The National Cancer Dataset Initiative

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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*

•*Identification of cases if no histopathology*

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

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

Using information to improve quality & choice

RCPath Datasets

- 46 RCPath Datasets
- NCIN/RCPath Partnership
- Mandate all CORE items
- Move towards electronic real-time proforma based reporting
- Coded data extracts to local registry
  - Working with CfH/Catalogue Project

NCIN Cancer Repository Data Views

Patient Pathway

Datasets/Sources	Referral	Diag	Rx	Rec/Mets	Rx	Pall. Care	Death
Pathology/ Radiology		■		■			
CWT	■		■	■	■	■	
MDTs	■	■	■	■	■	■	■
HES		■	■	■	■		
RTDS			■	■	■		
NCASP		■	■	■	■		■
Total = Ca. Reg	■	■	■	■	■	■	■

Using information to improve quality & choice

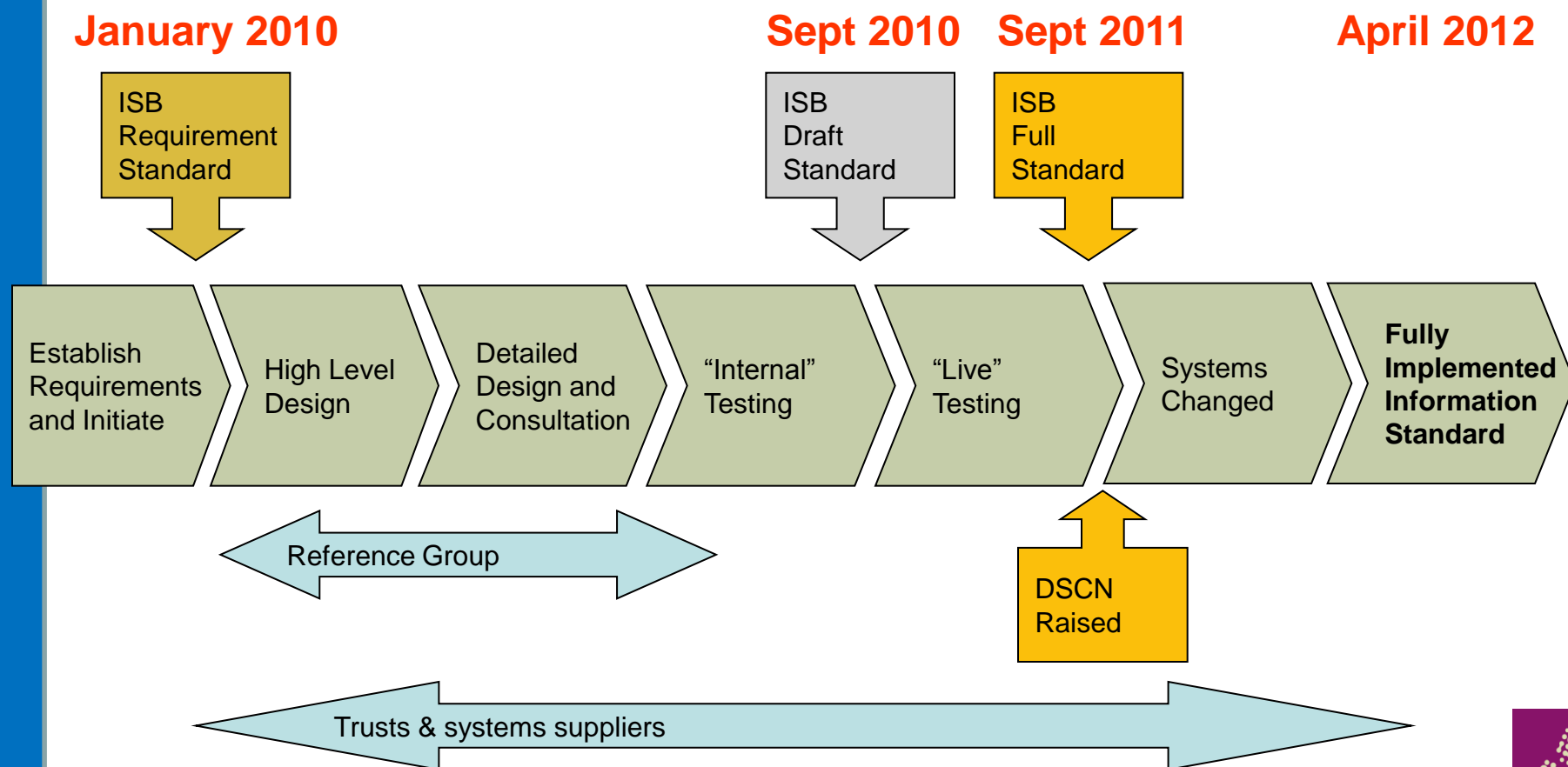| Type of Data	Source of Data
Demographics	Multiple
Referrals	MDTs & Cancer Waits
Diagnosis	RCPath, RIS & other multiple
Cancer Care Plan	MDTs
Staging	MDT, RCPath, RIS, other
Surgery and Other Procedures	PAS/HES
Pathology Details	RCPath – pathology
Chemotherapy and other drugs	Chemotherapy dataset - e-prescribing
Radiotherapy (Teletherapy)	Radiotherapy dataset - V&R machines
Radiotherapy (Brachytherapy)	??? PAS
Palliative Care	MDTs & Cancer Waits
Death Details	ONS

Challenges - 1

- Clinical data from MDTs – local & specialist?
- 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**

Process overview

January 2010   **Sept 2010**   **Sept 2011**   **April 2012**

ISB Requirement Standard

ISB Draft Standard

ISB Full Standard

| Establish Requirements and Initiate | High Level Design | Detailed Design and Consultation | "Internal" Testing | "Live" Testing | Systems Changed | **Fully Implemented Information Standard** |

Reference Group

DSCN Raised

Trusts & systems suppliers