

# National Disease Registration Service (NDRS)

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COSD for Clinical Nurse Specialist Teams  
v1 October 2024

Welcome to this NDRS training module on COSD for Clinical Nurse Specialist teams. This module can be paused at any time.

## Agenda

- The National Disease Registration Service
- COSD data collection for CNS Teams
- CancerStats II – Feedback on submitted data
- Summary



In this module we're going to look at what data we need from Clinical Nurse Specialists and their team members, why we need it, specific elements of the COSD dataset that we ask you to enter and the feedback available to you.

# The National Disease Registration Service

## In this section we will cover:

- The National Disease Registration Service
- Data feeds
- What the data is used for
- Why measure personalised care activity in cancer?

We're going to start off with a brief run through of what NDRS is and why we need the data

## The National Disease Registration Service (NDRS)

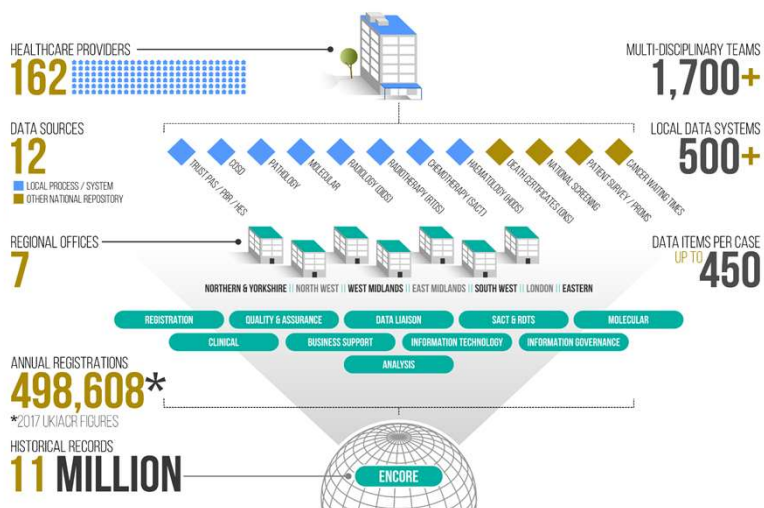
The National Disease Registration Service is part NHS England. Our purpose is to collect and quality-assure high-quality, timely data on a wide range of diseases and provide robust surveillance to monitor and detect changes in health and disease in the population.

The service includes:

- The National Cancer Registration & Analysis Service (NCRAS)
- The National Congenital Anomaly & Rare Disease Registration Service (NCARDRS)
- The Retinoblastoma Register
- Supporting Genetic Requests

The National Disease Registration Service collects and collates data on a number of diseases which allows for monitoring and detection of changes to the health of the population

## Data Feeds



We collect data from all NHS hospitals in England and from other organisations such as the Office for National Statistics, which allows us to make around half a million registrations every year.

## What the data is used for

- National Audits via NATCAN
- Research & Campaigns – Be Clear on Cancer
- Charities
- Strategic Review
- International Comparison
- Clinical Services Quality Measures
- Cancerdata
  - [www.cancerdata.nhs.uk](http://www.cancerdata.nhs.uk)
- Fingertips
  - <https://fingertips.phe.org.uk>
- CancerStats – HSCN only
  - <https://cancerstats.ndrs.nhs.uk>
- NDRS website
  - <https://digital.nhs.uk/ndrs>
- Predict tools
  - <https://breast.predict.nhs.uk/>
  - <https://prostate.predict.nhs.uk/>

What do we use it for? Actually, quite a lot... and this list is not exhaustive. Please be assured: the data you collect **is** important and **is** used.

## Partner Organisations



... in many cases by our partner organisations.

## Why measure Personalised Care activity in cancer?

- Personalised Care and Support Plans, Holistic Needs Assessments and End of Treatment Summaries must be offered to everyone by 2021 – **need to measure if this is on track or not**
- Personalised Care and Support Plans (PCSP) are a **headline Long Term Plan indicator**
- **Gain greater insight**, for example:
  - What proportion of people take up offer of PCSP/HNA?
  - Do PCSP/HNA/EOTS improve outcomes?
  - What staff are involved?
  - Are there cancer type differences?
  - Physical activity status

But why do we specifically measure personalised care activity for cancer patients? In part, because PCSPs are one of the Long Term Plan indicators and of course it leads to greater understanding of the patient's pathway.

## COSD data collection for Clinical Nurse Specialist Teams

### In this section we will cover:

- What is COSD
- Core Personalised Interventions
- Finding the Guidance
- CNS referral
- Patient Presentation
- HNA / PCSP
- EOTS

The specific data we ask Clinical Nurse Specialist teams to collect is part of the COSD dataset...

## What is COSD? - Cancer Outcomes and Services Dataset

- CWT is mainly about timeliness of service delivery
- COSD is all about the broader picture. It's about the patient and their cancer:
  - Is this a primary cancer, a recurrence or a progression?
  - If it's a primary cancer, how far has the cancer progressed at the point of diagnosis (what is the stage of the cancer)?
  - How well is the patient at the point of diagnosis (what is the performance status of the patient)?
  - What investigations were carried out?
  - Has the patient seen a Clinical Nurse Specialist?
  - Are there genetic elements to the cancer?
  - Exactly what treatment was given?

... and COSD has a broad remit, gathering data about the cancer, the patient and the service they receive.

## Core Personalised Care Interventions in COSD

**Personalised Care and Support Plan (PCSP) based on Holistic Needs Assessment (HNA)**

Ensures people's physical, practical, emotional, social needs are met and that resources are targeted to those who need them most

**End of Treatment Summary (EOTS)**

Completed by secondary care and given to the patient & GP. Provides detailed summary of treatment, potential side effects, signs and symptoms of recurrence and contact details to address any concerns

**Physical Activity Assessment**

An assessment of the physical activity level currently being achieved by the individual.  
Part of Health & Wellbeing Information and Support.

For CNS teams, the key areas of focus in COSD are the HNA & Personalised Care and Support Plan, the End of Treatment Summary and the Physical Activity Assessment

## Finding the Guidance

<https://digital.nhs.uk/ndrs/data/data-sets/cosd#downloads>

### COSD v10.0 downloads

This page contains downloads for the Cancer Outcomes and Services Dataset (COSD) Version 10.2.3 and Pathology v5.1.0.

#### Page contents

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[COSD main data set](#)  
[Pathology data set](#)

#### Introduction

These new data sets go LIVE on the 1st April 2024, please work with your local IT or software systems supplier to get your systems upgraded to these new versions.

If you have queries, requests for further information please contact the COSD helpdesk at [info@digital.nhs.uk](mailto:info@digital.nhs.uk) or your regional data liaison manager.

#### COSD main data set



COSD v10.2.0 final data set

41.8K 798 KB



COSD user guide v10.2.4

This guide supports users with the implementation and collection of data as part of the Cancer Outcomes and Services Data set (COSD) v10.2.4 data set.

#### 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 [Cancer Data 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: 17 September 2024 12:31 pm

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Details on this key data for CNS' can be found in the COSD User guide. We advise always going to the website to open the latest published guide. It should be noted that all data items referred to in this module relate to COSD v10.

## CNS Team specific data items in COSD

- CNS Indication Code
- Patient Presentation
- Holistic Needs Assessment
- Personalised Care and Support Plan
- End of Treatment Summaries



We'll start with the CNS Indication Code...

## CNS Referral section - CNS Indication Code

### Clinical Nurse Specialist Indication Code

Record if and when the patient saw an appropriate site-specific clinical nurse specialist. Please read all options to select the most appropriate code.

#### Clinical Nurse Specialist Indication Code table

National Code	National code definition
Y1	Yes - Clinical Nurse Specialist present when patient given diagnosis
Y3	Yes - Clinical Nurse Specialist not present when patient given diagnosis but saw patient during same Consultant Clinic Session
Y4	Yes - Clinical Nurse Specialist not present during Consultant Clinic Session when patient given diagnosis but saw patient at other time
Y5	Yes - Clinical Nurse Specialist not present when patient given diagnosis, but the patient was seen by a trained member of the Clinical Nurse Specialist team
NI	No - patient not seen at all by Clinical Nurse Specialist but Clinical Nurse Specialist informed of diagnosis
NN	No - patient not seen at all by Clinical Nurse Specialist and Clinical Nurse Specialist not informed of diagnosis
99	Not known (not recorded)

#### Notes:

- Y1 could be when either the patient was given the diagnosis of cancer by a consultant (with the Nurse Present) or by the clinical nurse specialist themselves (without a consultant) - clinical nurse specialist practice is becoming more independent and in some tumour sites, it will be the clinical nurse specialist that breaks the bad news to the patient
- Y5 was requested by many clinical nurse specialist teams as their workload is more diverse than originally accounted for, which is required to meet the rising demand for their services to help you assign the correct code - the following 3 expanded explanations have been provided:
  - cancer care coordinators are band 3/4 staff who have been employed to work within clinical nurse specialist teams to undertake a number of duties which do not need to be performed by a clinical nurse specialist including telephone triage, pathway management and in some cases acting as key worker to patients with non-complex disease requiring straight forward management
  - where care coordinators are acting as key workers, they have undergone appropriate communication skills training and have developed specific competencies to ensure they have the skills and knowledge to undertake this role which may include the support of patients at diagnosis
  - cancer care coordinators are recognised members of the multi-disciplinary team and are working under the supervision of the senior clinical nurse specialist, and with the approval of the MDT Lead

... where there are several options for a Yes answer, ranging from the CNS being present when the patient is given their diagnosis... to the patient being seen by another trained member of the CNS team. There are also two options for No depending on whether or not the CNS is aware of the diagnosis. This would be recorded as part of the CNS Initial Referral.

## Patient Presentation section - Tobacco Use

### Tobacco Smoking Status

This is specifically looking at tobacco smoking only. Specify the current tobacco smoking status of the patient. This data item could be collected at presentation either in outpatients or on the ward.

#### Tobacco Smoking Status table

National Code	National code definition
1	Current smoker
2	Ex-smoker
4	Never smoked
9	Unknown

### Tobacco Smoking Cessation

This is specifically looking at tobacco smoking treatments. Specify the tobacco smoking cessation treatment status of the patient. This data item could be collected at presentation either in outpatients or on the ward.

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This is specifically looking at tobacco smoking treatments. Specify the tobacco smoking cessation treatment status of the patient. This data item could be collected at presentation either in outpatients or on the ward.

#### Tobacco Smoking Cessation table

National Code	National code definition
1	Patient treated
2	Patient not treated
3	Patient offered treatment but declined
8	Not Applicable (Not current tobacco user)
9	Not Known (Not recorded)

As well as the CNS Indication code, other information is required if available (not necessarily collected by the CNS Team as data within the Patient Presentation section may be collected by **any** clinical team member). This includes smoking status and smoking cessation. Please be aware that these data items apply only to Tobacco smoking.

## Patient Presentation section - Alcohol use

### History of Alcohol (Current)

Specify the current history of alcohol consumption for the patient ( $\leq 3$  months) from date of diagnosis.

#### History of Alcohol (Current) table

National Code	National code definition
1	Heavy ( $>14$ Units per week)
2	Light ( $\leq 14$ Units per week)
3	None in this period
Z	Not Stated (patient asked but declined to provide a response)
9	Not Known (Not recorded)

### History of Alcohol (Past)

Specify the past history of alcohol consumption for the patient ( $>3$  months) from date of diagnosis.

#### History of Alcohol (Past) table

National Code	National code definition
1	Heavy ( $>14$ Units per week)
2	Light ( $\leq 14$ Units per week)
3	None ever
Z	Not Stated (patient asked but declined to provide a response)
9	Not Known (Not recorded)

Note:

- these are based on the UK Chief Medical Officers' Alcohol Guideline Review (Jan 2016)

Other pertinent information, also in the Patient Presentation section, includes Alcohol consumption, both current and historic, ...

## Patient Presentation section - Diabetes indicator

### Diabetes Mellitus Type 1 and Type 2 Indicator

This is a new data item in v10, and these are risk factors for many cancers. Record if the patient has a diagnosis of type 1 or type 2 diabetes mellitus? This information will normally be available in the patient record.

### Diabetes Mellitus Type 1 and Type 2 Indicator table

National Code	National code definition
1	Type 1 diabetes mellitus
2	Type 2 diabetes mellitus
3	Other diabetes mellitus not categorised as type 1 or type 2
4	No patient diagnosis of diabetes mellitus has been made
9	Not known

#### Notes:

- the presence of diabetes is an independent risk factor of development of HCC and many other cancers
- in v10 (on the request of clinician's) we have extended this to allow for the accurate recording of 'Type 1' or 'Type 2' diabetes

... information on the patient's diabetic status, ...

## Patient Presentation section - Menopausal Status

### Menopausal Status

This data item is a risk factor for many female cancers.

#### Menopausal Status table

National Code	National code definition
1	Premenopausal
2	Perimenopausal
3	Postmenopausal
9	Not Known

Numerous current treatment options are different according to the menopausal status of a patient (particularly those presenting with breast cancer).

... menopausal status where applicable, ...

## Patient Presentation section – Physical Activity (current)

### Physical Activity (Current)

This is to specify the current physical activity level of the patient.

#### Physical Activity (Current) table

National Code	National code definition
1	Achieves guidance level of physical activity
2	Does not achieve guidance level of physical activity
Z	Not Stated (PATIENT asked but declined to provide a response)
9	Not Known (Not recorded)

The activity assessment is based on the [Physical Activity Vital Sign \(PAVS\) form](#), which has been recommended for its utility in clinical practice compared to other measures such as International Physical Activity Questionnaires (IPAQ) and the General Practice Physical Activity Questionnaire (GPPAQ).

An alternative is to use the online 'quick activity calculator' version, which is part of the 'More Minute Conversation' resource for health professionals on the [Moving Medicine website](#). The following link will take you to the 'Explore current activity' tab

... and the patient's current level of physical activity.

## Living With and Beyond Cancer - HNA

### Assessment Offered

Record whether a PATIENT has been offered an Holistic Needs Assessment (HNA).

### Assessment Offered table

National Code	National code definition
01	Offered and undecided
02	Offered and declined
03	Offered and accepted
04	Not offered
05	Offered but patient unable to complete

It's important to capture the offer of personalised care, whether the HNA occurs or not. Equally, it may be clinically appropriate not to offer an HNA.

## Living With and Beyond Cancer – HNA/PCSP

### Assessment/Care Plan Status

This is a new data item for v10. This data item provides an indication of whether a PATIENT has been offered a Holistic Needs Assessment (HNA) and for Personalised Care and Support Plan (PCSP) and whether these have been completed.

### Assessment/Care Plan Status table

National Code	National code definition
01	Assessment completed and care plan not offered
02	Assessment completed and care plan offered
03	Assessment completed and care plan completed
04	Assessment completed and care plan declined
05	Assessment completed and care plan unable to be completed
06	Assessment completed and care plan not required (no concerns from HNA)

The Assessment/Care Plan Status captures what happens as part of the HNA and PCSP process once the initial offer of the HNA has been made and the HNA completed. If the offer of an HNA is declined or the assessment is not completed, this data item will not apply.

## Living With and Beyond Cancer – HNA / PCSP

### Assessment/Care Plan Point of Pathway

This is a new data item for v10. Record the point of the pathway where:

- a Holistic Needs Assessment or Personalised Care and Support Planning is offered or
- at which the decision is taken to not offer these

This point of the pathway should correspond to the CR7930 Assessment/Care Plan Date.

### Assessment/Care Plan Point of Pathway table

National Code	National code definition
01	Initial cancer diagnosis
02	Start of treatment
03	During treatment
04	End of treatment
05	Diagnosis of recurrence
06	Transition to palliative care
07	Prehabilitation
08	In palliative or end of life care
97	Other

You're asked to enter the point of pathway for the HNA/PCSP...

## Living With and Beyond Cancer – HNA / PCSP

### Staff Role Offering the Assessment (Choice 1)

This is a new data item for v10, and forms part of a choice. Record the role of the staff member offering the Holistic Needs Assessment. The staff member offering the care planning is recorded in CR7960 'Staff Role Offering the Planning' as this may be a different person.

### Staff Role Offering the Planning (Choice 2)

This is a new data item for v10, and forms part of a choice. Record the role of the staff member offering the Personalised Care and Support Planning after completion of the assessment.

National Code	National code definition
01	Cancer Nurse Specialist
02	Other nurse
03	Allied Health Professional
04	Support worker/Care navigator (band 3 or 4)
05	Mental health care professional
06	Consultant/Associate Specialist/Junior Doctor
08	Other
09	Not known

... as well as the staff role. HNA staff role and PCSP staff role are entered separately.

## Individual Treatments – End of Treatment Summary

- End of Treatment Summary
  - Date completed



You're also asked to enter the End of Treatment Summary which applies where a particular trust has had direct involvement in the patient's treatment. This data is entered on the individual treatments and the only data item necessary for the COSD dataset is the date the EOTS is completed.

## CancerStats II – Feedback on submitted data

**In this section we will cover:**

- Living With and Beyond Cancer
- COSD – CNS Contacts

You can get feedback on your data from our CancerStats ii website...

## Living With and Beyond Cancer - Reports

- End of Treatment Summary Analysis
- HNA Data Completeness
- PCSP Data Completeness



... where reports are available for three key areas under Living With and Beyond Cancer ...

## Living With and Beyond Cancer

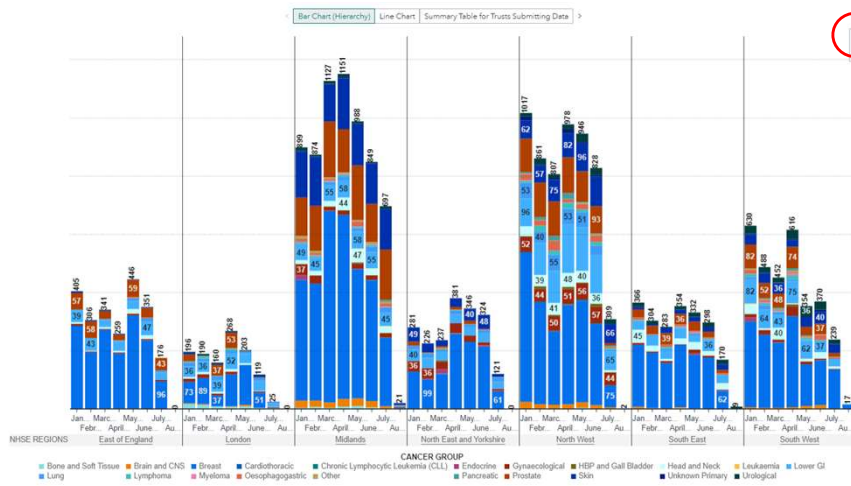
The screenshot shows the CancerStats website interface. At the top, there is a navigation bar with the CancerStats logo and a menu including 'LWBC', 'RTD', 'SACT', 'Cascade', 'CADIAS', 'RCRD', 'Genomics', 'Bespoke Reports', 'Guidance', 'My account', 'Logout', and 'Contact Us'. A red circle highlights the 'LWBC' menu item, which has opened a dropdown menu. This dropdown menu contains three options: 'End of Treatment Summary Data Analysis', 'HNA - Data Completeness', and 'PCSP - Data Completeness'. Below the navigation bar, the main content area features a large banner with the text 'Information, data and insight at your fingertips' and a 'READ MORE' button. Below the banner, there is a 'Welcome to CancerStats2' section with a brief description of the platform's purpose and a note about its security.

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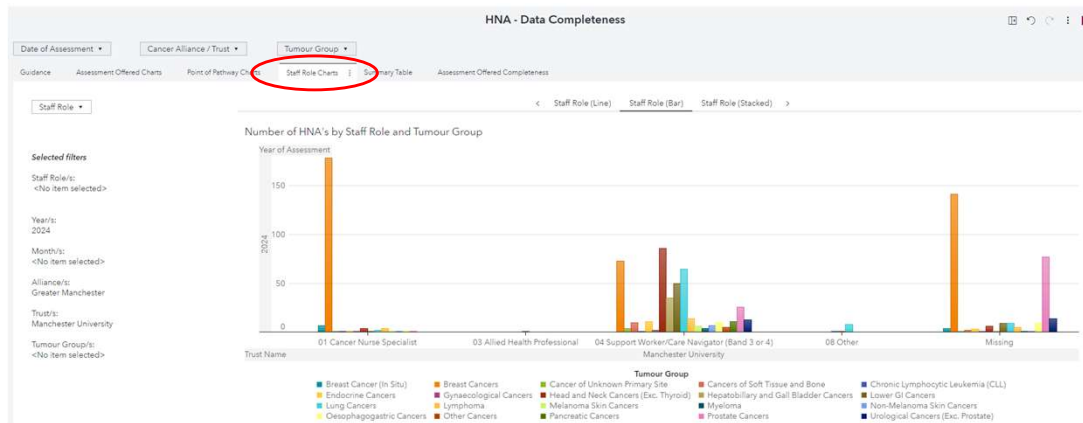
... You'll find feedback reports for End of Treatment Summaries, HNAs and PCSPs at Level 2 (Raw data, as submitted by the trusts). In here you can check your data, you can compare your data to that at other trusts or you can compare data at the level of individual cancer groups ...

# Living With and Beyond Cancer – End of Treatment Summary



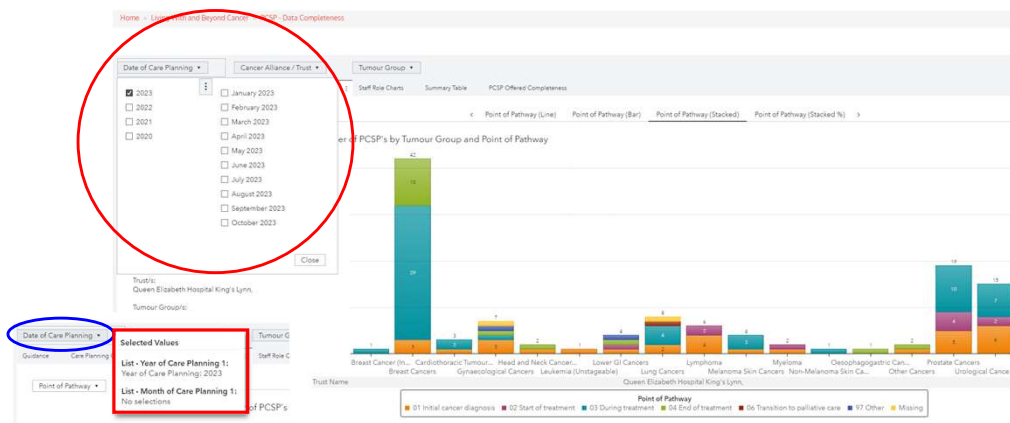
Shown here are the End of Treatment Summary dates collected in a given time period. These can be split by NHS region, cancer alliance or displayed for a specific trust. Individual images or the numbers behind them can be downloaded by clicking on the three dots on any graphic.

# Living With and Beyond Cancer - HNA



The HNA data completeness reports cover assessments being offered, point of pathway and staff role involved (as shown here) ...

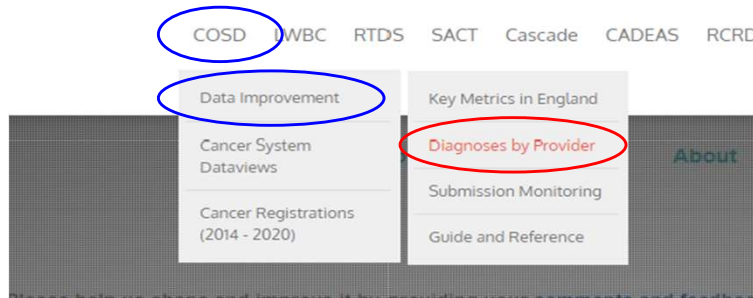
## Living With and Beyond Cancer - PCSP



... with similar reports being available for PCSPs. For all reports, make sure you've selected the dates / Cancer Alliance / Trust you want. Be aware that you *can* specify particular tumour sites and at the same time choose different options for displaying the data. Hovering over any drop-down will tell you which filters have been applied.

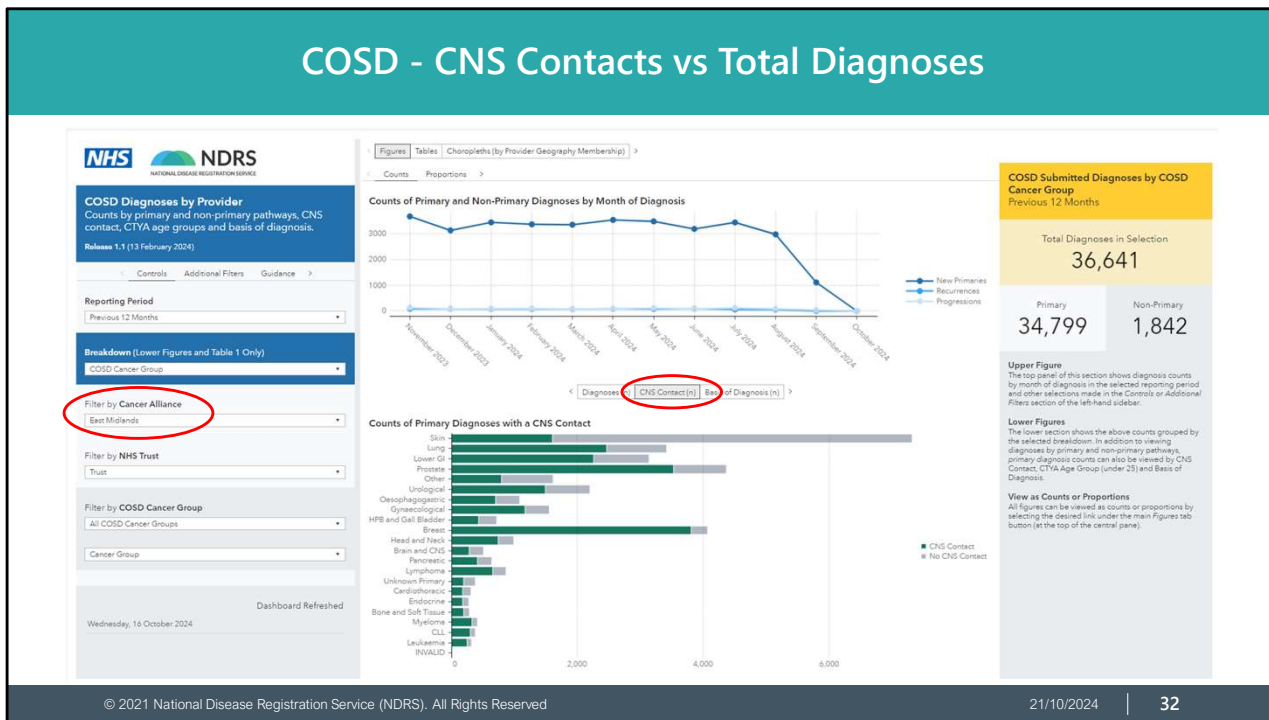
## COSD - CNS Contacts vs Total diagnoses

- The COSD Diagnoses by Provider dashboard:



Another useful graphic can be found on the Diagnoses by Provider dashboard, located in the COSD section of CancerStats ...

# COSD - CNS Contacts vs Total Diagnoses



... as this shows actual CNS *contacts* against total diagnoses, split by cancer group. You can select a specific Cancer Alliance (as shown) or you can specify an individual trust.



**Summary**

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In summary...

## Summary

**Personalised Care and Support Plan (PCSP) based on Holistic Needs Assessment (HNA)**

Ensures people's physical, practical, emotional, social needs are met and that resources are targeted to those who need them most

**End of Treatment Summary (EOTS)**

Completed by secondary care and given to the patient & GP. Provides detailed summary of treatment, potential side effects, signs and symptoms of recurrence and contact details to address any concerns

**Physical Activity Assessment**

An assessment of the physical activity level currently being achieved by the individual.  
Part of Health & Wellbeing Information and Support.

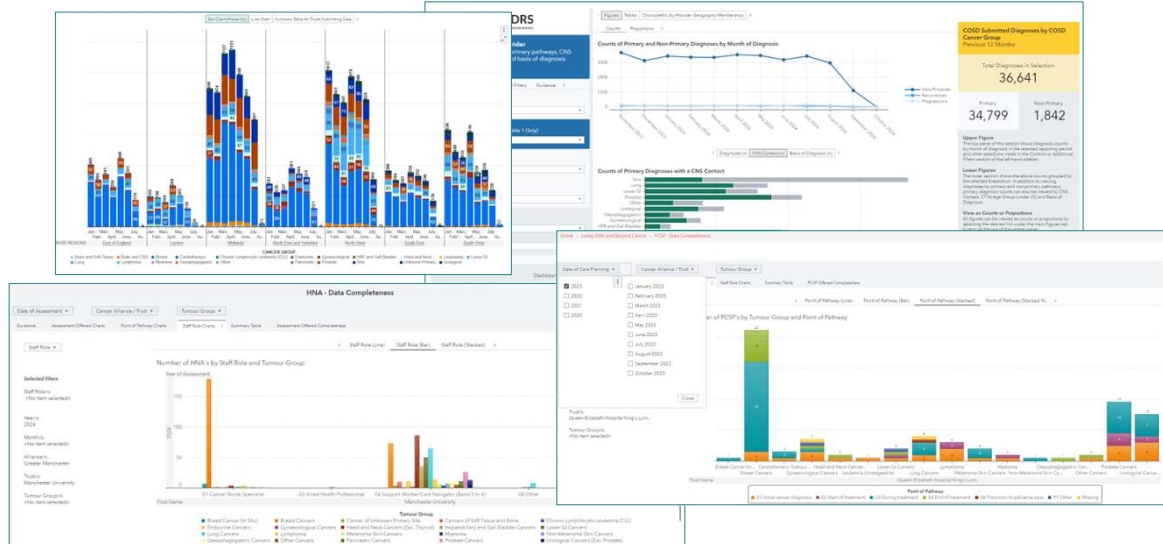
The data that you and your team add to your cancer data management system matters. National reporting looks at the holistic approach within the healthcare system but if it's not recorded and recorded somewhere where the data can be used, it won't be available for national reporting.

## Summary

- Your data is not collected in isolation
  - Part of a much bigger data picture
- Data isn't useful unless it reflects what is happening in reality
  - Enables review of the past
  - Monitoring of the present
  - Planning for the future
- You can access these dashboards
  - <https://cancerstats.ndrs.nhs.uk>
  - Click on *Create new account* to sign up

Having accurate data available allows for national assessment of past activity, maintenance of current activity and planning for future activity. You can sign up for a CancerStats account at the link shown...

# Summary



... where you can find a suite of reports, making it easy to see how complete your data is.

## Questions?

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

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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