Key Questions?

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- Can clinically relevant codes/groups of diseases be extracted and analysed?
- What caveats have to be placed on the information derived?
- Does the information have international comparability?

Data sources - patient-level data

National Feeds

Radiotherapy Data (RTDS)

Cancer Waiting Times

Chemotherapy Dataset (SACT)

ONS - Cancer and non-cancer deaths

Cancer screening programmes - Bowel, Cervix and Breast

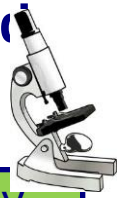
National PET-CT imaging

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

Hospital Episode Statistics (HES)

Local Feeds

Data from MDT software systems



Pathology full-text reports

Local imaging systems

Patient Administration Systems

Encore

Local clinical data systems

National Pilots

CRUK Stratified Medicine (Sept 2011)

Recurrent/ Metastatic Breast Audit Pilot

‘Cross-cutting’ Groups

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- Radiotherapy
- Chemotherapy
- Pathology (with RCPath)
- Radiology (with RCR)
- Co-morbidity
- National Cancer Staging Panel
- Primary Care (with RCGP)
- Health Economics (with Macmillan)

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The Problems

- **Incomplete ascertainment of all new cases (primary data resides in multiple laboratories and clinical databases)**
- **Lack of a standardized approach to diagnosis.**
- **Major benefit of network-based, integrated laboratories is ability to provide high-level ascertainment of new cases.**
- **Ascertainment of new cases and follow-up is required to derive incidence and prevalence data:**
  - **Cannot be derived from Death Certification Only data.**

WHO Classification

- NCIN and COSD dataset
- Challenges for Haematology:
  - Complex area of malignancy diagnosis:
    - 12 major disease groups with ~143 sub-diagnoses.

- **MPN's**
- **My & Ly neoplasms with Eosinophilia**
- **MDS/MPN**
- **MDS**
- **AML**
- **AL-Ambiguous lineage**
- **Precursor Lymphoid B & T**
- **Mature B-cell Lymphomas**
  - **Including overlap lymphomas**
- **Mature T-cell and NK cell Lymphomas**
- **Hodgkin Lymphoma**
- **Histiocytic and Dendritic cell neoplasms**
- **Immunodeficiency associated LPD's**

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QUALITY AND VALIDITY OF THE INFORMATION

Can the disease and code change in the process?

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- **Depends:**
  - **How many data hand-offs are there between?**

1. What the patient actually has?
2. What the histologist/clinician decide it is?
3. What is it submitted as?
4. What ICD-O 3 and ICD10 code is it assigned?
5. Additional information for confirmation, staging and prognosis?
   1. When does the information arrive in Registry?
   2. Does later information change MDM submitted diagnosis?
6. Accurately coded, defined it and retrieved?

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The MDT

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1. **<u>The ideal</u>:** Clinicians in MDT:

   >Diagnosis, stage + prognosis simultaneously

   >Coded real-time into IT software system in meeting by informed clinician:

   >Transferred to Registry database by automated interface

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MDM REALITY

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1. **Less optimal** *but much more common*:

>**Diagnosis** – Clinician, and recorded on paper in meeting. *(MDT Coordinator/Admin support)*

>**Stage** and **prognosis** *later*:

(MDT Coordinator, Cancer Data staff, etc)

>1. Recorded/coded onto local software programme eg Somerset, Infoflex etc.

(Cancer data clerk, Admin staff)

>2. **Manual secondary transfer** to Registry database. *(Cancer data clerk, Admin staff)*

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In the Registry

- Multiple pieces of information aggregated:
  - MDT outcomes, monthly Registry returns, histopathology, cytogenetics reports.
- Timing of arrival of information
  - How is this interpreted?
  - Hierarchy of information - What trumps what?
- Histopathology reports vs constellations of diagnostic clinical criteria.

Coding Implications

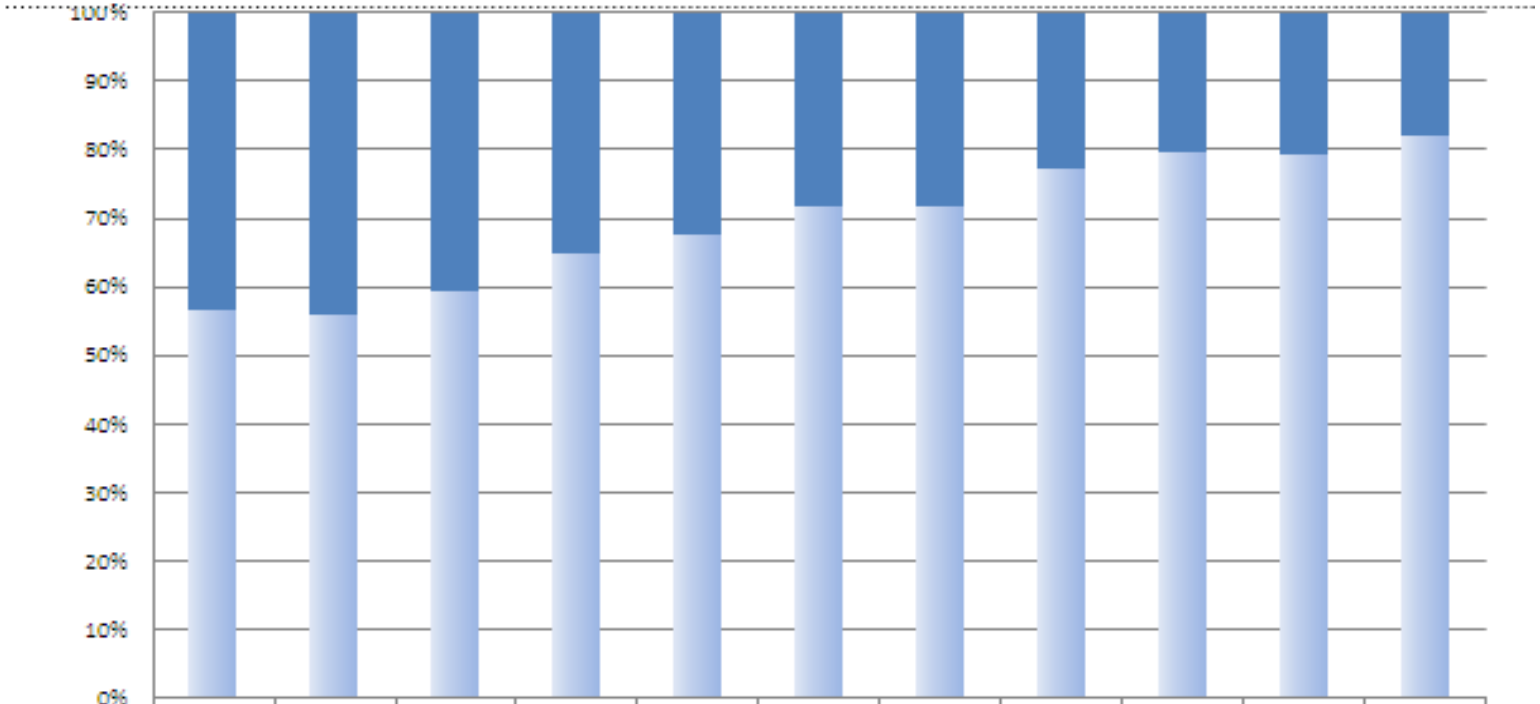
- **Coding from aggregated data but!**
  - No clinical input
  - What about diseases that don't have solid tissue histology like Lymphomas
    - eg CML, PRV, ET, Myeloma
    - Constellation of diagnostic criteria – not all are pathology based!
      - eg: ET persistent thrombocytosis of >450 x10^9/L for >3/12 and reactive causes excluded.

Variable Clinical/ Pathological Assessments

- CLL – PB only findings
- CML – PB findings only
- Myeloma – a constellation of pathology and non-pathology diagnostic criteria
- DLBC NHL – the NOS problem

NHL ‘NOS’ Morphology - England

With newer immunohistochemistry techniques it is now rare to be unable to subtype lymphomas into histological subgroups.



	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
NOS	43%	44%	40%	35%	32%	28%	28%	23%	20%	21%	18%
Specified	57%	56%	60%	65%	68%	72%	72%	77%	80%	79%	82%

- Nobody is treated for NOS - Nobody dies of NOS

Haematological malignancies – Solid or liquid or both?

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- ICD-10 codes – Topography
- ICD-O3 – Morphology
  - Don't always equate
- Used individually don't always distinguish between disease subtypes.
- Historical use of ICD-10
- More recent introduction of ICDO-3
- ICDO-3 does not have a single code for each Haematological diagnosis and has been highly adapted by WHO (In use in 2004 but only verified and published in 2012)

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Q: What would a good registration system look like?

- Complete ascertainment new cases
  - Accurate data on Diagnosis, Stage and PI's.
    - Contemporaneous
      - # Linkage to other datasets

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Future

Building Blocks present but must:

- Continue drive for accurate, clinically useful information.
- **Improve 'front-end' data collection/registration processes.**
- Be able to dissect out clinically useful subgroups
  - eg CML/CMML, FL, DLBC.
- Have measures that reflect data quality.
- Sufficient detail for:
  - Complete ascertainment, accururate diagnosis, staging and prognosis.
- Integrated links to **SACT** and **RT** Datasets

Level 1.1 - Have all the agreed COSD data files been received as per the COSD Data Transfer Partnership Agreement?

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ncrs National Cancer Registration Service

COSD Conformance Reporting Site

Home | Level 1 | Level 2 | Submission Due Dates | Documents Library | Log Out

Level 1 Reports

- Level 1.1 Report
- Level 1.2 Report
- Level 1.3 Report

Report Descriptions

Click headings to show descriptions...

> Level 1.1

Have all the agreed COSD data files been received as per the COSD Data Transfer Partnership Agreement?

Trusts would be expected to send a monthly submission of all files agreed in their COSD Data Transfer Partnership Agreement. For a trust to be compliant with Measure 1.1, ALL the required files must have been received on time for that month. If one or more is missing or late, the trust will be non-compliant. Please refer to Measure 1.2 to see details of individual data feeds.

> Level 1.2

> Level 1.3

Regional Office: East Midlands, Eastern, London, | Strategic Clinical Network: Cheshire And Mersey, East Midla

Region: 3 Counties, Anglia, Arden, Avon, | Year: 2014

1 of 1 | 100% | Find | Next | Select a format | Expo

London Cancer								
Essex	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug
The Princess Alexandra Hospital NHS Trust (RQW)								
North London	**Jan**	**Feb**	**Mar**	**Apr**	**May**	**Jun**	**Jul**	**Aug**
Barnet and Chase Farm Hospitals NHS Trust (RVL)								
Great Ormond Street Hospital for Children NHS Foundation Trust (RP4)								
Moorfields Eye Hospital NHS Foundation Trust (RP6)								
North Middlesex University Hospital NHS Trust (RAP)								
Royal Free London NHS Foundation Trust (RAL)								
Royal National Orthopaedic Hospital NHS Trust (RAN)								
The Whittington Hospital NHS Trust (RKE)								
University College London Hospitals NHS Foundation Trust (RRV)								
North East London	**Jan**	**Feb**	**Mar**	**Apr**	**May**	**Jun**	**Jul**	**Aug**
Barking, Havering and Redbridge University Hospitals NHS Trust (RF4)								
Barts Health NHS Trust (R1H)								
Homerton University Hospital NHS Foundation Trust (RQX)								
London Cancer Alliance								
West London	**Jan**	**Feb**	**Mar**	**Apr**	**May**	**Jun**	**Jul**	**N/A**
Chelsea and Westminster Hospital NHS Foundation Trust (RQM)								
Ealing Hospital NHS Trust (RC3)								
Imperial College Healthcare NHS Trust (RYJ)								
North West London Hospitals NHS Trust (RV8)								

Haematology 2014-15 Work Programme:

Public Health England

1. ***National measures for Haematology Clinical Service Profiles: A 'MUST DO'***
   - SACT completeness
   - COSD completeness
   - Entry to national trials
   - 1 and 5 year survival data for AML, DLBC , HL and MM
   - Place of death
2. ***Routes to diagnosis:*** **Preliminary analysis of emergency presentation for MM and NHL.**
3. ***Models of Care:*** **AML - Inpatient vs Ambulatory treatment.**
4. ***Variations in Clinical Practice:*** **Use of radiotherapy in NHL.**
5. ***Clinical Outcomes:*** **Hodgkin's Lymphoma - All cause deaths-** (younger patients 15 – 45 with sufficient years of follow up).

Haematology 2014-15
Parallel Projects

Public Health England

1. Defining and refining Clinical Lines of Enquiry to develop Service Profiles
2. CCG Clinical Outcomes Indicator Sets
3. COSD 1-3 Conformance Reports
4. Level 4 Performance Reports

CCG Outcomes Indicator Set

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1. **Preventing people from dying prematurely:**
   - Under 75 mortality from cancer
   - One year survival from all cancers
   - Diagnosis via emergency routes
   - Record of stage at diagnosis
   - Early detection

2. **Enhancing quality of life for long-term conditions:**
   - Ensuring people feel supported to manage their condition

3. **Helping people recover from ill-health and injury:**
   - Emergency readmissions within 30 days of discharge from hospital.

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CCG Outcomes Indicator Set

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4. Ensuring that people have a positive experience of care:

- **Improving people's experience of outpatient care**
  - Patient experience of outpatient services.
- **Improving hospitals' responsiveness to personal needs**
  - Responsiveness to in-patients' personal needs.
- **Improving the experience of care for people at the end of their lives**
  - Bereaved carers views on the quality of care in the last 3 months of life.
- **Improving people's experience of accident and emergency service**
  - Patient experience of A&E services
- **Improving people's experience of integrated care**
  - *In development. No CCG measure at present*

5. Treating/caring for in safe environment, protecting from avoidable harm:

- **Reducing the incidence of avoidable harm**
  - Incidence of healthcare associated infection: MRSA
  - Incidence of healthcare associated infection: C Difficile

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Summary - 1

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- There is a need for accurate and timely data collection for service planning.
- Haematology is the most complex diagnostic, staging/prognostication dataset (COSD).
- Encore has unified all the Cancer Registries and coding protocols – target 3/12 for full coding.

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Summary - 2

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- Strong shift in emphasis from 'clinical interest' projects to '**quality and commissioning' projects:**
  - Cancer Peer Review Measures, Clinical Lines of Enquiry, Service Profiles, and CCG Outcome indicator sets.
- NHS England is **contracting** with Trusts for the mandated datasets:
  - ***The onus is on clinicians and Trusts to submit completed diagnosis, ICD-O3 and ICD10 codes and staging information.***
  - ? Penalties through commissioning.

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- **“Improved ‘Front-end’ clinical data capture is the key to more useful ‘Back-end’ data analysis for clinical purposes, service development and patient care.”**