Future Direction for Cancer Registries

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Thames Cancer Registry

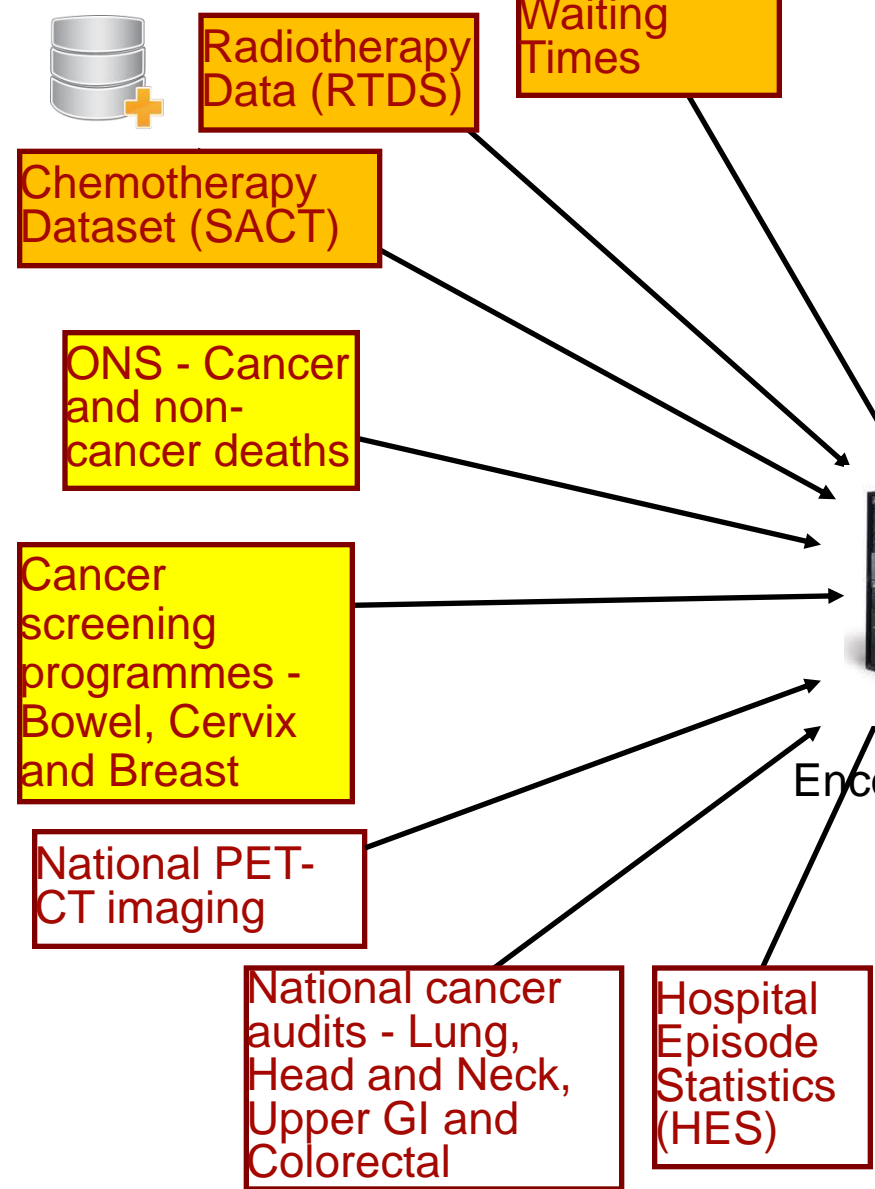# National Cancer Registration Service

- Single England wide system

- Cancer Outcomes and Services Dataset compliant

- Facilitates rapid processing of multiple local and national data sources

- Common standards and processes including data quality

- Provides rapid and direct feedback of data to clinical teams to enhance data quality

- Support for (near) real-time surveillance, cancer audit and analysis

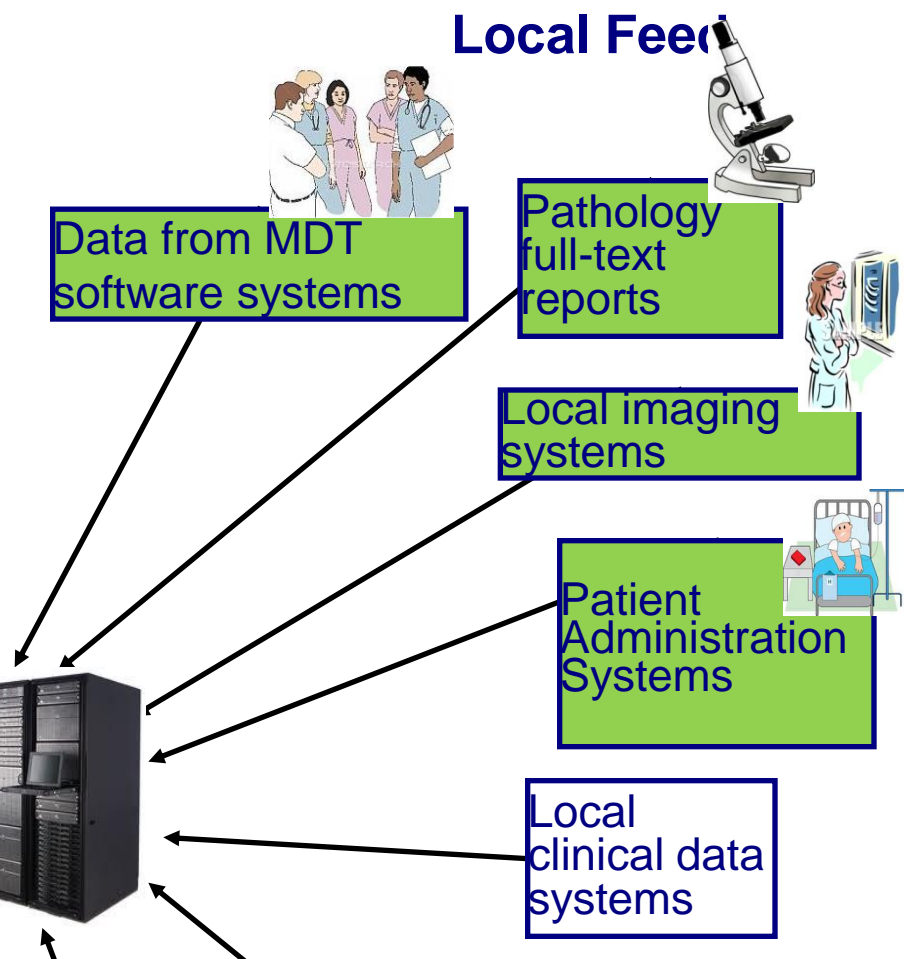- Datasets available for external analysis and research

Local data collection at MDTs is key to success
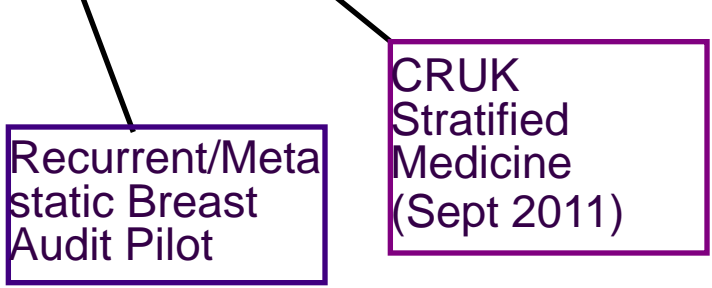
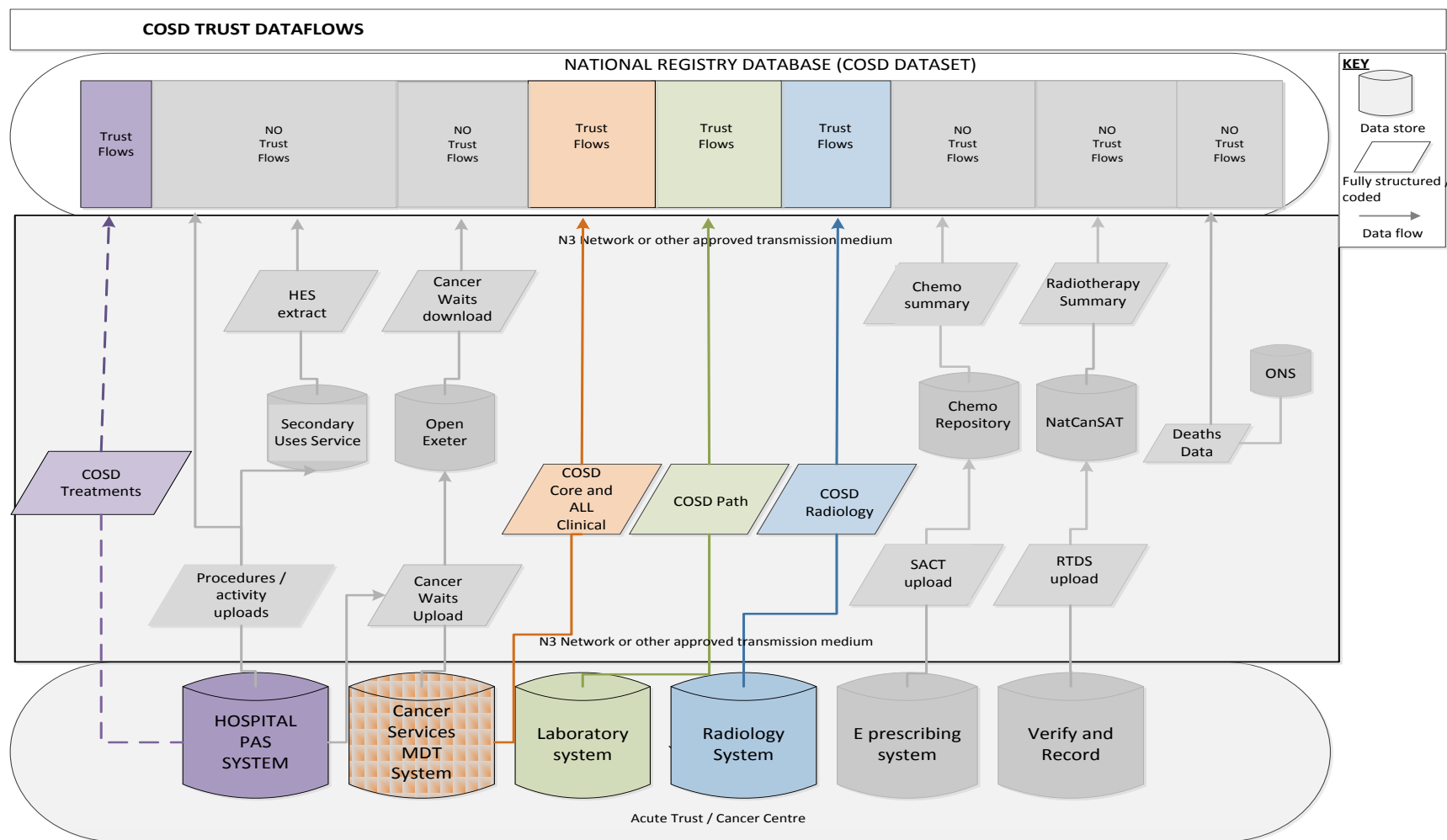# Data sources - patient-level data

National Feeds

Radiotherapy Data (RTDS)

Cancer Waiting Times

Chemotherapy Dataset (SACT)

ONS - Cancer and non-cancer deaths

Cancer screening programmes - Bowel, Cervix and Breast

National PET-CT imaging

National cancer audits - Lung, Head and Neck, Upper GI and Colorectal

Hospital Episode Statistics (HES)

Recurrent/Metastatic Breast Audit Pilot

Encore

Local Feed

Data from MDT software systems

Pathology full-text reports

Local imaging systems

Patient Administration Systems

Local clinical data systems

National Pilots

CRUK Stratified Medicine (Sept 2011)

Direct Provider data flows

Information Governance (1)

- S251 NHS Act exemption
  - All cancer registries covered – one annual application
  - Annual renewal through National Information Governance Board (NIGB) and corresponding statutory instrument
- Caldicott Guardian
  - sign-off required to allow transfer of data to and from organisations
 - existing signoff covers COSD

Information Governance (2)

- Data Protection Act
  - All cancer registries are registered under the DPA.
  - Fair processing notices, including rights to withdraw consent, are provided through the UKACR Patient Information Leaflet
  - Leaflet available from:

    www.orderline.dh.gov.uk/ecom_dh/public/home.jsf

    ACR078 About Cancer Registration

NHS

About cancer registration
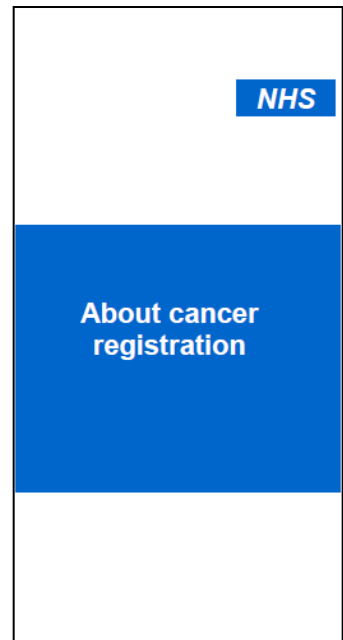
Feedback for Providers and Clinical Teams

- Monthly Conformance Report
    - Extract files received, number of cases, timeliness etc
- Data Quality
    - Initial completeness eg NHS number, stage, performance status
- Summary Information Indicators
    - Eg % histologically verified, RCPath data item completeness
- Clinical and Performance Indicators
    - NICE Quality Standards etc
        - Eg % lung resections
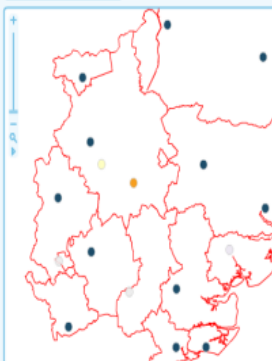   - % breast conserving surgery with no RT

Proposed Feedback Timetable

Standard clinical feedback reports ~ Mar 14

First Data quality reports ~ Oct 13

First feedback reports ~ April 13

First submission ~ March 13

July 12
ISN issued

Jan 13
CORE and SITE SPECIFIC STAGE

July 13
SITE SPECIFIC CLINICAL

Jan 14
SITE SPECIFIC PATHOLOGY

JAN 15
FULL COSD DATASET submitted in XML

Future Feedback?

The Future

- A single cancer registration system (ENCORE) for England

- COSD compliant

- Routine, timely feedback

- Improved registry/Network partnership working

- Provide powerful data for local, national and international analysis

Examples of Current Feedback

Core Dataset – Jan 2013

- Very similar to current Cancer Registry Dataset
- Some data items removed, some added
  - Staging certainty removed
  - Staging version added

  - AJCC Stage Group

Clinical Site Specific - July 2013

- 4 clinical site-specific skin data items
  - Grade of Clinician/Surgeon Operating
  - Clinical Diagnosis (Pre Histology)
  - Skin Cancer Lesion Indicator
  - Site Code of Specimen

Pathological Site-Specific – Jan 2014

- 19 pathological data items for skin
    - Clarkes/Breslow
    - Lesion Information
    - Nodes Sampled/Positive
    - Ulceration Indicator
    - Mitotic Rate
- All will continue to be extracted by Registry in the next few years.

Thank you!

Any questions?

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