

Radiotherapy Data Set (RTDS)

User Guide v6.1.1

About the NDRS

The National Disease Registration Service (NDRS) is part of NHS Digital (NHSD). Its purpose is to collect, collate and analyse data on patients with cancer, congenital anomalies, and rare diseases. It provides robust surveillance to monitor and detect changes in health and disease in the population. NDRS is a vital resource that helps researchers, healthcare professionals and policy makers make decisions about NHS services and the treatments people receive.

The NDRS includes:

- the National Cancer Registration and Analysis Service (NCRAS) and
- the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)

Healthcare professionals, researchers and policy makers use data to better understand population health and disease. The data is provided by patients and collected by the NHS as part of their care and support. The NDRS uses the data to help:

- understand cancer, rare diseases, and congenital anomalies
- improve diagnosis
- plan NHS services
- improve treatment
- evaluate policy
- improve genetic counselling



National Disease Registration Service
NHS Digital (NHSD)
The Leeds Government Hub
7 Wellington Place
Leeds
LS1 4AP

For queries relating to this document, please contact:

NDRSenquiries@nhs.net

Improving lives with data and technology – NHS Digital support NHS staff at work, help people get the best care, and use the nation's health data to drive research and transform services.



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Version Control

Version	Date	Brief Summary of Change	Editors
6.0 Final	16 June 2021	Final version for publication	Andrew Murphy
6.1.0 Final	3 February 2022	Updated user guide using NDRS publication standards throughout, plus: - new list of Radiopharmaceutical Procedure (SNOMED CT) codes pg34	Andrew Murphy
6.1.1 Final	28 April 2022	Updated user guide to correctly note NDRS full transition into NHS Digital from Public Health England	Andrew Murphy

Executive summary

The purpose of this document is to provide guidance intended to support all NHS Acute Trust providers of radiotherapy services in England, private facilities where delivery is funded by the NHS or IT software developers (both in-house and commercial system suppliers), to prepare for the implementation of the Radiotherapy Data Set (RTDS) v6.0 from April 2022.

This User Guide is one of a suite of documents to aid users in implementing the [RTDS Information Standard \(DAPB0111 Amd 84/2020\)](#). It includes all the data items in RTDS, 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 6.0 of the data set, which is available to download on the [RTDS website](#). It is important to note that there is a new website under construction by the National Disease Registration Service (NDRS), which will include pages dedicated to RTDS. An update to the landing page will be issued once launched.

Other guidance and supporting documents are also available on the English National Cancer Online Registration Environment (EnCORE) application programming interface ([API portal](#)).

Implementation of the Standard is carried out by the NDRS and the RTDS development team.

All Providers have access to their current monthly position via [CancerStats2](#) (NHS [HSCN connections](#) only), which is maintained by the NDRS. Examples of feedback given on the platform include:

- events (Attendances/Episodes/Prescriptions)
- radiotherapy machine reports
- intensity-modulated radiation therapy (IMRT)
- geography: England split by radiotherapy centre

Where a word or name is [highlighted](#), this indicates that there is an embedded link that will take you to a webpage outside of this document or directs you to another page within this document that provides additional information. Please use this facility throughout the user guide, as this improves the accessibility for users with visual impairment or those using screen readers.

Background

The RTDS standard (DAPB0111) is an existing standard that has required all NHS Acute Trust providers of radiotherapy services in England or private facilities where delivery is funded by the NHS, to collect and submit standardised data monthly against a nationally defined data set since 2009.

There are currently 51 NHS Acute Trusts delivering external beam radiotherapy in England, many of which are also delivering at least one form of non-external beam radiotherapy. In addition, there are approximately 40 NHS funded sites who do not deliver external beam radiotherapy but are known to be delivering molecular radiotherapy treatments.

The purpose of the standard is to collect consistent and comparable data across all English providers of radiotherapy or private facilities where delivery is funded by the NHS, to produce a timely and definitive analytical resource of radiotherapy services across England.

The standard continues to provide intelligence to underpin the strategic objectives for radiotherapy services defined in the NHS England/Cancer Research UK [“Vision for Radiotherapy 2014 - 2024”](#).

The main recommendations of these reports are synthesised in the [Achieving World Class Cancer Outcomes Strategy for England 2015 - 2020](#), which indicates the main areas where data and information can underpin the monitoring and outcomes of key dimensions of the future development of radiotherapy in England.

In addition, the RTDS will support through analysis the ambitions within the NHS [‘Five Year Forward View’](#), that patients will have access to sustainable high-quality, modern radiotherapy treatments wherever they live.

RTDS data items

Key to Data Item Tables

All data items are listed as follows:

Header Item	Description of each header
Data item No.	The reference number for the RTDS data item
Data Item Section	The section in which the data item appears
Data Item Name	The name of the data item. Please refer to the data set and/or schema for the data dictionary names
Format	Format required for submission of the data item
Schema specification (M/R/O/P)	<p>The detailed process for submission of the data is included in the Technical Guidance.</p> <p>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.</p> <p>R - Required: This data item may not be applicable to every patient, their tumour or their pathway. Where it is applicable, it should be submitted as soon as possible but is not required to validate the submitted record.</p> <p>O - Optional: This item may be submitted at the discretion of the Provider.</p> <p>P - Pilot: For use in a pilot project only.</p>
Moved data items	All data items that have moved within the data set since the last version will be indicated using bullet points following each data item description.
New data items	All new data items for v9, or those with a new description or attribute in an existing data item, are indicated throughout the user guide either within the description or in bullet points following each data item description. In some data items this may also indicate a change in the data item number, format or schema specification.

ICD-10 CODES

The RTDS data items should be collected for all cancers and other registerable conditions where applicable, receiving external beam radiotherapy (teletherapy), brachytherapy,

proton therapy, radioisotope therapy (including radioiodine) and molecular radiotherapy using this data set. See Appendix [A](#) to [B](#) for the full lists of ICD10 codes.

RTDS data items in detail

In order to ensure that records submitted can be linked appropriately, some key data fields must be completed for each record submitted. These are set to mandatory.

Linkage

This is a new linkage group for version 6.0 and these items are mandatory for every record in order to link patient records. To ensure that records submitted can be linked appropriately, all data fields must be completed for each record submitted.

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

Linkage Group – Patient Identity Details

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

Linkage Identifier Choice

Choice 1..2

Choice 1

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
LG1	NHS Number	n10	M

End of Choice 1

Choice 2

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
LG2	Local Patient Identifier	min an1 max an20	M

End of Choice 2

End of Linkage Identifier Choice

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
LG3	NHS Number Status Indicator Code	an2	M
LG4	Person Birth Date	an10 cyy-mm-dd	M
LG5	Organisation Identifier (Code of Provider)	min an3 max an5	M

Almost all patients should have an NHS Number, and this must always be included (within the linkage section) where available. For those who do not have an NHS Number, the hospital number (Local Patient Identifier) must be provided.

Linkage Identifier Choice:

This is a new linkage section (choice) in version 6.0, to help improve the ascertainment and data quality of the RTDS treatment pathway. A combination of either NHS Number and/or Local Patient Identifier are mandatory for the submission of data. Both can be submitted, but a record cannot be submitted without at least one of these data items.

Choice 1:

NHS Number:

This is a new data item in version 6.0. 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.

Choice 2:

Local Patient Identifier:

This is a new data item in version 6.0. 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.

Notes:

- this has been added to the data set as not every patient will have an 'NHS Number' assigned to them
- without this additional item, we will miss vital RTDS treatment pathways

NHS Number Status Indicator Code:

This is a new data item in version 6.0. The NHS Number Status Indicator Code indicates the verification status of the NHS number provided.

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

Person Birth Date:

This is a new data item in version 6.0. 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):

This is a new data item in version 6.0. The 'Organisation Identifier' of the organisation acting as a health care provider (an6 not applicable to COSD). This is the 3 or 5-digit code of the organisation submitting the demographic details. This will therefore normally be either the organisation where the referral is received or the treating organisation.

Notes:

- there is a new code structure (ANANA) for new organisation identifiers allocated by ODS from 01 September 2020 onwards - codes issued prior to this date will not be converted
- more details can be found on the NHS Digital website using the following link [here](#)

Linkage Group – Diagnostic Details

This is a new linkage group in version 6.0, to help improve the ascertainment and data quality of the RTDS treatment pathway.

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

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
LG6	Radiotherapy Diagnosis (ICD)	min an4 max an6	M
LG7	Radiotherapy Diagnosis (SNOMED CT)	min n6 max n18	R
LG8	Tumour Laterality	an1	M

Radiotherapy Diagnosis (ICD):

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

Notes:

- this data item moved from radiotherapy exposure (RE6) in version 5 to linkage group (LG6) in version 6.0 and is a mandatory data item

- the radiotherapy diagnosis is normally agreed at the MDT Meeting where the patient is discussed

Additional note:

- where the ICD10 code only has 3 characters, (C01), please add “X” as a ‘packing digit’ to meet the validation rules (for example C01.X, C07.X, C73.X etc.)

Radiotherapy Diagnosis (SNOMED CT):

‘Radiotherapy Diagnosis (SNOMED CT)’ is the SNOMED CT concept ID which is used to identify the clinical diagnosis given to the patient.

Notes:

- this is a new data item for version 6.0 and is a required data item
- although it is understood that not all Trusts will be able to report this initially, this is a requirement of NHS Digital and will futureproof the data set as SNOMED CT is rolled out across the NHS

NHS Digital have developed a SNOMED CT Browser at the following website <https://termbrowser.nhs.uk/>, which will help you identify the correct concept ID for the diagnosis using SNOMED CT.

This data item requires the SNOMED CT - Concept ID. Please refer to ‘[How to use termbrowser](#)’ and additional notes on ‘[How to find a Diagnosis](#)’ by clicking on the highlighted text, which will take you to that page within this document.

Tumour Laterality:

This is a new data item in version 6.0. Identifies the side of the body for a tumour relating to paired organs within a patient (This refers to the side of the body on which the cancer originates). For the ‘Central Nervous System’, the definition for bilateral is ‘evidence that the tumour is crossing the midline’.

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

Patient Group – Demographic Details

This is a new group in version 6.0, to help improve the ascertainment and data quality of the RTDS treatment pathway. 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.

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 submission (0..1)

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
PG1	Person Family Name	max an35	R
PG2	Person Given Name	max an35	R
PG3	Postcode of Usual Address	max an8	R
PG4	Person Stated Gender Code	an1	R
PG5	Administrative Category Code (Radiotherapy)	an2	R
PG6	Trust Internal System Patient ID	min an1 max an20	R
PG7	General Medical Practitioner (Specified)	an8	R
PG8	General Medical Practice Code (Patient Registration)	an6	R

Person Family Name:

This is a new data item in version 6.0. That part of a person's name which is used to describe family, clan, tribal group, or marital association.

Person Given Name:

This is a new data item in version 6.0. The forename(s) or given name(s) of a person.

Postcode Of Usual Address:

This is a new data item in version 6.0. The postcode of usual address nominated by the patient is the postcode with address association type of 'Main Permanent Residence' or 'Other Permanent Residence'

Person Stated Gender Code:

This is a new data item in version 6.0. Person's gender as self-declared (or inferred by observation for those unable to declare their 'Person Stated Gender').

National code	National code definition
1	Male
2	Female
9	Indeterminate (Unable to be classified as either male or female)
X	Not known (PERSON STATED GENDER CODE not recorded)

Administrative Category Code (Radiotherapy):

This is a new data item in version 6.0. The administrative category, which best describes the patient's administrative pathway.

National code	National code definition
01	NHS Patient
02	Private Patient
09	Not Known

Trust Internal System Patient ID:

This is a new data item in version 6.0. The ID used to identify the patient on the Trusts record and verify system.

General Medical Practitioner (Specified):

This is a new data item in version 6.0. 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.

Notes:

- this data item is not affected by the other changes to consultant codes throughout the dataset and has been agreed upon with NHS Digital
- you can find out more about what a PPD code is by [clicking this link](#)

General Medical Practice Code (Patient Registration):

This is a new data item in version 6.0. This is the code of the GP Practice that the patient is registered with.

Data Group – Radiotherapy Episode

This group has been refreshed in version 6.0, to help record accurately the actual RTDS treatment pathway. This group is required to carry the details of the radiotherapy episode.

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

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
RE1	Radiotherapy Episode Identifier	max an50	M
RE2	Decision to Treat Date (Radiotherapy Treatment Episode)	an10 ccyymm-dd	M
RE3	Earliest Clinically Appropriate Date	an10 ccyymm-dd	M
RE8	Referral Date	an10 ccyymm-dd	R

Note the following data items have been retired from version 6.0:

- Treatment Start Date (Radiotherapy Treatment Episode)
- Radiotherapy Intent

Note the following data items have been moved within a new group from version 6.0:

- Radiotherapy Diagnosis (ICD) – Linkage Group: Diagnostic Details
- Radiotherapy Prescription Priority – Data Group: Radiotherapy Prescription

Radiotherapy Episode Identifier:

This is the identifier that is used to identify the 'Radiotherapy Episode' on the radiotherapy record and verify system.

Decision To Treat Date (Radiotherapy Treatment Episode):

Record the date on which it was decided that the patient required a specific planned radiotherapy treatment episode. This is the date that the consultation between the patient and the clinician took place and a planned radiotherapy treatment episode was agreed.

Earliest Clinically Appropriate Date:

This is the first date that the patient would have been available to start radiotherapy.

Referral Date:

This is a new data item for version 6.0. Record the date the patient was referred to the radiotherapy department.

Data Group: Radiotherapy Prescription

This group has been refreshed in version 6.0, to help record accurately the actual RTDS treatment pathway. This group is required to carry the details of each radiotherapy Prescription.

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

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
RP1	Radiotherapy Prescription Identifier	max an50	M
RP2	Radiotherapy Treatment Region	max an2	M
RP3	Anatomical Treatment Site (Radiotherapy)	an4	M
RP9	Radiotherapy Treatment Modality	an1	M
RP10	Radiotherapy Prescription Priority	an1	M

Start of Section - Radiotherapy Prescribed Authorising Clinician

Section 0..1

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
RP11	Professional Registration Issuer Code - Radiotherapy Prescribed Authorising Clinician	an2	M
RP12	Professional Registration Entry Identifier - Radiotherapy Prescribed Authorising Clinician	min an1 max an32	M

End of Section - Radiotherapy Prescribed Authorising Clinician

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
RP13	Radiotherapy Laterality (Anatomical Treatment Site)	an1	R
RP14	Royal College of Radiologists (RCR) Category	an1	R
RP15	Radiotherapy Routes and Methods of Administration	min n6 max n18	R
RP16	Practitioner Licence Holder	min an2 max an5	R

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
RP17	Organisation Identifier (Code of Organisation COMMISSIONED to Provide Activity)	min an3 max an5	R
RP18	Radiotherapy Intent of Treatment	an2	M
RP19	Prescribed Radiotherapy Clinical Trial	an1	R

Note the following data items have been retired from version 6.0:

- Number of Teletherapy Fields
- Actual Fractions

Note the following data items have been moved within a new group from version 6.0:

- Radiotherapy Prescribed Dose – Data Group: Radiotherapy Plan
- Prescribed Fractions – Data Group: Radiotherapy Plan
- Radiotherapy Actual Dose – Data Group: Radiotherapy Plan

Radiotherapy Prescription Identifier:

The identifier that is used to identify the 'Radiotherapy Prescription' on the radiotherapy record and verify system.

Note:

- This data item has a new data item name, previously 'Prescription Identifier'

Radiotherapy Treatment Region:

Record the specific area to be treated with radiotherapy.

National code	National code definition
P	Primary
R	Regional Nodes
PR	Primary & Regional Nodes
A	Non-anatomically specific primary site
O	Prophylactic (to non primary site)
M	Metastasis

Anatomical Treatment Site (Radiotherapy):

This is now a mandatory data item in version 6.0. Record the part of the body to which the RADIO THERAPY ACTUAL DOSE is administered.

Notes:

- use OPCS 'Z' codes for anatomical treatment site
- only to be complete for entries A, O or M in 'Radiotherapy Treatment Region' field

Radiotherapy Treatment Modality:

and identifies the correct treatment modality administered to the patient.

National code	National code definition
1	External Beam Radiotherapy (excluding Proton Therapy)
2	Brachytherapy
3	Proton Therapy
4	Radioisotope Therapy (including Radioiodine)
8	Other Treatment

Notes:

- this has a new format range, previously 'an2'
- '1', '2', '3', '4' and '8' are new attributes in version 6.0
- '05' and '06' has been removed from this data item attribute in version 6.0
- gamma knife machines should be recorded as modality 2 – Brachytherapy
- modality 2 – Brachytherapy, excludes radioisotopes

Radiotherapy Prescription Priority:

Record the priority for this course of therapy as classified by the requesting clinician

National code	National code definition
E	Emergency (treatment required within 24 hours)
U	Urgent (to include the Royal College of Radiologists Category I)
R	Routine (to include the Royal College of Radiologists Category II)
D	Elective delay (Treatment delayed for reason)

Note:

- this data item moved from Radiotherapy Episode (RE4) in version 5 to Radiotherapy Prescription (RP10) in version 6.0

New Section:

The following two data items have been grouped within a section, the section itself is required, however if you choose to record these data you must record both data items as they are mandatory within the section to maintain data quality standards.

Professional Registration Issuer Code – Radiotherapy Prescribed Authorising Clinician:
This is a new data item in version 6.0 and is a subset of a larger data item managed by NHS Digital.

Record the code which identifies the PROFESSIONAL REGISTRATION BODY for the consultant or health care professional who is the radiotherapy prescribed authorising clinician.

National code	National code definition
03	General Medical Council
08	Health and Care Professions Council

Professional Registration Entry Identifier – Radiotherapy Prescribed Authorising Clinician:
This is a new data item in version 6.0. Record the registration identifier allocated by an organisation for the consultant or health care professional who is the radiotherapy prescribed authorising clinician.

Radiotherapy Laterality (Anatomical Treatment Site):
This is a new data item in version 6.0. Record the side of the body relating to the treatment site where the treatment has been administered.

National code	National code definition
L	Left
R	Right
M	Midline
B	Bilateral
8	Not applicable
9	Not Known

Royal College of Radiologists (RCR) Category:
This is a new data item in version 6.0. Record the category of the patient, as defined by the RCR document linked here ["The timely delivery of radical radiotherapy: guidelines for the management of unscheduled treatment interruptions, Fourth Edition"](#)

National code	National code definition
1	Patients whom the RCR defines as having the tumour types for which there is evidence that prolongation of treatment affects outcome, and who are being treated radically with curative intent.
2	Patients whom the RCR defines as having slower growing tumour types, who are being treated radically, where interruptions in radiotherapy leading to an extension of overall treatment time of more than five days are detrimental to both local control and survival.
3	Patients being treated palliatively.

Radiotherapy Routes and Methods of Administration:

This is a new data item in version 6.0. Record the administration route and method for the treatment delivered.

Note:

- only required if 06 (brachytherapy) or 19 (radioisotope) is selected in the modality field RP9

NHS Digital have developed a SNOMED CT Browser at the following website <https://termbrowser.nhs.uk/>, which will help you identify the correct concept ID from the 'radiotherapy routes and methods of administration' reference set in SNOMED CT.

This data item requires the SNOMED CT - Concept ID found in the Radiotherapy routes and methods of administration reference set #51971000001109. Please refer to '[How to use termbrowser](#)' by clicking on the highlighted text, which will take you to that page within this document.

Practitioner Licence Holder:

This is a new data item in version 6.0. Record the licence number for the Practitioner who justified this therapy, which is issued by the Administration of Radioactive Substances Advisory Committee (ARSAC).

Note:

- this may not be required for all patients and is not applicable for any external beam treatments

Organisation Identifier (Code of Organisation Commissioned to Provide Activity):

This is a new data item in version 6.0. The organisation identifier (code of organisation commissioned to provide activity) is the organisation identifier of the organisation who have been commissioned to provide this activity.

Notes:

- this is only applicable for NHS activity

- this is not the same as the treating Trust, for example Barts are commissioned to deliver the treatment but Moorfields actually deliver the treatment

It is important to understand who has been commissioned by NHS England to provide radiotherapy. The Trust who actually treats the patient is inferred from other data already submitted elsewhere in the data set. This meant we did not have to include additional data items for this purpose and thus reduced the burden of data collection for the front line staff.

Radiotherapy Intent of Treatment:

This is a new data item in version 6.0. Record the intent of the treatment being delivered.

National code	National code definition
01	Adjuvant
02	Neoadjuvant
03	Radical (and either not adjuvant or neo adjuvant or not more specifically known)
04	Disease modifying (palliative)
05	Symptom controlling (palliative)
97	Other (non cancer treatment)
98	Other
99	Not Known

Prescribed Radiotherapy Clinical Trial:

This is a new data item in version 6.0. Record whether the Radiotherapy Prescription has been delivered to the patient as part of the radiotherapy clinical trial.

National code	National code definition
Y	Yes - this prescription was part of a radiotherapy clinical trial
N	No - this prescription was not part of a radiotherapy clinical trial
9	Not Known

Note:

- this can include any clinical trial containing radiotherapy, not just NIHR sanctioned trials

Data Group: Radiotherapy Plan

This is a new data group in version 6.0, to help improve the ascertainment and data quality of the RTDS treatment pathway. Required to carry the details of each radiotherapy Plan.

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

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
RPL1	Radiotherapy Plan Identifier	max an50	M
RPL2	Type of Plan	an1	R
RPL3	Date of Planning Appointment	an10 cyy-mm-dd	O
RPL4	Plan Name	max an50	R
RPL5	Specialist Radiotherapy Treatments	an2	R
RPL6	Other Specialist Radiotherapy Treatments	max an75	O

Start of Repeating Item - Radiotherapy Plan Procedure (OPCS)

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
RPL7	Radiotherapy Plan Procedure (OPCS)	an4	M

End of Repeating Item - Radiotherapy Plan Procedure (OPCS)

Start of Repeating Item - Radiotherapy Plan Procedure (SNOMED CT)

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
RPL8	Radiotherapy Plan Procedure (SNOMED CT)	max an100	R

End of Repeating Item - Radiotherapy Plan Procedure (SNOMED CT)

Start Of Repeating Item -Radiotherapy Plan Procedure (Code Capture Additional Procedures)

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
RPL9	Radiotherapy Plan Procedure (Code Capture Additional Procedures)	an2	R

End of Repeating Item -Radiotherapy Plan Procedure (Code Capture Additional Procedures)

Start of Repeating Item - Other Radiotherapy Plan Procedure (Code Capture Additional Procedures)

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
RPL10	Other Radiotherapy Plan Procedure (Code Capture Additional Procedures)	max an40	R

End of Repeating Item - Other Radiotherapy Plan Procedure (Code Capture Additional Procedures)

Start of Section - Radiotherapy Prescribed Dose

Section (0..1)

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
PRL11	Radiotherapy Prescribed Dose	max n4.max n4	M
RPL12	Radiotherapy Prescribed Dose Unit of Measurement (SNOMED CT DM+D)	min n6 max n18	M

End of Section - Radiotherapy Prescribed Dose

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
RPL13	Prescribed Fractions	max n2	M

Start of Section - Radiotherapy Actual Dose

Section (0..1)

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
RPL14	Radiotherapy Actual Dose	max n4.max n4	M
RPL15	Radiotherapy Actual Dose Unit of Measurement (SNOMED CT DM+D)	min n6 max n18	M

End of Section - Radiotherapy Actual Dose

Radiotherapy Plan Identifier:

This is a new data item in version 6.0. Record the identifier that is used to identify the 'Radiotherapy Plan' on the radiotherapy record and verify system.

Type of Plan:

This is a new data item in version 6.0. An indicator used to state whether the plan is for a new prescription or (if it represents a replan for an existing prescription), whether it represents the remainder of the prescription or the complete prescription, including that already delivered.

National code	National code definition
C	Complete - the plan represents a complete prescription, and includes the complete dose to be delivered in the prescription. It may be either a new original plan or a revised version of the plan, but represents the complete dose both delivered and to be delivered.
P	Partial - the plan represents an existing prescription, and includes only the remaining undelivered portion of the prescription (commonly known as a replan)

Date of Planning Appointment:

This is a new data item in version 6.0. Record date of the first planning appointment in the radiotherapy department attended by the patient.

Plan Name:

This is a new data item in version 6.0. Record the name given to the plan. This is the name given to the plan using a combination of Side/Site/Orientation, for example RTLUNGAP.

Specialist Radiotherapy Treatments:

This is a new data item in version 6.0 and identifies a specialist type of radiotherapy being delivered for the plan

National code	National code definition
01	Simple (direct or parallel opposed fields)
02	Conformal
03	Intensity-Modulated Radiation Therapy (IMRT) excluding more specific definitions
04	Rotational IMRT - Inc. Volumetric Modulated Arc Therapy (VMAT)/RapidArc
05	Intraoperative Radiation Therapy (IORT)
06	Total Body/Skin Radiotherapy - Inc. Total Body Irradiation (TBI) and Total Body Electrons (TBE)
07	Stereotactic Ablative Body Radiotherapy (SABR)
08	Stereotactic Radiotherapy/Radiosurgery (SRT/SRS) excluding SABR
09	Proactive Adaptive Radiotherapy - Inc. the Magnetic Resonance Linear Accelerator (MR-Linac)
10	Real-Time Adaptive Radiotherapy
11	Contact Radiotherapy
98	Other Treatment

The following descriptions help define and explain specialist radiotherapy treatment codes, which identifies a specialist type of radiotherapy being delivered for the plan.

The Specialist Radiotherapy Treatment code should record the intent of the treatment plan prior to the delivery of any radiotherapy for the specified plan. Should the intent or category change during the delivery of radiotherapy (for example, for an IMRT plan to become adaptive) the Specialist Radiotherapy Treatment code should not change – in the example given, it should continue to say IMRT.

Please also note this code should not be used instead of an OPCS planning code but should be recorded in addition. In addition, the OPCS codes given below are used as examples of treatments that may fit the categories, they should not be considered exhaustive examples of all possible code combinations.

Simple direct or parallel opposed field plans:

- for example, direct spine fields, anterior posterior hip fields or whole brain lateral treatments:
 - these treatment plans could utilise CT planning technology with virtual simulation for field placement but would not include isodose distribution manipulation
 - these types of treatment planning may be classified as either a X67.4 preparation for simple radiotherapy with imaging and dosimetry or X67.5 preparation for simple radiotherapy with imaging and simple calculation

Conformal plans:

- for example, tangential breast, oesophagus or lung plans that use Multi Leaf Collimators (MLC's) to conform the fields but not using IMRT:
 - a CT scan with or without additional imaging modalities, would be taken and the treatment planning system would be used to produce an isodose distribution
 - these types of treatment plans may be classified as X67.7 preparation for complex conformal radiotherapy

Intensity Modulated Radiotherapy (Excluding more specific definitions):

- for example, radical breast and prostate plans:
 - this is a form of specialist three-dimensional planning that allows each treatment beam planned to be divided into smaller beams or beamlets
 - the MLC's move across the radiation beam at different speeds and patterns modifying the intensity of the radiation while the treatment is being delivered
 - these types of plan may be classified as X67.1 preparation for intensity modulated radiation therapy

Rotational Intensity Modulated radiotherapy (Including Volumetric Modulated Arc Therapy, VMAT/RapidArc) (Excluding more specific definitions):

- for example, brain or head and neck treatment plans:
 - rotational IMRT plans are delivered where the radiation treatment is delivered continuously as the treatment machine rotates
 - this technique allows the treatment to be accurately shaped while minimising dose to organs surrounding the tumour
 - these types of plans may be classified as X67.1 preparation for intensity modulated radiation therapy

Intraoperative Radiation therapy:

- for example, used for breast tumour treatments during surgery:
 - the treatments are used directly after surgery to remove a tumour prior to the excision site being closed
 - the technique involves the precise application of a high dose of radiation to the target volume area or region of interest, with minimal exposure to healthy tissue, which can be displaced or protected during the procedure
 - these types of plans may be classified as X68.2 preparation for intracavity brachytherapy

Total Body Irradiation (TBI):

- for example, may be used for the treatment of leukaemia, myeloma and lymphoma:
 - the radiotherapy treatment plan irradiates the whole body either as a single fraction or a fractionated regime depending on the condition being treated
 - these types of plan may be classified as X67.2 preparation for total body irradiation

Stereotactic Ablative Body Radiotherapy (SABR):

- this category should be selected for any stereotactic plans delivered to the body excluding intracranial treatments
- for example, for lung and oligometastatic lesions:
 - the radiotherapy treatment plans account for any tumour motion and enhanced immobilisation devices may be used
 - the dose distribution tightly covers the tumour with steep dose gradients away from surrounding tissues and organs
 - SABR plans will be delivered using IMRT or VMAT technologies
 - these types of plans may be classified as X67.1 preparation for intensity modulated radiation therapy

Stereotactic Radiotherapy/Radiosurgery (excluding SABR) (Excluding more specific definitions):

- this category should be selected for any plans delivered to the intracranial region excluding SABR body treatments

- for example, for brain metastases and oligometastatic lesions:
 - the radiotherapy treatment plans account for any tumour motion and enhanced immobilisation devices may be used
 - the dose distribution tightly covers the tumour with steep dose gradients away from surrounding tissues and organs
 - Stereotactic plans will be delivered using IMRT or VMAT technologies
 - these types of plans may be classified as X67.1 preparation for intensity modulated radiation therapy

Adaptive radiotherapy (including magnetic resonance linear accelerator) for example, plan of the day treatments or MRI linac treatments, are referring to a specific type of planning to use an adaptive approach from the outset of treatment.

This would not include patients of which the only form of adaptive radiotherapy delivered to them during their prescription was, reactive adaptive radiotherapy. The reactive adaptive radiotherapy plans, are plans that are only adapted during treatment, and after the initial planning stage, as a reaction based on the results of on treatment verification imaging. For example, due an unexpected contour change.

The majority of reactive adaptive radiotherapy, would be expected to be classified as IMRT or VMAT plans. All plans in which the only type of adaptive radiotherapy is delivered is reactive adaptive radiotherapy, should not be categorised as adaptive.

The specialist radiotherapy treatment defines adaptive radiotherapy as four categories. Of these four categories, three of these would have the expectation of being coded as an adaptive treatment for the specialist radiotherapy treatment item. Plans that would be included in the adaptive category may be classified as X67.1 preparation for intensity modulated radiation therapy.

Treatments coded as an adaptive treatment plan for the specialist radiotherapy treatment item, fall into three sub types as follows:

Scheduled Adaptive Radiotherapy:

- schedules re-planning in advance for predictable or extremely likely changes
- for example, this approach may be used for a head and neck treatment plan:
 - there may be small changes that can be monitored over time and at certain time periods a replan can be undertaken

Proactive Adaptive Radiotherapy:

- predicts changes likely to occur for example for plan of the day bladder treatments:

- a library of plans is prepared to compensate for these changes

Real-time Adaptive Radiotherapy:

- it is expected that this will predominantly be used for MRI linac treatment plans:
 - the prescription is created with the intent that the clinician will be producing new plans as and when they are required while the patient is on the treatment couch
 - this could be every fraction or when required
 - the important distinction between this and Reactive Adaptive Radiotherapy is that there is an intention by the prescribing clinician at the point of prescribing the treatment to take this approach to the delivery of the treatment

In addition, the following is not planned as adaptive:

Reactive Adaptive Radiotherapy:

- acts on observed changes which may have been highlighted during treatment verification

This ends the more detailed descriptions on specialist radiotherapy treatments.

Other Specialist Radiotherapy Treatments:

This is a new data item in version 6.0. Specify any other specialist radiotherapy treatment, which is not listed in either RP9 or RPL5

Radiotherapy Plan Procedure (OPCS):

This is new data item and is mandatory in version 6.0, and multiple procedures can be recorded. Record the radiotherapy procedure(s) as described within the plan using OPCS.

Note:

- this maybe recorded in addition to 'Radiotherapy Plan Procedure (SNOMED CT)'

Radiotherapy Plan Procedure (SNOMED CT):

This is a new data item and is required in version 6.0, and multiple procedures can be recorded. Record the radiotherapy procedure(s) as described within the plan using SNOMED CT.

Notes:

- this maybe recorded in addition to 'Radiotherapy Plan Procedure (OPCS)'

- this is a requirement of NHS Digital and will futureproof the data set as SNOMED CT is rolled out across the NHS from April 2022

NHS Digital have developed a SNOMED CT Browser at the following website <https://termbrowser.nhs.uk/>, which will help you identify the correct concept ID for the procedure(s) using SNOMED CT.

This data item requires the SNOMED CT - Concept ID. Please refer to '[How to use termbrowser](#)' and additional notes on '[How to find a Procedure](#)' by clicking on the highlighted text, which will take you to that page within this document.

Radiotherapy Plan Procedure (Code Capture Additional Procedures):

This is a new data item in version 6.0 and is a repeating data item. Record the radiotherapy plan procedures that are required for the accurate radiotherapy plan which are not currently defined in OPCS or SNOMED CT codes (indicated on code list)

National code	National code definition
01	CT Planning 4D scan
02	CT Planning 4D scan with contrast
03	CT Planning 3D scan
04	CT Planning 3D scan with contrast
05	MRI Planning 3D scan
06	MRI Planning 4D scan
07	Active Breathing Control (ABC)
08	Deep Inspiration breath hold (DIBH)
09	Abdominal compression device
10	Fiducial markers
11	Rectal spacer
12	Surface guided imaging
13	Ultrasound guided imaging
14	PET CT scan for the purpose of radiotherapy planning
15	PET MRI scan for the purpose of radiotherapy planning
98	Other

Note:

- these codes should be recorded in addition to planning OPCS or SNOMED CT codes

Other Radiotherapy Plan Procedure (Code Capture Additional Procedures):

This is a new data item in version 6.0 and is a repeating data item. If '98 - Other' selected in RPL9, specify any other 'Additional Plan Procedures', which are currently not listed

New Section:

The following two data items have been grouped within a section, the section itself is required, however if you choose to record these data you must record both data items as they are mandatory within the section to maintain data quality standards.

Radiotherapy Prescribed Dose:

Record the total prescribed absorbed radiation dose.

Note:

- this data item has moved from prescription (RP5) in version 5 to Plan (RPL11) in version 6.0 and has an updated format to provide improved data quality

Radiotherapy Prescribed Dose Unit of Measurement (SNOMED CT DM+D):

This is a new data item for version 6.0. Record the total prescribed radiation dose measurement using SNOMED CT® to identify the unit of measurement.

Note:

- this is a requirement of NHS Digital and will futureproof the data set as SNOMED CT® is rolled out across the NHS from April 2022

NHS Digital have developed a SNOMED CT Browser at the following website <https://termbrowser.nhs.uk/>, which will help you identify the correct concept ID for the radiotherapy prescribed dose using SNOMED CT.

This data item requires the SNOMED CT - Concept ID found in the Radiotherapy units of measure simple reference set #31491000001101. Please refer to 'How to use [termbrowser](#)' by clicking on the highlighted text, which will take you to that page within this document.

Prescribed Fractions:

Record the prescribed number of Radiotherapy Fractions delivered to the PATIENT as described in the Radiotherapy Plan.

Notes:

- this data item has a new format – previously 'n3'
- this data item has moved from prescription (RP6) in version 5 to Plan (RPL13) in version 6.0 and has an updated description and format to provide improved data quality

New Section:

The following two data items have been grouped within a section, the section itself is required, however if you choose to record these data you must record both data items as they are mandatory within the section to maintain data quality standards.

Radiotherapy Actual Dose:

Record the total actual absorbed radiation dose

Notes:

- this data item has a new format – previously 'max n3.max n2'
- this data item has moved from prescription (RP7) in version 5 to Plan (RPL14) in version 6.0 and has an updated format to provide improved data quality

Radiotherapy Actual Dose Unit of Measurement (SNOMED CT DM+D):

This is a new data item for version 6.0. Record the total actual absorbed radiation dose measurement using SNOMED CT® concept ID to identify the unit of measurement.

Note:

- this is a requirement of NHS Digital and will futureproof the data set as SNOMED CT is rolled out across the NHS from April 2022

NHS Digital have developed a SNOMED CT Browser at the following website <https://termbrowser.nhs.uk/>, which will help you identify the correct concept ID for the radiotherapy actual dose using SNOMED CT.

This data item requires the SNOMED CT - Concept ID found in the Radiotherapy units of measure simple reference set #31491000001101. Please refer to 'How to use [termbrowser](#)' by clicking on the highlighted text, which will take you to that page within this document.

Data Group: Radiotherapy Exposure

This group has been refreshed in version 6.0, to help record accurately the actual RTDS treatment pathway. This group is required to carry the details of each radiotherapy exposure.

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

Data item No.	RADIOTHERAPY EXPOSURE IDENTIFIER	Format	Schema specification (M/R/O/P)
RX1	Radiotherapy Exposure Identifier	max an50	M

Data item No.	RADIOTHERAPY EXPOSURE IDENTIFIER	Format	Schema specification (M/R/O/P)
RX2	Machine Identifier	max an12	R
RX3	Radiotherapy Beam Type	an2	R

Start of Section - Radiotherapy Beam Energy

Section (0..1)

Data item No.	RADIOTHERAPY EXPOSURE IDENTIFIER	Format	Schema specification (M/R/O/P)
RX4	Radiotherapy Beam Energy	max n6	M
RX7	Radiotherapy Beam Energy Unit of Measurement (SNOMED CT DM+D)	min n6 max n18	M

End of Section - Radiotherapy Beam Energy

Data item No.	RADIOTHERAPY EXPOSURE IDENTIFIER	Format	Schema specification (M/R/O/P)
RX5	Time and Date of Exposure	max an25	M

Radioisotope Choice

Choice 0..2

Radioisotope Choice 1

Data item No.	RADIOTHERAPY EXPOSURE IDENTIFIER	Format	Schema specification (M/R/O/P)
RX6	Radioisotope	max an6	R

End of Radioisotope Choice 1

Radioisotope Choice 2

Data item No.	RADIOTHERAPY EXPOSURE IDENTIFIER	Format	Schema specification (M/R/O/P)
RX8	Radiopharmaceutical Procedure (SNOMED CT)	min n6 max n18	R

End of Radioisotope Choice 2

End of Radioisotope Choice

Radiotherapy Exposure Identifier:

Record the identifier that is used to identify the 'Radiotherapy Exposure' on the radiotherapy record and verify system.

Note:

- this data item has a new name - previously 'Radiotherapy Field Identifier'

Machine Identifier:

A unique code ascribed to the radiotherapy equipment used to deliver this exposure. This is the unique code used to describe this machine as assigned by NCRAS (or historically NATCANSAT).

Radiotherapy Beam Type:

The prescribed type of beam for a radiotherapy exposure.

National code	National code definition
T1	Photon
T2	Electron
T8	Proton Only
T9	Other

Note:

- 'T3 - Other' has been removed from this data item attribute in version 6.0
- 'T8' and 'T9' are new attributes in version 6.0

New Section:

The following two data items have been grouped within a section, the section itself is required, however if you choose to record these data you must record both data items as they are mandatory within the section to maintain data quality standards.

Radiotherapy Beam Energy

Record the prescribed beam energy of a radiotherapy exposure used in external radiation therapy from the three types of particles as outlined in RX3.

Note:

- this data item has a new format – previously 'max n3.max n3'
- this data item is now a mandatory data item in version 6.0

Radiotherapy Beam Energy Unit of Measurement (SNOMED CT DM+D):

This is a new data item for version 6.0. Record the radiotherapy beam energy unit of measurement using SNOMED CT® concept ID to identify the unit of measurement.

Note:

- this is a requirement of NHS Digital and will futureproof the data set as SNOMED CT is rolled out across the NHS from April 2022

NHS Digital have developed a SNOMED CT Browser at the following website <https://termbrowser.nhs.uk/>, which will help you identify the correct concept ID for the radiotherapy beam energy unit of measurement using SNOMED CT.

This data item requires the SNOMED CT - Concept ID found in the Radiotherapy units of measure simple reference set #31491000001101. Please refer to 'How to use [termbrowser](#)' by clicking on the highlighted text, which will take you to that page within this document.

Time and Date of Exposure:

Record the time and date when the exposure was initiated.

Notes:

- this data item has a new name - previously 'Time of Exposure'
- this data item has a new format - previously 'HH:MM:SS'
- timestamps are now requested for this data item instead of 'Date and Time' to ensure clinical date and time information is recorded correctly, for example coded observation timestamp
- please refer to the following webpage for more information: https://v3.datadictionary.nhs.uk/data_dictionary/data_field_notes/c/co/coded_observation_timestamp_de.asp?shownav=1.

Choice: The following two data items form a new radiotherapy exposure radioisotope section (choice) in version 6.0, to help improve the ascertainment and data quality of the RTDS treatment pathway.

You can select either Radioisotope as currently defined by the RTDS team or Radiopharmaceutical Procedure (SNOMED CT). This section is only completed for those patients where radioisotopes are used as part of their delivered treatment.

Choice 1

Radioisotope:

Record the type of radioisotope used to deliver radiotherapy where an isotope is used (including brachytherapy and molecular), as current defined by the RTDS team.

Choice 2

Radiopharmaceutical Procedure (SNOMED CT):

This is a new data item in version 6.0. Record the type of radiopharmaceutical procedure used to deliver radiotherapy where an isotope is used (including brachytherapy and molecular) using SNOMED CT, this maybe recorded in addition to RX6.

Note:

- this is a requirement of NHS Digital and will futureproof the data set as SNOMED CT is rolled out across the NHS from April 2022

NHS Digital have developed a SNOMED CT Browser at the following website <https://termbrowser.nhs.uk/>, which will help you identify the correct concept ID for the radioisotope using SNOMED CT.

This data item requires the SNOMED CT - Concept ID, and a new SNOMED CT reference set is being created to collect these data. Please refer to 'How to use [termbrowser](#)' by clicking on the highlighted text, which will take you to that page within this document.

Whilst we wait for a SNOMED CT Reference Set to be created by NHS Digital, the following reference table will help support the correct reporting of radiopharmaceutical procedures using SNOMED CT procedure codes:

Nuclide	Chemical	Indication	SNOMED CT ID
131I	Iodine	treatment of benign thyroid disease	228698009
131I	Iodine	treatment of carcinoma of thyroid	431534004
131I	MIBG	treatment of malignancy	228700000
153Sm	EDTMP	treatment of bone metastases	427561000119104
169Er	colloid	treatment of arthritis	1363421000000108
177Lu	DOTATATE / DOTATOC / DOTANOC	treatment of neuroendocrine malignancy	1103661000000108
186Re	colloid	treatment of arthritis	1363431000000105
186Re	HEDP	treatment of bone metastases	433224001
223Ra	dichloride	treatment of bone metastases in castration resistant prostate cancer	16554931000119102
32P	phosphate	treatment of polycythemia vera and related disorders	228699001
89Sr	chloride	treatment of bone metastases	16554781000119103
90Y	colloidal silicate/citrate	treatment of arthritis	817761000000104
90Y	DOTATATE / DOTATOC / DOTANOC	treatment of neuroendocrine malignancy	431743005
90Y	microspheres	treatment of hepatic malignancy	764677008

Important notes:

- report only the 'SNOMED CT ID' concept code in your local system
- if new procedures become routine practice in the NHS, these will be added to the list and the user guide updated
- only routinely used radiopharmaceutical procedures are listed in SNOMED CT
- research procedures are currently not reportable

Data Group: Radiotherapy Attendance

This is a new data group in version 6.0, to help improve the ascertainment and data quality of the RTDS treatment pathway. Required to carry the details of the Radiotherapy Attendance.

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

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
RA1	Radiotherapy Attendance Identifier	max an50	M
RA2	Admitted Patient Attendance Indicator	an1	R
RA3	Radiotherapy Attendance Date and Time	an19 YYYY-MM-DDThh:mm:ss	M

Start of Repeating Item - Attendance Procedure (OPCS)

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
RA4	Radiotherapy Attendance Procedure (OPCS)	an4	M

End of repeating item - Attendance Procedure (OPCS)

Start of repeating item - Attendance Procedure (SNOMED CT)

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
RA5	Radiotherapy Attendance Procedure (SNOMED CT)	min n6 max n18	R

End of Repeating Item - Attendance Procedure (SNOMED CT)

Start of Repeating Item - Attendance Procedure (Code Capture Other Procedures)

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
RA6	Radiotherapy Attendance Procedure (Code Capture Additional Procedures)	an2	R

End of repeating item - Attendance Procedure (Code Capture Other Procedures)

Data item No.	Data Item Name	Format	Schema specification (M/R/O/P)
RA7	Other Radiotherapy Attendance Procedure (Code Capture Additional Procedures)	max an40	R
RA8	Local Version Number (Attendance)	max an5	R

Radiotherapy Attendance Identifier:

This is a new data item in version 6.0. Record the identifier that is used to identify the 'Radiotherapy Attendance' on the radiotherapy record and verify system.

Note:

- this data item is a mandatory data item in version 6.0

Admitted Patient Attendance Indicator:

This is a new data item in version 6.0. An indication of whether the Radiotherapy treatment was delivered while the patient is also an admitted patient at either the Treating or another Health Care Provider.

National code	National code definition
Y	Yes - the patient is an admitted patient
N	No - the patient is not an admitted patient
9	Not Known

Radiotherapy Attendance Date and Time:

This is a new data item in version 6.0. Record the date and time that the patient arrived for the radiotherapy attendance documented in this section.

Note:

- this data item is a mandatory data item in version 6.0

Radiotherapy Attendance Procedure (OPCS):

This is a new data item, and multiple procedures can be recorded in version 6.0. Record the procedure(s) carried out using OPCS, this maybe recorded in addition to Radiotherapy Attendance Procedure (SNOMED CT).

Note:

- this data item is a mandatory data item in version 6.0

Radiotherapy Attendance Procedure (SNOMED CT):

This is a new data item in version 6.0, and multiple procedures can be recorded. Record the procedure(s) carried out using SNOMED CT, this maybe recorded in addition to Radiotherapy Attendance Procedure (OPCS).

Note:

- this is a requirement of NHS Digital and will futureproof the data set as SNOMED CT is rolled out across the NHS from April 2022

NHS Digital have developed a SNOMED CT Browser at the following website <https://termbrowser.nhs.uk/>, which will help you identify the correct concept ID for the procedure(s) using SNOMED CT.

This data item requires the SNOMED CT - Concept ID. Please refer to '[How to use termbrowser](#)' and additional notes on '[How to find a Procedure](#)' by clicking on the highlighted text, which will take you to that page within this document.

Radiotherapy Attendance Procedure (Code Capture Additional Procedures):

This is a new data item in version 6.0. This is a repeating data item and allows the user to select codes for procedures not clearly defined in the OPCS or SNOMED CT. For codes designating a delivery of radiotherapy, the appropriate OPCS or SNOMED CT code must also be supplied (indicated on code list).

National code	National code definition
01	Imaging KV2D
02	Imaging KV3D
03	Imaging KV4D
04	Imaging MV2D
05	Imaging MV3D
06	MRI verification image
07	Active Breathing Control (ABC)
08	Deep Inspiration breath hold (DIBH)
09	Fiducial markers
10	Rectal spacer
11	Abdominal compression device
12	Surface guided imaging
13	Ultrasound guided imaging
98	Other

Other Radiotherapy Attendance Procedure (Code Capture Additional Procedures):

This is a new data item in version 6.0. If '98 - Other' selected in RA6 (above), specify any other 'Additional Radiotherapy Attendance Procedures', which are currently not listed.

Local Version Number (Attendance):

This is a new data item in version 6.0. Record the local record and verify system version number, currently being used by the Health Care Provider submitting the data.

What's changed since version 5.0

This 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 should be used to help data collection.

Although the overall size of the data set has increased, from 26 to 65 data items, by removing the additional requirement of collecting up-to 99 supporting data set items from the Commissioning Data Set (CDS), the overall size of the data set requested within RTDS version 6.0 has reduced by up-to 60 data items.

The following are the deleted items from version 5:

- Treatment Start Date (Radiotherapy Treatment Episode)
 - no longer required for RTDS
- Radiotherapy Intent
 - replaced with RP18 -Radiotherapy Intent of Treatment
- Number of Teletherapy Fields
 - no longer required for RTDS
- Actual Fractions
 - no longer required for RTDS

The following data items have been moved within RTDS to improve data quality:

- Radiotherapy Diagnosis (ICD)
 - now part of the mandatory linkage section
- Radiotherapy Priority
 - now part of the radiotherapy prescription section
- Radiotherapy Prescribed Dose
 - now part of the radiotherapy plan section
- Prescribed Fractions
 - now part of the radiotherapy plan section
- Radiotherapy Actual Dose
 - now part of the radiotherapy plan section

The following are the new items for version 6.0, these were all discussed within the RTDS User Group and Radiotherapy Information Strategy Group (RISG) following extensive consultation:

- NHS Number
 - new data item required to improve linkage and ascertainment for all records submitted, where available this MUST be provided
- Local Patient Identifier
 - new data item required to allow for records to be submitted where there is no NHS Number

- NHS Number Status Indicator Code
 - new data item required to identify if a records' NHS Number has been traced prior to submission
- Person Birth Date
 - new data item required to support additional patient identification/matching and tracing if required
- Organisation Identifier (Code of Provider)
 - new data item required to identify the organisation submitting the data
- Radiotherapy Diagnosis (SNOMED CT)
 - allows for a SNOMED CT diagnosis code (if known) to be recorded, required to comply with Information Standard SCCI0034
- Tumour Laterality
 - new data item required to support additional patient identification/matching and tracing if required
- Person Family Name
 - new data item required to allow for better patient matching and analysis
- Person Given Name
 - new data item required to allow for better patient matching and analysis
- Postcode of Usual Address
 - new data item required to allow for better patient matching and analysis
- Person Stated Gender Code
 - new data item required to allow for better patient matching and analysis
- Administrative Category Code (Radiotherapy)
 - new data item to identify the patient's administrative pathway
- Trust Internal System Patient ID
 - new data item accessible from all systems, identifying the patients assigned ID
- General Medical Practitioner (Specified)
 - new data item required to allow for better patient matching and analysis
- General Medical Practice Code (Patient Registration)
 - new data item required to allow for better patient matching and analysis
- Referral Date
 - new data item required to understand when the patient was referred to the radiotherapy department

- Professional Registration Issuer Code – Radiotherapy Prescribed Authorising Clinician
 - this is an enforced change throughout all new data sets by NHS Digitals' NHS Data Model and Dictionary Service
- Professional Registration Entry Identifier – Radiotherapy Prescribed Authorising Clinician
 - this is an enforced change throughout all new data sets by NHS Digitals, NHS Data Model and Dictionary Service
- Radiotherapy Laterality (Anatomical Treatment Site)
 - new data item required to identify the side of the body relating to the treatment site, where the treatment has been administered
- Royal College of Radiologists (RCR) Category
 - new data item to help understand the category of the patient, as defined by the RCR document
- Radiotherapy Routes and Methods of Administration
 - new data item required to record the administration route and method for the treatment delivered, as defined within a new SNOMED CT reference set # 51971000001109
- Practitioner Licence Holder
 - new data item required to record the Identification number for the Practitioner licence holder who justified this therapy
- Organisation Identifier (Code of Organisation Commissioned to Provide Activity)
 - new data item required to record the organisation commissioned to provide the activity
- Radiotherapy Intent of Treatment
 - new data item which better outlines the intent of treatment for radiotherapy being delivered
- Prescribed Radiotherapy Clinical Trial
 - new data item required to record whether this prescription is part of a trial that has a component of radiotherapy delivery included
- Radiotherapy Plan Identifier
 - new data item which specifies the unique identifier for each radiotherapy plan
- Type of Plan
 - new data item which specifies the type of plan to be recorded
- Date of Planning Appointment
 - new data item identifying the date of the first planning appointment in the radiotherapy department attended by the patient
- Plan Name
 - new data item allowing the name given to the plan to be recorded

- Specialist Radiotherapy Treatments
 - new data item required to identify a specialist type of radiotherapy being delivered for the prescription
- Other Specialist Radiotherapy Treatments
 - new data item to record any other external beam specialist radiotherapy treatment, which is not listed in either PR9 or PRL5
- Radiotherapy Plan Procedure (OPCS)
 - new data item to record the procedure(s) carried out using OPCS. This maybe recorded in addition to Radiotherapy Plan Procedure (SNOMED CT)
- Radiotherapy Plan Procedure (SNOMED CT)
 - new data item to record the procedure(s) carried out using SNOMED CT. This maybe recorded in addition to Radiotherapy Plan Procedure (OPCS)
- Radiotherapy Plan Procedure (Code Capture Additional Procedures)
 - new data item allowing the use of codes for procedures not clearly defined in the OPCS or SNOMED CT
- Other Radiotherapy Plan Procedure (Code Capture Additional Procedures)
 - new data item allowing the use of codes for procedures not clearly defined in RPL9
- Radiotherapy Prescribed Dose Unit of Measurement (SNOMED CT DM+D)
 - new data item to record the total prescribed radiation dose measurement, as defined within a new SNOMED CT reference set # 31491000001101
- Radiotherapy Actual Dose Unit of Measurement (SNOMED CT DM+D)
 - new data item required to accurately record the total actual absorbed radiation dose measurement, as defined within a new SNOMED CT reference set # 31491000001101
- Radiotherapy Beam Energy Unit Of Measurement (SNOMED CT DM+D)
 - new data item required to accurately record the total actual beam energy radiation dose measurement, as defined within a new SNOMED CT reference set # 31491000001101
- Radiopharmaceutical Procedure (SNOMED CT)
 - this is a new data item that accurately identifies the radiopharmaceutical procedure as defined within SNOMED CT
 - a new SNOMED CT reference set will be created, in the meantime use the table within the user guide above (pg34)
- Radiotherapy Attendance Identifier
 - new data item accessible from all systems, identifying the patients assigned attendance ID

- Admitted Patient Attendance Indicator
 - new data item to record whether the Radiotherapy treatment was delivered while the patient was also an Inpatient at either the Treating or another Health Care Provider
- Radiotherapy Attendance Date and Time
 - new data item allowing the date and time to be recorded when the patient arrived for their radiotherapy attendance appointment
- Radiotherapy Attendance Procedure (OPCS)
 - new data item to record the procedure(s) carried out using OPCS, this maybe recorded in addition to Radiotherapy Attendance Procedure (SNOMED CT)
- Radiotherapy Attendance Procedure (SNOMED CT)
 - new data item to record the procedure(s) carried out using SNOMED CT, this maybe recorded in addition to Radiotherapy Attendance Procedure (OPCS)
- Radiotherapy Attendance Procedure (Code Capture Additional Procedures)
 - new data item allowing the use of codes for procedures not clearly defined in the OPCS or SNOMED CT
- Other Radiotherapy Attendance Procedure (Code Capture Additional Procedures)
 - new data item allowing the use of codes for procedures not clearly defined in RA6
- Local Version Number (Attendance)
 - new data item to record the local version number of the format of the extract containing this attendance

There have been other changes to data items as well to improve the data requested, all of which are clearly explained in the data set itself, the main area of changes are as follows:

- amended attributes
- amended format
- description changes
- element name changes
- name changes
- schema specification

These changes also help to reduce the burden of data collected wherever possible and improve the quality of the data being requested. New analysis and reports will be created to monitor and improve the data ascertainment and address issues where there are local difficulties in collecting any of the new or changed data items.

Who does RTDS apply to:

This standard specifies a data set for use at both national and local levels to generate secondary uses information about radiotherapy treatment, to assist in achieving, supporting and monitoring the NHS Operating Framework, specialist commissioning and related policies.

All patients receiving radiotherapy in or funded by the NHS in England are covered by the standard. This includes adult and paediatric cancer patients receiving radiotherapy, in acute inpatient, day-case and outpatient settings for solid tumours and haematological malignancies, including patients in clinical trials.

RTDS applies to the following key groups and organisations:

- NHS acute providers of radiotherapy services and all other providers of NHS commissioned radiotherapy services
- developers and suppliers of electronic systems for use within NHS acute providers of radiotherapy services
- organisations purchasing radiotherapy linear accelerator radiotherapy machines (LINAC) for use in NHS commissioned cancer centres and NHS acute providers of radiotherapy services

Data users of radiotherapy at both national and local levels, include:

At a national level:

- National Cancer Registration and Analysis Service (NCRAS)
- Department of Health and Social Care (DHSC)
- National Disease Registration Service (NDRS)
- NHS England and NHS Improvement
- Care Quality Commission (CQC)
- NHS Digital

At a local level:

- radiotherapy operational delivery networks (ODN's)
- commissioners and providers
- cancer alliances/vanguards
- local NCRAS offices

Implementation start and full conformance timeline

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

- implementation will be between 20 July 2021 and 31 March 2022 (8 months)

- data collection will start from 1 April 2022 (with a 3-month roll-out period between 1 April 2022 and 30 June 2022)
- full conformance from 1 July 2022

Supporting documents

All the documents referred to were submitted to the Data Standards Assurance Service (DSAS) for review under DAPB0111 Amd 84/2020.

Following acceptance by the Data Alliance Partnership Board (DAPB) and confirmation of authority to publish by the Department of Health and Social Care, the official Information Standards Notice (ISN) and related documents was published on the 20 July 2021.

This user guide should be read in conjunction with the following documents, available at the designated website:

<http://www.digital.nhs.uk/isce/publication/dapb0111>:

- specification
- change request
- implementation guide
- information standard notice

http://www.ncin.org.uk/collecting_and_using_data/rtds:

- RTDS data set v6.0
- RTDS v6.0 technical guide

<https://nww.api.encore.nhs.uk/>:

- RTDS v6.0 Portal User Guide

These documents are intended to support providers and developers who wish to identify and plan changes to their systems. The standard will be formally issued via DAPB as an approved standard.

Please note that there is currently a new National Disease Registration Service (NDRS) website under construction and all RTDS publications will be accessible from there. Details of this launch and URL will be published in due course, RTDS will have a permanent section within this new website.

Related standards

The following should also be read in conjunction with this information standard:

- DCB0084 [OPCS Classification of Interventions and Procedures](#)

- DCB1521 [Cancer Outcome and Services Data Set](#)
- DCB1533 [Systemic Anti-Cancer Therapy Data Set](#)
- SCCI0021 [International Classification of Diseases](#)
- SCCI0034 [SNOMED CT](#)

Contacts

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

- RTDS helpdesk email address – rtds.helpdesk@nhs.net
- RTDS helpdesk telephone number – 01865 458350

Mapping local data to the RTDS information standard

There is no requirement to modify local clinical practices or data recording, however local system managers will be required to map local nomenclature and data formats to those defined in the RTDS information standard before transmission.

Provider organisations are encouraged to review the content of the standard and consider whether making primary data recording consistent with the standard would benefit their services in terms of safety and efficiency.

Note: This version change incorporates many data items previously requested from the Commissioning Data Set (CDS) as supporting data, but not mandated through the information standard. This protects the data set moving forward and prevents the RTDS and CDS being out of sequence with each other's development cycles.

Clinical terminology integration within RTDS

Why are we integrating clinical terminologies within the RTDS?

using SNOMED CT to capture outcome measures reduces the need for individual tables for each measure. In addition:

- a single table can capture multiple measures using a common structure
- the data set can respond more quickly to changes in clinical practice and information requirements
- terminology is updated at regular intervals and the data set automatically can capture the latest terms without the need for changing the data set through the DAPB process
- all NHS healthcare providers in England must now use SNOMED CT for capturing clinical terms within electronic patient record systems
- the use of SNOMED CT simplifies exchanging clinical information between systems

It is important to note that there is limited use of SNOMED CT within version 6.0, however this will be expanded to capture all clinical terminology from version 7. The delayed roll-out is due to the extensive work that is required to create new concepts and UK reference sets specifically for RTDS.

In addition, this delay in full integration will allow more time for software developers and providers of radiotherapy services in England to get use to SNOMED CT and prepare for a more comprehensive use from version 7.

How have we integrated clinical terminologies within the data set?

RTDS developers have been working closely with the NHS Digital Terminologies and Classifications team to restructure the data set to further cater for clinical terminology recording.

Within the RTDS:

- diagnoses can now be submitted using SNOMED CT as well as ICD
- radiotherapy plan procedures can now be submitted using SNOMED CT or OPCS
- prescribed and actual dose and radiotherapy beam energy unit of measurement SNOMED CT, can be used to define the unit of measurement using the reference set #31491000001101

- radiotherapy routes and methods of admission can now be defined within SNOMED CT accurately, using the reference set #51971000001109
- radioisotopes can now be submitted using a select choice of the RTDS current specification or SNOMED CT
- a new radiopharmaceutical procedures UK reference set is currently being created, in the meantime use the table on pg34 as reference
- radiotherapy attendance procedures can now be submitted using SNOMED CT or OPCS

What is SNOMED CT

SNOMED CT is the standard clinical terminology for the NHS to support recording of clinical information, in a way that supports data management and analysis to support patient care, while enabling data extraction and data exchange.

SNOMED CT provides a comprehensive set of clinical phrases or terms; this is called a terminology. SNOMED CT is much more than just a set of clinical phrases, for example it also includes groups with relationships between terms. It is the most comprehensive international terminology currently available and can be used across all care settings and all clinical domains.

SNOMED CT is managed and maintained internationally by [SNOMED International](#) and in the UK by the [UK National Release Centre](#) (part of NHS Digital). SNOMED CT is specified as the single terminology to be used across the health system in [Personalised Health and Care 2020: A Framework for Action](#).

Searching for concepts within SNOMED CT

NHS Digital have developed a SNOMED CT Browser at the following website <https://termbrowser.nhs.uk/>.

The NHS Digital SNOMED CT Browser provides ways to browser and search the SNOMED CT UK Edition. The SNOMED CT UK Edition is currently released twice per year and consists of the International Edition plus the UK-specific content provided within the UK Clinical Extension and UK Drug Extension including maps to ICD-10 and OPCS-4.

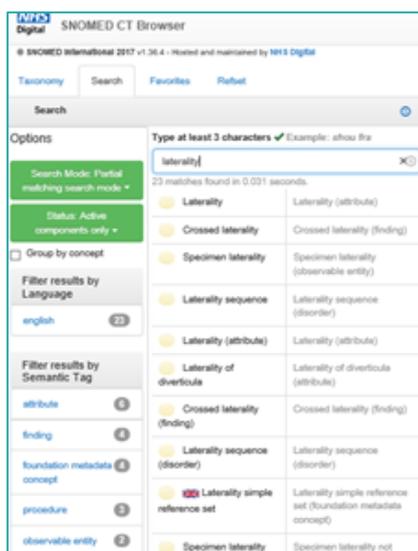
This is for use in the UK only.

A list of the SNOMED CT releases contained in the browser is maintained here https://hscic.kahootz.com/connect.ti/t_c_home/view?objectID=17185264.

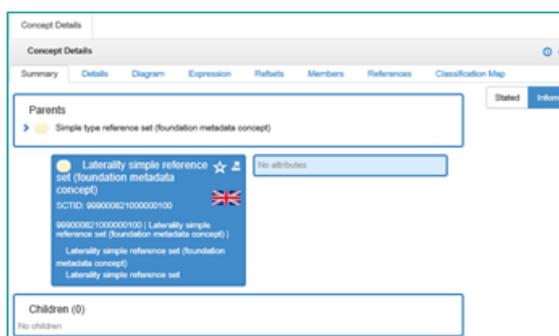
The Browser is provided by NHS Digital to anyone for reference purposes. The interface and REST APIs are not to be used as part of production systems in health care settings.

How to use termbrowser

1. Go to the website <https://termbrowser.nhs.uk/>
2. Click the 'Go Browsing' button
3. Click 'Search'
4. Enter the known ID or start typing the term required and all available concepts and reference sets will appear below



5. Select one of the search results. On the right will be the concept ID and information for the item you have selected



6. If this is a reference set, now select the members tab from the right hand window to view all member concepts and their ID's

Concept Details	
Concept Details	
Summary	Details
Term	Concept Id
Right (qualifier value)	24028007
Right and left (qualifier value)	51440002
Left (qualifier value)	7771000
3 Members	

How to find a Diagnosis:

When searching for a diagnosis, ensure that you use the (disorder) hierarchy, which will be in brackets at the end of the Fully Specified Name.

For example, if you search for 'Breast Cancer' a long list of available types of breast cancer diagnoses will appear for you to choose as follows:

The screenshot shows the SNOMED CT Browser interface. The search bar contains 'breast cancer' and shows 95 matches. The results are displayed in a table with columns for concept name and description. The 'Children' list on the right includes various breast cancer diagnoses, such as 'Breast cancer detected by national screening programme (disorder)', 'Carcinoma of breast (disorder)', and 'Malignant neoplasm of breast lower inner quadrant (disorder)'. The 'Classification Map' tab is visible at the bottom of the right-hand window.

You can then select the more granular level from the children list (on the right) and then cross reference your diagnosis by using the 'Classification Map' to ICD10.

For example, if you select 'Malignant neoplasm of breast lower inner quadrant (disorder)', the classification map displayed on the tab (in the right hand window), will show C50.3 as follows:

The screenshot shows the 'Classification Map' tab for the concept 'Malignant neoplasm of breast lower inner quadrant (disorder)'. The ICD10 code is C50.3. The map shows a single entry with a 'Rule' of TRUE and 'Advice' of ADDITIONAL CODE POSSIBLE.

Map Entries	Rule	Advice	Relative
1/1/1 C50.3 Malignant neoplasm, Lower-inner quadrant of breast	TRUE	ADDITIONAL CODE POSSIBLE	

How to find a Procedure:

When searching for procedures, it is important that you only use the (procedure) hierarchy, which will be in brackets at the end of the Fully Specified Name.

For example, you could search for mastectomy and a long list of available types of mastectomy will appear for you to choose as follows:

The screenshot shows a search interface with the following components:

- Search Bar:** Contains the text 'mastectomy' and indicates '208 matches found in 0.205 seconds'.
- Options Panel (Left):**
 - Search Mode: Partial matching search mode
 - Status: Active components only
 - Group by concept:
 - Filter results by Language: english (208)
 - Filter results by Semantic Tag:
 - procedure (153)
 - specimen (16)
 - situation (14)
 - morphologic abnormality (8)
 - disorder (8)
- Results Table (Middle):**

Type at least 3 characters ✓ Example: shou fra	Search Results
Mastectomy	Excision of breast tissue (procedure)
Total mastectomy	Simple mastectomy (procedure)
Simple mastectomy	Simple mastectomy (procedure)
Halsted mastectomy	Halsted mastectomy (procedure)
Radical mastectomy	Radical mastectomy (procedure)
Partial mastectomy	Partial mastectomy (procedure)
Mastectomy incision	Mastectomy incision (procedure)
Subtotal mastectomy	Partial mastectomy (procedure)
Bilateral mastectomy	Bilateral mastectomy (procedure)
- Concept Details Panel (Right):**
 - Parents:** Excision of breast tissue (procedure)
 - Selected Concept:** Simple mastectomy (procedure)
 - SCTID: 172043008
 - 172043008 | Simple mastectomy (procedure) |
 - SM - Simple mastectomy
 - Simple mastectomy
 - Simple mastectomy (procedure)
 - Total mastectomy
 - Children (7):**
 - Simple mastectomy of left breast (procedure)
 - Simple mastectomy of right breast (procedure)
 - Simple mastectomy with axillary lymph node sampling (procedure)
 - Simple mastectomy with complete axillary lymphadenectomy (procedure)
 - Simple mastectomy with excision of axillary lymph nodes (procedure)
 - Total mastectomy and division of pectoralis minor muscle (procedure)
 - Total mastectomy and excision of part of pectoral muscles and chest wall (procedure)

You can select the more granular level from the children list (on the right) and then cross reference your diagnosis by using the 'Classification Map' to OPCS.

For example, if you select 'Simple mastectomy of left breast (procedure)' the classification map will show two OPCS codes, B27.4 Total Mastectomy NEC and Z94.3 Left sided operation as follows:

The screenshot shows the 'Classification Map' for 'Simple mastectomy of left breast (procedure)'. It displays two map entries:

Map Entries	Rule	Advice	Relation
1/1/1 B27.4 Total mastectomy NEC	TRUE	ADDITIONAL CODE POSSIBLE	
1/2/1 Z94.3 Left sided operation	TRUE	ADDITIONAL CODE POSSIBLE	

What are the benefits of using SNOMED CT?

As the NHS moves to paperless, and the aspiration to exchange data electronically across the NHS, it is critical that all systems share the same clinical vocabulary. If every system uses its own vocabulary then interoperability is reduced to simply moving readable documents around the system and clinicians having to repeatedly transcribe data they need to be within their system, thus introducing errors.

The use of an international terminology enables system suppliers to design their system to a common terminology that can be implemented with less country specialisation across a number of countries. The last few years has seen a shift by suppliers from developing country specific solutions to global solutions with local configuration.

Further resources for SNOMED CT

More information about SNOMED CT can be found on the [NHS Digital SNOMED CT](#) pages including information about:

- Licensing:
 - the UK is a SNOMED International member country
 - use of SNOMED CT in the UK is free; however, the use of SNOMED CT does require a license
 - SNOMED CT licensing enquiries can be sent to information.standards@nhs.net
- Training:
 - NHS Digital offer a range of ways for individuals to learn more about SNOMED CT and its uses
 - for those who feel they need more understanding of SNOMED CT, NHS Digital provide a number of [training and education resources](#)
 - for an overview of SNOMED CT, pre-recorded webinars provide a good introduction; you will also find case studies, brochures and technical guidance detailed on this web page
 - for system suppliers, you may also be interested in the more technical guidance provided through the recorded webinars

Governance

Information governance, clinical safety and data protection

The primary purpose of the standard is for secondary uses only and will therefore have no direct impact on clinical safety and as such is not in scope of [DCB0129](#). Consequently, a clinical safety case report is not required to support the standard. RTDS is managed by the National Disease Registration Service (NDRS).

On 1st October 2021, as part of the government's strategy to transform the public health system in England, responsibility, and management of the NDRS which comprises the National Cancer Registration and Analysis Service (NCRAS) and the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) has been transferred to NHS Digital.

The data comprised in the registries maintained by NDRS was previously collected and analysed by Public Health England under section 2B of the National Health Service Act 2006 and Regulations 2 and 5 of the Health Services (Control of Patient Information) Regulations 2002 (COPI). The Secretary of State has now directed NHS Digital to maintain and operate the NDRS from 1st October 2021 under the National Disease Registries Directions 2021 (Directions).

The Directions enable NHS Digital to process confidential patient information for medical purposes relating to:

- individuals referred for the diagnosis or treatment of cancer (the NCRAS), and
- individuals with suspected, confirmed, or high genetic risk of congenital anomalies and rare or inherited diseases, and appropriate members of their family, such as where relevant, the parents of a child or fetus with a congenital anomaly and younger siblings of a child with a rare or inherited disease (the NCARDRS)

Such purposes include but are not limited to:

- the surveillance and analysis of health and disease
- the monitoring and audit of health and health related care provision and outcomes where such provision has been made
- the planning and administration of the provision made for health and health related care
- medical research
- the provision of information about individuals who have suffered from a particular disease or condition where:
 - that information supports an analysis of the risk of developing that disease or condition, and

- it is required for counselling and support of a person who is concerned about the risk of developing that risk or condition or concerned about the risk of their child developing that risk or condition

Benefits of the collection

Collection of data related to individuals referred for the diagnosis or treatment of cancer aims to provide the following benefits:

- increase prevention and early diagnosis of cancer
- improve the management of NHS cancer services
- improve NHS cancer treatment and care
- improve patient outcomes, including better quality of life and longer survival

Collection of data related to individuals with suspected, confirmed, or at high genetic risk of congenital anomalies and rare or inherited diseases, aims to provide the following benefits:

- provide a resource for clinicians to support high quality clinical practice
- support and empower patients, their carers and other family members by providing information relevant to their disease or disorder
- through research and study determine the causes of congenital anomalies and rare diseases
- improve diagnostics, treatment, and management of congenital anomalies and rare diseases
- inform the planning and commissioning of health and social care services for those affected or at risk

Legal basis for collection and analysis

NHS Digital has been directed by the Secretary of State under section 254 of the 2012 Act to establish and operate a system for the collection and analysis of the information specified for the NDRS: <https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notice/secretary-of-state-directions/national-disease-register-service-directions>

This information is required by NHS Digital under section 259(1)(a) and (b) of the 2012 Act to comply with the Directions.

In line with section 259(5) of the 2012 Act, all organisations in scope, in England, are required or requested (as indicated in the tables in Appendices A and B) to provide information to NHS Digital in the form, manner and period specified in this Data Provision Notice.

Under General Data Protection Regulation (GDPR) the lawful basis upon which the NDRS will process personal data is Article 6(1) (e) “processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority.”

The NDRS receives health and genetics data in accordance with the conditions for “special category” data set out in GDPR Article 9(1) (h) “processing is necessary for the...provision of health care or treatment or the management of health...care systems and services.”

And GDPR Article 9(2)(i) “processing is necessary for reasons of public interest in the area of public health such as... ensuring high standards of quality and safety of health care... on the basis of [UK] law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy.”

Reported data will be managed by the NDRS where there is long standing expertise in managing large volumes of confidential data. Although the data items which are flowed to the NDRS have changed, the data flows (for example, which organisations will be receiving the data in identifiable form) remain unchanged.

In compliance with the fair processing requirement within the Data Protection Act, provider organisations are expected to inform patients of this purpose for reporting their information and of the potential use of the information for service development, analysis and statistical research.

NDRS supports this process and provides privacy information to cancer patients in several ways. The NCRAS patient leaflet, for example:

- explains what cancer registration is, why it matters, where to go to find more information and how to opt-out
- was designed in partnership with patient groups and cancer charities and was approved by the Plain English Campaign
- is sent to Trusts’ cancer services, patient information centres, many site-specific Multi-Disciplinary Teams (MDTs), cancer charities and private health care providers
- is included in the Quality of Life (QoL) survey which people receive after they have had a cancer diagnosis
- is available on the [NDRS](#) patient facing website

In total, 166,000 copies of the leaflet were distributed in 2020 to 143 NHS Acute Trusts in England.

NDRS as part of NHSD, complies with the DHSC’s Data Protection Act registration with the Information Commissioner’s Office (ICO). The NDRS regularly reviews and harmonises its information governance policies to correlate them with those of NHSD and aligning with multiple mandatory training requirements (annually) for its employees.

These policies inform for example:

- access controls of data
- server security and encryption
- data transfer procedures

All NDRS employees handling patient identifiable data (PID), are required to complete information governance, data security and responsible for information mandatory training. There is also a 'Confidentiality Guidelines and Agreement' document, which is an individual declaration for all employees and must be read and signed annually. This is monitored as part of their appraisal process.

RTDS v6.0 – Proposed relationship and key changes

The relationship diagram (fig 1) shows the current schema relationships, whereas (fig 2) is based on the proposed changes for version 6.0 and should not be used in relationship with any other version. Please contact the rtds.helpdesk@nhs.net for any further information.

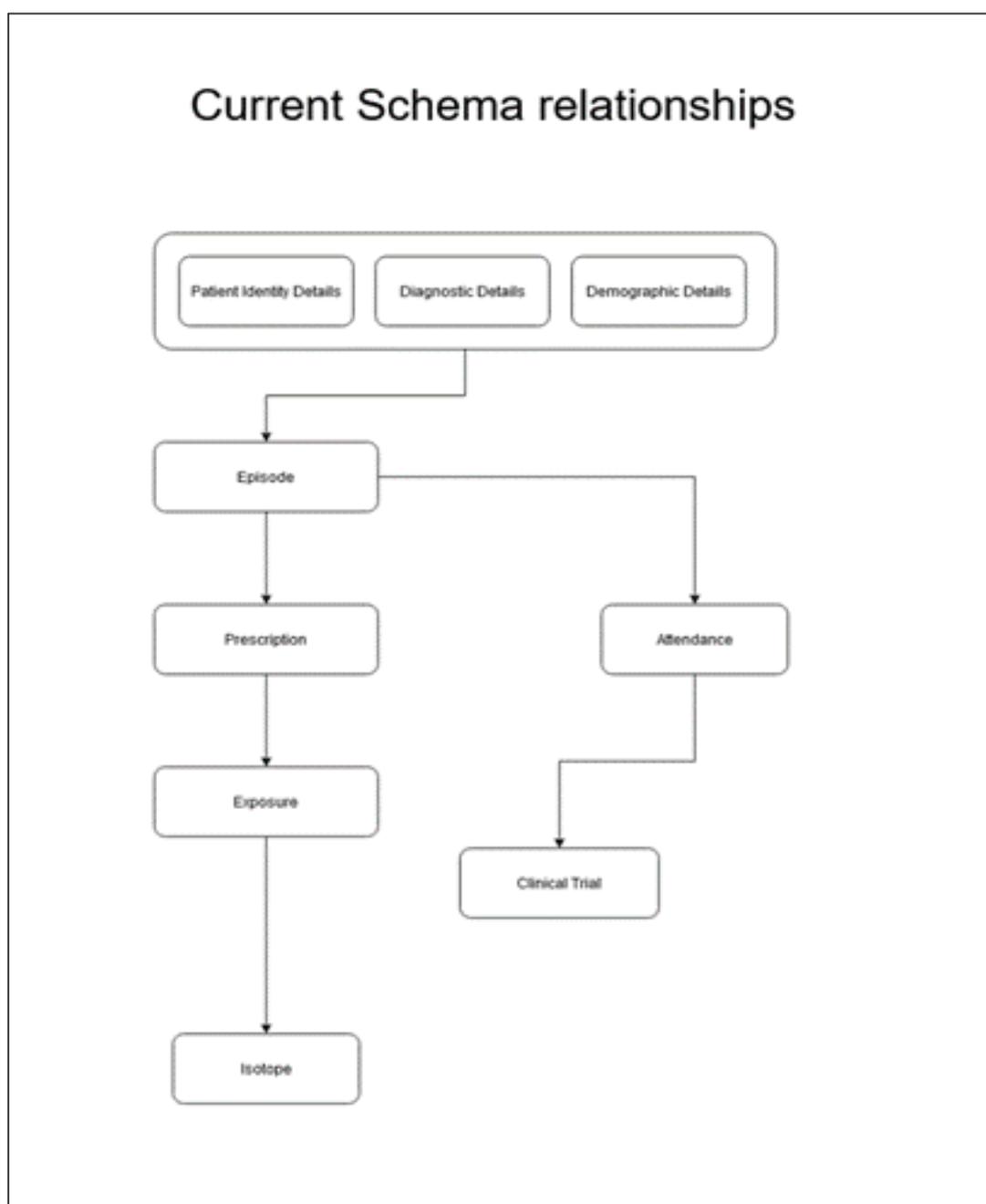


Fig 1: Current schema relationships for RTDS version 5.0

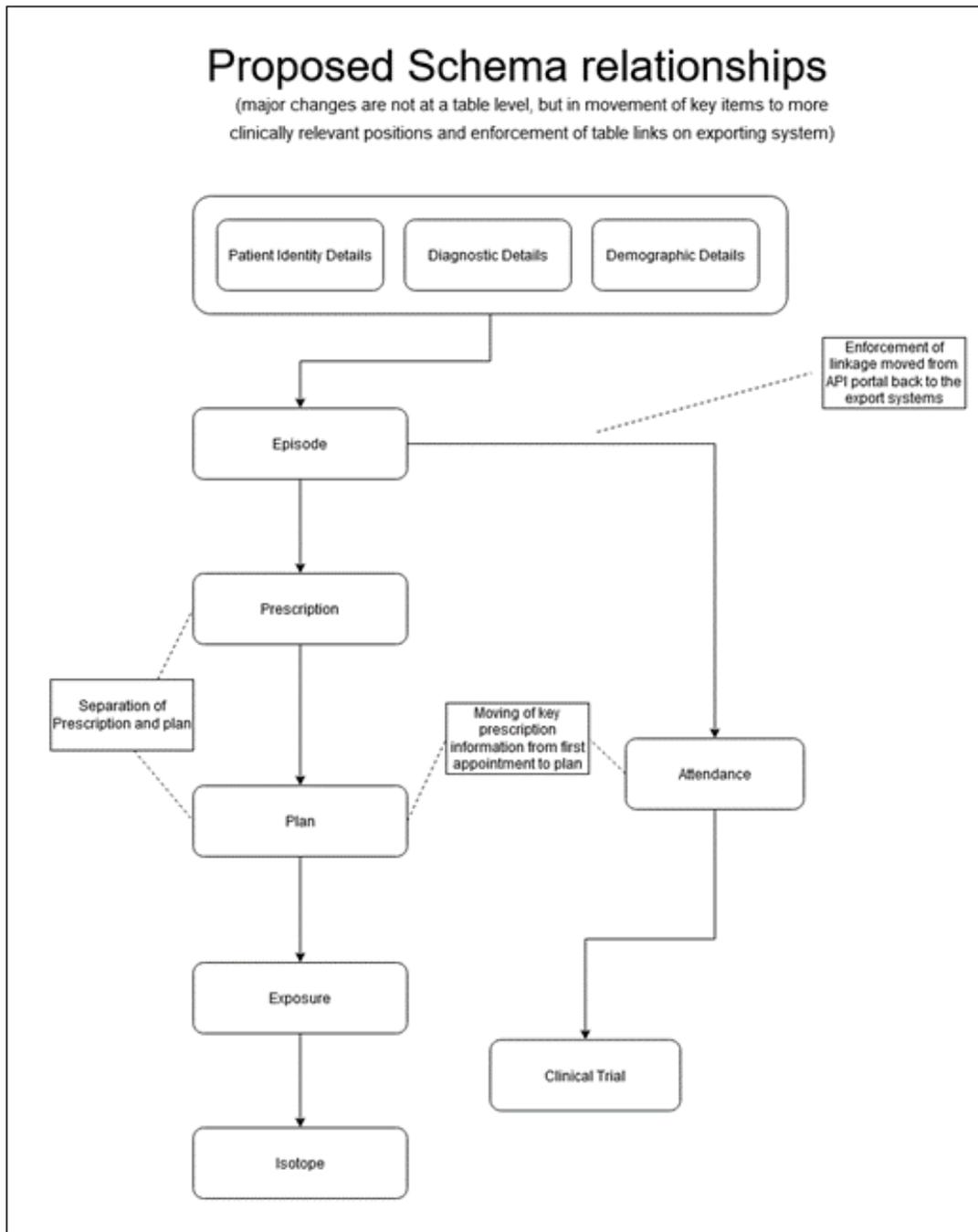


fig 2 Proposed schema relationship changes for version 6.0

Schema specification

For the purpose of RTDS v6.0, there will no longer be an expectation to convert local reporting to an XML schema. All Trusts should therefore continue to report using the formats specified in the technical document.

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.

Required

Most data-items are set as 'required'. This means that if they are applicable to the reported tumour, patient or treatment 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.

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 RTDS.

Pilot

In some cases, new data-items may be 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. There are no pilot data items in v6.0 of RTDS.

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).

List of Registerable Diseases

The ICD10 disease codes lists for all registerable conditions (C & D codes) are provided in Appendices A and B.

When should the data be submitted?

Data files are required to be submitted monthly, 20 working days after the end of the month for England, to be uploaded to RTDS as follows:

Month of treatment	Submission due date
April 2022	31 May 2022
May 2022	28 June 2022
June 2022	28 July 2022
July 2022	26 August 2022
August 2022	28 September 2022
September 2022	28 October 2022
October 2022	28 November 2022
November 2022	30 December 2023
December 2022	30 January 2023
January 2023	28 February 2023
February 2023	28 March 2023
March 2023	3 May 2023

Notes:

- files containing data must be uploaded to the portal and all errors on the file must be resolved
- this upload schedule will continue to apply to all future months

Appendix A: ICD10 codes and tumour groups for primary diagnoses

These are registerable conditions for the purposes of Cancer Registration and are 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
- further guidance is available from RTDS helpdesk

Key:

() = if applicable

* = different data set from CWT group specified

ICD-10 4th Edition

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	•			

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	
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	•			

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	
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	•			

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	
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	•			
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	•			

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	
C15.0	Cervical part of oesophagus	Upper Gastrointestinal	*			Usually treated by Head and Neck
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	•			

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	
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
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	•			

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	
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	•			

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	
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	•			
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	•			

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	
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		•		

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	
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		•		
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	•			

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	
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	•			

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	
C44.0	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

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	
						(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

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	
						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		●		

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	
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

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	
						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	•			

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	
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.
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	•			

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	
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	•			

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	
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.
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	•			

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	
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	•			

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	
C69.0	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	•			

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	
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	•			

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	
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		•		
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		•		

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	
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

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	
						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
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

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	
						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

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	
						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.
C78.6	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	Urological		•		Normally treated by MDT of site of primary tumour.

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	
	other and unspecified urinary organs					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				
C80.9	Malignant neoplasm, unspecified	Other				
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				

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	
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				
C82.9	Follicular lymphoma, unspecified	Haematological				
C83.0	Small cell B-cell lymphoma	Haematological				
C83.1	Mantle cell 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	
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				

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	
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				
C88.4	Extranodal marginal zone B-cell lymphoma of mucosa-associated lymphoid tissue (MALT-lymphoma)	Haematological				
C88.7	Other malignant immunoproliferative diseases	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	
C88.9	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				

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	
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				
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				

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	
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				

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	
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	•			
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

Further details to be provided regarding applicable data fields for each disease. These are additional mandatory registerable conditions, required for all RTDS data collection.

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

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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: Lip, oral cavity and pharynx	Head and Neck			•	
D00.1	Carcinoma in situ: Oesophagus	Upper Gastrointestinal			•	
D00.2	Carcinoma in situ: Stomach	Upper Gastrointestinal			•	
D01.0	Carcinoma in situ: Colon	Colorectal			•	
D01.1	Carcinoma in situ: Rectosigmoid junction	Colorectal			•	
D01.2	Carcinoma in situ: Rectum	Colorectal			•	
D01.3	Carcinoma in situ: Anus and anal canal	Colorectal			•	

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	
D01.4	Carcinoma in situ: Other and unspecified parts of intestine	Colorectal			•	
D01.5	Carcinoma in situ: Liver, gallbladder and bile ducts	Upper Gastrointestinal			•	
D01.7	Carcinoma in situ: Other specified digestive organs	Colorectal			•	
D01.9	Carcinoma in situ: Digestive organ, unspecified	Colorectal			•	
D02.0	Carcinoma in situ: Larynx	Head and Neck			•	
D02.1	Carcinoma in situ: Trachea	Lung			•	
D02.2	Carcinoma in situ: Bronchus and lung	Lung			•	
D02.3	Carcinoma in situ: Other parts of respiratory system	Lung			•	
D02.4	Carcinoma in situ: 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		•		

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	
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: Endocervix	Gynaecological			•	
D06.1	Carcinoma in situ: Exocervix	Gynaecological			•	
D06.7	Carcinoma in situ Other parts of cervix	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	
D06.9	Carcinoma in situ: Cervix, unspecified	Gynaecological			•	
D07.0	Carcinoma in situ: Endometrium	Gynaecological			•	
D07.1	Carcinoma in situ: Vulva	Gynaecological			•	
D07.2	Carcinoma in situ: Vagina	Gynaecological			•	
D07.3	Carcinoma in situ: Other and unspecified female genital organs	Gynaecological			•	
D07.4	Carcinoma in situ: Penis	Urological			•	
D07.5	Carcinoma in situ: Prostate	Urological			•	
D07.6	Carcinoma in situ: Other and unspecified male genital organs	Urological			•	
D09.0	Carcinoma in situ: Bladder	Urological	•			
D09.1	Carcinoma in situ: Other and unspecified urinary organs	Urological			•	
D09.2	Carcinoma in situ: Eye	Other			•	
D09.3	Carcinoma in situ: 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: Cerebral meninges	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	
D32.1	Benign neoplasm: Spinal meninges	Brain/Central Nervous System	•			
D32.9	Benign neoplasm: Meninges, unspecified	Brain/Central Nervous System	•			
D33.0	Benign neoplasm: Brain, supratentorial	Brain/Central Nervous System	•			
D33.1	Benign neoplasm: Brain, infratentorial	Brain/Central Nervous System	•			
D33.2	Benign neoplasm: Brain, unspecified	Brain/Central Nervous System	•			
D33.3	Benign neoplasm: Cranial nerves	Brain/Central Nervous System	•			
D33.4	Benign neoplasm: Spinal cord	Brain/Central Nervous System	•			
D33.7	Benign neoplasm: Other specified parts of central nervous system	Brain/Central Nervous System	•			
D33.9	Benign neoplasm: Central nervous system, unspecified	Brain/Central Nervous System	•			
D35.2	Benign neoplasm: Pituitary gland	Brain/Central Nervous System	•			
D35.3	Benign neoplasm: Craniopharyngeal duct	Other	•			Usually classified as CNS
D35.4	Benign neoplasm: Pineal gland	Brain/Central Nervous System	•			
D37.0	Neoplasm of uncertain or unknown behaviour: Lip, oral cavity and pharynx	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	
D37.1	Neoplasm of uncertain or unknown behaviour of: Stomach	Upper Gastrointestinal			•	
D37.2	Neoplasm of uncertain or unknown behaviour: Small intestine	Upper Gastrointestinal			•	
D37.3	Neoplasm of uncertain or unknown behaviour: Appendix	Colorectal			•	
D37.4	Neoplasm of uncertain or unknown behaviour: Colon	Colorectal			•	
D37.5	Neoplasm of uncertain or unknown behaviour: Rectum	Colorectal			•	
D37.6	Neoplasm of uncertain or unknown behaviour: Liver, gallbladder and bile ducts	Upper Gastrointestinal			•	
D37.7	Neoplasm of uncertain or unknown behaviour: Other digestive organs	Colorectal/Upper Gastrointestinal			•	
D37.9	Neoplasm of uncertain or unknown behaviour: Digestive organ, unspecified	Colorectal/Upper Gastrointestinal			•	
D38.0	Neoplasm of uncertain or unknown behaviour: Larynx	Head and Neck			•	
D38.1	Neoplasm of uncertain or unknown behaviour: Trachea, bronchus and lung	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	
D38.2	Neoplasm of uncertain or unknown behaviour: Pleura	Lung			•	
D38.3	Neoplasm of uncertain or unknown behaviour: Mediastinum	Lung			•	
D38.4	Neoplasm of uncertain or unknown behaviour: Thymus	Lung			•	
D38.5	Neoplasm of uncertain or unknown behaviour: Other respiratory organs	Lung			•	
D38.6	Neoplasm of uncertain or unknown behaviour: Respiratory organ, unspecified	Lung			•	
D39.0	Neoplasm of uncertain or unknown behaviour: Uterus	Gynaecological			•	
D39.1	Neoplasm of uncertain or unknown behaviour: Ovary	Gynaecological			•	
D39.2	Neoplasm of uncertain or unknown behaviour: Placenta	Gynaecological			•	
D39.7	Neoplasm of uncertain or unknown behaviour: Other female genital organs	Gynaecological			•	
D39.9	Neoplasm of uncertain or unknown behaviour: Female genital organ, unspecified	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	
D40.0	Neoplasm of uncertain or unknown behaviour: Prostate	Urological			•	
D40.1	Neoplasm of uncertain or unknown behaviour: Testis	Urological			•	
D40.7	Neoplasm of uncertain or unknown behaviour: Other male genital organs	Urological			•	
D40.9	Neoplasm of uncertain or unknown behaviour: Male genital organs, unspecified	Urological			•	
D41.0	Neoplasm of uncertain or unknown behaviour: Kidney	Urological			•	
D41.1	Neoplasm of uncertain or unknown behaviour: Renal pelvis	Urological	•			
D41.2	Neoplasm of uncertain or unknown behaviour: Ureter	Urological	•			
D41.3	Neoplasm of uncertain or unknown behaviour: Urethra	Urological	•			
D41.4	Neoplasm of uncertain or unknown behaviour: Bladder	Urological	•			
D41.7	Neoplasm of uncertain or unknown behaviour: Other urinary organs	Urological			•	

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	
D41.9	Neoplasm of uncertain or unknown behaviour: Urinary organs, unspecified	Urological			•	
D42.0	Neoplasm of uncertain or unknown behaviour: Cerebral meninges	Brain/Central Nervous System	•			
D42.1	Neoplasm of uncertain or unknown behaviour: Spinal meninges	Brain/Central Nervous System	•			
D42.9	Neoplasm of uncertain or unknown behaviour: Meninges, unspecified	Brain/Central Nervous System	•			
D43.0	Neoplasm of uncertain or unknown behaviour: Brain, supratentorial	Brain/Central Nervous System	•			
D43.1	Neoplasm of uncertain or unknown behaviour: Brain, infratentorial	Brain/Central Nervous System	•			
D43.2	Neoplasm of uncertain or unknown behaviour: Brain, unspecified	Brain/Central Nervous System	•			
D43.3	Neoplasm of uncertain or unknown behaviour: Cranial nerves	Brain/Central Nervous System	•			
D43.4	Neoplasm of uncertain or unknown behaviour: Spinal cord	Brain/Central Nervous System	•			
D43.7	Neoplasm of uncertain or unknown behaviour: Other parts of central nervous system	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	
D43.9	Neoplasm of uncertain or unknown behaviour: Central nervous system, unspecified	Brain/Central Nervous System	•			
D44.0	Neoplasm of uncertain or unknown behaviour: Thyroid gland	Head and Neck			•	
D44.1	Neoplasm of uncertain or unknown behaviour: Adrenal gland	Other			•	
D44.2	Neoplasm of uncertain or unknown behaviour: Parathyroid gland	Other			•	
D44.3	Neoplasm of uncertain or unknown behaviour: Pituitary gland	Brain/Central Nervous System	•			
D44.4	Neoplasm of uncertain or unknown behaviour: Craniopharyngeal duct	Brain/Central Nervous System	•			
D44 .5	Neoplasm of uncertain or unknown behaviour: Pineal gland	Brain/Central Nervous System	•			
D44 .6	Neoplasm of uncertain or unknown behaviour: Carotid body	Other			•	
D44 .7	Neoplasm of uncertain or unknown behaviour: Aortic body and other paraganglia	Other			•	
D44 .8	Neoplasm of uncertain or unknown behaviour: Pluriglandular involvement	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	
D44 .9	Neoplasm of uncertain or unknown behaviour: 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				
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				

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	
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: Bone and articular cartilage	Sarcoma			•	
D48.1	Neoplasm of uncertain or unknown behaviour: Connective and other soft tissue	Sarcoma			•	Only applicable for GISTs
D48.2	Neoplasm of uncertain or unknown behaviour: Peripheral nerves and autonomic nervous system	Other			•	
D48.3	Neoplasm of uncertain or unknown behaviour: 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: Peritoneum	Other			•	
D48.5	Neoplasm of uncertain or unknown behaviour: Skin	Skin			•	
D48.6	Neoplasm of uncertain or unknown behaviour: Breast	Breast			•	
D48.7	Neoplasm of uncertain or unknown behaviour: Other specified sites	Other			•	
D48.9	Neoplasm of uncertain or unknown behaviour, unspecified	Other			•	
E85.9	Amyloidosis, unspecified	Haematology	See the Haematological chapter of COSD User Guide for information regarding what is required to be submitted for these Haematological diseases.			

Although Primary amyloidosis (E85.9) is listed as an E ICD code in the World Health organization (WHO) disease classification, amongst clinicians it is widely acknowledged and subsequently treated as a cancer.

Whilst we await the WHO disease classification being updated to reflect this fact, it's inclusion as a registerable condition requiring collection has been agreed with the National Cancer Registration and Analysis Service.

Appendix C: Cancer registration leaflet

Below is the [cancer registration leaflet](#) (version 6.0), as of 6 January 2019.

Where can I find out more?

If you would like to find out why cancer registration is important or have any questions about the work we do, you can:

- visit us online at www.ndrs.nhs.uk
- talk to a member of the NHS cancer team treating you, or
- visit www.nhs.uk/your-data-matters to find out how the NHS uses information.



Can I see the information you hold about me?

Yes, we can give it to a doctor (GP) who knows who you are, so they can share all the information with you.

Can I ask for my information not to be included in the cancer registry?

Yes, you have the right to opt out of cancer registration. This will not affect the personal care you receive from your healthcare team.

If you do not want your information included in the national cancer registry, you can contact us at optout@phe.gov.uk or write to:

Director
National Cancer Registry
Public Health England
6th Floor, Wellington House
133-155 Waterloo Road
London SE1 8UG.

For information on your rights and privacy visit www.ndrs.nhs.uk/cancer-registration-your-rights-and-privacy
This leaflet is available in alternative formats. Contact us at NCRASfeedback@phe.gov.uk for more information.
This leaflet is reviewed regularly.
If you have any comments, please email NCRASfeedback@phe.gov.uk.
PHE publications gateway number: 2018747. Version 6, January 2019.

Crystal Mark 22491
Charity approved by Plain English Campaign

Cancer registration

Why it matters and what you need to know



Public Health England
Protecting and improving the nation's health



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