Cancer Outcomes and Services Dataset

Urology Clinical Leads Workshop
July 2011

Trish Stokes, COSD Programme Manager
Overview

- Multiple datasets
- COSD features
- Multiple collection
- Information Standard
- Can we/do we collect this data?
- Non active treatments
Cancer Datasets
- Sept 2012

- Cancer Registration Dataset – *mandated for several years*
- Going Further on Cancer Waits – Jan 2009
- Radiotherapy – April 2009
- *Chemotherapy (SACT)* – April 2012
- *Cancer Outcomes and Services Dataset* – Autumn 2012
- *(RC Pathology – Professional/Clinical Standards)*
- *(RC Radiology – Professional/Clinical Standards)*
- *National Audits*
COSD features

The new national cancer dataset
Secondary uses – from patient management
Aligned and standardised
Multiple data sources – collect once
Components
  • Core (Registration and Cancer Waits)
  • Site specific (cf nat audit)
  • Key pathology (core RCPPath)

Monthly submission
Monthly feedback
DATAFLOWS FINAL (APRIL 2014) PHASE 3

Procedures / activity uploads
HES extract
Cancer Waits download
Open Exeter
COSD Core and ALL Clinical
COSD Path
N3 Network or other approved transmission medium

HOSPITAL PAS SYSTEM
Cancer Services MDT System
Laboratory system

Acute Trust / Cancer Centre
DATAFLOWS FINAL (APRIL 2014) PHASE 3
Procedures / activity uploads
HES extract
Cancer Waits download
Open Exeter
Cancer Waits Upload
Procedures / activity uploads
N3 Network or other approved transmission medium
HOSPITAL PAS SYSTEM
Cancer Services MDT System
Laboratory system
Radiology System
E prescribing system
Verify and Record
Acute Trust / Cancer Centre

CANCER REGISTRY
NATIONAL REGISTRY DATABASE (COSD DATASET)

KEY
Data store
Fully structured / coded
Data flow
ISB Process – Where are we now?

- Establish Requirements and Initiate
- High Level Design
- Detailed Design and Consultation
- “Internal” Testing
- “Live” Testing
- Systems Changed
- Fully Implemented Information Standard

Timeline:
- January 2010
- Nov 2011
- Spring 2012
- Oct 2012

- ISB Requirement Standard
- ISB Draft Standard
- ISB Full Standard

- ISB Process – Where are we now?
- Trusts & systems suppliers
- Reference Group
- FEB 11 OPEN CONSULTATION
- DSCN Raised

NCIN
Using information to improve quality & choice
Definitional testing – general feedback

Support for

• cohesive and consistent dataset
• clear and comprehensive guides

Concerns

• increased burden of collection
• need for clinical involvement
## Site specific data items

### Kidney
- eGFR
- TUMOUR NECROSIS
- PERINEPHRIC FAT INVASION
- ADRENAL INVASION
- RENAL VEIN INVASION
- GEROTA'S FASCIA INVASION

### Bladder
- HYDRONEPHROSIS
- INTRAVESICAL CHEMOTHERAPY INDICATOR
- INTRAVESICAL IMMUNOTHERAPY INDICATOR
- DETRUSOR MUSCLE PRESENCE INDICATOR

### Testicular
- NORMAL LDH (Testicular only)
- S-CATEGORY (Testicular only)
- S-CATEGORY: AFP (ALPHA FETO-PROTEIN) (Testicular only)
- S-CATEGORY: HCG (HUMAN CHORIONIC GONADOTROPIN)
- S-CATEGORY: LDH (SERUM LACTATE DEHYDROGENASE)

### Prostate
- PSA AT DIAGNOSIS
- PSA (PRE-TREATMENT)
- GLEASON GRADE (PRIMARY)
- GLEASON GRADE (SECONDARY)
- GLEASON GRADE (TERTIARY)
- PERINEURAL INVASION
- ORGAN CONFINED
- SEMINAL VESICLES INVASION
- TURP TUMOUR PERCENTAGE

### Penile
- PATIENT HISTORY INDICATOR (HUMAN_PAPILLOMAVIRUS)
- CORPUS SPONGIOSUM INVASION
- CORPUS CAVERNOSUM INVASION
- URETHRA OR PROSTATE INVASION

### Pelvis, Ureter, Urethra, Urinary Bladder
- TUMOUR GRADE
- RETE TESTES INVASION
A mixed bag - can it be collected?
Site-Specific Pathology Capability Analysis
– Key staging components

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How to differentiate Active monitoring and Watchful Waiting

- Active monitoring and watchful waiting used by Cancer Waits and 18 weeks
- Different meaning from Urology
- Pragmatic approach!
Non active treatments recorded in CWT Oct - Dec 2010

- Sarcoma
- Brain/CNS
- Gynae
- Skin
- Breast
- Head & Neck
- Other
- Lower GI
- Upper GI
- Lung
- Haematology
- Urology

Bar chart showing categories and their respective counts for active monitoring, non-specialist palliative care, and specialist palliative care.
Patients requiring symptomatic support

Specialist Palliative Care:
“palliative care delivered under the management of a consultant in palliative medicine.

Non specialist palliative care:
“palliative care (excl active monitoring) given under the management of a consultant other than a consultant specialising in palliative medicine.”

Patients largely asymptomatic

Active monitoring:
“where a diagnosis has been reached but it is not appropriate to give any active treatment at that point in time but an active treatment is still intended/ may be required at a future date.”
ACTIVE MONITORING
INTENT:

To record the future intention of monitoring the patient. Use for all patients who are largely asymptomatic and may go progress to active treatment if the status of the disease progresses. (This will include “watchful waiting” as used clinically)

01 Patient placed on active monitoring regime with future curative intent
02 Patient placed on active monitoring regime with future palliative intent
03 Patient placed on active monitoring regime with unknown or uncertain future clinical intent
Thank you
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