The National Cancer Dataset Initiative

CTYA 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*

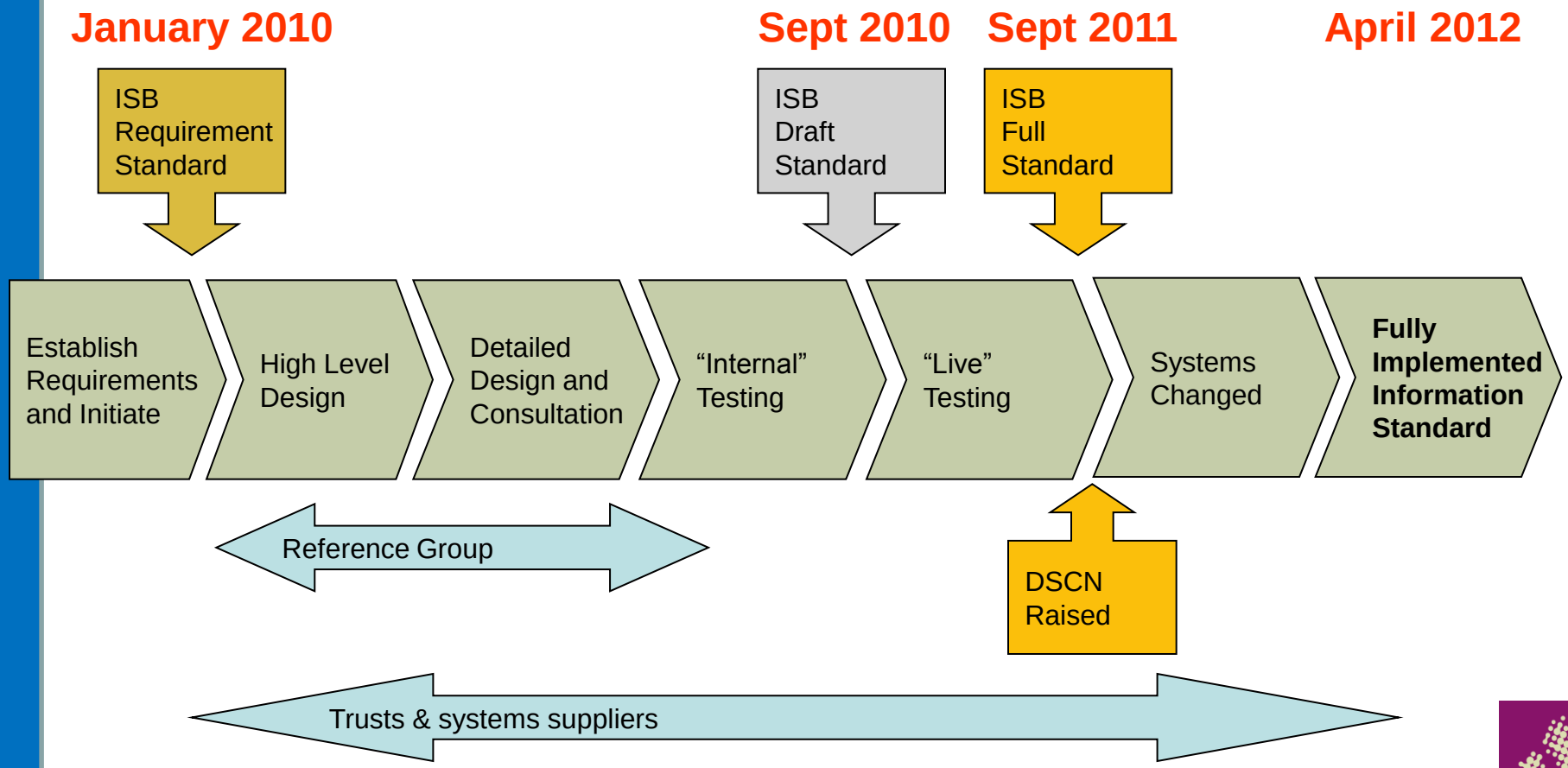
Project Purpose

- 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
- *To ensure covers all age ranges and patient types, but recognise the differences and similarities in data & processes*

SSCRG progress

- Approved mandated datasets
  - Cancer registration – additional review
  - GFoCW
  - Radiotherapy
  - Commissioning Datasets
  - (other existing datasets – CCLG, CYP v5.8)
- 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 – *ICDO*
  - Staging e.g. TMN, Dukes, FIGO, or *INSS, Murphy*
- 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. *Bone marrow/stem cell transplantation*

NCIN Cancer Repository Data Views

Patient Pathway

Datasets/Sources

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

Using information to improve quality & choice

Type of Data	Source of Data
Demographics	Multiple
Referrals	MDTs & Cancer Waits
Diagnosis	RCPath & other multiple
Cancer Care Plan	MDTs
Staging	MDT, RCPAth, RIS, other
Surgery and Other Procedures	PAS
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

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 – *for this age group*
- Impact on the service
- Promoting project to service

Site Specific Items – 'MUST HAVE'

CTYA additional data items	Notes
COUNTRY CODE	We do think that the identification of patients who reside outside UK at the time of diagnosis is important - this may be revealed by an allocated overseas postcodein the 'Usual Address (At Diagnosis) field but a text field will ensure this is collected if it is not the UK
PRIMARY DIAGNOSIS (TEXT)	There should be a text field for a standard description of the diagnosis (e.g. Wilms' tumour, Hodgkin's Disease) both because this makes sense to clinicians and is the language used to describe a patient's diagnosis, but also because this may assist in the small number of cases where coding is difficult or imprecise. This will be supplemented by record of the ICD-O T and M codes elsewher in this section. The text diagnosis shuld include a description of any major subtype of the principal diagnosis e.g. alveolar rhabdomyosarcoma; nodular lymphocyte predominant Hodgkin's disease
OTHER DIAGNOSIS IN THE PATIENT (TEXT)	The recording of 'Other diagnosis' in the patient is important - originally we thought that this might be the same as 'Co-Morbidity' but think this may no longer be the case. Examples of what might be included in this field are Down's Syndrome, NF1, Fanconi etc.
TYPE OF MDT	We wish to ensure that discussions at all MDTs are recorded, specifically if aTYA patient was discussed *both* at a site specific MDT *and* at a TYA MDT
STAGE	Staging is diagnosis specific for paediatric cancers although some tumours (notably leukaemia and most CNS tumours) do not have staging systems. For typical paediatric solid tumours, there are well described tumour specific staging systems. These have been identified in the previous work looking at individual diagnoses. In this context we need a data item which collects stage, where relevant, (e.g. I, II, III, IV etc) and a separate data item which names the system used (e.g. INSS, Murphy)
STAGING SYSTEM	
CUMULATIVE CHEMOTHERAPY EXPOSURE	It is critically important that the dataset mandates a summary of all chemotherapy exposure at the end of treatment. This should include a list of all drugs to which the patient was exposed and, for a selected number of drugs, what the cumulative dose exposure was. The definition of this selected group of drugs requires agreement
BONE MARROW / STEM CELL TRANSPLANTATION	Although the chemo radiotherapy incorporated in the conditioning for BMT will be collected under the chemotherapy and radiation therapy sections, there must be a field which documents the use of stem cell transplantation. Is this already included in the data set?
CLINICAL TRIAL IDENTIFIER	The details of the trial(s) into which the patient has ben entered should be collected at MDT. We will need to agree in what form this is done (coding system) - one already exists for current CCLG trials but the planned relocation of the portfolio will bring changes. Does NCRI have a system?
OVERALL DISEASE STATUS	We have previously indicated that it would be sufficient to have a single overall assessment of disease using the simplified coding system identified within the CTYA Data manual v5.8

Site Specific Items – 'NICE TO HAVE'

CTYA additional data items	Notes
PART OF A MULTIPLE BIRTH	This information may be of direct clinical value and is usually available. The response should record Yes / No.
GENDER OF EACH OTHER CHILD IN A MULTIPLE BIRTH (REPEATING FIELD TO A MAXIMUM OF 4)	Record Male / Female
REFERRER SPECIALITY CODE	The route by which patients are referred, and by whom, is of relevance in understanding referral pathways, particularly for certain groups of patients (e.g. all TYA, CNS tumours, sarcoma)
CONSULTANT SUB SPECIALITY CODE	It is important to recognise that main speciality code may not provide sufficient information about the treating consultant (e.g. Haematology may include both paediatric and adult haematologists) . There is a TYA coding list which separates out the principal sub codes of relevance to this patient group
DATE OF FIRST SYMPTOMS RELATING TO THIS DIAGNOSIS	This date may be approximate but is generally available from clinical history. This is critically important in understanding the referral pathway and the timing of delay in diagnosis
DATE FIRST SEEN FOR THOSE SYMPTOMS	This date may be approximate but is generally available from clinical history. This is critically important in understanding the referral pathway and the timing of delay in diagnosis
BY WHOM FIRST SEEN FOR THOSE SYMPTOMS	A simple coding system is required for this data item - alternatives include: GP, Community Health Serrvices; A&E department; Secondary care clinician: Tertiary care clinician etc. This information ought to be available from the clinical history or referral letter
OTHER DIAGNOSIS IN THE PATIENT (CODE)	At some point we may need to create a coding system and a drop down list which offers a number of more important alternatives would be useful. The RCPCH extension to ICD-10 (or a development thereof) may be suitable

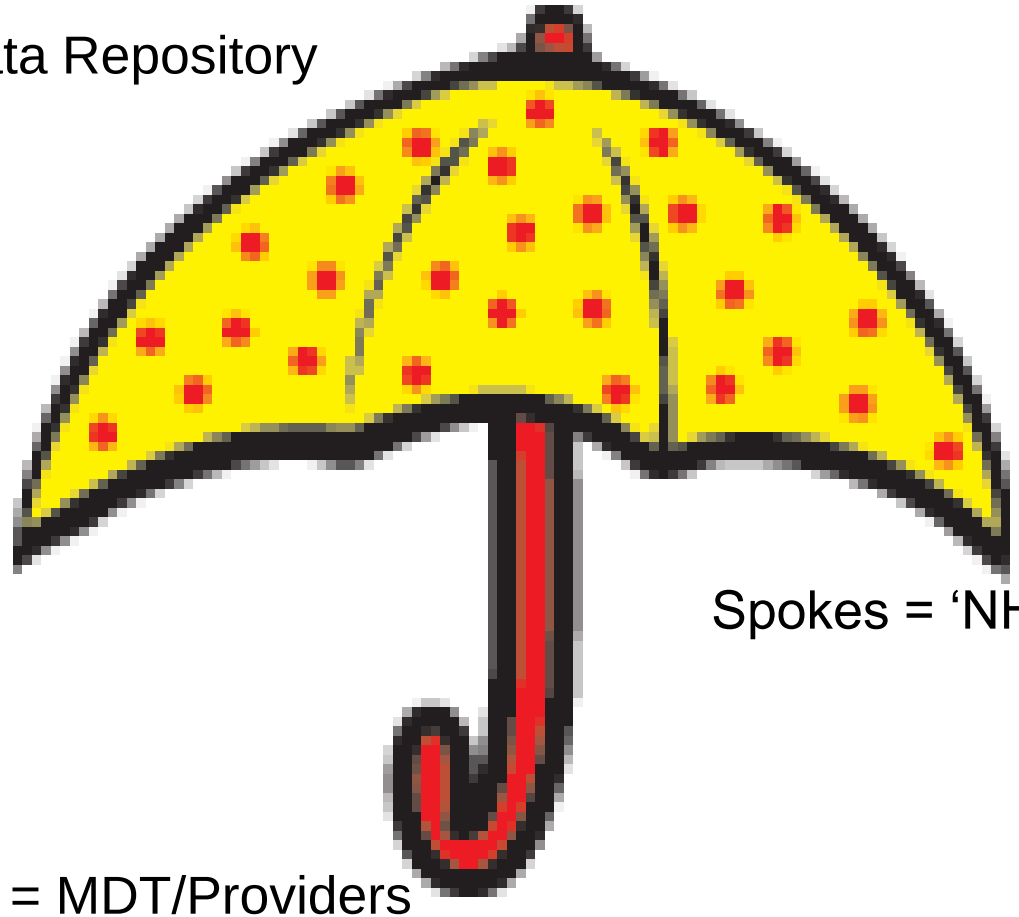
Site Specific Items – 'NICE TO HAVE'

CTYA additional data items	Notes
PRESENCE OF A CONFIRMED OR POSSIBLE FAMILIAL CANCER SYNDROME	Instructions and efinitions for this are currently provided for the TYAC registration form. The coding for this should distinguish beteween confirmed or possible diagnosis.
RELATIONSHIP OF PERSON TO THE PATIENT	
C0-MORBIDITY	We had previously suggested that co morbidity was either not applicable or defined differently for children but we now feel that we need to explore this further. For the time being, the data item should remain but further work is needed towards an appropriate understanding of its definition and value
SPECIALITY SUB CODE	We think it would be helpful to be able to identify that the consultant giving chemotherapy, if not an oncologist, is identifiable as a shared care consultant in a designated paediatric of TYA shared care unit
LONG TERM SEQUELAE	The core dataset identifies a series of dat items relating to treatment morbidity. This is important for CTYA but it is possible that the information could and should be collected in a different way. This needs to be discussed with the NHS CTYA Survivorship group but for the time being we should propose the collection of a series of data items relating to end of treatment assessments of important aspects of possible long term toxicity and to the recognition of proven late effects of therapy
END OF TREATMENT TOXICITY ASSESSMENT	This will need to be a repeating field and collect information about end of treatment measurement of, for example, cardiac, renal, lung, auditory and endocrine function. There will need also to be a field for 'other'
ESTABLISHED LATE EFFECTS OF THERAPY	A repeating field allowing collection of several data items recording proven late effects of therapy. A coding system may be agreed and implemented. This should not include issues for which the patient is a'at risk' - this type of information forms part of a separate care plan for each patient and can be derived form the treatment exposure detail already collected within the NCDS

Site Specific Items – 'REMOVED'

CTYA additional data items	Notes
CCLG REGISTRY NUMBER	This previously suggested additional data item is now redundant
CCLG CENTRE	This previously suggested additional data item is now redundant
COUNTRY CODE (AT DIAGNOSIS)	This is duplicated by the 'Patient Usual Address (at diagnosis)' (below)
POST TOWN (BIRTH)	This item can be identified from a linked birth record and need not be collected routinely
COUNTRY CODE (BIRTH)	This item can be identified from a linked birth record and need not be collected routinely
PERSON FAMILY NAME	Duplicate
PERSON GIVEN NAME	Duplicate
PERSON NAME CLASSIFICATION	Initially we had intended to collect the name of parents but do not think this is necessary or (for patients age > 18) permissable
PERSON POST TOWN	
OCCUPATION AT CHILD'S BIRTH (bio parent)	This information is incompletely and inaccurately collected - we longer wish to include this
OCCUPATION AT CHILD'S DIAGNOSIS (bio parent)	This information is incompletely and inaccurately collected - we longer wish to include this
CCLG CENTRE REFERRAL REASON	This data item should be replaced bycollection of supplementary items about timing of first symptoms and first consultation for those symptoms
IMAGING ANAESTHESIA	The use of anaesthesia is a major resource issue for young children undergoing imaging but we are not convinced that this merits collection as a separate data item. An alternative (if wished) would be to amend the coding of the modality to show whether or not anaesthesia was used (just as imaging with / without contrast is identified)
HISTOLOGY (ICCC-3 GROUP)	ICCC code can be derived from ICD-O
PRIMARY DIAGNOSIS OF RELATION (ICD)	This item is misplaced here and can be ignored

Cover** = Data Repository



Spokes = ‘NHS’ Data Flows

Handle = MDT/Providers

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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