



**Clinical
Oncological
Society of
Australia**

Adolescent and Young Adult (AYA) Cancer Workshop

**Wednesday 18 November 2009
Gold Coast Convention and Exhibition Centre
Broadbeach, Queensland**

COSA Adolescent and Young Adult (AYA) Cancer Workshop

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Background

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.

Over the past two years the Clinical Oncological Society of Australia (COSA) has been working with CanTeen and Cancer Australia in a national collaborative effort to improve outcomes for AYAs with cancer. COSA has convened two previous workshops – in May 2007 and November 2008 – to explore issues and challenges and develop strategies to improve the management and care of AYA cancer patients. In December 2008 COSA established a national AYA Cancer Steering Committee, chaired by Associate Professor David Thomas, to guide and help coordinate this activity.

Following the 2007 workshop initiated by COSA and CanTeen, Cancer Australia formed an AYA Reference Group in May 2007 and, with input from COSA and Canteen developed the [National Service Development Framework for Adolescents and Young Adults with Cancer](#). The Framework, published in February 2009, sets out quality standards for delivery of cancer care to AYAs.

In 2008 the Australian Government committed \$15 million funding for the Youth Cancer Networks Program to develop services for adolescents and young adults with cancer. Funding is allocated for five jurisdictional projects (\$12 million) and for national projects and evaluation (\$3 million). It will be administered by CanTeen in the period from November 2009 to June 2011.

COSA convened this workshop to bring together the key stakeholders in the Youth Cancer Networks Program (YCNP):

- to be updated about the YCNP by CanTeen
- to learn more about other projects funded by the program and
- to identify opportunities for national collaboration and/or coordination to support the jurisdictional projects and enhance AYA cancer services across Australia.

As well as the YCNP jurisdictional and national project leaders, invited participants included members of COSA's AYA Cancer Steering Committee and representatives of CanTeen, Cancer Australia, the Australian Government Department of Health and Ageing and relevant national cooperative clinical trials groups.

This summary report of the workshop was written by Lisa-Maree Herron for COSA.

The Youth Cancer Networks Program

Dr Andrew Young, CEO of CanTeen, outlined the background to and development of the Youth Cancer Networks Program, funded by the Australian Government. He explained:

- CanTeen's vision for systems change and ideals
- the structure and governance of CanTeen's AYA Fund (see Appendix 2)
- current status and next steps in implementation of the program.

Dr Young advised that all project definitions had been finalised and implementation was about to commence. Projects are to be completed by 30 June 2011. While there is no commitment to funding beyond that date, CanTeen and its corporate partners, particularly The Sony Foundation, aim to raise a further \$15 million to continue jurisdictional projects and some of the national projects.

Milestones

Nov 2009	Execute project agreements, commence funding Re-submit NSW/ACT proposal (to be confirmed)
Early 2010	Program launch/announcements (to be confirmed)
Early 2010	Complete tender process for Evaluation and Web portal projects
Late 2011	Complete Commonwealth <i>Youth Cancer Networks Program</i> and evaluation
2010-2014	Raise co-contribution funds in partnership with corporate supporters

YCNP projects

Jurisdiction projects

The YCNP allocates \$12 million to jurisdiction projects focused on developing and/or enhancing services for AYAs with cancer. Funding is to be allocated on a proportionate basis for five state/territory projects.

Dr Young said overall, the *ideal* outcomes for jurisdiction projects include:

- Strong contributions to the **six key elements of the National Service Delivery Framework (NSDF)**:
 - Increase access to AYA (psychosocial) support services.
 - Increase access to and enrolment in relevant clinical trials.
 - Access to care navigation throughout the cancer journey which will involve AYAs in decision making about treatment and support options.
 - Provide the opportunity for every AYA to be assessed at diagnosis by medical and psychosocial clinicians skilled in AYA care.
 - Ensure expertise in the management of AYA cancers through expert clinical MDTs skilled in AYA cancer – with adult and paediatric participation.
 - Include age appropriate facilities to treat and support 15-25 year-olds preferably incorporating the needs of inpatients and outpatients.
- **Sustainable** services/outcomes.
- **Adult and paediatric** collaboration; **specialist AYA support**.
- A single **statewide service** – in terms of governance and integration.

The information about key elements of the jurisdictional projects below is based on Dr Young's presentation and includes supplementary details provided by project leaders/representatives attending the workshop:

Western Australia	Rhonda Coleman (via teleconference)
Victoria	Adam Chapman
Queensland	Dr Wayne Nicholls
South Australia	Tracey Doherty / Dr Chris Karapetis

Western Australia

(10% of Australian population)

- Construction of a \$3m outpatient AYA facility as an integral part of the new comprehensive cancer centre at the Sir Charles Gairdner Hospital
- Dedicated **outpatient AYA Centre** including recreation room, meeting, counselling, consult/exam room, day ward and radiation treatment areas; base for psychosocial support team; close proximity to Solaris Care
- Project to be completed by end of calendar year 2011 (approximately)
- Jurisdiction commitment to **ongoing service delivery**: current staff include Youth Worker and Cancer Nurse Coordinator; aim to have a lead clinician for AYA cancers (depending on budget); YCNP funding contribution goes to capital
- Will add to the existing network-wide services, Johanna Sewell Adolescent Oncology Unit at Princess Margaret Hospital.

Queensland

(20% of Australian population)

- Project will (continue to) establish linked services based on three lead sites: Princess Alexandra Hospital, Royal Brisbane Hospital and Queensland Children's Cancer Centre
- Comprehensive **AYA support** team including care coordinator/s, social workers, psychologists, education/career support and leisure: some positions are in place; some are to be supported by YCNP funding; some will be funded by Queensland government
- Significant funding commitment to **clinical trial** support including employment of clinical research assistants
- **Refurbishment** of AYA wards at Princess Alexandra Hospital
- Projects focused on fertility preservation, transition care, outreach (given more than 30% of patients are treated outside Brisbane), private sector integration/partnerships, shared care protocols and evaluation
- Continuing **AYA MDTs** including adult and paediatric input to plan treatment and psychosocial support
- Jurisdiction commitment to all **ongoing service delivery** – some roles in partnership with CanTeen for 4 years, Queensland government beyond that.*

* Subject to evaluation outcomes and normal budget processes

South Australia and Northern Territory

(9% of Australian population)

- Project focuses on AYA services across two lead sites – Royal Adelaide Hospital and the Women's and Children's Hospital – with a single virtual AYA service working across multiple settings
- **AYA support** includes care coordinator/s, social workers, psychologists, educational support and exercise physiologist; developing a 'roving' psychosocial support service
- AYA **clinical leads**, Fellow, support for clinical MDTs
- **Clinical pathways and directory of services**; mobile communications **projects**
- **AYA refurbishment** at **Royal Adelaide Hospital**
- Development of **AYA facilities** at the **Women's and Children's Hospital** (with CanTeen support) including space for clinical trials support staff
- Jurisdiction commitment to all **ongoing service delivery** – some roles in partnership with CanTeen for 2 years, SA/NT government support beyond that*
- Jurisdiction commitment to **AYA space/s in future 'Royal Adelaide Hospital'**.

* Subject to evaluation outcomes and normal budget processes

Victoria and Tasmania

(27% of Australian population)

- Project proposal builds on Victoria's existing and ongoing commitment to improving AYA cancer outcomes via Victorian Adolescent Cancer Program (onTrac@Peter Mac: treatment, educational, social, psychology and more)
- Will support project officers within Integrated Cancer Services and in Tasmania to enable **development of statewide model** with focus on:
 - **Pathways and models of care** (increasing access to MDTs)
 - Increasing participation in **clinical trials**
 - Building the **workforce** to support these objectives
 - **Refurbishment** of AYA wards and facilities at Peter Mac.
- Project also includes a contribution to **evaluation** and support for an **ICT project**
- Jurisdiction commitment, in addition to ongoing commitment to onTrac program, is including **AYA-specific areas in the future Parkville**.

NSW/ACT

(34% of Australian population)

- Project proposal is not yet finalised or approved.

Dr Young advised he is "still hopeful and confident that we will be able to do that some time in the future".

National projects

The YCNP allocates \$3 million funding for national projects, evaluation and administration. National projects were identified by CanTeen (based on the recommendations of the NSDF) in consultation with COSA, Cancer Australia and the Commonwealth Department of Health and Ageing.

Overall, the national projects aim to:

- create a national service
- share (economies of scale and expertise) where appropriate
- fill gaps identified in the NSDF.

Project	Description	Lead agency
AYA Cancer Network	Establishment of a national network of health professionals providing care and support to AYAs with cancer.	COSA
Guidelines and protocols	Development and promotion of online evidence-based guidance on particular issues related to the care of AYA cancer patients.	COSA (+ CINSW)
Research/trials	Clinical research: increase participation in clinical trials and support/establish more trials for AYAs with cancer.	COSA
Professional education	AYA specific health education for professionals working with AYAs with cancer – accredited (postgraduate certificate) course and free-access version (EdCan). Course development + 20 scholarships.	The Centre for Adolescent Health/ University of Melbourne
Minimum dataset	Development of a dataset specification for AYAs with cancer to facilitate monitoring of diagnosis, stage, intervention and late effects, pilot test and implement an agreed dataset specification in at least two sites.	Cancer Australia
Web portal	Development of an AYA cancer services portal linking information about medical services (AYA lead sites/services), support (NGOs etc) and other issues and services for AYAs, families and clinicians.	Tender
Needs assessment	Development of a psychosocial needs assessment tool and manual specific to AYAs with cancer.	CanTeen
(Evaluation)	Evaluate the implementation of jurisdiction and national projects, to monitor and evaluate interim outcomes of the Youth Cancer Network Program	Tender

National projects: AYA cancer network, clinical practice guidelines and protocols and clinical research

COSA has been contracted to manage implementation of three separate but related national YCNP projects, which will draw on the expertise of its AYA Cancer Steering Committee and broader multidisciplinary membership to:

- develop a **national AYA cancer network**
- produce and promote **AYA cancer guidelines and protocols** (with the Cancer Institute NSW)
- increase **AYA cancer clinical research** and participation of AYAs with cancer in clinical trials.

The **national AYA Cancer Network** will link the individuals and organisations across Australia working to improve outcomes for AYAs with cancer. Associate Professor David Thomas noted that this workshop effectively initiated that project, bringing together key people who will be leading delivery of the YCNP projects.

COSA will develop communications strategies to extend the network membership and enable members to exchange information about the YCNP and access resources to assist them in improving AYA cancer care and support.

AYA cancer guidelines and protocols

COSA AYA Cancer Steering Committee member and project leader **Dr Marianne Phillips** briefly outlined this national project.

The aim is to develop evidence-based guidelines and protocols to optimise diagnosis, referral, treatment and psychosocial care of AYA cancer patients. It will produce online, succinct, evidence-based guidance on management and care of AYAs with cancer, with a focus on priority needs and reducing variations in practice.

Multidisciplinary expert working groups will be formed to identify priorities and inform development of the guidelines (using a Wiki platform) and treatment protocols (by the Cancer Institute NSW, as part of its eviQ website). There will be targeted promotion of availability of the new guidelines and treatment protocols via multiple mechanisms and channels.

By 30 June 2011 the project will deliver:

- best practice guidelines for at least three priority issues published online
- an AYA-specific menu on the eviQ website and up to 40 protocols for treatment and/or supportive care of AYAs with cancer
- widespread promotion of guidelines and protocols to health professionals providing care and support to AYA cancer patients.

Four workshop attendees were invited to share their experience to inform discussion about approaches to, and key considerations in, developing guidelines and protocols for management of AYA cancers:

- Emeritus Professor Tom Reeve, Senior Medical Adviser, Australian Cancer Network provided advice based on 15 years leading development of clinical guidelines for management of many different cancer types and issues.

- Associate Professor Matthew Links, St George Cancer Centre, demonstrated the use of Wiki software in developing [Cancer Solutions](#), an e-learning and resource-sharing system for cancer centre staff.
- Sue Sinclair, Director of Cancer Services and Education, Cancer Institute NSW demonstrated the [eviQ website](#), a repository of cancer treatment protocols and resources.
- Shoni Colquist from Queensland's Cancer Control and Analysis Team presented Queensland Oncology Online (QOOL), a web-based tool to support clinical decision-making, multidisciplinary care and research.

Key points from these brief presentations and recommendations from discussion have been provided to Dr Phillips for the consideration of the working group that will guide development of this project, when it is formed.

Clinical research

Dr Wayne Nicholls outlined the national project to increase AYA cancer clinical research which he will lead for COSA.

The project has two objectives:

- to promote and facilitate clinical research focussed on the issues particular for adolescents and young adults with cancer and their families
- to increase participation of adolescents and young adults in suitable clinical trials.

The project aims to improve access to and support for clinical trials to address priority AYA cancer/issues in collaboration with the existing national cooperative clinical trials groups. It will complement, support and leverage the clinical research activity of jurisdictions (funded by the YCNP).

By June 30, 2011:

- baseline number of AYA patients on clinical trials will be established
- a registry or database of currently available trials for AYAs will be developed
- AYA participation in clinical trials will increase to 10% of patients with cancers that have the worst outcomes for AYAs.

Research priorities and planned trials

COSA's AYA Cancer Steering Committee convened a meeting of its research subgroup with Chairs/nominees of the most relevant national cooperative clinical trials groups in August 2009 to begin developing strategies for increasing AYA participation in clinical research.

The group recommended the following priority areas for research, based on available data on AYA cancer incidence and 'survival gaps':

- haematological
- brain/central nervous system tumours (low and high grade gliomas and CNS tumours)
- metastatic melanoma
- sarcomas.

There are two trials focussed on AYA cancers that are about to open or are planned:

- **ALL6 Study**

Professor John Seymour, Chair of the ALLG, outlined this proposed national leukaemia study. The trial will investigate whether a paediatric acute lymphoblastic leukaemia (ALL) protocol (based on ANZCHOG Study 8) can be extended to patients aged 15-30 years in adult settings and examine factors that might impair dose delivery. At least 100 patients are needed, expected to be recruited over 3 to 4 years.

Associate Professor Penny Schofield explained a proposed psychosocial sub-study to explore factors affecting treatment compliance. This randomised study would test an intervention to increase patient adherence: nurse contact with patients to identify potential barriers, tailor medication regimes and monitor adherence via a text messaging system.

- **AYA-PK study**

This study will investigate pharmacological and pharmacodynamic activity of chemotherapy in patients with sarcoma and Hodgkin's lymphoma and how it varies as an effect of puberty and gender. The study is being coordinated in Victoria (Associate Professor Thomas is a chief investigator) with participants in Queensland, NSW and WA.

AYA cancer data

At COSA's request Professor Graham Giles, Chair of the Australasian Association of Cancer Registries, has begun investigating the availability of data to establish baselines, including:

- AYA cancer incidence
- where AYAs are treated and how many are treated at each institution
- rate of clinical trial participation of AYA patients
- recent survival data.

Professor Giles presented AYA age-specific incidence rates for selected cancer types for NSW and Victoria. He hopes to have national data by early next year and be able to complete the survival analysis and collate information about where AYA patients are treated by mid 2010.

Key points and recommendations from discussion have been provided to Dr Nicholls for the consideration of the working group that will guide development of this project.

Next steps

- CanTeen will liaise with project leaders to finalise and execute contracts.
- COSA will build the AYA Cancer Network and develop communications strategies and media to link and inform members. The next major workshop of project leaders and other stakeholders is planned for November 2010 in Melbourne.
- COSA will form working groups to progress implementation of the national Guidelines/protocols and Research projects.
- Participants interested in contributing to any of the COSA-led national projects were invited to contact Lisa Herron: lisa.herron@optusnet.com.au

Appendix 1: Workshop participants

Ilana Berger	Team leader	OnTrac @ Peter Mac
Jacqueline Bessa	AYA Fund Executive Officer	CanTeen
Catherine Bullivant	Project Officer, NSW Oncology Groups	CINSW
Professor Phyllis Butow	Chair	Psycho-oncology Cooperative Research Group (PoCoG)
Adam Chapman	Cancer and Palliative Care	Department of Human Services, Victoria
Ms Rhonda Coleman	Project Director, Cancer Redevelopment and Manager, WA Cancer & Palliative Care Network	WA Health
Shoni Colquist	Queensland Cancer Control and Assessment Team	Queensland Health
Dr Luce Dalla Pozza	Head of Oncology	Children's Hospital at Westmead, Sydney
Tracey Doherty	Oncology Nurse Consultant	SA Department of Health
Dr Peter Downie	Chair	Australian and New Zealand Children's Haematology/Oncology Group
Professor Graham Giles	Chair	Australian Association of Cancer Registries
Susan Hanson	Manager, Consumer Support	Cancer Australia
Lisa Herron	AYA Cancer Projects Coordinator	COSA
Ms Meryl Horsell	Manager, Clinical Service Planning	SA Department of Health
Dr Chris Karapetis	Medical Oncologist	South Australia
Professor Ray Lowenthal	Medical Oncologist	Tasmania
Professor Bruce Mann	President	COSA
Marg McJannett	Executive Officer	COSA
Dr Wayne Nicholls	Paediatric Oncologist	Royal Children's Hospital, Brisbane
Dr Lisa Orme	Paediatric Oncologist	Peter MacCallum Cancer Centre
Dr Marianne Phillips	Paediatric and Adolescent Oncologist and Palliative Care Specialist	Princess Margaret Hospital for Children, Perth
Professor Tom Reeve	Senior Medical Adviser	Australian Cancer Network
Tim Rogers	General Manager, National Services	RedKite
Nischal Sahai	Principal Project Officer	Queensland Health
Dr Megan Sanders	Protocol Development Coordinator	Australian Leukaemia and Lymphoma Group
Tony Sansom	Manager, Technical and Ethical Issues, Office of the Chief Health Officer	Tasmanian Department of Health and Human Services
Assoc. Prof. Penny Schofield		Peter MacCallum Cancer Centre
Assoc. Prof. John Seymour	Chair	Australian Leukaemia and Lymphoma Group
Nikki Shipard	Patient representative	NSW

Sue Sinclair	Director, Cancer Services and Education	Cancer Institute NSW
Assoc. Prof. David Thomas	Medical Director	onTrac@PeterMac
Kate Thompson	Manager	onTrac@PeterMac
Danielle Tindle	Project Officer	Queensland Health
Dr Toby Trahair	Paediatric Oncologist	Sydney Children's Hospital
Dr Euan Walpole	Medical Director, Cancer Services	Princess Alexandra Hospital, Brisbane
Denise Walshe		Department of Health and Human Services, Tasmania
Dr Andrew Young	CEO	CanTeen

Appendix 2: CanTeen AYA Fund

The **AYA Fund Program Committee** oversees the AYA Fund from an operational and administrative basis. It will report to the CanTeen Board on progress against key projects and any associated operational, finance or business risk that may arise out of the projects being overseen by the Fund.

The role of the **AYA Advisory Committee** is to ensure that expert views of health professionals and patients are given due consideration in decision making and administration of the AYA Fund. It comprises key stakeholders and experts who will provide advice to the AYA Fund Program Committee.

Members of both committees are listed below.

AYA Fund Program Committee

Name	Role and organisation
Chris Bond	CanTeen Board member and patient representative
Kylie Lewis	CanTeen Board member and patient representative
Geoff Scott	CanTeen Board member and patient representative
Dr Andrew Young	CEO, CanTeen
Dr Louise Messara	CEO, The Sony Foundation
Vivien Sonogo	Director, Camp Quality
Jenni Seton	CEO, RedKite
Professor Bruce Mann	President, Clinical Oncological Society of Australia
Martin Laverty	CEO, Catholic Health Australia (and lawyer)

AYA Advisory Committee

Name	Role and organisation
Associate Professor David Thomas (Chair)	Medical Director, OnTrac@PeterMac, Melbourne
Dr Martin Borg	Radiation Oncologist, Adult and Paediatric, Royal Adelaide Hospital
Dr Ken Bradstock	Adult Haematologist, Westmead Hospital, Sydney
Ms Susan Hanson	Manager Consumer Support, Cancer Australia
Dr Wayne Nicholls	Paediatric Oncologist, Royal Children's Hospital, Brisbane
Dr Marianne Phillips	Senior Paediatric and Adolescent Oncologist and Palliative Care Specialist, Princess Margaret Hospital, Perth
Anne Senner	CNC AYA Cancer Services, Sydney Children's/Prince of Wales/Royal Hospital for Women
Ms Nikki Shipard	Patient representative
Ms Kate Thompson	Social Worker and Manager, OnTrac@PeterMac, Melbourne
Dr Toby Trahair	Paediatric Oncologist, Sydney Children's Hospital