

A photograph of a group of people from behind, looking out at a sunset. One person in the center has their right arm raised with fingers spread. The scene is bathed in the warm, golden light of the setting sun. A large, semi-transparent blue 'C' logo is positioned in the upper right corner of the image.

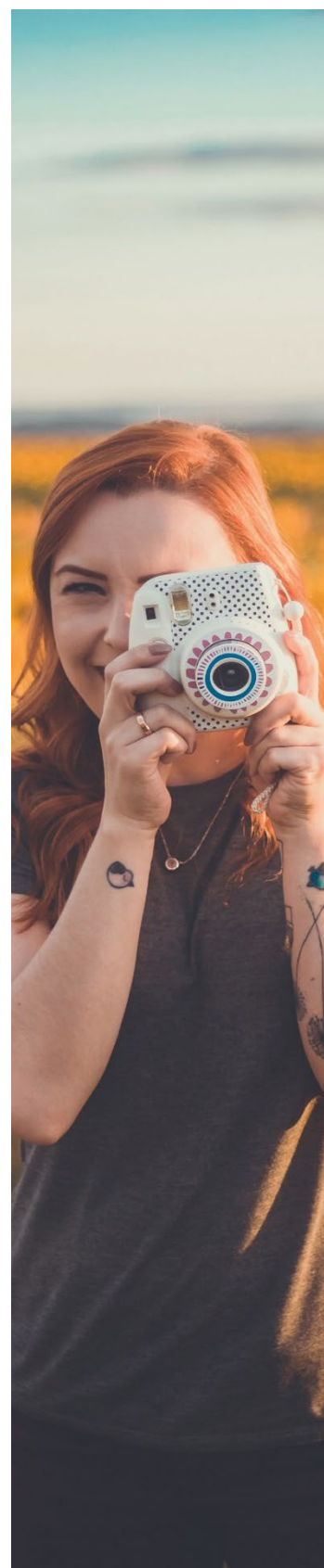
SUBMISSION

SA Cancer Plan

November 2022

Contents

Executive Summary	4
About Canteen Australia	4
Overview of submission	4
Key recommendations	4
Burden of disease	5
Cancer in South Australia.....	6
Adolescents and young adults.....	6
Diverse people and communities.....	6
Services	7
Youth Cancer Service	7
Canteen SA.....	7
Cancer Hub	8
What is working well	8
State-wide plans.....	8
SA Cancer Control Plan	8
SA Aboriginal Cancer Control Plan.....	8
State Public Health Plan.....	8
Optimal Care Pathways.....	8
Prevention	9
Tobacco control	9
SunSmart campaigns.....	9
Treatment	9
Research and innovation.....	10
Opportunities for improvement	10
Prevention	10
Treatment	10
Clinical trials.....	11
Data and systems	12
Support for South Australian families	13
Supporting young people.....	13
Supporting parents	14
Integrated care.....	14



Future initiatives and impacts 15

The Australian Bragg Centre15

Genetic science15

Virtual care16

Additional considerations 17

Australian Cancer Plan.....17

Expanding access to cancer medicines.....17

Measuring what matters 18

Vision 2033..... 18

References 19

KEY CONTACT

Angela Wicks
angela.wicks@canteen.org.au

PREPARED BY

Angela Wicks, Policy and Advocacy Manager, Canteen



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

Executive Summary

About Canteen Australia

Canteen Australia is a national 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.

Canteen is a national organisation with a service hub in the Adelaide CBD that provides state-wide services.

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.

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

Overview of submission

We welcome this review of the SA Cancer Control Plan and appreciate the opportunity to contribute.

This submission focuses on Canteen's area of expertise, which is young people impacted by cancer. This submission highlights the areas we believe are effective as well as opportunities for improvement in Adult & Young Adult (AYA) cancer care in South Australia.

Key recommendations

1. Update the SA Cancer Plan in line with new goals, evolving evidence and learning from other new Australian cancer plans, including the draft Australian Cancer Plan.
2. Advocate for and influence the adoption of a national AYA Cancer Optimal Care Pathway.
3. Maintain strong focus on cancer prevention and early detection, including tobacco control, skin cancer awareness, cancer screening and improving health literacy in South Australia.
4. Embed genuine consultation and service delivery codesign with young patients and clinicians, who are not just invited, but actively supported to participate.

5. Prioritise equitable access to specialised, age-appropriate clinical care and integrated, multidisciplinary psychosocial support services for all South Australians, including patients in regional and private hospitals.
6. Provide timely, accessible and affordable fertility preservation for young people diagnosed with cancer.
7. Ensure access to off-label and non-curative cancer treatments which are at no or minimal cost to the young patient.
8. Partner with other states and territories to improve access to AYA-specific clinical cancer trials through funding, and implementation of nationally consistent processes for trial initiation, ethics and governance. Facilitate the establishment of mechanisms to enable access to appropriate clinical trials for AYAs regardless of whether they are in paediatric or adult settings.
9. Mandate the collection of the national AYA minimum dataset for AYA cancer patients and enable the national collation of unit record data and linkage to other relevant national datasets.
10. Implement identification processes and referral pathways to meet psychosocial needs of all South Australians who are impacted by cancer, including patients, carers, partners, parents and offspring.
11. Develop evidence-based, blended virtual and face-to-face models of cancer care that are supported by technology infrastructure and a capable, flexible and responsive workforce.
12. Commit to ongoing investment in research and innovation in cancer care, including proton therapy, genetic science and personalised medicine.
13. Develop 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 South Australia.

Context

Burden of disease

In Australia, cancer causes the greatest burden compared with all other major disease groups, with an estimated 162,000 new cancer cases diagnosed in 2022^{3,4} People dying prematurely is a large part of the overall disease burden; an estimated 50,000 Australians will die from cancer in 2022.³ Cancer has a substantial social and economic impact on individuals, families and communities.⁴ For AYAs diagnosed with cancer in 2016, the total lifetime costs were estimated to be \$1.4 billion, which is equivalent to \$1.3 million per person.⁷

Cancer in South Australia

In South Australia, cancer is a leading burden of disease with an average of 31 new cancer diagnoses each day.^{4,6}

- In 2019, 11,349 South Australians were diagnosed with cancer
- In 2019, 3,808 South Australians died from cancer, an average of 10 South Australians each day.

Adolescents and young adults

Adolescent and young adult (AYA) means young people aged 15-25, although the specific age range can vary in different contexts. It is a critical life development stage that involves transition from childhood through adolescence to adulthood and the navigation of developmental changes and complexity associated with that. A cancer diagnosis can compound the complexity, thereby having a significant negative impact on a young person's normal developmental trajectory without appropriate support.

Young people have unique medical and psychosocial experiences and needs, distinct from those of paediatric and older adult patients.¹⁹

The overall 5-year overall survival of 15–29-year-olds with cancer in Australia is relatively favourable (88% in 2004–2010) however, survival is lower than that seen in their younger counterparts for several common malignancies.¹⁷

Around 1,000 AYAs receive a cancer diagnosis each year in Australia, approximately 85 of these in South Australia.² It is also estimated that a further 1,600 young South Australians are impacted by cancer every year through the diagnosis or death of a parent, brother, or sister.²

Diverse people and communities

People with cancer are not a homogenous group, they intersect with the rich spectrum of human experiences, including development stages across the lifespan, culturally and linguistically diverse people, Aboriginal and Torres Strait Islander peoples, geographically isolated communities, economically disadvantaged communities, LGBTQIA+ people, and people with disabilities in addition to the specific needs of AYAs. Diverse and historically marginalised populations experience reduced physical and mental health outcomes compared with their mainstream peers.⁵

The current SA Cancer Control Plan recognises that many social, economic, cultural, political, developmental and physical environmental factors contribute to health.

It is important that the particular needs of adolescents and young adults with cancer continue to be recognised and prioritised in South Australia, with early identification of AYA patients and referral to the Youth Cancer Service and other specialised services for young people.

We would also like to see LGBTQIA+ people and communities recognised in the new cancer plan as marginalised populations that experience barriers to accessing healthcare, poorer physical and mental health outcomes than the general population, and who have specific psychosocial needs.

Issues of diversity, identity and inclusion are often critical for young people during a time of significant developmental change. Safe, accessible and inclusive healthcare is particularly important for this group who may be dealing with issues of body image and sexual and gender identity as well as making decisions about fertility preservation as part of their cancer care.

Services

From an adolescent and young adult perspective, the key services for young people and families impacted by cancer in South Australia are:

Youth Cancer Service

Young people with cancer have specific physical, social, educational and practical support needs which require the assistance of expertly trained professionals both during and after treatment.

The [SA Youth Cancer Service](#) (YCS) is based at the Royal Adelaide Hospital. The YCS is designed specifically for the 15–25-year age group and cares for approximately 160 young people going through cancer every year.

The YCS provides youth-specific, multi-disciplinary treatment and support to young people with cancer. The team is comprised of medical, nursing and allied health professionals, all who are experts in providing clinical care and multidisciplinary support to young people with cancer.

Canteen SA

Based in the Adelaide CBD, Canteen SA provides state-wide psychosocial support services to young people and their families that are impacted by cancer. This includes individual psychosocial support, educational and vocational assistance and group-based psychosocial programs.

In addition, Canteen provides national digital support including online counselling and *Canteen Connect*, an online community for young people dealing with the impact of cancer. Parents are also provided with support through an online community, *Parenting through Cancer* and online counselling.

More information about services and programs can be found at:

<https://www.canteen.org.au/how-we-help/events-programs>.

Cancer Hub

[Cancer Hub](#) is a digital first point of call for families with children (0-25 years) when cancer impacts the family. Cancer Hub ensures that the needs of the family are identified, and then skilled cancer navigators connect individual family members to the supports they need, while expert counsellors assist them to deal with the immediate distress.

Cancer Hub is a collaboration between [Canteen](#), [Camp Quality](#) and [Redkite](#).

What is working well

State-wide plans

SA Cancer Control Plan

The current SA Cancer Control Plan is comprehensive, with clear principles, vision and recommended directions and actions. Much can be carried forward into the new SA Cancer Plan. However, this review is also an opportunity to consolidate and update the plan in line with new developments and evolving evidence, and to set new goals.

SA Aboriginal Cancer Control Plan

Publication of a standalone plan for Aboriginal cancer control in South Australia has been an important step. The new SA cancer plan should complement and refer to the SA Aboriginal Cancer Control Plan.

It is also recommended that the SA Cancer Plan align with the focus on Indigenous Australians in the new Australian Cancer Plan (expected to be published in early 2023).

State Public Health Plan

An important aspect of the [State Public Health Plan 2019-2024](#) is a focus on addressing the health needs of priority populations, especially Aboriginal people. The Plan recognises the disparities in the health status of South Australians and includes actions to address health inequities.

Optimal Care Pathways

South Australia led the way in recognising the unique needs of adolescents and young adults (15-25 years) with cancer in Australia. In 2010 SA Health published the South Australian [Adolescent and Young Adult Cancer Care Pathway](#). Now there is opportunity for South Australia to influence the implementation of a national AYA Optimal Care Pathway.

Optimal cancer care pathways are the current nationally accepted and endorsed approach to guide best practice cancer care. They are intended to guide the delivery of consistent, safe, high quality and evidence-based care for people with cancer. Currently, there is no specific nationally consistent optimal cancer care pathway

defined for young people with cancer, although several pathways include considerations for young people.

A high-level suggested optimal care pathway for young people with cancer is included in the [Australian Youth Cancer Framework](#), together with a recommendation for a nationally consistent pathway.¹⁰

Prevention

Tobacco control

The most important thing that can be done to prevent cancer is for people to not smoke. Smoking increases the risk of at least 12 types of cancer, including those with high mortality rates such as lung cancer.¹¹

The South Australian *Tobacco Control Strategy* and tobacco and e-cigarette legislation, including new laws banning advertising of e-cigarette products, have worked well in reducing smoking rates in South Australia.

However, it is important to continue work to reduce smoking rates, particularly among Aboriginal and Torres Strait Islander people who are disproportionately exposed to drivers of tobacco use, such as living in remote areas, socioeconomic factors, imprisonment, and trauma.²⁶

Additionally, the tobacco and vaping industries continue to target young people. For adolescents and young adults there is a particular risk of addiction to e-cigarettes containing nicotine, and of progressing from vaping to smoking tobacco.²⁷ Therefore we would like to see a strong focus on reducing smoking and vaping rates in young people in the new *Tobacco Control Strategy*, and consideration of further legislation to ensure young people never take up smoking.

SunSmart campaigns

Whilst Melanoma is still the most diagnosed cancer in young Australians, there has been a 54% decrease in age-standardised incidence rates of melanoma between 1985–1989 and 2010–2014.² This is a reduction from 25% of all AYA cancer to 15% over a 5-year period, which could potentially be attributed to SunSmart campaigns.

Treatment

In South Australia, young people with cancer have access to high quality, specialised care by the SA YCS. The SA YCS is staffed by a specialised multidisciplinary workforce who provide tailored care and age-appropriate information, resources, support, and treatment environments.

There is generally good care coordination within SA Health including early identification of AYA patients in the public health system and referral to the YCS by adult and paediatric sites. Young cancer patients are screened for psychosocial support needs at referral or early in the care pathway, and at key transition points.

Research and innovation

Establishment of the South Australian Health and Medical Research Institute (SAHMRI) has been an important investment for improving the health and wellbeing of people in South Australia and beyond. At Canteen we are particularly interested in research and the translation of findings as relevant to AYA cancer, including new treatment options, psychosocial impacts on patients and families and social determinants of cancer.

Opportunities for improvement

Prevention

Prevention is the most important aspect for reducing the impact of cancer. South Australia has many excellent prevention strategies in place, and we recommend a continued and increasing focus on prevention including tobacco control, skin cancer awareness and screening.

Prevention can also be supported by health education and health promotion aimed at all South Australians including children, young people, parents, carers and new South Australians.

Improving health literacy, both population and organisational, supports better outcomes and experiences at every point, through earlier detection, improved ability to find, understand and act on credible health information, better communication and shared decision making, and improved treatment adherence.

Treatment

The key opportunities for improvement in how we plan for or provide cancer care for AYA and their families in South Australia are:

- Genuine consultation and service delivery codesign with AYA patients and clinicians, who are not only invited but actively supported to participate.
- Improved pathways for early identification of AYAs in the private sector to ensure early and equitable access to specialised, age-appropriate clinical care and support services through SA YCS.
- Increased access to specialised, integrated, multidisciplinary psychosocial support for patients outside metropolitan public hospitals (including regional centres and the private sector).
- Provide timely, accessible and affordable fertility preservation for young people diagnosed with cancer.
- Ensure access to off-label and non-curative cancer treatments which are at no or minimal cost to the young patient.
- Increased access to AYA-appropriate clinical trials.

Clinical trials

Participation in clinical trials is known to improve patient outcomes through the development of more effective treatment regimens.¹ However, only 18% of AYAs diagnosed with cancer participate in trials, which is low when compared with participation rates for children and for older adults.¹⁹ Consequently, AYAs have not experienced the same increased survival rates in some higher lethality cancers as paediatric patients over the past 30 years, which is deeply concerning.²⁴

Availability of, and access to, suitable clinical trials (both medical and psychosocial) is an ongoing issue for young people with cancer in South Australia and beyond. Barriers to enrolment in trials are systemic and often include poor understanding of processes that support protocol approval, lack of paediatric-adult oncology relationships that reduce awareness of open trials and age exclusion (e.g., adolescents excluded from relevant adult trials and young adults excluded from relevant paediatric trials).

Facilitating trial participation amongst AYAs is particularly challenging as they may be treated in either a paediatric or adult setting. Some patients, typically those between 16 and 18 years of age, will therefore be too old to participate in a trial if treated in a paediatric hospital or too young if treated in an adult setting.

A lack of clinical tele-trials also means that patients and clinicians living in rural and remote communities face additional barriers to access and participation. This in turn can slow the development of new treatments.²²

Rare or less common cancers coupled with complex populations (including AYAs) make it difficult for drug development and clinical trials to occur in local settings and through local investment alone. With our small population and minimal funding to support international collaboration, South Australia's researchers and clinicians have fewer opportunities to influence research priorities and progress promising treatments.

The price of not addressing these rare and less common cancers is substantial. The lifetime economic impact of Australian AYA cancer diagnoses for 2016 alone is estimated at \$1.4B.^{7,9}

Meeting the challenge of conducting trials with small populations will become increasingly critical with advances in personalised medicines and development of treatments for specific genetic variations of cancers, as populations from which patients can be recruited will narrow.¹³

Efficient and nationally consistent processes for trial initiation, ethics and governance will be important for attracting industry investment in clinical trials for rare cancer populations. Given this, it is essential that there is a commitment to partnering with other jurisdictions on the resourcing and rollout of national trials for AYAs.

Therefore, we would like to see review of South Australia's approach to clinical trials, in collaboration with other states and territories, to achieve national consistency and in how clinical cancer trials are initiated, governed and coordinated for the benefit of AYAs.

Data and systems

To remain at the forefront of cancer research and clinical practice, and support continuous improvement in cancer care, South Australia will need to contribute to, and draw information from, a national cancer data set.

Components of cancer care service delivery in Australia are diverse and complex, including public and private hospitals, primary care, community care, and a diverse, community-based, not-for-profit (NFP) sector. Such complexity highlights the value of investing in the establishment of a national data set.

We envisage that a national data set would:

- consistently capture information about AYA cancer treatment (including participation in clinical trials) and patient outcomes
- be linked to other national datasets of significance including MBS, PBS and ABS
- be segmented by population groups (minority groups and priority populations)
- build an understanding of treatment options and outcomes to inform the research agendas
- inform the identification of gaps and other opportunities for service improvement
- support cross-sectorial, national and international collaboration and integration of care.

The absence of a national registry of newly diagnosed AYAs with cancer makes monitoring trends, tracking priorities and critical issues, and improving outcomes for this group challenging.²³

In lieu of national data systems, the Australian Youth Cancer Services currently capture national activity data relevant to priority areas such as clinical trial enrolment, onco-fertility, psychosocial care, and survivorship. This data is limited to patients who access support through the YCS, however it does provide an example of how coordinated initiatives could deliver, monitor and improve care for AYAs across Australia

A national, linked AYA dataset would facilitate

- identification of unmet patient needs
- identification of disparities in care and outcomes
- mapping of patterns of care across centres and cancers
- monitoring of emerging patterns of complications
- assessment of patient outcomes and disparities in care
- better costing of treatments and out-of-pocket expenses
- collaborative research.

A recent [Ministerial Roundtable](#) recognised national data linkage, and reporting of data on cancer stage, treatments and recurrence at the national level as opportunities to deliver the greatest impact on cancer outcomes in Australia.

Therefore, we recommend that SA Health commit to developing national partnerships to facilitate shared expertise, ideas, and learning via a specific, consistent national, minimum data set.

Support for South Australian families

Supporting young people

The need to recognise and respond to the psychosocial needs of adolescents and young adults (AYAs) impacted by cancer extends beyond the person with cancer to their parents, offspring, and siblings. There is enormous opportunity to improve how young people are supported when their family experiences cancer, from diagnosis, treatment, palliative care and survivorship.

Every year around 21,000 AYAs in Australia are told their parent has cancer, while a further 1,000 are told their sibling has cancer.² This equates to more than 1,600 young people in South Australia alone and over the next five years there is opportunity to better manage the impacts of cancer for 8,000 young people in South Australia.

Young people whose parent or sibling has cancer report levels of psychological distress that are three to six times higher than others their age.²⁰ Not only are distress levels significantly higher, but their distress and needs are more likely to go undetected as the family network focuses on caring for the person with cancer.¹⁴ For young people, navigating a critical developmental stage of life, the distress of family member's cancer, from diagnosis to bereavement, can have wide-ranging and long-lasting impacts.¹⁸ High levels of distress and disruptions to school, tertiary study, early career trajectories and social and emotional development while focusing on their loved one's care and support can have long term impacts.

Such impacts include their own health, mental health, social and emotional development and achievement of emotional and financial independence.

Early identification and individualised psychosocial intervention for young people and their families can help lessen negative effects of cancer and promote wellbeing.^{12,15} Consequently, investment in supporting young people whose life is disrupted by a parent's or sibling's cancer will have long term social and economic benefits.

Young people can be supported with information about the cancer, practical assistance, recreation and respite opportunities, counselling and peer support.²⁸ When these emotional and information needs are met, children and siblings of cancer patients report less distress.²¹

This area of support is a key focus for Canteen. Canteen offer resources for young people, including information books, individual support and counselling (face-to-face and online), peer support, psychosocial programs, and recreational camps and activities.

To support increased referral to Canteen and other support services we recommend implementation of processes in all cancer services to identify the family members who may need psychosocial support and clear referral pathways for them. For identification

of people who may benefit from Canteen services, routinely asking patients with a cancer diagnosis if they have children under 25 years old is recommended.

Supporting parents

Parental stress and depression can have far-reaching consequences for family functioning, including outcomes for children and young people.²⁸ Parents often find it difficult to talk openly and honestly with their children about their cancer and how they're coping.¹⁸ Good family communication is critical to mitigating the impacts of distress during this time and Canteen has previously developed [guides to support health professionals](#) facilitate these conversations.

Additionally, parents can access free expert advice and counselling and connect with other parents in similar situations via [Cancer Hub](#).

Parents and families are often overwhelmed particularly at the time of diagnosis and in the immediate aftermath. Their distress is often amplified by having to navigate a complex landscape to get the supports they need.

Therefore, routinely asking families who have a family member with a cancer diagnosis if they have children under 25 years old and offering referral to Cancer Hub is recommended.

Integrated care

There is opportunity for SA Health to strengthen relationships with key sectors in cancer care, especially the private, primary care and not-for-profit sectors, to provide more integrated, person-centred care.

CASE STUDY: online support for AYAs impacted by a parent's cancer

Daniel* is a 20-year-old male whose mother had been unwell with Lymphoma for much of his young life. Daniel reached out to the 'ad-hoc' chat service on the Canteen Online Support Service to seek support when it became clear that his mother's cancer couldn't be cured. He would find himself distracted at work, sometimes in tears, thinking about his mum's situation, and was apprehensive about 'opening up' to someone about his distress regarding his mother's cancer. Daniel opted for the webchat counselling option on Canteen Connect as he felt more at ease writing, reading, and typing than talking about his situation.

In counselling, Daniel worked towards telling his workplace about his mum's cancer, as he hadn't told anybody he knew. Daniel's counsellor supported him with weekly webchat sessions, where they focused on 'anticipatory grieving' and preparing for his mother's death. Daniel was encouraged to connect with memories, values, and interests that he and his mum shared, such as baking, gardening, and murder mystery shows. When Daniel's mother died, he was able to process this with his counsellor, and together they drew upon the familiar ways that Daniel could connect with his mother during his acute grieving process. Daniel receives ongoing support from the Canteen Online Support Service, and eventually would like to be connected with other young people who have lost a parent, through Canteen's digital events and programs.

**Name has been changed.*

Integration of care is particularly important for patients, families and carers at key transitions of care, such as:

- young people transitioning from paediatric to adult services
- people from regional areas transferring to Adelaide for treatment
- transitions from treatment to palliative care and survivorship.

Integrated cancer care includes paediatricians, general practitioners and families as essential member of the multidisciplinary cancer care team.

We also recommend ensuring strong and effective referral pathways to [Cancer Hub](#) for young patients, survivors and their family members, such as via HealthPathways.

Future initiatives and impacts

The Australian Bragg Centre

The new Bragg Centre for Proton Therapy and the Bragg Comprehensive Cancer Centre in Adelaide will impact cancer care planning in South Australia by consolidating advanced cancer treatment and research in the centre of Adelaide.

As the only therapy centre of its kind in the Southern Hemisphere, the Centre for Proton Therapy is likely to bring more cancer patients to South Australia. It is anticipated that this will include round 78 more adolescent and young adult patients per year. It will be important to plan for this and provide navigation, support and community connections for patients and their families coming from regional South Australia, interstate and overseas. It is recommended to provide a comprehensive multidisciplinary support centre and integration with Cancer Hub to support family members.

Genetic science

Cancer treatments in AYAs pose a distinctive set of challenges due to the unique behaviour of tumours in this cohort. Identifying and targeting responses to mutated genes are subsequently at the forefront of science and emerging technologies to optimise cancer care survival rates in AYA.¹⁶

Advances in knowledge of genomics have led to the development of targeted treatments for multiple cancers. The presence of genomic markers may also modify therapeutic decisions due to the responsiveness of different tumour types to different treatments or dosages.^{16,25} Ability to screen for predisposition to heritable cancers also has significant implications for treatment and surveillance of family members. Ongoing investment in genetic science that leads to innovative, lifesaving technologies should therefore be a priority for cancer research and care in South Australia.

Virtual care

Virtual care uses technology to safely connect health and care professionals with patients to deliver care when and where it is needed. Across the healthcare sector virtual care is also referred to as virtual health, digital health, telehealth, telemedicine and telepsychology. Virtual care modalities include telephone, videoconference, email, clinical apps and remote monitoring.

At Canteen the young people we work with have told us they want more virtual health services in the changing service delivery landscape. To continue delivering our psychosocial programs throughout the COVID-19 pandemic we accelerated digital transformation of our services. Evaluation of the experience has revealed a preference for the inclusion of digital psychosocial services alongside face to face, and an expectation from AYAs that online service delivery will remain an option under 'business as usual' service models.

Our experiences are reflected in health services across Australia, across the public, private and not-for-profit sectors. Virtual care must be incorporated into cancer care planning for the future.

Advantages of virtual care models include:

- Increased reach of services to people in diverse geographic locations.
- Increased accessibility of services for people who find it difficult to access face to face services, such as people who:
 - have a disability or illness that limits mobility
 - have a sensory disability
 - cannot easily access or pay for transport
 - have carer responsibilities
 - are time poor
 - are very sick and find the burden of travel overwhelming.
- More effective use of clinical resources, enabling more time to focus on patient needs and tailored interventions.
- Increased choice for consumers in how they engage with healthcare, supporting patient-centred healthcare.

Many aspects of cancer care cannot be replaced by virtual care and some patients prefer in-person care even when virtual care is an option. However, we believe that blended face to face and virtual models are the way forward, particularly for psychosocial aspects of cancer care. Therefore, it is important to consider technology infrastructure, workforce capabilities and training, and adapted models of care in planning how cancer care is provided in South Australia.

CASE STUDY: Bespoke digital intervention to provide a meaningful experience for a young person

Ashley*, a 24-year-old patient who was accessing individual support during her cancer journey, had just finished treatment. Unfortunately, due to COVID-19, she was unable to end treatment in the way she'd always dreamed – hugging the nurses, having photos on the ward, and ringing the bell!

During our individual support session, we came up with the idea of recreating a bell ringing ceremony online, to mark the end of her cancer treatment.

She attended our first 18+ Patient Survivor Meet-up online and, after courageously introducing her story (her first attendance to a peer event at Canteen), I invited the group to join in celebrating as we rang a bell! Amongst a group of seven new peers who all truly understood, we together clapped, cheered, fist pumped and celebrated this young person and her cancer journey.

**Name has been changed.*

We also recommend a commitment to research and evaluation of virtual care models and mechanisms. Research should focus on quality, consistency and equity of virtual care compared with face-to-face care with the goal of ensuring all patients receive a high standard of care.

Additional considerations

Australian Cancer Plan

The new Australian Cancer Plan: 2023-2033 is currently under development and expected to be released in early 2023. It is the first national 10-year plan and includes the objective of setting “a transformative agenda to accelerate world class cancer outcomes for all Australians affected by cancer”. It is recommended that the SA Cancer Plan complements and aligns with the national plan as appropriate.

Expanding access to cancer medicines

We believe there is a role for SA Health in supporting access to treatment for patients where there are substantial financial implications for treatment.

This role may include advocacy on behalf of South Australians to the Federal Government for expansion of the Pharmaceutical Benefits Scheme (PBS) to include non-curative cancer treatments that extend and improve quality of life.

The report [Counting the Cost: the true value of investing in cancer treatment](#), was commissioned by Canteen and Rare Cancers Australia. It found that investment in non-curative cancers provides a high social and economic return on investment. However Pharmaceutical Benefits Advisory Committee recommendations about which medicines to include on the PBS are based on cost effectiveness ratios that do not

factor in the breadth social and economic benefits that can be provided by extending life. Such benefits may include the benefits for a person's children of having extra years of love, mentorship and support from their parent, all of which can have long term social, emotional and financial impacts.

Measuring what matters

The Federal Government has committed to measuring what matters to improve the lives of all Australians. [Statement 4](#) of Budget Paper 1, 'Measuring What Matters', signals the government's objective to go beyond traditional macroeconomic indicators and consider broader social and environmental factors that influence quality of life and wellbeing. The statement explores what we can learn from international progress and well-being reporting exercises, as well as highlighting existing reporting frameworks used in Australia, and provides the beginnings of an Australian framework.

Measuring what matters is especially relevant in a healthcare context and important to consider in the development of the new SA Cancer Plan and for decisions about investment in cancer treatments.

The *Counting the Cost* report found that every \$1 invested in non-curative cancer treatments returns \$3.06 worth of economic and social value. The report also found that investments in new technologies, therapies and services to extend the prognosis and quality of life of people with non-curative cancers can return \$3.17 billion of social value alone (over five years).⁸

The Australian Government Treasury is currently undertaking [public consultation](#) to gather views on how to improve the economy and society by measuring what matters with the intention to develop a standalone Measuring What Matters statement in 2023.

AYA Vision 2033

Canteen Australia is currently developing [AYA Vision 2033](#), a national strategic document to guide focus and action on AYA cancer care in Australia over the next 10 years. AYA Vision 2033 draws on the foundations established by the [Australian Youth Cancer Framework](#) and aims to create the next platform for action that identifies priorities and strategies to achieve world leading AYA cancer care and support.

The goal of Vision 2033 is equitable access to world class services across the continuum of cancer care, from diagnosis, treatment, and long-term survivorship outcomes.

Vision 2033 presents an opportunity for SA Health to consider the ways in which third sector organisations can play a practical role in supporting the SA Cancer Plan through the development of specific and targeted cancer care and support strategies.

Canteen Australia evidences and recommends an approach that sees a genuine partnership between the government and community sector and calls for greater recognition and an identified role for community organisations in a collaborative response to cancer, based on shared vision and goals.

Vision 2033 is anticipated to be completed and implemented in 2023.

References

1. Australian Government. (2022). *Why talk to your patients about clinical trials*. Retrieved from Australian Clinical Trials: <https://www.australianclinicaltrials.gov.au/health-care-providers/why-talk-your-patients-about-clinical-trials>
2. Australian Institute of Health and Welfare. (2018). *Cancer in adolescents and young adults in Australia*. Retrieved from Australian Institute of Health and Welfare: <https://www.aihw.gov.au/getmedia/ed22109b-ab23-4273-8d23-7949a8922ea2/aihw-can-110.pdf.aspx?inline=true>
3. Australian Institute of Health and Welfare. (2022). *Cancer*. Retrieved from Australian Institute of Health and Welfare: <https://www.aihw.gov.au/reports/australias-health/cancer>
4. Australian Institute of Health and Welfare. (2022). *Cancer data in Australia*. Retrieved from Australian Institute of Health and Welfare: <https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/summary>
5. Baker, K., Adams, J., & Steel, A. (2021). Experiences, perceptions and expectations of health services amongst marginalized populations in urban Australia: A meta-ethnographic review of the literature. *Health Expectations*, 2166-2187.
6. Cancer Council SA. (2022). *Cancer statistics*. Retrieved from Cancer Council SA: <https://www.cancersa.org.au/research/cancer-statistics/>
7. Canteen. (2016). *The economic cost of cancer in adolescents and young adults*. Retrieved from Canteen: <https://www.canteen.org.au/about-us/canteen-reports/economic-cost-of-cancer-in-AYAs>
8. Canteen. (2022). *What price is a life?* Retrieved from Canteen: <https://www.canteen.org.au/about-us/news-reports/news/what-price-is-a-life#:~:text=The%20report%20'Counting%20the%20Cost,of%20economic%20and%20social%20value>
9. Canteen and Rare Cancers Australia. (2022). *Counting the cost: The true value of investing in cancer treatment*. Retrieved from Canteen: https://www.canteen.org.au/sites/default/files/2022-09/RCA4279_Counting_the_Cost_Report_FINAL_0.pdf
10. Canteen Australia. (2017). *Australian Youth Cancer Framework for Adolescents and Young Adults with Cancer*. Retrieved from Canteen: https://www.canteen.org.au/sites/default/files/2021-11/CanteenYCS_Australian_Youth_Cancer_Framework.pdf
11. Centers for Disease Control and Prevention. (2022). *Smoking and Cancer*. Retrieved from Centers for Disease Control and Prevention: [https://www.cdc.gov/tobacco/campaign/tips/diseases/cancer.html#:~:text=Quitting%20smoking%20lowers%20the%20risk,acute%20myeloid%20leukemia%20\(AML\)](https://www.cdc.gov/tobacco/campaign/tips/diseases/cancer.html#:~:text=Quitting%20smoking%20lowers%20the%20risk,acute%20myeloid%20leukemia%20(AML))
12. Cohen, J., Patterson, P., Noke, M., Clarke, K., & Husson, O. (2022). Development and Evaluation of the Canteen Connect Online Health Community: Using a Participatory Design Approach in Meeting the Needs of Young People Impacted by Cancer. *Cancers*, 1-21.
13. Fountzilias, E., Tsimberidou, A. M., Vo, H. H., & Kurzrock, R. (2022). Clinical trial design in the era of precision medicine. *Genome Medicine*.
14. Franklin, M., Patterson, P., Allison, K. R., Rosso-Buckton, A., & Walczak, A. (2018). An invisible patient: Healthcare professionals' perspectives on caring for adolescents and young adults who have a sibling with cancer. *European Journal of Cancer Care*, e:12970.

15. McDonald, F., Patterson, P., White, K., Butow, P., Costa, D., & Kerridge, I. (2016). Correlates of unmet needs and psychological distress in adolescent and young adults who have a parent diagnosed with cancer. *Psycho-Oncology*, 447–454.
16. McVeigh, T. P., Sundar, R., Diamantis, N., Kaye, S. B., Banerji, U., Lopez, J. S., . . . George, A. (2018). The role of genomic profiling in adolescents and young adults (AYAs) with advanced cancer participating in phase I clinical trials. *European Journal of Cancer*, 20-29.
17. Osborn, M., Little, C., Bowering, S., & Orme, L. (2013). Youth Cancer Services in Australia: Development and Implementation. International Perspectives on AYAO, Part 3. *Journal of Adolescent and Young Adult Oncology*, 118-124.
18. Patterson, P. (2016). *Life interrupted: young people need help moving forward after cancer*. Retrieved from The Conversation: <https://theconversation.com/life-interrupted-young-people-need-help-moving-forward-after-cancer-63704>
19. Patterson, P., Allison, K., Bibby, H., Thompson, K., Lewin, J., Briggs, T., . . . Anazodo, A. C. (2021). The Australian Youth Cancer Service: Developing and Monitoring the Activity of Nationally Coordinated Adolescent and Young Adult Cancer Care. *Cancers*, 2675.
20. Patterson, P., McDonald, F. E., White, K. J., Walczak, A., & Butow, P. N. (2017). Levels of unmet needs and distress amongst adolescents and young adults (AYAs) impacted by familial cancer. *Psycho-Oncology*. *Psycho-Oncology*, 1285-1292.
21. Patterson, P., Noke, M., McDonald, F. E., Kelly-Dalgety, E., Sidis, A., & Jones, B. L. (2019). Life Imprint and meaning construction for young people who have experienced the death of a family member from cancer. *Psycho-Oncology*, 1-4.
22. Queensland Health. (2019). *Queensland Health Teletrials Pilot Analysis Report*. Retrieved from Queensland Health: https://www.health.qld.gov.au/__data/assets/pdf_file/0033/856950/TELETRIALS-PILOT-ANALYSIS-29-July-2019.pdf
23. Roder, D. M., Warr, A., Patterson, P., & Allison, K. R. (2018). Australian Adolescents and Young Adults-Trends in Cancer Incidence, Mortality, and Survival Over Three Decades. *Journal of Adolescent and Young Adult Oncology*, 326-338.
24. Shaw, P. H., Reed, D. R., Yeager, N., Zebrack, B., Castellino, S. M., & Bleyer, A. (2015). Adolescent and Young Adult (AYA) Oncology in the United States: A Specialty in Its Late Adolescence. *Journal of Pediatric Hematology/Oncology*, 161-169(9).
25. Smith, A. W., Seibel, N. L., Lewis, D. R., Albritton, K. H., Blair, D. G., Blanke, C. D., . . . Zebrack, B. J. (2016). Next Steps for Adolescent and Young Adult Oncology Workshop: An Update on Progress and Recommendations for the Future. *Cancer*, 988-999.
26. Thomas, D., Davey, M., Briggs, V., & Borland, R. (2015). Talking about the smokes: Summary and key findings. *Medical Journal of Australia*, S3-4.
27. Wasowicz, A., Feleszko, W., & Goniewicz, M. (2015). E-Cigarette use among children and young people: the need for regulation. *Expert review of respiratory medicine*, 507-9.
28. Weeks, N., McDonald, F. E., Patterson, P., Konings, S., & Coad, J. (2019). A summary of high-quality online information resources for parents with cancer who have adolescent and young adult children: A scoping review. *Psycho-Oncology*, 2323-2335.