



# Clinical Oncological Society of Australia

## ***AYA Cancer Services Delivery: Challenges and Responses***

### **Adolescents and Young Adults (AYA) with Cancer Workshop Report**

**Friday 13 May 2011**

**Stamford Plaza Airport Hotel, Sydney**

**Report prepared by Karen Smith, COSA AYA Project Officer**

# Contents

<b>1</b>	<b>Executive summary</b> .....	<b>3</b>
<b>2</b>	<b>Background</b> .....	<b>5</b>
	2.1. Introduction.....	5
	2.2. Purpose and objectives .....	5
<b>3</b>	<b>Workshop summary</b> .....	<b>6</b>
	3.1. Recommendations and outcomes .....	6
	3.2. Conclusion .....	7
	3.3. Workshop evaluation .....	7
<b>4</b>	<b>Overview of sessions</b> .....	<b>8</b>
	4.1. Models of care/service delivery .....	8
	4.2. Engaging adult oncology: effective models and strategies.....	9
	4.3. Referral pathways .....	10
	4.4. YCNP Project Managers and Officers .....	11
	4.5. Clinical research.....	12
	4.6. Education opportunities.....	14
	4.7. Improving AYA cancer services .....	17
	4.8. Sustaining and enhancing AYA cancer services: beyond June 2012 .....	20
	4.9. Workshop close .....	22
<b>5</b>	<b>Acknowledgements</b> .....	<b>23</b>
	<b>Appendix 1 List of participants</b> .....	<b>24</b>
	<b>Appendix 2 Workshop evaluation summary</b> .....	<b>28</b>

# 1 Executive summary

The fifth COSA Adolescent and Young Adult (AYA) Cancer workshop was held Friday 13 May 2011 at the Stamford Plaza Airport Hotel, Sydney, with the theme “AYA Cancer Services Delivery: Challenges and Responses”. The focus was for project staff and stakeholders to exchange information and ideas about jurisdictional and national projects; to share experiences of referral pathways and engaging adult oncologists; and to consider sustainability of AYA programs.

The workshop consisted of 4 plenary and 4 concurrent break-out sessions and brought together more than 100 participants and key stakeholders with interests in AYA cancer. The attendees were predominately AYA project managers and staff, nurse/care coordinators, program managers and executives, reflecting the growing numbers of these roles with focus on AYA services and highlighting a need to frame future workshops around increasing the participation of adult oncologists and haematologists.

Key recommendations and outcomes of the day were:

- the importance of a multidisciplinary, flexible and collaborative approach
- to move forward with “AYA oncology champions”
- the ongoing desire to meet the emotional and psychosocial needs of the AYA population
- the need for appropriate support for patient transition between services i.e. paediatric to AYA and AYA to adult
- that models of care, referrals, engaging adult oncology are all interlinked -- solutions are likely to need involvement in all these areas with strong drivers, small steps and opportunities to be visible
- that major considerations remain advocacy, education, transition planning and securing consistent funding
- that AYA service infrastructure, staff support and professional development need to expand to support the growth in project officer, psychosocial worker and care coordinator roles
- to commence regular teleconferences for project managers under the Youth Cancer Networks Program (first meeting in June 2011) to keep up-to-date on projects, share and identify ideas and opportunities and reduce duplicated effort
- AYA participation in clinical trials could be increased by: broadening age eligibility (>12 (paediatric institutions) and <18 (reflecting nature of the disease)); trial registration on ANZCTR and/or [ClinicalTrials.gov](http://ClinicalTrials.gov) and keeping the trial status up-to-date
- for an Education Interest Group to address the identified questions and next steps for national education development, in liaison with COSA.

There have been significant achievements but still a long way to go in sustaining and improving the AYA programs that have been established. The challenge now is to maintain momentum, build on successful models of care and education, and strengthen the AYA position by interrelationships with other health professionals and partners.

An evaluation form was provided for feedback on the Workshop. The workshop overall was highly regarded, meeting attendee expectations (100% of respondents) and rating very good or excellent by 82% of respondents. All respondents felt there was value in this COSA-provided event where key stakeholders could network, exchange ideas, discuss national projects and consider future

development for AYA cancer services. Suggestions made as to format and activities for future events were welcomed to ensure continued support by COSA for the needs of the professional AYA cancer network.

## 2 Background

### 2.1. Introduction

Adolescents and young adults (AYAs) with cancer have distinctly different clinical, psychosocial, social and information needs to children and adults with cancer. AYAs have the lowest improvement in survival over the past 20-30 years of any age group.

The Clinical Oncological Society of Australia (COSA) is the peak national body for multidisciplinary health professionals working in cancer care and control. COSA has been contracted by CanTeen under the Australian Government funded Youth Cancer Networks Program to manage the National AYA Cancer Network project to establish and support a professional network of individuals and organisations with an interest in improving outcomes for AYAs diagnosed with cancer.

COSA has convened four previous AYA cancer workshops:

- May 2007 – to develop a shared understanding of the issues and challenges for treating AYA Cancer and reach agreement on the key elements of appropriate models of care
- November 2008 – to exchange information about the availability of funding, state-based actions to develop AYA cancer services, and the value of national collaboration to develop guidelines and key functions to support implementation of AYA cancer, which informed the development of the Youth Cancer Networks Program (YCNP)
- November 2009 – held following the announcement of the YCNP to enable project partners to meet and share information about their plans for service development
- November 2010 – to enable information exchange on jurisdictional and national projects and identify current issues/challenges for projects, communication, collaboration and membership with the aim of building sustainable mechanisms to support the initiatives already underway

This additional workshop in May 2011 with the theme of 'AYA Cancer Services Delivery: Challenges and Responses' was held in response to suggestions for further discussion from the November 2010 workshop.

### 2.2. Purpose and objectives

An invitation to attend the workshop was sent to members of the AYA Cancer Network, as well as other medical and allied health professionals, project partners, CanTeen, Cancer Australia and representatives of the Cancer Cooperative Trials Groups.

The purpose was to enable focussed discussion on various aspects of cancer service delivery and integration between health areas: for project staff and stakeholders to exchange information and ideas about jurisdictional and national projects; to share experiences of referral pathways and engaging adult oncologists, and to consider sustainability of AYA programs. These were areas of opportunity identified at the AYA Cancer Workshop held in November 2010.

## 3 Workshop summary

The fifth COSA AYA Cancer workshop was held Friday 13<sup>th</sup> May at the Stamford Plaza Airport Hotel, Sydney, with the theme “AYA Cancer Services Delivery: Challenges and Responses”. The workshop brought together more than 100 participants and key stakeholders with interests in Adolescent and Young Adult cancer (for a list of workshop attendees, see Appendix 1 of this report). COSA Executive Officer Marie Malica and AYA Steering Committee Chair Wayne Nicholls welcomed participants to the workshop.

The Workshop consisted of 4 plenary and 4 concurrent break-out sessions. Wayne Nicholls kindly MC'd during the plenary sessions. The first 3 plenaries were: Models of care/ service delivery, Engaging adult oncology and Referral pathways. Presentations of the current status, successes and challenges in these activities nationally and subsequent discussion enabled participants to identify what others are doing well and/or differently and the common issues they are facing.

The Sony Foundation presented the history of and success to date of the “Youth Cancer” phone donation fund-raising events via a short promotional video.

This was followed by 4 concurrent break-out sessions as a forum to discuss activities ‘on-the-ground’, covering specific areas of interest: project collaborations, clinical research, education opportunities and improving AYA cancer services.

The workshop concluded with feedback from the break-out groups and a further plenary on Sustaining and enhancing AYA cancer services beyond June 2012. A summary of each session can be found in Section 4.

### 3.1. Recommendations and outcomes

Key recommendations and outcomes of the day were:

- the importance of a multidisciplinary, flexible and collaborative approach
- to move forward with “AYA oncology champions”
- acknowledgement of the ongoing desire to meet the emotional and psychosocial needs of the AYA population
- the need for appropriate support for patient transition between services i.e. paediatric to AYA and AYA to adult
- that models of care, referrals, engaging adult oncology are all interlinked -- solutions are likely to need involvement in all these areas with strong drivers, small steps and opportunities to be visible
- that major considerations remain advocacy, education, transition planning and securing consistent funding
- that AYA service infrastructure, staff support and professional development need to expand to support the growth in project officer, psychosocial worker and care coordinator roles
- to commence regular teleconferences for project managers under the Youth Cancer Networks Program (first meeting in June 2011) to keep up-to-date on projects, share and identify ideas and opportunities and reduce duplicated effort
- AYA participation in clinical trials could be increased by: broadening age eligibility (>12 (paediatric institutions) and <18 (reflecting nature of the disease)); trial registration on ANZCTR and/or [ClinicalTrials.gov](http://ClinicalTrials.gov) and keeping the trial status up-to-date

- for an Education Interest Group to address the identified questions and next steps for national education development, in liaison with COSA.

### **3.2. Conclusion**

There have been significant achievements but still a long way to go in sustaining and improving the AYA programs that have been established. The challenge now is to maintain momentum, build on successful models of care and education, and strengthen the AYA position by interrelationships with other health professionals and partners.

### **3.3. Workshop evaluation**

An evaluation form was provided at the end of the workshop to gather attendee satisfaction and comments on the event in order to assist COSA's future planning. An overview of the evaluation findings can be found in Appendix 2.

## 4 Overview of sessions

### 4.1. Models of care/service delivery

**Synopsis:** Due to the often small and geographically distributed adolescent and young adult population and the spread across paediatric and adult hospitals, there is a need for service delivery models that can work within this framework. This session covered the key factors in selecting a care model, what models are currently in use and how they operate, including challenges and future considerations.

**Facilitator and speaker:** Dr Lisa Orme, Director, Victorian and Tasmanian Youth Cancer Project

Lisa opened the session which compared models of care in the various jurisdictions. Representatives from each state gave a summary and answered questions from the floor. Based on the National Services Delivery Framework, models of care aim to improve patient outcomes including psychosocial, medical, clinical trial and education needs.

#### **Victoria/ Tasmania**

- Hub and spoke model - onTrac as clinical lead with outreach via regional Integrated Cancer Services
- Importance of Project Officer role (although non-clinical) - scoping expertise; establishing links with clinical services; identifying AYA patients; facilitating screening, presentation at MDTs, education

#### *Benefits*

- Great opportunities and progress
- AYA awareness growth
- Central service has established oncology services; expertise can be shared
- Care and service based, flexible model

#### *Challenges*

- Spokes missing means patchy referrals and growth
- Aligning project and clinical teams
- Matching new model of care to established healthcare collaborative services
- Integrating medical and psychosocial
- Uncertainty for continued momentum after funding period

#### **New South Wales**

- Developing and growing team in each hospital
- Aims to: increase collaborations between paediatric and adult services; establish Clinical Care Coordinator network; provide education for health professional on AYA issues; increase access to resources through guidelines, protocols, referral guides
- Case-based integrated medical and psychosocial model

#### *Challenges*

- Some regions not well serviced by the model
- Physicians interested but concern around starting something if funding was not to continue

#### **Queensland**

- Similar to NSW - paediatric-adult collaborative, medical and psychosocial model
- Aim for centralised service

#### *Challenges*

- Important to define new roles
- Time and emotional commitment is needed for young people
- AYA and adult oncology share seeing patients
- Funding strategy is complex



### South Australia/ Northern Territory

- Paediatric-adult collaborative model - optimisation regarding relevant tumour expert with assistance of psychosocial services
- All patients discussed in AYA psychosocial MDTs
- Key worker allocated to each patient
- Importance of clinical trials, fertility preservation and research projects to inform service direction

### Western Australia

- Multidisciplinary AYA approach, some adult oncology involvement
- Changes to come with regards to inpatients and referrals
- Clinical Nurse coordinator has a key role

### Conclusions

- Different models among states yet most are flexible, collaborative, multidisciplinary and supportive care which is case-based
- Optimising access per disease expertise
- Moving forward with 'AYA oncology champions'
- All models have aims around education, sharing services across GP, oncology, psychosocial

Lisa closed with some areas for **discussion**:

- Access to surgeons, radiotherapists, private sector
- Data collection, sharing and ethics
- Shared care for regional patients
- Interfaces with transition/survivorship, palliative care, adolescent and mental health, family cancer genetics

---

## 4.2. Engaging adult oncology: effective models and strategies

**Synopsis:** Adolescent and young adult cancer patients have care needs that bridge both the paediatric and adult specialties. The prospective needs of these patients will require integration into and resources from adult health care environments. Strategies for collaboration (engagement, communication, educational credibility, clinical trials and joint needs with adult oncologists) and case studies of the patient journey were outlined in this session.

**Facilitator and speaker: Dr Antoinette Anazondo, Paediatric & Adolescent Oncologist, Sydney AYA Cancer Service, Sydney Children's Hospital**

**Speaker: Dr Toby Trahair, Paediatric Oncologist, Sydney Children's Hospital**

Antoinette spoke from the perspective of a new AYA cancer service in Sydney which operates between the paediatric and adult services.

6 strategies for engaging adult oncology were presented:

- **Patient-centred, flexible approach:** advocacy, planned visits and talks, discussion with both paediatric and adult colleagues
- **Psychosocial care:** key area for AYA patients, this may be the only service a patient is referred for, a case study was presented highlighting the key role of psychosocial care to the overall success of the patient's adherence and cancer care plan
- **AYA specific expertise**

- **Clinical trials:** important to consider age-appropriate trials with the involvement of both paediatric and adult oncology, these trials can be beneficial also to patients outside the service, trials are a challenge in that they are a lot of work relative to the handful of 18-40 y.o. that may be recruited
- **Education:** how to cover the education needs of diverse health professionals, sharing age-appropriate literature and discussion of cases
- **New services:** improving service provision through transition and fertility preservation planning, consideration of late effects, providing bereavement (a common gap) and peer support services, a case study was presented indicating the referrals that may be needed and the key role of AYA care navigation and social workers

Several key points were raised by both Antoinette and Toby regarding challenges and responses to engaging adult oncology. These included the importance of:

- **Equity:** acceptance that different models may be effective in different areas, the balance between paediatric and adult services, consideration of both age- and tumour-specific needs
- **The psychosocial team:** often key to dealing with AYA patient care, this 'support service' role may be the only AYA service involved but can be key in building awareness of AYA services to the adult oncology arena
- **Visibility:** participation in paediatric and adult MDTs, becoming familiar to the teams and advocating where AYA expertise can be utilized
- **Local expertise:** making use of existing expertise, whether it comes from paediatric, AYA or adult specialisation
- **A slow and steady process:** building awareness and engagement with adult oncology via individual relationships and patient-focused interactions

### 4.3. Referral pathways

**Synopsis:** Building on discussion from the previous topics, this session explored how referral pathways vary in different contexts, experiences with existing referral, ways to build better pathways, and some provocative questions to ask when planning the integration of AYA needs into referral pathways.

**Facilitator and speaker:** Dr Michael Osborn, Consultant Haematologist/ Oncologist, Women's & Children's Hospital Adelaide; Chair, SA/NT AYA Cancer Clinicians Advisory Committee

Michael commenced his session with the Australian Senate Community Affairs References Committee recommendations in "The Cancer Journey: Informing Choice" (2005):

**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.*

Michael outlined the background around referral and its complexity. The referrer plays a significant role in the overall process. AYAs are part of the whole health system and setting up an AYA unit in isolation is not enough. The GP and emergency centres need to be aware of AYA cancer as referrals most often come through these sources. Consequences from delayed referral were discussed. Some

data from studies was presented to show the treatment outcomes in relation to the centre and caseload.

The Referral pathways may be haphazard for the following reasons:

- **Financial:** due to insurance and health systems, issues around geography
- **Provider issues:** referrer determines the initial pathway, whether paediatric, adult or AYA-specific, public or private. Patients often have treatment desires such as 'close to home', 'where I can get the best care', age cut-offs at hospitals have consequences for transitions and continuity of care, there may be conflicting willingness to treat AYAs or an impression that paediatric oncologists are 'taking away' patients
- **Personal knowledge, beliefs, attitudes:** impressions that 'private is better', young people are often unaware that they have a choice, or that AYA services are available

How may better referral pathways be built?

- **Model of care:** Who is the primary consultant? The secondary consultant? What service is provided that is AYA-specific (comprehensive vs. psychosocial)?
- **Relationship with adult services:** interaction during patient care, making use of existing expertise, increasing the awareness of GPs and adult oncology so as to get the desired placing as an AYA specialist in the care pathway
- **Marketing of service:** using the model of a new specialist, who could be targeted?, engaging referrers by educational opportunities, being visible in MDTs, being proactive with interactions and invitations, consolidate by identifying champions in adult and paediatric sectors

Discussion was prompted by the following questions which were seen as being an excellent place to start thinking about **next steps** for integrating the needs of AYAs into referral pathways development.

- What are your local challenges to establishing referral pathways to an AYA Cancer service (anticipated or experienced)?
- Which of these challenges are easiest to address / most important to address?
- Is it realistic for us to expect that all AYA patients should be seen by the service given geographic, financial & staffing limitations?
- Should we engage the private sector? How?
- How can we formalise referral pathways with adult providers? How should this inform our model of care or location of care?
- Thoughts about referral out of AYA Service?

Representatives from each state made a few comments on their referral pathways.

During discussion, points were raised regarding the application of pathways used in other conditions such as liver disease, the equity between services inside and outside AYA. It was noted that another good reason to have dedicated AYA facilities is that awareness among young people is often by word of mouth.

---

## CONCURRENT SESSIONS

### 4.4. YCNP Project Managers and Officers

**Facilitator: Louise Devereux, Project Manager, Victorian and Tasmanian Youth Cancer Project**

The round-table discussion in this session focused on a few main topics:

- Definition and scope of the AYA cancer network - come a long way from the first group that made up the 'network'. How do we want this network to look and operate into the future to obtain/maintain the most benefit and keep members involved?
- Branding - the Youth Cancer Fund brand can provide a national image while established jurisdictional services maintain their own requirements
- More frequent formal organisation of knowledge exchange between project staff. Many project officers would value an opportunity to discuss jurisdictional projects in more detail, to be candid about challenges and what is problematic. There is a need for mechanisms to enable PO to share project updates, knowledge and form collaborations

**Next steps:**

CanTeen (Youth Cancer Fund) will establish a Project Managers and Officers Interest Group and conduct regular teleconferences for jurisdictional and national project representatives (rotational) in order to:

- share updates, not only from YCN projects but other projects of relevance so staff can obtain a broader picture
- exchange information and tools
- discuss challenges and possible solutions
- consider collaborations across project activities or other groups

Aim before first teleconference planned for early June 2011, is to establish Terms of Reference. It could be beneficial to share project updates regularly but outside of the TC, so the TC is focused on items for discussion and of reasonable length.

Minutes from these TCs will be distributed to the group and any identified issues, feedback or discussion points will be raised with the YCF Advisory Committee.

---

## 4.5. Clinical research

**Speaker: Professor David Roder, Professor of Cancer Epidemiology, University of South Australia; Consultant Epidemiologist, Cancer Australia**

### **National Minimum Dataset: Approach and Challenges**

Australia has reasonable demographic and incidence data compared with globally, but it is not in one central database (e.g. multiple screening registries, biospecimen databases, clinical registries etc). The information needs to be linked and disseminated (AIHW Cancer Data Monitoring Centre), but this can be difficult due to ethical and privacy concerns. There are also gaps in the data: the absence of staging and biomarker information is a major weakness, as well as the lack of data on psychosocial aspects, QoL, toxicity and side-effects.

Standard data sets are required across Australia and the government may be interested in linking AYA jurisdictional data into the national framework (emotional appeal and numbers are not large). The AYA data set would be a combination of the (L) and (R) columns of the table below (i.e. generic clinical data set specification (DSS) and AYA specific measures such as family history, co-morbidity, fertility preservation, post treatment recurrence).

	Generic Clinical Data Set Specification (DSS)	AYA Data Set Specification (DSS)
<b>Person:</b>	Name, home address, sex, DOB, Indigenous status, death date, death cause	English fluency - AYA patient, father, mother
<b>Presentation/ history:</b>		Family history (cancer), hereditary genetic events, personal genetic syndrome, date of symptom onset (AYA cancer), dates of initial consultation – specialist/GP/other primary health care
<b>Diagnosis:</b>	Diagnosis date, site, morphology, laterality, grade, basis of diagnosis, TNM/Other stage, clinical/ pathological stage, size (mm), nodes examined, nodes positive	ECOG, co-morbidity, distant metastatic site(s)
<b>Management/ treatment:</b>	<u>Surgery</u> - procedures, dates, target sites <u>Chemotherapy</u> - protocols/agents, dates, cycles <u>Hormone therapy</u> - protocols/agents, dates <u>Immunotherapy</u> - protocols/agents, dates <u>Radiotherapy</u> - type, dates, target sites, fractions, dose <u>Systemic therapy procedures</u> - procedures, dates <u>Other cancer treatments</u> - narrative descriptions	Establishment type, shared care, public/private, AYA MDT involvement, care coordination, differences in planned/delivered care, fertility counselling, fertility preservation, use of preserved tissue, successful pregnancy, research involvement (trial/supportive care/other), treatment intent, radiotherapy technique
<b>Outcome:</b>	Treatment response (complete, partial etc.) 1 <sup>st</sup> recurrence- date, region, basis of diagnosis	Treatment complications/adverse events/ toxicity – type, date assessed, grade Recurrences – surgery, radiotherapy, hormone therapy, immunotherapy, other
<b>Follow-up:</b>	Last contact date Cancer status at last contact	Late effects

#### **Key Discussion Points:**

- Is the data set being developed too complex? Measures have been defined and a pilot (involving a range of centres including adult oncologists) is underway to look at the burden of data collection. There may be a need to reduce the number of measures or to have a mandatory set of core data with the remainder optional for those with resources.
- Australian Commission on Safety and Quality will look at the cost for collecting the data nationally.
- Process: Working group will review the results of the pilot → Finalise AYA DSS with key stakeholders → Advocate for government to include AYA data in the national minimum data set.

**Facilitator and speaker: Dr Wayne Nicholls, Chair, AYA Cancer Steering Committee; Senior Staff Specialist, Royal Children’s Hospital Brisbane**

#### **Research Priorities and Facilitation**

This project entails encouraging and supporting development of new clinical research that addresses an identified priority, where there is a reasonable cohort of AYA patients and/or a significant survival gap.

In consultation with the Research Working Group, COSA developed criteria for assessing applications for funding and allocating the Clinical Trials Investment Fund provided as part of this project (\$92K). COSA liaised with Cancer Australia about AYA-related project applications that made it through the NHMRC process, and thus are scientifically sound, but were not successful in receiving funding. The

Research Working Group made the decision to assist ALLG with funding of ALL-6, as this study fit the NHMRC criteria as well as the 2 additional criteria of collaboration and strategic fit.

There are only around 5 dedicated studies for AYA patients. The **AYA-PK study** (investigating pharmacological and pharmacodynamic activity of chemotherapy in patients with Ewing sarcoma, osteosarcoma and Hodgkin's lymphoma and how it varies as an effect of puberty and gender) is now open and recruiting at several centres in Australia. The new **ALL-6 study** will investigate whether a paediatric acute lymphoblastic leukaemia (ALL) protocol can be extended to patients aged 15-40 years in adult settings and examine factors that might impair dose delivery.

### **Raising clinician awareness of AYA cancer trials and encouraging trial participation**

Another project objective is to collate information about and promote clinical trials recruiting AYA cancer patients to clinicians and patients, with the aim of increasing AYA participation rates. COSA has managed to create a comprehensive list of open cancer trials by collating data from ANZCTR, [ClinicalTrials.gov](http://ClinicalTrials.gov) and each of the CCTGs. A key obstacle was that in many cases the registry data is incomplete or has not been updated so the status of a trial is unclear (e.g. there were found to be 50 leukaemia trials open although many of these are likely to now be closed).

COSA has also assessed existing registers to determine the best approach to promoting AYA clinical research. There are already multiple databases (ACT Online, ANZCTR, clinicaltrials.gov, ANZCHOG, ASSG, Victorian Cancer Trials Link etc) so creating an additional, "standalone" registry is not practical. The preferred option is to advocate for sites to enter missing trials on ANZCTR and then leverage the new ACT Online which is updated daily with information from ANZCTR and clinicaltrials.gov.

#### **Challenges:**

- Need to ensure all trials are entered on ANZCTR and updated regularly so that accurate information is available to clinicians and patients from ACT Online.
- HoMER (Harmonisation of Multi-centre Ethical Review) and the NEAF (National Ethics Application Form) appear to be working quite well, however still seeing roadblocks in the Australian hospital system (e.g. budget and logistics are organised in parallel but take longer than ethics approval, thus causing delays).
- COG (Children's Oncology Group) studies are not readily accessible to AYAs.

#### **Proposals:**

- National approach to be involved in European studies (e.g. ASSG has done this effectively with the Euro-Ewing study). This could be considered for other tumour types (e.g. leukaemia).
- Ensure that the age eligibility criteria for a study reflects the true nature of the disease (i.e. don't limit to >18 just because of the difficulty of consenting minors).
- Have a uniform maximum age for paediatric centres across Australia (ranges from 12-14 in different states) and advocate for an increase in the age limit.

---

## **4.6. Education opportunities**

**Facilitator and speaker: Ms Linda Ewing, State Educator Paediatric Haematology/Oncology, Queensland Paediatric Haematology/Oncology Network (QPHON), Royal Children's Hospital Herston**

**Multidisciplinary Educational Opportunities/Challenges and Examples from Paediatric Oncology**

Linda presented the multidisciplinary approaches to education and training in AYA oncology. Various disciplines that have been identified as requiring education and training in this field include:

- nursing staff
- allied health staff including those belonging to social work
- psychology
- occupational therapy and physiotherapy disciplines
- oncologists
- GPs

Linda also presented a discussion of how the Paediatric Oncology Education Model works in Queensland and suggested a similar concept in relation to AYA Education. The mapping of the Paediatric Oncology Model in Queensland uncovered the need for a variety of educational pathways and has highlighted the complexities of working to meet the educational needs of these groups.

**Speakers: Ms Samantha van Staalduinen, Project Officer, Centre for Adolescent Health, Royal Children's Hospital Melbourne**

**Ms Andrea Krelle, Manager - Practice & Learning, Centre for Adolescent Health, Royal Children's Hospital Melbourne**

### **National Education Project Overview**

Progress on the development of the Post Graduate Certificate in Adolescent Health and Welfare Oncology Stream was presented by Andrea Krelle and Samantha Van Staalduinen.

This project is a joint initiative by The Centre for Adolescent Health, onTrac@PeterMac and The University of Melbourne as part of the seven national projects endorsed under the Youth Cancer Network Project. It is the first credentialed post graduate course in the field of AYA oncology outside the Coventry Course in the United Kingdom. The course commenced in March 2011 with an intake of 20 students in the Oncology Stream and with the support of 20 Canteen scholarships.

The course comprises 4 subjects:

- Young People in Context
- Professional Practice in Context
- Mental Health in Young People
- Cancer Care in Young People

The fourth subject: Cancer Care in Young People is under development by Samantha Van Staalduinen as the Project Officer, in consultation with a national curriculum advisory committee. This subject will comprise information on the medical characteristics of cancer in the AYA age group, the survival gap, common cancers and treatments, complementary therapies and clinical trials. The psychosocial impact of cancer will also be covered throughout the cancer journey. This will include aspects of the impact of a cancer diagnosis during these years on development, the importance of psychosocial screening and assessment, fertility and sexuality, family and relationship contexts, and education and vocation. The systemic aspects of the developing field of AYA oncology will also be covered including international and national models of care, policy and practice and the complexities of working across the adult and paediatric sectors.

An additional component to this project is the development of free, online training for people working in, or interested in the field of AYA oncology. This will be multidisciplinary and will be run using a program called SpacedEd. This is a program which has been developed by Harvard University and which sends emailed questions and resources to participants at predetermined spaced intervals.

Although the learning provided by this system will not be as in depth as the Post Grad Certificate, it will provide another option for accessible education and training for professionals working with young people with cancer.

**Speaker: Ms Kate Thompson, Social worker and Manager, OnTrac@PeterMac**

### **State, National and International AYA Initiatives**

Kate presented information on the current state, national and international initiatives in education and training. This included a discussion of a range of initiatives including:

- the Coventry Course out of the UK
- the new Post Graduate Certificate in Adolescent Health and Welfare Oncology Stream
- the newly developed Cancer Australia Learning Pathway which is presented online and includes information to support professionals working in the field of AYA oncology. This site can be found at: [http://www.cancerlearning.gov.au/plan/aya\\_pathway.php](http://www.cancerlearning.gov.au/plan/aya_pathway.php)
- the EviQ AYA site developed by the NSW Cancer Institute with the aim of providing oncology healthcare professionals with an online point of education activities and programs to standardise and implement best clinical practice.

Jurisdictional projects are also currently implementing a range of tailored education and training programs for multidisciplinary teams within their respective states. These may be moulded to the discipline requesting the training and based on experience of AYA cancer and the number of young people seen by professionals. The form of this education may include case discussions or consultations, in services, presentations and forums.

### **Common Challenges/Questions for Consideration:**

- Limited EFT to support the development of education and training within jurisdictional and national projects.
- What is the definition of education and training in this field especially given its multidisciplinary nature?
- Does everyone need 'education' or do some people just need 'awareness and knowledge of where to source information'?
- Does this continuum best run top down or bottom up in relation to disciplines. For example, do you work to educate clinicians who are skilled in adolescent health about oncology or clinicians skilled in oncology about adolescent health? It must work both ways.
- How does this fit with each discipline involved? What is the best model for each discipline?
- How can national approaches best be co-ordinated?
- How can approaches best be tailored to work within adult and paediatric sectors or across the two?
- How do we develop models working in this field which meet the geographical spread of professionals?
- There are a wealth of resources relating to general adolescent development and health education, consider tapping into these resources – it's not all about the cancer!
- Lack of evidence-base in some areas
- Are there some key principles we can work from?
- Ongoing funding beyond the Youth Cancer Network Project is unclear for education and training. Is this something that needs to be adopted by lead sites to ensure ongoing work in this area?



### **Where to From Here?**

The development of an AYA Education Interest Group is essential to identify key people to develop models and content in this area and ensure the coordination of national and jurisdictional development.

This group may consider the importance of:

- a nationally agreed upon principle base for education and training
- an agreed upon definition of education and training
- not just extrapolating from extant adult and paediatric models.

This group needs to devise means of defining the interest groups involved; mapping disciplines involved, and defining the scope of awareness/education and training for this field. From here there is the need to identify current avenues and evidence based models of education and training to link in with community based organisations already providing education in this area, for example, the Youth Affairs Council and The Centre for Adolescent Health.

Linda Ewing and Kate Thompson will follow up with COSA regarding a plan to move forward regarding a National Approach to AYA Education.

---

## **4.7. Improving AYA cancer services**

**Facilitator: Dr Marianne Phillips, Senior Paediatric & Adolescent Oncologist & Palliative Care Specialist, Princess Margaret Hospital for Children Perth**

The session opened with Dr Marianne Phillips providing an overview of the YCNP national project.

She outlined the Youth Cancer Networks Program funded by the Australian Government and administered by CanTeen. The objective of the program is to deliver better models of care for adolescents and young adults (aged 15-25 years) diagnosed with cancer.

**Speaker: Ms Natalie Roney, Executive Officer, CanTeen Youth Cancer Fund Project**

Natalie provided an update on what has been achieved so far with the National Projects.

### **AYA Networks, Guidelines and Research - COSA**

#### *Network*

- COSA have facilitated communications, working groups and workshops
- Network established consisting of interested clinicians, health professionals, policymakers, hospital and health service executives and organisations involved in the development of youth cancer services
- Has networking and knowledge-sharing helped improve AYA services?
- What are the future needs and how to fund?

#### *Guidelines*

- 3 Guidelines to be finalised over the next 6 months
- AYA Protocols under development to be published on eviQ

#### *Research*

- Developed criteria for assessing applications for funding for AYA cancer research projects
- Funding allocation to lymphoblastic leukaemia trial ALL6

- Developed a comprehensive list of cancer trials open to AYAs; ACT Online can be used to search for these trials
- Challenges obtaining baseline AYA patient trial participation data

### **Web Portal and Psychosocial needs - CanTeen**

#### *Web portal*

- An online service directory, providing access to information about youth cancer services for AYAs with cancer and their families
- Testing underway and marketing strategy developed
- Your involvement needed! - Services working with AYAs to upload their service information into the portal
- Site launch by 30<sup>th</sup> June 2011

#### *Psychosocial needs*

- Creation of a needs assessment toolkit for young people with cancer, led by Pandora Patterson
- High level of consultation, support and input from clinicians and young people
- AYA Psychosocial Care Manual published, first training completed 12<sup>th</sup> May 2011
- CanTeen plans to support another training workshop later this year

### **National Minimum dataset - Cancer Australia**

- Wide consultation to develop a list of all possible data items, truncated to a list relevant to a point-of-care medical setting
- Pilot testing begun assessing feasibility, availability of items, barriers to collection
- Data collected by 3 sites over 5-6 months using a web-based tool
- Pilot and report completed by end 2011
- What will be the uptake of dataset, collection and analysis of data?

### **Oncology Education Post Graduate certificate - University of Melbourne and Centre for Adolescent Health**

- First students commenced the professional development postgraduate certificate course for AYA health professionals in January 2011
- Oncology stream to commence 2<sup>nd</sup> semester (end July 2011)
- Introductory online modules being developed using Spaced Education platform and will be accessible by end July 2011

### **Evaluation - Siggins Miller**

- External independent evaluation of the *Youth Cancer Network Program*, assessing the achievements of projects under the Program

### **Speaker: Ms Janine Deevy, AYA Cancer Care Coordinator, Royal Brisbane & Women's Hospital**

Janine presented on how the Royal Brisbane Women's Hospital is moving towards **establishing AYA services**. She said the **key challenges** were:

- Leadership – who will drive the service? A Cancer Care Coordinator has limited influence or authority to get key people to meetings
- The Youth Cancer Networks Program is funding AYA project staff in partnership with Queensland Health. Staff recruitment and allocation has occurred at different times, resulting in staff contracts of varying length. Despite longer-term funding commitments being in place, staff have not had confirmation of this and contracts have not been updated, leaving AYA staff in vulnerable positions
- Integration into current cancer services has been difficult; it has been somewhat a political minefield as no consultative processes had taken place
- Initially, the AYA team were not making headway in linking in with existing services and staff and therefore had to take a different approach. They arranged meetings with relevant hospital staff,

asking the key questions and informing staff members that the aim is to form a service which complements the existing hospital services with a collaborative approach to achieve this

- AYA staff had to be very flexible as to meeting the professional staff working across the various tumour streams. Being accepted and participating in MDT meetings is making an impact
- Having the current consultant led referral process for a patient to be linked into the AYA services is difficult, the AYA team cannot get involved with the patient and they cannot access the services

Group Discussion took place around how best to **move forward** with establishing the AYA services:

- Involve the key people in the AYA Steering Group so that they understand the aims and objectives of the integrated services
- Having a Medical Oncologist or Haematologist representing the AYA services helps with leading and involving the medical teams
- Inclusion of consumer/s as advocates in the advisory committee tends to be very effective
- To maintain and attract interest in people attending AYA steering committee meeting's provide incentives to attend, e.g. lunch & refreshments
- It is important the steering group sets clear goals and objectives and then tick off their achievements. Once achieved then close the group, otherwise there will be loss of interest
- It is essential to identify the key people who can assist with service and program improvement in the steering group. Also invite the more difficult or negative clinicians into the group. This can help to understand the challenges and may also lead to gaining a champion for the AYA cause
- Including the Cancer Services Manager is very valuable

#### **Speaker: Ms Sharon Bowering, AYA Cancer Care Coordinator & Nurse Specialist, Women's & Children's Hospital**

Sharon spoke to her experiences with **collaborations across AYA, paediatric and adult services.**

Sharon began her role as an AYA nurse (in 2007) with the following activities:

- Created a mud map of where AYA patients were reviewed and treated
- E-mailed out to professional staff in a bid to identify those who had an interest or were involved in AYA cancer care
- Scheduled meetings to educate the specialists and began the long journey of building relationships, with a focus on visibility, availability, sharing resources and establishing advisory committees
- Ran education sessions on why young people are different, communicating with AYAs, self care and also seminars in the private system to educate staff on AYA issues

In her talk she referred to 'what worked' and 'what wasn't so great'.

#### ***What worked:***

- Asking and listening
- Starting from a nursing/ social work partnership
- Consumer pressure
- Intensive medical education
- Including the primary consultant
- Being a long term team player - awareness of ongoing patient status

#### ***What wasn't so great:***

- Resistant clinicians
- The need to constantly prove the value of the AYA service
- Non-referral and expectations
- Low resources and no physical workspace, even though accepted as part of the team

**Key challenges:**

In South Australia fertility preservation has been traditionally undertaken only in the private sector, this has been difficult and expensive for the patient. Sharon has developed an effective referral pathway and plan for both public and private patients. Recently there has been a public clinic established, however fertility preservation intervention costs still remain high for patients. She believes that there was agreement amongst attendees that all AYA patients should have fertility discussed.

---

#### 4.8. Sustaining and enhancing AYA cancer services: beyond June 2012

**Synopsis:** The last 3-4 years have been a proactive and productive time for AYA oncology in Australia. An AYA Network has been established and many strategies, frameworks and projects have been identified and implemented. This session covered the activities and implemented programs, considerations for growing and maintaining AYA cancer services; priorities for care; targets for enhancing services; future goals, challenges and some possible solutions.

**Facilitator and speaker: Dr Marianne Phillips, Senior Paediatric & Adolescent Oncologist & Palliative Care Specialist, Princess Margaret Hospital for Children Perth**

Marianne as the final speaker was tasked with perhaps one of the largest topics of the day - that of considerations for sustaining and enhancing AYA cancer services. She framed the following areas as relevant to this aim:

- AYA Network framework
- AYA cancer services up to and beyond 2012
- Advocacy strategies
- Resource requirements
- Connecting AYA with wider population health
- Sustainability

The AYA cancer population is small in the overall scheme of population health, but it does have several unique characteristics which are pertinent to the gaps in the current care pathway.

The priorities for care were identified as the following:

- High quality service
- Models of care
- Cohesive multidisciplinary teams
- Place of care
- Clinical trials and research
- Education

The targets for enhancing AYA services include:

- Prevention and diagnosis
- Referral pathways
- Clinical trials and research
- Models of care
- Adherence
- Transition and survivorship
- Data
- Standards
- Education and training
- Funding
- Awareness campaigns
- Advocacy

The National Service Delivery Framework (2009) also outlines some parameters for 'best care' which reflect the unique needs of AYAs and current ideas for addressing the current survival gap in this group of Australian cancer patients.

Some of the achievements to date were outlined by Marianne such as the Youth Cancer Network Program and associated projects; Psychosocial Assessment Tool; Oncology Education Postgraduate Certificate; Minimum dataset; developing models of care.

Future goals for AYA cancer services could be considered as:

- Prevention and health awareness - AYA awareness is reaching professionals but not the AYAs themselves
- Referral pathways - Currently delays in referral and diagnosis. Referral patterns are haphazard. What is the AYA recommendation for referral pathway? Who should be the driver?
- Transition/ Survivorship - There are 2 transitions to consider: paediatric to AYA and AYA to adult. 1:250 young adults (20-40 y.o.) is a cancer survivor. 2/3 have some chronic condition and ongoing health need. What should we be doing with the survivors? Who is responsible?
- Clinical trials and research - Getting access to American clinical trials is difficult. Clinical trials in Australia are challenging with the amount of effort required vs. the number of patients /site. How do we maximise access to biological and translational research?

There are also other aims for the future of AYA cancer services relating to collaboration, equity, standards (and audit). How would performance indicators be measured? What process followed for audit? Evidence-based change requires before and after measurements. What responsibilities are there for informing the public about expectations and performance?

Marianne's final slides really summed up several of the key points from the day with obstacles to be overcome and some solutions that could be applied.

#### **Obstacles**

- Finance
- Govt and health dept mandates and policies
- Private vs. public health systems
- Rural/ remote areas
- Division between doctors, medicine, other health areas
- Resources and obtaining the required infrastructure
- Outcome measures and cost-benefit ratios

#### **Solutions?**

- Advocacy and awareness
- Evidence base from data and trials
- Training/ education
- Influencing health decision makers by lobbying
- Mandate financial pathways in health
- Change 'champions'
- Opportunities for collaboration with not-for-profit

The session concluded with some positive statements on the current momentum, excellent start with the current funding and ideas for collaborations. Staff funded by the Youth Cancer Networks Program has grown from 2, 3 years ago, to around 100 nationwide today. The challenge will be how best to use likely decreasing government funding in a sustainable way.

## **4.9. Workshop close**

**Dr Wayne Nicholls, Chair, AYA Cancer Steering Committee; Senior Staff Specialist, Royal Children's Hospital Brisbane**

**Ms Marie Malica, Executive Officer, COSA**

Wayne and Marie thanked participants for their attendance and participation at the workshop.

## 5 Acknowledgements

COSA would like to thank the CanTeen Youth Cancer fund, enabling COSA to hold this AYA cancer workshop; also the workshop speakers and session facilitators for preparing the presentations and leading the discussions, COSA staff for their assistance with registrations and preparations on the day, all of the attendees for their interest and participation, and those attendees who completed the evaluation form.

## Appendix 1 List of participants

First Name	Role	Organisation	State
Shiraz Abdulla	Acting Nurse Unit Manager	Sydney Cancer Centre, Royal Prince Alfred Hospital	NSW
Megan Achilles	Consultant	Siggins Miller	NSW
Frank Alvaro	Paediatric Oncologist	John Hunter Children's Hospital	NSW
Antoinette Anazondo	Paediatric & Adolescent Oncologist; Director of AYA Cancer Services	Sydney AYA Cancer Service, Sydney Children's Hospital (Randwick)	NSW
Kathy Ansell	Project Coordinator	COSA	NSW
Emilia Armytage	Manager, Financial & Material Support	RedKite Australia	QLD
Ediz Babacan	AYA Advisory Board Member		VIC
Cameron Banks	Project Officer, AYA Web Portal	CanTeen	NSW
Kate Baychek	Clinical Nurse Educator - Chemotherapy	Sydney Cancer Centre, Royal Prince Alfred Hospital	NSW
Ilana Berger	Team Leader, onTrac@PeterMac	Peter MacCallum Cancer Centre	VIC
Sharon Bowering	AYA Cancer Care Coordinator, Nurse Specialist	Women & Children's Hospital	SA
Charlotte Bradley-Peni	Research Assistant	Flinders University	SA
Lisa Brady	Project Officer, Youth Cancer Network	South Melbourne Integrated Cancer Service	VIC
Linda Brown	Senior Project & Services Coordinator	RedKite Australia	QLD
Samantha Bruce	Project Manager, Youth Cancer Fund Project	CanTeen	NSW
Kate Burns	Senior Lecturer, School of Humanities & Social Sciences	Newcastle University	NSW
Caroline Corin	Social Worker	RedKite Australia	QLD
Angela Cotroneo	Social Worker, Psycho-Oncology Counsellor	Sydney Cancer Centre, Royal Prince Alfred Hospital	NSW
Rhonda Cousins	Project Coordinator	COSA	NSW
Anne Craig	Cancer+ Coordinator & Tasmanian YCNP Working Group member	Cancer Council Tasmania	TAS
Bailey de Paiva	Nurse Care Coordinator, Project Officer	Capital Region Cancer Service, ACT Health	ACT
John de Zwart	Associate Director, CanTeen	Tower Australia Ltd	NSW
Janine Deevy	AYA Cancer Care Coordinator	Royal Brisbane & Women's Hospital	QLD
Jessica Delaney	Project Officer	Cancer Institute NSW	NSW
Louise Devereux	Project Manager	Victorian & Tasmanian Youth Cancer Network	VIC
Karen Dobinson	Cancer Control Section	Dept of Health and Aging	ACT
Sarah Drew	Project Officer	Royal Children's Hospital Melbourne Adolescent Health and Social Environments Program	VIC
Linda Ewing	State Educator Paediatric Haematology/Oncology	Queensland Paediatric Haematology/Oncology Network (QPHON), Royal Children's Hospital Herston	QLD



First Name	Role	Organisation	State
Clare Fitzmaurice	Member Liaison Officer	CanTeen	NSW
Nicole Gavin	Nurse Researcher - Cancer Care Services	Royal Brisbane & Women's Hospital	QLD
Courtney Goddard	Communications Manager	The Sony Foundation	NSW
Lyndal Gray	Leisure Therapist, AYA	Princess Alexandra Hospital	QLD
Allan Hayward	Program Manager, AYA Cancer Service SA/NT	Royal Adelaide Hospital	SA
Elizabeth Hesketh	Paediatric Oncologist; AYA Clinical Lead	John Hunter Children's Hospital	NSW
Lucy Holland	Researcher	Peter MacCallum Cancer Centre	VIC
Deborah Howell	Clinical Trials Project Officer	Victorian & Tasmanian Youth Cancer Network	VIC
Alisha Jackson	Education Project Officer	Victorian & Tasmanian Youth Cancer Network	VIC
Melissa Jessop	Staff Specialist, Paediatric & Adolescent Oncology	Qld Children's Cancer Centre, Royal Children's Hospital Herston	QLD
Wendy Johnson	Nursing Unit Manager, Haematology	Calvary Mater Hospital Newcastle	NSW
Jenni King	Registered Nurse - Radiation Oncology	Prince of Wales Hospital	NSW
Brigette Learmonth	Project Officer, Youth Cancer Network	Capital Region Cancer Service, ACT Health	ACT
Kylie Lewis	CanTeen Board member and patient representative		VIC
Toni Lindsay	Clinical Psychologist	Sydney Cancer Centre, Royal Prince Alfred Hospital	NSW
Fiona Maguire	AYA Clinical Nurse Consultant	Prince of Wales Hospital/ Sydney Children's Hospital	NSW
Marie Malica	Executive Officer	COSA	NSW
Jane Manalang	Registered Nurse - Chemotherapy Suite	Sydney Cancer Centre, Royal Prince Alfred Hospital	NSW
Anna Mascitti	Project Officer	Victorian & Tasmanian Youth Cancer Network, North Eastern Metropolitan Integrated Cancer Service	VIC
Claire Masula	AYA Social Worker - Cancer Care Services	Royal Brisbane & Women's Hospital	QLD
Belinda Matigian	AYA Social Worker	Adolescent & Young Adult Cancer Service, Princess Alexandra Hospital	QLD
Maria McCarthy	Director, Psycho-oncology program	Royal Children's Hospital Melbourne, Paediatric Integrated Cancer Service	VIC
Louise McCorley	Social Worker - Community Based Support Team	RedKite Australia	QLD
Geoffrey McCowage	Director, AYA Oncology Services	Sydney Children's Hospital Network (Westmead)	NSW
Kate Melvin	AYA Social Worker	Children, Youth & Women's Health Service Oncology, Women & Children's Hospital	SA
Elena Moody	Senior Psychologist, Cancer Specialist	AYA Cancer Care Services, Child and Youth Mental Health Service, Royal Children's Hospital Herston	QLD
Gillian Myles	AYA Cancer Care Coordinator, Clinical Nurse Consultant	Division of Cancer Services, Princess Alexandra Hospital	QLD
Danielle Nearmy	AYA Clinical Psychologist	Royal Adelaide Hospital	SA

<b>First Name</b>	<b>Role</b>	<b>Organisation</b>	<b>State</b>
Rowena Nelson	Project Officer	Cancer Institute NSW	NSW
Wayne Nicholls	Senior Staff Specialist, Paediatric Oncologist	Royal Children's Hospital Herston	QLD
Linda Nolte	Cancer Quality Program Manager	Dept of Health Victoria, Cancer Strategy & Development	VIC
Colleen Oakley Browne	Project Officer	Tasmanian Youth Cancer Clinical Network	TAS
Dan O'Brian	AYA Advisory Board Member		VIC
Cath O'Dwyer	Clinical Nurse Consultant	Prince of Wales Hospital	NSW
Lisa Orme	Paediatric Oncologist; Medical Director OnTrac@PeterMac	Children's Cancer Centre, Royal Children's Hospital Melbourne/ Peter MacCallum Cancer Centre	VIC
Michael Osborn	Consultant Haematologist/Oncologist	Women & Children's Hospital	SA
Libby Paton	Executive Officer	ANZ Melanoma Trials Group	NSW
Pandora Patterson	National Research & Evaluation Manager; Psychologist	CanTeen	NSW
Louise Pearce	Clinical Nurse Consultant, Care Coordinator	Melanoma Institute Australia	NSW
Marianne Phillips	Senior Paediatric and Adolescent Oncologist and Palliative Care Specialist	Princess Margaret Hospital	WA
Ross Pinkerton	Staff Specialist Paediatric Oncology & Director	Qld Children's Cancer Centre, Royal Children's Hospital Herston	QLD
Francesca Pinzone	Manager, Services & Policy Team	CanTeen	NSW
Megan Plaster	Paediatric & Adolescent Cancer Nurse Coordinator	WA Cancer & Palliative Care Network	WA
Christina Portelli	AYA Social Worker	Victorian & Tasmanian Youth Cancer Network	VIC
Angela Richards	Social Worker	Children's Cancer Centre, Royal Children's Hospital Melbourne	VIC
David Roder	Professor of Cancer Epidemiology; Consultant Epidemiologist	University of South Australia	SA
Tim Rogers	General Manager National Services	RedKite Australia	QLD
Kirsty Rollason	Project Officer	Barwon South West Regional Integrated Cancer Service	VIC
Natalie Roney	Executive Officer, Youth Cancer Fund Project	CanTeen	NSW
Sophie Ryan	Chief Executive Officer	The Sony Foundation	NSW
Susan Sawyer	Director	Centre for Adolescent Health, Royal Children's Hospital Melbourne	VIC
Kristyn Schilling	Clinical Nurse Consultant, Sarcoma	Royal Prince Alfred Hospital	NSW
Michael Seldon	Staff Specialist, Haematologist	Calvary Mater Hospital Newcastle	NSW
Orietta Simons	Youth Development Officer	WA Cancer & Palliative Care Network	WA
Felicity Sleeman	AYA Psychologist	Peter MacCallum Cancer Centre	VIC
Karen Smith	Project Coordinator, AYA	COSA	NSW
Fiona Spargo	Project Officer	Royal Melbourne Hospital	VIC
Catherine Spooner	Senior Consultant	Siggins Miller	NSW

<b>First Name</b>	<b>Role</b>	<b>Organisation</b>	<b>State</b>
Kylie Swyer	AYA Oncology Social Worker	Psychosocial Services, Royal Children's Hospital Herston	QLD
Kate Thompson	Social Worker and Manager, OnTrac@PeterMac	Peter MacCallum Cancer Centre	VIC
Damien Thomson	Director of Medical Oncology	Princess Alexandra Hospital	QLD
Danielle Tindle	Senior Project Officer	AYA Cancer Services, Queensland Health	QLD
Toby Trahair	Paediatric Oncologist	Centre for Children's Cancer & Blood Disorders, Sydney Children's Hospital	NSW
Claire Treadgold	Programs Manager	CanTeen	NSW
Gela-Marie Van Horen	Manager, Hospital & Community Based Support	RedKite Australia	QLD
Samantha Van Staaldin	Project Officer	Centre for Adolescent Health, Royal Children's Hospital Melbourne	VIC
Claire Wakefield	Program Leader - Behavioural Sciences Unit & NH&MRC Postdoctoral Clinical Research Fellow	Centre for Children's Cancer & Blood Disorders, Sydney Children's Hospital & School of Women's & Children's Health, Faculty of Medicine, UNSW	NSW
Pauline Warburton	Director of Haematology	Wollongong Hospital	NSW
Jane Williamson	Program Manager	Royal Children's Hospital Melbourne, Paediatric Integrated Cancer Service	VIC
Ginny Youmans	Registered Nurse - Chemotherapy Suite	Royal Prince Alfred Hospital	NSW
Andrew Young	Chief Executive Officer	CanTeen	NSW

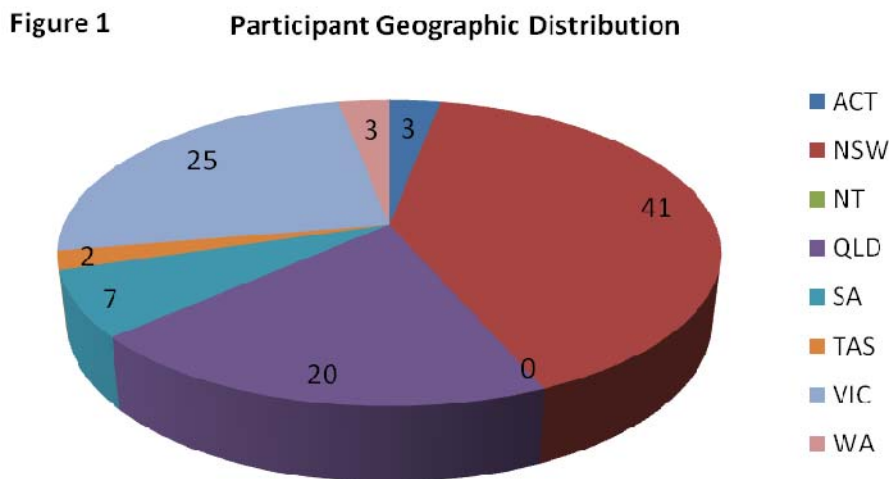
## Appendix 2 Workshop evaluation summary

### Demographics

The total number of participants at the meeting was 101. Fifty-seven percent of respondents currently work in a dedicated AYA program, hospital or facility. Approximately half are members of COSA (47%).

Participant geographic distribution by state can be found in Figure 1. The majority of attendees were from NSW, Victoria and Queensland (41, 25, 20 % respectively).

Distribution of attendees by discipline (Figure 2) shows a high proportion of project staff and managers (31%) and nursing/care coordination (14%), reflecting the growing staff in these areas involved in AYA services. Low numbers of medical oncologists and haematologists indicates that there is indeed effort needed in finding ways to increase the attendance of these disciplines at AYA cancer events.



### Observations

#### ***Reasons for attending the workshop***

The main reason for attending the AYA Cancer workshop was to network with other health professionals (92% of respondents), followed by discussion of solutions to current national and/or jurisdictional issues (76%), to attend workshop sessions relevant to area of practice (59.5%) and to learn about the area of AYA oncology (57%).

#### ***Workshop program***

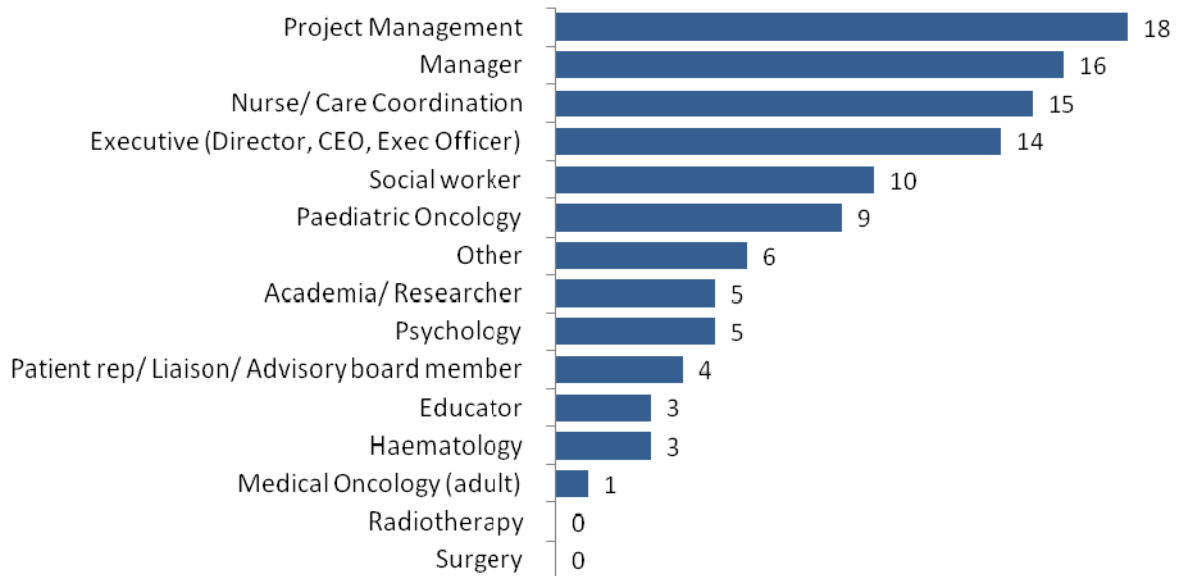
All workshop evaluation form respondents indicated that the workshop met their expectations (completely, 69% or somewhat, 31%). The overall workshop was rated excellent or very good by 82% of respondents. All sessions were well received, with 64% of respondents rating the break-out sessions and 91% for the plenary sessions as excellent or very good.

#### ***Value of COSA hosting future similar events for AYA cancer***

All respondents indicated that there is value in COSA hosting future workshops or similar events for AYA cancer, and that they would attend or recommend attendance at a future AYA cancer workshop.

**Figure 2**

**Participant Attendance by Discipline**



Comments on the value of COSA continuing to run the AYA cancer workshop include:

- COSA has an integral role to play in the coordination of discussion about national projects and service development in AYA oncology. Enabling the formation of interest groups, advisory boards and forums for discussion and brainstorming about issues encountered within these processes is essential to ensure the coordination of service development for young people across Australia.
- There are not many opportunities to attend AYA specific sessions with such AYA expertise.
- Multiple services/ projects, helpful to have a neutral body to facilitate bringing everyone together.
- Good to have AYA specific meetings where you meet other clinicians.
- The opportunity for networking & information sharing is invaluable.
- Great opportunity to see how the rest of the country is tackling problems/ what other states are doing/ where they are up to with projects.
- Thoroughly enjoyed the day. Lots of new developments and interest in AYA. Well worth attending.

**Considerations for future events**

From the comments received, it is clear that there is continued value in conducting the AYA cancer workshops. There were also suggestions for similar events, such as networking days or creating opportunities to visit AYA facilities. Some of the most cited suggestions from grouped comments are:

- Hearing about project highlights
- Additional focus on non-medical - allied health, psychosocial and support services, how other groups can engage AYA sector i.e. charities reaching AYAs
- Separate or specific sessions for newcomers to AYA oncology and those more familiar
- More sessions of 'workshop' format to brainstorm and develop solutions
- More time in between sessions for networking
- Embed within or run adjacent to adult oncology forums/meetings to increase adult oncology participation

- Opportunities for staff to have site visits at other established centres
- Networking days

COSA will consider these suggestions when making plans for future AYA cancer events.