

SUBMISSION

Australian Cancer Plan consultation draft

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Introduction

About Canteen Australia

Canteen Australia is a national, non-government organisation that supports young people aged 12-25 impacted by cancer, whether their own diagnosis or that of a family member.

Canteen works by having young people at the centre of everything we do. Our counselling services, individualised support, and youth-friendly resources help young people develop skills and resilience to cope with cancer. Young people can join our 24/7 online community or attend multi-day evidence-based programs or recreation days to connect with peers with similar cancer experiences.

There are Canteen service hubs across Australia, in capital cities and major regional centres as well as the [Canteen Connect](#) online service. Canteen also [supports parents of young people](#) through their cancer diagnosis with free expert advice, counselling and facilitating connections to other parents in similar situations.

Canteen also administers the multidisciplinary [Youth Cancer Services](#), supporting young patients in hospitals across Australia. Guided by our internationally regarded research into the impact of cancer and best-practice care, Canteen understands how cancer is different in a young person's world.

Canteen also works with [Camp Quality](#) and [Redkite](#) to provide [Cancer Hub](#) for families. Cancer Hub is a digital first point of call for families with children aged 0-25 years when cancer impacts the family. Cancer Hub ensures the practical and emotional support needs of the family are identified and individual family members are connected to counselling and services by skilled cancer navigators.

Canteen provides services to, and advocates for, a diverse range of people. Above all we represent young people and their families who are impacted by cancer.

More information about Canteen and the work we do can be found at www.canteen.org.au

About this submission

We congratulate the Australian Cancer Plan Taskforce on the draft Australian Cancer Plan (the draft Plan) and the comprehensive consultation processes. Consideration of Canteen's [previous submission](#) and this opportunity for final comment on the draft Plan are appreciated.

This submission aligns with [Canteen's strategic priorities](#) around treatment and support for those with cancer. Accordingly, the submission focuses on treatment and support for young people and families impacted by a cancer diagnosis.

Overall, Canteen supports the vision, guiding principles and six strategic objectives in the draft Plan as well as the strong focus on equity and social justice. We also believe

that the identified goals and actions for each objective will contribute to achievement of the 10-year ambitions under each strategic objective. This submission suggests additional considerations for some of the goals and actions, as relevant.

Canteen would particularly like to highlight support for these aims of the draft Plan:

- Achieving equitable outcomes for marginalised groups, especially Aboriginal and Torres Strait Islander peoples.
- Recognising and responding to the unique characteristics and needs of adolescents and young adults impacted by cancer.
- Person-centred care in a system that respects and values diversity and is responsive to the needs and preferences of individuals.
- Smooth navigation through the health system, especially at transition points, for all patients, carers and families, including timely access to psychosocial services and long-term survivorship support.
- Effective use of data and information.
- Collaboration and knowledge sharing across the cancer control sector.

We welcome acknowledgment that implementation will be a shared responsibility with joint efforts from the entire cancer control sector. Effective and sustainable cancer care should utilise the resources and expertise of all sectors, including:

- Consumers (patients, carers, families, consumer advocates and peak bodies)
- State, territory and federal health systems
- Community controlled healthcare
- Private healthcare
- Research and academia
- Not-for-profit cancer care.

The not-for-profit health and social care sector has expertise in psychosocial support services and the interface with clinical cancer care. Effective implementation of the draft Plan should include genuine partnerships with the community not-for-profit cancer care sector, leveraging the sector's influence and expertise in a collaborative response to cancer in Australia.

Priority population groups

We are pleased that adolescents and young adults (AYAs) are recognised in the draft Plan as a priority population group. The unique characteristics and needs of AYAs are well described and the desired future state for AYAs aligns with Canteen's vision, incorporating key aspects including:

- equity in access and outcomes
- comprehensive data
- person-centred navigation and transition support
- inclusive long-term survivorship models.

It is great to see implementation considerations for priority populations groups included in the draft Plan. We have offered some additional implementation considerations for AYAs in this submission.

AYA Vision 2033

As noted on page 25 of the draft Plan, Canteen is developing a national vision document that will guide the focus and action on priority issues for Australian AYA cancer care for the next 10 years. We are now undertaking final consultation with Youth Cancer Services and will launch the vision in 2023.

We have recently updated the name of the document from AYAVision2032 to **AYA Vision 2033**, reflecting that this 10-year strategic plan commences in 2023. Therefore, please update to the new name in the ACP and anywhere else it appears.

For more information about AYA Vision 2033 please see our [website](#).

Strategic Objectives

Strategic Objective 1: Maximising Cancer Prevention and Early Detection

10-year ambition: A cancer control system that seeks to eliminate racism, proactively reduces cancer risk and supports all Australians to access personalised, evidence-based cancer prevention and early detection strategies.

We support the 10-year ambition statement for Strategic Objective 1, although it may be strengthened with a minor wording change.

A system that supports Australians to access prevention and detection is a good goal, however we suggest the word 'enables' instead of 'supports' which is more consumer focused and more ambitious. An enabled consumer is not only supported with prevention and screening services that are available, affordable and safe; they also have the confidence, skills, knowledge and ability to ask for and access these services (Batterham, Osborne, McPhee, Mech, & Townsend, 2017).

Goals and actions

1.1.1. Deliver cancer prevention and health promotion activities, including healthy lifestyles, immunisation, and population screening participation, co-designed and tailored to a range of settings.

Implementation of prevention and health promotion activities for young people must consider the unique characteristics of people in this key life development stage. Young people are establishing independence, exploring sexuality and identity, developing lifestyle habits and behaviours, and finding their place.

Specific implementation considerations for AYAs may include:

- Programs targeting healthy lifestyle behaviours, such as not smoking or vaping, good nutrition, and physical activity.
- Health promotion and health literacy programs that target and empower AYAs and complementary programs that target parents of young people
- Targeted screening programs for AYAs at higher risk of cancer due to genetic predisposition or other factors.

1.2.3. Implement new, and improve existing, evidenced-based, risk-stratified cancer screening programs.

Implementation of screening programs for young people should consider:

- Screening for inherited or acquired genetic mutations that increase cancer risk.
- Delivery of informative resources for young people and their families and carers on the importance of risk-stratified cancer screening programs.

Strategic Objective 2: Enhanced Consumer Experience

10-year ambition: People affected by cancer are partners in culturally safe, equitable and responsive cancer care, and health services and systems are trusted and supported for optimal experience, quality of life and cancer outcomes.

We strongly support the 10-year ambition statement for Strategic Objective 2 and agree that the statement is suitably ambitious.

Goals and actions

We support the identified priority areas for action in the ACP in relation to Strategic Objective 2:

- Consumer navigation
- Supportive care
- Information and support
- Communication.

All these areas are priorities for AYAs who have specific needs as they deal with cancer during a significant period of social, emotional and cognitive development and change. The distinct challenges for AYAs are well described on page 53 of the draft Plan.

We strongly support the focus on health literacy in this section, and the associated 2-year goals. Improving health literacy is an important goal for cancer care as it is associated with better health outcomes and better value healthcare (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). Health literacy development is important during the AYA developmental stage. Skills and knowledge about how to access, understand and apply health information provide long term benefits for individuals, families, healthcare providers and health systems.

2.1.1. Develop a national framework for and pilot integrated multi-channel, multi-disciplined navigation models that ensure the right support at the right time for every consumer across the cancer continuum.

AYAs have specific navigation needs and therefore development and implementation of a national navigation framework must consider:

- Enabling young people to actively participate in codesign.
- People's navigation needs beyond clinical navigation and how to incorporate those in a comprehensive national navigation model. [Cancer Hub](#) is a strong example of using federal and not-for-profit resources effectively and efficiently to simplify access for children/young people (0-25 years) and their family members to appropriate support services for a diversity of needs.
- Support for parents and siblings of children and young people with cancer and for children and young people whose parents have been diagnosed with cancer needs to be part of a national navigation response such as Cancer Hub.
- Needs of patients, carers and families who are transitioning from paediatric to youth or adult cancer services, including navigating the complexities of clinical trial access across paediatric and adult services (Ellis, et al., 2022).
- Support needs of young people navigating the transition from dependence on their parents or guardians, to the autonomy of adulthood and actively managing their own health and care.
- Peer navigators can be beneficial for AYAs as this age group highly values social acceptance and tends to favour peers as sources of advice and support (Hall, Short, Giberson, & Howe-Martin, 2020; Miller & van der Eijk, 2019).
- That young people can be especially affected by access barriers related to culture, race, sexuality and gender as they explore and develop their personal identity.
- The communication skills and preferences of young people.
- Navigation support for long-term survivorship care and the role of community not-for-profits in this space.
- Allocation of resources to keep navigation information, including psychosocial and supportive care services and referral pathways, up to date following initial development.

5-year goal: Personalised models of navigation in cancer care are widely available to all Australians affected by cancer – engaging consumers in culturally safe, equitable and responsive cancer care, and driving re-orientation of health service systems, including training and distribution of cancer health workforce

Canteen strongly supports this medium-term goal as it is an important opportunity to improve consumer experiences and outcomes. However, it could be strengthened with a focus on shared decision-making as opposed to consumer involvement in decision making (page 55). Shared decision-making is a specific process in healthcare (Hoffmann, et al., 2014) whereas 'consumer involvement' is vague. In the next five years

we would like to see clinicians and consumers use shared decision-making processes as standard practice for making decisions together, drawing on the clinical expertise of the clinician and the personal expertise of the consumer. This would include using culturally and developmentally appropriate decision aids and other resources, tying in with action 2.2.2.

Strategic Objective 3: World Class Health Systems for Optimal Care

10-YEAR AMBITION: Integrated, coordinated, data-driven, high quality health service systems that consistently deliver optimal cancer care and excellence in outcomes.

We strongly support the 10-year ambition statement for Strategic Objective 3. We agree that the statement is ambitious enough, applaud the commitment to integrating care, and support the priority areas for action.

As noted in the draft Plan, key issues for AYA cancer care include safety and efficacy limits to conventional cytotoxic therapies and timely, affordable access to cancer drugs via clinical trials and the Pharmaceutical Benefits Scheme (PBS).

The challenges and benefits of access to cancer drugs via the PBS were explored in a recent [report](#). Analysis found there is a 3 to 1 social return on investment for cancer treatments that prolong and improve quality of life, even when the cancer is non-curative (Canteen, Rare Cancers Australia and HTAnalysts, 2022). We hope that issues with access to rare cancer drugs will be resolved through the current Health Technology Assessment (HTA) policy and methods [review](#) and a move to measuring what matters when making health funding decisions.

Goals and actions

Canteen supports the 5-year and 2-year goals for Optimal Care Pathways (OCPs):

3.1.1. Develop and implement a national framework that standardises the development, update, evaluation, and uptake of OCPs, including for priority population groups

3.2.1 Integrate OCPs as routine cancer care using a monitoring and evaluation system that links the implementation of OCPs to patient outcomes and experience

OCPs, including those tailored for priority populations, are essential in achieving the 10-year ambition to deliver consistent, high-quality care. OCPs are the current nationally accepted and endorsed approach to guide best practice cancer care. OCPs are intended to guide delivery of consistent, safe, high quality and evidence-based care for people with cancer.

Currently, there is no specific nationally consistent optimal cancer care pathway defined for young people with cancer, although there are some state-based pathways (Cancer Institute NSW, 2019; Adolescent and Young Adult Working Party of the

Statewide Cancer Clinical Network, 2010) and several national pathways include considerations for young people (Cancer Australia, 2023).

A high-level suggested OCP for young people with cancer is included in the [Australian Youth Cancer Framework](#) together with a recommendation for a nationally consistent pathway (Canteen, 2017).

In addition to the specific needs for AYAs identified on page 70 of the draft Plan (regarding clinical and psychosocial needs and tailored care plans) we suggest considering:

- Timely, accessible and affordable fertility preservation for young people diagnosed with cancer is an important aspect of an AYA oncology OCP.
- That optimal cancer care would utilise the whole cancer care sector including the not-for-profit and community care sectors. These sectors are well placed to support patients' non-acute care needs such as psychosocial support, peer support, family and carer services, transition to survivorship and long-term survivorship support. Collaborative cross-sectorial partnerships and referral pathways are important aspects of optimal care.

3.1.2 Develop a national framework for networked comprehensive cancer care, including the role of comprehensive cancer centres to enhance patient outcomes, strengthen transparency and accountability, and drive continuous improvements.

Canteen supports the components of a comprehensive cancer care model described, including the special considerations for AYAs on page 72. We also note the key role that [Youth Cancer Services](#) play in the delivery of such care. Additionally, comprehensive cancer centres should incorporate multidisciplinary support centres and integration with [Cancer Hub](#) to support family members.

Strategic Objective 4: Strong and Dynamic Foundations

10-YEAR AMBITION: A modern, fit for purpose cancer control infrastructure, advanced by the innovative application of technology, research, and data to improve Australia's cancer outcomes.

We strongly support the 10-year ambition statement for Strategic Objective 4 and agree that the statement is suitably ambitious. Research, data, technology and innovation are essential components of a modern and effective cancer control system.

Goals and actions

4.1.1. Develop an agreed national cancer data framework to improve accessibility, consistency and comprehensiveness of integrated data assets.

Canteen supports development of a national cancer data framework to underpin improved cancer outcomes. As noted in the draft Plan, a national data registry of newly diagnosed AYA cancers is needed to facilitate monitoring of cancer information and trends to promote improved outcomes for AYAs.

Implementation considerations for AYAs should include:

- A national minimum AYA dataset and improved data collection to better understand the experiences and outcomes of AYAs with cancer and inform research and service innovation.
- Collection of data that helps identify psychosocial needs of patients and their loved ones and supporters, facilitating appropriate referral to services.

4.1.2 Ensure targeted and innovative research investment into areas of unmet and emerging need; and improve clinical trial design and equitable access.

Canteen strongly supports the 5-year goal for *a clinical trials landscape in which all Australians have equal access* and the proposed action to improve clinical trial design and equitable access. Availability of, and access to, suitable clinical trials (both medical and psychosocial) is an ongoing issue for young people with cancer.

Implementation considerations for AYA in relation to action 4.1.2 include:

- Barriers to enrolment in trials are systemic and often include poor understanding of processes that support protocol approval and lack of paediatric-adult oncology relationships that would increase awareness of open trials (Ellis, et al., 2022).
- Collaborative efforts and communication between adult and paediatric cancer services will be essential in overcoming the issue of AYAs being blocked from straightforward access to clinical trials (VCCC Alliance, 2021).
- Facilitating trial participation for AYAs is challenging as treatment can be in either paediatric or adult settings. Some patients, typically those between 16 and 18 years of age, are too old to participate in a trial if treated in a paediatric hospital or too young if treated in an adult setting (Ellis, et al., 2022; VCCC Alliance, 2021).
- Rare or less common cancers coupled with complex AYA populations make it difficult for drug development and clinical trials to occur in local settings and through local investment alone. A small population and minimal funding to support international collaboration, means Australia's researchers and clinicians have fewer opportunities to influence research priorities and progress promising treatments (Queensland Health, 2019).

4.1.3 Identify opportunities to improve equitable cancer care through the digital health ecosystem.

We support identification of opportunities to improve equitable cancer care through the digital health ecosystem. We suggest prioritising improvements for people with the most need or preference for digital health, such as AYAs, neurodiverse people, and people living in rural and remote locations.

We agree that further research is needed on how the modalities and models of virtual cancer care impact the experiences and outcomes for priority populations and potential risks associated with digital models of care.

Additional implementation considerations for AYAs might include:

- Information and guidance for adolescents and their families on the use of virtual care, including informed consent.
- The role of digital health in supporting smooth transitions between paediatric, youth and adult cancer services.
- Digital health ecosystems to support maintained connection with education, work and social networks during this critical developmental stage of life.
- Development of AYA specific PREMs and PROMs.

4.2.3 Explore and test innovative approaches to pool and redirect funding to address areas of need in cancer care.

We welcome consideration of funding reform to address areas of need, such as access to treatments that enhance and extend life for non-curative, rare cancers. As noted in the draft Plan, collaboration, public/private partnerships, tailored, targeted solutions and impact evaluation should all be considered.

In exploring innovative funding approaches, it will be important to ensure maximum return on investment by evaluating the broader and long term social and economic benefits of investment in cancer treatments, in addition to immediate impacts for primary patients (Canteen, Rare Cancers Australia and HTAnalysts, 2022).

Strategic Objective 5: Workforce to Transform the Delivery of Cancer Care

10-YEAR AMBITION: An engaged, capable, and future-focused cancer workforce that is culturally safe and responsive, well-equipped, well-supported and driven by collaboration, continuous improvement, and diversity to enable inclusive care for all Australians affected by cancer

We strongly support the 10-year ambition statement for Strategic Objective 5 and agree that the statement is ambitious enough. Investment and support for the cancer workforce is a critical component of optimal cancer care.

As others have noted, a diverse cancer care workforce is an important component of person-centred cancer care. Canteen strongly supports initiatives that help grow a diverse workforce.

A flexible and responsive health workforce is also key for future-focused care. However, this needs to be balanced with workforce specialisation that enables staff to provide responsive, person-centred care, especially for priority populations. Maintaining Youth Cancer Services and staff with expertise in working with young people will be important for supporting this strategic objective.

Cross sectorial collaboration is also important to support the workforce in transforming the delivery of cancer care. A workforce well connected across the public, private and not-for-profit sectors enables more comprehensive, holistic care, including provision of

long-term survivorship support and management of long-term impacts on mental health and life trajectories for children and families.

Goals and actions

5.1.2. Build on existing capability of the primary care workforce to collaboratively and sustainably support the needs of consumers

Additional implementation considerations for AYAs could be:

- Extended scope for other health practitioners working in AYA cancers (not just medicine) to provide supportive care, navigation assistance and survivorship care. Nurses and allied health can perform these roles in primary and acute settings.
- The roles of community organisations and not-for-profit organisations in providing supportive care, peer support, navigation assistance, survivorship care and other services for AYAs and their families and communities who are impacted by cancer.

5.2.2. Work with the sector to support all cancer care practitioners to practice at the top of their scope, increase retention and ensure ongoing access to continuing professional development.

We agree with the implementation consideration regarding AYAs' needs to be included and involved in decision making but would suggest broadening the consideration, for example:

- Increase cancer care workforce understanding of adolescent and young adults needs, preferences and abilities to participate in conversations and decisions about their care throughout the care continuum from screening and diagnosis to palliative care, end of life and survivorship.

Some additional implementation considerations could be:

- The availability of specialised training for AYA oncology and AYA oncology psychosocial care.
- That all clinicians working with AYAs should have training and skills in the process of shared decision making and be able to source culturally and developmentally appropriate decision aids and tools.

Strategic Objective 6: Achieving Equity in Cancer Outcomes for Aboriginal and Torres Strait Islander people

10-YEAR AMBITION: Supporting Aboriginal and Torres Strait Islander knowledge, strength and sovereignty in a health system that achieves equity for Aboriginal and Torres Strait Islander people affected by cancer.

Canteen strongly agrees with this ambition and the focus on equity for Aboriginal and Torres Strait Islander people and other priority populations affected by cancer throughout this draft Australian Cancer Plan.

As an organisation, Canteen is committed to national reconciliation in recognition of cancer's disproportionate impact on Aboriginal and Torres Strait Islander peoples. Our [Innovate Reconciliation Action Plan 2022 - 2024](#) incorporates Canteen's vision for reconciliation: that First Nations' young people and their families, parents and kinship carers experience equitable and safe access to cancer support and health services.

The ACP ambition for equity for all Aboriginal and Torres Strait Islander people affected by cancer reflects the focus on holistic, person-centred care in the draft Plan. The families, carers, kinship groups and communities of the individual with cancer are affected too. Therefore, supporting the supporters by ensuring equitable access to culturally appropriate supports and resources for the people around the patient and for bereaved families and communities could be one of the actions falling under this strategic objective.

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