Cancer Outcomes and Services Dataset

Central Nervous System Clinical Leads Workshop
17th March 2011

Trish Stokes, NCIN

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**

Cancer Datasets - *Sept 2012*

- Cancer Registration Dataset – *mandated for several years*
- Going Further on Cancer Waits – Jan 2009
- Radiotherapy – April 2009
- *Chemotherapy (SACT) – April 2012*
- ***Cancer Outcomes and Services Dataset – Autumn 2012***
- *(RC Pathology – Professional/Clinical Standards)*
- *(RC Radiology – Professional/Clinical Standards)*
- ?National Audits

The last twelve months

- Core dataset reviewed
- Additional core items identified
- Site specific datasets agreed by Clinical Reference Groups
- MDT Software Suppliers Day
- First draft COSD dataset
- Definitional testing (incl key path for staging)
- Open consultation begun
- Work begun with RC Pathologists and RC Radiologists on clinical content

NCIN Cancer Registration Data Views

NCIN national cancer intelligence network

Patient Pathway

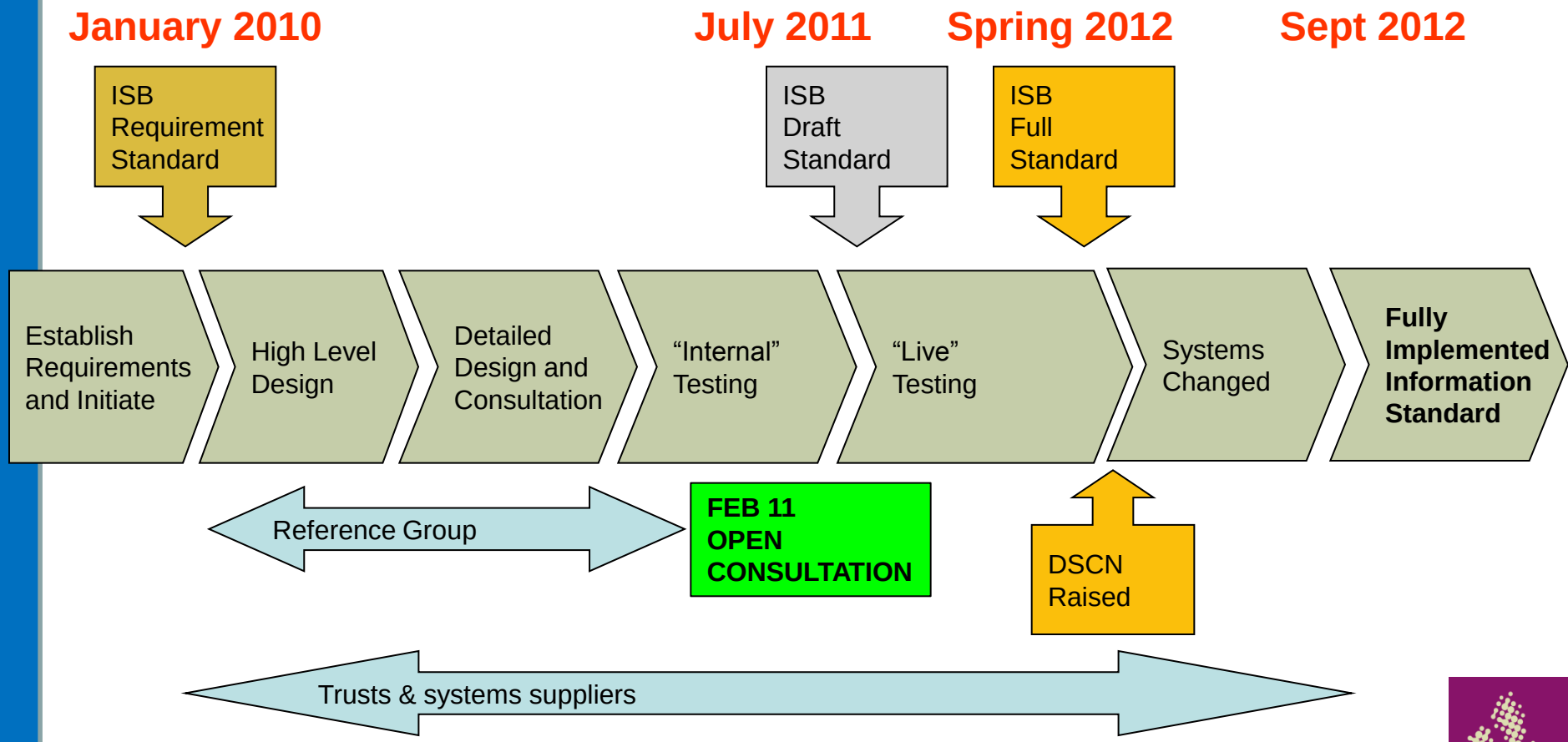
Datasets/Sources

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

Using information to improve quality & choice

CRI National Cancer Research Institute

Where are we now?



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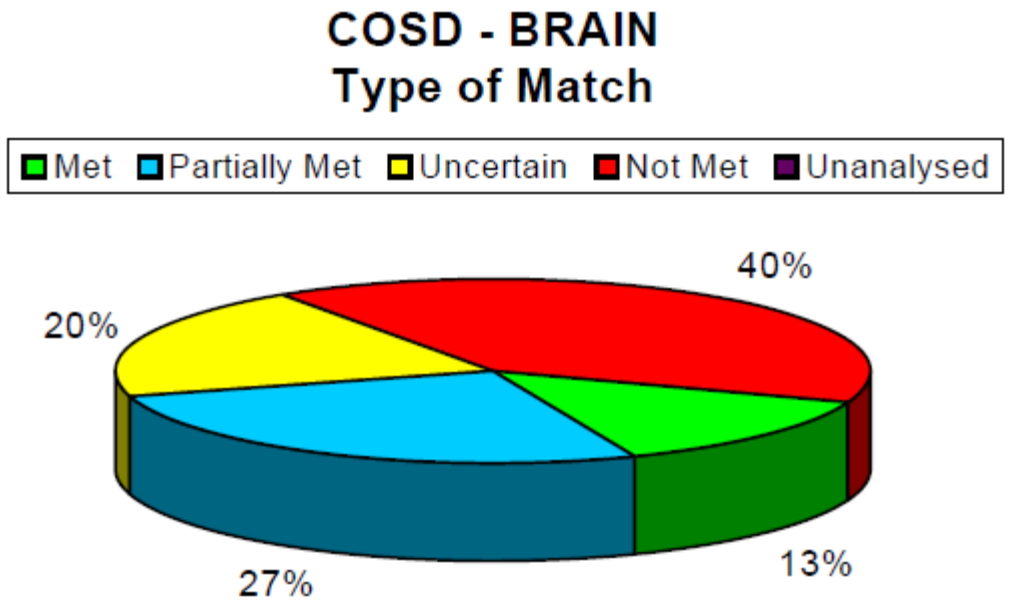
Definitional testing – general feedback

- Support for
  - cohesive and consistent dataset
  - clear and comprehensive guides
- Concerns
  - increased burden of collection
  - need for clinical involvement

Definitional testing reports – can the systems collect the data?

Number of COSD Brain Data Items	**15**
Number of Sites Analysed	**2**



Using information to improve quality & choice

NCRI National Cancer Research Institute

Definitional testing reports – are the data items useful?

- ??? No response from testing

Definitional testing reports – are the data items collected?

- Clinical ???? No response from testing
- Pathology
  - Only tested at one site
  - only one of three items collected

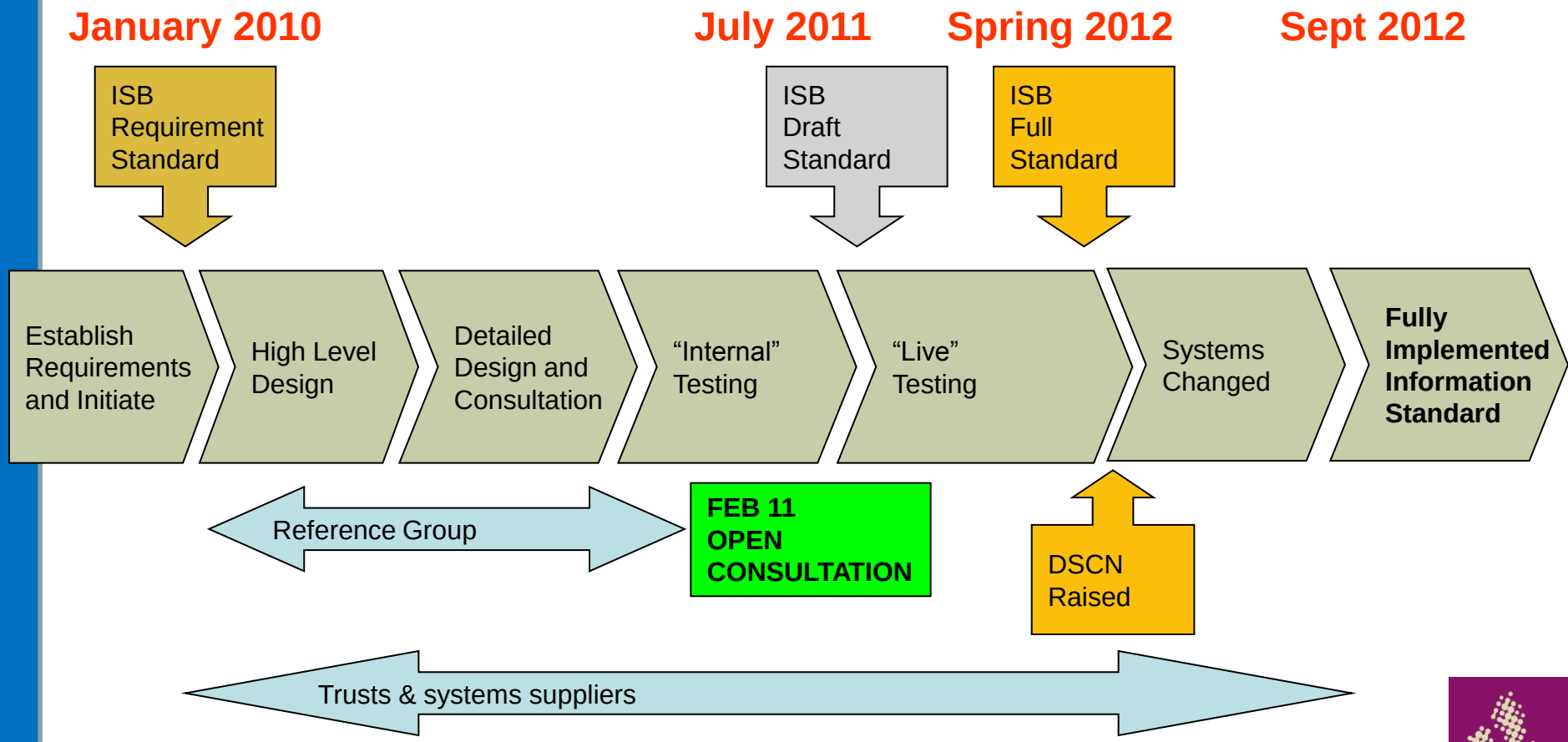
COSD Dataset

Dataset Section	COUNT
Core (with additions)	**143**
Breast	30
CNS	**16**
Colorectal	30
CTYA	66
Gynae	41
Haematology	60
Head & Neck	44
Lung	19
Sarcoma	16
Skin	70
Upper GI	166
Urology	30
	731

COSD

Using information to improve quality & choice

The next twelve months



NCIN
national cancer
intelligence network

Operational Testing volunteers wanted

datasets@ic.nhs.uk

NCRI
National
Cancer
Research
Institute

Data template

Cancer Outcomes and Services Dataset - CNS

Version: 0.2

Data Item Name		Format	National Code	National code definition
RADIOLOGICAL PRIMARY DIAGNOSIS	Primary diagnosis based on imaging. In many cases this will be the definitive clinical diagnosis, but needs to be distinguished from the subsequent pathological diagnosis - if it becomes available.	ICD10		
MOLECULAR DIAGNOSTICS	Chromosomal or genetic markers associated with the brain tumour. This may involve selection of more than one values for each tumour.	an1	1	Evidence of IDH1 or IDH2 mutation
			2	Evidence of methylation of the MGMT gene CpG island
			3	Evidence of total loss of 1p and 19q
			4	Evidence of KIAA 1549-BRAF fusion gene
			5	Other
MDT WORKING DIAGNOSIS	Working diagnosis as defined at MDT which forms the basis of treatment, and is the clinical opinion informed by biopsy, radiological and/or other investigations.	ICD10/SNOMED		

Draft Data Items (1)

Data Item Name	Description
LOCATION OF LESION (RADIOLOGICAL)	Radiologically determined anatomical location of lesion(s)
LESION DISTRIBUTION (RADIOLOGICAL)	Radiologically determined distribution of lesion(s)
SIZE OF LESION (RADIOLOGICAL)	Radiological estimate in millimetres of the maximum diameter of the tumour.
FEATURES OF LESION (RADIOLOGICAL)	Radiologically identified features of lesion such as density, necrosis. This may involve selection of more than one value for each tumour.
IMAGING PROCEDURE (DIAGNOSTIC)	Type of imaging procedure undertaken to diagnose the tumour
RADIOLOGICAL PRIMARY DIAGNOSIS	Primary diagnosis based on imaging. In many cases this will be the definitive clinical diagnosis, but needs to be distinguished from the subsequent pathological diagnosis - if it becomes available.
MOLECULAR DIAGNOSTICS	Chromosomal or genetic markers associated with the brain tumour. This may involve selection of more than one values for each tumour.
MDT WORKING DIAGNOSIS	Working diagnosis as defined at MDT which forms the basis of treatment, and is the clinical opinion informed by biopsy, radiological and/or other investigations.
PRIMARY SURGICAL PROCEDURE	This is the primary operative procedure in the management of the patient. It is the same information usually collected in PAS and used by the organisation for PbR submissions.
TUMOUR LOCATION (SURGICAL)	Surgical location and extent of tumour within the brain
RADIOSURGERY	Did patient have radiosurgical treatment
DATE OF RADIOSURGERY	Date of radiosurgical treatment
ASA SCORE	The ASA physical status classification system is a system for assessing the fitness of patients before surgery. If the surgery is an emergency, the physical status classification is followed by “E” (for emergency).
RESECTION TYPE	Identify whether excision is Partial or Total

Draft Data Items (2)

Data Item Name	Description
RADIOLOGICAL PRIMARY DIAGNOSIS	Primary diagnosis based on imaging. In many cases this will be the definitive clinical diagnosis, but needs to be distinguished from the subsequent pathological diagnosis - if it becomes available.
MDT WORKING DIAGNOSIS	Working diagnosis as defined at MDT which forms the basis of treatment, and is the clinical opinion informed by biopsy, radiological and/or other investigations.
PRIMARY SURGICAL PROCEDURE	This is the primary operative procedure in the management of the patient. It is the same information usually collected in PAS and used by the organisation for PbR submissions.
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RESECTION TYPE	Identify whether excision is Partial or Total
HORMONE EXPRESSION	For Pituitary adenomas only: Hormone expression by immunohistochemistry (Multiple values may be entered - query for IC and Data Dictionary - how would you want to model this?)
WHO TUMOUR GRADE (CNS)	The grade of the tumour using WHO classification for tumours of the central nervous system

Useful links

NHS Information Centre (dataset)

http://www.ic.nhs.uk/services/datasets/current-consultations/cancer-outcomes-and-services-data-set-consultation

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