

# Future Direction for Cancer Registries

Barry Plewa  
Quality Assurance and Improvement Manager

Thames Cancer Registry

# National Cancer Registration Service

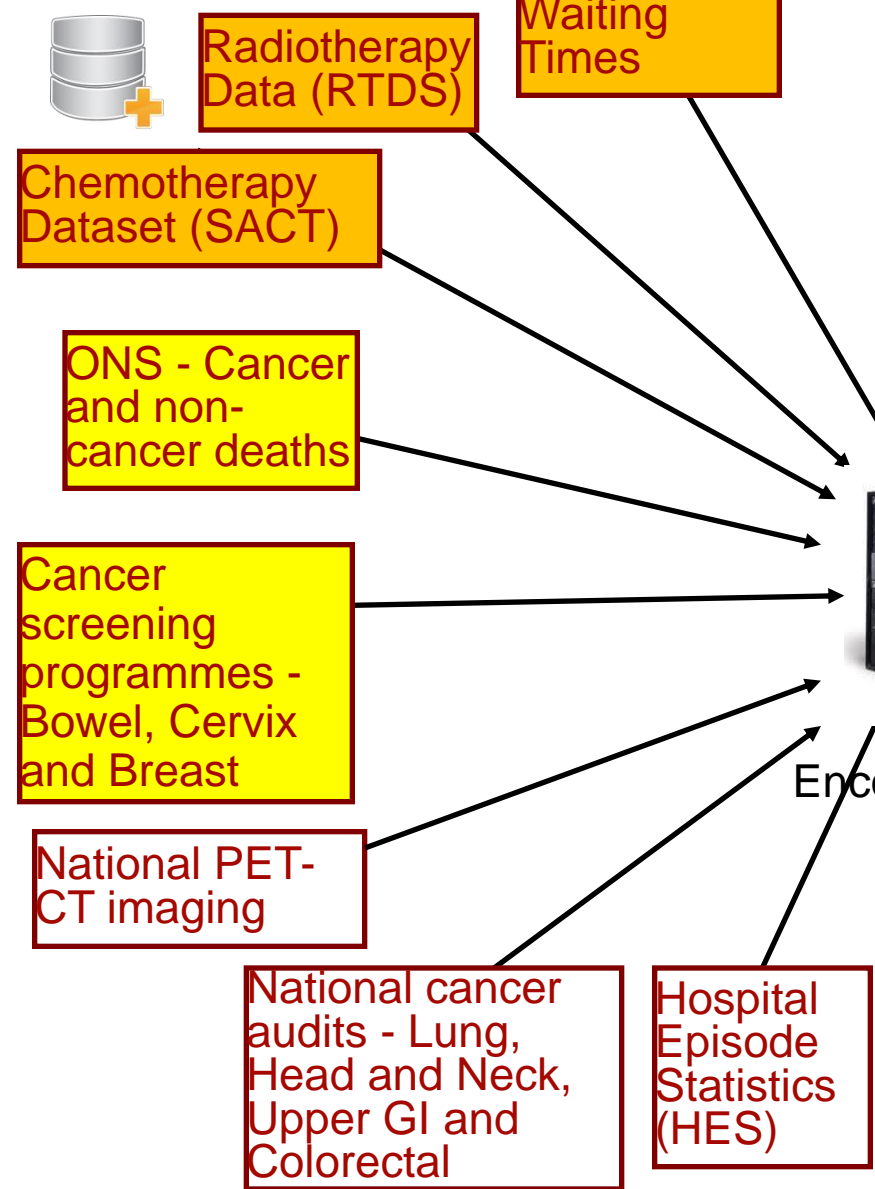


- Single England wide system
- Cancer Outcomes and Services Dataset compliant
- Facilitates rapid processing of multiple local and national data sources
- Common standards and processes including data quality
- Provides rapid and direct feedback of data to clinical teams to enhance data quality
- Support for (near) real-time surveillance, cancer audit and analysis
- Datasets available for external analysis and research

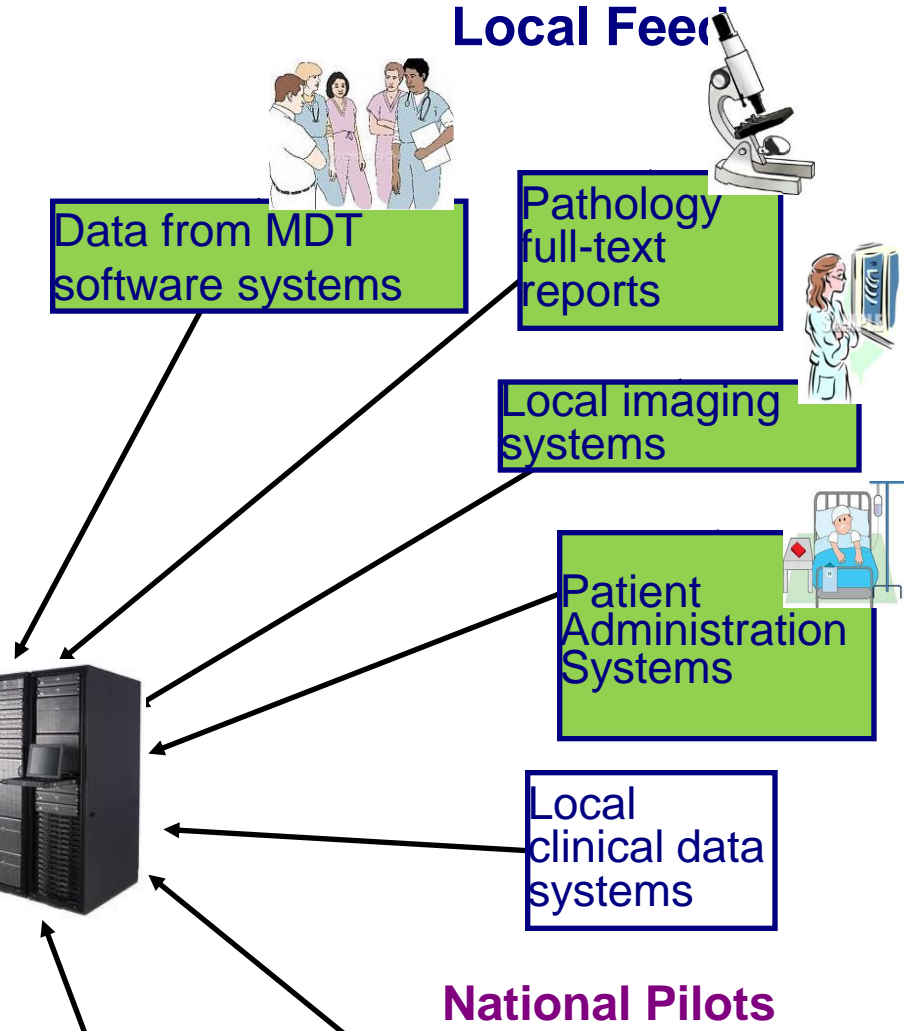
**Local data collection at MDTs is key to success**

# Data sources - patient-level data

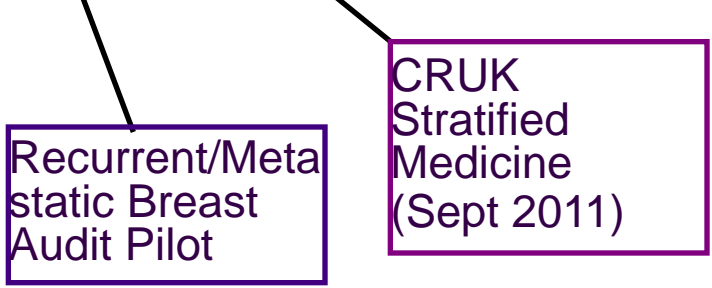
## National Feeds



## Local Feeds

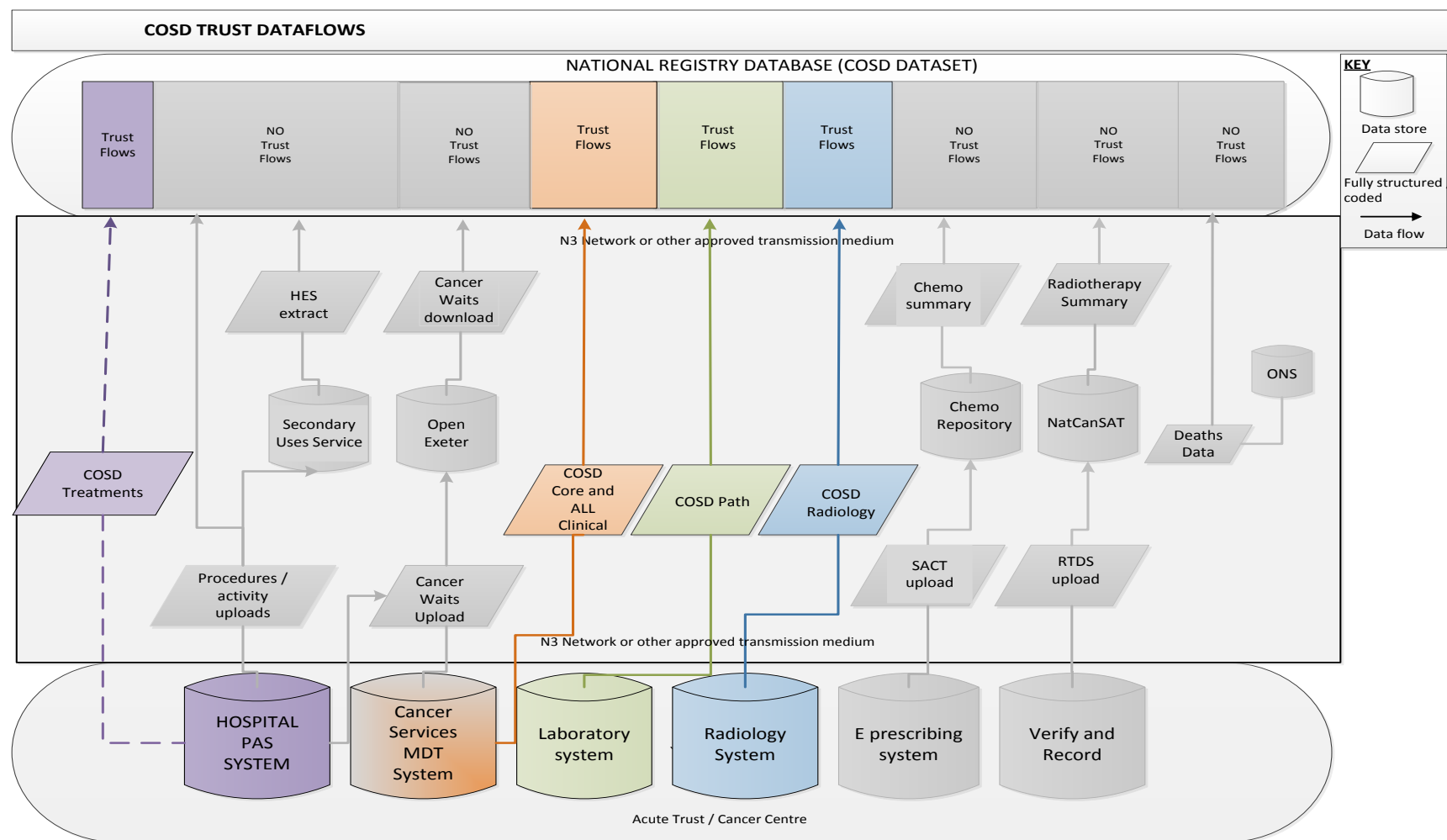


## National Pilots



Encore

# 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

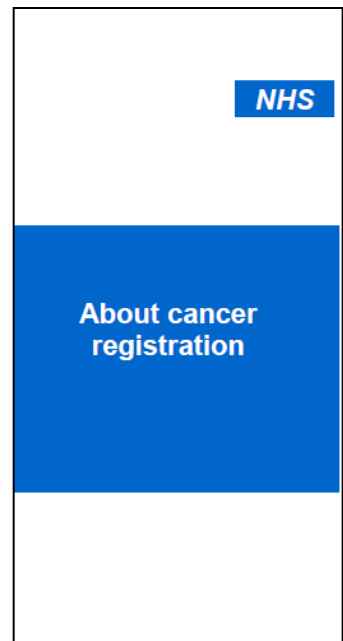
# Information Governance (2)

- 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](http://www.orderline.dh.gov.uk/ecom_dh/public/home.jsf)

ACR078 About Cancer Registration

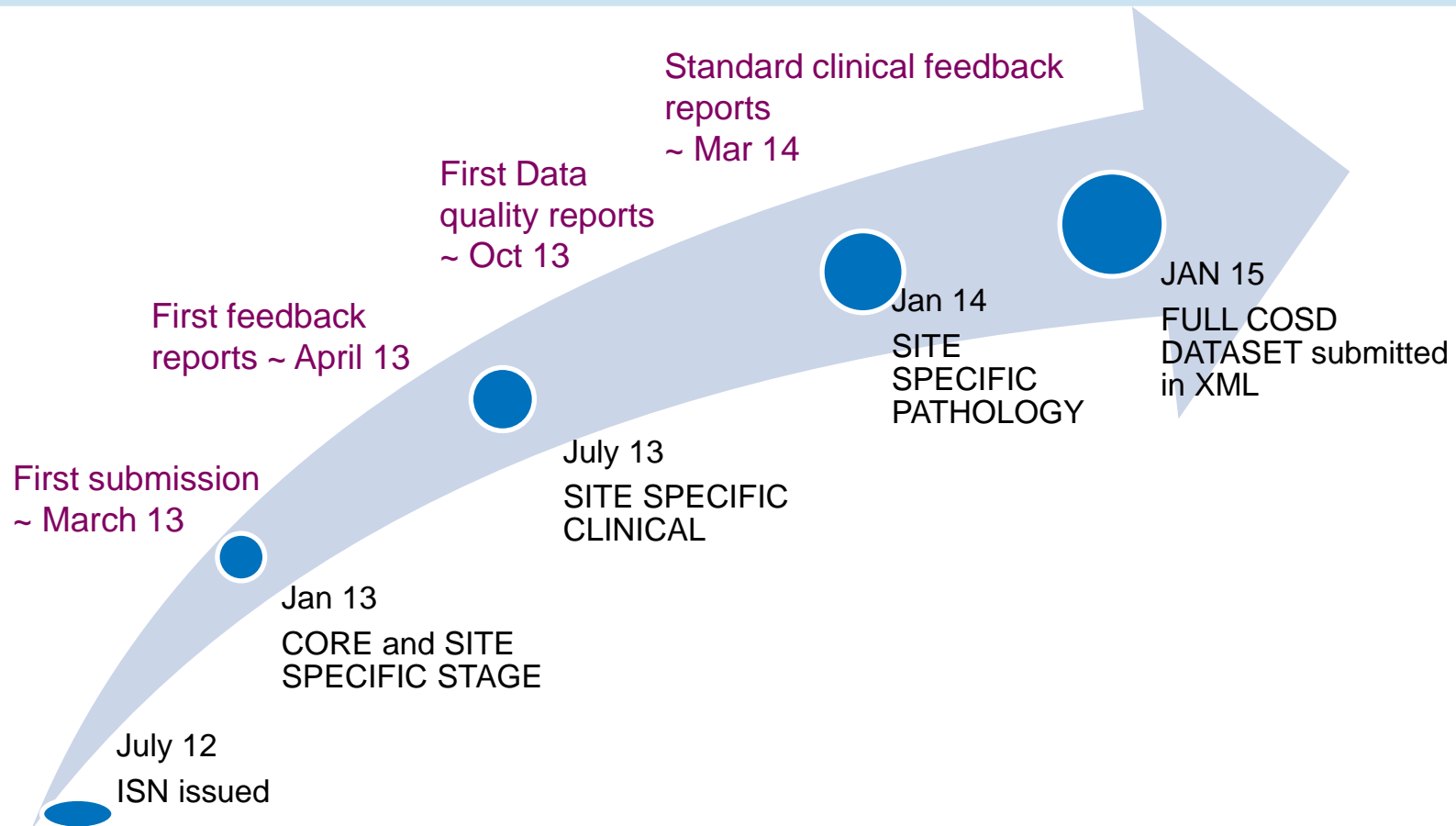


# Feedback for Providers and Clinical Teams



- 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





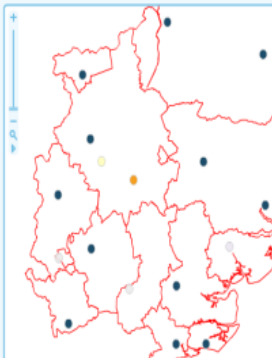
# Examples of Current Feedback



# Future Feedback?

## MDT Data Completeness

Filter



This report shows the completeness of certain key data items received as discussed at MDT. By clicking on your Trust from the map above, you will appear on the performance chart to the right. You can compare your Trust's performance with other Trusts by clicking on the 'Compare' button. The data is displayed by clicking on the data icon on the left side of the map. A full user guide is available by clicking the 'Help' icon. This will give you detailed instructions on how to use this report effectively. The report shows 'No Data' or 'No MDT', additional information about a specific Trust is available by clicking the 'Notes' icon before the hospital's name in the MDT Data Completeness report.

**Patient Pathways** LOAD DATA OPEN SAVE PRINT DISPLAY PROPERTIES

Lung Cancer / Mount Vernon Cancer Network / 2000 - 2009

| Patient ID | Age | Gender | Diagnosis Date | Treatments | Outcome   |
|------------|-----|--------|----------------|------------|-----------|
| 6767986392 | 63  | M      | 03/05/2006     | CT/RT      | Remission |
| 8489389283 | 55  | M      | 04/11/2003     | S/CT/RT    | Remission |
| 7837487298 | 68  | F      | 23/06/2002     | S/CT/RT    | Remission |
| 9540949444 | 45  | M      | 21/04/2005     | RT         | Relapse   |
| 4903940930 | 77  | F      | 03/03/2006     | CT         | Remission |
| 9409503940 | 56  | F      | 17/10/2004     | S/CT/RT    | Relapse   |
| 8743892328 | 94  | F      | 05/09/2008     | Palliative | Death     |
| 2938223822 | 72  | M      | 12/11/2007     | CT/RT      | Death     |
| 4893829339 | 53  | M      | 30/03/2003     | S/CT/RT    | Remission |
| 3234982094 | 69  | F      | 16/07/2005     | CT/RT      | Remission |
| 8324982920 | 90  | M      | 29/04/2006     | Palliative | Death     |
| 2093804982 | 68  | M      | 11/07/2007     | RT         | Remission |
| 2448748374 | 55  | F      | 20/05/2002     | CT         | Relapse   |

**FILTERS /**

**PATIENT INFO**

AGE select inverse  
0 - 75 yrs

**GENDER**  
☒ Male ☒ Female

**TUMOUR INFO**  
Stage: Stage 4

To: 2009

☒ Surgery  
☒ Radiotherapy

Andrew Murphy Log out

unprocessed data filters  
with unprocessed records

Search

| ID     | MDT 18/0-2 | Date of |
|--------|------------|---------|
| 0046/3 |            | 01.06   |
| 0041/3 |            | 08.06   |
| 0140/3 |            | 15.06   |
| 0046/3 |            | 12.03   |
| 0041/3 |            | 08.06   |
| 0046/3 |            | 08.06   |
| 0140/3 |            | 18.06   |
| 0046/3 |            | 28.09   |
| 0010/3 |            | 12.03   |
| 0046/3 |            | 15.03   |

# 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

# Core Dataset – Jan 2013



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

# Clinical Site Specific - July 2013



- 13 clinical site-specific Upper GI data items
  - Body Mass Index
  - Biliary Stent Intent/Deployment/Complications
  - ASA Score
  - Surgical Details – Access/Palliation/Complications
  - Post Operative Tumour Site
  - Liver Mets/HCC – Ablative Therapy/TACE

# Clinical Site Specific - July 2013



- 5 site-specific items from other sources
  - Endoscopy
  - Radiology
- Data from PAS system

# Pathological Site-Specific – Jan 2014

- 5 pathological data items for Upper GI
  - Pathology for Liver Mets (3)
  - Excision Margins (Proximal/Circumferential)
- All will continue to be extracted by Registry in the next few years.

# Thank you!

## Any questions?

Barry Plewa  
barry.plewa@kcl.ac.uk

[barry.plewa@nhs.net](mailto:barry.plewa@nhs.net) (secure – data transmission)