The National Cancer Dataset Initiative Colorectal SSCRG

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CRS, December 2007

.....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

CRS, December 2007

.....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

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

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

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

Datasets/Sources

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

Using information to improve quality & choice

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**

Site Specific Items – Colorectal

Diagnostic Route
Date of CT Scan
Date of FIRST MRI Scan
Date of SECOND MRI Scan
Date of Endoanal Ultrasound
Date of Adbominal Ultrasound
SYNCHRONOUS_SITES
HEIGHT_ABOVE_ANAL_VERGE
MODIFIED_DUKES
Surgical Access
POSITIVITY_CUT_COLON_OR_RECTUM
CIRCUMFERENTIAL_MARGINS
DISTANCE_TO_CIRCUM_MARGIN
PERF_OR_SEROSAL_INVOLVEMENT
DIST_LOWENDTUM_TO_RESMARGIN
DIST_LOWENDCAN_TO_DENTLINE

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Suggestions to 'Generic' Core

- Smoking Status
  - Year stopped smoking
  - Estimated pack years
- Alcohol Status
- Co-morbidity
- BMI – or components
- Roles of CNS [LUCADA]
- Equalities items
- NAEDI items

CNS Related Items

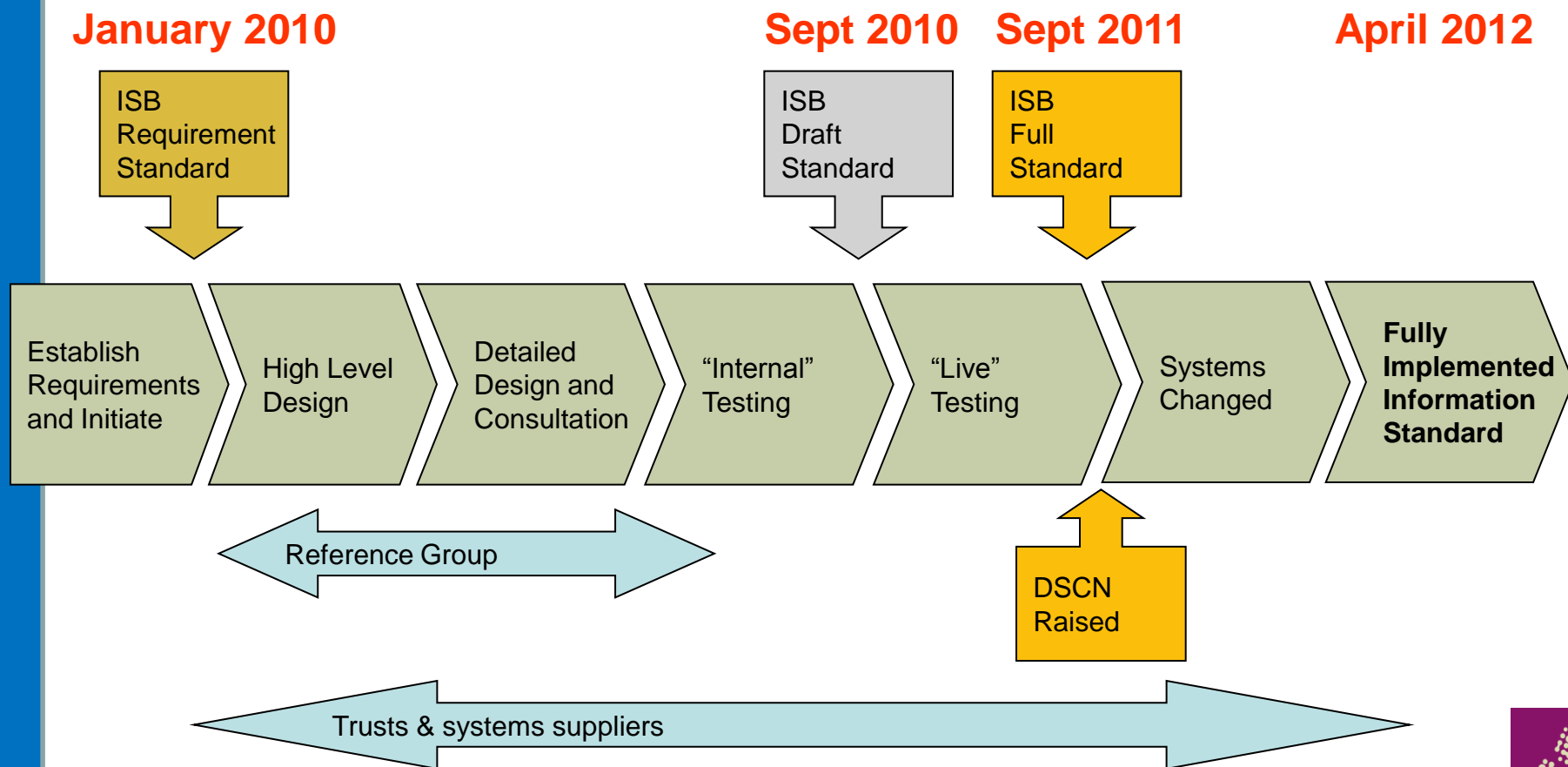| |
|---|
| PATIENT ASSESSED BY LUNG CANCER NURSE SPECIALIST |
| DATE FIRST ASSESSMENT BY LUNG CANCER NURSE SPECIALIST |
| HOW WAS PATIENT FIRST ASSESSED BY LUNG CANCER NURSE SPECIALIST |
| AT WHAT STAGE(S) IN THE PATIENT JOURNEY WAS THE PATIENT ASSESSED BY THE LUNG CANCER NURSE SPECIALIST |
| LUNG CANCER NURSE SPECIALIST PRESENT WHEN THE PATIENT RECEIVED THEIR DIAGNOSIS |

Process overview

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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