



Public Health  
England

Protecting and improving the nation's health

## **Cancer Outcomes and Services Dataset Version 6.1a**

### **Conformance Framework**

## About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health, and are a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

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## The Intelligence Networks

Public Health England operates a number of intelligence networks, which work with partners to develop world-class population health intelligence to help improve local, national and international public health systems.

### **National Cancer Intelligence Network**

The National Cancer Intelligence Network (NCIN) is a UK-wide initiative, working to drive improvements in cancer awareness, prevention, diagnosis and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

### **National Cardiovascular Intelligence Network**

The National cardiovascular intelligence network (NCVIN) analyses information and data and turns it into meaningful timely health intelligence for commissioners, policy makers, clinicians and health professionals to improve services and outcomes.

### **National Child and Maternal Health Intelligence Network**

The National Child and Maternal Health Intelligence Networks (NCMHIN) provides information and intelligence to improve decision-making for high quality, cost effective services. Their work supports policy makers, commissioners, managers, regulators, and other health stakeholders working on children's, young people's and maternal health.

### **National Mental Health Intelligence Network**

The National Mental Health Intelligence Network (NMHIN) is a single shared network in partnership with key stakeholder organisations. The Network seeks to put information and intelligence into the hands of decision makers to improve mental health and wellbeing.

### **National End of Life Care Intelligence Network**

The National End of Life Care Intelligence Network (NEoLCIN) aims to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to adults approaching the end of life. This intelligence will help drive improvements in the quality and productivity of services.

## Version control

This document is owned by the COSD Governance Board. For further information please contact the COSD Datasets Manager through [cosd@phe.gov.uk](mailto:cosd@phe.gov.uk).

Implementation will be carried out by the National Cancer Registration and Analysis Service in collaboration with Providers and the COSD Governance Board.

Version	Date	Author	Details of approvals and amendments
6.0	31-12-2014	B. Plewa	Updated to Dataset v6.0
6.1	01-03-2016	B. Plewa	Included conformance for COSD XML Pathology submissions
7.0	01-06-2017	A. Murphy	Updated to support v7.0 of COSD

**REVIEW:** This document to be reviewed annually.

**Next Review:** November 2017

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## 1. Executive Summary and Status

The Cancer Outcomes and Services Dataset (COSD) Conformance Framework provides guidance for submission of the dataset and how conformance with the COSD Information Standard is reported and monitored. The Framework will require on-going development to take account of other generic and site-specific data items. This will be developed in consultation with key stakeholders particularly local clinical teams and the Public Health England (PHE) Site Specific Clinical Reference Groups (SSCRGs).

The National Cancer Registration and Analysis Service (NCRAS) will provide initial feedback to Providers within two working days of the submission deadline, confirming that the files were received on time and in the appropriate format (Level 1 Report). A monthly summary of this information by Provider will be submitted to the COSD Governance Board.

Once initial validation has been carried out further feedback will be provided within a month of the submission deadline giving summary information on key fields such as the number of new diagnoses submitted etc. (Level 2 Report). This will not be formally submitted to the COSD Governance Board although a summary of this information by Provider will be provided to the COSD Governance Board when required for them to review progress.

More detailed analysis of the data will be available from the NCRAS to Providers once the record has been registered with all the sources of data combined (Level 3 Reports). The aim of the NCRAS is to produce the Level 3 Reports 8 months after the date of cancer diagnosis (see Appendix I). Summary level 3 Reports will be available to the COSD Governance Board. It is the intention of the NCRAS to ensure that Trusts and their clinical teams receive timely and meaningful feedback on all of their data submissions to allow local conversations about improvements in timeliness of reporting and data quality.

The implementation of COSD is managed by the NCRAS directly with its data providers. The principal approach will be to work in partnership with clinicians and their information, management and multi-disciplinary teams to implement the Standard successfully. The NCRAS is strengthening the resources and coordination of its Data Liaison team to make sure that there is constructive dialogue with regard to improving the timeliness and quality of data provided. However, in the event that such constructive dialogue is not having the desired effect, the Framework includes an escalation process using leverage at various levels to try to bring things back on track.

This document has been approved by the COSD Governance Board. It was originally developed by the COSD Working Group on Conformance Monitoring which included representatives from Provider organisations, Cancer Networks, the NCRAS and the COSD Project Team.

## 2. Introduction

The purpose of this document is to outline the reporting framework to monitor Provider conformance with the Cancer Outcomes and Services Dataset (COSD). The document is intended to support the NCRAS, Providers of Cancer Services (Providers) and Commissioners in tracking progress of the implementation of COSD.

Formerly this document was used in conjunction with an annual Data Transfer Partnership Agreement (DTPA) but this has now been removed. The DTPA only repeated the obligations that Trusts have under the Information Standards Notice for COSD, contractually enforceable through the NHS Standard Contract, and which are reinforced in this Framework. The NCRAS responsibilities for providing timely feedback on data completeness and quality are also fully covered in this document.

The Framework specifies the basic reports that will be supplied to Providers submitting the COSD to support nationally consistent comparative assessment against the Standard. The reports form one part of the NCRAS's wider commitment to engage with Providers and their clinical teams in supplying comprehensive feedback on the timeliness and quality of cancer data submissions to the NCRAS. COSD reports will be incorporated within local improvement plans agreed between the NCRAS data liaison teams and local providers and their clinical teams.

In the event that issues arise that cannot be resolved through partnership working and local dialogue, the Framework includes an escalation process using leverage at various levels to try to bring things back on track.

The strategic aim of COSD, together with the establishment of the NCRAS and the national registration system is to create a national repository of timely, high quality, patient level cancer data. This will become the definitive source for national and local cancer analyses, providing the backbone of both national and local cancer intelligence needs for all those involved in the planning, provision or commissioning of cancer care. As a consequence of this COSD reports specified in this Framework will be made available via the CancerStats Reporting Portal (see page 6) and accessible to all Providers, Strategic Clinical Networks and Commissioners nationally. In addition, frozen monthly reports will be produced and circulated to data providers and clinical teams by their local office of the NCRAS.

This Conformance Framework relates to the COSD Standard ISB1521 Amd 01/2016 and Specification v7.0, which is available on the Information Standards Board website: <http://content.digital.nhs.uk/isce/publication/scci1521>.

The conformance document specifies the feedback which will be made available to Providers and other interested parties for evaluating submission of the COSD and specifies the criteria and processes that will be used to monitor conformance.

The NCRAS has legal support to collect confidential patient information relating to patients referred for the diagnosis or treatment of neoplasia under Section 251 of the NHS Act 2006 (Statutory Instruments 2002 No. 1438 The Health Service (Control of Patient Information) Regulations 2002).

This document identifies the minimum reporting feedback required. Additional information may be agreed between individual Providers and the NCRS.

The NCRAS will supply feedback reports via the CancerStats Reporting Portal and via its data liaison teams to the Provider on the content of the submission measured against the agreed criteria. Reports will be produced which will allow data to be available in monthly, quarterly and annual views.

Operational level reports are included in the Framework to enable Providers to monitor their progress towards meeting the standard. Summary reports will also be provided for the COSD Governance Board for oversight.

If data are supplied in the required COSD XML format then full feedback will be supplied by the NCRAS. If the data are not supplied in the required or agreed formats, then feedback may be more limited or fall outside the timelines described. Discussion on the content will be subject to local negotiation with the NCRAS.



### 3. Reporting structure

Level 1-3 Reports will be made available to Providers via the national web-based CancerStats Reporting Portal:

#### **CancerStats**

You can access the national reporting portal at the following web address:

**<https://nww.cancerstats.nhs.uk/>**

If you do not yet have an account for the portal, you may request one here.

Customisable reports are available both online and in downloadable PDF format for distribution to teams within the Trusts. Your local registry will also arrange for the circulation of reports to key contacts via e-mail.

- providers are able to customise reports and produce spreadsheets of figures for local use
- providers are able to compare reports over time and to compare against national averages
- cumulative annual and monthly snapshot are available when applicable, actual figures as well as percentages are provided
- definitions of how percentage calculations are made are available on the portal
- reports provided are reviewed to ensure they remain fit for purpose
- reports reflect Compliance/Non-compliance levels as specified in Section 5

Reporting is underpinned by partnership working between the NCRAS data liaison teams and Providers' cancer clinical, management and data teams. Most commonly this is evidenced in agreed local data improvement plans.

Summary information derived from Level 1 and 3 Reports is provided formally to the COSD Governance Board for their oversight (see page 16). Level 2 Reports are primarily intended for operational feedback and implementation support to Providers. Summary information on level 2 reports is provided as required to the COSD Governance Board for their oversight.

Reports are as follows:

- level 1: Quality Control (Conformance - Raw Data)
- level 2: Quality Control (Operational Feedback - Validated Data)
- level 3: Quality Assurance (Conformance/Operational Feedback - Summarised Data)

Clinical Headline Indicators: Clinical Analysis (Operational Feedback - Summarised Data). These reports will not be used for conformance monitoring and are currently outside the scope of this Framework.

Reports will be run following the monthly submission deadlines. See Appendix I (Reporting Schedule).

### 3.1 Level 1: Quality Control (Conformance - Raw Data)

**Purpose:** Ensure that correct files have been submitted on time and in the agreed formats.

Monthly report - produced 2 operational days after 25 operational day submission deadline (see Appendix I), The Patient Administration System (PAS) data submissions will be reported a month in arrears to accommodate the alternative deadline for these data submissions.

#### Measures:

##### **For each Trust:**

L1.1 - Have all the agreed COSD data files been received?

##### **For each file:**

L1.2 - Was the file received by the due date given in the COSD Reporting Schedule?

- pathology (within 25 operational days)
- clinical (also called MDT or COSD XML) (within 25 operational days)
- PAS (within 35 operational days to fall in line with national Secondary Uses Service (SUS) deadline)

##### **File Format compliance:**

L1.3a - Was Clinical submission received in COSD XML format?

- 'Yes' files received in XML format
- 'No' files received in a non-compliant format

L1.3b - Was Pathology submission received in COSD XML format?

- 'Yes' files received in XML format
- 'No' files received in a non-compliant format

**Note:** If Trusts are not able to deliver a data file on time, they should inform the NCRAS with a valid reason for lateness, no later than 48 hours before the data deadline.

#### Compliance Levels:

LEVEL/ REPORT #	Compliant	Non-compliant		
		Minor	Moderate	Severe
L1.1	YES – agreed files received			
L1.2 (a/b/c)	YES - File received by due date	File not received by due date – 1st occurrence	File not received by due date – 2nd occurrence	File not received by due date – 3rd occurrence

Cancer Outcomes and Services Data set (COSD) – Conformance Framework version 6.1a

<b>L1.3 (a/b)</b>	YES - File received XML format			File not received in XML format
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### 3.2 Level 2a: Quality Control – Clinical Data (Operational Feedback)

**Purpose:** To enable Providers to assess clinical submissions against approximate expected numbers and completion rates for specified key data items. Providers may wish to use this to review submissions and inform local discussions.

**Note: These reports will be based only on valid data received through the clinical submissions.**

Monthly report for operational purposes. These reports will not be used for conformance monitoring although summary information will be submitted to the COSD Governance Board to monitor overall progress. Each report will show the previous four months figures, with most recent three months being provisional numbers and the other being complete figures. This is to allow for the accumulation of data (specifically staging) over the patient pathway.

#### **Measures:**

L2.1 - Number of tumours diagnosed in the calendar month. For all diagnoses in the month, the number and percentage of cases supplied:

- with a treatment record submitted
- with a first treatment of surgery (to inform responsibility for integrated staging - see 2.3c)
- with a basis of diagnosis (not including “not known”)
- with a histological basis of diagnosis
- with a clinical nurse specialist indication code (not including “not known”)
- who had contact with a clinical nurse specialist
- for patients aged under 25
- discussed at a multi-disciplinary team (MDT) meeting

L2.2 - For all cases discussed at an MDT meeting, the number and percentage supplied

- with performance status (not applicable for patients aged under 16)
- with a full stage value
- with performance status **and** a full stage value

L2.3 - For all cases discussed at an MDT meeting, the breakdown of staging completeness by cases having

- any stage
- pretreatment stage
- integrated stage (for all cases with a first treatment of “surgery” [2.1c])
- site-specific stage

L2.4 - All cases receiving treatment in the calendar month broken down by

- surgery
- radiotherapy
- chemotherapy
- non-active therapy

Staging will be categorized as “Full”, “Partial” or “None” based on the following definitions:

- 1) all invasive cancers that are discussed at MDT will be included in the analysis to ascertain staging completeness
- 2) cases with valid T, N, and M staging components and a confirmed version number will be accepted as having a full stage
- 3) T, N and M components must not include invalid values such as N/A, Null, O (letter) and? Invalid TNM combinations will also be excluded e.g. TX NX MX or T0 N0 M0
- 4) cases with no separate TNM components but a stage group will be accepted as a full stage
- 5) cases with a known primary site (excluding ICD10 C76-C80) and M1 component do not need a valid T or N component to be accepted as a full stage
- 6) other site specific prognostic indicators such as ‘Clarkes’, ‘Breslow Thickness’, ‘Gleason Score’, ‘Fuhrman Grade’, ‘WHO Grade’, and ‘NPI’ will not be classed as a valid stage
- 7) In addition to the TNM staging classification, the following site specific staging classifications will also be accepted as a full stage:

DATA ITEM	COSD SECTION	ITEM DESCRIPTION
CO5170	COLORECTAL - STAGING	MODIFIED DUKES
CT6250	CTYA - STAGING - NON HODGKIN LYMPHOMA	MURPHY (ST JUDE) STAGE
CT7050	CTYA - STAGING - NEUROBLASTOMA	INTERNATIONAL NEUROBLASTOMA STAGING SYSTEM
CT6270	CTYA - STAGING - HODGKIN LYMPHOMA	ANN ARBOR STAGE
CT6280		ANN ARBOR SYMPTOMS
CT6290		ANN ARBOR EXTRANODALITY
CT6330	CTYA - STAGING - RENAL TUMOURS	WILMS TUMOUR STAGE
CT6590	CTYA - STAGING - GERM CELL NON CNS TUMOURS	TNM STAGE GROUPING FOR NON CNS GERM CELL TUMOURS
CT6560	CTYA - STAGING - CSF (Cerebrospinal Fluid)	CHANG STAGING FOR MEDULLOBLASTOMA
GY7010	GYNAECOLOGY - STAGING	FINAL FIGO STAGE
GY7020	GYNAECOLOGY - PATHOLOGY - NODES	NODAL STATUS CERVICAL CANCER
CT6350	CTYA - DIAGNOSIS - RHABDOMYOSARCOMA and OTHER SOFT TISSUE SARCOMAS	IRS POST SURGICAL GROUP
CT6500	CTYA - STAGING - HEPATOBLASTOMA	PRETEXT STAGING SYSTEM STAGE
HA8240	HAEMATOLOGY - STAGING - CLL	BINET STAGE
HA8560	HAEMATOLOGY - STAGING - MYELOMA	ISS STAGE for MYELOMA

HA8280	HAEMATOLOGY - STAGING - ANN ARBOR - HODGKIN, FOLLICULAR, DLBCL, OTHER LYMPHOMAS	ANN ARBOR STAGE
HA8290		ANN ARBOR SYMPTOMS
HA8300		ANN ARBOR EXTRANODALITY
HA8310		ANN ARBOR BULK <sup>1</sup>
SK12510	SKIN - STAGING	AJCC STAGE GROUP
UR15300	UROLOGY - STAGING - TESTICULAR	STAGE GROUPING (TESTICULAR)

#### BARCELONA STAGING:

To calculate site specific staging use the COSD data items listed in the table above. Please refer to Appendix E of the COSD User Guide for more information on the various staging systems used to record this data.

### 3.3 Level 2b: Quality Control – Pathology Data (Conformance)

**Purpose:** To enable Providers to assess pathology submissions against approximate expected numbers and completion rates for specified key data items. Providers may wish to use this to review submissions and inform local discussions.

**These reports will be based only on valid data received through the pathology submissions.**

These reports will be used for conformance monitoring and summary information will be submitted to the COSD Governance Board to monitor overall progress.

#### **Measures:**

L2.5 - For all reports received in the month, the number and percentage of reports supplied: EXCLUDE UNCERTAIN

- with CR1020 [PATHOLOGY REPORT TEXT] submitted
- with an identifiable specific site code *either*:
  - CR0530 [TOPOGRAPHY SNOMED]
  - CR3060 [TOPOGRAPHY SNOMED CT]
  - CR0810 [PRIMARY DIAGNOSIS ICD PATHOLOGICAL]
- with a valid morphology code related to a tumour diagnosis HAEM?? Either:
  - CR0850 [MORPHOLOGY SNOMED]
  - CR3070 [MORPHOLOGY SNOMED]
- with CR3170 [PERSON STATED GENDER CODE]
- with CR0050 [PERSON FAMILY NAME] and CR0060 [PERSON GIVEN NAME]
- with CR0790 [CONSULTANT CODE PATHOLOGIST]

L2.6 - For all INVASIVE **malignant** reports, the number and percentage of reports supplied:

- that have a known grade either

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<sup>1</sup> This item is not included in the CTYA dataset for Hodgkin Lymphoma

- CR0860 [GRADE OF DIFFERENTIATION PATHOLOGICAL] of (G1, G2, G3, G4)
- BR4170 [INVASIVE GRADE BREAST] of (1, 2 or 3)
- BA3160 [WHO TUMOUR GRADE CNS] of (1, 2, 3, 4)
- GY7150 [TUMOUR GRADE] of (L, I, H)
- HN9380 [HISTOLOGICAL GRADE SALIVARY TUMOUR] of (1, 2)
- SA11120 [HISTOPATHOLOGICAL TUMOUR GRADE] of (1, 2, 3)
- UR15290 [TUMOUR GRADE (UROLOGY)] of (L, H)
- UR15210 [GLEASON GRADE (PRIMARY)] of (1, 2, 3, 4, 5)
- with an excision margin stated
  - CR0880 [EXCISION MARGIN] is (01, 02, 03, 04, 05, 07, 08, 09)
- with a stated lesion size
  - CR0830 [LESION SIZE PATHOLOGICAL] is (>0)

### 3.4 Compliance Levels:

LEVEL/ REPORT #	Compliant	Non-compliant		
		Minor	Moderate	Severe
L2.5a	Greater than 90% complete			Less than 90% complete
L2.5b	Greater than 75% complete	Between 50% and 75% complete	Between 20% and 50% complete	Less than 20% complete
L2.5c	Greater than 75% complete	Between 50% and 75% complete	Between 20% and 50% complete	Less than 20% complete
L2.5d				
L2.5e				
L2.5f				
L2.6a				
L2.6b				
L2.6c				

### 3.5 Level 3: Quality Assurance (6 month post-diagnosis validated Data)

**Purpose:** To enable Providers to assess final figures for specified key diagnostic data items. This data will be compared to Level 2 submissions information to highlight gaps in data.

**Note:** These reports will be based only on complete COSD data processed

**through the ENCORE system and will include all data sources and full pathway data.**

Monthly report for operational/conformance purposes.

### **Measures:**

#### **L3.1a) Total Number of Diagnoses**

##### **SINGLE PATHWAY**

These counts show patients whose complete pathway is restricted to a single Trust. It can therefore be assumed that this Trust would be fully responsible for the collection of all COSD data items.

##### **SHARED PATHWAY**

These counts show patients whose pathway has been partially handled by the Trust, but who has also visited other Trusts. At the end of the Trust summary report for Level 3, there is a breakdown of the Trusts which have handled the shared pathway patients.

#### **L3.1b) Basis of diagnosis**

This is the method used to confirm the cancer.

This will be broken down into:

- death certificate: the only information available is from a death certificate
- clinical: a clinical method of confirming cancer, one of:
  - clinical: diagnosis made before death but without the benefit of any other investigation
  - clinical investigation: includes all diagnostic techniques (e.g. X-rays, endoscopy, imaging, ultrasound, exploratory surgery and autopsy) without a tissue diagnosis
  - specific tumour markers: includes biochemical and/or immunological markers which are specific for a tumour site
- histology: a histological method on confirming cancer, one of:
  - 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
  - histology of a metastasis: histological examination of tissues from a metastasis, including autopsy specimens
  - 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
- unknown: no information on how the diagnosis has been made (e.g. PAS or HISS record only)





### **L3.1c) Clinical Nurse Specialist indication code**

Records if and when the patient saw an appropriate site specific clinical nurse specialist around the time of diagnosis. Although included in the section on Cancer Care Plan, this information will not necessarily be available at the meeting. It would be expected that this would be completed by the relevant nursing staff when appropriate. This will vary between specialties depending on patient pathway. As one of the intentions is to identify patients not seen by the Clinical Nurse Specialist it may not be possible to collect at time of patient contact.

This will be broken down by:

- ‘Yes’, nurse involved
  - Y1 - Yes, including nurse 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
- ‘No’, nurse not involved
  - NI - No, patient not seen at all by nurse but nurse informed of diagnosis
  - NN - No, patient not seen at all by nurse and nurse not informed of diagnosis
- ‘Unknown’

### **L3.1d) Age at diagnosis**

This will be broken down into the following groupings:

- Under 25
- 25-45
- 45-65
- 65-85
- Over 85

Age can be broken down further into individual years.

### **L3.1e) Multi-Disciplinary Team (MDT) Discussion Indicator**

An indication of whether the patient’s care plan was discussed at a Multidisciplinary Team Meeting.

This will be broken down by:

- A - The PATIENT was discussed at a Multidisciplinary Team Meeting
- B - The PATIENT was not discussed at a Multidisciplinary Team Meeting

### **L3.1f) Performance Status at diagnosis**

A World Health Organisation classification indicating a person’s status relating to activity/disability. This is the Performance Status agreed at the time that the treatment planning is carried out by the MDT.

This will be broken down by:

- 0 - Able to carry out all normal activity without restriction
- 1 - Restricted in physically strenuous activity, but able to walk and do light work
- 2 - Able to walk and capable of all self-care, but unable to carry out any work. Up and about more than 50% of waking hours
- 3 - Capable of only limited self-care, confined to bed or chair more than 50% of waking hours
- 4 - Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair
- 9 - Not recorded

### **L3.1g) Final Stage Group (Registry Derived)**

This is the overall TNM stage grouping of the tumour, derived by the NCRS from all the evidence available from all sources after treatment. This includes each T, N and M component (or site-specific equivalent) provided by 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 to the NCRS following the first surgical procedure(s).

### **L3.1h) Final Stage Group (Integrated)**

This is 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) i.e. 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.

**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.**

Both measures will be broken down by:

- Stage 0
- Stage 1
- Stage 2
- Stage 3
- Stage 4
- Unstageable
- Unknown

Each stage grouping can be further broken down into individual components (e.g. 1A, 1B, 1C).

### L3.2 - Numbers of Treatments

This will be broken down by:

- surgery
- radiotherapy
  - teletherapy
  - brachytherapy
  - chemoradiotherapy
  - proton therapy
  - radioisotope therapy (including radioiodine)
  - radiosurgery
- anti-cancer therapies
  - anti-cancer drug regimen (cytotoxic chemotherapy)
  - anti-cancer drug regimen (hormone therapy)
  - biological therapies (excluding immunotherapy)
  - anti-cancer drug regimen (immunotherapy)
  - anti-cancer drug regimen (other)
- non-active therapy
- active monitoring (excluding non-specialist palliative care)
- non-specialist palliative care (excluding active monitoring)
- all treatment declined
- hyperbaric oxygen therapy (only record here if there are no active treatments planned)
- other
- cryotherapy
- light therapy (including photodynamic therapy and psoralen and ultra violet a (PUVA) therapy)
- laser treatment (including argon beam therapy)
- other active treatment
- radio frequency ablation (RFA)
- high intensity focussed ultrasound (HIFU)

All Level 2 and 3 measures will be provided as both a complete Trust summary and broken down into the following tumour site categories:

COSD SITE GROUP DESCRIPTION	ICD10 SITES TO BE INCLUDED
INVASIVE HEAD AND NECK CANCERS (EXCLUDING THYROID)	C00-C14, C30-C32
INVASIVE OESOPHAGOGASTRIC CANCERS	C15-C16
INVASIVE LOWER GI CANCERS	C17-C21 , C26
INVASIVE HEPATO BILLARY AND GALL BLADDER CANCERS	C22-C24
INVASIVE PANCREATIC CANCERS	C25
INVASIVE LUNG CANCERS	C33-C34
INVASIVE CARDIOTHORACIC TUMOURS (EXCLUDING LUNG)	C37-C39, C45.0, C45.2

INVASIVE CANCERS OF SOFT TISSUE (OUTSIDE OF NAMED ORGANS) AND BONE	C40-C41, C46, C48-C49
INVASIVE MELANOMA SKIN CANCERS	C43
INVASIVE NON - MELANOMA SKIN CANCERS	C44
BRAIN & CENTRAL NERVOUS SYSTEM	C47, C69-C72, C75.1, C75.2, C75.3, D32-D33
INVASIVE BREAST CANCERS	C50
INVASIVE GYNAECOLOGICAL CANCERS	C51-C57
INVASIVE UROLOGICAL CANCERS	C60, C62-C68
INVASIVE PROSTATE CANCERS	C61
INVASIVE ENDOCRINE CANCERS (THYROID, PARATHYROID, ADRENAL AND PARAGANGLIA)	C73-C75.0
CANCER OF UNKNOWN PRIMARY SITE	C77-C80
INVASIVE HAEMATOLOGICAL CANCERS	C81-C96 <sup>2</sup>
OTHER INVASIVE CANCERS	C45.1, C45.7, C45.9, C76, C97
NON-INVASIVE BREAST CANCER	D05
NON-INVASIVE BLADDER CANCER	D09.0
NON-INVASIVE CERVICAL CANCER	D06
NON-INVASIVE MELANOMA SKIN CANCERS	D03
ALL OTHER NON INVASIVE CANCERS	ALL D CODES (EXCEPT D03,D05,D06,D09.0,D32 and D33)

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<sup>2</sup> Haematological Cancers will be classified using ICDO-3 in a future version of the Conformance Framework

## 4. Escalation Process and the role of the COSD Governance Board

The following roles within organisations would be expected to have responsibility for non-compliant data submissions at the suggested levels. There is some flexibility depending on the severity and nature of the issue.

Level	National Cancer Registration and Analysis Service	Data Provider	COSD Governance Board	Clinical Commissioning Group (CCG)	Action	Response expected
<b>Mild</b>	Named Contact for Receipt of Data	Named Contact for Data Source	Not Involved	Not involved	Phone call alert  Informal support from NCRS	Informal resolution of issue by the Provider within 5 working days. Provider notifies NCRS on resolution
<b>Moderate</b>	Named Contact for Provider Liaison	Lead Accountable Officer for the COSD (Provider) / Director with Lead Responsibility for Cancer Services	Dependent on issue	Dependent on issue	Phone call alert and written formal letter/e-mail  Support from NCRS	Provider submits a robust report detailing the actions they intend to take to become compliant within the timeframe that they have agreed with the NCRAS.  A regular update is required from the Provider on progress and upon completion of actions to become compliant.
<b>Severe</b>	Head of Cancer Registration/ Deputy Director of Disease Registration	Chief Executive	Involved	Involved	Formal Letter to Chief Executive of Provider and written notification to the COSD Governance Board  Support from NCRS	Response within 25 working days, detailing specific actions to be undertaken by the Provider to become compliant.
If resolution of the issue is not reached and conformance with the ISN is breached (in accordance with the Data Transfer Partnership Agreement), external intervention via the COSD GOVERNANCE BOARD as specified below will be invoked.						

#### 4.1 Dataset conformance monitored by the COSD Governance Board:

1.	NHS Providers must submit COSD data items as specified in the Implementation Guidance within the defined time period and in the format specified in these documents.
2.	All submitted data files must contain the specified linkage items at record level to enable linkage of the relevant cancer registration records.
3.	NHS Providers must submit the agreed data items within 25 working days of the month end following diagnosis date.
4.	NHS Providers must submit the agreed data items within 25 working days of the month end following treatment start date.
5.	NHS Providers must submit further records for all cases within 25 working days of the month end following any additional or amendments to the data items.
6.	NHS Providers must agree methods of submission with the NCRS for all items not flowed as part of the standard extract.
7.	NHS Providers must notify the NCRS of any known reasons for significant variation in the number of new cases submitted monthly if applicable.
8.	NHS Providers must review monthly feedback from the NCRS
9.	NHS Providers must audit case ascertainment, quality and completeness on receipt of quarterly feedback reports from the NCRS and notify the NCRS of reasons for any discrepancies.
10.	Providers must report a minimum of 80% of all expected cases annually by Site specific Tumour Group as agreed with the NCRS.*
11.	NHS Providers must have a plan to submit the dataset in XML.

#### 4.2 The Governance board will also be provided with the following completeness reports for possible action:

Metric	Source	Frequency
Timeliness and quality of data submissions	Level 1	M
Percentage with integrated stage and/or percentage with final pre-treatment stage completed	Level 3	M
Performance status completion rates	Level 3	Q/A
Clinical nurse specialist completion rates	Level 3	Q/A
Basis of diagnosis completion rates	Level 3	Q/A
Annual case ascertainment * (Expected 80%+)	Level 3	A
Percentage of key pathological data items completed (to be agreed)	Level 3	Q/A
Other site specific items (to be agreed)	Level 3	Q/A
NCRS-Derived stage completeness (indicator of data quality and completeness levels)	Level 3	Q/A

Frequency: M=Monthly, Q=Quarterly, A=Annually

### **4.3 External Intervention by the COSD Governance Board**

If resolution of the issue is not reached and a provider has not delivered data in accordance with the ISN requirements:

- 1) The COSD Governance Board will inform the relevant Co-ordinating Commissioners (which may be a CCG and/or the relevant Area Team), who would then be in a position, under the terms of the NHS Standard Contract, to notify the provider that they intend to instruct all the relevant local commissioners to withhold the sums set out in contract if the information is not provided within 5 days. The sum withheld is up to 1% of the monthly sum payable by the Commissioner under Service Condition 36 (Payment Terms) for each month the information breach continues, as set out in Service Condition 28.12 (Information Requirements).
- 2) Where the Co-ordinating Commissioner fails to take effective action, the COSD Governance Board will escalate the issue to the Director of the relevant NHS England Area Team to utilise their performance management function.
- 3) Where the Director of the Area Team fails to take effective action, the COSD Governance Board will escalate the issue to the NHS Medical Director and the National Clinical Director for Cancer.



## Appendix I: Reporting schedule 2015

Data submission is due 25 working days after end of month of diagnosis or treatment. Feedback reports from the National Cancer Registration and Analysis Service (NCRAS) will be provided according to the schedule below. See also Appendix II.

The Data Transfer Partnership Agreement should be completed before the start of the calendar year and feedback on this will be provided by NCRAS, before the first submission deadline for the year.

			DATE REPORT DUE				
			Quality Control (Conformance -Raw Data)	Quality Control (Operational Feedback – Validated Data)	Quality Assurance (6 month post-diagnosis validated Data)		
MONTH OF DIAGNOSIS/ TREATMENT	SUBMISSION DUE DATE (MDT/Pathology)	SUBMISSION DUE DATE (PAS)	LEVEL 1 (Monthly QC)	LEVEL 2 (Monthly QC)	LEVEL3 Monthly	LEVEL 3 Quarterly	LEVEL 3 Annual
JAN 2015	06 MAR 2015	20 MAR 2015	10 MAR 2015	31 MAR 2015	End Oct 2015	End Dec 2015	End Sep 2016
FEB 2015	09 APR 2015	23 APR 2015	13 APR 2015	30 APR 2015	End Nov 2015		
MAR 2015	08 MAY 2015	22 MAY 2015	12 MAY 2015	29 MAY 2015	End Dec 2015		
APR 2015	08 JUN 2015	22 JUN 2015	10 JUN 2015	30 JUN 2015	End Jan 2016	End Mar 2016	
MAY 2015	02 JUL 2015	16 JUL 2015	06 JUL 2015	31 JUL 2015	End Feb 2016		
JUN 2015	04 AUG 2015	18 AUG 2015	06 AUG 2015	31 AUG 2015	End Mar 2016		
JUL 2015	07 SEP 2015	21 SEP 2015	09 SEP 2015	30 SEP 2015	End Apr 2016	End Jun 2016	
AUG 2015	02 OCT 2015	16 OCT 2015	06 OCT 2015	30 OCT 2015	End May 2016		
SEP 2015	04 NOV 2015	18 NOV 2015	06 NOV 2015	30 NOV 2015	End Jun 2016		
OCT 2015	04 DEC 2015	18 DEC 2015	08 DEC 2015	31 DEC 2015	End July 2016	End Sep 2016	
NOV 2015	07 JAN 2016	21 JAN 2016	11 JAN 2016	29 JAN 2016	End Aug 2016		
DEC 2015	05 FEB 2016	19 FEB 2016	09 FEB 2016	29 FEB 2016	End Sep 2016		

## Appendix II: Technical Specification of Reports

Criteria Number	Title	Description & Comments	COSD Data Items used to calculate
<b>L2.1 Data Quality and Completeness for Diagnosis Period</b>			
<b>L2.1a</b>	Diagnosed	Numerical field - Number of cases diagnosed within the reporting month either as a Trust overall summary or by selected site groups	CR0370 (Primary Diagnosis ICD10) and CR2030 (Date of Diagnosis)
<b>L2.1b</b>	Treated	Numerical field - Number of cases diagnosed within the reporting month for which a treatment record was submitted either as a Trust overall summary or by selected site groups	CR0370 (Primary Diagnosis ICD10), CR1340 (Cancer Treatment Event Type), CR1370 (Treatment Start Date), CR2040 (Cancer Treatment Modality) and CR1450 (Organisation Site Code) to identify treating Trust
<b>L2.1c</b>	Surgery	Numerical field - Number of cases diagnosed within the reporting month where the first treatment was surgery either as a Trust overall summary or by selected site groups	CR0370 (Primary Diagnosis ICD10), CR1340 (Cancer Treatment Event Type), CR1370 (Treatment Start Date), CR2040 (Cancer Treatment Modality) and CR1340 equals "01"
<b>L2.1d</b>	Basis of Diagnosis	Numerical field - Number of cases diagnosed within the reporting month where a Basis of Diagnosis was provided either as a Trust overall summary or by selected site groups	CR0370 (Primary Diagnosis ICD10) and CR2030 (Date of Diagnosis) and CR0390 (Basis of Diagnosis) does not equal blank and does not equal 9
<b>L2.1e</b>	Histological Diagnosis	Numerical field - Number of cases diagnosed within the reporting month where the Basis of Diagnosis was Histological either as a Trust overall summary or by selected site groups	CR0370 (Primary Diagnosis ICD10) and CR2030 (Date of Diagnosis) and CR0390 (Basis of Diagnosis) equals 7
<b>L2.1f</b>	CNS Indicator	Numerical field - Number of cases diagnosed within the reporting month where a CNS Indicator was submitted either as a Trust overall summary or by selected site groups	CR2030 (Date of Diagnosis) and where CR2050 (CNS Indication Code) does not equal blank and does not equal 99
<b>L2.1g</b>	CNS Contact	Numerical field - Number of cases diagnosed within the reporting month who had a CNS contact either as a Trust overall summary or by selected site groups	CR2030 (Date of Diagnosis) and where CR2050 (CNS Indication Code) equals Y1 (Yes, inc Nurse present when pt was given diagnosis), Y3 or Y4.
<b>L2.1h</b>	MDT Discussion	Numerical field - Number of cases diagnosed within the reporting month where discussed at MDT Meeting.	CR0370 (Primary Diagnosis ICD10) and CR2030 (Date of Diagnosis) and CR0420 (MDT Discussion Indicator) equals A and/or CR0430 (MDT Discussion Date) does not equal blank

<b>L2.2 -Data Quality and Completeness for Diagnosed Cases Discussed at MDT</b>			
<b>L2.2a</b>	With a Performance Status	Numerical field - Total cases diagnosed within the reporting period discussed at MDT with a valid performance status value (i.e. 0-4) either as a Trust overall summary or by selected site groups	CR0370 (Primary Diagnosis ICD10) and CR2030 (Date of Diagnosis) and CR0420 (MDT Discussion Indicator) equals A and/or CR0430 (MDT Discussion Date) does not equal blank and where the CR0510 (Performance Status Adult) equals 0-4
<b>L2.2b</b>	Cases with a full stage	Numerical field - Of the total cases diagnosed within the reporting period the total with a full stage either as a Trust overall summary or by selected site groups	CR0370 (Primary Diagnosis ICD10) and CR2030 (Date of Diagnosis) and CR0420 (MDT Discussion Indicator) equals A and/or CR0430 (MDT Discussion Date) does not equal blank AND a full stage value
<b>L2.2c</b>	Cases with a full stage and a performance status	Numerical field - Of the total cases diagnosed within the reporting period the total with a full stage either as a Trust overall summary or by selected site groups	CR0370 (Primary Diagnosis ICD10) and CR2030 (Date of Diagnosis) and CR0420 (MDT Discussion Indicator) equals A and/or CR0430 (MDT Discussion Date) does not equal blank AND where the CR0510 (Performance Status Adult) equals 0-4
<b>L2.3 -Breakdown of Staging Completeness for Diagnosed Cases Discussed at MDT (see Page 8-9 for further information on staging measurement)</b>			
<b>L2.3a</b>	With any stage	Numerical field - Of the above total stageable cases, the cases with any stage either as a Trust overall summary or by selected site groups	CR0370 (Primary Diagnosis ICD10) and (Date of Diagnosis) and CR0420 (MDT Discussion Indicator) equals A and/or CR0430 (MDT Discussion Date) does not equal blank AND the pre-treatment, integrated and site specific staging fields broken down by completeness
<b>L2.3b</b>	With a Pre-treatment Stage	Numerical field - Of the above total stageable cases, the cases with a pre-treatment stage either as a Trust overall summary or by selected site groups	CR0370 (Primary Diagnosis ICD10) and (Date of Diagnosis) and CR0420 (MDT Discussion Indicator) equals A and/or CR0430 (MDT Discussion Date) does not equal blank AND the pre-treatment staging fields broken down by completeness
<b>L2.3c</b>	With an Integrated Stage	Numerical field - Of the above total stageable cases, the cases with an integrated stage either as a Trust overall summary or by selected site groups	CR0370 (Primary Diagnosis ICD10) and (Date of Diagnosis) and CR0420 (MDT Discussion Indicator) equals A and/or CR0430 (MDT Discussion Date) does not equal blank AND a First Treatment of "Surgery" (See measure 2.1c) AND the integrated stage fields broken down by completeness
<b>L2.3d</b>	With a Site Specific Stage	Numerical field - Of the above total stageable cases, the cases with a site specific stage either as a Trust overall summary or by selected site groups	CR0370 (Primary Diagnosis ICD10) and CR2030 (Date of Diagnosis) and CR0420 (MDT Discussion Indicator) equals A and/or CR0430 (MDT Discussion Date) does not equal blank AND the site specific stage fields broken down by completeness.

## Appendix III: Stageable Tumour Sites

The following cancers are considered stageable based on their ICD10 code for the purposes of the COSD reports.

Peripheral neuroblastic tumours	Any site
Gastrointestinal stromal tumours	Any site
Oral cavity	C00, C02-C06
Pharynx	C01, C05, C09,C10.0,C10.2,C10.3,C11,C12,C13
Salivary gland	C07, C08
Oesophagus	C15
Stomach	C16
Gastrointestinal endocrine tumours	C16,C17,C24,C25,C18,C19,C20
Colorectum	C18,C19,C20
Liver	C22
Bile ducts and pancreas	C24, C25
Nasal cavities & paranasal sinuses	C30,C31.0, C31.1
Larynx	C32, C10.1
Lung	C34
Soft tissue	C38.1-3, C47-C49 (plus other sites of soft tissue sarcoma)
Bone	C40,C41
Skin	C43,C44
Ovary	C48.1, C48.2, C56, C57.0, D39.1
Breast	C50
Vulva	C51
Cervix	C53
Uterine sarcoma	C53,C54 (except C54.1),C55
Endometrium	C54,C55
Penis	C60
Prostate	C61
Testis	C62
Adult kidney	C64
Renal tumours of childhood	C64
Urinary collecting system	C65-C69
Conjunctival melanoma	C69.0
Retinoblastoma	C69.2
Uveal melanoma	C69.3, C69.4
Thyroid	C73
Adrenal	C74.0
Lymphoma	C81-C85
Myeloma	C90
Chronic lymphocytic leukaemia	C91.1