# Cancer Outcomes and Services Dataset
# An update

Haematology workshop
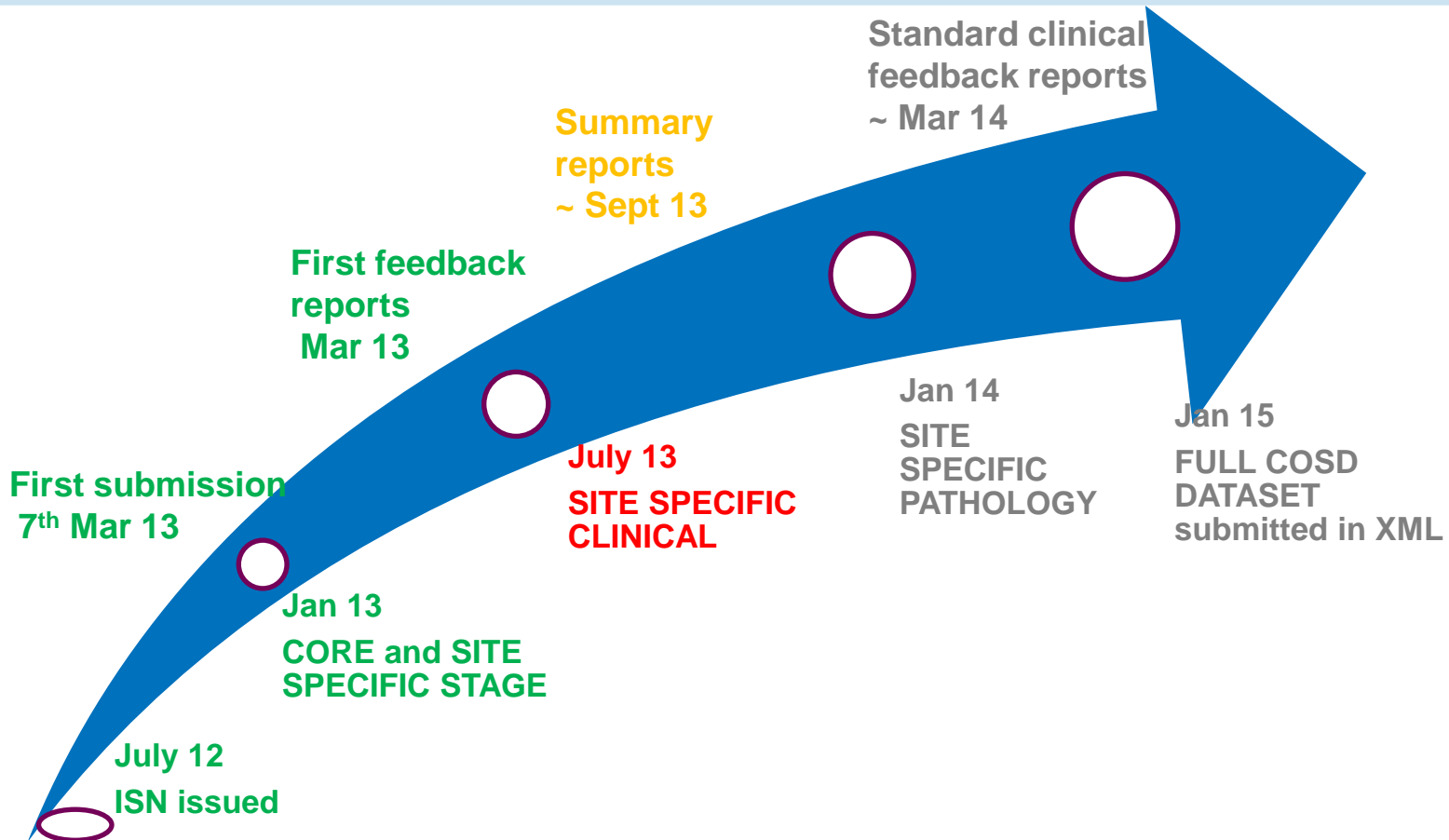
July 2013

Trish Stokes

The National Cancer Intelligence Network will be hosted by Public Health England from 1st April 2013

# A recap - COSD

- New national cancer dataset
- Includes generic and site specific data
- Replaces submission to cancer registries
- Trigger is new diagnosis/updates
- Can be submitted from different sources
- Submitted monthly
- RCPath extracted from reports
- Aligned with national audits
- Monthly feedback

# Timetable



**Standard clinical feedback reports ~ Mar 14**

**Summary reports ~ Sept 13**

**First feedback reports Mar 13**

**First submission 7th Mar 13**

**July 13 SITE SPECIFIC CLINICAL**

**Jan 14 SITE SPECIFIC PATHOLOGY**

**Jan 15 FULL COSD DATASET submitted in XML**

**Jan 13 CORE and SITE SPECIFIC STAGE**

**July 12 ISN issued**

# Core data – from Jan 2013

- Updated generic dataset for whole patient pathway

- Cancer Waits items apply to all cases
    - Referral section
    - METASTATIC SITE (at diagnosis)

- New CORE data items
    - DATE OF DIAGNOSIS (CLINICALLY AGREED)
    - CANCER SYMPTOMS FIRST NOTED DATE (CTYA only)
    - MORPHOLOGY (ICDO3) – Haem only
    - ACE 27 SCORE (Optional)
    - CLINICAL NURSE SPECIALIST
    - TNM EDITION NUMBER
    - MONITORING INTENT (Urology and Lung)

# Key Haematology data – from July 2013 (site specific clinical)

- Disease specific prognostic scoring systems
    - CYTOGENETIC GROUP – AML
    - SOKAL & HASFORD – CML
    - IPSS – MYELODYSPLASIA
    - FLIPI – Follicular Lymphoma
    - (R)IPI – DLBCL
    - HASENCLEVER – Hodgkin stage 3 & 4
- Disease specific stage/prognosis components
    - Eg BLOOD LYMPHOCYTES, ALBUMIN LEVEL, PRIMARY EXTRANODAL SITE etc

# User Guide - coding

| ICD-O-3 | ICD-O-3 WHO Description | ICD-10 (4th Edition) | ICD10 Description | Clinical dataset | WHO DISEASE GROUP |
|---|---|---|---|---|---|
| 9591/3 D | B cell lymphoma, NOS | C85.1 | B-cell lymphoma, unspecified | Other Lymphomas | 9 |
| 9597/3 | Primary cutaneous follicle centre lymphoma | C82.6 | Cutaneous follicle centre lymphoma | Follicular | 9 |
| 9650/3 | Classical Hodgkin lymphoma | C81.9 | Hodgkin lymphoma, unspecified | Hodgkin | 11 |
| 9680/3 | Diffuse large B-cell lymphoma (DLBCL), NOS | C83.3 | Diffuse large B-cell lymphoma | DLBCL | 9 |
| 9729/3 | T lymphoblastic lymphoma | C83.5 | Lymphoblastic (diffuse) lymphoma | ALL | 8 |
| 9731/3 | Solitary plasmacytoma of bone | C90.3 | Solitary plasmacytoma | CORE ONLY | 9 |
| 9732/3 | Plasma cell myeloma | C90.0 | Multiple myeloma | Myeloma | 9 |

# User Guide – data items

## 7.3 HAEMATOLOGY – CLINICAL DATASETS AND APPLICABLE DATA ITEMS

The following table shows which of the site specific data items are applicable to each clinical dataset.

*Note: There are also some core data items which are used to calculate some of the indices, e.g. Age, gender, performance status)*

| Clinical Dataset | | DATA ITEM # | SITE SPECIFIC DATA ITEM |
|---|---|---|---|
| AML | WBC | HA8150 | WHITE BLOOD CELL COUNT (HIGHEST PRE TREATMENT) |
| | Cytogenetics group | HA8160 | CYTOGENETIC GROUP (ACUTE MYELOID LEUKAEMIA) |
| ALL | WBC | HA8150 | WHITE BLOOD CELL COUNT (HIGHEST PRE TREATMENT) |
| | Extramedullary disease | HA8270 | EXTRAMEDULLARY DISEASE |
| CML | Spleen | HA8000 | SPLEEN CM BELOW COSTAL MARGIN |
| | Platelets | HA8030 | PLATELET COUNT |
| | Blood Myeloblasts | HA8040 | BLOOD MYELOBLASTS |
| | Blood Basophils | HA8050 | BLOOD BASOPHILS PERCENTAGE |
| | Blood Eosinophils | HA8060 | BLOOD EOSINOPHILS PERCENTAGE |
| | Hasford score | HA8010 | SOKAL INDEX (CHRONIC MYELOID LEUKAEMIA) |
| | Sokol score | HA8020 | HASFORD INDEX (CHRONIC MYELOID LEUKAEMIA) |

# What will you get back?
**Standard monthly feedback reports**

- By MDT/Tumour group and Provider for month of diagnosis

- Available within **one month** of submission

- Breakdown by:
  - Number of new diagnoses
  - Number of patients treated
  - Basis of diagnosis
  - Stage
  - Performance status completed

# Reporting Portal

| | A | B | C | D | E | F | G | H |
|---|---|---|---|---|---|---|---|---|
| 54 | L2.3d | Breakdown of stage by tumour group and percentage with completed | | | | | | |
| 55 | | stage grouping | | | | | | |
| 56 | | Diagnosed | % Staged | Stage 1 | Stage 2 | Stage 3 | Stage 4 | Other Stage |
| 57 | Brain/Central Nervous System (invasiv | 0 | | 0 | 0 | 0 | 0 | 0 |
| 58 | Breast (invasive) | 11 | 55% | 3 | 2 | 1 | 0 | 0 |
| 59 | Colorectal (invasive) | 13 | 100% | 0 | 5 | 6 | 0 | 2 |
| 60 | Gynaecological (invasive) | 11 | 73% | 0 | 0 | 0 | 0 | 8 |
| 61 | Haematological (invasive) | 19 | 0% | 0 | 0 | 0 | 0 | 0 |
| 62 | Head and Neck (invasive) | 8 | 88% | 1 | 2 | 0 | 4 | 0 |
| 63 | Lung (invasive) | 20 | 90% | 0 | 0 | 0 | 0 | 18 |
| 64 | Sarcoma (invasive) | 0 | | 0 | 0 | 0 | 0 | 0 |
| 65 | Skin (invasive) | 0 | | 0 | 0 | 0 | 0 | 0 |
| 66 | Upper Gastrointestinal (invasive) | 10 | 30% | 0 | 0 | 1 | 2 | 0 |
| 67 | Urological (invasive) | 78 | 55% | 10 | 8 | 6 | 2 | 17 |
| 68 | Other (invasive) | 4 | 25% | 1 | 0 | 0 | 0 | 0 |
| 69 | L2.3e | Percentage with Performance Status field populated | | | | | | |
| 70 | Number diagnosed (from L2.3a) | 224 | | | | | | |
| 71 | Number with Performance Status | 204 | | | | | | |
| 72 | % with Performance Status | 91% | | | | | | |
| 73 | L2.3f | Breakdown of basis of diagnosis by tumour group | | | | | | |
| 74 | | Clinical Diagnosis | Clinical Invest. | Specific Tumour Marker | Cytology | Histology (Metastasis) | Histology (Primary) | Unknown |
| 75 | Brain/Central Nervous System (invasiv | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 76 | Breast (invasive) | 0 | 0 | 0 | 1 | 0 | 10 | 0 |
| 77 | Colorectal (invasive) | 0 | 0 | 0 | 0 | 0 | 13 | 0 |
| 78 | Gynaecological (invasive) | 0 | 0 | 0 | 0 | 0 | 11 | 0 |
| 79 | Haematological (invasive) | 7 | 7 | 1 | 2 | 0 | 2 | 0 |
| 80 | Head and Neck (invasive) | 0 | 1 | 0 | 0 | 0 | 7 | 0 |
| 81 | Lung (invasive) | 1 | 3 | 0 | 0 | 1 | 15 | 0 |

# What will you get back?
## Compiled monthly summary reports

- By MDT/Tumour group and Provider for month of diagnosis

- Available within **six months** of submission

- Breakdown by:
  - Diagnosis
  - **Treatment type**
  - Basis of diagnosis
  - Stage
  - **Performance Status**
  - **Completion of pathology data**
  - **???other relevant site specific feedback**

# What will you get back?
## Clinical reports

- Development begins this year

- Consultation with clinical teams
  - Haematology SSCRG
  - Network site specific groups

- Need to align with
  - Service profiles
  - Peer review clinical lines of enquiry
  - National and professional body audits

# Haematology Implementation issues

- Annual minor revisions to dataset expected
- How to inform the clinical teams
  - MGUS – removed from dataset
  - Updates to ICD codes (ICD10 and ICDO3)
  - Haemoglobin measurement will be amended
- Ann Arbor Stage/Extranodality
- Primary Amyloid – (when) should we collect
- Myelodysplasia - IPSS/IPSS-R/WPSS
- Differences from CTYA dataset

# Thank you

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