

**Notifications of
teenagers and young adults with cancer to
a Principal Treatment Centre
2009-2010**

Children, Teenagers and Young Adults SSCRG

Notifications of teenagers and young adults with cancer to a Principal Treatment Centre 2009-2010

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Please note that on 1st April 2013 The North West Cancer Intelligence Service will transfer to Public Health England and TYA cancer intelligence work will be delivered jointly by the Knowledge and Intelligence Division and the National Cancer Intelligence Network

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Introduction

To help improve outcomes and patient experience for 16 to 25 year olds with cancer, the National Institute for Health and Clinical Excellence (NICE) published its Improving Outcomes Guidance for Children and Young People with Cancer (CYPIOG) in 2005⁽¹⁾ recommending the provision of age-appropriate care. Since then NHS Trusts in England have been working to implement these recommendations. Thirteen trusts in England have TYA principal treatment centre (PTC) status along with designated “shared care” institutions. TYA specialist care facilities should now be accessible by all TYA cancer patients, with those aged 16 to 18 years being managed at a PTC and those aged 19 to 24 years being assessed at a PTC and being given the choice of where they are treated.

This report provides the first robust examination of the actual number of patients in England diagnosed with cancer being notified to a principal treatment centre or Children’s Cancer and Leukaemia Group (CCLG)¹ centre in England. By matching TYAC notification data with the most current population based cancer registration data percentage notifications have been calculated for patients resident in England who were diagnosed 2009-2010. Characteristics and place of treatment of patients who have not been notified were also examined. These analyses were limited to patients resident in England as the level of patient identifiable data required for this analysis was not available for the other UK countries.

The original criterion for a PTC to submit a TYAC notification form to NWCIS for each TYA patient was that the patient had been notified to a specialist Teenage and Young Adult Multidisciplinary Team (TYA MDT) at the PTC. This criterion has been interpreted slightly differently from PTC to PTC but for the purposes of this report we have assumed

- 1) that each notification form received by NWCIS relates to a patient that the PTC is aware of,
- 2) that the patient has been discussed at the regional TYA MDT and
- 3) that the care pathway for that patient, including where they are treated, is ultimately the responsibility of the PTC.

The TYAC notification system was initiated and developed by founding members of Teenagers and Young Adults with Cancer (TYAC) in 2008. This system is similar to that managed by the Children’s Cancer and Leukaemia Group for paediatric cancer patients. At that time notification of new cancer cases and collation of regional cancer registrations into a national dataset was still a lengthy process.

¹ Where a patient aged 15 years or over is referred to a Children’s Cancer and Leukaemia Group (CCLG) centre, notifications are received by NWCIS for those patients either directly from the CCLG centre or via the Children’s Cancer Research Group (CCRG) in Oxford.

The aim of the notification system was to create a more timely method of identifying TYA patients, providing high quality diagnostic details, and identifying the institutions at which these patients were being managed. This process was designed to allow access to information to help inform assessments on how well the guidelines of the cancer reform strategy were being implemented for this age group. This process of notification, through the TYA principal treatment centres, helps us understand better where young people with cancer are treated and ultimately understand how different patient pathways influence outcomes.

As a member of TYAC and as the National Cancer Intelligence Network (NCIN) lead registry for cancer in teenagers and young adults North West Cancer Intelligence Service (NWCIS) was tasked with setting up a process of notification and began receiving notifications at the start of 2009.

Since 2009 NWCIS has received notifications of more than 3000 patients from the PTCs and CCLG centres. We are now able to use this information to inform regional cancer service providers on the number and proportion of patients who are being notified to PTCs and the proportion of patients who are not. Cancer service providers are then able to use this information to establish where improvements are needed for the process of referring patients to specialist care.

National cancer registration processes are currently undergoing a major programme of renovation and innovation, including the introduction of the cancer outcomes and services dataset⁽²⁾. The aim is to create a more efficient and more effective cancer registration system that will provide access to more timely and higher quality cancer data and intelligence. The TYAC notification process is expected to be superseded by this improved national cancer registration and will be phased out once the data are shown to be as timely and informative as those provided by the TYAC notification process. The process will be reviewed in March 2014. Until that time the TYAC notification process will continue to be the most important source of data for monitoring referrals to TYA specialist care in the UK.

Methods

Data included here were collected by each PTC, usually by or with support of the MDT coordinator. Data were submitted via secure email to NWCIS using the TYAC notification form. Once received, the data were collated into a national TYA database, which links data from the national cancer data repository (NCDR), Hospital Episode Statistics (HES), Cancer Waiting Times (CWT) and other available NHS data resources. The data were verified and quality assured and every six months PTCs were given the opportunity to check and resubmit their data as necessary.

Diagnostic groups

Diagnoses were categorised using specialist TYA diagnostic groupings⁽³⁾. Because of small numbers, the miscellaneous specified and unspecified groups have been combined into a single group.

Age groups

The Improving Outcomes Guidelines (IOG) for Children and Young Adults (2005) classifies paediatric patients as being up to and including age 15 years and sub-classifies teenagers and young adults as two groups, those aged 16 to 18 and those aged 19 to 24 years. However, 15 year olds are not included in the paediatric equivalent of this report produced annually by the Children's Cancer Research Group (CCRG) in Oxford. Therefore to ensure these patients are accounted for we have included them in this report along with the 16 to 18 year olds. TYAC notifications received for patients under the age of 15 years are forwarded to CCRG and appear in their annual reports. Patients aged 15 years and older that are notified to CCRG by CCLG centres are forwarded to NWCIS by CCRG and have been included in this report.

Geographies

Data are presented by area of patient residence. These have been aggregated to two levels 1) government office region (GOR) and 2) the cancer network areas as in existence at 31st December 2010.

Percentage Notifications

All TYAC notifications were matched against cancer registrations of all malignancies and all borderline or benign brain and CNS tumours among patients aged 15 to 24 years in England diagnosed 1st January 2009 to 31st December 2010. Using the 2010 NCDR⁽⁴⁾, we linked cancer registrations and TYAC notifications on NHS number, forename, surname, date of birth and postcode. Once all patients notified via the TYAC system had been matched to the national data, we categorised those patients who were and were not notified via the TYAC system by age, diagnosis and area of residence. A small number of notifications have been excluded as no cancer registration match could be found. This may be due to the patients' initial diagnoses at the time of notification being changed to a non-registerable diagnosis at a later date or that some information recorded was incorrect and prevented a match being found. Where there were discrepancies between data sources, the cancer registration data were taken as the primary source. Percentage notifications are presented as funnel plots by cancer network of residence using the Association of Public Health Observatories funnel plot templates⁽⁵⁾.

Non-notified patients

All patients who were diagnosed 2009-2010 for whom no TYAC notification form was received were matched to a subset of cancer waiting times (CWT) data that comprised all patients with a CWT decision to treat date between 1st January 2009 and the 31st December 2010. Each CWT treatment record contains information on the organisation at which a treatment starts and the treatment start date. If patients had treatments at more than one trust, we selected the first PTC trust to provide a treatment following diagnosis. If none of the trusts providing treatment was a PTC, we sorted the treatments by date of start of treatment and then allocated the patient to the first treating trust. Trusts were categorised as designated² and non-designated trusts. Designated status has been introduced only recently and was not in place at the time these patients were treated. Also for some regions the designation process is still ongoing. However, this categorisation is intended to serve as a guide to where the non-notified patients received treatment.

² *TYA designated hospitals are able to provide treatment to TYA patients aged 19 to 24 years who choose not to be treated at the PTC. These hospitals have agreed to work with the PTC and to undergo peer review when appropriate.*

Results

Key Points

- 62% of patients aged 15 to 18 years were notified by a PTC or CCLG centre, 34% of patients aged 19 to 24 years were notified.
- For 15 to 18 year olds percentage notifications ranged from 21% for skin carcinomas and melanomas to 87% for bone tumours. The pattern was the same for patients aged 19 to 24 years; 14% for skin carcinoma and melanoma patients to 69% for bone tumours.
- For patients aged 15 to 18 years the percentage of patients notified ranged from 48% to 74% across GORs and from 35% to 87% across cancer networks.
- For the 19 to 24 year olds percentage notifications ranged from 20% to 54% across GORs and from 6% to 70% across cancer networks.
- An additional 7% of patients who were not notified were identified as receiving treatment at a PTC.
- A large number of non-PTC trusts were recorded as treating non-notified patients.

During 2009 and 2010, 3,772 patients in England aged 15 to 24 years were newly diagnosed with a malignant tumour or borderline/benign CNS tumour. Of those aged 15 to 18 years, 62% were notified by a PTC. This compares with just 34% of patients aged 19 to 24 years. For both age groups, percentage notifications varied significantly by diagnosis (Figure 1).

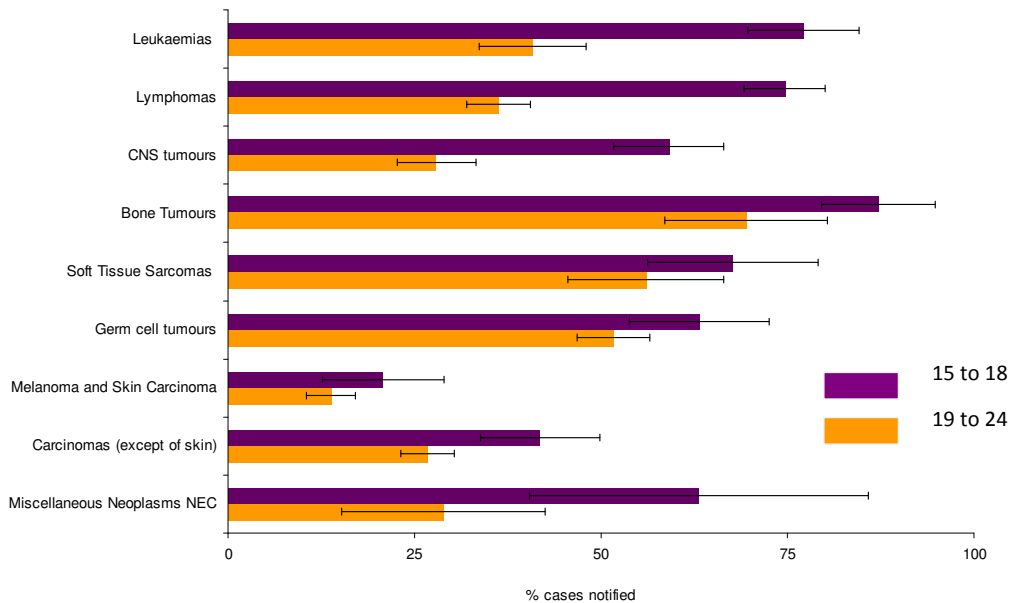


Figure 1: Percentage of patients diagnosed 2009-2010 who were notified by age group and diagnosis. Error bars represent 95% confidence intervals.

Differences by age

For each of the diagnostic groups, patients aged 15 to 18 years had higher percentage notifications than patients aged 19 to 24 years. These differences were statistically significant for all diagnostic groups except soft tissue sarcomas and skin carcinomas and melanomas. Despite carcinoma registrations being 3 times more common in the 19 to 24 age group than the 15 to 18 age group, percentage notifications were 15% lower in the older age group.

Differences by diagnosis

Within the 15 to 18 age group, percentage notifications ranged from 21% for skin carcinomas and melanomas to 87% for bone tumours. If skin carcinomas were excluded³ notifications for melanomas increased to 32% but remained the lowest of all diagnostic groups. The pattern was the same for patients aged 19 to 24 years; the lowest percentage notification was observed among skin carcinoma and melanoma patients (14%) and highest for bone tumour patients (69%). Notifications for melanoma patients in the 19 to 24 age group was 20%.

³ *Completeness of registrations of skin carcinomas may vary from region to region which in turn can affect percentage notifications*

Differences in percentage notifications between the leukaemia disease groups were not statistically significant for the 15 to 18 age group. For the 19 to 24 age group, percentage notifications for chronic myeloid leukaemia (CML) were significantly lower (9%) than for other leukaemias. For the 15 to 18 age group percentage notifications for Hodgkin lymphoma (HL) were statistically higher (78%) than for non-Hodgkin's lymphoma (NHL) (65%). Percentage notifications for HL (37%) and NHL (34%) were not significantly different for the 19 to 24 age group.

Within the CNS tumour group, patients with malignant tumours were more likely to be notified than patients with a borderline or benign tumour in both age groups:

- 15 to 18 year olds: 35% of borderline/benign CNS tumours
77% of malignant CNS tumours
- 19 to 24 year olds: 7% of borderline/benign CNS tumours
47% of malignant CNS tumours

For bone tumours, patients aged 19 to 24 years with a chondrosarcoma appeared less likely to be notified (17% notifications) than patients with other bone tumours (osteosarcomas 81% and Ewing tumours 77%) but the number of cases was very small (less than 5 cases per year). These differences were not apparent in the younger age group. In the 15 to 18 age group, patients with fibromatous neoplasms, including the borderline malignant desmoid fibromatoses, were less likely to be notified (33%) compared with rhabdomyosarcoma patients (86%) and patients with other soft tissue sarcomas (65%). A similar pattern was seen in the older age group (33% fibromatous neoplasm, 100% rhabdomyosarcomas and 57% for other STS). Again, the number of cases of fibromatous neoplasms was very small in both age groups. For germ cell tumours, among patients aged 15 to 18 years, extragonadal tumours had higher percentage notifications than gonadal tumours (90% vs 58%). A similar trend was seen in the older age group but the differences were not statistically significant (70% vs 51%).

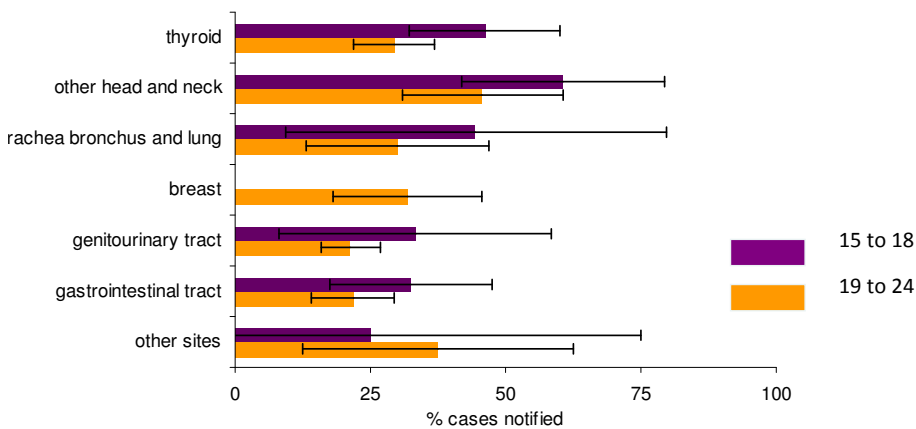


Figure 2: Percentage of carcinoma patients diagnosed 2009-2010 who were notified by age group and tumour site. Error bars represent 95% confidence intervals

Notification of carcinomas was generally poor (Figure 2) and, with the exception of non-thyroid head and neck carcinomas in 15 to 18 year olds, below 50%. Non-thyroid head and neck carcinomas had the highest percentage notifications in both age groups (61% for 15 to 18 year olds, 46% for 19 to 24 year olds). There were only 5 cases of breast carcinoma in the 15 to 18 age group, none of which were notified.

Differences by gender

There were no significant differences in percentage notifications among males and females except for carcinomas in the older age group (Figures 3 and 4) and of these only thyroid carcinomas had significantly higher percentage notifications in males than females. There were only 27 cases of thyroid carcinomas diagnosed in males aged 19 to 24, 2009-2010, half of which were notified. Among females of the same age there were 123 cases of thyroid carcinomas of which one quarter were notified.

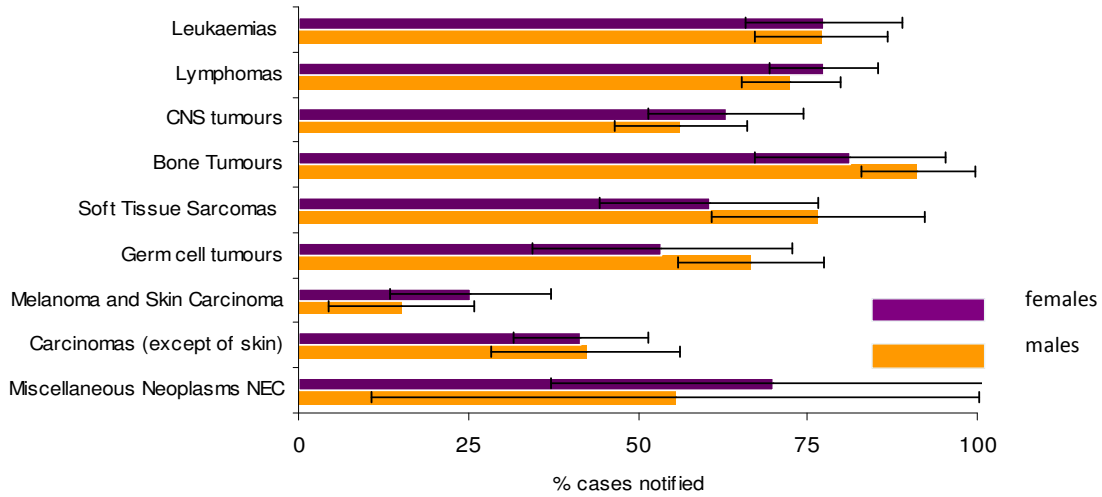


Figure 3 Percentage of patients aged 15 to 18 years diagnosed 2009-2010 who were notified by gender and diagnosis. Error bars represent 95% confidence intervals

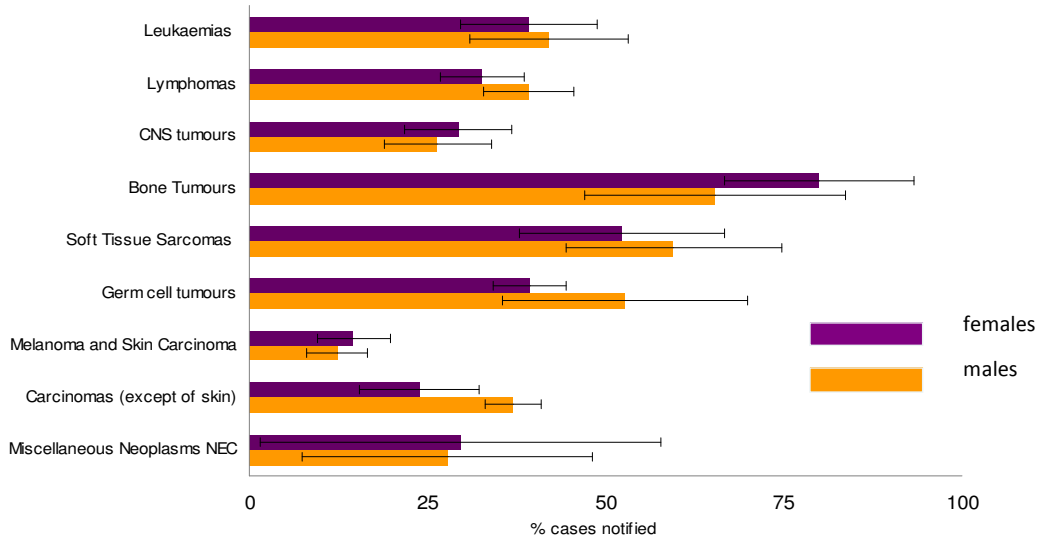


Figure 4 Percentage of patients aged 19 to 24 years diagnosed 2009-2010 who were notified by gender and diagnosis. Error bars represent 95% confidence intervals

Differences by area of residence

There was also considerable variation by area of residence for patients of both age groups diagnosed 2009-2010. This variation was more stark in the older age group. While the England average for patients aged 15 to 18 years was 62% the percentage of patients notified ranged from 48% to 74% between GORs (Figure 5). If skin carcinomas were excluded, percentage notifications ranged from 49% to 78%. The variation between cancer networks was greater than that between GORs, from 35% to 87% (Figure 6).

An even larger discrepancy in the proportions notified by area of residence was seen for the 19 to 24 year olds. Notifications ranged from 20% to 54% between GORs (Figure 6) and from 6% to 70% between cancer networks (Figure 6). If skin carcinomas were excluded the variation between GORs was 20% to 58% and between cancer networks 6% to 75%.

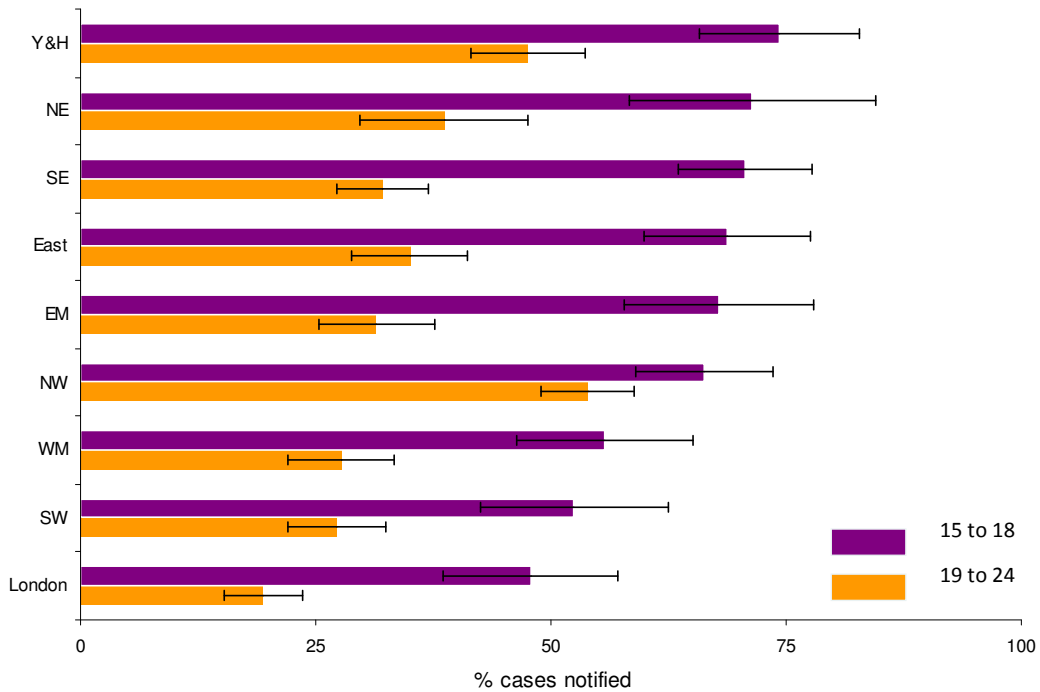
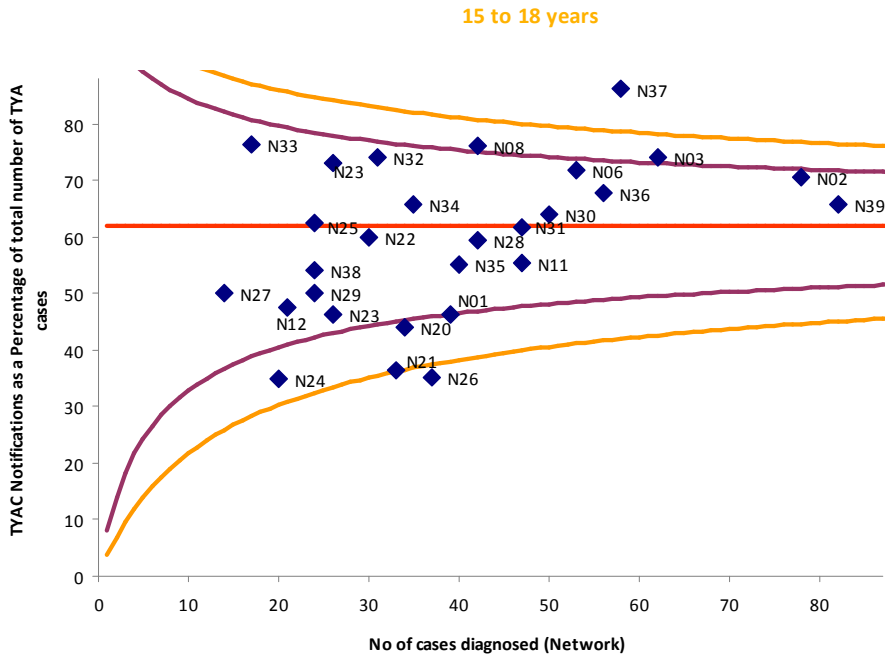


Figure 5 Percentage of patients diagnosed 2009-2010 who were notified by age group and government office region (GOR) of residence. Error bars represent 95% confidence intervals



Cancer networks in England					
N01	Lancashire and South Cumbria	N12	Arden	N26	Peninsula
N02	Greater Manchester and Cheshire	N20	Mount Vernon	N27	Dorset
N03	Merseyside and Cheshire	N21	West London	N28	Avon, Somerset and Wiltshire
N06	Yorkshire	N22	North London	N29	3 Counties
N07	Humber and Yorkshire Coast	N23	North East London	N30	Thames Valley
N08	North Trent	N24	South East London	N31	Central and South Coast
N11	Pan Birmingham	N25	Arden	N32	Surrey, West Sussex and Hampshire
				N33	Sussex
				N34	Kent and Medway
				N35	Greater Midlands
				N36	North of England
				N37	Anglia
				N38	Essex
				N39	East Midlands

◆ networks
 — Average
 — 2SD limits
 — 3SD limits

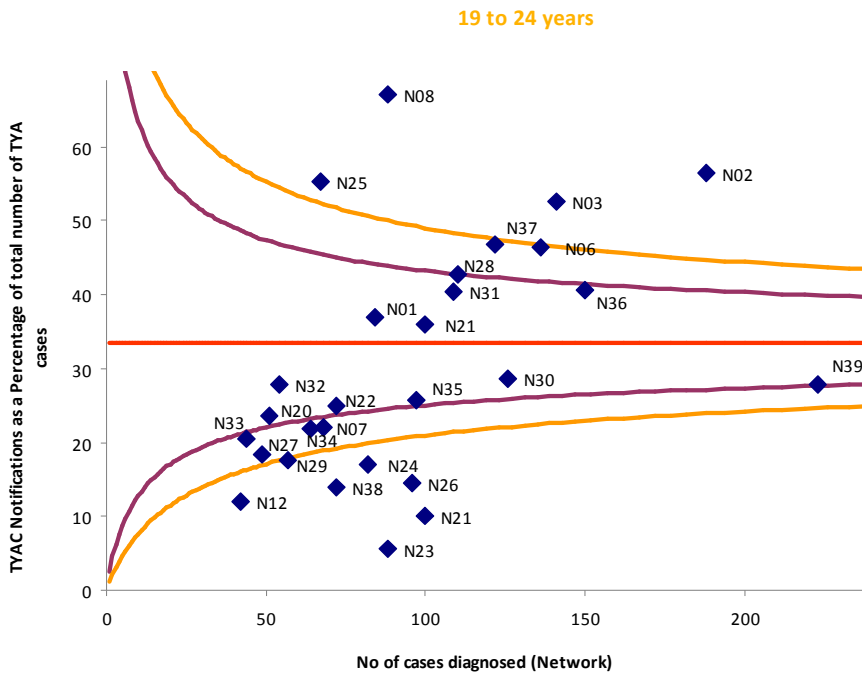
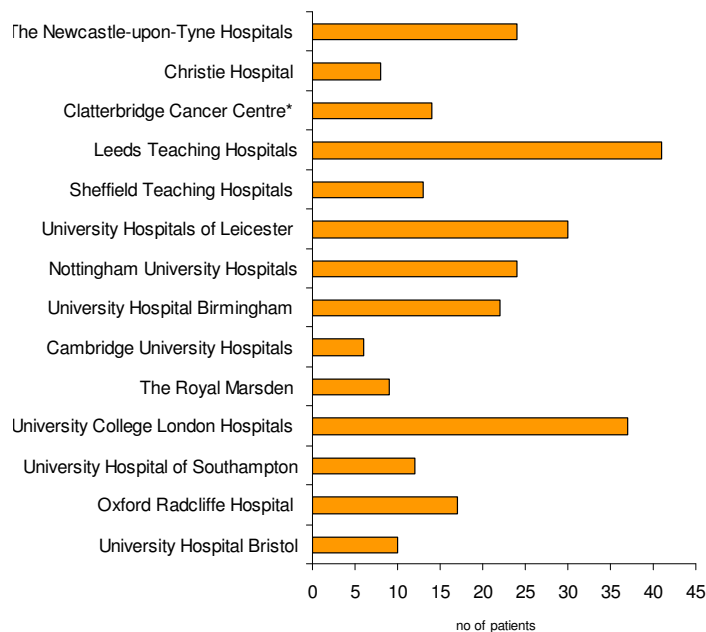


Figure 6 Percentage of patients aged 15 to 18 years and 19 to 24 years diagnosed 2009-2010 who were notified by cancer network of residence in England.

Analyses of non-notified patients

2197 of 3772 TYA patients diagnosed 2009-2010 in England were not notified to a PTC or, by assumption, to the regional TYA MDT: 415 were aged 15 to 18 and 1782 were aged 19 to 24. Of these, 218 of the 15 to 18 year olds and 1109 of the 19 to 24 year olds were matched to cancer waiting times (CWT) data.

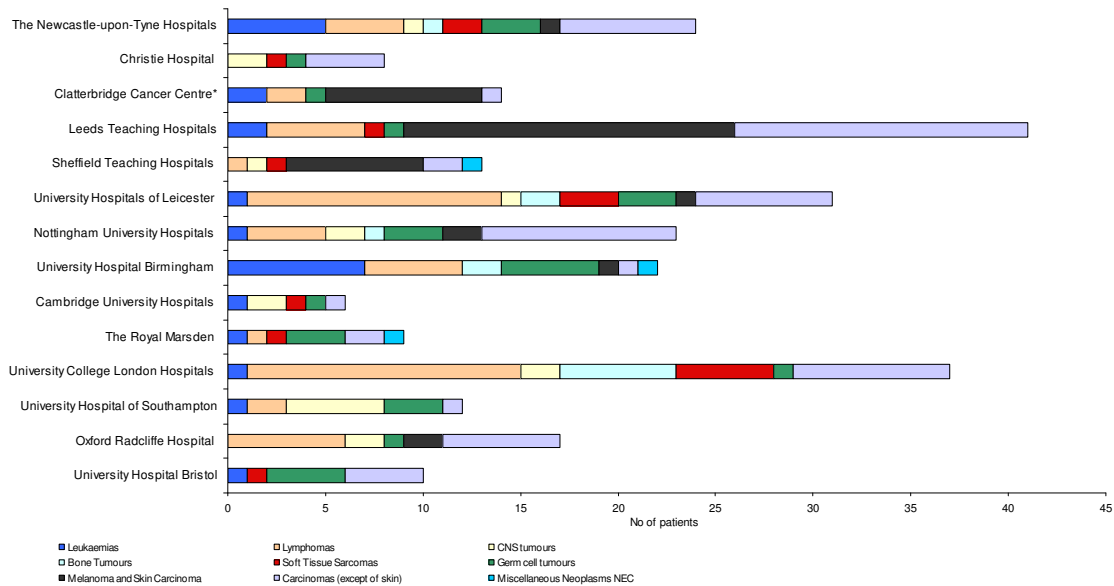
From the CWT data we identified all trusts recorded as providing treatment (using the organisation_code_treatment_start field) for each patient and identified which of these were PTCs. We found 268 non-notified patients who appeared to have received some treatment at a PTC. 55% of these were diagnosed in 2009 and 45% in 2010. 83% of the patients were aged 19 to 24 years. Figure 7 shows the number of non-notified patients diagnosed 2009-2010 who were treated at each of the PTCs. Figure 8 shows the diagnostic distribution of these patients. If these patients had been notified to the TYA MDT within that Trust and, by assumption, undergone TYAC notification, their inclusion would have increased the percentage notifications for 2009-2010 by 4% to 66% for 15 to 18 year olds and by 7% to 41% for 19 to 24 year olds.



* includes Alder hey and The Royal Liverpool Hospital patients

† University of Leicester and Nottingham University Hospitals act together as the Teenage and Young Adult East Midlands Integrated Cancer Service

Figure 7 Number of patients aged 15 to 24 years diagnosed 2009 to 2010 who were treated at each PTC and not notified



* includes Alder hey and The Royal Liverpool Hospital patients

† University of Leicester and Nottingham University Hospitals act together as the Teenage and Young Adult East Midlands Integrated Cancer Service

Figure 8 Number of patients aged 15 to 24 years diagnosed 2009 to 2010 who were treated at a PTC and not notified by diagnosis and treating PTC

1059 patients were not notified and were identified, using CWT data, as having treatment within a trust that is not a PTC. Figures 9 A and B show the number of patients treated at each of these non-PTC trusts (each patient being allocated to a single trust only – being matched to the first treating trust by date of start of treatment). Trusts were categorised as designated⁴ and non-designated trusts. Designated status has been introduced only recently and was not in place at the time these patients were treated. The designation process is still ongoing in some regions. This categorisation is presented as a guide to where these non-notified patients received treatment.

Non-notified TYA patients received treatment at a large number of trusts across all of the regions, with non-PTC trusts treating between 1 and 40 patients each. Most of the treatments recorded were surgery (52%), cytotoxic chemotherapy (31%) and external beam radiotherapy (9%). Other treatments recorded for between 2 and 17 patients were brachytherapy, radiofrequency ablation, hormone therapy and other drugs, chemoradiotherapy, palliative care and active monitoring. “Other treatment” was recorded for 8 patients.

⁴ TYA designated hospitals are able to provide treatment to TYA patients aged 19 to 24 years who choose not to be treated at the PTC. These hospitals have agreed to work with the PTC and to undergo peer review when appropriate.

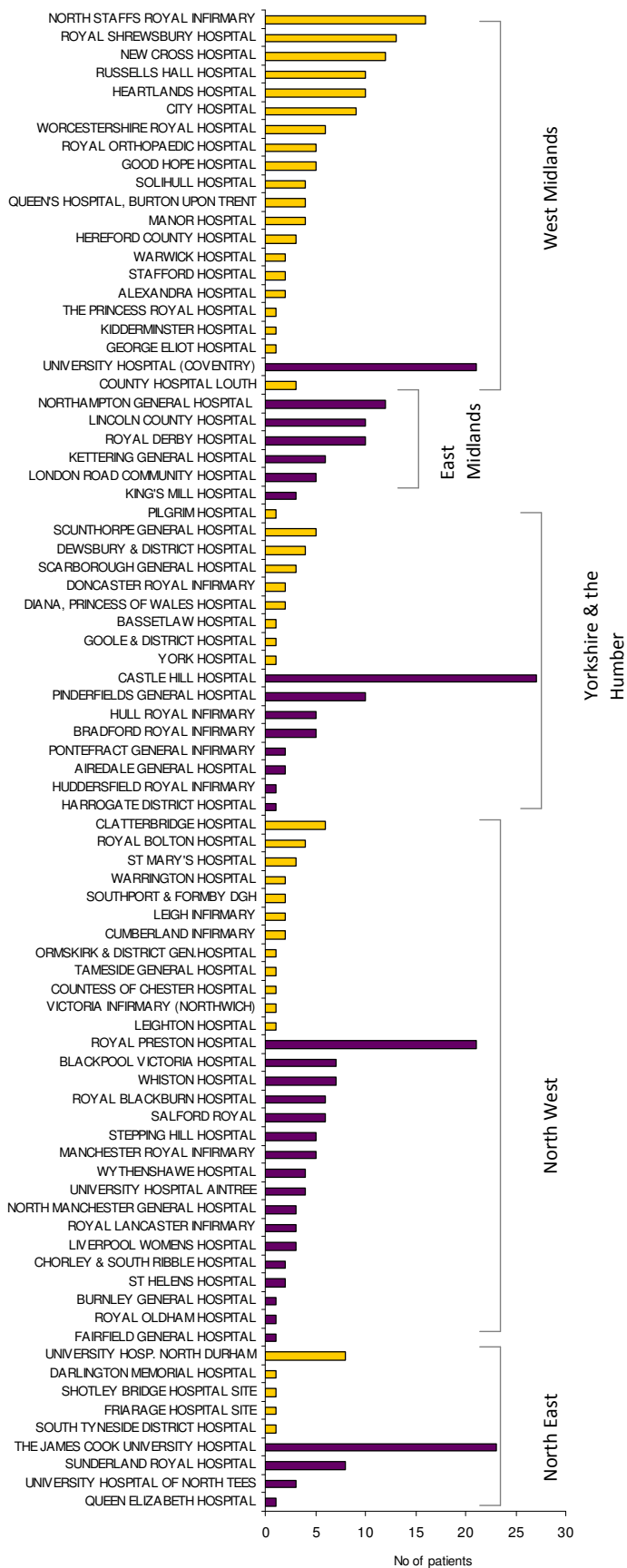


Figure 9A: Number of TYA patients who were diagnosed 2009-2010 and not notified and who were matched to CWT by treating hospital. Designated hospitals working alongside the PTC shown as purple bars. Orange bars are non-designated hospitals. Hospitals have been grouped by region of the trust.

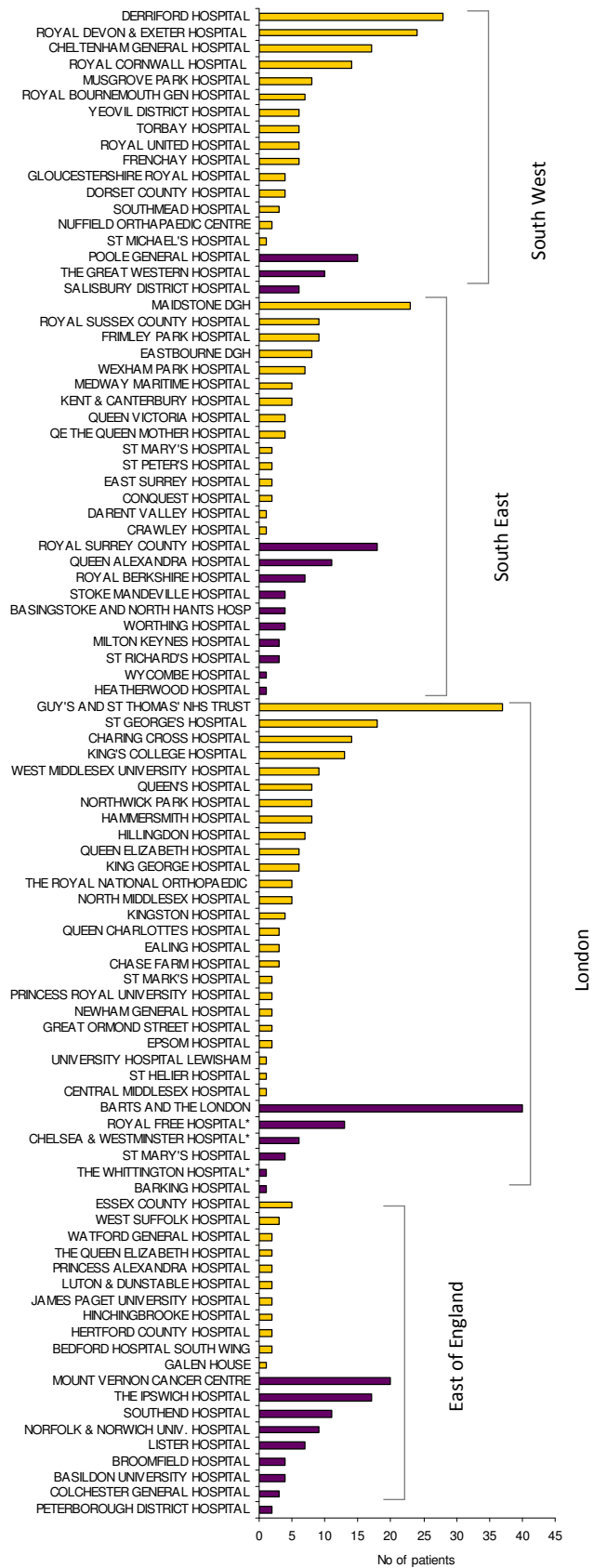


Figure 9B: Number of TYA patients who were diagnosed 2009-2010 and not notified and who were matched to CWT by treating hospital. Designated hospitals working alongside the PTC shown as purple bars (those marked with an asterisk offer limited services). Orange bars are non-designated hospitals. Hospitals have been grouped by region of the trust.

870 TYA patients diagnosed 2009-2010 were not notified and their treatment was not recorded in cancer waits treatment data. For some patients no treatment may have been required. In both age groups the majority of these were CNS tumour, carcinoma or melanoma patients (Figure 10).

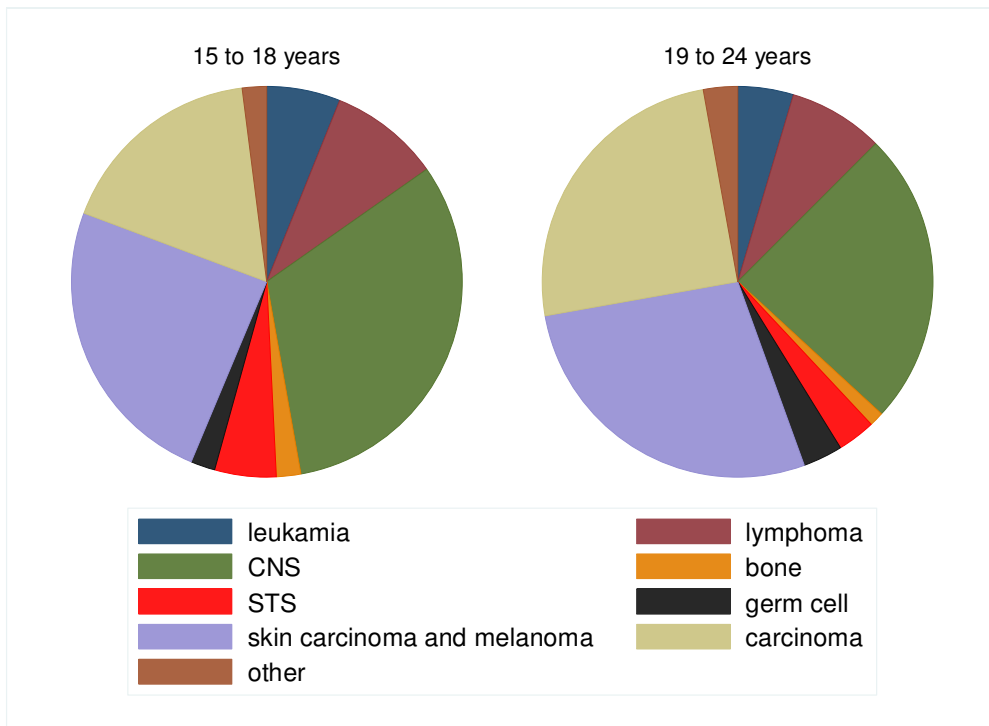


Figure 10: Diagnostic distribution of non-notified TYA patients diagnosed 2009-2010 who were not matched to CWT data by age at diagnosis.

Figure 11 shows the age distribution of these patients and Figure 12 shows the geographical distribution of patient residence. The percentage of non-notified patients who were not recorded in CWT data decreased with age from 66% to 36%. The percentage of non-notified patients who were not included in the CWT data ranged across government office regions from 30% to 53%.

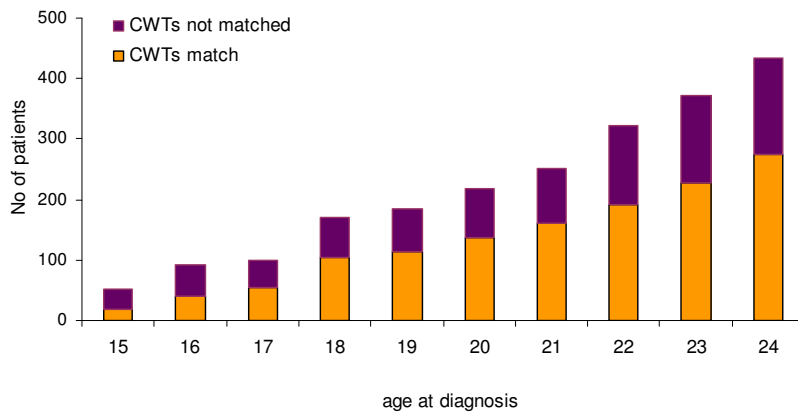


Figure 11: Number of non-notified TYA patients diagnosed 2009-2010 who were matched to CWT data by age at diagnosis.

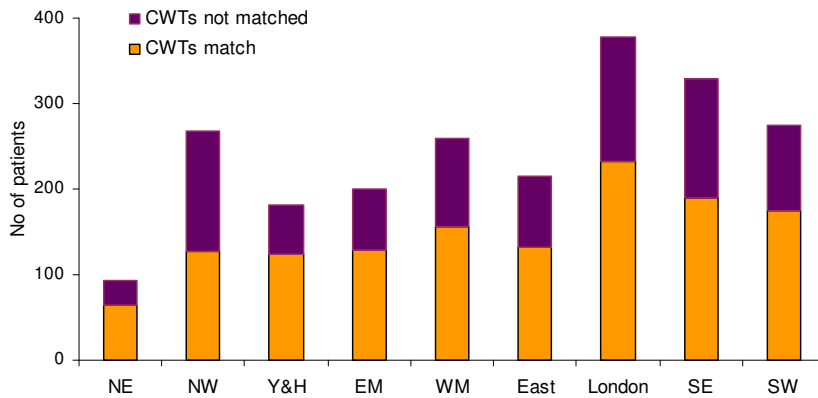


Figure 12: Number of non-notified TYA patients diagnosed 2009-2010 who were matched to CWT data by government office region of residence.

NWCIS, over the coming year, will match these patients to hospital episode statistics (HES) data to identify where these patients received treatment, if at all, and to try to establish their referral pathways. We will also match the patients to the routes to diagnosis dataset⁽⁶⁾ to identify how these patients were referred for diagnosis. These extra analyses will hopefully provide a more complete picture of patient pathways for teenagers and young adults. We will also extend this work to include patients diagnosed in 2011.

Discussion

The Improving Outcomes Guidelines for children and young adults (CYPIOG), published in 2005, resulted in the establishment of 13 principal treatment centres (PTCs) in England. All 16 to 18 year olds with cancer should be referred to the PTC and treatment delivered at the PTC. Patients aged 19 to 24 years should have their care discussed within the PTC but may make an informed choice of their place of care, either at a PTC or at a designated hospital fulfilling certain criteria recently defined in the TYA cancer measures.

The TYAC notification process was set up to help monitor the implementation of these guidelines and here we present the first population based assessment of the proportion of teenagers and young adults with cancer who were notified to a principal treatment centre in England. By linking data on patients notified with cancer registration data we have for the first time, been able to accurately identify those patients who were not notified. In addition by utilising additional routine NHS data sources, we have been able to identify where some of the non-notified patients received treatment.

The most significant findings of this report were 1) that the proportion of cancer patients in England aged 15 to 18 years diagnosed in 2009-2010 notified to a PTC was almost twice that of patients aged 19 to 24 years and 2) that percentage notifications varied across cancer networks by more than 50% for both age groups. We also identified just under 270 patients who appeared to have been treated at a PTC without being notified. One possibility for this is that PTCs did not complete TYAC notification forms for all patients that had been referred to the TYA MDT. A small audit was carried out on 86 cases at three PTCs. This revealed that while notifications were missing for some patients who had been referred to a TYA MDT, approximately half of these cases were confirmed as not having been referred to the TYA MDT. Fifteen of these cases were melanoma patients and 4 were skin carcinomas.

We also identified the treating trusts for around 1930 other non-notified patients. This work highlights the number of different trusts that TYA patients attended for treatment during the period investigated and the number of patients treated at each of the trusts, both designated and non-designated. The trust of treatment for 870 cases could not be identified. The majority of these patients had CNS tumour, carcinoma and melanoma diagnoses. Not all disease types are recorded in cancer waiting times data and further work is underway to locate the place of treatment for these patients using additional data sources such as hospital episode statistics data. Improved cancer registration data via the cancer outcomes and services dataset will also allow us to identify more readily where patients were diagnosed and any treatment received as outpatients.

In 2012, we published a report that investigated place of treatment for patients diagnosed 2003-2005⁽⁷⁾. We found that for this period, prior to the introduction of the CYPIOG, half of all TYA patients in England received at least some treatment as an inpatient within a hospital trust that is now a principal treatment centre (PTC). Although not directly comparable, the pattern of results presented in

this report is not dissimilar to those reported in 2012. In 2003-2005, 64% of patients aged 15 to 18 years were treated as inpatients within a PTC compared with 46% of patients aged 19 to 24 years. Similar to the results reported here, higher proportions of bone tumour patients in 2003-2005 of both age groups were treated within a PTC than any other diagnostic group. Also, in 2003-2005 males with soft tissue sarcomas were more likely to be treated within a PTC than females. The main difference between the 2012 report and this current report is the former included only those patients that had a record of treatment as an inpatient, whereas this report covers the entire TYA cancer population. We plan to repeat the inpatient place of treatment analyses for 2009-2010 patients. We will also use the CWT and hospital episodes statistics data to verify primary place of treatment recorded in the TYAC notification data.

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%⁽⁸⁾. 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^(9,10,11,12). It is hoped that the introduction of centralised care for 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. 25% of the TYA notified patients in England diagnosed with leukaemia, lymphoma, or CNS, bone/soft tissue and germ cell tumours in 2009-2010 were recorded as recruited to a clinical trial – slightly less than the 29% of all TYA patients reported in 2012 by Fern et al⁽¹³⁾. Further work is needed to verify the completeness of our data presented here.

Future Work

We intend to make wider use of data linkage capabilities between TYAC notification data and other NHS data sources to understand more fully the patient pathway of TYA notified and non-notified patients e.g. treatment received, time spent as inpatients and time between inpatient episodes and ultimately outcomes.

National cancer registration processes and the way cancer intelligence is delivered are currently undergoing a major programme of renovation and innovation. This programme is expected to broaden and strengthen the type of data and intelligence accessible to the cancer community thus contributing further to evidence-based decision making around cancer services. The Intelligence team at NWCIS under NCIN and the new Knowledge and Intelligence division of Public Health England will continue to deliver this intelligence service for cancer in teenagers and young adults.

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

We are grateful to the TYAC Board for their support of this work and to members of both the NCIN children's, teenagers and young adults clinical reference group (CTYA CRG), and NWCIS' TYA advisory group, for their helpful comments. We offer extended thanks to Jill Birch and Robert Alston (CRUK Paediatric and Familial Cancer Research Group) for sharing their expertise and classification system with us. 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 Teenage Cancer Trust (TCT) and Clic Sargent.

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Appendix

Table 1: Percentage of TYA patients diagnosed 2009-2010 who were notified by age group and diagnosis group

Diagnostic group	15 to 18			19 to 24		
	% notifications	95% CIs		% notifications	95% CIs	
Leukaemias	76.4	69.0	83.8	40.9	33.8	47.9
Lymphomas	74.6	69.4	79.9	36.3	32.1	40.5
CNS tumours	76.5	68.2	84.8	28.1	22.8	33.3
Bone Tumours	87.2	79.7	94.7	69.4	58.7	80.2
Soft Tissue Sarcomas	67.6	56.4	78.9	56.0	45.8	66.3
Germ cell tumours	62.9	53.6	72.2	51.7	46.9	56.5
Melanoma and Skin Carcinoma	20.8	12.8	28.8	13.8	10.6	17.0
Carcinomas (except of skin)	41.8	34.0	49.7	26.8	23.3	30.3
Miscellaneous Specified Neoplasms	64.3	38.2	90.4	30.3	14.4	46.2
Miscellaneous Unspecified Neoplasms	60.0	11.9	108.1	25.0	0.0	50.6
All tumour sites	62.0	59.1	64.9	33.5	31.7	35.3

Table 2: Percentage of TYA patients diagnosed 2009-2010 who were notified by age group and disease type

	15 to 18			19 to 24		
	% notifications	95% CIs		% notifications	95% CIs	
ALL	85.2	76.2	94.3	58.7	46.4	71.1
AML	66.7	52.1	81.2	39.4	27.9	51.0
CML	64.3	38.0	90.6	9.1	0.0	19.1
other leukaemias	90.0	70.2	100.0	42.1	19.1	65.1
NHL	65.1	53.2	77.0	34.0	26.4	41.6
HL	77.6	71.8	83.4	37.3	32.2	42.3
borderline/benign CNS	35.1	24.1	46.2	6.6	2.4	10.8
malignant CNS	76.5	68.1	84.8	46.8	38.8	54.7
osteosarcoma	90.0	78.9	101.1	80.6	66.3	95.0
chondrosarcoma	75.0	25.2	124.8	16.7	0.0	49.9
ewings sarcoma	94.6	100.0	0.0	76.7	61.0	92.3
other bone tumours	42.9	2.6	83.1	20.0	0.0	59.9
fibromatous neoplasms	33.3	0.1	66.6	33.3	13.8	52.9
rhabdomyosarcoma	86.4	71.4	100.0	100.0		
other specified STS	76.2	57.2	95.2	52.6	36.3	68.9
unspecified STS	50.0	24.2	75.8	66.7	44.0	89.4
gonadal germ cell	57.5	46.9	68.0	50.8	45.8	55.7
extra-gonadal germ cell	89.5	75.1	100.0	70.0	49.3	90.7
Carcinomas						
thyroid	46.2	32.4	59.9	29.3	22.0	36.7
other head and neck	60.7	42.1	79.3	45.7	31.1	60.2
trachea bronchus and lung	44.4	9.7	79.2	30.0	13.3	46.7
breast				31.9	18.4	45.4
genitourinary tract	33.3	8.4	58.2	21.4	15.9	26.9
gastrointestinal tract	32.5	17.7	47.3	21.7	14.2	29.3
other sites	25.0	0.0	74.4	37.5	13.0	62.0

Table 3: Percentage of TYA patients diagnosed 2009-2010 who were notified by age group, gender and diagnosis group

Diagnostic group	Males			Females			
	15 to 18 years	% notifications	95% CIs	% notifications	95% CIs		
Leukaemias		77.0	67.4	86.7	77.4	66.0	88.7
Lymphomas		72.5	65.4	79.7	77.5	69.7	85.3
CNS tumours		56.3	46.7	65.9	63.0	51.9	74.2
Bone Tumours		91.3	83.1	99.5	81.3	67.5	95.0
Soft Tissue Sarcomas		76.7	61.3	92.1	60.5	44.8	76.3
Germ cell tumours		66.7	56.1	77.2	53.6	34.7	72.4
Melanoma and Skin Carcinoma		15.2	4.7	25.7	25.5	13.8	37.1
Carcinomas (except of skin)		42.3	28.7	55.9	41.6	31.9	51.3
Miscellaneous Neoplasms		55.6	21.1	90.0	70.0	40.0	100.0
all tumour sites		63.8	59.9	67.7	59.9	55.6	64.2

Diagnostic group	Males		Females				
	19 to 24 years	% notifications	95% CIs	% notifications	95% CIs		
Leukaemias		42.1	32.7	51.5	39.2	28.4	50.1
Lymphomas		39.1	33.4	44.9	32.7	26.6	38.9
CNS tumours		26.4	19.1	33.8	29.3	22.0	36.6
Bone Tumours		65.4	52.3	78.4	80.0	62.0	98.0
Soft Tissue Sarcomas		59.6	45.4	73.8	52.3	37.3	67.2
Germ cell tumours		52.7	47.7	57.8	39.4	22.5	56.3
Melanoma and Skin Carcinoma		12.4	7.4	17.3	14.7	10.6	18.8
Carcinomas (except of skin)		37.0	28.9	45.2	23.9	20.1	27.7
Miscellaneous Neoplasms		27.8	49.1	90.0	29.6	12.1	47.2
all tumour sites		39.9	37.3	42.5	27.2	24.8	29.5

Table 4: Percentage of TYA patients diagnosed 2009-2010 who were notified by age group, and government office region (GOR) of residence

region	% notifications	15 to 18		19 to 24		
		% notifications	95% CIs	% notifications	95% CIs	
NE	71.4	58.6	84.2	38.7	29.9	47.4
NW	66.3	59.1	73.4	53.9	49.0	58.8
Y&H	74.3	65.9	82.7	47.6	41.6	53.6
WM	55.8	46.5	65.0	27.7	22.2	33.1
EM	67.8	57.9	77.7	31.4	25.4	37.5
East	68.8	60.1	77.4	35.0	28.9	41.1
London	47.9	38.8	57.0	19.5	15.4	23.6
SE	70.7	63.7	77.7	32.2	27.4	36.9
SW	52.5	42.7	62.3	27.2	22.1	32.4

Table 5: Percentage of TYA patients diagnosed 2009-2010 who were notified by age group, and cancer network of residence

cancer networks	% notifications	15 to 18		19 to 24		
		% notifications	95% CIs	% notifications	95% CIs	
N01	47.4	31.3	63.5	37.8	27.2	48.4
N02	69.9	59.3	80.5	61.3	54.0	68.6
N03	75.9	64.7	87.0	53.3	44.9	61.7
N06	72.9	60.2	85.6	47.7	39.1	56.3
N07	73.1	55.7	90.5	22.7	12.5	32.9
N08	77.5	64.4	90.6	69.9	59.9	79.8
N11	56.1	40.7	71.5	37.1	27.4	46.8
N12	47.6	25.7	69.5	13.5	2.3	24.7
N20	45.2	27.3	63.0	23.5	11.8	35.3
N21	37.5	20.4	54.6	10.6	4.4	16.9
N22	68.0	49.3	86.7	26.5	15.9	37.0
N23	48.0	28.0	68.0	6.0	0.9	11.0
N24	35.0	13.5	56.5	16.9	8.5	25.3
N25	62.5	42.7	82.3	56.9	44.8	69.1
N26	39.4	22.4	56.3	15.7	8.1	23.3
N27	50.0	22.8	77.2	18.8	7.6	29.9
N28	60.0	44.6	75.4	42.7	33.4	52.0
N29	52.2	31.3	73.1	17.5	7.6	27.5
N30	73.2	59.4	86.9	31.0	22.4	39.5
N31	63.0	48.9	77.2	42.3	32.8	51.9
N32	73.3	57.2	89.4	28.3	16.1	40.6
N33	86.7	68.8	104.5	20.5	8.4	32.5
N34	67.6	51.7	83.6	23.0	12.3	33.6
N35	62.9	46.6	79.1	26.9	17.8	35.9
N36	68.6	55.8	81.5	41.3	33.2	49.4
N37	87.0	78.0	96.1	51.4	41.9	60.8
N38	52.4	30.5	74.3	15.6	6.7	24.6
N39	67.9	57.5	78.4	28.6	22.4	34.7

The NCIN is a UKwide 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.

The National Cancer Intelligence Unit will be hosted by Public Health England from 1st April 2013

Our aims and objectives cover five core areas to improve the quality and availability of cancer data from its collection to use:

- Promoting efficient and effective data collection throughout the cancer journey
- Providing a common national repository for cancer datasets
- Producing expert analyses, to monitor patterns of cancer care
- Exploiting information to drive improvements in cancer care and clinical outcomes
- Enabling use of cancer information to support audit and research programmes