Haematological Malignancy Research Network: A Model for Population-Based Data Collection?

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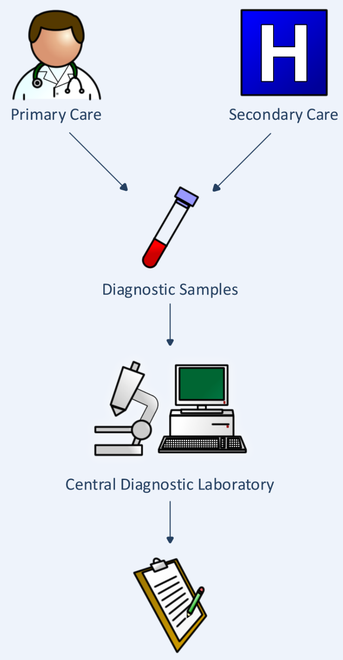
Background

Collection of information on cancer patients is increasingly seen as integral to the delivery of good quality oncology services. For haematological malignancies, national data are traditionally presented using the conventional groupings of leukaemia, non-Hodgkin lymphoma, Hodgkin lymphoma and myeloma. The use of this largely site-based classification masks the heterogeneity and complexity of haematological malignancies restricting the meaning of data used for clinical audit, health service planning and measurement of outcome.

Pivotal to the collection of functional data for haematological malignancies was the publication of the World Health Organisation (WHO) classification in 2001. Unlike previous haematological classifications, this was adopted into clinical practice globally and formed the basis of the revision of the International Classification of Disease for Oncology (ICD-O-3).

The population-based Haematological Malignancy Research Network (HMRN) was established in the UK in 2004 (www.hmrn.org). HMRN was set up to address the need for accurate and high quality data about haematological malignancies, including their diagnosis, prognosis, treatment, response to therapy and outcome.



Methods

HMRN collects detailed information about all haematological malignancies diagnosed in two adjacent UK Cancer Networks: Yorkshire and Humber & Yorkshire Coast. It covers a population of 3.6 million, and accrues around 2,000 incident haematological malignancy patients each year. The population age and sex structure closely mirrors that of the UK as a whole. Within HMRN, patient care is provided by a unified clinical network operating across 14 hospitals and 5 multi-disciplinary teams. Regional diagnostic services are centralised at the Haematological Malignancy Diagnostic Service (HMDS), which uses a sophisticated custom-designed web database to handle clinical diagnoses, specimen tracking and reporting facilities – **H**MDS **I**ntegrated **L**aboratory **I**nformation **S**ystem (HILIS). All diagnoses in HMRN are made and expertly coded to ICD-O-3 by clinicians and clinical scientists at HMDS.

Research nurses abstract a core clinical dataset, using a specially structured form tailored to each malignancy which includes information on demographics, prognostics and staging, as well as details about all treatments, response and relapse. Data are entered onto HILIS, along with the treatment decision agreed during the multi-disciplinary team meetings. Copies of all forms can be seen on the HMRN website (www.hmrn.org). A critically important feature of the data collection process is the emphasis on primary source abstraction.

All patients in HMRN are 'flagged' at the Central Register and death certification details obtained.

Results

8,136 patients had a haematological malignancy diagnosed for the first time within the HMRN region over the four years 1st September 2004 to August 2008. Progression from indolent to more aggressive disease is a feature of haematological malignancy, and 225 (2.8%) of the 8,136 patients had a subsequent haematological malignancy diagnosed during the four-year period, yielding 8,361 diagnoses in total There are over 50 different diagnostic subtypes and for analysis purposes these have been classified into 23 main groups shown in Figure 1 beginning with the myeloid disorders at the top right and moving clockwise through the lymphoid B-cell and T-cell disorders, and ending with the Hodgkin lymphomas at the top left.

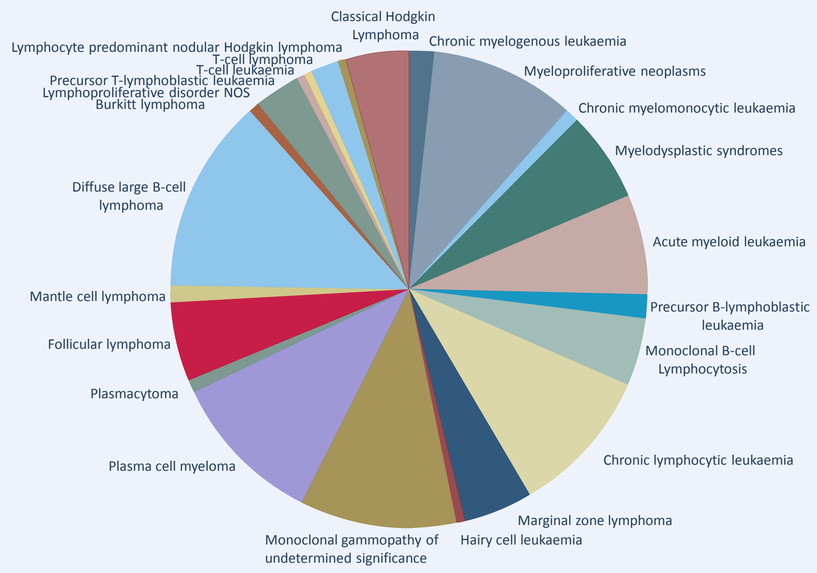


Figure 1
Diagnostic Distribution: Haematological Malignancy Research Network (HMRN), 2004-2008

Prognostic data are disease-specific and for each disorder the individual components are entered into HILIS.

As an example, prognostic data for a patient with diffuse large B-cell lymphoma (DLBCL) are shown in Figure 2. Stage of disease is recorded if documented in the patient's medical notes - shown by the Ann Arbor in red. However, stage is also calculated by HILIS using information abstracted from primary source data (CT scan report, bone marrow report and recorded clinical presentation) - shown by the Ann Arbor in blue. The International Prognostic Index (IPI) Score is subsequently calculated from its components – age, Ann Arbour stage, number of extranodal sites, performance status and serum levels of Lactose dehydrogenase (LDH).

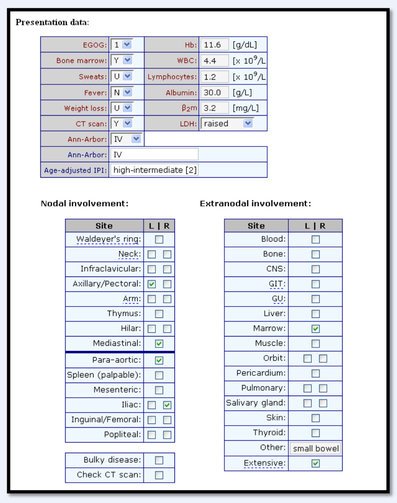


Figure 2
Screenshot from HILIS showing the presentation data collected for diffuse large B-cell lymphomas

All HMRN patients are followed up from time of diagnosis. All episodes of treatment, trial entry and response to therapy are systematically documented.

Figure 3 shows the distribution of first line therapy for Acute Myeloid Leukaemia (AML). Approximately one-third of patients were recruited to a clinical trial and two-thirds of patients were treated with curative intent.

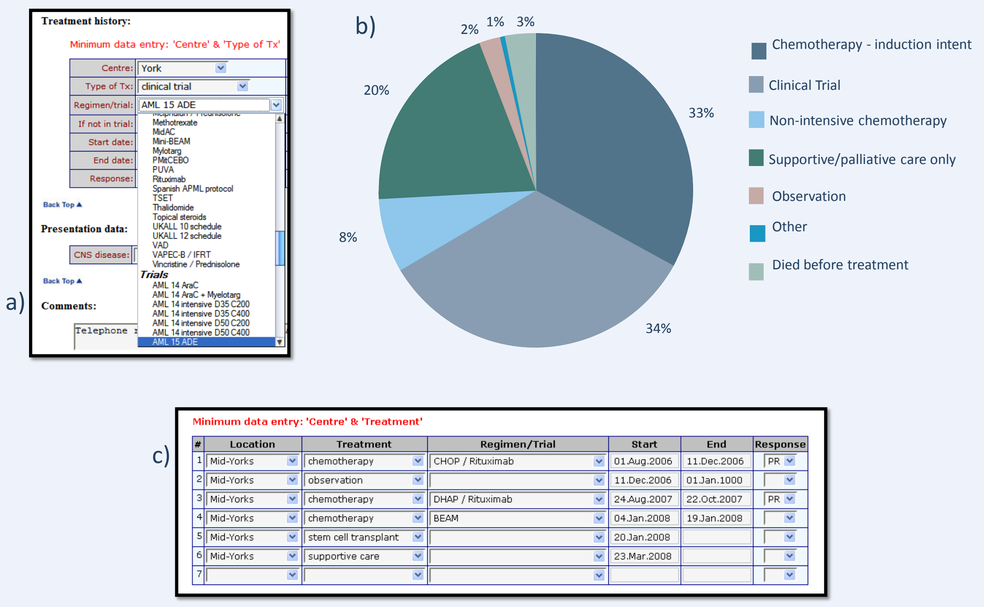


Figure 3
a) Screenshot from HILIS showing standardised treatment terms. b) First line treatment distribution for AML patients. c) Screenshot from HILIS demonstrating capture of all episodes of treatment and response to therapy

The importance of examining specific disease entities is demonstrated by the Kaplan-Meier plots for AML survival shown in Figure 4.

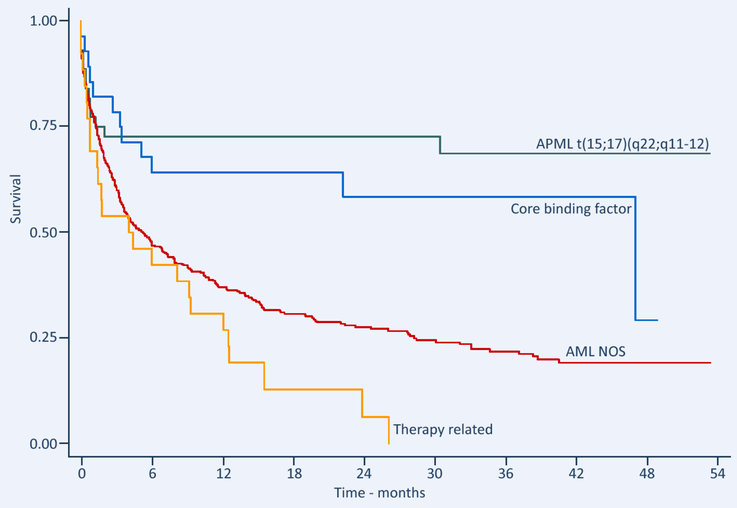


Figure 4
Kaplan – Meier estimate of overall survival for AML patients by ICD-O-3 subtype.

Conclusions

Haematological malignancies, unlike many other cancers, are generally diagnosed using a combination of histology, cytology, immunophenotype, cytogenetics, imaging and clinical data. HMRN demonstrates the importance of a fully integrated specialist diagnostic service in the ascertainment, diagnosis and classification of haematological malignancies as recommended in the NICE Guidance on Improving Outcomes in Haematological Cancers.

HMRN is a unique population-based collaboration between a cohesive clinical network, a single integrated haematopathology laboratory and a specialist epidemiology unit. HMRN provides an opportunity for monitoring patterns of cancer care, clinical audit and high quality population-based research in an area that has not traditionally been well served by national datasets.

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HMRN is a collaboration between the Yorkshire Cancer Network, the Humber and Yorkshire Coast Cancer Network, the Haematological Malignancy Diagnostic Service (HMDS) and the Epidemiology & Genetics Unit (EGU)

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