# NCIN Haematological Malignancy

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NCIN
national cancer
intelligence network

# “Quite simply, we want to have the best cancer information service in the world by 2012”

**Mike Richards**
**Britain against Cancer**
**Dec 2007**

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# Intelligence in cancer care

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**Lead areas for cancer registries:**

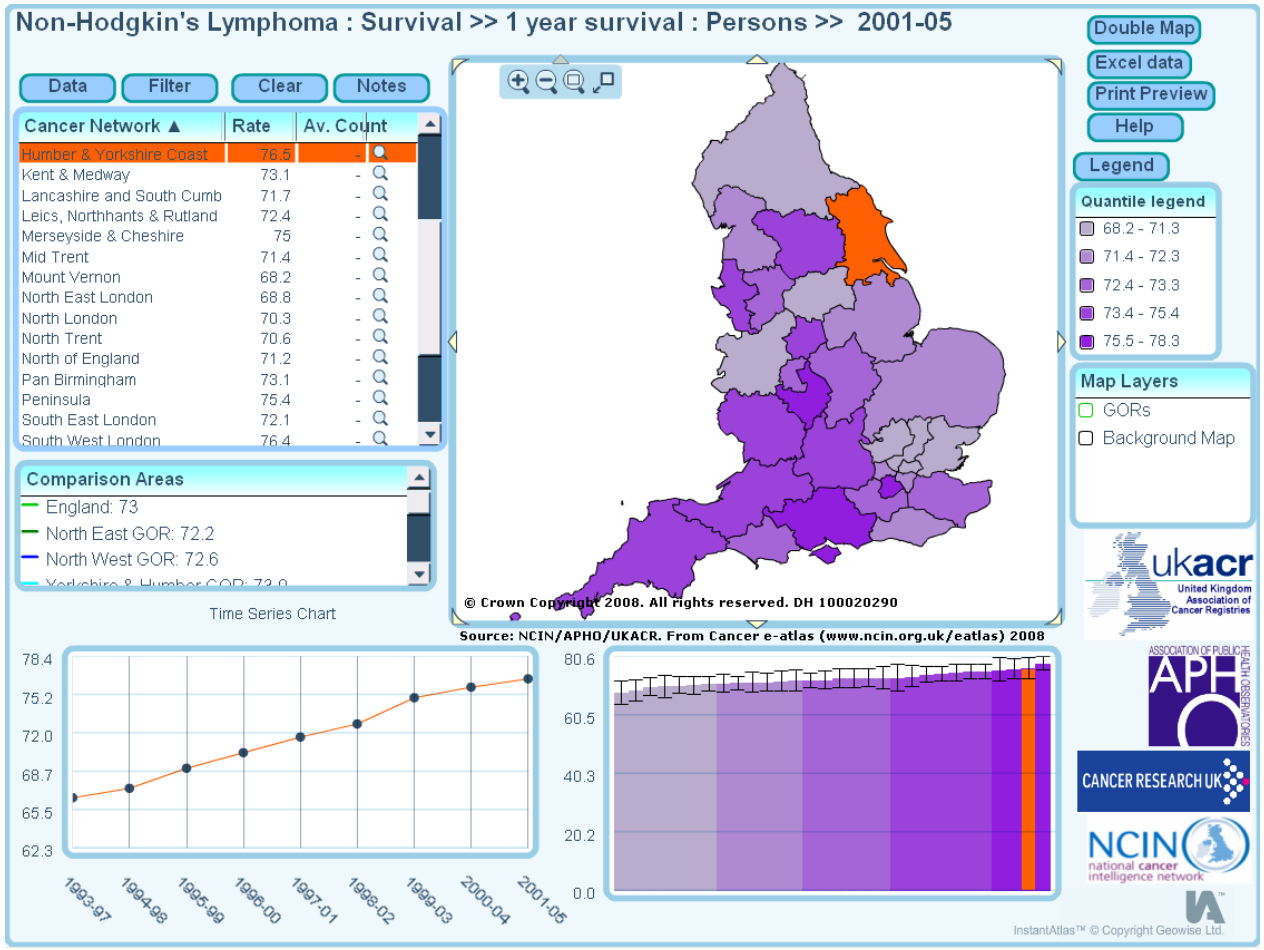
- Lung – Thames
- Breast – WMCIU
- Colorectal – NYCRIS
- Urology – SWCIS
- CNS – ECRIC
- Gynae – Trent
- Head &Neck – Oxford
- TYAC – NWCIS
- Skin – SWCIS
- Upper GI – Thames
- Sarcoma – WMCIU
- Haematology – NYCRIS
- Children – CCRG

**To be supported by National Clinical Reference Groups**

# NCIN OUTPUTS

# National Cancer e-Atlas

## www.ncin.org.uk/eatlas

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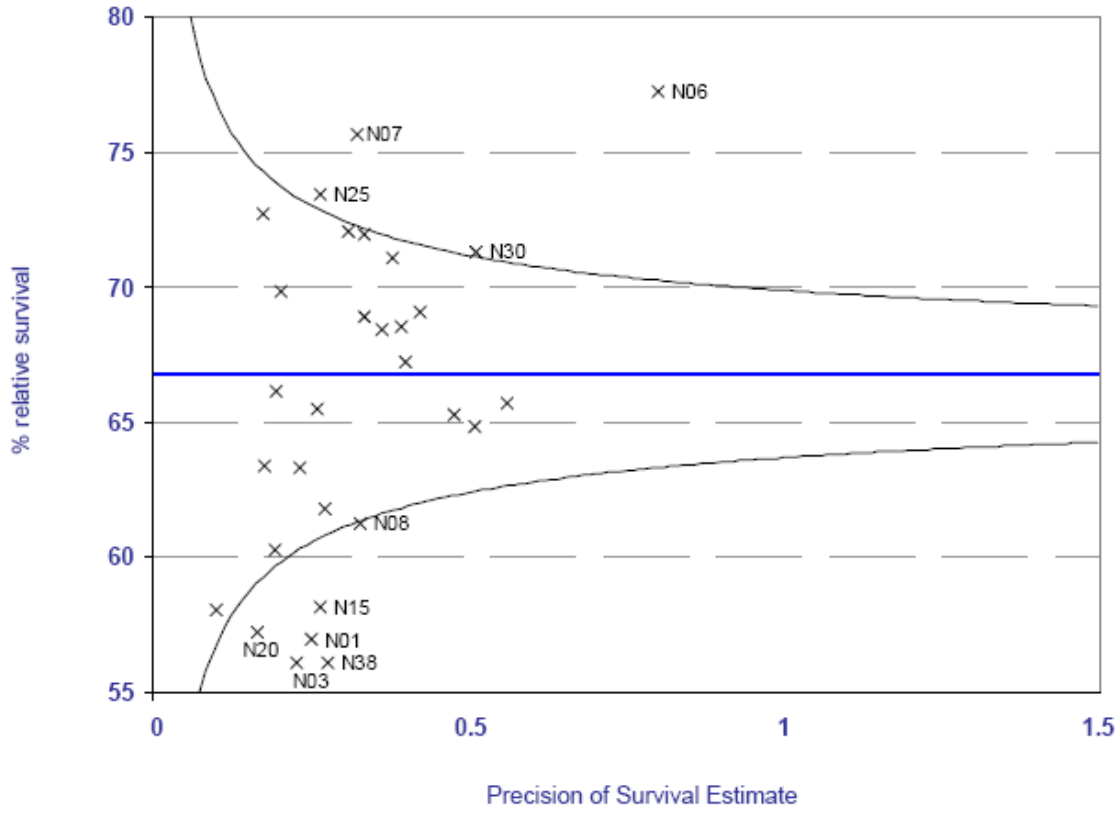
# One year cancer survival, by Cancer Network, England, for patients diagnosed 2000-2004 Leukaemia: C91-95




**Networks above 99.8% control limit:**

N06 Yorkshire
N07 Humber and Yorkshire Coast
N25 South West London
N30 Thames Valley

**Networks below 99.8% control limit:**

N01 Lancashire and South Cumbria
N03 Merseyside and Cheshire
N08 North Trent
N15 Leics, Northants and Rutland
N20 Mount Vernon
N38 Essex

# Cancer Incidence and Mortality By Cancer Network, UK, 2005

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**New cancer cases, crude and age-standardised* incidence rates per 100,000 (with 95% confidence intervals), Cancer Networks, UK, 2005**

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C91-C95: Leukaemia

**Cancer deaths, crude and age-standardised* mortality rates per 100,000 (with 95% confidence intervals), Cancer Networks, UK, 2005**

NCIN national cancer intelligence network

C91-C95: Leukaemia

| | Males | | | | | Females | | | | | Persons | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Cancer Network | Number of deaths | Crude rate | ASR | 95% confidence interval | | Number of deaths | Crude rate | ASR | 95% confidence interval | | Number of deaths | Crude rate | ASR | 95% confidence interval | |
| N01 Lancashire and South Cumbria CN | 74 | 9.4 | 7.4 | 5.6 - | 9.1 | 62 | 7.5 | 4.0 | 2.9 - | 5.1 | 136 | 8.5 | 5.7 | 4.7 - | 6.7 |
| N02 Greater Manchester and Cheshire CN | 104 | 7.0 | 6.1 | 4.9 - | 7.3 | 74 | 4.8 | 3.2 | 2.4 - | 4.0 | 178 | 5.9 | 4.7 | 3.9 - | 5.4 |
| N03 Merseyside and Cheshire CN | 60 | 6.5 | 5.4 | 4.0 - | 6.8 | 61 | 6.2 | 4.0 | 2.9 - | 5.1 | 121 | 6.3 | 4.7 | 3.8 - | 5.6 |
| N06 Yorkshire CN | 96 | 7.6 | 6.6 | 5.3 - | 8.0 | 77 | 5.8 | 3.4 | 2.6 - | 4.3 | 173 | 6.7 | 5.0 | 4.2 - | 5.8 |
| N07 Humber and Yorkshire Coast CN | 42 | 8.3 | 5.9 | 4.1 - | 7.8 | 49 | 9.3 | 5.7 | 3.9 - | 7.4 | 91 | 8.8 | 5.8 | 4.5 - | 7.1 |
| N08 North Trent CN | 79 | 9.2 | 7.0 | 5.5 - | 8.6 | 47 | 5.2 | 3.2 | 2.2 - | 4.1 | 126 | 7.2 | 5.1 | 4.2 - | 6.0 |
| N11 Pan Birmingham CN | 60 | 6.5 | 5.7 | 4.2 - | 7.1 | 70 | 7.3 | 4.7 | 3.5 - | 5.9 | 130 | 6.9 | 5.2 | 4.2 - | 6.1 |
| N12 Arden CN | 42 | 8.5 | 6.7 | 4.6 - | 8.8 | 33 | 6.6 | 4.4 | 2.7 - | 6.1 | 75 | 7.5 | 5.5 | 4.2 - | 6.9 |
| N13 Mid Trent CN | 85 | 10.7 | 7.7 | 6.0 - | 9.4 | 55 | 6.7 | 3.9 | 2.8 - | 5.1 | 140 | 8.7 | 5.8 | 4.8 - | 6.9 |

# Cancer Incidence by Deprivation England, 1995-2004

C82-C85 & C96: Non-Hodgkin lymphoma

# Cancer Incidence by Deprivation England, 1995-2004

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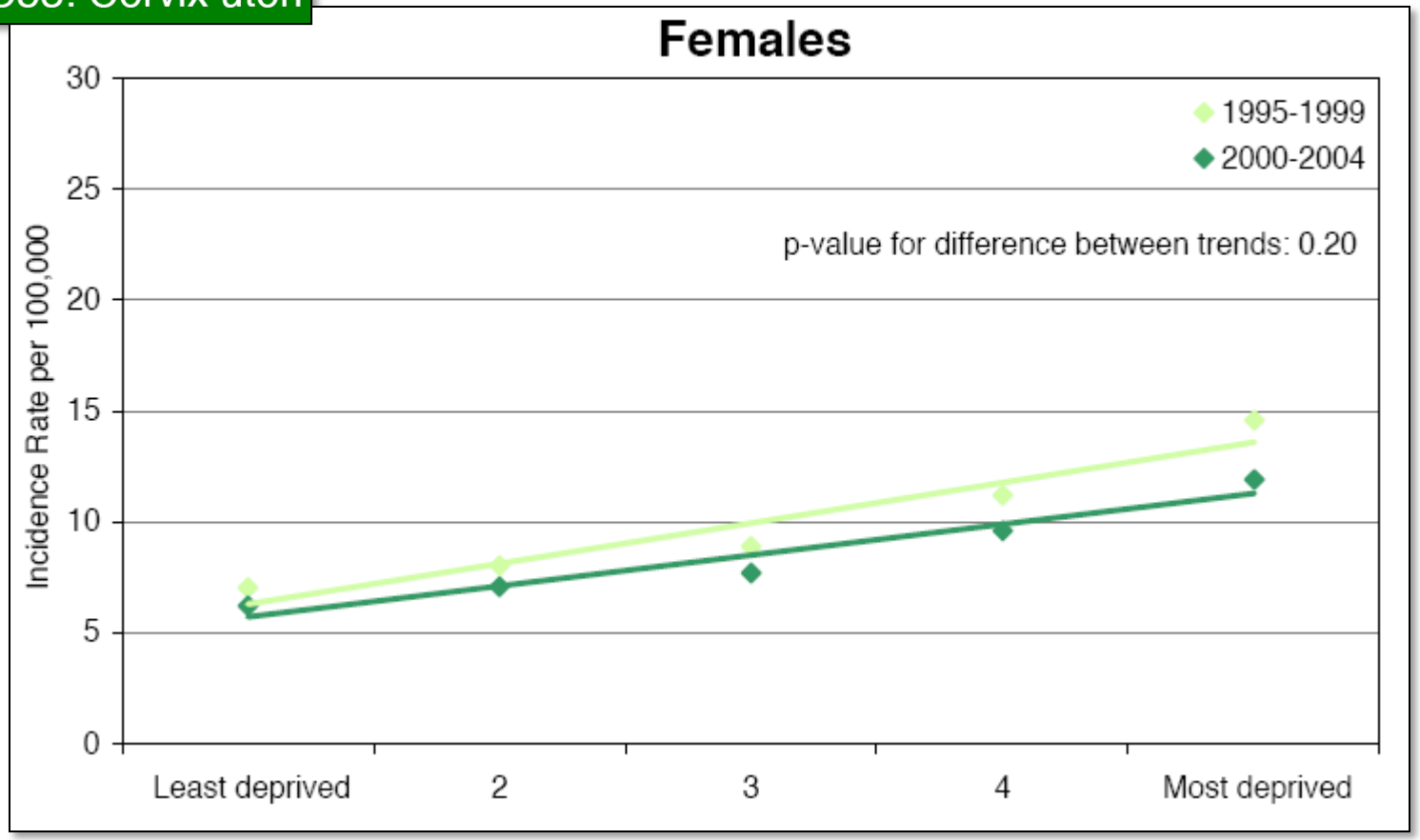
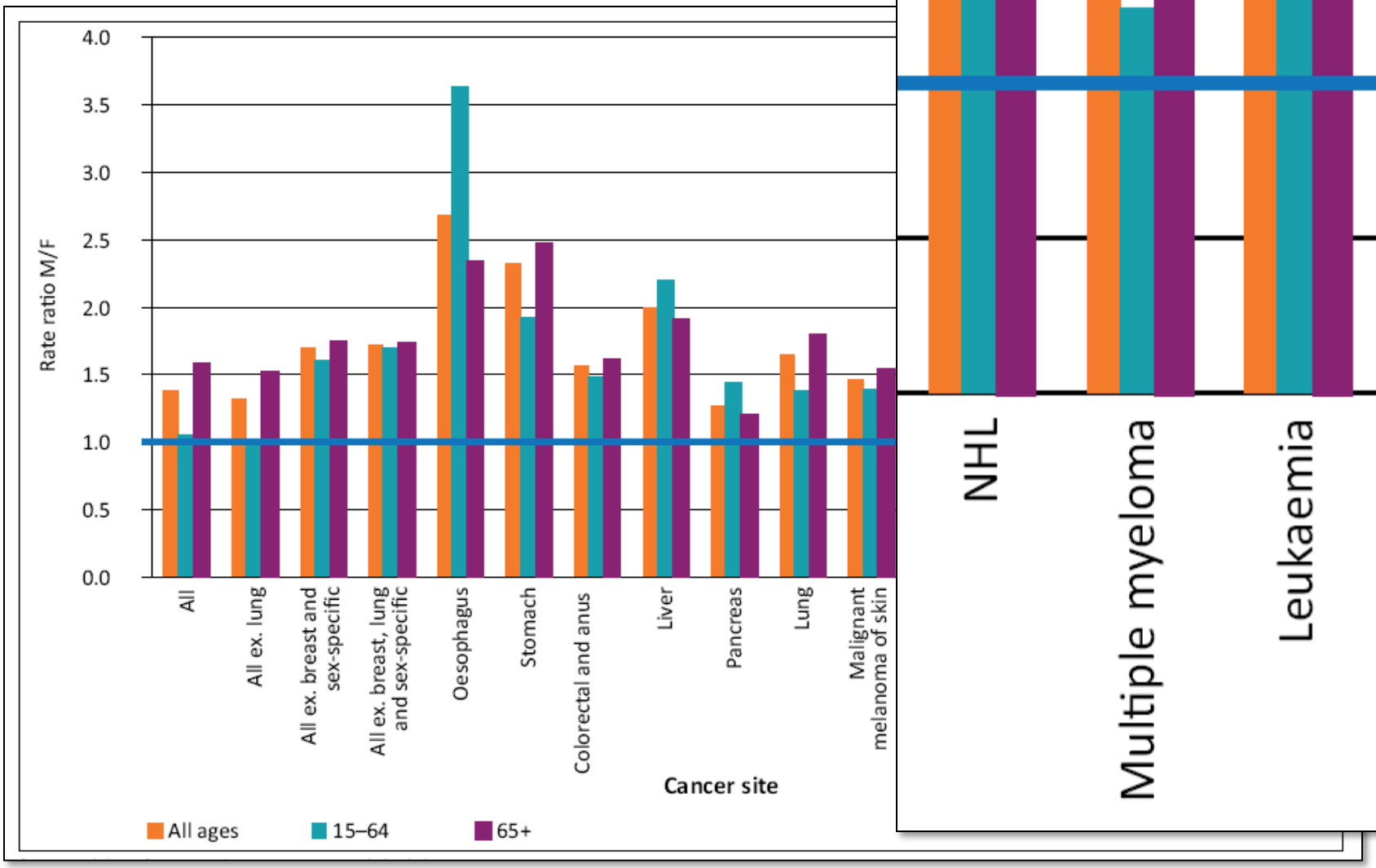
C53: Cervix uteri



# The Excess Burden of Cancer in Men in the UK



# Cancer Incidence and Survival By Major Ethnic Group, England, 2002 - 2006

## C88-C90: Myeloma

| | | <65 years | | | ≥65 years | | | All ages | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Distribution of unknowns | Rate ratio | 95% Confidence Interval Lower | Upper | Rate ratio | 95% Confidence Interval Lower | Upper | Rate ratio | 95% Confidence Interval Lower | Upper |
| Asian | As known | 0.81 | 0.66 - | 1.00 | 0.83 | 0.70 - | 0.99 | 0.82 | 0.72 - | 0.94 |
| | All White | 0.69 | 0.56 - | 0.84 | 0.66 | 0.56 - | 0.79 | 0.67 | 0.59 - | 0.77 |
| | Non-White relative increase | 0.88 | 0.71 - | 1.07 | 0.92 | 0.77 - | 1.09 | 0.90 | 0.79 - | 1.03 |
| Black | As known | 2.83 | 2.12 - | 3.77 | 2.16 | 1.73 - | 2.69 | 2.40 | 2.01 - | 2.86 |
| | All White | 2.40 | 1.79 - | 3.20 | 1.72 | 1.38 - | 2.14 | 1.96 | 1.65 - | 2.34 |
| | Non-White relative increase | 3.05 | 2.29 - | 4.07 | 2.38 | 1.91 - | 2.97 | 2.62 | 2.20 - | 3.12 |

**Asian ethnic group compared with the White ethnic group**

There is some evidence that rates for males aged 65 years and over and of all ages were lower in the Asian ethnic group but this was not statistically significant under the assumption that cases with unknown ethnicity were relatively increased in non-White ethnic groups. Results were inconclusive for males under 65 years in the Asian ethnic group.

**Black ethnic group compared with the White ethnic group**

Rates for males under 65 years, 65 years and over and of all ages were higher in the Black ethnic group with statistically significant results for all three assumptions regarding the distribution of cases with unknown ethnicity.

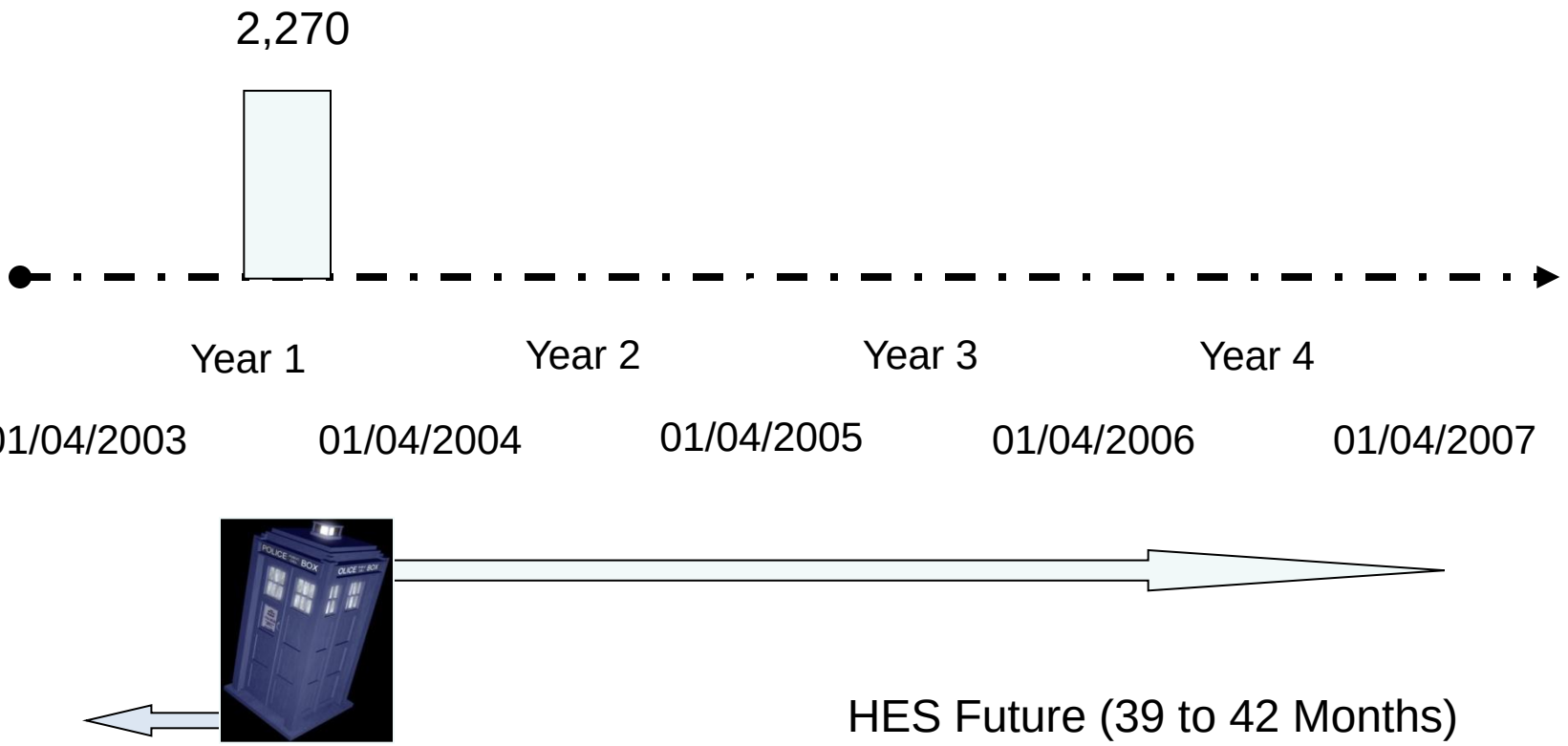
# National Haematological Malignancy Data Repository

- Cancer registration data (1990-2007)
- English NHS Hospital Episode Statistics (HES) (1997-2007)
- De-duplication of registrations
- De-duplication of HES
- Matching on NHS Number : DOB : Postcode : Sex

# What is possible through linkage?

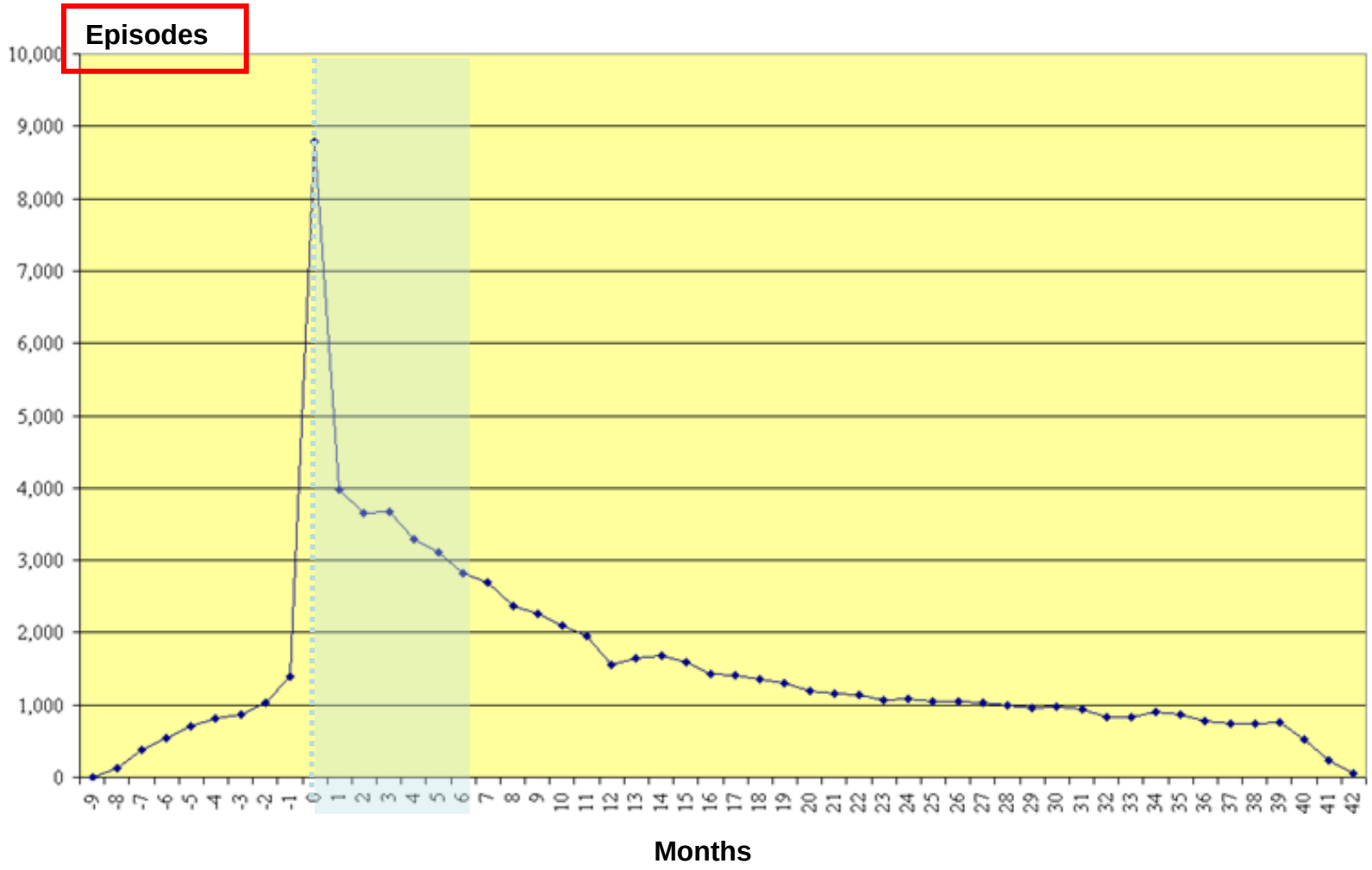
- Pilot work on haematological malignancy
- Three registries (NWCIS, NYCRIS, SWCIS)
  - Haematological Neoplasm (C000 to D489)
  - Date of Diagnosis 1st Oct. 2003 to 31st Dec. 2003
  - 2,270 Patients
- Hospital Episode Statistics 2003-2007

# Haematological Cohort




HES Past (6 to 9 Months)

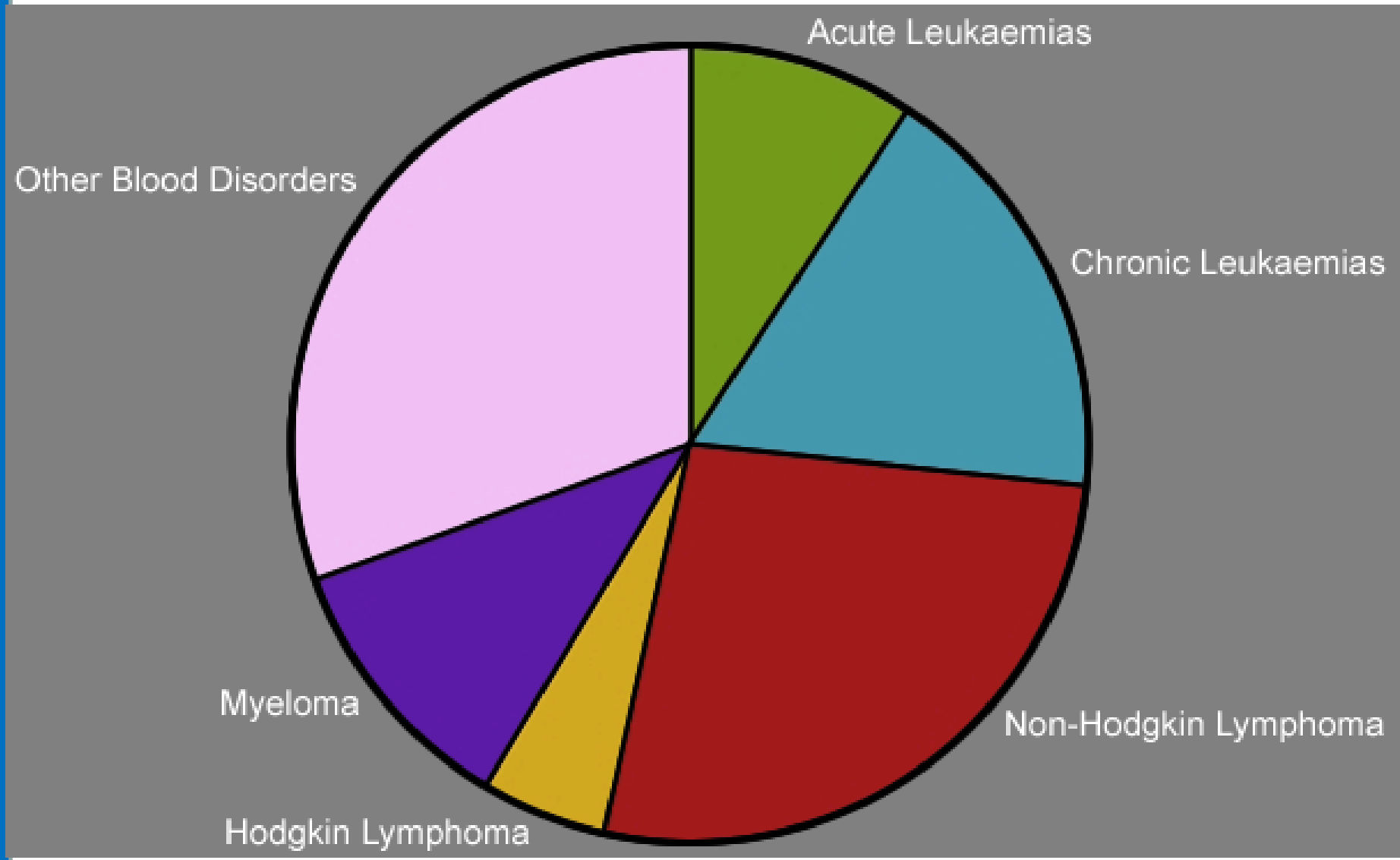
# HES activity before and after registry date of diagnosis



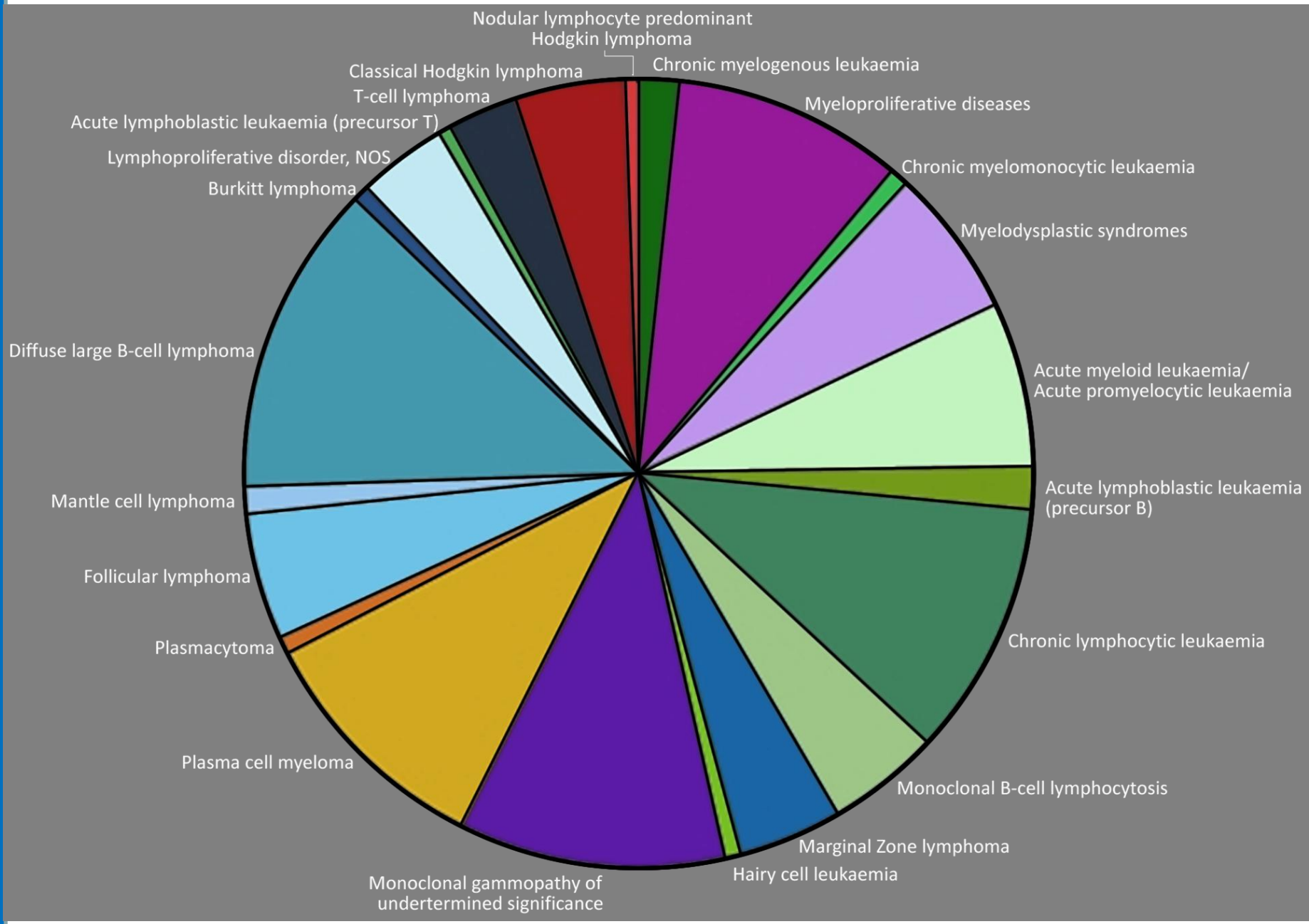
# Clinical Registries and Databases

- Adding value by linkage to clinical registries and databases will form an important aspect of the data repository
- e.g. regional Haematological Malignancy Research Network
  - Based around HMDS at Leeds
  - Initiated September 2004

# Traditional Disease Classification




1st September, 2004 to 31st August 2007 (n=5957)


Nodular lymphocyte predominant Hodgkin lymphoma
Chronic myelogenous leukaemia
Classical Hodgkin lymphoma
T-cell lymphoma
Myeloproliferative diseases
Acute lymphoblastic leukaemia (precursor T)
Lymphoproliferative disorder, NOS
Chronic myelomonocytic leukaemia
Burkitt lymphoma
Myelodysplastic syndromes
Diffuse large B-cell lymphoma
Acute myeloid leukaemia/
Acute promyelocytic leukaemia
Acute lymphoblastic leukaemia
(precursor B)
Mantle cell lymphoma
Follicular lymphoma
Chronic lymphocytic leukaemia
Plasmacytoma
Plasma cell myeloma
Monoclonal B-cell lymphocytosis
Marginal Zone lymphoma
Hairy cell leukaemia
Monoclonal gammopathy of
undertermined significance

# Place of death

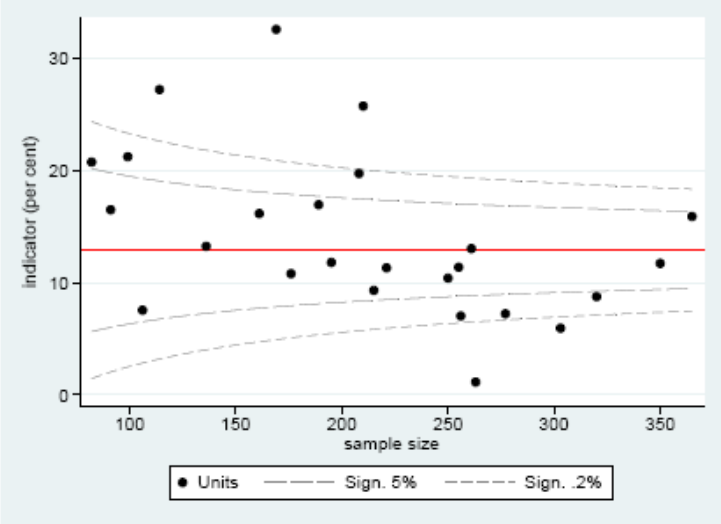
There is weak but consistent evidence that palliative care is used less in haematological cancers than in patients with solid tumours, and that access to specialised palliative care support may have been less available to haematologists than solid tumour oncologists, particularly for patients in the final phase of illness. Much of this evidence originates outside the UK, but whilst it is not clear how similar attitudes here may be to those in the US and Australia (where most studies have been carried out), information from the UK does point to the same conclusions.

# Place of death

- Data from 2001-2007
- 69,500 deaths coded to haematological malignancy
- Classified as ‘Home’, ‘Hospital’, ‘Hospice’, ‘Other’ on basis of *Establishment* codes
- Coded to Network on postcode at death
- Proportion dying in each location adjusted for age, sex and year of death

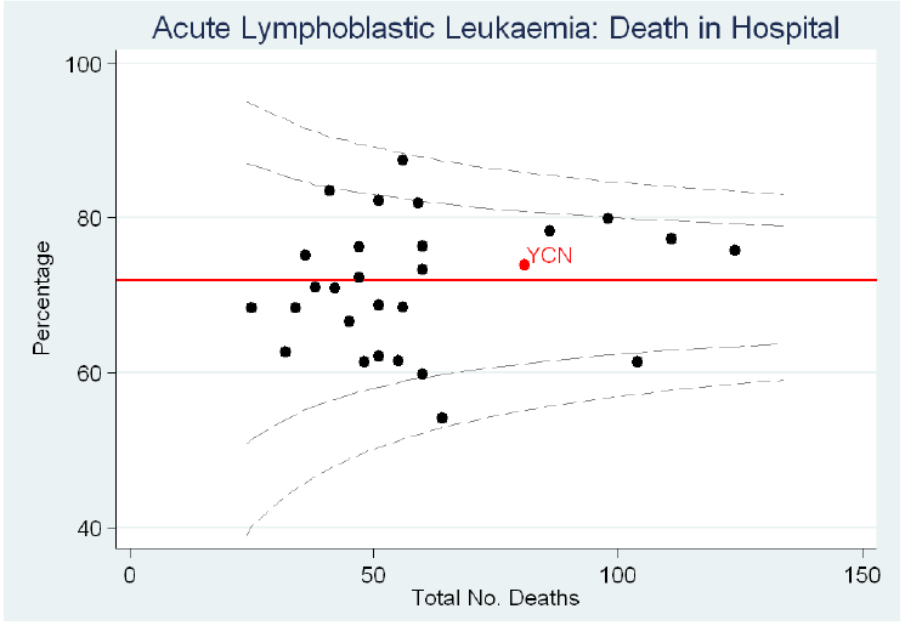
# Place of death

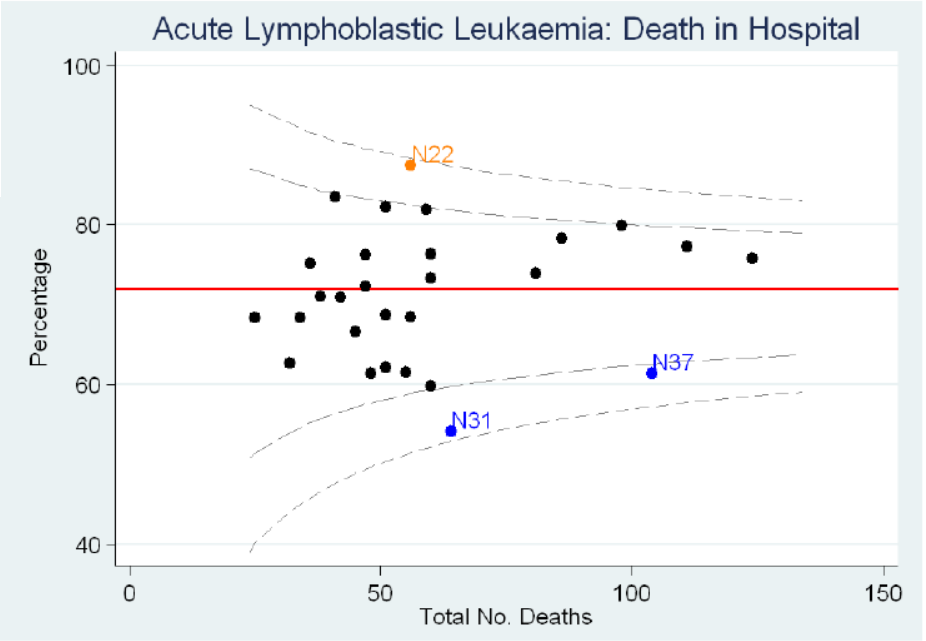
## Funnel Plot




- **Scatterplot** of observed indicators against a measure of its precision, tipically the sample size
- **Horizontal line** at a target level, typically the group avarage
- **Control Limits** at 95% ($\approx 2SD$) and 99.8% ($\approx 3SD$) levels, that narrow as the sample size gets bigger

# Place of death

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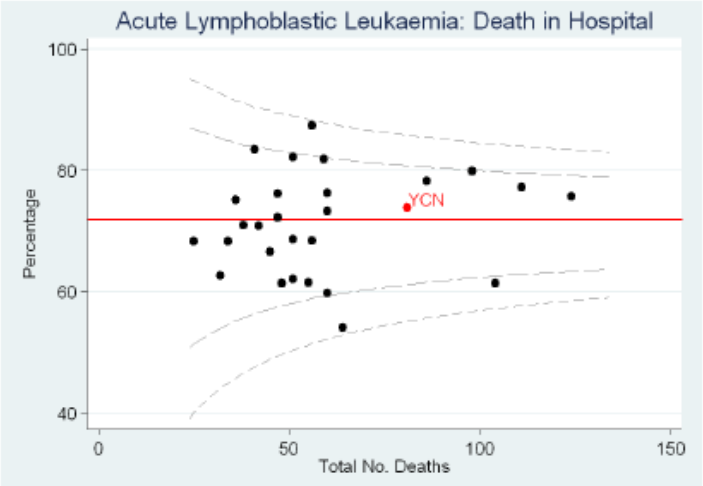
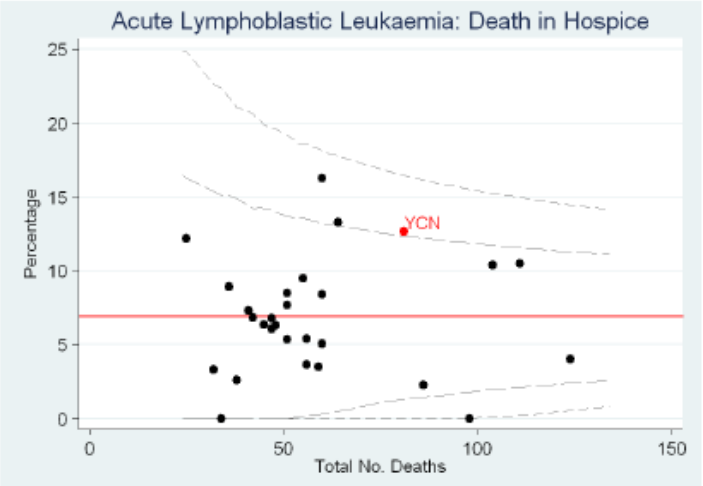
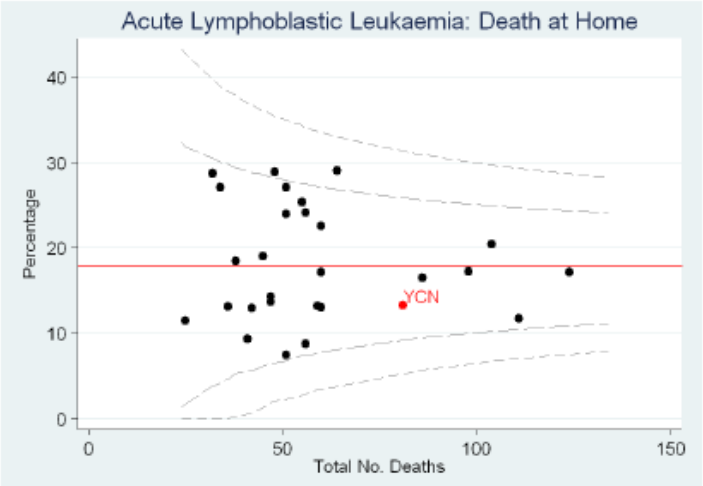
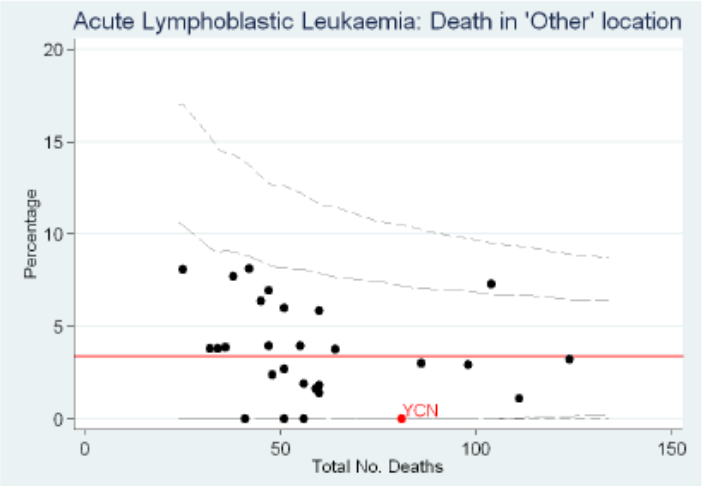
# Place of death



# Place of death

- How do these data fit with your local experience?
- What fits, what doesn't?
- Email – steven.oliver@hyms.ac.uk

# Work programme

- Survey of current and planned practice in registration
- Report on quality of cancer registration
- Evaluation of National Cancer registration data using regionally enhanced data from Haematological Malignancy Research Network (HMRN).
- Place of Death for patients with haematological cancer
- “NHS footprints” examining broader impact of haematological cancer on NHS services (pre- and post diagnosis)
- Myeloma incidence/survival
- Site-specific training materials for cancer registries
- ‘Non-cancer outcomes’ in patients with haematological cancer. In particular estimating incidence of cardiovascular events (from HES and other sources) in survivors of haematological cancer
- Piloting follow-up of patients in clinical trials through linkage to NCDR