PLACE OF TREATMENT FOR TEENAGERS AND YOUNG ADULTS DIAGNOSED WITH CANCER 2003 TO 2005

Report on TYA cancer services in England prior to the implementation of IOG guidelines for cancer in children and young adults

NCIN national cancer intelligence network
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Place of treatment for teenagers and young adults diagnosed with cancer in England 2003 to 2005

TYA cancer services in England prior to the implementation of IOG guidelines for cancer in children and young adults. Report for the National Cancer Intelligence Network, April 2012

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SUMMARY

Key findings

- 4,957 individuals aged 15 to 24 years were diagnosed in England between 2003 and 2005 with a malignant neoplasm or borderline or benign CNS tumour.
- 86% of these diagnoses (N = 4,255) were identified as having a hospital in-patient episode (HES) and included in this study.
- 52% of patients in the study received at least some treatment as an in-patient within a hospital trust that is now a principal treatment centre (PTC).
- 64% of 15 to 18 year olds were admitted to a PTC for treatment compared with only 46% of 19 to 24 year olds.
- The diagnosis with the largest proportion of PTC admittance was bone tumours - 90% for 15 to 18 year olds and 82% 19 to 24 year olds.
- The diagnosis with the smallest proportion of PTC admittance was melanoma and skin carcinomas - 34% for 15 to 18 year olds and 33% for 19 to 24 year olds.
- For all diagnoses except STS, the proportion of males and females admitted to a PTC was similar. For STS, males aged 19 to 24 years were more likely to be admitted to a PTC than females.
- The East Midlands had the largest proportion of patients admitted to a PTC.
- The SW of England had the smallest proportion of patients admitted to a PTC.
- The amount of time patients spent admitted to hospital (number of bed days) was largely dependent upon diagnosis.
- Patients diagnosed with leukaemia or bone tumours spent the most number of days as in-patients inhospital, melanoma and skin carcinoma patients spent the least days.
- For many sub-diagnoses, PTC patients spent more bed days as in-patients than non-PTC patients.

EXECUTIVE SUMMARY

The aim of this study was to provide base line information on where teenagers and young adults with cancer were treated prior to the implementation of the Improving Outcomes Guidelines for children and young adults. The guidelines direct patients towards treatment within specialist TYA cancer centres and as these specialist care arrangements become fully established, health service providers now wish to monitor and measure what impact this approach to TYA care is having on clinical and psychosocial outcomes and on patient satisfaction. We provide here the first set of evidence for England on where adolescents with cancer received care prior to the implementation of the NICE guidelines.

Our study included 86% of all patients aged 15 to 24 years diagnosed with a malignant neoplasm or borderline or benign CNS tumour in England between 2003 and 2005. All diagnoses were identified from cancer registration records. These records were then linked to in-patient hospital episodes (HES) records to obtain information on place of treatment. Nine percent of diagnosed patients aged 15 to 18 years and 15% of diagnosed patients aged 19 to 24 years were excluded as the cancer registration records could not be linked to a HES in-patient record. An additional 45 cases across both age groups were excluded as all their HES records were for in-patent episodes that occurred more than 3 months prior to or more than 12 months after diagnosis.

The main findings of our study are summarised in the reports key findings. Fifty-two percent of patients included in the study were admitted at least once to a hospital trust that is now a principal treatment centre (PTC). A larger proportion of patients aged 15 to 18 years were admitted to a PTC compared with 19 to 24 year olds. The largest proportion of PTC admittance was seen in-patients with bone tumours. The smallest proportion of patients admitted to a PTC was seen in-patients with a melanoma or skin carcinoma diagnosis. For all diagnoses except STS, the proportion of males admitted to a PTC was not dissimilar to females. However, among STS patients aged 19 to 24 years, males were more likely to be admitted to a PTC than females.

Patients of both age groups resident in the East Midlands region of England were more likely to be admitted to a PTC than residents of any other region. Patients resident in the South West of England from both age groups were least likely to be admitted to a PTC. There was no clear relationship between socio-demographic status and PTC admittance but

this may be influenced by the use of national IMD quintiles. Further work is planned that will look at intra-regional variation using regional IMD quintiles.

The amount of time patients spent admitted to hospital was largely dependent upon diagnosis. Patients diagnosed with leukaemia or bone tumours spent the most number of days in hospital, melanomas and skin carcinoma patients spent the least days. PTC patients also spent more bed days as in-patients than non-PTC patients.

There are certain limitations to this study that are acknowledged. Undertaking a study of patient services based on in-patient admission is very difficult and looking at admission to a TYA principal treatment centre versus non-principal treatment centres is particularly so. The data do not allow differentiation of the type of service received within the PTC trust itself. Furthermore, patients who received treatment only as outpatients are not accounted for. Consequently our analysis may be an under-estimate of patients actually being managed by the PTC. Stage of disease at diagnosis and also progression of disease within the first 12 months of diagnosis may have contributed to the variation in place of treatment and bed usage that we observed within our study population. However, we were unable to test the degree of this influence quantitatively.

Future work is planned that is hoped will address at least some of these limitations. We are continuing to monitor referrals to TYA specialist care, identifying those patient groups that are slowest to respond to the availability of TYA specialist care. We are developing a process to inform cancer networks and regional commissioning groups about the level of TYA referrals in their regions, helping them to identify trusts whose patients are not been referred to a specialist TYA MDT. We also plan to investigate possible explanations for the apparent differences in bed day use between PTC patients and non-PTC patients.

INTRODUCTION

National cancer policy in England recognises teenagers and young adults with cancer as a patient group distinct from children and older adults and through the publication of the Improving Outcomes Guidelines for children and young adults (CYPIOG), has advocated the provision of specialist cancer care for 16 - 24 year olds (NICE 2005). The guidelines promote access to tumour site-specific expertise and care being delivered within age appropriate environments and direct patients towards treatment within specialist TYA cancer centres. Implementation of these guidelines has resulted in the establishment of 13 principal treatment centres (PTCs) in England. TYA PTCs are primarily responsible for the management of care of all 16 to 24 year olds, ensuring that all 16 to 24 years are discussed by a TYA specialist Multidisciplinary Team (MDT). Treatment for 16 to 18 year olds should be co-ordinated by the PTCs and delivered either at the PTC or at a designated hospital fulfilling certain criteria recently defined in the TYA cancer measures. Patients aged 19 to 24 years should have their care discussed with the PTC and may make an informed choice of their preferred place of care, either at a PTC or a designated hospital.

As these specialist care arrangements become fully established, health service providers now wish to monitor and measure what impact this approach to TYA care is having on clinical and psychosocial outcomes and on patient satisfaction. In order to successfully do this, it is necessary to have baseline data from which to measure change. Yet, to date, there is little evidence about how adolescents with cancer were managed prior to the implementation of the NICE guidelines. In 2007, data were published on where patients in the South East of England received chemotherapy treatment (Whelan *et al.* 2007) but this has not so far been extended nationally.

This report describes where TYA patients, diagnosed in England, were admitted for care prior to the implementation of the CYPIOG and the degree of variation in hospital care required by different patients. The North West Cancer Intelligence Centre (NWCIS) is the NCIN national cancer registry for teenagers and young adults. We have established a national TYA cancer registration database linking TYA cancer registrations with hospital episodes statistics (HES), NHS cancer waits data and with TYAC notifications. Using this database, we have identified the role played by the 13 trusts that are now TYA PTCs in

providing TYA cancer patient care prior to 2006 alongside the CCLG centres. With these data we aim to provide a baseline measure against which the effects of the introduction of specialist TYA care can be monitored and assessed. We also provide an insight into which TYA patients are most at risk of not accessing TYA specialist care and which patients are likely to require most hospital resources.

Access to age specialist care was introduced for children in the mid 1970s and over the last 30 years the percentage of children managed by specialist paediatric cancer centres has risen to approximately 90% (Stiller 2010). In parallel, survival rates for many childhood cancers have progressively improved, a positive trend attributed, at least in part, to the role that these specialist centres play in recruiting patients to clinical trials (Stiller 1988, 1989, 1994; Pritchard-Jones *et al.* 2008).

It is hoped that the introduction of specialist centres for the teenagers and young adults will have a similar influence on outcomes for this age group as well as improving the patient experience by offering more age appropriate facilities for young people.

The impact of this strategy on outcomes and patient experience will be measurable in time once each specialist centre's facilities are fully operational. Here we provide a starting point for such measures.

METHODS

In England, cancer registries record the occurrence of cancer in their residential populations. Registration is initiated by clinical and pathology information received from hospital trusts and by information about deaths from the National Health Service Central Registration through the Office for National Statistics. Data are collected on demographic and tumour details and on treatments received. The version of the TYA national cancer database used for this study was compiled by NWCIS in 2008 by collating together data extracts for the 15 to 24 year age group kindly provided by each of the English cancer registries. These collated data were then linked to the Hospital Episodes Statistics (HES) data by Thames Cancer registry on our behalf. We classified each diagnosis according to the TYA diagnostic groupings as described by Birch and colleagues (Birch *et al.* 2002) based on site of tumour and tumour histology (see Appendix 1). We identified from these classifications all diagnoses of malignant neoplasms and borderline and benign CNS tumours.

For this study, we identified all patients aged 15 to 24 years diagnosed in England between 2003 and 2005 with a diagnosis of malignant neoplasm or borderline and benign CNS tumours (N = 4,957). We excluded all patients who did not have at least one HES record relating to a hospital in-patient episode within 3 months prior and 12 months following diagnosis (N = 702). Our final study population comprised 4,255 patients (Table 2).

For each patient we identified diagnosis, age at diagnosis, sex, government office region (GOR) of residence and deprivation quintile. Deprivation quintiles have been assigned using the Income Domain of the Index of Multiple Deprivation (IMD) 2007. Diagnoses are grouped into 9 main diagnostic groups (Table 2/Appendix 1). As the number of cases within diagnostic groups 9 and 10 were very small these have been grouped together as 'other neoplasms'. For analysis of bed days, diagnoses have also been classified into sub-diagnosis groups.

For each hospital episode we identified hospital trust, date of episode start, date of episode end and whether or not the hospital spell was complete.

Admittance to a PTC trust

All hospital trusts identified in the HES records were classified as a specialist PTCs if they were either one of 13 current designated TYA principal treatment centres in England or one of the additional Children's Cancer and Leukaemia Group (CCLG) centres in England (some trusts are both TYA and CCLG specialist centres). Table 1 provides a list of all trusts that were included as a PTC trust. All other trusts were counted as non-PTCs.

Table 1: NHS Trusts in England classified as Principal Treatment Centres

Designated TYA Principal Treatment Centres (TYA PTC)
Cambridge University Hospitals NHS Foundation Trust
Clatterbridge Centre For Oncology NHS Foundation Trust
Leeds Teaching Hospitals NHS Trust
Nottingham University Hospitals NHS Trust and University Hospitals of Leicester NHS Trust
Oxford Radcliffe Hospitals NHS Trust
Sheffield Teaching Hospitals NHS Foundation Trust
Southampton University Hospitals NHS Trust
The Christie NHS Foundation Trust
The Newcastle Upon Tyne Hospitals NHS Foundation Trust
The Royal Marsden NHS Foundation Trust
University College London Hospitals NHS Foundation Trust
University Hospital Birmingham NHS Foundation Trust
University Hospitals Bristol NHS Foundation Trust
Additional Children's Cancer and Leukaemia Group (CCLG) centres
Alder Hey Children's NHS Foundation Trust
Barts and the London NHS Trust
Birmingham Children's Hospital NHS Foundation Trust
Central Manchester and Manchester Children's University Hospitals NHS Trust
Great Ormond Street Hospital for Children NHS Trust
Sheffield Children's Hospital
The Middlesex Hospital, London

All patients with at least one hospital episode within a TYA PTC or a CCLG centre were flagged as being PTC patients. All other patients were considered non-PTC patients. No assessment was made of the amount of treatment received at the PTC versus a non-PTC. A single episode at a PTC was sufficient for an individual to be considered a PTC patient. Analyses by region were by region of residence, not by region of the PTC where the

patient received treatment. Therefore a patient resident in region X was counted as a PTC patient of region X irrespective of the region that the patient was treated in. PTC admittance is presented as the proportions of total cases within an in-patient HES record with a PTC status. Binomal exact (95%) confidence intervals are also presented.

Variation in hospital bed use

For these analyses we excluded any incomplete spells and duplicate and overlapping episodes. In addition all day case episodes were excluded, retaining only those episodes that were shown to include at least one overnight stay. Based on this population of in-patients, we compared the total number of days each patient spent in hospital in the 3 months leading up to and in the 12 months following diagnosis, by age, diagnosis and where patients were treated (i.e. PTC patients versus non-PTC patients). As the distribution of bed days within each diagnostic group and age group are highly skewed we present medians along with 95% confidence intervals and total ranges (min-max) to illustrate variation in bed day use. The 95% confidence intervals for median bed usage are calculated using a binomial method that makes no assumptions about the underlying distribution of the variable. We also present. For all sub-diagnosis group analyses, where the number of cases within each group was less than 5, the results have been suppressed to avoid potential data disclosure.

All statistical analyses were undertaken using STATA version 11. Where any two or more groups are compared, groups can broadly be interpreted as being significantly different if the 95% confidence intervals of the groups being compared do not overlap.

STUDY POPULATION

Cases included

Table 2: Number of cases included in the study

	males		females	
	15 to 18	19 to 24	15 to 18	19 to 24
leukaemias	117	116	70	85
lymphomas	173	313	136	293
CNS	129	162	91	163
bone tumours	72	72	36	47
soft tissue sarcomas	39	67	39	73
germ cell tumours	121	502	31	31
melanomas and skin carcinomas	41	135	60	231
non skin carcinomas	51	138	104	470
other neoplasms	11	15	3	18
all cancers	754	1520	570	1411

Cases excluded with no HES in-patient record

A total of 657 cases were excluded as no HES record match was found. A further 45 cases were excluded as all HES records found for the individuals fell outside of the defined study period i.e. either occurring more than 3 months prior to diagnosis or more than 12 months following diagnosis. The majority of cases with no in-patient HES records belonged to the 19 to 24 year age group and comprised primarily germ cell tumours, melanoma and skin carcinoma and non-skin carcinomas.

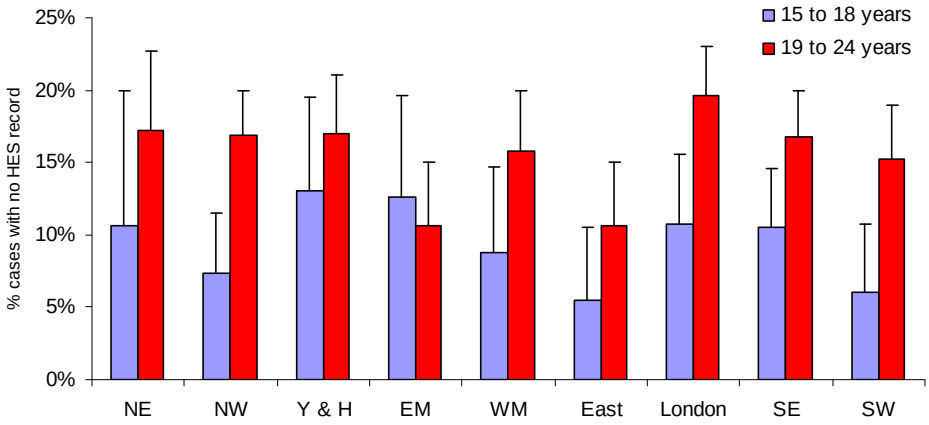
Table 3: No of cases excluded (no HES in-patient record within study time period) by diagnosis, gender and age

	males		females	
	15 to 18	19 to 24	15 to 18	19 to 24
leukaemias	0	11	2	3
lymphomas	16	29	9	17
CNS	17	16	7	14
bone tumours	4	2	2	2
soft tissue sarcomas	4	5	0	5
germ cell tumours	5	37	1	8
melanomas and skin carcinomas	16	102	34	168
non skin carcinomas	2	35	21	104
other neoplasms	1	1	0	2
all cancers	65	238	76	323

Table 4: Percentage of total diagnoses excluded (no HES in-patient record within study time period) by diagnosis, gender and age

	males (%)		females (%)	
	15 to 18	19 to 24	15 to 18	19 to 24
leukaemias	0	9	3	3
lymphomas	8	8	6	5
CNS	12	9	7	8
bone tumours	5	3	5	4
soft tissue sarcomas	9	7	0	6
germ cell tumours	4	7	3	21
melanomas and skin carcinomas	28	43	36	42
non skin carcinomas	4	20	17	18
other neoplasms	8	6	0	10
all cancers	8	14	12	19

The diagnostic group 'melanoma and skin carcinoma' had the largest proportion of cases with no in-patient HES record compared with all other diagnosis. This pattern was consistent for both age groups and both sexes (Table 4). For both age groups, there was some variation in the proportion of cases with no HES record by region of residence, the East of England having the smallest proportion of cases without a HES record (Figure 1). These regional differences may indicate discrepancies in how day-case patients are recorded i.e. as in-patients versus out-patients. Alternatively, they may reflect true regional differences in treatment pathways decisions i.e. to admit patient for treatment or to treat as an out-patient.



T *Error bars represent 95% confidence intervals*

Figure 1: Percentage of total diagnoses excluded with no HES in-patient record by age group and region of residence

Cases excluded as day-case-only patients

In total 54,354 episodes were identified among the HES records for the entire study population. Of these we identified 35,352 as being day case episodes ie the start date and end date were identical. These were excluded from the analyses of bed usage. Among these excluded records were records belonging to 606 individuals whose HES records comprised entirely of day case episodes. These individuals were excluded from the study population for the bed usage analyses and our study population for bed use analysis comprised 3,649 cases (Table 5)

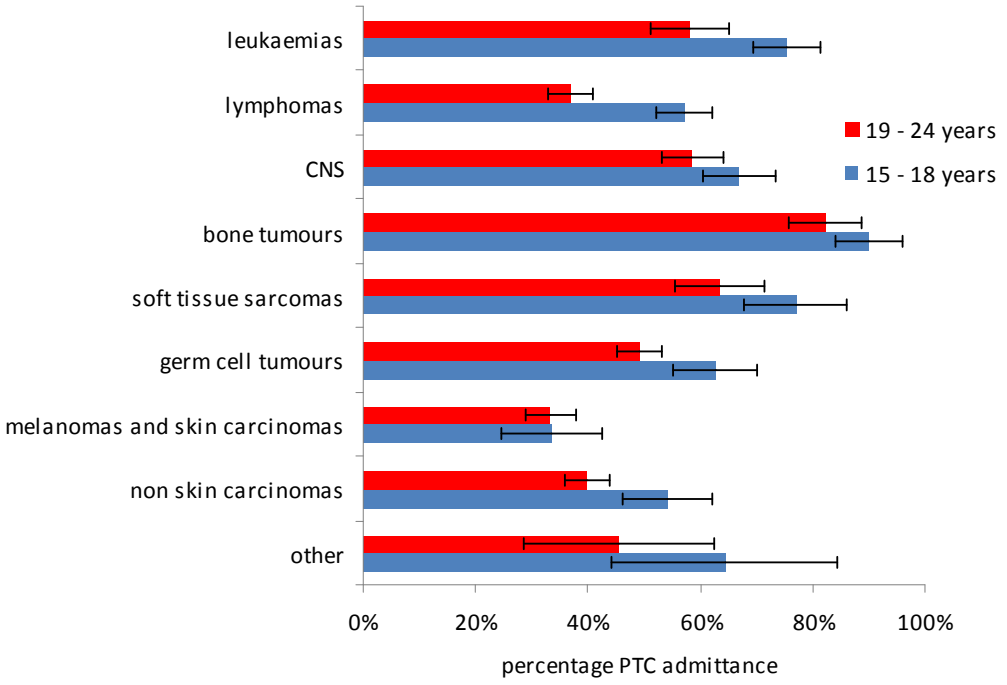
Table 5: Number of cases included in the bed use analyses

	males		females	
	15 to 18	19 to 24	15 to 18	19 to 24
leukaemias	115	111	70	79
lymphomas	145	247	120	240
CNS	124	156	85	160
bone tumours	72	72	35	47
soft tissue sarcom	37	62	37	63
germ cell tumours	112	449	31	31
melanomas and sl	20	62	21	81
non skin carcinom	50	133	104	435
other neoplasms	10	14	3	16
all cancers	685	1306	506	1152

RESULTS

Admittance to a PTC trust

The main contributory factor in determining where TYA patients were admitted for treatment between 2003 and 2005 appeared to be age at diagnosis. During this period, 64% of 15 to 18 year old cancer patients were admitted for treatment to a trust that is now a designated PTC compared with only 46% of 19 to 24 year olds. There was also considerable variation by diagnosis (Figure 2).



T *Error bars represent 95% confidence intervals*

Figure 2: Percentage of TYA patients admitted to a PTC by TYA diagnostic group and age group

For both age groups, patients with bone tumours were most likely to be admitted to a PTC (90% for 15 to 18 year olds and 82% 19t o 24 year olds). Patients with a melanoma or skin carcinoma diagnosis were least likely (34% for 15 to 18 year olds and 33% 19 to 24 year olds). For most diagnoses there was no difference in the proportion of males and females

admitted to a PTC for either age group (Figure 3). The only exception to this was soft tissue sarcomas in the 19 to 24 years where the proportion of admittance to a PTC was larger in males (76%) than females (52%).

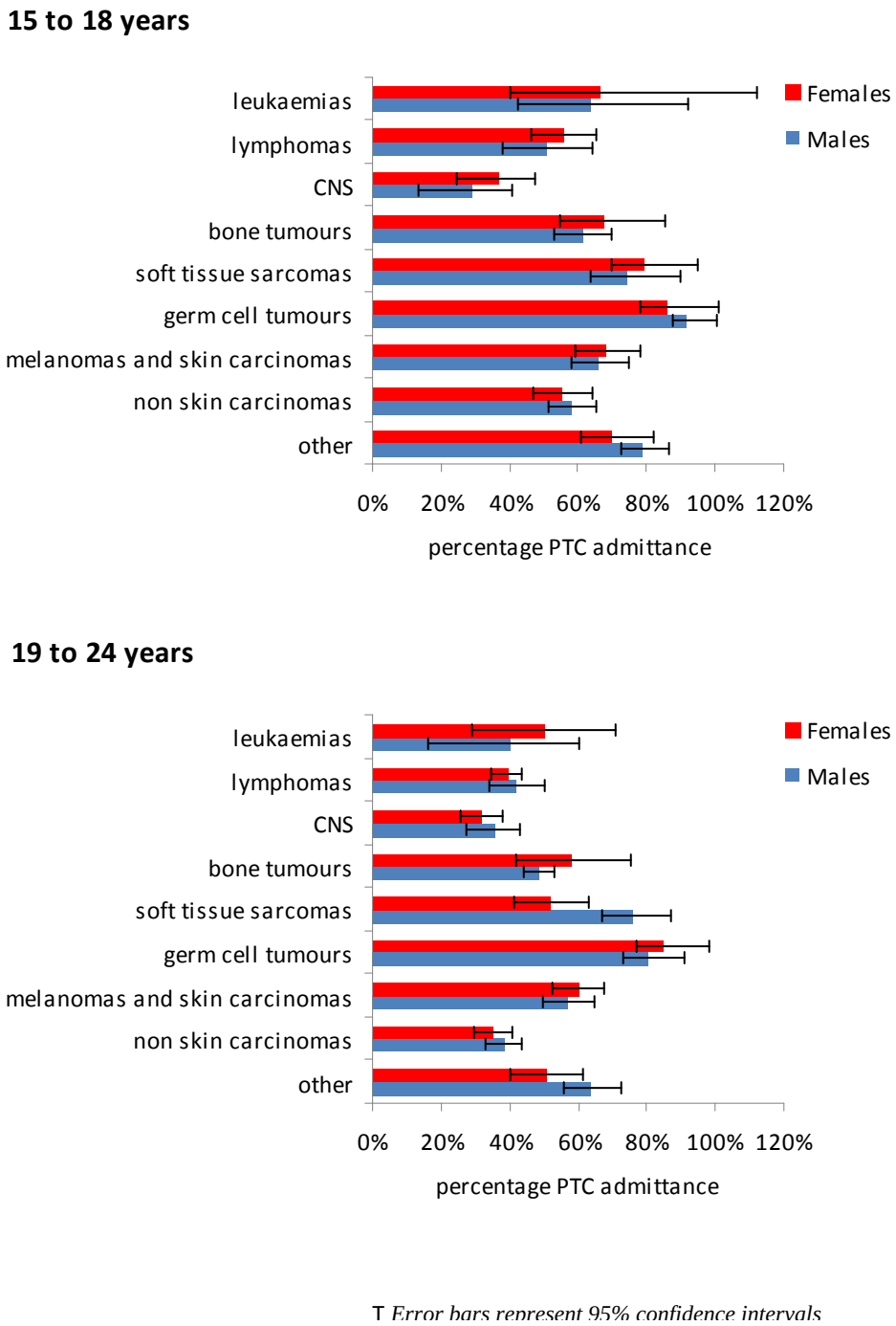


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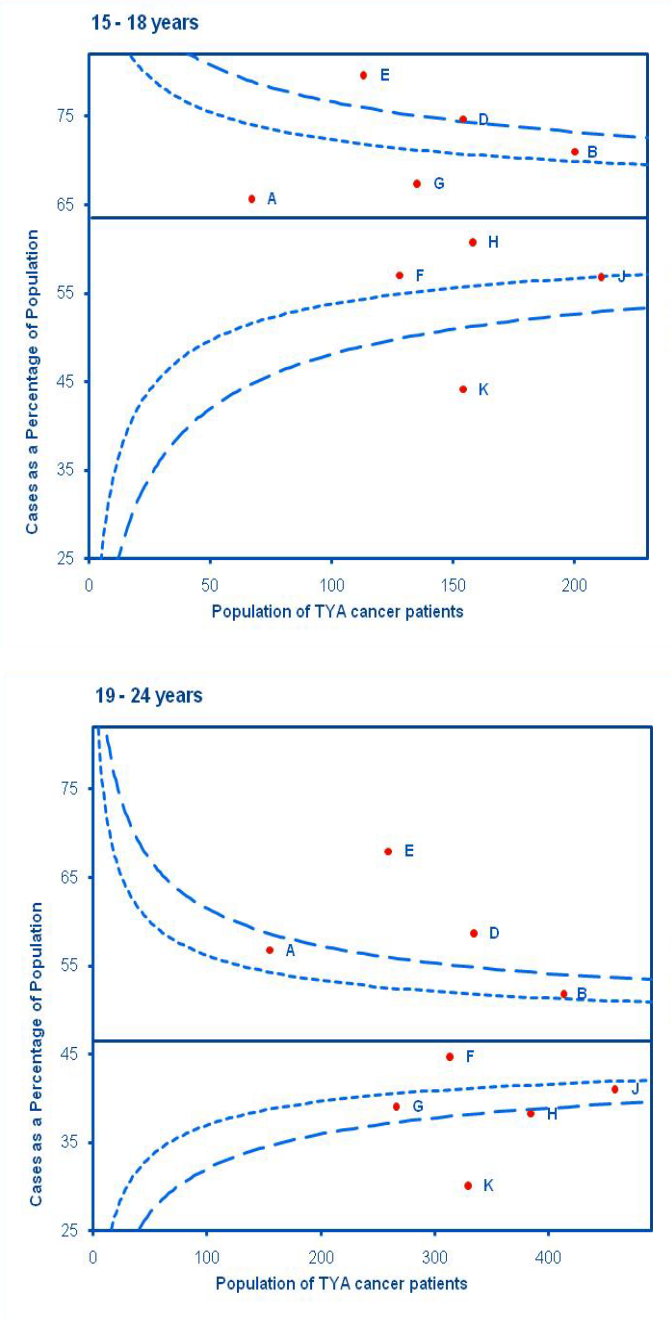
Figure 3: Percentage of TYA patients admitted to a PTC by TYA diagnostic group, age group and gender



Data points are government office regions of England:

A= NE England, B = NW England, D = Yorkshire and the Humber,

E = East Midlands, F = West Midlands, G = East England, H = SE England, J = London,

K = SW England

Figure 4: Funnel plots of percentage of TYA patients resident in each GOR of England admitted to a PTC by age group (all cancers combined)

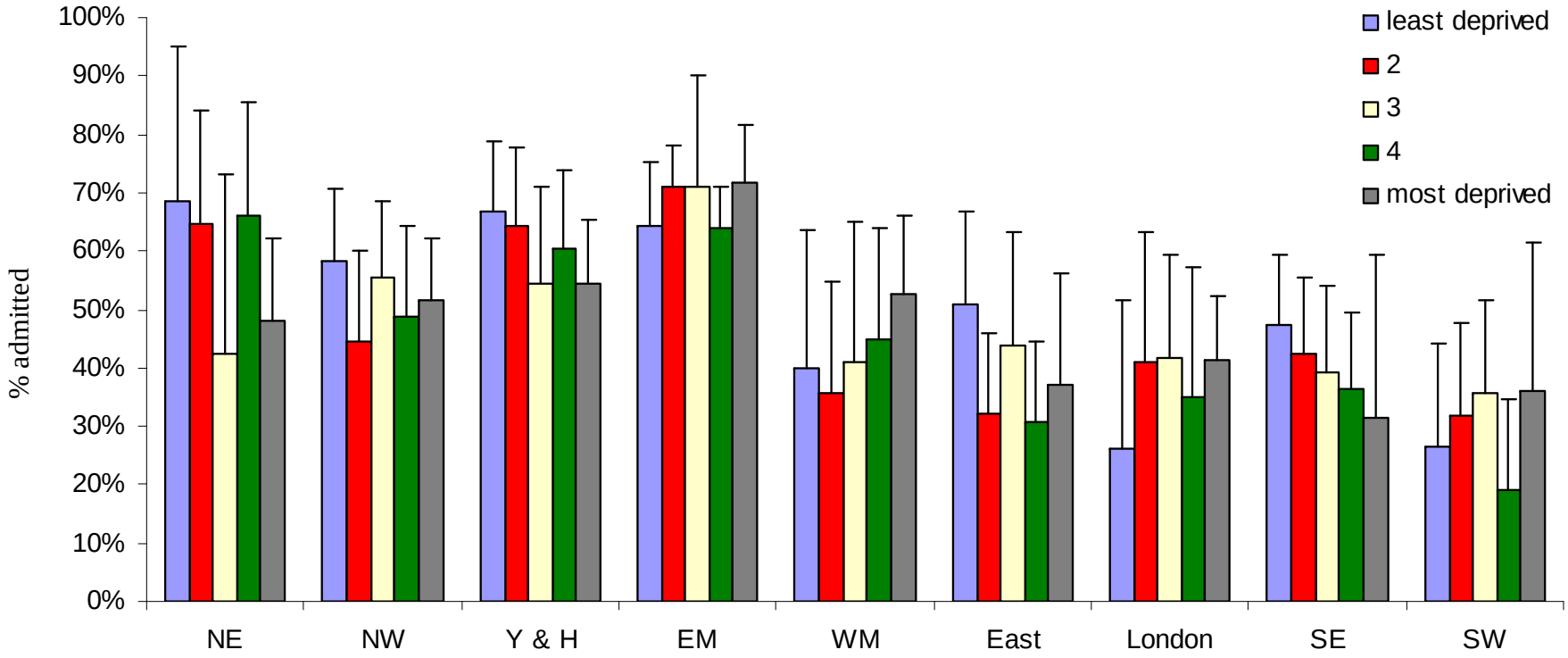
Patient admittance to a PTC was also highly variable by region of residence, especially in the 19 to 24 year age group. Figure 4 shows the proportion of patients within each region in England admitted to a PTC for the 15 to 18 year age group (funnel plot 1) and for the 19 to 24 year age group (funnel plot 2). The central horizontal line across each of the funnel plots depicts the average for England for each age group (64% for the 15 to 18 year olds and 46% for the 19 to 24 year olds). The 2 sets of dotted lines on each funnel plot indicate the respective 95% and 99% confidence limits. Those regions that sit above the two upper dotted lines have a larger proportion of PTC patients than the England average. Regions that sit below the two lower dotted lines have a smaller proportion of patients admitted to a PTC. Patients of both age groups resident in the East Midlands GOR (data point E) were more likely to be admitted to a PTC (79% 15 to 18 year olds, 68% 19 to 24 year olds) than residents of any other region. Patients resident in the South West of England (data point K) from both age groups were least likely to be admitted to a PTC.

The relationship between socio-demographic status and patient admittance to a PTC (Table 6) was unclear. For some diagnoses, patients from areas of least deprivation had a higher likelihood of being admitted to a PTC trust than those from more deprived areas but there was no consistent pattern across all diagnoses. Furthermore, the relationship was not linear; the most deprived areas did not have the smallest proportion of patients admitted to a PTC.

Table 6: Percentage of TYA patients admitted to a PTC by deprivation quintile (IMD) and diagnosis (all ages)

	IMD deprivation quintile				
	least deprived	2	3	4	most deprived
leukaemias	73	67	68	58	67
lymphomas	47	41	40	47	42
CNS	73	62	59	62	56
bone tumours	91	83	89	72	88
soft tissue sarcomas	81	56	71	69	68
germ cell tumours	56	54	51	44	56
melanomas and skin carcinomas	34	37	25	28	45
non skin carcinomas	38	46	39	39	50
other	40	50	56	13	58

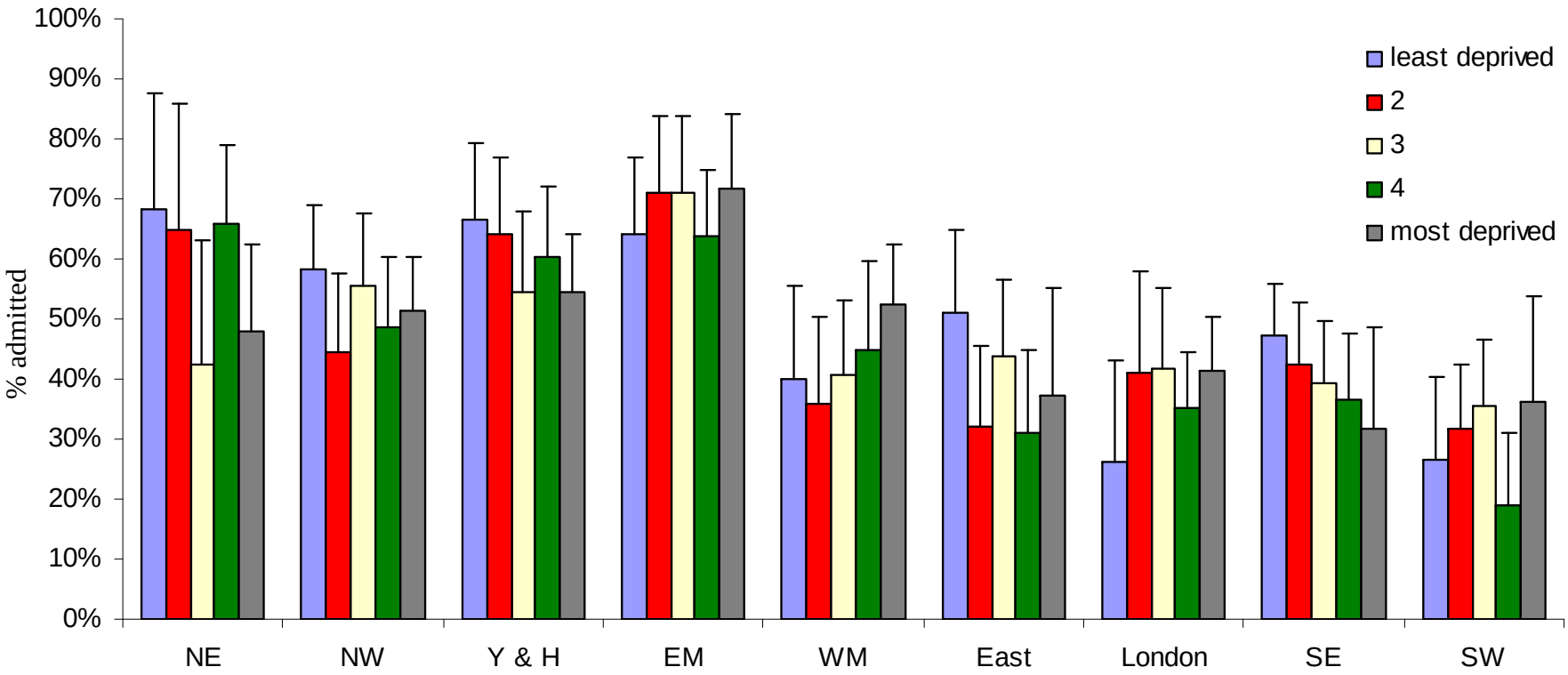
15 to 18 years



T *Error bars represent 95% confidence intervals*

Figure 5: Percentage of TYA patients aged 15 to 18 years admitted to a PTC by regional of residence and deprivation quintile (IMD)

19 to 24 years



T *Error bars represent 95% confidence intervals*

Figure 6: Percentage of TYA patients aged 19 to 24 years admitted to a PTC by region of residence and deprivation quintile (IMD)

A similar non-determinate pattern was seen when the data were analysed by region of residence and deprivation quintile (Figures 5 and 6). There were differences in the proportion of patients admitted to a PTC between the deprivation quintile groups within some of the regions. However no consistent trends were seen that would suggest a strong relationship between socio-demographic status (as assessed using the national quintiles) and PTC admittance. Any relationship between socio-demographic status and PTC admittance is likely to be inter-correlated with region of residence, regional deprivation quintiles and other factors such as ease of access to the PTC and how that access varied by deprivation quintile within each region.

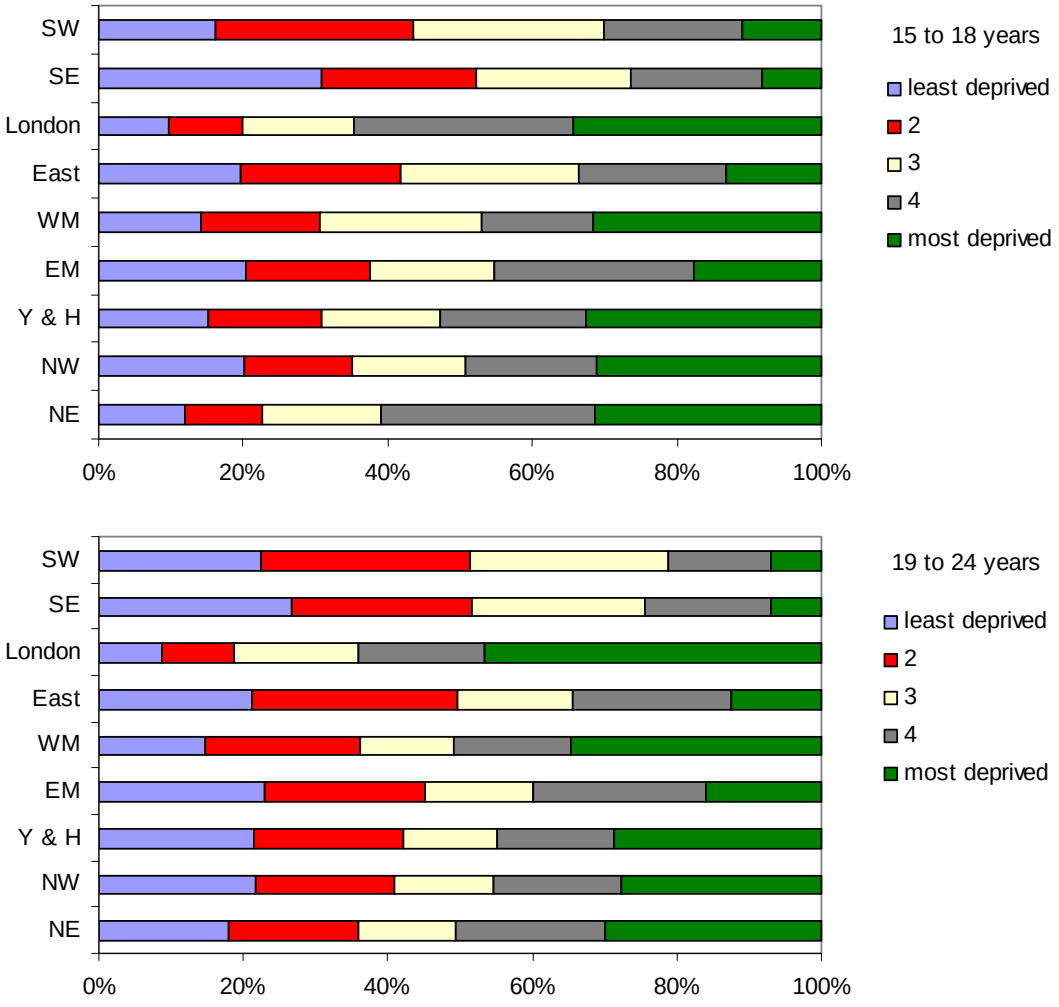


Figure 7: Distribution of cases within each age group by deprivation quintile and region residence

Figure 7 shows how TYA cancer cases with a HES record were distributed across the deprivation quintiles within each region by age group. For this study, we used national IMD quintiles as this is considered to be the most appropriate approach for national analyses. However national quintiles may cloak within-region socio-demographic effects. For instance, the London region had a larger proportion of 19 to 24 year olds in the most deprived quintile compared with the South West of England and a smaller proportion in the least deprived quintile. However, both London and the South West had the smallest proportions of PTC patients aged 19 to 24 years. Further work using regional deprivation quintiles is required to clarify these associations. It is nevertheless noteworthy that the relationship between some diagnoses and PTC admittance was consistent across all levels of deprivation – bone tumour patients of all socio-demographic backgrounds were most likely to be admitted to a PTC.

Bed usage

The number of days a TYA cancer patient spent in hospital in the 15 month period surrounding diagnosis was highly variable ranging from 1 to 511 days. Most of this variation could be attributed to diagnosis (Figure 8).

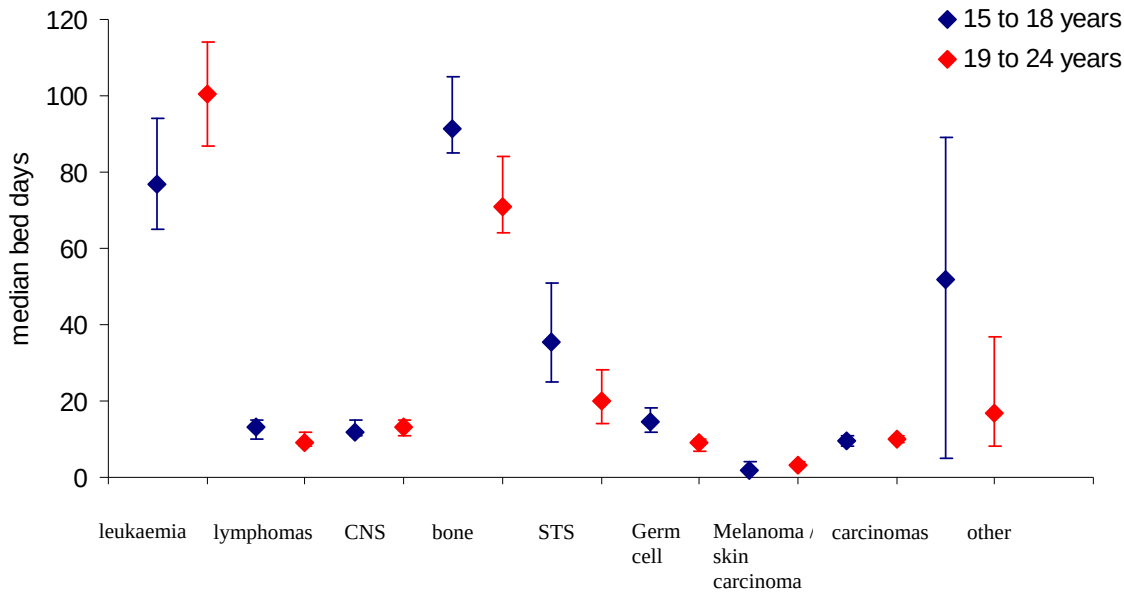


Figure 8: : Median number of bed days TYA patients spent as in-patients during 15 month period surrounding diagnosis by diagnosis and age group (error bars represent 95% confidence intervals).

The number of days each patient spent in hospital was highly skewed, most patients spending only one or two days admitted to hospital and a very small number of patients spending many months in hospital. We have therefore presented the median number of bed days with 95% confidence intervals rather than mean number of days. For both age groups, patients diagnosed with leukaemia or bone tumours spent the most number of days as in-patients, melanomas and skin carcinoma patients spent least days. However, within the leukaemia and bone tumour groups, and indeed within all diagnostic groups, there was a large amount of variation in bed usage.

Possible explanations for the variation in in-patient bed days within each diagnostic group are differences in the incidence of specific diagnoses e.g. Acute Myeloid Leukaemia (AML) vs. Acute Lymphoblastic Leukaemia (ALL) vs. 'other leukaemias'. To examine this we looked at

median bed days by the main diagnostic sub groups and stratified by age group and gender (Table 7).

This analysis provided more detailed information on variation in bed usage between diagnoses and age groups. For example, within the leukaemia diagnostic group, AML patients across all ages had higher bed usage than those with ALL or 'other leukaemias'. Within the ALL sub-group 19 to 24 year olds had higher bed usage than 15 to 18 year olds. The same was not seen in the AML sub-group. Similar subgroup-specific differences in bed usage across all ages were seen within other diagnostic groups, while age-specific differences were seen for Hodgkin lymphoma, non-Hodgkin lymphoma, gonodal germ cell tumours in males and Ewing sarcoma.

To investigate the impact of place of care on bed use within and across diagnostic groups we compared bed use between PTC and non-PTC patients (Figure 9). For many of the diagnoses, PTC patients had a higher median number of bed days than non-PTC patients. There was wide variation in bed use within diagnostic groups for PTC and non-PTC patients. To examine this further we analysed diagnostic sub-groups by age and PTC status (Table 8). Across both age groups PTC patients with Hodgkin lymphoma, non-Hodgkin lymphoma, other STS and gonadal germ cell tumours had higher bed usage than non-PTC patients.

Table 7: Comparisons of median measures and interquartile range by diagnostic subgroup, age group and gender

	15 to 18 years								19 to 24 years							
	Males				Females				Males				Females			
	N	median	UCL-LCL	min-max	N	median	UCL-LCL	min-max	N	median	UCL-LCL	min-max	N	median	UCL-LCL	min-max
ALL	74	70	(54-90)	(2-273)	34	70	(52-105)	(11-378)	57	115	(94-136)	(18-225)	25	112	(70-131)	(1-320)
AML	29	110	(81-176)	(3-321)	24	118	(75-151)	(19-261)	36	103	(68-144)	(1-253)	42	111	(94-134)	(3-327)
Other leukaemias	12	52	(39-70)	(7-193)	12	66	(39-99)	(2-314)	18	31	(14-49)	(2-159)	12	50	(11-113)	(1-222)
HL	87	8	(5-10)	(1-167)	91	9	(6-12)	(1-132)	156	5	(3-5)	(1-91)	171	6	(4-9)	(1-511)
NHL	58	50	(38-64)	(2-259)	29	69	(24-91)	(1-145)	91	37	(21-57)	(1-136)	69	30	(18-36)	(2-192)
High grade glioma	11	19	(15-43)	(3-70)	6	18	(6-64)	(5-69)	27	26	(11-39)	(2-212)	8	29	(9-58)	(4-78)
Low grade glioma	35	14	(8-36)	(1-191)	24	10	(6-15)	(3-101)	37	11	(7-18)	(2-35)	38	15	(10-22)	(2-132)
Other CNS	78	12	(9-15)	(1-317)	55	12	(8-18)	(1-123)	92	12	(10-16)	(1-289)	114	11	(9-14)	(1-176)
Chondrosarcoma									8	18	(6-78)	(4-186)				
Ewing sarcoma	30	92	(73-99)	(4-212)	14	101	(69-115)	(43-143)	30	69	(58-84)	(17-27)	19	69	(58-104)	(28-148)
Osteosarcoma	34	114	(86-135)	(2-361)	14	90	(78-122)	(17-183)	29	102	(69-124)	(3-116)	15	131	(59-156)	(1-179)
Other bone					6	58	(17-129)	(17-130)	5	54	(11-93)	(11-165)	9	29	(23-91)	(5-130)
Fibrosarcoma									9	4	(2-9)	(2-124)	13	5	(2-10)	(1-51)
Other STS	18	20	(11-82)	(1-201)	26	36	(10-49)	(1-120)	42	29	(14-46)	(1-93)	40	17	(10-25)	(1-131)
Rhabdomyosarcoma	16	57	(28-90)	(25-176)	7	73	(45-104)	(41-113)	11	54	(26-89)	(10-16)	10	45	(20-123)	(10-243)
Gonodal germ cell	88	11	(8-15)	(1-114)	28	24	(20-26)	(2-77)	420	8	(7-9)	(1-234)	27	21	(9-30)	(4-147)
Non-gonodal germ cell	24	15	(11-58)	(3-128)					29	40	(19-55)	(6-174)				
Melanoma	17	3	(2-6)	(1-65)	16	2	(1-9)	(1-15)	46	5	(3-7)	(1-145)	70	3	(2-4)	(1-66)
Skin carcinomas					5	2	(1-4)	(1-4)	16	2	(2-4)	(1-188)	11	1	(1-5)	(1-68)
Carcinoma of non-thyroid head and neck	13	7	(4-32)	(3-71)	16	6	(2-22)	(1-172)	21	19	(10-39)	(2-98)	30	6	(3-10)	(1-52)
Carcinoma of the breast													39	8	(9-10)	(2-43)
Carcinoma of the GI tract	21	11	(5-35)	(1-69)	13	32	(7-85)	(4-134)	59	21	(16-24)	(3-57)	62	20	(12-29)	(1-159)
Carcinoma of the GU tract					28	7	(5-13)	(2-100)	10	10	(6-31)	(4-91)	159	8	(7-9)	(1-131)
Carcinoma of the thyroid	7	11	(7-14)	(6-15)	38	9	(6-11)	(2-28)	28	9	(7-12)	(2-119)	125	8	(7-9)	(1-39)
Carcinoma of the trachea, bronchus, lung and pleura									5	36	(10-119)	(10-83)	7	16	(8-42)	(8-53)
Other carcinomas	5	50	(18-65)	(18-65)					10	25	(6-79)	(1-55)	13	19	(13-72)	(3-161)
Other neoplasms	10	52	(2-93)	(1-102)					14	16	(4-46)	(1-118)	16	27	(7-37)	(4-227)

** Sub-groups with less than 5 cases have been suppressed*

*** High grade glioma comprises glioblastomas and anaplastic astrocytomas and oligodendrogliomas with histological code 94513. Low grade glioma comprises pilocytic astrocytomas, other low grade astrocytomas and astrocytomas NOS plus oligodendrogliomas with histological ICD-0 code M94500 or M94503*

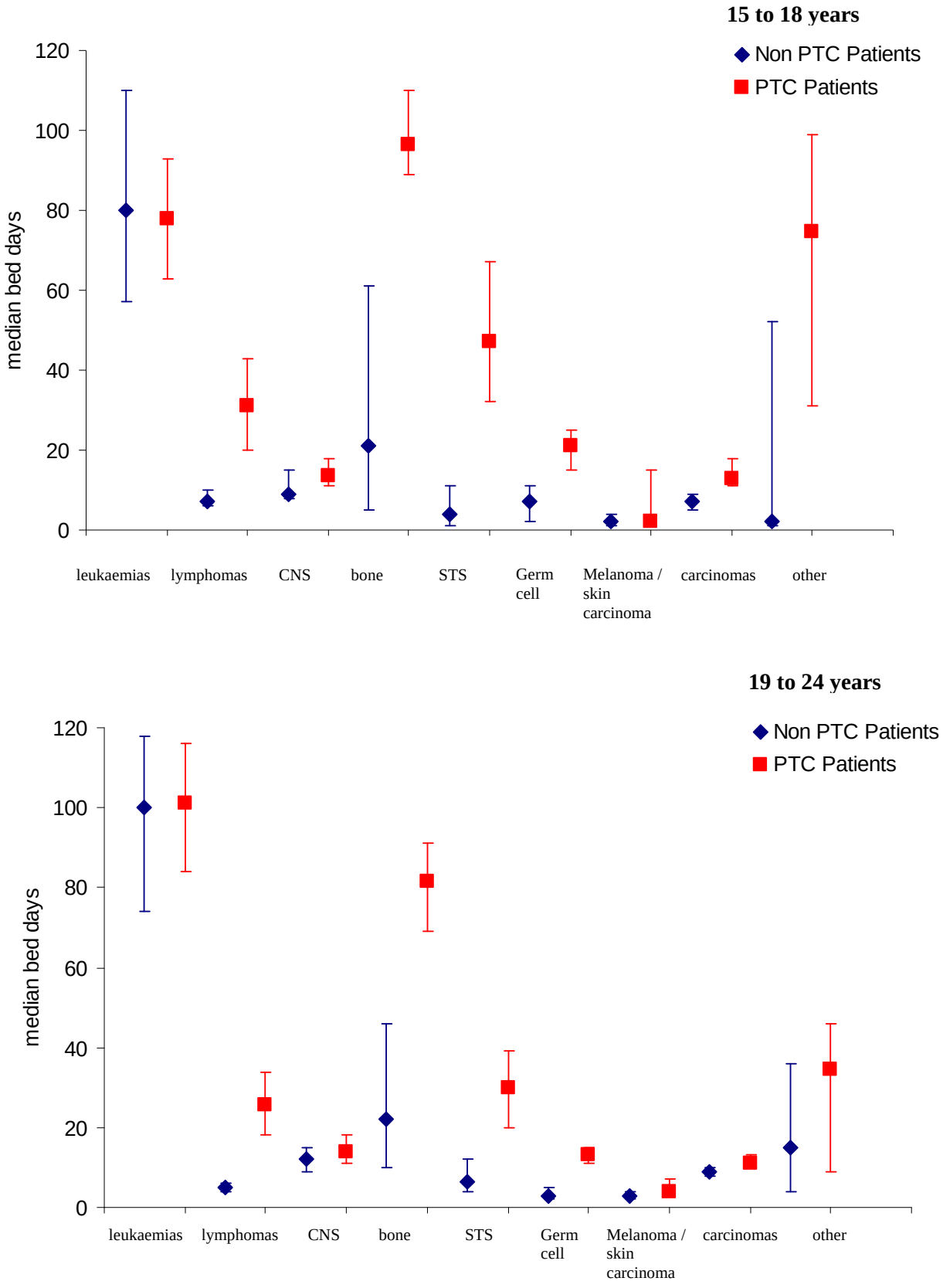


Figure 9: Median number of bed days PTC patients spent as in-patients during 15 month period surrounding diagnosis compared with non-PTC patients by diagnosis and age group (error bars represent 95% confidence intervals)

Table 8: Comparisons of median measures and interquartile range by diagnostic subgroup, age group and PTC status

	15 to 18 years								19 to 24 years							
	No PTC				PTC				No PTC				PTC			
	N	median	UCL-LCL	min-max	N	median	UCL-LCL	min-max	N	median	UCL-LCL	min-max	N	median	UCL-LCL	min-max
ALL	23	103	(55-164)	(2-273)	85	65	(52-79)	(5-378)	24	115	(59-147)	(1-320)	58	114	(96-131)	(25-215)
AML	15	101	(59-165)	(3-247)	38	112	(89-150)	(12-321)	36	110	(94-140)	(1-327)	42	105	(75-134)	(31-253)
Other leukaemias	8	47	(5-64)	(2-71)	16	66	(42-136)	(7-314)	15	24	(7-92)	(2-138)	15	48	(29-57)	(1-222)
HL	92	6	(4-7)	(1-101)	86	13	(9-17)	(1-167)	226	4	(3-5)	(1-511)	101	15	(9-25)	(1-234)
NHL	31	15	(10-36)	(1-259)	56	66	(53-83)	(3-206)	77	20	(10-33)	(1-192)	83	44	(32-60)	(1-145)
High grade Glioma	5	22	(3-70)	(3-70)	12	19	(17-39)	(5-69)	12	19	(6-34)	(2-54)	23	33	(15-44)	(5-91)
Low grade Glioma	27	15	(8-51)	(3-191)	32	11	(8-14)	(1-173)	37	14	(9-20)	(2-212)	38	15	(9-20)	(2-71)
Other CNS	43	8	(7-13)	(1-317)	90	13	(11-20)	(2-173)	80	10	(9-13)	(1-176)	126	12	(10-17)	(1-289)
Chondrosarcoma									9	10	(4-40)	(3-75)				
Ewing sarcoma					42	93	(83-105)	(43-212)					46	69	(62-82)	(22-186)
Osteosarcoma					44	114	(89-127)	(2-361)	5	45	(21-151)	(21-151)	39	112	(86-131)	(1-179)
Other bone					8	60	(22-123)	(17-130)					10	66	(23-92)	(14-130)
Fibrosarcoma									13	5	(2-11)	(1-51)	9	4	(3-8)	(2-30)
Other STS	12	5	(1-16)	(1-114)	32	43	(23-60)	(2-201)	23	7	(4-17)	(1-102)	59	28	(19-42)	(1-159)
Rhabdomyosarcoma					22	69	(30-84)	(25-176)					21	52	(30-81)	(10-243)
Gonodal germ cell males	37	2	(2-9)	(1-96)	51	16	(12-26)	(1-114)	213	3	(2-3)	(1-78)	207	11	(10-13)	(1-124)
Gonodal germ cell females	10	15	(5-25)	(2-30)	18	25	(23-27)	(18-77)	12	7.5	(5-20)	(4-30)	15	30	(22-39)	(8-147)
Non-gonodal germ cell					23	15	(10-67)	(3-128)	8	39	(17-81)	(14-92)	25	24	(15-54)	(6-136)
Melanoma	23	2	(1-5)	(1-11)	10	7	(2-15)	(1-65)	80	3	(2-5)	(1-66)	36	5	(3-7)	(1-47)
Skin carcinomas	7	2	(1-13)	(1-15)					19	2	(1-3)	(1-6)	8	4	(2-33)	(1-68)
Carcinoma of non-thyroid head and neck	20	6	(3-9)	(1-39)	9	29	(6-69)	(2-172)	33	6	(3-11)	(1-65)	18	17	(10-50)	(2-98)
Carcinoma of the breast									26	7	(6-10)	(3-43)	13	10	(6-24)	(2-40)
Carcinoma of the GI tract	18	8	(3-11)	(1-93)	16	40	(27-68)	(2-134)	83	18	(12-22)	(1-159)	38	30	(20-38)	(4-188)
Carcinoma of the GU tract females	13	6	(4-11)	(3-25)	15	8	(5-56)	(2-100)	96	7	(7-8)	(1-131)	63	10	(7-15)	(2-131)
Carcinoma of the GU tract males									9	9	(6-32)	(4-57)				
Carcinoma of the thyroid	14	8	(5-12)	(2-28)	31	9	(7-11)	(4-19)	75	8	(7-9)	(1-43)	78	9	(7-10)	(2-91)
Carcinoma of the trachea, bronchus, lung and pleura									7	17	(9-48)	(8-53)	5	17	(9-119)	(9-119)
Other carcinomas					8	32	(11-64)	(10-65)	9	18	(4-49)	(3-57)	14	32	(15-93)	(1-165)
Other neoplasms	5	2	(1-52)	(1-52)	8	75	(31-99)	(31-99)	16	15	(4-36)	(1-118)	14	35	(9-46)	(1-227)

** Sub-groups with less than 5 cases have been suppressed*

*** High grade glioma comprises glioblastomas and anaplastic astrocytomas and oligodendrogliomas with histological code 94513. Low grade glioma comprises pilocytic astrocytomas, other low grade astrocytomas and astrocytomas NOS plus oligodendrogliomas with histological ICD-0 code M94500 or M94503*

DISCUSSION

Main finding of this study

By the end of 2005, half of all TYA patients in England were receiving at least some treatment as an in-patient within a hospital trust that is now a principal treatment centre (PTC). Our data suggest that the reasons why 50% of TYA cancer patients were not being admitted to these PTCs for treatment, prior to the introduction of the CYPIOG are complex but not random. The clearest indicators are age and diagnosis. Younger patients, up to the age of 18, were more likely to be admitted to one of PTC hospital trusts than their older counterparts, irrespective of diagnosis. However, even among the younger age group, only 64% of 15 to 18 year olds were admitted to a PTC for treatment. The only diagnoses where PTC admittance varied by gender was among soft tissue sarcoma patients within the 19 to 24 year age group where the proportion of admittance to a PTC was greater in males. The relationship between region, socio-demographic status and PTC admittance is unclear but likely to be inter-correlated with region of residence and regional deprivation quintiles as well as other factors such as how historical referral practices, ease of access to the PTC and how that varied by deprivation quintile within each region. For this study, we used national IMD deprivation quintiles but these may cloak within-region socio-demographic effects. Further analyses based on regional deprivation quintiles will be undertaken later this year as part of a project to look at current TYA patient management post IOG implementation.

Our examination of bed usage showed that time spent as an in-patient was largely dependent upon diagnosis although there was substantial variation in bed day use within the diagnostic groups themselves and also differences between age groups for some diagnostic sub-groups. There was also variation between PTC and non-PTC patients for some diagnostic sub-groups with PTC patients spending more bed days as in-patients than non-PTC patients. One possible explanation for this observation is that patients with more advanced stage disease or with complex associated problems were more likely to be admitted to a PTC. Alternatively, PTCs may have had a greater tendency to admit for longer. Data on stage at diagnosis will allow further interrogation of these differences.

Survival rates for the main childhood cancers have steadily improved over the last 20 years, a positive trend that has been correlated with the introduction of specialist paediatric cancer centres. A study by Whelan and colleagues (Whelan *et al.* 2007) concluded that in the South East of England, many young people with cancer were not being referred to services that are likely to be able to provide both clinical expertise in the treatment of their tumour type and support tailored to the needs of their age group.

We have been able to extend this assessment to the whole of England and bring the assessment up to the point when the provision of specialist cancer services for TYA patients was made national policy. We have here provided a set of baseline data, against which services commissioners can measure the process of TYA specialist service implementation. The results provide some insight into which groups of TYA cancer patients are most at risk of not accessing the specialist services that are available to them and also provide a means of predicting how the distribution of service delivery and resource requirement is likely to change over time.

Limitations of this study

Undertaking a retrospective study of patient services based on in-patient admission data poses several major challenges. Patients who received treatment only as outpatients were not accounted for at all. Thus, PTC patients whose PTC-led treatment was outpatient-based but whose in-patient admissions may have occurred with the agreement of PTC and non-PTC clinicians at a local, non-PTC hospital would not be recognised as PTC patients by our analyses. Variable coding of day-case treatment as in-patient or outpatient may have caused additional discrepancies. Furthermore, the data available did not allow differentiation of how services were configured within the PTC trusts, for instance whether PTC patients were admitted to the specialist unit or to a general ward, without age-specific expertise within the same trust Therefore we were able to say only whether the patient had the potential of being treated within a PTC TYA unit.

Some age-related variation in in-patient versus outpatient treatment would be due to differences in ‘paediatric’ and ‘adult’ treatment protocols. For example, ‘paediatric’ protocols for non-Hodgkin lymphoma generally require in-patient chemotherapy, while 'adult' chemotherapy protocols for the same, or similar, diseases may be exclusively out-patient.

Disease stage at diagnosis and disease progression within the first 12 months of diagnosis may have contributed to the variation in place of treatment and bed usage that we observed within our study population. However, we were unable to test the degree of this influence quantitatively. Stage data captured as part of the cancer registration process during this study period were insufficiently complete to include this variable in our analysis.

Finally, as acknowledged by Whelan et al (2007), we have not been able to account for patient choice. Some 19 to 24 year olds opt not to be admitted to age-appropriate facilities or to a centre with age-specific expertise for their treatment. The factors that contribute to such choices are complex and largely unknown.

Future Work

We are continuing to monitor referrals to TYA specialist care and are looking at what socio-demographic and diagnostic groups are being slowest to respond to the availability of TYA specialist care. We will assess further the relationship between referral to a regional TYA MDT and place of treatment, looking at how time spent as an in-patient is distributed between the PTC and local shared care facilities As more data become available we will also be able to assess the impact of TYA specialist care on outcomes and including an assessment of disease stage in our evaluations.

We are also currently developing a process to inform cancer networks and regional commissioning groups about the level of TYA referrals in their regions, helping them to identify those trusts whose patients are not been referred to a specialist TYA MDT and providing data to feed into peer review measures.

We also plan to investigate possible explanations for the apparent differences in bed day use between PTC patients and non-PTC patients, focusing particularly on time from diagnosis to first admission, number of re-admissions and time between admissions and also records of other conditions.

For more information about the work we are currently undertaking at NWCIS on cancer in teenagers and young adults please visit our website www.nwcis.nhs.uk or contact us at info@nwcis.nhs.net.

ACKNOWLEDGEMENTS

Thanks are due to all the Cancer Registry Directors in England for sharing their data with us prior to the development of the national cancer data repository and to the Informatics team at Thames Cancer registry for kindly providing their services in linking the cancer registry data with HES data. We are also very grateful to Jill Birch and Robert Alston (CRUK Paediatric and Familial Cancer Research Group) for sharing their expertise and classification system with us and also to Charles Stiller (CCRG) for his valuable advice on the analyses and content. Thanks are also due to the NCIN children's, teenagers and young adults clinical reference group (CTYA CRG), and NWCIS' TYA advisory group, in particular to the CTYA CRG Chair, Mike Stevens, and the TYA Advisory Group Chair, Jeremy Whelan, for their review of the report. Much appreciation is further extended to NWCIS' Research and Intelligence Team for help in putting the report together. Finally, we gratefully acknowledge the support of the Teenage Cancer Trust (TCT) and TYAC.

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Appendix 1: Diagnostic Groups (after Birch et al. 2002 – updated to version 12)

Diagnostic Code	Diagnostic Group
GROUP 1: Leukaemias	
1.1.	Acute lymphoid leukaemia (ALL)
1.2.	Acute myeloid leukaemia (AML)
1.3.	Chronic myeloid leukaemia (CML)
1.4.	Other and unspecified leukaemia (Other Leuk)
1.4.1.	Other and unspecified lymphoid leukaemias
GROUP 2: Lymphomas	
2.1.	Non-Hodgkin lymphoma (NHL)
2.1.1.	Non-Hodgkin lymphoma, specified subtype
2.1.2.	Non-Hodgkin lymphoma, subtype not specified
2.2.	Hodgkin lymphoma (HL)
2.2.1.	Hodgkin lymphoma, specified subtype
2.2.2	Hodgkin lymphoma, subtype not specified
GROUP 3: Central Nervous System & other Intracranial & Intraspinal Neoplasms (CNS tumours)	
3.1.	Astrocytoma
3.1.1.	Pilocytic astrocytoma
3.1.2.	Other low grade astrocytoma
3.1.3.	Glioblastoma and anaplastic astrocytoma
3.1.4.	strocytoma not otherwise specified
3.2.	Other gliomas
3.2.1.	Oligodendroglioma
3.2.2.	Other specified glioma
3.2.3	Glioma NOS
3.3.	Ependymoma
3.4	Medulloblastoma and other primitive neuroectodermal tumours
3.4.1	Medulloblastoma
3.4.2	Supratentorial PNET.
3.5.	Other specified intracranial and intraspinal neoplasms (Other CNS)
3.5.1	Craniopharyngioma
3.5.2	Pituitary tumours
3.5.3	Pineal tumours
3.5.4	Choroid plexus tumours
3.5.5	Meningioma
3.5.6	Nerves sheath tumour of the brain
3.5.7	Other specified tumours
3.6	Unspecified intracranial and intraspinal neoplasms tumours
3.6.1.	Unspecified malignant intracranial and intraspinal neoplasms
3.6.2.	Unspecified non-malignant intracranial and intraspinal neoplasms
GROUP 4: Osseous and Chondromatous Neoplasms, Ewing tumour and other Neoplasms of Bone (Bone Tumours)	
4.1.	Osteosarcoma
4.2.	Chondrosarcoma
4.3.	Ewing sarcoma
4.3.1	Ewing sarcoma of bone
4.3.2	Extraskeletal Ewing sarcoma
4.3.3	Ewing sarcoma of unknown site
4.4.	Other specified and unspecified bone tumours (Other bone tumours)
4.4.1.	Other specified bone tumours
4.4.2.	Unspecified bone tumours

GROUP 5: Soft Tissue Sarcomas (STS)

5.1.	Fibromatous neoplasms (Fibrosarcoma)
5.1.1.	Fibrosarcoma
5.1.2.	Malignant fibrous histiocytoma
5.1.3.	Dermatofibrosarcoma
5.2.	Rhabdomyosarcoma
5.3.	Other specified soft tissue sarcomas
5.3.1.	Liposarcoma
5.3.2.	Leiomyosarcoma
5.3.3.	Synovial sarcoma
5.3.4	Clear cell sarcoma
5.3.5	Blood vessel tumours
5.3.6	Nerve sheath tumours
5.3.7	Alveolar soft part sarcoma
5.3.8	Miscellaneous specified soft tissue sarcoma
5.4	Unspecified soft tissue sarcomas

GROUP 6: Germ Cell & Trophoblastic Neoplasms (Germ cell tumours)

6.1	Gonadal germ cell & trophoblastic neoplasms
6.2	Germ cell & trophoblastic neoplasms of non-gonadal sites
6.2.1.	Intracranial germ cell and trophoblastic tumours
6.2.2.	Other non-gonadal germ cell and trophoblastic tumours

GROUP 7: Melanoma and Skin Carcinoma

7.1.	Melanoma
7.2.	Skin carcinoma

GROUP 8: Carcinomas (except of skin)

8.1.	Carcinoma of thyroid
8.2.	Other carcinoma of head and neck
8.2.1.	Nasopharyngeal carcinoma
8.2.2.	Carcinoma of other sites in lip oral cavity and pharynx
8.2.3.	Carcinoma of nasal cavity, middle ear, sinuses, larynx and other ill-defined sites in head and neck
8.3.	Carcinoma of trachea, bronchus, lung and pleura
8.4.	Carcinoma of breast
8.5.	Carcinoma of genito-urinary (GU) tract
8.5.1.	Carcinoma of kidney
8.5.2.	Carcinoma of bladder
8.5.3.	Carcinoma of ovary
8.5.4.	Carcinoma of cervix
8.5.5.	Carcinoma of other and ill-defined sites in GU
8.6.	Carcinoma of gastro-intestinal (GI) tract
8.6.1.	Carcinoma of colon and rectum
8.6.2.	Carcinoma of stomach
8.6.3.	Carcinoma of liver and intrahepatic bile ducts
8.6.4.	Carcinoma of pancreas
8.6.5.	Carcinoma of other and ill-defined sites in GI tract
8.7.	Carcinomas of other & ill-defined sites not elsewhere classified (NEC)
8.7.1.	Adrenocortical carcinoma
8.7.2.	Other carcinomas NEC

GROUP 9: Miscellaneous Specified Neoplasms NEC

9.1.	Embryonal tumours NEC
9.1.1.	Wilms tumour
9.1.2.	Neuroblastoma
9.1.3.	Other embryonal tumours NEC
9.2	Other rare miscellaneous specified neoplasms
9.2.1.	Paraganglioma and glomus tumours
9.2.2.	Other specified gonadal tumours NEC
9.2.3.	Myeloma, mast cell tumours and miscellaneous reticuloendothelial
9.2.4.	Other specified neoplasms NEC

GROUP 10: Unspecified Malignant Neoplasms NEC

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The North West Cancer Intelligence Service (NWCIS) is the NCIN lead registry for cancer in teenagers and young adults in England. Our role is to provide a research and intelligence support function for the TYA cancer community. Dr Martin McCabe is a Clinical Senior Lecturer in Paediatric Oncology at The University of Manchester, and a member of the NCIN Children and TYA site specific clinical reference group (CTYA SSCRG) that supports NWCIS in its lead registry function.

NHS

North West Cancer Intelligence Service

NCIN national cancer intelligence network

Using information to improve quality & choice

The National Cancer Intelligence Network is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research. Sitting within the National Cancer Research Institute (NCRI), the NCIN works closely with cancer services in England, Scotland, Wales and Northern Ireland. In England, the NCIN is part of the National Cancer Programme.