



# Australian Youth Cancer Framework

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**FOR ADOLESCENTS AND YOUNG ADULTS WITH CANCER**

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This document is available at [www.youthcancer.com.au](http://www.youthcancer.com.au)

# Acknowledgments

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The Framework was developed using a comprehensive evidence base and an extensive stakeholder consultation methodology. Engagement with key informants from the National Cancer Expert Reference Group and with Youth Cancer Services Governance Groups nationally has been critical in formulating the recommendations contained in this Framework.

CanTeen would like to acknowledge the significant contributions by expert advisors and leaders, educators, clinicians, consumers, policy makers, researchers, health service planners, cancer control organisations, and paediatric and adult cancer professional groups. Youth engagement has also been integral to the process of developing the Framework.

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ZEST Health Strategies was engaged to facilitate development of the Framework, in consultation with contributing organisations and groups. The University of New South Wales was engaged to undertake a literature review of evidence to inform development of this Framework.

# Foreword

In 2008, Cancer Australia and CanTeen published the National Service Delivery Framework (NSDF), helping to set the strategic direction for the establishment of specialist, multidisciplinary adolescent and young adult (AYA) cancer care in Australia. This foundational document articulated a coordinated service delivery model, responsive to the medical, psychosocial and supportive care needs of AYAs diagnosed with cancer. Building from this call to action, significant investment and national collaborative effort over the last decade have driven the establishment and growth of the Youth Cancer Services, which provides age appropriate, high quality care to 15-25 year old Australians diagnosed with cancer.

With many of the goals outlined in NSDF having now been achieved, the new Australian Youth Cancer Framework (AYCF) will build on the foundations set by its predecessor to lay out a refreshed vision for best-practice AYA cancer care in Australia.

The AYCF presents an opportunity for Australia to re-commit to the ongoing delivery of specialist, age appropriate treatment and support to young cancer patients and their families. Guided by the AYCF, individual, service and system-level action within and beyond the healthcare sector will allow the greatest number of young cancer patients to benefit from the world-class expertise of the Youth Cancer Services.

Towards 2020 and beyond, Australia must plan for a changing healthcare environment adapting to emerging technologies, e-health and the impact of personalised medicine on traditional service delivery models. In addition to the critical function of a sustainable and capable service delivery network and workforce, ongoing development of data monitoring infrastructure, and robust and globally relevant clinical trial and research agendas will be critical.

Looking towards Phase 3 of the Youth Cancer Services, the AYCF will build from the successes of the NSDF to provide continued direction for service delivery and address the growing body of evidence on AYA cancer care, emerging technologies and high priority areas including access to clinical trials and research. Successful implementation of the AYCF calls for leadership across all levels of government, partnerships between health, industry and community sectors and meaningful collaboration with young cancer patients and their families to drive improvements in outcomes.

Over the coming years, the AYCF will inspire future policy direction, investment and action to ensure Australia can meet new challenges in an evolving healthcare landscape, so that every young Australian with cancer has access to the best practice, age appropriate care and support they need to optimise their health, wellbeing and survival, and facilitate meaningful participation across all aspects of life.



Peter Orchard

# Introduction

## CANCER AND YOUNG AUSTRALIANS

Each year, approximately 1,200 young Australians (aged 15–25 years) are diagnosed with cancer.(1) This reflects an incidence rate that is 90% higher than worldwide estimates for this age group and higher than rates in comparable countries including Canada, the United Kingdom and New Zealand.(2) The higher incidence is primarily due to the higher rates of melanoma in Australia.

Overall, survival rates are high, with 88% 5-year relative survival for the similar 15–29 years cohort.(3) While this is good news, there is a growing number of young cancer survivors living with a range of significant, life-changing late effects of cancer and its treatment.

Despite high survival rates, cancer remains the most common cause of non-accidental death among young people.(4) Cancers with poorer survival rates in this age group include cancers of the brain, soft tissue and acute leukaemias.(3) Reasons for poorer survival are believed to include: the distinct biology of cancers encountered in this age group, the physiology of adolescents and young adults and their response to existing child or adult treatments;(5) diagnoses of rare cancers;(6) and poorer access to clinical trials.(7)

## THE NEEDS OF YOUNG PEOPLE WITH CANCER

Young people with cancer face an unexpected, life-changing and extraordinary challenge to accept, manage and overcome a critical illness during this transformative stage of life.

In addition to facing a potentially life-threatening illness at a time that is usually filled with life-affirming potential, young people with cancer face a range of challenges that have particularly significant impact at this stage of life (Figure 1).

Adolescence and young adulthood is a time in which young people develop independence, emotional maturity, intimate and sexual relationships, and an emerging sense of identity. A cancer diagnosis can interrupt this developmental pathway in different and lasting ways. These can include increased reliance on parents, limiting privacy and impacting independence and identity formation (8,9); negative body image, impacting relationship, intimacy and emotional maturity (10,11); and an impact on fertility with an associated sense of loss.

A cancer diagnosis can also have an effect on a young person's career and financial prospects, in the short and long term. Cancer and its treatment interrupt education, training and/or employment pathways.(12, 13) The interruptions can be lasting due to longer term effects on energy, memory and ability to concentrate, with reduced income over time.(9, 14-16)

From a financial perspective, cancer during adolescence or young adulthood is associated with significant financial burden on the young person, their family and the health system in the form of healthcare costs, out of pocket expenses, forfeited income, additional education costs and long term diminished employment opportunities. Healthcare costs alone average \$24,000.(17)

Survivors of cancer in adolescence and young adulthood have a significantly higher chance of poor long term health. They have a higher long-term risk of hospitalisations and impacts to their physical health, mental health and wellbeing, compared with cancer survivors in other age groups.(18-20)

Young people with cancer often find themselves in health and support services designed for either younger children or older adults that do not understand the unique needs and challenges being faced during this stage of life.

*“It was so important to me to feel like I was not being treated as a child. But ... as a 22 year old I didn't want to feel like I was comparable with an elderly person.”*

22 year old, diagnosed with a rare cancer, QLD

If we are to ensure their survival, health, wellbeing and positive contribution to society, young people with cancer must have their unique age-related, clinical, physical, psychosocial and practical needs met. This requires specialised age appropriate care and broad, ongoing support that also reaches far beyond the healthcare setting.

## THE AUSTRALIAN YOUTH CANCER FRAMEWORK

The Australian Youth Cancer Framework articulates a national vision to 2020 and beyond for young people with cancer to achieve optimal survival, health, wellbeing and meaningful participation across all areas of life. It was developed in collaboration with a wide range of experts and national leaders in cancer and in consultation with young people and their families.

The Framework sets out priority focus areas and principles for action, while allowing for flexibility in the way that individual jurisdictions or organisations address these. The Framework is intended to guide the development of nationally comparable and locally responsive implementation plans, to be tailored to suit local contexts, systems and workforce capacity.

The Framework is intended to complement and enhance national and local efforts to improve outcomes for young people with cancer, including state-based cancer plans and related policies, health service frameworks, and action plans. The principles and priorities outlined in this document will guide implementation planning and service delivery by the Youth Cancer Services into the next decade. It will additionally provide direction for AYA cancer relevant health policy and highlights key research priorities and gaps in evidence to further the development of high quality care for young people with cancer and their families.

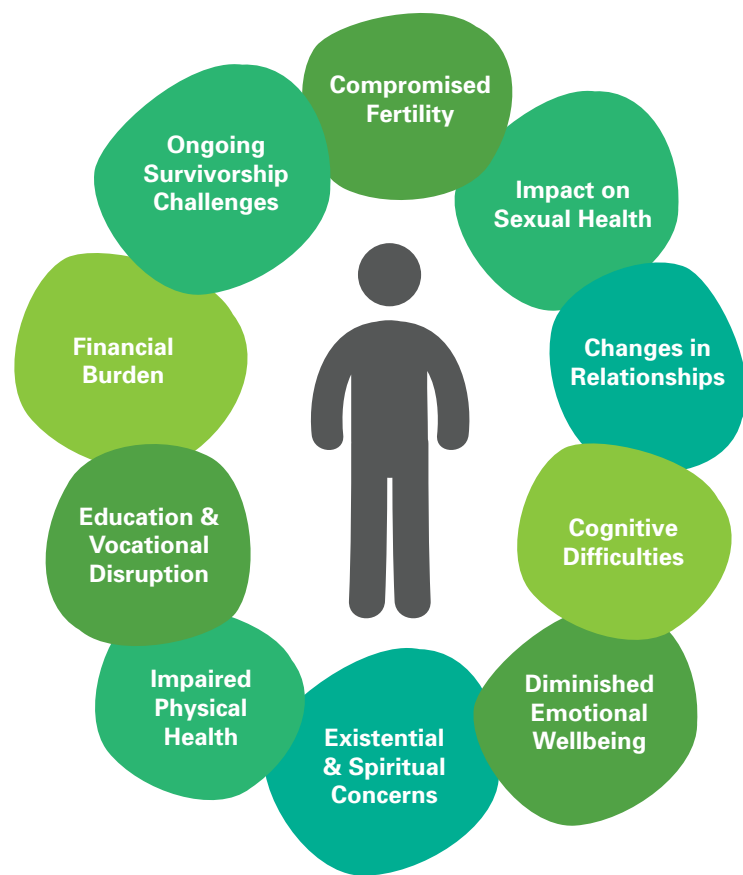


Figure 1: Challenges Faced by Young People with Cancer

## IMPROVING LIVES OF YOUNG PEOPLE WITH CANCER: AN EVOLUTION

Many significant milestones have been reached over the last decade, driving improvements in the lives of young people with cancer and their families. These achievements provide a strong foundation for the next phase of national action to improve outcomes for young Australians with cancer.

- 2007** National Service Delivery Framework, developed in partnership between Cancer Australia, CanTeen and key stakeholders, provided guidance and direction for the establishment of Youth Cancer Services (21)
- 2008 to 2010** National Service Delivery Framework published. Significant investment from the Commonwealth Government (Youth Cancer Fund) and five State Governments to establish the Youth Cancer Services across Australia
- 2011** National network of Youth Cancer Services launched. National projects established focussing on AYA cancer research, data, professional development, clinical guidance, tools and resources
- 2013** Further Commonwealth and State funding for Youth Cancer Services. National priorities continue to build effective services, research infrastructure, agreed national data collection and reporting
- 2014** Determining Research Priorities for Adolescent and Young Adult Cancer in Australia report released
- 2015** Research into survivorship, data and health professional development informed consultation with state health services, key stakeholder workshops, and expert advice to review achievements, gaps and priorities for the current Framework (22)
- 2016** Development of this Australian Youth Cancer Framework in collaboration with young people and their families, health professionals, researchers, service planners and Youth Cancer Service providers and other stakeholders

## YOUTH CANCER SERVICES IN AUSTRALIA

Funding in 2009 and the launch of a national network of Youth Cancer Services in 2011 marked a significant development in the journey towards improving the care and outcomes for young people with cancer, and their families.

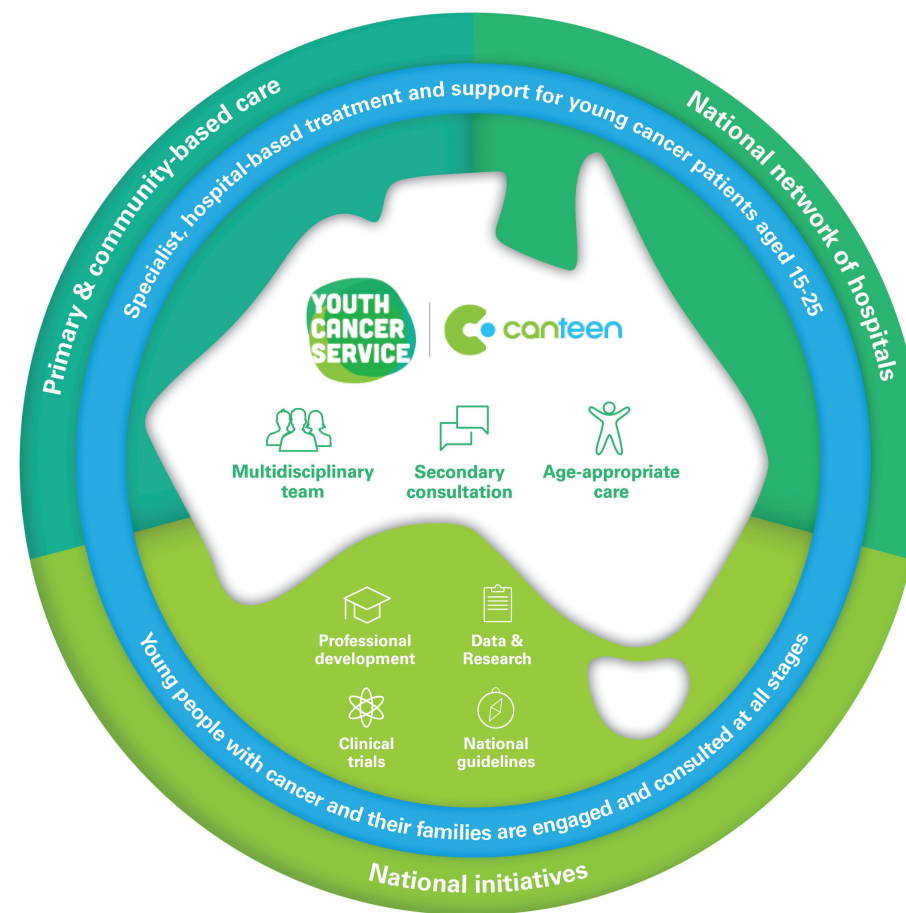
Youth Cancer Services were established in Western Australia, New South Wales, Queensland, Victoria and South Australia with outreach to Tasmania, the Northern Territory and the Australian Capital Territory to provide oversight of specialised treatment and support services for young people with cancer. In addition to providing high quality, age appropriate cancer care, Youth Cancer Services provide leadership and support to other health professionals and services. This enables young people to access high quality care, highly skilled teams, resources, research and support within cancer service networks across Australia.

*“There’s nothing worse than being stuck on a ward that caters primarily to people twice your own age. The Youth Cancer Service ensures that younger patients can be treated as part of a system that understands and accommodates for the differences between a 60 year old and a 20 year old”*

23 year old, diagnosed with acute myeloid leukemia, WA

The comprehensive model of care offered by Youth Cancer Services is consistent with national Optimal Cancer Care Pathways developed by the Australian Government’s National Cancer Expert Reference Group (Appendix 1). Specialist, age appropriate medical, nursing and allied health treatment and support is offered to young cancer patients via a national network of hospitals. Youth Cancer Services teams conduct outreach and secondary consultations with their colleagues across the health system to support best-practice care of young cancer patients, regardless of treatment setting. Each state / territory adapts this coordinated, multidisciplinary model of care to align with local needs, network structures, local frameworks and broader adult and paediatric service models. Integration with primary and community-based care is critical both in facilitating referrals into Youth Cancer Service teams and ensuring continuity of care post-treatment.

The overall program is coordinated at a national level by CanTeen. This facilitates a consistent national approach to AYA cancer care and drives critical national initiatives, including professional development, national data collection and research, improved access to clinical trials and the development and implementation of national guidelines. Importantly, young people with cancer and their families are engaged and consulted at all stages of development, implementation and delivery of the Youth Cancer Services program to ensure optimal outcomes for young Australian cancer patients.



### Federal, State & Territory Government and CanTeen co-investment National coordination by CanTeen

Figure 2: The Youth Cancer Services Program

## KEY CONCEPTS IN THE FRAMEWORK

<b>Concept of 'Family'</b>	The Framework refers to both young people and their family - families play a critical role in supporting young people through their cancer care pathway.  The concept of family is broad and unique to each individual. It can represent a broader set of close family members or carers beyond parents, such as older siblings, grandparents or a partner or spouse.
<b>Broader Social Networks</b>	Broader social networks can be very important to young people and may also include friends and / or a range of extended family members supporting them.
<b>Cancer Care Pathway</b>	Describes all stages of the cancer care experience, from prevention and diagnosis through to monitoring, survivorship issues, late effects of treatment, palliative care and life-long support within and beyond the healthcare setting.
<b>Young People with Cancer</b>	Refers to people aged 15–25 years when diagnosed with cancer.

## ENGAGING WITH YOUNG PEOPLE WITH CANCER

Young people with cancer and their families should be engaged and consulted at all stages of their health care, support and survivorship experience beyond the immediate treatment phase.

In the words of a young person with cancer::

*“Listening to the voices of young people means getting your hands dirty in the richness and uncomfortable complexity of their lives and journeying with them through all of it.”*

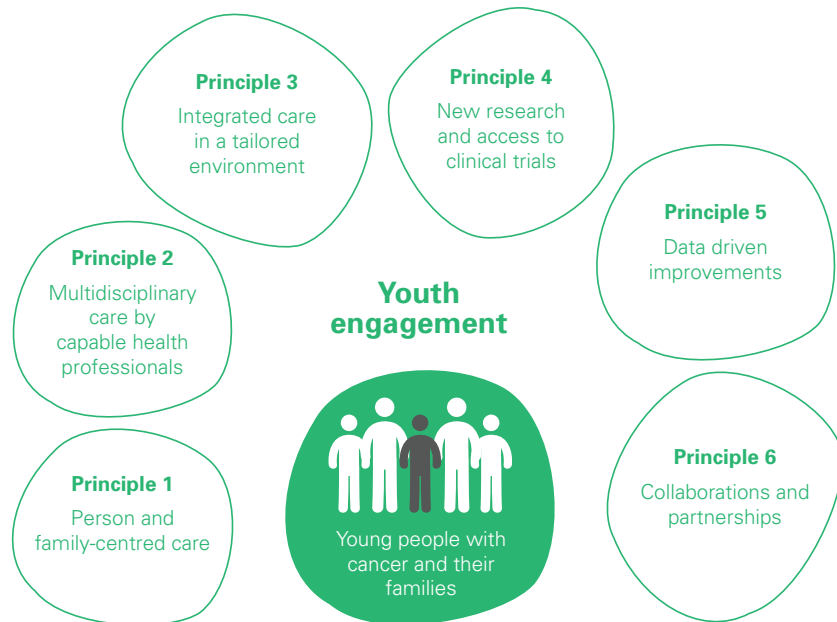
23 years old, diagnosed with embryonal rhabdomyosarcoma, NSW

## ELEMENTS OF THE FRAMEWORK EXPLAINED

<b>Vision, Goal &amp; Outcome</b>	The <b>vision</b> describes the desired future state of care and support provided to young people with cancer and their families, following successful implementation of the Framework.  The <b>goal</b> and <b>outcome</b> statements outline the intended change and impact of the Framework.
<b>Strategic Priorities</b>	The four <b>strategic priorities</b> are intended to focus current activity, targeting key areas of unmet need. They may change over time.
<b>Principles</b>	The six critical <b>principles</b> of the Framework underpin the priorities and strategic activity. They support achievement of the Framework’s vision and will remain integral to the Framework over time.
<b>Actions</b>	Under each of the principles are high-level, strategic action areas and some detailed <b>activities</b> to support delivery of the principles.
<b>Individual, Services &amp; Systems Levels</b>	<b>Actions and activities are described at three different levels:</b>  <b>Individual level</b> refers to actions to improve direct interactions between health professionals or other service providers and young people with cancer.  <b>Services level</b> refers to interventions that apply across whole services, including health services, community support and other organisations important to a young person’s wellbeing, such as including education, training, vocational, financial and counselling services.  <b>Systems level</b> refers to “bigger picture”, higher level interventions that are broader than the local service context (often national) and cut across geographic regions, services and/or sectors.
<b>What Success will Look Like</b>	Linked to the actions and activities is a suite of success indicators. These are multidimensional and intended to reflect success at a national level, rather than for individual clinicians or services.
<b>Youth Engagement</b>	Is a critical way of thinking and working to ensure that young people with cancer and their families are engaged and have a ‘seat at the table’ in all key stages of planning and implementing policy, research and service delivery.

# Australian Youth Cancer Framework

## THE FRAMEWORK AT A GLANCE



### Strategic Priorities



**Service delivery networks**



**Health professionals**

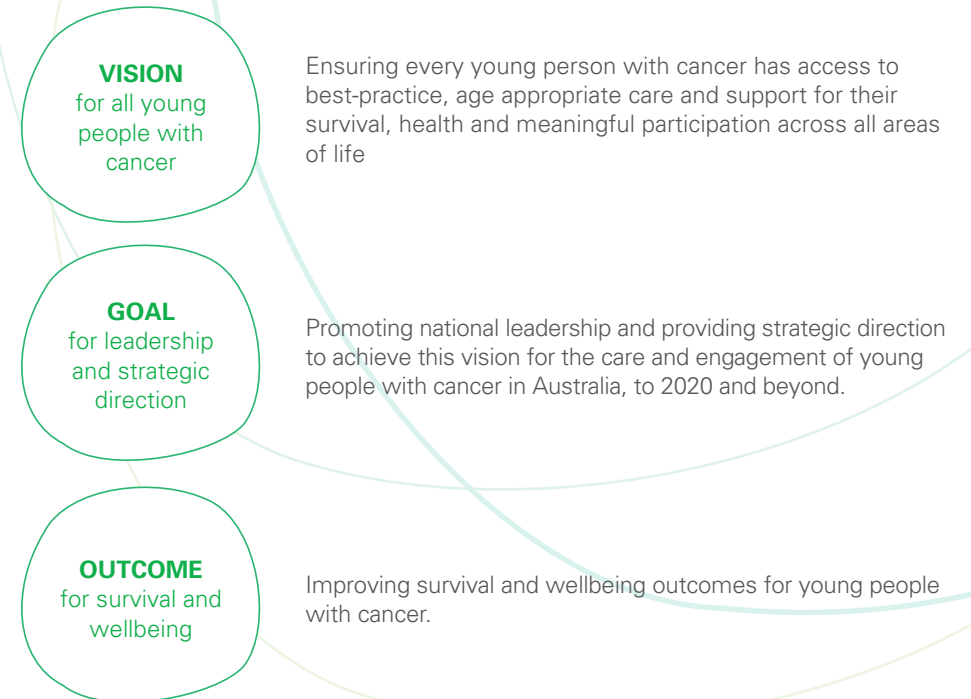


**Data & information**



**Research**

## VISION, GOAL AND OUTCOME





## STRATEGIC PRIORITIES

The Framework is underpinned by four strategic priorities, which highlight key areas of focus for the coming years. Activity associated with each strategic priority is at a varying stage of development.



### Service delivery networks

Service delivery networks across the health sector provide equity of access to best practice diagnosis, treatment and care at the right place, right time and by the right people, for all young people with cancer.



### Health professionals

Capable health professionals and a sustainable workforce provide disease-specific and supportive care and support for young people with cancer.



### Data and information

A national dataset for young people with cancer is consistently collected for monitoring, reporting and evaluation of clinical outcomes.

Data guides improvements and innovations in services and care for young people with cancer (including addressing access and equity issues).



### Research

Extend the infrastructure, mechanisms and models to support research that addresses the unmet needs of young people with cancer and builds an evidence base for best practice treatment and support.

Facilitate access for young people into clinical trials, including rapid enrolment and equity of access. Facilitate access to new technologies and treatments.

## PRINCIPLES OF THE FRAMEWORK

Youth Engagement Young people with cancer and their families are engaged and consulted at all stages	<b>Principle 1</b>	<b>Person and family-centred care</b> Young people with cancer and their families are central to best practice care, which is tailored to the person's needs.
	<b>Principle 2</b>	<b>Multidisciplinary care by capable health professionals</b> Young people with cancer receive high quality care that is provided with guidance from capable, multidisciplinary teams throughout their lives.
	<b>Principle 3</b>	<b>Integrated care in a tailored environment</b> Young people with cancer receive coordinated and seamless care from relevant health professionals and services across the cancer care pathway, within age-appropriate and respectful environments.
	<b>Principle 4</b>	<b>New research and access to clinical trials</b> Innovative research opportunities are created and access to clinical trials is equitable for young people with cancer.
	<b>Principle 5</b>	<b>Data driven improvements</b> Collection and analysis of national youth cancer data is ongoing and informs evidenced-based care delivery, appropriate resourcing and evaluation.
	<b>Principle 6</b>	<b>Collaborations and partnerships</b> Partnerships within and outside the health sector are established, nurtured and leveraged to improve outcomes for young people with cancer.

## PRINCIPLE 1: PERSON AND FAMILY-CENTRED CARE

**1** Young people with cancer and their families are central to best practice care, which is tailored to the person's needs.

*“The best way to understand the needs or concerns of any individual is to ask them... healthcare professionals can't understand the youth cancer experience because they likely haven't been in that position themselves.”*

23 year old, diagnosed with acute myeloid leukaemia, WA

Young people with cancer and their families are engaged and consulted at all stages

### Individual level

#### ACTION: Provide information and resources

Listen to, and provide young people with cancer (and their families) with responsive, age appropriate, evidence based information and resources that:

- consider their level of health literacy
- are relevant to their clinical and supportive care needs
- support timely shared decision-making across the cancer care pathway
- consider the breadth of unique challenges being faced such as those related to fertility, sexuality, relationships, cognition, education, employment, financial situation, survivorship or end-of life care

#### What success will look like

- Young people with cancer and their families feel listened to, empowered, informed, respected and supported to make decisions throughout the cancer care pathway and beyond
- Young people are aware of potential impacts of treatment to fertility and the fertility preservation options available to them
- Young people with cancer and their families report a positive patient experience and satisfaction with their care
- Young people with cancer and their families feel their own strengths, resilience and capacity has been respected and enhanced

Young people with cancer and their families are engaged and consulted at all stages

### Services level

#### ACTION: Provide personalised care

Establish processes and systems that consider the personal strengths, circumstances (including breadth of impacts on financial situation, education, employment, fertility, relationships), beliefs, culture, location, preferences and supportive needs of young people with cancer and their families.

#### What success will look like

- Delivery of cancer care (and beyond) is holistic and age appropriate for young people and their families
- The young person's specific needs and preferences are heard, documented by health professionals and appropriately responded to
- Young people receive proactive support and guidance for reengagement with education, training and employment

### Systems level

#### ACTION: Consolidate national guidance

Ensure evidence-based resources and tools are accessible, to empower young people with the knowledge they need for shared decision making about cancer care and beyond (including addressing the breadth of potentially life-long impacts of cancer and treatment), covering the specific needs of young people.

#### What success will look like

- Relevant, evidence-based information and tools are available and used to support effective person- and family-centred care to young people with cancer

## PRINCIPLE 2: MULTIDISCIPLINARY CARE BY CAPABLE HEALTH PROFESSIONALS

2

Young people with cancer receive high quality care that is provided with guidance from capable, multidisciplinary teams throughout their lives.

Young people with cancer and their families are engaged and consulted at all stages

### Individual level

#### ACTION: Provide multidisciplinary care

Ensure young people with cancer and their families:

- are overseen by a multidisciplinary team at diagnosis, with assessment and/or treatment recommendations clearly documented
- participate in shared-decision making across all stages of the cancer care pathway
- have a documented, agreed treatment plan
- receive best practice multidisciplinary care across the cancer care pathway, including disease-focussed and psychosocial care

#### What success will look like

- A documented treatment plan is agreed with every young person and their family, regularly updated for each pathway stage and communicated with all relevant health professionals
- All young people with cancer have access to all relevant treatment and supportive care options that address the unique needs of their life stage, are fully informed of their treatment options and potential associated impacts, and have input into their treatment plans

Young people with cancer and their families are engaged and consulted at all stages

### Services level

#### ACTION: Support capable, specialised networks

- Youth Cancer Services lead, advocate, organise and coordinate networks of cross-sector services and teams to provide age-appropriate, multidisciplinary care across the cancer care pathway
- Provide health service teams with access to the appropriate skill mix to provide best practice clinical treatment and psychosocial care
- Collaborate with specialist youth cancer networks and cross-sector specialists and services
- Educate and support health professionals with awareness, knowledge and relevant referral pathways required to provide best practice, age appropriate care (and referrals)

#### What success will look like

- Coordination mechanisms and processes support delivery of multidisciplinary care across the cancer care pathway and beyond health services and sectors
- Clear referral mechanisms across service and sector boundaries are established
- Unwarranted variation in care delivery is minimised
- Health professionals have access to evidence-based information and education to support best practice care (including via referral) for young people with cancer

### Systems level

#### ACTION: Ensure sustainable, capable workforce and services

- Establish multi-level strategy to develop workforce capacity (general oncology as well as specialist adolescent and young adult oncology) to ensure the cancer care needs and developmental needs of young people are met in a range of contexts
- Develop and promote an evidence-based cancer care pathway for young people with cancer, based on the Optimal Cancer Care Pathways

- Support national and international collaborations for professional development to prevent duplication, leverage existing strategies, develop a professional development framework, promote access to peer learning at the highest levels and support knowledge sharing (23)

What success will look like

- Specialist professional education programs and networking opportunities are developed, utilised and continuously improved under an AYA Oncology Professional Development Framework(23)
- Oncology health professionals have general knowledge and skills for working with young people, including respecting young people’s autonomy, understanding developmental and age-related issues, and appropriately referring to holistic care (general workforce capacity)
- Specialist adolescent and young adult oncology health professionals provide expert advice and care (specialist workforce capacity)
- Health professionals demonstrate leadership in specialised youth cancer care across disciplines and services, support and participate in continuous learning and relevant research to improve practice
- Health professionals participate in peer review opportunities and are accountable for their practice
- A range of professional colleges consider defined specialisation or sub-specialty in youth or adolescent and young adult oncology

**PRINCIPLE 3: INTEGRATED CARE IN A TAILORED ENVIRONMENT**

3

Young people with cancer receive coordinated and seamless care from relevant health professionals and services across the cancer care pathway, within age-appropriate and respectful environments.

**Individual level**

**ACTION: Provide specialised care that meets individual needs**

Provide young people with cancer and their families with:

- best practice, expert clinical care, most appropriate for the individual diagnosis
- a coordinated, seamless care plan to address their specific needs at any stage in the cancer care pathway (e.g. treatment plan, transition plan, survivorship plan)
- shared decision-making and self-management opportunities where appropriate, within their skills and capabilities

**ACTION: Support navigation of the health system**

Support young people and their families to navigate their care and needs between services, within and beyond the healthcare sector.

Support young people and their families in transition between paediatric and adult services, using a planned, supported, and appropriate approach.

What success will look like

- Young people with cancer receive the ‘right treatment and care’ by the ‘right professionals’, and the ‘right time’, taking into account their development stage and unique needs

	<ul style="list-style-type: none"> <li>• Young people with cancer have an individual care plan to support seamless, coordinated care, including clearly document transition pathways for patients with transitions across rural-metropolitan locations, public-private sectors and/ or paediatric-adult services</li> <li>• Young people with cancer are communicated with about their specific care and needs at every stage across the cancer care pathway</li> <li>• Young people and their families understand the cancer care pathway and efficiently transition between services and sectors</li> <li>• Young people and their families know who to contact to help them navigate their pathway and ensure their needs are met</li> </ul>
<b>Services level</b>	<b>ACTION: Support self-management</b> Promote and support independence through self-managed care options where appropriate (recognising existing capabilities and resilience), especially for follow-up and survivorship.
	<b>ACTION: Support age-appropriate design of facilities and services</b> Orient service improvement projects (and newly designed facilities) to the needs of young people and their families.
	<b>ACTION: Facilitate access for priority groups</b> Facilitate access for priority groups, including young people and families from: <ul style="list-style-type: none"> <li>• culturally and linguistically diverse backgrounds</li> <li>• Aboriginal and Torres Strait Islander communities</li> <li>• rural and remote locations</li> <li>• low socio-economic backgrounds</li> </ul>
	<b>What success will look like</b> <ul style="list-style-type: none"> <li>• Service networks access appropriate support, services and partnerships to facilitate access for priority groups</li> <li>• Information and tools to support self-management are developed and available to young people and their families across the cancer care pathway</li> </ul>

	<ul style="list-style-type: none"> <li>• Policies, processes and secure e-health solutions are in place to support integrated and real-time updates and information exchange during active treatment, follow-up and survivorship</li> <li>• Improved information exchange between health professionals, facilities and primary care</li> <li>• Co-design methodology and principles are utilised in the development of new facilities and spaces for young people</li> <li>• Young people from priority groups have equitable access to appropriate cancer services and support, and have equitable outcomes</li> </ul>
<b>Systems level</b>	<b>ACTION: Implement systems for information sharing</b> Implement seamless, effective systems in cancer services for managing young people with cancer across the cancer care pathway, for their life-long follow-up, surveillance, care and support.
	<b>ACTION: Provide leadership on integrated systems</b> <ul style="list-style-type: none"> <li>• Implement national and state policy and strategic plans to facilitate integrated care for young people with cancer</li> <li>• Integrate life-long care (including monitoring of late effects from treatment and through adulthood, and linkages with psychosocial support, education, employment and other contributors to long term wellbeing) into health system planning</li> <li>• Incorporate identification and removal of health system barriers (for young people with cancer) into continuous improvement cycles</li> <li>• Advocate nationally for improvements to lifelong, holistic care and services for young people with cancer</li> </ul>
	<b>What success will look like</b> <ul style="list-style-type: none"> <li>• Resourcing support for coordination and navigation is included/considered in strategic/business plans</li> <li>• Principles for age-appropriate design of Youth Cancer Services and facilities are nationally available</li> <li>• e-health and technology are used appropriately to engage with and support young people with cancer in transitions across the cancer care pathway</li> <li>• Clear cancer care pathways and models are effective for young people during active treatment and through adulthood</li> </ul>

## PRINCIPLE 4: NEW RESEARCH AND ACCESS TO CLINICAL TRIALS

4

Innovative research opportunities are created and access to clinical trials is equitable for young people with cancer.

*“The research I participated in completely shaped my way of thinking and empowered me in my survivorship - just when I needed it most.”*

23 year old, diagnosed with embryonal rhabdomyosarcoma, NSW

Young people with cancer and their families are engaged and consulted at all stages

<b>Individual level</b>	<p><b>ACTION: Raise awareness and increase informed participation</b></p> <p>Discuss opportunities to participate in research or clinical trials with young people with cancer, their families and health professionals at relevant stages of the cancer care pathway, using a shared decision-making process.</p> <p>What success will look like</p> <ul style="list-style-type: none"> <li>• Young people with cancer and their families are aware of opportunities to participate in clinical trials and research, and of the benefits associated with participation</li> <li>• Discussions and decisions about participation in research and clinical trials are documented in the young person's care plan and/or medical record</li> </ul>
<b>Services level</b>	<p><b>ACTION: Facilitate equitable access to research and clinical trials</b></p> <p>Provide effective access to national and international research and clinical trials for adolescents and young adults with cancer and advocate for increased focus on clinical trials for this population.</p> <p>What success will look like</p> <ul style="list-style-type: none"> <li>• Health services and health professionals are aware of relevant available clinical trials</li> </ul>

Young people with cancer and their families are engaged and consulted at all stages

- Access and recruitment of young people with cancer to research and clinical trials is equitable (compared with other age groups)
- National and international clinical trials are accessible and support recruitment of Australian young people with cancer

**Systems level**

**ACTION: Advocate to expand existing research**

Partner and advocate with peak research bodies, to extend the age-eligibility criteria of existing and proposed oncology research to include the adolescent and young adult population.

What success will look like

- Increased number of cancer research studies and clinical trials including 15–25 year olds in their patient cohorts

**ACTION: Inform the research agenda**

Build the evidence base to understand the needs of young people with cancer through national research groups and networks by:

- determining research gaps and priorities (addressing unmet needs, impacts, health services and health economics in research)
- undertaking high quality research into the needs of young people with cancer
- linking and partnering with international research bodies
- planning for cutting edge technologies and personalised medicine

What success will look like

- A world-class, comprehensive, sustainable and innovative national research agenda for youth cancer
- Australian young people with cancer and Australian researchers are part of a global research agenda for young people with cancer
- Research informs improvements in health systems and services

## PRINCIPLE 5: DATA DRIVEN IMPROVEMENTS

5

Collection and analysis of national youth cancer data is ongoing and informs evidenced-based care delivery, appropriate resourcing and evaluation.

*“This will be the catalyst for change in the treatment, care and support of young people living with cancer. How else can you measure improvements or target research?”*

24 year old, diagnosed with hemangiopericytoma of the brain, VIC

Young people with cancer and their families are engaged and consulted at all stages

<b>Individual level</b>	<b>ACTION: Measure and monitor patient experience</b>
	<ul style="list-style-type: none"> <li>Seek feedback from young people and their families via survey and additional feedback mechanisms, about their experiences and needs across the cancer care pathway</li> <li>Capture young people’s self-reported outcomes, to feedback into their care across the pathway</li> </ul>
	<b>What success will look like</b>
	<ul style="list-style-type: none"> <li>Patient reported outcomes and feedback data are collected and inform service improvements, research gaps and priorities</li> <li>Continuous improvement initiatives for service delivery and outcomes are informed by patient and family feedback</li> <li>Tools are available for young people to capture their clinical, survivorship and quality of life outcomes</li> <li>Cancer care pathways and plans are adjusted, based on patient feedback</li> </ul>
<b>Services level</b>	<b>ACTION: Use monitoring and evaluation data for service improvement</b>
	<ul style="list-style-type: none"> <li>Collect, review and monitor data to deliver best practice care, better understand the patient experience and reported outcomes, inform continuous improvement and minimise unwarranted clinical variation</li> </ul>

Young people with cancer and their families are engaged and consulted at all stages

- Collect and review both qualitative and quantitative data, to inform continuous improvement initiatives
- Use data reports to identify variation in care and inform service planning and resourcing gaps
- Evaluate service networks and programs, including by tracking activity against key indicators
- Promote multidisciplinary peer review of clinical practice

### What success will look like

- Data are regularly monitored, reported, reviewed and communicated to clinicians and service planners within and between jurisdictions
- Service planning priorities are identified and prioritised
- Services and programs have evaluation plans in place

### Systems level

#### ACTION: Implement national systems improvements

- Use data to inform development of national benchmarks, key indicators for quality cancer systems and research priorities for young people with cancer
- Leverage broader national and jurisdictional data initiatives and data linkage opportunities
- Use data to inform formative, process and summative evaluation questions for quality cancer systems and outcome improvements for young people with cancer

### What success will look like

- National benchmarks and measures are mapped to the cancer care pathway and monitored regularly
- A national evaluation framework and implementation plan is developed, including benchmarking against the international experience

## PRINCIPLE 6: COLLABORATIONS AND PARTNERSHIPS

6

Partnerships within and outside the health sector are established, nurtured and leveraged to improve outcomes for young people with cancer.

Young people with cancer and their families are engaged and consulted at all stages

### Individual level

#### ACTION: Tailor partnerships

- Engage health professionals in partnerships with relevant specialists across the pathway (e.g. fertility specialists, vocational specialists) to meet the needs of young people with cancer and their families.
- Engage young people with cancer and their families to be active partners in the planning and delivery of their own care, and planning for life beyond the acute cancer healthcare setting

#### What success will look like

- Tailored, person-centred care that does not duplicate effort and resources
- Documented shared decisions and referrals across the cancer care pathway

### Services level

#### ACTION: Enable effective collaborations

- Implement processes, systems and tools to enable effective collaborations, across health and cross-sector services/ jurisdictions, to meet the needs of young people with cancer.

#### What success will look like

- Collaborations create effective service delivery models to meet the needs of young people with cancer
- Feedback on services and programs is captured from multiple sources, including from young people with cancer and their families, to inform continuous improvement

### Systems level

#### ACTION: Establish strategic partnerships and collaborations

- Establish strategic partnerships and collaborations within and beyond the health sector to implement this Framework

#### What success will look like

- Partnerships and collaborations that drive and support the Framework's strategic priorities are evident across the systems that support the cancer care pathway
- Improvements in cancer control outcomes.



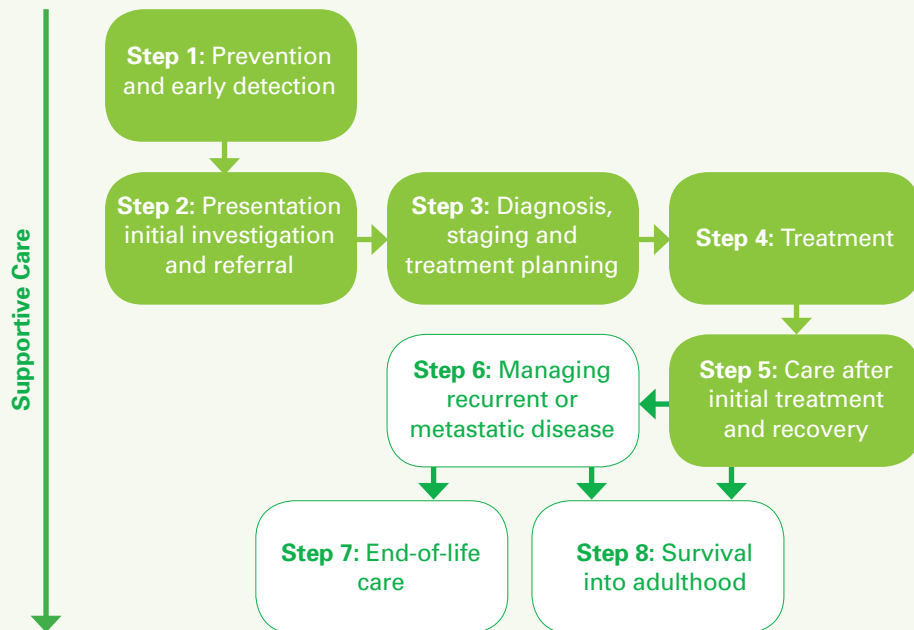
# Appendices

## APPENDIX 1: OPTIMAL CANCER CARE PATHWAY FOR YOUNG PEOPLE WITH CANCER

Optimal care pathways have been developed by the National Cancer Expert Reference Group (NCERG) for different tumour types. (24) Optimal cancer care pathways are the current nationally accepted and endorsed approach to guide best practice cancer care. They are intended to guide the delivery of consistent, safe, high quality and evidence-based care for people with cancer.

**Currently, there is no specific nationally consistent optimal cancer care pathway defined for young people with cancer. However, several of the pathways include considerations for young people.**

There are known requirements applicable for all young people that consider age appropriate care and the life-long impact of a cancer diagnosis, regardless of the cancer type. A suggested optimal cancer care pathway for young people with cancer is summarised graphically below.



## APPENDIX 2: GLOSSARY OF TERMS

The Framework glossary of terms is sourced from the online Cancer Australia Glossary, with additional references as indicated.

<b>Young People with Cancer</b>	Refers to adolescents and young adults (AYA) aged 15–25 years when diagnosed with cancer. (21)
<b>Family &amp; Broader Social Networks</b>	<p>The concept of 'family' is broad and unique to each individual. It can represent a broader set of close family members or carers beyond parents, such as older siblings, grandparents or a partner or spouse. Broader social networks can be very important to young people and may also include a partner, friend and / or a range of other family members supporting them.</p> <p>Young people affected by cancer may be dependent on their families or other carers from their broader social networks during their cancer care experience. Specific attention to these relationships is an important part of optimal cancer care. (21)</p>
<b>Cancer Care Pathway</b>	<p>Describes all stages of the cancer care journey, from prevention and diagnosis through to monitoring, survivorship issues, late effects of treatment and life-long support within and beyond the healthcare setting. It includes:</p> <ul style="list-style-type: none"> <li>• prevention and early detection</li> <li>• presentation initial investigation and referral</li> <li>• diagnosis, staging and treatment planning</li> <li>• treatment</li> <li>• care after initial treatment and recovery</li> <li>• managing recurrent or metastatic disease</li> <li>• survivorship into adulthood</li> <li>• palliative care and end-of-life care.</li> </ul> <p>Not all young people will follow every stage of the pathway.</p>
<b>Youth Engagement</b>	Is a critical way of thinking and working to ensure that young people are engaged, and have a seat at the table in all key stages of planning and implementing policy, research and service delivery.

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**Multi-Disciplinary Care** An integrated team approach to cancer care. This happens when medical, nursing and allied health professionals involved in a patient's treatment together consider all treatment options and personal preferences of the patient and collaboratively develop an individual care plan that best meets the needs of that patient.

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**Multi-Disciplinary Team** A health care team consisting of a group of experts, including doctors, nurses and other health professionals who specialise in the treatment of specific types of cancer. Most doctors who treat the common types of cancer work with experts in a multidisciplinary team. A multidisciplinary team includes all health professionals required to meet the specific needs of young people with cancer, a general practitioner, a surgeon, a medical oncologist, a radiation oncologist, a palliative care specialist, a nurse consultant, nurses, a dietician, a physiotherapist, an occupational therapist, a social worker, a psychologist, a psychologist or counsellor and a pastoral/spiritual care worker.

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**Optimal Cancer Care Pathway** Optimal cancer care pathways outline the best cancer care for specific tumour types. The pathways are designed to promote a full understanding of the patient experience to foster quality cancer care from the point of diagnosis. Each pathway identifies specific points and recommended care at each stage. Both detailed and quick reference guides have been developed for specific tumour types by the Cancer Council. (24)

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**Supportive Care** All forms of care and support, particularly forms of care that supplement clinical treatment, that aim to improve the comfort and quality of life of young people living with cancer, cancer survivors and their families.(25)

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**Survivorship** In cancer, survivorship focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to follow-up care, late effects of treatment, second cancers, and quality of life. Family members, friends, and caregivers are also part of the survivorship experience.

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**Youth Cancer Services** Specialised services of treatment and support for young people with cancer aged 15-25 (the age range is flexible in some jurisdictions). Youth Cancer Services are based in hospitals around Australia and offer treatment and support to young people with cancer. They are the only place in Australia to access cancer care designed specifically for young people aged 15-25.(26)

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## APPENDIX 3: REFERENCES

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