Blood Cancers Data Quality Report

National Cancer Data Repository (NCDR) - 2010

Haematological Malignancies Site-Specific Clinical Reference Group

Knowledge and Intelligence Team (Northern and Yorkshire)
National Cancer Registration Service (Northern and Yorkshire)
Public Health England

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Introduction

The National Cancer Intelligence Network (NCIN) Haematological Site Specific Clinical Reference Group advises which data should be collected and analysed with the aim of improving clinical care in the area of haematological cancers. The Public Health England's Knowledge and Intelligence Team (Northern and Yorkshire) analyses these cancers using the records held in the National Cancer Data Repository (NCDR).

In order to produce robust analyses it is important to recognise and understand where data are missing or data quality is poor. This report aims to assess the data quality and completeness of the cancer registry data within the NCDR where diagnosis occurred between 2000 and 2010. More detailed analyses have been conducted for tumours diagnosed in 2010.

Blood cancers are a very diverse range of diseases including various forms of leukaemia, lymphomas and myeloma. These diseases differ in how they present to services, in how they are diagnosed and treated and in their eventual outcome, all factors that can influence the quality of information available and recorded in cancer registries. Therefore, in this report, the quality of data is examined separately for a range of broad disease groups.

Over the time period covered in this report the eight English cancer registries operated separate data collection and quality assurance processes and therefore the quality of data has also been presented on each individual registry.

Key messages

- The completeness of ascertainment of blood cancers by English cancer registries has varied over the period 2000-2010. There have been substantial changes in the numbers of some forms of cancer recorded in some registries.

- The disease groups in which changes in ascertainment have been most marked are chronic lymphocytic leukaemia, chronic myeloid leukaemia and myeloma.

- The cancer registry catchment areas in which most variation has been seen over time in registrations for blood cancers are the North West Cancer Intelligence Service, Oxford Cancer Intelligence Unit, South West Cancer Intelligence Service and Thames Cancer Registry Service.

- Information held in the NCDR 2010 on the staging and treatment of blood cancers is not sufficiently complete to support national analysis.

Data included in the quality report

The data analysed for this report comprise all cancer registrations with a haematological malignancy with a diagnosis date between 1 January 2010 and 31 December 2010. Additional analyses on time trends include all registrations from 1 January 2000. These data are made up of tumour level records submitted to the Office of National Statistics (ONS) by the eight English Cancer Registries. The ONS dataset has been collated, cleaned and uses standardised data items. To establish the NCDR, the ONS dataset has been further linked to an extract of the English NHS Hospital Episode Statistics (HES).

Data have been presented for haematological cancers categorised into disease groups on the basis of the following ICD-10 (International Classification of Diseases) codes:

- **Acute lymphoblastic leukaemia (ALL)** - C910
- **Acute myeloid leukaemia (AML)** - C920, C924, C925, C930, C940, C942
- **Chronic lymphocytic leukaemia (CLL)** - C911
- **Chronic myeloid leukaemia (CML)** - C921
- **Hodgkin lymphoma (HL)** - C81
- **Non-Hodgkin lymphoma (NHL)** - C82-C85
- **Myeloma** - C90
- **Malignant Immunoproliferative Disease (MID)** - C88
- **Other haematological malignancies -** C912-9, C922-3, C927-9, C931-9, C943-9, C95, C96
- **Neoplasms of uncertain or unknown behaviour (*Myelodysplasia, Myeloproliferative Neoplasms,. Monoclonal Gammopathy of Uncertain Significance*)** – D45, D46, D47

As the quality of cancer registration may vary between cancer registries data have also been presented separately for each of the eight English cancer registries.

- **Eastern Cancer Registration and Information Centre (ECRIC)**
- **North West Cancer Intelligence Service (NWCIS)**
- **Northern and Yorkshire Cancer Registry and Information Service (NYCRIS)**
- **Oxford Cancer Intelligence Unit (OCIU)**
- **South West Cancer Intelligence Service (SWCIS)**
- **Thames Cancer Registry Service (Thames)**
- **Trent Cancer Registry (Trent)**
- **West Midlands Cancer Intelligence Unit (WMCIU)**

Over the registration period 1 January 2010 and 31 December 2010 there were 28,428 cancer registrations for haematological malignancies.

Registration quality summary

A small range of indicators have been chosen to explore variability in the quality of data in the NCDR by disease group and cancer registry. These indicators examine both the quality of the cancer registration data and the linkage of datasets within the NCDR. The results of this summary are displayed in Table 1.

Markers of cancer registration data quality

"Death Certificate Only" registration (DCO):
Death certificates remain an important source of notification of cancer for registries in England but in the overwhelming majority of cases it subsequently proves possible to identify an earlier time point at which the diagnosis was established. When no earlier information can be established a cancer will be recorded as 'Death Certificate Only' (DCO). Whilst some cancers are truly only detected at the time of death, a low proportion of registrations being DCO is a marker of good quality registration.

Basis of Diagnosis:
Cancer registries record the basis for the diagnostic information they hold within the NCDR. In most cases, cancer registrations are based on evidence recorded through examination of the cells making up the cancer ('microscopically verified') but in some case the only evidence available will be a clinical opinion. The accuracy of the cancer diagnosis is greater when it is based on microscopic evidence and so a high proportion of microscopically verified cases is a marker of higher quality data. The following groups were used in these analyses

Office For National Statistics Category	Basis of Diagnosis Category
Cytology/haematology	Microscopically verified
Histology metastases	Microscopically verified
Histology of primary tumour	Microscopically verified
Specific tumour marker	Clinically verified
Clinical	Clinically verified
Clinical investigation	Clinically verified
Death Certificate Only (DCO)	Clinically verified
Unknown	Not known

Morphology:
Blood cancers include a very wide variety of individual disease types, and this diversity is best captured in the detailed classification of the cell structure and cell biology which is broadly referred to as 'disease morphology' by cancer registries. Cancer registries record disease morphology using the International Classification of Diseases for Oncology (ICD-O). Absence of any morphology record is a basic measure of the quality of registration. More detailed work is required if the accuracy of the underlying morphology recorded is to be assessed.

Markers of the quality of data linkage and derived variables

The NCDR is made up of information from cancer registries and linked data drawn from an extract of the national data held on inpatient admission to English NHS hospitals, the Hospital Episode Statistics (HES). The HES extract held by the NCIN is made up of the records of all patients who have ever been recorded as having a diagnosis of cancer within the HES data fields. Examining data derived from this information

is dependent on the quality of (i) information needed to link datasets (unique personal identifiers) (ii) the completeness and accuracy of the HES data set.

HES link:
Whilst not every patient with a diagnosis of cancer requires inpatient care, and therefore not every registered cancer will have a linked HES record, a high proportion of cases having such a link is an indicator of a high quality of linkage.

Ethnicity:
One variable in the NCDR currently derived from linkage to HES is an indicator of the ethnicity of patients with cancer. This information is clearly only available if a link with HES has been achieved for a patient, but the completeness of this field is also dependent on the information held in HES. Records have been categorised as having a 'Known' (that is that the HES records contain a valid ethnicity code) or 'Not Known' (that is that the HES records do not contain a valid code or there is no link to HES). A higher level of 'Known' ethnicity has been taken as a marker of higher data quality.

Key points to note in Table I

1. The proportion of registrations that were Death Certificate Only was low across disease groupings and cancer registries with the percentage of DCO registrations generally between 0-4%. Registrations for neoplasms of uncertain or unknown behaviour were more likely to be DCO. These are often more chronic, long-term conditions and it is harder to obtain good quality trace back information.

2. It is noticeable that registrations of Chronic Lymphocytic Leukaemia (CLL) are less likely to have a link with HES data. Individuals with CLL may be managed entirely in the community and therefore have never had a hospital admission in which a diagnosis of cancer was recorded. Levels of HES linkage are also lower in neoplasms of uncertain or unknown behaviour. Many of these cases will also be managed in the community and in addition it is possible that the coding of these cases is less complete in hospital admissions, and therefore, fewer cases will be included in the HES extract.

3. Morphology was recorded for all registrations. However more detailed review will be required to determine the proportion of registrations that have disease-specific morphologies recorded.

4. In general, registrations were microscopically verified. In NWCIS this was not the case, with only registrations with lymphomas having high rates of microscopic verification. In 2010, NWCIS acknowledged under-reporting from some laboratories and also increased use of data flows that did not contain basis of diagnosis. This was expected to improve year on year. (UKACR Annual Performance Indicators 2012).

5. There were low levels of ethnicity data available in two registries, NWCIS and Thames. In NWCIS it seems that ethnicity data has not been drawn comprehensively from available HES data. In Thames there are also high levels of linked HES records that lack specific ethnicity data.

Key point 1: *Proportion of Death Certificate Only registrations is low*

Key point 2: *Not all diseases have the same degree of HES linkage*

Key point 3: *Morphology is recorded for all registrations*

Table 1: Registration quality markers by disease group and cancer registry

	Site Groupings	ALL		AML		CLL		CML		HL		NHL		Myeloma		MID		Other		Neoplasms of uncertain or unknown behaviour	
National	*Total Records*	*570*		*2,270*		*2,706*		*596*		*1,556*		*10,273*		*3,941*		*224*		*970*		*5,322*	
DCO	Death Certificate Only	*2*	0%	*47*	2%	*58*	2%	*12*	2%	*4*	0%	*142*	1%	*75*	2%	*6*	3%	*45*	5%	*350*	7%
	NonDCO registrations	*568*	100%	*2,223*	98%	*2,648*	98%	*584*	98%	*1,552*	100%	*10,131*	99%	*3,866*	98%	*218*	97%	*925*	95%	*4,972*	93%
Basis of Diagnosis	Microscopically verified	*513*	90%	*1,906*	84%	*2,128*	79%	*478*	80%	*1,480*	95%	*9,421*	92%	*3,306*	84%	*163*	73%	*776*	80%	*4,367*	82%
	Clinically Verified	*42*	7%	*292*	13%	*424*	16%	*92*	15%	*65*	4%	*716*	7%	*505*	13%	*42*	19%	*132*	14%	*610*	11%
	Not Known	*15*	3%	*72*	3%	*154*	6%	*26*	4%	*11*	1%	*136*	1%	*130*	3%	*19*	8%	*62*	6%	*345*	6%
Morphology	Known	*570*	100%	*2,270*	100%	*2,706*	100%	*596*	100%	*1,556*	100%	*10,273*	100%	*3,941*	100%	*224*	100%	*970*	100%	*5,322*	100%
	Not Known	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%
HES links	Linked record in HES	*543*	95%	*2,008*	88%	*1,843*	68%	*520*	87%	*1,396*	90%	*8,542*	83%	*3,388*	86%	*181*	81%	*759*	78%	*3,978*	75%
	No linked record in HES	*27*	5%	*262*	12%	*863*	32%	*76*	13%	*160*	10%	*1,724*	17%	*552*	14%	*43*	19%	*211*	22%	*1,344*	25%
Ethnicity	Known	*409*	72%	*1,575*	69%	*1,402*	52%	*342*	57%	*993*	64%	*6,584*	64%	*2,473*	63%	*118*	53%	*589*	61%	*3,324*	62%
	Not Known	*161*	28%	*695*	31%	*1,304*	48%	*254*	43%	*563*	36%	*3,689*	36%	*1,468*	37%	*106*	47%	*381*	39%	*1,998*	38%
ECRIC	*Total Records*	*63*		*242*		*265*		*57*		*161*		*1,186*		*425*		*16*		*105*		*531*	
DCO	Death Certificate Only	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%
	NonDCO registrations	*63*	100%	*242*	100%	*265*	100%	*57*	100%	*161*	100%	*1,186*	100%	*425*	100%	*16*	100%	*105*	100%	*531*	100%
Basis of Diagnosis	Microscopically verified	*61*	97%	*237*	98%	*239*	90%	*55*	96%	*157*	98%	*1,139*	96%	*372*	88%	*15*	94%	*92*	88%	*510*	96%
	Clinically Verified	*2*	3%	*4*	2%	*15*	6%	*1*	2%	*2*	1%	*37*	3%	*45*	11%	*0*	0%	*7*	7%	*16*	3%
	Not Known	*0*	0%	*1*	0%	*11*	4%	*1*	2%	*2*	1%	*10*	1%	*8*	2%	*1*	6%	*6*	6%	*5*	1%
Morphology	Known	*63*	100%	*242*	100%	*265*	100%	*57*	100%	*161*	100%	*1,186*	100%	*425*	100%	*16*	100%	*105*	100%	*531*	100%
	Not Known	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%
HES links	Linked record in HES	*61*	97%	*185*	76%	*161*	61%	*49*	86%	*137*	85%	*922*	78%	*341*	80%	*12*	75%	*73*	70%	*378*	71%
	No linked record in HES	*2*	3%	*57*	24%	*104*	39%	*8*	14%	*24*	15%	*264*	22%	*84*	20%	*4*	25%	*32*	30%	*153*	29%
Ethnicity	Known	*57*	90%	*206*	85%	*175*	66%	*45*	79%	*129*	80%	*955*	81%	*332*	78%	*10*	63%	*80*	76%	*398*	75%
	Not Known	*6*	10%	*36*	15%	*90*	34%	*12*	21%	*32*	20%	*231*	19%	*93*	22%	*6*	38%	*25*	24%	*133*	25%
NWCIS	*Total Records*	*72*		*260*		*423*		*106*		*220*		*1,334*		*499*		*73*		*135*		*494*	
DCO	Death Certificate Only	*0*	0%	*4*	2%	*19*	4%	*2*	2%	*0*	0%	*16*	1%	*8*	2%	*4*	5%	*10*	7%	*54*	11%
	NonDCO registrations	*72*	100%	*256*	98%	*404*	96%	*104*	98%	*220*	100%	*1,318*	99%	*491*	98%	*69*	95%	*125*	93%	*440*	89%
Basis of Diagnosis	Microscopically verified	*35*	49%	*100*	38%	*111*	26%	*34*	32%	*190*	86%	*1,071*	80%	*229*	46%	*29*	40%	*47*	35%	*97*	20%
	Clinically Verified	*36*	50%	*131*	50%	*255*	60%	*61*	58%	*25*	11%	*221*	17%	*230*	46%	*29*	40%	*75*	56%	*257*	52%
	Not Known	*1*	1%	*29*	11%	*57*	13%	*11*	10%	*5*	2%	*42*	3%	*40*	8%	*15*	21%	*13*	10%	*140*	28%
Morphology	Known	*72*	100%	*260*	100%	*423*	100%	*106*	100%	*220*	100%	*1,334*	100%	*499*	100%	*73*	100%	*135*	100%	*494*	100%
	Not Known	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%
HES links	Linked record in HES	*67*	93%	*245*	94%	*320*	76%	*96*	91%	*195*	89%	*1,130*	85%	*436*	87%	*57*	78%	*98*	73%	*351*	71%
	No linked record in HES	*5*	7%	*15*	6%	*103*	24%	*10*	9%	*25*	11%	*202*	15%	*63*	13%	*16*	22%	*37*	27%	*143*	29%
Ethnicity	Known	*7*	10%	*75*	29%	*79*	19%	*23*	22%	*32*	15%	*281*	21%	*88*	18%	*21*	29%	*35*	26%	*145*	29%
	Not Known	*65*	90%	*185*	71%	*344*	81%	*83*	78%	*188*	85%	*1,053*	79%	*411*	82%	*52*	71%	*100*	74%	*349*	71%

Key point 4: *A smaller proportion of registrations in NWCIS are recorded as microscopically confirmed.*

Key point 5: *The proportion of registrations for which an ethnicity is recorded is low in some registries*

Table 1: Registration quality markers by disease group and cancer registry

	Site Groupings	ALL		AML		CLL		CML		HL		NHL		Myeloma		MID		Other		Neoplasms of uncertain or unknown behaviour	
NYCRIS	*Total Records*	*64*		*332*		*433*		*74*		*199*		*1,300*		*479*		*13*		*108*		*731*	
DCO	Death Certificate Only	*0*	0%	*2*	1%	*3*	1%	*0*	0%	*1*	1%	*7*	1%	*7*	1%	*0*	0%	*1*	1%	*13*	2%
	NonDCO registrations	*64*	100%	*330*	99%	*430*	99%	*74*	100%	*198*	99%	*1,293*	99%	*472*	99%	*13*	100%	*107*	99%	*718*	98%
Basis of Diagnosis	Microscopically verified	*64*	100%	*300*	90%	*390*	90%	*66*	89%	*198*	99%	*1,253*	96%	*422*	88%	*11*	85%	*103*	95%	*648*	89%
	Clinically Verified	*0*	0%	*32*	10%	*41*	9%	*7*	9%	*1*	1%	*47*	4%	*57*	12%	*2*	15%	*5*	5%	*82*	11%
	Not Known	*0*	0%	*0*	0%	*2*	0%	*1*	1%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*1*	0%
Morphology	Known	*64*	100%	*332*	100%	*433*	100%	*74*	100%	*199*	100%	*1,300*	100%	*479*	100%	*13*	100%	*108*	100%	*731*	100%
	Not Known	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%
HES links	Linked record in HES	*61*	95%	*294*	89%	*255*	59%	*60*	81%	*186*	93%	*1,128*	87%	*421*	88%	*8*	62%	*86*	80%	*456*	62%
	No linked record in HES	*3*	5%	*38*	11%	*178*	41%	*14*	19%	*13*	7%	*170*	13%	*58*	12%	*5*	38%	*22*	20%	*275*	38%
Ethnicity	Known	*61*	95%	*297*	89%	*257*	59%	*62*	84%	*180*	90%	*1,106*	85%	*409*	85%	*12*	92%	*82*	76%	*469*	64%
	Not Known	*3*	5%	*35*	11%	*176*	41%	*12*	16%	*19*	10%	*194*	15%	*70*	15%	*1*	8%	*26*	24%	*262*	36%
Oxford	*Total Records*	*50*		*122*		*175*		*33*		*91*		*518*		*218*		*12*		*51*		*522*	
DCO	Death Certificate Only	*1*	2%	*6*	5%	*5*	3%	*1*	3%	*1*	1%	*20*	4%	*9*	4%	*0*	0%	*8*	16%	*27*	5%
	NonDCO registrations	*49*	98%	*116*	95%	*170*	97%	*32*	97%	*90*	99%	*498*	96%	*209*	96%	*12*	100%	*43*	84%	*495*	95%
Basis of Diagnosis	Microscopically verified	*49*	98%	*109*	89%	*166*	95%	*32*	97%	*85*	93%	*468*	90%	*195*	89%	*12*	100%	*41*	80%	*493*	94%
	Clinically Verified	*0*	0%	*7*	6%	*4*	2%	*0*	0%	*5*	5%	*39*	8%	*14*	6%	*0*	0%	*3*	6%	*4*	1%
	Not Known	*1*	2%	*6*	5%	*5*	3%	*1*	3%	*1*	1%	*11*	2%	*9*	4%	*0*	0%	*7*	14%	*25*	5%
Morphology	Known	*50*	100%	*122*	100%	*175*	100%	*33*	100%	*91*	100%	*518*	100%	*218*	100%	*12*	100%	*51*	100%	*522*	100%
	Not Known	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%
HES links	Linked record in HES	*49*	98%	*109*	89%	*124*	71%	*31*	94%	*83*	91%	*440*	85%	*183*	84%	*10*	83%	*37*	73%	*436*	84%
	No linked record in HES	*1*	2%	*13*	11%	*51*	29%	*2*	6%	*8*	9%	*77*	15%	*35*	16%	*2*	17%	*14*	27%	*86*	16%
Ethnicity	Known	*48*	96%	*102*	84%	*88*	50%	*20*	61%	*77*	85%	*420*	81%	*141*	65%	*7*	58%	*24*	47%	*160*	31%
	Not Known	*2*	4%	*20*	16%	*87*	50%	*13*	39%	*14*	15%	*98*	19%	*77*	35%	*5*	42%	*27*	53%	*362*	69%
SWCIS	*Total Records*	*76*		*313*		*424*		*95*		*202*		*1,678*		*648*		*38*		*170*		*1,356*	
DCO	Death Certificate Only	*0*	0%	*6*	2%	*8*	2%	*2*	2%	*1*	0%	*39*	2%	*16*	2%	*1*	3%	*10*	6%	*75*	6%
	NonDCO registrations	*76*	100%	*307*	98%	*416*	98%	*93*	98%	*201*	100%	*1,639*	98%	*632*	98%	*37*	97%	*160*	94%	*1,281*	94%
Basis of Diagnosis	Microscopically verified	*76*	100%	*306*	98%	*413*	97%	*93*	98%	*180*	89%	*1,456*	87%	*624*	96%	*37*	97%	*154*	91%	*1,284*	95%
	Clinically Verified	*0*	0%	*1*	0%	*1*	0%	*0*	0%	*21*	10%	*205*	12%	*1*	0%	*0*	0%	*4*	2%	*0*	0%
	Not Known	*0*	0%	*6*	2%	*10*	2%	*2*	2%	*1*	0%	*17*	1%	*23*	4%	*1*	3%	*12*	7%	*72*	5%
Morphology	Known	*76*	100%	*313*	100%	*424*	100%	*95*	100%	*202*	100%	*1,678*	100%	*648*	100%	*38*	100%	*170*	100%	*1,356*	100%
	Not Known	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%
HES links	Linked record in HES	*71*	93%	*297*	95%	*360*	85%	*89*	94%	*186*	92%	*1,448*	86%	*587*	91%	*36*	95%	*156*	92%	*1,220*	90%
	No linked record in HES	*5*	7%	*16*	5%	*64*	15%	*6*	6%	*16*	8%	*230*	14%	*61*	9%	*2*	5%	*14*	8%	*136*	10%
Ethnicity	Known	*70*	92%	*279*	89%	*364*	86%	*81*	85%	*179*	89%	*1,387*	83%	*572*	88%	*33*	87%	*141*	83%	*1,185*	87%
	Not Known	*6*	8%	*34*	11%	*60*	14%	*14*	15%	*23*	11%	*291*	17%	*76*	12%	*5*	13%	*29*	17%	*171*	13%

Table 1: Registration quality markers by disease group and cancer registry

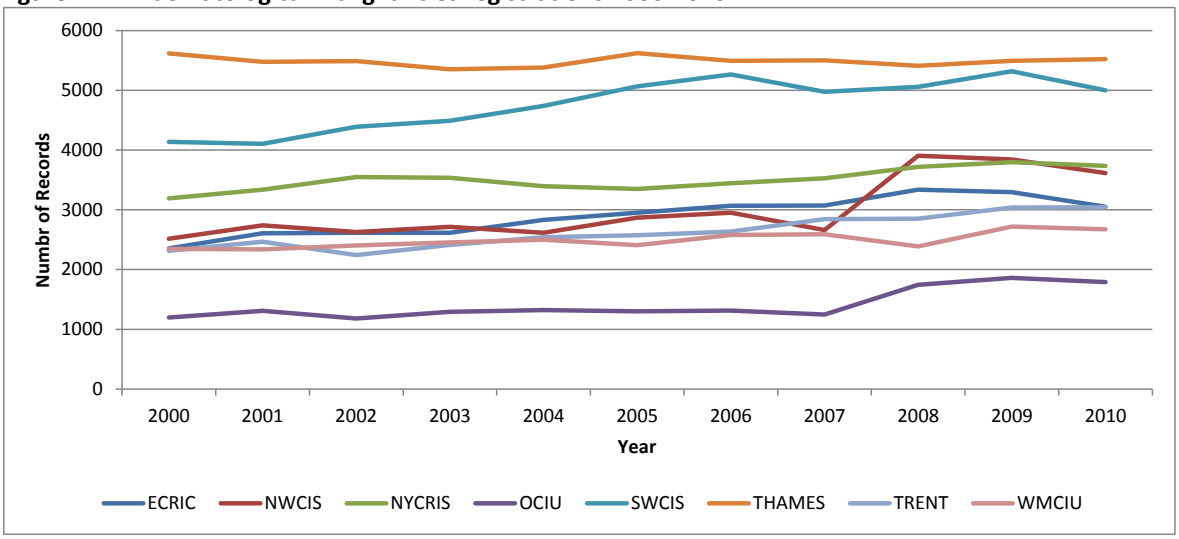
	Site Groupings	ALL		AML		CLL		CML		HL		NHL		Myeloma		MID		Other		Neoplasms of uncertain or unknown behaviour	
Thames	*Total Records*	*136*		*523*		*387*		*129*		*375*		*2,137*		*839*		*31*		*178*		*788*	
DCO	Death Certificate Only	*0*	0%	*5*	1%	*4*	1%	*1*	1%	*1*	0%	*18*	1%	*15*	2%	*0*	0%	*5*	3%	*62*	8%
	NonDCO registrations	*136*	100%	*518*	99%	*383*	99%	*128*	99%	*374*	100%	*2,119*	99%	*824*	98%	*31*	100%	*173*	97%	*726*	92%
Basis of Diagnosis	Microscopically verified	*134*	99%	*477*	91%	*365*	94%	*120*	93%	*369*	98%	*2,059*	96%	*780*	93%	*28*	90%	*155*	87%	*700*	89%
	Clinically Verified	*1*	1%	*42*	8%	*13*	3%	*7*	5%	*6*	2%	*68*	3%	*55*	7%	*3*	10%	*16*	9%	*86*	11%
	Not Known	*1*	1%	*4*	1%	*9*	2%	*2*	2%	*0*	0%	*10*	0%	*4*	0%	*0*	0%	*7*	4%	*2*	0%
Morphology	Known	*136*	100%	*523*	100%	*387*	100%	*129*	100%	*375*	100%	*2,137*	100%	*839*	100%	*31*	100%	*178*	100%	*788*	100%
	Not Known	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%
HES links	Linked record in HES	*130*	96%	*469*	90%	*289*	75%	*111*	86%	*330*	88%	*1,712*	80%	*697*	83%	*27*	87%	*139*	78%	*490*	62%
	No linked record in HES	*6*	4%	*54*	10%	*98*	25%	*18*	14%	*45*	12%	*424*	20%	*141*	17%	*4*	13%	*39*	22%	*298*	38%
Ethnicity	Known	*63*	46%	*186*	36%	*109*	28%	*33*	26%	*113*	30%	*651*	30%	*204*	24%	*7*	23%	*56*	31%	*291*	37%
	Not Known	*73*	54%	*337*	64%	*278*	72%	*96*	74%	*262*	70%	*1,486*	70%	*635*	76%	*24*	77%	*122*	69%	*497*	63%
Trent	*Total Records*	*61*		*271*		*291*		*52*		*147*		*1,059*		*457*		*17*		*125*		*561*	
DCO	Death Certificate Only	*0*	0%	*10*	4%	*8*	3%	*2*	4%	*0*	0%	*13*	1%	*5*	1%	*0*	0%	*4*	3%	*62*	11%
	NonDCO registrations	*61*	100%	*261*	96%	*283*	97%	*50*	96%	*147*	100%	*1,046*	99%	*452*	99%	*17*	100%	*121*	97%	*499*	89%
Basis of Diagnosis	Microscopically verified	*47*	77%	*227*	84%	*247*	85%	*46*	88%	*144*	98%	*1,003*	95%	*396*	87%	*16*	94%	*113*	90%	*397*	71%
	Clinically Verified	*2*	3%	*22*	8%	*11*	4%	*1*	2%	*2*	1%	*23*	2%	*26*	6%	*1*	6%	*5*	4%	*64*	11%
	Not Known	*12*	20%	*22*	8%	*33*	11%	*5*	10%	*1*	1%	*33*	3%	*35*	8%	*0*	0%	*7*	6%	*100*	18%
Morphology	Known	*61*	100%	*271*	100%	*291*	100%	*52*	100%	*147*	100%	*1,059*	100%	*457*	100%	*17*	100%	*125*	100%	*561*	100%
	Not Known	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%
HES links	Linked record in HES	*58*	95%	*219*	81%	*161*	55%	*43*	83%	*126*	86%	*849*	80%	*389*	85%	*16*	94%	*94*	75%	*390*	70%
	No linked record in HES	*3*	5%	*52*	19%	*130*	45%	*9*	17%	*21*	14%	*210*	20%	*68*	15%	*1*	6%	*31*	25%	*171*	30%
Ethnicity	Known	*58*	95%	*260*	96%	*185*	64%	*47*	90%	*138*	94%	*918*	87%	*416*	91%	*14*	82%	*103*	82%	*442*	79%
	Not Known	*3*	5%	*11*	4%	*106*	36%	*5*	10%	*9*	6%	*141*	13%	*41*	9%	*3*	18%	*22*	18%	*119*	21%
WMCIU	*Total Records*	*48*		*207*		*308*		*50*		*161*		*1,061*		*376*		*24*		*98*		*339*	
DCO	Death Certificate Only	*1*	2%	*14*	7%	*11*	4%	*4*	8%	*0*	0%	*29*	3%	*15*	4%	*1*	4%	*7*	7%	*57*	17%
	NonDCO registrations	*47*	98%	*193*	93%	*297*	96%	*46*	92%	*161*	100%	*1,032*	97%	*361*	96%	*23*	96%	*91*	93%	*282*	83%
Basis of Diagnosis	Microscopically verified	*47*	98%	*150*	72%	*197*	64%	*32*	64%	*157*	98%	*972*	92%	*288*	77%	*15*	63%	*71*	72%	*238*	70%
	Clinically Verified	*1*	2%	*53*	26%	*84*	27%	*15*	30%	*3*	2%	*76*	7%	*77*	20%	*7*	29%	*17*	17%	*101*	30%
	Not Known	*0*	0%	*4*	2%	*27*	9%	*3*	6%	*1*	1%	*13*	1%	*11*	3%	*2*	8%	*10*	10%	*0*	0%
Morphology	Known	*48*	100%	*207*	100%	*308*	100%	*50*	100%	*161*	100%	*1,061*	100%	*376*	100%	*24*	100%	*98*	100%	*339*	100%
	Not Known	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%	*0*	0%
HES links	Linked record in HES	*46*	96%	*190*	92%	*173*	56%	*41*	82%	*153*	95%	*913*	86%	*334*	89%	*15*	63%	*76*	78%	*257*	76%
	No linked record in HES	*2*	4%	*17*	8%	*135*	44%	*9*	18%	*8*	5%	*147*	14%	*42*	11%	*9*	38%	*22*	22%	*82*	24%
Ethnicity	Known	*45*	94%	*170*	82%	*145*	47%	*31*	62%	*145*	90%	*866*	82%	*311*	83%	*14*	58%	*68*	69%	*234*	69%
	Not Known	*3*	6%	*37*	18%	*163*	53%	*19*	38%	*16*	10%	*195*	18%	*65*	17%	*10*	42%	*30*	31%	*105*	31%

Key point 5: *The proportion of registrations for which an ethnicity is recorded is low in some registries*

Number of registrations:

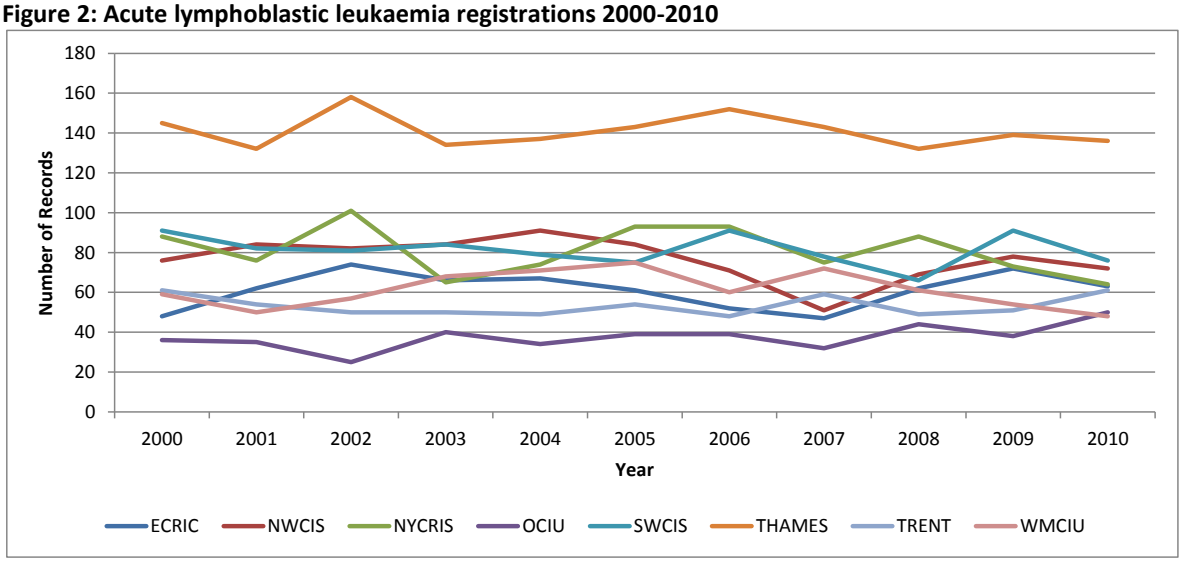
The NCDR is currently derived by bringing together the data collected and recorded by eight individual cancer registries and, whilst these organisations have worked to a common set of policies, there have been variations between registries in the practice of registration. In addition, the classification of blood cancers has changed over time and clinicians and registries have adopted new forms of classification at different points in time. To understand the quality of data on blood cancers held in the NCDR, it is helpful to look at the trends in registration of individual forms of blood cancer. The following figures 1 to10 present time trends in registration by disease group and registry with a short commentary where relevant.

Figure 1: All Haematological malignancies registrations 2000-2010



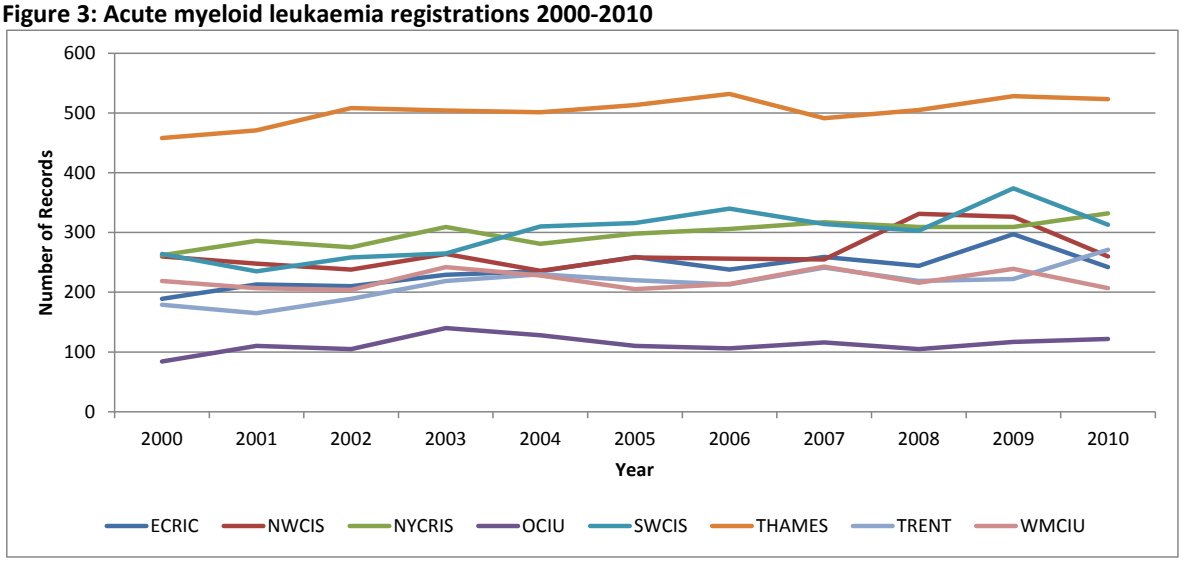
Comments: The most marked change in the overall registrations for blood cancers is seen in NWCIS from 2008 onwards. This has been attributed by NWCIS to access to information from Multidisciplinary team (MDT) data systems at this time, which in turn provided notifications of some individual blood cancer types which had been poorly ascertained previous to this time (in particular forms of leukaemia and myeloma). A similar pattern is seen in the OCIU. In other registries the numbers of blood cancers either show a gradual increase over time or have remained broadly constant.

Figure 2: Acute lymphoblastic leukaemia registrations 2000-2010



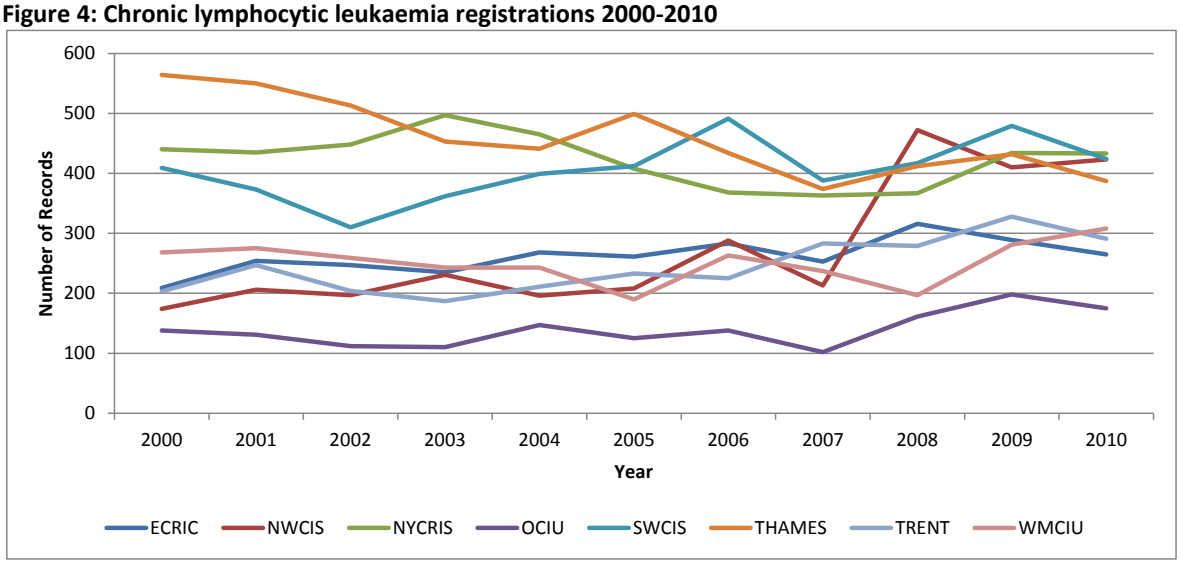
Comments: Registrations for ALL do not show any major change over time. This is a rare form of cancer but the intensity of treatment makes it unlikely to be under-ascertained by registries.

Figure 3: Acute myeloid leukaemia registrations 2000-2010



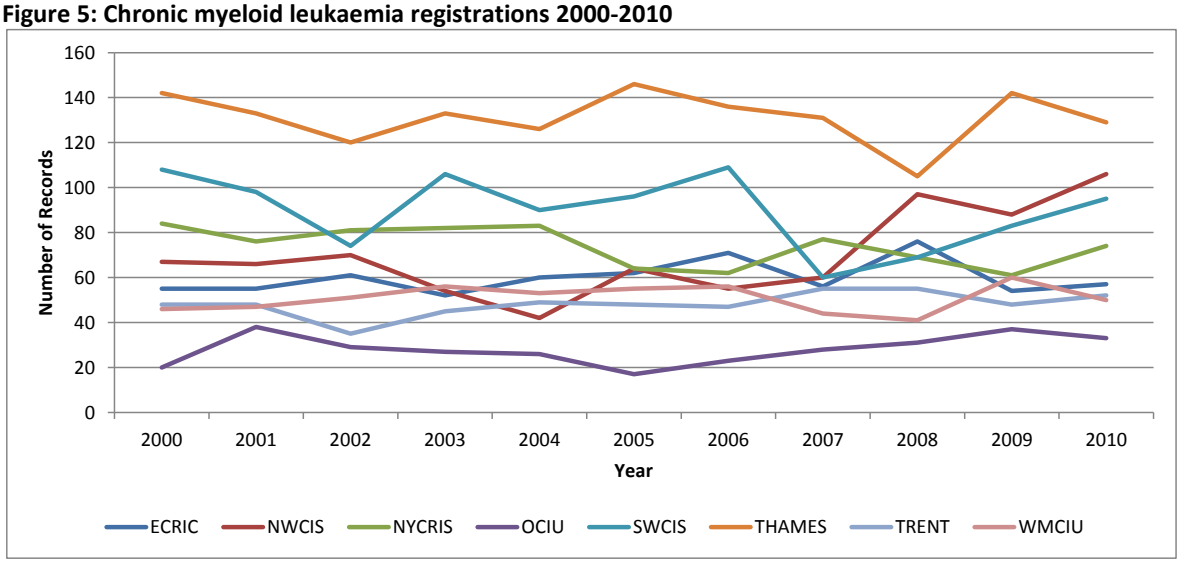
Comments: Registrations for AML do not show major shifts within individual registries between years.

Figure 4: Chronic lymphocytic leukaemia registrations 2000-2010



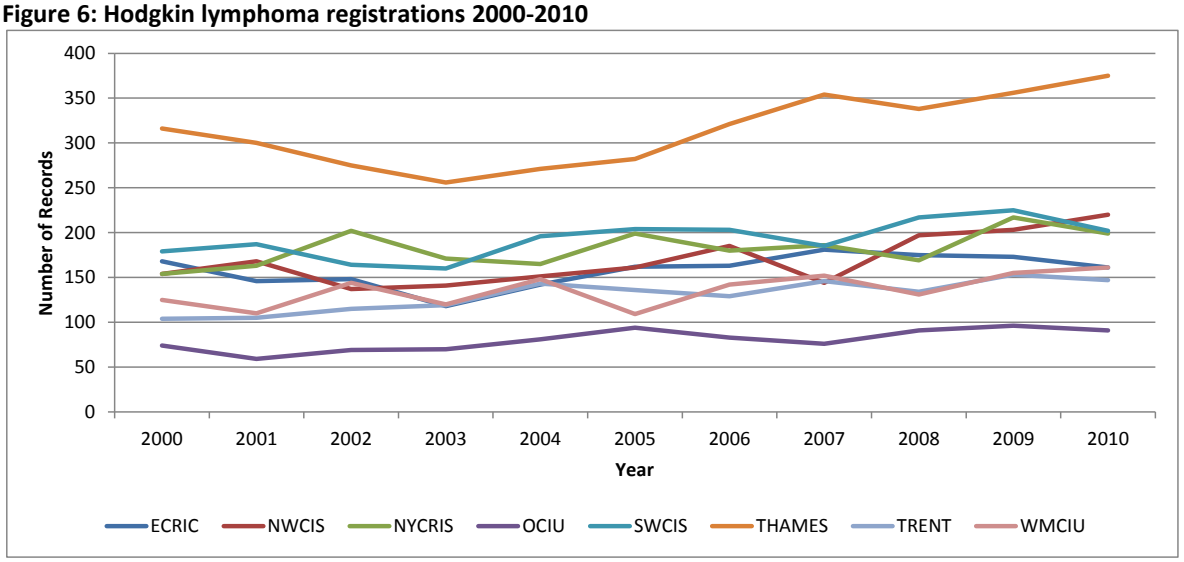
Comments: Marked change can be seen in the number of registrations for CLL in 2008 in NWCIS following access to MDT information. The completeness of registration for CLL is known to vary substantially between registries [*Haematological malignancies & cancer registration in England (2004-2008)* www.ncin.org.uk/view?rid=1725]. It is noticeable in this figure that Thames Cancer Registry, which has a substantially larger catchment population than other English registries, is not recording a proportionally higher number of CLL cases and there has been a decline over time.

Figure 5: Chronic myeloid leukaemia registrations 2000-2010



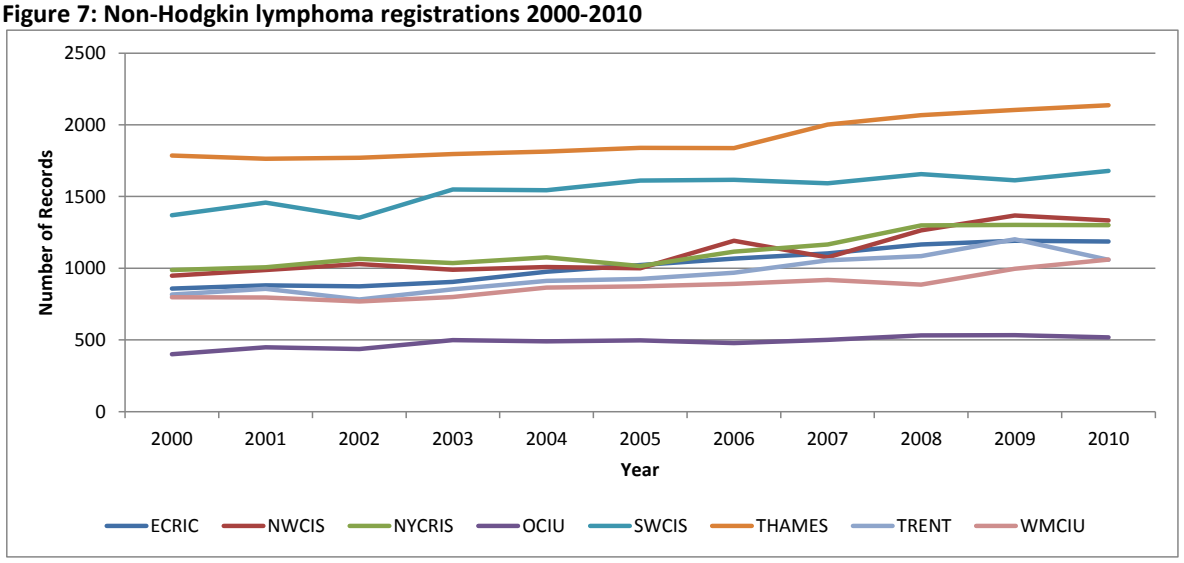
Comments: CML is a rare blood cancer. For this reason, there is substantial year-to-year variation within registries. However, the impact of enhanced notification sources in NWCIS in 2008 is again visible for this disease group.

Figure 6: Hodgkin lymphoma registrations 2000-2010



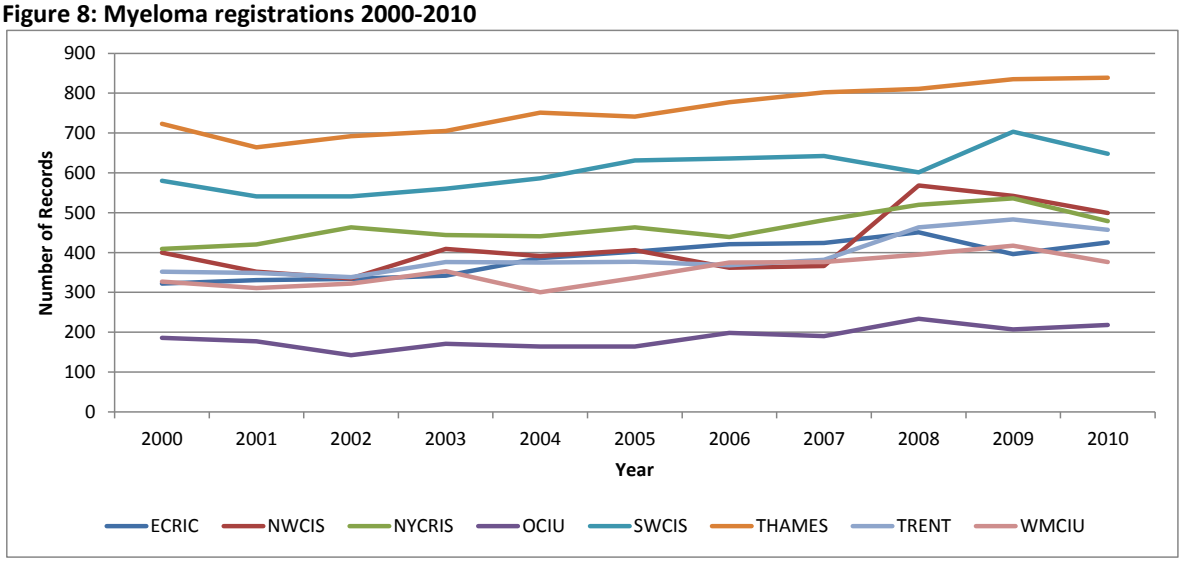
Comments: There has been a general increase in registrations of Hodgkin lymphoma over time but no marked changes in the year-to-year variation within registries.

Figure 7: Non-Hodgkin lymphoma registrations 2000-2010



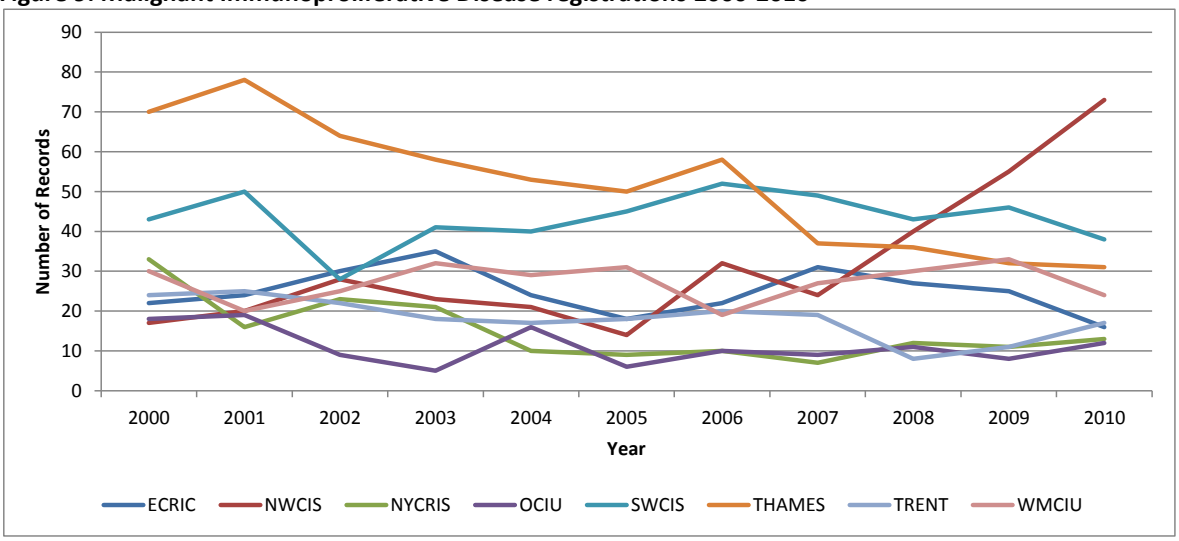
Comments: There has been a general increase in registrations of Non-Hodgkin lymphoma over time but no marked changes in the year-to-year variation within registries.

Figure 8: Myeloma registrations 2000-2010



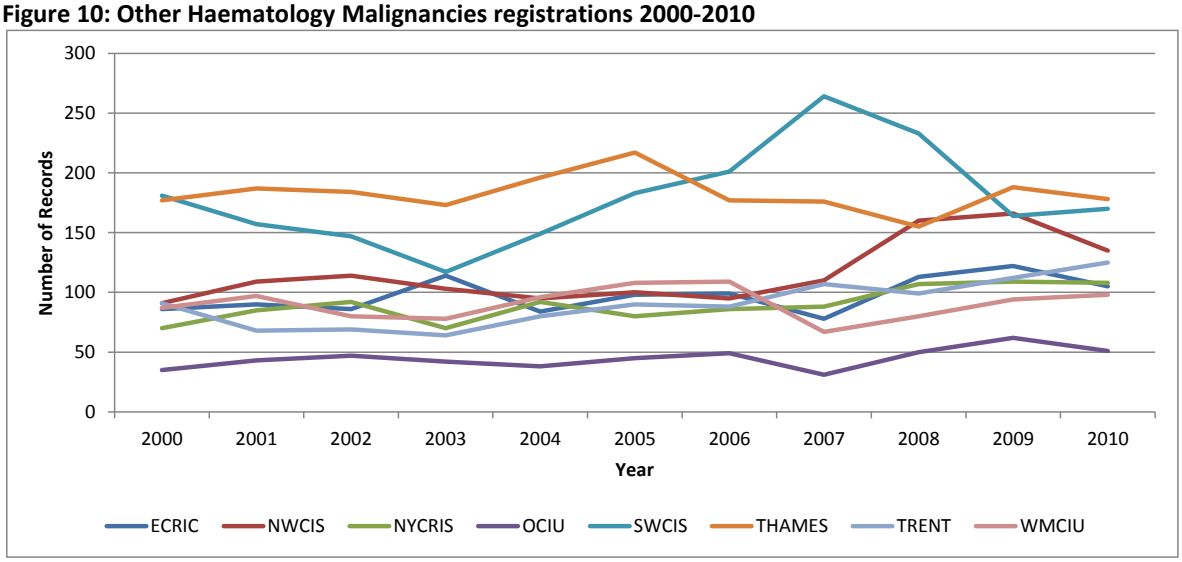
Comments: A step upwards in registrations for myeloma in 2008 in NWCIS is apparent; there is little variability in other registries.

Figure 9: Malignant Immunoproliferative Disease registrations 2000-2010



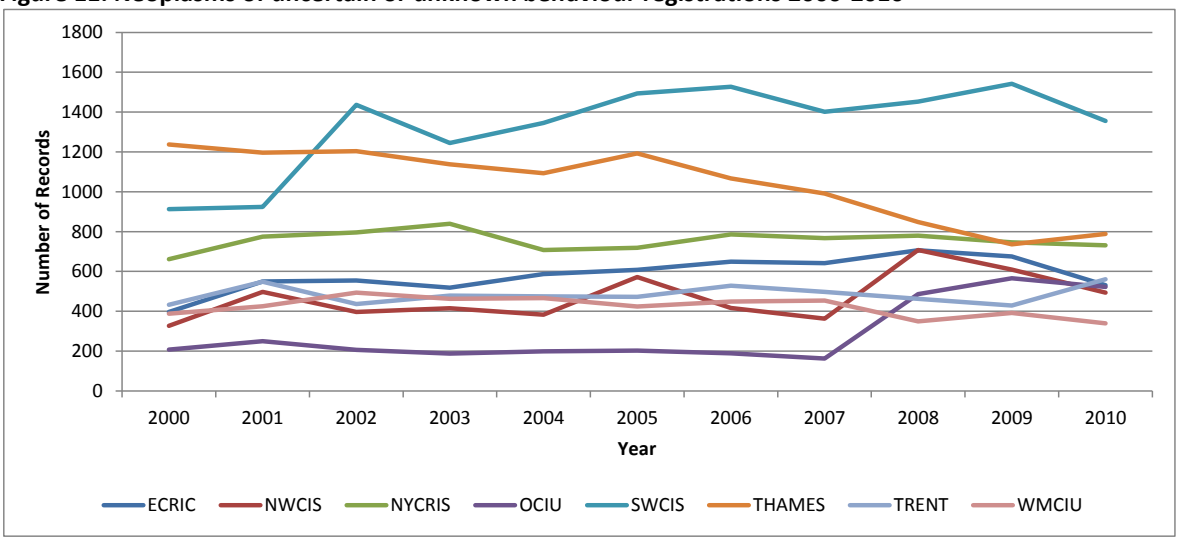
Comments: These are uncommon blood cancers and, with the exception of increases in registration in NWCIS and a decline in registrations in Thames, there are no other obvious patterns apparent across time.

Figure 10: Other Haematology Malignancies registrations 2000-2010



Comments: This is a small category of registrations for blood cancers; there is no obvious explanation for the changes observed within SWCIS.

Figure 11: Neoplasms of uncertain or unknown behaviour registrations 2000-2010



Comments: Individual registries have varied in their approach to registering these conditions. It is clear that Thames cancer registry has a lower rate of notification than most other registries and that this had fallen over time. There have also been recent changes in registrations in NWCIS and OCIU which may result from access to new notification sources.

Staging

The stage of disease at presentation is an important predictor of prognosis; less advanced stage may also be a marker of earlier diagnosis. Whilst prognostic scores and measures are available for a number of different blood cancers, the only types of cancer where staging has previously been recorded by cancer registries are the lymphomas, where the Ann Arbor staging system has been used.

Within the 2010 NCDR, no single field holds all staging information; there are five fields within the dataset that contain some level of registered staging. For this report we have taken any evidence of staging in any of these fields as a marker of information on stage.

The NCDR does not contain a staging field specific to Ann Arbor and a consistent approach to recording has not been attempted between registries. For this report a simple four category version of the Ann Arbor staging system has been applied. The completeness and distribution of staging is shown in figures 12 to 13.

As can be seen from the figures, the NCDR 2010 does not hold staging data of a quality and completeness to support inclusion in national analyses. The ECRIC registry is the only registry to hold staging data, illustrating that staging data can be achieved in over 90% of registrations for lymphoma. However, at this point four registries (Thames, SWCIS, OCIU, Trent) were providing little or no information on staging and completeness of staging data was low in the remaining three registries (WMCIU, NYCRIS, NWCIS).

Figure 12: Staging information 2010 registrations - Hodgkin lymphoma

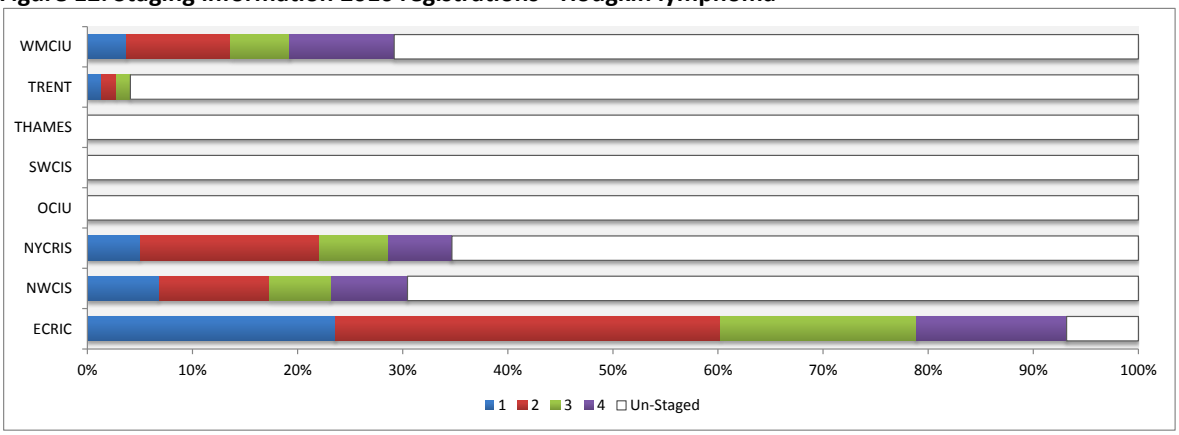
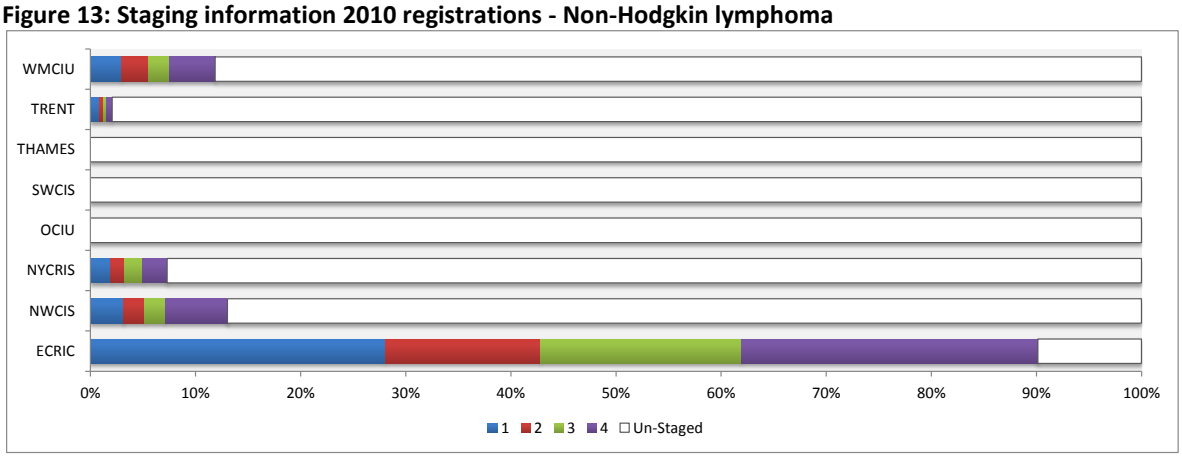


Figure 13: Staging information 2010 registrations - Non-Hodgkin lymphoma



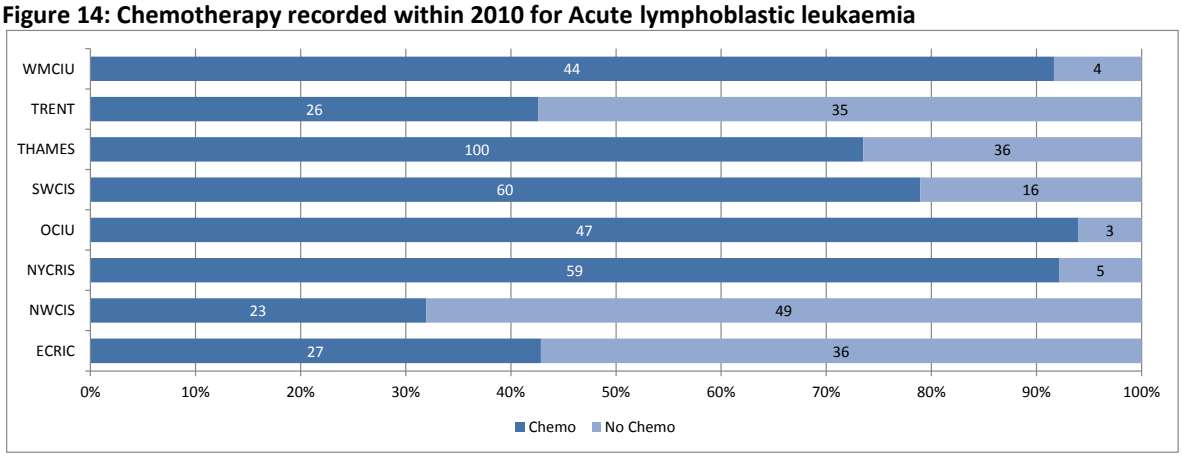
Treatment

Cancer registries seek to record treatment received by patients in the first six months following diagnosis, and have classified treatment received in to broad categories (not mutually exclusive): chemotherapy, radiotherapy, hormone therapy and surgery. The numbers and proportions of individuals registered with blood cancers in 2010 with information indicating treatment with chemotherapy and radiotherapy for a range of disease groups are shown in figures 14 to 20.

Chemotherapy

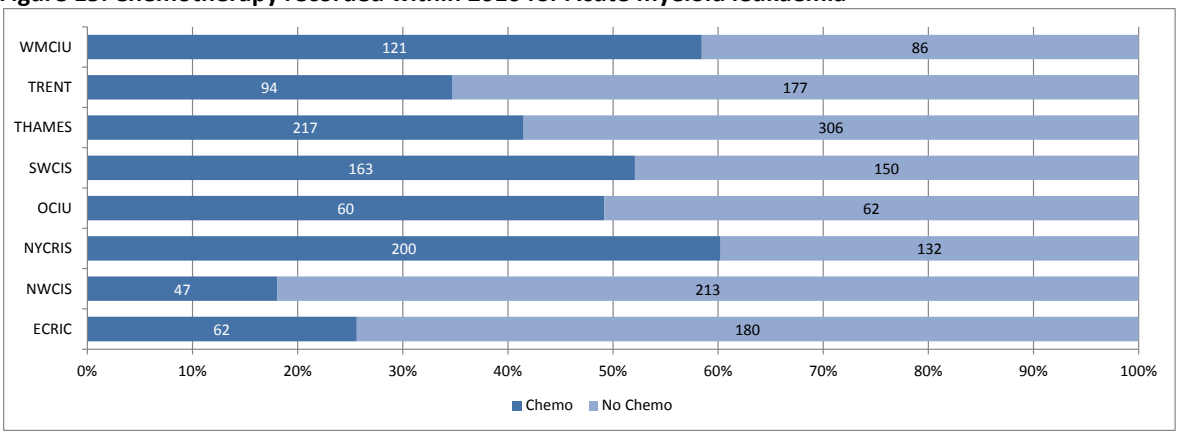
Chemotherapy in various forms is the major treatment received by patients with all types of blood cancer. The treatments differ between disease groups and at different time points and stages of disease. Chemotherapy may be used to eliminate and cure a blood cancer, or it may be used to reduce the symptoms of disease.

Figure 14: Chemotherapy recorded within 2010 for Acute lymphoblastic leukaemia



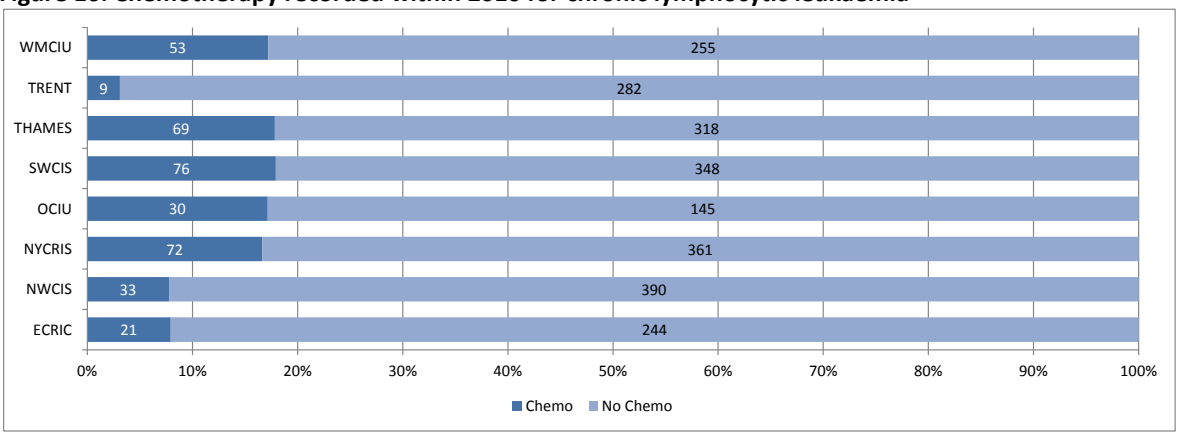
Comments: It would be exceptional for a patient with ALL not to receive chemotherapy; chemotherapy is clearly not being identified comprehensively in most cancer registries with the possible exception of WMCIU, OCIU and NYCRIS.

Figure 15: Chemotherapy recorded within 2010 for Acute myeloid leukaemia



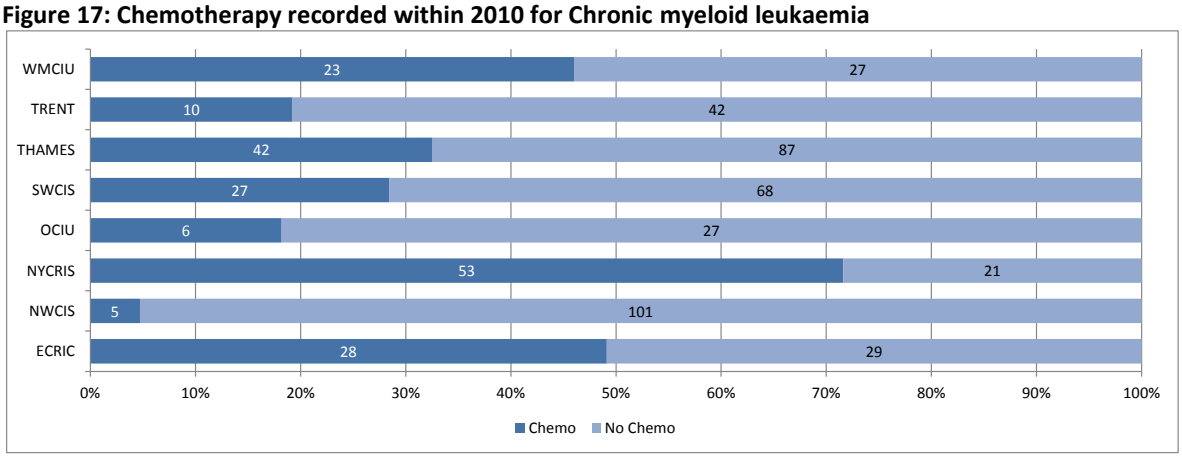
Comments: The variability in the distribution of recorded treatment indicates substantial under-recording of treatment in some registries.

Figure 16: Chemotherapy recorded within 2010 for chronic lymphocytic leukaemia



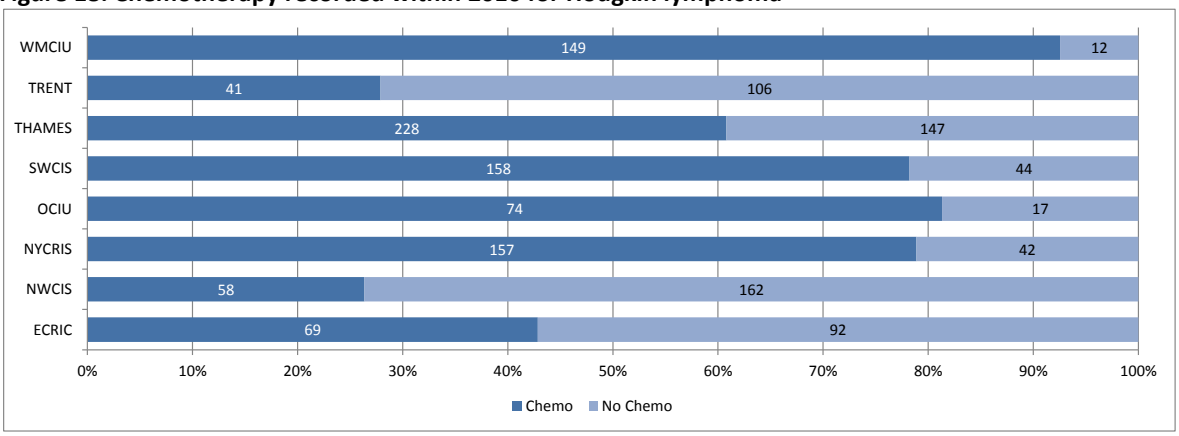
Comments: Many patients diagnosed with CLL will not receive chemotherapy in the first six months after diagnosis; those who are treated largely receive chemotherapy as an outpatient or in the community.

Figure 17: Chemotherapy recorded within 2010 for Chronic myeloid leukaemia



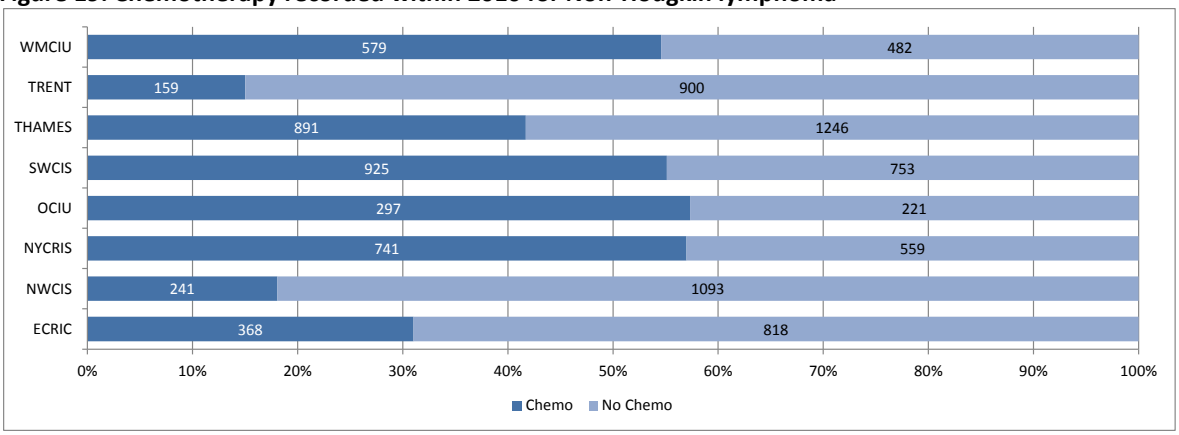
Comments: Almost all patients with CML will receive chemotherapy, but this therapy is predominantly delivered in the community. This may contribute to the low levels of chemotherapy recorded in cancer registries.

Figure 18: Chemotherapy recorded within 2010 for Hodgkin lymphoma



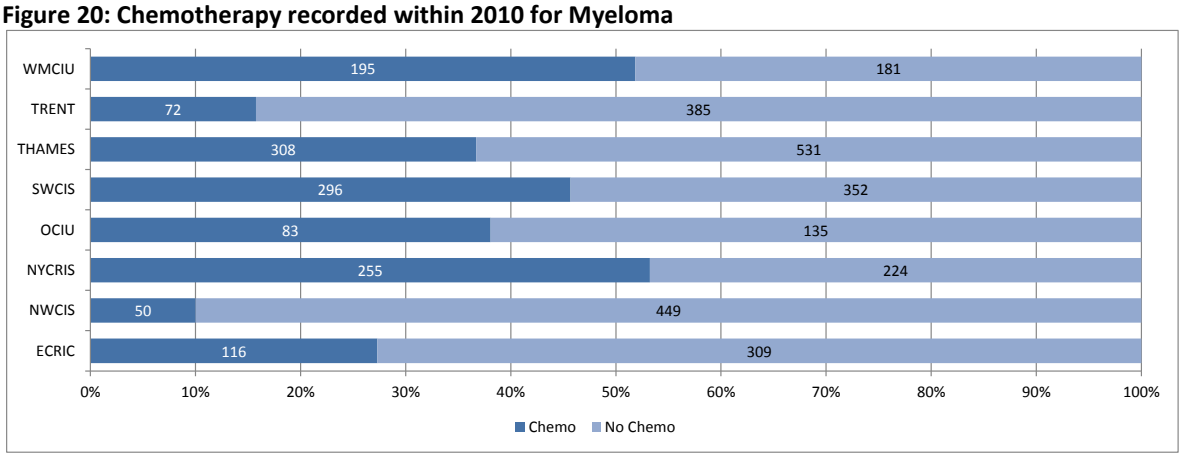
Comments: Most patients with Hodgkin lymphoma will receive chemotherapy in the first six months after diagnosis. The variability in the distribution of recorded treatment indicates substantial under-recording of treatment in some registries.

Figure 19: Chemotherapy recorded within 2010 for Non-Hodgkin lymphoma



Comments: The variability in the distribution of recorded treatment indicates substantial under-recording of treatment in some registries.

Figure 20: Chemotherapy recorded within 2010 for Myeloma



Comments: The variability in the distribution of recorded treatment indicates substantial under-recording of treatment in some registries.

Radiotherapy

Radiotherapy may form part of the primary treatment received by some patients with lymphomas (Hodgkin and Non-Hodgkin) and some patients with myeloma may receive treatment with radiotherapy to parts of the bony skeleton affected by the disease (although this may occur at any point in their pathway after diagnosis, not just in the first six months). In the absence of a 'gold standard' measure of the true use of radiotherapy, it is difficult to comment on the level of capture of this information by registries. Figures 21 to 23 demonstrate levels of variation between registries which indicate that substantial under-ascertainment of radiotherapy is occurring in some registries.

Figure 21: Radiotherapy recorded within 2010 for Hodgkin lymphoma

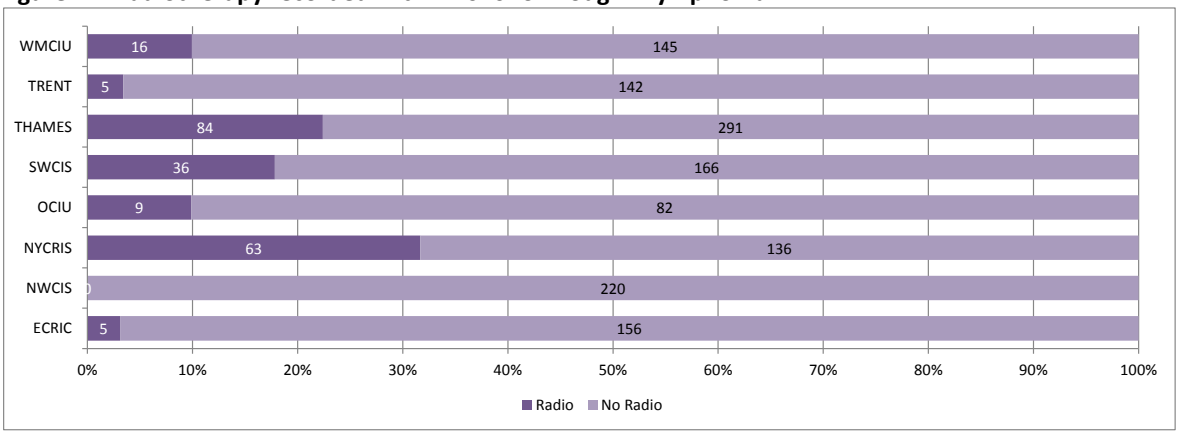


Figure 22: Radiotherapy recorded within 2010 for Non-Hodgkin lymphoma

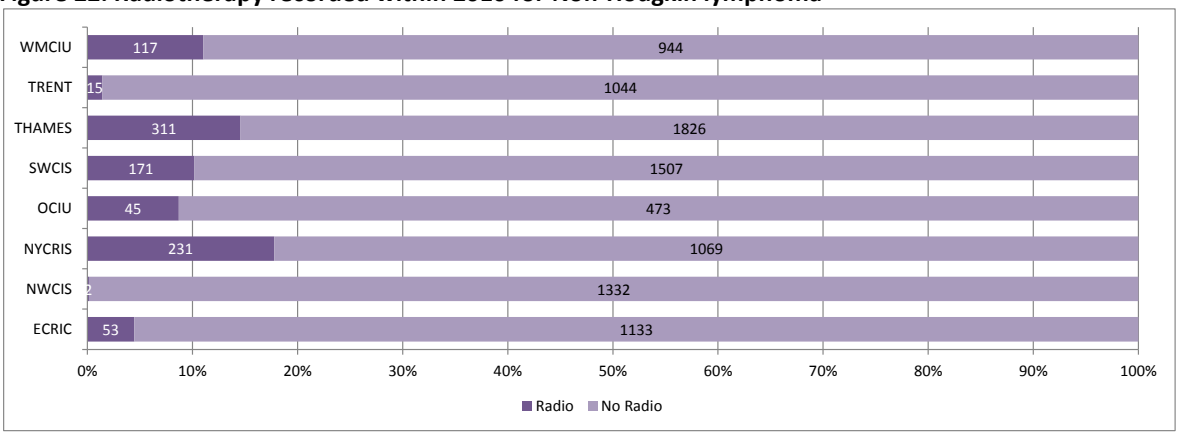
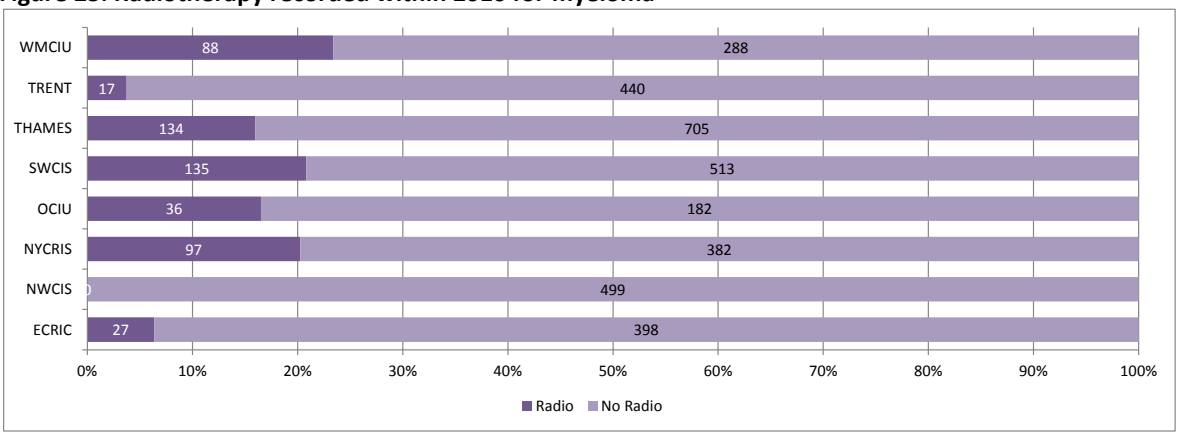


Figure 23: Radiotherapy recorded within 2010 for myeloma



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.