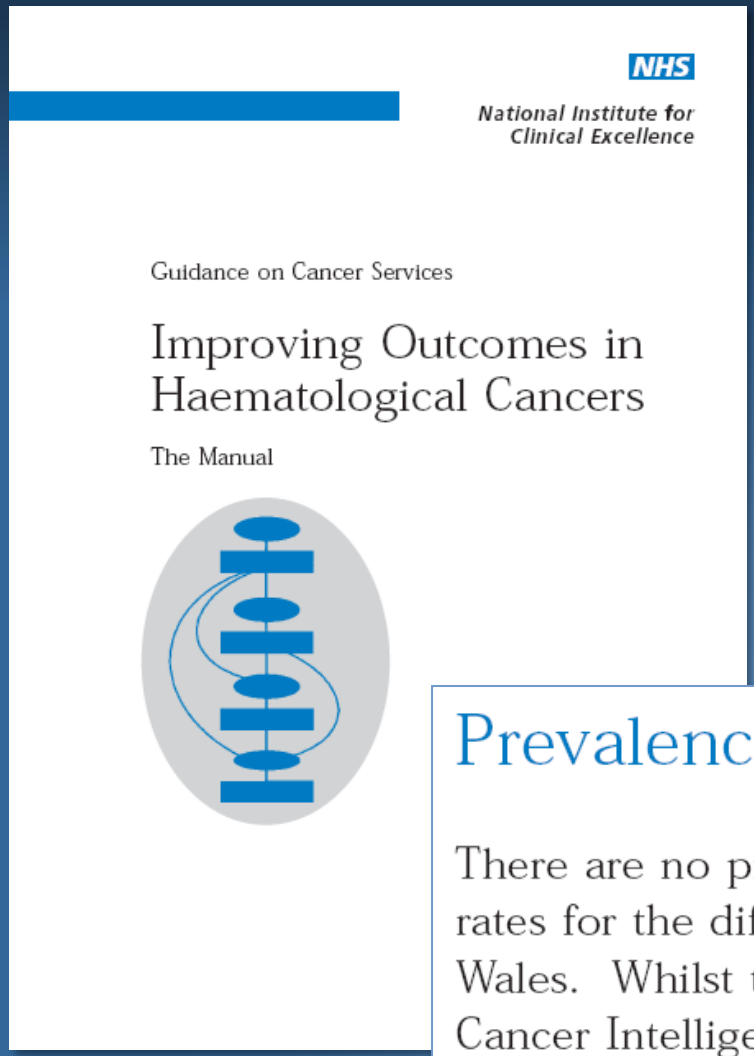


Cancer Network Haematology Clinical Leads Workshop September 2010

Dr Steven Oliver

Prevalence, incidence and survival rates

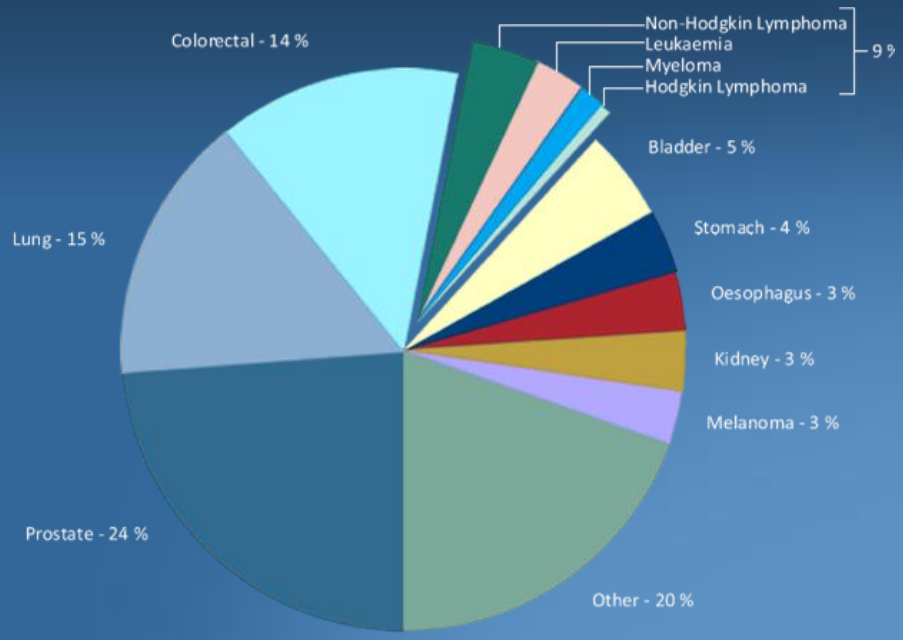
There are no precise and reliable figures for incidence and survival rates for the different forms of haematological cancer in England and Wales. Whilst the Office for National Statistics (ONS) and the Wales Cancer Intelligence and Surveillance Unit do publish descriptive statistics (Table 1), there are many problems with these figures. For example, there is evidence that many cases are never reported to cancer registries, so the actual number of patients could be substantially higher than national figures suggest.[1]

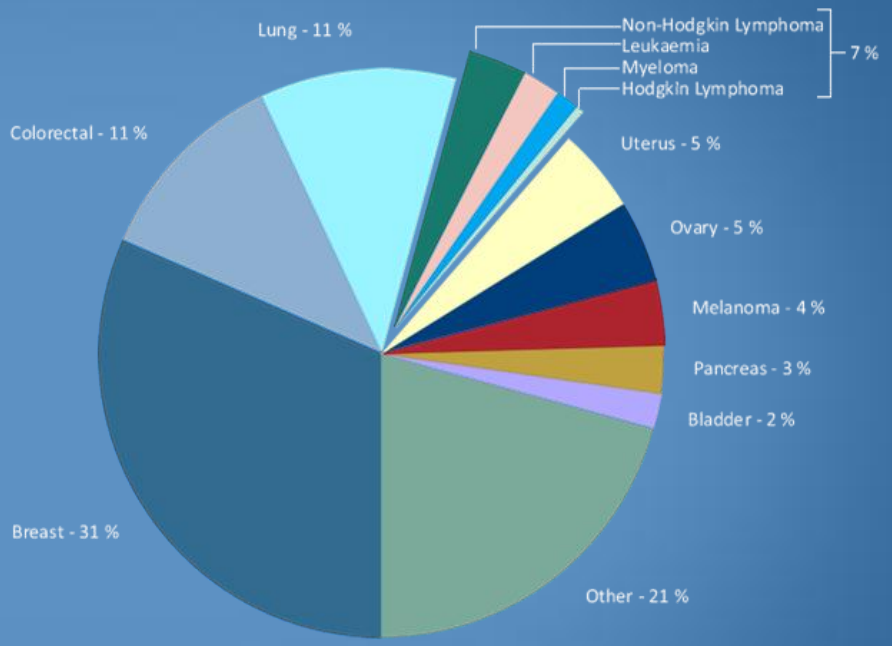
NCIN
national cancer
intelligence network

hmrn.org

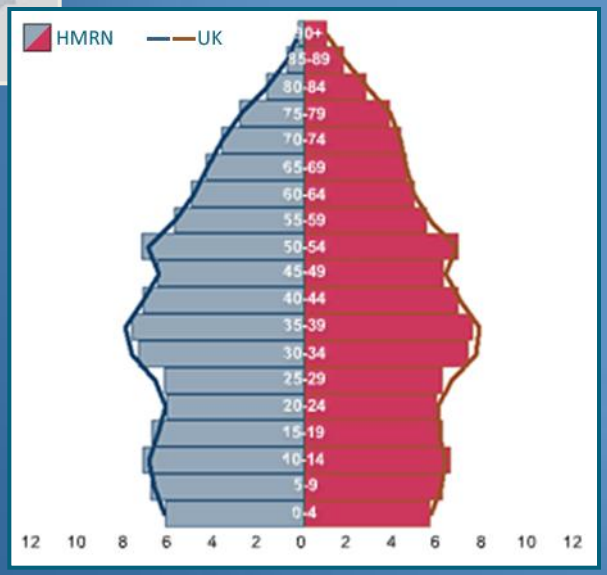
Haematological Malignancy Research Network

Background – National Data





HMRN – Where



- Population 3.6 million
- Similar socio-demographic structure to the UK
  - Age
  - Sex
  - Urban/rural status
  - Affluence/deprivation
  - Ethnicity

HMRN - Who

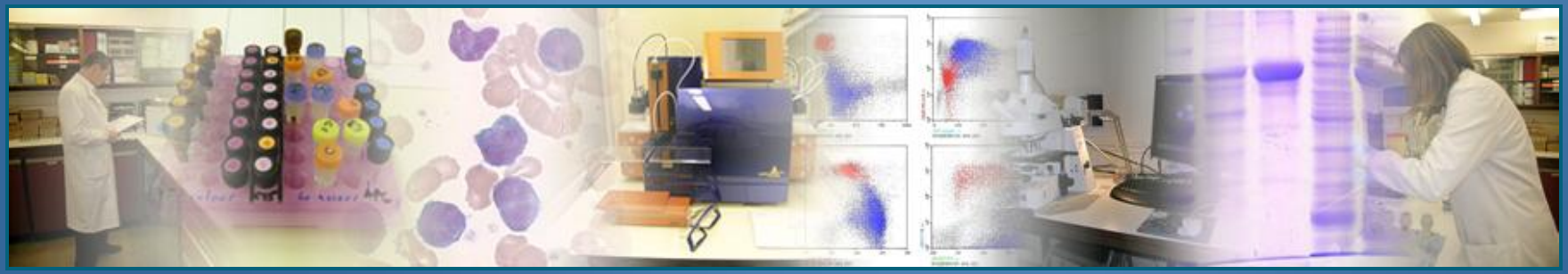
Epidemiology &
Genetics
Unit

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

Haematological
Malignancy
Diagnostic
Service

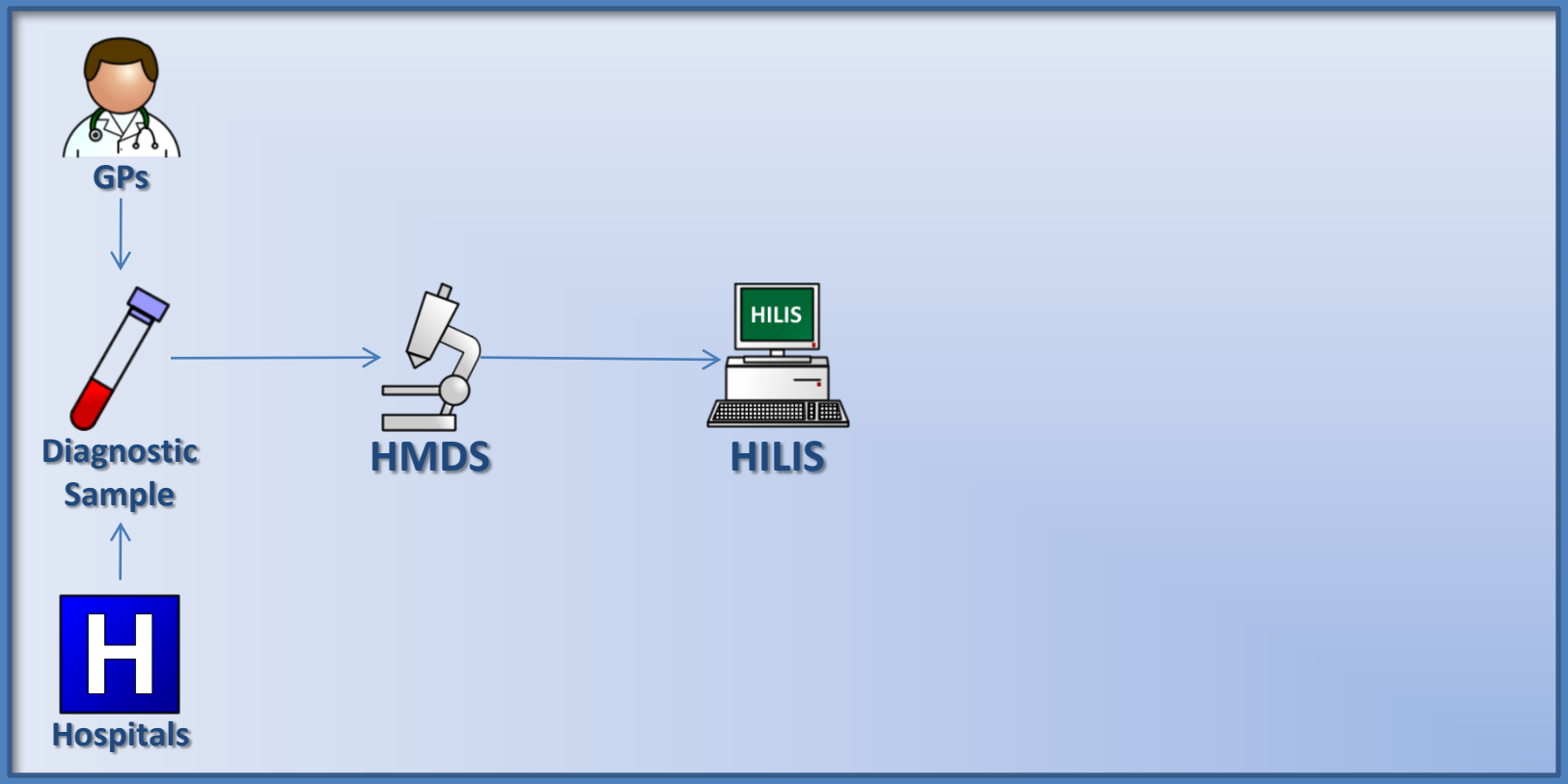
Haematological Malignancy Diagnostic Service

- Central specialist diagnostic laboratory
- 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 system & reporting facility

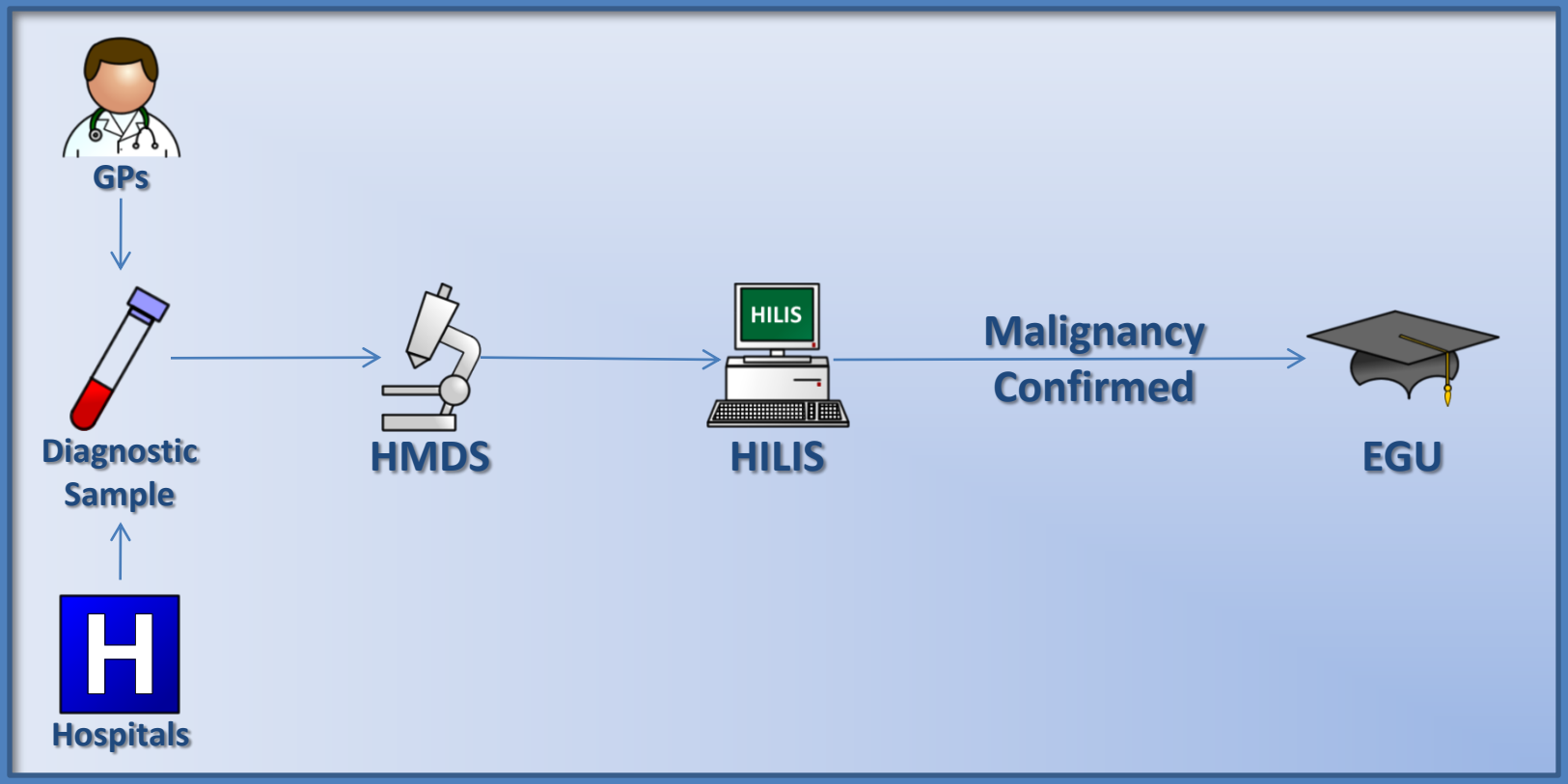


Case Notification

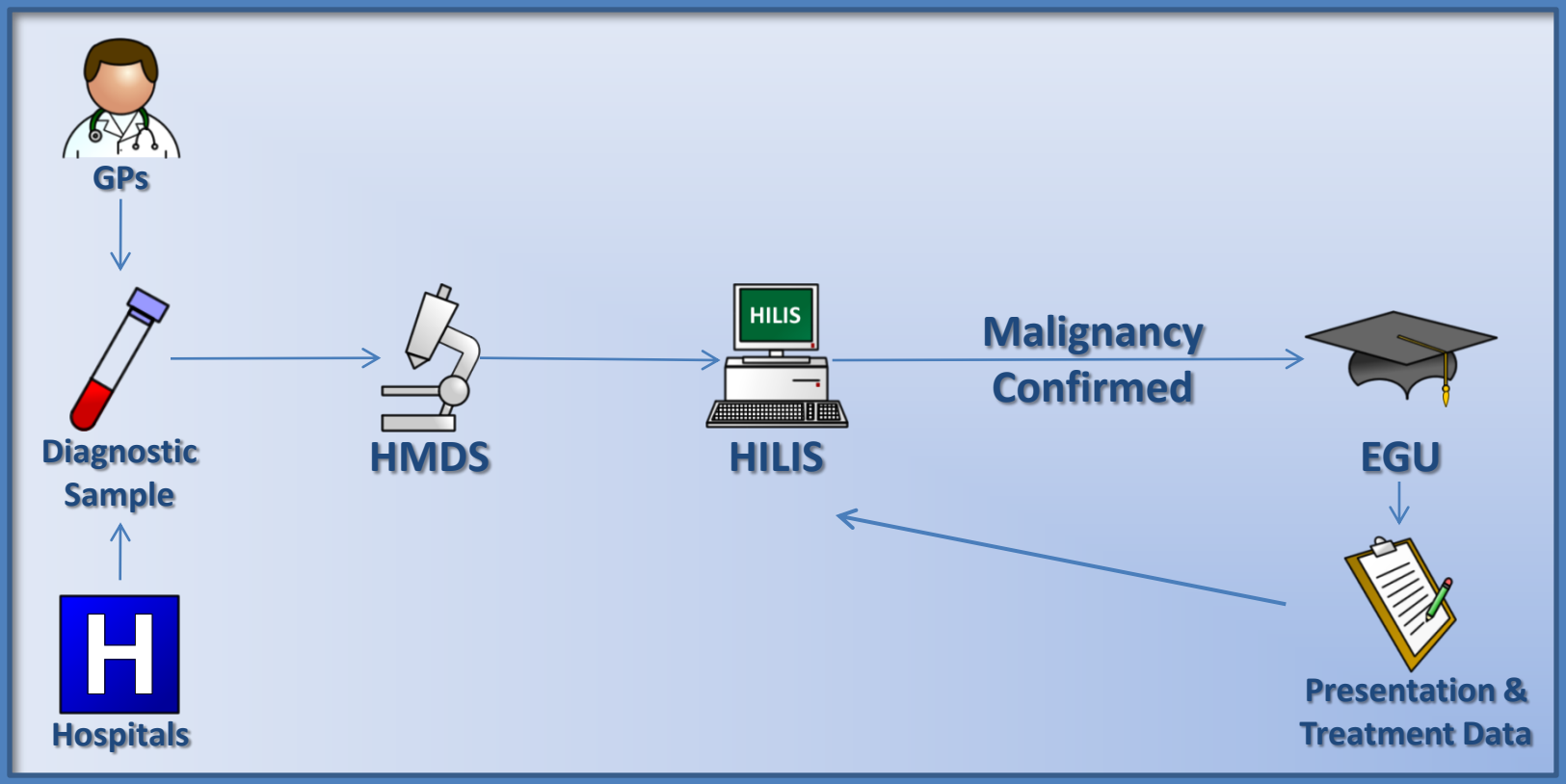
Case Notification



Case Notification



Routine Data Collection



HMDS Integrated Laboratory Information System

Search Results Page requested: **10:35:04** Script runtime: 1.28

History | Screen | Results | Report | PID | Delete | Unlock | YHHN | Print

Name	DoB	NHS No.	Lab No.	Date	Source	Clinician	Specimen
			H12509/04	22.Dec.2004	Leeds General Infirmary	Ong	LU

Screened as **Tissue biopsy** by **S Richards** on **22.Dec.2004** E-mailed

Results:	Flow: B-cells = 49% of leucocytes, of which 90% are monoclonal (l-k+M+D+G-), phenotype CD5-CD20+(strong)CD38+ CD10+/-CD22+FMC7+ CD23-CD11a+CD52+ CD79b+(strong). The remainder are polyclonal.

New Diagnosis:	**Follicular lymphoma; large cell**	Reported by:	AS Jack	Date:	30.Dec.2004
Clinical Details:	Cervical lymphadenopathy. Night sweats. Lymph node biopsy.				
Gross Description:	Piece of tissue 62mm in length.				
Morphology/Comment:	This is an enlarged lymph node in which the architecture is replaced by lymphoma. The tumour has a predominantly follicular growth pattern. The follicles consist of a relatively monomorphic population of large				
Specimen Quality:	Adequate	Authorised By:	D Swirsky	Date:	31.Dec.2004

Flow Screen

B-lymph:	
Outreach:	
Plasma cell:	
Rituximab:	
Stem cell:	
T-lymph:	

Miscellaneous

PML:	
Perls:	

Cytometry

AML:	
B-ALL:	
CLL:	
Extended B:	AK
Extended T:	
Immunol:	
MDS:	
Myeloma:	
PNH:	
T-ALL:	
Checked by:	AR

Molecular

ALL:	
AML:	
B clones:	
CML:	
CML-RQ:	
Chimerism:	
FCL:	
JAK2:	
T clones:	
FISH:	
Cytogenetics:	

Histology

Cut-up: AC,23/12,F1,P3 H&E: 29/12,DB,7

Common B:		AI T-cell:	
Common T:		B-ALL:	
HD Common:		Carcinoma:	
HD LPN:		Myeloid:	
Paediatric:		NK/T-cell:	
Plasma Cell:		Other#1:	DB
T-ALL:		Other#2:	
TB Culture:		Other#3:	

Flow Details: exb 1-8,11

Histology Details: bcl-2,bcl-6,foxp1,p53,p21,ki67,mum1,cd21

View history :: Print history

Yorkshire and North Lincolnshire Haematology Registry - Mozilla Firefox

File Edit View History Bookmarks Tools Help

https://nww.hmds.leedsth.nhs.uk/cgi-bin/hilis3/yhhn/yhhn.cgi?uid=ALEXS.7111a6d1c0dcddf6ee682ec9f42cd1bf;YHHN=H12509/04

Yorkshire and North Lincolnshire Hae...

Yorkshire and North Lincolnshire Haematology Registry

Alex

Search

Register

Worklist

Resources

LogOut

<< Back

Follicular lymphoma; large cell [9698/3]

Chronicle

Name	DoB	NHS No.	Lab No.	Reported	Source	Clinician
			H12509/04	30.Dec.2004	Leeds General Infirmary	Ong

Jump to: Demographic | Antecedant | Treatment | Presentation | Comments

MDT meeting:

Date:	06.Jan.2005	Decision:	CHOP / Rituximab
Date:	17.Mar.2005	Decision:	CHOP / Rituximab
Date:	19.May.2005	Decision:	Observation
Date:	18.May.2006	Decision:	DHAP / Rituximab
Date:	27.Jul.2006	Decision:	Not stated
Date:	28.Dec.2006	Decision:	Observation
Date:		Decision:	

Demographic data:

Gender:	F
Address at diagnosis:	
Post code:	
GP ID:	B00000 [decode ID]

Chronological data:

Date of diagnosis:	31.Dec.2004
Age at diagnosis:	54
First haem appointment:	30.Dec.2004
Palliative referral date:	
Date of death:	

Back Top ▲

Antecedent/concurrent events:

Event:	None	Previous radiotherapy:	☐
		Previous chemotherapy:	☐

Treatment history:

Minimum data entry: 'Centre' & 'Treatment'

#	Location	Treatment	Regimen/Trial	Start	End	Response
1	Leeds	chemotherapy	CHOP / Rituximab	13.Jan.2005	19.May.2005	CR
2	Leeds	observation		19.May.2005	10.Jun.2006	PD
3	Leeds	chemotherapy	DHAP / Rituximab	10.Jun.2006	01.Jan.1000	CR

Routine Data Collection

Demographics, referral pathway and antecedent events

Demographic data:

Gender:	F
Address at diagnosis:	
Post code:	
GP ID:	B00000 [decode ID]

Chronological data:

Date of diagnosis:	31.Dec.2004
Age at diagnosis:	54
First haem appointment:	30.Dec.2004
Palliative referral date:	
Date of death:	

Antecedent/concurrent events:

Event: None

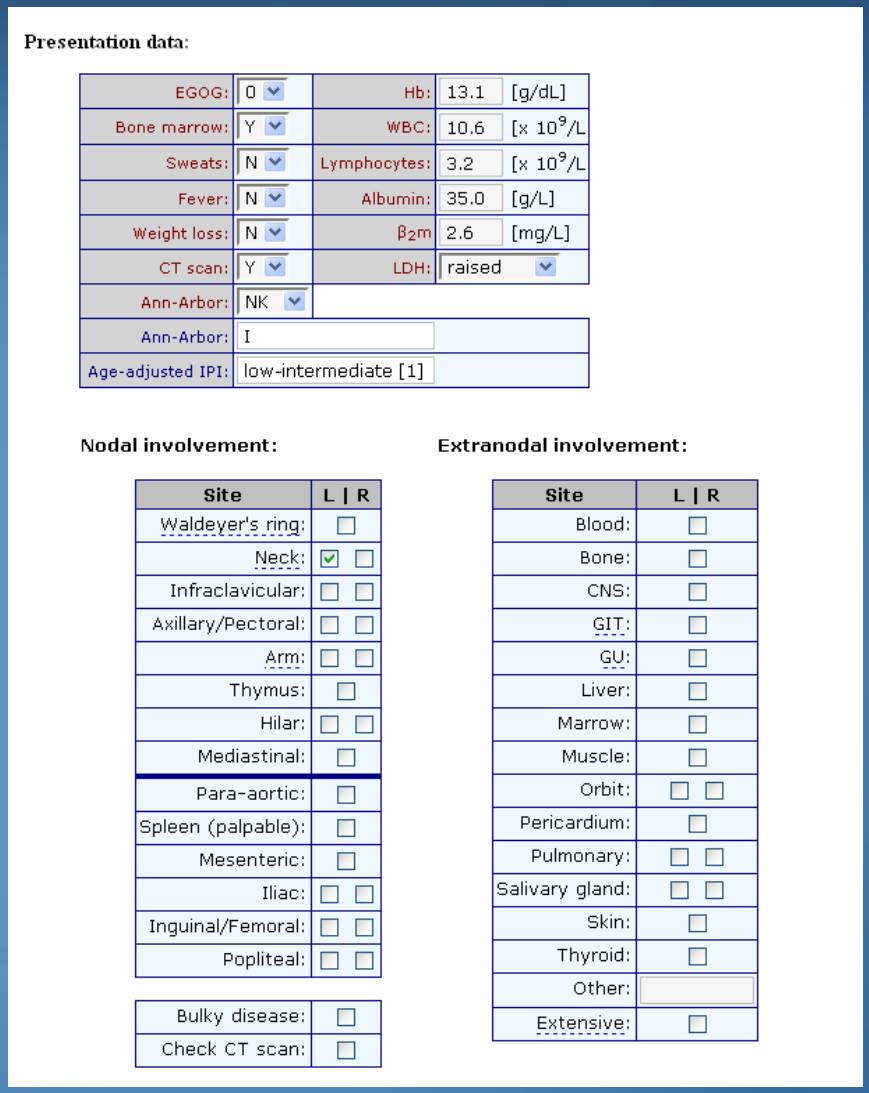
Previous radiotherapy: ☐

Previous chemotherapy: ☐

- None
- Coeliac disease
- Down's syndrome
- Haem & non-haem malignancies
- Haematological malignancy
- Hashimoto's thyroiditis
- Helicobacter pylori
- Immunodeficiency
- Monoclonal B lymphocytosis
- Monoclonal gammopathy
- Non-haematological malignancy
- Organ transplantation
- Other (see comments)
- Rheumatoid arthritis
- Sjogren's syndrome
- Unknown

Routine Data Collection

- Prognostic data from primary sources
- Individual components of prognostic score collected
- Algorithm in HILIS calculates:
  - Stage
  - Prognostic scores



Presentation data:

EGOG:	0	Hb:	13.1 [g/dL]
Bone marrow:	Y	WBC:	10.6 [x 10^9/L
Sweats:	N	Lymphocytes:	3.2 [x 10^9/L
Fever:	N	Albumin:	35.0 [g/L]
Weight loss:	N	β_2m	2.6 [mg/L]
CT scan:	Y	LDH:	raised
Ann-Arbor:	NK		
Ann-Arbor:	I		
Age-adjusted IPI:	low-intermediate [1]		

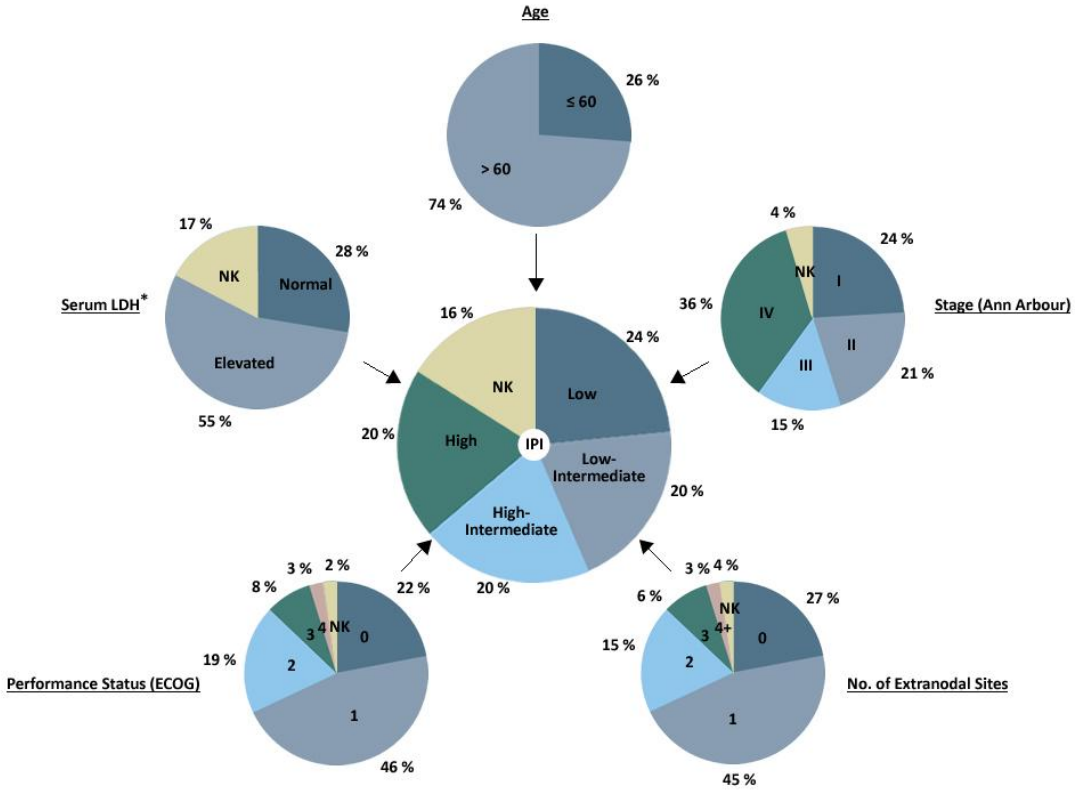
Nodal involvement:

Site	L	R
Waldeyer's ring:	☐	
Neck:	☑	☐
Infraclavicular:	☐	☐
Axillary/Pectoral:	☐	☐
Arm:	☐	☐
Thymus:	☐	
Hilar:	☐	☐
Mediastinal:	☐	
Para-aortic:	☐	
Spleen (palpable):	☐	
Mesenteric:	☐	
Iliac:	☐	☐
Inguinal/Femoral:	☐	☐
Popliteal:	☐	☐
Bulky disease:	☐	
Check CT scan:	☐	

Extranodal involvement:

Site	L | R
Blood:	☐
Bone:	☐
CNS:	☐
GIT:	☐
GU:	☐
Liver:	☐
Marrow:	☐
Muscle:	☐
Orbit:	☐ ☐
Pericardium:	☐
Pulmonary:	☐ ☐
Salivary gland:	☐ ☐
Skin:	☐
Thyroid:	☐
Other:	
Extensive:	☐

Diffuse large B-cell lymphoma: HMRN 2004-8



Performance Status (ECOG)

0	No symptoms
1	Symptoms but ambulatory
2	Bedridden less than half the day
3	Bedridden half the day or longer
4	Chronically bedridden and requiring assistance with activites of daily living

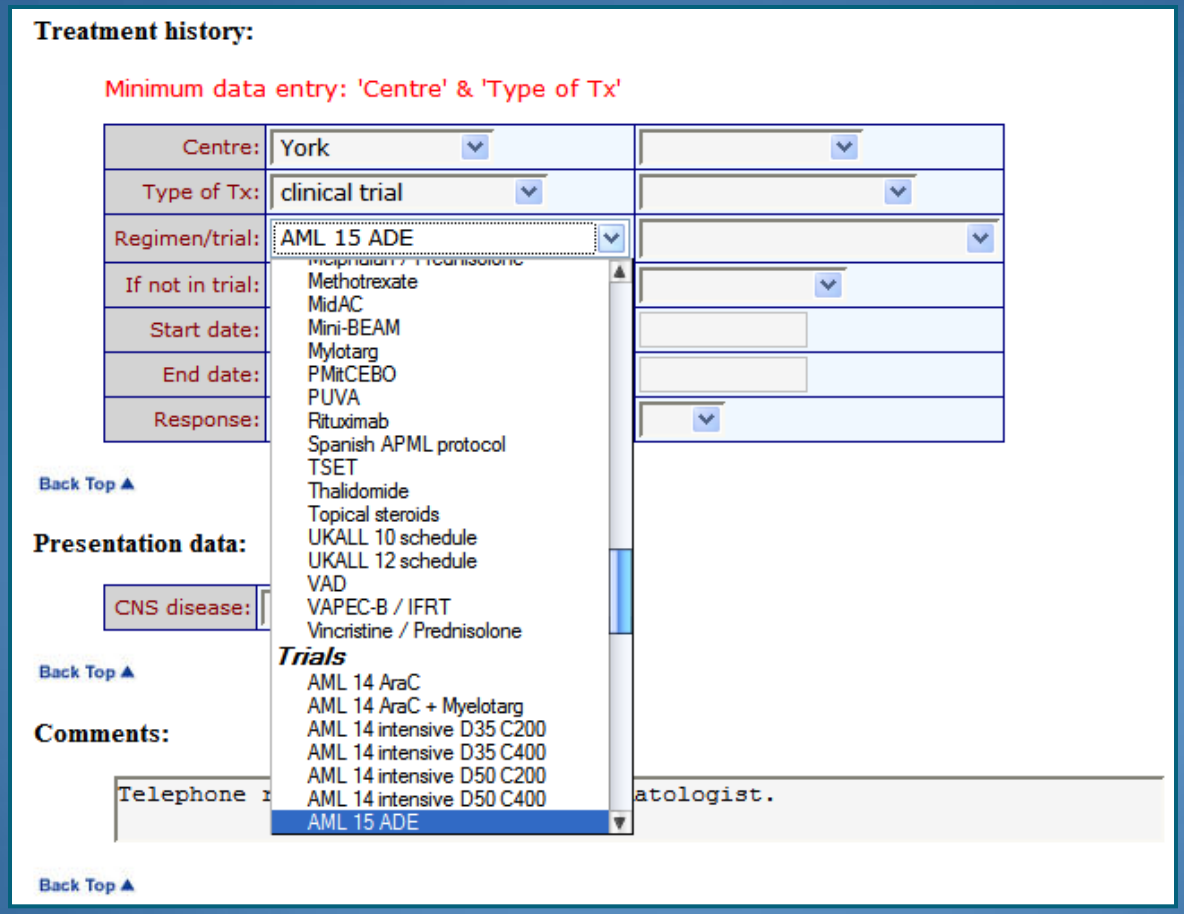
*LDH - Lactate Dehydrogenase

Ann Arbour Staging System

Stage I	A single node
IE	A single extralymphatic site
Stage II	Two or more nodal regions on the same side of the diaphragm
IIE	A single extralymphatic site plus nodal involvement on the same side of the diaphragm
IIS	Splenic involvement in addition to lymph nodes on the same side of the diaphragm
Stage III	Lymph nodes on both sides of the diaphragm
IIIE	A single extralymphatic site with nodes on both sides of the diaphragm
IIIS	Splenic involvement with nodes on both sides of the diaphragm
Stage IV	Disseminated extralymphatic disease

Routine Data Collection

- Treatment data entered using standardised terms



Routine Data Collection

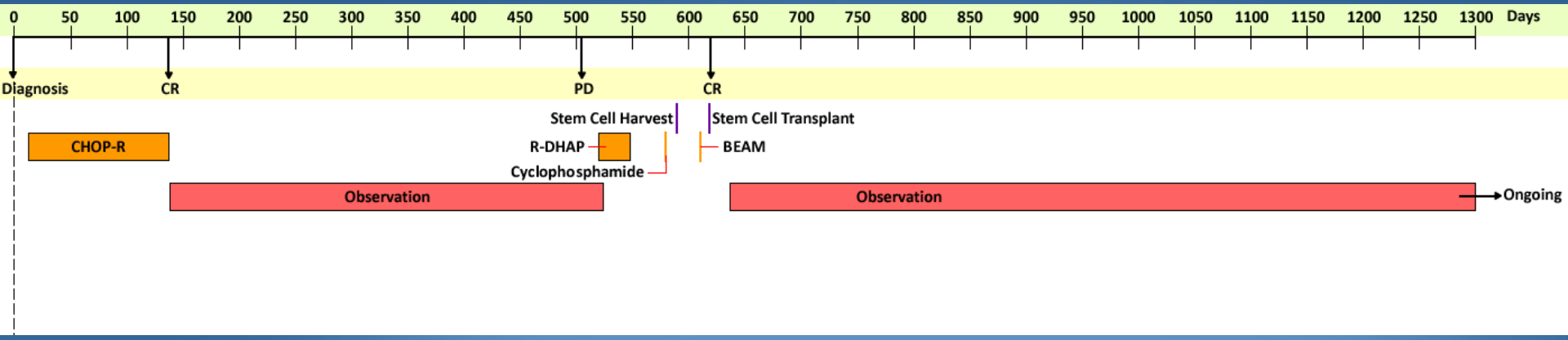
- Patients are followed from time of diagnosis onwards
- All treatment episodes are recorded
- Information collected on treatment response

Treatment history:

Minimum data entry: 'Centre' & 'Treatment'

#	Location	Treatment	Regimen/Trial	Start	End	Response
1	Leeds	chemotherapy	CHOP / Rituximab	13.Jan.2005	19.May.2005	CR
2	Leeds	observation		19.May.2005	10.Jun.2006	PD
3	Leeds	chemotherapy	DHAP / Rituximab	10.Jun.2006	04.Jul.2006	
4	Leeds	chemotherapy	Cyclophosphamide	04.Aug.2006	04.Aug.2006	
5	Leeds	chemotherapy	BEAM	04.Sep.2006	01.Jan.1000	
6	Leeds	stem cell transplant		12.Sep.2006	12.Sep.2006	CR
7	Leeds	observation		29.Sep.2006		
8						

Summary of Patient Pathway: Follicular Lymphoma



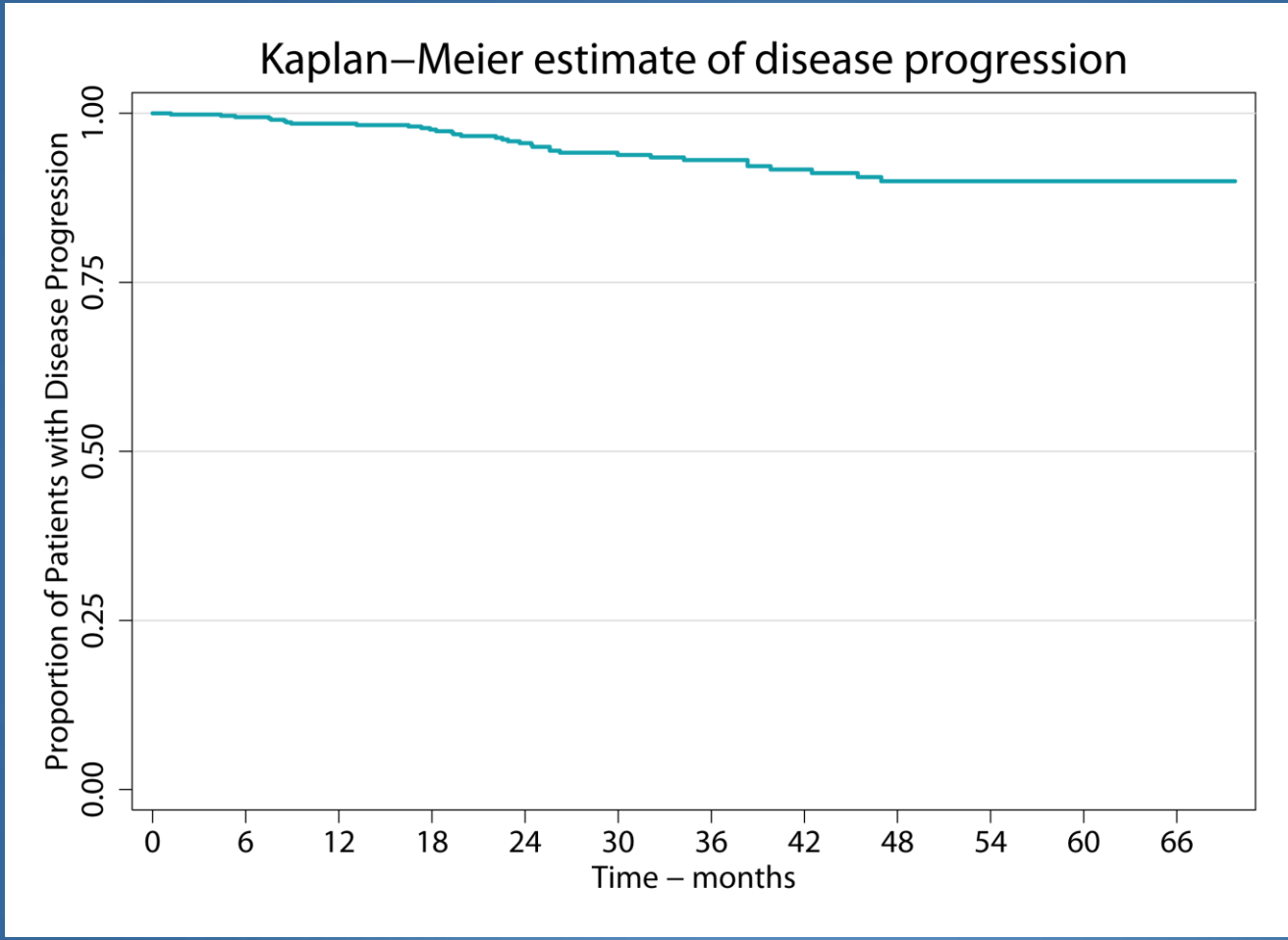
CR = complete remission PD = progressive disease

CHOP-R = Cyclophosphamide, Vincristine, Doxorubicin, Prednisolone - Rituximab R-DHAP = Rituximab - Dexamethasone , Cisplatin, Cytarabine GCSF = Granulocyte Colony-Stimulating Factor
BEAM = Carmustine, Cytarabine, Etoposide, Melphalan, Thaw and re-infuse haemopoietic stem cells CVP-R = Rituximab - Cyclophosphamide, Vincrisitine, Prednisolone
FCR = Fludarabine, Mitoxantrone, Dexamethasone - Rituximab

Patient Follow-up: Outcomes

- Response recorded using standard criteria
- Disease progression

Disease Progression

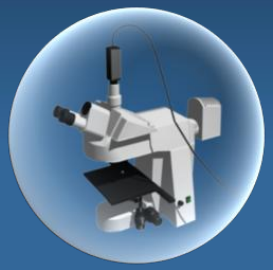


Follicular Lymphoma (n=543) to Diffuse Large B cell Lymphoma (n=36)

Patient Follow-up: Outcomes

- Response recorded using standard criteria
- Disease progression
- Survival
  - All HMRN patients ‘flagged’ at the NHS Central Register
  - Electronic Monthly Updates
    - Date of Death
    - Cause of Death
    - Underlying Cause of Death

Summary of Routine Data Sources and Analysis



Diagnostics

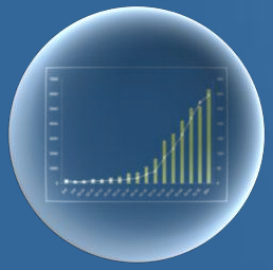
Demographics

Prognostics

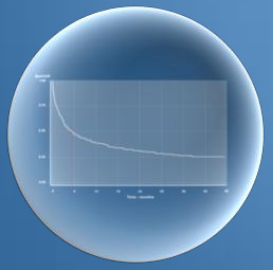
Treatment

Death Certificates

Follow Up



Descriptive Epidemiology



Survival

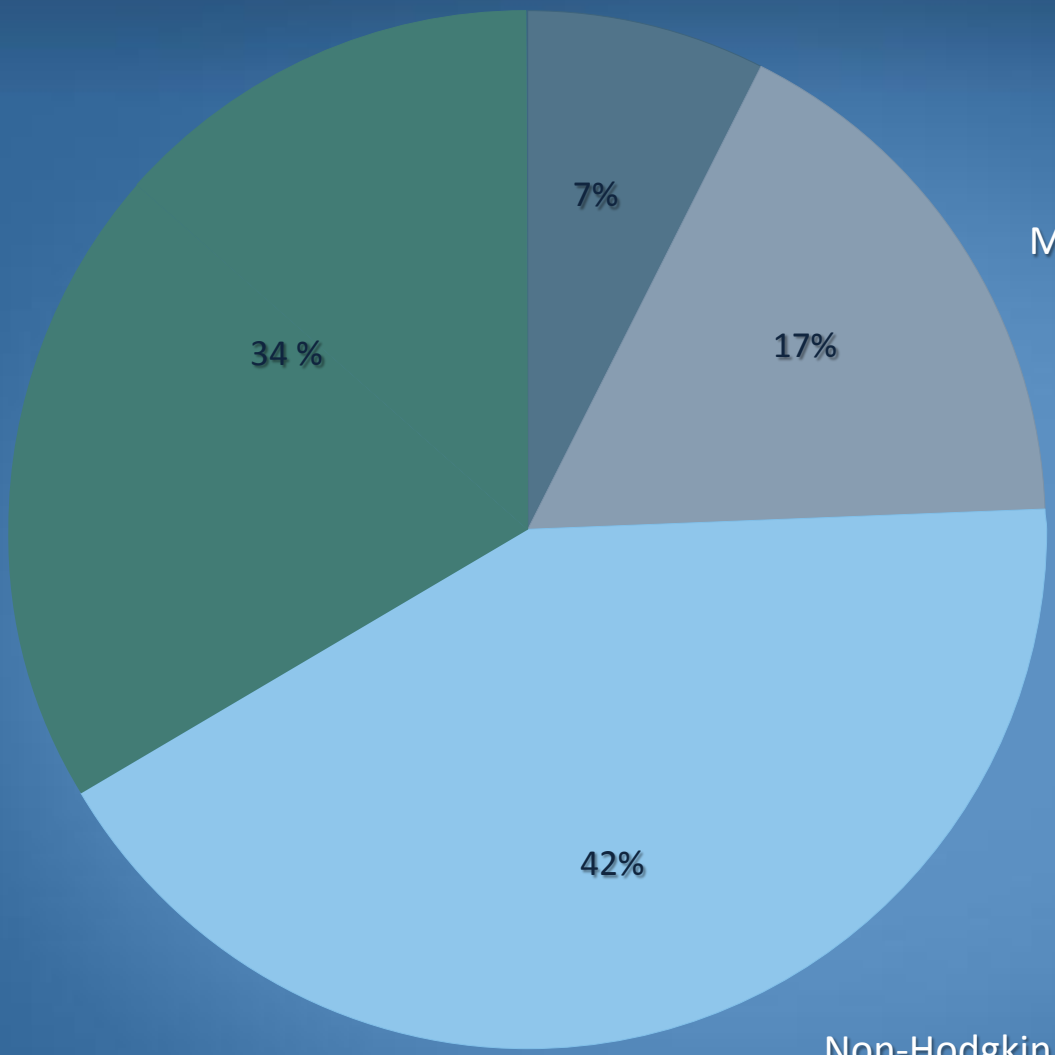
Aetiology

Patient Pathway

Health Economics

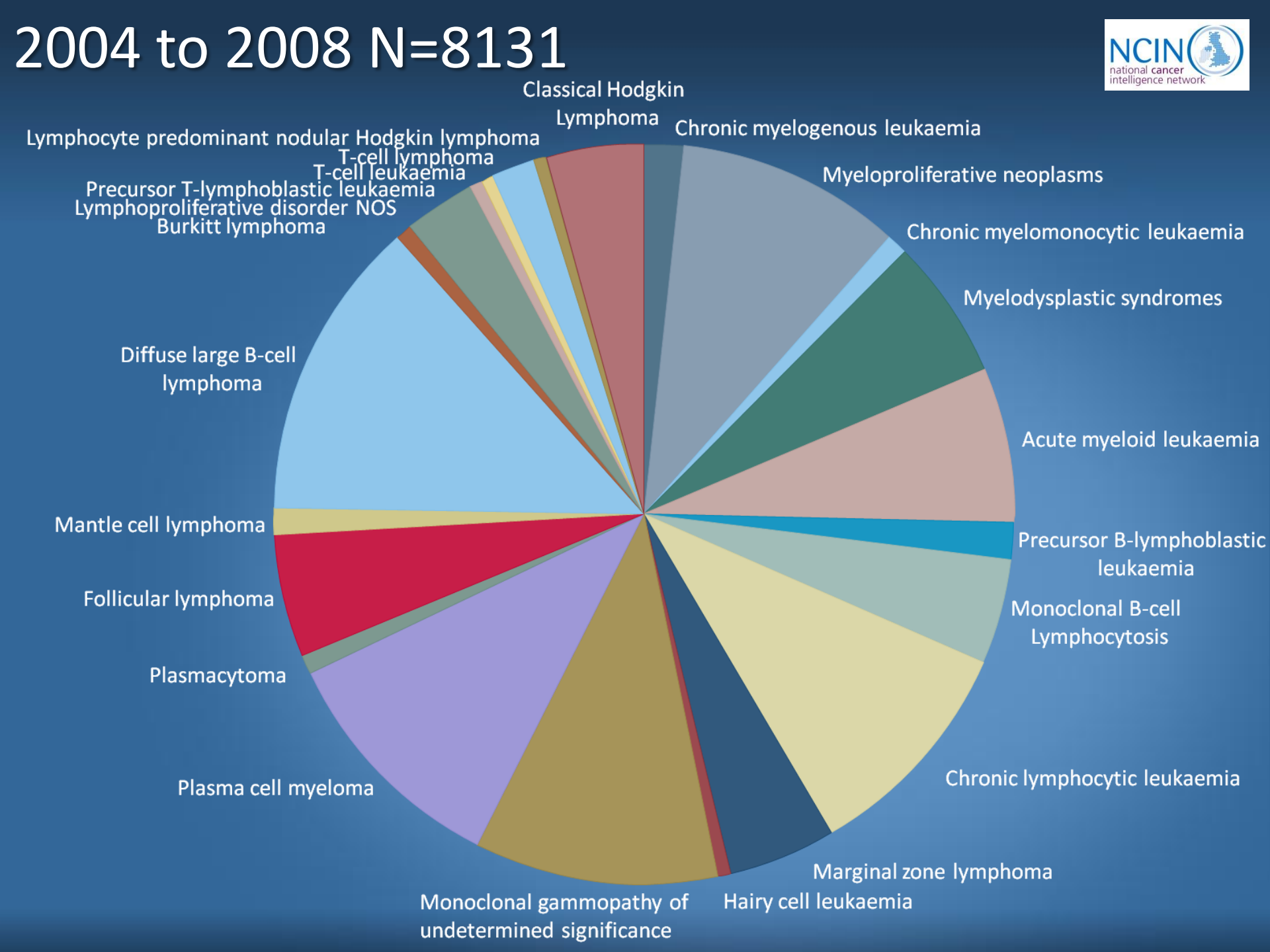
Audit

2004 to 2008, ICD-10 (n=8131)



*www.hmrn.org

2004 to 2008 N=8131



Welcome to the Haematological Malignancy Research Network

On these pages you will find information about haematological cancers and related blood disorders

HMRN is a comprehensive population-based register that effectively links diagnostics and prognostics with data on outcome and treatment, providing a unique opportunity to gain insight into aspects of haematological cancer that cannot be studied elsewhere

This site is intended for anyone interested in haematological malignancy. It contains information for patients, statistics for researchers, as well as a section for the clinical teams working across the network

Click the button below to enter the site

HMRN covers a population of 3.6 million and accrues around 2,000 new haematological cancers each year. It is based in the UK Cancer Networks of Yorkshire and Yorkshire Coast, and the population is broadly representative of the UK as a whole. All haematological malignancies, including transformations and progressions, are centrally reviewed and coded using the latest techniques by internationally recognized experts. Clinical care is provided by a single unified network, and following diagnosis information on demographics, prognostics and staging, as well as details about all treatments, responses and relapses is abstracted onto highly structured forms - each cancer having its own specially tailored version. A critically important feature of the abstraction process is the emphasis on primary source data, which enables embedded computerised algorithms to automatically generate staging and prognostic scores at the time of data entry.

Google™ Custom Search Search

Haematological Malignancy Research Network

Click one of the buttons below to view an area of the site

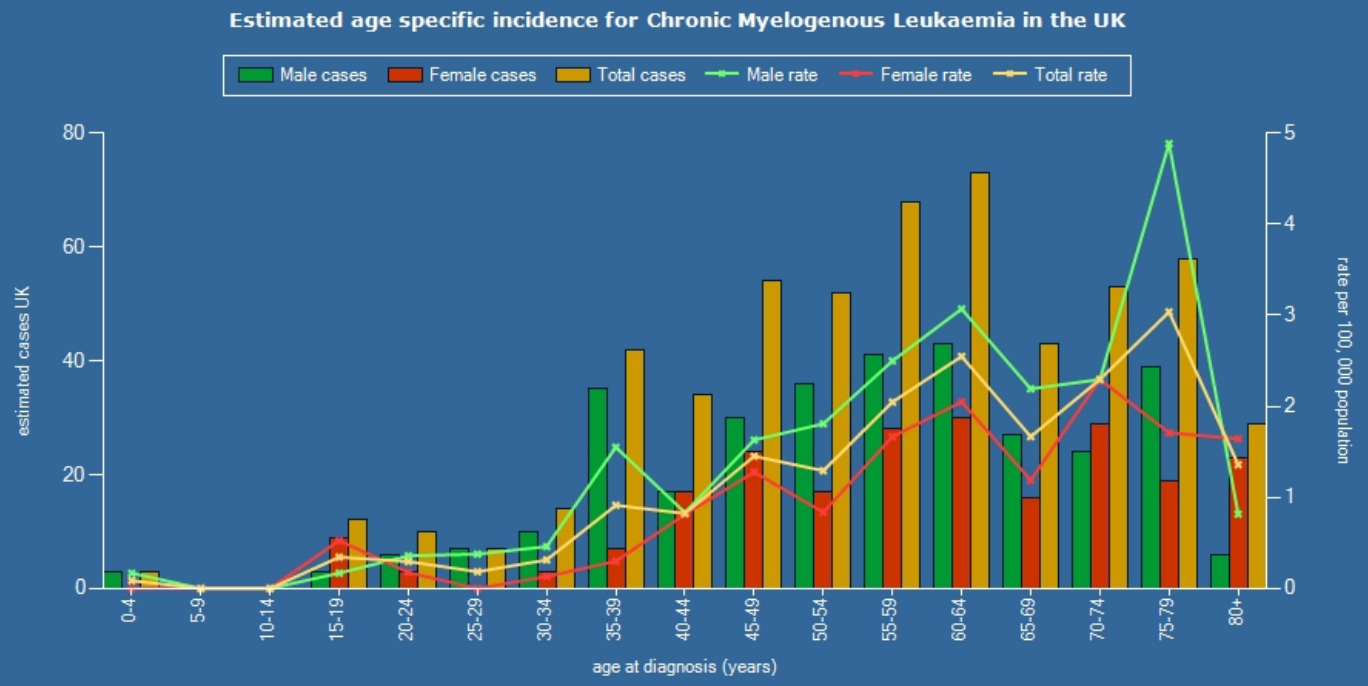
Chronic Myelogenous Leukaemia (CML) accounts for approximately 1.6% of all haematological neoplasms newly diagnosed in the UK.

Incidence

Quickstats

Rate per 100,000[1]			M:F rate ratio[1]	Median age at diagnosis[1]	Expected UK cases per year[2]	ASR per 100,000[3]		
Total	Male	Female				Total	Male	Female
1.0	1.2	0.7	1.7	59	550	0.9	1.1	0.6

[1] HMRN 2004-09
[2] Estimated by applying HMRN age and sex specific rates to 2001 UK population census strata
[3] Age standardised rates (European)



[Download As Excel]

How can HMRN data inform national understanding?

Comparing HMRN and National Cancer Data Repository Data

- Eighteen month project funded by NCIN
- Key elements
  - Develop predictive models at national level for disease incidence and prevalence based on HMRN data
  - Comparison between predicted and observed data (i.e. registered) initially within NYCRIS (HMRN based in 2 of the 3 regional networks)
  - Comparisons between predicted and observed data for all English registries
- Seek better understanding of levels of under-enumeration and misclassification

What other work is going on?

- National incidence, mortality and survival by 'clinical groups'
  - Limited to ICD-10 categories
  - Separate out: ALL, AML, CML, CLL...
- Place of death – updated to 2009
- Hospital activity in the last year of life
- Bed stay and pathways through secondary care
- Work with UK Association of Cancer Registries on coding rules for haematological cancer