The burden of cancer in 25–29 year olds in New Zealand: a case for a wider adolescent and young adult age range?

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ABSTRACT

AIMS: New Zealand currently defines the adolescent and young adult (AYA) group for cancer services as young people 12–24 years of age, while other countries favour a designation of 15–29 years. This study was undertaken to compare cancer incidence and survival among 25–29 year olds to New Zealand's younger AYA population and to assess survival for our 15–29 year population against international benchmarks.

METHODS: Diagnostic and demographic information for cancer registrations between 2000 and 2009 for 25–29 year olds was obtained from the New Zealand Cancer Registry. Incidence rates (IR) and five-year relative survival estimates were calculated according to AYA diagnostic group/sub-group, sex and prioritised ethnicity.

RESULTS: 1,541 new primary malignant cancers were diagnosed (IR: 588 per million). Five-year relative survival was 85%, but was significantly lower for Māori and Pacific peoples (both 77%) compared to non-Māori/non-Pacific peoples (88%). In the overall 15–29 year AYA cohort, disease-specific outcomes for bone tumours (46%) and breast cancer (64%) were inferior to international standards.

CONCLUSION: New Zealand 25 to 29 year olds are at twice the risk of developing cancer as those 15–24 years. Given that the survival disparities identified were remarkably consistent with those for younger AYA, consideration should be given widening New Zealand's AYA age range.

Adolescent and young adult (AYA) oncology is described as "the interface of paediatric and adult oncology".[1] A diverse range of cancers affect this age group, including cancers such as acute leukaemia more commonly seen in children, malignant bone tumours which peak in the teenage years, and cancers that are most common in the AYA population such as thyroid carcinoma, Hodgkin lymphoma and gonadal germ cell tumours. Although the majority of cancers diagnosed among AYAs do not appear to be linked to environmental or inherited factors, following adolescence there is a dramatic increase in the incidence of cancers with an environmental influence, such as malignant melanoma and cervical carcinoma.

A relative lack of improvement in the survival of AYAs with cancer compared to younger and older age groups was first recognised two decades ago. This has been attributed to a range of factors such as biological differences in the presenting disease, a lack of research on cancer in this age group, limited access to and participation in clinical trials, treatment adherence issues and a low awareness of cancer risk among the AYA population and primary healthcare providers leading to delays in diagnosis.[1–3] From a service perspective, AYA patients with cancer have often fallen through the gap between paediatric and adult cancer services, resulting in some patients being referred to centres less experienced in treating their disease,

inconsistency in treatment and follow-up services, and a lack of access to psychosocial resources appropriate for this age group.[4,5] In order to support the facilitation of evidence-based and age-appropriate care for young people, the New Zealand AYA Service Specifications were introduced nationally in 2009.[6] Central to this was the recommendation to establish AYA multidisciplinary teams in the tertiary centres which incorporated the existing adult and paediatric cancer services, and the funding and employment of six regional AYA Key Workers. AYA patients continued to be referred to the relevant services for cancer treatment—such as medical oncology, haematology and paediatric oncology—but were also now referred to the AYA cancer service. The aim was to coordinate the range of complex cancer services required for AYA that involve many disciplines/professional groups and cross organisational, district and institutional boundaries.

The optimal age range for the care of cancer patients in the AYA population is the subject of ongoing international debate. Some argue that a defined AYA age range is a prerequisite for advancing AYA clinical care and research, while others call for a more flexible approach which considers the developmental and psychosocial needs of the individual patient in conjunction with the underlying biology of their disease.[7] Generally Europe, the UK and Australia define AYA as 15–24 years of age,[8–10] the US Surveillance Epidemiology and End Results (SEER) programme and the Canadian Cancer Society favour 15–29 years,[7] while for epidemiological studies, the upper bound may be up to 45 years or more.[11,12] In New Zealand the AYA Cancer Service Specifications define AYA as 12–24 years of age, consistent with two key Ministry guiding documents—"Youth Health: A Guide to Action"[13] and "Youth Development Strategy Aotearoa"[14]—and similar to the definition adopted by major charitable supporter of this age group, CanTeen. However, in New Zealand, the 12–15 year age group is already encompassed by existing comprehensive paediatric oncology services. Moreover, those aged 25–29 years often have similar psychosocial issues to their younger peers; a cancer diagnosis may greatly impact their relationships, physical appearance and career goals during a developmental period in which establishing a strong sense of identity is crucial.[7] The AYA Cancer Service Specifications acknowledge the limitations of defining AYA solely in chronological terms and emphasise that referral pathways should be determined according to what best meets the treatment and psychosocial needs of the individual patient and their whānau.

In 2012, a 2000–2009 AYA cancer incidence and survival analysis was undertaken at the request of the AYA Advisory Group. The analysis identified unique ethnic differences in the spectrum of cancers diagnosed in the 15–24 year population, including a higher incidence of bone tumours and gonadal germ cell tumours among Māori, leukaemia among Pacific peoples and melanoma among non-Māori/non-Pacific peoples.[15–16] Five-year relative survival in New Zealand (80.6%) appeared poorer than had been achieved in other high-income countries, particularly for AYA with bone tumours (48.5%). Overall five-year relative survival was poorer for Māori (69.5%) and Pacific peoples (71.3%) compared to the non-Māori/non-Pacific 15–24 year population (84.2%). The following year, the AYA Cancer Network Aotearoa was established by the Ministry of Health and charged with providing strategic direction and leadership of cancer care for the 12–24 year age group. However, given that the framework for AYA cancer care is currently under development by the AYA Cancer Network and that the AYA age range extends up to 29 years in many other countries, it is timely to provide data pertaining to the burden of cancer among our 25–29 year population. This study was undertaken to identify the spectrum of cancers specifically affecting New Zealanders aged 25–29 years and to determine whether the ethnic survival disparities and poorer outcomes for some tumour groups observed in the 15–24 year population are also evident for the upper AYA age bracket. In addition, this study aimed to assess New Zealand's cancer survival for the wider 15–29 year group against international benchmarks.

Method

Diagnostic and demographic data for 1,541 registrations of new primary malignant tumours diagnosed among those aged 25–29 years old between 1 January 2000 and 31 December 2009 were obtained from the New Zealand Cancer Registry (NZCR). Squamous and basal cell carcinomas and non-malignant central nervous system tumours were not included in this analysis as such cases are not notifiable to the registry. The data items provided were National Health Index number, ethnicity, sex, date of birth, date of diagnosis, date of death, coded tumour site, coded morphology and basis of diagnosis. Cancers were re-coded according to the AYA Cancer Classification Scheme[17] using the site-recode scheme developed by Surveillance, Epidemiology End Results (SEER).[18] The AYA Cancer Classification Scheme has 10 major diagnostic groups and 32 diagnostic subgroups and uses a combined morphology/site classification system suitable for both the paediatric and adult malignancies which affect the AYA population. The 25–29 year analysis replicated the methodology of the earlier 15–24 year AYA analysis to aid age-group comparisons.[15–16] In addition, the 25–29 year dataset was combined from the 15–24 year dataset from the original AYA analysis in order to make survival comparisons with published studies, which more commonly define the AYA population as encompassing those aged 15–29 years of age.

Ethnicity was classified using a prioritised ethnicity system; Māori, Pacific peoples and non-Māori/non-Pacific peoples. When prioritised ethnicity is applied to 2006 census data, the 25–29 year AYA population comprised of 15.7% Māori, 6.9% Pacific peoples and 77.4% non-Māori/non-Pacific peoples (12.9% Asian, 1.2% Other Ethnicity, 5.3% 'Not Elsewhere Included' and 58.0% European/New Zealander).

Age-specific incidence and relative survival estimates were calculated using SAS® and Stata® software. Incidence rates (IR) per million inhabitants were calculated based on person-years derived from Statistics New Zealand's annual estimated resident population by age and sex. Relative risk (RR) estimates were calculated for males compared to females and 95% confidence intervals (CIs) were calculated assuming the cases were drawn from a Poisson distribution. Five cases informed by autopsy or death certificate only or with a survival of zero days were included in incidence counts but excluded from the survival analyses. Relative survival estimates were derived from the observed survival data, using record linkage to the National Mortality Collection, and expected survival data, calculated according to the Ederer II method using life-tables produced by Statistics New Zealand based on 2006 census data. All cases were followed up until death or 31 December 2010, whichever came first. Ethical approval was granted by the Multi-region Committee of the Health and Disability Ethics Committee (MEC/12/EXP145).

Results

Between 2000 and 2009 there were an average of 154 primary malignant tumours diagnosed each year among New Zealanders aged 25–29 years (IR: 588 per million; 95% CI: 558–617). This was approximately equal to the annual number of cancers diagnosed among those aged 15–24 years (n=161, IR: 275 per million; 95% CI: 261–288)[15] and greater than the annual number of new diagnoses in the entire child population aged 0–14 years (n=133, IR: 149 per million; 95% CI: 141–157).[19] Figure 1 shows that of the 10 major diagnostic groups, the most common cancers were carcinomas (33.4%), melanomas (24.6%) and germ cell tumours (16.4%) with most of the remaining tumour groups recording only a very small number of cases on a national annual basis. Table 1 reports cancer incidence by ethnicity and sex according to AYA diagnostic group and subgroup. Cancer incidence was higher for females (n=841, IR: 626 per million; 95% CI: 584–669) than males (n=700, IR: 547 per million; 95% CI: 507–588), but this difference was not statistically significant. Males were significantly more likely than females to be diagnosed with germ cell tumours (RR 14.5, 95% CI 9.9–21.2) and leukaemias (RR 1.8, 95% CI 1.1–3.0) and significantly less likely to be diagnosed with genitourinary tract carcinomas (RR 0.1, 95% CI 0.1–0.2), melanoma (RR 0.6, 95% CI 0.5–0.7), thyroid cancers (RR 0.2, 95% CI 0.1–0.3) and breast carcinomas.

Figure 1: Average annual number of new cancer cases among young adults aged 25–29 years in New Zealand, 2000–2009.

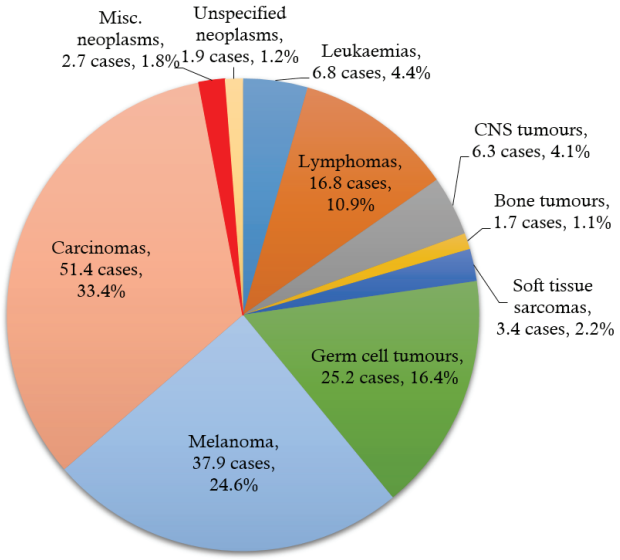

Table 1: Cancer incidence per million among New Zealand's 25–29 year old population by sex and prioritised ethnicity, 2000–2009.

AYA diagnostic group and selected subgroups	Sex						Prioritised ethnicity									Total 25–29 years		
	Male		Female		Relative risk		Māori			Pacific peoples			non-Māori/non-Pacific peoples					
	Cases	IR	Cases	IR	M:F	95% CI	Cases	IR	95% CI	Cases	IR	95% CI	Cases	IR	95% CI	Cases	IR	95% CI
1. Leukaemias	43	34	25	19	1.8	1.1–3.0	10	26	10–43	9	54	19–89	49	26	19–33	68	26	20–32
1.1 Acute lymphoid leukaemia	11	9	7	5	[a]	[a]	2	5	0–13	2	12	0–29	14	8	4–11	18	7	4–10
1.2 Acute myeloid leukaemia	19	15	11	8	1.8	0.9–3.8	6	16	3–28	4	4	1–47	20	1	6–15	30	11	7–16
2. Lymphomas	92	72	76	57	1.3	0.9–1.7	22	58	34–82	9	54	19–89	137	73	61–85	168	64	54–74
2.1 Non-Hodgkin lymphoma	50	39	33	25	1.6	1.0–2.5	14	37	18–56	5	30	4–56	64	34	26–43	83	32	25–39
2.2. Hodgkin lymphoma	42	33	43	32	1.0	0.7–1.6	8	21	7–36	4	24	1–47	73	39	30–48	85	32	26–39
3. Central nervous system tumours	39	31	24	18	1.7	1.0–2.8	13	34	16–53	8	48	15–81	42	22	16–29	63	24	18–30
4. Osseous and chondromatous neoplasms	12	9	5	4	[a]	[a]	6	16	3–28	0	-	-	11	6	2–9	17	7	3–10
5. Soft tissue sarcomas	20	16	14	10	1.5	0.8–3.0	7	18	5–32	2	12	0–29	25	13	8–19	34	13	9–17
6. Germ cell and trophoblastic neoplasms	235	184	17	13	14.5	9.9–21.2	79	207	162–253	8	48	15–81	165	88	75–101	252	96	84–108
6.1 Germ cell and trophoblastic neoplasms of gonads	230	180	13	10	18.6	12.3–28.0	77	202	157–247	8	48	15–81	158	84	71–97	243	93	81–104
7. Melanoma and skin carcinomas	138	108	241	180	0.6	0.5–0.7	13	34	16–53	1	6	0–18	365	195	175–215	379	145	130–159
8. Carcinomas[b]	100	78	414	308	0.3	0.2–0.3	117	307	251–363	41	245	170–320	356	190	170–210	514	196	179–213
8.1 Thyroid carcinoma	17	13	92	69	0.2	0.1–0.3	26	68	42–95	14	84	40–128	69	37	28–46	109	42	34–49
8.2 Other carcinoma of head and neck	18	14	15	11	1.3	0.6–2.5	3	8	0–17	2	12	0–29	28	15	9–21	33	13	8–17
8.4 Carcinoma of breast	0	-	101	75	[a]	[a]	30	79	51–107	4	24	1–47	67	36	27–44	101	39	31–46
8.5 Carcinoma of genitourinary tract	15	12	155	115	0.1	0.1–0.2	37	97	66–128	8	48	15–81	125	67	55–78	170	65	55–75
8.6 Carcinoma of gastro-intestinal tract	45	35	42	31	1.1	0.7–1.7	19	50	27–72	11	66	27–105	57	30	23–38	87	33	26–40
9. Miscellaneous specified neoplasms	12	9	15	11	0.8	0.4–1.8	6	16	3–28	10	60	23–97	11	6	2–9	27	10	6–14
10. Unspecified neoplasms	9	7	10	7	[a]	[a]	4	11	0–21	1	6	0–18	14	8	4–11	19	7	4–11
Total cancers diagnosed	**700**	**547**	**841**	**626**	**0.9**	**0.8–1.0**	**277**	**727**	**641–813**	**89**	**532**	**422–643**	**1,175**	**626**	**591–662**	**1,541**	**588**	**558–617**

AYA: adolescent and young adult; IR: incidence rate (per million); CI: confidence interval.
[a]Relative risk was not calculated due to the small number of cases for one or both groups.
[b]Due to the small number of cases diagnosed within the 10-year period, incidence rates for diagnostic subgroups '8.3: Carcinomas of trachea, bronchus, and lung' (six cases) and '8.7: Carcinomas of other and ill-defined sites' (eight cases) were not reported in the table.

Cancer incidence among 25–29 year olds was 532 per million for Pacific peoples (95% CI: 422–643), 626 per million for non-Māori/non-Pacific peoples (95% CI: 591–662) and 727 per million for Māori (95% CI: 641–813). Although the ethnic differences in overall cancer incidence were not yet statistically significant, several notable ethnic differences were observed in the spectrum of AYA cancers diagnosed. Melanoma was rare among Māori (IR: 34 per million) or Pacific peoples (IR: six per million) but importantly it still accounted for nearly one-third of all cancers diagnosed among non-Māori/non-Pacific peoples in this age group (IR: 195 per million). Compared to non-Māori/Pacific peoples, Māori had a significantly higher incidence of gonadal germ cell tumours (IR: 207 per million c.f. 88 per million) and carcinomas (IR: 307 per million c.f. 190 per million), particularly breast carcinomas (IR: 79 per million c.f. 36 per million).

Table 2: Five-year relative survival among New Zealand's 25–29 year old population by sex and prioritised ethnicity, 2000–2009.

AYA diagnostic group and selected subgroups	Sex				Prioritised ethnicity						Total 25–29 years		Total 15–29 years	
	Male		Female		Māori		Pacific peoples		non-Māori/non-Pacific peoples					
	5-year survival (%)	95% CI	5-year survival (%)	95% CI	5-year survival (%)	95% CI	5-year survival (%)	95% CI	5-year survival (%)	95% CI	5-year survival (%)	95% CI	5-year survival (%)	95% CI
1. Leukaemias	72	55–83	62	40–78	60	25–83	67	28–88	69	53–81	68	55-78	68	62–74
1.1 Acute lymphoid leukaemia	81	43–95	72	26–92	[a]	[a]	100	[b]	71	40–88	78	51–91	66	55–75
1.2 Acute myeloid leukaemia	64	38–81	42	13–69	50	11–81	50	6–85	57	31–76	55	35–71	66	55–75
2. Lymphomas	85	74–91	81	70–89	81	57–93	75	32–93	84	75–89	83	76–88	87	83–90
2.1 Non-Hodgkin lymphoma	81	66–90	69	50–82	70	38–88	50	6–85	79	67–88	76	65–84	78	70–84
2.2. Hodgkin lymphoma	89	72–96	90	73–97	100	[b]	100	[b]	88	75–94	90	79–95	93	88–96
3. Central nervous system tumours	58	39–73	62	37–79	34	10–60	63	23–86	68	49–82	60	45–72	60	51–68
4. Osseous and chondromatous neoplasms	41	11–69	[a]	[a]	17	1–52	-	-	43	11–73	31	9–57	46	37–56
5. Soft tissue sarcomas	89	62–98	62	31–82	86	34–98	100	[b]	75	52–88	78	59–89	67	57–75
6. Germ cell and trophoblastic neoplasms	98	95–99	100	[b]	95	87–98	100	[b]	99	95–100	98	95–99	95	93–97
6.1 Germ cell and trophoblastic neoplasms of gonads	98	95–99	100	[b]	95	86–98	100	[b]	99	98–100	98	95–99	96	94–98
7. Melanoma and skin carcinomas	91	84–95	97	93–98	100	[b]	[a]	[a]	94	91–96	95	91–97	94	92–96
8. Carcinomas[c]	78	68–85	83	78–86	72	61–80	75	58–86	86	81–89	82	78–85	82	79–85
8.1 Thyroid carcinoma	101	[b]	99	93–100	100	[b]	93	59–99	100	[b]	99	94–100	100	97–100
8.2 Other carcinoma of head and neck	95	65–100	91	51–99	100	[b]	[a]	[a]	96	73–100	93	74–99	92	81–97
8.4 Carcinoma of breast	-	-	65	53–74	47	25–66	100	[b]	70	56–80	65	53–74	64	53–72
8.5 Carcinoma of genitourinary tract	86	54–97	93	87–96	83	65–92	87	36–98	95	89–98	92	87–96	92	88–95
8.6 Carcinoma of gastro-intestinal tract	63	46–76	52	33–69	54	27–74	34	10–62	63	46–77	57	44–68	56	47–64
9. Misc. specified neoplasms	84	48–96	72	42–89	84	27–98	90	48–99	61	26–84	78	56–89	68	55–78
10. Unspecified neoplasms	67	28–88	66	27–88	50	6–85	0	[a]	76	43–92	66	39–83	76	55–88
Overall survival	**86**	**83–89**	**85**	**82–87**	**77**	**72–82**	**77**	**66–85**	**88**	**86–90**	**85**	**83–87**	**83**	**82–84**
Overall survival (excluding melanoma)	**85**	**82–88**	**80**	**76–83**	**76**	**70–81**	**77**	**66–84**	**85**	**82–87**	**82**	**80–85**	**80**	**78–81**

[a]Five-year relative survival and 95% confidence intervals 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.
[c]Due to the small number of cases diagnosed within the 10-year period, survival estimates for diagnostic subgroups '8.3: Carcinomas of trachea, bronchus, and lung'(six cases) and '8.7: Carcinomas of other and ill-defined sites' (eight cases) were not reported in the table.

Overall five-year relative survival estimates for the 25–29 year population (85%; 95% CI: 83–87%, see Table 2) were very similar to the survival reported in the earlier AYA analysis for 20–24 year olds (85%; 95% CI: 82–87%) but significantly higher than survival for adolescents aged 15–19 years (75%; 95% CI: 71–78%).[15] Five-year survival for carcinomas overall was 82% although this varied considerably according to diagnostic subgroup, ranging from 99% for the 109 individuals diagnosed with thyroid carcinoma to 33% for the six 25–29 year olds diagnosed with "carcinoma of the trachea, bronchus and lung". There were no five-year survival differences for the 25–29 year population according to sex, but marked differences according to ethnicity. Five-year relative survival was 88% in non-Māori/Pacific peoples, significantly higher than the 77% survival estimate for both Māori and Pacific peoples. Although not reaching statistical significance, there were noteworthy differences in five-year survival for Māori compared to non-Māori/non-Pacific 25–29 year olds diagnosed with CNS tumours (34% c.f. 68%), and bone tumours (17% c.f. 43%). When melanoma cases were excluded, Māori five-year survival (76%) remained 9% lower than for non-Māori/non-Pacific peoples (85%).

Discussion

The relative rarity of cancer in the 25–29 AYA age group and spectrum of cancers differs significantly from that seen in the mature adult population. While many cancer diagnoses in the 25–29 AYA group are similar to the younger AYA group (lymphomas, melanoma and gonadal germ cell tumours) this age group also sees the emergence of other cancers less commonly seen in the 15–24 age bracket, namely carcinomas of the breast, gastrointestinal and reproductive tracts. In addition, there are marked ethnic and gender differences in the spectrum of cancers diagnosed. New Zealand's overall cancer incidence for 25–29 year olds of 588 per million was comparable to the incidence reported for the US and Canada within a similar time period.[20–21] A notable exception is the incidence of melanoma, which is considerably higher than has been reported elsewhere for this age group, but in keeping with New Zealand's known high rates of melanoma due to our ethnic composition and geographical location.[22]

For the 25–29 year group, five-year survival varied considerably across the tumour groups. Five-year relative survival for many diagnostic groups such as germ cell tumours (98%) and melanoma (95%) was high and in line with international benchmarks.[23–24] However, bone tumour survival for 25–29 year olds was just 31%. When combined with the 15–24 data, New Zealand bone tumour survival for 15–29 year olds was 46%, 20% lower than achieved in Australia during a comparable time period.[23] Regardless of the model for service delivery across the age spectrum, the data provides compelling evidence of the need for a coordinated national approach to improve the outcomes for those AYA diagnosed with this rare and complex group of tumours. In addition, poorer survival outcomes were identified for AYA with breast cancer. New Zealand's five-year relative survival for AYA 15–29 years diagnosed with breast carcinomas was 64%, while Australia, the US and Germany all reported survival of over 80% for a similar time period. [23–24]

This analysis showed that overall survival for Māori and Pacific 25–29 year olds diagnosed with cancer is lower than that for non-Māori/non-Pacific peoples. However, the small number of cases has restricted ethnic comparisons at a diagnostic group level and the survival disparities may be attributed, in part, to the different patterns of cancer in our ethnic populations. When melanoma cases were excluded, five-year relative survival for Māori remained significantly poorer than for non-Māori/non-Pacific peoples. Combining the 25–29 year cohort with those aged 15–24 years provided a larger cohort and stronger evidence of five-year survival disparities for Māori 15–29 year olds compared with non-Māori/non-Pacific peoples, with differences of around 20% recorded for Māori diagnosed with bone tumours (33% c.f. 52%), CNS tumours (40% c.f. 65%) and leukaemias (53% c.f. 73%). Māori women appear to be at higher risk of both developing breast cancer in young adulthood as well as dying of their disease (five-year survival: 43% c.f. 69%).

These ethnic survival disparities may be multifactorial, and include delays in diagnosis, differential access to treatment or possible biological differences.[25] For example, studies in the US have shown that survival is poorer for Black AYAs diagnosed with breast cancer compared to Whites, that Blacks diagnosed with breast cancer are much more likely to have triple-negative breast cancer than Whites and that reception of treatment among AYAs with breast cancer varies by ethnicity.[26–27] Although it was beyond the scope of the present study, future qualitative and quantitative research is needed in order to explore such factors as cytogenetics, disease staging at presentation, referral pathways, treatment adherence and access to culturally appropriate psychosocial support, which may explain and address the ethnic survival disparities which were identified.

Widening New Zealand's definition of AYA from its current 12–24 years to 12–29 years potentially has resource implications. Based on the 2000–2009 cancer registrations, the number of patients eligible for support from AYA cancer services, such as Key Worker coordination, would increase by 84%, although this would be lessened if simple treatable cancers such as localised melanoma were excluded. The national standards for the care of AYA with cancer, launched by the AYA Cancer Network in May 2017, describe the standard of care that all AYA are entitled to receive from the time of their diagnosis to well beyond treatment.[28] Given that the AYA Cancer Network Aotearoa has only recently been established and already has a number of priorities, a case could be made for focusing only on improving cancer services for patients aged 12–24 years. However, many of the AYA standards, such as encouraging the harmonisation of treatment approaches with evidence-based treatment protocols and improving access to appropriate clinical trials, may also benefit 25–29 year olds without necessarily having a manifest impact on clinical workloads.

There is evidence for the AYA population that enrolment in open clinical trials, or treatment of specific diseases—such as acute leukaemia and sarcomas—according to paediatric rather than adult protocols, confers overall survival advantages.[29,30] Yet access and enrolment on open collaborative clinical trials in the AYA age group has historically been poor. In contrast to the AYA experience, children with cancer have benefited greatly from access to international collaborative clinical trials leading to a progressive improvement in overall survival over the last 30 years. The two paediatric oncology units in Auckland and Christchurch are members of multiple international clinical trials consortia, including the US-based Children's Oncology Group and many European disease-specific clinical trials groups. Many clinical trials available in New Zealand for children and adolescents include extended age ranges into the adult age group; COG clinical trials for leukaemia, lymphoma, solid and brain tumours are typically eligible for patients up to 29 years while the current European Ewing Sarcoma trial (EE08) is open to patients aged up to 50 years.

Unfortunately, many barriers currently exist that limit the ability of adult cancer centres to enrol patients onto these trials outside the two children's cancer centres. Low likely annual accrual often precludes membership to the trials group or renders the huge resource involved with opening and recruiting to an individual trial difficult to justify in an existing clinical research programme. Equally, barriers exist for paediatric institutions opening adult cooperative group trials. Recently the US National Cancer Trials Network (NCTN) system, which is a US-Government supported cancer collaborative group trials programme run through the National Cancer Institute, has moved to allow centres that have membership to the NCTN via a particular collaborative group (COG or one of four adult groups) to open studies that are run by the other groups. The rationale for this is to increase access for AYA. Given the same institutional barriers currently exist for patients aged 25–29 years as for younger AYA, initiatives by the AYA Cancer Network to facilitate AYA participation in international collaborative clinical trials are likely to also directly benefit 25–29 year olds. Similarly, cancer prevention and symptom awareness campaigns which target young people and their primary healthcare providers may also lead to earlier diagnosis and improved survival outcomes for this older AYA group.

Clinicians in adult cancer services are highly experienced in treating the melanomas and carcinomas, which together account for 58% of cancers diagnosed in the 25–29 population, yet they may be less familiar in addressing the complex psychosocial needs of this patient group given that they account for such a small proportion of their overall caseload. Conversely, the majority of 12–14 year olds have a paediatric cancer and are cared for under child cancer services, which already provide comprehensive psychosocial wrap-around care. Given that there is no evidence of survival disparities for 12–14 year olds,[31] there is some debate around whether AYA cancer services should continue to prioritise and resource the care of this age group. By not routinely supporting 12–14 year olds, resources would become available to provide additional support, such as access to AYA Key Workers, for those 25–29 year old cancer patients identified as high risk due to psychosocial or disease factors.

The main findings of this additional analysis of AYA aged 25–29 years are remarkably consistent with the findings from the earlier analysis of AYA aged 15–24 years; namely the poor survival for those young people diagnosed with bone sarcomas, and the poorer overall cancer survival for Māori and Pacific peoples. In addition, it provides evidence of poorer outcomes for young people, particularly Māori, diagnosed with breast cancer. The study highlights that although it may be more convenient from an organisational or research perspective to apply a chronological age range for AYA, it leads to the exclusion of patients who would benefit from being included in the AYA community. The data presents a compelling case for expanding the AYA upper age limit in New Zealand and applying a more flexible approach with regards to who can access AYA cancer services. A tiered model of service delivery for this age group could be considered, whereby the AYA Service Specifications prioritise clinical service delivery, such as Key Worker coordination, to the 15–24 year old age group and the AYA Cancer Network provide national oversight, advocacy, and strategic direction for cancer care for AYA aged 12–29 years.

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