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Adolescent and Young Adult Cancer Incidence and Survival in New Zealand

2000 - 2009

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Report prepared for the AYA Advisory Group
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Contents

Executive Summary

This report presents a comprehensive overview of New Zealand adolescent and young adult (AYA) cancer incidence and survival from 2000 to 2009. It is intended to provide an evidence-base to inform decisions regarding the future provision of AYA cancer services.

While the outcome for children (0-14 years) with cancer has steadily improved over the last 30 years, with 80% now cured of their disease, such survival improvements have not been seen within the AYA population. This age-based disparity in cancer outcome was first recognised over ten years ago and appears to be due to a complex mix of factors including differences in cancer diagnosis, disparity in access to coordinated cancer treatment, lower enrolment in clinical trials, and poorer treatment compliance.

Recognising the need to improve the coordination of care for adolescent and young adults with cancer in New Zealand, a national AYA programme was initiated in 2006. However, until now there has been little objective national data on the incidence and outcome of cancer diagnosed in young people from 15-24 years of age. New Zealand has a unique cultural and ethnic mix of peoples of Maori, Pacific, Asian and European origin, and as such we may have unique patterns of cancer, differences in access to care, and responses to cancer treatment.

Using a data set provided by the New Zealand Cancer Registry and cross-linked to the New Zealand Mortality Collection, we have identified all cases of cancer diagnosed in the 15-24 year age group for the ten years from 2000-2009 and categorised them according to the AYA cancer classification scheme. This analysis is intended to inform future service development and develop treatment strategies for this unique age group of young people.

Between 2000 and 2009, 1606 new cases of malignant cancer were diagnosed among those aged 15-24 years. The overall age standardized incidence for the entire 15-24 year age group was 275 per million, with incidence of 229 per million and 326 per million in the 15-19 and 20-24 year age groups respectively. Although there is considerable variation year-on-year, this equates to an average of 69 adolescents aged 15-19 years and 92 young adults aged 20-24 years diagnosed with cancer each year.

Whereas lymphomas (20%) and leukaemias (15%) are the two most common cancers seen in New Zealand adolescents, by young adulthood these are replaced by melanoma and carcinomas (both at 23% of all diagnoses). Notably, melanoma is the most common cancer seen in the entire 15-24 year age group and importantly is the third most common cancer (13%, 9 cases per year) seen in adolescents.

Analysis by gender for the whole AYA group shows non-Hodgkin lymphoma and gonadal germ cell tumours are significantly more frequent in males, whereas breast cancer, melanoma, thyroid carcinoma and genitourinary carcinoma are significantly more common in the female AYA population.

There is little difference in *overall* AYA cancer incidence by ethnicity; the cancer incidence for the 15-24 year population for the 2000-2009 period was 287 per million for Maori, 278 per million for Pacific Peoples, and 280 per million for non-Maori/Pacific Peoples. However, there are many notable significant differences in cancer incidence *by diagnostic subgroup* according to prioritised ethnicity. These included a higher incidence of leukaemia amongst Pacific Peoples; a higher incidence of Ewing tumours, carcinoma of the gastro-intestinal tract, and gonadal germ cell tumours amongst Maori; and a higher incidence of melanoma amongst non-Maori/Pacific Peoples. A unique and notable observation is the very high proportion of gastric cancers diagnosed in the Maori AYA population; of the 22 cases of gastric cancer, 18 (81.8%) were diagnosed in Maori.

The ten-year interval of this study encompasses a period of contemporary therapy and has allowed for the first comprehensive analysis of cancer survival for the AYA population in New Zealand. During this period, a greater proportion of 15-19 year olds diagnosed with cancer died of their disease, compared to children or those aged 20-24. The overall five-year relative survival for adolescents was 75.1%, which was significantly lower than the 84.6% survival for young adults and 80.7% survival for children aged 0-14 years. The age group disparity in outcome may be partly attributed to differences in cancer diagnoses by age. For example, the incidence of bone tumours peaks at 15-19 years and the five-year relative survival for this diagnostic group was just 48.5%.

In terms of ethnicity, five-year relative survival for AYA (15-24 years) was significantly lower for Maori (69.5%) and Pacific Peoples (71.3%) than non-Maori/Pacific Peoples (84.2%). Although the survival gap narrowed when melanoma was excluded from the analysis, Maori five-year relative survival (69.0%) remained significantly below non-Maori/Pacific Peoples (80.9%). This is in contrast to our child cancer analysis for the same time period, in which no ethnic disparities were found.

Perhaps the most important observation we report is a comparative analysis of cancer survival in the New Zealand AYA population compared to those in other similar high income countries. When compared with other published data, New Zealand five-year relative survival for the 15-24 year age group (80.6%) was significantly lower than reported by the European EUROCARE group (87.4%). The New Zealand five-year relative survival for adolescents 15-19 years (75.1%) was also significantly lower than the survival reported by the United States (81.8%) and Canada (81%) for comparable time periods. Specifically, New Zealand adolescents diagnosed in 2000-2009 with bone tumours, soft tissue sarcomas, and acute lymphoblastic leukaemia had poorer survival than has been achieved by other comparable countries. The examination of a range of factors, such as disease staging at diagnosis, which may have contributed to the survival deficits highlighted above is beyond the scope of this analysis, but warrants further investigation.

The comparative outcome analysis suggests the need for New Zealand health services to review the model of care and the cancer care pathways for specific cancers such as acute lymphoblastic leukaemias, bone tumours, and sarcomas. This analysis also clearly highlights the need to identify and address the underlying causes of the ethnic survival disparities which are evident in the AYA population.

1 Introduction

1.1 Background to this report

In 2011 we were allocated funding by the National Child Cancer Network (NCCN) to conduct an analysis of the New Zealand Children's Cancer Registry (NZCCR) to report the incidence and survival for children aged 0-14 years diagnosed with cancer in New Zealand from 2000 to 2009. Following our presentation of the preliminary child cancer report to the NCCN, it was requested that a similar analysis be conducted for the adolescent and young adult (AYA) population. As only some AYA would have received treatment at a paediatric oncology centre, and therefore have been registered on the NZCCR, approval from the Health and Disability Multi-region Ethics Committee was obtained to access the AYA cancer registrations held by the New Zealand Cancer Registry (NZCR). Although the Ministry of Health (MOH) regularly publishes NZCR data, the age and diagnostic groupings are, by necessity, wider than those which are required for an in-depth analysis of the impact of cancer specifically on the AYA population.

The following report contains the incidence and relative survival for adolescents and young adults diagnosed with a primary malignant cancer in New Zealand from 2000 to 2009. Cancers have been classified according to the AYA Classification Scheme and the International Classification of Childhood Cancers (ICCC-3). Where possible, the incidence and outcomes have been analysed according to gender, ethnicity, and age at diagnosis. Comparisons have also been made with international and earlier New Zealand published AYA cancer data and also the child cancer incidence and survival which we reported for the identical time period.

1.2 The emerging field of AYA oncology

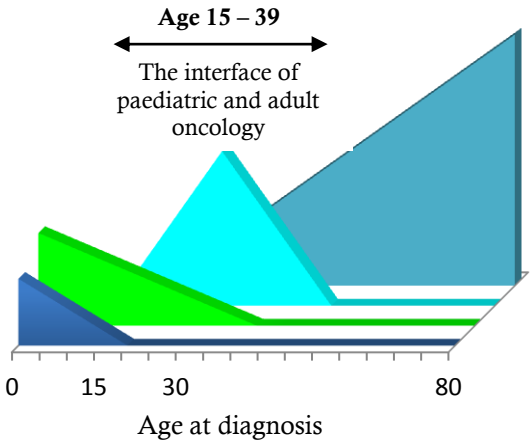
Internationally, in recent decades there has been a relative lack of progress in survival improvements among adolescents and young adults diagnosed with cancer compared to other age groups[1,2]. This relative lack of survival improvement for AYA, referred to as the 'AYA gap', is a complex issue and is undoubtedly due to multiple factors. Poorer outcomes have been attributed to patient factors such as a lack of awareness of cancer risk, which is estimated to be one in 210 for those aged between 15-29 years of age, their under-utilisation of healthcare services, and poorer treatment adherence[1]. The literature also highlights the low rates of enrolment of AYA in clinical trials, which are known to improve outcomes, and the age-based division between paediatric and adult oncology services which may not best meet the treatment and psychosocial needs of some AYA patients[1,3,4]. In recent years there has been a greater focus on the unique needs of the AYA population, leading to the formation of such groups as the Children's Oncology Group (COG) Adolescent and Young Adult Committee, and the Livestrong Young Adult Alliance in the United States. These groups are dedicated to improving survival and the quality of life of those young people diagnosed with cancer, increasing their participation in clinical trials, raising awareness of cancer risk for this age group, and promoting relevant research[1].

1.3 Cancer in the AYA population

A distinct range of cancers affect AYA (See Figure 1.3). The spectrum of AYA cancers includes some paediatric cancers such as acute lymphoblastic leukaemia and central nervous system tumours, while malignant bone tumours peak in the teenage years. Thyroid cancer, Hodgkin lymphoma, and testicular cancer become

increasingly common in this age group[1,5,6]. The vast majority of cases of cancer diagnosed in AYA do not appear to be linked to environmental or inherited factors. However, compared to childhood cancers, the incidence of cancers with an environmental influence, such as malignant melanoma and cervical carcinoma, start to increase dramatically from adolescence[5,6].

Figure 1.3: The interface of paediatric and adult oncology



- Embryonal - nephroblastoma, neuroblastoma, retinoblastoma, hepatoblastoma
- Paediatric - central nervous system, leukaemia, lymphoma
- AYA - thyroid, melanoma, Hodgkin lymphoma, connective tissue, gonadal germ cell
- Carcinomas - lung, breast, gastrointestinal, urinary tract, head/neck

Adapted from Bleyer & Barr, 2006[1]

1.4 Defining the adolescent and young adult cancer population

Adolescence and young adulthood have been defined in numerous ways, without any one of them being universally accepted. The World Health Organisation (WHO) defines adolescents as those aged 10-19, youth as those age 15-24 years, and those aged 10-24 as a young person. In North America, the US Surveillance Epidemiology and End Results (SEER) programme and the Canadian Cancer Society define the AYA cancer population as those aged between 15 and 29, while the Journal of Adolescent and Young Adult Oncology, the National Cancer Institute, and Livestrong Young Adult Alliance favour a higher upper bound of 39 years. Elsewhere in the world, the consortium of 23 countries contributing to EUROCARE define AYA as encompassing those aged 15-24 years, Australia tends to use 15-29 years, while the United Kingdom defines teenagers and young adults (TYA) as those aged between 13 and 24.

In New Zealand, The Youth Development Strategy defines young people as those aged 10-24 and Canteen supports young people with cancer aged between 13 and 24. The New Zealand Ministry of Health AYA Cancer Service Specification[7] outlines the difficulty in defining the AYA cancer population in chronological terms; definitions based on the onset of puberty, neurophysiological brain maturity, age of legal consent, and societal markers of adulthood all have considerable limitations. The service specification's definition of service users applies to adolescents and young adults from the ages 12-24 years inclusive, while acknowledging that the most appropriate treatment centre will be determined according to what best meets the needs of the individual patient[7].

This current report defines AYA as 15-24 years and follows on directly from the NZCCR child cancer incidence and survival reports which cover ages 0-14 years. However, where possible, we have also included the 12-14 year age group within this report. This is in order to provide the AYA Advisory Group with data pertaining to the entire age bracket which they are charged with supporting.

1.5 Classification systems for AYA cancers

The diagnostic classification of AYA cancers presents considerable challenges due to the unique type of cancers which affect this age group. Yet, until recently, limited attention has been focused on the unique aspects of registration and classification of AYA cancers. There is now growing international consensus that the adoption of a standard classification system would aid comparisons of AYA cancer incidence and survival across different population-based cancer registries and advance research for this currently understudied population[2]. The following section provides a brief overview of two classification schemes used to report AYA cancer; the International Classification of Childhood Cancers[8] and the AYA Classification Scheme[9].

1.5.1 The International Classification of Childhood Cancers (ICCC-3)[8]

The first internationally accepted childhood cancer classification system was developed by Birch and Marsden in 1987[10] and was used for generating international comparisons for the International Incidence of Childhood Cancer, Volume 1, published by the International Agency for Research on Cancer (IARC)[11]. While adult cancers are classified according to the location in the body where the cancer originates, the International Classification of Childhood Cancer (ICCC) recognises that for childhood cancers it is the tissue of origin which best predicts the tumour behaviour and dictates the required treatment. The ICCC, currently in its third edition (ICCC-3)[8], is the standard for the presentation of international data on childhood cancer incidence and survival, accepted by the WHO, International Association of Cancer Registries and the US SEER. The ICCC-3 has also often been used to classify cancers diagnosed in those aged 15-19 years when this age group has been included as the upper age limit for reporting cancers diagnosed in childhood[11,12,13].

The ICCC-3 contains 12 diagnostic groups (see Table 1.5.1), which are further divided into 47 diagnostic subgroups. Appendix A2 provides full details of the ICCC-3 based on the International Statistical Classification of Diseases for Oncology, Third edition (ICD-O-3) site and histology[14].

Table 1.5.1 The ICCC-3[8] diagnostic groups

Group	Title (the abbreviated title used throughout this report is highlighted in bold)
I	**Leukaemias,** myeloproliferative diseases, and myelodysplastic diseases
II	**Lymphomas** and reticuloendothelial neoplasms
III	Central nervous system (**CNS**) **tumours** and miscellaneous intracranial and intraspinal neoplasms[a]
IV	**Neuroblastoma** and other peripheral nervous cell tumours
V	**Retinoblastoma**
VI	**Renal tumours**
VII	**Hepatic tumours**
VIII	**Malignant bone tumours**
IX	**Soft tissue sarcomas** and other extraosseous sarcomas
X	**Germ cell tumours,** trophoblastic tumours, and neoplasms of gonads
XI	**Other malignant epithelial neoplasms** and malignant melanomas
XII	**Other and unspecified** malignant neoplasms

[a] Non-malignant CNS tumours, such as juvenile pilocytic astrocytoma, are registered according to the ICCC as they have a similar prognosis, clinical symptoms, and late effects to malignant neoplasms.

1.5.2 The AYA cancer classification scheme

Although the ICCC-3 is often used to classify cancers occurring in children and adolescents up to 19 years of age, it is extremely rare for embryonal tumours to be diagnosed beyond childhood, making the diagnostic groups such as 'V: retinoblastoma' and 'IV: neuroblastoma and other peripheral nervous cell tumours' largely redundant for the AYA population. Conversely, the proportion of cases in the 'other' subgroups increases dramatically from childhood to young adulthood and carcinomas often diagnosed in young adults are not given adequate attention in the ICCC-3. To address the limitations of the ICCC-3 for the AYA population, Ronald Barr and Jillian Birth developed a cancer classification scheme specifically for this group[9]. The AYA cancer classification scheme was developed following a comprehensive review of 25,000 cancer cases in 15-24 year olds in England.[9]

The AYA classification scheme has been used to report AYA cancer incidence and survival in Canada[15] and Europe[16,17] and adapted by SEER to report cancer incidence and trends for individuals aged between 15 and 29 years[18]. The SEER site-recode of AYA tumours, derived from the ICD-O-3 primary site and histology, can be found in Appendix A2.

The AYA classification scheme, like the ICCC, is based on the ICD-O. It is structured into 3 levels of hierarchical classifications: 10 main diagnostic groups, 32 diagnostic subgroups, and 2 to 9 divisions of selected subgroups (see Appendix A3 and Table 1.5.2). As for the ICCC, in situ tumours and benign/neoplasms of uncertain behaviour are not registered according to the AYC classification scheme unless they arise in the CNS. The key differences are that the AYA classification scheme groups the embryonal tumours together and addresses carcinomas in significantly more detail than the ICCC. 'Melanomas and skin cancers' are also given their own diagnostic group, reflecting their significance to the AYA population.

There are some other, more subtle differences between the AYA classification scheme and ICCC. For example, lymphomas are classified simply as 'Hodgkin' and 'non-Hodgkin' in the AYA classification scheme, while the ICCC diagnostic group 'II: lymphomas and reticuloendothelial neoplasms' reports Burkitt lymphomas separately and has five subgroups in total. Also, Ewing tumours have their own subgroup in the AYA classification scheme but are separated into two different diagnostic groups of the ICCC depending on whether the tumours arise in the bone or soft tissue. These examples are provided to illustrate why the numbers reported for some similarly labelled diagnostic groups and subgroups may differ depending on whether the ICCC or AYA classification scheme has been applied. As a final note, for simplicity purposes, AYA diagnostic group 4, 'osseous and chondromatous neoplasms', is often referred to as the 'bone tumour' group within this report.

Table 1.5.2 The AYA cancer classification scheme[9]

	Full Title
1	Leukaemias
2	Lymphomas
3	CNS and other intracranial and intraspinal neoplasms (all behaviours)
4	Osseous and chondromatous neoplasms
5	Soft tissue sarcomas
6	Germ cell and trophoblastic neoplasms
7	Melanoma and skin carcinomas
8	Carcinomas
9	Miscellaneous specified neoplasms, not otherwise specified
10	Unspecified malignant neoplasms

2 Methodology

2.1 Data selection, validation, and conversion

This study was given expedited approval by the Chair of the Health and Disability Multi-region Ethics Committee (ethics ref: MEC/12/EXP/045) in April 2012. The approval included permission to access case files to retrieve additional staging and treatment information (which is not recorded on the New Zealand Cancer Registry) should it be required for subsequent, more in-depth, analysis.

Diagnostic and demographic information for all NZCR registrations of primary malignant tumours for those aged between 15-24 years between January 1 2000 and December 31 2009 was provided by the MOH. The date of death was also obtained from the Mortality Collection. Registrations for the early adolescent group (aged 12-14) which are included in some sections of this report were obtained from the NZCCR 2000-2009 dataset. These registrations had already been cross-matched with the NZCR and Mortality Collection as part of the data verification process for the childhood cancer incidence and survival analysis. A summary of the data selection process is provided in Figure 2.1.

The NZCR codes cancer information using an Australian modification of the International Classification of Disease and Related Health Problems (ICD-10)[19] and the WHO International Classification of Diseases for Oncology (ICD-O)[14]. Two versions of the ICD-O were used by the NZCR within the study period; the ICD-O-2 until the end of 2002, and the ICD-O-3 from January 1 2003 onward). The ICD-10 site and ICD-O histology codes were used to classify cancers according to the ICCC-3[8]. The ICD-O-3 codes were also re-coded according to the classification scheme for AYA tumours using the SEER AYA site recode groupings, which updated the original ICD-O-2-based classification scheme for AYA tumours proposed by Barr and colleagues[9].

The released NZCR data were matched against the data held in the New Zealand Children's Cancer Registry (NZCCR) for those adolescents who had dual registration. However, due to ambiguity in the past surrounding whether adolescents should be registered, the NZCCR may not hold data for all adolescents who received treatment in a paediatric oncology setting and therefore the NZCCR was not utilised in any further analysis.

An important area covered by both the ICCC and the AYA cancer classification scheme are the benign/low grade CNS tumours. There is international agreement that these classes of tumour should be registered in children and AYA as they require significant intervention and are associated with significant morbidity and some deaths[8]. However, many international cancer registries, including the NZCR, register malignant CNS tumours only (i.e. those malignant tumours with a ICD-O behaviour code of '3'). As the registrations for those early adolescents aged 12-14 years come from the NZCCR, registrations for this group include a number of non-malignant CNS tumours (20 within the ten year period). However, non-malignant CNS tumours are almost certainly underreported for those AYA aged 15-24 years.

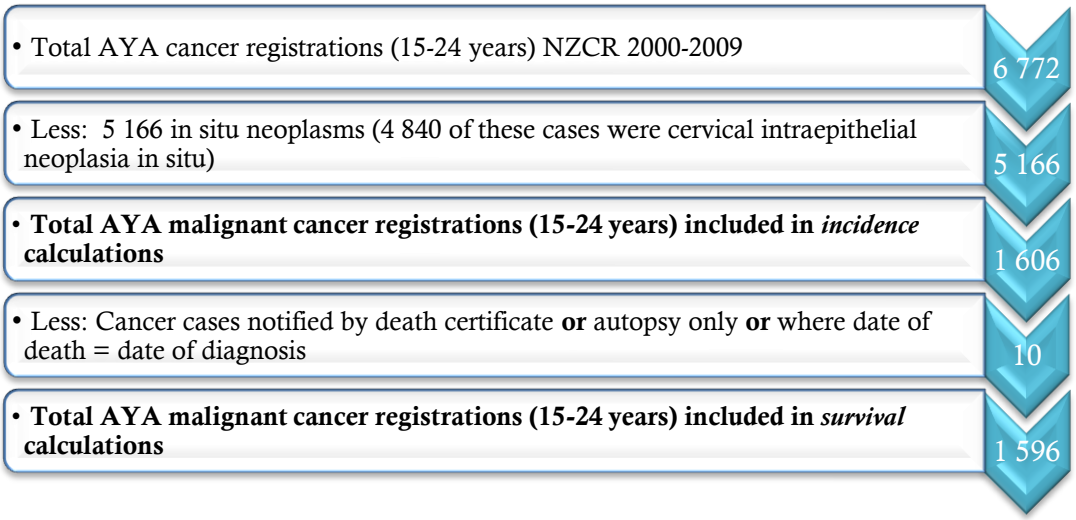
Although non-malignant neoplasms (with a behaviour code of '0' or '1') are not registered on the NZCR, it does hold registrations of in situ neoplasms (behaviour code '2') arising at any site. In accordance with the ICCC-3 and the classification scheme for AYA tumours, all in-situ cancers were excluded from the overall analyses. The vast majority of the excluded in situ cases were cervical intraepithelial neoplasia, grade III (CIN III). A brief summary of the incidence of CIN III has been included in Section 5.

It should be noted that the NZCR does not register squamous and basal cell skin cancers. Also, there were a number of changes to the coding of cancers when the NZCR adopted the ICD-O-3 in place of the ICD-O-2 on January 1 2003. For example, polycythaemia vera, myelodysplastic syndromes, and chronic myeloproliferative

disorders were re-classified as malignant and registered for the first time, while pilocytic astrocytomas were no longer classified as malignant and were not recorded on the NZCR from this date forward. However, the changeover from the ICD-O-2 to the ICD-O-3 should not have greatly impacted our reporting of AYA cancer incidence, as the malignancies referred to above are not commonly diagnosed within the AYA population.

In this report we have classified all cancers using the AYA cancer classification scheme[9], except when making direct comparisons with other studies which have used the ICCC-3, such as New Zealand data for the 1988-2002 published as an occasional paper by the MOH in 2006[20].

Figure 2.1 Selection of the final dataset: AYA 15-24 years



2.2 Prioritised ethnicity

According to MOH ethnicity data protocols, individuals may select up to three ethnic groups that they identify with. When a prioritised ethnicity system is used, each respondent is assigned to a single ethnic group using a priority system; Maori, Pacific Peoples, and non-Maori/Pacific Peoples (European, Asian, Middle Eastern, Latin American, and 'Not Elsewhere Reported'). Assigning a single ethnicity simplifies the data as the ethnic group populations sum to the total New Zealand population but there are limitations with prioritisation; an increasing number of New Zealand children and young people identify with more than one ethnic group and the use of prioritised ethnicity goes against the principle of self-identification. However, prioritised output is often used in the health and disability sector to ensure that Maori and Pacific Peoples, whose health status is lower on average than that of other New Zealanders, are not swamped by the European group[21].

It should be noted that the group 'non-Maori/Pacific Peoples' includes those whose ethnicity was unknown. An interim analysis showed that the group of patients who had no ethnicity recorded had a higher overall cancer survival than any other group. Ethnicity data is not reported directly to the NZCR, with this information obtained from the National Health Index (NHI), hospital discharge summaries, and the Mortality Collection. In the cases of 'unknown' ethnicity, the fact that no ethnicity data was collected may suggest that the person was diagnosed with a cancer which had an excellent prognosis, requiring minimal treatment and little, if any, involvement with the public health system. Although there was a small number of 'unknown' ethnicity overall, the inclusion of the 'unknowns' within the non-Maori/Pacific Peoples ethnic group has potentially slightly overinflated this group's cancer survival.

Table 2.2 shows the New Zealand population aged 15-24 years by prioritised ethnicity according to the 2006 census. These figures were used as the denominators for calculating cancer incidence by ethnicity. Please note that there are limitations with using census data in that the figures have not been adjusted for potential census undercount issues. It is known that Maori were more systemically undercounted than other ethnic groups in the 2006 census.

Table 2.2 Population by prioritised ethnicity in New Zealand, 2006 census

	Maori	Pacific Peoples	Non-Maori/ Pacific Peoples	Total
15 - 19 years	58 533	22 818	218 850	300 198
20 - 24 years	42 771	17 886	210 315	270 978
Total	141 340	55 702	557 739	754 781
% of total AYA population	**19.2%**	**7.5%**	**73.3%**	**100%**

2.3 Incidence calculations

Incidence is defined as the number of new primary cancer cases diagnosed in a specified population, for example 15-19 year olds or males aged 15-24 years, during a specified time period (usually one year). Due to the relatively small number of cases diagnosed annually, cancer incidence is usually expressed as a rate per 100,000 or 1,000,000 population per year.

Incidence should not be confused with prevalence, which is defined as the number of people currently alive with a particular condition. Given that the treatment duration for many cancers is up to three years, the number of adolescents receiving active treatment in New Zealand at any given year will be higher than the number of new cancer cases.

2.3.1 Age-specific incidence rates

Age-specific rates provide information on the cancer incidence in an age group relative to the total number of people at risk in that age group. Age-specific incidence rates for each year are calculated simply by dividing the number of cases diagnosed each year for each age group by the population for that same period. We have used the estimated resident population (as at June 30) reported annually by Statistics New Zealand.

$$\text{Incidence rate for period} = \frac{\text{Number of new cases over the specified period}}{\text{Person-years at risk over period}} \times 1{,}000{,}000$$

2.3.2 Age-standardised incidence rates

Since the risk of cancers varies by age group, it is common practice to age-standardise incidence rates to allow for more valid comparisons over time or between populations that have different age structures. Given that the 15-19 and 20-24 year age groups do not have radically different population structures, it may not have been necessary to age-standardise in this instance. However, to maintain methodological consistency with the

NZCCR child cancer analysis, we have chosen to also age-standardise the incidence rates for the AYA population.

The incidence rates presented in this report have been calculated by the direct age-standardisation method, where the age-specific incidence rates are multiplied by a standard population. The age-standardised rates reported throughout this document have been age-standardised to the 2006 New Zealand census population (see Table 2.3.2). All age-standardised incidence calculations were conducted using SAS® software v9.3.

Confidence intervals for incidence rates were calculated assuming the cases were drawn from a Poisson distribution. As rates based on small numbers may be distorted due to random fluctuations, age standardised incidence rates were censored for rare diagnostic subgroups where there were fewer than ten cases reported. However, in section 3.7 we have chosen to include incidence rates for all major diagnostic groups and subgroups for the three prioritised ethnic groups, regardless of the number of cases registered. This is because there were many between-group differences which warrant discussion even though there may have been very few cases diagnosed amongst one or more ethnic groups during the study period (melanoma incidence is an excellent example of this).

Table 2.3.2 Population by age group and sex in New Zealand, 2006 Census

	Male	Female	Total
15-19 years	152 439	147 759	300 198
20 -24 years	135 087	135 891	270 978
TOTAL 15-24 years	**287 526**	**283 650**	**571 176**

2.4 Survival calculations

A range of measures can be used to report cancer survival. The most commonly used measure of survival when reporting data from population-based cancer registries is relative survival. Relative survival ratios are calculated by dividing the observed survival (i.e. the proportion of people who remain alive following their cancer diagnosis) by the expected survival of a group from the general population which is comparable with respect to age, gender, and the time period under investigation. Relative survival does not require information about the actual cause of death and allows comparisons between different areas with different population structures. Two approaches are commonly used for calculating relative survival; the cohort method and the period method. This study uses the period method, which has been shown to provide more accurate survival predictions for recently diagnosed patients[13].

The data required for calculating observed survival was obtained from the New Zealand Cancer Registry and Mortality Collection, which are both administered by the Ministry of Health. The final date of follow up was December 31 2010, and those who were still alive at that date were censored. To avoid bias, patients whose cancer diagnosis was based on death certificate only, autopsy only, or who had a survival time of zero days were excluded. Expected survival data was calculated according to the Ederer II method using life-tables for the total New Zealand resident population. These tables are produced by Statistics New Zealand and based on 2006 census data. The observed survival and expected survival data were used to calculate estimated cancer survival ratios using the Stata statistical software package.

Although relative survival should technically be expressed as a ratio, we have chosen to convert the ratios to a percentage. This report is intended for a wide audience and we consider that using percentages makes the report easier for the general reader to follow. Also, within this report we are making comparisons with AYA survival data published by other cancer registries all of which have expressed relative survival as a percentage. Note that it is possible for relative survival to be greater than 100%. That is, those AYA diagnosed with a particular cancer may have survival which is actually better than the survival for the general AYA population. For example, survival for AYA diagnosed with thyroid carcinoma was 100.3% as there was not a single death recorded among this group of patients within the study period.

For this analysis we have calculated survival by age quintile and have not calculated survival specifically for the 12-14 year age group which is considered part of both the child and AYA population. In some subsections, the survival for those children aged 10-14 years has been reported alongside that of those aged 15-19 and 20-24 years in order to represent the younger AYA group.

2.5 Confidence intervals and statistical significance

A confidence interval (CI) is used to report the level of accuracy of statistical estimates. The reported 95% confidence intervals can be interpreted as indicating that there is a 95% probability that the true cancer incidence/survival lies somewhere within the reported lower and upper values. If two statistics have non-overlapping 95% confidence intervals, they are necessarily significantly different at the $p<0.05$ level.

In general, the more cases involved in calculating the estimate, the smaller the confidence interval. For some cancer diagnostic groups and subgroups there were very few cases recorded for AYA in New Zealand within the ten year period; this is reflected in the wide 95% confidence intervals which are reported alongside. Therefore, **any between-group differences in the incidence or survival reported, or any differences in comparison to other published data, should be interpreted extremely cautiously.**

3 AYA Cancer Incidence

The following section reports the incidence of cancer in New Zealand AYA between January 1 2000 and December 31 2009. Sections 3.1-3.4 describe the number of cancer cases and ***age-specific*** cancer incidence rates reported for those aged ***12-24 years.*** Sections 3.5-3.8 focus on reporting cancer incidence rates for AYA aged ***15-24 years*** which have been ***age-standardised*** to the 2006 New Zealand standard population. An analysis of AYA cancer incidence by prioritised ethnicity and gender is also provided.

3.1 Overall AYA cancers by gender and age group

Table 3.1 shows that half (49.7%) of all AYA cancer cases were diagnosed in those aged 20-24 years. Despite comprising nearly a quarter (24.0%) of the total AYA population, only 12.9% of all cancer cases were diagnosed in the 12-14 year age group. There was little difference between the overall numbers of cancers diagnosed in males (951) compared to females (892) within the ten-year period.

Table 3.1 Number of cancers diagnosed in AYA aged 12-24 years by gender and age group, New Zealand, 2000-2009

	Cancers diagnosed 2000-2009		AYA total population	
	Total cases	% of AYA cancer cases	Population base[a]	% of the total AYA population
Gender				
Male	951	51.6	389 688	50.8
Female	892	48.4	377 631	49.2
Age Group				
12-14 years	237	12.9	184 246	24.0
15-19 years	690	37.4	301 864	39.7
20-24 years	916	49.7	281 209	35.8
TOTAL 12-24 YEARS	**1 843**	**100.0**	**767 319**	**100.0**

[a] An average of the estimated New Zealand resident population as at June 30 for the years 2000-2009, Statistics New Zealand

3.2 Annual age-specific cancer incidence by age group

Table 3.2 shows the annual age-specific incidence rates by age group. The annual age-specific incidence rates fluctuated considerably, ranging from 87.5 per million to 217.2 per million for the 12-14 year group, 201.0 per million to 275.4 per million for the 15-19 year group, and 226.8 to 399.9 per million for the 20-24 year group. The overall age-specific cancer incidence rate for each age group was 128.6 per million for those aged 12-14 years, 228.6 per million for the 15-19 year age group, and 325.7 per million for those aged 20-24 years. Table 3.2 serves to show not only the large natural fluctuation in the number of cases diagnosed each year, but also the small numbers of cases involved, especially in the 12-14 year age group.

Table 3.2 Annual age-specific cancer incidence (per million) in AYA by age group, New Zealand, 2000-2009

	12-14 years			15-19 years			20-24 years		
	Cases	Popula-tion base[a]	Age-specific incidence rate (per million)	Cases	Popula-tion base[a]	Age-specific incidence rate (per million)	Cases	Popula-tion base[a]	Age-specific incidence rate (per million)
2000	15	171 510	87.5	55	273 650	201.0	98	254 330	385.3
2001	24	175 730	136.6	56	277 620	201.7	77	255 630	301.2
2002	14	182 570	76.7	70	286 760	244.1	106	265 040	399.9
2003	24	188 870	127.1	69	295 280	233.7	101	278 360	362.8
2004	19	191 830	99.0	65	300 440	216.3	108	285 110	378.8
2005	27	191 270	141.2	68	306 090	222.2	82	288 380	284.3
2006	28	188 540	148.5	75	313 560	239.2	87	291 180	298.8
2007	19	186 830	101.7	74	319 510	231.6	91	293 140	310.4
2008	40	184 130	217.2	69	322 540	213.9	97	296 620	327.0
2009	27	181 180	149.0	89	323 190	275.4	69	304 290	226.8
Average (95% CI)	**23.7**	**184 246**	**128.6**	**69.0**	**301 864**	**228.6 (211.5 - 245.6)**	**91.6**	**281 209**	**325.7 (304.6 - 346.8)**

[a] Estimated New Zealand resident population as at June 30, Statistics New Zealand

3.3 Average number of cases diagnosed annually by AYA diagnostic group and subgroup

From an AYA service delivery planning perspective and for prioritising the opening of new clinical trials it may be useful to simply consider the average number of new cancers diagnosed annually in 12-24 year olds according to each diagnostic group/subgroup.

In terms of the diagnostic subgroups most frequently diagnosed in those aged 12-24 years, there were an average of 31 new cases of melanoma each year, 23 gonadal germ cell tumours, 19 Hodgkin lymphomas, 12 acute lymphoblastic leukaemias, and 11 non-Hodgkin lymphomas. Other major diagnostic subgroups were acute myeloid leukaemia and thyroid carcinoma, which both had approximately 9 new cases per year. There were also around 14 malignant bone tumours diagnosed in those aged 12-24 years each year; on average six were osteosarcomas and six were Ewing tumours.

Table 3.3 Average number of AYA cancer cases per year by age group, New Zealand, 2000-2009

AYA classification	Average number of cases per year				
	12-14 years	15-19 years	20-24 years	Total 12-24 years	Total 15-24 years
1. Leukaemias	**5.5**	**10.2**	**7.8**	**23.5**	**18.0**
1.1 Acute lymphoid leukaemia	3.6	5.5	2.8	11.9	**8.3**
1.2 Acute myeloid leukaemia	1.7	3.4	3.9	9.0	**7.3**
1.3 Chronic myeloid leukaemia	-	0.6	0.7	1.3	**1.3**
1.4 Other & unspecified leukaemia	0.2	0.7	0.4	1.3	**1.1**
2. Lymphomas	**4.2**	**13.6**	**11.8**	**29.6**	**25.4**
2.1 Non-Hodgkin lymphoma	2.3	4.8	4.0	11.1	**8.8**
2.2 Hodgkin lymphoma	1.9	8.8	7.8	18.5	**16.6**
3. CNS tumours	**4.5**	**5.0**	**4.5**	**14.0**	**9.5**
3.1 Astrocytoma	2.0	1.5	2.6	6.1	**4.1**
3.2 Other gliomas	0.7	1.2	0.6	2.5	**1.8**
3.3 Ependymoma	0.4	0.5	0.7	1.6	**1.2**
3.4 Medulloblastoma & other PNET	0.4	1.1	0.4	1.9	**1.5**
3.5 Other specified intracranial and intraspinal neoplasms	0.9	0.1	0.2	1.2	**0.3**
3.6 Unspecified intracranial and intraspinal neoplasms	0.1	0.6	-	0.7	**0.6**
4. Osseous & chondromatous neoplasms	**3.1**	**8.2**	**2.3**	**13.6**	**10.5**
4.1 Osteosarcoma	1.5	3.8	1.0	6.3	**4.8**
4.2 Chondrosarcoma	0.1	0.2	0.1	0.4	**0.3**
4.3 Ewing tumour	1.4	3.8	1.2	6.4	**5.0**
4.4 Other bone tumours	0.1	0.4	-	0.5	**0.4**
5. Soft tissue sarcomas	**1.6**	**3.8**	**4.4**	**9.8**	**8.2**
5.1 Fibromatous neoplasms	0.1	0.4	1.0	1.5	**1.4**
5.2 Rhabdomyosarcoma	0.5	1.1	0.4	2.0	**1.5**
5.3 Other soft tissue sarcoma	1.0	2.3	3.0	6.3	**5.3**
6. Germ cell & trophoblastic neoplasms	**1.6**	**8.6**	**15.4**	**25.6**	**24.0**
6.1 Germ cell & trophoblastic neoplasms of gonads	0.7	7.5	14.3	22.5	**21.8**
6.2 Germ cell & trophoblastic neoplasms of non-gonadal sites	0.9	1.1	1.1	3.1	**2.2**
7. Melanoma and skin carcinomas	**1.1**	**9.3**	**21.0**	**31.4**	**30.3**
7.1 Melanoma	1.1	9.3	20.9	31.3	**30.2**
7.2 Skin carcinomas	-	-	0.1	0.1	**0.1**
8. Carcinomas	**1.4**	**8.6**	**20.9**	**30.9**	**29.5**
8.1 Thyroid carcinoma	0.3	2.5	6.1	8.9	**8.6**
8.2 Other carcinoma of head and neck	0.7	1.5	1.9	4.1	**3.4**
8.3 Carcinomas of trachea, bronchus and lung	0.2	0.4	0.4	1.0	**0.8**
8.4 Carcinoma of breast	-	-	1.8	1.8	**1.8**
8.5 Carcinoma of genitourinary(GU) tract	0.1	1.8	5.1	7.0	**6.9**
8.6 Carcinoma of gastro-intestinal (GI) tract	0.1	2.2	5.0	7.3	**7.2**
8.7 Carcinomas of other and ill-defined sites	-	0.2	0.6	0.8	**0.8**
9. Miscellaneous specified neoplasms, NOS	**0.7**	**1.4**	**2.6**	**4.7**	**4.0**
10. Unspecified malignant neoplasms	**-**	**0.3**	**0.9**	**1.2**	**1.2**
Total cancers diagnosed	**23.7**	**69.0**	**91.6**	**184.3**	**160.6**

3.4 The most common cancers by age group

Figures 3.4a-3.4d show the proportion of cancers registered between 2000 and 2009 for each age group according to AYA diagnostic group. There were considerable differences in the types of cancers diagnosed in the younger and older AYA. Leukaemias, lymphomas and CNS tumours were the most commonly registered cancer diagnostic groups in young adolescents aged 12-14 years, with leukaemias accounting for nearly one in four (23%) of all cancers diagnosed. By 15-19 years, lymphomas overtook leukaemias as the most commonly diagnosed cancer group (20%), while melanoma and carcinomas started to account for a greater proportion of cancer cases. For the 20-24 year age group, the three major diagnostic groups of melanoma, carcinomas, and germ cell tumours accounted for nearly two thirds (63%) of all cancers diagnosed.

Figure 3.4a Cancers diagnosed in young adolescents aged 12-14, New Zealand 2000-2009

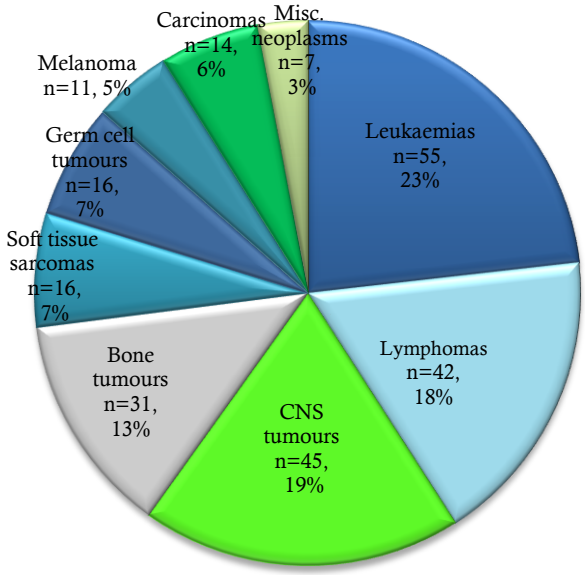


Figure 3.4b Cancers diagnosed in adolescents aged 15-19, New Zealand 2000-2009

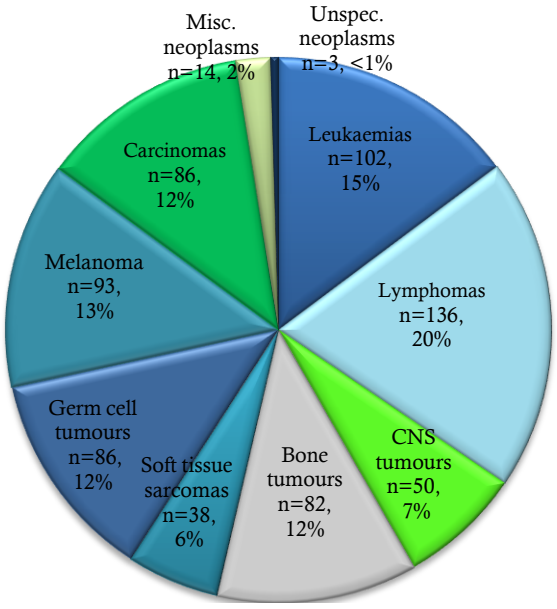


Figure 3.4c Cancers diagnosed in young adults aged 20-24, New Zealand, 2000-2009

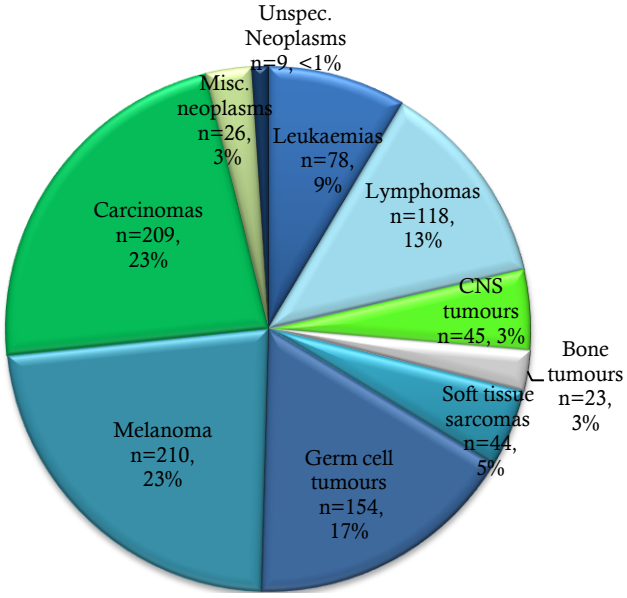
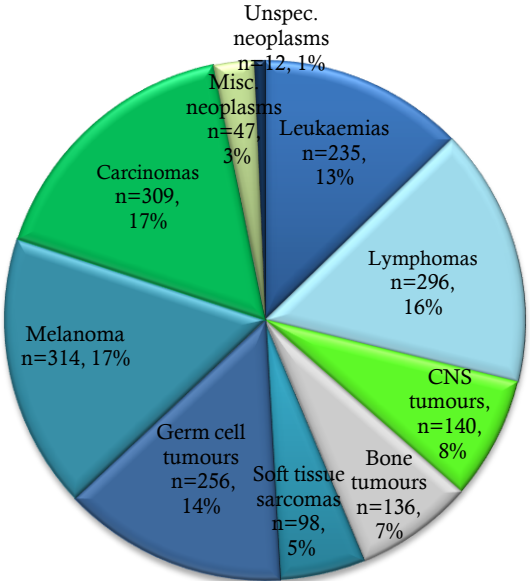


Figure 3.4d Cancers diagnosed in AYA aged 12-24, New Zealand, 2000-2009



3.5 Incidence by age and AYA cancer classification scheme

Incidence rates for leukaemias, lymphomas, CNS tumours, and soft tissue sarcomas were relatively similar for the adolescent (15-19 years) and young adult (20-24 years) groups, while the incidence of germ cell tumours (54.8 per million c.f. 28.5 per million), melanoma and skin carcinomas (74.7 per million c.f. 30.8 per million) and carcinomas (74.3 per million c.f. 28.5 per million) increased dramatically during young adulthood. Malignant bone tumours was the only cancer diagnostic group for which the adolescent group had a significantly higher incidence rate than young adults (27.2 per million c.f. 8.2 per million).

Table 3.5 AYA cancer incidence (per million) by age group and AYA diagnostic group and selected subgroups, New Zealand, 2000-2009

AYA diagnostic group/subgroup	15-19 years			20 - 24 years			15 - 24 years		
	Cases per year	Age-specific incidence (per million)[a] (95% CI)		Cases Per year	Age-specific incidence (per million)[a] (95% CI)		Cases per year	Age standardised incidence (per million)[a] (95% CI)	
1. Leukaemias	**10.2**	**33.8**	**(27.2 - 40.4)**	**7.8**	**27.7**	**(21.6 - 33.9)**	**18.0**	**30.9**	**(26.4 - 35.4)**
1.1 Acute lymphoid leukaemia	5.5	18.2	(13.4 - 23.0)	2.8	10.0	(6.3 - 13.7)	8.3	14.3	(11.2 - 17.4)
1.2 Acute myeloid leukaemia	3.4	11.3	(7.5 - 15.1)	3.9	13.9	(9.5 - 18.2)	7.3	12.5	(9.6 - 15.4)
1.3 Chronic myeloid leukaemia	0.6	2.0	(0.4 - 3.6)	0.7	2.5	(0.7 - 4.3)	1.3	2.2	(1.0 - 3.4)
2. Lymphomas	**13.6**	**45.1**	**(37.5 - 52.6)**	**11.8**	**42.0**	**(34.4 - 49.5)**	**25.4**	**43.6**	**(38.2 - 49.0)**
2.1 Non-Hodgkin lymphoma	4.8	15.9	(11.4 - 20.4)	4.0	14.2	(9.8 - 18.6)	8.8	15.1	(12.0 - 18.3)
2.2 Hodgkin lymphoma	8.8	29.2	(23.1 - 35.2)	7.8	27.7	(21.6 - 33.9)	16.6	28.5	(24.2 - 32.8)
3. CNS tumours	**5.0**	**16.6**	**(12.0 - 21.2)**	**4.5**	**16.0**	**(11.3 - 20.7)**	**9.5**	**16.3**	**(13.0 - 19.6)**
3.1 Astrocytoma	1.5	5.0	(2.5 - 7.5)	2.6	9.3	(5.7 - 12.8)	4.1	7.0	(4.9 - 9.1)
3.2 Other gliomas	1.2	4.0	(1.7 - 6.2)	0.6	2.1	(0.4 - 3.8)	1.8	3.1	(1.7- 4.5)
3.3 Ependymoma	0.5	1.7	(0.2 - 3.1)	0.7	2.5	(0.7 - 4.3)	1.2	2.1	(0.9 - 3.2)
3.4 Medulloblastoma & other PNET	1.1	3.6	(1.5 - 5.8)	0.4	1.4	(0.0 - 2.8)	1.5	2.6	(1.3 - 3.9)
4. Osseous & chondromatous neoplasms	**8.2**	**27.2**	**(21.3 - 33.0)**	**2.3**	**8.2**	**(4.8 - 11.5)**	**10.5**	**18.2**	**(14.7 - 21.6)**
4.1 Osteosarcoma	3.8	12.6	(8.6 - 16.6)	1.0	3.6	(1.4 - 5.8)	4.8	8.3	(6.0 - 10.7)
4.3 Ewing tumour	3.8	12.6	(8.6 - 16.6)	1.2	4.3	(1.9 - 6.7)	5.0	8.6	(6.3 - 11.0)
5. Soft tissue sarcomas	**3.8**	**12.6**	**(8.6 - 16.6)**	**4.4**	**15.7**	**(11.0 - 20.3)**	**8.2**	**14.0**	**(11.0 - 17.1)**
5.1 Fibromatous neoplasms	0.4	1.3	(0.0 - 2.6)	1.0	3.6	(1.4 - 5.8)	1.4	2.4	(1.1 - 3.6)
5.2 Rhabdomyosarcoma	1.1	3.6	(1.5 - 5.8)	0.4	1.4	(0.0 - 2.8)	1.5	2.6	(1.3 - 3.9)
5.3 Other soft tissue sarcoma	2.3	7.6	(4.5 - 10.7)	3.0	10.7	(6.9 - 14.5)	5.3	9.1	(6.6 - 11.5)
6. Germ cell & trophoblastic neoplasms	**8.6**	**28.5**	**(22.5 - 34.5)**	**15.4**	**54.8**	**(46.1 - 63.4)**	**24.0**	**41.0**	**(35.8 - 46.1)**
6.1 Germ cell & trophoblastic neoplasms of gonads	7.5	24.9	(19.2 - 30.5)	14.3	50.9	(42.5 - 59.2)	21.8	37.2	(32.3 - 42.1)
6.2 Germ cell & trophoblastic neoplasms of non-gonadal sites	1.1	3.6	(1.5 - 5.8)	1.1	3.9	(1.6 - 6.2)	2.2	3.8	(2.2 - 5.4)
7. Melanoma and skin carcinomas	**9.3**	**30.8**	**(24.6 - 37.1)**	**21.0**	**74.7**	**(64.6 - 84.8)**	**30.3**	**51.6**	**(45.8 - 57.4)**
7.1 Melanoma	9.3	30.8	(24.6 - 37.1)	20.9	74.3	(64.3 - 84.4)	30.2	51.5	(45.7 - 57.3)

[a] incidence rates (and corresponding confidence intervals) for AYA diagnostic subgroups 1.4, 3.5, 3.6, 4.2, and 7.2 have been censored due to the small number of cases (fewer than ten) recorded within the ten-year study period.

Table 3.5 (cont.) AYA cancer incidence (per million) by age group and AYA diagnostic group and selected subgroups, New Zealand, 2000-2009

AYA diagnostic group/subgroup	15-19 years			20 - 24 years			15 - 24 years		
	Cases per year	Age-specific incidence (per million)[a] (95% CI)		Cases per year	Age-specific incidence (per million)[a] (95% CI)		Cases per year	Age standardised incidence (per million)[a] (95% CI)	
8. Carcinomas	**8.6**	**28.5**	**(22.5 - 34.5)**	**20.9**	**74.3**	**(64.3 - 84.4)**	**29.5**	**50.2**	**(44.5 - 56.0)**
8.1 Thyroid carcinoma	2.5	8.3	(5.0 - 11.5)	6.1	21.7	(16.3 - 27.1)	8.6	14.6	(11.6 - 17.7)
8.2 Other carcinoma of head and neck	1.5	5.0	(2.5 - 7.5)	1.9	6.8	(3.7 - 9.8)	3.4	5.8	(3.9 - 7.8)
8.4 Carcinoma of breast	-	-	-	1.8	6.4	(3.4 - 9.4)	1.8	3.0	(1.6 - 4.4)
8.5 Carcinoma of genitourinary tract	1.8	6.0	(3.2 - 8.7)	5.1	18.1	(13.2 - 23.1)	6.9	11.7	(9.0 - 14.5)
8.6 Carcinoma of gastro-intestinal tract	2.2	7.3	(4.2 - 10.3)	5.0	17.8	(12.9 - 22.7)	7.2	12.3	(9.4 - 15.1)
9. Misc. specified neoplasms	**1.4**	**4.6**	**(2.2 - 7.1)**	**2.6**	**9.3**	**(5.7 - 12.8)**	**4.0**	**6.8**	**(4.7 - 8.9)**
9.2 Other specified and embryonal tumours, NOS	1.0	3.3	(1.3 - 5.4)	2.2	7.8	(4.6 - 11.1)	3.2	5.5	(3.6 - 7.3)
10. Unspecified (malig.) neoplasms	**0.3**	**1.0**	**(0.0 - 2.1)**	**0.9**	**3.2**	**(1.1 - 5.3)**	**1.2**	**2.0**	**(0.9 - 3.2)**
Total cancers diagnosed	**69.0**	**228.6**	**211.5 - 245.6**	**91.6**	**325.7**	**304.6 - 346.8**	**160.6**	**274.7**	**261.2 - 288.1**

[a] incidence rates (and corresponding confidence intervals) for AYA diagnostic subgroups 8.3, 8.7, and 9.1 have been censored due to the small number of cases (fewer than ten) recorded within the ten-year study period.

3.6 AYA cancer incidence by gender

There was little difference in overall cancer incidence for AYA by gender; in the ten year study period; 779 cases were diagnosed in females (270.0 per million) and 827 in males (279.2 per million). For the more commonly diagnosed AYA subgroups, incidence by gender was similar for Hodgkin lymphoma and acute myeloid leukaemia, but males had a higher relative risk (RR) of developing acute lymphoblastic leukaemia (RR=1.7) and non-Hodgkin lymphoma (RR=1.8) (see Table 3.6). AYA males were also significantly more likely than females to develop a gonadal germ cell tumour (RR=5.2). In contrast, males were at lower risk of developing melanoma (RR=0.7) and most carcinomas (overall RR=0.4), particularly thyroid carcinoma (RR=0.2). All breast carcinomas and the vast majority of carcinoma of the genitourinary tract were diagnosed in females. These gender differences are consistent with those reported for AYA internationally[18,22]. Figures 3.6a and 3.6b show that carcinomas and melanoma combined represented half of all cancers diagnosed in females aged 15-24 years, but only one quarter of those cancers diagnosed in males.

Figure 3.6a Cancers diagnosed in male AYA aged 15-24 years, New Zealand, 2000-2009

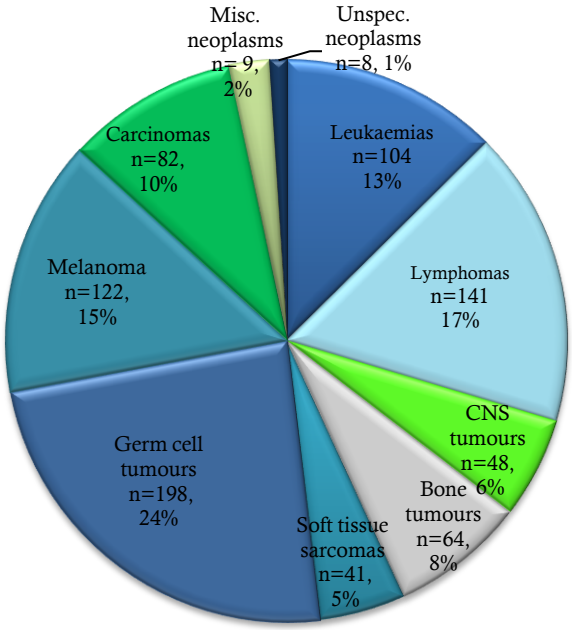


Figure 3.6b Cancers diagnosed in female AYA aged 15-24 years, New Zealand, 2000-2009

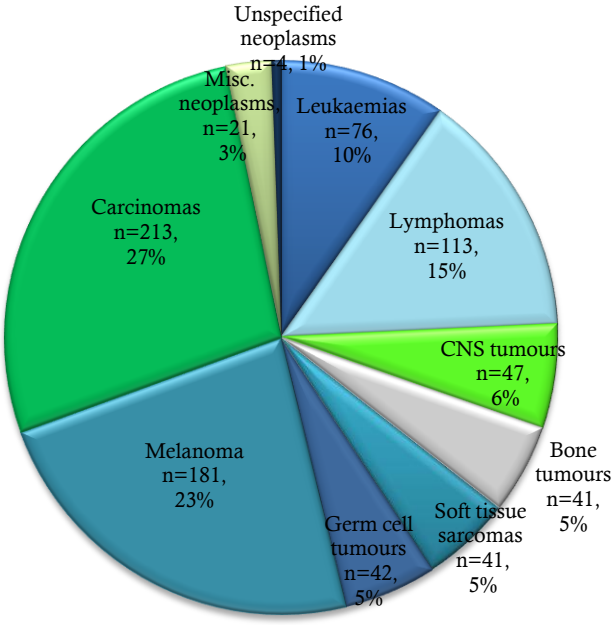


Table 3.6 AYA cancer incidence (per million) and relative risk by gender and AYA diagnostic group and selected subgroups, New Zealand, 2000-2009

AYA diagnostic group/selected subgroups	Male		Female		Relative risk male to female (95% CI)	
	Cases per year	Age-standardised incidence (per million)	Cases per year	Age-standardised incidence (per million)		
1. Leukaemias	**10.4**	**35.4**	**7.6**	**26.4**	**1.3**	**(1.0 - 1.8)**
1.1 Acute lymphoid leukaemia	5.2	17.8	3.1	10.8	1.7	(1.1 - 2.6)
1.2 Acute myeloid leukaemia	3.6	12.3	3.7	12.8	1.0	(0.6 - 1.5)
2. Lymphomas	**14.1**	**47.7**	**11.3**	**39.3**	**1.2**	**(0.9 - 1.6)**
2.1 Non-Hodgkin lymphoma	5.7	19.3	3.1	10.8	1.8	(1.2 - 2.8)
2.2 Hodgkin lymphoma	8.4	28.4	8.2	28.5	1.0	(0.7 - 1.4)
3. CNS tumours	**4.8**	**16.2**	**4.7**	**16.4**	**1.0**	**(0.7 - 1.5)**
3.1 Astrocytoma	2.5	8.4	1.6	5.5	1.5	(0.8 - 2.8)
4. Osseous & chondromatous neoplasms	**6.4**	**21.8**	**4.1**	**14.4**	**1.5**	**(1.0 - 2.2)**
4.1 Osteosarcoma	3.1	10.6	1.7	5.9	1.8	(1.0 - 3.2)
4.3 Ewing tumour	2.8	9.5	2.2	7.7	1.2	(0.7 - 2.1)
5. Soft tissue sarcomas	**4.1**	**13.9**	**4.1**	**14.2**	**1.0**	**(0.6 - 1.5)**
6. Germ cell & trophoblastic neoplasms	**19.8**	**66.5**	**4.2**	**14.6**	**4.6**	**(3.4 - 6.2)**
6.1 Germ cell and trophoblastic neoplasms of gonads	18.4	61.8	3.4	11.8	5.2	(3.8 - 7.2)
7. Melanoma and skin carcinomas	**12.2**	**41.1**	**18.1**	**62.5**	**0.7**	**(0.5 - 0.8)**
7.1 Melanoma	12.1	40.7	18.1	62.5	0.7	(0.5 - 0.8)
8. Carcinomas	**8.2**	**27.5**	**21.3**	**73.6**	**0.4**	**(0.3 - 0.5)**
8.1 Thyroid carcinoma	1.7	5.7	6.9	23.9	0.2	(0.2 - 0.4)
8.2 Other carcinoma of head and neck	1.5	5.0	1.9	6.6	0.8	(0.4 - 1.5)
8.4 Carcinoma of breast	-	-	1.8	6.2	[a]	[a]
8.5 Carcinoma of genitourinary tract	0.4	1.3	6.5	22.5	[a]	[a]
8.6 Carcinoma of gastro-intestinal tract	4.0	13.5	3.2	11.0	1.2	(0.8 - 1.9)
9. Miscellaneous specified neoplasms, NOS	**1.9**	**6.4**	**2.1**	**7.3**	**0.9**	**(0.5 - 1.6)**
10. Unspecified malignant neoplasms	**0.8**	**2.7**	**0.4**	**1.4**	[a]	[a]
Overall cancer incidence (95% CI)	**82.7**	**279.2 (260.2 - 298.3)**	**77.9**	**270.0 (251.1 - 289.0)**	**1.0**	**(0.9 - 1.1)**

[a] relative risk was not calculated due to the small number of cases for one or both gender groups

3.7 AYA cancer incidence by ethnicity

Within the rest of this report incidence rates were not reported for those diagnostic groups and subgroups where there were fewer than ten cases registered within the ten year period, as rates based on small numbers may be distorted due to random fluctuations. However, in this section we have included age standardised incidence rates for all major diagnostic groups and subgroups for the three prioritised ethnic groups, regardless of the number of cases registered. We have chosen to do this because there are many differences between the three prioritised ethnic groups which warrant discussion even though there were very few cases diagnosed amongst one or more ethnic group during the study period (melanoma incidence is an excellent example of this). Please note that, as in many instances the incidence rates and confidence intervals are derived from a small number of cases, any between-group differences in the incidence reported should be interpreted extremely cautiously.

There was little difference in overall AYA cancer incidence by ethnicity; Table 3.7 shows that cancer incidence for the 15-24 year population for the 2000-2009 period was 287.3 per million for Maori, 277.6 per million for Pacific Peoples, and 280.1 per million for non-Maori/Pacific Peoples. However, there was significant variability in incidence according to cancer diagnostic groupings.

Leukaemia incidence among Pacific Peoples was 61.4 per million, which was over double that of non-Maori/ Pacific Peoples (27.3 per million). By diagnostic subgroup, there was a higher incidence of acute myeloid leukaemia (31.9 per million) among Pacific Peoples compared with non-Maori/Pacific Peoples (10.0 per million).

Non-Maori/Pacific AYA were significantly more likely to be diagnosed with melanoma (68.0 per million) than Pacific Peoples (9.8 per million) or Maori (6.9 per million). It is interesting to note that for the AYA population as a whole, melanoma had the highest incidence of all cancers. However, only seven cases of melanoma were diagnosed in Maori within the entire ten year period and only four cases were reported for Pacific Peoples.

Maori had a significantly higher incidence of Ewing tumours (19.7 per million c.f. 6.1 per million in non-Maori/Pacific Peoples) and gonadal germ cell tumours (63.2 per million c.f. 14.7 per million in Pacific Peoples and 34.5 per million for non-Maori/Pacific Peoples).

Eighteen of the 22 cases (81.8%) of 'carcinoma of the stomach' (a subgroup of 'group 8.6 carcinoma of gastro-intestinal tract') were diagnosed in AYA of Maori ethnicity. Certain Maori families in New Zealand have been identified as carriers of a CDH1 gene mutation which is linked to gastric cancer. The number of gastric cancers diagnosed in the AYA group, and Maori in particular, is likely to be due to the comprehensive screening and surveillance programme in place for this small subsection of the population.

Table 3.7 AYA cancer incidence (per million) by ethnicity and AYA diagnostic group and selected subgroups, New Zealand, 2000-2009

	Maori			Pacific Peoples			Non-Maori/ Pacific Peoples		
	Total cases	Age-standardised incidence (per million) (95% CI)		Total cases	Age-standardised incidence (per million) (95% CI)		Total cases	Age-standardised incidence (per million) (95% CI)	
1. Leukaemias	**38**	**37.5**	**(25.6 - 49.4)**	**25**	**61.4**	**(37.3 - 85.5)**	**117**	**27.3**	**(22.3 - 32.2)**
1.1 Acute lymphoid leukaemia	15	14.8	(7.3 - 22.3)	11	27.0	(11.1 - 43.0)	57	13.3	(9.8 - 16.7)
1.2 Acute myeloid leukaemia	17	16.8	(8.8 - 24.8)	13	31.9	(14.6 - 49.3)	43	10.0	(7.0 - 13.0)
2. Lymphomas	**35**	**34.6**	**(23.1 - 46.0)**	**19**	**46.7**	**(25.7 - 67.7)**	**200**	**46.6**	**(40.1 - 53.1)**
2.1 Non-Hodgkin lymphoma	15	14.8	(7.3 - 22.3)	11	27.0	(11.1 - 43.0)	62	14.5	(10.9 - 18.0)
2.2 Hodgkin lymphoma	20	19.7	(11.1 - 28.4)	8	19.7	(6.0 - 33.3)	138	32.2	(26.8 - 37.5)
3. CNS tumours	**11**	**10.9**	**(4.4 - 17.3)**	**4**	**9.8**	**(0.2 - 19.5)**	**80**	**18.6**	**(14.6 - 22.7)**
3.1 Astrocytoma	4	4.0	(0.1 - 7.8)	1	2.5	(0.2 - 19.5)	36	8.4	(5.7 - 11.1)
4. Osseous & chondromatous neoplasms	**33**	**32.6**	**(21.5 - 43.7)**	**8**	**19.7**	**(6.0 - 33.3)**	**64**	**14.9**	**(11.3 - 18.6)**
4.1 Osteosarcoma	12	11.9	(5.1 - 18.6)	3	7.4	(0.0 - 15.7)	33	7.7	(5.1 - 10.3)
4.3 Ewing tumour	20	19.7	(11.1 - 28.4)	4	9.8	(0.0 - 17.3)	26	6.1	(3.7 - 8.4)
5. Soft tissue sarcomas	**23**	**22.7**	**(13.4 - 32.0)**	**7**	**17.2**	**(4.5 - 30.0)**	**52**	**12.1**	**(8.8 - 15.4)**
6. Germ cell & trophoblastic neoplasms	**71**	**70.1**	**(53.8 - 86.4)**	**8**	**19.7**	**(6.0 - 33.3)**	**161**	**37.5**	**(31.7 - 43.3)**
6.1 Germ cell & trophoblastic neoplasms of gonads	64	63.2	(47.7 - 78.7)	6	14.7	(3.0 - 26.5)	148	34.5	(28.9 - 40.0)
7. Melanoma and skin carcinomas	**7**	**6.9**	**(1.8 - 12.0)**	**4**	**9.8**	**(0.2 - 19.5)**	**292**	**68.0**	**(60.2 - 75.8)**
8. Carcinomas	**61**	**60.2**	**(45.1 - 75.3)**	**32**	**78.6**	**(51.4 - 105.9)**	**202**	**47.1**	**(40.6 - 53.6)**
8.1 Thyroid carcinoma	9	8.9	(3.1 - 14.7)	10	24.6	(9.3 - 39.8)	67	15.6	(11.9 - 19.4)
8.2 Other carcinoma of head and neck	8	7.9	(2.4 - 13.4)	3	7.4	(0.0 - 15.7)	23	5.4	(3.2 - 7.6)
8.4 Carcinoma of breast	4	4.0	(0.1 - 7.8)	2	4.9	(0.0 - 11.7)	12	2.8	(1.2 - 4.4)
8.5 Carcinoma of genitourinary tract	15	14.8	(7.3 - 22.3)	8	19.7	(6.0 - 33.3)	46	10.7	(7.6 - 13.8)
8.6 Carcinoma of gastro-intestinal tract	23	22.7	(13.4 - 32.0)	6	14.7	(3.0 - 26.5)	43	10.0	(7.0 - 13.0)
9. Misc. specified neoplasms	**10**	**9.9**	**(3.8 - 16.0)**	**4**	**9.8**	**(0.2 - 19.5)**	**26**	**6.1**	**(3.7 - 8.4)**
10. Unspecified (malig.) neoplasms	**2**	**2.0**	**(0.0 - 4.7)**	**2**	**4.9**	**(0.0 - 11.7)**	**8**	**1.9**	**(0.6 - 3.2)**
Overall cancer incidence (95% CI)	**291**	**287.3**	**(254.2-320.3)**	**113**	**277.6**	**(226.4-328.8)**	**1202**	**280.1**	**(264.2-295.9)**

3.8 International comparisons of AYA cancer incidence (per million)

As New Zealand has a small population and cancer among the AYA population is relatively rare, any small fluctuations in the number of cancer cases diagnosed within a specified time period, which may simply be due to chance, can greatly affect the incidence rates. Therefore, any differences in cancer incidence in comparison with other internationally published data should be interpreted cautiously.

Incidence of bone tumours (27.2 per million) appears higher in the New Zealand 15-19 year age group when compared to incidence reported by the United Kingdom (16.3 per million) and SEER (18 per million). However, for the young adult population there was little difference between New Zealand in bone tumour incidence and that reported elsewhere. New Zealand reports the lowest lymphoma incidence for young adults (42.0 per million, c.f. 75 per million reported by SEER and 62.4 per million for the United Kingdom).

New Zealand, which has the highest incidence of melanoma in the world, recorded 'melanoma and skin carcinomas' incidence rates which were considerably higher than in the United States and United Kingdom AYA population.

Table 3.8 International comparisons of AYA cancer incidence (per million)

AYA diagnostic group	Adolescents 15-19 years			Young adults 20-24 years			Total AYA 15-24 years	
	NZ 2000-2009	SEER 2000-2009[18]	UK 2000-2009[22]	NZ 2000-2009	SEER 2000-2009[18]	UK 2000-2009[22]	NZ 2000-2009	UK 2000-2009[22]
1. Leukaemias	33.8	29	25.0	27.7	24	20.9	30.9	22.9
2. Lymphomas	45.1	50	46.2	42.0	75	62.4	43.6	54.3
3. CNS tumours[a]	16.6	21	17.6	16.0	24	19.8	16.3	18.7
4. Osseous & chondromatous neoplasms	27.2	18	16.3	8.2	10	10.4	18.2	13.4
5. Soft tissue sarcomas	12.6	16	9.6	15.7	20	11.1	14.0	10.3
6. Germ cell & trophoblastic neoplasms	28.5	28	22.9	54.8	61	57.1	41.0	40.0
7. Melanoma and skin carcinomas	30.8	18	14.6	74.7	50	43.6	51.6	29.1
8. Carcinomas	28.5	38	26.2	74.3	100	74.8	50.2	50.5
9. Misc. specified neoplasms	4.6	3	[b]	9.3	4	[b]	6.8	[b]
10. Unspecified (malig.) neoplasms	1.0	-	[b]	3.2	2	[b]	2.0	[b]
Overall cancer incidence	**228.6**	**220**	[b]	**325.7**	**371**	[b]	**274.7**	**267.0**

[a] includes malignant CNS tumours only
[b] incidence has not been reported

4 AYA Cancer Survival

Section 4 reports the relative survival for those AYA (aged 15-24 years) diagnosed with cancer between January 1 2000 and December 31 2009, with follow up to December 31 2010. Relative survival is calculated by dividing the observed survival (i.e. the proportion of people who remain alive following their cancer diagnosis) by the expected survival of a group from the general population which is comparable with respect to age, gender, and the time period under investigation (see section 2.4 for further details). Survival by diagnostic group is reported using the AYA Cancer Classification Scheme, except when making direct comparisons in section 4.6 with other studies which have used the ICCC-3.

For some diagnostic groups and subgroups there were very few cases recorded, and in such cases the true survival cannot be reliably estimated; this is reflected in the wide 95% confidence intervals which are reported alongside. In such cases, any between-group differences in survival or any differences in comparison to other published data should be interpreted extremely cautiously. It should also be noted that confidence intervals cannot be calculated in instances where there were either no deaths or no survivors within the period. Finally, relative survival was not calculated specifically for the younger AYA population aged 12-14 years. To provide an indicative figure, the survival for those children aged 10-14 years has been included in some subsections.

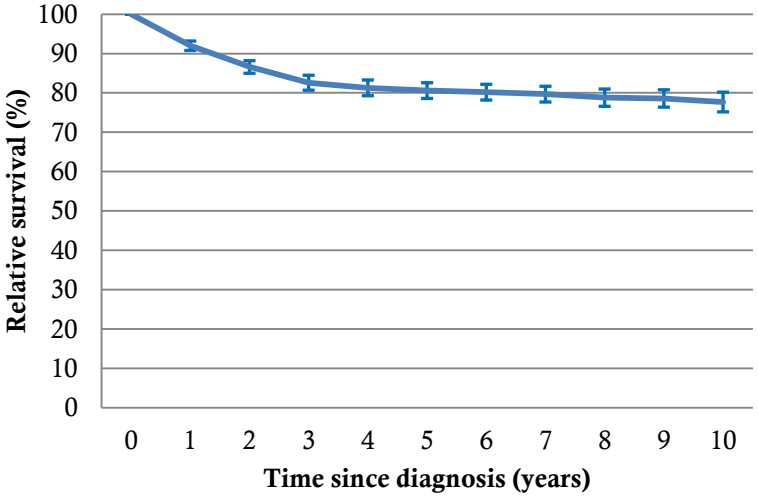
4.1 Overall AYA cancer relative survival

The overall cancer relative survival for AYA aged 15-24 years was 92.0% at one year, 82.6% at three years, and 80.6% at five years (see Table 4.1 and Figure 4.1). Ten-year survival for those AYA diagnosed in the year 2000 that were followed up for the full ten year duration was 77.7%.

Table 4.1 Overall AYA cancer relative survival, New Zealand, 2000-2009

Years since diagnosis	Total		
	n	Cumulative relative survival (95% CI)	
1	1596	**92.0**	(90.5 - 93.2)
2	1467	**86.6**	(84.8 - 88.2)
3	1243	**82.6**	(80.6 - 84.5)
4	1044	**81.3**	(79.2 - 83.3)
5	891	**80.6**	(78.4 - 82.6)
6	756	**80.2**	(78.0 - 82.2)
7	628	**79.7**	(77.4 - 81.7)
8	501	**78.8**	(76.4 - 81.0)
9	357	**78.6**	(76.1 - 80.8)
10	218	**77.7**	(74.9 - 80.2)

Figure 4.1 Overall AYA cancer relative survival, New Zealand, 2000-2009



4.2 Five-year relative survival by AYA cancer classification scheme

Table 4.2 shows that the diagnostic groups which had the lowest five-year survival were the bone tumours (48.5%), CNS tumours (60.9%), soft tissue sarcomas (62.8%), and leukaemias (68.2%). Survival probabilities of around 90% were recorded for melanoma (93.7%), germ cell tumours (92.7%), and lymphomas (89.2%). Survival was significantly higher for Hodgkin lymphoma (94.6%) than non-Hodgkin lymphoma (78.8%) and five-year relative survival for leukaemias was nearly 20% higher for 20-24 year olds (78.8%) than for 15-19 year olds (60.0%).

Table 4.2 AYA five-year relative survival by AYA cancer classification scheme, New Zealand, 2000-2009

	15 – 19 years			20 – 24 years			Total AYA 15-24 years		
	Total cases	Five-year survival (%) (95% CI)		Total cases	Five-year survival (%) (95% CI)		Total cases	Five-year survival (%) (95% CI)	
1. Leukaemias	**102**	**60.0**	**(48.9 - 69.5)**	**78**	**78.8**	**(66.8 - 86.9)**	**180**	**68.2**	**(60.1 - 74.9)**
1.1 Acute lymphoid leukaemia	55	57.6	(42.3 - 70.2)	28	73.8	(52.3 - 86.8)	**83**	**63.1**	**(50.9 - 73.1)**
1.2 Acute myeloid leukaemia	34	60.6	(40.3 - 76.0)	39	79.6	(60.8 - 90.2)	**73**	**70.9**	**(57.5 - 80.7)**
1.3 Chronic myeloid leukaemia	6	83.7	(27.4 - 97.9)	7	75.3	(12.9 - 96.5)	**13**	**81.1**	**(41.2 - 95.4)**
1.4 Other & unspecified leukaemia	7	57.3	(17.2 - 84.0)	4	100.4	[a]	**11**	**73.0**	**(37.2 - 90.6)**
2. Lymphomas	**136**	**90.2**	**(82.3 - 94.7)**	**117**	**88.2**	**(80.0 - 93.2)**	**253**	**89.2**	**(84.0 - 92.9)**
2.1 Non-Hodgkin lymphoma	48	78.4	(61.6 - 88.6)	39	79.6	(63.1 - 89.4)	**87**	**78.8**	**(67.6 - 86.6)**
2.2 Hodgkin lymphoma	88	96.5	(85.7 - 99.4)	78	92.6	(82.2 - 97.1)	**166**	**94.6**	**(88.5 - 97.6)**
3. CNS tumours	**48**	**54.8**	**(38.6 - 68.4)**	**43**	**67.9**	**(50.8 - 80.3)**	**91**	**60.9**	**(49.3 - 70.7)**
3.1 Astrocytoma	15	56.9	(27.4 - 78.3)	25	66.5	(43.5 - 82.0)	**40**	**63.2**	**(45.4 - 76.6)**
3.2 Other gliomas	11	18.2	(2.9 - 44.3)	5	60.2	(12.6 - 88.4)	**16**	**31.3**	**(11.4 - 53.8)**
3.3 Ependymoma	5	100.3	[a]	7	80.3	(20.5 - 97.3)	**12**	**90.3**	**(47.5 - 98.9)**
3.4 Medulloblastoma & other PNET	11	58.0	(22.0 - 82.4)	4	75.2	(12.8 - 96.3)	**15**	**63.0**	**(31.9 - 83.1)**
3.5 Other specified intracranial and intraspinal neoplasms	1	100.5	[a]	2	50.3	(0.6 - 91.5)	**3**	**67.0**	**(5.4 - 95.0)**
3.6 Unspecified intracranial and intraspinal neoplasms	5	80.2	(20.4 - 97.1)	-	-	-	**5**	**80.2**	**(20.4 - 97.1)**
4. Osseous & chondromatous neoplasms	**81**	**50.0**	**(38.0 - 60.9)**	**23**	**43.5**	**(23.2 - 62.3)**	**104**	**48.5**	**(38.1 - 58.1)**
4.1 Osteosarcoma	37	51.3	(33.5 - 66.6)	10	49.3	(17.4 - 75.2)	**47**	**50.8**	**(35.2 - 64.5)**
4.2 Chondrosarcoma	2	100.5	[a]	1	100.5	[a]	**3**	**100.5**	[a]
4.3 Ewing tumour	38	45.9	(28.4 - 61.8)	12	33.5	(10.3 - 59.2)	**50**	**42.9**	**(28.3 - 56.7)**
4.4 Other bone tumours	4	50.1	(5.8 - 84.7)	-	-	-	**4**	**50.1**	**(5.8 - 84.7)**
5. Soft tissue sarcomas	**38**	**51.8**	**(34.0 - 66.9)**	**44**	**72.1**	**(54.7 - 83.8)**	**82**	**62.8**	**(50.6 - 72.9)**
5.1 Fibromatous neoplasms	4	75.2	(12.8 - 96.3)	10	100.3	[a]	**14**	**93.1**	**(59.2 - 99.2)**
5.2 Rhabdomyosarcoma	11	21.8	(3.5 - 50.0)	4	50.2	(5.8 - 84.8)	**15**	**29.9**	**(9.5 - 54.0)**
5.3 Other soft tissue sarcoma	23	61.7	(37.4 - 78.9)	30	66.7	(45.0 - 81.5)	**53**	**64.7**	**(49.0 - 76.6)**

[a] Confidence intervals cannot be calculated in instances where there were either no deaths or no survivors within the period

Table 4.2 (cont.) AYA five-year relative survival by AYA cancer classification scheme, New Zealand, 2000-2009

	15 – 19 years			20 – 24 years			Total AYA 15-24 years		
	Total cases	Five-year survival (%) (95% CI)		Total cases	Five-year survival (%) (95% CI)		Total cases	Five-year survival (%) (95% CI)	
6. Germ cell & trophoblastic neoplasms	**86**	**91.2**	**(81.7 - 96.0)**	**153**	**93.6**	**(88.0 - 96.7)**	**239**	**92.7**	**(88.2 - 95.6)**
6.1 Germ cell & trophoblastic neoplasms of gonads	75	93.9	(83.4 - 98.0)	142	94.6	(89.0 - 97.5)	217	94.3	(89.8 - 97.0)
6.2 Germ cell & trophoblastic neoplasms of non-gonadal sites	11	73.0	(37.2 - 90.6)	11	80.1	(40.4 - 94.9)	22	77.0	(53.0 - 89.9)
7. Melanoma & skin carcinomas	**93**	**92.1**	**(83.8 - 96.3)**	**210**	**94.3**	**(90.0 - 96.9)**	**303**	**93.7**	**(90.1 - 96.0)**
7.1 Melanoma	93	92.1	(83.8 - 96.3)	209	94.3	(90.0 - 96.9)	302	93.7	(90.1 - 96.0)
7.2 Skin carcinomas	-	-	-	1	100.5	[a]	1	100.5	[a]
8. Other & unspecified carcinomas	**86**	**83.3**	**(73.2 - 89.8)**	**207**	**81.7**	**(75.4 - 86.5)**	**293**	**82.0**	**(76.9 - 86.2)**
8.1 Thyroid carcinoma	25	100.2	[a]	61	100.3	[a]	86	100.3	[a]
8.2 Other carcinoma of head and neck	15	93.1	(59.2 - 99.2)	19	88.2	(59.3 - 97.2)	34	90.2	**(71.9 - 97.0)**
8.3 Carcinoma of trachea, bronchus & lung	4	100.2	[a]	3	100.3	[a]	7	100.2	[a]
8.4 Carcinoma of breast	-	-		18	56.7	(29.7 - 76.8)	18	56.7	**(29.7 - 76.8)**
8.5 Carcinoma of genitourinary tract	18	89.1	(62.5 - 97.3)	51	94.0	(82.1 - 98.2)	69	92.5	**(82.7 - 97.0)**
8.6 Carcinoma of gastrointestinal tract	22	51.0	(27.4 - 70.5)	49	53.3	(37.9 - 66.5)	71	52.5	**(39.7 - 63.8)**
8.7 Carcinoma of other/ill-defined sites	2	[b]	[b]	6	67.0	(19.6 - 90.9)	8	62.8	**(23.0 - 86.4)**
9. Miscellaneous neoplasms, NOS	**14**	**56.5**	**(27.3 - 77.8)**	**26**	**64.9**	**(43.1 - 80.1)**	**40**	**61.5**	**(44.1 - 74.9)**
9.1 Other paediatric & embryonal tumors, NOS	4	75.3	(12.8 - 96.4)	4	35.8	(1.0 - 79.5)	8	57.2	(16.5 - 84.3)
9.2 Other specified & embryonal tumors, NOS	10	50.2	(18.4 - 75.6)	22	68.3	(44.6 - 83.6)	32	62.2	(42.9 - 76.7)
10. Unspecified (malig.) neoplasms	**3**	**100.2**	[a]	**8**	**87.8**	**(38.9 - 98.5)**	**11**	**91.3**	**(51.0 - 99.1)**
Total cancers diagnosed	**687**	**75.1**	**(71.4 - 78.4)**	**909**	**84.6**	**(82.0 - 86.9)**	**1596**	**80.6**	**(78.4 - 82.6)**

[a] Confidence intervals cannot be calculated in instances where there were either no deaths or no survivors within the period
[b] Five-year relative survival could not be calculated as no cases had a full five-years of follow up

4.3 AYA cancer relative survival by age group

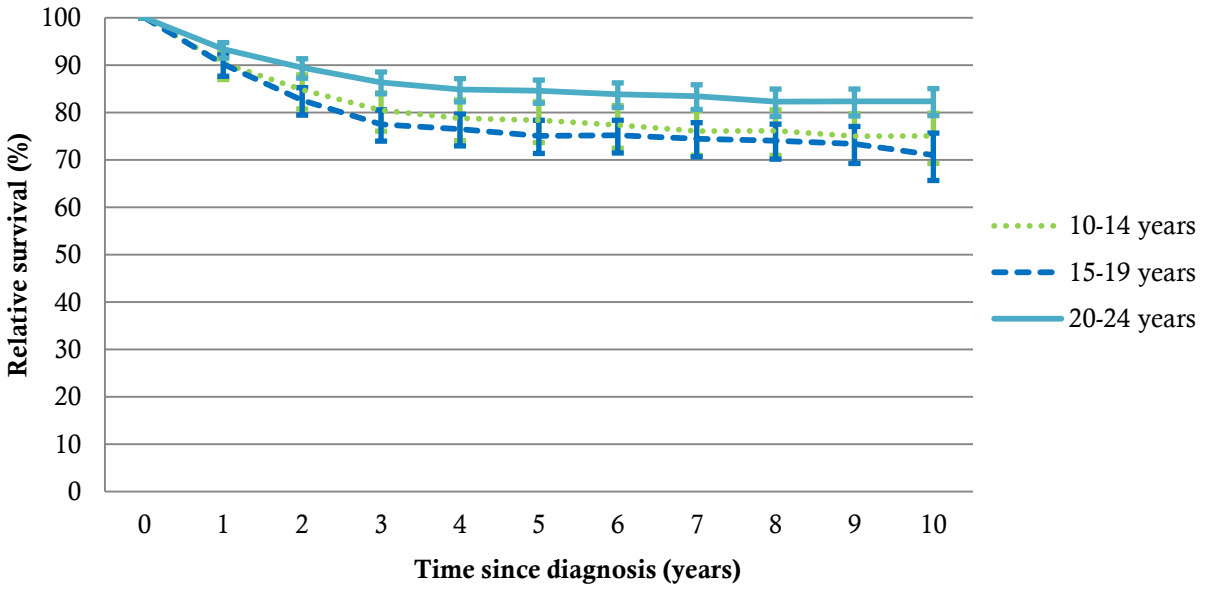
4.3.1 Overall AYA cancer relative survival, by age group

Table 4.3.1 and Figure 4.3 show that the overall cancer survival for the 20-24 year group was significantly higher than for adolescents aged 15-19 years for every year except the first year following diagnosis. One-year, three-year and five-year relative survival for young adults aged 20-24 years was 93.4%, 86.4% and 84.6% respectively. For adolescents aged 15-19 the corresponding figures were 90.2%, 77.5% and 75.1%. Survival for the 10-14 year cancer population more closely resembled the 15-19 year group, with survival declining from around 90% (90.4%) at one year following diagnosis to less than 80% (78.4%) at Year Five.

Table 4.3.1 AYA cancer relative survival by age group, New Zealand, 2000-2009

Years since diagnosis	Young people 10-14 years			Adolescents 15-19 years			Young Adults 20-24 years		
	Total cases	Cumulative relative survival (95% CI)		Total cases	Cumulative relative survival (95% CI)		Total cases	Cumulative elative survival (95% CI)	
1	395	**90.4**	(87.0 - 92.9)	687	**90.2**	(87.7 - 92.2)	909	**93.4**	(91.5 - 94.8)
2	357	**84.8**	(80.8 - 88.0)	619	**82.6**	(79.5 - 85.3)	848	**89.5**	(87.3 - 91.4)
3	299	**80.5**	(76.1 - 84.2)	492	**77.5**	(74.0 - 80.6)	751	**86.4**	(84.0 - 88.6)
4	238	**78.8**	(74.1 - 82.7)	406	**76.5**	(73.0 - 79.7)	638	**84.9**	(82.3 - 87.2)
5	203	**78.4**	(73.7 - 82.3)	342	**75.1**	(71.4 - 78.4)	549	**84.6**	(82.0 - 86.9)
6	166	**77.4**	(72.5 - 81.5)	282	**75.2**	(71.5 - 78.4)	474	**83.9**	(81.1 - 86.3)
7	134	**76.1**	(71.0 - 80.5)	233	**74.5**	(70.7 - 77.9)	395	**83.5**	(80.7 - 85.9)
8	105	**76.2**	(71.0 - 80.6)	187	**74.1**	(70.2 - 77.6)	314	**82.3**	(79.2 - 85.0)
9	73	**75.0**	(69.3 - 79.8)	130	**73.4**	(69.3 - 77.1)	227	**82.4**	(79.3 - 85.0)
10	49	**75.1**	(69.3 - 79.9)	81	**71.0**	(65.7 - 75.7)	137	**82.4**	(79.4 - 85.1)

Figure 4.3 Overall AYA cancer relative survival (including 95% CI), by age group, New Zealand, 2000-2009



4.3.2 Cancer deaths in AYA first diagnosed between 2000 and 2009, by age group

Figures 4.3a-c show the number of deaths which were recorded within this study population analysed by diagnostic group. In effect, each 'piece of the pie' is determined by the diagnostic group's survival weighted by incidence. Note that the numbers of deaths reported for this cohort are not the same as AYA mortality for the 2000-2009 period, as the figures omit AYA who died within this period but who had been diagnosed prior to the year 2000. Moreover, as the cause of death has not been reported, it cannot be confirmed if cancer was the primary/contributing cause of death in all cases or if one or more individuals died of unrelated causes. However, the raw numbers and percentages do give an *indication* of the likely main causes of death within this cohort of AYA diagnosed with cancer between 2000 and 2009.

Deaths in the 15-19 year cohort were associated with three diagnostic groups; bone tumours (39 deaths, 24%), leukaemias (37 deaths, 23%) and CNS tumours (22 deaths, 13%). For the 20-24 year group, around one in four deaths in the cohort occurred in those diagnosed with a carcinoma (38 deaths, 26%). The remaining deaths were relatively evenly distributed across multiple diagnostic groups, including melanoma (16 deaths, 11%), CNS tumours (16 deaths, 11%), leukaemias (15 deaths, 10%), lymphomas (14 deaths, 10%) and bone tumours (13 deaths, 9%).

Comparing Figures 4.3a and 4.3c, it can be seen that the greatest number of deaths in the 10-14 year age group (representing over two thirds of all deaths) were associated with the same three diagnostic groups as for the 15-19 year age group; CNS tumours (24 deaths, 29%), leukaemias (21 deaths, 25%), and bone tumours (20 deaths, 24%). Although overall cancer survival for the 10-14 and 15-19 year age groups were similar, overall cancer incidence was much lower for the 10-14 year group, and therefore the total number of deaths in the 10-14 year group was considerably lower (84 deaths were recorded for those aged 10-14 years compared with 163 for the 15-19 year group).

Figure 4.3a Deaths within the cohort of New Zealand AYA aged 15-19 years diagnosed with cancer between 2000 and 2009

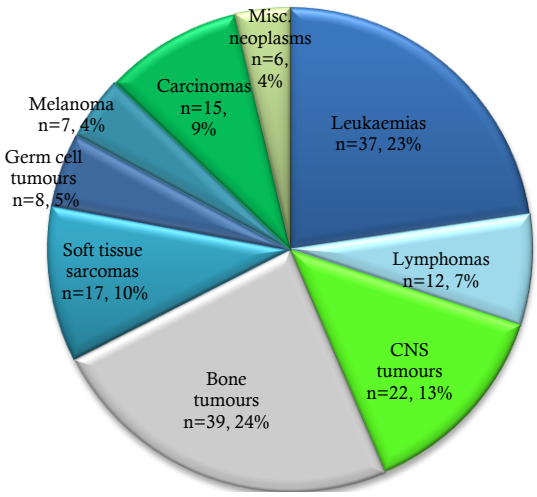


Figure 4.3b Deaths within the cohort of New Zealand AYA aged 20-24 years diagnosed with cancer between 2000 and 2009

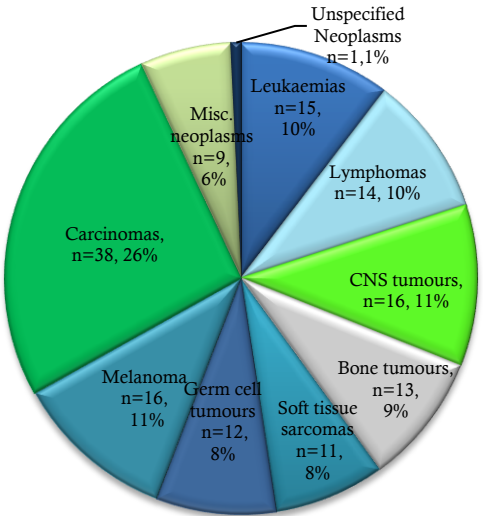
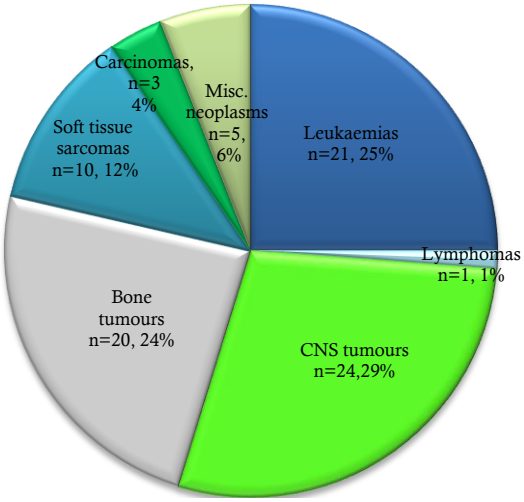


Figure 4.3c Deaths within the cohort of New Zealand children aged 10-14 years diagnosed with cancer between 2000 and 2009



4.4 AYA cancer relative survival by gender

4.4.1 Five-year relative survival for all AYA cancers, by gender

At five years, female relative survival was 83.5%, 5.7% higher than the reported male survival of 77.8% (see Table 4.4.1). This reflects the different relative risks reported earlier for some diagnostic groups, with females more likely to be diagnosed with melanoma and thyroid cancer, which typically have more favourable outcomes, and males more likely to be diagnosed with acute lymphoblastic leukaemia and bone tumours, which have comparatively poorer survival. The five-year overall cancer survival for females aged 15-19 years was 79.1%, compared with male survival of 71.5%. For those females and males aged 20-24 years, survival was 86.6% and 82.7%, respectively.

Five-year relative survival for females aged 15-24 years diagnosed with carcinomas was 86.3%, which was significantly higher than the 71.0% survival reported for males. However, this was distorted due to the higher incidence of thyroid carcinomas amongst female AYA, which has a relative survival of above 100% (i.e. the survival for AYA diagnosed with thyroid carcinoma was actually slightly higher than for the AYA population as a whole). Other notable differences in survival, although not reaching statistical significance, were seen in leukaemias (75.8% for female AYA c.f. 62.5% for male) and bone tumours (55.3% for female AYA c.f. 44.2% for male).

Table 4.4.2 Five-year survival by gender and AYA diagnostic group and selected subgroups, New Zealand, 2000-2009

	Males 15-24 years			Females 15-24 years		
	Total cases	Five-year survival (%) (95% CI)		Total cases	Five-year survival (%) (95% CI)	
1. Leukaemias	**104**	**62.5**	**(51.4 - 71.8)**	**76**	**75.8**	**(63.7 - 84.4)**
1.1 Acute lymphoid leukaemia	52	58.2	(42.0 - 71.4)	31	70.4	(50.6 - 83.5)
1.2 Acute myeloid leukaemia	36	63.5	(43.7 - 78.1)	37	77.9	(58.3 - 89.1)
2. Lymphomas	**140**	**88.7**	**(81.6 - 93.3)**	**113**	**90.2**	**(81.4 - 95.0)**
2.1 Non-Hodgkin lymphoma	56	77.6	(63.4 - 86.9)	31	81.4	(59.4 - 92.3)
2.2 Hodgkin lymphoma	84	96.1	(87.1 - 99.1)	82	93.4	(82.8 - 97.6)
3. CNS tumours	**47**	**58.8**	**(42.4 - 72.1)**	**44**	**63.0**	**(45.7 - 76.1)**
3.1 Astrocytoma	25	57.4	(34.7 - 74.8)	15	72.9	(42.6 - 89.0)
4. Osseous & chondromatous neoplasms	**63**	**44.2**	**(31.3 - 56.3)**	**41**	**55.3**	**(37.9 - 69.7)**
4.1 Osteosarcoma	30	46.4	(27.0 - 63.7)	17	58.2	(31.7 - 77.6)
4.3 Ewing tumour	28	34.7	(17.8 - 52.3)	22	53.1	(28.0 - 73.0)
5. Soft tissue sarcomas	**41**	**60.7**	**(43.0 - 74.4)**	**41**	**65.1**	**(47.1 - 78.3)**
6. Germ cell & trophoblastic neoplasms	**197**	**92.2**	**(86.9 - 95.4)**	**42**	**95.3**	**(82.0 - 98.9)**
6.1 Germ cell & trophoblastic neoplasms of gonads	183	94.4	(89.2 - 97.2)	34	94.2	(78.1 - 98.7)
7. Melanoma & skin carcinomas	**122**	**91.0**	**(84.0 - 95.2)**	**181**	**95.4**	**(90.9 - 97.8)**
8. Other & unspecified carcinomas	**82**	**71.0**	**(59.4 - 79.9)**	**211**	**86.3**	**(80.6 - 90.5)**
8.1 Thyroid carcinoma	17	100.5	[a]	69	100.2	[a]
8.2 Other carcinoma of head and neck	15	78.4	(46.1 - 92.9)	19	100.2	[a]
8.4 Carcinoma of breast	-	-	-	18	56.7	(29.7 - 76.8)
8.5 Carcinoma of genitourinary tract	4	100.5	[a]	65	92.0	(81.6 - 96.7)
8.6 Carcinoma of gastrointestinal tract	40	53.5	(36.4 - 67.9)	31	50.9	(31.2 - 67.6)
9. Miscellaneous neoplasms, NOS	**19**	**73.7**	**(47.6 - 88.4)**	**21**	**50.2**	**(26.8 - 69.7)**
10. Unspecified malignant neoplasms	**7**	**86.2**	**(33.6 - 98.4)**	**4**	**100.2**	[a]
Total cancers diagnosed	**822**	**77.8**	**(74.7 - 80.7)**	**774**	**83.5**	**(80.5 - 86.1)**

[a] Confidence intervals cannot be calculated in instances where there were either no deaths or no survivors within the period

4.5 AYA cancer relative survival by ethnicity

The following section reports AYA cancer survival by prioritised ethnicity; Maori, Pacific Peoples, and non-Maori/Pacific Peoples. As noted earlier, any between-group differences must be interpreted with caution as often there are a small number of cases and differences may not be statistically significant. Also, any differences in survival may be explained by a number of other factors. For example, a greater proportion of non-Maori/Pacific Peoples were diagnosed with lymphomas and melanoma, which have much higher overall than many of the other cancer groups in which Maori and Pacific Peoples were potentially overrepresented.

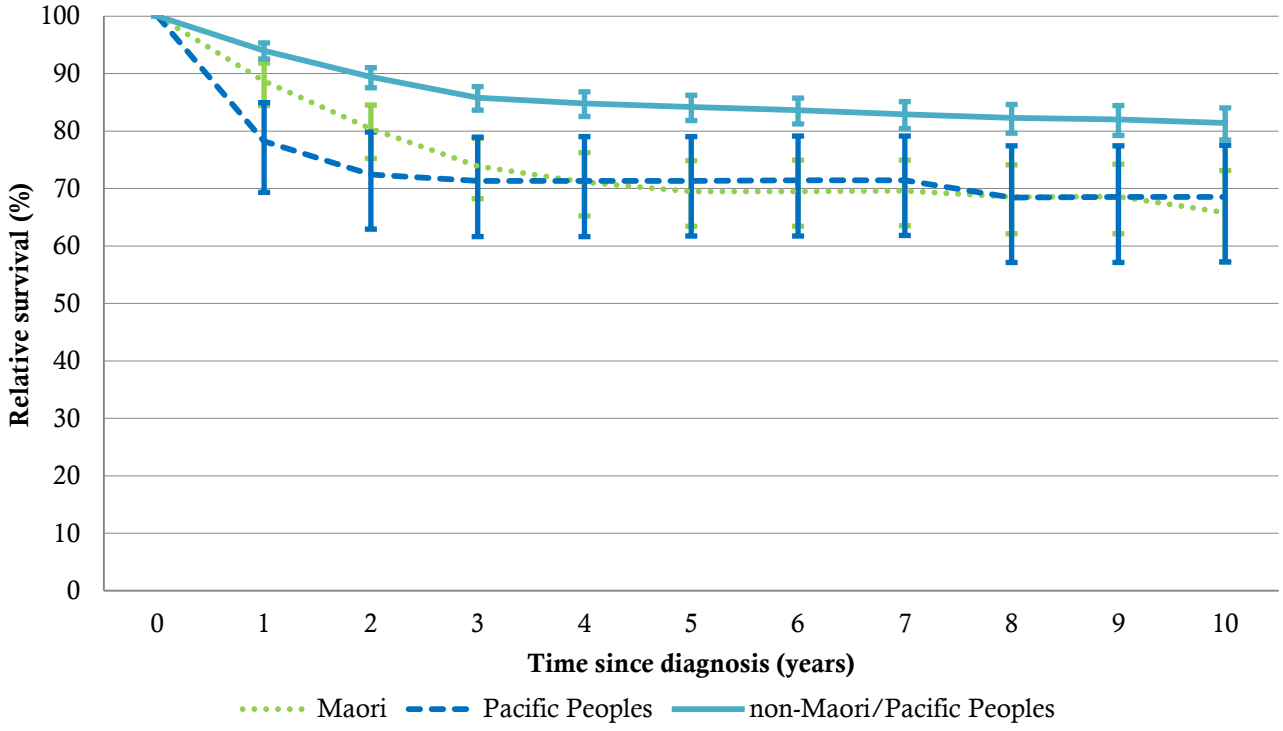
4.5.1 Relative survival for all AYA cancers, by ethnicity

For AYA aged 15-24 years, the survival for Maori and Pacific Peoples at each year of follow up was significantly lower than for non-Maori/Pacific Peoples (see Table 4.5.1 and Figure 4.5). By five years, AYA cancer survival for Maori (69.5%) and Pacific Peoples (71.3%) was 12-15% less than for those from other ethnic backgrounds (84.2%) and this gap did not narrow within the subsequent five years of follow-up. Around one in five AYA of Pacific descent passed away within one year of their initial cancer diagnosis.

Table 4.5.1 Relative survival for all AYA cancers by ethnicity, New Zealand, 2000-2009

Years since diagnosis	Maori			Pacific Peoples			Non-Maori/Pacific Peoples		
	Total cases	Cumulative relative survival (95% CI)		Total cases	Cumulative relative survival (95% CI)		Total cases	Cumulative relative survival (95% CI)	
1	290	**88.7**	(84.4 - 91.8)	110	**78.2**	(69.3 - 84.9)	1196	**94.0**	(92.5 - 95.3)
2	257	**80.4**	(75.2 - 84.5)	86	**72.4**	(62.9 - 79.8)	1124	**89.4**	(87.5 - 91.0)
3	206	**73.9**	(68.2 - 78.7)	67	**71.3**	(61.6 - 78.9)	970	**85.8**	(83.6 - 87.7)
4	171	**71.1**	(65.2 - 76.2)	57	**71.3**	(61.6 - 79.0)	816	**84.8**	(82.5 - 86.8)
5	138	**69.5**	(63.4 - 74.8)	47	**71.3**	(61.7 - 79.0)	706	**84.2**	(81.8 - 86.2)
6	117	**69.5**	(63.4 - 74.9)	40	**71.4**	(61.7 - 79.1)	599	**83.6**	(81.2 - 85.7)
7	99	**69.6**	(63.5 - 74.9)	28	**71.4**	(61.8 - 79.1)	501	**82.9**	(80.4 - 85.1)
8	76	**68.5**	(62.1 - 74.1)	26	**68.4**	(57.1 - 77.4)	399	**82.3**	(79.6 - 84.6)
9	49	**68.6**	(62.1 - 74.2)	20	**68.5**	(57.1 - 77.4)	288	**82.0**	(79.2 - 84.4)
10	30	**65.8**	(57.2 - 73.1)	11	**68.5**	(57.2 - 77.5)	177	**81.4**	(78.4 - 84.0)

Figure 4.5 Overall AYA cancer relative survival (including 95% CI), by ethnicity, New Zealand, 2000-2009



4.5.2 Five-year relative survival for all AYA cancers by age group and ethnicity

Table 4.5.2 shows that the five-year relative survival for non-Maori/Pacific Peoples aged 15-19 years was just under 80% (78.9%). In stark contrast, the relative survival for Maori was 65.8% and Pacific Peoples was 65.6%. This means around one in three adolescents of Maori or Pacific descent died within five years of their cancer diagnosis.

Overall, AYA cancer five-year survival for Maori (69.5%) and Pacific Peoples (71.3%) was significantly lower than for non-Maori/Pacific Peoples (84.2%). This is in contrast to the child cancer survival reported for the same period, where no significant differences according to prioritised ethnicity were found.

Table 4.5.2 Five-year relative survival for all AYA cancers by age group and ethnicity, New Zealand, 2000-2009

	10 - 14 years			15 -19 years			20 - 24 years			Total 15-24 years		
	Total cases	Five-year relative survival (95% CI)		Total cases	Five-year relative survival (95% CI)		Total cases	Five-year relative survival (95% CI)		Total cases	Five-year relative survival (95% CI)	
Maori	76	**74.2**	(62.5 - 82.8)	140	**65.8**	(56.3 - 73.8)	150	**72.6**	(64.3 - 79.3)	290	**69.5**	(63.4 - 74.8)
Pacific Peoples	38	**79.9**	(61.9 - 90.1)	60	**65.6**	(51.7 - 76.5)	50	**78.0**	(63.6 - 87.3)	110	**71.3**	(61.7 - 79.0)
Non-Maori/ Pacific Peoples	281	**79.3**	(73.7 - 83.9)	487	**78.9**	(74.8 - 82.5)	709	**87.7**	(84.8 - 90.0)	1196	**84.2**	(81.8 - 86.2)
Total	**395**	**78.4**	**(73.7 - 82.3)**	**687**	**75.1**	**(71.4 - 78.4)**	**909**	**84.6**	**(82.0 - 86.9)**	**1596**	**80.6**	**(78.4 - 82.6)**

4.5.3 Five-year relative survival by ethnicity and AYA cancer classification scheme

As melanoma incidence is significantly lower for Maori and Pacific Peoples, it is possible that the excellent melanoma survival for AYA contributed to the survival differences seen across these three groups. When melanoma were excluded from the analysis, there was minimal change to the overall AYA cancer survival for Maori (-0.5%) and Pacific Peoples (-1.1%), while survival for non-Maori/Pacific Peoples dropped more markedly (-3.3%) (see Table 4.5.3). Although the survival gap narrowed when melanoma were excluded, Maori relative survival (69.0%) remained significantly below non-Maori/Pacific Peoples (80.9%). However, the relative survival for AYA of Pacific descent (70.2%) was no longer statistically significantly lower than non-Maori/Pacific Peoples.

When comparing survival by ethnicity and diagnostic group, notable differences were found in leukaemia survival between Maori and non-Maori/Pacific Peoples. The five-year relative survival for Maori diagnosed with leukaemia was 50.3% (38 cases) compared with 74.2% (117 cases) for those whose ethnicity was recorded as non-Maori/Pacific Peoples. This was mainly due to the poor survival reported for Maori diagnosed with acute lymphoblastic leukaemia (45.2% c.f. 67.1%). Also of note was the poor survival for Maori diagnosed with malignant bone tumours (37.0%, 33 cases).

Table 4.5.3 AYA cancer five-year relative survival by ethnicity and AYA diagnostic group and selected subgroups, New Zealand, 2000-2009

	Maori			Pacific Peoples			Non-Maori/Pacific Peoples		
	Total cases	Five-year relative survival (95% CI)		Total cases	Five-year relative survival (95% CI)		Total cases	Five-year relative survival (95% CI)	
1. Leukaemias	38	**50.3**	(31.9 - 66.1)	25	**67.7**	(45.5 - 82.6)	117	**74.2**	(64.4 - 81.8)
1.1 Acute lymphoid leukaemia	15	**45.2**	(19.5 - 68.1)	11	**73.0**	(37.2 - 90.6)	57	**67.1**	(52.2 - 78.4)
1.2 Acute myeloid leukaemia	17	**63.9**	(32.1 - 83.9)	13	**61.3**	(30.3 - 81.9)	43	**76.1**	(58.0 - 87.3)
2. Lymphomas	35	**83.9**	(64.2 - 93.4)	19	**89.9**	(64.3 - 97.2)	199	**90.2**	(84.3 - 94.0)
2.1 Non-Hodgkin lymphoma	15	**69.6**	(35.9 - 88.0)	11	**91.3**	(51.0 - 99.1)	61	**79.4**	(66.2 - 88.0)
2.2 Hodgkin lymphoma	20	**95.3**	(69.7 - 99.6)	8	**87.8**	(38.8 - 98.4)	138	**95.0**	(87.9 - 98.1)
3. CNS tumours	11	**46.3**	(14.6 - 73.6)	3	[a]	[a]	77	**63.8**	(51.1 - 74.0)
4. Osseous & chondromatous neoplasms	33	**37.0**	(19.6 - 54.5)	8	**60.8**	(20.7 - 85.6)	63	**52.5**	(39.2 - 64.3)
4.1 Osteosarcoma	12	**38.0**	(12.1 - 64.3)	3	**60.1**	(2.5 - 93.4)	32	**54.9**	(35.7 - 70.6)
4.3 Ewing tumour	20	**33.3**	(12.1 - 56.5)	4	**50.1**	(5.8 - 84.7)	26	**47.6**	(27.0 - 65.6)
5. Soft tissue sarcomas	23	**54.1**	(31.2 - 72.3)	7	**28.7**	(1.5 - 69.3)	52	**71.2**	(55.9 - 82.0)
6. Germ cell tumours	71	**90.5**	(79.0 - 96.0)	7	**71.6**	(25.9 - 92.2)	161	**94.5**	(89.3 - 97.3)
6.1 Gonadal germ cell tumours	64	**90.8**	(77.9 - 96.5)	5	**80.2**	(20.4 - 97.1)	148	**96.1**	(91.1 - 98.5)
7. Melanoma & skin carcinomas	7	**85.9**	(33.5 - 98.1)	4	**100.3**	[b]	292	**93.8**	(90.1 - 96.1)
8. Other & unspecified carcinomas	61	**75.7**	(62.2 - 85.0)	31	**77.2**	(57.9 - 88.6)	201	**84.7**	(78.6 - 89.2)
9. Miscellaneous neoplasms	10	**59.5**	(24.3 - 82.7)	4	**50.1**	(5.8 - 84.7)	26	**64.0**	(41.8 - 79.7)
10. Unspecified (malig) neoplasms	1	[a]	[a]	2	**50.1**	(0.6 - 91.3)	8	**100.4**	[b]
Total cancers diagnosed	**290**	**69.5**	**(63.4 - 74.8)**	**110**	**71.3**	**(61.7 - 79.0)**	**1 196**	**84.2**	**(81.8 - 86.2)**
Total cancers excluding melanoma	**283**	**69.0**	**(62.8 - 74.4)**	**106**	**70.2**	**(60.3 - 78.1)**	**904**	**80.9**	**(78.0 - 83.5)**

[a] Five-year relative survival could not be calculated as no cases had a full five-years of follow up
[b] Confidence intervals cannot be calculated in instances where there were either no deaths or no survivors within the period

4.5.4 Deaths within the cohort of New Zealand AYA first diagnosed with cancer between 2000 and 2009, by ethnicity

Within the study period (with follow up to December 31 2010) there were 85 deaths recorded for Maori, 32 for Pacific Peoples, and 192 for non-Maori/Pacific Peoples. Of the 33 Maori in this cohort who were diagnosed with a bone tumour, 19 died. The other main diagnostic groups associated with deaths amongst Maori AYA were leukaemias (17 deaths), carcinomas (14 deaths) and sarcomas (10 deaths). For Pacific Peoples, the two main diagnostic groups associated with deaths in this cohort were leukaemias (eight deaths) and carcinomas (seven deaths). Deaths within the study population for those of all other ethnicities were predominantly associated with a diagnosis of carcinoma (32 deaths), CNS tumour (31 deaths), bone tumour (30 deaths), or leukaemia (27 deaths).

Figure 4.5a Deaths within the cohort of New Zealand AYA of Maori ethnicity diagnosed with cancer between 2000 and 2009

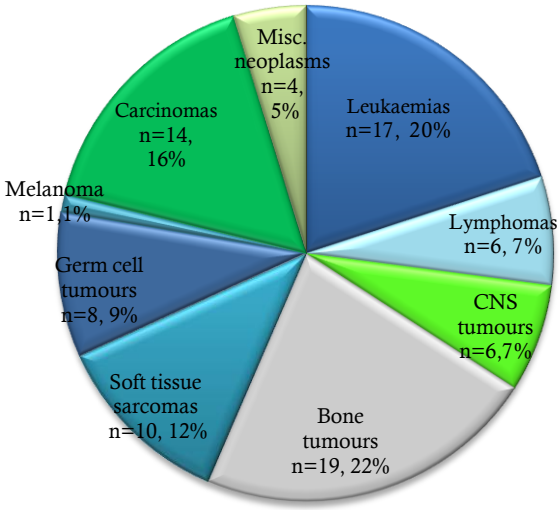


Figure 4.5b Deaths within the cohort of New Zealand AYA of Pacific descent diagnosed with cancer between 2000 and 2009

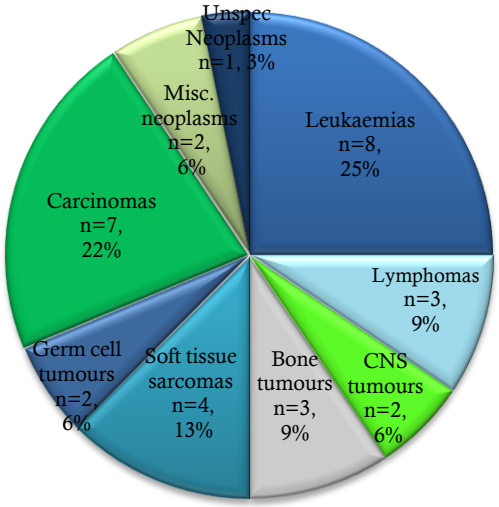
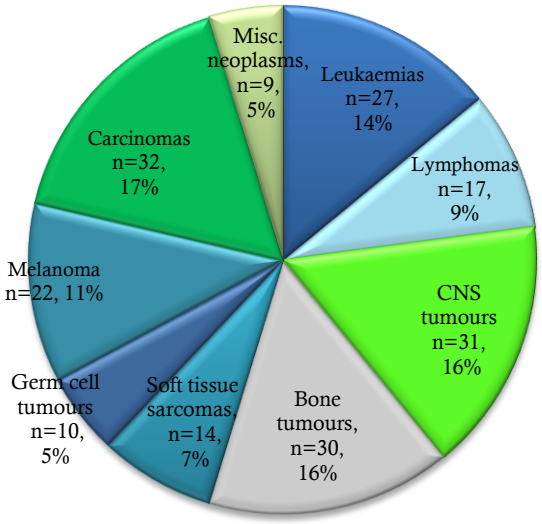


Figure 4.c Deaths within the cohort of New Zealand Non-Maori/Pacific AYA diagnosed with cancer between 2000 and 2009



4.6 AYA cancer survival comparisons

The following section compares AYA cancer survival with New Zealand child cancer survival for the same time period, New Zealand AYA survival in 1988-2002, and cancer survival which has been published by other cancer registries according to the ICCC classification system. Please note that the ICCC and AYA classification scheme often use similar labels for their diagnostic groups and subgroups however there may be subtle differences in the way that the neoplasms are categorised (see section 1.5.2 for further details). Therefore the numbers reported in this section, by ICCC, may differ slightly to the numbers reported within the rest of this report in which the AYA cancer classification scheme has been applied.

4.6.1 AYA cancer survival compared with child cancer survival

The five-year relative survival for AYA cancer was 80.6%, almost identical to the relative survival reported for child cancer (80.7%), (see Table 4.6.1). However, a greater proportion of AYA cancer cases were epithelial neoplasms (including melanoma and thyroid carcinoma) and Hodgkin lymphoma, which typically have excellent survival. When comparing by diagnostic group/subgroup, acute lymphoblastic leukaemia survival for AYA was significantly lower than for children (63.1% c.f. 89.4%). Other notable differences in survival were for non-Hodgkin lymphoma (77.9% cf. 95.0%), malignant bone tumours (46.2% c.f. 66.8%), and soft tissue sarcomas (61.1% c.f. 73.1%). Five-year CNS tumour survival for AYA was also lower than that reported for children (60.4% c.f. 70.8%). However, as noted earlier, the AYA cancer registrations, provided by the NZCR, did not include any CNS tumours of benign/uncertain behaviour. These tumours, which were included in the NZCCR child cancer analysis, would be expected to have a more favourable prognosis.

Table 4.6.1 Five-year relative survival for AYA and children by ICCC-3 diagnostic group and selected subgroups, New Zealand, 2000-2009

	Children 0-14 years (NZCCR)			AYA 15-24 years (NZCR)		
	Total cases	Five-year relative survival (%) (95% CI)		Total cases	Five-year relative survival (%) (95% CI)	
I. Leukaemias	455	**85.0**	(81.1 - 88.2)	196	**69.4**	(61.9 - 75.8)
I(a) Acute lymphoid leukaemias	352	**89.4**	(85.3 - 92.4)	83	**63.1**	(50.9 - 73.1)
I(b) Acute myeloid leukaemias	78	**69.2**	(56.7 - 78.8)	77	**70.0**	(57.1 - 79.6)
II. Lymphomas	114	**92.9**	(86.2 - 96.5)	254	**89.3**	(84.0 - 92.9)
II(a) Hodgkin lymphomas	36	**97.4**	(82.0 - 99.8)	166	**94.6**	(88.5 - 97.6)
II(b) Non-Hodgkin lymphomas (excl. Burkitt lymphomas)	58	**95.0**	(84.9 - 98.4)	68	**77.9**	(64.8 - 86.6)
III. CNS tumours[a]	283	**70.8**	(64.9 - 75.9)	93	**60.4**	(48.8 - 70.1)
III(b) Astrocytomas	116	**77.7**	(68.7 - 84.4)	40	**63.2**	(45.4 - 76.6)
IV. Neuroblastoma	87	**66.1**	(54.6 - 75.5)	6	**50.2**	(11.1 - 80.7)
V. Retinoblastoma	39	**100.3**	[b]	-	**-**	-
VI. Renal tumours	61	**96.7**	(86.8 - 99.3)	10	**89.2**	(43.5 - 98.7)
VII. Hepatic tumours	13	**69.4**	(37.4 - 87.4)	4	**0.0**	[a]
VIII. Malignant bone tumours	72	**66.8**	(53.8 - 76.9)	79	**46.2**	(34.3 - 57.3)
VIII(a) Osteosarcoma	37	**66.8**	(48.9 - 79.7)	47	**50.8**	(35.2 - 64.5)
VIII(c) Ewing tumour & related sarcomas of bone	28	**61.3**	(37.6 - 78.3)	25	**28.6**	(11.0 - 49.2)
IX. Soft tissue sarcomas	94	**73.1**	(62.4 - 81.2)	107	**61.1**	(50.6 - 70.0)
X. Germ cell tumours	57	**96.8**	(86.9 - 99.4)	269	**92.8**	(88.7 - 95.5)
X(c) Malignant gonadal germ cell tumours	23	**100.3**	[b]	215	**94.8**	(90.3 - 97.3)
XI. Other epithelial neoplasms	42	**84.9**	(69.1 - 93.0)	564	**88.3**	(85.2 - 90.8)
XI(b) Thyroid carcinomas	6	**100.1**	[b]	86	**100.3**	[b]
XI(d) Malignant melanoma	16	**93.9**	(63.3 - 99.3)	302	**93.7**	(90.1 - 96.0)
XII. Other and unspecified	4	**50.1**	(5.8 - 84.7)	14	**48.4**	(20.9 - 71.5)
Total cancers diagnosed	**1 321**	**80.7**	**(78.4 - 82.9)**	**1 596**	**80.6**	**(78.4 - 82.6)**

[a] Note that the survival figures for this group are not directly comparable, as child cancer survival includes non-malignant CNS tumours, which are not registered for AYA

[b] Confidence intervals cannot be calculated in instances where there were either no deaths or no survivors within the period

4.6.2 AYA cancer survival compared with child cancer survival by prioritised ethnicity

Compared to the child cancer population of the same ethnicity, five-year cancer survival for the 2000-2009 period was higher for non-Maori/Pacific AYA (84.2% c.f. 81.7%) but lower for Maori (69.5% c.f. 76.9%) and Pacific AYA (71.3 c.f. 81.4%), (see Table 4.6.2). Leukaemia survival for Maori AYA was 52.8%, significantly lower than the leukaemia survival for Maori children diagnosed in the same time period (81.2%). This was primarily due to the poorer survival in Maori AYA with acute lymphoblastic leukaemias (45.2% c.f. 89.8%). Five-year survival for Pacific Peoples diagnosed with leukaemia was also lower for AYA than for children (64.1% c.f. 86.2%) but this did not reach statistical significance.

Table 4.6.2 Comparison of AYA and child cancer survival by prioritised ethnicity and ICCC-3 diagnostic group and selected subgroups, New Zealand, 2000-2009

	Non-Maori/Pacific Peoples				Maori				Pacific Peoples			
	Children		AYA		Children		AYA		Children		AYA	
	Total cases	Five-year relative survival (95% CI)	Total cases	Five-year relative survival (95% CI)	Total cases	Five-year relative survival (95% CI)	No. of cases	Five-year relative survival (95% CI)	Total cases	Five-year relative survival (95% CI)	Total cases	Five-year relative survival (95% CI)
I. Leukaemias	309	85.9 (81.1 - 89.6)	126	76.3 (67.0 - 83.3)	92	81.2 (70.8 - 88.3)	42	52.8 (35.3 - 67.6)	54	86.2 (72.9 - 93.3)	28	64.1 (43.3 - 79.0)
Ia. Acute lymphoid leukaemias	253	89.4 (84.6 - 92.9)	57	67.1 (52.2 - 78.4)	62	89.8 (76.3 - 95.8)	15	45.2 (19.5 - 68.1)	37	88.0 (70.6 - 95.4)	11	73.0 (37.2 - 90.6)
Ib. Acute myeloid leukaemias	47	69.3 (51.5 - 81.7)	45	77.5 (60.2 - 88.0)	23	65.4 (42.5 - 81.1)	19	57.2 (29.0 - 77.7)	8	75.1 (31.5 - 93.2)	13	61.3 (30.3 - 81.9)
II. Lymphomas	83	94.0 (86.0 - 97.6)	200	90.3 (84.4 - 94.1)	22	90.9 (68.0 - 97.7)	35	83.9 (64.2 - 93.4)	9	88.3 (41.1 - 98.4)	19	89.8 (64.3 - 97.6)
IIa. Hodgkin lymphomas	27	96.5 (76.6 - 99.6)	138	95.0 (87.9 - 98.1)	8	100.1[a]	20	95.3 (69.7 - 99.6)	1	100.1[a]	8	87.8 (38.8 - 98.4)
IIb. Non-Hodgkin lymphomas (excl. Burkitt lymphoma)	44	95.6 (83.1 - 99.0)	44	79.0 (63.1 - 88.7)	10	90.1 (47.4 - 98.7)	14	68.3 (34.6 - 87.3)	4	100.1[a]	10	90.4 (47.5 - 98.9)
III. CNS tumours[b]	209	72.7 (65.8 - 78.5)	79	59.8 (32.3 - 79.2)	52	66.4 (51.5-77.7)	11	46.3 (14.6 - 73.6)	22	63.8 (40.4 - 80.0)	3	[c]
VIII. Malignant bone tumours	45	65.5 (48.3 - 78.3)	52	51.9 (37.0 - 64.9)	14	54.4 (25.0 - 76.6)	23	29.5 (11.8 - 49.8)	13	83.6 (48.4 - 95.7)	4	71.7 (9.0 - 95.8)
VIIIa. Osteosarcomas	22	72.2 (48.1 - 86.5)	32	54.9 (35.7 - 70.6)	8	47.8 (13.1 - 76.5)	12	38.0 (12.1 - 64.3)	7	71.5 (25.8 - 92.1)	3	60.1 (2.5 - 93.4)
VIIIc. Ewing tumour	18	53.0 (24.8 - 75.0)	15	41.8 (16.0 - 66.0)	4	45.1 (3.3 - 83.0)	10	13.4 (0.8 - 43.0)	6	100.1[a]	-	-
IX. Soft tissue sarcomas	74	75.5 (63.4 - 84.1)	63	68.3 (54.6 - 78.6)	17	64.3 (37.1-82.2)	33	54.3 (35.0 - 70.3)	3	[c]	11	39.9 (11.0 - 68.3)
IXa. Rhabdomyosarcomas	39	72.3 (54.3 - 84.2)	8	47.9 (13.4 - 76.7)	9	66.7 (28.2 - 87.9)	6	16.8 (0.8 - 51.9)	2	[c]	1	[c]
X. Germ cell tumours	30	97.0 (78.8 - 99.8)	180	95.1 (90.4 - 97.6)	16	94.1 (63.5 - 99.5)	77	90.0 (79.3 - 95.5)	11	100.1[a]	12	74.8 (40.1 - 91.3)
XI. Other epithelial neoplasms	33	90.5 (72.9 - 97.0)	474	90.4 (87.2 - 92.8)	6	83.4 (27.4 - 97.6)	60	77.2 (63.6 - 86.2)	3	[c]	30	76.6 (56.9 - 88.3)
Total cancers diagnosed	**933**	**81.7 (79.0 - 84.2)**	**1196**	**84.2 (81.8 - 86.2)**	**259**	**76.9 (71.0 - 81.8)**	**290**	**69.5 (63.4 - 74.8)**	**129**	**81.4 (73.1 - 87.3)**	**110**	**71.3 (61.7 - 79.0)**

[a] Confidence intervals cannot be calculated when there were no deaths recorded for the period
[b] Note that the survival figures for this group are not directly comparable, as child cancer survival includes non-malignant CNS tumours, which are not registered for AYA
[c] Five-year relative survival figures could not be calculated for this group because no patient was followed-up for the full five-year duration

4.6.3 AYA cancer survival 2000-2009 compared to 1988-2002

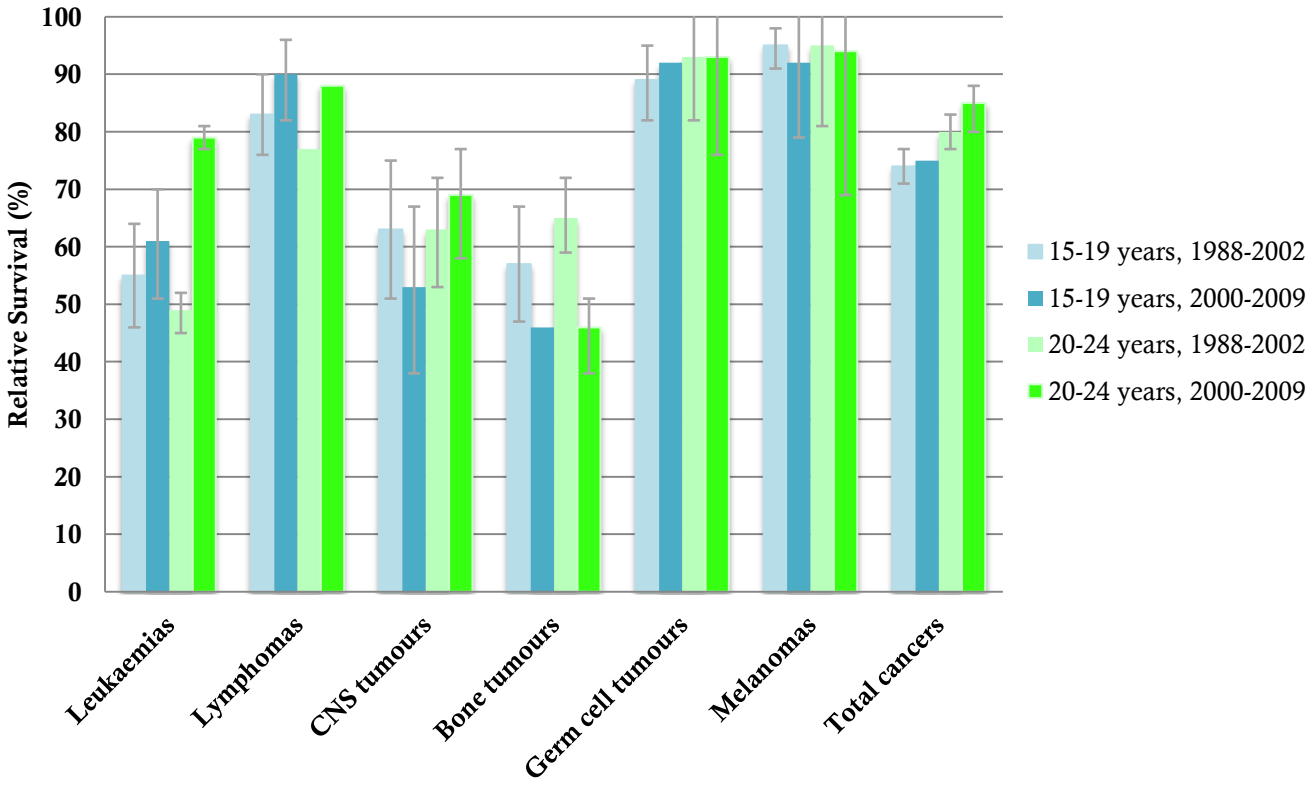
Overall cancer five-year relative survival for 15-19 year olds in 2000-2009 (75%) was similar to the five-year relative survival reported in 1988-2002 (74%) (see Table 4.6.3 and Figure 4.6). For young adults aged 20-24 years, cancer survival was 85%, an improvement on the 80% survival reported for 1988-2002. Of note, leukaemia survival for each study period was similar for 15-19 year olds (61% in 2000-2009 c.f. 55% in 1988-2002) but had improved significantly for those aged 20-24 years (79% c.f. 49% in 1988-2002). Non-Hodgkin lymphoma survival for 20-24 year olds also increased from 58% in 1988-2002, to 80% in 2000-2009. However, malignant bone tumour survival in 2000-2009 for 15-19 year olds (46%) and 20-24 year olds (46%) was lower than reported for 1988-2002 (57% and 65% respectively).

Table 4.6.3 AYA cancer five-year relative survival for selected ICCC-3 diagnostic groups and subgroups, New Zealand 1988-2002 and 2000-2009

	AYA 15-19 years 1988-2002[20]			AYA 15 -19 years 2000-2009			AYA 20-24 years 1988-2002[20]			AYA 20 -24 years 2000-2009		
	Total cases	Five-year relative survival[a] (%) (95% CI)		Total cases	Five-year relative survival[b] (%) (95% CI)		Total cases	Five-year relative survival[a] (%) (95% CI)		Total cases	Five-year relative survival[b] (%) (95% CI)	
I. Leukaemias	132	**55**	(46 - 64)	108	**61**	(51 - 70)	111	**49**	(39 - 58)	88	**79**	(68 - 87)
I(a) Acute lymphoid leukaemias	76	**53**	(41 - 64)	55	**58**	(42 - 70)	47	**41**	(26 - 55)	28	**74**	(52 - 87)
I(b) Acute myeloid leukaemias	42	**59**	(44 - 74)	36	**57**	(38 - 73)	45	**60**	(46 - 75)	41	**81**	(63 - 91)
II. Lymphomas	133	**83**	(76 - 89)	136	**90**	(82 - 95)	169	**77**	(71 - 84)	118	**88**	(80 - 93)
II(a) Hodgkin lymphomas	86	**93**	(87 - 99)	88	**97**	(86 - 99)	100	**87**	(81 - 94)	78	**93**	(82 - 97)
II(b) Non-Hodgkin lymphomas	33	[c]	[c]	33	**76**	(55 - 88)	54	**58**	(44 - 71)	35	**80**	(62 - 90)
III. CNS tumours	66	**63**	(51 - 75)	49	**53**	(38 - 67)	80	**63**	(52 - 74)	44	**69**	(52 - 81)
III(b) Astrocytomas	38	**58**	(41 - 74)	15	**57**	(27 - 78)	49	**56**	(41 - 70)	25	**67**	(44 - 82)
VIII. Malignant bone tumours	93	**57**	(47 - 67)	64	**46**	(33 - 59)	46	**65**	(51 - 79)	15	**46**	(21 - 69)
X. Germ cell tumours	111	**89**	(82 - 95)	98	**92**	(84 - 97)	270	**93**	(90 - 96)	171	**93**	(88 - 96)
XI. Other epithelial neoplasms	232	[c]	[c]	164	**88**	(82 - 92)	689	[c]	[c]	400	**88**	(85 - 91)
XI(d) Malignant melanoma	160	**95**	(91 - 98)	93	**92**	(84 - 96)	433	**95**	(92 - 97)	209	**94**	(90 - 97)
Total cancers diagnosed	**875**	**74**	**(71 - 77)**	**687**	**75**	**(71 - 78)**	**1512**	**80**	**(78 - 82)**	**909**	**85**	**(82 - 87)**

[a] Follow up to 30 June 2005. Survival and 95% CI were rounded to the nearest percent.
[b] Follow up to December 31 2010. Survival and 95% CI were rounded to the nearest percent.
[c] Survival for some diagnostic groups and subgroups were not reported. Note that survival for AYA diagnosed with soft tissue sarcomas (diagnostic group IX) were also unreported due to the small number of cases diagnosed between 1988 and 2002.

Figure 4.6 AYA five-year cancer survival for selected ICCC diagnostic groups (including 95% CI), New Zealand 1988-2002 and 2000-2009



4.6.4 AYA cancer survival international comparisons

There are few cancer registry publications that specifically report AYA cancer survival, and of those that do use a variety of age definitions for AYA (e.g. 13-24 years, 15-29 years) making it difficult to establish how well New Zealand AYA survival compares internationally. Table 4.6.4 compares New Zealand cancer survival for 15-19 year olds with the five-year survival reported from other countries for a similar time period: the United States (SEER), the United Kingdom, and Canada. However, any differences in the survival reported should be interpreted extremely cautiously due to the different statistical methods used and the small overall number of cases for many of the diagnostic groups/subgroups.

New Zealand's overall five-year relative survival for those aged 15-19 years (75%) was lower than that reported by SEER (82%), and Canada (81%). The 7% gap between New Zealand's five-year survival for 15-19 year olds and North America's represents approximately five additional cancer deaths in the New Zealand adolescent population each year. Survival was comparable for lymphomas, germ cell tumours, and 'other epithelial neoplasms'. However, the survival reported by SEER (63%), the United Kingdom (57%) and Canada (61%) was notably higher than New Zealand survival for those adolescents diagnosed with malignant bone tumours (46%).

Five-year relative survival for 'ICCC-3 diagnostic group IX: soft tissue sarcomas' was poorer for New Zealand adolescents (56%) compared to Canada (75%) and SEER (68%). It also appears that there is room for improvement in New Zealand's five-year survival for acute lymphoblastic leukaemia (58%) when compared with Canada and SEER's reported survival of 69%. Although New Zealand's CNS tumour survival may be lower than other countries due to the exclusion of non-malignant CNS tumours, the survival of 53% was still

significantly lower than the 76% survival reported by SEER, which had also included malignant CNS tumours only.

The 23 European countries which contribute cancer registry data to the EUROCARE consortium reported a population-weighted five-year survival of 87.4% for AYA aged **15-24** years diagnosed in 2000-2002[17], which was significantly higher than the 80.6% survival we have reported New Zealand AYA diagnosed in 2000-2009. AYA overall cancer five-year survival for individual countries ranged from 84.7% in Malta to 92.4% in Iceland. Survival by ICCC was only available for selected diagnostic groups. Of those survival figures reported, most were comparable to New Zealand AYA survival. However, there was a noteworthy difference between the 48.0% survival reported by the EUROCARE for 'ICCC-3 Group VIII(c): Ewing tumours' and the 28.6% for New Zealand AYA.

Table 4.6.4 Five-year cancer survival for adolescents (15-19 years) in selected countries, by ICCC-3

	New Zealand Total 15-19 years 2000-2009		SEER 2002-2008[18]	United Kingdom 2001-2005[23]		Canada 1999-2003[13]	
	Five-year relative survival (%)[a] (95% CI)		Five-year relative survival (%)[a]	Five-year relative survival (%)[a] (95% CI)		Five-year observed survival (%)[a] (95% CI)	
I. Leukaemias	**61**	(51 - 70)	**65**	[b]	[b]	**59**	(52 - 66)
I(a) Acute lymphoid leukaemias	**58**	(42 - 70)	**69**	**65**	(59 - 71)	**69**	(59 - 77)
I(b) Acute myeloid leukaemias	**57**	(38 - 73)	**52**	**58**	(48 - 66)	**41**	(28 - 53)
II. Lymphomas	**90**	(82 - 95)	**90**	[b]	[b]	**87**	(84 - 90)
II(a) Hodgkin lymphomas	**97**	(86 - 99)	**96**	**93**	(90 - 95)	**94**	(90 - 96)
II(b) Non-Hodgkin lymphomas (excl. Burkitt lymphoma)[c]	**76**	(55 - 88)	**80**	**82**	(77 - 86)	**76**	(66 - 83)
III. CNS tumours[d]	**53**	(38 - 67)	**76**	**81**	(78 - 84)	**77**	(71 - 83)
VIII. Malignant bone tumours	**46**	(33 - 59)	**63**	**57**	(51 - 63)	**61**	(51 - 69)
VIII(a) Osteosarcomas	**51**	(34 - 67)	**61**	[b]	[b]	**53**	(39 - 64)
VIII(c) Ewing tumours	**28**	(9 - 52)	**55**	[b]	[b]	**58**	(40 - 73)
IX. Soft tissue sarcomas	**56**	(41 - 68)	**68**	**59**	(51 - 66)	**75**	(66 - 82)
IX(a) Rhabdomyosarcomas	**22**	(4 - 50)	**49**	[b]	[b]	**42**	(20 - 62)
X. Germ cell tumours	**92**	(84 - 97)	**92**	[b]	[b]	**88**	(83 - 91)
XI. Other epithelial neoplasms	**88**	(82 - 92)	**92**	[b]	[b]	**93**	(89 - 95)
XI(b) Thyroid carcinoma	**100**	[e]	**99**	**100**	[e]	[b]	[b]
XI(d) Malignant Melanoma	**92**	(84 - 96)	**96**	**93**	(89 - 95)	**97**	(91 - 99)
TOTAL Cancers Diagnosed	**75**	**(71 - 78)**	**82**	[b]	[b]	**81**	**(79 - 83)**

[a] Survival and 95% CIs were rounded to nearest percent
[b] Survival was not reported for this diagnostic group/subgroup
[c] UK data includes Burkitt lymphoma
[d] NZ and SEER data excludes non-malignant CNS tumours, Canadian and UK data includes non-malignant CNS tumours
[e] Confidence intervals cannot be calculated in instances where there were either no deaths or no survivors within the period

5 Cervical Intraepithelial Neoplasia, Grade III (CIN III)

The dataset provided by the NZCR of 15-24 year olds registered between January 1 2000 and December 31 2009 included 6772 cases. However, the NZCR routinely registers in situ neoplasms (ICD-O behaviour code '2'). In this time period 5166 of cases recorded on the NZCR were not a primary malignant neoplasm, including 4840 cases of cervical intraepithelial neoplasia, grade III (CIN III) amongst 15-24 year olds (and an additional 3 recorded cases amongst young adolescents aged 12-14 years). Following the international standard for cancer reporting, all in situ cancers were excluded from the main analyses. However, given the high incidence of CIN III amongst the AYA female population, a brief overall summary of CIN-III diagnoses by age and ethnicity has been provided below.

Figure 5 shows the rapid increase in number of CIN III cases diagnosed from adolescence to early adulthood. Table 5 shows that of the 4843 cases of CIN III diagnosed between 2000 and 2009, 19.4% of CIN-III cases were diagnosed in those of Maori descent, which was consistent with the proportion of Maori in the AYA population (19.2%). However, only 1.8% were diagnosed in Pacific Peoples (this group makes up approximately 7.5% of the AYA population) and 1.6% in Asian (which accounts for approximately 11.6% of the AYA population). In contrast, the European population were overrepresented; 72% of all CIN-III cases were diagnosed in this ethnic group (Europeans account for approximately 56.5% of the AYA population).

Figure 5 AYA CIN III reported to the NZCR 2000-2009 by age at diagnosis

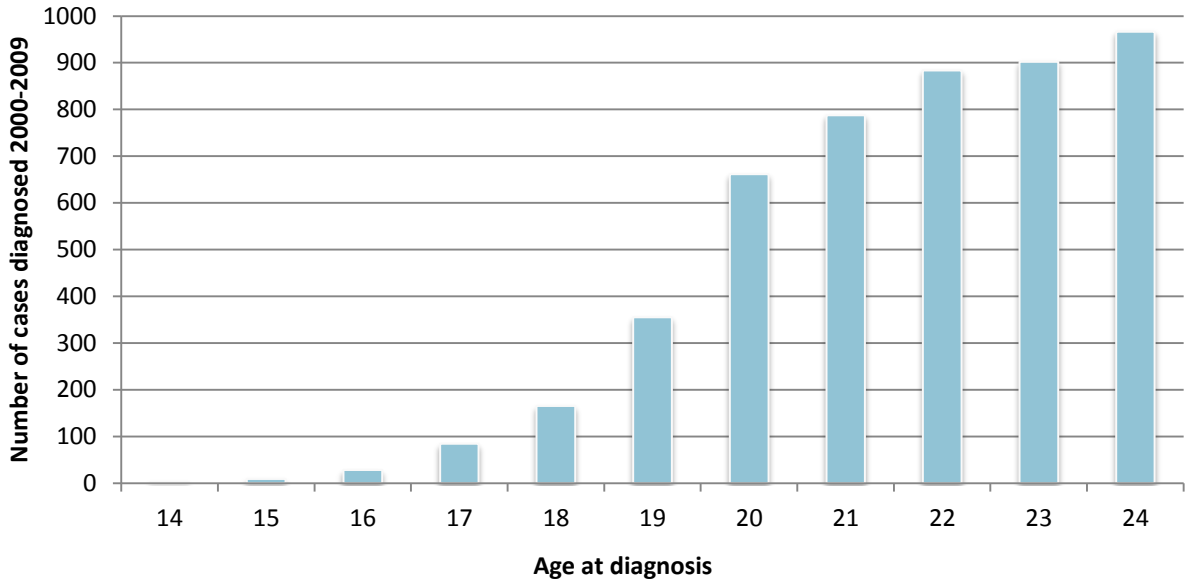


Table 5 AYA CIN III cases by prioritised ethnicity

	Prioritised Ethnicity						Total
	Maori	Pacific Peoples	Asian	All Other Specified	Not specified	European	
12 - 14 years	2	-	-	-	-	1	3
15 - 19 years	160	19	4	1	22	435	641
20 - 24 years	778	68	74	13	214	3 052	4 199
TOTAL	**940**	**87**	**78**	**14**	**236**	**3 488**	**4 843**
Total % of all cases	**19.4**	**1.8**	**1.6**	**0.3**	**4.9**	**72.0**	**100**

References

[1] Bleyer, A., & Barr, R. (2006). Highlights and Challenges. In A. Bleyer, M. O'Leary, R. Barr, & L. Ries (Eds), *Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, Including SEER Incidence and Survival: 1975-2000*. National Cancer Institute, NIH Pub. No. 06-5767. Bethesda, MD.

[2] Pollock, B., & Birch, J. (2008). Registration and classification of adolescent and young adult cancer cases. *Paediatric Blood and Cancer, 50,* 1090-1093.

[3] De, P., Ellison, L., Barr, R., Semenciw, R., Marrett, L., Weir, H., Dryer, D., & Grunfeld, E. (2011). Canadian adolescents and young adults with cancer: opportunity to improve coordination and level of care. *CMAJ, 183* (3), e187-e194.

[4] Barr, R. (2011). Adolescents, young adults, and cancer – the international challenge. *Cancer, 117,* 2245-2259.

[5] Barr, R. (2007). Common cancers in adolescents. *Cancer Treatment Reviews, 33,* 597-602.

[6] Stiller, C. (2007). International patterns of cancer incidence in adolescents. *Cancer Treatment Reviews, 22,* 631-645.

[7] Ministry of Health (2009). *Coordination of the adolescent/young adult cancer service, service specification tier level three.* Ministry of Health: Wellington.

[8] Steliarova-Foucher, E., Stiller, C., Lacour, B., & Kaatsch, P. (2005) International classification of childhood cancer, third edition. *Cancer*, *103*(7) 1457-1467.

[9] Barr, R., Holowaty, E., & Birch, J. (2006). Classification schemes for tumors diagnosed in adolescents and young adults. *Cancer, 107*(7), 1425-1430.

[10] Birch, J., & Marsden, H. (1987). A classification scheme for childhood cancer. *International Journal of Cancer, 40,* 620-624.

[11] Parkin, D., Stiller, C., Draper, G., Bieber, C., Terracini, B., & Young, J. (eds.) (1988). *International incidence of childhood cancer.* IARC scientific publication no 87. Lyon: International Agency for Research on Cancer.

[12] Li, J., Thompsom, T., Miller, J., Pollack, L., Stewart, S. (2008). Cancer incidence among children and adolescents in the United States, 2001-2003. *Pediatrics, 121,* e1470-1477.

[13] Ellison, L., Pogany, L., Mery, L. (2007). Childhood and adolescent cancer survival: A period analysis of data from the Canadian Cancer Registry. *European Journal of Cancer, 43,* 1967-1975.

[14] Fritz, A., Percy, C., Jack, A., Shanmugarathnam, K., Sobin, L., Parkin, D., & Whelan, S., eds. (2000) *International Classification of Diseases for Oncology. 3rd edition.* Geneva: World Health Organization.

[15] Furlong, W., Rae, C., Greenberg, M., & Barr, R. (2012). Surveillance and survival among adolescents and young adults in Ontario, Canada. *International Journal of Cancer.* Doi: 10.1002/ijc.27523

[16] Alston, R., Geraci, M., Eden, T., Moran, A., Rowan, S., & Birch, J. (2007). Changes in cancer incidence in teenagers and young adults (ages 13 to 24 years) in England 1979-2003. *Cancer, 113*(10), 2807-2815

[17] Gatta, G., Zigon, G., Capocaccia, R., Coebergh, J., Desandes, E., Kaatsch, P., Pastore, G., Peris-Bonet, R., Stiller, C. the EUROCARE Working Group (2009). Survival of European children and young adults with cancer diagnosed 1995-2002. *European Journal of Cancer, 45,* 992-1005

[18] Howlader N, Noone AM, Krapcho M, Neyman N, Aminou R, Altekruse SF, Kosary CL, Ruhl J, Tatalovich Z, Cho H, Mariotto A, Eisner MP, Lewis DR, Chen HS, Feuer EJ, Cronin KA (eds). (2012*) SEER Cancer Statistics Review, 1975-2009* (Vintage 2009 Populations), National Cancer Institute. Bethesda, MD,

http://seer.cancer.gov/csr/1975_2009_pops09/, based on November 2011 SEER data submission, posted to the SEER web site, April 2012.0000000

[19] NCCH. (2000). *The International Statistical Classification of Diseases and Related Health Problems* (10th revision, Australian modification, 2nd edition). Sydney: National Centre for Classification in Health.

[20] William's G. (2006). *Cancer among New Zealand adolescents and young people 1988-2002: An occasional paper.* Wellington: Ministry of Health

[21] Ministry of Health (2004). *Ethnicity data protocols for the health and disability sector.* Wellington: Ministry of Health

[22] Cancer Research UK (2013). *Cancer statistics data table: teenage and young adult cancer incidence, UK, 2000-2009.* Retrieved from: publications.cancerresearchuk.org/downloads/Product/CS_DT_TYA.pdf.

[23] O'Hara, C., Moran, A., & the TYA National Cancer Intelligence Advisory Group (2012). *Survival in teenagers and young adults (TYA) with cancer in the UK.* National Health Service. Retrieved from: http://www.ncin.org.uk/publications/reports/survival_in_teenagers_and_young_adults_with_cancer_in_the_uk

Appendix

A1 Abbreviations

AYA	Adolescents and Young Adults
CI	Confidence interval
CIN III	Cervical intraepithelial neoplasia, grade III
CNS	Central Nervous System
COG	Children's Oncology Group
IARC	International Agency for Research on Cancer
ICCC-3	International Classification of Childhood Cancer, Third revision
ICD-10	International Statistical Classification of Diseases and Related Health Problems, Tenth revision
ICD-O-3	International Statistical Classification of Diseases for Oncology, Third edition
NCCN	National Child Cancer Network
NZCCR	New Zealand Children's Cancer Registry
NZCR	New Zealand Cancer Registry
MOH	Ministry of Health
PNET	Peripheral Neuro Ectodermal Tumours
RR	Relative risk
SEER	Surveillance, Epidemiology and End Results (U.S. Cancer Statistics)
TYA	Teenagers and Young Adults
WHO	World Health Organisation

A.2 AYA cancer classification scheme based on ICD-O-3 Site & Histology[12]

Diagnostic Group / Subgroup	ICD-O-3 Histology	ICD-O-3 Site
1 Leukemias		
1.1 Acute lymphoid leukemia	C000-C809	9826-9827, 9835-9837
1.2 Acute myeloid leukemia	C000-C809	9840, 9861, 9866-9867, 9871-9874, 9891, 9895-9897, 9910, 9920
1.3 Chronic myeloid leukemia	C000-C809	9863, 9875-9876
1.4 Other and unspecified leukemia	C000-C809	9742, 9800-9801, 9805, 9820, 9823, 9831-9834, 9860, 9870, 9930-9931, 9940, 9945-9946, 9948, 9963-9964
2 Lymphomas		
2.1 Non-Hodgkin lymphoma	C000-C809	9590-9591, 9596, 9670-9671, 9673, 9675, 9678-9680, 9684, 9687, 9689-9691, 9695, 9698-9702, 9705, 9708-9709, 9714, 9716-9719, 9727-9729
2.2 Hodgkin lymphoma	C000-C809	9650-9655, 9659, 9661-9665, 9667
3 CNS and Other Intracranial and Intraspinal Neoplasms (all behaviors)		
3.1. Astrocytoma		
3.1.1 Specified low-grade astrocytic tumors	C723	9380
	C000-C809	9410-9411, 9420-9421, 9424
3.1.2 Glioblastoma and anaplastic astrocytoma	C000-C809	9401, 9440-9442
3.1.3 Astrocytoma, NOS	C000-C809	9400
3.2 Other glioma	C000-C722, C724-C809	9380
	C000-C809	9381-9384, 9423, 9430, 9450-9451, 9460
3.3 Ependymoma	C000-C809	9391-9394
3.4. Medulloblastoma and other PNET		
3.4.1 Medulloblastoma	C716	9470-9474
3.4.2 Supratentorial PNET	C000-C715, C717-C809	9470-9474
3.5 Other specified intracranial and intraspinal neoplasms	C000-C699, C730-C750, C754-C809	9350-9351, 9360-9362, 9390, 9480, 9530-9535, 9537-9539, 9541, 9550, 9562, 9570
	C700-C729, C751-C753	9161, 9361-9362, 9390, 9530-9531, 9535, 9538, 9540, 9560, 9571
	C700	9532, 9534, 9537, 9539
	C753	9360
	C711	9480, 9539
	C713	9480, 9533
	C719	9350
	C714,C717	9480
	C709	9539
3.6 Unspecified intracranial and intraspinal neoplasms		
3.6.1 Unspecified malignant intracranial and intraspinal neoplasms	C700-C729, C751-C753	8000-8005
3.6.2 Unspecified benign/borderline intracranial and intraspinal neoplasms	C700-C729, C751-C753	8000-8005
4 Osseous & Chondromatous Neoplasms		
4.1 Osteosarcoma	C000-C809	9180-9187, 9192-9194
4.2 Chondrosarcoma	C000-C809	9220-9221, 9230-9231, 9240, 9242-9243
4.3 Ewing tumor	C000-C809	9260, 9364-9365
4.4 Other specified and unspecified bone tumors	C000-C809	8812, 9250, 9261, 9370-9372
	C400-C419	8000-8005, 8800-8803, 8805-8806, 9200

Diagnostic Group / Subgroup	ICD-O-3 Histology	ICD-O-3 Site
5 Soft Tissue Sarcomas		
5.1 Fibromatous neoplasms	C000-C809	8810-8811, 8813-8815, 8820-8824, 8830, 8832-8833, 8835-8836, 9252
5.2 Rhabdomyosarcoma	C000-C809	8900-8904, 8910, 8912, 8920-8921, 8991
5.3 Other soft tissue sarcoma		
5.3.1 Specified soft tissue sarcoma		
5.3.1.1 Specified (excluding Kaposi sarcoma)	C000-C809	8804, 8825, 8840-8897, 8982-8983, 8990, 9040-9044, 9120-9139, 9141-9150, 9170, 9251, 9561, 9580-9581, 9970
	C000-C699, C730-C750, C754-C809	9540, 9560, 9571
5.3.1.2 Kaposi sarcoma	C000-C809	9140
5.3.2 Unspecified soft tissue sarcoma	C000-C399, C420-C809	8800-8803, 8805-8806
6 Germ Cell and Trophoblastic Neoplasms		
6.1 Germ cell and trophoblastic neoplasms of gonads	C569,C620-C629	9060-9065, 9070-9073, 9080-9085, 9090-9091, 9100-9102, 9105
6.2 Germ cell and trophoblastic neoplasms of non-gonadal sites		
6.2.1 Intracranial (all behaviors)	C700-C729, C751-C753	9060-9065, 9070-9073, 9080-9085, 9090-9091, 9100-9102, 9105
6.2.2 Other non-gonadal	C000-C568, C570-C619, C630-C699, C730-C750, C754-C809	9060-9065, 9070-9073, 9080-9085, 9090-9091, 9100-9102, 9104-9105
7 Melanoma and Skin Carcinomas		
7.1 Melanoma	C000-C809	8720-8723, 8726, 8728, 8730, 8740-8746, 8761, 8770-8774, 8780
7.2 Skin carcinomas	C440-C449	8010-8589
8 Carcinomas		
8.1 Thyroid carcinoma	C739	8010-8589
8.2 Other carcinoma of head and neck		
8.2.1 Nasopharyngeal carcinoma	C110-C119	8010-8589
8.2.2 Other sites in lip, oral cavity and pharynx	C000-C109, C120-C148	8010-8589
8.2.3 Nasal cav,mid ear,sinuses,larynx,oth ill-def head/neck	C300-C329, C760	8010-8589
8.3 Carcinoma of trachea,bronchus, and lung	C330-C349	8010-8589
8.4 Carcinoma of breast	C500-C509	8010-8589
8.5 Carcinoma of genitourinary tract		
8.5.1 Carcinoma of kidney	C649	8010-8589
8.5.2 Carcinoma of bladder	C670-C679	8010-8589
8.5.3 Carcinoma of gonads	C569,C620-C629	8010-8589
	C000-C809	8590-8593
8.5.4 Carcinoma of cervix and uterus	C530-C559	8010-8589
8.5.5 Carc of other and ill-def sites, geniourinary tract	C510-C529, C570-C579, C600-C619, C630-C639, C659,C669, C680-C689	8010-8589

Diagnostic Group / Subgroup	ICD-O-3 Histology	ICD-O-3 Site
8.6 Carcinoma of gastrointestinal tract		
8.6.1 Carcinoma of colon and rectum	C180-C218	8010-8589
8.6.2 Carcinoma of stomach	C160-C169	8010-8589
8.6.3 Carcinoma of liver and intrahepatic bile ducts	C220-C221	8010-8589
8.6.4 Carcinoma of pancreas	C250-C259	8010-8589
8.6.5 Carcinoma other and ill-def sites, gastrointestinal tract	C150-C159, C170-C179, C230-C249, C260-C269	8010-8589
8.7 Carcinoma of other and ill-def sites		
8.7.1 Adrenocortical carcinoma	C740-C749	8010-8589
8.7.2 Carcinoma of other and ill-defined sites, NOS	C149,C219, C222-C229, C270-C299, C350-C439, C450-C499, C561-C568, C580-C599, C640-C648, C650-C658, C660-C668, C690-C738, C750-C759, C761-C809	8010-8589
	C809	9010
9 Miscellaneous specified neoplasms, NOS		
9.1 Other pediatric and embryonal tumors, NOS		
9.1.1 Wilms tumor	C000-C809	8959-8960
9.1.2 Neuroblastoma	C000-C809	9490, 9500
9.1.3 Other pediatric and embryonal tumors, NOS	C000-C809	8963-8964, 8970-8973, 8981, 9363, 9501-9523
9.2 Other specified and embryonal tumors, NOS		
9.2.1 Paraganglioma and glomus tumors	C000-C809	8680-8711
9.2.2 Other specified gonadal tumors	C000-C809	8600-8650, 9000
	C569	8670, 9013-9015, 9054
9.2.3 Myeloma, mast cell, misc. lymphoreticular neo., NOS	C000-C809	9731-9741, 9743-9764, 9766, 9769, 9960
9.2.4 Other specified neoplasms, NOS	C000-C809	8930-8951, 8980, 9020, 9050-9053, 9110, 9160, 9270-9330, 9950, 9962, 9980, 9982
	C421	9961, 9975, 9989
	C000-C699, C730-C750, C754-C809	9161
10 Unspecified Malignant Neoplasms	C000-C399, C420-C699, C730-C750, C754-C809	8000-8005
Unclassified		

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A.3 International Classification of Childhood Cancer, Third Edition (ICCC-3)[8]

Diagnostic Group / Subgroup	ICD-O-3 Histology	ICD-O-3 Site
I. Leukaemias, myeloproliferative diseases & myelodysplastic diseases		
(a) Lymphoid leukaemias	9820, 9823, 9826, 9827, 9831-9837, 9940, 9948	C000-C809
(b) Acute myeloid leukaemias	9840, 9861, 9866, 9867, 9870-9874, 9891, 9895-9897, 9910, 9920, 9931	C000-C809
(c) Chronic myeloproliferative diseases	9863, 9875, 9876, 9950, 9960-9964	C000-C809
(d) Myelodysplastic syndrome and other myeloproliferative diseases	9945, 9946, 9975, 9980, 9982-9987, 9989	C000-C809
(e) Unspecified and other specified leukaemias	9800, 9801, 9805, 9860, 9930	C000-C809
II. Lymphomas and reticuloendothelial neoplasms		
(a) Hodgkin lymphomas	9650-9655, 9659, 9661-9665, 9667	C000-C809
(b) Non-Hodgkin lymphomas (except Burkitt lymphoma)	9591, 9670, 9671, 9673, 9675, 9678-9680, 9684, 9689-9691, 9695, 9698-9702, 9705, 9708, 9709, 9714, 9716-9719, 9727-9729, 9731-9734, 9760-9762, 9764-9769, 9970	C000-C809
(c) Burkitt lymphoma	9687	C000-C809
(d) Miscellaneous lymphoreticular neoplasms	9740-9742, 9750, 9754-9758	C000-C809
(e) Unspecified lymphomas	9590, 9596	C000-C809
III. Central Nervous System and miscellaneous intracranial and intraspinal neoplasms		
(a) Ependymomas and choroid plexus tumor	9383, 9390-9394	C000-C809
(b) Astrocytomas	9380	C723
	9384, 9400-9411, 9420, 9421-9424, 9440-9442	C000-C809
(c) Intracranial and intraspinal embryonal tumors	9470-9474, 9480, 9508	C000-C809
	9501-9504	C700-C729
(d) Other gliomas	9380	C700-C722, C724-C729, C751, C753
	9381, 9382, 9430, 9444, 9450, 9451, 9460	C000-C809
(e) Other specified intracranial and intraspinal neoplasms	8270-8281, 8300, 9350-9352, 9360-9362, 9412, 9413, 9492, 9493, 9505-9507, 9530-9539, 9582	C000-C809
(f) Unspecified intracranial and intraspinal neoplasms	8000-8005	C700-C729, C751-C753
IV. Neuroblastoma and other peripheral nervous cell tumours		
(a) Neuroblastoma and ganglioneuroblastoma	9490, 9500	C000-C809
(b) Other peripheral nervous cell tumours	8680-8683, 8690-8693, 8700, 9520-9523	C000-C809
	9501-9504	C000-C699, C739-C768, C809
V. Retinoblastoma	9510-9514	C000-C809
VI. Renal tumours		
(a) Nephroblastoma and other non-epithelial renal tumours	8959, 8960, 8964-8967	C000-C809
	8963, 9364	C649
(b) Renal carcinomas	8010-8041, 8050-8075, 8082, 8120-8122, 8130-8141, 8143, 8155, 8190-8201, 8210, 8211, 8221-8231, 8240, 8241, 8244-8246, 8260-8263, 8290, 8310, 8320, 8323, 8401, 8430, 8440, 8480-8490, 8504, 8510, 8550, 8560-8576	C649
	8311, 8312, 8316-8319, 8361	C000-C809
(c) Unspecified malignant renal tumours	8000-8005	C649

Diagnostic Group / Subgroup	ICD-O-3 Histology	ICD-O-3 Site
VII. Hepatic tumours		
(a) Hepatoblastoma	8970	C000-C809
(b) Hepatic carcinomas	8010-8041, 8050-8075, 8082, 8120-8122, 8140, 8141, 8143, 8155, 8190-8201, 8210, 8211, 8230, 8231, 8240, 8241, 8244-8246, 8260-8264, 8310, 8320, 8323, 8401, 8430, 8440, 8480-8490, 8504, 8510, 8550, 8560-8576	C220, C221
	8160-8180	C000-C809
(c) Unspecified malignant hepatic tumours	8000-8005	C220, C221
VIII. Malignant bone tumours		
(a) Osteosarcomas	9180-9187, 9191-9195, 9200	C400-C419, C760-C768, C809
(b) Chondrosarcomas	9210, 9220, 9240	C400-C419, C760-C768, C809
	9221, 9230, 9241-9243	C000-C809
(c) Ewing tumour and related sarcomas of bone	9260	C400-C419, C760-C768, C809
	9363-9365	C400-C419
(d) Other specified malignant bone tumours	8810, 8811, 8823, 8830	C400-C419
	8812, 9250, 9261, 9262, 9270-9275, 9280-9282, 9290, 9300-9302, 9310-9312, 9320-9322, 9330, 9340-9342, 9370-9372	C000-C809
(e) Unspecified malignant bone tumours	8000-8005, 8800, 8801, 8803-8805	C400-C419
IX. Soft tissue & other extraosseous sarcomas		
(a) Rhabdomyosarcomas	8900-8905, 8910, 8912, 8920, 8991	C000-C809
(b) Fibrosarcomas, peripheral nerve sheath tumours, and other fibrous neoplasms	8810, 8811, 8813-8815, 8821, 8823, 8834-8835	C000-C399, C440-C768, C809
	8820, 8822, 8824-8827, 9150, 9160, 9491, 9540-9571, 9580	C000-C809
(c) Kaposi sarcoma	9140	C000-C809
(d) Other specified soft tissue sarcomas	8587, 8710-8713, 8806, 8831-8833, 8836, 8840-8842, 8850-8858, 8860-8862, 8870, 8880, 8881, 8890-8898, 8921, 8982, 8990, 9040-9044, 9120-9125, 9130-9133, 9135, 9136, 9141, 9142, 9161, 9170-9175, 9231, 9251, 9252, 9373, 9581	C000-C809
	8830	C000-C399, C440-C768, C809
	8963	C000-C639, C659-C699, C739-C768, C809
	9180, 9210, 9220, 9240	C490-C499
	9260	C000-C399, C470-C759
	9364	C000-C399, C470-C639, C659-C699, C739-C768, C809
	9365	C000-C399, C470-C639, C659-C768, C809
(e) Unspecified soft tissue sarcomas	8800-8805	C000-C399, C440-C768, C809

Diagnostic Group / Subgroup	ICD-O-3 Histology	ICD-O-3 Site
X. Germ cell tumours, trophoblastic tumours, and neoplasms of gonads		
(a) Intracranial and intraspinal germ cell tumours	9060-9065, 9070-9072, 9080-9085, 9100, 9101	C700-C729, C751-C753
(b) Malignant extracranial and extragonadal germ cell tumours	9060-9065, 9070-9072, 9080-9085, 9100-9105	C000-C559, C570-C619, C630-C699, C739-C750, C754-C768, C809
(c) Malignant gonadal germ cell tumours	9060-9065, 9070-9073, 9080-9085, 9090, 9091, 9100, 9101	C569, C620-C629
(d) Gonadal carcinomas	8010-8041, 8050-8075, 8082, 8120-8122, 8130-8141, 8143, 8190-8201, 8210, 8211, 8221-8241, 8244-8246, 8260-8263, 8290, 8310, 8313, 8320, 8323, 8380-8384, 8430, 8440, 8480-8490, 8504, 8510, 8550, 8560-8573, 9000, 9014, 9015	C569, C620-C629
	8441-8444, 8450, 8451, 8460-8473	C000-C809
(e) Other and unspecified malignant gonadal tumours	8590-8671	C000-C809
	8000-8005	C569, C620-C629
XI. Other malignant epithelial neoplasms and malignant melanomas		
(a) Adrenocortical carcinomas	8370-8375	C000-C809
(b) Thyroid carcinomas	8010-8041, 8050-8075, 8082, 8120-8122, 8130-8141, 8190, 8200, 8201, 8211, 8230, 8231, 8244-8246, 8260-8263, 8290, 8310, 8320, 8323, 8430, 8440, 8480, 8481, 8510, 8560-8573	C739
	8330-8337, 8340-8347, 8350	C000-C809
(c) Nasopharyngeal carcinomas	8010-8041, 8050-8075, 8082, 8083, 8120-8122, 8130-8141, 8190, 8200, 8201, 8211, 8230, 8231, 8244-8246, 8260-8263, 8290, 8310, 8320, 8323, 8430, 8440, 8480, 8481, 8500-8576	C110-C119
(d) Malignant melanomas	8720-8780, 8790	C000-C809
(e) Skin carcinomas	8010-8041, 8050-8075, 8078, 8082, 8090-8110, 8140, 8143, 8147, 8190, 8200, 8240, 8246, 8247, 8260, 8310, 8320, 8323, 8390-8420, 8430, 8480, 8542, 8560, 8570-8573, 8940, 8941	C440-C449
(f) Other and unspecified carcinomas	8010-8084, 8120-8157, 8190-8264, 8290, 8310, 8313-8315, 8320-8325, 8360, 8380-8384, 8430-8440, 8452-8454, 8480-8586, 8588-8589, 8940, 8941, 8983, 9000, 9010-9016, 9020, 9030	C000-C109, C129-C218, C239-C399, C480-C488, C500-C559, C570-C619, C630-C639, C659-C729, C750-C768, C809
XII. Other and unspecified malignant neoplasms		
(a) Other specified malignant tumours	8930-8936, 8950, 8951, 8971-8981, 9050-9055, 9110	C000-C809
	9363	C000-C399, C470-C759
(b) Other unspecified malignant tumours	8000-8005	C000-C218, C239-C399, C420-C559, C570-C619, C630-C639, C659-C699, C739-C750, C754-C809

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