SaxInstitute

Final Report

Youth Cancer Services
Phase 3
Final Evaluation Report

Prepared by the Sax Institute for Canteen

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Youth Cancer Services Phase 3 Final Evaluation Report

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Acronyms and abbreviations

ACT	Australian Capital Territory
AYA	Adolescents and young adults, persons aged 15-25
AYCF	Australian Youth Cancer Framework
CMO	Chief Medical Officer
CoP	Community of Practice
DAG	Data Advisory Group
DoH	Department of Health
FTE	Full Time Equivalent
GAYAC	Global Adolescent & Young Adult Cancer Congress
HHS	Health and Hospital Service (Queensland)
JHCH	John Hunter Children's Hospital
KPIs	Key Performance Indicators
MDT	Multidisciplinary team
NSW	New South Wales
NT	Northern Territory
NYAG	National Youth Advisory Group
QLD	Queensland
QCH	Queensland Children's Hospital
RAH	Royal Adelaide Hospital
RPAH	Royal Prince Alfred Hospital (NSW)
SA	South Australia
SAG	Strategic Advisory Group
SDAG	Service Delivery Advisory Group
TAS	Tasmania
VIC	Victoria
WA	Western Australia
YAG	Youth Advisory Groups (jurisdictional)
YCS	Youth Cancer Services

Executive Summary

Introduction

The Youth Cancer Services (YCS) is a national initiative focused on improving services, support and the coordination of care for cancer patients between the ages of 15-25 years. The YCS initiative commenced in 2009, and is a partnership between Canteen, the Commonwealth Department of Health, state and territory governments and the YCS teams across Australia. The initiative includes the YCS, which is delivered across 26 hospitals nationally, and three national projects (workforce development, the national minimum data set on young people with cancer, and research in AYA cancer survivorship). The YCS is delivered by specialised multidisciplinary teams who provide information and support to young people living with cancer and link them to appropriate clinical services and care coordination. A goal of the YCS is to enable access to nationally consistent age-appropriate cancer treatment and support from multidisciplinary teams across five jurisdictions: NSW/Australian Capital Territory (NSW/ACT), Queensland, Victoria/Tasmania (VIC/TAS), South Australia (SA) and Western Australia (WA).

Purpose of this report

The Sax Institute, in partnership with Professor Marion Eckert, Director, Rosemary Bryant AO Research Centre, were engaged by Canteen to evaluate Phase 3 of the YCS. This report assesses implementation of Phase 3, factors that influenced implementation, and considerations for future strategy development.

The evaluation used a mixed-method design, which included review and analysis of quarterly activity data collected by YCS jurisdictions and collated by Canteen, a review of existing documentation and other secondary data, and consultations with a range of stakeholders involved in the delivery of YCS across Australia. In total 34 consultations were conducted with 76 individuals across all five YCS jurisdictions including YCS multidisciplinary teams, non-YCS clinicians, state government and hospital representatives, Canteen executives and Canteen advisory groups.

Findings

The evaluation findings highlight the success of the YCS partnership in supporting AYAs with cancer to receive age-appropriate care. In Phase 3, the reach of the YCS continued to grow, with the number of new and recurring patients increasing from 1,417 in the final year of Phase 2, to 1,647 in 2017-18 and 1,759 in 2018-19. The results suggest that continued significant growth of the YCS is unlikely, based on current resources, as most YCS services have reached capacity.

The activity data demonstrates that the national YCS initiative provided multidisciplinary care and psychosocial support to many AYAs along the cancer care pathway. KPI performance data highlights that the initiative was implemented in line with the requirements of the DoH contract, and that most deliverables and performance targets were met. Consultations with representatives from all jurisdictions identified a dedicated, passionate YCS workforce with a strong shared vision of AYA-specific supportive care. This strength was also identified in the Phase 2 evaluation.

The Experience of Care survey found that AYAs and their family members/supportive others valued the support and care provided, that was tailored to the specific needs of AYAs. Results indicate there is a high level of satisfaction with the care provided by the YCS, with almost all patients and family members/supportive others reporting that they were satisfied with the support and assistance received from the YCS. As well, 89% of patients reported that the YCS generally treated them like an AYA, which was just right (with 6% who were not sure, and 6% who responded that they were treated like an older adult), and 89% of family members/supportive others also reported that their loved one was treated like an AYA.

Throughout Phase 3 Canteen convened significant expertise in the form of the Strategic Advisory Group (SAG), the Data Advisory Group (DAG), the Service Delivery Advisory Group (SDAG) and the National Youth Advisory Group (NYAG). These groups are a valuable source of guidance for Canteen, and there were a number of suggestions from the SAG for how the value of this group could be optimised in Phase 4, including: prioritising the strategic areas where advice is required; increasing involvement in the progress of clinical trials and survivorship care; providing advice on variation across jurisdictions and strategies for addressing this where needed; and advising on Key Performance Indicators, SAG membership, and strategies for maintaining Canteen’s role as the national peak body for AYA cancer.

Several successful workforce and network development events were implemented in Phase 3, including four Community of Practice events and the Adolescent and Young Adult Cancer Global Accord Conference (GAYAC). Positive feedback was received for all these events, although the qualitative consultations suggest further streaming and targeting of workforce development strategies could be valuable, especially given that many in the YCS network now have considerable experience and expertise, as the YCS is no longer a new initiative in cancer care.

The evaluation identified a number of opportunities for enhancing the YCS initiative, including: enhancing the role of the SAG in strategy development; developing the youth leadership approach; revising activity data definitions and templates; further streaming of workforce development activities; optimising communication between Canteen and the YCS teams in relation to governance processes and decision-making; and continuing to facilitate relationships between YCS teams and trial consortia.

This evaluation was conducted prior to the COVID-19 pandemic, which is of particular concern for the YCS as AYA cancer patients are an at-risk population. The response of YCS to the COVID-19 pandemic may influence models of care in the future.

The findings highlight the success of the YCS partnership in supporting AYAs with cancer to receive age-appropriate care. It was found that Canteen was effective in administering the initiative and was instrumental in promoting and co-ordinating nationally consistent practice, data collection, and access to clinical trials across the national network. The advocacy role of Canteen was consistently identified as a key achievement, with the recent success in securing funding for AYA clinical trials cited as a positive example of this leadership. The YCS teams include a dedicated, passionate workforce with a strong shared vision of AYA-specific supportive care, with considerable evidence of the achievements of the YCS teams in delivering information and support to young people living with cancer, including social and emotional support, and linking them with appropriate services.

Introduction

Background

Youth Cancer Services (YCS) is a national initiative focused on improving services, support and the coordination of care for cancer patients between the ages of 15-25 years. The YCS initiative commenced in 2009, and is a partnership between Canteen, the Commonwealth Department of Health, state and territory governments and the YCS teams across Australia. The initiative includes the YCS, which is delivered across 26 hospitals nationally, and three national projects (workforce development, the national minimum data set on young people with cancer, and research in AYA cancer survivorship). The YCS is delivered by specialised multidisciplinary teams who provide information and support to young people living with cancer and link them to appropriate clinical services and care coordination. A goal of the YCS is to enable access to nationally consistent age-appropriate cancer treatment and support from multidisciplinary teams across five jurisdictions: NSW/Australian Capital Territory (NSW/ACT), Queensland, Victoria/Tasmania (VIC/TAS), South Australia (SA) and Western Australia (WA).

In 2010–2014, 4,843 new cases of cancer were diagnosed in young Australians[i] - an average of 969 young people per year. While the total number of new cases of cancer diagnosed in Adolescents and Young Adults (AYA) increased from 3,836 in 1985–1989 to 4,843 in 2010–2014, the age-standardised incidence rate for all cancers combined in AYAs has decreased more recently, from 330 new cases per 1 million in 1995–1999 to 308 new cases per 1 million in 2010–2014. This decrease in the age-standardised incidence rate is largely attributable to a reduction in melanoma. The six most commonly diagnosed cancer types for AYAs in 2010-2014 were Melanoma (15% of new cancers), gonadal germ cell cancer (14% of new cancers), Hodgkin’s lymphoma (14% of new cancers), Thyroid carcinoma (9% of new cancers), colorectal carcinoma (7% of new cancers) and non-Hodgkin’s lymphoma (6% of new cancers). [ii] Around 77% of AYA patients are from NSW, Victoria and Queensland (see Table 1 for incidence by all states and territories).

Table 1 - Incidence of all cancers (excluding melanoma) by state/territory, 15-24 years, 2009-13

State/Territory	Number	Rate	ASR	% of all cancers
New South Wales	1,426	295.5	292.1	35%
Victoria	913	236.5	232.8	23%
Queensland	768	245.1	242.8	19%
Western Australia	465	279.9	276.2	12%
South Australia	273	247.6	245.0	7%
Tasmania	88	266.6	267.0	2%
Australian Capital Territory	77	264.9	257.0	2%

State/Territory	Number	Rate	ASR	% of all cancers
Northern Territory	29	161.7	152.6	<1%
Australia	**4,039**	**262.5**	**259.2**	**100%**

Source: AIHW, 2018

For young people with cancer, the journey is exceptionally challenging, occurring at a very significant period in their lives as they transition from childhood to adulthood. A cancer diagnosis can interrupt this developmental pathway, sometimes with significant consequences. These can include increased reliance on parents limiting privacy and impacting identity formation; negative body image affecting relationships, intimacy and emotional maturity;[iii] and concerns about fertility.[iv] Cancer and its treatment can also interrupt education, training and employment pathways impacting the young person's career and financial prospects.[v]

While survival rates for cancer among AYA overall are high (around 89% 5-year relative survival), there are a growing number of young cancer survivors living with a range of significant, life-changing effects of cancer and its treatment. For cancers with poorer survival rates, it is believed that there are a number of factors that may contribute to this outcome, including: the distinct biology of the cancers encountered in this age group; the physiology of adolescents and young adults and their response to treatment;[vi] diagnoses of rare cancers[vii] and poor access to clinical trials.[viii]

Purpose of this report

The Sax Institute, in partnership with Professor Marion Eckert, Director, Rosemary Bryant AO Research Centre, were engaged by Canteen to evaluate Phase 3 of the YCS. This report assesses implementation of Phase 3, factors that influenced implementation, and considerations for future strategy development.

History of the YCS

The YCS partnership between Canteen, the DoH, state and territory governments and the YCS teams started in 2009, with the aim of delivering specialist multidisciplinary treatment and support services to AYAs with a cancer diagnosis across Australia. YCS is delivered through 26 hospitals nationally (see Figure 1 - YCS jurisdictions and hospitals). In the financial year 2018-2019, 1,759 new and recurring patients were supported by YCS nationally, including 509 newly diagnosed patients (based on activity data provided by each YCS jurisdiction).

Figure 1 - YCS jurisdictions and hospitals

In Phase 1 (2009-12), the Commonwealth Government provided $15 million in funding to Canteen to support the YCS. Funds contributed to youth-specific hospital roles and the creation of youth-friendly environments in some hospitals. Canteen also used funding to create a patient dataset, develop guidelines on fertility preservation, facilitate psychosocial support and early diagnosis, and develop online graduate certificate and diploma courses in AYA cancer care.

In Phase 2 (financial years 2013-17) the Commonwealth Government provided $17.88 million to support five YCS jurisdictions covering all Australian states and territories and implementation of three national initiatives: The National YCS network, the National Research Agenda, and National Data Collection Strategy. Phase 2 demonstrated the significant reach of the national YCS network. On average, the YCS reached 68% of all AYAs diagnosed with cancer in Australia across the four years, with a 55% growth in the total number of young people directly supported by YCS nationally from 2013 to 2017.[ix]

Phase 3 of the YCS

Phase 3 (financial years 2017-20) was supported by $14,465,264 funding from the Commonwealth Government and $288,297 from Canteen, which was allocated to the following areas: [x]

Table 2 – YCS funding Phase 3

Activity	Funding
Service Delivery	$10,817,015.00
National Projects	
Data	$449,837.00
Research	$405,000.00
Best Practice	$1,617,922.00
Administration	$1,463,788.00
Total	**$14,753,562.00**

Source: Canteen

This phase focused on consolidating and strengthening national YCS delivery and delivering three national initiatives, with the aim of improving services, support and the co-ordination of care for AYAs aged 15-25 years with cancer. Phase 3 included the following activities, as listed in the DoH contract:

Table 3 - YCS activities, as listed in the Phase 3 DoH contract

- Assist with ensuring that multidisciplinary teams are maintained to provide information and support to young people living with cancer and link them with appropriate services
- Provide facilities for treatment and support for young people, including social and emotional support
- Implement a national minimum data set on young people with cancer
- Facilitate young patients' access to clinical trials, and
- Develop and implement national and local strategies to support the delivery of high-quality youth cancer services – which include but are not limited to:
    - Building capacity through workforce development
    - Ensuring collaboration and consistency across the Hubs[1] through network development
    - Contributing to the AYA oncology evidence base through the provision of funding to support and conduct research in AYA cancer survivorship, and
    - Improving survivorship care for AYAs by establishing referral pathways from acute care to high quality follow-up survivorship care

Phase 3 continues the partnership model between the DoH, Canteen, state and territory governments and the YCS teams to support services across Australia in the five jurisdictions. The role of each key stakeholder in the initiative is set out below:

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[1] Hubs refer to the different jurisdictions and hospitals who deliver YCS

- The **Department of Health** provides Commonwealth funding to Canteen, and monitors activity through annual reporting including eight Key Performance Indicators (KPIs - see Appendix 1).

- **Canteen** provides administrative and management support as well as oversight and support across all states and territories. This includes financial, performance and risk monitoring and reporting; being the primary contact for governing bodies and funders; and supporting services through guidance, coordination and shared learning to create a national network and consistent high-quality service provision. Phase 3 funding is allocated to key roles within multidisciplinary teams in each YCS. The level of Commonwealth funding allocated to each jurisdiction is considered in line with population and project viability.[2] Canteen also drives implementation of three national projects: the national database, workforce development, and survivorship research.

- The **Youth Cancer Services** in each jurisdiction comprise **multidisciplinary teams** including Commonwealth-funded key roles of service manager, lead clinician, and clinical nurse coordinator (CNC). The teams receive funding from **state and territory governments** in each jurisdiction, and some also receive other philanthropic funding. Table 24**Table 24** - Overview of YCS for each Jurisdiction, Phase 3 provides a snapshot of the YCS in each jurisdiction. The YCS teams are responsible for:
    - Treatment and/or related care
    - Psychosocial assessment and care planning using the AYA Oncology Screening Tool
    - Psychosocial support
    - Providing fertility information and referral
    - Collection of the AYA Minimum Dataset
    - Conducting Multidisciplinary Team reviews
    - Providing secondary consultations to other health professionals involved in a patient's treatment and/or support
    - Providing information about the Canteen Online Peer Community (which is another federally funded initiative)
    - Engagement of patients in appropriate clinical trials and research projects including prioritisation of national YCS trials and research projects
    - Survivorship assessment and planning using the AYA Survivorship Oncology Screening Tool

The jurisdictions report quarterly to Canteen on activity in the above areas (excluding collection of the AYA Minimum Dataset and information about the Canteen Online Peer Community). The DoH KPIs are drawn from this activity data.

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[2] Phase 3 funding proposal template

Methodology

Evaluation questions

The evaluation focused on the following key evaluation questions (KEQ) highlighted in the table below. These inform sub-questions and areas for inquiry developed in collaboration with Canteen.

Table 4 - Evaluation questions

KEQ1 - How well was the YCS implemented and was it implemented as intended?

1. **How the YCS is tracking, including meeting Department of Health (DoH) KPIs**
   - Targets for % of new patient referrals and number of patients treated, assessments completed, and consultations undertaken
   - Implementation of national AYA cancer dataset
   - Workforce capacity building activities implemented
   - Progress of AYA cancer survivorship research agenda

2. **What is working well, what is not working well?**
   - Multidisciplinary teams providing information and support to young people living with cancer and linking them with appropriate services
   - Facilities for treatment and support for young people, including social and emotional support
   - Implementing a national minimum data set on young people with cancer
   - Facilitating young patients access to clinical trials
   - Building capacity through workforce development and ensuring collaboration and consistency through network development
   - Contributing to the AYA oncology evidence base through the provision of funding to support and conduct research in AYA cancer survivorship
   - Improving survivorship care for AYAs by establishing referral pathways from acute care to high quality follow-up survivorship care

3. **What factors influenced implementation?**
   - Including variation in implementation at the jurisdictional level

4. **Role and impact of Canteen in administration, management, support and oversight**

KEQ 2 - What are key considerations for future strategy development?

Methods

The evaluation used a mixed-method design. This included review and analysis of quarterly activity data collected by YCS jurisdictions and collated by Canteen, and a review of existing documentation and other secondary data including the DoH contract, proposals from each jurisdiction, and existing monitoring and evaluation reports (see Table 5). Consultations were undertaken with a range of stakeholders involved in the delivery of YCS across Australia. In total 34 consultations were conducted with 76 individuals across all five YCS jurisdictions including YCS multidisciplinary teams, non-YCS clinicians, state government and hospital representatives, Canteen executives and Canteen advisory groups.

Quantitative and secondary data sources

Table 5 - Quantitative and secondary sources reviewed

Data sources
Quarterly activity data, Phase 3 Quarterly activity data from the YCS jurisdictions, provided by Canteen, was reviewed for the first 2.5 years of Phase 3 (from 1 July 2017 to 31 December 2019). At the end of each financial year, the jurisdictions also provide annual counts across the various data items, and in most cases these annual data rather than quarterly data were analysed in this evaluation. Canteen also noted that variations between quarters are not particularly meaningful. While activity data for the first two quarters of 2019-2020 were provided, the inclusion of this in the evaluation report has been limited, given the variation across quarters. The activity data provides an overview of YCS activities implemented across jurisdictions. This is the only national dataset on YCS activities, and has been collected throughout phase 2 and 3 (since 2013). There were some reservations raised about the accuracy of the activity data in the consultations, which are discussed in 'strengths and limitations of the evaluation' at the end of this section).
Experience of Care Survey The Experience of Care (EoC) survey asks YCS patients and family members/supportive others about the YCS treatment and support they received across the cancer pathway. Data collection commenced in 2016. YCS staff invite patients and family members/supportive others to participate in the survey, and when there is agreement to participate, consent-to-contact forms are forwarded to Canteen, and Canteen then makes contact and distributes the survey (with three contacts for each person made in total). The completed surveys are returned directly to Canteen. Up to 13 March 2020, Canteen had received 274 consent-to-contact forms, and 118 patients and 74 family members/supportive others had completed a survey (this included 54 matched

Data sources

patient/family member surveys). This equates to a 70% response rate for those who consented to be contacted.

Canteen provided a data summary report of responses up to 13 March 2020 (118 patients and 74 family members/supportive others).

Victoria and NSW accounted for the majority of completed patient surveys (60% and 31% respectively). Patient survey numbers are as follows: 71 from Peter MacCallum Cancer Centre, Victoria; 36 from NSW (24 from Calvary Mater Newcastle, 7 from Sydney Children's Hospital, 4 from Westmead Hospital (Adults) and 1 from Prince of Wales Hospital); 9 from Royal Adelaide Hospital, SA and 2 from Queensland Children's Hospital. Family/supportive others survey numbers are as follows: 43 from Peter MacCallum Cancer Centre, Victoria, 28 from NSW (18 from Calvary Mater Newcastle, 10 from Sydney Children's Hospital), 2 from Royal Adelaide Hospital, SA and 1 from Queensland Children's Hospital.

There have been site specific delays in implementing the EoC survey in QLD, SA and WA due to delays in obtaining ethics approvals, and availability of staff, as a result of staff mobility and staff vacancies. While the EoC data provides a snapshot of the experience for YCS patients, care is needed when interpreting the results in relation to generalisability nationally, given the higher representation of respondents from Victoria and NSW (91% of all patients).

Community of Practice Evaluation Summaries, 2018 and 2019

Summary evaluation reports prepared by Canteen were provided for each Community of Practice event, based on evaluation feedback forms completed, as follows:

- Brisbane, 30 April - 1 May 2018 (n =62, 62% of attendees)
- Melbourne 30 April - 1 May 2019 (n=45, 64% of attendees)
- Adelaide, 11 - 12 November 2019, (n=50, 67% of attendees)

Global Adolescent & Young Adult Cancer Congress (GAYAC) 2018 Evaluation and Workshop summaries

Evaluation undertaken by Canteen of the GAYAC and associated Workshop

- GAYAC Evaluation Report (n=161, 35% of attendees). Included respondents from 13 different countries, with 45% from Australia
- GAYAC Workshop Evaluation Report (Workshop 1: n=13, 76% of attendees, Workshop 2: n=15, 52% of registrants, Workshop 3: n=8, 44% of registrants, Workshop 4: n=18, 90% of registrants)

Phase 3 jurisdictional proposal documents

These documents are prepared by each jurisdiction based on a template provided by Canteen. The purpose of the document is to outline aims, challenges and strategies of Phase 3 and commitments by the respective services. These were completed prior to the commencement of Phase 3.

Data sources
DoH contract, KPI section The contract between Canteen and the Commonwealth DoH setting out objectives, deliverables and KPIs for Phase 3.

Qualitative consultations

A stakeholder discussion guide matrix was developed by the Sax Institute based on the evaluation questions, and the discussion guide matrix was reviewed by Canteen. Consultations were conducted with: key stakeholders responsible for service delivery, and executive and strategic aspects of the YCS; MDT members from each of the five jurisdictions; co-funders of the YCS partnerships; Canteen Strategic Advisory Group (SAG) and Data Advisory Group (DAG) members[3]; and two young people with national leadership experience in Phase 3 of the YCS. Consultations were conducted through a mix of face-to-face interviews, group discussions and telephone interviews. Site visits were conducted in NSW, VIC, SA and Queensland. Table 6 summarises the consultations conducted, and the full list of qualitative consultations are provided in Appendix 2.

Table 6 - Qualitative consultations conducted

Jurisdiction	Stakeholders
NSW/ACT (17 in total)	Service Manager (1), Lead Clinician and SAG member (1) MDT at Westmead (4), Hunter (4), and Randwick (3) NSW Ministry of Health (3), Executive, Canberra Hospital (1)
QLD (11 in total)	Service Manager (1) and Lead Clinician (1) State-wide MDT members (6) Clinicians (1 partially DoH funded, 1 non-DoH funded), Medical Director (1 non-DoH funded)
SA (12 in total including youth representative)	Lead Clinician and Service Manager (2) Adelaide-based MDT members (6) Clinicians (2, non-DoH funded), Central Adelaide Local Health Network (1) Former Phase 3 National Youth Advisory Member (1)

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[3] Consulted as part of existing advisory group meetings

Jurisdiction	Stakeholders
VIC/TAS (15 in total)	Service Manager and SAG member (1) and Lead Clinician (1) Lead Clinician (1) and CNC, Royal Children's Hospital (1) Peter MacCallum Cancer Centre (1) MDT (9) Department of Health and Human Services, Victoria (1)
WA (9 in total, including youth representative)	Service manager (1) and Lead Clinician (1) MDT (4) Clinician (non-DoH funded) and local Strategic Advisory Committee (1), Phase 3 National Youth Advisory Member (1), Sir Charles Gairdner Hospital (1)
Canteen (12 in total)	CEO and General Manager, Research & YCS (2), Data Advisory Group (4), Strategic Advisory Group members (6)

Analysis

All qualitative interviews and focus groups were audio recorded (with consent), transcribed, coded by two experienced researchers utilising NVivo software, and synthesised using a thematic analysis. Themes were derived primarily to answer the evaluation questions, but emergent themes were also explored. A database of raw activity data provided by Canteen was reviewed by an experienced quantitative analyst. Triangulation of the qualitative and quantitative data and secondary sources was conducted in order to synthesise the results into consolidated evaluation findings in response to each of the key evaluation questions. During the report drafting phase a workshop was conducted with the SAG (April 2020) to collaboratively review the evaluation findings and discuss future opportunities. Feedback from this discussion has been incorporated in the final section of this report, in relation to key considerations for future strategy development.

Strengths and limitations of the evaluation

The YCS is a national initiative involving a partnership between the DoH, state/territory governments, the YCS teams, and Canteen. The main data sources for this evaluation were qualitative feedback from jurisdictions focusing on service implementation at the local level and on Canteen's role in administering the initiative, activity data, and a review of secondary data. A strength of this evaluation is that it garnered views from a wide range of stakeholders involved in the delivery of YCS, from every YCS jurisdiction across Australia, covering a diverse range of roles. Another strength was that a range of data sources were analysed and reviewed.

These data sources provide information on the national YCS initiative, as well as implementation in each jurisdiction. Information on implementation in each jurisdiction is based on the activity data and consultations with those directly involved in delivering the YCS. Evaluating the YCS at the jurisdictional level in relation to outcomes was outside the scope of this evaluation.

While the evaluation draws on the Experience of Care survey which includes feedback from patients and family members/supportive others, this is the only source of feedback from AYAs about the treatment they received from the YCS, which is a limitation of this evaluation. The sample size for these surveys was relatively small, and the data was predominantly collected from NSW and Victoria (due to site specific delays as mentioned earlier), so there are limitations in generalising this for the national YCS.

Only two representatives with experience of the National Youth Advisory Group (NYAG) were consulted (one current and one previous member), and it is worth noting there are 10 NYAG members in total at any one time. Both participants had played leadership roles nationally and within the relevant YCS jurisdiction. The small number of interviews resulted in minimal feedback on the youth leadership approach in Phase 3, and opportunities for enhancing youth leadership in Phase 4.

The quarterly activity data used in this evaluation provides national activity data across the five jurisdictions, and is the only national dataset on YCS activities. The activity data includes information on YCS patient numbers and the provision of a range of AYA-specific care, and provides information on the delivery of YCS over time, as it has been collected throughout Phase 2 and Phase 3. The consultations identified some limitations with this data, such as inconsistencies in how data are reported across jurisdictions (with considerable inconsistencies in how secondary consultations are reported), variability across quarters[4], and potential duplication as the data is aggregated and requires collation of data from multiple hospital sites and different electronic medical record platforms. As mentioned earlier, the analysis for this evaluation used annual rather than quarterly data, to mitigate the limitations with variability across quarters. It is was noted by Canteen that the jurisdictions invest considerable time to avoid duplication, where possible (for example, if an AYA has already been seen by another jurisdiction, the second jurisdiction does not include this AYA in their activity data)[5].

As mentioned above, this evaluation gathered feedback a wide range of stakeholders involved in the delivery of YCS and a range of data sources were reviewed. As such, despite the limitations mentioned above, this evaluation provides valuable information on the implementation of Phase 3 and future opportunities.

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[4] The variation across quarters is mostly due to changes nationally in some of the definitions (at the end of quarter 2, year 1), in order to more accurately reflect the work being done, as well as changes within jurisdictions in relation to their data collection

[5] Canteen commented that the activity data is likely to be an underestimate of the services provided, given the difficulties with capturing all the services delivered across multiple staff and sites

Key Evaluation Question 1: How well was the YCS implemented and was it implemented as intended?

This section of the report explores how well the YCS was implemented and whether it was implemented as intended.

- Section 1 reviews national performance against Department of Health (DoH) Key Performance Indicators (KPIs).
- Section 2 discusses the key components of the initiative in terms of what worked well or not so well, based on the key components listed in the DoH contract.
- Section 3 discusses factors that have influenced implementation, including describing implementation at the jurisdictional level.
- Section 4 discusses the role and impact of Canteen in administration, management, support and oversight of the initiative.

Section 1: How is the YCS tracking in achieving Department of Health KPIs?

This section presents progress to date in relation to each of the KPIs in the DoH contract. This section is informed by a review of Canteen's activity data as well as commentary and contextual information provided by Canteen.

At the time of writing, the majority of KPI targets had been achieved or are tracking well. Overall, KPI performance demonstrates the wide reach of the YCS for AYA in Phase 3, and that the YCS is being implemented as intended, in line with the requirements of the DoH contract.

Performance Indicator 1: YCS Continued delivery of multi-disciplinary services to young cancer patients and their families for treatment and care

Target: Five contracts executed by August 2017 with each of the jurisdictions

Result: Achieved but with some delays

The earliest contract sign date was 1 December 2017 (VIC/TAS) and the latest was 9 February 2018 (SA). It is noted that for NSW/ACT, an interim contract for the period 1 July 2017 to 30 June 2018 was executed with Sydney Children's Hospital Network on 5 February 2018. A contract for the period 1 July 2018 to 30 June 2020 was executed with NSW Ministry of Health on 19 December 2018.

Performance Indicator 2: Increased awareness and referrals by health professionals to specialised AYA cancer services and Youth Cancer Centres

Target: 12% increase in new patients referred by health professionals to specialised AYA cancer services and Youth Cancer Centres between 2017 and 2020

Result: Not achieved

The total number of new AYA patients[6] referred to the YCS remained consistent over the last three years, when comparing the total number of new patients for 2016-2017 (the final year of Phase 2), and the next two subsequent years in Phase 3 (see Table 7). For the first six months of 2019-2020 (to 31 December 2019) there were 348 new AYA patients, and if this rate of new AYA referrals continues for the remainder of 2019-2020, this would result in a 2% increase overall from 2016-2017 to 2019-2020. The results indicate that while Phase 2 was a period of growth, Phase 3 has been a period of consolidation, with similar levels of new AYA patients referred over the last 3-4 years.

Table 7 - Total new referrals to YCS, 2016-17 to 2019-20

Year		Total new AYA patients[7]	Overall increase
Phase 2	2016-2017	682	
Phase 3	2017-2018	641	No increase
	2018-2019	688	
	2019-2020 (6 months only)	348	2% increase

Source: Phase 3 Activity Database to up to Year 3 Q2 (1 July 2017 – 31 Dec 2019) provided by Canteen.
Note: Grey denotes target not achieved.

Canteen's 2018-2019 DoH progress report noted that a 12% overall increase in new AYA patients by the end of Phase 3 would be unlikely, as the target was based on growth trends throughout Phase 1 (2009-2012) and Phase 2 (2013-2017), and literature available at the time that suggested there would be an increase in incidence of cancer in AYAs. More recently, the AIHW released a report (2018) that found that there has been an overall decrease in the age-standardised incidence rate for all cancers

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[6] New patients include: Newly diagnosed patients (those newly referred to the YCS after a new cancer diagnosis), relapsed patients (those newly referred to YCS because of relapse from disease diagnosed when under 15 years) and other new patients (those newly referred to YCS who were diagnosed elsewhere, or where the tumour is non-malignant but undergoing cancer-like treatment or procedure)

[7] The total number of new patients is based an annual data reported by the YCS jurisdictions to Canteen

for those aged 15-24 years from 330 new cases per 1 million in 1995-1999 to 308 new cases per 1 million in 2010-2014.[xi] This data further confirms that reaching this target was unlikely by the end of Phase 3.

Performance Indicator 3 (FY 2017-2018), Performance Indicator 4 (FY 2018-2019): Number of patients treated, assessments completed, and consultations undertaken [8]

Target: New and recurring patients supported, newly diagnosed young cancer patients treated and supported, psychosocial screens, secondary consultations, survivorship assessments, care plans, and patients referred to community-based support services

Result: Most targets achieved

For the first two years of Phase 3, all targets have been achieved except for two (see Table 8 and Table 9). Those achieved include number of new and recurring patients supported by the YCS, secondary consultations undertaken, survivorship assessments completed, care plans completed, and patients referred to community-based services. On the other hand, the KPI targets for newly diagnosed patients treated and supported, and psychosocial assessments completed were not met.

Table 8 - National Key Performance Indicators 3: 2017-2018

Indicator[9]	Target 2017-18	Annual total	% above/ below KPI	Number above/ below KPI
Total number of new and recurring patients supported by YCS nationally	1350	1647	22% over	297 over
Newly diagnosed young cancer patients treated and supported by YCS nationally	75%	(442) 65%	14% below	72 below
Psychosocial assessments completed for new AYA patients	75%	62%	18% below	59 below
Secondary consultations undertaken	550	884	61% over	334 over
Survivorship assessments completed for patients supported by YCS who complete treatment	45%	61%	36% over	37 over
Care plans completed for patients supported by YCS who complete treatment	45%	53%	17% over	17 over

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[8] KPI 5 requires data for 2019-2020, which was not available at time of writing, therefore KPI5 is not included in this section

[9] Newly diagnosed patients are those newly referred to the YCS after a new cancer diagnosis. Psychosocial assessments refer to the number of newly diagnosed patients who completed the AYA Oncology Screen (Distress Thermometer Tool). Secondary consultation is the provision of clinical advice and support to external health professionals and community service providers at their request. Psychosocial survivorship assessment is the AYA Oncology Psychosocial Survivorship Screening Tool. Survivorship care plan is the AYA Oncology Psychosocial Survivorship Care Plan or other. Community-based support services are non-hospital-based services provided by general practitioners, not-for-profit agencies or education and vocational support providers.

Patients who completed treatment referred to community-based support services by the time they complete treatment	45%	81%	80% over	82 over

Source: Phase 3 Activity Database for year 1 (1 July 2017 – 30 June 2018) provided by Canteen.
Note: Green denotes target achieved or above target, grey denotes target not achieved.

Table 9 - National Key Performance Indicators 4: 2018-2019

Indicator	Target 2018-19	Annual total	% above/ below KPI	Number above/ below KPI
Total number of new and recurring patients supported by YCS nationally	1400	1759	26% over	359 over
Newly diagnosed young cancer patients treated and supported by YCS nationally	80%	(509) 74%	7% below	39 below
Psychosocial assessments completed for new AYA patients	75%	64%	14% below	54 below
Secondary consultations undertaken	625	1046	67% over	421 over
Survivorship assessments completed for patients supported by YCS who complete treatment	55%	71%	29% over	37 over
Care plans completed for patients supported by YCS who complete treatment	55%	62%	12% over	16 over
Patients who completed treatment referred to community-based support services by the time they complete treatment	55%	72%	30% over	39 over

Source: Phase 3 Activity Database for Year 2 (1 July 2018 – 30 June 2019) provided by Canteen.
Note: Green denotes target achieved or above target, grey denotes target not achieved.

As shown above, nationally the KPI for newly diagnosed patients treated and supported was not met. Table 10 shows that this target was met in both periods by WA YCS only. Canteen noted that the forecasted growth in newly diagnosed patients was miscalculated by several jurisdictions, which has likely resulted in this KPI not being met.

Table 10 - KPI performance by jurisdiction - Newly diagnosed patients treated and supported

Indicator	Year (target)	NSW/ACT	QLD	SA	VIC/TAS	WA
Newly diagnosed patients treated and supported	2017-2018 (75%)	62%	60%	64%	67%	90%
	2018-2019 (80%)	75%	81%	104%	61%	80%

Source: Phase 3 Activity Database to up to Year 2 (1 July 2017 – 30 June 2019), provided by Canteen.
Note: Green denotes target achieved or above target, grey denotes target not achieved.

Table 11 shows performance by jurisdiction in relation to the KPI for psychosocial assessments. Assessments are only counted in this data if the Distress Thermometer (DT) tool is used. Canteen identified contributing factors for this KPI not being met, including: (1) lower than expected use of the assessment DT tool (distress thermometer and needs checklist screen), as some clinicians administer a single comprehensive assessment tool rather than the use of a screening tool as part of a stepped care assessment approach (initial screening, followed by more comprehensive assessment as required); (2) patients being counted as new referrals in a reporting period but not screened until the following reporting period; and (3) psychosocial staffing shortages in NSW during Phase 3.[10] It should be noted that for Phase 4 the definition used for this item in the activity data will be broadened to include the 'Home and Environment, Education and Employment, Activities, Drugs, Sexuality, Suicide/Depression' (HEADSS) Adolescent Psychosocial Assessment tool, which is being used by some jurisdictions, and is the tool suggested for more comprehensive assessment following the administration of the DT as outlined in the AYA Oncology Psychosocial Care Manual.[xii]

Table 11 - Psychosocial assessments KPI performance by jurisdiction

Indicator	Year (target)	NSW/ACT	QLD	SA	VIC/TAS	WA
Psychosocial assessments completed for new AYA patients	2017-2018 (75%)	45%	58%	80%	69%	75%
	2018-2019 (75%)	46%	52%	83%	84%	75%

Source: Phase 3 Activity Database to up to year 2 (1 July 2017 – 30 June 2019), provided by Canteen.

Note: Green denotes target achieved or above target, grey denotes target not achieved.

Performance Indicators 6, 7 and 8 – National projects about data, workforce development and survivorship research

The table below outlines achievement against the final three DoH KPIs. Further information on the implementation and outcomes for these three national projects is included in Section 2.

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[10] A psychologist was appointed to the Westmead YCS hub in July 2019 following finalisation of the NSW Ministry of Health contract in in December 2018

Table 12 - DoH KPIs 6 to 8

Number	Indicator	Target	Result
6	Youth Cancer Data – National Project	National AYA cancer dataset implemented across five jurisdictions	Progress made
7	Capacity building through workforce development	Ongoing professional development provided to YCS workforce across Australia	Achieved
8	Building the AYA cancer evidence base	Ongoing investment in AYA cancer survivorship research	Progress made

Section 2: What worked well or not so well in Phase 3?

In assessing implementation, the evaluation has focused on the key activities of the YCS initiative, as listed in the DoH contract (see Table 3). This section discusses the implementation for each of these key deliverables in relation to what worked well or what did not work well.

Multidisciplinary teams to provide information and support to young people living with cancer and link them with appropriate services

There has been a steady increase in AYA patients (new and recurring) being supported by YCS multidisciplinary teams over Phase 3, from 1,417 AYA patients in the last year of Phase 2 (2016-2017) to 1,647 and 1,759 for the first two years of Phase 3 (2017-2018 and 2019-2020).[11]

Commonwealth funding supported core MDT roles as stipulated by the DoH contract in all jurisdictions (lead clinician, service delivery manager and Clinical Nurse Consultant (CNC)). In addition to these core roles, specific makeup of the YCS MDTs varied across jurisdictions (see Table 24, Section 3 for a description for each jurisdiction), although it should be noted that all MDTs included psychosocial support, nursing, and other allied health roles in line with the requirements of the DoH contract. The YCS teams also include psychosocial and/or medical roles funded through state governments and in some cases other NGOs such as Red Kite.

Consultations with representatives from all jurisdictions identified a dedicated, passionate YCS workforce with a strong shared vision of AYA-specific supportive care. This strength was also identified in the Phase 2 evaluation.[xiii] Phase 3 activity data for the last two years (from 1 July 2017 to 30 June 2019)[12] shows that 811 newly diagnosed YCS patients had their treatment discussed and a treatment plan developed at a medical multidisciplinary team (MDT) meeting, representing over eight in ten newly diagnosed patients (85%, with n=951 total newly diagnosed patients over these two years).

YCS staff in all jurisdictions work closely with non-YCS clinicians and community service providers to provide information and support to AYAs, including the provision of clinical advice and support to external medical and allied health professionals (defined as secondary consultations). The activity data reported that to date in Phase 3 (from 1 July 2017 to 31 December 2019), 2470 secondary consultations have been conducted, and as shown in Table 8 and Table 9 (Section 1), secondary consultations for the first two years of Phase 3 exceeded DoH targets. YCS teams noted that this is an important task, especially as it supports AYA patients to access care, where possible, in their own communities. There has been a large increase in the number of secondary consultations conducted in Phase 3, with an average of 988 per year in Phase 3, compared to an average of 728 per year in Phase 2.

The activity data reported that to date in Phase 3 (from 1 July 2017 to 31 December 2019) the YCS also linked 418 patients who had completed treatment (74% of all completed patients) to community-based services, defined as non-hospital based services provided by general practitioners, not-for-profit agencies or education and vocational support providers. The Experience of Care (EoC) survey also demonstrates the links to other support provided by the YCS, with 94% of patients (102 of

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[11] Phase 3 activity data – 01 July 2017 to 30 June 2019

[12] Data definitions changed after the first two reporting periods of 2017-2018 (after 31 December 2017), so data for the first two reporting periods is slightly higher than subsequent data

n=109) and 88% of family member/supportive others (63 of n=72) reporting that they were told about other organisations they could contact for support.

Providing information on fertility, and linking AYAs with fertility services where relevant is particularly important for AYA patients. As can be seen in Table 13 below, the majority of new AYA patients were reported to have been provided information on the impacts of treatment on fertility and options for preserving fertility (58%) with just over one in three new patients receiving a fertility preservation procedure (37%). For just under one in three patients, fertility preservation was reported as not relevant. Canteen noted that the proportion of new YCS patients who received fertility information is likely to be higher, as new YCS patients who were not newly diagnosed are likely to have received fertility information from previous services. The activity data reports that 27% of new YCS patients in Phase 3 were either relapsed patients, newly referred to YCS and diagnosed elsewhere, or patients with a tumour that is non-malignant but are undergoing cancer-like treatment or procedure.

This is supported by the findings from the EoC survey (

Table 14), where almost all patients (90%) reported that they were told about possible impacts to their fertility due to treatment, most recalled that they were told about things they could do to preserve their fertility (95%), and eight in ten reported that they were offered a referral to a fertility specialist. Around nine in ten respondents felt that fertility was discussed in a sensitive, supportive way, with 65% reporting that this was definitely the case.

Table 13 - Fertility information and services provided to new patients

Service	Number of new patients *(% of all new patients, n=1677)*
Fertility information provided	976 (58%)
Fertility preservation procedure	627 (37%)
Fertility preservation not applicable	472 (28%)

Source: Phase 3 Activity Database to up to Year 3 Q2 (1 July 2017 – 31 Dec 2019) provided by Canteen.

Table 14 - Experience of Care Survey data - Fertility (patient responses)

Question	Yes		No	Not sure / can’t remember
Were you told about possible impacts of treatment on your fertility before you started treatment? *(n=111, missing data for 7 AYAs)*	100 90%		5 5%	6 5%
***For those who were told that there would be impacts on their fertility** (n=94)*	**Yes, definitely**	**Yes, I think so**	**No**	**Not sure / can’t remember**
Was fertility discussed in a sensitive, supportive way?	61 65%	25 27%	4 4%	4 4%
Were you told about things you could do to preserve your fertility?	80 85%	9 10%	3 3%	2 2%
Were you offered a referral to a fertility specialist? *(n=88, n=6 reported that they did not need this)*	69 78%	7 8%	10 11%	2 2%

Source: Experience of Care Survey data summary report, 13 March 2020, provided by Canteen

Facilities for treatment and support for young people, including social and emotional support

A key component of the YCS is the social and emotional support provided to AYAs, and the activity data indicates a high proportion of patients received psychosocial and supportive care. In 2017-2018 and 2018-2019 the total number of patients who were reported as having received any psychosocial care through hospital-based YCS services was 1,377 and 1,254 respectively, representing around eight in ten patients (see Table 15). Psychosocial care is defined as care enabling patients, families and healthcare providers to manage any psychological, behavioural and social aspects of the illness. There were also high numbers reported for the provision of supportive care through hospital-based YCS services, with 1,417 and 1,692 patients reported as having received supportive care through hospital-based YCS services in 2017-2018 and 2018-2019 respectively. Supportive care is defined as all forms of care and support, including psychosocial care, that supplement clinical treatment and aims to improve the comfort and quality of life of patients and families.

For newly diagnosed patients, in the first two years of phase 3 almost all had their care discussed and a psychosocial care plan developed at an MDT meeting (404 or 91% of all newly diagnosed patients in 2017-2018 and 486 or 95% of all newly diagnosed patients in 2018-2019). As mentioned in section 1, the AYA Oncology Screen (Distress Thermometer Tool) was completed for almost two in three newly diagnosed patients (see

Table **16**).

Table 15 -Total number of patients (all) who received any psychosocial and supportive care through hospital-based YCS services

Activity (all patients)	**Year**	**NSW/ ACT**	**QLD**	**SA**	**VIC/ TAS**	**WA**	**Total**	**% of all patients**
	2017-18, n=	*486*	*194*	*156*	*631*	*180*	*1647*	
	2018-19, n=	*515*	*220*	*147*	*697*	*180*	*1759*	
Psychosocial care	2017-2018	450 93%	186 96%	115 74%	459 73%	167 93%	1377	84%
	2018-2019	331 64%	179 81%	111 76%	457 66%	176 98%	1254	71%
Supportive care	2017-2018	439 90%	178 92%	144 92%	476 75%	180 100%	1417	86%
	2018-2019	472 92%	196 89%	147 100%	697 100%	180 100%	1692	96%

Source: Phase 3 Activity Database to up to year 2 (1 July 2017 – 30 June 2019), provided by Canteen

Table 16 - Total number of newly diagnosed patients who received an AYA Oncology Screen and had care discussed and care plan developed at an MDT meeting

Activity (newly diagnosed patients)	**Year**	**NSW/ ACT**	**QLD**	**SA**	**VIC/ TAS**	**WA**	**Total**	**% of all newly diagnosed patients**
	2017-18, n=	*130*	*79*	*35*	*135*	*63*	*442*	
	2018-19, n=	*149*	*112*	*59*	*129*	*60*	509	
Completed AYA Oncology Screen [13]	2017-2018	59 45%	46 58%	28 80%	93 69%	47 75%	273	62%
	2018-2019	68 46%	58 52%	49 83%	109 84%	44 73%	328	64%
	2017-2018	130	71	33	107	63	404	91%

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[13] Also known as the Distress Thermometer Tool

Care discussed & psychosocial care plan developed at MDT meeting [14]		100%	90%	94%	79%	100%		
	2018-2019	139 93%	126 113%	54 92%	109 84%	58 97%	486	95%

Source: Phase 3 Activity Database to up to year 2 (1 July 2017 – 30 June 2019), provided by Canteen

These results are reflected in the Experience of Care survey (see Table 17), where almost all patients (96%) and family members/supportive others (99%) reported that they had been offered emotional support by a health professional/hospital staff, and that throughout their care, there had been a health professional or team who provided ongoing emotional support (e.g. social worker, psychologist, AYA nurse) if they felt they needed it (97% and 98% respectively). Similarly, 94% of patients reported that throughout the cancer journey, there was a health care professional or team they could contact questions about the care, or for help or advice. Significantly, for all these different types of support, most identified that the support had been provided by the YCS team.

There were also nine in ten patients and family members/supportive others who reported that staff from the YCS asked questions to find out how they were coping and whether they needed any support or assistance.

Table 17 - Experience of Care Survey data - Emotional support provided

Question	Yes, from YCS	Yes, from other	Yes, unsure of team	No	Not sure/ can't remember
Offered emotional support *Patients (n=110)*	96 87%	29 26%	17 15%	2 2%	2 2%
Family members/supportive others (n=71)	63 89%	18 25%	7 10%	1 1%	
Provided ongoing emotional support *Patients (n=110)*	83 75%	13 12%	12 11%	2 2%	1 1%
Family member/ supportive others (n=71)	55 77%	10 14%	6 8%	2[15] 2%	
A health care professional or team to contact with questions about care or if you needed help or advice *Patients (n=110)*	72 66%	24 22%	9 8%	3 3%	3 3%
Staff from the YCS asked questions to find out how	101 91%	N/A	N/A	7 6%	3 3%

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[14] MDT meeting can be either medical or psychosocial, and Plan can be AYA Oncology Care Plan or other

[15] One responded that this was not wanted, and one responded that they wish they had this

you/they were coping and whether you/they needed any support or assistance					
Patients (n=111)					
Family member/ supportive others (n=72)	65 90%	N/A	N/A	2 3%	5 7%

Source: Experience of Care Survey data summary report, 13 March 2020, provided by Canteen

Results from the Experience of Care survey indicate that there is a high level of satisfaction with the care provided by the YCS, with almost all patients and family members/supportive others reporting that they were satisfied with the support and assistance received from the YCS (see Table 18). As well, 89% of patients reported that the YCS generally treated them like an AYA, which was just right (with 6% who were not sure, and 6% who responded that they were treated like an older adult), with 89% of family members/supportive others also reporting that their loved one was treated like a AYA[16].

Table 18 - Experience of Care Survey data – Satisfaction with support provided by YCS

Question	Very satisfied	Satisfied	Neutral	Very/ Dissatisfied	Not sure / can't remember
Satisfaction with the support and assistance received from the YCS *Patients (n=110)*	84 76%	22 20%	2 2%	2 2%	-
Family member/ supportive others (n=71)	58 82%	10 14%	3 4%	-	-

Source: Experience of Care Survey data summary report, 13 March 2020, provided by Canteen

There was a high level of agreement that the YCS provided care tailored to AYA, with 94% of patients and family members/supportive others agreeing that YCS staff knew enough about young people and cancer to be helpful (Table 19). Over eight in ten patients also reported that the YCS offered help or advice to discuss the cancer experience with friends and family, return to work or study, and manage finances, and provided information relevant to their age. Three in four young people had been provided with the opportunity to meet with other young cancer patients/survivors.

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[16] As noted in the method section, the EoC survey results are skewed to patients from Victoria and NSW

Table 19 - Experience of Care data - Perceptions of age-appropriate support provided by YCS

Question	Yes	No	Not sure / can't remember
Thinking about the staff from YCS…..Do you think they knew enough about young people and cancer to be helpful? (e.g. good with young people, knowledgeable about cancer and its treatment)			
Patients (n=109)	103 94%	2 2%	4 4%
Family member/ supportive others (n=72)	68 94%	0 0%	4 6%
Did you have the opportunity to talk to them alone if you wanted to? (e.g. to discuss personal topics) *Patients (n=110)*	103 94%	4 4%	3 3%
Did your family or loved ones have enough opportunity to talk to them? *Patients (n=110)*	92 84%	14 13%	4 4%
Did the staff from the YCS…. Offer you the chance to meet with other young cancer patients/survivors? *Patients (n=110)*	81 74%	26 24%	3 3%
Offer to help you to discuss your cancer experience with family and friends? *Patients (n=110)*	91 83%	12 11%	7 6%
Offer to help you with returning to school, uni, TAFE or work? *Patients (n=110)*	95 86%	8 7%	7 6%
Offer you help or advice about money? (e.g. paying medical costs, getting support for bills, education or accommodation) *Patients (n=110)*	92 84%	9 8%	9 8%
Throughout your cancer experience….Were you given information that was relevant to your age group? (e.g. hearing the experiences of other young people) *Patients (n=110)*	92 84%	14 13%	4 4%

Source: Experience of Care Survey data summary report, 13 March 2020, provided by Canteen

Implementing a national minimum data set on young people with cancer (KPI 6)

Implementation of a national AYA cancer dataset across five jurisdictions is a KPI of the Phase 3 DoH contract. While Canteen progressed implementation of the national minimum dataset in Phase 3 under the guidance of the Data Advisory Group, ultimately this initiative was not implemented as intended in Phase 3.

The original plan for implementing a national dataset in Phase 3 proposed that jurisdictions provide unit record data to a single repository/third party for national analysis. Canteen and the DAG reported that developing a national dataset for YCS is extraordinarily complex and difficult, and that there were several challenges in implementing this approach, primarily in relation to reluctance from jurisdictions to provide unit record data to a single repository/third party. The reasons for this reluctance were reported as concerns about losing control of their data, not knowing how the data will be used (and potentially be misinterpreted), and concerns about patient privacy and confidentiality, especially in jurisdictions with smaller patient numbers. The DAG members also noted that the Commonwealth Government has various levers they can utilise to support these national datasets (such as legislation and funding), but that this is more challenging for a non-government organisation who does not have access to these policy levers.

As a result of these challenges, a new method was proposed, discussed and endorsed by the Data Advisory Group (DAG) in late 2019. The method is based on the jurisdictions remaining custodians of patient data and conducting data analyses at the jurisdictional level following an approach endorsed by the DAG. Meta-analyses would then be undertaken by a third party agreeable to all jurisdictions, with potential patient identification mitigated by aggregating the dataset across several years. An Australian Youth Cancer Database Specification identifying data items to be collected was developed in March 2019.

The DAG commented that the new approach has involved collaboration with NSW, Victoria and Queensland jurisdictions, including sharing the protocols and developing these further with input from the various jurisdictions. These jurisdictions were targeted for the first stage of implementing the national dataset, as these states represent 77% of patient numbers in terms of AIHW data on incidence of all cancers by state/territory.[xiv] Given the larger patient numbers for these jurisdictions, this enables more detailed analyses to be conducted. These states also have greater resources internally for analysis of patient datasets.

The next stage will explore options for the smaller jurisdictions (WA, SA, ACT, Tasmania and NT), which is currently being negotiated.

Implementation of the national dataset will help drive a nationally consistent approach to cancer care and service planning and build capacity for national collection of demographic data. A national minimum dataset will include some demographic information: sex at birth, age, Aboriginal and Torres Strait Islander status, language spoken at home, and residential location. This type of information about patients in the YCS is not currently being collected at the national level. The utility of demographic data would be explorative, and will help scope what information may be available and inform reach /service planning. It is positive that a new approach has been agreed upon which accommodates the priorities of all stakeholders.

Facilitating young patients access to clinical trials

Facilitating AYA patients' access to clinical trials is a key component of the national YCS initiative. Separate to the Phase 3 contract and funding, Canteen secured $5 million in funding in July 2018 through the Medical Research Future Fund to support clinical trials for high lethality cancers.

Following a competitive grants process, the funding was distributed to the following clinical trials for research into high lethality AYA cancers: [xv]

- Personalised targeted therapy for Adolescent and Young Adult medulloblastoma (brain cancer) patients
- Ewing Sarcoma (bone or soft tissue cancer) Clinical Trials Programme in AYA Population.
- Improving the Treatment of Australian Adolescents and Young Adults with Acute Lymphoblastic Leukaemia
- AYA-Most: A Molecular Screening and Therapeutics trial for Australian Adolescents and Young Adults with advanced cancer

Along with funding the trials, the grant supported the development of an AYA ClinTrial Refer app, research nurse positions to help facilitate access to clinical trials, and administration.

Securing funding to support clinical trials for these high lethality cancers was seen as a significant achievement of Canteen in facilitating equitable access to clinical trials for AYAs, and the jurisdictions acknowledged, appreciated and commended Canteen's advocacy to the Commonwealth to secure this funding. It is also worth noting that the trials identified above align with current AIHW data on the three highest lethality cancers for AYAs.[xvi]

Quarterly activity data for Phase 3 (see Table 20) recorded that 342 YCS patients were newly enrolled in clinical trials (medical and non-medical) in 2017-2018 and 2018-2019, which represents 10% of all YCS patients (n=3406 total patients over the two years). There were also 503 YCS patients enrolled in other research, representing 15% of all YCS patients. This is an increase in participation in clinical trials when compared to Phase 2, where 8% of patients were enrolled in clinical trials (medical and non-medical). There were 14% of all YCS patients enrolled in other research in Phase 2. In the quarterly activity reporting template, a medical clinical trial is defined as a trial designed to test the efficacy or safety of a medical intervention (e.g. drug, surgical procedure or diagnostic test) on a clinical outcome, and a non-medical clinical trial is defined as a trial designed to test the efficacy or safety of a nonmedical intervention (e.g. behavioural therapy, preventive care, education) on a clinical outcome. Other research includes non-clinical trial research, such as observational or validation studies.

Table 20 - Phase 3 clinical trial and research recruitment, 2017-2018 and 2018-2019

	NSW/ACT n=1001	**VIC/TAS** n=1328	**WA** n=360	**SA** n=303	**QLD** n=414	**National total** (n=3406)
Clinical trial - Medical	47 5%	103 8%	13 4%	5 2%	22 5%	190 6%
Clinical trial - Non-medical	50 5%	41 3%	15 4%	1 0%	45 11%	152 4%
Clinical trials - Medical and non-medical	97 10%	144 11%	28 8%	6 2%	67 16%	342 10%
New research (other)	111 11%	269 20%	67 19%	44 15%	12 3%	503 15%

Source: Phase 3 Activity Database to up to year 2 (1 July 2017 – 30 June 2019), provided by Canteen

There was some inconsistency in how jurisdictions report to Canteen about clinical trial recruitment, with some reporting the number recruited and the name of the trial the AYAs are enrolled in, while others provide enrolment numbers only. Consistent reporting that includes enrolment numbers and name of the trial could be valuable and assist monitoring and co-ordination, as well as support the development of strategies to improve recruitment.

VIC/TAS noted that the Victorian Comprehensive Cancer Centre includes a specific AYA component related to clinical trial access, including CAR-T cell trials which are not available in any other jurisdiction. This has likely had an influence on the strong performance from VIC/TAS in clinical trial recruitment.

Some comments were made by YCS representatives that additional communication and transparency of the decision-making process for the national clinical trials would have been preferred, as well as further communication on the expectations for the YCSs. On the other hand, Canteen and members of the SAG noted that there was a clear process followed in selecting the clinical trials and communicating with jurisdictions.

Qualitative consultations with the jurisdictions recognised the importance of clinical trials for AYA patients, and a number of recruitment challenges were identified. While comprehensive analysis of clinical trial recruitment and barriers to recruitment has not been conducted as part of this evaluation, the feedback highlights several considerations:

- The financial burden upon patients and their families of costs associated with travel, relocation and accommodation, especially for rural/regional patients was identified as a significant barrier to accessing clinical trials for non-metropolitan AYAs
- Some hospitals require a minimum number of eligible patients before opening a trial, which could be challenging for AYA specific trials with smaller patient numbers
- In some cases, trials are being opened at paediatric sites, and the majority of AYAs in this specific jurisdiction are not treated at the paediatric sites
- Time is needed for achieving governance sign-off for clinical trials at the jurisdictional and LHD level

It was acknowledged that the additional research nurse positions will help address the workload issue. Canteen also acknowledged that there is work planned to establish relationships between trial consortia and YCS teams, and that Canteen may be able to play a role in facilitating this. Overall, maintaining access to clinical trials comparable with Phase 2 rates was seen as a significant achievement, given the evolving and complex landscape and the diverse range of stakeholders involved.

Building capacity through workforce development and collaboration and consistency through network development (KPI 7)

Network and workforce development for the YCS was supported by a range of events in Phase 3, including Community of Practice meetings, the Adolescent and Young Adult Cancer Global Accord Conference, quarterly SDAG meetings, quarterly activity data review meetings with service managers, quarterly meetings with research nurses, and newsletters.

To date in Phase 3, Canteen has delivered five events focused on building capacity, collaboration and consistency through workforce development and network development, including four Community of Practice events (with a fifth scheduled for June 2020) and the Adolescent and Young Adult Cancer Global Accord Conference (see Table 21). These events brought together health professionals from across Australia, and internationally, and demonstrate a strong performance against KPI 7 of the DoH contract. There were 70-100 attendees at each Community of Practice, and on average, 75% of core YCS staff attended the Community of Practice events throughout Phase 3.

Table 21 - Summary of workforce development events Phase 3

Date and location	Event	Theme	Attendees and feedback source
30 April -1 May 2018 **Brisbane**	Community of Practice	Survivorship	100 health professionals working in YCS hospital-based positions nationally, and staff from affiliated hospitals and community-based healthcare providers n=62 evaluation forms (62% of attendees)
4 - 6 December 2018 **Sydney**	Adolescent and Young Adult Cancer Global Accord Conference (GAYAC) Including Community of Practice	‘Navigating the road through AYA cancer’ Included workshops on consumer engagement, nursing, clinical communication skills	435 attendees from 18 countries n=161 evaluation forms (35% of attendees) Respondents from 13 different countries, with 45% from Australia
30 April -1 May 2019 **Melbourne**	Community of Practice	Youth health	70 YCS team members and affiliates N=45 evaluation forms (64% of attendees)
11 – 12 November 2019 **Adelaide**	Community of Practice	A range of topics including medicinal cannabis, cancer in Indigenous Australian and LGBTQI groups.	75 health professionals working in YCS hospital-based positions as well as staff from affiliated hospitals and community-based healthcare providers. N=50 evaluation forms (67% of attendees)

During Phase 3, five scholarships for post-graduate certificates were funded to support staff to advance knowledge and practice, providing an opportunity for staff within the YCS and partner sites to access post-graduate education. These were funded by Canteen and jurisdictional partners.

An online learning platform is also under development during the final period of Phase 3. The purpose of the platform is to foster collaboration and further facilitate the growth of the national YCS Community of Practice. The platform will provide national networking and communication opportunities as well as host resources and training such as webinars and a comprehensive staffing list which will assist clinicians to identify appropriate expertise in broader YCS networks. The platform is expected to be ready by June 2020.

Conversus Leaders, in collaboration with a working party that included Canteen and YCS representatives, developed a leadership program in 2019-2020 to upskill emerging leaders in YCS teams to integrate and advocate for their service within their respective local health system. The program focuses on:

- Self-awareness - to gain a deep awareness of personal strengths, values, defaults and behaviour patterns;
- Working in Complexity - to explore the different variables that combine in making the everyday experiences of YCS complex;
- Working in a multidisciplinary environment - to learn how to collaborate across difference in ways that enable shared learning and collective wisdom;
- Resilience and Wellbeing - to learn what is required for personal well-being as well as strategies to effectively respond to workplace stresses and thrive in the system.

The aim of the program is to develop a compassionate and resilient culture within the YCS, to promote healthcare professional wellbeing, ongoing professional growth and development, and improve retainment in the AYA oncology field to support optimal patient care. Program activities are highly interactive and comprise a range of learning experiences over the course of three months, including three face-to-face workshops, two hour-long self-managed online learning sessions, and two half-hour individual learning support check-ins. The program pilot commenced in February 2020, with participants including YCS Service Managers, emerging leaders from the YCS teams, and Canteen staff.

Canteen undertook evaluations of all events listed in Table 21, and feedback on all events was positive. For example, the evaluation of the AYA Oncology Global Accord Conference in Sydney in December 2018 received very positive feedback:

- 86% reported that they would be likely to attend the Congress in the future
- 92% reported that they would be likely to recommend that someone else attend the Congress in the future
- 98% were satisfied with the quality of the oral presentations
- 89% were satisfied with relevance of oral presentation topics
- 93% agreed that they attended to learn something new about AYA psycho-oncology, and 92% agreed they achieved this outcome
- 97% agreed that they attended to learn something they can use in their workplace, and 90% agreed they achieved this outcome
- 90% agreed that they attended for networking opportunities, and 82% agreed they achieved this outcome

Across the Brisbane, Melbourne and Adelaide Community of Practice evaluations, there was very positive feedback on the logical flow of the sessions (over 90% agreed), the appropriateness of the venue and facilities (over 90% agreed), providing an environment conducive to learning and discussion (an average of 90% agreed) and encouraging attendees to reflect on their knowledge and skills (an average of 95% agreed). Feedback was also gathered on each individual session of the Community of Practice, and in most cases over 80% of respondents agreed that the individual session provided relevant and useful information and provided content that was relevant to their learning needs.

The qualitative consultations also identified the value of the networking opportunities provided by these events for the YCS workforce, especially in relation to meeting counterparts from other jurisdictions and sharing challenges and successes.

There were some suggestions for improvement identified in both the consultations and evaluation surveys for future workforce development events:

- There were some participants in the qualitative consultations who felt that the Community of Practice meetings were less relevant for them as they did not support their professional development, with suggestions for Community of Practice events to be broken into two streams for experienced and new YCS staff respectively, to support their varying professional development needs (this was mentioned by participants who had considerable YCS experience, often in relation to advancing levels of clinical practice). Several of these participants also noted that this was a consideration when deciding whether to attend or not, given their work, family and other professional development commitments. However, as noted earlier, on average 75% of core YCS staff attended the Community of Practice events throughout Phase 3.

- Event feedback summaries for the 2018 and 2019 events also included suggestions for stream-specific meeting options at future events.

- Some comments were provided in the evaluation feedback forms, and in the consultations, requesting greater collaboration with the national YCS teams when organising the Community of Practice meetings. A few YCS staff with experience hosting the Community of Practice commented that collaboration with Canteen in finalising the agenda could be improved, with additional time allocated for planning and more cooperation when finalising possible agenda items and speakers. It is also worth noting that Canteen commented that they prioritise working closely with the team who is hosting the Community of Practice when planning the agenda, and in the past, they have attempted to follow-up all the speakers proposed by the hosting jurisdictions.

- Some comments were received requesting that the Community of Practice agenda be distributed earlier, with this noted as a challenge when making decisions about attending.

- It was suggested that Canteen could use workforce development funding to support professional development at the local level, which would allow a targeted approach to upskilling the workforce depending on existing skills and identified areas for improvement.

Contributing to the AYA oncology evidence base through the provision of funding to support and conduct research in AYA cancer survivorship (KPI 8)

In Phase 3 Canteen implemented a range of activities towards conducting research in AYA cancer survivorship:

- Continuation of the Distress Thermometer (DT) Validation Study, which has two parts. The first concerns the on-treatment version of the DT and problem checklist (PCL) for AYAs diagnosed with cancer and the second, the survivorship version of the DT/PCL for AYAs who have completed cancer treatment. For both, the primary aim is to assess the validity and clinical utility of the DT/PCL for AYAs. Specifically this involves: determining the validity of the DT against other screening measures and determining appropriate cut-off scores on the DT for clinical use, assessment of the clinical utility for the DT/PCL (appropriateness, practicability, and acceptability) of the tools, confirming the content validity of the checklists, and conducting international comparisons. Secondary aims include measuring prevalence and predictors (e.g. demographic, cancer, health literacy, family functioning, and spirituality variables) of distress and psychosocial concerns (measured by the PCL), service responsiveness, and conducting international comparisons of prevalence. All ethics are in place for the survivorship version of the DT/PCL Validation study and recruitment commenced in 2016. To date, 17 survivors have completed the main study questionnaire and 6 have taken part in the follow-up interview. The first survivor completed the questionnaire on 21/09/2016 and the first interview was completed on 06/02/2019. An amendment for ethics is currently being submitted nationally to expand eligibility criteria for the study which will assist with recruitment. The ethics amendment also includes revision of the predictor variables based on more recent understanding of the concerns of AYAs post cancer treatment.

- Application for an NHMRC partnerships grant in 2018 developed with the Adolescent Health Centre for Research Excellence and led by Professor Kate Steinbeck in collaboration with Canteen and YCS staff. The grant was unsuccessful despite a positive assessment which noted:

  > *“The fundamental premise that the transition from acute cancer care to long term medical and psychosocial care is currently problematic for AYA cancer survivors is well established in clinical practice, as are the key elements of the Pathway. Accordingly, the project was considered highly relevant to health policy and practice in this area. If fully implemented and effective, the application has clear potential to influence health practice in Australia and internationally.”*

- Appointed a Research Officer in August 2019 to commence scoping and develop potential collaborations for a longitudinal survivorship study. Ethics approval will commence in 2020.

- A national survivorship workshop was planned for March 2020, with the aim of identifying AYA survivorship research priority areas, research aims and methodologies, building on a 2014 report by Canteen on Determining Research Priorities for Adolescent and Young Adult Cancer in Australia and a 2015 report Exploring Survivorship Care for Adolescent and Young Adult Cancer Survivors in Australia. Unfortunately, due to the situation with Covid-19 the workshop was cancelled. Plans are underway to develop the study protocol with input from relevant stakeholders.

Improving survivorship care for AYAs by establishing referral pathways from acute care to high quality follow-up survivorship care

National YCS activity data demonstrates that survivorship care is being provided to the majority of AYAs who have completed treatment (defined as patients who completed adjuvant or definitive primary treatment). The activity data (see Table 22) reports that 66% of YCS patients who completed treatment have received a survivorship psychosocial assessment[17], 57% have had a survivorship care plan[18], and 76% have received referral to community-based services (non-hospital based services provided by general practitioners, not-for-profit agencies or education and vocational support providers). For just over half of those who completed treatment (53%), their GP had been provided with a medical treatment summary. Table 22 shows that targets for referrals to community-based services for completed treatment were exceeded nationally and by every jurisdiction. While it is clear referrals to these organisations are occurring, there is not currently visibility of which organisations patients are being referred to. This could be addressed by amending activity reporting templates to capture this information.

Table 22 - Phase 3 YCS activity data: Survivorship care (numbers and % of patients who completed treatment), 2017-2018 and 2018-2019

Indicator	NSW/ ACT	VIC/ TAS	WA	SA	QLD	Total	DoH target 2018-19
All patients – completed treatment, n=	117	214	43	52	32	458	NA
Survivorship psychosocial assessment*	42 36%	177 83%	35 81%	28 54%	21 66%	303 66%	55%
Survivorship care plan*	12 10%	168 79%	33 77%	26 50%	23 72%	262 57%	55%
GP given medical summary	62 53%	125[19] 58%	30 70%	4 8%	21 66%	242 53%	NA
Completed patients - Community referral*	101 86%	145 68%	35 81%	46 88%	23 72%	350 76%	55%

* Denotes DoH KPI. National targets and performance discussed Section 1. Source: Phase 3 Activity Database to up to year 2 (1 July 2017 – 30 June 2019), provided by Canteen

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[17] Psychosocial survivorship assessment is the AYA Oncology Psychosocial Survivorship Screening Tool

[18] Survivorship care plan is the AYA Oncology Psychosocial Survivorship Care Plan or other

[19] This number is an underestimate, as VIC/TAS only record this when the YCS has provided the summary directly to the GP, and it has been noted that most, if not all, patients have a summary provided to the GP from the lead oncology/haematology team

Consultations with each of the jurisdictions discussed survivorship care, with the YCS teams identifying this as a significant and growing area of demand, both in terms of numbers and the psychosocial complexities of life after treatment. These consultations also provided information on the variation in relation to survivorship care across jurisdictions, which goes some way to explain the variation in activity reported in Table 22 above. Table 23 provides a summary of the jurisdiction's approach in supporting survivorship, highlighting the variations across jurisdictions in the level of maturity and the mechanisms to support survivorship care (such as processes and staffing). This variation across jurisdictions in relation to survivorship care was also discussed in the consultation with the SAG, which they felt reflected the extent to which this had been identified as a priority in the various jurisdictions. It was also noted in the SAG consultation that the survivorship approach includes collaborations with tumour streams for longer term patient follow-up/surveillance, although this was not explored in this evaluation, so has not been included in the following summaries.

Table 23 - Description of survivorship approach by jurisdiction, based on qualitative consultations

The **VIC/TAS** YCS includes a dedicated AYA survivorship nurse coordinator CNC (funded by the Sony Foundation) who convenes a dedicated survivorship multidisciplinary meeting and clinic up to 12 months post treatment completion, with young people outside this time period referred to primary care and community services. The VIC/TAS YCS has also developed a resource for GPs to support transition of care.

WA reported that it has allocated considerable effort and resources to survivorship care in Phase 3. Local grant funding, and nursing and data management time was invested to develop an End of Treatment pathway, transitioning patients to primary care in the 12 months after treatment has been completed, with tertiary tumour-surveillance where medically appropriate. During the process, patients and GPs are provided with a Survivorship Care Plan and Treatment Summary document that guides the transition back to primary care and provides patients with information, tools and referrals to achieve their identified life and survivorship goals. The focus on survivorship is reflected in the Phase 3 activity data, where WA had high patient numbers across all survivorship care activities (see Table 22).

NSW reported that currently there is no official psychosocial survivorship clinic or framework, but that research is being undertaken to develop a locally tailored framework for transition of care from acute cancer treatment to survivorship. The research will provide a mechanism for clinicians and AYAs to engage, contribute and collaborate to develop a feasible and sustainable transition service. Table 22 shows that NSW recorded significantly lower rates of survivorship assessments and survivorship care plans for patients completing treatment compared to the other jurisdictions. The evaluation did not consult with ACT stakeholders at the service delivery level.

SA reported that they did not have a well-developed survivorship program at the beginning of Phase 3 but have been developing this throughout Phase 3. The activity data shows that the proportion of completed patients who received a psychosocial survivorship assessment and a survivorship care plan increased from 48% and 42% respectively in 2017-2018 to 63% for both in 2018-2019.

Queensland reported that treatment-based clinical work is their current focus, in combination with GP engagement, and that more needs to be done to support survivorship. Further, staff turnover in the Queensland YCS central office was identified as a challenge to developing central survivorship care coordination.

Section 3: Implementing the YCS at the jurisdictional level

The YCS is a partnership between the YCS teams in each jurisdiction, the relevant State Governments, the Commonwealth Government, and Canteen. As well, during Phase 3 in some jurisdictions the YCS was also supported by other organisations including Red Kite (Victoria and SA), Sony (Victoria), Queensland University of Technology (QLD), Chris O'Brien Lifehouse[20] (NSW) and University of Sydney (NSW). This section provides an overview of implementation across jurisdictions and summarises specific highlights and challenges in implementation for each jurisdiction, including the range of factors that have influenced implementation. The information in this section is based on activity and KPI data, qualitative consultations with representatives from each jurisdiction, and information provided by Canteen.

National overview

Table 24 provides a brief overview of the YCS in each jurisdiction. As can be seen, most jurisdictions have a centralised approach to service delivery, except for NSW which operates as a series of hubs. As well, most jurisdictions provide care to AYAs through several partner hospitals (with 26 hospitals nationally supporting the YCS), except in WA where the majority of AYAs receive care at Sir Charles Gairdner Hospital (SCGH) and Fiona Stanley Hospital.

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[20] Philanthropic grant

Table 24 - Overview of YCS for each Jurisdiction, Phase 3

Jurisdiction	Patients supported 2017-18, 2018-19[21]	Lead agency for YCS contract	Service description and list of partner hospitals[22]	DoH Canteen FTE[23]	State govt. FTE[24]	Other orgs FTE[25]	YCS MDT roles[26]
NSW/ACT Phase 1,2,3 Est. 2009	486 515	Interim Contract FY 2017- 2018: Sydney Children's Hospital Network Dec 2018 onwards: NSW Ministry of Health	Series of hubs (Sydney metro, Western Sydney and Newcastle) with multidisciplinary DoH-funded YCS staff based at each hub. Services delivered in ACT by Canberra Hospital under MOU with NSW Ministry of Health. Care provided across all partner hospitals, usually determined by a patient's residential address. • Calvary Mater Newcastle (adult), Newcastle • John Hunter Children's Hospital, Newcastle • Chris O'Brien Lifehouse (adult) • Royal Prince Alfred Hospital (adult) • Prince of Wales Hospital (adult) • Sydney Children's Hospital, Randwick • Children's Hospital, Westmead • Westmead Hospital (adult) • The Canberra Hospital Referrals occurs at any of the hubs	7.3	2.6	1.2	Staff based across all partner hospitals. Service Manager Clinicians: Lead Clinician (AYA oncologist), AYA Oncologist (joint appointment across Westmead and Chris O'Brien Lifehouse), AYA Oncologist (joint appointment across John Hunter and Calvary Mater), Medical oncologist (RPA) Nursing: CNCs (including Research Nurse), Psychosocial: Social Workers, Clinical Psychologists

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[21] Phase 3 activity data – Annual reported totals for first two years of Phase 3 only (01 July 2017 to 30 June 2019). Actual numbers supported are reported by jurisdictions to Canteen at the end of each year.

[22] From DoH contract, Phase 3 jurisdictional service proposals and qualitative consultations with service managers. Verified by service managers.

[23] Information provided by Canteen

[24] From Phase 3 jurisdictional service proposals

[25] From Phase 3 jurisdictional service proposals. Organisations include Red Kite (Victoria and SA), Sony (Victoria), Queensland University of Technology (Queensland), University of Sydney (NSW), and Chris O'Brien Lifehouse (NSW)

[26] Based on Phase 3 jurisdictional service proposals, and consultations with YCS representatives. Includes all YCS roles (funded by DoH, State Govt and other NGOs)

Jurisdiction	Patients supported 2017-18, 2018-19[21]	Lead agency for YCS contract	Service description and list of partner hospitals[22]	DoH Canteen FTE[23]	State govt. FTE[24]	Other orgs FTE[25]	YCS MDT roles[26]
VIC/TAS **Phase 1,2,3** Est. 2007	631 697	Peter MacCallum Cancer Centre (Peter Mac)	Centralised model with YCS team based at Peter Mac and DoH-funded FTE also based at RHH, Tasmania and RCH, Victoria. Care provided across all partner hospitals. • Royal Hobart Hospital (RHH) • Royal Children's Hospital (RCH), Victoria Automatic referral /opt-out model for patients treated at Peter Mac	6.5	6.6	1.7	Staff based across all partner hospitals Program Manager Clinicians: Medical Director (AYA Oncology), Paediatric & AYA Haematologist Nursing: AYA Nurse Coordinators, Survivorship Coordinator, Research Nurse Psychosocial: Psychologists, Adolescent Psychiatry, Social Work, Other: Music Therapy, Exercise Physiology, Occupational Therapy School/Education and Vocation Support, Team Leader, Administration, State-wide educator
WA Phase 2,3 Est. 2015	180 180	North Metropolitan Health Service	Nurse-led 'hub and spoke' model with YCS team based at Sir Charles Gairdner Hospital (SCGH) and providing services to partner spokes (listed below). Majority of AYA patients have care delivered at SCGH and FSH, with a small percentage receiving treatment at private centres and fewer still at PMH. • Princess Margaret Hospital (Paediatric) • Royal Perth Hospital • Hollywood Private (Ramsay Health Care) • St John of God Health Care • Fiona Stanley Hospital (FSH)	3.3	2.5	0	Service Manager (includes clinical nursing component) Clinicians: Lead Clinician Nursing: Cancer Nurse Coordinator, Clinical Nurse Specialist Psychosocial: Youth Counsellor Other: Exercise Physiologist, Youth Development Officer, Research and Data Coordinator

Jurisdiction	Patients supported 2017-18, 2018-19[21]	Lead agency for YCS contract	Service description and list of partner hospitals[22]	DoH Canteen FTE[23]	State govt. FTE[24]	Other orgs FTE[25]	YCS MDT roles[26]
			Public system referrals: through a central mechanism overseen by Cancer Nurse Coordinator. Private system: professional / personal contact (email/phone).				
SA **Phase 1,2,3** Est. 2011	156 147	Central Adelaide Local Health Network	Centralised model with the team based at Royal Adelaide (RAH). Services provided to 11 metropolitan cancer care sites including WCH, FMC, and 9 other public and private hospitals. Majority of patients treated in the metropolitan area. • Women's and Children's (WCH) • Flinders Medical Centre (FMC) Referrals - Patient list review and formal mechanisms.	3.7	1.7	0.5-0.6	Service Manager Clinicians: Lead Clinician (RAH and WCH) Nursing: Cancer Nurse Coordinator, Psychosocial: Social Workers, Clinical Psychologist Other: Exercise Physiologist, Music Therapist, Administration, Research Nurse
QLD Phase 2,3 Est. 2013	194 220	Children's Health Queensland Hospital and Health Service (Queensland Department of Health)	'Hub and spoke' model with central team of DoH-funded staff based at Queensland Children's Hospital (QCH) and links to YCS-affiliated staff at partner hospitals. Majority of care provided at partner hospitals rather than QCH. • Royal Brisbane and Women's Hospital • Princess Alexandra Hospital • Townsville Hospital • Gold Coast University Hospital Referrals based on clinician relationships at each site.	3.8	8.0	0.4	Service Manager Clinicians: Lead Clinician, Medical Champion Nursing: Clinical Nurse, Research Nurse, Private Sector CNC, CNCs, Cancer Care Coordinator Psychosocial: Snr Social Worker, Snr Psychologist Other: Educator State-wide, Senior Research Fellow, Leisure Therapist

NSW/ACT

Service description

The YCS in NSW is a series of hubs with multidisciplinary YCS staff based at all eight NSW partner hospitals, and care is provided across all partner hospitals, usually determined by a patient's residential address. YCS services are provided in the ACT by Canberra Hospital under a MOU with the NSW Ministry of Health, which funds nursing and psychosocial positions. The ACT service does not receive funding through the Commonwealth or Canteen, except for participation in workforce development opportunities. Strong links and clear transition pathways exist between specialist services in Sydney and Canberra hospital, and ACT patients are routinely shared between the networks to deliver clinical care. The ACT is included in the NSW Ministry-coordinated model of care and steering group, however, there have been challenges in governance with NSW YCS staff having limited jurisdictional influence or responsibility for services in the ACT.

Highlights and challenges of implementation

NSW experienced a fragmented start to Phase 3 due to the NSW Government not contributing funds to the YCS. An interim contract between Canteen and the Sydney Children's Hospital Network covered the first 18 months of Phase 3 until an agreement between Canteen and the NSW Ministry of Health was finalised in December 2018. Canteen played an important role in advocating for the YCS with NSW Ministry of Health at this time. New permanent Ministry-funded roles were subsequently appointed, which expanded the Hunter and Westmead hubs' capacity for service delivery. A new service manager was recruited in May 2018, and prior to this there was considerable turnover in this role.

A key achievement for NSW/ACT in Phase 3 was collaboration with the Ministry, Cancer Institute NSW, Canteen and the YCS team to develop a model of care which articulates a standard for best practice for AYA with cancer in NSW and the ACT. Next steps will be to produce a YCS delivery plan including shared care models, flexible access to YCS and formalised relationships between YCS and Local Health District cancer services. The involvement of the CINSW has significantly improved access and consistency in data collection for the NSW YCS.

KPI performance

The challenging start to Phase 3 and delays in recruitment to key roles impacted NSW's capacity to meet several KPIs. The KPIs met by NSW in both year one and two of Phase 3 included total number of patients and number of community referrals for those who had completed treatment. All other KPIs were not met, including number of new patients and newly diagnosed patients, number of newly diagnosed patients who completed the AYA Oncology Screen, number of secondary consultations provided, and number of psychosocial survivorship assessment and survivorship care plans completed. Canteen noted that the appointment of new staff or the return of existing staff to psychosocial roles in NSW at Hunter, Lifehouse and Westmead sites in 2018-2019 are expected to increase capacity for psychosocial screening. Indeed, this has been the case, with a substantial improvement in this KPI in Q1 and Q2 2019-20. They are currently exceeding the KPI with 78% of newly diagnosed patients screened. Prior to this the CNCs at Westmead attempted to provide psychosocial support or refer out where possible, however they had limited capacity for this due to the commitments of their substantive role. Canteen also noted that because services are widely distributed geographically (Hunter, metropolitan Sydney, western Sydney, Canberra) the service manager has less day to day oversight of all activities in each of the sites, and that these challenges are reflected in underperformance against targets.[27]

It was also noted by NSW representatives that the lower number of secondary consultations does not necessarily reflect the substantial effort dedicated this service, especially when providing support for patients with very complex needs, where many YCS staff may be highly involved at regular intervals, while this is only counted once.

NSW staff commented that the absence of any formal mechanisms, such as psychosocial survivorship clinics or frameworks, impacted performance against the survivorship KPIs. At the time of writing NSW were conducting research into a locally tailored survivorship framework.

VIC/TAS

Service description

The VIC/TAS YCS is a well-established Youth Cancer Service, with the Victorian Government funding an AYA- specific cancer service at the Peter MacCallum Cancer Centre (Peter Mac) since 2007. The model includes a specialised clinical service, state-wide secondary consultation service, education and training, and a research program.

AYA patients treated at Peter Mac are automatically referred to the VIC/TAS YCS and it is an opt-out system. The team sees 60% of the AYAs with cancer in Victoria each year, and when including the secondary consultation process, the service supports around 70-80% of patients in Victoria. The VIC/TAS YCS supported the highest number of AYAs in Phase 3, with 631 in 2017-2018 and 697 in 2018-2019.

Highlights and challenges of implementation

Approximately 20% of young people diagnosed with cancer in Victoria live regionally, and a key feature of the VIC/TAS model is education and capacity building for regional sites. Victoria also reported a well-developed survivorship framework including a dedicated CNC chairing a survivorship MDT, as reflected in the strong performance in relation to the survivorship KPIs (Table 22).

KPI performance

VIC/TAS had strong performance for most KPIs in Phase 3, meeting all except those related to number of new patients and number of newly diagnosed patients in 2018-2019. VIC/TAS acknowledged that at the end of Phase 2, their forecasted growth in new diagnoses/new referrals was overestimated. Victoria noted that while targets for new patients were not met, they were already working at capacity, due to the significant number of patients resulting from the opt-out model, and that new patients had to be risk-stratified, with the highest needs seen by the YCS. It was noted that supporting patients from other jurisdictions is time consuming and does not count towards patient numbers. This included time spent with patients who had come from other jurisdictions for CAR-T cell therapy only available in Victoria.

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[27] Canteen (2018-2019 NSW/ACT Annual Review notes)

WA

Service description

The WA YCS is a centralised, nurse-led ‘hub and spoke’ model with all YCS positions based at the Sir Charles Gairdner Hospital where the majority of patients receive treatment. The YCS team also provides outreach services to other partner sites in Perth where smaller numbers of AYAs are treated, and shares care with regional cancer nurse coordinators outside of the YCS. The team reported that significant education and training was undertaken in Phase 3 with other health professionals, which was key to supporting clinical pathways, building effective professional relationships, and maintaining the profile of the YCS across the state.

Highlights and challenges of implementation

Phase 3 Commonwealth funding for WA was 20% lower than that received in Phase 2[28], and the YCS lost a number of roles and reduced its clinical FTE as a result. The service reported that it is at capacity providing care with little time to undertake projects to build their service and support quality improvement, which were identified as relevant because it was a relatively new service.

There was frequent staff turnover in the WA lead clinician role throughout Phase 3, which led to this role being unfilled for some time. From July 2017 to June 2019 the role was held by an adolescent health specialist. Most recently, the lead clinician role was filled on a temporary basis from June 2019 to September 2019 by a palliative care specialist with experience in General Practice and adolescent/young adult health. A lead clinician was formally appointed and commenced in April 2020. Since January 2020, a locum advanced trainee provided some medical support and maintenance of the End of Treatment clinic.

The WA YCS reported that it received strong support and oversight from the WA YCS Strategic Advisory Committee and the WA Cancer & Palliative Care Network.

KPI performance

WA met five of the eight KPIs, similar to the national YCS results, with lower numbers of new patients and newly diagnosed patients. While WA did not meet the KPI in relation to completing the AYA Oncology Screen in 2017-2018 and 2018-2019, they were only 1-2% lower than the target.

Queensland

Service description

Queensland YCS is a centralised model, with the DoH funded staff based centrally at Queensland Children’s Hospital (YCS team), and clinical state government funded staff at the four partner hospitals (MDT staff). Unlike other centralised models, most of the care provided to AYA patients occurs at partner hospitals, rather than at QCH where the DoH funded YCS staff are based.

Highlights and challenges of implementation

Some MDT representatives based in the ‘spoke’ sites felt that staff turnover in the central team based at QCH was a key challenge in Phase 3. During this consultation, the MDT representatives reported that there were frequent vacancies in Phase 3, including a number of roles unfilled at the time of

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[28] Based on numbers of AYA population in WA

consultation (October 2019). It was felt that inconsistent staff in the central hub impacted engagement with clinical trial expert reference groups and clinicians, and the progress of the state-wide model of care. There was also interest among the MDT representatives in developing the survivorship capacity of the service, however it was felt that achieving stability in other YCS central team staffing was a priority.

Some members of the MDT questioned whether a central model was realistic for the state, and some did not feel there was value in the central office being included in the MDTs, given that the YCS clinical expertise is based in the spoke sites where the majority of patients are treated, and that few patients are treated at the central (paediatric) site.

Despite these structural challenges, MDT members felt that patient care and communication between clinicians across sites worked well in Phase 3. Some concerns were raised, however, that there is no Commonwealth FTE funding across the five partner sites. There were also concerns about visibility of patients in populous regional areas where there were no YCS staff or YCS champions, such as Mackay.

There may be an opportunity for Canteen to collaborate with QLD stakeholders in considering the effectiveness of the current ‘hub-and-spoke’ model and the location of the ‘hub’ site at a Children’s hospital away from where most care is provided to AYA patients. This may be timely given that the QLD YCS is currently reviewing its model of care. There may also be an opportunity for Canteen to work with the Queensland service manager to develop cohesion in the service and build its profile in Queensland.

KPI performance

Queensland met four of the eight KPI targets in 2018-2019 and met three in 2017-2018. In both years, numbers of all and new patients were lower than the target, as were numbers of newly diagnosed patients who completed the AYA Oncology Screen.

It was noted that Queensland overestimated their targets for numbers of ‘newly diagnosed’ and ‘new patients referred’. During Phase 3 the service sought updated state-wide AYA cancer data from the Queensland Cancer Control Analysis Team (QCCAT) to provide data on patient numbers and reach. YCS staff commented that low numbers of community-based referrals reported in the activity data were a result of using different data definitions, as they did not capture referrals prior to the end of treatment (whereas all other jurisdictions captured referrals during and after treatment). Some psychosocial assessments were undertaken with the HEADSS tool and not the DT, which has impacted performance against the psychosocial KPI.

South Australia

Service description

SA has a centralised model with the YCS team based at Royal Adelaide Hospital and outreach provided to 11 other metropolitan cancer care sites.

Highlights and challenges of Phase 3

Phase 3 Canteen-administered funding for the SA YCS was lower than in Phase 2. As a result, some funding for an administrative assistant was reallocated to maintain clinical positions. Previously funded operational costs were also removed. The team commented that these funding cuts have impacted the service, but that they have worked hard to ensure that patients are not disadvantaged.

The YCS team noted that their current capacity is ‘very stretched’, and that at the start of Phase 3 several key positions were already working at capacity.

The SA YCS team noted that they have a state-wide focus, with strong support from other clinicians and smaller sites across the state. The team commented that raising awareness of the YCS and building relationships with smaller sites and other clinicians was key to maintaining the profile of the service and referral numbers.

KPI performance

Overall SA performed well against the KPIs, meeting all except one in 2018-2019, where there were slightly lower numbers for all patients. In 2017-2018, SA had lower numbers of new patients, but this increased considerably in the following year.

Northern Territory

During Phase 2, YCS funding supported a Cancer Care Coordinator (CCC) based at Darwin Hospital, who provided ongoing care to NT AYA cancer patients across their treatment pathway. There was a funding cut in Phase 3 for SA, and as a result the Darwin CCC was discontinued due to the relatively small numbers of AYA cancer patients in the NT (AIHW data notes less than 1% of all cancers in AYAs (excluding melanoma) occurred in the Northern Territory),[29] and the high number of NT cancer patients who are treated interstate.

There was a reduction in Phase 3 in the number of NT AYA patients who received part or all their treatment in the SA YCS, from 23 NT patients over the four years of Phase 2, to five patients (to date) in Phase 3. It was noted that this is likely due to enhanced capacity in the NT to provide more cancer treatments, although this does not include AYA specific expertise.

No AYA-specific data was collected for the NT in Phase 3, so there is no information on the impact of this decision, although it was noted that the networks between Darwin and Adelaide during Phase 3 were maintained due to the goodwill of relevant staff.

Canteen’s Strategic Advisory Group reported that they were unaware that the NT funding would be discontinued when reviewing Phase 3 funding proposals, and requested that they be informed about the implications of this decision, including being provided with information on service demand to inform an understanding of the most appropriate model for providing AYA-specific cancer care in the NT, and evidence of whether secondary support is working effectively to support AYAs in the NT. Some members of the SAG also noted that not having a presence in the NT may have particular challenges given the more complex needs and general burden of poor health among rural/remote and Aboriginal and Torres Strait Islander populations.

It is pleasing to note that in Phase 4, the Northern Territory Department of Health has reinstated the AYA cancer care coordinator nursing position based at the Royal Darwin Hospital, who will work closely with the SA YCS.

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[29] AIHW, 2018, p49

Section 4: Role and impact of Canteen in administration, management, support and oversight of the initiative

Canteen is responsible for administration, management, support and oversight of the YCS across all states and territories. The data reviewed for this evaluation demonstrates that Canteen is effective in administering and supporting the YCS. State partners also recognised that Canteen plays an important advocacy role driving the national YCS initiative in a complex national and jurisdictional landscape, and plays a critical role in advocating for Commonwealth and state governments to support the YCS partnership funding model. While separate to the Phase 3 funding, securing funding for national clinical trials for high lethality cancers for AYAs was also recognised as an important achievement led by Canteen.

Advisory groups

Canteen's coordination of the YCS initiative is supported by the expertise of a range of Advisory Groups, including the Strategic Advisory Group, the Service Delivery Advisory Group, the Data Advisory Group, and the National Youth Advisory Group.

Membership of the Strategic Advisory Group includes high level expertise across clinical, research, data, service delivery, strategic and governance aspects of AYA cancer. The group is engaged and invested in supporting the YCS and is a strong asset to the initiative. The SAG was positive about their role and the role of Canteen as a coordinating body, commenting that Canteen has been effective in articulating consumer needs, and building partnerships between State and Federal governments and an NGO to provide a service to AYAs, which was felt to be a significant achievement. The group also highlighted the focus in Phase 3 on addressing the survival gap by increasing participation in clinical trials, which they felt was an important evolution of the YCS, as Phase 1 and 2 were focused on establishment of the YCS.

There were several suggestions from SAG members for optimising their contribution to the YCS. Whilst it was acknowledged that consultation on strategic issues is a key focus of the SAG meetings, feedback suggested that this could be enhanced by prioritising the strategic areas where advice is required and limiting discussion on progress and updates (as this could be provided in another format). One area where the SAG was interested in having greater involvement was in relation to the progress of clinical trials and survivorship care, as they felt this was likely to have a greater focus in Phase 4. They felt the SAG could provide advice on progress of and participation in the clinical trials, understanding and addressing barriers to enrolment, and service level needs for facilitating participation (for example, meeting with pharmaceutical companies, administration support, and streamlining processes). It should be noted that Canteen also has a Clinical Trials Expert Advisory Group they engage with for these types of issues.

Other areas that the SAG felt could be a focus in the future included reviewing and advising on variation across jurisdictions and strategies for addressing this where needed (taking into account the political and population differences across jurisdictions), advising on KPIs, providing suggestions for SAG membership, and identifying strategies to maintain Canteen's role as the national peak body for AYA cancer.

Data Advisory Group membership comprises key stakeholders from Cancer Australia, the Australian Institute of Health and Welfare, Cancer Council, University of South Australia, as well as representatives from Queensland, Victoria, South Australia, and NSW YCS. Members who participated in the consultation felt that the DAG worked well, that the Terms of Reference were appropriate, and that their advice was valued by Canteen. It was felt the group contains the appropriate expertise to help drive implementation of the national dataset.

Only two members of the National Youth Advisory Group (NYAG) were consulted (one former and one current member), which is a limitation of this evaluation. Both participants had participated in a range of leadership opportunities supported by Canteen and were very positive about these opportunities.

The approach for the NYAG is currently being reviewed, as there has been inconsistent membership more recently, and there were suggestions that the new approach needs to clarify the expectations and responsibilities between jurisdictional youth advisory committees/boards, the NYAG, and Canteen's national youth advisory team (which represents the broader group of young people Canteen supports). It was felt that the lack of differentiation between the state and national youth leadership groups and responsibilities could potentially dilute the focus on the YCS, and cause confusion for youth participants about their responsibilities. For example, a SAG member commented that running the NYAG concurrently with Canteen's national leadership programs has reduced the focus in these meetings on the YCS.

It was also noted that there are effective state networks of youth advisory boards that inform health service models in the various jurisdictions, with varying models across jurisdictions, which were seen as an important strength of the YCS. The SAG members felt there is an opportunity to build on this and develop the "national collective", while taking into account the needs of each of the jurisdictions and nationally in relation to youth input and advice. In 2019 and 2020 Canteen has been working with the coordinators of the local Youth Advisory Groups to develop strategies to enhance youth engagement for Phase 4.

Communication

Canteen have a number of communication mechanisms with the YCS in each jurisdiction, which include quarterly Service Delivery Advisory Group (SDAG) meetings with all lead clinicians and service managers, quarterly activity data review meetings with service managers, quarterly meetings with research nurses, newsletters, and face-to-face workforce development opportunities such as the Community of Practice meetings.

While the jurisdictions felt that the availability of communication forums was sufficient, there were several comments requesting improvements in the level of transparency of processes and decision making (identified in nine out of 34 consultations).

The most common request was for greater transparency in relation to decision-making for the YCS program, including funding decisions, allocation, and the basis for these decisions (there were several comments requesting information on how the funding is allocated nationally, the delineation across the states, and how this is decided). Canteen note that allocation of Commonwealth funding across jurisdictions for Phase 3 was determined proportional to the general population of 15-25-year-old persons, and that this information has been provided to the YCS jurisdictions.

Other requests included:

- Information on the governance processes for decision-making, including the roles and responsibilities for those involved in YCS governance (for example, identifying and communicating the role of Canteen, the Board, the SAG, and the SDAG in decision-making).

- Clear lines of communication and engagement with YCS representatives, including seeking input on key decisions and initiatives. For example, it was noted that decisions in relation to funding for clinical nurses to support the clinical trials did not include any discussion with the YCS teams prior to this being communicated with the relevant CEOs.

All of these opportunities for improvement were identified in the Phase 2 evaluation, and a couple of comments were made about improvements over Phase 3.

Activity monitoring

Collection of national activity data across five jurisdictions and 26 hospitals is a significant task that is implemented by the YCS and coordinated and overseen by Canteen. This is the only national dataset on YCS activities, and is highly valued. The activity data includes information on YCS patient numbers and the provision of a range of AYA-specific care, and provides information on the delivery of YCS over time, as it has been collected throughout Phase 2 and Phase 3.

Some YCS representatives noted that there are limitations with the activity data, which are likely to be addressed in the future with the implementation of the national AYA dataset and future digitisation of medical health record data. It was felt the activity data does not fully represent the breadth, depth and quality of the services provided, and that reporting is time consuming as it requires collation of data from multiple hospital sites and different electronic medical record platforms. Canteen and jurisdictional staff also noted that there are inconsistencies in how data are reported across jurisdictions and quarters, and that there could be duplication as the data is aggregated. Given that the national AYA dataset is a longer term project, there may be value in Canteen continuing to work with the jurisdictions in the short term to review and potentially refine current activity data items, to include items that reflect the quality of service delivery if possible. Canteen staff noted that time was dedicated to discussing the activity data at the most recent Community of Practice.

Key Evaluation Question 2 - What are key considerations for future strategy development?

The YCS is delivered through a partnership between Canteen, the DoH, the state health departments, and the YCS teams working across 26 hospitals nationally. These results highlight the success of this partnership in supporting AYA with cancer to receive age-appropriate care.

The YCS supported higher numbers of new and recurring patients nationally in Phase 3, from 1,647 in 2017-18 to 1,759 in 2018-19[30], compared with 1417 in the final year of Phase 2.[31] The profile of the YCS has grown over Phase 3, which is a significant achievement for the initiative, with a stable number of patients and newly diagnosed patients across Phase 3.

Overall, the activity data demonstrates that the national YCS initiative provided multidisciplinary care and psychosocial support to many AYAs along the cancer care pathway. KPI performance data highlights that the initiative was implemented in line with the requirements of the DoH contract, and that most deliverables and performance targets were met. The Experience of Care survey found that AYAs and their family members/supportive others valued the support and care provided, that was tailored to the specific needs of AYAs.

The majority of quantitative DoH KPIs were met nationally, except for the target of achieving a 12% increase in new patients referred by health professionals to specialised YCS between 2017 and 2020, and the target of completing psychosocial assessments for 75% of new AYA patients. The findings suggest that there is unlikely to be continued increases in new AYA patients being referred to YCS, especially as the YCS in each jurisdiction appears to have reached capacity as they are providing care to a larger number of AYA patients, are providing secondary consultations to a broad range of health professionals and community service providers, and are developing improved survivorship care pathways for AYAs completing treatment. Given this, a reduced KPI target for newly diagnosed patients should be considered.

Throughout Phase 3 Canteen convened significant expertise in the form of the Data Advisory Group, the Strategic Advisory Group (SAG), the Service Delivery Advisory Group and the National Youth Advisory Group. These groups are a valuable source of guidance for Canteen, and there were a number of suggestions from the SAG for how the value of this group could be optimised in Phase 4, including: prioritising the strategic areas where advice is required; increasing involvement in the progress of clinical trials and survivorship care; providing advice on variation across jurisdictions and strategies for addressing this where needed; and advising on Key Performance Indicators, SAG membership, and strategies for maintaining Canteen’s role as the national peak body for AYA cancer.

Continued focus on the national minimum data set will be important in Phase 4; successfully negotiating and realising the approach proposed by the DAG. This will include implementing the new

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[30] Phase 3 Activity data

[31] Nous Group. Evaluation of Youth Cancer Services Phase 2 (2013-2017): Final report. 2017

model in NSW, Victoria and Queensland, as well as negotiating appropriate processes for the smaller jurisdictions.

Consideration is required to develop a strategy for enhancing youth engagement and leadership at the national level, and Canteen should continue to work closely with the jurisdictions to support an approach that builds on existing youth leadership networks.

Several successful workforce and network development events were implemented in Phase 3, including four Community of Practice events and the Adolescent and Young Adult Cancer Global Accord Conference (GAYAC). Positive feedback was received for all these events, although the qualitative consultations suggest further streaming and targeting of workforce development strategies could be valuable, especially given that many in the YCS network now have considerable experience and expertise.

There was some inconsistency in how jurisdictions report to Canteen about clinical trial recruitment, with some reporting the number recruited and the name of the trial the AYAs are enrolled in, while others provide enrolment numbers only. Given the likely increase in focus on clinical trials for Phase 4, consistent reporting that includes numbers and name of the trial could be valuable and assist monitoring and co-ordination, as well as support strategies to improve recruitment. Canteen could also consider facilitating relationships between YCS teams and trial consortia, considering the barriers to recruitment identified in the qualitative consultations.

Targets for referrals to community-based services for completed treatment were exceeded nationally and by every jurisdiction. While it is clear referrals to these organisations are occurring, there is not currently visibility of which organisations patients are being referred to. This could be addressed by amending activity reporting templates to capture this information.

There are opportunities to enhance the partnership with YCS teams and Canteen in supporting the effective coordination and collaboration of the national YCS. Consistent themes emerged in relation to enhanced transparency for decision-making of the YCS program, including funding decisions and allocation. As well, there is a desire for greater clarity of the YCS governance processes, including the roles and responsibilities of those involved in YCS governance. Finally, there is an appetite for more direct lines of communication and engagement with YCS representatives, including seeking input on key decisions and initiatives.

This evaluation was conducted prior to the COVID-19 pandemic, which is of particular concern for the YCS as AYA cancer patients are an at-risk population. The response of the YCS to the COVID-19 pandemic may influence models of care in the future.

The findings indicate that Canteen was effective in administering the YCS initiative and instrumental in promoting and co-ordinating nationally consistent practice, data collection, and access to clinical trials across the national network. The advocacy role of Canteen was often identified as a key achievement. The YCS teams include a dedicated, passionate workforce with a strong shared vision of AYA-specific supportive care, with considerable evidence of the achievements of the YCS teams in delivering information and support to young people living with cancer, including social and emotional support, and linking them with appropriate services.

The following table summarises the key future considerations for the YCS initiative.

Table 25 – Key considerations for the YCS initiative

Area	Consideration
SAG	• Prioritising time at meetings for strategic areas where advice is required • Reviewing and advising on KPIs during Phase 4, to inform future KPIs that reflect the continued development of the YCS, and take into account additional data provided through the national minimum dataset. This will include prioritising strategic areas of focus, identifying vulnerable groups and supporting equitable access/reach to these populations (which will be possible with the national minimum dataset) • Work with Canteen to identify the range of organisations engaged in supporting AYAs with cancer, and consider future strategic implications in relation to their level of influence, and opportunities for enhancing collaboration and engagement to support AYAs with cancer • Providing strategic advice on survivorship, with consideration of the advocacy role of Canteen for AYAs with cancer, and foreshadowing survivorship priorities for the future. This could include understanding the variations in the definition of survivorship adopted across the YCS, identifying quality indicators for survivorship care after treatment, developing a shared definition for the YCS, reviewing literature to understand the current context and identify priorities for future research (such as longer-term survivorship outcomes including psychosocial, educational attainment, etc), and highlighting future opportunities/priorities • Providing advice on variation across jurisdictions and strategies for addressing this where needed. This would include monitoring access to care for AYA from the NT, to understand implications of the revised approach, and identify how best to support the NT given the more complex needs and general burden of poor health among rural/remote and Aboriginal and Torres Strait Islander populations • Advising on SAG membership, and strategies for maintaining Canteen's role as the national peak body for AYA cancer These considerations align with the existing Terms of Reference for the SAG.
NYAG	• Continued focus on enhancing youth engagement and leadership at the national level, working with the jurisdictions to support an approach that builds on existing youth leadership networks
KPIs / Activity data	• Canteen to continue to work with the jurisdictions in the short term to review and potentially refine current activity data items, to include items that reflect the quality of service delivery if possible. Opportunities highlighted in this evaluation include: ○ Capturing information on the type of organisations patients are being referred to post treatment ○ Enhancing consistency in definitions used when reporting secondary consultations

Area	Consideration
	○ Reducing the KPI target for newly diagnosed patients
Clinical trials	• Consider revising the activity reporting on clinical trials, so that number and the name of the trial is consistently reported, to assist monitoring and co-ordination • Canteen to continue to facilitate relationships between YCS teams and trial consortia
Workforce development	• Further streaming and targeting of workforce development strategies, reflecting varying professional development needs of those with different levels of experience
Role of Canteen in administration and coordination	• Optimising communication on governance processes (including the roles and responsibilities of those involved in YCS governance), funding allocation for the DoH funding (including across jurisdictions, national projects and operational costs, and the basis of these decisions) and processes for gathering input from YCS jurisdictions for decision-making

Appendices

Appendix 1 – DoH Performance Indicators Phase 3

Number	Description	Target
1	YCS continued delivery of multidisciplinary service to young people and their families for treatment and care	Five contracts executed by August 2017
2	Increased awareness and referrals by health professionals to specialised AYA cancer services and Youth Cancer Centre	12% increase in new patients referred by health professionals to specialised AYA cancer services and Youth Cancer Centres between 2017-20
3	Number of patients treated, assessments completed, and consultations undertaken during 2017-18	75% of all newly diagnosed young cancer patients treated and supported by YCS nationally
		1,350 new and recurring patients treated and supported by YCS nationally
		Psychosocial assessments completed for 75% of new AYA patients
		550 secondary consultations undertaken
		Survivorship assessments completed for 45% of patients supported by YCS who complete treatment
		Care plans completed for 45% of patients supported by YCS who complete treatment
		45% of patients supported by YCS who complete treatment will be referred to community-based support services by the time they complete treatment

Number	Description	Target
4	Number of patients treated, assessments completed, and consultations undertaken during 2018-19	80% of all newly diagnosed young cancer patients treated and supported by YCS nationally
		1400 new and recurring patients treated by YCS nationally
		Psychosocial assessments completed for 75% of new AYA patients
		625 secondary consultations undertaken
		Survivorship assessments completed for 55% of patients supported by YCS who complete treatment
		Care plans completed for 55% of patients supported by YCS who complete treatment
		55% of patients supported by YCS who complete treatment will be referred to community-based support services by the time they complete treatment
5	Number of patients treated, assessments completed, and consultations undertaken during 2019-20	85% of all newly diagnosed young cancer patients treated and supported by YCS nationally
		1450 new and recurring patients treated by YCS nationally
		Psychosocial assessments completed for 65% of new AYA patients
		700 secondary consultations undertaken
		Survivorship assessments completed for 65% of patients supported by YCS who complete treatment
		Care plans completed for 65% of patients supported by YCS who complete treatment
		65% of patients supported by YCS who complete treatment will be referred to community-based support services by the time they complete treatment
6	Youth Cancer Data – National Project	National AYA cancer dataset implemented across five jurisdictions
7	Capacity building through workforce development	Ongoing professional development provided to YCS workforce across Australia
8	Building the AYA cancer evidence	Ongoing investment in AYA cancer survivorship research

Appendix 2 – Qualitative consultations

Jurisdiction	Stakeholder	Consultation
ACT	Executive, Canberra Hospital	Phone interview
NSW/ACT	NSW Ministry of Health	Focus group (3)
NSW/ACT	Westmead MDT	Focus group (4)
NSW/ACT	Service Manager	Interview
NSW/ACT	MDT, Hunter	Phone focus group (4)
NSW/ACT	MDT, Randwick	Focus group (3)
NSW/ACT	Lead Clinician and SAG member	Interview
QLD	Clinician, (non-DoH funded)	Phone interview
QLD	Clinician (YCS affiliated)	Interview
QLD	State-wide MDT members	Focus group inc. video (6)
QLD	Lead Clinician	Interview
QLD	Service Manager	Interview
QLD	Medical Director (non-DoH funded)	Interview
SA	Adelaide-based MDT	Focus group inc. phone (6)
SA	Lead Clinician and Service Manager	Interview (2)
SA	Clinician (non-DoH funded)	Phone interview
SA	Clinician (non-DoH funded)	Phone interview
SA	Central Adelaide Local Health Network	Phone interview
SA	Former Phase 3 National Youth Advisory Member	Phone interview
VIC/TAS	Lead Clinician and CNC, Royal Children's Hospital	Interview (2)
VIC/TAS	MDT	Focus group (9)
VIC/TAS	Chief Medical Officer, Peter MacCallum Cancer Centre	Interview
VIC/TAS	Lead Clinician	Interview
VIC/TAS	Service Manager and SAG member	Interview
VIC/TAS	Department of Health and Human Services, Victoria	Phone interview
WA	Service Manager and Lead clinician	Phone interview (2)

Jurisdiction	Stakeholder	Consultation
WA	MDT	Focus group videocall (4)
WA	Clinician (non-DoH funded) and local Strategic Advisory	Phone interview
WA	Phase 3 National Youth Advisory Member	Phone interview
WA	Sir Charles Gairdner Hospital	Phone interview
Canteen	Data Advisory Group	Focus group (4)
Canteen	CEO and General Manager, Research & YCS	Interview (2)
Canteen	Strategic Advisory Group	Focus group (6)

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