

# The National Cancer Dataset Initiative

## Breast 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:*

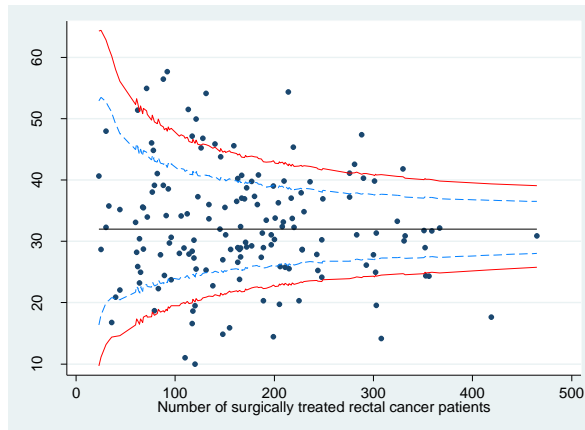
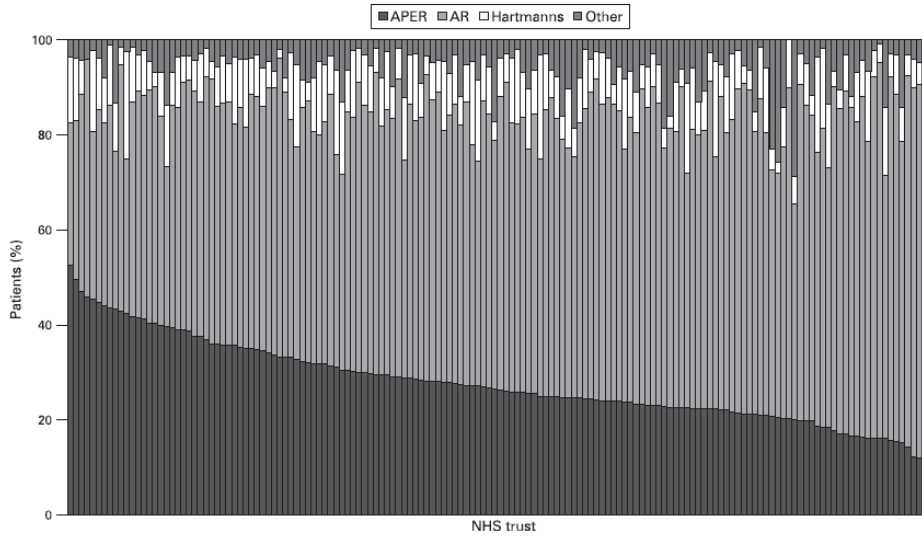
*.....Clinical outcomes, including survival, with adjustments for co-morbidity and stage of disease.*

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*

# Unacceptable variation in abdominoperineal excision rates for rectal cancer: time to intervene?

E Morris,<sup>1,2</sup> P Quirke,<sup>2</sup> J D Thomas,<sup>1,2</sup> L Fairley,<sup>4</sup> B Cottier,<sup>3</sup> D Forman<sup>1,4</sup>



# 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
- *To reduce burden of data capture by linking existing NHS data sources centrally*
  - *If data exist e.g. in path. system no need to collect twice*

# 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

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

# 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 – Breast

**Best practice diagnostic guidelines for patients presenting with breast symptoms:**

<b>Section: Diagnosis and imaging</b>
Date of breast clinical/physical examination
Hospital of breast clinical/physical examination
Result of breast clinical/physical examination
Date of breast imaging mammography
Hospital of breast imaging mammography
Result of breast imaging mammography
Date of ultrasound of the breast
Hospital of ultrasound of the breast
Results of ultrasound of the breast
Date of ultrasound of the axilla
Hospital of ultrasound of the axilla
Results of ultrasound of the axilla

# Site Specific Items – Colorectal

<b>Section : Pathology</b>
Date breast FNAC sample taken
Hospital of breast FNAC
Pathologist reporting breast FNAC
Results of breast cytology fine needle aspiration cytology (FNAC)
Date breast core biopsy taken
Hospital of breast core biopsy
Pathologist reporting breast core biopsy
Results of breast core biopsy

# 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

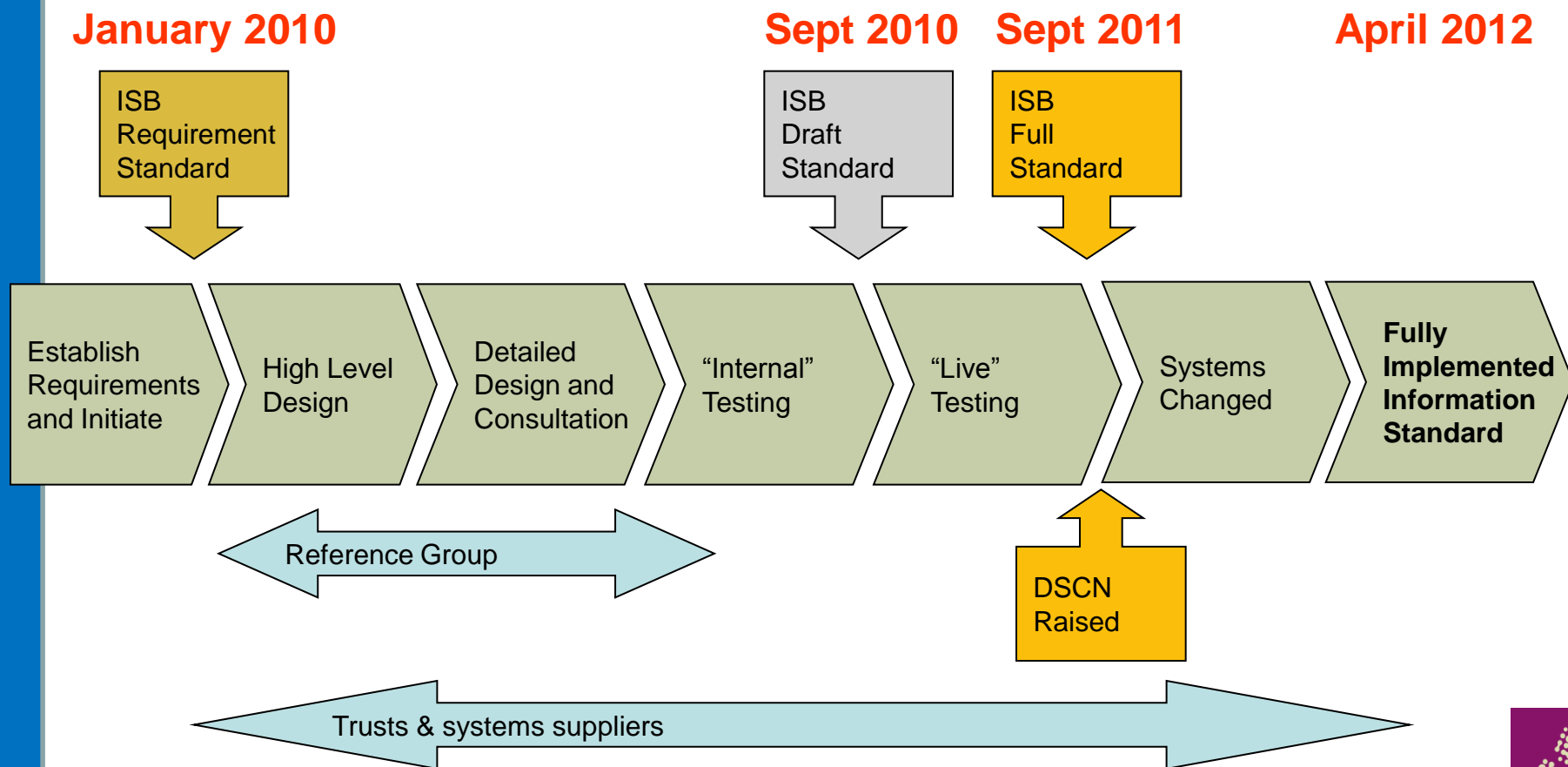
DATE FIRST ASSESSMENT BY LUNG CANCER  
NURSE SPECIALIST

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



# In Summary

- Identify key data items for:
  - Audit & outcomes analysis
- Collect once & ‘recycle’
  - If in NHS system no need to enter somewhere else!
  - Central linkage by cancer registries
  - Mandate through Information Standards Board
  - WMCIU Lead Registry
- Rapid/flexible update process

NCIN



national cancer  
intelligence network

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*Using information to improve quality & choice*

*Thank you*

[www.ncin.org.uk](http://www.ncin.org.uk)



NCRI  
National  
Cancer  
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