

INTRODUCTION

Ninety percent of children with cancer are now referred to a paediatric specialist centre which is considered to have led to better survival. To help improve outcomes and patient experience for 16 to 25 year olds, national recommendations were made in 2005 for the provision of age-appropriate care, and NHS Trusts in England have been working to implement this. Thirteen trusts 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 16-18 managed at a PTC and 19-24 year olds assessed at a PTC but given the choice of where they are treated.

Our aim was to assess the proportion of TYA cancer patients currently accessing these services.

METHODS

We used national cancer registration data to identify malignancies and border-line and benign CNS tumours diagnosed in England 2009-2010 among 15 to 24 year olds. We used the TYAC notification database to identify patient referrals to a TYA specialist MDT and cancer waiting times (CWT) data to identify place of treatment. Diagnoses were classified using the TYA classification system (Birch et al 2002). We then calculated the proportion of patients registered with a cancer diagnosis 2009-2010 who were notified via TYAC notifications as being referred to a TYA specialist MDT. These are presented by age, diagnosis and region (GOR) cancer network of residence. We also show the number and diagnostic distribution of patients by PTC who were not notified but who had a record of treatment at a PTC and show the age distribution of patients who were not notified and had no record of treatment at a PTC within CWT data.

RESULTS

- 63% of 15 to 18 years olds and 34% of 19 to 24 years olds diagnosed 2009-2010 were notified as referred to a TYA specialist MDT.
- 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. (figure 1)
- 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 (figure 2).

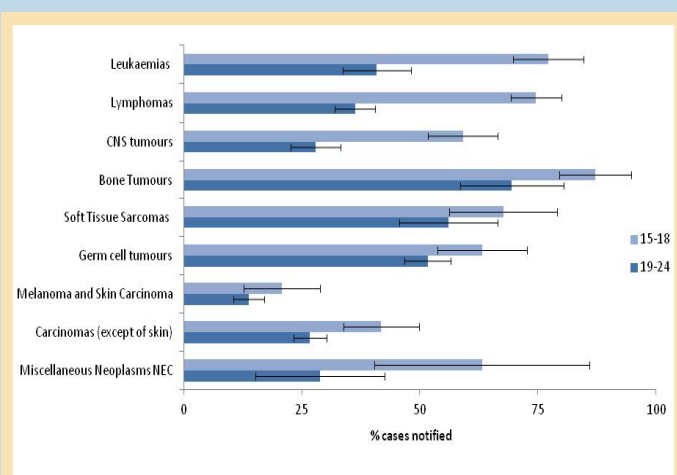


Figure 1: Percentage of patients diagnosed 2009-2010 who were notified by age group and diagnosis. Error bars represent 95% confidence intervals.

- For the 19 to 24 year olds percentage notifications ranged from 20% to 54% across GORs and from 6% to 70% across cancer networks (figure 2).
- 1347 (66%) patients who were not notified were matched to CWT data.
- 270 of these patients with a range of diagnoses (figure3) had a record of treatment at a PTC; 83% of which were aged 19 to 24 years
- 172 patients aged 15 to 18 and 888 patients aged 29 to 34 were not notified and had a CWT record of being treated at a non-PTC trust but not at a PTC trust (figure 4).

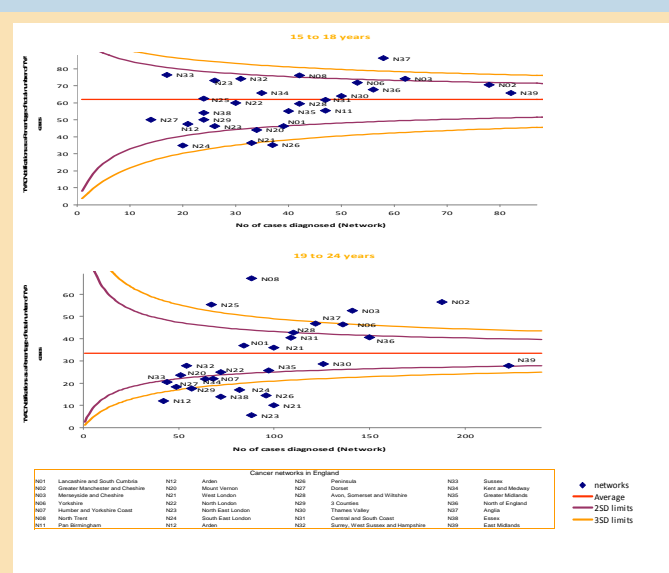


Figure 2: Percentage of patients aged 15 to 18 years and 19 to 24 years diagnosed 2009-2010 who were notified by cancer network of residence in England.

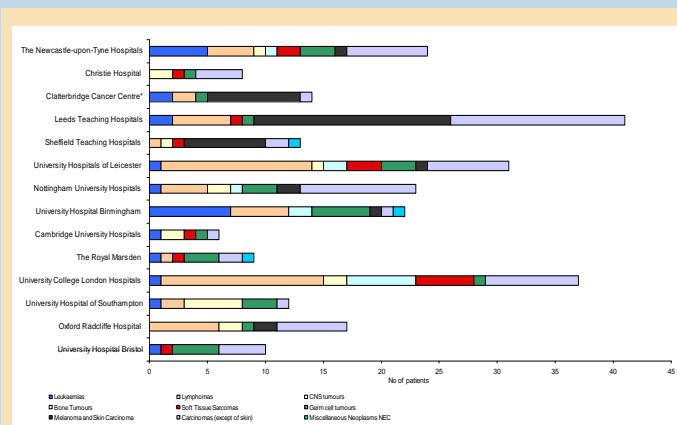


Figure 3: Number of patients aged 15 to 24 years diagnosed 2009 to 2010 who were treated at a PTC and not notified by diagnosis and treating PTC

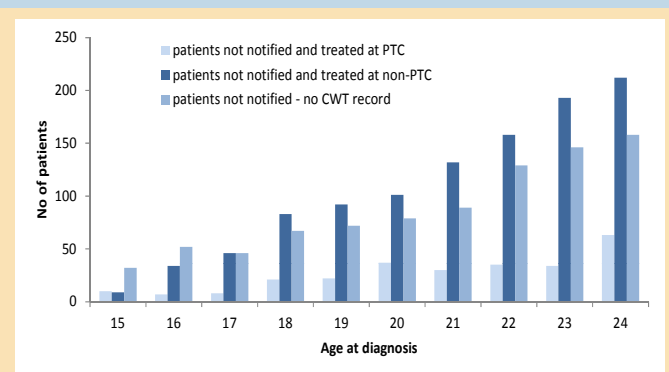


Figure 4: Non-notified TYA patients diagnosed 2009-2010 by age at diagnosis.

DISCUSSION

The most significant findings of this study 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.

Further work is underway to identify place of treatment for those patients whose place of treatment could not be identified using CWT data. Recent advancements in national cancer registration processes including the national cancer registration database (Encore) and COSD will provide a better understanding of the apparent disparities in PTC referral patterns for this age group across England.

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