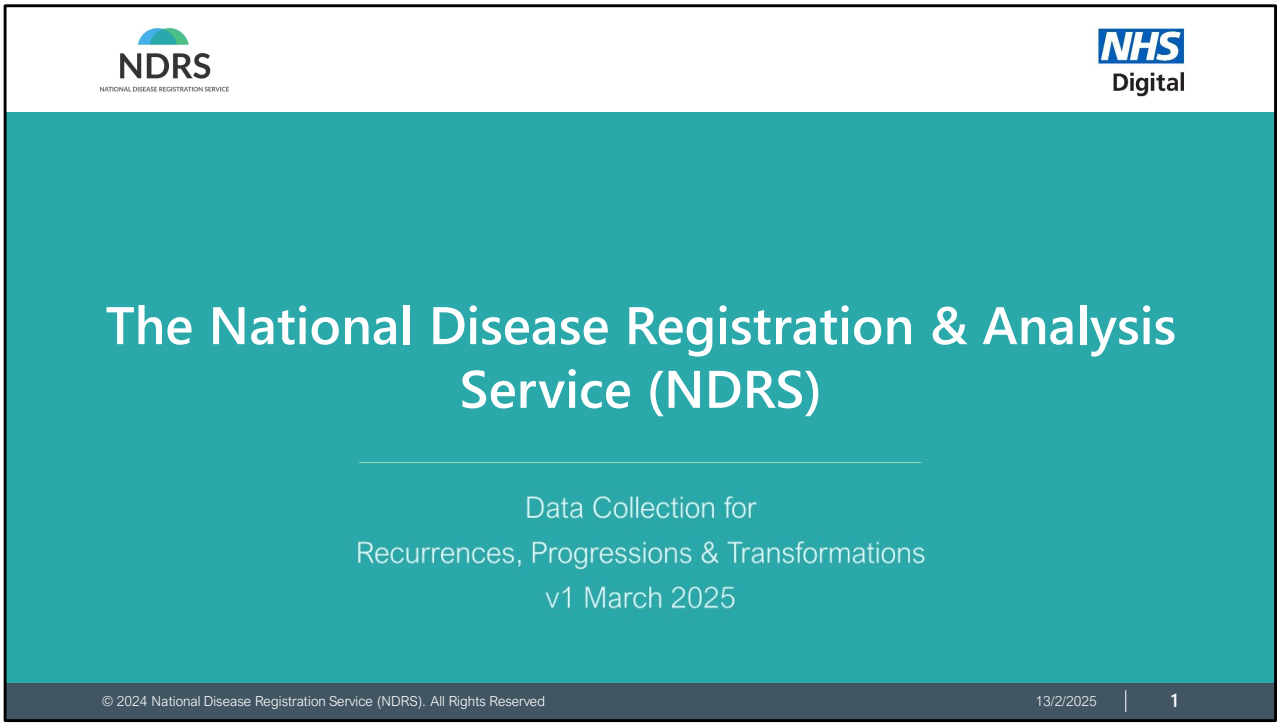
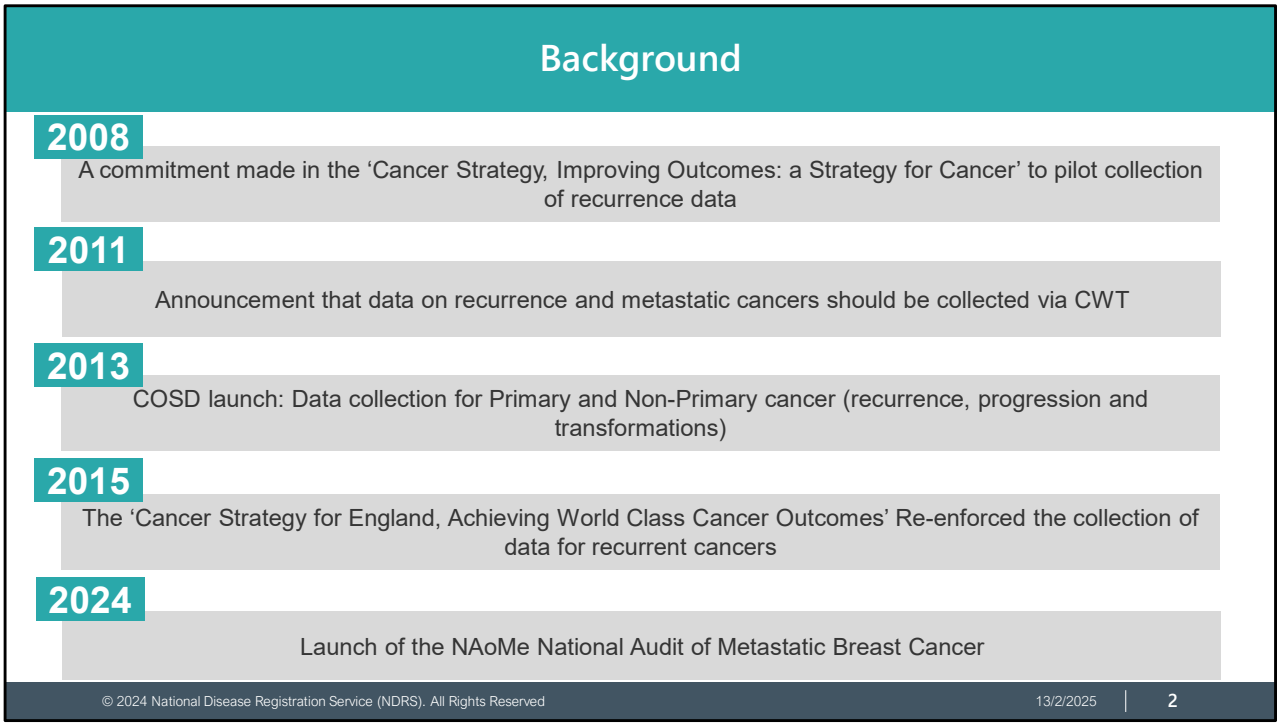


Welcome to this NDRS training module, which has been designed as a guide to data collection for non-primary pathways.



First, a little background. In 2008, a commitment was made to pilot the collection of recurrence data. It took a while for this to actually come about but in 2013, COSD was launched to enable collection of data for both primary **and** non-primary cancers. The Cancer strategy for England reinforced the collection of recurrent cancers in 2015 and in 2024 the new national audit of metastatic breast cancers was launched…

Headlines in 2024

2024

Breast Cancer Network Australia

Incomplete data means those living with metastatic breast cancer are also invisible to our health systems and policymakers. Without this figure we cannot advocate, plan or invest to ensure our health systems are meeting the needs of this group.
https://www.bcna.org.au/latest-news/bcna-news/making-metastatic-breast-cancer-count/

April

BREAST CANCER NOW

'The First ever publication of secondary breast cancer data met with concerns around absence of critical data'

https://breastcancernow.org/about-us/media/press-releases/first-ever-publication-of-secondary-breast-cancer-data-met-with-concerns-around-absence-of-critical-data/

April

CANCER RESEARCH UK

THE LANCET

Lack of information on numbers of people with metastatic breast cancer
'Even though 20-30% of patients with early breast cancer experience relapse, relapse is not typically recorded by most cancer registries. Therefore, the number of patients living with metastatic breast cancer is not known. Meeting the needs of an under-measured patient population is difficult, as a result, feelings of abandonment and isolation are common among those living with the condition. '
https://crukcambridgecentre.org.uk/news/lancet-commission-breast-cancer-publishes-recommendations-change

… the only problem is, in too many cases, the data simply isn't there. Not just in the UK …

Headlines in 2024

October

International Agency for Research on Cancer

World Health Organization

'The number of survivors of breast cancer is growing, but ***the number of women experiencing metastatic recurrence is unknown*** due to a lack of international guidelines for the registration and analysis of recurrence data and support for cancer registries to routinely collect this important data item'
https://www.iarc.who.int/news-events/collecting-long-term-outcomes-in-population-based-cancer-registry-data-the-case-of-breast-cancer-recurrence/

May

METUPUK #DyingForACure

Kat Southwell METUPUK Blog:
'Since recording of MBC data was made mandatory but never adhered to in 2013, just shy of 130,000 women will have died of metastatic breast cancer'

Kat stated **'We are only counted when we are dead'**
https://metupuk.org.uk/2024/05/data-collection-for-metastatic-breast-cancer-we-are-only-counted-when-we-are-dead-kat-southwell/

… but internationally. In her blog for METUPUK Kat Southwell wrote:
Since recording of MBC data was made mandatory (but never adhered to) in 2013, just shy of 130,000 women will have died of metastatic breast cancer.
She also noted: **We are only counted when we are dead.**

Everyone's talking about 'metastatic patients'

Metastatic cancer

- This is where a cancer spreads from where it has started

Metastasis

- The process by which the cancer cells spread

Type

- Local – Cancer has returned in the original tumour site
- Regional – Cancer has spread to regional lymph nodes
- Distant – Cancer that has spread from its original location to other parts of the body it is known as late-stage cancer, Stage 4 cancer or M1 (TNM1)

If a disease changes from an **in-situ** tumour or **non-invasive** lesion (including non-invasive urothelial carcinoma) **to a new primary** invasive lesion, this must be recorded as a **new malignant primary diagnosis of cancer**

The term "metastatic patient" only applies to patients whose primary malignant cancer has spread, either in the form of a recurrence after a cancer-free period, or in the form of spread to other locations for an existing cancer

Definitions of non-primary cancers

Recurrence

When a patient has been told that they are free of cancer ***or*** *when the cancer can not be detected –* ***and has subsequently returned***

Progression

Where a patient is living with a cancer diagnosis and there is a ***change*** *to the* ***spread*** *of cancer*

Transformation

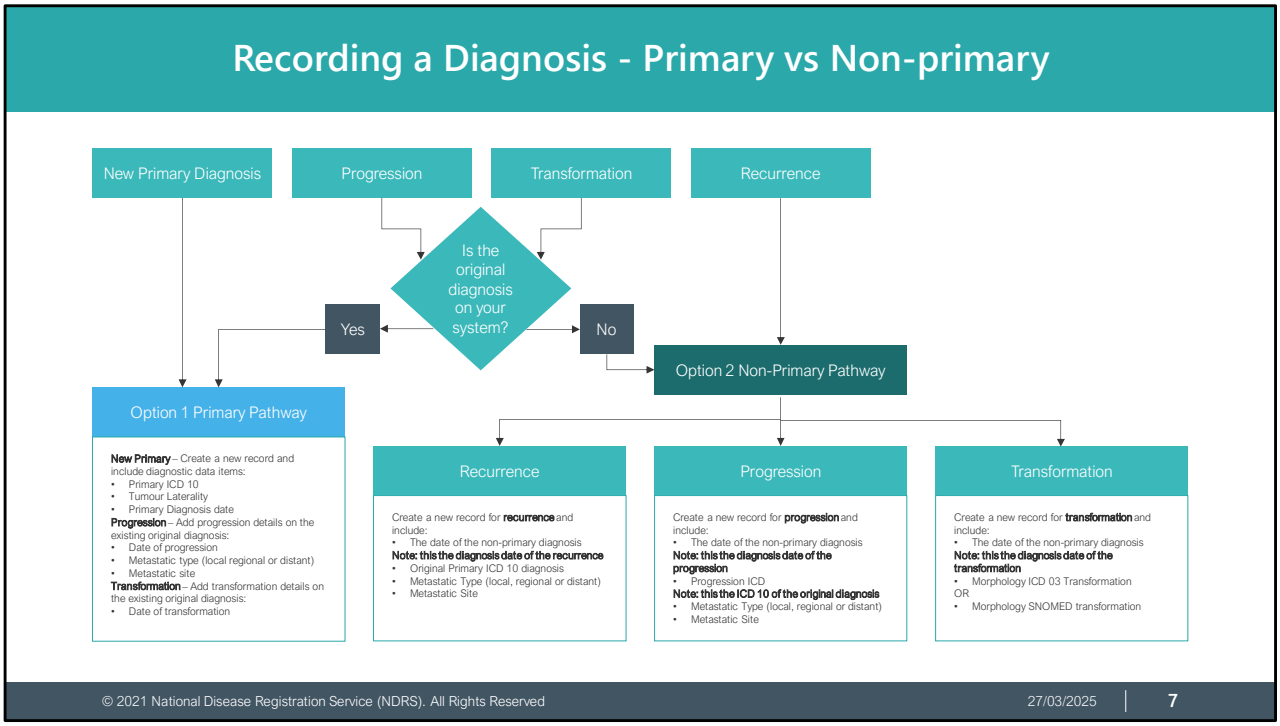
Where there is a ***change*** *in the cancer* ***type***

A Recurrence indicates the reappearance of a malignant cancer where the patient had previously been told their cancer was no longer detectable.

A Progression diagnosis indicates that their existing cancer has **spread** since it was originally diagnosed.

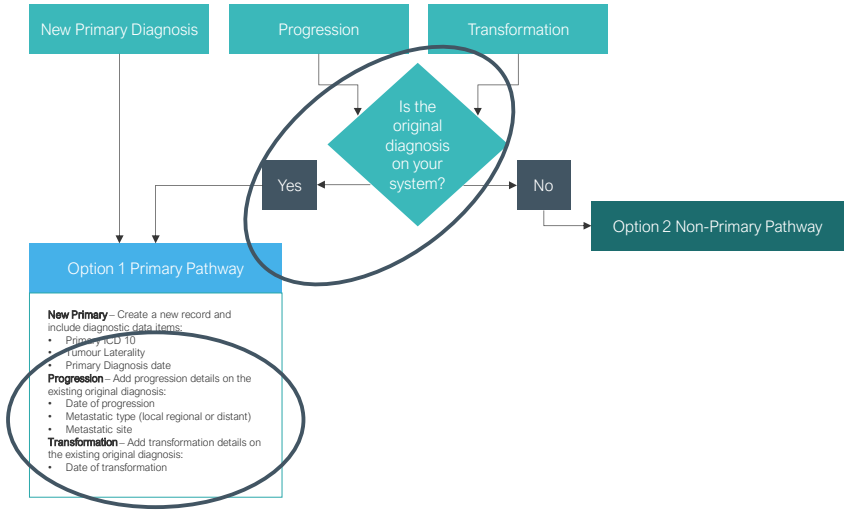
Haematology, Brain/CNS and Sarcoma are the cancer sites where transformations are mainly diagnosed.
A transformation is recorded where there is a change in the cancer type (morphology) or possibly the ICD10 code (this might occur in Haematology).

These are all types of **non-primary pathway**



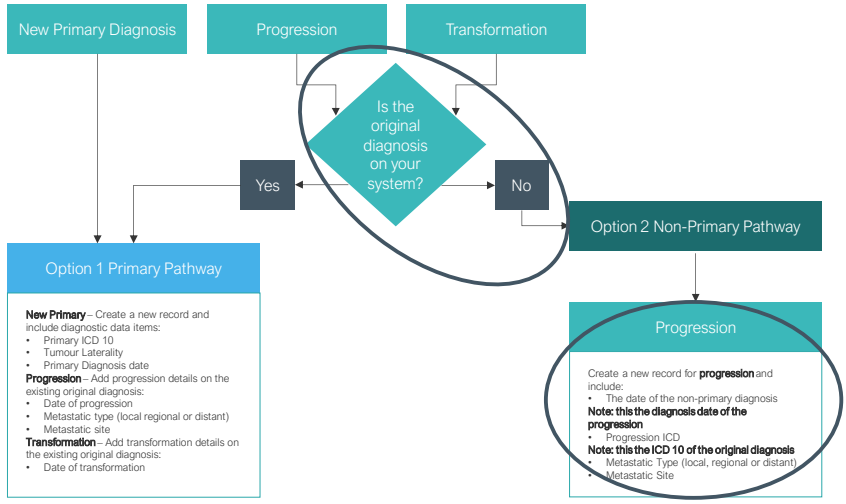
So how do you go about recording these progressions, transformations and recurrences? This graphic is included in the COSD user guide to help you decide. It details the options for recording both primary and non-primary pathways and we're going to go through it step-by-step.

Recording a Diagnosis - Primary vs Non-primary

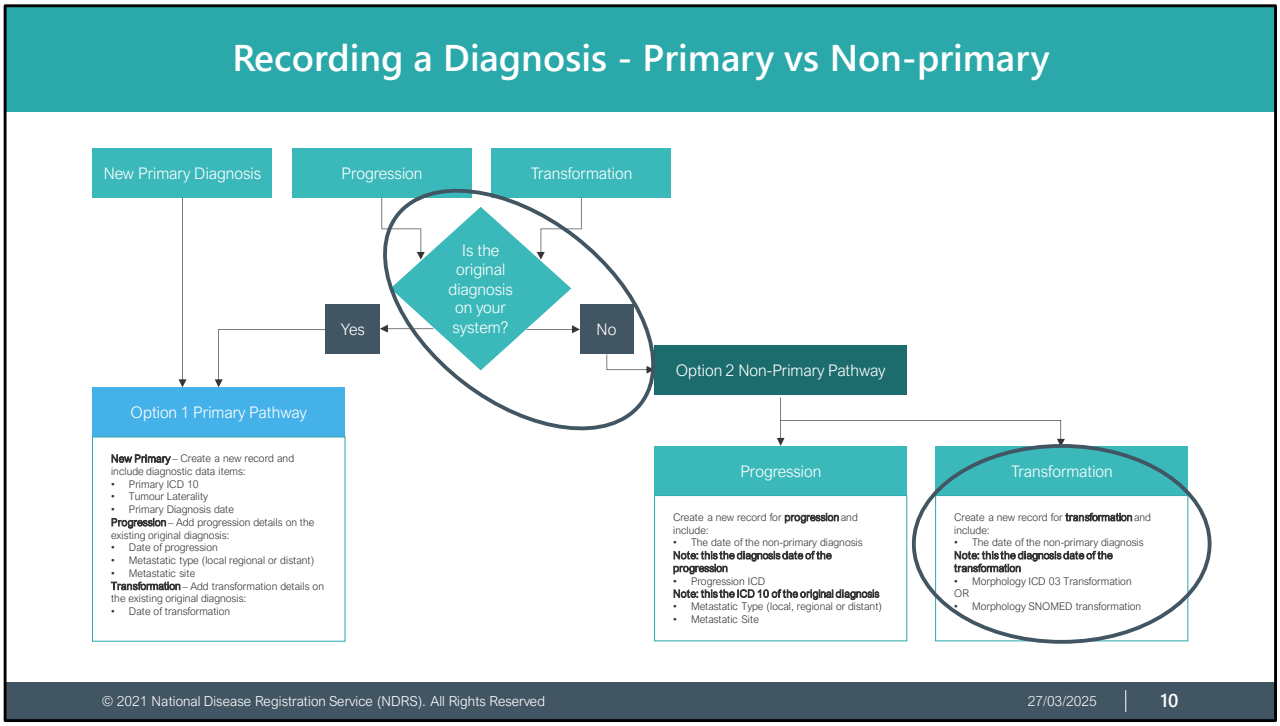


If a patient presents with a progression or a transformation, you must first determine if the original primary diagnosis is already on your cancer management system. If it is, record any progression or transformation on the original primary pathway.

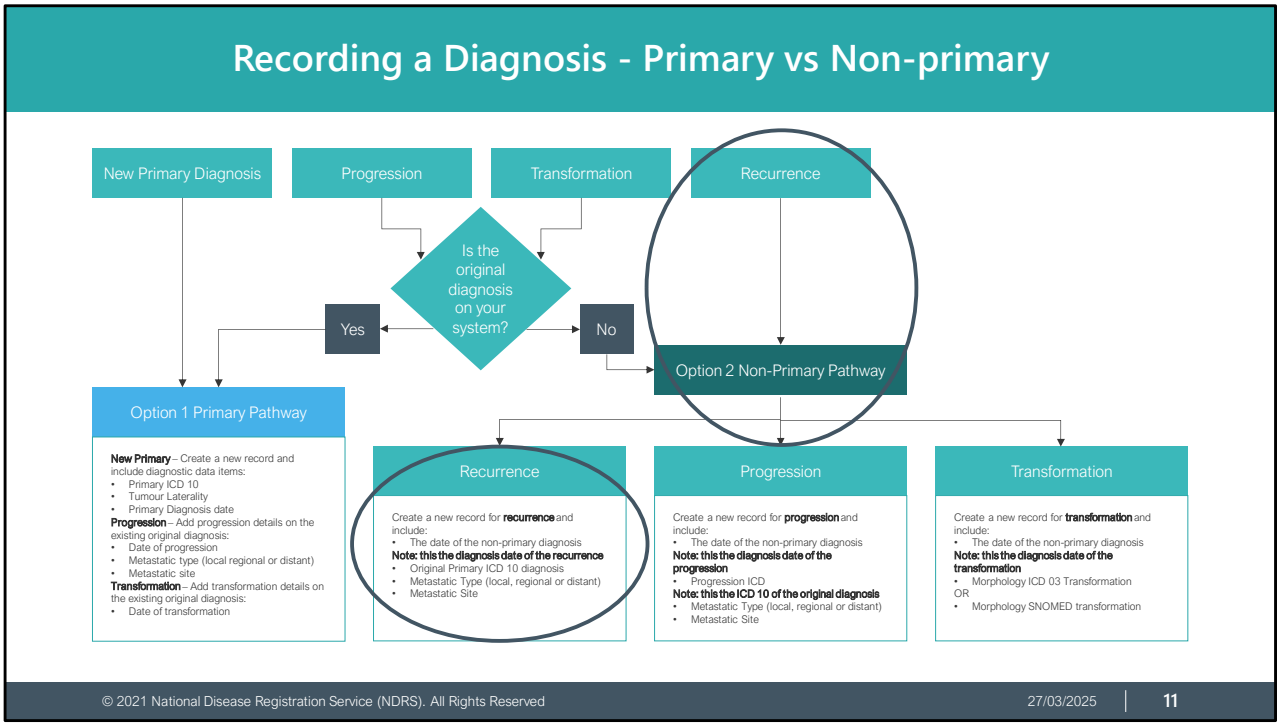
Recording a Diagnosis - Primary vs Non-primary



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. Most cancer systems will automatically classify this as a non-primary pathway when a progression diagnosis is selected.



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. Again, classification as a non-primary pathway is automatic in most systems.



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.

Non-Primary Dataset

All Non-Primary:

- Date of Non-Primary Cancer Diagnosis (Clinically Agreed)
- Original Primary Diagnosis (ICD)
- Metastatic Type
- Metastatic Site
- Palliative Care Specialist Seen Indicator
- Method of Detection

Transformations:

- Morphology (ICD-O-3) Transformation
- Morphology (SNOMED) Transformation
- SNOMED Version Current (Transformation)

The non-primary dataset includes certain basic data items that apply to **all** types of non-primary pathway…

Non-Primary Dataset

All Non-Primary:

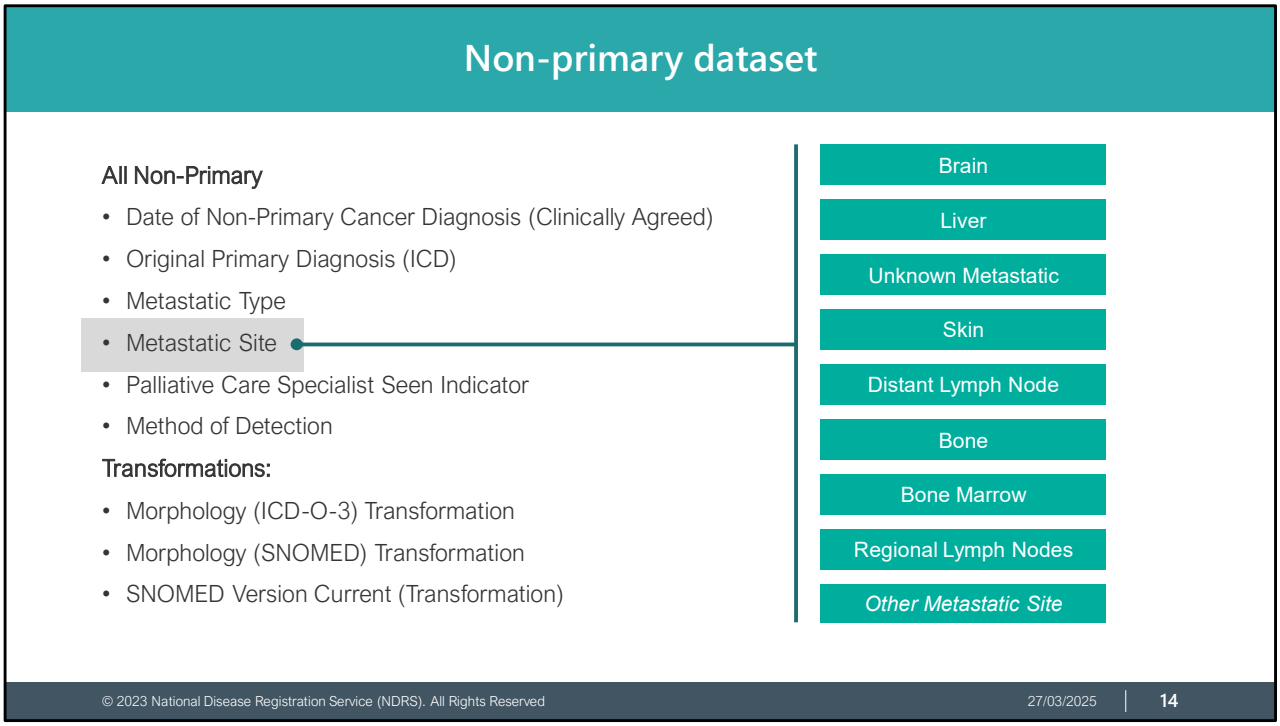
- Date of Non-Primary Cancer Diagnosis (Clinically Agreed)
- Original Primary Diagnosis (ICD)
- Metastatic Type
- Metastatic Site
- Palliative Care Specialist Seen Indicator
- Method of Detection

Transformations:

- Morphology (ICD-O-3) Transformation
- Morphology (SNOMED) Transformation
- SNOMED Version Current (Transformation)

Metastatic Type → **Local** | **Regional** | **Distant**

… which includes the metastatic type, which might be **local** to the original cancer, in the same **region** as the original cancer – this would mean in the regional lymph nodes, or in a **distant** location…



… the metastatic site – are the metastatic deposits in specific organs, regional or distant lymph nodes or somewhere else?...

Non-primary dataset

All non-primary

- Date of Non-Primary Cancer Diagnosis (Clinically Agreed)
- Original Primary Diagnosis (ICD)
- Metastatic Type
- Metastatic Site
- Palliative Care Specialist Seen Indicator
- Method of Detection

Transformations

- Morphology (ICD-O-3) Transformation
- Morphology (SNOMED) Transformation
- SNOMED Version Current (Transformation)

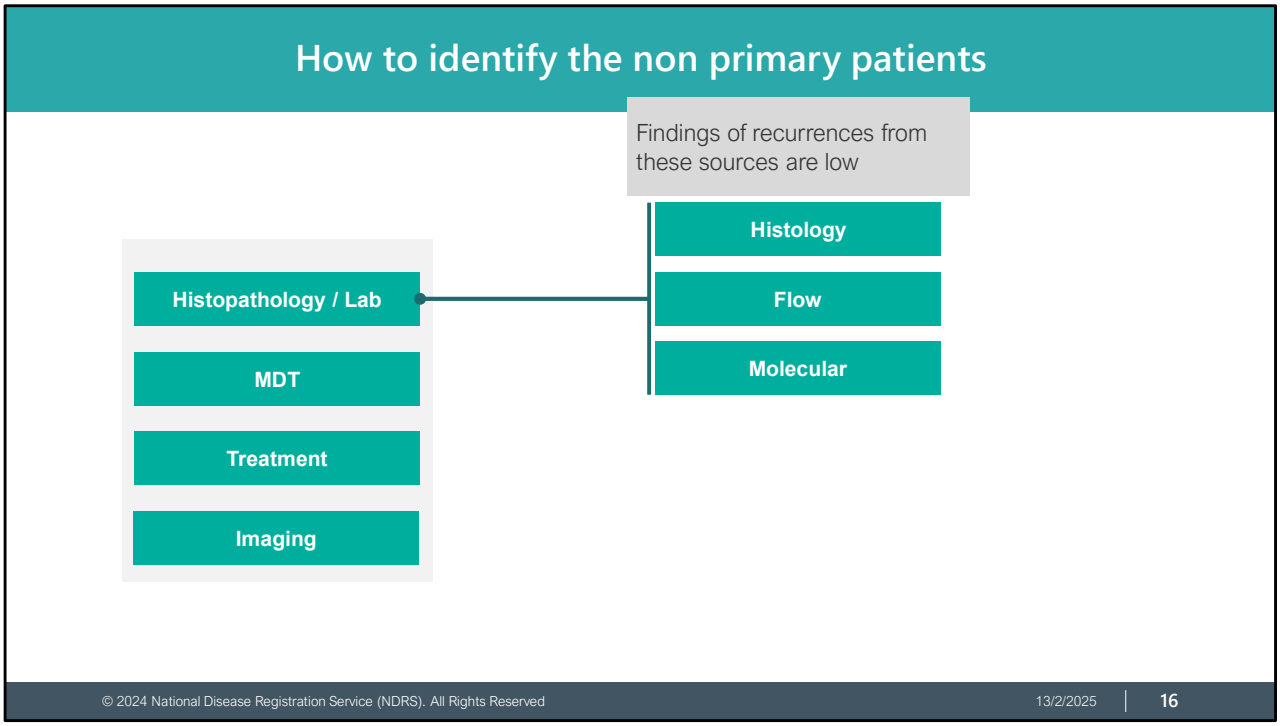
Histology

Flow

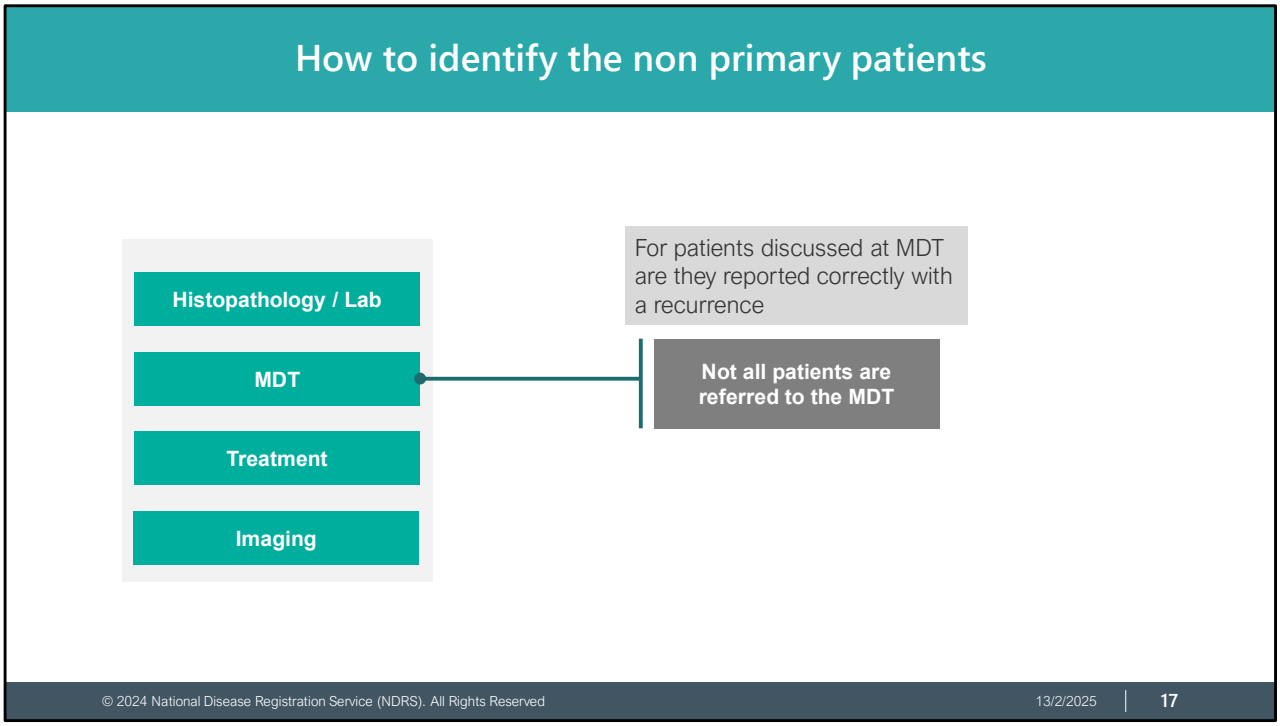
Molecular

Clinical Exam

… and **how** were the metastases found?

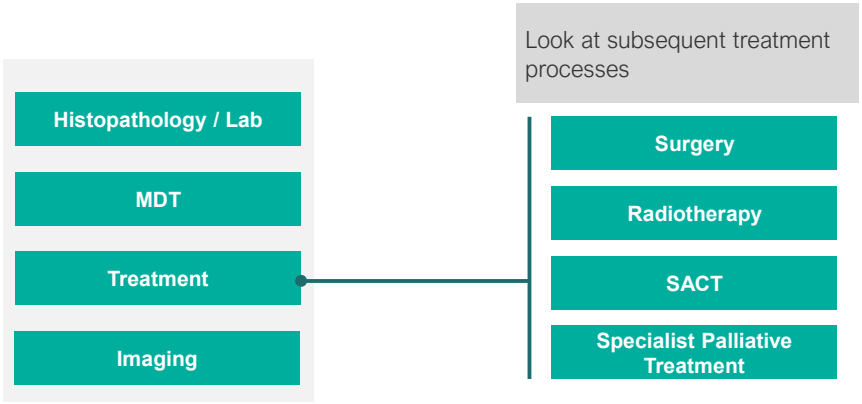


Histological identification of non-primary diagnoses is uncommon …



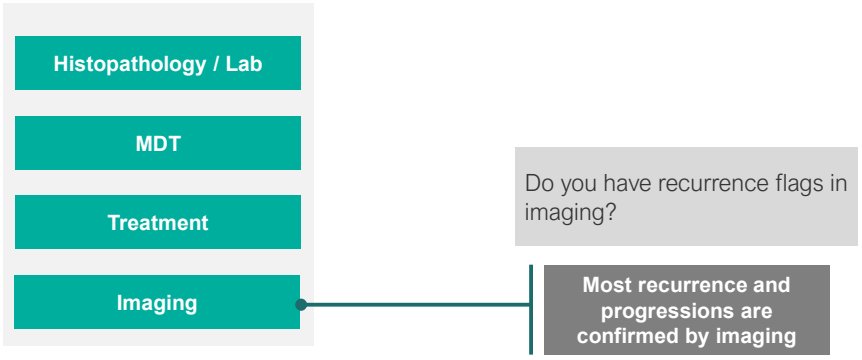
...and not all patients are referred to MDT – we know this but for those that are, are they being reported correctly?

How to identify the non primary patients



Where patients on existing pathways have a subsequent treatment, is this subsequent treatment in response to disease progression and is this progression being recorded?

How to identify the non primary patients



A lot of recurrences and progression will however be confirmed by imaging...

New: Cancer flag in imaging dataset DID's

This is a pilot data item that would be part of the imaging dataset

The CANCER INDICATION CODE (IMAGING) flags that a cancer (or the suspicion of a cancer) has been found and requires further investigation.

01 Confirmation of primary cancer
02 Suspected primary cancer
03 Confirmation of cancer recurrence
04 Suspected cancer recurrence

Planned for release in 2026 there will be a new data item in the Diagnostic Imaging Dataset – this dataset is submitted direct from radiology systems … in the meantime, are the imaging reports that indicate progression being flagged and recorded?

How to identify the non primary patients

In 2024

- Top providers (7) – report between 15% and 29% of their overall COSD submissions on non-primary pathways
- 103 (76%) are reporting under 6%


Referral for new or recurrence


Under follow-up (outpatients)


Incidental finding

The top 7 providers in the country reported between 15 and 29% of their diagnoses as non-primary pathways in 2024 … but ¾ of providers reported less than 6% of their total diagnoses as non-primary pathways.

How to identify the non primary patients

In 2024

- Top providers (7) – report between 15% and 29% of there overall COSD submissions on non-primary pathways
- 103 (76%) are reporting under 6%

Referral for new or recurrence

Under follow-up (outpatients)

Incidental finding

Cancer Management System
- CWT
- COSD

Where a patient is referred in for a suspected new primary cancer that turns out to be a recurrence, these **are** more likely to be recorded because the “suspected cancer” pathway is already in the system…

How to identify the non primary patients

In 2024

- Top providers (7) – report between 15% and 29% of there overall COSD submissions on non-primary pathways
- 103 (76%) are reporting under 6%

Referral for new or recurrence

Under follow-up (outpatients)

Incidental finding

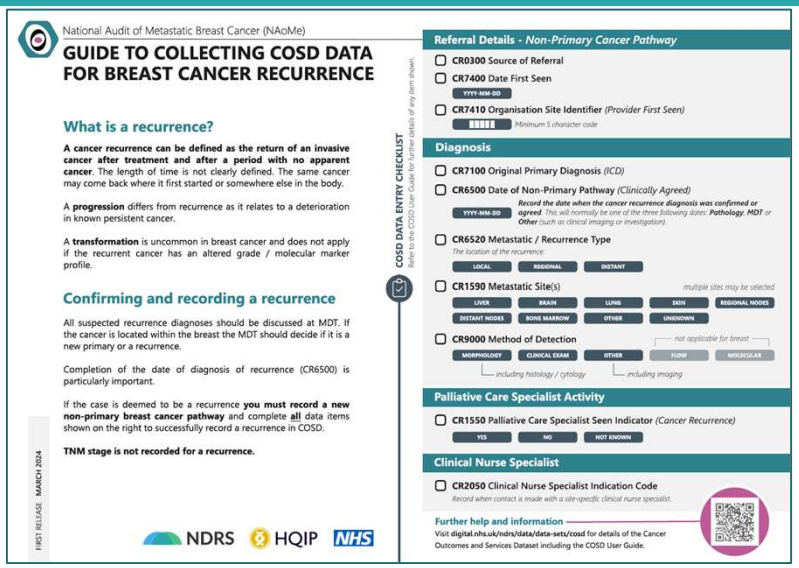
Cancer Management System
- CWT
- COSD

Is there a system for notifying either the MDT or your Cancer Services Administration?

… but what happens where a patient is under out-patient follow up OR there's an incidental finding? Is there a robust system in place to capture **these** non-primary diagnoses?

Tools to support you – Breast and other solid tumour sites

https://digital.nhs.uk/ndrs/data/cancer-data-training-materials



National Audit of Metastatic Breast Cancer (NAoMe)

GUIDE TO COLLECTING COSD DATA FOR BREAST CANCER RECURRENCE

What is a recurrence?

A cancer recurrence can be defined as the return of an invasive cancer after treatment and after a period with no apparent cancer. The length of time is not clearly defined. The same cancer may come back where it first started or somewhere else in the body.

A **progression** differs from recurrence as it relates to a deterioration in known persistent cancer.

A **transformation** is uncommon in breast cancer and does not apply if the recurrent cancer has an altered grade / molecular marker profile.

Confirming and recording a recurrence

All suspected recurrence diagnoses should be discussed at MDT. If the cancer is located within the breast the MDT should decide if it is a new primary or a recurrence.

Completion of the date of diagnosis of recurrence (CR6500) is particularly important.

If the case is deemed to be a recurrence **you must record a new non-primary breast cancer pathway** and complete **all** data items shown on the right to successfully record a recurrence in COSD.

TNM stage is not recorded for a recurrence.

FIRST RELEASE MARCH 2024

NDRS HQIP NHS

COSD DATA ENTRY CHECKLIST

Referral Details - *Non-Primary Cancer Pathway*

- CR0300 Source of Referral
- CR7400 Date First Seen — YYYY-MM-DD
- CR7410 Organisation Site Identifier *(Provider First Seen)* — Minimum 5 character code

Diagnosis

- CR7100 Original Primary Diagnosis *(ICD)*
- CR6500 Date of Non-Primary Pathway *(Clinically Agreed)* — YYYY-MM-DD — *Record the date when the cancer recurrence diagnosis was confirmed or agreed. This will normally be one of the three following dates: **Pathology**, **MDT** or **Other** (such as clinical imaging or investigation).*
- CR6520 Metastatic / Recurrence Type — *The location of the recurrence:* LOCAL | REGIONAL | DISTANT
- CR1590 Metastatic Site(s) — *multiple sites may be selected* — LIVER | BRAIN | LUNG | SKIN | REGIONAL NODES | DISTANT NODES | BONE MARROW | OTHER | UNKNOWN
- CR9000 Method of Detection — *not applicable for breast* — MORPHOLOGY *including histology / cytology* | CLINICAL EXAM | OTHER | FLOW | MOLECULAR *including imaging*

Palliative Care Specialist Activity

- CR1550 Palliative Care Specialist Seen Indicator *(Cancer Recurrence)* — YES | NO | NOT KNOWN

Clinical Nurse Specialist

- CR2050 Clinical Nurse Specialist Indication Code — *Record when contact is made with a site-specific clinical nurse specialist.*

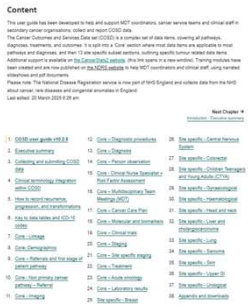
Further help and information

Visit **digital.nhs.uk/ndrs/data/data-sets/cosd** for details of the Cancer Outcomes and Services Dataset including the COSD User Guide.

Where recurrences are found, we have a tool to help you with the recording. This downloadable PDF was put together for recurrences in Breast cancer but in truth can be applied to recurrences for **all solid tumour sites** and is available to download from our training modules page

Tools to support you

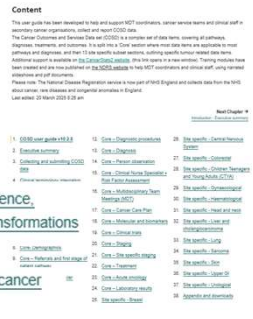
COSD User Guide (online):
https://digital.nhs.uk/ndrs/data/data-sets/cosd/cosd-user-guide-v10



There's also help available in the COSD guidance…

Tools to support you

COSD User Guide (online):
https://digital.nhs.uk/ndrs/data/data-sets/cosd/cosd-user-guide-v10



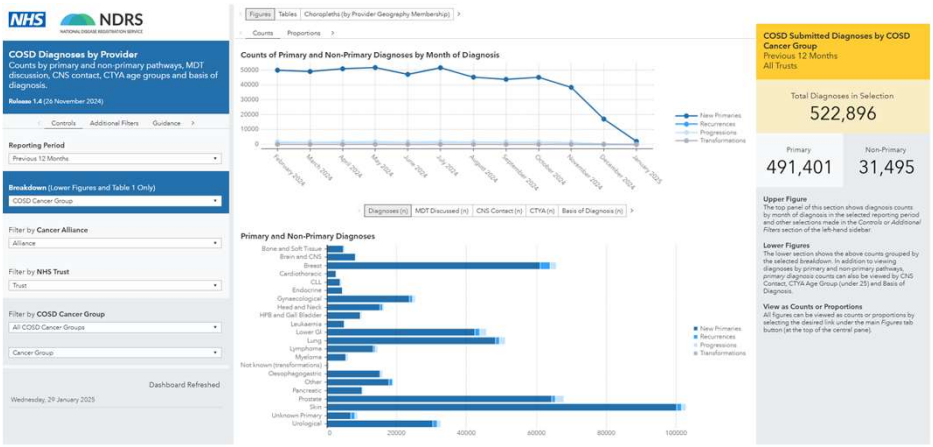
5. How to record recurrence, progression, and transformations

10. Core - Non primary cancer pathway – Referral

… specifically in sections 5 and 10 which guide administrators through the necessary data items…

Tools to support you

CancerStats:
https://cancerstats.ndrs.nhs.uk/



…we also have feedback for you – **types** of diagnosis are shown in the Diagnoses dashboard on Cancerstats. If you want to know what your data looks like but don't have a CancerStats account – go to the link shown and sign up…

Tools to support you

Your Regional Data Liaison Manager:

East Midlands & West Yorkshire: **Simon Cairnes** – simon.cairnes@nhs.net
Eastern: **Marianne Mollett** – marianne.mollett@nhs.net
London & South East: **Katrina Sung** – katrina.sung@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

… and don't forget that NDRS is a resource too! We're here to help.

Wrapping Up

- Over recent years the focus for Trusts has been improving stage data
  - 10 years ago, it was said what you are achieving wouldn't be possible
- We need to show the same commitment with recording recurrences and progressions
- We don't how many people are living with metastatic cancer
- It can take years of data before trends, something meaningful, can be identified
- For every year we don't collect this well, it means another year where this work can't even begin

Trust focus in the last few years has been on improving stage, something that was not, at the time, universally accepted as possible – **but you went and did it anyway**, demonstrating extraordinary commitment to the gathering of accurate data on new primary cancers. We're now being asked to demonstrate that same level of commitment for non-primary pathways because we **genuinely** don't know how many people are living with metastatic cancer. Accumulating a meaningful amount of data takes years: the sooner we start getting the data **in**, the sooner we can **work** with it.

Let's change this statement

Data collection for metastatic breast cancer,

"we are only counted when we are dead"

– Kat Southwell – METUPUK

We can change this.