



Original research

Recent trends in childhood, teenage and young adult cancer incidence in England (2001–2020)

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ABSTRACT

Introduction: Cancer remains a leading cause of death among children, teenagers and young adults (CTYAs) in England with a distinct incidence profile compared to older adults. We examined trends in cancer incidence among individuals aged < 25 years in England from 2001 to 2020 using openly available National Disease Registration Service (NDRS) data.

Materials and Methods: All malignancies (ICD-10 C00–C97) diagnosed between 2001 and 2020 were extracted from published NDRS official registration statistics. Analyses were stratified into children (0–14 years) and TYAs (15–24 years), with subanalyses by gender. Joinpoint regression analysis (SEER v5.4.0) was used to calculate annual percentage change (APC) in age-specific incidence and identify trend changes. 2020 data were excluded from trend analyses due to COVID-19 related disruption. Instant rate ratios (IRRs) directly compared rates in 2020–2019.

Results: Between 2001 and 2020, cancer incidence was 147 and 273 per million person-years in children and TYAs, respectively. In children, lymphoid leukaemia and brain/CNS tumours accounted for 46% of diagnoses. Among TYAs, Hodgkin lymphoma (15%) and malignant melanoma (9%) were most common, and 24% of male cancers were testicular. TYA colorectal cancer incidence increased until 2015, then declined from 2015 to 19 (APC –37.59%, $p < 0.001$). Thyroid cancer incidence rose throughout the study period (APC +5.49%, $p < 0.001$), while cervical cancer incidence declined from 2015 to 19 (APC –21.9%, $p = 0.03$). Cervical cancer incidence fell the most from 2019 to 2020 (IRR 0.38, $p = 0.09$).

Conclusions: Overall cancer incidence in CTYAs remains low. Trends in colorectal and cervical cancer may reflect appendiceal carcinoid reclassification, HPV vaccination, and COVID-19 related disruption to diagnostic and screening services.

1. Introduction

Cancer incidence amongst children, teenagers and young adults (CTYAs) is generally lower compared with older adults [1]. However, it remains a leading cause of death in this group in England. In 2024, cancer was the most common cause of mortality in children (0–14 years) outside the first year of life. In TYAs (15–24 years), only accidental deaths and suicide accounted for higher mortality rates [2]. Cancer in CTYAs has a significant long-term physical and mental health impact on

those affected [3], and national care standards recommend these patients are managed either in age-specialised oncology units or with age-appropriate multi-disciplinary team input [4].

Globally, cancer incidence in CTYAs varies considerably by age, cancer type and geographical region [5]. This may reflect variation in underlying genetic, infectious and environmental exposures, but also likely differences in access to healthcare, diagnostic capacity and completeness of cancer registration [6]. Studies based on international registry data suggest that childhood cancer rates have increased since

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the late 20th century, however, there is less to suggest significant change within the last 20 years [5,7]. Among adolescents and young adults, cancer incidence has reportedly increased in a number of high-income countries with increasing numbers of colorectal, thyroid, breast and gonadal tumours highlighted as drivers of this trend [8–10].

This analysis aimed to describe changes in cancer incidence in CTYAs in England, using gold standard cancer registry data from the National Disease Registration Service (NDRS) who provide national cancer statistics for England. By extracting incidence for specific cancers by age and gender over a period of 20 years, we aimed to better understand which cancers are driving incidence trends and how these have changed over time. Data from 2020 allowed illustration of the early effects of the COVID-19 pandemic on CTYA cancer diagnoses in England.

2. Materials and methods

Incidence data from the National Disease Registration Service (NDRS) accredited official national statistics for cancer registrations [11] were analysed for all malignant International Classification of Diseases (ICD-10) codes, C00-C97, in England between 2001 and 2020. Data were extracted for under 25 s in England, grouped into children (0–14 years) and TYAs (15–24 years). NDRS is part of NHS England and includes the National Cancer Registration and Analysis Service (NCRAS) which is the repository for the national cancer registry for England [12]. A national directive through Section 254 of the Health and Social Care Act 2012 allows NDRS to collect confidential individual-level data on patients with cancer without explicit consent, which is then reported anonymously. Healthcare providers are obliged to provide this information; data quality is rigorously assessed and monitored by NDRS. Data are collected via the nationally standardised Cancer Outcomes and Services Dataset (COSD) (multidisciplinary team meeting outcomes), introduced in 2013, pathology datafeeds, mortality datasets and Patient Administration System data to form a cancer registration. Prior to 2013, data were collected via eight regional cancer registries using similar sources [13]. Anonymised incidence rates released by NDRS are openly available and not identifiable; thus, patient consent was not required for this study. Denominator population data by five-year age group were extracted from the Office for National Statistics Official Census and Labour Market Statistics [14].

Diagnoses in the NDRS database are to the level of whole number ICD-10 codes based on the site of disease. Where overall cancer rates have been quoted, this is referring to the codes C00-C97 (all malignant cancers). Where rates have been broken down by malignancy, the below ICD-10 codes have been used, grouped where necessary for meaningful analysis. Those not listed were grouped as “other”.

- C18–20 – colorectal
- C40–41 – bone and articular cartilage
- C43 – malignant melanoma
- C44 – other malignant neoplasms of skin
- C49 – other connective and soft tissue
- C53 – cervical
- C56 - ovarian
- C62 - testicular
- C64 – kidney, excluding renal pelvis
- C69 – eye and adnexa
- C70–72 – brain and CNS
- C73 - thyroid
- C81 – Hodgkin lymphoma
- C82–86 – non-Hodgkin lymphoma
- C91 – lymphoid leukaemia
- C92–94 – myeloid leukaemia including acute monocytic, erythroleukaemic and megakaryocytic subtypes

All primary cancer diagnoses are counted in NDRS other than Basal Cell Carcinomas (BCC) and cutaneous Squamous Cell Carcinomas

(cSCC), included in C44 (non-melanoma skin cancers), which are reported using the 1st per patient per annum method. This means that only the first tumour diagnosed in a specific patient during each calendar year is recorded [13].

Joinpoint Regression Analysis Software (SEER v5.4.0) was used to form regression models and calculate annual percentage change (APC) for age-specific cancer incidence rates, with subanalyses by gender. The number of joinpoints recommended by the software was used, with a maximum of four joinpoints permitted. Holm-Bonferroni correction was applied to p-values for APC within age groups to account for multiple hypotheses.

Chi-squared analysis was performed to compare incidence of specific malignancies between genders. Statistical tests were 2-tailed and significance was defined as $p < 0.05$. Age specific incidence rates were reported as per 1,000,000 person years. Due to the impact of the COVID-19 pandemic on healthcare services, 2020 data were excluded from trend analyses. Incidence rate ratios (IRR) were calculated to directly compare rates in 2020–2019 using Medcalc and Poisson 95% confidence intervals [15]. As for APC, Holm-Bonferroni correction was applied to p-values for IRRs within age groups to account for multiple hypotheses.

3. Results

3.1. Overall incidence

Between 2001 and 2020 there were 64,276 new cancer diagnoses amongst CTYAs in England, with incidence rates of 147 per million person years in children and 273 per million person years in TYAs.

When divided into age bands (Table 1), incidence rates were highest amongst those aged 20–24 years and those under one year. The lowest rates were amongst those aged 5–14 years.

Overall cancer incidence in children showed a small but consistent increase across the study time period (APC +0.67%, $p < 0.001$). By contrast, cancer incidence amongst TYAs increased from 2001 to 2015 (APC +1.9%, $p < 0.001$) then fell from 2015 to 2019 (APC –3.1%, $p = 0.02$).

3.2. Incidence by malignancy

Amongst children, as seen in Fig. 1, lymphoid leukaemias made up 25% of diagnoses, brain and CNS neoplasms 21% and neoplasms of the kidney, excluding renal pelvis 6%.

Of the ten most common malignancies, rates of non-Hodgkin lymphoma markedly increased from 2017 to 2019, however, this was not statistically significant (APC +18.1%, $p = 0.67$). The rates of all ten malignancies can be seen in Table 2 and Fig. 2. Supplementary figure 1 shows a more detailed delineation of age-specific incidence rates by excluding lymphoid leukaemia.

Amongst TYAs, Hodgkin lymphomas encompassed 15% of diagnoses, cutaneous malignant melanomas 9% and brain and CNS neoplasms 7% of malignancies occurring in both genders (Fig. 3).

Of the ten most common malignancies (Table 3, Fig. 4), colorectal cancer, thyroid cancer and Hodgkin lymphoma showed significant changes in incidence over time. Colorectal cancer incidence increased from 2008 to 2015 (+18%, $p = 0.24$) then decreased from 2015 to 2019

Table 1
Age specific incidence rates 2001–2020 by age band.

Age band	Age-specific incidence rate 2001–2020 (per million person years)
Under 1 year	221
1–4 years	199
5–9 years	112
10–14 years	125
15–19 years	201
19–24 years	341

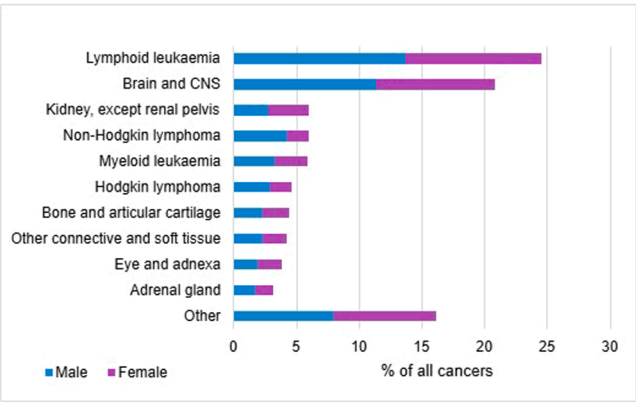


Fig. 1. Ten most common malignancies from 2001 to 2020 as a percentage of total C00-C97 diagnoses in children.

Table 2
Changing rates (per million person years) of the ten most common malignancies amongst children with identified jointpoints (ns = not significant).

Malignancy	Rate in 2001	Rate in 2019	APC with jointpoints
Lymphoid leukaemia	33.0	34.3	+ 0.10% (ns)
Brain and CNS	31.9	31.4	+ 0.15% (ns)
Kidney, excluding renal pelvis	8.5	8.3	+ 0.20% (ns)
Non-Hodgkin lymphoma	7.9	12.0	2001–2017: + 0.08% (ns) 2017–2019: + 18% (ns)
Myeloid leukaemia	8.3	9.0	-0.21% (ns)
Hodgkin lymphoma	6.2	7.4	-0.46% (ns)
Bone and articular cartilage	6.5	7.8	+ 0.31% (ns)
Other connective and soft tissue	5.8	5.6	2001–2017: + 1.9% (ns) 2017–2019: -17% (ns)
Eye and adnexa	3.9	5.5	+ 0.69% (ns)
Adrenal gland	4.8	6.5	+ 1.9% (ns)

(-38%, $p < 0.001$). APC in thyroid cancer was + 5.5% from 2001 to 2019 ($p < 0.001$) and Hodgkin lymphoma was + 1.8% ($p < 0.001$).

The incidence of malignant melanoma trended downwards from 2005 onwards (APC -3.0%, $p = 0.13$) and other malignant neoplasms of skin from 2013 (APC -6.4%, $p = 0.14$). A more detailed view of age-specific incidence excluding Hodgkin lymphoma can be seen in [supplementary figure 2](#).

3.3. Comparison by gender

In children, overall cancer incidence was slightly higher amongst males than females with rates of 157 per million and 137 per million, respectively. Non-Hodgkin lymphoma had a male:female incidence ratio of 2.3 (95% CI 2.1–2.6, $p < 0.001$) whereas renal tumours had a male:female ratio of 0.82 (95% CI 0.75–0.91, $p < 0.001$).

In TYAs, overall cancer incidence was similar for both genders (273 per million person years in males, 274 per million person years in females). Testicular cancers were the most common malignancy seen in male TYAs accounting for 24% of total diagnoses. In females, ovarian and cervical cancers were significant contributors to overall cancer burden making up 6.3% and 4.9% of total diagnoses, respectively.

Although to a lesser extent than in children, non-Hodgkin lymphoma

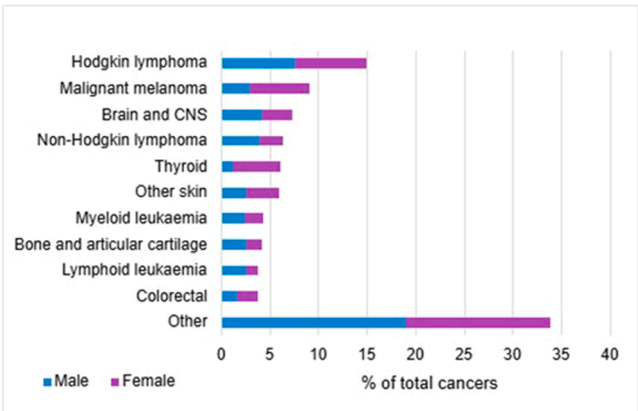


Fig. 3. Ten most common malignancies across 2001–2020 as a percentage of total C00-C97 diagnoses in TYAs.

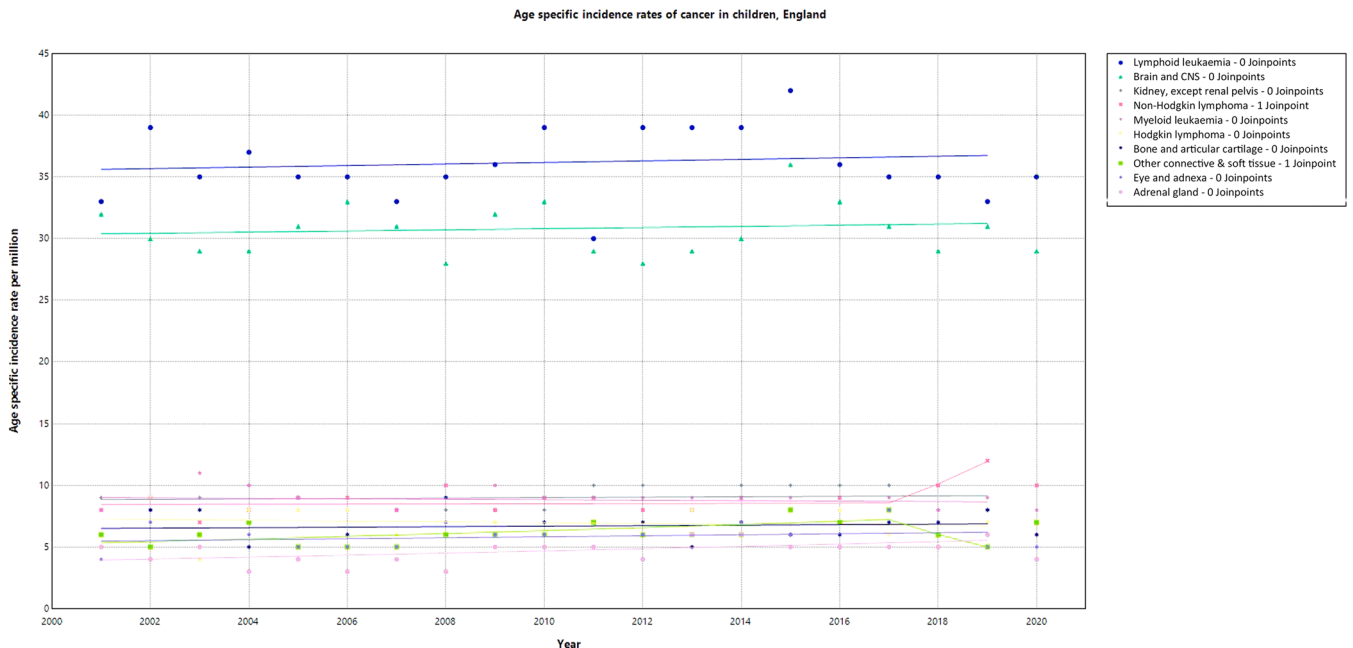


Fig. 2. Age specific incidence rates by year for the ten most common childhood malignancies (2000–2019) with jointpoints.

Table 3

Changing rates (per million person years) of the ten most common malignancies amongst TYAs with identified joinpoints (ns = not significant).

Malignancy	Rate in 2001	Rate in 2019	APC joinpoints
Hodgkin lymphoma	36.8	47.7	+ 1.8% (p < 0.001)
Malignant melanoma	27.2	18.0	2001–2005: + 6.4% (ns)2005–2019: –3.0% (ns)
Brain and CNS	17.2	21.2	+ 0.96% (ns)
Non-Hodgkin lymphoma	19.6	18.0	2001–2004: –5.4% (ns)2004–2019: + 0.70% (ns)
Thyroid	7.6	22.3	+ 5.5% (p < 0.001)
Other skin	12.3	13.7	2001–2013: + 3.6% (p = 0.01)2013–2019: –6.3% (ns)
Myeloid leukaemia	12.3	11.6	+ 0.94% (ns)
Bone and articular cartilage	13.1	12.9	–0.27% (ns)
Lymphoid leukaemia	9.0	9.6	+ 0.33% (ns)
Colorectal	5.8	5.0	2001–2008: + 1.8% (ns)2008–2015: + 18% (ns)2015–2019: –38% (p < 0.001)

was more frequent in male TYAs compared to females (M:F ratio 1.64 (95% CI 1.51–1.79, p < 0.001)). In female TYAs, thyroid cancer and malignant melanoma incidence were both elevated compared to males (M:F 0.26 (95% CI 0.23–0.29, p < 0.001); 0.47 (95% CI 0.44–0.51, p < 0.001)).

In male TYAs, testicular cancer incidence declined from 2014 to 2019 (APC –3.0%, p = 0.06). In female TYAs, incidence of cervical cancer increased from 2011 to 2015 (APC +16%, p = 0.06) then fell from 2015 to 2019 (APC –22%, p = 0.03). Rates of ovarian cancer showed a smaller, but significant, increase across the time period (APC +2.7%, p < 0.001).

3.4. Effect of COVID-19

Overall incidence was lower across all ages in 2020 compared to 2019, although the differences were not statistically significant. In

children, the incidence rate ratio (IRR) was 0.95 and in TYAs 0.94. The most marked difference was seen in cervical cancer incidence amongst female TYAs (IRR 0.38, 95% CI 0.17–0.79, p = 0.1).

4. Discussion

Overall CTYA cancer incidence rates remained low compared to older age groups and aligned with those reported for other countries in Europe, North America and Oceania [5,7]. However, there was a small but significant increase in rates of childhood cancer from 2001 to 2019, and a reduction in TYA rates from 2015. This is not in keeping with reports of an ongoing increase in rates amongst adolescents and young adults in developed countries [7,9,10]. One potential explanation for this discrepancy is the contribution of the marked rise and then fall of colorectal cancer incidence, which coincides with the changing classification of appendiceal carcinoid tumours. Updates in WHO classifications and ICD-O-3 behaviour codes meant that many of these neuroendocrine tumours that would previously have been classified as benign were counted as malignant from around 2013. From 2015, however, they were assigned a separate ICD code so were no longer included in colorectal cancer (C18–20) registration numbers [16,17].

There are several reports of increasing rates of early onset colorectal cancer [18,19] with proposed mechanisms including the increased prevalence of obesity and increased exposure to other lifestyle related risk factors [20]. Notably, however, early onset is generally defined as under 50 years with less focus on the TYA group. A recent study in Germany [21] found an APC in colorectal cancer incidence of + 4.4% in males and + 6.4% in females aged 20–29 from 1999 to 2018, which fell to + 0.77% in males and + 0.53% in females with the exclusion of appendiceal cancers. It is also noted that absolute numbers of colorectal cancers remain low (under 50 cases per year) in this group compared to older age bands.

Rising rates of thyroid cancer in TYAs have been widely reported [22], and increased detection of early-stage disease is thought to play a significant role [23]. However, increased prevalence of obesity amongst adolescents and young adults in developed countries has also been implicated [23,24].

Declining skin cancer incidence in TYAs (melanoma and non-melanoma subtypes) was not statistically significant in our study.

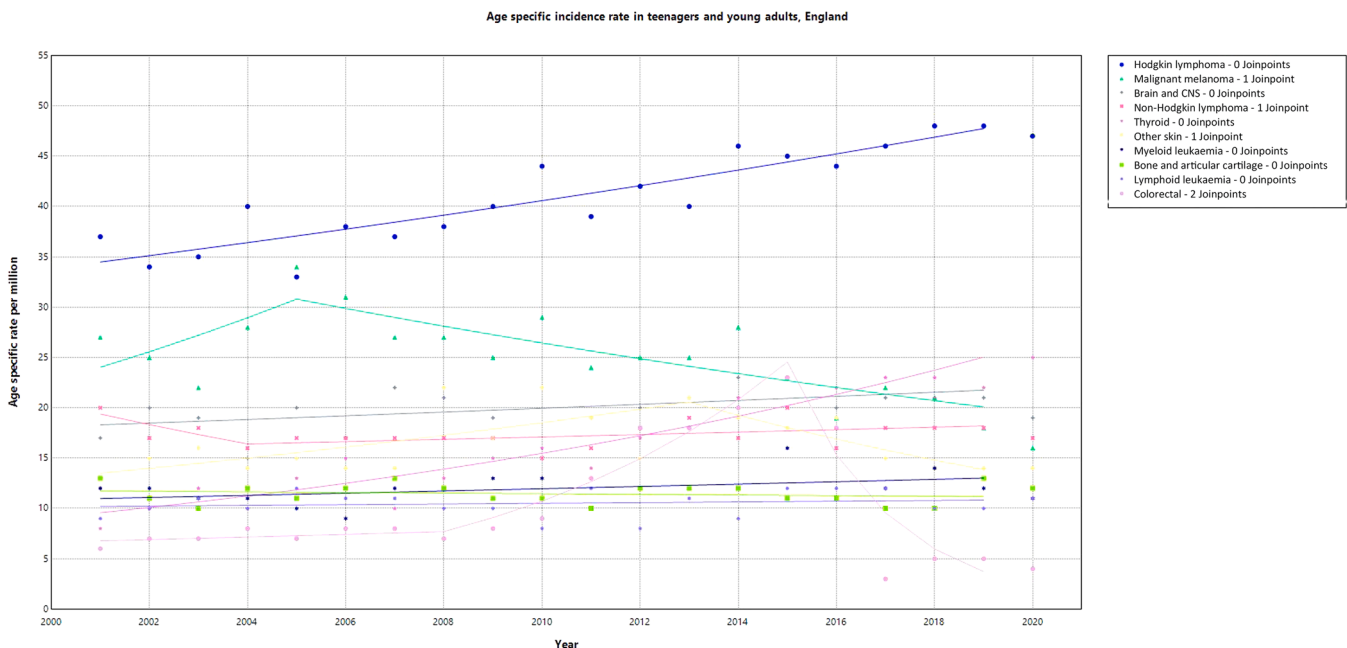


Fig. 4. Age specific incidence rates by year for the ten most common TYA malignancies (2000–2019) with joinpoints.

However, the same trend has been reported in similarly predominantly fair-skinned populations elsewhere [25–27], and hypothesised to reflect increased awareness of risk factors such as sun exposure and outdoor behaviour. The TYA population in England is also increasingly ethnically diverse with greater representation of more melanin-rich skin types which confer lower risk of developing these cancers [27].

Of note, non-melanoma skin cancers made up just over 6% of total diagnoses in the TYA group. The majority of these cases are BCC and cSCC, which are reported in NDRS using the first per patient per annum method, felt to better represent tumour burden than the first all-time method previously used. It was therefore not possible in this analysis with publicly available data to estimate what proportion of total TYA patients had non-melanoma skin cancers, particularly as patients in this age group are likely to have and are uniquely predisposed to multiple tumours per person through predisposition syndromes such as Gorlin syndrome. However, detailed statistics published by NDRS 2013–2020 reported that 81.9% of BCCs and cSCCs in under 25 s were first all-time tumours [28,29]. Anecdotally, non-melanoma skin cancers make up less than 6% of diagnoses typically referred to regional TYA cancer services, leading to a suspicion that some patients may not be accessing TYA-specific care via standard commissioning pathways. Moreover, many international cancer registries [30,31] do not collect data on BCC and cSCC incidence. We stress the need for better representation of BCCs and cSCCs in global cancer statistics given their not insignificant contribution to TYA cancer burden in our study.

Cervical cancer incidence showed increased then subsequently declined over the second decade of the study period. The observed initial increase, whilst not statistically significant, aligns with a change to the UK screening programme in 2012 when the age of first invitation was lowered from 25 to 24.5 years and thus diagnoses made via screening were included in the TYA group for the first time [32]. Split by five-year age band, 988 of 1027 (96%) of cervical cancer diagnoses amongst TYAs from 2001 to 2020 were in those aged 20–24 compared to 15–19 years [28]. The noted significant subsequent decline in incidence could partially reflect the early effects of the HPV vaccination programme rolled out in the United Kingdom in 2008 [33].

The negative impact of the COVID-19 pandemic on cancer diagnosis and treatment was a global issue. Studies in adult populations have identified associated delays in presentation and likely increased morbidity and mortality [34]. A recent study of GP records in England correlated with our findings of reduced diagnoses in CTYAs during the pandemic period [35]. Moreover, it found that children diagnosed with cancer during the pandemic were more likely to be admitted to intensive care in the 14 days prior to diagnosis. Cervical cancer rates, unsurprisingly, appear to have been especially affected. Routine cervical cancer screening invitations in England were substantially reduced from April to June 2020. Even when reinstated at full volume, survey data suggests that a significant proportion of women were reluctant to attend screening appointments during this time due to fears related to COVID-19 [36].

This study identified temporal trends in cancer incidence, and whilst potential contributors to these have been discussed, causal mechanisms cannot be inferred from our data. Several other factors should also be considered when interpreting these trends. For instance, advances in imaging techniques were associated with a stepwise increase in recorded incidence for childhood CNS tumours in the late 20th century [37] and are likely to have had an impact on thyroid cancer numbers in our study as described above. Changes in tumour classification can also affect incidence estimates. NDRS acknowledges some regional variability in coding practices prior to 2013, and specific trends must be interpreted with more caution because of this. Pre-2013 registration numbers for non-melanoma skin cancers, for instance, may be underestimated and thus unreliable for temporal comparison [13].

Strengths of this study include national data coverage. Whilst NDRS shifted from data collection via regional cancer registries to the national provider-based reporting system in 2013, the eight regions together still

provided comprehensive coverage with cancer registrations estimated to be 96–99% complete for each year since 2001 [38]. By contrast, global availability of cancer incidence data is variable, and even where countries have a population-based registry this does not guarantee geographical coverage. Recent data from 190 countries found that only 52% had a population-based registry and 43% had national coverage [39]. Indeed, another study aiming to depict international childhood cancer incidence trends estimated that 11.4% of the world population aged 0–14 were covered by the analysed registry data [5]. Often registries are based on datasets from specific hospitals or regions, risking data that is not generalisable to the whole country.

A significant limitation of this study is its reliance on site-based ICD-10 codes presented in the publicly available data which are limited to the level of whole numbers and do not optimally capture many of the tumours common in children and young people. Neuroblastomas, for example, are tumours originating from neural crest cells, multipotent stem cells seen in embryonal development, and are the most common extra-cranial solid tumour seen in children globally [40]. They can present throughout the body and will therefore be included in adrenal, autonomic nervous system and other site numbers in our study. Furthermore, renal tumours made up 6% of childhood cancers in our study. The NDRS detailed statistics output for kidney cancer [28] report that 89% of renal cancers in this group 2013–2020 were nephroblastomas (Wilms tumours), however, this is not inferable from ICD-10 data alone.

Overall, these data depict the current CTYA cancer landscape in England and inform the need for an ongoing tailored approach to oncology care in this group compared to older adults. The effect of appendiceal carcinoid tumours on colorectal cancer trends needs to be extracted to better understand whether there has been a true change in TYA colorectal cancer rates and, if so, whether lifestyle-related risk factors such as obesity are playing a role. Non-melanoma skin cancers made up more TYA diagnoses than expected, and ensuring appropriate systems are in place for referral of these patients for age-specific care should be a focus moving forwards. Finally, the COVID-19 pandemic clearly had an impact on cancer care and, particularly in the case of cervical cancer, it will be important to analyse the longer-term effects of reduced cancer screening and diagnoses during this time.

CRedit authorship contribution statement

Charles Stiller: Writing – review & editing. **McCabe Martin:** Writing – review & editing, Supervision. **Venables Zoe:** Writing – review & editing, Resources, Methodology, Data curation, Conceptualization. **Levell Nick:** Writing – review & editing. **Sophie Thompson:** Writing – review & editing, Writing – original draft, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization.

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Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Zoe C Venables: Non financial conflict supporting research projects from Regeneron, Merck and SkinAnalytics with funds provided only to the local research department. ZV is section editor for the British Journal of Dermatologists. ‘All remaining authors have declared no conflicts of interest’

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.ejca.2026.117448](https://doi.org/10.1016/j.ejca.2026.117448).

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