

# The National Cancer Dataset Initiative

## Skin 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:*

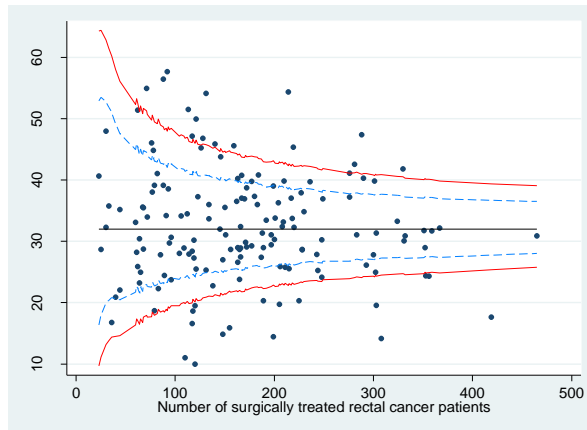
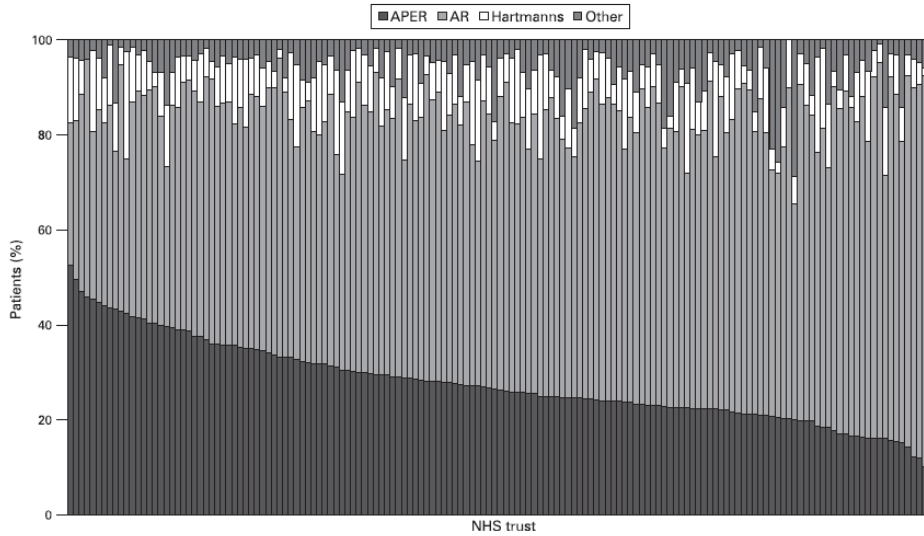
*.....Clinical outcomes, including survival, with adjustments for co-morbidity and stage of disease.*

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>




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### Rectal surgeons using 'wrong op'

**Claims that many rectal cancer patients receive an "inappropriate" operation have been rejected by surgeons.**

Leeds University researchers said hospital data showed the APE operation, which leaves patients with a permanent colostomy, was being used too often.

Surgery can leave a patient needing a colostomy

SEE ALSO

- Why is the UK lagging on cancer? 21 Aug 07 | Health
- Fat hormone 'boosts colon cancer' 07 Apr 07 | Health
- Trial slashes bowel cancer risk 09 Oct 06 | Health

RELATED INTERNET LINKS

- Gut
- Association of Coloproctology of Great Britain and Ireland
- Cancer Research UK

TOP HEALTH STORIES

- Birth defect test guru knighted
- Shirdj cracks amnesia attack tactic

What this does is serve

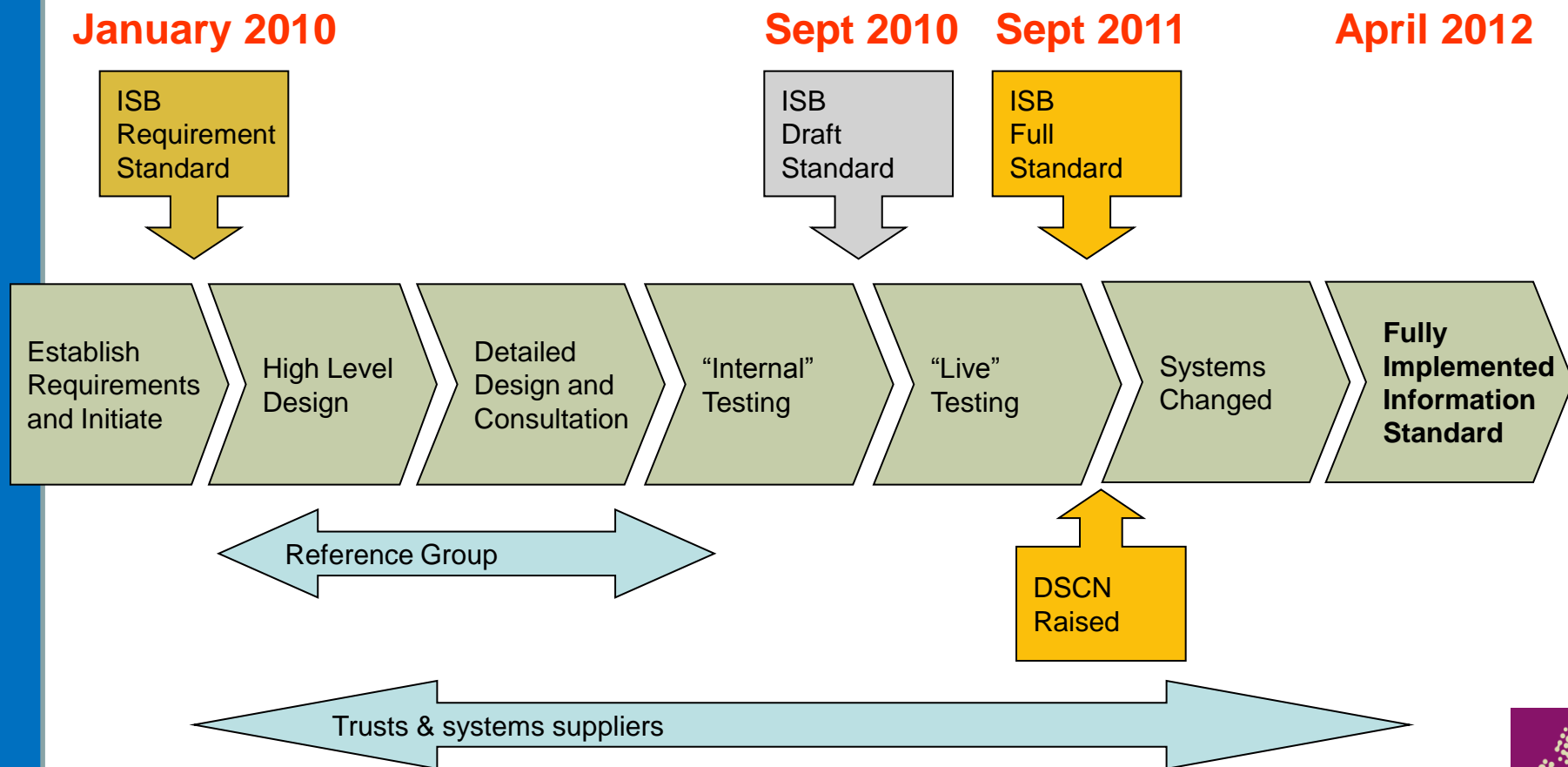
# Project Purpose

- 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

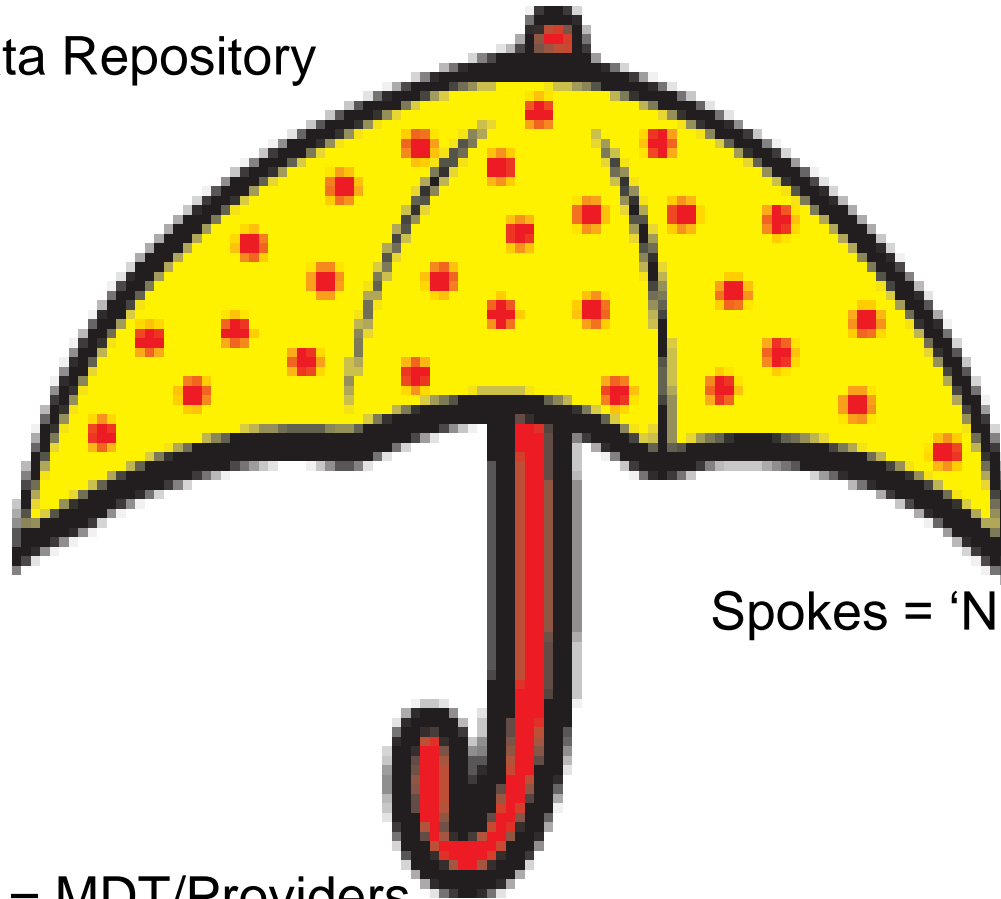
**Datasets/Sources**

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

*Using information to improve quality & choice*



Cover\*\* = Data Repository



Spokes = 'NHS' Data Flows

Handle = MDT/Providers

Type of Data	Source of Data
<b>Demographics</b>	Multiple
<b>Referrals</b>	MDTs & Cancer Waits
<b>Diagnosis</b>	RCPATH & other multiple
<b>Cancer Care Plan</b>	MDTs
<b>Staging</b>	MDT, RCPATH, RIS, other
<b>Surgery and Other Procedures</b>	PAS
<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

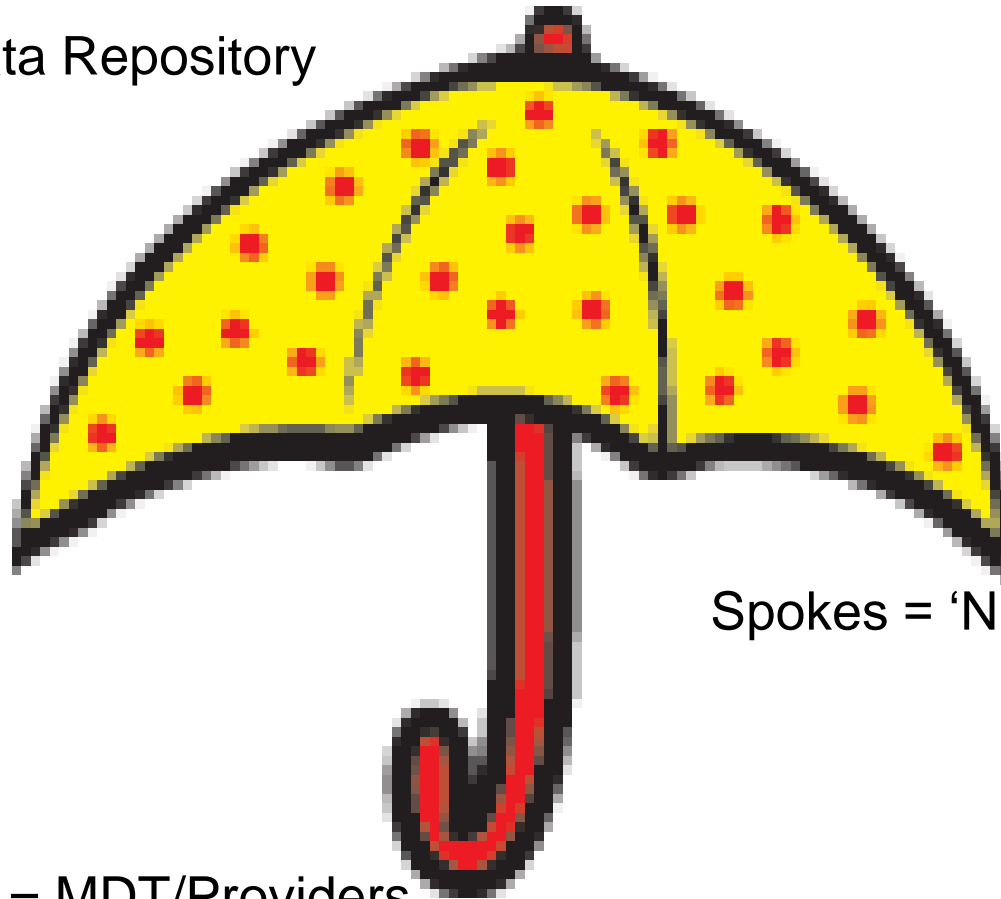
- Identifying 'business requirements'
- Future-proofing
- Adequate time for consultation & debate
- Specific issues – co-morbidity
- Impact on the service
- Promoting project to service

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

# Suggestions to 'Generic' Core

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

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# 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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