

A SNAPSHOT OF ADOLESCENT/YOUNG ADULT (AYA) **CANCER IN AOTEAROA**

HE PITOPITO KI TE MATE PUKUPUKU KUA PĀ KI TE HUNGA TAIOHI KI AOTEAROA

Every year approximately **190** young New Zealanders aged 12 to 24 years are told they have cancer.

'I was numb. I mean what did cancer mean for my plans for university? What about life and marriage and even kids? I hadn't thought about kids before but now I had to.'

AYA patient

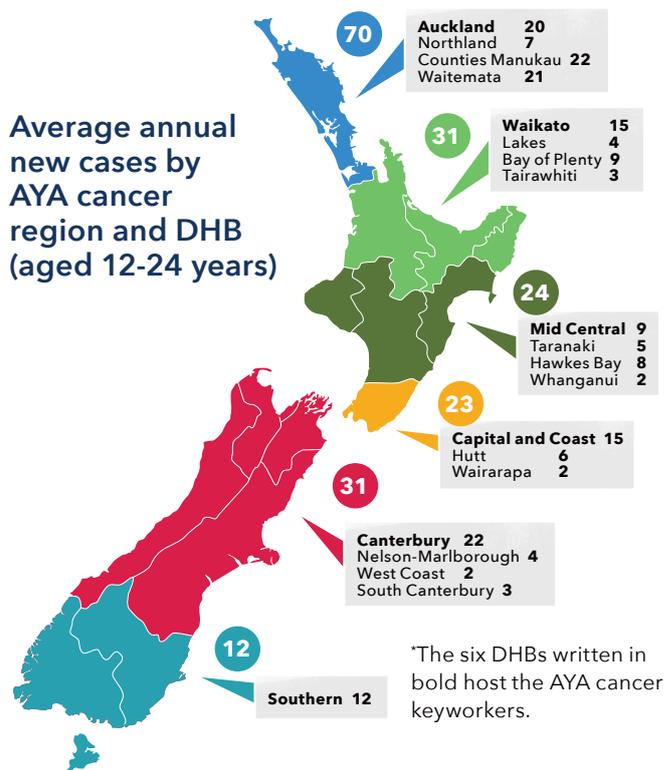


It is widely recognised that the AYA cancer population have distinct and unique developmental needs.

The spectrum of cancers that present in this age group differ to child and adult cancers, as do tumour and host biology factors. In addition, the psychosocial care needs of AYAs with cancer tend to be broader in scope and intensity than children or older adults. This is due to the many emotional, developmental and social changes that occur during this time.

Our 2000-2009 AYA cancer survival rates painted a bleak picture of AYA cancer care in New Zealand. Over the past decade we have seen innovative and responsive actions to address these survival disparities for our young people. Reassuringly an improvement in overall AYA cancer survival has been observed over the 2008-2017 period - these details are presented in this snapshot. Central to this was the funding of AYA cancer keyworkers who provide specialised cancer care coordination and oversight for AYAs within New Zealand's six AYA cancer regions.

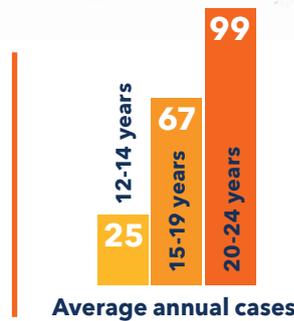
Average annual new cases by AYA cancer region and DHB (aged 12-24 years)



ADOLESCENTS AND YOUNG ADULT CANCER INCIDENCE (2000 - 2009 versus 2008 - 2017)

The average annual number of cancer cases among AYA (190 per year) has remained **relatively stable** over the past decade.

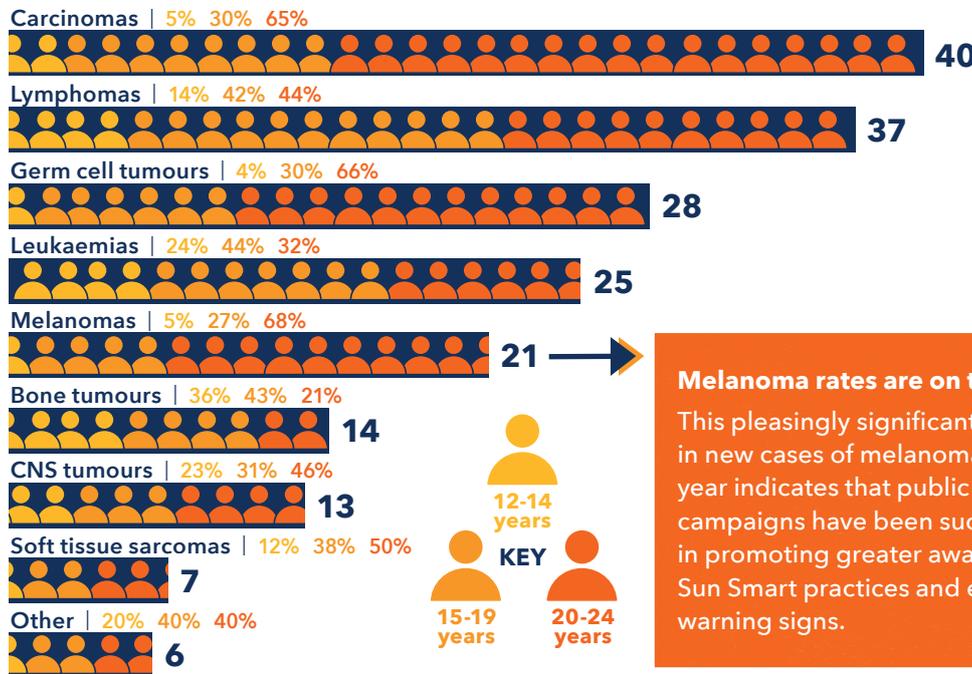
Overall, carcinomas (such as cancers of the thyroid, breast, and gastrointestinal tract), lymphomas and germ cell tumours are the three most common diagnostic groups affecting New Zealand AYA. But the rates differ considerably depending on age, sex and ethnicity.



AYA cancers by age

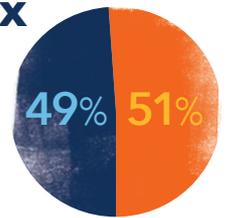
The number of new cancer diagnoses among AYA increases with age. Over 50% of AYAs diagnosed with cancer are in the 20 to 24 year old age group.

The most common cancers affecting New Zealand AYA



By sex

There is little difference in the proportion of cancers diagnosed in males (49%) compared to females (51%).



Melanoma rates are on the decline

This pleasingly significant reduction in new cases of melanoma each year indicates that public health campaigns have been successful in promoting greater awareness of Sun Smart practices and early warning signs.

31 Cases per year 2000-2009

Down to 21 cases per year 2008-2017

Prioritised ethnicity 15-24 years

By prioritised ethnicity, **overall** cancer incidence is similar for the three main ethnic groups. 22% of 15-24 year olds diagnosed with cancer are Māori and 10% are Pacific Peoples.



But while there were no significant differences in **overall** cancer incidence, when it is broken down by tumour group we see some clear ethnic differences in the spectrum of cancers seen by each of the three groups. These increased risks are remarkably consistent compared to a decade ago.

Increased risk of incidence by ethnicity

Māori

- Carcinoma of the GI tract
- Ewing tumours
- Gonadal germ cell tumours

Pacific Peoples

- Leukaemias (AML)

All Other

- Melanoma

We don't know why the risk of developing some cancers varies according to ethnicity but such findings help us to identify future research directions which will add to our understanding of how these cancers develop and how to treat them most effectively. We do know that Māori are more likely to have a rare genetic mutation, CDH1, which places the carrier at high risk of developing stomach cancer (one of a number of cancers found in the gastrointestinal tract). Recently, new guidelines have been developed to ensure that all Māori with a family member who has had stomach cancer can access testing for the CDH1 mutation.

5 YEAR CANCER SURVIVAL IMPROVEMENTS IN THE PAST DECADE (2000 - 2009 versus 2008 - 2017)

AYA cancer survival rate in New Zealand



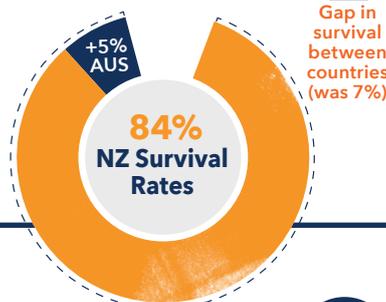
By sex

The survival gap between sex has closed over the past decade

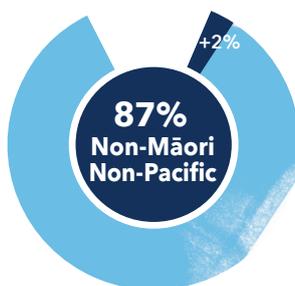
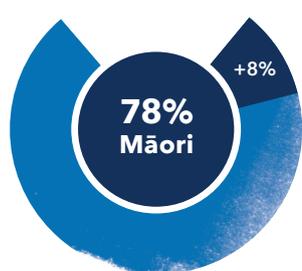
Male **▲ 6%**
Female **▲ 1%**



In comparison to Australia over the last decade

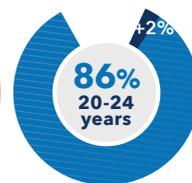
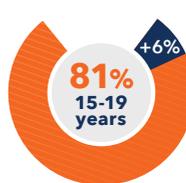


Prioritised ethnicity - the ethnic survival gap still exists but is narrowing



GAP BETWEEN THE AGES

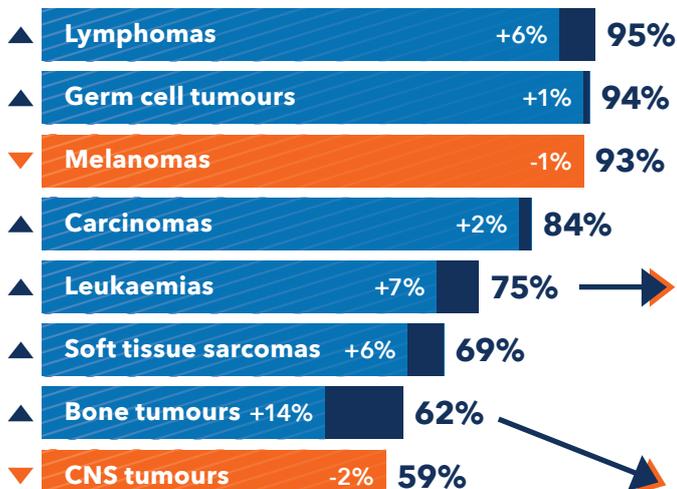
By age



The percentages in the middle are survival rates for 2008 to 2017.

The smaller percentages are how much survival rates have improved over the last decade.

Diagnostic group



The blue percentages are 2008 to 2017 survival rates. The white percentages show how much survival rates have improved over the last decade.

Five year survival is improving for many of our most common AYA cancers.

Survival rates for acute lymphoblastic leukaemia (ALL) and Ewing's tumour (two types of cancer which were previously identified as being of particular concern), have significantly improved over the past decade.

Acute Lymphoid Leukaemia (ALL)

Survival for 15-24 year olds diagnosed with ALL has improved by 9% and for 15 to 19 year olds (Adolescents) by 18%.



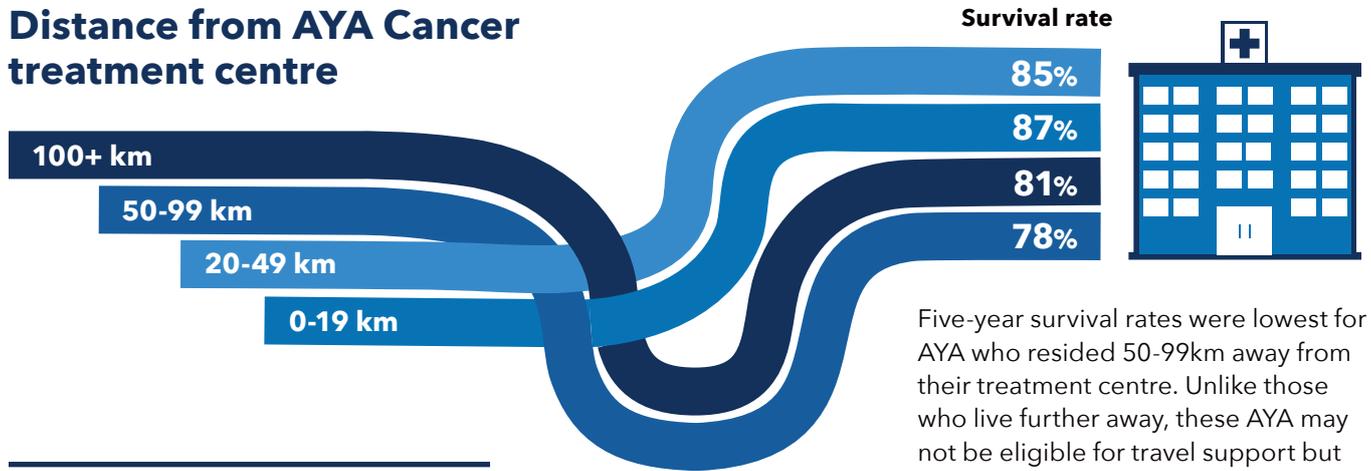
Ewing Tumours

Survival improvements for 15-24 year olds diagnosed with bone tumours is mostly attributable to the survival gains for Ewing's tumour.



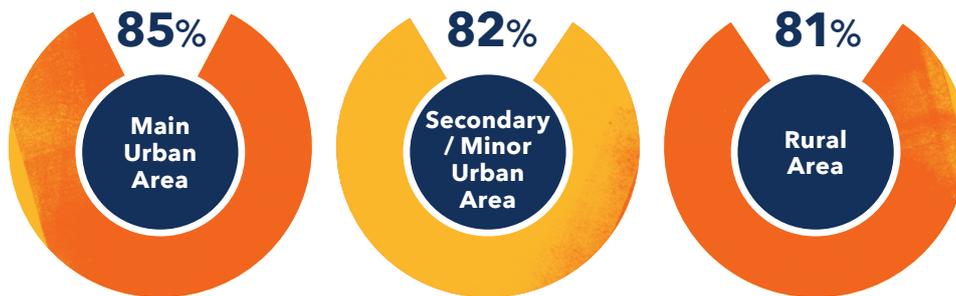
WHERE A YOUNG PERSON LIVES MAKES A DIFFERENCE TO THEIR SURVIVAL

Distance from AYA Cancer treatment centre



Five-year survival rates were lowest for AYA who resided 50-99km away from their treatment centre. Unlike those who live further away, these AYA may not be eligible for travel support but could still find it difficult to travel for treatment and appointments.

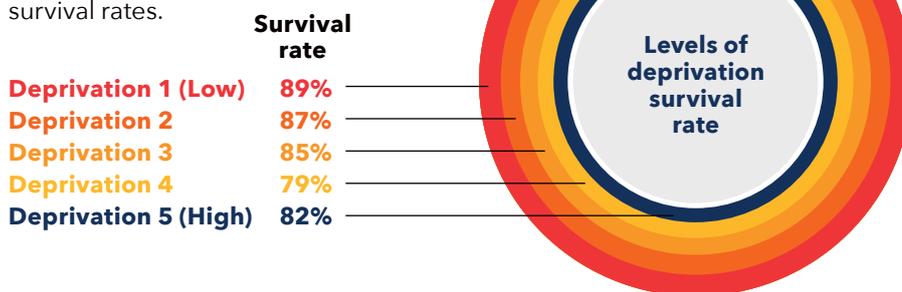
Rural - Urban Residence



Those living in major urban areas recorded the highest five-year survival rates.

Level of deprivation

Those living in the highest deprivation areas recorded the poorest five-year survival rates.



'Finding the right support was tough; there are so many barriers that existed for us as low income earners. I was relying on charities to donate me petrol vouchers to get me to appointments. It was pretty crazy'

AYA Patient

A clear trend can be seen whereby the highest survival rates are for those who reside within 20 kilometres of the tertiary hospital, live in a major urban area, and have low levels of deprivation.

By AYA Cancer Region, five-year survival estimates range from 77% to 91%. Each of Aotearoa's 20 district health boards differ in terms of their population's ethnic composition, levels of deprivation, and geographic spread - all of which may contribute to survival differences.

IN SUMMARY

The 2000-2009 AYA cancer incidence and survival analysis identified many concerning disparities for AYA.

This snapshot provides strong evidence that the efforts locally and nationally over the last decade to close the gap in survival for young people with cancer are working.

- ✓ AYA cancer incidence is stable
- ✓ The incidence of melanoma has decreased significantly among AYA
- ✓ AYA cancer survival is improving, particularly for:
 - Māori & Pacific Peoples
 - 15-19 year olds
 - Males
 - AYA diagnosed with ALL and bone tumours.

Although we are encouraged by these improvements we must not become complacent. **Unacceptable** disparities, inequities and variation in cancer care outcomes for young New Zealanders still exist.

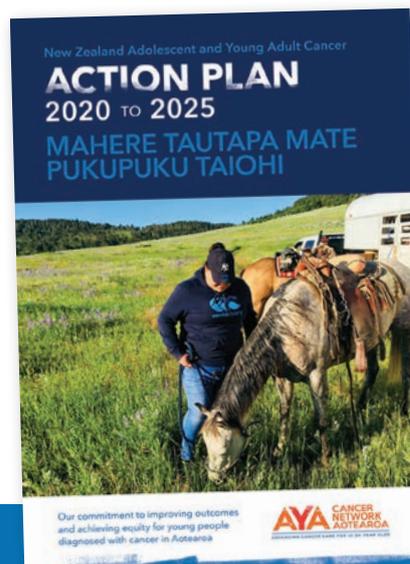
- ✗ An ethnic survival gap remains
- ✗ There has been no survival improvement for those AYA with CNS tumours in the past decade
- ✗ Survival varies according to where a young person lives.
- ✗ The 5-year survival rate for 15-24 year olds diagnosed with cancer in New Zealand is 5% lower than for those in Australia.

‘As a young Cook Island Māori woman I believe there is a gap in our system – sitting back and taking things, we’ve moved past this now. We want our voices to be heard. We have things to say and we want things addressed.’

AYA Advisory Group Member

Where to next?

It is for these reasons the AYA Cancer Network will continue to lead, prioritise and respond to the needs of Aotearoa’s young people. The recently launched New Zealand AYA Cancer Action Plan 2020 to 2025 describes where and how our attention will be focused over the next 5 years in order to ‘close the gap’ in AYA cancer.



GOAL: By 2025 all young New Zealanders diagnosed with cancer will have equitable access to high quality medical and supportive care regardless of where they live, their age or ethnicity.

To read the full incidence and survival report and to find out more about the AYA Cancer plan visit: ayacancernetwork.org.nz | Follow us on:

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AYA CANCER NETWORK AOTEAROA
ADVANCING CANCER CARE FOR 12-24 YEAR OLDS