

Cancer Outcomes and Services Dataset Sept 2011

Trish Stokes,
COSD Programme Manager NCIN





Are communications working?



Cancer Outcomes and Services Dataset (COSD) Update (August 2011)

What is the COSD?

The COSD will be the new national standard for reporting cancer in the NHS in England. It will replace the current National Cancer Dataset and will include the Cancer Registration dataset and additional site specific data items relevant to the different tumour types. It will be aligned with existing national cancer datasets ([Cancer Waits](#) and [Radiotherapy](#)) and with the [Systemic Anti Cancer Therapy dataset](#) (SACT), currently in development.

Why is it needed?

We needed to revise the national cancer dataset to ensure that we meet the current information requirements for the NHS. The Cancer Reform Strategy (2007) identified better information and stronger commissioning as two of the key drivers to achieve the goal that cancer services in this country should be amongst the best in the world. The subsequent Improving Outcomes: A Strategy for Cancer (January 2011) further supports this concept to demonstrate cancer outcomes using high quality data and intelligence for all stakeholders.

What is different from current data collection?

COSD will clarify the items that need to be submitted electronically directly to the cancer registries on a monthly basis. Many Trusts are already sending data directly to the registries from systems such as MDT software, PAS (Patient Administration Systems) and Pathology; COSD will confirm the definitions and values for these items. Many other items in COSD are already being submitted through standard NHS routes such as Cancer Waits and, apart from key items, these will not need to be resent. Most of the remaining items in COSD are site specific and are required for patient management and clinical care. These will also need to be submitted directly to the registries. Data from all sources will be linked by the registries at patient level using NHS number to complete the full dataset.

What is happening next?

The draft dataset was made available for comment through the NHS Information Centre website earlier this year. This version can be downloaded from the [COSD page](#) of the NCIN website. However, an updated version of the dataset is being prepared following the consultation and will be available for download from the NCIN website by the end of August. There will then be a "feasibility test" of the data items in this revised draft. This will include pilot collection of the new items in a range of Trust MDTs (Multidisciplinary Teams).

When will the standard apply?

Any final amendments to the dataset will be made following the testing phase with the final version due to be submitted to the NHS Information Standards Board (ISB) in March 2012. If approved by the ISB the COSD will become a new Information Standard and is expected to be mandated for all NHS Trusts from 1st October 2012.

Further information?

The project management and running of the COSD project has now transferred from the NHSIC to the NCIN as explained in the joint NHSIC/NCIN position statement on the [NCIN website](#).

For further information please email cosd@ncin.org.uk

Trish Stokes, COSD Programme Manager, NCIN



NCIN website

The screenshot shows the NCIN website homepage. At the top left is the NCIN logo with the tagline "national cancer intelligence network" and "Using information to improve quality & choice". To the right is a search bar with a magnifying glass icon and a "SEARCH" button. Below the logo is a navigation menu with the following items: "About NCIN", "News and Events", "Collecting and Using Data", "Publications", "Cancer Information Tools", and "Cancer Type and Topic Specific Work". The main content area features four tiles:

- COSD Cancer Outcomes and Services Dataset**: "Following the recent consultation exercise, an updated version of the COSD dataset is now available for download."
- Site specific work**: "See details of NCIN's publications and work on particular cancer sites and types during 2010-11."
- UK Cancer e-Atlas now available**: "National and local cancer statistics for incidence, mortality and survival". The tile includes a small image of a map of the UK and a screenshot of a data table.
- Cancer Commissioning Toolkit**: "Key cancer information and data for use by commissioners". The tile includes a screenshot of a software interface with various icons and text.

National Cancer Intelligence Network

The NCIN is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

[Find out more about NCIN.](#)

NCIN FOR...

- ▶ Analysts
- ▶ Commissioners and Policy Makers
- ▶ Health Professionals

Improving Outcomes: A Strategy for Cancer

January 2011

Alignment with NHS reforms

- ‘Improving outcomes: A strategy for cancer’ sets out how the future direction for cancer will be aligned with:
- Equity and Excellence: Liberating the NHS
- Healthy Lives; Healthy people
- The new emphasis on:
 - Patient information and choice
 - Outcomes not process targets
 - Stronger commissioning
 - New arrangements for public health and local democratic legitimacy

Key changes

- Outcomes agenda – new analyses
- Standard datasets
- Improved timeliness of data & reporting
- Shared ‘data’ ownership

“We can only be sure to improve what we
can actually measure”

Darzi, High Quality Care for All, June 2008

Avoidable deaths pa if survival in England = best in World

Breast	~ 2000	Myeloma	250
Colorectal	~1700	Endometrial	250
Lung	~1300	Leukaemia	240
Oesophagogastric	~ 950	Brain	225
Kidney	~ 700	Melanoma	190
Ovary	~ 500	Cervix	180
NHL/HD	370	Oral/Larynx	170
Bladder	290	Pancreas	75

[NB Prostate has been excluded as survival 'gap' is likely to be due to differences in PSA testing rates.]

Data derived from Abdel-Rahman et al, BJC Supplement December 2009

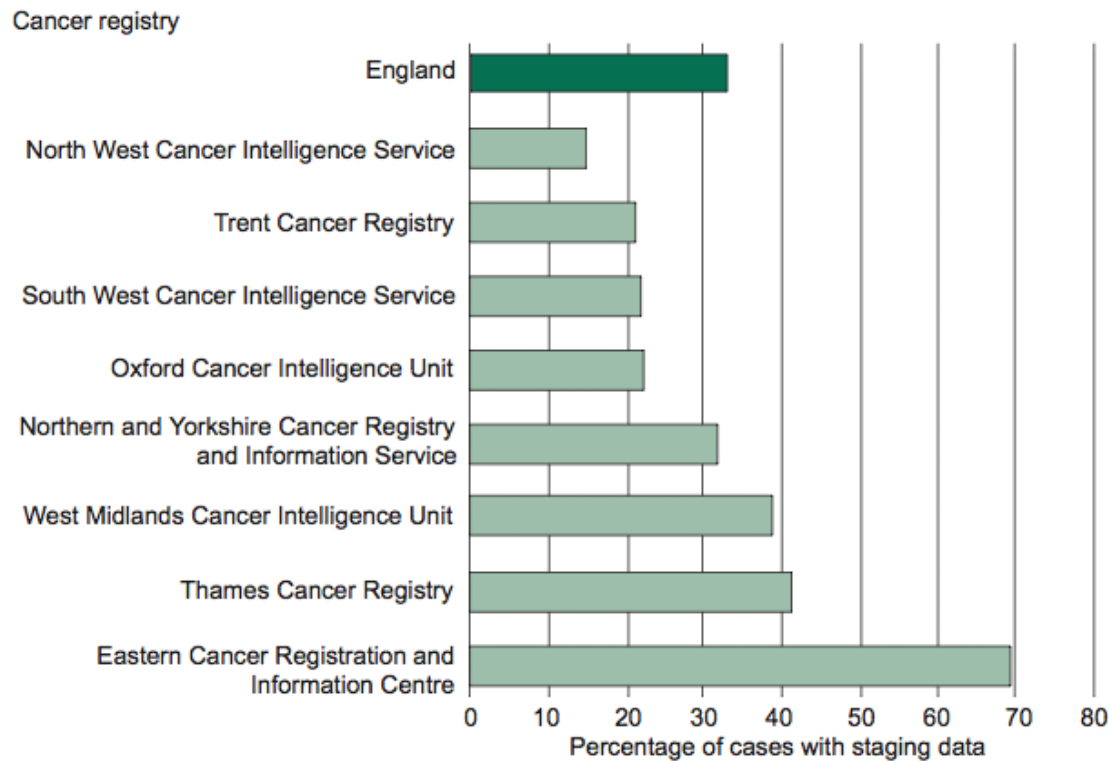
All Persons	Screen detected	Two Week Wait	GP referral	Other outpatient	Inpatient elective	Emergency presentation	Death Certificate Only	Unknown	Total	Number of patients
Acute leukaemia		3%	17%	14%	4%	57%	0%	4%	100%	2,551
Bladder		32%	28%	15%	2%	18%	0%	4%	100%	7,665
Brain & CNS		1%	17%	14%	4%	58%	0%	6%	100%	4,147
Breast	21%	42%	12%	9%	0%	4%	0%	12%	100%	34,232
Cervix	14%	16%	25%	16%	2%	12%	0%	13%	100%	2,085
Chronic leukaemia		10%	30%	12%	2%	30%	1%	16%	100%	2,869
Colorectal		26%	24%	15%	4%	25%	1%	6%	100%	27,903
Kidney		20%	29%	18%	1%	24%	1%	6%	100%	5,172
Larynx		31%	32%	21%	1%	12%	0%	3%	100%	1,583
Lung		22%	20%	13%	1%	38%	1%	5%	100%	29,420
Melanoma		41%	29%	11%	1%	3%	0%	16%	100%	8,117
Multiple myeloma		13%	27%	15%	1%	38%	0%	6%	100%	3,145
Non-Hodgkin's lymphoma		16%	30%	17%	2%	28%	0%	7%	100%	7,777
Oesophagus		25%	21%	17%	10%	21%	1%	4%	100%	6,001
Oral		26%	28%	30%	1%	6%	0%	9%	100%	3,062
Other		14%	25%	15%	2%	36%	1%	7%	100%	27,730
Ovary		26%	22%	15%	1%	29%	1%	6%	100%	5,012
Pancreas		13%	18%	12%	2%	47%	1%	6%	100%	5,989
Prostate		20%	38%	16%	3%	9%	0%	14%	100%	28,362
Stomach		17%	21%	16%	7%	32%	1%	5%	100%	5,841
Testis		48%	14%	16%	2%	10%		10%	100%	1,569
Uterus		35%	31%	16%	1%	8%	0%	8%	100%	5,733
Total	3%	25%	24%	14%	2%	23%	1%	8%	100%	225,965

Routes to Diagnosis

3% - screening
 25% - TWR
 24% - GP or O/P
23% - emergency
 8% - n/k



Staging project Registry completeness - 2007



Source: National Cancer Intelligence Network

Staging pledge 2012

70% completeness

- TNM
- Dukes
- FIGO
- Ann Arbor

Other Haem Staging

CLL:

- PLATELET COUNT
- HEPATOMEGALY INDICATOR
- SPLENOMEGALY INDICATOR
- NUMBER OF LYMPHADENOPATHY AREAS
- RAI STAGE/
- BINET STAGE

Myeloma:

- ALBUMIN
- BETA2 MICROGLOBULIN LEVEL
- ISS STAGE for MYELOMA

Cancer Datasets

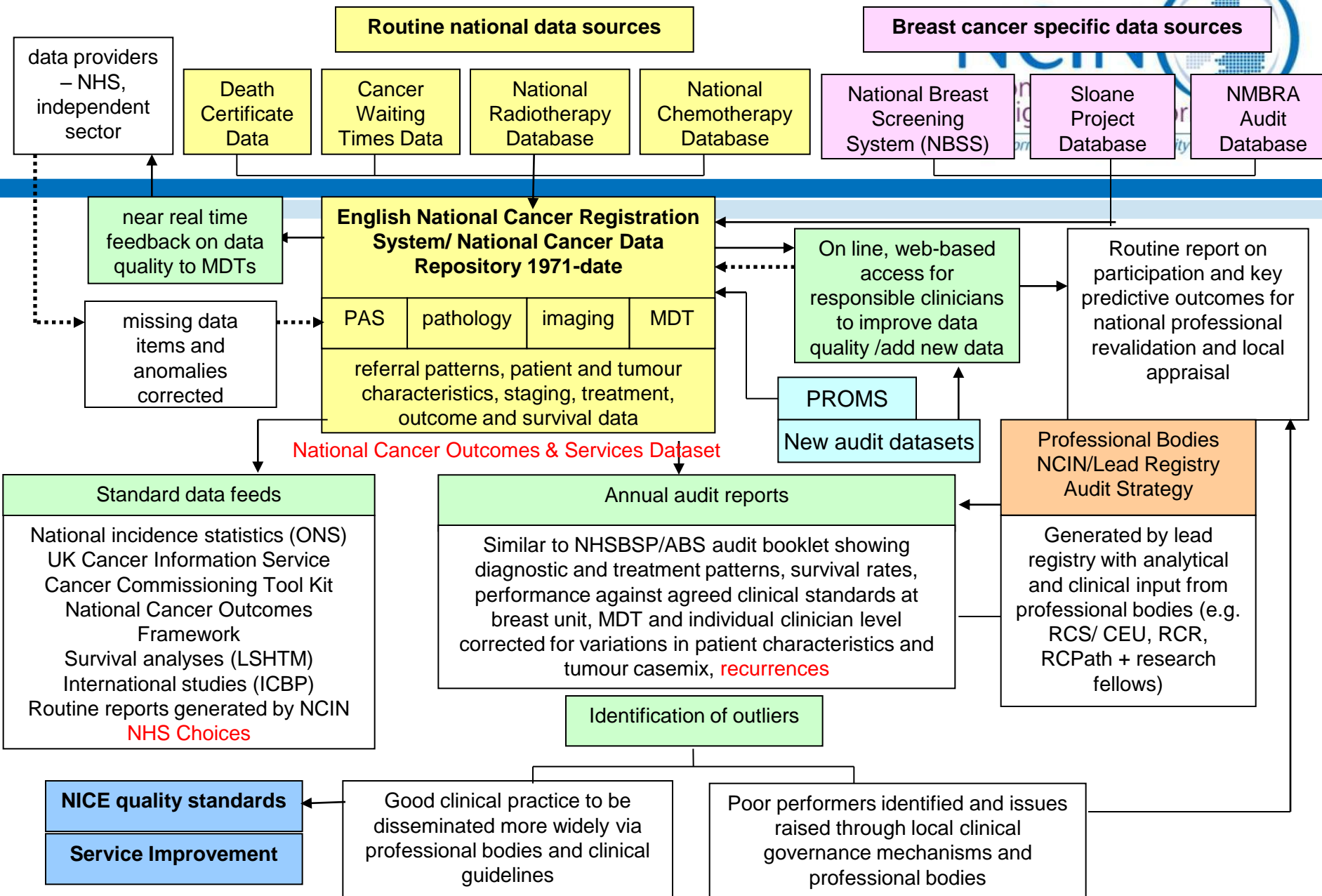
- Sept 2012

- Cancer Registration Dataset – *mandated for several years*
- Going Further on Cancer Waits – Jan 2009
- Radiotherapy – April 2009
- *Chemotherapy (SACT) – April 2012*
- ***Cancer Outcomes and Services Dataset – Autumn 2012***
- *(RC Pathology – Professional/Clinical Standards)*
- *(RC Radiology – Professional/Clinical Standards)*
- ?National Audits

COSD features

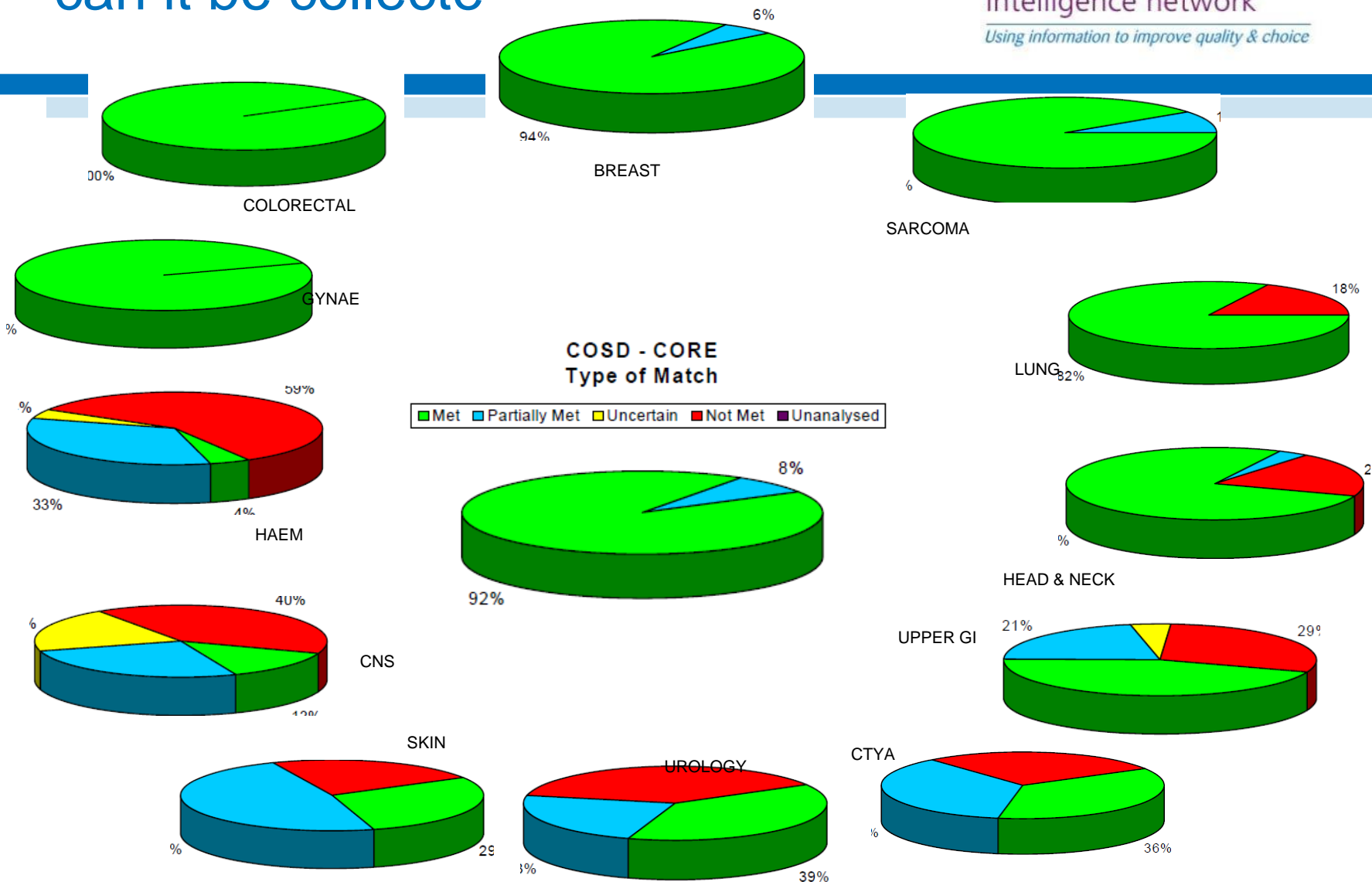
- The new national cancer dataset
- Reporting needs v Trust submissions
- Secondary uses – from patient management
- All registerable conditions
 - And secondary breast cancer
- Aligned and standardised
- Multiple data sources – collect once
- Components
 - Core (Registration and Cancer Waits)
 - Site specific (cf nat audit)
 - Key pathology (core RCPATH)
- Monthly submission
- Monthly feedback

National Cancer Audit Strategy



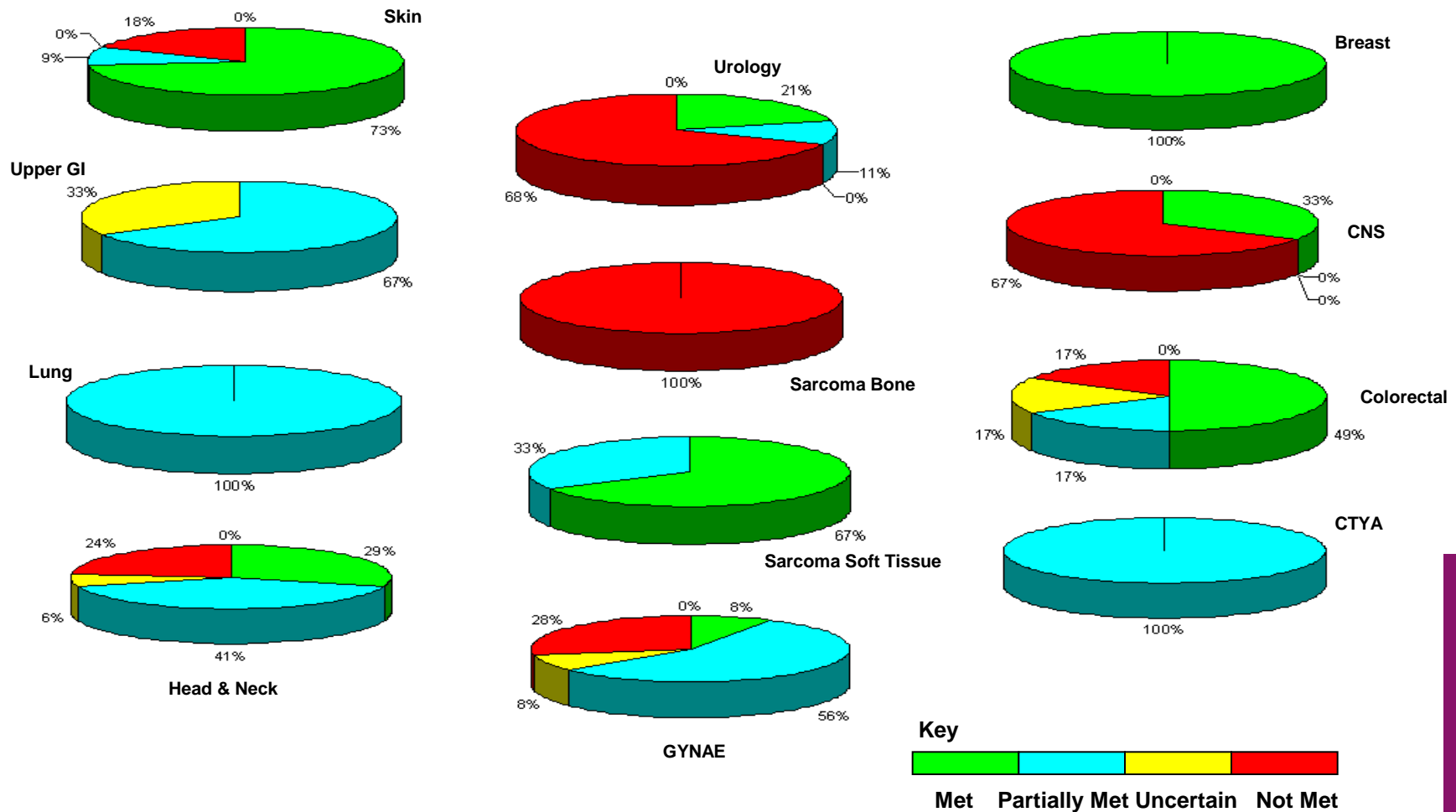
A mixed bag

- can it be collected?

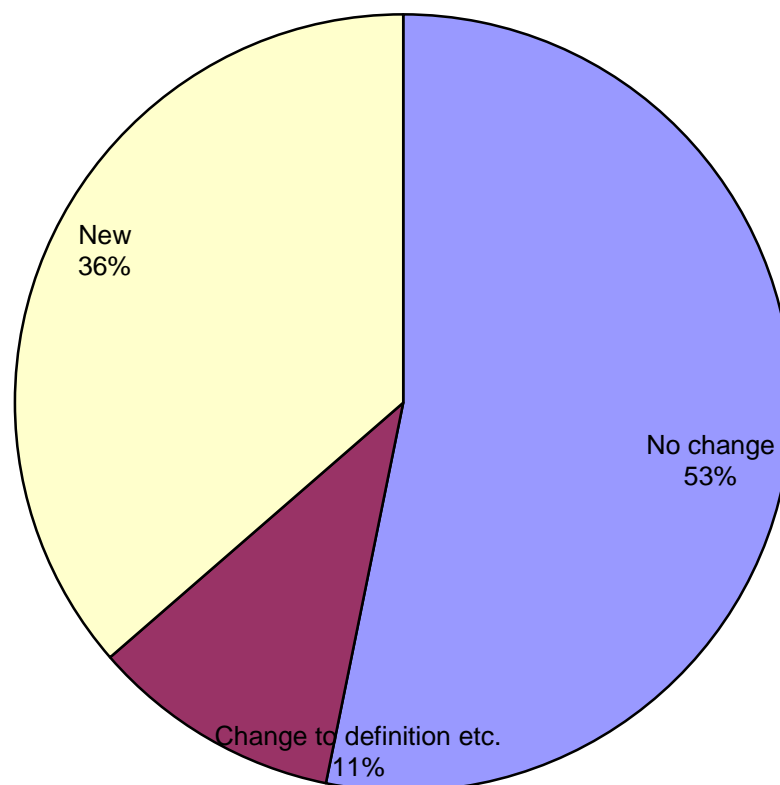


Site-Specific Pathology Capability Analysis

– Key staging components

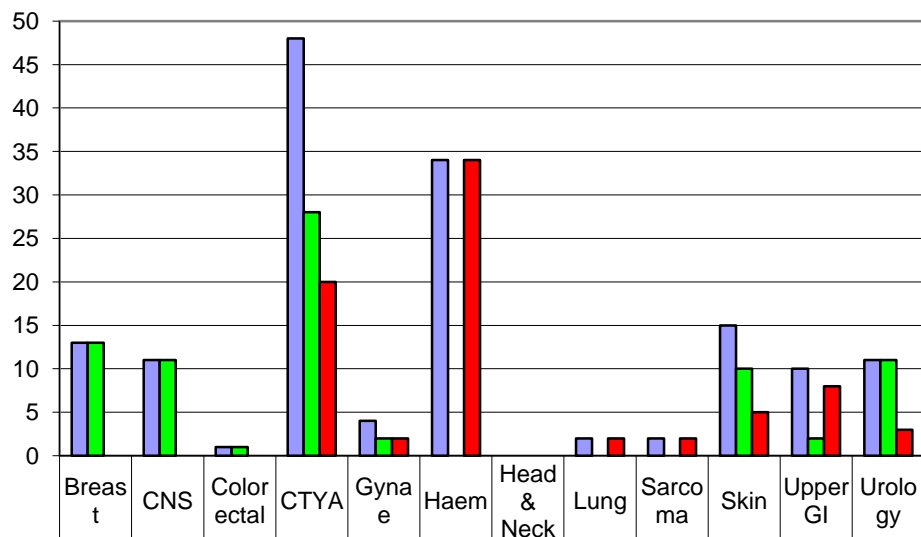


The latest dataset



“New” data?

Completeness Evidence



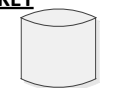
■ Total number of New data items	13	11	1	48	4	34	0	2	2	15	10	11
■ Completed (strong and medium data completeness)	13	11	1	28	2	0	0	0	0	10	2	11
■ Partially or not evidence of completeness (Weak and no evidence/no response recorded)	0	0	0	20	2	34	0	2	2	5	8	3

Patient pathway



CANCER REGISTRY

KEY



Data store



Fully structured / coded

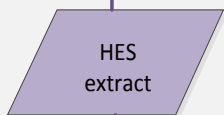


Data flow

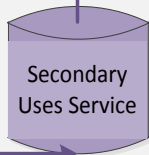


NATIONAL REGISTRY DATABASE
(COSD DATASET)

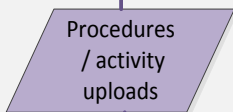
N3 Network or other approved transmission medium



HES
extract

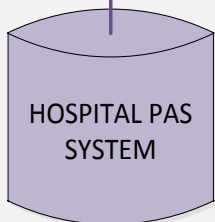


Secondary
Uses Service



Procedures
/ activity
uploads

N3 Network or other approved transmission medium



HOSPITAL PAS
SYSTEM

CANCER REGISTRY

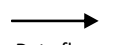
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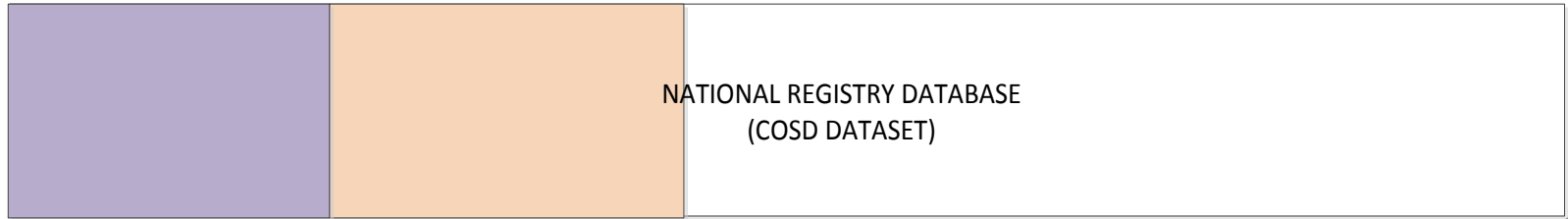
Data store



Fully structured / coded



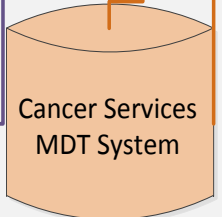
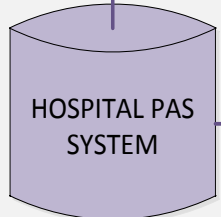
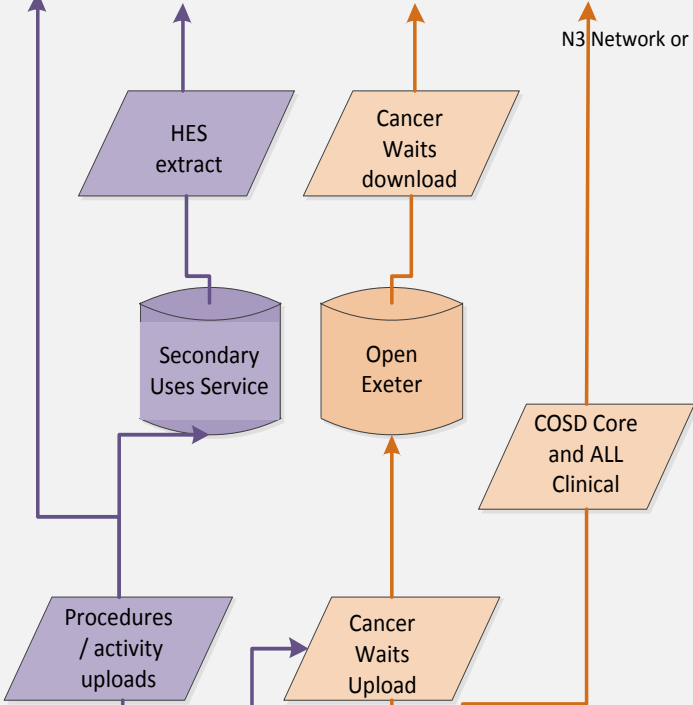
Data flow



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(COSD DATASET)

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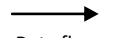
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Data store



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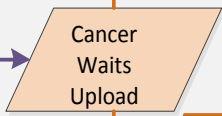
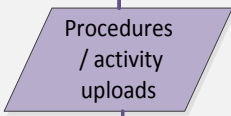
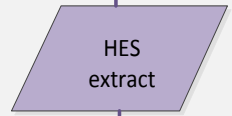
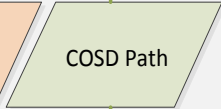
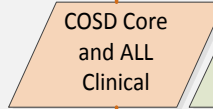
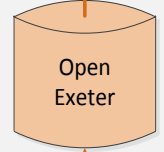
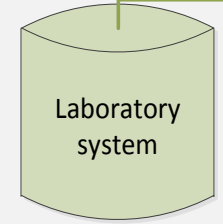
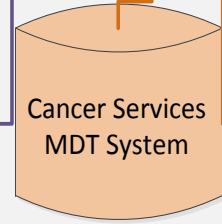
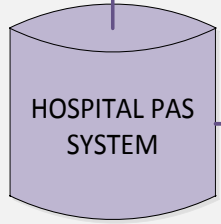
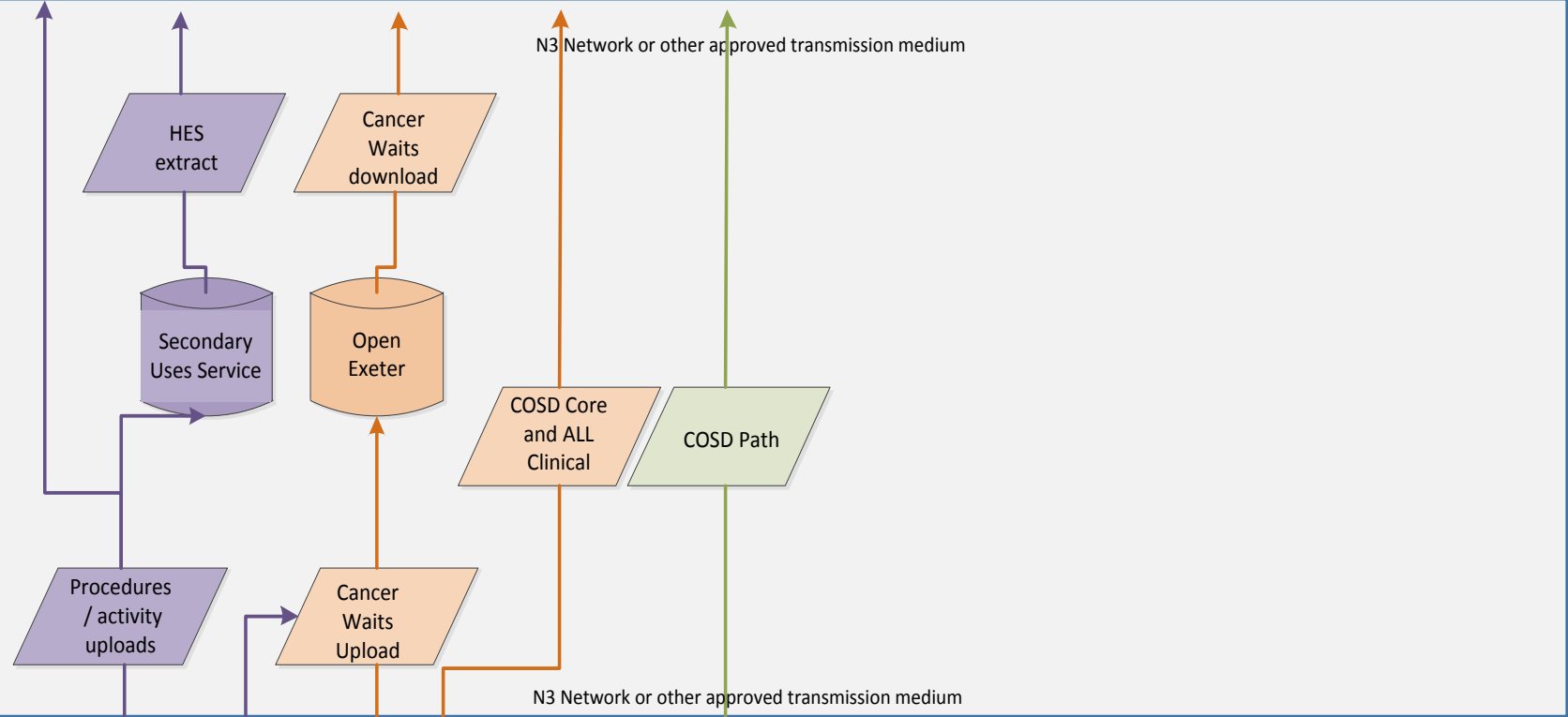
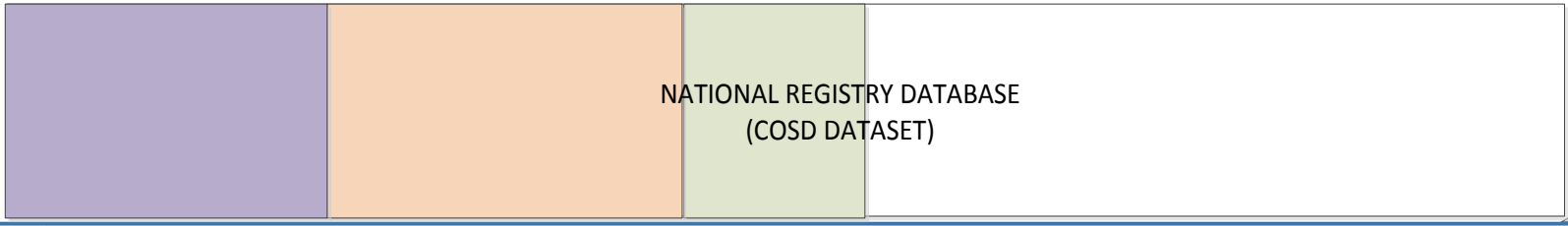
Data flow

NATIONAL REGISTRY DATABASE
(COSD DATASET)

N3 Network or other approved transmission medium

N3 Network or other approved transmission medium

Acute Trust / Cancer Centre



CANCER REGISTRY

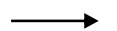
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Data store



Fully structured / coded

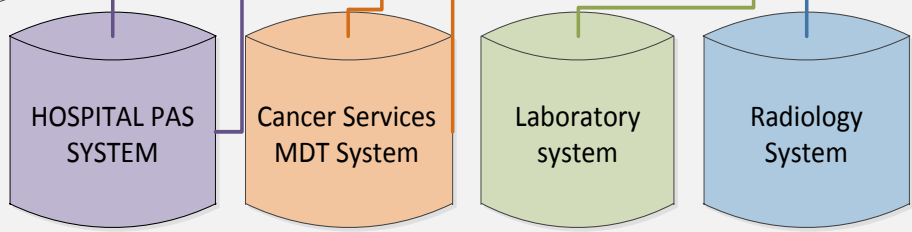
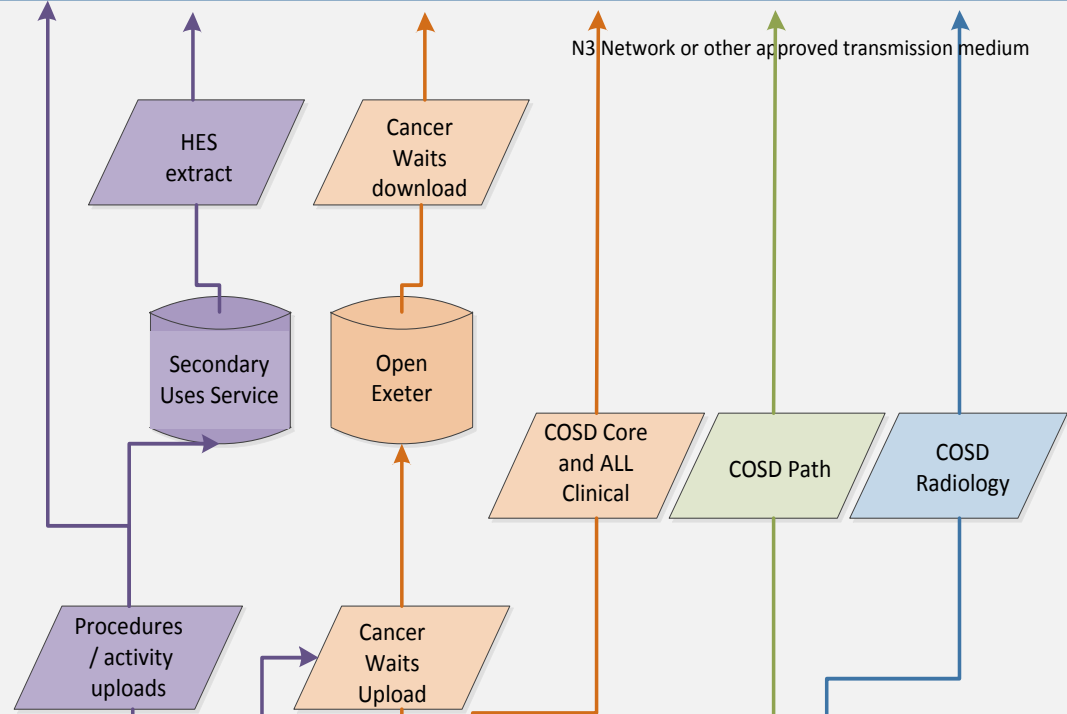


Data flow

NATIONAL REGISTRY DATABASE
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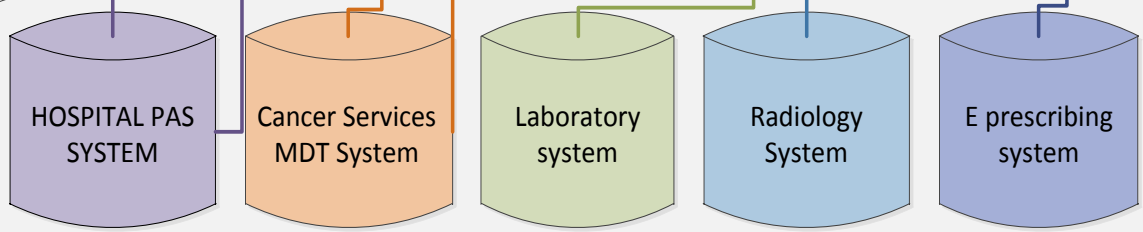
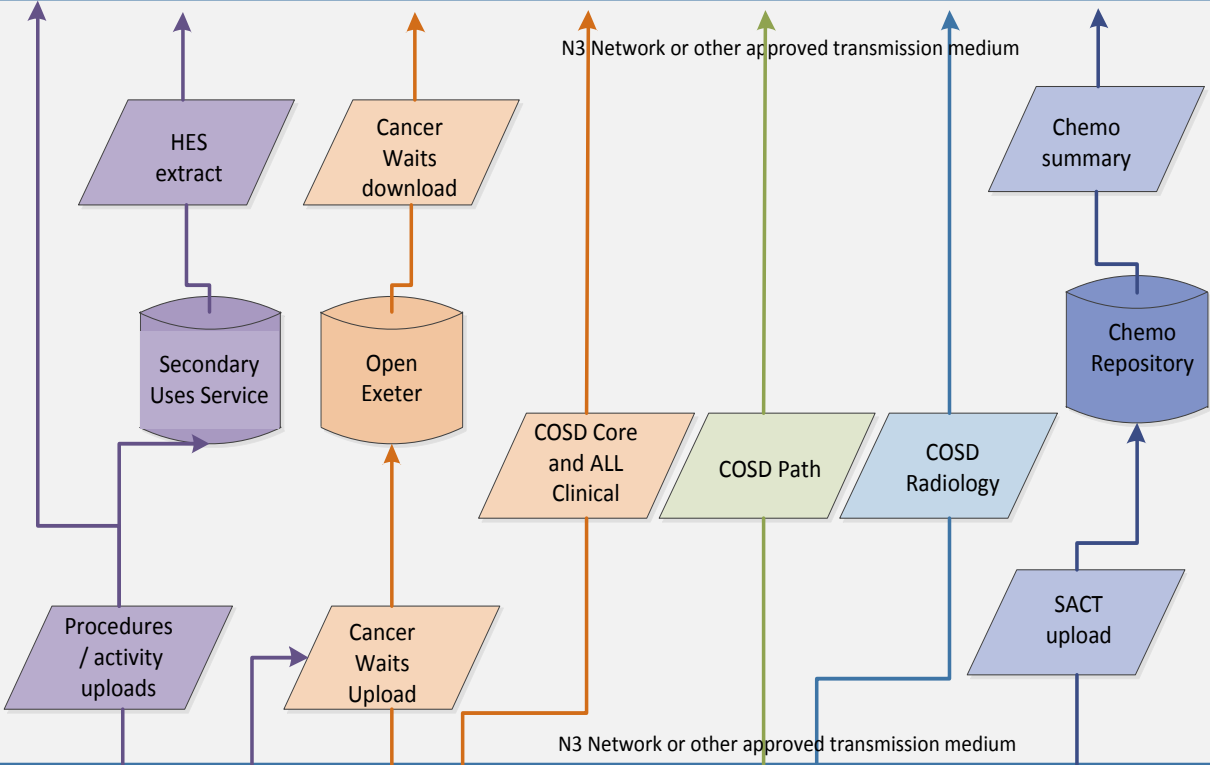
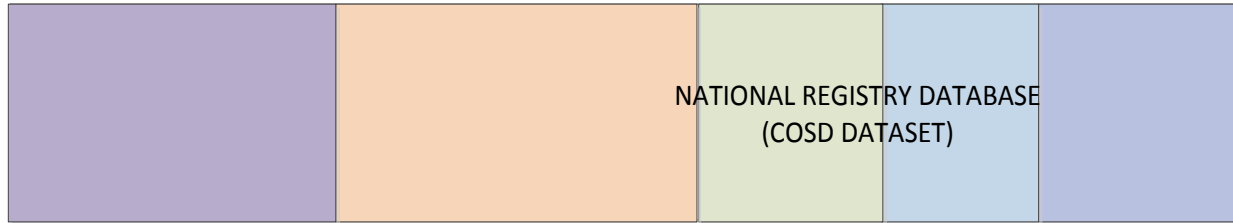
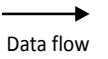
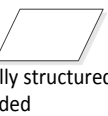
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CANCER REGISTRY

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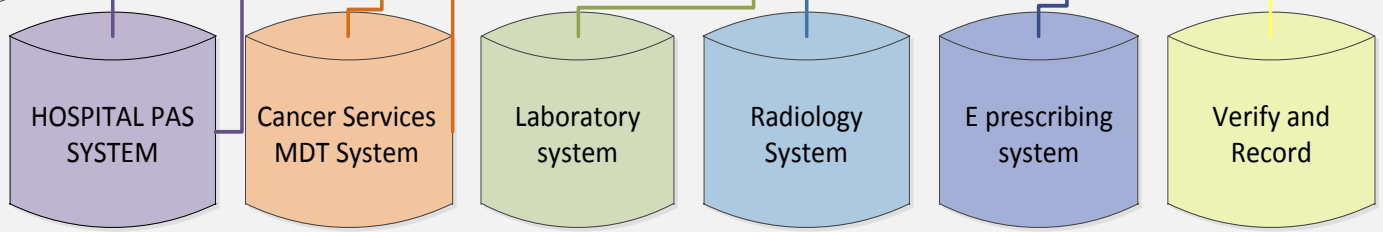
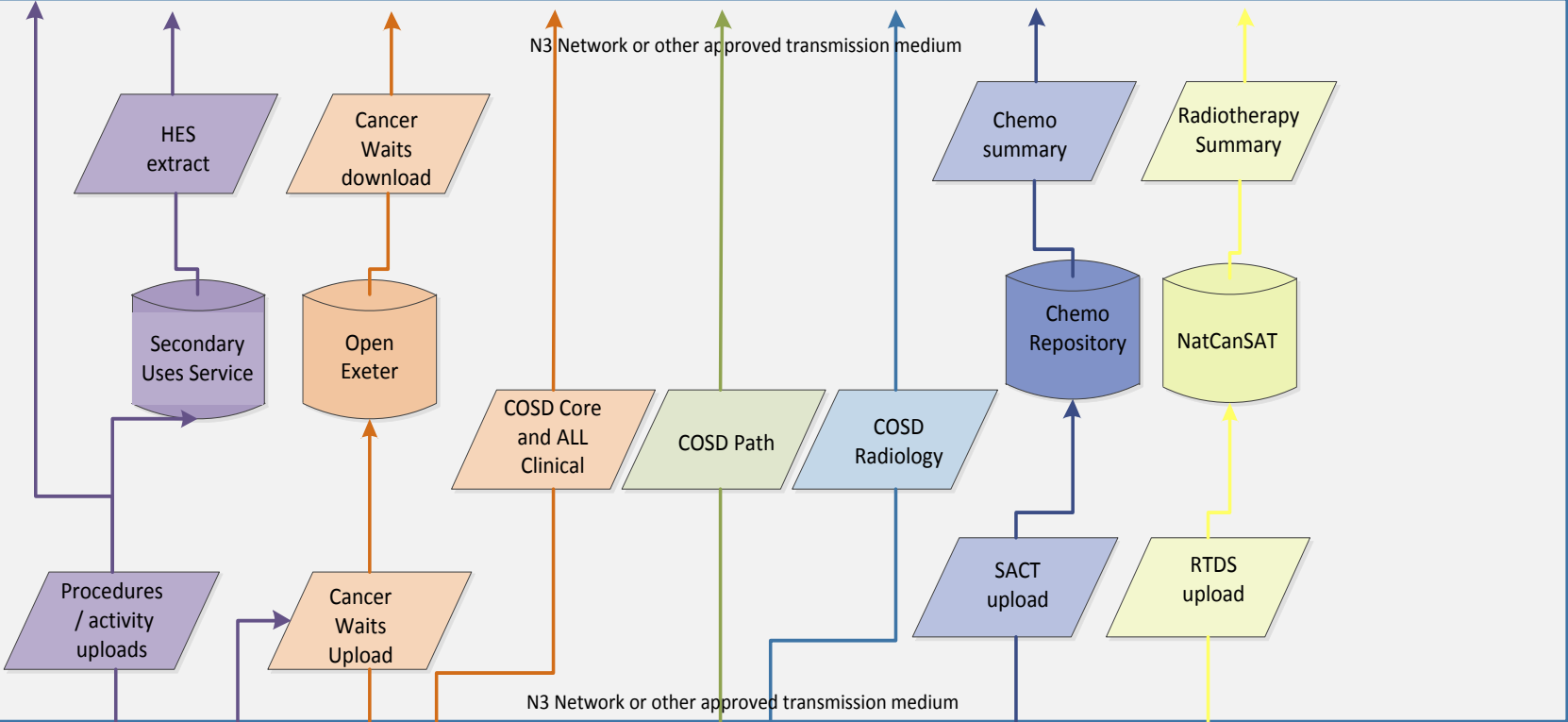
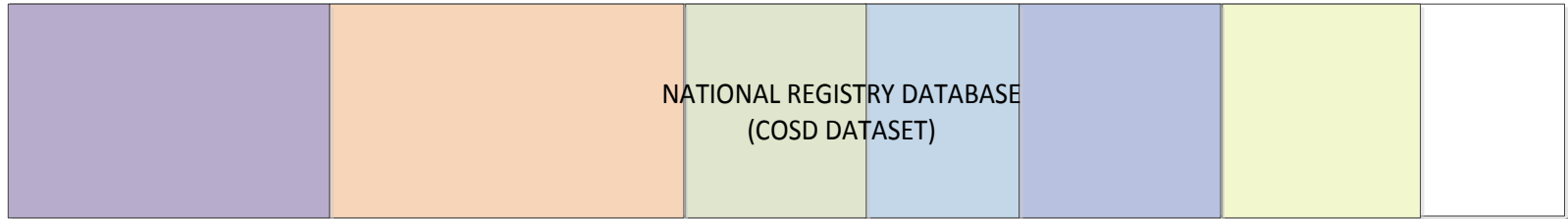
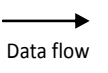
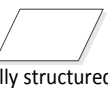


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CANCER REGISTRY

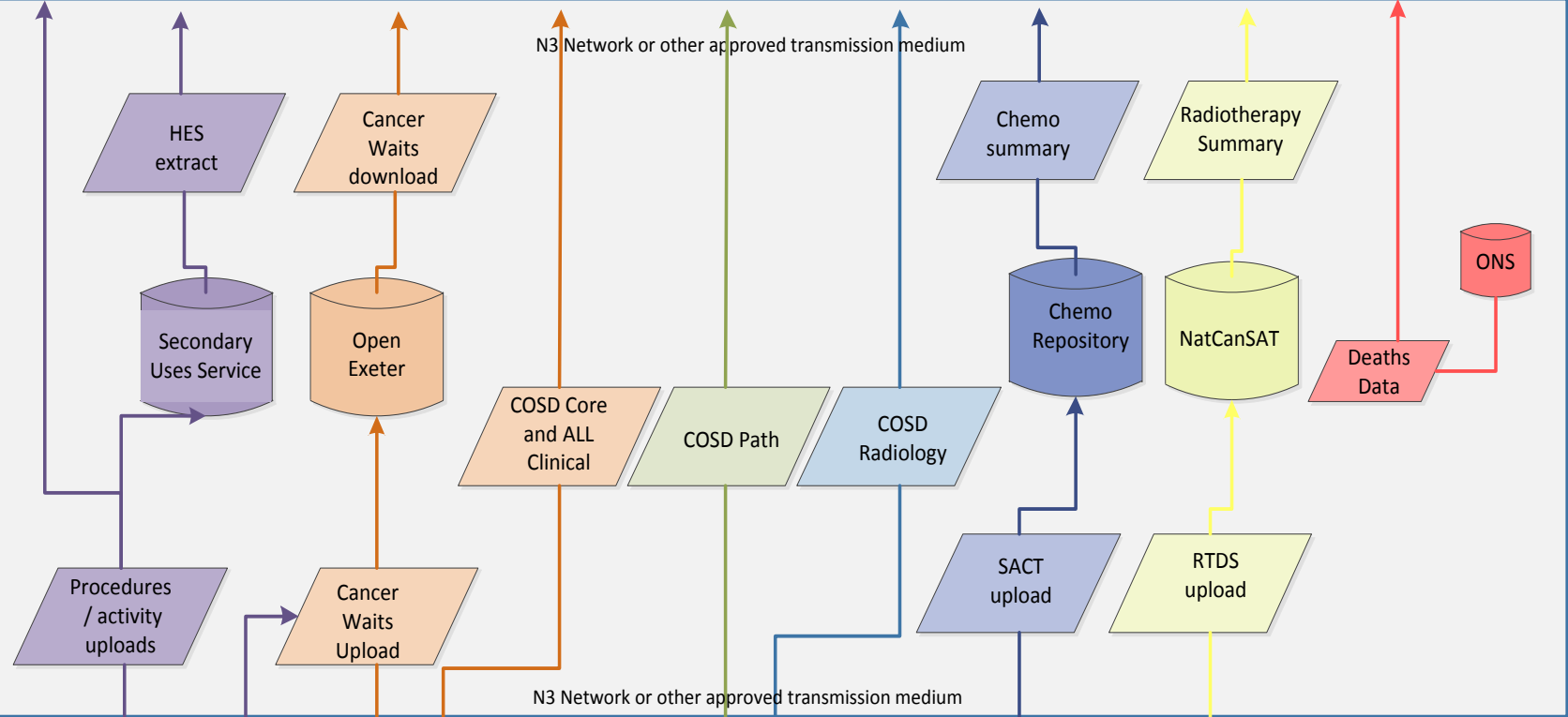
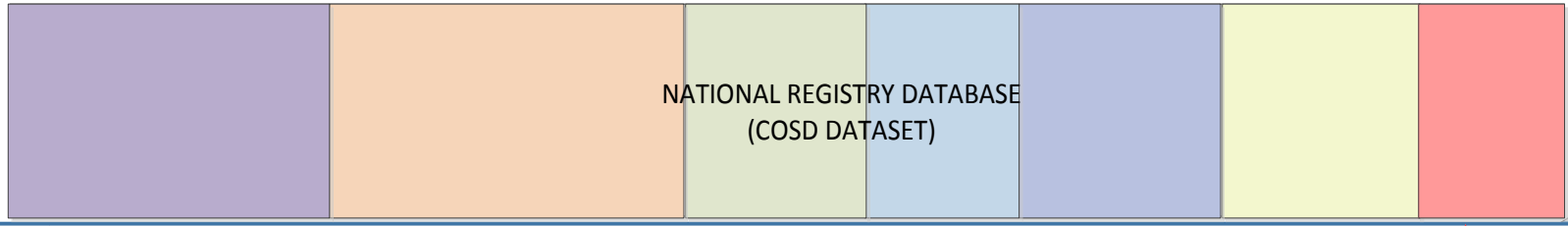
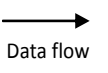
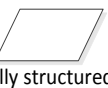
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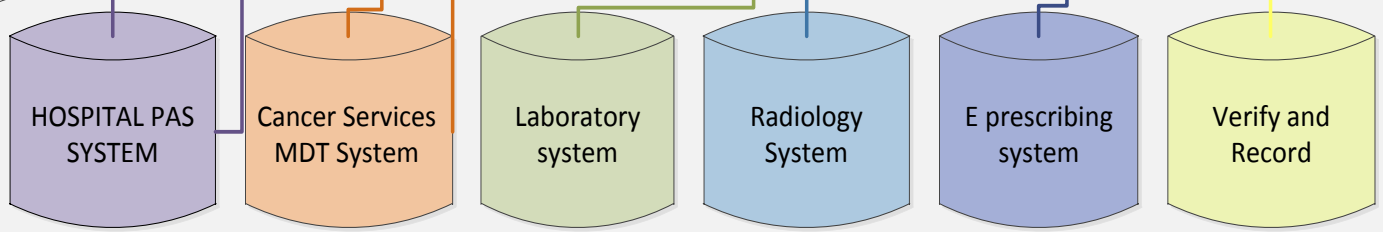
CANCER REGISTRY

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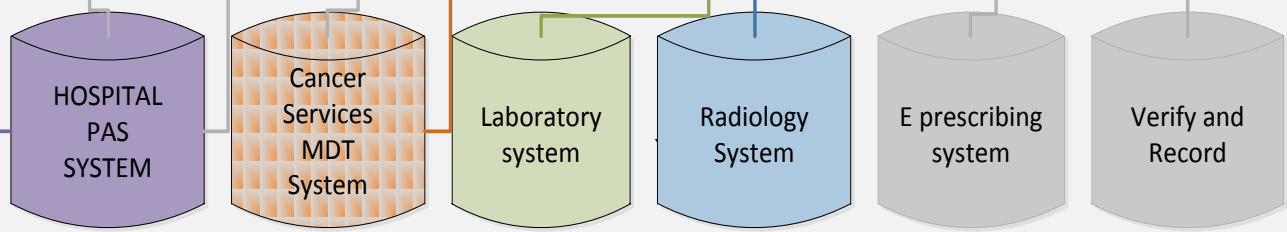
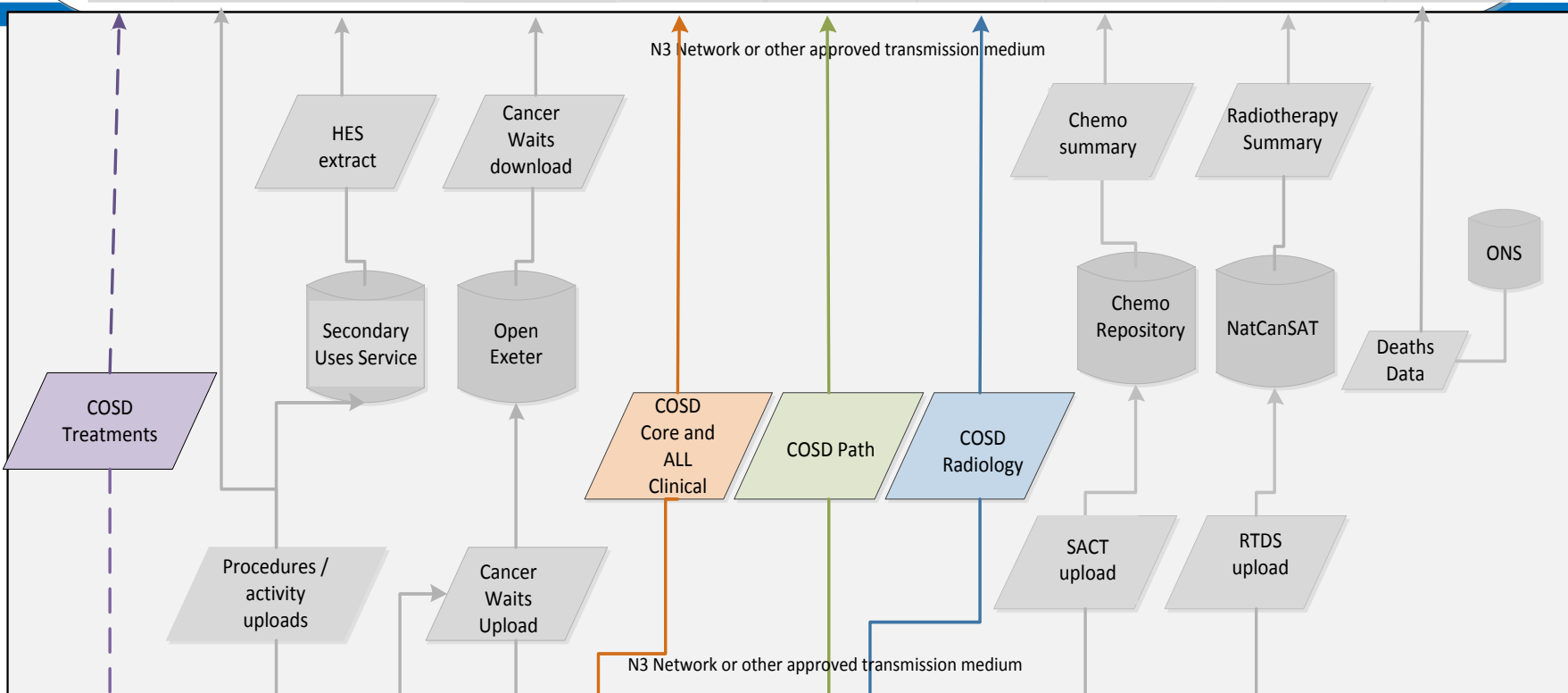
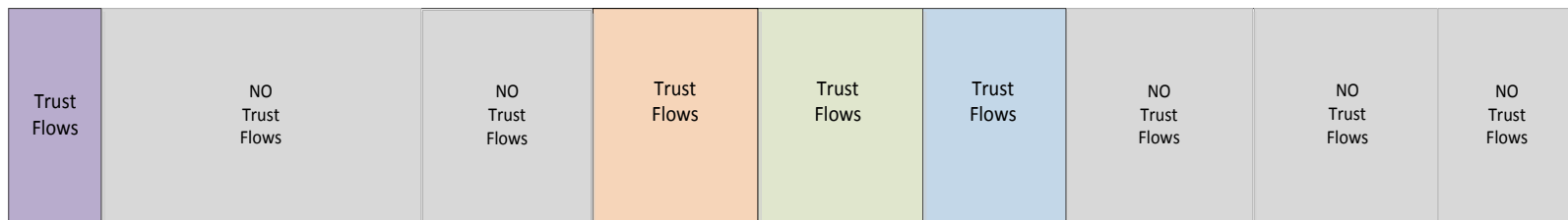
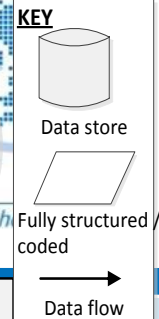
N3 Network or other approved transmission medium



Acute Trust / Cancer Centre

COSD TRUST DATAFLOWS

NATIONAL REGISTRY DATABASE (COSD DATASET)



Acute Trust / Cancer Centre

Thank you
Any Questions

[*cosd@ncin.org.uk*](mailto:cosd@ncin.org.uk)

[*www.ncin.org.uk*](http://www.ncin.org.uk)