

Cancer Outcomes and Services Dataset

**CTYA Clinical Leads Workshop
24th November 2010**

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NCIN Objectives



- **Promoting efficient and effective data collection throughout the cancer journey**
- Providing a common national repository for cancer datasets
- Producing expert analyses, based on robust methodologies, to monitor patterns of cancer care
- **Exploiting information to drive improvements in standards of cancer care and clinical outcomes**
- Enabling use of cancer information to support audit and research programmes

Using information to improve quality & choice

Essentials for success

- **Clinical engagement**
- **Credible data**
 - High level of data completeness
 - Case mix adjustment
 - Timely
- **Reporting**
 - Easy access to clear, ‘bespoke’ reports
 - ‘Real time’ – on line; Annual reports
 - Targeting reports: Clinicians; Trusts; SHAs ; PCTs etc
- **Dissemination in Peer-reviewed settings**
 - Publication, Conferences, Workshops, etc
- **Incorporating performance and outcome data into:**
 - Commissioning
 - Cancer Peer Review & Service Improvement

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Cancer Datasets

- Sept 2012

- Cancer Registration Dataset – *mandated for several years*
- Going Further on Cancer Waits – January 2009
- Radiotherapy – April 2009
- *Chemotherapy (SACT) – April 2012*
- ***New COSD – September 2012***
- *Pathology/Radiology – Professional/Clinical Standards*

NCIN Cancer Registration Data Views

Patient Pathway

Datasets/Sources

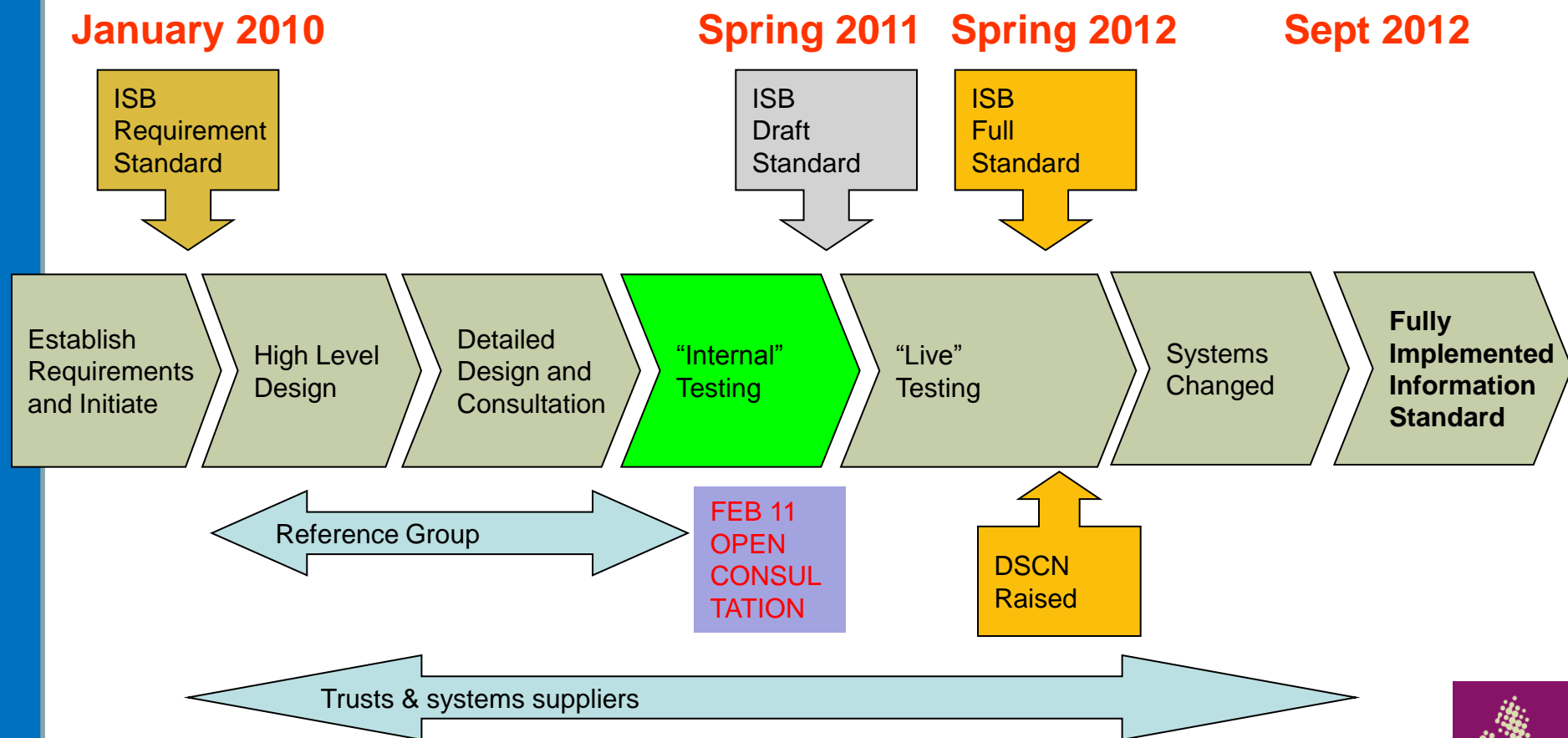
	Referral	Diag	Rx	Rec/Mets	Rx	Pall. Care	Death
CWT							
MDT							
RTDS							
HES							
NCASP							
Ca. Reg							
TOTAL							

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Progress

- Core dataset review
- Additional core items identified
- Site specific dataset agreed by Clinical Reference Group
- Software Suppliers Day
- First draft COSD dataset
- Definitional testing
- Identify key RC Path items

Process overview



Testing volunteers wanted

Definitional testing reports

National Datasets Service

Cancer Outcomes and Services Dataset (COSD) - CTYA

Data Discovery Analysis - Site Data Report

Site Name: XXXXX

Date of Report: 17/11/2010

Type of Match (Capability)

COSD - Children, Teenagers, and Young Adults (CTYA)

Number of COSD CTYA Data Items = 61

Systemic Capability*		%
System Capability	37	61%

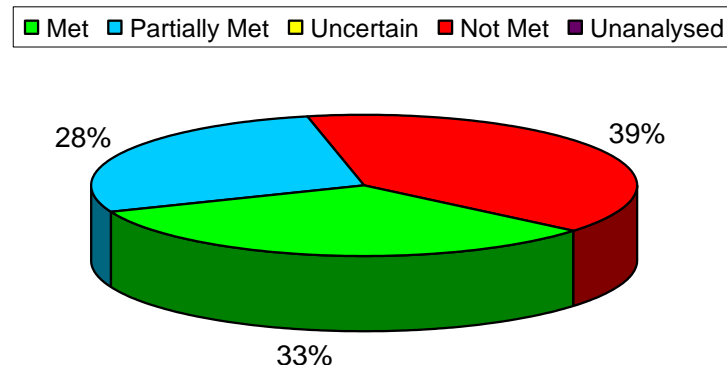
* Including Met and Partially Met

Type of Match Category ¹	No. Data Items	%
Met	20	33%
Partially Met	17	28%
Uncertain	0	0%
Not Met	24	39%
Unanalysed	0	0%
TOTAL NO. DATA ITEMS	61	100%

SYSTEMS MAPPED

Cnodes
Cancer Wait Times (ICT system)

COSD - CTYA Type of Match



¹ Definitions of Type of Match Categories

Met = Data item and all associated values can be fully mapped

Partially Met = The equivalent system data item exists but there is not an exact match of associated values

Uncertain = More information is required before determining whether the data item can be mapped

Not Met = The data item and/or values cannot be successfully mapped or matched to a data item in the system

Unanalysed = Data item not analysed

COSD Dataset

Dataset Section	# Items
Core	133
Additions to Core	10
Brain	15
Breast	17
Colorectal	28
CTYA*	61
Gynae	5
Haematology*	69
Head & Neck	30
Lung	11
Sarcoma*	10
Skin*	52
Upper GI*	163
Urology	13
	617

[COSD](#)

*** Include some disease specific and some repeating data items within the subsets**

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COSD Dataset – CTYA

- General and disease specific subsets

- CTYA (18)
 - ALL (4)
 - AML (3)
 - NHL (2)
 - Hodgkin (3)
 - Neuroblastoma (3)
 - Wilms (2)
 - Rhabdomyosarcoma (5)
 - Osteosarcoma (5)
 - Ewings (4)
 - Hepatoblastoma (3)
 - CNS tumours (5)
 - Germ Cell tumours (3)
 - Retinoblastoma (1)
-
- Age appropriate setting, Familial history
 - Site specific Staging, Prognostic factors

CTYA draft dataset

www.ic.nhs.uk/services/datasets/document-downloads/cancer

Cancer Outcomes and Services Dataset - CTYA

Version: 0.2

Data Item Name	Description	Format	National Code	National code definition
PATIENT DETAILS				
COUNTRY CODE	Country of residence at time of diagnosis.	a3		COUNTRY CODE
REFERRALS				
DATE FIRST SEEN WITH SYMPTOMS	Date first seen in secondary care for these symptoms	an10 cyy-mm-dd		
SPECIALTY (FIRST SEEN WITH SYMPTOMS)	Specialty of consultant in secondary care where patient first seen for these symptoms (Table 1 Main Specialty codes from Data Dictionary).	n3	-	Main Specialty and Treatment Function Codes
CONSULTANT SPECIALTY (AT DIAGNOSIS)	The specialty of the consultant responsible for the patient at the time of diagnosis (Table 1 Main Specialty codes from Data Dictionary).	n3	-	Main Specialty and Treatment Function Codes
CONSULTANT AGE SPECIALTY (AT DIAGNOSIS)	The age group specialty of the consultant responsible for the patient at the time of diagnosis. This will be defined by the MDT.	an1	P	Paediatric
			T	Teenage and Young Adult
			A	Adult
				Insert extra rows here
SPECIALTY (REFERRER TO SPECIALIST)	The specialty of person referring to Principal Treatment Centre or age specific Specialist TYA MDT.	n3	-	Main Specialty and Treatment Function Codes

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Data Item Name	Description	Format	National Code	National code definition
DIAGNOSIS				
PRIMARY DIAGNOSIS COMMENT	Additional comments on diagnosis where coding difficult or imprecise	an255		
OTHER SIGNIFICANT DIAGNOSIS (CODE)	Types (ICD10 codes) of other significant conditions (e.g. Downs Syndrome, NF1, Fanconi) which may predispose to cancer or influence treatment.	ICD10		
OTHER SIGNIFICANT DIAGNOSIS (COMMENT)	Additional comments on other significant conditions where coding is difficult or imprecise	an255		
FAMILIAL CANCER SYNDROME	Indicate whether there is a possible or confirmed familial cancer syndrome	an2	Y	Yes
			N	No
			P	Possible
			99	Not Known
				Insert extra rows here
FAMILIAL CANCER SYNDROME COMMENT	Additional comments on familial cancer syndrome where coding difficult or imprecise	an255		
MDT TYPE(S)	Type(s) of MDT where care plan for patient was discussed	an1	P	Paediatric
			T	Teenage and Young Adult
			A	Adult
				Insert extra rows here
ICD-O-3	HISTOLOGY CODE TO TEXT TRANSLATION	an6	see code list below	

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Data Item Name	Description	Format	National Code	National code definition
STEM CELL TRANSPLANTATION				
STEM CELL INFUSION SOURCE	Source of stem cells for infusion (autologous or allogenic)	an1	1	Auto
			2	Allo
				Insert extra rows here
STEM CELL INFUSION TYPE	Type of stem cell infusion	an1	B	BONE MARROW
			P	PERIPHERAL
				Insert extra rows here
STEM CELL INFUSION DATE	Date of stem cell infusion (Day 0)	an10 ccyy-mm-dd		
CHEMOTHERAPY				
SPECIALTY SUB CODE (CHEMOTHERAPY CONSULTANT)	The age group specialty of the consultant responsible for prescription of chemotherapy.	an1	P	Paediatric
			T	Teenage and Young Adult
			A	Adult Only
				Insert extra rows here
CLINICAL TRIAL				
CLINICAL TRIAL IDENTIFIER	The name of the clinical trial into which patient was entered to be recorded for each course of treatment	an10		

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Useful links

NHS Information Centre (dataset)

www.ic.nhs.uk/services/datasets/document-downloads/cancer

Datasets@ic.nhs.uk

NCIN

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