NDRS
NATIONAL DISEASE REGISTRATION SERVICE

NHS England

European Network of Cancer Registries

Recurrence Workshop

Using data pathways to capture and improve recurrence data submissions in England

Karen Graham & Jennifer Lai

November 13, 2023. Granada

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Background

The Cancer Outcomes and Services dataset **(COSD)** was launched in 2013. **Data providers (NHS Trusts in England) are mandated to collected and submit this data.**

COSD collects the whole the patient pathway from referral, investigation, diagnosis, MDT and treatments. It is:

- **mandated** dataset,
- sign off from the Royal Colleges,
- submitted monthly,
- including all added and amended records and events,
- collecting primary and non-primary cancer cases:
  - from January 2013 - all primary cases and breast non-primary cases.
  - from July 2014 - collecting all non-primary cases.

Non-primary pathways are:

- Recurrence
- Progression
- Transformation

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Definition: Recurrence

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***

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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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Transformations:

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- Morphology (SNOMED) Transformation
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- Brain
- Liver
- Unknown Metastatic
- Skin
- Distant Lymph Node
- Bone
- Bone Marrow
- Regional Lymph Nodes
- *Other Metastatic Site*

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Non-primary dataset

All non-primary

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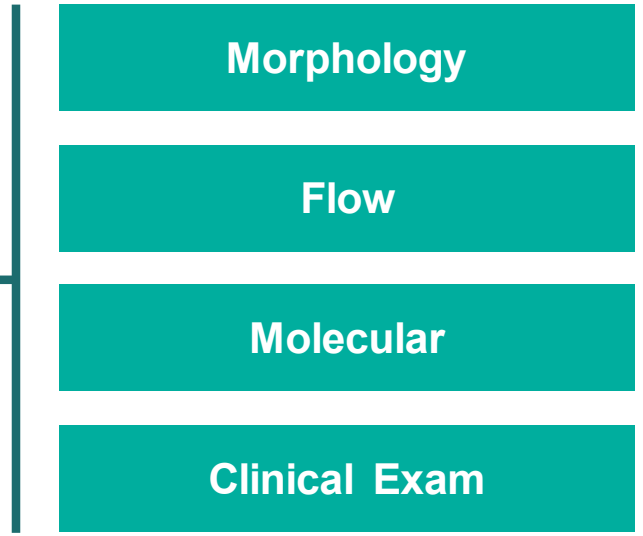

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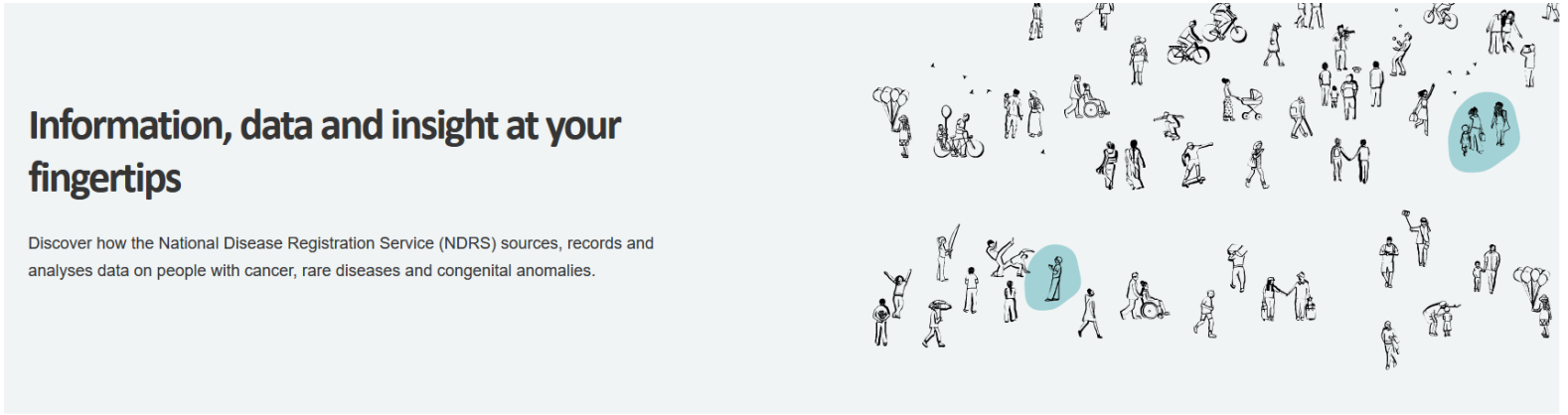
Working with providers

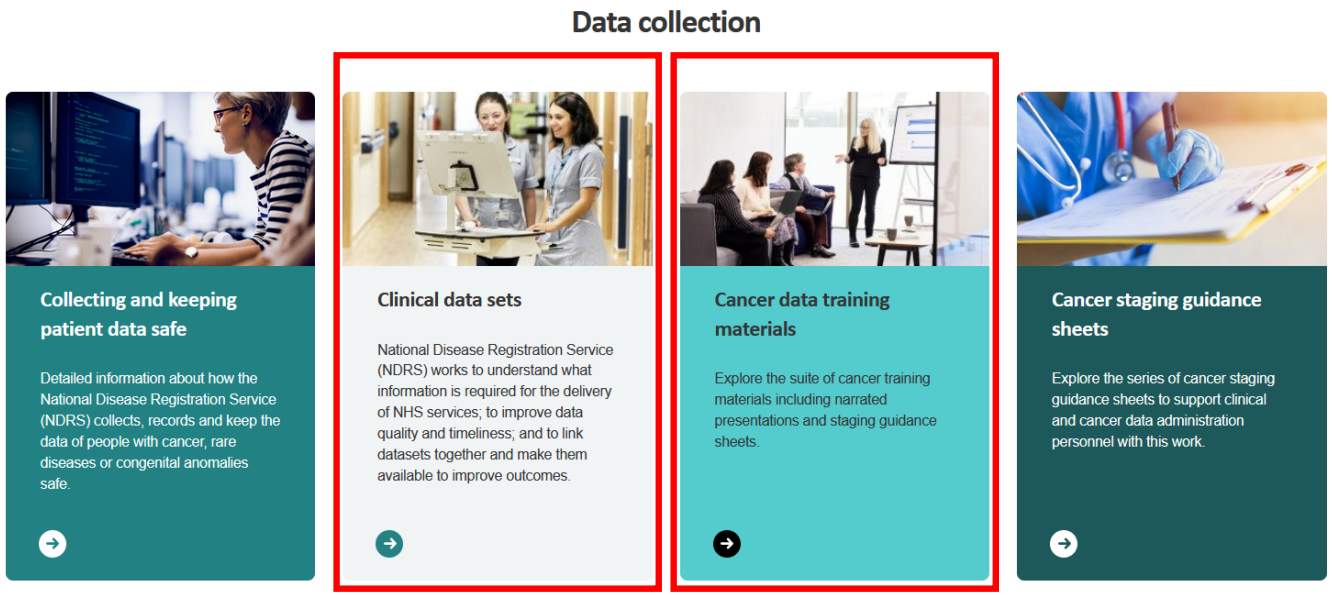
Data Improvement Teams

Training materials and guidance on Data Sets

Training slides: **Recording a diagnosis**

https://digital.nhs.uk/ndrs/data





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Working with providers

Data Improvement Suite:

- represents a complete reporting outputs to support data improvement programmes.
- comprises three new dashboards with daily updates
- Includes a **monthly feedback report which is distributed to all providers** and a comprehensive live reference resource which describes the common methods and datasets used across all reports in the suite.

This suite empowers providers with the information they need to enact and monitor their own improvement programmes.

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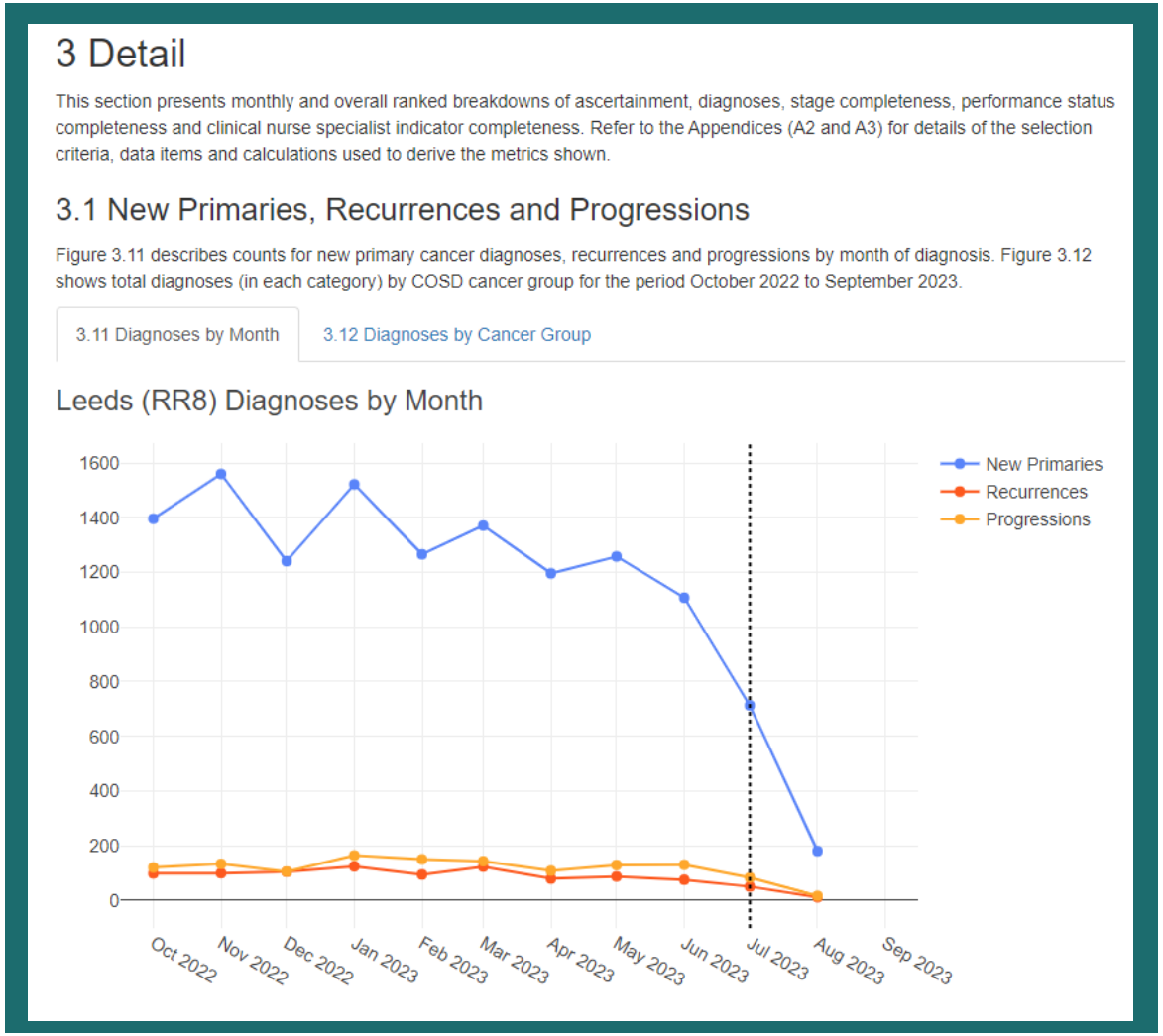
Working with providers

Monthly feedback reports

HTML format (uses Javascript for interactive elements) at a provider level



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Working with providers

Monthly feedback reports

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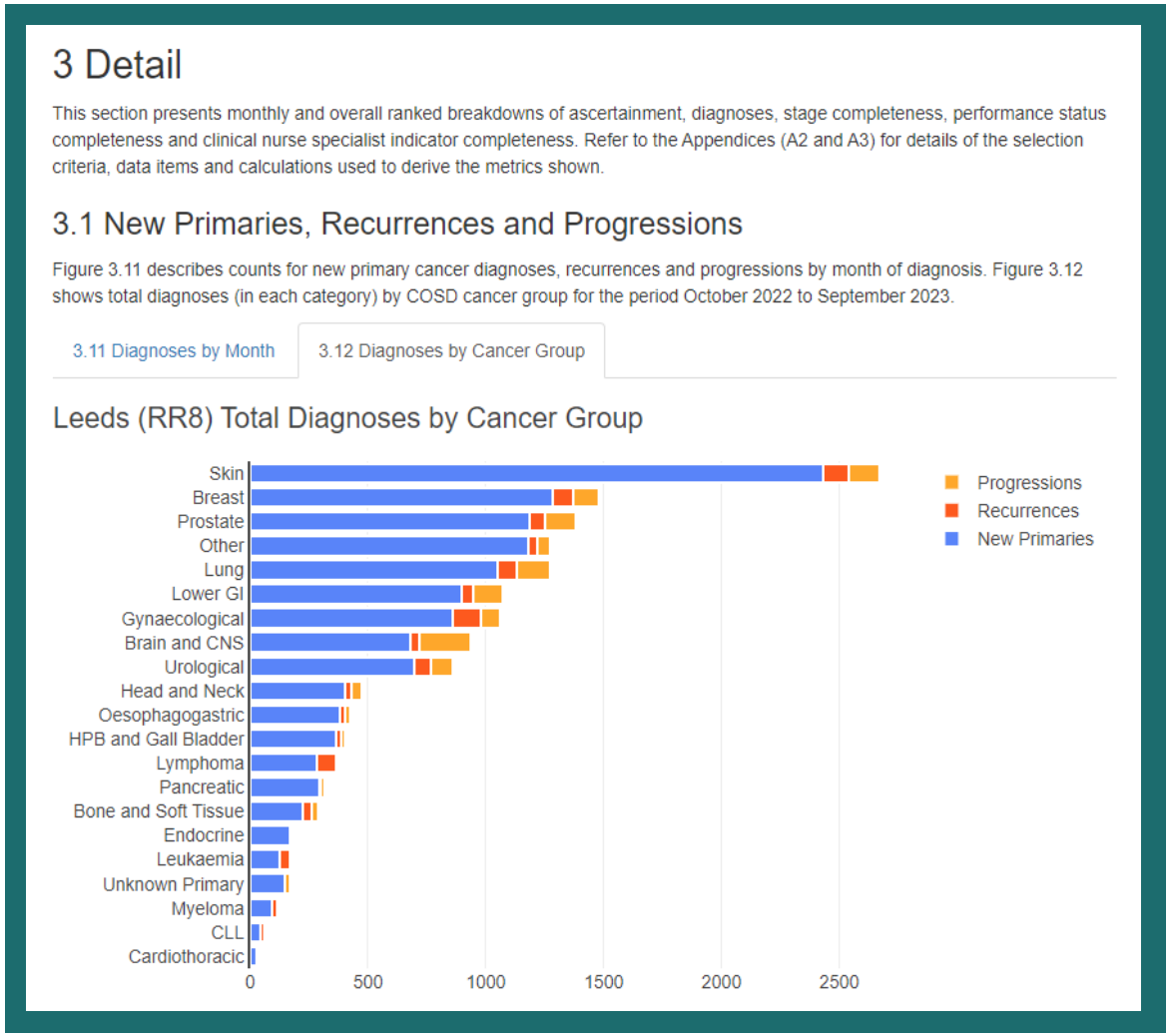

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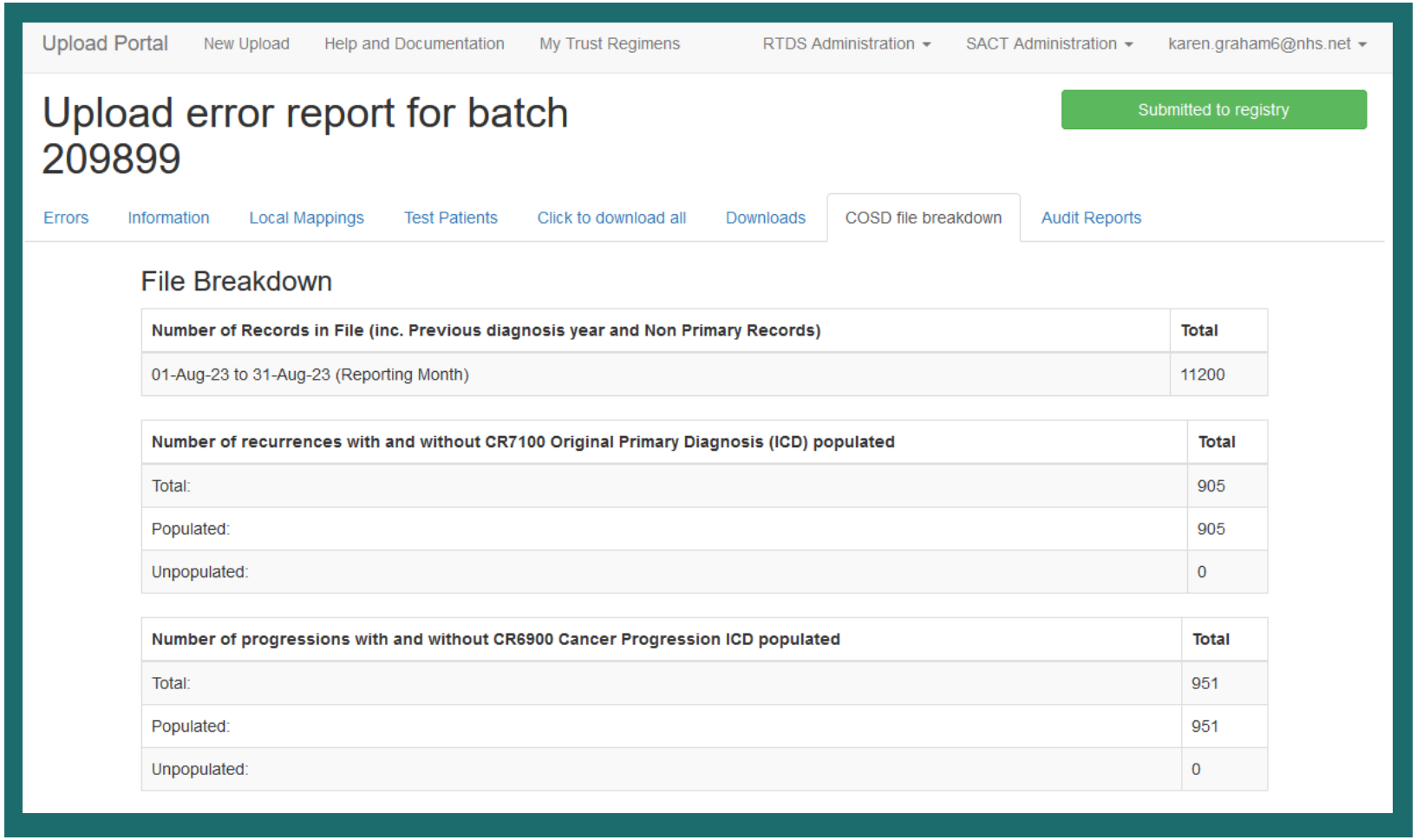
Working with providers

Loading portal

- All COSD is submitted in a loading portal
- Validation of data
- Instant feedback at submission



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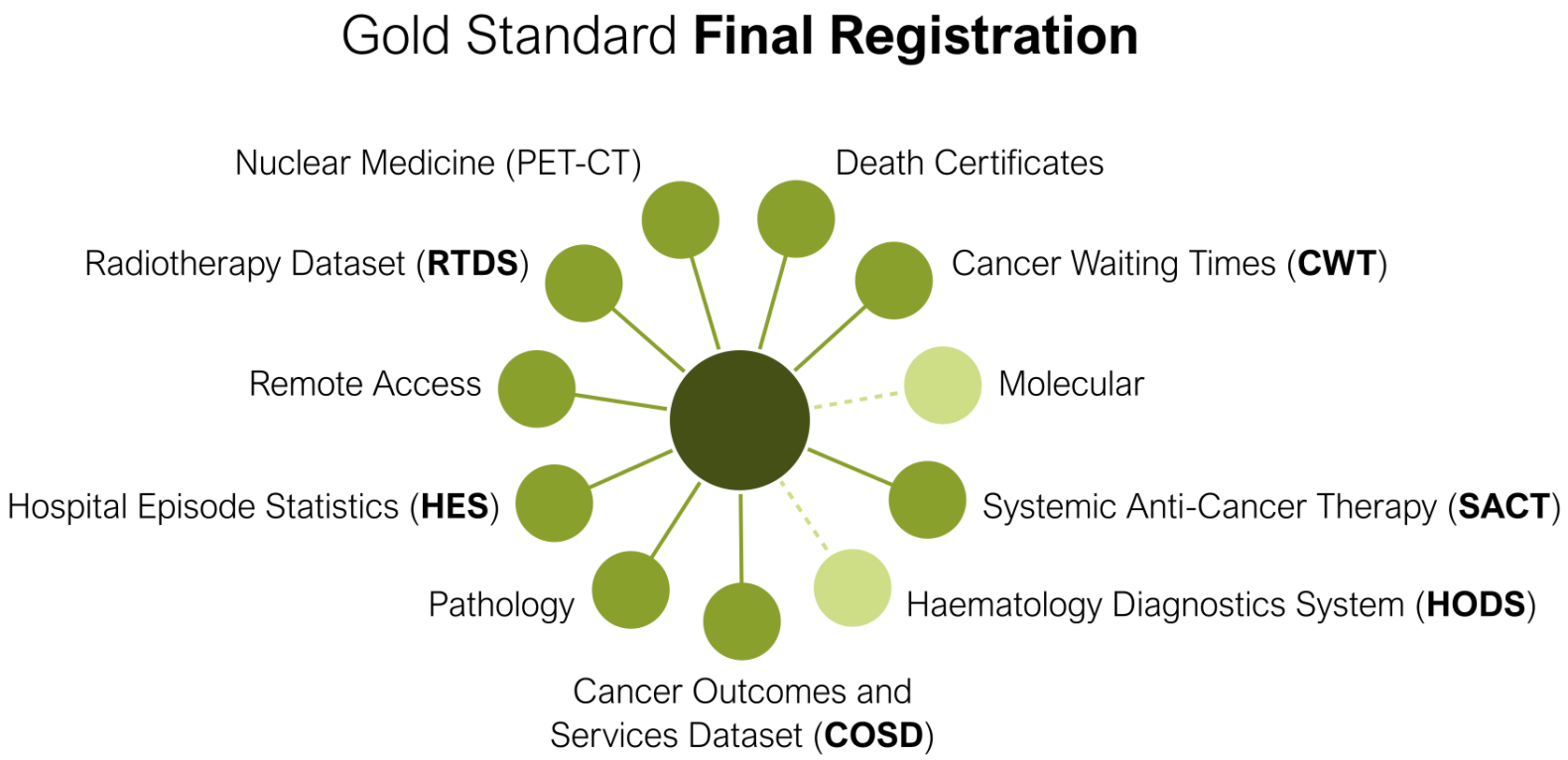
Data Sources for final registration



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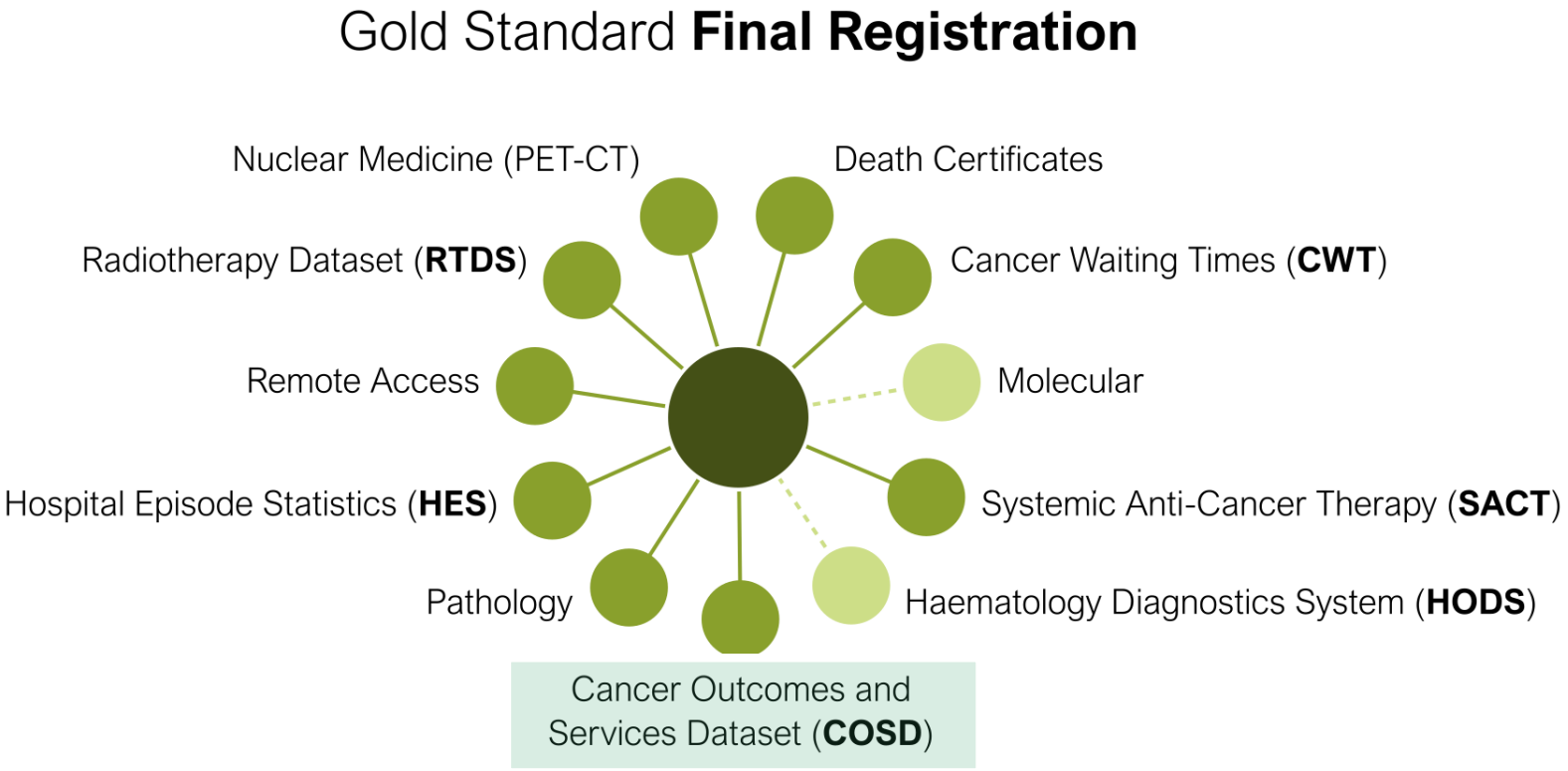
Cancer Outcomes and Services Data set (COSD)

COSD

- Collected data prospectively across the patient's pathway from referral, investigations, diagnosis, MDT and treatments
- Data points for capture are; referral, multi-disciplinary meeting and treatment



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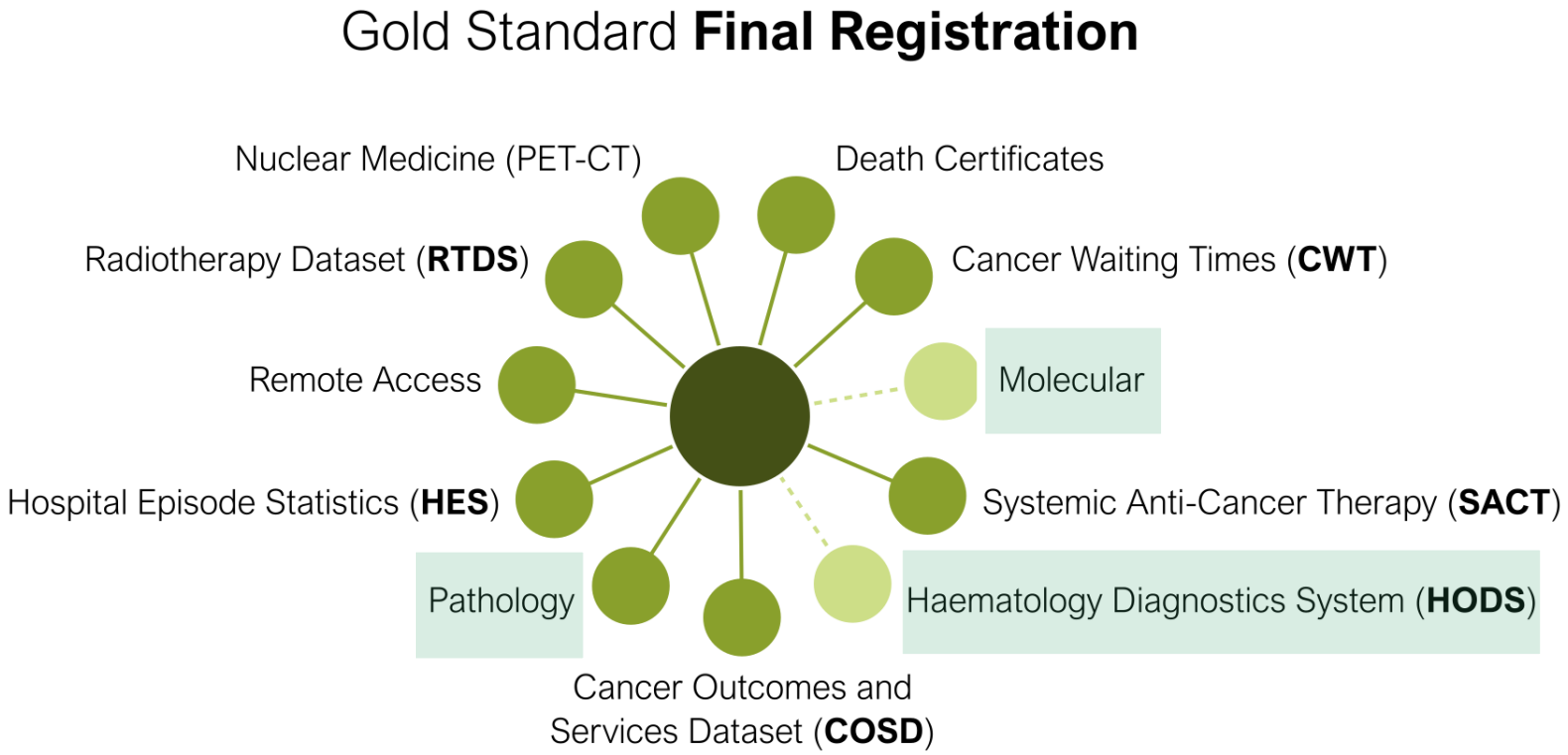
Pathology

Pathology

- Non-primary pathways do not routinely have a histology taken
- HODS is a good data source of identifying transformations



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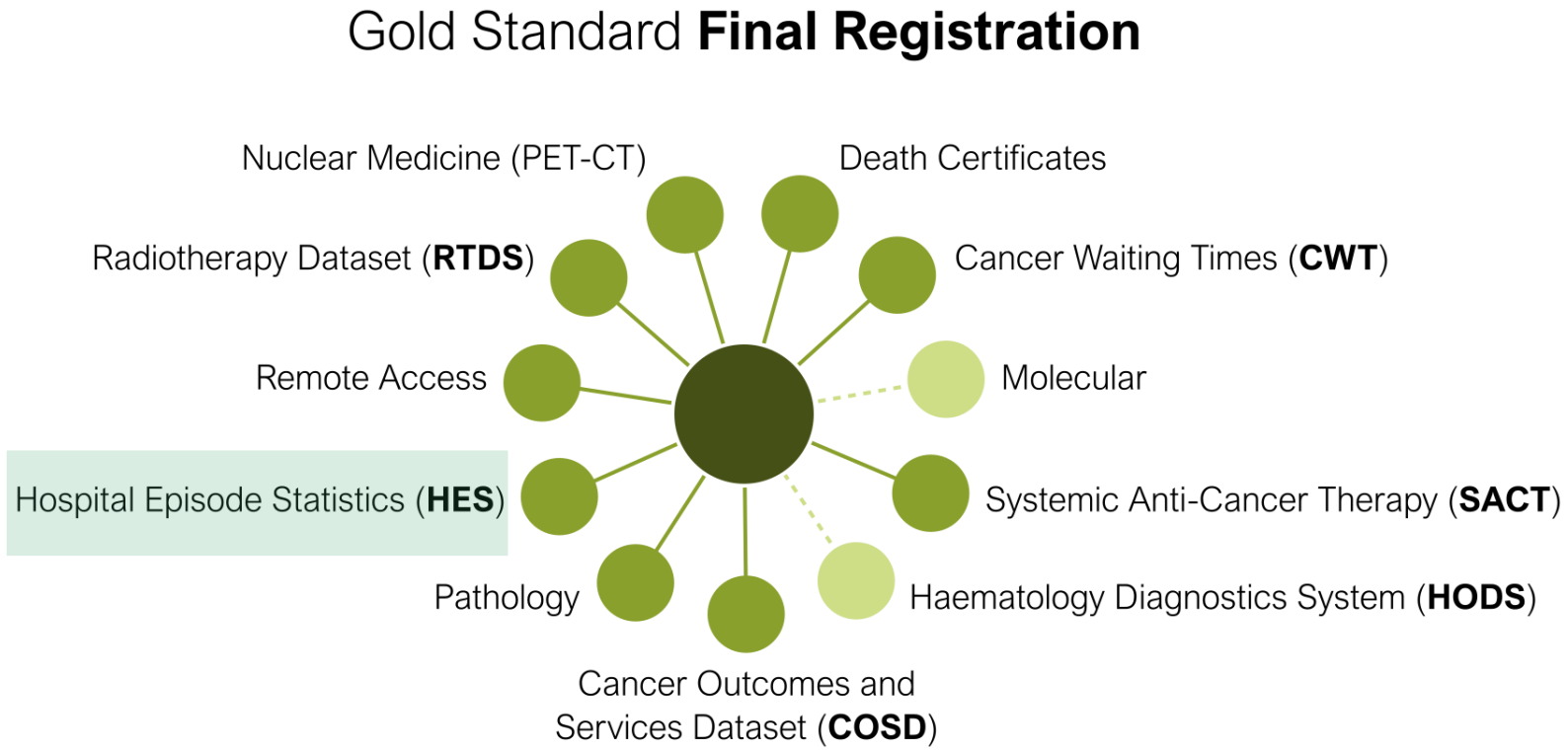
Hospital Episode Statistics (HES)

HES

- Identifies the cases where the patient has had an inpatient stay.
- Patients who have had an inpatient stay - the date of recurrence is not recorded
- Outpatients are not coded



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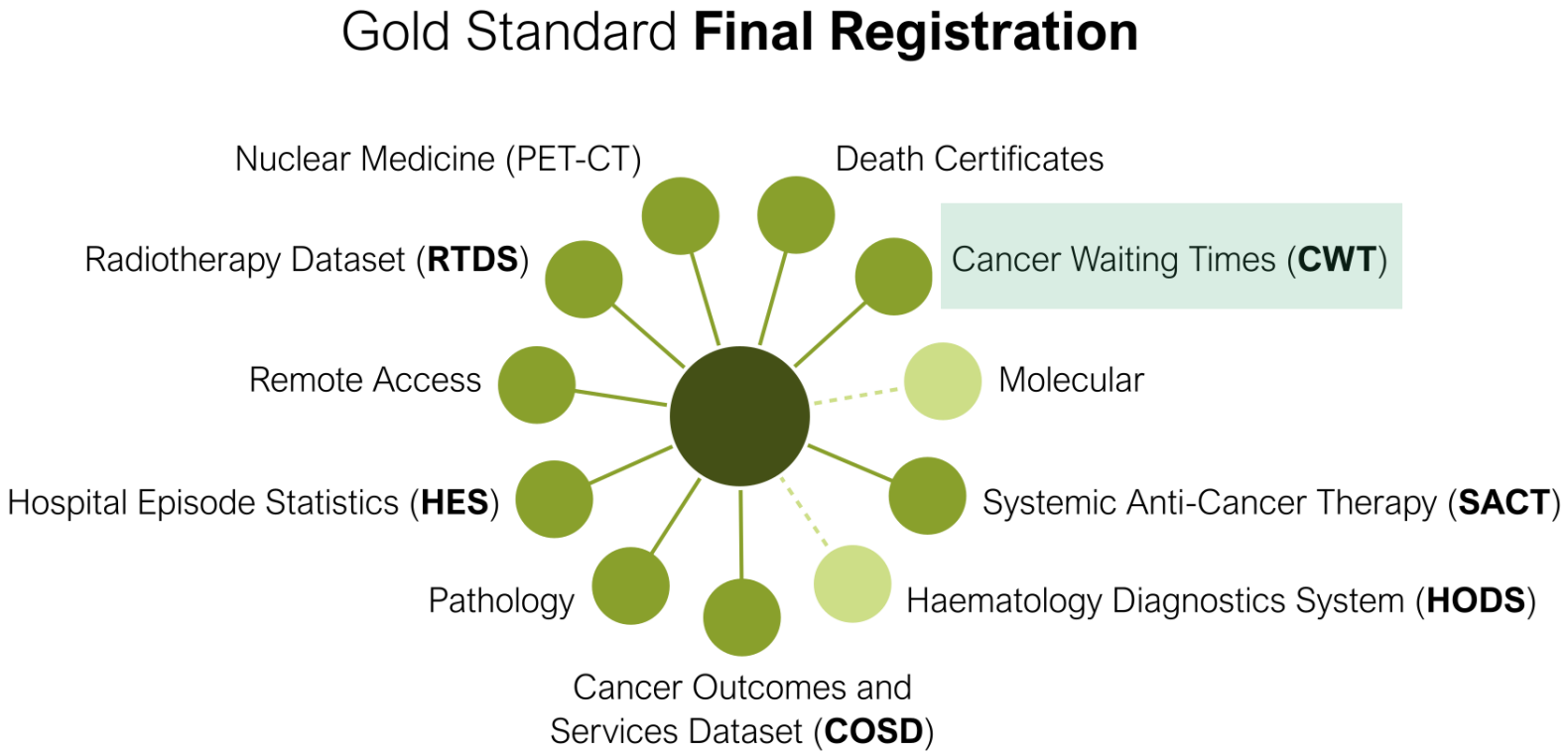
Cancer Waiting Times (CWT)

Cancer Waiting Times

- Mandated dataset monitoring suspected cancers and **cancers treatments**
- **Treatments** for recurrence, transformation and progression are reportable in CWT



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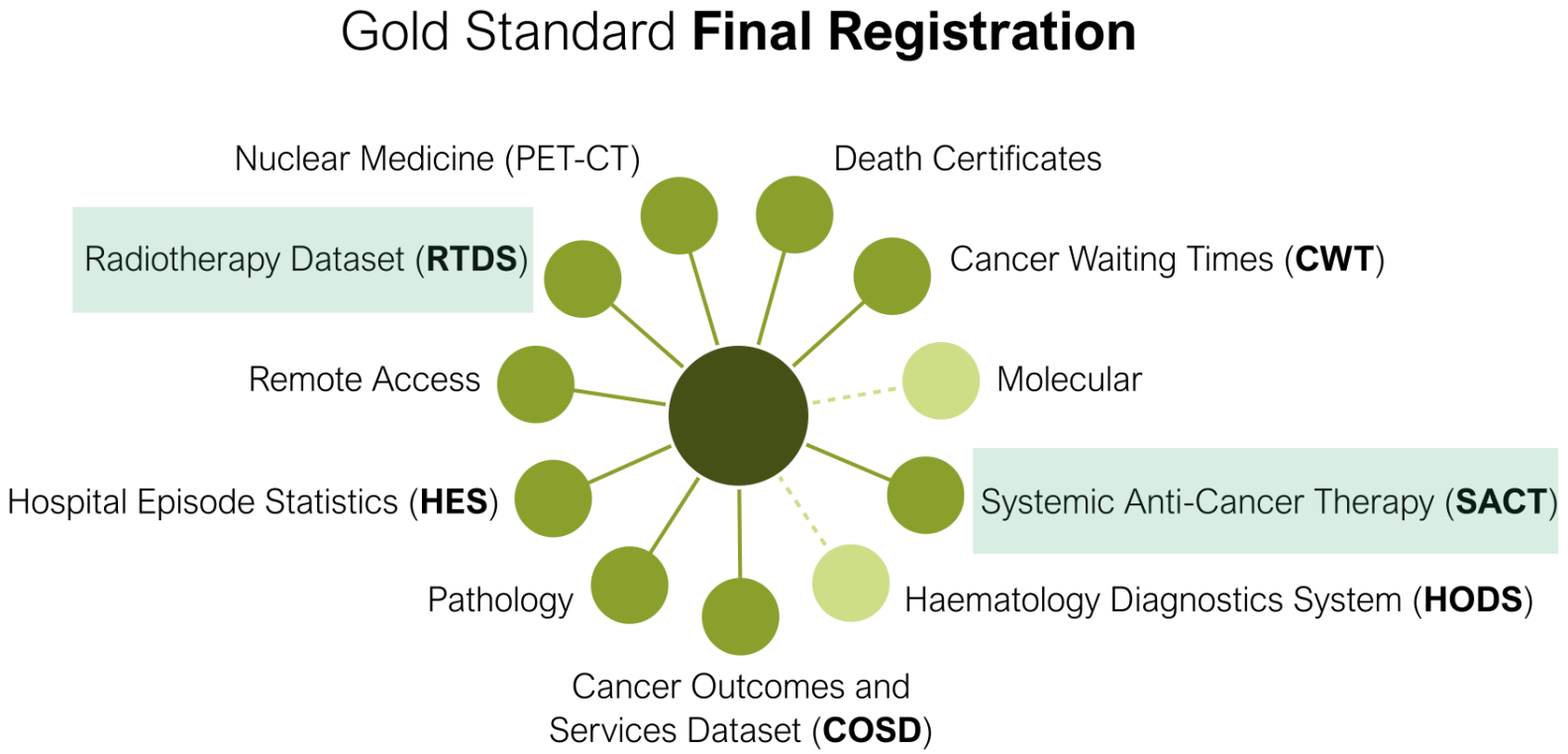
Radiotherapy and systemic anti-cancer therapy

RTDS and SACT

- Treatments reported monthly from clinical systems
- Recurrence and progressions are not coded



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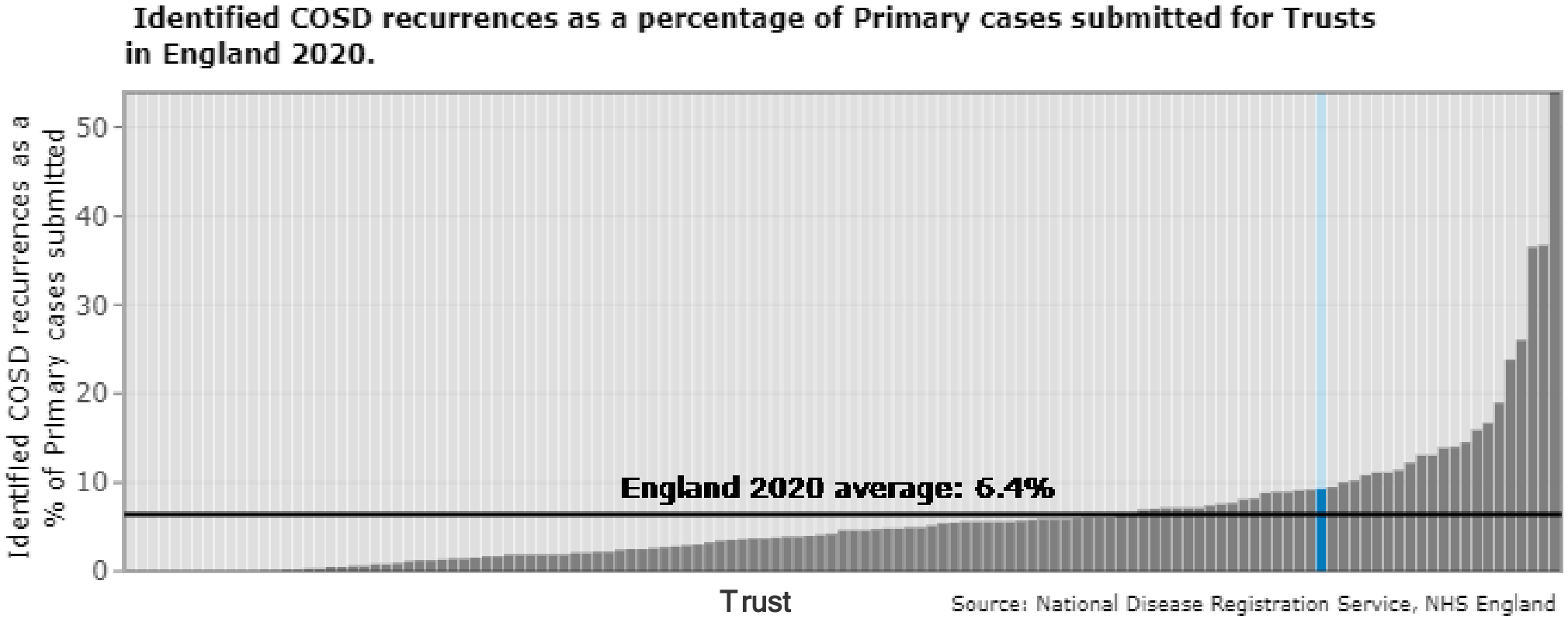
COSD and CWT – output for recurrence

- Non Primary Cancers including recurrences by Trust (https://www.cancerdata.nhs.uk/recurrence)



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Cancer Dataset Pathway - Linked data

- NDRS receives data from lots of data sources including COSD and CWT but also treatment datasets e.g. radiotherapy, chemotherapy, surgery and lots more
- Cancer pathway dataset combines and summarises events across the patient pathway from referral to diagnosis to treatment and death
    - *First referral*
    - *First seen in secondary care*
    - *Diagnosis*
    - *First treatment*
    - *End of initial treatment period*
    - *Treatment for recurrence*

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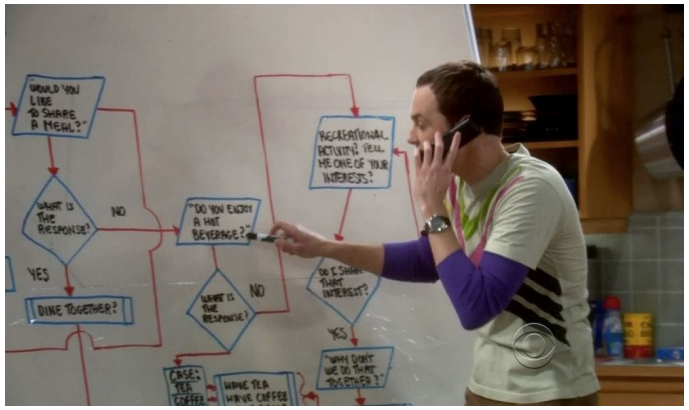
Cancer Pathway Dataset - Event Extraction

Oracle SQL Developer



4000< lines of sql code

Unique IDs
- Event ID
- Tumour ID
- Patient ID

Event type (A&E, etc.) — Event Type

3 selected properties
- Event Property 1
- Event Property 2
- Event Property 3

Event start and end
- Event start date
- Event end date

Trust of event — Trust Code

Source of original data
- Source table
- Sourceid

AVPID	PATIENTID	TUMOURID	EVENT_TYPE	EVENT_PROP_1	EVENT_PROP_2	EVENT_PROP_3	EVENT_DATE	EVENT_END	TRUST_CODE	SOURCEID	SOURCE_TABLE
1	8	6	11D	U072		6	13-Apr-20			58375	AV_PATIENT
2	7	3	19E091	01a			08-Jun-15		RGR	79805	AV_TREATMENT
9	8	6	100				08-Jun-15		RGR	68684	AV_TUMOUR

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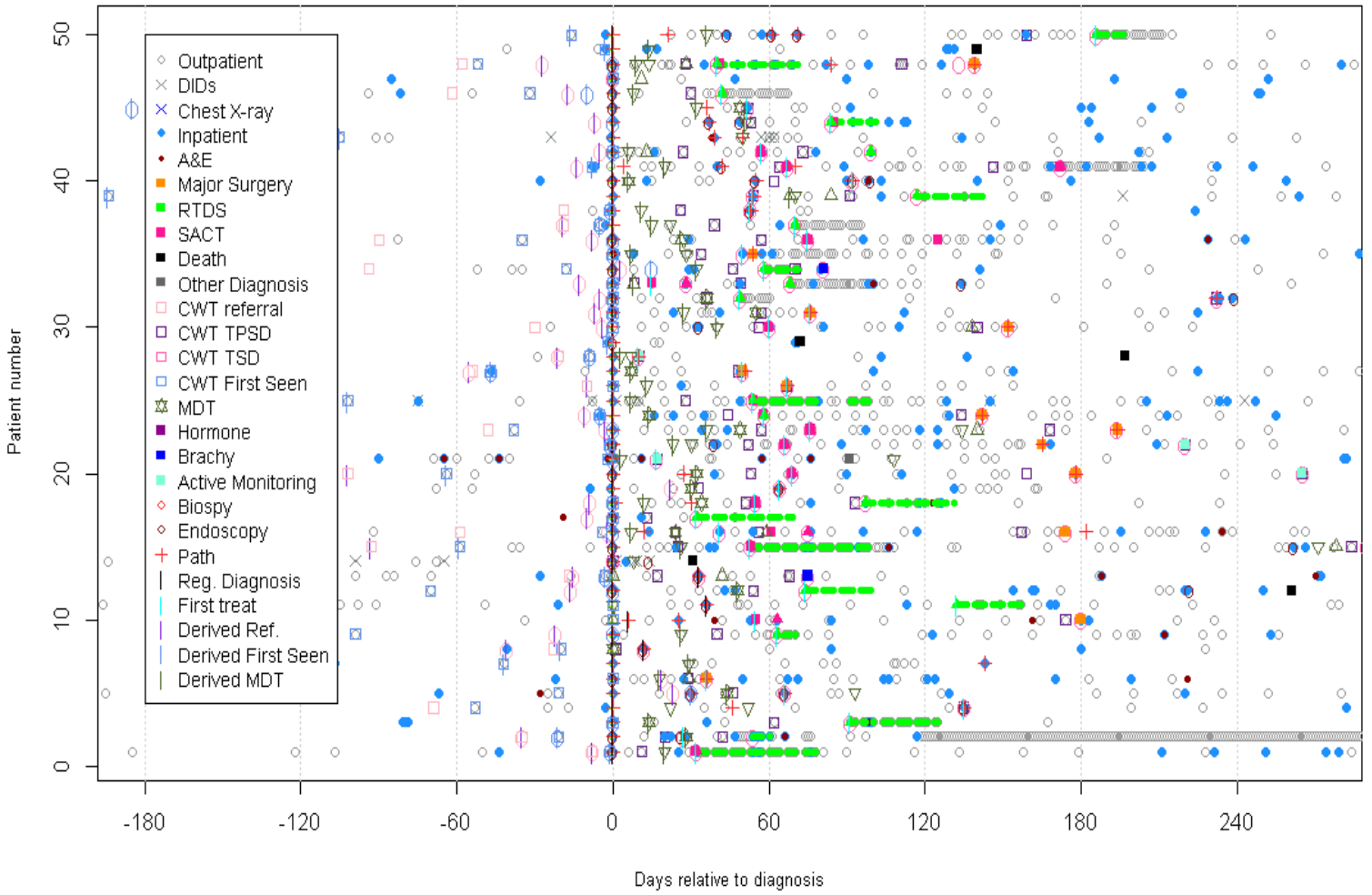
Cancer Pathway Dataset - Individual level pathway visualisation



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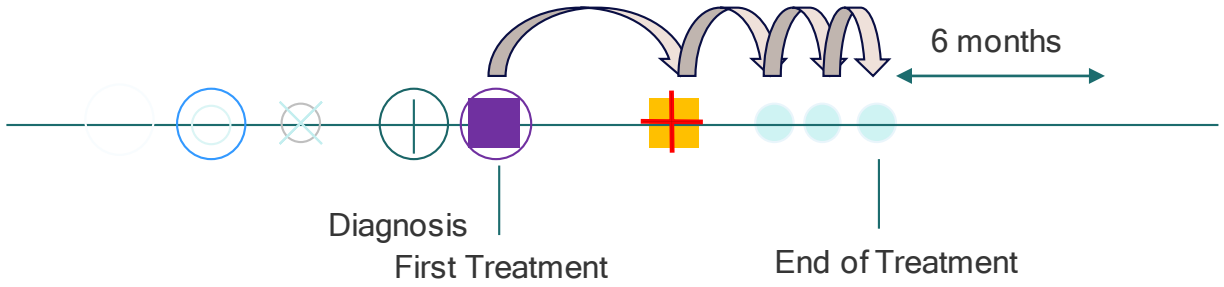
Cancer Pathway Dataset - Defining end of treatment

- CWT referral
- CWT first seen
- Outpatient
- Scan
- Pathology
- MDT
- Decision to treat
- Hormones
- Surgery
- Inpatient
- Chemotherapy
- Death



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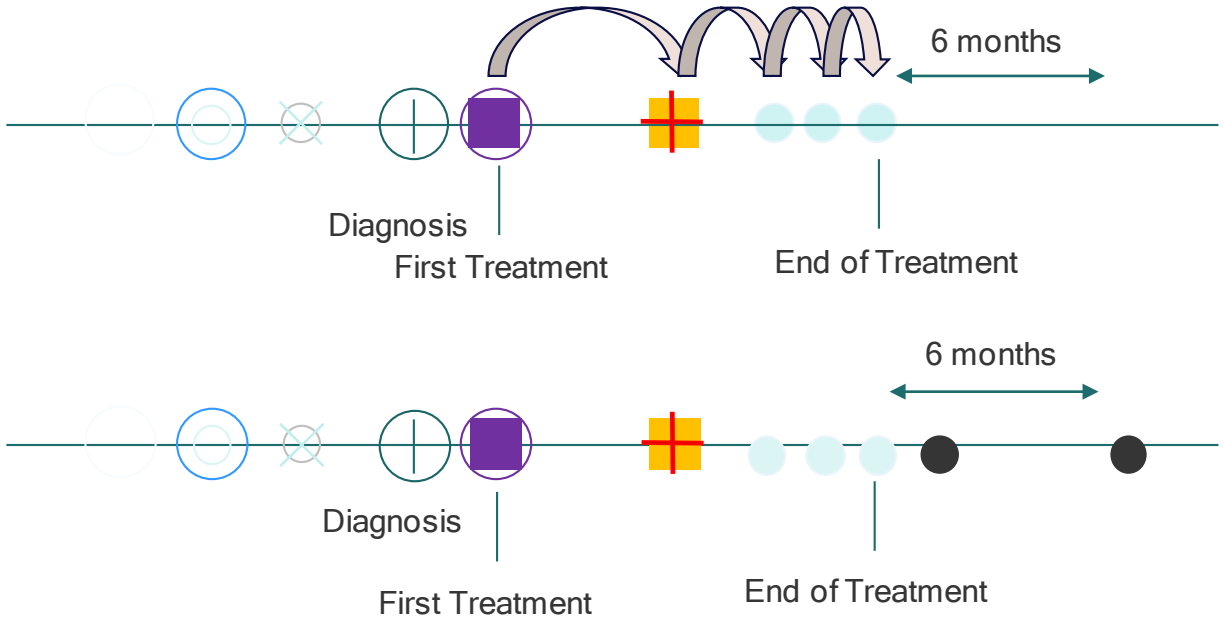
Cancer Pathway Dataset - Defining end of treatment & death



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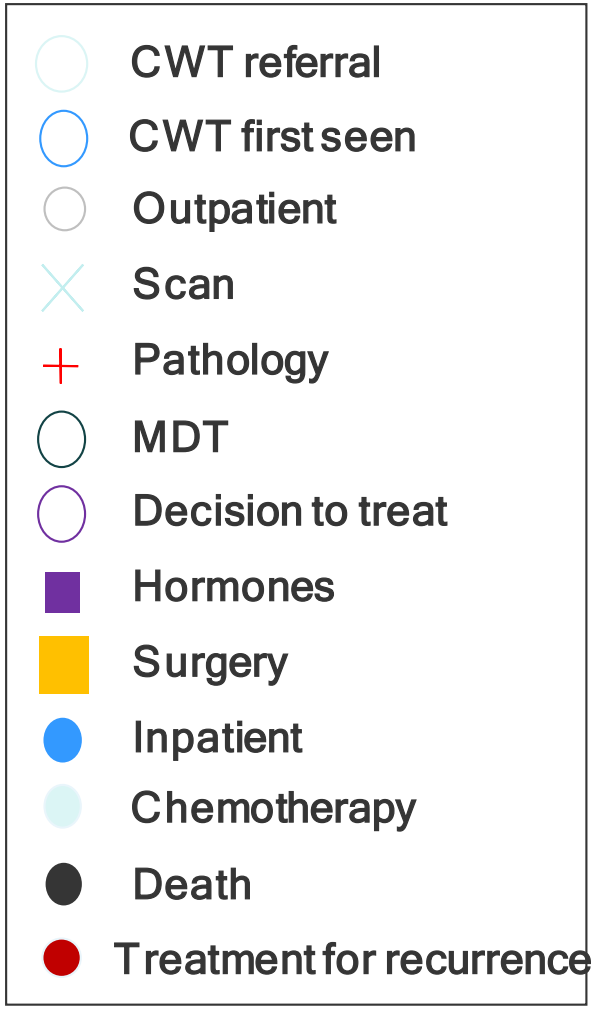
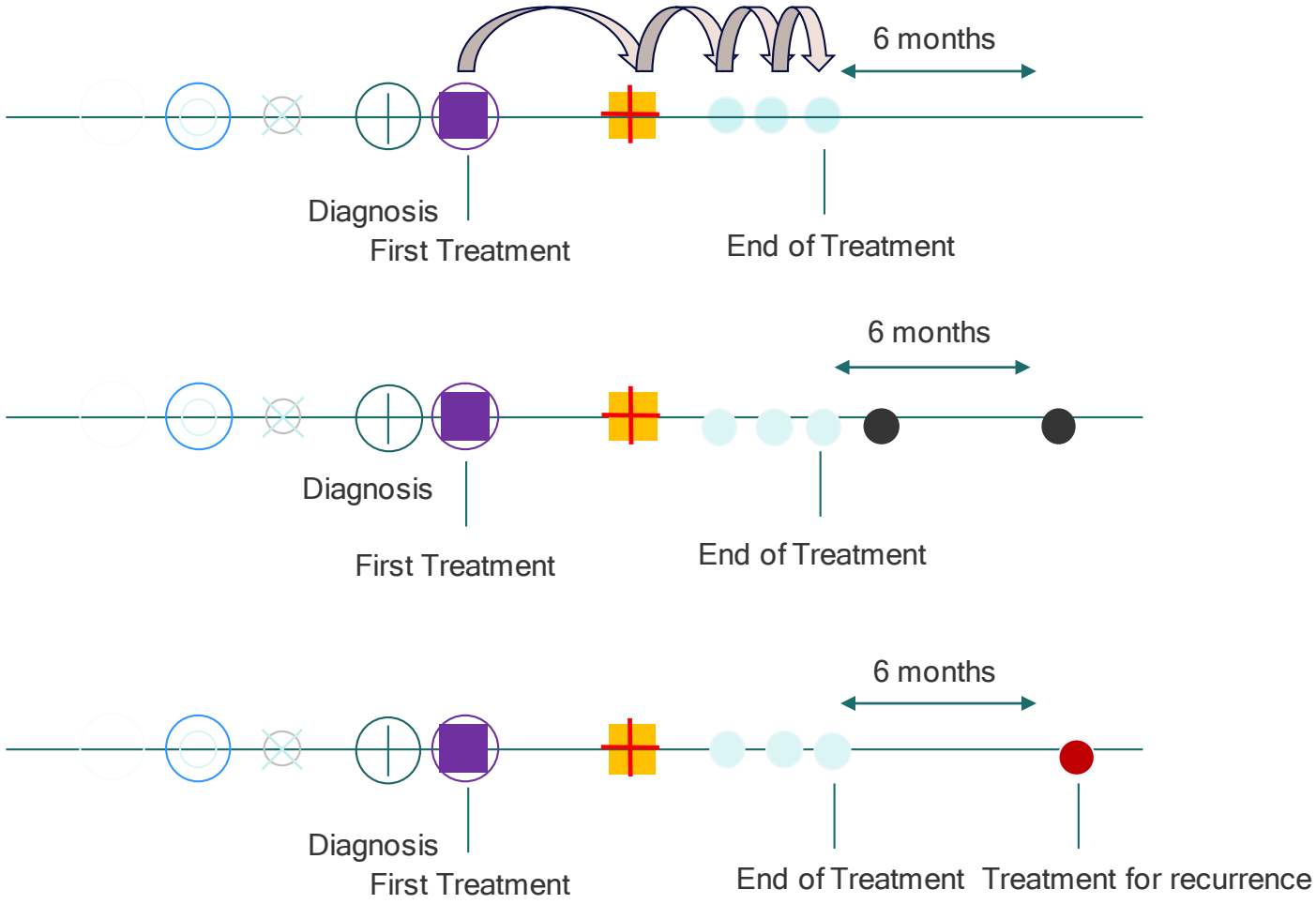
Cancer Pathway Dataset - Defining end of treatment & death





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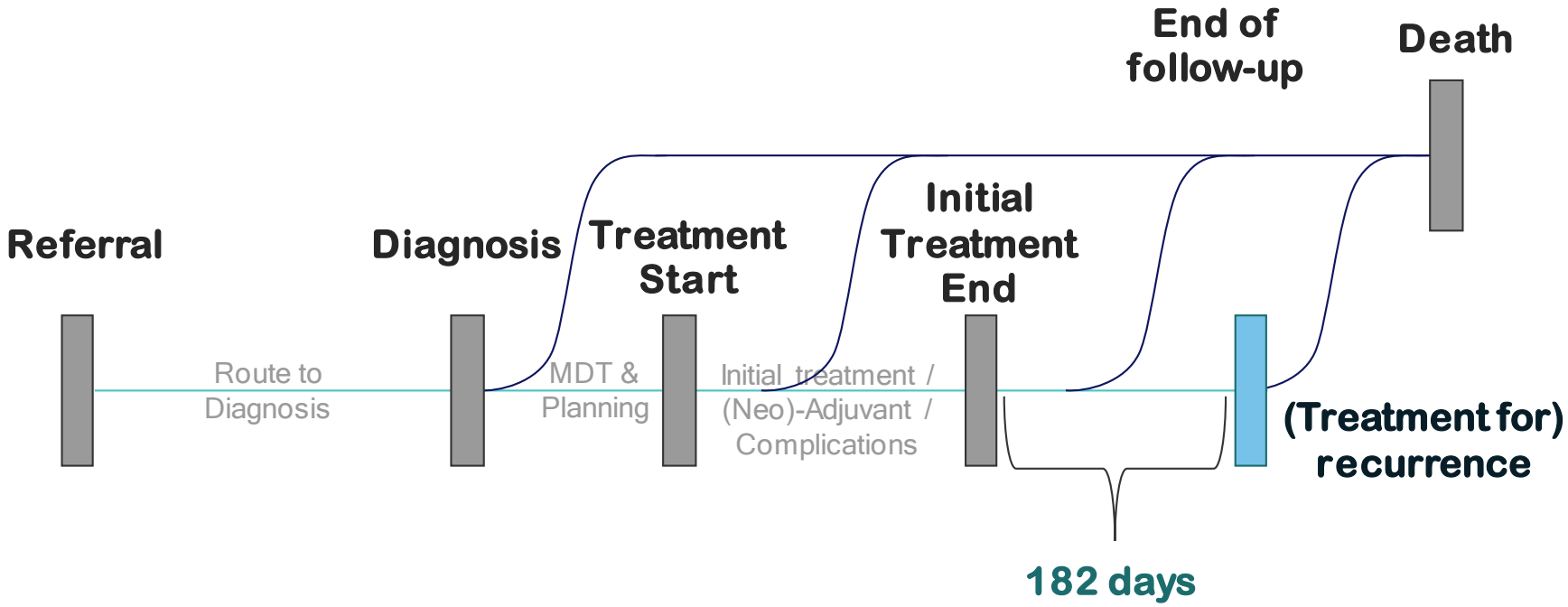
Cancer Pathway Dataset -Derived event: Treatment for recurrence



- Starts with Initial treatment end
- Looks for treatment proceeding Initial treatment end (after 182 days gap)

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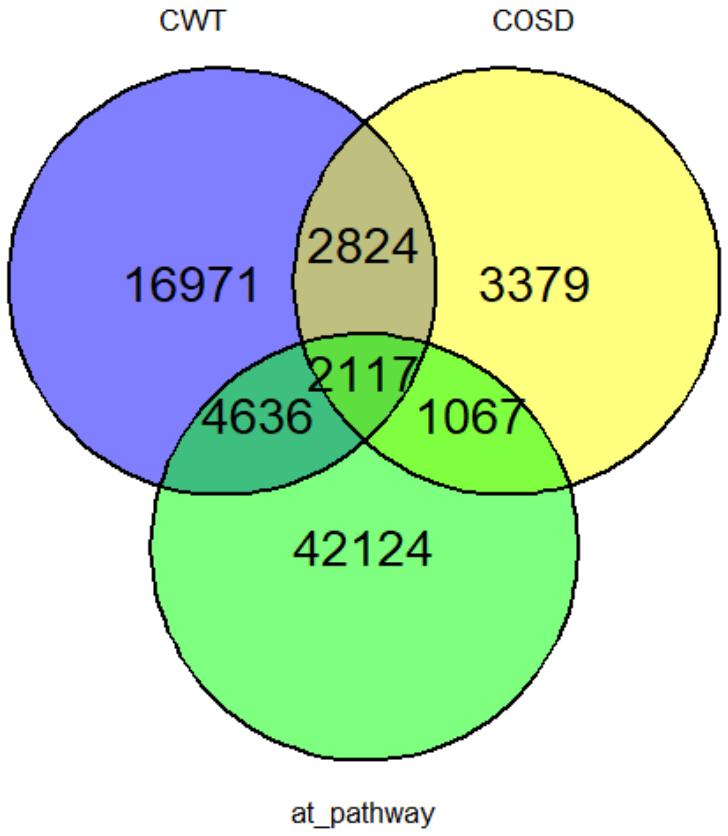
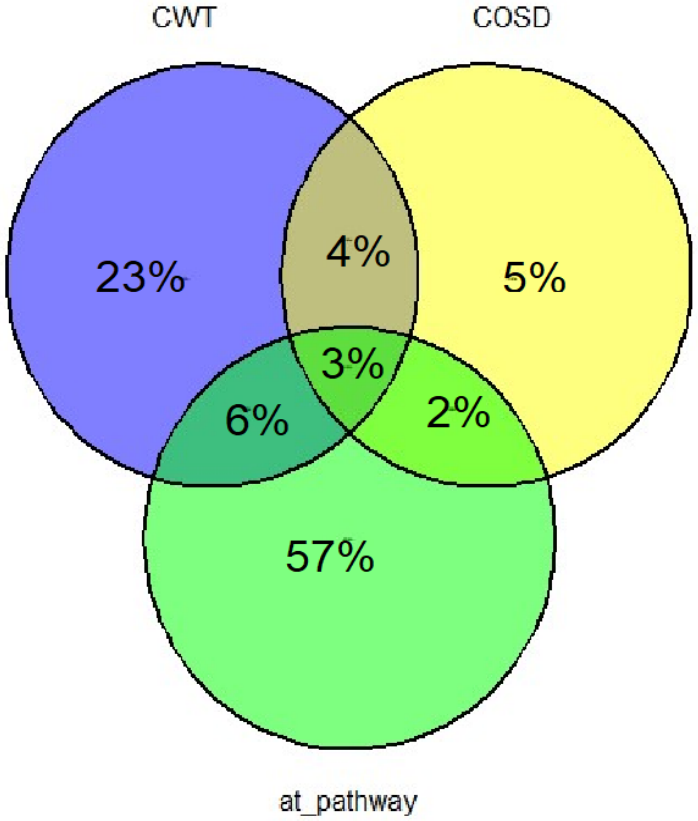
Overlap of recurrence data 2020

Following recurrence definitions, 9k COSD recurrences, 26k CWT recurrences and 50k pathway recurrences

Overlap = 3% **BUT**

- Time periods are difficult to match
- Imputed recurrences produce greater numbers of recurrences





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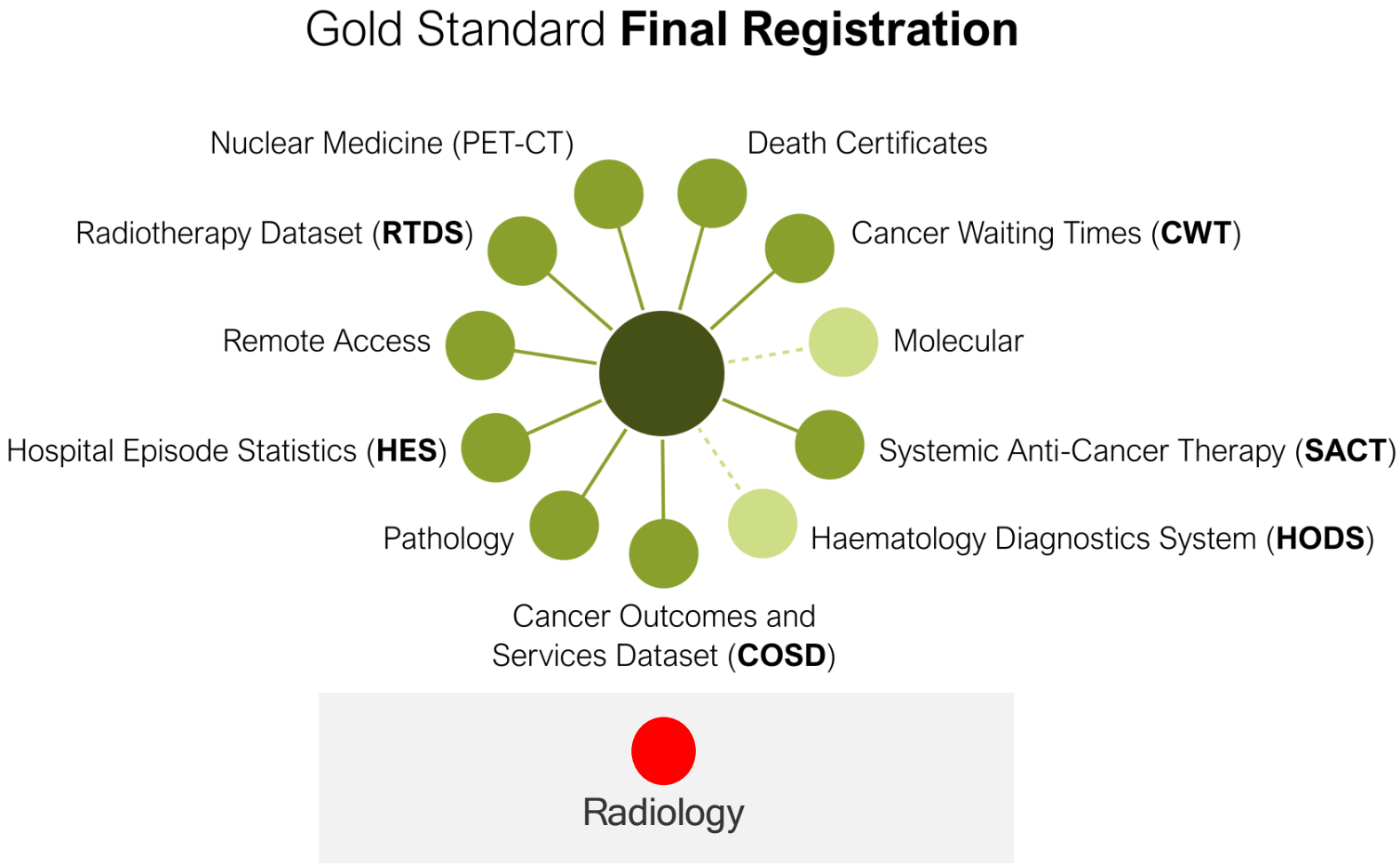
Data Sources – What is missing?

- Patients who are under follow up and do not hit the data pathways.
- Many patients are referred to primary care for end-of-life treatment
- Patients will get a diagnosis from a radiology investigation



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Coding of radiology reports

Asked providers – Can you add a coding system to their radiology systems for non-primary cases?

- 55 providers are either creating a code, flag or an alert in the radiology outcome report
- Providers wanted to identify these cases
- Different approaches applied depending on the resource or system usage

DORSET COUNTY HOSPITAL NHS TRUST

There is something the reporting radiologist will add to the report, so when the report goes back to the requesting clinician it highlights the incidental finding - An i-communicator alert is sent to the referrer for unexpected findings.

MILTON KEYNES HOSPITAL NHS TRUST

Radiology send a weekly list of cancers diagnosed on imaging to cancer services

CHESTERFIELD ROYAL HOSPITAL NHS TRUST

Utilise the 'UUUU' code on any suspicious radiology to alert the relevant cancer team

THE ROYAL WOLVERHAMPTON NHS TRUST

Daily list of cancer suspicious patients received from radiology - cancer suspicious box gets checked by reporter which enables list to be generated (includes new and recurrent cancers)

SALISBURY NHS FOUNDATION TRUST

Yes, we do put alerts on suspected cancer, urgent and unexpected findings, cancer and non-cancer and this would include recurrence. The alert is CODE RED, which makes the report visible in red on the result/review system. If suspected cancer they are faxed or clinician phoned.

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Next Steps…

Flag patients in the Radiology systems

- NHS England are reviewing the radiology data set this year
- Exploring adding two data items to the radiology report to flag patients
- Other registration services could be used, such as congenital anomaly
- Removes the data collection burden from clinical and data teams and reports the non-primary directly from radiology

Proposal

Add data items:

- **Alert**
- **Type of Alert**

Alert Drop down options example:

Report to registration Service - Congenital Anomaly
Report to registration Service - Rare Diseases
Report to registration Service - Cancer

Type of Alert dropdown options example:

New Primary cancer or Suspicion of
Recurrence of cancer or Suspicion of
Progression of cancer or Suspicion of
Congenital anomaly or suspicion of
Rare Disease or suspicion of

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Next Steps…

Research Project with the University of Oxford

- There is a research project being undertaken with the University of Oxford to assess **whether signals of progression, recurrence and metastatic spread** can be **detected in existing data sets**. The initial phase of this project is being written up for publication and **suggests metastatic spread can be reliably detected**; further work to map disease progression before metastatic disease is attained is planned.

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Thank you

Karen Graham, Head of Data Improvement, karen.graham36@nhs.net

&

Jennifer Lai, Senior Cancer Intelligence Analyst, jennifer.lai2@nhs.net

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