The National Cancer Dataset Initiative

Haematology SSCRG

2010 UPDATE

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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

(New) NHS Priorities

- patients at the heart of everything we do
- **focus on improving outcomes for patients – not inputs or processes, but results.**
- **empower clinicians to deliver improvements.**
- prioritise prevention and create a public health service.
- closer integration in how services are commissioned and provided.
- cutting bureaucracy and improving efficiency

Using information to improve quality & choice

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 identified 'site specific' items
    - Link to 'output' requirements
    - Preliminary consultation with CN TSSGs lead clinicians – late 2009/2010

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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
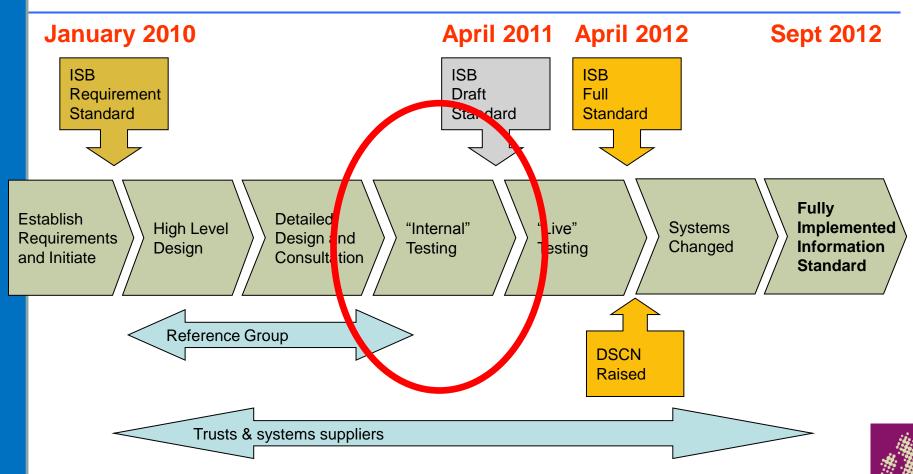 - Specific to cancer type/site e.g. Hasenclever index for Hodgkins Lymphoma

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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	🟥	🟥	🟥	🟥	🟥	🟥	🟥

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Process overview

Site Specific Items – Haem

Find the missing cases?

Better reporting of ICD03 & receipt of lab results by registries?

Role of MDTs and clinical teams

Diagnosis Group	Data item	Result
AML	WBC	Number
	Cytogenetics group	Favourable/Adverse/Intermediate
ALL	WBC	Number
CML	Spleen	cm below costal margin
	Platelets	Number
	Blood Myeloblasts	%
	Blood Basophils	%
	Blood Eosinophils	%
	Hasford score	Calculated
	Sokol score	Calculated

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Diagnosis Group	Data item	Result
CLL	Hepatomegaly	Yes No
	Splenomegaly	Yes No
	Lymphadenopathy	Number of enlarged areas
	Hb	Number
	Platelets	Number
	Binet	Derived
	Rai	Derived
MDS	Hb	Number
	Platelets	Number
	Neutrophils	Number
	Marrow blasts	%
	Karyotype	Good/Intermediate/Poor
	IPSS index	Derived

Diagnosis Group	Data item	Result
Myeloma	Albumin	Number
	Beta 2 microglobulin	Number
	ISS Stage	Derived
NHL Follicular	Ann Arbor stage	1 2 3 4
	Ann Arbor symptoms	A B
	Ann Arbor extranodality	Yes No
	Ann Arbor Bulk	Yes No
	Nodal areas	Number
	Primary Extranodal Site	Site (from code list provided)
	Hb	Number
	LDH	Number
	FLIPI	Derived

Diagnosis Group	Data item	Result
NHL Diffuse Large B Cell	Ann Arbor stage	1 2 3 4
	Ann Arbor symptoms	A B
	Ann Arbor extranodality	Yes No
	Ann Arbor Bulk	Yes No
	Extranodal sites	Number
	Primary Extranodal Site	Site (from code list provided)
	LDH	Number
	(R)IPI	Derived

Diagnosis Group	Data item	Result
NHL Malt, Mantle, some others	Ann Arbor stage	1 2 3 4
	Ann Arbor symptoms	A B
	Ann Arbor extranodality	Yes No
	Ann Arbor Bulk	Yes No
	Primary Extranodal Site	Site (from code list provided)
	LDH	Number

Diagnosis	Data Item	Result
Hodgkins	Ann Arbor stage	1 2 3 4
	Ann Arbor symptoms	A B
	Ann Arbor extranodality	Yes No
	Ann Arbor Bulk	Yes No
	Primary Extranodal Site	Site (from code list provided)
	Hb	Number
	Albumin	Number
	WBC	Number
	Lymphocytes	Number
	Hasenclever index	Derived

Data Capture

- Many items in haem path labs
  - Difficult to access
- Are items part of MDT discussion?
  - Capture at time of MDT
  - Transfer to regional registry

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**