Australian Government
Cancer Australia

Childhood, Adolescent and Young Adult Cancer Roadmap

May 2026

Statement of Acknowledgement

Cancer Australia acknowledges Aboriginal and Torres Strait Islander people as the Traditional Custodians of Country throughout Australia. We pay our respects to Elders, past and present.

We celebrate the ongoing connections of Aboriginal and Torres Strait Islander peoples to Country, culture, community, family and tradition and recognise these as integral to health, healing and wellbeing.

Cancer Australia acknowledges great diversity among Aboriginal and Torres Strait Islander peoples, and the contribution of the many voices, knowledge systems and experiences that guide all efforts to create a culturally safe and responsive cancer system that is equitable to all.

Cancer Australia also acknowledges the ongoing work of the childhood and adolescent and young adult cancer sector to improve outcomes and experiences for children, young people and their families. In particular, we recognise and thank those with lived experience who generously gave their time, insights and energy to strengthen the Roadmap through its development.

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© Cancer Australia 2026.
ISBN Online: 978-1-74127-023-5

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Executive Summary

Each year in Australia, around 2,000 children and young people aged up to 24 years are diagnosed with cancer, with 184 children and young people dying of cancer in 2025. While survival rates are improving for majority of childhood cancers, there are some cancer types where survival remains low. Many children, adolescents and young adults (AYA) and their families experience significant long-term effects from cancer and its treatment, including physical, psychosocial, educational and financial. These effects can be compounded for priority populations, including Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse (CALD) backgrounds, those living with disability, people in lower socioeconomic groups, and those living in regional, rural and remote areas.

At the request of the Minister for Health and Ageing, Cancer Australia led the development of the *Childhood, Adolescent and Young Adult Cancer Roadmap*. The Roadmap is a high-level document designed to guide policy and investment decisions. It is underpinned by the Australian Cancer Plan (the Plan) and aims to improve outcomes and experiences for children and AYA.

It has been informed by consultation, with clinicians, researchers, jurisdictions, philanthropy and advocacy groups, and those with lived experiences. This included a Ministerial Roundtable, workshops and broad engagement with the sector on a draft of the Roadmap.

The Roadmap is supported by three pillars for action:

- **Supportive care**: Strengthening access to optimal, age-appropriate and culturally safe supportive care across the cancer continuum, including development of an Optimal Care Pathway (OCP) for children with cancer, review of the OCP for AYA, and improved guidance/resources for priority populations and families.
- **Access to emerging technologies and therapies**: Improving equitable access to emerging diagnostics and treatments, including precision medicine, novel therapies and advanced radiation techniques.
- **Research and clinical trials**: Supporting targeted, coordinated and sustainable investment in research and clinical trials, including improving equitable access, strengthening national and international collaboration, building workforce capability, and developing an integrated national data ecosystem.

Implementation of the Roadmap will be a shared responsibility across the sector, supported by ongoing monitoring and evaluation through the Plan. By aligning effort and investment around agreed priorities, the Roadmap seeks to deliver meaningful improvements in outcomes and experiences for all children and AYA affected by cancer in Australia.

Roadmap on a page

Childhood and AYA Cancer Roadmap

In line with the Australian Cancer Plan, the Roadmap aims to deliver world-class outcomes and experiences for children, adolescents and young adults with cancer by:

1. Enhancing supportive care
2. Enabling better access to emerging technologies and therapies
3. Ensuring targeted investment into research and clinical trials

Supportive care	Emerging technologies and therapies	Research and clinical trials
SC1: Equitable access to optimal care, including supportive care, for children with cancer, through the development of an *Optimal care pathway for children with cancer* and accompanying consumer guide.	**ETT1:** Embedding availability of precision medicine diagnostics as part of standard care to enable access to best practice, including emerging therapies.	**RCT1:** Equitable access to clinical trials and research for children, adolescents and young adults across the entire cancer care continuum.
SC2: Improved outcomes and experiences for adolescents and young adults, through a review of the *Optimal care pathway for adolescents and young adults with cancer* and the development of an accompanying consumer guide.	**ETT2:** Accelerated development of new therapies for children, adolescents and young adults with cancer.	**RCT2:** Coordinated investment from government, philanthropic, and private sectors to drive innovative, equity-focused research and sustainable funding.
SC3: Provision of tailored and appropriate optimal and supportive care guidance for children, AYA and their families in priority populations, including Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds, people living with disability, people in lower socioeconomic groups, and people living in rural and remote areas.	**ETT3:** Equitable access to emerging therapies and technologies.	**RCT3:** Build an integrated national data ecosystem with harmonised, comprehensive data infrastructure to support research, clinical trials and future priority-setting.

Introduction

Every year, 2,025 children and young people aged up to 24 are diagnosed with cancer[1], with over 20,000 people alive today living with the long-term effects of a childhood cancer diagnosis[2]. Although childhood cancer incidence is increasing, survival rates are also increasing, with 87% of people aged 0-19 years diagnosed with cancer living more than 5 years after their diagnosis[3]. In 2025, 183 children and young people died of cancer, with the highest mortality caused by brain cancer in children (40% of deaths), and bone cancer (22%) in adolescents and young adults.

A cancer diagnosis for a child has broad and long-reaching effects, both for the child and their families. Cancer accounts for 8,090 disability-adjusted life years (DALYs) in children and 6,806 DALYs in AYA with cancer, representing the relatively high impact of healthy life years lost when a younger person is diagnosed with cancer.

As more children and young people survive their cancer diagnoses, there is an increased need for long-term supportive care after treatment ends. For a child who survives their cancer diagnosis, long-term effects can follow them into adulthood, with survivors of childhood cancer at higher risk of adverse long-term health conditions due to their cancer and its associated treatment. These include secondary cancers and a range of serious, chronic health conditions that carry significant morbidity and mortality[4].

Additionally, rapid biological, psychological, and social development during early life means that cancer can disrupt mental health, education, financial stability, long-term health, and fertility preservation and reproductive health needs, with psychosocial concerns often going undetected or under-treated despite their significant impact on wellbeing.

For families, the effect of a childhood cancer diagnosis can be profound, including long-term psychological effects, reduced family functioning, and financial toxicity due to the need to relocate for cancer treatment, or one (or both) carers needing to stop working, as well as cancer-related expenses[5].

Many of these effects present outside traditional treatment settings, are best addressed through supportive care. Supportive care includes both wraparound care during treatment, as well as support for patients and their families after treatment, including social, emotional, spiritual and other supports.

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[1] The Australian Cancer Plan defines children as those between 0 and 14 years of age, and AYA as those between 15 and 24, while acknowledging that the effects of a cancer diagnosis early in life can follow children throughout their lives.

[2] ACCR late effects study (unpublished), Cancer Council Queensland

[3] Australian Institute of Health and Welfare (AIHW) 2025. Cancer Data in Australia; Cat. no. CAN 122. Canberra: AIHW.

[4] Cancer Council Queensland 2022. Childhood Cancer Research Program. Accessed: October 2022; https://cancerqld.org.au/research/viertel-cancer-research-centre/childhood-cancer

[5] Roser K, Erdmann F, Michel G, Winther JF, Mader L. The impact of childhood cancer on parents' socio-economic situation—A systematic review. Psycho-Oncology. 2019;28:1207–1226. https://doi.org/10.1002/pon.5088

Programs such as the Australian Cancer Nursing and Navigation Program (ACNNP) and the embedded Child and Youth Cancer Alliance's Cancer Hub (Cancer Hub) provide coordinated practical, psychosocial, and system navigation support for families affected by cancer, building on and linking existing sector and community resources and programs. Hospital-based initiatives such as Youth Cancer Service (YCS) provide specialised medical, nursing, psychosocial, and allied health treatment and support for AYA cancer patients. However, specialist support is not universally available, with referral options limited particularly in rural, regional, and remote areas.

Disparities also persist for Aboriginal and Torres Strait Islander people, who have a relatively younger age profile than the non-Indigenous population. Aboriginal and Torres Strait Islander children represent 33% of the total Aboriginal and Torres Strait Islander population and 5.7% of the total child population in Australia[6,7].

Survival differs between Aboriginal and Torres Strait Islander young people and non-Indigenous young people: 5-year relative survival is 82% for Indigenous people aged 15-24 years, and 89% for non-Indigenous people.[8] Intersectionality can compound inequities for children and AYA with cancer—for example, for those living with disability, LGBTIQA+ young people, and those experiencing social or geographic disadvantage. Tailored, culturally safe, and accessible services are needed to ensure equitable experiences and outcomes.

Improving outcomes for all children and AYA with cancer also requires dedicated research funding, particularly into cancers where survival is not improving, or where experiences are not optimal. Dedicated and sustained effort is needed to continue to innovate, develop and deliver new treatments and technologies through targeted and strategic research funding, informed by co-design with priority population groups.

Access to clinical trials has already transformed the way children access precision medicine. Outcome data from the Zero Childhood Cancer Program (ZERO), which has enrolled over 3,300 children with cancer since 2017, shows that 70% of children who received ZERO-recommended personalised treatment showed a complete or partial response, or disease stabilisation.[9,10] Recent government funding to expand this to include young people aged 19 to 25 with paediatric-type cancers, will mean that more young people diagnosed with cancer in Australia have access to the program.

As new technologies and therapies emerge, systematic evaluation and implementation are essential to ensure equitable, evidence-based cancer care is accessible for all children and

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[6] Australian Bureau of Statistics 2022. Population: Census. Accessed: October 2022; https://www.abs.gov.au/statistics/people/population/population-census/latest-release#cite-window1

[7] Australian Bureau of Statistics 2022. Aboriginal and Torres Strait Islander people: Census. Accessed: October 2022; https://www.abs.gov.au/statistics/people/aboriginal-and-torres-strait-islander-peoples/aboriginal-and-torres-strait-islander-people-census/2021

[8] Australian Institute of Health and Welfare (AIHW) (2023) Cancer in adolescents and young adults in Australia 2023, AIHW, Australian Government, accessed 3 March 2026. https://www.aihw.gov.au/reports/cancer/cancer-in-adolescents-young-adults-australia-2023/contents/summary

[9] Wong M *et al*. Whole-genome, transcriptome and methylome profiling in high-risk pediatric cancer. *Nat Med*. 2020;26(11):1742–53.

[10] Lau, L.M.S., Khuong-Quang, DA., Mayoh, C. *et al*. Precision-guided treatment in high-risk pediatric cancers. *Nat Med* **30**, 1913–1922 (2024). https://doi.org/10.1038/s41591-024-03044-0

young people with cancer. The health system is undergoing change brought about through policies on new treatments, including reforms based on the Health Technology Assessment (HTA) Policy and Methods Review recommendations. The current challenge for the cancer sector is to advance an approach to care that incorporates a willingness to engage with clinical trials (research) and emerging technologies and therapies at an earlier stage as part of care planning and improved supportive care.

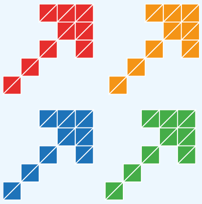
In response to this challenge, the Minister for Health and Ageing requested Cancer Australia to lead the development of the Roadmap.

Aim

This Roadmap is a high-level policy document which aims to improve experiences and outcomes for children and AYA with cancer by guiding policy and investment decision-making across the sector. Its ambitions and underlying framework are centred on three pillars identified through sector consultations and supported by clear priorities and actions.

The Roadmap directly responds to the unmet needs identified at the Childhood and AYA Cancer Ministerial Roundtable in June 2025 and has been shaped by ongoing engagement with cancer consumers, clinicians, researchers, philanthropy and jurisdictions.

Importantly, the Roadmap is intended as a practical tool for the prioritisation and coordination of funding, enabling government and philanthropic partners to maximise impact in areas of greatest need. This coordinated approach will help reduce fragmentation, avoid duplication, and ensure that research efforts are responsive to emerging challenges, ultimately delivering tangible improvements in outcomes for children and young people affected by cancer.



Ambition Statement

In line with the Australian Cancer Plan, the Roadmap aims to deliver world-class outcomes and experiences for children, adolescents and young adults with cancer by:

1. Enhancing supportive care
2. Enabling better access to emerging technologies and therapies
3. Ensuring targeted investment into research and clinical trials

The Australian Cancer Plan

As Australia’s national plan for cancer control, the Plan, and its guiding principles, strategic objectives and actions, form the foundation of the *Childhood, Adolescent and Young Adult Cancer Roadmap*. The ongoing implementation of the Plan and its foundational frameworks and initiatives will support and enable the ambitions of the Roadmap, ensuring its continued relevance and position over the 10 years of the Plan.

The Plan is designed to improve cancer experiences and outcomes for all people with cancer, regardless of their diagnosis and where they live. It calls out priority population groups that require dedicated and targeted action to improve equity of outcomes and experiences.[11] This includes children and adolescents and young adults with cancer.

Several frameworks and initiatives have been developed under the Plan that complement and align with the Roadmap, and will enable its implementation:

- Australian Comprehensive Cancer Network Framework
- Optimal Care Pathways and the National Optimal Care Pathways Framework
- National Cancer Data Framework
- National Framework for Genomics in Cancer Control
- Australian Cancer Nursing and Navigation Program

The Roadmap has been written with specific alignment with the Plan’s Strategic Objectives and Actions in mind. Mapping of the Roadmap’s Priorities to the Plan’s Strategic Objectives, and the Roadmap’s Actions to the Plan’s Actions, is provided at **Appendix A**.

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[11] Including but not limited to Aboriginal and Torres Strait Islander people; those living in rural and remote areas; Lesbian, Gay, Bisexual, Transgender, Intersex, Queer and Asexual (LGBTIQA+) people, those living with disability, and those in lower socioeconomic groups. For more information, visit the Australian Cancer Plan website.

Principles

Eight overarching principles guided the development of the Plan and underpin the Roadmap:

Person-centred

Designing initiatives and programs with, and for, all people affected by cancer. For children and AYA this also takes into consideration the needs of their parents, caregivers, family and communities.

Future-focused

Addresses both current and emerging cancer and health trends to leverage new opportunities for improved outcomes. The Plan will help drive future strategies such as this Roadmap to improve outcomes and experiences for children and AYA.

Evidence- and data-driven

Underpinned by robust evidence and ongoing data collection, using research, clinical trials, and comprehensive datasets to inform policy, monitor outcomes, and drive continuous improvement.

The Plan highlights the importance of research into the unique risk factors, cancer biology and aetiology, and survivorship issues for children and AYA, and calls for improved data collection (including national registries) to better understand and address their specific cancer burdens and outcomes.

Encompassing the cancer control continuum

Spanning the continuum of cancer care – from prevention and early detection, diagnosis and treatment, to survivorship care, palliative care, end-of-life care, and supportive care – to ensure a holistic, coordinated approach to cancer control. The Plan highlights the importance of age-appropriate prevention, early detection, timely diagnosis, and access to clinical trials for children and AYA. It also emphasises the need for specialised survivorship and supportive care, acknowledging that cancer experiences and requirements differ significantly from adults and necessitate tailored pathways and services.

Equity-focused

Equity is at the core of the Plan. It considers an intersectional and health equity approach for all priority population groups and acknowledges that people identifying as belonging to diverse populations may identify across multiple priority population groups . This intersectionality can result in compounding impacts of social, cultural, commercial and environmental determinants of health on cancer experiences and outcomes.

Strengths-based

The Plan adopts a strengths-based approach which identifies gaps and issues in the system, and builds on the strengths, opportunities, and the diversity of Australia’s population groups and our cancer care system.

All cancers

Addressing issues relevant to all cancer types, with a focus on addressing disparity of experience and outcome. The plan addresses the full spectrum of cancer types affecting children and AYA, while recognising that their cancer origin, profiles and responses to treatment often differ from adults.

Collaborative

Implementation of the Plan and Roadmap, as with their development, will encourage and involve system-wide, cross-sector, inter-jurisdictional and national collaboration. The Plan advocates for networked cancer care, providing children and young people the highest level of integrated and quality care.

Priorities

Priorities to deliver on the ambition of the Roadmap fall into three pillars: supportive care; access to emerging technologies and therapies; and research and clinical trials. These priorities are outlined here and expanded further below.

Each priority has a number of supporting Actions, with specific timeframes (2, 5 and 8 years) that will deliver on the Roadmap's ambitions. Like the Plan, implementation will be a shared responsibility of the sector. Ongoing monitoring and evaluation of the Roadmap's Actions will be facilitated through the Plan's monitoring and evaluation.

1. Supportive care

Children, young people and their families have unique supportive care needs distinct from adult populations, that require specialised action to address. This includes access to tailored information, psychological, social and educational support, and support with long-term physical and psychosocial side effects from cancer and its treatment for both children and families[12,13,14].

Actions include enhancing access to optimal and supportive care through the development of an *Optimal Care Pathway* (OCP*) for children with cancer* and associated resources (a Quick Reference Guide for health professionals and health services, and a consumer guide to support patients and their families). The existing *OCP for adolescents and young adults with cancer* and Quick Reference Guide will be reviewed and updated and a consumer guide will be developed to align with this OCP. These priorities align with the National Optimal Care Pathways Framework (OCP Framework), by providing nationally consistent, evidence-based guidance to support health professionals and services to deliver optimal care, and ensure OCPs are available to, and resonate with, people affected by cancer regardless of where they live or their personal circumstances.

It is essential to provide tailored and appropriate optimal and supportive care guidance for children and AYA in priority populations. This guidance must recognise the added complexities faced by intersectional groups, such as Aboriginal and Torres Strait Islander people, those from CALD backgrounds, people living with disability, individuals in lower socioeconomic groups, and those residing in rural and remote areas.

Activities in these priority areas would connect with and build on existing programs and services working to support children and AYA with cancer, including YCS, and other programs and services delivered through the ACNNP, such as Cancer Hub.

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[12] Larsen MH, Hansson KE, Larsen EH, Fridh MK, Petersen NN, Mellblom AV, et al. *The gap between expectations and reality: A qualitative study of psychosocial challenges of young childhood cancer survivors from the PACCS study*. European Journal of Cancer Care. 31(6):e13696.

[13] Davies J, O'Connor M, Halkett GKB, Kelada L, Gottardo NG. *"I Don't Get to Play With My Mum Anymore": Experiences of Siblings Aged 8–12 of Children With Cancer: A Qualitative Study*. Journal of Pediatric Hematology/Oncology Nursing. 2024;41(4):265-275.

[14] Children's Cancer CoLab, *Beyond the cliff: patient and family voices on childhood cancer survivorship*, Children's Cancer CoLab, 2025, https://www.cccolab.org.au/impact/survivorship-consultation-report, accessed 12 December 2025

2. Access to emerging technologies and therapies

There has been a rapid evolution of cancer diagnostics and treatments, including in genomics, immunotherapies, proton beam therapy (PBT), and Chimeric Antigen Receptor T-cell (CAR T-cell) therapy. Children and young people increasingly benefit from precision medicine, as many young people cancers present with identifiable germline or somatic variants that inform prognosis and treatment selection. Programs such as ZERO demonstrate the clinical value of genomics-informed care, however access issues to emerging technologies remain. System level reforms to Health Technology Assessment HTA processes will be critical to sustaining equitable access into the future.

Priorities include accelerating development of new therapies for children with cancer and embedding availability of precision medicine diagnostics as part of standard care to improve and enable access to emerging technologies and therapies. Access to emerging technologies is dependent on Australia's ability to leverage international networks, infrastructures and capabilities.

3. Research and clinical trials

There is a need to coordinate research investment, improve clinical trial access, and establish an integrated cancer data ecosystem to advance care for children and AYA with cancer. Research priorities must be shaped by unmet needs identified through broad consultation to ensure that research funding is targeted, innovative and aligned with Government policies and strategies as well as consumer voices.

Improving equitable access to clinical trials is a priority, which involves expanding and diversifying trial opportunities by removing unnecessary age-based eligibility barriers and developing therapies suitable for children across a range of ages. This approach also includes decentralising trials, reducing administrative burden, strengthening connections between paediatric and adult oncology services, and leveraging international clinical trials, networks and partnerships.

These priorities are aligned with Government initiatives, such as the National One Stop Shop, to streamline health and medical research for healthcare professionals, academics, health services, sponsors, and patients. Culturally safe, community-led research and inclusive trial design will also ensure all children and AYA can benefit from advances in cancer science.

Sustainable investment is essential to developing innovative models of care, strengthening the research workforce, reducing duplication across the sector and advancing equity focused research. There are also opportunities to coordinate investment by the government, philanthropic and private sectors, guided by appropriate governance groups and informed by those with lived experience. National and international partnerships will play a critical role to accelerate discovery and ensure Australia remains a global leader in childhood and AYA cancer research.

There is a need to build an integrated national data ecosystem to support high quality research, clinical trial activity and policy development. Unified data standards, improved interoperability across registries and systems, and coordinated national infrastructure are needed to enable real-time insights into incidence, outcomes and survivorship. Enhanced cancer data capability is essential to delivering personalised treatments, strengthening survivorship care and driving continuous system improvement.

Challenges and opportunities

Roadmap structure

The three pillars are interdependent by design; many foundational principles and elements such as equity, data, frameworks, workforce and access, are systemic enablers rather than pillar-specific activities. Cross-over across the pillars reflects:

- structural issues across the cancer system
- recurring stakeholder priorities raised at the 2025 Ministerial Roundtable and workshops
- areas requiring cross-sector coordination.

Workforce

The Roadmap recognises the need for a sustainable and supported workforce to deliver on its various priorities and activities. This workforce is multi-disciplinary and cross-sectoral, recognising the multi-faceted nature of care across the care continuum for children and young people with cancer.

It encompasses all professionals engaged in the care of children and young people with cancer, and their families. The workforce involves the clinical (medical, nursing and allied health professionals) and non-clinical workforce, including but not limited to researchers, clinician scientists, geneticists, genetic pathologists, community organisations, clinical trial staff and the supporting clinical trial infrastructure (including governance, ethics, and administrative staff).

Training pathways and workforce pipelines should be considered as key enablers of improved outcomes and experiences for young people with cancer.

The Plan sets a 10-year ambition of an engaged, capable, and future-focused cancer workforce that is culturally safe and responsive, well-equipped and well-supported to enable inclusive care for all Australians affected by cancer. For the childhood and AYA contexts, this involves increased training in paediatric and adolescent oncology, psychosocial care, and communication skills, as well as workforce planning to ensure sufficient specialists and support staff are available to meet the unique needs of these age groups, including in rural and remote areas.

Implementation

Like the Plan, implementation of the Roadmap will be a shared responsibility of the sector. The challenge of ensuring the availability of an appropriate workforce to implement the Roadmap, particularly to deliver optimal care in alignment with OCPs, is recognised.

Cancer Australia is working to enhance the use of the OCPs, making them more accessible for patients, families and clinicians, as well as developing ongoing monitoring to support evidence-based recommendations to enhance optimal care.

Cancer workforce development and driving OCP uptake are continuing priorities of the broader shared implementation of the Australian Cancer Plan.

Service delivery in disparate settings

Children and AYA with cancer, and their families, receive care (both immediate treatment, and ongoing survivorship care) and support in disparate settings, which will evolve as the child ages and passes from active treatment into survivorship care. These settings are wide-ranging, from specialist services within a hospital, to allied health, as well as the significant amount of support provided by community organisations. This presents multiple challenges for implementation of best-practice care, as there is a significant level of coordination and alignment required to ensure the child or AYA, and their family, receives this care.

The work to enhance OCPs and establish the Australian Comprehensive Cancer Network (ACCN) provide avenues for this alignment, as well as the priorities identified in this Roadmap.

Development of the Roadmap

In June 2025, Cancer Australia hosted a Childhood, Adolescent and Young Adult Cancer Ministerial Roundtable (the Roundtable), at the request of the Hon Mark Butler MP, Minister for Health and Ageing. The Roundtable was well-attended by representatives from across the childhood and AYA cancer sector, including, consumers, philanthropic groups, researchers, clinicians and other experts, including from children's cancer centres and research institutions.

The Roundtable revealed a consensus on the need for targeted, long-term funding for childhood and AYA cancer research and the need to enhance equitable access to optimal care and novel technologies. The outcomes from the Roundtable formed the basis for this Roadmap, and are included at **Appendix B.**

Following the Roundtable, the Minister requested that Cancer Australia lead the development a Roadmap in consultation with the sector.

Cancer Australia established an Expert Reference Group (ERG), comprising cross-sector representation (see membership at **Appendix C)** to provide advice to guide the Roadmap's development. The Roadmap's development was subsequently informed by two online consultation workshops conducted in December 2025. These workshops were attended by over 80 individuals representing consumers, philanthropic organisations, researchers, clinicians, and policy representatives from all jurisdictions and the Commonwealth.

A draft of the Roadmap was published on Cancer Australia's website in March 2026, and feedback was gathered from the sector through a consultation survey. 53 responses were received from a range of stakeholders including consumers, community organisations, clinicians, researchers and policymakers. Key themes emerging during consultation included the importance of those with lived experience including families, survivorship care, workforce, and emerging technologies and therapies.

Other relevant policies, frameworks and guidelines

- Australian Cancer Plan
- Australian Comprehensive Cancer Network Framework
- HTA Policy and Methods Review
- HTA Implementation Advisory Group Report
- Strategy for Proton Beam Therapy for cancer patients in Australia
- National Framework for Genomics in Cancer Control
- National Optimal Care Pathways Framework
- Optimal care pathway for adolescents and young adults with cancer (1st edition)
- Australian Government Response to the Senate Inquiry into Equitable access to diagnosis and treatment for individuals with rare and less common cancer
- National Health and Medical Research Strategy
- National Health Genomics Policy Framework and Implementation Plan
- National Health Reform Agreement (NHRA) Addendum
- Framework for the assessment, funding and implementation of high cost, highly specialised therapies and services
- National Cancer Data Framework

Supportive care

Introduction

Equitable access to optimal care is essential for children and AYA with cancer to achieve the best possible outcomes. Optimal cancer care includes supportive care, which is the prevention and management of the adverse effects of cancer and its treatment[15] and includes the management of the physical, emotional, practical, and spiritual needs of individuals affected by cancer and their families.

Highlighted in the Plan as a priority area to enhance person-centred care, the delivery of supportive care is shared across tertiary, primary, and community care settings. Examples of supportive care include alleviating cancer symptoms and effects of treatment (such as impacts on fertility), improving communication and navigation of services (including at key transition points), and psychosocial support for those living with and beyond cancer to improve quality of life.

Children, AYA, and their families have unique supportive care needs common across both population groups, including access to tailored information, psychological, social and educational support, and support with long-term physical and psychosocial side effects from cancer and its treatment[16,17,18].

Children and AYA can face challenges at transition points in their cancer experience[19], such as from treatment to survivorship, and between childhood, adolescent, and adult services. Improved support for patients and families at these points is needed[20], as well as programs tailored to each group's needs.

Equity of care presents differing challenges for children and AYA patients. Many AYA patients receive treatment in adult systems, which can create barriers in accessing the full range of therapies. There are also often significant gaps in AYA age-appropriate services dependent on

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[15] Multinational Association of Supportive Care in Cancer (MASCC) *What is supportive care*? MASCC 2025. https://mascc.org/what-is-supportive-care/ Accessed 8 April 2026

[16] Larsen MH, Hansson KE, Larsen EH, Fridh MK, Petersen NN, Mellblom AV, et al. *The gap between expectations and reality: A qualitative study of psychosocial challenges of young childhood cancer survivors from the PACCS study*. European Journal of Cancer Care. 31(6):e13696.

[17] Davies J, O'Connor M, Halkett GKB, Kelada L, Gottardo NG. *"I Don't Get to Play With My Mum Anymore": Experiences of Siblings Aged 8–12 of Children With Cancer: A Qualitative Study*. Journal of Pediatric Hematology/Oncology Nursing. 2024;41(4):265-275.

[18] Children's Cancer CoLab, *Beyond the cliff: patient and family voices on childhood cancer survivorship*, Children's Cancer CoLab, 2025, https://www.cccolab.org.au/impact/survivorship-consultation-report, accessed 12 December 2025

[19] Victorian Paediatric Integrated Cancer Service 2022*, Optimal care pathway for adolescents and young adults with cancer. 1st edn*, Paediatric Integrated Cancer Service, Melbourne, Australia

[20] Canteen, *AYA Vision 2033*, 2023, https://www.canteen.org.au/sites/default/files/2023-07/AYA_Vision_2033.pdf

where a patient lives. While coordinated and networked specialised cancer services provide essential care and support for children, AYA, and their families, many experience financial hardship and travel challenges due to the limited number of centres in Australia, with additional challenges faced by those seeking treatment abroad.

Survivors of childhood and AYA cancer face a high risk of long-term health complications, with more than 60% developing one or more chronic conditions after treatment[21]. Infertility is a common consequence, making fertility preservation a critical component of the standard of care. Access to these services is not routine for all patients, and costs vary significantly across jurisdictions*.

Children and AYA are priority population groups identified in the Plan, and health professionals and services must be supported and equipped to meet their unique needs and to deliver optimal cancer care. Defining and measuring optimal care for children and AYA with cancer can support the delivery of high-quality, patient-centred care, irrespective of their circumstances or where they live.

OCPs provide guidance to best practice care across the whole cancer continuum from prevention and early detection through to survivorship and end-of-life care. OCPs are used to identify and address variations in care delivery, which is particularly important for priority population groups where intersectionality can compound the impacts of cancer on experiences and outcomes.

The capacity for health services to measure optimal care will be strengthened by the identification of national quality data indicators developed through the implementation of the National Cancer Data Framework. Core indicators will be established to assess adherence to OCPs, including measurement of supportive care.

In partnership with the sector, Cancer Australia is working to transform OCPs into accessible digital products that can be tailored to improve accessibility, functionality, and increase their real-world uptake. Digitising OCPs will improve search functionality, support information navigation, and enable content across several OCPs to be viewed simultaneously as relevant to an individual (e.g. both a cancer-specific, and population-based OCP). This will support the future integration of OCPs into existing health platforms enabling health systems to embed them into routine cancer care.

Programs and services delivered through the YCS as well as through the ACNNP, such as Cancer Hub, play a complementary role in strengthening supportive care. Cancer Hub helps families with children aged 0-25 years affected by cancer by improving access to practical and emotional support, while the Youth Cancer Service provides specialist treatment and support for people aged 15-25 in major hospitals. The ACNNP helps to guide patients, families, friends,

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[21] PDQ® Pediatric Treatment Editorial Board. PDQ Late Effects of Treatment for Childhood Cancer. Bethesda, MD: National Cancer Institute. Updated 14 April 2025. Available at: https://www.cancer.gov/types/childhood-cancers/late-effects-hp-pdq. Accessed 15 December 2025. [PMID: 26389273]

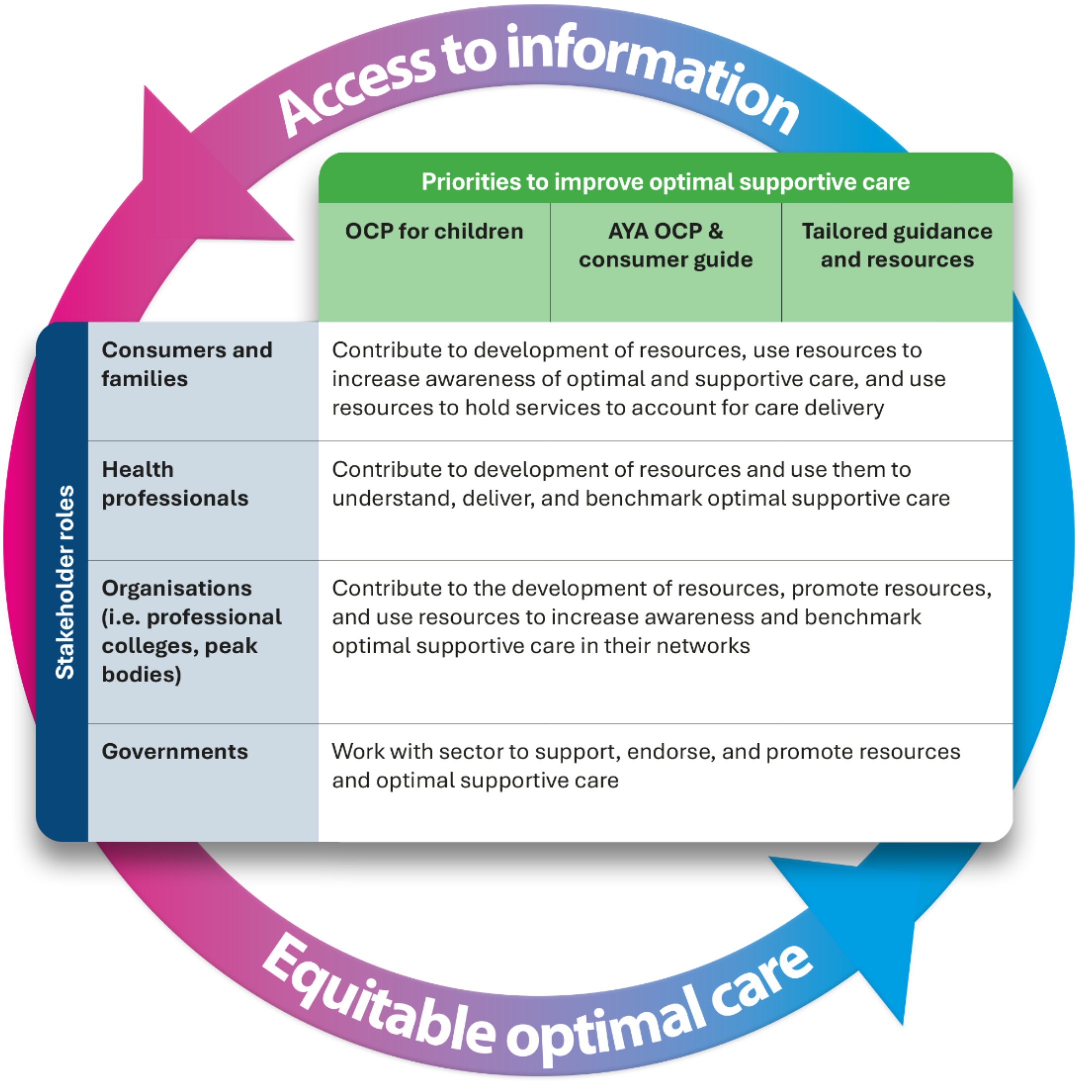
* In Time is a fertility preservation for children and young people (up to 25 years old) throughout Australia at no cost to families, available to every patient who is clinically eligible.

and carers to support patients to navigate the health system and connect with existing resources and support available across the sector.

Effective supportive care throughout the cancer continuum significantly influences survivorship experiences. Children, AYA, and their families who identify across other priority population groups, as well as the health professionals and services caring for them, require tailored, appropriate information and resourced services to enable optimal care.

Assessing and addressing gaps in optimal and supportive care will ensure more equitable, effective, and person-centred care for all children, AYA, and their families affected by cancer.

Figure 1: Access to information as an enabler of optimal care



		Priorities to improve optimal supportive care		
		OCP for children	AYA OCP & consumer guide	Tailored guidance and resources
Stakeholder roles	**Consumers and families**	Contribute to development of resources, use resources to increase awareness of optimal and supportive care, and use resources to hold services to account for care delivery		
	Health professionals	Contribute to development of resources and use them to understand, deliver, and benchmark optimal supportive care		
	Organisations (i.e. professional colleges, peak bodies)	Contribute to the development of resources, promote resources, and use resources to increase awareness and benchmark optimal supportive care in their networks		
	Governments	Work with sector to support, endorse, and promote resources and optimal supportive care		

Priorities

SC1: Equitable access to optimal care, including supportive care, for children with cancer, through the development of an *Optimal care pathway for children with cancer* and accompanying consumer guide.

SC2: Improved outcomes and experiences for AYA through a review of the *Optimal care pathway for adolescents and young adults with cancer* and accompanying consumer guide.

SC3*:* Provision of tailored and appropriate optimal and supportive care guidance for children, AYA and their families in priority populations, including Aboriginal and Torres Strait Islander people, people from CALD backgrounds, people living with disability, people in lower socioeconomic groups, and people living in rural and remote areas.

SC1: Equitable access to optimal care, including supportive care, for children with cancer, through the development of an *Optimal care pathway for children with cancer* and accompanying consumer guide.

An OCP for children with cancer would outline nationally agreed best practice for a child with cancer and their family, across the entire cancer continuum. It would be used by health professionals to deliver optimal care, health services to benchmark care, and families and carers to understand and advocate for optimal care, holding the system to account.

The OCP for children with cancer would guide the sector workforce – including clinical and non-clinical workforce, including but not limited to researchers, clinician scientists, geneticists, genetic pathologists, clinical trial staff and the supporting clinical trial infrastructure navigation, nursing, community organisations, allied health, and psychosocial teams – to understand and deliver best practice care and measure care against national benchmarks.

It would facilitate improved understanding of personalised cancer care including genomics, clinical trials, and supportive care, including survivorship, palliative care and end-of-life care. The OCP would describe optimal care to identify and support the impacts of the late effects of treatment, ensure educational and financial needs are identified, and outline transition pathways for children into adolescent and adult services. It would also address unique treatment and support needs across the cancer continuum for children and their families.

Appropriate access to palliative care services needs to be a key component of delivering the OCP. To manage side effects of treatment palliative care should be offered to children and AYA as a support to the patient as well as the family. For childhood and AYA cancers with poor prognosis, advanced care should start early to strengthen knowledge and awareness of patients and their families on what to expect during end-of-life care.

OCPs are available online and include three resources: a full OCP and Quick Reference Guide for health professionals and health services, and a consumer guide for consumers and their families. Development of an OCP for children with cancer would include these three resources. Population-based OCPs are designed to be used in conjunction with both cancer-specific and other relevant population-based OCPs to describe optimal care in line with personal circumstances.

While OCPs are developed, owned, and implemented by the sector, Cancer Australia leads the policy approach to ensure OCPs align with the Plan and OCP Framework, and are consistent with the OCP Toolkit. Development of a new OCP takes approximately 18 months, and involves the use of best practice co-design approaches, to authentically involve relevant diverse stakeholders as partners in priority setting and development.

The ACCN provides an opportunity to support implementation of the OCP. It is a virtual network that facilitates collaboration across health services and jurisdictions to deliver best practice care, as close to home as safely as possible. ACCN member services commit to deliver care in line with OCPs. The ACCN provides structure and support for networked comprehensive care, enabling children and families to transition to local health services for maintenance or surveillance once treatment ends. It fosters partnerships between local sites and tertiary centres, and where relevant, can support regional and rural clinicians to provide follow-up care and reduce travel burdens for families. It can also support linkages between local adult and paediatric services, enhancing collaboration and continuity of care between care settings.

Actions

- SC1.1: Develop an *Optimal care pathway for children with cancer*. The OCP will outline best practice care across the cancer continuum (including survivorship care); and will align with the National Optimal Care Pathways Framework. (Within 2 years)
- SC1.2: Embed the new OCP into routine cancer care across the sector through integrating the OCP into health care settings, systems and processes. (Within 5 years)
- SC1.3: Evaluate OCP use and adherence against national quality data indicators aligned with the National Cancer Data Framework and the development of the National Performance Reporting Framework. (Within 8 years)

SC2: Improved outcomes and experiences for AYA, through a review of the existing *Optimal care pathway for adolescents and young adults with cancer* and the development of an accompanying consumer guide.

The *Optimal care pathway for adolescents and young adults with cancer* (AYA OCP) is an effective tool to assist health professionals consider optimal care for AYA with cancer, not only in the context of their disease but importantly in consideration of their life stage. The AYA OCP was developed before the finalisation of the OCP Framework and does not currently include an accompanying consumer guide for use by young people affected by cancer and their families.

Undertaking a review of the AYA OCP to align with the OCP Framework would also provide an opportunity to ensure the currency of recommended care. Development of a consumer guide would complement the OCP by providing tailored guidance for AYA consumers, and align the resources available for this OCP with the suite of other OCPs.

The updated OCP and new consumer guide would address transition models for AYA patients across paediatric and adult services to support continuity of care. It would outline key steps along the cancer continuum, including recommendations for routine access to fertility preservation and guidance about supportive care, including education needs and travel requirements. The OCP would consider standardised survivorship care planning, provide recommendations for long-term follow-up, and emphasise early clinician awareness of supportive care, palliative care, survivorship, and late effects of cancer and its treatment. The OCP, including all associated resources, would link with existing services including Cancer Hub.

Cancer Australia facilitates national endorsement of all OCP resources and would support the review and management of processes for an updated OCP and new consumer guide for AYA with cancer, once developed.

Actions

- SC2.1: Commence the update of the *Optimal care pathway for adolescents and young adults with cancer* (AYA OCP) to align with the National Optimal Care Pathways Framework, and develop an accompanying consumer guide. (Within 2 years)
- SC2.2: Embed the AYA OCP and consumer guide into routine cancer care across the sector through integration of the OCP into health care settings, systems and processes. (Within 5 years)
- SC2.3: Evaluate OCP use and adherence against national quality data indicators aligned with the National Cancer Data Framework and the development of the National Performance Reporting Framework. (Within 8 years)

SC3: Provision of tailored and appropriate optimal and supportive care guidance for children, AYA and their families in priority populations, including Aboriginal and Torres Strait Islander people, people from CALD backgrounds, people living with disability, people in lower socioeconomic groups, and people living in rural and remote areas.

Equity in cancer outcomes is central to the Plan. The Plan recognises that disparities in outcomes exist between specific population groups within Australia and across jurisdictions and acknowledges that individuals can be part of multiple priority population groups, compounding complexity and disparity in accessing equitable and appropriate care.

The delivery of optimal and supportive care for children and AYA with cancer requires the consideration of intersectionality across priority populations, including Aboriginal and Torres Strait Islander people, people from CALD backgrounds, people living with disability, people in lower socioeconomic groups, and people living in rural and remote areas. Inclusion of nationally consistent approaches to care for children, and the development and adoption of co-ordinated care models across jurisdictions for AYA, will support collaboration and co-ordination across the cancer continuum to facilitate equitable, optimal care.

Co-designing tailored resources, services, and communication with communities in priority populations would help achieve improved outcomes for children and AYA with cancer, and support families through a cancer diagnosis and into palliative care and survivorship care. Supporting community members and organisations to contribute to the development and implementation of co-designed resources is key to realising this goal. Guidance should recognise and respond to the social, cultural, and geographical determinants of health that impact access to care. Co-design fosters greater engagement and innovation, builds trust, and improves understanding about how resources can be targeted for greatest impact.

Resources and educational tools and programs should be harnessed, developed, and promoted to explain and address the unique supportive care and survivorship needs of children, AYA and their families. Consideration should be given to factors that impact consumers and families across the cancer continuum, such as genomics, clinical trials, fertility preservation, school support, and care location. Communication and resources need to be accessible, age and audience appropriate, and available across multiple formats and channels. Existing programs that fund development of resources and education tools, such as the Supporting People with Cancer grant program, and the Cancer Patient Support Program, should promote alignment with OCPs.

Actions

- SC3.1: Map existing resources for children and AYA with cancer and their families in priority populations to identify gaps and to prioritise resource development. (Within 2 years)
- SC3.2: Commence the development of co-designed resources with key stakeholders from priority populations and experts across the sector, to address identified gaps. (Within 2 years)

Access to emerging technologies and therapies

Introduction

There has been a rapid evolution of cancer diagnostics and treatments, with significant potential to improve cancer outcomes and experiences for children and young people with cancer.

Emerging technologies and therapies are defined here as cancer diagnostic and therapeutic tools that are in active transition between research and established standard of care. While they are supported by maturing evidence that demonstrates clinical promise or benefit (for instance, clinical trials, real-world program data, and international consensus), they are not yet in widespread use in Australia and often require active evaluation for long-term outcomes, cost-effectiveness, optimal timing, and use in specific populations and for different diagnoses.

The Roadmap discusses precision medicine[22], and other treatment modalities such as PBT, immunotherapies and cellular therapies, including, PBT, and CAR T-cell therapy and cancer vaccines, but is designed to be broadly applicable to new technologies and therapies as they emerge.

The use of precision medicine in cancer care is transforming our approach to cancer prevention, screening, diagnosis and treatment. Advancements in novel technologies, including genomics and other 'omics', are rapidly evolving toward broader applicability for cancer patients, offering significant therapeutic potential.

The benefits of genomic testing at specific time points through the cancer journey include:

- confirming, refining or challenging a diagnosis
- determining whether a particular treatment is indicated
- determining the risk of cancer or the expected course of the disease (prognostic value)
- ongoing detection of minimal residual disease
- identifying familial cancer risk
- providing information for the person (the value of knowing).

Many pathogenic variants in early childhood cancers arise years prior to diagnosis and are either inherited from a parent or arise in early embryonic development. In children and AYA with newly diagnosed cancer, between 50% and 95% are found to have either an inherited (germline)

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[22] *Personalised medicine (also known as precision medicine) uses the knowledge of genetics, and genomics including the specific links between genes and some diseases, and between genes and the effectiveness of some medicines or treatments, to predict disease development and to influence decisions about lifestyle choices or to tailor treatment to an individual.*

or new (somatic) genetic variant and precision-guided treatment options may be available for between 25% and 65% of patients based on their variant profile.[23,24,25,26,27]

Approximately 18% of children and AYA with cancer are found to carry germline variants associated with hereditary cancer syndromes.[28,29,30] Germline variants are more common in solid tumours than blood cancers, and rare cancers are associated with the highest incidence of germline variants. Knowledge of germline variants can be used to guide treatment decisions, resulting in better outcomes than standard therapy. For siblings of children with cancer with identified germline variants, testing to identify their risk of developing cancer is also important.[31]

After a cancer diagnosis, genomic testing can help identify variants in genes that drive various cancer behaviours; from how aggressive the cancer may be, to whether it is likely to spread and how it will respond to treatment.

Children and young people have special needs and considerations in this context. Genetic and genomic testing technologies are being continually improved and becoming more precise, accessible and cost-effective. The health system is currently undergoing transition in response to the rapidly evolving field of emerging and novel treatments, including in response to the HTA Policy and Methods Review.

Research programs like ZERO have demonstrated potential for a model of care where children and young people with a cancer diagnosis receive comprehensive multiomic profiling including whole genome sequencing at diagnosis to support access to matched therapies.

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[23] Newman S et al. Genomes for Kids: The Scope of Pathogenic Mutations in Pediatric Cancer Revealed by Comprehensive DNA and RNA Sequencing. Cancer Discov. 2021;11(12):3008-3027.

[24] Wadensten E et al. Diagnostic Yield From a Nationwide Implementation of Precision Medicine for all Children With Cancer. JCO Precision Oncology. 2023;(7):e2300039.

[25] George SL et al. A tailored molecular profiling programme for children with cancer to identify clinically actionable genetic alterations. Eur J Cancer. 2019;121224- 235.

[26] Comitani et al. Diagnostic classification of childhood cancer using multiscale transcriptomics. Nat Med. 2023;29(3):656-666.

[27] Church AJ et al. Molecular profiling identifies targeted therapy opportunities in pediatric solid cancer. Nat Med. 2022;28(8):1581-1589.

[28] *Personalised medicine (also known as precision medicine) uses the knowledge of genetics, and genomics including the specific links between genes and some diseases, and between genes and the effectiveness of some medicines or treatments, to predict disease development and to influence decisions about lifestyle choices or to tailor treatment to an individual.*

[29] Villani A, et al. The clinical utility of integrative genomics in childhood cancer extends beyond targetable mutations. Nat Cancer. 2023 Feb;4(2):203-221. doi: 10.1038/s43018-022-00474-y. Epub 2022 Dec 30. PMID: 36585449; PMCID: PMC9970873.

[30] Fuentes-Bolanos NA, et al. Integrated germline and somatic molecular profiling to detect cancer predisposition has a high clinical impact in poor-prognosis paediatric cancer. Clinical Cancer Research. 2026 Feb 13.

[31] Vears DF, Ayres S, Boyle J, Mansour J, Newson AJ. Human genetics Society of Australasia position statement: predictive and presymptomatic genetic testing in adults and children. Twin Research and Human Genetics. 2020 Jun;23(3):184-9.

Priorities

ETT1: Embedding availability of precision medicine diagnostics as part of standard care to enable access to best practice, including emerging therapies.

ETT2: Accelerated development of new therapies for children and AYA with cancer.

ETT3: Equitable access to emerging therapies and technologies.

ETT1: Embedding availability of precision medicine diagnostics as part of standard care to enable access to best practice, including emerging therapies.

Embedding precision medicine diagnostics in routine cancer care for young people would ensure that diagnostic and treatment decisions are informed by the molecular characteristics of each child's cancer. This would involve integrating multidisciplinary molecular tumour boards (MTBs) into clinical pathways so that complex genomic findings can be interpreted collaboratively by oncologists, pathologists, geneticists, and other specialists. With decision support tools available at the point of care, clinicians can more confidently tailor therapies to the genomic profile of each patient, improving precision and reducing delays. New international consensus recommendations now provide a clear and practical framework for the consistent, high-quality operation of multidisciplinary MTB processes, helping jurisdictions expand equitable access to molecular diagnostics and matched therapies.[32]

ZERO commenced in 2017 as a precision medicine research program to guide potential treatment options, initially for children with poor outcome cancers and expanded in 2023 to all children diagnosed with cancer in Australia. The majority of children who received ZERO-recommended precision-guided treatments showed a complete or partial response, or disease stabilisation. Two-year progression-free survival was more than double that of children who received standard therapy (26% vs 12%), and five times higher than that of children who received an unguided treatment (a novel agent not chosen on the basis of molecular findings). [33,34,35]

The evolution of the ZERO program will require careful system integration of precision-guided care, and ongoing research to ensure it remains evidence-based. For complex, multiomic precision medicine platforms, this transition should include a highly specialised, clinical,

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[32] Molecular Tumor Boards: A Consensus Statement From the International Association for the Study of Lung Cancer. Aldea, Mihaela et al. Journal of Thoracic Oncology, Volume 20, Issue 11, 1594 - 1614. https://www.jto.org/article/S1556-0864(25)00831-7/fulltext

[33] Wong M *et al.* Whole-genome, transcriptome and methylome profiling in high-risk pediatric cancer. *Nat Med.* 2020;26(11):1742–53.

[34] https://www.zerochildhoodcancer.org.au/about/our-impact - accessed 13 February 2026

[35] Lau, L.M.S., Khuong-Quang, DA., Mayoh, C. *et al.* Precision-guided treatment in high-risk pediatric cancers. *Nat Med* **30**, 1913–1922 (2024). https://doi.org/10.1038/s41591-024-03044-0

laboratory and bioinformatics workforce to ensure quality, consistency, equity, and patient safety. Testing, interpretation and reporting should be delivered through accredited specialist centres with the requisite depth of multidisciplinary expertise, digital infrastructure and governance.

Additional principles for facilitating research-driven clinical care include:

- Research integrity, including appropriate clinical trials.
- Transparency in the costs across the precision medicine pathway, including genomic sequencing, triaging to clinical trials access and development and selection of matched therapies.
- Secure and comprehensive data sharing, including with cancer registries.
- Strong research and clinical governance to ensure best practice patient management, with consideration of independent oversight.

Enhancing national registries and systematically capturing real-world data (RWD) enables continuous evaluation of emerging technologies used in paediatric and AYA cancer care. Such datasets provide valuable insights into treatment effectiveness, safety, and long-term outcomes across diverse clinical contexts, complementing evidence generated through clinical trials.

By analysing trends in real-world use, policy makers and clinicians can refine eligibility pathways, optimise resource allocation, and identify where additional research or system supports are needed. Embedding RWD into routine practice therefore strengthens national governance of new technologies and supports iterative improvements to ensure that children and young people receive the highest quality, evidence-informed care.

Opportunities exist to link ZERO data with the Australian Childhood Cancer Registry (ACCR) and Australian and New Zealand Children's Haematology Oncology Group (ANZCHOG) data collections, and to leverage emerging data sharing mechanisms and infrastructure, to continuously expand the real-world evidence base of childhood cancer.

Continued implementation of genomics in paediatric and AYA cancer care should align with the National Framework for Genomics in Cancer Care (the Framework), which calls for equitable access to personalised cancer care for all Australians affected by cancer, as well as emerging new policies as appropriate. The Framework's implementation plan is in development in consultation with key stakeholders, and will outline ongoing and upcoming activities to achieve the actions within the Framework. Cancer Australia is working closely with the Department of Health, Disability and Ageing and Genomics Australia to support implementation of the Framework.

Actions

- ETT1.1: Support the evolution of precision medicine diagnostics from the research setting to availability as part of standard care, coupled with ongoing research to ensure it remains evidence-based. (Within 5 years)
- ETT1.2: Deliver genomics upskilling for the multidisciplinary workforce and expand access to specialist genetic counselling where required. Health services need to adapt

to embed evidence-based genomic testing, multidisciplinary and molecular tumour boards, to personalise treatment. (Within 5 years)
- ETT1.3: Enhance national registries and use of real-world data to collect outcomes and safety data on emerging technologies in children and AYA, to inform management decisions and continuous service improvement. (Within 5 years)

ETT2: Accelerated development of new therapies for children and AYA with cancer.

Timely and equitable development and implementation of emerging therapies is essential to improving outcomes for children and AYA with cancer, particularly for rare or high-risk cancers where conventional treatments may offer limited benefit. By leveraging international clinical trials, drug discovery collaborations and streamlined approval pathways, Australia can provide earlier and more equitable access to cutting-edge therapies within the country, reducing reliance on overseas treatments. Refer to *Research and Clinical Trials* for more information about international trials.

These therapies include genomically-guided small molecule and protein-degrading drugs, genome-editing therapies, immunotherapies (including cancer vaccines and cellular therapies), as well as standard chemotherapies optimised to reduce toxicity, in order to improve quality of life during and after treatment. Genomic-guided therapies enable clinicians to select interventions that directly target identifiable tumour mutations, while immunotherapies and cellular therapies provide new avenues for harnessing the ability of the immune system to attack or eliminate cancer.

Introducing treatments with lower toxicity profiles further supports not only improved survival but also long-term quality of life, reducing the physical and cognitive burden of cancer therapy. A streamlined pathway to support transition of experimental treatments to approved therapies with childhood cancer indications will help to ensure that promising therapies emerging from paediatric trials can move more seamlessly into routine care. This includes strengthening regulatory, reimbursement and translational processes that enable early and compassionate access for children when evidence demonstrates clear benefit. Embedding incentives for age-agnostic approaches to drug access recognises that biological factors, and Mechanism of Action rather than chronological age, should guide therapeutic decision-making.

It recognises the critical gap in genomic-guided and other novel treatments for children, where limited paediatric-specific evidence and slow translation of research into practice continue to constrain access to precision therapies.

Central to this approach is encouraging pharmaceutical companies and research organisations to prioritise development of treatments designed specifically for children, addressing longstanding gaps in paediatric drug development and leveraging international collaborations to provide access for Australian children to novel therapies. Industry needs to be willing to develop therapies that can be appropriately trialled in children.

In addition to improving drug access, a streamlined and economically viable pathway for the development of new drugs specifically targeting paediatric malignancies is an urgent need.

Drawing on alternative approaches to drug development is recommended to improve the availability and development of targeted, genomic-guided, and other novel therapies. An age-agnostic model which strengthens commercial incentives to drive ongoing drug development is crucial.

Achieving this ambition also relies on partnering with the workforce, medical training infrastructure and national and international partners to support a strong clinician–scientist pathway, fostering the expertise needed to translate scientific advances into meaningful improvements in patient care.

Actions

- ETT2.1: Accelerate development of genomic-guided treatments for children through prioritising paediatric cancer clinical trials in Australia and providing earlier access to international trials. (Within 5 years)
- ETT2.2: Streamline the pipeline from clinical trials to standard of care for novel targeted and genomic-guided therapies. (Within 5 years)
- ETT2.3: Establish translational hubs that link discovery, trials, and implementation of novel therapies to enable equitable access nationwide. (Within 5 years)
- ETT2.4: Partner across health services, researchers and industry, to establish clinician–scientist pathways, including through fellowships and protected research time. (Within 8 years)

ETT3: Equitable access to emerging therapies and technologies.

A coordinated national approach to patient referral for, eligibility for, and funding of emerging therapies would ensure that children and young people benefit from consistent, transparent pathways to access novel therapies, regardless of their geographic location. Current reform activities aim to strengthen national consistency and reduce variability. This should include work to refine and clarify patient eligibility pathways, ensuring that criteria are transparent, evidence-based and responsive to advances in health technologies.

By establishing shared criteria and streamlined referral mechanisms, clinicians can confidently identify eligible patients and expedite access to advanced treatments. Nationally aligned funding frameworks would also reduce fragmentation and uncertainty, helping to avoid delays caused by complex jurisdictional processes such as paediatric access to CAR T-cell therapy across jurisdictional boundaries.

The HTA Review recommended that health technology funding and assessment processes, including the level of evaluation, should be fit-for-purpose and proportionate to the level of clinical benefit, clinical need, complexity and financial risk relating to the health technology submission. Future sustainable funding models to support equitable cost-effective access require building on current funding mechanisms including Medical Benefit Schedule (MBS) items, activity-based funding under the National Health Reform Agreement (NHRA), and other state and territory arrangements.

Pathways to access emerging technologies should not be considered as an option of last resort but instead as a potential tool during care planning. Reframing emerging technologies as earlier lines of therapy based on available evidence rather than last-resort measures ensures that young people can access innovative therapies when they have the greatest potential impact.

When supported by evidence demonstrating safety and efficacy, these technologies should be considered part of the standard suite of treatment options. Positioning these technologies earlier in clinical decision-making enables optimal care, reduces treatment delays, and supports clinicians and families in making informed and timely choices about modern therapeutic options.

A hub and spoke approach allows highly specialised and complex therapies to be delivered safely within expert centres while enabling preparatory and follow-up care to occur closer to home. This structure helps ensure that children receive the benefits of specialist expertise for high-risk or technically intensive components of care, while minimising the burden of repeated long-distance travel.

By strengthening the capability of local services to provide coordinated follow-up care, the model will reduce wait times, support continuity of care, and enhance the overall experience for families navigating intensive treatment journeys.

When travel is unavoidable—such as accessing radiation facilities available only in certain centres—it should be integrated into early care planning rather than treated as an emergent, last-minute necessity. Care teams must consider the child's clinical stability and wellbeing to ensure that travel occurs at a time when they can safely endure transport and benefit from the required intervention.

Early planning also allows families to prepare logistically and emotionally, and ensures that treatment sequencing, supportive care and accommodation needs are managed proactively. This approach avoids unsafe or distressing last-resort transfers and promotes safer, more effective treatment delivery.

As identified in the *Strategy for Proton Beam Therapy for cancer patients in Australia*, service delivery planning must account for patients who require higher levels of support, such as paediatric, AYA patients and their carers, given the specific factors that impact their cancer experience, including developmental stage of life at diagnosis and educational disruption. Similarly, a strengthened national approach to administering CAR T-cell therapy in Australia is required, to ensure equitable, cost-effective access for cancer patients.

Robust digital infrastructure is essential for ensuring timely access to specialist expertise and emerging health technologies. Virtual multidisciplinary team meetings allow experts from across the country to collaborate in real time, supporting rapid decision-making for complex cases. Telehealth enables families to access specialist consultations without the challenges of travel, while e-referrals streamline care coordination and reduce administrative delays. Scalable digital systems create more flexible, responsive clinical pathways and ensure that children and young people can receive expert-guided care without avoidable delays tied to geography or service availability.

Actions

- ETT3.1: Implement reform activities which focus on clarifying eligibility, referral and funding to enable timely, equitable access to emerging technologies such as genomic-guided and cellular therapies. (Within 2 years)
- ETT3.2: Improve clinical coordination and embed models of care to enable improved access, underpinned by digital infrastructure. (Within 5 years)

Research and clinical trials

Introduction

Research investment must be targeted, innovative, and focused on areas of greatest need in alignment with the strategic objectives of the Australian Cancer Plan, National Health and Medical Research Strategy, and the National Cancer Data Framework.

The Roadmap calls for targeted investment in research that addresses the full spectrum of care, recognising the unique needs of young people and building on existing priority-setting initiatives. At Roadmap consultation workshops, consumer advocates, philanthropic representatives, and clinicians highlighted initial research priorities for childhood and AYA cancer, including novel therapies, low-incidence paediatric tumours, and studies focused on neurocognition, endocrine, and cardiac health. There was also significant support for research to improve supportive and survivorship care.

A central ambition is to develop a blueprint for achieving equity in access to clinical trials and research for all child and AYA cancer patients and survivors, regardless of geography, background, or circumstance.

Significant disparities persist in trial participation and research representation, particularly for AYA patients and for priority populations such as Aboriginal and Torres Strait Islander children and young people, those living in rural and remote areas, and those from CALD backgrounds.

There are opportunities to address inequities by promoting inclusive research design, expanding trial access through decentralised and virtual models, and supporting culturally safe, community-led research. By embedding equity measures and prioritising research that reflects the lived experiences of diverse populations, the Australian Government aims to ensure that all young Australians benefit from advances in cancer care.

Priorities

RCT1: Equitable access to clinical trials and research for children and AYA across the entire cancer care continuum.

RCT2: Coordinated investment from government, philanthropic, and private sectors to drive innovative, equity-focused research and sustainable funding.

RCT3: Build an integrated national data ecosystem with harmonised, comprehensive data infrastructure to support research, clinical trials and future priority-setting.

RCT1: Equitable access to clinical trials and research for children and AYA across the entire cancer care continuum.

Equity is key in childhood and AYA cancer research to make participation in clinical trials fairer and easier to improve outcomes and experiences. Achieving equity in childhood and AYA cancer research requires addressing ongoing barriers such as limited trial availability, small cohort sizes, and arbitrary age restrictions, that restrict participation and impact outcomes, especially for AYA. Key implementation considerations include:

- ensuring sustainability and futureproofing of the research workforce through early career pathways, including fellowships and support for early and mid career researchers
- reviewing age eligibility criteria and ethical considerations, noting implications for informed consent (age cut-offs are often considered arbitrary from a cancer biology perspective)
- carefully considering the length of trials, particularly where travel is required
- exploring pathways for enrolment at clinical trial sites other than a patient’s primary treatment location
- adaptive and tailored research and trial designs, including for rare and less common cancers
- streamlining ethics, governance, and administrative requirements to facilitate enrolment and retention and to reduce the burden on patients, families and carers
- building stronger links and coordination between paediatric centres and adult oncology services to leverage research and expand access to clinical trials
- harnessing international collaborations and clinical trials to expand cohort sizes and access to cutting-edge research.

These strategies in research and clinical trials will guide improvements to standard of care for children and AYA with cancer (See ‘Pillar 1’ for further information on optimal care).

Improving access to culturally safe care and awareness of available research is key for Aboriginal and Torres Strait Islander children and AYA, and for those with CALD backgrounds. Accountability for the delivery of culturally safe care and promotion of research will be shared across research institutions, clinical trial sites and broader health networks. Importantly, cultural safety should be embedded in research design from the outset and through all stages of research, including in trial information and resources and the ownership, collection and use of data.

Research in this field should take a strengths-based approach, recognising and building on the capabilities and resilience within communities. This pillar calls for a commitment to prioritising research led by, or designed through, genuine partnership with Aboriginal and Torres Strait Islander and CALD communities.

Children and AYA with cancer in rural and remote areas face unique barriers to research participation and access to innovative treatments. While tele-trials and virtual care models are more common, their application across the cancer care continuum and cancer types remains inconsistent. Decentralising trials, empowering regional leadership, expanding tele-trials, enrolment at local sites and for follow-up, and providing appropriate travel and accommodation support are critical. Sustaining rural and remote trial sites also depends on adequate infrastructure and ongoing workforce support.

An engaged and capable workforce will be equally critical to implement the strategies under this pillar. Through appropriate training and supports for early- and mid-career researchers, the research sector can respond to the unique needs of young people with cancer across Australia, including in adult centres that treat AYA – moving away from adult care and research models that are not tailored to young people.

A flexible, sustainable and future-focused workforce is needed, including an adequate supply of specialists in emerging areas, such as genomics and genetic counselling services as part of multidisciplinary care. Across Australia the research sector needs to be itself diverse and aware of the need for, and supported to provide, culturally safe and responsive care to all young Australians and their families.

Ultimately, clinical trials and research seek to expand the provision of safe, innovative treatments that meaningfully improve cancer outcomes and experiences for patients and their families. Bridging gaps in the translation of research into clinical practice requires a well-supported system to ensure therapies from paediatric clinical trials move efficiently into routine care. This includes strengthening regulatory, reimbursement and translational processes that enable early and compassionate access for children when evidence demonstrates clear benefit.

For example, embedding incentives for age-agnostic approaches to drug access recognises that biological factors, rather than chronological age, should guide therapeutic decision-making. Building a clear pathway from discovery to delivery will help accelerate the uptake of transformative treatments and care for young Australians affected by cancer.

Actions

- RCT1.1: Address barriers that limit participation in clinical trials – including limited trial availability, small cohort sizes, and arbitrary age restrictions by leveraging international partnerships and clinical trials. (Within 8 years)

- RCT1.2: Embed cultural safety in all stages of research design and delivery - including trial information, consent processes, and the collection, use and governance of data – prioritising research led by, or developed in genuine partnership with, Aboriginal and Torres Strait Islander communities and CALD communities. (Within 5 years)
- RCT1.3: Expand access through decentralised and flexible trial delivery models, including regional leadership, tele-trials, local enrolment and follow-up, and appropriate travel and accommodation support. (Within 5 years)
- RCT1.4: Strengthen workforce capability by providing training, improved career pipelines and support so the research sector can meet the unique needs of children and AYA with cancer, including AYA treated in adult centres. (Within 2 years)

RCT2: Coordinated investment from government, philanthropic, and private sectors to drive innovative, equity-focused research and sustainable funding.

Greater sustained investment in research enables continued advancement and translation of innovative cancer care across the continuum, from prevention and early detection to diagnosis, treatment, survivorship and end-of-life care.

Research and investment must be distributed across the continuum and remain responsive to emerging needs, gaps in care, and new evidence; including innovative models that strengthen psychosocial and supportive care and survivorship[36]. Importantly, improving cancer outcomes for young people is a shared responsibility, requiring coordinated effort across research, policy and service delivery sectors.

Government, philanthropic, and private sectors will work together towards coordinated, sustainable research efforts, reducing duplication and fragmentation. Competitive funding targets resources to research with the highest potential or most urgent need.

Longer term funding will ensure ongoing improvement in patient care, supports long-term projects, and safeguards against financial instability, building a resilient research system and sustainable workforce. To support translation into practice, this coordination should align with existing funding pathways, including MBS-funded diagnostics, funding for public hospital care under the NHRA, and Pharmaceutical Benefits Scheme (PBS) arrangements where therapies are applicable.

Aligning investment with these established structures will support consistent national implementation. Through government and funding partner grant programs, investment strategies can be pivoted, new funding models can be tested, and the broader research sector can adapt to changing priorities, ensuring funding is responsive and aligned with national health priorities.

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[36] Survivorship guidelines from the Children's Oncology Group and Scottish Intercollegiate Guidelines Network can inform Australian models.

Guided by expert advisory groups, the Australian Government will define research priorities that address unmet need, respond to emerging challenges, and align with the broader cancer control agenda. Philanthropic and research organisations will be trusted partners in pooling funding and amplifying targeted investments.

Those with lived experience will be engaged throughout, building on existing priority-setting efforts to avoid duplication and better reflect their perspectives[37]. Collaboration will be encouraged, with clear governance to ensure transparency and accountability. This partnership is synergistic, with guidance from consumer, philanthropic and research sectors also shaping future priorities and funding models.

Partnering with organisations led by or supporting priority population groups will be central in advocating for research priority-setting for all young Australians, including continued engagement with funding partners, such as the Australian Brain Cancer Mission Partners.

Research prioritisation under the Roadmap must consider intersectionality, understanding the needs of those identifying across multiple priority populations. Leadership and partnership with Aboriginal and Torres Strait Islander community organisations will be invaluable to support community-based research, Indigenous data sovereignty and integrate culturally safe care.

International partnerships, in line with the National Health and Medical Research Strategy, will be critical to address shared health priorities, monitor global risks and opportunities, and position Australia as a leader in improving cancer outcomes and experiences for young people. Global collaboration will expedite scientific discovery and improve access to emerging technologies and international research, including participation in clinical trials overseas, or through sites in Australia.

The national Multi-site Collaborative Cancer Clinical Trials Groups (CTGs) are critical to leveraging international clinical trials for enrolment in Australia. These groups are partially funded by Cancer Australia under the Support for Cancer Clinical Trials (SCCT) program to build their capacity to design investigator-initiated and industry-independent cancer clinical trials. ANZCHOG, as the CTG for childhood and adolescent cancers in Australia and New Zealand, is a key facilitator for national access to international childhood and AYA clinical trials in Australia and abroad.

Actions

- RCT2.1: Direct responsive and evidence driven research and investment to gaps in care and emerging needs across both the full cancer care continuum and research spectrum – including discovery, translational, clinical and health services research. (Within 2 years)
- RCT2.2: Strengthen coordinated, sustainable research efforts by aligning government, philanthropic and private sector investment to reduce duplication and fragmentation. (Within 2 years)
- RCT2.3: Define research priorities that address unmet need, respond to emerging challenges and align with the broader national cancer agenda. (Within 2 years)

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[37] For instance, priorities already identified through the Australian Child and Adolescent Cancer Priority Setting Partnership.

- RCT2.4: Build and maintain international research and clinical trial partnerships, consistent with the National Health and Medical Research Strategy, to address shared priorities, monitor global risks and opportunities, and support professional development for Australia's research workforce and leadership in improving outcomes for children and AYA with cancer. (Within 5 years)

RCT3: Build an integrated national data ecosystem with harmonised, comprehensive data infrastructure to support research, clinical trials and future priority-setting.

Establishing an integrated cancer data ecosystem is essential to the timely, nationally consistent, high-quality collection, management, and use of childhood and AYA health and population data – including both cancer and non-cancer data. Improved data informs future policy, research, and priority-setting, addressing unique clinical pathways, treatment protocols, and survivorship challenges faced by children, AYA, and their families. Comprehensive and high-quality data informs understandings of incidence, treatment outcomes and long-term effects, in turn supporting tailored treatments, interventions and equitable access to care.

Comprehensive national reporting for children and AYA is hindered by existing data gaps, variable timelines, availability and incomplete information. Addressing these challenges requires nationally consistent definitions, targeted efforts to identify and prioritise gaps,[38] and consideration of data requirements needed to support applications to the Medical Services Advisory Committee (MSAC) and Pharmaceutical Benefits Advisory Committee (PBAC).

The National Cancer Data Framework (Data Framework) strongly aligns with this priority, and outlines the strategic direction for addressing these challenges. Implementation of the Data Framework's strategic objectives will establish a mature performance reporting system, leveraging existing frameworks to create a data ecosystem that is sustainable, accessible, integrated and fit for purpose.

This involves improving interoperability of data stored in population-based and clinical quality registries, hospital systems, and research datasets, including enabling secure and routine linkage of genomic data with clinical e-health records, and monitoring of outcomes across the cancer care continuum. This also involves the establishment of a comprehensive national performance monitoring system to enable benchmarking and reporting of child and AYA data across the cancer care continuum,[39] including measurement of adherence to OCPs.

Currently, childhood and AYA data are collected across numerous population-based and clinical quality registries, and clinical trial platforms. Cancer Council Queensland has established the ACCR Advisory Group which seeks to reduce duplication across the sector.

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[38] NCDF, Strategic Objective 2: A sustainable and fit-for-purpose data system – 2.2.1, 2.5.1, 2.6.2, 2.6.3.

[39] National Cancer Data Framework (NCDF), Strategic Objective 1: A mature performance reporting system – Action 1.3.1.

Future efforts should focus on strengthening the centralised collection, management, and use of childhood and AYA data.

Potential mechanisms to reduce duplication may include either a national data platform supporting data capture, trial matching, and outcome reporting, or greater harmonisation among existing data collections, stored centrally for researcher access, using data linkage systems such as the National Health Data Hub. Other potential options include development of a collaboration of national data custodians to streamline legal, ethical and compliance processes through mutual recognition and other means.[40]

Success of any shared infrastructure requires state and territory and sector-wide commitment and coordination, including collaboration with key bodies such as the Australian Institute of Health and Welfare and the Australian Cancer Data Alliance. Implementing such approaches will facilitate greater data sharing, support enduring linkages to jurisdictional and federal data assets,[41] and enable the identification of gaps and fragmentation, reducing barriers to treatment innovation and improving psychosocial outcomes.

Inconsistent data definitions and collection methods across public and private assets contribute to this fragmentation, disproportionately affecting Aboriginal and Torres Strait Islander and CALD children and AYA, as well as other priority groups. Data systems should include consistent, culturally safe equity measures, adhering to the principles of Indigenous Data Sovereignty.

By acknowledging the intersectionality between children and AYA populations, as outlined in the Plan, we can better represent them and address their unique age-related needs, which supports more personalised health decisions.

Expanding survivorship data, including broader outcome measures and psychosocial indicators, will help address longitudinal impacts, particularly during the transition from childhood to AYA, and improve the collection of AYA specific data for paediatric-type cancers. Data collection should also be supported by appropriate education for children and AYA, and their families to ensure active, informed, and ongoing consent for the collection, use, and storage of their health data.[42]

Establishing an integrated data ecosystem through unified minimum data standards, and improved linkage and monitoring arrangements informed by consistent performance measures align with the short[43] and long-term[44] actions of the Data Framework. This supports the improved collection of child and AYA data and enables personalised treatments and informing real-time decision-making for children and AYA affected by cancer.

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[40] NCDF, Strategic Objective 3: User-centred, integrated and accessible data – Action 3.3.2

[41] NCDF, Strategic Objective 3: User-centred, integrated and accessible data – Action 3.3.4.

[42] Canteen AYA Vision 2033 report, Strategic Priority 1: Deliver evidence-based, data-driven and research-led AYA-specific models of care aligned with Optimal Care Pathways – Action 1.4.3.

[43] NCDF, Short-term actions – 1.3.1, 2.2.1, 2.5.1, 2.6.1, 2.6.2 and 3.3.4.

[44] NCDF, Long-term Actions – 1.3.2 and 2.3.4.

Actions

- RCT3.1: Establish an integrated national data ecosystem using unified minimum data standards with improved linkage and monitoring, reducing duplication for the enhanced timely collection and use of consistent, high-quality childhood and AYA cancer and non-cancer data. (Within 8 years)
- RCT3.2: Reduce duplication by strengthening centralised data collection and coordinated management of child and AYA data across registries, clinical systems and research platforms. (Within 5 years)
- RCT3.3: Embed consistent, culturally safe equity measures in data systems, in line with Indigenous Data Sovereignty principles. (Within 5 years)
- RCT3.4: Implement unified minimum data standards, and improved linkage and monitoring arrangements, in line with the National Cancer Data Framework, to support tailored treatments, real-time decision-making, and improved quality and completeness of childhood and AYA cancer data. (Within 8 years)
- RCT3.5: Researchers receiving government funding should incorporate the collection of data meeting the minimum data standards in their research projects, and follow open science principles to make data available in a safe way to support further research and analysis. (Within 2 years)

Appendices

Appendix A: Childhood AYA Cancer Roadmap Priorities and Actions mapped against Australian Cancer Plan Strategic Objectives and Actions

Roadmap Priorities and Actions	Aligning ACP Strategic Objectives and Actions
SC1: Equitable access to optimal care, including supportive care, for children with cancer, through the development of an *Optimal care pathway for children with cancer* and accompanying consumer guide.	• **Strategic Objective 2: Enhanced Consumer Experience.** • **Strategic Objective 3: World Class Systems for Optimal Care.** • **Strategic Objective 4: Strong and Dynamic Foundations.**
SC1.1 Develop an *Optimal care pathway for children* with cancer. The Optimal Care Pathway will outline best practice care across the cancer continuum (including survivorship care); and will align with the National Optimal Care Pathways Framework. (Within 2 years)	**2.2.1** Develop a national framework for and implement integrated multi-channel, multidisciplined navigation models that ensure the right support at the right time for every consumer across the cancer continuum **2.2.2** Improve availability of co-designed, tailored information and care for consumers to improve health literacy and reduce cancer-related stigma. **3.2.1** Develop and implement a national framework that standardises the development, update, evaluation and uptake of Optimal Care Pathways (OCPs), including for priority population groups. **3.2.4** Develop and refine integrated care models to maximise access to high-quality, timely and evidence-based palliative and end of-life care, including voluntary assisted dying
SC1.2: Embed the new OCP into routine cancer care across the sector through integrating the OCP into health care settings, systems and processes (Within 5 years).	**2.2.3** Support health services to provide co-designed, culturally responsive resources to enable healthcare providers to communicate respectfully with consumers. **2.5.1** Evaluate, adapt and scale nationally integrated care navigation models across the cancer care continuum **3.2.4** Develop and refine integrated care models to maximise access to high-quality, timely and evidence-based palliative and end of-life care, including voluntary assisted dying

Roadmap Priorities and Actions	Aligning ACP Strategic Objectives and Actions
	3.5.1 Integrate Optimal Care Pathways (OCPs) as routine cancer care using a monitoring and evaluation system that links the implementation of OCPs to patient outcomes and experience.
SC1.3: Evaluate OCP use and adherence against national quality data indicators aligned with the National Cancer Data Framework and the development of the National Performance Reporting Framework (Within 8 years).	**3.2.1** Develop and implement a national framework that standardises the development, update, evaluation and uptake of Optimal Care Pathways (OCPs), including for priority population groups. **4.5.1** Design and embed patient reported experience and patient reported outcomes into national performance monitoring and reporting for all providers, to assess services for all population groups and establish an evidence base.
SC2: Improved outcomes and experiences for AYA, through a review of the *Optimal care pathway for adolescents and young adults with cancer* and the development of an accompanying consumer guide.	• **Strategic Objective 2: Enhanced Consumer Experience.** • **Strategic Objective 3: World Class Systems for Optimal Care.** • **Strategic Objective 4: Strong and Dynamic Foundations.**
SC2.1: Commence the update of the *Optimal care pathway for adolescents and young adults with cancer* (AYA OCP) to align with the National Optimal Care Pathways Framework and develop an accompanying consumer guide (Within 2 years).	**3.2.1** Develop and implement a national framework that standardises the development, update, evaluation and uptake of Optimal Care Pathways (OCPs), including for priority population groups.
SC2.2: Embed the AYA OCP and consumer guide into routine cancer care across the sector through integration of the OCP into health care settings, systems and processes (Within 5 years).	**2.2.2** Improve availability of co-designed, tailored information and care for consumers to improve health literacy and reduce cancer-related stigma. **3.5.1** Integrate Optimal Care Pathways (OCPs) as routine cancer care using a monitoring and evaluation system that links the implementation of OCPs to patient outcomes and experience.
SC2.3: Evaluate OCP use and adherence against national quality data indicators aligned with the National Cancer Data Framework and the development of the National Performance Reporting Framework (Within 8 years).	**3.2.1** Develop and implement a national framework that standardises the development, update, evaluation and uptake of Optimal Care Pathways (OCPs), including for priority population groups.

Roadmap Priorities and Actions	Aligning ACP Strategic Objectives and Actions
	4.5.1 Design and embed patient reported experience and patient reported outcomes into national performance monitoring and reporting for all providers, to assess services for all population groups and establish an evidence base.
SC3: Provision of tailored and appropriate optimal and supportive care guidance for children, AYA and their families in priority populations, including Aboriginal and Torres Strait Islander people, people from CALD backgrounds, people living with disability, people in lower socioeconomic groups, and people living in rural and remote areas.	• **Strategic Objective 1: Maximising Cancer Prevention and Early Detection.** • **Strategic Objective 2: Enhanced Consumer Experience.** • **Strategic Objective 6: Achieving Equity in Cancer Outcomes for Aboriginal and Torres Strait Islander people.**
SC3.1 Map existing resources for children and AYA with cancer, and their families in priority populations to identify gaps and to prioritise resource development. (Within 2 years)	**1.2.5** Strengthen health literacy for Aboriginal and Torres Strait Islander people through co-designed health promotion and lifestyle strategies for cancer prevention. **2.2.3** Support health services to provide co-designed, culturally responsive resources to enable healthcare providers to communicate respectfully with consumers.
SC3.2 Commence the development of co-designed resources with key stakeholders from priority populations and experts across the sector, to address identified gaps (Within 2 years).	**1.2.5** Strengthen health literacy for Aboriginal and Torres Strait Islander people through co-designed health promotion and lifestyle strategies for cancer prevention. **2.2.3** Support health services to provide co-designed, culturally responsive resources to enable healthcare providers to communicate respectfully with consumers. **6.2.1** Embed Aboriginal and Torres Strait Islander voices in policymaking on cancer prevention, care delivery and standards through leadership, collaboration and co-design processes.
ETT1: Embedding availability of precision medicine diagnostics as part of standard care to enable access to best practice, including emerging therapies.	• **Strategic Objective 1: Maximising Cancer Prevention and Early Detection.** • **Strategic Objective 4: Strong and Dynamic Foundations.** • **Strategic Objective 5: Workforce to Transform the Delivery of Cancer Care.**
ETT1.1: Support the evolution of precision medicine diagnostics from the research setting to availability as part of standard care, coupled with ongoing research to ensure it remains evidence based. (Within 5 years)	**4.5.3** Explore and test innovative approaches to health service funding models to address areas of need, and system improvement, in cancer care.

Roadmap Priorities and Actions	Aligning ACP Strategic Objectives and Actions
ETT1.2: Deliver genomics upskilling for the multidisciplinary workforce and expand access to specialist genetic counselling where required. Health services need to adapt to embed evidence-based genomic testing, multidisciplinary and molecular tumour boards, to personalise treatment. (Within 5 years)	**1.5.4** Develop a policy framework for genomics in cancer control across the cancer care continuum. **5.5.2** Assist the sector to support all cancer care practitioners to work at the top of their scope of practice, increase retention and ensure ongoing access to continuing professional development.
ET1.3: Enhance national registries and use of real-world data to collect outcomes and safety data on emerging technologies in children and AYA to inform management decisions and continuous service improvement. (Within 5 years)	**4.2.1** Develop an agreed national cancer data framework to improve accessibility, consistency and comprehensiveness of integrated data asset. **4.5.1** Design and embed patient reported experience and patient reported outcomes into national performance monitoring and reporting for all providers, to assess services for all population groups and establish an evidence base.
ETT2: Accelerated development of new therapies for children and AYA with cancer.	• **Strategic Objective 1: Maximising Cancer Prevention and Early Detection.** • **Strategic Objective 3: World Class Systems for Optimal Care.** • **Strategic Objective 4: Strong and Dynamic Foundations.** • **Strategic Objective 5: Workforce to Transform the Delivery of Cancer Care.**
ETT2.1: Accelerate development of genomic-guided treatments for children through prioritising paediatric cancer clinical trials in Australia and providing earlier access to international trials. (Within 5 years)	**1.5.4** Develop a policy framework for genomics in cancer control across the cancer care continuum **4.2.2** Ensure targeted and innovative research investment into areas of unmet and emerging need; and improve clinical trial design and equitable access.
ETT2.2: Streamline the pipeline from clinical trials to standard of care for novel targeted and genomic guided therapies (Within 5 years)	**1.5.4** Develop a policy framework for genomics in cancer control across the cancer care continuum. **4.2.2** Ensure targeted and innovative research investment into areas of unmet and emerging need; and improve clinical trial design and equitable access.
ETT2.3: Establish translational hubs that link discovery, trials, and implementation of novel therapies to enable equitable access nationwide (Within 5 years)	**Action 3.5.2** Establish an Australian Comprehensive Cancer Network (ACCN) to ensure connectivity and sharing of expertise between Comprehensive Cancer Centres, other cancer services, regional hospitals, community and primary

Roadmap Priorities and Actions	Aligning ACP Strategic Objectives and Actions
	care. The establishment of an ACCN will increase equity of access across services for all patients, deliver cancer care close to home, and monitor evidence-based system performance. **4.2.2** Ensure targeted and innovative research investment into areas of unmet and emerging need; and improve clinical trial design and equitable access. **4.5.2** Expand access to digitally enabled cancer care to improve equity and access to quality cancer care, particularly in regional, rural and remote areas.
ETT2.4: Partner across health services, researchers and industry, to establish clinician–scientist pathways, including through fellowships and protected research time. (Within 8 years)	**5.5.2** Assist the sector to support all cancer care practitioners to work at the top of their scope of practice, increase retention and ensure ongoing access to continuing professional development.
ETT3: Equitable access to emerging therapies and technologies.	• **Strategic Objective 1: Maximising Cancer Prevention and Early Detection.** • **Strategic Objective 2: Enhanced Consumer Experience.** • **Strategic Objective 3: World Class Systems for Optimal Care.** • **Strategic Objective 4: Strong and Dynamic Foundations.**
ETT3.1 Implement reform activities which focus on clarifying eligibility, referral and funding to enable timely, equitable access to emerging technologies such as genomic-guided and cellular therapies. (Within 2 years)	**1.5.4** Develop a policy framework for genomics in cancer control across the cancer care continuum. **2.2.1** Develop a national framework for and implement integrated multi-channel, multidisciplined navigation models that ensure the right support at the right time for every consumer across the cancer continuum. **4.5.2** Expand access to digitally enabled cancer care to improve equity and access to quality cancer care, particularly in regional, rural and remote areas. **4.5.3** Explore and test innovative approaches to health service funding models to address areas of need, and system improvement, in cancer care.

Roadmap Priorities and Actions	Aligning ACP Strategic Objectives and Actions
ETT3.2 Improve clinical coordination and embed models of care to enable improved access, underpinned by digital infrastructure. (Within 5 years)	**2.2.1** Develop a national framework for and implement integrated multi-channel, multidisciplined navigation models that ensure the right support at the right time for every consumer across the cancer continuum. **3.5.3** Improve equitable access to evidence-based, innovative models of integrated multidisciplinary care across the cancer continuum **4.5.2** Expand access to digitally enabled cancer care to improve equity and access to quality cancer care, particularly in regional, rural and remote areas. **4.5.4** Expand the use of technology and virtual care to increase access for Aboriginal and Torres Strait Islander people and to support communities across the cancer care continuum.
RCT1: Equitable access to clinical trials and research for children and AYA across the entire cancer care continuum.	• **Strategic Objective 3: World Class Systems for Optimal Care.** • **Strategic Objective 4: Strong and Dynamic Foundations.** • **Strategic Objective 5: Workforce to Transform the Delivery of Cancer Care.** • **Strategic Objective 6: Achieving Equity in Cancer Outcomes for Aboriginal and Torres Strait Islander people.**
RCT1.1: Address barriers that limit participation in clinical trials — including limited trial availability, small cohort sizes, and arbitrary age restrictions by leveraging international partnerships and clinical trials. (Within 8 years)	**3.2.3** Implement innovative, evidence-based and cost-effective models of care for people living with and beyond cancer. **4.2.2** Ensure targeted and innovative research investment into areas of unmet and emerging need; and improve clinical trial design and equitable access.
RCT1.2: Embed cultural safety in all stages of research design and delivery - including trial information, consent processes, and the collection, use and governance of data - prioritising research led by, or developed in genuine partnership with, Aboriginal and Torres Strait Islander communities and CALD communities. (Within 5 years)	**4.2.4** Establish Aboriginal and Torres Strait Islander-led initiatives which strengthen Indigenous Data Sovereignty and governance of cancer data. **5.5.1** Implement a cancer care workforce pipeline that meets demand for optimal cancer care, with diversity measures in training, recruitment and talent management to ensure the cancer workforce represents the diversity of patient populations.

Roadmap Priorities and Actions	Aligning ACP Strategic Objectives and Actions
	5.5.3 Routinely integrate cultural safety training programs for cancer service providers, including through community-based partnerships with priority population groups. **6.2.2** Strengthen collaboration with service providers, regulatory authorities and the Aboriginal and Torres Strait Islander cancer workforce to establish clear accountability for culturally safe care and compliance with national standards.
RCT1.3: Expand access through decentralised and flexible trial delivery models, including regional leadership, tele-trials, local enrolment and follow-up, and appropriate travel and accommodation support. (Within 5 years)	**4.2.2** Ensure targeted and innovative research investment into areas of unmet and emerging need; and improve clinical trial design and equitable access **4.2.3** Identify opportunities to improve equitable cancer care through the digital health ecosystem **4.5.2** Expand access to digitally enabled cancer care to improve equity and access to quality cancer care, particularly in regional, rural and remote areas. **4.5.3** Explore and test innovative approaches to health service funding models to address areas of need, and system improvement, in cancer care **4.5.4** Expand the use of technology and virtual care to increase access for Aboriginal and Torres Strait Islander people and to support communities across the cancer care continuum
RCT 1.4: Strengthen workforce capability by providing training so the research sector can meet the unique needs of children and AYA with cancer, including AYA treated in adult centres. (Within 2 years)	**5.5.1** Implement a cancer care workforce pipeline that meets demand for optimal cancer care, with diversity measures in training, recruitment and talent management to ensure the cancer workforce represents the diversity of patient populations. **5.5.2** Assist the sector to support all cancer care practitioners to work at the top of their scope of practice, increase retention and ensure ongoing access to continuing professional development.
RCT2: Coordinated investment from government, philanthropic, and private sectors to drive innovative, equity-focused research and sustainable funding.	• **Strategic Objective 1: Maximising Cancer Prevention and Early Detection.** • **Strategic Objective 4: Strong and Dynamic Foundations.**

Roadmap Priorities and Actions	Aligning ACP Strategic Objectives and Actions
	• **Strategic Objective 5: Workforce to Transform the Delivery of Cancer Care.** • **Strategic Objective 6: Achieving Equity in Cancer Outcomes for Aboriginal and Torres Strait Islander people.**
RCT2.1 Direct responsive and evidence driven research and investment to gaps in care and emerging needs across both the full cancer care continuum and research spectrum - including discovery, translational, clinical and health services research. (Within 2 years)	**1.2.4** Undertake ongoing assessment of the evidence for risk-based, cost-effective population cancer screening. **4.2.2** Ensure targeted and innovative research investment into areas of unmet and emerging need; and improve clinical trial design and equitable access. **4.5.3** Explore and test innovative approaches to health service funding models to address areas of need, and system improvement, in cancer care
RCT 2.2 Strengthen coordinated, sustainable research efforts by aligning government, philanthropic and private sector investment to reduce duplication and fragmentation. (Within 2 years)	**4.2.2** Ensure targeted and innovative research investment into areas of unmet and emerging need; and improve clinical trial design and equitable access. **6.2.2** Strengthen collaboration with service providers, regulatory authorities and the Aboriginal and Torres Strait Islander cancer workforce to establish clear accountability for culturally safe care and compliance with national standards.
RCT2.3 Define research priorities that address unmet need, respond to emerging challenges and align with the broader national cancer agenda. (Within 2 years)	**4.2.2** Ensure targeted and innovative research investment into areas of unmet and emerging need; and improve clinical trial design and equitable access.
RCT2.4 Build and maintain international research and clinical trial partnerships, consistent with the National Health and Medical Research Strategy, to address shared priorities, monitor global risks and opportunities, and support professional development for Australia's research workforce and leadership in improving outcomes for children, adolescents and young adults with cancer. (Within 5 years)	**4.2.2** Ensure targeted and innovative research investment into areas of unmet and emerging need; and improve clinical trial design and equitable access. **5.5.2** Assist the sector to support all cancer care practitioners to work at the top of their scope of practice, increase retention and ensure ongoing access to continuing professional development.
RCT3: Build an integrated national data ecosystem with harmonised, comprehensive data infrastructure to support research, clinical trials and future priority-setting.	• **Strategic Objective 4: Strong and Dynamic Foundations.**

Roadmap Priorities and Actions	Aligning ACP Strategic Objectives and Actions
RCT3.1 Establish an integrated national data ecosystem using unified minimum data standards with improved linkage and monitoring, reducing duplication for the enhanced timely collection and use of consistent, high-quality childhood and AYA cancer and non-cancer data. (Within 8 years)	**4.2.1** Develop an agreed national cancer data framework to improve accessibility, consistency and comprehensiveness of integrated data assets. **4.5.1** Design and embed patient reported experience and patient reported outcomes into national performance monitoring and reporting for all providers, to assess services for all population groups and establish an evidence base.
RCT 3.2 Reduce duplication by strengthening centralised data collection and coordinated management of child and AYA data across registries, clinical systems and research platforms. (Within 5 years)	**4.2.1** Develop an agreed national cancer data framework to improve accessibility, consistency and comprehensiveness of integrated data assets. **6.2.2** Strengthen collaboration with service providers, regulatory authorities and the Aboriginal and Torres Strait Islander cancer workforce to establish clear accountability for culturally safe care and compliance with national standards.
RCT 3.3 Embed consistent, culturally safe equity measures in data systems, in line with Indigenous Data Sovereignty principles. (Within 5 years)	**4.2.1** Develop an agreed national cancer data framework to improve accessibility, consistency and comprehensiveness of integrated data assets. **4.2.4** Establish Aboriginal and Torres Strait Islander-led initiatives which strengthen Indigenous Data Sovereignty and governance of cancer data.
RCT 3.4 Implement unified minimum data standards, and improved linkage and monitoring arrangements, in line with the National Cancer Data Framework, to support tailored treatments, real-time decision-making, and improved quality and completeness of childhood and AYA cancer data. (Within 8 years)	**4.2.1** Develop an agreed national cancer data framework to improve accessibility, consistency and comprehensiveness of integrated data assets. **4.5.1** Design and embed patient reported experience and patient reported outcomes into national performance monitoring and reporting for all providers, to assess services for all population groups and establish an evidence base.
RCT 3.5 Researchers receiving government funding should incorporate the collection of data meeting the minimum data standards in their research projects and follow open science principles to make data available in a safe way to support further research and analysis. (Within 2 years)	**4.2.1** Develop an agreed national cancer data framework to improve accessibility, consistency and comprehensiveness of integrated data assets. **4.2.2** Ensure targeted and innovative research investment into areas of unmet and emerging need; and improve clinical trial design and equitable access.

Appendix B: Childhood Adolescent and Young Adult Cancer Ministerial Roundtable – Summary

Topic 1: Considerations for the delivery of optimal care for children and AYA with cancer

- Agreement on the need for an Optimal Care Pathway (OCP) for children with cancer, which considers intersectionality and the needs of priority populations.
  - While there is an OCP for Aboriginal and Torres Strait Islander people, it is focused on adults and would need tailoring for First Nations children with cancer.
- Due to centralised services and treatment models, clinical care for children is generally consistent, but with gaps in supportive care. The supportive care and survivorship needs of children and AYA with cancer are unique (e.g. mental, education and social needs). This and the workforce required to support these needs should be recognised in the OCP. Effective supportive care throughout cancer treatment and beyond impacts survivorship experiences.
- While there is an OCP for adolescents and young adults with cancer, AYA with cancer can face challenges during treatment due to the transition between children's and adult services.
- Consistent and nationally linked data is essential for measuring and benchmarking care delivered against Optimal Care Pathways.
- Optimal care for children living in rural and remote areas needs to balance the benefits of centralised care (concentrated expertise and consistent care) with the benefits of localising treatment and follow-up care closer to home.

Topic 2: Childhood and AYA cancer research

- Unmet needs
  - Survivorship and supportive care research is needed for this population, given the physical and psychosocial impacts of childhood and AYA cancer can extend into adulthood.
  - Clinical trials for AYA, where the number of trials and enrolment is generally lower than for childhood cancer and can be restricted for AYA with paediatric-type cancers.
  - Implementation and development of novel therapies for children, including immunotherapy, cell therapies, and treatments with lower toxicity to improve quality of life during and after treatment.
- Other areas of research needed include: neurocognitive outcomes, prevention and early detection (particularly for AYA populations, e.g. cervical cancer vaccination), cancer biology and aetiology.
- Research mechanisms
  - Value of partnerships between government and philanthropy to enable greater overall investment and reduce fragmentation and duplication across the sector. Setting research priorities as a sector enables investments to be better targeted towards areas of unmet need.
  - Opportunity for Australia to lead international collaborative clinical trials.
- Equitable access to clinical trials

- Need to support priority population access to clinical trials, including Aboriginal and Torres Strait Islander children and AYA, and children and AYA from culturally and linguistically diverse (CALD) backgrounds. In particular, ensure communication materials are appropriate for the age level of participants, and cultural and language background of participants and their families.
- The need for more cancer services outside of metropolitan areas with greater capacity and capability to deliver clinical trials, recognising the need for data on how many children are treated outside metropolitan areas.
- Consider access to clinical trials for children and AYA with very rare cancers.
- Travel support and funding for children and AYA to access clinical trials, as most support offered by governments and charities is for general treatment, even though best practice is for children to access treatment through clinical trials.
- Enhanced participation in international clinical trials, and Australia being seen as a destination for clinical trials.

Appendix C: Expert Reference Group – Membership

Professor Dorothy Keefe PSM MD (Chair)	Chief Executive Officer, Cancer Australia
Mr Duncan Young	First Assistant Secretary, Evidence and Research Division, Department of Health, Disability and Ageing
Ms Margaret Fitzherbert	Chief Executive Officer, Children’s Cancer Foundation
Professor Michelle Haber AM	Executive Director, Children's Cancer Institute
Dr Michael Osborn	Chief Cancer Officer, South Australian Comprehensive Cancer Network (SACCaN)
Professor Nick Gottardo	Head, Department of Paediatric and Adolescent Oncology and Haematology, Perth Children’s Hospital and former Chair, Australian & New Zealand Children’s Haematology/Oncology Group (ANZCHOG)
Mr Owen Finegan	Chief Executive Officer, The Kids' Cancer Project
Dr Richard Mitchell	Director, Kids Cancer Centre, Sydney Children's Hospital
Ms Siona Hardy	Chief Executive Officer, Canteen