



**Clinical
Oncological
Society of
Australia**

**REPORT OF THE
ADOLESCENT AND YOUNG ADULT (AYA)
CANCER WORKSHOP**

21 NOVEMBER 2008

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EXECUTIVE SUMMARY

The Clinical Oncological Society of Australia (COSA) is Australia's peak multidisciplinary society for health professionals working in cancer research, treatment, rehabilitation or palliative care. With a membership of over 1250 individuals in 22 cancer professional groups, COSA's overarching mission is to develop and maintain high-quality clinical care of cancer patients in Australia.

COSA convened a workshop on 21 November 2008 to bring together oncologists, health and other professionals and consumers interested in improving the treatment and care of adolescents and young adults diagnosed with cancer.

The **objectives** were:

- to update stakeholders about proposed Federal Government and CanTeen funding to establish adolescent and young adult (AYA) cancer services and the status of the National Service Development Framework for AYA cancer services,
- to exchange information about work underway to develop AYA cancer services in some states, and
- to develop national guidelines for implementation of AYA cancer services.

COSA President Professor David Goldstein facilitated the workshop. Participants are listed in appendix 1. This workshop report was written by Lisa-Maree Herron on behalf of COSA.

PROPOSED FUNDING AND FRAMEWORK FOR AYA CANCER CENTRES

Dr Andrew Young, CEO of CanTeen, explained delays in receiving Australian Government funding (\$15 million over three years) for capital and establishment costs of AYA cancer centres, and in dissemination of the *National Service Delivery Framework for Adolescents and Young Adults with Cancer* (see page 7).

PROGRESS TOWARDS DEVELOPMENT OF AYA CANCER SERVICES

Representatives from Western Australia, Victoria, South Australia, Queensland and New South Wales reported on activity and/or planning to develop AYA cancer services in those states. Summaries of their presentations are included in this report (from page 8).

NATIONAL GUIDELINES AND COORDINATION

Participants agreed that while the nature of AYA cancer services should be determined by each state and territory jurisdiction, it would be beneficial to have national guidelines for implementation of AYA cancer services. National coordination of key functions to support AYA cancer services, such as research, professional development and evaluation, would prevent duplication and ensure equity for people affected by AYA cancers across Australia.

RECOMMENDATIONS

Workshop participants recommended that a **national AYA Cancer Interest Group be established under the auspices of COSA** to lead:

1. National coordination of functions to support AYA cancer services, such as research, professional development and evaluation
2. Development of key performance indicators for AYA cancer services
3. Development of national guidelines for implementation of AYA cancer services.

1. Functions to be coordinated nationally

It was recommended that the following key functions to support AYA cancer services be nationally coordinated and/or centralised:

- **Research**
 - development of a platform for national coordination and collaboration
- **Education, training and professional development**
 - including the development of streams and pathways
- **Program evaluation**
 - development of key performance indicators for AYA cancer services as part of national framework
- **Data registration and tumour banking**
 - development of a national registry of AYA cancer patients and tumour bank for research and for service planning and improvement
- **Advocacy**
 - increasing awareness of the distinct needs of adolescents and young adults with cancer and lobbying for support for AYA cancer services
- **Clinical trials**
 - collating information about and promoting available trials; developing infrastructure and enablers to increase access to trials for adolescents and young adults with cancer
- **Collaboration**
 - bringing together non-government organisations with an interest in the care and support of adolescents and young adults with cancer to encourage a more coordinated approach.

2. Key performance indicators for AYA cancer services

It was recommended that the AYA Cancer Interest Group develop a set of key performance indicators (KPIs) to enable evaluation of the impact of new services.

KPIs and measures should be defined for:

- Clinical trial participation
- Use of national minimum dataset
- Mapping of patient journey
- Outcomes, including recurrence/survival, psychosocial, education and career outcomes
- Outcomes for patient's family members/partner eg financial, psychosocial
- Research (non clinical trial) activity and outcomes
- Shared care networks
- Education, training and credentialing
- Engagement of private AYA cancer professionals
- Patient satisfaction and involvement
- Late effects management

3. Guidelines for implementation of AYA cancer services

It was recommended that the AYA Cancer Interest Group develop national guidelines to assist states and territories in implementing the National Service Delivery Framework (NSDF), including:

- Guidance about **minimum requirements of an AYA cancer service**, as well as elements that are strongly recommended
- **Benchmarks and ratios** (eg number of AYA patients a social worker could support) to help determine the number and specialties of staff needed for AYA cancer services.

NEXT ACTIONS

- An interim steering committee was formed and will meet in December to formulate the national program of work for the COSA AYA Cancer Interest Group.
- COSA will support the interim steering committee by funding teleconferences and initial scoping work. COSA will seek funding from CanTeen to employ a project officer to support the ongoing work of the Interest Group in developing care standards, benchmarks, clinical guidelines and performance indicators and other national activities to improve services for adolescent and young adult cancer patients.
- A COSA working group has been formed to develop national guidelines for implementation of AYA cancer services. Workshop participants and other stakeholders will be invited to comment on the draft National Service Development Framework via the COSA website. All comments will be reviewed and collated by Dr Marianne Phillips, with the assistance of the working group members and COSA's AYA cancer project officer, then submitted to the AYA Cancer Interest Group. Draft guidelines are to be disseminated for comment by the end of February 2009.
- COSA will provide monthly email updates on the progress of the interim steering committee, then the AYA Cancer Interest Group, to all workshop participants and other interested stakeholders.

BACKGROUND AND CONTEXT

Adolescents and young adults with cancer have distinctly different medical, psychosocial, social and information needs to children and adults with cancer. There is growing recognition that age-appropriate treatment and support and better access to clinical trials would significantly improve survival rates and psychosocial outcomes for adolescents and young adults with cancer.

AYA Cancer Forum (May 2007)

In May 2007 the Clinical Oncological Society of Australia (COSA), Australian and New Zealand Children's Haematology/Oncology Group (ANZCHOG) and CanTeen, with support from Cancer Council Australia, convened a forum to explore issues and challenges in the treatment and care of adolescents and young adults with cancer and to agree on key elements of appropriate models of care. Participants included a broad representation of clinicians, health professionals, consumers and other stakeholders.

The forum identified key principles for the effective treatment and care of AYA cancer patients. These principles were provided to Cancer Australia's AYA Cancers Reference Group to develop a framework for AYA cancer services in Australia. The Reference Group completed a final draft of a *National Service Delivery Framework for Adolescents and Young Adults with Cancer* in mid 2008.

Australian Government funding (October 2007)

In October 2007 the incoming Labor Federal Government committed \$15 million towards national funding for capital costs and establishment of AYA cancer services. In May 2008 the Federal Budget confirmed \$15 million would be provided over three years to CanTeen to "establish Youth Cancer Networks in Australia to improve coordination of services, support and care for teenagers and young adults with cancer, and their families. The networks will include six new adolescent and young adult cancer centres in mainland states" (Minister for Health and Ageing's media release, 13 May 2008).

AYA Cancer Workshop (November 2008)

COSA convened this workshop to bring together key stakeholders 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 services.

FUNDING AND NATIONAL FRAMEWORK FOR AYA CANCER SERVICES

Dr Andrew Young
CEO, CanTeen

Dr Young advised that CanTeen's role and intention was to support and facilitate efforts to develop specialised AYA cancer services in the states and territories.

Dr Young explained the funding committed by the Australian Government (\$15 million over three years) for capital and establishment costs of AYA cancer centres is budgeted over the 2008/09, 2009/10 and 2010/11 financial years, and that the details surrounding the administration of that funding are still under negotiation with the Government. The first tranche of this funding has not yet been paid. He committed to informing stakeholders when issues regarding funding were resolved. CanTeen has committed to raising an additional \$15 million over three years to support AYA cancer services.

Dr Young said how the funding could be allocated had not yet been fully articulated and will depend, in part, on the outcome of current negotiations with the Federal Government. The election commitment was to funding for capital and establishment costs of AYA cancer centres, but the definition of "establishment" is to be further defined. Upon receipt of government funding, CanTeen plans to establish an ancillary fund with a governing group and a transparent and consultative process for allocating both the government and CanTeen funds.

Dr Young reported that the National Service Delivery Framework for AYA Cancers (NSDF), developed by Cancer Australia and CanTeen through a broad-based consultative process, was completed a few months ago. It is intended to provide a model for implementation of services but is not prescriptive about the nature, location or funding of services. Given delays in publication of the framework, the final draft will be provided to state and territory working groups to assist them in planning services.

CanTeen believes that the determination of detailed implementation models, preferably based on the principles in the NSDF, is a state responsibility and CanTeen is already working and will continue to work in coming months to support the process of State consultation around these models.

DEVELOPMENT OF STATE AYA CANCER SERVICES

Lead clinicians and program managers from Western Australia, South Australia, Victoria, New South Wales and Queensland (in order of presentation) reported on activity and/or planning to develop AYA cancer services in those states.

WESTERN AUSTRALIA

Dr Marianne Phillips

Senior Paediatric and Adolescent Oncologist and Palliative Care Specialist

Princess Margaret Hospital for Children

Lead clinician, Paediatric and Adolescent Collaborative

Dr Phillips said progress in developing AYA cancer services in WA was largely due to effective collaboration, educating the workforce, and providing the evidence base to support change.

WA Paediatric and Adolescent Collaborative

The WA Cancer and Palliative Care Network, established in 2006, created a “Model of Care for Cancer”, Cancer Nurse Coordinators positions and 16 tumour collaboratives, one of which is for Paediatric and Adolescent cancers. Tumour collaboratives are intended to achieve best practice and excellent outcomes for all patients by actions such as developing benchmarks, facilitating multidisciplinary care and developing evidence-based management guidelines.

In order to provide evidence for a model of care, the Paediatric and Adolescent Collaborative conducted an **audit** of AYA cancer incidence treatment and outcomes. The audit looked at data for three age groups: 10-14, 15-19 and 20-24 years for the period 2000-2004. The audit found that the incidence of cancer in these age groups was increasing. It identified 567 patients treated at 44 separate institutions (seeing from 1 to 146 cases).

Service mapping was completed in 2006, looking at existing services for paediatric and adolescent patients, pathways and gaps. With this information, the Collaborative started working on an appropriate **model of care** for cancer in paediatric and adolescent patients.

Service development

Specific service development has commenced across psychosocial, therapeutic and physical realms:

- ***Psychosocial***

The psychosocial team includes an AYA Cancer Nurse Coordinator (CNC), support workers and educators. There are plans to employ a CNS to focus on psychosocial late effects and a fertility CNC.

- ***Therapeutic***

The focus has been on achieving collaboration, including establishing multidisciplinary teams for paediatric, sarcoma, haematology, GI and neuro-oncology.

Work has started on a clinical trials register.

▪ **Physical**

Two specific facilities have been developed:

1. Inpatient facilities for patients aged up to 17 or 18 years at Princess Margaret Hospital, including:

- Senior school teacher (1 FTE)
- Late effects/transition support (0.5 FTE nurse)
- Adolescent support worker (1 FTE)
- Fertility CNS

2. Ambulatory facilities for AYA cancer at Sir Charles Gairdner Hospital Comprehensive Cancer Centre.

The Paediatric and Adolescent Collaborative is working on a proposed **Service Model** for ambulatory care facilities. The draft document, published November 2008, describes size and location of the facility, staffing complement, how it should operate and specific protocols and policies to be used.

Dr Phillips said future challenges included development of referral pathways, best practice guidelines and standards for credentialing/audit; addressing the need to facilitate age-appropriate clinical trials across sites; how to provide “outreach” or “hub and spoke” model; and how to provide inpatient facilities for older adolescents and young adults.

SOUTH AUSTRALIA

Dr Petra Ritchie

***Oncologist, Women’s and Children’s Hospital, Adelaide
Chair, SA AYA Working Party***

Dr Ritchie reported on two key initiatives in South Australia: establishment of an AYA cancer mobile team, and the AYA cancer working party.

AYA cancer mobile team

The mobile team comprises:

- New AYA Cancer Care Coordinator (CCC) position (0.6 FTE nursing position) – based at CYWHS site but provides consultation and support to all referred AYA cancer patients across public and private sector
- Redkite AYA social worker (0.5 FTE) – with specific AYA focus and works with the AYA CCC to support 12-23 year olds.
- CanTeen AYA Cancer and Vocational Support Officer – to commence soon
- CanNET AYA MDT Coordinator (0.2 FTE for AYA) – to organise and coordinate MDT meetings where AYA will be discussed, type up and distribute recommendations and care plans, and keep data set of patients discussed. To commence December 2008, for 6 month pilot.

The team is based at Adelaide’s Women’s and Children’s Hospital (WCH) but sees patients in both paediatric and adult settings, public and private.

The team has gained Executive support to extend the admitting age of WCH to 25 years for certain oncology patients and support from other adult oncology units for this to occur. There is increased awareness of AYA cancer issues as result of education and exchange opportunities. Strategies used to generate interest across the cancer treatment centres in Adelaide in improving treatments and support for adolescents and young adults with cancer include attending adult oncology, haematology and GP meetings; setting up an email network to share information and

interesting articles; and initiating AYA case meetings, to compare adult and paediatric treatment options, discuss trial eligibility and share literature.

AYA Working Party

The AYA Working Party is a subcommittee of the Optimising Cancer Care committee, one of six committees addressing parts of the Statewide Cancer Plan. (See Dr Ritchie's presentation in Appendix 2 for SA Cancer Network structure.)

The AYA Working Party's aim is to implement a statewide patient pathway for adolescents and young adults with cancer. The focus is on the 15-24 years age range; recommendations apply to any young person with cancer.

The Working Party is:

- developing simplified referral pathways, using multidisciplinary teams supported by treatment protocols
- improving data collection for decision making and research
- identifying workforce requirements for the new models of care and implementation strategies to secure, retain and develop the workforce
- developing an integrated approach to research, including a clinical trials register: http://cancersa.org.au/asp/clinical_trials_search.aspx

To improve supportive care, the Working Party is:

- developing evidence-based standards of care and referral pathways for sexual health and fertility counselling;
- identifying need for age-appropriate resources;
- advocating for Medicare rebates to reduce cost to patients.

Dr Ritchie said a national group could support state-based service delivery by developing or coordinating:

- National guidelines for AYA assessments
- Psychosocial research – to evaluate the impact of changes in AYA management
- KPIs eg diagnosis delay, clinical trial enrolment, survival outcomes
- A national AYA data register
- Web-based tool for health professionals and consumers to use

VICTORIA

Kate Thompson

Manager, onTrac@PeterMac

Victorian Adolescent & Young Adult Cancer Service

Dr Lisa Orme

Adolescent and Young Adult Oncologist, onTrac@PeterMac and The Peter Mac Sarcoma Service

Ms Thompson explained the core principles of the onTrac@PeterMac program:

- Based in adult cancer system, where 90% of AYA cancer is currently treated
- Breaching the artificial divide between paediatric and adult cancer care
- Practice based on research and innovation
- Multidisciplinary care with a focus on developmentally targeted supportive care
- Working with Integrated Cancer Services across Victoria: hub-and-spokes model

The service has a defined and well established multidisciplinary team, including: Adult & Paediatric Oncologist, Nurse Consultant, Adolescent Psychologist, Social Worker, Psychiatrist, Education & Career Advisor, Music Therapist, Palliative Care Nurse Specialist, Research Officer, Training & Education Officer

The focus this year has been on development of medical services with the cross appointment of a paediatric oncologist (Lisa Orme) and development of common protocols and clinical management for young people living with cancer. In addition the Service has collaborated with regional healthcare professionals to run its first regionally based outpatient clinics.

The **Paediatric Oncologist position** is funded by CanTeen. Dr Orme explained that she provides two sessions: one sarcoma service (weekly multidisciplinary outpatient clinic) and one session at onTrac@PeterMac (Victorian AYA cancer services; writing papers, grants, research). Advantages of the paediatric collaboration include:

- Enriched MDT discussions Peter MacCallum Cancer Centre and the Royal Children's Hospital
- Eased patient referral between institutions
- Better able to make location of care decisions
- Concept of joint care
- Opportunity to facilitate patient transition
- Improving access to clinical trials, and access across age range
- Harmonisation of treatment regimens
- Opportunities to do collaborative research projects eg pharmacokinetic handling (AYAPK) project
- Educational opportunities eg collaborative professional training day
- Exploring approaches to AYA oncology issues such as fertility preservation

In addition to providing direct clinical support to young people with complex needs, onTrac@PeterMac supports capacity building of existing healthcare services including:

- Secondary consultation service, information & advice to health and community agencies, particularly for rural and regional clinicians
- resource development – web-based and other age-appropriate resources
- development of AYA Practice Framework (for adult health sector)
- collaborative AYA training with Royal Children's Hospital (RCH)

Research

Several studies are underway including a psychosocial longitudinal study, development of an integrative model of palliative care for AYA and exploration of ICT in delivery of care to young people. Dr Orme explained the collaborative PMCC and RCH AYAPK study, examining whether differences in survival across a range of cancers may be related to chemotherapy handling.

Access to clinical trials

Associate Professor David Thomas (Medical Director, onTrac@PeterMac) commented on data re access to clinical trials, stating that the solution to improving survival for adolescents and young adults with cancer is disease-focussed, not age-focussed.

Training and education

onTrac@PeterMac is collaborating with Melbourne University and The Centre for Adolescent Health to develop an AYA oncology training and education program. An international scoping exercise has been completed and an extensive local scoping exercise is planned for early 2009.

Centre for Clinical Research Excellence (CCRE) in AYA Oncology

Associate Professor Thomas explained the need to set up a CCRE to establish an evidence base going forward. The Centre would be developed in partnership with the key clinical trials groups (ASSG, ALLG, COGNO, ANZCHOG/ACCT). Its program would include:

- AYA cancer biology (basic research into cancers that affect AYA)
- Translational/clinical/psychosocial eg AYAPK study, meta-analysis of AYA data in osteosarcoma and Ewing sarcoma, longitudinal psychosocial impact study, ICT study
- Public health eg program evaluation of AYA cancer services

NEW SOUTH WALES

Dr Tracey O'Brien

Paediatric and Adolescent Haematologist/Oncologist,

Centre for Children's Cancer and Blood Disorders, Sydney Children's Hospital

CINSW Child and Adolescent Oncology Group

The Cancer Institute NSW, established in 2003, has formed 11 clinical oncology groups, one of which is Child and Adolescent (established late 2005). Oncology Group goals include developing best-practice methods and clinical pathways; identifying data needed to monitor and improve outcomes; promoting sub-specialised knowledge and education; and promoting clinical trial participation.

The Child and Adolescent NSWOG established a subcommittee on AYA cancers in February 2006, to report on AYA cancer data, treatments (type and location), clinical trial participation, models of care, etc. The subcommittee convened a **Priority Project Workshop** in November 2007. NSW AYA cancer incidence, mortality and activity data and a high-level literature review were presented and attendees discussed key features, advantages and enablers of different models of care.

Multidisciplinary team grants

CI NSW has provided two MDT grants in AYA (2007):

1. Randwick campus

- AYA CNC care navigator (1 FTE)
- Exploring best model of MDT/integration into current services
- Developing referral pathways/process
- Education, liaison and research across campus and the wider Area Health Service
- Team includes medical oncologist, social worker and psychologist (university and benevolent funding)

2. Westmead

- AYA CNC appointed to canvas service needs at Westmead children's and adult hospitals
- Focus is on transition of care and late effects

Working group – 2008 and beyond

The NSW Cancer Institute's Paediatric and Adolescent Tumour Group (lead by current Chair Dr Luce Dalla Pozza) continues to look at best models of care, integration and harnessing of current infrastructure and expertise, referral pathways and best practice for AYA cancer patients in NSW.

QUEENSLAND

Professor Ross Pinkerton

**Staff specialist Paediatric Oncology and Director of Cancer Services,
Children's & Mater Children's Hospitals, Brisbane**

Dr Wayne Nicholls

Medical Oncologist, Royal Children's Hospital, Brisbane

In Queensland there are four cancer networks: three are geographic regions and the fourth is the statewide Paediatric Haematology Oncology Network. The Paediatric Network is officially to focus on services for children under 15, but has established an **AYA Working Group** to forge links between appropriate facilities and services across children's and adult cancer care sectors.

The key players are the Princess Alexandra, Royal Brisbane Women's and Mater Hospitals (which treat the majority of AYA cancer patients – see below) and the Royal Children's Hospital and the new Queensland Children's Hospital.

Location of treatment for AYA cancer patients (2003/04):

>100 patients	Princess Alexandra, Royal Brisbane
> 50 patients	Mater
20-50 patients	Gold Coast, Ipswich, Logan, Townsville, Toowoomba
10-20 patients	7 hospitals
<10 patients	31 hospitals

There are two main KPIs for the delivery of AYA cancer services in Queensland:

1. Access for AYA patients to age-appropriate facilities
2. Access to clinical trials

Access to age-appropriate facilities

An **AYA support team** has been established to identify people in this age range and increase access to age-appropriate supportive care. One team has been established at PAH and funding is in place for a second team at RBWH. The support team comprises a Care Coordinator, Social worker and Senior Medical Officer.

Establishment of multidisciplinary teams with specific interest and expertise in AYA for both treatment planning and psychosocial support is also planned.

It is proposed that the new QCH will admit patients up to age 16, but has discretion to admit patients up to 18 years, or end of schooling for specialised services. There is the possibility of a more defined AYA facility at PAH for patients aged 15 to 25 years.

Increasing clinical trials enrolment

One of the AYA Working Party's objectives is to increase AYA involvement in multi-centre collaborative clinical trials. An important tool to support this is the NCI's Cancer Trials Support Unit (CTSU) web register (www.ctsuo.org). The CTSU supports networks of physicians to participate in trials, most of which are sponsored by the major US Cooperative Clinical Trials Groups. The Children's Oncology Group (COG) is soon to be involved. Some COG trials are open to patients aged up to 30 years.

A barrier to clinical trial participation for AYA cancer patients in Queensland has been that older patients can not join a COG trial if they are not being treated at a COG centre (most are in adult hospitals). The CTSU is seen as a way of addressing this and increasing AYA enrolment in clinical trials: if studies become part of CTSU, non-COG sites/individuals can participate as independent clinical research sites.

Development of AYA cancer services: A snapshot

Note: This table includes only the information presented at the workshop and may not be complete.

Development of AYA cancer services	WA	SA	VIC	NSW	QLD
Lead agency/ working group	Paediatric and Adolescent Collaborative	AYA Cancer Working Party	AYA Cancer Service (onTrac@PeterMac)	Cancer Institute NSW AYA Working Group	Paediatric Haematology and Oncology Network – AYA Working Group
Model	Psychosocial team 2 specific facilities – 1 inpatient, 1 ambulatory care	Mobile team	Specific facility (adult hospital); hub and spokes (working with all ICS); paediatric collaboration	2 MDT projects	AYA support team to link children's and adult cancer centres
MDTs	Paediatric, sarcoma, haematology, GI, neuro-oncology	6 month pilot starting Dec 2008	Well-established and large MDT	In development (Randwick)	Planned (for treatment planning and psychosocial)
Improving access to clinical trials	Started work on register	Developing register			Using CTSU register to increase access to COG trials
Plans/pathways/protocols	Model of Care for cancer in paediatric and adolescent patients	Developing standards of care and referral pathways	Clinical protocols; AYA Practice Framework (adult sector)	Developing referral pathways/process	
Professional education	Yes (not detailed)		Collaboration with RCH + developing an AYA oncology training & education program		

IMPLEMENTATION OF THE NATIONAL SERVICE DEVELOPMENT FRAMEWORK

Associate Professor David Thomas

Associate Professor Thomas outlined the key elements of the *National Service Delivery Framework for Adolescents and Young Adults with Cancer* (NSDF) and a proposal for national development of key functions of AYA cancer services to complement state-based programs.

Key elements of the draft NSDF model include:

- Establishing a network mapped nationally to deliver high quality cancer services for AYAs through lead national sites with robust linkages to local care
- Care provided by health professionals with knowledge and skills in adolescent and young adult health
- Comprehensive assessment for all adolescents and young adults with cancer by multidisciplinary medical, and psychosocial and supportive teams
- Care coordinated across settings in formalised networks
- Young Australians affected by cancer are empowered in decision-making and are provided with access to cancer clinical trials
- Multidisciplinary medical teams expert in tumour-specific cancers, and psychosocial and supportive teams with expert skills in adolescent health.

National program of work

Associate Professor Thomas identified key functions that need to be developed nationally to complement state-based programs, increase efficiencies and ensure equity:

- Syllabus for core AYA training, accreditation and professional development
- Research – some kind of mechanism that brings together individuals/activities so that everyone can participate and have a hand in shaping
- Metrics and tools for program evaluation – how to measure improvements in patient care, decreasing psychosocial morbidity, etc.

National AYA Cancer Interest Group

Associate Professor Thomas proposed creation of a national AYA Cancer Interest Group under the auspices of COSA to:

- Represent and liaise with the state-based groups
- Establish a clinical network to support implementation of state-based programs (with sub-groups focussed on particular tumours or issues such as clinical trials)
- Oversee national program of work: consensus guidelines, research, education and training, program evaluation.

RECOMMENDATIONS

Workshop participants divided into three groups to discuss priorities and develop recommendations regarding:

- Guidelines for AYA cancer services eg types of cancer, number and specialties of professional staff, etc.
- Key performance indicators and measures of service performance
- Core functions to support AYA cancer services that should be coordinated nationally.

DISCUSSION GROUP REPORTS AND RECOMMENDATIONS

(in order of presentation)

1. Functions to be coordinated nationally

The group recommended that the following key functions to support AYA cancer services be nationally coordinated and/or centralised:

- **Research**
 - development of a platform for national coordination and collaboration
- **Education, training and professional development**
 - including the development of streams and pathways
- **Program evaluation**
 - development of key performance indicators for AYA cancer services as part of national framework
- **Data registration and tumour banking**
 - development of a national registry of AYA cancer patients and tumour bank for research and for service planning and improvement
- **Advocacy**
 - increasing awareness of the distinct needs of adolescents and young adults with cancer and lobbying for support for AYA cancer services
- **Clinical trials**
 - collating information about and promoting available trials; developing infrastructure and enablers to increase access to trials for adolescents and young adults with cancer
- **Collaboration**
 - bringing together non-government organisations with an interest in the care and support of adolescents and young adults with cancer to encourage a more coordinated approach.

The group recommended a **national AYA Cancer Interest Group be formed, under the auspices of COSA, to progress this national work.** An interim steering committee was formed, comprising a nominee from each mainland state, three psychosocial/supportive care professionals and one consumer, to develop a constitution and agenda for the Interest Group.

Nominations were invited, and the following people agreed to join the interim steering committee:

Associate Professor David Thomas (Vic) (Chair)
Dr Wayne Nicholls (Qld)
Dr Tracey O'Brien (NSW)
Dr Marianne Phillips (WA)
Dr Petra Ritchie (SA)
Maeve Downes
Anne Senner
Kate Thompson
Consumer - to be determined

2. Key performance indicators for AYA cancer services

The group recommended a set of key performance indicators (KPIs) was needed to enable evaluation of the impact of new services. KPIs and measures [*the group's suggestions are in italics*] should be defined for:

- **Clinical trial participation**
 - *increased number of available trials, and increased enrolment of AYA cancer patients*
- **Use of national minimum dataset**
- **Mapping of patient journey**
 - *assessment at multidisciplinary team meetings (treatment and psychosocial)*
 - *referrals from primary care*
 - *patients entered into late effects follow up programs*
- **Outcomes**, including recurrence/survival, psychosocial, education and career outcomes
- **Outcomes for patient's family members/partner** eg financial, psychosocial
- **Research** (non clinical trial)
 - *activity*
 - *outcomes eg psychosocial, fertility, biology/translational*
- **Shared care networks**
 - *compliance with agreed standards*
- **Education, training and credentialing**
 - *Availability, participation in and efficacy of training program*
- **Engagement of private AYA cancer professionals**
 - *Patients who are at private facility who have their care discussed at tumour-specific MDT?*
- **Patient satisfaction and involvement**
 - *How many patients have a treatment plan? (Noting that existence of plan does not mean patient has been consulted or informed.)*
- **Late effects management**
 - *How many patients have late effects plans or end of treatment guidelines?*

3. Guidelines for implementation of AYA cancer services

The group recommended national guidelines are needed to assist states and territories in implementing the National Service Delivery Framework (NSDF).

The group recommended that the national AYA Cancer Interest Group review the NSDF and provide guidance to states and territories about **minimum requirements of an AYA cancer service, as well as elements that are strongly recommended.**

The group also recommended the development of **benchmarks and ratios** (eg number of AYA patients a social worker could support) to help determine the number and specialties of staff needed for AYA cancer services. The group noted this could not be prescriptive because of influencing factors such as distance and types of cancers.

NEXT ACTIONS

- An interim steering committee was formed and will meet in December to formulate the national program of work for the COSA AYA Cancer Interest Group.
- COSA will support the interim steering committee by funding teleconferences and initial scoping work. COSA will seek funding from CanTeen to employ a project officer to support the ongoing work of the Interest Group in developing care standards, benchmarks, clinical guidelines and performance indicators and other activities to improve services for adolescent and young adult cancer patients.
- A COSA working group has been formed to develop national guidelines for implementation of AYA cancer services. Workshop participants and other stakeholders will be invited to comment on the draft National Service Development Framework via the COSA website. All comments will be reviewed and collated by Dr Marianne Phillips, with the assistance of the working group members and COSA's AYA cancer project officer, then submitted to the AYA Cancer Interest Group. Draft guidelines are to be disseminated for comment by the end of February 2009.

Working group members (and focus topic):

Dr Wayne Nicholls (clinical trials)

Dr Tracey O'Brien (national structure)

Professor Ross Pinkerton (networking)

Ms Emma Sayers (non-government organisations)

Associate Professor David Thomas (guideline development)

Ms Elizabeth Tracey (epidemiology)

- COSA will provide monthly email updates on the progress of the interim steering committee, then the AYA Cancer Interest Group, to all workshop participants and other interested stakeholders.

APPENDIX 1: LIST OF ATTENDEES

Name	Discipline	State
Jim Bishop	CEO, Cancer Institute	NSW
Alison Baker	Nursing Unit Manager	NSW
Lynnell Bassett	Speech Pathologist	QLD
Sharon Bowering	Cancer Care Coordinator	SA
Ken Bradstock	Haematologist	NSW
Catherine Bullivant	NSWOG Secretariat, Cancer Institute	NSW
Rhonda Coleman	Radiation Oncologist	WA
Maeve Downes	Nursing Unit Manager	WA
Peter Downie	ANZCHOG Chair, Medical Oncologist	VIC
Jodie Enderby	Paediatric Oncology Social Worker	NSW
Jodie Fleming	Paediatric Oncology Psychologist	NSW
Spiri Galetakis	Acting Manager, Integrated Cancer Services, Department of Human Services	VIC
Davinda Gill	Haematologist	QLD
David Goldstein	Medical Oncologist	NSW
Tina Griffiths	Clinical Nurse Consultant	VIC
Susan Hanson	National Manager Centre for Gynaecological Cancers/Consumer Support, Cancer Australia	ACT
Michael Hopkins	Social Worker, AYA	NSW
Melissa Jessop	Medical Oncologist	QLD
Kirstin Linke	Cancer Care Coordinator	SA
Margaret McJannett	Executive Officer, COSA	NSW
Fiona McGuire	Registered Nurse	NSW
Kate Melvin	Social Worker	SA
Fiona Menzies	Executive Officer, ANZCHOG	VIC
Kelly Mock	Medical Oncologist	NSW
Wayne Nicholls	Medical Oncologist	QLD
Tracy O'Brien	Paediatric Haematologist/Oncologist	NSW
Lisa Orme	Haematologist Oncologist	VIC
Susan Palmer	Psychologist	VIC
Marianne Phillips	Paediatric Medical Oncologist	WA
Ross Pinkerton	Paediatric Medical Oncologist	QLD

Name	Discipline	State
Megan Plaster	Clinical Nurse Consultant, AYA	WA
Petra Ritchie	Medical Oncologist	SA
Emma Sayers	Project Officer, RedKite Foundation	NSW
Anne Senner	Clinical Nurse Consultant AYA	NSW
Helen Stanley	Advocacy Manager, CanTeen	ACT
David Thomas	Medical Oncologist	VIC
Emily Thomas	Clinical Psychologist	NSW
Aaron Thompson	Clinical Nurse Consultant	QLD
Kate Thompson	Manager/Social Worker, onTrac@PeterMac	VIC
Elizabeth Tracey	Epidemiologist, NSW Cancer Institute	NSW
Clare Wakefield	Psychologist	NSW
Amy Walker	Nursing Unit Manager	NSW
Jane Williamson	Program Manager, Paediatric Integrated Cancer Services	VIC
Andrew Young	CEO, CanTeen	NSW