

Working together to improve outcomes for young people with cancer, improving survival and quality of life.

# EXPLORING SURVIVORSHIP CARE

**FOR ADOLESCENT AND YOUNG ADULT CANCER SURVIVORS IN AUSTRALIA**

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## Glossary of Abbreviations

Abbreviation	Referent
%	Percent
N	Number
≤	less than or equal to
ALL	acute lymphoblastic leukaemia
AML	acute myeloid leukaemia
CCSS	Childhood Cancer Survivor Study
CNS	central nervous system
COSA	Clinical Oncology Society of Australia
DT	Distress Thermometer
HCP	health care professional
IT	information technology
SCP	survivorship care plan
UK	United Kingdom
US	United States of America
YCS	Youth Cancer Services

## EXECUTIVE SUMMARY

The Youth Cancer Services (YCS) currently provide treatment and support to almost 70% of the Australian adolescents and young adults (AYAs) newly diagnosed with cancer each year who require in-hospital treatment(1). A significant majority of these patients will survive for many years past the completion of their treatment. The design and delivery of post-treatment survivorship care is therefore of high importance to the YCS. Accordingly, in 2014, CanTeen's YCS Research Advisory Group recommended scoping the landscape of Australian AYA cancer survivorship care as a key priority area for this age group. The purpose of this report is to explore and highlight the opportunities and challenges that underlie the development of survivorship care for AYA cancer in Australia. In order to do this, this report draws on information from:

- Australian and international literature on AYA cancer survivorship (Sections 2, 3 and 4);
- findings of an online survey of consumers' and health care professionals' AYA cancer research priorities (Section 4);
- insights of consumers and health care professionals who took part in focus groups and semi-structured interviews (Section 4).

While it was found that many of the survivorship issues common to AYAs were similar to those of other age groups (including the need for risk-stratification, survivorship care pathways, and holistic medical and psychosocial care), some more unique life stage issues were also prominent, such as fertility, peer-relations and youth disengagement from community-based health care.

From the perspective of health care professionals, enthusiasm about the opportunities to build on research and clinical experience to improve AYA survivorship care was high, but it was tempered by the logistics of insufficient funding, out-dated technological infrastructure, large volumes of patients and institutional reluctance to embrace new models of care.

A series of recommendations to advance the development of national AYA cancer survivorship care for Australia has been developed through this work and is detailed in the conclusion of this report.

## 1 INTRODUCTION

The genesis of the concept of “cancer survivorship” is generally attributed to Fitzhugh Mullan,(2) a physician with cancer who reflected upon the inadequacy of the concepts of sickness and cure in an essay entitled “Seasons of Survival: Reflections of a Physician with Cancer”, published in 1985.(3) In his essay, Mullan explored three seasons of survival: (1) acute survival, in which diagnosis and therapeutic intervention dominate; (2) extended survival, when cancer is in remission, the role of doctors and nurses diminishes and psychological distress, fear of cancer recurrence and physical limitations become manifest; and (3) permanent survival, roughly equated with ‘cure’. Mullan writes, “No matter how long we live, cancer patients are survivors – at once wary and relieved, bashful and proud”.(3, p.272)

In Australia, whilst it is acknowledged that cancer survivorship begins at diagnosis,(4) and that there are unclear boundaries between the three seasons of survival, models of survivorship care tend to be focussed upon the second season, that of post-acute extended survival. As argued by Mullan, it is in this season that a void can open up, that cancer patients and their families can be left to fend for themselves and that systematic referrals that could point patients to support services that would be of aid in promoting recovery in the “healthy” world are sadly lacking. It is upon the second season of survival, that of post-treatment recovery and rehabilitation, that this report focusses.

### 1.1 Australian AYA cancer survival: key facts

An important complication for deriving and interpreting AYA cancer data arises when one considers the various definitions of the AYA age interval. The Australian YCS definition of 15–25 years is somewhat at variance with international definitions, such as the age brackets used in Canada (15–29 years),(5) the UK (13–24 years)(6) and the US (15–39 years).(7) Within Australia, reporting of AYA is not standardised to 15–25 years, with the majority of statistics reflecting the Australian Institute of Health and Welfare’s definition of AYA as 15–29 years.(8) The significance of these differences lies in the fact that both the types of cancer diagnosed, and the incidence of new cancer diagnoses, differ



markedly for every 5-year interval (such that 25–29 year olds account for as many diagnoses as 15–24 year olds).(8)

### 1.1.1 Relative rates of survival

The survival prospects of Australian AYAs diagnosed with cancer are high relative to those of age- and sex-matched peers from the general population. At one year post-diagnosis, the relative rate of survival for AYAs aged 15–29 years is 95%.(8) At five years post-diagnosis, relative survival is 88%.(8) These overall figures reflect the high rates of survival of AYAs with the most common cancers, whilst masking the poorer outcomes of some less common cancers, whose rates of five year relative survival can be as low as 41%.(8, 9)

### 1.1.2 Change in survival prospects over time

The overall outlook for Australian AYAs with cancer has improved significantly over time, with improvements in rates of relative survival observed across the 1983-1989 to 2004-2010 calendar periods at both one year (92% to 95%) and five years (80% to 88%) post-diagnosis.(10) However, analysis of the survival trends for twenty of the twenty-four most frequently occurring AYA cancers (among American 15–39 year olds) reveals that only eight of these cancers have shown statistically significant improvements since 1985.(11)

### 1.1.3 Survival prospects of AYAs compared to younger and older cancer patients

Considered in relation to children aged 0–14 years and adults aged 30–39 years, Australian AYAs aged 15–29 years have slightly better prospects for survival at one year post-diagnosis, with this advantage increasing by five years post-diagnosis.(8) However, the trend lines for improvements in five year relative survival across time indicate that both children and older adults have made greater gains than AYAs over the past three decades, and therefore that the gap in overall rates of survival is reducing.(10) This trend is also observable in the US.(12)

### 1.1.4 Factors moderating AYAs' survival prospects

While the prospect for survival does not differ between AYAs living within or outside major Australian cities, superior outcomes have been observed for AYAs with the highest socioeconomic status (SES) compared to AYAs with the lowest SES status, at both one (97% vs 94%) and five years (90% vs 85%) post-diagnosis.(10) Indigenous status accounts for excess mortality, with Aboriginal

AYAs experiencing almost 50% excess mortality overall, 25% excess mortality for those diagnosed with carcinomas, and mortality rates of almost seven times those of non-indigenous AYAs with germ cell tumours.(9) Among American AYAs (aged 15–39 years), males have poorer rates of survival than females in nineteen of twenty-one types of common AYA cancers.(11) Similar survival decrements are observed for Australian males compared to Australian females.(9)

### 1.1.5 Physical and psychosocial outcomes

Depending upon their type of cancer diagnosis and its associated treatment, post-treatment AYAs may experience a range of physical performance deficits and psychosocial challenges associated with depression, anxiety, posttraumatic stress and difficulties with reintegration into social, educational and vocational contexts.(13)

## 1.2 Purpose

Each year, there are approximately one thousand new cases of cancer diagnosed among Australian AYAs, aged 15–25 years.(14) Of these, approximately 75% require hospital treatment. In 2014–15, 510 newly diagnosed young cancer patients were treated within the Youth Cancer Services (YCS).(1) This represented approximately 70% of those AYAs who required in-hospital cancer care and treatment that year. Around a quarter of these young people with a recent cancer diagnosis experience psychological distress that substantially impacts their ability to function in daily life (15).

Despite the potentially devastating effects of a cancer diagnosis, a significant majority of AYAs survive their cancer treatment and thus become post-treatment cancer survivors, often with a number of ongoing physical, developmental and psychosocial implications of having had an AYA cancer diagnosis and its associated medical treatment.(13) Planning for the ongoing care of AYA cancer survivors is therefore an area of high priority for the YCS, and was identified to be of foremost importance through the results of a large-scale scoping study of AYA cancer research priorities that was undertaken at the behest of the YCS Research Advisory Group in 2014.(16, 17)

The present scoping study was designed to inform the development of AYA cancer survivorship care processes to be enacted within Australia through creating an overview of current survivorship care available, opportunities and challenges. The focus of this report is on cancer survivorship for those young people who were diagnosed in the AYA years. While there is some overlap between this

group and survivors of childhood cancers, the unique issues of the latter group are beyond the scope of this report.

### 1.3 Method

In order to gain insight into the experiences and challenges facing AYA cancer survivors following completion of primary treatment, a comprehensive review of the literature was undertaken (Sections 2, 3 and 4). These findings were broadened and extended by stakeholder consultation with consumers and health care professionals (HCPs) using data previously collected through an online survey for our research project on determining national AYA oncology research priorities(17) , focus groups, and through semi- structured, key informant interviews (Section 4).

## 2 WHEN ACTIVE THERAPY HAS FINISHED: ONGOING CHALLENGES

Although an exciting time, the successful completion of active treatment is also a challenging time. Many AYAs develop serious chronic health problems which can lower quality of life and result in premature death.(5, 18) Psychosocial challenges associated with a return to 'normalcy' are also likely to be encountered, as are the many challenges of transitioning from the active-treatment health care services environment to less well co-ordinated off-treatment settings such as primary care.(19, 20)

### 2.1 Medical late effects

#### 2.1.1 Second primary malignancies

Long-term follow-up of survivors of childhood, adolescent and young adult cancer indicates a heightened risk of future malignancy in young survivors compared to either the general population(21, 22) or survivors of adult-onset cancers (40 years and older).(23) For example, exposure to cranial radiation during treatment for acute lymphoblastic leukaemia (ALL) is associated with subsequent tumours of the central nervous system (CNS) as well as thyroid cancer, lymphoma and acute myeloid leukaemia (AML).(24) Also, excess subsequent malignancies are observed in survivors of childhood and adolescent AML, including those who have not undergone total body irradiation.(22)

#### 2.1.2 Cardiac complications

Five-year survivors of childhood and AYA ( $\leq 21$  years) cancers demonstrate a range of cardiac complications at significantly greater rates than their siblings, with the cumulative incidence of adverse cardiac outcomes increasing up to thirty years post-diagnosis.(25) Manifestations include congestive heart failure, myocardial infarction, pericardial disease and valvular abnormalities.(25)

### 2.1.3 Endocrinologic late effects

Abnormalities in thyroid function are common among survivors of cancers treated with radiation exposure to the head and neck, especially among females and those treated in early childhood.(24) Some of the implications of CNS radiation include short adult stature, increased obesity and gonadal dysfunction in both males and females.(24)

### 2.1.4 Physical performance outcomes

Deficits in physical performance are common among survivors of childhood and adolescent cancers, and appear to have the greatest impact upon survivors of cancers of the CNS, bones and soft tissues, and Hodgkin's disease.(26, 27) Treatment variables such as the use of radiation and combinations of alkylating agents and anthracyclines are also predictors of poor physical performance.(27) Shortness of breath and fatigue may lead to reductions in the types of physical activity that are required to maintain good health,(28) but even survivors who report similar levels of physical activity to that of their siblings demonstrate poorer outcomes on measures of strength, mobility and fitness.(26) Physical performance deficits increase with age and the prevalence of pre-frailty and frailty normally associated with approximately 10% of the general population aged over 65 years is high among survivors aged on average in their thirties, affecting approximately 45% of women and 16% of men.(28) Significantly more AYA cancer survivors are overweight or obese than controls with no history of cancer.(29)

## 2.2 Neuro-cognitive outcomes

Deficits in neuro-cognitive functioning are well documented for survivors of childhood cancers, especially when treatment was undertaken at a young age.(24, 30) Risk for certain cognitive impairments has also been demonstrated to increase over time (as a function of cranial radiation therapy dose).(30) The effects of AYA cancer and its treatment on future cognitive performance are less well documented, typically involving smaller sample sizes and self-report instruments. Rather than failing to acquire cognitive skills, young adult survivors may report concerns with cognitive decline.(31) Return to full-time school/university or work is the norm, and return to part-time education or work is less common.(32) Educational and work performance may be impaired (especially for survivors of very intensive treatment),(32, 33) but many survivors report positive results such as having returned to pre-cancer academic levels(33) and even exceeding higher educational and vocational outcomes than those of comparison groups drawn from the general population.(34)

## 2.3 Psychosocial outcomes

AYA cancer coincides with one of life's most significant developmental stages, transition from childhood to early adulthood. During this transition, young people are developing autonomy from parents, establishing a sexual identity, embarking on careers or higher education, and becoming increasingly involved in peer relationships, including establishing future families.(13, 35) Cancer-related disruptions to these essential activities can involve significant levels of distress that endure beyond the completion of active treatment.(36)

### 2.3.1 Psychosocial screening

Psychosocial assessment of AYA cancer survivors is advocated as providing a means of understanding the impact of cancer, its treatment and sequelae upon the psychosocial development of young people, to identify AYAs' preventable risky behaviours and to help inform long-term management plans within the health care system.(37) However, a recent systematic review highlighted the scarcity of psychosocial instruments validated for use with AYA cancer survivors.(38) To remedy this, CanTeen and its research partners are currently assessing the Distress Thermometer (DT),(39) which is a well-known screening tool regularly used to screen for distress in adult cancer populations.(40) The purpose of the assessment is to determine the applicability, usability and clinical utility of the DT and an associated problem checklist for AYA cancer populations, and to determine an appropriate cut-off level for clinical referral.

### 2.3.2 Psychological distress

Distress in AYA cancer patients and survivors is common, with one longitudinal study demonstrating that 28% of patients screened within four months of diagnosis showed clinically elevated distress scores, with symptom levels dipping at re-assessment six months later but then increasing above population norms at re-assessment twelve months after initial screening.(41) AYA cancer survivors also demonstrate elevated symptoms of post-traumatic stress; rates of 39% at six months and 44% at twelve months post-diagnosis, with just under a third of survivors (29%) exhibiting symptoms severe enough to be suggestive of post-traumatic stress disorder.(36) Many more years post-diagnosis (years since diagnosis:  $M=13.68$  years;  $SD=6.02$ ), survivors continue to report clinically relevant levels of post-traumatic stress at three times the levels of controls, and women reporting symptoms of depression and anxiety at approximately double the rate of controls.(42)

Interestingly, while AYAs' subjective judgements of the severity of their illness have been shown to be the strongest predictors of their post-traumatic stress, these judgements are not associated with

the actual severity of their illness, as determined by medical indicators.(43) This finding has important implications for routine assessment of all AYAs' psychological distress, regardless of the actual severity of their illness. As with other age cohorts including young to middle-aged adults,(44-48) AYAs' fear of cancer recurrence is also an important consideration in the post-treatment phase.(19, 49)

### 2.3.3 Spiritual wellbeing and meaning making

A cancer diagnosis during adolescence or young adulthood can have a profound impact upon AYAs' sense of self-identity, mortality, values, spiritual beliefs and sense of purpose or meaning.(50, 51) Impacts can be either positive or negative(52) and, as with post-traumatic stress, post-traumatic growth is more highly associated with *perceived* than *objective* severity of disease, with greater perceived severity associated with greater growth.(53)

## 2.4 Social outcomes

Young adult survivors of both childhood and AYA cancer report concerns about the impact of having cancer upon their relationships with their peers, family members and romantic partners.(31) Some of these concerns include the necessity of having awkward conversations about their cancer and its potential implications for their fertility, the impact of changes in values and priorities, and the need to protect parents from worry.(31)

At approximately fifteen years post-diagnosis, German survivors of adolescent cancer in their twenties and thirties reported a number of indicators of delayed social development compared to sex-matched controls. For example, female survivors were less likely to have had a first boyfriend, or they began their first relationship later than female controls. Male survivors were more likely to be living in their parental home than male controls. While there were no differences between survivors and controls in rates of long term relationships, fewer survivors had married or had children. Those survivors who did marry and have children did so at an older age than controls.(54)

The impact of AYA cancer also extends to the areas of employment and finances, with survivors of AYA cancers reporting lower levels of paid employment than controls with no history of cancer,(29) and negative impacts upon their financial situation.(52)

## 2.5 Cultural and linguistic diversity in health care provision

AYA cancer survivors from ethnic minority groups are known to encounter additional challenges associated with post-treatment care, which is reflected in greater reporting of unmet needs for ongoing treatment, fear of cancer recurrence and self-surveillance, and financial support for medical care.<sup>(55)</sup> Ethnicity-based disparities have also been observed with access to fertility preservation in young women.<sup>(56)</sup> Building a trusting relationship with HCPs can be made more complicated by the complex interplay of cultural and language barriers encountered by both AYAs and doctors, nurses and allied health.<sup>(57)</sup> Overcoming ethnicity-based disparities in health care outcomes requires that HCPs develop awareness and skills in the provision of culturally competent care, with special attention paid to engaging parents of younger AYAs (e.g. respecting parental authority and educating parents about adolescent developmental stages).<sup>(57, 58)</sup> Issues of timely diagnosis, appropriate treatment and effective case management all stand to gain from greater attention to overcoming language challenges and cross-cultural barriers.<sup>(57)</sup>

Worldwide, Indigenous populations are often marginalised and have the poorest health indicators within their nation states.<sup>(59, 60)</sup> In Australia, the many complexities associated with delivering timely diagnoses and effective health care to Aboriginal and Torres Strait Islander people is evident at a federal policy level right down to individual health providers.<sup>(61, 62)</sup>

## 2.6 Survivorship transitions

### 2.6.1 The breadth of transition services

Transition into post-treatment survivorship is a complex process that is ideally supported by a suite of transition services tailored to address AYAs' diverse health and supportive care needs.<sup>(20, 31, 63-68)</sup> Some of these include:

- education about cancer, its treatment and potential late effects;
- long-term surveillance and screening for medical and psychosocial late effects;
- management of medical complications arising from cancer or its treatment;
- treatment for psychological distress, trauma, anxiety and depression;
- developmentally appropriate psychosocial support to reintegrate into educational and vocational contexts;
- peer support; and,
- access to legal and financial aid.



## 2.6.2 Health care services transition

The completion of active cancer treatment in Australia may be marked by transition from acute hospital-based care to ongoing community-based primary care, referral to a survivorship clinic or continued care and surveillance within the acute setting. While differences between patients may exist due to varying levels of risk, it is generally recommended that AYAs should maintain contact with their primary treating clinician for a minimum of twelve months upon completing treatment.(19, 69) In order to minimise problems associated with transition between services, there is general agreement among advocates for AYA survivors (19, 63, 69-72) that:

- planning for transition should begin before the completion of cancer treatment;
- AYAs and their families should be prepared well in advance for transition away from specialist cancer services;
- staff should be trained to facilitate smooth transition (including understanding their potential roles in assisting the AYA to reintegrate into 'normal' society and the role of community-based services);
- there should be a formal end-of-treatment consultation between the AYA and the primary treating clinician;
- comprehensive treatment summaries and survivorship care plans (SCPs) should developed by HCPs involved in acute care in partnership with the AYA, and provided to new health care providers; and,
- AYAs should be supported to become increasingly confident about taking responsibility for managing their cancer and treatment history.

## 3 AYA SURVIVORSHIP CARE

AYA cancer care is currently emerging as an internationally recognised sub-specialty within oncology.(13, 73, 74) As such, it has become the focus of a number of position statements advocating both the need for an AYA focus and recommendations regarding the potential coordinated divisions of labour into various work streams.(5, 6, 75-78) One of the recurring themes within these statements concerns working to improve survivorship research, surveillance and health care service delivery for AYAs who have completed cancer treatment. This section provides an overview of Australian survivorship initiatives identified through a literature review and key informant interviews. It should be noted that this is by no means an exhaustive account of these initiatives but provides an overview of some of the more established, well known ones. A list of additional initiatives that it was beyond the scope of this report to consider in-depth is included in Appendix B.

### 3.1 Survivorship care in Australia

Improved understanding and practice in survivorship care in Australia for survivors of all ages is promoted through a number of established Cancer Survivorship Centres (e.g., NSW Cancer Survivors Centre, the Sydney Survivorship Centre and the Australian Cancer Survivorship Centre in Victoria), position statements from peak bodies (such as COSA, see below), and a new cancer survivorship website: <http://cancersurvivorship.net.au> This website is endorsed by Cancer Australia, and was developed and funded by the Australian Cancer Survivorship Centre,(79) a Richard Pratt legacy, based at Peter MacCallum Cancer Centre Melbourne in collaboration with Cancer Australia, Queensland University of Technology and the University of Sydney. It features a series of educational and advocacy videos together with six online learning modules designed for HCPs seeking to become up to date about contemporary thinking on cancer survivorship care.

### 3.1.1 The essential elements of survivorship care: Livestrong recommendations

Embedded within the above-mentioned website's learning modules is application of the Livestrong "essential elements of survivorship care" recommendations for implementing an effective cancer survivorship program.(80) These recommendations are organised into three tiers depending upon the level of consensus achieved among expert stakeholders as to the elements' potential impact, implementation feasibility and evidence base, and are stated as follows:

#### Tier 1 - Consensus Elements

All medical settings **MUST** provide direct access or referral to the following elements of care:

- Survivorship care plan, psychosocial care plan, and treatment summary;
- Screening for new cancers and surveillance for recurrence;
- Care co-ordination strategy which addresses care co-ordination with primary care physicians and primary oncologists;
- Health promotion education; and,
- Symptom management and palliative care.

#### Tier 2 - High-Need Elements

All medical settings **SHOULD** provide direct access or referral to these elements of care for high-need patients and to all patients when possible:

- Late effects education;
- Psychosocial assessment;
- Comprehensive medical assessment;
- Nutrition services, physical activity services, and weight management;
- Transition visit and cancer-specific transition visit;
- Psychosocial care;
- Rehabilitation for late effects;
- Family and caregiver support;
- Patient navigation; and,
- Educational information about survivorship and program offerings.

#### Tier 3 - Strive Elements

All medical settings should **STRIVE** to provide direct access or referral to these elements of care:

- Self-advocacy skills training;
- Counselling for practical issues;
- Ongoing quality improvement activities;
- Referral to specialty care; and,
- Continuing medical education.

## 3.2 COSA Model for Wellness in Cancer Survivorship

The Clinical Oncology Society of Australia (COSA) presented its newly developed draft 'COSA Model for Wellness in Cancer survivorship'(4) at the Flinders Survivorship conference in February 2015. The model incorporates the World Health Organisation's definition of wellness(81) (reflecting an emphasis on health and well-being rather than the absence of disease or infirmity), and features a holistic, person-centred approach to risk-stratification, education, rehabilitation, surveillance, supported self-management, supportive care, and end-of-life transition in a collaborative context of survivors, community and health professionals (see Figures 1 and 2). This draft model is currently undergoing extensive consultation and the final version should be available in mid-late 2016.

# Cancer Survivorship

A process for living well with and beyond a cancer diagnosis



**Principles:**

*How we do it*

- Survivor centred (enabling, engaging, empowering)
- Integrated care across all service levels at every time point
- Coordinated care

*What we do*

- Promote well-being
- Prevent illness
- Manage symptoms and issues

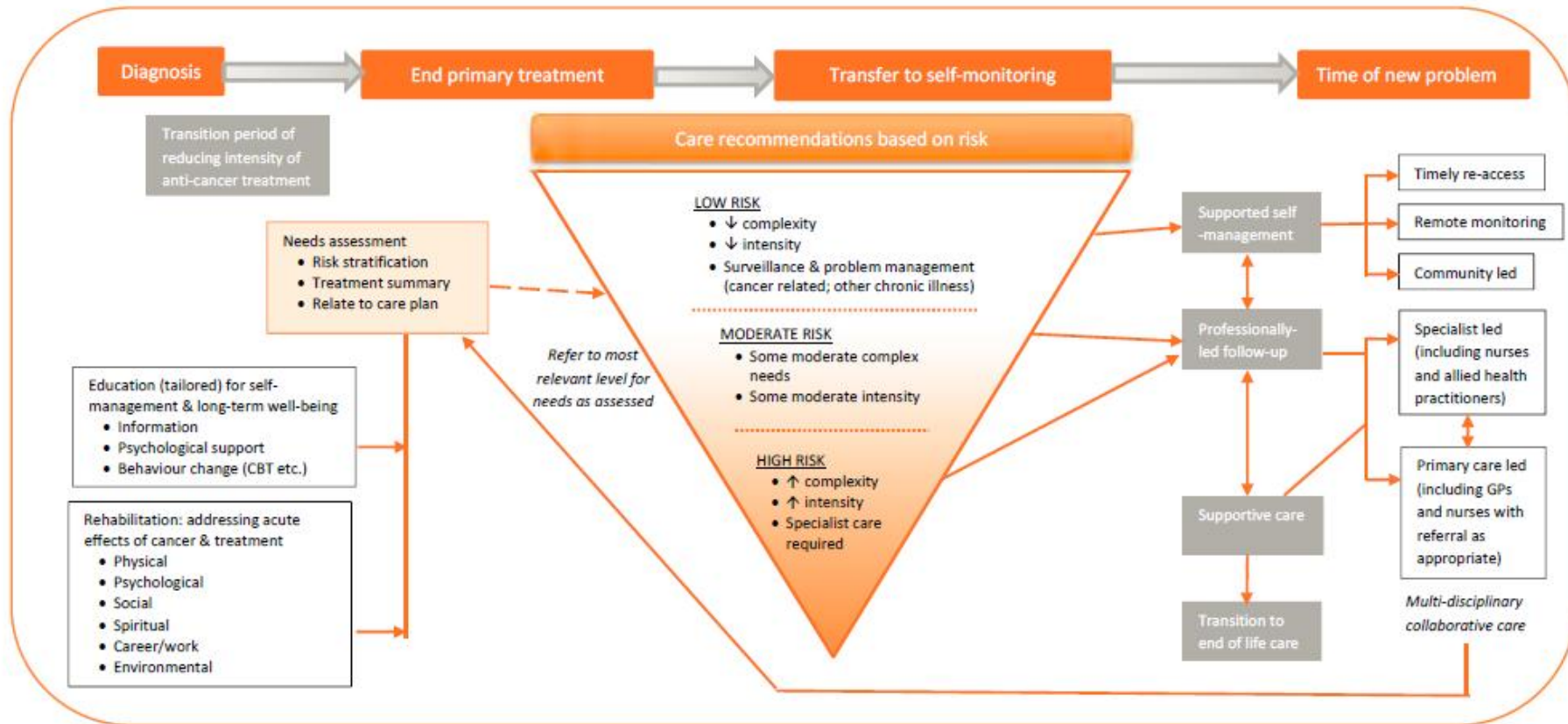


Figure 1. COSA Model for Wellness in Cancer Survivorship (draft)

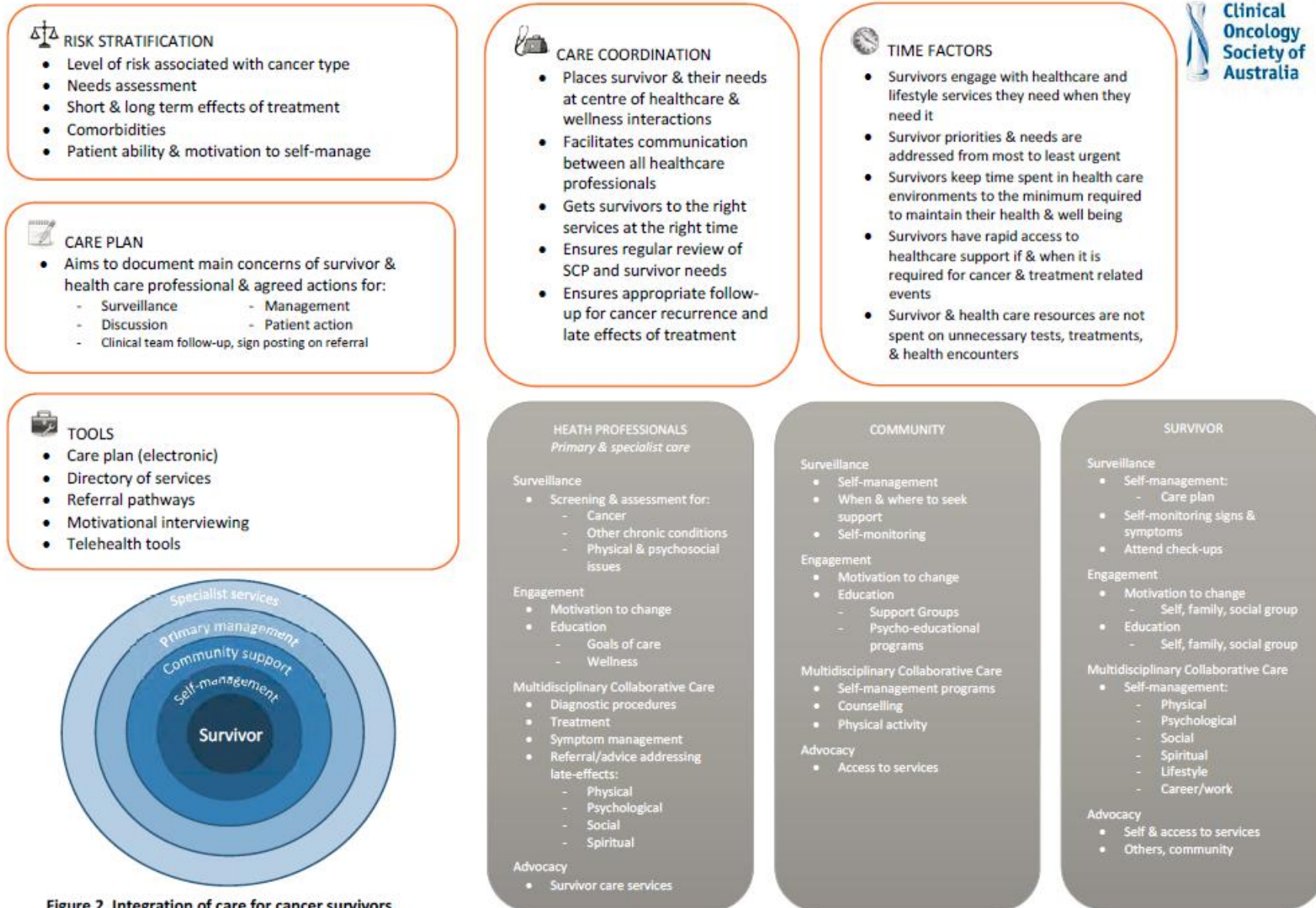


Figure 2. Integration of care for cancer survivors

Figure 2. COSA Integration of Care for Cancer Survivors

### 3.3 AYA survivorship care programs in Australia

As a small sub-set of the overall cancer survivorship population, AYAs have unique needs relating to their age, developmental stage and potential years of life lost to disability or sub-optimal health and wellbeing. Within Australia, there is increasing focus on designing and implementing survivorship care programs that are responsive to AYAs' needs, and that will be sustainable into the future. The most appropriate model of care for AYA survivors, whether paediatric, adult or a new model entirely, is still under deliberation, with emphasis upon what survivorship clinics should and should not include, the role of the GP and core competencies for all HCPs. The following examples highlight work recently undertaken with a life stage specific focus upon AYA cancer survivorship care.

#### 3.3.1 Survivorship Connections: A model of youth-friendly survivorship care in Victoria

'Survivorship Connections' is a new survivorship support program developed specifically for AYAs with cancer in Victoria, Australia. The program was recently piloted at the onTrac@PeterMac Victoria and Tasmania YCS with 46 AYAs aged 15-25 years and 9 carers. The purpose of conducting the pilot project was "... to improve understanding of the complex post-treatment needs and experience of AYA patients and their carers".(82, p.3)

Specifically, the aims of the pilot project were to:

- i. explore the acceptability of a pilot model of survivorship care for young people with cancer in Victoria, their GPs and other HCPs involved in their care;
- ii. explore the survivorship needs, levels of distress, burden of disease and quality of life of young people with cancer and how these change over time;
- iii. explore the impact of a pilot model of shared care on the acute health care facility and GPs;
- iv. explore the survivorship needs of carers of young people with cancer; and
- v. develop a suite of Australian AYA survivorship resources for young people with cancer.(82,p.13)

The pilot project largely addressed its aims, with gains in understanding in the above mentioned areas and, in collaboration with CanTeen, has led the development of an AYA survivorship resource that is near completion.

### 3.3.1.1 AYA Survivorship Pathway and recommendations

One of the principal outcomes of the Survivorship Connections project was the development of an AYA Survivorship Pathway that is recommended for dissemination and implementation “... into state-wide routine oncology care for young people from the time of treatment completion”(82, p.3) (see Figure 3).



Figure 3. onTrac@PeterMac Victoria and Tasmania Youth Cancer Service AYA Survivorship Pathway (82, Figure 5, p.34)

A series of recommendations for embedding the AYA Survivorship Pathway into routine oncology care within Victoria is also offered.(82, p.39-40) These recommendations have the potential to be broadened to apply to a national roll-out (given appropriate funding and infrastructure) and may be broadly construed to read:

- that the AYA Survivorship Pathway is implemented as part of routine AYA survivorship care in the post-treatment period for young people;
- that state-based lead hospitals support the delivery of the AYA Survivorship Pathway;
- that formal education and secondary consultation services at state-based lead hospitals continue to support AYA champions and professionals caring for AYA patients;
- that additional research into AYA survivorship aims further to:
  - α establish causality between quality of life, burden of disease, needs and distress;
  - α define and revise the psychosocial criteria against which AYA patients should be risk-stratified post treatment completion; and
  - α explore the needs of carers of young cancer survivors and ensure the implementation and evaluation of evidence-informed interventions which aim to meet these needs and reduce the carer burden.



- physical function, fitness and wellbeing should be prioritised for young people, and addressed within a structured programmatic model of care that is robustly evaluated;
- that patient self-management is prioritised through a structured approach to develop young people's skills and enable them to manage their own health care and negotiate care between a range of health care services following treatment completion;
- AYA specific information and resources need to be maintained and developed in an ongoing manner to support young people.

### 3.3.2 South Australian Adolescent and Young Adult Cancer Care Pathway

The 'South Australian Adolescent and Young Adult Cancer Care Pathway' is a clinical pathway developed by the Adolescent and Young Adult Working Party of the Statewide Cancer Clinical Network with project support from CanNET SA. The Pathway was designed to guide care of AYAs from prevention, early detection and diagnosis through supportive care, palliative care and survivorship (see Figure 4).(83) Each step of the pathway was designed to provide AYAs with evidence-based, developmentally appropriate medical and psychosocial care.

### 3.3.3 AYA psychosocial survivorship care

Another important recently developed resource in Australia is a manual designed to facilitate assessment of AYA cancer survivors' psychosocial functioning and to assist in the initiation of appropriate psychosocial care processes and pathways (see Figure 5). The manual was developed in conjunction with AYA cancer survivors and Australian AYA clinicians under the leadership of the South Australia/Northern Territory YCS, and is designed to guide the survivorship care process via the use of a screening tool and care plan to improve psychosocial outcomes for cancer survivors aged between 15 and 25 years. Development of a manual for comprehensive psychosocial care is consonant with calls to integrate all aspects of psychosocial assessment and intervention into cancer treatment and survivorship.(84)

This diagram shows the steps along the AYA cancer diagnosis and treatment pathway and the optimal care required. Not all patients will follow every step of the pathway.

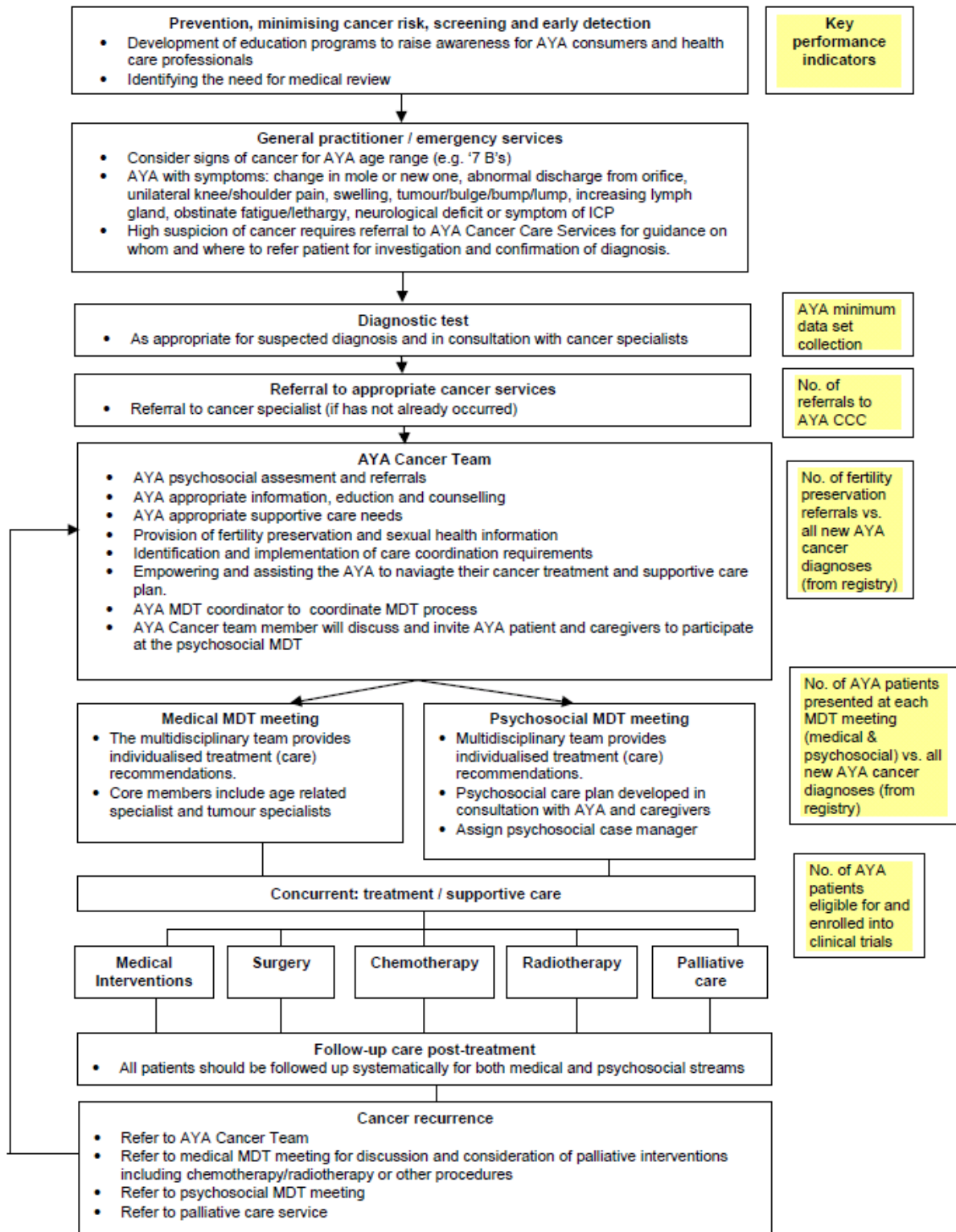


Figure 4. South Australian AYA Cancer Care Pathway

# AYA Psychosocial Survivorship Care Pathway

## Best-practice AYA Patient Management

This process begins with the assumption that best-practice AYA patient management, including psychosocial screening and assessment, individualised care plans, age-based referral, clinical support and information provision to support healthy survivorship, has been provided throughout the treatment period.

## Psychosocial Survivorship Information

It is recommended that survivorship information relevant to the journey of the individual patient is provided at approximately two weeks prior to treatment completion or at the time of final treatment. This information should contain basic survivorship information, the survivorship care pathway for the treating institution, the next steps planned for the patient in relation to their survivorship, and details of who to contact with any survivorship questions in the time between treatment completion and their full survivorship consultation.

## Psychosocial Survivorship Screening Tool

A full survivorship consultation is recommended at approximately six weeks post treatment completion. This consultation should involve the treating oncologist in some capacity and other members of the treating team as relevant. Along with the treatment summary from the medical team, the first survivorship screening tool is to be administered at this time point. The results of the screening tool will form the foundations for the survivorship care plan.

## Dialogue between survivor and clinician

## Psychosocial Survivorship Care Plan

The individualised survivorship care plan is developed following the administration of the screening tool. Depending on the process decided by the treating institution, and the level of need identified by the survivor, this can occur immediately following completion of the screening tool or at an agreed time over the next fortnight. The development of the survivorship care plan should not occur without in-depth dialogue with the young person and informed by the results of the screening tool. Time to do this thoroughly should be taken into account when determining institutional process. Based on the needs identified by the screening tool, three types of intervention are recommended.

### Direct Support

This occurs in instances where the treating team is best placed to manage the areas of unmet need. Examples include regular psychological consultations for goal setting or educational support to apply for special consideration. This would be based on the resources and remit of the treating institution.

### Information Provision

Many of the areas of unmet need can be addressed by providing appropriate AYA information. Pertinent topics include; *Individualised cancer and treatment information; Fertility support; Familial cancer; Psychosocial support; Education support; Support groups; Employment assistance; Financial support; Health promotion.* Survivorship teams should have ready access to such information.

### Referral

Where needs identified are managed most effectively by external agencies, referral information should be provided in a timely manner. It is recommended that each treating institution has a referral directory of appropriate community supports. The referral information should be highlighted as part of the care plan and, once the initial contact has been made, managed by the young person.

Figure 5. Adolescent and Young Adult Oncology Psychosocial Survivorship Care Process

## 3.4 Implementation and evaluation of survivorship care programs

While provision of cancer survivorship care programs is widely endorsed internationally,(5, 6, 31, 64, 70, 71, 85-87) few centres have implemented them in practice. Evaluation data on the impact of

survivorship care pilot programs are scarce,(88) with evaluation results only recently beginning to emerge within Australia.(89-91)

One such evaluation was conducted by the Australian Cancer Survivorship Centre.(89) The evaluation was of a Survivorship Care Planning Project that aimed to improve: (a) the care co-ordination and transition of patients post-treatment; and, (b) information and support of cancer survivors and their carers. Results from the evaluation of survivorship care plans (SCPs) included:

- high patient, nurse and GP endorsement of the usefulness of the SCPs;
- improved actual or anticipated communication between GP-patient and GP-nurse dyads by means of SCPs;
- information technology inefficiencies requiring 60-90 minutes to complete each SCP; and,
- lack of awareness of and resources for the project, and limited leadership and commitment within the organisation for implementing SCPs.

The Department of Health in Victoria recently evaluated six survivorship care pilot projects (one of which, “Survivorship Connections: A model of youth-friendly survivorship care”, was considered in detail above (see Section 3.3.1)).(91) The six projects included the development of SCPs, and all of these projects sought to collaborate with GPs. Key findings included:

- positive endorsement of SCPs by survivors, hospital staff and GPs;
- successful piloting of risk-stratified pathways for transition to GP follow-up or shared care for survivors of certain tumour groups;
- positive outcomes for survivor self-management; and,
- new insights into cost shifts and sustainability of shared-care models

An in-depth evaluation of the pilot projects from a workforce perspective was also conducted.(90) Project enablers and barriers at individual, organisational and systems levels were identified.

These evaluations have collectively given rise to a number of recommendations that are intended to be responsive to the observed enablers and barriers to survivorship care program implementation, and provide guidance in the areas of:

- organisational commitment and leadership;
- education across all sectors;
- IT requirements;
- allocation of project resources;
- cost-benefit analysis;
- workforce readiness.

## 4 STAKEHOLDER CONSULTATIONS

Consultations with key stakeholders were conducted through an in-depth online survey, a focus group, and individual semi-structured interviews.

The online survey was conducted as part of a prior project assessing research priorities for AYAs with cancer from prevention, through all stages of diagnosis and treatment, to long-term survivorship and palliative care. Twenty-six consumers (consisting of 19 AYAs, one sibling and six parents/carers) and 75 HCPs (including academics, oncologists, nurses, allied health professionals) took part in the survey, details of which have been published elsewhere.<sup>(17)</sup> Open-ended questions regarding AYA cancer survivorship were mined to elucidate common themes, concerns and priorities.

The focus group was conducted in March 2015 with nine members of the YCS Youth Advisory Group, which is comprised of AYA cancer survivors from across Australia. Finally, individual semi-structured, key informant interviews were conducted with thirty-one HCPs and four consumers (consisting of two AYAs and two parents) (see Appendix C for a list of focus group and interview participants).

The following themes and quotations are representative of the results extracted from the above three data sets, and are supported by references from academic research.

### 4.1 Re-engagement with life for AYA cancer survivors

AYAs with cancer emphasised that they were unaware of how difficult the immediate post-

*“... cancer changes your life but there is a life after cancer that is hard to adjust back into after treatment” (Survivor, 19 years)*

treatment phase of their cancer journey would be, and that re-engaging with work or study, sporting activities and social occasions was made more difficult through a variety of factors including: loss of confidence; breakdowns in friendships; changes in appearance; being out of practice in interacting with others; being physically

weak; not knowing how or whether to talk about their cancer experience with new acquaintances;

and feeling that friends, GPs, schools and universities lacked knowledge and resources about how to support AYA cancer survivors post-treatment.

Accordingly, AYAs identified the need for ongoing psychosocial care, physical rehabilitation, social connectedness, greater peer support from other survivors and visits from HCPs to schools/universities (to explain the chronic condition and need for flexibility around attendance and deadlines). The diversity of diagnoses, treatment regimens, support-structures and ongoing health and psychosocial issues experienced by different AYAs suggests that it is not possible to design a 'one size fits all' program of support.

*AYA survivorship  
care is not  
"one size fits all"*

Health care professionals identified a number of avenues for improved survivorship care for facilitating AYAs to re-engage with life. These included:

- planning for re-integration into 'normal' life during active therapy and re-configuring goals as necessary;
- setting higher expectations for physical recuperation;
- providing access to exercise physiology programs as part of a minimum standard of care;
- extending nutrition education programs to the post-treatment phase to accommodate changing dietary requirements and prevent obesity;
- creating fact sheets for patients, carers and GPs;
- assisting schools, universities and workplaces to support the AYA upon return;
- providing appropriate referrals (e.g. to counsellors and online resources);
- creation and promotion of digital resources as 'gateways' to face-to-face counselling and social interactions; and
- creation of smartphone apps to assist AYAs to self-assess and prompt GP visits.

## 4.2 Families and carers

An AYA cancer diagnosis impacts upon numerous aspects of family functioning and can include: being bombarded with information that was provided using unfamiliar terminology; seeing the AYA hospitalised in age-inappropriate paediatric settings with children or in "dreary" adult wards; being displaced from familiar care roles with well siblings; experiencing parental loneliness and isolation, or sibling worry and feelings of guilt; enduring the AYA's pain and suffering; and confronting the difficulties of planning end-of-life care.(92-97) These disruptions and challenges to family life continue well after treatment is completed, or the young person has died.(97, 98)

In the interviews conducted for this report, parents spoke of feeling “lost in space” at the completion of their child’s cancer treatment, with limited understanding of their rights to seek guidance and assistance. Immediately post-treatment, parents were confronted with a “silhouette” of their child, a young person in need of “colouring in”. Taking on responsibility for re-vitalising the young person, restoring confidence, setting goals and determining appropriate milestones are just some of the challenges that parents faced. While they recognised the need for a variety of support services to help rehabilitate their child post-treatment, parents were left to seek further information on their own, with many reporting no assistance in the form of a care plan or parent network to guide them. Parents suggested that more information in the form of a “manual” for cancer treatment and survivorship would be worthwhile, and that the creation of a parent network to provide mutual support would also be of benefit. The financial burden arising from medical screening and treatment, and ongoing allied health care services, was also highlighted.

*Parents feel  
“lost in space”*

Parents also offered several valuable insights into some of the issues that are relevant to engaging AYAs in survivorship care. For example, loss of confidence due to the cancer experience can lead to a reluctance on the part of the young person to speak with strangers. This has clear implications for planning for hand-over of care post-treatment, suggesting that introductions to new HCPs and community groups should be initiated as early as possible. Both AYAs and parents commented that the young person does not necessarily want to talk about cancer once treatment is over, does not want to be identified as a ‘survivor’, and that it may take many years before the young person feels ready to become engaged with survivorship care. Again, understanding this aspect of youth (dis)engagement with the health system, and thinking creatively about how to overcome it, will be integral to planning for AYA cancer survivorship care.

*“[AYAs] are fragile psychologically and dealing with a cancer diagnosis and the associated alienation that brings, actual or implied, means they require specific targeted programs to aid their psychological and spiritual wellbeing”*

*(Parent)*

### 4.3 Fertility

AYAs reported a wide range of experiences within the area of fertility monitoring and preservation. For example, one young woman from the AYA focus group had been offered (and had taken up) the option to freeze eggs and embryos, while another had been advised not to delay child-bearing if she was in a stable relationship by the age of 25 years. These examples are indicative of some of the

positive options and helpful advice that may be available to AYAs depending upon their age and relationship status. However, one young man reported having to initiate and pursue fertility testing, while several AYAs reported that the possibility of diminished fertility was not discussed with them.

HCPs regularly reported that the assessment and monitoring of fertility was of high priority for AYAs with cancer, and that a better understanding of the ongoing costs associated with fertility preservation was merited. It would therefore appear that there is a mismatch between HCPs' appreciation of the importance of fertility monitoring and preservation, and various health services' approaches to communicating this to AYAs who are entering into treatment. This finding is in accordance with the international literature, which details some of the barriers and opportunities to discussing and initiating fertility preservation with AYAs,(99-103) as well as some of the technical

*Young people require greater access to information about the prospects, processes and costs of fertility and the costs*

issues and advances of recent years.(104-107) Particularly noteworthy is the recently established Australian "Future Fertility" study that will monitor the uptake and use of fertility preservation and assess complications associated with assisted reproductive treatments.(108) The new knowledge gained from this project is anticipated to assist

clinicians with making accurate risk projections of their patients' fertility prospects.

#### 4.4 Ongoing research and data collection

AYAs and HCPs reported a desire for ongoing survivorship care research, particularly in the areas of the benefits of physical and psychological therapies. HCPs also identified the need for ongoing surveillance, prospective research and improved systems of data collection and sharing in order to overcome current gaps in knowledge on AYA cancer survivors' long term health outcomes. Understanding the true impact of cancer and its treatment requires long-term follow-up of survivors' health and wellbeing. Over the past twenty years, much has been learned about the impact of childhood cancer through the ongoing research of the Childhood Cancer Survivor Study (CCSS), which is funded by the National Cancer Institute (NCI) in the United States and run out of St. Jude Children's Research Hospital in Memphis, in collaboration with forty other hospital and university-based research institutions.(109) No such large-scale undertaking exists for survivors of AYA cancers, for whom age-specific data are difficult to come by and short-term in focus.



Some HCPs therefore expressed hope that the CCSS's example of what can be learned across the spectrum of medical late effects, modifiable risk factors, reproductive complications, psychosocial issues and health-related behaviours will inspire a similar approach to documenting and responding to the corollaries of AYA cancer and its treatment throughout the lifespan of survivors. They acknowledged that there are barriers to life-long data collection, and that researchers must be sensitive to reporter burden and any other potential negative effects upon survivors. The potential role of data linkage and other data systems, up-front consent and research protocols would all be important in devising prospective research of this magnitude.

*“There is a significant need for recording of data to support the reporting of the outcomes of the various treatment regimes” (Manager, Dept. of Health)*

## 4.5 Engagement with primary care

AYAs reported difficulties with the abrupt transition from dependence upon medical staff during active treatment to assumed ‘competent independence’ in the post-treatment phase. Self-monitoring for symptoms is difficult, for example knowing whether or not a cut or bruise is significant. AYAs also reported an absence of GP involvement during active treatment and GPs not knowing how to support them post-treatment. A breakdown in the relationship with the family GP was reported by several young people, due to misdiagnoses and other delays in detecting the AYA's cancer, and HCPs reported that only about one-third of AYA survivors visit a GP with regularity. Resentment and lack of trust towards the family GP were commonly reported, even among AYAs who had completed treatment several years earlier. This presents as a significant barrier to transition back to community-based care.

*Delayed engagement with primary care can result in a “problem dump”*

While AYA perspectives were largely negative towards the potential for engaging with GPs following active treatment, a variety of HCPs highlighted the critical issue of the need for earlier engagement with primary care, citing that engagement at time of discharge comes too late and results in a ‘problem dump’ for which GPs are unprepared and for which they lack the requisite skills to manage. It was suggested that earlier engagement could address some issues around how best to support AYAs post-treatment. Flinders University is trialling a process of GP integration during active treatment and will be investigating GPs' skills at recognising

symptoms and signs of cancer recurrence and more effectively transitioning patients to primary care for post-treatment follow-up. Models of survivorship care as a unique discipline, or as a component of general medicine, are also under consideration. Peter MacCallum Cancer Centre is similarly piloting a program of integrating GPs into palliative care.

Given the limited number of AYA cancer survivors that any one GP is likely to encounter, HCPs acknowledged that general education for all GPs about AYA cancer was inappropriate. Alternatives such as targeted information for GPs who are involved in AYA cancer survivorship care, or identification of GPs who are interested in both cancer survivorship and the AYA age group, may be more promising.

## 4.6 Treatment summaries and survivorship care plans (SCPs)

None of the AYAs interviewed had received a treatment summary or SCP, nor even heard of the possibility of receiving such. However, the general principles behind treatment summaries and SCPs, and the prospects for using them to gain a better understanding of their diagnosis, treatment and recommended follow-up, were greeted by the young people with enthusiasm.

A significant majority of HCPs endorsed the principles behind providing survivors with treatment summaries and SCPs, and agreed that these should be (but only very rarely are) shared with GPs to assist them to plan for future cancer surveillance and other aspects of

*SCPs should be provided to AYAs, and shared with GPs*

medical and psychosocial assessment and intervention in their patients. However, HCPs were also sensitive to time and cost issues arising from IT systems that did not support auto-population of SCPs, and the current necessity of nurses spending in excess of three hours to complete one SCP, have it endorsed, and discuss its content and use with AYAs and GPs. HCPs diverged in their views on

*Creating SCPs takes time ... lots of time*

the necessity of evaluating the benefits of providing survivors with treatment summaries and SCPs, with some strongly advocating the need to demonstrate that SCPs lead to lower

cost and better health care outcomes, and others expressing frustration at the need for this evidence in the absence of harm arising from providing survivors with SCPs.

## 4.7 Health care system

As noted above, cancer survivorship care has only recently emerged as an oncology sub-specialty within Australia. HCPs commented that this movement towards integrated survivorship care is taking place within a complex health care system that is slow to change. Yet change is needed at multiple levels, from policy to service provision, and system requirements are currently under review by the National Cancer Expert Working Group. While it is generally recognised among HCPs that an integrated approach to developing models of survivorship care would be ideal, the reality is that this undertaking is fragmented, with pockets of work underway across Australia, often led by individuals in the absence of formal processes and structures. These initiatives can be short-lived in the absence of dedicated funding. AYA-specific survivorship support organisations and initiatives that were identified through stakeholder consultations are listed in Appendix A. YCS initiatives are listed in Appendix B.

HCPs also cited the need for more research to explore the efficacy and efficiency of models of survivorship care, and the need to engage consumers at all stages of planning and development. Support for nurse-led survivorship initiatives was high among both AYAs and HCPs, with the former identifying nurses as people with whom they had built relationships during hospital-based treatment, and the latter identifying the need to trial these initiatives, as is currently happening at Peter MacCallum Cancer Centre in Victoria and Flinders University in South Australia.

## 4.8 Shared care and collaboration

Health care professionals suggested that there are many challenges to the development of models of shared care, with a ‘silo’ approach as the current status quo. Awareness among the acute sector of potentially beneficial community services is thought to be low, suggesting an avenue of education for HCPs about the potential for shared-care partnerships.

*We currently have a ‘silo’  
approach towards  
survivorship care*

One suggestion for advancing shared care was the development of a “Survivorship Share Plan” and an associated tool to assess needs and facilitate communication and delegation of roles between the acute and community sectors. HCPs highlighted the need for training within the community sector in order that providers are equipped with the knowledge to deliver and support AYA cancer survivors, for example through appropriate diet and exercise classes.

## 4.9 Inequities of cancer survivorship care

HCPs identified a number of gaps within equitable cancer survivorship care, such as some Australian states (notably Victoria, South Australia and NSW) leading the way with new initiatives while others have yet to implement any, and greater advancement in survivorship care for some types of cancer over others (e.g., Canadian survivors of breast cancer have access to much better survivorship care than do survivors of haematological cancers). Similar inequities were noted between Australian AYAs treated in paediatric versus adult hospitals, with the former historically having significantly better co-ordinated transition arrangements, such as through the Sydney Children’s Hospital Network’s specialist transition service ‘Trapeze’. The need for transition co-ordinators in all states and territories was highlighted by AYAs, who likened a good co-ordinator to a ‘concierge’.

HCPs noted that access to care must be designed to be inclusive of all AYAs, with creative approaches to providing services to youth who are known to be marginalised from health services by their ethnicity, poverty, refugee status, developmental delay or regional residential location. In particular, HCPs identified Aboriginal and Torres Strait Islander youth as having poorer health and quality of life outcomes than their non-indigenous counterparts. A significant role for youth workers was identified as a potential avenue for keeping AYAs engaged with post-treatment cancer survivorship care.

## 4.10 Resource development

AYAs reported low levels of awareness of the availability of rehabilitation and support services, such as psycho-oncology and exercise physiology. HCPs involved in service provision cited the need for well-developed informational resources covering aspects of cancer survivorship such as body awareness, relationships with GPs and maintaining connections with health services and understanding what they do. There was a strong sense that ‘life stage’ more so than ‘disease’ was appropriate for resource development, and that adopting this approach would permit inclusion of areas of common interest and relevance to an AYA audience, such as vocational, fertility and peer-relationship information.

*Resources should focus on issues of “life” not “disease”*

Both AYAs and HCPs showed a preference for general resources to be made available online, and individual resources (such as personal treatment summaries and SCPs) to be available on USB sticks. From the perspective of the young people, there was a disinclination to leave treatment with too

much paper, such as a directory of services. Instead, a brief summary document (on paper) and a USB stick containing more information and links to services was deemed preferable. HCPs highlighted several advantages of an online approach to information provision, such as cost efficiencies, links providing access to information that is regularly updated, flexibility as information may be accessed and returned to at any time, less-personal and less-confronting modes of engaging young people with HCPs (such as through interactive webinars) that may subsequently lead to face-to-face contact, and young people's existing habits and preferences to seek information online.

## 4.11 Funding

Funding was almost universally identified as the most important barrier to providing survivorship care to AYAs, and it was acknowledged that funding one service or patient group must always result

*Limited funding is the biggest barrier to providing survivorship care*

in a denial of funds to an alternative scheme or population. HCPs running survivorship clinics routinely reported that they were run on good will or invisible "soft money", and also cited the need actively to raise funds in order to operate specific classes. Survivorship clinics were reported to be "over-flowing"

and were projected to become ever-increasingly more so as new survivors sought their services and current survivors continued to attend. Accordingly, new staffing arrangements incorporating multi-disciplinary teams, expanded facilities such as more consulting rooms and better integrated systems for co-ordinating survivorship care to reduce waiting times and minimise survivors' visits to clinics were all identified as high priorities.

HCPs working in hospitals and community-based services reported similar funding-based barriers to delivering optimal survivorship care. All HCPs recognised the need for medical and psychosocial risk stratification not only as a mechanism for targeting care to the needs of the survivor, but also as a means of directing funds more equitably among survivors.

*"All decisions about treatment and services are actually about the allocation of resources"*  
*(Head of Research Centre).*

## 4.12 Policy and advocacy

While the emergence of cancer survivorship initiatives may be viewed as a positive response to an identified need, enthusiasm for change has outpaced system-wide understanding of this need. Accordingly, HCPs cited the necessity of ongoing advocacy for resources to be directed towards the development of comprehensive survivorship initiatives, and associated policies to underpin an

equitable and sustainable system of care. HCPs also highlighted that, for AYAs, there are additional challenges associated with being a minority group among cancer survivors, and that there are unique issues related to cancer coinciding with what is arguably one of the most dramatic developmental stages across the lifespan. It was well understood among HCPs that catering to the needs of this small but diverse group will require dedicated advocacy from AYA specialists who have a firm grasp of the developmental trajectories of young people who are transitioning into adulthood.

## 5 SUMMARY & RECOMMENDATIONS

### 5.1 Summary

The ongoing physical and psychosocial impacts of cancer upon AYA survivors necessitate the creation and implementation of developmentally appropriate, long-term programs of health care,(31, 110-112) psychosocial assessment to identify those in need of intervention(37, 113, 114) and educational and vocational support.(32, 110, 115) Development of these programs must take into account the finding that health and supportive care needs vary in response to an individual AYA survivor's age, gender and stage of survivorship,(116) and also that these needs may differ in some regards from the priorities of health care professionals.(49, 117) Additional considerations for program development include understanding AYAs' health risk behaviours and other medical management issues that are of relevance to successful long-term follow-up and health care delivery.

As detailed throughout this report, many individual and institutional factors are to be considered in the strategic development of survivorship care for Australian AYAs who have completed cancer treatment. Considerations of cost, feasibility, making best use of current resources, engaging AYAs, empowering young people and parents, developing shared models of care, and building upon existing evidence on survivorship care pathways are all important. Wider considerations such as whether AYA survivors are best integrated into mainstream cancer survivorship programs, or better served through integration with programs of long-term follow-up and care for AYAs with other chronic illnesses, should also be taken into account.

Risk stratification and determining appropriate limits for time periods spent by AYA cancer survivors in any newly developed survivorship program will impact upon attempts to create equitable systems of access to care, and will be a pre-cursor to developing and implementing successful transition processes between services. No matter what form post-treatment survivorship care takes, AYAs and their parents require 'concierge' services to maintain the momentum of trust and confidence in health care that arises during acute care, and quickly dissipates upon discharge. There is a large body

of work already in existence on the necessity (and complexity) of transitions between services that will be instrumental in guiding the development of these processes.<sup>18,62,68-71</sup> Empowerment of young people and their families to self-manage with confidence, while still being supported by appropriate community services, is another important consideration.

Consultation with a cross-section of consumers and HCPs has provided optimism about the prospects for collaboration between individuals and institutions. Internationally, as well as locally, discussion is now beyond the question of the need for comprehensive cancer survivorship care. Momentum is now building to capitalise upon the insights of survivors and those most intimately involved in their care, as well as researchers, heads of departments and service providers, and to develop these insights into strategically driven programs of care that are equitable, sustainable and lead to better long-term health outcomes, wellness and productivity for AYA cancer survivors.

## 5.2 Recommendations

The following recommendations for improving nation-wide AYA cancer survivorship care are derived from key findings from the literature and stakeholder consultations.

**Key finding** AYAs have high rates of survival and the potential for many years of life ahead of them. Medical, neuro-cognitive and psychosocial late effects require ongoing assessment and surveillance to optimise opportunities to promote wellness. The provision of post-treatment survivorship care to AYAs in Australia varies according to local infrastructure and systems. This potentially results in over-servicing of some survivors, and under-servicing of others:

**Recommendation 1** Development of a national AYA Survivorship Pathway for improvements in the co-ordination and integration of care for AYA cancer survivors post-treatment.



**Key finding** The input of AYA cancer survivors and their families has been instrumental to the development of an understanding of the lived experience of an AYA cancer diagnosis, its treatment and the years that follow. This input will be critical to the ongoing planning of AYA survivorship care:

**Recommendation 2** Engagement of AYA cancer survivors and their families to provide advice and input into the development of national AYA cancer survivorship work

**Key finding** Positive findings from preliminary research on implementing an AYA 'survivorship care pathway' indicate that large-scale, prospective research is warranted:

**Recommendation 3** Prospective research on the potential outcomes, infrastructure and resource requirements of implementing a national, AYA 'survivorship care pathway' is required

**Key finding** There is currently no system in place for the collection and sharing of data on the long-term medical and psychosocial outcomes of AYA cancer survivors. This undermines the development of a knowledge base of AYA cancer, and is out of step with the approach taken in paediatric cancer:

**Recommendation 4** Improved data collection on AYA cancer survivors to create a comprehensive knowledge base and inform future treatment and survivorship care protocols

**Key finding** Adolescence and young adulthood is a developmentally unique stage within the lifespan. The lived experience of AYA survivors and their families is often one of feeling lost because they do not fit easily into either the paediatric or adult system of health care. HCPs and community workers need to be equipped with the skills and resources to provide life stage appropriate care to AYA cancer survivors:

**Recommendation 5** Development of AYA cancer survivorship guidelines and training for HCPs

**Key finding** Models of wellness in cancer survivorship emphasise the importance of integrated care involving survivors, community and health professionals. However, the often reported silo approach to conducting research and implementing initiatives is indicative of a lack of engagement between key stakeholders:

**Recommendation 6** Cultivation of partnerships between researchers, policy makers and service providers to foster improved translation of research into evidence-based policies and practices to benefit AYA cancer survivors and their families post-treatment

**Key finding** AYAs and their carers require timely provision of targeted information about re-integration into life, diet and exercise, modifiable risks, surveillance and services. The proliferation of digital practices among AYAs, taken together with their personal preferences for digital communications, suggests that there is great scope for the development of e-health resources to engage AYAs in survivorship care:

**Recommendation 7** Investment in e-health technology including smartphone apps, tele-health services and informational resources to promote engagement of AYAs in accessible, comprehensive cancer survivorship care

**Key finding** Challenges to the establishment of comprehensive survivorship care for AYAs include lack of widespread acknowledgement of their unique developmental, treatment and follow-up needs, and an associated lack of AYA-focussed survivorship care resourcing:

**Recommendation 8** High level advocacy to promote AYA cancer survivorship care within the Australian health system, focussing upon appropriate funding, integration and training of health professionals

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## 7 APPENDICES

### Appendix A AYA cancer survivorship initiatives and Australian and international cancer support organisations

AYA CANCER SURVIVORSHIP INITIATIVES		
Australian Initiatives	Overview	Link/Contact
Future fertility	<ul style="list-style-type: none"> <li>first web-based, multi-site 'Australasian Oncofertility Registry' (AOFR) collecting international data from cancer and fertility centres</li> </ul>	<a href="http://futurefertility.com.au/">http://futurefertility.com.au/</a>
Survivorship Connections ONTrac@PeterMac	<ul style="list-style-type: none"> <li>A Pilot Model of Post Treatment Shared Survivorship Care for Adolescent and Young Adult (AYA) Cancer Patients in Victoria</li> </ul>	<a href="http://www.petermac.org/education/survivorship-education/implementing-survivorship-care">http://www.petermac.org/education/survivorship-education/implementing-survivorship-care</a>
Paediatric Integrated Cancer Service (PICS)	<ul style="list-style-type: none"> <li>Long-term follow-up service provides each individual child or AYA cancer survivor with a tailored approach to meet their ongoing needs and an appropriate transition plan to adult-based, community or hospital services</li> </ul>	<a href="http://www.pics.org.au/LongTermFollowupProgramLTFP">http://www.pics.org.au/LongTermFollowupProgramLTFP</a>
Trapeze	<ul style="list-style-type: none"> <li>Specialist transition service for The Sydney Children's Hospitals Network assisting young people aged 14-25 with any chronic condition as they make the leap from their children's hospital to adult health services</li> <li>information, social and emotional support, tips on how to manage conditions better, and guidance to find the right professionals</li> <li>Facilitation, monitoring and coordinating care during transition and strengthening links with local adult services, especially GPs, so that young people are able to manage their conditions better and stay out of hospital</li> </ul>	<a href="http://www.trapeze.org.au/">http://www.trapeze.org.au/</a>



<b>Stupid Cancer Initiatives</b>	<b>Overview</b>	<b>Link/Contact</b>
Stupid Cancer USA	<ul style="list-style-type: none"> <li>• advocacy</li> <li>• research</li> <li>• support</li> <li>• outreach</li> <li>• mobile health</li> <li>• social media</li> </ul>	<a href="http://www.stupidcancer.org">www.stupidcancer.org</a>
Instapeer	<ul style="list-style-type: none"> <li>• mobile app supporting 1-on-1 peers support</li> </ul>	<a href="http://instapeer.org">http://instapeer.org</a>
Stupid Cancer Show	<ul style="list-style-type: none"> <li>• radio podcast giving a voice to the young adult cancer movement</li> </ul>	<a href="http://stupidcancershow.org">http://stupidcancershow.org</a>
CancerCon	<ul style="list-style-type: none"> <li>• global conference with young adult cancer patients, survivors, caregivers, advocates, providers, researchers and digital health partners uniting for change</li> </ul>	<a href="http://cancercon.org">http://cancercon.org</a>
OMG! Cancer Summits for Young Adults	<ul style="list-style-type: none"> <li>• large regional conferences and networking events for patients, survivors and caregivers affected by young adult cancer</li> </ul>	<a href="http://omgsummit.org">http://omgsummit.org</a>
Stupid Cancer Boot Camps	<ul style="list-style-type: none"> <li>• single-day regional young adult cancer support workshops produced in partnership with local cancer centres to build and empower communities</li> </ul>	<a href="http://www.stupidcancer.org">www.stupidcancer.org</a>
Stupid Cancer Town Halls	<ul style="list-style-type: none"> <li>• single-topic evening seminars produced collaboratively with community cancer centres and local retail or commercial partners and collaborators</li> </ul>	<a href="http://www.stupidcancer.org">www.stupidcancer.org</a>
Stupid Cancer Meet-Ups	<ul style="list-style-type: none"> <li>• signature community development, outreach, awareness and peer-connection program, complementing existing support group services in local areas</li> </ul>	<a href="http://stupidcancer.org/meetup">http://stupidcancer.org/meetup</a>
Stupid Cancer Road Trips	<ul style="list-style-type: none"> <li>• an annual two-week, cross-country goodwill tour hosting special local events along the way with cancer centres and survivors in major US markets</li> </ul>	<a href="http://stupidcancerroadtrip">http://stupidcancerroadtrip</a>
<b>Livestrong Young Adult Alliance Initiatives</b>	<b>Overview</b>	<b>Link/Contact</b>
Critical Mass	<ul style="list-style-type: none"> <li>• We highlight the unique features of the AYA cancer experience with the goal of improving treatments and outcomes. We envision a world where AYA's with cancer have every resource necessary to survive and thrive</li> </ul>	<a href="http://www.criticalmass.org">www.criticalmass.org</a> .
Anti-stigma Campaigns	<ul style="list-style-type: none"> <li>• addressing the issue of stigma and silence associated with cancer by empowering cancer survivors and their families to share their cancer experiences with their communities</li> </ul>	<a href="http://www.livestrong.org/what-we-do/our-actions/programs-partnerships/anti-stigma-campaign/">http://www.livestrong.org/what-we-do/our-actions/programs-partnerships/anti-stigma-campaign/</a>
Livestrong Fertility	<ul style="list-style-type: none"> <li>• educational information and access to resources for cancer patients and survivors whose cancer and its treatment present risks to their fertility</li> </ul>	<a href="http://www.livestrong.org/we-can-help/fertility-services/">http://www.livestrong.org/we-can-help/fertility-services/</a>

Livestrong at the YMCA	<ul style="list-style-type: none"> <li>supporting people affected by cancer in reaching their health and wellness goal</li> </ul>	<a href="http://www.livestrong.org/what-we-do/our-actions/livestrong-programs/ymca/">http://www.livestrong.org/what-we-do/our-actions/livestrong-programs/ymca/</a>
Livestrong Survivorship Centers of Excellence	<ul style="list-style-type: none"> <li>A collaborative effort of LIVESTRONG and leading cancer centres to share best practices in providing direct survivorship services</li> </ul>	<a href="http://www.livestrong.org/what-we-do/our-actions/programs-partnerships/livestrong-survivorship-centers-of-excellence/">http://www.livestrong.org/what-we-do/our-actions/programs-partnerships/livestrong-survivorship-centers-of-excellence/</a>
Cancer Transitions: Moving Beyond Treatment	<ul style="list-style-type: none"> <li>supporting and empowering survivors as they transition from active treatment to post-treatment. Evidence-based program for survivors mainly targeted to individuals who have completed their treatment within the last 24 months. Participants learn the benefits of exercise, nutrition, emotional support and medical management—core issues for cancer survivors.</li> </ul>	<a href="http://www.livestrong.org/what-we-do/our-actions/programs-partnerships/cancer-transitions/">http://www.livestrong.org/what-we-do/our-actions/programs-partnerships/cancer-transitions/</a>
Livestrong at School	<ul style="list-style-type: none"> <li>School curriculum offers online lessons for grades K–12 to help teachers teach their students about cancer in a way that is age-appropriate, inspiring and empowering.</li> </ul>	<a href="http://www.livestrong.org/what-we-do/our-actions/programs-partnerships/livestrong-at-school/">http://www.livestrong.org/what-we-do/our-actions/programs-partnerships/livestrong-at-school/</a>

### AUSTRALIAN ORGANISATIONS

Organisation	Overview	Link/Contact
Cancer Australia	Links to AYA cancer resources <ul style="list-style-type: none"> <li>Guides and reports</li> <li>Learning activities</li> <li>Professional groups</li> <li>Refereed journal/article</li> <li>Textbooks</li> <li>EdCaN case studies</li> <li>Nursing and Allied Health Specific</li> <li>Patient support resources</li> </ul>	<a href="http://www.cancerlearning.gov.au/find/aya.php">http://www.cancerlearning.gov.au/find/aya.php</a>
Cancer Council	Peak national cancer organisation <ul style="list-style-type: none"> <li>research</li> <li>information &amp; support</li> <li>helpline 13 11 20</li> </ul>	<a href="http://www.cancer.org.au">www.cancer.org.au</a>
Clinical Oncology Society of Australia (COSA)	Peak national body representing HCPs from all disciplines involved in the care of cancer patients <ul style="list-style-type: none"> <li>supporting the professional and educational needs of cancer health professionals</li> <li>enhancing cancer care and control through network development</li> <li>advocating for improvements in cancer care and control</li> <li>facilitating research across the spectrum of cancer</li> </ul>	<a href="http://www.cosa.org.au">www.cosa.org.au</a>

Redkite	<ul style="list-style-type: none"> <li>• consumer support &amp; info services</li> <li>• vocational counselling</li> <li>• financial support</li> <li>• bereavement support</li> <li>• education and vocational information, grants &amp; counselling</li> <li>• carer/parent psychosocial support</li> <li>• national information &amp; support line (including bereavement support)</li> <li>• face to face, telephone &amp; group counselling</li> <li>• books &amp; resources</li> </ul>	<a href="http://www.redkite.org.au">www.redkite.org.au</a>
CanTeen	<ul style="list-style-type: none"> <li>• face-to-face &amp; tele-health counselling</li> <li>• peer support</li> <li>• individual support</li> <li>• books &amp; resources</li> <li>• Youth Cancer Services</li> </ul>	<a href="http://www.canteen.org.au">www.canteen.org.au</a>
Leukaemia Foundation	<ul style="list-style-type: none"> <li>• information</li> <li>• emotional support</li> <li>• education &amp; support programs</li> <li>• accommodation</li> <li>• transport</li> <li>• financial assistance</li> <li>• legal advice</li> </ul>	<a href="http://www.leukaemia.org.au">www.leukaemia.org.au</a>
Cancer Council NSW	<ul style="list-style-type: none"> <li>• Enrich: exercise and healthy eating program</li> <li>• face-to-face &amp; telephone support</li> <li>• webinars</li> <li>• information libraries &amp; centres</li> <li>• Cancer Connect peer support</li> <li>• living well after cancer program</li> </ul>	<a href="http://www.cancercouncil.com.au">www.cancercouncil.com.au</a>
<b>INTERNATIONAL ORGANISATIONS</b>		
<b>Organisation</b>	<b>Overview</b>	<b>Link/Contact</b>
Livestrong Foundation (USA)	<ul style="list-style-type: none"> <li>• advocacy</li> <li>• programs &amp; partnerships</li> <li>• information</li> <li>• financial support</li> <li>• survivorship care planning</li> </ul>	<a href="http://www.livestrong.org">www.livestrong.org</a>
Brightlight (UK)	<ul style="list-style-type: none"> <li>• a national study looking at specialist cancer care received by those aged 13-24. Following over 1000 young people with cancer over three years to find out about their treatment and care.</li> </ul>	<a href="http://www.brightlightstudy.com/">http://www.brightlightstudy.com/</a>

Young Adult Cancer Canada	<ul style="list-style-type: none"> <li>• Mission to support young adults as they move through and beyond cancer. A connection to peers, bridge out of isolation, and source of inspiration. Any cancer, any stage, YACC's got your back.</li> </ul>	<a href="http://www.youngadultcancer.ca/">http://www.youngadultcancer.ca/</a>
Young Survival Coalition (USA)	<ul style="list-style-type: none"> <li>• Young women facing breast cancer together</li> <li>• conferences</li> <li>• research</li> <li>• advocacy</li> <li>• peer support</li> <li>• outreach</li> </ul>	<a href="https://www.youngsurvival.org/survivorlink">https://www.youngsurvival.org/survivorlink</a>
Clic Sargent	<ul style="list-style-type: none"> <li>• Information and support for young people who have recently been diagnosed, or are living with cancer</li> </ul>	<a href="http://www.clicsargent.org.uk/content/young-people">http://www.clicsargent.org.uk/content/young-people</a>

These survivorship initiatives were mentioned in the literature or by the key informants as part of the scoping of this project and by no means represent all the initiatives currently underway or completed.

## Appendix B Youth Cancer Services AYA cancer survivorship initiatives

YOUTH CANCER SERVICES SURVIVORSHIP INITIATIVES		
YCS Vic/Tas	Overview	Link/Contact
	<ul style="list-style-type: none"> <li>AYA Survivorship Clinic at Peter Mac</li> </ul>	Donna Gairns
	<ul style="list-style-type: none"> <li>Development of a Model of Transition collaborating with The Royal Children's Hospital, The Royal Melbourne Hospital, Peter Mac &amp; The Austin</li> </ul>	Dr Lisa Orme
	<ul style="list-style-type: none"> <li>AYA Resource Development as part of the Victorian Department of Health &amp; Human Services funding for Survivorship Connections: A Pilot Model of Post Treatment Shared Survivorship Care for Adolescent and Young Adult (AYA) Cancer Patients in Victoria</li> </ul>	Ms Kate Thompson
YCS SA/NT	Overview	Link/Contact
Exercise Study	<ul style="list-style-type: none"> <li>Exercise study post treatment for cancer</li> </ul>	Morgan Atkinson (EP)
Transition Clinic	<ul style="list-style-type: none"> <li>Transition from Paediatric to Adult care for survivors of childhood/adolescent cancer</li> </ul>	Mel Jones (RN)
Link to known survivorship clinics	<ul style="list-style-type: none"> <li>Link to known survivorship clinics in SA – ie BMT, Lymphoma, LTFU</li> </ul>	Mel Jones (RN)
Statewide survivorship initiative	<ul style="list-style-type: none"> <li>Working group focussing on a consensus model of care for survivorship in SA</li> </ul>	Dr Michael Osborn (Haematologist, working group member)
EOT care plan	<ul style="list-style-type: none"> <li>End of Treatment distress tool and care plan available for all YCS patients completing treatment</li> </ul>	Mel Jones (RN)
YCS Qld	Overview	Link/Contact
	<ul style="list-style-type: none"> <li>"AYA End of Treatment Summary – Patient and GP" currently being evaluated to determine helpfulness of information when communicating with GP or when changing GP. AYA preferences for hard and/or soft copy being determined.</li> </ul>	Ms Fiona Henderson
YCS WA	Overview	Link/Contact
	<ul style="list-style-type: none"> <li>End of Treatment / Survivorship workshop for AYAs completed treatment for cancer</li> </ul>	Dr Rachel Hughes
	<ul style="list-style-type: none"> <li>Implementation and evaluation of an end of treatment clinic for AYA cancer patients</li> </ul>	Dr Rachel Hughes

YCS NSW/ACT	Overview	Link/Contact
WSYCS	<ul style="list-style-type: none"> <li>• AYA Long Term Follow Up/Survivorship program to begin later in 2015</li> </ul>	Jennifer Chard / Dr Vivek Bhadri
HNNYCS	<ul style="list-style-type: none"> <li>• Late Effects Clinic – monthly at John Hunter Children’s Hospital</li> </ul>	Ms Lyndal Moore
	<ul style="list-style-type: none"> <li>• End-of-treatment appointment to discuss and review finishing treatment and “getting back” to activities regardless of where patients were treated (paediatric or adult setting) – Calvary Mater</li> </ul>	Ms Karen Matthews
Kids Cancer Centre	<ul style="list-style-type: none"> <li>• Late Effects Clinic held once a month providing a comprehensive evaluation of the patient's current physical health. This has been running for over 30 years.</li> </ul>	
Prince of Wales Hospital	<ul style="list-style-type: none"> <li>• Established an adult survivorship program 5 years ago which provides evaluation and assessment of adult cancer patients.</li> </ul>	

## Appendix C List of Key Informants and Focus Group Participants

### Consumers

#### AYA focus group

Bron Kilby (WA)  
Keifer King (WA)  
Jarrod Eggins (NT)  
Thomas Binns (SA)  
Mark Haseloff (SA)  
Xenia Alexander (VIC)  
Tom Puttick (NSW)  
Jenna Maloney (QLD)  
Anthony Mackett (NSW)

#### AYA patients

Maisy Stratford-Hutchings (VIC)  
Keifer King (WA)

#### Parents of AYA patients

Kerry Madigan  
Suzi Stratford-Hutchings

N.B. All focus group members provided written consent for their names to be included in this report.

### Health Care Professionals

#### Australia

##### Dr Antoinette Anazodo

Director of Adolescent and Young Adult Cancer Service  
Sydney Children's Hospital  
Prince of Wales Hospital  
NSW

##### Mr Morgan Atkinson

Exercise Physiologist  
Youth Cancer Service  
South Australia

##### Dr Daniel Byrne

General Practitioner  
Chandlers Hill Surgery  
Happy Valley  
South Australia

##### A/Professor Richard Cohn

Head  
Clinical Oncology and Long Term Follow-Up  
Kids Cancer Centre  
Sydney Children's Hospital  
Randwick NSW

##### Dr Jane Barry

General Practitioner  
Stratford Medical Centre  
Cairns QLD

##### Dr Haryana Dhillon

Research Fellow  
Cancer Survivorship  
Centre for Medical Psychology and Evidence-based Decision-making (CeMPED)  
University of Sydney  
NSW

##### Professor Marion Haas

Professor of Health Economics  
Centre for Health Economics Research and Evaluation

##### A/Professor Michael Jefford

Director, Australian Cancer Survivorship Centre, A Richard Pratt Legacy  
Deputy Head  
Department of Medical Oncology  
Peter MacCallum Cancer Centre  
Melbourne, Victoria

##### Professor Bogda Koczwara

Senior Staff Specialist  
Flinders Centre for Innovation in Cancer  
South Australian Health Service  
South Australia

**Dr Jordana McLoone**

Post-doctoral Researcher  
Psychologist  
Behavioural Sciences Unit  
Kids Cancer Centre  
Sydney Children's Hospital  
Randwick NSW

**Ms Annie Miller**

Manager of Practical Support  
Cancer Council  
NSW

**Ms Jill Mills**

Young Adult Programs  
Cancer Council  
NSW

**Ms Lyndal Moore**

Clinical Nurse Consultant  
Youth Cancer Service  
NSW

**Ms Bronwyn Penny**

Exercise Physiologist  
Division Manager  
CanTeen  
NSW

**Professor David Roder**

Chair of Cancer Epidemiology and Population  
Health  
School of Population Health  
University of South Australia

**Ms Ursula Sansom-Daly**

Psychologist  
Youth Cancer Service  
NSW

**Professor Kate Steinbeck**

Medical Foundation Chair in Adolescent Medicine  
Academic Department of Adolescent Medicine  
The University of Sydney

**Dr Heather Tapp**

Acting Head  
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Women's and Children's Hospital  
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**Professor David Thomas**

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Kinghorn Cancer Centre  
Garvan Institute  
NSW

**Ms Kate Thompson**

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ONTrac at Peter Mac  
Victorian Adolescent & Young Adult (AYA) Cancer  
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**Ms Kate Turpin**

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**Ms Natalie VanderHaak**

Dietitian  
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**Ms Kathryn Whitfield**

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Department of Health  
Victoria

**Professor Patsy Yates**

Head  
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Queensland University of Technology  
Queensland

**International****Dr Norma D'Agostino**

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**Dr Lorna Fern**

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Teenage and Young Adult Clinical Studies Group  
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**Ms Devon McGoldrick**

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**A/Professor Christopher Recklitis**

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