

March 2020

Cancer in Adolescents and Young Adults

A companion report to Youth Cancer Quality Index:
Indicators of safe, quality cancer care, Private and
Public Hospitals 2014-2018



Message from the Chair

Although cancer incidence in Adolescents and Young Adults (AYAs) has decreased in the last 20 years and survival rates are very good for most cancers, AYAs face challenges that are unique from any other age group. Cancer and the treatment are complex and multifaceted with significant psychosocial implications. Treatment often requires multimodal therapies, long hospital stays and longer recovery times. This can impact the young persons' fertility, opportunities to establish meaningful relationships, and independence from their parent/caregiver; all key developmental milestones for this age group. These patients fall between two systems; paediatric and adult centres, adding to the complexity of coordinating treatment, and currently most lacking for AYAs; clinical trials. The potential result is harrowing and requires a health system which is aware, and capable of providing this much needed specialised AYA focus to ensure best possible outcomes in terms of survival, and success into adulthood. This is a companion report to the [Queensland Youth Cancer Quality Index](#), which provides a detailed, technical analysis of AYA cancer.



Dr. Rick Walker
Chair Youth Cancer Subcommittee



The cancer burden for adolescents and young adults is unique

Adolescent and Young Adult cancer patients have complex medical and psychosocial challenges which impact outcomes and survivorship.

Cancers in this age-group form approximately 1% of all cancer diagnoses in Queensland. While AYA cancer patients fare well, with 92% of patients alive five years from diagnosis, they face unique challenges which require specialised responses.

Cancer incidence is lower than in older adults, however, AYA cancer survivors will live 50 to 60 years beyond their diagnosis. Late effects from cancer and cancer treatment can continue to be issues throughout their lives. Navigating this in the midst of establishing a career, finding independence and developing relationships can add another layer of challenges unique to AYAs.

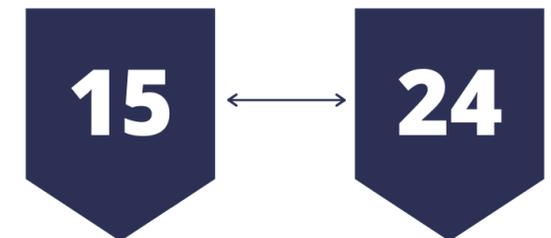
A significant need exists for specialised AYA health care professionals to assist the young person navigate the cancer, the treatment and the psychosocial impact. Health care professionals well versed in these challenges can minimise the short and long term cancer impact for young people with cancer.

IN QUEENSLAND

231



**INDIVIDUALS
AGED**



(AYAs)

**were diagnosed
with cancer in 2018**

AYA cancers are different from those in children and adults

The most common cancers for AYAs are different from those in other stages of life, and can require more aggressive forms of treatment.

The most common cancers among AYA patients are melanoma, lymphoma, germ cell tumours, thyroid and appendix tumours. This is in contrast to older adults who are more likely to develop cancers of the breast, colon and rectum, melanoma, lung and prostate.

While incidence rates vary by age across cancer groups, there are two cancers where peak incidence rates occur in the AYA age group: bone sarcomas and Hodgkin lymphoma.

Testicular cancer is also more common in the AYA group than in adults aged 40+.

Treatment is complex and invasive for these cancers, and as a result the impact psychosocially is significant.

Most common cancers by age

0-14

Leukemia
CNS and brain
Bone and soft tissue
Lymphoma



15-24

Melanoma
Lymphoma
Germ cell
Thyroid
Appendix

25-39

Melanoma
Breast
Thyroid
Colorectal
Testis
Cervix

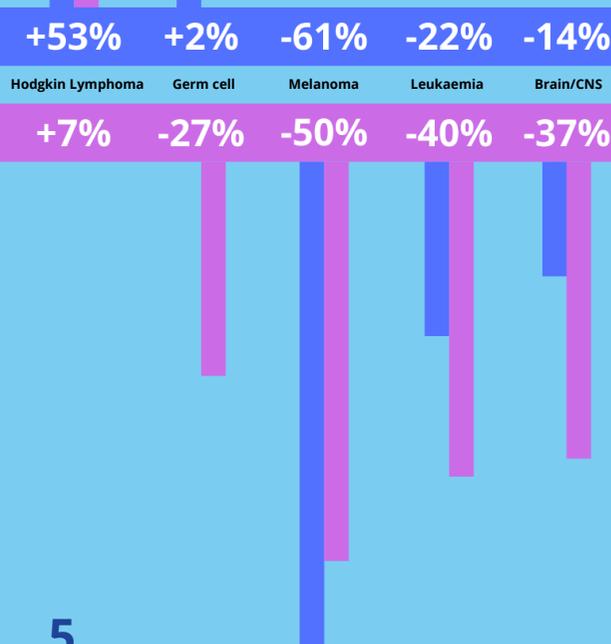


40+

Prostate
Melanoma
Breast
Colorectal
Lung

Percent change in age-standardised incidence between 1992-1996 and 2012-2016 for selected cancers

- Males
- Females



Between 1992 and 2016 there was an 18% decrease in the incidence of cancer among the AYA population



Cancer incidence in AYAs has decreased by almost 20% over the last two decades. This decrease is mainly due to falling rates of melanoma among AYAs.

Incidence of cancer among AYAs decreased from 43.5/100,000 in 1992-1996 to 35.6/100,000 in 2012-2016. The decrease was most prominent in melanoma, which fell from 18.5 to 8.3 per 100,000 over this period. Notable decreases were also evident for leukaemia and brain/CNS.

The preventative Sun Safety campaign in the early 1980's is the main contributor for decreasing melanoma rates.

Incidence rose for Hodgkin Lymphoma from 3.1 to 3.8 per 100,000. This was largely due to a 53% increase among males. Additional research is required to further understand this.

The largest increases were observed for appendix and thyroid carcinomas. This is largely due to a change in clinical practice which has led to an increase in detection, not necessarily an increase in incidence. Survival rates for these cancers are close to 100%.

Ten-year relative survival* for AYAs with cancer is almost 90%

Survival does however, vary by cancer type. Only 50-55% of patients with bone sarcomas or brain/CNS tumours survive ten years. Ten-year survival for AYAs with leukaemia and soft tissue sarcomas is also lower at 75%.

*The likelihood of people diagnosed with cancer surviving for ten years compared with similar people (same age and sex) in the general population

TEN-YEAR RELATIVE SURVIVAL

Cancer Type	1997-2001 (%)	2012-2016 (%)
Appendix tumours	96.6	97.9
Bone sarcomas	63.8	52.6
Ewing tumour	55.8	na
Osteosarcoma	59.8	51.0
Other bone tumour	91.1	100
Brain/CNS	52.6	55.0
Carcinomas*	89.9	86.8
Germ cell tumours	93.9	96.4
Gonadal (testicular/ovary)	94.2	96.9
Non-gonadal	90.0	85.9
Leukamias	51.8	74.1
Acute leukaemia	51.1	72.8
Chronic leukaemia	na	82.4
Lymphomas	86.3	93.3
Hodgkin lymphoma	96.1	92.4
Non-Hodgkin lymphoma	68.8	95.6
Melanomas	94.1	96.5
Soft-tissue sarcomas	79.7	75.2
Thyroid carcinomas	100	99.4
All cancers	86.9 %	88.9 %

*Carcinomas defined as per AYA SEER cancer groupings. See Appendix 1 of Queensland Youth Cancer Quality Index for further details.

na = not available

For further information, refer to [Queensland Youth Cancer Quality Index pages 12-13](#)



Some AYA cancers require less complex treatment

Treatment for patients diagnosed with **melanoma, appendix and thyroid*** cancer is relatively uncomplicated and survival is very good. Treatment most often involves simple surgery and typically has minimal effect psychosocially in comparison to other cancers common among AYAs. Recovery is generally quick and these patients tend to have the least contact with a cancer facility, which is appropriate for the needs of these patients.

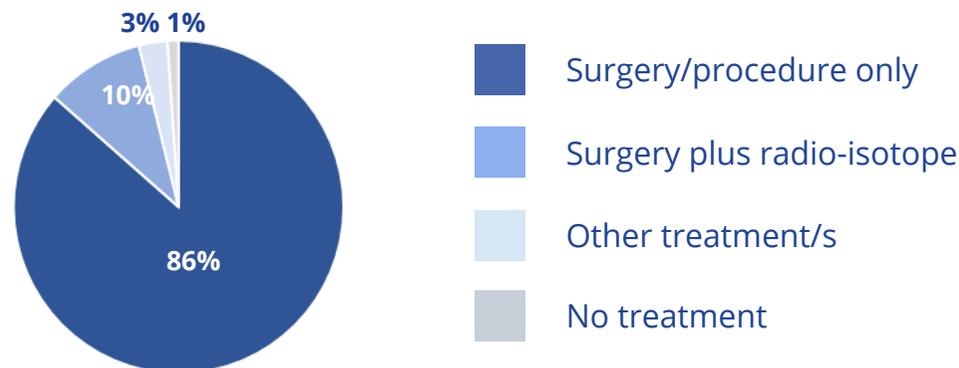
*Due to the decreased complexity of treatment, these cancers have been excluded from the remainder of the analysis

Of all diagnosed **appendix** cancers, most were the neuroendocrine type. This type of cancer has a very high survival rate, and are usually found as a result of treatment for appendicitis. Patients with appendix cancer were primarily treated with surgery, mainly appendicectomy. However, a quarter of patients with larger tumours had further major colorectal surgery.

Thyroid cancer patients most often had their thyroid removed surgically. Just over a third of patients were also treated with radioiodine-isotope (a mild form of oral radiation).

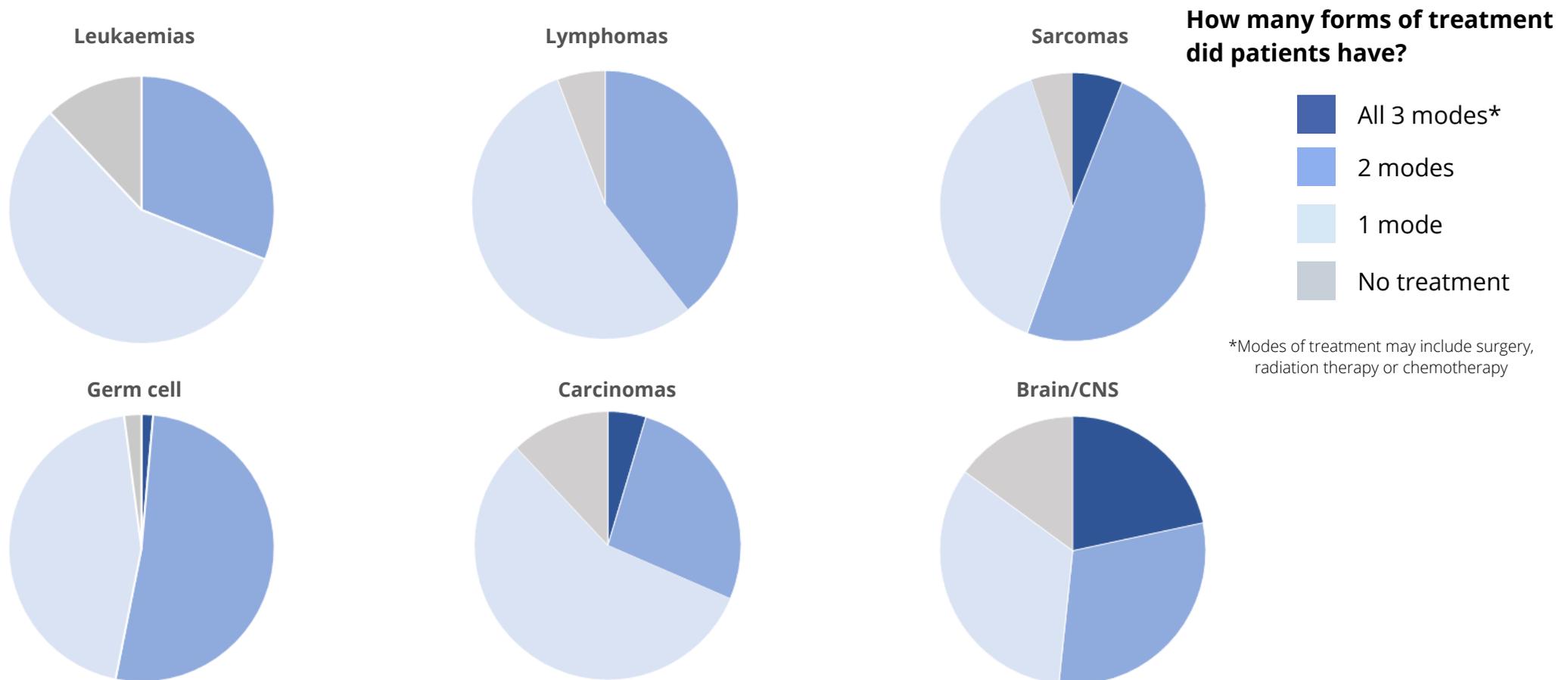
A high percentage of **melanoma** patients were treated in a community skin clinic with simple excision of the skin. 17% of patients required additional lymph node surgery.

Treatment breakdown for melanoma/appendix/thyroid cancers

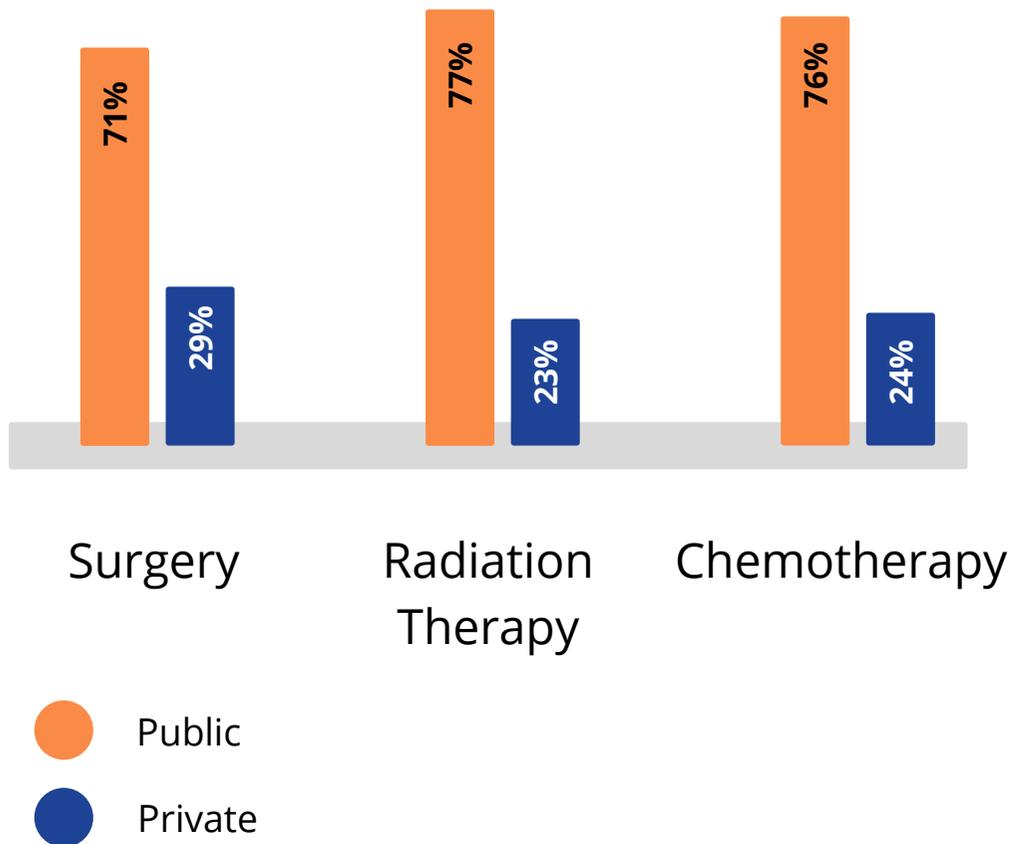


Many AYAs undergo complex, multimodal treatment

Between 30% and 40% of those with a diagnosis of leukaemia or lymphoma will receive both chemotherapy and radiation therapy. Similarly, over half of brain/CNS cancer patients will receive two or three modes of treatment. Multimodal cancer treatment increases the cancer burden experienced by patients with an increased potential for side effects, late effects and a longer recovery time.



Cancer treatment for AYAs is mainly delivered in public hospitals



During the period 2014 to 2018 the proportion of treatment delivered in public hospitals was:

- 71% of surgery
- 77% of radiation therapy
- 76% of chemotherapy

*Melanoma, appendix and thyroid cancers have been excluded

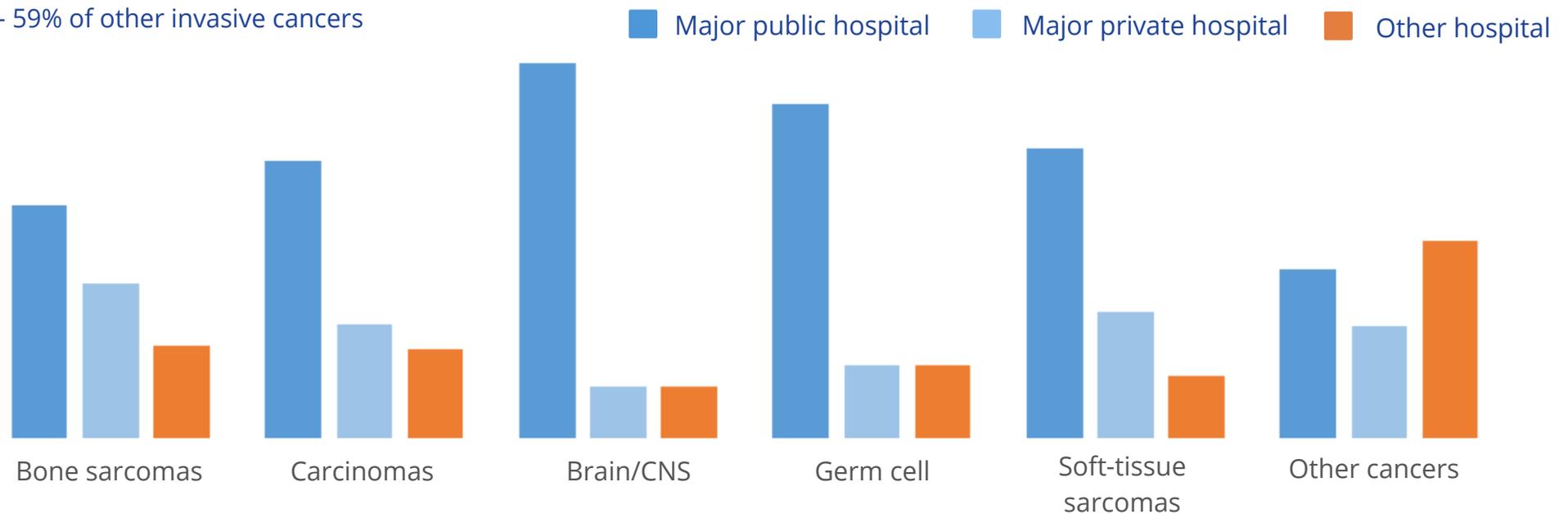
Most AYA cancer surgery is performed in a major hospital

Queensland's major hospitals are performing surgical resection for:

- 85% of germ cell tumours
- 89% of brain/CNS tumours
- 87% of soft-tissue sarcomas
- 82% of carcinomas
- 81% of bone sarcomas
- 59% of other invasive cancers

Major public hospitals offer AYA specialist care which is optimal for the complex needs of AYA cancer patients. These specialists also connect the young person to community supports during treatment and survivorship, when patients will have less regular contact with a major hospital.

*Melanoma, appendix and thyroid cancers have been excluded





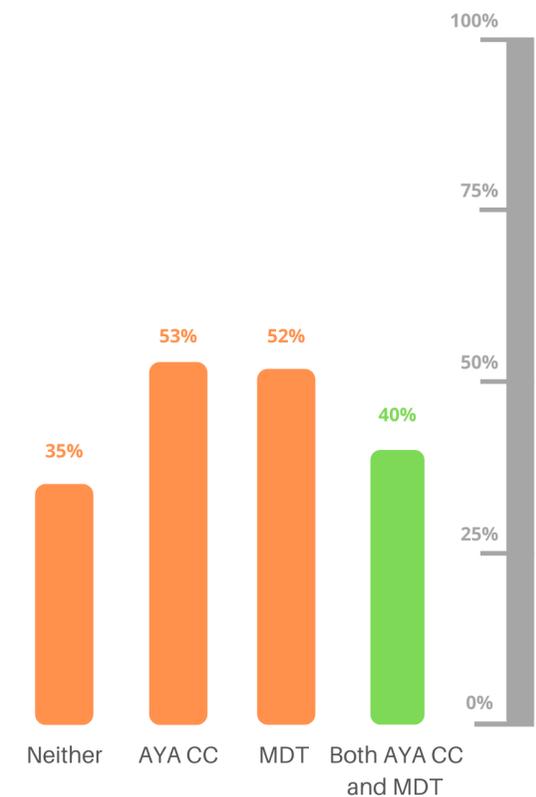
Only 40% of patients had access to a MDT & an AYA Care Coordinator*

AYA cancer patients should have access to a multidisciplinary team (MDT) and an AYA care coordinator*

Almost half of patients treated for their cancer did not have their treatment plan discussed at a MDT, and similarly, 47% did not have access to an AYA care coordinator.

A treatment MDT ensures a patient is discussed with doctors from different disciplines to create an individualised treatment plan; a gold standard of care that should be available to all cancer patients. An AYA care coordinator ensures discussions regarding fertility, coping, developmental milestones take place and where gaps exist, referral to appropriate health care professionals are made.

*Care coordinators are specialist nurses or social workers



* Includes only patients undergoing treatment. Melanoma, appendix and thyroid cancers have been excluded.

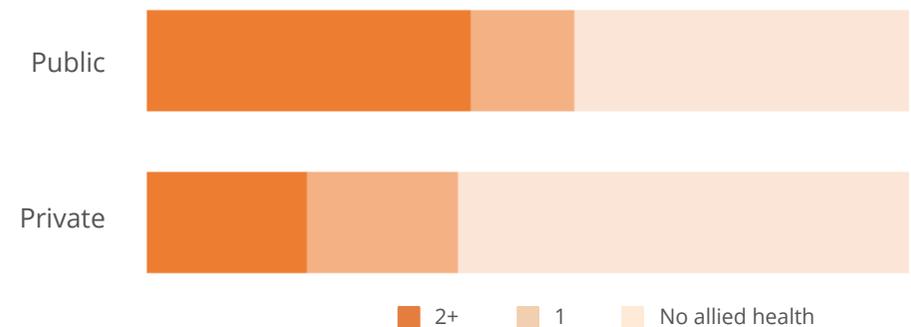
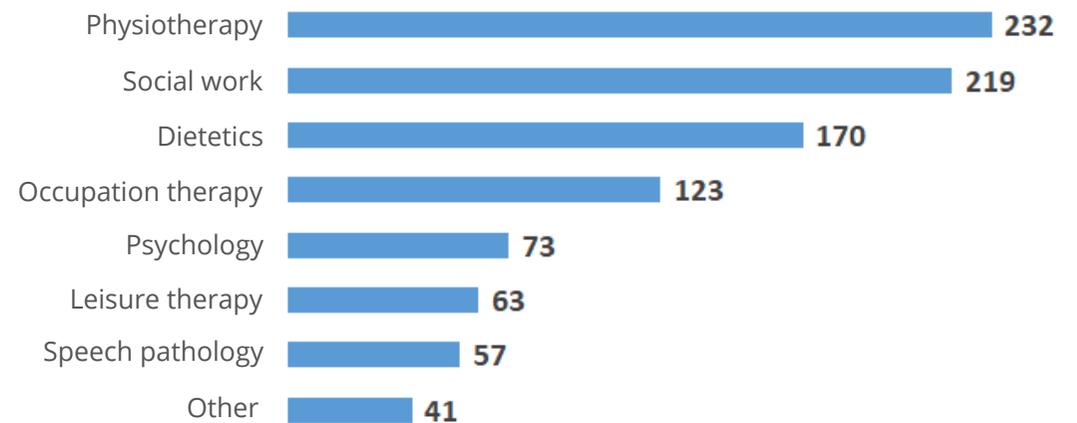
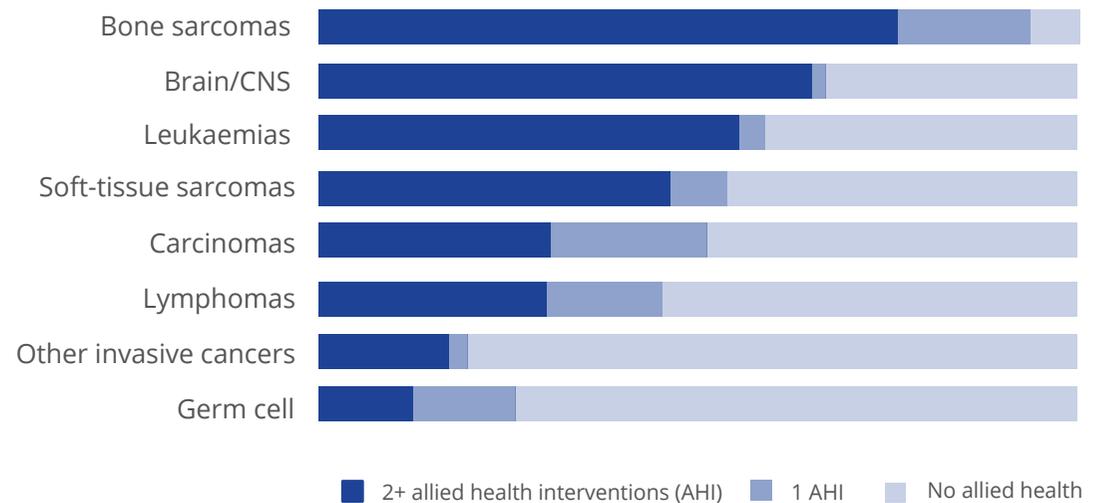
Allied health forms a crucial part of support and recovery

During hospital admissions, young people are able to access allied health support services. These may include physiotherapy, dietetics, occupational therapy, psychology, speech pathology, music therapy and more. Fewer than half of AYA accessed allied health during their treatment (based on in-hospital episodes of allied health)

Patients diagnosed with sarcomas, leukaemia and CNS and brain cancers are most likely to receive allied health interventions.

The most commonly accessed allied health interventions were: physiotherapy, social work, dietetics and occupational therapy.

Public patients were more likely to access allied health with 43% of public patients utilising two or more types of allied health interventions.



*Melanoma, appendix and thyroid cancers have been excluded

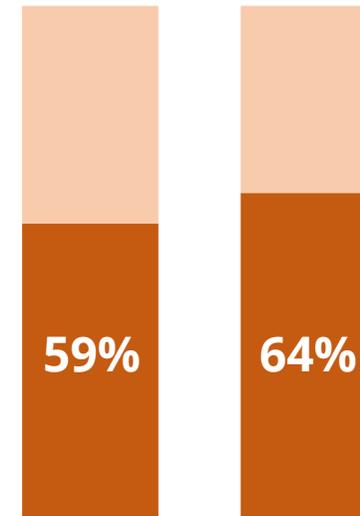
AYA cancer patients experience a **double trauma**; firstly the cancer diagnosis and secondly, the potential loss of fertility



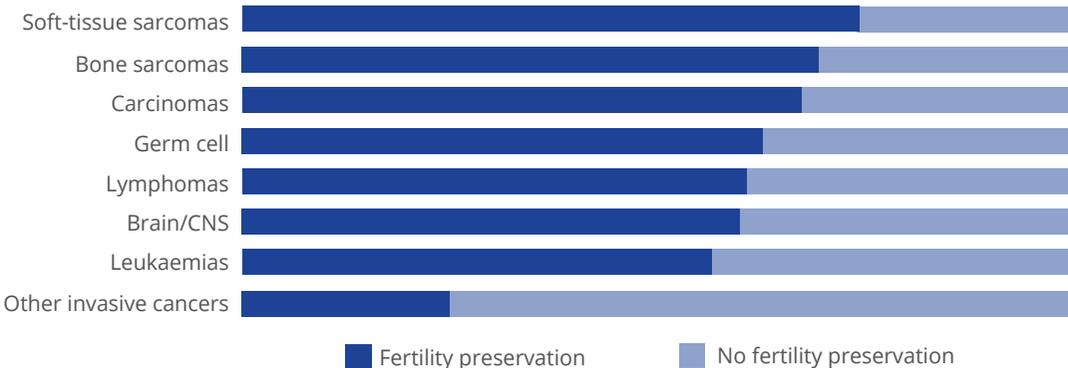
Some cancer treatments can have toxic affects on the reproductive organs and affect the young persons ability to conceive a child in the future. A fertility specialist can discuss all the options with the young person, and as appropriate, plan the fertility preservation procedure.

There are some cases in which fertility preservation may not be an option. These cases are not the majority and young people with cancer are falling short of having fertility preservation.

Females **Males**



■ Fertility preservation ■ No fertility preservation



Less than 60% of female patients having chemotherapy underwent fertility preservation

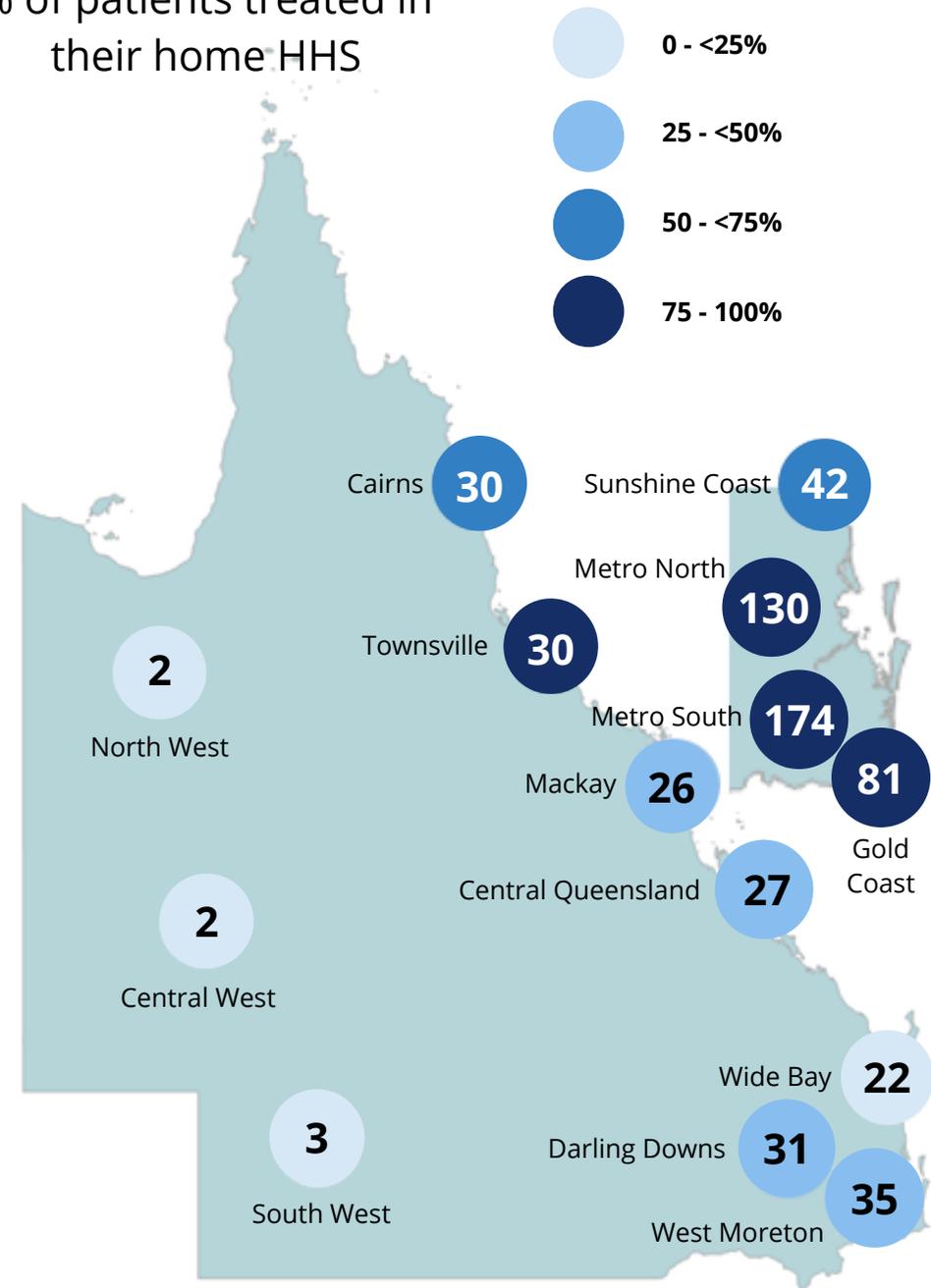
*Melanoma, appendix and thyroid cancers have been excluded

More than half of AYA patients had to travel for treatment

For every 10 patients needing to travel for treatment, 9 travelled to Brisbane. The burden of travelling for cancer treatment is further highlighted for AYA cancer patients. Travelling for treatment and being away from their home environment makes it much more difficult to establish themselves as independent from their parent/s, rather, needing their parent more for financial and emotional support. Being away from their peer group impacts the ability to make vital friendships and romantic relationships. Missed school and work can also put them behind and at a disadvantage.

*Melanoma, appendix and thyroid cancers have been excluded

% of patients treated in their home HHS



81 denotes 81 patients reside in this HHS

What else can be done to improve outcomes for AYA cancer patients?



Clinical trials - Increased funding, improved participation and seamlessly offering trials across paediatric and adult hospital settings are solutions to current issues facing AYA clinical trials. Clinical trials hold the answers to better understand AYA cancer biology, to enhance tailored treatment and improve understanding of the cancer impact psychosocially.

AYA psychosocial MDT - AYA psychosocial MDT's are an extension of best practise for AYA cancer patients, similar to treatment MDTs for all cancer patients. A team that have the tools and skills to ensure that not only fertility, education, career, and peer relationships have been addressed, but also ensure the patient has been reviewed at a treatment MDT, and that possible clinical trial participation has been considered. Membership may include, but is not limited to, a psychologist, social worker, AYA nurse coordinator, representative from key NGO(s), and medical oncologist.

Collaboration among clinicians and consumer representatives - Decisions driven equally by best clinical advice from experts and consumer representatives with personal experiences of AYA cancer will lead to improved patient and health team communication, compliance with treatment and increased likelihood of the young person seeking assistance when needed. Patients and families are more likely to have an improved experience with the cancer when a collaborative approach is adopted.

Continued support after treatment (Survivorship) - AYA cancer patients will live 50-60 years beyond their cancer diagnosis and as a result, are at a greater risk of experiencing late effects. Late effects may occur many years after treatment has been completed and can include second cancers, organ dysfunction and psychosocial issues. Long term follow up can assist with early detection and intervention and maximise the quality of health for young cancer patients.

About us

Cancer Alliance Queensland brings together The Queensland Cancer Control Safety and Quality Partnership (The Partnership), Queensland Cancer Control Analysis Team (QCCAT), and the Queensland Cancer Register.

Cancer Alliance Queensland supports a clinician-led, safety and quality program for cancer across Queensland. As a gazetted Quality Assurance Committee, a key role of The Partnership is to provide cancer clinicians, Hospital and Health Services, hospitals, and treatment facilities with cancer information and tools to deliver the best patient care. Since 2004, QCCAT have compiled and analysed a vast amount of information about cancer incidence, mortality, treatment, and survival. This matched and linked data is housed in the Queensland Oncology Repository, which contains approximately 50 million records from 1982-2020.

Note from the team

We hope this impact report gives you some insights into the innovation employed by Cancer Alliance Queensland. Our work spans the continuum of cancer control from diagnosis to multidisciplinary care through to cancer treatment, end of life, and survivorship and cuts across that continuum with initiatives to monitor and improve cancer system performance and mobilise evidence to drive service improvements.

For a more detailed version of the report, including definitions of terms and methodology descriptions, go to the [Queensland Youth Cancer Quality Index 2014-2018](#)

Should you have any questions about Youth Cancer, or require support, visit [Queensland Youth Cancer Service](#) or call (07) 3068 4176.

We gratefully acknowledge past and present members of The Partnership and individual members of QCCAT who have conceived many of the original ideas and made significant contributions to the Cancer Alliance Queensland program of work.

We thank the members of the Youth Cancer Subcommittee for their valuable comments and leadership: Rick Walker (Chair), Ashleigh Sullivan, Lucy Holland, Po Inglis and Kirk Morris.

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The report was prepared by Danica Cossio, Pardeep Dhanda, Nathan Dunn and Shoni Philpot and (QCCAT). We thank Professor David E Theile AO for his guidance throughout the production of this report.

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