

The National Cancer Dataset Initiative

UGI SSCRG

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.....Better information on cancer services and outcomes will enhance patient choice, drive up service quality and underpin stronger commissioning;

.....Collection of defined datasets on all cancer patients will be mandated through the national model contract. PCTs will be responsible for ensuring that this information is collected by MDTs and sent to cancer registries

.....We particularly need to collect and use high quality data on:

.....Clinical outcomes, including survival, with adjustments for co-morbidity and stage of disease.

8.14 The most important gaps in data collection have been identified as follows:

- *Information on staging and co-morbidity is only variably recorded by teams caring for cancer patients*
- *Information on histopathology and cytopathology is inadequately recorded*

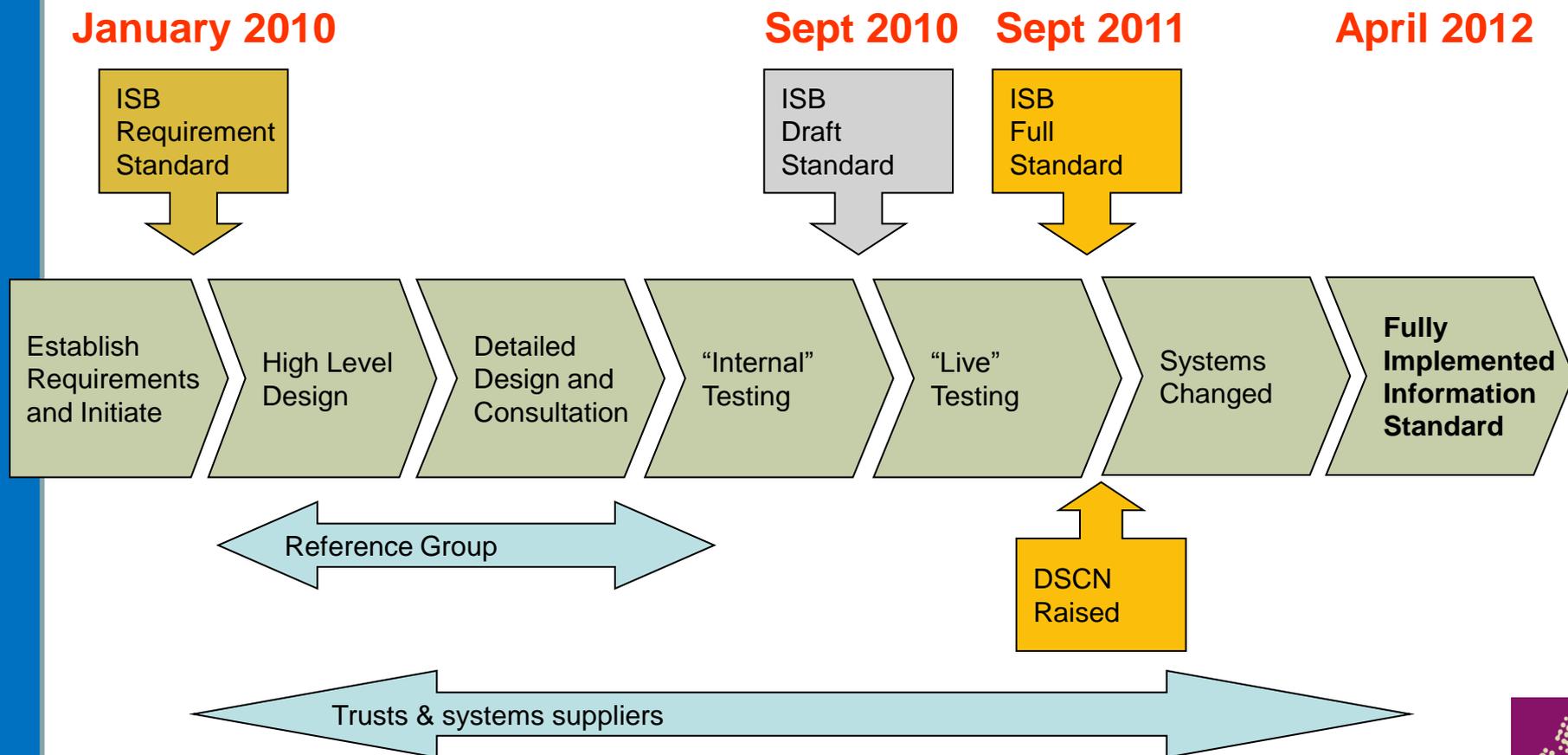
Project Purpose

- To redevelop the National Cancer Dataset for use as a full operational standard in England
- To review the current business needs for the collections and make sure that the output is fit for purpose

SSCRG progress

- Approved mandated datasets
 - Cancer registration – additional review
 - GFoCW
 - Radiotherapy
 - Commissioning Datasets
 - (national audits/college datasets)
- 12 SSCRGs identifying ‘site specific’ items
 - Link to ‘output’ requirements
 - Considering existing datasets e.g. NCASP, BAUS
 - Preliminary consultation with CN TSSGs lead clinicians
 - late 2009/2010

Process overview



Data 'Types'

- 'Generic' Core
 - Standard for all patients e.g. NHS number, DOB, etc
- 'Site Specific' Core
 - Pathology – RCPATH Datasets
 - Staging e.g. TMN, Dukes, FIGO, etc.
- Specialist/Cross-cutting Datasets
 - Going Further on Cancer Waits (January 2009)
 - Radiotherapy Dataset (April 2009)
 - Chemotherapy Dataset (under development)
- 'Site Specific' Data Elements
 - Specific to cancer type/site e.g. ER Status for Ca. Breast

NCIN Cancer Repository Data Views

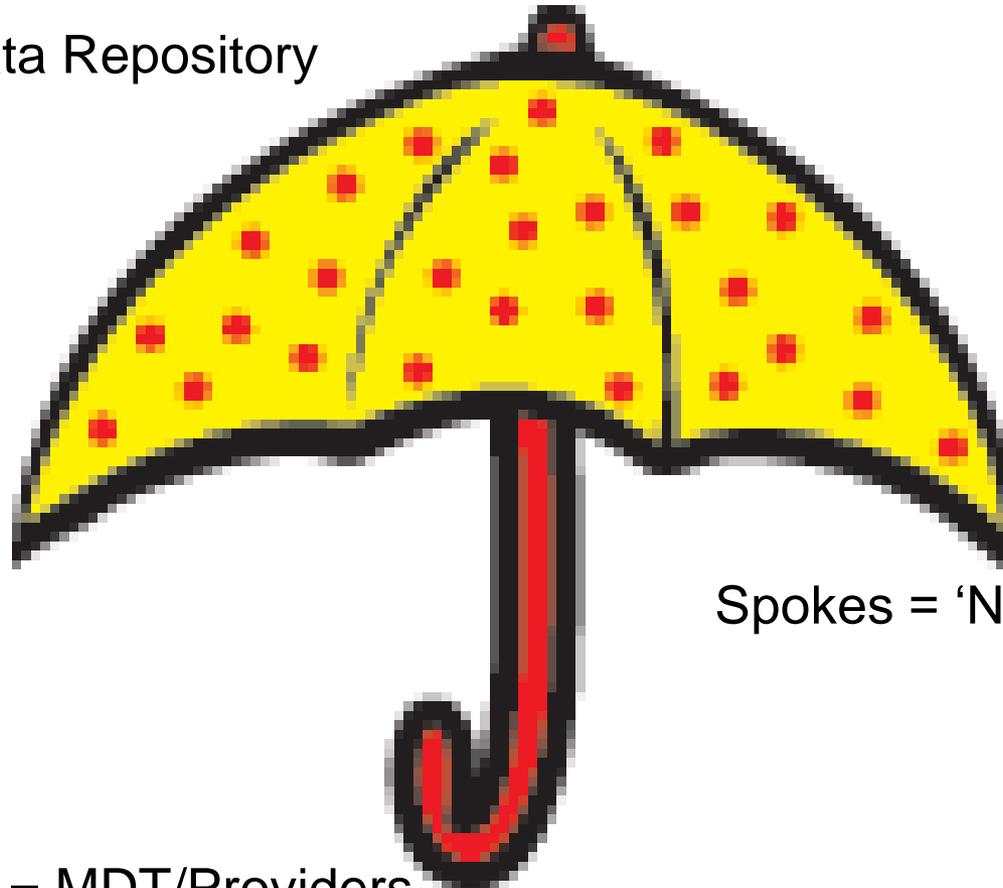


Patient Pathway

Datasets/Sources

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

Cover** = Data Repository



Spokes = 'NHS' Data Flows

Handle = MDT/Providers

Challenges - 1

- Clinical data from MDTs?
- Coded data from path/radiology/etc
- Transport via standard NHS data flows
 - SUS, Open Exeter (Cancer Waits)
 - Direct Cancer Registries & Nat. Repository
 - Direct to NCASP
- Linking activity and ‘care record’ data
 - OPCDS + radiotherapy
 - CWT + ‘registration’
- Timely

Challenges - 2

- Identifying 'business requirements'
- Future-proofing
- Adequate time for consultation & debate
- Specific issues – co-morbidity
- Impact on the service
- Promoting project to service

**If we get this right - minimal impact on the service
But maximum impact on improving care**

Suggestions to 'Generic' Core

- Smoking Status
- Alcohol Status
- Morbid Obesity
- BMI – or components
- Roles of CNS [LUCADA]

UGI SSCRG – Site Groups

UGI dataset

Group_3 (4-way split)	ICD10 codes
Upper oesophagus	C15.0, C15.1, C15.3, C15.4
Gastro-oesophageal junction	C15.2, C15.5, C16.0
Stomach (excl Cardia)	C16.1, C16.2, C16.3, C16.4, C16.5, C16.6, C16.8, C16.9
Oesophagus unknown	C15.8, C15.9

HPB dataset

Group_1 (5-way split)	ICD10
Liver excl Intrahepatic bile duct	C22.0, C22.2, C22.3, C22.4, C22.7, C22.9
Intrahepatic bile duct	C22.1
Gallbladder	C23
Bile duct, Biliary tract	C24.0, C24.8, C24.9
Ampulla of Vater	C24.1
Pancreas	C25 (all)

Site Specific Items – ‘O-G’

“Must have’s”

- ASA Grade
- Surgical access
 - Thoracic, abdominal
- Nodal dissection
- Surgical complications
- Return to theatre
- Post operative tumour site
- Margins Involved
 - Proximal, distal, circumferential

For further discussion

- Endoscopic palliative therapy
 - Type, stent type, consultant/org code, date, complications
- Urgency of surgery
- Lung functions
 - Fev %, fvc%
- Feeding adjunct
- Other organ removed
- Reason for palliative treatment
- QOL
 - Hosp participating in QOL studies
 - Eligible, enrolled
 - Patient satisfaction studies
 - Eligible, enrolled

Site Specific Items – ‘HPB’



“Must have’s”

For further discussion

Still under discussion

Useful links



NHS IC project website (containing project summary info)

<http://www.ic.nhs.uk/services/datasets/dataset-list/cancer>

Contact us; Any questions please email

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Or call

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Using information to improve quality & choice

