Public Health England

Children, teenagers and young adults UK cancer statistics report 2021

Report on behalf of the National Cancer Registration and Analysis Service for England (Public Health England), the Northern Ireland Cancer Registry, the Scottish Cancer Registry (part of Public Health Scotland), and the Welsh Cancer Intelligence and Surveillance Unit (part of Public Health Wales)

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Executive summary

Cancer is rare during childhood, adolescence and young adulthood. Successive national cancer strategies have recommended that cancer among this age group should be managed in an age-appropriate environment by professionals with expertise both in the cancers that occur at this age and in the holistic care of children and teenagers and young adults (TYA) respectively. As a result, childhood and TYA cancer care has become increasingly specialised and successive periods have witnessed improvements in survival outcomes. However, despite some notable successes in improving survival, cancer remains the most common cause of childhood death outside of infancy, and the most common disease-related cause of death in teenagers and young adults (TYAs): only accidents and suicide are responsible for more deaths in this age group.

For many years, UK-wide data on the incidence and survival of childhood cancer (ages 0-14 years) were reported by the University of Oxford's National Registry of Childhood Tumours, and subsequently TYA cancer data (15-24 years) were collated and reported by the North West Cancer Intelligence Service. There have been no detailed UK-wide reports of cancer incidence, survival or mortality since 2012, and there has never been a report that combined the analysis of data throughout the child-TYA age spectrum, despite many cancers typical of this age affecting both children and TYA. The absence of contemporary UK-wide data and the siloed nature of age-specific analyses limited to children and TYA are recognised to be unhelpful in understanding UK-wide progress in the management of these rare cancers. Therefore, the four UK national cancer registries have come together to describe for the first time the incidence, survival and mortality from cancer diagnosed among children, teenagers and young adults resident in the United Kingdom, based on data from the National Cancer Registration and Analysis Service for England (Public Health England), the Northern Ireland Cancer Registry, the Scottish Cancer Registry, and the Welsh Cancer Intelligence and Surveillance Unit. Our analysis relates to children and young people who were diagnosed with cancer under the age of 25 during the 20-year period of 1997-2016. The UK cancer registries use data provided by patients that is collected by the health service as part of their care and support.

Cancer occurrence and outcomes in children and in TYAs are already included in reports by population-based cancer registries of the United Kingdom. However, there are several reasons why a special analysis is needed. The classification of tumours used for adults is principally based on their anatomical site, while it is the cell type that is more important in classifying cancers in children and TYA. The International Classification of Childhood Cancer, third edition (ICCC-3) is a more meaningful alternative and has been used in this report. Cancers in children and young people are relatively uncommon but as a result it can be difficult to draw inferences from small numbers in individual cancer registries. It is therefore an advantage to bring together data from all countries that comprise the United Kingdom to provide more precise results.

While cancer is rare in young people there were around 75,000 young persons diagnosed with cancer over the twenty years of this study, approximately 3,755 per year. There were around 33,000 cases diagnosed in children (0-14 year olds), an average of 1,645 cases per year, and 42,000 cases for TYAs (15-24 year olds), 2,110 per year.

Among children aged 0-14 years at diagnosis, leukaemia accounted for 31% of registrations, central nervous system (CNS) and miscellaneous intracranial and intraspinal neoplasms for 25%, lymphomas for 10%, soft-tissue sarcomas for 6%, neuroblastoma and other peripheral nervous cell tumours for 6%, and renal tumours for 6%. Among TYA aged 15-24 years at diagnosis, carcinomas (other than renal, hepatic and gonadal) and malignant melanomas accounted for 30% of registrations, lymphomas for 20%, germ cell, trophoblastic and gonadal tumours for 16%, CNS and miscellaneous intracranial and intraspinal neoplasms for 12%, leukaemia for 9%, and soft-tissue sarcomas for 5%. No other diagnostic groups accounted for more than 5% of registrations in the respective age ranges.

Among young people aged 15-24 malignant melanoma was twice as frequent in females as it was in males. Melanoma accounted for 10% of all cancer registrations in this age group, and skin carcinomas for a further 5%. Both of these cancer types are highly amenable to primary prevention, and health improvement interventions to reduce exposure to ultraviolet light and particularly to avoid sunburn and use of sunbeds[1] could potentially prevent around 15% of all cancers in young people aged 15-24. Cervical carcinoma accounted for 6% of cancers in females aged 15-24 and is largely preventable through vaccination against human papillomavirus.

Overall, five-year survival increased from 77% for children under 15 years of age who were diagnosed in 1997-2001 to 84% for those diagnosed in 2012-2016. Five-year survival for TYA aged 15-24 years increased from 79% to 87% between the same two periods. Survival also increased over the study period for many categories of cancer, including lymphoid leukaemia, acute myeloid leukaemia, chronic myeloid leukaemia, chronic myeloproliferative diseases, myelodysplastic syndrome (in children), Hodgkin lymphoma, non-Hodgkin lymphomas, astrocytoma, other and mixed gliomas, brain stem glioma (in children), meningioma (in TYA), neuroblastoma (in children), osteosarcoma, Ewing sarcoma family of tumours (in TYA), rhabdomyosarcoma, CNS germinoma (in TYA), breast carcinoma (in TYA) and malignant melanoma (in TYA).

Some categories which already had an excellent prognosis with five-year survival exceeding 90% during the study period, with little room for further improvement; include pilocytic astrocytoma, pituitary adenoma and carcinoma, craniopharyngioma, retinoblastoma, nephroblastoma (Wilms tumour), gonadal germ-cell tumours, thyroid carcinoma and skin carcinoma.

[1] T.R. Fears, J. Scotto, M.A. Schneiderman. Mathematical models of age and ultraviolet effects on the incidence of skin cancer among whites in the United States. Am. J. Epidemiol., 105 (5) (1977), pp. 420-427

The trend of survival increase was not uniform across the entire period, and there are several cancers with poorer prognosis which there has been little evidence of improvement in the most recent periods, notably ependymoma, medulloblastoma, hepatoblastoma, Ewing sarcoma in children and colorectal carcinomas in TYAs. TYAs continued to have worse survival than children for osteosarcoma, Ewing sarcoma and rhabdomyosarcoma, without any recent improvement. However, while TYA survival remains worse than childhood survival for acute lymphoid and myeloid leukaemia and non-Hodgkin lymphomas, the gap has reduced over time.

Cancer in children, teenagers and young adults accounts for 0.3% of all cancer deaths in the UK. In 2018 there were around 260 childhood cancer deaths, accounting for 7% of all childhood deaths (0-14 year olds). For teenagers and young adults (15-24 year olds) there were nearly 290 cancer deaths, accounting for 11% of all TYA deaths. For comparison, cancer accounts for almost 30% of all deaths in the whole UK population.

The present report provides detailed baseline data on cancer incidence and survival among children and TYA in the four UK nations over the 20-year period 1997-2016. In addition to providing updated statistics, future work might include analysis of trends in incidence rates and research into the reasons for any variations in incidence and survival between the four nations.

Sources of cancer data and classification schemes used in the report

Cancer registration data were obtained from Public Health England's National Cancer Registration and Analysis Service (NCRAS), the Northern Ireland Cancer Registry, the Scottish Cancer Registry, and the Welsh Cancer Intelligence and Surveillance Unit. The incidence data in this report relate to children and young people who were residents of the UK, under 25 years of age and diagnosed with a malignant neoplasm or non-malignant CNS tumour included in the International Classification of Childhood Cancer, Third Edition (ICCC-3)[2] during 1997-2016. The cancer classification by Birch and Barr[3] has a more detailed classification schema for cancers of epithelial origin (carcinomas) and is frequently used to classify cancers of adolescence and young adulthood. However, the Birch and Barr classification is not sufficiently detailed for the description of cancers of childhood particularly for those cancers that occur in early childhood. For this report, a decision was made to use the ICCC-3 for all cases irrespective of age, with modifications to adequately classify carcinomas and to allow direct comparison between children,

[2] Steliarova-Foucher E[1], Stiller C, Lacour B, Kaatsch P (2005). International Classification of Childhood Cancer, third edition. *Cancer*, 1457-1467

[3] Barr RD, Holowaty EJ, Birch JM (2006). Classification schemes for tumors diagnosed in adolescents and young adults, *Cancer,* Apr 1;106(7):1425-30

teenagers and young adults. Langerhans cell histiocytosis and neuroendocrine/carcinoid tumours of appendix were excluded, because they were mostly regarded as non-malignant until towards the end of the study period and registration was consequently not complete. The total number of cancer registrations analysed was 75,103.

ICCC-3 was defined according to codes in the International Classification of Diseases for Oncology, Third Edition (ICD-O-3). For this report, ICCC-3 was modified to accommodate morphology codes that have been introduced in the first and second revisions of ICD-O-3. The classification of carcinomas in ICCC-3 was expanded to cover all the most common sites for these tumours in the TYA age range. For some detailed analyses, certain categories were split as follows: Ic Chronic myeloproliferative diseases into chronic myeloid leukaemia and other chronic myeloproliferative diseases; Id myelodysplastic syndrome and other myeloproliferative diseases into juvenile myelomonocytic leukaemia & chronic myelomonocytic leukaemia and myelodysplastic syndrome; IIIa.2 choroid plexus tumours into choroid plexus carcinoma and choroid plexus papilloma; astrocytoma into pilocytic astrocytoma and other astrocytomas. Part or all of existing categories were combined to create additional categories for brain stem gliomas, optic nerve tumours, Ewing sarcoma family of tumours, and hepatic sarcomas. For tumours of paired organs, multiple diagnoses of the same tumour morphology (or one that was compatible but less specific) in the same patient with different laterality were converted into a single bilateral case. The cancer classifications used for this report are listed in Appendix A.

Cancer incidence

Numbers of newly diagnosed cancer cases:

Cancer incidence measures the number of new cases of cancer in an at-risk population diagnosed over a given period. It is a useful measure of the need for diagnostic and treatment services and, in some cases, of the effectiveness of preventive interventions. Statistics can be provided as the total number of cases or as rates. Rates are often presented as the number of cases per 100,000 population per year. In this report incidence rates are presented as the number of cases per million population as this makes smaller numbers more meaningful. Incidence rates can be ‘crude’ or age-standardised. The crude rate is the actual observed rate calculated by dividing the number of patients who live in a given area by the population of that area. Age-standardised rates (ASRs) adjust the proportions of different age-groups so that they are always the same, using the World Standard Population. This minimises the effects of differences in the age structure of populations over time or between countries.

Our analysis relates to children and young people who were diagnosed with cancer under the age of 25 and who were residents of the UK during the 20-year period of 1997-2016. Incidence rates were calculated per million person years for the age groups 0-4, 5-9, 10-

14, 15-19 and 20-24 years based on annual UK population estimates.[4] For children aged 0-14, teenagers and young adults aged 15-24, and the full 0-24 age range, age-standardised rates were calculated using the World Standard Population, which assigns weights of 12, 10, 9, 9 and 8 to the age groups 0-4, 5-9, 10-14, 15-19 and 20-24 years respectively.[5] Cumulative risk was calculated as the sum of the age-specific incidence rates for the five-year age groups, each multiplied by 5, the number of years contained in each age group.

Table 2 in Appendix B shows numbers of cancer registrations in the 12 main ICCC-3 cancer groups, together with the percentage recorded as having microscopic verification (%MV) and the percentage registered from a death certificate only (%DCO) for the UK and the constituent countries. Table 3 in Appendix B shows the same data as Table 2 for subgroups and divisions of the diagnostic classification and for certain other subsets of particular interest, for the UK only.

There were 75,103 young persons diagnosed with cancer over the 20 years of this study, approximately 3,755 per year. The mean numbers of cancer registrations per year were 1,645 in children and 2,110 in TYA. The mean annual numbers in the four UK nations were 3,112 (1,378 children and 1,734 TYA) in England, 123 (53 children and 70 TYA) in Northern Ireland, 318 (129 children and 189 TYA) in Scotland and 202 (85 children and 117 TYA) in Wales.

Figures 1 and 2 show the annual numbers of registrations for the ICCC-3 main groups and subgroups among children and TYA respectively. Similar data for all subgroups are shown in table 3 in Appendix B. Among children, leukaemia accounted for 31% of registrations, CNS and miscellaneous intracranial and intraspinal neoplasms (hereafter referred to as CNS tumours) for 25%, lymphomas for 10%, soft-tissue sarcomas for 6%, neuroblastoma and other peripheral nervous cell tumours for 6%, and renal tumours for 6%. Among TYA, lymphomas accounted for 20% of registrations, germ cell, trophoblastic and gonadal tumours for 16%, CNS tumours for 12%, malignant melanomas for 10%, leukaemia for 9%, and soft-tissue sarcomas, skin carcinomas and thyroid carcinomas each for 5%. Carcinomas (other than renal, hepatic and gonadal) and malignant melanomas accounted for 30% of cancers among TYA. No other diagnostic groups accounted for more than 5% of registrations in the respective age ranges.

[4] Population Estimates for UK, England and Wales, Scotland and Northern Ireland, Crown Copyright Office for National Statistics, accessed December 2019

[5] Glossary of Terms, Cancer Incidence in Five Continents (CI5) series, International Association of Cancer Registries, https://ci5.iarc.fr/CI5I-X/Pages/glossary.aspx

There were several distinctive patterns of occurrence by age (Figure 3 and Table 3). For many types of cancer, numbers were highest before five years of age. These included lymphoid leukaemia, ependymoma & choroid plexus tumours, intracranial & intraspinal embryonal tumours (mainly medulloblastoma), neuroblastoma, retinoblastoma, nephroblastoma & other nonepithelial renal tumours, hepatoblastoma, and rhabdomyosarcoma. For other types, numbers were low in the first few years of life and increased throughout childhood and the TYA age range. Examples include Hodgkin lymphoma, non-Hodgkin lymphoma, malignant melanoma, and nearly all carcinomas. Numbers were lowest at 5-9 years of age for acute myeloid leukaemia, and for malignant extracranial and extragonadal germ cell tumours. Leukaemia formed the most frequent group before five years of age, when they accounted for 37% of all cancers. At age 5-9 years, leukaemia and CNS tumours each accounted for 32-33% of all cancers for this age group.

By contrast, numbers increased to reach a maximum at age 10-14 or 15-19 and decreased thereafter for osteosarcoma, Ewing sarcoma family of tumours, and intracranial & intraspinal germ cell tumours. CNS tumours were the most frequent group at age 10-14, accounting for 26% of all cancers. At age 15-19 years, lymphomas accounted for 23% of all cancers. At age 20-24 years, 36% of all cancers were carcinomas. Comparisons of incidence by sex are covered in the incidence rates section below.

Overall, 92.7% of registrations were recorded as microscopically verified. In general, a pathological sample (microscopic verification) is needed to confirm a cancer diagnosis and guide treatment. However, for some cancer sites (for example, those of the central nervous system) it is sometimes not safe or not needed to take a tissue sample and the diagnosis is then usually based on radiological findings. We would therefore expect the MV proportion to be high but not 100%. There was some variation between countries in the proportion of cases overall and by disease group with microscopic verification. To some extent this may be a coding issue: practices have changed differently over time in the four national registries. In general, recording of microscopic verification is better now than at the start of the period, and is a focus of attention for the individual registries.

The only main diagnostic groups to have less than 90% MV were CNS tumours (80.8%), retinoblastoma (68.1%) and other and unspecified malignant neoplasms (38.3%). The lower %MV for CNS tumours and retinoblastoma are a consequence of the relatively low proportions of tumours in these categories that are biopsied, while the low %MV for other and unspecified malignant tumours reflects the provisional nature of the data for a high proportion of patients in this small and miscellaneous group.

Overall, only 0.2% of all registrations were DCO; the percentage of DCO was below 0.4% in all the main diagnostic groups except other and unspecified malignant neoplasms, where they accounted for 1.1% of registrations. The relative frequencies of the %MV and

%DCO overall and for the main diagnostic groups were typical of those for cancer registries with high-quality data in Europe, North America and Oceania.[6]

[6] International Incidence of Childhood Cancer 3 (IICC-3), https://iicc.iarc.fr/

Figure 1: Mean number of newly diagnosed cancer cases per year registered among children under 15 years of age and resident in the UK, 1997-2016, grouped according to 'International Classification of Childhood Cancer, Third Edition' (ICCC-3)

Source: National Cancer Registration and Analysis Service for England (Public Health England), the Northern Ireland Cancer Registry, the Scottish Cancer Registry, and the Welsh Cancer Intelligence and Surveillance Unit

Mean number of cases for persons are shown in brackets by the cancer classifications labels. The mean number for persons does not always sum the mean number of males and females due to rounding. Only cancer groupings I-XI with 10 cases per year and over are displayed on the chart.

= Males, main ICCC-3 cancer classification
= Males, subgroup ICCC-3 cancer classification
= Females, main ICCC-3 cancer classification
= Females, subgroup ICCC-3 cancer classification

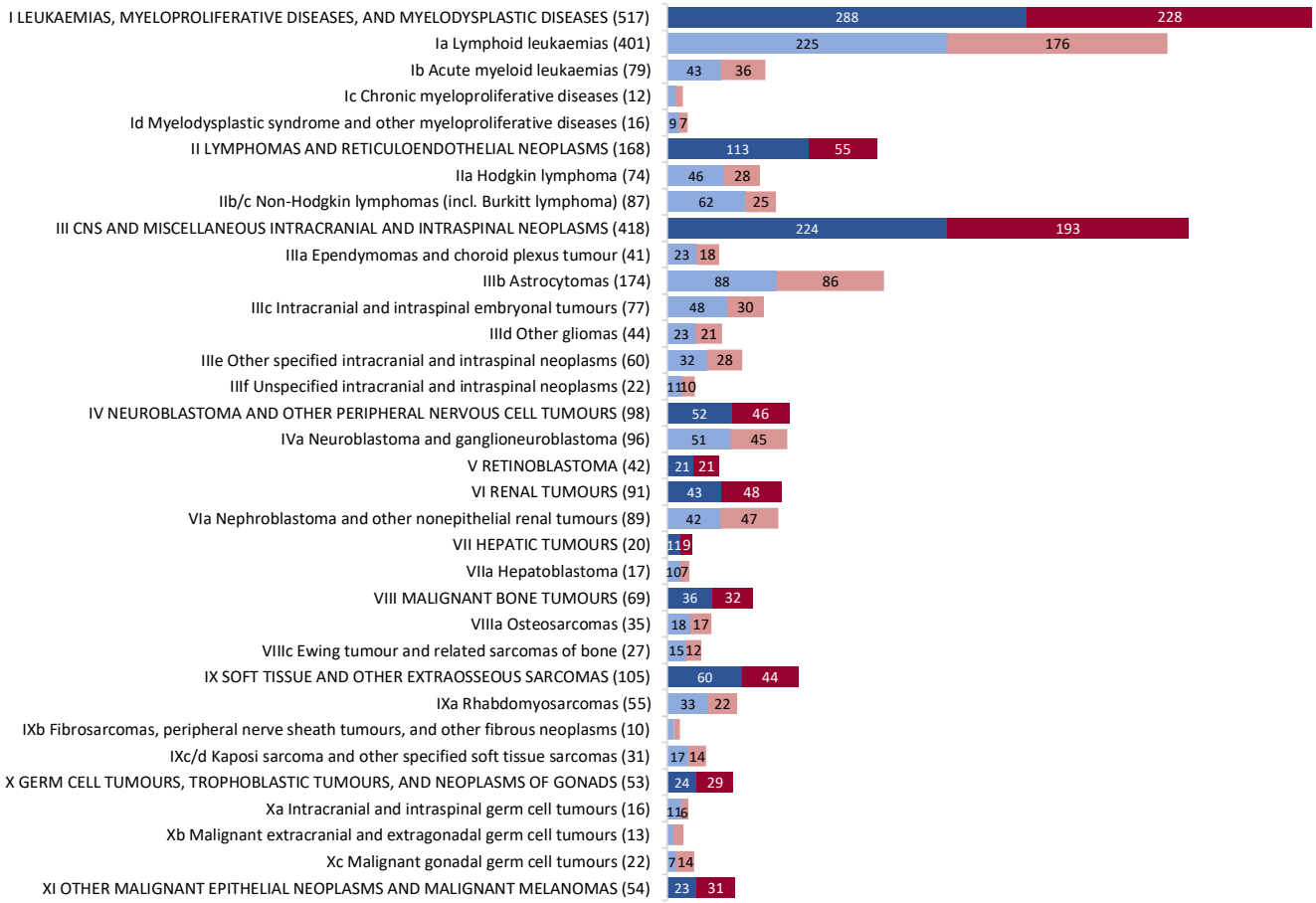


Figure 2: Mean number of newly diagnosed cancer cases per year registered among teenagers and young adults 15-24 years of age and resident in the UK, 1997 to 2016, grouped according to 'International Classification of Childhood Cancer, Third Edition' (ICCC-3)

Source: National Cancer Registration and Analysis Service (NCRAS) for England (Public Health England), the Northern Ireland Cancer Registry, the Scottish Cancer Registry, and the Welsh Cancer Intelligence and Surveillance Unit

Mean number of cases for persons are shown in brackets by the cancer classifications labels. The mean number for persons does not always sum the mean number of males and females due to rounding. Only cancer groupings I-XI with 20 cases per year and over are displayed on the chart.

= Males, main ICCC-3 cancer classification
= Females, main ICCC-3 cancer classification
= Males, subgroup ICCC-3 cancer classification
= Females, subgroup ICCC-3 cancer classification

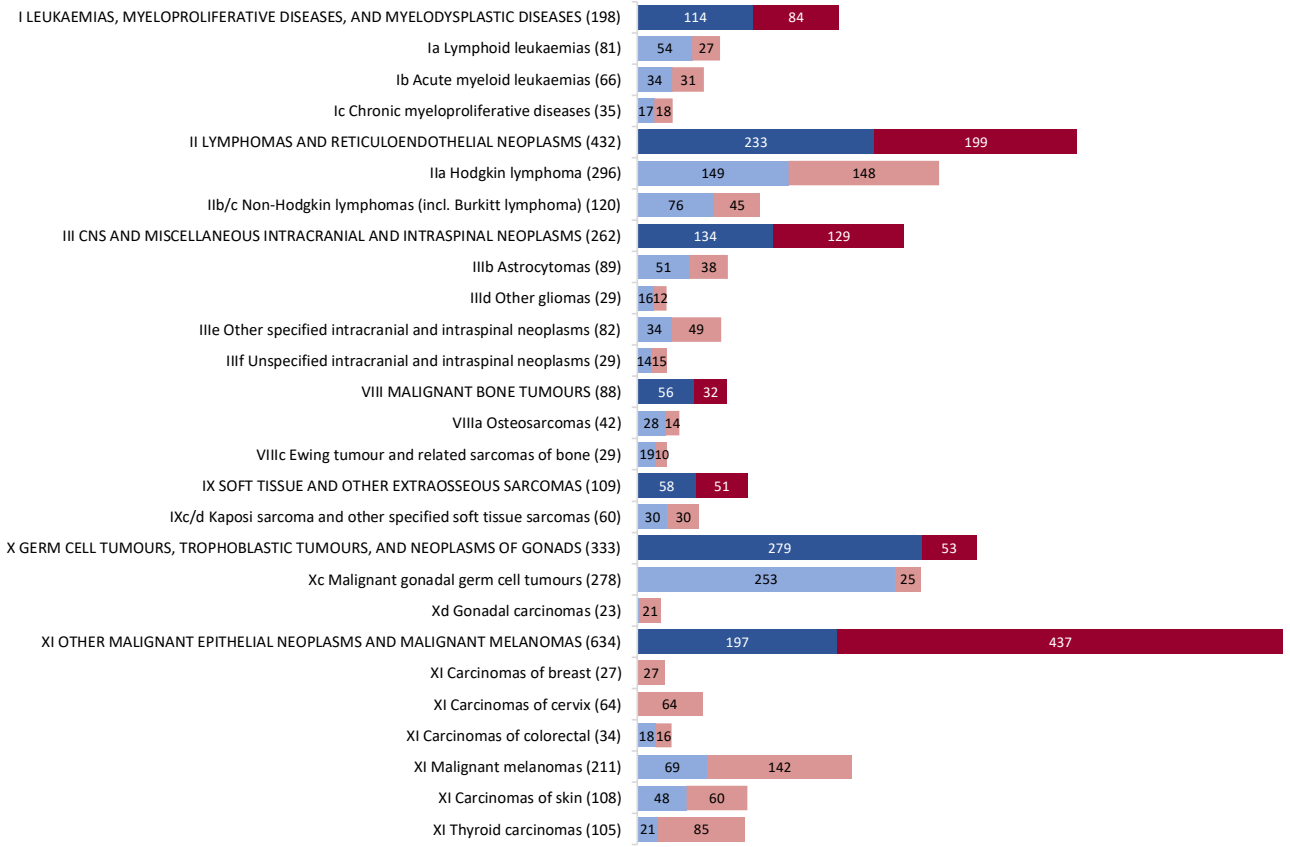
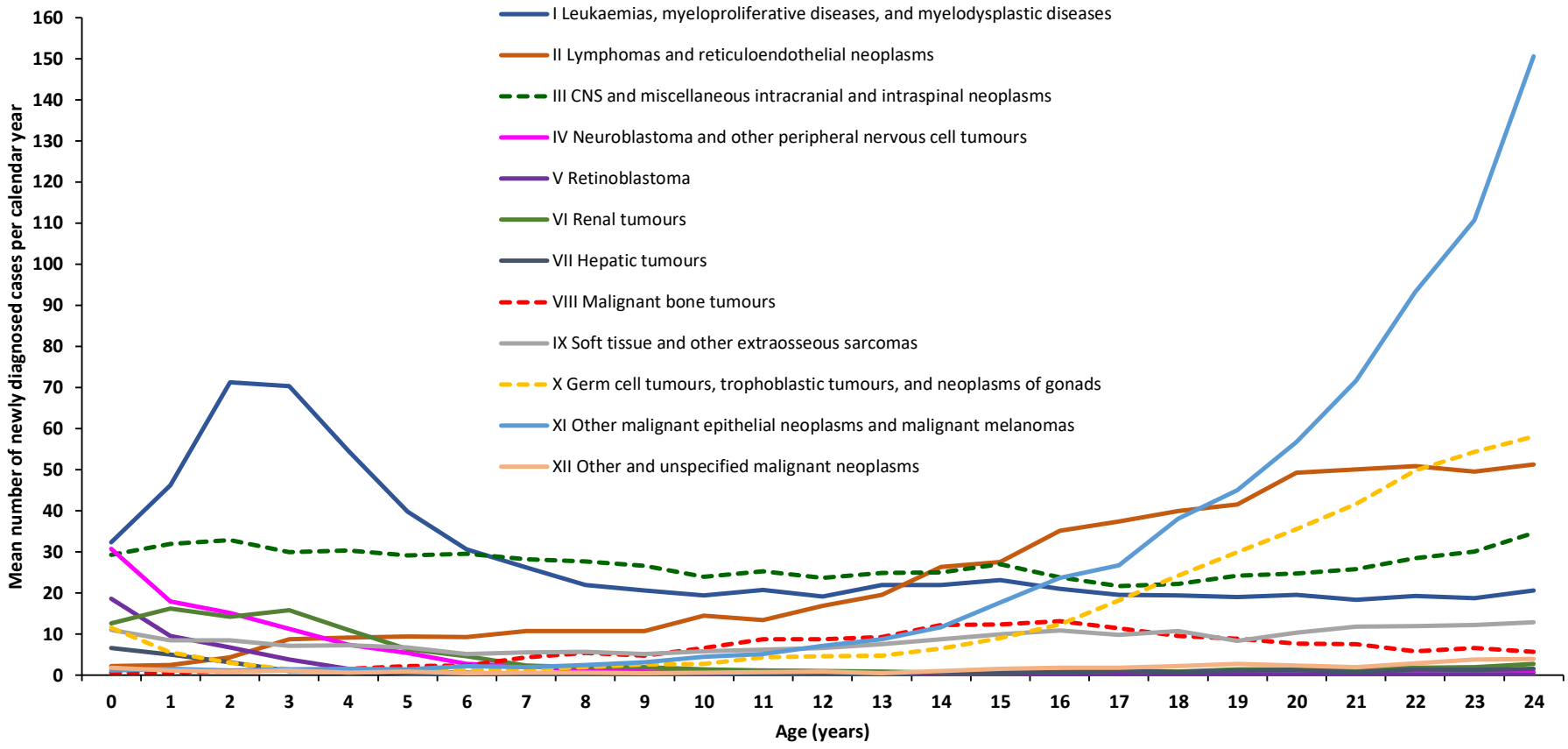


Figure 3: Mean number of newly diagnosed cancer cases per year registered among those under 25 years of age and resident in the UK, 1997-2016, grouped according to 'International Classification of Childhood Cancer, Third Edition' (ICCC-3) and age

Source: National Cancer Registration and Analysis Service (NCRAS) for England (Public Health England), the Northern Ireland Cancer Registry, the Scottish Cancer Registry, and the Welsh Cancer Intelligence and Surveillance Unit



Incidence rates:

Table 4 in Appendix B shows cancer incidence rates in children, teenagers and young adults by ICCC-3 main group for males and females separately for the UK and the constituent countries. Corresponding data for subgroups and divisions of the diagnostic classification and for certain other subsets of particular interest are shown in Table 5, for the UK only.

The total ASR for age 0-24 years was 202 per million in males and 182 per million in females. For children aged 0-14 years, the ASR was 162 per million in males and 141 per million in females. For TYA aged 15-24 years, the ASR were 273 per million in males and 258 per million in females. The sex ratio of ASRs was M/F=1.11 overall, M/F=1.15 at age 0-14, and M/F=1.06 at age 15-24.

The cumulative risk of being diagnosed with cancer in the first 15 years of life was 1 in 422 for males and 1 in 488 for females. The cumulative risk within the TYA age range was 1 in 361 for males and 1 in 382 for females. The total cumulative risk in the first 25 years of life was 1 in 194 for males and 1 in 214 for females. Within childhood, incidence was highest in the first five years for both males and females, fell to a minimum at age 5-9 years, and was slightly higher at age 10-14 years, marking the start of the unbroken rise in incidence that continues into the teenage years and throughout adulthood. Incidence rates were within the ranges reported from other countries in Europe, North America and Oceania.[7,8]

Generally, the incidence rates across the UK nations are comparable. Where there was some variation in incidence rates between UK nations, possible explanations for the differences include chance findings (made more likely by multiple statistical testing), differences in the proportion of registrations with information on morphology, and real differences in incidence. Differences in rates for CNS tumours might also result from differences in coding or recording of cases between registries (for instance, increased recording of certain asymptomatic or low grade tumours). Higher incidence of melanoma in Scotland and Northern Ireland than in England and Wales is consistent with the pattern throughout adulthood.[8]

The variation between UK nations in the incidence of carcinoma of the cervix below age 25 during 1997-2016 reflects differences between the nations over time in the age at first invitation to cervical cancer screening. At the start of the study period in 1997, the age at first invitation was 20 years throughout the UK. It was increased to 25 years in England in 2004, then slightly lowered to 24.5 years in 2012 in order to increase the proportion of young women screened as

[7] International Incidence of Childhood Cancer 3 (IICC-3), https://iicc.iarc.fr/

[8] Bray F, Colombet M, Mery L, Piñeros M, Znaor A, Zanetti R and Ferlay J, editors (2017). Cancer Incidence in Five Continents, Vol. XI (electronic version). Lyon: International Agency for Research on Cancer. Available from: https://ci5.iarc.fr, accessed January 2021

close as possible to their 25th birthday.[9] Age at first invitation was increased from 20 to 25 in Northern Ireland in January 2011, in Wales in September 2013, and in Scotland in June 2016.

The sex ratio varied between diagnostic categories. Among diagnostic categories with at least 50 registrations (Table 5), the highest sex ratio of ASRs was for malignant gonadal germ cell tumours, M/F=5.9. This is largely because testicular tumours are mainly of germ cell origin. There were also relatively marked male excesses for intracranial & intraspinal germ cell tumours, M/F=2.8, non-Hodgkin lymphoma (including Burkitt lymphoma), M/F=2.0, and medulloblastoma, M/F=1.8. For several categories of epithelial cancers, incidence was higher among females than males. Breast carcinoma, which is extremely rare in males of all ages, had a sex ratio of F/M>100. Other categories with at least 50 registrations that had marked female excesses were gonadal carcinoma, M/F=0.1, thyroid carcinoma, M/F=0.3, malignant melanoma, M/F=0.5, salivary carcinoma, M/F=0.5, and skin carcinoma, M/F=0.8. There was also a pronounced female excess for nephroblastoma (Wilms tumour), M/F=0.8.

There were also some notable variations in sex ratio by age. For lymphoid leukaemia, astrocytoma other than pilocytic, osteosarcoma, Ewing sarcoma family of tumours, and CNS germ cell tumours, the male excess was much more pronounced among TYA than among children. Contrastingly, Hodgkin and non-Hodgkin lymphomas both had substantial male excesses in childhood, whereas at age 15-24 years the male excess of non-Hodgkin lymphoma was much smaller, and males and females had approximately equal ASRs for Hodgkin lymphoma; Hodgkin lymphoma in fact had the highest incidence of any cancer among female TYA. Malignant melanoma was more frequent among females than males at all ages, but the sex ratio F/M increased with age from 1.3 in childhood to 1.9 at aged 15-19 and 2.2 at age 20-24; malignant melanoma was the most frequent cancer among females aged 20-24 years. Gonadal germ cell tumours were more frequent among males than females at age 0-4 and, especially, at age 15-24 years, whereas at age 5-14 there was a marked female excess. Testicular germ cell tumours were the most frequent cancer among male TYA and accounted for 29% of all cancers among males aged 20-24 years.

Population-based survival

Survival estimates are the percentages of patients who are still alive at a specified time after their diagnosis of cancer, in this report we focus on five-year survival. Survival is a useful measure of the effectiveness of efforts to detect and diagnose cancers at an early stage and to treat them effectively.

Our analyses are for children and TYA who were residents of the UK and had a diagnosis of any malignant neoplasm or non-malignant CNS tumour included in ICCC-3

[9] Castanon A, Sasieni P. Is the recent increase in cervical cancer in women aged 20-24 years in England a cause for concern? Prev Med. 2018;107:21-28

during the 20-year period of 1997-2016. The dataset was the same as for the incidence analyses, except that cases ascertained by death certificate only were excluded (135 cases) and cases removed if lost to follow-up. For people with multiple primary tumours, when calculating survival for all cancers combined, only the first primary tumours within the study period were included in the cohort count (1,077 multiple cases were removed).[10] The study censoring date for follow-up was 31 December 2018. Observed survival was estimated actuarially by Kaplan-Meier analysis using the 'complete' approach, in which all patients are included, not just those who have at least five years of follow-up. Trend in survival by single year of diagnosis was analysed by Cox regression and tested by the $\chi 2$ test with 1 degree of freedom. A trend was defined as statistically significant if the p-value was less than 0.05. Given the large number of cancer groups for which a test for trend is reported, it should be remembered that some significant results would be expected to occur by chance.

Five-year survival rates for all cancers combined and for ICCC-3 main groups are shown in Tables 6, 7 and 8 in Appendix B for children, TYA and the whole 0-24 age group respectively for the UK and the constituent countries. Detailed results for cancer subgroups and divisions of the diagnostic classification and for certain other subsets of particular interest are tabulated in Tables 9, 10 and 11 in Appendix B, for the UK only. In addition to results for persons diagnosed during the single 20-year period 1997-2016, results are given for 1997-2001, 2002-2006, 2007-2011 and 2012-2016 for diagnostic categories with at least 30 registrations in each of the four five-year periods.

Figures 4, 5 and 6 below show survival for all cancers combined for 0-14 year olds, 15-24 year olds and 0-24 year olds in the UK. Appendix C shows the UK survival charts for subgroups and divisions of the diagnostic classification and for certain other subsets of particular interest.

Five-year survival by age:

Five-year survival for children under 15 years of age who were diagnosed with cancer in 1997-2016 was 81%, slightly lower than for TYA aged 15-24 years, 84% (Tables 6 and 7). This pattern was not, however, replicated across all diagnostic categories; with some instances where children aged under 15 had the better survival.

Despite relatively small numbers, the survival estimate was higher in Wales for childhood and TYA CNS tumours and for TYA leukaemias than in England and the UK as a whole. Possible explanations for this observation include: differences in coding or recording of cases between registries (for instance, increased recording of certain

[10] This follows the principle used for survival analysis published by the Office for National Statistics and Public Health England. The number of cases included in this survival analysis will differ to National Statistics released by each UK nation, such as the "*Childhood cancer survival in England: Children diagnosed from 2001 to 2017 and followed up to 2018)*" published by the Office for National Statistics and Public Health England. The cancer cases for the analysis in this report have been classified using ICD-O-3 and with different definitions from those used for the National Statistics. For example, cancers of the skin other than melanoma and secondary and unspecified malignant neoplasms were included in our study but were excluded in the National Statistics. The data cleaning process for the analysis in this report also differs from that applied for the National Statistics.

populations of asymptomatic or low grade tumours such as children with neurofibromatosis type I-related optic pathway gliomas); a chance finding (made more likely by multiple statistical testing of a defined population); and a real difference in survival. The differences were most marked in the early period and are a focus for investigation by the registries.

Overall, five-year survival from diagnosis with leukaemia was higher for children than for TYA, 85% compared with 68% in the UK. Children also had markedly higher survival than TYA for lymphoid leukaemia (89% vs. 65%) and acute myeloid leukaemia (67% vs. 57%), but lower survival than TYA for chronic myeloproliferative diseases (85% vs. 92%) and myelodysplastic syndrome and other myeloproliferative diseases (68% vs. 81%).

Survival from all lymphomas combined was 90% for children and for TYA. Survival from Hodgkin lymphoma was very high both for children (96%) and TYA (95%). For non-Hodgkin lymphoma (including Burkitt lymphoma) children had higher survival (86%) than TYA (80%), and the difference between the age groups was most marked for precursor-cell lymphomas (82% vs. 63%) and for Burkitt lymphoma (88% vs. 79%). Treatment strategies vary between the two age groups and it is unclear to what extent the differences in survival between children and TYA, albeit modest, reflect different biology versus different treatment approaches.

Survival from CNS tumours was lower for children (74%) than for TYA (78%). The survival gap in favour of TYA was wider for ependymoma (children 71%, TYA 88%), medulloblastoma (children 65%, TYA 75%) and for mixed and unspecified gliomas (children 44%, TYA 64%). Survival exceeded 90% in both children and TYA for pilocytic astrocytoma, craniopharyngioma and neuronal and mixed neuronal glial tumours. For astrocytomas other than pilocytic astrocytoma, children had higher survival (66%) than TYA (50%). The spectrum of CNS tumours is different between young children, older children, adolescents and young adults, and a simple comparison of survival between CNS tumours in children and TYA misses much relevant detail. Even within a single tumour type, there may be marked morphological and biological differences with age. For example, the four major medulloblastoma subgroups have characteristic and distinct age peaks and outcomes that vary between infancy, mid-childhood and young adulthood, while the molecularly defined grade II-III ependymomas characteristic of young children are uncommon in TYA and older adults, who are more likely to have WHO grade I tumours or molecularly distinct grade II-III tumours.

Survival from neuroblastoma and other peripheral nervous cell tumours was similar for children (66%) and TYA (69%). Within that category, however, survival from neuroblastoma (including ganglioneuroblastoma) was higher for children (66%) than for TYA (53%).

Five-year survival of children with retinoblastoma was 99% while no cases were registered among TYA during the study period.

Children with renal tumours had higher survival (88%) than TYA (71%). The great majority of renal tumours in children were nephroblastoma (Wilms tumour), with survival of 91%, whereas most renal tumours in TYA were carcinomas, with somewhat lower survival of 71%. The survival gap in favour of children was much greater for hepatic tumours (children 74%, TYA 30%). Most hepatic tumours in children were hepatoblastoma, with five-year survival of 79%, but nearly all those in TYA were carcinomas for which survival was only 29%.

Children had higher survival than TYA from bone tumours (66% vs. 62%) and soft-tissue sarcomas (71% vs. 65%). The largest difference in survival within these categories was for rhabdomyosarcoma (children 69%, TYA 37%). Rhabdomyosarcoma still has one of the worst outcomes of any cancers in the TYA age group. The difference between childhood and TYA rhabdomyosarcoma survival is likely to be due, at least in part, to the relatively higher prevalence of fusion-negative tumours in children and fusion-positive or pleomorphic tumours in TYAs. Children also had higher survival than TYA with Ewing sarcoma family tumours, arising in bone and soft tissues (children 67%, TYA 52%). Survival from osteosarcoma, the most frequent bone tumour in people under 25 years old, was 60% for ages 0-24 years with little difference between children and TYA.

Survival of children and TYA with CNS germ-cell tumours was 88%, with little difference between the two age groups. For germ-cell tumours of other extragonadal and extracranial sites, children had higher survival (87%) than TYA (71%). Survival from gonadal germ-cell tumours was over 96% for children and for TYA. Gonadal carcinomas were rare in children but had survival of 77% in TYA.

Among children, five-year survival exceeded 95% for carcinomas in each of the two most frequent sites, thyroid and skin. Among TYA, in whom carcinomas are more frequent, survival varied widely by subgroup. Within the head and neck, five-year survival ranged from over 95% for thyroid and salivary glands to 73% for nasopharynx and 79% for other head and neck sites. Survival from carcinomas of trachea, bronchus and lung was 78% overall, but within this group of sites it was 97% for neuroendocrine tumours and 44% for other histological types. Five-year survival of TYA with carcinomas in the other most frequent sites was 99% for skin, 84% for cervix, 80% for breast, 57% for colorectal (except appendix), and 41% for stomach and other upper gastrointestinal tract. Survival from malignant melanoma was lower for children (86%) than for TYA (94%).

Survival trends:

Overall, five-year survival was 77% for children under 15 years of age who were diagnosed in 1997-2001, 79% for those diagnosed in 2002-2006, 82% for those diagnosed

in 2007-2011, and 84% for those diagnosed in 2012-2016 (Table 6). Five-year survival was 79% for teenagers and young adults aged 15-24 years who were diagnosed in 1997-2001, 83% for those diagnosed in 2002-2006, 86% for those diagnosed in 2007-2011, and 87% for those diagnosed in 2012-2016 (Table 7). For both age groups, the trends in survival by period of diagnosis were highly significant ($p<0.001$).

There were also significant increasing trends in survival during 1997-2016 for many diagnostic categories, including lymphoid leukaemia, acute myeloid leukaemia, chronic myeloid leukaemia, chronic myeloproliferative diseases, myelodysplastic syndrome (in children), Hodgkin lymphoma, non-Hodgkin lymphomas, astrocytoma, other and mixed gliomas, brain stem glioma (in children), meningioma (in TYA), neuroblastoma (in children), osteosarcoma, Ewing sarcoma family of tumours (in TYA), rhabdomyosarcoma, CNS germinoma (in TYA), breast carcinoma (in TYA) and malignant melanoma (in TYA).

Some categories which already had an excellent prognosis with five-year survival exceeding 90% during the study period, with little room for further improvement; include pilocytic astrocytoma, pituitary adenoma and carcinoma, craniopharyngioma, retinoblastoma, nephroblastoma (Wilms tumour), gonadal germ-cell tumours, thyroid carcinoma and skin carcinoma.

The trend of survival increase was not uniform across the entire period, and there are several cancers with poorer prognosis which there has been little evidence of improvement in the most recent periods, notably ependymoma, medulloblastoma, hepatoblastoma, Ewing sarcoma in children and colorectal carcinomas in TYAs. TYAs continued to have worse survival than children for osteosarcoma, Ewing sarcoma and rhabdomyosarcoma, without any recent improvement. However, while TYA survival remains worse than childhood survival for acute lymphoid and myeloid leukaemia and non-Hodgkin lymphomas, the gap has reduced over time.

The improvements in survival witnessed in acute myeloid leukaemia and acute lymphoblastic leukaemia during the period, which were relatively greater in TYA than in children, were likely to be due to successive improvements in treatment related to clinical trials in the two diseases, combined with a change in overall treatment strategy in acute lymphoblastic leukaemia in TYA patients from a typical 'adult' strategy to a more 'paediatric' strategy following the recognition that TYA patients had higher survival when treated according to paediatric protocols.

The introduction of novel targeted treatments for both Hodgkin and non-Hodgkin lymphomas is likely to have contributed to improvements in survival in both age groups seen over the study period seen over the study period.

The gradual improvement in survival seen across several CNS tumours throughout the period in children and TYA is encouraging but cannot be ascribed to a single factor.

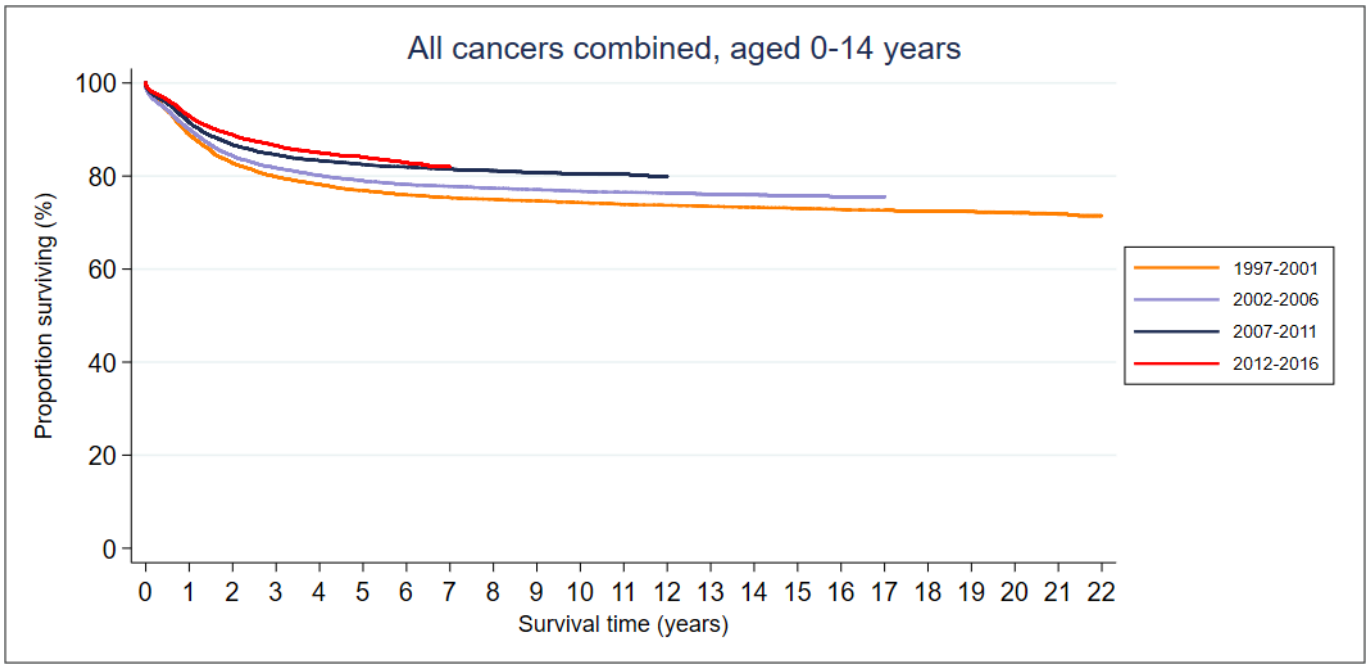
Increasing specialisation of diagnostic imaging, molecular pathology and histopathology, and technical refinements in neurosurgery and radiotherapy are likely to have played a part. For the malignant brain tumours ependymoma and medulloblastoma, there was little evidence of improvement. It was not possible to distinguish between patients with high risk and standard risk medulloblastoma, defined by a combination of age, stage, completeness of resection and histological and molecular features. Therefore, it is possible that there have been improvements in survival for some groups that were not detectable in this analysis. Future analyses should be able to better distinguish between patients with standard and high risk disease. For ependymoma, the SIOP Ependymoma II clinical trial and the national Ependymoma Multidisciplinary Advisory Group (EMAG) collaborative began subsequent to the incident period examined in this report and their influence on the survival of childhood or TYA ependymoma have not yet been measured in national data.

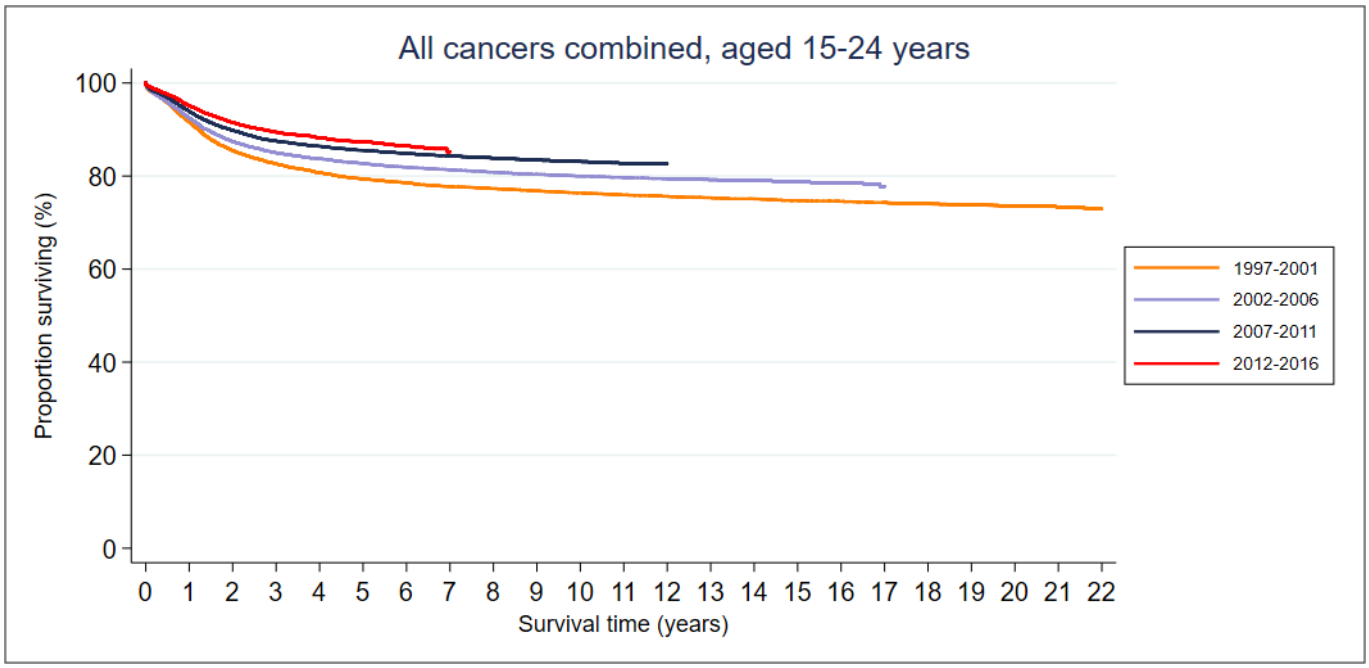
The progressive improvements in the survival of osteosarcoma are welcome and somewhat difficult to explain. The last major clinical trial in osteosarcoma failed to show a difference between standard and escalated treatments, and the chemotherapy regimen in use has been standard for many years. It is likely, therefore, that the improvements in survival throughout the period are related to centralisation and increasing specialisation of surgical services, for a minority of patients the availability of high dose proton therapy for inoperable tumours, and greater standardisation of the established chemotherapy regimen.

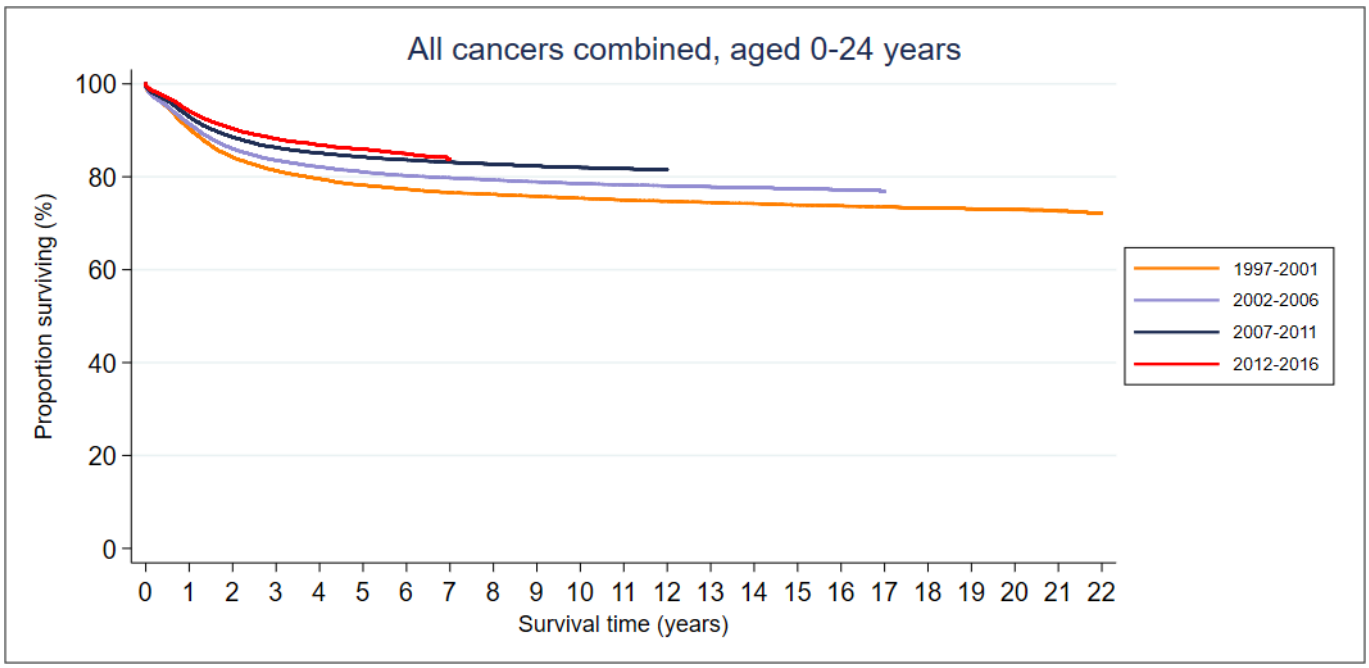
One barrier impacting on the recent improvement in survival for rhabdomyosarcoma in TYA may be that successive European rhabdomyosarcoma trials have historically had an arbitrary upper age threshold for inclusion of 21 years. While these trials are routinely opened in paediatric centres, they are not routinely available to TYA patients. The abolition of an arbitrary age threshold for trial recruitment is a cause for hope for the future for these patients.

For Ewing sarcoma, there was an improvement in survival in TYA but not in children over the 20 year study period. The improvement in TYA is encouraging in a disease that is quoted in clinical trial literature as having no survival improvement for several decades. While TYA survival remains lower than that in childhood, the gap is now less than at the beginning of the study period. The improvement over time is not fully explained: most of the trials undertaken during this period did not report improvements in survival other than the most recent trial, EuroEwing 2012, which took place during the most recent period. The improvements may reflect greater centralisation of care, more treatment according to standardised chemotherapy protocols and more centralised decision-making around local disease control via a national UK Ewing sarcoma multi-disciplinary team (MDT).

Figures 4 to 6: Population-based survival of children, teenagers and young adults with cancer in UK diagnosed 1997-2016, all cancers combined







Cancer mortality and prevalence

Cancer mortality is a measure of the number of people diagnosed with cancer who have died in a given period. Mortality rates are affected by changes in incidence and survival: if more people develop cancer but survival does not change (i.e. treatment remains equally effective), more people die of cancer and therefore mortality increases; if incidence remains constant but treatment becomes more effective and survival improves, fewer people die of cancer and therefore mortality falls.

Cancer in children, teenagers and young adults accounts for 0.3% of all cancer deaths in the UK. In 2018 there were around 260 childhood cancer deaths, accounting for 7% of all childhood deaths (0-14 year olds). For teenagers and young adults (15-24 year olds) there were nearly 290 cancer deaths, accounting for 11% of all TYA deaths. For comparison, cancer accounts for almost 30% of all deaths in the whole UK population.[11]

Of approximately 32,500 children diagnosed with cancer between 1997-2016, around 7,000 had died at any age by the end of 2018, and around 25,500 were still alive. Of approximately 41,500 teenagers and young adults diagnosed with cancer between 1997-2016, around 7,700 had died at any age by the end of 2018, and nearly 33,800 were still alive.

[11] Office for National Statistics, NOMIS Official Labour Market Statistics, Mortality statistics 2018, Deaths registered in England and Wales https://www.nomisweb.co.uk/articles/960.aspx
National Records of Scotland, Vital Events Reference Tables 2018, Section 6: Deaths – Causes https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/general-publications/vital-events-reference-tables/2018/section-6-death-causes
Northern Ireland Statistics and Research Agency, Registrar General Annual Report 2018 Cause of Death, https://www.nisra.gov.uk/publications/registrar-general-annual-report-2018-cause-death

Appendix A – Cancer classifications codes

Table 1: Cancer classification coding list used for this report, based on ICD-O-3

Primarily based on the International Classification of Childhood Cancer, Third edition (ICCC-3) and then modified and expanded to allow more detailed analyses; to accommodate morphology codes that have been introduced in the first and second revisions of ICD-O-3; and to cover the most common sites for tumours in the teenage and young adult age range.

Diagnostic group	Morphology codes	Behaviour codes	Specific site codes
I Leukaemias, myeloproliferative diseases, and myelodysplastic diseases			
(a) Lymphoid leukaemias	9820, 9823, 9826, 9827, 9831-9836, 9940, 9948	3,6,9	
	9811-9819, 9837	3,6,9	C42.0, C42.1, C42.3, C42.4, C80.9
(a.1) Precursor cell leukaemias	9835, 9836	3,6,9	
	9811-9819, 9837	3,6,9	C42.0, C42.1, C42.3, C42.4, C80.9
(a.2) Mature B-cell leukaemias	9823, 9826, 9832, 9833, 9940	3,6,9	
(b) Acute myeloid leukaemias	9840, 9861, 9865-9867, 9869-9874, 9877-9879, 9891, 9895-9898, 9910-9912, 9920, 9931	3,6,9	
(c) Chronic myeloproliferative diseases	9863, 9875, 9876, 9960-9964	3,6,9	
Ic (subset) Chronic myeloid leukaemia	*9863, 9875, 9876*	*3,6,9*	
Ic (subset) Other chronic myeloproliferative diseases	*9960-9964*	*3,6,9*	
(d) Myelodysplastic syndrome and other myeloproliferative diseases	9945, 9946, 9975, 9980, 9982-9987, 9989, 9991-9993	3,6,9	
(d) (subset) Myelodysplastic syndrome	*9980-9989, 9991-9993*	*3,6,9*	
(d) (subset) Juvenile myelomonocytic leukaemia & chronic myelomonocytic leukaemia	*9945, 9946*	*3,6,9*	
(e) Unspecified and other specified leukaemias	9800, 9801, 9805-9809, 9860, 9930, 9965-9968	3,6,9	
II Lymphomas and reticuloendothelial neoplasms			
(a) Hodgkin lymphomas	9650-9655, 9659, 9661-9665, 9667	3,6,9	
(b)(c) Non-Hodgkin lymphomas (including Burkitt lymphoma)	9591, 9597, 9670, 9671, 9673, 9675, 9678-9680, 9684, 9687-9691, 9695, 9698-9702, 9705, 9708, 9709, 9712, 9714-9719, 9724-9729, 9731-9735, 9737, 9738, 9760-9762, 9764-9769, 9970, 9971	3,6,9	
	9811-9819, 9837	3,6,9	C00.0-C41.9, C42.2, C44.0-C77.9

Diagnostic group	Morphology codes	Behaviour codes	Specific site codes
(b.1) Precursor cell lymphomas	9727-9729	3,6,9	
	9811-9819, 9837	3,6,9	C00.0-C41.9, C42.2, C44.0-C77.9
(b.2) Mature B-cell lymphomas (excluding Burkitt lymphoma)	9597, 9670, 9671, 9673, 9675, 9678-9680, 9684, 9688-9691, 9695, 9698, 9699, 9712, 9731-9735, 9737, 9738, 9761, 9762, 9764-9766, 9769, 9970, 9971	3,6,9	
(b.3) Mature T-cell and NK-cell lymphomas	9700-9702, 9705, 9708, 9709, 9714-9719, 9724-9726, 9767, 9768	3,6,9	
(b.4) Non-Hodgkin lymphomas, NOS	9591, 9760		
(c) Burkitt lymphoma	9687	3,6,9	
(d) Miscellaneous lymphoreticular neoplasms	9740-9742, 9749, 9750, 9755-9759	3,6,9	
(e) Unspecified lymphomas	9590, 9596	3,6,9	
III CNS and miscellaneous intracranial and intraspinal neoplasms			
(a) Ependymomas and choroid plexus tumour	9383, 9390-9394, 9396	0,1,3,6,9	
(a.1) Ependymomas	9383, 9391-9394, 9396	0,1,3,6,9	
(a.2) (subset) Choroid plexus carcinoma	*9390*	*3,6,9*	
(a.2) (subset) Choroid plexus papilloma	*9390*	*0,1*	
(b) Astrocytomas	9380	0,1,3,6,9	C72.3
	9384, 9400-9411, 9420-9425, 9440-9442, 9445	0,1,3,6,9	
(b.1) Pilocytic astrocytoma	9421	0,1,3,6,9	
(b.2) Other Astrocytomas	9380	0,1,3,6,9	C72.3
	9384, 9400-9411, 9420, 9422-9425, 9440-9442, 9445	0,1,3,6,9	
(c) Intracranial and intraspinal embryonal tumours	9470-9478, 9480, 9508	0,1,3,6,9	
	9501-9504	0,1,3,6,9	C70.0-C72.9
(c.1) Medulloblastomas	9470-9472, 9474-9477, 9480	0,1,3,6,9	
(c.2) CNS embryonal tumour NOS	9473, 9478	0,1,3,6,9	
(c.3) Medulloepithelioma	9501-9504	0,1,3,6,9	C70.0-C72.9
(c.4) Atypical teratoid/rhabdoid tumour	9508	0,1,3,6,9	
(d) Other gliomas	9380	0,1,3,6,9	C70.0-C72.2, C72.4-C72.9, C75.1, C75.3
	9381, 9382, 9385,9430-9432, 9444, 9450, 9451, 9460	0,1,3,6,9	
(d.1) Oligodendrogliomas	9450, 9451, 9460	0,1,3,6,9	
(d.2) Mixed and unspecified gliomas	9380	0,1,3,6,9	C70.0-C72.2, C72.4-C72.9, C75.1, C75.3
	9382, 9385	0,1,3,6,9	
(d.3) Neuroepithelial glial tumours of uncertain origin	9381, 9430-9432, 9444	0,1,3,6,9	

Diagnostic group	Morphology codes	Behaviour codes	Specific site codes
(e) Other specified intracranial and intraspinal neoplasms	8270-8281, 8300, 9350-9352, 9360-9362, 9395, 9412, 9413, 9492, 9493, 9505-9507, 9509, 9530-9539, 9582	0,1,3,6,9	
(e.1) Pituitary adenomas and carcinomas	8270-8281, 8300	0,1,3,6,9	
(e.2) Tumours of the sellar region (craniopharyngiomas)	9350-9352, 9582	0,1,3,6,9	
(e.3) Pineal parenchymal tumours	9360-9362, 9395	0,1,3,6,9	
(e.4) Neuronal and mixed neuronal-glial tumours	9412, 9413, 9492, 9493, 9505-9507, 9509	0,1,3,6,9	
(e.5) Meningiomas	9530-9539	0,1,3,6,9	
(f) Unspecified intracranial and intraspinal neoplasms	8000-8005	0,1,3,6,9	C70.0-C72.9, C75.1-C75.3
(subset) Brain stem gliomas	*9380-9382, 9384, 9385, 9400-9411, 9420-9425, 9430-9432, 9440-9442, 9444, 9450, 9451, 9460*	*0,1,3,6,9*	*C71.7*
(subset) Optic glioma tumours	*9380, 9384, 9400-9411, 9420-9425, 9440-9442*	*0,1,3,6,9*	*C72.3*
IV Neuroblastoma and other peripheral nervous cell tumours			
(a) Neuroblastoma and ganglioneuroblastoma	9490, 9500	3,6,9	
(b) Other peripheral nervous cell tumours	8680-8683, 8690-8693, 8700, 9520-9523	3,6,9	
	9501-9504	3,6,9	C00.0-C69.9, C73.9-C76.8, C80.9
V Retinoblastoma	9510-9514	3,6,9	
VI Renal tumours			
(a) Nephroblastoma and other nonepithelial renal tumours	8959, 8960, 8964-8967	3,6,9	
	8963, 9364	3,6,9	C64.9
(a.1) Nephroblastoma (Wilms tumour)	8959, 8960	3,6,9	
(a.2) Rhabdoid renal tumour	8963	3,6,9	C64.9
(a.3) Kidney sarcomas	8964-8967	3,6,9	
(a.4) pPNET of kidney	9364	3,6,9	C64.9
(b) Renal carcinomas	8010-8041, 8050-8075, 8082, 8120-8122, 8130-8141, 8143, 8155, 8190-8201, 8210, 8211, 8221-8231, 8240, 8241, 8244-8246, 8260-8263, 8290, 8310, 8320, 8323, 8401, 8430, 8440, 8480-8490, 8504, 8510, 8550, 8560-8576	3,6,9	C64.9
	8311, 8312, 8316-8319, 8361	3,6,9	
(c) Unspecified malignant renal tumours	8000-8005	3,6,9	C64.9

Diagnostic group	Morphology codes	Behaviour codes	Specific site codes
VII Hepatic tumours			
(a) Hepatoblastoma	8970	3,6,9	
(b) Hepatic carcinomas	8010-8041, 8050-8075, 8082, 8120-8122, 8140, 8141, 8143, 8155, 8190-8201, 8210, 8211, 8230, 8231, 8240, 8241, 8244-8246, 8260-8264, 8310, 8320, 8323, 8401, 8430, 8440, 8480-8490, 8504, 8510, 8550, 8560-8576	3,6,9	C22.0, C22.1
	8160-8180	3,6,9	
(c) Unspecified malignant hepatic tumours	8000-8005	3,6,9	C22.0, C22.1
VIII Malignant bone tumours			
(a) Osteosarcomas	9180-9187, 9191-9195, 9200	3,6,9	C40.0-C41.9, C76.0-C76.8, C80.9
(b) Chondrosarcomas	9210, 9220, 9240	3,6,9	C40.0-C41.9, C76.0-C76.8, C80.9
	9221, 9230, 9241-9243	3,6,9	
(c) Ewing tumour and related sarcomas of bone	9260	3,6,9	C40.0-C41.9, C76.0-C76.8, C80.9
	9363-9365	3,6,9	C40.0-C41.9
(d) Other specified malignant bone tumours	8810, 8811, 8814, 8823, 8830,	3,6,9	C40.0-C41.9
	8812, 9250, 9261, 9262, 9270-9275, 9280-9282, 9290, 9300-9302, 9310-9312, 9320-9322, 9330, 9340-9342, 9370-9372	3,6,9	C00.0-C80.9
(e) Unspecified malignant bone tumours	8000-8005, 8800, 8801, 8803-8805	3,6,9	C40.0-C41.9
IX Soft tissue and other extraosseous sarcomas			
(a) Rhabdomyosarcomas	8900-8905, 8910, 8912, 8920, 8991	3,6,9	
(a.1) Rhabdomyosarcomas - Embryonal	8910, 8991	3,6,9	
(a.2) Rhabdomyosarcomas - Alveolar	8920	3,6,8	
(a.3) Rhabdomyosarcomas - Other and unspecified	8900-8905, 8912	3,6,9	
(b) Fibrosarcomas, peripheral nerve sheath tumours, and other fibrous neoplasms	8810, 8811, 8813-8815, 8821, 8823, 8834-8835	3,6,9	C00.0-C39.9, C44.0-C76.8, C80.9
	8820, 8822, 8824-8827, 9150, 9160, 9491, 9540-9571, 9580	3,6,9	
(b.1) Fibroblastic and myofibroblastic tumours	8810, 8811, 8813-8815, 8821, 8823, 8834-8835	3,6,9	C00.0-C39.9, C44.0-C76.8, C80.9
	8820, 8822, 8824-8827, 9150, 9160	3,6,9	
(b.2) Nerve sheath tumours	9540-9571	3,6,9	

Diagnostic group	Morphology codes	Behaviour codes	Specific site codes
(c)(d) Kaposis sarcoma and other specified soft tissue sarcomas	8587, 8710-8714, 8806, 8831-8833, 8836, 8840-8842, 8850-8858, 8860-8862, 8870, 8880, 8881, 8890-8898, 8921, 8990, 9040-9044, 9120-9125, 9130-9133, 9135, 9136, 9137, 9140-9142, 9161, 9170-9175, 9231, 9251, 9252, 9373, 9581	3,6,9	
	8830	3,6,9	C00.0-C39.9, C44.0-C76.8, C80.9
	8963	3,6,9	C00.0-C63.9, C65.9-C69.9, C73.9-C76.8, C80.9
	9180, 9210, 9220, 9240	3,6,9	C49.0-C49.9
	9260	3,6,9	C00.0-C39.9, C47.0-C75.9
	9364	3,6,9	C00.0-C39.9, C47.0-C63.9, C65.9-C69.9, C73.9-C76.8, C80.9
	9365	3,6,9	C00.0-C39.9, C47.0-C63.9, C65.9-C76.8, C80.9
(d.1) & (d.2) Extraosseous Ewing sarcoma family tumours	9260	3,6,9	C00.0-C39.9, C47.0-C75.9
	9365	3,6,9	C00.0-C39.9, C47.0-C63.9, C65.9-C76.8, C80.9
	9364	3,6,9	C00.0-C39.9, C47.0-C63.9, C65.9-C69.9, C73.9-C76.8, C80.9
(d.3) Extrarenal rhabdoid tumour	8963	3,6,9	C00.0-C63.9, C65.9-C69.9, C73.9-C76.8, C80.9
(d.5) Fibrohistiocytic tumours	8830	3,6,9	C00.0-C39.9, C44.0-C76.8, C80.9
	8831-8833, 8836, 9251, 9252	3,6,9	
(d.7) Synovial sarcomas	9040-9044	3,6,9	
(e) Unspecified soft tissue sarcomas	8800-8805	3,6,9	C00.0-C39.9, C44.0-C76.8, C80.9
(subset) Hepatic sarcomas	*8800-8805, 8991*	*3,6,9*	*C22.0-C22.1*
(subset) Ewing sarcoma family of tumours	*9260*	*3,6,9*	*C40.0-C41.9, C76.0-C76.8, C80.9*
	9363-9365	*3,6,9*	*C40.0-C41.9*
	9260	*3,6,9*	*C00.0-C39.9, C47.0-C75.9*
	9365	*3,6,9*	*C00.0-C39.9, C47.0-C63.9, C65.9-C76.8, C80.9*
	9364	*3,6,9*	*C00.0-C39.9, C47.0-C63.9, C65.9-C69.9, C73.9-C76.8, C80.9*

Diagnostic group	Morphology codes	Behaviour codes	Specific site codes
X Germ cell tumours, trophoblastic tumours, and neoplasms of gonads			
(a) Intracranial and intraspinal germ cell tumours	9060-9065, 9070-9072, 9080-9085, 9100, 9101	0,1,3,6,9	C70.0-C72.9, C75.1-C75.3
(a.1) CNS germinoma	9060-9065	0,1,3,6,9	C70.0-C72.9, C75.1-C75.3
(a.2)-(a.6) CNS non-germinoma germ cell	9070-9072, 9080-9085, 9100, 9101	0,1,3,6,9	C70.0-C72.9, C75.1-C75.3
(b) Malignant extracranial and extragonadal germ cell tumours	9060-9065, 9070-9072, 9080-9086, 9100-9105	3,6,9	C00.0-C55.9, C57.0-C61.9, C63.0-C69.9, C73.9-C75.0, C75.4-C76.8, C80.9
(c) Malignant gonadal germ cell tumours	9060-9065, 9070-9073, 9080-9085, 9090-9093, 9100, 9101	3,6,9	C56.9, C62.0-C62.9
(d) Gonadal carcinomas	8010-8041, 8044, 8050-8075, 8082, 8120-8123, 8130-8141, 8143, 8190-8201, 8210, 8211, 8221-8241, 8244-8246, 8249, 8260-8263, 8290, 8310, 8313, 8320, 8323, 8380-8384, 8430, 8440, 8480-8490, 8504, 8510, 8550, 8560-8573, 9000, 9014, 9015	3,6,9	C56.9, C62.0-C62.9
	8441-8444, 8450, 8451, 8460-8473	3,6,9	
(e) Other and unspecified malignant gonadal tumours	8590-8671	3,6,9	
	8000-8005	3,6,9	C56.9, C62.0-C62.9
XI Other malignant epithelial neoplasms and malignant melanomas			
Adrenocortical carcinomas	8370-8375	3,6,9	
	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454, 8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030	3,6,9	C74
Thyroid carcinomas	8010-8158, 8190-8231, 8240-8369, 8376-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030	3,6,9	C73
Nasopharyngeal carcinomas	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454, 8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030	3,6,9	C11.0-C11.9
Malignant melanomas	8720-8780, 8790	3,6,9	C00.0-C80.9
Skin carcinomas	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454, 8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030	3,6,9	C44.0-C44.9
Carcinomas of colon (excluding appendix)	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454, 8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030	3,6,9	C18-C21 except C18.1
Carcinomas of breast	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454, 8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030	3,6,9	C50
Carcinomas of cervix uteri	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454, 8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030	3,6,9	C53
Carcinomas of bladder	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454, 8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030	3,6,9	C67
Carcinomas of salivary glands	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454, 8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030	3,6,9	C07.9-C08.9

Diagnostic group	Morphology codes	Behaviour codes	Specific site codes
Other carcinomas of head and neck	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454, 8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030	3,6,9	C00-C06, C09-C10, C12-C14, C30-C32, C76.0
Carcinomas of stomach and upper GI	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454, 8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030	3,6,9	C16, C15, C17, C23, C24, C26
Carcinomas of pancreas	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454, 8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030	3,6,9	C25
Carcinomas of trachea, bronchus & lung	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454, 8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030	3,6,9	C33-C34
(subset) Carcinomas of trachea, bronchus & lung (neuroendocrine)	*8013, 8240-8249*	*3,6,9*	*C33-C34*
(subset) Carcinomas of trachea, bronchus & lung (other)	*8010-8012, 8014-8158, 8190-8231, 8250-8369, 8376-8440, 8452-8454, 8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030*	*3,6,9*	*C33-C34*
Carcinomas of other specified sites	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454, 8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030	3,6,9	C37-C39, C48, C51-C52, C54-C55, C57, C58, C60-C61, C63, C65-C66, C68, C69, C75.0, C75.4-C75.9
Carcinomas of unspecified site	8010-8158, 8190-8231, 8240-8369, 8376-8440, 8452-8454, 8480-8589, 8941, 8983, 9000, 9010-9016, 9020, 9030	3,6,9	C70-C72, C76.1-C80
XII Other and unspecified malignant neoplasms			
(a) Other specified malignant tumours	8930-8936, 8940, 8950, 8951, 8971-8982, 9050-9055, 9110	3,6,9	C00.0-C80.9
	9363	3,6,9	C00.0-C39.9, C47.0-C75.9
(b) Other unspecified malignant tumours	8000-8005	3,6,9	C00.0-C21.8, C23.9-C39.9, C42.0-C55.9, C57.0-C61.9, C63.0-C63.9, C65.9-C69.9, C73.9-C75.0, C75.4-C80.9

Appendix B – Cancer incidence and survival tables

Tabulations showing the number, crude and age-standardised rates of newly diagnosed cancers registered among children, teenagers and young adults under 25 years of age and resident in the UK, 1997 to 2016 and population-based 5-year survival of children, teenagers and young adults (0-24 year olds) with cancer in the UK, diagnosed 1997 to 2016, by period of diagnosis, grouped according to 'International Classification of Childhood Cancer, Third Edition' (ICCC-3)

Appendix C – Survival charts (PowerPoint)

Survival charts showing population-based survival of children, teenagers and young adults (0-24 year olds) with cancer in the UK, diagnosed 1997 to 2016, by period of diagnosis, grouped according to 'International Classification of Childhood Cancer, Third Edition' (ICCC-3)

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-leading science, research, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health and Social Care, and a distinct delivery organisation with operational autonomy. We provide government, local government, the NHS, Parliament, industry and the public with evidence-based professional, scientific and delivery expertise and support.

Public Health England
Wellington House
133-155 Waterloo Road
London SE1 8UG
Tel: 020 7654 8000

www.gov.uk/phe
Twitter: @PHE_uk
www.facebook.com/PublicHealthEngland

Prepared by: Charles Stiller, Lucy Irvine and Catherine Welham
For queries relating to this document, please contact: lucy.irvine@phe.gov.uk

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