

Nine months of COSD – first impressions

CTYA Workshop
December 2013
Trish Stokes



A recap - COSD



- New national cancer dataset incorporates registration
- Whole patient pathway
- Aligned and rationalised with other cancer datasets
- Includes generic and site specific data
- Submitted monthly most data from MDT systems and Path systems
- Monthly feedback
- Phased implementation Jan 13 Jan 15

A recap – Cancer registration



- Using information to improve quality & choice
- Separation of registration and analysis within PHE
- National Cancer Registration Service
- Single system (ENCORE) and processes
- Collate data from multiple sources
- Timely feedback
- Analysis by PHE Knowledge and Intelligence Teams and NCIN

Core dataset



- Referral through to treatment for all patients
- Initial Focus on :
 - Diagnosis
 - Basis of diagnosis
 - Performance status (for adults)
 - Contact with CNS
 - MDT discussion
 - Stage (TNM and site specific)

CTYA – Pathway data



- Specialty of referrer to specialist MDT
- Consultant at diagnosis specialty and age specialism
- MDT at treatment decision Age specialism of MDT/s discussing patient
- Age specialism of oncologist

CTYA - Patient data



- Symptoms first noted
- Primary diagnosis additional information
- Secondary diagnosis
- Other significant diagnosis
- Familial cancer syndrome
- Stem cell infusion

CTYA – disease specific data



- ALL
- AML
- NHL
- Hodgkin Lymphoma
- Neuroblastoma
- Renal tumours/Wilms
- Rhabomyosarcoma and other STS
- Osteosarcoma/Ewings
- Germ cell tumours
- Hepatoblastoma/Hepatocellular

Which dataset should we collect for patients under 25?



- Age specific MDTs (paediatric or TYA) at Principal Treatment Centres
 - Complete CTYA dataset (and existing registration process)
- Site specific MDTs
 - Complete site specific dataset AND IF PATIENT NOT REFERRED TO PTC
 - Age specific elements of CTYA dataset (pathway and patient)
- Disease covered by CTYA and site specific dataset
 - Only complete one set of site specific data
- Disease not covered by CTYA dataset
 - Complete site specific dataset AND
 - Age specific elements of CTYA dataset (pathway and patient)

Implementation progress

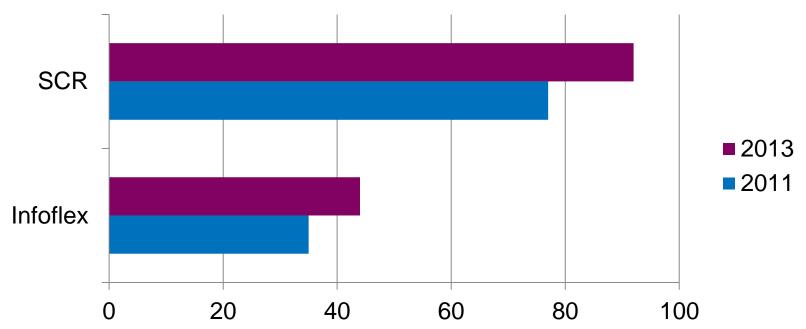


- Implementation led by NCRS
- Data Transfer Agreements signed with Trusts
- ~160 trusts submitting MDT data files
- Data liaison lead appointed to work with Trusts
- Reporting portal established feedback on files received and key fields in raw data submitted
- Revision of reporting feedback in progress
- Registration feedback deferred to early 2014
- Oversight by COSD Governance Board

MDT systems in place



25% increase in use of two main systems

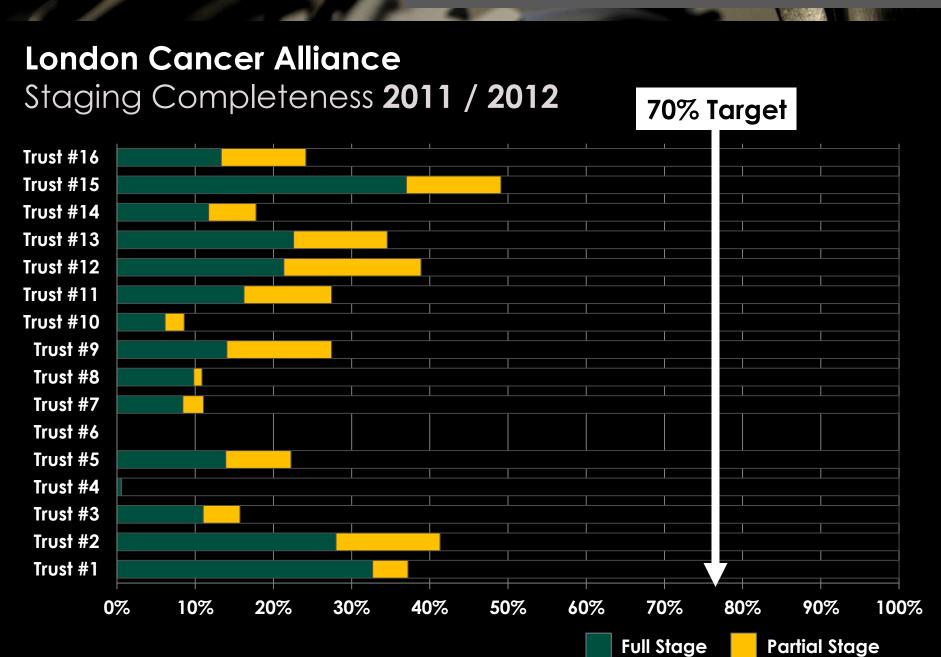


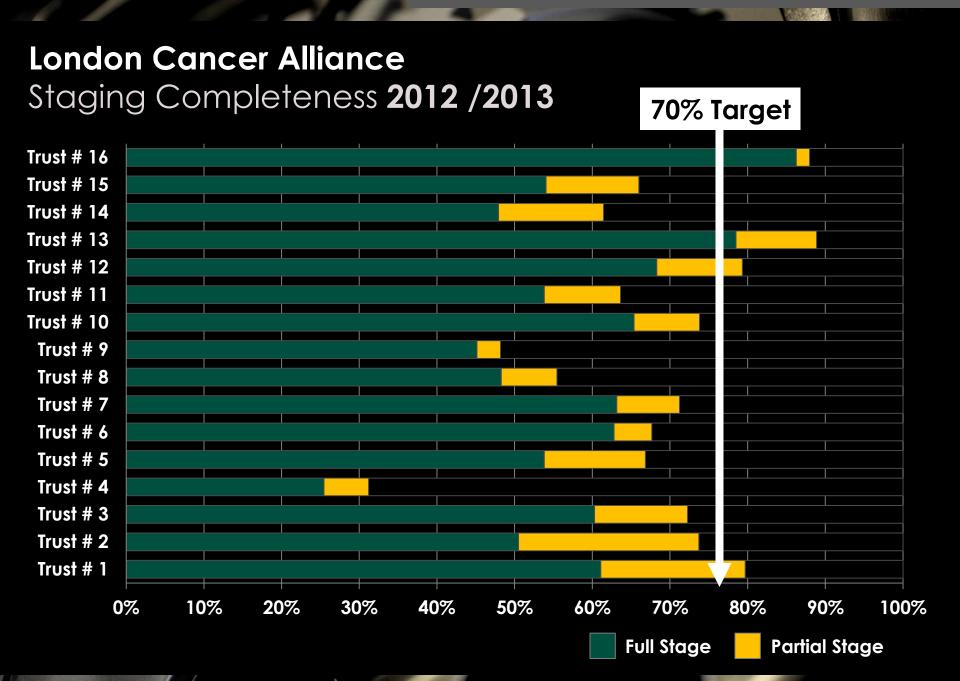
Standard template for trusts with no system

Data Liaison Team



- National lead appointed
- Officer at each branch office
- Working with Trusts to improve data quality and completeness
- Concentration on key fields to start with eg stage completeness





Reporting feedback



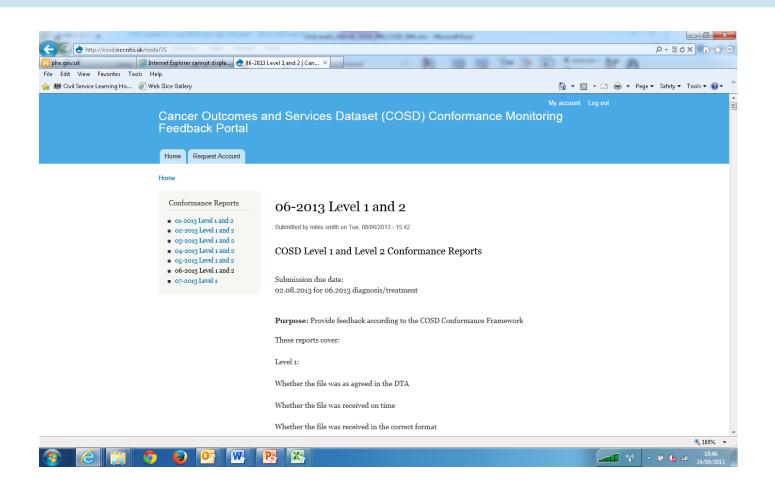
- Reporting portal
- 1. Fact of submission (files)
- 2. Data Quality (raw data)
- 3. Quality assurance (processed data)

- Analytical reports led by NCIN
- 4. Clinical analysis (processed/summarised data)

Reporting portal http://cosd.ncr.nhs.uk/



Using information to improve quality & choice



Level 1 – Submission



Using information to improve quality & choice

Level 1 reporting deadline for this data: close of play on 06.08.2013

Level 2 reporting deadline for this data: close of play on 30.08.2013

Report generated: 30.08.2013 16:54

Registry / Provider	Source type	L1.1 conformance Agreed files received?	L1.2 conformance Plans for exceptional circumstances?	L1.3 conformance File received by due date?	L1.4 conformance File in COSD compliant format?	Level 2 reports						
NCRS NORTHERN AND YORKSHIRE BRANCH (Y0201)												
AIREDALE NHS FOUNDATION TRUST (RCF)	MDT (COSD XML/compliant)	Yes	Yes	Yes	Yes	Level 2						
	PATHOLOGY	163		Yes	N/A	[2]						
BRADFORD TEACHING HOSPITALS NHS FOUNDATION TRUST (RAE)	MDT (COSD XML/compliant)	Yes	Yes	Yes	Yes	Level 2						
	PATHOLOGY			Yes	N/A	[2]						
CALDERDALE AND HUDDERSFIELD NHS FOUNDATION TRUST (RWY)	MDT (COSD XML/compliant)	Yes	Yes	Yes	Yes	Level 2						
	PATHOLOGY	100		Yes	N/A	[2]						
CITY HOSPITALS	MDT (COSD			Yes	Yes	Level 2						

Level 2

Data quality – raw data



- By MDT/Tumour group and Provider for month of diagnosis (invasive and non invasive)
- Available within one month of submission
- For Trusts submitting in XML format

Extract from current Level 2 Report



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L2.3d	3d Breakdown of stage by tumour group and percentage with completed stage grouping										
	Diagnosed	% Staged	Stage 1	Stage 2	Stage 3	Stage 4	Other Stage				
Brain/Central Nervous System (invasive)	19	0%	0	C	0	C	0				
Breast (invasive)	84	26%	0	C	0	C	22				
Colorectal (invasive)	75	41%	0	C	0	C	31				
Gynaecological (invasive)	62	79%	32	5	5 5	7	0				
Haematological (invasive)	58	12%	1	2	2 2	2	. 0				
Head and Neck (invasive)	29	62%	2	C	0	C	16				
Lung (invasive)	108	81%	0	С	0	C	88				
Sarcoma (invasive)	13	8%	0	С	0	С	1				
Skin (invasive)	92	36%	5	2	2 1	C	25				
Upper Gastrointestinal (invasive)	76	34%	0	1	1	C	24				
Urological (invasive)	147	17%	7	1	0	C	17				
Other (invasive)	31	55%	0	C) 2	2	13				

Reporting feedback developments



- Revised feedback reports in progress (Level 1 and 2)
- Changes to be shown over time
- Separate online reports for each tumour group
- Revised tumour groupings and total by Trust
- Compiled registrations (Level 3) deferred to early 2014
- How do you want to get feedback?

Conformance/Reporting feedback – key fields



- Diagnosis (ICD10 and morphology)
- Basis of diagnosis
- Stage
- Performance Status (adults only)
- Clinical Nurse specialist (to be added)
- Treatments

Other key fields to be agreed with clinical teams (Discussions with CTYA in progress)

Proposed groupings for CTYA reports?



- Under 16
- **■** 16 18
- **19 -24**

Maintenance and ISB process



- Maintenance led by NCIN
- Regular Newsletter, User Guide and website
- Annual revision to keep dataset up to date
- Complex dataset not quite got it right yet for CTYA!
- Latest revisions –approved by ISB
- Standardisation of size measurements to 2dp
 - New fields for Report groupings to align with CCGs
 - Other minor amendments for clarity and current practice
 - SNOMED CT pilot project
 - Procedure codes and Path T and M fields
- Formal change request process through COSD helpdesk
- Development of Level 4 reports

Level 4 - Clinical reports



- NCIN leading
- Development deferred to 2014
- Consultation with clinical teams
 - SSCRGs
 - Network site specific groups
- Need to align with
 - Service profiles
 - Peer review clinical lines of enquiry
 - Commissioning and SCNs
 - National and professional body audits

Online learning for non clinical staff



Using information to improve quality & choice





Cancer Outcomes Conference 9 & 10 June 2014 Hilton Birmingham Metropole

www.ncin.org.uk/conference



The Cancer Outcomes Conference 2014 will explore the 'power of information' both locally and nationally.

It will examine how UK-wide cancer registration data and other health related datasets are being exploited to reduce cancer incidence, mortality and morbidity.

To find out more, visit www.ncin.org.uk/conference





Summary



Using information to improve quality & choice

- NCRS leading implementation
- NCIN leading maintenance and ISB
- Making good progress
- Reporting feedback under revision
- Summary reports early next year
- Analytical reports later next year
- Communications and support for clinical teams
 - NCRS Data Liaison team
 - COSD Newsletter and website
 - Online learning
 - Re-establish links following changes to structure



Thank you

Queries to: cosd@ncin.org.uk