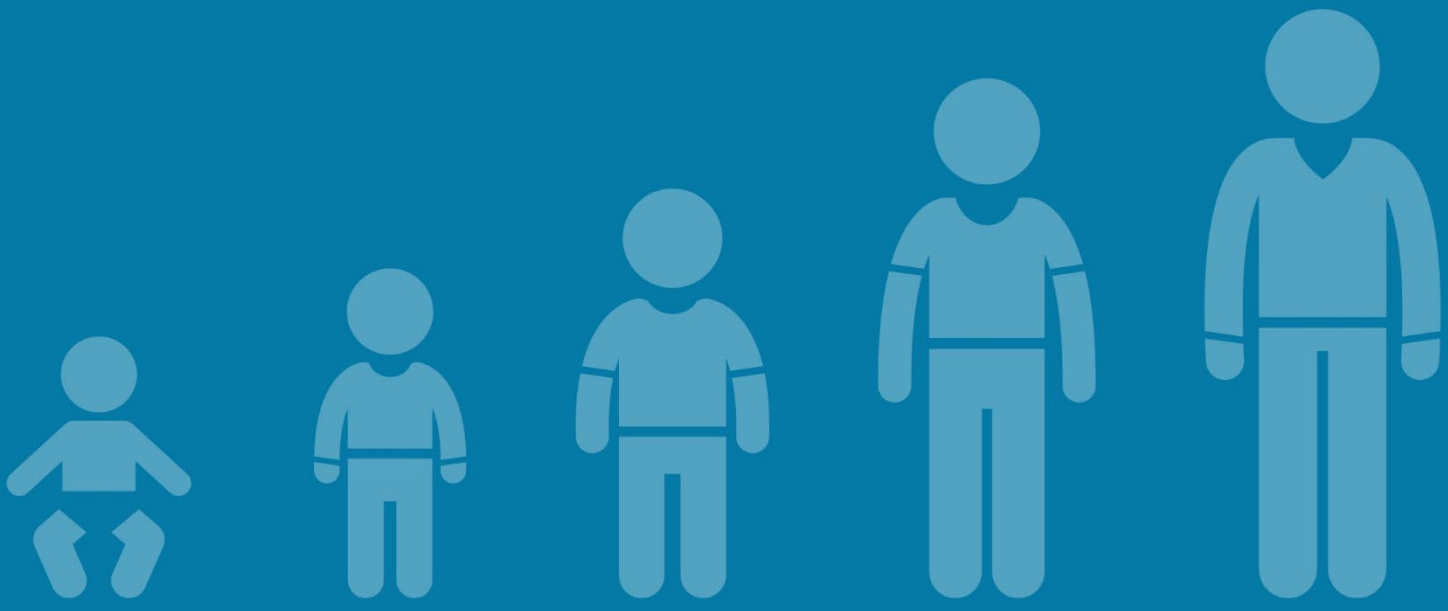
National Cancer Registry Ireland

# CHILDHOOD, ADOLESCENT & YOUNG ADULT CANCER

## Cancer Trends Report



THE NATIONAL CANCER REGISTRY

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National Cancer Registry Ireland

# Cancer Trends

## Childhood, adolescent and young adult cancer

This is the third Cancer Trends Report the National Cancer Registry Ireland (NCRI) has published on childhood cancers[i] and the first to include cancers in adolescents and young adults (AYA) (up to 24 years of age) [1], [2]. While data presented in the NCRI annual statistical report include cases diagnosed in children and AYA, results are not presented by age-group [3]. In addition, the International Classification of Diseases (ICD-10) used to group cancers by primary site of origin, is not appropriate for use in childhood cancers. This report uses the International Classification of Childhood Cancer (ICCC) coding system, which was developed specifically for childhood and AYA cancers [4].

While cancer incidence in children and AYA is significantly lower than that observed in older adults, cancer remains the most common cause of death in those under the age of 25 years, excluding congenital and external causes [5]. In 2020, one third of the total population of Ireland (over 1.6 million people) was under 25 years of age. Although this proportion has been steadily decreasing since the late 1970s/early 1980s (when it was around 48% of the total population), overall the absolute number of people under the age of 25 in Ireland has been increasing since the start of the millennium [6]. The treatment and care of young people with cancer has unique challenges. While incidence is low, survival rates for many of these cancers are high, at least in resource rich countries. The successful treatment of cancer, in children and AYA, has significant implications for service provision in both paediatric and adult cancer services, as well as for other services which support patients with the long-term consequences of cancer diagnosis and treatment (e.g., primary care, allied health and social care services, radiology, cardiology, fertility, psychological supports etc).

In Ireland, care for children (aged 0-15 years) diagnosed with cancer is centralised to the National Children's Cancer Service (NCCS) at Children's Health Ireland (CHI), Crumlin. AYA (aged 16-24 years) are managed by adult services. The National Cancer Control Programme (NCCP) has recently published a framework for the provision of cancer services to young people (aged 16-24 years) in Ireland [7].

[i] Previous NCRI reports on childhood cancers presented data for children aged 0-14 years of age, in this report the age-groups 0-15 years and 16-24 years are used, to align with the organisation of cancer services in Ireland.

# Main Points/Summary

## Children

### Incidence

- Over the period 2011-2020 on average 191 cancers were diagnosed per year in children (0-15 years).
- The most commonly diagnosed cancers in this age group were brain and CNS tumours (27%), leukaemias (27%) and lymphomas (12%).
- The crude incidence rate of all cancers in both sexes combined increased significantly by 1.3% per year from 1996 to 2020.

### Survivors and survival

- It is estimated that of the 4357 children (0-15 years) diagnosed with cancer since the NCRI was established, 3506 (80%) were still alive at the end of 2020.
- 5-year observed survival for all cancers combined was 87% in children (0-15 years) diagnosed 2011-2019. This has increased from 5-year observed survival of 82% in those diagnosed 2002-2010.

### Mortality

- In children (0-14 years), the mortality rate of all malignant neoplasms combined has decreased significantly since the mid to late 1960s for both males and females.

## Adolescents and young adults

### Incidence

- Over the period 2011-2020 on average 178 cancers were diagnosed per year in adolescents and young adults (16-24 years).
- The most commonly diagnosed cancers in this age group were other epithelial tumours and melanomas (33%), lymphomas (21%) and brain and CNS tumours (15%).
- The crude incidence rate of all cancers in both sexes combined increased significantly by 1.1% per year from 1996 to 2020.
- The crude incidence of melanoma in females significantly decreased from 2014-2020 by 17.3% per year

### Survivors and survival

- It is estimated that of the 4617 adolescents and young adults (16-24 years) diagnosed with cancer since the NCRI was established, 3848 (83%) were still alive at the end of 2020.
- 5-year observed survival for all cancers combined was 90% in adolescents and young adults (16-24 years) diagnosed 2011-2019, this had increased from 87% in those diagnosed 2002-2010.

### Mortality

- In adolescents and young adults (15-24 years), the mortality rate of all malignant neoplasms combined has also decreased significantly, with the decreasing trend in males starting in the early 1970s, and in females in the late 1980s.

## Case numbers and histological types

Between 2011 and 2020, an average of 191 cancers were diagnosed per year in children aged 0-15 years (Table 1). A further 178 cases were diagnosed per year in AYA (16-24 years), giving a total of 369 cases of cancer diagnosed per year in 0-24 year olds (Table 1).

The most common cancers diagnosed in children aged 0-15 years were leukaemias, lymphomas and brain and central nervous system cancers (66% of cancers).

In 16-24 year olds, one third of cases were other malignant epithelial tumours and melanomas with leukaemias, lymphomas and brain and central nervous system cancers accounting for 43% of cancers and germ cell tumours accounting for a further 14%.

The case count grouped by cancer type per year is provided in Appendix 1a and 1b.

***Table 1. Annual average number of cancers diagnosed in children and AYA in Ireland 2011-2020***

| | 0-15 years | | 16-24 years | | 0-24 years | |
|---|---|---|---|---|---|---|
| **ICCC group** | **N** | **% of all** | **N** | **% of all** | **N** | **% of all** |
| I Leukaemias & related | 51 | 27% | 12 | 7% | 63 | 17% |
| II Lymphomas & related | 23 | 12% | 37 | 21% | 60 | 16% |
| III Brain and CNS[ii] | 52 | 27% | 26 | 15% | 78 | 21% |
| IV Neuroblastoma & peripheral nervous system tumours | 10 | 5% | <1 | 0% | 10 | 3% |
| V Retinoblastoma | 4 | 2% | 0 | 0% | 4 | 1% |
| VI Renal tumours | 8 | 4% | 2 | 1% | 10 | 3% |
| VII Hepatic tumours | 3 | 1% | 1 | 0% | 4 | 1% |
| VIII Malignant bone tumours | 8 | 4% | 6 | 3% | 14 | 4% |
| IX Soft tissue sarcomas | 11 | 6% | 8 | 4% | 19 | 5% |
| X Gonadal & germ cell tumours[ii] | 5 | 3% | 25 | 14% | 30 | 8% |
| XI Other epithelial tumours & melanomas[iii] | 13 | 7% | 60 | 33% | 73 | 20% |
| XII Other & unspecified | 4 | 2% | 2 | 1% | 6 | 2% |
| **All ICCC I-XII cancers** | **191** | **100%** | **178** | **100%** | **369** | **100%** |

Note: numbers and/or percentages may not add up to totals due to rounding.

[ii] Includes tumours of benign and uncertain behaviour.

[iii] See Appendix 2 for a list of ICCC subgroups and equivalent ICD-10 cancer sites.

## Incidence rates and variation by sex

The crude incidence of all cancers combined 2011-2020 was slightly higher in males than females for 0-15 year olds (186/million vs 175/million), but there was very little difference between the sexes in 16-24 year olds (Table 2).[iv]

***Table 2. Number of cases diagnosed per year and crude incidence rates per million by sex and age-group, 2011-2020***

| | 0-15 year olds | | 16-24 year olds | |
|---|---|---|---|---|
| | **Average annual case count 2011-2020** | **Crude rate/million (95% CI)** | **Average annual case count 2011-2020** | **Crude rate/million (95% CI)** |
| **All ICCC I-XII cancers** | | | | |
| Female | 91 | 175 (163.6-186.4) | 88 | 339 (316.5-361.4) |
| Male | 101 | 186 (174.2-197.1) | 90 | 338 (316.2-360.4) |
| **Malignant cancers only (excl NMSC)** | | | | |
| Female | 75 | 146 (135.1-155.9) | 75 | 290 (269.4-311.0) |
| Male | 88 | 163 (152.2-173.7) | 78 | 293 (272.7-313.8) |

Note: numbers may not add up to totals due to rounding

Overall in 0-15 year olds, the highest incidence rate was for brain and central nervous system cancers with an average of 52 cases/year (crude incidence rate 49/million) followed by leukaemias with 51 cases per year (crude incidence rate 48/million) and lymphomas with 23 cases/year (crude incidence rate 21/million) (Figure 1). With the exception of lymphomas, where incidence rates in males were significantly higher than in females (26/million vs 17/million) (Figure 1), no statistically significant differences in the rates across sexes were detected. The higher incidence of lymphomas in males compared to females has been described previously in Ireland [1], [2].

In 16-24 year olds the highest incidence rate was for other epithelial tumours and melanomas with an average of 60 cases/year (crude incidence rate 113/million) followed by lymphomas with 37 cases/year (crude incidence rate 71/million) and brain and central nervous system cancers with 26 cases/year (crude incidence rate 50/million). The only significant differences observed by sex were for germ cell tumours where males had significantly higher crude rates than females (78/million vs 16/million respectively), and for other epithelial tumours and melanomas where females had significantly higher crude rates than males (148/million vs 80/million respectively).

As the calculation of age-standardised rates require cases to be grouped using conventional 5-year age-groups (i.e., 0-4, 5-9, 10-14, 15-19 and 20-24 years) it is not possible to present age-standardised incidence rates for the age-groups 0-15 and 16-24 years. Age-standardised incidence rates for the standard age-groups 0-14 and 15-24 (for comparison with previously published Irish and international reports) are provided in Appendix 3a and 3b.

[iv] Incidence rates are used to measure the number of new cases over time in the population, in general incidence rates are reported per 100,000 population, however as childhood cancers are rare, they are reported per million population. Crude incidence = (number of cases in an age-group/total population of that age-group)*1,000,000

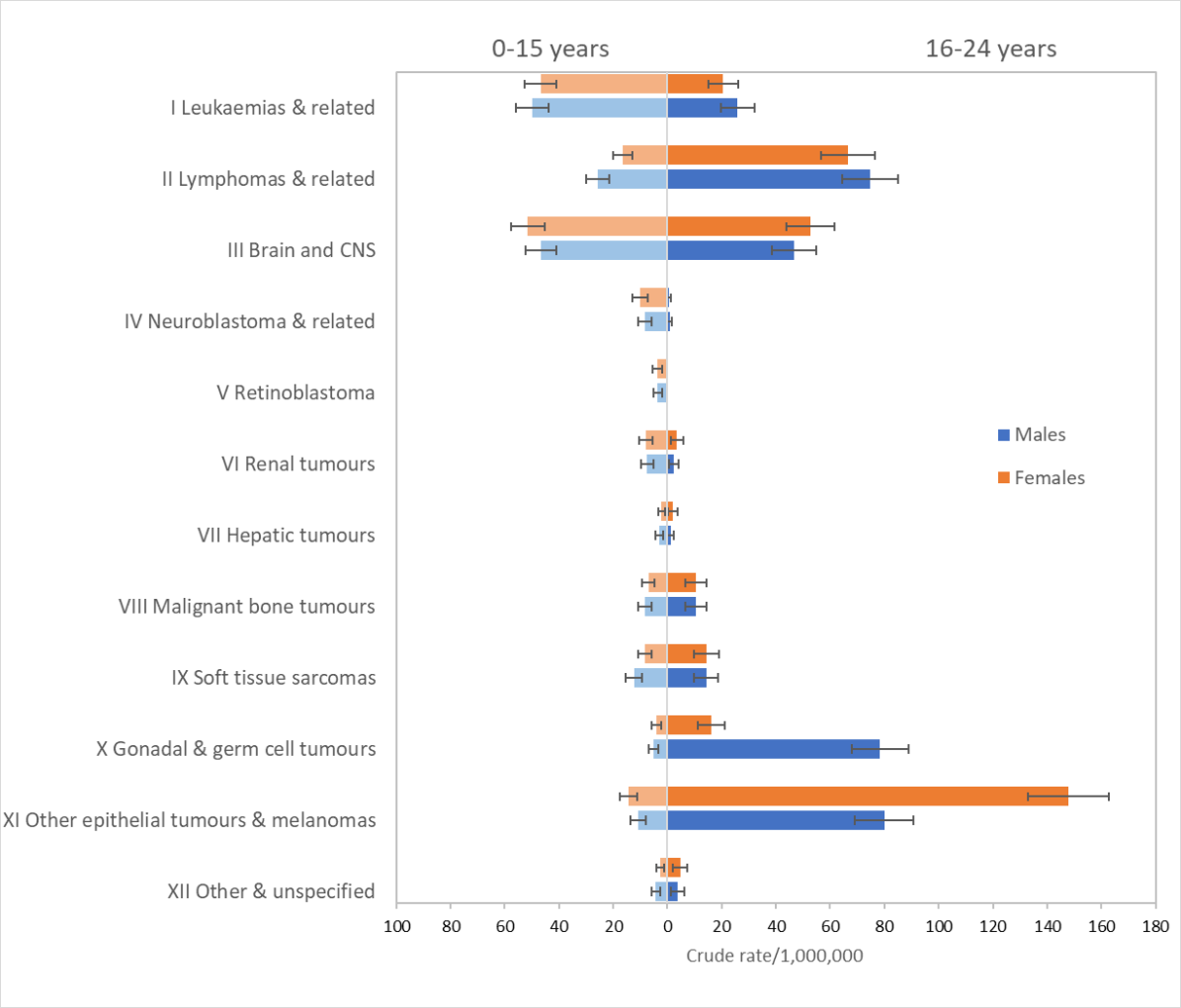



***Figure 1. Incidence rates of each childhood cancer type (ICCC I-XII) by sex and age-group, 2011-2020 (see also Appendix 4)***

## Age at diagnosis

There is considerable variation between cancer types in the age at which cases were diagnosed, with leukaemias and brain and central nervous system cancers being more commonly diagnosed in younger children while the incidence of other cancers, such as lymphomas, germ cell tumours and other epithelial tumours and melanomas increase with age (Figure 2).

Certain subgroups of cancers almost exclusively occur in younger children, for example neuroblastoma and ganglioneuroblastoma, retinoblastoma and hepatoblastoma are diagnosed almost exclusively in children under 6 years of age, while diagnoses of other subgroups such as Hodgkin lymphoma, non-Hodgkin lymphoma, and malignant melanoma occur at a later age (Figure 2).

The patterns in age at diagnosis seen in Figure 2 are similar to what was reported previously for those aged up to 14 years of age [2].


***Figure 2. Age at diagnosis for ICCC cancer groups and most common sub-groups (average annual number of cases), 2011-2020***

## Geographical distribution

A breakdown of case numbers by HSE region of residence is presented in Table 3, providing an indicator of current distribution of caseloads for service-provision planning.

***Table 3. Total case counts by HSE region[v] by ICCC group, 2011-2020***

| | 0-15 year olds | | | | 16-24 year olds | | | |
|---|---|---|---|---|---|---|---|---|
| | Dublin & Mid-Leinster | Dublin & North East | South | West | Dublin & Mid-Leinster | Dublin & North East | South | West |
| **I Leukaemias & related** | 134 | 125 | 141 | 112 | 26 | 33 | 35 | 28 |
| **II Lymphomas & related** | 61 | 54 | 57 | 54 | 105 | 77 | 102 | 87 |
| **III Brain & CNS** | 151 | 127 | 128 | 114 | 81 | 64 | 58 | 57 |
| **IV Neuroblastoma & peripheral nervous system tumours** | 28 | 24 | 27 | 18 | <5 | <5 | <5 | <5 |
| **V Retinoblastoma** | 8 | 15 | 10 | 6 | 0 | 0 | 0 | 0 |
| **VI Renal tumours** | 25 | 29 | 17 | 12 | <5 | 6 | <5 | 5 |
| **VII Hepatic tumours** | 11 | 5 | 6 | 5 | <5 | <5 | <5 | <5 |
| **VIII Malignant bone tumours** | 27 | 19 | 16 | 19 | 17 | 13 | 18 | 7 |
| **IX Soft tissue sarcomas** | 26 | 24 | 32 | 28 | 21 | 17 | 16 | 21 |
| **X Gonadal & germ cell tumours** | 16 | 8 | 16 | 9 | 70 | 48 | 73 | 60 |
| **XI Other epithelial tumours & melanomas** | 38 | 18 | 38 | 39 | 177 | 130 | 147 | 141 |
| **XII Other & unspecified** | 11 | 8 | 9 | 9 | 10 | 5 | 5 | <5 |
| **Total** | **536** | **456** | **497** | **425** | **511** | **395** | **460** | **411** |

## Incidence trends over time

The proportion of cancers in each group has remained relatively stable over time, in both age-groups and sexes (Figure 3). In children aged 0-15 years, leukaemias accounted for between 27% and 29% of all tumours in each of the three periods displayed in Figure 3, brain and central nervous system cancers accounted for between 24% and 27% and lymphomas accounted for between 12% and 13% of cases each period.

In 16-24 year olds other epithelial tumours and melanomas accounted for between 33% and 34% of cancers, lymphomas between 18% and 21% of cancers and germ cell tumours accounted for between 14% and 18% of cancers over the three periods (Figure 3).

[v] Dublin & Mid Leinster: North Dublin, Louth, Meath, Cavan, Monaghan
Dublin & North East: South Dublin, Longford, Westmeath, Laois, Offaly, Kildare, Wicklow
South: Cork, Kerry, Waterford, South Tipperary, Carlow, Kilkenny, Wexford
West: Clare, Limerick, North Tipperary, Galway, Mayo, Roscommon, Sligo, Leitrim, Donegal.

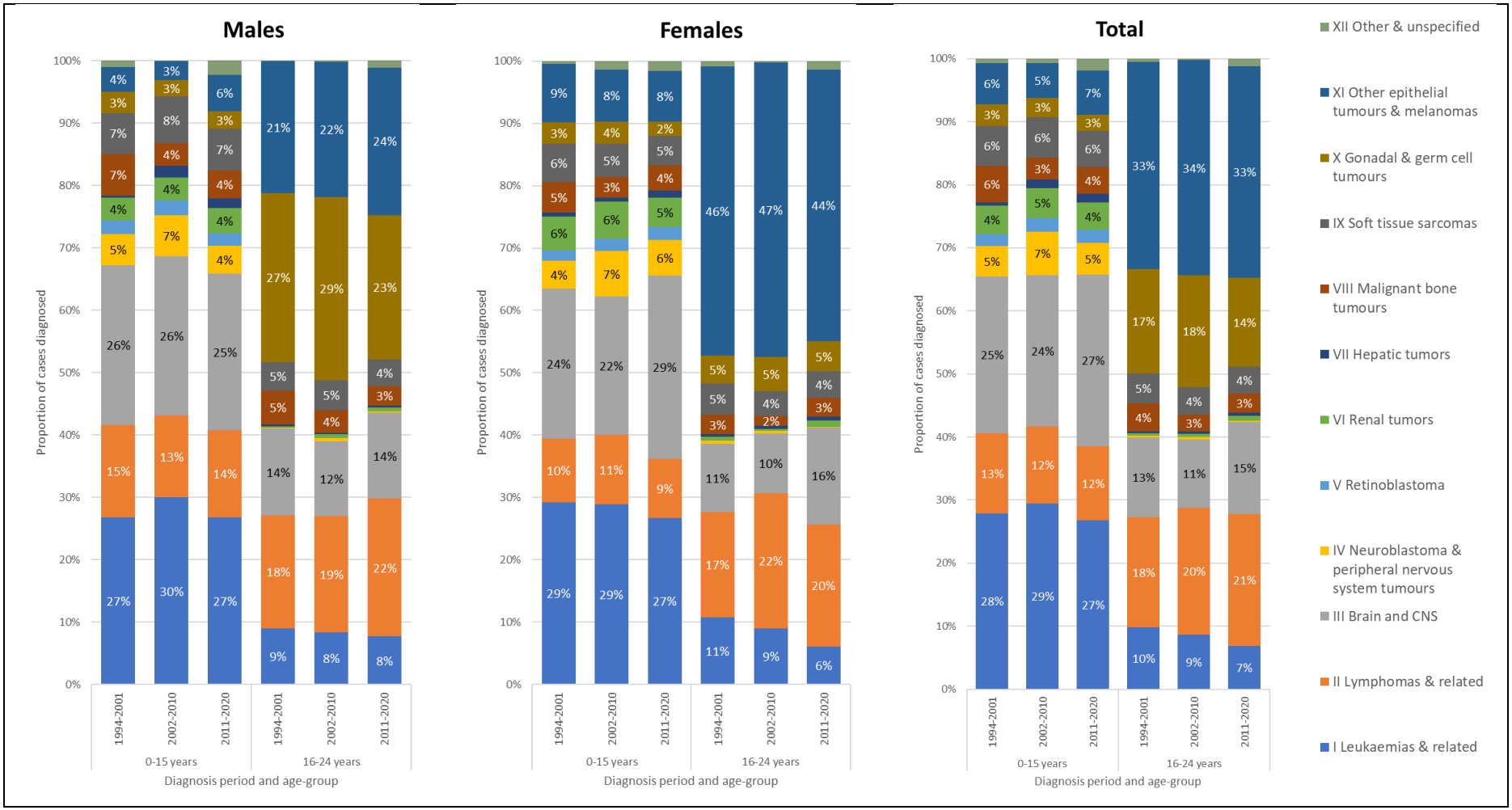



***Figure 3. Percentage breakdown of childhood cancers (ICCC I-XII) by sex, age-group, and diagnosis period***

Although the distribution of cancer types has remained relatively stable, there has been a significant increasing trend in the crude incidence rate of all cancers (combined) for both age-groups from 1996[vi] to 2020 (annual percentage change (apc) 1.3% in 0-15 year olds and apc 1.1% in 16-24 year olds). When crude incidence rates are examined by sex, significant increasing trends are seen in males in both age-groups from 1996 to 2020 (apc 1.2% in 0-15 year olds and apc 0.9% in 16-24 year olds) as well as in females aged 0-15 years (apc 1.3%). However, while the incidence in 16-24 year old females increased significantly (apc 2.2%) between 1996 and 2015, there has been a significant decreasing trend in this age-group since 2015 (apc -5.5%) (Figure 4).

The incidence rate of childhood cancer is increasing in many countries, the reasons for which are not fully understood but are likely to be due to a combinations of factors, including improvements in diagnostic methods and cancer registration [8].

Figure 5 shows the trends in crude incidence rates for three of the most common cancers (leukaemias, lymphomas, and brain and central nervous system cancers) over time by age-group.

There were no significant trends in the crude incidence rate of leukaemia for either age-group (Figure 5).

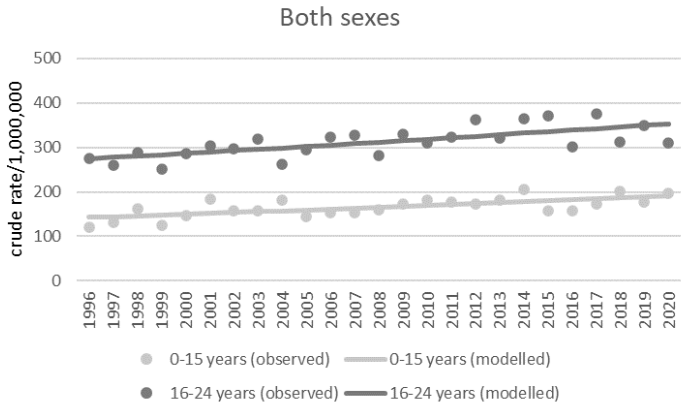
The trend in lymphoma incidence in 0-15 year olds was stable between 1996 and 2020, however there was a significantly increasing trend in 16-24 year olds over the same period (apc 2.0%) (Figure 5).

Significant increasing trends in the crude incidence rate of brain and central nervous system cancers were identified in both 0-15 year olds and 16-24 year olds between 1996 and 2020 (apc 2.1% and 2.0% respectively) (Figure 5).

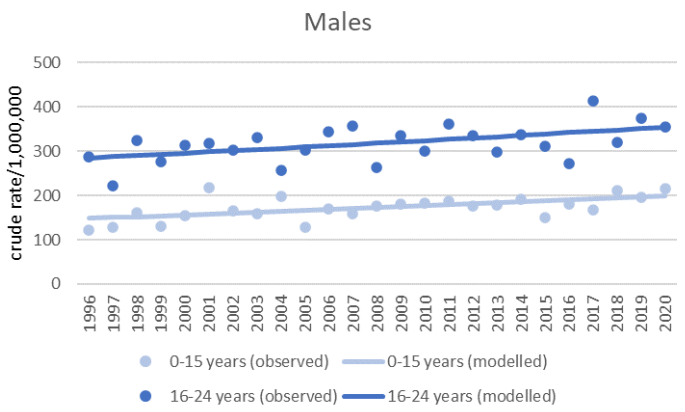
The identified trends in leukaemias, lymphomas or brain and central nervous system cancers do not explain the fall off in crude incidence of all cancers among 16-24 year old females in Figure 4. When trends in other epithelial tumours and melanomas were examined however, a similar decreasing (but not statistically significant) trend was found in 16-24 year old females from 2016-2020 (Figure 6). Analysis of trends in crude incidence by subgroups of other epithelial tumours and melanomas and sex among 16-24 year olds found that there has been a significant decrease in the crude incidence of melanoma in females between 2014-2020 (apc -17.3%).

[vi] Trends analysed from 1996 as that is the earliest year where annual population data are available by single year of age.

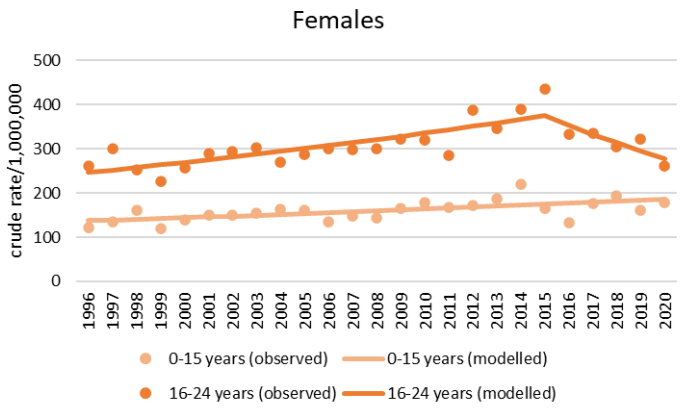
  




| Age-group | From-to | APC (95% CI) | Trend |
|---|---|---|---|
| **0-15** | 1996-2020 | 1.3 (0.7, 1.8) | ↑ |
| **16-24** | 1996-2020 | 1.1 (0.6, 1.5) | ↑ |




| Age-group | From-to | APC (95% CI) | Trend |
|---|---|---|---|
| **0-15** | 1996-2020 | 1.2 (0.5, 2) | ↑ |
| **16-24** | 1996-2020 | 0.9 (0.3, 1.6) | ↑ |




| Age-group | From-to | APC (95% CI) | Trend |
|---|---|---|---|
| **0-15** | 1996-2020 | 1.3 (0.6, 2) | ↑ |
| **16-24** | 1996-2015 | 2.2 (1.5, 3) | ↑ |
| | 2015-2020 | -5.8 (-10.9, -0.3) | ↓ |

From-to= range of years; APC=annual percentage change over range (%); CI=confidence intervals of APC for each distinct range; trend: ↑=significant increase, ↓=significant decrease, ↔=no change, at the 95% level

***Figure 4. Trends in crude incidence rate (per 1,000,000), by sex for all childhood cancers (ICCC I-XII), 0-15 year olds and 16-24 year olds, 1996-2020.***

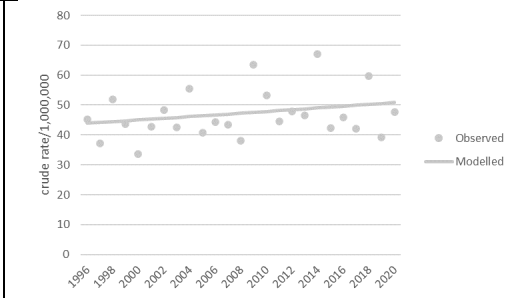
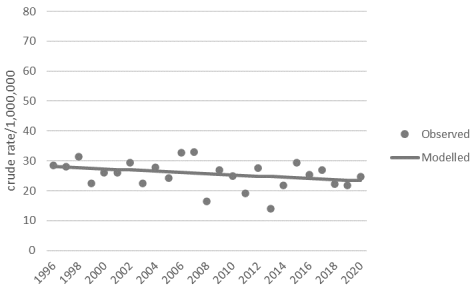
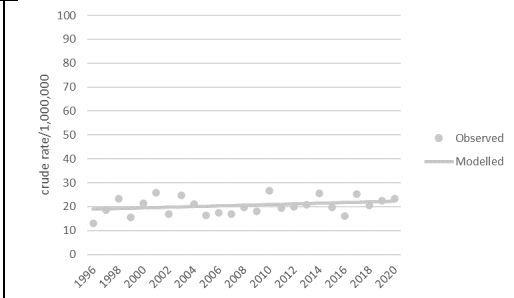
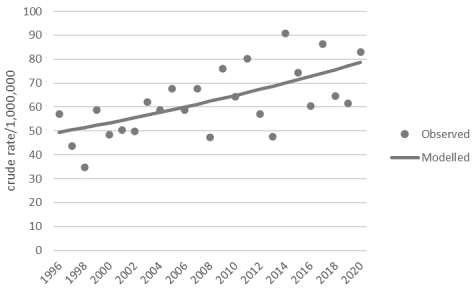
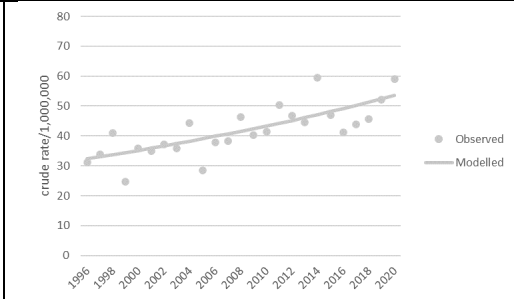
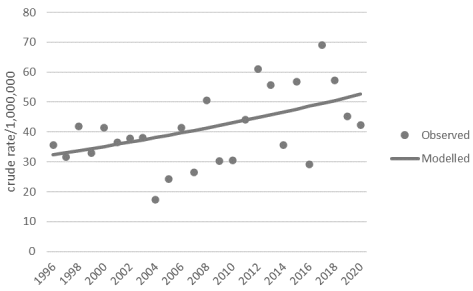
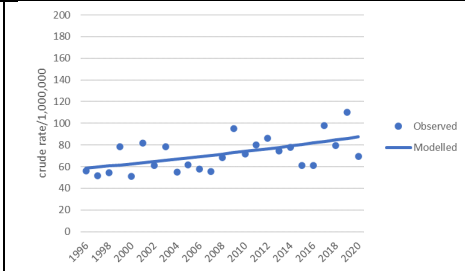
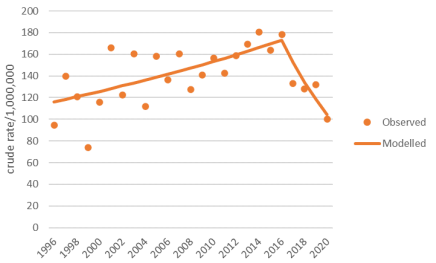
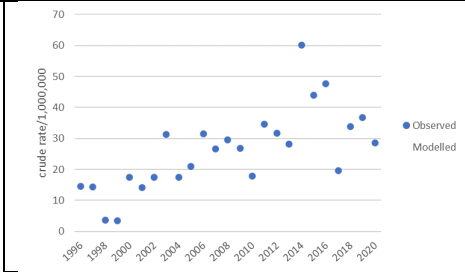
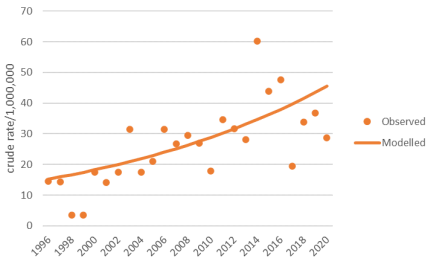
| ICCC Group | 0-15 years | 16-24 years |
|---|---|---|
| I Leukaemias & related |  |  |
| | From-to: 1996-2020 — APC (95% CI): 0.6 (-0.4, 1.6) — Trend: ↔ | From-to: 1996-2020 — APC (95% CI): -0.8 (-1.8, 0.2) — Trend: ↔ |
| II Lymphomas & related |  |  |
| | From-to: 1996-2020 — APC (95% CI): 0.7 (-0.3, 1.7) — Trend: ↔ | From-to: 1996-2020 — APC (95% CI): 2.0 (0.9, 3.0) — Trend: ↑ |
| III Brain & CNS |  |  |
| | From-to: 1996-2020 — APC (95% CI): 2.1 (1.3, 2.9) — Trend: ↑ | From-to: 1996-2020 — APC (95% CI): 2.0 (0.5, 3.6) — Trend: ↑ |

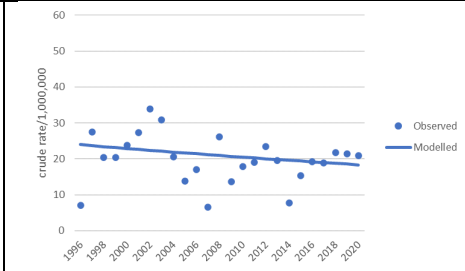
***Figure 5. Trends in crude incidence rate (per 1,000,000) for the most frequent childhood cancer ICCC groups, 0-15 years and 16-24 years, 1996-2020***

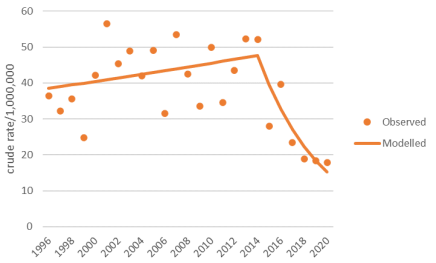
<table>
<tr><th>ICCC Group</th><th>Males</th><th>Females</th></tr>
<tr><td>XI Other epithelial tumours and melanoma</td><td> 

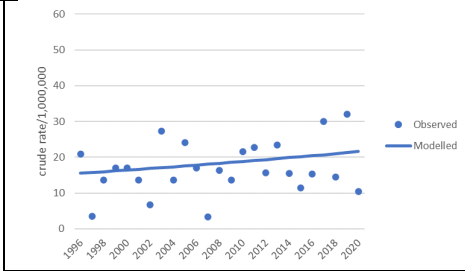
<table><tr><th>From-to</th><th>APC (95% CI)</th><th>Trend</th></tr><tr><td>1996-2020</td><td>1.7 (0.6, 2.8)</td><td>↑</td></tr></table></td><td> 

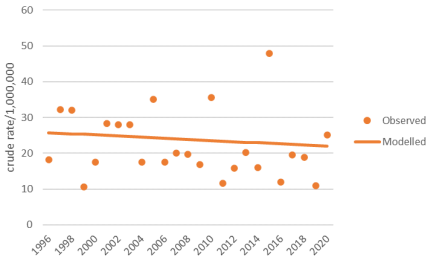
<table><tr><th>From-to</th><th>APC (95% CI)</th><th>Trend</th></tr><tr><td>1996-2016</td><td>2.0 (0.7, 3.3)</td><td>↑</td></tr><tr><td>2016-2020</td><td>-11.9 (-24.7, 3.1)</td><td>↔</td></tr></table></td></tr>
<tr><td>XIb Thyroid carcinomas</td><td> 

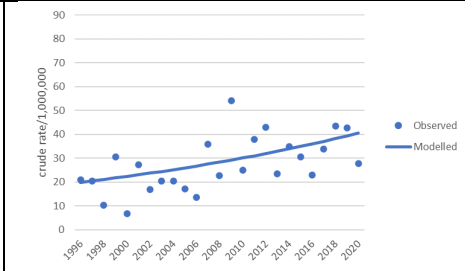
joinpoint modelling of group XIb was not possible due the presence of years with no cases</td><td> 

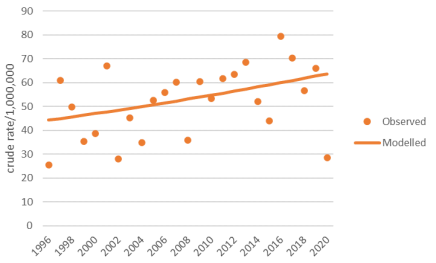
<table><tr><th>From-to</th><th>APC (95% CI)</th><th>Trend</th></tr><tr><td>1996-2020</td><td>4.7 (2.3, 7.1)</td><td>↑</td></tr></table></td></tr>
<tr><td>XId Malignant melanomas</td><td> 

<table><tr><th>From-to</th><th>APC (95% CI)</th><th>Trend</th></tr><tr><td>1996-2020</td><td>-1.1 (-3, 0.8)</td><td>↔</td></tr></table></td><td> 

<table><tr><th>From-to</th><th>APC (95% CI)</th><th>Trend</th></tr><tr><td>1996-2014</td><td>1.2 (-0.8, 3.2)</td><td>↔</td></tr><tr><td>2014-2020</td><td>-17.3 (-27.9, -5.1)</td><td>↓</td></tr></table></td></tr>
<tr><td>XIe Skin carcinomas</td><td> 

<table><tr><th>From-to</th><th>APC (95% CI)</th><th>Trend</th></tr><tr><td>1996-2020</td><td>1.4 (-1, 3.8)</td><td>↔</td></tr></table></td><td> 

<table><tr><th>From-to</th><th>APC (95% CI)</th><th>Trend</th></tr><tr><td>1996-2020</td><td>-0.7 (-2.9, 1.7)</td><td>↔</td></tr></table></td></tr>
<tr><td>XIf Other and unspecified carcinomas[vii]</td><td> 

<table><tr><th>From-to</th><th>APC (95% CI)</th><th>Trend</th></tr><tr><td>1996-2020</td><td>3 (0.9, 5.2)</td><td>↑</td></tr></table></td><td> 

<table><tr><th>From-to</th><th>APC (95% CI)</th><th>Trend</th></tr><tr><td>1996-2020</td><td>1.5 (-0.1, 3.1)</td><td>↔</td></tr></table></td></tr>
</table>

***Figure 6. Trends in crude incidence rate (per 1,000,000) for Group XI Other epithelial tumours and melanoma, and most common subgroups, in 16-24 year olds by sex, 1996-2020***

[vii] Of all group XIf Other and unspecified carcinomas diagnosed at age 16-24 years 1994-2020, 55% were colorectal carcinomas (including carcinoids), and specifically 47% were appendiceal carcinoids (now considered malignant by ICD-O3).

## Survival

For children (0-15 years), five year observed survival[viii] for all cancers combined increased from 82% in those diagnosed between 2002-2010 to 87% in 2011-2019. For AYA (16-24 years), five year observed survival increased from 87% in 2002-2010 to 90% for those diagnosed in 2011-2019 (Figure 7).

Most of the individual ICCC diagnostic groups also showed evidence of improvements in survival over time, albeit sometimes modest and (especially groups with smaller numbers of cases and wider confidence intervals) not always showing a clear trend across the three periods (Figure 7).

A further breakdown of survival for major subgroups is provided in Appendix 5a and 5b.

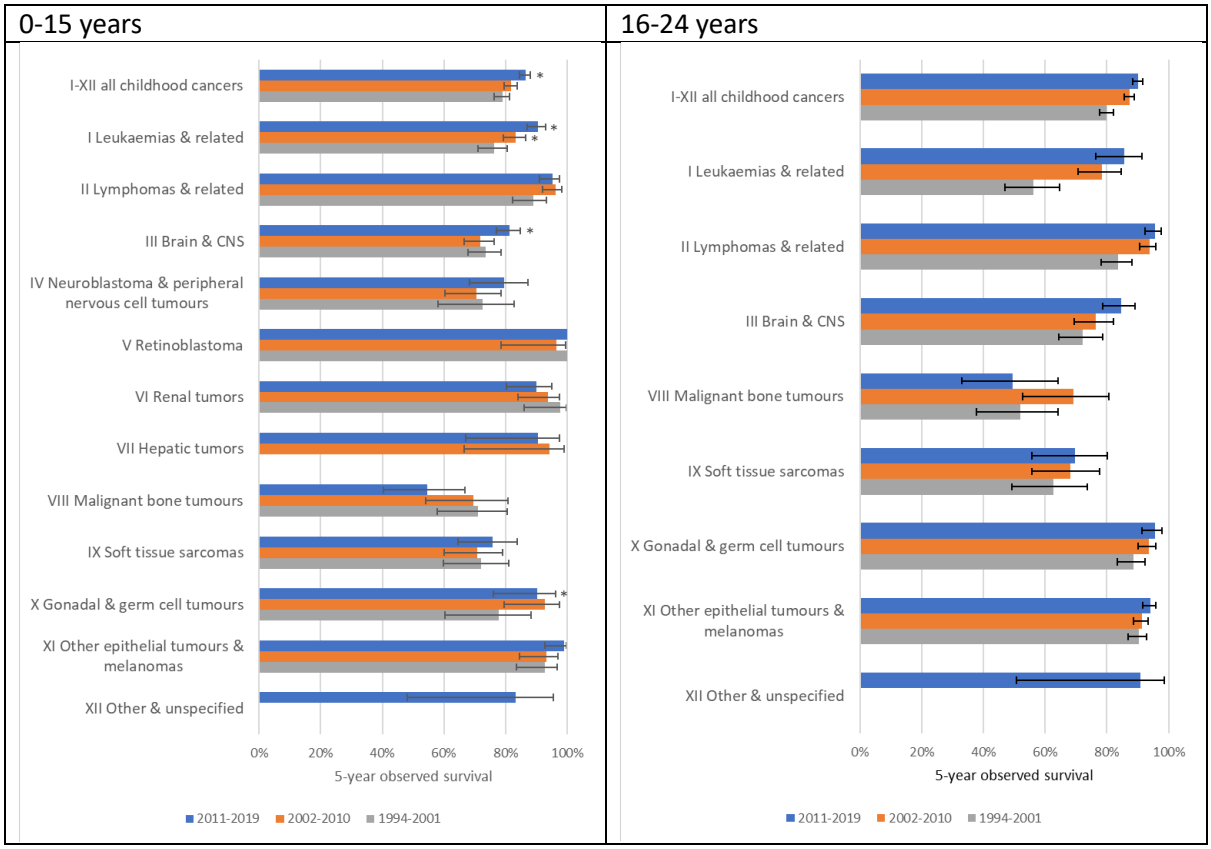



***Figure 7. Five year observed survival among both sexes combined by diagnosis period (with 95% confidence intervals) for all cancers combined and for ICCC groups I-XII.* indicates significant difference from observed survival in 1994-2001 at 95% level[ix]***

[viii] Five year observed survival is the percentage of people alive 5 years after their diagnosis. The cause of death may or may not be cancer. By convention, observed survival is used to report childhood cancer survival in high-income countries as the majority of deaths in childhood cancer patients will be cancer related. *Non-melanoma skin cancer & benign/uncertain-behaviour CNS tumour cases **were included** in the calculation of five year observed survival if they were the **only** tumour in a given patient.*

[ix] Adjusted for age and sex, group I-XII all childhood cancers was also adjusted for cancer group.

## Prevalence: numbers of childhood cancer survivors

Of the 8974 children and AYA diagnosed with cancer between 1994 and 2020, 7354 (82%) were still alive at the end of 2020 (3506/4357, 80%, for those diagnosed aged 0-15 years and 3848/4617, 83%, for those diagnosed aged 16-24 years).[x]

Of the survivors, 3755 (51%) were male and 3599 (49%) were female; 1445 (20%) had been diagnosed aged 0-4 years, 797 (11%) aged 5-9 years, 962 (13%) aged 10-14 years, 1675 (23%) aged 15-19 years and 2475 (34%) aged 20-24 years. At the end of 2020, the age of survivors ranged from 0 to almost 52 years, with 20% (n=1,446) aged 0-15, 24% (n=1,765) aged 16-24 years and 56% (n=4,143) 25 years of age or older.

The breakdown of survivors by their first diagnosed cancer is shown in Figure 9. The most commonly diagnosed cancers were other epithelial tumours and melanomas (22%), followed by lymphomas (18%), and leukaemias and brain & CNS cancers (both 17%).

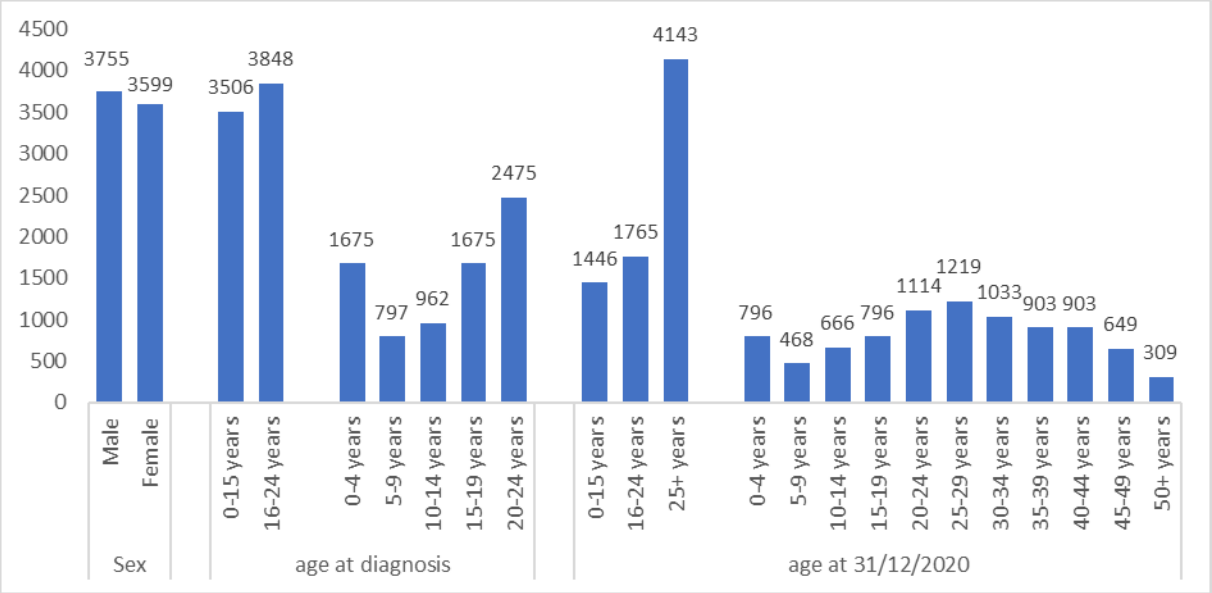



***Figure 8. Number of childhood and AYA cancer survivors diagnosed 1994-2020 alive on 31/12/2020, by sex, age at diagnosis, and current age on 31/12/2020.***

[x] Cancer prevalence describes the number of people living with cancer at a point in time, it reflects both the number of cases diagnosed as well as survival. It includes those who were recently diagnosed in 2020 as well as those who may have been diagnosed decades ago and no longer regard themselves as having cancer. The prevalence estimate presented is the fixed duration prevalence (1994-2020) it is calculated by adding all the cases diagnosed 1994-2020 and subtracting the number known to have died before 31/12/2020. It does not include people who were diagnosed before 1994, and it is possible some of the people who are included no longer reside in Ireland.

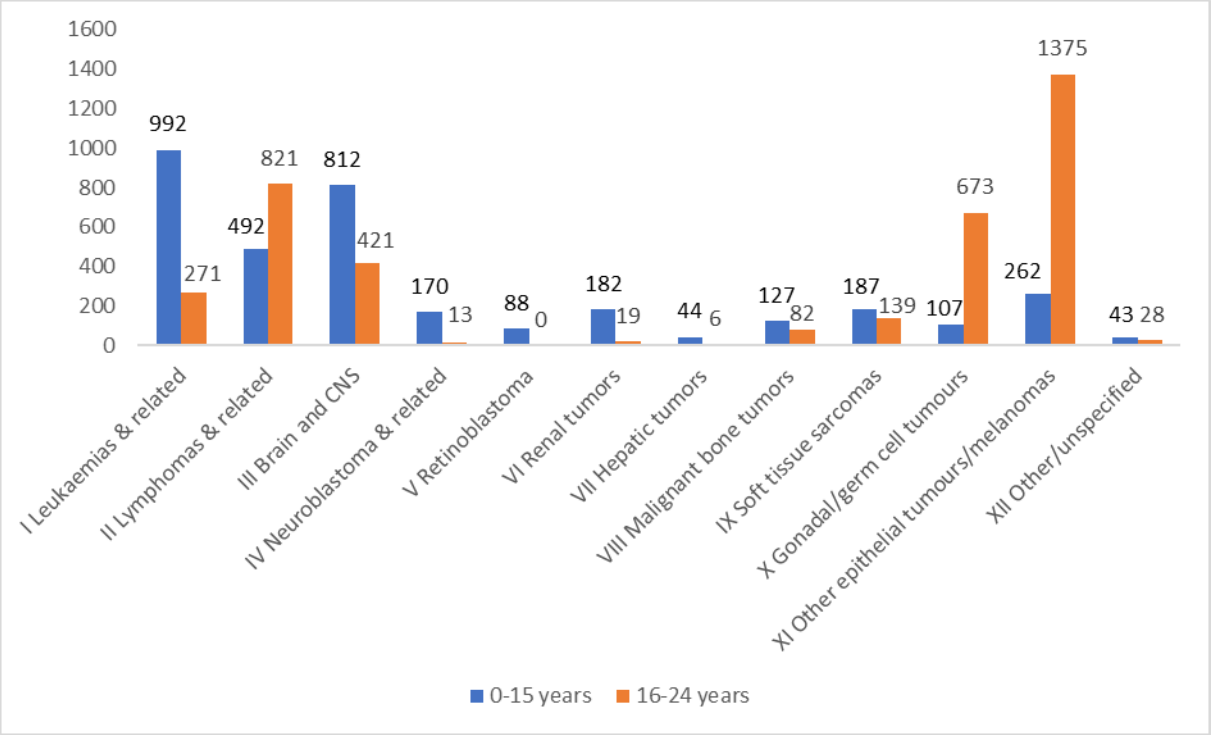


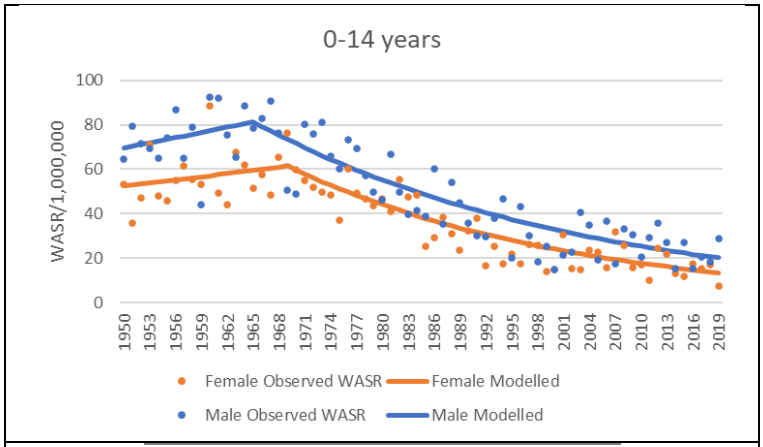

***Figure 9. Number of childhood and AYA cancer survivors diagnosed 1994-2020 alive on 31/12/2020 by cancer type.***

## Long term trends in mortality rates

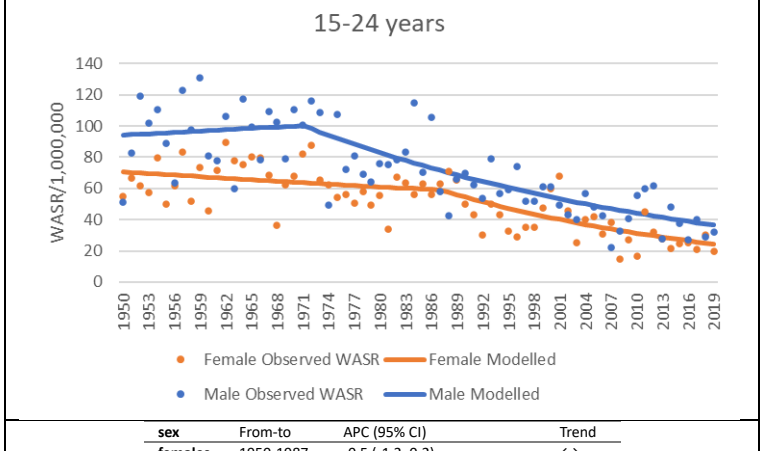
Mortality data, including cause of death, are collated by the Central Statistics Office (CSO) in Ireland. The number of deaths due to malignant neoplasms reported by the CSO and internationally, are only available by standard 5-year age-groups (i.e., 0-14 and 15-24 years).

The mortality rates for cancer in childhood (0-14 years) show significant decreasing trends since the late 1960s, with an average decrease of 3% per year in the world age-standardised rate (WASR) since 1969 in females and 2.6% per year in males since 1965. The mortality rates in AYA (15-24 years) have also been decreasing significantly, by 2.7% per year from 1987 in females and by 2.1% per year from 1971 in males (Figure 10).

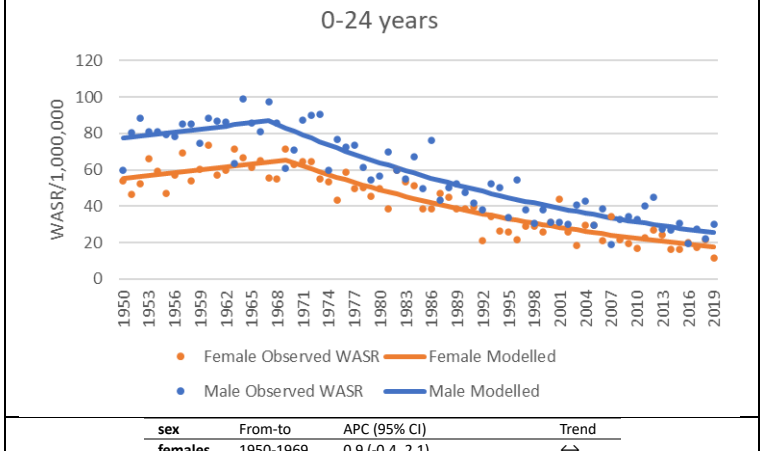
  




| sex | From-to | APC (95% CI) | Trend |
|---|---|---|---|
| females | 1950-1969 | 0.8 (-0.8, 2.5) | ↔ |
| | 1969-2019 | -3.0 (-3.5, -2.5) | ↓ |
| males | 1950-1965 | 1.1 (-1.1, 3.2) | ↔ |
| | 1965-2019 | -2.6 (-3.0, -2.2) | ↓ |




| sex | From-to | APC (95% CI) | Trend |
|---|---|---|---|
| females | 1950-1987 | -0.5 (-1.2, 0.2) | ↔ |
| | 1987-2019 | -2.7 (-3.7, -1.7) | ↓ |
| males | 1950-1971 | 0.3 (-1.3, 1.9) | ↔ |
| | 1971-2019 | -2.1 (-2.6, -1.6) | ↓ |




| sex | From-to | APC (95% CI) | Trend |
|---|---|---|---|
| females | 1950-1969 | 0.9 (-0.4, 2.1) | ↔ |
| | 1969-2019 | -2.6 (-2.9, -2.2) | ↓ |
| males | 1950-1967 | 0.7 (-0.7, 2.1) | ↔ |
| | 1968-2019 | -2.3 (-2.7, -2.0) | ↓ |

***Figure 10. World age-standardised cancer mortality rates[xi] per million population by age-group 1950-2019 (death data 1950-2015 [9], 2016-2019 [5], [10];population data 1950-2019 [6])***

[xi] Segi (1960) World standard population

In the 2010s on average 21 deaths occurred annually in children aged 0-14 years (9 in females and 12 in males) compared to 52-61 deaths annually in the same age-group in the 1950s-1970s. The number of deaths has also decreased in 15-24 year olds, from a peak of over 40 deaths per year in the 1980s to 21 deaths per year in the 2010s (8 in females and 13 in males) (Table 4). These reductions largely reflect improvements in diagnostics and treatments since the 1970s. The number of deaths in males has been consistently higher than the number of deaths in females across all periods and both age-groups, which is consistent with the fact that the number of cancer diagnoses in children and AYA in Ireland has tended to be higher in males than in females since records began in 1994. A similar preponderance of cancer diagnoses in males is seen in previous decades in countries where cancer registries were established in the 1950s and 1960s (e.g. Norway, Sweden and Denmark) [11].

***Table 4. Annual average number of deaths from cancer (C00-C97) from 1950s to 2010s by age at death (1950-2015 [9], 2016-2019 [5], [10])***

| | 0-14 years | | | 15-24 years | | |
|---|---|---|---|---|---|---|
| | Females | Males | Total | Females | Males | Total |
| **1950s** | 22 | 30 | 52 | 13 | 21 | 34 |
| **1960s** | 26 | 35 | 61 | 14 | 20 | 34 |
| **1970s** | 24 | 32 | 56 | 16 | 23 | 39 |
| **1980s** | 19 | 25 | 44 | 18 | 24 | 42 |
| **1990s** | 10 | 14 | 24 | 12 | 20 | 32 |
| **2000s** | 9 | 12 | 21 | 13 | 14 | 27 |
| **2010s** | 9 | 12 | 21 | 8 | 13 | 21 |

As has been previously reported, the average annual number of deaths due to leukaemia, lymphoma and brain and central nervous system cancer in 0-14 year olds has decreased from their peaks in the 1960s/1970s [2]. The number of deaths due to leukaemia, lymphomas and brain and central nervous system cancers was not presented previously for 15-24 year olds. While the number of deaths from these cancers was never as high as in the younger age-group, the number of deaths in 15-24 years olds has also decreased in recent decades (Table 5). It should be noted that as death may occur many years after diagnosis a proportion of the deaths in 15-24 year olds would have been diagnosed while under 15 years of age, similarly some people diagnosed as children or AYA die after the age of 24.

***Table 5. Annual average number of childhood and AYA deaths for the main cancers each decade from the 1950s to 2019 by age at death (1950-1954 [12]–[16], 1955-1967 [17], 1968-1978 [18], 1979-2015 [9], 2016-2019 [5], [10])***

| | 0-14 years | | | 15-24 years | | |
|---|---|---|---|---|---|---|
| | Leukaemia | Lymphoma | Brain & CNS | Leukaemia | Lymphoma | Brain & CNS |
| **1950s** | 24 | 5 | 8 | 9 | 5 | 2 |
| **1960s** | 28 | 5 | 13 | 8 | 7 | 5 |
| **1970s** | 21 | 4 | 17 | 9 | 7 | 6 |
| **1980s** | 17 | 4 | 11 | 10 | 7 | 6 |
| **1990s** | 7 | 1 | 9 | 8 | 4 | 5 |
| **2000s** | 7 | 1 | 8 | 5 | 3 | 5 |
| **2010s** | 5 | 1 | 8 | 3 | 2 | 4 |

## International variation in incidence and mortality

Estimates of childhood cancer incidence and mortality rates for European countries are available from the European Cancer Information System (ECIS). These estimates are based on historical data from the Cancer Incidence in five continents (CI5) series and the WHO mortality database.[xii] Care should be taken when comparing incidence and mortality rates as diagnostic practices and cancer registration processes vary between countries.

Ireland's estimated incidence rate in 0-24 year olds in 2020, of 21.3/100,000 approximated the EU average of 21.2/100,000, albeit based on extrapolations from pre-2014 data, and Ireland ranked 10th highest of the 27 EU countries included (Figure 11). The estimated mortality rate for Ireland in 2020 was 2.8/100,000 (based on more recent observed data than for incidence) and was similar to the EU average of 2.6/100,000. Ireland's mortality estimate ranked 8th highest of the 27 EU countries included. The equivalent rankings for 0-14 year olds were 19th and 15th highest for incidence and mortality respectively, data were not downloadable for 15-24 year olds.

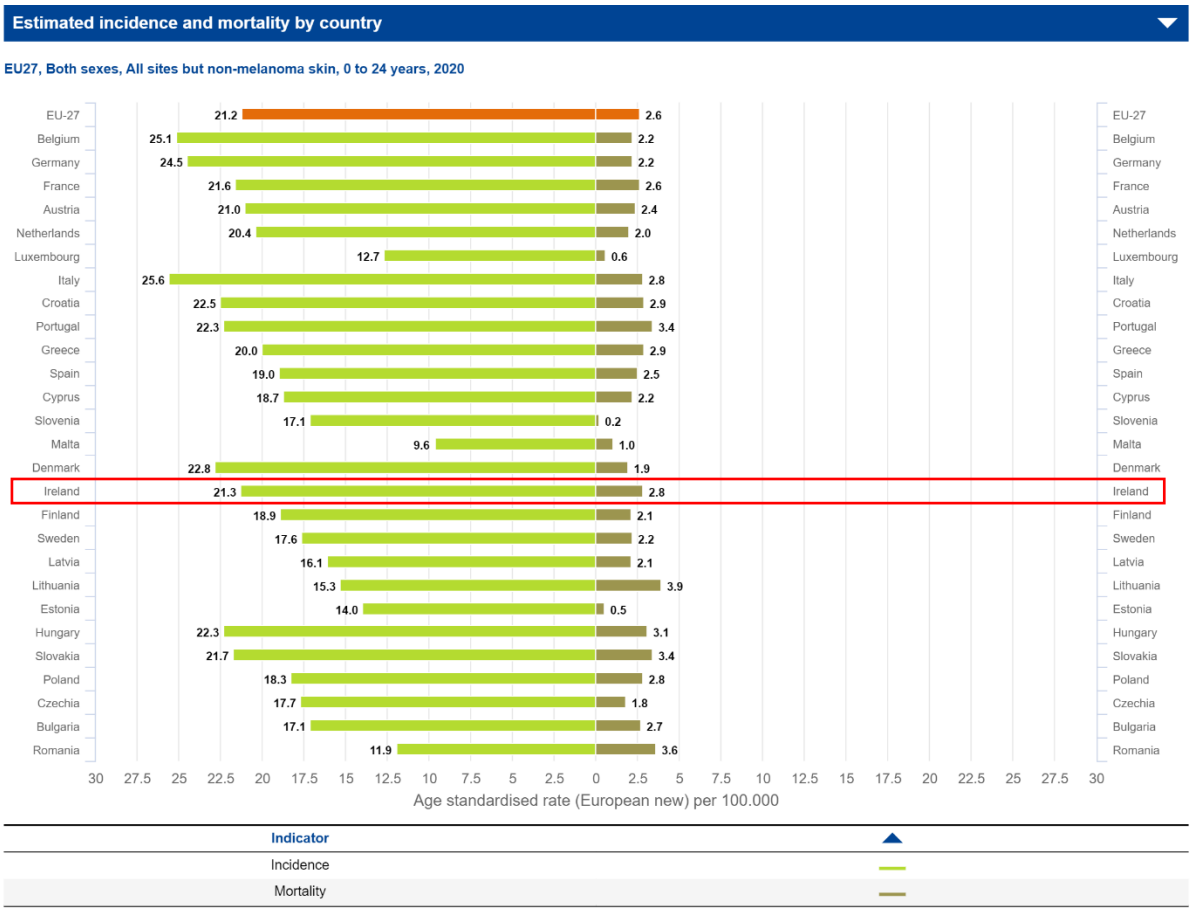



***Figure 11. Estimated age-standardised incidence and mortality rates in 2020 (cases/deaths per 100,000, new European age-standardised) for cancers in 0-24 year olds in Europe (source https://ecis.jrc.ec.europa.eu/)***

[xii] for further information on the methodology used by ECIS see https://ecis.jrc.ec.europa.eu/info/initiatives.html#iarc

## International variation in survival

The most recent published data on childhood cancer survival (age 0-14 years) across Europe are from the EUROCARE-6 project, for the period 2010-2014, and are shown in Figure 12 [19]. Survival analysis of childhood cancers generally includes non-malignant tumours of the brain and CNS (central nervous system) but difficulties in differentiating between benign and malignant tumours can lead to variability in the coding of data between countries. For this reason, EUROCARE-6 present survival estimates both including and excluding CNS tumours.

For all cancers combined, 5-year observed survival for Ireland was 79.4% (95% CI 75.3%-82.9%), slightly lower (but with overlapping 95% confidence intervals) than the pooled EUROCARE-6 estimate of 81.3% (95% CI 80.8%-81.7%) (Figure 12). Ireland's 5-year observed survival estimate for all cancers combined ranked 23$^{rd}$ out of the 30 participating countries (20$^{th}$ out of 30 when CNS tumours were excluded). Highest survival was observed in Iceland, Cyprus and Denmark (albeit with wide confidence intervals for Iceland and Cyprus) while poorest survival was seen for children in Lithuania, Bulgaria and Estonia.

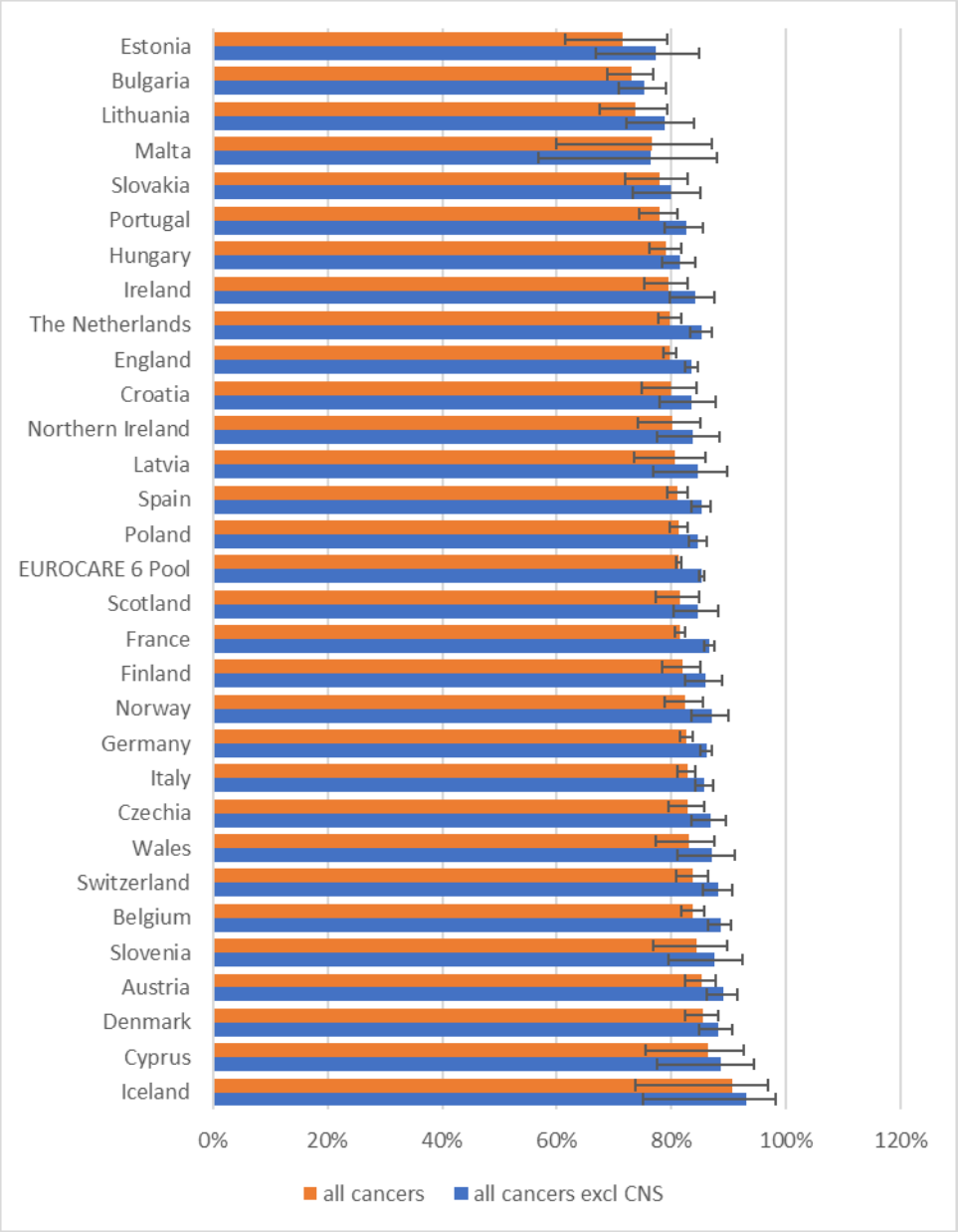



***Figure 12. Five year observed survival, with 95% confidence intervals, for all cancers combined, with and without CNS tumours, period estimate 2010-2014, by country, children aged 0-14 years [19].***

## Conclusion

This report summarises the most recent data available on the incidence, survival and mortality of cancers diagnosed in children and AYA in Ireland. The incidence rate of all cancers combined in are increasing significantly in both children (0-15 years) and AYA (16-24 years) (Figure 4). The reasons for this increase is unclear, but similar increases have also been described internationally and may, at least in part, be due to changes in diagnostic practices and cancer registration. Conversely, patient outcomes, both in terms of overall mortality and 5-year observed survival, have continued to improve over time reflecting the advances that have been made in diagnostics, treatment and care.

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## Appendix 1a. Case counts per year per diagnosis period, children 0-15 years of age

| Diagnostic Group | 1994 | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | Avg |
|---|---|---|---|---|---|---|---|---|---|
| I Leukaemias & related | 27 | 42 | 42 | 34 | 47 | 39 | 30 | 38 | **37** |
| II Lymphomas & related | 16 | 14 | 12 | 17 | 21 | 14 | 19 | 23 | **17** |
| III Brain and CNS | 43 | 42 | 29 | 31 | 37 | 22 | 32 | 31 | **33** |
| IV Neuroblastoma & peripheral nervous system tumours | <5 | 7 | <5 | 6 | <5 | 7 | 6 | 13 | **6** |
| V Retinoblastoma | <5 | <5 | <5 | <5 | <5 | <5 | 5 | 5 | **3** |
| VI Renal tumours | 5 | <5 | <5 | 7 | 5 | 6 | 7 | 12 | **6** |
| VII Hepatic tumours | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | **1** |
| VIII Malignant bone tumours | 9 | 12 | 6 | 5 | 7 | <5 | 7 | 14 | **8** |
| IX Soft tissue sarcomas | 11 | 7 | 5 | 5 | 7 | 10 | 11 | 12 | **9** |
| X Gonadal & germ cell tumours | 5 | 5 | <5 | <5 | 5 | 6 | <5 | 7 | **5** |
| XI Other epithelial tumours & melanomas | 13 | 11 | 6 | 9 | 9 | <5 | 10 | 7 | **9** |
| XII Other & unspecified | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | **1** |

| Diagnostic Group | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | Avg |
|---|---|---|---|---|---|---|---|---|---|---|
| I Leukaemias & related | 43 | 38 | 50 | 37 | 41 | 41 | 37 | 63 | 54 | **45** |
| II Lymphomas & related | 15 | 22 | 19 | 15 | 16 | 16 | 19 | 18 | 27 | **19** |
| III Brain and CNS | 33 | 32 | 40 | 26 | 35 | 36 | 45 | 40 | 42 | **37** |
| IV Neuroblastoma & peripheral nervous system tumours | 6 | 16 | 11 | 7 | <5 | 13 | 14 | 10 | 14 | **11** |
| V Retinoblastoma | <5 | <5 | <5 | 5 | <5 | <5 | 6 | 5 | <5 | **3** |
| VI Renal tumours | 7 | 6 | 8 | 6 | 6 | 6 | 9 | 11 | 6 | **7** |
| VII Hepatic tumours | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | **2** |
| VIII Malignant bone tumours | 6 | <5 | 7 | 9 | 7 | <5 | 6 | <5 | 6 | **5** |
| IX Soft tissue sarcomas | 11 | 14 | 8 | 9 | 6 | 13 | 5 | 11 | 12 | **10** |
| X Gonadal & germ cell tumours | <5 | <5 | 6 | 6 | 9 | <5 | 5 | <5 | <5 | **5** |
| XI Other epithelial tumours & melanomas | 8 | <5 | 10 | 10 | 10 | 9 | 7 | 6 | 14 | **8** |
| XII Other & unspecified | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | **1** |

| Diagnostic Group | 2011 | 2012 | 2013 | 2014 | 2015 | 2016 | 2017 | 2018 | 2019 | 2020 | Avg |
|---|---|---|---|---|---|---|---|---|---|---|---|
| I Leukaemias & related | 46 | 50 | 49 | 71 | 45 | 49 | 45 | 64 | 42 | 51 | **51** |
| II Lymphomas & related | 20 | 21 | 22 | 27 | 21 | 17 | 27 | 22 | 24 | 25 | **23** |
| III Brain and CNS | 52 | 49 | 47 | 63 | 50 | 44 | 47 | 49 | 56 | 63 | **52** |
| IV Neuroblastoma & peripheral nervous system tumours | 11 | 8 | 13 | 9 | 7 | 9 | 9 | 13 | 8 | 10 | **10** |
| V Retinoblastoma | 6 | 7 | <5 | 5 | <5 | 5 | <5 | 6 | <5 | <5 | **4** |
| VI Renal tumours | 8 | 9 | 14 | 12 | 8 | 11 | <5 | 6 | 6 | 5 | **8** |
| VII Hepatic tumours | <5 | <5 | <5 | <5 | 6 | <5 | <5 | <5 | <5 | <5 | **3** |
| VIII Malignant bone tumours | 8 | 9 | 7 | 5 | 6 | 10 | 9 | 9 | 7 | 11 | **8** |
| IX Soft tissue sarcomas | 11 | 10 | 13 | 10 | 6 | 8 | 11 | 15 | 16 | 10 | **11** |
| X Gonadal & germ cell tumours | 5 | <5 | 5 | 5 | <5 | 5 | 7 | 8 | <5 | 5 | **5** |
| XI Other epithelial tumours & melanomas | 12 | 10 | 14 | 8 | 10 | 10 | 21 | 17 | 18 | 13 | **13** |
| XII Other & unspecified | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | 7 | 15 | **4** |

## Appendix 1b. Case counts per year per diagnosis period, adolescents and young adults 16-24 years of age

| Diagnostic Group | 1994 | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | Avg |
|---|---|---|---|---|---|---|---|---|---|
| I Leukaemias & related | 19 | 9 | 16 | 16 | 18 | 13 | 15 | 15 | **15** |
| II Lymphomas & related | 27 | 21 | 32 | 25 | 20 | 34 | 28 | 29 | **27** |
| III Brain and CNS | 16 | 13 | 20 | 18 | 24 | 19 | 24 | 21 | **19** |
| IV Neuroblastoma & peripheral nervous system tumours | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | **1** |
| V Retinoblastoma | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | **1** |
| VI Renal tumours | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | **0** |
| VII Hepatic tumours | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | **1** |
| VIII Malignant bone tumours | <5 | 7 | 6 | 9 | 8 | 6 | 6 | 8 | **7** |
| IX Soft tissue sarcomas | 8 | 6 | 10 | 8 | 7 | <5 | 9 | 8 | **7** |
| X Gonadal & germ cell tumours | 19 | 28 | 24 | 16 | 37 | 26 | 32 | 22 | **26** |
| XI Other epithelial tumours & melanomas | 52 | 45 | 42 | 54 | 50 | 44 | 48 | 71 | **51** |
| XII Other & unspecified | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | **1** |

| Diagnostic Group | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | Avg |
|---|---|---|---|---|---|---|---|---|---|---|
| I Leukaemias & related | 17 | 13 | 16 | 14 | 19 | 20 | 10 | 16 | 14 | **15** |
| II Lymphomas & related | 29 | 36 | 34 | 39 | 34 | 41 | 29 | 45 | 36 | **36** |
| III Brain and CNS | 22 | 22 | 10 | 14 | 24 | 16 | 31 | 18 | 17 | **19** |
| IV Neuroblastoma & peripheral nervous system tumours | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | **1** |
| V Retinoblastoma | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | **0** |
| VI Renal tumours | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | **1** |
| VII Hepatic tumours | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | **1** |
| VIII Malignant bone tumours | 7 | <5 | 6 | 6 | <5 | <5 | <5 | 5 | 7 | **5** |
| IX Soft tissue sarcomas | 10 | 8 | 6 | <5 | 10 | 7 | 11 | 9 | 7 | **8** |
| X Gonadal & germ cell tumours | 30 | 29 | 31 | 29 | 40 | 42 | 29 | 29 | 26 | **32** |
| XI Other epithelial tumours & melanomas | 53 | 69 | 48 | 63 | 56 | 65 | 60 | 70 | 64 | **61** |
| XII Other & unspecified | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | **0** |

| Diagnostic Group | 2011 | 2012 | 2013 | 2014 | 2015 | 2016 | 2017 | 2018 | 2019 | 2020 | Avg |
|---|---|---|---|---|---|---|---|---|---|---|---|
| I Leukaemias & related | 10 | 14 | 7 | 11 | 15 | 13 | 14 | 12 | 12 | 14 | **12** |
| II Lymphomas & related | 42 | 29 | 24 | 46 | 38 | 31 | 45 | 35 | 34 | 47 | **37** |
| III Brain and CNS | 23 | 31 | 28 | 18 | 29 | 15 | 36 | 31 | 25 | 24 | **26** |
| IV Neuroblastoma & peripheral nervous system tumours | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | **0** |
| V Retinoblastoma | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | **0** |
| VI Renal tumours | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | **2** |
| VII Hepatic tumours | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | **1** |
| VIII Malignant bone tumours | 5 | 6 | 6 | 5 | 5 | <5 | 6 | 6 | 9 | <5 | **6** |
| IX Soft tissue sarcomas | 5 | <5 | 9 | 8 | 7 | 14 | 6 | 8 | 7 | 9 | **8** |
| X Gonadal & germ cell tumours | 23 | 32 | 24 | 27 | 36 | 14 | 26 | 19 | 28 | 22 | **25** |
| XI Other epithelial tumours & melanomas | 58 | 62 | 61 | 65 | 57 | 61 | 60 | 56 | 67 | 48 | **60** |
| XII Other & unspecified | <5 | <5 | <5 | <5 | <5 | <5 | <5 | <5 | 7 | <5 | **2** |

## Appendix 2. Total case counts 1994-2020 by age group for ICCC Group XI subgroups and equivalent ICD-10 cancer types.

| ICCC Group XI subgroup | Equivalent invasive icd10 site (code) | 0-15 years | 16-24 years |
|---|---|---|---|
| XIa. Adrenocortical carcinomas | adrenal gland (C74) | 0 | 0 |
| XIb. Thyroid carcinomas | thyroid gland (C73) | 31 | 220 |
| XIc. Nasopharyngeal carcinomas | nasopharynx (C11) | 6 | 20 |
| XId. Malignant melanomas | melanoma of skin (C43) | 39 | 421 |
| | non-cutaneous melanoma (mainly C69) | <5 | 13 |
| XIe. Skin carcinomas | other skin (C44) | 19 | 292 |
| XIf. Other and unspecified carcinomas | colorectal (C18-C20) | 135 | 318 |
| | head and neck (C00-C14, C30-C32) | 21 | 44 |
| | cervix uteri (C53) | <5 | 51 |
| | lung and trachea (C33-C34) | 7 | 41 |
| | breast (C50) | 0 | 43 |
| | stomach (C16) | 0 | 17 |
| | pancreas (C25) | <5 | 12 |
| | adrenal gland (C74) | 7 | <5 |
| | other ICD codes | 6 | 53 |

Note: Not all cases of a specific ICD-10-defined cancer necessarily fall within a single ICCC subgroup, depending on the morphology or topographic subsite involved.

## Appendix 3a. Average annual case counts, crude rates and world age-standardised rates[xiii], children 0-14 years 2011-2020

| | Females Annual avg | Crude rate/million (95% CI) | WASR/million (95% CI) | Males Annual avg | Crude rate/million (95% CI) | WASR/million (95% CI) | Total Annual avg | Crude rate/million (95% CI) | WASR/million (95% CI) |
|---|---|---|---|---|---|---|---|---|---|
| I Leukaemias & related | 23 | 47 (41-53.2) | 50 (43.2-56.1) | 26 | 51 (44.5-56.9) | 53 (46.5-59.5) | 49 | 49 (44.6-53.3) | 51 (46.8-56) |
| II Lymphomas & related | 7 | 14 (10.4-17) | 14 (10.3-16.9) | 12 | 24 (19.5-27.9) | 23 (19-27.3) | 19 | 19 (16.1-21.5) | 19 (15.8-21.2) |
| III Brain and CNS | 25 | 52 (45.2-58) | 52 (45.6-58.6) | 24 | 46 (40.1-51.9) | 47 (40.6-52.6) | 49 | 49 (44.4-53.1) | 49 (44.9-53.7) |
| IV Neuroblastoma & peripheral nervous system tumours | 5 | 11 (7.8-13.5) | 12 (8.7-15.3) | 4 | 9 (6.1-11.2) | 10 (6.8-12.5) | 10 | 10 (7.7-11.5) | 11 (8.6-13) |
| V Retinoblastoma | 2 | 4 (2.1-5.6) | 4 (2.4-6.3) | 2 | 4 (2.2-5.6) | 5 (2.5-6.5) | 4 | 4 (2.7-5.1) | 4 (3-5.8) |
| VI Renal tumours | 4 | 9 (6-11.2) | 9 (6.6-12.3) | 4 | 8 (5.6-10.5) | 9 (5.9-11.1) | 8 | 8 (6.5-10.1) | 9 (7-10.9) |
| VII Hepatic tumours | 1 | 2 (0.9-3.6) | 3 (1-4.1) | 2 | 3 (1.5-4.4) | 3 (1.6-4.9) | 3 | 3 (1.6-3.6) | 3 (1.8-4) |
| VIII Malignant bone tumours | 3 | 6 (4.1-8.6) | 6 (3.9-8.2) | 4 | 7 (4.9-9.6) | 7 (4.6-9.1) | 7 | 7 (5.2-8.4) | 6 (4.9-8) |
| IX Soft tissue sarcomas | 4 | 8 (5.1-10) | 8 (5.2-10.2) | 6 | 13 (9.5-15.6) | 13 (9.7-16) | 10 | 10 (8.1-12.1) | 10 (8.3-12.3) |
| X Gonadal & germ cell tumours | 2 | 4 (2.1-5.6) | 4 (2.2-5.9) | 3 | 5 (3-6.8) | 5 (2.9-6.6) | 4 | 4 (3.1-5.7) | 4 (3.1-5.7) |
| XI Other epithelial tumours & melanomas | 5 | 11 (7.9-13.8) | 10 (7.4-12.8) | 5 | 9 (6.2-11.4) | 8 (5.8-10.6) | 10 | 10 (7.9-11.8) | 9 (7.3-10.9) |
| XII Other & unspecified | 1 | 3 (1.4-4.4) | 3 (1.5-4.7) | 2 | 4 (2.5-6.1) | 4 (2.6-6.4) | 4 | 4 (2.4-4.8) | 4 (2.6-5.1) |
| All cancers (I-XII) | 83 | 169 (157.8-180.9) | 175 (162.6-186.6) | 93 | 182 (169.9-193.3) | 186 (173.8-197.9) | 176 | 176 (167.4-183.9) | 180 (171.8-188.8) |

[xiii] Based on Segi (1960) World standard population

## Appendix 3b. Average annual case counts, crude rates and world age-standardised rates[xiv], adolescents and young adults 15-24 years 2011-2020

| | Females Annual avg | Crude rate/million (95% CI) | | WASR/million (95% CI) | | Males Annual avg | Crude rate/million (95% CI) | | WASR /million (95% CI) | | Total Annual avg | Crude rate/million (95% CI) | | WASR /million (95% CI) | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| I Leukaemias & related | 7 | 23 | (17.1-28) | 23 | (17.2-28.3) | 8 | 27 | (21-32.7) | 27 | (20.8-32.5) | 15 | 25 | (20.7-28.8) | 25 | (20.7-28.7) |
| II Lymphomas & related | 19 | 66 | (56.8-75.6) | 66 | (56.5-75.2) | 22 | 73 | (63.5-82.9) | 73 | (62.9-82.2) | 41 | 70 | (63-76.5) | 69 | (62.5-76) |
| III Brain and CNS | 15 | 52 | (44-60.7) | 52 | (43.8-60.5) | 14 | 48 | (39.8-55.5) | 48 | (40-55.7) | 29 | 50 | (44.3-55.7) | 50 | (44.3-55.7) |
| IV Neuroblastoma & peripheral nervous system tumours | <1 | 0 | (-0.3-1) | 0 | (-0.3-1) | <1 | 1 | (-0.1-2.1) | 1 | (-0.1-2.1) | <1 | 1 | (0-1.4) | 1 | (0-1.3) |
| V Retinoblastoma | 0 | | | | | 0 | | | | | 0 | | | | |
| VI Renal tumours | 1 | 3 | (1.1-5.2) | 3 | (1-4.9) | 1 | 2 | (0.4-3.6) | 2 | (0.4-3.6) | 2 | 3 | (1.3-3.9) | 2 | (1.2-3.7) |
| VII Hepatic tumours | 1 | 2 | (0.2-3.3) | 2 | (0.2-3.4) | <1 | 1 | (0-2.7) | 1 | (0-2.8) | 1 | 2 | (0.5-2.5) | 2 | (0.6-2.7) |
| VIII Malignant bone tumours | 3 | 11 | (7.3-14.9) | 11 | (7.3-15.1) | 4 | 12 | (8.1-16) | 12 | (8.3-16.3) | 7 | 12 | (8.8-14.4) | 12 | (9-14.6) |
| IX Soft tissue sarcomas | 4 | 15 | (10.5-19.4) | 15 | (10.5-19.5) | 4 | 14 | (9.6-18) | 14 | (9.4-17.8) | 8 | 14 | (11.3-17.4) | 14 | (11.2-17.3) |
| X Gonadal & germ cell tumours | 4 | 15 | (10.7-19.8) | 15 | (10.8-19.8) | 21 | 71 | (61.6-80.8) | 70 | (60.8-79.7) | 26 | 44 | (38.3-49) | 43 | (37.8-48.4) |
| XI Other epithelial tumours & melanomas | 40 | 140 | (126.1-153.4) | 139 | (125-152.1) | 23 | 76 | (66.3-86.1) | 75 | (65.4-85) | 63 | 107 | (99.1-115.9) | 106 | (98.1-114.8) |
| XII Other & unspecified | 1 | 4 | (1.8-6.5) | 4 | (1.7-6.2) | 1 | 4 | (1.5-5.9) | 4 | (1.5-5.7) | 2 | 4 | (2.3-5.5) | 4 | (2.2-5.3) |
| All cancers (I-XII) | 96 | 331 | (310.5-352.5) | 330 | (308.9-350.8) | 98 | 329 | (308.4-349.7) | 326 | (305.9-346.9) | 194 | 330 | (315.5-344.9) | 328 | (313.4-342.6) |

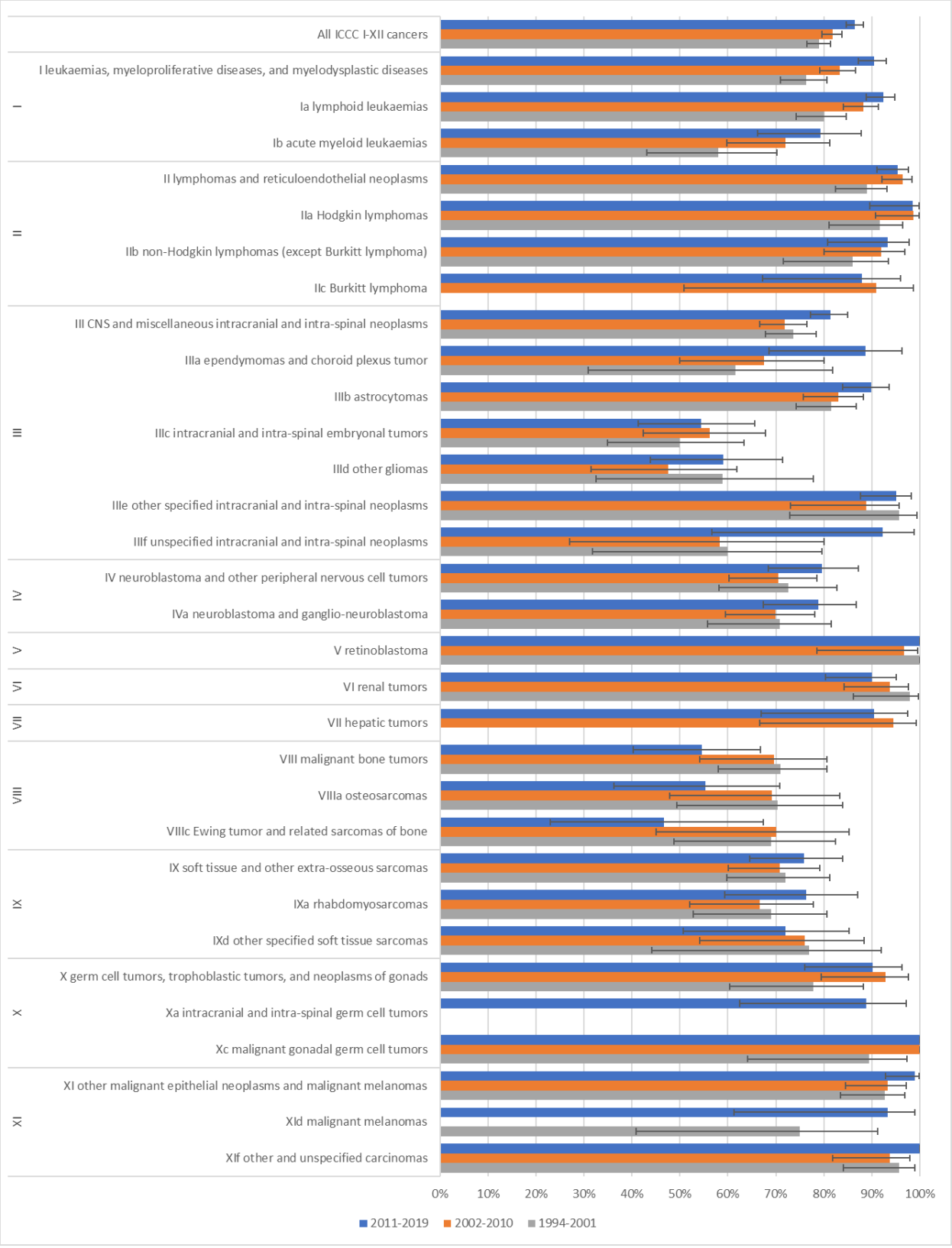
[xiv] Based on Segi (1960) World standard population

## Appendix 4. Crude incidence rate per million (95% CI) by ICCC group by age-group and sex.

| ICCC group | 0-15 years | | 16-24 years | |
|---|---|---|---|---|
| | Females | Males | Females | Males |
| I Leukaemias & related | 46.7 (40.8-52.6) | 49.8 (43.8-55.7) | 20.5 (15-26) | 25.9 (19.8-32) |
| II Lymphomas & related | 16.6 (13.1-20.1) | 25.8 (21.5-30.1) | 66.6 (56.6-76.5) | 74.7 (64.3-85.1) |
| III Brain and CNS | 51.5 (45.3-57.7) | 46.6 (40.9-52.4) | 52.6 (43.8-61.5) | 46.6 (38.4-54.7) |
| IV Neuroblastoma & related | 10 (7.3-12.8) | 8.3 (5.9-10.7) | 0.4 (-0.4-1.1) | 0.8 (-0.3-1.8) |
| V Retinoblastoma | 3.7 (2-5.3) | 3.7 (2.1-5.3) | | |
| VI Renal tumours | 8.1 (5.7-10.6) | 7.6 (5.2-9.9) | 3.5 (1.2-5.8) | 2.3 (0.5-4.1) |
| VII Hepatic tumours | 2.1 (0.9-3.4) | 2.9 (1.5-4.4) | 1.9 (0.2-3.6) | 1.1 (-0.1-2.4) |
| VIII Malignant bone tumours | 6.9 (4.7-9.2) | 8.3 (5.9-10.7) | 10.4 (6.5-14.4) | 10.5 (6.6-14.4) |
| IX Soft tissue sarcomas | 8.3 (5.8-10.8) | 12.4 (9.4-15.3) | 14.3 (9.7-18.9) | 14.3 (9.7-18.8) |
| X Gonadal & germ cell tumours | 4.1 (2.3-5.8) | 5.2 (3.3-7.1) | 16.3 (11.3-21.2) | 78.5 (67.8-89.1) |
| XI Other epithelial tumours & melanomas | 14.3 (11-17.5) | 10.9 (8.1-13.7) | 147.8 (133-162.6) | 80 (69.2-90.7) |
| XII Other & unspecified | 2.7 (1.3-4.1) | 4.2 (2.5-6) | 4.6 (2-7.3) | 3.8 (1.4-6.1) |

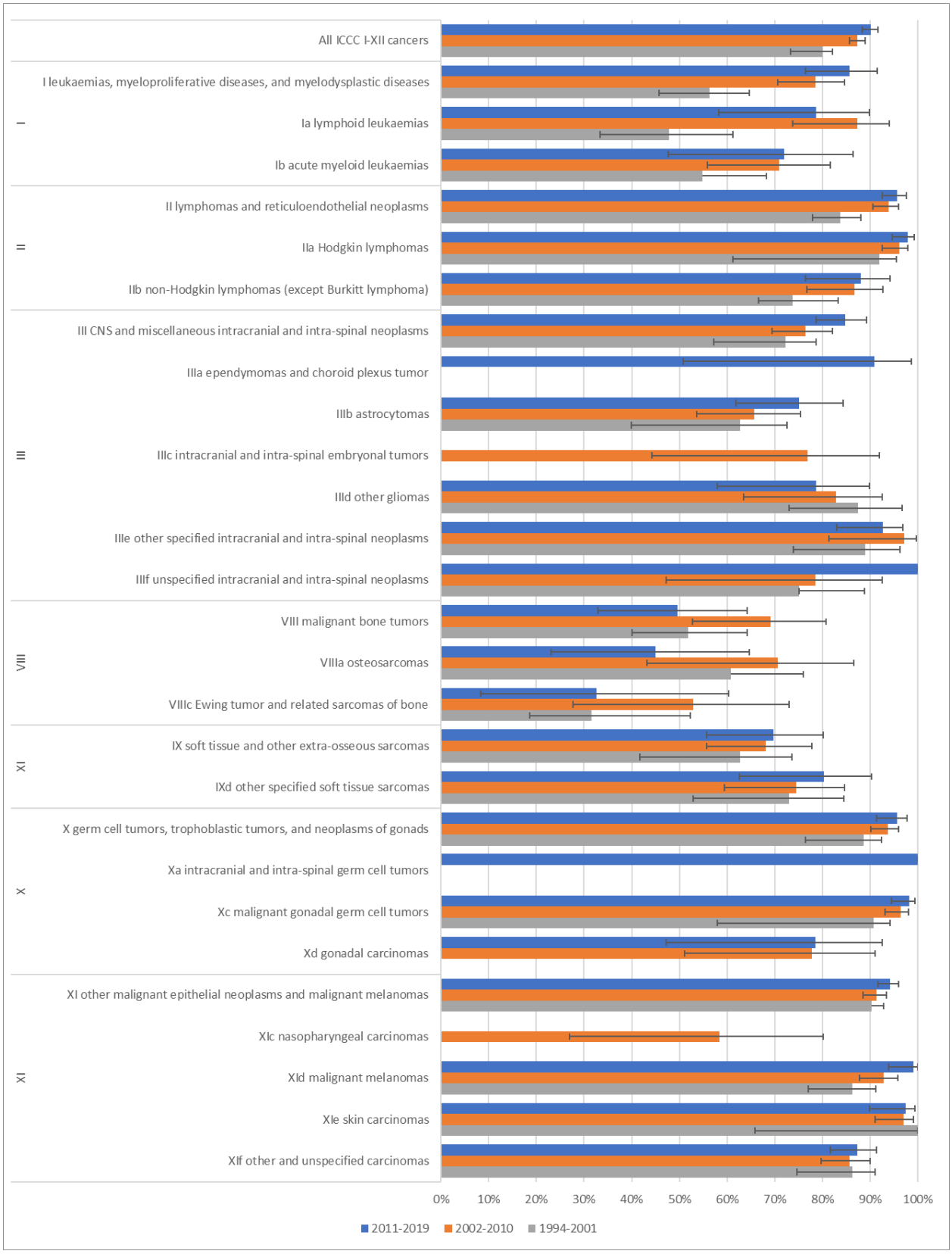
## Appendix 5a. 5-year observed survival by ICCC subgroup, 0-15 year olds




Note: 5-year observed survival estimated for subgroups with 10 or more cases diagnosed per time period

## Appendix 5b. 5-year observed survival by ICCC subgroup, 16-24 year olds




Note: 5-year observed survival estimated for subgroups with 10 or more cases diagnosed per time period