongue	Head and Neck	•			
C02.2	Ventral surface of tongue	Head and Neck	•			
C02.3	Anterior two-thirds of tongue, part unspecified	Head and Neck	•			
C02.4	Lingual tonsil	Head and Neck	•			
C02.8	Overlapping lesion of tongue	Head and Neck	•			
C02.9	Tongue, unspecified	Head and Neck	•			
C03.0	Upper gum	Head and Neck	•			
C03.1	Lower gum	Head and Neck	•			
C03.9	Gum, unspecified	Head and Neck	•			
C04.0	Anterior floor of mouth	Head and Neck	•			

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C04.1	Lateral floor of mouth	Head and Neck	•			
C04.8	Overlapping lesion of floor of mouth	Head and Neck	•			
C04.9	Floor of mouth, unspecified	Head and Neck	•			
C05.0	Hard palate	Head and Neck	•			
C05.1	Soft palate	Head and Neck	•			
C05.2	Uvula	Head and Neck	•			
C05.8	Overlapping lesion of palate	Head and Neck	•			
C05.9	Palate, unspecified	Head and Neck	•			
C06.0	Cheek mucosa	Head and Neck	•			
C06.1	Vestibule of mouth	Head and Neck	•			
C06.2	Retromolar area	Head and Neck	•			
C06.8	Overlapping lesion of other and unspecified parts of mouth	Head and Neck	•			
C06.9	Mouth, unspecified	Head and Neck	•			
C07	Malignant neoplasm of parotid gland	Head and Neck	•			
C08.0	Submandibular gland	Head and Neck	•			
C08.1	Sublingual gland	Head and Neck	•			
C08.8	Overlapping lesion of major salivary glands	Head and Neck	•			
C08.9	Major salivary gland, unspecified	Head and Neck	•			
C09.0	Tonsillar fossa	Head and Neck	•			
C09.1	Tonsillar pillar (anterior) (posterior)	Head and Neck	•			
C09.8	Overlapping lesion of tonsil	Head and Neck	•			
C09.9	Tonsil, unspecified	Head and Neck	•			
C10.0	Vallecula	Head and Neck	•			
C10.1	Anterior surface of epiglottis	Head and Neck	•			
C10.2	Lateral wall of oropharynx	Head and Neck	•			
C10.3	Posterior wall of oropharynx	Head and Neck	•			
C10.4	Branchial cleft	Head and Neck	•			
C10.8	Overlapping lesion of oropharynx	Head and Neck	•			
C10.9	Oropharynx, unspecified	Head and Neck	•			
C11.0	Superior wall of nasopharynx	Head and Neck	•			
C11.1	Posterior wall of nasopharynx	Head and Neck	•			
C11.2	Lateral wall of nasopharynx	Head and Neck	•			
C11.3	Anterior wall of nasopharynx	Head and Neck	•			
C11.8	Overlapping lesion of nasopharynx	Head and Neck	•			
C11.9	Nasopharynx, unspecified	Head and Neck	•			
C12	Malignant neoplasm of piriform sinus	Head and Neck	•			
C13.0	Postcricoid region	Head and Neck	•			

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C13.1	Aryepiglottic fold, hypopharyngeal aspect	Head and Neck	•			
C13.2	Posterior wall of hypopharynx	Head and Neck	•			
C13.8	Overlapping lesion of hypopharynx	Head and Neck	•			
C13.9	Hypopharynx, unspecified	Head and Neck	•			
C14.0	Pharynx, unspecified	Head and Neck	•			
C14.2	Waldeyer ring	Head and Neck	•			
C14.8	Overlapping lesion of lip, oral cavity and pharynx	Head and Neck	•			
C15.0	Cervical part of oesophagus	Upper Gastrointestinal	*			Usually treated by Head and Neck MDT.
C15.1	Thoracic part of oesophagus	Upper Gastrointestinal	•			
C15.2	Abdominal part of oesophagus	Upper Gastrointestinal	•			
C15.3	Upper third of oesophagus	Upper Gastrointestinal	•			
C15.4	Middle third of oesophagus	Upper Gastrointestinal	•			
C15.5	Lower third of oesophagus	Upper Gastrointestinal	•			
C15.8	Overlapping lesion of oesophagus	Upper Gastrointestinal	•			
C15.9	Oesophagus, unspecified	Upper Gastrointestinal	•			
C16.0	Cardia	Upper Gastrointestinal	•			
C16.1	Fundus of stomach	Upper Gastrointestinal	•			
C16.2	Body of stomach	Upper Gastrointestinal	•			
C16.3	Pyloric antrum	Upper Gastrointestinal	•			
C16.4	Pylorus	Upper Gastrointestinal	•			
C16.5	Lesser curvature of stomach, unspecified	Upper Gastrointestinal	•			
C16.6	Greater curvature of stomach, unspecified	Upper Gastrointestinal	•			
C16.8	Overlapping lesion of stomach	Upper Gastrointestinal	•			
C16.9	Stomach, unspecified	Upper Gastrointestinal	•			
C17.0	Duodenum	Colorectal		•		Usually treated by Upper GI MDT
C17.1	Jejunum	Colorectal		•		Usually treated by Upper GI MDT
C17.2	Ileum	Colorectal		•		Usually treated by Upper GI MDT
C17.3	Meckel diverticulum	Colorectal		•		Usually treated by Upper GI MDT
C17.8	Overlapping lesion of small intestine	Colorectal		•		Usually treated by Upper GI MDT
C17.9	Small intestine, unspecified	Colorectal		•		Usually treated by Upper GI MDT

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C18.0	Caecum	Colorectal	●			
C18.1	Appendix	Colorectal		●		
C18.2	Ascending colon	Colorectal	●			
C18.3	Hepatic flexure	Colorectal	●			
C18.4	Transverse colon	Colorectal	●			
C18.5	Splenic flexure	Colorectal	●			
C18.6	Descending colon	Colorectal	●			
C18.7	Sigmoid colon	Colorectal	●			
C18.8	Overlapping lesion of colon	Colorectal	●			
C18.9	Colon, unspecified	Colorectal	●			
C19	Malignant neoplasm of rectosigmoid junction	Colorectal	●			
C20	Malignant neoplasm of rectum	Colorectal	●			
C21.0	Anus, unspecified	Colorectal		●		
C21.1	Anal canal	Colorectal		●		
C21.2	Cloacogenic zone	Colorectal		●		
C21.8	Overlapping lesion of rectum, anus and anal canal	Colorectal		●		
C22.0	Liver cell carcinoma	Upper Gastrointestinal	●			Liver cell carcinoma is also known as HCC.
C22.1	Intrahepatic bile duct carcinoma	Upper Gastrointestinal	●			
C22.2	Hepatoblastoma	Upper Gastrointestinal	●			
C22.3	Angiosarcoma of liver	Upper Gastrointestinal	●			
C22.4	Other sarcomas of liver	Upper Gastrointestinal	●			
C22.7	Other specified carcinomas of liver	Upper Gastrointestinal	●			
C22.9	Liver, unspecified	Upper Gastrointestinal	●			
C23	Malignant neoplasm of gallbladder	Upper Gastrointestinal	●			
C24.0	Extrahepatic bile duct	Upper Gastrointestinal	●			
C24.1	Ampulla of Vater	Upper Gastrointestinal	●			
C24.8	Overlapping lesion of biliary tract	Upper Gastrointestinal	●			
C24.9	Biliary tract, unspecified	Upper Gastrointestinal	●			
C25.0	Head of pancreas	Upper Gastrointestinal	●			
C25.1	Body of pancreas	Upper Gastrointestinal	●			
C25.2	Tail of pancreas	Upper Gastrointestinal	●			
C25.3	Pancreatic duct	Upper Gastrointestinal	●			
C25.4	Endocrine pancreas	Upper Gastrointestinal	●			
C25.7	Other parts of pancreas	Upper Gastrointestinal	●			

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C25.8	Overlapping lesion of pancreas	Upper Gastrointestinal	•			
C25.9	Pancreas, unspecified	Upper Gastrointestinal	•			
C26.0	Intestinal tract, part unspecified	Colorectal	•			
C26.1	Spleen	Colorectal		•		
C26.8	Overlapping lesion of digestive system	Colorectal		•		
C26.9	Ill-defined sites within the digestive system	Colorectal		•		
C30.0	Nasal cavity	Head and Neck	•			
C30.1	Middle ear	Head and Neck	•			
C31.0	Maxillary sinus	Head and Neck	•			
C31.1	Ethmoidal sinus	Head and Neck	•			
C31.2	Frontal sinus	Head and Neck	•			
C31.3	Sphenoidal sinus	Head and Neck	•			
C31.8	Overlapping lesion of accessory sinuses	Head and Neck	•			
C31.9	Accessory sinus, unspecified	Head and Neck	•			
C32.0	Glottis	Head and Neck	•			
C32.1	Supraglottis	Head and Neck	•			
C32.2	Subglottis	Head and Neck	•			
C32.3	Laryngeal cartilage	Head and Neck	•			
C32.8	Overlapping lesion of larynx	Head and Neck	•			
C32.9	Larynx, unspecified	Head and Neck	•			
C33	Malignant neoplasm of trachea	Lung	•			
C34.0	Main bronchus	Lung	•			
C34.1	Upper lobe, bronchus or lung	Lung	•			
C34.2	Middle lobe, bronchus or lung	Lung	•			
C34.3	Lower lobe, bronchus or lung	Lung	•			
C34.8	Overlapping lesion of bronchus and lung	Lung	•			
C34.9	Bronchus or lung, unspecified	Lung	•			
C37	Malignant neoplasm of thymus	Lung	•			
C38.0	Heart	Lung		•		
C38.1	Anterior mediastinum	Lung		•		
C38.2	Posterior mediastinum	Lung		•		
C38.3	Mediastinum, part unspecified	Lung		•		
C38.4	Pleura	Lung		•		
C38.8	Overlapping lesion of heart, mediastinum and pleura	Lung		•		
C39.0	Upper respiratory tract, part unspecified	Lung		•		
C39.8	Overlapping lesion of respiratory and intrathoracic organs	Lung		•		

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C39.9	Ill-defined sites within the respiratory system	Lung		•		
C40.0	Scapula and long bones of upper limb	Sarcoma	•			
C40.1	Short bones of upper limb	Sarcoma	•			
C40.2	Long bones of lower limb	Sarcoma	•			
C40.3	Short bones of lower limb	Sarcoma	•			
C40.8	Overlapping lesion of bone and articular cartilage of limbs	Sarcoma	•			
C40.9	Bone and articular cartilage of limb, unspecified	Sarcoma	•			
C41.0	Bones of skull and face	Sarcoma	•			
C41.1	Mandible	Sarcoma	•			
C41.2	Vertebral column	Sarcoma	•			
C41.3	Ribs, sternum and clavicle	Sarcoma	•			
C41.4	Pelvic bones, sacrum and coccyx	Sarcoma	•			
C41.8	Overlapping lesion of bone and articular cartilage	Sarcoma	•			
C41.9	Bone and articular cartilage, unspecified	Sarcoma	•			
C43.0	Malignant melanoma of lip	Skin	•			
C43.1	Malignant melanoma of eyelid, including canthus	Skin	•			
C43.2	Malignant melanoma of ear and external auricular canal	Skin	•			
C43.3	Malignant melanoma of other and unspecified parts of face	Skin	•			
C43.4	Malignant melanoma of scalp and neck	Skin	•			
C43.5	Malignant melanoma of trunk	Skin	•			
C43.6	Malignant melanoma of upper limb, including shoulder	Skin	•			
C43.7	Malignant melanoma of lower limb, including hip	Skin	•			
C43.8	Overlapping malignant melanoma of skin	Skin	•			
C43.9	Malignant melanoma of skin, unspecified	Skin	•			
C44.0	Skin of lip	Skin	(•)	(•)	(•)	See the Skin chapter of the COSD User Guide (Overview Section) for further information on the collection of this Skin disease.

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C44.1	Skin of eyelid, including canthus	Skin	(•)	(•)	(•)	See the Skin chapter of the COSD User Guide (Overview Section) for further information on the collection of this Skin disease.
C44.2	Skin of ear and external auricular canal	Skin	(•)	(•)	(•)	See the Skin chapter of the COSD User Guide (Overview Section) for further information on the collection of this Skin disease.
C44.3	Skin of other and unspecified parts of face	Skin	(•)	(•)	(•)	See the Skin chapter of the COSD User Guide (Overview Section) for further information on the collection of this Skin disease.
C44.4	Skin of scalp and neck	Skin	(•)	(•)	(•)	See the Skin chapter of the COSD User Guide (Overview Section) for further information on the collection of this Skin disease.
C44.5	Skin of trunk	Skin	(•)	(•)	(•)	See the Skin chapter of the COSD User Guide (Overview Section) for further information on the collection of this Skin disease.
C44.6	Skin of upper limb, including shoulder	Skin	(•)	(•)	(•)	See the Skin chapter of the COSD User Guide (Overview Section) for further information on the collection of this Skin disease.
C44.7	Skin of lower limb, including hip	Skin	(•)	(•)	(•)	See the Skin chapter of the COSD User Guide (Overview Section) for further information on the collection of this Skin disease.

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C44.8	Overlapping lesion of skin	Skin	(•)	(•)	(•)	See the Skin chapter of the COSD User Guide (Overview Section) for further information on the collection of this Skin disease.
C44.9	Malignant neoplasm of skin, unspecified	Skin	(•)	(•)	(•)	See the Skin chapter of the COSD User Guide (Overview Section) for further information on the collection of this Skin disease.
C45.0	Mesothelioma of pleura	Lung		•		
C45.1	Mesothelioma of peritoneum	Lung		•		
C45.2	Mesothelioma of pericardium	Lung		•		
C45.7	Mesothelioma of other sites	Lung		•		
C45.9	Mesothelioma, unspecified	Lung		•		
C46.0	Kaposi sarcoma of skin	Sarcoma		•		
C46.1	Kaposi sarcoma of soft tissue	Sarcoma		•		
C46.2	Kaposi sarcoma of palate	Sarcoma		•		
C46.3	Kaposi sarcoma of lymph nodes	Sarcoma		•		
C46.7	Kaposi sarcoma of other sites	Sarcoma		•		
C46.8	Kaposi sarcoma of multiple organs	Sarcoma		•		
C46.9	Kaposi sarcoma, unspecified	Sarcoma		•		
C47.0	*Peripheral nerves of head, face and neck*	*Brain/Central Nervous System*		•		*Usually treated by Sarcoma MDT.*
C47.1	*Peripheral nerves of upper limb, including shoulder*	*Brain/Central Nervous System*		•		*Usually treated by Sarcoma MDT.*
C47.2	*Peripheral nerves of lower limb, including hip*	*Brain/Central Nervous System*		•		*Usually treated by Sarcoma MDT.*
C47.3	*Peripheral nerves of thorax*	*Brain/Central Nervous System*		•		*Usually treated by Sarcoma MDT.*
C47.4	*Peripheral nerves of abdomen*	*Brain/Central Nervous System*		•		*Usually treated by Sarcoma MDT.*
C47.5	*Peripheral nerves of pelvis*	*Brain/Central Nervous System*		•		*Usually treated by Sarcoma MDT.*
C47.6	*Peripheral nerves of trunk, unspecified*	*Brain/Central Nervous System*		•		*Usually treated by Sarcoma MDT.*
C47.8	*Overlapping lesion of peripheral nerves and autonomic nervous system*	*Brain/Central Nervous System*		•		*Usually treated by Sarcoma MDT.*
C47.9	*Peripheral nerves and autonomic nervous system, unspecified*	*Brain/Central Nervous System*		•		*Usually treated by Sarcoma MDT.*

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C48.0	*Retroperitoneum*	*Sarcoma*	●			*Usually treated by Sarcoma MDT.*
C48.1	*Specified parts of peritoneum*	*Sarcoma*	● *			** Sarcoma and Gynaecological Data sets to be collected where applicable.*
C48.2	*Peritoneum, unspecified*	*Sarcoma*	● *			** Sarcoma and Gynaecological Data sets to be collected where applicable.*
C48.8	Overlapping lesion of retroperitoneum and peritoneum	Sarcoma	●			
C49.0	Connective and soft tissue of head, face and neck	Sarcoma	●			
C49.1	Connective and soft tissue of upper limb, including shoulder	Sarcoma	●			
C49.2	Connective and soft tissue of lower limb, including hip	Sarcoma	●			
C49.3	Connective and soft tissue of thorax	Sarcoma	●			
C49.4	Connective and soft tissue of abdomen	Sarcoma	●			
C49.5	Connective and soft tissue of pelvis	Sarcoma	●			
C49.6	Connective and soft tissue of trunk, unspecified	Sarcoma	●			
C49.8	Overlapping lesion of connective and soft tissue	Sarcoma	●			
C49.9	Connective and soft tissue, unspecified	Sarcoma	●			
C50.0	Nipple and areola	Breast	●			
C50.1	Central portion of breast	Breast	●			
C50.2	Upper-inner quadrant of breast	Breast	●			
C50.3	Lower-inner quadrant of breast	Breast	●			
C50.4	Upper-outer quadrant of breast	Breast	●			
C50.5	Lower-outer quadrant of breast	Breast	●			
C50.6	Axillary tail of breast	Breast	●			
C50.8	Overlapping lesion of breast	Breast	●			
C50.9	Breast, unspecified	Breast	●			
C51.0	Labium majus	Gynaecological	● *			* Gynaecological and Skin Data sets to be collected where applicable.

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C51.1	Labium minus	Gynaecological	● *			* Gynaecological and Skin Data sets to be collected where applicable.
C51.2	Clitoris	Gynaecological	● *			* Gynaecological and Skin Data sets to be collected where applicable.
C51.8	Overlapping lesion of vulva	Gynaecological	● *			* Gynaecological and Skin Data sets to be collected where applicable.
C51.9	Vulva, unspecified	Gynaecological	● *			* Gynaecological and Skin Data sets to be collected where applicable.
C52	Malignant neoplasm of vagina	Gynaecological	●			
C53.0	Endocervix	Gynaecological	●			
C53.1	Exocervix	Gynaecological	●			
C53.8	Overlapping lesion of cervix uteri	Gynaecological	●			
C53.9	Cervix uteri, unspecified	Gynaecological	●			
C54.0	Isthmus uteri	Gynaecological	●			
C54.1	Endometrium	Gynaecological	●			
C54.2	Myometrium	Gynaecological	●			
C54.3	Fundus uteri	Gynaecological	●			
C54.8	Overlapping lesion of corpus uteri	Gynaecological	●			
C54.9	Corpus uteri, unspecified	Gynaecological	●			
C55	Malignant neoplasm of uterus, part unspecified	Gynaecological	●			
C56	Malignant neoplasm of ovary	Gynaecological	●			
C57.0	Fallopian tube	Gynaecological	●			
C57.1	Broad ligament	Gynaecological	●			
C57.2	Round ligament	Gynaecological	●			
C57.3	Parametrium	Gynaecological	●			
C57.4	Uterine adnexa, unspecified	Gynaecological	●			
C57.7	Other specified female genital organs	Gynaecological	●			
C57.8	Overlapping lesion of female genital organs	Gynaecological	●			
C57.9	Female genital organ, unspecified	Gynaecological	●			
C58	Malignant neoplasm of placenta	Gynaecological	●			
C60.0	Prepuce	Urological	● *			* Urological and Skin Data sets to be collected where applicable.
C60.1	Glans penis	Urological	● *			* Urological and Skin Data sets to be collected where applicable.

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C60.2	Body of penis	Urological	● *			* Urological and Skin Data sets to be collected where applicable.
C60.8	Overlapping lesion of penis	Urological	● *			* Urological and Skin Data sets to be collected where applicable.
C60.9	Penis, unspecified	Urological	● *			* Urological and Skin Data sets to be collected where applicable.
C61	Malignant neoplasm of prostate	Urological	●			
C62.0	Undescended testis	Urological	●			
C62.1	Descended testis	Urological	●			
C62.9	Testis, unspecified	Urological	●			
C63.0	Epididymis	Urological	●			
C63.1	Spermatic cord	Urological	●			
C63.2	Scrotum	Urological		●		
C63.7	Other specified male genital organs	Urological	●			
C63.8	Overlapping lesion of male genital organs	Urological	●			
C63.9	Male genital organ, unspecified	Urological	●			
C64	Malignant neoplasm of kidney, except renal pelvis	Urological	●			
C65	Malignant neoplasm of renal pelvis	Urological	●			
C66	Malignant neoplasm of ureter	Urological	●			
C67.0	Trigone of bladder	Urological	●			
C67.1	Dome of bladder	Urological	●			
C67.2	Lateral wall of bladder	Urological	●			
C67.3	Anterior wall of bladder	Urological	●			
C67.4	Posterior wall of bladder	Urological	●			
C67.5	Bladder neck	Urological	●			
C67.6	Ureteric orifice	Urological	●			
C67.7	Urachus	Urological	●			
C67.8	Overlapping lesion of bladder	Urological	●			
C67.9	Bladder, unspecified	Urological	●			
C68.0	Urethra	Urological	●			
C68.1	Paraurethral glands	Urological	●			
C68.8	Overlapping lesion of urinary organs	Urological	●			
C68.9	Urinary organ, unspecified	Urological	●			
C69.0	Conjunctiva	Brain/Central Nervous System		●		Not normally treated by CNS MDT.
C69.1	Cornea	Brain/Central Nervous System		●		Not normally treated by CNS MDT.
C69.2	Retina	Brain/Central Nervous System		●		Not normally treated by CNS MDT.
C69.3	Choroid	Brain/Central Nervous System		●		Not normally treated by CNS MDT.

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C69.4	Ciliary body	Brain/Central Nervous System		•		Not normally treated by CNS MDT.
C69.5	Lachrymal gland and duct	Brain/Central Nervous System		•		Not normally treated by CNS MDT.
C69.6	Orbit	Brain/Central Nervous System		•		Not normally treated by CNS MDT. Maybe treated by Sarcoma MDT.
C69.8	Overlapping lesion of eye and adnexa	Brain/Central Nervous System		•		Not normally treated by CNS MDT.
C69.9	Eye, unspecified	Brain/Central Nervous System		•		Not normally treated by CNS MDT.
C70.0	Cerebral meninges	Brain/Central Nervous System	•			
C70.1	Spinal meninges	Brain/Central Nervous System	•			
C70.9	Meninges, unspecified	Brain/Central Nervous System	•			
C71.0	Cerebrum, except lobes and ventricles	Brain/Central Nervous System	•			
C71.1	Frontal lobe	Brain/Central Nervous System	•			
C71.2	Temporal lobe	Brain/Central Nervous System	•			
C71.3	Parietal lobe	Brain/Central Nervous System	•			
C71.4	Occipital lobe	Brain/Central Nervous System	•			
C71.5	Cerebral ventricle	Brain/Central Nervous System	•			
C71.6	Cerebellum	Brain/Central Nervous System	(•) (*)			CTYA data set collected for Medulloblastoma patients under 25.
C71.7	Brain stem	Brain/Central Nervous System	•			
C71.8	Overlapping lesion of brain	Brain/Central Nervous System	•			
C71.9	Brain, unspecified	Brain/Central Nervous System	•			
C72.0	Spinal cord	Brain/Central Nervous System	•			
C72.1	Cauda equina	Brain/Central Nervous System	•			
C72.2	Olfactory nerve	Brain/Central Nervous System	•			
C72.3	Optic nerve	Brain/Central Nervous System	•			
C72.4	Acoustic nerve	Brain/Central Nervous System	•			
C72.5	Other and unspecified cranial nerves	Brain/Central Nervous System	•			
C72.8	Overlapping lesion of brain and other parts of central nervous system	Brain/Central Nervous System	•			
C72.9	Central nervous system, unspecified	Brain/Central Nervous System	•			
C73	Malignant neoplasm of thyroid gland	Head and Neck		•		

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C74.0	Cortex of adrenal gland	Other		•		
C74.1	Medulla of adrenal gland	Other		•		
C74.9	Adrenal gland, unspecified	Other		•		
C75.0	Parathyroid gland	Other		•		
C75.1	Pituitary gland	Other	*			Usually treated by CNS MDT.
C75.2	Craniopharyngeal duct	Other	*			Usually treated by CNS MDT.
C75.3	Pineal gland	Other	*			Usually treated by CNS MDT.
C75.4	Carotid body	Other		•		
C75.5	Aortic body and other paraganglia	Other		•		
C75.8	Pluriglandular involvement, unspecified	Other		•		
C75.9	Endocrine gland, unspecified	Other		•		
C76.0	Head, face and neck	Other		•		Other and ill defined - use only if unable to code to specific primary site
C76.1	Thorax	Other		•		Other and ill defined - use only if unable to code to specific primary site
C76.2	Abdomen	Other		•		Other and ill defined - use only if unable to code to specific primary site
C76.3	Pelvis	Other		•		Other and ill defined - use only if unable to code to specific primary site
C76.4	Upper limb	Other		•		Other and ill defined - use only if unable to code to specific primary site
C76.5	Lower limb	Other		•		Other and ill defined - use only if unable to code to specific primary site
C76.7	Other ill-defined sites	Other		•		Other and ill defined - use only if unable to code to specific primary site
C76.8	Overlapping lesion of other and ill-defined sites	Other		•		Other and ill defined - use only if unable to code to specific primary site
C77.0	Lymph nodes of head, face and neck	Head and Neck	•			Secondary - only use if unable to code to specific primary site
C77.1	Intrathoracic lymph nodes	Other		•		Secondary - only use if unable to code to specific primary site

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C77.2	Intra-abdominal lymph nodes	Other		•		Secondary - only use if unable to code to specific primary site
C77.3	Axillary and upper limb lymph nodes	Other		•		Secondary - only use if unable to code to specific primary site
C77.4	Inguinal and lower limb lymph nodes	Other		•		Secondary - only use if unable to code to specific primary site
C77.5	Intrapelvic lymph nodes	Other		•		Secondary - only use if unable to code to specific primary site
C77.8	Lymph nodes of multiple regions	Other		•		Secondary - only use if unable to code to specific primary site
C77.9	Lymph node, unspecified	Other		•		Secondary - only use if unable to code to specific primary site
C78.0	Secondary malignant neoplasm of lung	Lung		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C78.1	Secondary malignant neoplasm of mediastinum	Lung		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C78.2	Secondary malignant neoplasm of pleura	Lung		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C78.3	Secondary malignant neoplasm of other and unspecified respiratory organs	Lung		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C78.4	Secondary malignant neoplasm of small intestine	Colorectal		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C78.5	Secondary malignant neoplasm of large intestine and rectum	Colorectal		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C78.6	Secondary malignant neoplasm of retroperitoneum and peritoneum	Sarcoma		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C78.7	Secondary malignant neoplasm of liver and intrahepatic bile duct	Upper Gastrointestinal		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C78.8	Secondary malignant neoplasm of other and unspecified digestive organs	Colorectal		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.0	Secondary malignant neoplasm of kidney and renal pelvis	Urological		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.1	Secondary malignant neoplasm of bladder and other and unspecified urinary organs	Urological		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.2	Secondary malignant neoplasm of skin	Skin		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.3	Secondary malignant neoplasm of brain and cerebral meninges	Brain/Central Nervous System		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.4	Secondary malignant neoplasm of other and unspecified parts of nervous system	Brain/Central Nervous System		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.5	Secondary malignant neoplasm of bone and bone marrow	Sarcoma		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.6	Secondary malignant neoplasm of ovary	Gynaecological		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C79.7	Secondary malignant neoplasm of adrenal gland	Other		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.8	Secondary malignant neoplasm of other specified sites	Other		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.9	Secondary malignant neoplasm, unspecified site	Other		•		Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C80.0	Malignant neoplasm, primary site unknown, so stated	Other		•		Only use if unable to code to specific primary site.
C80.9	Malignant neoplasm, unspecified	Other		•		Only use if unable to code to specific primary site.
C81.0	Nodular lymphocyte predominant Hodgkin lymphoma	Haematological	See the Haematological chapter of COSD User Guide for information regarding what is required to be submitted for these Haematological diseases.			
C81.1	Nodular sclerosis (classical) Hodgkin lymphoma	Haematological				
C81.2	Mixed cellularity (classical) Hodgkin lymphoma	Haematological				
C81.3	Lymphocytic depleted (classical) Hodgkin lymphoma	Haematological				
C81.4	Lymphocyte-rich (classical) Hodgkin lymphoma	Haematological				
C81.7	Other (classical) Hodgkin lymphoma	Haematological				
C81.9	Hodgkin lymphoma, unspecified	Haematological				
C82.0	Follicular lymphoma grade I	Haematological				
C82.1	Follicular lymphoma grade II	Haematological				
C82.2	Follicular lymphoma grade III, unspecified	Haematological				
C82.3	Follicular lymphoma grade IIIa	Haematological				
C82.4	Follicular lymphoma grade IIIb	Haematological				
C82.5	Diffuse follicle centre lymphoma	Haematological				
C82.6	Cutaneous follicle centre lymphoma	Haematological				
C82.7	Other types of follicular lymphoma	Haematological				

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C82.9	Follicular lymphoma, unspecified	Haematological				
C83.0	Small cell B-cell lymphoma	Haematological				
C83.1	Mantle cell lymphoma	Haematological				
C83.3	Diffuse large B-cell lymphoma	Haematological				
C83.5	Lymphoblastic (diffuse) lymphoma	Haematological				
C83.7	Burkitt lymphoma	Haematological				
C83.8	Other non-follicular lymphoma	Haematological				
C83.9	Non-follicular (diffuse) lymphoma, unspecified	Haematological				
C84.0	Mycosis fungoides	Haematological				
C84.1	Sézary disease	Haematological				
C84.4	Peripheral T-cell lymphoma, not elsewhere classified	Haematological				
C84.5	Other mature T/NK-cell lymphomas	Haematological				
C84.6	Anaplastic large cell lymphoma, ALK-positive	Haematological				
C84.7	Anaplastic large cell lymphoma, ALK-negative	Haematological				
C84.8	Cutaneous T-cell lymphoma, unspecified	Haematological				
C84.9	Mature T/NK-cell lymphoma, unspecified	Haematological				
C85.1	B-cell lymphoma, unspecified	Haematological				
C85.2	Mediastinal (thymic) large B-cell lymphoma	Haematological				
C85.7	Other specified types of non-Hodgkin lymphoma	Haematological				
C85.9	Non-Hodgkin lymphoma, unspecified	Haematological				
C86.0	Extranodal NK/T-cell lymphoma, nasal type	Haematological				
C86.1	Hepatosplenic T-cell lymphoma	Haematological				
C86.2	Enteropathy-type (intestinal) T-cell lymphoma	Haematological				
C86.3	Subcutaneous panniculitis-like T-cell lymphoma	Haematological				
C86.4	Blastic NK-cell lymphoma	Haematological				
C86.5	Angioimmunoblastic T-cell lymphoma	Haematological				
C86.6	Primary cutaneous CD30-positive T-cell proliferations	Haematological				
C88.0	Waldenström macroglobulinaemia	Haematological				
C88.2	Other heavy chain disease	Haematological				
C88.3	Immunoproliferative small intestinal disease	Haematological				

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C88.4	Extranodal marginal zone B-cell lymphoma of mucosa-associated lymphoid tissue (MALT-lymphoma)	Haematological				
C88.7	Other malignant immunoproliferative diseases	Haematological				
C88.9	Malignant immunoproliferative disease, unspecified	Haematological				
C90.0	Multiple myeloma	Haematological				
C90.1	Plasma cell leukaemia	Haematological				
C90.2	Extramedullary plasmacytoma	Haematological				
C90.3	Solitary plasmacytoma	Haematological				
C91.0	Acute lymphoblastic leukaemia [ALL]	Haematological				
C91.1	Chronic lymphocytic leukaemia of B-cell type	Haematological				
C91.3	Prolymphocytic leukaemia of B-cell type	Haematological				
C91.4	Hairy-cell leukaemia	Haematological				
C91.5	Adult T-cell lymphoma/leukaemia (HTLV-1-associated)	Haematological				
C91.6	Prolymphocytic leukaemia of T-cell type	Haematological				
C91.7	Other lymphoid leukaemia	Haematological				
C91.8	Mature B-cell leukaemia Burkitt-type	Haematological				
C91.9	Lymphoid leukaemia, unspecified	Haematological				
C92.0	Acute myeloid leukaemia [AML]	Haematological				
C92.1	Chronic myeloid leukaemia [CML], BCR/ABL-positive	Haematological				
C92.2	Atypical chronic myeloid leukaemia, BCR/ABL-negative	Haematological				
C92.3	Myeloid sarcoma	Haematological				
C92.4	Acute promyelocytic leukaemia [PML]	Haematological				
C92.5	Acute myelomonocytic leukaemia	Haematological				
C92.6	Acute myeloid leukaemia with 11q23-abnormality	Haematological				
C92.7	Other myeloid leukaemia	Haematological				
C92.8	Acute myeloid leukaemia with multilineage dysplasia	Haematological				
C92.9	Myeloid leukaemia, unspecified	Haematological				
C93.0	Acute monoblastic/monocytic leukaemia	Haematological				

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C93.1	Chronic myelomonocytic leukaemia	Haematological				
C93.3	Juvenile myelomonocytic leukaemia	Haematological				
C93.7	Other monocytic leukaemia	Haematological				
C93.9	Monocytic leukaemia, unspecified	Haematological				
C94.0	Acute erythroid leukaemia	Haematological				
C94.2	Acute megakaryoblastic leukaemia	Haematological				
C94.3	Mast cell leukaemia	Haematological				
C94.4	Acute panmyelosis with myelofibrosis	Haematological				
C94.6	Myelodysplastic and myeloproliferative disease, not elsewhere classified	Haematological				
C94.7	Other specified leukaemias	Haematological				
C95.0	Acute leukaemia of unspecified cell type	Haematological				
C95.1	Chronic leukaemia of unspecified cell type	Haematological				
C95.7	Other leukaemia of unspecified cell type	Haematological				
C95.9	Leukaemia, unspecified	Haematological				
C96.0	Multifocal and multisystemic (disseminated) Langerhans-cell histiocytosis [Letterer-Siwe disease]	Haematological				
C96.2	Malignant mast cell tumour	Haematological				
C96.4	Sarcoma of dendritic cells (accessory cells)	Haematological				
C96.5	Multifocal and unisystemic (disseminated) Langerhans-cell histiocytosis	Haematological				
C96.6	Unifocal Langerhans-cell histiocytosis	Haematological				
C96.7	Other specified malignant neoplasms of lymphoid, haematopoietic and related tissue	Haematological				
C96.8	Histiocytic sarcoma	Haematological				
C96.9	Malignant neoplasms of lymphoid, haematopoietic and related tissue, unspecified	Haematological				
C97	Malignant neoplasms of independent (primary) multiple sites	Other		•		
D05.0	Lobular carcinoma in situ	Breast	•			

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
D05.1	Intraductal carcinoma in situ	Breast	•			
D05.7	Other carcinoma in situ of breast	Breast	•			
D05.9	Carcinoma in situ of breast, unspecified	Breast	•			

Appendix B: mandatory registerable conditions

MANDATORY REGISTERABLE CONDITIONS

Further details to be provided regarding applicable data fields for each disease. These are additional Cancer Registration i.e. 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

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
C00.0 - C97	Malignant neoplasms (See Appendix A for full list)					
D00.0	Carcinoma in situ of Lip, oral cavity and pharynx	Head and Neck			•	
D00.1	Carcinoma in situ of Oesophagus	Upper Gastrointestinal			•	
D00.2	Carcinoma in situ of Stomach	Upper Gastrointestinal			•	
D01.0	Carcinoma in situ of Colon	Colorectal			•	
D01.1	Carcinoma in situ of Rectosigmoid junction	Colorectal			•	
D01.2	Carcinoma in situ of Rectum	Colorectal			•	
D01.3	Carcinoma in situ of Anus and anal canal	Colorectal			•	
D01.4	Carcinoma in situ of Other and unspecificed parts of intestine	Colorectal			•	
D01.5	Carcinoma in situ of Liver, gallbladder and bile ducts	Upper Gastrointestinal			•	
D01.7	Carcinoma in situ of Other specified digestive organs	Colorectal			•	
D01.9	Carcinoma in situ of Digestive organ, unspecified	Colorectal			•	
D02.0	Carcinoma in situ of Larynx	Head and Neck			•	

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
D02.1	Carcinoma in situ of Trachea	Lung			•	
D02.2	Carcinoma in situ of Bronchus and lung	Lung			•	
D02.3	Carcinoma in situ of Other parts of respiratory system	Lung			•	
D02.4	Carcinoma in situ of Respiratory system, unspecified	Lung			•	
D03.0	Melanoma in situ of lip	Skin		•		
D03.1	Melanoma in situ of eyelid, including canthus	Skin		•		
D03.2	Melanoma in situ, of ear and external auricular canal	Skin		•		
D03.3	Melanoma in situ of other and unspecified parts of face	Skin		•		
D03.4	Melanoma in situ of scalp and neck	Skin		•		
D03.5	Melanoma in situ of trunk	Skin		•		
D03.6	Melanoma in situ of upper limb, including shoulder	Skin		•		
D03.7	Melanoma in situ of lower limb, including hip	Skin		•		
D03.8	Melanoma in situ of other sites	Other			•	
D03.9	Melanoma in situ, unspecified	Skin		•		
D05.0	Lobular carcinoma in situ	Breast	•			
D05.1	Intraductal carcinoma in situ	Breast	•			
D05.7	Other carcinoma in situ of breast	Breast	•			
D05.9	Carcinoma in situ of breast, unspecified	Breast	•			
D06.0	Carcinoma in situ of endocervix	Gynaecological			•	
D06.1	Carcinoma in situ of exocervix	Gynaecological			•	
D06.7	Carcinoma in situ of other parts of cervix	Gynaecological			•	
D06.9	Carcinoma in situ of cervix, unspecified	Gynaecological			•	
D07.0	Carcinoma in situ of endometrium	Gynaecological			•	
D07.1	Carcinoma in situ of vulva	Gynaecological			•	
D07.2	Carcinoma in situ of vagina	Gynaecological			•	
D07.3	Carcinoma in situ of other and unspecified female genital organs	Gynaecological			•	

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
D07.4	Carcinoma in situ of penis	Urological			•	
D07.5	Carcinoma in situ of prostate	Urological			•	
D07.6	Carcinoma in situ of other and unspecified male genital organs	Urological			•	
D09.0	Carcinoma in situ of Bladder	Urological	•			
D09.1	Carcinoma in situ of other and unspecified urinary organs	Urological			•	
D09.2	Carcinoma in situ of eye	Other			•	
D09.3	Carcinoma in situ of thyroid and other endocrine glands	Head and Neck			•	
D09.7	Carcinoma in situ of other specified sites	Other			•	
D09.9	Carcinoma in situ, unspecified	Other			•	
D32.0	Benign neoplasm of cerebral meninges	Brain/Central Nervous System	•			
D32.1	Benign neoplasm of spinal meninges	Brain/Central Nervous System	•			
D32.9	Benign neoplasm of meninges, unspecified	Brain/Central Nervous System	•			
D33.0	Benign neoplasm of brain, supratentorial	Brain/Central Nervous System	•			
D33.1	Benign neoplasm of brain, infratentorial	Brain/Central Nervous System	•			
D33.2	Benign neoplasm of brain, unspecified	Brain/Central Nervous System	•			
D33.3	Benign neoplasm of cranial nerves	Brain/Central Nervous System	•			
D33.4	Benign neoplasm of spinal cord	Brain/Central Nervous System	•			
D33.7	Benign neoplasm of other specified parts of central nervous system	Brain/Central Nervous System	•			
D33.9	Benign neoplasm of central nervous system, unspecified	Brain/Central Nervous System	•			
D35.2	Benign neoplasm of Pituitary gland	Brain/Central Nervous System	•			
D35.3	*Benign neoplasm of Craniopharyngeal duct*	*Other*	•			*Usually classified as CNS*
D35.4	Benign neoplasm of Pineal gland	Brain/Central Nervous System	•			
D37.0	Neoplasm of uncertain or unknown behaviour of lip, oral cavity and pharynx	Head and Neck			•	
D37.1	Neoplasm of uncertain or unknown behaviour of Stomach	Upper Gastrointestinal			•	

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
D37.2	Neoplasm of uncertain or unknown behaviour of Small intestine	Upper Gastrointestinal			•	
D37.3	Neoplasm of uncertain or unknown behaviour of Appendix	Colorectal			•	
D37.4	Neoplasm of uncertain or unknown behaviour of Colon	Colorectal			•	
D37.5	Neoplasm of uncertain or unknown behaviour of Rectum	Colorectal			•	
D37.6	Neoplasm of uncertain or unknown behaviour of Liver, gallbladder and bile ducts	Upper Gastrointestinal			•	
D37.7	Neoplasm of uncertain or unknown behaviour of Other digestive organs	Colorectal/Upper Gastrointestinal			•	
D37.9	Neoplasm of uncertain or unknown behaviour of Digestive organ, unspecified	Colorectal/Upper Gastrointestinal			•	
D38.0	Neoplasm of uncertain or unknown behaviour of Larynx	Head and Neck			•	
D38.1	Neoplasm of uncertain or unknown behaviour of Trachea, bronchus and lung	Lung			•	
D38.2	Neoplasm of uncertain or unknown behaviour of Pleura	Lung			•	
D38.3	Neoplasm of uncertain or unknown behaviour of Mediastinum	Lung			•	
D38.4	Neoplasm of uncertain or unknown behaviour of Thymus	Lung			•	
D38.5	Neoplasm of uncertain or unknown behaviour of Other respiratory organs	Lung			•	
D38.6	Neoplasm of uncertain or unknown behaviour of Respiratory organ, unspecified	Lung			•	
D39.0	Neoplasm of uncertain or unknown behaviour of Uterus	Gynaecological			•	
D39.1	Neoplasm of uncertain or unknown behaviour of Ovary	Gynaecological			•	
D39.2	Neoplasm of uncertain or unknown behaviour of Placenta	Gynaecological			•	

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
D39.7	Neoplasm of uncertain or unknown behaviour of Other female genital organs	Gynaecological			•	
D39.9	Neoplasm of uncertain or unknown behaviour of Female genital organ, unspecified	Gynaecological			•	
D40.0	Neoplasm of uncertain or unknown behaviour of prostate	Urological			•	
D40.1	Neoplasm of uncertain or unknown behaviour of testis	Urological			•	
D40.7	Neoplasm of uncertain or unknown behaviour of other male genital organs	Urological			•	
D40.9	Neoplasm of uncertain or unknown behaviour of male genital organs, unspecified	Urological			•	
D41.0	Neoplasm of uncertain or unknown behaviour of kidney	Urological			•	
D41.1	Neoplasm of uncertain or unknown behaviour of renal pelvis	Urological	•			
D41.2	Neoplasm of uncertain or unknown behaviour of ureter	Urological	•			
D41.3	Neoplasm of uncertain or unknown behaviour of urethra	Urological	•			
D41.4	Neoplasm of uncertain or unknown behaviour of bladder	Urological	•			
D41.7	Neoplasm of uncertain or unknown behaviour of other urinary organs	Urological			•	
D41.9	Neoplasm of uncertain or unknown behaviour of urinary organs, unspecified	Urological			•	
D42.0	Neoplasm of uncertain or unknown behaviour of cerebral meninges	Brain/Central Nervous System	•			
D42.1	Neoplasm of uncertain or unknown behaviour of spinal meninges	Brain/Central Nervous System	•			
D42.9	Neoplasm of uncertain or unknown behaviour of meninges, unspecified	Brain/Central Nervous System	•			
D43.0	Neoplasm of uncertain or unknown behaviour of brain, supratentorial	Brain/Central Nervous System	•			
D43.1	Neoplasm of uncertain or unknown behaviour of brain, infratentorial	Brain/Central Nervous System	•			

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
D43.2	Neoplasm of uncertain or unknown behaviour of brain, unspecified	Brain/Central Nervous System	•			
D43.3	Neoplasm of uncertain or unknown behaviour of cranial nerves	Brain/Central Nervous System	•			
D43.4	Neoplasm of uncertain or unknown behaviour of spinal cord	Brain/Central Nervous System	•			
D43.7	Neoplasm of uncertain or unknown behaviour of other parts of central nervous system	Brain/Central Nervous System	•			
D43.9	Neoplasm of uncertain or unknown behaviour of central nervous system, unspecified	Brain/Central Nervous System	•			
D44.0	Neoplasm of uncertain or unknown behaviour of thyroid gland	Head and Neck			•	
D44.1	Neoplasm of uncertain or unknown behaviour of adrenal gland	Other			•	
D44.2	Neoplasm of uncertain or unknown behaviour of parathyroid gland	Other			•	
D44.3	Neoplasm of uncertain or unknown behaviour of pituitary gland	Brain/Central Nervous System	•			
D44.4	Neoplasm of uncertain or unknown behaviour of Craniopharyngeal duct	Brain/Central Nervous System	•			
D44 .5	Neoplasm of uncertain or unknown behaviour of pineal gland	Brain/Central Nervous System	•			
D44 .6	Neoplasm of uncertain or unknown behaviour of carotid body	Other			•	
D44 .7	Neoplasm of uncertain or unknown behaviour of aortic body and other paraganglia body	Other			•	
D44 .8	Neoplasm of uncertain or unknown behaviour of pluriglandular involvement	Other			•	
D44 .9	Neoplasm of uncertain or unknown behaviour of endocrine gland, unspecified	Other			•	
D45	Polycythaemia vera	Haematological	See the Haematological chapter of COSD User Guide for information regarding what is required to be submitted for these Haematological diseases.			
D46.0	Refractory anaemia without ringed sideroblasts, so stated	Haematological				
D46.1	Refractory anaemia with ringed sideroblasts	Haematological				

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
D46.2	Refractory anaemia with excess of blasts (RAEB)	Haematological				
D46.4	Refractory anaemia, unspecified	Haematological				
D46.5	Refractory anaemia with multi-lineage dysplasia	Haematological				
D46.6	Myelodysplastic syndrome with isolated del(5q) chromosomal abnormality	Haematological				
D46.7	Other myelodysplastic syndromes	Haematological				
D46.9	Myelodysplastic syndrome, unspecified	Haematological				
D47.0	Histiocytic and mast cell tumours of uncertain and unknown behaviour	Haematological				
D47.1	Chronic myeloproliferative disease	Haematological				
D47.3	Essential (haemorrhagic) thrombocythaemia	Haematological				
D47.4	Osteomyelofibrosis	Haematological				
D47.5	Chronic eosinophilic leukaemia (hypereosinophilic syndrome)	Haematological				
D47.7	Other specified neoplasms of uncertain or unknown behaviour of lymphoid, haematopoietic and related tissue	Haematological				
D47.9	Neoplasm of uncertain or unknown behaviour of lymphoid, haematopoietic and related tissue, unspecified	Haematological				
D48.0	Neoplasm of uncertain or unknown behaviour of Bone and articular cartilage	Sarcoma			•	
D48.1	Neoplasm of uncertain or unknown behaviour of Connective and other soft tissue	Sarcoma			•	Only applicable for GISTs
D48.2	Neoplasm of uncertain or unknown behaviour of Peripheral nerves and autonomic nervous system	Other			•	
D48.3	Neoplasm of uncertain or unknown behaviour of Retroperitoneum	Other			•	

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Expected Data set to be collected			Comment
			Core and Site Specific Data set	Core Data set	Path Only	
D48.4	Neoplasm of uncertain or unknown behaviour of Peritoneum	Other			•	
D48.5	Neoplasm of uncertain or unknown behaviour of Skin	Skin			•	
D48.6	Neoplasm of uncertain or unknown behaviour of Breast	Breast			•	
D48.7	Neoplasm of uncertain or unknown behaviour of Other specified sites	Other			•	
D48.9	Neoplasm of uncertain or unknown behaviour unspecified	Other			•	
E85.9[17]	Amyloidosis, unspecified	Haematology	See the Haematological chapter of COSD User Guide for information regarding what is required to be submitted for these Haematological diseases.			

[17] Although Primary amyloidosis (E85.9) is listed as an E ICD code in the World Health Organisation (WHO) disease classification, amongst clinicians it is widely acknowledged and subsequently treated as a cancer, receiving Chemotherapy in cases. 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 Cancer Registration Service of Public Health England.

Appendix C: WHO classification of tumours of haematopoietic and lymphoid Tissue

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).

GROUP #	Description
GROUP 1	Myeloproliferative neoplasms
GROUP 2	Myeloid and lymphoid neoplasms with eosinophilia and abnormalities of PDGFRA, PDGFRB or FGFR1
GROUP 3	Myelodysplastic/myeloproliferative neoplasms
GROUP 4	Myelodysplastic syndromes
GROUP 5	Acute myeloid leukaemia (AML) and related Precursor neoplasms
GROUP 6	Acute leukaemias of ambiguous lineage
GROUP 7	Precursor B lymphoid neoplasms
GROUP 8	Precursor T lymphoid neoplasms
GROUP 9	Mature B cell neoplasms
GROUP 10	Mature T-cell and NK-cell neoplasms
GROUP 11	Hodgkin lymphoma
GROUP 12	Histiocytic and dendritic cell neoplasm
GROUP 13	Post-transplant lymphoproliferative disorders (PTLD)

Appendix D: CTYA – associated conditions

Associated conditions to be recorded on Childhood Cancer Registration Forms. 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 main categories that are likely to be of interest and should therefore be recorded are as follows, listed by Chapter within ICD-10.

ICD10 Chapter	ICD 10 Codes	Conditions	Examples
I	B15-B19	Viral hepatitis	
	B20-B24	HIV disease	
II	C00-C97	Malignant neoplasms	Any malignancy diagnosed before the subject of the current registration
	D00-D48	Benign and unspecified neoplasms	Melanocytic naevus, neurofibroma
III	D50-D98	Diseases of blood, blood-forming organs & immune system	Thalassaemia, sickle-cell disease or trait, spherocytosis, Diamond-Blackfan anaemia, Fanconi anaemia, aplastic anaemia, Von Willebrand disease, severe combined immune deficiency, Wiskott-Aldrich syndrome
IV	E00-E90	Endocrine, nutritional & metabolic diseases	Goitre, diabetes, congenital adrenal hyperplasia, albinism, cystic fibrosis
V	F70-F79	Mental retardation	
	F80-F89	Disorders of psychological development	Autism
	F90-F98	Early-onset behavioural & emotional disorders	Attention deficit hyperactivity disorder
VI	G11	Hereditary ataxia	Ataxia telangiectasia
	G25.3	Opsoclonus-myoclonus	
	G40	Epilepsy	
	G51.0	Bell's palsy	
	G71.0	Muscular dystrophy	
	G90	Autonomic nervous system disorders	Horner syndrome
VII	H50	Strabismus	
XI	K40	Inguinal hernia	
XII	L20-L30	Dermatitis & eczema	

ICD10 Chapter	ICD 10 Codes	Conditions	Examples
	L81.3	Café au lait spots	
XIII	M08	Juvenile arthritis	
XVI	P00-P96	Conditions originating in perinatal period	Extreme prematurity, birth asphyxia, congenital rubella syndrome, neonatal jaundice, congenital hydrocele
XVII	Q00-Q89	Congenital malformations	Coloboma, aniridia, cardiac defects, cleft lip or palate, Hirschsprung disease, cryptorchism, hypospadias, (pseudo-)hermaphroditism, congenital malformations of kidney, neurofibromatosis, tuberous sclerosis, hemihypertrophy, Beckwith-Wiedmann syndrome
	Q90-Q99	Constitutional chromosomal abnormalities	Down syndrome, Turner syndrome, Klinefelter syndrome, gonadal dysgenesis, fragile X chromosome
XVIII	R01	Heart murmur	
	R62	Developmental delay	

The list given above 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), https://www.ncbi.nlm.nih.gov/omim, should be recorded.

Appendix E: recommended staging to be collected by cancer registries

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 Data set.

It is also important to note that both UICC and AJCC coding systems have updated to v8.0, please refer directly to the TNM Staging Books, for the most recent and accurate stage groupings/combination[1].

Note: The change from TNM 7 and TNM 8 took effect from 1 January 2018 apart from for head & neck sites which took effect from 1 January 2019. FIGO 2018 for cervical cancer takes effect from 1 January 2020.

TUMOUR TYPE	STAGING SYSTEM (from 1 January 2019)	STAGING SYSTEM (from 1 January 2020)
ADRENAL CORTEX TUMOURS	UICC TNM 8	UICC TNM 8
AMPULLA OF VATER – CARCINOMA	UICC TNM 8	UICC TNM 8
AMPULLA OF VATER – NEUROENDOCRINE TUMOURS	EUROPEAN NEUROENDOCRINE TUMOUR SOCIETY TNM	ENETS - EUROPEAN NEUROENDOCRINE TUMOUR SOCIETY TNM
ANAL CANAL	UICC TNM 8	UICC TNM 8
APPENDIX – CARCINOMA	UICC TNM 8	UICC TNM 8
APPENDIX – NEUROENDOCRINE TUMOURS	EUROPEAN NEUROENDOCRINE TUMOUR SOCIETY TNM	EUROPEAN NEUROENDOCRINE TUMOUR SOCIETY TNM**
BONE	UICC TNM 8	UICC TNM 8
BREAST	UICC TNM 8	UICC TNM 8
CERVIX	FIGO (2009) and N STAGE	FIGO (2018)
CHRONIC LYMPHOCYTIC LEUKAEMIA	BINET	BINET
COLON AND RECTUM – CARCINOMA	UICC TNM 8	UICC TNM 8
COLON AND RECTUM – GIST	UICC TNM 8	UICC TNM 8
COLON AND RECTUM – NEUROENDOCRINE TUMOURS	EUROPEAN NEUROENDOCRINE TUMOUR SOCIETY TNM	ENETS - EUROPEAN NEUROENDOCRINE TUMOUR SOCIETY TNM
CONJUNCTIVA – CARCINOMA	UICC TNM 8	UICC TNM 8
CONJUNCTIVA – MELANOMA	UICC TNM 8	UICC TNM 8
CUTANEOUS SQUAMOUS CELL CARCINOMA AND OTHER CUTANEOUS CARCINOMA	UICC TNM 8	UICC TNM 8
EXTRAHEPATIC BILE DUCT – PERIHILAR	UICC TNM 8	UICC TNM 8
EXTRAHEPATIC BILE DUCTS – DISTAL	UICC TNM 8	UICC TNM 8

[1] http://www.wileyanduicc.com/

FALLOPIAN TUBE	FIGO (2013)	FIGO (2013)
GALLBLADDER	UICC TNM8	UICC TNM8
GESTATIONAL TROPHOBLASTIC DISEASE	FIGO (2009)	FIGO (2009)
GLOTTIS	UICC TNM 8	UICC TNM 8
HEPATOBLASTOMA (CTYA)	PRETEXT STAGING SYSTEM STAGE	PRETEXT STAGING SYSTEM STAGE
HODGKIN LYMPHOMA	ANN-ARBOR	ANN ARBOR STAGE
HYPOPHARYNX	UICC TNM 8	UICC TNM 8
KIDNEY	UICC TNM 8	UICC TNM 8
KIDNEY, WILMS	WILMS TUMOUR STAGE (NWTSG)	WILMS TUMOUR STAGE (NWTSG)
LACRIMAL GLAND – CARCINOMA	UICC TNM 8	UICC TNM 8
LIP	UICC TNM 8	UICC TNM 8
LIVER – INTRAHEPATIC BILE DUCTS	UICC TNM 8 & BARCELONA STAGE	UICC TNM 8 & BARCELONA STAGE
LIVER – HEPATOCELLULAR	UICC TNM 8 & BARCELONA STAGE	UICC TNM 8 & BARCELONA STAGE
LUNG	UICC TNM 8	UICC TNM 8
MAJOR SALIVARY GLANDS	UICC TNM 8	UICC TNM 8
MAXILLARY SINUS	UICC TNM 8	UICC TNM 8
MEDULLOBLASTOMA	CHANG STAGING SYSTEM	CHANG STAGING SYSTEM
MYELOMA	INTERNATIONAL STAGING SYSTEM (ISS)	REVISED INTERNATIONAL STAGING SYSTEM (R-ISS)
NASAL CAVITY AND PARANASAL SINUSES	UICC TNM 8	UICC TNM 8
NASOPHARYNX	UICC TNM 8	UICC TNM 8
NEUROBLASTOMA	INTERNATIONAL NEUROBLASTOMA RISK GROUP	INTERNATIONAL NEUROBLASTOMA RISK GROUP (INRG) STAGING SYSTEM
NON-HODGKIN LYMPHOMA (ADULT)	ANN-ARBOR	ANN ARBOR STAGE
NON-HODGKIN LYMPHOMA (CHILDREN)	MURPHY ST. JUDE STAGING SYSTEM	MURPHY ST. JUDE STAGING SYSTEM
OESOPHAGUS INCLUDING OESOPHAGOGASTRIC JUNCTION – CARCINOMA	UICC TNM 8	UICC TNM 8
OESOPHAGUS INCLUDING OESOPHAGOGASTRIC JUNCTION – GIST	UICC 8	UICC 8
ORAL CAVITY	UICC TNM 8	UICC TNM 8
OROPHARYNX	UICC TNM 8	UICC TNM 8
OMENTUM AND MESENTERY – GIST	none recommended (if UICC TNM 8 is submitted this will be recorded by the NCRAS)	none recommended (if UICC TNM 8 is submitted this will be recorded by the NCRAS)
OVARY AND PERITONEUM	FIGO (2013)	FIGO (2013)
PANCREAS	UICC TNM 8	UICC TNM 8
PANCREAS – NEUROENDOCRINE TUMOURS	EUROPEAN NEUROENDOCRINE TUMOUR SOCIETY TNM	ENETS - EUROPEAN NEUROENDOCRINE TUMOUR SOCIETY TNM
PENIS	UICC TNM 8	UICC TNM 8
PLEURAL MESOTHELIOMA	UICC TNM 8	UICC TNM 8
PROSTATE	UICC TNM 8	UICC TNM 8
RENAL PELVIS AND URETER	UICC TNM 8	UICC TNM 8
RETINOBLASTOMA	UICC TNM 8	UICC TNM 8 and INTERNATIONAL STAGING

		SYSTEM FOR RETINOBLASTOMA
RHABDOMYOSARCOMA and OTHER SOFT TISSUE SARCOMAS (CTYA)	UICC TNM 8 & IRS POST SURGICAL GROUP	UICC TNM 8 & IRS POST SURGICAL GROUP
HEPATOBLASTOMA (CTYA)	PRETEXT STAGING SYSTEM STAGE	PRETEXT STAGING SYSTEM STAGE
SARCOMA OF ORBIT	UICC TNM 8	UICC TNM 8
SKIN – MALIGNANT MELANOMA	UICC TNM 8	UICC TNM 8
SKIN – MERKEL CELL CARCINOMA**	UICC TNM 8	UICC TNM 8
SKIN OF EYELID – CARCINOMA	UICC TNM 8	UICC TNM 8
SMALL INTESTINE – GIST	none recommended (if UICC TNM 8 is submitted this will be recorded by the NCRAS)	none recommended (if UICC TNM 8 is submitted this will be recorded by the NCRAS)
SMALL INTESTINE – NEUROENDOCRINE TUMOURS	EUROPEAN NEUROENDOCRINE TUMOUR SOCIETY TNM	ENETS - EUROPEAN NEUROENDOCRINE TUMOUR SOCIETY TNM
SMALL INTESTINE – CARCINOMA	UICC TNM 8	UICC TNM 8
SOFT TISSUE	UICC TNM 8	UICC TNM 8
STOMACH – CARCINOMA	UICC TNM 8	UICC TNM 8
STOMACH – GIST	none recommended (if UICC TNM 8 is submitted this will be recorded by the NCRAS)	none recommended (if UICC TNM 8 is submitted this will be recorded by the NCRAS)
STOMACH – NEUROENDOCRINE TUMOURS	EUROPEAN NEUROENDOCRINE TUMOUR SOCIETY TNM	ENETS - EUROPEAN NEUROENDOCRINE TUMOUR SOCIETY TNM
SUBGLOTTIS	UICC TNM 8	UICC TNM 8
SUPRAGLOTTIS	UICC TNM 8	UICC TNM 8
TESTIS	UICC TNM 8	UICC TNM 8
THYMUS	UICC TNM 8	UICC TNM 8
THYROID	UICC TNM 8	UICC TNM 8
UPPER AERODIGESTIVE TRACT – MALIGNANT MELANOMA	UICC TNM 8	UICC TNM 8
URETHRA	UICC TNM 8	UICC TNM 8
URINARY BLADDER	UICC TNM 8	UICC TNM 8
UTERUS – ENDOMETRIUM	FIGO (2009)	FIGO (2009)
UTERUS – UTERINE SARCOMA	FIGO (2009)	FIGO (2009)
UVEA – MALIGNANT MELANOMA	UICC TNM 8	UICC TNM 8
VAGINA	FIGO (2009)	FIGO (2009)
VULVA	FIGO (2009)	FIGO (2009)
VULVA – MALIGNANT MELANOMA	UICC TNM 8	UICC TNM 8

Note: The use of preferred staging systems (which should be used), is under frequent review and may change in the future. This 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).

Following discussions with NCRAS, the British Association of Gynaecological Pathologists (BAGP) and BGCS Council, we have agreed that we should implement the transition for the purposes of cancer registration data from the 2009 to the 2018 FIGO

staging systems for cervical cancer for all cases diagnosed on and beyond 1 January 2020.

This provides adequate time to implement changes to IT system capturing staging data including Infoflex and Somerset, as certain disease stages did not previously exist in the old staging system (such as, cervical cancer IIIC1 and IIIC2).

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 version 9.0

Submissions are accepted as follows for Version 8.0 and/or v9.0

Diagnosis month	data set	schema	Accepted MDT system submission format	Accepted Pathology submission format
January 2020	v8.0	v8.0	XML only	XML only
February 2020	v8.0	v8.0	XML only	XML only
March 2020	v8.0	v8.0	XML only	XML only
April 2020	v8.0 or v9.0	v8.0 or v9.0	XML only	XML only
May 2020	v8.0 or v9.0	v8.0 or v9.0	XML only	XML only
June 2020	v8.0 or v9.0	v8.0 or v9.0	XML only	XML only
July 2020	v8.0 or v9.0	v8.0 or v9.0	XML only	XML only
August 2020	v8.0 or v9.0	v8.0 or v9.0	XML only	XML only
September 2020	v8.0 or v9.0	v8.0 or v9.0	XML only	XML only
October 2020	v9.0	v9.0	XML only	XML only
November 2020	v9.0	v9.0	XML only	XML only
December 2020	v9.0	v9.0	XML only	XML only
January 2021	v9.0	v9.0	XML only	XML only

*SITE SPECIFIC STAGE ITEMS TO BE SUBMITTED FROM START OF IMPLEMENTATION

CNS – CTYA
CTYA
- Chang Staging System Stage
- 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

Liver
- Barcelona Clinic Liver Cancer (BCLC) Stage

Urological
- Stage Grouping (Testicular)
  - as defined by The Royal Marsden Hospital (RMH)

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 OUTPATIENTS
- 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 OUTPATIENTS:

SOURCE OF REFERRAL FOR OUT-PATIENTS will normally be either:

03	referral from a GENERAL MEDICAL PRACTITIONER
92	referral from a GENERAL DENTAL PRACTITIONER
12	referral from a GENERAL PRACTITIONER with Special Interest

Or if referred from another Hospital

05	referral from a CONSULTANT, other than in an Accident and Emergency Department

Other referral sources listed may also be applicable

SCENARIO 3: PATIENTS INITIALLY SEEN AS EMERGENCIES BUT THEN REFERRED TO ANOTHER CONSULTANT:

SOURCE OF REFERRAL FOR OUT-PATIENTS will be either:

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 outpatient 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: PATIENTS WHERE 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: PATIENTS WHERE CANCER WAS AN INCIDENTAL FINDING OF ANOTHER TREATMENT OR PROCESS.

SOURCE OF REFERRAL FOR OUT-PATIENTS will be

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

The following is a new proforma for v9 that shows which of the site specific data items are applicable to each haematological diagnosis group.

HAEMATOLOGY – CLINICAL DATASET

Name_____ NHS Number _____

Hospital Number _____ Performance Status _____

Diagnosis _____ Date of Diagnosis ___/___/____

Date of MDT ___/___/____ Completed ☐ Yes ☐ No

Clinical Dataset	SITE SPECIFIC DATA ITEM	VALUE
AML	WBC	Range 0.0 to 999.9 (to 1dp)
	European Leukaemia Net	F I A N
	Cytogenetics subsidiary	Comment
ALL	WBC	Range 0.0 to 999.9 (to 1dp)
	Cytogenetics subsidiary	Comment
	Post Induction MRD	1 2 3 4 5 6 9
	Extramedullary disease	1 2 3 4 9
CML	Sokal score	
CLL	Splenomegaly	Yes ☐ No ☐
	Binet	A B C
	Binet stage date	
	Staging organisation code	
Myelodysplasia (MDS)	Bone marrow blasts	(%) Range 0 – 100
	IPSS-R index	Score range 0 to 10
Myeloma	R-ISS Stage	1 2 3
	R-ISS stage date	
	Staging organisation code	
Follicular	Ann Arbor stage	1 2 3 4
	Ann Arbor stage date	
	Staging organisation code	
	Ann Arbor symptoms	A B
	Ann Arbor extranodality	E (Extranodal involvement) 0 (none)
	Ann Arbor Bulk	X (Yes, "bulky" disease present) 0 (none)
	Splenic involvement	S (Spleen involvement or splenomegaly) 0 (none)
	Abnormal nodal areas	Count
	FLIPI 2	Range 0 - 5
DLBCL	Ann Arbor stage	1 2 3 4
	Ann Arbor stage date	
	Staging organisation code	
	Ann Arbor symptoms	A B
	Ann Arbor extranodality	E (Extranodal involvement) 0 (none)
	Ann Arbor Bulk	X (Yes, "bulky" disease present) 0 (none)
	Splenic involvement	S (Spleen involvement or splenomegaly) 0 (none)
	Extranodal sites	0 1 2
	Primary Extranodal Site	01 02 03 04 05 06 07 08 09 10 11 12 13 14 15
	Abnormal nodal areas	Count
	(R)IPI	Range 0 - 5

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Other Lymphomas	Ann Arbor stage	1 2 3 4
	Ann Arbor stage date	
	Staging organisation code	
	Ann Arbor symptoms	A B
	Ann Arbor extranodality	E (Extranodal involvement) 0 (none)
	Ann Arbor Bulk	X (Yes, "bulky" disease present) 0 (none)
	Splenic involvement	S (Spleen involvement or splenomegaly) 0 (none)
Hodgkin	Ann Arbor stage	1 2 3 4
	Ann Arbor stage date	
	Staging organisation code	
	Ann Arbor symptoms	A B
	Ann Arbor extranodality	E (Extranodal involvement) 0 (none)
	Ann Arbor Bulk	X (Yes, "bulky" disease present) 0 (none)
	Splenic involvement	S (Spleen involvement or splenomegaly) 0 (none)
	Primary Extranodal Site	01 02 03 04 05 06 07 08 09 10 11 12 13 14 15
	Abnormal nodal areas	Count
	Hasenclever index	Range 0-7

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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 in the guidance section of cancerstats (https://cancerstats.ndrs.nhs.uk/).