



AYA Vision 2033

For adolescents and young
adults with cancer

**YOUTH
CANCER
SERVICE**

 **conteen**

Acknowledgement of Country

Canteen acknowledges Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of this land. We pay respect to Elders past, present and future. We are committed to providing inclusive and appropriate support for Aboriginal and Torres Strait Islander young people, their kin and community impacted by cancer.

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Acknowledgement

Canteen would like to thank and acknowledge the multiple key stakeholders as well as Adolescents and Young Adults (AYA) living with or beyond cancer for their significant contribution of time, expertise, and resources to the development of AYA Vision 2033. These stakeholders have been instrumental in identifying the specific challenges faced by AYAs and have worked diligently to address these issues in the framework.

Building on foundations established by the Australian Youth Cancer Framework, AYA Vision 2033 was developed using a comprehensive and evidenced-based approach utilising co-design principles ensuring the creation of a comprehensive and effective plan for action for AYAs who experience cancer. The involvement of young people has been crucial in the development of AYA Vision 2033.

AYA Vision 2033 was led by The National Reference Group. We would also like to acknowledge the significant contribution of the Youth Cancer Services. Members of these groups are listed in the Appendix.

Nous Group were engaged to facilitate the development of AYA Vision 2033 in consultation with the key stakeholders. The Leading Partnership led the initial consultation interviews with senior leaders across the health sector.

Foreword

We are excited to introduce AYA Vision 2033, a cancer plan for Australian adolescent and young adult (AYA) patients. This purposeful statement of intent provides guidance and a plan for action for AYAs who experience cancer, their families, and carers, as well as government, care providers, and academics. Through its realisation, young people can look forward, to a future where their goals and vision can also be grasped.

As young people with a cancer experience, we have lived the unique set of challenges presented to AYAs in their cancer management due to the rapid biological, psychological, and social development experienced during this period of life and know AYAs require tailored, age-appropriate support that extends far beyond treatment. Meeting the individual needs of young people with cancer is at the heart of AYA Vision 2033, a plan developed after consultation with AYAs with lived experience of cancer. Their voices shine through.

AYA Vision 2033 highlights the need for specialist care and support to ensure the survival, health, wellbeing, and ongoing positive contribution to society of AYAs with cancer. The principles and priorities outlined will guide the sector broadly, and support implementation planning and service delivery by Youth Cancer Services into the next decade. This report builds on the foundations established by the Australia Youth Cancer Framework, developed in 2017, to construct a renewed platform for service and system-level action that identifies priorities and strategies for AYA cancer over the next 10 years.

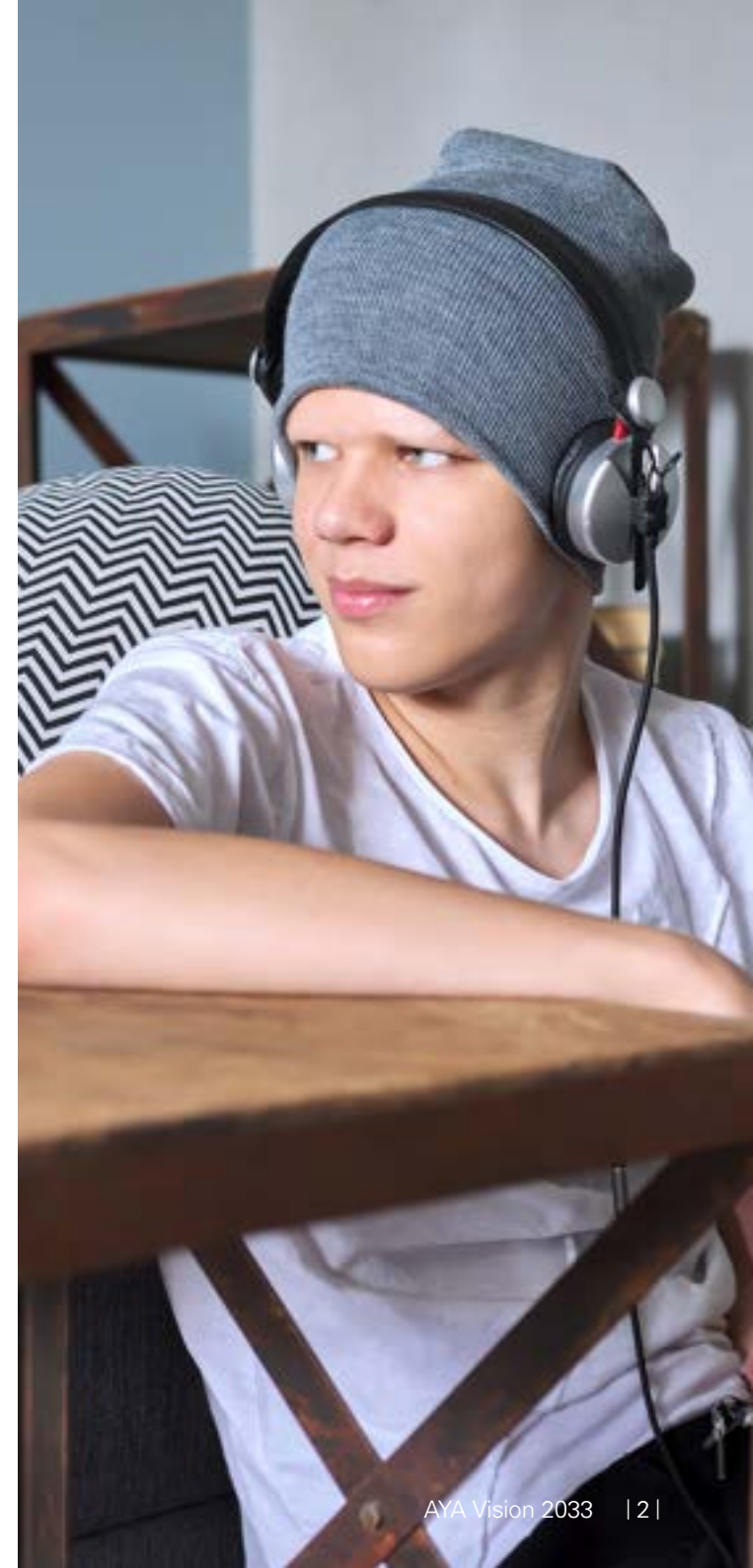
As co-chairs of the National Reference Group for its development, we believe that AYA Vision 2033 will serve as a valuable resource for the sector throughout the next decade. This report will complement and enhance work happening nationally, in each jurisdiction, and locally in facilities and health services to improve outcomes for AYAs with cancer, their families, and carers.

AYA Vision 2033 makes a commitment to seeing the best possible outcomes for all young people; that they will have control over their care decisions and access to the best available care and support at all stages of the cancer journey.

It is a bold plan. But we can aim for nothing less if every young person with cancer is to achieve their own vision for their future.

Dr Kathryn Woodward – Deputy Chair of the Canteen Board

Joey Lynch – Canteen Board member





AYA Vision 2033

Vision for AYAs with cancer, their families and carers

All AYAs with experience of cancer have control over and are central to their care options and decisions – AYAs, their families and carers have technology-enabled, targeted, research-driven and world-leading care and support through all stages of optimal care pathways.

Goals

All AYAs with cancer have world-leading medium and long-term physical and psychosocial health outcomes, including survival rates.

All AYAs with cancer experience socio-economic outcomes comparable to AYAs without cancer.

Guiding principles

EQUITY-LED ● EVIDENCE-INFORMED ● PERSON-CENTRED AND FAMILY INCLUSIVE ● TRANSITION-FOCUSED ● COLLABORATION-INFORMED

Strategic priorities

Deliver evidence-based, data-driven and research-led AYA-specific models of care aligned to Optimal Care Pathways

Support better connections within the health system

Support integration between health, relevant systems and community supports

Enablers

Consumer engagement

Technology, data and digitisation

Multidisciplinary workforce

Policy and legislative environment

A photograph of three young women of diverse backgrounds smiling warmly at the camera. The woman on the left has dark curly hair and is wearing a denim shirt. The woman in the middle has short dark hair and is wearing a striped shirt. The woman on the right is wearing a red hijab and a dark jacket. The background is slightly blurred, showing an outdoor setting with trees and buildings.

Purpose

AYA Vision 2033 provides guidance and a plan for action for Australian adolescent and young adults (AYAs)¹ who experience cancer, and their families and carers, as well as clinicians, researchers, organisations and governments.

As a result of the rapid biological, psychological and social development experienced in their period of life, AYA patients will experience their cancer treatment differently to those diagnosed in childhood or adulthood, leading to a unique set of challenges in their management.^{2,3} The unique nature of AYAs with cancer highlights the need for specialist care and support to ensure their survival, health, wellbeing, and ongoing positive contribution to society.⁴ AYAs require tailored, developmentally-appropriate support that extends far beyond treatment and promotes healthy survivorship.^{5,6}

AYA Vision 2033 is intended to complement and enhance work happening nationally, in each jurisdiction, and locally in facilities and health services to improve outcomes for AYAs with cancer, their families and carers. This includes national and state-based cancer plans and related policies, health service frameworks, and action plans. The principles and priorities outlined in AYA Vision 2033 will guide the sector broadly, and support implementation planning and service delivery by Youth Cancer Services (YCS) into the next decade.

The ultimate aim of AYA Vision 2033 is to achieve optimal care and support for AYAs through all stages of the cancer pathway.

Key groups may wish to use AYA Vision 2033 in different ways to shape their work, priorities, and interactions with the systems that provide care and support.

IMPORTANCE OF AYA VISION 2033

Youth Cancer Services (YCS)

Provide an overview of key activities that YCSs should consider including as part of strategic and operational plans – so as to support consistency across YCS jurisdictions.

Provide evidence and a tool that could support YCSs in their efforts to build greater collaboration and integration with other service providers.

Guide key data collection activities to support monitoring and evaluation of AYA Vision 2033 and allow for continuous improvement.

Other service providers

Provide an overview of key activities that other service providers should consider including as part of strategic and operational plans – so as to provide the best care and support for AYAs with cancer, their families and carers.

Provide an overview of activities that YCSs may be leading – so as to support coordinated and integrated support.

Researchers

Provide an overview of key activities and themes that researchers should consider as part of future research projects and collaborations – so as to drive forward research in areas of critical importance.

Provide guidance to support researchers and research teams increase the access to and participation in research (including clinical trials) by AYAs with cancer, their families and carers.

Peak bodies and advocacy groups

Support and guide advocacy efforts to enhance the care and support provided by services – so as to drive coordinated responses and seek collective impact.

Governments and policy makers

Guide policy making regarding care and support provided to AYAs with cancer, their families and carers.



Background and context

Recent years have seen considerable progress in care and support provided to AYAs

In Australia between 2014-2018, 5,302 new cases of cancer were diagnosed in AYAs.⁷ The incidence of AYA cancer in Australia is higher than rates in comparable countries, such as Canada, the UK and New Zealand.⁸

OVERVIEW OF AYA-RELATED CANCER⁹

Commonly diagnosed cancers in 2014-2018

13%

Hodgkin lymphoma

12%

melanoma of the skin

12%

testicular germ cell cancers

11%

carcinoma of the thyroid

10%

carcinoma of the colon and rectum

In 2013-2017,

17%

bone cancers and central nervous system cancers

15%

soft tissue sarcomas

were the leading causes of cancer mortality in AYAs.

In 2014-2018, AYAs diagnosed with cancer had, on average, a

90%

chance of surviving for 5 years compared with other people their age.

458

AYAs died from cancer in 2016-2020. This reduced slightly from 2011-2015, where 499 AYAs died from cancer.

Recent years have seen a significant number of positive developments in the support for AYAs with cancer, including:

An increase in the 5-year survival rates across all cancers for AYAs, from **89%** in 2010-14 to **90%** in 2014-2018.¹⁰

An increase in access to expert multidisciplinary specialist care in major hospitals across Australia, including via YCS.

An increase in the number of trials and evaluations of eHealth initiatives for AYAs with cancer.

The recent release of the **first optimal care pathway** for adolescents and young adults with cancer.¹¹

The development of several **AYA-specific psychosocial assessment measures**.

The bolstering of the sector by many **AYA 'champions'**, who advocate for the specialised care required by AYAs.

The development of a **dedicated cohort** of AYA health professionals.^{12, 13}



AYAs require unique supportive care due to the rapid physiological and psychosocial changes that occur alongside their cancer diagnosis.

Despite the successes, there are various challenges that need to be addressed over the next decade

AYAs experience significant disparities when compared to other cohorts with cancer.

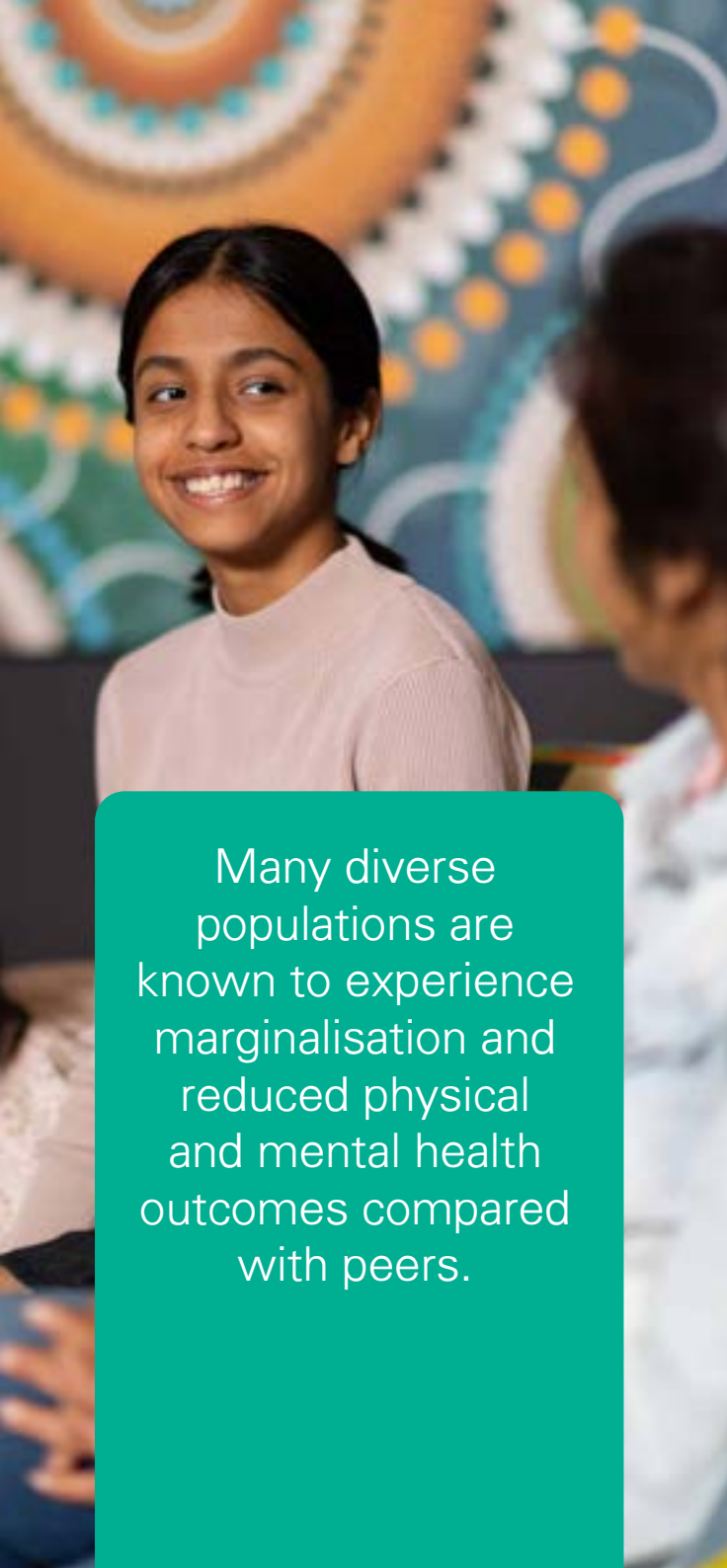
There are significant differences in incidence, outcome and burden of disease for AYAs affected by cancer when compared to the experience of their paediatric and adult counterparts. For example, whilst participation in clinical trials is known to improve patient outcomes,^{14, 15, 16} AYA enrolment in clinical trials is lower when compared with children.^{17, 18} AYAs face multifactorial issues that impact their survival rates. This includes unique cancer biology, uncertainty of treatment protocol, the disproportionate diagnosis of AYAs with rare cancers, and the ongoing challenges regarding the availability and accessibility of relevant clinical trials.^{19, 20}

AYAs do not always receive specific and developmentally appropriate care.

AYA patients are commonly described as experiencing cancer at the interface between paediatric and adult care. They often receive support services that have been designed for either younger children or older adults, which do not cater to the unique challenges faced during this stage of life.

AYAs require unique supportive care due to the rapid physiological and psychosocial changes that occur alongside their cancer diagnosis. Adolescence and young adulthood include important developmental milestones, such as establishing personal identity, exploring peer and intimate relationships, considering education and employment opportunities, and seeking increased independence.^{21, 22, 23} When adolescence and young adulthood coincide with a cancer diagnosis, wellbeing and development can be significantly impacted.^{24, 25} AYAs diagnosed with cancer experience disrupted education, employment, and careers after a cancer diagnosis,²⁶ including reduced school attendance, increased unemployment and under-employment compared to their same-age peers.²⁷

Key psychosocial concerns experienced by AYA cancer patients and survivors include depression, stress, isolation, fear of cancer recurrence, low self-esteem, negative body image, uncertainty about cancer-related disclosure with partners or friends, and disrupted education, work, and finances.^{28, 29, 30, 31, 32} Sexual and reproductive health issues are also of particular concern to AYAs, and cancer or its treatment can negatively impact fertility and sexual function.^{33, 34, 35}



Many diverse populations are known to experience marginalisation and reduced physical and mental health outcomes compared with peers.

Survivorship can be challenging for young people and requires additional consideration.

While medical and technological advances and supportive care have increased the five-year survival rate for AYAs with cancer in recent decades,^{36, 37, 38} survival after cancer can be challenging for young people. AYA patients' experience of finishing treatment is suboptimal, both physically and psychosocially,^{39, 40, 41, 42} and AYA cancer survivors frequently experience one or more chronic health conditions by the age of 40, resulting in an elevated risk of morbidity and mortality.^{43, 44, 45}

There remains a gap in knowledge regarding the long-term, distinct age-related quality of life and health impacts on AYA cancer survivors,^{46, 47} and ongoing research into survivorship care is a priority for AYAs with cancer.⁴⁸

A broader approach to AYAs with cancer is required.

As a cohort, AYAs encompass a rich diversity of experiences, including culturally and linguistically diverse (CALD) populations, First Nations Australians, geographically isolated and economically disadvantaged communities, LGBTIQ+ young people, those living with a mental health condition and those living with a disability. Many of these diverse populations are known to experience marginalisation and reduced physical and mental health outcomes compared with peers.^{49, 50, 51, 52, 53, 54, 55, 56}

For example:

- Cancer patients from CALD backgrounds of all age groups often experience poor quality of life during survivorship, and they are often underrepresented in research.⁵⁷
- First Nations people are more likely to die from cancer compared with non-First Nations people.⁵⁸ Differences in cancer type, remoteness of residence, socioeconomic disadvantage, access to care, and adherence to therapy are some of the factors explaining the survival disadvantage of Aboriginal and Torres Strait Islander children with cancer.⁵⁹
- The LGBTIQ+ population is increasingly being recognised as a “growing and medically underserved” population in cancer care,⁶⁰ with LGBTIQ+ AYAs at risk of particularly poor outcomes due to psychosocial and systemic vulnerabilities.⁶¹

The unique needs of families and carers of AYAs also need to be considered. The impact of a cancer diagnosis can be wide-ranging and long-lasting, causing significant disruptions to the dynamics and functioning for families of AYAs.^{62, 63, 64} Parents are at a high risk of experiencing distress,^{65, 66} and have a strong influence on their child's psychosocial outcomes post-treatment.⁶⁷ More than half of AYA siblings report symptoms of cancer-related post-traumatic stress⁶⁸ and almost 60% have high or very high levels of distress.⁶⁹



AYA Vision 2033 builds on the foundations established by the Australia Youth Cancer Framework

The Australia Youth Cancer Framework (AYCF), developed in 2017, articulated a national vision for best-practice AYA cancer care to 2020 and beyond. AYCF set out priority areas and principles for action, with the intention to guide the development of nationally comparable and locally responsive plans that were tailored to suit local contexts, systems, and workforce capability.

AYA Vision 2033 builds on the foundations established by the AYCF, creating a renewed platform for service and system-level action that identifies priorities and strategies for AYA cancer over the next 10 years. AYA Vision 2033 is intended to guide the system, including government, care providers and academics, throughout the next decade.

The development of AYA Vision 2033

The development of AYA Vision 2033 was led by Canteen, an Australian not-for-profit that provides free and tailored support to young people impacted by cancer. AYA Vision 2033 was iteratively drafted and developed by Canteen in partnership with the AYA Vision 2033 National Reference Group (NRG)⁷⁰ and other stakeholders.

The development of the document has been informed by extensive research and consultation with cancer sector and youth representatives with a lived experience of cancer, including:

- Development of a scoping review conducted by Canteen of academic and grey literature to identify trends and emerging developments in the care of AYAs impacted by cancer over the last five years.
- Online interviews and workshops with AYAs with cancer, including members of Canteen's Youth Advisory Team (YAT), attendees at the National Youth Cancer Consumer Forum, and other interested AYAs.
- In-depth one-on-one and small group consultations with senior leaders across the health sector and a range of clinicians, academics, sector experts and government representatives.
- Consultation with Canteen's Youth Cancer Services Strategic Advisory Group (SAG).
- Consultation with the NRG, during which key elements of AYA Vision 2033 were tested and refined.
- Consultation with the YCS in each jurisdiction, to test the elements of AYA Vision 2033.

A photograph of three young people sitting on a colorful patterned picnic blanket in a grassy park. In the center is a young man with curly red hair, wearing a white t-shirt and a necklace, looking down at his brown leather shoes. To his left is a young woman with long brown hair, wearing a black top, looking towards him. To his right is a young woman with blonde hair tied in a ponytail with a pink scrunchie, wearing a blue and white striped shirt and jeans, looking down. There are water bottles and a red snack bag on the blanket. In the background, there is a tree and a wall covered in graffiti.

AYA Vision 2033

Vision

All AYAs with experience of cancer have control over and are central to their care options and decisions – AYAs, their families and carers have technology-enabled, targeted, research driven and world-leading care and support through all stages of optimal care pathways.

The Vision describes the ideal future state for AYAs with cancer, their families and carers, and the supporting systems across the next 10 years. While significant achievements have been made in recent years in the identification, treatment and support of AYAs with cancer, improvements are required to ensure all AYAs and their families and carers experience optimal care and support at all stages of the cancer pathway.

Goals

All AYAs with cancer have world-leading medium and long-term physical and psychosocial health outcomes, including survival rates.

All AYAs with cancer experience socio-economic outcomes comparable to AYAs without cancer.

The Goals represent two bold and ambitious outcomes that will assist the sector to understand progress towards achieving the Vision. AYA Vision 2033 and other strategies will contribute to achieving these goals.



Guiding Principles

Five Guiding Principles inform the way that stakeholders will work together to develop and deliver initiatives as part of AYA Vision 2033. They underpin all elements of AYA Vision 2033 and reflect critical requirements to achieving the future state.

EQUITY-LED

All AYAs with cancer have equitable access – including across cancer types, within populations, and between AYAs and other people with experience of cancer.

Being fair and equal means recognising and addressing sociocultural privileges and bias, and how this may contribute to poorer access and outcomes for marginalised Australians. AYAs are not a uniform group, but encompass a rich array of human experiences, including CALD populations, First Nations Australians, geographically isolated and economically disadvantaged communities, LGBTIQ+ young people, those living with a mental health condition and/or those with a disability.

All activities delivered as part of AYA Vision 2033 should have equity at their core. This may mean developing tailored approaches to engagement or service delivery that address social and cultural determinants of health, environment and personal situation, and/ or ensuring that data collected can be stratified to understand the specific experience of different populations.

EVIDENCE-INFORMED

Activities and initiatives leverage and contribute to a strong and evolving evidence base.

All models of care, treatment, support and ways of engaging with AYAs should be informed by a robust evidence base. This means that there may need to be an active focus on expanding the evidence base for AYA cancer care. Given the relatively small size of the AYA population relative to other cancer cohorts, there are some areas where evidence is lacking.

An ongoing focus on using and developing evidence is critical to drive, understand, and evaluate the performance of Australia's cancer care system and enhance the care and outcomes for AYAs with cancer.

STANDING
UP TO

PATIENT-CENTRED AND FAMILY-INCLUSIVE

All AYAs receive developmentally appropriate care and, along with their families and carers, are empowered and in-control of decisions; all experience a system that is designed to respond to their needs, throughout the entire cancer pathway.

Being patient-centred involves a focus on ensuring that prevention, screening, treatment, care and support services are informed by AYAs experiences and are responsive to their health and psychosocial⁷¹ needs and preferences – including ensuring services are culturally safe, responsive and appropriate. All information, communication and care systems should be accessible, easy to navigate and tailored to each individual, to support informed decision making.

As detailed in the recently released optimal care pathway for adolescents and young adults with cancer (the OCP for AYA),⁷² for AYAs with cancer their period of ill-health coincides with a crucial period of growth and development including the transition to independence. Optimal AYA cancer care should be a patient-centred and collaborative model of care that supports the individual's emerging autonomy whilst being adaptive to the involvement of families, carers and significant others.

Cancer services should meet the needs of family, carers and community, and the importance of their role in the care of AYAs with cancer is to be acknowledged. AYAs with cancer, and their families and carers should be empowered to make informed decisions and be full partners in their care.

TRANSITION-FOCUSED

The systems that support AYAs with cancer, both within and outside the health system, effectively and collaboratively work together at key transition points.

Transitions here refer to AYA transitions along the cancer pathway, such as into survivorship and palliative care, as well as their transitions in and out of different systems, such as to adult care, or to education and employment. Research and consultations highlight that transition points need to be an area of focus – for it is at these points where AYAs with cancer, their families and carers, can experience disrupted or sub-optimal care, or can be lost to the system.

Activities delivered under AYA Vision 2033 must, where relevant, ensure that there is a specific focus on supporting AYAs with cancer, their families and carers, at these key transition points.

COLLABORATION-DRIVEN

Activities and initiatives involve system-wide, cross-sector, inter-jurisdictional, and national collaboration.

Systems, services, healthcare professionals and providers and teams, community-based supports, government, non-government organisations (NGOs), academics, education providers, and consumers should work together with clear roles, accountabilities and governance to achieve the best outcomes for AYAs, as they move along the cancer pathway. This includes partnering across government, including across education, health and social services, to ensure that cancer is considered in strategies, frameworks and plans relevant to AYAs, and working with partners to ensure that activities related to cancer care are integrated into other health systems.

Five Guiding Principles inform the way that stakeholders will work together to develop and deliver initiatives as part of AYA Vision 2033. They underpin all elements of AYA Vision 2033 and reflect critical requirements to achieving the future state.

Strategic priorities

The Strategic Priorities provide direction for system-wide effort over the next 10 years. Actions have been provided on a 2-, 5- or 10-year timeframe during which they aim to be achieved.



STRATEGIC PRIORITY 1

Deliver evidence-based, data-driven and research-led AYA-specific models of care aligned to Optimal Care Pathways (OCPs)

This Strategic Priority focuses on ensuring AYAs receive best-practice care. By this, we mean care that is evidence-based, data-driven and research-led, targeted to the unique needs of AYAs, and addresses the cancer pathway from diagnosis through to survivorship. AYA patients should be able to access the right care, in the right place, at the right time. Importantly, this care should also be affordable. Inherently, this requires increasing access for AYAs to clinical trials, as well as adopting emerging technology and strengthening national datasets. Models of care should be based on a growing evidence base and driven by data insights at national, state and local levels.

The Strategic Priority refers to Optimal Care Pathways (OCPs). OCPs offer a model of nationally consistent comprehensive cancer treatment and support, and incorporate clinical guidelines, best practice standards, and current research.⁷³ OCPs place patients at the centre of their care and aim to improve patient outcomes by facilitating safe, evidence-based care that is well coordinated between primary care, YCSs, other services, and the acute setting. They help to ensure all Australians receive the same standard of high-quality care regardless of where they live or their treatment setting.⁷⁴ OCPs currently exist for 23 cancer types⁷⁵ (with additional OCPs in development for a range of blood cancers), and the majority of these include a focus on AYAs, as well as target population groups, for example, First Nations Australians. There is also a dedicated OCP for AYAs,⁷⁶ which has been designed to complement the existing cancer-specific OCPs.

WHAT THIS LOOKS LIKE IF WE ARE SUCCESSFUL

AYAs with cancer, their families and carers

receive best-practice care that is culturally appropriate, and supports their physical, emotional, social and spiritual needs. They are empowered to voice their opinions and be genuine partners in their own care.

Health services provide evidence-based, multidisciplinary care to all AYAs with cancer, their families and carers, regardless of where people are receiving services.

The **system** has structures and enablers that support and encourage world-leading research and the translation of research into practice, and to systematically capture and use linked patient data.

What this means in practice

1.1

Enhance the representation and participation of AYAs with cancer in research and clinical trials

1.1.1 Advocate for and consider AYAs in research agendas

AYAs should be considered in research agendas to enhance the evidence-base of their care. This includes as both the focus of research, as well as an important component and cohort variable in broader cancer research programs.

TIMEFRAME: 2 YEARS

1.1.2 Develop and implement strategies to enhance AYAs' ease of access to research and clinical trials, including through YCS

Develop and implement systematic strategies that will enable all relevant clinicians and AYAs to readily find appropriate clinical trials for AYA cancers as well as facilitating access by AYAs to research including clinical trials. The strategies should also consider and account for system-level factors that limit participation in research and clinical trials such as such as transition between sites; access to subsidies to support participation; availability; access for rural and regional patients; and paediatric-adult arrangements, as well as build on existing factors that work well to increase AYA participation.

This will improve care and outcomes, through the development of components such as more effective treatment regimens and holistic models of care. It will also work to increase and enhance the representation/participation of AYAs from regional, rural and remote areas.

TIMEFRAME: 2 YEARS

1.1.3 Investigate, develop and support approaches to enable cross-site participation in clinical trials

Many AYAs are currently unable to enter into clinical trials because they are being treated at facilities that are not

trial sites. This may be due to factors including very few eligible patients; geographic accessibility; or lack of financial resources to support institutional trial participation.

Approaches should be developed to enable AYAs to enrol into relevant clinical trials even when these are at sites other than their primary treatment location. For example, an AYA receiving care in an adult hospital setting should be supported and enabled to enrol in a clinical trial being run from a paediatric setting.

TIMEFRAME: 2 YEARS

1.1.4 Establish national and state research grants with a focus on AYAs with cancer, across all stages of the OCP

National and state research funding programs should provide specific grants targeting research of AYAs across all stages of the cancer pathway, to increase the quality and quantity of research focusing on this cohort.

TIMEFRAME: 5 YEARS

1.1.5 Advocate for all appropriate cancer clinical trials to include an AYA-specific component, and ensure AYA-specific research is being conducted across all relevant cancer types.

All appropriate cancer clinical trials should include an AYA-specific component where possible, or at a minimum an AYA-appropriate approach, to address the unique needs of the cohort. This may take into account factors such as treatment site (paediatric or adult facilities); family involvement; and the highly mobile nature of the cohort.

TIMEFRAME: 10 YEARS

1.1.6 Review and adapt OCPs, models of care and therapies (where appropriate) to incorporate and promote scientific and technological advancements that meet the unique needs of AYA

OCPs, including the OCP for AYAs, should be routinely reviewed and updated, taking into account new scientific and technological advancements across diagnostics, treatment and support. This will ensure that pathways reflect the latest evidence, and that AYAs receive world-leading care and support. Also, ensuring the affordability and accessibility of relevant technologies, advances and medications will enable more equitable care and outcomes for all AYAs.

TIMEFRAME: 10 YEARS



WE'LL KNOW WE'RE SUCCESSFUL BY LOOKING AT:

Maintenance of regular forums that focus on AYA research

Number of specific state and national grants targeting AYA research

Proportion of eligible AYAs who are involved in clinical trials

What this means in practice

1.2

Ensure all AYAs with cancer receive holistic, developmentally appropriate, and best practice cancer care

1.2.1 Increase awareness of the OCP for AYAs and how it should be used in combination with cancer specific OCPs to deliver best practice care for AYAs

The availability and importance of the OCP for AYAs should be promoted across all relevant cancer services to support its uptake and use. In particular, clinicians and other stakeholders should be reminded of the importance of delivering care in line with the OCP for AYAs and cancer-specific OCPs. Together, these contribute to the delivery of best-practice care and support.

TIMEFRAME: 2 YEARS

1.2.2 Promote awareness of culturally appropriate care throughout the AYA cancer care system; provide culturally appropriate care through YCS, especially in the context of First Nations AYAs

All AYAs, especially First Nations AYAs, should equitably receive targeted and appropriate care to ensure wellbeing and optimal healthcare outcomes. Guidelines and best practice regarding culturally appropriate care should be promoted across all services and implemented in YCS.

TIMEFRAME: 2 - 5 YEARS

1.2.3 Empower AYAs to play an active role in their care

Activities, programs and resources that strengthen decision-making by AYAs about their care will facilitate increased wellbeing and an improved sense of agency.

TIMEFRAME: 2 - 5 YEARS



WE'LL KNOW WE'RE SUCCESSFUL BY LOOKING AT:

AYA self-reported satisfaction with care

Use and reporting of PREMs and PROMs scores for AYAs

Internal and external evaluations of YCS regarding care provided and ability to meet 'best practice' guidelines



What this means in practice

1.3 Expand the reach of YCS across Australia and advocate for sustainable funding streams/mechanisms

1.3.1 Establish and monitor virtual care models within YCS to increase access to care, including for regional, rural and remote (RRR) AYA patients and priority populations

Virtual care models for RRR AYAs should be prioritised to support equity of access. Monitoring frameworks should be developed for new and emerging virtual models of care (such as virtual follow up and survivorship care), and learnings used to iterate and improve their design.

TIMEFRAME: 5 YEARS

1.3.2 Investigate and identify strategies to maximise access by AYAs to YCS care

To continue to increase the care options available to AYAs, an understanding needs to be gained of where and why AYAs are not being referred to YCSs, and the potential strategies that could be employed to help improve equity of access.

TIMEFRAME: 5 YEARS

1.3.3 Seek support for sustainable funding streams/mechanisms for YCS

Sustainable funding will allow for the ongoing functioning and continual improvement of YCS.

TIMEFRAME: 10 YEARS



WE'LL KNOW WE'RE SUCCESSFUL BY LOOKING AT:

Proportion of all hospitals across Australia linked to YCS
.....

Proportion of AYAs with cancer linked to a YCS

What this means in practice

1.4 Develop a linked, national dataset for AYAs with cancer

1.4.1 Coordinate and leverage existing data regarding AYAs with cancer across their journey, and between sectors

Linking existing data will allow for a more comprehensive overview of the experience of AYAs and highlight opportunities for system improvement. This action will require addressing system-wide barriers that currently exist in relation to developing a linked, national dataset for AYAs with cancer.

TIMEFRAME: 2 YEARS

1.4.2 Prioritise funding for nationally-coordinated data capture, analysis and use projects

Available state/territory and federal funding should prioritise projects for AYA data capture, analysis and use, to contribute to the monitoring of trends, tracking of priorities and critical issues, and improvement of outcomes at a national level.

A linked population-wide AYA cancer dataset would: facilitate identification of unmet AYA needs; enable assessments of care across the population, including across clinical centres and by cancer type; facilitate better identification and monitoring of emerging clinical complications; assist the costings of treatments and out-of-pocket expenses; and strengthen assessments of outcomes of collaborative research.

TIMEFRAME: 5 YEARS

1.4.3 Ensure active, informed and ongoing consent for collection, use and storage of AYA data for research purposes, including through education of AYA

Systems are needed to collect consent in line with legal and research ethics committee requirements, in order to increase availability of data for research and related purposes.

For consent to be informed, education programs will be necessary to ensure AYA understanding of data use. Processes and procedures are needed to support the informed consent process, including the use of ethics approved research protocols, and strong data capture and storage governance.

TIMEFRAME: 5 YEARS

1.4.4 Embed comprehensive data collection and analysis of AYAs with cancer at YCS, and advocate for the roll out of similar processes at other health services

YCS should undertake robust and consistent data collection and analysis at all sites, while advocating for the same activities to occur in other health services. This will facilitate the monitoring of trends, the tracking of priorities and critical issues, and improvements in outcomes for the AYA population.

TIMEFRAME: 5 YEARS

1.4.5 Collaborate in the setting of national goals and performance measures

National goals, performance measures and baseline data regarding AYA cancer care and outcomes should be advocated, to improve data capture and the validity and reliability of data outputs.

TIMEFRAME: 10 YEARS



WE'LL KNOW WE'RE SUCCESSFUL BY LOOKING AT:

Creation of a high quality, national data asset of unit-level AYAs with cancer

- Available patient data at a unit record level is collated and analysed nationally
- Available patient data at a unit record level is linked to existing data assets, such as PBS / MBS data
- Assessment of the quality of the linked data asset (quantitative and qualitative)
- Link national goals and performance measures to national data asset

Quantity of AYA-relevant data mapped between ABS and AIHW and / or other data assets



Connections between all parts of the health system will be required to deliver holistic, developmentally-appropriate, best-practice care

STRATEGIC PRIORITY 2

Support better connections within the health system

This Strategic Priority focuses on supporting improved connections within the health system. This includes connections between different health practices, such as between oncology and other relevant areas of health, as well as between paediatrics, AYA and adult health specialisations, and services and supports surrounding the transitions through the cancer pathway, including to survivorship and palliative care. Connections between jurisdictions and Commonwealth strategies will be required to ensure a shared understanding of the priorities and expertise to shape and influence activities and funding.

WHAT THIS LOOKS LIKE IF WE ARE SUCCESSFUL

AYAs with cancer, their families and carers

seamlessly transition between health services including across primary, secondary and tertiary settings, and post-treatment to survivorship or palliative care.

Health services share information and actively coordinate to best meet the unique care needs of AYAs across the cancer pathway and over time.

The health **system** is integrated and supports patient transitions. A system of linked data and embedded technology drives the high performance of the health system in its care for AYA.

What this means in practice

2.1

Build the capability and capacity of the current and future health workforce to address the specific needs of AYAs with cancer

2.1.1 Raise awareness and provide AYA-specific training for the national health workforce engaged with AYAs on the unique needs of the cohort and how to address these needs

Increased awareness of the unique needs of AYAs will enable the health workforce to better meet these needs and provide care in a developmentally appropriate way. The MDT workforce is critical to AYA-specific care; building the capacity of multidisciplinary team members beyond YCSs should be prioritised.

TIMEFRAME: 2 YEARS

2.1.2 Investigate options for establishing the future workforce pipeline for AYAs with cancer care

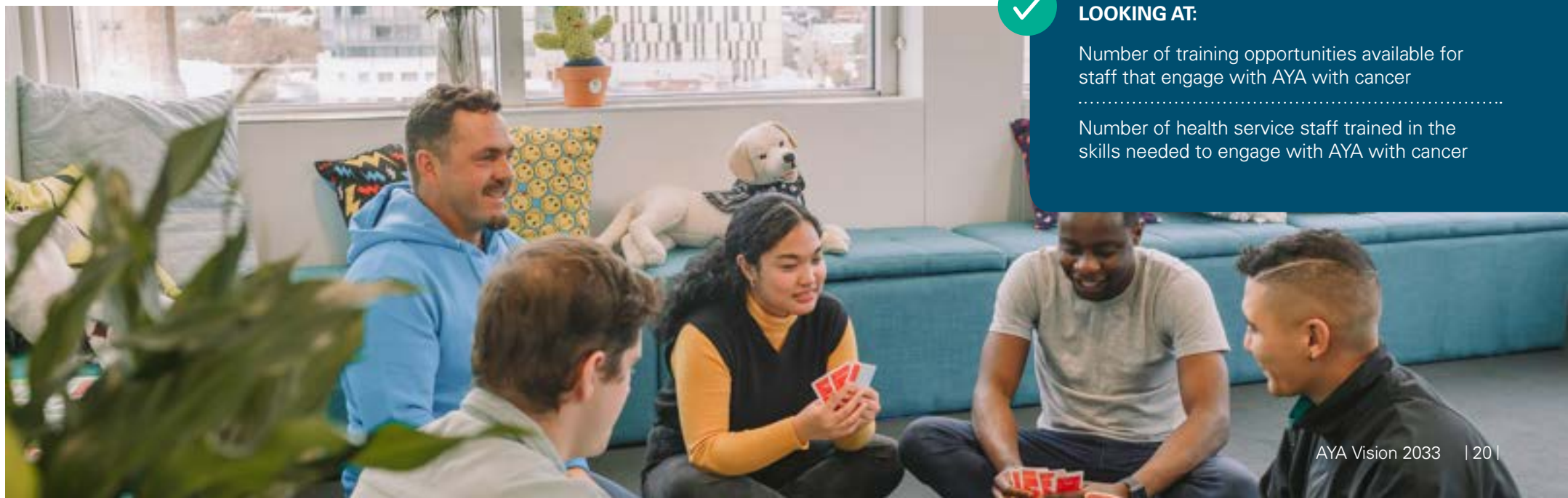
Establishing a specific future workforce pipeline will ensure sufficient workforce capacity to care for the current and future AYA cohort, across multiple health settings.

TIMEFRAME: 5 YEARS

2.1.3 Ensure there are accredited AYA health and oncology training courses available for the health workforce.

Educating the health workforce of the cohort's unique needs will ensure a solid base of understanding that can be further developed with ongoing education and experience.

TIMEFRAME: 5 YEARS



WE'LL KNOW WE'RE SUCCESSFUL BY LOOKING AT:

Number of training opportunities available for staff that engage with AYA with cancer

Number of health service staff trained in the skills needed to engage with AYA with cancer

What this means in practice

2.2 Develop sustainable co-designed, integrated service models and AYA-focused models of care

2.2.1 Ensure all YCS and other relevant supports are included in all relevant HealthPathways

An up-to-date directory of YCS within HealthPathways will ensure primary care providers are supported to refer AYA patients to services designed to meet their needs and expectations. HealthPathways is an online clinical and referral information portal for health professionals. This could be supported through enhanced promotion of referrals to YCSs, as well as building the profile and awareness of YCSs throughout the sector.

TIMEFRAME: 2 YEARS

2.2.2 Co-design integrated, multidisciplinary service models, within and beyond YCS

Co-design and/or co-creation of service models with consumers and multidisciplinary teams will provide a targeted approach to meet the access and equity requirements for communities and meet holistic needs of diverse cohorts of AYA patients.

A critical aspect of these service models will be supporting the effective transition back primary care and NFPs once acute care has ended, and ensuring that General Practitioners and other members of the primary care workforce have the skills and capabilities needed to support lifelong care.

TIMEFRAME: 5 YEARS

2.2.3 Empower AYAs to be involved and contribute to their health record

Ensuring AYAs ‘own’ their data, can increase well-being and improved sense of agency throughout their cancer journey. AYAs should be involved in information capture and appropriate transfer between services.

TIMEFRAME: 5 YEARS

2.2.4 Continue to build AYAs’ leadership capacity, including confidence in providing service design input

Building leadership capacity of AYAs will increase their wellbeing and agency, as well as improve any co-design approaches.

TIMEFRAME: 5 YEARS



WE’LL KNOW WE’RE SUCCESSFUL BY LOOKING AT:

- Number of new co-designed, AYA-focussed service models available for use (within and outside of YCS)
-
- Involvement of AYA in projects reviewing cancer service design
-
- Availability of YCS (and other Canteen-provided supports) in HealthPathways
-
- Number of AYA involved in formal leadership building activities
-
- Number of AYA self-reporting direct contribution to their health records or related data assets



AYAs with cancer, their families and carers should experience a system that is responsive to their lived experiences, needs and circumstances

STRATEGIC PRIORITY 3

Support integration between health, relevant systems and community supports

This Strategic Priority focuses on integrating the health system with the full range of relevant community and social systems, including education, employment and social services, as well as community supports. This includes the integration of data, knowledge and best practice regarding AYAs with cancer across different systems.

WHAT THIS LOOKS LIKE IF WE ARE SUCCESSFUL

AYAs with cancer, their families and carers

experience a system that is responsive to their lived experiences, needs and circumstances, and supports the cohort to live to their full potential.

Health services are closely linked with other services such as education, employment and community support at a local level.

The broader **system** has a clear and consistent person-centred vision that guides how systems connect. Data is meaningfully collected and reported to improve connections within the system.

What this means in practice

3.1 Ensure AYAs and their families and carers are connected with other systems and the community

3.1.1 Continue to develop and distribute evidence-based support resources and programs for AYAs, their families and carers, including system navigation

YCS should continue to support AYAs, their families and carers to navigate the health, education, social services, employment systems, and community supports to improve their experience of transitioning between active treatment and into survivorship and palliative care. This may include via resources and educational programs.

TIMEFRAME: 2 YEARS

3.1.2 Ensure family members of AYAs with cancer are referred to appropriate specialist services, primary care, and other supports such as Cancer Hub

Specialist services and primary care are central to survivorship plans and Cancer Hub provides Australia-wide cancer navigation services, to ensure all family members of AYAs with cancer can have their needs identified and connections made to a wide range of community supports, as well as providing immediate access to online counselling support.

TIMEFRAME: 2 YEARS

3.1.3 Facilitate the empowerment of AYAs and their carers/families in their navigation of, and interactions across, other systems and at all stages of active treatment, including through the proactive support of YCS

Note this will be partially addressed by SP1.3

AYAs and their families and carers should be empowered to interact confidently with various systems, so that they make informed choices. YCS will support AYAs, their families and carers, navigate another systems, including health, education, social services and employment systems and related community supports, to assist with transitioning through the cancer pathway and improve their long term physical and psychosocial outcomes.

TIMEFRAME: 5 YEARS



WE'LL KNOW WE'RE SUCCESSFUL BY LOOKING AT:

Self-reported measure by AYAs, their families and carers, regarding confidence related to system navigation

Proportion of AYAs, their families and carers, referred to primary care and Cancer Hub via YCS

Proportion of AYAs, their families and carers, referred to other community supports via YCS



What this means
in practice

3.2 Share performance-enhancing information between systems and stakeholders

3.2.1 Facilitate information sharing, including appropriate data, evidence and other context across health, other systems and community supports

Shared understanding of the needs of AYAs, as well as progress to date, best practice and evidence, will enable more streamlined development of shared practices and models between different systems.

TIMEFRAME: 10 YEARS



WE’LL KNOW WE’RE SUCCESSFUL BY LOOKING AT:

Establishment of referral pathways between systems supporting AYA with cancer

Provision of appropriate information, such as research and policy insights, between other systems and other forms of engagement between systems

Establishment of an information sharing system including relevant AYA patient data at an appropriate and enforced level of privacy, within each jurisdiction, that covers key systems



What this means in practice

3.3

Work with relevant systems to increase awareness of and address the unique needs of AYAs and the impact of cancer on life outcomes

3.3.1 Enhance awareness within other systems of the unique needs of AYAs, and the impact of cancer on life outcomes

Education and professional development processes will broaden the understanding and awareness of key stakeholders, to ensure that AYAs are a focus in relevant policies, frameworks, and activities.

TIMEFRAME: 2 YEARS

3.3.2 Encourage shared responsibility and system-wide collaborations to support and aid navigation for AYAs with a cancer experience (e.g., primary care, cancer support organisations, schools, universities and mental health services amongst others)

Shared responsibility will ensure a more integrated experience of transitioning between systems of AYAs and their families and carers.

TIMEFRAME: 5 YEARS



WE'LL KNOW WE'RE SUCCESSFUL BY LOOKING AT:

Number of system-wide collaborations to support and aid navigation for AYAs with experience of cancer



Enablers

The Strategic Priorities and action items will be supported by four groups of system enablers.

The enablers are associated with activities occurring outside of the cancer care system and will support the achievement of the Vision and the actions of AYA Vision 2033. The enablers are broader than just the cancer control system and require collaboration and coordination across systems and stakeholders.



CONSUMER ENGAGEMENT

Best practice engagement approaches should be developed and embedded, including co-design of services, to ensure services meet the needs and expectations of AYAs with cancer, their families and carers, and that services are equipped to effectively and appropriately engage with AYAs.

Best-practice engagement approaches that include AYAs with cancer and their families and carers should be identified and implemented across all areas pertaining to AYA support and care. Engagement includes across the design and delivery of any inter-sector activities, such as research and service design, as well as care and support at an individual patient level.

Patient and consumer engagement is highlighted in one of the National Safety and Quality Health Service (NSQHS) Standards developed by the Australian Commission on Safety and Quality in Healthcare.⁷⁷ Additional investment in consumer engagement, research, and co-design or co-creation of service and system responses are needed and will ensure a dedicated approach can be tailored to meet the access and equity requirements for these communities.

TECHNOLOGY, DATA AND DIGITISATION

Digital and scientific developments, such as advances in data capture and analysis, genetic science, robotics and artificial intelligence, are shaping the future of healthcare delivery, and will be required to advance the care of AYAs.

Emerging digital and scientific developments are shaping the future of healthcare delivery and should be leveraged to optimise AYA cancer outcomes. Advances in digital health and their application in optimising AYA cancer outcomes need to be considered as AYAs are pervasive users of technology. Examples of emerging digital technologies to consider include:

- telehealth for facilitating group-based or individual psychosocial interventions, or clinical trials
- online health communities offering peer support; telepresence robots, video gaming and virtual reality to support psychosocial and physiological functioning of AYAs

Similarly, emerging developments in genetic science and cancer treatment, such as oncogenes, CAR T-Cell therapy, fusion gene products, and personalised medicine can lead to the development of targeted treatments.⁷⁸

National-level systems for capturing critical patient information have been identified as successful in facilitating the sharing of expertise, ideas, and learnings internationally.⁷⁹ Current efforts in developing technology platforms and data capture methods should be leveraged to support the success of AYA cancer-specific linked datasets. National data systems will enable greater visibility on AYA short- and long-term outcomes and inform policy and system design. Data systems would also allow for analysis of incidence, survival, mortality, stage, other risk stratification indices, and risk stratified survival and care patterns over time and by socio-demographic sub-group.⁸⁰

A linked AYA dataset would also facilitate:

- the identification of unmet patient needs
- mapping of patterns of care across cancers
- monitoring of emerging patterns of complications
- better costing of treatments and out-of-pocket expenses
- monitoring of the performance of collaborative research
- monitoring of patterns, such as of incidence and outcome by cancer type, and of complications

MULTIDISCIPLINARY WORKFORCE

Federal and jurisdictional efforts to build the health workforce of the future – including strategic planning – should consider the specific multidisciplinary workforce needs for AYAs with cancer, their families and carers. A multidisciplinary workforce that is trained and competent in identifying and responding to the treatment and support needs of AYAs is required.

A greater focus is needed on the systematic approach to current and future gaps in the AYA cancer workforce. The planning, support and training opportunities to improve the capacity and capability of this workforce should take into account the present and future workforce needs of AYAs with cancer and their families and carers. Workforce considerations may include the development of accredited training programs and placements, continued capacity building for staff 'on the ground' in regional, rural and remote areas, and the development of new roles within the MDT (e.g. allied health). Funding for speciality roles involved in AYA care (e.g. psychologists, exercise physiologists, AYA

Nurse Care Coordinators, and AYA-trained Aboriginal Liaison Officers) is considered to be critical to best meet the needs of AYAs.

POLICY AND LEGISLATIVE ENVIRONMENT

Broader policy and legislative changes – including efforts to enhance collaboration across jurisdictions – will create an enabling environment to achieve AYA Vision 2033.

Broader policy and legislative changes will help achieve progress towards the vision for AYAs with cancer, their families and carers. Therefore, it is essential that national and state/territory cancer plans reference the needs of AYAs and their families. There is also the need to ensure that state/territory and national research agendas and processes provide for the specific needs of AYAs. Given that the cancers AYAs experience are rare or rarer than other cohorts, national resourcing, coordination and recruitment is essential. Alignment with existing strategies, frameworks and plans should be strengthened, including those developed by the state/territory governments, the Australian Department of Health and Aged Care, Cancer Australia, the National Aboriginal Community Controlled Health Organisation (NACCHO), and non-governmental organisations.

Additionally, a common understanding by stakeholders of the priorities associated with AYA cancer care at a policy and legislative level will benefit the development of future cancer policies, clinical guidelines, legislation, cancer program funding, and ensure that AYAs are a focus.



Abbreviations

AYA

Adolescent and young adult

AYCF

Australian Youth Cancer Framework

CALD

Culturally and linguistically diverse

LGBTIQ+

Lesbian, Gay, Bisexual, Transgender, Intersex, Queer, and Asexual (+ other marginalised gender identities and sexualities)

OCP

Optimal Care Pathway

MDT

Multidisciplinary Team

NRG

National Reference Group

NSQHS

National Safety and Quality Health Service

YAT

Youth Advisory Team

YCS

Youth Cancer Services

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