

Adolescents, Young Adults and Cancer in New South Wales

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Contents

Foreword from the Minister	iii	<i>Growth and development</i>	14
Chief Cancer Officer’s Report	iv	<i>Behavioural effects</i>	14
Introduction	1	<i>Post-traumatic stress</i>	15
Methods	2	<i>Education</i>	15
Results	3	<i>Suicide</i>	16
		<i>Long- or late-term effects</i>	16
		<i>Possible late-effects</i>	16
Incidence of cancers, survival rates and common cancer types in adolescents and young adults	3	Palliative care for adolescents and young adults with cancer	17
<i>Cancer incidence and survival rates</i>	3	<i>Home palliation</i>	17
<i>Common cancer types</i>	4	<i>Hospice care</i>	17
<i>North America</i>	5	<i>Skilled specialists</i>	17
<i>Australia</i>	6	<i>Recommendations for hospitals</i>	17
Cancer treatments and therapies	7	International treatment models for cancer in adolescents and young adults	19
<i>Treatment setting</i>	7	<i>United Kingdom and Teenage Cancer Trust Units</i>	19
<i>Clinical outcomes</i>	7	<i>United States</i>	20
<i>Referral pathways</i>	8	Australian policy context	21
<i>Lack of resource concentration</i>	8	Australian treatment models for adolescents and young adults with cancer	22
<i>Medical awareness and expertise with cancer in adolescents and young adults</i>	9	<i>Victoria: OnTrac@PeterMac, Melbourne</i>	22
Clinical trials	9	<i>Western Australia: Johanna Sewell Adolescent Oncology Unit, Princess Margaret Children’s Hospital</i>	22
<i>Reasons for lack of adolescent and young adult participation in clinical trials</i>	11	<i>New South Wales</i>	23
Psychological issues for adolescents and young adults with cancer	12	<i>CanTeen proposed models for adolescent and young adult cancer units</i>	24
<i>Independence</i>	12	Stakeholder considerations in developing adolescent and young adult cancer services	24
<i>Relationships and sexuality</i>	13	<i>Tumour specific treatment regimes</i>	24
<i>Grieving and loss</i>	13	<i>Flexibility to adapt to individuals</i>	25
<i>Patient satisfaction</i>	13		
<i>Effects and late-effects of cancer in adolescents and young adults</i>	14		

<i>Collaboration: paediatric and adult oncology</i>	25
<i>Establishment of referral pathways</i>	25
<i>Multidisciplinary treatment team (MDT)</i>	25
<i>Hub and spoke model</i>	25
<i>Psychosocial needs</i>	26
<i>Peer Support</i>	26
<i>Age-appropriate facilities</i>	26
<i>Education capacity</i>	26
<i>Implementation of research and development</i>	26
<i>Palliative care options to address survivorship issues</i>	26
<i>Training for staff in adolescent health</i>	26
<i>Clinical treatment driven by age</i>	26
<i>Comparatively low cancer incidence in adolescent and young adults ages</i>	26
<i>Adolescent and young adult capture</i>	27
Conclusion	28
Appendix	
<i>Workshop attendees, 29 November 2007</i>	29
References	30

Foreword from the Minister

The Cancer Institute NSW was established in 2003 as a direct response to decreasing the cancer burden in our state. The Cancer Institute NSW is Australia's first statewide government-supported cancer control agency. It aims to improve cancer outcomes in NSW through cancer prevention, detection, innovation, research and information.

This report, *Adolescents, Young Adults and Cancer in NSW*, allows us to further understand specific issues surrounding adolescent and young adult (AYA) cancer patients. It presents an overview of the literature related to AYA cancer and provides valuable insight into the range of clinical and psychosocial issues that impact upon this patient group.

This information will provide a framework for the development of strategies to improve the level of cancer treatment for adolescents and young adults.

The Hon. Jodi McKay MP

Minister for Tourism

Minister for the Hunter

Minister for Small Business

Minister for Science and Medical Research

Minister Assisting the Minister for Health (Cancer)

Chief Cancer Officer's Report

Cancer is the largest disease burden in the community. The Cancer Institute NSW predicts there will be over 30 per cent more cases of cancer in the next 10 years than there were in the last, increasing the risk of premature death and the loss of years of productive life. This impact on the community is devastating, and requires careful planning and service delivery specific to individual patient needs.

A review of data related to childhood and older adult cancers has shown a large increase in survival rates. In comparison, adolescent and young adult (AYA) survival rates have shown a smaller increase.

Cancer services in NSW produce good cancer outcomes. For AYA cancers, further benefits would result from a more tailored approach to the specific service needs of a population undergoing intense physiological and psychosocial change. By consulting the leading specialists in the State, a comprehensive picture has emerged describing the current treatment of AYA with cancer in NSW.

The experience of those undergoing cancer treatments and their quality of life is an important consideration of the Cancer Institute NSW, and the findings of this report will inform strategies to better support AYA with cancer. Armed with this comprehensive picture, the Cancer Institute NSW plans to inform work in this important area, with the hope of improving survival and quality of life for this age group.

Professor Jim Bishop AO MD MMed MBBS FRACP FRCPA

**Chief Cancer Officer and CEO, Cancer Institute NSW
Professor of Cancer Medicine, University of Sydney**



Introduction

In the past decade, the incidence of cancer in adolescents and young adults (AYA) has increased. However, survival for this group of patients has shown small improvement in comparison to the advance in childhood and adult cancers.

The issue of adolescent and young adult care has been on the national agenda since a 2005 Australian Senate Community Affairs References Committee inquiry that recommended a review of cancer care for adolescents and young adults.¹ In May 2008, the Commonwealth Government announced provision of \$15 million dollars over three years to CanTeen to establish AYA cancer centres in mainland states.²

This report is the first step for NSW in understanding the issues surrounding the care needs of AYA with cancer. It provides an overview of the current treatment pathways and models of care for AYA with cancer, their access to and participation in clinical trials, palliative and psychosocial support needs and the psychosocial and late-effects for this unique group of cancer patients in NSW.

The impact of cancer on an adolescent or young person who is already undergoing the physiological and psychosocial complexities of development is severe. However, unlike the paediatric model of care, where excellence in multi-disciplinary care is concentrated in tertiary cancer centres, treatment of adolescents with cancer is widely dispersed.³ Adolescents and young adults with cancer may be treated in an adult hospital, sharing a ward with elderly patients, or with children in a paediatric facility.

It is estimated that only 30 per cent of AYA patients have a specific teenage onset cancer, the majority being either childhood or early onset adult disease.⁴ As a result, there is variation in clinical protocols for these cancers which may be treated with either a paediatric or adult protocol. The absence of a patient cluster also limits the experience of staff in dealing with physiological and psychological issues of AYA patients. Further, with a minority of these patients treated at a specialist dedicated centre, access to and participation in clinical trials is low.

This report provides an overview of the current treatment pathways and models of care for adolescents and young adults with cancer.

A comprehensive understanding of the issues specific to AYA patients including best practice for tumour types, survival, education, employment and financial issues, specialist palliation for symptom management and age-specific emotional, psychological and spiritual needs is imperative in developing appropriate referral pathways and service delivery options.

Methods

A literature review and expert consultation were completed to understand the current treatment of adolescents and young adults with cancer.

Two pieces of work were completed to understand the current treatment of AYA with cancer in NSW.

Literature Review

A high-level literature review was completed documenting evidence-based best practice treatment and outcomes and models of care for AYA with cancer. Literature profiles on AYA cancers included treatment and referral pathways of the five most common cancers; Australian and international treatment models; physical and psychological effects and late-effects; and recommendations for palliative care. Reviewed literature included peer-reviewed national and international journals, internet web pages and organisation web sites.

Stakeholder Consultation

Twenty-six paediatric and adult cancer specialists and other key stakeholders attended a workshop at the Cancer Institute NSW in November 2007 to discuss the findings of the literature review and develop key principals of AYA cancer services and possible service delivery options (see **Appendix** for a list of participants). The outcomes of the workshop were supplemented with data from in-depth interviews with tumour stream experts who identified AYA treatment pathways for specific cancer types, how pathways differed from equivalent paediatric and adult pathways and ways to improve treatment.

Age definitions used in this review

The terms childhood, adolescent and young adult are vague in their actual definition, and age boundaries between the three vary in the literature. Definitions of childhood, adolescent and young adult in various dictionaries refer to concepts of development and maturity rather than actual specific ages:

- **childhood:** the period of life between infancy and puberty⁵
- **adolescent:** growing to manhood or womanhood, youthful⁶
- **young adult:** a person in the early years of adulthood.⁷

The World Health Organisation (WHO) defines an adolescent as someone between 10–19 years of age, and youth as someone aged 15–24 years of age.⁸ However, these age ranges do not necessarily reflect the changes in treatment protocols observed for young people with cancer.

In this review, **childhood** will refer to children aged 14 years or less, **adolescence** will refer to people aged 15–19 years (inclusive) and **young adult** will refer to people aged 20–29 years (inclusive). Age ranges will be individually defined where any variation to this occurs.

Results

Incidence of cancers, survival rates and common cancer types in adolescents and young adults

Cancer incidence and survival rates

In 2005, there were 34,227 new cases of cancer diagnosed in NSW; 19,316 in males and 14,911 in females. The age-standardised incidence rates for all cancers were 569.5 new cases per 100,000 for males and 388.8 for females.⁹

There were 181 cancers diagnosed in NSW children in 2005 (106 in boys, 75 in girls). The most common cancers in children were leukaemia (38 per cent), followed by cancers of the central nervous system (15 per cent), lymphomas (nine per cent) and neuroblastomas (6 per cent).⁹

The most common cancer types by age group in NSW in 2005 are presented in **Table 1**.

There have been worldwide efforts to decrease the mortality rates of childhood cancers, but fewer targeted efforts on adolescent and young adult (AYA) cancers. This has resulted in a smaller percentage increase in survival rates for AYA (typically depicted as 15–30 years of age) cancer over the past 25 years compared to childhood and older adult cancers.

Over the past 20–25 years, the proportion of children surviving five years post diagnosis of cancer in North America has increased nearly 40 per cent.¹⁰ This has not been the case for AYA cancer, which has seen an increase in incidence over the last 25 years, with only marginal increases in survival rates.¹¹

Table 2 (from Bleyer and Ries 2002), indicates survival rates for 0–14-year-olds has improved by, on average, 1.8 per cent. In comparison, survival rates for 15–39-year-olds are much

Variation in referral pathways and treatment protocols has lead to a large distribution of AYA with cancer across paediatric and adult facilities.

lower. For people aged 25–39 years, survival rates have decreased.¹²

In Australia, similar percentage increases in survival have been observed compared to the survival rates in the United States. Australian increases in survival are less than US comparisons for children under 10 years of age and adults over 80 years, but slightly higher for adults aged 50–70 years.

For AYA in NSW, the majority of cancer patients diagnosed between 1980 and 2003 were alive at the end of 2004. The five-year survival from the period 1980 to 2003 was 86 per cent in females and 82 per cent in males.¹³

Many of the cancer types and the pattern of cancer distribution which occurs in the AYA age group are distinct from both childhood and older adult cancer. Although AYA cancers are more aligned with the spectrum of cancers observed in children than the common types of adult cancer, AYA cancers are also distinctly different and require an age-specific approach.¹⁰ Adolescent and young adult cancers have unique features in addition to the special medical, physical, psychological, and social needs of patients in this age group. The spectrum of malignant diseases is different from any other period in life, and it is strikingly different from the pattern in older persons.¹⁴

Table 1 Most common cancers in NSW by age category⁹

Ranking	0–14	15–39	40–64	65+	All Ages
1	Leukaemia	Melanoma	Breast	Prostate	Prostate
2	Brain	Breast	Prostate	Bowel	Bowel
3	Kidney	Testis	Bowel	Lung	Breast
4	Non Hodgkin's lymphoma	Thyroid	Melanoma	Breast	Melanoma
5	Bone	Non Hodgkin's lymphoma	Lung	Melanoma	Lung

Table adapted from Tracey et al., (Cancer Institute NSW) 2007.⁹

Table 2 Average annual percentage change in US cancer survival, by age, 1975–1998¹²

Age (Years)	0–4	5–9	10–14	15–19	20–24	25–29	30–34	35–39
Incidence	1.1%	0.5%	1.1%	0.7%	.0.9%	1.6%	1.5%	1.0%
Mortality	-2.2%	-2.3%	-1.9%	-1.7%	-1.2%	-1.1%	-0.9%	-1.0%
5-Year Survival	1.8%	1.7%	2.0%	1.1%	0.7%	-0.4%	-0.6%	-0.2%

Table from Bleyer and Ries 2002.¹² Based on data from the US Surveillance Epidemiology and End Results (SEER) program.

Common cancer types

Although there is an overlap in the cancer types of children's (0–14 years) and adolescents (15–19 years)/young adults (20–29 years) the distribution of cancer types in AYA patients is unique and distinct from both paediatric and older adult cancer distributions.

In Australia, melanoma was 30 per cent of total cancers in NSW in cases aged 15–30 years, compared to 30 per cent of Australians aged 12–24 and 11 per cent of Americans aged 15–29 years. Within each age category of interest, melanoma ranks first with 23 per cent, 31 per cent and 30 per cent of all cases for each age category.¹³

Although many AYA cancer types are often considered paediatric (as they are rarely observed in older adults), the distribution patterns suggest some cancers considered paediatric are really AYA cancer types as they have a much higher prevalence in this age group. For example, Hodgkin's disease (16 per cent of adolescent cancers, but only four per cent of childhood cancers) and germ cell tumours (15 per cent of adolescent cancers, but only four per cent of childhood cancers) should both theoretically be considered as AYA cancers rather than paediatric cancers.¹⁵ Another characteristic of AYA cancers is the infrequent occurrence of cancers which are typically common amongst older adults, such as epithelial cancers.¹⁵

Despite the overlap of some paediatric and older adult cancer types in the AYA age group, the biology of the cancers in the AYA age group is often considered to be different due to the physical and pubertal changes occurring at this time. However, it is still not clear why AYA have a lower survival rate than children with the same cancer type, despite similar treatment regimes offered. It is possible

this is not age related, but simply a result of AYA cancer being further progressed at diagnosis. For example, many Ewing's sarcomas in AYA are further advanced with large primary tumours compared to those observed in children. In addition, many AYA and adult cancers are treated less aggressively than children's cancers which may also contribute to lower survival rates.¹⁶

Some reasons why AYA present with more advanced cancers are due to education and awareness of the AYA population and general practitioners (GPs) caring for AYA.

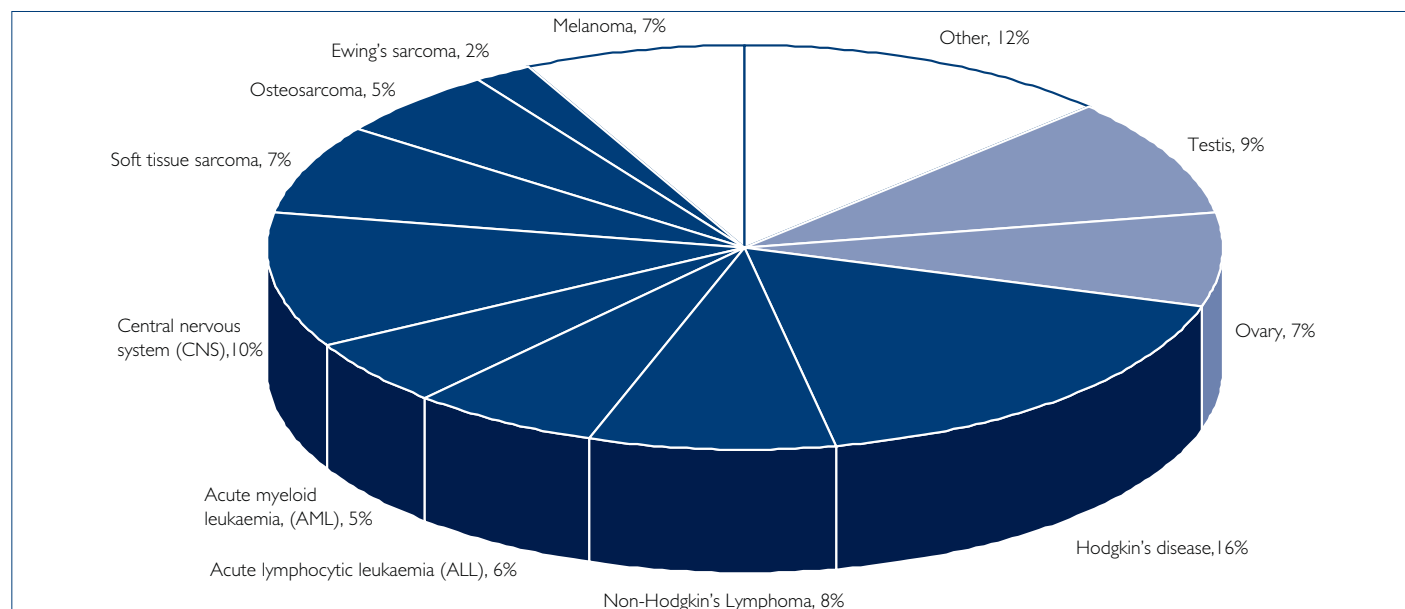
In a review by Albritton and Bleyer (2003) reasons for delayed diagnosis in AYA were:

- the sense of invincibility of AYA age group which may minimise physical findings or delay the seeking of professional advice out of denial or embarrassment
- lack of clinical suspicion of cancer in AYA as they are typically a healthy age group
- lack of regular primary health care in the AYA age group
- physicians untrained for the AYA age group
- lack of health insurance for many AYA limiting medical options/advice sought.¹⁶

However, in a recent study of new drug therapies for Ewing's sarcoma in which patients aged 30 years or less were eligible, the results suggested that the adolescent survival rate (10–17 years old) was significantly less than the children's (less than 10 years old) survival rate: 44 per cent compared to 70 per cent, respectively. This indicates children and adolescents may require different treatment regimes.¹⁷

North America

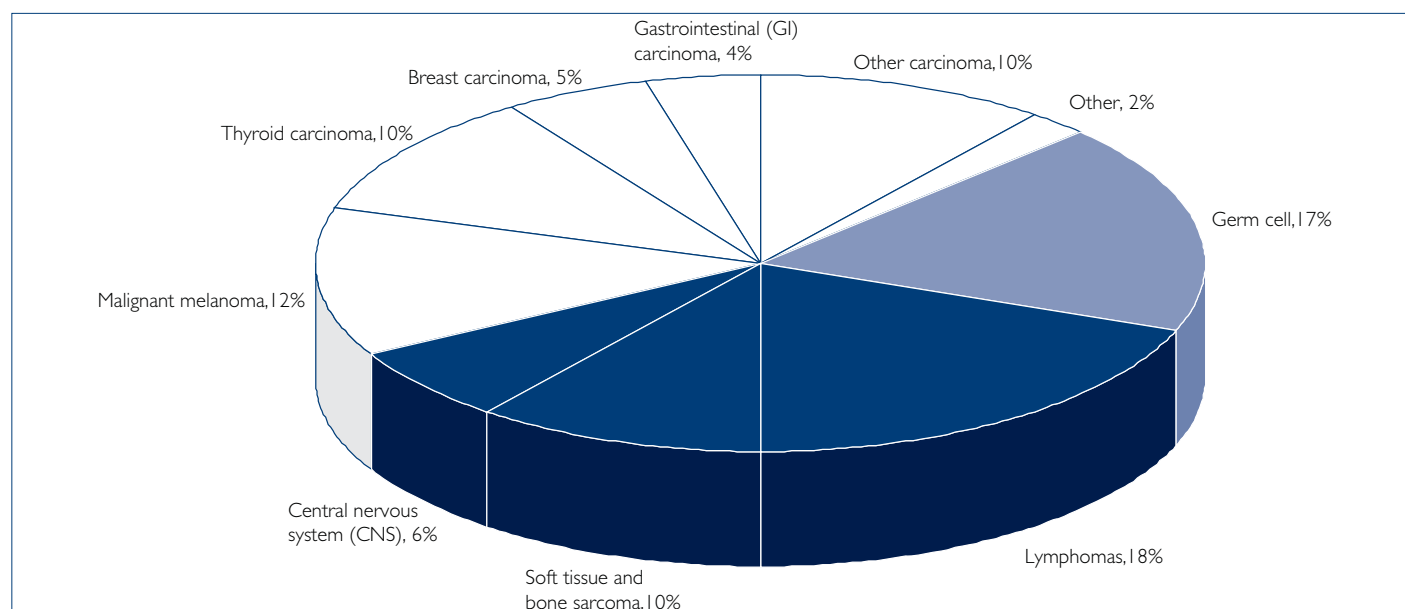
Figure 1 Common cancer in adolescents (15–19 years)¹⁶



Adapted from Albritton and Bleyer 2003.¹⁶

Dark blue represents an overlap with paediatric cancers, pale blue represents a partial overlap with paediatric cancers, white represents no overlap with paediatric cancers.

Figure 2 Common cancers in young adults (20–29 years)¹⁶

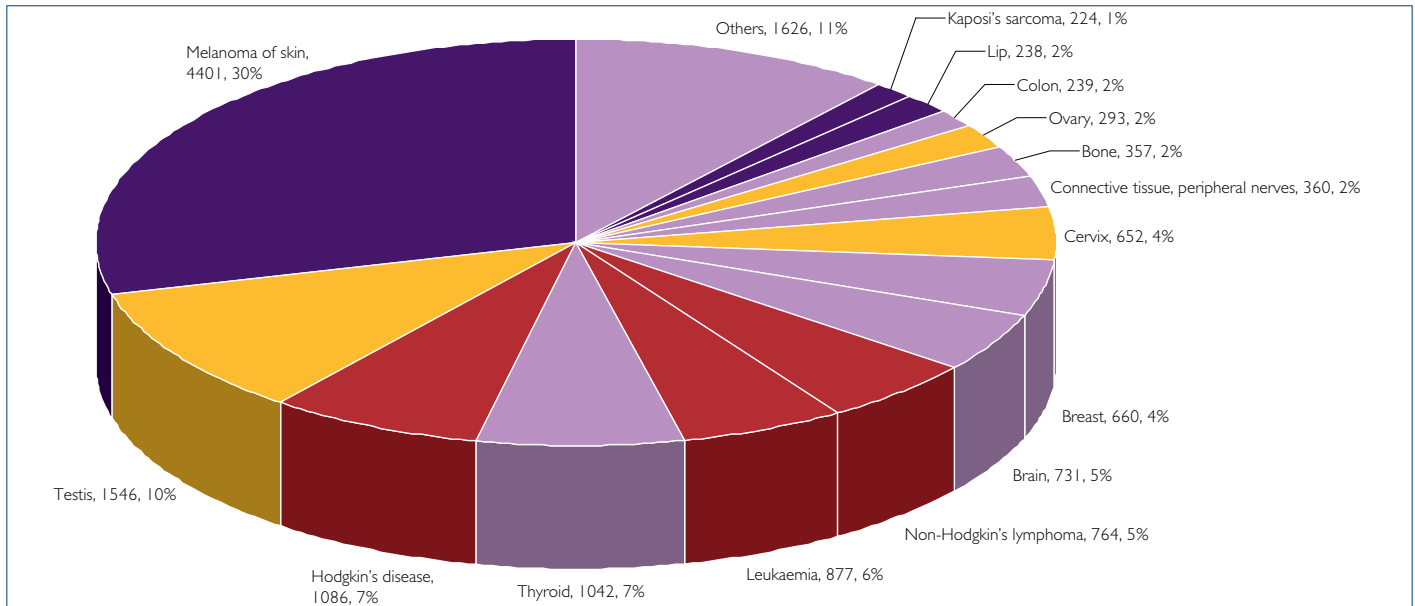


Adapted from Albritton and Bleyer 2003.¹⁶

Dark blue represents an overlap with paediatric cancers, pale blue represents a partial overlap with paediatric cancers, white represents no overlap with paediatric cancers.

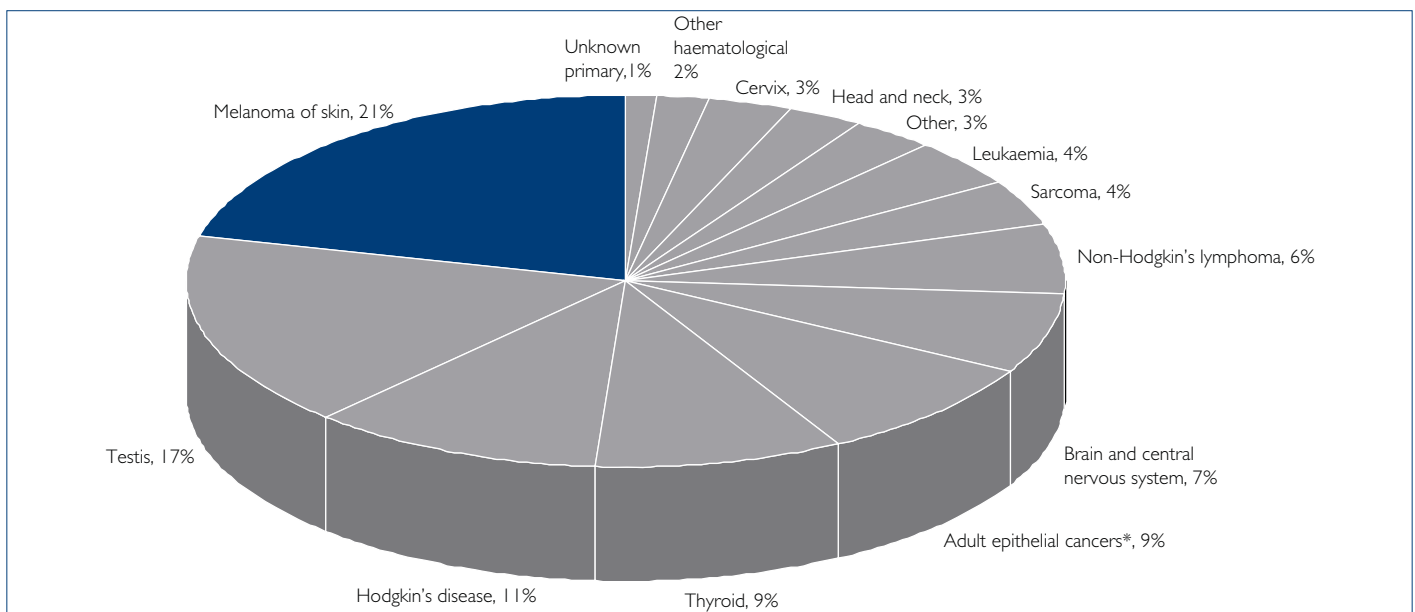
Australia

Figure 3 New cases by cancer site in AYA 1980–2004 in NSW (15–30 years)¹³



Source: Tracey EA., 2007. Cancer in Adolescents and Young Adults in NSW.¹³ Dark purple colour indicates skin related cancers, yellow indicates male and female reproductive cancers and red indicates lymphohaematopoietic (leukaemia and lymphomas).

Figure 4 AYA cancer types in Victoria in 2003¹⁷



From Thomas et al. (2006).¹⁷ Based on data from the 366 patients aged 15 to 30 years registered with the Cancer Council in Victoria in 2003. *Adult epithelial cancer include: breast, bowel, thyroid, kidney, ovary, other digestive tract cancers.



Cancer treatments and therapies

Treatment of adolescent and young adults with cancer in NSW is widely dispersed. Majority of AYA cancers represent a transition from paediatric to adult cancer types and it is estimated that only 30 per cent of patients have a specific teenage onset cancer.⁴

Treatment setting

The differences between a paediatric facility and an adult hospital are not only limited to their treatment protocols. To start, paediatric tumours are classed based on morphology, while adult tumours are based on the location (organ) of the primary tumour (based on the International Codes of Disease (ICD-0)).¹⁵

Cancer care in the paediatric setting is family orientated, holistic and provided by multidisciplinary teams which include paediatric oncologists, nurses, dieticians, social workers and counsellors. Treatment is provided in child-friendly environments and the child is likely to have access to clinical trials and other best practice models of treatment and therapy. There is also a relatively high cure rate for paediatric cancers, resulting in a large focus on recovery and future care.

However, the majority of AYA cancers are treated in adult centres, as the majority of AYA patients are over the age of 18.

There can be some blurring in the location of treatment for patients in the 15–16 year age category. In haematology oncology, NSW clinicians explained that after an assessment of biological age and the level of family support, it is not uncommon for adolescents older than 15 years to be treated in an adult setting. Clinicians in NSW felt the approach to managing AYA cancers needs a disease specific approach, not an age focus.

Adults treated at specialist cancer centres are likely to have access to clinical trials and best practice models of care, unlike paediatric treatment protocols, adults with cancer have limited access to multidisciplinary care. Patients in an adult setting often have to search for social workers or counsellors independently. Despite advances in adult cancer research and treatments, the cure rate is not as high as

paediatric cancers. As a result, there is more clinical focus on prolonging survival time, rather than long term recovery.

Adolescent and young adults represent a transition from paediatric to adult cancer types and often are not treated in the most appropriate setting. The psychosocial impact is significant for AYA who may be sharing a room with a child or an elderly person.¹⁶

Clinical outcomes

There have been several studies that indicate treatment of adolescents with paediatric cancers have better outcomes if treated in paediatric settings. This variation in clinical regime was also highlighted by clinicians, who used the example of treatment of acute lymphoblastic leukaemia (ALL). Acute lymphoblastic leukaemia is a cancer type predominantly seen in children, who are treated for the disease with aggressive chemotherapy. In contrast, adults with ALL are physiologically unable to cope with this same intensity of treatment. An adolescent, however, is likely to benefit from treatment regimes used in the paediatric setting, while applying a paediatric regime to a young adult aged older than 25 years won't have the same positive impact. Therefore age related physiologies should define the treatment regime.

This is supported by a French study (Boissel et al., 2003) of adolescents aged 15–19 years enrolled in paediatric (FRALLE–93) or adult (LALA–94) clinical trials for the treatment of ALL. Results indicated that adolescents in the paediatric trial had higher rates of complete remission (94 per cent in the paediatric trial compared to 83 per cent in the adult trialⁱ) and higher rates of event-free survival for five years (67 per cent in the paediatric trial compared to 41 per cent in the adult trial). The main difference between the two treatment protocols was the use of more intensive drug therapy in the paediatric trial (including high dose usage of L-asparaginase and prednisone). These results demonstrate that treatment of adolescents with ALL has better outcomes on paediatric treatment protocols.¹⁸

These results are consistent with other studies on the treatment of ALL, including an American study which showed a 64 per cent six-year survival rate for adolescents (16–21 years) treated on a paediatric trial compared to a 38 per cent six-year survival rate for those treated on an adult

i. Majority of differences in complete remission were seen in patients with B-cell precursor ALL (98% complete remission in the paediatric trial compared to 81% in the adult trial), whilst patients with T-cell ALL had similar complete remission rates (83% in the paediatric trial and 89% in the adult trial).

trial protocol (reviewed by Albritton and Bleyer, 2003).¹⁶ Additional research by the Dana Faber Institute (Dana Faber Paediatric ALL Consortium and Dana Faber Combined Adult/Paediatric Consortium) showed a need to develop new best practice protocols for adult treatment of ALL, especially the AYA age group.¹⁹ An example of different adult/paediatric protocols suggested for review was the belief that adults do not tolerate asparagine treatment, but the Dana Faber research indicated that both adults (18–50 years) and children (10–18 years) tolerated equal doses of asparagine therapy to the same extent.¹⁸

In another American study at the University of Texas M.D Anderson Cancer Center, adults with acute myeloid leukaemia (AML) were treated with a protocol derived from paediatric clinical trials. In this study, patients' outcomes were improved after the paediatric based protocol was introduced²⁰, indicating that AYA and adults in general with cancer may benefit from the lessons learnt in paediatric clinical trial protocols.

The enforcement of the '18+' ruleⁱⁱ drives a clinical approach to services delivery and care. For example, an 18-year-old with a brain tumour is most likely to be treated in an adult hospital, regardless of the type of brain tumour. Childhood brain tumours tend to be more responsive to aggressive chemotherapy, whilst adult brain tumours do not and the survival rate of this type of tumour is very low.

These examples highlight the need to define best practice treatments that consider the cancer/tumour response as well as the person response.

Referral pathways

Referral pathways for treatment vary largely by cancer type. Some referrals can be made through an emergency department, and others can be via a GP. There is also clinical evidence showing pathways can vary according to whom the primary clinician refers a patient.

In general, AYA patients with cancer are not referred to specialist cancer centres. If the cancer is diagnosed by a paediatrician, it is likely the patient will be referred to a paediatric hospital with specialist paediatric oncologists. However, if the cancer is diagnosed by a GP or hospital

intern, patients over 16 years of age will be referred to local adult hospitals.

Using the example of melanoma, a GP may refer a patient to a dermatologist, general or plastic surgeon or surgical oncologist with a special interest in melanoma.

However, pathways can vary according to where a patient is referred. For example, the treatment of cervical cancer can vary according to whether the GP refers to a gynaecologist or a gynaecological oncologist.

Standardised referral pathways for different cancer types should be promoted to ensure consistent and early diagnosis and treatment for cancers.

Lack of resource concentration

The current variation in referral pathways and treatment protocols has led to a large distribution of AYA with cancer across paediatric and adult facilities in NSW. Without a concentration of clinical expertise or patient volume, health outcomes, in general, are poorer.²⁰

Due to the small number of AYA cases seen at any one hospital, resident oncologists are unable to gain experience or knowledge of the cancer type or best practice protocols for treatment. These informal referral patterns for AYA cancer result in a large distribution of patients within this age group across many hospitals. Unlike children's cancers, there is no cohort of similar AYA cancer types in any one place. In Victoria, of the 366 cancers diagnosed in patients aged 15–30 years, 71 per cent were seen across 66 Victorian hospitals (49 hospitals of which each saw three or fewer cases).¹⁷

New South Wales clinicians acknowledged the distribution of cancer expertise and specialist management of different cancer types reflects the prevalence and incidence of cancer types, the current mix of clinical services available in different geographic areas and the need for specialist treatment regimes.

For example, the diffuse treatment model is used in haematological cancers such as leukaemia's, which are generally treated across multiple teaching hospital sites, especially at the higher end of the AYA age group.ⁱⁱⁱ In

ii. 18+ rule: patients 18 years and over must not be treated in a paediatric setting, according to the NSW Health Act.

iii. Above 18 years, when patients are required to be treated in adult hospitals, according to NSW Department of Health treatment guidelines.



contrast, in the concentrated treatment model for cancers in reproductive organs (e.g. testicular, ovarian and cervical cancers) is driven by the location of specialists in a smaller number of sites. For example, there is testicular radiation oncology expertise in approximately six centres in NSW, with a similar situation for specialist gynaecological oncology expertise for cervical/ovarian cancer.

As reviewed by Thomas et al., (2006), there are a number of examples where patients treated at specialist cancer centres had better than average outcomes (survival rates). For example, patients with germ cell tumours had higher three-year survival rates when treated at the Sloan Kettering Memorial Hospital of 94 per cent compared to the United States average rate of 73 per cent (based on the SEER data registry).¹⁷

Another confounding problem in Australia is the 'tyranny of distance'. In 2003, 20 per cent of the AYA patients aged under 24 years at the Peter MacCallum Cancer Centre were from rural areas of Australia. This indicates that access for young people with cancer living in rural and remote areas is limited.¹⁷

Medical awareness and expertise with cancer in adolescents and young adults

The limited expertise of adult cancer oncologists in relation to AYA cancer types has been blamed for the lower survival rates of AYA cancer patients treated in adult hospitals, in comparison to paediatric settings. While some 'paediatric' cancers show better outcomes for AYA patients, there have been no studies to explain the finding. Different treatment regimes or lack of awareness of best practice protocols may be considered, and there has been little research on the treatment setting and outcomes of AYA patients with an 'adult' type cancer, such as breast cancer or melanoma.¹⁷

The progression of the cancer at diagnosis may also account for lower survival rates in AYA. Presentation to primary care providers, such as GPs, may delay diagnosis as cancer is not necessarily an obvious explanation to, say, tiredness in an otherwise seemingly healthy teenager.¹⁶

Through better education for primary care providers and

development of appropriate referral processes for AYA, early diagnosis may result in better outcomes for the patient.

Haase and Phillips (2004), in an article for the Journal of Pediatric Nursing, discuss the 'invisibility' of AYA patients. The article says that, because there is variability in "staff philosophy of care and comfort and skill in engaging in AYA-appropriate activities", there is also variability in both the delivery of treatment (including trials) and in evaluating effectiveness of treatments.²¹ However, further research is required on the best practice protocols for different types of AYA cancer, particularly adult cancers, to provide evidence of the best treatment setting.

Clinical trials

Advances in medical treatments are evidenced through clinical trials of new drugs, new drug combinations and regimes, and new treatment therapies in general. These trials provide best practice evidence for disease treatment protocols internationally. However, in the oncology field there are far fewer AYA patients entered into clinical trials compared with children and older adults.

In the United States, 90 per cent of children aged 15 years or less are treated at institutions participating in National Cancer Institute (NCI) sponsored clinical trials and approximately 55–65 per cent of these children are entered into clinical trials. However, only 20–35 per cent of AYA aged 15–19 years are treated at institutes participating in NCI trials, with a mere 5–10 per cent entered into trials. For AYA aged 10–19 years, only 10 per cent are treated at such institutions and only one–two per cent are entered into trials.^{12,14,16}

Similar results were observed in a Victorian study of AYA cancer patients. This study showed that of patients aged 10–24 years old between 1992 and 1996, significantly more adolescents (10–19 years) were enrolled in clinical trials if treated in a paediatric setting (38 per cent compared to three per cent in an adult setting), and only four per cent of young adults (aged 20–24 years) were enrolled in clinical trials.²²

Better outcomes for cancer patients entered into clinical trials has been documented in several studies. In the United States, adolescents aged 15–19 years were shown to have better five-year survival outcomes for ALL, AML, osteocarcinoma and Ewing's sarcoma if treated in trials conducted by the Child Cancer Group (CCG) or Paediatric Oncology Group (POG).^{10, 14} Similarly, the Pentheroudakis and Pavlidis (2004) review found that participants in clinical trials for embryonal tumours (e.g. retinoblastoma), central nervous system (CNS) tumours, lymphomas, and ALL had better survival rates in children compared to AYA patients.¹⁵ However, it was not clear from these studies the cause of the differing survival rates, which could be related to the differing biology of cancer in differing age groups, differing responses to drug therapy in differing age groups, or the use of combined or single modality therapy.¹⁵

Other cancer types had similar outcomes and/or survival rates across all age groups. For example, germ cell tumours, testicular cancer, and osteosarcoma were shown to have higher survival rates in AYA than children.¹⁵ This is consistent with a Victorian study, which indicated survival rates of 10–24-year-olds with germ cell tumours did not alter regarding the place of treatment.²² Survival of leukaemia and lymphoma was also shown not to be dependant on the place of treatment in Victoria.²²

For some cancer types, such as Hodgkin's disease, there was contention as to whether or not survival was increased in children compared to AYA.^{10, 15} Regardless, these studies show that clinical trial protocols do benefit some AYA patients, although this is cancer specific. Cancers such as germ cell cancers were shown to have similar survival rates with or without clinical trial protocols because of the high survival rates of non-trial protocols already.¹⁵ Brain tumours were the only cancer type reported to have equally low survival rates with or without clinical trial protocols, indicating that this cancer type requires further research to adequately increase survival rates.¹⁵

The recent Victorian study of AYA patients (10–24 years) enrolled in clinical trials between 1992 and 1996 did not show any significant difference in five-year survival rates overall between the three designated age groups (10–15 years, 16–19 years and 20–24 years).²² However, when

individual tumour types were examined, bone tumours showed significantly more patients aged 10–15 years were entered into clinical trials compared to those aged 16–19 years (46 per cent compared to 5.5 per cent, respectively). Five-year survival rates also increased in patients treated in a paediatric setting (almost all patients aged over 16 years were treated in adult hospitals).²² These results suggest that AYA patients with bone tumours would benefit from participation in clinical trials.

Irrespective of the immediate outcomes for clinical trial participants, clinical trials are essential for the testing of new treatment regimes and development of subsequent best practice protocols which will benefit many more patients in the future. As such, it is essential AYA patients are included in this research.

There is a lack of clinical data for characteristics of 'adult' type cancers, such as epithelial cancers, breast cancer and ovarian cancer; and comparative survival rates across AYA and older adults. However, many AYA patients with a typically 'adult' cancer have a genetic predisposition for the cancer, which may also impact on the survival rates.¹⁵ Further research is required.

The Australian Government, through the Strengthening Cancer Care initiative, provides \$5 million a year for four years to increase conduct of cancer clinical trials. In addition, new cancer-support networks and AYA cancer groups have been established to address some of the emerging issues in AYA cancer.²³

It has been suggested that inequity of access to clinical trials for adolescent patients can be improved by concentrating these rare cancers to dedicated centres where resources are sufficient to support clinical trial operation. This will also facilitate enrolment for younger adolescent patients currently denied access because eligibility for protocols in adult facilities usually requires age to be 18 years or older.

Reasons for lack of adolescent and young adult participation in clinical trials

Some of the barriers AYA cancer patients have to accessing clinical trials described in the literature are detailed below:

Clinician Barriers	Institutional Barriers	Patient/Carer Barriers	Industry Barriers
Reluctance to enrol patients in clinical trials due to time and cost of procedures.	Private providers not referring a patient to a public provider involved in clinical trials.	Difficulty in obtaining informed consent.	Lack of collaboration between adult trial cooperatives, due to spread of AYA cancer patients and no critical mass.
Perceived non-compliance of AYA patients ^{iv} may reduce clinician willingness to enrol AYA patients.	Provider lack of knowledge around benefits of multimodal therapies for AYA cancer treatment.	Unaware of trial opportunities.	Health insurance agencies deterring referral of AYA to centres participating in clinical trials (e.g. specialised cancer centres which are usually publicly funded, i.e. Peter Mac).
Lack of collaboration between paediatric and adult trials may limit AYA access.	Unaware of trial opportunities.	Patient/family unwilling to participate.	Lack of suitable trials for the AYA age group.
	Hospital age policies may prevent AYA access to clinical trials (e.g. 18 years may be considered too old for a paediatric hospital) or age restrictions of the trial.		Research funding methods may not encourage collaborative trials and hence limit AYA numbers. ^{14, 16, 17} National Health and Medical Research Council (NHMRC) in Australia funds research based primarily on the publication record of researchers. Large multi-collaborative trials may not result in many publications for one researcher, and therefore may limit funding opportunities for further research.

iv. Interestingly, the recent Victorian study did not find any significant numbers of non-compliance across age ranges 10–24 years, suggesting that the perception of non-compliance in AYA patients may not be accurate and should be further investigated.

Psychological issues for adolescents and young adults with cancer

In NSW, it is estimated that 25 per cent of childhood cancer survivors demonstrate clinically significant levels of psychosocial-related distress.²⁴

Early adolescence is a time of physical and cognitive changes; including rapid growth, sexual development, the ability for abstract thought, and the ability to understand consequences and make plans for the future.²⁵ Adolescents with a life threatening or terminal illness must deal with these changes, as well as issues associated with their illness, treatment, side-effects and confrontation with their own mortality.

In NSW, a quarter of survivors reported issues relating to depression and anxiety.²⁴

The melanoma expert consulted noted that specialist psychological support can be required for any patient, regardless of their prognosis. The stigma of the diagnosis can be enough to precipitate a significant anxiety state or to exacerbate an underlying psychological problem.

Independence

A developmental change during adolescence and young adulthood is the desire to define identity—within relationships, career decisions and lifestyle choices.

A young person undergoing treatment, however, may find these desires occurring simultaneously with their increased dependence on parents/carers, who will often make decisions on their behalf. Not only is their independence to make decisions diminished, an AYA in a hospital environment is isolated from healthy peers who play an important part in fostering autonomy.

In Lynette Hoffman's article in *The Australian* newspaper, which was awarded the Clinical Oncology Society of Australia 2006 Luminous Award, she interviews a 17-year-old cancer patient who had her first round of treatment when she was 14 years old; *"I was crushed, being 17 the opposite sex was now a greater issue in life, and I was devastated thinking that no boys would ever want to go out with the girl with cancer. ... My hair fell out and I looked different and I was asked on many occasions if I was a boy."*²⁶

Young people with cancer understand that cancer and its treatment have left permanent physical, emotional and mental scars on their lives. Living with the knowledge that the illness could reappear at any time can make planning for the future or developing any life/work/education goals seem futile.

These feelings can increase the potential for depression and the risk of self-medicating with drugs and alcohol. As Finella Craig (2006) says in her review of illness in AYA, *"the psychological impact of impaired, lost, or potentially unachievable independence can be immense, especially when the young person sees healthy peers and siblings become increasingly independent."*²⁵ Due to the complex emotional demands of AYA, all staff involved in their care should receive training that enables them to offer appropriate support and advice.

Stevens (2004) argues that the way family, friends and peers react will have a significant effect on how successfully adolescents with a life-threatening illness cope and their freedom to make their own choices.²⁷ Craig advises parents, carers and medical teams to encourage and facilitate a young person's move to independence.

It is often a challenge for care teams treating AYA to include the young person in discussions regarding their health care—including prognosis, treatment and future management, as well as day-to-day life decisions. But, including AYA in at least some level of the discussion can foster feelings of independence and ensure there is informed decision making. Craig advises that *"professionals must be sensitive to the difficulties faced by parents and young adults when the balance of responsibility starts to shift, and should start to prepare them [both parents and adolescents] for this transition well in advance."*²⁵

Equally important is support of educational and career aspirations. Limited financial independence, due to interrupted schooling and ongoing treatment, should not prevent a young person undergoing cancer treatment from receiving comprehensive career advice and support to access vocational or further education.

As was highlighted by the melanoma expert consulted, financial support is particularly important as many AYA and

their partners will have dependents and have not made provision for loss of income.

Relationships and sexuality

One of the key concerns for adolescents with cancer is the ability to form relationships and maintain friendships. Craig notes that: *“opportunities for peer identification are limited when poor health, physical appearance or impaired cognitive function identify a young person as different.”*²⁵ The difficulties are compounded for AYA with cancer who have had their mobility restricted, as they are less able to participate in social activities and may be isolated and ostracised by their peers. Care plans should consider young people’s needs for social interaction and leisure activities, as well as educational and vocational support.

An additional concern is emerging sexuality, resulting from pubertal change. Craig cautions: *“young people [with cancer] who develop sexual maturity alongside their peers may find physical disabilities, or anxiety associated with their disability, in addition to a lack of appropriate social contact and limited independence, impair their opportunity to experience a similar level of sexual activity.”*²⁵ Young people with terminal illness may go through intense grief that they may not live to experience sexual intimacy, while others may engage in overt, risk-taking sexual behaviour in an attempt to gain “normality”. Young people struggling with homosexuality face an added layer of complexity.

Grieving and loss

Stevens discusses the significant grieving that AYA with cancer encounter at various stages of their illness. It was suggested that adolescents with cancer mourn the following:²⁷

- loss of their pre-diagnosis identity
- altered body image due to weight gain, hair loss, amputation and other side-effects of treatment
- loss of the perception (by others) that they are a healthy person and therefore being treated as vulnerable by everyone
- missing out on the day-to-day life at school

- inability (or restricted ability) to push for independence
- changes to family dynamic caused by the stresses (financial and emotional) of the young person’s illness
- relationships with girl/boy friends
- loss of certainty about the future
- struggle to maintain hope and any sense of joy.

Patient satisfaction

Patient satisfaction in NSW was measured as part of the NSW Cancer Patient Satisfaction Survey.²⁸ Interim results indicate younger inpatients, aged 20–39 years, reported statistically significantly lower ratings compared to other age groups for two dimensions of care; the information and education that they received, and coordination of care.²⁸ Young adults 20–39 years old expressed a fear that information is being withheld from them and staff are not being completely honest about their condition and prognosis; and a feeling of vulnerability and powerless in relation to the coordination of their clinical and supportive care.²⁸

Walker et al., (2003), examined patient satisfaction with treatment planning and follow up appointments and argue that patient satisfaction with treatment is an important early indicator of medical outcome for cancer patients. They reported that predictors of overall satisfaction were age (younger clients were more satisfied with treatment and follow-up); gender (females were more likely to be satisfied with care); and overall levels of attention paid by care staff to how well patients were coping with their illness. Walker et al., show satisfaction with cancer treatment correlates to continuity of care and treatment compliance. They also cite a 2001 study by Bredart et al., which showed that patient satisfaction may also be an indicator of quality of life and psychological distress.²⁹

Haas and Phillips define a conceptual misunderstanding of healthcare providers, who see AYA as not being committed to or compliant with treatment.²¹ However, the authors cite various research results which show that AYA do construct their own view of both their illness and treatment and it is this view which will influence individual commitment to treatment regimens. Similarly with studies of cultural

understandings of illness, the 'world view' should be accommodated in the development of treatment plans, not overridden by the 'correct', scientific world view.

Many adult cancer care teams still cite non-compliance as one of their concerns regarding AYA patients. Clinicians gave the example of counselling for testicular cancer, which if offered, is unlikely to be accepted due to the characteristics of the recipient group of young adult males not interested in fertility counselling.

As defined by Haas and Phillips, *"AYA perception of treatment decisions and decision-making processes, and their perception of the extent of their connectedness to health care providers can influence their commitment to treatment regimes, thus confirming that if treatment plans do not resonate with the young person's view of their body and illness, and if the treatment team does not connect to the young cancer patient, compliance with treatment will suffer."*^{21, 30}

More attention needs to be paid by health practitioners to the age of diagnosis and the subsequent interruption caused by treatment regimes to normal developmental events and processes.³⁰

Effects and late-effects of cancer in adolescents and young adults

Many more children and adolescents with cancer will be cured. However, many of the curative therapies themselves either predispose survivors to secondary malignancies or affect their long-term health and quality of life in a number of ways.

Melissa Hudson (2005) argues that the growing recognition of the adverse effects of cancer treatment on growth and development, organ function, reproduction and fertility and the creation of secondary malignancies has led to *"the development of risk-adapted treatment approaches for paediatric malignancies."*³¹ Identification of vulnerable survivors is essential for providing timely interventions to detect, ameliorate, reduce, or prevent cancer-related sequelae, including psychosocial effects and quality of life.

Growth and development

Hudson argues that adverse effects on growth and development are particularly problematic for younger cancer patients because it can effect the maturation of the skeleton, intellectual function and cognitive development, as well as emotional and sexual development and maturation. Furthermore, she states that the *"detrimental effects on vital organs may be asymptomatic, only to be manifest after the completion of growth or during aging."*³¹ This is of particular relevance to questions of secondary malignancies and of fertility.

Nagarajan et al., (2003) report that while medical sequelae can be correlated with the type, intensity and schedule of antineoplastic therapy, psychosocial functioning reflects the interaction between cancer treatments, social supports, and the emotional and physical maturity of the patient at the time of diagnosis and treatment.³²

One of the groups that are continually mentioned as having particularly negative outcomes from treatment are survivors of cancers effecting the brain or central nervous system. As a result, the intensive central nervous system therapy seems to impair cognitive development and lead to a number of poor cognitive, educational, social and adjustment difficulties. The other group that is continually mentioned as having poor outcomes are survivors of paediatric bone cancer. Patenaude and Kupst state that while treatments have improved for these patients in that amputation is no longer inevitable, some of the newer limb-sparing surgeries involve more complicated recovery and result in reduced functionality so that quality of life *"...may actually be reduced with the less-invasive surgery."*³⁰

Behavioural effects

Schulz et al., (2007) conducted an evaluation of behavioural and social outcomes of adolescent childhood cancer survivors, using data collected by the Childhood Cancer Survivor Study (US). Six problematic behavioural and social domains were assessed (depression/anxiety, degree of 'headstrong' behaviour, attention deficit, peer conflict/social withdrawal, antisocial behaviours and social competence) using parent-reported assessment and scores for survivors



and their siblings. They found that survivors were more likely than their siblings to have depression/anxiety and antisocial behaviours.

Significantly, they found that *“scores in the depression/anxiety, attention deficit and antisocial domains were significantly elevated in adolescents treated for leukemia and CNS tumors”*³³ and that survivors of neuroblastoma also had difficulty in the depression/anxiety and antisocial domains, particularly if they had received cranial radiation or intrathecal methotrexate.³⁴

Post-traumatic stress

Studies conducted in early 2000 began exploring the link between cancer survival and post-traumatic stress. A number of studies quoted by Patenaude and Kupst found that moderate to severe symptoms are present in between five to 20 per cent of survivors with young adults experiencing more post-traumatic stress than younger survivors.³⁰

The obvious bias in the Schulz et al., study is that it is overly reliant upon parental assessment of their child’s behaviour, with the understanding that parents may be overly attentive and worried about, children who have survived cancer. As a word of caution, Schulz et. al., cite Carpiantiri (1993), who found that even when parents and teachers reported psychosocial concerns for adolescent survivors of brain tumours *“the adolescents themselves reported minimal difficulties.”*³³

Other studies have shown that survivors show good adjustment on psychological self-report measures and that their scores are not significantly different from those of controls, including siblings, or comparison groups.³¹ In 2003, more than 5,000 childhood cancer survivors in the US were sent the Childhood Cancer Survivor Survey. Researchers analysing the results of this survey found rates of depression in survivors were comparable to those in the general population.

Education

There have been a number of studies indicating that the long-term educational outcomes of childhood leukaemia and brain tumour survivors are poor. It is estimated that

up to one-third of childhood cancer survivors in NSW have educational-related issues, especially leukaemia and brain tumour patients.²⁴

According to Barrera et al., (2005), some reports also suggest that survivors of childhood cancer in general *“and brain tumors in particular”* are less competent socially and tend to be more isolated than their healthy peers.³⁵ The survey conducted by Barrera, used parental reports, which indicated that child and adolescent survivors of cancer were more likely to experience educational difficulties and were less likely to have close friends or to use friends as confidants compared with population controls of the same age and gender.

Consistent with previous studies, the results by Barrera et al., showed that survivors of CNS tumours and leukaemia were most likely to have educational difficulties. Repeated absences from school have been associated with poor social integration for survivors, and for patients with CNS tumours and leukaemia who miss more school during therapy, this inability for social integration is greater. Barrera and colleagues argue that children and adolescents who survive neuroblastoma, leukaemia and CNS tumours should be closely monitored for educational and social difficulties to ensure support is at hand to help survivors achieve their academic and social potential.³⁵

Eiser (1998), however, cautions against attributing all negative health and social outcomes to secondary physical defects arising from treatment. Rather, he encourages researchers to consider that some of these outcomes may be the outcomes of deliberate choice – such that poor educational/career outcomes may actually be due to the recasting of the importance of these outcomes in light of cancer survival – or of psychological factors, such as reduced cognitive ability caused by treatment or reluctance to parent due to persistent fears of early death.³⁰

Haas and Phillips also emphasise research that indicates that AYA patients are resilient, deriving positive, strengthening meanings from their experience of illness. Citing research by Hendricks-Ferguson and others, they argue that *“derived meaning of an experience is an important variable linked with resolution and acceptance in illness.”*²¹

Eakin and colleagues investigated long-term health effects in Australian cancer survivors, using quality of life, overall health status, 'days out of role' and mental well-being as measures of health. They surveyed 968 cancer survivors and 5,808 age-and-sex matched control respondents. The key finding of the research was that long-term cancer survivors reported significantly lower results for health status, days out of role, mental health – but not quality of life. In addition, the likelihood of poor health outcomes was found to be higher in those survivors with co-morbid chronic conditions.³⁶

Suicide

Recklitis et al. (2006) reported that the risk of suicide in adult survivors of childhood cancer is highest in the first few months after diagnosis. They surveyed more than 200 survivors to examine the prevalence of suicidal ideation and to track past suicide attempts in adult survivors of childhood cancers. They found a minority of adult survivors report suicidal symptoms, however, symptoms were related to cancer treatment and post-treatment mental and physical health. They argue that the *“relationship of physical well-being to suicidality underscores the need for a multidisciplinary approach to survivor care”*³⁷ in the long-term.

Long- or late-term effects³⁸

The long-term effects of cancer are many and varied and include physical effects such as impediments to neuro-cognitive development, organ damage, decreased growth and infertility (short and long-term). These physical sequelae also have repercussions for a survivor's ability to form and develop relationships, achieve academic and career success, and affect their general ability to 'function' in society.

Possible late-effects

As stated by Bottomley and Kassner, the degree to which an individual experiences late-effects of cancer treatment is dependant upon the location and extent of the primary disease, the type of treatment and its intensity, age at diagnosis and the level of physical and psychological development at the time of diagnosis and treatment. Some of the late-effects of cancer therapy are:³⁹

- Neurologic: including seizures, deficits in motor function, memory and hand-eye coordination.
- Endocrine: including hormone deficiencies causing arrested pubertal development, hypothyroidism, disruptions to sexual function and fertility.
- Hearing and vision: including permanent hearing loss, tinnitus, abnormal speech development, loss of vision, blurred vision and decreased tear production.
- Head and neck: including alterations to bone causing facial asymmetry, skin changes and hair loss or discolouration.
- Cardiac: cardiomyopathy, coronary artery disease, congestive heart failure or arrhythmia can occur months or years following chemotherapy.
- Respiratory: because radiation therapy late-effects are related to cumulative dosage, the volume of lung that is irradiated, and fraction size, the younger the child at the time of treatment, the greater the risk because of the combined effect of the treatment and its impairment of normal growth and development.
- Gastrointestinal: intestinal fibrosis and enteritis are most common.
- Hepatic: hepatic (liver) dysfunction, fibrosis and cirrhosis.
- Genitourinary: treatment can adversely affect kidneys, bladder, ureters and/or reproductive organs.
- Musculoskeletal: similar to respiratory damage, effects are related to radiation dose, treatment duration and age at treatment. Effects include spinal abnormalities, limb length discrepancies, osteoporosis and delayed or arrested tooth development.
- Hematopoietic/immunologic: older children and those who receive high dose chemotherapy are at greatest risk of hematopoietic (production of blood cells) dysfunction, leaving survivors at risk of compromised immunity.
- Second malignancies: these can be caused either from genetic predisposition or from the cancer treatment received for the first cancer. Second malignancies can present as leukaemia, solid tumours or as central nervous system tumours.
- Psychosocial: including compromised academic achievement, employment and career discrimination, difficulty maintaining friendships and relationships, concerns over fertility, anxiety and depression and in some instances post-traumatic stress disorder, and grief.



Palliative care for adolescents and young adults with cancer

Providing adolescents and young adult patients dying of cancer with a choice over where they die is a *crucial* aspect of providing quality care.^{40–45}

Home palliation

According to Hynson et al., (2003) in their article for the *Medical Journal of Australia*, most families will elect to provide palliative care for their child at home, if this is presented to them as a realistic option. They state that many parents feel that *“this is the last thing they can do for their child”* and that *“palliative care is an extension of the care they would normally provide.”*⁴⁵ There are many benefits to home care including privacy, the inclusion of siblings and extended family in the child’s care as well as a familiar environment for the child.

Craig (2006) confirms that many young people may choose to die at home. However, as primary carers, parents may not be able to access nursing support due to the ‘in-between’ age of their child and may have difficulty with the physical demands of palliative care for their child. Home care for a dying child is a *“monumental task.”*²⁵ In addition to the obvious emotional strain on parents, they are obliged to become quasi-nurses, often providing round-the-clock care, administering multiple medications and learning tasks such as nasogastric feeds and home ventilation. Despite the difficulties and pressures, Hynson and colleagues report that many parents describe the experience as a positive one, giving them greater insight into and appreciation of life.⁴⁵

Hospice care

Brain tumours are the most common solid tumour in AYA with a low cure rate. The biggest issue for young adults with brain tumour is palliative care, and the lack of age-appropriate hospices or nursing homes which has resulted in young adults receiving palliative care with elderly patients. All AYA patients requiring palliation face the same difficulties, with some hospices also enforcing age restrictions.

Craig states that, in the face of continued lack of youth specific hospices, *“many will continue to be admitted to acute*

*hospital wards for terminal care”*²⁵, a less than ideal outcome for a vulnerable population of young people. In their UK study of cancer deaths in young people aged 0–24 in the years 1995–1999, Higginson and Thompson (2003) found that very few children or young people died in hospices; of those that did, a significant number died from brain tumours. Among young adults, they found that home deaths were less likely with increasing age. This may be due to the greater adult hospice options available to young adults. In spite of this, home was an important place of death: 52 per cent of children and adolescents and 30 per cent of young adults died of their cancer at home.⁴⁴

Skilled specialists

Craig cautions that young people with terminal cancer may not be able to find specialists skilled or confident in providing palliative care for a young person who is dying. She says that paediatric teams may lack confidence in the symptom management of older adolescent patients, while community nurses and palliative care teams feel less confident with much younger patients than they are used to.²⁵ In Victoria, the Pain and Palliative Care Department of the Peter Macallum Cancer Institute, in conjunction with OnTrac@PeterMac, the Victorian multidisciplinary AYA service, has received a \$250,000 grant in Round 3 of the National Palliative Care Program (DOHA) project grants. This funding is for three years, and commenced in May 2006. The project aims to evaluate decision making at critical points in AYA patients’ cancer journey which impact on provision of optimum palliative care. They also plan to integrate a palliative care Clinical Nurse Consultant (CNC) and medical consultant into the OnTrac@PeterMac team.⁴⁶

Recommendations for hospitals

Much of the literature describing palliative care for AYA relates to the care needs of children and their families. Issues of shock and grief resonate for all young cancer sufferers, however, the determination of palliative care needs should, where possible and to age-appropriate levels, be driven by the needs and desires of the young person themselves. The care team should also work closely with family members in order to ensure they are supported through the period

of palliative care and in the event of the young person's death.²⁷ Craig also argues that multidisciplinary care teams should include a 'case worker' – someone who has the specialist training and knowledge to support the young persons emotional, psychological and spiritual needs, as well as facilitating the practical medical concerns related to both healing and palliative care.²⁵

There are also profound implications of cultural and religious beliefs on palliative care. It is important for care staff to be familiar with the patients' and families' attitudes to serious illness, dying, death and the mourning of the deceased. Stevens argues that by understanding the customs and beliefs of other cultures, regarding illness and death, care providers can avoid providing additional stress to patients and their

families during treatment, palliative care and in the days following the patients' death.²⁷

Stevens, in his article on supporting family through the care of a dying child, states that a family's successful transition and acceptance of palliative care is strongly affected by their experiences earlier in a child's illness. The way the diagnosis and early treatment are handled by care staff has a big impact: *"effective communication with the child's parents in the days after diagnosis is vital in laying the foundation for effective palliative care later, should that become necessary."*²⁷

Some of the points identified by Stevens for effective communication between treating teams and parents are listed in **Table 3**.²³

Table 3 Suggestions for good communication with parents of children with cancer

Short term
Ensure that both parents are present at the initial consultation.
Have another member of the care team (such as a nurse) present in order to identify areas for discussion.
Give parents a clear description of the illness and always identify it as cancer.
Assure parents that treatment is available that has cured other children.
Provide enough time for parents to ask questions and not feel rushed. Encourage them to write points down for discussion at the next consultation.
A written summary of the discussion, or a tape-recording, may be helpful.
At an early stage, meet with the patient's siblings and grandparents and liaise with the child's school.
Have the family meet a child with a similar diagnosis who has done well.
Long term
Be easy for parents to contact.
Regular seminars, support meetings and newsletters for parents of surviving and deceased patients improves parents knowledge and helps them feel supported.
Patient-held medical records provides families with accessible information about the progress of treatment.
Encourage parents to form a liaison committee to assist in optimal patient management and to pass information from oncology staff and patients' families.
Always allow parents to hope, no matter how poor the outlook or prognosis.

Source: Modified from a table in Stevens.²⁷



Stevens also states that attention should be given by the care team to the siblings of the ill young person to preempt potential feelings of resentment towards the ill person. He quotes a study which looked at the adaptation of healthy siblings to their brother or sister's cancer. This revealed that *"siblings of children with cancer have the same significant anxieties, fears for their own health, social isolation, and other stresses once thought to be peculiar to the patients themselves."*²⁷

Stevens argues that young adolescents (12–15) with cancer are more concerned by the way their family and other loved ones will be affected by their death than about themselves. He also states that *"they are not so much afraid of death, as of the process of dying."* In other words, depending on the young person's developmental stage, they may not yet be old enough to have an existential crisis. They may still consider death as abstract, much like children do, and therefore confront it matter-of-factly. This is clearly not the case with older adolescents and young people, who, when confronted with their own mortality, go through a number of stages of grief and fear and require specialised support and counselling in addition to their clinical care.²⁷

Obviously, a young person with cancer is confronted with their mortality and, as an adolescent, does not necessarily have the emotional and psychological maturity to tackle the existential and spiritual questions which necessarily arise. In addition to the grief, sadness and depression caused by the cancer, its treatment and the young person's isolation from their peers; young people with cancer also mourn the loss of their potential for love, work and family. Clinical psychologists and social workers specialising in youth mental health should be a part of the multidisciplinary care team treating AYA cancer patients. Questions of spirituality may also become important during this time and young people should be supported in exploring and expressing their beliefs.

International treatment models for cancer in adolescents and young adults

In the United Kingdom and the USA, national taskforces have developed solutions for the emerging issues surrounding AYA cancer treatment models.

United Kingdom and Teenage Cancer Trust Units

In the United Kingdom, there are eight dedicated cancer units for teenagers, established by The Teenage Cancer Trust (TCT). These Teenage Cancer Units exist within National Health Service (NHS) hospitals throughout the UK.

The units are designed specifically for teenagers with cancer. As well as having excellent medical facilities, they are equipped with day rooms, kitchens, chill-out rooms, internet access, pool tables, video games, satellite TV, musical instruments and gardens, to provide teenagers with opportunities to 'relax and feel at home or have friends and family to visit in a comfortable environment'. The aim of the units is to provide teenagers and their families with an environment where they can meet others in a similar situation and develop friendships and/or mechanisms to cope with the cancer.⁴⁷

The TCT has built eight units across the UK so far, at a cost of more than £2 million per unit:

- University College Hospital, London (19 beds)
- Christie Hospital, Manchester (13 beds)
- St James University Hospital, Leeds (6 beds)
- Royal Victoria Infirmary, Newcastle (6 beds)
- Alder Hey Hospital, Liverpool (6 beds)
- Queen Elizabeth Hospital, Birmingham (6 beds)
- Beatson West of Scotland Cancer Centre (6 beds)
- Weston Park Hospital, Sheffield (5 beds).⁴⁷

In addition to funding the physical facility, TCT funds cover musical instruments and computers as well as medical equipment. TCT has also begun funding specialist staff, including lead nurses and activity co-ordinators. Charity events, company sponsorship, entertainment and sporting

star sponsorship supplement the funding, along with dedicated fundraising by teenagers and their families/friends. After opening the first unit in 2005, TCT realised a network of units across the country was required to provide equitable access for teenagers with cancer. TCT estimates at least another 15 teenager units are required.⁴⁷

Comments from teenager cancer patients who have experienced the TCT units are provided in **Box 1**.⁴⁷

Box 1

"It's a good place to be if you're having a bad time."

"When I was first diagnosed with leukaemia I was lucky enough to experience one of the Teenage Cancer Trust units. I remember first walking onto the ward and seeing people my own age, all with smiles on their faces, with music playing and fights over what telly channel to watch. I thought I must have the wrong place. I was looking for a cancer unit full of sick people moping around but this was more like a youth club for me, apart from the odd drip stand and the occasional moan of 'not another injection!!' This is how I experienced the TCT unit. I first thought I was going to a place where every one was sick, but because of the lively atmosphere, we didn't have time to feel sick, we were too busy enjoying ourselves and rather than a place where every one was sick, it felt like a place to get better."

"If the units did not exist, I sometimes question whether I would be here today celebrating my third year of remission, as I believe my attitude played a big part in my recovery. I would not have been so optimistic and positive if I had been surrounded by young children or very old, terminally ill cancer patients, who would not be able to appreciate the opportunities that I was missing during such an important time of my life, such as pubbing, clubbing, education, socialising etc."

A 2007 study of referral patterns for children, adolescents and young adults with cancer (10–24 years) in the UK demonstrated that despite the development of the TCT teenage cancer units, only 23 per cent of AYA aged 15–19 years with cancer were treated in one of these units (the remainder being treated in paediatric or adult settings), compared to 87 per cent of those aged 10–14 years being treated in either paediatric or teenage units.⁴⁸

Similarly, while 76 per cent of children aged 10–14 years were referred to cancer networks outside of their residential area, only 56 per cent of adolescents (15–19 years) and 42 per cent of young adults (20–24 years) were referred to outside cancer networks.⁴⁹ These results indicate that there is still a lack of awareness of the new teenage specific units in the medical community and more time (and perhaps more marketing) is required to modify current referral patterns for patients in the AYA age group.

This compares to the 20 designated Children's Cancer Study Group Centres where almost all children under 15 with cancer are treated. For young adults, there are very few identifiable specialist services.⁴⁹

United States

In the United States, the National Cancer Institute (NCI), in collaboration with the Lance Armstrong Foundation and the LIVESTRONG Young Adult Alliance, has established the Adolescent and Young Adult Oncology (AYAO) Progress Review Group (PRG). This is a public and private partnership of prominent members of the scientific, medical and advocacy communities, with the aim of developing a national agenda for adolescent/young adult oncology.

The AYAO PRG has been charged with:

- assessing research in AYA oncology including defining and describing issues facing AYA with cancer and identifying area of strength, gaps and opportunities in the research
- defining and prioritising investment areas for AYA oncology
- preparing a report on the unmet opportunities and needs for AYA oncology and describing development and delivery methods, including an action plan focused on priority areas
- identifying and acting on collaborative strategic implementation initiatives.⁵⁰

Cancer and the Adolescent, published in 2006, concludes with a discussion of various models of care for AYA with cancer. The authors believe that an ideal model is a specialised centre for AYA staffed by people with specific expertise in addressing the complex needs of the adolescent cancer patient.⁵¹

Australian policy context

In 2005, the Australian Senate initiated an inquiry into services and treatment options for persons with cancer, coordinated by the Community Affairs Reference Committee.¹ The inquiry examined the delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:

- the efficacy of a multidisciplinary approach to cancer treatment
- the role and desirability of a case manager/case coordinator to assist patients and/or their primary care givers
- differing models and best practice for addressing psychosocial factors in patient care
- differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians
- current barriers to the implementation of best practice in the above fields.

One of the outcomes of this inquiry was a review of the incidence and treatment of cancer in young people. The inquiry found that:

“In the past 10 years, the incidence of cancer in young people (aged 10–24 years) has increased by 30 per cent, higher than increases in any other age group. Presently, there are no guidelines for the referral of adolescents and young adults (AYA) with cancer to specialist care, which results in patients often being referred to either paediatric or adult cancer physicians. However, there are growing concerns internationally for the adolescent and young adult cancer population and mounting evidence for targeting improvements for this patient group.”¹

The inquiry further identified the psychosocial care needs of adolescents with cancer differ from those of adults or children and are not currently being addressed. Inappropriate physical facilities and lack of age appropriate support services add to the frustrations teenage patients experience when being treated in a children’s environment. Similar frustrations are experienced by adolescents treated in a ward with very sick adults.

Issues for adolescents and young adults (AYA) with cancer include:

- poor access to clinical trials leading to a decrease in the likelihood of accessing state-of-the-art treatment
- being less likely to be treated in specialised multidisciplinary cancer care units where the best results are achieved
- psychosocial issues/frustrations relating to treatment settings¹
- biological differences in cancer types and responses to treatment.

Depending on the type of AYA cancer, recent evidence suggests there is a significant survival advantage when patients are treated within specialist centres, including a multidisciplinary team comprising both medical, surgical and radiation oncological disciplines.

Recognition also needs to be given to the resourcing associated with treatments in adult and paediatric settings. Systemic resourcing issues relating to the ratios of oncologists to patients in adult and paediatric settings may influence treatment outcomes.

It was suggested to the Senate Committee that the way to address issues for AYA cancer patients is to establish specialised teenage cancer units where there could be collaboration between paediatric and adult cancer specialists. Such units would utilise a multidisciplinary team to deliver appropriate medical and psychosocial care.¹

The Committee made two recommendations related to multidisciplinary care:

Recommendation 31: The Committee recommends that Cancer Australia consider the development of appropriate referral pathways that take account of the particular difficulties confronted by adolescents with cancer.

Recommendation 32: The Committee recommends that State and Territory Governments recognise the difficulties experienced by adolescent cancer patients being placed with inappropriate age groups and examine the feasibility of establishing specialised adolescent cancer care units in public hospitals.¹

In the lead up to the 2007 Australian election, both major parties announced a commitment to funding research and treatment for adolescent and young adult cancer.

On 26 October 2007 (National Bandana Day), Nicola Roxon—then Shadow Minister for Health—announced a planned investment of \$15 million for the establishment of AYA cancer networks.⁵² Tony Abbott, then Minister for Health and Ageing, also released a press statement on 26 October 2007 and confirmed the Liberal Party's commitment to also providing \$15 million for the establishment of six collaborative cancer centres dedicated to the needs of patients aged 15–25 years.⁵³

In May 2008, the Commonwealth Government committed \$15 million capital contribution to CanTeen for the establishment of six cancer centres for adolescents and young adults.² This will be matched by fundraising by CanTeen for a further \$15 million, with a notional amount of \$5 million per site.

Australian treatment models for adolescents and young adults with cancer

Current treatment models for AYA with cancer in Australia include the AYA focused program at the Peter MacCallum Cancer Centre in Melbourne, Victoria (OnTrac@PeterMac) and Australia's first dedicated AYA unit at the Princess Margaret Children's Hospital in Western Australia.

Victoria: OnTrac@PeterMac, Melbourne

In response to the recent Senate inquiry on cancer and the unmet needs of AYA cancer patients, the Peter MacCallum Cancer Centre in Melbourne, Victoria, has established a program targeting young people with cancer.

OnTrac@PeterMac is a consultancy service with a unique multidisciplinary team, including a medical director, a clinical nurse specialist, educational advisor, psychologist, social worker, palliative care specialist and music therapist, all working from an age-appropriate developmental framework. The team also works with referring specialists or primary care providers.

Established in 2004, the aim of the service is to provide optimal treatment, care and support for AYA with cancer and ultimately improve survival rates. It is focussed on coordinating and improving oncology, treatment, research and care for AYA patients, through three major activities:

- provision of medical, psychological, education and social support services
- research and implementation of best practice guidelines
- encouragement of participation in clinical trials and protocols.⁵⁴

The program recognises the developmental and psychosocial issues of AYA with cancer, and provides a range of clinical services and psychosocial care, including individual and family counselling; schooling/education; employment assistance and advice as well as financial and practical assistance. To assist with these issues, the service also facilitates community referrals.⁵⁴

OnTrac@PeterMac has also developed a social events program, encouraging AYA patients to interact in a developed peer support network, with regular social outings.

In addition to clinical service provision, OnTrac@PeterMac is committed to research into AYA cancers and the experience. Outcomes will assist in the ongoing development of evidence-based guidelines and service development.

Recent partnerships have been developed with CanTeen's The Australian Organisation for Young People Living with Cancer in order to collaborate over further service development of the program. OnTrac@PeterMac, together with its partners, is establishing a collaborative process to improve access to clinical trials for adolescents and young adult patients.⁵⁴

Western Australia: Johanna Sewell Adolescent Oncology Unit, Princess Margaret Children's Hospital

The Princess Margaret Children's Hospital opened the first Australian age-specialised adolescent oncology unit in December 2006; the Johanna Sewell Adolescent Oncology Unit. The new adolescent oncology unit is named after

Johanna Sewell, who died in an adult hospital in 1989, aged 17 years. Johanna advocated for the need for a teenage cancer unit to provide an age-appropriate environment for AYA with cancer. Her mother, Helen Sewell, donated \$3 million as a part of the upgrade of Princess Margaret Hospital's cancer unit, for the adolescent specific wing. The Unit includes two single and three double rooms (total of eight beds); a new schoolroom plus a fully operational kitchen/lounge area for cooking and social activities; four offices for support staff, including a clinical psychologist; pain management equipment in the treatment room; a quiet room; and flat screen TVs with DVD players at the foot of each bed.^{55, 56}

Johanna, who suffered from osteogenic sarcoma – considered a paediatric tumour – was admitted to an adult hospital, but treated at the Princess Margaret. Discussing Johanna's cancer experience, Helen Sewell said: *"She had never been in hospital before – it was a terrifying time for her, especially on her first night in an eight-bed ward... the adult hospitals are great but they expect people to behave like adults. Teenagers lose their confidence entirely."*⁵⁶

The new wing is a dedicated facility with specialist multidisciplinary teams and clinical trials to provide the best treatment available for AYA cancer patients and is expected to treat about 50 patients per year.⁵⁶

New South Wales

There are three tertiary centres for child health in NSW; The Sydney Children's Hospital, The Children's Hospital at Westmead and John Hunter Children's Hospital.

Although there has been no development of AYA cancer services and service delivery options in NSW, discussions have begun with key adult and paediatric health professionals in the state.

Twenty-six paediatric and adult cancer specialists and other key stakeholders attended the Cancer Institute NSW workshop in November 2007, to discuss possible service delivery options and key principals for the development of AYA cancer services. The following key service delivery principals were identified by stakeholders:

- recognition of the differing needs of adolescents and young adults

- age-appropriate services
- age-appropriate facilities
- treatment based, evidence based guidelines for best outcomes
- collaboration to promote enhanced outcomes.

In addition to scoping the needs of AYA, four treatment models for the future provision of AYA cancer treatment were presented, including:

<p>Option 1: Enhance provision of AYA cancer services by existing service providers</p>	<p>Key features:</p> <ul style="list-style-type: none"> ▪ Evidence based guidelines by cancer type including treatment pathways. ▪ Enhanced access to clinical trials.
<p>Option 2: Dedicated AYA Unit(s)</p>	<p>Key features:</p> <ul style="list-style-type: none"> ▪ Multidisciplinary teams. ▪ Dedicated cancer centre. ▪ Location: paediatric / or adult? ▪ Specialist services. ▪ Psychosocial support. ▪ Fertility advice. ▪ Education support. ▪ Palliative care. ▪ Follow-up capacity.
<p>Option 3: Hub and spoke model</p>	<p>Key features:</p> <ul style="list-style-type: none"> ▪ As for Option 2, but formalise linkages between AYA hubs and service delivery spokes (access to state-of the art facility / discipline specialists).
<p>Option 4: Virtual AYA model</p>	<p>Key features:</p> <ul style="list-style-type: none"> ▪ Additional to option 2 and 3 provides support to service providers (access to knowledge, outside the metropolitan area through tele-medicine services).

A dedicated AYA unit, located in close proximity to both adult and paediatric facilities, was seen to have the greatest advantages in fostering a collaborative medical method between paediatric and adult oncology services.

Clinicians agreed that a concentration of resources would ensure access to state-of-the-art technology and psychosocial support. A cohort of AYA patients, surrounded by their peers, would further serve to reduce psychosocial impact and avoid possible late-effects. The capacity for clinical trials would be enhanced by having a patient cohort in a facility designed to undertake trials, promote them to patients and streamline referral for AYA being treated in specialist facilities. Collaboration between adult and paediatric trials would ultimately develop better clinical practice.

However, there was debate surrounding the location of such a facility. For example, due to the extensive use of bone marrow transplants for patients with haematological cancers, NSW clinicians emphasised the need for any AYA centre to be located on an adult campus with existing access to these facilities. Haematologists treating AYA aged over 18 years suggested there would be difficulties developing dedicated AYA units in a generic adult setting as the numbers of AYA cases in an adult teaching hospital at any one time is generally only one or two cases.

CanTeen proposed models for adolescent and young adult cancer units

Lead by CanTeen, The Australian Organisation for Young People (aged 12–24) Living with Cancer, a model for AYA cancer centres has been proposed.^{57, v}

Under the CanTeen model, multidisciplinary centres of cancer excellence would be established in each Australian state, where AYA cancer patients could be referred to or treated locally with support from the AYA cancer centre (or a combination method).⁵⁷

The model has the following features:

- Adolescent and Young Adult: the age range should extend at least to the mid-twenties (e.g. the international age range definition for a young adult is to 25 years).

- Adult and Paediatric Collaboration: The AYA Cancer Centres should involve collaboration between paediatric and adult cancer specialists. The centres should be shared between major paediatric and adult hospitals.
- Age-Appropriate Support Services: AYA Cancer Centres should include a range of age-appropriate support services (psychology, social work, education support, peer support), including a combination of in-house services and shared services.
- Distributed Support Model: where possible, patients should still receive treatment locally, with support services provided through a 'hub and spokes' support model. This could be facilitated through the provision of care navigators. High-risk cancers would be treated more centrally.
- Age-Appropriate Environment: the cancer centres should have an environment appropriate for the age group including facilities for continuing education and receiving visiting family and friends.
- Improving Protocols: the centres should facilitate and participate in an increasing number of clinical trials. Treatment for rare cancers will also improve through improved critical mass of patients, even where an appropriate trial may not exist.
- Improving Referral: the centres will facilitate best-practice referral for the age group.

Stakeholder considerations in developing cancer services for adolescents and young adults

Through comprehensive consultation with stakeholders in NSW, key themes regarding the treatment of AYA cancer patients emerged.

Tumour specific treatment regimes

Regardless of their area of expertise, there was consensus among health professionals involved in the care of AYA in NSW for the need of specific clinical management protocols and best practice guidelines according to cancer type and stage.

v. The CanTeen model is based on the UK National Institute for Health and Clinical Excellence (NICE) guidelines (available from: <http://guidance.nice.org.uk/csgcyp>) and NZ AYA Cancer Centre (Wellington Hospital, in collaboration with CanTeen NZ) strategy and planning documents.

The difference in current models of care across cancer types and stages is not unique to the AYA area, however, it does have implications for AYA treatment and support needs. Treatment regimes for different tumour types are important in determining the type of supports required, for example, there is a requirement for brachetherapy for later stage cervical cancers but not early stage cervical cancers (which rely on surgery).

Aside from clinical supports, the allied health and psychosocial supports required will vary depending on the type of tumour, and the stage of the cancer. For example, it is likely a cancer diagnosed and treated early will require less psychosocial supports in comparison to cancer diagnosed/treated late, where the support needs generated by the treatment process or risk of death or has increased.

Although key clinicians in the state agreed with the need for specialist treatment regimes, there is not a uniform view about the most appropriate clinical regime that should apply.

Flexibility to adapt to individuals

A comprehensive AYA treatment model needs to be responsive to individual cancer and tumour types and different cancer stages. For example, it is important to keep treatment of thyroid and lip cancers at hospitals with expertise in these areas due to sensitivity of the areas undergoing surgery (i.e. lip to minimise physical deformity and thyroid to minimise damage to the surrounding tissue including larynx).

Similarly, some cancer treatment should not be modified on the basis of age. It was the expert opinion that treatment of melanoma should be irrespective of age, taking comorbidities into account. A specialised AYA centre would not have enough throughput to maintain the expertise and experience required to optimally manage melanoma.

Defining best practice treatment regimes needs to consider both the cancer/tumour response to treatment, as well as the person response. In relevant cancers, age-related physiologies should depict the treatment regime.

Collaboration: paediatric and adult oncology

Collaboration between adult and paediatric health care professionals is important in the development of tumour specific regimes and referral pathways. Through exchange of information across facilities, best practice treatment will

evolve, along with research and clinical trial activity.

It was noted in the area of haematology oncology that adult physicians could benefit from greater dialogue with paediatric oncologists on the treatment protocols that should be applied to conditions such as ALL. Paediatric oncologists see this disease more regularly and may have greater insights about treating individual cases.

Establishment of referral pathways

Referral pathways for treatment vary largely depending on the type of cancer. For example, some referrals can be via an emergency department, and others can be via a GP. There was also evidence provided by NSW clinicians that pathways can vary according to whom the primary clinician refers a patient. For example, pathways for a patient with cervical cancer can vary according to whether the GP refers to a gynaecologist or a gynaecological oncologist.

Standardised referral pathways for different cancer types should be promoted to ensure consistent and early diagnosis and treatment for cancers. Establishing referral pathways within standard practice should be based on best treatment options for tumour type.

Multidisciplinary treatment team (MDT)

The definition of MDT differs across tumour types and depends largely on the type of clinical and allied health supports required in the treatment regime. In addition, psychosocial supports should be included in the MDT. The development of AYA multidisciplinary teams is an important consideration and may require specialised training in AYA health.

Hub-and-spoke model

Service delivery to AYA patients occurs in multiple settings across diverse geographic areas.

NSW clinicians highlighted advantages of a 'hub and spoke' model that would commence initially with one unit or centre of excellence and expand regional services and outreach where necessary and/or possible.

The geographical difficulties already faced by some AYA patients would be enhanced with one AYA centre in NSW, with patients required to travel varying distances in order to access the best advice and treatment available.

The use of IT infrastructure or a virtual model would enhance the capacity of remote support and streamline care for AYA in NSW.

Psychosocial needs

New South Wales health professionals considered the psychosocial needs of AYA to be of high importance. Majority of AYA cancers are treated in adult centres, as the majority of AYA patients are over the age of 18 years. Although the clinical treatment may be best practice in this setting, the psychosocial supports will vary greatly between a teenager, a young adult and older adults, and the nature of the tumour – and may not be easily accessible or identified for a patient treated in an adult facility.

Peer Support

In NSW, 25 per cent of childhood cancer survivors reported a feeling of isolation due to their cancer experience, with a desire to speak with a peer who had gone through a similar experience.²⁴ Clinicians acknowledged the psychosocial benefit of an AYA cancer patient supported by peers undergoing similar illness.

Age-appropriate facilities

The development of AYA facilities should accommodate differences in teenage specific facilities and young adult tailored facilities.

Education capacity

The continuation of study would be fostered in an environment with those at similar education levels and allow appropriate collaboration of teaching resources. A dedicated service would have resource capacity to develop links with educational institutions as well as social services such as Centrelink and rehabilitation programs for re-entry into the workforce. These programs would further impact positively on compliance and follow-up.

Implementation of research and development

Infrastructure for tumour banking and clinical trials was

recommended as a key principal in the development of cancer services for this patient cohort. NSW clinicians acknowledged the need for support of ongoing research to ensure evidence based best practice is identified and implemented.

Palliative care options to address survivorship issues

The palliation needs of AYA with cancer are unique, and clinicians emphasised the need for a model of care that supported age-appropriate hospice facilities for young people dying of cancer, and training for specialists in supporting the needs and gaining confidence in treating this age-group. Survivors of cancer during adolescence and young adulthood have specific needs and late effects that are unique to the age-group and need strategic monitoring and care.

Training for staff in adolescent health

There is clinical interest in AYA with cancer, and this needs to be formally fostered with staff training and development of expertise. The creation of a dedicated unit for AYA would allow a cohort of professionals to develop and subsequently educate peers. In addition, there was emphasis on training primary care providers to ensure early diagnosis and therefore better outcomes.

Clinical treatment driven by age

The enforcement of the '18+' rule^{vi} drives a clinical approach to services delivery and care. For example, an 18 year old with a brain tumour is most likely to be treated in an adult hospital, regardless of the type of brain tumour. Childhood brain tumours tend to be more responsive to aggressive chemotherapy, whilst adult brain tumours do not and the survival rate of this type of tumour is very low.

Comparatively low cancer incidence in adolescent and young adult ages

The incidence and prevalence of cancer is low in the AYA age group compared to cancers in other age ranges. Service delivery tends to be tailored to the needs of the largest demographic where incidence occurs. For example, bowel cancer treatment is tailored to the needs of older adults which are the largest demographic for this cancer type.

vi. 18+ rule: patients 18 years and over must not be treated in a paediatric setting, according to NSW Health Act.



Adolescent and young adult capture

Clinicians questioned the point at which patients should be captured and registered for AYA services and/or treatment. Should this occur at diagnosis or treatment, or expected treatment completion? Should the cut off for AYA services be age, psychosocial needs or location of treatment?

Further to the key themes regarding AYA cancer care, experts suggested the following recommendations:

- A comprehensive AYA treatment model to be responsive to different cancer/tumour types and different cancer stages.
 - Service planning is required to assess the number and location of service delivery points and whether they are appropriate for different AYA cancer types. Decisions about the appropriate location and number of service delivery points for different AYA tumour types should influence how a comprehensive model of AYA care evolves. For example, different supports would be required for cancers (such as brain tumours) currently treated at specialist sites compared to those requiring treatment across multiple teaching hospital sites (i.e. ALL).
 - Any AYA centre should be located on an adult campus with existing access to specialised facilities.
 - A tailored approach to developing comprehensive AYA care is required for tumours that have a high incidence in the adult population.
 - Specialist expertise in AYA psychosocial supports is critical in developing an AYA treatment pathway, including fertility counselling, sexuality counselling, employment, financial and educational supports. Psychosocial support should be available through an outreach service, mobile teams and should include telephone access to expertise for professionals.
 - An AYA centre of excellence should be used for long term care, survivorship and shared care with specialist centres.
 - The application of administrative rules should be reassessed if there is evidence that they are influencing clinical outcomes for patients.
 - Defining best practice guidelines for treatment regimes should consider the person (age related) response as well as the tumour response to treatment.
- The varying referral patterns impacts on where a patient will be treated and should be better communicated to GPs and other service providers.
 - The development of best practice guidelines for all cancer types would ensure consistent and up to date treatment protocols across NSW regardless of where treatment occurs. In addition, the use of information technology will aid in delivering advice to professionals in rural/remote areas, or across metropolitan areas to maintain consistency and best practice. This technology will promote multidisciplinary team (MDT) meetings for patients across multiple treatment sites.
 - A comprehensive AYA model of care needs to develop a consensus view about which patients are considered as being 'within scope' of an AYA service.
 - Standardised definitions of MDT should be developed for each tumour type to ensure consistency of treatment across NSW.

In summary, the development of best practice guidelines for all cancer types would ensure consistent and up-to-date treatment protocols throughout NSW, regardless of where treatment occurs.

There is a need to define best practice for individual tumour types, which will ultimately inform the development of referral pathways and service delivery options.

The use of information technology could aid in delivering advice to professionals in rural/remote areas, or even across metropolitan areas to maintain consistency and best practice. This technology can also be used to promote multidisciplinary team (MDT) meetings for patients across multiple treatment sites.

The incremental implementation of this hub-and-spoke model, supported by IT infrastructure and MDTs with access to expert advice, was considered ideal by the leading stakeholders consulted in NSW.

Access to psychosocial services specific to this cohort of patients is an important area across all tumour streams. Psychosocial support could be improved through an AYA specialist centre, with emphasis on outreach. This flexible model would address the clinical, psychosocial, survival, education, employment and financial issues identified for this unique patient cohort.

Conclusion

A flexible model of multidisciplinary care would address the clinical, psychosocial, survival, education, employment and financial issues for AYA.

Review of the current treatment of AYA with cancer in NSW identified distinct differences in cancer patients aged between 15 and 30 years from paediatric and adult patients, including comparatively smaller improvement in survival rates, unique cancer types affecting this cohort and special medical, physical, psychological and social needs.

There is consistency between the literature and the view of clinicians in NSW when describing the variation in treatment regimes and the relationship to clinical outcomes. While there are indications that outcomes are generally better for AYAs treated in a paediatric setting, treatment should consider the disease response as well as the person response. Variability in treatment regimes is largely due to the lack of a significant patient cohort. Depending on their referral pathway, an AYA in NSW may be treated at a multidisciplinary paediatric facility with access to best practice and clinical trials, or sharing a ward with elderly people in an adult hospital. Without patient volume or a concentration of clinical expertise, health outcomes may be poorer as limited clinical experience and awareness can compromise best practice.

Creating a cluster of patients of similar age was identified by the literature and health professionals as an opportunity to create consistency of treatment and outcomes, and also improve access to and enrolment in clinical trials. Creating an age-specific environment would also serve to address the psychosocial needs of AYA patients undergoing cancer treatment, surrounded by peers with health practitioners trained to address the emotional complexities and combat the interruption caused by treatment regimes to normal developmental events and processes. It is important to consider the long-term health and quality of life of AYA. Being confronted with cancer and mortality during

adolescence and young adulthood requires a specific palliative care approach by specialist health professionals with the skills to support the young persons emotional, psychological and spiritual needs, as well as facilitating the practical medical concerns related to both healing and palliative care.

There are currently eight dedicated cancer units for teenagers in the UK. In Australia, the care of AYA with cancer has been on the national agenda since a Senate Inquiry in 2005, and more recently with the Commonwealth Government committing funds towards the development of cancer centres for AYA. In NSW, discussions have begun with key adult and paediatric health professionals and agreement reached on a model that will develop best practice guidelines for individual tumour types to ensure consistent and up to date treatment protocols and referral pathways across NSW regardless of where treatment occurs. There is a need for psychosocial services specific to this cohort of patients that could be improved through an AYA specialist centre, with emphasis on outreach, as used in the Victorian multidisciplinary team model that provides services across the state. This flexible model would address the clinical, psychosocial, survival, education, employment and financial issues identified for this unique patient cohort.

The Cancer Institute NSW is committed to understanding the needs of adolescent and young adults with cancer and informing future models of care to ultimately improve the survival and long-term physical and psychosocial health of these patients in NSW.

Appendix Cancer Institute NSW workshop attendees, 29 November 2007

Title	First Name	Last Name	Role	Hospital/Organisation
Dr	Verity	Ahern	Radiation Oncologist	Westmead Hospital
Dr	Lesley	Ashton	Senior Paediatric Epidemiology	Children's Cancer Institute Australia
Dr	Christopher	Arthur	Director Area Cancer Services	Royal North Shore Hospital
Ms	Alison	Baker	NUM	The Children's Hospital at Westmead
Ms	Justine	Battersby	Long Term Follow up Clinic Co-ordinator,	The Children's Hospital at Westmead
Ms	Kirsty	Campbell	Program Development and Quality Manager	The Children's Hospital at Westmead
Dr	Susan	Carroll	Radiation Oncologist	Royal Prince Alfred Hospital & Prince of Wales Hospital
Dr	Richard	Cohn	Paediatric Haematologist/Oncologist	Sydney Children's Hospital
Dr	John	Collins	Head Pain & Palliative Care Unit	The Children's Hospital at Westmead
Ms	Angela	Cotroneo	Social Worker	Royal Prince Alfred Hospital
Ms	Jane	Ewing	Masters Student	University of Technology, Sydney
Ms	Karen	Johnston	Nurse	Sydney Children's Hospital
Prof	Glenn	Marshall	Paediatric Haematologist and Oncologist	Sydney Children's Hospital
Ms	Barbara	Merz	AYA Reference Group Project Officer	Cancer Australia and CanTeen
Dr	Geoffrey	McCowage	Staff Specialist	Sydney Children's Hospital
Dr	Kelly	Mok	Medical Oncologist	Prince of Wales Hospital
Ms	Kathryn	Nattress	Cancer Nurse Coordinator	Sydney Cancer Centre Royal Prince Alfred Hospital
Dr	Tracey	O'Brien	Paediatric & Adolescent Haematologist/Oncologist	Sydney Children's Hospital
	Libba	O'Riordan		
Ms	Anne	Senner	CNC Clinical Practise Development	Sydney Children's Hospital
Dr	Michael	Stevens	Senior Staff Specialist	The Children's Hospital at Westmead
Dr	Judith	Trotman	Haematologist Haematology Department	Concord Repatriation General Hospital
Ms	Monica	Tucker	Care Coordinator	Sydney Melanoma Unit
Ms	Amy	Walker	Registered Nurse	The Children's Hospital at Westmead
Prof	Kate	White	Director Research Support Unit	University of Sydney
Dr	Andrew	Young	Chief Executive Officer	CanTeen
Ms	Sue	Sinclair	Director, Cancer Services and Education	Cancer Institute NSW
Mr	Mark	Anns	Manager, Quality and Clinical Collaboration	Cancer Institute NSW
Ms	Catherine	Bullivant	Project Officer, NSWOG	Cancer Institute NSW
Ms	Elizabeth	Tracey	Senior Epidemiologist	Cancer Institute NSW
Ms	Raquelle	David	Administrative Officer, NSWOG	Cancer Institute NSW
Mr	Wayne	Kinrade	Director	Healthcare Management Advisors
Mr	Matt	Baron	Managing Consultant	Healthcare Management Advisors
Ms	Deborah	Roczo	Senior Consultant	Healthcare Management Advisors

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