

# Cancer Outcomes and Services Dataset

Thyroid Workshop  
May 2011

Trish Stokes, NCIN

# NCIN core objectives



- **Promoting efficient and effective data collection throughout the cancer journey**
- Providing a common national repository for cancer datasets
- Producing expert analyses, based on robust methodologies, to monitor patterns of cancer care
- **Exploiting information to drive improvements in standards of cancer care and clinical outcomes**
- Enabling use of cancer information to support audit and research programmes

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# 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*
- *Diagnostics Project – April 2012*
- *Recurrent/Metastatic Breast Cancer – April 2012*
- **Cancer Outcomes and Services Dataset – Sept 2012**
- *(RC Pathology – Professional/Clinical Standards)*
- *(RC Radiology – Professional/Clinical Standards)*
- National Audits

# COSD features

- The new national cancer dataset
- Components
  - Core (Registration and Cancer Waits)
  - Site specific (cf nat audit)
  - Key pathology (core RCPATH)
- Secondary uses
- From clinical patient management
- Aligned and standardised
- Multiple data sources
- Monthly submission
- Monthly feedback

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# COSD Dataset

Dataset Section	COUNT
<b>Core (with additions)</b>	<b>143</b>
Breast	30
CNS	16
Colorectal	30
CTYA	66
Gynae	41
Haematology	60
<b>Head &amp; Neck</b>	<b>44</b>
Lung	19
Sarcoma	16
Skin	70
Upper GI	166
Urology	30
<u>COSD</u>	<b>731</b>

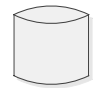
COSD

CANCER REGISTRY

NATIONAL REGISTRY DATABASE  
(CSOD DATASET)

N3 Network or other approved transmission medium

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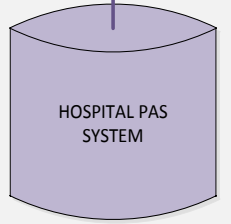
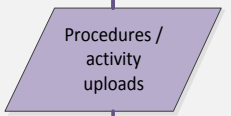
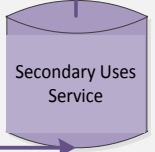
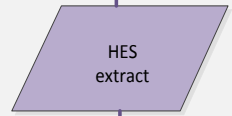
Data store



Fully structured /  
coded



Data flow



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CANCER REGISTRY

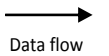
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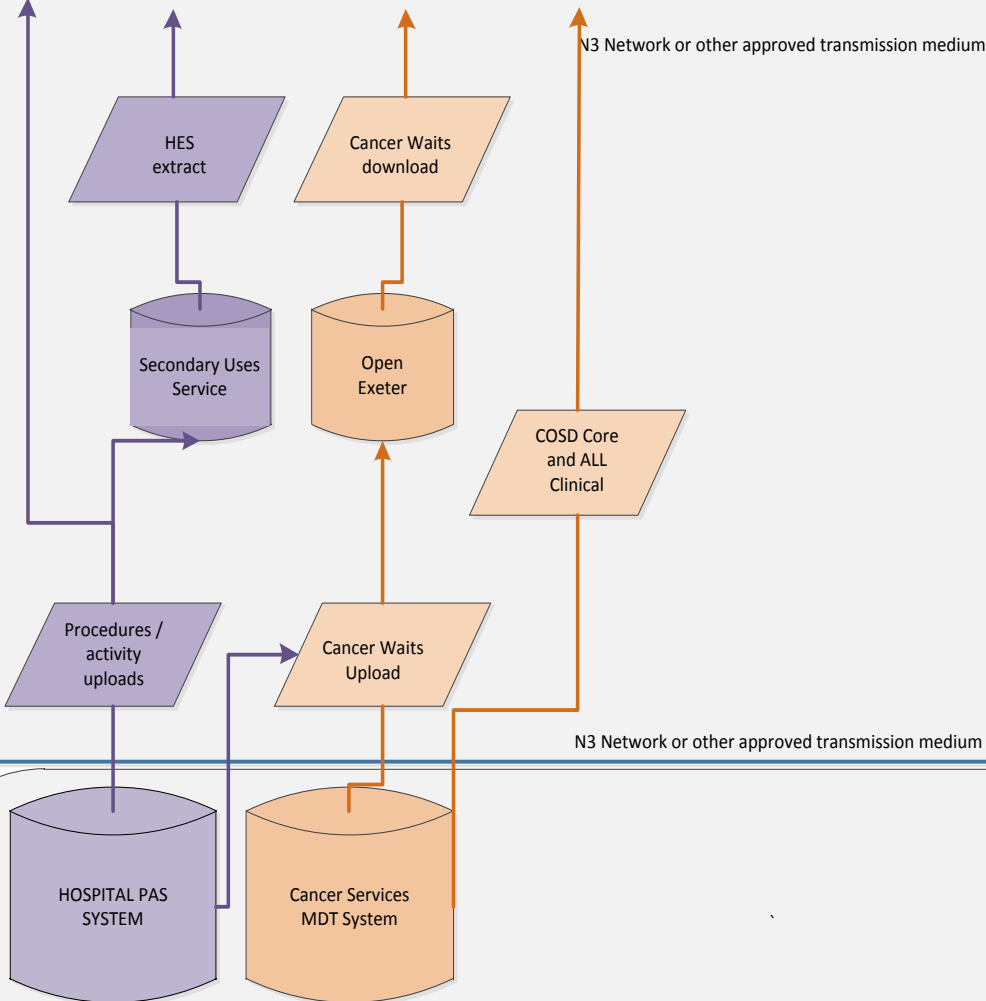
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Data flow



CANCER REGISTRY

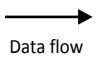
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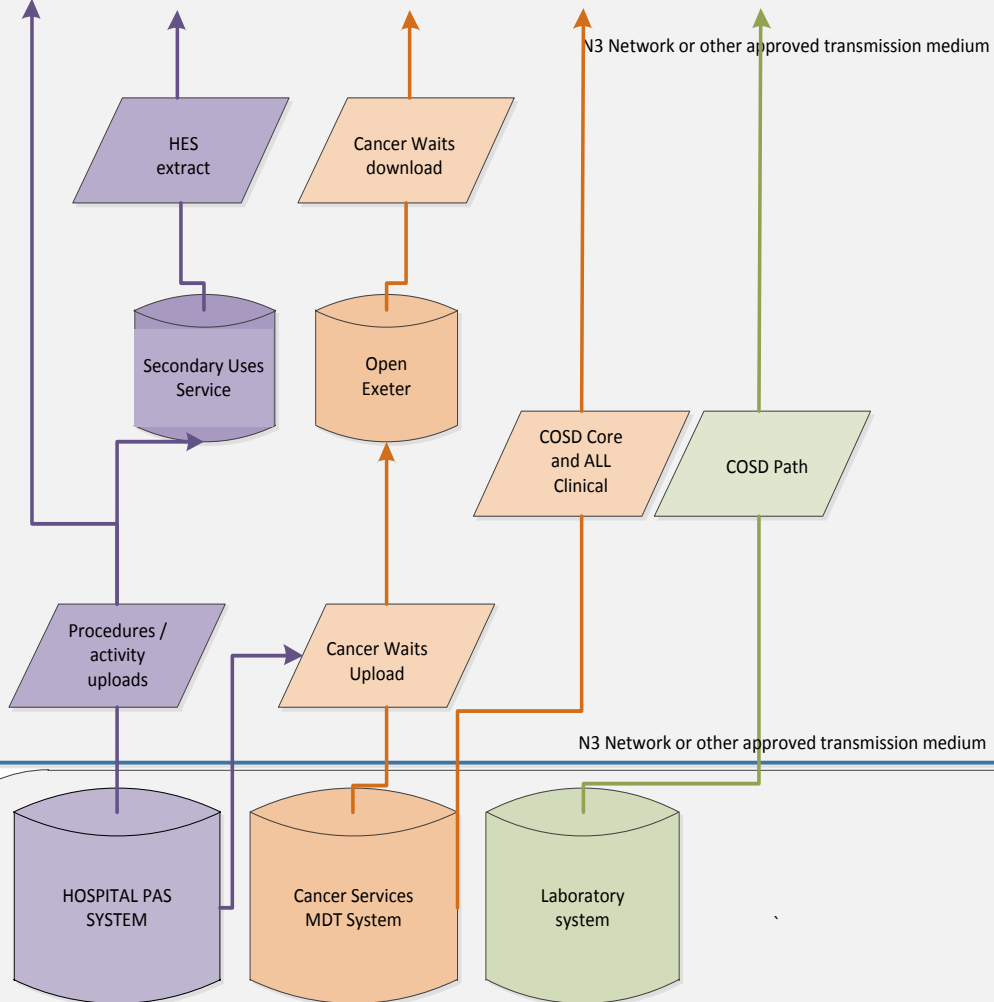
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Data flow





CANCER REGISTRY

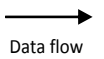
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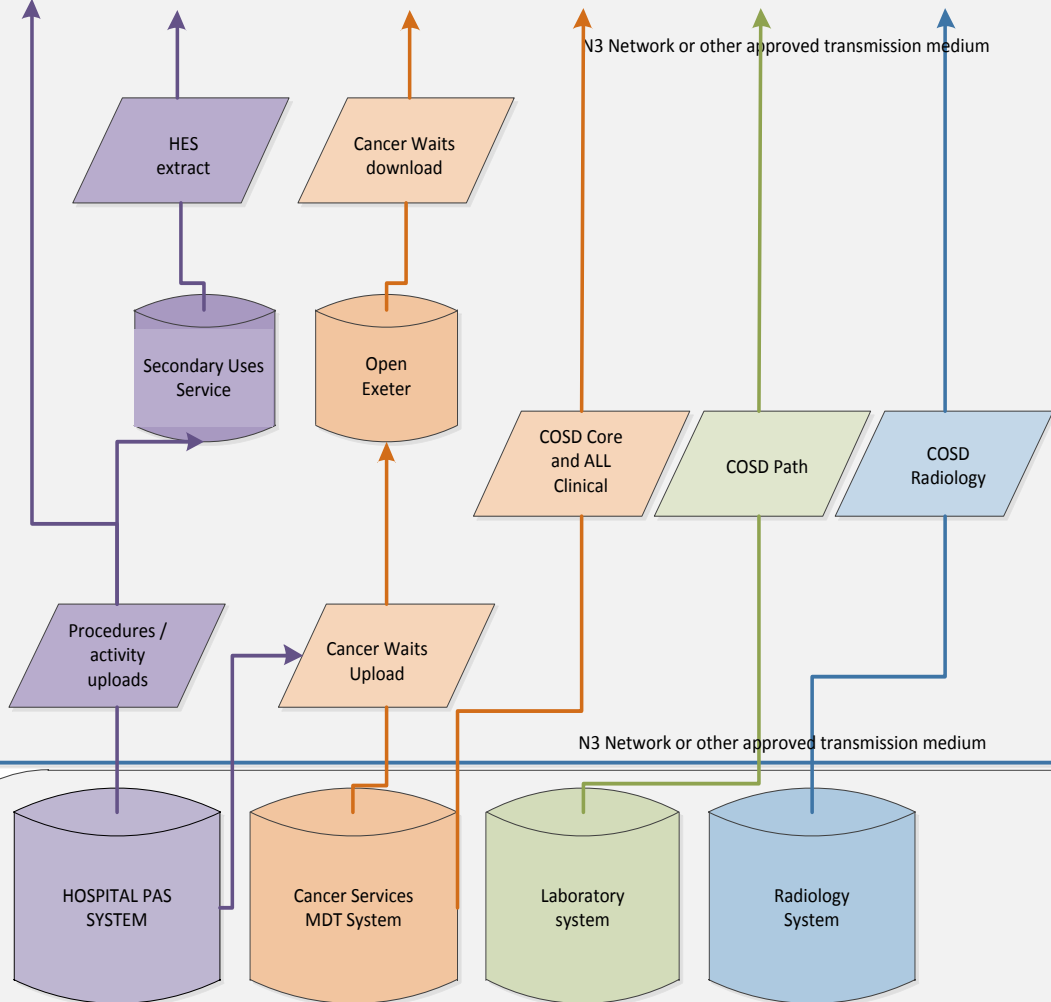
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Data flow



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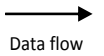
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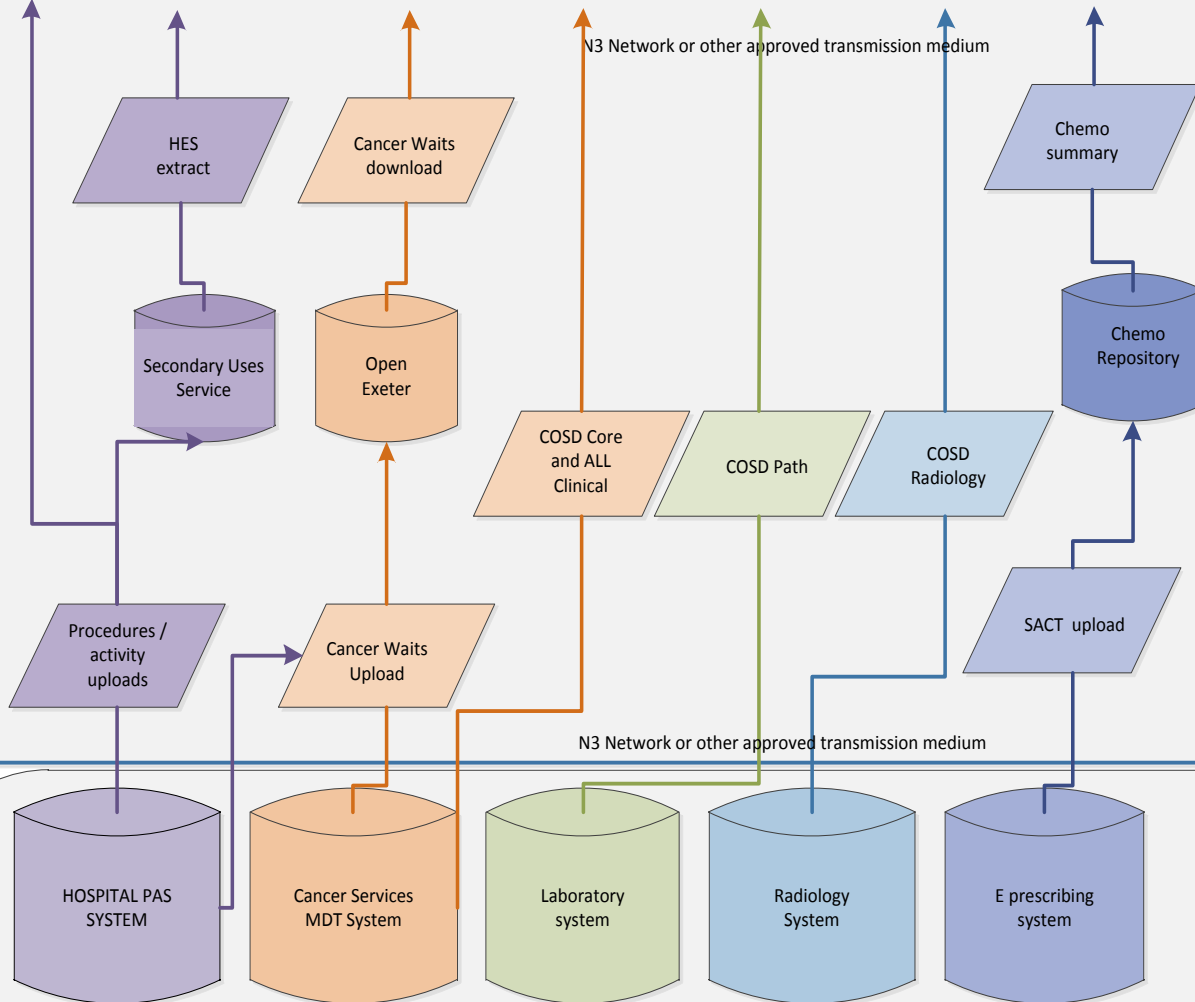
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Data flow



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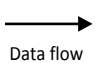
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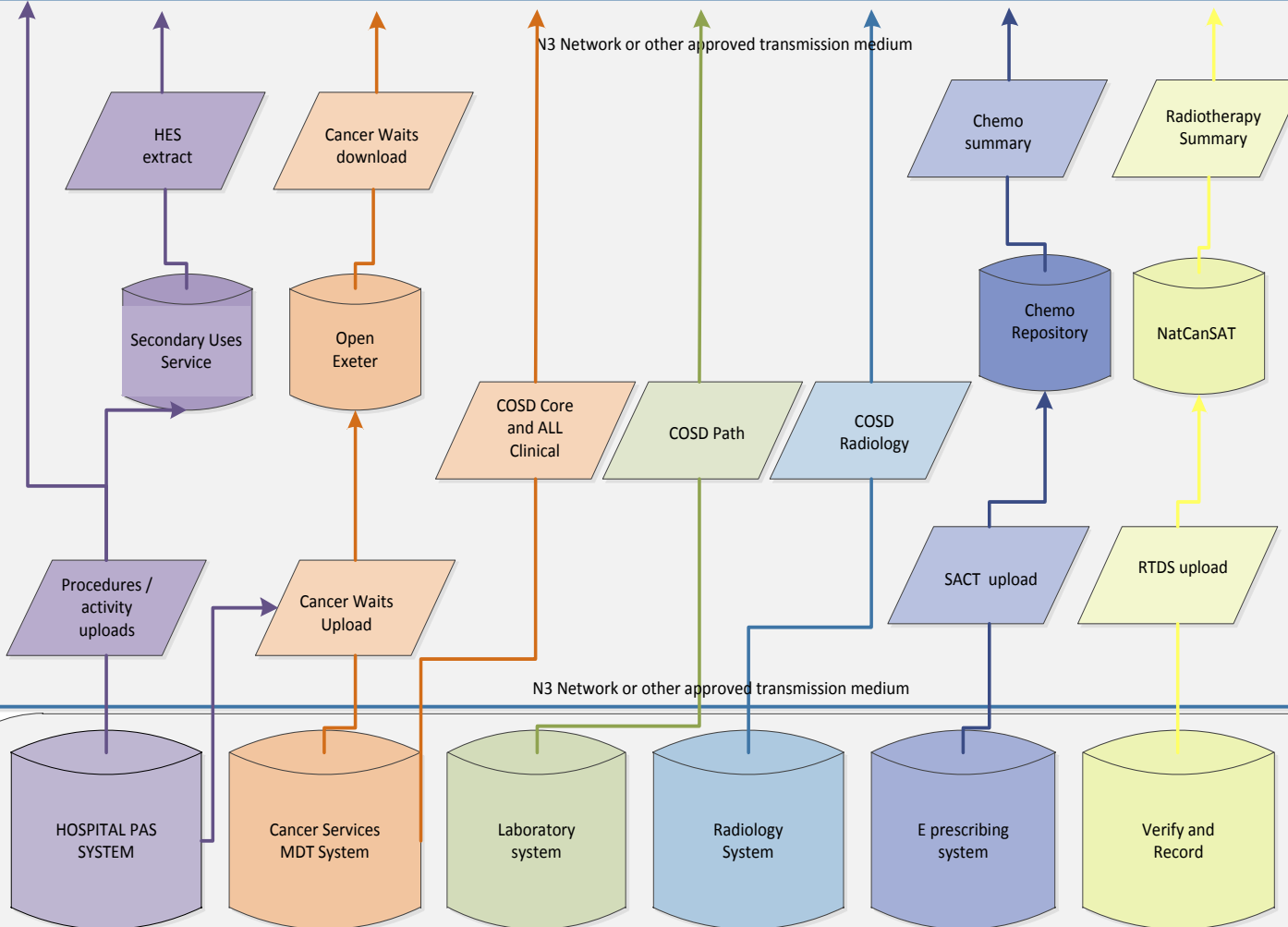
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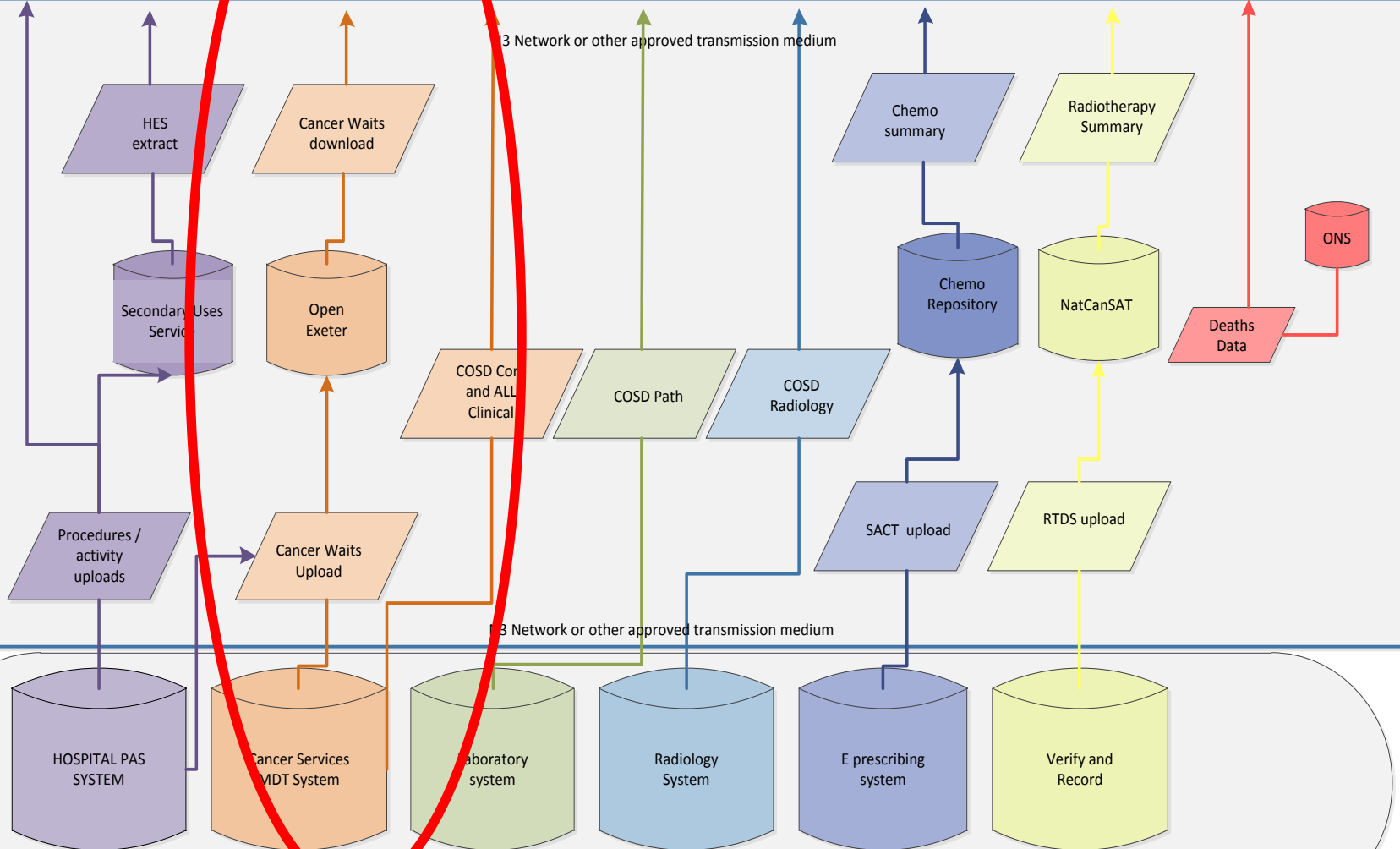
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# Essentials for success

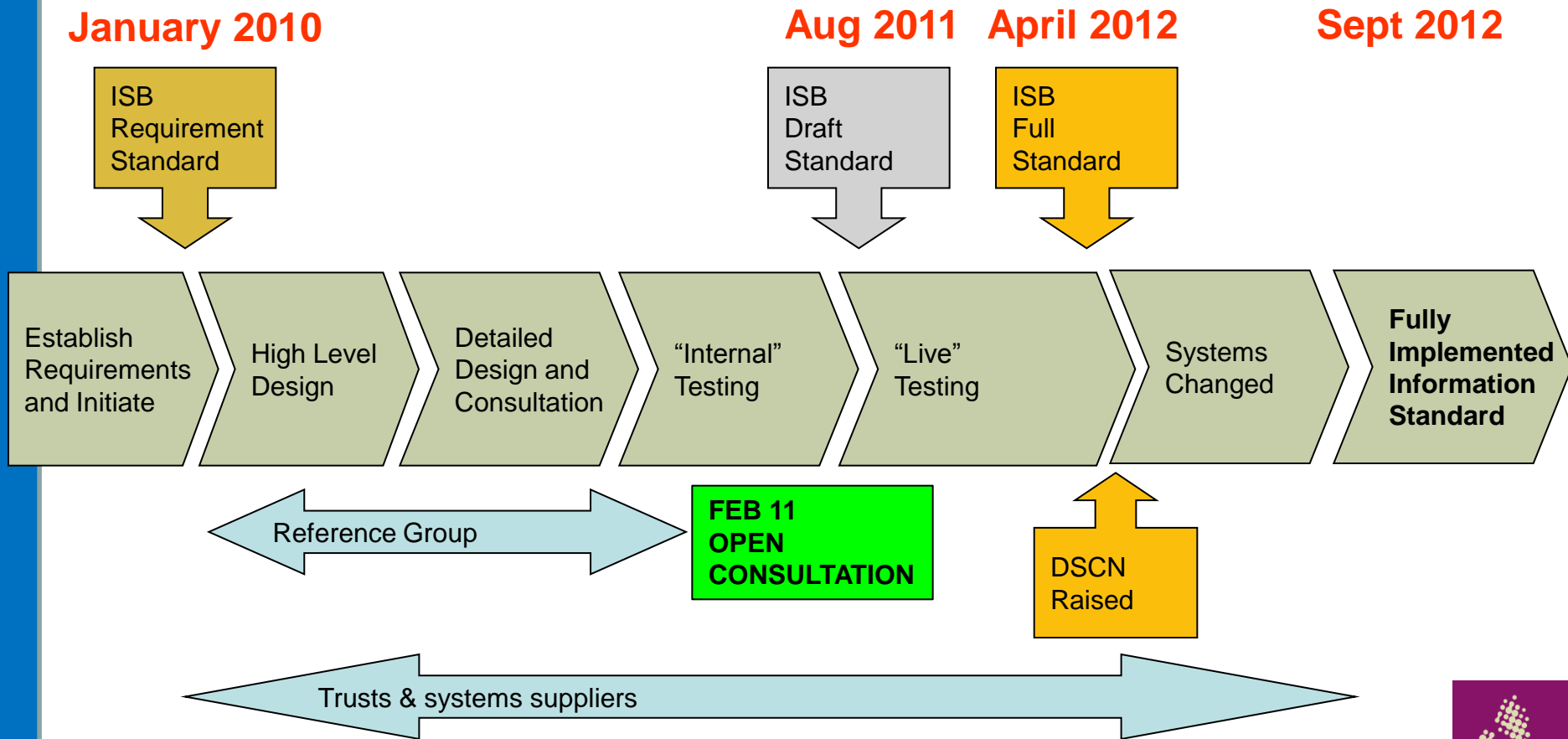
- **Clinical engagement**
- **Credible data**
  - High level of data completeness
  - Case mix adjustment
  - Timely
- **Reporting**
  - Easy access to clear, ‘bespoke’ reports
  - ‘Real time’ – on line; Annual reports
  - Targeting reports: Clinicians; Trusts; SHAs ; PCTs etc
- **Dissemination in Peer-reviewed settings**
  - Publication, Conferences, Workshops, etc
- **Incorporating performance and outcome data into:**
  - Commissioning
  - Cancer Peer Review & Service Improvement

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# The last twelve months

- First draft COSD dataset
  - Core dataset reviewed
  - Additional core items identified
  - Site specific datasets agreed by Clinical Reference Groups
- MDT Software Suppliers Day
- Work begun with RC Pathologists and RC Radiologists on clinical content
- Definitional testing (incl key path for staging)
- Open consultation

# ISB Process – Where are we now?



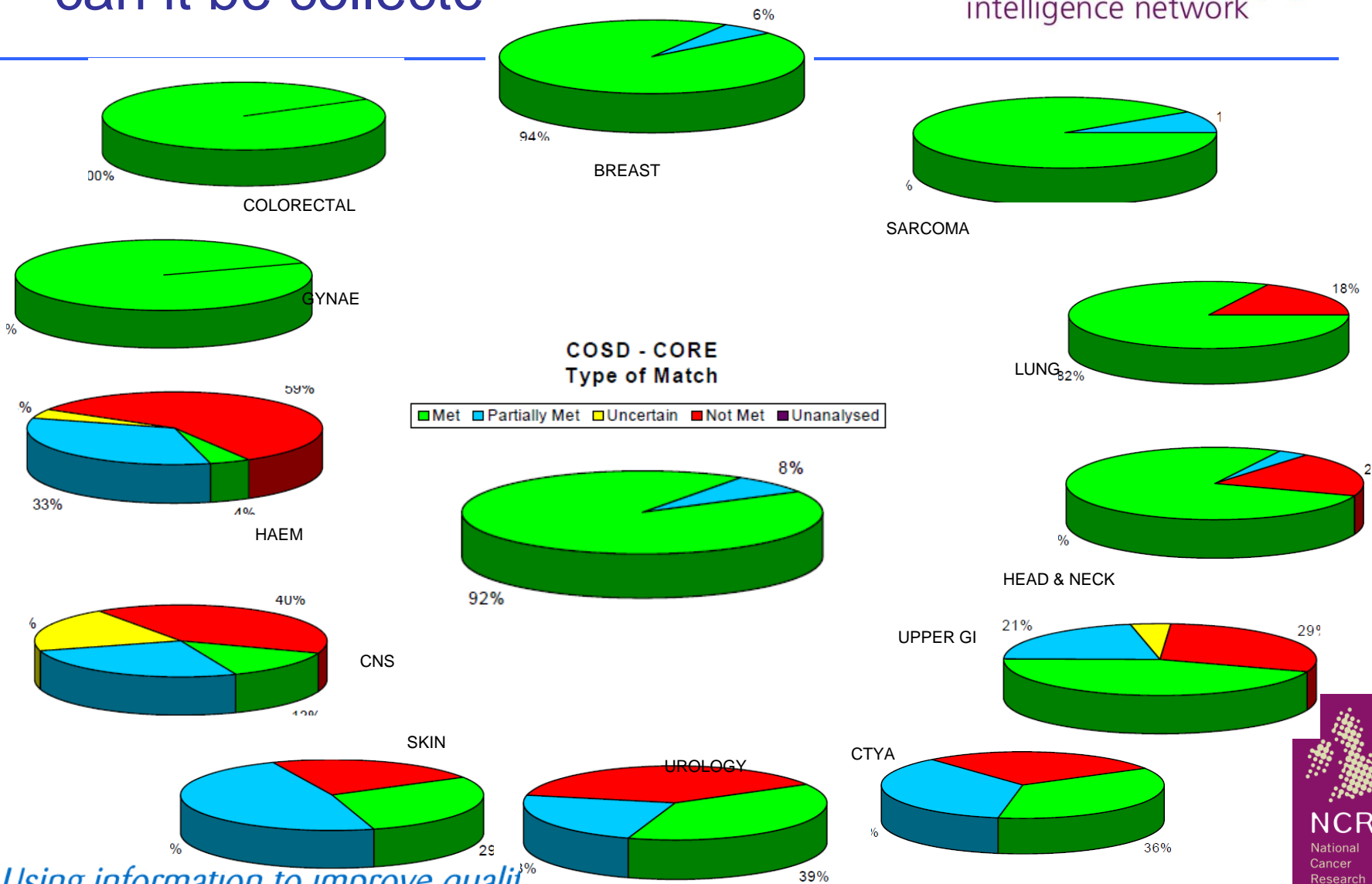
# Definitional testing – general feedback

- Support for
  - cohesive and consistent dataset
  - clear and comprehensive guides
- Concerns
  - increased burden of collection
  - need for clinical involvement



# A mixed bag

## - can it be collected?

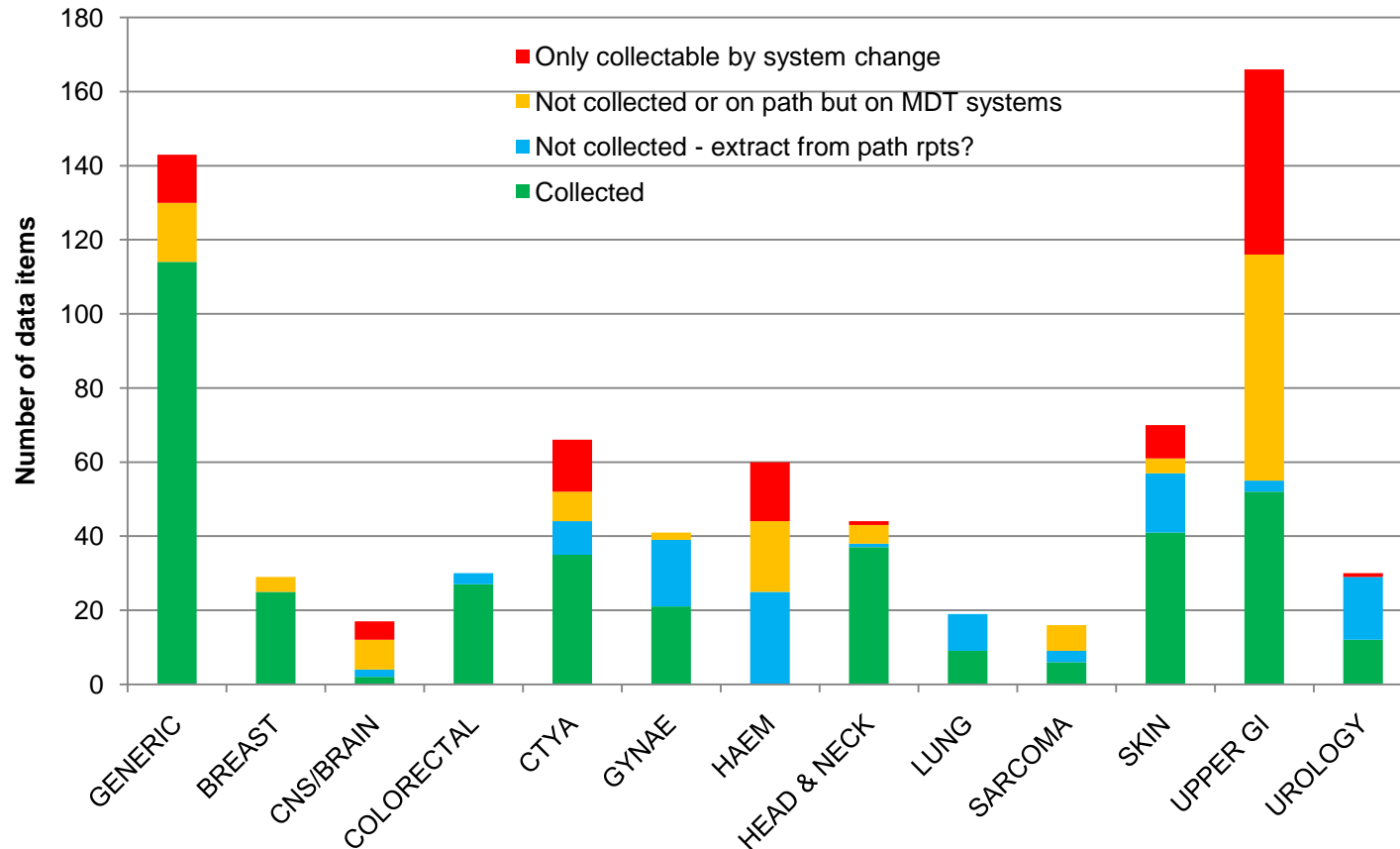


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# Phased implementation – which approach

- By Trust?
- By Tumour site?
- By data item?

# Implementation - State of readiness



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# Next Steps...

- Pilot data collection with Trusts
  - How easy to collect?
  - Changes to processes
  - Data quality and completeness
  - Validation
  - Other sources
- Documents for draft ISB submission
- Approach to implementation

# Challenges...

- Implicit to explicit
- Time for recording
- Clinical buy-in
- Clinical validation
- Specific issues – co-morbidity, stage and pathology

**If we get this right - minimal impact on the service  
But maximum impact on improving care**

**MDT input and meeting are critical to success**

# Useful links

NCIN

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

[trish.stokes@nhs.net](mailto:trish.stokes@nhs.net)

[Driley@nhs.net](mailto:Driley@nhs.net)

NHS Information Centre (dataset)

[Datasets@ic.nhs.uk](mailto:Datasets@ic.nhs.uk)