Clinical Oncological Society of Australia

ADOLESCENT AND YOUNG ADULT (AYA) CANCER FORUM

28 MAY 2007

SUMMARY REPORT

PEOPLE • ACHIEVEMENT • LEADERSHIP • MANAGEMENT

PALM CONSULTING GROUP

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1. EXECUTIVE SUMMARY

The Clinical Oncological Society of Australia convened a forum on Adolescent and Young Adult (AYA) Cancer to develop a shared understanding of the issues and challenges in the treatment and care of adolescents and young adults with cancer, and to agree on the key elements of appropriate models of care. Forum participants included a broad representation of stakeholders and practitioners.

AYA cancer patients are a significant population and have distinctive medical, psychosocial, social and information needs which necessitate age-appropriate therapy, care and support. These distinctive needs include developmental needs, loss of independence, fertility preservation, financial and economic dependency concerns, peer support/integration as well as the management of the return and transition to school and work. Currently AYA patients are achieving less than optimal outcomes, such as lack of improved survival rates, delayed diagnosis and poor access to clinical trials and this will require an improved focus on AYA cancer. This will be achieved through recognition of AYA cancer as a sub-speciality and a collaborative approach to combine resources and expertise.

The forum identified the following key principles for the effective treatment and care of AYA cancer patients.

ACCESS TO TREATMENT AND CARE

All AYA cancer patients should have access to appropriate treatment and care regardless of their location. Appropriate treatment will be facilitated by:

- a national approach to AYA cancer, including incentives and monitoring and reporting processes
- state-based pathways which identify availability of clinical services
- networks of treatment centres comprising specialist services, primary care and patient support (psychosocial care and peer and family support)
- defined minimum standards of treatment and care.

A PATIENT AND FAMILY-CENTRED APPROACH

The approach to treatment and care will be focussed on the needs of AYA cancer patients and their families. The approach will be characterised by:

- co-ordination of care provided by a multidisciplinary care team which combines the expertise and resources of paediatric and adult oncology services
- treatment supported by clinical guidelines
- education and training, including continuing education, to support the focus on AYA cancer and the co-ordinated multidisciplinary care team.

SYSTEM LEVEL SUPPORT

At the system level, AYA cancer treatment and care will be supported by appropriate **incentives** and processes for **monitoring and reporting**, including benchmarking. A national approach to **clinical trials** will ensure that AYA patients have access to clinical trials and their participation in trials is maximised. Approaches to AYA cancer will also be supported by targeted **research** and an **evidence base** to support effective practice.

Participants agreed on the need for an improved approach to AYA cancer and agreed to work individually and collectively to progress the directions agreed at the forum.

2. BACKGROUND AND PURPOSE

The Clinical Oncological Society of Australia convened a forum on Adolescent and Young Adult (AYA) Cancer in Sydney on 28 May 2007. The purpose of the forum was to develop a shared understanding of the issues and challenges in the treatment and care of adolescents and young adults with cancer, and to agree on the key elements of appropriate models of care. The forum outcomes will inform a meeting of Cancer Australia's AYA National Reference Group to be held on 29 May 2007, and contribute knowledge to the future development of policy options.

Forum participants included a broad representation of stakeholders and practitioners and a list of participants is included with this report. The forum included invited presentations and table and plenary discussions, and the outcomes of these discussions are summarised in this report. Copies of the presentations are available separately.

Lynette Glendinning of PALM Consulting Group facilitated the forum and this summary report was developed by Douglas Smith, also of PALM Consulting Group.

3. KEY ISSUES IN AYA CANCER

3.1 PERSPECTIVES ON THE PERSONAL EXPERIENCE

Ms Emma Sayers and Mrs Clare Sayers
Emma and her mother Clare spoke of their personal experiences as an AYA patient and carer, highlighting issues such as the loss of independence, emotional vulnerability, the need for practical support and assistance, career interruptions and return to work issues.

3.2 ISSUES IN AYA CANCER

Dr Karen Albritton
Director, AYA Oncology
Dana Farber Cancer Institute

Dr Albritton provided an outline of key issues in AYA cancer, many of which result from the treatment of AYA in the paediatric and medical oncology setting while not being a specific focus of either. Key issues for AYA cancer include:

- lack of improvement in survival rates, which is in part a result of delays in diagnosis
- lack of clinical trial participation
- the impact of service delivery on health outcomes
- lack of understanding of the biology of AYA cancer

- current unmet needs of AYA patients.

AYA patients have specific medical, psychosocial and social needs which necessitate age-appropriate therapy, care and support. The issues requiring such support include fertility preservation, the involvement of parents and significant others in treatment and care, financial and economic dependency concerns, as well as issues arising from the developmental needs of puberty and adolescence such as identity and self image and the management of school and the transition to work. Dr Albritton suggested that collaboration between paediatric and medical oncology specialties would improve outcomes for AYA cancer, particularly by combining patient numbers (for research and trials) and by combining expertise.

Since AYA cancer patients are a significant population with distinctive cancers and distinctive needs which are currently achieving less than optimal outcomes and have a poor scientific focus, there is now a case for developing a new field of AYA oncology.

3.3 PRIORITIES AND DIRECTIONS FOR AYA CANCER

Table groups were tasked to discuss the key priorities for AYA cancer and the desired outcomes for AYA cancer in 2012.

PRIORITIES FOR AYA CANCER

In order to strengthen the AYA field and improve outcomes for patients it was suggested that firstly there was a need to improve **collaboration**, particularly by better using and working through the existing organisations such as Cancer Australia, the Cancer Council, COSA, CanTeen and others to raise the profile of AYA cancer and improve the focus on meeting the distinctive needs of AYA patients.

The AYA field also needs to be strengthened through specific **capacity building** strategies such as provision of training and fellowship opportunities and the creation of dedicated senior staff positions for AYA cancer specialists.

There is a need for increased **resourcing** for AYA cancer and to do this, a clear case with supporting data and evidence will need to be presented to governments, to the community more broadly and to patients and clinicians.

There are a number of **specific areas** of AYA cancer which will need to be improved, particularly:

- an improved focus on the distinctive psychosocial needs of AYA patients
- development of clear clinical pathways which are evidence-based

bridging the artificial divide between paediatric and adult cancer services to develop a patient-focused model of care

- improved access to clinical trials, including centralised co-ordination and ‘tumour banking’
- development of a national cancer registry for AYA cancer.

Clearly there is also a need to address the **governance** of AYA cancer through the current organisations.

OUTCOMES FOR 2012

The forum identified the following desired outcomes for AYA cancer by 2012:

- government will recognise the distinctive needs of AYA cancer and provide dedicated resources
- a recognised training scheme will be in place which includes training positions and senior staff positions
- medical and allied health practitioners will have increased awareness and education regarding AYA cancer issues (including multidisciplinary and palliative care) through their undergraduate, postgraduate and continuing education
- an agreed and consistent approach to AYA cancer will be in use across all speciality groups
- most AYA patients will have access to a multidisciplinary team with:
  - a diagnosis and treatment team with expertise in each cancer type, where this is critical to outcomes a psychosocial support team, including appropriate peer support and palliative care as needed
  - care co-ordination
  - management of the transition and follow-up of AYA patients from paediatric to other treatment areas, such as a late effects clinic
  - facilities to support multidisciplinary care
- there will be an increase in both the number of clinical trials which AYA patients can access and the number of AYA participants in clinical trials.

4. PRINCIPLES, STRATEGIES AND OPTIONS

4.1 CURRENT APPROACHES TO AYA CANCER

NEW ZEALAND

Dr Robin Corbett
Medical Director, South Island Child Cancer Service
NZ Ministry of Health

Dr Corbett outlined the initiatives in New Zealand to focus on AYA cancer, which included specific objectives and strategies in the New Zealand Cancer Control Strategy. Through the AYA Cancer Working Party, service specifications were developed which included a multidisciplinary care team with a lead clinician. Teams are located in each treatment centre and linked by videoconference. Each multidisciplinary care team includes:

- treatment specialists
- fertility specialist
- diagnostic support specialists
- physical support
- psychosocial support.

The service specifications also include a cancer key worker with a case management and care co-ordination role, including co-ordination of the multidisciplinary care team meetings. The decision regarding place of the treatment is determined by the multidisciplinary care team and based on factors such as the patient's age and needs and wishes, the type of cancer and the patient's maturation stage (puberty, cognition, need for family support and the patient's living arrangements).

WESTERN AUSTRALIA

Megan Plaster
Paediatrics / AYA Cancer Nurse Co-ordinator
WA Cancer and Palliative Care Network
WA Department of Health

Megan provided some data from the as yet incomplete audit in Western Australia which shows that for the period 2000-2004, 612 new patients aged 10-24 were diagnosed with cancer. This represents approximately 122 per year. These patients are treated in up to 31 treatment settings across Western Australia, with the result that resources are thinly spread across this group. Western Australia has opened the first dedicated adolescent cancer unit in December 2006, located within a paediatric facility. It is anticipated that this unit will ultimately be relocated on a shared adult-paediatric tertiary health campus currently being planned.

Megan's role as the AYA Cancer Nurse Co-ordinator is a combination of clinical service and strategic roles, in particular prioritising activities in service development, informing the State's AYA cancer control activities and contributing to governance strategies.

VICTORIA

Dr David Thomas
Group Leader, Sarcoma Genomics and Genetics Laboratory
Peter MacCallum Cancer Centre

The Peter MacCallum Cancer Centre established a multidisciplinary care team approach (onTrac@PeterMac) in 2004 using philanthropic funds. The team includes:

- Medical director
- Social worker (0.5EFT)
- Psychologist (0.8EFT)
- Data manager (0.5EFT)
- Education advisor (0.6EFT)
- Palliative care nurse (0.5EFT)
- Project co-ordinator (CanTeen)
- Music therapist

The approach is underpinned by the following principles:

- care should be provided as safely and effectively as possible, then as close to home as possible

- all young people, regardless of cancer type, have in common unique needs which must be met
- cancer care is often best delivered in a multidisciplinary setting with the best possible expertise and resources, and should combine paediatric and adult expertise when necessary
- patterns of referral should be based on need, which will vary by cancer type
- research is critical.

4.2 PANEL DISCUSSION - STRATEGIES AND OPTIONS

The panel comprised the following members:

- **Frank Alvaro**
  Paediatric Oncologist
  The John Hunter Hospital
  Chair, The Australian and New Zealand Children's Haematology / Oncology Group
- **John Seymour**
  Haematology Department Head
  Peter MacCallum Cancer Centre
- **Susan Palmer**
  Psychologist, onTrac@PeterMac
  Peter MacCallum Cancer Centre
- **Tracey O'Brien**
  Head, Stem Cell Transplant Program
  The Centre for Cancer and Blood Disorders
  Sydney Children's Hospital

PRINCIPLES

The panel reflected on the principles identified in Dr Thomas' presentation and added that the approach to improving AYA cancer services needs to be embedded in the **broader cancer initiatives**, particularly to ensure that the effort was not duplicated. In addition, building on the role of research, it will be necessary for **data and evidence** to build the case for change in AYA cancer services. This includes building a better understanding of current practices at the local practitioner level, such as patterns of referral. This information will be critical to building an appropriate model of service for AYA cancer.

In relation to the location of care, this should be guided by the principle of **safe delivery of care**, however as there is a need to address risk in the initial diagnosis, the location will need to provide opportunities for review, even if only by telephone. AYA cancer services also need to place a greater emphasis on **psychosocial care**, and important principles in this regard include taking a holistic and preventive approach and ensuring that AYA patients are able to move back into their adult lives and achieve a quality of life.

OPTIONS

The panel considered the options to developing AYA cancer services and made the following suggestions:

- harness the opportunities provided by telemedicine and innovative models of care, recognising the high levels of technological literacy of AYA cancer patients (e.g. web, SMS)
- a national process for ethics committee approval to remove what is currently a significant constraint to improved models of care for AYA cancer patients
- better recognition of the distinctiveness of AYA cancer and of the needs of AYA cancer patients
- combination and concentration of expertise focussed on AYA cancer
- increased ownership and recognition of AYA as a separate discipline.

4.3 CONSTRAINTS AND OPPORTUNITIES

In plenary discussion, and building on the panel discussion, the forum identified the key constraints and opportunities which AYA cancer faces.

CONSTRAINTS

AYA cancer is constrained by lack of awareness and understanding at all levels. At the government level, this is manifest in inadequate resourcing, particularly in the resourcing of allied health staff (for care co-ordination). At the practitioner level, there is a lack of ownership of AYA cancer and a reluctance to collaborate across speciality areas. This narrow focus results in insufficient depth of expertise in the area of AYA cancer.

The practice of AYA cancer is currently constrained by the lack of agreed treatment plans and inappropriate practices such as delays in diagnosis, which impacts health outcomes for AYA cancer patients.

OPPORTUNITIES

The current goodwill, interest and support within cancer and medical organisations provide an opportunity to develop AYA cancer models of care and treatment networks. There is also the opportunity to take advantage of other current initiatives in cancer control to focus the effort and ensure effective use of resources.

Specific options for the AYA cancer model of service include:

- identification of key health workers or care co-ordinators to support the provision of co-ordinated multidisciplinary care and assist patients in navigating the system
- implementation of peer review processes to ensure that AYA cancer patients receive appropriate treatment
- development of a national approach to clinical trials to increase AYA patient access and participation.

4.4 KEY PRINCIPLES

The forum identified the following key principles for effective treatment and care of AYA patients.

ACCESS TO TREATMENT AND CARE

All AYA cancer patients should have access to appropriate treatment and care regardless of their location. Appropriate treatment will be facilitated by:

- a national approach to AYA cancer, including incentives and monitoring and reporting processes
- state-based pathways which identify availability of clinical services
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The approach to treatment and care will be focussed on the needs of AYA cancer patients and their families. The approach will be characterised by:

- co-ordination of care provided by a multidisciplinary care
- treatment supported by clinical guidelines
- education and training, including continuing education, to support the focus on AYA cancer and the co-ordinated multidisciplinary care team.

SYSTEM LEVEL SUPPORT

At the system level, AYA cancer treatment and care will be supported by appropriate **incentives** and processes for **monitoring and reporting**, including benchmarking. A national approach to **clinical trials** will ensure that AYA patients have access to clinical trials and their participation in trials is maximised. Approaches to AYA cancer will also be supported by targeted **research** and an **evidence base** to support effective practice.

Specific incentives and resources should be provided to promote innovative, cross-institutional links between paediatric and adult units that treat similar cancers, aimed at facilitating harmonisation of treatment protocols and approaches and creating a critical mass for clinical trials.

5. FUTURE DIRECTIONS FOR AYA CANCER

5.1 A NETWORK OF TREATMENT CENTRES

Networks of treatment centres for AYA cancer will comprise specialist services (including initial diagnostic teams), primary care and support services including psychosocial care and peer and family support. These services will be linked and co-ordinated with specialist advice and consultation available across the network. Communication and collaboration across the network will be important to ensure clear referral pathways and effective linkages between paediatric and adult cancer services. This will necessitate increased awareness of practitioners and the community of the network and the available options and choices for patients.

While the networks will effectively link services within geographic areas, they will also provide links to broader services and between networks as appropriate. Regional and local networks will need to be supported by a national approach, particularly in relation to education, data, and co-ordination of clinical trials.

5.2 CO-ORDINATED MULTIDISCIPLINARY TEAM CARE

AYA cancer patients will receive co-ordinated multidisciplinary team care throughout all stages of the patient journey. The following options for the provision of multidisciplinary team care were identified. It should be noted that in all cases, the primary care team would continue to share care to minimise disruption to patients normal lives and families. It should also be noted that access to these models cannot be provided for all tumours in all treatment centres. It is therefore likely that the final format of the service within each health care system will comprise a balance of the following elements.

HOSPITAL-BASED AYA SERVICE

In this model an AYA cancer planning team provides services within the hospital. This team (the initial diagnostic team) comprises:

- Multidisciplinary paediatric and adult cancer specialists , recognising that the progressive development of disease-focused medical care is critical to optimal medical outcomes and clinical trials. This team will include surgical, radiation, and medical oncology, and access to outside specialised opinion in the case of disease entities uncommon in this age group (eg young person with rectal cancer) expert radiology and pathology resources, and specialist nursing and allied health support
- clinical trials infrastructure and data manager
- care co-ordinator.

This centralised team provides direct clinical care to AYA cancer patients with complex needs as well as consultation and advice and communication with GPs. Services available to AYA cancer patients also include an AYA-specific psychosocial care team.

CONSULTATIVE SERVICE

This model takes a tumour-based approach by enabling the clinical team to consult with regional tumour streams, thereby increasing access to specialist expertise. This model has the weakness of limited patient knowledge and would be seen as an interim model only.

CONSULTATION TEAM

In this model a regionally-based AYA team comprising physician services, psychosocial support and care co-ordination provide services to multiple hospitals – essentially taking the multidisciplinary care team to the patient.

5.3 RESEARCH PRIORITIES FOR AYA CANCER

The priorities for research in AYA cancer include:

- establishment of a national data base including information on age, diagnosis and outcomes such as access to multidisciplinary care teams and participation in clinical trials
- identifying research projects by examining current data (state cancer registries and tumour data) to identify gaps in research and evidence and appropriate research projects, particularly audits and studies to identify particular care requirements
- building evidence in relation to models of care, including referral pathways
- development of performance indicators, particularly for outcomes and impacts, including surrogate markers (for example screening)
- monitoring, evaluation and reporting of impacts, including quality of life.
- promoting recognition of the need for inclusion of AYA within relevant existing disease-specific trials groups, as well as greater co-ordination between such groups to facilitate quality of life and psychometric outcome measures. Such groups include but are not limited to the Australian Leukaemia and Lymphoma Study Group; the ANZ Germ Cell Trials Group; the ANZ Children’s Haematology and Oncology Group (DG)

5.4 IMPROVED PARTICIPATION IN CLINICAL TRIALS

As participation in clinical trials is critical to health outcomes for AYA patients, there is a need to build awareness and support of the structure, process and benefits of clinical trials. To be effective, clinical trials need to be integrated in health care delivery and supported by an effective infrastructure, in particular a national ethics committee or process for approvals and removal of regulatory barriers such as age limits on participation. The infrastructure also needs to include support in the form of data managers and researchers.

The operation of clinical trials also needs greater collaboration and co-operation around standards and consistent processes. Clinical trials can also benefit from interaction and co-operation with international clinical trials groups. This co-operation will not only ensure the effective operation of trials, feedback from co-operative trials groups can also contribute to research and improvements in practice and inform future policy development.

5.5 CHANGES IN CLINICAL PRACTICE

Mechanisms to facilitate change in clinical practice include:

- secure ownership of the case for change by building recognition and support with governments, the community, practitioners and patients
- recognise AYA cancer as a sub-speciality, including:
  - create AYA cancer appointments to bridge and link paediatric and adult cancer practice
  - set accreditation standards for AYA cancer as a separate practice area
  - develop practice guidelines, linked to accreditation
- empower consumers by raising their awareness of the availability and benefits of AYA cancer services
- use incentives including financial incentives to promote the uptake of AYA cancer services
- build the workforce capacity by including a stronger focus on cancer competencies, and AYA cancer competencies in particular, in education and training programs
- strengthen clinical trials, including links to accreditation
- identify and support change ‘champions’.

6. PROPOSED ACTIONS

Professor Ian Olver, CEO of the Cancer Council, concluded the discussion by noting that action could be taken by individuals as well as by the sponsoring organisations. In response forum participants identified a number of actions which could be taken at individual and local levels as well as through the sponsoring organisations.

INDIVIDUAL AND LOCAL ACTIONS

Forum participants agreed that individuals could progress AYA cancer services at a number of levels including:

- building the focus on AYA cancer in jurisdictions’ current and planned cancer control strategies
- advocating AYA cancer in the workplace and through professional groups and other networks
- using case meetings and other opportunities to bring like-minded people together to improve the focus on AYA cancer
- developing and implementing local policies, guidelines and practices on AYA cancer
- identifying a local AYA cancer liaison person and / or champion.

SPONSORING ORGANISATIONS

Individually, sponsoring organisations can progress AYA through a range of current and planned initiatives. Examples include:

- CanTeen – continuing advocacy, information sharing, patient education of clinicians and service providers and funding of AYA cancer pilot projects
- Red Kite – creation of new positions addressing AYA cancer (music therapy and social worker)

- COSA – development of clinical guidelines (with Cancer Australia)
- Cancer Australia – development of clinical guidelines (with COSA) and improvement in clinical trials through a national ethics process, removal of the age barrier and support of the National Clinical Trials Groups.

These and other organisations can also work together to progress AYA cancer by developing a joint press release about the outcomes of the forum and by developing a joint position paper on AYA cancer, particularly in relation to the rationale and benefits of a focus on AYA cancer, including improved health and socio-economic outcomes.

Consideration should also be given to links with international organisations to strengthen efforts in advocacy and promotion. The Lance Armstrong Foundation *LIVESTRONG*™ Young Adult Alliance is an example of an international collaboration focussing an AYA cancer.

There is a need for continued advocacy and promotion of AYA cancer issues, particularly to encourage collaboration between clinicians and between medical groups and cancer organisations. Strengthening the networks of advocates for AYA cancer, including consumers, medical colleges and other stakeholders will also be important.

The sponsoring organisations also have a strong advocacy role in negotiations on harmonised Sate and federal arrangements and identification of performance indicators and processes for reporting and benchmarking.

The forum was closed by Professor Dr David Goldstein. On behalf of the sponsors he thanked participants for their contribution and undertook to ensure that the report of the forum was made available to participants and to take the agenda agreed at the forum forward.

7. LIST OF PARTICIPANTS

Title	First Name	Surname	Location
Dr	Verity	Ahern	NSW
Dr	Karen	Albritton	USA
Dr	Roger	Allison	QLD
Dr	Frank	Alvaro	NSW
Dr	Brad	Augustson	WA
Ms	Alison	Baker	NSW
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Dr	Sue	Carroll	NSW
Dr	Robyn	Cheuk	QLD
Dr	Richard	Cohn	NSW
Dr	Robin	Corbett	NZ
Ms	Angela	Cotroneo	NSW
Mr	Keith	Cox	NSW
Ms	Ella	Curnow	ACT
Dr	Luciano	Dalla Pozza	NSW
Ms	Rosemary	Dillon	NSW
Ms	Maeve	Downes	SA
Ms	Donna	Drew	NSW
Ms	Anita	Edwards	VIC
Ms	Leanne	Fowler	NSW
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Professor	David	Goldstein	NSW
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Ms	Susan	Hanson	ACT
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Professor	Glen	Marshall	NSW
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Ms	Marg	McJannett	NSW
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Dr	Andrew	Parasyn	NSW

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Dr	Phil	Rowlings	NSW
Mr	Nischal	Sahai	QLD
Dr	Robyn	Saw	NSW
Dr	Susan	Sawyer	VIC
Ms	Emma	Sayers	NSW
Mrs	Clare	Sayers	NSW
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Ms	Anne	Senner	NSW
Dr	John	Seymour	VIC
Dr	Catherine	Shannon	QLD
Ms	Sue	Sinclair	NSW
Dr	Colum	Smith	NSW
Dr	Ray	Snyder	VIC
Dr	Peter	Steadman	QLD
Dr	Michael	Stephens	NSW
Professor	Martin	Tattersall	NSW
Dr	David	Thomas	VIC
Ms	Kate	Thompson	VIC
A / Professor	Damien	Thomson	QLD
Ms	Danielle	Tindle	QLD
Ms	Shannon	Tracey	NSW
Ms	Melissa	Walls	QLD
Dr	Euan	Walpole	QLD
Dr	Greg	Wheeler	VIC
Professor	Les	White	NSW
A / Professor	Brenda	Wilson	SA
Dr	Giselle	Withers	VIC
Dr	Rosemary	Young	TAS
Mr	Andrew	Young	NSW