

Registration for Blood Cancers in England: comparison of routine data with a specialist population-based register

NCIN Data Briefing

Introduction

Blood cancers (leukaemias, lymphomas and myelomas) comprise around 1 in 10 of all new cancers diagnosed in the UK. There are over 60 different subtypes, each differing widely in clinical presentation, treatment options and prognosis.

Concerns have been raised about the accuracy and completeness of information captured on these cancers by routine registrations systems. These concerns stem from the fact that the range and depth of laboratory data required to code these malignancies is challenging for cancer registries to access; forming a barrier not only to complete ascertainment, but also to the systematic implementation of the latest World Health Organization (WHO) coding systems.

To investigate the impact of this, an evaluation was carried out comparing cancer registrations held by English registries with predictions made by the Haematological Malignancy Research Network (www.hmrn.org) – a high quality population-based registry that collects data to clinical trial standards. Within HMRN (population >3.6 million) all diagnoses (>2,200 per annum) are made and coded directly by haematologists/clinical scientists at the Haematological Malignancy Diagnostic Service (www.hmds.org); an integrated specialist laboratory identified in the English Cancer Reform Strategy as ‘the model for delivery of complex diagnostic services’.

Methods

For the purposes of this project, HMRN’s incidence rates (2004-10) were used to generate the numbers of cancers expected in England (2004-8). Full details of the methods are provided in the report (see **Further Information**). Briefly, a bridge-coding algorithm was used to distribute 63 WHO International Classification of Diseases for Oncology (ICD-O3) codes used by HMRN, to one of ten ICD 10th revision (ICD-10) codes used by English Cancer Registries. The resulting age/sex specific rates were applied to the corresponding national population estimates for 28 English Cancer Networks and eight Cancer Registries.

It is important to note that several ICD-O3 categories either overlap ICD-10 categories, or have no clear ICD-10 counterpart; and for some the definitions have changed over time. More detail is provided in the full report, see **Further Information**.

KEY MESSAGES:

Marked variations were observed at both the Cancer Network and Registry levels; reflecting differences in the approaches taken to registering blood cancers.

Improvement in the quality of information on blood cancers requires greater standardisation of registry practice and improved access to data from integrated diagnostic services.

Results

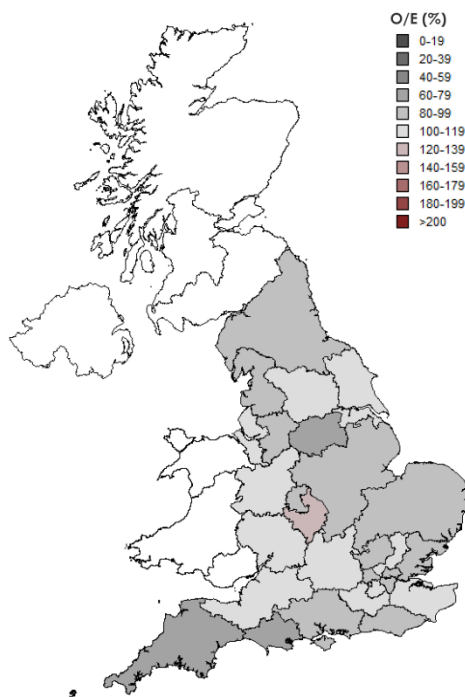
For England as a whole, the observed/expected annual registration ratios for nine ICD-10 groupings are compared in Table 1. Conditions are ordered according to the magnitude of the ratio.

Table 1: Comparison of Observed annual frequency of blood cancer in England 2004-8, with those Expected on the basis of HMRN rates 2004-10

| ICD-10 | Observed | Expected | Observed/Expected Ratio (95% confidence interval) |
|--------------------------------------|----------|----------|---------------------------------------------------|
| <i>Chronic lymphocytic leukaemia</i> | 2,364 | 3,199 | 74 (71-77) |
| <i>Myeloproliferative neoplasms</i> | 2,187 | 2,745 | 80 (76-83) |
| <i>Hodgkin lymphoma</i> | 1,413 | 1,477 | 96 (91-101) |
| <i>Acute lymphoblastic leukaemia</i> | 602 | 592 | 102 (94-110) |
| <i>Non-Hodgkin lymphoma</i> | 9,367 | 9,120 | 103 (101-105) |
| <i>Myeloma</i> | 3,633 | 3,479 | 103 (101-108) |
| <i>Acute myeloid leukaemia</i> | 2,217 | 2,030 | 109 (105-114) |
| <i>Chronic myeloid leukaemia</i> | 540 | 470 | 115 (105-125) |
| <i>Myelodysplastic syndromes</i> | 2,187 | 1,876 | 117 (112-122) |

As might be predicted, with ratios close to 100, overall agreement is best for aggressive acutely presenting conditions, such as acute lymphoblastic leukaemia (ALL). Furthermore, for ALL there is little evidence of any significant variation in recording across the country as whole, as can be seen from Figure 1 which shows the data (ordered by observed/expected ratio) presented at Cancer Network level

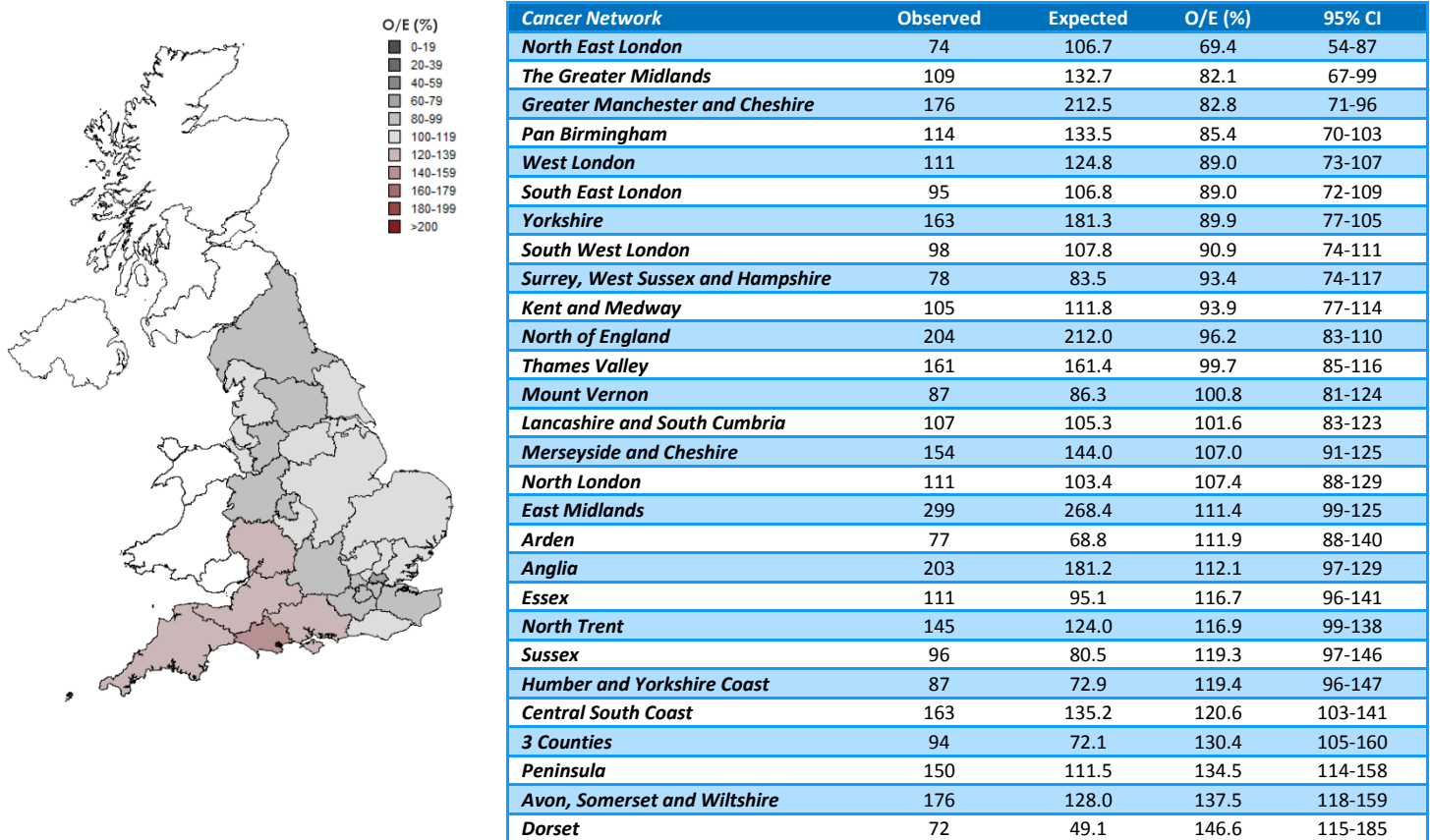
Figure 1: Acute lymphoblastic leukaemia (ALL) - annual observed (England, 2004-8) and expected based on HMRN rates (2004-10)



| Cancer Network | Observed | Expected | O/E (%) | 95% CI |
|------------------------------------------|----------|----------|---------|--------|
| <i>Dorset</i> | 6 | 8.4 | 71.9 | 26-156 |
| <i>North Trent</i> | 16 | 21.1 | 75.9 | 43-123 |
| <i>Peninsula</i> | 15 | 19.0 | 79.1 | 44-130 |
| <i>Sussex</i> | 11 | 13.7 | 80.3 | 40-144 |
| <i>Lancashire and South Cumbria</i> | 15 | 17.9 | 83.8 | 47-138 |
| <i>Essex</i> | 14 | 16.2 | 86.6 | 47-145 |
| <i>West London</i> | 19 | 21.2 | 89.5 | 54-140 |
| <i>South East London</i> | 17 | 18.2 | 93.6 | 55-150 |
| <i>Mount Vernon</i> | 14 | 14.7 | 95.3 | 52-160 |
| <i>Central South Coast</i> | 22 | 23.0 | 95.7 | 60-145 |
| <i>Greater Manchester and Cheshire</i> | 35 | 36.1 | 96.9 | 67-135 |
| <i>Pan Birmingham</i> | 22 | 22.7 | 96.9 | 61-147 |
| <i>Anglia</i> | 30 | 30.8 | 97.4 | 66-139 |
| <i>East Midlands</i> | 45 | 45.6 | 98.6 | 72-132 |
| <i>North East London</i> | 18 | 18.1 | 99.2 | 59-157 |
| <i>North of England</i> | 36 | 36.1 | 99.8 | 70-138 |
| <i>Yorkshire</i> | 32 | 30.8 | 103.8 | 71-147 |
| <i>Kent and Medway</i> | 20 | 19.0 | 105.2 | 64-162 |
| <i>Surrey, West Sussex and Hampshire</i> | 15 | 14.2 | 105.6 | 59-174 |
| <i>Avon, Somerset and Wiltshire</i> | 23 | 21.8 | 105.7 | 67-159 |
| <i>The Greater Midlands</i> | 24 | 22.6 | 106.3 | 68-158 |
| <i>South West London</i> | 20 | 18.3 | 109.1 | 67-168 |
| <i>Humber and Yorkshire Coast</i> | 14 | 12.4 | 113.0 | 62-190 |
| <i>3 Counties</i> | 14 | 12.3 | 114.2 | 62-192 |
| <i>Merseyside and Cheshire</i> | 28 | 24.5 | 114.4 | 76-165 |
| <i>Thames Valley</i> | 32 | 27.5 | 116.6 | 80-165 |
| <i>North London</i> | 21 | 17.6 | 119.5 | 74-183 |
| <i>Arden</i> | 15 | 11.7 | 128.1 | 72-211 |

In contrast, systematic geographic variations were seen for conditions where a correct diagnosis requires the integration of information from clinical and laboratory sources. This is illustrated by myeloma in Figure 2. Similar patterns were seen for most other blood cancers (as well as other malignancies); strongly suggesting an underlying difference between registries in case ascertainment and coding procedures. More information on this can be found in the main report (see **Further Information**).

Figure 2: Myeloma - annual observed (England, 2004-8) and expected based on HMRN rates (2004-10)



In addition to examining geography, ratios were also examined by age. Whilst for many conditions there was little variation by age when the data for the country as a whole were combined (e.g. AML, Figure 3), for other cancers there was less consistency (e.g. CML, Figure 4).

Figure 3: Acute myeloid leukaemia (AML)

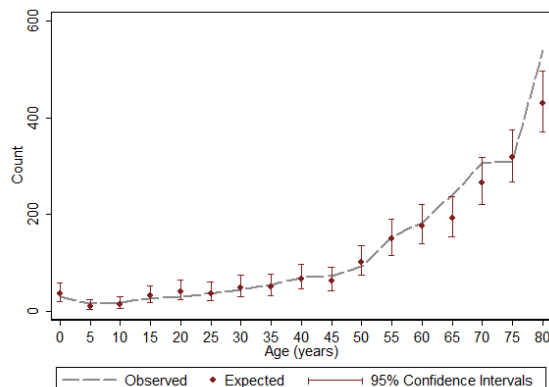
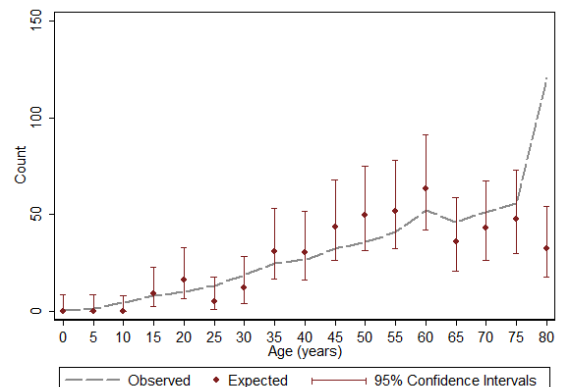


Figure 4: Chronic myeloid leukaemia (CML)



Figures show average annual **observed** (England 2004-08) age-specific cancer registration counts and **expected** registration counts based on HMRN rates (2004-10)

What needs to happen now?

Overall, this comparison provides broad reassurance that there is not systemic under-registration of blood cancers in England. Further quality improvement in cancer registration is likely to come from standardisation of procedures between individual registries and through the increased use of information directly from integrated laboratory services and multi-disciplinary teams (MDTs) to enable more accurate categorisation of disease. The Cancer Outcomes and Services Dataset (COSD) is the new national standard for reporting cancer information in England, it includes standardised coding for haematological diseases to help ensure consistency of classification.

NYCRIS as the lead registry for blood cancers within the NCIN has identified the following action plan for work at a national level to improve the quality of data on haematological malignancies.

- To work with colleagues in NCIN and Public Health England on standard operating procedures for registries collecting data within the new English cancer registry system ENCORE, to ensure that the gains in standardising practice are fully realised for haematological cancers.
- To work with proposed new European Network of Cancer Registries (ENCR) rules for registration for haematological malignancies to improve standardisation of recording of transformations and multiple registrations for haematological malignancies.
- To maintain intelligence on the information sources available to registries when recording haematological malignancies, as this is likely to remain important in interpretation of incidence and outcome measures at a sub-national level for some time.
- To facilitate linkage, wherever possible, between integrated diagnostic laboratory services and cancer registries. Such services and access to their information systems is a key determinant of the quality and completeness of registration for haematological cancers.
- To explore with specific cancer registries reasons for differences between observed and predicted registrations to inform new operating procedures.

Further information

Further information on the comparisons undertaken between observed and predicted cancer registrations can be found in *Haematological malignancies & cancer registration in England (2004-2008)*. <http://www.ncin.org.uk/view.aspx?rid=1725>

Find out more:

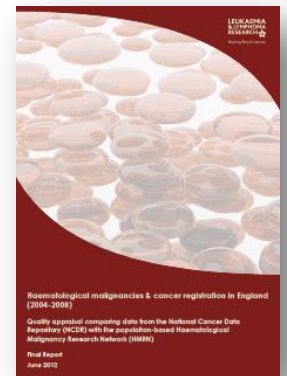
Northern and Yorkshire Cancer Registry and Information Service (NYCRIS)

NYCRIS is the lead Cancer Registry for haematological malignancies. <http://www.nycris.nhs.uk>

Haematological Malignancy Research Network (HMRN)

This site is intended for anyone interested in haematological malignancy; and contains information and statistics for clinicians and researchers. <http://www.hmrn.org>

Other useful resources within the NCIN partnership: Cancer Research UK CancerStats – Key facts and detailed statistics for health professionals <http://info.cancerresearchuk.org/cancerstats/>



The National Cancer Intelligence Network (NCIN) is a UK-wide partnership operated by Public Health England. The NCIN coordinates and develops analysis and intelligence to drive improvements in prevention, standards of cancer care and clinical outcomes for cancer patients