



Public Health
England

National Cancer Registration Service (NCRS) and registration changes for haematology

Haematology Workshop, 5 July 2013



National Cancer Registration Service (NCRS)

- Sits within the Chief Knowledge Officer's (CKO) Directorate of Public Health England (PHE)
- Led nationally by Jem Rashbass, National Director for Disease Registration
- Currently employs approximately 200 people across 8 teams
- Each office is led by a local Head of Cancer Registration
 - Northern and Yorkshire – Caroline Brook
 - North West – Roger Hartley
 - East Midlands – Alexandra Thackeray
 - Oxford – Kellie Peters
 - West Midlands – Kellie Peters
 - Eastern – Jane Richardson
 - South West – Tina Ball
 - London – Steve Raynor





National Cancer Registration Service (NCRS)

- Single England-wide IT system (Encore)
- Cancer Outcomes and Services Dataset (COSD) compliant
- Facilitates rapid processing of multiple local and all national data sources
- Common standards and processes including data quality
- Provides rapid and direct feedback of data to clinical teams
to enhance data quality
- Support for (near) real-time surveillance, cancer audit and analysis

Local data collection at MDTs is key to success



NCRS – Summary of key deliverables 13/14

1. Migration of all registries to Encore and standardisation of processes.
2. Completion of national incidence for 2012 by 31/12/13.
3. Staging data collection to support the Public Health Outcomes Framework.
4. Roll out and conformance monitoring of COSD.
5. Development of a national MDT directory to facilitate data feedback.
6. Development of data feedback systems for data providers.
7. Information Governance compliance for all offices.
8. Development of a national cancer registration training programme.
9. Development and prototyping of a safe haven model for data access.
10. Various projects to incorporate new data sources into Encore/NCRS.

Data sources - patient-level data

National Feeds (inc COSD indirect)



Radiotherapy Data (RTDS)

Cancer Waiting Times

Chemotherapy Dataset (SACT)

ONS - Cancer and non-cancer deaths

Cancer screening programmes - Bowel, Cervix and Breast

National PET-CT imaging

National cancer audits - Lung, Head and Neck, Upper GI and Colorectal

Hospital Episode Statistics (HES)

Local Feeds (COSD direct)



Data from MDT software systems

Pathology full-text reports



Local imaging systems



Patient Administration Systems



Local clinical data systems



Encore

National Pilots

Recurrent/Metastatic Breast Audit Pilot

CRUK Stratified Medicine (Sept 2011)



Haematological cancer registration

- Historically, this has been difficult to do in a standardised way, due to
 - Differences in the availability and quality of the data sources received by the registries
 - Different IT systems, requiring data to be processed in different ways
 - Some variability in applying registration practice.
- As a result, it has been difficult to observe true patterns and trends in incidence and management of these cancers.
- This has also been further complicated by the introduction of ICDO3, particularly effecting haematological malignancies.



Moving forward...

- Encore provides NCRS with a new baseline on which to improve standardisation of registration for haematological malignancies (as well as all other cancers).
- COSD should provide a more complete and standardised flow of haematological data to NCRS from acute providers via MDTs.
- The UK formally adopted the ENCR (European Network of Cancer Registries) rules on the standard registration practice for haematological malignancies in March 2013.



Implications of ENCR rules

The document specifically identifies where

- Tumours are classed as “the same” when
 - one morphology is more specific than the other
 - e.g. Leukaemia NOS M9800/3 followed by CML M9875/3
 - or they are in the same “family”
 - e.g. T-cell/histiocyte rich large B-cell lymphoma M9688/3 = Primary effusion lymphoma M9678/3
- Transformations where another registration is not required, but details of the transformation showing the date of transformation, topography and morphology of the transformed disease are retained
 - e.g. Chronic myelomonocytic leukaemia M9945/3 – this would transform into AML M9801/3
- New/different tumours where a new registration is required.
 - e.g. Hodgkin lymphoma M9650/3 followed by acute myeloid leukaemia M9861/3



ENCR rules (continued)

- Whilst the document provides clear guidance for the practice of registration, it is important the MDTs **do not** try to apply these rules when recording details of a patient. NCRS should receive the maximum information available on which to base decisions



Plans for implementation

- Requires additional development on Encore to hold details of the transformations. (timescale unknown – following final registry migration)
- Rules will be retrospectively applied from 1 January 2013 to coincide with COSD data feeds commencing.
- Propose all “potential duplicate” registrations for haematology tumours be reviewed by a small number of people to consistently apply “same” and “transformation” rules moving forwards.
- In addition, this will allow for an audit of consistency of haematology data feeds via MDTs across the country in terms of completeness and coding.
- Results will be reviewed and used to improve data flows from any MDTs/NCRS local offices as required.