Children and Young People with Cancer in Scotland

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Introduction

This publication by Public Health Scotland (PHS) provides information on cancer in children (ages 0-14) and young people (ages 15-24) in Scotland.

The occurrence and outcomes of cancer in children and young people in Scotland deserves particular attention. While our existing publications on cancer incidence and cancer mortality include children and young people, the classification of cancer types included in those publications is based on anatomical site and is more suited to cancers diagnosed in adults. Many adult cancers are caused by modifiable lifestyle factors or are associated with increasing age but the determinants of cancers in children and young people are very different. As children and young people usually live many decades after a diagnosis of cancer, the implications for their future health, including fertility, are different from those of adults diagnosed in later life.

Improving the wellbeing of children and young people after cancer treatment, and into their adulthood, has increasing major resource implications, not only on paediatric and adult cancer services, but also other fields, such as radiology, fertility and cardiology for long term follow-up. The Scottish Government strategy, Collaborative and Compassionate Cancer Care: The Cancer Strategy for Children and Young People in Scotland 2021–2026, addresses all of these issues.

This is an annual publication that has been developed in collaboration with the Managed Service Network for Children and Young People with Cancer. Information is included on cancer incidence, survival, mortality, place of death and prevalence covering the years 2010-2019.

Cancer registration in Scotland

The Scottish Cancer Registry is the source of the Children and Young People with Cancer data provided in this publication. More information on the registry can be found on the Public Health Scotland website.

Acknowledgement

This publication uses data shared by patients and collected by the NHS as part of their care and support.
Main points

• Each year in Scotland around 330 children and young people (CYP) under 25 years old are diagnosed with cancer; almost one person every day.

• The numbers of new cancers in children has generally increased over time but there has been no change for young people.

• In the ten-year period 2010-2019, 1,312 children (aged 0-14, 53% male) and 1,970 young people (aged 15-24, 52% female) were diagnosed with cancer.

• Cancer occurrence in children and young people varies by age and sex.

• Nearly one third (31%) of childhood cancers were leukaemia and just over a quarter (26%) were cancers of the brain and central nervous system (CNS).

• The most common diagnoses in young people were carcinomas (22%), lymphomas (19%), and CNS tumours (14%).

• While survival rates are high from most cancers in children and young people, 1 in 15 children (6.6%) and 1 in 30 young people (3.3%) dies in the first year after a cancer diagnosis.

• Most children and young people will be cured of their cancer. 86% of children and 90% of young people diagnosed with cancer can expect to be alive at least five years after the diagnosis. However, some cancers are harder to treat than others and collaborative working with palliative care services is essential.

• Cancer is the commonest cause of disease-related death in children and young people. In Scotland, around 40 CYP die from cancer every year. Similar proportions of CYP died in hospital (46%) or at home/a private address (40%), while one in seven (14%) died in a hospice.

• For the 2,584 children diagnosed with cancer (aged 0-14) between 2000 and 2019, 2,055 of them were still alive as at 31 December 2019. For the 3,895 young people diagnosed with cancer (aged 15-24) between 2000 and 2019, 3,194 of them were still alive as at 31 December 2019. Similarly, there were 3,790 people still alive at 31 December 2019 of the 5,733 who had been diagnosed with cancer as a child at any time between 1975 and 2019; this gives the 45-year prevalence figure. The corresponding 45-year prevalence for the 8,121 young people diagnosed with cancer between 1975 and 2019 was 5,635. These numbers of cancer survivors have major resource implication for medics, nurses, and Allied Health Professionals who provide long term follow-up and they have impacts upon other departments such as radiology, fertility and cardiology.
**Methods**

The Scottish Cancer Registry regularly publishes data on cancer at all ages, but the classification used (the 10th edition of the International Classification of Diseases or ICD-10) is more suited to adult cancers. These cancers are classified primarily by the part of the body where the cancer is located, whereas cancers in children and young people are more appropriately classified by the type of tumour (i.e. which cell types are involved).

Thus, the analyses of cancer incidence, survival and prevalence included in this publication initially select cases based on ICD-10 and then use the more appropriate classifications of the disease to group them. For children (ages 0-14), cancers are described using the third edition of the **International Classification of Childhood Cancer (ICCC-3)**. For young people (ages 15-24), cancers are described using the **Birch-Alston classification**. It should be noted that these classifications include some types of disease that would not be described as being malignant using ICD-10; however, these still greatly affect the lives of the children and young people who have them, which is why they are included in these classifications. Therefore, in addition to the ICD-10 codes (C00-C96; C97 is not used by the Scottish Cancer Registry) which are normally used in the general publications, this publication also includes certain non-malignant ICD-10 codes (D32-D33, D35.2-D35.4, D42-D43, D44.3-D44.5). For this reason, there may be small differences in the numbers of cases, deaths and survival estimates included in this publication when compared to the statistics for all ages.

Furthermore, while the general cancer publications include net survival, which takes into account other causes of death which may affect survival, for children and young people this is less appropriate. We therefore present one and five year observed survival rates.

Survival analysis has been presented for both one and five years comparing the periods 2009-2013 and 2014-2018. Survival is censored at 31 December 2019. This means that any patient who is still alive at this single cut-off point is given this date as the end of follow-up of vital status, whereas patients who have died before or on the 31 December 2019 have their end of follow-up as their death date.
Results and commentary

1 Cancer Incidence (2010-2019)

1.1 Cancer Incidence in Children (ages 0-14)

In the ten-year period 2010-2019, 1,312 children (53% males - 696) were diagnosed with cancer in Scotland. Cancer in children represented less than 1% of all cancers diagnosed in 2019. Around one in 945 children will develop some form of cancer by the age of 15 years.

The proportion of microscopically verified tumours has been 90% or above for most of the last ten years [CYPC Incidence - Childhood Chart 1]. This proportion will not reach 100% because, for example, it is not always safe to take a tissue sample from some anatomical sites, and some childhood tumours are conventionally diagnosed based on radiological characteristics.

The annual number of new cancers in children has generally increased over time. The World age-adjusted rate – or risk – of cancer in children in Scotland increased over the period 2010-2019. For all children, the increase was almost 21% (p=0.006) between 2010 and 2019. The increase in boys (12.8%, p=0.23) was smaller and may be a chance finding but the increase in girls (30.1%, p=0.01) was larger and unlikely to be due to chance. In boys, there was an increase in lymphomas and reticuloendothelial neoplasms (up 177%) and decrease in neuroblastomas and other peripheral nervous cell tumours (down 53%) between 2010 and 2019. There was also an increase (by 131%) in neuroblastomas and other peripheral nervous cell tumours in girls over the same period. The numbers of each type of tumour in any year are small and therefore changes over time are also affected by relatively small differences in numbers. For example, the annual number of lymphomas and reticuloendothelial tumours in boys was 4 in 2010, 8 in 2015 and 10 in 2019. An increase in incidence in childhood cancers over time has previously been reported in Europe and the British Isles.¹

The most common cancer diagnoses in children were in the category leukaemias and other blood cell cancers (the majority of which were lymphoid leukaemias) and cancers of the brain and central nervous system (CNS). These comprised 31% and 26% of all childhood cancers respectively [CYPC Incidence - Childhood Table 2a]. Diagnoses varied by age, for example, with a peak in leukaemias at age 2 [CYPC Incidence - Childhood Chart 2]. The number, and risk, of childhood cancers was about one and a half times as great among children under 5 years of age as those aged 5-9 or 10-14 for most categories. However, a different pattern was seen for lymphomas and reticuloendothelial neoplasms, bone tumours and other malignant epithelial and malignant melanomas (at any site), which are more common as age increases.

Figures 1 and 2. Children aged 0-14: mean number of cancer diagnoses\(^1\) per year by age and diagnostic grouping, Scotland, 2010-2019.

1. The diagnosis groupings are explained further in the glossary.

European (EASR) and World (WASR) age-standardised incidence rates for childhood cancer were 151.1 and 156.5 per million person-years respectively. Overall, the World age-standardised incidence rate was higher in boys compared with girls (162.1 per million person-years compared with 150.9 for females). Incidence rates were higher in boys for: lymphoid leukaemias; lymphomas; soft tissue and other extraosseous sarcomas; central nervous system tumours; and retinoblastoma. Conversely, rates were higher in girls for: malignant bone tumours; neuroblastoma and other peripheral nervous cell tumours; other (non-lymphoid) leukaemias; renal tumours; other
malignant epithelial neoplasms and malignant melanomas; germ cell tumours, trophoblastic tumours and neoplasms of gonads.

### Table 1. Standardised incidence rates\(^1\) in children (ages 0-14) by sex and ICCC-3 category\(^2,3\), Scotland, 2010-2019.

<table>
<thead>
<tr>
<th>Diagnostic category</th>
<th>WASR</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Females</td>
</tr>
<tr>
<td>Leukaemias, myeloproliferative diseases, and myelodysplastic diseases \textit{(leukaemias and other blood cell cancers)}</td>
<td>45.5</td>
</tr>
<tr>
<td>- Lymphoid leukaemias</td>
<td>36.6</td>
</tr>
<tr>
<td>- Other leukaemias</td>
<td>9.0</td>
</tr>
<tr>
<td>Lymphomas and reticuloendothelial neoplasms \textit{(Lymphomas)}</td>
<td>8.6</td>
</tr>
<tr>
<td>CNS and miscellaneous intracranial and intraspinal neoplasms \textit{(cancers of the brain and central nervous system (CNS))}</td>
<td>39.1</td>
</tr>
<tr>
<td>Neuroblastoma and other peripheral nervous cell tumours</td>
<td>11.1</td>
</tr>
<tr>
<td>Retinoblastoma</td>
<td>4.4</td>
</tr>
<tr>
<td>Renal tumours</td>
<td>8.4</td>
</tr>
<tr>
<td>Hepatic tumours</td>
<td>2.2</td>
</tr>
<tr>
<td>Malignant bone tumours</td>
<td>6.8</td>
</tr>
<tr>
<td>Soft tissue and other extraosseous sarcomas</td>
<td>9.8</td>
</tr>
<tr>
<td>Germ cell tumours, trophoblastic tumours and neoplasms of gonads</td>
<td>6.2</td>
</tr>
<tr>
<td>Other malignant epithelial neoplasms and malignant melanomas</td>
<td>6.5</td>
</tr>
<tr>
<td>Other and unspecified malignant tumours</td>
<td>2.2</td>
</tr>
<tr>
<td><strong>All diagnoses</strong></td>
<td><strong>150.9</strong></td>
</tr>
</tbody>
</table>

Source: Scottish Cancer Registry, Public Health Scotland (PHS)

1. World age-standardised rate (WASR) per million person-years at risk.
2. Cancers in Children are classified according to ICCC diagnostic groupings as based on the Steliarova-Foucher methodology (ICCC Third Edition).
3. The diagnosis groupings are explained further in the glossary.
1.2 Cancer Incidence in Young People (ages 15-24)

In the ten-year period 2010-2019, 1,970 young people were diagnosed with some form of cancer as defined by the Birch-Alston classification. Of these, 1,024 (52%) were female. As with children, cancers in this age group represented less than 1% of cancers diagnosed in 2019.

There is no convincing overall trend in incidence over time between 2010 and 2019. European and World age-standardised rates were 292.8 and 286.8 per million person-years respectively, for all cancers in young people between 2010 and 2019. However, in males, there was a significant decrease in melanomas (at any site) and skin cancers (down 58%) and increase in carcinomas (up 60%) between 2010 and 2019.

Carcinomas collectively account for the largest group (22% of all cancers in this age group), followed by lymphomas (19%); and melanoma and skin cancers (14%). Cancer incidence increased with age; numbers and risks were almost twice as high in 20-24 year olds compared to 15-19 year olds. Overall – and in contrast to patterns in children – females had higher World age-standardised incidence rates of cancers compared with males (298.2 per million person-years compared with 275.4 per million person-years for males). Females had over three times the rate of carcinomas and almost twice (1.86 times) the rates of melanoma and skin cancers, compared with males. In contrast, germ cell tumours were 5.5 times more common in males than females (these were mainly due to testicular malignancies comprising largely germ cell tumours).

Carcinomas in females aged 20-24 were notably high at 139.4 per million person-years. Rates of carcinomas rose continuously in females from age 18 upwards. A quarter (25.0%) of these carcinomas were cervical and 1 in 7 (14.3%) were colorectal.

In males, the four most common cancers in young people in descending order are: germ cell tumours; lymphomas; CNS tumours and carcinomas.

In females, the four most common cancers in young people in descending order are: carcinomas; lymphomas; melanomas and skin cancer and CNS tumours.

For all young people, carcinomas were mainly gastrointestinal tumours (30%), thyroid cancers (28%) and genitourinary cancers (23%).

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2 The age specific rates of all cancers combined in 13-24 year olds has increased in England from 233.1 per million in 2001 to 299.7 per million in 2015. Further information can be found in the report "13-24 year olds with cancer in England: Incidence, mortality and survival".
Table 2. Standardised incidence rates\(^1\) in young people (ages 15-24) by sex and Birch-Alston category\(^2,3\), Scotland, 2010-2019.

<table>
<thead>
<tr>
<th>Diagnostic category</th>
<th>WASR</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Females</td>
<td>Males</td>
<td>Both</td>
</tr>
<tr>
<td>Leukaemias</td>
<td>17.8</td>
<td>26.3</td>
<td>22.1</td>
</tr>
<tr>
<td>- Acute lymphoid leukaemia (ALL)</td>
<td>8.4</td>
<td>14.8</td>
<td>11.6</td>
</tr>
<tr>
<td>- Other leukaemias</td>
<td>9.4</td>
<td>11.5</td>
<td>10.5</td>
</tr>
<tr>
<td>Lymphomas</td>
<td>53.6</td>
<td>59.0</td>
<td>56.3</td>
</tr>
<tr>
<td>CNS tumours</td>
<td>42.9</td>
<td>38.1</td>
<td>40.5</td>
</tr>
<tr>
<td>Bone tumours</td>
<td>10.7</td>
<td>15.7</td>
<td>13.2</td>
</tr>
<tr>
<td>Soft tissue sarcomas</td>
<td>14.1</td>
<td>12.6</td>
<td>13.3</td>
</tr>
<tr>
<td>Germ cell tumours</td>
<td>11.2</td>
<td>61.4</td>
<td>36.3</td>
</tr>
<tr>
<td>Melanoma and skin cancer</td>
<td>48.4</td>
<td>26.0</td>
<td>37.2</td>
</tr>
<tr>
<td>Carcinomas</td>
<td>94.6</td>
<td>29.3</td>
<td>62.0</td>
</tr>
<tr>
<td>Miscellaneous specified neoplasms NEC</td>
<td>4.5</td>
<td>6.7</td>
<td>5.6</td>
</tr>
<tr>
<td>Unspecified malignant neoplasms NEC</td>
<td>0.4</td>
<td>0.3</td>
<td>0.3</td>
</tr>
<tr>
<td><strong>All diagnoses</strong></td>
<td><strong>298.2</strong></td>
<td><strong>275.4</strong></td>
<td><strong>286.8</strong></td>
</tr>
</tbody>
</table>

Source: Scottish Cancer Registry, Public Health Scotland (PHS)

1. World age-standardised rate (WASR) per million person-years at risk.
2. Cancers in Young People are classified according to Birch-Alston diagnostic groupings.
3. The diagnosis groupings are explained further in the glossary.
2 Cancer Survival (2009-2018, with follow-up to 31 December 2019)

2.1 Cancer Survival in Children (ages 0-14)

One-year survival did not change between 2009-2013 and 2014-2018. It was 92.5% (95% CI: 90.1% to 94.4%) for children diagnosed in the period 2009-2013 and 93.4% (95% CI: 91.3% to 95.1%) for children diagnosed in the period 2014-2018. It can be difficult to infer whether one-year survival reflects the effectiveness of therapy because many treatments continue to be given for over a year - for example, for leukaemia, neuroblastoma, bone tumours, rhabdomyosarcomas and some central nervous system tumours. However, 1 in 15 children (6.6%) dies within a year of a cancer diagnosis.

Five-year survival, where it could be calculated, did not change between 2009-2013 and 2014-2018 (83.7% (95% CI: 80.4% to 86.4%) and 85.7% (95% CI: 82.4% to 88.5%), respectively). It should be noted that in the latter period, 2014-2018, information on survival for the full five years can currently be measured only for patients diagnosed during 2014. This also means that the benefits of recent changes in treatment may not be apparent.

The proportion of children who live at least five years after their cancer is diagnosed varies by cancer type [CYPC Survival - Childhood Table 5a]. Generally, children diagnosed with a haematological tumour (the leukaemias and other blood cell cancers and the lymphomas) do better than the children diagnosed with CNS tumours and neuroblastomas. This is true at one year after diagnosis and becomes more obvious after five years.
Figure 4 shows five-year survival in children diagnosed in 2009-2013 and 2014-2018 by cancer type. The small numbers can make it difficult to be certain if any differences are due to chance alone and so the black bars (95% confidence intervals) indicate if there is an overlap which indicates no convincing difference. [CYPC Survival - Childhood Table 5a].

Figure 4. Five year observed survival in children diagnosed in 2009-2013 and 2014-2018 by ICCC-3 category\(^1,2,3\), with 95% confidence intervals.

Source: Scottish Cancer Registry, Public Health Scotland (PHS)

1. The diagnosis groupings are explained further in the glossary.  
2. Hepatic tumours: survival probabilities are not calculated where there are fewer than 10 cases.  
3. Survival is censored at 31 December 2019. Therefore, cases diagnosed in 2015-2018 do not have a full 5 years' follow-up.

2.2 Cancer Survival in Young People (ages 15-24)

For young people, one-year survival increased from 95.1% (95% CI: 93.6% to 96.3%) in those diagnosed from 2009-2013 to 96.7% (95% CI: 95.3 to 97.6%) in 2014-2018. 1 in 30 young people (3.3%) dies within a year of a cancer diagnosis.

Five-year survival did not change between the two periods. It was 89.0% (95% CI 86.9 to 90.8) and 89.6% (95% CI 87.0 to 91.7) in 2009-2013 and 2014-2018, respectively.

Survival varies by cancer type. It was higher for: malignant melanoma and skin cancers; germ cell tumours; and lymphomas. It was lower for bone tumours and leukaemias. [CYPC Survival - Young People Table 6a].
Figure 5 shows changes in five-year survival in young people between 2009-2013 and 2014-2018 by cancer type. Given the small numbers in many of the categories, caution is needed when interpreting any changes over time. The black bars (95% confidence intervals) of one period overlap the best estimate in the other in all cases, indicating that there is no convincing difference.

For all of these categories, the only convincing improvement was in one-year survival for soft tissue sarcomas and other extraosseous sarcomas. Between the two periods, one-year survival increased significantly from 73.7% to 98.0%, with a corresponding 20 percentage point increase in five-year survival (63.2% to 84.2%) Where survival has improved, it may be due to better supportive care, changes in treatment to paediatric protocols or participation in clinical trials.3

Figure 5. Five year observed survival in young people diagnosed in 2009-2013 and 2014-2018 by Birch-Alston category1,2, with 95% confidence intervals.

Source: Scottish Cancer Registry, Public Health Scotland (PHS)

1. The diagnosis groupings are explained further in the glossary.
2. Survival is censored at 31 December 2019. Therefore, cases diagnosed in 2015-2018 do not have a full 5 years' follow-up.

3 Cancer Mortality (2010-2019)

Cancer mortality information comes from National Records of Scotland death records. These include only the anatomical site of cancer. This is less suited to describing cancers in children and young people than the tumour cell type that is available from the Scottish Cancer Registry to describe incidence and survival. It also means that some diagnoses will fall into different classifications for deaths than for incidence and survival.

3.1 Cancer Mortality in Children (ages 0-14)

In the ten-year period 2010-2019, 186 children died of cancer in Scotland: 79 females and 107 males. The higher number in males is consistent with higher rates of cancer incidence. Deaths are described by the year in which the death was registered rather than occurred. Cancer is the most common cause of disease-related death in children.4

The most common causes of death from cancer in children were: cancers of the brain and central nervous system; leukaemia; cancer of the adrenal gland. These caused around 77% of deaths from cancer in children in 2010-2019 (Table 5). The average number of cancer deaths in children was 19 per year, though there was no clear trend over time.

Table 5. Number of deaths from cancer in children (ages 0-14) by sex and diagnostic category\textsuperscript{1}, 2010-2019.

<table>
<thead>
<tr>
<th>Diagnosis category</th>
<th>Females</th>
<th>Males</th>
<th>Both</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leukaemia</td>
<td>15</td>
<td>17</td>
<td>32</td>
</tr>
<tr>
<td>Hodgkin lymphoma</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>-</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Brain, CNS</td>
<td>28</td>
<td>60</td>
<td>88</td>
</tr>
<tr>
<td>Adrenal gland</td>
<td>9</td>
<td>14</td>
<td>23</td>
</tr>
<tr>
<td>Eye</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Kidney</td>
<td>7</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Liver</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Bone</td>
<td>3</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Connective and soft tissue</td>
<td>8</td>
<td>4</td>
<td>12</td>
</tr>
<tr>
<td>Ovary</td>
<td>1</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Testis</td>
<td>x</td>
<td>-</td>
<td>x</td>
</tr>
<tr>
<td>Skin (melanoma and NMSC)</td>
<td>-</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Thyroid</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Other cancers</td>
<td>5</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td><strong>All cancers</strong></td>
<td><strong>79</strong></td>
<td><strong>107</strong></td>
<td><strong>186</strong></td>
</tr>
</tbody>
</table>

Source: National Records for Scotland (NRS)

\textsuperscript{1} = zero value.
\textsuperscript{x} = not applicable (single sex only).

1. The diagnosis category for mortality is based on ICD-10 disease classification (C00-C97, D32-D33, D35.2-D35.4, D42-D43, D44.3-D44.5).

2. As ICD 10 focusses on anatomical site, it should be noted that deaths from “adrenal gland” cancers are highly likely to represent deaths from neuroblastoma. Not all neuroblastomas involve the adrenal gland, and some neuroblastoma deaths may be represented in alternative anatomical sites or in the “Other cancers” deaths.
3.2 Cancer Mortality in Young People (ages 15-24)

In the ten-year period 2010-2019, 218 young people died of cancer in Scotland: 107 females and 111 males. Note that these young people may have been diagnosed as children. The most common causes of death from cancer in this age group were: cancers of the brain and central nervous system; bone cancer; and leukaemias. Table 6 shows all causes of death from cancer in Scotland in this age group in 2010-2019. The average number of cancer deaths in young people was 22 per year and there was no clear trend over time.

Table 6. Number of deaths from cancer in young people (ages 15-24) by sex and diagnostic category1, 2010-2019.

<table>
<thead>
<tr>
<th>Diagnosis category</th>
<th>Number of deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Females</td>
</tr>
<tr>
<td>Leukaemia</td>
<td>12</td>
</tr>
<tr>
<td>Hodgkin lymphoma</td>
<td>5</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>4</td>
</tr>
<tr>
<td>Brain, CNS</td>
<td>23</td>
</tr>
<tr>
<td>Adrenal gland</td>
<td>2</td>
</tr>
<tr>
<td>Eye</td>
<td>1</td>
</tr>
<tr>
<td>Kidney</td>
<td>2</td>
</tr>
<tr>
<td>Liver</td>
<td>1</td>
</tr>
<tr>
<td>Bone</td>
<td>19</td>
</tr>
<tr>
<td>Connective and soft tissue</td>
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</tr>
<tr>
<td>Ovary</td>
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</tr>
<tr>
<td>Testis</td>
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</tr>
<tr>
<td>Skin (melanoma and NMSC)</td>
<td>4</td>
</tr>
<tr>
<td>Thyroid</td>
<td>-</td>
</tr>
<tr>
<td>Other cancers</td>
<td>19</td>
</tr>
<tr>
<td><strong>All cancers</strong></td>
<td><strong>107</strong></td>
</tr>
</tbody>
</table>

Source: National Records for Scotland (NRS)

1. 'x' = zero value.
2. '=not applicable (single sex only).

3.3 Place of Death

Information on place of death was available for all of the 404 deaths that occurred in children and young people (aged 0-24 years) between 2010 and 2019. Similar proportions died in hospital and at home or a private address – 46% and 40%, respectively. One in seven (14%) died in a hospice
and none was recorded as having died in a care home or other institution [CYPC Mortality - Place Death Table 11].

4 Cancer Prevalence as at 31 December 2019

Cancer prevalence describes the number of people living with the disease at a point in time. The method used in this publication is to describe the numbers of individuals who are still alive after a cancer diagnosis. This approach will include a range of people – from children and young people who have just been diagnosed in 2019 to adults who were diagnosed several decades ago who may not consider themselves still to have cancer. However, there may still be a need for long term follow-up services and major resource implications for medics, nurses, and Allied Health Professionals, as well as impacts upon other departments such as radiology, fertility and cardiology. These estimates are for guidance only and due to population migration they tend to become less reliable with longer time periods, especially beyond 20 years. The 45-year period was chosen because at the time of publication it is the longest period for which ICD-O morphology was available to define cancer incidence in children and young people.

4.1 Cancer Prevalence in Children (ages 0-14)
These were calculated as the numbers of people who were alive on 31 December 2019 after a diagnosis of cancer when they were up to 14 years old, going back 20 years and going back 45 years. As at 31 December 2019, 916 children (aged 0-14) and 1,139 people aged 15 and older were alive after a cancer diagnosis when they were aged 0-14 up to 20 years previously [CYPC Prevalence - Childhood Table 13]. 3,790 people were alive after a diagnosis of cancer when they aged 0-14 in the previous 45 years.

4.2 Cancer Prevalence in Young People (ages 15-24)
These were calculated as the numbers of people who were alive on 31 December 2019 after a diagnosis of cancer when they were between 15 and 24 years old, going back 20 years and going back 45 years.
As at 31 December 2019, 678 15-24 year olds were alive after a diagnosis of cancer when they were between 15 and 24 years old. A further 2,516 adults aged 25 and older were alive after a cancer diagnosis when they were aged 15-24. [CYPC Prevalence - Young People Table 15]. 5,635 people were alive after a diagnosis of cancer when they were aged 15-24 in the previous 45 years.
These statistics and statistics for all ages on cancer incidence, cancer mortality, lifetime risk, prevalence and survival can be found on the Public Health Scotland website cancer topic area.
**Glossary**

**Age-adjusted rate**
The number of people of different ages may vary over time in the same population or vary between different populations. These differences may account for observed differences in the rate, or risk, of cancer. Age-adjusted rates use consistent international standard populations that do not vary. See European Age Standardised Rate (EASR) and World Age-Standardised Rate (WASR) below.

**Benign tumour**
A tumour that does not invade and destroy local tissue or spread to other sites in the body.

**Birch-Alston category**
For young people (ages 15-24), cancers are described using the Birch-Alston classification. It groups cancers by their cell types rather than by the anatomical site of the cancer (which is used to group most adult cancers).

**Cancer registry**
The Scottish Cancer Registry is responsible for the collection of information on all new cases of cancer arising in residents of Scotland. More detailed information is available on the PHS website here.

**Carcinoma**
A tumour which arises in the epithelial tissue (i.e. the skin or the lining that covers all the body’s organs) is called a carcinoma. Most cancers are carcinomas.

**CNS and miscellaneous intracranial and intraspinal neoplasms**
Tumours which arise from different types of cells in the brain and the spinal cord. These are classified according to the cell type and area of the Central Nervous System (CNS) in which they began.

**Confidence interval (CI)**
The interval or range of values that is likely to contain the true value of a parameter.

**Crude rate**
The number of cases divided by the population. The crude rate does not attempt to adjust for differences in age and sex structures between different populations. See European Age Standardised Rate (EASR) and World Age-Standardised Rate (WASR) below. Typically expressed as the number of cases per 100,000 population.

**European Age Standardised Rate (EASR)**
The rate that would have been found if the population in Scotland had the same sex and age-composition as the hypothetical standard European population. The 2013 European Standard Population (ESP2013) has been used to calculate EASRs within this publication. It is used to help
make comparisons between different countries or when the age-structure of a population has changed over time.

**Germ cell tumours, trophoblastic tumours and neoplasms of gonads**

Germ cell tumours (GCT) is a diverse group of tumours that arise from cells that develop into sperm in males or eggs in females. Most develop within the ovaries or testes; these are called gonadal germ cell tumours. However, germ cell tumours can also occur in other parts of the body.

**Hepatic tumours**

Liver tumours.

**ICCC-3 category**

For children (ages 0-14), cancers are described using the third edition of the International Classification of Childhood Cancer (ICCC-3). It groups cancers with more emphasis on the cell type rather than the anatomical site (which is used to group most adult cancers).

**ICD-10**

The 10th revision of the International Statistical Classification of Diseases and Related Health Problems produced by the World Health Organisation (WHO). It assigns codes to particular diseases and conditions, not only for cancer but for all diseases.

**Incidence**

Incidence refers to the number of new cases of a condition in a defined population during a defined period and is typically expressed as the number of new cases per million person-years at risk (or other suitable units).

**Leukaemias, myeloproliferative diseases, and myelodysplastic diseases**

Tumours which arise in bone marrow and cover diseases of blood cells and plasma cells.

**Lymphomas and reticuloendothelial neoplasms**

Tumours which arise in the immune system and affect the cells in the lymph nodes and tissues around the kidney, spleen and bone marrow.

**Malignant tumour**

Cancerous growth.

**Mortality rate**

The number of deaths as a rate per million population.

**Microscopically verified tumours (MV)**

Microscopic verification improves the accuracy of the diagnosis and helps to guide treatment. Microscopic verification includes histologically confirmed cases, cases diagnosed on the basis of exfoliative cytology specimens, and cases of leukaemia diagnosed on the basis of haematological examination (without examination of bone marrow). The main use of MV proportion is as an indicator of data capture and recording quality.

**Neuroblastoma and other peripheral nervous cell tumours**
Tumours which arise in immature cells of non-central nervous systems. For example, tumours forming in the adrenal glands, and other nerves in the abdomen. Neuroblastomas are almost exclusively found in young children.

**Other malignant epithelial neoplasms and malignant melanomas**

Melanomas are tumours of the pigment-producing cells called melanocytes usually in the skin but also found in the eye and other parts of the body. There are a few types of tumours which form in the epithelial tissues (making them carcinomas) but which are not in the skin – for example, thyroid carcinomas.

**Observed survival**

The percentage of people still alive for a given period of time after diagnosis.

**Percentage**

A number or amount in each hundred.

**Prevalence**

The number of people with a diagnosis of a particular condition who are alive at a given point in time.

The estimates of prevalence are for guidance only, due to population migration, and tend to become less reliable with longer time periods, especially beyond 20 years.

**Retinoblastoma**

A rare form of cancer that rapidly develops from the immature cells of a retina, the light-detecting tissue of the eye. It is the most common primary malignant intraocular cancer in children, and it is almost exclusively found in children under the age of 6.

**Soft tissue and other extraosseous sarcomas**

Tumours arising in connective and supporting structures are called sarcomas. This group covers all of the sarcomas which are not found in the bone (osseous sarcomas). These structures include muscles, fat and cartilage, for example.

**World Age Standardised Rate (WASR)**

The rate that would have been found if the population in Scotland had the same sex and age-composition as the hypothetical standard World population. The World Standard Population (WSP) has been used to calculate WASRs within this publication. It is used to help make comparisons between different countries or when the age-structure of a population has changed over time.
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Further information

Further information and data for this publication are available from the publication page on the PHS website.

The next release of this publication will be September 2022.

Open data

Data from this publication is available to download from the Scottish Health and Social Care Open Data Portal.

Rate this publication

Let us know what you think about this publication via the link at the bottom of this publication page on the PHS website.
Appendices

Appendix 1 – Background information

Source of data

The Scottish Cancer Registry is the source of the Children and Young People with Cancer data provided in this publication. More information on the registry can be found on the Public Health Scotland website.

The Scottish Cancer Registry has been collecting information on cancer since 1958. Data collected by the Registry are published by PHS. This information is used for a wide variety of purposes including: public health surveillance; health needs assessment, planning and commissioning of cancer services; evaluation of the impact of interventions on incidence and survival; clinical audit and health services research; epidemiological studies; and providing information to support genetic counselling and health promotion. New developments in the Scottish Cancer Registration and Intelligence Service (SCRIS) will make cancer data more readily available and will add new data on diagnosis and treatment to the Registry.

Note that cancer registrations differ from recorded hospital admissions for cancer, the statistics for which can be found on the Hospital Care pages on the PHS Website. An individual diagnosed with a new primary cancer would have a single registration for that cancer, whereas he/she might have multiple admissions to hospital for the cancer. Moreover, the diagnosis and treatment of cancer does not inevitably lead to hospital admission in every case.

Data completeness

Cancer registrations are believed to be essentially complete for the year 2019, but it is important to note that the cancer registration database is dynamic. In common with other cancer registries, cancer incidence rates in Scotland can take up to five years after the end of a given calendar year to stabilise due to the continuing accrual of late registrations coming to light, for example through death certification.

Comparisons – UK and international

Children and Young People with Cancer publications for the rest of the UK can be found at the following link: Cancer in children, teenagers and young adults

Wales and Northern Ireland currently publish information on Children and Young people with Cancer based only on the classification (the 10th edition of the International Classification of Diseases or ICD-10). This is not directly comparable to the data in this publication.

Comparison of Scottish and UK cancer data to that of other countries is a complex process because of the wide variation amongst data collection and coding practices, as well as variation in the quality and completeness of data. The International Agency for Research on Cancer (IARC) maintain an online database, Global Cancer Observatory, that is searchable for comparative data.
Age-adjusted incidence and mortality rates

Based on the number of cancer registrations in each of the calendar years, the following rates were calculated for this publication:

Crude Rate

The crude rate is the total number of people with an illness (or who die) in a country or region, divided by the total population of that country or region, and is normally expressed ‘per 1,000’, ‘per 10,000’ or ‘per 100,000’. Crude rate is calculated per million person-years at risk in this publication due to small numbers.

Making comparisons based on the crude rate can be misleading if the age structures of the populations of the countries or regions are quite different. Areas with larger percentages of younger people are unlikely to have as high levels of incidence as areas with larger percentages of older people – and therefore if we do not adjust for these differences we may draw the wrong conclusion about the health of an area simply because of the age-structure of the population. European and World Age-Sex Standardised Rates (ASRs) allow us to make comparisons between different geographical areas as they allow the effects of having different age structures in either the same population over time or different geographies to be removed.

European Age-Sex Standardised Rate (EASR) using 2013 European Standard Population (ESP2013)

For each 5 year age group, the crude rate is calculated and then the weighted average of all age groups is taken based on the weightings of the ESP2013, to give the overall EASR.

World Age-Sex Standardised Rate (WASR) using World Standard Population

For each 5 year age group, the crude rate is calculated and then the weighted average of all age groups is taken based on the weightings of the World Standard Population, to give the overall WASR.
Appendix 2 – Publication metadata

Publication title
Children and Young People with Cancer in Scotland (2010-2019)

Description
Information is included on cancer incidence, mortality, place of death and prevalence covering the years 2010-2019 and survival covering the years 2009-2018 at Scotland level.

Theme
Health and Social Care

Topic
Conditions and Diseases

Format
Excel workbooks

Data source(s)
Scottish Cancer Registry (SMR06)
National Records of Scotland (NRS)

Date that data are acquired
22 February 2021

Release date
21 September 2021

Frequency
Annual

Timeframe of data and timeliness
Data up to 31 December 2019.

Continuity of data
Reports include data from 2010 to 2019 with prevalence analysis using diagnosis information going back 20 and 45 years. Ten year percentage change uses data from 2009 to 2019. Coding of cancer registrations moved from ICD-9 to ICD-10 and from ICD-O to ICD-O-2 in incidence year 1997, then to ICD-O-3 in incidence year 2006. ICD codes have been back-mapped to 1989 for continuity of reporting.

Revisions statement
As with other population-based cancer registries, the Scottish Cancer Registry is dynamic, with ongoing updating of records. Future releases will include a refresh of the previous years, and as new registrations from previous years come to light, or changes in the coding are taken into account, the numbers may change.
Revisions relevant to this publication
N/A

Concepts and definitions
See the Cancer Information FAQs

Relevance and key uses of the statistics
Help inform and improve care for children and young people with cancer.

Accuracy
Registry data are subject to validation at data entry and quality assurance procedures. See the Cancer Information FAQs. Reported data are compared to previous years’ figures and to expected trends.

Completeness
At time of extraction, data for the most recent year was almost 100% complete.

Comparability
Children and Young People with Cancer publications for the rest of the UK can be found at the following link: Cancer in children, teenagers and young adults
Wales and Northern Ireland currently publish information on Children and Young people with Cancer based only on the classification (the 10th edition of the International Classification of Diseases or ICD-10). This is not directly comparable to the data in this publication.

Accessibility
It is the policy of Public Health Scotland to make its web sites and products accessible according to published guidelines. More information on accessibility can be found on the PHS website.

Coherence and clarity
All tables are accessible via the Cancer pages on the PHS website within Excel spreadsheets.

Value type and unit of measurement
Incidence and Mortality - Number of cases of cancer as count (newly diagnosed cases, deaths); rates of cancer/deaths as crude, European age-standardised, World age-standardised, and as Standardised incidence/mortality rates.
Survival probabilities (%)
Prevalence - Number and crude rate of cancer survivors.

Disclosure
The PHS protocol on Statistical Privacy Protocol is followed.

Official Statistics designation
Official statistics

UK Statistics Authority Assessment
Not assessed

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15 September 2020

Next published
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Date of first publication
26 February 2019

Help email
phs.cancerstats@phs.scot

Date form completed
19 August 2021
Appendix 3 – Early access details

Pre-Release Access

Under terms of the "Pre-Release Access to Official Statistics (Scotland) Order 2008", PHS is obliged to publish information on those receiving Pre-Release Access ("Pre-Release Access" refers to statistics in their final form prior to publication). The standard maximum Pre-Release Access is five working days. Shown below are details of those receiving standard Pre-Release Access.

Standard Pre-Release Access:

Scottish Government Health Department
NHS Board Chief Executives
NHS Board Communication leads

Early Access for Quality Assurance

These statistics will also have been made available to those who needed access to help quality assure the publication:

Managed Service Network for Children and Young People with Cancer - Clinical Governance and Quality Assurance Group
Appendix 4 – PHS and Official Statistics

About Public Health Scotland (PHS)

PHS is a knowledge-based and intelligence driven organisation with a critical reliance on data and information to enable it to be an independent voice for the public’s health, leading collaboratively and effectively across the Scottish public health system, accountable at local and national levels, and providing leadership and focus for achieving better health and wellbeing outcomes for the population. Our statistics comply with the Code of Practice for Statistics in terms of trustworthiness, high quality and public value. This also means that we keep data secure at all stages, through collection, processing, analysis and output production, and adhere to the ‘five safes’.