



Clinical Oncology Society of Australia

AYA Clinical Professional Day Report

AYA Cancers, Genetic/Ethical Challenges and AYA Cancer Survivorship

Friday 5th December 2014

Melbourne Convention and Exhibition Centre

Introduction

The AYA Clinical Professional Day (CPD) was held on Friday 5th December directly following the COSA Annual Scientific Meeting. The CPD was funded by a COSA CPD grant and the program was developed by the COSA AYA Executive Committee.

The 2014 COSA ASM theme was survivorship, palliative care, lung cancer and metastases. The COSA AYA Clinical Professional Day was designed around two themes; the theme of Survivorship for AYA's to complement this broader ASM theme and the theme of AYA cancers and genetic and ethical challenges.

The AYA Executive Committee were pleased to be able to include several international speakers from the WCC AYA symposium in the all-day program as well as local expert speakers.

Background

COSA has convened five previous AYA Cancer Workshops (2007-2011) to enhance AYA service delivery and build networks under the Youth Cancer Networks Program and a sixth workshop in 2012 on the theme 'expanding the continuum of care'.

Aim

The aim of the CPD was to provide health professionals engaged in the care of AYA's with the opportunity to network and have professional development on current AYA Oncology issues.

The COSA AYA Executive Committee felt the COSA audience would primarily want clinical and research information, rather than core competencies and identified the education of adult oncologists and other COSA members in AYA oncology as a continuing area of need.

Program

Time	Session Title	Speaker	Organisation
8.45am	Registration		
9.00am	Welcome and Introduction	Wayne Nicholls	Paediatric Oncologist, Royal Children's Hospital Brisbane
Session Theme: AYA Cancers and Genetic/Ethical Challenges, Chair: Antoinette Anazodo			
9.15am	Breast Cancer in Young Women (including genetic risk assessment)	Alison Trainer	Consultant Clinical Geneticist, Peter MacCallum Cancer Centre
10.00am	Colorectal Cancer in AYAs (including genetic risk assessment)	Lara Lipton	Medical Oncologist, Royal Melbourne Hospital
10.45am	Morning Tea		
11.15am	Sarcomas and Genetic Cancer Risk: The Kindred Study	Paul James	Clinical Geneticist, Peter MacCallum Cancer Centre

11.45am	Pros and Cons of Genetic Testing of Offspring and Siblings	Paul James	
12.00pm	Panel Discussion: Genetics and Ethics	Lara Lipton Paul James Rebecca Johnson Alison Trainer	
12.30pm	Lunch		
Session Theme: AYA Cancer Survivorship, Chair: Wayne Nicholls			
1.30pm	Fertility Preservation in Australia	Antoinette Anazodo Kate Stern	Adolescent Oncologist, Sydney Children's Hospital Gynaecologist & Head of Clinical Research, Melbourne IVF
2.00pm	Optimising Fertility Preservation	Rebecca Johnson	Medical Director, AYA Oncology Program Seattle Children's Hospital, USA
2.30pm	AYA distress screening and developmentally appropriate oncology care	Norma D'Agostino	Psychologist, Princess Margaret Cancer Centre, Canada
3.15pm	Afternoon Tea		
3.30pm	Nutritional Status and Perceived Nutritional Needs of Adolescents & Young Adults with Cancer	Natalie VanderHaak	Senior Dietician, Women's and Children's Health Network, SA
4.15pm	CanTeen Online Support Platform	John Friedsam	Counselling services manager, CanTeen
4.30pm	Panel Discussion: Survivorship	Antoinette Anazodo Kate Stern Rebecca Johnson Norma D'Agostino Natalie VanderHaak John Friedsam	
5.00pm	Close		

Genetics and Ethics Panel Discussion Key Points

Discussions with AYA's seeking predictive genetic testing are complex and nuanced. Members of families with a strong family history of cancer may have a very high expectation of risk. This is a self-selected population of information seekers. Often the perception of risk is higher than the actual risk. Counselling and screening programs need to go hand in hand with predictive testing.

It is important to address family issues as part of the process and have psychological support available. Discussions around predictive genetic testing may bring up feelings of grief. An

example of this is young women who have lost their mothers to breast cancer having genetic testing in order to reassure the remaining parent.

There is very little data about how different cultures view genetic information and this includes indigenous Australians. This is a big area where more information is required. An interpreter should be compulsory for genetic counselling. There are very complicated concepts in the genetic discussion even for people from a non-English speaking background who are proficient in English. Conversations with AYA's from different linguistic or cultural backgrounds are even more difficult.

There is a trend towards young women requesting bilateral mastectomy at diagnosis. The decision may have become a reflex. Young women need information from the multi-disciplinary team including geneticists not just the breast surgeon. The late psychological effects of bilateral mastectomy for young women has not been well studied. The contralateral risk for young women is a long term risk which means it can be discussed at a later time not necessarily at diagnosis.

Tamoxifen can be prescribed for oestrogen receptor positive breast cancer for up to 10 years. This may coincide with the reproductive window for some young women. Oncologists need to be prepared to discuss interrupting Tamoxifen for child bearing for women in this situation.

There are great concerns about equity of access to genetic information and services and AYA's are even more vulnerable.

AYA Cancer Survivorship Panel Discussion Key Points

The panel discussion focused on questions and discussion about the FUTuRE Fertility study and the Australasian Oncofertility Registry. There is potential for the registry to become a national database in the future. Long term late effects data in Australia is poorly collected. The registry will supply more information than is currently available.

The first phase of the project will focus on uptake and referral – the registry will help clarify referral pathways at the level of cancer centres, state level and eventually nationally.

There is a need to up skill more fertility specialists and increase availability of services with tertiary referral as required.

Clinical Professional Day Evaluation

Summary

The clinical professional day was attended by 43 delegates. Please refer to Appendix 1 for a full list of participants.

As with previous workshops, the opportunity to network with other health professionals was a major draw-card for respondents (71%) and learning about the area of AYA oncology (57%). However, the most popular reason for attendance (93%) was the opportunity to hear from international speakers.

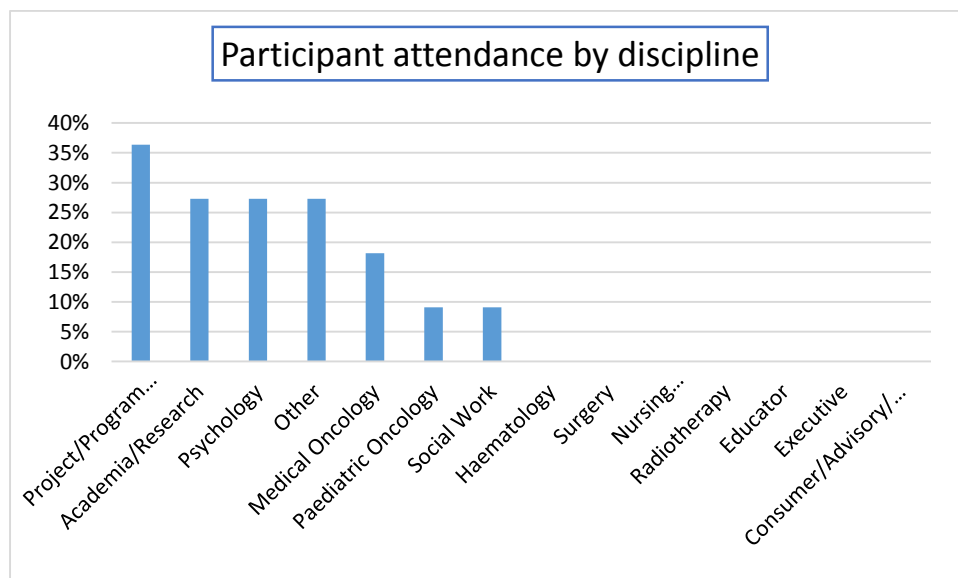
Overall, the workshop was highly regarded. All respondents indicated that the workshop met their expectations either completely (71%) or somewhat (29%). All program sessions were very well received and most respondents (92%) felt there was value in COSA hosting future events for AYA cancer. Pleasingly all respondents (100%) indicated that they would attend/recommend others to attend future COSA AYA Clinical Professional Days.

Participant Demographics

The clinical professional day evaluation was completed by 14 out of the 43 participants (32%). The majority of respondents worked in project/program management (36%), psychology (27%) and academia/research (27%) (Figure 1).

Half of the respondents do not currently work in a dedicated AYA program, hospital or facility (50%).

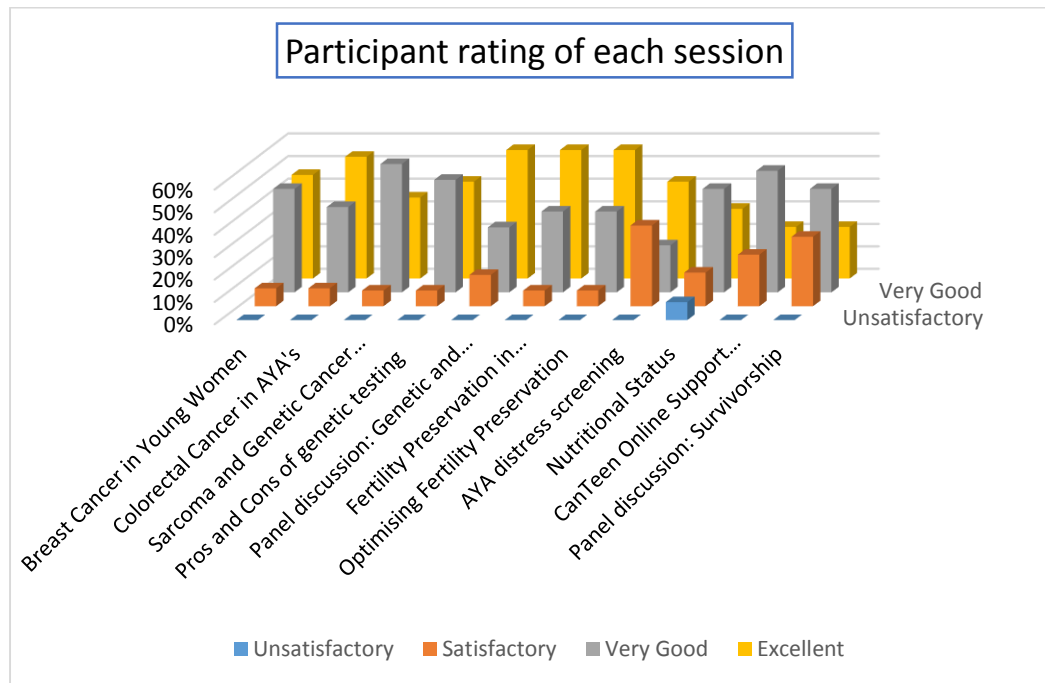
Figure 1.



Program Evaluation

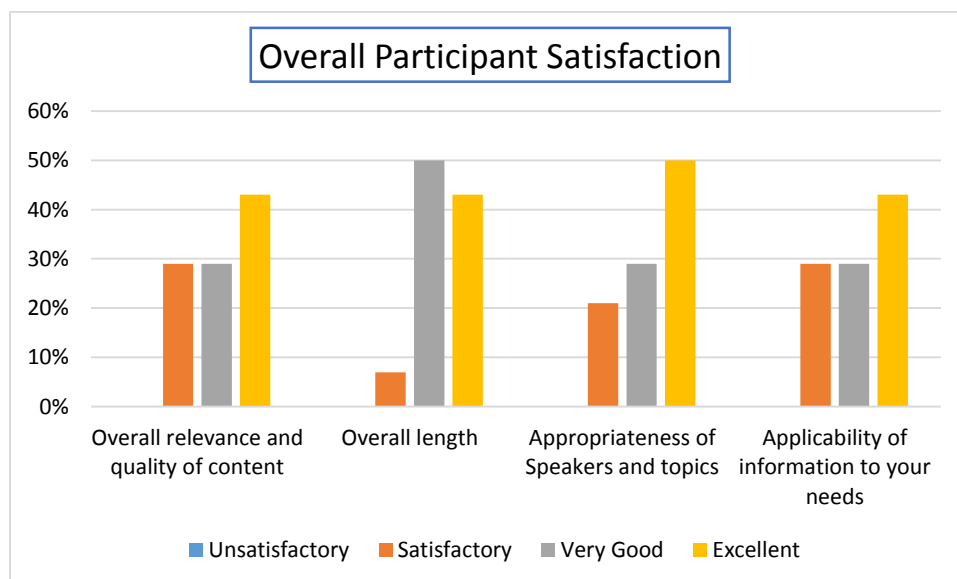
All CPD sessions were well received (Figure 2).

Figure 2.



Respondents also rated the overall relevance, content, length, appropriateness and applicability of the CPD highly (Figure 3).

Figure 3.



Reasons for Attending the Workshop

The majority of respondents' reasons for attending the COSA AYA CPD were:

- Opportunity to hear from international speakers (93%)
- Opportunity to network with other health professionals (71%)
- To learn about the area of AYA oncology (57%)

Value of COSA Hosting Future Similar Events for AYA cancer

The majority of respondents (92%) feel there is value in COSA hosting future Clinical Professional Days or similar events for AYA cancer. Comments included:

- "This is an area that is often poorly addressed in adult centres"
- "It is a growing field with many factors that make it different to adult psycho-oncology"
- "Good opportunity for networking and hearing the latest evidence-based practice"
- "Yes- it is an emerging area and a useful opportunity for professionals to get together and network"

Acknowledgments

The AYA Executive Committee responsible for planning the program for the CPD are:

- Dr Wayne Nicholls (Chair) - Paediatric oncologist, QLD
- Dr Lisa Orme (Deputy Chair) – Paediatric and adolescent oncologist
- Dr Antoinette Anazodo - AYA oncologist, NSW
- Dr Kylie Mason – Haematologist, VIC
- Dr Michael Osborn – Paediatric oncologist and haematologist, SA
- Dr Marianne Phillips - Adolescent oncologist, WA
- Dr Martin Tattersall – Medical oncologist, NSW
- Ms Kate Thompson - Manager, ONTrac at Peter Mac, VIC
- Dr Toby Trahair - Paediatric oncologist, NSW

Appendix Two: AYA CPD Participants

First Name	Last Name	Organisation	State	Country
Judy	Allen	EasternHealth	VIC	Australia
Antoinette	Anazodo	Sydney Children's Hospital	NSW	Australia
Ilana	Berger	ONTrac at Peter Mac Victorian AYA Cancer Service	VIC	Australia
Jenni	Bourke	Peter MacCallum Cancer Centre	VIC	Australia
Norma	D'Agostino	Princess Margaret Cancer Centre	Ontario	Canada
Emily	Dawson	Melbourne health	VIC	Australia
Hera	Dimitriadis	NSW/ACT YCS	NSW	Australia
Carly	Fay	Cancer Council Queensland	QLD	Australia
Alana	Fitzgibbon	Royal Hobart Hospital	TAS	Australia
John	Friedsam	CanTeen	NSW	Australia
Lyndal	Gray	Princess Alexandra Hospital	QLD	Australia
Ana	Guinea	CanTeen	NSW	Australia
Allan	Hayward	Youth Cancer Service SA/NT- RAH	SA	Australia
Rachel	Hughes	Sir Charles Gairdner Hospital	WA	Australia
Paul	James	Peter MacCallum Cancer Centre	VIC	Australia
Rebecca	Johnson	Seattle Children's Hospital	WA	United States
Melissa	Jones	SA/NT Youth Cancer Service	SA	Australia
Francois	Joseph	Illawarra Shoalhaven Local Health District	NSW	Australia
Lara	Lipton	Royal Melbourne Hospital	VIC	Australia
Janine	MacDonald	CanTeen	NSW	Australia
Jillian	Mills	Cancer Council NSW	NSW	Australia
Lauren	Muir	Peter MacCallum Cancer Centre	VIC	Australia
Andrew	Murnane	Peter MacCallum Cancer Centre	VIC	Australia
Wayne	Nicholls	Royal Children's Hospital	QLD	Australia
Lisa	Orme	Peter MacCallum Cancer Institute	VIC	Australia
Genia	Rozen	Royal Women's Hospital	VIC	Australia
Corinne	Ryan	Queensland Health	QLD	Australia
Kate	Stern	Melbourne IVF	VIC	Australia
Michelle	Stewart	Redkite	VIC	Australia
Rebecca	Strutt	Liverpool Hospital	NSW	Australia
Kate	Thompson	ONTrac at Peter Mac Victorian AYA Cancer Service	VIC	Australia
Danielle	Tindle	Institute of Health and Biomedical Innovation, Queensland University of Technology	QLD	Australia
Alison	Trainer	Peter MacCallum Cancer Centre	VIC	Australia

First Name	Last Name	Organisation	State	Country
Megumi	Uchida	Nagoya City University Graduate School of Medical sciences		Japan
Samantha	Van Staalduin	ONTrac at Peter Mac Victorian Adolescent & Young Adult Cancer Service	VIC	Australia
Natalie	VanderHaak	Women's and Children's Hospital	SA	Australia
Amy	Wallis	Edith Cowan University	WA	Australia
Peter	Wilson	Royal Childrens Hospital	QLD	Australia
Bernadette	Zappa	Eastern Health	VIC	Australia