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Childhood cancer survival in Aotearoa, New Zealand 2010 – 2019

A report on behalf of the New Zealand Child Cancer Registry Working Group

New Zealand Children's Cancer Registry Working Group

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TE AHO O TE KAHU CANCER CONTROL AGENCY

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Appendices & Supplementary Files

Lay summary

What does the data tell us about childhood cancer survival in Aotearoa, New Zealand?

1. **More than eight out of ten children diagnosed with cancer in New Zealand will survive at least 5 years**.
   Overall, 85.5% of children diagnosed with cancer between 2010 and 2019 survived for at least 5-years. This means that childhood cancer outcomes in Aotearoa, New Zealand are on-par with other high-income countries such as Australia, the United Kingdom and the United States of America.

2. **Childhood cancer survival in Aotearoa, New Zealand has improved steadily over time**
   Thanks to clinical trials and better treatments, survival rates have improved for all types of childhood cancer in the past decade. The greatest improvements in survival were observed in central nervous system (CNS) tumours, neuroblastomas and soft tissue sarcomas. For some cancer types such as Hodgkin lymphoma, retinoblastoma, and renal tumours, 5-year cancer survival was over 90%.

3. **Patterns of poorer survival by cancer type, age and ethnicity deserve focused attention**
   Although childhood cancer survival rates are high and have increased over time, there are several cancer types that have poorer survival than others, notably CNS tumours, liver tumours and soft tissue sarcomas. Similarly, whilst improvements in survival have been observed for all ethnicity groups, the greatest gains were observed among non-Māori and Pacific peoples. The noteworthy survival gap between Māori, non-Māori and Pacific peoples should be acknowledged and warrants attention. This gap in survival between ethnicity groups was particularly pronounced among older children aged 10-14 years at diagnosis. Work is underway to understand in more detail factors which contribute towards this pattern and identify actions which could further improve Māori and Pacific child cancer outcomes.

Context

Cancer is rare among children but is one of the most common causes on non-accidental death among child in high-income countries. As advances in medicine occur there are more children surviving childhood cancer. Population-based studies of childhood cancer survival indicate whether childhood malignancies are being treated successfully and provide a 'benchmark' for paediatric oncology services.

In Aotearoa, New Zealand there are two specialist childhood cancer centres; the Starship Blood and Cancer Centre in Auckland and the Children's Haematology/Oncology Centre (CHOC) based in Christchurch Hospital. These specialist treatment centres work closely with Shared Cancer Centres (SCC's) to ensure that the diagnosis, management and follow-up of children with cancer and is safe, effective and delivered as close to the patient's home (i.e. locally) as possible. The National Child Cancer Network (NCCN) provides oversight of the arrangements between specialist treatment centres and share care centres to ensure a nationally consistent approach is taken.

NCCN upholds and honours its commitment to Te Tiriti o Waitangi, its principles, and its intentions. Consistent with the ngā uaratanga (values) of Te Aho o Te Kahu, Cancer Control Agency, NCCN is whānau centred, knowledge driven and outcomes focussed. NCCN recognizes the five principles of Te Tiriti o Waitangi as outlined within Waitangi Tribunal's Hauroa report (WAI2575) (25) as guiding principles:

- Tino Rangatiratanga: The principle of self-determination –the right for Māori to exercise self-determination and mana motuhake in the design, delivery and monitoring of child cancer services.
- Pātuitanga: The principle of partnership – NCCN is committed to working with Māori in a strong and enduring relationship.
- Mana Taurite: The principle of equity – NCCN is committed to ensuring equitable access to cancer care and outcomes.
- Whakamarumarutia: The principle of active protection – NCCN takes all reasonable actions to ensure Māori achieve equity and informs Māori of the impact of these actions.
- Kōwhiringa: The principle of options –NCCN is committed to ensuring that child cancer services are provided in a culturally appropriate way that recognises and supports the expression of te ao Māori worldviews.

With a specific focus upon enabling the delivery of high-quality care for all children with cancer regardless of who they are, and where they live, the notion of equity is central to the work of NCCN. NCCN seeks to protect Māori custom, cultural integrity and whanau structures, and reinforces Māori control over Māori wellbeing.

Purpose

The purpose of this report is to provide an updated analysis of childhood cancer survival in Aotearoa, New Zealand for the period 1st January 2010 to the 31st of December 2019, with follow-up to 31st of December 2021. In order to aid comparisons, the methodology replicates the previously published 2000-2009[1] and 2005-2014[2] reports wherever possible.

Sources of cancer data and classification schemes

Cancer and mortality data were obtained from the New Zealand Children's Cancer Registry (NZCCR) and New Zealand Cancer Registry (NZCR). The NZCCR is a national cancer registry held by NCCN, containing childhood cancer data provided by specialist paediatric oncology centres in Aotearoa, New Zealand. NZCR is a population based cancer registry which collects data on all malignant cancers diagnosed in Aotearoa, New Zealand. Pathological laboratory reports are the primary source of cancer data in NZCR, however a small number of registrations are received from death certificates, coroners' reports, and hospital discharge data included on the national minimum dataset (NMDS). Prior to analyses, data from both registries were cross-matched to verify and identify anomalies. The total number of cancer registrations included in the final survival analysis was 1522.

The International Association of Cancer Registries (IACR) and European Network of Cancer Registries (ENCR) definition of incidence date was adopted, whereby the date of the first event in the following order of precedence to occur chronologically was chosen as the incidence date; I. first histological or cytological confirmation of malignancy; II. date of admission to hospital because of malignancy; III. date of first consultation because of malignancy, and IV. date of diagnosis other than I, II, or III, or date of death because of malignancy.

All cancer data were coded according to the International Statistical Classification of Disease for Oncology, 3rd Edition (ICD-O-3)[4] and converted to the ICCC-3 classification scheme. In keeping with the ICCC-3 classification scheme, non-malignant intracranial and intraspinal tumours of benign or uncertain behaviour which are routinely registered in NZCCR, but not NZCR, were included in the analysis. In addition, despite the 2020 ICD-O-3.2 revision to change Langerhans Cell Histocytosis (LCH) to a non-malignant cancer (behaviour code /1), LCH cases were included within the analyses and are reported within ICCC-3 Group IId, Miscellaneous Lymphoreticular Neoplasms. Non-malignant haematological conditions, conditions not defined by ICCC-3 (e.g. in-situ carcinomas), second primary malignancies, and children from overseas who were diagnosed in Aotearoa, New Zealand were excluded from analysis. Patients diagnosed on the basis of autopsy or death certificate only, or where the date of death was the same as the date of diagnosis were excluded from the survival analysis.

Ethnicity was prioritised to Māori, Pacific Peoples, Asian, Middle Eastern/Latin American/African (MELAA), Other, and NZ European according to Ministry of Health data protocols.[4] In keeping with previous childhood cancer survival reports[1,2] individuals who identified as non-Māori (Asian, Middle Eastern/Latin American/African (MELAA), Other, and NZ European) were classified as one group.

Statistical Analysis

Cancer survival estimates are the percentages of patients who are still alive at a specified time after their cancer diagnosis. Observed overall survival was estimated using the Kaplan-Meier estimator to account for cases lost by censoring; this approach includes all patients are included in the analysis, not just those with at least 5-years of follow-up. The final study censoring date for follow-up was 31 December 2021 and the maximum length of follow-up time was 11-years. Survival estimates were produced for 1, 3, 5 and 10 year intervals for each ICCC-3 main group and ICCC-3 sub-group stratified by sex, (male, female), age group (0-4 years, 5-9 years and 10-14 years) and ethnicity (Māori, non-Māori and Pacific). Between group differences in survival were analysed using log rank tests and tested by the Chi-square test with 1 degree of freedom. Additional Cox proportional hazard models were fitted to analyse survival trends between prioritised ethnicity groups adjusted for age at diagnosis, sex and cancer type. A between group difference was defined as significant if the p-value was less than 0.05. Caution should be taken when interpreting these between-group comparisons as the small number of cases and deaths within age, sex and ethnicity sub-groups may mean some between group differences occur due to Type I statistical error. To avoid presenting data which is misleading, and to discourage misinterpretation of the data, relative standard error (RSE) values were also computed to provide a measure of reliability for all estimates of survival. An RSE value ≥30 indicates the survival rate is statistically unstable and therefore not a reliable prediction due to the limited case numbers. Case or death counts ≤5 are suppressed within tables. These approaches to handling small case numbers are in keeping with Stats NZ data standards[5] for confidentiality and Centres for Disease Control and Prevention (CDC) standards for reporting rates and proportions based on counts less than 10.[6]

Results

In total 1,522 childhood cancer cases (including CNS tumours of benign and uncertain behaviour) diagnosed in Aotearoa, New Zealand between 2010-2019 were included in the analyses.

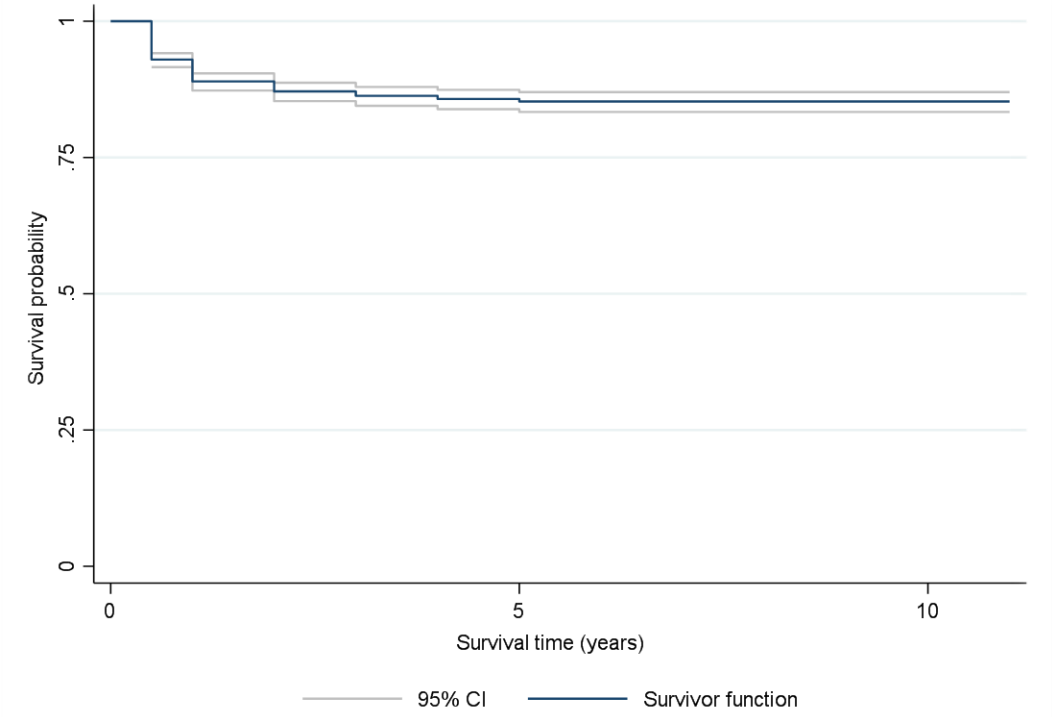
Overall childhood cancer survival

For all childhood cancers combined the observed survival rate was 92.9% (95% CI 91.5 – 94.1) at 1-year, 87.0% (95% CI 85.2 – 88.6) at 3-years and 85.5% (95% CI 83.6 -87.2) at 5-years **(Figure 1, Table 1).** In comparison to the previous period childhood cancer survival rates had significantly improved ($p<0.05$); the difference in 1-year survival was 1.6%, difference in 3-year survival was 2.5% and difference in 5-year survival was 2.6%. Refer to **Appendix A** for additional comparisons between periods of time.

Table 1. Observed 1-year, 3-year and 5-year survival by sex, age group and ethnicity

	Cases	1 year survival		3 year survival		5 year survival		Deaths
Sex	n	%	95% CI	%	95% CI	%	95% CI	n
Female	673	93.0	(90.8- 94.7)	86.6	(83.8 - 89.0)	85.9	(83.0 - 88.3)	97
Male	849	92.9	(90.9 - 94.4)	87.3	(84.8 - 89.3)	85.2	(82.6 - 87.5)	122
Age group								
0-4 years	716	91.5	(89.1 - 93.3)	86.3	(83.6 - 88.6)	85.3	(82.5 - 87.7)	104
5-9 years	396	93.4	(90.5 - 95.4)	88.2	(84.6 -91.0)	86.3	(82.4 - 89.4)	53
10-14 years	410	95.1	(92.5 - 96.8)	86.9	(83.2 - 89.8)	85.0	(81.1 - 88.2)	62
Ethnicity								
Māori	385	89.6	(86.1 - 92.2)	83.3	(79.2 - 86.7)	80.9	(76.5 - 84.6)	71
Pacific	160	91.8	(86.4 - 95.2)	84.2	(77.5 - 89.0)	82.6	(75.6 -87.7)	28
Non-Māori	977	94.4	(92.8 - 95.7)	88.9	(86.8 -90.7)	87.8	(85.6 - 89.7)	120
Overall	**1522**	**92.9**	**(91.5- 94.1)**	**87.0**	**(85.2 - 88.6)**	**85.5**	**(83.6 - 87.2)**	**219**

Figure 1. Observed survival for all childhood cancers diagnosed in New Zealand between 2010 and 2019



Observed childhood cancer survival by sex, age-group and ethnicity

Table 1 presents a summary of 1-year, 3-year and 5-year cancer survival by sex, age-group, and ethnicity.

Sex

There was no significant difference in survival between males and females (85.2% vs 85.9% 5-year survival respectively). Compared to the period 2005-2014 5-year survival for both males and females had increased by 2.1% and 3% respectively **(Appendix A, Table I.c).**

Age

Observed survival rates between age-groups (0-4 years, 5-9 years and 10-14 years) were comparable (85.3%, 86.3% and 85.3%, respectively). Compared to the period 2005-2014 improvements in survival were observed in all age groups but were greatest in children aged 10-14 years at 1-year (diff since 2005-2014 period: +3.2%) and children aged 0-4 years at 5-years (diff since 20015-2014 period: +3.1%) **(Appendix A, Table Ic).**

Ethnicity

Five-year survival ranged from 80.9% (95% CI 76.5% – 84.6%) for Māori, 82.6% (95% CI 75.6% - 87.7%) for Pacific, to 87.8% (95% CI 85.6%- 89.7&%) for non-Māori. Compared to the period 2005-2004 improvements in survival were observed for all ethnicity groups **(Appendix A. Table Ic**). Survival improvements were greater for non-Māori and Pacific peoples (+2.7% and +5.7% improvements, respectively) compared to Māori (+2% improvement).

The unadjusted difference in 5-year survival rate between non-Māori and Pacific peoples (5.2%) was statistically non-significant (p=0.07) but the difference between Māori and non-Māori (6.9%) was significant (p=0.002) **(Figure 2).** When stratified by age at diagnosis, in both adjusted and unadjusted models, it was clear that the difference in survival between Māori and non-Māori prioritised ethnicity groups was most marked (p<0.05) among children who were 10–14 years of age at diagnosis **(Table 2)**.

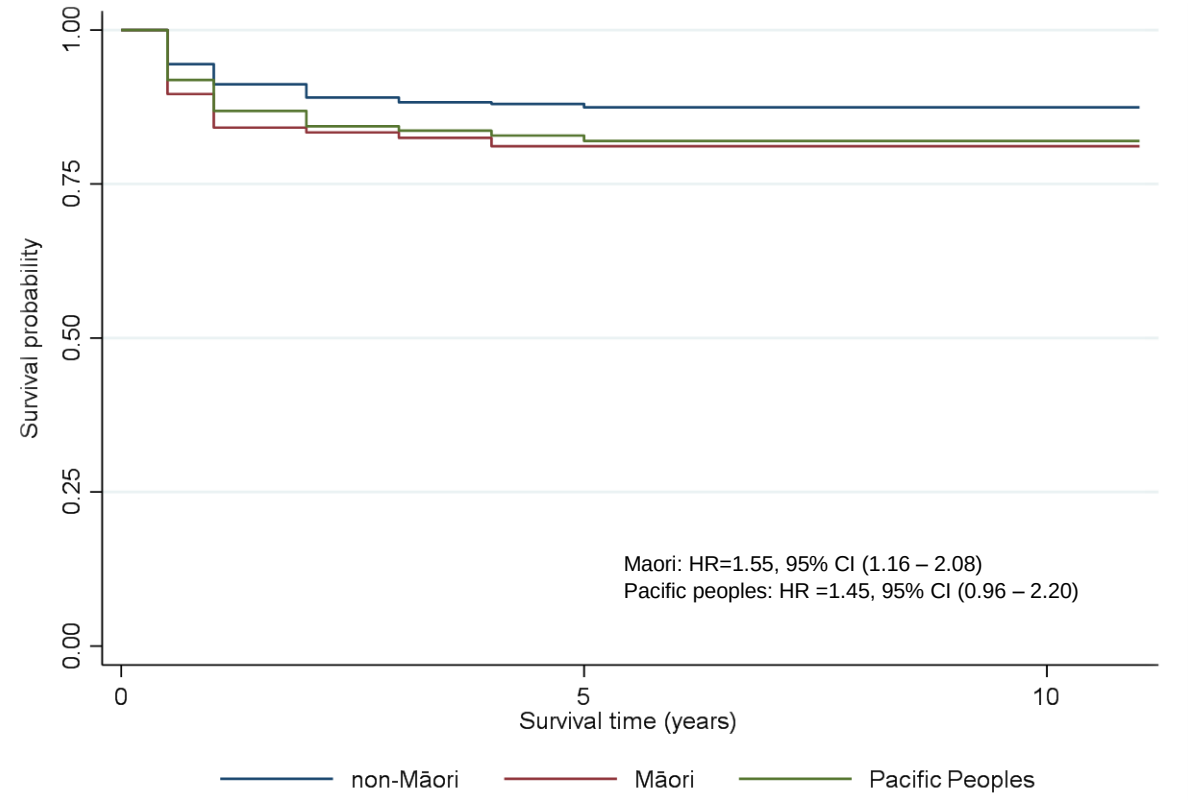
Table 2. Observed 5-year survival by prioritised ethnicity and age alongside adjusted and unadjusted multivariable cox regression models comparing survival trends between prioritised ethnicity groups

	0-4 years		5-9 years		10-14 years	
Observed 5-year survival						
	% (95% CI)		% (95% CI)		% (95% CI)	
non-Māori	86.8 (83.4 – 89.5)		88.0 (82.9 – 91.7)		89.5 (85.0 – 92.6)	
Māori	81.4 (74.5 -86.6)		85.0 (76.9 – 90.4)		74.9 (64.7 – 82.6)	
Pacific peoples	84.6 (73.2 – 91.4)		81.8 (67.8 – 90.1)		80.6 (64.8 – 89.8)	
Multivariable cox regression						
Unadjusted	HR (95% CI)	p	HR (95% CI)	p	HR (95% CI)	p
non-Māori	1		1		1	
Māori	1.45 (0.94 - 2.2)	0.90	1.27 (0.69 – 2.35)	0.43	2.34 (1.37 – 4.01)	0.02
Pacific peoples	1.16 (0.60 – 2.2)	0.64	1.72 (0.83 – 3.58)	0.14	1.82 (0.83 – 3.97)	0.13
Adjusted[a]						
non-Māori	1		1		1	
Māori	1.38 (0.89 – 2.14)	0.14	1.39 (0.74 – 2.63)	0.30	2.19 (1.26 – 3.79)	0.005
Pacific peoples	1.22 (0.62 – 2.39)	0.55	1.67 (0.80 – 3.50)	0.17	1.50 (0.68 – 3.32)	0.30

HR = hazard ratio and 95% Confidence Interval [a]Adjusted for cancer type (ICCC-3 group) and sex

Figure 2. Observed survival between Māori, Pacific peoples and non-Māori for all childhood cancers diagnosed in New Zealand between 2010 – 2019

HR = hazard ratio and 95% Confidence Interval, non- Māori comparator group



Survival by International Childhood Cancer Classification (ICCC-Third Edition) group and sub-group

Table 3 presents 5-year survival for each ICCC-3 diagnostic group and sub-group. **Supplementary File A** containing 5-year survival estimates for each ICCC-3 group stratified by sex, age and prioritised ethnicity is available upon request.

ICCC-3 diagnostic groups

Five-year survival exceeded 70% for all 12 ICCC-3 diagnostic groups. The highest 5-year survival rates were for retinoblastoma (ICCC-3 Group V, 5-year survival rate 100%, no deaths observed among 45 cases), germ cell tumours (ICCC-3 Group X, 98.1% 5-year survival rate, <5 deaths observed among 53 cases), renal tumours (ICCC-3 Group VI, 94.8% 5-year survival rate, <5 deaths observed among 69 cases) and lymphomas (ICCC-3 Group II, 94.8% 5-year survival rate, 11 deaths observed among 195 cases).

Compared to the previous period, 2005-2014, improvements in 5-year survival were observed for all cancer types with the greatest improvements being observed in ICCC-3 Group IX Soft tissue sarcoma (+7.4%), Group III CNS tumours (+4.3%) and Group IV Neuroblastoma (+6.4%) **(Appendix A, Table III.a).**

ICCC-3 diagnostic sub-groups

Acute lymphoblastic leukaemia (ALL) (ICCC-3 Group Ia) survival was greater than acute myeloid leukaemia (AML) (5-year survival 92.5% versus 74.5%). Observed 5-year survival for ICCC-3 Group II sub-groups (Hodgkin lymphoma, non-Hodgkin lymphoma, Burkitt lymphomas, miscellaneous lymphoreticular neoplasms, and unspecified lymphomas) ranged from 86.4% (95% 70.5 – 94.1) for Burkitt lymphomas to 100% for Miscellaneous lymphoreticular neoplasms (including Langerhans cell histiocytosis cases). Analysis of ICCC-3 Group III subgroups indicates 5-year survival was greatest among patients diagnosed with other specified intracranial and intraspinal neoplasms (no deaths recorded among 42 cases) and Astrocytomas (5 –year survival 87.8%, 95% 80.0 -92.8; 13 deaths among 110 cases). Patients diagnosed with intracranial and intraspinal embryonal tumours (ICCC-3 Group IIIc) and other gliomas (ICCC-3 Group IIId) had the poorest 5-year survival (55.6% and 49.7%, respectively). Ewings tumour (ICCC-3 sub-group VIIIc) 5-year survival was nominally greater than Osteosarcoma (ICCC-3 subgroup VIIIa) (85.6% vs 80.4%, respectively). Within ICCC-3 Group IX (soft tissue sarcomas) survival was greatest for fibrosarcomas and other fibrous neoplasms (ICCC-3 sub-group IXb) and other specified soft tissue sarcomas (ICCC-3 sub-group IXe), 100% and 83.3% respectively. Rhabdomyosarcoma (ICCC-3 Group IX a) survival was 73.8% (95% CI 56.7- 85.0).

Table 3. 5-year survival by ICCC-3 subgroup

ICCC-3 Diagnostic Group / Subgroup		5-year survival		
		n	%	95% CI
I.	**Leukaemias, myeloproliferative & myelodysplastic diseases**	**476**	**89.4**	**(86.2-91.8)**
Ia.	Lymphoid leukaemias	370	92.5	(89.2 - 94.9)
Ib.	Acute myeloid leukaemias	75	74.5	(63.0 - 82.9)
Ic.	Chronic myeloproliferative diseases	7	85.7*	(33.4 - 97.8)
Id.	Other myeloproliferative diseases	14	100	[a]
Ie.	Other and unspecified leukaemia	10	70*	(32.9 - 89.1)
II.	**Lymphoma & reticuloendothelial neoplasms**	**195**	**94.8**	**(90.5-97.16)**
IIa.	Hodgkin lymphomas	62	98.1*	(87.6 - 99.7)
IIb.	Non-Hodgkin lymphomas (excl. Burkitt lymphomas)	39	89.7*	(74.9 - 96.0)
IIc.	Burkitt lymphomas	37	86.4*	(70.5 - 94.1)
IId.	Miscellaneous lymphoreticular neoplasms	57	100	[a]
IIe.	Unspecified lymphomas	-	-	-
III.	**Central nervous system & intracranial/intraspinal neoplasms**	**337**	**73.5**	**(68.3-77.8)**
IIIa.	Ependymomas and choroid plexus tumours	35	82.4*	(64.9 - 91.7)
IIIb.	Astrocytomas	110	87.8	(80.0 - 92.8)
IIIc.	Intracranial and intraspinal embryonal tumours	88	55.6	(44.4 - 65.5)
IIId.	Other gliomas	52	49.7*	(35.4 - 62.3)
IIIe.	Other specified intracranial and intraspinal neoplasms	41	100	[a]
IIIf.	Unspecified intracranial and intraspinal neoplasms	11	54.5*	(22.8 - 77.9)
IV.	**Neuroblastoma & other peripheral nervous cell tumours**	**96**	**79.5**	**(69.7-86.4)**
IVa.	Neuroblastoma & ganglioneuroblastoma	96	79.5*	(69.0 - 86.4)
IVb.	Other peripheral nervous cell tumours	-	-	-
V.	**Retinoblastoma**			
		45	100	[a]
VI.	**Renal tumours**	**69**	**94.2**	**(85.1-97.7)**
VIa.	Nephroblastoma & other non-epithelial renal tumours	69	94.1*	(85.1 - 97.7)
VIb.	Renal carcinomas	-	-	-
VII.	**Hepatic tumours**	**22**	**72.7**	**(49.1-86.7)**
VIIa.	Hepatoblastoma	18	83.3*	(56.7 - 94.3)
VIIb.	Hepatic carcinomas	<5	-	-
VIIc.	Unspecified malignant hepatic tumours	-	-	-
VIII.	**Malignant bone tumours**	**77**	**81.0**	**(69.9-88.3)**
VIIIa.	Osteosarcomas	37	80.4*	(63.2 - 90.1)
VIIIb.	Chondrosarcomas	-	-	-
VIIIc.	Ewing tumours & related bone sarcomas	30	85.6*	(65.7 - 94.3)
VIIId.	Other specified malignant bone tumours	10	70*	(32.8 - 89.1)
VIIIe.	Unspecified malignant bone tumours	-	-	-
IX.	**Soft tissue and other extraosseous sarcomas**	**84**	**76.7**	**(65.8-84.4)**
IXa.	Rhabdomyosarcomas	39	73.8	(56.7 - 85.0)
IXb.	Fibrosarcomas & other fibrous neoplasms	7	100	[a]
IXc.	Kaposi sarcomas	-	-	-
IXd.	Other specified soft tissue sarcomas	32	73.7*	(54.0 - 86.0)
IXe.	Unspecified soft tissue sarcomas	6	83.3*	(27.3-97.4)
X.	**Germ cell tumours, trophoblastic tumours & neoplasms of gonads**	**53**	**98.1**	**(87.3-99.7)**
Xa.	Intracranial & intraspinal germ cell tumours	21	95.2*	(70.7 - 99.3)
Xb.	Malignant extracranial & extragonadal germ cell tumours	16	100	[a]
Xc.	Malignant gonadal germ cell tumours	14	100	[a]
Xd.	Gonadal carcinomas	<5	100	[a]
Xe.	Other & unspecified malignant gonadal tumours	<5	100	[a]

Table 3. 5-year survival by ICCC-3 sub-group (continued)

XI.	**Other epithelial neoplasms & melanomas**	**66**	**93.8**	**(84.3-97.6)**
XIa.	Adrenocortical carcinomas	5	80*	(20.4 - 96.9)
XIb.	Thyroid carcinomas	10	100	[a]
XIc.	Nasopharyngeal carcinomas	3	100	[a]
XId.	Melanomas	12	100	[a]
XIe.	Skin carcinomas	-	-	-
XIf.	Other & unspecified carcinomas	36	94.4*	(79.5-98.5)
XII.	**Other & unspecified malignant neoplasms**			
XIIa.	Other specified malignant tumours	<5	100	[a]
XIIb.	Other unspecified malignant tumours	<5	100	[a]

**RSE Value ≥30 indicating statistical instability. Caution should be taken when interpreting the survival estimate.* [a] *95% CI could not be produced in instances where there were either no deaths or no survivors within the period. - No cases diagnosed within the period.* [<5] *Less than 5 cases of cancer were diagnosed in the period 2010-2019*

Childhood cancer deaths

A total of 219 childhood cancer deaths were recorded. **Figure 3** outlines the proportion of deaths attributed to each cancer type. Approximately two-thirds (64%, n=140) of childhood cancer deaths were due to CNS and miscellaneous intracranial and intraspinal neoplasms (ICCC-3 Group III, n=91 deaths) and Leukaemias (ICCC-3 Group I, n=49 deaths). As shown in **Figure 3,** 18% (n=40) of childhood cancer deaths were due to Intracranial and intraspinal embryonal tumours (ICCC-3 sub-group IIIc).

Figure 3. Proportion of deaths attributed to each ICCC-3 group

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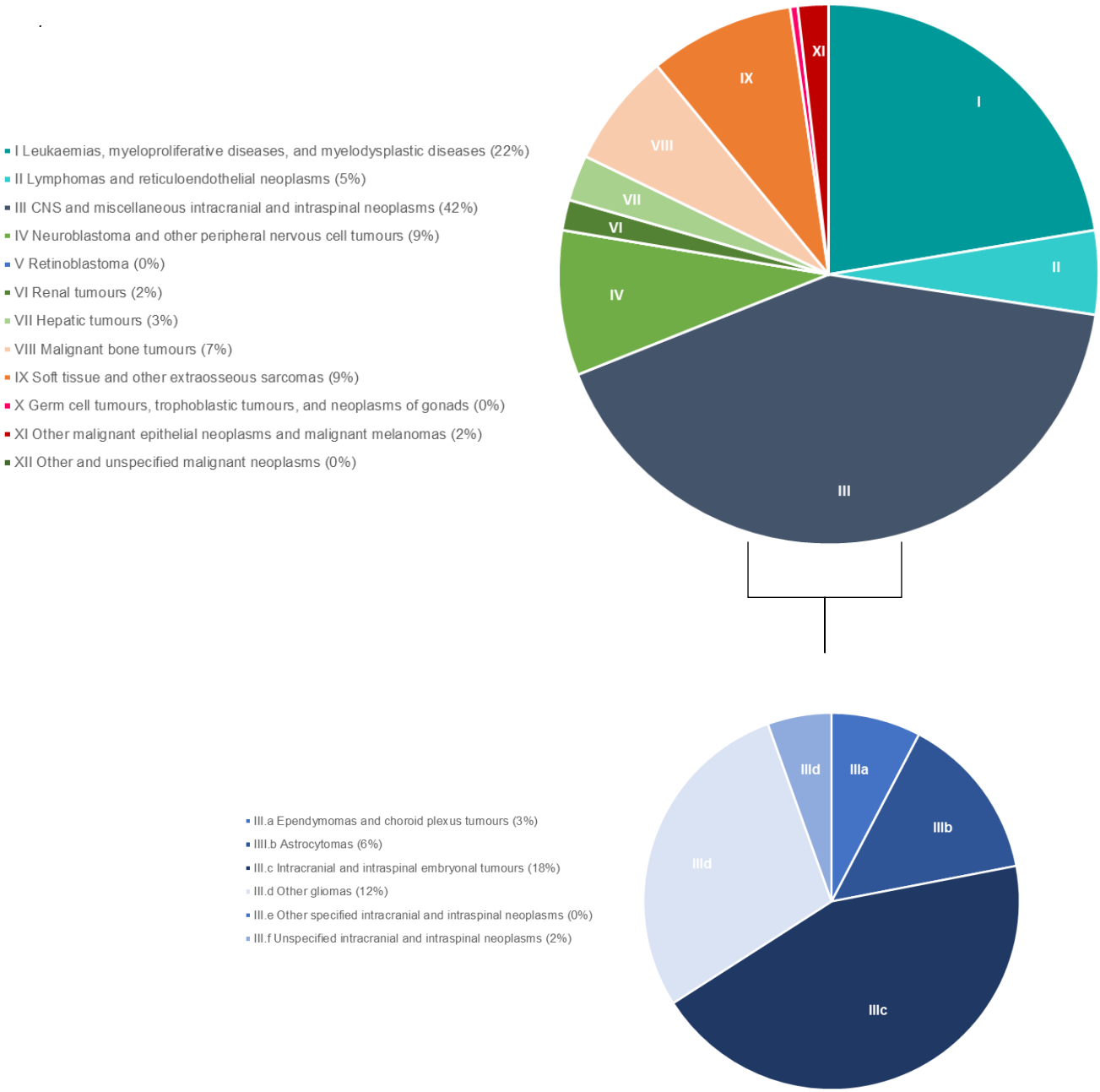

Childhood cancer survival in Aotearoa, New Zealand comparisons with other countries

Aotearoa, New Zealand's 5-year survival rate (85.6%) is comparable with the survival rates of other high-income countries (see **Table 4** overleaf). Aotearoa, New Zealand 5-year survival rates ranked highly for leukaemia, lymphoma, renal tumours, hepatic tumours and soft tissue sarcomas. At 73.5% (95% CI 68.3 – 77.8) Aotearoa, New Zealand CNS tumour survival was high and comparable to that of the UK and Australia (both countries had 76% 5-year survival rates). Aotearoa, New Zealand's malignant bone tumour and germ cell tumour 5-year survival were higher than other high-income countries. Comparisons between countries should be interpreted cautiously as differences in survival estimates may be due to differences in childhood cancer registration practices and survival calculation methodologies.

Table 4. Population-based 5-year childhood cancer survival of other high-income countries

ICCC-3 Group	Australia	United Kingdom	Canada	United States SEER
	Relative Survival (95% CI) 2005-2014	Observed survival (95% CI) 2012-2016	Observed survival (95% CI) 2013-2017	Observed survival (95% CI) 2012 – 2018
All cancers	85.0 ([a])	84.0 (83.2- 84.8)	84.0 (83.0 – 85.0)	85.1 (84.6 -85.7)
I Leukaemias, myeloproliferative diseases, and myelodysplastic diseases	90.0 (88.7 – 91.3)	88.3 (87.0 – 89.5)	88.0 (87.0-90.0)	[b]
II Lymphomas and reticuloendothelial neoplasms	94.4 (92.3 – 95.9)	93.2 (91.2 – 94.7)	92.0 (89.0-94.0)	[b]
III CNS and miscellaneous intracranial and intraspinal neoplasms	76.0 (73.7 – 78.0)	76.6 (74.7 – 78.4)	72.0 (69.0 – 75.0)	[b]
IV Neuroblastoma and other peripheral nervous cell tumours	77.2 (73.0 – 81.0)	70.0 (65.4 - 74.1)	84.0 (79.0 -88.0)	[b]
V Retinoblastoma	98.3 (94.4 - 99.6)	99.1 (96.4 -99.8)	94.0 (85.0 – 98.0)	[b]
VI Renal tumours	90.1 (86.1 – 92.9)	89.1 (85.9 – 91.7)	96.0 (91.0 – 98.0)	[b]
VII Hepatic tumours	75.1 (65.0 – 82.6)	74.4 (65.4 – 81.4)	72.0 (58.0 – 82.0)	[b]
VIII Malignant bone tumours	80.3 (74.5 -85.0)	71.2 (65.5 – 76.1)	72.0 (64.0 -78.0)	[b]
IX Soft tissue and other extraosseous sarcomas	75.8 (71.2 – 79.9)	77.3 (73.3 – 80.8)	70.0 (64.0 – 76.0)	[b]
X Germ cell tumours, trophoblastic tumours, and neoplasms of gonads	94.2 (90.7 – 96.4)	91.1 (87.0 – 93.9)	91.0 (85.0 – 95.0)	[b]
XI Other malignant epithelial neoplasms and malignant melanomas	93.3 (89.5 – 95.8)	91.6 (87.6 – 94.3)	92.0 (86.0 – 95.0)	[b]
XII Other and unspecified malignant neoplasms	-	87.5 (74.0 – 94.3)	80.0(55.0 – 92.0)	[b]

[a] *Lower and upper 95% confidence intervals not reported.* [b] *The United States cancer statistics review (CSR) is no longer available by ICCC-3 classification, the new cancer statistics explorer produces survival by ICD-O-10 site codes.*

Discussion

Cancer survival is often used as the benchmark of clinical success and is used to inform population-level cancer control policies. The observed 5-year cancer survival rate among children in Aotearoa, New Zealand is 85.6%, meaning more than 8 out of 10 children will survive for 5 or more years following their diagnosis. As five-year survival for all childhood cancer types exceeds 70%, childhood cancer survival outcomes in Aotearoa, New Zealand remain comparable with other high-income countries.

The high childhood cancer survival in Aotearoa, New Zealand is multifactorial but is largely due to nationally co-ordinated and agreed standards of care for children with cancer. Child cancer services are delivered by two specialist centres in partnership with fourteen shared care centres. The specialist treatment centres retain overall responsibility for the cancer treatment plan with elements (such as some outpatient based chemotherapy) being delivered in the shared-care centres situated in the paediatric department of regional hospitals. Contractual shared care agreements define responsibilities and standards of delivery of cancer therapy at shared-care centres. Such a model of child cancer care allows children to receive cancer therapy as close to home as possible and minimises variability in patient access to clinical services, therapeutic clinical trials, and supportive care. This model has formally existed in Aotearoa, New Zealand since 2010, following establishment of the National Child Cancer Network (NCCN). Analysis of five-year intervals (2005-2010, 2011-2014, 2015-2019, **Appendix C)** indicate that cancer survival outcomes have markedly improved over time, (5-year survival 2005-2010 vs 2011-2014 vs 2015-2019, 81.6% vs 83.8% vs 87.4%), which likely reflects a combination of therapeutic improvements, as well as clinical care refinements as coordinated by NCCN.

The high childhood cancer survival rates observed in Aotearoa, New Zealand may partly be explained by successive improvements in treatment and increased access to clinical trials. Similarly, advances in diagnostic imaging, molecular pathology, histopathology, and refinements in surgical practices are likely to have also contributed to the improvements in child cancer outcomes. However, despite such advances, children diagnosed with some cancer types (namely intracranial and intraspinal embryonal tumours and other gliomas, ICCC-3 Group IIIc and IIId) still experience relatively poor prognostic outcomes (5-year survival <70%). Several international consortiums (including COG, ANZCHOG, SIOP), of which Aotearoa, New Zealand clinicians are members, are focused on identifying approaches to better treat and manage children with these types of cancer.

Similar to previous reports, there was a small but noteworthy survival gap between Māori, non-Māori and Pacific peoples when considering all childhood cancers combined. Stratified analysis highlights that this between group difference was most apparent between Māori and non-Māori aged 10-14 years at diagnosis. If using statistical equivalence (i.e p>0.05) to indicate 'equity of outcome', survival equity is apparent between all ethnic groups of children aged 0-9 years of age at diagnosis and for all types[1] of childhood cancer. Importantly 'survival equity' is present for the three main types of cancer (Leukaemia, CNS tumours and Lymphoma) which comprise over two-thirds of all child cancer cases. Nevertheless, the consistent pattern of slightly lower survival for Māori and Pacific peoples warrants attention. Work is underway to investigate in greater both detail cause-specific mortality among children with cancer and the child cancer whānau/patient journey, to identify potential factors which could further improve Māori and Pacific child cancer outcomes.

Limitations

Whilst this report presents robust estimates of childhood cancer outcomes in Aotearoa, New Zealand between 2010 and 2019, caution should be taken when interpreting the findings and making judgements about patterns of childhood cancer survival in Aotearoa, New Zealand.

Observed survival

There are a number of different statistical methods to calculate survival which can broadly be classed into three groups: overall survival (also referred to as all-cause, observed and crude survival); relative survival and cause-specific survival (also referred to as cancer-related crude mortality). Overall survival is the probability that a patient is still alive at a certain time point after diagnosis; relative survival is the ratio of overall survival

[1] *Supplementary File A, data available upon request,*

for cancer patients to the expected survival of a comparable group of cancer-free individuals and cause-specific survival is the probability of cancer related death.[7] Whilst previous childhood cancer survival analyses in Aotearoa, New Zealand have reported relative survival within this report observed survival was used. As competing causes of death are rare among children with cancer in high-income countries observed survival is an accepted survival rate and is considered appropriate.[8]

Small case numbers: statistical stability, privacy and confidentiality

The primary limitation to child cancer research in Aotearoa, New Zealand is the limited absolute number of children diagnosed with cancer. This report includes a total sample of 1,522 child cancer cases diagnosed with over 40 different sub-types of cancer. Further stratification of the sample into cancer type, sex, age and prioritised ethnicity groups results in subset numbers that may be insufficiently powered to make strong or any conclusions. Cancer survival estimates based on a large sample population, although subject to random variation, typically produce stable 'true' estimates which do not fluctuate over time. Conversely, cancer survival estimates based on small sample populations can vary considerably over time because of random variation. Cancer survival estimates with standard error ≥20%[8] or RSE values ≥30[6] are considered 'unstable' and therefore not reliable. As a sensitivity check and to avoid presenting data which may be misleading RSE values were computed for each 5-year survival rate. In instances where RSE values ≥30 the accompanying 5-year survival rate includes a notation to indicate that the rate is considered 'unstable'. Caution should be taken when interpreting these survival rates as the estimate may not be a true reflection of the actual survival probability of the population. This is especially true of survival rates calculated for sex, age and prioritised ethnicity sub-groups.

Small case numbers also present privacy and confidentiality challenges. A privacy and confidentiality breach is loss, unauthorized access, use or disclosure of personal information. In the context of research this includes the release of anonymised information in a way that may allow an individual to be indirectly identified. Stats NZ rules for data privacy were applied and suppression of case or death counts <5 occurred. This limited the opportunity to present all sub-group comparisons of cancer survival by cancer type, sex, age and prioritised ethnicity.

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Ethics

Approval for the collection, analysis and publication of NZCCR data has been provided by the Multi-region Ethics Committee (Ethics ref: MEC/11/EXP/134)