Evaluation of Youth Cancer Services Phase 2 (2013-2017): Final Report

CanTeen

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Contents

Glossary

Term	Description
ACT	Australian Capital Territory
AYA	Persons aged 15-25 years
ANZHOG	Australia New Zealand Children's Haematology Oncology Group
AYANBDS	Adolescent and Young Adult cancer (clinical) National Best Practice Data Set
COSA	Clinical Oncology Society of Australia
DAG	Dataset Advisory Group
DOH	Federal Department of Health. Funder for Youth Cancer Services Phase 1 and 2
DTT	Distress Thermometer Tool
ETAG	Education and Training Advisory Group
FTE	Full Time Equivalent
GP	General Practitioner
Medical multi-disciplinary team (MDT)	A team of medical specialists, which may include an oncologist, haematologist, radiation oncologist, surgeon and/or pathologist.
NSW	New South Wales
NT	Northern Territory
NYAG	National Youth Advisory Group
Other health professionals	Health professionals who provide services to youth with cancer but are not YCS-funded or YCS-affiliated staff. This includes General Practitioners and allied health professionals.
Psychosocial care	The culturally sensitive provision of psychological, social and spiritual care.[1]
RAG	Research Advisory Group
SA	South Australia
SAG	Strategic Advisory Group
Supportive care	Non-medical care, such as exercise physiology, music therapy and educational support.
TAS	Tasmania
VIC	Victoria
WA	Western Australia
YCS	Youth Cancer Service
YCS Advisory Groups	Advisory Groups established for YCS Phase 2 that provide guidance and expertise for delivery of initiatives. The Advisory Groups include the Strategic Advisory Group, Youth Advisory Group, Dataset Advisory Group, Education and Training Advisory Group and Research Advisory Group.
YCS Leadership Group	The group of Lead Clinicians and Service Managers from each YCS and senior CanTeen staff that lead the operational aspects for YCS service delivery and national initiatives.
YCS program	The five jurisdictional YCSs that deliver care and support to adolescents and young adults with cancer and the three national initiatives (the National Network, National Research Agenda and National Data Collection Strategy).
YCS-affiliated staff	Health professionals who work at YCS lead and partner sites who provide provider services to young people with cancer and who interact closely with YCS-funded staff (e.g. staff at lead or partner sites who are part of pre-existing AYA cancer teams).
YCS-funded staff	All staff employed by YCSs including clinical, operational and administrative staff.

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[1] National Breast Cancer Centre and National Cancer Control Initiative. 2003. *Clinical practice guidelines for the psychosocial care of adults with cancer.* National Breast Cancer Centre.

1 Executive Summary

Context

Through the Youth Cancer Service (YCS) program Phase 2, CanTeen and the YCSs significantly improved the comprehensive, multi-disciplinary care provided to adolescents and young adults (AYAs) with cancer in Australia. CanTeen and the YCSs can claim substantial successes against the Department of Health (DOH) and broader evaluation indicators that measured the implementation and effectiveness of Phase 2 from 2013 to 2017.

It is important to recognise that CanTeen and the YCSs delivered YCS Phase 2 in a challenging environment. CanTeen played a pivotal role in leading a nationally consistent approach for adolescent and young adult (AYA) cancer care through the YCSs. CanTeen and the YCSs had to navigate complex service delivery contexts in eight states and territories and build relationships with state health departments, public and private hospitals, other cancer services, non-government organisations (NGOs) and other health professionals.

Achievements of Phase 2 – the YCSs[2][3]

The YCS program reached a significant proportion of all AYAs diagnosed with cancer in Australia (68% on average over the four years).[4] Major achievements related to the delivery of YCSs included the:

- establishment of YCSs at 27 sites across Australia in all five YCS jurisdictions.
- provision of support and care to over 4,900 AYA patients with cancer in total during Phase 2 (new and recurring patients). The annual YCS patient load increased from 900 patients in 2013 to more than 1,400 by the end of Phase 2 in 2017.
- facilitation of access to age-appropriate and youth specific multi-disciplinary teams (MDTs) for AYAs with cancer. This was evidenced by the increasing number of new referrals each year (a 25% increase over Phase 2) and the large proportion of patients that had care provided by a MDT team (on average 77% of new patients each year between 2014-15 and 2016-17).
- provision of psychosocial and supportive care to a large proportion of YCS patients to help ensure they and their families were supported and had positive long-term health outcomes. Almost all YCS patients received psychosocial care each year between 2014-15 and 2016-17 (91% on average per year). Almost half of all YCS patients received supportive care across the same period (48%).[5]
- provision of access to fertility preservation for AYAs with cancer, including access to information and treatment. In each year of Phase 2, on average almost 60% of new YCS patients received information, 42% were referred to a fertility preservation specialist and one-third underwent treatment.

Achievements of Phase 2 – the national initiatives

In addition to delivery of the YCSs, CanTeen and the YCSs progressed three national initiatives. These aimed to: build a skilled YCS workforce; ensure collaboration and consistency across sites; target AYA cancer research in high priority areas; and improve collection of AYA cancer data. Major achievements included:

- establishment of a YCS workforce of 47 staff, comprised of specialist clinicians and staff with a deep understanding of AYA needs and knowledge of specific diseases and tumours. The professional development program increased the skills and competencies of staff and supported nationally consistent care.
- facilitation of access to clinical trials, which maintained a participation rate above the Department of Health (DOH) target for the duration of Phase 2 (averaging 8% participation across Phase 2). CanTeen and the YCSs sought to enrol AYA patients in trials, invested in clinical trial research and research nurse capacity in YCS teams and advocated to government on AYA specific research priorities.
- improved collection of consistent, comprehensive AYA cancer data over Phase 2 and agreement on a national AYA minimum dataset (due for implementation in 2018).

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[2] A small number of activity data figures in this report differ from CanTeen's reports to the DOH. The small discrepancies are because Nous and CanTeen used independent verification processes to confirm activity data with the jurisdictional YCSs throughout Phase 2.

[3] Four-year aggregate totals and averages across Phase 2 may include double counting of some patients across years.

[4] In Australia, there were approximately 1,000 AYA cancer diagnoses on average each year (based on CanTeen estimates using AIHW cancer incidence data). In 2016-17, 682 AYAs were referred into YCSs (including newly diagnosed and relapsed and other patients) (based on 2016-17 jurisdictional activity data reports).

[5] The proportion of all YCS patients who received any supportive care reduced from 63% in 2015-16 to 33% in 2016-17 due to the lack of a funded supportive care position in NSW/ACT in 2016-17. Supportive care can include, but is not limited to, music therapy, exercise physiology, education or vocational support, occupational therapy or access to a dietician.

The evaluation of YCS Phase 2 measured improvements in services, supports and care coordination for AYAs with cancer and the effectiveness of the YCS national initiatives. Consistent with the Evaluation Plan, the evaluation assessed all activities undertaken as part of Phase 2. These were a combination of activities under the DOH funding agreement and additional activities funded through other means (e.g. CanTeen donor funds). The DOH key performance indicators (KPIs) comprise one part of the broader evaluation indicators. For specific information on progress against the DOH KPIs, see *Findings Part 1*.

1.1 Background

CanTeen has been working with national and state partners to deliver specialist cancer services to AYAs diagnosed with cancer across Australia. In Phase 2 (2013-2017), CanTeen aimed to build from Phase 1 (2009-2012) by enhancing the five jurisdictional services hubs and implementing three national initiatives (the National Network, National Research Agenda and National Data Collection Strategy).

CanTeen engaged Nous Group (Nous) to evaluate implementation of YCS Phase 2. Nous assessed the improvement in services and coordination of care for AYAs with cancer through the YCSs and the effectiveness of the national initiatives.

The health service context in which CanTeen and the YCSs operate is complex. YCSs are embedded within existing health care settings (across eight states and territories). Patients and clinicians may find it difficult to distinguish YCS-specific care and support from other care. For example, a patient may not easily be able to identify whether YCS staff, YCS-affiliated staff and/or another health professionals treated them. In addition, a YCS position may be funded from multiple sources (including CanTeen and state governments).

Whether patients are able to identify that a staff member who treated them is a YCS staff member is not important in the context of patient outcomes and the care experience. It does have implications when evaluating the care and support specifically provided through YCSs (within this complex environment).

This evaluation focused on YCSs specifically. Nous interpreted analyses and provided caveats for the findings as needed in recognition of the complex delivery context.

1.2 Methodology and evaluation limitations

Nous conducted the evaluation between July 2014 and November 2017. An Evaluation Plan, approved by the Strategic Advisory Group (SAG) in 2014, guided evaluation activities. Nous developed the Final Report based on data for the period 1 July 2013 to 30 July 2017 (the four years of Phase 2). Data sources included:

- YCS program documentation
- jurisdictional activity data for Phase 2
- surveys of YCS staff and other health professionals who work with AYAs with cancer (collected in 2015, 2016 and 2017)
- interviews and focus groups with AYAs, families and carers, YCS staff, YCS-affiliated staff, Advisory Groups, CanTeen Executive members and stakeholders from federal and state health departments, other cancer services, private hospitals and NGOs.

Nous and CanTeen used independent verification processes to confirm activity data with the jurisdictional YCSs (throughout Phase 2). This resulted in small discrepancies between a small number of activity data indicators (as detailed in Appendix I).

1.3 Evaluation findings

The evaluation findings are structured in two parts:

- **Part 1** reports on progress against the DOH KPIs, a subset of the overall evaluation findings.
- **Part 2** reports on overall evaluation findings based on the Evaluation Plan and Data Collection Plan, of which the DOH KPIs were a subset (see Appendix A).

Findings Part 1: DOH KPIs

CanTeen fully achieved four of the DOH KPIs and made significant progress against the remaining two KPIs, almost fully achieving them. Progress against the two KPIs almost achieved was limited by external factors often outside the control of CanTeen and the YCSs (as detailed in section 4).

CanTeen achieved the KPIs related to increased participation in clinical research by young people, improved practice by health professionals in treating AYA patients, increased awareness and referrals by health professionals to YCSs and the delivery of YCSs in all states and territories. CanTeen made significant progress against the collection of AYA data to ensure an appropriate workload for YCSs (based on four specific measures, three of which CanTeen and the YCSs fully achieved).

Table 1 provides an assessment of achievements against the DOH KPIs.

Table 1: Summary of progress against DOH KPI

#	Performance indicator	Target	High-level summary of achievements	Assessment
1	Collection of AYA data	An agreed national dataset which all 5 hubs contribute to	CanTeen and the Dataset Advisory Group (DAG) had agreed a highest priority national minimum AYA dataset, but had not yet implemented it according to planned timeframes.	◕ Mostly achieved
2	Clinical research with increased participation by young people	Increase in participation by young people in clinical research from current levels of 3%	CanTeen and the YCSs achieved and exceeded this target. 8% of all new YCS patients during Phase 2 were newly enrolled in clinical trials and 14% were newly enrolled in research studies.	● Achieved
3	Improved practice by health professionals in treating AYA patients, through increased compliance with guidelines	Guidelines disseminated to General Practitioners through online strategies	CanTeen and Clinical Oncology Society of Australia (COSA) developed and disseminated three clinical guidances for health professionals who work with AYAs with cancer. In 2016 and 2017, CanTeen worked with Cancer Australia to review the National Youth Cancer Framework (2008), which outlined best practice in AYA Oncology.	● Achieved
4	Increased awareness and referrals by health professionals to specialised AYA Cancer Services and Youth Cancer Centres	15% increase in referrals by health professionals to specialised AYA cancer services and Youth Cancer Centres between 2013 and 2017	CanTeen and the YCSs increased referrals by health professionals to YCSs by 25% during Phase 2 (from 2013-14 to 2016-17).	● Achieved
5	YCSs are delivered in all States and Territories through 5 lead hospitals based in Sydney, Melbourne, Perth, Brisbane and Adelaide	Five contracts were executed	YCSs were operating in all states and territories.	● Achieved

#	Performance indicator	Target				High-level summary of achievements	Assessment
6A 6B	Appropriate workload for YCSs measured by[6]:	**2013-14**	**2014-15**	**2015-16**	**2016-17**	**CanTeen and the YCSs mostly achieved this indicator, as they achieved three of the four sub-indicators during Phase 2.**	◕ Mostly achieved
	- Number of patients treated by YCS nationally (new and recurring)	475	1,050	1,250[7]	1,300	CanTeen and the YCSs achieved the annual target number of patients treated in all years of Phase 2. In total, over 4900 new and recurring patients were supported through YCSs nationally in Phase 2.	
	- Number of new AYA patients treated by YCS nationally[8]		525	575	625	CanTeen and the YCSs achieved the annual target number of new AYA patients treated in all years of Phase 2. In total, YCSs treated over 2600 new AYA patients nationally in Phase 2.	
	- Assessments completed[9]	500	- 75% of new AYA patients			Canteen and the YCSs achieved the target for number of assessments in 2015-16 only; however, the average for the full four-year period of Phase 2 was 73% of new patients completing assessments using the DTT (only slightly lower than the target of 75%). CanTeen indicated this was due to some YCS staff not being trained in the DTT. Staff vacancies also impacted on the capacity of YCS staff to use the tool. The DTT is still in the process of validation which began partway through Phase 2 and will continue in to Phase 3.	
	- Secondary consultations undertaken	215	245	305	305	CanTeen and the YCSs achieved the annual target number of secondary consultations undertake in all years of Phase 2. In total, YCSs undertook over 2400 secondary consultations in Phase 2.	

Findings Part 2: Evaluation indicators

Overall, evaluation findings show that CanTeen and the YCSs delivered almost all planned activities and achieved the majority of the program's intended short-term outcomes (based on the Evaluation Plan). Table 2 provides a summary of evaluation findings, structured against the three lines of enquiry.

Table 2: Summary of evaluation findings for YCS Phase 2

	Summary of evaluation findings
What was delivered through YCS Phase 2?	- Five state-wide YCSs delivered cancer services, informed by the views of young people, to AYAs across Australia. - YCSs provided AYAs undergoing cancer treatment with access to a range of services and supports; the availability of services varies across the YCS sites. - CanTeen undertook five projects to increase access to YCSs for AYAs with cancer. - CanTeen undertook activities aimed at improving the capacity of health professionals to identify and diagnose cancer in AYAs at an earlier stage. - CanTeen's advocacy work increased recognition of AYA cancer needs amongst governments. - Under the **National Network**, CanTeen delivered activities that improved collaboration and consistency of service delivery across YCSs and YCS staff skills. - Through the **National Research Agenda**, CanTeen formed the Research Advisory Group (RAG) and

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[6] DOH performance indicator descriptors and targets were revised in January 2015 for the periods 2014-15, 2015-16, 2016-17.

[7] DOH agreed to a revised figure of 1250 from 1600. The 1600 figure included a high number of duplicate counts as it aggregated four quarters of activity data. The current formula gives a more accurate number of new patients per annum.

[8] This performance indicators was not part of the DOH KPIs in 2013-14.

[9] Assessments completed refers to the number of YCS patients who completed the Distress Thermometer Tool (DTT).

	Summary of evaluation findings
	supported targeted research activities. CanTeen invested in more than 20 research projects and supported four clinical trials, in line with six AYA cancer research priorities. • CanTeen developed the **National Data Collection Strategy** and set up the DAG, undertook a pathfinder initiative and finalised a highest priority national AYA minimum dataset. CanTeen and the DAG distributed the final minimum dataset to stakeholders in 2017.
What short-term outcomes were achieved through YCS Phase 2?	• The YCSs provided comprehensive support and treatment to a significant proportion of all AYAs with cancer across Australia during Phase 2. • Overall access to and awareness of YCSs increased; despite this, many stakeholders believed access was more difficult for AYAs in the private system and those who live in regional and rural areas. • YCSs improved young peoples' cancer experience, mainly through the provision of high quality medical treatment, supportive staff and tailored services. • The YCS program improved shared care arrangements across all relevant settings, but to a lesser extent between public and private hospitals.[10] • Based on available data, it was difficult to determine the extent to which YCSs built the capacity of GPs to diagnose cancer in AYAs at an earlier stage. • **National Network:** CanTeen and the YCSs supported knowledge sharing and capability across YCSs, including through effective National Network meetings. CanTeen developed educational, promotional and programmatic resources that helped improve consistency in service delivery across YCSs during Phase 2. An effective professional development program helped to improve the skills and competencies of YCS staff in all jurisdictions. • **National Research Agenda:** CanTeen supported a robust research agenda that involved the prioritisation and investment in line with the six agreed AYA cancer research priorities. Youth participation in clinical trials was well above the target of 3% throughout Phase 2. • **National Data Collection Strategy**: The consistency and accuracy of activity data improved during Phase 2; some YCS staff were unclear on some data definitions and the relevance of some indicators. CanTeen provided quarterly feedback to YCSs on their performance, but the majority of jurisdictional YCS stakeholders in consultations in 2016 and 2017 indicated that more comprehensive, local-level feedback would support evidence-based service planning and delivery.
What were the strengths and areas for improvement of YCS Phase 2?	• The YCS program had many strengths that contributed to delivery of comprehensive, tailored cancer care for AYAs. • CanTeen and YCS stakeholders identified some challenges and four critical success factors for the establishment of YCS Phase 2. These were funding aligned to national priorities, communication of the shared national vision, profile raising of YCSs and engagement with AYAs to inform service delivery. • The **National Network** meetings and strong professional development program were key strengths of the National Network. • Investment in priority research needs and support for AYA participation in clinical trials were key strengths of the **National Research Agenda**. • The main strength of the **National Data Collection Strategy** was that it drove development of the national AYA minimum dataset.

1.4 Overarching learnings from YCS Phase 2

Based on the evaluation of YCS Phase 2, Nous identified four principles that were critical in successful delivery of the YCS program. The strengths and the areas for improvement of the YCS Program helped to inform development of these principles (see section 5.3). Therefore, the principles are a combination of things that were done well in Phase 2 that should be continued in Phase 3 and things that were done less well that should be improved.

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[10] YCS staff, other health professionals and stakeholders from private hospitals typically agreed the YCS program had improvement shared care arrangements across public hospitals and between metropolitan and rural areas, adult and paediatric settings, states and territories and hospitals and primary care settings.

Consideration of these principles during planning and delivery of Phase 3 may be useful for CanTeen and the YCSs, in building on what worked in Phase 2. The four principles are:

- **Clear governance and advisory arrangements**. Clearly defined and communicated governance and advisory arrangements were a commonly cited requirement for successful delivery of the YCS program (through multiple evaluation data sources over the course of Phase 2). This includes articulation of roles and responsibilities of positions/groups involved in YCS governance, including what is in-scope for advisory groups (e.g. clear role descriptions). It also includes confirmation of decision-making powers for CanTeen's national governance, the national advisory groups and local-level jurisdictional governance.
- **Effective and ongoing engagement between CanTeen and YCS stakeholders to seek input on key decisions and initiatives**. Many stakeholders throughout the Phase 2 evaluation indicated effective engagement between CanTeen and the many stakeholders involved in delivery of YCSs was critical. This includes engaging stakeholders in key decisions about the YCS program (where appropriate) and better engagement in the development, design and implementation of initiatives and activities. It also includes ongoing engagement between CanTeen and the YCSs, amongst the YCSs themselves and with other jurisdictional stakeholders (e.g. private hospitals, other health professionals and health departments).
- **Transparency in decision-making about the YCS program**. Transparency around key decisions related to the delivery of YCS, such as funding distribution and YCS priorities, was important in supporting a sustainable program and engaged stakeholders (based on multiple data sources throughout the evaluation). This includes CanTeen being transparent about YCS decisions with YCS jurisdictions and vice versa.
- **Ongoing, regular communications between CanTeen and YCS stakeholders to provide progress updates and program news**. Many stakeholders throughout Phase 2 indicated regular communication between CanTeen and the YCSs stakeholders was important, given the complexity of the YCS program across 27 sites. This refers to communication about what is happening in the YCS program, upcoming events, news and achievements (as opposed to engaging people's input and views on key decisions). Stakeholders indicated that regular communication supported an informed workforce and greater program engagement.

2 Background

Background to the YCS program

Approximately 1,000 Australian young people will be diagnosed with cancer each year.[11] A cancer diagnosis presents unique challenges for a young person. They are transitioning through physical, psychological and social development and need to navigate a healthcare system that does not always meet their needs.[12] In this context, AYA patients are at risk of receiving sub-optimal care and poorer treatment outcomes.

CanTeen has been working with national and state partners to deliver cancer services that improve treatment and support for AYAs with cancer. In Phase 1 (2009-2012), CanTeen funded youth specific hospital roles and contributed funds for the creation of youth friendly environments in some hospitals. CanTeen also used funding to develop: a patient dataset; guidelines on fertility preservation, psychosocial support and early diagnosis; and an online graduate certificate and diploma courses.

In 2013, the federal government committed $18.2 million to CanTeen to continue the Youth Cancer Networks Program. CanTeen added around $900,000 of additional funds.[13] In Phase 2, CanTeen focused on the establishment of five state-wide services (the YCSs, which cover all Australian states and territories) and implement three national initiatives (the National Network, National Research Agenda and National Data Collection Strategy). The four objectives of Phase 2 were to:

1. Develop a national network of integrated and multi-disciplinary YCSs with five lead sites, and over 20 partner hospitals, fully staffed by a skilled and dedicated workforce.
2. Ensure the best chance of survival and positive long term health outcomes for young cancer patients by providing the best possible medical treatment and psychosocial support delivered in age appropriate facilities.
3. Improve the survival rates and quality of life for young cancer patients through collaborative research to build the evidence base.
4. Ensure young cancer patients and their families are supported along the treatment pathway from diagnosis to survivorship or end of life care.[14]

Context for this evaluation

CanTeen engaged Nous to evaluate implementation of YCS Phase 2. The evaluation aims to measure the:

- improvement in services and coordination of care for AYAs with cancer through the YCSs
- effectiveness of the national initiatives.

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[11] This figure is a CanTeen estimate of the annual cancer diagnoses in the 15-25 year age range (based on AIHW data). The AIHW cancer incidence data are presented by five-year age groups. The annual mean incidence for the 15-24 year age range (2008-2012) was 911 diagnoses. This excludes young people aged 25 (which are part of the YCS eligible age range). To account for this, CanTeen estimated cancer incidence for the 15-25 year age range at 1,000 per annum.

[12] Palmer S & Thomas D 2008. A practice framework for working with 15–25 year-old cancer patients treated within the adult health sector. Melbourne: onTrac@PeterMac Victorian Adolescent and young adult cancer service.

[13] Plibersek T (Minister for Health) 2013, *Gillard Government funds fight against cancer,* media release, 14 May 2013, viewed 30 June 2016, available at: https://www.health.gov.au/internet/budget/publishing.nsf/Content/7F69704E8AAB2B89CA257CA0003FF562/$File/healthmedia02.pdf

[14] CanTeen 2013, *Youth Cancer Services National Strategic Plan,* Sydney: CanTeen.

Consistent with the Evaluation Plan, the evaluation assessed all activities undertaken by CanTeen and the YCSs as part of Phase 2.[15] This includes activities outlined in the DOH funding agreement (see Figure 1) and additional activities funded through other means (e.g. CanTeen donor funds).

Figure 1: Tasks outlined in the DOH funding agreement for YCS Phase 2

Key tasks outlined in the DoH funding agreement

- Development and implementation of a National Minimum Data Set on young people with cancer and analysis of health outcomes (including identification of a minimum data set and its collection from the five service hubs)
- Development of a network to ensure collaboration and consistency across the five state-wide hubs
- Increased access of young people with cancer to youth cancer support services
- Increased access to and enrolment of young patients with cancer in clinical research, including trials
- Improved capacity in general practice to identify and diagnose cancer in AYA at an earlier stage through the dissemination of national guidelines of diagnosis and treatment
- Development and implementation of national and local strategies which assist services to reach their potential

Purpose of this report

This Final Report provides CanTeen and the SAG with findings on the delivery of YCS Phase 2. The report provides findings on the period from 1 July 2013 to 30 June 2017. This report provides:

- the evaluation methodology, including data sources and limitations (section 3)
- findings on progress against the DOH KPIs (section 4)
- findings on the establishment and delivery of YCSs and the national initiatives, including what has been delivered, short-term outcomes, strengths and areas for improvement (section 5).

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[15] CanTeen and the SAG approved the Evaluation Plan and Data Collection Plan in September 2014.

3 Methodology

Nous conducted the evaluation between July 2014 and November 2017. Upon commencement of the evaluation, Nous developed an Evaluation Plan and Data Collection Plan to structure the evaluation (see Appendix A). The SAG approved the Evaluation Plan in late 2014. Three evaluation questions guided evaluation activities, each of which was supported by research questions and indicators:

1. What was delivered through YCS Phase 2?
2. What short-term outcomes were achieved through YCS Phase 2?
3. What were the strengths and areas for improvement of YCS Phase 2?

Nous monitored risks and provided updates to the CanTeen project team (monthly) and to the SAG (six monthly). Nous and CanTeen agreed on governance and reporting arrangements. The CanTeen project team monitored implementation of the evaluation. The SAG was responsible for oversight of the evaluation and endorsement of major project deliverables.

Nous drew on multiple data sources to develop evaluation findings (see Appendix B). This included:

- YCS program documentation.
- jurisdictional activity data for Phase 2.
- surveys of YCS staff and other health professionals who work with AYAs with cancer (collected in 2015, 2016 and 2017).
- interviews and focus groups with AYAs, families and carers, YCS staff, YCS-affiliated staff, Advisory Groups, CanTeen Executive members and stakeholders from federal and state health departments, other cancer services, private hospitals and NGOs.

Nous and CanTeen used independent verification processes to confirm activity data with the YCSs throughout Phase 2. This resulted in small discrepancies in seven activity data indicators (see Appendix I for detail). Key data limitations are outlined in Table 3.

Table 3: Key data limitations in the Evaluation of YCS Phase 2

Key data limitations
The variability in the quality of YCS jurisdictional activity data During Phase 2, CanTeen and the YCSs have made significant progress in the development of an effective method to collect activity data. Four factors affected the quality of jurisdictional activity data presented in this report: ◦ CanTeen and the YCSs refined some indicators in the data collection templates between years one and two of Phase 2, which affected the comparison of indicators over time. ◦ Jurisdictional YCSs used different reporting templates in some quarters, which affected the comparability of data both between jurisdictions and over time. ◦ Some YCSs improved their data collection processes, which led to significant increases or decreases in some indicators between quarters (particularly NSW/ACT YCS in 2015-16 and WA in 2016-17). ◦ Some participating YCS hospitals provided activity data after the start of Phase 2, due to delayed ethics approvals.
Limited data on the views and experiences of some stakeholders who interact with YCSs Nous collected the views of stakeholder groups who interact with YCSs through online surveys and consultations (i.e. private hospitals, other cancer services, NGOs and government stakeholders). Nous did not include the surveys broad stakeholder groups who interact with the YCSs as a data source for the Final Report, due to low response rate. Nous collected the views of these stakeholders through consultations.

Key data limitations

Limited data sources on the experience of AYAs with cancer and their families and carers.
Nous collected views of young people and their families and carers through consultations. CanTeen distributed a patient experience of care survey and an experience of care survey for their families and their carers. There were 18 responses to the patient survey (comprised of 16 responses from VIC/TAS YCS and two responses from NSW/ACT YCS) and nine responses to the families and carers survey. Nous did not include these surveys as a data source for the Final Report, due to the response rate. The impact on the findings in this report is minimal. Nous collected the views of AYAs and their families and carers through consultations in all jurisdictions (except WA).

Structure of this report

The findings of the evaluation are structured in two parts in this report:

- **Part 1** reports on a subset of the overall evaluation findings. It solely focuses on progress against the DOH KPIs. These KPIs relate to activities in the scope of the DOH funding agreement.
- **Part 2** reports on overall evaluation findings. These evaluation findings relate to the broader evaluation questions and indicators (of which the DOH KPIs are a subset), as outlined in the Evaluation Plan and Data Collection Plan (see Appendix A).

4 Findings Part 1: Department of Health key performance indicators

This section, *Findings Part 1,* reports on findings against the six DOH KPIs, which were a subset of the overall evaluation findings (detailed in section 5).

Assessment of progress against the DOH KPIs

CanTeen fully achieved four of the DOH KPIs and made significant progress against the remaining two KPIs, almost fully achieving them. Progress against the two KPIs almost achieved was limited by external factors often outside the control of CanTeen and the YCSs (detailed further below).

CanTeen achieved the KPIs related to increased participation in clinical research by young people, improved practice by health professionals in treating AYA patients, increased awareness and referrals by health professionals to YCSs and the delivery of YCSs in all states and territories. CanTeen made significant progress against the collection of AYA data to ensure an appropriate workload for YCSs (based on four specific measures, three of which CanTeen and the YCSs fully achieved).

Table 4 provides an assessment of CanTeen and the YCSs achievements of the DOH KPIs.

Table 4: Assessment of progress against DOH KPIs between 2013-14 and 2016-17

#	Performance indicator	Target	Assessment
1	Collection of AYA data	An agreed national dataset which all 5 hubs contribute to	◕ Mostly achieved
2	Clinical research with increased participation by young people	Increase in participation by young people in clinical research from current levels of 3%	● Achieved
3	Improved practice by health professionals in treating AYA patients, through increased compliance with guidelines	Guidelines disseminated to General Practitioners through online strategies	● Achieved
4	Increased awareness and referrals by health professionals to specialised AYA Cancer Services and Youth Cancer Centres	15% increase in referrals by health professionals to specialised AYA cancer services and Youth Cancer Centres between 2013 and 2017	● Achieved
5	YCSs are delivered in all States and Territories through 5 lead hospitals based in Sydney, Melbourne, Perth, Brisbane and Adelaide	Five contracts were executed	● Achieved

#	Performance indicator	Target				Assessment
6A 6B	Appropriate workload for YCSs measured by[16]:	**2013-14**	**2014-15**	**2015-16**	**2016-17**	◕ Mostly achieved
	Number of patients treated by YCS nationally (new and recurring)	475	1050	1250[17]	1300	
	Number of new AYA patients treated by YCS nationally	-	525	575	625	
	Assessments completed	500	75% of new AYA patients			
	Secondary consultations undertaken	215	245	305	305	

Supporting evidence for each KPI

KPI 1: Collection of AYA data

#	Performance indicator	Target	Assessment
1	Collection of AYA data	An agreed national dataset which all 5 hubs contribute to	◕ Mostly achieved

CanTeen and the YCSs made significant progress towards implementation of a national dataset for AYA cancer during Phase 2. Activities CanTeen, the DAG and YCSs undertook to develop the dataset included:

- CanTeen developed a National Data Collection Strategy and established the DAG to drive its implementation of it.
- In 2015, CanTeen undertook a pathfinder initiative to collect and analyse existing AYA cancer data. CanTeen engaged with data custodians on data availability (nationally and internationally).
- Cancer Australia, in conjunction with CanTeen, developed an AYA Cancer (clinical) National Best Practice Data Set (AYANBDS) in 2010-11. The National Health Information and Performance Principal Committee endorsed the AYANBDS and recommended it as best practice in 2015 (though it was not mandated).
- CanTeen and the DAG subsequently consulted with a range of stakeholders to identify a highest priority national AYA minimum dataset for collection through YCS teams (based on program documentation and consultations). The DAG also worked closely with YCS jurisdictions and other stakeholders to trial the dataset in all jurisdictions and to begin implementation (based on consultations).
- Canteen, the DAG and the YCS teams made significant progress in agreeing on an approach for collection of the national AYA minimum dataset items to ensure accessibility of data. This included finalising definitions and confirming aspects related to governance, data security and ethics.

The majority of stakeholders indicated they were supportive of the AYA minimum dataset (based on consultations). Feedback indicated that the dataset is focused on highly relevant data items accessible

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[16] DOH performance indicator descriptors and targets were revised in January 2015 for the periods 2014-15, 2015-16, 2016-17.

[17] DOH agreed to a revised figure of 1250 from 1600. The 1600 figure included a high number of duplicate counts as it aggregated four quarters of activity data. The current formula gives a more accurate number of new patients per annum.

through YCS teams (based on program documentation and consultations). CanTeen and the DAG effectively leveraged existing data as part of the pathfinder initiative and the AYANBDS where possible to maximise practicality and efficiency.

At the end of Phase 2, CanTeen had distributed the dataset to stakeholders and begun implementation planning. CanTeen and the YCSs are due to implement the dataset in 2018.

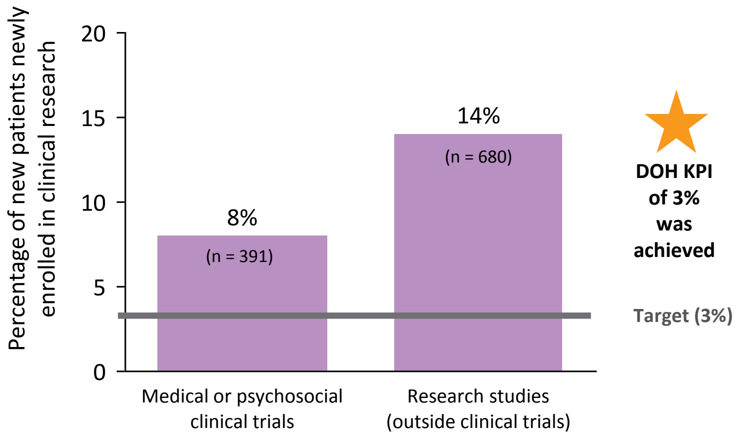
KPI 2: Clinical research

#	Performance indicator	Target	Assessment
2	Clinical research with increased participation by young people	Increase in participation by young people in clinical research from current levels of 3%	● Achieved

CanTeen and the YCSs successfully improved AYAs' access to clinical trials and research studies (outside clinical trials), as shown in Figure 2.

Between 2013 and 2017, 391 patients participated in clinical trials. This represented 8% of the toal number of patients supported by the YCSs over the same time period, more than double the DOH KPI. Over the same time period 680 patients participated in research studies. This represented 14% of the total number of patients supported by the YCSs, more than four times the DOH KPI.

Figure 2: Percentage of YCS patients newly enrolled in a clinical trial or research study during Phase 2[18]



Based on the annual YCS staff surveys, an increasing proportion of YCS staff somewhat or strongly agreed that YCS staff provide AYAs with adequate access to relevant clinical trials and research studies (peaking at 95% of all respondents in 2017 (37 respondents)).[19]

CanTeen advocated for additional funding to assist AYAs with cancer to access clinical trials. CanTeen submitted the Australian Youth Cancer Clinical Trials Initiative proposal to the DOH in December 2015. The objective of the submission was to improve outcomes for AYA cancer patients through increased

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[18] The percentage of all YCS patients is calculated based on the total patients supported through the YCS (including all medical/surgical treatment & psychosocial care) each year. The significant increase in these indicators between 2014-15 and 2015-16 was due in part to a significant increase in their values between Q2 and Q3 2015-16 in NSW/ACT. This, in turn, may be due to improvements in the quality of the NSW/ACT YCSs' data collection.

[19] In the 2015 YCS staff survey 86% (36) of respondents somewhat or strongly YCS provides adolescents and young adults with adequate access to relevant clinical trials and research studies. In the 2016 YCS staff survey 89% (33) of respondents somewhat or strongly YCS provides adolescents and young adults with adequate access to relevant clinical trials and research studies.

participation in high quality clinical trial research. The DOH accepted the proposal and announced $5 million of funding for nationally coordinated clinical trials for youth cancer.

KPI 3: Improved practice by health professionals

#	Performance indicator	Target	Assessment
3	Improved practice by health professionals in treating AYA patients, through increased compliance with guidelines	Guidelines disseminated to General Practitioners through online strategies	● Achieved

As part of Phase 2, CanTeen aimed to improve the capacity of health professionals to identify and diagnose cancer in AYAs at an earlier stage. This can be difficult as a primary care clinician may only see one AYA cancer diagnosis in their career.

CanTeen undertook two major activities aimed at improving the practice of health professionals in treating AYA patients, which were:

1. **Dissemination of the Phase 1 clinical guidance documents**. During Phase 1, CanTeen and COSA developed three clinical guidances for health professionals who work with AYAs with cancer. One of these was for GPs to assist them with the early detection of cancer in AYAs.[20] CanTeen disseminated this during Phase 2 and ran a media awareness campaign in late 2014.
2. **Revision of the National Youth Cancer Framework**. In 2016 and 2017, CanTeen worked with Cancer Australia to review the National Youth Cancer Framework (2008), which outlined best practice in AYA Oncology.[21] The Framework outlines a national vision aimed at supporting young people with cancer to achieve optimal survival, health, wellbeing and meaningful participation across all areas of life. CanTeen published the revised National Youth Cancer Framework in late 2017.

As part of Phase 2, CanTeen planned to refresh the three Phase 1 clinical guidances and explore the development of additional guidances. This was not progressed during Phase 2 (as reported by CanTeen).

KPI 4: Increased awareness and referrals by health professionals

#	Performance indicator	Target	Assessment
4	Increased awareness and referrals by health professionals to specialised AYA Cancer Services and Youth Cancer Centres	15% increase in referrals by health professionals to specialised AYA cancer services and Youth Cancer Centres between 2013 and 2017	● Achieved

CanTeen and the YCSs achieved the DOH KPI target for increased awareness and referrals by health professionals into YCSs. The total number of new referrals into YCSs increased by 25% during Phase 2, from 545 new referrals in 2013-14 to 682 new referrals in 2016-17 (see Figure 3 overleaf). This is significantly higher than the DOH KPI target of 15%.

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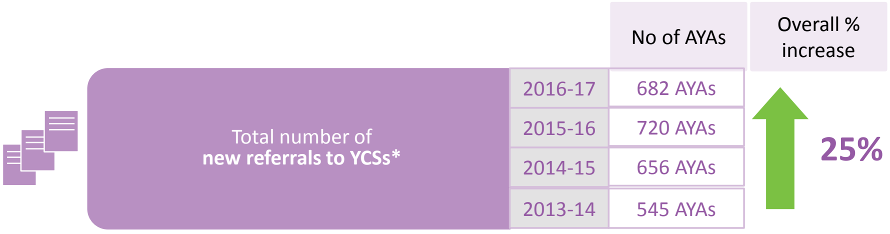
[20] The three guidances developed with COSA as part of Phase 1 were on the early detection of cancer in AYAs, psychosocial care and fertility preservation. The early detection guidance is available at: http://wiki.cancer.org.au/australia/COSA:Early_detection_of_cancer_in_AYAs

[21] Australian Government through Cancer Australia in collaboration with CanTeen, 2008, National Service Delivery Framework for Adolescents and Young Adults with Cancer, Canberra; Commonwealth of Australia. Available at: https://canceraustralia.gov.au/sites/default/files/publications/national_service_delivery_framework_for_adolescents_and_young_adults_with_cancer_teen_52f301c25de9b.pdf

Figure 3: Total new referrals to YCSs, 2013-14 to 2016-17[22]



Total number of new referrals to YCSs*	No of AYAs	Overall % increase
2016-17	682 AYAs	25%
2015-16	720 AYAs	
2014-15	656 AYAs	
2013-14	545 AYAs	

Note: The percentage indicates the overall percentage change between 2013-14 and 2016-17.

Overall, awareness of YCSs amongst stakeholders increased during Phase 2. This was evidenced in part by the increase of new referrals to YCSs, but also through consultations in 2016 and 2017. In particular, awareness increased amongst AYAs with cancer, their families and friends, state and federal health departments and other health professionals who interact with YCSs, but are not employed by YCSs (based on 2016 and 2017 consultations, annual YCS staff surveys and surveys of other health professionals).

KPI 5: Nation-wide delivery

#	Performance indicator	Target	Assessment
5	YCSs are delivered in all States and Territories through 5 lead hospitals based in Sydney, Melbourne, Perth, Brisbane and Adelaide	Five contracts were executed	● Achieved

CanTeen signed five contracts with jurisdictions for the delivery of YCSs in late 2013.

As at 31 December 2016, CanTeen and the YCSs had recruited staff into all funded YCS positions in all jurisdictions.[23] YCSs employed 47 YCS staff from Phase 2 funding, with capacity ranging from 0.1 FTE to 1.0 FTE. These staff mainly made up core MDTs at lead hospitals. Core YCS staff worked with YCS-affiliated staff at lead hospitals and partner sites to provide multi-disciplinary, youth-specific care for AYAs with cancer across Australia.

Figure 4 overleaf shows the locations of YCS sites. Over the course of Phase 2, as many as 27 sites were involved in the YCS program.[24]

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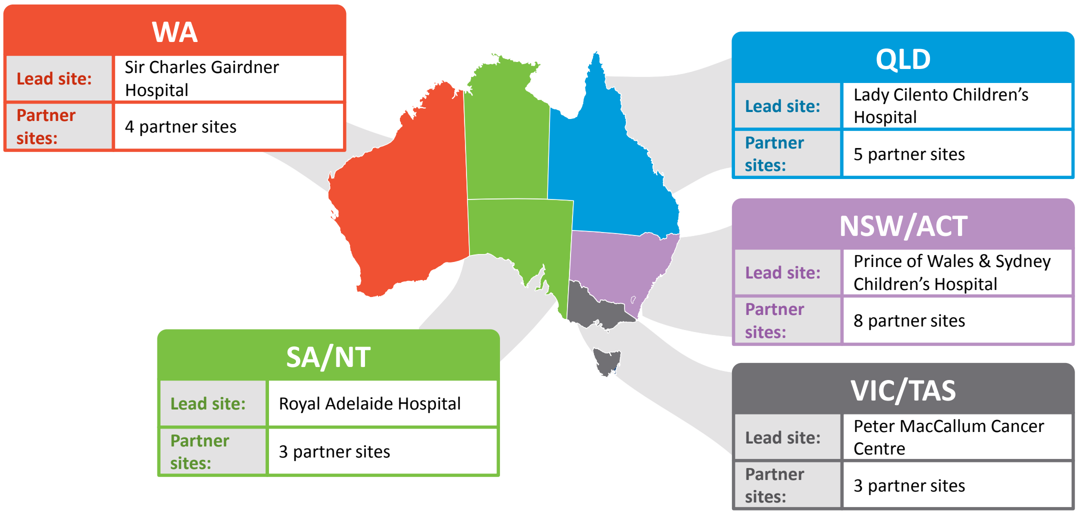
[22] The 'total number of new referrals figure' includes newly diagnosed and relapsed and other patients. Detailed figures for 2013-14, 2014-15, 2015-16 and 2016-17 activity data are provided in Appendix E.

[23] CanTeen 2017, *Youth Cancer Service Program Third Performance Report July-Dec 2016.* Sydney: CanTeen.

[24] As indicated by CanTeen in September 2017.

Figure 4: Phase 2 YCS sites[25]



WA
Lead site: Sir Charles Gairdner Hospital
Partner sites: 4 partner sites

QLD
Lead site: Lady Cilento Children's Hospital
Partner sites: 5 partner sites

NSW/ACT
Lead site: Prince of Wales & Sydney Children's Hospital
Partner sites: 8 partner sites

SA/NT
Lead site: Royal Adelaide Hospital
Partner sites: 3 partner sites

VIC/TAS
Lead site: Peter MacCallum Cancer Centre
Partner sites: 3 partner sites

KPI 6A and 6B: Appropriate workload for YCSs

#	Performance indicator	Target				Assessment
6A **6B**	Appropriate workload for YCSs measured by[26]:	**2013-14**	**2014-15**	**2015-16**	**2016-17**	Mostly achieved
	- Number of patients treated by YCS nationally (new and recurring)	475	1050	1250[27]	1300	Achieved
	- Number of new AYA patients treated by YCS nationally		525	575	625	Achieved
	- Assessments completed	500	75% of new AYA patients			Mostly achieved
	- Secondary consultations undertaken	215	245	305	305	Achieved

CanTeen achieved three of the four specific targets for the KPI related to the workload for YCSs. Performance against each indicator is provided below.

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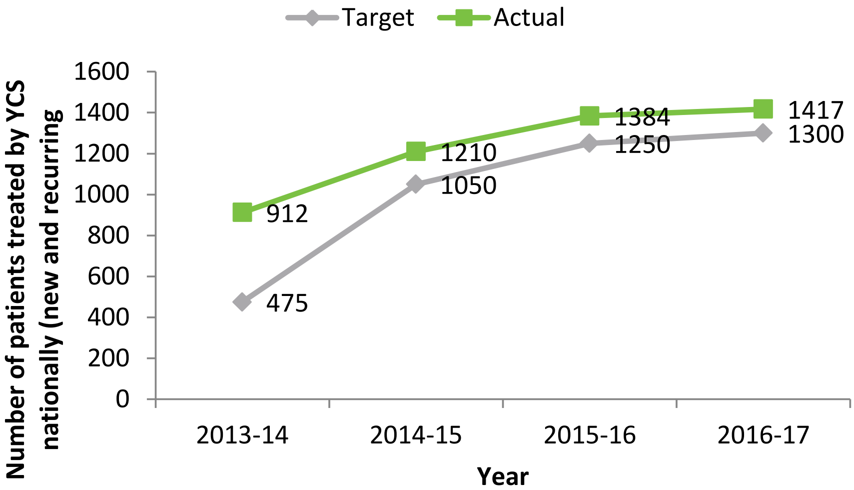
[25] YCS lead and partner site data was provided by CanTeen in September 2017. Some hospitals in the same precinct could be considered to be one 'site' such as Westmead Adult's and Westmead Children's hospitals or the Prince of Wales Hospital and Sydney Children's hospital precinct at Randwick.

[26] DOH performance indicator descriptors and targets were revised in January 2015 for the periods 2014-15, 2015-16, 2016-17.

[27] As at March 2016, CanTeen had requested DOH reduce this figure be amended from 1600 to 1250. The 1600 figure includes a high number of duplicate counts as it aggregates four quarters of activity data, rather than using the new agreed formula, which gives a more accurate number of new patients per annum.

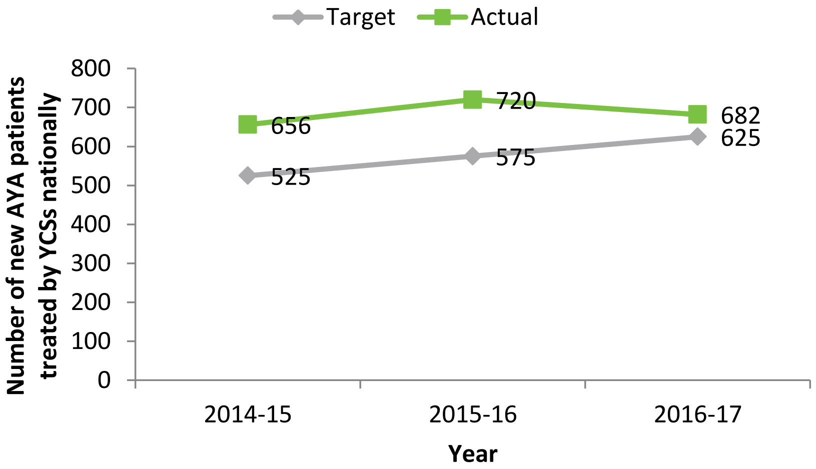
Number of patients treated by YCS nationally: CanTeen and the YCSs achieved the targets for the number of patients treated nationally each year of Phase 2, as shown in Figure 5.

Figure 5: Number of patients treated by YCSs nationally (new and recurring), actual versus target



Number of new AYA patients treated by YCS nationally: CanTeen and the YCSs achieved the target for the number of new AYA patients treated by YCSs nationally each of the three years a target was in place, as shown in Figure 6.

Figure 6: Number of new AYA patients treated by YCSs nationally, actual versus target

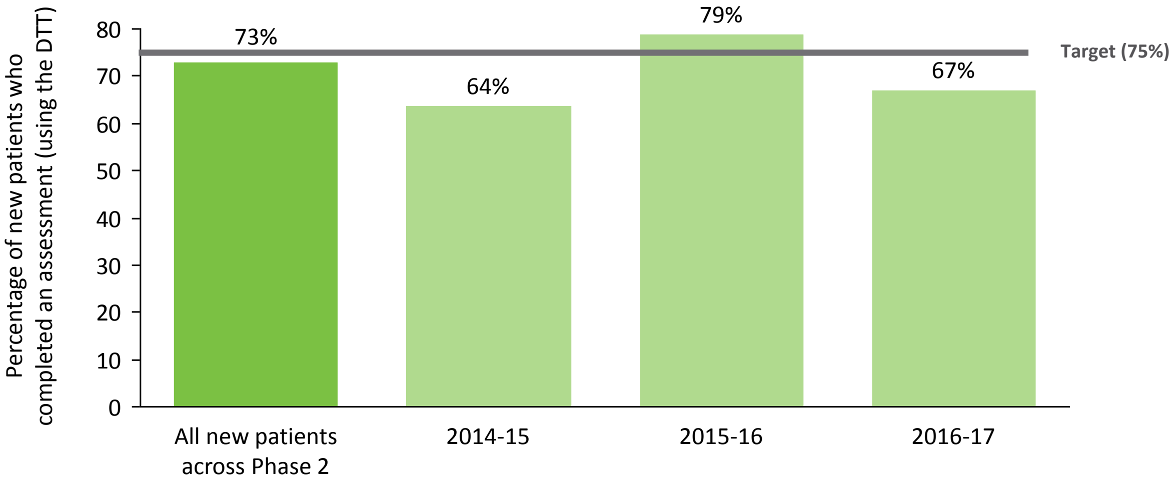


DTT assessments completed: Assessments completed reflects the percentage of newly diagnosed YCS patients who complete a psychosocial assessment with a YCS staff member who used the DTT. This indicator does not count patients who may have completed a psychosocial assessment using a different tool.

CanTeen and the YCSs achieved the target for this KPI in one year (2015-16) and were close to achieving it in the remaining three years. The target was revised to a percentage of new patients who completed an assessment in 2014-15. Using the revised target, 73% of new patients completed assessments using the DTT over the course of Phase 2 (including 2013-14), which was only slightly lower than the target of 75%. Figure 7 overleaf indicates the actual versus target assessments completed for the entire Phase 2 as well as the three years the revised target was in use.

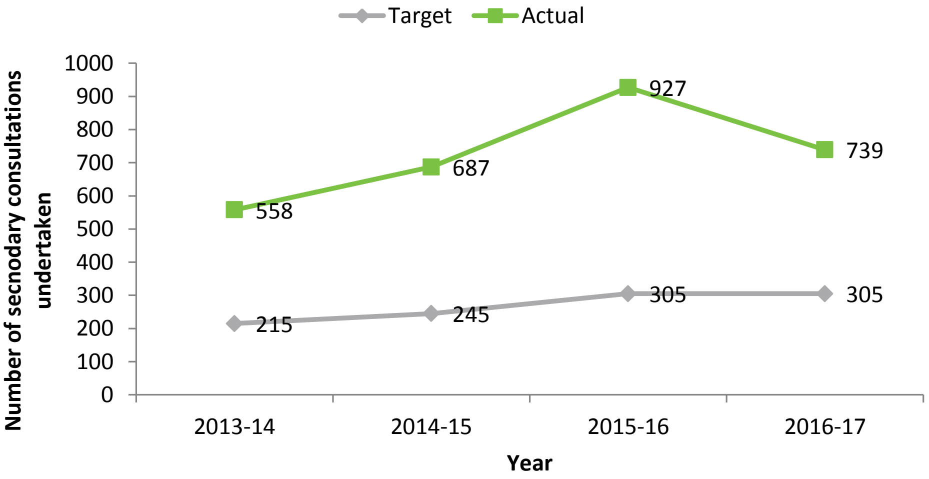
CanTeen and the YCSs indicated this indicator was not achieved in some years as some YCS staff were not trained in the DTT. Staff vacancies also impacted on the capacity of YCS staff to use the tool. This means that YCS staff often used other tools (which were not counted under this indicator).The DTT is still in the process of validation which began partway through Phase 2 and will continue in to Phase 3.

Figure 7: DTT assessments completed, actual versus target



Secondary consultations undertaken: CanTeen and the YCSs exceeded the target for the number of secondary consultations undertaken each year of Phase 2, as shown in Figure 8.

Figure 8: Number of secondary consultations undertaken, actual versus target



5 Findings Part 2: Evaluation indicators

This section, *Findings Part 2*, reports on findings based on the Evaluation Plan. The Evaluation Plan outlined evaluation questions and indicators, of which the DOH KPIs were a subset. Nous used the three key lines of enquiry to structure the *Findings Part 2* section as follows:

- What was delivered through YCS Phase 2? (section 5.1)
- What short-term outcomes were achieved through YCS Phase 2? (section 5.2)
- What were the strengths and areas for improvement of YCS Phase 2? (section 5.3).

For specific information on progress against the DOH KPIs, see *Findings Part 1* (in section 4).

5.1 What was delivered through YCS Phase 2?

This sub-section details what was delivered through the YCSs and under each of the national initiatives.

5.1.1 What was delivered through the YCSs?

Five state-wide YCSs delivered cancer services, informed by the views of young people, to AYAs across Australia.

CanTeen signed five contracts with jurisdictions for the delivery of YCSs in late 2013 (additional detail is provided in Findings Part 1, see section 4).

Five national advisory groups helped CanTeen govern the YCS program. The SAG provided advice to CanTeen on strategic priorities and YCS operations. The National Youth Advisory Group (NYAG) ensured the views of young people inform service planning, delivery and evaluation. The RAG, the Education and Training Advisory Group (ETAG) and the DAG provided advice on the delivery of national initiatives.[28] The Leadership Group encompasses Lead Clinicians and Service Managers from each YCS jurisdiction.

The inclusion of the consumer voice is a critical pillar of the YCS program. CanTeen and the YCSs gathered the views of young people through four main mechanisms:

- The NYAG met up to four times per year to provide advice to CanTeen on national-level service planning and delivery. The NYAG developed the YCS Charter for young people with cancer, which outlined the expectations of young cancer patients and informed the delivery of YCS.
- CanTeen and the YCSs established youth advisory groups in each jurisdiction to provide advice and feedback on local service delivery.
- YCS staff at each site were encouraged to seek ongoing feedback from AYA patients on their needs and expectations. Most AYA consultation participants commonly agreed YCS staff sought and listened to their views during their cancer treatment (based on 2016 consultations). The majority of YCS staff survey respondents in 2015, 2016 and 2017 somewhat or strongly agreed the YCS program provides opportunities for the inclusion of consumer perspectives in service planning and delivery (see Figure 9).

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[28] The ETAG was formed part way through Phase 2 and was disbanded prior to the completion of Phase 2.

- Nous consulted with AYAs in each jurisdiction (except WA) to ensure evaluation activities considered the views of young people.

Figure 9: Percentage of YCS staff survey respondents who somewhat or strongly agreed with the following statements

		2015	2016	2017
YCS staff survey	YCSs **involve AYAs and families** in service planning	93% (37)	92% (34)	100% (38)
	YCSs provide **ongoing opportunities for feedback** from AYAs about what works and areas for improvement	88% (36)	86% (32)	97% (37)

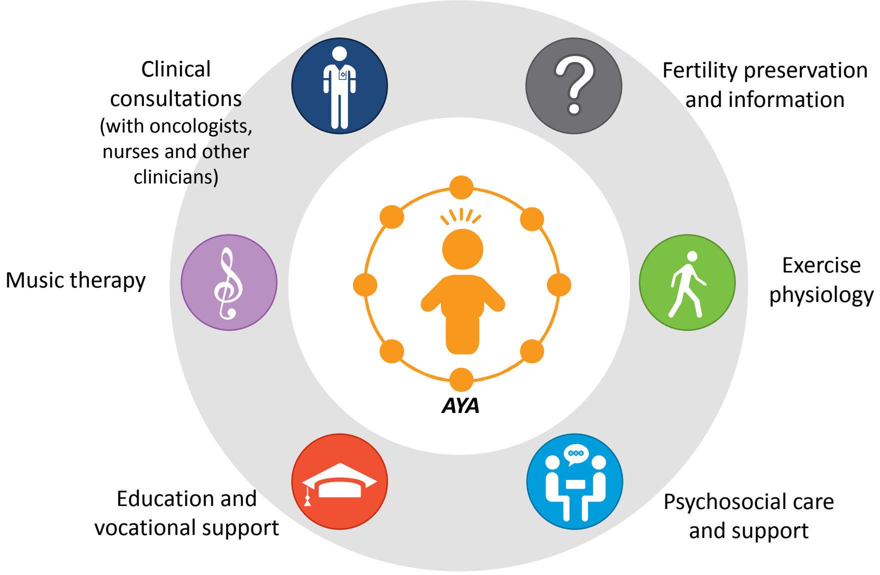
Total respondents for first statement was 40 in 2015, 37 in 2016 and 38 in 2017.
Total respondents for second statement was 41 in 2015, 37 in 2016 and 38 in 2017.

YCSs provided AYAs undergoing cancer treatment with access to a range of services and supports; the availability of services varies across the YCS sites.

The YCS program provides comprehensive care and support to AYAs undergoing cancer treatment. YCS sites offered different types of services during Phase 2, based on the ability of sites to recruit and retain staff and the service model in initial jurisdictional Phase 2 proposals. All five YCS hubs provided medical, nursing, psychosocial services and education and vocational support. CanTeen also funded research nurse positions in YCS teams late in Phase 2.

Figure 10 shows the services that were available through the YCS program during Phase 2. Some sites provided additional support (e.g. exercise physiology and music therapy).

Figure 10: Services and supports the YCSs provided in Phase 2



CanTeen undertook four major projects to improve the quality of YCS services:

- **Validation of the DTT**. In 2015-16, CanTeen began validating the DTT in Phase 2 (an ongoing project). This helped to ensure the provision of high quality psychosocial assessments for AYAs (see section 5.1.3).
- **Research on survivorship care**. In 2015, CanTeen undertook a research project to better the opportunities and challenges for survivorship care for AYAs with cancer (see section 5.1.3).[29] CanTeen introduced three indicators on survivorship care into activity data, collected by some YCSs from 2016, to provide baseline information.[30]
- **Revision of the psychosocial care manual**. CanTeen revised the manual in 2015.
- **Research on fertility preservation protocols**. In 2015, CanTeen published a protocol to guide fertility preservation interventions for AYAs with cancer.[31]

CanTeen undertook five major projects to increase access to YCSs for AYAs with cancer.

As part of Phase 2, CanTeen and the YCSs aimed to increase access to YCSs (mainly through improved awareness). CanTeen undertook five major projects to achieve this, which are listed below. These projects are major projects CanTeen undertook to increase access to YCSs, but are not a comprehensive list of all initiatives conducted during Phase 2. Major projects included:

- **Maintenance of the YCS website**. The YCS website provides AYAs, families and the public with information on the services available in each jurisdiction.[32] CanTeen updated the YCS website in 2015 and 2017 to include additional resources and content. Consultations with AYAs informed the design and content development.[33]
- **Documentation of the YCS care pathway**. The YCS Leadership Group documented the YCS care pathway to support a consistent standard of care and equitable access to services. The document outlined the medical care pathway from prevention through to survivorship care. It also detailed the complementary, supportive and palliative care and education that ensures comprehensive care for AYA patients.
- **Delivery of education and outreach projects.** CanTeen held the first International AYA Cancer Congress in December 2015, which 257 Australian and international delegates attended. The then federal Health Minister (the Hon Sussan Ley) attended the conference, which aided with awareness raising (as reported in consultations). CanTeen also held a National Youth Summit in December 2015, which 146 young cancer patients and national and international AYA clinicians attended (see section 5.1.2).

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[29] Activities related to survivorship care were not within the scope of the DOH funding agreement. CanTeen and the YCSs delivered additional activities under YCS Phase 2 covered by additional CanTeen donor funds.

[30] CanTeen 2017, *Youth Cancer Service Program Third Performance Report July-Dec 2016.* Sydney: CanTeen.

[31] Anazodo A and Gerstl B, 2015. *Protocol Advisory Subcommittee Report: Protocol to guide the assessment and fertility preservation for cancer patients and non-malignant patients receiving gonadotoxic treatment*. Sydney; CanTeen Australia and FUTuRE Fertility.

[32] The YCS website is available at: http://www.youthcancer.com.au/

[33] CanTeen 2017, *Youth Cancer Service Program Third Performance Report July-Dec 2016.* Sydney: CanTeen.

- **Exploration of the use of technology to deliver services**. CanTeen developed an online platform for patients to access professional counsellors and their peers (both during and after their treatment). It provides information, tools, professional psychosocial support services and connections to peers all through one portal (a 'one stop shop'). The platform was one of the first such platforms worldwide. It was funded by both Australian Government funding and CanTeen donor support.

  CanTeen also developed the Getting Cancer Young YouTube resource (previously titled digital care pathway), in partnership with the NYAG. These were videos created by AYAs with cancer, their families and friends and health professionals, which provide guidance on dealing with cancer.

- **Delivery of pilot projects to address inequities**. In 2016, CanTeen undertook a research project to examine the use of telehealth to deliver services.

CanTeen undertook activities aimed at improving the capacity of health professionals to identify and diagnose cancer in AYAs at an earlier stage.

CanTeen aimed to improve the capacity of health professionals to identify and diagnose cancer in AYAs at an earlier stage. Additional information is provided in Findings Part 1, see section 4.

CanTeen's advocacy work increased recognition of AYA cancer needs amongst governments.

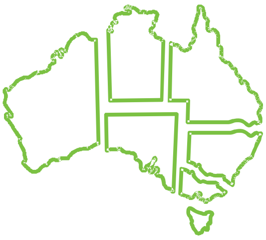
CanTeen aims to embed AYA-specific cancer priorities in national and state health plans to ensure sustainability of the YCS program. As at August 2016, government stakeholders in Victoria, WA and NSW had recognised the importance of AYA cancer care needs (but had not developed a youth cancer policy).

At a federal level, DOH stakeholders indicated CanTeen was an effective advocate for AYA cancer care needs (in 2016 and 2017 consultations). CanTeen's advocacy on fertility preservation for AYAs resulted in recognition of it as a national priority within the DOH (as reported in 2016 consultations). CanTeen worked with a Committee under Australian Health Ministers' Advisory Council to support national consistency in data collection. CanTeen also successfully advocated for funding for Phase 3 of the YCS Program.

Many stakeholders in 2016 and 2017 consultations reported CanTeen effectively advocated to help address the challenge of AYA access to clinical trials. Examples of CanTeen's advocacy include:

- A submission to the Senate Inquiry on the availability of new, innovative and specialist cancer drugs in Australia.
- A proposal to the DOH outlining a national and coordinated strategic approach to improving AYA cancer patient access to clinical trials.

In mid-2016, the Minister for Health announced a new national initiative to recruit AYAs with cancer to clinical trials and remove age restrictions on participation in clinical trials.



At the state level, stakeholders from Victorian and WA health departments revised their (not youth-specific) cancer plans. The revised Victorian plan had a new medical research strategy, focused on improving access to clinical trials and improving the availability of fertility preservation for AYAs with cancer.[34] Health department stakeholders in WA indicated they were exploring the optimal care pathway for AYAs (with strong consumer involvement). In NSW, the government announced new health infrastructure that intends to improve physical infrastructure for AYAs with cancer.[35]

5.1.2 What was delivered by the National Network (including the professional development program)?

Under the National Network, CanTeen delivered activities that improved collaboration and consistency of service delivery across YCSs and YCS staff skills.

The National Network aimed to improve collaboration between jurisdictions and ensure YCSs were staffed by a skilled, engaged workforce. CanTeen worked to achieve this purpose through three strategies. These were to:

1. increase collaboration and knowledge sharing across the five YCS jurisdictions
2. improve consistency in service delivery
3. develop the skills and competencies of YCS staff.[36]

The YCS Strategic Plan 2013-2017 outlined activities to deliver on these strategies. CanTeen delivered the majority of these activities during Phase 2, including the National Network meetings, professional development initiatives and program resources. CanTeen supported 30 of the 40 planned scholarships. CanTeen did not offer the scholarships in 2017 due to a reduction in the number of individuals seeking to undertake the graduate program (decided in consultation with the ETAG).[37] Investment in alternative professional development opportunities throughout Phase 2, including the International AYA Cancer Congress and the nurse clinical innovation and mentorship program, also factored into the decision.

Figure 11 provides a summary list of key National Network activities CanTeen delivered. This list is not exhaustive; it highlights major activities undertaken against the YCS Strategic Plan 2013-2017.

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[34] Department of Health and Human Services, 2016, *Victorian cancer plan 2016–2020*, State of Victoria; Melbourne.

[35] A major development at Westmead Hospital aims to provide integrated care and an adolescent hub at the Bright Alliance Building (Randwick) has a model of care that better integrates adult and adolescent cancer services (as reported in 2017 consultations).

[36] These strategies align with Objective 1 of the YCS Phase 2 Strategic Plan 2013-2017.

[37] The ETAG advised many similar courses with a narrow target audience experienced similar periodic reductions in demand, as courses reach a saturation point (i.e. reaching the target audience).

Figure 11: Key activities delivered by the National Network from 2013-14 to 2016-17[38]

Strategy	Summary of key activities	Intended activities	Progress in Phase 2	Rationale
1.Increase collaboration and knowledge sharing across the five YCS jurisdictions	• Held two **National Network Days** per year for all YCS teams from 2013-14 to 2015-16 and one in 2016-17 • Held eight **leadership group** and nine **service manager meetings** • Held 10 **SAG** and 17 **NYAG meetings** • Appointed all **YCS staff funded positions** • Hosted an **International AYA Cancer Congress and Youth Summit** for AYAs and clinicians • Investment in a leadership course for Service Managers and Lead Clinicians	• Hold two National Network Day per year • Hold two leadership group and service manager meetings per year • Appoint all YCS funded staff • Hold four SAG and four NYAG meetings per year (from year of establishment) • Hold an Australasian AYA conference and Youth Summit	● Achieved	• All major activities achieved • One fewer National Network Day held than planned
2.Improve consistency in service delivery	• Reviewed the **National Service Delivery Framework** for AYAs with Cancer • Developed **brochures, factsheets and posters** on YCS and AYA cancer • Developed **education materials** for YCS staff • Developed **YCS staff position descriptions** for the five YCS jurisdictions • Upgraded the **YCS website** • Launched **the Online Support Platform**, an e-mental health service for AYAs with cancer • Produced **quarterly YCS e-newsletters** called 'YCS Matters'	• Support the YCS jurisdictions by developing consistent YCS materials and clinical guidelines, and promoting the YCS program. • Create consistent national position descriptions for core state-wide YCS positions • Upgrade the YCS website • Produce quarterly YCS e-newsletter	● Achieved	• All major activities achieved • Delay in developing some position descriptions
3.Develop the skills and competencies of YCS staff	• Funded 30 **postgraduate AYA oncology scholarships** for YCS staff • Held 689 **staff education sessions** for YCS staff • Provided Psychosocial Distress Screening Training to YCS staff • Invested in **leadership capacity training** for Service Managers and Lead Clinicians in 2014 and 2015. • Presented at 329 **health conferences and workshops** in Australia and overseas (oral or poster presentation) • Established the **Education and Training Advisory Group** • Established and evaluated a **Nurse Research and Clinical Innovation Mentor Program** • Reviewed the **professional development program**	• Fund 10 scholarships per year (40 in total) • Establish Education and Training Advisory Group • Provide leadership training for YCS service managers and lead clinicians	◕ Mostly achieved	• All major activities mostly achieved • 10 fewer scholarships offered than the 40 scholarships that were planned

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[38] Under Strategy 3, CanTeen planned to develop a credentialing framework for YCS staff. In July 2016, the CanTeen project team indicated they were no longer progressing this activity.

5.1.3 What was delivered through the National Research Agenda?

Through the National Research Agenda, CanTeen formed the RAG and supported targeted research activities.

The National Research Agenda aimed to support advancements in cancer care for AYAs through research and AYA participation in clinical studies. CanTeen worked to achieve this purpose through two strategies. These were to:

1. support research in the areas of highest need in AYA cancer
2. increase access to and enrolment of young patients in research studies and clinical trials.[39]

In 2014-15, CanTeen established the RAG to help drive implementation of the National Research Agenda. It met four times during Phase 2. Most stakeholders agreed the RAG had successfully driven the research agenda. Some stakeholders indicated that the RAG should meet more frequently and meetings should allow more time to seek advice and input from RAG members on the research agenda (based on 2016 and 2017 consultations).

CanTeen invested in more than 20 research projects and supported four clinical trials, in line with six AYA cancer research priorities.

CanTeen delivered all major planned activities under the National Research Agenda. CanTeen invested in more than 20 research projects and supported four clinical trials. A key part of the National Research Agenda was increasing access to and enrolment of young patients in research studies and clinical trials (see Findings Part 1, section for detail).

CanTeen and the RAG developed a Research Priorities Report, which formed the basis for a Discussion Paper that outlined six priority areas of need in AYA cancer research (see Figure 12).[40] They did this in consultation with researchers, clinicians, AYAs and other stakeholders.

Figure 12: Research priorities for AYA cancer[41]

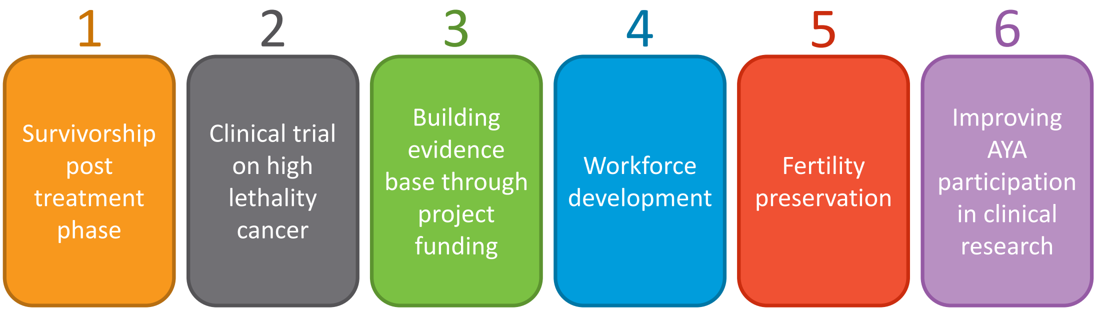

Figure 13 overleaf provides a summary of the major National Research Agenda activities CanTeen delivered. This list is not exhaustive; it highlights major activities undertaken against the YCS Strategic Plan 2013-2017.

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[39] These strategies align with Objective 2 of the YCS Phase 2 Strategic Plan 2013-2017.

[40] CanTeen Australia 2015, *Briefing to Nous*, 26 June 2015 Australia: CanTeen (unpublished); CanTeen Australia 2014, *Determining Research Priorities for Adolescent and Young Adult Cancer in Australia.* Australia: CanTeen (unpublished).

[41] Development of research priorities was not part of the DOH funding agreement or YCS Strategic Plan (2013-2017). CanTeen developed them subsequently as part of their broader work plan and used them to prioritise research.

Figure 13: Key activities delivered by the National Research Agenda from 2013-14 to 2016-17[42]

Strategy	Summary of key activities	Intended activities	Progress in Phase 2	Rationale

1.Support research in areas of highest need in AYA cancer (including by leveraging existing research)	• Formed the **Research Advisory Group (RAG)**, which met four times
	• Conducted a **research mapping project to identify six research priorities** for AYA cancer
	• Conducted **internal studies and evaluations**, including:
	  • Survivorship care research report
	  • Experience of care study (still being conducted)
	• Funded **external projects and data collection**, including:
	  • Collaboration with the Australia New Zealand Children's Haematology Oncology Group (ANZCHOG) to fund four projects on advanced care planning, fertility and sleep disorders and exercise physiology
	  • Structured exercise research (co-funded by ANZCHOG)
	  • Study of activity-based funding to develop a model of unit of cost care in non-admitted settings
	• Partnered with **cancer research organisations on major research initiatives,** including:
	  • Australasian Sarcoma Study Group (ASSG) for an International Sarcoma Kindred Study which has recruited 47 AYAs and families
	• Collected **activity data** on AYA cancer research, including:
	  • Indicators on survivorship care
	  • Indicators on fertility preservation
	• Developed and validated **AYA treatment manuals and tools** and launched on the YCS website, including:
	  • Distress Thermometer Tool validation
	  • AYA psychosocial manual and tools
	  • Survivorship care manual and tools for health professionals
	• **Developed research capabilities** of AYAs, the NYAG, nurses and other YCS staff, including:
	  • Establishment of the Nurse Research and Clinical Innovation Mentor Program (in collaboration with the University of Sydney).
	  • Workshops with AYA staff
	  • Research training for the NYAG delivered in partnership with ANZCHOG
	  • NYAG members ' participation in CanTeen's People and Ethics Committee
	  • Involvement of AYA patients in research decision making and selection of successful research grants
	• Supported numerous peer-reviewed publications on AYA cancer and presented 329 abstracts at health conferences (through oral or poster presentations)
		• Form a new Youth Cancer Research Advisory Group
		• Identify strategic research priorities for AYA cancer patients
		• Commence validation work for the Psychosocial Screening tool
		• Support existing and new research projects on areas of high need in AYA cancer, including support for at least two research studies and obtainment of external funding for an AYA research project
		• Publish research results and outcomes in peer review journals and present findings at conferences
			●
			Achieved and exceeded
				• All major activities achieved
				• More than 20 research projects supported, significantly more than planned

2.Increase enrolment of AYA patients in clinical research	• Supported 391 **YCS patients to newly enrol in clinical trials** (8% of all YCS patients) • Supported 680 **YCS patients to newly enrol in research studies** (14% of all YCS patients) • **Advocated to government** on increasing AYA participation in clinical research and lowering the age of consent for clinical research to allow greater access • Collected **activity data** on AYA participation in clinical trials	• Be on track to increase AYA participation in clinical trials and research studies by 3% by the end of Phase 2	● Achieved and exceeded	• All major activities achieved • 8% of YCS patients were newly enrolled in clinical trials during phase 2, which is more than double the target of 3%.

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[42] This figure does not include the total number of publications for Phase 2 as the data was unable to be confirmed by CanTeen and the YCSs.

5.1.4 What was delivered by the National Data Collection Strategy?

CanTeen developed the National Data Collection Strategy, set up the DAG, undertook a pathfinder initiative and finalised the national AYA minimum dataset.

The National Data Collection Strategy aimed to provide CanTeen and other organisations with high-quality data on AYA cancer. CanTeen's three strategies to achieve this aim were to:

1. ensure the collection of a minimum dataset for AYAs diagnosed with cancer in Australia
2. undertake regular analysis of existing national AYA cancer data
3. collect activity data from the YCSs on a quarterly basis.[43]

CanTeen worked with stakeholders, data custodians and data experts to identify and agree on a highest priority national AYA minimum dataset (additional detail is provided in Findings Part 1, section 4).

CanTeen and the DAG distributed the final minimum dataset to stakeholders in 2017.

CanTeen and the DAG planned to implement the national minimum AYA dataset by March 2016 (based on the Youth Cancer Dataset Discussion Paper). The minimum dataset was developed within this timeframe, but not implemented. External factors that delayed its development and delivery included:

- difficulties in accessing data for the pathfinder initiative[44]
- the need to engage with many different data custodians
- challenges over the appropriate mechanism for collecting and accessing a minimum dataset
- the need for alignment with other national cancer data initiatives (e.g. Cancer Australia's Stage, Treatment, and Recurrence (STAR) project).[45]

Whilst the national AYA minimum dataset was in development, CanTeen piloted and improved jurisdictional activity data reporting processes (see section 5.2.4).

Figure 14 provides a summary of National Data Collection Strategy activities CanTeen delivered. This list is not exhaustive; it highlights the major activities undertaken against the YCS Strategic Plan 2013-2017.

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[43] These strategies align with Objective 3 of the YCS Phase 2 Strategic Plan 2013-2017.

[44] The pathfinder initiative was agreed as a priority initiative by the DAG and other stakeholders (at the national workshop in March 2014). Stakeholders agreed to undertake pathfinder work to collect and analyse existing data and consider opportunities for the future collection of an AYA dataset.

[45] These factors are based on CanTeen's national initiative reporting templates for Phase 2 and additional CanTeen commentary. CanTeen provides Nous six-monthly summaries of all activities undertaken under the three national initiatives (see Appendix D for the documents that informed this report).

Figure 14: Key activities delivered under the National Data Collection Strategy from 2013-14 to 2016-17[46]

Strategy	Summary of key activities	Intended activities	Progress in Phase 2	Rationale
1. Ensure the collection of a national minimum dataset for AYA cancer	• Established the **DAG**, which met seven times • Commissioned the South Australian Health and Medical Research Institute (SAHMRI) to develop a **Youth Cancer Dataset Discussion Paper** • Convened a **workshop to test data needs and priorities** with stakeholders • Received the National Health Information and Performance Principal Committee's approval for the specification for the **national minimum dataset**, which now appears in the National Health Data Dictionary • Distributed the **national minimum dataset specification** to stakeholders and began implementation planning • **Consulted the AIHW, cancer registries and other organisations** to understand the data they hold and potential data linkages • Recruited a **Project Manager** and a **Data Officer**	• Form a new DAG • Undertake a scoping study to inform directions for strategic national AYA data collection • Hold a dataset workshop with key stakeholders to agree directions for strategic national AYA data collection • Implement the national minimum AYA dataset	◕ Mostly achieved	• CanTeen has not yet implemented the national AYA minimum dataset.
2. Undertake regular analysis of AYA cancer data	• Analysed AYA data to **benchmark Australia** internationally • Analysed AIHW data cubes to **determine trends in AYA cancer incidence and mortality** and develop **fact sheets and key statistics** • Started talks to access **data on melanoma**, degree of spread, patterns of care and patient experiences, and the long-term risk of other cancers for people diagnosed with AYA cancer	• Undertake regular analysis of existing AYA cancer data to understand current cancer patterns and prevalence	● Achieved	• All major activities achieved
3.Collect activity data from the YCSs	• Developed and piloted an **activity data reporting template** • Developed a **data dictionary and other materials** for YCSs to train their staff in data collection • Undertook **site assessments** with four of the five YCSs to assess their IT systems and needs • Collected **quarterly jurisdictional activity data** from 2013-14 to 2016-17	• Collect and analyse quarterly YCS activity data	● Achieved	• All major activities achieved

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[46] CanTeen and the DAG had planned to implement the national minimum AYA dataset between July 2014 and March 2016 (based on the Youth Cancer Dataset Discussion Paper).

5.2 What short-term outcomes were achieved through YCS Phase 2?

This sub-section details the short-term outcomes achieved through the YCSs and under each of the national initiatives.

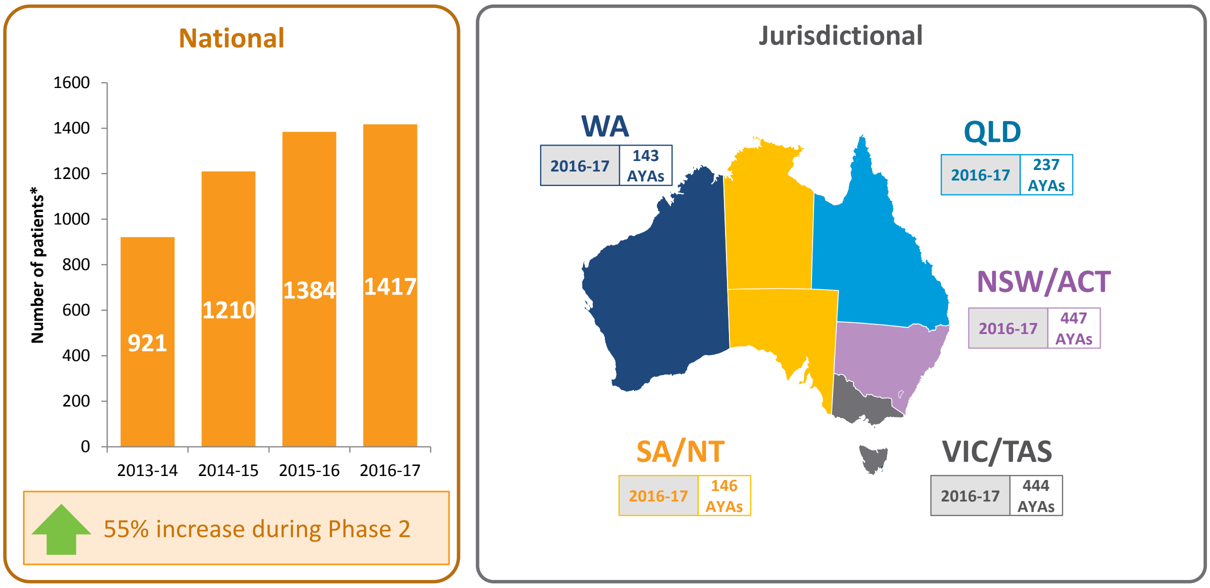
5.2.1 What short-term outcomes were achieved by the YCSs?

The YCSs provided comprehensive support and treatment to a significant proportion of all AYAs with cancer across Australia during Phase 2.

The YCS program provided an increasing number of AYAs with cancer support and treatment. Between 2013-14 and 2016-17, the total patients supported through the YCSs increased by 55% (from 912 patients in 2013-14 to 1,417 patients in 2016-17).[47] In 2016-17, the five YCSs reached approximately 68% of all AYAs diagnosed with cancer in Australia.[48]

Figure 15 shows the number of AYAs YCSs supported (nationally and per jurisdiction). QLD and VIC/TAS YCSs experienced the largest increase in patient numbers between 2013-14 and 2016-17 (a doubling of patients in QLD and VIC/TAS YCSs during Phase 2).

Figure 15: Patients supported through the YCS (all medical/surgical treatment & psychosocial care)[49]



YCS staff indicated the filling of vacant YCS staff roles and/or improved data collection methods in most jurisdictions influenced reported patient numbers. Delays in staff recruitment in SA/NT and WA earlier in Phase 2 affected patient numbers in these jurisdictions (as reported in 2016 consultations).

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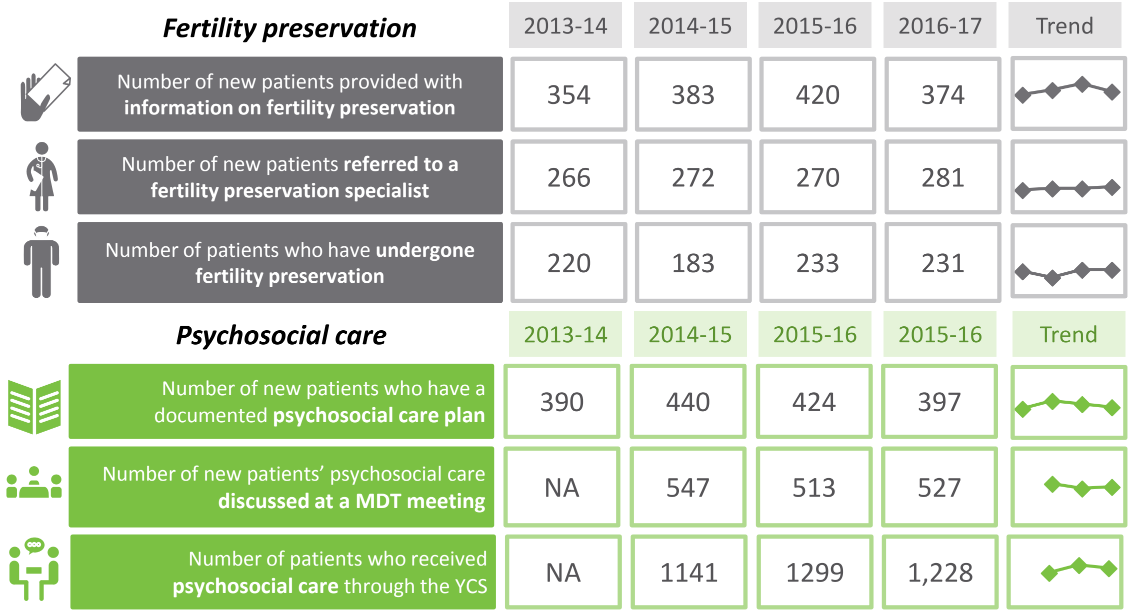
[47] The figure for total patients supported through YCSs includes all medical/surgical treatment & psychosocial care.

[48] In Australia, there were approximately 1,000 AYA cancer diagnoses on average each year (based on CanTeen estimates using AIHW cancer incidence data). In 2016-17, 682 AYAs were referred into YCSs (including newly diagnosed and relapsed and other patients) (based on 2016-17 jurisdictional activity data reports).

[49] Based on consultations, the differences in patient numbers per year in each jurisdiction was typically due to improvements in data collection each year or the recruitment of additional staff (which increased the capacity of the services). This is a DOH KPI. The 2014-15 target (1050 patients treated by YCS nationally) was achieved. The 2013-14, 2015-16 and 2016-17 targets were not achieved.

Figure 16 provides activity data trends for additional measures other than those captured under the DOH KPIs (see Findings Part 1, section 4). Five of the six measures in Figure 16 increased between 2013-14 and 2016-17 (or 2014-15 where data was not available for 2013-14). The number of new patients who had their psychosocial care discussed at a MDT meeting recorded a minor decrease.

Figure 16: Key activity data statistics, 2013-14 to 2016-17[50]



Fertility preservation	2013-14	2014-15	2015-16	2016-17	Trend
Number of new patients provided with **information on fertility preservation**	354	383	420	374	
Number of new patients **referred to a fertility preservation specialist**	266	272	270	281	
Number of patients who have **undergone fertility preservation**	220	183	233	231	

Psychosocial care	2013-14	2014-15	2015-16	2015-16	Trend
Number of new patients who have a documented **psychosocial care plan**	390	440	424	397	
Number of new patients' psychosocial care **discussed at a MDT meeting**	NA	547	513	527	
Number of patients who received **psychosocial care** through the YCS	NA	1141	1299	1,228	

Overall access to and awareness of YCSs increased; despite this, many stakeholders believed access was more difficult for AYAs in the private system and those in regional and rural areas.[51]

Access to YCSs

AYAs' access to age and tumour specific services and support improved. The increase in the number of patients during Phase 2 (55%) is evidence of increased access to and reach of the program. In addition, the majority of YCS staff respondents somewhat or strongly agreed AYAs were able to access optimal cancer treatment and that initiatives to improve access were effective (see Figure 17).

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[50] Data for number of a) patients who received psychosocial care through the YCS or b) number of new patients' psychosocial care discussed at an MDT meeting was not available for 2013-14. The 'number of patients who received supportive care' was excluded as NSW/ACT YCS had no funded supportive care positions for 2016-17; therefore the national figures were not comparable with previous years.

[51] Activities related to improving access to and awareness of YCSs were not within the scope of the DOH funding agreement. CanTeen and the YCSs delivered additional activities under YCS Phase 2 covered by additional CanTeen donor funds.

Figure 17: YCS staff survey respondents who somewhat or strongly agreed access to YCSs were adequate

YCS staff survey

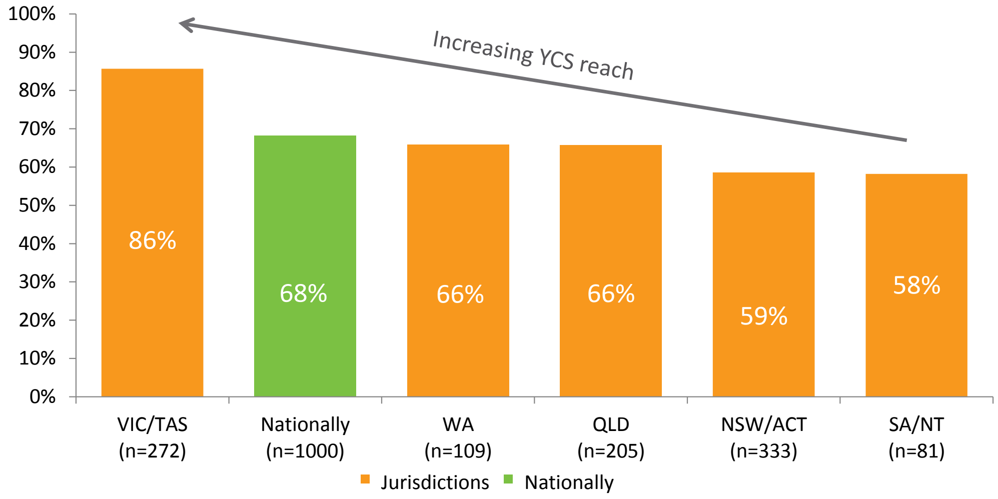
The YCS in my jurisdiction…	2015	2016	2017
Ensures all AYAs are able to **access optimal cancer care and treatment**, irrespective of socio-economic factors, culture or sexuality	85% (41)	85% (33)	86% (32)
Encourages **access to YCS services by AYAs in rural and regional** areas through outreach and secondary consultations	77% (37)	87% (34)	81% (30)
Promotes its services to increase awareness amongst the broader community	64% (30)	76% (29)	66% (25)

Total respondents for first statement was 48 in 2015, 39 in 2016 and 38 in 2017.
Total respondents for second statement was 48 in 2015, 39 in 2016 and 37 in 2017.
Total respondents for third statement was 47 in 2015, 38 in 2016 and 38 in 2017.

While there was an overall increase in access to YCSs during Phase 2, access relative to total AYA cancer diagnoses varied between jurisdictions and remained unequal for groups, as detailed below:

- **Varying access between YCS jurisdictions.** Nous estimated that each YCS reached a different proportion of total AYAs diagnosed with cancer in their jurisdiction. Based on estimates for 2016-17, VIC/TAS YCS reached the greatest proportion of all AYAs diagnosed with cancer in its jurisdiction (86% of all AYAs diagnosed with cancer). SA/NT YCS reached the lowest proportion (58% of all AYAs diagnosed with cancer, as shown in Figure 18.

Figure 18: Approximate proportion of AYAs diagnosed with cancer who are referred to YCSs[52]



- **Unequal access across public and private hospital settings**. In consultations in 2016 and 2017, many YCS staff reported complexities engaging with individual private hospitals affected their access to AYAs in private settings. They indicated this is due to difficulty credentialing YCS

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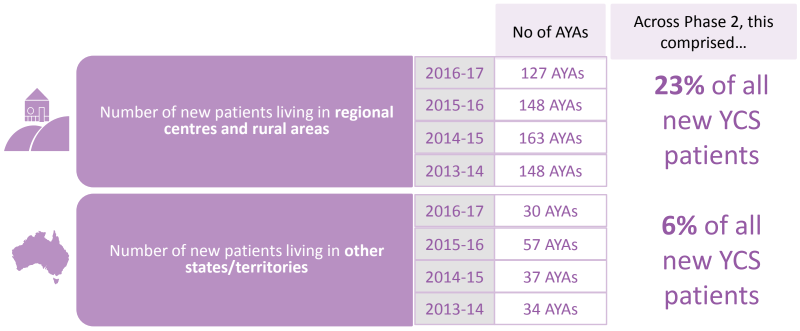
[52] Jurisdictional reach of YCSs was calculated using a three-step process: (1) Nous used the CanTeen estimate for the number of Australians aged 15-25 diagnosed with cancer per year (1,000). This figure is CanTeen's estimate of the annual cancer diagnoses in the 15-25 year age range (based on AIHW annual reports on *Cancer Incidence in Adolescents and Young* Adults, which provides cancer incidence data for the 15-24 year age range). To account for young people aged 25 who are included in the YCS cohort, CanTeen extrapolated the AIHW data to estimate cancer incidence for the 15-25 year age range at 1,000 per annum. (2) Nous distributed this estimate of national incidence across states/territories, based on data realised by the ABS in 2016 on the size of the Australian population aged 15-25 in each state/territory as of June 2015. (3) Nous combined this with YCS jurisdictional activity data on the number of new referrals to the YCSs in 2016-17. Note: The estimates shown in this figure are approximate, as they are based on data sources from three different time periods.

clinicians or confidentiality concerns in sharing patient information. In 2014-15, 4.5% of all YCS patients were treated in private hospitals (55 patients out of 1,210 YCS patients treated in private hospitals).[53]

- **Limited access to patients at the threshold of the lower age limit**. In 2016 consultations, some stakeholders reported YCSs did not reach AYAs with cancer who were at the threshold of the lower age limit when diagnosed. For example, a patient who is 14 at the time of diagnosis would currently not be referred to a YCS; however, if their treatment continues for a number of years, they would become eligible for services provided by YCS. They may not access it if not referred mid-treatment or during survivorship.

There was a perception amongst the majority of jurisdictional YCS stakeholders that AYAs who live in rural or regional areas did not have equitable access to YCSs (based on 2016 and 2017 consultations).[54] Jurisdictional activity data suggests that this is not true. In total for Phase 2, 23% of new referrals into YCSs were patients who were living in rural, regional or remote areas (586 patients), as shown in Figure 19. This is a relatively high proportion, given approximately 15% of Australians live in rural and regional areas.[55]

Figure 19: Referrals to YCSs, 2013-14 to 2016-17



		No of AYAs	Across Phase 2, this comprised…
Number of new patients living in **regional centres and rural areas**	2016-17	127 AYAs	**23%** of all new YCS patients
	2015-16	148 AYAs	
	2014-15	163 AYAs	
	2013-14	148 AYAs	
Number of new patients living in **other states/territories**	2016-17	30 AYAs	**6%** of all new YCS patients
	2015-16	57 AYAs	
	2014-15	37 AYAs	
	2013-14	34 AYAs	

YCS staff, AYAs with cancer and families reported access may seem more difficult for AYAs in regional and rural areas due to lower awareness (e.g. they or their local health professional were not initially aware YCSs existed) or difficulties attending YCS sites (e.g. due to expenses such as travel and accommodation).

Awareness of YCSs

Overall, awareness of YCSs amongst stakeholders increased during Phase 2, evidenced by the increase of new referrals to YCSs and through consultations in 2016 and 2017. Awareness of YCSs increased amongst:

- **State and federal health departments.** Awareness of YCSs amongst state and federal health department staff was variable, but reportedly increased during Phase 2 (based on consultations in 2016 and 2017). In 2016, stakeholders from the federal, NSW, VIC and WA health departments indicated relevant staff in their departments had a high level of awareness about

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[53] More recent data on the number of YCS patients treated through private hospitals was not available due to limitations in the jurisdictional activity data from 2015-16 and 2016-17 for this indicator.

[54] Some stakeholders in 2016 and 2017 YCS staff consultations and some 2016 government stakeholders indicated they thought access to YCSs may be more difficult for patients in rural and regional areas.

[55] 655 new AYA patients were referred in YCS in 2016-17. This includes newly diagnosed, relapsed and other patients. In 2011, 85% of Australians lived in urban areas and 15% in regional or rural areas based on: Australian Bureau of Statistics 2014, '*Australian Historical Population Statistics, 2014).* Date accessed: 13/09/2016. Available at: http://www.abs.gov.au/ausstats/abs@.nsf/0/632CDC28637CF57ECA256F1F0080EBCC?Opendocument

YCSs (and that their awareness had increased during Phase 2). Health department stakeholders in QLD and Tasmania indicated a more variable level of awareness amongst departmental staff (i.e. that awareness varied between individual staff members).

- **AYAs with cancer and their families and friends**. Many YCS stakeholders reported awareness levels amongst AYAs and families appeared to have increased during Phase 2, although some reported that the overall level of awareness was still low amongst some groups (such as AYAs who live in regional or rural areas), as reported by jurisdictional stakeholders in 2016 and 2017. An increasing number of website visits suggested increased awareness amongst the public. Website visits increased by 172% from 6,232 in year one of Phase 2 (2013-14) to 16,921 visits in the final year of Phase 2 (2016-17).[56]
- **Health professionals who interact with AYAs with cancer**. See Findings Part 1, section 4 for information about increased awareness of YCSs amongst health professionals.

> “There has been increased awareness and engagement over the past 12 months. Many more people know about the YCS service [and have] been engaging with NGOs and GPs.”
> *(YCS staff member, online survey, 2017)*

YCSs improved young peoples’ cancer experience, mainly through the provision of high quality medical treatment, supportive staff and tailored services.

All AYA and parents/carers who participated in 2016 consultations agreed YCSs improved the cancer treatment experience (whilst noting the cancer diagnosis and treatment experience could be highly traumatic).[57] All AYA consultation participants reported experiencing approachable and supportive YCS staff that provided high quality medical care. They noted these factors were particularly important for young people undergoing cancer treatment. Most participants in AYA and parent/carer consultations in 2016 also indicated YCSs provided an appropriate level of support and adequately included the voice of young people in service planning and delivery.

> “It’s very easy with [the Clinical Nurse Coordinator]. You can text her and she will reply to you. She wants to be involved. But she’s not over the top, forcing me to talk to her if I don’t want.”
> *(AYA patient, stakeholder consultation, 2016)*

AYAs and parents/carers were less likely to indicate YCSs provided adequate information (e.g. the right content, in the right format, at the right time). All AYAs and parents/carers indicated the treatment facilities and lack of networking opportunities with other AYAs and families negatively affected the experience of AYAs with cancer (as reported in consultations).

Figure 20 shows the most commonly agreed aspects of the cancer treatment that improved or detracted from AYAs experience (based on consultations with AYAs and parents/carers).[58]

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[56] The 2016-17 data covers the period from July 2016 to 21 June 2017, as the new YCS website was launched on this date. The additional nine days in June not accounted for in the 2017 data are not likely to affect the overarching finding of increased website traffic.

[57] Nous undertook consultations with AYAs and parents/carers in all YCS jurisdictions except WA in 2016. Nous did not undertake additional consultations with these groups in 2017.

[58] Figure 20 reports findings that more than three-quarters of AYA participants or parents/carers agreed with. These views may not be representative. The information in this figure is based on consultations with 13 AYAs with cancer and nine parents/carers of AYAs with cancer (across the QLD, NSW/ACT, SA and VIC/TAS jurisdictions).

Figure 20: Aspects of YCSs that AYAs and parents/carers indicated improve the cancer treatment experience for AYAs[59]

Most participants in AYA and parent/carer consultations indicated **YCSs provided**:
- high quality medical treatment
- quality relationships with YCS staff
- an appropriate and effective level of support
- inclusion of consumer voice in service planning and delivery.

Most participants in AYA and parent/carer consultations indicated **YCSs did not provide**:
- adequate facilities dedicated for young people
- network opportunities for AYAs with cancer and the families
- targeted information in the right format at the right time .

YCS staff survey findings on the appropriateness of YCS support typically aligned with the views expressed by AYAs and parents/carers in consultations. The majority of YCS staff survey respondents agreed YCS staff provided appropriate and comprehensive care for AYAs (see Figure 21 overleaf). YCS staff survey respondents were:

- **most likely to agree** that YCS staff helped and supported AYAs to navigate the health system and provide helpful information about fertility preservation (100%, 37 respondents in the 2017 survey for each statement).
- **increasingly likely to agree** that YCS staff provided effective information about survivorship care (from 85%, 35 respondents in 2015 to 100%, 31 respondents in 2017).
- **less likely to agree** that YCS staff provided psychosocial care and support between 2015 (98%, 41 respondents) and 2017 (84%, 36 respondents).

> They understood what cancer is like for young people. I didn't feel patronised by them. They showed empathetic, not sympathetic or pitying [sic].
> (*AYA patient, Experience of Care survey, 2017*)

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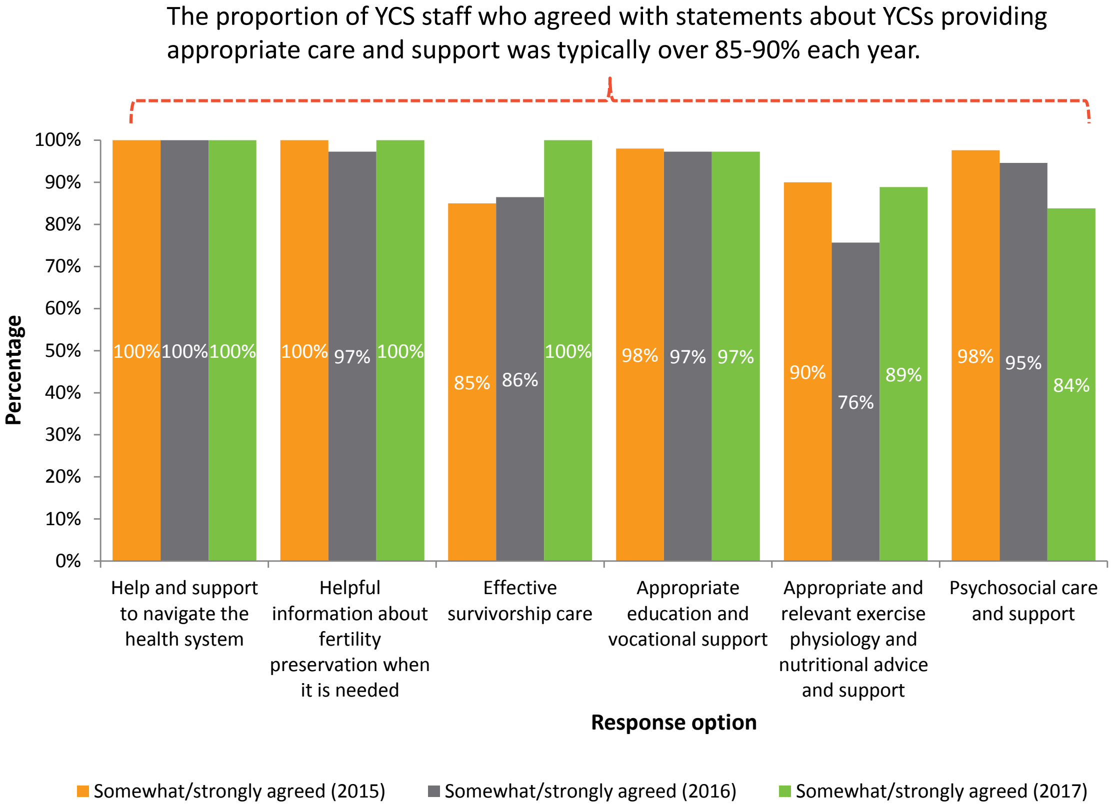
[59] Based on consultations with AYAs and parents/carers in 2016. Whilst measuring views on whether there were ‘adequate facilities for young people’ is part of the broader evaluation, it was not an activity under the DOH funding agreement.

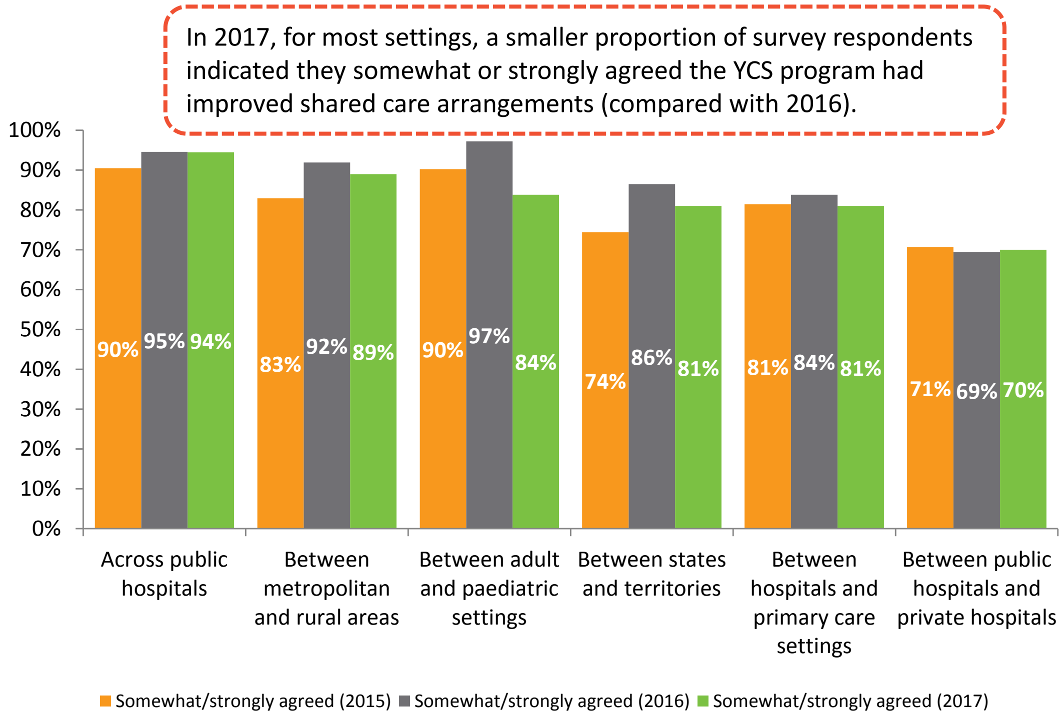
Figure 21: YCS staff survey respondents who somewhat or strongly agreed YCS staff provided different types of care and support



The YCS program improved shared care arrangements across all relevant settings, but to a lesser extent between public and private hospitals.

The majority of YCS staff, other health professionals and stakeholders from private hospitals agreed the YCS program had improved shared care arrangements, as shown in Figure 22 overleaf (based on annual YCS staff survey responses and 2016 and 2017 consultations). Stakeholders were most likely to agree YCSs improved shared care arrangements across public hospitals and between metropolitan and rural areas (based on the 2017 YCS staff survey).

Figure 22: YCS staff survey respondents who somewhat or strongly agreed the YCS program improved shared care arrangements across the following settings:


In 2017, for most settings, a smaller proportion of survey respondents indicated they somewhat or strongly agreed the YCS program had improved shared care arrangements (compared with 2016).

Based on annual YCS staff survey responses, commonly cited factors that enhanced shared care arrangements included:

- strong relationships between treating teams, YCS staff and other clinicians and service providers
- clear governance arrangements (e.g. state-wide steering committees in each jurisdiction)
- shared care through co-location and dual training
- strong communication channels between hospitals and state-wide referral pathways.

Based on available data, it was difficult to determine the extent to which YCSs built the capacity of GPs to diagnose cancer in AYAs at an earlier stage.

COSA's early detection guidance, developed in consultation with CanTeen, aimed to improve the ability of primary care clinicians to diagnose cancer in AYAs (as discussed in section 5.1.1).

In 2015, CanTeen worked with COSA to monitor dissemination and update the COSA early detection clinical guidance (developed in Phase 1). CanTeen worked with Nous and COSA to distribute surveys that sought feedback on awareness, uptake and use of the guidance documents. Limited responses meant Nous was unable to draw meaningful insights from the survey responses on the extent to which the guidances had built the capacity of primary care clinicians.[60] CanTeen did not undertake any further work on building the capacity of GPs after 2015 (as reported by CanTeen).

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[60] Nous did not include the 'other health professionals' survey as a key data source in the evaluation due to the low response rate. There were 12 respondents to the survey of health professionals on the awareness, uptake and use of the early detection guidance. 33% of respondents (4) were already aware of the early intervention guidance. 25% (1) of survey respondents who were aware of the early detection guidance had accessed it.

5.2.2 What short-term outcomes were achieved by the National Network (including the professional development program)?

CanTeen and the YCSs supported knowledge sharing and capability across YCSs, including through effective National Network meetings.

The National Network meetings, International AYA Cancer Congress and Youth Summit supported knowledge sharing and collaboration between the five YCSs. In the annual surveys of YCS staff, the majority of respondents agreed they had the opportunity to participate in national initiatives such as national network meetings, data collection and research projects (94%, 33 respondents in 2016-17).[61]

> “The national network has effectively brought together people from different jurisdictions to share best practice and learn from each other.”
> *(SAG member, stakeholder consultation 2017)*

More than 80% of YCS staff survey respondents agreed that the five YCS jurisdictions effectively shared knowledge and information to improve service delivery in 2013-14 and 2015-16.

The majority of YCS staff indicated the National Network meetings were relevant, useful and effectively supported knowledge sharing and capability development (based on 2016 and 2017 consultations and participant evaluation forms). Some YCS staff indicated that the National Network meetings would be more effective in the future if the sessions were tailored to the professional development needs of YCS staff based on their profession, jurisdictional context and level of expertise. Many YCS staff indicated CanTeen could better sustain engagement with YCSs between meetings to support continuous learning and networking (based on the YCS staff survey free text responses and 2016 and 2017 consultations). For example, CanTeen could include key messages from meetings in communications to staff in the months following the meetings.

CanTeen promoted the sharing of international best practice in AYA cancer care through the International AYA Cancer Congress and Youth Summit in 2016. More than 90% of respondents to participant evaluations for both events rated them as ‘excellent’ or ‘very good.’

CanTeen developed educational, promotional and programmatic resources that helped improve consistency in service delivery across YCSs during Phase 2.

CanTeen increased the range of resources available for YCS staff during Phase 2, with the aim of increasing consistency across the five YCS jurisdictions. In the annual YCS staff surveys, more than 80% of respondents somewhat or strongly agreed CanTeen provided relevant and appropriate educational materials and promotional materials that supported consistency (see Figure 23 overleaf).

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[61] In the 2015 and 2016 YCS staff surveys 97% or more respondents somewhat or strongly agreed they had the opportunity to participate in national initiatives such as national network meetings, data collection and research projects.

Figure 23: YCS staff survey respondents who somewhat or strongly agreed CanTeen provided adequate resources to improve consistency

	CanTeen supported YCS at the national level by providing…	2015	2016	2017
YCS staff survey	relevant and appropriate YCS **educational materials** (e.g. guidances and fact sheets)	90% (38)	83% (30)	82% (28)
	consistent YCS **promotional materials** (e.g. brochures and posters)	95% (40)	81% (29)	88% (30)
	useful **professional development materials** (e.g. position descriptions and the Psychosocial manual and tools)	80% (33)	78% (28)	82% (28)

Total respondents for first and second statements was 42 in 2015, 36 in 2016 and 34 in 2017.
Total respondents for second statement was 41 in 2015, 36 in 2016 and 34 in 2017.

An effective professional development program helped to improve the skills and competencies of YCS staff in all jurisdictions.

In annual surveys of YCS staff, the majority of staff agreed the professional development program improved their skills, competencies and knowledge (see Figure 24). YCS staff commonly cited post-graduate scholarships and National Network meetings as the most effective National Network activities.

Figure 24: YCS staff survey respondents who somewhat or strongly agreed with statements relating to the professional development program

		2015	2016	2017
YCS staff survey	There are **regular opportunities** at YCSs to improve my skills and knowledge	88% (37)	86% (30)	79% (26)
	CanTeen offering **post-graduate scholarships** is an effective way to develop the skills and competencies of YCS staff	98% (40)	86% (30)	78% (25)
	The national professional development **forums and sessions** are effective at developing the skills/competencies of staff	83% (34)	83% (29)	78% (25)

Total respondents for first statement was 42 in 2015, 35 in 2016 and 33 in 2017.
Total respondents for second and third statement was 41 in 2015, 35 in 2016 and 33 in 2017.

5.2.3 What short-term outcomes were achieved by the National Research Agenda?

CanTeen supported a robust research agenda and prioritised investments in line with the six agreed AYA cancer research priorities.

CanTeen effectively prioritised and invested in research activities that aligned with the AYA cancer research priorities (based on program documentation and 2016 and 2017 consultations).[62] All research initiatives undertaken during Phase 2 aligned to one of the six agreed research priorities. Figure 25 provides examples of research projects CanTeen supported. Members of the RAG agreed the National

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[62] It is important to note that CanTeen is not primarily a research funding body and has limited funds to invest in research.

Research Agenda was an effective mechanism for focusing research efforts on areas of high need (based on 2016 consultations).[63]

Figure 25: Phase 2 research projects in line with research priorities

AYA cancer research priority	Project description	How the project supports priority needs for AYAs with cancer
Survivorship – post-treatment phase[64]	AYA Survivorship Report on the current state of survivorship care in Australia and challenges for patients and their families at the end of treatment.	The report outlined eight recommendations for improving survivorship care in Australia.
Clinical trials on high lethality cancer	Collaboration between CanTeen and the Australian Sarcoma Study Group on international research study into high lethality cancers.	The study will contribute to research on improving early detection through genetic profiling. As of November 2016, the investigators had invited 153 AYA patients and their families to participate in the study, 47 of whom had agreed to participate.
Workforce development	Literature review of the current context, scope and status of professional development programs and initiatives in AYA oncology (funded by CanTeen, conducted by the Centre for Health Service Development, University of Wollongong).	The report will inform improvements and advocacy efforts to expand professional development in AYA oncology for health professionals.
Fertility preservation	Pilot research study on psychological issues for fertility preservation in AYA participants (jointly funded by CanTeen and the Australia New Zealand Children's Haematology Oncology Group (ANZHOG)).	The project will inform improvements in fertility preservation advice and support for AYAs with cancer.
Building the evidence base through project funding	Two pilot research studies jointly funded by CanTeen and ANZHOG on: ○ new advanced care planning guide for AYAs with cancer ○ cardian and sleep disruption and the impact on quality of life amongst AYAs with cancer.	The studies will inform improvements in end of life care for AYAs with cancer.
Improving AYA participation in clinical research	A pilot randomised controlled trial of a structured exercise intervention after the completion of cancer treatment for AYAs (jointly funded by CanTeen and ANZHOG).	The trial found that that a 10-week exercise intervention is associated with greater improvements in VO2peak for AYAs with cancer and will inform improvements in exercise physiology.

Some jurisdictional YCS stakeholders indicated that the National Research Agenda did not provide enough support for research that focuses on local research needs in jurisdictions (as reported in 2016 and 2017 consultations). Some YCS staff indicated more information about the process for selecting research projects would be useful to support applications for local research.

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[63] Nous and CanTeen agreed Nous would not consult with the RAG in 2017 as their meeting schedule did not align with consultation timing.

[64] Activities related to survivorship care were not within the scope of the DOH funding agreement. CanTeen and the YCSs delivered additional activities under YCS Phase 2 covered by additional CanTeen donor funds.

Youth participation in clinical trials was well above the target of 3% throughout Phase 2.

Throughout Phase 2, the proportion of YCS patients enrolled in clinical research was well above the DOH KPI target of 3% per year. See Findings Part 1, section 4 for information on youth participation in clinical trials and research studies.

5.2.4 What short-term outcomes were achieved by the National Data Collection Strategy?

This section focuses on the short-term outcomes related to collection of jurisdictional activity data. Short-term outcomes related to development of the national AYA minimum dataset are outlined in Findings Part 1 (see section 4). The national AYA minimum dataset did was not implemented in Phase 2, so Nous was unable to assess the short-term outcomes related to collection of data against it.

The consistency and accuracy of activity data improved during Phase 2; some YCS staff were unclear on some data definitions and the relevance of some indicators.

At the beginning of Phase 2, the quality and reliability of activity data varied significantly across jurisdictions, but overall was relatively low (as reported through consultations and based on Nous' analysis of activity data). The quality improved considerably over the course of Phase 2. Some stakeholders indicating that the jurisdictional activity data templates and processes improved the accuracy, consistency and timeliness of AYA data collection (based on 2016 and 2017 consultations).

Factors that affected the consistency and quality of data collection between jurisdictions included:

- **Some YCS staff interpreted the data indicators differently.** CanTeen and the YCSs refined the reporting template and trained YCS staff in its use. Despite this, some YCS staff indicated they were unclear on how to accurately collect and interpret some data items (based on 2016 and 2017 consultations).
- **CanTeen was not able to collect activity data from some YCS partner hospitals.** Hospitals in the Australian Capital Territory (ACT) and Tasmania did not provide activity data until 2015-16.
- **Confidentiality issues led to double counting of patients across hospitals.** Confidentiality and privacy concerns around sharing data between hospitals meant some patients may have been double counted in the activity data (as indicated by CanTeen).
- **Quality of activity data was sometimes affected by poor system integration between hospital reporting requirements and CanTeen requirements**. Some stakeholders indicated that their record-keeping processes, templates and hospital systems supported hospital reporting requirements but did not align with CanTeen requirements. This sometimes affected the quality of data provided to CanTeen (based on 2017 consultations).

Many YCS stakeholders reported limitations associated with the activity data indicators and data collection process. It is important to note the purpose of the activity data when considering these reported limitations. The primary purpose of activity data is to report on KPIs related to the DOH funding agreement (as reported by CanTeen). Based on consultations, activity data limitations included:

- activity data indicators did not adequately consider the complexity of service delivery (based on 2016 and 2017 consultations). For example, YCS stakeholders reported that the purpose and relevance of some indicators was unclear.
- activity data was not the right suite of data, as it focused on processes and outputs. It did not allow for assessment of outcomes nor take into consideration important nuances in the engagement of YCSs with patients. For example, activity data collections 'instances of care', as

opposed to ‘hours of care’, which means only the initial engagement was counted, even though the care may have occurred over a long period of time and/or across multiple teams and hospitals.

CanTeen provided quarterly feedback to YCSs on their performance, but many jurisdictional stakeholders indicated that more comprehensive, local-level feedback would support evidence-based service planning and delivery.

CanTeen indicated they provide some analysis of activity data to jurisdictions. For example, CanTeen provided feedback through quarterly meetings with each jurisdiction and at Lead Clinician and Service Manager meetings.

Despite this, many YCS stakeholders reported the feedback they receive on their activity data could be more comprehensive (based on 2016 and 2017 consultations). For example, more comprehensive feedback could include comparisons against national benchmarks for some KPIs and/or more local-level analysis of service delivery and performance (for example, this could be a short report provided back to each jurisdiction that shows its performance against DOH KPIs and other activity data indicators, compared to other YCS jurisdictions and the national average).

Many jurisdictional stakeholders indicated more comprehensive performance feedback would help them to use the data to:

- inform service delivery and quality
- improve patient outcomes
- support continuous improvement (based on 2016 and 2017 consultations).

5.3 What were the strengths and areas for improvement of YCS Phase 2?

This sub-section details the strengths of the YCSs and each of the national initiatives.

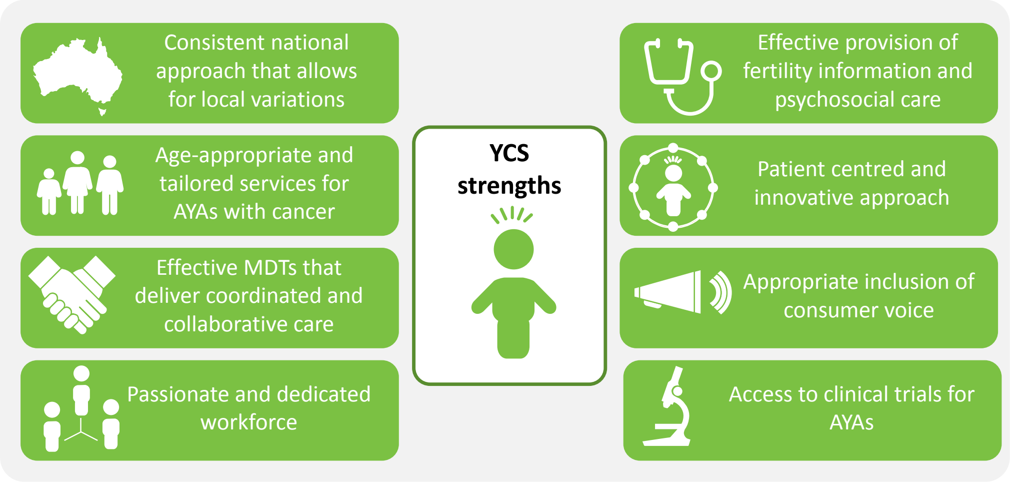
5.3.1 What were the strengths of the YCSs?

The YCS program had many strengths that helped support delivery of comprehensive, tailored cancer care for AYAs.

Overall, the main strengths of YCSs were the flexible national approach, AYAs access to MDTs with youth-specific expertise and the passionate, dedicated workforce. AYAs and parents/carers commonly cited the approachable, personable and accessible YCS staff that provided an appropriate level of care and support as particularly valuable (based on annual surveys of YCS other health professionals and consultations).

Figure 26 summarises the main strengths of YCSs (based on jurisdictional activity data and annual surveys of YCS staff and other health professionals and consultations).

Figure 26: Strengths of the YCSs in Phase 2



Each strength is detailed further below:

- **a consistent national approach that allows for local variations**. CanTeen and the YCSs implemented the YCS program using a national approach, which allowed for jurisdictional-level service delivery variations. This supported a shared vision and national priorities, knowledge sharing, local hospital buy-in and a minimum standard of care that was informed by the Charter of Rights (based on program documentation and consultations).
- **access to age-appropriate and tailored services for AYAs with cancer**. AYAs with cancer had access to specialist clinicians and staff with a deep understanding of AYA needs and specialist knowledge of specific diseases and tumours. YCS staff tailored services to the age-specific and individual needs of patients (based on jurisdictional activity data, YCS staff surveys and consultations).
- **effective MDTs that deliver coordinated and collaborative care.** YCS staff worked effectively with each other in MDTs to deliver a variety of supports and well-coordinated, collaborative and

high quality care for AYAs with cancer (based on jurisdictional activity data, YCS staff surveys and consultations).

- **passionate and dedicated workforce**. YCS staff had a shared commitment to delivering high quality care and support to AYAs and their families (based on the YCS staff surveys and consultations). The YCS workforce was passionate, dedicated, accessible and highly professional. AYAs and families particularly appreciated having a ‘go to’ person and continuity of staff (e.g. the CNCs).
- **effective provision of fertility information and psychosocial care**. YCS staff provided AYAs with comprehensive psychosocial care and assessment and fertility preservation information that existing teams (i.e. standard care approaches) did not typically provide (based on jurisdictional activity data, YCS staff surveys and consultations).
- **patient centred and innovative approach**. The YCS program took a holistic, patient centred approach, focused on the specific needs of each AYA (based on program documentation and consultations). The YCS program supported innovative approaches, which meant AYAs had access to services that may not have had access to otherwise (such as access to an exercise physiologists and awareness of fertility preservation).
- **appropriate inclusion of consumer voice**. AYAs with cancer were involved in planning their treatment and provided with clear information to inform their decision making (based on consultations with AYAs and the NYAG). The views of AYAs with cancer informed YCS service planning and delivery, largely through the national and local youth advisory groups. This helped to ensure the YCS program best met the needs of young people with cancer (based on program documentation and consultations).
- **access to clinical trials for AYAs**. The YCS program enhanced AYAs opportunities to access national and international clinical trials (based on jurisdictional activity data, program documentation, staff surveys and consultations). This was mainly through increased awareness of clinical trials and funding for specific research projects.

CanTeen and YCS stakeholders identified some challenges and four critical success factors for the establishment of YCS Phase 2.

CanTeen and YCS stakeholders reported challenges during the establishment and delivery of YCS Phase 2 (based on consultations). Stakeholders reported these challenges did not impact the achievement of YCS objectives, but may have delayed delivery of some activities. Common challenges cited by stakeholders during consultations were:

- a lack of certainty and transparency about Phase 2 funding, which impacted the relationship between YCS teams and existing AYA teams at some YCS sites. For example, some existing teams saw YCS as a ‘temporary service’ without confirmed levels of funding in Phase 2 and/or for Phase 3. YCS teams reported that this meant at times existing teams could be resistant to the YCS model ‘disrupting’ the existing service model if it was only going to be a temporary service (as reported in 2016 consultations by approximately half of all YCS jurisdictions).
- a lack of trust and initial tensions between some stakeholders (particularly some hospitals in each jurisdiction), which delayed the establishment of YCSs at some hospital sites.
- a lack of awareness and understanding of what the YCS program offers, how it operates and its benefits for AYAs and families, particularly amongst partner hospitals, GPs and in rural areas. This affected the growth and national reach of the YCS program. Many stakeholders indicated that awareness about YCS increased over the course of Phase 2 (as reported through consultations in 2016 and 2017).

- high staff turnover at the YCSs and at CanTeen and difficulty filling vacant roles, which sometimes affected the delivery and availability of YCS support and care and data collection at some YCS sites. As at December 2016, the YCSs had recruited staff into all funded YCS positions in their jurisdictions.
- difficulty improving shared care arrangements. This was due to limited communication between hospitals and other service providers, lack of access to private facilities and low awareness of YCSs in rural communities.
- difficulty credentialing clinicians to work in both public and private hospital settings, which may have affected shared care arrangements and the continuity of care. This affected YCS reach into private hospitals and the effectiveness of shared care arrangements.
- difficulty raising awareness of COSA's clinical guidances, which impacted on CanTeen's ability to improve the capacity of health professionals to diagnose cancer at an earlier stage.

The differing level of investment between jurisdictional health departments was an additional challenge for delivery of YCS Phase 2 (as reported by CanTeen). For example, NSW Health invested less than other health departments, which CanTeen indicated affected staffing levels (particularly across Western, South Western and South East Sydney Local Health Districts and the northern metropolitan region).

Despite some initial challenges, there were four factors critical to the successful delivery of YCS Phase 2 shown in Figure 27 (as reported in consultations).

Figure 27: Factors that supported delivery of Phase 2

Funding aligned to national priorities	Communication with YCS staff and stakeholders	Profile raising of YCSs	Engagement of AYAs to inform service planning and delivery
YCS funds supported the most appropriate initiatives and activities in line with agreed national priorities	Communication of the shared national vision and purpose of the YCS program ensured all parties worked towards a shared goal	Increased awareness about the existence, offerings and benefits of YCSs facilitated increased access for AYAs and relationship building with relevant parties (e.g. other hospitals)	CanTeen (through the NYAG) and the YCSs (through local advisory groups and patient interactions) ensured the views of young people informed the YCS program. This meant the service was tailored, comprehensive and best met the needs of AYAs with cancer

5.3.2 What were the strengths of the National Network (including the professional development program)?

The National Network meetings and strong professional development program were key strengths of the National Network.

Overall, the main strengths of the National Network were the National Network meetings and professional development opportunities. Figure 28 shows the main strengths (based on participant evaluations of National Network meetings, activity data, surveys of YCS staff and consultations).

Figure 28: Strengths of the National Network in Phase 2

Each strength is detailed further below:

- **National Network meetings that support networking and information sharing.** Many YCS stakeholders indicated the National Network meetings were important to increase collaboration and knowledge sharing between YCS staff. YCS staff reported they were high quality, engaging and fostered lasting relationships and networking between YCS staff (based on annual YCS staff surveys and consultations).
- **the effective professional development program.** The majority of YCS staff agreed the professional development program provided a comprehensive range of educational initiatives and resources (based on staff surveys and consultations). While the majority of YCS staff reported high satisfaction with the professional development program, YCS staff satisfaction in relation to the national professional development program decreased each year during Phase 2 (based on staff surveys). The two professional development activities most commonly cited as effective were:
  - the postgraduate AYA oncology scholarships, which increased participants' specialised knowledge in and commitment to AYA oncology
  - the Nursing Research and Clinical Innovation Mentor program, which enabled YCS nurses to learn from other YCSs and deepen their clinical expertise in AYA oncology.
- **high profile international events and conferences.** The Youth Summit and International AYA Cancer Congress effectively enabled experts, health professionals, and young people and their families to contribute to and learn from international best practice in AYA cancer care (based on consultations).
- **quality promotional and educational materials.** CanTeen developed guidelines, tools, factsheets and other materials, which helped improve consistency and quality across YCSs and raise the profile of the YCS program (based on program documentation, staff surveys and consultations).

5.3.3 What were the strengths of the National Research Agenda?

Investment in priority research needs and support for AYA participation in clinical trials were key strengths of the National Research Agenda.

Overall, the main strengths of the National Research Agenda were the effective prioritisation of high-need research projects and support for AYA participation in clinical trials. Figure 29 summarises the main strengths (based on the program documentation, activity data, YCS staff surveys and consultations).

> "CanTeen has effectively supported research studies of high need – the research proposals were well chosen based on a competitive process."
> *(YCS staff member, stakeholder consultation)*

Figure 29: Strengths of the National Research Agenda in Phase 2

National Research Agenda strengths

Prioritisation of research investments to areas of high need

Initiatives to increase AYA access to clinical trials and research studies

Strong advocacy on priority issues for AYA cancer

Each strength is detailed further below:

- **prioritisation of research investments to areas of high need.** The six AYA cancer research priorities enabled CanTeen to focus efforts on high need areas and AYA cancer researchers to coordinate their efforts (based on program documentation, jurisdictional activity data and consultations).
- **initiatives to increase access to clinical trials for AYAs with cancer.** CanTeen and the YCSs proactively sought to enrol AYA patients in trials, invested in clinical trial research and advocated to government (based on program documentation, jurisdictional activity data, YCS staff surveys and consultations).
- **strong advocacy on priority issues for AYA cancer.** CanTeen advocated to governments and other stakeholders in line with the six priority research areas (based on program documentation and consultations). For example, CanTeen undertook campaigns to improve Medicare item numbers for fertility preservation (in collaboration with FUTuRE Fertility) and increase access to clinical trials.

5.3.4 What were the strengths of the National Data Collection Strategy?

The main strength of the National Data Collection Strategy was that it drove development of the national AYA minimum dataset.

The main strength of the National Data Collection Strategy was the focus it provided in driving identification and agreement of a highest priority national minimum dataset for implementation (based on consultations). Figure 30 summarises the main strengths of the National Data Collection Strategy (based on program documentation and consultations).

Figure 30: Strengths of the National Data Collection Strategy

National Data Collection Strategy strengths

Collaborative, consultative approach for development

Practical, comprehensive national AYA minimum dataset

Knowledgeable, experienced DAG

Increased quality and consistency of data collection and reporting

Each strength is detailed further below:

- **collaborative, consultative approach for development.** CanTeen consulted with a broad range of stakeholders to identify a highest priority national AYA minimum dataset (based on program documentation and consultations). For additional information, see Findings Part 1, section 4).
- **practical, comprehensive national AYA minimum dataset.** CanTeen and the DAG identified and sought agreement on a comprehensive highest priority national AYA minimum dataset (additional information provided in Findings Part 1, see section 4).
- **knowledgeable, experienced DAG.** DAG members had relevant expertise and experience in youth cancer and research (based on consultations). Their reputations and networks helped engage the right people in identification and agreement of a highest priority national AYA minimum dataset. The DAG provided effective leadership in driving: (i) improved data collection processes for the YCS program; and (ii) the pathfinder initiative (to collect and analyse existing data on AYAs with cancer and engage with data custodians on current data availability (based on consultations).
- **improved the quality and consistency of data collection and reporting.** The quality and consistency of data collection by the YCSs significantly increased across the course of Phase 2 (based on analysis of 2013-14 to 2016-17 jurisdictional activity data). This indicated that YCSs increased their understanding of data collection and improved their data management systems. Several YCS staff indicated that they still found the data collection process confusing and that there was a risk of misinterpretation of data definitions and indicators (based on YCS staff consultations).

In the Mid-Term Report, Nous provided CanTeen with a number of areas for improvement for the YCSs and national initiatives (identified through consultations, surveys and other evaluation data sources). The areas for improvement helped to inform the overarching learnings from Phase 2 presented in this Final Report. The areas for improvement at the time of the Mid-Term Report are provided in Appendix C.