

**Routes to diagnosis:  
investigating the different pathways for cancer  
referrals in England for Teenagers and Young  
Adults**

Children, Teenagers and Young Adults SSCRG



North West Cancer Intelligence Service

**Routes to diagnosis: investigating the different pathways for cancer referrals in England for Teenagers and Young Adults**

**A report looking at the different routes to diagnosis for cancer comparing the TYA group with children aged 0 to 14 years and adults aged 25 to 49 years**

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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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## Executive Summary

This report follows up on work previously undertaken by Elliss-Brookes and colleagues (2012) at the National Cancer Intelligence Network (NCIN) defining the different routes to diagnosis that cancer patients take and examining associations between diagnosis route and survival differences<sup>(1)</sup>. We have here capitalised on this innovative work by taking a more detailed look at the pattern of referrals specifically for TYA cancer patients diagnosed in England and more broadly for those under the age of 50.

The main finding of this work was that the pattern of routes to diagnosis for patients diagnosed 2004-2008 was very different for teenagers and young adults to that of younger and older patients and that the diagnostic group played a major role in determining which route a TYA patient was likely to be referred by. While the Two Week Wait (TWW) route was reportedly common in the older adult patients<sup>(1)</sup>, this was seen only occasionally in the under 25s.

For TYA cancer patients, overall, the most common route to diagnosis was via non-TWW GP referrals (26%) followed closely by emergency presentations (24%). In contrast, the most predominant diagnostic route for patients aged 0 to 14 was emergency presentations (54%). The percentage of referrals by the emergency route declined with age to only 13% in the 25 to 49 age group. The opposite was true of non-TWW referrals by a GP; paediatric patients were much less likely to be diagnosed via a non-TWW GP referral (14%) than both the TYA age group (26%) and the 25 to 49 age group (27%). The older age group had the highest proportion of patients diagnosed via the TWW (29%) compared with just 17% of TYA and 1% of children.

Route to diagnosis in the TYA age group was largely dependent upon diagnosis but even within disease groups, there were differences between younger and older patients. Among ALL patients, 0 to 14 year olds had a significantly higher proportion of cases diagnosed via emergency presentations (70%) compared with 15 to 24 year olds (61%). For AML, the proportion of patients diagnosed via emergency presentations was similar for both paediatric patients and TYA patients (65%) and higher than the older age group (55%).

There were some gender differences in routes to diagnoses. A higher proportion of males with leukaemia were diagnosed via the emergency presentation route (62%) compared with females (54%). This was also the case for lymphomas, CNS tumours, melanomas and carcinomas. Conversely, females with germ cell tumours were more likely to be diagnosed via emergency

presentations (36%) than males (17%). Females with leukaemia were more likely to be diagnosed via non-TWW GP referrals (13%) than males (7%). Differences were also observed between males and females for thyroid and colorectal carcinomas.

In older adults, patients diagnosed via emergency presentations were shown to have lower one year survival than patients diagnosed via other routes for all diagnoses<sup>(2)</sup>. Our examination of percentage of deaths in the first year among TYA patients diagnosed with ALL and AML showed higher percentage deaths among patients referred via the emergency presentation route compared with all other routes but these were not statistically significant.

This report provides an interesting insight into routes to diagnosis for teenagers and young adults and how pathways to referral vary by age. Overall it appears that the TWW route is not routinely used for this age group but that non-TWW GP referrals and emergency presentations feature much more for teenagers and young adults with emergency presentations being most prevalent among children. Further work is required to understand why children and to a less extent TYA patients have such high numbers of patients diagnosed via the emergency presentation route and whether this is related to a worse outcome as appears to be the case in older adults. The implementation of the COSD this year, with more complete details on stage and other prognostic indicators will provide a more complete picture of how important routes to diagnosis are for affecting outcomes for those aged 49 years and under.

## Introduction

The overarching goal of the National Awareness and Early Diagnosis Initiative (NAEDI) announced in the Cancer Reform Strategy (Department of Health, 2007) is to coordinate and provide support to activities and research that promote the earlier diagnosis of cancer, thereby improving survival rates and reducing cancer mortality. Diagnosis via an emergency presentation route rather than primary care referrals has been shown to be associated with poorer prognosis<sup>(2)</sup> and a better understanding of what underpins this variation in diagnostic routes can help both inform awareness and early diagnosis initiatives, such as the NAEDI, and act as an indicator of their success.

It is important to recognise however that routes to diagnosis may not mean the same thing for all patient groups, particularly different age groups as revealed by the work undertaken by Ellis-Brookes and colleagues (2012)<sup>(1)</sup>. Their project was the first to explore the feasibility of using routine data to evaluate how cancer patients access the health service, defining the different routes to diagnosis that cancer patients take and examining whether the routes are associated with survival differences.

We have here capitalised on this innovative work by taking a more detailed look at the pattern of referrals specifically for TYA cancer patients diagnosed in England and more broadly for those under the age of 50. Cancer is the most common cause of death after accidental deaths in teenagers and young adults. However the spectrum of cancers experienced by young people and indeed children are very different to those typically seen in older adults. In turn cancer services are likely to be accessed differently by children and young people. This report provides insight into some of those differences.

Our study focuses on cancer routes to diagnoses in England in the teenage and young adult age group (ages 15 to 24 years), and provides a comparison of diagnosis routes with those for paediatric patients and those aged 25 to 49 years, a comparison of routes between males and females in the TYA age group and look at a possible association between age related differences in outcomes and age related differences in diagnostic pathways.

## Methods

We identified all patients resident in England who were diagnosed with a malignant neoplasm (excluding non-melanoma skin cancer) between 2004-2008 aged 0 to 49 years. We used the 2008 version of the National Cancer Data Repository (NCDR), which is an amalgamated dataset of all cancer registrations for England 1985 to 2008 and classified patients by diagnosis using a specialist diagnostic classification system based on cancer site and morphology<sup>(3)</sup>. All cancer diagnoses included in this report were coded according to ICD-02 morphology and behaviour. Although borderline and benign CNS tumours are usually included in analyses of cancer among children and TYA patients, these have been excluded from this report due to insufficient data being available on routes to diagnosis for this particular tumour group. Pilocytic astrocytomas which are now classified as borderline according to ICD-03 are included as they were classified as malignant according to ICD-02 as are borderline ovarian carcinomas. Cases classified as death certificate only (N = 186) were also excluded. Patients were further grouped by age at diagnosis (0-14, 15-24 and 25-49 years) and by region of residence (government office region GOR).

Cancer registration records were then linked at patient level to a “routes to diagnosis” (RTD) indicator from the RTD dataset as provided by the NCIN analysis team. 7672 patients aged 15 to 24 years diagnosed in England between 2004 and 2008 were matched to the NCIN routes to diagnosis indicators. The RTD indicators were derived by NCIN using administrative NHS datasets including HES, National Cancer Waiting Times, National Breast Screening Programme and National Bowel Screening Programme<sup>(4)</sup>. Patients were classified into eight RTD groups. In our age group of interest, there were only a small number of cases for some routes, therefore for the purpose of this report we have condensed the 8 RTD groups to 5 indicators for this report (Table 1).

The NCIN reports were limited to the period 2006-2008 as cancer waits data as the central collection of Cancer Waiting Times (CWT) was new during that time and breast screening data for 2004 were not available. However because of the small number of incident cases for our study group (teenagers and young adults), and as screening data for breast cancer does not apply to this age group, we felt it was appropriate to include these years to increase our sample size. The concordance of our results for 2004-2008 with those reported by NCIN for 2006-2008 for the under 50s age group for all cancers combined suggest this is a valid approach and we report where we feel the incompleteness of CWT data may have affected the results.

Results are presented as percentages with 95% confidence intervals by age, sex, cancer group, region of residence (GOR), TYA cancer groups and over time, for the 15-24 age group. Detailed results are provided in the Appendix. We also look at routes to diagnosis for leukaemia patients in more detail.

**Table I: Eight routes to diagnosis and 5 RTD Indicators**

Diagnosis route	Description	Route to diagnosis indicator
Two Week Waits (TWW)	Urgent GP referral with a suspicion of cancer	Two week waits
Emergency presentation	An emergency route via A&E, emergency GP referral, emergency transfer, emergency consultant outpatient referral, emergency admission or attendance	Emergency presentation
GP referral	Routine and urgent referrals where the patient was not referred under the TWW referral route	Non TWW GP referral
Screen-detected	Detected via the breast, cervical or bowel screening programmes	Others
Inpatient elective	Where no earlier admission can be found before admission from a waiting list, booked or planned	Others
Other Outpatient	An elective route starting with an outpatient appointment : either self-referral, consultant to consultant, other or unknown referral	Others
DCO (Death Certificate Only)	No data available from Inpatient or Outpatient HES, CWT( Cancer Waiting Times), Screening and with a DCO flagged by the registry in the NCDR	Excluded
Unknown	No data available from Inpatient or Outpatient HES, CWT( Cancer Waiting Times) and Screening	Unknown

## Results

### 1) Variation in route to diagnosis among teenagers and young adults and comparisons by age group

This section of the report focuses on the routes to diagnosis for teenage and young adult (TYA) age group, comparing routes in this age group with those in the 0 to 14 age group and those in the 25 to 49 age group.

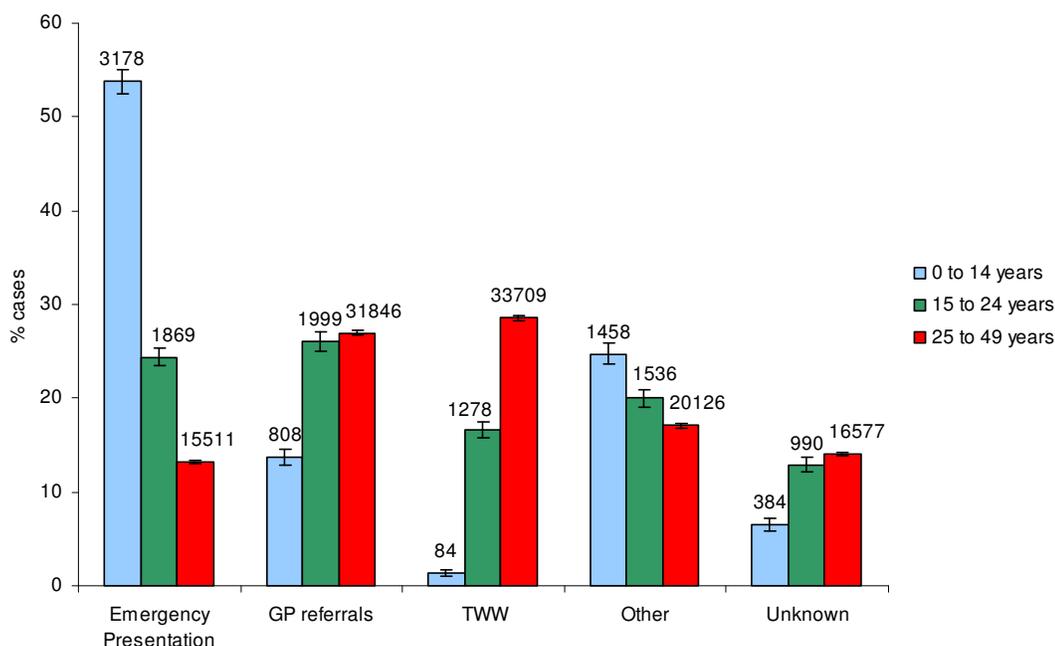


Figure 1: Number and percentage of cases diagnosed via each route by age group. Numbers above bars represent number of cases. Error bars represent the 95% confidence intervals. GP referrals are non-TWW and non-emergency GP referrals.

For TYA cancer patients the most common route to diagnosis recorded was via non-TWW GP referrals (26%, 95% CI 25-27) followed closely by emergency presentations (24%, 95% CI 23-25) (Figure 1, Appendix table I). This pattern contrasts with patients aged 0 to 14 years whose predominant diagnostic route was emergency presentations (54%). The second most common route for the paediatric age group was “other” which included elective inpatient admissions and outpatient routes. The percentage of referrals by emergency route declined with age to only 11% in the 25 to 49 age group. The opposite was true of non-TWW referrals by a GP. Paediatric

patients were much less likely to be diagnosed via a non-TWW GP referral (14%) than both the TYA age group (26%) and the 25 to 49 age group (27%). The older age group had the highest proportion of patients diagnosed via the TWW (24%) compared with just 13% of TYA and 1% of children. The proportion of cases referred by unknown sources was also lowest in the 0 to 14 age group.

Regionally, there were some differences in the proportion of patients diagnosed via each route between the age groups. Figure 2 shows the percentage of cases diagnosed by emergency presentation for each age group in each region. Patients aged 0 to 14 years in the North East were more likely to be diagnosed via emergency presentation route (60%, 95% CI 55-63) than those in London (47%, 95% CI 44-50). Similarly patients aged 15 to 24 years in the South East were less likely to be referred via emergency presentation (22%, 95% CI 20-24) than those of the same age in the North East (29%, 95% CI 25-33). For 25 to 49 years the proportion of patients referred via emergency presentation ranged from 12% to 15%.

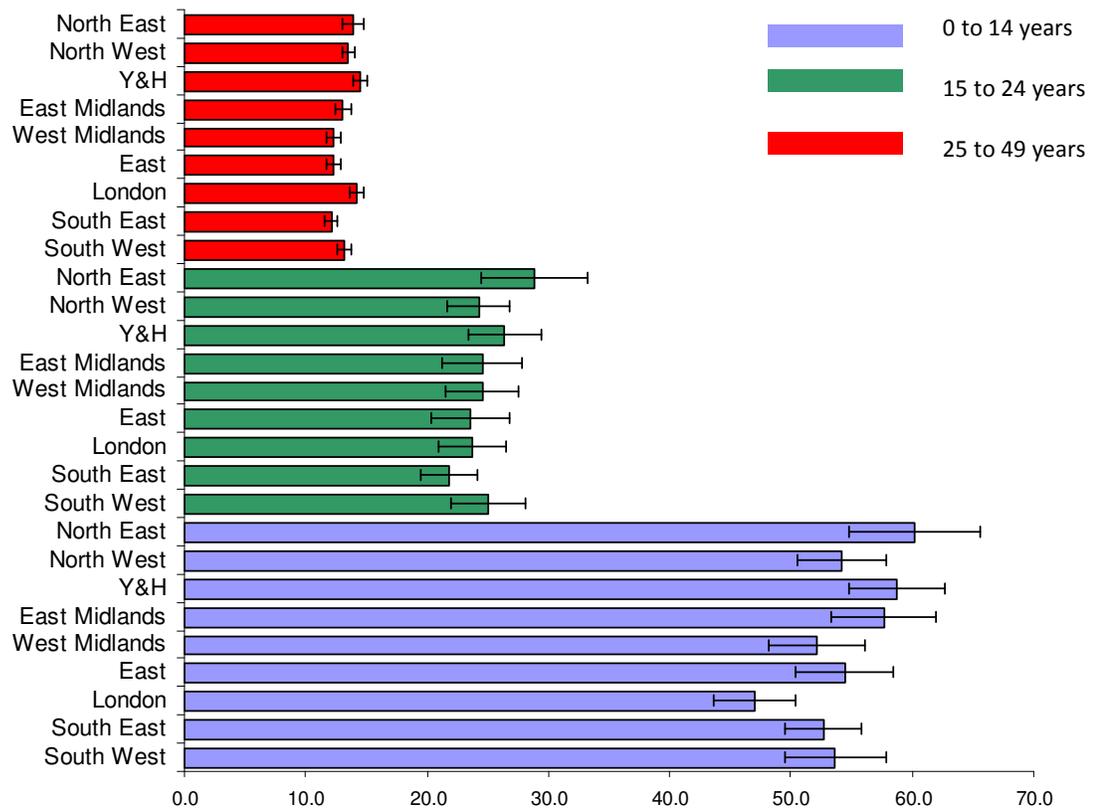


Figure 2: Percentage of cases diagnosed by emergency presentation by region of residence and age group

Non-TWW GP referrals also varied by region for each age group (Figure 3). Among the 0 to 14 year olds non-TWW GP referrals ranged from 11% in London (95% CI 9-13) to 19% in the East of England (95% CI 16-23). Among 15 to 24 year olds, London again had the lowest percentage of patients referred via GPs at 22% (95% CI 20-25) and the North East had the highest (31%, 95% CI 27-35). For the older age group non-TWW GP referrals range from 24% in the South East to 31% in the North West. All routes by age and region are presented in Appendix Table II.

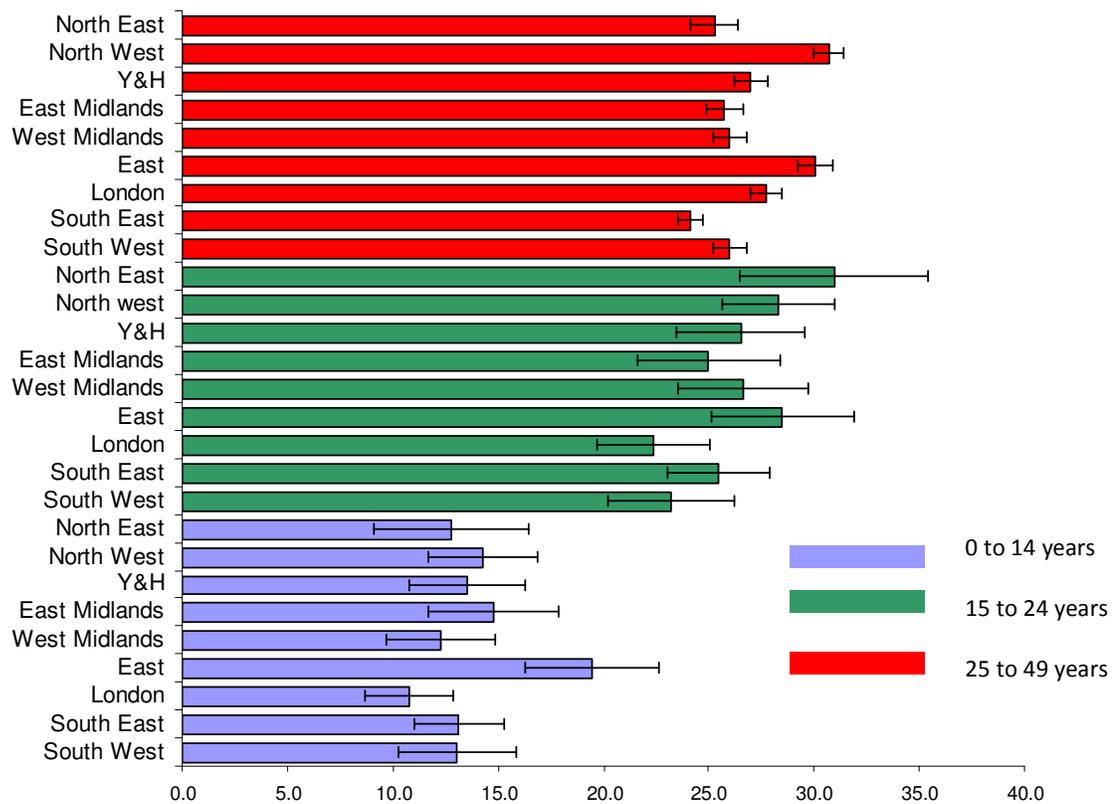


Figure 3: Percentage of cases diagnosed by non-TWW, non-emergency GP referral by region of residence and age group

Although route to diagnosis appears to be largely dependent upon diagnosis, this does not account for all of the age-related differences observed. For the majority of diagnostic groups, patients aged 0 to 14 years were significantly more likely to be diagnosed via emergency presentation than both TYA patients and patients aged 25 to 49 years (Figure 4)

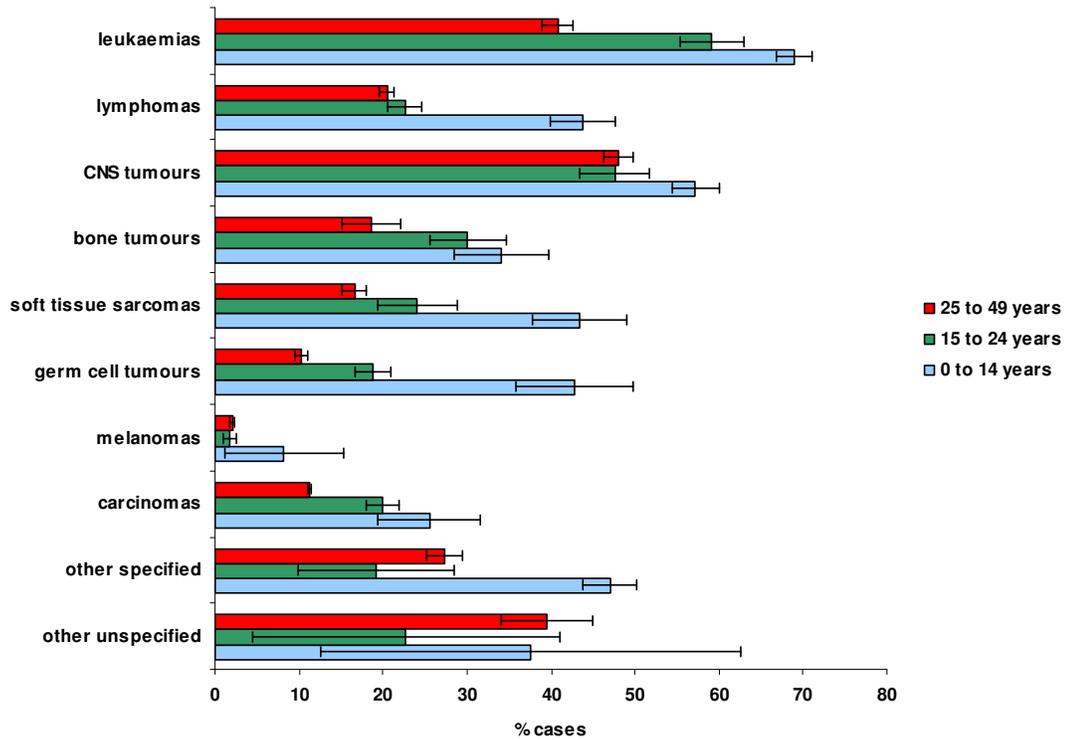


Figure 4: Percentage of cases diagnosed by emergency presentation by diagnosis group and age group

The pattern for non-TWW GP referrals between age groups was less clearly defined (Figure 5). For leukaemias and bone tumours TYA and paediatric patients were similar with smaller proportions of patients being referred via GPs than the older age group. For lymphomas and soft tissue sarcomas TYA patients were more similar to the older age group than the 0 to 14s. For CNS tumours referrals via GPs were similar across the age groups. For carcinomas TYA patients were more likely to be referred by a GP than both the younger and older age groups. These results need to be considered in the context of differing population sizes between the age groups and also differences in the distribution of diagnostic subtypes between the age groups that are considered below.

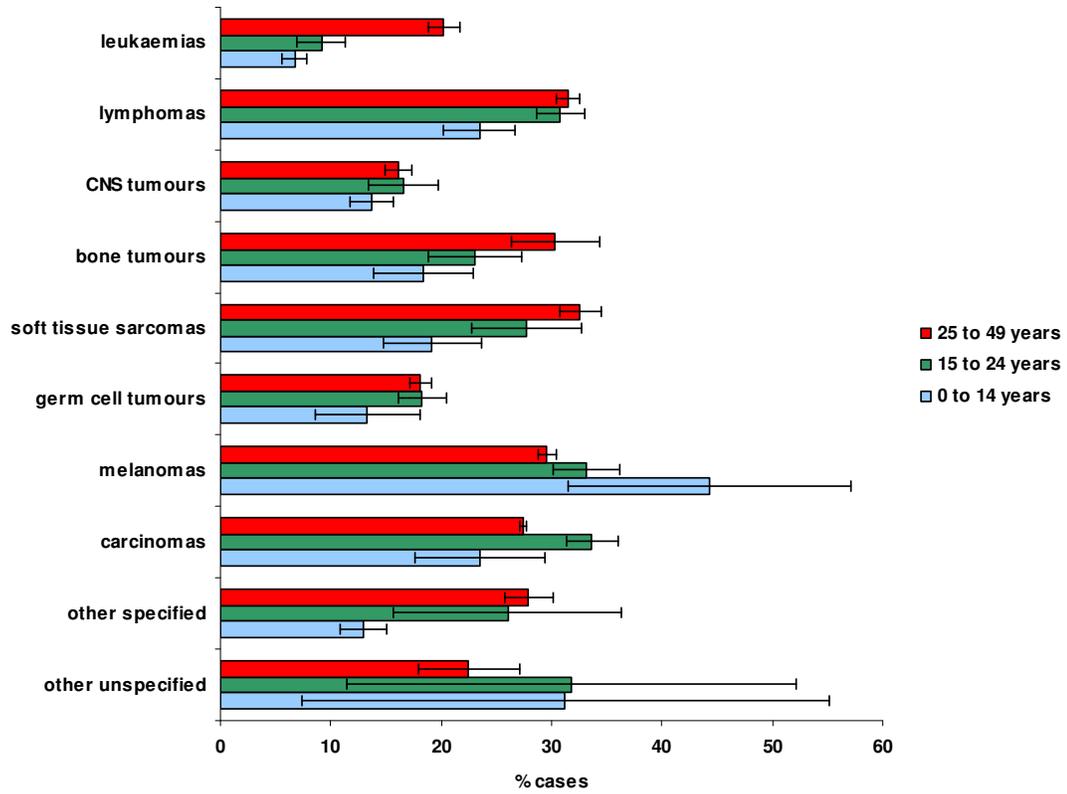


Figure 5: Percentage of cases diagnosed by non-TWW, non-emergency GP referral by diagnosis group and age group

Detailed data on the number and percentage of referrals by each route by 15-24, 0-14 and 25-49 age groups are presented in Appendix tables III, IV and V respectively.

## 2) Changes in routes to diagnoses over time

The proportion of TYA cases diagnosed by the emergency presentation route remained more or less constant between 2004 and 2008 (Figures 6-8) for each of the age groups. For teenagers and young adults, the percentage of non-TWW GP referrals decreased by 8% from 31% (95% CI 28-33) in 2004 to 23% (95% CI 21-25) in 2008. This was offset by an increase in referrals via the TWW route increasing from 12% (95% CI 10-13) in 2004 to 21% (95% CI 19-23) in 2008. This may be an artefact of data completeness for TWWs during 2004-2005 when this system was in its early stages. For the 0 to 14 year olds, there was little change in non-TWW referrals by GP or TWWs over time. A trend of decreasing non-TWW referrals by GP along with an increase in the TWWs was observed for the 25 to 49 year olds (Figure 8). Referrals by “Other” routes of diagnosis have more or less remained the same over time for all age groups.

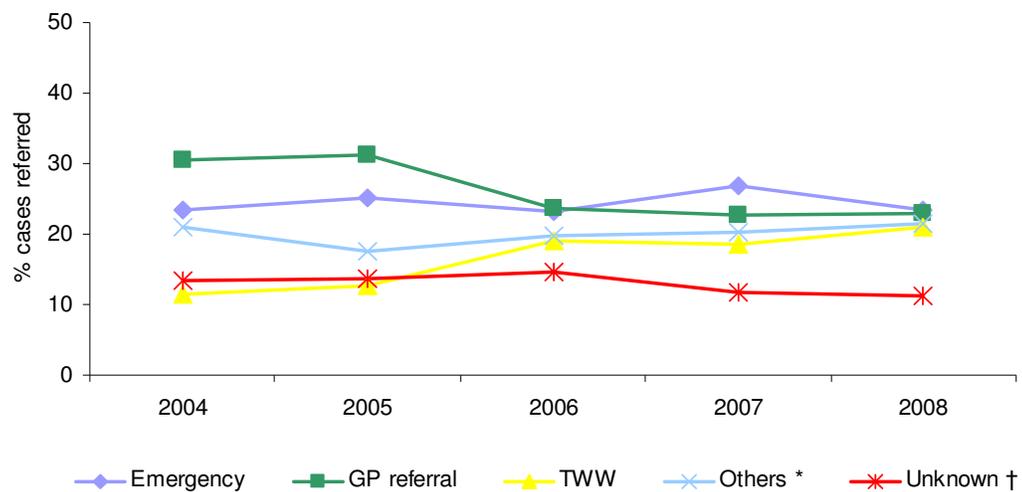


Figure 6: Trends in routes to diagnosis 2004 to 2008 for ages 15 to 24 years, all cancers. GP referrals are non-TWW and non-emergency GP referrals.

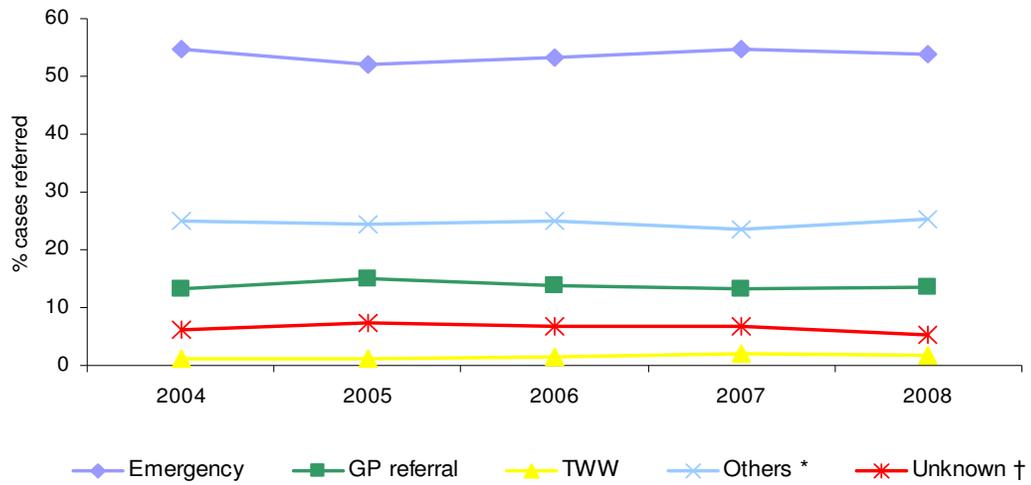


Figure 7: Trends in routes to diagnosis 2004 to 2008 for ages 0 to 14 year olds, all cancers. GP referrals are non-TWW and non-emergency GP referrals.

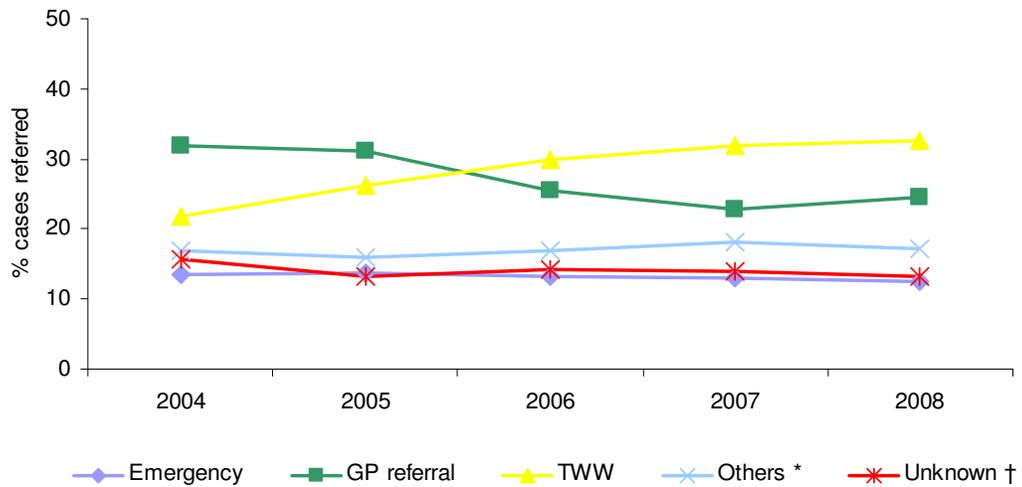


Figure 8: Trends in routes to diagnosis 2004 to 2008 for ages 25 to 49 year olds, all cancers. GP referrals are non-TWW and non-emergency GP referrals.

### 3) A comparison of routes to diagnoses by gender among the 15 to 24 age group

There were some differences in the routes to diagnoses taken by males and females (Figure 9). A higher proportion of males with leukaemia were diagnosed via the emergency presentation route (62%) compared with females (54%) (Table 2), which may at least in part be explained by the relatively higher proportion of leukaemias that are acute lymphoid leukaemias (51%) in males compared with females (40%). Higher proportions of emergency presentation diagnoses among males compared with females were also apparent for lymphomas, CNS tumours, melanomas and carcinomas, some of which may also be associated with the relative distribution of different disease sub-types in males and females. Further investigation is needed.

Females with germ cell tumours were more likely to be diagnosed via emergency presentations (36%) than males (17%). Females with leukaemia were more likely to be diagnosed via non-TWW GP referrals (13% 95% CI 9-17) compared with males (7%, 95% CI 5-10) as were females with melanomas: females 35% (95% CI 32-39), males 30% (95% CI 25-35).

Within the germ cell tumours the most common route for diagnosis among TYA females was emergency presentations; 36% of females with germ cell tumours were diagnosed via this route. This compares with just 17% of TYA males. For TYA males with germ cell tumours the most predominant route was TWW (40%). These differences are largely attributable to differences in the diagnostic routes for ovarian germ cell tumours in females, 35% of which were diagnosed via emergency presentations, and diagnostic routes for testicular germ cell tumours in males (15% of which are diagnosed via emergency presentations). There was little difference between males and females in the proportion of germ cell tumours of non-gonadal sites that were diagnosed via emergency presentations (males 41%, females 44%).

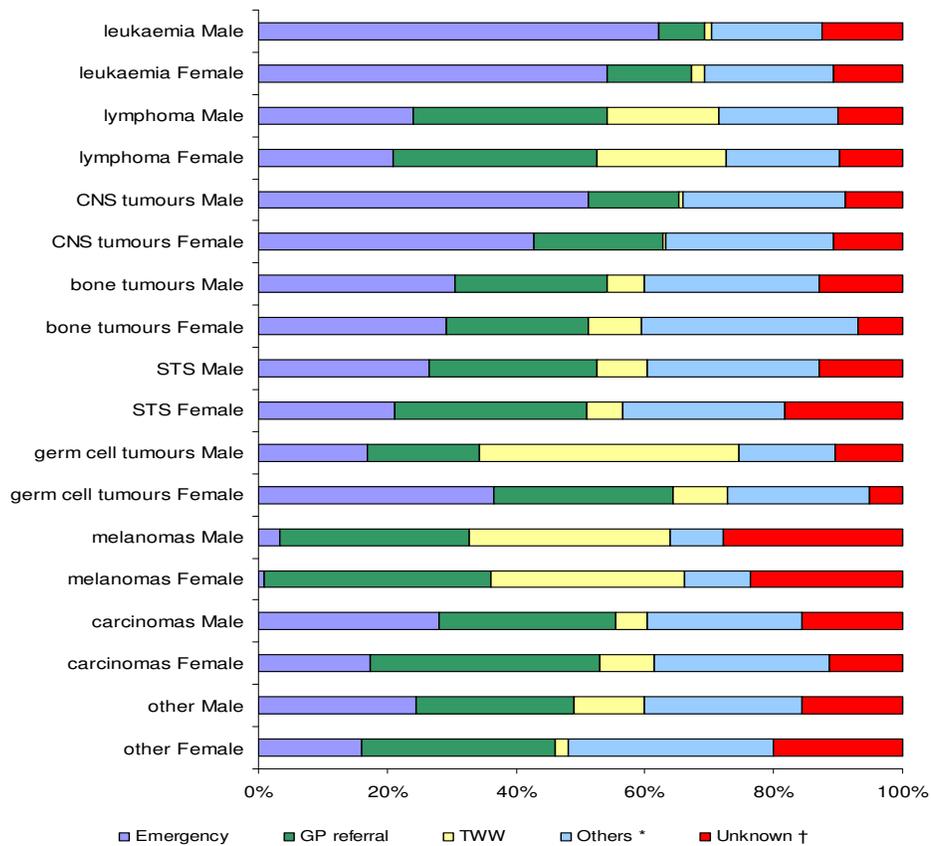


Figure 9: Distribution of diagnostic routes for patients aged 15 to 24 years by diagnosis and gender. GP referrals are non-TWW and non-emergency GP referrals.

Within the carcinoma group, the most common route for diagnosis for TYA females was non-TWW GP referrals (36%) followed closely by “other” routes (27%). Among TYA males with carcinomas, the most common routes were emergency presentations (28%), non-TWW GP referrals (27%) and other (24%). Some of these differences are likely to reflect differences in the relative frequency of carcinomas of different sites by gender. In TYA males the most common carcinomas are colorectal, thyroid and head and neck making up almost 60% of all carcinomas in males in this age group. In TYA females, the most common carcinomas are those of the thyroid, cervix and ovary. In females, a higher proportion of patients with germ cell ovarian neoplasms were diagnosed via an emergency presentation (35%, 95% CI 26-47) than for females with ovarian carcinomas (24%, 95% CI 19-30) but these differences were not statistically significant.

Table 2: Percentage of TYA cases diagnosed via the emergency presentation route by diagnostic group and gender

diagnostic group	% cases	MALES		FEMALES	
		95% Conf Intervals	% cases	95% Conf Intervals	% cases
leukaemia	62.0	(57.5 - 66.5)	54.2	(48.0 - 60.4)	
lymphoma	24.0	(21.3 - 26.8)	21.0	(18.1 - 23.8)	
CNS tumours	51.1	(45.6 - 56.5)	42.7	(36.4 - 49.1)	
bone tumours	30.7	(25.0 - 36.4)	29.1	(22.0 - 36.2)	
STS	26.6	(20.0 - 33.1)	21.1	(14.5 - 27.7)	
Germ cell tumours	16.9	(14.8 - 19.1)	36.4	(27.7 - 45.2)	
Melanomas	3.3	(1.4 - 5.1)	0.9	(0.2 - 1.7)	
carcinomas	28.1	(23.7 - 32.4)	17.2	(15.1 - 19.4)	
other specified	24.3	(10.3 - 38.3)	13.9	(2.4 - 25.3)	
other unspecified	25.0	(0 - 57.1)	21.4	(0 - 43.7)	

We looked at more detail at some of the non-gender specific carcinomas. For thyroid carcinomas, females were most commonly diagnosed via non-TWW GP referrals (57%) whereas males were most commonly diagnosed via “other” routes (37%); 30% of males were diagnosed via non-TWW GP referrals. Only 19% of females were diagnosed via “other” routes. 11% of males and 7% of females were diagnosed via TWWs. Among colorectal carcinoma patients males and females were both more likely to be diagnosed via emergency presentations than any other route, however the proportion of female patients diagnosed via this route was 10% higher in females (60%, 95% CI 51-69) than males (49%, 95% CIs 40-58). Males were more likely to be diagnosed via non-TWW GP referrals (19%, 95% CI 12-26) than females (12%, 95% CI 6-18).

#### 4) Unknown Routes

Across all age groups, a number of cases had no route to diagnoses identified either because no data were available from Inpatient or Outpatient HES, CWT data or screening. As shown by Figure 9, for both males and females of the TYA age group, the largest proportions of these were observed among melanoma patients. This was also the case for the younger and older age groups (see Appendix tables III – VI)

### 5) Further analyses of routes to diagnosis among leukaemia patients

As route to diagnosis was highly associated with diagnosis, there was a strong possibility that the difference observed between routes to diagnosis among the three age groups could be attributed to differences in the relevant occurrence of different diagnoses within each of the three age groups investigated (see Figure 10).

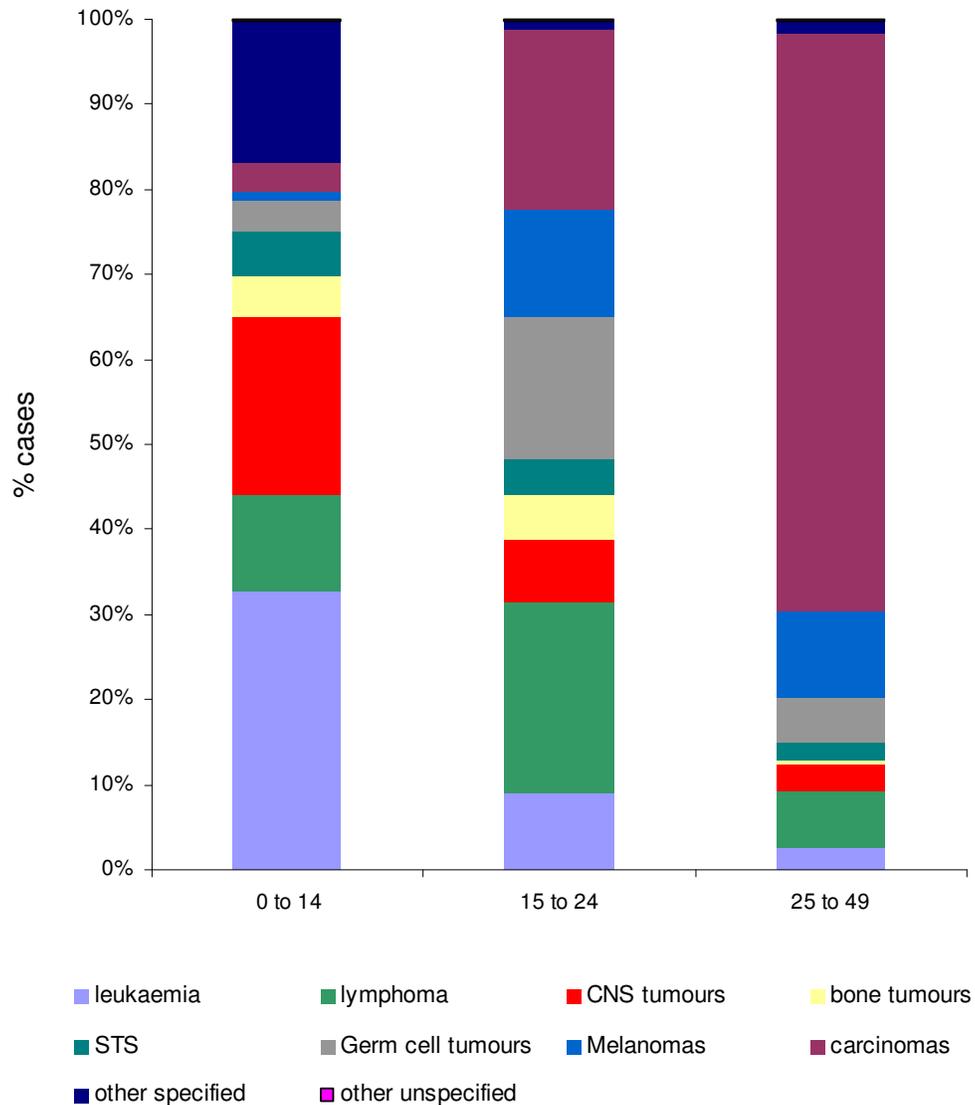


Figure 10: Distribution of cancer types by age at diagnosis

Therefore we decided to look at a single diagnostic group in more detail to assess the validity of this explanation. Leukaemia is observed across the entire age range and was shown to have the

highest proportion of patients referred via the emergency presentation route. We have also previously shown significant differences in survival rates across the age groups for both acute myeloid leukaemia and acute lymphoblastic leukaemia<sup>(5)</sup>. Thus we have focused on leukaemia and compared the proportion of patients diagnosed via each route for all leukaemia diagnoses and for each type of leukaemia.

Leukaemia patients had the highest proportion of patients referred by emergency presentation route of all diagnostic groups for 0-14 and 15-24 year olds, and second highest, after CNS, for the 25-49 age group. However, there was a significantly higher proportion of patients diagnosed via the emergency presentation route among 0 to 14 year olds (69%) than among the TYA age group (59%) which in turn had a significantly larger proportion of emergency presentation diagnoses than the 25 to 49 age group (41%) (Table 3). The reverse trend was seen for non-TWW GP referrals ranging from 20% in the 25 to 49 age group to 7% in the 0 to 14s. For teenagers and young adults and for children, “other routes” was the second most common route for diagnosis for leukaemia patients which included inpatient and out patient events. In each age group, the TWW route featured in only a very small proportion of cases, being highest in the 25 to 49 year olds (5% of cases).

**Table 3: Number and percentage of leukaemia cases diagnosed via each routes by age group**

Routes to diagnosis	agegroup			
N % (CI)	0-14	15-24	25-49	Total
Emergency presentation	1,331 68.9 (66.8-71.0)	416 59.3 (55.6-62.9)	1,214 40.9 (39.1-42.6)	2,961
GP referral	130 6.8 (5.6-7.8)	65 9.3 (7.1-11.4)	601 20.2 (18.8-21.7)	796
Two Week Waits	14 0.7 (0.3-1.1)	10 1.4 (0.5-2.3)	149 5.0 (4.2-5.8)	173
Others	342 17.7 (16.0-19.4)	128 18.2 (15.4-21.1)	614 20.7 (19.2-22.1)	1,084
Unknown	115 6.0 (4.9-7.0)	83 11.8 (9.4-14.2)	393 13.2 (12.0-14.4)	591
<b>Total</b>	<b>1,932</b>	<b>702</b>	<b>2,971</b>	<b>5,605</b>

Numbers in parentheses are the 95% confidence limits. GP referrals are non-TWW and non-emergency GP referrals.

Figure 11 shows the distribution of leukaemia types for each age group. Acute lymphoblastic leukaemia (ALL) is the most common leukaemia subtype for the 0 to 14 year age group accounting for almost 80% of all new cases per year.

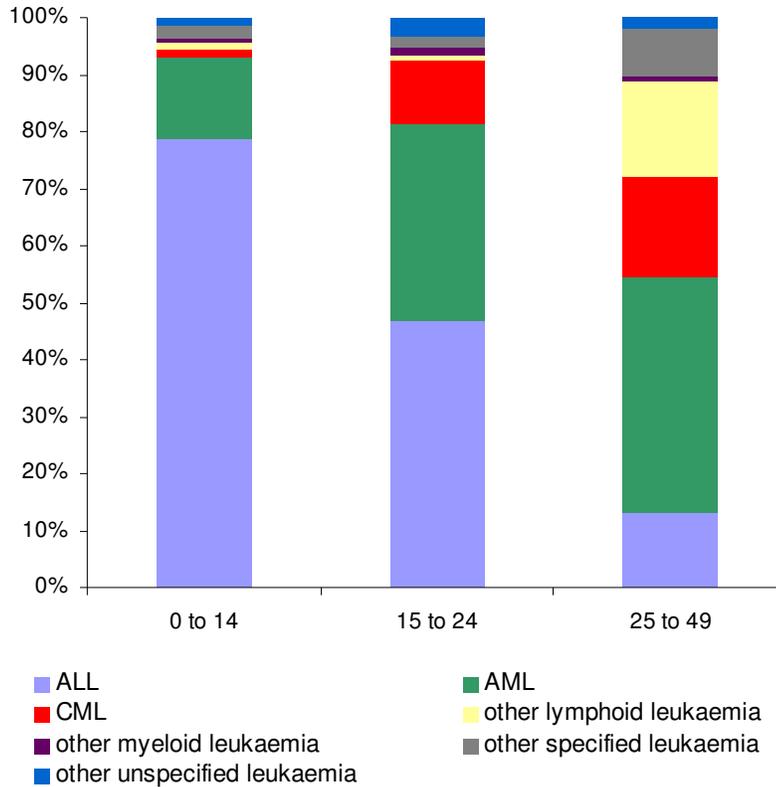
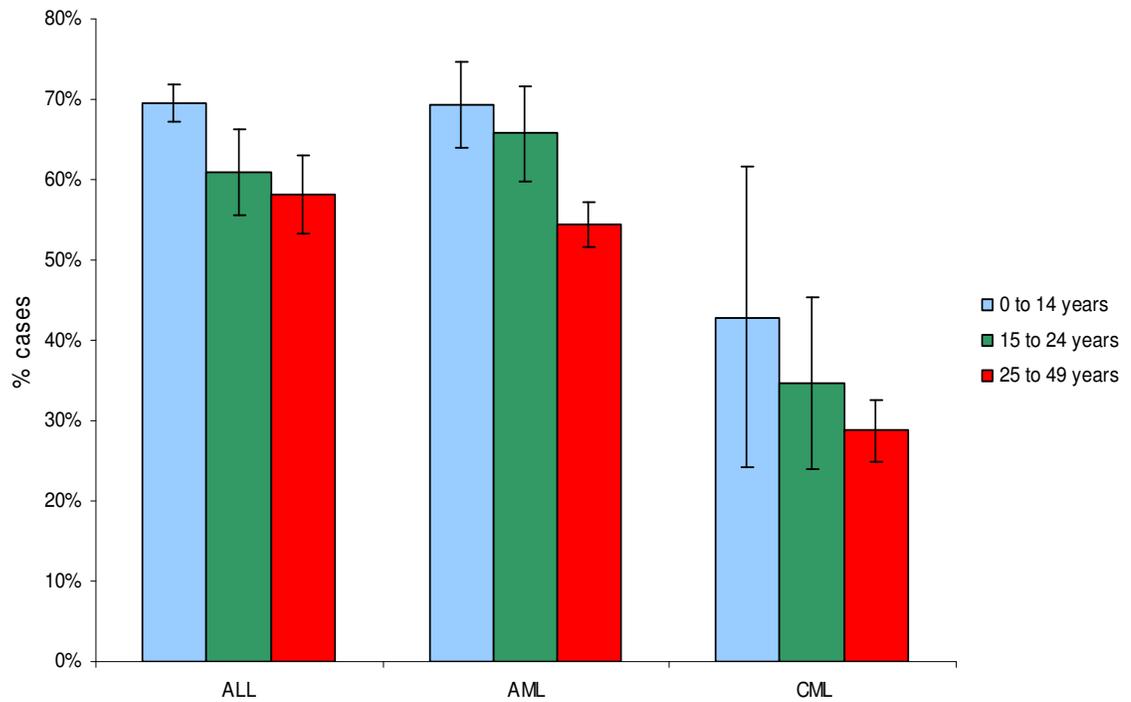


Figure 11: Distribution of leukaemia subtypes by age at diagnosis

In the 15 to 24 age group ALL is also the most common leukaemia but represents a smaller proportion of all cases (47%) than in the paediatric group. The proportion of cases is smaller still in the 25 to 49 age group (13%). In the TYA age group, 34% of cases are acute myeloid leukaemia (AML) and 11% of cases are chronic myeloid leukaemia (CML). The other group collectively account for the remaining 7% of cases. In the 25 to 49 age group the most common type is AML (41%) followed by CML (18%), other lymphoid leukaemias (17%) and ALL (13%).

Figure 12 shows the percentage of cases diagnosed via the emergency presentation route for each type. For ALL, 0 to 14 year olds continued to have a significantly higher proportion of patients diagnosed via emergency presentation (70%, 95% CIs 67-72) compared with 15 to 24 year olds (61%, 95% CIs 56-66). For ALL, the TYA age group had similar proportions of patients diagnosed via emergency presentations to the 25 to 49 year age group. There were no significant

differences in the proportion of patients diagnosed via emergency presentations for AML or CML between paediatric patients and TYA patients (although the number of cases within the 0 to 14 year olds was very small). TYA patients with AML did however have a larger proportion of patients diagnosed via the emergency route (66% 95% CI 60-72) compared with the older age group (54% 95% CI 52-57).



Error bars represent the 95% confidence intervals

Figure 12: Percentage of leukaemia cases diagnosed via the emergency presentation route by leukaemia subtype and age group

6) Analyses of association between routes to diagnosis and deaths within one year of diagnosis among leukaemia patients

Our final analysis looked at whether the route to diagnosis had any detectable impact on outcome for patients with leukaemia. We compared the percentage of ALL and AML patients who died within one year following an emergency presentation with those diagnosed via all other routes combined. We found little difference in the percentage of early deaths from ALL. A higher proportion of those with AML who presented as emergencies died in the first year compared with all other routes combined, though the differences were not statistically significant.

Table 4: Number and percentage of ALL and AML cases who die within one year of diagnosis by route of diagnosis and age group.

Age	Route to diagnosis	total cases	ALL			AML			
			% deaths in first year	95% CL		% deaths in First year	95% CL		
0 to 14	emergency presentations	1056	3.9	2.9	5.2	192	18.8	13.9	24.9
0 to 14	all other routes	463	3.0	1.8	5.0	85	14.1	8.3	23.1
15 to 24	emergency presentations	200	16.5	12.0	22.3	159	26.4	20.2	33.8
15 to 24	all other routes	128	15.6	10.3	22.9	83	22.9	15.2	33.0
25 to 49	emergency presentations	228	35.1	29.2	41.5	667	33.9	30.4	37.6
25 to 49	all other routes	164	36.6	29.6	44.2	559	29.5	25.9	33.4

## 7) Results for the whole group aged 0 to 49 years

Across the 0-49 year age range , 16% of cases (95% CI 15-16) were diagnosed via emergency referrals which is less than the 24% reported by NCIN for all age groups (0-99 years) <sup>(6)</sup>. The two most common routes were referrals by a GP (26%) and the TWW (27%). Fourteen percent of patients were referred by unknown routes not identified by the sources used for this report. Previous work has reported this to be just 8% for all ages<sup>(6)</sup>.

There was marginal variation in diagnostic route by region of patient residence (Appendix table VI). The Yorkshire and the Humber and the North East of England had the highest proportion of patients referred via emergency presentations (17%); the East of England had the smallest (15%). The England average for emergency presentations was 16%. The North West and East of England had the highest proportion of patients referred via non-TWW GP referrals (30%), and the South East the lowest (24%). The England average was 26%. Two week waits route ranged from 15% in the East to 19% in the North East and North West. London had the highest proportion of routes unknown (22%) compared with an England average of 14%.

The diagnostic pathway for the whole age group 0 to 49 years was found to be associated with diagnostic group and age. Over half (53%) of all leukaemia patients were diagnosed via the emergency presentation route (Appendix table VII) which was similar but slightly lower than the proportion reported by NCIN for all ages (57%)<sup>(6)</sup>. Similarly 50% of CNS tumour patients were diagnosed via emergency presentations. Only 2% of melanomas were diagnosed via this route. 11% of carcinomas presented as emergencies. Carcinoma patients were most likely to be diagnosed via TWW (31%) or via the GP (28%).TWW referrals were seen most predominantly in breast cancer patients. Of the 3500 female breast cancer patients aged 0 to 49 years, 52% were diagnosed via TWW, 23% via non-TWW GP referrals and only 2% via screening. Among females with carcinomas of the cervix and uterus (N=6579), 36% via non-TWW GP referrals, 8% via TWW and a further 6% were diagnosed via emergency, 20% were diagnosed via screening.

For detailed information please refer to Table VI and VII in the Appendix.

## Discussion

This report follows up on work previously undertaken by Ellis-Brookes and colleagues (2012) at the National Cancer Intelligence Network (NCIN) defining the different routes to diagnosis that cancer patients take<sup>(4,6)</sup>. Our approach has been to take a more detailed look at the pattern of referrals specifically for TYA cancer patients diagnosed in England and more broadly for those under the age of 50.

Our results emphasise how the pattern of routes to diagnosis in the under 50s differs to that seen for the entire cancer population, of which the under 50s represents approximately 10%. In the under 50s as a whole the two most common routes for all cancers were TWWs and non-TWW GP referrals with only 16% of patients diagnosed via emergency presentations. This is a different pattern to that reported for all ages where emergency presentations ran a close second to TWWs<sup>(6)</sup>. Nevertheless, half of all CNS tumour patients under the age of 50 were diagnosed via emergency presentations, compared with 62% of all ages. Patients with carcinoma of the liver and pancreas aged 0 to 49 years were also most likely to be diagnosed via emergency presentations than any other route.

We also highlight here the differences between teenagers and young adults compared with older and younger patients and the wide variation in diagnostic routes across different cancer types and some differences in diagnostic routes by gender.

Emergency presentations occurred most commonly in patients aged 0 to 14 years. Among TYA cancer patients, emergency presentations were less common than among paediatric patients but were relatively frequent compared with the older age group, just under one quarter being diagnosed via an emergency presentation (just over one quarter of patients were diagnosed via non-TWW GP referrals). The percentage of referrals by emergency route declined with age to only 13% in the 25 to 49 age group. The opposite was true of referrals by a GP. The proportion of paediatric patients diagnosed via a non-TWW GP referral was almost half that of the TYA age group and the 25 to 49 age group. The proportion of TYA patients diagnosed via the TWW was almost half that of the older age group at just 17%. Care needs to be taken in interpreting these differences, as referrals classified under the same route to diagnosis may vary in detail and in consequences by age group. For example, emergency admissions in the 0-24 year age group may mainly refer to GP emergency admissions and not patients presenting at A and E.

The most striking age related differences were observed among leukaemia patients. Over half of all leukaemia patients were diagnosed following an emergency presentation but significantly greater proportions of children with ALL were referred via emergency presentations than both TYA patients and patients aged 25 to 49 and significantly greater proportions of patients aged 0 to 14 years and 15 to 24 years with AML were diagnosed via emergency presentations than those aged 25 to 49. These differences may reflect differences in patient and patient family behaviour in seeking primary and secondary care, or differences in clinical responses to patient presentation, or may be attributable to differences in disease severity and/or symptoms at the time of presentation. Further work is needed to help elucidate these possible causes of the differences observed.

Males with leukaemias, lymphomas, CNS tumours, melanomas and carcinomas were all more likely to be diagnosed via the emergency presentation route than females, though several of these are based on relatively small numbers. Females with germ cell tumours were twice as likely to be diagnosed via emergency presentations as males, reflecting differences in presentation of testicular and ovarian tumours. Differences in routes were also observed for thyroid carcinoma and colorectal carcinoma patients. While some of these differences may be associated with differences in the relative distributions of different disease types and sub-types in males and females, the possibility of differences in the way males and females access health services warrants further investigation.

Diagnosis via an emergency presentation route is thought to be an indicator of late diagnosis and corresponding worse prognosis. This may not be the case for children or TYA patients. Patients of all ages diagnosed via the emergency presentation route were previously shown to have lower one year survival than patients diagnosed via other routes for all diagnoses<sup>(6)</sup>. Our examination of percentage of deaths that occurred within the first year following diagnosis for ALL and AML showed little difference in the percentage of early deaths from ALL but a higher, although not statistically significant, proportion of deaths in the first year among those who presented as an emergency with AML when compared with all other routes combined. These results suggest that being diagnosed via an emergency presentation may not always be associated with a worse prognosis at least for ALL patients under the age of 50 years. The lack of statistical significance around the higher percentage deaths for AML patients may be due to the small sample size preventing the detection of a real difference and future work will look further at the possible clinical significance of these results as well as the outcomes for other diagnoses in TYA patients.

This report expands the work previously undertaken by NCIN, providing a closer look at routes to diagnosis for teenagers and young adults and how pathways to referral vary by age for the under 50s. Overall it appears that the two week wait route is not routinely used for this age group but that non-TWW GP referrals and emergency presentations feature much more for both children and teenagers and young adults. Future work will involve incorporating information on stage and other prognostic indicators that will provide a more complete picture of how routes to diagnosis may influence outcomes for teenagers and other cancer patients under the age of 50.

For more information about the work we are currently undertaking at NWCIS on cancer in teenagers and young adults please visit the NCIN website [www.ncin.org.uk](http://www.ncin.org.uk) or visit our website [www.nwcis.nhs.uk](http://www.nwcis.nhs.uk) or contact us at [info@nwcis.nhs.net](mailto:info@nwcis.nhs.net).

All Routes to Diagnosis work undertaken by NCIN can be found at [http://www.ncin.org.uk/publications/routes\\_to\\_diagnosis.aspx](http://www.ncin.org.uk/publications/routes_to_diagnosis.aspx)

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Appendix

Table I: Number and percentage of patients referred by each routes by age group

Route to Diagnosis	Age group	N	% cases	95% CL	
Emergency Presentation	0 to 14	3,178	53.8	52.5	55.0
	15 to 24	1,869	24.4	23.4	25.3
	25 to 49	15,511	13.2	13.0	13.4
GP referrals	0 to 14	808	13.7	12.8	14.5
	15 to 24	1,999	26.1	25.1	27.0
	25 to 49	31,846	27.0	26.8	27.3
TWW	0 to 14	84	1.4	1.1	1.7
	15 to 24	1,278	16.7	15.8	17.5
	25 to 49	33,709	28.6	28.4	28.9
Other	0 to 14	1,458	24.7	23.6	25.8
	15 to 24	1,536	20.0	19.1	20.9
	25 to 49	20,126	17.1	16.9	17.3
Unknown	0 to 14	384	6.5	5.9	7.1
	15 to 24	990	12.9	12.2	13.7
	25 to 49	16,577	14.1	13.9	14.3

Table II: Number and percentage of patients referred by each routes by age group and region of residence

Route to Diagnosis	Age group	Region	% cases	95% Cis		Route to Diagnosis	Age group	Region	% cases	95% CIs			
EP	0 to 14	South West	53.7	49.6	57.7	Other	0 to 14	South West	24.9	21.4	28.5		
	15 to 24	South West	25.1	22.1	28.1		15 to 24	South West	22.8	19.9	25.8		
	25 to 49	South West	13.1	12.6	13.7		25 to 49	South West	17.6	16.9	18.2		
	0 to 14	South East	52.7	49.6	55.7		0 to 14	South East	26.1	23.4	28.8		
	15 to 24	South East	21.8	19.6	24.1		15 to 24	South East	19.8	17.6	21.9		
	25 to 49	South East	12.1	11.6	12.6		25 to 49	South East	17.5	16.9	18.0		
	0 to 14	London	47.0	43.7	50.4		0 to 14	London	24.9	22.0	27.8		
	15 to 24	London	23.8	21.1	26.4		15 to 24	London	18.2	15.7	20.6		
	25 to 49	London	14.2	13.6	14.7		25 to 49	London	16.0	15.4	16.6		
	0 to 14	East	54.4	50.5	58.3		0 to 14	East	22.2	18.9	25.4		
	15 to 24	East	23.6	20.5	26.7		15 to 24	East	19.5	16.6	22.4		
	25 to 49	East	12.3	11.7	12.9		25 to 49	East	14.2	13.6	14.9		
	0 to 14	West Midlands	52.2	48.2	56.1		0 to 14	West Midlands	28.1	24.6	31.6		
	15 to 24	West Midlands	24.5	21.6	27.5		15 to 24	West Midlands	19.4	16.7	22.1		
	25 to 49	West Midlands	12.4	11.8	12.9		25 to 49	West Midlands	17.8	17.1	18.5		
	0 to 14	East Midlands	57.7	53.4	61.9		0 to 14	East Midlands	21.9	18.4	25.5		
	15 to 24	East Midlands	24.5	21.3	27.8		15 to 24	East Midlands	21.2	18.1	24.3		
	25 to 49	East Midlands	13.1	12.4	13.7		25 to 49	East Midlands	17.7	16.9	18.4		
	0 to 14	Y&H	58.7	54.8	62.7		0 to 14	Y&H	21.8	18.5	25.1		
	15 to 24	Y&H	26.4	23.4	29.4		15 to 24	Y&H	19.6	17.0	22.3		
	25 to 49	Y&H	14.5	13.9	15.1		25 to 49	Y&H	16.1	15.4	16.7		
	0 to 14	North West	54.2	50.6	57.8		0 to 14	North West	26.3	23.1	29.5		
	15 to 24	North west	24.3	21.7	26.8		15 to 24	North west	21.5	19.1	23.9		
	25 to 49	North west	13.5	13.0	14.0		25 to 49	North west	18.5	17.9	19.1		
	0 to 14	North East	60.2	54.9	65.5		0 to 14	North East	23.4	18.8	28.0		
	15 to 24	North East	28.9	24.6	33.1		15 to 24	North East	16.9	13.3	20.4		
	25 to 49	North East	14.0	13.1	14.8		25 to 49	North East	18.9	18.0	19.9		
	GP referrals	0 to 14	South West	13.1	10.3		15.8	Unknown	0 to 14	South West	6.8	4.7	8.9
		15 to 24	South West	23.2	20.3		26.1		15 to 24	South West	9.9	7.8	11.9
		25 to 49	South West	26.0	25.2		26.8		25 to 49	South West	11.4	10.8	11.9
		0 to 14	South East	13.1	11.1		15.2		0 to 14	South East	6.7	5.2	8.3
		15 to 24	South East	25.5	23.1		27.9		15 to 24	South East	15.6	13.7	17.6
		25 to 49	South East	24.1	23.6		24.7		25 to 49	South East	19.5	18.9	20.0
0 to 14		London	10.8	8.7	12.8	0 to 14	London		15.9	13.4	18.3		
15 to 24		London	22.4	19.8	25.0	15 to 24	London		25.4	22.7	28.2		
25 to 49		London	27.7	27.0	28.4	25 to 49	London		22.4	21.8	23.1		
0 to 14		East	19.4	16.3	22.5	0 to 14	East		3.7	2.2	5.2		
15 to 24		East	28.5	25.2	31.8	15 to 24	East		11.0	8.7	13.3		
25 to 49		East	30.1	29.2	30.9	25 to 49	East		16.3	15.7	17.0		
0 to 14		West Midlands	12.3	9.7	14.9	0 to 14	West Midlands		4.8	3.1	6.5		
15 to 24		West Midlands	26.6	23.6	29.6	15 to 24	West Midlands		11.5	9.3	13.7		
25 to 49		West Midlands	26.0	25.2	26.8	25 to 49	West Midlands		12.0	11.4	12.6		
0 to 14		East Midlands	14.7	11.7	17.8	0 to 14	East Midlands		4.9	3.1	6.8		
15 to 24		East Midlands	25.0	21.7	28.3	15 to 24	East Midlands		7.4	5.4	9.4		
25 to 49		East Midlands	25.8	24.9	26.6	25 to 49	East Midlands		9.2	8.6	9.8		
0 to 14		Y&H	13.5	10.8	16.3	0 to 14	Y&H		4.3	2.7	5.9		
15 to 24		Y&H	26.5	23.6	29.5	15 to 24	Y&H		11.1	9.0	13.2		
25 to 49		Y&H	27.0	26.2	27.8	25 to 49	Y&H		11.3	10.7	11.8		
0 to 14		North West	14.3	11.8	16.8	0 to 14	North West		3.3	2.1	4.6		
15 to 24		North west	28.3	25.7	30.9	15 to 24	North west		9.7	8.0	11.4		
25 to 49		North west	30.7	30.0	31.4	25 to 49	North west		9.1	8.7	9.5		
0 to 14		North East	12.8	9.2	16.4	0 to 14	North East		3.0	1.2	4.9		
15 to 24		North East	30.9	26.6	35.3	15 to 24	North East		8.5	5.9	11.2		
25 to 49		North East	25.3	24.2	26.3	25 to 49	North East		9.1	8.4	9.8		
TWW		0 to 14	South West	1.6	0.6	2.6							
		15 to 24	South West	19.0	16.3	21.7							
		25 to 49	South West	31.9	31.1	32.7							
		0 to 14	South East	1.4	0.7	2.1							
		15 to 24	South East	17.3	15.2	19.3							
		25 to 49	South East	26.8	26.2	27.4							
	0 to 14	London	1.4	0.6	2.2								
	15 to 24	London	10.3	8.4	12.2								
	25 to 49	London	19.7	19.0	20.3								
	0 to 14	East	0.3	-0.1	0.8								
	15 to 24	East	17.4	14.6	20.2								
	25 to 49	East	27.1	26.3	27.8								
	0 to 14	West Midlands	2.7	1.4	4.0								
	15 to 24	West Midlands	17.9	15.3	20.6								
	25 to 49	West Midlands	31.8	31.0	32.7								
	0 to 14	East Midlands	0.8	0.0	1.5								
	15 to 24	East Midlands	21.8	18.7	25.0								
	25 to 49	East Midlands	34.3	33.4	35.2								
	0 to 14	Y&H	1.7	0.6	2.7								
	15 to 24	Y&H	16.4	13.9	18.8								
	25 to 49	Y&H	31.1	30.3	31.9								
	0 to 14	North West	1.9	0.9	2.8								
	15 to 24	North west	16.3	14.1	18.4								
	25 to 49	North west	28.2	27.5	28.9								
	0 to 14	North East	0.6	-0.2	1.4								
	15 to 24	North East	14.8	11.4	18.1								
	25 to 49	North East	32.7	31.6	33.9								

Table III: Percentage of patients referred by each routes among 15 to 24 year olds by diagnosis group

diagnosis group	route to diagnosis	% cases	95% CIs	
leukaemias	emergency presentations	59.3	55.6	71.0
	GP referrals	9.3	7.1	72.0
	TWW	1.4	0.5	73.0
	Other	18.2	15.4	74.0
	Unknown	11.8	9.4	75.0
lymphomas	emergency presentations	22.6	20.6	76.0
	GP referrals	30.9	28.7	77.0
	TWW	18.6	16.7	78.0
	Other	17.9	16.1	79.0
	Unknown	10.0	8.6	80.0
CNS	emergency presentations	47.7	43.6	81.0
	GP referrals	16.5	13.5	82.0
	TWW	0.5	-0.1	83.0
	Other	25.6	22.0	84.0
	Unknown	9.6	7.2	85.0
bone tumours	emergency presentations	30.0	25.6	86.0
	GP referrals	23.0	18.9	87.0
	TWW	6.8	4.4	88.0
	Other	29.5	25.1	89.0
	Unknown	10.7	7.7	90.0
STS	emergency presentations	24.1	19.4	91.0
	GP referrals	27.8	22.9	92.0
	TWW	6.8	4.0	93.0
	Other	25.9	21.1	94.0
	Unknown	15.4	11.5	95.0
germ cell tumours	emergency presentations	18.8	16.6	96.0
	GP referrals	18.3	16.2	97.0
	TWW	37.4	34.7	98.0
	Other	15.7	13.7	99.0
	Unknown	9.9	8.3	100.0
melanomas	emergency presentations	1.7	0.9	101.0
	GP referrals	33.2	30.3	102.0
	TWW	30.3	27.5	103.0
	Other	9.7	7.8	104.0
	Unknown	25.0	22.3	105.0
carcinomas	emergency presentations	20.0	18.1	106.0
	GP referrals	33.6	31.3	107.0
	TWW	7.4	6.2	108.0
	Other	26.6	24.4	109.0
	Unknown	12.4	10.8	110.0
other specified	emergency presentations	19.2	10.1	111.0
	GP referrals	26.0	15.9	112.0
	TWW	8.2	1.9	113.0
	Other	30.1	19.5	114.0
	Unknown	16.4	7.9	115.0
other unspecified	emergency presentations	22.7	4.8	116.0
	GP referrals	31.8	11.9	117.0
	TWW	0.0	0.0	118.0
	Other	22.7	4.8	119.0
	Unknown	22.7	4.8	120.0

Table IV: Percentage of patients referred by each routes among 0 to 14 year olds by diagnosis group

diagnosis group	route to diagnosis	% cases	95% CIs	
leukaemias	emergency presentati	68.9	66.8	71.0
	GP referrals	6.7	5.6	7.8
	TWW	0.7	0.3	1.1
	Other	17.7	16.0	19.4
	Unknown	6.0	4.9	7.0
lymphomas	emergency presentati	43.8	40.0	47.5
	GP referrals	23.5	20.3	26.7
	TWW	3.5	2.1	4.9
	Other	22.8	19.6	25.9
	Unknown	6.5	4.6	8.3
CNS	emergency presentati	57.2	54.4	60.0
	GP referrals	13.8	11.8	15.7
	TWW	0.5	0.1	0.9
	Other	22.3	20.0	24.6
	Unknown	6.3	4.9	7.6
bone tumours	emergency presentati	33.9	28.4	39.4
	GP referrals	18.7	14.2	23.2
	TWW	3.5	1.3	5.6
	Other	31.1	25.8	36.5
	Unknown	12.8	8.9	16.7
STS	emergency presentati	43.4	37.9	48.9
	GP referrals	19.2	14.8	23.5
	TWW	2.2	0.6	3.8
	Other	27.7	22.7	32.6
	Unknown	7.5	4.6	10.5
germ cell tumours	emergency presentati	42.9	36.0	49.7
	GP referrals	13.3	8.6	18.0
	TWW	1.5	-0.2	3.1
	Other	36.9	30.3	43.6
	Unknown	5.4	2.3	8.5
melanomas	emergency presentati	8.2	1.3	15.1
	GP referrals	44.3	31.7	56.8
	TWW	6.6	0.3	12.8
	Other	23.0	12.3	33.6
	Unknown	18.0	8.3	27.8
carcinomas	emergency presentati	25.5	19.5	31.4
	GP referrals	23.6	17.8	29.3
	TWW	1.9	0.1	3.8
	Other	42.8	36.0	49.5
	Unknown	6.3	3.0	9.5
other specified	emergency presentati	47.0	43.9	50.2
	GP referrals	13.0	10.9	15.1
	TWW	1.2	0.5	1.9
	Other	33.3	30.4	36.3
	Unknown	5.4	4.0	6.8
other unspecified	emergency presentati	37.5	13.0	62.0
	GP referrals	31.3	7.8	54.7
	TWW	0.0	0.0	0.0
	Other	31.3	7.8	54.7
	Unknown	0.0	0.0	0.0

Table V: Percentage of patients referred by each routes among 25 to 49 year olds by diagnosis group

diagnosis group	route to diagnosis	% cases	95% CIs	
leukaemias	emergency presentations	40.9	39.1	42.6
	GP referrals	20.2	18.8	21.7
	TWW	5.0	4.2	5.8
	Other	20.7	19.2	22.1
	Unknown	13.2	12.0	14.4
lymphomas	emergency presentations	20.4	19.6	21.3
	GP referrals	31.5	30.5	32.6
	TWW	16.1	15.3	16.9
	Other	19.9	19.0	20.8
	Unknown	12.0	11.3	12.7
CNS	emergency presentations	48.0	46.4	49.7
	GP referrals	16.2	14.9	17.4
	TWW	0.6	0.4	0.9
	Other	26.2	24.8	27.7
	Unknown	8.9	8.0	9.9
bone tumours	emergency presentations	18.8	15.4	22.1
	GP referrals	30.3	26.4	34.2
	TWW	7.2	5.0	9.4
	Other	31.4	27.5	35.4
	Unknown	12.3	9.5	15.1
STS	emergency presentations	16.6	15.1	18.1
	GP referrals	32.6	30.8	34.5
	TWW	7.9	6.9	9.0
	Other	24.1	22.4	25.8
	Unknown	18.8	17.2	20.3
germ cell tumours	emergency presentations	10.2	9.5	10.9
	GP referrals	18.1	17.2	19.1
	TWW	43.6	42.4	44.8
	Other	15.5	14.6	16.4
	Unknown	12.6	11.8	13.4
melanomas	emergency presentations	2.1	1.8	2.3
	GP referrals	29.6	28.8	30.4
	TWW	35.8	34.9	36.6
	Other	9.5	9.0	10.1
	Unknown	23.0	22.3	23.8
carcinomas	emergency presentations	11.2	11.0	11.4
	GP referrals	27.5	27.1	27.8
	TWW	31.0	30.7	31.4
	Other	17.0	16.8	17.3
	Unknown	13.3	13.0	13.5
other specified	emergency presentations	27.3	25.2	29.4
	GP referrals	27.9	25.8	30.1
	TWW	8.6	7.3	10.0
	Other	25.7	23.6	27.7
	Unknown	10.5	9.0	11.9
other unspecified	emergency presentations	39.5	34.2	44.8
	GP referrals	22.5	18.0	27.0
	TWW	7.0	4.2	9.8
	Other	20.1	15.7	24.4
	Unknown	10.9	7.6	14.3

Table VI: Number and percentage of patients referred by each routes for patients aged 0-49 years, by region of residence (GOR)

region	RTD	n	percentage cases	95% CI	
North East	Emergency presentation	1191	17.1	16.2	17.9
North west	Emergency presentation	2931	15.8	15.3	16.3
Y&H	Emergency presentation	2384	17.2	16.6	17.8
East Midlands	Emergency presentation	1832	15.8	15.1	16.4
West Midlands	Emergency presentation	2048	14.9	14.3	15.5
East	Emergency presentation	2016	14.9	14.3	15.4
London	Emergency presentation	2765	16.4	15.9	17.0
South East	Emergency presentation	3205	14.5	14.1	15.0
South West	Emergency presentation	2186	15.5	14.9	16.1
England	Emergency presentation	20,558	15.7	15.5	15.8
North East	GP referral	1747	25.0	24.0	26.0
North west	GP referral	5544	29.9	29.2	30.5
Y&H	GP referral	3659	26.4	25.6	27.1
East Midlands	GP referral	2926	25.2	24.4	26.0
West Midlands	GP referral	3493	25.4	24.7	26.1
East	GP referral	4003	29.5	28.7	30.3
London	GP referral	4473	26.5	25.9	27.2
South East	GP referral	5230	23.7	23.2	24.3
South West	GP referral	3578	25.3	24.6	26.0
England	GP referral	34,653	26.4	26.1	26.6
North East	Others *	2102	30.1	29.0	31.2
North west	Others *	4900	26.4	25.8	27.1
Y&H	Others *	4013	28.9	28.2	29.7
East Midlands	Others *	3719	32.0	31.2	32.9
West Midlands	Others *	4078	29.7	28.9	30.4
East	Others *	3437	25.3	24.6	26.1
London	Others *	3065	18.2	17.6	18.8
South East	Others *	5527	25.1	24.5	25.6
South West	Others *	4230	29.9	29.2	30.7
England	Others *	35,071	26.7	0.1	26.5
North East	TWW	1328	19.0	18.1	19.9
North west	TWW	3523	19.0	18.4	19.6
Y&H	TWW	2298	16.6	15.9	17.2
East Midlands	TWW	2098	18.1	17.4	18.8
West Midlands	TWW	2525	18.4	17.7	19.0
East	TWW	2021	14.9	14.3	15.5
London	TWW	2796	16.6	16.0	17.2
South East	TWW	3965	18.0	17.5	18.5
South West	TWW	2566	18.2	17.5	18.8
England	TWW	23,120	17.6	0.1	17.4
North East	Unknown †	611	8.8	8.1	9.4
North West	Unknown †	1650	8.9	8.5	9.3
Y&H	Unknown †	1521	11.0	10.4	11.5
East Midlands	Unknown †	1033	8.9	8.4	9.4
West Midlands	Unknown †	1597	11.6	11.1	12.2
East	Unknown †	2098	15.5	14.8	16.1
London	Unknown †	3751	22.3	21.6	22.9
South East	Unknown †	4118	18.7	18.2	19.2
South West	Unknown †	1572	11.1	10.6	11.6
England	Unknown †	17,951	13.7	13.5	13.9

Table VII: Number and percentage of patients referred by each routes for patients aged 0-49 years, by TYA diagnosis group

diagnosis group	RTD	n	percentage cases	95% CI	
leukaemias	Emergency presentation	2,954	52.8	51.5	54.1
lymphomas	Emergency presentation	2,332	22.3	21.5	23.1
CNS tumours	Emergency presentation	2,682	50.1	48.7	51.4
Bone tumours	Emergency presentation	320	26.1	23.6	28.5
soft tissue sarcomas	Emergency presentation	614	20.2	18.7	21.6
germ cell tumours	Emergency presentation	970	12.4	11.7	13.2
melanomas	Emergency presentation	271	2.1	1.8	2.3
carcinomas	Emergency presentation	9,333	11.4	11.2	11.6
other specified	Emergency presentation	941	34.0	32.3	35.8
other unspecified	Emergency presentation	141	38.4	33.4	43.4
leukaemias	GP referral	795	14.2	13.3	15.1
lymphomas	GP referral	3,230	30.9	30.0	31.8
CNS tumours	GP referral	838	15.6	14.7	16.6
Bone tumours	GP referral	308	25.1	22.7	27.5
soft tissue sarcomas	GP referral	935	30.7	29.1	32.3
germ cell tumours	GP referral	1,406	18.0	17.2	18.9
melanomas	GP referral	3,905	29.9	29.1	30.7
carcinomas	GP referral	22,525	27.6	27.3	27.9
other specified	GP referral	625	22.6	21.0	24.2
other unspecified	GP referral	86	23.4	19.1	27.8
leukaemias	TWW	173	3.1	2.6	3.5
lymphomas	TWW	1,641	15.7	15.0	16.4
CNS tumours	TWW	32	0.6	0.4	0.8
Bone tumours	TWW	76	6.2	4.8	7.5
soft tissue sarcomas	TWW	220	7.2	6.3	8.1
germ cell tumours	TWW	3,233	41.5	40.4	42.6
melanomas	TWW	4,596	35.2	34.4	36.0
carcinomas	TWW	24,911	30.5	30.2	30.8
other specified	TWW	166	6.0	5.1	6.9
other unspecified	TWW	23	6.3	3.8	8.8
leukaemias	Others *	1,084	19.4	18.3	20.4
lymphomas	Others *	2,068	19.8	19.0	20.6
CNS tumours	Others *	1,354	25.3	24.1	26.4
Bone tumours	Others *	377	30.7	28.1	33.3
soft tissue sarcomas	Others *	751	24.7	23.1	26.2
germ cell tumours	Others *	1,254	16.1	15.3	16.9
melanomas	Others *	1,254	9.6	9.1	10.1
carcinomas	Others *	14,114	17.3	17.0	17.5
other specified	Others *	788	28.5	26.8	30.2
other unspecified	Others *	76	20.7	16.6	24.9
leukaemias	Unknown †	590	10.5	9.7	11.3
lymphomas	Unknown †	1,180	11.3	10.7	11.9
CNS tumours	Unknown †	449	8.4	7.6	9.1
Bone tumours	Unknown †	146	11.9	10.1	13.7
soft tissue sarcomas	Unknown †	525	17.2	15.9	18.6
germ cell tumours	Unknown †	933	12.0	11.2	12.7
melanomas	Unknown †	3,020	23.1	22.4	23.9
carcinomas	Unknown †	10,822	13.2	13.0	13.5
other specified	Unknown †	245	8.9	7.8	9.9
other unspecified	Unknown †	41	11.2	7.9	14.4

The NCIN 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.

The National Cancer Intelligence Unit will be hosted by Public Health England from 1<sup>st</sup> 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