

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



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

National Pilots

Recurrent/Metastatic Breast Audit Pilot

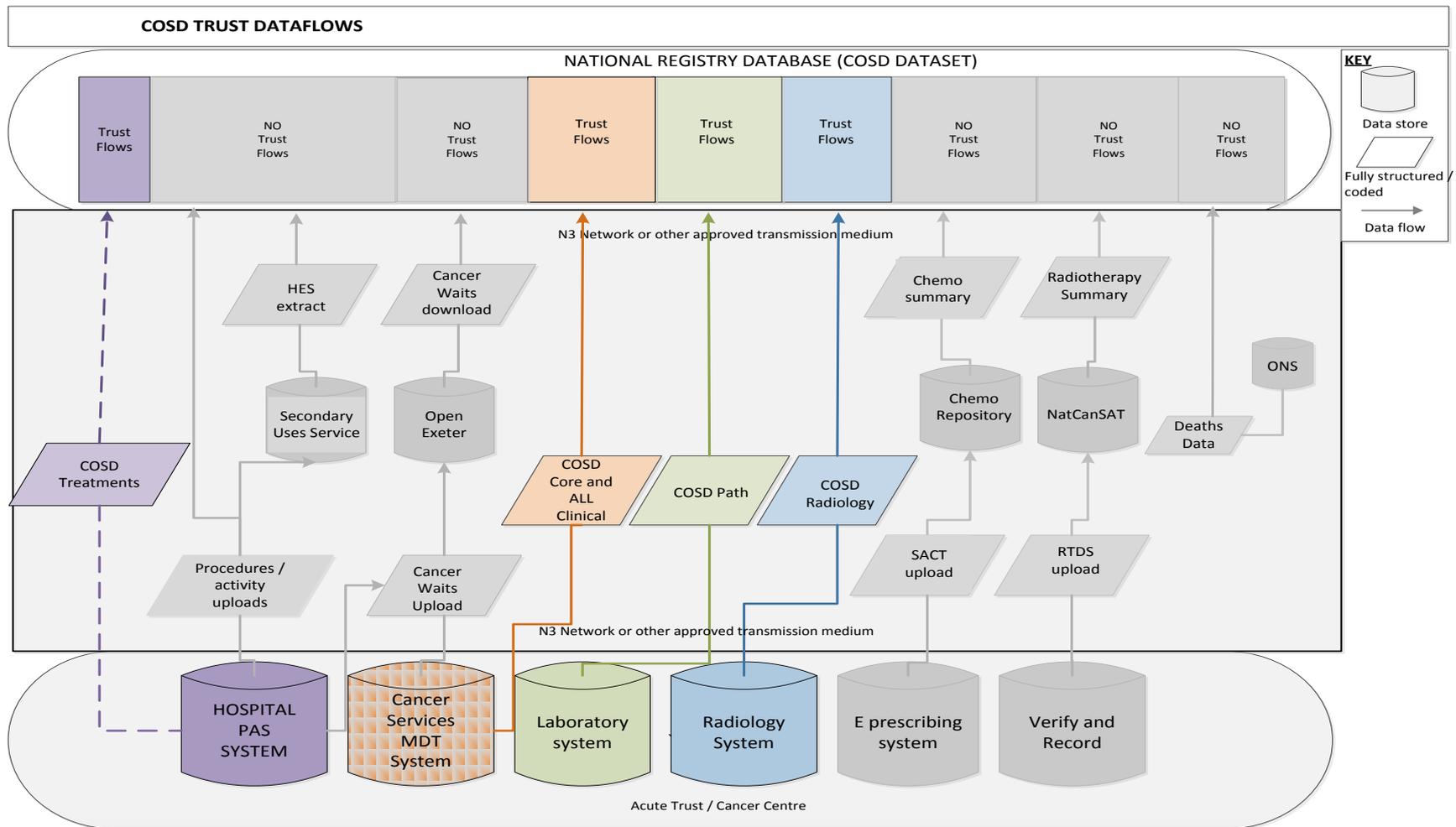
CRUK Stratified Medicine (Sept 2011)



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

ACR078 About Cancer Registration

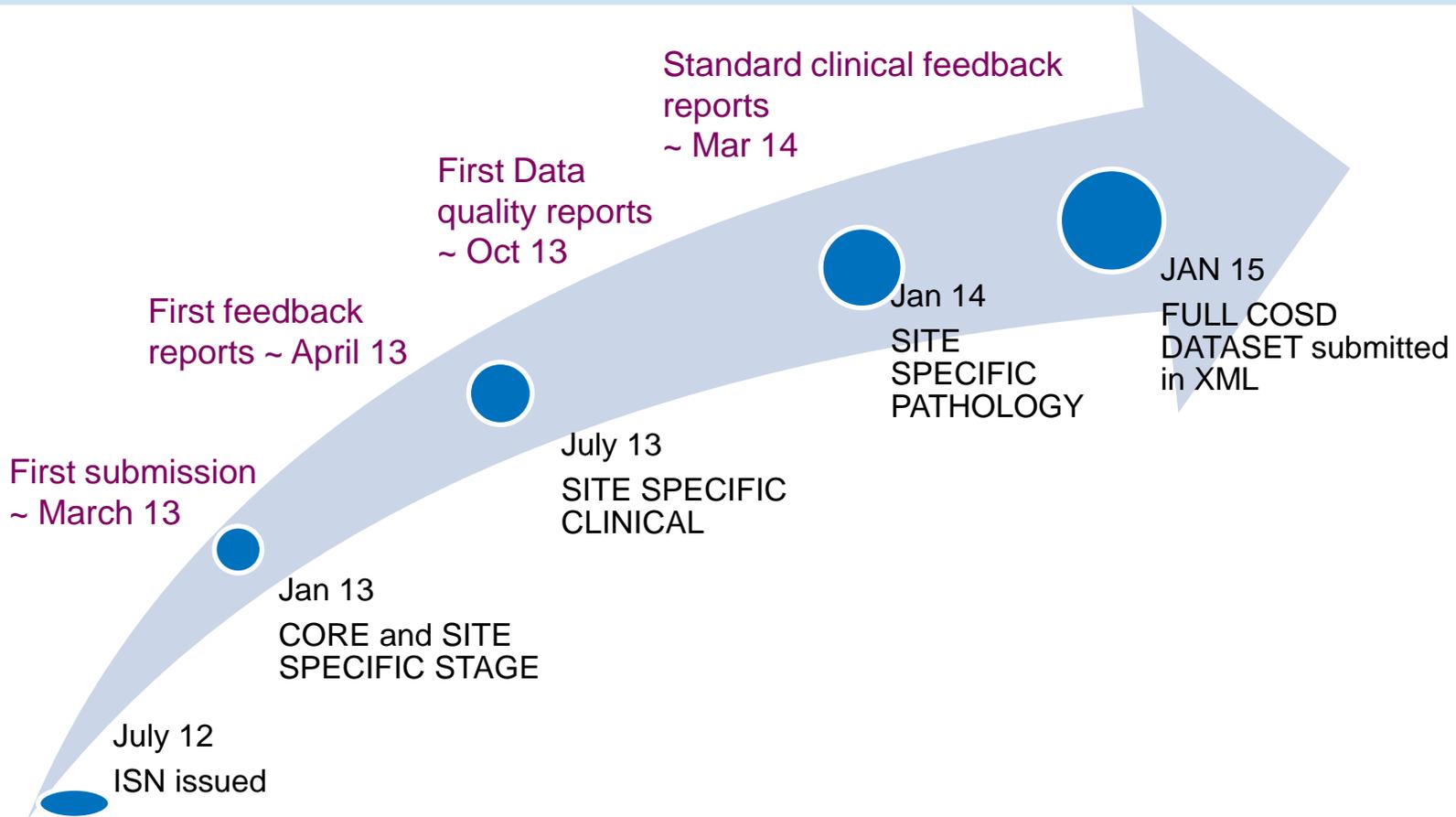


Feedback for Providers and Clinical Teams



- 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

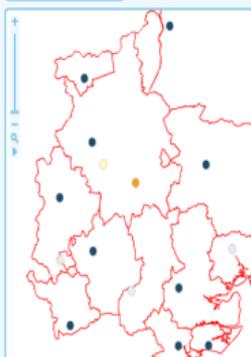
Proposed Feedback Timetable



Future Feedback?

MDT Data Completeness

Filter

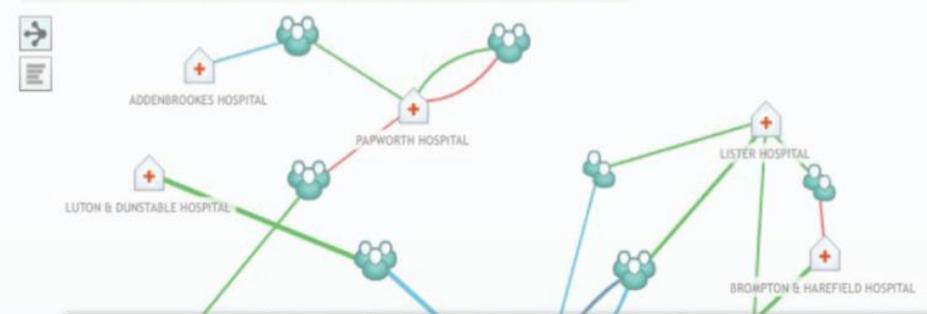


This report shows the completeness of certain key data items received as discussed at MDT. By clicking on your Trust from the map above you can see the performance chart to the right. You can compare your Trust to other Trusts by clicking the 'Compare' button and selecting another Trust. You can scroll the data to the left by hovering over the data and using the mouse wheel or holding the left mouse button and moving down. A full user guide is available by clicking the 'Help' icon. This will give you detailed instructions on how to use this report effectively. If you see 'No Data' or 'No MDT', additional information about a specific Trust can be accessed by clicking the 'Notes' icon before the hospital's name in the MDT Display.

Patient Pathways

LOAD DATA OPEN SAVE PRINT DISPLAY PROPERTIES

Lung Cancer / Mount Vernon Cancer Network / 2000 - 2009



FILTERS /

PATIENT INFO

AGE select inverse

0 - 75 yrs

GENDER

Male Female

TUMOUR INFO

Stage: Stage 4

To: 2009

Surgery

Radiotherapy

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

Andrew Murphy Logout

unprocessed data filters with unprocessed records

Search

Date	MDT 16/0/2	Date
10/04/2		01.06
10/04/2		08.06
11/04/2		15.06
10/04/2		13.03
10/04/2		08.06
10/04/2		08.06
11/04/2		18.06
10/04/2		20.09
10/10/2		12.05
10/04/2		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

Examples of Current Feedback



KING'S College LONDON Incoming Data Submissions Report

Home MDT Pathology

MDT Staging Completeness

April 2012 - March 2013

Front Page

Section 1
Data Completeness Summary

All Tumour Sites
Stageable Tumour Sites
All Tumour Sites - Dashboard
Stageable Tumour Sites - Dashboard

Section 2
Staging Completeness by MDT

Completeness by MDT
Completeness by MDT - Dashboard

Section 3
Staging Completeness by Trust

Completeness by Trust
Completeness by Trust - Dashboard

North East London

- Barking, Havering & Redbridge Univ. Hospitals NHS Trust
- Barts Health NHS Trust - Barts and the London
- Barts Health NHS Trust - Newham University Hospital
- Barts Health NHS Trust - Whipps Cross University Hospital
- Homerton University Hospital NHS Trust

North London

- Barnet and Chase Farm Hospitals NHS Trust
- North Middlesex University Hospital NHS Trust
- Royal Free Hampstead NHS Trust
- Royal National Orthopaedic Hospital NHS Trust
- University College London Hospitals NHS Trust
- Whittington Hospital NHS Trust

North West London

- Chelsea and Westminster Hospital NHS Trust
- Ealing Hospital NHS Trust

NHS Incoming Data Submissions Report

Home MDT Pathology

Pathology Data Counts

Introduction

This report is a monthly breakdown of the number of cases received from each provider of pathology based on the date of diagnosis.

Those fields highlighted in red are cases that fall below the lower threshold of cases received, and those in orange are greater than the upper threshold. The thresholds are compared to the average number of cases received from a pathology provider for the last six months.

Network: South East London, South West | Filter by Hospital: Ashford and St Peter's Hospitals

Filter by Year: 2011, 2012 | Select Lower Threshold: -20%

Select Upper Threshold: 20%

14 | 1 | of 3 | 100% | Find | Next | Select a format | Report

Incoming Pathology Data Report
Diagnosis Month Summary (All Trusts)

- This report is a monthly breakdown of the number of cases received from each provider of pathology based on the date of diagnosis.
- Those fields highlighted in red are cases that fall below the lower threshold of cases received, and those in orange are greater than the upper threshold. The thresholds are compared to the average number of cases received from a pathology provider for the last six months.

	2011												Total
	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	
North East London	1924	1998	2080	1911	2253	2231	2259	2197	2376	2171	1807	1695	24902
Barking, Havering and Redbridge University Hospitals	666	766	809	714	943	831	813	733	769	833	868	756	9401
Barts and The London	891	809	812	850	1025	1021	1048	1039	1125	1001	443	610	10674
Whipps Cross University Hospital	367	423	439	347	385	379	398	425	483	337	496	328	4827
North West London	2818	2786	3367	2704	2643	2850	2903	2694	2465	2498	2691	2269	32607
Barnet and Chase Farm Hospitals	340	334	423	290	358	389	338	376	377	359	361	338	4267
Ealing Hospital	469	369	483	556	437	346	458	486	347	410	416	336	5310
Hillingdon Hospital	255	244	360	252	336	383	345	348	379	387	380	268	3037
Imperial College Healthcare - Hammersmith	787	766	862	682	646	634	851	369	432	435	535	424	7623
Imperial College Healthcare - St Marys	215	322	371	186	238	229	207	207	241	232	265	269	2774
North West London Hospitals	465	386	672	443	717	330	331	352	365	335	353	321	4760
Royal Brompton and Harefield	119	99	122	116	110	117	138	136	111	129	144	130	1491
West Middlesex University Hospital	228	189	224	179	217	211	215	220	213	211	237	191	2535
North London	6626	6692	7600	5912	6743	7546	6811	6530	7241	7131	7643	6403	82887
Great Ormond Street Hospital for Children	55	71	63	41	76	51	61	46	48	54	46	41	647
North Middlesex University Hospital	197	263	273	246	230	302	303	211	210	262	268	214	2982
Royal Free Hampstead	467	510	514	445	464	539	474	502	390	461	590	515	6273
Royal National Orthopaedic Hospital	183	179	252	160	224	415	192	206	389	297	383	693	3661
University College London Hospitals	5425	5433	6215	4867	5385	5905	6323	5726	6233	5983	6889	4721	65020

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?

Barry Plewa
barry.plewa@kcl.ac.uk

barry.plewa@nhs.net (secure – data transmission)