

Youth Cancer Services: Evaluation Report Summary

CANTEEN & NOUS GROUP

May 2024

Youth Cancer Services (YCSs) provide specialist, age-appropriate medical treatment and psychosocial support for young cancer patients aged 15 to 25 at hospitals around Australia.

Canteen engaged Nous Group (Nous) to evaluate Phase 4 of the YCS initiative (2020-2024). The evaluation team used a mixed-methods approach, consulting a range of stakeholders and analysing YCS activity data, clinical trials data, program documents and other literature. This report summarises the evaluation findings.

We would like to thank everyone who has shared their time and knowledge to support this evaluation. We are delighted to share this summary with you.

Nous Group acknowledges Aboriginal and Torres Strait Islander peoples as the First Australians and the Traditional Custodians of country throughout Australia. We pay our respect to Elders past, present and emerging, who maintain their culture, country and spiritual connection to the land, sea and community.

WE CONSULTED 67 STAKEHOLDERS THROUGH 25 CONSULTATIONS

11

Service managers and clinical leads

25

YCS multidisciplinary team representatives

9

Executive contract holder representatives

10

Youth advisory group representatives

4

Other key stakeholder group representatives

8

YCS strategic advisory group representatives



About youth cancer

Each year, approximately 1,300 adolescents and young adults (AYA) between the ages of 15-25 are diagnosed with cancer in Australia.¹ The impact of a cancer diagnosis presents a unique set of challenges for people in this age cohort due to the rapid biological, psychological and social development that takes place during this period of life. At a time when young people are attempting to define themselves, cancer can significantly disrupt their social relationships, employment, education and financial stability.²

AYAs with cancer have different medical and psychosocial needs to children and adults.^{2,3} YCSs are the only cancer services that are focused on AYAs. Around three quarters of AYAs with cancer are with a YCS.⁴ **This means a quarter may not be receiving age-appropriate care, which can significantly impact on the efficacy of their cancer treatment and their broader health and wellbeing.**

When I was 18, I was trying to get independence and was trying to set out who I wanted to become. A lot of 15-25-year-olds are having those experiences. When you are hit with a diagnosis, you comprehend and understand what is happening, but your parents step in and you don't take charge. Doctors don't know who to talk to, don't know how to distribute information and there is a lot of confusion from lots of stakeholders.

BETWEEN 2010-2018, **9,142** AYA WERE DIAGNOSED WITH CANCER. SPECIFICALLY:¹



HODGKIN LYMPHOMA was the most diagnosed cancer, followed by melanoma of the skin, testicular germ cell cancers, carcinoma of the thyroid and carcinoma of the colon and rectum.¹

In 2013-2017, bone cancers and central nervous system cancers, and soft tissue sarcomas were the **LEADING CAUSE OF CANCER MORTALITY IN AYAs.**¹

In the past three decades, there has been a **266% INCREASE IN BOWEL CANCER** incidence rates for AYAs.³

In 2016-2020 **458 AYAs DIED FROM CANCER.** This reduced slightly from 2011-2015, where 499 AYAs died from cancer.¹

In 2015-2016, health system expenditure on AYAs with cancer was around **\$200M.**⁶

1. Australian Institute of Health and Welfare (AIHW), Cancer in adolescents and young adults in Australia (2023), Canberra.
2. K Leuteritz, M Friedrich, A Sender, Y Stobel-Richter & K Geue, Life situation and psychosocial care of adolescent and young adult (AYA) cancer patients – study protocol of a 12-month prospective longitudinal study (2017), National Library of Medicine.
3. Patterson, P.; Allison, K.R.; Bibby, H.; Thompson, K.; Lewin, J.; Briggs, T.; Walker, R.; Osborn, M.; Plaster, M.; Hayward, A.; et al. The Australian Youth Cancer Service: Developing and Monitoring the Activity of Nationally Coordinated Adolescent and Young Adult Cancer Care. *Cancers* (2021).
4. Canteen, YCS Activity Data (2024).
5. A Tsirtsakis, Bowel cancer incidence rates up 266% among 15-24-year-olds. The Royal Australian College of General Practitioners (2023).
6. AIHW, Health system expenditure on cancer and other neoplasms in Australia 2015-16 (2016), Canberra.

About YCS

The YCS initiative was established 15 years ago to provide AYAs with cancer – as well as their families and carers – with specialist, age-appropriate clinical treatment and psychosocial support to improve the overall health outcomes and survivorship rates of AYAs with cancer.

YCSs are the only age-specific cancer service for AYAs in Australia. Care is provided by multidisciplinary teams, including specialist doctors, nurses and allied health workers.

The YCS are delivered differently across Australia to address the diverse needs of AYAs with cancer in each jurisdiction. There are five YCS spanning all of Australia: ACT/NSW, QLD, SA/NT, VIC/TAS and WA.

The YCS initiative was in Phase 4 of service delivery (2020-2024) at the time of the evaluation. The Australian Department of Health and Ageing committed \$22 million for Phase 4, which was administered by Canteen.

The YCS provide clinical treatment and holistic supports to AYAs with cancer, including:

Medical care across the cancer control continuum

Psychosocial support and counselling

Care navigation

Exercise and rehabilitation support

Fertility preservation support

Clinical trial opportunities

Survivorship support

Financial and accommodation support

The YCS initiative promotes best practice in AYA cancer care through:

- ▶ Professional development and networking for health professionals
- ▶ Data and research activities
- ▶ Engagement with young people to inform the design and delivery of YCSs



Canteen and YCS have always shone a light on young people with cancer, their unique needs and best care practices. They have always expressed the need to focus on this group which has not always been appreciated in terms of research, medicine, specific care, etc.

Strategic Advisory Group representative



The National YCS team have supported a lot of professional development in QLD including our attendance at national conferences, support in local education delivery, running annual workshops for satellite sites, and succession planning for partner sites.

Youth Cancer Services Manager



Before I was diagnosed, I had no idea the YCS existed, but wow I am so glad that it does. It helped save me.

Youth Advisory Group representative

WHAT DID WE FIND?

Overall, the YCS initiative provided important access to age-appropriate clinical care and treatment, and holistic supports for AYAs with cancer across Australia, and improved their quality of life.



I was always at the YCS. They would always text and check in. If I had a weird side effect, I could just call and they would make me feel better. YCS staff are expert in their field and it is really reassuring. They are the middle person between the doctors and the wider treatment team. Having the nurse specialists was incredible. I saw the exercise physio once a week in the gym, and you could chat about anything with them. One of them helped me out with university – the staff member would help me with administration and supported me to get a learning access plan so I could get exemptions from exams and assignments when I was feeling ill. It made such a difference.

Youth Advisory Group representative

Reach of the YCS

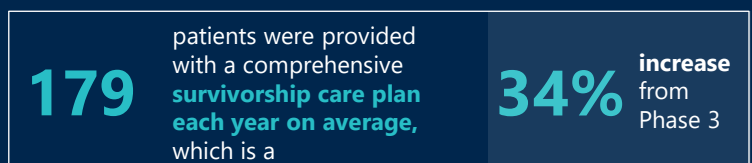
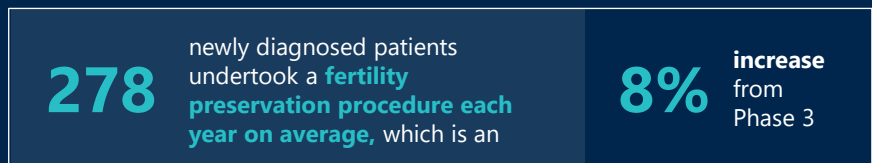
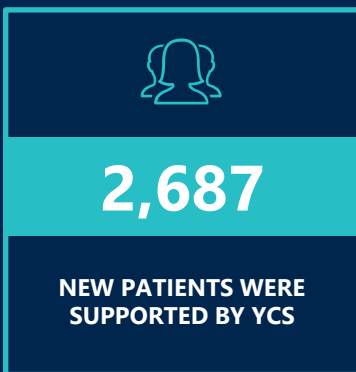
The five YCSs expanded their reach and delivered care to slightly more AYAs with cancer in Phase 4 than previous phases. There was a **6% increase** in the average annual number of new patients supported by the YCS multidisciplinary teams, and a significant uptick in other core YCS activities since Phase 3. On average, the YCS supported 1,914 AYAs with cancer each year in Phase 4 (as at March 2024), which was 20% above the target set by the Department of Health and Aged Care.¹



The thing I valued the most was that the team was so supportive and I was always aware of the supports that were available. It was a person-centred approach – I could decide what support I wanted and what I didn't. It was really catered to my individual needs

Youth Advisory Group representative

IN PHASE 4 (as at March 2024):¹



1. Canteen, YCS Activity Data, July 2020 to March 2024 (data for the final quarter of Phase 4, April to June 2024, was not available at the time of writing because the evaluation was finalised in May 2024).

Fit-for-purpose model of care

Each YCS effectively iterated the model of care and operating model across jurisdictions to reflect diverse and dynamic operating contexts and needs. They delivered and operated the YCS differently, based on the needs of young people and unique context of the state or territory. The YCS were delivered primarily through 26 hospitals based across Australia.

Workforce constraints

The YCS initiative saw the delivery of a high-quality service across each jurisdiction despite significant workforce constraints and under-resourcing in certain jurisdictions. This was impacted by staff shortages in the broader health workforce. Staff from various jurisdictions, that provide in-person consultations in hospitals, reported funding their own transport to deliver YCS services. YCS staff from multiple jurisdictions reported working extended hours to accommodate staff shortages and highlighted the risk of burnout.

The COVID-19 pandemic

The YCS initiative was impacted by the COVID-19 pandemic, which exacerbated existing workforce recruitment challenges and hindered the ability of YCS to deliver in-person supports, particularly in jurisdictions that experienced lockdowns and restrictions. Despite the associated impacts of the COVID-19 pandemic, the YCS was able to significantly improve their telehealth capabilities, which has become part of their business as usual following the pandemic and supports greater accessibility of the service. Ongoing development of telehealth capabilities should continue to be a focus of YCS in the future to ensure all AYAs with cancer have access to the YCS.

Professional development activities

The professional development activities delivered by the YCS strengthened the capability of YCS staff, promoted retention and helped to generate awareness of the unique needs of AYAs. The YCS initiative delivered a broad range of professional development activities to YCS staff and other health clinicians at both a national and jurisdictional level to strengthen capability and build awareness of AYA needs and best care practices.

Youth engagement

Youth engagement has been a priority of the YCS since 2013 and these activities significantly expanded during Phase 4 to contribute to enhancements across the Australian cancer sector. In Phase 4, 32 local Youth Advisory Group meetings were hosted across the country. Additionally, the YCS hosted two National Youth Cancer Consumer Forums (one in person and one online). The in-person forum was attended by 54 young patients and survivors from across the country.

National cancer care priorities

The YCS initiative was closely aligned with national priorities of the Australian cancer sector and led national strategic initiatives pertaining to AYAs with cancer, such as those outlined in AYA Vision 2033 and the Australian Cancer Plan.

Partnerships

The YCS strengthened partnerships at the national, jurisdictional and local levels. At a national level, the YCS partnership with Canteen was a key enabler for YCS service delivery. At a state level, State Governments have provided varying levels of funding to YCS and, in some jurisdictions, provided complementary supports, such as greater access to fertility preservation opportunities. At the local level, non-government organisations provided significant supports, such as accommodation and monetary assistance to AYAs during treatment.



I used YCS a lot during treatment. It was helpful having this sort of support while you are feeling extremely sick. The physical support allowed me to get some strength and feel better, deal with the treatment, and be more comfortable. It made me feel like I could still live my life.

Youth Advisory Group representative

Recommendations to enhance the YCS initiative

The evaluation identified seven recommendations to support continued implementation and increase the impact of the YCS initiative.

Service Delivery

1. Expand the reach and accessibility of the YCS across Australia by strengthening referral pathways within jurisdictions and strengthening YCS service delivery in high growth metropolitan areas, and in states that do not have a direct, or have limited YCS presence
2. Promote greater consistency of YCS care across Australia, while tailoring care to specific contexts
3. Empower AYAs with cancer, and those with lived experience of cancer, to play an active role in their care by continuing to invest in and support the YAGs across jurisdictions

Governance and funding

4. Facilitate long-term strategic planning for the YCS by strengthening governance and exploring complementary and sustainable local funding partnerships
5. Further strengthen the current and future workforce pipeline, and build capability to address the specific needs of AYAs with cancer

Partnerships

6. Explore additional partnerships at the national, jurisdiction and local levels to deepen the impact of the YCS

Data and analytics

7. Continue to promote greater data consistency across jurisdictions by improving patient data capture and providing clear guidance on KPIs and recommended data collection methods

Opportunities to further expand the impact of the YCS

The evaluation also identified six further opportunities to drive progress towards the strategic priorities of AYA Vision 2033 and Australian Cancer Plan.

1. Consider establishing new YCS sites in areas that have experienced significant AYA population growth to support equitable access to age-appropriate cancer care
2. Consider how YCS activities can be designed and delivered in a more equitable way for AYAs with cancer of all backgrounds
3. Contribute to the expansion of a robust evidence base to enhance the care and outcomes for AYAs with cancer
4. Consider opportunities to embed a patient-centred approach more deeply to YCS activities, particularly in jurisdictions without a direct YCS-presence
5. Consider expanding and extending YCS supports to deliver more robust survivorship care
6. Consider how the YCS could collaborate with other stakeholders to deepen their impact, and contribute to shared national goals across Australia's cancer sector



We see patients across the entire state. Every single hospital. Telehealth has allowed us to connect with people in regional and remote areas.

Youth Cancer Services Manager

The YCS National Team have been helpful in a number of ways – decisions are made collaboratively and we feel like when we voice our input, we are always being heard

Youth Cancer Services Manager



A bigger idea of success

Nous Group is an international management consultancy operating across Australia, New Zealand, the United Kingdom, Ireland and Canada. We are inspired and determined to improve people's lives in significant ways. When our strengths complement yours and we think big together, we can transform businesses, governments, and communities.

We realise a bigger idea of success.

A bigger idea
of success

750

PEOPLE

75

PRINCIPALS

5

COUNTRIES

+80.7

2020-22 NET PROMOTER SCORE
– global consulting average: +76.6