

# Cancer Outcomes and Services Dataset

Urology Clinical Leads Workshop  
July 2011

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# Overview

- Multiple datasets
- COSD features
- Multiple collection
- Information Standard
- Can we/do we collect this data?
- Non active treatments

# 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

Secondary uses – from patient management

Aligned and standardised

Multiple data sources – collect once

Components

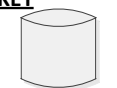
- Core (Registration and Cancer Waits)
- Site specific (cf nat audit)
- Key pathology (core RCPATH)

Monthly submission

Monthly feedback

CANCER REGISTRY

KEY



Data store



Fully structured / coded



Data flow

NATIONAL REGISTRY DATABASE  
(COSD DATASET)

N3 Network or other approved transmission medium

HES  
extract

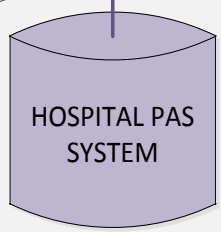
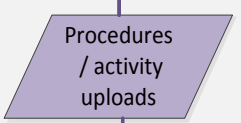
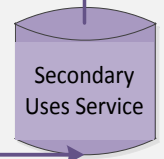
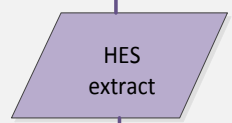
Secondary  
Uses Service

Procedures  
/ activity  
uploads

N3 Network or other approved transmission medium

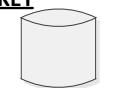
HOSPITAL PAS  
SYSTEM

Acute Trust / Cancer Centre



CANCER REGISTRY

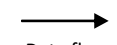
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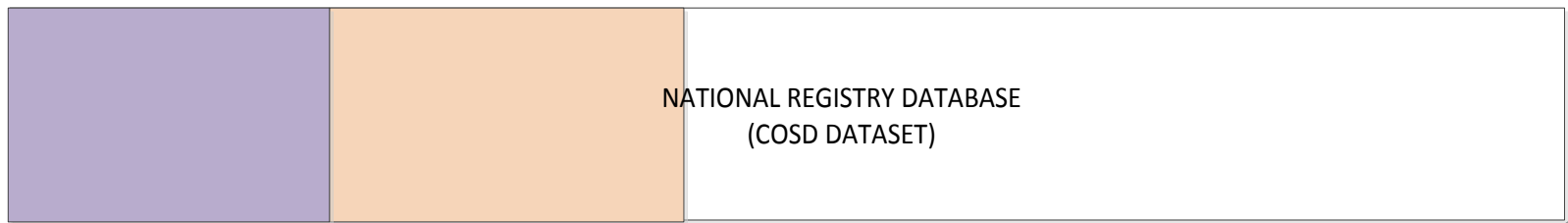
Data store



Fully structured / coded



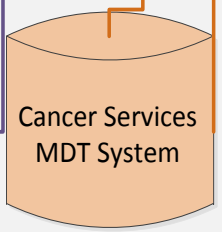
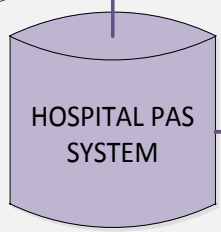
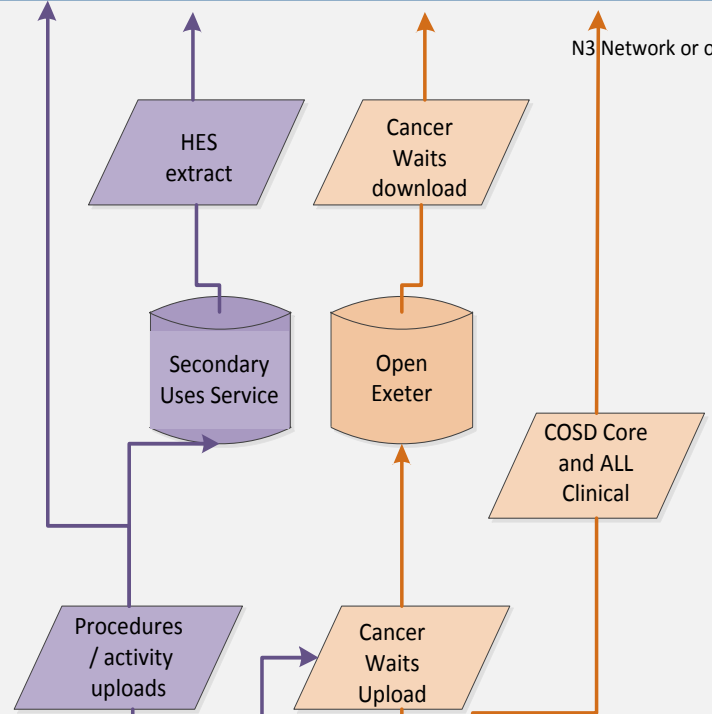
Data flow



NATIONAL REGISTRY DATABASE  
(COSD DATASET)

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CANCER REGISTRY

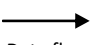
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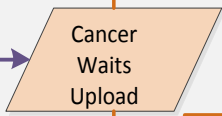
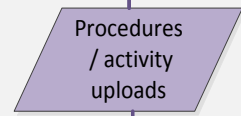
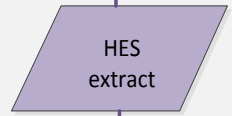
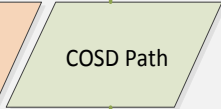
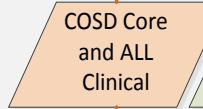
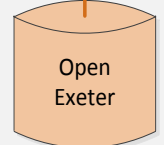
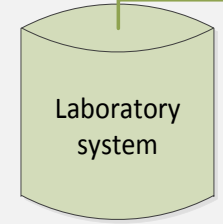
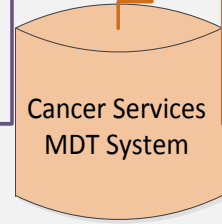
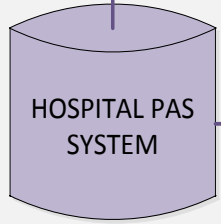
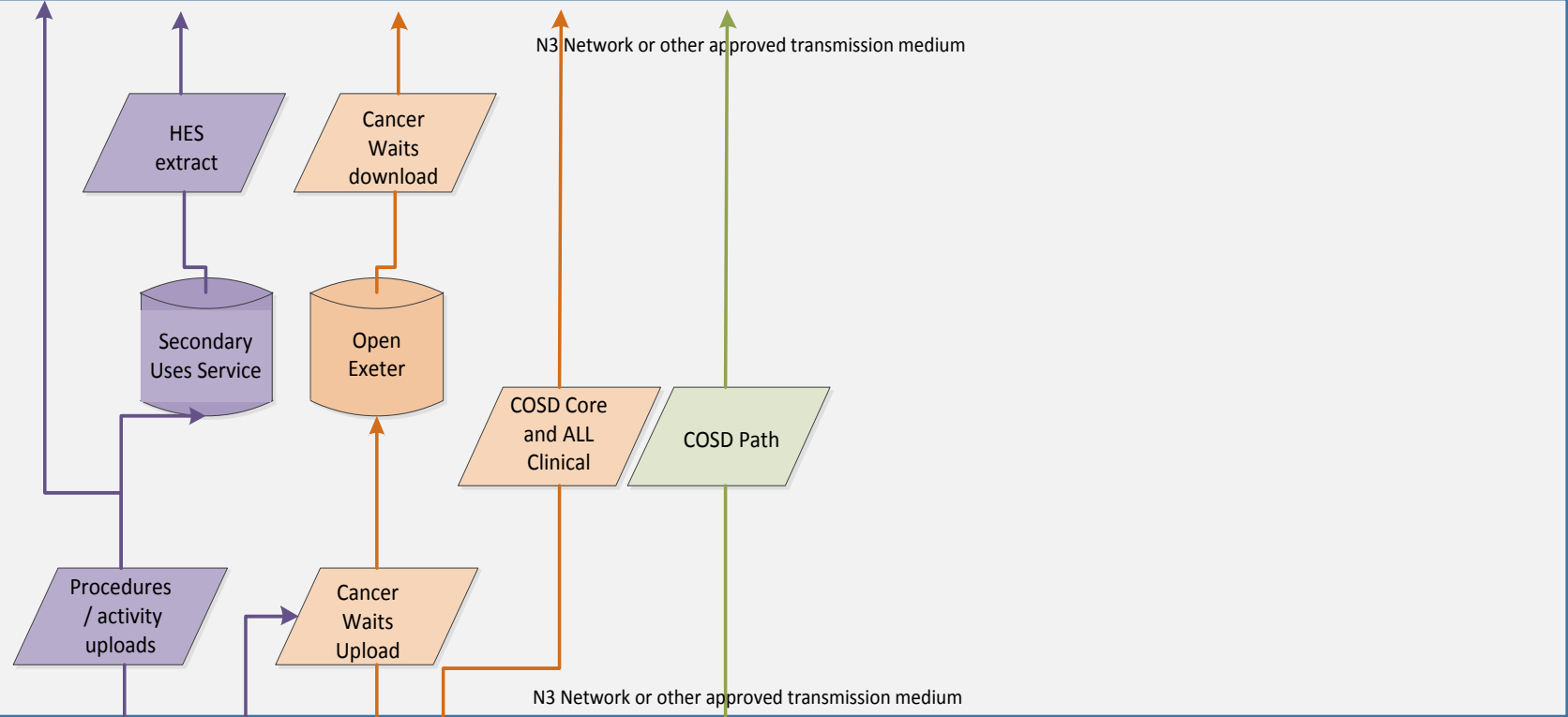
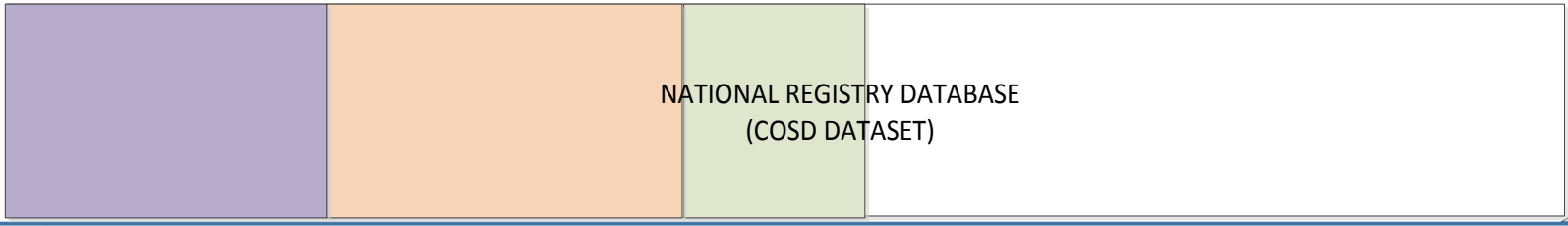
Data flow

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

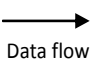
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Data store



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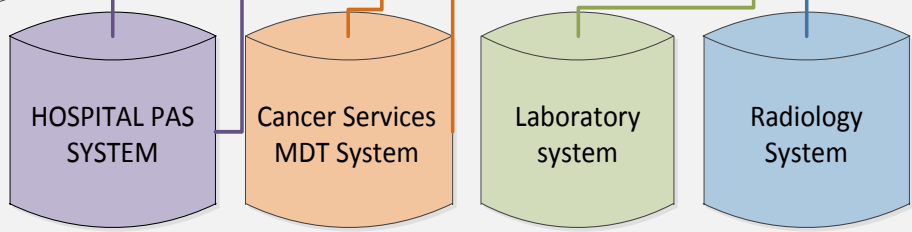
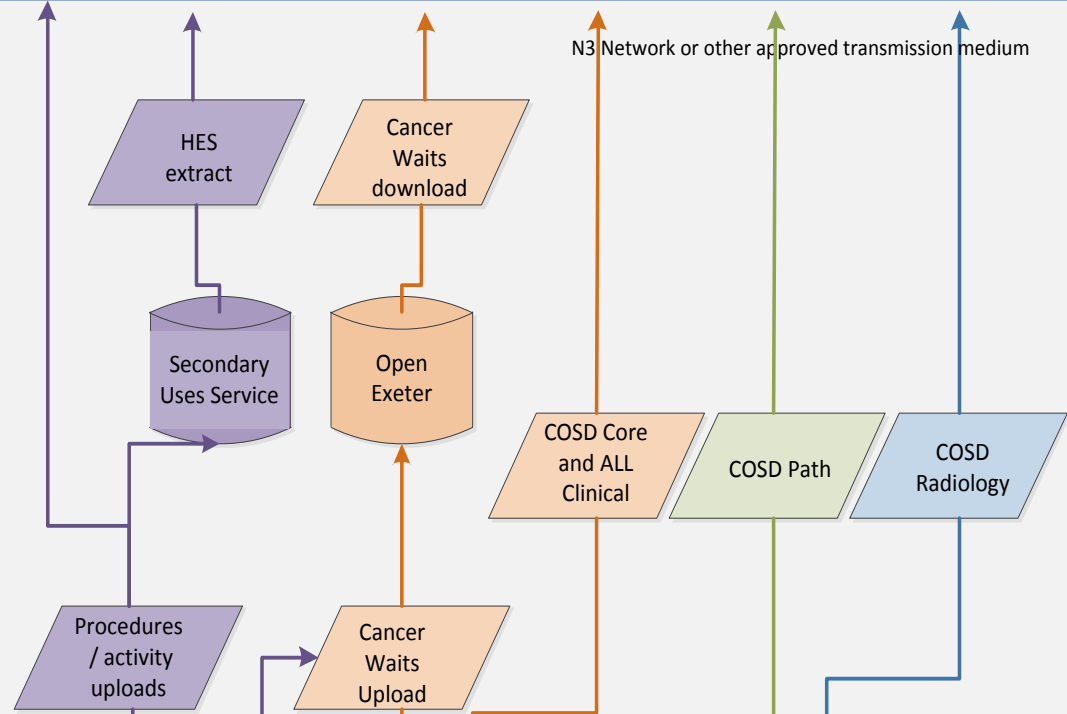


Data flow

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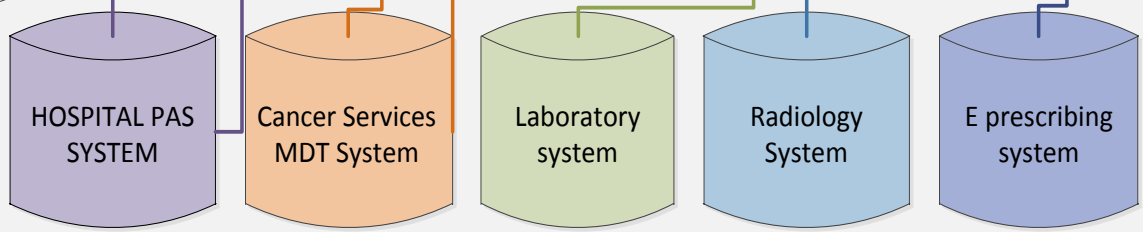
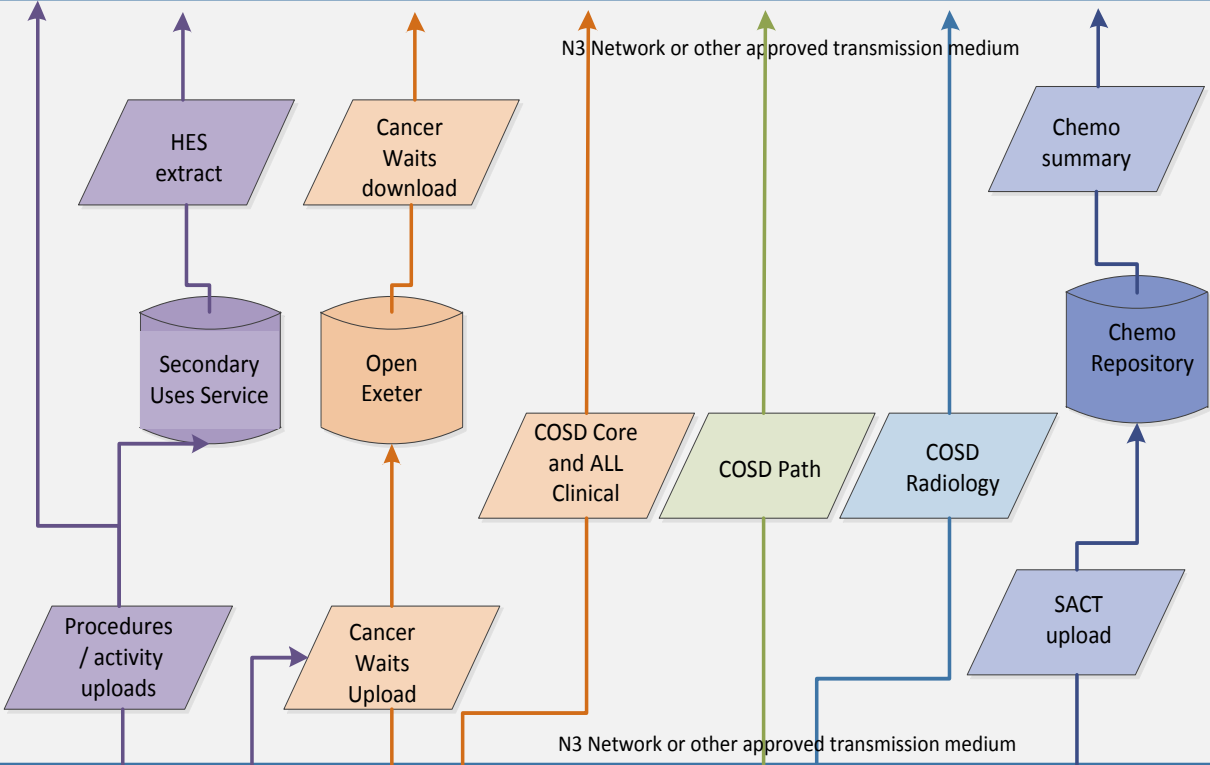
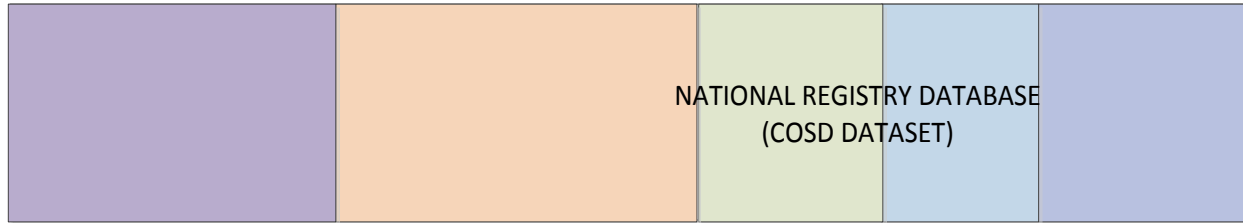
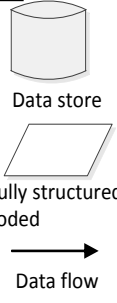


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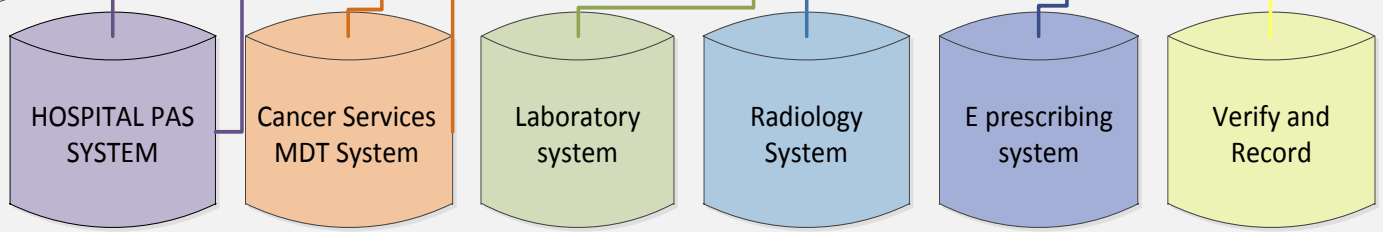
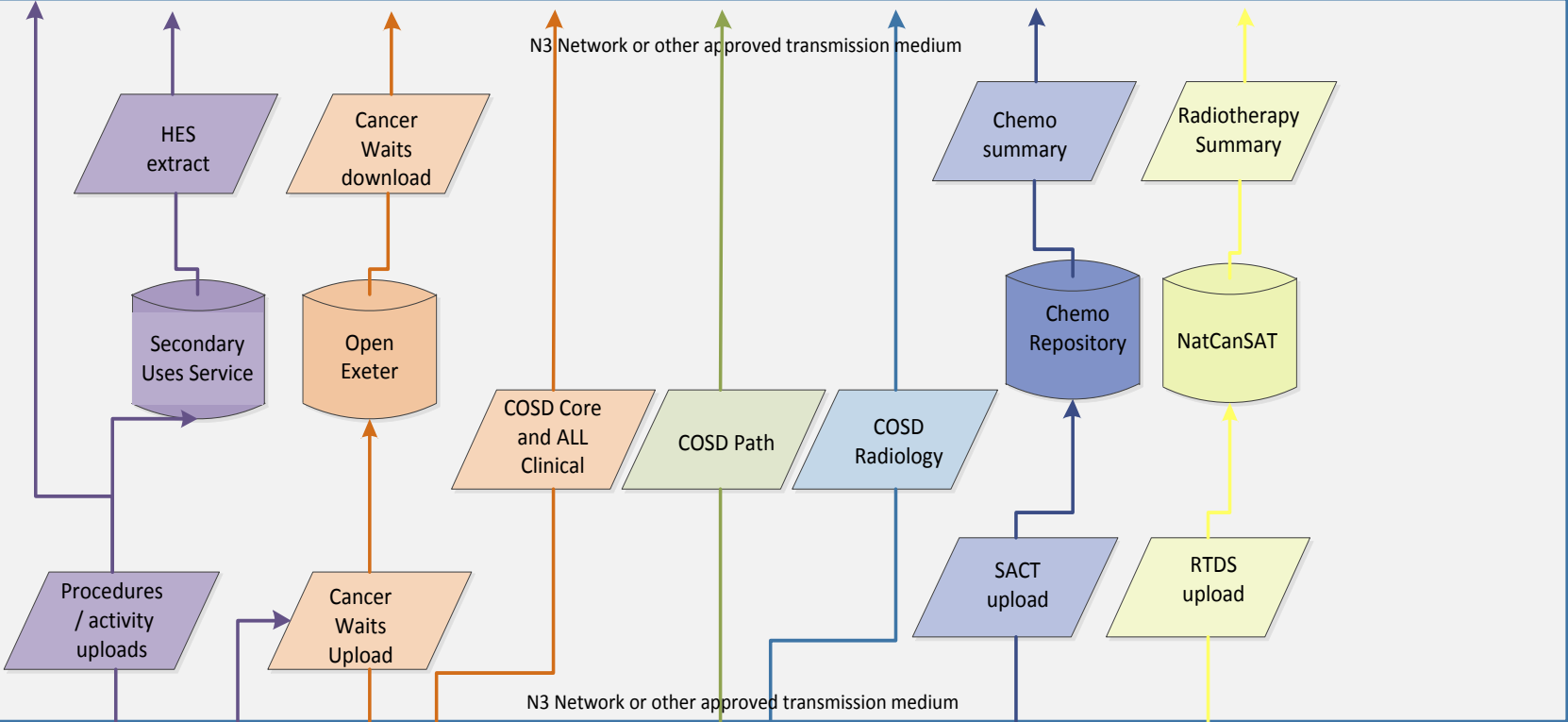
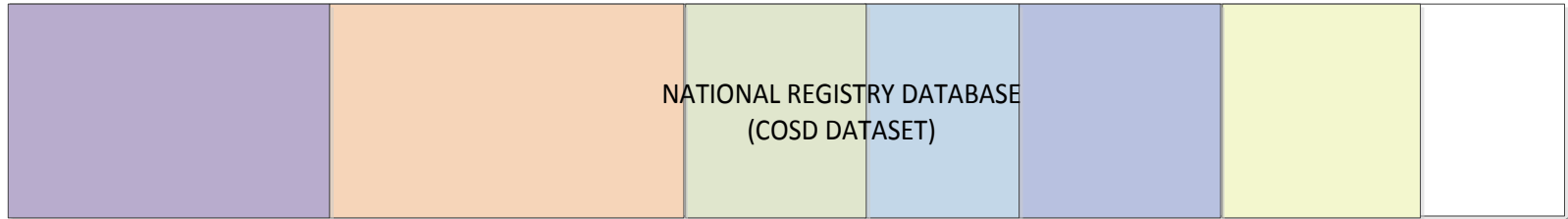
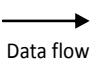
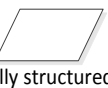
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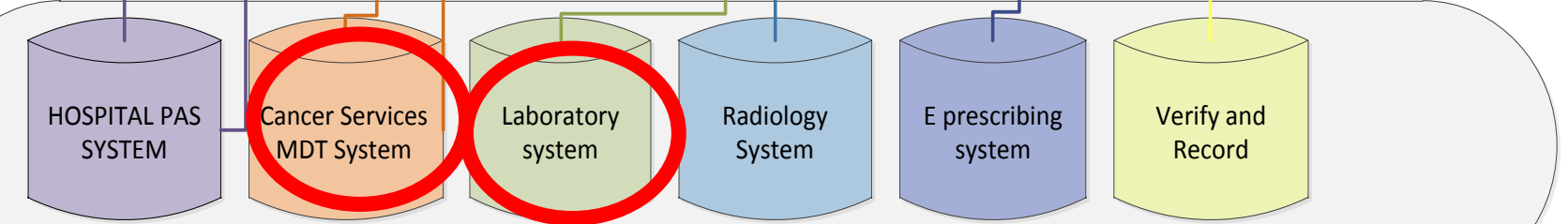
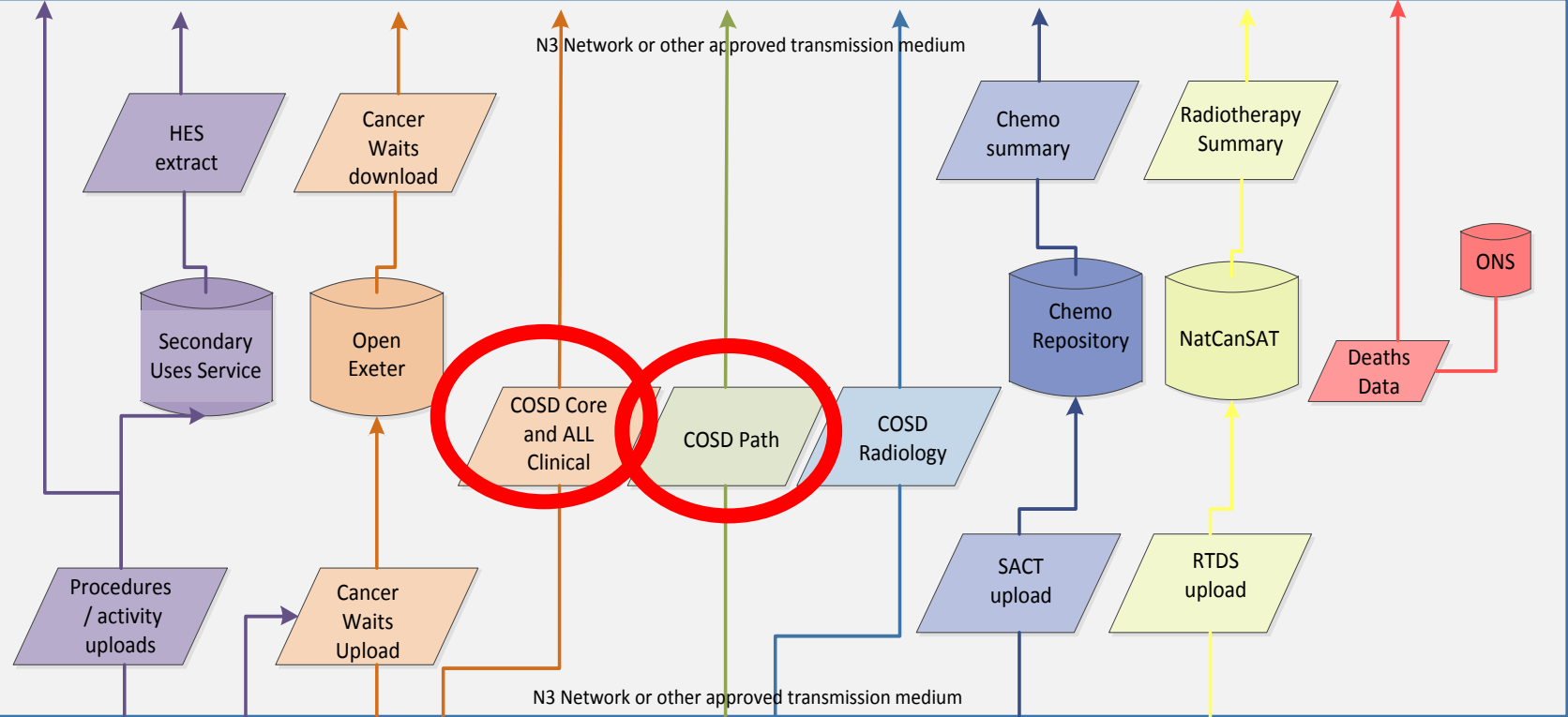
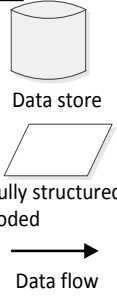
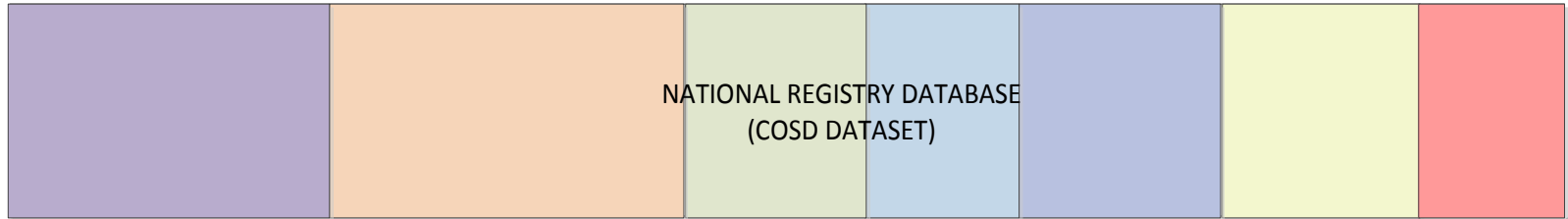
CANCER REGISTRY

KEY



CANCER REGISTRY

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# Definitional testing – general feedback

## Support for

- cohesive and consistent dataset
- clear and comprehensive guides

## Concerns

- increased burden of collection
- need for clinical involvement

# Site specific data items

## Kidney

eGFR

TUMOUR NECROSIS

PERINEPHRIC FAT INVASION

ADRENAL INVASION

RENAL VEIN INVASION

GEROTA'S FASCIA INVASION

## Bladder

HYDRONEPHROSIS

INTRAVESICAL CHEMOTHERAPY INDICATOR

INTRAVESICAL IMMUNOTHERAPY INDICATOR

DETRUSOR MUSCLE PRESENCE INDICATOR

## Testicular

NORMAL LDH (Testicular only)

S-CATEGORY (Testicular only)

S-CATEGORY: AFP (ALPHA FETO-PROTEIN) (Testicular only)

S-CATEGORY: HCG (HUMAN CHORIONIC GONADOTROPIN)

S-CATEGORY: LDH (SERUM LACTATE DEHYDROGENASE)

## Prostate

PSA AT DIAGNOSIS

PSA (PRE-TREATMENT)

GLEASON GRADE (PRIMARY)

GLEASON GRADE (SECONDARY)

GLEASON GRADE (TERTIARY)

PERINEURAL INVASION

ORGAN CONFINED

SEMINAL VESICLES INVASION

TURP TUMOUR PERCENTAGE

## Penile

PATIENT HISTORY INDICATOR (HUMAN\_PAPILLOMAVIRUS)

CORPUS SPONGIOSUM INVASION

CORPUS CAVERNOSUM INVASION

URETHRA OR PROSTATE INVASION

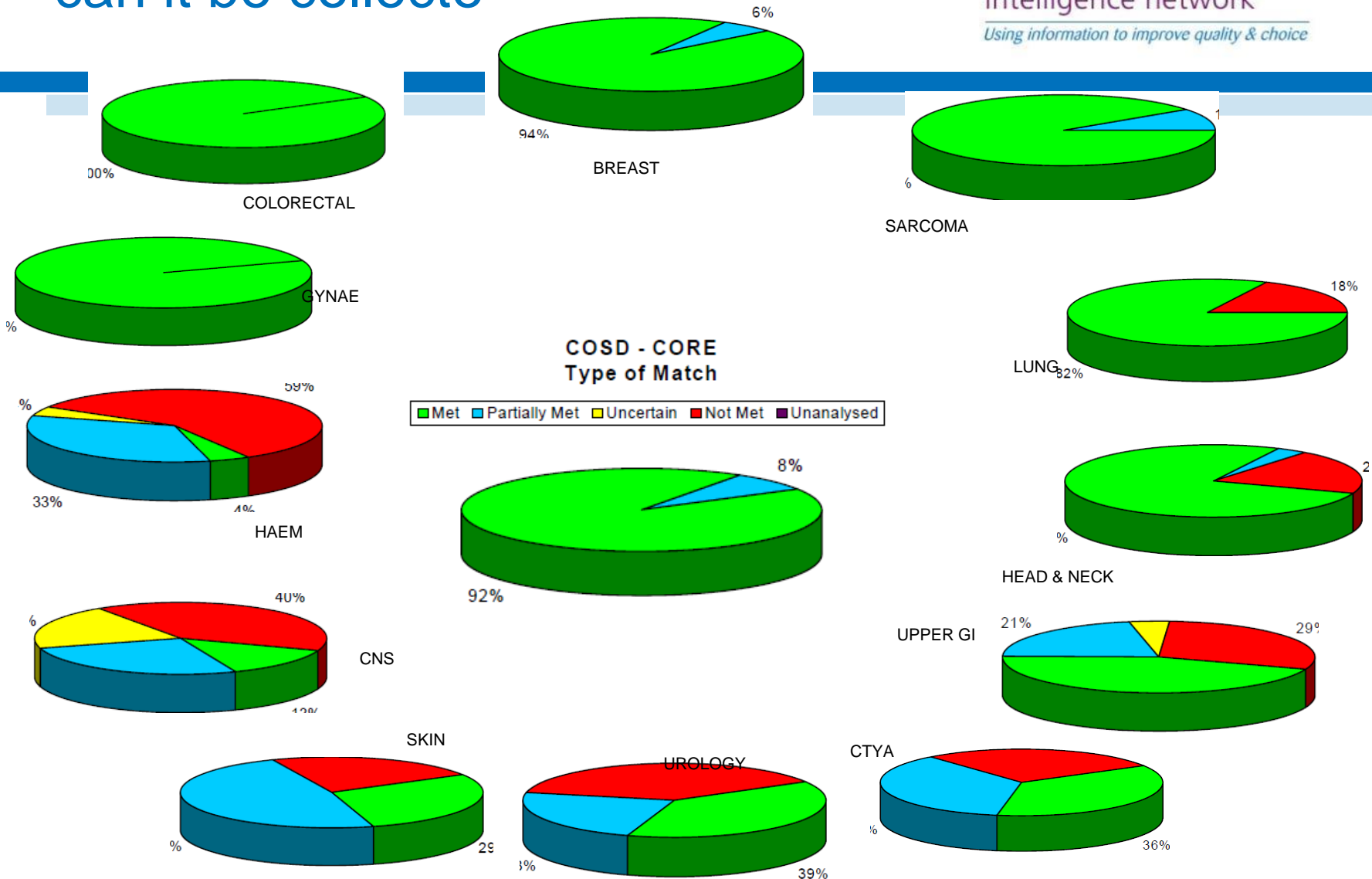
## Pelvis, Ureter, Urethra, Urinary Bladder

TUMOUR GRADE

RETE TESTES INVASION

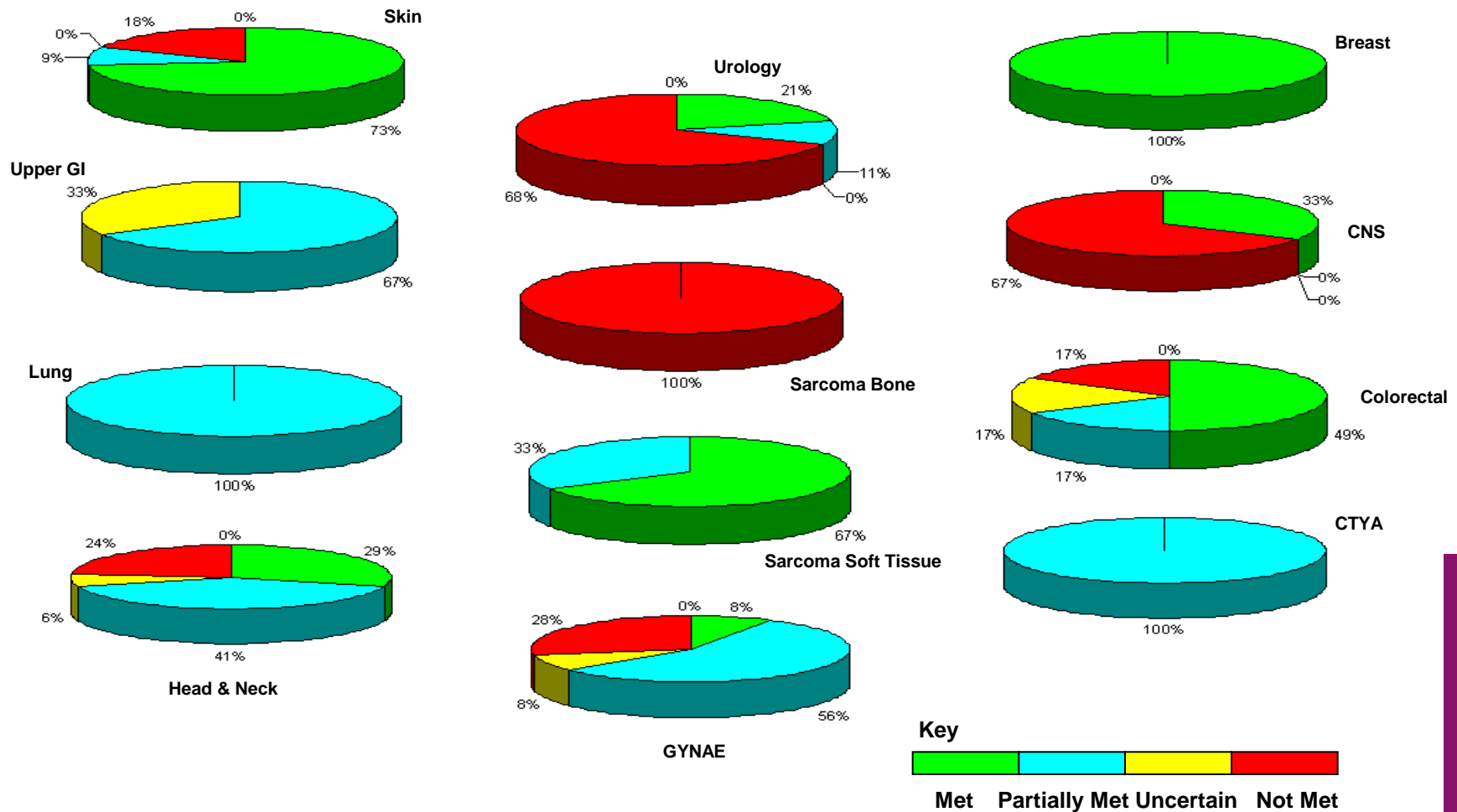
# A mixed bag

- can it be collected?



# Site-Specific Pathology Capability Analysis

## – Key staging components



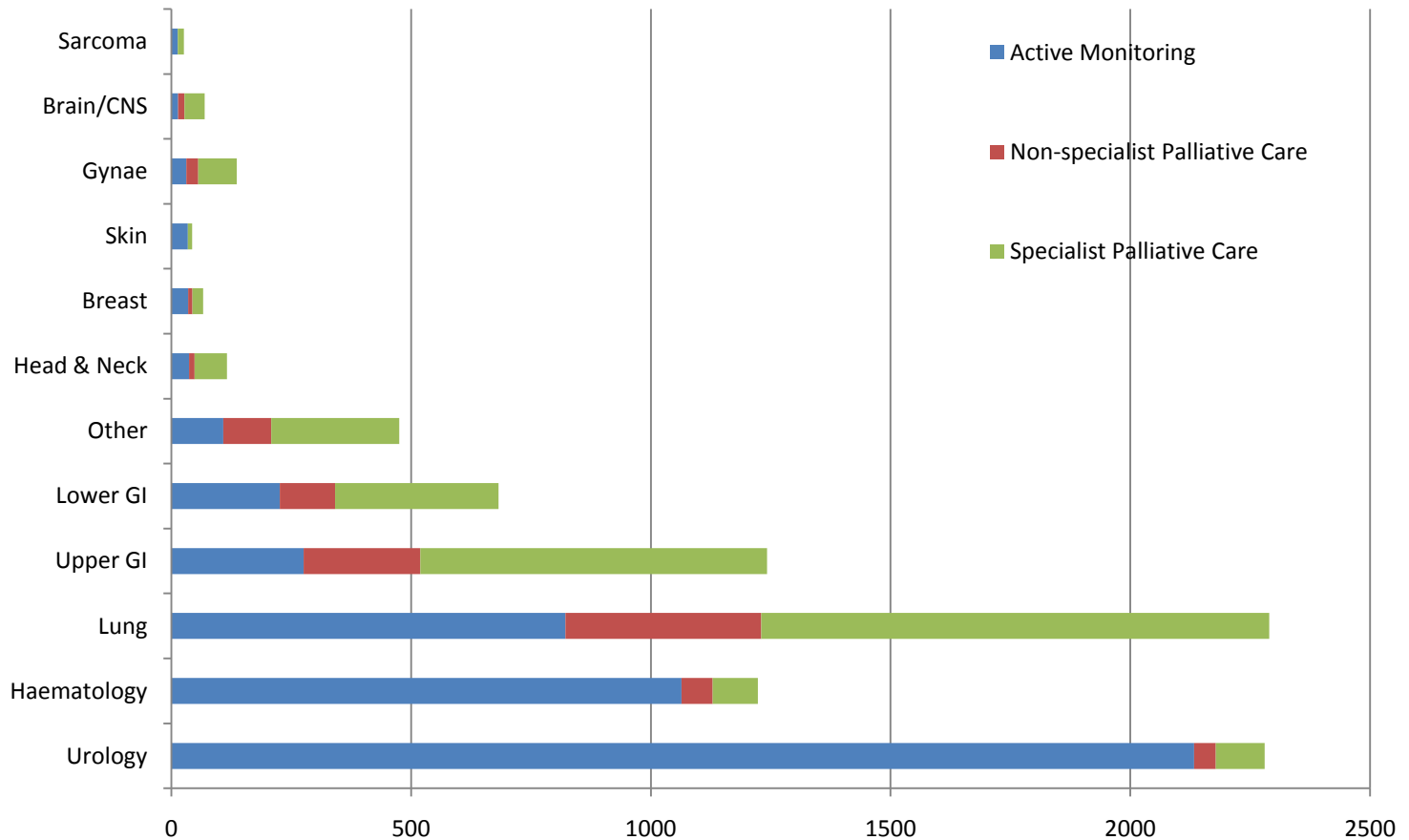


# How to differentiate Active monitoring and Watchful Waiting

- Active monitoring and watchful waiting used by Cancer Waits and 18 weeks
- Different meaning from Urology
- Pragmatic approach!

# Non active treatments

Non active treatments recorded in CWT Oct - Dec 2010



# Non Active Treatments

## *CWT User Guidance*

## Patients requiring symptomatic support

### Specialist Palliative Care:

***“palliative care delivered under the management of a consultant in palliative medicine.***

### Non specialist palliative care:

**“palliative care (excl active monitoring) given under the management of a consultant other than a consultant specialising in palliative medicine.”**

## Patients largely asymptomatic

### Active monitoring:

***“where a diagnosis has been reached but it is not appropriate to give any active treatment at that point in time but an active treatment is still intended/ may be required at a future date.”***

# ACTIVE MONITORING INTENT:

To record the future intention of monitoring the patient. Use for all patients who are largely asymptomatic and may go on to active treatment if the status of the disease progresses. (This will include “watchful waiting” as used clinically)

- 01 Patient placed on active monitoring regime with future curative intent
- 02 Patient placed on active monitoring regime with future palliative intent
- 03 Patient placed on active monitoring regime with unknown or uncertain future clinical intent



Thank you

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