

# The National Cancer Dataset Initiative

## Sarcoma 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

# 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



# Core Items

## Appendix E

Surname .....  
Hospital .....  
Date of request .....  
Pathologist .....

### Clinical information

Site of tumour .....

Depth from surface:                      Cutaneous                       Subcutaneous                       Fascial/subfascial

Not known

### Pathological information

Maximum tumour dimension: ..... mm

Histological type (and subtype): .....

Grade (FNCLCC):                      1                       2                       3

Tissue planes involved (indicate all planes):

Cutaneous                       Subcutaneous                       Deep fascia                       Subfascial

Not known

Status of margins

Distance to nearest margin ..... mm

Type of tissue at margin .....

Cytogenetic and molecular genetic data (for small round cell tumours):  
.....

SNOMED Codes:                      T.....                      M.....

Pathologist: .....

Date: .....

# Non-core Items

	To record the presence of unequivocal tumour in vascular spaces.	non core
<b>Lympho-vascular invasion:</b>		
<b>Nerve Invasion</b>		non core
<b>Duration of lesion</b>		non core
<b>Previous surgery</b>		non core
<b>previous irradiation or chemotherapy</b>		non core
<b>consistency - presence of cysts, calcification</b>		non core
<b>Colour</b>		non core
<b>bone invasion</b>		non core
<b>Immunohistochemistry (including Ki67 index)</b>		non core
<b>Cytogenic and molecular genetic data (non core expect for small round cell tumours)</b>		non core

# 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 – Sarcoma

DEMOGRAPHICS		
<b>C1</b>	Surname 1.5 PATIENT FAMILY OR SURNAME	NCDS
<b>C2</b>	Forename 1.6 PATIENT FORENAME OR PERSONAL NAME	NCDS
<b>C3</b>	NHS Number 1.1 NHS Number	NCDS
<b>C4</b>	Date of Birth 1.10 BIRTH DATE	NCDS
<b>C5</b>	Address 1.7 PATIENT USUAL ADDRESS (AT DIAGNOSIS)	NCDS
<b>C6</b>	Postcode 1.8 POSTCODE OF USUAL ADDRESS (AT DIAGNOSIS)	NCDS
<b>C7</b>	Gender 1.9 SEX	NCDS
PRE-OPERATIVE		
<b>C8</b>	Date of Referral 2.5 CANCER REFERRAL DECISION DATE	CWT
<b>C9</b>	Referral Centre 1.3 ORGANISATION CODE [CODE OF PROVIDER]	CWT
<b>C10</b>	Source of Referral 2.16 SOURCE OF REFERRAL FOR OUT-PATIENTS	CWT
<b>C11</b>	Specialty of Referrer 2.3 REFERRER CODE	CWT
<b>C12</b>	Imaging Modality 3.3 CANCER IMAGING MODALITY	NCDS - Sarcoma specific codes
<b>C13</b>	Date of Diagnosis 4.1 DIAGNOSIS DATE [CANCER]	NCDS
<b>C14</b>	Tumour Site SA.1 SARCOMA TUMOUR SITE	SA.1 Sarcoma CDS
<b>C15</b>	Anatomical Site Examined 3.4 ANATOMICAL SITE EXAMINED (OPCS4)	NCDS - Sarcoma specific codes
<b>C16</b>	Primary Site 4.2 PRIMARY DIAGNOSIS (ICD)	NCDS - Sarcoma specific codes

SURGICAL TREATMENT		
<b>C30</b>	Hospital of Surgical Treatment 7.1 SITE CODE (OF SURGERY)	NCDS
<b>C31</b>	Surgeon 7.2 CONSULTANT CODE	NCDS
<b>C32</b>	Date of Surgery 7.9 PROCEDURE DATE	NCDS
<b>C33</b>	Main Surgical Procedure 7.10 PRIMARY PROCEDURE (OPCS)	NCDS
<b>C34</b>	Surgical Sub-procedure(s) 7.11 PROCEDURE (OPCS)	NCDS
<b>C35</b>	Morbidity 14.8 MORBIDITY CODE (CANCER SURGERY) (ICD-10)	NCDS

# Site Specific Items – Sarcoma

POST-OPERATIVE		
<b>C36</b>	Hospital of Radiotherapy Treatment 10.1 SITE CODE (OF TELETHERAPY)	RTDS
<b>C37</b>	Oncologist 10.2 CONSULTANT CODE	RTDS
<b>C38</b>	Radiotherapy Start Date 10.8 START DATE (OF TELETHERAPY)	RTDS
<b>C39</b>	Radiotherapy Dose 10.13 RADIOTHERAPY ACTUAL DOSE	RTDS
<b>C40</b>	Radiotherapy Field 10.18 TELETHERAPY FIELDS	RTDS
<b>C41</b>	Hospital of Chemotherapy Treatment 10.1 SITE CODE (OF CHEMOTHERAPY)	CTDS
<b>C42</b>	Oncologist 9.2 CONSULTANT CODE	CTDS
<b>C43</b>	Chemotherapy Start Date 9.10 START DATE (ANTI-CANCER DRUG REGIMEN)	CTDS
<b>C44</b>	Drug Treatment 9.9 DRUG REGIMEN ACRONYM (CANCER) EUROEWING	CTDS - Sarcoma specific codes



# Site Specific Items – Sarcoma

FOLLOW UP		
<b>C45</b>	Date of Diagnosis of Locally Recurrent Disease	CWT
<b>C46</b>	Date of Diagnosis of Metastases	CWT
<b>C47</b>	Date of Death 15.1 DEATH DATE	NCDS
<b>C48</b>	Cause of Death 15.7 DEATH CAUSE CODE [underlying]	NCDS

# 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

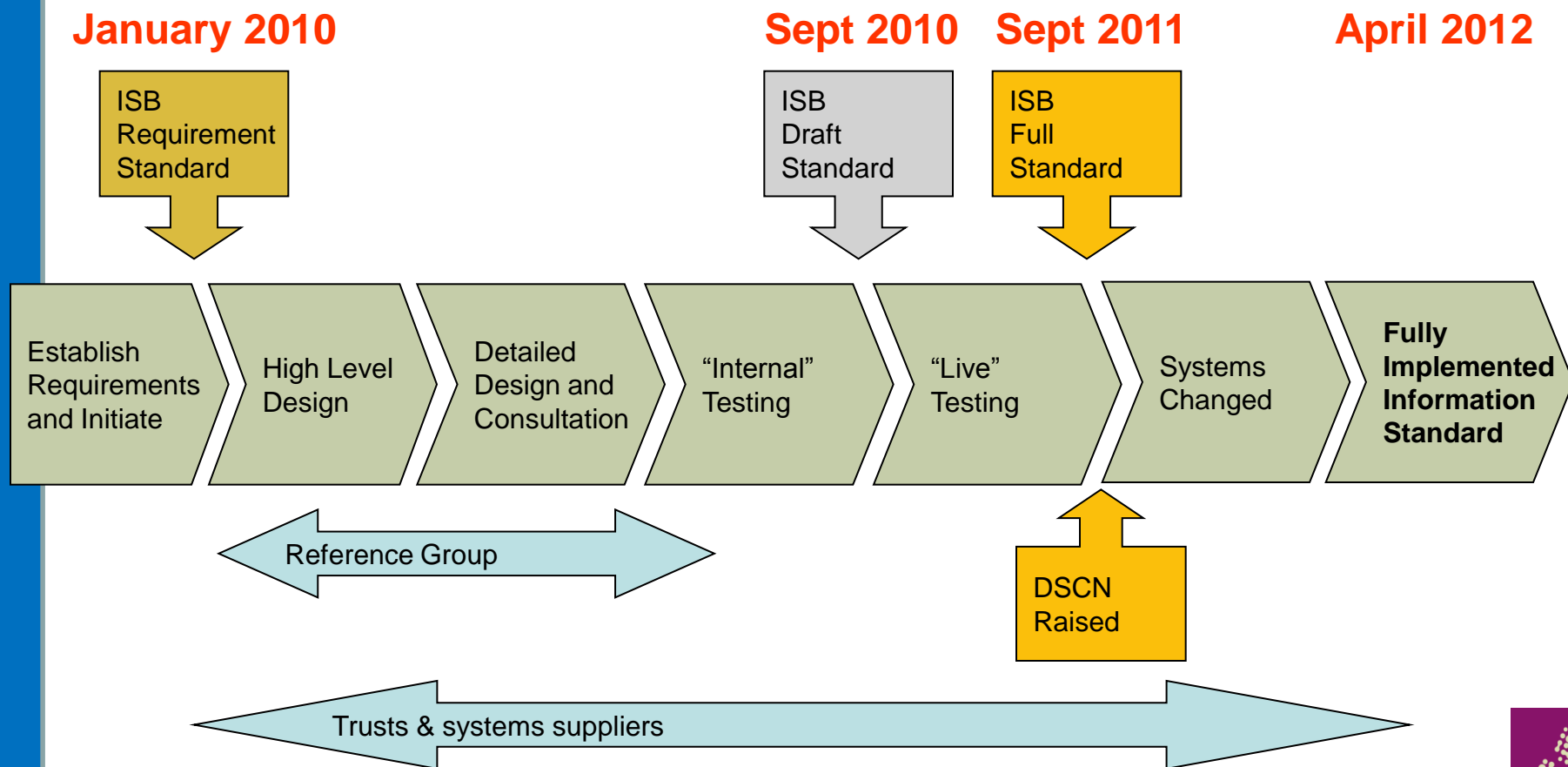
DATE FIRST ASSESSMENT BY LUNG CANCER  
NURSE SPECIALIST

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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Or call

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