

National Disease Registration Service (NDRS)

Recording a Diagnosis for COSD
v6 September 2024

Welcome to this NDRS training module on recording a diagnosis for the Cancer Outcomes and Services Dataset, also known as COSD. Remember, this module may be paused at any time.

Agenda

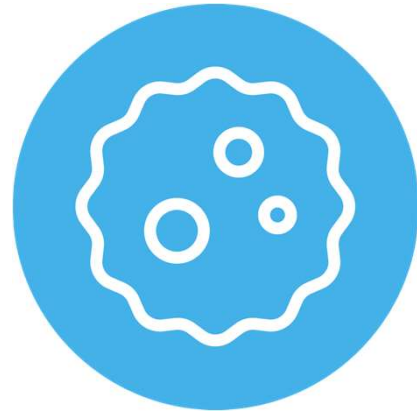
- Types of diagnosis
 - New primary diagnosis
 - Progression
 - Transformation
 - Recurrence
- ICD10 codes - C codes & D codes
- Recording a diagnosis
- What if a diagnosis changes?
- In summary



The range of diagnoses and recording options for various types of cancer **can** be daunting when you first start dealing with cancer data. In this training module, we'll look at the different types of diagnoses you might come across ... the ICD10 codes you should record for COSD ... and how to record each type of diagnosis appropriately

Types of Diagnosis - New Primary diagnosis

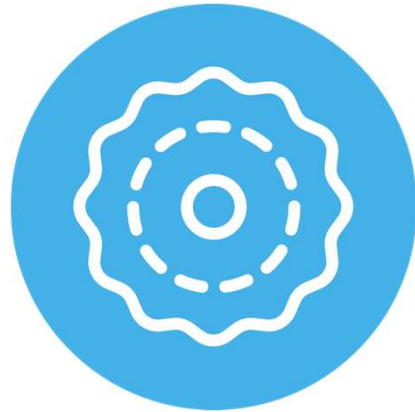
- Applies to the primary tumour / disease
- Usually invasive (see Appendices A, B & C of the COSD User Guide for the full list of mandatory registrable conditions)
- The COSD User Guide may be downloaded here:
- <https://digital.nhs.uk/ndrs/data/data-sets/cosd#downloads>



We're going to start by looking at the types of diagnosis. A new primary diagnosis will apply to a newly diagnosed primary disease. These are usually invasive cancers but COSD also requires some non-invasive tumours and conditions be recorded.

Types of Diagnosis - Progression

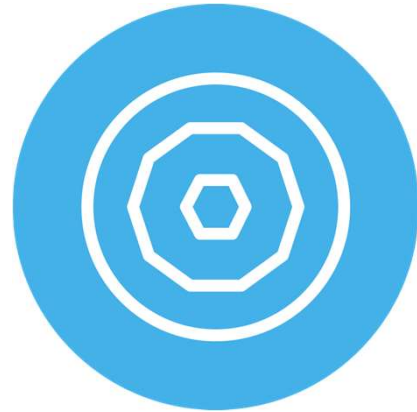
- Applies to invasive primary diagnoses only
- Applies where the patient is living with their cancer and has not been told that their cancer is no longer detectable
- A progression diagnosis indicates that the previously diagnosed cancer has spread
- Most cancer management systems will automatically categorise a progression diagnosis as a non-primary pathway
- NDRS does not currently require a stage for a progression diagnosis



A progression diagnosis applies where the patient has an ongoing invasive cancer and has not been told they are cancer free. A progression diagnosis indicates that the cancer has spread.

Types of Diagnosis - Transformation

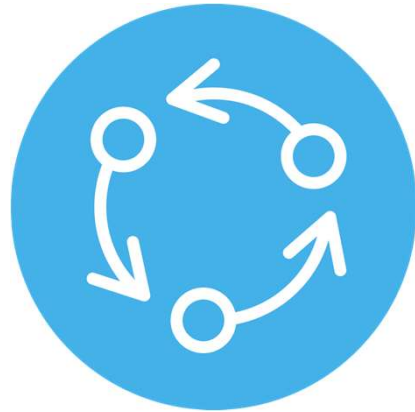
- Applies to primary diagnoses in Sarcoma, Haematology and Brain & Central Nervous System
- A transformation diagnosis indicates that the original diagnosis has transformed into another diagnosis – the ICD10 code and/or the morphology may change
- Most cancer management systems will automatically categorise a transformation diagnosis as a non-primary pathway
- NDRS does not currently require a stage for a transformation diagnosis



In specific cancer sites it's possible for a cancer to transform – to change from one diagnosis to another. Transformation diagnoses are currently recorded for Sarcoma, Haematology and Brain & Central Nervous System

Types of Diagnosis - Recurrence

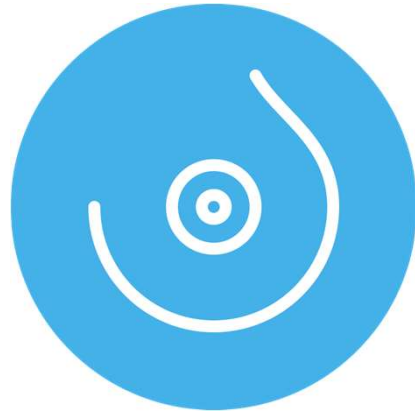
- Applies to invasive primary diagnoses only
- A recurrence diagnosis indicates that a previously diagnosed invasive cancer has returned
- A recurrence can only be recorded if the patient has at some point been told that their previously diagnosed cancer is no longer detectable
- A recurrence may be local / regional / distant
- Most cancer management systems will automatically categorise a recurrence diagnosis as a non-primary pathway
- NDRS does not currently require a stage for a recurrence diagnosis



Recurrence diagnoses apply only to invasive primary cancers. A recurrence can only be recorded if the patient has previously been told they are cancer-free and the same cancer comes back.

ICD10 codes - C codes & D codes

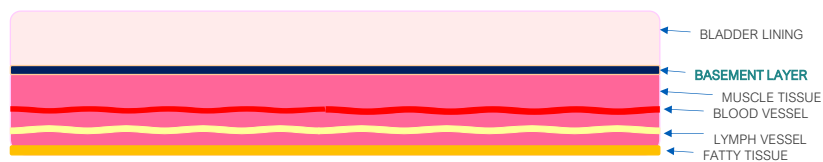
- With COSD in mind you would add the diagnosis to your system for:
- Any C prefix conditions plus D05 In-Situ Breast cancers as listed in the CWT guidance
- ...plus specified D/E coded conditions



We're now going to look at how you would determine if a non-invasive tumour or condition should be recorded. In addition to the range of cancers you'd record for CWT, there are a number of D or E coded conditions that must also be added to your cancer management system. You may at this point be wondering why...

ICD10 codes - C codes & D codes

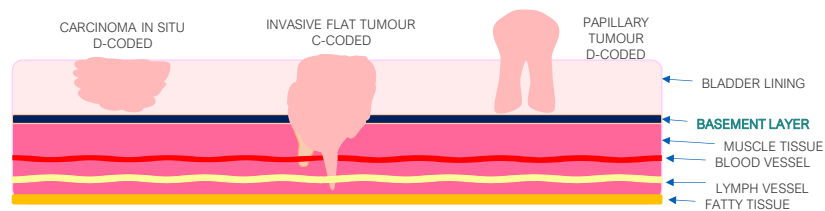
- For solid epithelial tumours, the difference between a D coded in-situ cancer and a C coded invasive cancer is the basement layer
- Composed mostly of basal cells, this forms the boundary between the epithelial (surface) cells on one side ... and the layers of muscle tissue (with blood and lymph vessels) on the other



For solid epithelial tumours, the key difference between D coding and C coding is something called the basement layer. This lies between the epithelial cells on the surface – in this case, they constitute the lining of the bladder – and the layers of muscle with blood and lymph vessels underneath

ICD10 codes - C codes & D codes

- Cancers that have not broken through the basement layer are usually deemed to be in-situ and would be coded with a D prefix in ICD10
- Once a cancer has broken through the basement membrane and has access to the vascular and lymph vessels, it can travel to other parts of the body and is classified as invasive. Invasive cancers are coded with a C prefix in ICD10



Where a tumour has not broken through the basement layer, it's classified as in-situ and is D coded in ICD10. Cancers that have broken through this basement layer can access a transport system in the form of those blood and lymph vessels. These are deemed to be invasive and are C coded.

ICD10 codes - C codes & D codes

- If in any doubt as to whether you should be recording a diagnosis, please refer to the latest COSD User Guide, Appendices A, B and C
- <https://digital.nhs.uk/ndrs/data/data-sets/cosd#downloads>

Do please remember, guidance **is** available on our website. You can download the COSD User Guide by clicking on this link and selecting the COSD version appropriate to your trust.

ICD10 codes - C codes & D codes

In addition to the invasive cancers detailed in Appendix A, the Mandatory Registrable Conditions list is contained within Appendix B of the latest COSD User Guide. 40+ solid tumour ICD 10 “D” codes are listed

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	
C05.0 - C57 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		*		

Once you have the COSD User Guide open, look for the appendices. Appendix A of the COSD User Guide lists the conditions registrable for CWT. COSD uses that same list plus those solid tumours in Appendix B as well as the D & E codes defined in Appendix C for Haematology

ICD10 codes - C codes & D codes

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, Ectocervix	Gynaecological		*		
D06.7	Carcinoma in situ, Other parts of cervix	Gynaecological		*		
D06.9	Carcinoma in situ, Cervix, unspecified	Gynaecological		*		
D07.0	Carcinoma in situ, Endometrium	Gynaecological		*		
D07.1	Carcinoma in situ, Vagina	Gynaecological		*		
D07.2	Carcinoma in situ, Uterus	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		*		

In addition to the invasive cancers detailed in Appendix A, the Mandatory Registrable Conditions list is contained within Appendix B of the latest COSD User Guide. 40+ solid tumour ICD 10 “D” codes are listed

If the line is showing a dot in either of the first two columns, a COSD record is required

The Appendix B list is shown in the form of a grid. Those ICD10 codes that show a mark in either the Core & Site specific dataset column or the Core dataset column do require a COSD submission, so will need to be recorded in your cancer management system.

ICD10 codes - C codes & D codes

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, Ectocervix	Gynaecological		*		
D06.7	Carcinoma in situ, Other parts of cervix	Gynaecological		*		
D06.9	Carcinoma in situ, Cervix, unspecified	Gynaecological		*		
D07.0	Carcinoma in situ, Endometrium	Gynaecological		*		
D07.1	Carcinoma in situ, Vagina	Gynaecological		*		
D07.2	Carcinoma in situ, Vagile	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		*		

In addition to the invasive cancers detailed in Appendix A, the Mandatory Registrable Conditions list is contained within Appendix B of the latest COSD User Guide. 40+ solid tumour ICD 10 “D” codes are listed

If the line is showing a dot in either of the first two columns, a COSD record is required

If the third column (Path Only) has the dot, no COSD record is needed. The information on these cancers is provided direct from the Pathology Laboratories

However, if the mark is displayed in the Path only column, the data is provided direct from the path lab and no COSD record is required.

ICD10 codes - C codes & D codes

ICD-O-3	ICD-O-3 WHO Description	ICD-10 4 th Edition	ICD10 Description	Clinical data set	WHO DISEASE GROUP
97401 A	Cutaneous mastocytosis	D47.0	Histiocytic and mast cell tumours of uncertain and unknown behaviour	CORE ONLY	1
97401 B	Extracutaneous mastocytoma	D47.0	Histiocytic and mast cell tumours of uncertain and unknown behaviour	CORE ONLY	1
97402	Mast Cell Sarcoma	C96.2	Malignant mast cell tumour	CORE ONLY	1
9741/1	Incident systemic mastocytosis	D47.0	Histiocytic and mast cell tumours of uncertain and unknown behaviour	CORE ONLY	1
9741/2	Systemic mastocytosis (including systemic mastocytosis with ANHMD or aggressive systemic mastocytosis)	C96.2	Malignant mast cell tumour	CORE ONLY	1
9742/2	Mast Cell Leukaemia	C94.3	Mast cell leukaemia	CORE ONLY	1
9875/0	Chronic Myelogenous Leukaemia, BCR-ABL1 positive	C92.1	Chronic myeloid leukaemia [CML], BCR/ABL-positive	CML	1
9875/0 A	Chronic Myelogenous Leukaemia, Accelerated Phase	C92.1	Chronic myeloid leukaemia [CML], BCR/ABL-positive	CML	1
9875/0 B	Chronic Myelogenous Leukaemia, Blastic Phase	C92.1	Chronic myeloid leukaemia [CML], BCR/ABL-positive	CML	1
9875/0 C	Chronic Myelogenous Leukaemia, Chronic Phase	C92.1	Chronic myeloid leukaemia [CML], BCR/ABL-positive	CML	1
9876/0	Atypical chronic myeloid leukaemia, BCR-ABL1 negative	C92.2	Atypical chronic myeloid leukaemia, BCR/ABL-negative	MDS	1
995/0	Polycythaemia vera*	D45	Polycythaemia vera	CORE ONLY	1
996/1/0	Primary myelofibrosis*	D47.4	Osteomyelofibrosis	CORE ONLY	1

Appendix C includes a further 18 conditions that are D/E coded in ICD 10

All listed Haematology codes require a COSD submission which must include the ICD-O-3 morphology code

Haematology also requires a COSD record for certain D coded conditions, and one E coded condition. Please bear in mind when recording these conditions that the morphology code must be included.

ICD10 codes - C codes & D codes

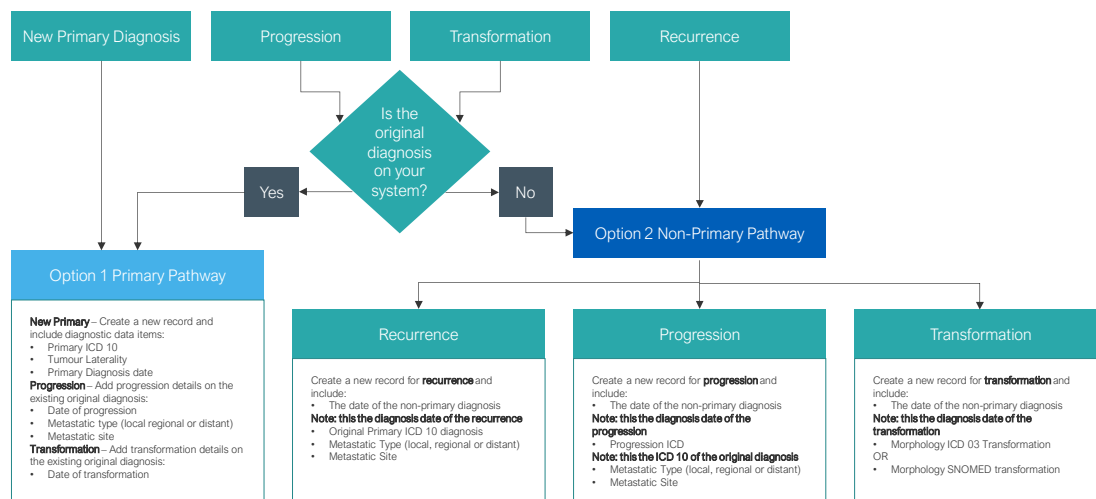
Remember:

There is no clash with CWT – The addition of a D/E code diagnosis (other than D05) will exclude the pathway from any CWT targets and the CWT submission.

If in doubt, check the CWT / COSD guidance

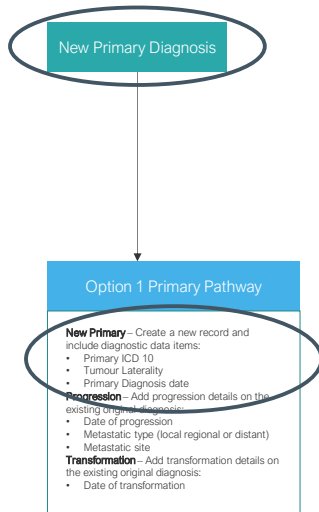
Remember - Your cancer management system will automatically exclude these additional COSD diagnoses from the CWT submission so there is no clash between CWT and COSD.

Recording a Diagnosis - Primary vs Non-primary



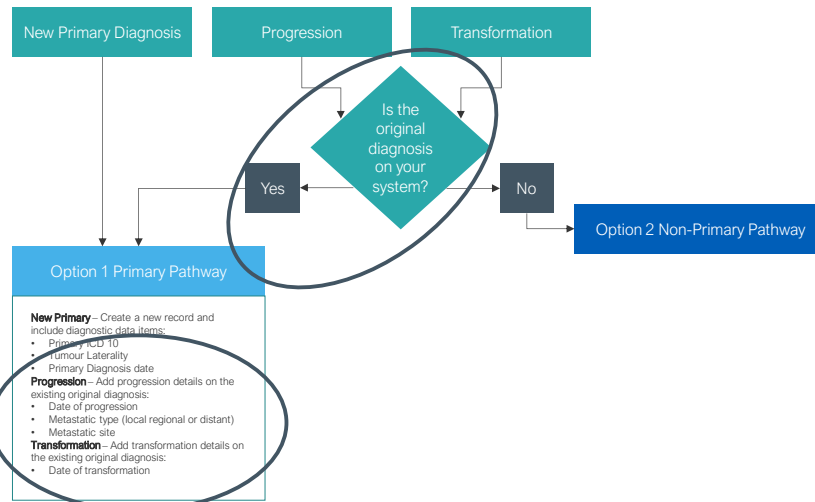
So how do you go about recording these new primary diagnoses, progressions, transformations and recurrences? This graphic is also contained within the COSD user guide to help you decide. It details the options for recording both primary and non-primary pathways and we're going to go through it step-by-step.

Recording a Diagnosis - Primary vs Non-primary



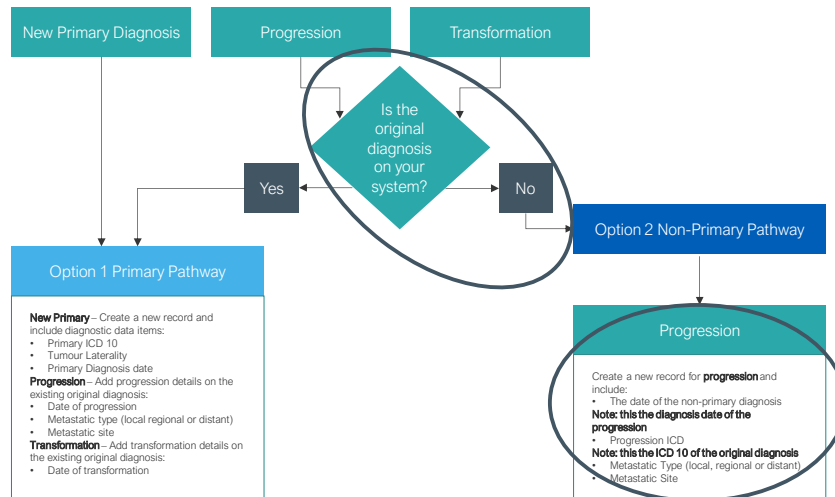
A new primary diagnosis is recorded on its own pathway. Details required will include the primary ICD10 code, any applicable tumour laterality and the primary diagnosis date.

Recording a Diagnosis - Primary vs Non-primary



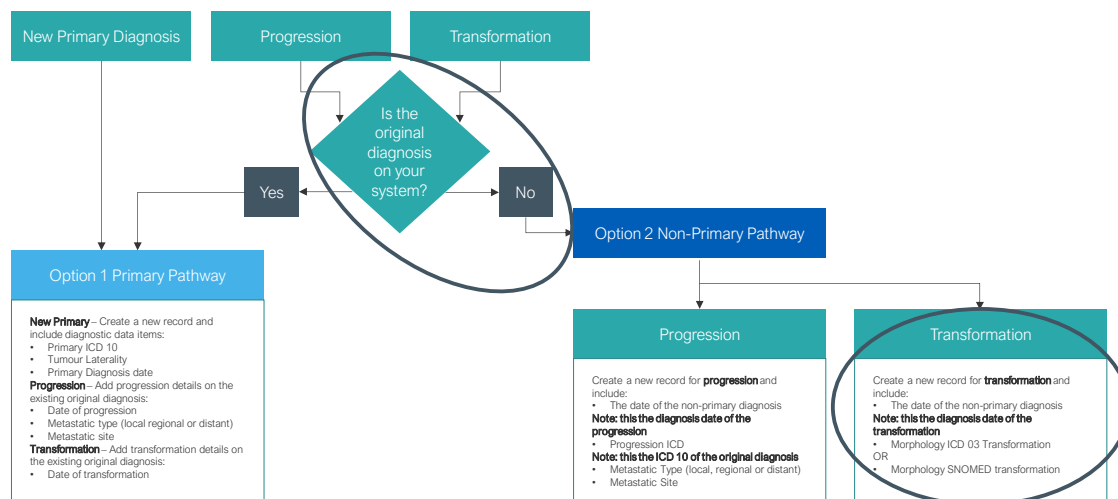
If a patient presents with a progression or a transformation, you must first determine if the original primary diagnosis is already on your cancer management system. If it is, record any progression or transformation on the original primary pathway.

Recording a Diagnosis - Primary vs Non-primary



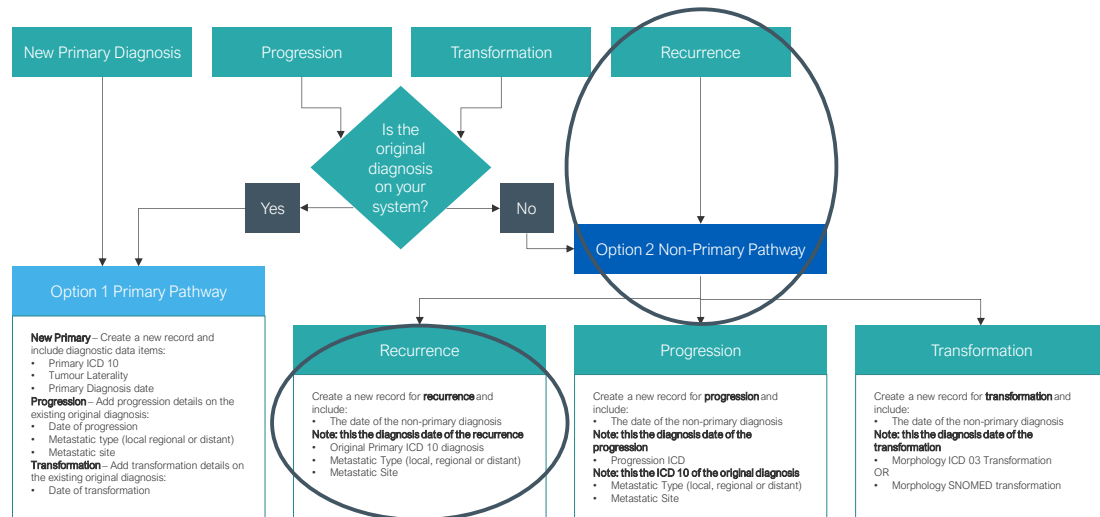
But if a patient's original primary pathway is not on your cancer management system, record any progression on a new non-primary pathway. The progression details needed include the ICD10 code of the primary cancer and the type & site of the metastases.

Recording a Diagnosis - Primary vs Non-primary



Similarly, where the patient's original primary pathway is not on your cancer management system, a transformation will need to be recorded on it's own non-primary pathway. Details needed will include the date of the transformation and the morphology.

Recording a Diagnosis - Primary vs Non-primary



A recurrence is always recorded on a separate non-primary pathway. Details required will include the date of the recurrence diagnosis and the type & site of metastases.

Topography – Metastatic New Primary Cancers, Recurrences & Progressions

- When recording a diagnosis that includes nodal or distant metastases – which may be an invasive new primary cancer, a recurrence or a progression – if the primary tumour site is identified as a specific cancer site, the primary ICD10 code must be recorded relevant to the site of the **primary** tumour, not any metastases
- In many cases, the primary tumour may be identified in the histology report for a metastatic tumour
 - Record the primary tumour ICD10 code as indicated on the pathology report – if in doubt, consult with the clinical team
 - Details of the site and type of metastases must be recorded under Mets at Diagnosis (i.e. Brain, Lung, Liver, Lymph nodes etc., certainty and whether it's Local / Regional / Distant) for all cases. If the site is Other, please provide details
 - Refer to the relevant site-specific modules for lists of regional lymph nodes – other lymph nodes are normally considered distant but if in doubt, consult with your clinical team
- For new primary diagnoses of a known primary tumour with **distant** metastases, please record an M stage of M1

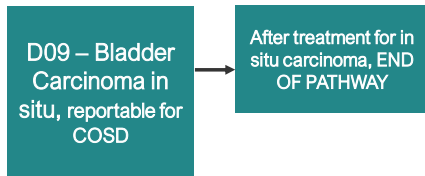
When recording a metastatic cancer, which may be an invasive new primary cancer with mets, a recurrence or a progression, it's important to record the primary ICD10 code correctly. Where the primary tumour has been identified – this would be detailed in the path report - the primary ICD10 code you record would always be relevant to the **primary** cancer, not the metastasis. Details of the site and type of mets would need to be recorded under Mets at Diagnosis. In the case of a new primary diagnosis of a known primary with **distant** mets, the M stage must be recorded as M1.

Topography – Metastatic New Primary Cancers, Recurrences & Progressions

- Recurrences & progressions do not require a stage for COSD
- For the purposes of COSD, **where the primary tumour site is not known**, ICD10 codes C76-C80 inclusive may be used for the primary ICD10 code as appropriate. Staging is not required for these ICD10 codes for the purposes of COSD

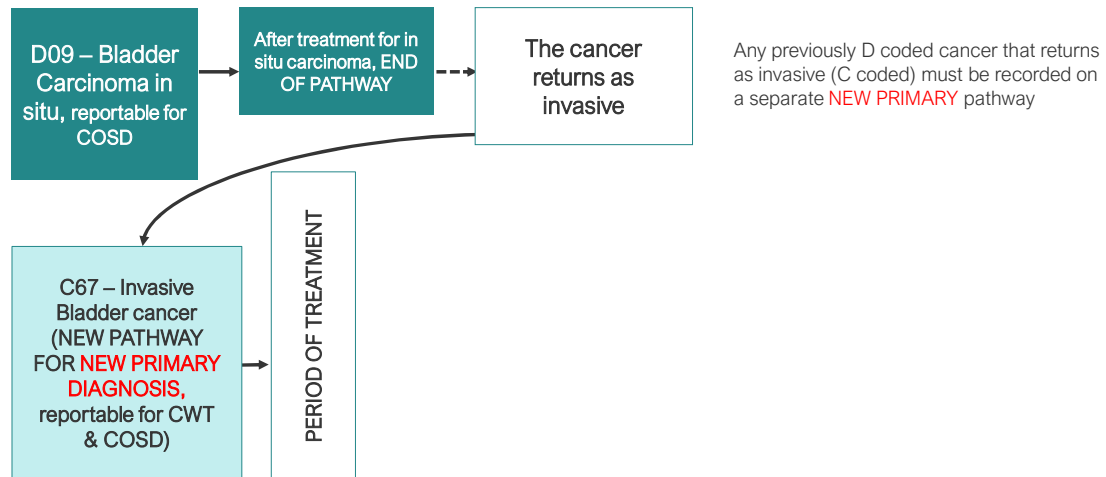
Where the primary tumour site is **unknown**, a secondary tumour ICD10 code, such as C80, may be used instead. Secondary tumour ICD10 codes, recurrences and progressions do not require a stage for the purposes of COSD

Recording a Diagnosis - An example pathway



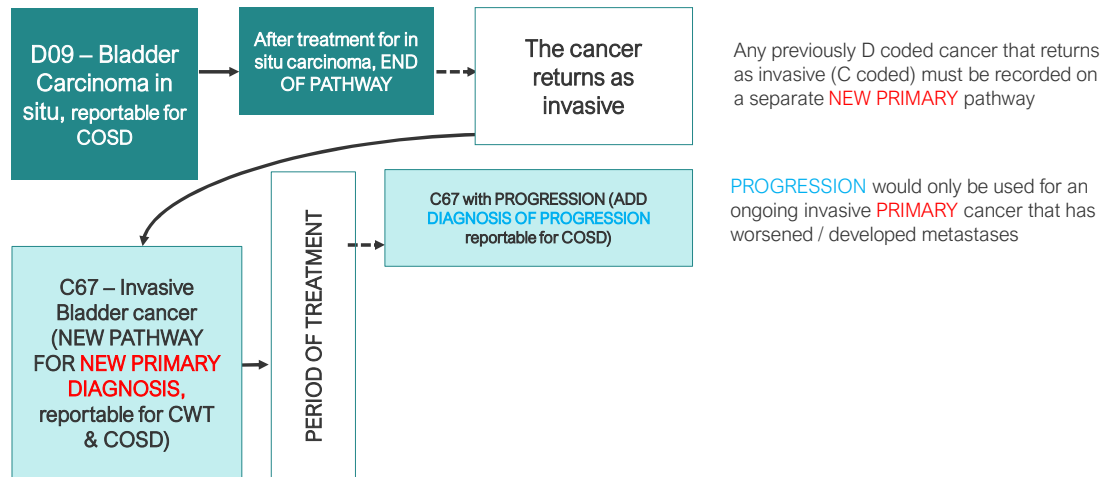
We're now going to look at some scenarios and how you would record them. Using the bladder as an example, this patient has had a non-invasive, in-situ bladder carcinoma which is D coded in ICD10. The tumour has been excised, the carcinoma in-situ recorded, and the pathway closed.

Recording a Diagnosis - An example pathway



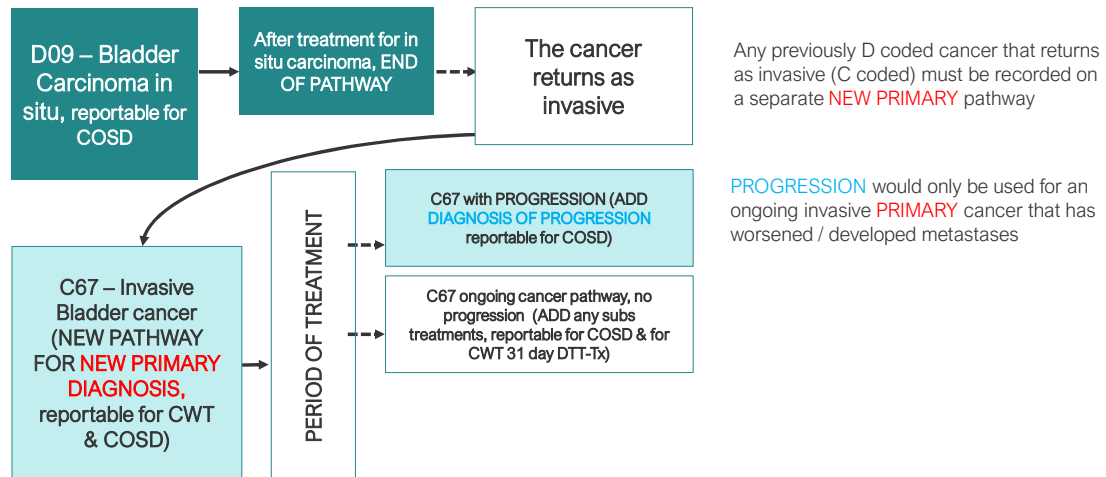
At some point later, the cancer has returned as invasive. Invasive cancers must be C coded and require a new pathway for an invasive new primary diagnosis. There will be a period of treatment, whatever that might be, and after this treatment period, there are several possible outcomes...

Recording a Diagnosis - An example pathway



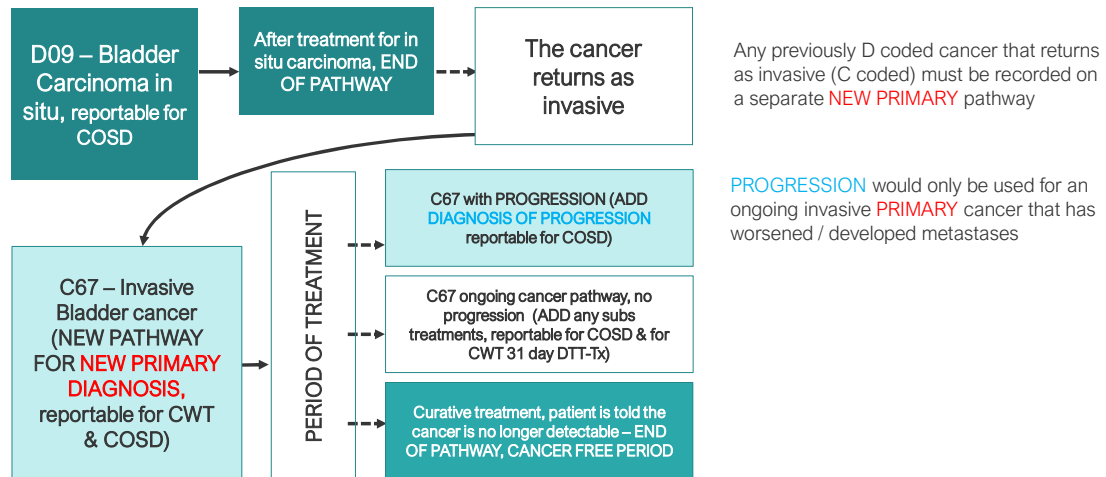
If the patient's treatment does not cure the cancer, they would then be living with an ongoing cancer. If at some point the cancer spreads, this would be a progression diagnosis. In this example, the invasive primary diagnosis is already on the system so the progression diagnosis would be added to that existing pathway.

Recording a Diagnosis - An example pathway



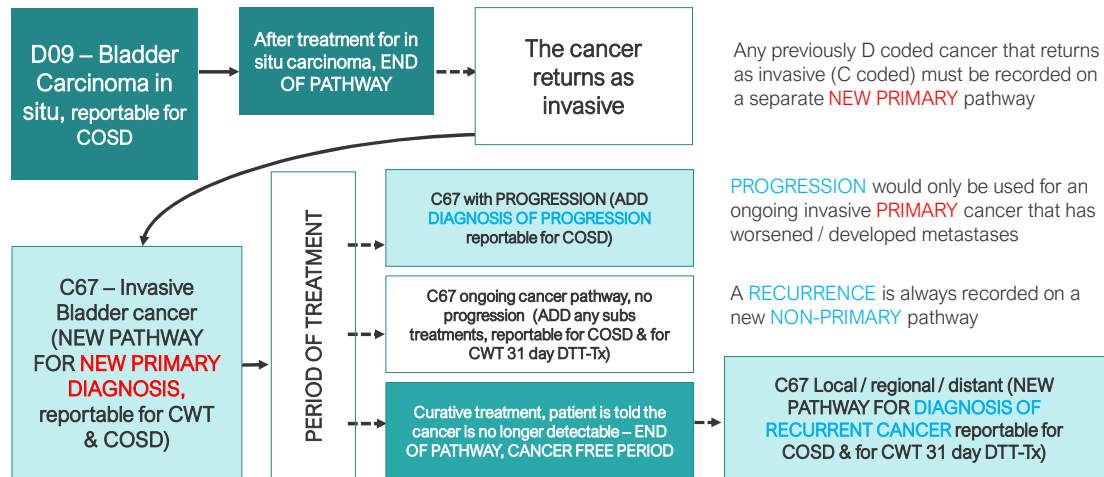
Another possibility may be that the patient is living with their ongoing cancer and the cancer does not progress. In this scenario, any subsequent treatments would be added to the invasive primary pathway in the usual manner...

Recording a Diagnosis - An example pathway



If the treatment successfully removes all signs of the cancer the patient will be told that their cancer is no longer detectable. The pathway is closed and the patient enters a cancer-free period...

Recording a Diagnosis - An example pathway



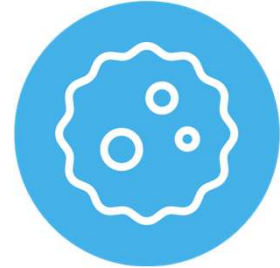
If however, the same invasive cancer returns after a cancer-free period (the length of which is not defined), this would be a recurrence. Recurrences only apply to invasive cancers and may be local, regional or distant. Recurrences are always recorded on a new non-primary pathway.

What if a Diagnosis changes?

Sometimes a diagnosis may be amended by the clinical team after further investigations

It's likely that someone else at your trust submits the COSD data but it can be helpful to understand the process and what triggers a record to be included in the submission

First some background information

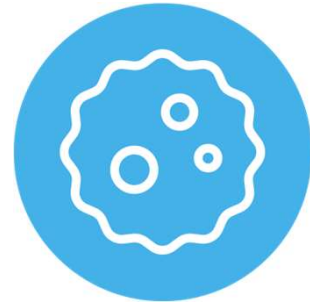


But what if a diagnosis changes? Clinical teams may discover that a diagnosis needs to be amended after further investigations, meaning you'd need to change the diagnosis in your cancer management system. It's helpful here to have an understanding of how your cancer management system extracts data for submission to the Registry

What if a Diagnosis changes?

Cancer data management systems are usually set up to provide a COSD extract, normally for a specified month, based on:

- Diagnosis date (is it within the date range specified for the extract?)
- Diagnosis (is it on our list of registrable conditions? See Appendices A, B & C of the COSD User Guide)



The COSD submission is extracted from your cancer data management system, usually on a monthly basis. Pathways with a registrable condition and a diagnosis date within the specified date range are automatically selected for the extract

What if a Diagnosis changes?

Some cancer management systems automatically include updates to records with registrable conditions diagnosed on other dates (where the pathway has been amended within the specified date range). Other systems do not

These other systems may need a specific box to be ticked or a completely separate refresh file to be uploaded at an agreed interval by the person submitting the data

Only registrable ICD10 codes will be selected for the extract



Some systems also automatically include pathways that have been amended within the specified date range. Other systems require a box to be ticked or a refresh to be sent on an agreed schedule. Either way, only pathways containing a registrable diagnosis are included in the extract.

What if a Diagnosis changes?

Diagnosis change from one registrable condition to another registrable condition (ie: C50.5 to D05.0):

- Diagnosis / amendment date (is it within the date range specified for the extract?) – condition met
- Diagnosis (is it on our list of registrable conditions?) – condition met

Depending on your system, you may not need to do anything or you may need to simply tick a box to include the amended pathway in a COSD submission. If in doubt, please consult with your line manager

If a diagnosis were to change from, for instance, an invasive C50 diagnosis to an in situ D05.0 diagnosis, that wouldn't be an issue. We would be notified as the new diagnosis is a registrable condition.

What if a Diagnosis changes?

Diagnosis change from a registrable condition to a non-registrable condition (ie; C50.5 to “No new cancer”):

- Diagnosis date / amendment date (is it within the date range specified for the extract?) – condition met
- Diagnosis (is it on our list of registrable conditions?) – condition NOT met

This record would not be included in the extract. NDRS would NOT automatically be notified of this change to the diagnosis because the revised condition is not registrable

We need you to tell us

But if a new diagnosis is NOT registrable, if for instance it's changed in the system to “No new Cancer”, it wouldn't be included in the extract. Meaning that the registry would not be informed of this change. We need you to tell us

What if a Diagnosis changes?

Why is this important?

NDRS data needs to be an accurate record. It is used for national reporting, audits and decision making in the healthcare sector

It is also used for patient contact via surveys after a cancer diagnosis

Please let us know when a registrable diagnosis changes to a non-registrable condition so we can update our system



This is important because NDRS data has many uses, including national reporting and decision making in the healthcare sector, so data needs to be accurate. NHS England also uses registry data to send surveys to patients after they've had a cancer diagnosis. Please let us know if a diagnosis changes to a non-registrable condition

What if a Diagnosis changes?

Diagnosis change from a registerable condition to non-registerable condition

Send an email from a secure email system to your Regional Data Liaison Manager's nhs.net email address, detailing:

- Subject line:
 - "Change of diagnosis" (please do not include any patient details in the subject line – unlike the email itself, the subject line is not encrypted)
- In the body of the email:
 - Patient's NHS number & Date of Birth
 - Original diagnosis
 - Original diagnosis date & method
 - New non-registerable diagnosis
 - New diagnosis date & method

We ask that the trust sends a secure email to the relevant Data Liaison Manager's nhs.net email address - The body of the email should detail the basic patient demographics, original diagnosis, diagnosis date & method and the same details for the new diagnosis

What if a Diagnosis changes?

East Midlands: **Simon Cairnes** – simon.cairnes@nhs.net

Eastern: **Marianne Mollett** – marianne.mollett@nhs.net

London & South East: **Katrina Sung** – katrina.sung@nhs.net

London & South East: **Karen Graham** – karen.graham36@nhs.net

North West: **Paul Stacey** – p.stacey@nhs.net

Northern & Yorkshire: **Rachael Mann** – rachaelmann@nhs.net

Oxford: **Gemma Feeney** – gemma.feeney@nhs.net

South West: **James Withers** – james.withers@nhs.net

West Midlands: **Gemma Feeney** – gemma.feeney@nhs.net

The secure email address of your Regional Data Liaison Manager can be found here.

In Summary

- For the purposes of COSD, diagnoses may be for:
 - a new primary
 - a progression
 - a transformation
 - a recurrence

To summarise: for COSD there are several types of diagnosis – primary, progression, transformation and recurrence.

In Summary

- For the purposes of COSD, diagnoses may be for:
 - a new primary
 - a progression
 - a transformation
 - a recurrence
- Primary diagnoses are usually invasive but may be in-situ

Whilst many primary tumours are invasive and as such are C coded in ICD10, COSD also requires you to record selected non-invasive tumours and conditions.

In Summary

- For the purposes of COSD, diagnoses may be for:
 - a new primary
 - a progression
 - a transformation
 - a recurrence
- Primary diagnoses are usually invasive but may be in-situ
- The pathway on which a progression or transformation diagnosis is recorded may depend on whether the original pathway is already in your system

When recording a progression or transformation diagnosis, check first to see if the primary pathway is already on your system. If it isn't you will need to raise a new non-primary pathway

In Summary

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 - a new primary
 - a progression
 - a transformation
 - a recurrence
- Primary diagnoses are usually invasive but may be in-situ
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- Primary diagnoses are usually invasive but may be in-situ
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- If a diagnosis changes to a non-registrable condition, please tell your Regional Data Liaison Manager via a secure email system to their nhs.net email address

And importantly, if a diagnosis changes to a non-registrable condition, please tell us using a secure email system

Questions?

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If you have any questions on the information contained within this module or about COSD in general, do please feel free to email your regional Data Liaison Manager