AYA Cancer Workshop 2010

Friday 12 November, 1.30pm to 5.00pm
Melbourne Convention and Exhibition Centre

1 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.

The Youth Cancer Networks Program (YCNP) is a national initiative to improve services and care for AYAs diagnosed with cancer across Australia. The YCNP is funded by the Australian Government and administered by CanTeen as part of its Youth Cancer Fund. Government funding of $15 million has been allocated to five jurisdictional projects ($12 million) and seven national projects, including evaluation ($3 million) between November 2009 and June 2012.

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 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. This workshop is one of the Network activities to enable project partners and other key stakeholders to share information and experiences to support implementation of the YCNP projects and other efforts to improve AYA cancer services and outcomes.

COSA has convened three previous AYA cancer 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, which informed the development of the YCNP; and in November 2009 – after the announcement of the program, to enable project partners to meet and share information about their plans for service development.

Purpose and objectives

The workshop brought together more than 40 participants and key stakeholders in the Youth Cancer Networks Program. An invitation to participate was sent to all project partners (via CanTeen) and to all members of the AYA Cancer Network.

The purpose was to enable project partners and stakeholders to exchange information and ideas about the YCNP jurisdictional and national projects, to identify opportunities for collaboration, national collaboration and/or to prevent duplication in the development of AYA cancer services and programs.

Workshop summary

COSA President Professor Bruce Mann welcomed workshop participants to the 2010 AYA cancer workshop, the fourth convened by COSA since May 2007.

The first session featured brief updates about the YCNP (from CanTeen) and the objectives and progress of each of the five jurisdictional and seven national projects, presented by the project manager or a nominated representative. A précis of each presentation is in section 2. This enabled participants to identify what other project partners are doing well and/or differently and the common issues they are facing.

This was followed by discussion about the common challenges and potential strategies to address them, kindly facilitated by Sue Sinclair (General Manager of the National Breast and Ovarian Cancer Centre and former Director of Cancer Services and Education, Cancer Institute NSW).

Participants highlighted several opportunities for collaboration and/or national coordination and recommended strategies to:

- improve inter-project communication and knowledge sharing
- increase awareness of YCNP initiatives, via national and state/territory program launches
- ensure program branding is effective and integrated in cancer services
- more effectively engage Adult Oncologists
- coordinate advocacy and strategies to secure sustainability of new services and programs
- share referral pathways and learnings about models
- implement the AYA cancer minimum data set
- ‘grow the network’ – to reduce the current heavy burden on a few key players
- manage opportunities to build on the work to date.

These issues are further detailed in section 3.

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

2 Summary of presentations

Youth Cancer Fund

Natalie Roney, Executive Officer, Youth Cancer Fund, CanTeen

CanTeen has established the Youth Cancer Fund, to establish youth cancer centres with essential support services across state/territory regions.

The fund will total $50 million, comprising:
- federal government Youth Cancer Networks Program funding: $15m (3 years to June 2012) – administered by CanTeen
- State government commitments to service delivery costs: $20m in first 5 years
- CanTeen and Sony Foundation fundraising commitment: $15m

Program progress
- The final contract was executed in July 2010; all projects are now in implementation.
- Business Plan developed and submitted to the Department of Health and Ageing in August 2010; has been accepted.
- Siggins Miller has been selected as the national evaluation partner and is developing an evaluation framework (due 1 December 2010).
- National launch of YCNP is being planned.

Next steps
- CanTeen is starting discussions with all project partners now, over the next 12 months, regarding continuation or further development of projects after this funding round ends.
- Through its partnership with Sony Foundation, CanTeen aims to raise another $15 million to continue service development and delivery.
- A ‘Youth Cancer’ brand is in development, with the aim to build public awareness, improve referral and ‘cut through’ to target audience.

Jurisdictional projects

Queensland

Danielle Tindle, Senior Project Officer, Adolescent and Young Adult Cancer Services, Queensland Health

The Queensland jurisdictional project involves:
- service delivery: developing support services at lead tertiary sites ($2 million)
- capital works: development/refurbishment of AYA oncology centre at Princess Alexandra Hospital with age-appropriate facilities ($300,000).

The **aims of service development** are to:
- develop a statewide model of specialised cancer care for AYA
- improve collaboration between adult and paediatric services
- increase research and access to clinical trials (priorities aligned with the national clinical research project)
- improve referral pathways and decisions (and the transition process from children’s to adult centres)
- ensure there are integrated age-appropriate support services (within and between care settings)
- provide AYA education and training to health professionals throughout Queensland.

Service delivery plan includes:

- providing access to AYA multidisciplinary team meetings, for treatment planning and referral to psychosocial support services
- improving AYA access to and participation in clinical trials – through employment of Clinical Research Associates at each site
- specific projects:
  - Outreach integration / regional services – how to balance providing care as close to home as possible with access to specialist AYA expertise
  - Private health care issues (given nearly 50% of AYA patients in Queensland currently use private services)
  - Fertility preservation
  - Transitional care
  - Education
  - Evaluation.

Integrated AYA Cancer Services Model
New positions created or in development across the three lead sites include:

Royal Children's Hospital AYA Cancer Service
AYA social worker
AYA education/careers advisor (across three sites – PAH, RBWH, RCH)
AYA clinical research associate
Transition care coordinator
Project officers – Private sector, Outreach integration, Fertility preservation

Royal Brisbane and Women's Hospital AYA Cancer Service
AYA psychologist (provides services to RCH and RBWH)
AYA social worker
AYA leisure therapist
AYA care coordinator
AYA clinical research associate

Princess Alexandra Hospital AYA Cancer Service
AYA oncologist (also works with RCH)
AYA care coordinator
AYA leisure therapist
AYA social worker
AYA clinical research associate

What has been successful?

- A 'paradigm shift' in the governance of the statewide service in the past year with the creation of the **Cancer Control Team – AYA Steering Committee**. The project has evolved from being a paediatric-driven initiative to having shared paediatric/adult ownership and responsibility, aimed at ensuring sustainability and outcomes long term. The RBWH and PAH have set up **AYA Steering Committees** to oversee the development of the AYA service teams within their hospitals, develop models of care, referral process, and ensure that linkages exist between the three sites, especially regarding the shared positions. The statewide **AYA Advisory Group** acts as an information sharing forum with multidisciplinary membership from paediatric and adult cancer services, NGOs and consumer advocate representation.
- Involvement of AYA support team member in tumour-specific multidisciplinary team meetings at Princess Alexandra Hospital has worked well – engages adult and paediatric medical and surgical specialists and is a forum to share ideas.
- AYA Care Coordinators – who lead the AYA psychosocial MDT and are champions of the AYA services.
- Projects – A model of care for the regional centres and private sector has been drafted.
- Education – Queensland AYA cancer conference in October 2010 provided education for staff especially in regional centres and an opportunity to engage staff in private hospitals

- Research – increasing recruitment of AYAs to clinical trials will be helped by employment of Clinical Research Associates.

Challenges
- Low number of AYA cancer patients and geographical spread.
- Significant private practice in Queensland.
- Dearth of specialised AYA practitioners.
- Delays in recruitment, pending funding being made available.
- Delays in starting capital works – contingent on larger oncology build at the PA Hospital.
- Communication and collaboration – between adult and paediatric centres, metro and regional centres, and public and private hospitals.

NSW/ACT

Elena Manning, Manager, Cancer Services Performance, Cancer Institute NSW

The NSW/ACT AYA cancer project is focused on six key streams:

1. Collaboration
Clinical fellowships, development of protocols and guidelines.

2. Coordination and support
Establishing a network of Cancer Care Coordinators.

3. Research
Clinical trials enhancement project to identify strategies to increase AYAs' participation in clinical trials.

4. Infrastructure and access
Development of referral pathways and a facility at South Eastern Sydney and Illawarra Area Health Service.

5. Psychosocial support
Working with stakeholders to promote validated distress tool for AYAs.

6. Communication and dissemination
Raising awareness of existing services and resources across health services and the two jurisdictions.

Project progress
All project milestones have been met to date, despite the delay in recruiting a Project Officer (started on 1 November 2010) and the fact that NSW is currently undergoing a major health services restructure as part of the national health reform agenda.

Achievements
- AYA Clinical Enhancement Project established and in the process of appointing a consultant
- Funded two Clinical Fellowships, to provide oncology specialists the opportunity to develop expertise in treatment of AYAs with cancer. A second round (two more fellowships) is closing in December.
- Currently recruiting dedicated AYA staff at several sites, to coordinate MDT meetings, enhance clinical trial capacity and ensure optimal patient care (at Prince of Wales and Sydney Children's Hospitals, John Hunter Children's Hospital, Calvary Mater Hospital, Children's Hospital Westmead, Royal Prince Alfred Hospital and The Canberra Hospital).

Challenges/next steps

- Engaging key stakeholders in Area Health Services/Local Health Networks, given delay in project implementation. There has been a great level of commitment from key clinicians but that needs to be expanded.
- Establish Project Reference Group and working groups.
- Develop communication and education strategies.
- Develop clinical guidelines and referral pathways.
- Establish Cancer Care Coordinator Network.

Victoria/Tasmania

Louise Devereux, Project Manager, Victorian and Tasmanian Youth Cancer Project

The Victoria/Tasmania project aims to improve outcomes for AYAs with cancer through:

- development of a sustainable model of care throughout Victoria and Tasmania
- improved access to clinical trials
- building the capacity of health professionals to meet the needs of AYAs through education and training
- increased engagement of young people through the development of appropriate ambulatory care facilities.

Project funding is $3.2 million over two years, including $230,000 for capital works. The project began in April 2010.

The lead site is OnTrac@PeterMac, as the biggest provider of AYA cancer care in Victoria. The project aims to complement and further develop the services that onTrac currently provides.

Project progress

- Completed scoping study to determine the number of patients, their diagnoses, and where located (by Integrated Cancer Service).
- Working with Integrated Cancer Services to recruit Project Officers – most ready to start in January 2011.
  Their role is to:
  - understand what is happening now – where patients are being diagnosed, referral pathways, current services and gaps
  - assist in identifying medical leads in the adult service sector (in about 15 hospitals across Victoria and Tasmania that are providing complete care for AYAs with cancer)
  - identify new patients early
  - undertake initial screening and present to a central psychosocial MDT, lead by onTrac staff via Webex – to assess clinical trial suitability and develop a psychosocial care plan
  - help implement the psychosocial support plan with the primary treating team
  - advocate for the needs of AYAs within participating hospitals
  - collect evaluation data
  - coordinate local professional development activities.
- Supporting clinical trials
  - contributed to startup funding for ALL6 trial, opening in multiple sites across Australia and internationally
  - collaborating with COSA trying to establish baseline for CT participation rates
  - promoting real time access to clinical trial information via Victorian Cancer Trials – AYA search option added
  - developing a screening tool to document reasons for non-participation in trials.
- Developing education and training
  - conducted needs assessment of education and training needs
  - acknowledging that AYA cancer care is a relatively small component of the work of most health professionals in the adult sector (and thus training needs to be

    useful and timely), investigating potential to contribute consistent AYA information and resources as an ‘add on’ to multiple postgraduate courses
    - investigating potential for fellowship/clinical placement models.
- Established a Consumer Advisory Group.

Challenges

- Small number of AYA patients spread across multiple hospitals and tumour streams.
- Some difficulty with engaging medical oncologists (as AYA patients are considered a relatively small component of their work).
- Understanding national v state-based project activities – as there is a lot of activity, quite a bit of crossover, and uncertainty about how national projects impact on work at state level.

Louise also highlighted several potential issues for discussion, including:

- how to determine and respond to different levels of patient need for psychosocial support
- the best model for supporting families, and ways of ensuring that service models meet the needs of individual AYA patients but also of their families
- ensuring the sustainability of improvements made beyond the life of the projects.

South Australia and Northern Territory

Dr Michael Osborn, Chair, SA/NT AYA Cancer Clinicians Advisory Committee

There are about 40-50 new AYA (15 to 25 year old) cancer patients in SA each year, historically spread across the Royal Adelaide, Women’s and Children’s and other tertiary and private hospitals.

Given this small number of patients, spread across paediatric and adult hospitals, the SA/NT project is developing a mobile AYA cancer service – taking a team of professionals to patients in multiple settings, rather than referring patients to a single service.

The SA/NT project also includes development of clinical leads, referral pathways, support for multidisciplinary teams, increasing research participation and establishing AYA inpatient rooms at the RAH.

AYA Cancer Service model

The team – expected to be rolled out in first quarter of 2011 – will comprise:

• Lead Clinician	0.8 FTE
• Project Manager / Allied Health Lead	1.0 FTE
• Nurse Specialist	0.5 FTE
• Psychologist	0.6 FTE
• Social Worker	2 x 0.5 FTE
• Exercise Physiologist	0.5 FTE
• Educational / Occupational Officer	0.6 FTE
• Data Manager / Admin Support	1.0 FTE
• Clinical Fellow or an Advanced trainee (from 2012)	

The service will be based at the Royal Adelaide Hospital but travel to other hospitals. The lead clinician will report to both the head of adult medical oncology services and head of paediatric oncology.

The aim is for all AYA patients in SA and NT to have access to AYA services but also still have access to an appropriate disease-specific expert clinician. The team aims to facilitate choices and flexibility for patients while also avoiding potential turf wars between services.

There are two **pathways into the service**:

1. Following initial referral to Medical Oncology or Haematology, consultant has the option to:

- continue responsibility of care with support of AYA team
- offer responsibility of care to AYA lead clinician.

2. If there is a direct referral to AYA Cancer Service, AYA Lead Clinician has option to:
- continue responsibility of care
- offer responsibility of care to identified disease expert.

The **service model** involves:
- developing a central referral pathway to minimise delays
- a medical MDT discussion for all patients
- psychosocial assessment for all patients
- psychosocial MDT discussion for all patients
- active dialogue/engagement with clinicians
- care navigation e.g. supporting patients in transition to adult services.

The service also aims to **foster resilience and prepare for survivorship** by:
- providing age/stage-appropriate social work, psychology and exercise rehabilitation services to help maintain physical fitness and psychosocial health and maintain links to school/university/work and facilitate return
- facilitating peer support
- optimising fertility preservation – through links with local reproductive medicine unit
- establishing a survivorship/late effects clinic.

Progress
- AYA inpatient rooms at the Royal Adelaide Hospital are opening in January 2011
- AYA Cancer Service is in development:
    - funding is finalised
    - SA/NT AYA Cancer Service Steering Committee has been meeting monthly
    - AYA Specialist nurse and 0.5FTE Social Worker already employed
    - other position descriptions developed, ready for recruitment
    - presentation/feedback sessions with all SA haematology and oncology services and promoting through medical media
    - already running weekly psychosocial MDT meetings (mainly at the WCH) and started the exercise rehabilitation program.
- Identified gaps in clinical trials and studying patterns of clinical trial participation (with aim of maximising opportunities for patients to join appropriate trials).

Next steps
- Finalise referral pathways and details of service delivery.
- Recruitment and roll-out.

Western Australia

Natalie Roney presented slides provided by

Rhonda Coleman, Project Director, Cancer Redevelopment and Acting Director of WA Cancer and Palliative Care Network

The WA project involves construction of a $3 million outpatient AYA facility as an integral part of the new WA Comprehensive Cancer Centre in Perth.

Milestones achieved
- Contractor for construction of AYA facility appointed – March 2010.
- Contractor on site and construction commenced – April 2010.
- Facility due to be completed in April 2012 including AYA spaces.
- Commonwealth funding fully expended.
- Contract being drafted by CanTeen ready for their payments to this capital works project.

Other AYA activities [funded by WA Health]

- Meg Plaster continues to give excellent care as the Cancer Nurse Coordinator for the state for this cohort of patients
- The clinical service plan for North Metropolitan Health has been completed. Implementation will take approximately 3 to 5 years as resources become available.
- Focus group meetings were held with consumers to identify and plan for their needs.
- Based on this feedback a youth worker is going to be employed in the new year.
- The WA Cancer & Palliative Care Network is looking at educational opportunities for health professionals that will upskill staff about AYA-specific needs.

National projects

Education and professional development

Andrea Krelle, Manager Practice & Learning, Centre for Adolescent Health (Project Manager)

The education and professional development project is managed by a partnership between onTrac@PeterMac and the Centre for Adolescent Health.

The project outputs are:

- a Graduate Certificate in AYA oncology
- a learning module for Cancer Australia's e-learning platform.

Project progress

- Established a National Curriculum Advisory Committee – comprising 22 members, multidisciplinary and broad geographic representation and a 'stunning' level of commitment and collaboration.
- Completed development of the Graduate Certificate/Diploma/Masters in Adolescent Health and Welfare oncology stream:
    - Program delivered by the University of Melbourne's Department of Paediatrics, within the School of Medicine
    - Oncology stream builds on the existing Adolescent Health and Welfare program
    - Four core subjects:
      – Young People in Context
      – Professional Practice in Context
      – Mental Health & Young People
      – Cancer Care in Young People
      (Exit point for Graduate Certificate)
    - Program is delivered by distance education – entirely online learning – and is necessarily part-time (core subjects are not repeated).

Key steps in the course development process:

- Formation of Project Management Team (November 2009) and National Curriculum Advisory Committee. First curriculum workshop with NCAC in April 2010 to confirm scope of course.
- University of Melbourne Academic Board approved course.
- First round promotion for course and scholarships.
- Second Curriculum Workshop with NCAC – November 2010.
- Applications for course and scholarships processed.
- Course framework and content developed in consultation with NCAC.
- Resources developed in consultation with young people.
- Course commences with first oncology cohort in 2011.
- Third Curriculum Workshop with NCAC – March 2011.

CanTeen scholarships
The project funding included an allocation for 20 scholarships for 2011, worth $5000 (course fee is $6,512). A subcommittee of the project management team will select the recipients, based on merit and equity.

Sustainability
The postgraduate program is the result of a major investment, and is expected to be a significant contribution to workforce development in this field. In order to ensure sustainability, the project team is working towards/advocating for:

- scholarships to support local enrolments
- the course to be dynamic, delivering:
    - evidence-base practice
    - up-to-date research
    - current debates and discourse
    - international perspectives.

Future plans include:

- developing the course in response to feedback from participants
- seeking recognition for professional accreditation
- opening the program to international students.

Psychosocial assessment tools and manual

Dr Susan Palmer, Psychologist (Project Manager)

This project, managed by CanTeen, has resulted in development of a psychosocial assessment tool and manual specific to the needs of AYAs with cancer.

The development process involved an extensive scoping exercise and literature review, clinical and patient focus groups and interviews, and consultation with clinical and patient working parties.

Project outcomes

A three step process has been developed to assess and respond to the psychosocial needs of AYAs diagnosed with cancer:

1. Screening tool – to:

- identify current distress
- identify current needs
- provide information
- build rapport
- highlight ongoing involvement
- act on immediate need

The screening tool uses a distress thermometer measure, based on the measure that is used quite widely but with additional AYA-relevant sections (based on patients' recommendations) e.g. fitness and sporting ability, general appearance, sexual concerns (libido, pain when having sex) and information provision/communication (understanding information, feeling listened to and respected by the treating team).

The tool is accompanied by a manual that includes recommendations about interpreting and acting on the information – based on data from research with adults using the distress thermometer.

2. Develop care plan – to:

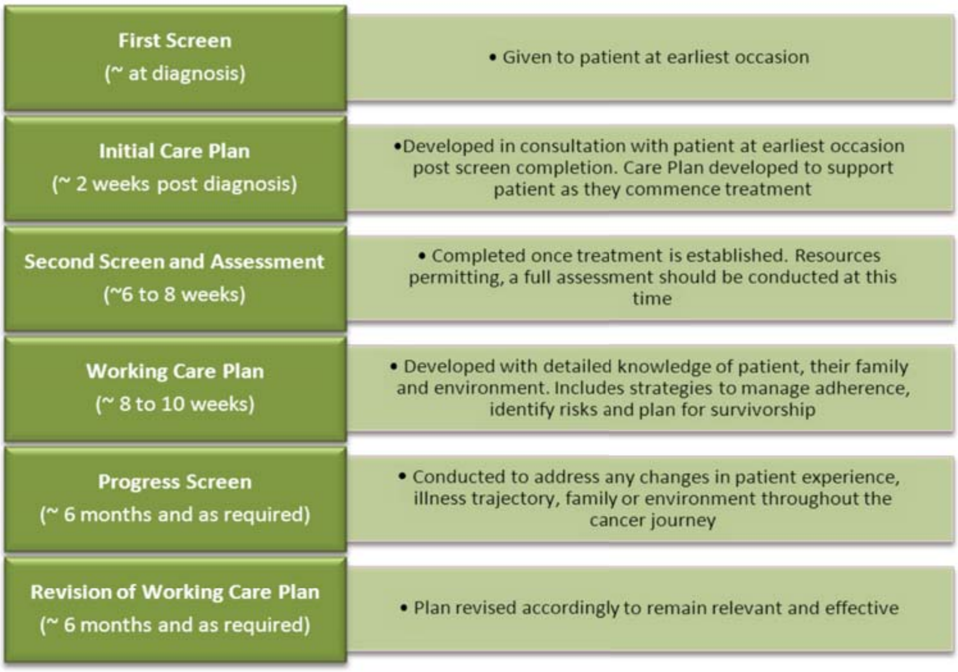
- act on current need
- dstablish rapport

- identify referrals
- create document for circulation
- empower the AYA patient.

In developing the care plan, the clinician identifies what need to be addressed, assigning a rating (**L**ow concern, **M**edium concern, **H**igh concern or **UR** – urgent response required) and intervention code (assessment, referral, information provision, risk assessment or standard team management). The process is quick and easy. But using a standard measure and recording this information enables data collection for future research.

3. Assessment measure (based on HEADSS assessment with AYA-specific additions) – to:
- revise and refine the Care Plan
- develop in-depth understanding of patient
- understand risk factors and protective factors
- promote healthy survivorship.

Care process/timelines



First Screen (~ at diagnosis)	• Given to patient at earliest occasion
Initial Care Plan (~ 2 weeks post diagnosis)	•Developed in consultation with patient at earliest occasion post screen completion. Care Plan developed to support patient as they commence treatment
Second Screen and Assessment (~6 to 8 weeks)	• Completed once treatment is established. Resources permitting, a full assessment should be conducted at this time
Working Care Plan (~ 8 to 10 weeks)	• Developed with detailed knowledge of patient, their family and environment. Includes strategies to manage adherence, identify risks and plan for survivorship
Progress Screen (~ 6 months and as required)	• Conducted to address any changes in patient experience, illness trajectory, family or environment throughout the cancer journey
Revision of Working Care Plan (~ 6 months and as required)	• Plan revised accordingly to remain relevant and effective

Next steps
- Aim to deliver training in using the tool and manual in mid-2011.
- Dissemination to AYA cancer centres.

Web portal

Francesca Pinzone, Manager, Services and Policy Team, CanTeen

Youth Cancer Search (www.youthcancersearch.com.au) is an online service directory for AYAs with cancer and their families. It is searchable by:
- the type of person needing services (young people with cancer, their siblings and their parents)
- the type of service (based on the needs of the young person)
- the location of the service
- the type of cancer
- the age of the user.

The types of services listed are based on the needs of young people with cancer – determined by focus groups and input from young people and families. They include:

- Youth Cancer Centres
- Treatment services
- Complementary services
- Coping with side effects
- Palliative care
- Emotional/psychosocial support
- Travel and accommodation services
- Domestic Help
- Financial support
- Educational/vocational support
- Respite/diversion services
- Information resources
- Cancer awareness/education
- Advocacy support.

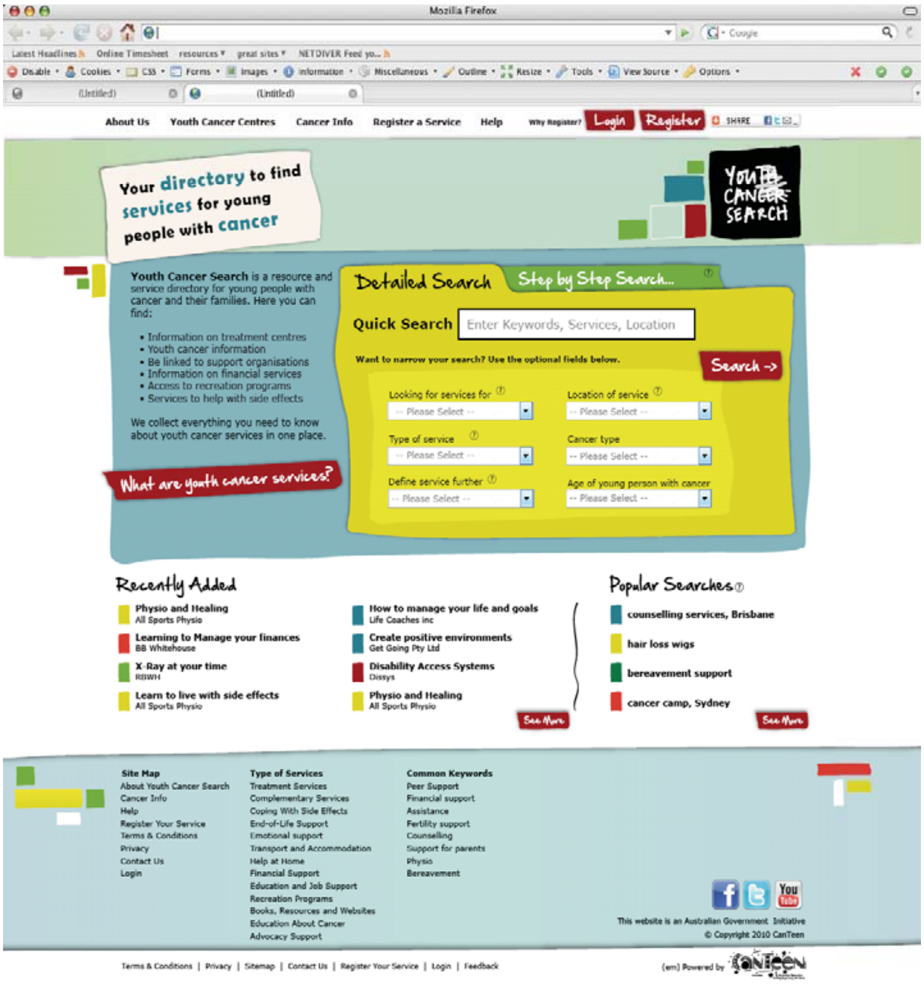
Service providers include any organisation that provides services that meet the needs of young people with cancer. Service providers upload and manage their own content, after applying and being granted approval by the Youth Cancer Search team. They will be able to edit and maintain their profile over time, and will receive reminders to check validity of information.

Project progress

- An extensive scoping study was completed to inform project design, followed by a tender process to select the web development company.
- Set up a Steering Committee, comprising representatives of AYA clinicians, service providers and young people, and a Youth Advisory Group.
- Focus group testing completed with users.
- Initial wireframes and functional specifications completed.

Site presentation

Francesca presented the site design (screen grab below) and explained key features and search functions.



Your directory to find services for young people with cancer

Youth Cancer Search is a resource and service directory for young people with cancer and their families. Here you can find:

- Information on treatment centres
- Youth cancer information
- Be linked to support organisations
- Information on financial services
- Access to recreation programs
- Services to help with side effects

We collect everything you need to know about youth cancer services in one place.

Quick Search Enter Keywords, Services, Location

Want to narrow your search? Use the optional fields below.

Looking for services for: -- Please Select --
Location of service: -- Please Select --
Type of service: -- Please Select --
Cancer type: -- Please Select --
Define service further: -- Please Select --
Age of young person with cancer: -- Please Select --

Recently Added

- **Physio and Healing** All Sports Physio
- **Learning to Manage your finances** BB Whitehouse
- **X-Ray at your time** RBWH
- **Learn to live with side effects** All Sports Physio
- **How to manage your life and goals** Life Coaches inc
- **Create positive environments** Get Going Pty Ltd
- **Disability Access Systems** Dissys
- **Physio and Healing** All Sports Physio

Popular Searches

- counselling services, Brisbane
- hair loss wigs
- bereavement support
- cancer camp, Sydney

Site Map
About Youth Cancer Search
Cancer Info
Help
Register Your Service
Terms & Conditions
Privacy
Contact Us
Login

Type of Services
Treatment Services
Complementary Services
Coping With Side Effects
End-of-Life Support
Emotional support
Transport and Accommodation
Help at Home
Financial Support
Education and Job Support
Recreation Programs
Books, Resources and Websites
Education About Cancer
Advocacy Support

Common Keywords
Peer Support
Financial support
Assistance
Fertility support
Counselling
Support for parents
Physio
Bereavement

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Next steps

1. Prototype soon to be built and one-on-one tested with young people, service providers and health professionals.
2. Necessary changes will be made to wireframes and functional specifications.
3. Development of site.
4. Marketing and promotions strategy to engage service providers and gather content.
5. Site launch (May/June 2011).

Minimum data set

Dr Cleola Anderiesz, Director – Research, Clinical Trials and Data, Cancer Australia

Cancer Australia is developing a data set specification (DSS) for adolescents and young adults. A DSS is a meta dataset that is not mandated for collection but is recommended best practice. The aim is to facilitate more accurate data collection and therefore more accurate monitoring of elements such as cancer diagnosis, stage, intervention and late effects in adolescents and young adults.

The final dataset will be submitted to the National Health Data Standards Committee for endorsement as best practice.

Project progress

- Cancer Australia established a working group to oversee development of the data set specification – lead by Professor David Roder and including representatives of paediatric oncologists, consumers, AYA cancer nurse coordinators, social work, epidemiology as well as CanTeen and COSA.
- Consulted widely to develop a 'maxi' list of possible data items.
- Working group pruned list and developed a list of clinical and 'non-clinical' items. The non-clinical items include psychosocial issues, education/vocation, sexual health, survivorship data, etc. – based on the AYA distress screening tool developed by Dr Susan Palmer.
- Clinical items have been circulated for stakeholder consultation – seeking feedback about whether all items are relevant and which are most important to collect.

Next steps

- Working group to review feedback from stakeholders (which was due by 22 November).
- Finalise data elements for clinical and non-clinical DSS.
- Develop data definitions and create a data dictionary:
    - stakeholder consultation to ensure items are described appropriately
    - pilot testing (assessing feasibility of collecting the data items that have been identified).
- Finalise DSS and submit to National Health Data Dictionary Group.

Cancer Australia is seeking expressions of interest from sites interested in pilot testing collection of DSS items (approximately 28).

Evaluation

Dr Catherine Spooner, Siggins Miller

Siggins Miller has been selected to conduct the evaluation of the Youth Cancer Networks Program.

Siggins Miller will be conducting a process and output evaluation of the program – to assess what has been done, how well was it done and how the government's $15 million investment has contributed to the *National Service Delivery Framework for Adolescents and Young Adults with Cancer*.

Project progress

- Currently completing an evaluability assessment – reviewing project plans and talking to each of the project managers to ensure understanding of projects and determine whether projects are on track and identify data that project teams are already collecting or planning to collect.
- After collating this information, Siggins Miller will design an implementation and output evaluation framework. The evaluation framework will use project documentation such as progress reports and local evaluations to minimise the burden of data collection and will allow for assessment of both project- and national-level achievements. It is likely to be a multi-method evaluation, including document review, key informant interviews and focus groups.
- Final evaluation framework is due to CanTeen on 1 December 2010.

Evaluation timeline

• Evaluation plan to CanTeen	1 December 2010
• Refine plan	Early 2011
• Data collection	Early 2011 – early 2012
• Final report	July 2012

AYA Cancer Network / Clinical practice guidelines and protocols / Clinical research

Lisa Herron, Consultant, COSA AYA Cancer Projects

COSA is leading three national projects to improve management and care of AYAs with cancer by

1. facilitating the AYA Cancer Network

2. developing AYA cancer clinical practice guidance protocols

3. increasing clinical research focussed on AYA cancer priorities and increasing participation of AYAs with cancer in clinical trials.

AYA Cancer Network

The AYA Cancer Network aims to link all interested clinicians and health professionals providing treatment, care and/or support to AYAs with cancer as well as policymakers and hospital and health service executives involved in the development of AYA cancer services.

The aim is to facilitate better communication between stakeholders across all jurisdictions and disciplines, to:

- promote the objectives, activities and achievements of the Youth Cancer Networks Program and other initiatives aimed at improving AYA cancer care and outcomes
- create opportunities for YCNP project partners to exchange information and learnings and identify opportunities for collaboration or national coordination.

Activity to date:

- ***AYA Cancer Workshops***
  This is the fourth national AYA Cancer Workshop convened by COSA: two preceded and helped inform development of the YCNP (May 2007, November 2008), one at the start of the program (November 2009) and now this 'mid-program' workshop.

- ***Sharing information about YCNP projects and progress***
  Given the budget and time constraints, the emphasis has been on using COSA's existing channels:
  - *The Marryalyan* newsletter – distributed 3 times per year to COSA's almost 1400 members and other stakeholders – includes reports of YCNP activities.
  - COSA's website – just redeveloped and relaunched – provides information about AYA cancer management issues and links to reports, publications and useful resources.

  COSA's communications about the project have been limited to keeping COSA members and stakeholders informed about development of the YCNP at a general level and the COSA projects in particular, given CanTeen's plans for a national program launch and the need for confidentiality or caution in communicating about some project issues.

- ***Supporting 'champions'***
  Given their experience and senior roles, COSA's AYA Cancer Steering Group members are effective 'champions' of the need for improved research, services and supportive care for AYAs with cancer to improve outcomes. The Network has linked like-minded people and helped driving the AYA oncology agenda forward.

- ***Enabling expert and multidisciplinary advice***
  COSA has been able to identify and recommend clinical experts to provide advice to support various YCNP national and jurisdictional projects. The Network also provides access to the broader group of multidisciplinary health professionals to review and promote the clinical practice guidance COSA is developing (see below).

Clinical practice guidelines and protocols

COSA has been contracted to produce, publish and disseminate clinical practice guidelines and, with Cancer Institute NSW (CINSW), protocols for the treatment and care of AYAs with cancer.

COSA's AYA Cancer Steering Group has identified and prioritised areas of practice where there is an identified need for guidance and/or significant variations in practice.

The three guidance topics are:
- fertility preservation for AYAs diagnosed with cancers and related issues, including monitoring for late effects on reproductive function and endocrine and sexual health
- AYA developmental and psychosocial issues, including recommendations for assessment and referral
- information for GPs to increase awareness of the signs and symptoms of cancer ('lumps and bumps') in AYA patients, reduce delays in diagnosis and increase appropriate referral.

Each guidance will be developed by a multidisciplinary working group of experts and patient reps, using an evidence-based approach based on the NHMRC model and recommendations for developing clinical practice guidelines.

Guidelines will be produced using COSA's Wiki platform – making the information very easy to access, easy to review (at consultation stage) and easy to keep up to date.

Protocols are being developed by the CINSW to be added to the eviQ Cancer Treatments Online website in a dedicated AYA subsection. CINSW is presently doing the research and developing a number of point of care protocols and information sheets.

Increasing clinical research

The project objectives are to:

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

COSA has established an AYA Cancer Research Working Group, comprising representatives of the relevant cooperative clinical trials groups and other stakeholders, to advise on strategies to achieve the project objectives.

This group reviewed incidence and mortality rates and gaps in cancer survival within the AYA group, and identified the following cancers as priorities:

- leukaemia
- brain/CNS tumours (low and high grade gliomas and CNS germ cell tumours)
- melanoma (metastatic)
- sarcomas.

The group also highlighted the need for psychosocial and supportive care studies, particularly to measure survivorship quality for those AYA cancers in which outcomes are good (germ cell tumors, Hodgkin lymphoma, thyroid cancer, melanoma).

Progress:

- The Steering Group has supported two clinical trial opportunities (and helped facilitate start up funding for one) for high priority diseases: the ALL6 study (which will open in early 2011) and the AYAPK study (now recruiting patients).
- The Steering Group is consulting with the cooperative trials groups to identify opportunities to support and/or facilitate new collaborations to develop protocols for studies in other priority cancers and/or studies of psychosocial issues or quality of life of survivors of AYA cancers.
- The group has developed criteria for allocating the Clinical Trials Investment Fund ($92,000) and has discussed with Cancer Australia appropriate mechanisms to ‘piggyback’ on the existing NHMRC/Cancer Australia cancer research grant processes e.g. to fund project/s that address the identified priorities but missed out on funding from Cancer Australia’s Priority-driven Collaborative Cancer Research Scheme.

Another element of this project is establishing baseline data in order to measure the impact of the project strategies. The Australian Institute of Health and Welfare is currently undertaking the collation and analyses of incidence, mortality and survival data (initiated by this project), expected to be published in early 2011. Identifying treatment locations has proved more difficult, as it requires review of medical and other records – so that will need to be a separate and longer-term process.

COSA is consulting with the cooperative clinical trials groups (CCTGs) through the Steering Group and the COSA & CCTGs Executive Officers Network to establish current AYA trial participation rates.

3 Discussion

The second part of the workshop was led by Sue Sinclair (General Manager of the National Breast and Ovarian Cancer Centre and former Director of Cancer Services and Education, Cancer Institute NSW).

Sue noted that with all YCNP projects underway, and efforts and project strategies are starting to come to fruition, the aim now is to maintain and share participants' enthusiasm and collective knowledge about AYA cancer care, and build sustainable mechanisms to support efficient communication and collaboration nationally.

In this part of the workshop, participants were invited to consider four key questions:

- What are the common issues/challenges for YCNP project leaders?
- How can we increase communication and knowledge sharing between projects?
- What are the opportunities for national collaboration/cooperation?
- How can we increase the reach and membership of the AYA Cancer Network?

Common issues/challenges

Workshop participants identified a number of common issues and challenges and recommended possible strategies or approaches to addressing them. These are summarised below, in the order in which they were raised.

All recommendations are also collated in a table at the end of this report.

Better inter-project communication/knowledge sharing

As many Project Officers are new to the area of AYA cancer care, they would value an opportunity to meet and discuss jurisdictional projects in more detail. There is a need for mechanisms to enable Project Officers to share knowledge and form collaborations.

Participants agreed there would be value in convening another AYA cancer workshop early in 2011, for further discussion about different models and approaches – why they've been selected, how they work and which have been successful – and to further identify areas for collaboration or efficiencies. This could lead to the formation of interest groups in relation to education and training or research, for example.

Recommendations:

- Convene a teleconference of jurisdictional Project Managers early in 2011.
- Convene another AYA Cancer Workshop early in 2011 – focused on service delivery models and strategies, common challenges and forming interest groups.
- Develop a strategy for better use of existing platforms (COSA, CanTeen, eviQ) by project partners to exchange information and knowledge.
- Engage 'non-clinical' service providers e.g. RedKite early in project development.

Engaging Adult Oncologists

Several participants noted that service delivery is currently very paediatric-driven and the challenges of engaging adult oncologists. Participants queried whether this is because of lack of awareness of AYA-specific needs and/or the specialist services and psychosocial care an AYA services can provide, or logistical or practical issues in terms of how adult service is run, or a combination of both? There was discussion about perceived barriers to engaging adult oncologists and strategies that have been effective in some areas (e.g. the Sydney Children's Hospital AYA service).

Recommendations:

- Enable project partners to share learnings about barriers and enablers to engaging adult oncologists and case studies of effective models/strategies.
- Advocate for inclusion of AYA oncology in adult oncology training curriculum.

Increasing public awareness/understanding

There is a need to increase public awareness and understanding of the Youth Cancer Network Program aims and initiatives.

Recommendation:

- National and state/territory launches of the YCNP should be conducted as soon as possible.

Sustainability

Ensuring sustainability is a common challenge for the jurisdictional services. It was noted that there are very different models developing in each jurisdiction, but that there is potential benefit in having a national framework and evaluation of different models to help support jurisdictions in securing state-wide funding for a minimum model of care (core roles and responsibilities).

There was discussion about the need to promote the models of care being developed, especially referral pathways and processes and consumer engagement, so that recognising and responding to the needs of AYA patients becomes 'part of the normal business of all healthcare professionals'. Some participants suggested that sustainability depends on increasing organisational capacity at a state-wide level.

In response to questions about the availability of ongoing funding, Dr Young advised that CanTeen has already made a commitment to raising another $15 million and has started discussions about continuing the jurisdictional projects and sustaining/building on national projects. Most of the state and territory governments have made in principle commitments to the services established, usually 'subject to evaluation and future budget considerations'.

***Recommendations**:*

- Develop a national strategy for coordinating advocacy at a national level, and supporting efforts at the jurisdictional effort, to maintain and increase funding for AYA cancer services.
- 'Grow the network' – identify more individuals who can champion and lead development of AYA cancer services and care, to reduce the current heavy burden on a few key players.

Developing referral pathways

It was noted that several jurisdictions are developing referral pathways as part of their YCNP projects.

Recommendation:

- Project partners should share referral pathway models and learnings.

Branding

It was noted that to be effective, the proposed common branding will need to be integrated in cancer services and that it will be challenging to gain the 'buy in' of all the services involved.

Supporting wider systems change

Professor Sawyer encouraged participants to consider the opportunity to leverage gains in the oncology setting to benefit AYA health and welfare more generally; to contribute to wider systems change beyond the cancer field.

Building on the work to date

Participants questioned how to coordinate efforts to maintain and build on the achievements of the YCNP national projects once they are completed. When there are natural 'next steps', who will be responsible?

Recommendations:

- COSA to develop a clearing house/resource repository and maintain a national AYA cancer steering group (COSA Interest Group) to share information and ensure future work is coordinated and there is no unnecessary duplication.

Implementation of the AYA cancer minimum data set

Dr Anderiesz noted that the national project to develop an AYA cancer minimum data set will result in recommendation of a 'best practice' data set, but there are concerns about ensuring implementation and uptake of that data set. This will require engagement of each state/territory jurisdiction to resolve questions about ownership and release of the data, etc.

Recommendation:

- Establish a working group to develop an implementation plan.

Summary of recommendations

Recommendations	Responsible*	Timeline*
YCNP and inter-project communications		
Conduct national and state/territory launches of the YCNP as soon as possible.	CanTeen and jurisdictional project partners	
Convene a teleconference of jurisdictional Project Managers early in 2011.	CanTeen	
Convene another AYA Cancer Workshop early in 2011 – focused on service delivery models and strategies, common challenges and forming interest groups.	COSA	March/April 2011
Enable project partners to share learnings about barriers and enablers to engaging adult oncologists and case studies of effective models/strategies.	COSA – via 2011 workshop	March/April 2011
Project partners should share referral pathway models and learnings.	Project partners – via workshop	March/April 2011
Develop a strategy for better use of existing platforms (COSA, CanTeen, eviQ) by project partners to exchange information and knowledge.	COSA and CanTeen	
COSA to develop a clearing house/resource repository and maintain a national AYA Cancer Steering Group (COSA Interest Group) to share information and ensure future work is coordinated and there is no unnecessary duplication.	COSA	
'Grow the network' – identify more individuals who can champion and lead development of AYA cancer services and care, to reduce the current heavy burden on a few key players.	COSA	Ongoing
Program/project strategies		
Develop a national strategy for coordinating advocacy at a national level, and supporting	CanTeen, COSA and project partners	

efforts at the jurisdictional effort, to maintain and increase funding for AYA cancer services.		
Engage ‘non-clinical’ service providers e.g. RedKite and Cancer Councils early in project development.	Project partners	
Advocate for inclusion of AYA oncology in adult oncology training curriculum.	COSA	
Establish a working group to develop a plan for implementation of the AYA cancer minimum data set.	Cancer Australia, with advice from COSA’s AYA Cancer Steering Group	

* The organisation/individuals responsible and timeline were nominated by COSA and CanTeen at a meeting after the workshop to review recommendations.

Conclusion

During the workshop many participants acknowledged the value of COSA facilitating the AYA Cancer Workshops, to bring together project partners and clinicians to learn more about other projects and share their experiences and advice.

COSA and CanTeen will meet to develop communications strategies and plan another AYA Cancer Workshop in early 2011.