



Public Health
England

Protecting and improving the nation's health

National Cancer Intelligence Network

Cancer Outcomes and Services Dataset (COSD) Version 6.0

Change request

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

Public Health England
Wellington House
133-155 Waterloo Road
London SE1 8UG
Tel: 020 7654 8000
www.gov.uk/phe
Twitter: [@PHE_uk](https://twitter.com/PHE_uk)
Facebook: www.facebook.com/PublicHealthEngland

OGL © Crown copyright 2015

This publication is licensed under the terms of the Open Government Licence v3.0 except where otherwise stated. To view this licence, visit: nationalarchives.gov.uk/doc/open-government-licence/version/3 or write to the Information Policy Team, The National Archives, Kew, London TW9 4DU, or email: psi@nationalarchives.gsi.gov.uk.

Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

Any enquiries regarding this publication should be sent to us at publications@phe.gov.uk

Published February 2015
PHE publications gateway number: 201



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.

Contents

1.Overview	7
1.1.Summary	7
1.2.Supporting products	8
1.3.Related standards	9
1.4.Status of Documents	9
2.Change specification	11
2.1.New items	11
2.2.Amendments	14
2.3.Deletions	21
2.4.Extension of scope	21

Document information

Title	Cancer Outcomes and Services Dataset (COSD) version 6.0 – Change request		
SCCI reference	SCCI 1521 Amd 17/2014		
Sponsor	Jane Allberry	Status	Final
Senior responsible officer	Sean Duffy	Version	1.2
Author(s)	Trish Stokes		
Version Date	30/01/2015		

Amendment history:

Version	Date	Amendment history
0.1	07/11/2014	First draft for comment
0.2	11/12/2014	Second draft for branding
1.0	18/12/2014	Final for submission
1.1	16/01/2015	Post ISAS appraisal meeting. Amendments to figures re new and amended items and additional information on changes to schema
1.2	30/01/2015	Implementation completion date amended to 1st January 2016

Approvals:

Name	Organisation	Version	Date
COSD Governance Board	COSD Governance Board	1.2	16/02/2015

Related documents:

Ref #	Doc Reference	Title	Version	Date
1	www.ncin.org.uk/collecting_and_using_data/data_collection/cancer_outcomes_and_services_dataset_cosd_latest_downloads	COSD specification	6.2	30/01/2015
2	www.ncin.org.uk/collecting_and_using_data/data_collection/cancer_outcomes_and_services_dataset_cosd_latest_downloads	COSD dataset	6.0	30/01/2015

Glossary of terms:

Term	Acronym	Definition
Cancer		For the purposes of this standard the term ‘cancer’ is used throughout the standard and related documents to cover all conditions defined as registerable by the UK and Ireland Association of Cancer Registries (UKIACR).
Cancer Outcomes and Services Dataset	COSD	The COSD is the national standard for reporting cancer in the NHS in England. It replaced the previous National Cancer Dataset and includes the former Cancer Registration dataset and additional site specific data items relevant to the different tumour types.
Extensible Markup Language	XML	Extensible markup language (XML) is a set of rules for encoding documents in machine-readable form.
Information Standard	IS	A measure that ensures that information is managed in a consistent manner across health and social care, both by the computers and the staff.
International Statistical Classification of Diseases and Related Health Problems	ICD	A medical classification list for the coding of diseases, signs and symptoms, abnormal findings, complaints, social circumstances and external causes of injury or diseases, as maintained by the World Health Organization (WHO). (The title is followed by the revision number, eg ICD10 is the tenth revision.)
International Classification of Diseases for Oncology	ICD-O	An extension of the ICD coding system used principally in tumour or cancer registries for coding the site (topography) and the histology (morphology) of neoplasms. (The title is followed by the revision number, eg ICD-O-3 is the third revision.)
National Cancer Intelligence Network	NCIN	A UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and

Term	Acronym	Definition
		research. NCIN is one of a number of Health Intelligence Networks operated by Public Health England
National Cancer Registration Service	NCRS	The NCRS is the national cancer registration service for England collecting cancer data from all NHS Providers of cancer care in England. The NCRS is a function within the National Disease Registration Service within Public Health England
National Cancer Waiting Times Monitoring Dataset	NCWTMDS	The Information Standard (ISB0147) used to monitor the time that patients with suspected and diagnosed cancer have wait for appointments, tests and treatments.
Royal College of Pathologists	RC Path	A professional membership organisation committed to setting and maintaining professional standards and to promoting excellence in the practice of pathology.
Systematised Nomenclature of Medicine – Clinical Terms	SNOMED CT	A systematically organised computer processable collection of medical terminology covering most areas of clinical information such as diseases, findings, procedures, microorganisms, and substances which allows a consistent way to index, store, retrieve, and aggregate clinical data across specialties and sites of care.
U K and Ireland Association of Cancer Registries	UKIACR	The UKIACR brings together organisations with an interest in developing cancer registration as a resource for studying and controlling cancer in the UK.
User guide		Instruction documentation to aid those who will be involved in the process of collecting the dataset.
XML schema		The documentation, definitions and descriptions required to enable the production and transmission of data for a specific XML language.

1. Overview

1.1. Summary

Standard	
Standard number	SCCI 1521
Standard title	Cancer Outcomes and Services Dataset (COSD)
Release	
Release number	Amd 17/2014
Release title	Version 6.0
Description	<p>This is a change to the standard which introduces some amendments to the current dataset, an extension of scope and a revision of the current schema specification in order to continue to meet the business objectives of the standard. There has also been an extension to the deadline for submitting data in XML structured format agreed for pathology in recognition of the difficulties encountered in meeting the initial deadline of January 2015. The deadline has now been extended to 1 January 2016 and providers are asked to provide a plan to the NCRS for meeting this requirement by July 2015.</p> <p>The changes are:</p> <p>Relax mandation in schema specification for all except linkage items from mandatory' to 'required' in order to support registration process and provide early identification of gaps in data.</p> <p>Extend scope for recurrences from breast cancer cases only to all recurrences, with a minimal collection of demographic and diagnosis data only.</p> <p>Extend deadline for XML submissions of pathology data to 1 January 2016.</p> <p>Changes to dataset: In order to align with current business needs and clinical practice, and to support data quality 32 new items have been added. Most of these data are either collected already in cancer management systems (for example the date when the stage data was recorded).</p> <p>A further two items have been added to support a pilot project and will only be required for agreed pilot sites (holistic needs assessment data).</p> <p>Two items have been deleted - one is a duplication and the other has been replaced by a new item.</p> <p>Twenty seven data items have been amended to align with changes in clinical practice or other datasets (eg revisions to Royal</p>

	<p>College of Pathologists datasets), to support data quality (eg identify absence of a condition as opposed to value not being entered) or as a result of requests during implementation (eg additional options for recording the role of the clinical nurse specialist). A small number of these are corrections to administrative errors.</p> <p>Four items have been moved to a different section, either to better reflect the collection point on the patient pathway or because they no longer need to be submitted directly by providers and can be derived nationally.</p> <p>Minor modifications have been made to 32 data items for better synchronisation across the NHS Data Dictionary or for clarification of descriptions and do not impact the collection of the data.</p>
Implementation start and completion date	Between 1 April 2015 and 1 January 2016

1.2. Supporting products

Ref #	Reference	Title
1	https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/384661/IOSC fourth annual report FINAL.pdf	Improving outcomes: a strategy for cancer (fourth annual report)
2	http://www.ncin.org.uk/collecting_and_using_data/data_collection/cancer_outcomes_and_services_dataset_cosd_latest_downloads	COSD user guide v6.0
3	http://www.ncin.org.uk/collecting_and_using_data/data_collection/cancer_outcomes_and_services_dataset_cosd_latest_downloads	COSD dataset 6.0

1.3. Related standards

Ref #	Reference	Title
ISB 0147	http://www.isb.nhs.uk/documents/isb-0147/amd-23-2011/index.html	Cancer Waiting Times Monitoring Dataset
ISB 0111	http://www.isb.nhs.uk/documents/isb-0111/amd-26-2012	Radiotherapy Dataset
ISB 1533	http://www.isb.nhs.uk/documents/isb-1533/amd-24-2013	Systemic Anti Cancer Therapy Dataset
ISB 1577	http://www.isb.nhs.uk/documents/isb-1577/amd-10-2011/index.html	Diagnostic Imaging Dataset
ISB 0021	http://www.isb.nhs.uk/documents/isb-0021	International Classification Of Diseases
ISB 0034	http://www.isb.nhs.uk/documents/isb-0034/amd-26-2006/index.html	SNOMED CT
n/a	http://www.rcpath.org/professional-standards	RC Pathologists professional standards

1.4. Status of Documents

Assurance that this information standard is appropriate for the use specified in the specification document has been provided by the Standardisation Committee for Care Information (SCCI), a sub-group of the National Information Board.

This information standard comprises the following documents:

- specification
- implementation guide

In addition, this change request document provides an overview of the change from the last version of the standard.

An Information Standards Notice (SCCI1521 Amd 17/2014) has been issued as a notification of use and implementation timescales. Please read this alongside the listed documents.

The controlled versions of these documents can be found on the [HSCIC website](#).

2. Change specification

2.1. New items

This is a complex dataset covering 200 diseases and requiring alignment with changing clinical practice. It is therefore expected that regular changes will be required. The current new items reflect this and are introduced to align with current business needs and clinical practice, and to support data quality.

The majority of the new items (18) have been added to enable the date of recording the relevant stage of disease to be entered and only one of these data items is required to be completed for each record.

Most of the remaining items are site specific items now used clinically to identify stage and prognostic factors and again only apply to a small number of cases.

The multidisciplinary team items are mostly from reference data which will be entered on software systems only once.

Additionally two items have been added to support a pilot project and are not required for submission from providers at present unless taking part in the pilot. They are, however, available for local use if required.

Full details are provided in the COSD Dataset v6.0 and COSD User Guide v6.0.

PERSON STATED GENDER CODE

CORE – DEMOGRAPHICS

HOLISTIC NEEDS ASSESSMENT COMPLETED DATE

CORE - HOLISTIC NEEDS ASSESSMENT

HOLISTIC NEEDS ASSESSMENT POINT OF PATHWAY

CORE - HOLISTIC NEEDS ASSESSMENT

MULTIDISCIPLINARY TEAM MEETING DATE

CORE – MDT

HOSPITAL SITE CODE OF MULTIDISCIPLINARY TEAM MEETING

CORE – MDT

MULTIDISCIPLINARY TEAM MEETING TYPE

CORE – MDT

MULTIDISCIPLINARY MEETING TYPE COMMENT

CORE – MDT

STAGE DATE (FINAL PRETREATMENT STAGE)

CORE – STAGING

STAGE DATE (INTEGRATED STAGE)

CORE – STAGING

MODIFIED DUKES STAGE DATE

COLORECTAL – STAGING

MURPHY (ST JUDE) STAGE DATE

CTYA - NON HODGKIN LYMPHOMA

ANN ARBOR STAGE DATE

CTYA - HODGKIN LYMPHOMA

INTERNATIONAL NEUROBLASTOMA STAGING SYSTEM DATE

CTYA – NEUROBLASTOMA

WILMS TUMOUR STAGE DATE

CTYA - RENAL TUMOURS

IRS POST SURGICAL GROUP DATE

CTYA - RHABDOMYOSARCOMA AND OTHER SOFT TISSUE SARCOMAS

CHANG STAGING FOR MEDULLOBLASTOMA DATE

CTYA – MEDULLOBLASTOMA

RETINOBLASTOMA ASSESSMENT DATE

CTYA – RETINOBLASTOMA

RETINOBLASTOMA ASSESSMENT LATERALITY

CTYA - RETINOBLASTOMA

INTERNATIONAL CLASSIFICATION FOR INTRAOCULAR RETINOBLASTOMA

CTYA - RETINOBLASTOMA

INTERNATIONAL STAGING SYSTEM FOR RETINOBLASTOMA
CTYA - RETINOBLASTOMA

FINAL FIGO STAGE DATE
GYNAECOLOGY – STAGING

RAI STAGE DATE
HAEMATOLOGY - CANCER CARE PLAN – CLL

BINET STAGE DATE
HAEMATOLOGY - CANCER CARE PLAN – CLL

ISS STAGE FOR MYELOMA DATE
HAEMATOLOGY - CANCER CARE PLAN – MYELOMA

ANN ARBOR STAGE DATE
HAEMATOLOGY - STAGING - HODGKIN, FOLLICULAR, DLBCL, OTHER
LYMPHOMAS

ANN ARBOR SPLENIC INVOLVEMENT
HAEMATOLOGY - STAGING - HODGKIN, FOLLICULAR, DLBCL, OTHER
LYMPHOMAS

AJCC STAGE GROUP DATE
SKIN – STAGING

BARCELONA CLINIC LIVER CANCER (BCLC) STAGE
UPPER GI - STAGING - LIVER HCC

BARCELONA CLINIC LIVER CANCER (BCLC) STAGE DATE
UPPER GI - STAGING - LIVER HCC

CHILD-PUGH SCORE
UPPER GI - STAGING - LIVER HCC

NUMBER OF LESIONS (RADIOLOGICAL)
UPPER GI - STAGING - LIVER HCC

PORTAL INVASION
UPPER GI - STAGING - LIVER HCC

CLINICAL STAGE (PANCREATIC CANCER)

UPPER GI - STAGING – PANCREAS

CLINICAL STAGE (PANCREATIC CANCER) DATE

UPPER GI - STAGING – PANCREAS

REFERRAL REQUEST RECEIVED DATE (INTER-PROVIDER TRANSFER)

(REFERENCE – OTHER STANDARDS) CORE – REFERRALS

This is a potential new item which is expected to be added to national cancer waiting times monitoring data set from 1 October 2015. It has, therefore, been included here for potential future use but has not been counted in the overall totals. It will not be submitted directly by providers to the NCRS.

2.2. Amendments

New or amended text is marked in **blue highlight**. Text that has been deleted is in ~~marked with a strikethrough~~.

Full details are provided in the COSD dataset v6.0 and user guide v6.0

TUMOUR LATERALITY

CORE - DIAGNOSTIC DETAILS

CLINICAL NURSE SPECIALIST INDICATION CODE

CORE – DIAGNOSIS

Y1	Yes, nurse present when patient given diagnosis
Y2	Yes, but nurse not present when patient given diagnosis
Y3	Yes, nurse not present when patient given diagnosis but saw patient during same consultant clinic session
Y4	Yes, nurse not present during consultant clinic session when patient given diagnosis but seen at other time
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.
99	Not Known

CANCER VASCULAR OR LYMPHATIC INVASION

CORE - PATHOLOGY DETAILS

Amended values to align with revised Royal College of Pathologists standards and datasets for histopathology reporting on cancers and tissue pathways

EXCISION MARGIN

CORE - PATHOLOGY DETAILS

Amended values to align with Royal College of Pathologists standards and datasets for histopathology reporting on cancers and tissue pathways

NU	No - vascular/lymphatic invasion not present
YU	Yes - vascular/lymphatic invasion present
YV	Vascular invasion only present
YL	Lymphatic invasion only present
YB	Both lymphatic and vascular invasion present
UU	Uncertain whether vascular/lymphatic invasion is present or not
XX	Cannot be assessed
99	Not Known

DEATH LOCATION TYPE

CORE - DEATH DETAILS (ALSO IN REFERENCE – OTHER SOURCES)

10	Hospital
20	Private residence
21	Patient's own home
22	Other private residence (eg relatives home, carers home)
30	Hospice
40	Care home
41	Care home with nursing
42	Care home without nursing
50	Other

DISTANCE TO MARGIN

BREAST – PATHOLOGY

Distance to closest relevant margin (mm). Distance to nearest margin whether invasive or non invasive. (For COSD measurement to the nearest mm is sufficient but may be recorded to nearest tenth of mm)

Format: max n2.max n1

SURGICAL ACCESS

COLORECTAL - SURGERY & OTHER PROCEDURES

1	Open operation
2	Laparoscopic with planned conversion to open surgery
3	Laparoscopic with unplanned conversion to open surgery
4	Laparoscopic completed
Z	Not applicable

EXTRAMEDULLARY DISEASE

CTYA - ACUTE LYMPHOBLASTIC LEUKAEMIA AND ACUTE MYELOID LEUKAEMIA

Site/s of disease identified outside bone marrow
(More than one option can be recorded)

ANN ARBOR EXTRANODALITY

CTYA - HODGKIN LYMPHOMA

E	Extranodal involvement
0	No Extranodal involvement

SURGEON GRADE

GYNAECOLOGY - SURGERY & OTHER PROCEDURES

Grade of senior surgeon present at operation

Note: 'Colposcopist - NOS'. Where the procedure is a colposcopy, this may be a qualified colposcopist who is not a surgeon

S	Subspecialist gynaecological oncologist
C	Consultant gynaecologist (not subspecialist)
F	Sub-specialty fellow
A	Associate specialist / staff grade
R	SPR / ST3+
O	SHO / ST1 or ST2
G	General surgeon / other surgical speciality
Z	Colposcopist NOS

FINAL FIGO STAGE

GYNAECOLOGY – STAGING

Format: max an7

EXTRAMEDULLARY DISEASE

HAEMATOLOGY - CANCER CARE PLAN - ACUTE LYMPHOBLASTIC LEUKAEMIA

Site/s of disease identified outside bone marrow
(More than one option can be recorded)

ANN ARBOR EXTRANODALITY

HAEMATOLOGY - STAGING - HODGKIN, FOLLICULAR, DLBCL, OTHER LYMPHOMAS

E	Extranodal involvement
0	No Extranodal involvement

ANN ARBOR BULK

HAEMATOLOGY - STAGING - HODGKIN, FOLLICULAR, DLBCL, OTHER LYMPHOMAS

X	"Bulky" disease present
0	No 'bulky' disease present

PERINEURAL INVASION

SKIN - PATHOLOGY - BCC & SCC

Amended values to align with revised Royal College of Pathologists standards and datasets for histopathology reporting on cancers and tissue pathways

Is there perineural invasion (invasion into perineurium of nerve bundles- PNI)

Y	Yes
N	No
U	Uncertain
X	Cannot be assessed
9	Not Known

LESION DIAMETER GREATER THAN 20MM INDICATOR

SKIN - PATHOLOGY - BCC & SCC

Amended values to align with revised Royal College of Pathologists standards and datasets for histopathology reporting on cancers and tissue pathways

Y	Yes (Greater than 20mm)
N	No (Less than or equal to 20mm)

U	Uncertain
X	Cannot be assessed
9	Not Known

DEEP INVASION INDICATOR FOR PT3

SKIN - PATHOLOGY - BCC & SCC

Amended values to align with revised Royal College of Pathologists standards and datasets for histopathology reporting on cancers and tissue pathways

Y	Yes
N	No
U	Uncertain
X	Cannot be assessed

DEEP INVASION INDICATOR FOR PT4

SKIN - PATHOLOGY - BCC & SCC

Amended values to align with revised Royal College of Pathologists standards and datasets for histopathology reporting on cancers and tissue pathways

Y	Yes
N	No
U	Uncertain
X	Cannot be assessed

CLARKS LEVEL IV INDICATOR

SKIN - PATHOLOGY - SCC & MM

Amended values to align with revised Royal College of Pathologists standards and datasets for histopathology reporting on cancers and tissue pathways

Y	Yes
N	No
U	Uncertain
X	Cannot be assessed

LESION VERTICAL THICKNESS GREATER THAN 2MM INDICATOR

SKIN - PATHOLOGY – SCC

Amended values to align with revised Royal College of Pathologists standards and datasets for histopathology reporting on cancers and tissue pathways

Y	Yes
N	No
U	Uncertain
X	Cannot be assessed

ULCERATION INDICATOR

SKIN - PATHOLOGY – MM

Amended values to align with revised Royal College of Pathologists standards and datasets for histopathology reporting on cancers and tissue pathways

Y	Yes
N	No
U	Uncertain
X	Cannot be assessed
9	Not Known

MICROSATELLITE OR IN-TRANSIT METASTASIS INDICATOR

SKIN - PATHOLOGY – MM

Amended values to align with revised Royal College of Pathologists standards and datasets for histopathology reporting on cancers and tissue pathways

Y	Yes
N	No
U	Uncertain
X	Cannot be assessed
9	Not Known

TUMOUR REGRESSION INDICATOR

SKIN - PATHOLOGY – MM

Amended values to align with revised Royal College of Pathologists standards and datasets for histopathology reporting on cancers and tissue pathways

Y	Yes
N	No
U	Uncertain
X	Cannot be assessed
9	Not Known

RENAL VEIN TUMOUR

UROLOGY - PATHOLOGY – KIDNEY

Amended values to align with revised Royal College of Pathologists standards and datasets for histopathology reporting on cancers and tissue pathways

Y	Yes
N	No
U	Uncertain

PERINEURAL INVASION

UROLOGY - PATHOLOGY – PROSTATE

Amended values to align with revised Royal College of Pathologists standards and datasets for histopathology reporting on cancers and tissue pathways

Is there perineural invasion (invasion into perineurium of nerve bundles- PNI)

N	No
Y	Yes
X	Cannot be assessed
9	Not Known

CARE PROFESSIONAL MAIN SPECIALTY CODE (FIRST SEEN)

(REFERENCE - OTHER SOURCES) CORE – REFERRALS

CARE PROFESSIONAL MAIN SPECIALTY CODE (TREATMENT)

(REFERENCE - OTHER SOURCES) CORE – TREATMENT

In addition all data items currently marked as ‘mandatory’ in the schema, with the exception of CORE LINKAGE items will be amended to ‘required’. This is

requested by the NCRS in order to receive any available data as soon as possible. It is not intended to reduce the importance of collecting the items previously marked as mandatory in the schema. All items marked as required continue to be essential for inclusion in the submission where applicable and as soon as available.

2.3. Deletions

The following two items are deleted for the reasons stated against each item

PERSON GENDER CODE CURRENT

CORE – DEMOGRAPHICS

(replaced by **PERSON STATED GENDER CODE**)

DISTANCE TO CIRCUMFERENTIAL EXCISION MARGIN

COLORECTAL – PATHOLOGY

(duplication of **DISTANCE TO CIRCUMFERENTIAL MARGIN**)

2.4. Extension of scope

Breast recurrences have been within scope since January 2013 and data collection continues as previously specified. For all other recurrences a separate record should now be submitted to include the demographics and diagnosis data items as minimum.

Further details are provided in the COSD user guide v6.0.