

# The National Disease Registration & Analysis Service (NDRS)

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Data Collection for  
Recurrences, Progressions & Transformations  
Data Liaison Manager – James Withers

# Background

**2008**

A commitment made in the 'Cancer Strategy, Improving Outcomes: a Strategy for Cancer' to pilot collection of recurrence data

**2011**

Announcement that data on recurrence and metastatic cancers should be collected via CWT

**2013**

COSD launch: Data collection for Primary and Non-Primary cancer (recurrence, progression and transformations)

**2015**

The 'Cancer Strategy for England, Achieving World Class Cancer Outcomes' Re-enforced the data collection of recurrence cancers

**2024**

Launch of the NAOme National Audit of Metastatic Breast Cancer

# 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.

April



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

April

THE LANCET

**Lack of information on numbers of people with metastatic**

'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.'

# Headlines in 2024

October

## International Agency for Research on Cancer



'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'

May



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'

# Everyone's talking about 'metastatic patients'

## Metastatic cancer

- This is where the 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** cancer 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**

# 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***

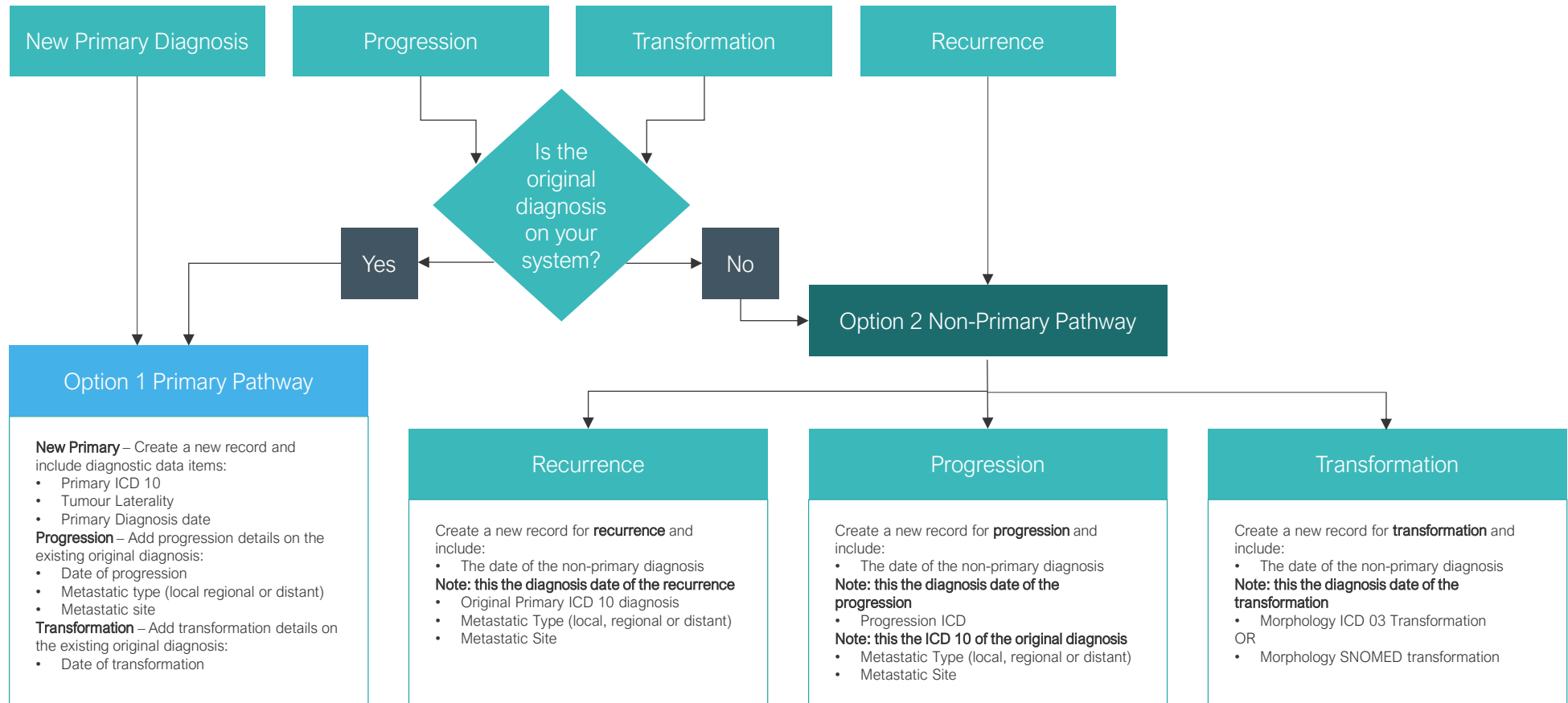
## Progression

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

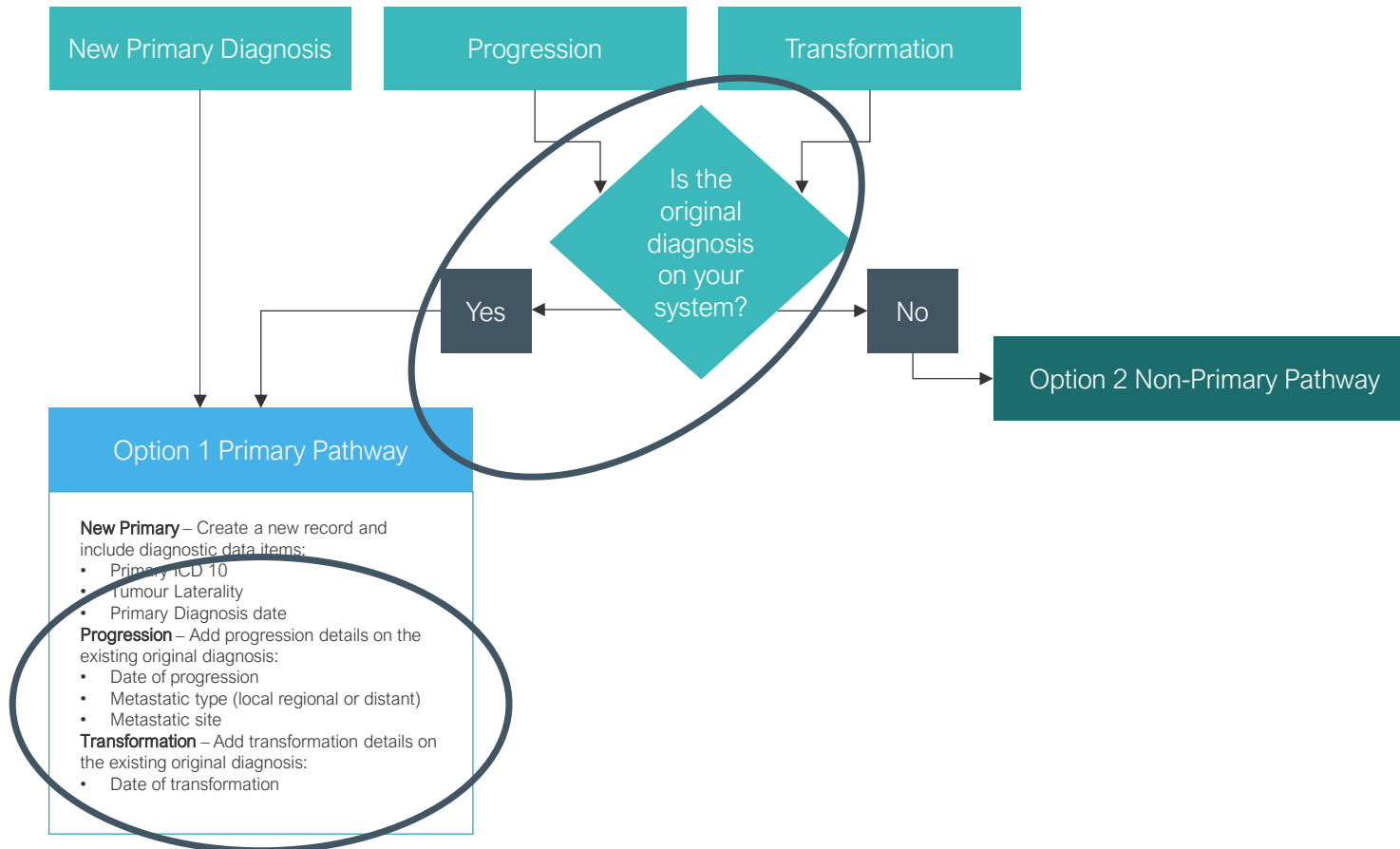
## Transformation

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

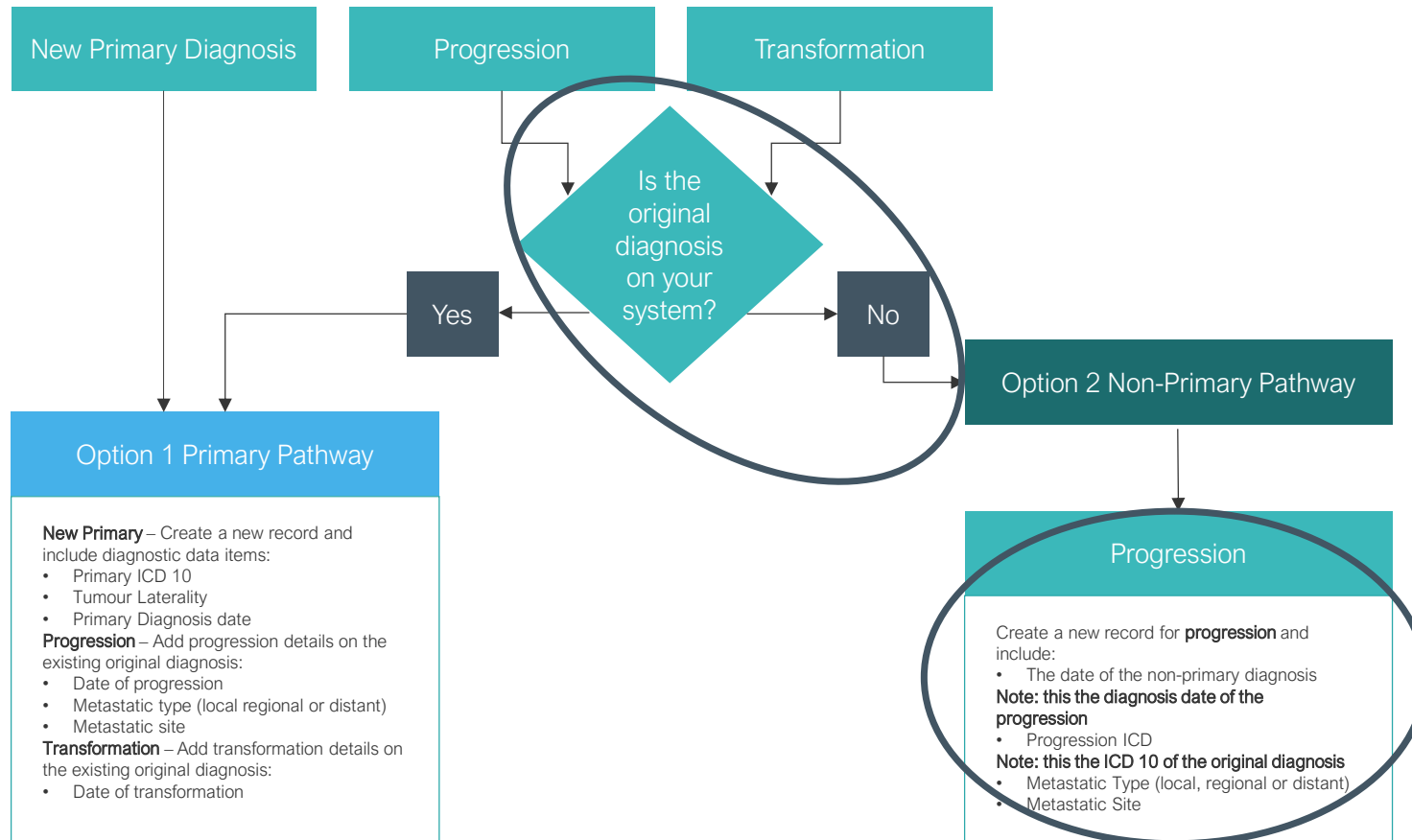
# Recording a Diagnosis - Primary vs Non-primary



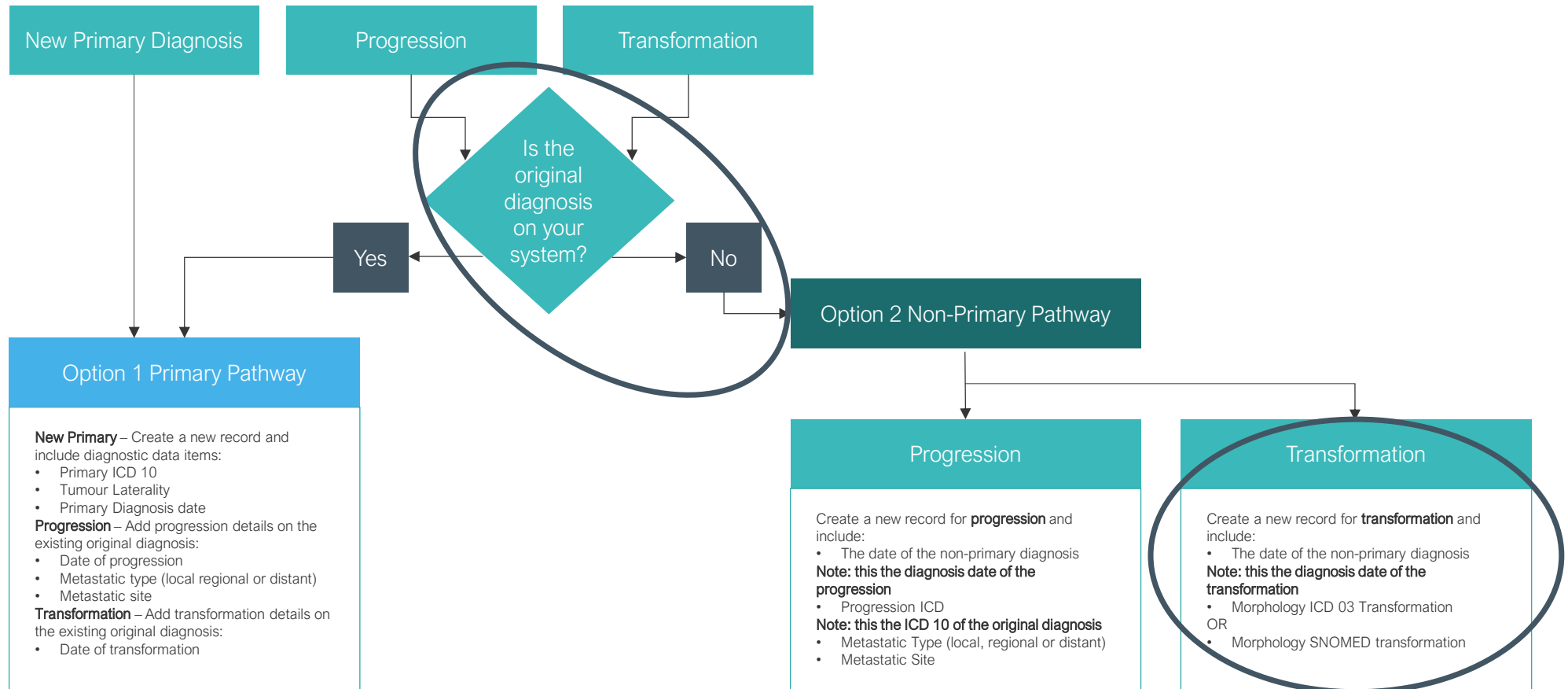
# Recording a Diagnosis - Primary vs Non-primary



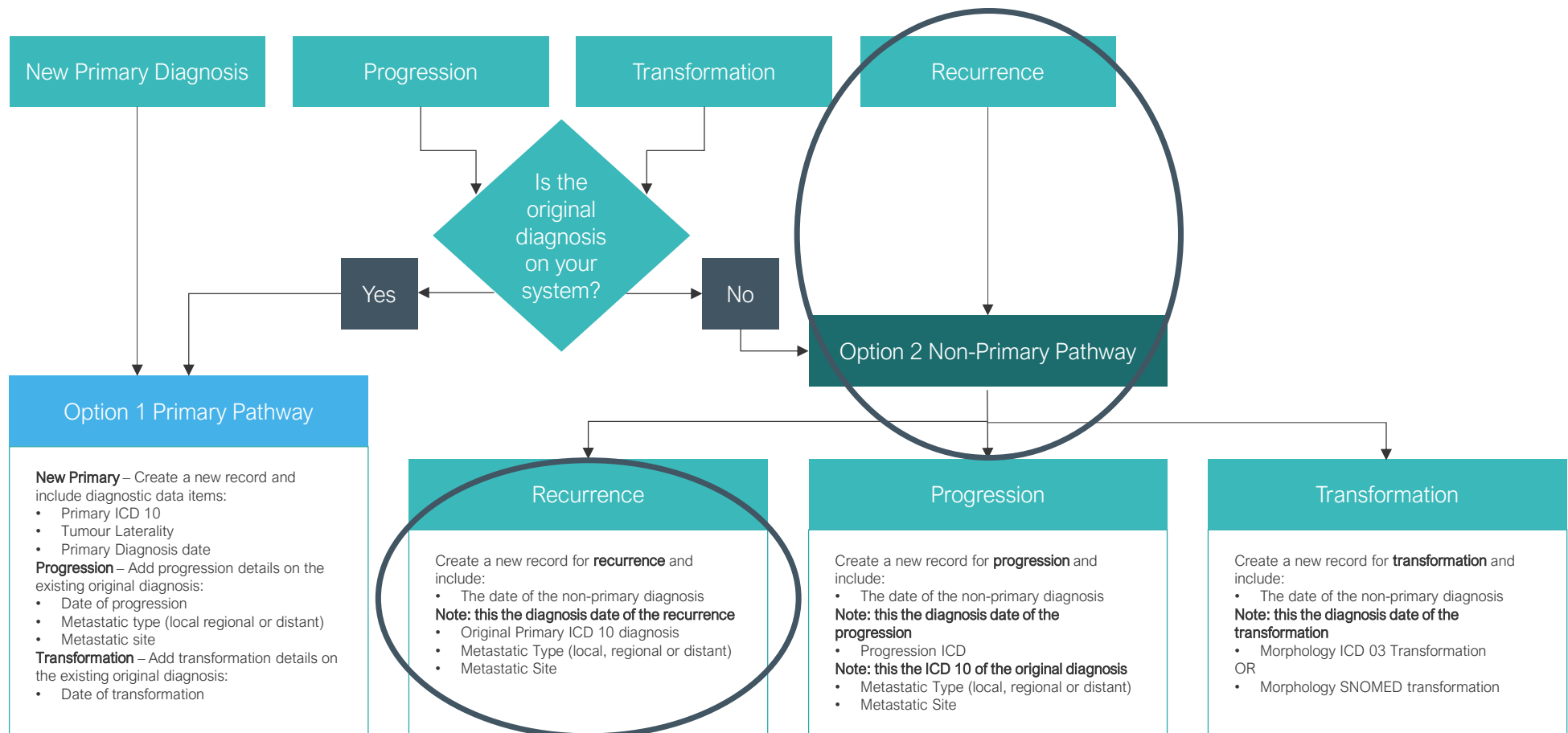
# Recording a Diagnosis - Primary vs Non-primary



# Recording a Diagnosis - Primary vs Non-primary



# Recording a Diagnosis - Primary vs Non-primary



# 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)

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Local

Regional

Distant

# Non-primary dataset

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## Transformations:

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

Brain

Liver

Unknown Metastatic

Skin

Distant Lymph Node

Bone

Bone Marrow

Regional Lymph Nodes

*Other Metastatic Site*

# Non-primary dataset

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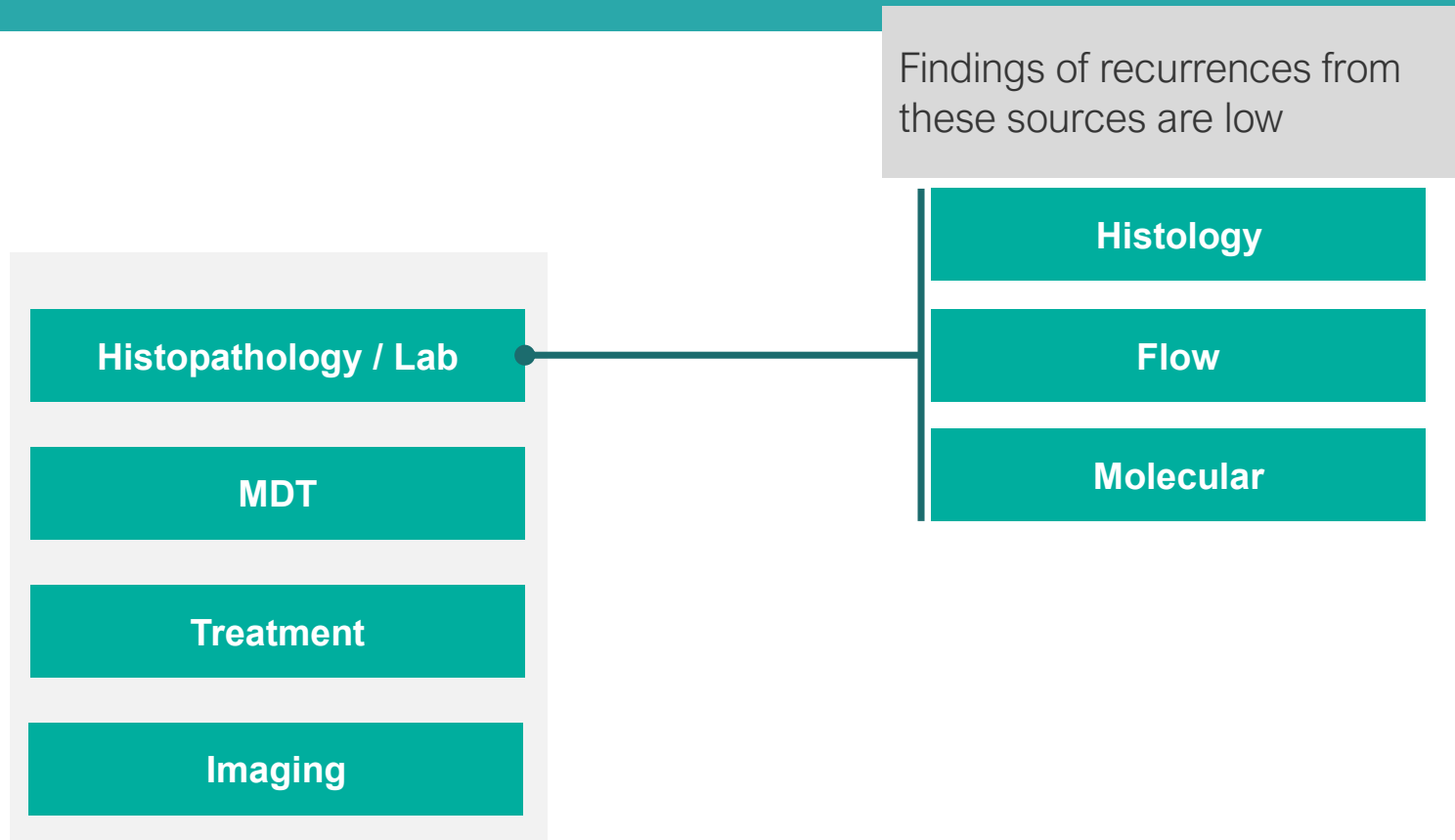
**Histology**

**Flow**

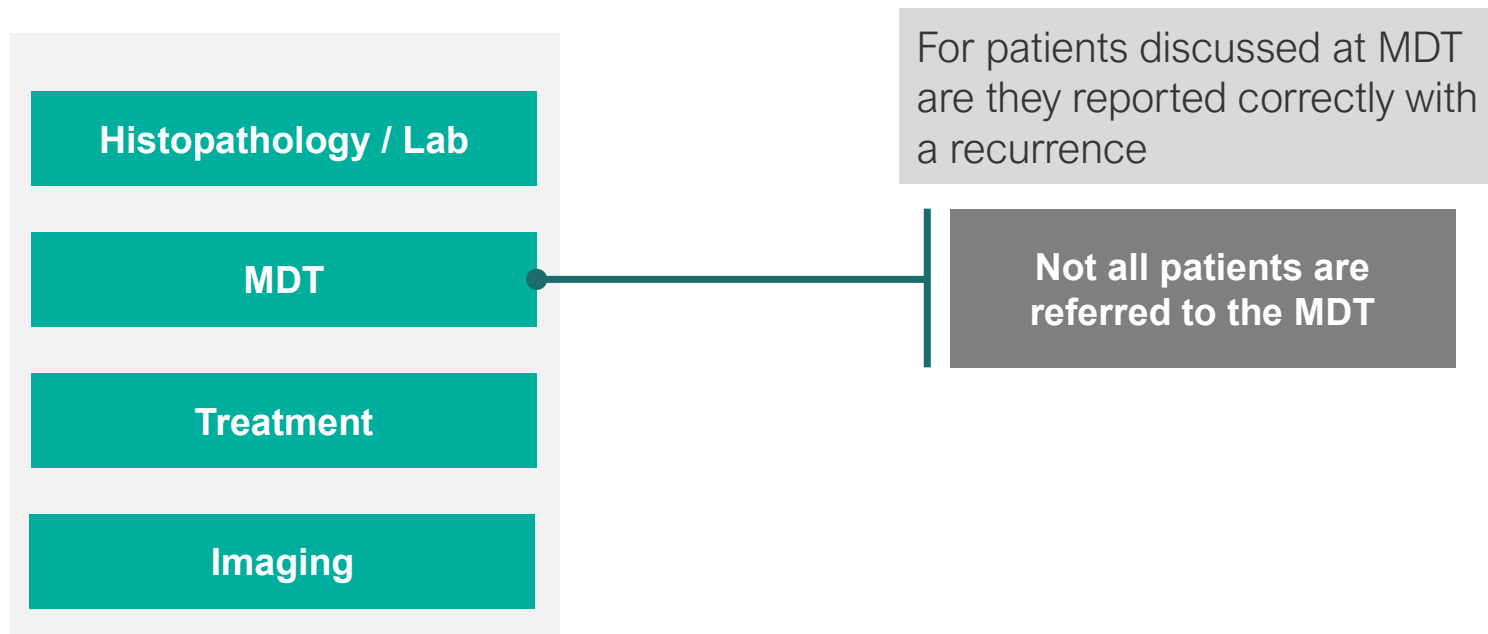
**Molecular**

**Clinical Exam**

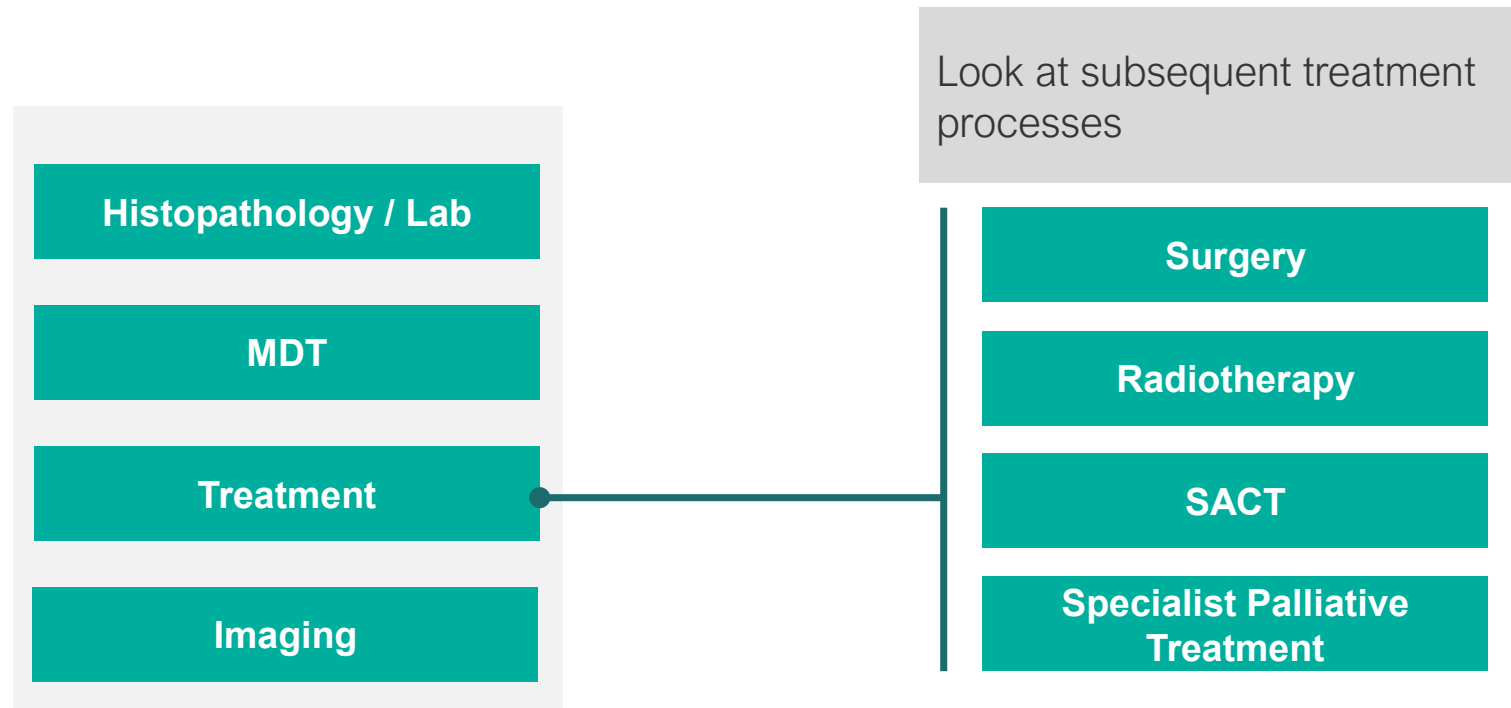
# How to identify the non primary patients



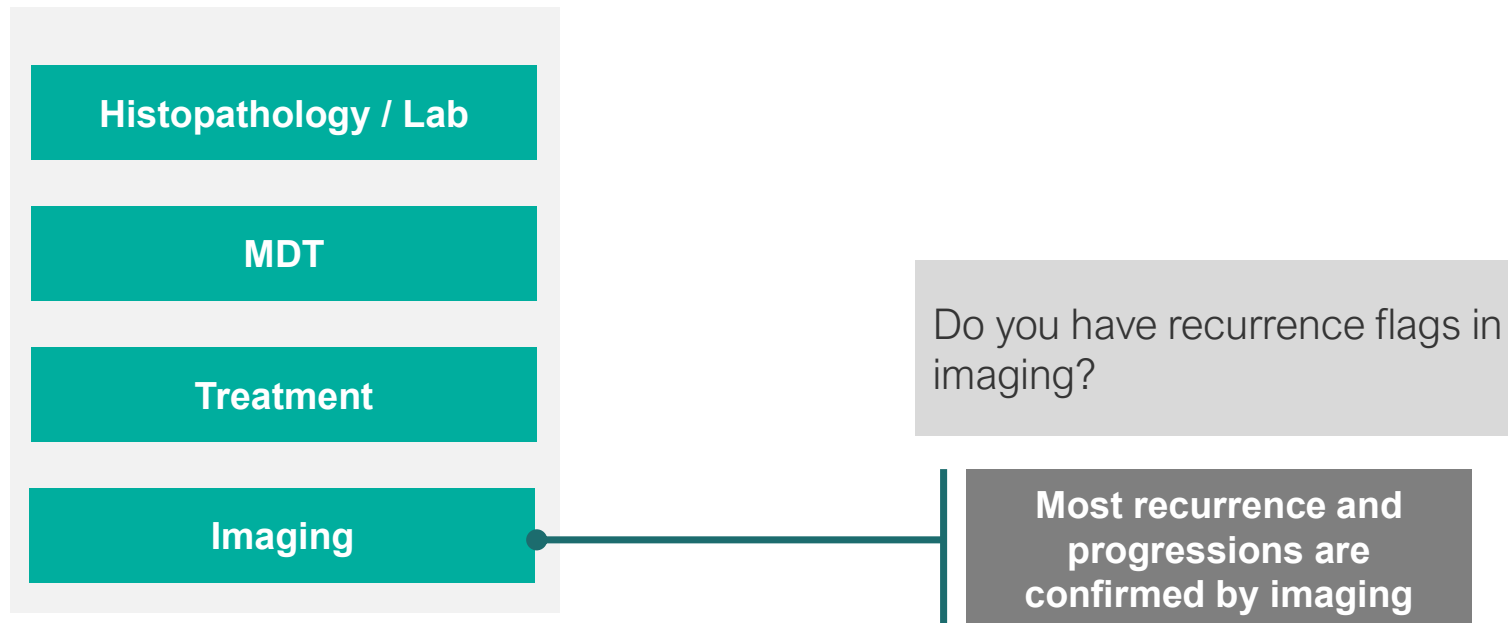
# How to identify the non primary patients



# How to identify the non primary patients



# How to identify the non primary patients



# 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

# 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

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Referral for new or recurrence



Under follow-up (outpatients)



Incidental finding

Cancer Management System

- CWT
- COSD

# How to identify the non primary patients

In 2024

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- 103 (76%) are reporting under 6%



Referral for new or recurrence

Cancer Management System

- CWT
- COSD



Under follow-up (outpatients)

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



Incidental finding

# Resources 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



COSD DATA ENTRY CHECKLIST  
Refer to the COSD User Guide for further details of any item shown.

### 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 CLINICAL EXAM OTHER FLOW MOLECULAR  
*including histology / cytology 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](https://digital.nhs.uk/ndrs/data/data-sets/cosd) for details of the Cancer Outcomes and Services Dataset including the COSD User Guide.



# Resources to support you

COSD User Guide (online):

<https://digital.nhs.uk/ndrs/data/data-sets/cosd/cosd-user-guide-v10>

### COSD user guide v10.2.8

This guide supports users with the implementation and collection of data as part of the Cancer Outcomes and Services Data set (COSD) v10.2.8

**Date Published:** 9 September 2023

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COSD user guide v10.2.8  
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## Content

This user guide has been developed to help and support MDT coordinators, cancer service teams and clinical staff in secondary cancer organisations, collect and report COSD data. The Cancer Outcomes and Services Data set (COSD) is a complex set of data items, covering all pathways, diagnoses, treatments, and outcomes. It is split into a 'Core' section where most data items are applicable to most pathways and diagnoses, and then 13 site specific sub-sections, outlining specific tumour related data items. Additional support is available on [the CancerStats website](#), (this link opens in a new window). Training modules have been created and are now published on [the NDRS website](#) to help MDT coordinators and clinical staff, using narrated slideshows and pdf documents.

Please note: The National Disease Registration service is now part of NHS England and collects data from the NHS about cancer, rare diseases and congenital anomalies in England.  
Last edited: 20 March 2025 8:20 am

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| <a href="#">2. Executive summary</a>  | <a href="#">13. Core - Diagnosis</a>   | <a href="#">27. Site specific - Colorectal</a>                                 |
| <a href="#">3. Collecting and submitting COSD data</a>                        | <a href="#">14. Core - Person observation</a>                                | <a href="#">28. Site specific - Children Teenagers and Young Adults (CTYA)</a> |
| <a href="#">4. Clinical terminology integration within COSD</a>               | <a href="#">15. Core - Clinical Nurse Specialist+ Risk Factor Assessment</a> | <a href="#">29. Site specific - Gynaecological</a>                             |
| <a href="#">5. How to record recurrence, progression, and transformations</a> | <a href="#">16. Core - Multidisciplinary Team Meetings (MDT)</a>             | <a href="#">30. Site specific - Haematological</a>                             |
| <a href="#">6. Key to data tables and ICD-10 codes</a>                        | <a href="#">17. Core - Cancer Care Plan</a>                                  | <a href="#">31. Site specific - Head and neck</a>                              |
| <a href="#">7. Core - Linkage</a>   | <a href="#">18. Core - Molecular and biomarkers</a>                          | <a href="#">32. Site specific - Liver and cholangiocarcinoma</a>               |
| <a href="#">8. Core - Demographics</a>  | <a href="#">19. Core - Clinical trials</a>                                   | <a href="#">33. Site specific - Lung</a>                                       |
| <a href="#">9. Core - Referrals and first stage of patient pathway</a>        | <a href="#">20. Core - Staging</a>   | <a href="#">34. Site specific - Sarcoma</a>                                    |
| <a href="#">10. Core - Non primary cancer pathway - Referral</a>              | <a href="#">21. Core - Site specific staging</a>                             | <a href="#">35. Site specific - Skin</a>                                       |
| <a href="#">11. Core - Imaging</a>  | <a href="#">22. Core - Treatment</a>   | <a href="#">36. Site specific - Upper GI</a>                                   |
|   | <a href="#">23. Core - Acute oncology</a>                                    | <a href="#">37. Site specific - Urological</a>                                 |
|   | <a href="#">24. Core - Laboratory results</a>                                | <a href="#">38. Appendix and downloads</a>                                     |
|   | <a href="#">25. Site specific - Breast</a>                                   |  |

# Resources to support you

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# Resources to support you

CancerStats:

<https://cancerstats.ndrs.nhs.uk/>

**NHS NDRS**  
NATIONAL DISEASE REGISTRATION SERVICE

**COSD Diagnoses by Provider**  
Counts by primary and non-primary pathways, MDT discussion, CNS contact, CTYA age groups and basis of diagnosis.  
Release 1.4 (26 November 2024)

Controls Additional Filters Guidance

Reporting Period  
Custom Period (Additional Filters)

Breakdown (Lower Figures and Table 1 Only)  
COSD Cancer Group

Filter by Cancer Alliance  
Wessex

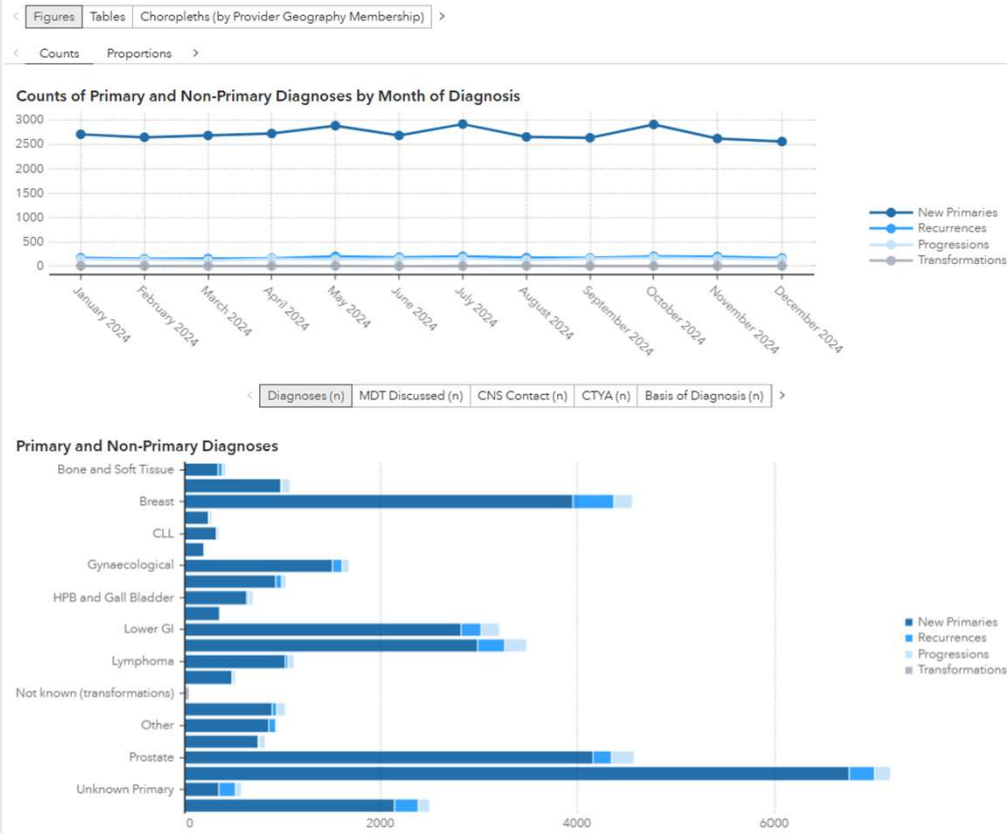
Filter by NHS Trust  
Trust

Filter by COSD Cancer Group  
All COSD Cancer Groups

Cancer Group

Dashboard Refreshed

Tuesday, 7 October 2025



**COSD Submitted Diagnoses by COSD Cancer Group**  
Custom Period (Additional Filters)  
All Trusts

Total Diagnoses in Selection  
**36,708**

Primary	Non-Primary
<b>32,731</b>	<b>3,977</b>

**Upper Figure**  
The top panel of this section shows diagnosis counts by month of diagnosis in the selected reporting period and other selections made in the Controls or Additional Filters section of the left-hand sidebar.

**Lower Figures**  
The lower section shows the above counts grouped by the selected breakdown. In addition to viewing diagnoses by primary and non-primary pathways, primary diagnosis counts can also be viewed by CNS Contact, CTYA Age Group (under 25) and Basis of Diagnosis.

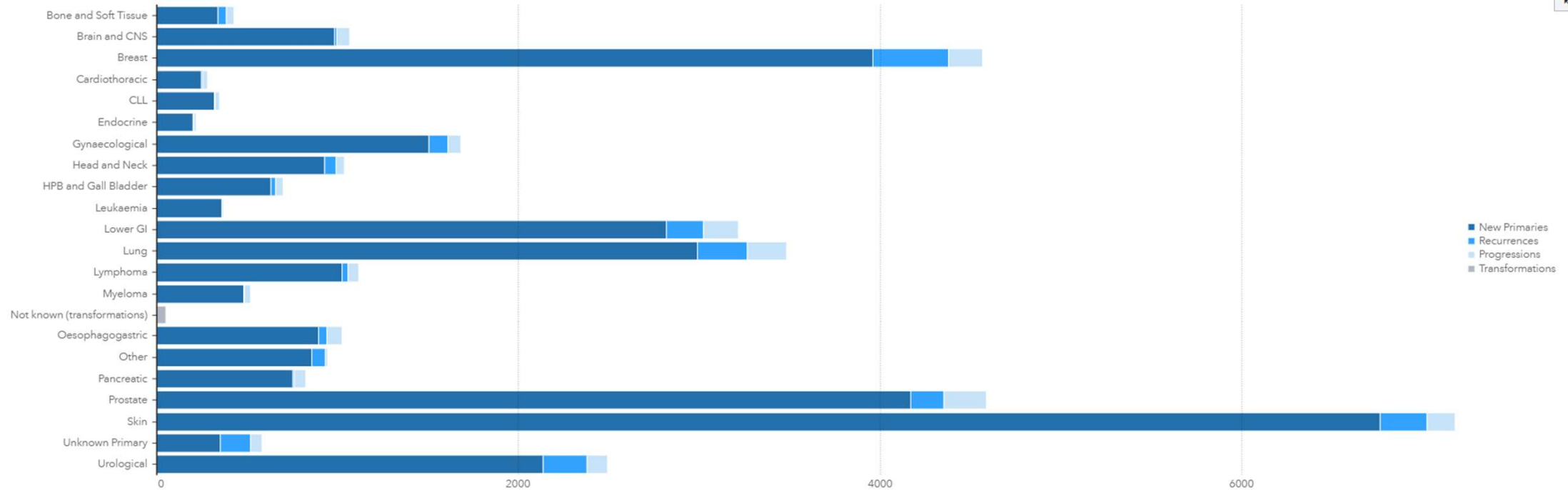
**View as Counts or Proportions**  
All figures can be viewed as counts or proportions by selecting the desired link under the main Figures tab button (at the top of the central pane).

# Resources to support you

CancerStats:

<https://cancerstats.ndrs.nhs.uk/>

## Primary and Non-Primary Diagnoses



# Resources to support you

## Your Regional Data Liaison Manager:

East Midlands & West Yorkshire: **Simon Cairnes** – [simon.cairnes@nhs.net](mailto:simon.cairnes@nhs.net)

Eastern: **Marianne Mollett** – [marianne.mollett@nhs.net](mailto:marianne.mollett@nhs.net)

London & South East: **Katrina Sung** – [katrina.sung@nhs.net](mailto:katrina.sung@nhs.net)

North West: **Paul Stacey** – [p.stacey@nhs.net](mailto:p.stacey@nhs.net)

Northern & Yorkshire: **Rachael Mann** – [rachaelmann@nhs.net](mailto:rachaelmann@nhs.net)

Oxford: **Gemma Feeney** – [gemma.feeney@nhs.net](mailto:gemma.feeney@nhs.net)

South West: **James Withers** – [james.withers@nhs.net](mailto:james.withers@nhs.net)

West Midlands: **Gemma Feeney** – [gemma.feeney@nhs.net](mailto:gemma.feeney@nhs.net)

# In conclusion

- Over recent years the focus for Trusts has been improving staging data
  - 10 years ago, it was said what you are achieving now wouldn't be possible
  - Staging completeness nationally is routinely around 80%
- We need to show the same commitment with recording recurrences and progressions
- **We don't know 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

# We need to change this statement

Data collection for metastatic breast cancer,

“we are only counted when we are dead”

– Kat Southwell – METUPUK