Evaluation of the completeness of national haematological malignancy registration: comparison of national data with a specialist population-based register.

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Background

The quality of national incidence and survival data for haematological cancers in England and Wales has been questioned by clinicians and researchers[1]. These concerns stem from the fact that, unlike many other cancers, haematological neoplasms are diagnosed using multiple parameters including histology, cytology, immunophenotyping, cytogenetics, imaging and clinical information. This range and depth of data can be difficult for cancer registries to access systematically; forming a barrier to both complete ascertainment and the collection of information detailed enough to implement the WHO classification system[2-3].

With the aim of evaluating the national registration of haematological malignancies, data from a specialist population-based haematological register - the Haematological Malignancy Research Network[4] (www.HMRN.org) - are being used to predict the incidence of haematological cancers across the UK as a whole, using the latest disease classification.

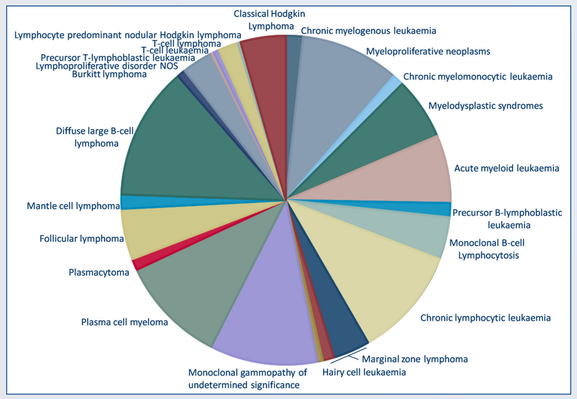

Figure 1: HMRN diagnoses 2004 to 2009, ICD-O-3 (n=10,727)

Methods

HMRN covers a population of 3.6 million in the two adjacent Cancer Networks of Yorkshire and Humber & Yorkshire Coast. All diagnoses are made at a single integrated laboratory (www.hmds.org) and expertly coded according to the latest WHO International Classification of Diseases for Oncology – currently the 3rd edition (ICD-O-3).

Using incident HMRN diagnoses 2004-2009 (Figure 1, n= 10,727) and census data, incidence rates and corresponding 95% confidence intervals were estimated in 5-year age strata for males and females using Poisson regression. Expected numbers were estimated for each diagnostic group nationally and by Cancer Network. Information on cancer registrations for the years 2004-2007 were extracted from the National Cancer Data Repository for the following diagnostic categories: acute lymphoblastic leukaemia (ALL), acute myeloid leukaemia (AML), chronic lymphocytic leukaemia (CLL), Hodgkin lymphoma, non-Hodgkin lymphoma (NHL) and myeloma. Comparisons were made between the observed and expected numbers at both national and Cancer Network levels.

Results

Nationally, the disease-specific observed:expected ratios for England were: ALL: 106% (95% CI: 97-114%); AML: 113% (CI: 108-117%); CLL: 72% (CI: 69-75%); CML: 115% (CI: 106-126%); HL 100% (CI: 95-105%); NHL: 116% (CI: 113-118%); Myeloma 104% (CI: 101-108%) (Figure 2). Observed:Expected Ratios for the Cancer Networks are shown for HL and CLL in Figure 3.

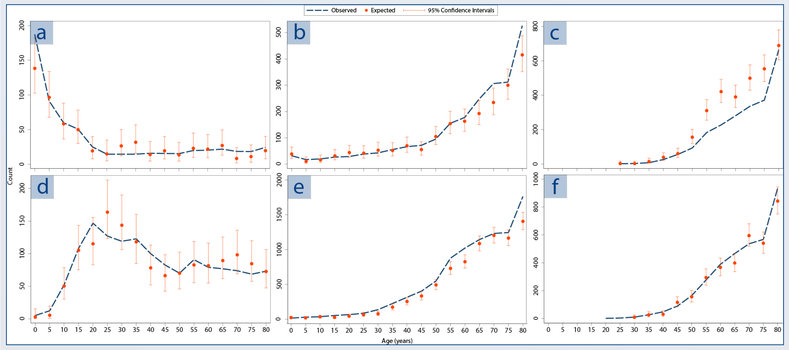

Figure 2: Observed and expected rates a) ALL; b) AML; c) CLL; d) HL; e) NHL; f) Myeloma

As expected, there is little variation between the Networks for HL. By contrast, there is more divergence for CLL.

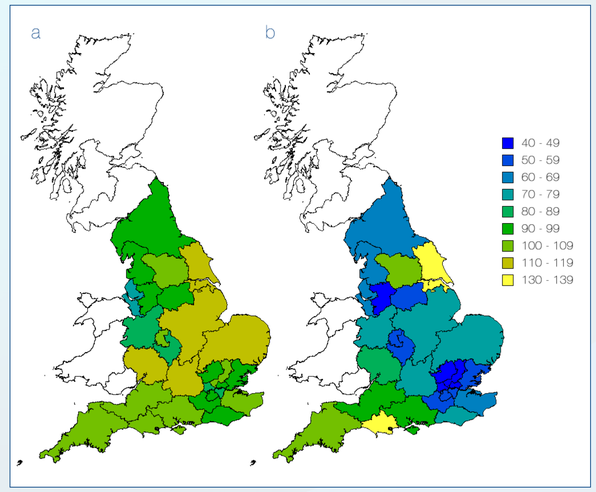

Figure 3: Observed:Expected Ratios by Cancer Network a) HL; b) CLL

Conclusions

Overall, there was good agreement between the observed number of cancer registrations and the number expected on the basis of HMRN rates.

This project demonstrates that cancer registries appear to be ascertaining all cases of haematological malignancy, but further investigation is needed to explain the degree of variation in disease classification across the country.

Future work will include prediction of the disease burden of haematological malignancies (incidence and prevalence) by WHO ICD-O-3 classification.

References

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hmrn Haematological Malignancy Research Network
Leukaemia & Lymphoma Research BEATING BLOOD CANCERS
NCIN national cancer intelligence network Using information to improve quality & choice
NHS Northern and Yorkshire Cancer Registry and Information Service