

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 circle is in the top right corner.

SUBMISSION

Australian Cancer Plan 2023-2033

KEY CONTACT

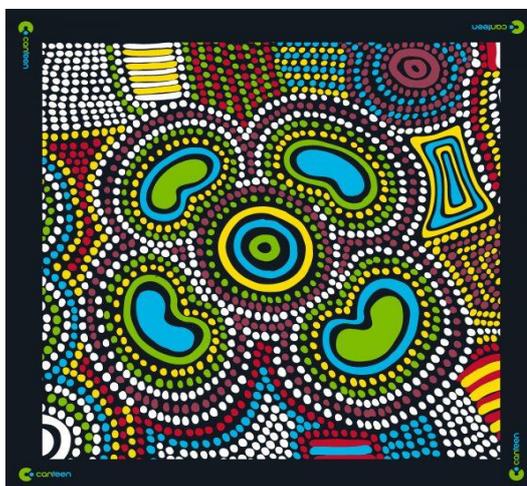
Pandora Patterson

General Manager, Research, Policy and Patient Programs
Canteen Australia

Email: pandora.patterson@canteen.org.au

PREPARED BY

1. Julia Hutton—Policy and Advocacy Officer
2. Laura Vidal—Policy and Advocacy Manager
3. Pandora Patterson—General Manager, Research, Policy, and Patient Programs



Canteen acknowledges 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.



CONTENTS

ABOUT CANTEEN AUSTRALIA	4
INTRODUCTION	4
PART ONE: GOALS AND OPPORTUNITIES	5
(1) Recognising the Need for Specialisation	5
<i>1.1 Building an adaptable workforce</i>	5
<i>1.2 Specialist responses to diverse and underserved populations</i>	6
(2) Clinical Interventions	7
<i>2.1 A national Adolescent and Young Adult Optimal Cancer Care Pathway</i>	7
<i>2.2 Improved access to new and innovative drugs and medical technologies, including clinical trials for AYAs</i>	8
<i>2.3 Standardised end-of-life care guidelines for AYAs</i>	11
(3) National Dataset	13
<i>3.1 Established national datasets of AYAs with cancer, by cancer type</i>	13
(4) Holistic and Comprehensive Support	14
<i>4.1 Modernised digital technologies</i>	14
<i>4.2 Improved access to financial support for AYAs and their families throughout treatment</i>	15
<i>4.3 Innovative models of care to improve the psychosocial support needs of AYAs with an experience of cancer</i>	17
<i>4.4 Recognition of families in the cancer care continuum</i>	19
(5) Survivorship	21
<i>5.1 Standardised survivorship guidelines for AYAs</i>	21
PART TWO: BEST PRACTICE EXAMPLES	24
(1) Youth Cancer Services	24
(2) Child and Youth Cancer Alliance: Digital Services (CYCADS)	25
(3) Australian Youth Cancer Framework and Vision 2032	26
REFERENCES	28



ABOUT CANTEEN AUSTRALIA

Canteen Australia supports young people aged 12-25 impacted by cancer, be it their own or a member of their family. 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 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.

INTRODUCTION

Canteen Australia wishes to thank Cancer Australia for the opportunity to contribute to the **Australian Cancer Plan: 2023-2033** (Plan) consultation. As the first national 10-year plan, we welcome Cancer Australia's objective of setting "a transformative agenda to accelerate world class cancer outcomes for all Australians affected by cancer". Canteen further commends Cancer Australia's process of engaging multiple stakeholders in co-designing this important piece of work, thereby ensuring the strategy is relevant and appropriate to the needs of all Australians with an experience of cancer, including adolescents and young adults, and their families.

Canteen has responded to all three focus questions provided; the first two questions are answered in Part One of the submission, whilst the third question is answered in Part Two. This submission makes 31 recommendations, and corresponding sub-recommendations, which seek to provide specific strategies relating to the needs of young people impacted by cancer, and their families, as populations with distinct vulnerabilities.



PART ONE: GOALS AND OPPORTUNITIES

This section will address questions one and two of the Australian Cancer Plan consultation survey:

Q1: What would you like to see the Australian Cancer Plan achieve? and

Q2: What are the opportunities with the greatest potential to realise your vision?

(1) Recognising the Need for Specialisation

1.1 Building an adaptable workforce

Canteen Australia is observing an emergent desire for digital health services amongst AYAs as a result of the changing service delivery landscape—not least, influenced by COVID-19 pandemic. Canteen Australia delivers a [full suite of psychosocial programs](#) that support adolescents, young people, and their families to cope with a cancer diagnosis be it their own, their siblings or their parents. Throughout the pandemic we were required to accelerate and expand a digital transformation process that was already underway. What is emerging from this experience is a preference, and almost, an expectation from AYAs that this ongoing online service delivery environment remain an option for them as a 'business as usual' approach. There are significant advantages to this including our ability to offer support regardless of geographical location; and our ability to tailor smaller and more bespoke initiatives to populations of AYAs and their families when specific needs arise. However, the transition to the online environment is not without its challenges, including a distinct need to invest in and bolster the workforce to transition from what would have been a face-to-face service delivery environment to an online environment. Alongside our own experience, we understand from our engagement with other like organisations that the transition to online service delivery, whilst necessary, has come without dedicated investment to the workforce who have made this pivot.

IMPACT CASE STUDY: Bespoke digital intervention to provide a meaningful experience to young people



Ashley*, a 24-year-old patient who was accessing individual support during her breast 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.*



The ongoing uptake of digital and telehealth mechanisms and advocacy for this to remain part of the Australian health care system brings into focus the need to ensure research around telehealth mechanisms. This research should be focused on ensuring that the quality, consistency, and equity of health care remains. We make this recommendation here, whilst also acknowledging our advocacy for this in our 2021 submission to Australian Medical Research Advisory Board Consultation on the Medical Research Future Fund Strategy (2021-2026). We recommend that tools and clinical assessment mechanisms being used in the digital and telehealth environment be the subject of evaluation to understand their usage and resources be dedicated to support any necessary adjustments. Additionally, developing a greater understanding about the holistic use of digital and telehealth services is required.

Canteen Australia supports the inclusion of the following priority area which emerged from the Australian Cancer Plan's *Ministerial Roundtable* (2021, p.2): "Plan future workforce capability requirements by identifying national trends, addressing current and future skills shortages, and planning for future care needs". This inclusion would also create scope for ensuring that the impacts of the COVID-19 pandemic on the cancer care workforce are understood and planned for, to not lose the specialised nature of care that is required through staffing shortages and health system redeployments.

1.2 Specialist responses to diverse and underserved populations

Of course, AYAs are not a homogenous group but rather intersect with the rich spectrum of human experiences, including culturally and linguistically diverse populations, Aboriginal and Torres Strait Islander peoples, geographically isolated and economically disadvantaged communities, LGBTQIA+ young people, and those with disability. While issues of diversity and inclusion are recognised as critical to AYAs – particularly during a time of significant developmental change – such diverse and historically marginalised populations are known to experience reduced physical and mental health outcomes compared with their mainstream peers (Desai et al, 2021; Shé et al, 2021; Janssen et al, 2021; Youlden et al, 2021; Baird et al, 2019; Pinkerton et al, 2018; Osborn et al, 2019; Devine et al, 2018; Patterson et al, 2017).

Certainly, such groups are frequently reported to encounter obstacles when accessing healthcare and endure unmet needs during treatment and into survivorship, further entrenching existing health disparities (Desai et al, 2021; Shé et al, 2021; Janssen et al, 2021; Youlden et al, 2021). Common barriers to accessing care amongst these populations might include limited organisational knowledge about their specific needs, which can lead to confusion, distress, and disengagement by already vulnerable groups (Shé et al, 2021; Baird et al, 2019; Ussher et al, 2021). It is therefore likely that these groups represent underserved populations who will suffer poorer health and quality-of-life outcomes (Baird et al, 2019; Patterson et al, 2017).

A considered and dedicated approach to access and equity requirements for these communities highlights the need for specialisation and must be adopted within the Australian Cancer Plan. Additional research and investment are required to ensure care initiatives, resources and support services can be deliberately and appropriately tailored to meet this population's needs (Desai et al, 2021; Perez et al, 2020; Clarke et al, 2019; Shé et al, 2021; Baird et al, 2019). Ensuring the ongoing training of healthcare staff, implementing reasonable adjustments, and exploring ways to empower diverse AYA cohorts to engage with care across the spectrum – from screening programs, to diagnosis, treatment, and



end-of-life care or survivorship – are necessary for improving the experiences and health and wellbeing outcomes of young people who are also impacted by cancer (Shé et al, 2021).

Recommendations

1. Prioritise research into the quality, consistency, and equity of digital health care.

Including:

1.1 The validation of tools and clinical assessment mechanisms within the digital and telehealth environment.

1.2 Understanding workforce needs to ensure ongoing, high-quality online service delivery.

2. Plan for future workforce capability requirements including and beyond the digital service delivery space, recognising the potential impacts that the COVID-19 pandemic and other health emergencies may have on reducing access to specialist staff due to staff shortages and health system redeployments.

3. Include a targeted goal in the Australian Cancer Plan for ‘whole of health sector’ capacity building related to the long-term impacts and care needs of individuals with an experience of cancer, including identifying the specific needs of target populations such as AYAs to eliminate disparities in cancer care outcomes, particularly into survivorship.

4. Recognise the need for specialist cancer care in supporting the unique and identified needs of diverse and underserved populations both within and outside of the AYA cohort, ensuring adequate resourcing within a long-term vision. Including:

4.1 Investing in research to improve the cancer care pathway amongst at-risk and underserved AYA oncology populations.

4.2 Developing targeted resources and support services tailored to the needs of at-risk and underserved AYA oncology populations.

4.3 Investing in education programs for healthcare staff to ensure mainstream service providers can identify and implement reasonable adjustments to empower diverse AYAs from marginalised populations to engage with care across the treatment continuum.

(2) Clinical Interventions

2.1 A national Adolescent and Young Adult Optimal Cancer Care Pathway

Optimal Care Pathways (OCPs) offer a model of nationally consistent comprehensive cancer treatment and support (NCERG, 2016). They include reference to clinical guidelines, best practice standards, and current research (Peter Mac, 2021). OCPs place patients at the centre of their care and aim to improve patient outcomes by facilitating safe, evidence-based care (NCERG, 2016). They help to ensure all Australians receive the same standard of high-quality care regardless of where they live or their treatment setting (Cancer Council, n.d.). OCPs currently exist for 18 cancer types (with a further six currently in development for a range of blood cancers) as well as target population groups, for example, Aboriginal and Torres Strait Islander peoples (Cancer Council, n.d.; Leukaemia Foundation, 2021). Cancer Australia has a strong history of endorsing OCPs alongside the National Cancer Expert Reference Group and the Cancer Council Australia (Cancer Council, n.d.).



The South Australian Department of Health (in partnership with the Australian Government and CanNET) developed a state-based [Adolescent and Young Adult Cancer Care Pathway](#) in 2010, while Victoria has committed to developing its own AYA Optimal Care Pathway (Peter Mac, 2021). The most recent Australian Youth Cancer Framework (AYCF) also suggests an OCP for young people with cancer, including a [summary of its key requirements](#) from prevention and early detection through to end-of-life care or survival (Canteen, 2017b, p. 30). However, a national OCP for AYAs does not yet exist. Additionally, OCP considerations for young people with a brother, sister, or parent with cancer are strongly warranted given the known adverse implications and outcomes for these populations without proper psychosocial intervention (Long et al, 2021; Patterson et al, 2017). Embedding OCPs as the national standard for cancer care was identified as an opportunity which would deliver a significant impact during Cancer Australia's recent *Ministerial Roundtable* discussions (Cancer Australia, 2021).

Recommendation

5. Develop and promote an evidence-based Optimal Care Pathway for adolescents and young adults with cancer, or who are impacted by familial cancer, based on existing Optimal Cancer Care Pathways, with the goal of reducing disparities and improving outcomes for these populations.

2.2 Improved access to new and innovative drugs and medical technologies, including clinical trials for AYAs

2.2.1 Investing in genetic science

Cancer treatments in AYAs pose a distinctive set of challenges due to the unique behaviour of tumours in this cohort (McVeigh et al, 2018; Isenalumhe et al, 2016). Understanding the molecular genetic processes of such tumours – and their effect on prognosis – is therefore necessary for the development of new and innovative treatments (Smith et al, 2016). Identifying and targeting responses to mutated genes are subsequently at the forefront of science and emerging technologies designed to optimise cancer care and improve survival rates (Smith et al, 2018; McVeigh et al, 2018).

Advances in knowledge of genomics have led to the development of targeted treatments for some types of acute leukaemia, colon and rectum cancer, melanoma, sarcomas, and breast cancer (Smith et al, 2016). For example, the BRCA-1 gene has been linked to early incidence of aggressive breast cancer which can then be screened for using genetic testing to aid early intervention (Smith et al, 2016; McVeigh et al, 2019). The presence of genomic markers might also modify therapeutic decisions due to the responsiveness of different tumour types to different treatments or dosages (Smith et al, 2018; McVeigh et al, 2019). The ability to screen a predisposition to heritable cancers also has significant implications for the treatment and surveillance of family members (McVeigh et al, 2019). An ongoing investment in genetic science that leads to innovative, lifesaving technologies remains a significant priority for the AYA cohort.

2.2.2 Clinical trials

Participation in clinical trials is known to improve patient outcomes through the development of more effective treatment regimens (Pollock, 2020; Isenalumhe et al, 2016). Yet with just 18% of AYAs diagnosed with cancer participating in trials, enrolment is lowest amongst this age group when compared with children and older adults (Patterson et al,



2021; Smith et al, 2016). AYAs have therefore not experienced the same increased survival rates as paediatric and adult cancer patients over the past 30 years (Shaw et al, 2011; Walczak et al, 2018). Low rates of investment and enrolment in clinical trials for AYAs with cancer are of profound concern (Osborn et al, 2019; Isenalumhe et al, 2016; Smith et al, 2016).

Barriers to enrolment are systemic and include restrictive age-related eligibility criteria, a lack of available trials relevant to rare AYA cancers, and an absence of paediatric-adult oncology relationships which reduces awareness of open trials amongst both clinicians and patients (Ellis et al, 2021; Osborn et al, 2019; Isenalumhe et al, 2016; Smith et al, 2016). 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 can also mean that patients and clinicians living in rural and remote communities face additional barriers to access and participation, which can in turn slow the development of new treatments (Walczak et al, 2018; SCHACS, 2021). In the case of excluding AYAs based on age, such obstacles remain despite not being grounded in evidence; for example, Temrikar et al (2020) found no differential effects by age should adolescents be provided access to certain lifesaving treatments that were originally restricted to adult trials.

As we submitted to the Medical Research Future Fund consultation to inform the third [Australian Medical Research and Innovation Priorities \(2020-2022\)](#), low yearly incidence of rare or less common cancers and complex populations, including AYAs (AIHW, 2018), makes drug development and clinical trials for these cancers even more difficult through domestic investment and effort alone. Opportunities to set priorities and progress promising treatments largely fall to more populous countries with advanced clinical research industries. Despite potential benefits, there is little international coordination of efforts for these cancers, contributing to the minimal pharmaceutical industry focus on these patients. The price of not addressing these cancers is substantial, with the lifetime economic impact of Australia AYA cancer diagnoses for 2016 alone estimated at \$1.4B (Canteen, 2017). With our small, dispersed population and minimal funding to support international collaboration, Australia's researchers and clinicians have few opportunities to influence treatment and develop trial planning for these cancers, particularly at the early stages in the drug discovery pipeline. Australian AYA population considerations are therefore highly unlikely to be addressed, and trial designs generally won't be suitable for such small and diffused populations. Meeting the challenge of carrying out trials in small populations will become increasingly critical as advances in personalised medicines and development of treatments for specific genetic variations of cancers becomes the norm and populations from which patients can be recruited become narrower (Walczak et al, 2018).

Furthermore, as asserted in our [submission to the Australian Medical Research and Innovation Five Year Strategy \(2016-2021\)](#), contributing to the poor availability of such trials in Australia are inconsistent regulatory, ethics and governance frameworks and procedures in different states and health districts. Lengthy clinical trial ethics and governance processes persist despite efforts to make them more efficient. Workforce preparedness, capacity, and willingness to initiate and conduct clinical trials can also be variable and cross-institutional collaboration challenges persist, including barriers to initiating trials across paediatric and adult healthcare settings. These issues can be particularly critical for conducting trials involving patients with rare cancers as trials will typically need to be



established in multiple settings to recruit sufficient patients within viable timeframes. Variable engagement with rare cancer consumer organisations and with patients themselves in the development, promotion and recruitment stages of clinical trials and inconsistent involvement of general practitioners in clinical trials are also problematic. Taken together, these issues limit the attractiveness of Australian hospitals as sites for internationally conducted clinical trials for rare cancers.

The establishment of efficient and nationally consistent trial initiation, ethics and governance processes and costs will be critical to attracting industry investment in clinical trials for rare cancer populations and ensuring Australian hospitals are well placed to be involved in international trials. Rapid recruitment, multinational collaboration and cost-saving data sharing initiatives will also be vital to ensure that Australian patients participate in ground-breaking, potentially life-saving clinical trials. Efforts to drive consistent practices and efficient recruitment will require national coordination, led by new or existing services with strong clinical and research networks. Investment in building and maintaining workforce capacity to recruit to and conduct clinical trials in complex rare cancer populations is required in the multiple contexts where such patients are treated. This will include ensuring that staff across paediatric, adult and community health settings are knowledgeable about trials for rare cancer populations and have capacity and confidence to engage in recruitment activities.

A critical focus of the Australian Cancer Plan must be high level engagement with key researchers, clinicians, clinical trial groups, industry, and community representatives to develop and implement a consistent national approach to conducting clinical trials in rare cancer populations. This will support not only domestically initiated trials but also inclusion of Australian sites in international trials. Additionally, it will be important to ensure trials are well publicised amongst rare cancer advocacy groups likely to be in contact with patients suitable for, and seeking involvement in, clinical trials. It will also be vital to build networks with multinational trial groups and pharmaceutical industry bodies focussed specifically on rare cancers. This will assist in attracting co-investment by industry and philanthropic organisations, ensuring ongoing sustainable support for rare cancer-focussed clinical trials in Australia. Co-investment opportunities with pharmaceutical industry, clinical trial groups and philanthropic partners will also be a priority to ensure the long-term sustainability of supporting access to clinical trials for patients with rare cancers. Many of these challenges and opportunities were further addressed within the recent [Parliamentary Inquiry into Approval Processes of New Drug and Novel Medical Technologies in Australia](#).

Registry-based trials offer an innovative and systematic approach to cancer clinical trials by establishing mechanisms for sharing clinical trial databases and observational studies specific to disease, health service, or product (VCCC Alliance, 2022). Registry-based trials capture clinical information and support longitudinal follow-up and better data linkage which enhances the real-world representation of patients (VCCC Alliance, 2022). They have been identified as offering a cost-effective and timely solution to addressing clinical gaps in knowledge (Foroughi et al, 2018). Such approaches have previously been recognised for their potential within cardiology (Foroughi et al, 2018). The Victorian Comprehensive Cancer Care Alliance (VCCC) have developed [one example](#) for establishing registry-based trials within an oncology setting, upon which a national clinical trial registry might feasibly be based (VCCC Alliance, 2022). Additional strategies such as investment and ongoing support for the establishment of biobanks, prospective clinical databases, and illness registries with linkages to patient records are likely to prove complementary (Casali et al, 2015).



Improving access to new cancer therapies and treatments, accelerating the adoption of personalised medicine, better understanding the role of genomics, developing, and embedding new models of care, and increasing equity of access to cancer clinical trials were identified as opportunities which would deliver the greatest impact during Cancer Australia's (2021, p.2) recent *Ministerial Roundtable* discussions. A coordinated, nationally focused approach would aid in addressing such critical issues. The following recommendations will provide an opportunity to enhance the overarching framework and improve access to life saving treatments, particularly for AYAs.

Recommendations

6. Include a review of Australia's overall approach to clinical trials as part of the Australian Cancer Plan, specifically with the view to:

6.1 Expanding access by AYAs to suitable adult and pediatric trials.

6.2 Creating systematic approaches to enhance the enrolment of suitable patients into clinical trials by targeting knowledge gaps across clinicians and consumers.

6.3 Establishing a national mechanism for central coordination and support for researchers to initiate and conduct trials.

6.4 Building a national clinical trial register that collects and facilitates patient identification, recruitment, retention, and completion rates — in line with Recommendation 23 of the [Parliamentary Inquiry into Approval Processes of New Drug and Novel Medical Technologies in Australia](#). The dataset should also capture trial participation, treatment, and patient outcomes with the capacity to segment by population group.

6.5 Establishing efficient and nationally consistent trial initiation, ethics and governance processes and costs to ensure industry investment in clinical trials for rare cancer populations remains attractive, and Australian hospitals are well placed to be involved in international trials — in-line with Recommendation 22 of the [Parliamentary Inquiry into Approval Processes for New Drug and Novel Medical Technologies in Australia](#).

6.6 Developing a nationally standardised process for rapid workforce recruitment, led by new or existing services with strong clinical and research networks, and investment in building and maintaining workforce capacity to recruit to and conduct clinical trials in complex rare cancer populations.

6.7 Developing a national standard approach to support and strengthen the capacity to conduct clinical tele-trials to address equity of access in rural, remote and regional areas — in-line with Recommendation 25 of the [Parliamentary Inquiry into Approval Processes for New Drug and Novel Medical Technologies in Australia](#).

7. Identify a priority area in the Australian Cancer Plan for international collaborative research focused on increasing opportunities for Australian researchers and clinicians to influence treatment development and trial planning due to the critical need for research pertaining to AYA cancers and the comparatively small domestic trial participant cohort.

2.3 Standardised end-of-life care guidelines for AYAs

Cancer is the leading cause of disease-related death within the AYA population (Isenalumhe et al, 2016). End-of-life care is often an incredibly challenging time due to AYAs'



developmental stage and the complex dynamics between patient, family, and clinicians, with a growing body of evidence drawing attention to the negative impact of poor psychosocial care at end-of-life (Sansom-Daly et al, 2020; Wiener et al, 2015; Pinkerton et al, 2018). Consequently, there are significant gaps in care and resultant unmet needs – both during treatment as well as into bereavement – in relation to end-of-life care for AYAs affected by cancer and their families (Perez et al, 2020; Osborn et al, 2019; McDonald et al, 2020; Pinkerton et al, 2018).

One critical gap is a lack of guidance for healthcare professionals in relation to best-practice palliative care and communication practices when working with AYAs and their families (Sansom-Daly et al, 2020; Wiener et al, 2015). Research shows that AYAs impacted by cancer think about death and want to talk about it – regardless of diagnosis or prognosis – yet clinicians often refrain from initiating such discussions (Perez et al, 2020; Pinkerton et al, 2018). Given their developmental stage and emerging coping skills, young people are especially susceptible to experiencing higher levels of distress and developing mental health disorders when faced with the combination of medical challenges and poor psychosocial support (Perez et al, 2020; Sansom-Daly et al, 2020). Likewise, one seminal study revealed that parents were more likely to develop moderate-severe depressive symptoms if they had not involved their children in discussions about death and later regretted this decision, when compared to parents who had talked to their children about dying (none of whom reported regrets) (Kreicbergs et al, 2004).

Currently, there is no consensus as to the best time to introduce end-of-life discussions within AYA cancer care, and it is unclear how often young people themselves are involved in such conversations (Sansom-Daly et al, 2020; Pinkerton et al, 2018; Isenalumhe et al, 2016; Wiener et al, 2015). However, there *is* consistent recognition that competent, compassionate, and honest communication and planning can alleviate distress and anxiety, provide a greater sense of control to AYAs, and aid the grieving process for family and friends (Wiener et al, 2015; Pinkerton et al, 2018; Isenalumhe et al, 2016; Sansom-Daly et al, 2020). Ensuring the development and systematic implementation of high-quality palliative care guidelines tailored to the support needs of AYAs and their families is therefore essential (Sansom-Daly et al, 2020; Wiener et al, 2015). Such guidelines must prioritise collaboration and coordination between medical specialist, allied health professionals, palliative care services, and community-based supports to reduce gaps and provide comprehensive care, prevent duplication in services, and avoid assumptions about different roles (Wiener et al, 2015; Perez et al, 2020; Osborn et al, 2019).

Recommendations

- 8.** Review the current approach to AYA end-of-life care including a priority area for the establishment of guidelines that include a collaborative approach between specialist medical teams, allied health professionals, palliative care services and coordination with community-based support services to ensure the needs of AYAs and their families are adequately considered in a systematic way.
- 9.** Invest in the development of population specific resources aimed at reducing the risk of psychological distress and mental illness amongst bereaved cohorts.



(3) National Dataset

3.1 Established national datasets of AYAs with cancer, by cancer type

The absence of a national registry of newly diagnosed AYAs means that monitoring trends, tracking priorities and critical issues, and improving outcomes can be difficult for this population (Smith et al, 2018; Pollock, 2020; Roder et al, 2018). A national, linked AYA dataset would facilitate (1) identification of unmet patient needs; (2) mapping of patterns of care across centres and cancers; (3) monitoring of emerging patterns of complications; (4) assessment of patient outcomes and disparities in care; (5) a better costing of treatments and out-of-pocket expenses; and (6) the performance of collaborative research. As we have previously suggested, Canteen Australia envisions that the Australian Cancer Database could serve as the central data spine. This would allow for analysis of incidence, survival, mortality, stage, other risk stratification indices, and risk stratified survival and care patterns over time and by socio-demographic sub-group. A national AYA clinical cancer registry would also most likely result in higher quality data.

In lieu of such national systems, the Australian Youth Cancer Services (YCS) captures national activity data relating to priority areas such as clinical trial enrolment, oncofertility, psychosocial care, and survivorship (Patterson et al, 2021b). While our data collection is limited to those accessing support through the YCS in each state and territory, such processes provide a model of how coordinated initiatives may be utilised to deliver, monitor, and improve the provision of quality care for AYAs across Australia (Patterson et al, 2021b). Certainly, we have previously argued that national priorities and a national approach to data and research are particularly critical and must be prioritised over jurisdictional interests, particularly in the case of rarer cancers. Improved data collection regarding minority groups and underserved populations is also critical to ensuring better outcomes (Clark et al, 2019).

National-level systems for capturing critical patient information have seen significant success in facilitating the sharing of expertise, ideas, and learnings internationally (Osborn et al, 2019). Continuing efforts to “strengthen national data linkage, and reporting of data that relates to cancer stage, treatments and recurrence of cancer at the national level” were therefore recognised as opportunities to deliver the greatest impact on cancer outcomes in Australia during the recent *Ministerial Roundtable* (Cancer Australia, 2021, p.2). In the first phase of YCS, Canteen Australia collaborated with Cancer Australia on the development of a national dataset specification: the [Adolescent and young adult cancer \(clinical\) National Best Practice Data Set](#). We recommend looking to this guidance as a beginning point for developing a specific, national, minimum data set. We note that the success of this will rely on Cancer Australia driving State and Territory partnerships to ensure consistent data gathering and the establishment of information sharing protocols that allow for the collation of a national minimum dataset that can be accessed and used to drive ongoing service improvements.

The unique landscape of health service delivery in Australia – including the mix of public and private hospitals, the robust primary care sector, and diverse community-based, not-for-profit (NFP) health sector – highlight the value of investing in the establishment of a national dataset. This national-level system would capture clinical information pertaining to treatment (including participation in clinical trials) and patient outcomes, segmented by population groups and will ultimately build an understanding of treatment options and outcomes to inform the research agendas (Pollock, 2020; Osborn et al, 2019).

Recommendation

10. Include a specific goal in the Australian Cancer Plan for the establishment of a national cancer dataset, allowing segmentation by population group including AYA cancer patients.

(4) Holistic and Comprehensive Support

4.1 Modernised digital technologies

In addition to the roughly 1,000 AYAs who receive a cancer diagnosis themselves each year in Australia (AIHW, 2018), approximately 21,000 more AYAs are told their parent has cancer and another 1,000 will learn their brother or sister has cancer (AIHW, 2016; AIHW, 2011; ABS, 2011; de Vaus 2004). While a cancer diagnosis presents significant developmental challenges for a young person confronting their own ill-health, so too can it disrupt the lives of AYAs involved in their parent's or sibling's cancer care (Patterson, 2016; Grabiak et al, 2007; Zebrack, 2011). These disruptions can lead to greater psychological distress and behavioural challenges (Patterson et al, 2017; Walczak et al, 2018). Fortunately, early identification and individualised psychosocial intervention for young people and their families can help to lessen the negative effects of cancer and promote wellbeing (Zebrack et al, 2014; Zebrack, 2011; McDonald et al, 2016). Digital health offers one means of delivering such specialist psychosocial support (Cohen et al, 2022).

The past decade has seen substantial growth in the use of digital health interventions (McCann et al, 2019). Digital health is the “use of technology in the promotion, prevention, treatment, and maintenance of health and health care” (Devine et al, 2018, p. 1). It encompasses a wide range of technologies including e-health and telehealth and can be used in multiple ways such as information delivery and two-way assessment (Kaal et al, 2018; Devine et al, 2018). Advances in digital health and their application in optimising AYA cancer outcomes are particularly relevant given AYAs are pervasive users of technology, with demonstrated acceptability (Allison et al, 2021; Devine et al, 2018; Kaal et al, 2018). The rapid shift to digital and telehealth under COVID-19 initiatives has also shown promising benefits, particularly in increasing the accessibility of healthcare delivery in a highly mobile population.

IMPACT CASE STUDY: The role of multiple formats of online support for AYAs with an experience of 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.*



Canteen Australia has been at the forefront of delivering digital psychosocial and mental health support to young people – including the siblings and offspring of someone with cancer – and, more recently, parents with an experience of cancer themselves. Our experience, which pre-dates the shift to online service delivery as a result of COVID-19, has demonstrated that young people, especially those who are in regional and remote communities, benefit from a community of people who understand their experience in addition to accessible counselling and specialist mental health support that is tailored to their needs. Certainly, existing data credits digital health interventions with improved therapeutic outcomes – both physical and psychological – during active treatment and into survivorship (Kaal et al, 2018; Devine et al, 2018).

Recommendations

11. Include a review of best evidence as it relates to the use of digital health services including, but not limited to, telehealth, with a view to:

11.1 Establishing a clear clinical pathway which ensures quality and sustainable delivery of online services to children and young people, and their families, to access the support they need, when they need it.

11.2 Ensuring online service delivery is specialised and targeted, with innovative and cutting-edge technology in place to provide equitable access across all children, young people, and their families impacted by cancer.

12. Invest in research regarding emergent design, practice, and delivery models to determine the best practice use of digital health interventions, engaging young people in co-design and co-implementation.

13. Ensure sufficient funding is allocated toward the design of new digital health resources, including resourcing for product maintenance, data gathering and analysis, and user training or support requirements.

4.2 Improved access to financial support for AYAs and their families throughout treatment

Despite universal access to publicly funded healthcare, Australians with a disability or chronic illness – including young people with cancer – commonly encounter financial hardship (Paul et al, 2016), with almost 20% of health costs falling on young patients and their families (Canteen, 2017). In addition to the physical and emotional suffering endured following a cancer diagnosis, AYAs and their families are also subjected to the dual challenge of increased medical expenses and lost income due to a reduced ability to work while being treated for, and recovering from, cancer (Durber et al, 2021; McNeil et al, 2018; Paul et al, 2017; Gordon et al, 2017a). The cost of prescription medication alone is the cause of financial burden for more than one-third of Australian cancer patients (Paul et al, 2017). Medical costs increase drastically should an AYA with cancer require access to an international lifesaving clinical trial which is otherwise not available to them within Australia – an issue which has recently been [spotlighted by Canteen](#). Furthermore, some aspects of care, such as fertility preservation, are more likely to be encountered by the AYA oncology cohort than older patients with cancer, potentially producing additional out-of-pocket expenses (Anazodo et al, 2018; Cancer Council, 2020).

Patients can also encounter non-medical out-of-pocket expenses such as travel, accommodation, parking, home help, and childcare-related expenses (Durber et al, 2021;



Pearce et al, 2019; McNeil et al, 2018). This is particularly evident in rural and remote Australia, with patients living outside metropolitan settings 17 times more likely to report locational or financial barriers to care (Paul et al, 2017). Given approximately one-third of new cancer diagnoses occur amongst patients living in these areas, the issue of financial toxicity amongst rural and remote patients is significant (Bygrave et al, 2021; Pearce et al, 2019). Unfortunately, increased financial burden is associated with diminished medication adherence, worse psychological wellbeing, and poorer cancer outcomes (Durber et al, 2021; Bygrave et al, 2021; Chan et al, 2019; Pearce et al, 2019).

As a result of their age and limited resources, young people are instead forced to borrow money, forgo spending (including on healthcare), return to work prematurely, or rely on family or income support payments (Pearce et al, 2019; Gordon et al, 2017b; Paul et al, 2017; Canteen, 2017). This need often continues throughout treatment and into survivorship, when the late effects of cancer appear (Fardell et al, 2018; Canteen, 2017), with the financial burden of cancer shown to last many years after diagnosis (Pearce et al, 2019; McNeil et al, 2018). Cancer in AYAs subsequently places a significant financial burden not only on the young person but also their family (McNeil et al, 2018; Fardell et al, 2018; Canteen, 2017). Indeed, it is often the family and friends of a young person diagnosed with cancer who take on informal caring roles and responsibilities (Canteen, 2017). The costs imposed upon informal carers therefore adds another dimension to the cumulative financial impact of cancer (Canteen, 2017). This is because the care provided, although free of charge, means time away from other activities, including paid work (Durber et al, 2021; Canteen, 2017), with nearly one-third of families caring for a child with cancer falling below the poverty line in Australia (Bygrave et al, 2021).

Taken together, an experience of cancer can severely disrupt a young people's trajectory toward financial independence (Ghazal et al, 2021; Perez et al, 2020; Fardell et al, 2018). The term "financial toxicity" has therefore been adopted to describe the adverse effects cancer can have on a patient's financial situation and subsequent health and wellbeing outcomes for both themselves and their families (Durber et al, 2021; Bygrave et al, 2021). At least 48% of cancer patients experience financial toxicity (Pearce et al, 2019). Consequently, Canteen Australia, in partnership with other leading Australian cancer charities, has been at the forefront of advocating increased transparency regarding the cost of cancer treatment through the development of the [Standard for Informed Financial Consent](#). The recent Australian Cancer Plan's *Ministerial Roundtable* (2021, p.2) further concluded that reducing the financial burden of cancer on consumers, including out-of-pocket-expenses, represented a significant opportunity to improve cancer outcomes in Australia.

Ensuring access to adequate financial support from the point of diagnosis through to survivorship is clearly a priority in AYA cancer care and support (Janssen et al, 2021). Additional research into how financial toxicity presents and its impact on Australian AYAs – particularly those from rural or regional communities, and Aboriginal and Torres Strait Islander populations – is needed to identify suitable mechanisms for support (Ghazal et al, 2021; Durber et al, 2021).

Recommendations

- 14.** Build national understanding about the financial strain of those with an experience of cancer who do not have access to a basic income including the implications of this in meeting both costs of living and ongoing medical expenses.



15. Partner with the Department of Social Services to develop a new income support payment for people with chronic illness, including cancer, with consideration to this being one part of a comprehensive support package that is customised for individuals diagnosed with cancer. The payment would be time-limited and not contingent on evidence of independence. It is recommended that this payment is paid at the rate of the Disability Support Pension.

16. Ensure access to financial support is streamlined and prioritised to reflect the reduced capacity of claimants to submit applications for assistance due to ill-health and high levels of distress. This includes considering how existing Cancer Care Navigator models can support patients in accessing financial support.

17. Invest in research concerning financial toxicity and its impact on Australian AYAs, particularly those from diverse or at-risk and underserved populations, to identify suitable mechanisms for support.

4.3 Innovative models of care to improve the psychosocial support needs of AYAs with an experience of cancer

The distinct developmental vulnerabilities of the AYA cohort necessitate a tailored response to their social and emotional wellbeing (Zebrack et al, 2016). Given the timing at which AYAs receive their cancer diagnosis corresponds with developmental issues characteristic of their age, the burden of cancer – both medical and psychological – is far greater than that of their adult counterparts (Patterson et al, 2021a). The ability of health services to recognise these needs and implement specialist supports sits along a continuum, from no specialist support through to a comprehensive and dedicated model of AYA cancer care which includes access to, for example, clinical trials, education and employment supports, and peer support opportunities (Fardell et al, 2018). However, the impact of cancer often means ongoing care throughout their lifetime, not just in the acute setting (Patterson et al, 2021a).

Currently, when young people complete treatment, their experience of being discharged from acute settings and getting connected to community-based care is variable. The acute and primary care sectors are overburdened and not always able to address the psychosocial needs of patients – particularly those with complex and chronic illnesses (ACSC, 2019). Even when the need for specialist support is identified and referrals to community-based services are made, young people are frequently subjected to high gap payments and long waitlists, often resulting in them accessing generic services which are ill-equipped to meet their needs instead.

Despite the potential to address these challenges, the community based, NFP health sector faces challenges in reaching the patients most likely to benefit from the services it offers, in part due to a lack of integration into the broader Australian health system. Canteen has previously reported on the difficulties and opportunities associated with developing models of care for the AYA population, including the need for better coordination and consultation between hospitals and community-based services (Patterson, 2016). Addressing the sub-optimal integration of effective services delivered by the NFP health sector presents an opportunity to better meet the needs of patients and families while reducing the burden on acute and primary care settings. We have previously worked with other prominent Australian cancer charities, for example, as part of the [Australian Cancer Survivorship Centre](#), to articulate the value of the NFP health sector in the provision of care across the cancer continuum, to improve understanding of the role for community support organisations across the health sector more broadly. Supporting patients to navigate



IMPACT CASE STUDY: Referral pathways from hospital to the community create psychological safety for AYAs



Margery* is a 19-year-old university student, whose older sister was diagnosed with an aggressive form of brain cancer in 2019. Margery was experiencing high levels of distress and anxiety adjusting to the rapid changes in her family life in responding to her sister's cancer. Margery was given a Canteen brochure at the hospital and learned that counselling was available to her sister, herself, and her parents. Margery was relieved to discover that the Canteen Online Support Service offered free and unlimited counselling sessions, as she did not have the means to pay for a private psychologist and was hoping to receive consistent, long-term support as her situation changed and evolved (rather than the 10 sessions available through Medicare).

In counselling, Margery was able to learn effective communication strategies to use with her family members, which helped her to navigate tensions during her sister's treatment interstate. She was pleased to have a space where she could identify and validate her growing feelings of uncertainty and worry, without 'placing more pressure' on her parents. Margery was invited to join the monthly Sibling Discussion Group run by the Canteen Online Support Service, where she could meet and learn from other young people across the country who have also been impacted by a sibling with cancer.

**Name has been changed.*

health systems and coordinate their care across primary, secondary, and tertiary settings, as well as between the public and private health systems, was further identified during Cancer Australia's recent *Ministerial Roundtable* discussions, as was considering the sustainability of specialist community services and ensuring they are available to all who need them (Cancer Australia, 2021).

Innovative models of care – or models of wellness, as is the preferred conceptualisation for people who have survived cancer – are therefore required to address the unmet needs of the AYA oncology population, especially at critical junctures throughout a cancer experience – namely diagnosis, during treatment, and transition to survivorship (Patterson et al, 2021a; Devine et al, 2018; Ke et al, 2018; Janssen et al, 2021; Osborn et al, 2019; Pinkerton et al, 2018). Such models must be centred on an integrative approach between providers across the continuum of care – from hospitals to GPs, community mental health services to specialist cancer support organisations – rather than the currently siloed system (Baird et al, 2019). One such example of integrative care which Canteen is working to establish are Canteen Clinics, which aim to offer multidisciplinary care and support for AYAs and their parents to access comprehensive survivorship care.

As we have previously argued, a key challenge for the Australian health system is ensuring the optimal utilisation of all sectors and services. The NFP sector is critical to this approach, targeting a multitude of health conditions, delivering essential services, support, and resources, and relieving a considerable burden on the primary and acute care sectors (ACSC, 2019). This has been clearly evidenced throughout COVID-19, which profoundly changed the landscape of healthcare across Australia, including increased reliance on community and home-based care. The NFP health sector have significant visibility and connection with the community, being activated and relied on to supplement the acute



and primary health care settings. For example, they were recruited to support the COVID-19 vaccine administration program, roll out and endorse public health messaging, and provide mental health support to health care sector workers and communities at large. Canteen Australia acknowledges that the COVID-19 environment, more than ever, has highlighted the social determinants of health (AIHW, 2020); coupled with an increasing focus on a values-based health care framework which prioritises integrating care in the health system across sectors, including social care (Zonneveld et al, 2020), the inclusion of a priority area focused on the NFP health sector would be both timely and necessary to ensure ongoing strategic partnerships which ensure integrated practice.

Ensuring the NFP health sector services are well integrated into the health system is particularly needed alongside efforts to map services, develop referral pathways, and implement shared models of care. Support for collaborative funding and advocacy opportunities is further needed (ACSC, 2019). Effective integration (including systems as well as focus areas, such as physical and mental health) depends to a large degree on having a robust evidence-base for the services offered by all health care sectors. It is also vital to ensure the NFP health sector has the capacity and infrastructure to evaluate their services, conduct and participate in health services research, and leverage data to drive continuous improvement. Establishing a stand-alone priority focussed on the NFP health sector will enhance the evidence-base for the health services, programs, interventions, and resources provided by this critical third sector of the Australian health system. It will also support the integration of this sector into the continuum of care across health sectors.

Recommendations

18. Invest in research regarding innovative models of care for AYA cancer patients, paying due attention to their unique developmental needs.

18.1 Build a research agenda which comprehensively addresses the social determinants of health as they relate to AYA cancer.

19. Improve education and training opportunities for cancer specialists and general practitioners to improve knowledge and shared care arrangements of the unique developmental needs of AYAs impacted by cancer.

20. Invest in support coordination roles which transcend hospital boundaries, for example, Cancer Care Nurse Navigators or Social Workers who specialise in supporting the holistic care needs of AYAs impacted by cancer.

21. Invest in long-term health sector service delivery planning and support which effectively integrates not-for-profit services as part of a model of comprehensive shared cancer care.

21.1 Include sufficient resourcing for robust data collection and evaluation, to build the evidence-base for services, programs, interventions, and resources delivered by the not-for-profit health sector, and to drive improvement.

4.4 Recognition of families in the cancer care continuum

The ability to recognise and adequately respond to the distinct psychosocial needs of AYAs extends beyond the person with cancer themselves to their parents, offspring, and siblings who might also experience disruptions to their lives (Patterson, 2016; Grabiak et al, 2007; Zebrack, 2011). Each year, approximately 21,000 AYAs in Australia are told their parent has cancer, while a further 1,000 are told their sibling has cancer (AIHW, 2011; AIHW, 2016; de



Vaus 2004; ABS 2011). The impacts of such news can be wide-ranging and long-lasting (Patterson, 2016). For example, young people frequently become involved in their loved one's care and support needs, often impacting their own routines and progress towards increased social, emotional, and financial independence (Gabiak et al, 2007; Zebrack, 2011; Patterson, 2016; Visser et al, 2004). These life changes can lead to increased distress and behavioural challenges, from diagnosis through to bereavement (McDonald et al, 2020; Patterson et al, 2021a; Patterson et al, 2017; Walczak et al, 2018).

One recent study found that young people with a parent with cancer report levels of psychological distress three to six times higher than others their age (Patterson et al, 2017). Similarly, many siblings experience high levels of distress following diagnosis (Patterson et al, 2017). However, the reorganisation of the family network to care for the person with cancer often means that offspring and siblings' distress and needs go undetected (Patterson, 2016; Franklin et al, 2018). Consequently, offspring often report unmet needs around information about the cancer, practical assistance (e.g., with school, work, or home life), recreation and time-out, family support, emotional support, and peer support (Weeks et al, 2019), while siblings often identify the importance of strengthening their relationship with their sibling as a priority (Patterson et al, 2017). When the emotional and information needs of offspring and siblings are met, they tend to report less distress (Weeks et al, 2019; Patterson et al, 2017). Likewise, lower distress has been positively associated with increased family support and practical assistance, as well as recreation and peer support (Weeks et al, 2019). Unfortunately, few specialist support services exist to address these needs (Weeks et al, 2019). Canteen has sought to address this gap through offering a range of resources including [information books](#), individual support and counselling (face-to-face and [online](#)), [peer support](#), psychosocial programs, and [recreational camps and activities](#).

Meanwhile, parental stress and depression can have far-reaching consequences for family functioning, including child outcomes (Weeks et al, 2019). Yet, parents – especially fathers – might feel challenged with their emotional expression and talking openly and honestly with their children about their cancer and how they're coping (Weeks et al, 2019; Patterson, 2016). In fact, how to talk to children about cancer and how to help their children deal with difficult emotions are two of the most commonly expressed needs amongst parents (Weeks et al, 2019). 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 (Patterson, 2016).

Research has subsequently identified various unmet needs unique to this cohort both during and after the cancer experience (Cohen et al, 2022; McDonald et al, 2020). For example, in the case of bereavement, one study found that offspring experience an average of 27 unmet needs, while siblings experience an average of 23 unmet needs, with higher levels of psychological distress associated with having more unmet needs (McDonald et al, 2020; Patterson et al, 2019; Weeks et al, 2019). The unmet needs of AYAs impacted by familial cancer, and vice-versa, therefore necessitates future research to help professionals identify and respond to gaps in care sooner and to aid the development of AYA-specific resources to reduce risk of psychological distress and mental illness amongst these cohorts (Weeks et al, 2019; McDonald et al, 2020).



IMPACT CASE STUDY: The role of 'whole-of-family' support for AYAs in responding to a cancer diagnosis in the family



David* reached out to the Canteen Online Support Service to access Parent Support, after discovering that his wife was diagnosed with bowel cancer. David has two teenage girls, who were responding to this news very differently. David was offered space to reflect upon how the cancer diagnosis has demanded different things from him, his wife, and his kids as they tried to juggle treatment, oncology appointments whilst maintaining a sense of routine and normalcy for his daughters in high school.

David's counsellor introduced him to mindfulness relaxation techniques and helped him clarify his priorities as a parent. While David felt supported by his local network, he turned to Canteen's Parent Support to draw upon the cancer-specific expertise that the counsellor was able to offer when it came to understanding the behaviour of his teenagers. Feeling stretched for time already, David was pleased to be able to access appointments on Sunday – as this is the only day, he doesn't have other commitments to tend to. David appreciates the flexibility to be able to book an appointment the week after receiving test results back, so he can discuss next steps, and what to communicate to his kids with his individual counsellor.

**Name has been changed.*

Recommendations

- 22.** Embed an approach within the Australian Cancer Plan that recognises and responds to the needs of families, including parents, offspring and siblings, as part of the continuum of cancer care and support.
- 23.** Recognise the critical need for specialist cancer support services in the provision of care for siblings, offspring, and parents of AYAs with an experience of cancer, including through adequate resourcing for existing specialist providers as well as by implementing educational and training opportunities to upskill mainstream health services to execute the goals of the Australian Cancer Plan.
- 24.** Commit to ensuring the needs of families impacted by cancer form part of Cancer Australia's research agenda, ensuring continued investment and support for research. This will aid in the development of population specific resources aimed at reducing the risk of psychological distress amongst this population.

(5) Survivorship

5.1 Standardised survivorship guidelines for AYAs

Medical and technological advances have increased the five-year survival rate for AYAs with many cancer types in recent decades (Baird et al, 2019; Roder et al, 2018; van Dorp et al, 2016). However, young people do not simply return to 'normal' life once their cancer is treated, but rather deal with a range of complex health needs (Baird et al, 2019). Practice experience and research tell us that young patient's experience of finishing cancer treatment is suboptimal, with adverse consequences across multiple physical and psychosocial domains (Skaczkowski et al, 2017; Baird et al, 2019).

Certainly, survivors of AYA cancer frequently experience one or more chronic health condition – with an elevated risk of morbidity and mortality – by age 40 (van Dorp et al,



2018; Ke et al, 2018). The presence of psychological distress is also common, particularly in relation to fear of recurrence which is more common amongst AYA cancer survivors (Baird et al, 2019), with data suggesting up to 41% of AYA survivors experience such symptoms (Smith et al, 2016). However, survivorship care predominantly emphasises the monitoring of cancer recurrence and second primary malignancies while paying insufficient attention to the corresponding psychosocial needs, late effects of cancer and treatment, emergence and management of other chronic illnesses, and attention to modifiable risk factors such as diet, exercise, smoking or UV exposure.

Although the conclusion of treatment and transition into survivorship is often the first-time young people begin to emotionally and intellectually process their cancer experience and how it might affect their life into the future, the timing tends to correspond with diminished contact with specialist support services (Patterson et al, 2021a; Janssen et al, 2021; Tindle et al, 2019; Baird et al, 2019). Changes to the nature of social relationships during and after treatment might create additional adjustment and support challenges, while returning to education or employment can be difficult due to potentially prolonged absences and the late effects of treatment (Baird et al, 2019). Unsurprisingly, adjusting to life after cancer for both survivors and their families was a key challenge identified by one recent study (Baird et al, 2019).

The fragmented and often unsupported transition to community-based care has subsequently been described as a “problem dump”, with long and complex pathways to diagnosis and limited involvement during active treatment straining the AYA-GP relationship, producing additional challenges when re-engaging with primary care (Baird et al, 2019, p.3). Reduced knowledge of treatments, their associated risks, and appropriate follow-up further can further erode trust and compromise care (Janssen et al, 2021; Baird et al, 2019). One solution is the use of treatment summaries or survivor care plans as a means of communicating such information by specialists to GPs (Baird et al, 2019). However, the use of such processes is currently inconsistent (Baird et al, 2019; White et al, 2018; Patterson, et al 2021b).

Clearly, the dominant siloed approach, characterised by poor communication and coordination, is not providing optimal care (Baird et al, 2019). Canteen Australia is currently working to address some of the identified gaps in survivorship care through the establishment of the Canteen Clinic. Here, we aim to create a multidisciplinary team of allied health professions such as general practitioners, psychologists, dietitians, and exercise physiologists so that young people and their parents can access free, bulk-billed support under Medicare Mental Health Treatment Plans and Chronic Disease Management Plans. Such innovative approaches clearly represent an opportunity with great potential to achieve flexible and responsive survivorship care, with the need to develop new community-based models of survivorship care highlighted during Cancer Australia’s recent *Ministerial Roundtable* (Cancer Australia, 2021).

Considering the above, we strongly endorse a specialised and dedicated survivorship response for AYAs with an experience of cancer within the Australian Cancer Plan as a necessary next step in cancer and survivorship care – one that will see a reduced burden of disease as young people who have been compromised during key developmental stages have their needs identified and met in timely and age-appropriate ways – with dedicated funding and investment in AYA cancer survivors.



Recommendations

- 25.** Recognise the role for, and invest in, specialist and dedicated survivorship response services within both community and health settings for AYAs with an experience of cancer with the view to meet their identified needs and reduce the burden of disease in a timely and age-appropriate way.
- 26.** Include the development of standardised end-of-treatment guidelines as part of a comprehensive and holistic approach to survivorship care. The guidelines will assist with ensuring best practice and should consider both medical and psychosocial needs regardless of treatment location or follow-up provider.
- 27.** Develop and embed new models of survivorship care including referral pathways, shared care, and transition programs from the acute setting back into community-based survivorship services, programs, and peer support with a corresponding increase in support for community-based providers given the prolonged nature of the therapeutic relationship with such services.
- 28.** Invest in education for specialist and community-based clinicians to ensure best practice survivorship care for AYAs with an experience of cancer, regardless of where initial treatment occurred.



PART TWO: BEST PRACTICE EXAMPLES

This section addresses question three of the Australian Cancer Plan consultation survey:

Q3: What examples and learnings can we build on as we develop the Australian Cancer Plan?

Canteen has been the leading AYA cancer support organisation in Australia for over 35 years. As a dedicated support organisation for AYAs and their families with an experience of cancer, we have identified and invested in the need to ensure that specific populations of people impacted by cancer have access to targeted support that best meets their needs. Through this experience we conclude and consequently advocate for specialist treatment and support options for AYAs impacted by cancer and call on Cancer Australia to consider the ways in which the Australian Cancer Plan can provide specificity within its strategy to ensure that the unique needs of various population groups are considered in their own right and responded to accordingly.

In the case of AYAs, it has been identified that: “quality cancer care ... is necessarily complex and multifaceted: the intersection of developmental needs with impacts of cancer and treatment creates unique challenges, which must be addressed if care is to be truly comprehensive” (Patterson et al, 2021b, p.10).

This section of the submission highlights several Canteen Australia initiatives that illustrate how targeted strategies for identified population groups hold significant value. By providing this snapshot, we seek to exemplify the ways in which specialist interventions offer improved cancer outcomes and experiences whilst also continuing to profile the unique and distinct needs of AYAs for consideration by Cancer Australia in the development of the Plan.

(1) Youth Cancer Services

YCS is a leading model of AYA cancer care. The coordinated and multi-disciplinary approach, with investment by both State/Territory and Federal government, is a critical pillar of support for AYAs with cancer. YCS is delivered across just under 30 hospitals nationally and, in 2020-2021, YCS saw 1,750 new and recurring patients, including 518 newly diagnosed patients. YCS provides young cancer patients with:

- Specialist care by an expert multi-disciplinary team of medical and allied health professionals with experience treating cancer in young people,
- A designated Cancer Care Coordinator – a nursing or allied health consultant – who is a personal guide to young cancer patients through the often-confusing health and social care system,
- Psychosocial screening, assessment and care planning focused on the unique psychological, social, and emotional needs of young cancer patients including difficult feelings such as guilt and boredom, social concerns like missing out on activities, physical challenges such as hair loss, or managing changes in relationships,
- Access to fertility preservation information and options,
- Improved access to new clinical trials and research, and
- Youth-friendly, age-appropriate facilities with other patients of similar ages.

Service delivery within the YCS is informed by the AYCF which is discussed in detail below. Patients and a nominated caregiver recently provided feedback on their experience and levels of satisfaction of the YCS via the [Experiences of Care Survey](#) (Noke et al, 2018). The



survey found high levels of satisfaction with the support provided by the YCS and a recent comparison (using the same measure) with patients in the US found that, while satisfaction with medical care was similar, satisfaction was generally higher in Australia for fertility services and supportive care, including communication and psychosocial support (Patterson et al, 2021c).

In addition to the direct services offered by YCS, Canteen Australia drives four national projects which are all aimed at enhancing the care and support options available to AYAs. These projects include developing a national AYA cancer database; delivering workforce development for YCS staff; funding and improving access to clinical trials; and research into survivorship to ensure young people continue to be supported post-treatment. These national projects are an example of how evidence-driven practice can continue through specialist treatment options, noting that best-practice and workforce development is a key feature of ensuring the unique medical and psychosocial experiences and care needs of AYAs are continually identified and responded to.

The YCS is currently in its fourth phase of service delivery. At the conclusion of phase three, the Sax Institute conducted an independent evaluation which highlights the success of the YCS specifically noting its value in:

- Providing multidisciplinary care and psychosocial support,
- Tailoring support to the specific needs of AYAs, as reported by the Experience of Care Survey, and
- Drawing on the expertise of multiple advisory groups which ensure ongoing high levels of service delivery, support in prioritising strategic areas for ongoing strengthening of the YCS, and involvement with progressing clinical trials and survivorship care (Graham et al, 2020).

Recent published research identifies that Australia's approach to YCS cancer care is not entirely unique, with other international jurisdictions also engaging in specialist AYA cancer care, including cross-institutional coordination (Patterson et al, 2021a; Osborn et al, 2019) and as such provides further evidence to the ways in which Cancer Australia can consider coordinated and specialist cancer care treatment across multiple target populations. The key, however, is assurance of consistent and predictable care—therefore, we also advocate for the institutionalisation of these coordinated models across health ministries nationally; this includes the guarantee of recurrent and/or long-term funding agreements.

(2) Child and Youth Cancer Alliance: Digital Services (CYCADS)

The mental health impacts on young people with an experience of cancer have been well documented (McDonald et al, 2020; Walczak et al, 2018; Patterson et al, 2021a). The Australian Government recognised the inextricable link between cancer and the high prevalence of mental health conditions and symptoms when it first funded Canteen Connect through the Teleweb initiative in 2013. Canteen Connect provides an online counselling service integrated with an online community for young people (12-25 years). Canteen Connect has undergone a three-phased evaluation, and across all studies it was reported that connection with others through the platform has helped to reduce social isolation and normalised and validated their experience (Cohen et al, 2022). In the third study on the current version of Canteen Connect, approximately three-quarters of young people who accessed the platform indicated positive experiences not only with the platform, but with the use of an online community to support them through the



psychological distress related to either their own, or their family member's diagnosis of cancer (Cohen et al, 2022).

Another critical aspect to recognise about online communities is the way in which multiple types of support can be offered, in turn meeting diverse needs across multiple users and responding to the changing needs of individual users. For AYAs impacted by their own or a family member's cancer, this type of accessible and flexible support – particularly that which connects them with other young people in similar situations – is invaluable (Allison et al, 2021). The evaluation that Canteen Australia undertook on our Canteen Connect service offers a compelling evidence base for the consideration and ongoing investment in digital mental health interventions, including the ways in which the Australian Cancer Plan can formally recognise specialist mental health support as equal to the clinical interventions required to respond to cancer.

In 2021, Canteen Australia and Camp Quality welcomed funding from the federal government to fund a partnership which will see the expansion of digital cancer support services across Australia: Child and Youth Cancer Alliance: Digital Services (CYCADS). The CYCADS initiative responds directly to our experiences of young people and their families being confronted with a complex web of medical, psychosocial, and other support services which are distressingly difficult to navigate—including our identification that there is no clear pathway for children and young people (0-25 years) and their parents to access the support they need, when they need it, in the way they need it. CYCADS is a consolidation of all the Canteen and Camp Quality digital services into a single hub for children and young people (aged 0-25 years) and provides cancer care navigation and counselling. It builds off the success of Canteen Australia's Canteen Connect and the first partnership initiative between Camp Quality and Canteen Australia's Parenting through Cancer platform.

This initiative identifies the significant value in community-based support services being recognised as playing a vital role in assisting young people and their families to navigate health systems and be provided with psychosocial support—in turn, ensuring better health and wellbeing outcomes amidst their cancer journey. Whilst this initiative is in its early stages of development and delivery, the recognition and resourcing of community-based support services is something we continue to advocate for given the value they offer to providing comprehensive and wrap-around support to individuals impacted by cancer. We recommend that Cancer Australia include in the Australian Cancer Plan a dedicated and formally recognised role for community organisations across the continuum of cancer care and support—including identifying specific and targeted roles for specialist third sector organisations to implement the goals of the Australian Cancer Plan.

(3) Australian Youth Cancer Framework and Vision 2032

In 2008, Cancer Australia and Canteen developed the [National Service Delivery Framework \(NSDF\)](#) which articulated a strategic direction for the provision of specialist multidisciplinary AYA cancer care. This was a foundational document which articulated a coordinated service delivery model, responsive to the medical, psychosocial, and supportive care needs of AYAs diagnosed with cancer. In 2017, recognising that many of the goals in the NSDF has been achieved, Canteen Australia, together with an expert National Reference Group and with the support of community and health practitioner partners, released the AYCF. This was a pivotal opportunity for Australia to re-commit to the ongoing delivery of specialist, age-appropriate treatment and support to young cancer



patients and their families. The AYCF provides a guide for individual, service, and system-level action within and beyond the healthcare sector and stands as an important feature of ensuring that young cancer patients benefit from the world class expertise of the YCS.

In 2021, Canteen Australia commenced a similar process to develop Vision 2032. Vision 2032 draws on the foundations established by the AYCF and aims to create the next platform for action that identifies priorities and strategies to achieve world leading AYA cancer care and support. Recognising the achievements under the AYCF and of the YCS, Vision 2032 seeks to push beyond the boundaries of existing care and support with the goal of ensuring that access to world leading services spans the continuum of the cancer experience from diagnosis, treatment, and long-term survivorship outcomes. Vision 2032 presents an opportunity for Cancer Australia to consider the ways in which third sector organisations can play a practical role in supporting the Australian Cancer Plan through the development of specific and targeted cancer care and support strategies. As illustrated above via the YCS and CYCADS initiatives, Canteen Australia evidences and recommends an approach that sees a genuine partnership between government and the community sector and calls for greater recognition and an identified role for community organisations in Australia's response to cancer.

Recommendations

- 29.** Embed an approach within the Australian Cancer Plan that identifies and entrenches specialist treatment and support options for identified target populations.
- 30.** Commit to consistent and predictable care by ensuring the Australian Cancer Plan recognises the need to institutionalise coordinated multi-disciplinary models of care across national health ministries, including a budgetary approach which guarantees recurrent and/or long-term funding agreements.
- 31.** Recognise and resource community-based support services as a critical pillar in the support of Australians with an experience of cancer. This includes, but is not limited to, the identification of specific and targeted roles for specialist third sector organisations in implementing the goals of the Australian Cancer Plan.



REFERENCES

Allison, K. R., Patterson, P., Guilbert, D., Noke, M. & Husson, O. (2021). Logging On, Reaching Out, and Getting By: A Review of Self-reported Psychosocial Impacts of Online Peer Support for People Impacted by Cancer. *Proceedings on the ACM on Human-Computer Interaction*, 5, 95-130.

Anazodo, A., Ataman-Millhouse, L., Jayasinghe, Y. & Woodruff, T. K. (2018). Oncofertility—An emerging discipline rather than a special consideration. *Pediatric Blood & Cancer*, 65(11), e27297.

Australian Bureau of Statistics (ABS). (2011). *Census QuickStats*. Retrieved from: https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2011/quickstat/0

Australian Cancer Survivorship Centre. (ACSC). (2019). *Community Support Organisations' Cancer Survivorship Care Consensus Statement*. Retrieved from: https://www.petermac.org/sites/default/files/media-uploads/NGO_ConsensusStatement.pdf

Australian Institute of Health and Welfare (AIHW). (2020). *Social determinants of health*. Retrieved from: <https://www.aihw.gov.au/reports/australias-health/social-determinants-of-health>

Australian Institute of Health and Welfare (AIHW). (2018). *Cancer in adolescents and young adults in Australia* Canberra: AIHW.

Australian Institute of Health and Welfare (AIHW). (2016). *Australian cancer incidence and mortality books* Canberra: AIHW.

Australian Institute of Health and Welfare (AIHW). (2011). *Young Australians: their health and wellbeing* Canberra: AIHW.

Baird, H., Patterson, P., Medlow, S. & Allison, K.R. (2019). Understanding and Improving Survivorship Care for Adolescents and Young Adults with Cancer. *Journal of Adolescent and Young Adult Oncology*, 8(5), 1-6.

Bygrave, A., Whittaker, K., Paul, C., Fradgley, E. A., Varlow, M and Aranda, S. (2021). Australian Experiences of Out-of-Pocket Costs and Financial Burden Following a Cancer Diagnosis: A Systematic Review. *International Journal of Environmental Research and Public Health*, 18, 2422.

Casali, P. G., Bruzzi, P., Bogaerts, J. & Blay, J. Y. (2015). Rare Cancers Europe (RCE) methodological recommendations for clinical studies in rare cancers: a European consensus position paper. *Annals of Oncology*, 26(2), 300-306.

Cancer Australia. (2021). *Cancer Australia launches the development of the first Australian Cancer Plan*. Retrieved from: https://consultations.health.gov.au/cancer-care/australian-cancer-plan/supporting_documents/2021_acp_australian_cancer_plan_communique.pdf



Cancer Council. (2020). *Fertility and Cancer: A guide for people with cancer, their families and friends* Cancer Council Australia: New South Wales.

Cancer Council. (n.d.). *Optimal care pathways*. Retrieved from: <https://www.cancer.org.au/health-professionals/optimal-cancer-care-pathways>

Canteen Australia (Canteen). (2017a). *The Economic Cost of Cancer in Adolescents and Young Adults*. News South Wales. Retrieved from: <https://www.canteen.org.au/about-us/canteen-reports/economic-cost-of-cancer-in-AYAs>

Canteen Australia (Canteen). (2017b). *Australian Youth Cancer Framework for Adolescents and Young Adults with Cancer*. Retrieved from: https://www.canteen.org.au/sites/default/files/2021-11/CanteenYCS_Australian_Youth_Cancer_Framework.pdf

Chan, R. J., Gordon, L. G., Tan, C. J., Chan, A., Bradford, N. K., Yates, P., Agbejule, O. A. and Miaskowski, C. (2019). Relationships Between Financial Toxicity and Symptom Burden in Cancer Survivors: A Systematic Review. *Journal of Pain and Symptom Management*, 57(3), 646-661.

Clarke, M., Lewin, J., Lazarakis S. and Thompson, K. (2019). Overlooked Minorities: The Intersection of Cancer in Lesbian, Gay, Bisexual, Transgender, and/or Intersex Adolescents and Young Adults. *Journal of Adolescent and Young Adult Oncology*, 8(5), 525-528.

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*, 14(50), 1-21.

Devine, K. A., Viola, A. S., Coups, E. J. & Wu, Y. P. (2018) Digital Health Interventions for Adolescent and Young Adult Cancer Survivors. *American Society of Clinical Oncology*, (2), 1-15.

de Vaus D. (2004). *Diversity and change in Australian families: statistical profiles*. Melbourne: Australian Institute of Family Studies.

Durber, K., Halkett, G. K. B., McMullen, M. and Nowak, A. K. (2021). Measuring financial toxicity in Australian cancer patients – Validation of the Comprehensive Score for financial Toxicity (FACT COST) measuring financial toxicity in Australian cancer patients. *Asia-Pacific Journal of Clinical Oncology*, 17, 377-387.

Ellis, J. A., Malalasekera, V. S., Allan, C., Choong, P. F., Hansford, J. R., Hehir, R., Morello, N., O'Callaghan, S., Orme, L., Phillipson, N., Rosenthal, M. A, Sawyer, S., Strong, R., Super, L., Watt, A., Williams, C., Woollett, A., Robertson, A. and Lewin, J. (2021). Systems-Level Change to Alleviate Barriers to Cancer Clinical Trial Access for Adolescents and Young Adults in Australia. *Journal of Adolescent Young Adult Oncology*. Doi: 10.1089/jayao.2021.0026.

Fardell, J. E., Patterson, P., Wakefield, C. E., Signorelli, C., Cohn, R. J., Anazodo, A., Zebrack, B. & Sansom-Daly, U. M. (2018). A narrative review of models of care for adolescents and young adults with cancer: barriers and recommendations. *Journal of Adolescent and Young Adult Oncology*, 7(2), 148-152.



Fardell, J. E., Wakefield, C. E., Patterson, P. Lum, A., Cohn, R. J., Pini, S. A. & Sansom-Daly, U. M. (2018). Narrative Review of the Educational, Vocational, and Financial Needs of Adolescents and Young Adults with Cancer: Recommendations for Support and Research. *Journal of Adolescent and Young Adult Oncology*, 7(2), 143-147.

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*, 27, e:12970.

Frederick, N., Campbell, K., Kenney, L. B., Moss, K., Speckhart, A. and Bober, S. L. (2018). Barriers and facilitators to sexual and reproductive health communication between paediatric oncology clinicians and adolescent and young adult patients: The clinician perspective. *Pediatric Blood & Cancer*, 65, 1-9.

Foroughi, S., Wong, H., Gately, L., Lee, M., Simons, K., Tie, J., Wilks Burgess, A. and Gibbs, P. (2018). Re-inventing the randomized controlled trial in medical oncology: The registry-based trial. *Asia-Pacific Journal of Clinical Oncology*, 14, 365-373.

Ghazal, L. V., Gormley, M., Merriman, J. D. and Santacroce, S. J. (2021). Financial Toxicity in Adolescents and Young Adults with Cancer: A Concept Analysis. *Cancer Nursing*, 44(6), 636-651.

Gordon, L. G., Merollini, K., Lowe, A. and Chan, R. J. (2017a). Financial toxicity – what it is and how to measure it. *Cancer Forum*, 41(2), 30-35.

Gordon, L. G., Merollini, K., Lowe, A. and Chan, R. J. (2017b). A Systematic Review of Financial Toxicity Among Cancer Survivors: We Can't Pay the Co-Pay. *Patient*, 10, 295-309.

Gabiak, B. R., Bender, C. M. & Puskar, K. R. (2007). The impact of parental cancer on the adolescent: an analysis of the literature. *Psycho-oncology*, 16(2), 127-137.

Graham, E., Redman, A. & Liu, A. (2020). Youth Cancer Services Phase 3 Evaluation: Final Report Sydney: Sax Institute.

Isenalumhe, L. L., Fridgen, O., Beaupin, L.K., Quinn, G. P. and Reed, D. R. (2016). Disparities in Adolescents and Young Adults with Cancer. *Cancer Control*, 23(4), 424-433.

Janssen, S. H. M., van der Graaf, W. T. A, van der Meer, D. J., Manten-Horst, E. and Husson, O. (2021). Adolescent and Young Adult (AYA) Cancer Survivorship Practices: An Overview. *Cancers*, 13, 1-23.

Kaal, S. E. J., Husson, O., van Dartel, F., Hermans, K., Jansen, R., Manten-Horst, E., Servaes, P., van de Belt, T. H., Engelen, L., Prins, J. B., Verberne, S. and van der Graaf, W. T. A. (2018). Online support community for adolescents and young adults (AYAs) with cancer: user statistics, evaluation, and content analysis. *Patient Preference and Adherence*, 12, 2615-2622.

Ke, Y., Ng, T. and Chan, A. (2018). Survivorship care models for breast cancer, colorectal cancer, and adolescent and young adult (AYA) cancer survivors: a systematic review. *Supportive Care in Cancer*, 26, 2125–2141.



Kreicbergs, U., Valdimarsdóttir, U., Onelöv, E., Henter, J. & Steineck, G. (2004). Talking About Death with Children Who Have Severe Malignant Disease. *The New England Journal of Medicine*, 351(12), 1175–1186.

Leukaemia Foundation. (2021). *Revised AML, DLBCL and HL Optimal Care Pathways released*. Retrieved from: <https://www.leukaemia.org.au/stories/revised-aml-dlbcl-and-hl-optimal-care-pathways-released/>

Long, K. A., Patterson, P., Katz, F. L., Amaro, C. M. & Alderfer, M. A. (2021). Creating a pathway for psychosocial support in siblings of youth with a chronic illness: Findings from an International Summit. *Developmental and Behavioral Paediatrics*, 42(4), 331-339.

McCann, L., McMillan, K. A. & Pugh, G. (2019). Digital Interventions to Support Adolescents and Young Adults with Cancer: Systematic Review. *JMIR Cancer*, 5(2), e12071, p.1-15.

McDonald, F. E. J., Patterson, P. and Tindle, R. (2020). What young people need when a family member dies of cancer. *Supportive Care in Cancer*. Doi: 10.1007/s00520-019-04973-0.

McDonald, F. E. J., Patterson, P., Kim, B. & White, K. (2018). Working beyond the patient and cancer for adolescents and young adults. *European Journal of Cancer Care*, 27(6), e12967.

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*, 25, 447–454.

McNeil, R. J., McCarthy, M., Dunt, D., Thompson, K., Kosola, S., Orme, L., Drew, S. and Sawyer, S. (2018). Financial Challenges of Cancer for Adolescents and Young Adults and Their Parent Caregivers. *Social Work Research*, 43(1), 17-30.

McVeigh, T. P., Sundar, R., Diamantis, N., Kaye, S. B., Banerji, U., Lopez, J. S., de Bono, J., van der Graaf, W. T. A, and George, A. J. (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*, 95, 20-29.

National Cancer Expert Reference Group (NCERG) (2016). *A Framework for Optimal Cancer Care Pathways in Practice: Supporting continuous improvement in cancer care*. Retrieved from:

https://www.nemics.org.au/icms_docs/252504_A_Framework_for_Optimal_Cancer_Care_Pathways_in_Practice.pdf#:~:text=The%20National%20Cancer%20Expert%20Reference%20Group%20is%20a%20panel%20of,of%20australian%20Governments%20in%202010.

Noke, M., Patterson, P., Thompson, K., Anazodo, A., Hayward, A., Henney, R. & Payne, D. (2018, December). Understanding experiences of care through the Australian Youth Cancer Services: patient and family members' perspectives. Paper presented at the 3rd Global Adolescent & Young Adult Cancer Congress. Sydney, Australia.

Osborn, M., Johnson, R., Thompson, K., Anazodo, A., Albritton, K., Ferrari, A and Stark, D. (2019). Models of care for adolescent and young adult cancer programs. *Pediatric Blood & Cancer*, 66, 1-13.



Patterson, P., Agostino, N. M. D., McDonald, F. E. J., Church, T. D., Costa, D. S. J., Rae, C. S., Siegel, S. E., Hu, J., Bibby, H., Stark, D., & International AYA Cancer Distress Screening Group. (2021a). Screening for distress and needs: Findings from a multinational validation of the Adolescent and Young Adult Psycho-Oncology screening tool with newly diagnosed patients. *Psycho-Oncology*. Doi: 10.1002/pon.5757

Patterson, P., Allison, K., Bibby, H., Thompson, K., Lewin, J., Briggs, T., Walker, R., Osborn, M., Plaster, M., Hayward, A. I., Henney, R., George, S., Keuskamp, D., & Anazodo, A. (2021b). The Australian Youth Cancer Service: Development and Monitoring the Activity of Nationally Coordinated Adolescent and Young Adult Cancer Care. *Cancers*. <https://www.mdpi.com/2072-6694/13/11/2675/htm#B18-cancers-13-02675>

Patterson, P., Pflugeisen, B. M., McDonald, F.E.J., Jacobsen, R.L., Bibby, H., Thompson, K., Lewin, J., Anazodo, A., Kok, C., Osborne, M., Hayward, A. & Johnson, R.H. (2021, December). Beyond Medical Care: How Different National Models of Care Impact the Experience of AYA Cancer Patients. Oral presentation accepted at the 4th Global Adolescent and Young Cancer Congress, London, UK.

Patterson, P., Noke, M., McDonald, F. E. J., Kelly-Dalgety, E., Sidis, A. and 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.

Patterson, P. McDonald, F. E. J., 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*, 26(9), 1285-1292.

Patterson, P. (2016). *Life interrupted: young people need help moving forward after cancer*. Retrieved from: <https://theconversation.com/life-interrupted-young-people-need-help-moving-forward-after-cancer-63704>

Paul, C. L., Fradgley, E. A., Roach, D. and Baird, H. (2017). Impact of financial costs of cancer on patients – the Australian experience. *Cancer Forum*, 41(2), 4-9.

Paul, C., Boyes, A., Hall, A., Bisquera, A., Miller, A. and O'Brien, L. (2016). The impact of cancer diagnosis and treatment on employment, income, treatment decisions and financial assistance and their relationship to socioeconomic and disease factors. *Support Care Cancer*, 24, 4739-4746.

Pearce, A., Tomalin, B. Kaambwa, B., Horevoorts, N., Duijts, S., Mols, F., van de Poll-Franse, L. and Koczwara, B. (2019). Financial toxicity is more than costs of care: the relationship between employment and financial toxicity in long-term cancer survivors. *Journal of Cancer Survivorship*, 13, 10-20.

Perez, G. K., Salsman, J. M., Fladeboe, K., Kirchhoff, A. C., Park, E. R. and Rosenberg, A. R. (2020). Taboo Topics in Adolescent and Young Adult Oncology: Strategies for Managing Challenging but Important Conversations Central to Adolescent and Young Adult Cancer Survivorship. *American Society of Clinical Oncology Education Book*, March 40, 1-15.



Peter MacCallum Cancer Centre (Peter Mac). (2021). *AYA Cancer Research*. Retrieved from: <https://www.petermac.org/ontrac/research>

Pinkerton, R., Donovan, L. and Herbert, A. (2018). Palliative Care in Adolescents and Young Adults with Cancer—Why Do Adolescents Need Special Attention? *The Cancer Journal*, 26(6), 336-341.

Pollock, B.H. (2020). What's Missing in the Assessment of Adolescent and Young Adult (AYA) Cancer Outcomes? *Journal of the National Cancer Institute*, 112(10), 975-976.

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*, 7(3), 326-338.

Sansom-Daly, U. M., Wakefield, C. E., Patterson, P., Cohn, R. J., Rosenberg, A.R., Wiener, L. & Fardell, J. E. (2019). End-of-life communication needs for adolescents and young adults with cancer: Recommendations for research and practice. *Journal of Adolescent and Young Adult Oncology*, 9(2), 157-165.

Shaw, P., Boyiadzis, M., Tawabi, H., Welsh, A., Kemmerer, A., Nancy, D., Ritchley, K. (2011). Improved clinical trial enrolment in adolescent and young adult (AYA) oncology patients after the establishment of an AYA oncology program uniting paediatric and medical oncology divisions. *Cancer*, 118 (14), 3614-3617.

Skaczkowski, G., White, V., Thompson, K., Bibby, H., Coory, M., Pinkerton, R., Orme, L. M., Conyers, R., Phillips, M. B., Osborn, M., Harrup, R. and Anazodo, A. (2017). Do Australian adolescents' and young adults' experiences of cancer care influence their quality of life? *Psycho-Oncology*, 27, 990-997.

Smith, A. W., Seibel, N. L., Lewis, D. R., Albritton, K. H., Blair, D. G., Blanke, C. D., Bleyer, W. A., Freyer, D. R., Geiger, A. M., Hayes-Lattin, B., Tricoli, J. V., Wagner, L. I. and Zebrack, B. J. (2016). Next Steps for Adolescent and Young Adult Oncology Workshop: An Update on Progress and Recommendations for the Future. *Cancer*, 122, 988-999.

Standing Committee on Health, Aged Care and Sport (SCHACS). (2021). *The New Frontier – Delivering better health for all Australians*. Retrieved from: https://parlinfo.aph.gov.au/parlInfo/download/committees/reportrep/024755/toc_pdf/TheNewFrontier-DeliveringbetterhealthforallAustralians.pdf;fileType=application%2Fpdf

Statewide Cancer Clinical Network (SCCN). (2010). *South Australian Adolescent and Young Adult Cancer Care Pathway*. Retrieved from: https://www.sahealth.sa.gov.au/wps/wcm/connect/7ef2330045a683d68fc1af9f9859b7b1/AYA+Cancer+Care+Pathway+Dec+2014.pdf?MOD=AJPERES&CACHEID=ROOTWORKS_PACE-7ef2330045a683d68fc1af9f9859b7b1-nKQdPdo

Temrikar, Z. H., Suryawanshi, S. and Meibohm, B. (2020). Pharmacokinetics and Clinical Pharmacology of Monoclonal Antibodies in Pediatric Patients. *Paediatric Drugs*, 22(2), 199-216. Doi: 10.1007/s40272-020-00382-7.



Ussher, J. M., Perz, J., Allison, K. Power, R. Hawkey, A. Dowsett, G. W., Hickey, M. Parton, C., McDonald, F. E. J., Davis, I. D., Quinn, G. P., Boydell, K., Robinson, K. H., Chambers, S. & Anazodo, A. (2021). Attitudes, knowledge and practice behaviours of oncology health care professionals towards lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI) patients and their carers: A mixed-methods study. *Patient Education and Counseling: Advanced*, online publication. Doi: 10.1016/j.pec.2021.12.008.

van Dorp, W., Mulder, R. L., Kremer, L. C. M., Hudson, M. M., van den Heuvel-Eibrink, M.M., van den Berg, M. H., Levine, J. M., van Dulmen-den Broeder, E., di Iorgi, N., Albanese, A., Armenian, S. H., Bhatia, S., Constine, L. S., Corrias, A., Deans, R., Dirksen, U., Gracia, C. R., Hjorth, L., Kroon, L., Lambalk, C. B., Landier, W., Levitt, G., Leiper, A., Meacham, L., Mussa, A., Neggers, S. J., Oeffinger, K. C., Revelli, A., van Santen, H. M., Skinner, R., Toogood, A., Wallace, W. H. and Haupt, R. (2016). Recommendations for Premature Ovarian Insufficiency Surveillance for Female Survivors of Childhood, Adolescent, and Young Adult Cancer: A Report from the International Late Effects of Childhood Cancer Guideline Harmonization Group in Collaboration with the PanCareSurFup Consortium. *Journal of Clinical Oncology*, 34(28), 3440-3452.

Visser, A., Huizinga, G. A., van der Graaf, W.T., Hoekstra, H. J. & Hoekstra-Weebers, J. E. (2004). The impact of parental cancer on children and the family: a review of the literature. *Cancer Treatment Reviews*, 30(8), 683-694.

Walczak, A., Patterson, P. & Thomas, D. (2018). Trials and tribulations: improving outcomes for adolescents and young adults with rare and low survival cancers. *The Medical Journal of Australia*, 209(8), 330-333.

Walczak, A., McDonald, F., Patterson, P., Dobinson, K. & Allison, K. (2018). How does parental cancer affect adolescent and young adult offspring? A systematic review. *International Journal of Nursing Studies*, 77, 54-80.

Weeks, N., McDonald, F. E. J, 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.

Wiener, L., Shaw Weaver, M., Bell, C. J. & Sansom-Daly, U. M. (2015). Threading the cloak: palliative care education for care providers of adolescents and young adults with cancer. *Clinical Oncology in Adolescents and Young Adults*, 5, 1-18.

White, V., Skaczkowski, G., Thompson, K., Bibby, H., Coory, M., Pinkerton, R., Nicholls, W., Orme, L. M., Conyers, R., Phillips, M. B., Osborn, M., Harrup, R. & Anazodo, A. (2018). Experiences of Care of Adolescents and Young Adults with Cancer in Australia. *Journal of Adolescent and Young Adult Oncology*, 7(3), 315-325.

Youlten, D. R., Baade, P. D., McBride, C. A., Pole, J. D., Moore, A. S., Valery, P. C., Young, A. & Aitken, J. F. (2021). Changes in cancer incidence and survival among Aboriginal and Torres Strait Islander children in Australia, 1997–2016. *Pediatric Blood & Cancer*, e29492, 1-11.

Zebrack, B., Santacroce, S. J., Patterson, P. & Gubin, A. (2016). Adolescents and Young Adults with Cancer: a Biopsychosocial Approach. In: Abrams, A. N., Muriel, A. C. & Wiener, L. (Eds.),



Pediatric Psychosocial Oncology: Textbook for Multidisciplinary Care (pp. 199–217). New York: Springer.

Zebrack, B. J., Corbett, V., Embry, L., Aguilar, C., Meeske, K. A., Hayes-Lattin, B., Block, R., Zeman, D. T. & Cole, S. (2014). Psychological distress and unsatisfied need for psychosocial support in adolescent and young adult cancer patients during the first year following diagnosis. *Psycho-Oncology*, 23, 1267–1275.

Zebrack, B. (2011). Psychological, social, and behavioural issues for young adults with cancer. *Cancer*, 117(10), 2289–2294.

Zonneveld, N. Raab, J. & Minkman, M. (2020). Towards a values framework for integrated health services: an international Delphi study. *BMC Health Services Research*, 20(224). Doi: 10.1186/s12913-020-5008-y.

