National data on haematological cancer - how good is it?

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Background

- *‘There are no precise and reliable figures for incidence and survival rates for the different forms of haematological cancers in England and Wales.’*

- *‘One of the reasons for the lack of trustworthy statistics is that a reliable classification system for haematological malignancies has only recently been developed and agreed by oncologists and pathologists.’*

NICE, Improving Outcomes in Haematological Cancers, The Manual, 2003

Main Objectives

- To use data from a specialist population-based register (HMRN) to estimate incidence and prevalence of haematological cancers in England, accurately categorised into clinically meaningful diagnostic groups

- In collaboration with UK cancer registries, conduct comparisons of predicted and observed cancer registrations to evaluate the quality of routine cancer registration

Observed Data (2004-2008) National Cancer Data Repository

Diagnostic Groups	ICD-10 code
Total Haematological	C81.0 – 96.9; D45-47.9
Acute Lymphoblastic Leukaemia (ALL)	C91.0
Acute Myeloid Leukaemia (AML)	C92.0, 92.4, 92.5, 93.0, 94.0, 94.2
Chronic Lymphocytic Leukaemia (CLL)	C91.1
Chronic Myeloid Leukaemia (CML)	C92.1
Hodgkin Lymphoma (HL)	C81
Non-Hodgkin Lymphoma (NHL)	C82.0-85.9
Myeloma	C90.0
MGUS	D47.2
Myeloproliferative Neoplasms (MPN)	D45, 47.0-47.9
Myelodysplastic Syndromes (MDS)	D46.0-46.9
Other	C88, 90.1, 90.2,91.2-91.9, 92.3-92.9, 93.1-93.9, 94.0-96.9

COLLECTING AND USING DATA

- Data Collection
  - Cancer Outcomes and Services Dataset (COSD)
  - National Radiotherapy Dataset (RTDS)
  - Going Further on Cancer Waits
  - Co-morbidity
  - Systemic Anti-Cancer Therapy Dataset (Chemotherapy)
  - GP access to diagnostic tests
- National Cancer Data Repository
  - Merged English Cancer Registry Data
  - ONS Minimum Cancer

National Cancer Data Repository

The national cancer data repository has been described as the 'jewel in the crown' of NCIN. It contains merged data on all cancer patients in England from the sources described below. Each of the English cancer registries holds a copy of the database; applications for data from the repository may be made in line with NCIN's data access policies.

The database is updated yearly with a new iteration expected by October 2012 to include registrations to the end of 2010. The specification given in the pages linked below is for the 2008 version of the repository. Previous versions of the repository have a similar specification; the details of any request should be discussed with the relevant cancer registry at an early stage.

Merged English Cancer Registry Data (1990 - 2008)

Merged data from the eight English cancer registries covering the period 1990 to 2008. This dataset provides details of cancer diagnoses and demographic information about cancer patients.

ONS Minimum Cancer Dataset (1985 - 2008)

Basic information from the Office for National Statistics database of cancer registrations in England, allowing the repository to be reconciled to official national statistics.

Hospital Episode Statistics (April 1997 - March 2010)

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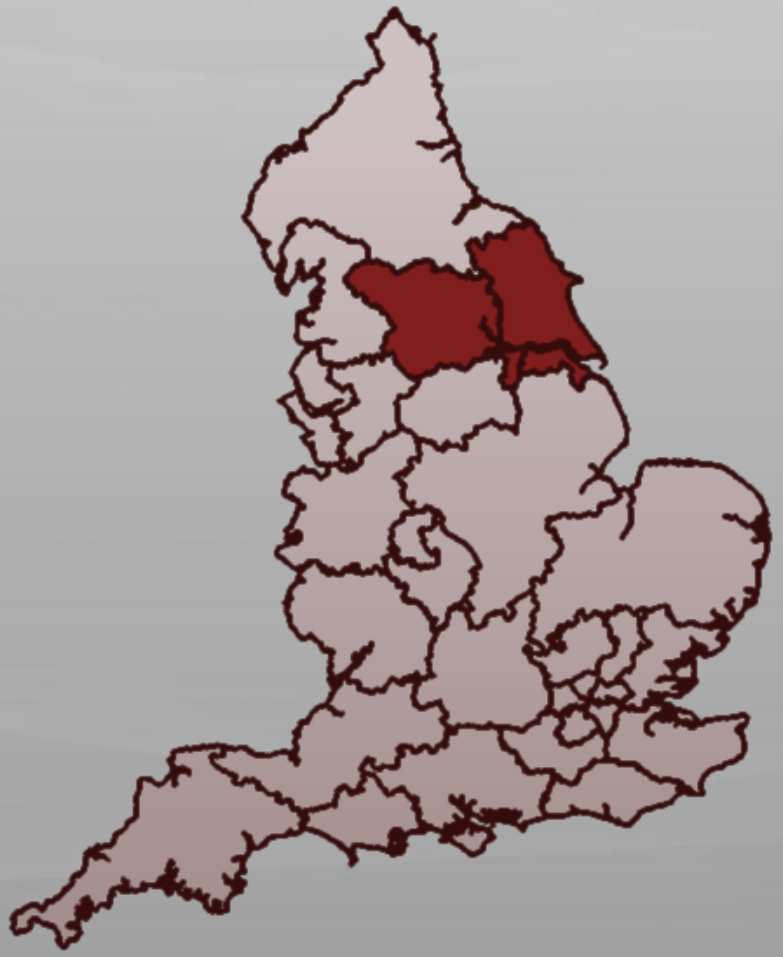
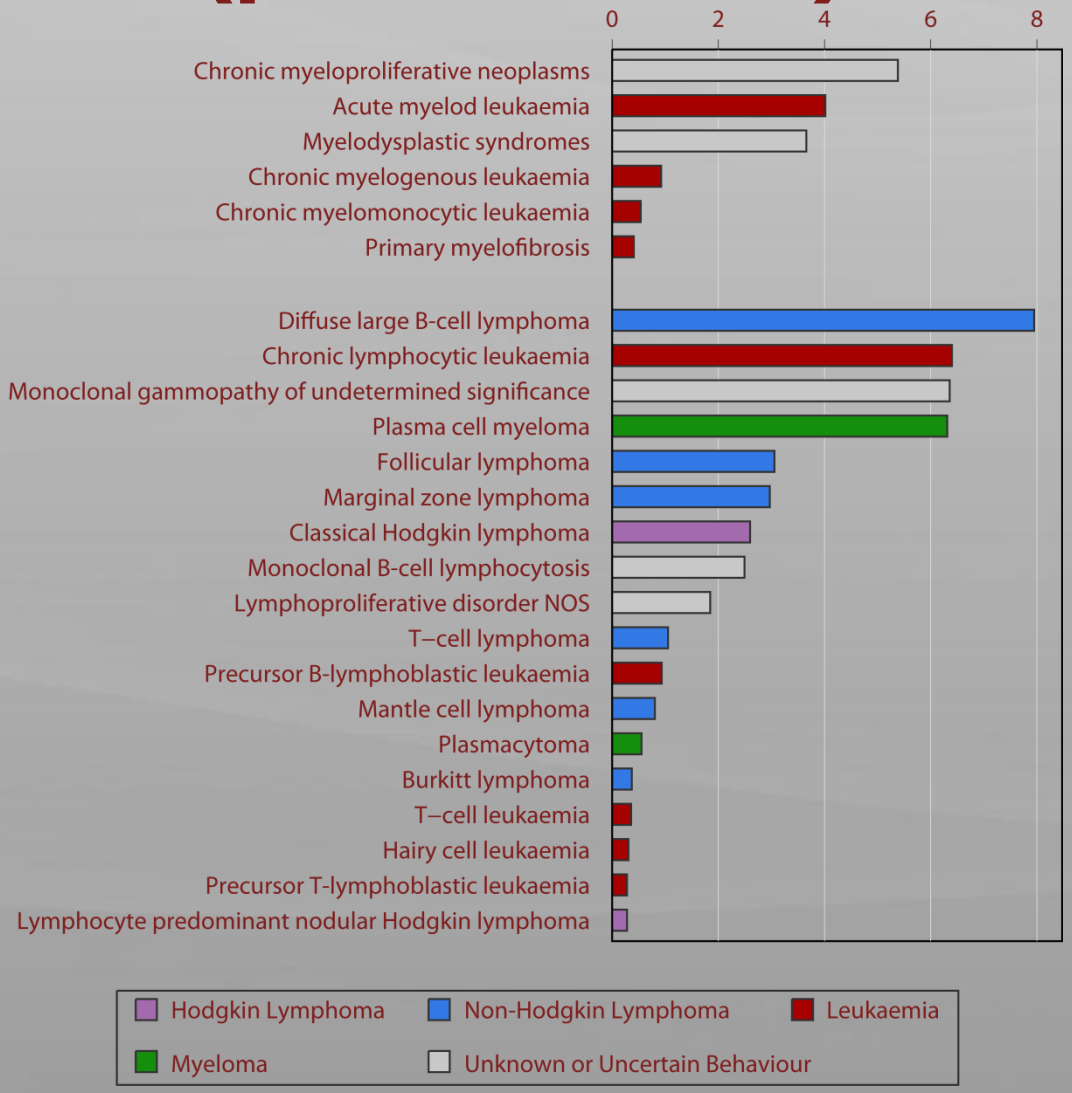
Haematological Malignancy Research Network

- Established 2004
- 2 Cancer Networks
- Cases ascertained from integrated diagnostic service - Haematological Malignancy Diagnostic Service
- Coded to ICD-O3
- Treatment, prognostic & outcome data



HMRN annual incidence rates (per 100,000)

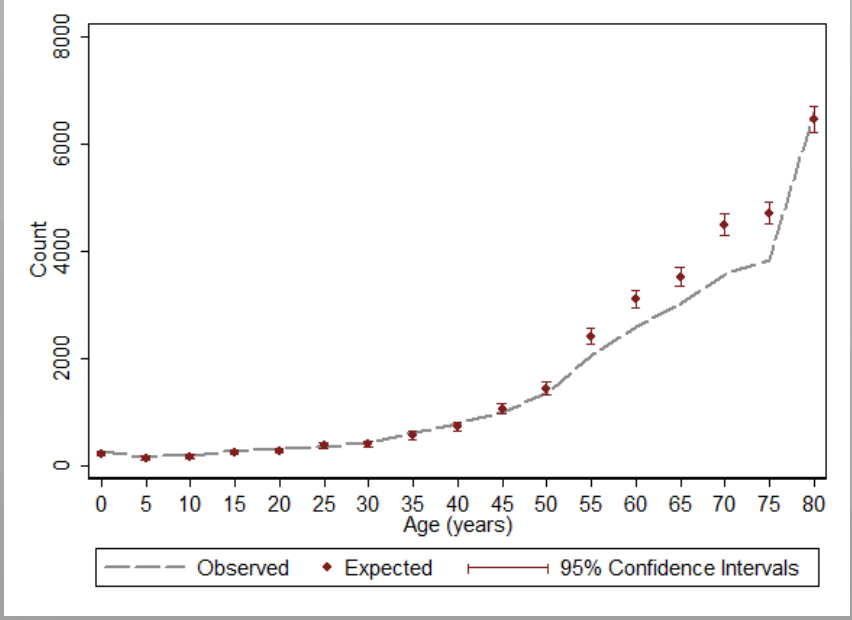


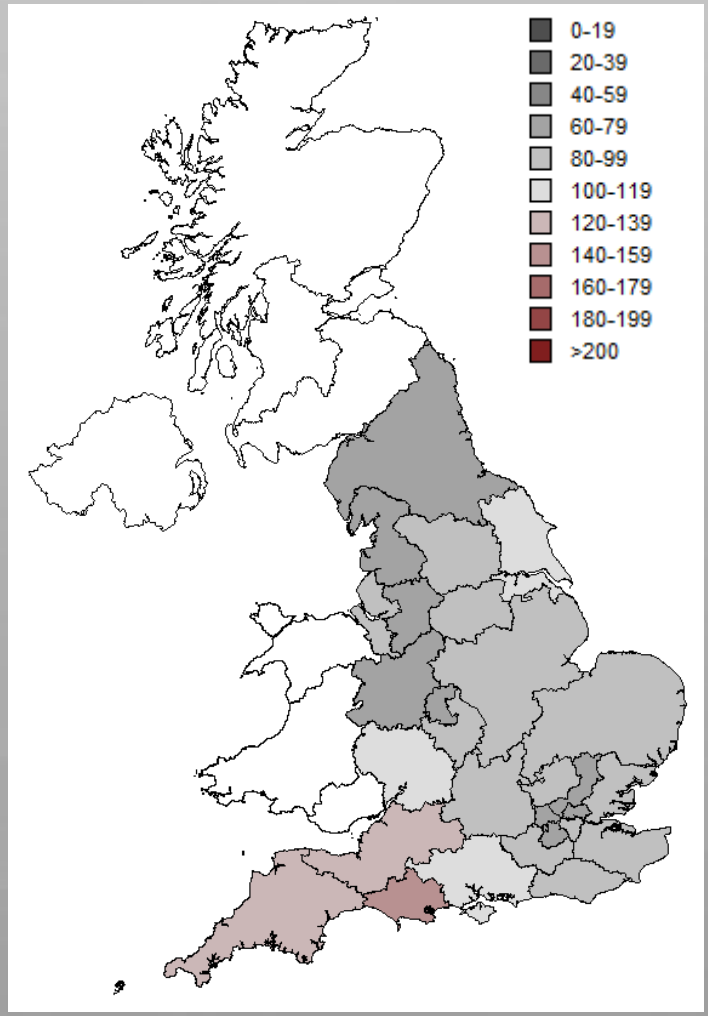
Methods Expected Data - HMRN

- Incidence (95% CI) rates estimated using HMRN 2004-2010 cases
  - 5-year age strata
  - Sex
- Expected numbers estimated by diagnostic group
  - Nationally
  - Cancer Registry
  - Cancer Network
- Observed:Expected & 95% Confidence Intervals

All Haematological Registrations

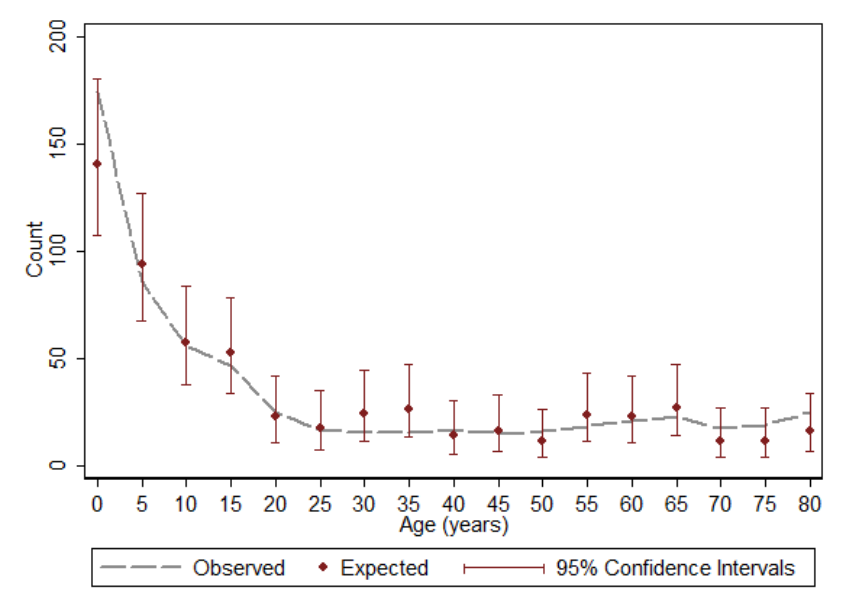
Observed= 26,827
Expected= 30,100
O/E= 89% (CI: 88-90)

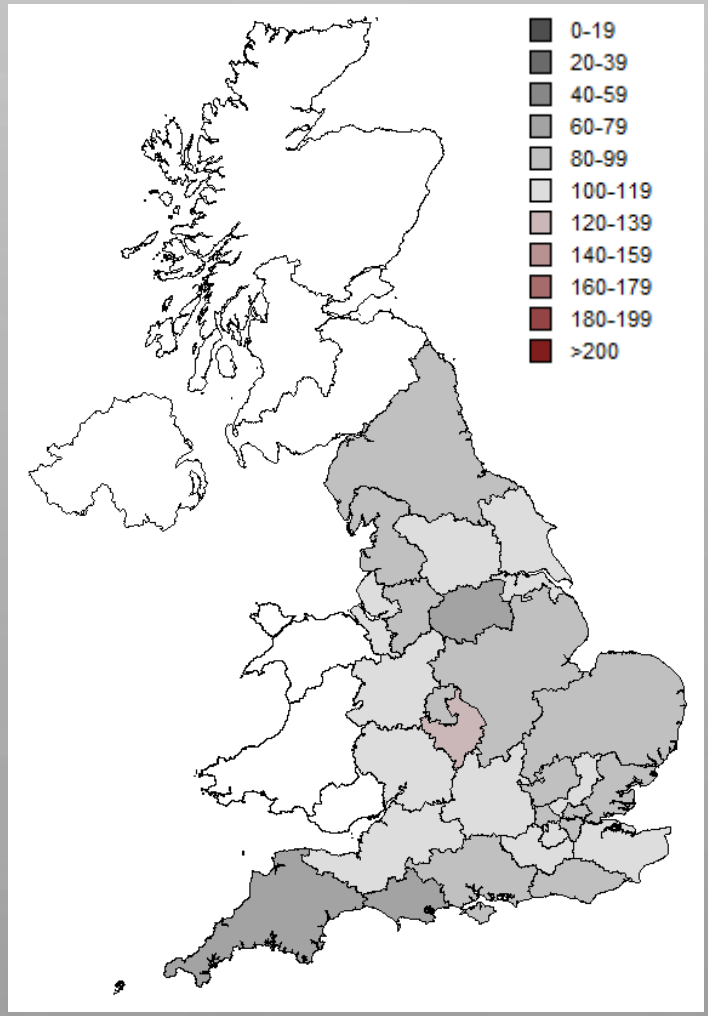




Acute Lymphoblastic Leukaemia

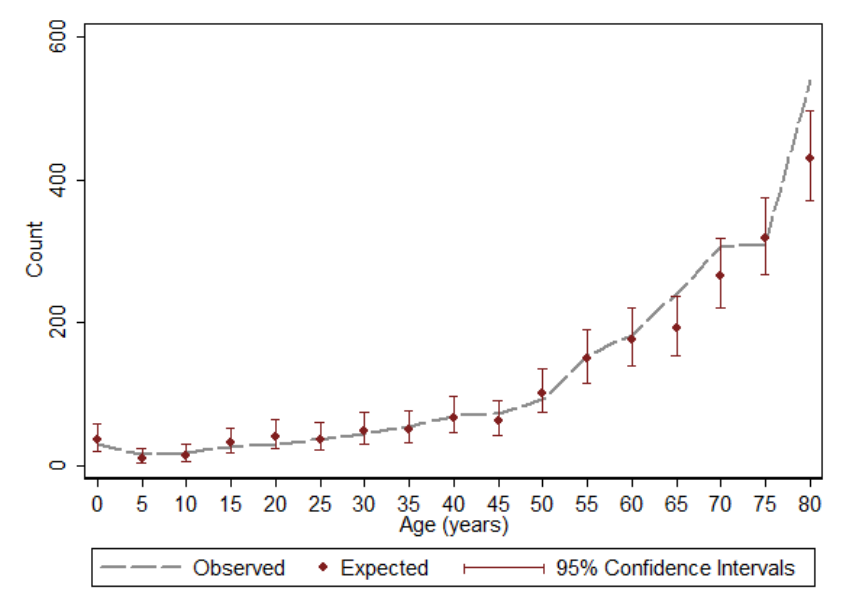
Observed=602
Expected= 592
O/E= 101.7% (CI: 94-110)

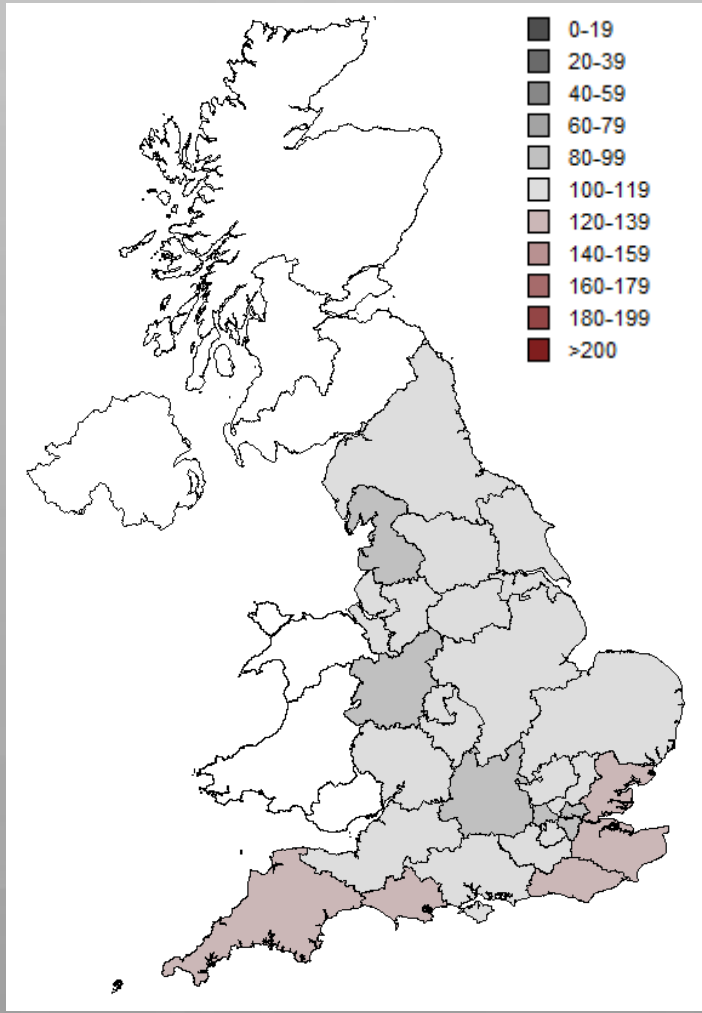




Acute Myeloid Leukaemia

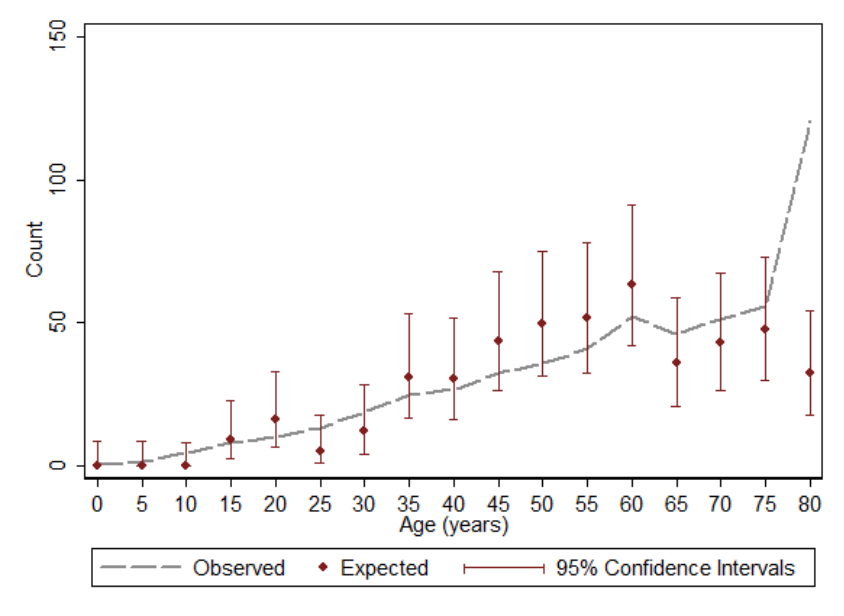
Observed= 2,217
Expected= 2,030
O/E= 109.2% (CI: 105-114)

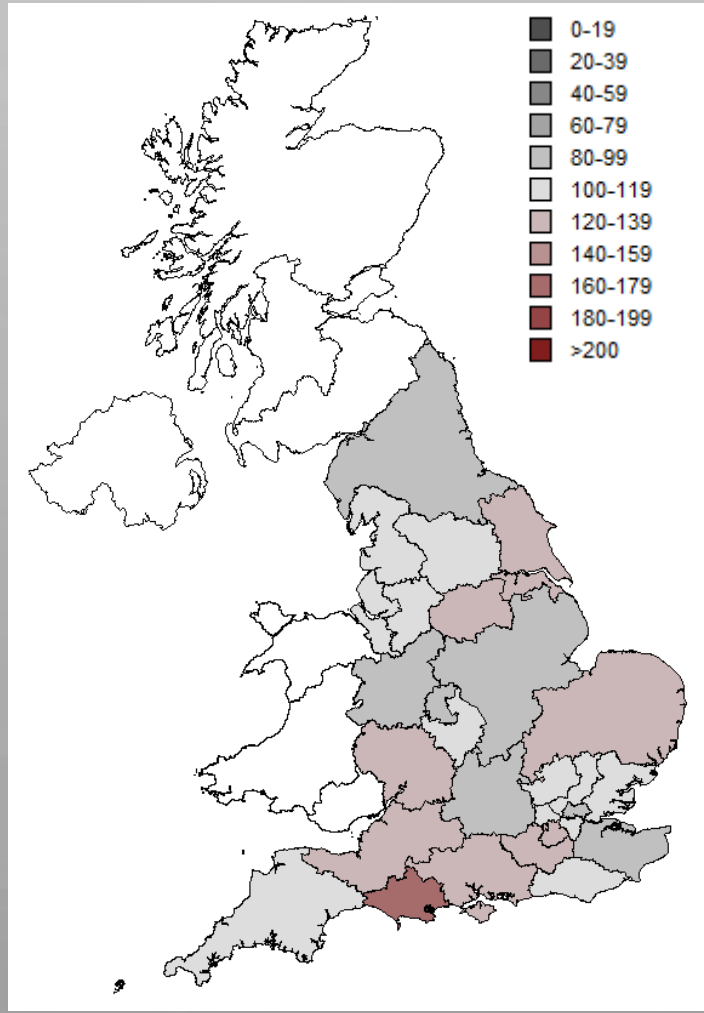




Chronic Myeloid Leukaemia

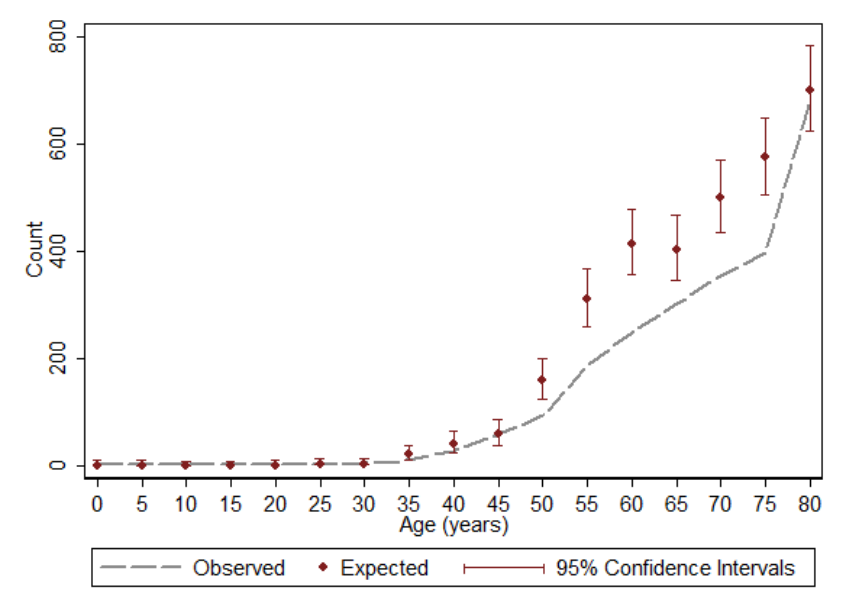
Observed= 540
Expected= 470
O/E= 114.9% (CI: 105-125)

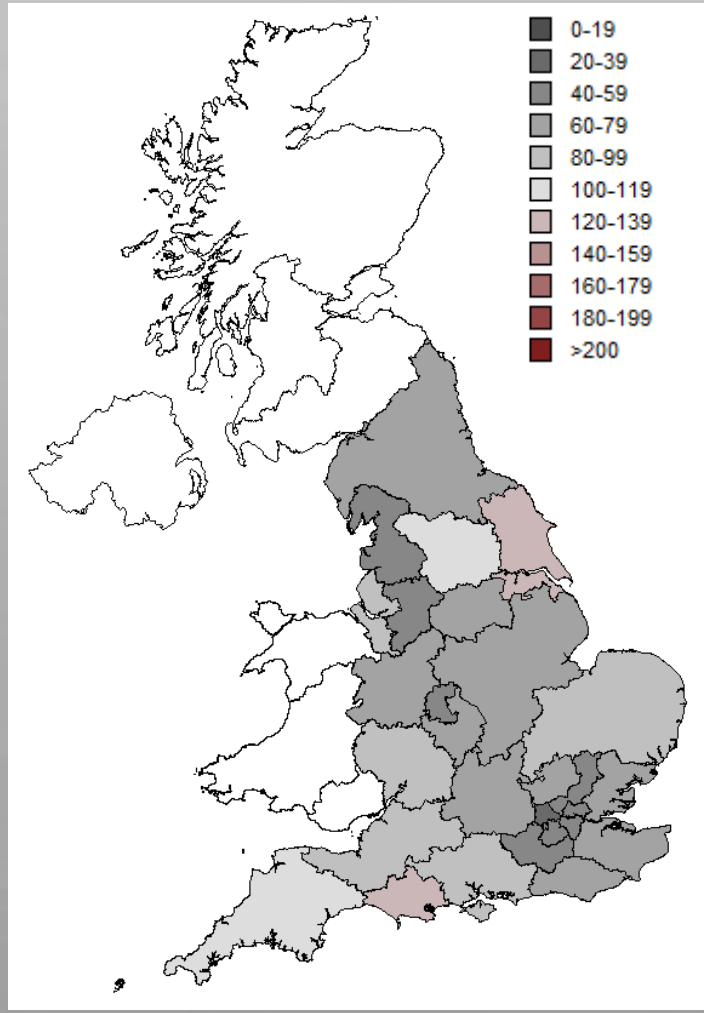




Chronic Lymphocytic Leukaemia

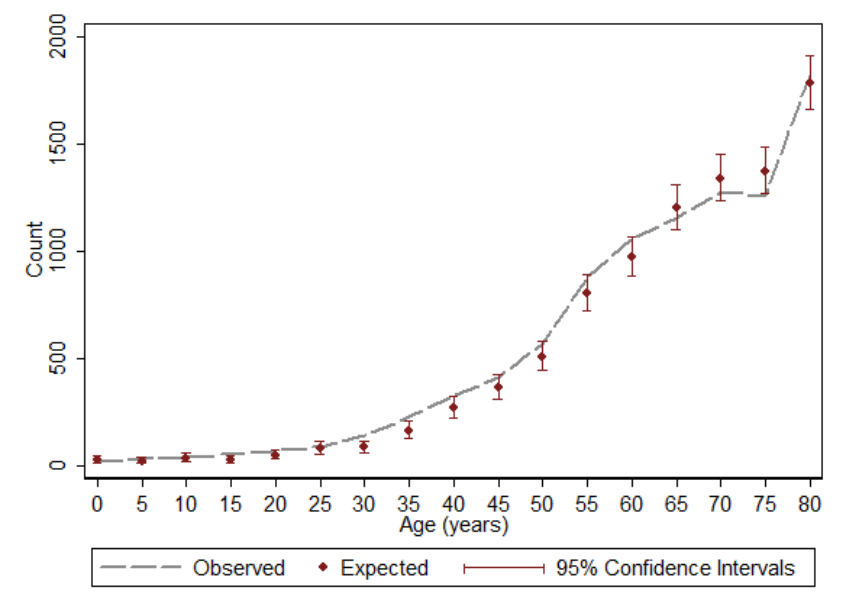
Observed= 2,364
Expected= 3,197
O/E= 73.9% (CI: 71-77)

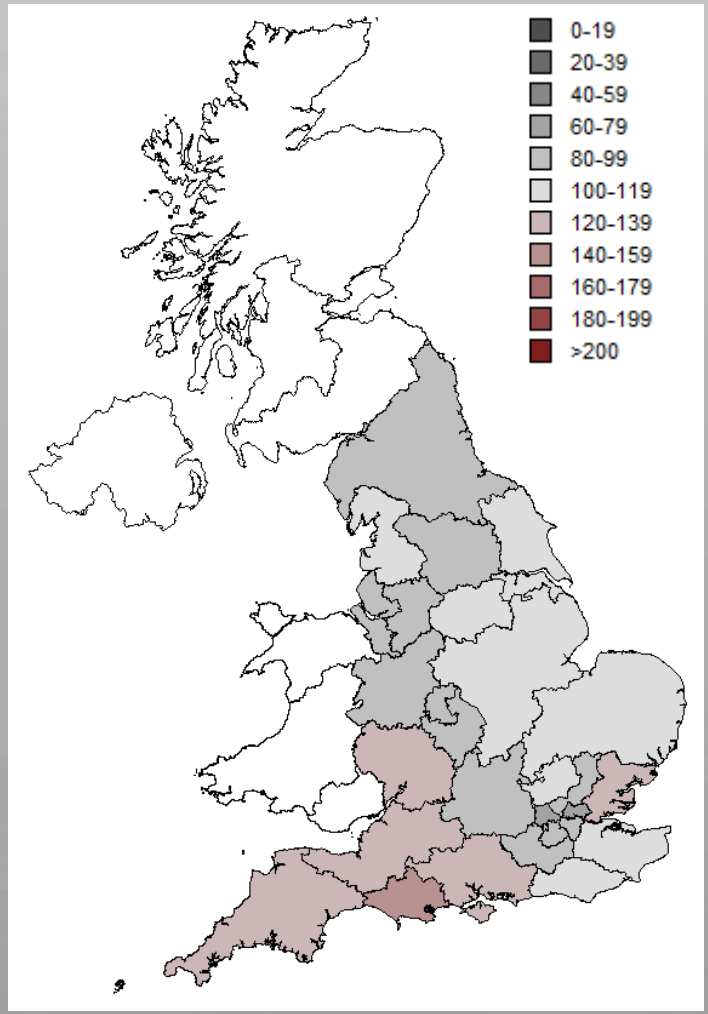




Non-Hodgkin Lymphoma

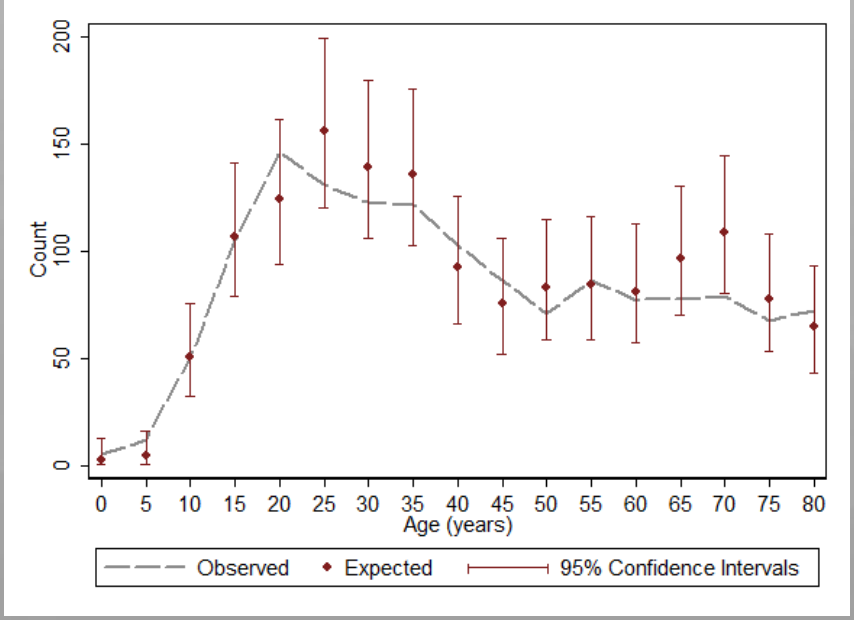
Observed=9,397
Expected= 9,120
O/E= 103% (CI: 101-105)

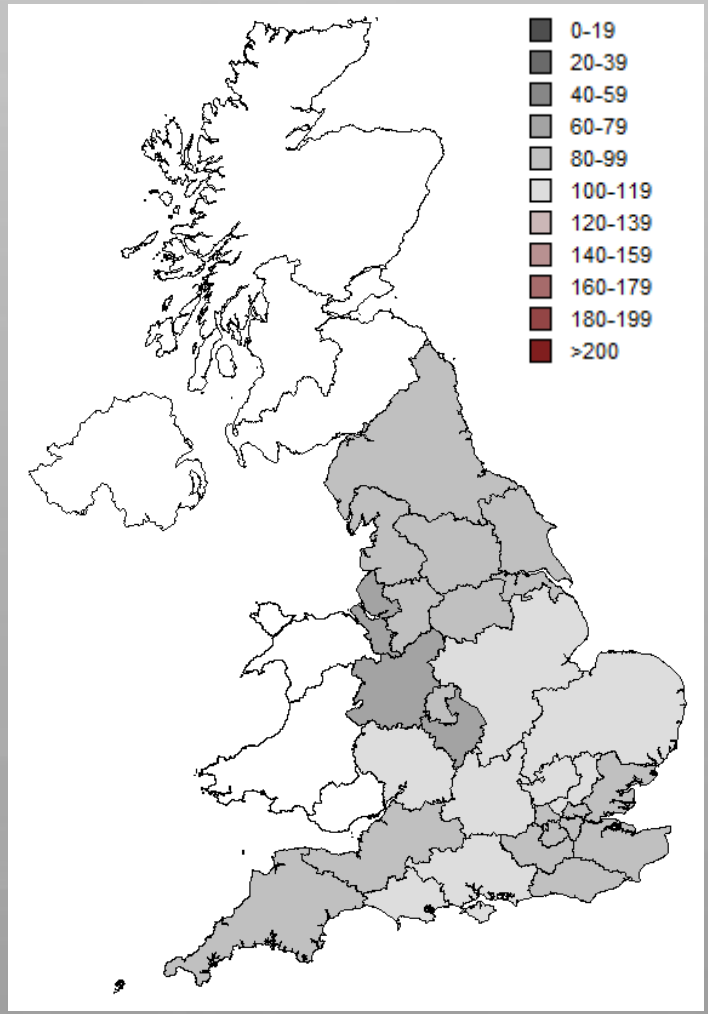




Hodgkin Lymphoma

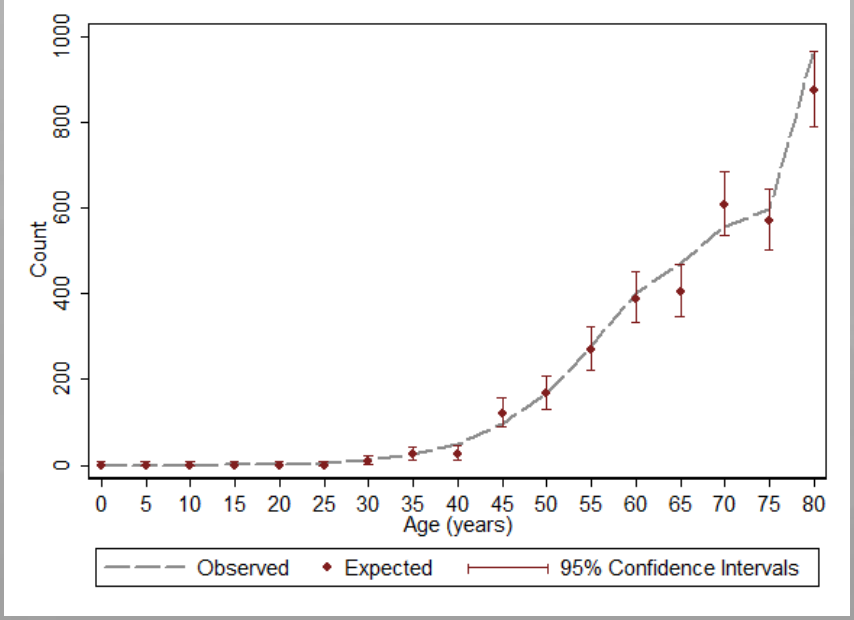
Observed= 1,413
Expected= 1,477
O/E= 95.7% (CI: 91-101)

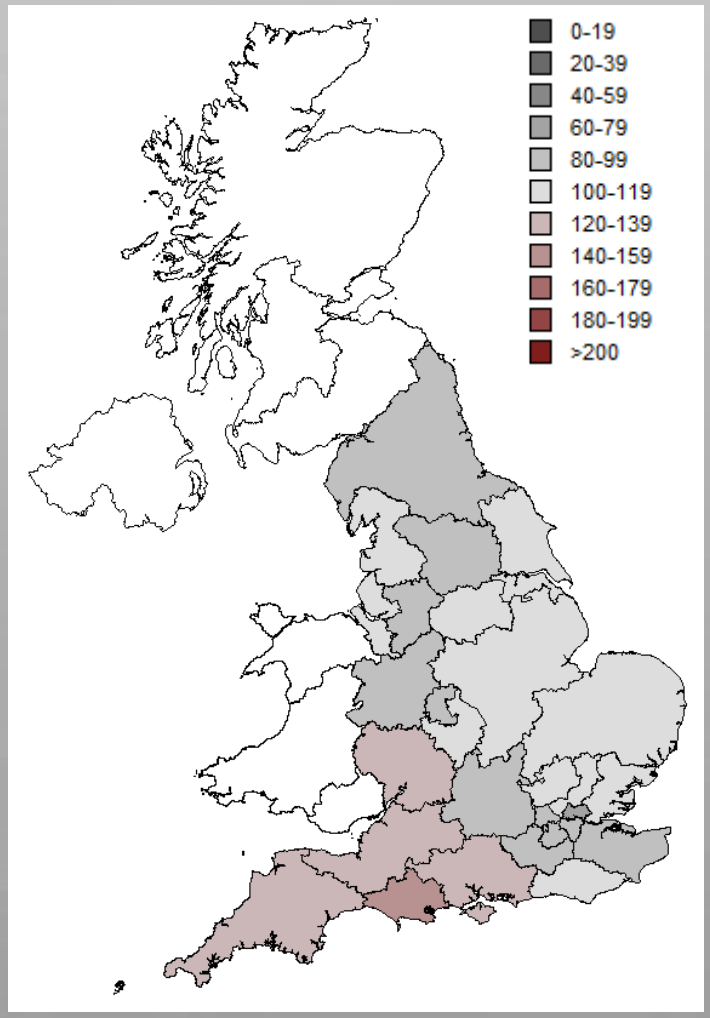




Myeloma

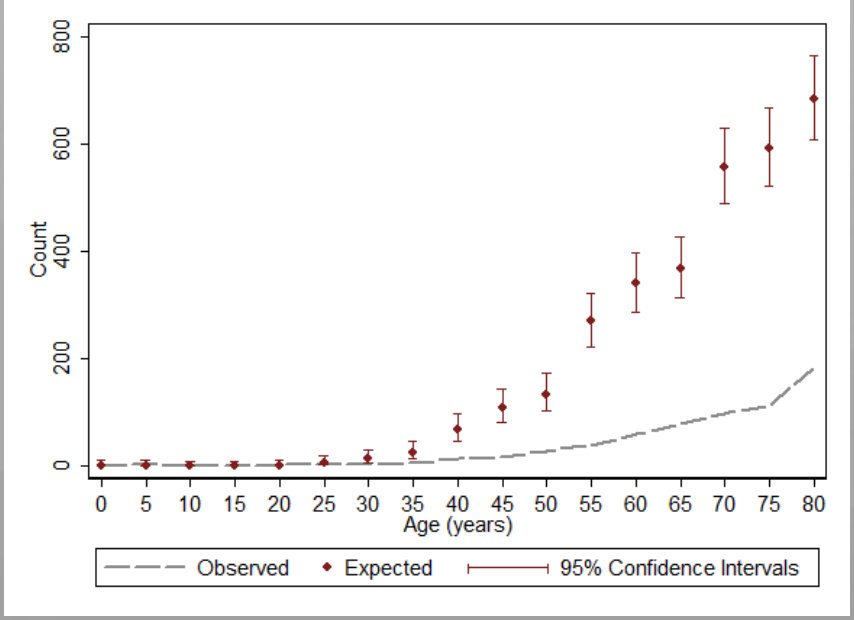
Observed= 3,633
Expected= 3,479
O/E= 104.4% (CI: 101-108)

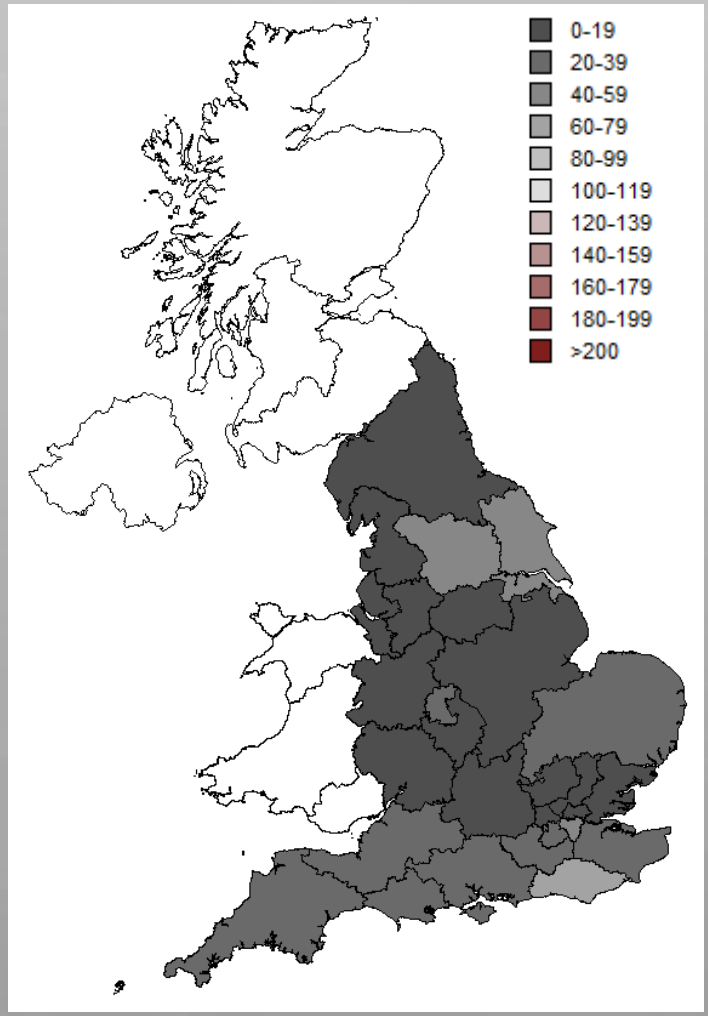




Monoclonal Gammopathy of Undetermined Significance

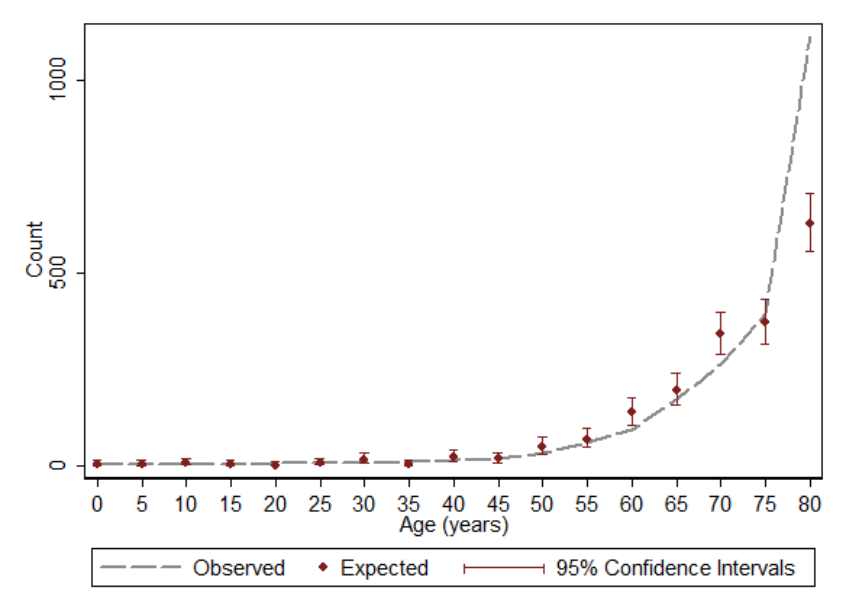
Observed= 623
Expected= 3,169
O/E= 19.7% (CI: 18-21)

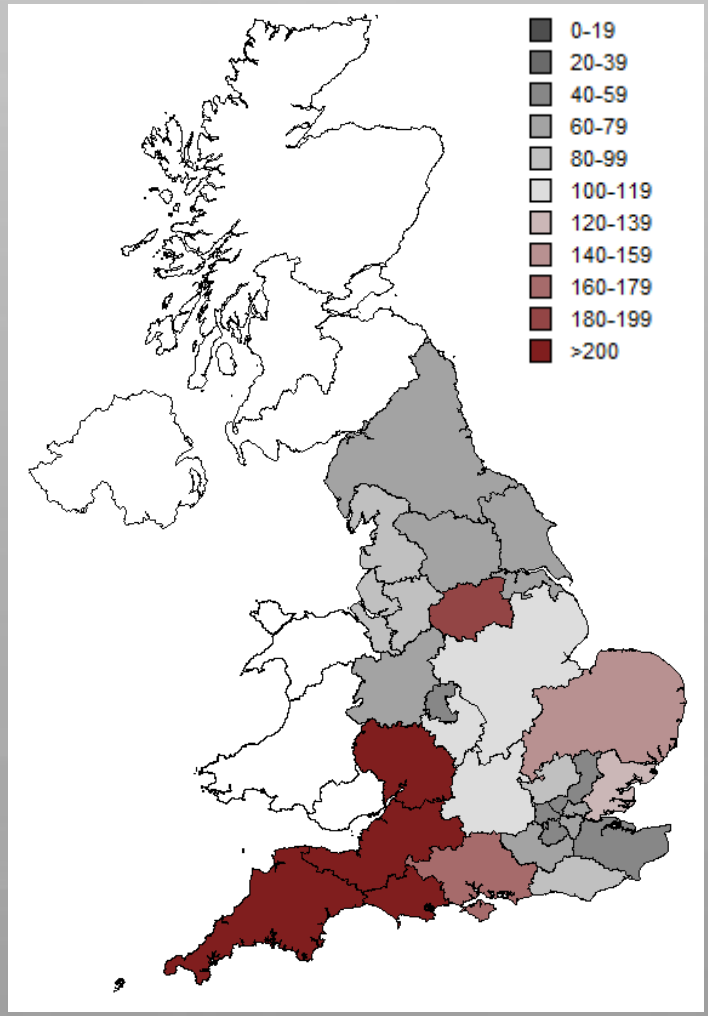




Myelodysplastic Syndromes

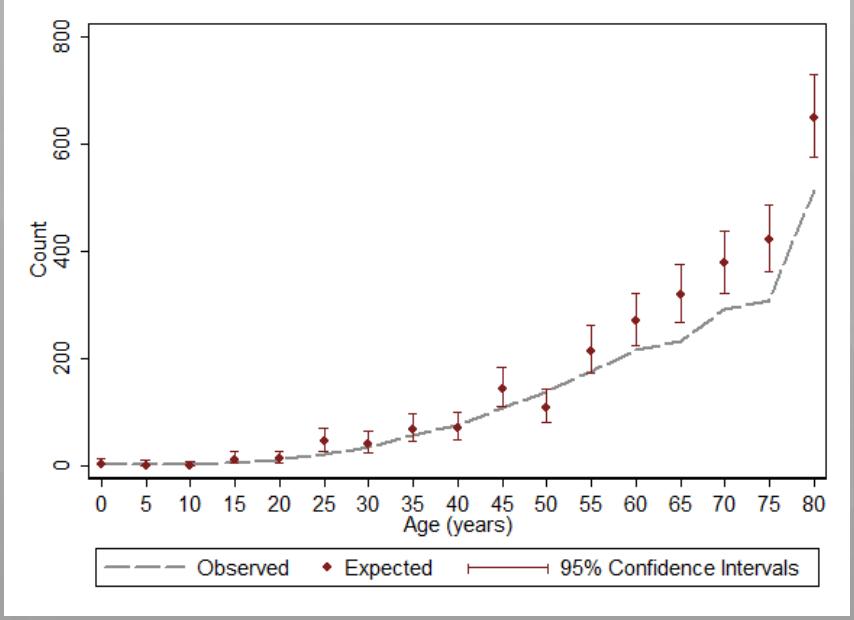
Observed= 2,187
Expected= 1,876
O/E= 116.6% (CI: 112-122)

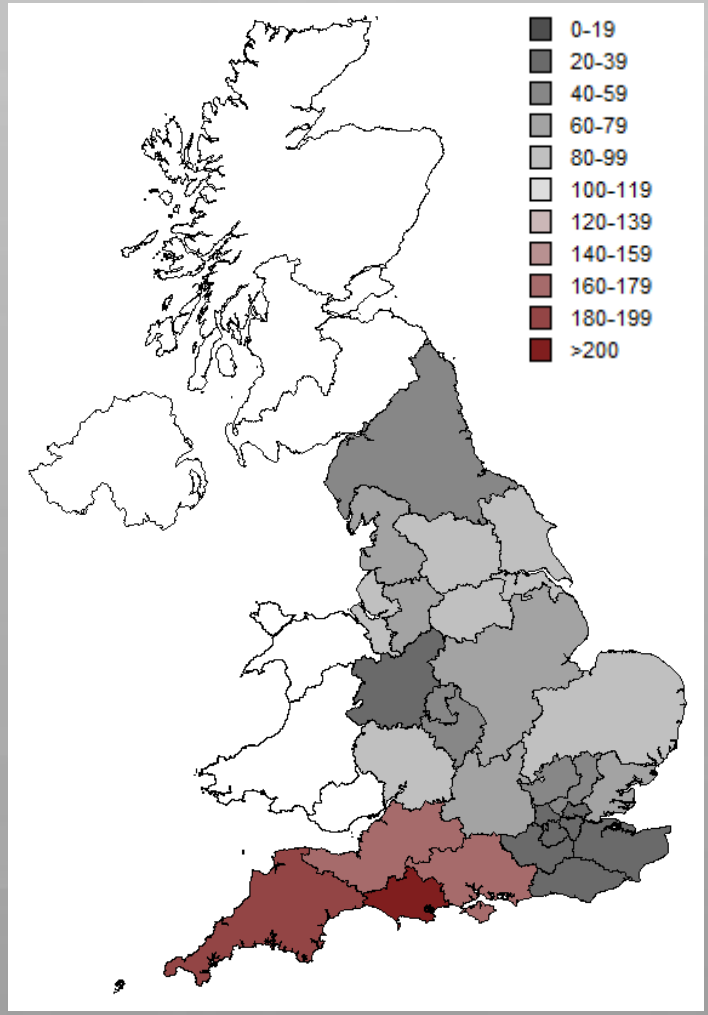




Myeloproliferative Neoplasms

Observed= 2,187
Expected= 2,745
O/E= 79.7% (CI: 76-83)

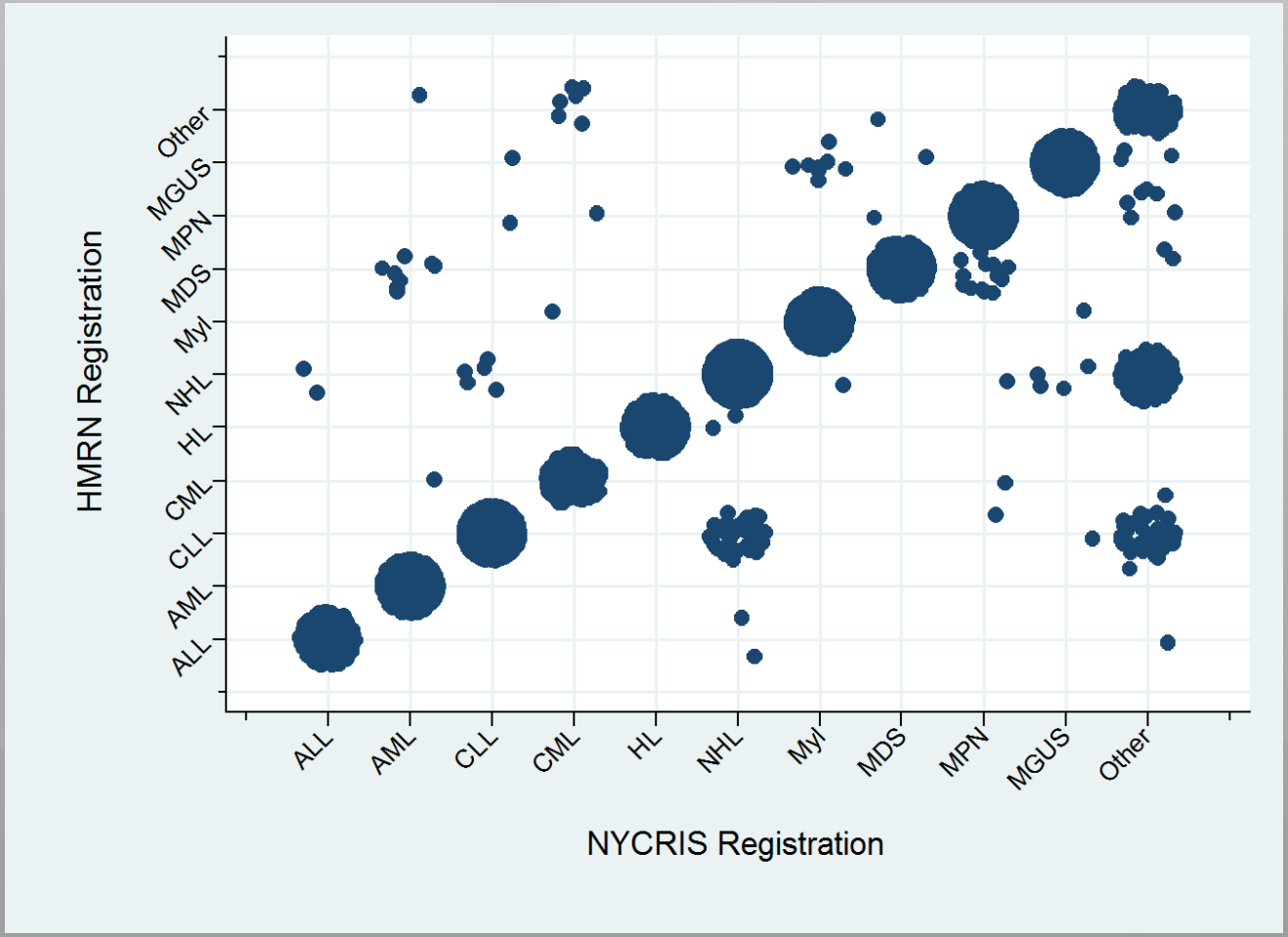




Summary

	O/E (95% CI)	O-E
Total	89% (CI: 88-90)	-3273
MDS	116.6% (CI: 112-122)	311
CML	114.9% (CI: 105-125)	70
AML	109.2% (CI: 105-114)	187
Myeloma	104.4% (CI: 101-108)	154
NHL	103% (CI: 101-105)	277
ALL	101.7% (CI: 94-110)	10
HL	95.7% (CI: 91-101)	-64
MPN	79.7% (CI: 76-83)	-558
CLL	73.9% (CI: 71-77)	-835
MGUS	19.7% (CI: 18-21)	-2546

Comparison between NYCRIS and HMRN



Summary

- Good agreement between observed and expected numbers for 7/10 diagnostic groups
- There is geographic variation which does not reflect underlying aetiological factors
- National leukaemia data can be reported by clinically meaningful groups ?NHL
- Caveats:
  - HMRN's rates based on lowest estimate
    - "new to haematology 2004"
    - 100% pathologically confirmed
  - Difficulties bridge-coding WHO classification to ICD10
    - i.e. Blast count for AML

Acknowledgements

- NCIN for commissioning & funding the report
- NYCRIS
  - Ed Bolton, Caroline Brook, Brian Ferguson, Steven Oliver, Shelia Pass
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