ukacr
United Kingdom Association of Cancer Registries

NCIN national cancer intelligence network
Using information to improve quality & choice

Future Direction for Cancer Registries

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Thames Cancer Registry

NCRI National Cancer Research Institute

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)

Local Feeds

Data from MDT software systems

Pathology full-text reports

Local imaging systems

Patient Administration Systems

Local clinical data systems

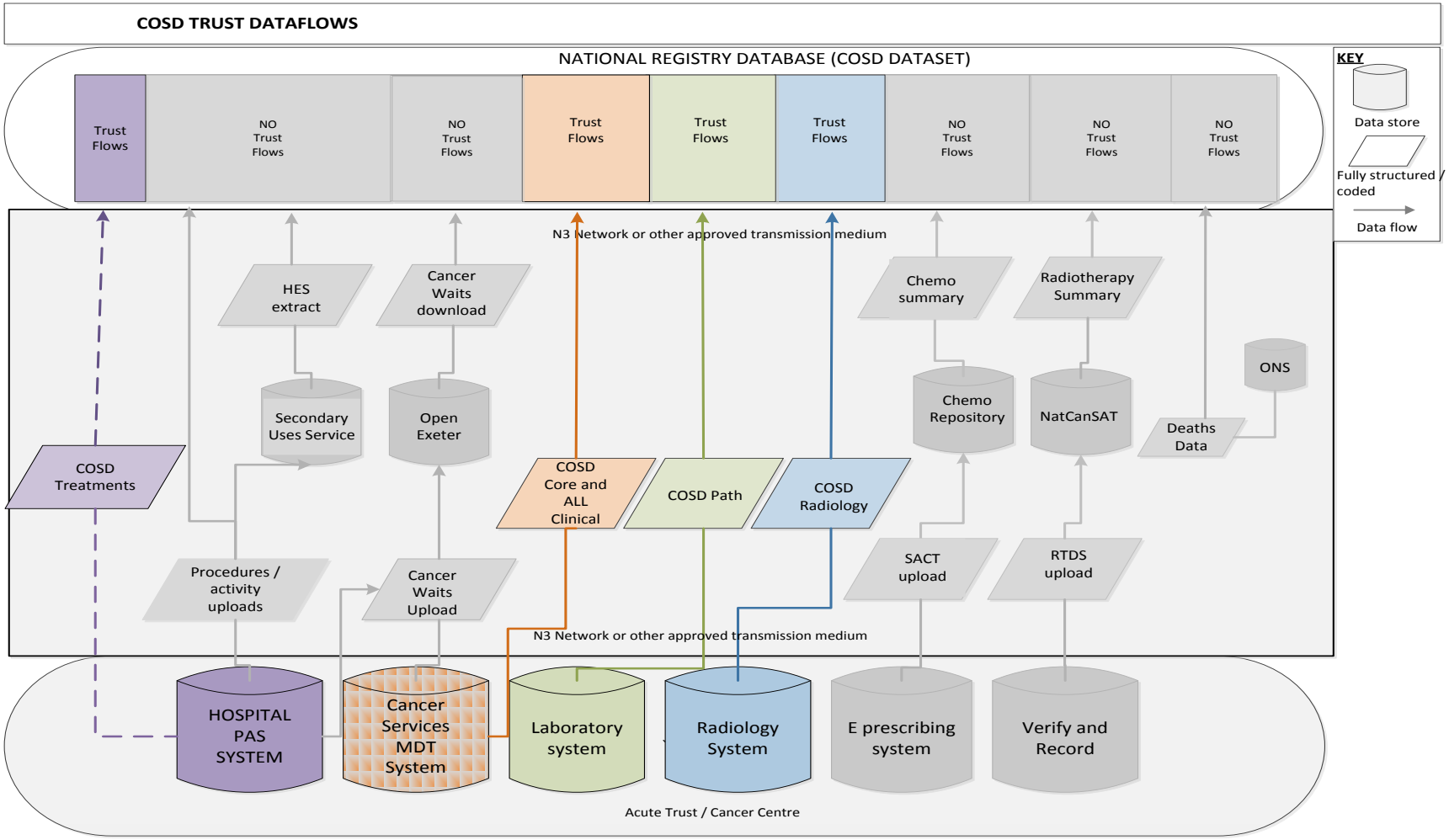
Encore

National Pilots

CRUK Stratified Medicine (Sept 2011)

Recurrent/Metastatic Breast Audit Pilot

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:

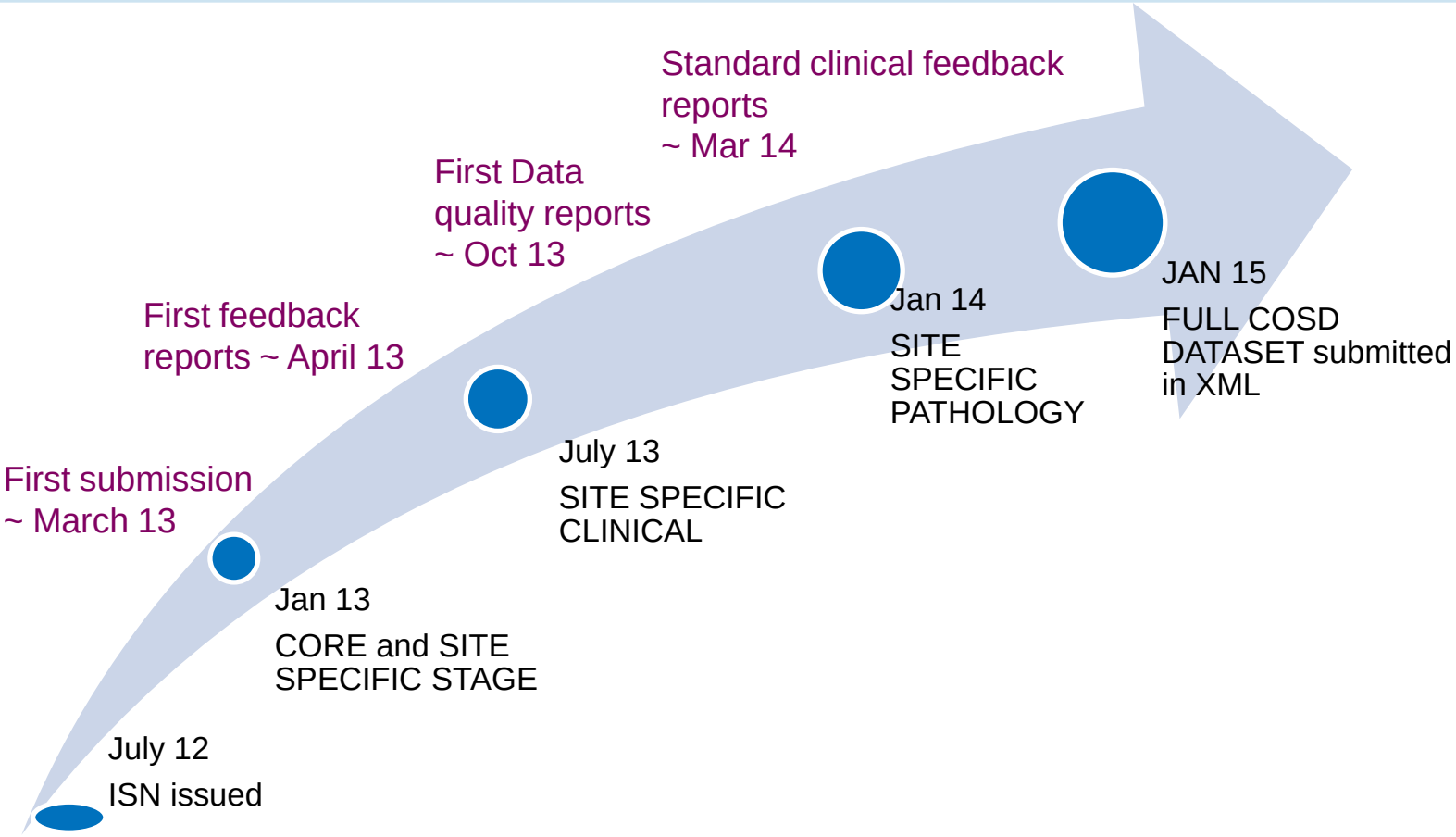
www.orderline.dh.gov.uk/ecom_dh/public/home.jsf

ACR078 About Cancer Registration

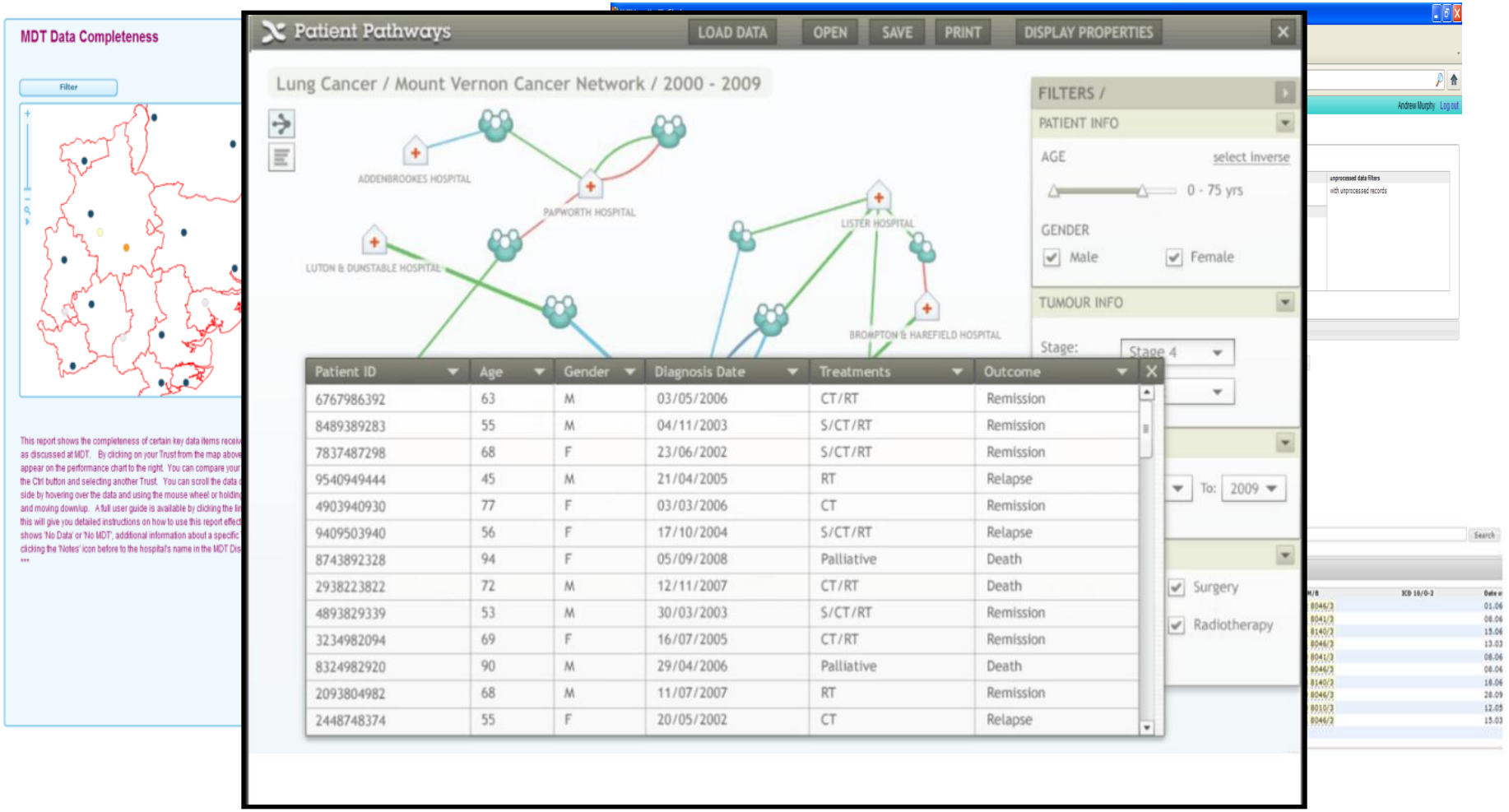
Feedback for Providers and Clinical Teams

- 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



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

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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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