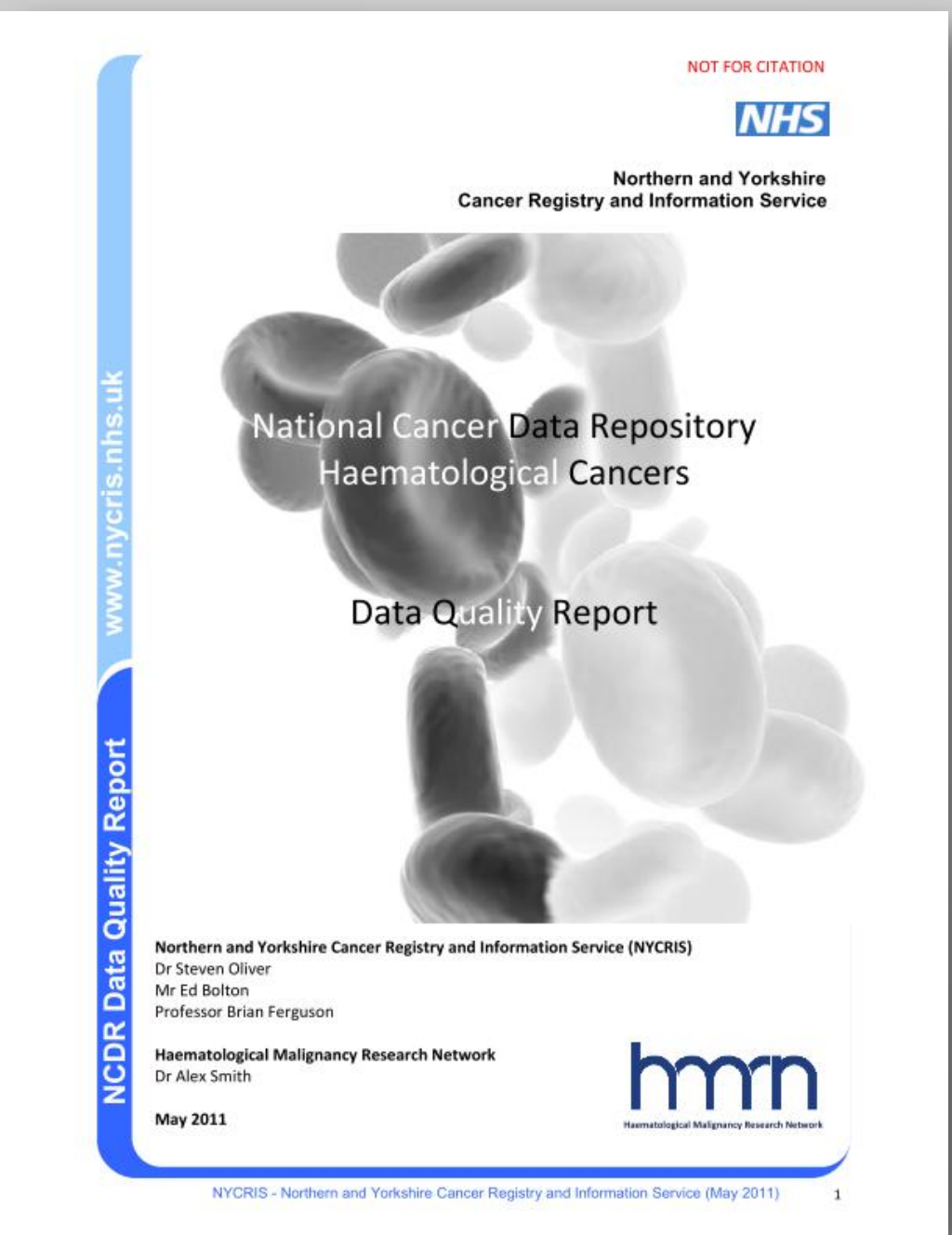
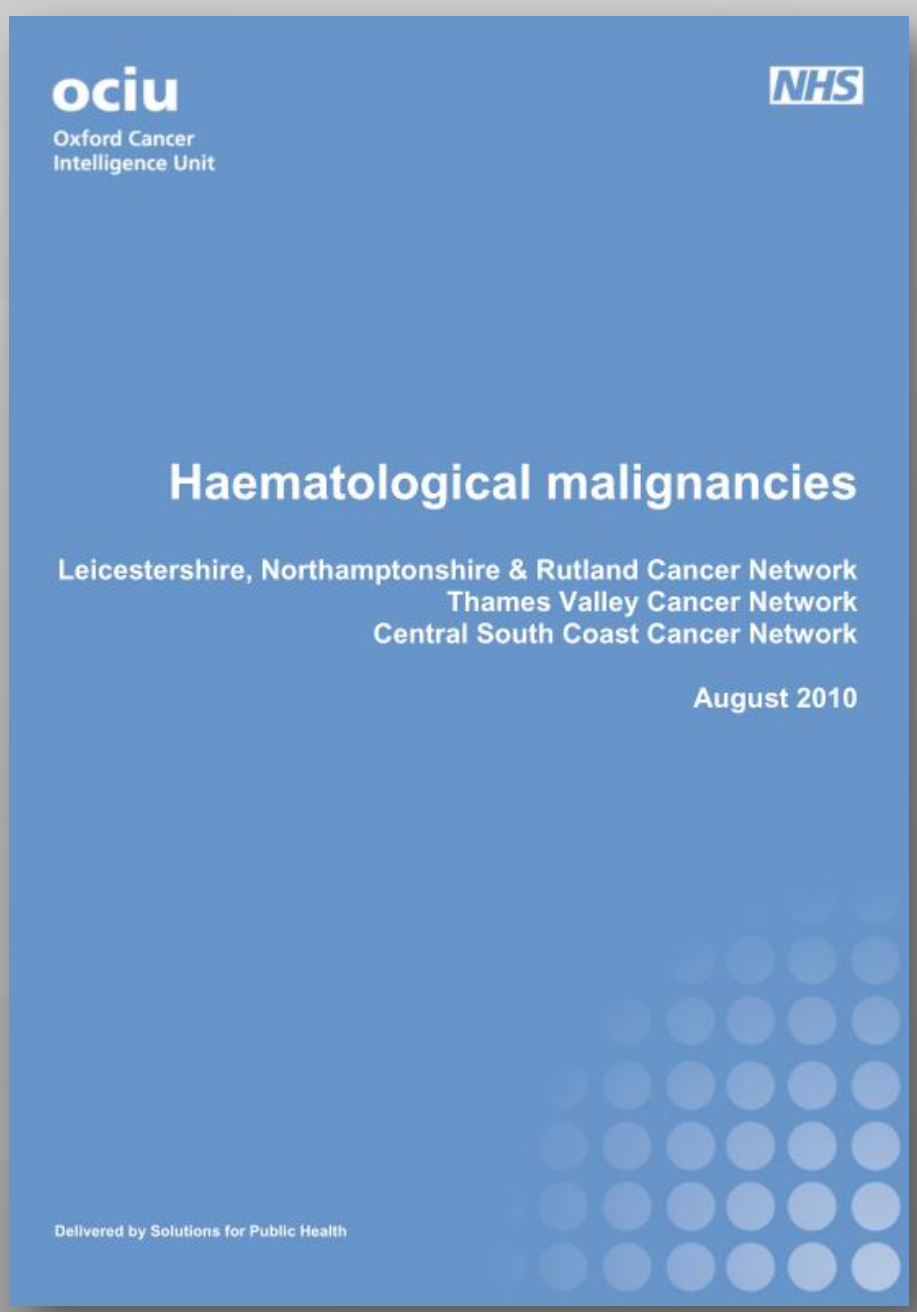
# Ongoing and planned analyses of data on haematological malignancies

# Data quality



# Incidence, mortality and survival of haematological cancer by ‘clinically meaningful categories’



# Evaluation of routine national cancer registration for haematological malignancy using population-based data from a specialist haematological malignancy register

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

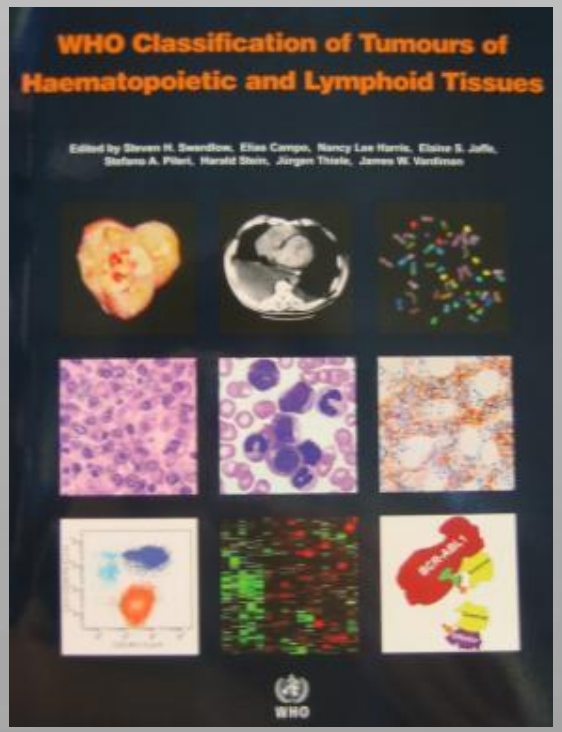
- *'There are no precise and reliable figures for incidence and survival rates for the different forms of haematological cancers in England and Wales.'*

- *'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.'*

# Haematological malignancy classification

2001 - WHO consensus classification defined individual disease entities in terms of:

- Morphology
- Immunophenotype
- Molecular Cytogenetics
- Clinical features




Adopted into clinical practice almost uniformly around the world

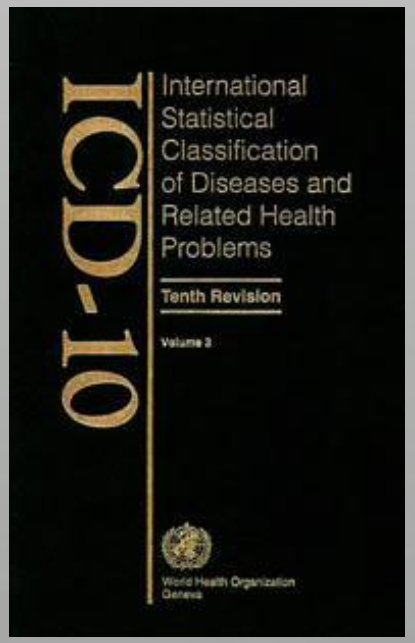
# The problem

- Haematological neoplasms are diagnosed using multiple parameters including a combination of:-

- Histology
- Cytology
- Immunophenotyping
- Cytogenetics
- Imaging
- Clinical data

➢ This range of data is difficult for cancer registries to systematically abstract

➢ Widespread use anatomically based classifications has continued



# Main Objectives

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

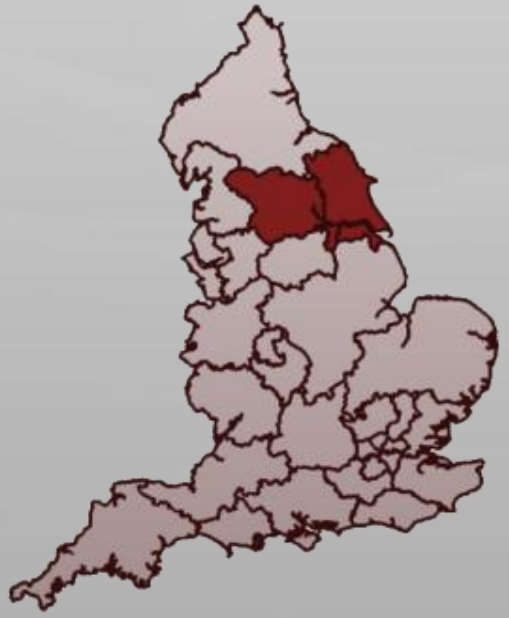
- In collaboration with UK cancer registries, conduct comparisons of predicted and observed cancer registrations to evaluate the quality of routine cancer registration

# HAEMATOLOGICAL MALIGNANCY RESEARCH NETWORK

# HMRN - where

- Population 3.6 million

- Similar socio-demographic structure to the UK
  - Age
  - Sex
  - Urban/rural status
  - Affluence/deprivation

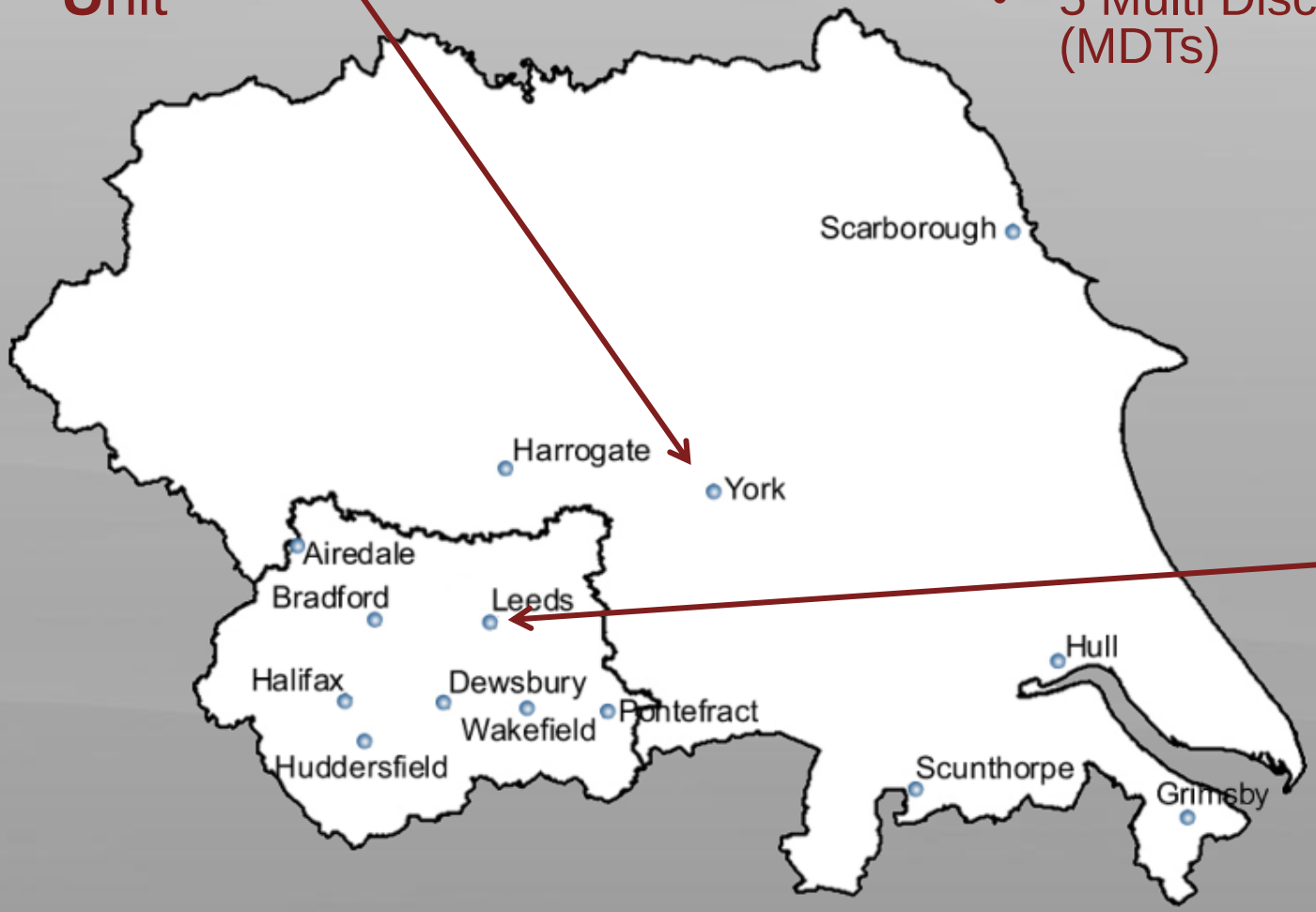


# HMRN - Who

**E**pidemiology &
**G**enetics
**U**nit

**Clinical Network**

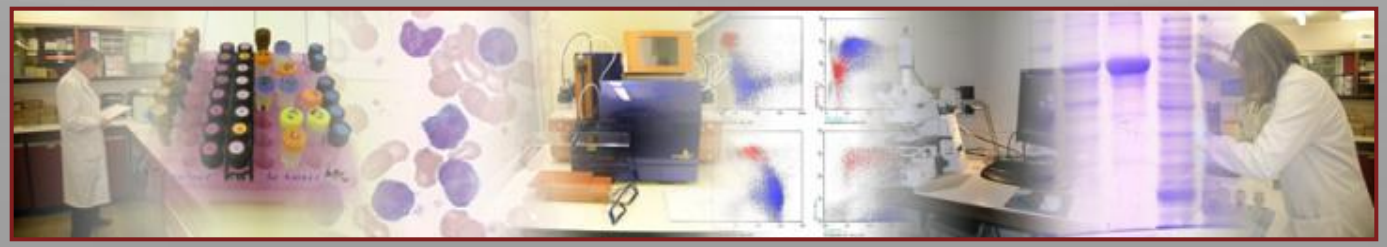
- 2 Cancer Networks
- 14 Hospitals
- 5 Multi Disciplinary Teams (MDTs)



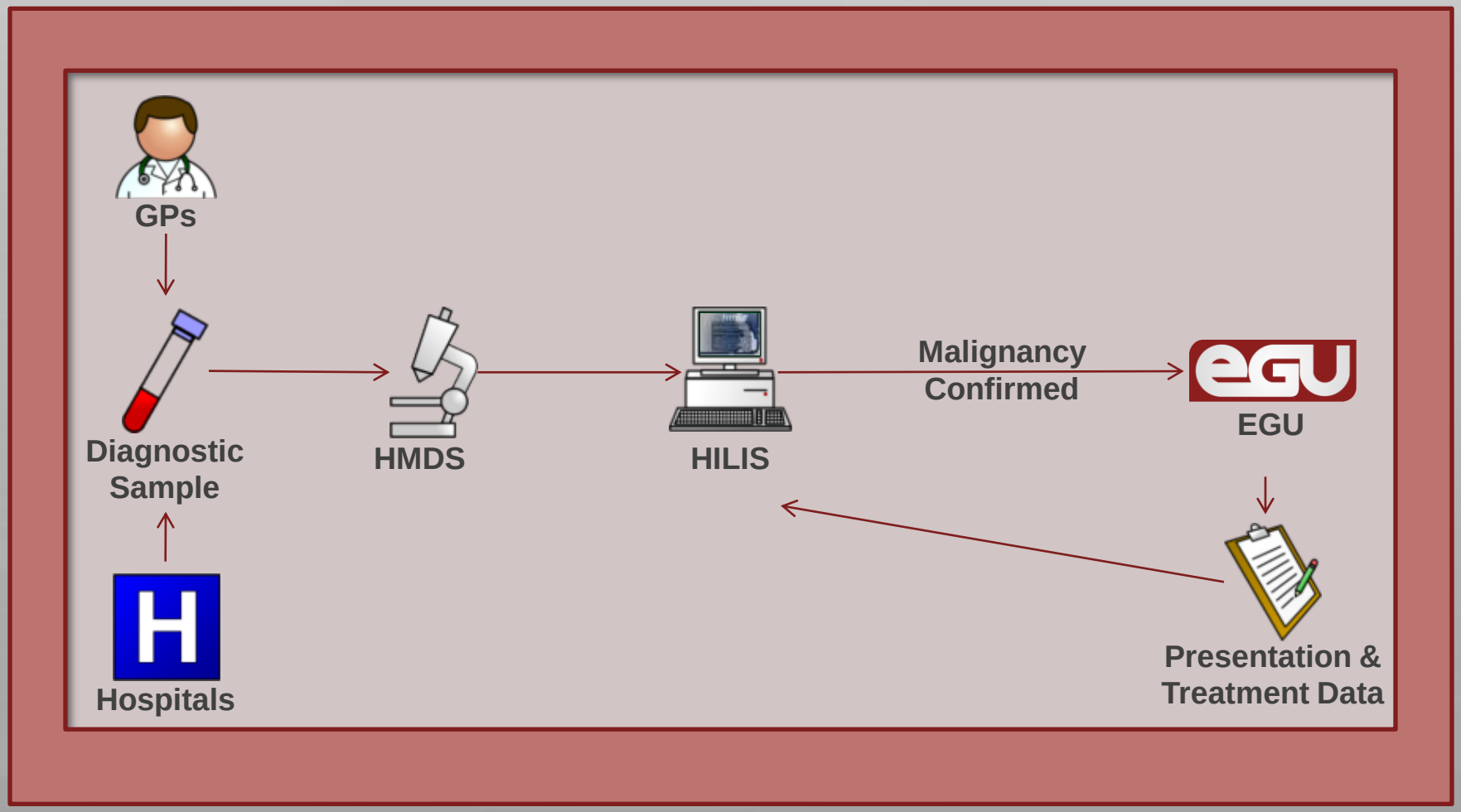

**H**aematological
**M**alignancy
**D**iagnostic
**S**ervice

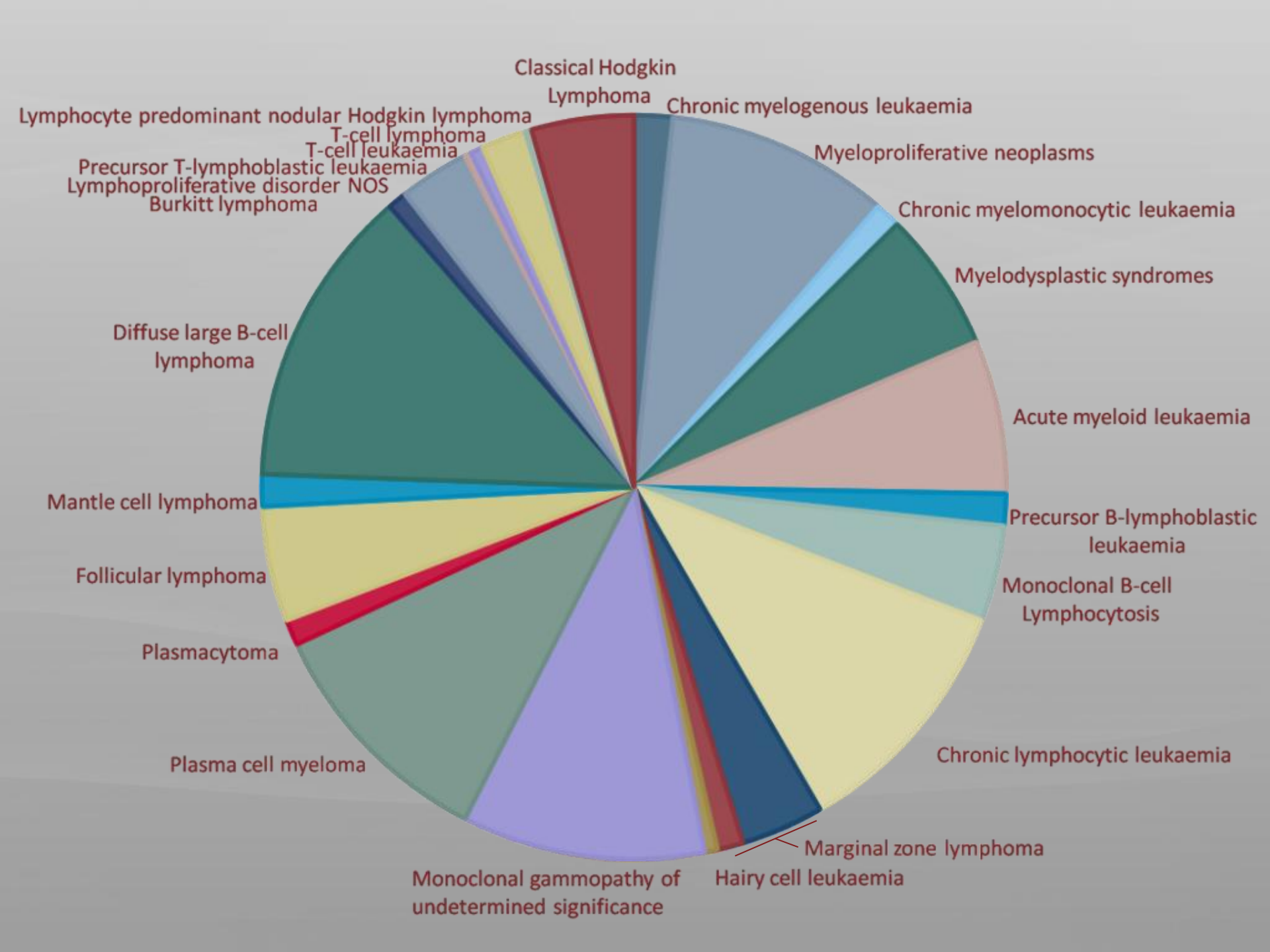
# Haematological Malignancy Diagnostic Service

- Central specialist diagnostic laboratory
- Providing a fully integrated diagnostic pathway
  - Including histology, cytology, immunophenotyping & molecular genetics
- Cancer Reform Strategy 2007:
  - ‘model for the delivery of complex diagnostic services’
- HILIS:
  - **H**MDS **I**ntegrated **L**aboratory **I**nformation **S**ystem
  - In-house web based specimen tracking and reporting facility



# Case ascertainment and data collection




Classical Hodgkin Lymphoma
Chronic myelogenous leukaemia
Lymphocyte predominant nodular Hodgkin lymphoma
T-cell lymphoma
T-cell leukaemia
Myeloproliferative neoplasms
Precursor T-lymphoblastic leukaemia
Lymphoproliferative disorder NOS
Burkitt lymphoma
Chronic myelomonocytic leukaemia
Myelodysplastic syndromes
Diffuse large B-cell lymphoma
Acute myeloid leukaemia
Mantle cell lymphoma
Precursor B-lymphoblastic leukaemia
Follicular lymphoma
Monoclonal B-cell Lymphocytosis
Plasmacytoma
Chronic lymphocytic leukaemia
Plasma cell myeloma
Marginal zone lymphoma
Hairy cell leukaemia
Monoclonal gammopathy of undetermined significance

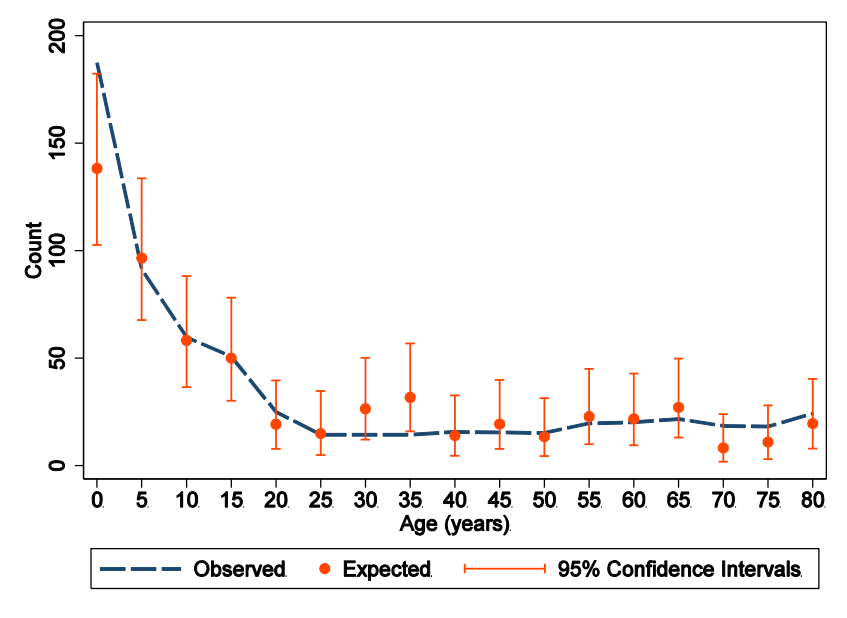
# Methods Observed Data - National Cancer Data Repository

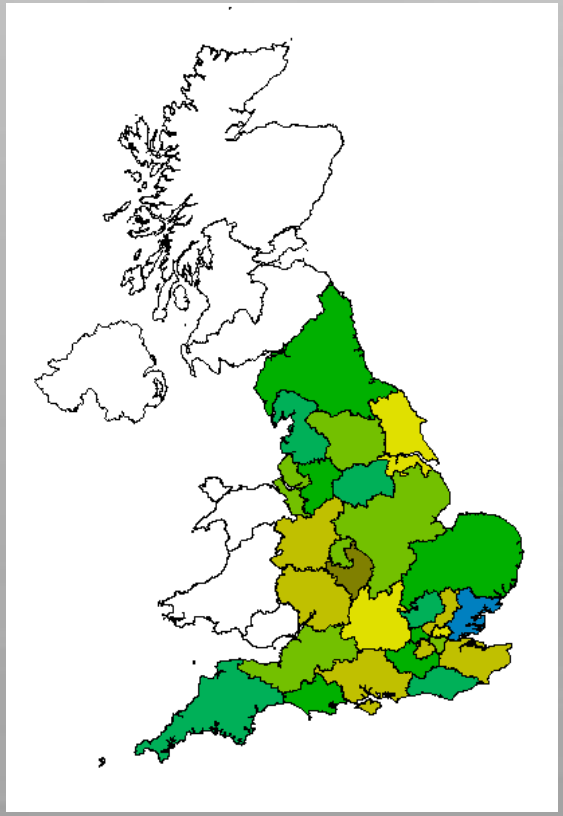
- Average annual observed counts calculated from 2004-2007 registrations for the following:
  - Acute Lymphoblastic Leukaemia
  - Acute Myeloid Leukaemia
  - Chronic Lymphocytic Leukaemia
  - Chronic Myeloid Leukaemia
  - Hodgkin Lymphoma
  - Non-Hodgkin Lymphoma
  - Myeloma

# Methods Expected Data - HMRN

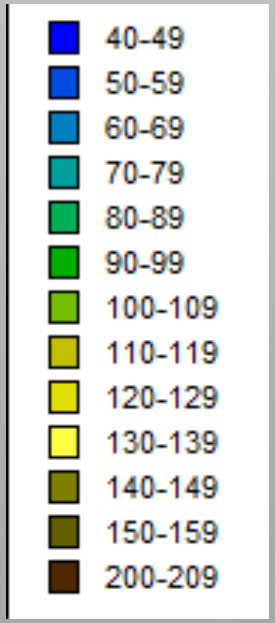
- Incidence (95% CI) rates estimated using HMRN 2004-2009 cases
  - 5-year age strata
  - Sex
- Expected numbers estimated by diagnostic group
  - Nationally
  - Cancer Network
- Observed:Expected & 95% Confidence Intervals

# National Observed/HMRN Expected ALL



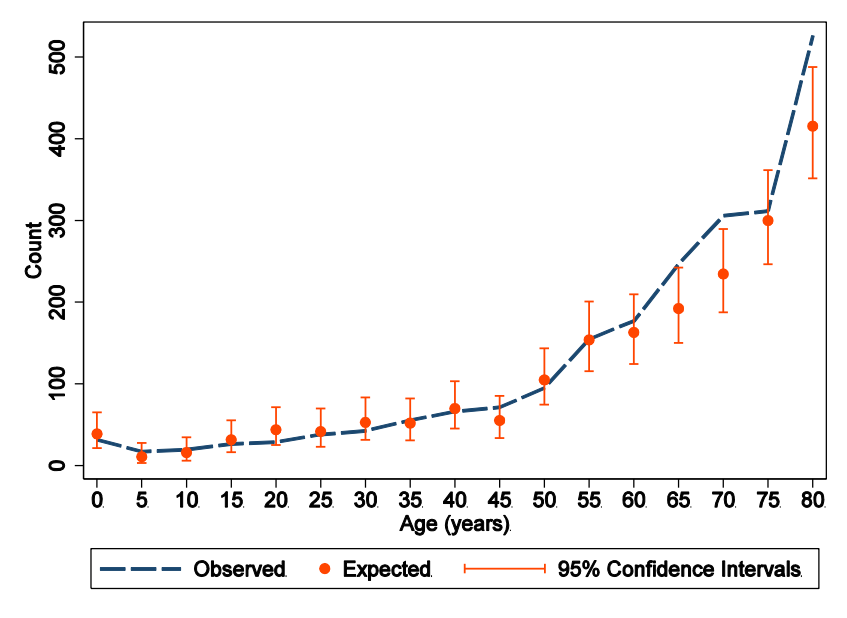



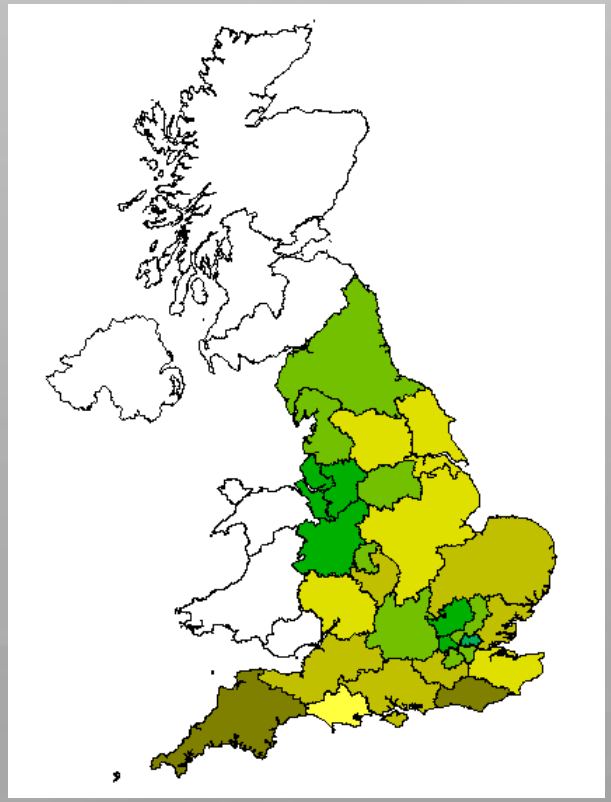
Obs:Exp




**Obs:Exp 106% (95% CI: 97-114%)**

# National Observed/HMRN Expected AML



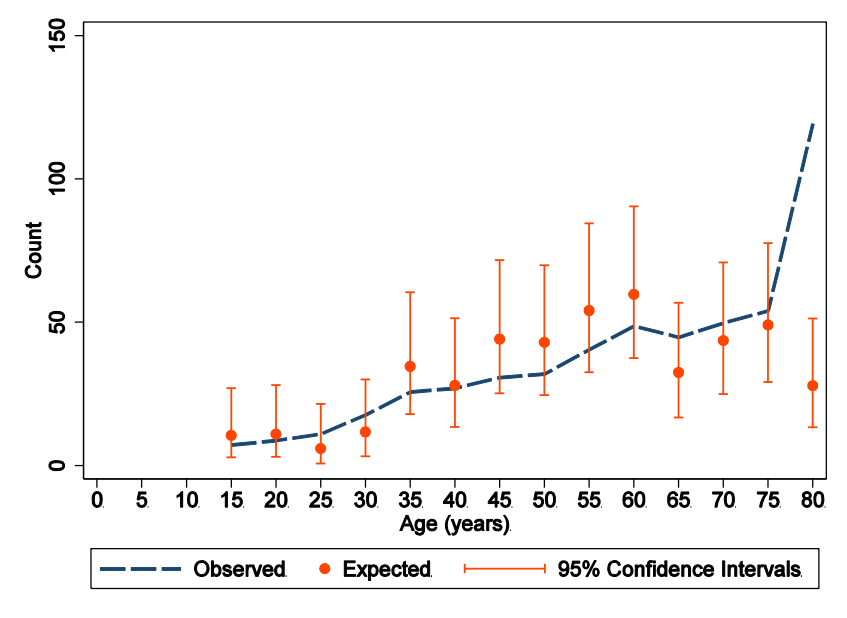



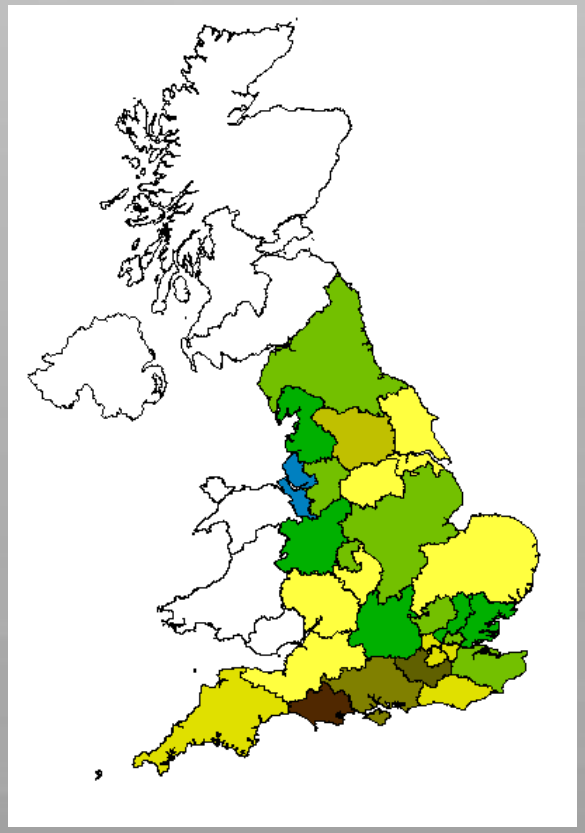
Obs:Exp

- 40-49
- 50-59
- 60-69
- 70-79
- 80-89
- 90-99
- 100-109
- 110-119
- 120-129
- 130-139
- 140-149
- 150-159
- 200-209

**Obs:Exp 113% (CI: 108-117)**

# National Observed/HMRN Expected CML



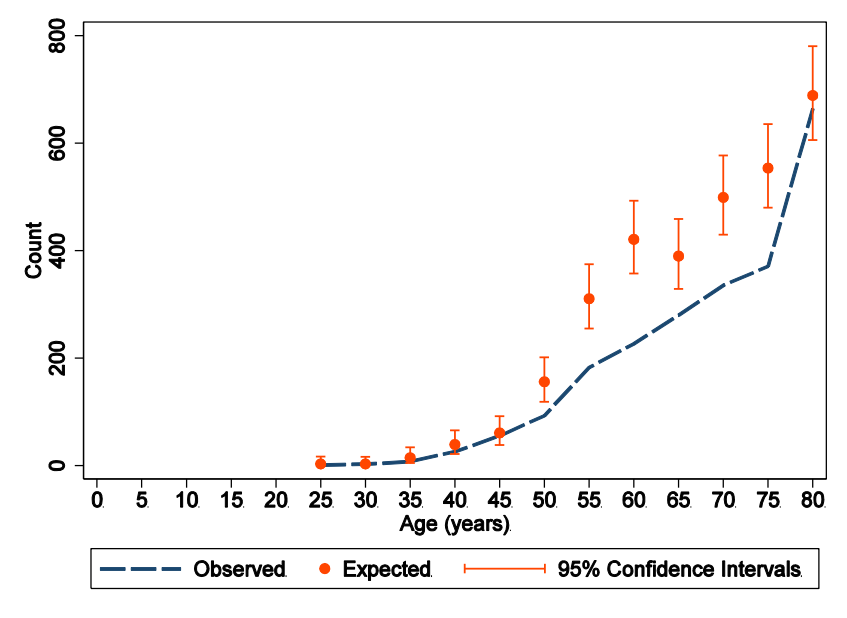



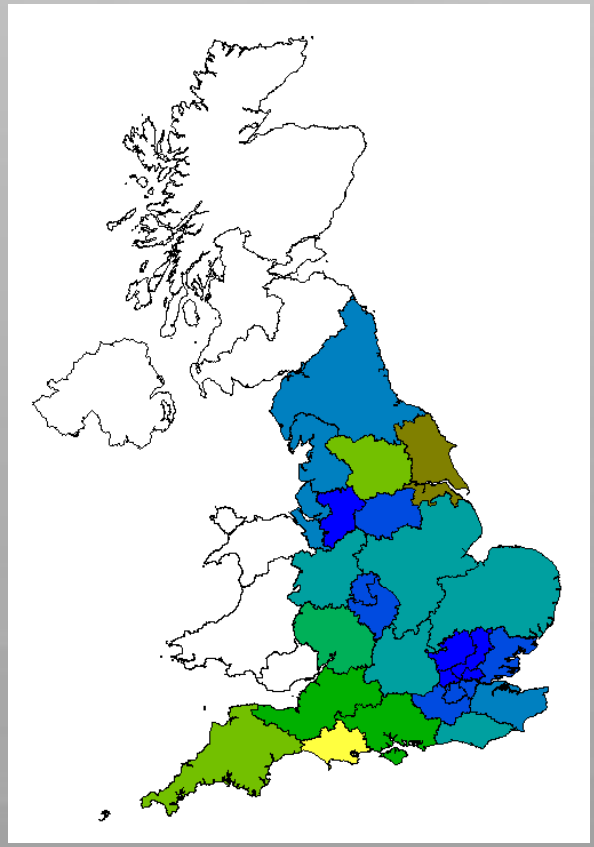
Obs:Exp

- 40-49
- 50-59
- 60-69
- 70-79
- 80-89
- 90-99
- 100-109
- 110-119
- 120-129
- 130-139
- 140-149
- 150-159
- 200-209

**Obs:Exp 115% (CI: 106-126%)**

# National Observed/HMRN Expected CLL



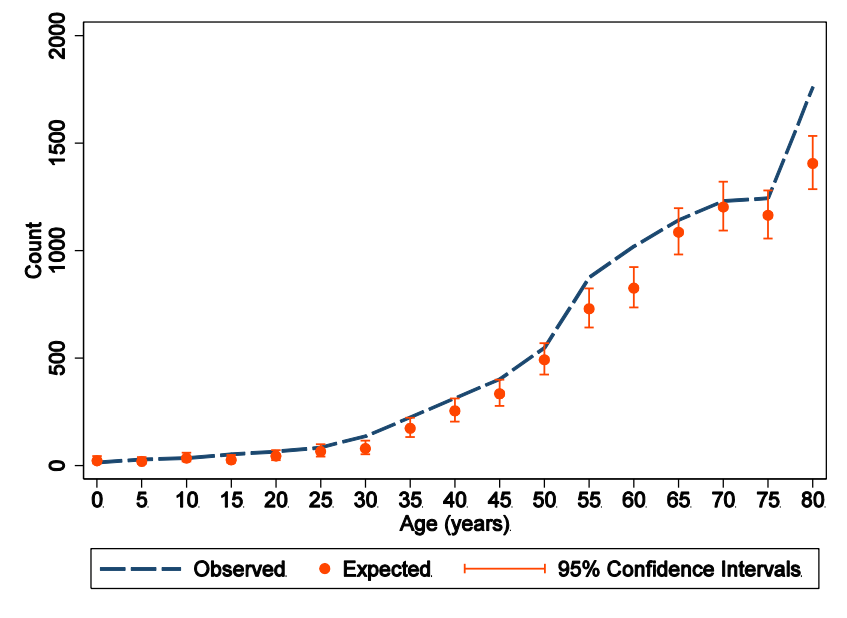



Obs:Exp

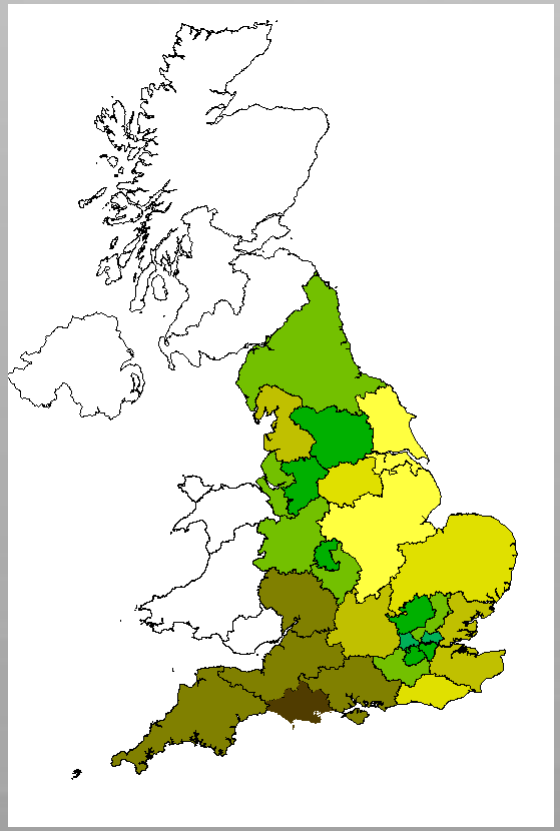
- 40-49
- 50-59
- 60-69
- 70-79
- 80-89
- 90-99
- 100-109
- 110-119
- 120-129
- 130-139
- 140-149
- 150-159
- 200-209

**Obs:Exp 72% (CI: 69-75%)**

# National Observed/HMRN Expected NHL



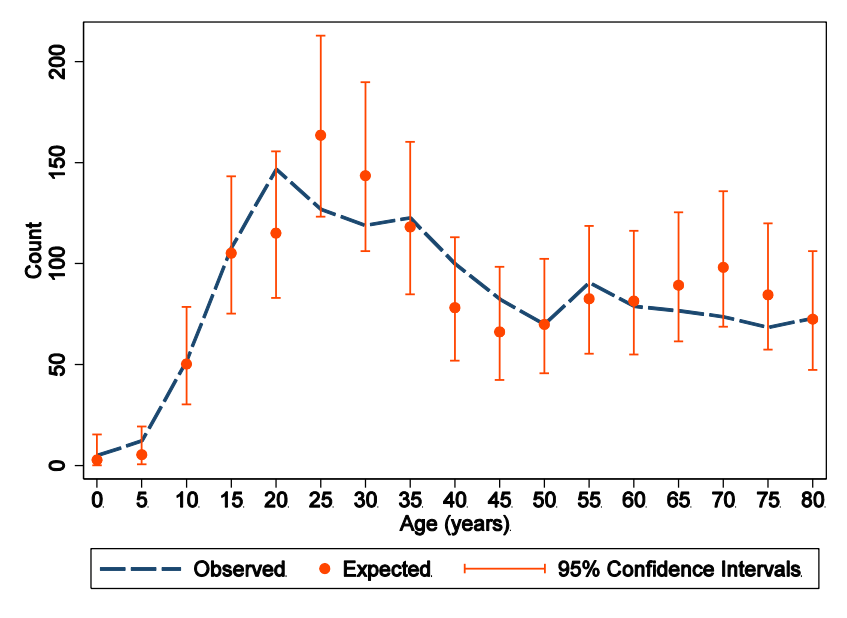

**Obs:Exp 116 (CI: 113-118)**

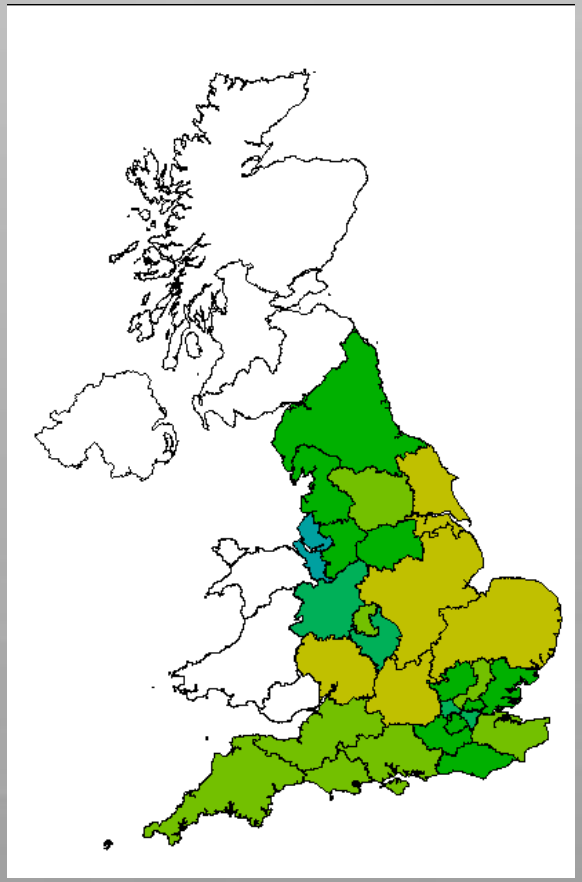


Obs:Exp

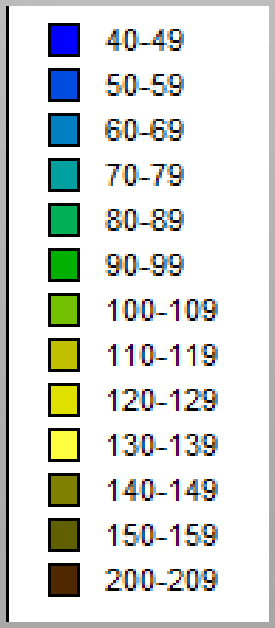
- 40-49
- 50-59
- 60-69
- 70-79
- 80-89
- 90-99
- 100-109
- 110-119
- 120-129
- 130-139
- 140-149
- 150-159
- 200-209

# National Observed/HMRN Expected Hodgkin Lymphoma



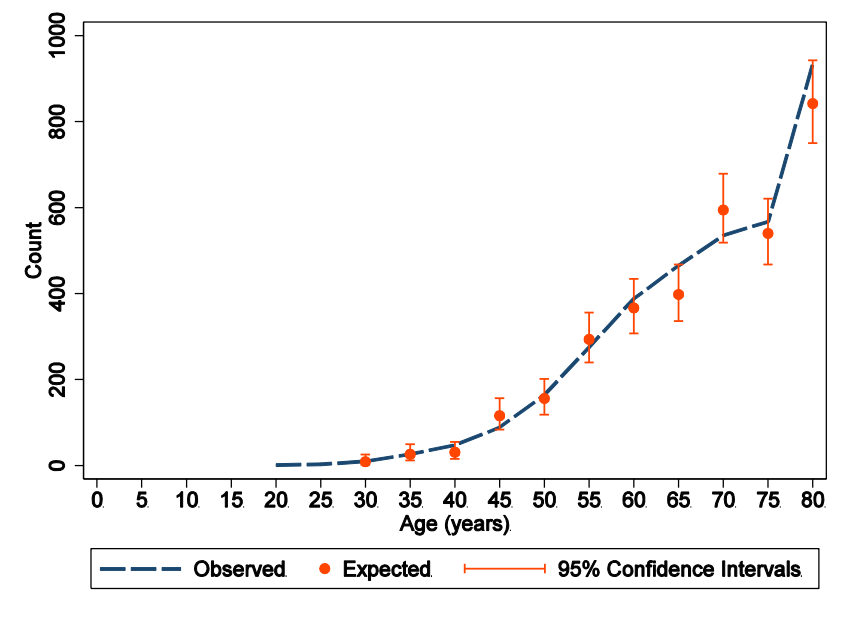



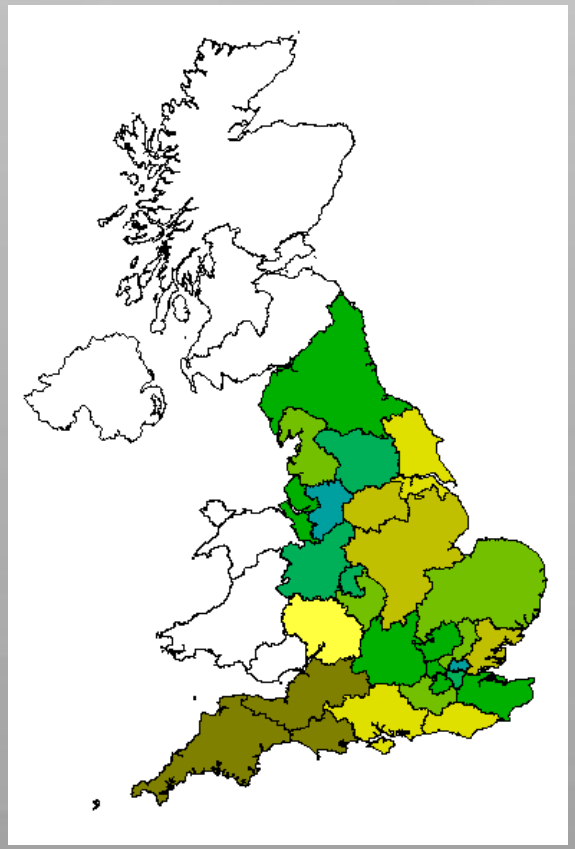
Obs:Exp




**Obs:Exp 100% (CI: 95-105%)**

# National Observed/HMRN Expected Myeloma



Obs:Exp

- 40-49
- 50-59
- 60-69
- 70-79
- 80-89
- 90-99
- 100-109
- 110-119
- 120-129
- 130-139
- 140-149
- 150-159
- 200-209

**Obs:Exp 104% (CI: 101-108%)**

# Conclusions

- Overall, there was good agreement between observed and expected numbers

- Cancer Registries appear to be ascertaining all cases, but further investigation is needed to explain the degree of variation in disease classification across the country

# On-going/Future Work

- Results are now being shared with individual cancer registries
- A direct comparisons between NYCRIS and HMRN data is underway
- eAtlas by cancer registry and network level
- Predictions of national burden of disease in clinically meaningful groups  (WHO classification)
  - Incidence
  - Prevalence

# End of life care

NCIN national cancer intelligence network

## Where do patients with blood cancers die?

### NCIN Data Briefing

**KEY MESSAGES:**

*Most people dying of a haematological cancer do so in hospital.*

*Compared to other cancers, fewer deaths occur at home or in a hospice.*

*This pattern is seen at all ages.*

*The proportion of deaths occurring in hospital is falling, but less than seen in other cancers.*

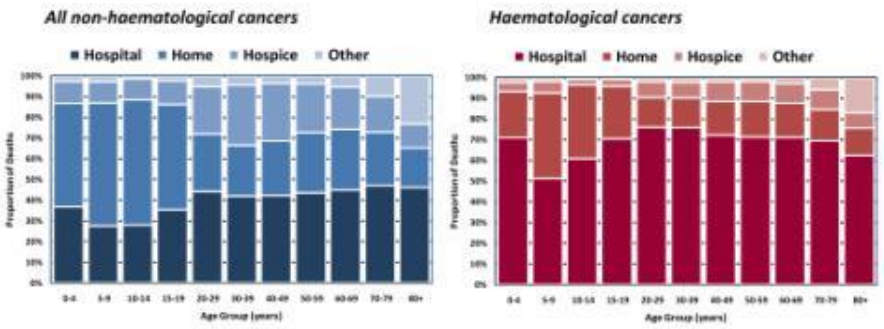
### Background

When asked, most people say they would prefer not to die in a hospital – although in fact this is where most people do die. Individuals with cancer are more likely than others to die in a hospice and are generally less likely to die in a hospital. However, this pattern is not seen for all forms of cancer. Individuals dying of haematological malignancies (the blood cancers: leukaemia, lymphoma, myeloma) have previously been reported to have a very different pattern of place of death. We examined the most recent national mortality data to establish the current situation in England and Wales.

### Results

In the nine years from 2001 to 2009 there were 94,962 deaths in England and Wales in which a haematological cancer was identified as the underlying cause of death. Of these, for 64,965 (68%) individuals the death occurred in a hospital; 14,316 (15%) deaths happened at home; 8,277 (9%) deaths were in a hospice; for 7,404 (8%) death occurred in another type of location, chiefly a nursing or care home. When compared to the 1,128,910 deaths caused by other forms of cancer over the same period, people with haematological cancer were far more likely to die in hospital.

**Place of Death by age** (England and Wales 2001-2009)




The proportions of deaths from non-haematological cancers occurring in different locations were: in-hospital deaths 526,928 (47%), deaths at home 277,619 (25%), deaths in a hospice 194,110 (17%), other location 130,253 (12%). As shown in the figure, the pattern of fewer deaths from haematological cancer happening either at home of in a hospice was seen across all age-groups.

www.ncin.org.uk/databriefings

*Using information to improve quality and choice*

2011

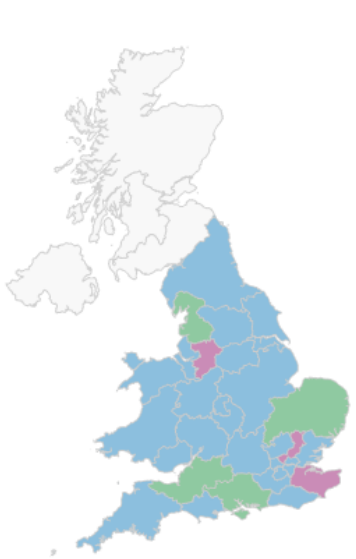
# Where do patients with blood cancer die? Place of death by cancer network, England and Wales 2001-2009

**Proportion of deaths occurring in Hospital>>Acute Lymphoblastic Leukaemia >> All years 2001-2009**

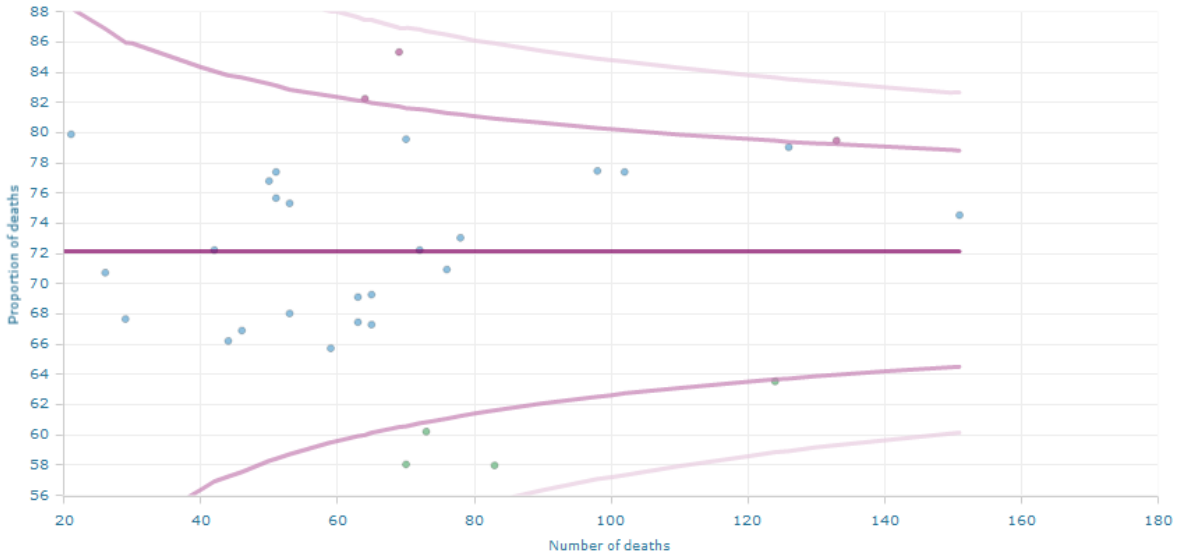
NCIN national cancer intelligence network
*Using information to improve quality & choice*

Place of death | Save | Print | Help
Blood Cancer Type | Show/Hide Location List

## Map



## Funnel Plot




All years 2001-2009 | 2001-2005 | 2006-2009

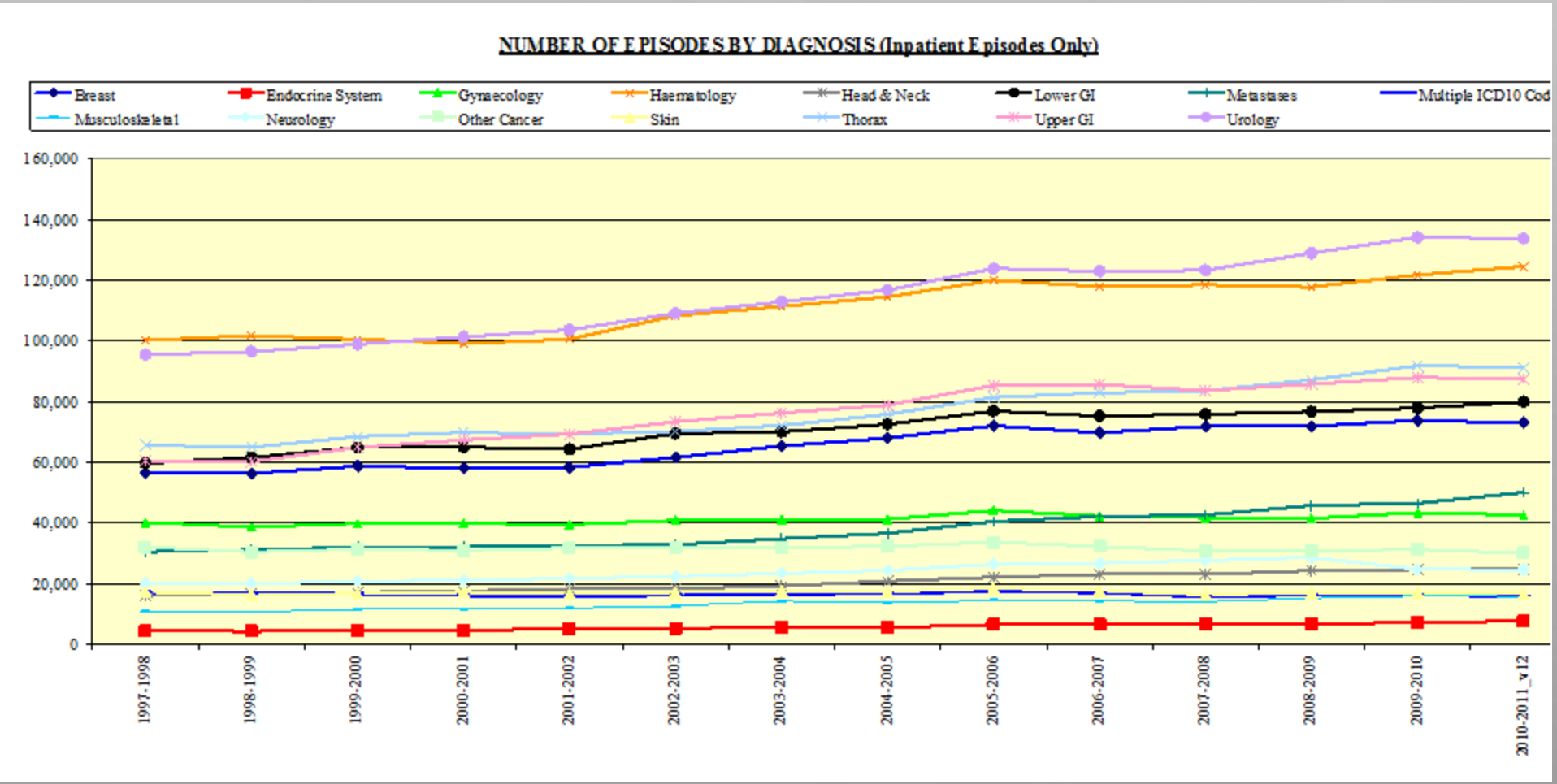
## Legend

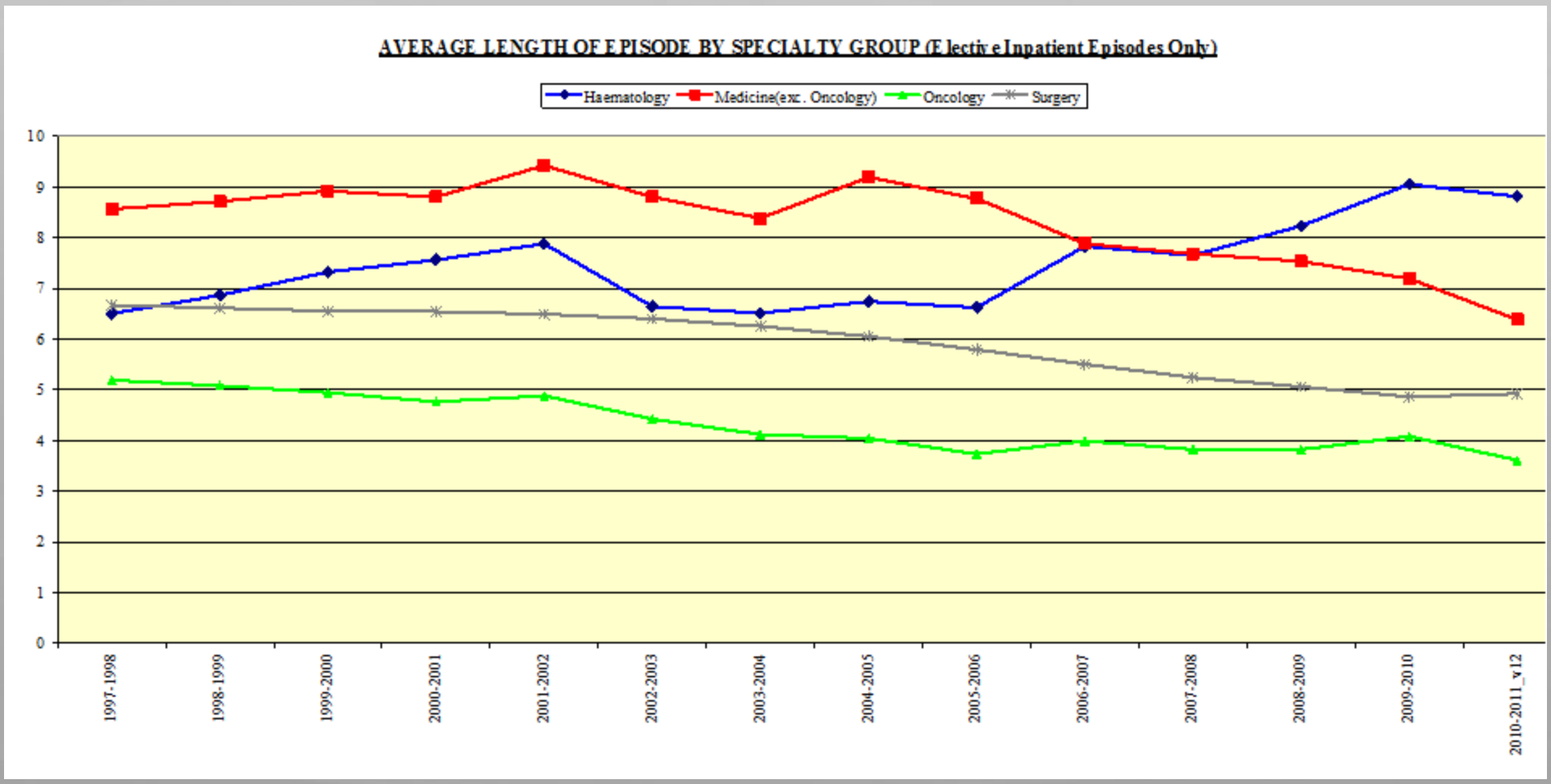
- Proportion of deaths occurring in Hospital
- Very Low
- Low
- Normal
- High
- Very High

## Background

Acute lymphoblastic leukaemia (ALL) [ICD 10 C91.0] is a rare form of blood cancer. It accounts for approximately 2.2% of all blood cancers with an estimated 730 patients newly diagnosed in the UK each year. Whilst this disease can affect people of any age, it tends to be more common in children. In the funnel plot the solid horizontal line represents the average proportion of deaths from ALL that occurred in hospital for England and Wales in the period 2001-09. The proportion has been adjusted for age, sex, year of death, level of deprivation and the proportion of all non-blood cancers that occur in hospital within the network. The other lines are the 95% (_____) and 99.8% (_____) control limits. Networks that lie between the inner control limits are consistent with the national average, those above the upper control limits have a significantly higher proportion of deaths occurring in hospital than expected and those below the lower control limits significantly lower, these may be considered as 'outliers'.

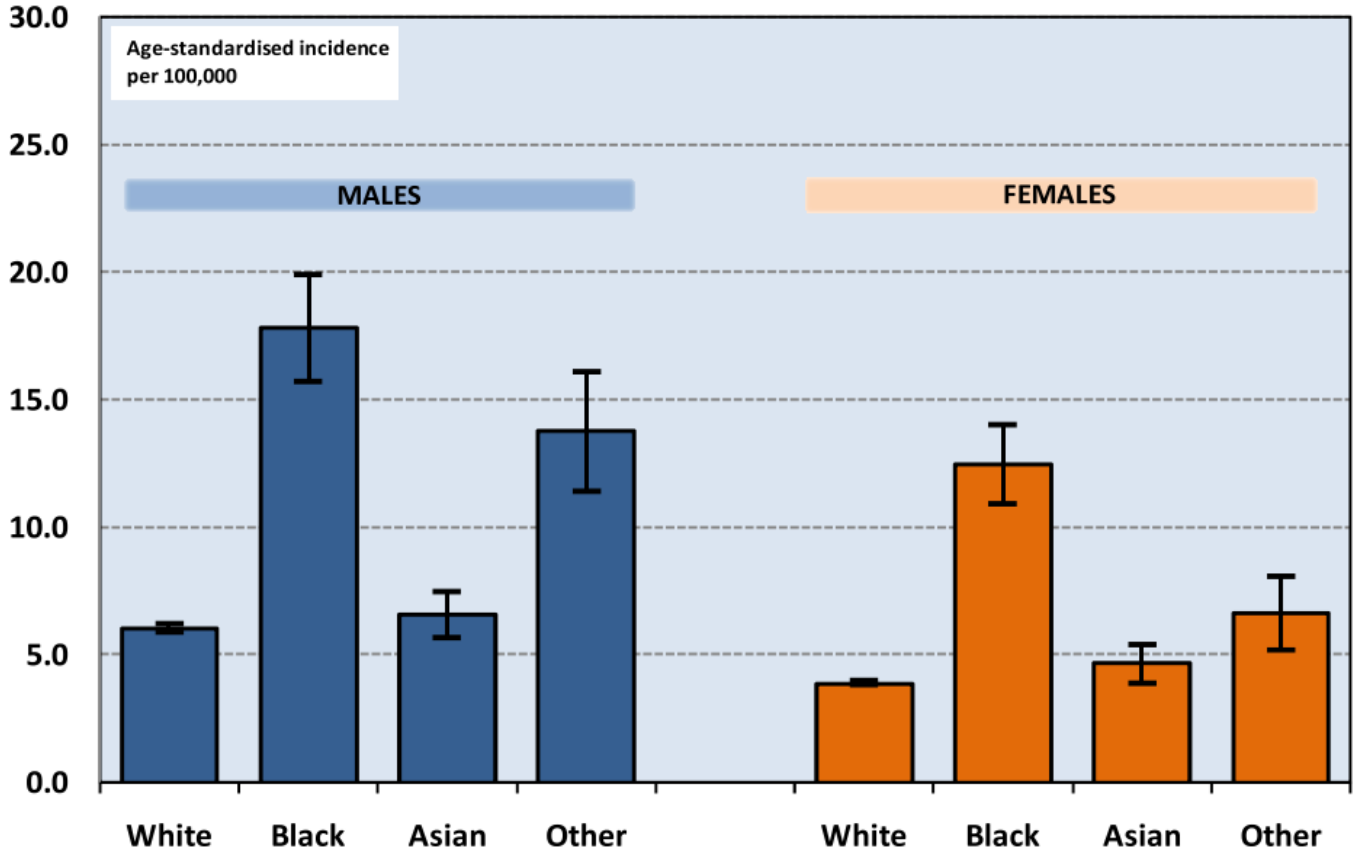
# Bed stay variation by disease, time from diagnosis




AVERAGE LENGTH OF EPISODE BY SPECIALTY GROUP (Elective Inpatient Episodes Only)
Haematology
Medicine(exc. Oncology)
Oncology
Surgery
10
9
8
7
6
5
4
3
2
1
0
1997-1998
1998-1999
1999-2000
2000-2001
2001-2002
2002-2003
2003-2004
2004-2005
2005-2006
2006-2007
2007-2008
2008-2009
2009-2010
2010-2011_v12

# Ethnicity and incidence and outcomes for haematological cancer

**Figure 1: Age-standardised incidence (post-imputation) by sex: Myeloma (2002-07) England**



# The use of radiotherapy, by haematological diagnosis, by centre

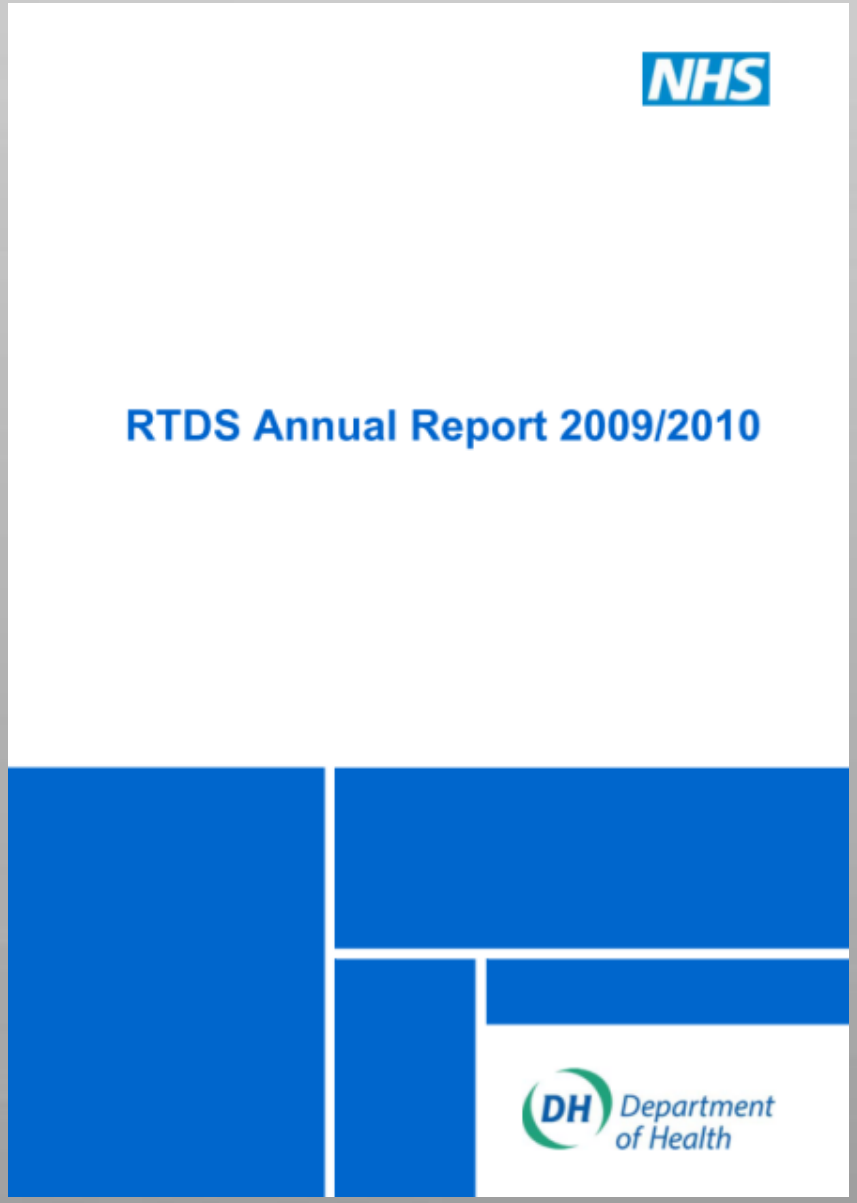


**Figure 1-1 Summary of data submitted to the Radiotherapy Dataset 2009/10**

| | | Episodes | | | Attendances | |
|---|---|---|---|---|---|---|
| | **Total** | **126,400** | | | **1,738,781** | |
| Gender | Male | 59,292 | 46.91% | | 849,574 | 48.86% |
| | Female | 66,379 | 52.52% | | 884,892 | 50.89% |
| | Not Recorded | 729 | 0.58% | | 4,315 | 0.25% |
| Age | 0-18 | 704 | 0.56% | | 12,831 | 0.74% |
| | 19-49 | 14,520 | 11.49% | | 232,462 | 13.37% |
| | 50-69 | 55,511 | 43.92% | | 818,579 | 47.08% |
| | 70-79 | 31,662 | 25.05% | | 431,866 | 24.84% |
| | 80+ | 15,097 | 11.94% | | 133,287 | 7.67% |
| | Not Recorded | 8,906 | 7.05% | | 109,756 | 6.31% |
| Intent | 'Radical' (15+ attendances) | 62,295 | 49.28% | | 1,437,347 | 82.66% |
| | 'Palliative' | 64,105 | 50.72% | | 301,434 | 17.34% |
| Primary Tumour Site | Brain/CNS | 3,454 | 2.73% | | 74,296 | 4.27% |
| | Breast | 35,534 | 28.11% | | 506,102 | 29.11% |
| | Endocrine | 551 | 0.44% | | 8,110 | 0.47% |
| | Gynae | 4,834 | 3.82% | | 86,877 | 5.00% |
| | Haematology | 5,811 | 4.60% | | 52,621 | 3.03% |
| | Head & Neck | 6,499 | 5.14% | | 151,858 | 8.73% |
| | Lower GI | 8,039 | 6.36% | | 126,501 | 7.28% |
| | Lung | 16,833 | 13.32% | | 132,647 | 7.63% |
| | Other | 9,636 | 7.62% | | 72,415 | 4.16% |
| | Sarcoma | 1,548 | 1.22% | | 25,655 | 1.48% |
| | Skin | 4,975 | 3.94% | | 43,259 | 2.49% |
| | Upper GI | 4,009 | 3.17% | | 44,985 | 2.59% |
| | Urology | 23,056 | 18.24% | | 402,132 | 23.13% |
| | Not Recorded | 1,621 | 1.28% | | 11,323 | 0.65% |

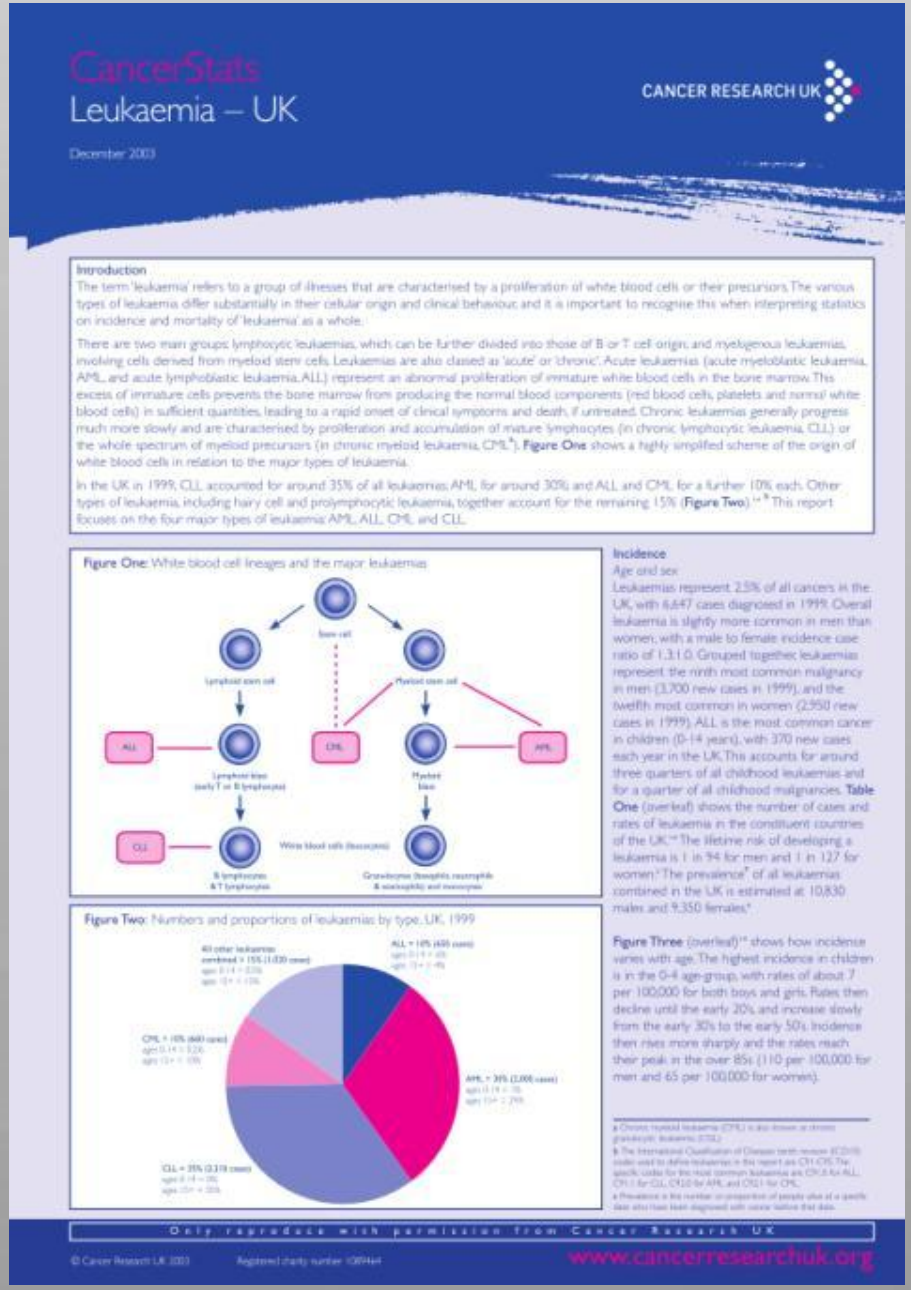
# Analysis of emergency presentations

***Routes to diagnosis by cancer type for all malignant diagnoses, excluding C44 (non-melanoma skin cancer) and multiples, in England, 2007***

| All Persons | Screen detected | Two Week Wait | GP referral | Other outpatient | Inpatient elective | Emergency presentation | Death Certificate Only | Unknown | Total | Number of patients |
|---|---|---|---|---|---|---|---|---|---|---|
| Acute leukaemia | | 3% | 17% | 14% | 4% | 57% | 0% | 4% | 100% | 2,551 |
| Bladder | | 32% | 28% | 15% | 2% | 18% | 0% | 4% | 100% | 7,665 |
| Brain & CNS | | 1% | 17% | 14% | 4% | 58% | 0% | 6% | 100% | 4,147 |
| Breast | 21% | 42% | 12% | 9% | 0% | 4% | 0% | 12% | 100% | 34,232 |
| Cervix | 14% | 16% | 25% | 16% | 2% | 12% | 0% | 13% | 100% | 2,085 |
| Chronic leukaemia | | 10% | 30% | 12% | 2% | 30% | 1% | 16% | 100% | 2,869 |
| Colorectal | | 26% | 24% | 15% | 4% | 25% | 1% | 6% | 100% | 27,903 |
| Kidney | | 20% | 29% | 18% | 1% | 24% | 1% | 6% | 100% | 5,172 |
| Larynx | | 31% | 32% | 21% | 1% | 12% | 0% | 3% | 100% | 1,583 |
| Lung | | 22% | 20% | 13% | 1% | 38% | 1% | 5% | 100% | 29,420 |
| Melanoma | | 41% | 29% | 11% | 1% | 3% | 0% | 16% | 100% | 8,117 |
| Multiple myeloma | | 13% | 27% | 15% | 1% | 38% | 0% | 6% | 100% | 3,145 |
| Non-Hodgkin's lymphoma | | 16% | 30% | 17% | 2% | 28% | 0% | 7% | 100% | 7,777 |
| Oesophagus | | 25% | 21% | 17% | 10% | 21% | 1% | 4% | 100% | 6,001 |
| Oral | | 26% | 28% | 30% | 1% | 6% | 0% | 9% | 100% | 3,062 |
| Other | | 14% | 25% | 15% | 2% | 36% | 1% | 7% | 100% | 27,730 |
| Ovary | | 26% | 22% | 15% | 1% | 29% | 1% | 6% | 100% | 5,012 |
| Pancreas | | 13% | 18% | 12% | 2% | 47% | 1% | 6% | 100% | 5,989 |
| Prostate | | 20% | 38% | 16% | 3% | 9% | 0% | 14% | 100% | 28,362 |
| Stomach | | 17% | 21% | 16% | 7% | 32% | 1% | 5% | 100% | 5,841 |
| Testis | | 48% | 14% | 16% | 2% | 10% | | 10% | 100% | 1,569 |
| Uterus | | 35% | 31% | 16% | 1% | 8% | 0% | 8% | 100% | 5,733 |
| **Total** | **3%** | **25%** | **24%** | **14%** | **2%** | **23%** | **1%** | **8%** | **100%** | **225,965** |

**The table has been colour coded using a gradation in intensity to highlight data distribution and variation in the percentages, a darker colour indicates a higher value.**

# Contribution to development of 4 CancerStats reports on haematological cancers.



CancerStats

Leukaemia – UK

December 2003

CANCER RESEARCH UK

**Introduction**

The term 'leukaemia' refers to a group of illnesses that are characterised by a proliferation of white blood cells or their precursors. The various types of leukaemia differ substantially in their cellular origin and clinical behaviour, and it is important to recognise this when interpreting statistics on incidence and mortality of 'leukaemia' as a whole.

There are two main groups: lymphocytic leukaemias, which can be further divided into those of B or T cell origin, and myelogenous leukaemias, involving cells derived from myeloid stem cells. Leukaemias are also classed as 'acute' or 'chronic'. Acute leukaemias (acute myeloblastic leukaemia, AML, and acute lymphoblastic leukaemia, ALL) represent an abnormal proliferation of immature white blood cells in the bone marrow. This excess of immature cells prevents the bone marrow from producing the normal blood components (red blood cells, platelets and normal white blood cells) in sufficient quantities, leading to a rapid onset of clinical symptoms and death, if untreated. Chronic leukaemias generally progress much more slowly and are characterised by proliferation and accumulation of mature lymphocytes (in chronic lymphocytic leukaemia, CLL) or the whole spectrum of myeloid precursors (in chronic myeloid leukaemia, CML[a]). **Figure One** shows a highly simplified scheme of the origin of white blood cells in relation to the major types of leukaemia.

In the UK in 1999, CLL accounted for around 35% of all leukaemias, AML for around 30%, and ALL and CML for a further 10% each. Other types of leukaemia, including hairy cell and prolymphocytic leukaemia, together account for the remaining 15% (**Figure Two**).[b] This report focuses on the four major types of leukaemia: AML, ALL, CML and CLL.

**Figure One:** White blood cell lineages and the major leukaemias



**Figure Two:** Numbers and proportions of leukaemias by type, UK, 1999



**Incidence**

*Age and sex*

Leukaemias represent 2.5% of all cancers in the UK, with 6,647 cases diagnosed in 1999. Overall leukaemia is slightly more common in men than women, with a male to female incidence rate ratio of 1.3:1.0. Grouped together, leukaemias represent the ninth most common malignancy in men (3,700 new cases in 1999), and the twelfth most common in women (2,950 new cases in 1999). ALL is the most common cancer in children (0-14 years), with 370 new cases each year in the UK. This accounts for around three quarters of all childhood leukaemias and for a quarter of all childhood malignancies. **Table One** (overleaf) shows the number of cases and rates of leukaemia in the constituent countries of the UK.[c] The lifetime risk of developing a leukaemia is 1 in 94 for men and 1 in 127 for women.[d] The prevalence[e] of all leukaemias combined in the UK is estimated at 10,830 males and 9,350 females.[e]

**Figure Three** (overleaf)[c] shows how incidence varies with age. The highest incidence in children is in the 0-4 age-group, with rates of about 7 per 100,000 for both boys and girls. Rates then decline until the early 20s and increase slowly from the early 30s to the early 50s. Incidence then rises more sharply and the rates reach their peak in the over 85s (110 per 100,000 for men and 65 per 100,000 for women).

a Chronic myeloid leukaemia (CML) is also known as chronic granulocytic leukaemia (CGL).

b The International Classification of Diseases tenth revision (ICD-10) codes used to define leukaemias in the report are C91-C95. The specific codes for the most common leukaemias are C91.0 for ALL, C91.1 for CLL, C92.0 for AML and C92.1 for CML.

c Prevalence is the number or proportion of people alive at a specific date who have been diagnosed with cancer before that date.

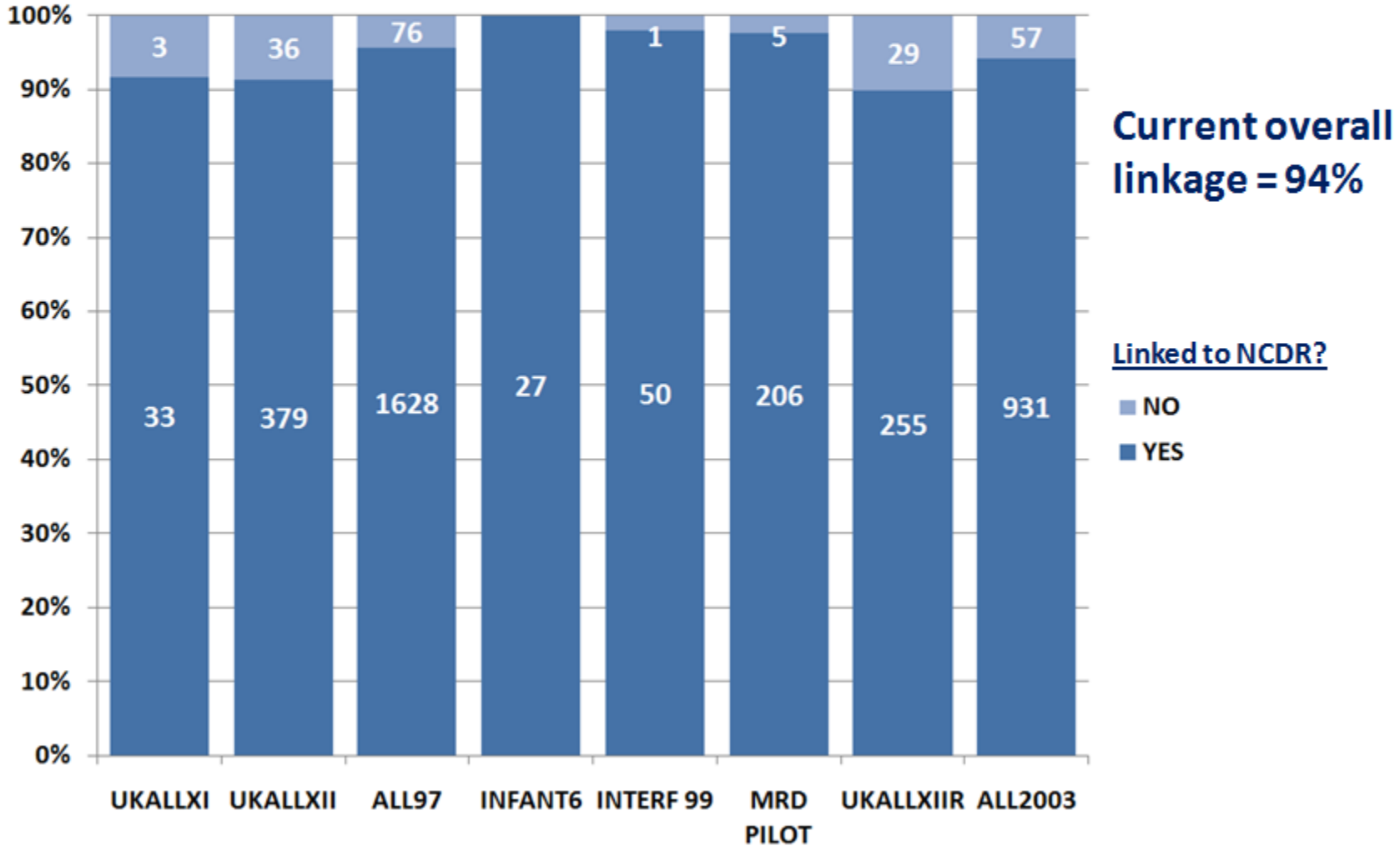
# CancerStats

# Leukaemia – UK

December 2003

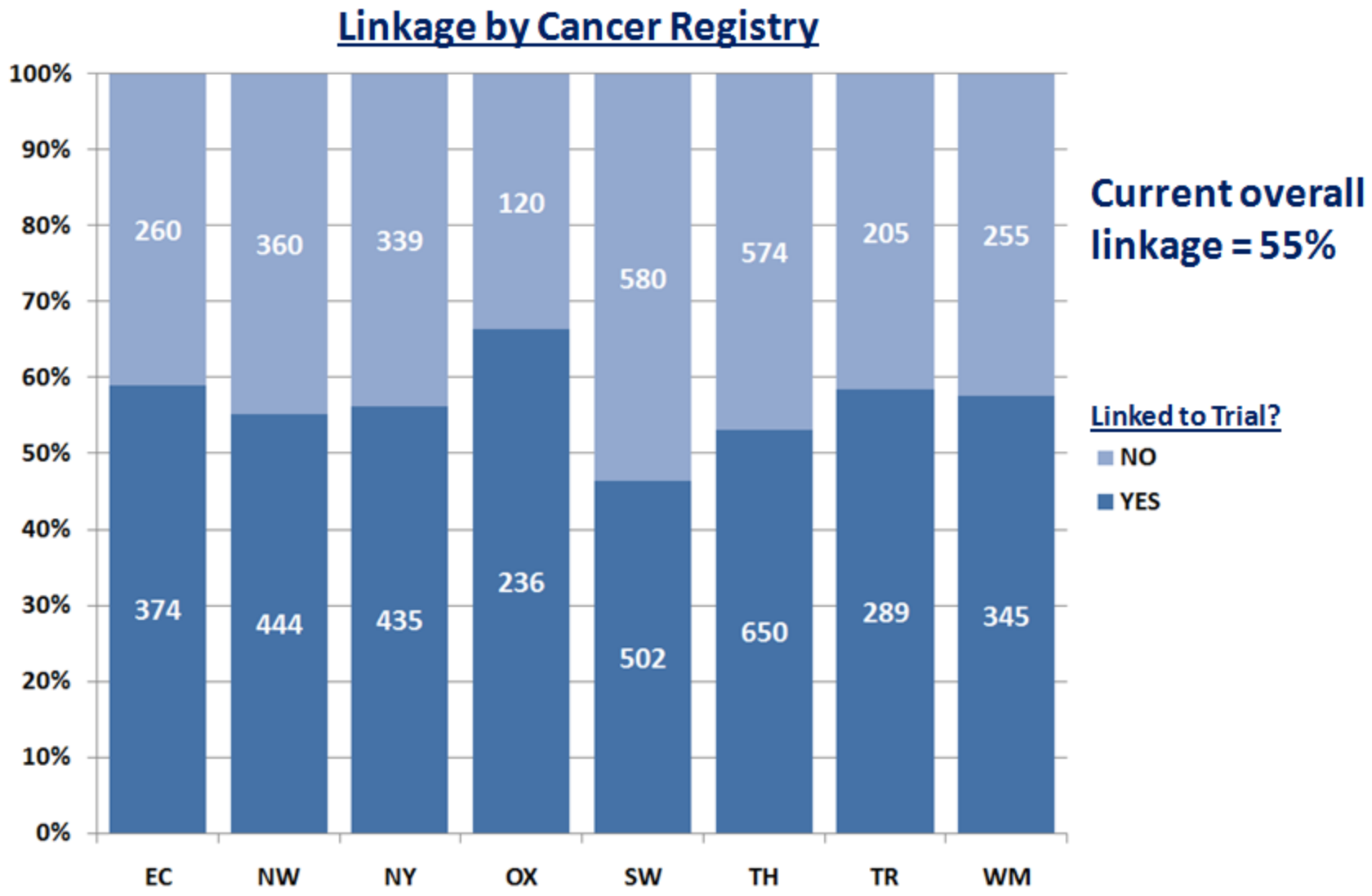
# Use of the NCDR to inform haematological cancer trials

## 3,716 Trial Participants (1997-2006)
## Acute Lymphoblastic Leukaemia
## Linkage to NCDR-haem




**Current overall linkage = 94%**

# 5,968 NCDR registrations
# Acute Lymphoblastic Leukaemia (ICD 91.0)



# 5,968 NCDR registrations
# Acute Lymphoblastic Leukaemia (ICD 91.0)