

3rd Global Adolescent & Young Adult Cancer Congress

December 4 - 6, 2018
Sydney | Australia

Pre Congress Workshops | December 3, 2018



Program & Abstract Handbook

#AYACANCERCONGRESS

The 3rd Global AYA Cancer Congress Scientific Committee

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Prof Paul Grundy

Dr Norma D'Agostino

FRANCE

Dr Valerie Laurence

JAPAN

Dr Miyako Takahashi

DENMARK

A/Prof Pia Riis Olsen

BELGIUM

Johan De Munter

Welcome to Sydney

On behalf of CanTeen Australia and the Adolescent and Young Adult Cancer Global Accord, we are delighted to welcome you to the 3rd Global AYA Cancer Congress. Following on from the success of previous Global AYA Cancer Congresses in Edinburgh and Atlanta, this year's event is welcoming over 400 delegates from more than 20 countries.

The program theme of the 2018 congress: Navigating the road through AYA cancer, will emphasise the importance of addressing all aspects of AYA cancer from prevention and diagnosis, through acute treatment, to survivorship, palliative care and rehabilitation.

We are incredibly grateful for all the wonderful contributors to the program which, in addition to our plenary program speakers and the adolescents and young adults who will share their insights, will be enriched with daily concurrent sessions, poster and rapid-fire presentations. We received an overwhelming 240 abstract submissions from 17 countries - we thank you all for your participation, time and energy to help shape a truly global approach to the congress. In addition to the primary program, we also held 4 pre-congress workshops. We are very appreciative to the many facilitators and convenors that produced such a valued addition to the congress.

During the breaks we encourage you to visit our exhibition space which will house a variety of organisations who have generously helped sponsor this important event. The exhibition area will showcase My Life Before, With and Beyond Cancer: Creative Consumer Contributions to the AYA Conversation – a wonderful opportunity for young people impacted by cancer to share their experiences of 'Navigating the road through AYA Cancer'. The mixed media exhibition is on display for all three days and we encourage you to view the wonderful art works.

We trust that you will enjoy our social events; the Welcome Reception and Gala Dinner, taking the opportunity to meet new colleagues with a shared passion in improving outcomes for AYAs and their families with cancer and also catching up with friends in the field.

We do hope you enjoy the next three days and some of the unique Australian sights, culture, tastes and sounds we have weaved into the scientific and social program for you.

Thank you again for your presence, contributions and collaboration. It is our aim that the 2018 AYA Global Accord Congress inspires you to return to your work with new ideas, connections and knowledge to drive forward advancements in practice and care of young people with cancer.

Best Wishes,



Professor Ian Olver AM
Chair, Scientific Committee
Professor of Translational Cancer Research
Director, University of South Australia
Cancer Research Institute



Peter Orchard
Chief Executive Officer
CanTeen Australia

3rd Global Adolescent and Young Adult Cancer Congress Program Quick Glance

Day 1 – Life Before Cancer

Tuesday 4 December 2018

7.45am	Registration		
8.30am	Opening Ceremony: Grand Ballroom 1 Prof Ian Olver: Official opening of congress Mr Glen Doyle: Welcome to country The Hon. Greg Hunt MP, Federal Minister for Health: Video Message Opening address from the Global Accord partners: CanTeen: Mr Peter Orchard Teen Cancer America: Mr Simon Davies Teenage Cancer Trust: Ms Kate Collins		
9.00am	Plenary 1: AYA Priority Setting & Practice Innovation Chair Introduction: Dr Norman Swan & Mr Joey Lynch Grand Ballroom 1		
9.05am	Professor Paul Grundy - Establishing AYA cancer as a national priority: the Canadian experience		
9.25am	Dr Lorna Fern – Adolescent & young adult diagnostic timelines, pathways & impact on patient outcomes		
9.45am	A/Professor Pia Riis Olsen & Ms Mette de Fine Licht – The difference a friend can make		
10.10am	Speaker panel discussion and audience Q&A		
10.30am	Morning Break – Exhibition & Poster Viewing		
11.00am	RAPID FIRE 1.1 & POSTER VIEWING Chair: Mr Peter Orchard Grand Ballroom 1	RAPID FIRE 1.2 & POSTER VIEWING Chair: Dr Ursula Samson-Daly Hyde Park Room	
11.30am	CONCURRENT 1.1 – LEADERSHIP IN AYA CANCER Co-Chairs: Dr Miyako Takahashi & Ms Madeleine Way Phillip Room	CONCURRENT 1.2 – AYA CANCER POLICY & PRIORITIES Co-Chairs: Dr Allison Werner-lin & Mr Jessada Phuntuya Hyde Park Room	CONCURRENT 1.3 – RARELY HEARD VOICES & MINORITY POPULATIONS Co-Chairs: Ms Louise Sue & Ms Aggie Kasicka Grand Ballroom 1
1.00pm	Lunch Break – Exhibition & Poster Viewing		
1.45pm	CONCURRENT 2.1 – PREVENTION & EARLY DETECTION Co-Chairs: Dr Natalie Bradford & Mr Terence Rumblow Grand Ballroom 1	CONCURRENT 2.2 – PROFESSIONAL DEVELOPMENT Co-Chairs: Dr Stu Siegal & Mr Sean Dondas Hyde Park Room	CONCURRENT 2.3 – AYA CANCER DATA & EPIDEMIOLOGY Co-Chairs: Mr Johan De Munter & Ms Kathryn Woodward Phillip Room
3.15pm	Afternoon Break – Exhibition & Poster Viewing		
3.15pm	AYA Consumer Closed Networking Session – Phillips Room		
3.35pm	Plenary 2: AYA Cancer Risk –Melanoma, Lifestyle & Inherited Risk Profiles Co-Chair Introduction: Dr Norman Swan & Ms Tilly Gorce Grand Ballroom 1		
3.40pm	Professor Richard Scolyer – Melanoma: Progress to Date and Future Prospects in the Fight Against Australia's National Cancer		
4.00pm	A/Professor Gill Hubbard – Approaches to addressing lifestyle-based cancer risks amongst adolescents & young adults		
4:20pm	Dr Allison Werner-Lin – Communicating genetic testing results in family and social networks: Meeting the unique psychosocial needs of AYAs		
4:40pm	Speaker panel discussion and audience Q&A		
5.00pm	Day 1 Close		
5.00pm	Welcome Reception – Sheraton Grand Sydney Hyde Park		

3rd Global Adolescent and Young Adult Cancer Congress Program Quick Glance

Day 2 – Life With Cancer

Wednesday 5 December 2018

7.45am	Registration		
8.15am	<u>Plenary 3: Therapeutic advances – New treatments, clinical trials & exercise</u> Co-Chair Introduction: Dr Norman Swan & Ms Kathryn Woodward Grand Ballroom 1		
8.20am	Professor Miles Prince – Predicting the future use of novel immunotherapy; experience to date in blood cancer proves that 'one size does not fit all'		
8.40am	Professor David Thomas – The International Sarcoma Kindred Study: mapping the genetic basis of sarcoma risk		
9.00am	A/Professor Prue Cormie – Exercise medicine for cancer		
9.20am	Professor David Freyer – Cancer Clinical Trial Participation: Understanding the Problem to Unlock the Potential		
9.40am	Speaker panel discussion and audience Q&A		
10.00am	Morning Break – Exhibition & Poster Viewing		
10.30am	RAPID FIRE 2.1 & POSTER VIEWING Chair: Dr Fiona McDonald Grand Ballroom 1	RAPID FIRE 2.2 & POSTER VIEWING Chair: Ms Mette De Fine Licht Hyde Park Room	
11.00am	CONCURRENT 3.1 – AYA TREATMENT ADVANCES Co-Chairs: Dr Tristan Pettit & Mr Joey Lynch Phillip Room	CONCURRENT 3.2 – FERTILITY Co-Chairs: Dr Karen Fasciano & Ms Madeleine Way Grand Ballroom 1	CONCURRENT 3.3 – MEASURING DISTRESS & NEEDS Co-Chairs: Prof Nick Hulbert-Williams & Mr Sean Dondas Hyde Park Room
12.30pm	Lunch Break – Exhibition & Poster Viewing		
1.30pm	CONCURRENT 4.1 – CLINICAL TRIALS ACCESS Co-Chairs: Dr Antoinette Anazodo & Ms Aggie Kasicka Phillip Room	CONCURRENT 4.2 – AYA CANCER PROGRAMS Co-Chairs: Prof Paul Grundy & Ms Tilly Gorce Grand Ballroom 1	CONCURRENT 4.3 – SURVIVORSHIP CONSIDERATIONS Co-Chairs: Dr Haryana Dhillon & Mr Terence Rumblow Hyde Park Room
3.00pm	Afternoon Break – Exhibition & Poster Viewing		
3.00pm	AYA Consumer Closed Networking Session – Phillip Room		
3.20pm	<u>Plenary 4: Addressing life stage & cultural complexities</u> Co-Chair Introduction: Ian Olver & Mr Jessada Phuntuya Grand Ballroom 1		
3.25pm	Ms Heidi Watson – Understanding the issues faced by taitamariki with cancer in Aotearoa		
3.45pm	Mr Kyran Dixon – Understanding Cancer within Indigenous Australian Adolescents and Young Adults		
4.05pm	A/Professor Donald Payne – Adolescent and Young Adult Medicine and Oncology		
4.25pm	Professor Nick Hulbert Williams – Acceptance and Commitment Therapy (ACT) for people affected by cancer: what does the evidence tell us, and how can we do better?		
4.45pm	Speaker panel discussion and audience Q&A		
5.00pm	Day 2 Close		
7.00pm	Congress Gala Dinner – Doltone House, Jones Bay Wharf		

3rd Global Adolescent and Young Adult Cancer Congress Program Quick Glance

Day 3 – Life Beyond Cancer

Thursday 6 December 2018

8.00am	Registration		
8.30am	<u>Plenary 5 - Financial toxicity, fertility & family</u> Co-Chair Introduction: Dr Norman Swan & Mr Sean Dondas Grand Ballroom 1		
8.35am	Ms Lynne Pezzullo & Ms Kathryn Woodward - The economic cost of cancer in adolescents and young adults		
9.00am	Dr Antoinette Anazodo – Fertility outcomes in adolescent and young adult cancer survivors		
9.20am	Dr Miyako Takahashi – The impact of cancer on adolescent and young adult survivors' job seeking and continuation of work: needs for comprehensive support		
9.40am	A/Professor Melissa Alderfer & A/Professor Pandora Patterson – Recent Developments in Supporting Siblings of Young Cancer Patients and Conceptualizing their Experience		
10.05am	Speaker panel discussion and audience Q&A		
10.30am	Morning Break – Exhibition & Poster Viewing		
11.00am	RAPID FIRE 3.1 & POSTER VIEWING Chair: Dr Adam Walczak Grand Ballroom 1	RAPID FIRE 3.2 & POSTER VIEWING Chair: Dr Stu Siegel Hyde Park Room	
11.30pm	5.1 – SURVIVORSHIP PROGRAMMING Co Chairs: Mr Andrew Murnane & Ms Aggie Kasicka Grand Ballroom 1	5.2 – END OF LIFE CARE Chair: Ian Olver Hyde Park Room	5.3 – FAMILY, BEREAVEMENT & THE IMPACT OF CANCER BEYOND THE PATIENT Chair: A/Prof Pandora Patterson Phillip Room
1.00pm	Lunch Break – Exhibition & Poster Viewing		
1.45pm	Garmin Watch prize draw 1:45pm @ Garmin Stand, exhibition hall		
1.30pm	AYA Consumer Closed Networking Session – Phillip Room		
2.00pm	<u>Plenary 6: Bereavement, survivorship & integration of a cancer diagnosis into life after treatment</u> Co-Chair Introduction: Dr Norman Swan & Ms Madeleine Way Grand Ballroom 1		
2.05pm	Professor Kevin Oeffinger – AYA Cancer Survivors, Risk-Based Health Care, and the Role of the Primary Care Physician		
2.25pm	Q&A		
2.30pm	Professor Barbara Jones – Adolescents and Young Adults with Cancer: Facing Loss, Finding Meaning, Focusing on the Future		
2:50pm	Q&A		
2.55pm	Introduction of Survivor panel & Tilly Gorce poetry slam		
3.00pm	International AYA Survivor Panel: AYA Advocates from around the globe discuss & reflect on their cancer experiences, learnings from the congress & future priorities for the AYA cancer community Facilitator: Prof Barbara Jones and Dr Norman Swan Panellists: Mr Terence Rumblow (United Kingdom), Ms Mette de fine Licht (Denmark) Mr Kyrán Dixon (Australia), Ms Becca Jacobsen (USA), Ms Yumiko Shirai (Japan)		
3.45pm	Closing Remarks • Best Poster & Best Oral Award Professor Ian Olver AM Ms Kate Collins		
4.00pm	Congress Close		

Welcome to Country

CanTeen together with our Global Accord partners, acknowledge Aboriginal and Torres Strait Islander peoples as the traditional custodians of our land – Australia.

We acknowledge the Gadigal people of the Eora Nation as the traditional custodians of this place we now call Sydney.

As a mark of respect to the traditional custodians, the Congress will be opened with a Welcome to Country ceremony performed by Glen Doyle. The aim of the ceremony is to acknowledge the traditional custodians and welcome the wider community.

Glen Doyle - Indigenous Performer.



Born on Gadigal Land, Glen grew up on Dharwhal (pronounced Darr-a-whal) Land. His mother is a descendant of the Murra-Wari (pronounced Moora-worry) located near North West NSW.

Glen has performed for the Queens Diamond Jubilee, State of Origin and World Master's Games, and many other events across the world.

Acknowledgements

The 3rd Global Adolescent and Young Adult Cancer Congress is supported by funding from the Australian Government under the Youth Cancer Services Program



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Global Accord Welcome



Peter Orchard

Peter Orchard has been involved in the planning, review and delivery of services specifically for young people for almost 30 years. His work has spanned cancer, mental health and homelessness. Peter is the CEO of CanTeen, an organisation for young people (12-25 years) dealing with their own cancer or that of a close relative, including those experiencing bereavement. CanTeen conducts research, provides clinical psychosocial and other support to young people and their families and works closely with Australian and State health departments as well as hospitals to provide national, hospital-based Youth Cancer Services. In addition, CanTeen will have funded the rollout of early phase clinical trials for young cancer patients across Acute Lymphoblastic Leukaemia, Ewing's Sarcoma, Medulloblastoma and a Genomic Medicine program. CanTeen also has young people involved at every level of the organisation, including the Board and is committed to both advocating for and supporting their needs.



Simon Davies

Now in its sixth year, Simon leads Teen Cancer America, the only national charity in the USA working directly with academic and community hospitals to advise, support and fund them in the development of specialized programs and facilities for adolescents and young adults with cancer. The charity is built on the successful model of Teenage Cancer Trust, UK where Simon was Chief Executive Officer for 13 years before launching Teen Cancer America in 2012. His early career was in the management of substantial social and health care services in the fields of Learning Disability and Mental Health. As a recipient of an honorary Doctorate in Education by University of Coventry for his work in the field of Adolescent and Young Adult Cancer, Simon has developed an international reputation for success in bringing about change within traditionally structured health systems.



Kate Collins

Kate has worked in UK charities for nearly 20 years and joined Teenage Cancer Trust in 2009 initially to lead fundraising, becoming a Director in 2013 and, in March 2018 Chief Executive. Teenage Cancer Trust has led the way in the creation of world-class cancer services for young people, providing life-changing care and support. The charity has 28 specialist units within NHS hospitals bringing young people (aged 13 – 24) together; ensuring they are treated by teenage cancer experts. There is an expanding Teenage Cancer Trust team of clinical specialists of nurses & youth workers and Teenage Cancer Trust is the only UK charity providing this much needed specialist nursing and support. Kate is leading a strategy to ensure the charity can reach all young people with cancer in the UK and is ensuring that young people and their needs remain at the heart of everything the charity does.

Congress MC



Dr Norman Swan FRCP, DCH, MD (Hon Causa)

Dr Norman Swan hosts The Health Report on the ABC's Radio National, and Tonic on ABC News24 (Television). The Health Report is the world's longest running health programme in the English speaking world and Norman has won many awards for his work including Australia's top prize for journalism, the Gold Walkley. He was only the third person to be awarded the prestigious medal of the Australian Academy of Science and was given an honorary MD by the University of Sydney on its 150th anniversary.

Norman trained in medicine in Scotland and paediatrics in London and Sydney before joining the ABC and has hosted many other programmes on radio and television.

He was the medical host on Channel Ten's Biggest Loser for six seasons and is a guest reporter on ABC's Four Corners. Norman created, wrote and narrated Invisible Enemies, a four part series on disease and civilisation for Channel 4 UK and broadcast in 27 countries.

He has consulted to the World Health Organisation and co-chaired a global meeting of health ministers in Bamako West Africa focused on evidence based policy and priorities in health research. He has been the Australian correspondent for both the Journal of the American Medical Association (JAMA) and the British Medical Journal (BMJ).

Norman is also co-founder of Tonic Health Media, an integrated health television channel and production company which has over 15 million viewers per month.

Congress Chair



Ian Olver AM

Ian Olver AM is a medical oncologist, bioethicist and researcher. He is currently Professor of Translational Cancer Research, and Director University of South Australia Cancer Research Institute where he heads a psycho-oncology research team. He completed a PhD at Monash University on end-of-life issues. He is the immediate past President of the Multinational Association of Supportive Care in Cancer and sits of the Youth Cancer Services Strategic Advisory Group of CanTeen.

AYA Participation at the 2018 Congress

It is a shared priority amongst the Global Accord partners to ensure that the energy, ideas and presence of young people is a feature of the Global AYA Cancer Congress. Role modelling genuine partnership between professionals and AYA consumers in the Congress, we are proud to say we have enjoyed the creative, practical and meaningful input of young people at all stages of planning and delivery.

This year's Congress includes an international Creative Consumer Contributions Exhibition and the wonderful 'Getting Cancer Young' online resource which was developed by the Australian Youth Cancer Services National Youth Advisory Group. This resource will be shown throughout the Congress and we encourage you to utilise this tool in the work you do with young people and their families.

It is an absolute honour to work alongside and support young people who so generously take up leadership in the cancer arena, making a positive difference in this world.

Enjoy,



Nat Hornyak
National Manger - Youth Leadership

Invited speakers



Dr Melissa Alderfer

Dr. Alderfer is a Principal Research Scientist at the Center for Healthcare Delivery Science of the Nemours Children's Health System/A. I. duPont Hospital for Children and Associate Professor of Pediatrics at Sidney Kimmel Medical College of Thomas Jefferson University. She is Licensed Clinical Psychologist and has nearly 20 years of research experience in pediatric oncology focused upon understanding and improving family adjustment to cancer. She has over 100 peer-reviewed publications and chapters and has secured funding from the National Cancer Institute, American Cancer Society, the Department of Defense, LIVESTRONG, Alex's Lemonade Stand Foundation, and the Andrew McDonough B+ Foundation for research regarding families and specifically siblings of children with cancer.



Dr Antoinette Anazodo

Dr Anazodo trained in Paediatric and Adolescent Oncology in the United Kingdom and completed her training with a clinical fellowship in the Kids Cancer Centre at Sydney Children's Hospital. During her training and fellowship Dr Anazodo completed a postgraduate diploma in Adolescent Oncology.

Dr Anazodo was appointed as Director of Adolescent and Young Adult (AYA) Cancer at Sydney Children's and Prince of Wales Hospital in October 2010 and has subsequently developed a comprehensive AYA cancer service across both the paediatric and adult cancer centre. Her appointment across the paediatric and adult campus has also provided opportunities for clinical and research collaboration. Dr Anazodo has been part of the AYA national leadership group working with national and state partners to develop specialist Youth Cancer Services (YCS) across Australia providing vital treatment and support to young patients.

Dr Anazodo leads the Future Fertility research program on reproductive concerns of cancer patients and in addition to the medical and psychological studies she has been instrumental in the development of Medicare item numbers for public funding for oncofertility care in Australia and leads international work on oncofertility models of care and a global competency framework. Dr Anazodo is the chair for the Australian AYA fertility preservation group and guidelines group.

Dr Anazodo has received a number of awards, including a Champions Award from Prince of Wales Hospital, Pride of Australia award in 2015, Churchill Fellowship in 2015 and nomination for Women of the Year in February 2016 and 2017 for her work on reproductive concerns in cancer patients. She has recently been shortlisted for a Premiers Award for 'Improving Government Services' for Oncofertility care.

[@ANZoncofert](#)



A/Professor Prue Cormie

Associate Professor Prue Cormie is an Accredited Exercise Physiologist whose research and clinical work focuses on the role of exercise in the management of cancer. Her track record includes over \$3 million in competitive research grant funding and over 70 refereed publications. Prue has produced influential research exploring the efficacy of targeted exercise prescriptions in counteracting significant side effects of cancer and cancer treatments. Prue is the inaugural Chair of the Clinical Oncology Society of Australia Exercise Cancer Group and the Exercise and Sports Science Australia Cancer Special Interest Group. A core component of her work is invested to translating research into practice for meaningful improvements in health care services for people with cancer.

@pruecormie



Mette De Fine Licht

Teenage cancer survivor, author and speaker Mette de Fine Licht has written 10 books, including the memoir, *Willpower Girl — A Teenager's Trek Through Cancer*.

Born in 1985, Mette de Fine Licht was diagnosed with Ewing's Sarcoma when she was just sixteen years old. After undergoing chemotherapy and extensive surgery, which included the placement of an internal prosthesis in her leg, she was cured.

On the blog at willpowergirl.com Mette de Fine Licht writes about life as a teenage cancer patient, about the challenges and victories every day of being a teenage cancer survivor and about becoming a mom after cancer. Mette de Fine Licht is also an often booked speaker with valuable insights for both teenage cancer patient.

Today Mette de Fine Licht is a partner in the book agency *Skriveværkstedet*, where she advises other authors on writing, publishing and promoting, and she teaches writing workshops in Denmark and Bali. She is a sought-after ghostwriter and communications advisor to authors, publishers and companies. Mette de Fine Licht lives in Copenhagen, Denmark, with her husband Martin and their two sons Erik and Harald. In 2012 she was awarded as *Fighter Of The Year* in Denmark.

At the 3rd AYA Global Cancer Congress 2018 in Sydney Mette de Fine Licht will speak about the importance of including the patient's network. She will share insights from her own story and reveal how the nurses and oncologists guided her friends and family to be the best support during her treatments, and what difference that made for her.



Kyran Dixon

Braving two battles with cancer, Kyran Dixon is a role model for young Indigenous people in his community. After being diagnosed with bone tumour in his hip when he was just 11, this talented Australian Rules footballer had to press pause on his sporting ambitions. Working his way back to football, Kyran joined the Port Adelaide Football Club Academy before disaster struck. A second diagnosis, this time Acute Myeloid Leukemia in 2014, demanded lifesaving treatment. While enduring rounds of chemotherapy, Kyran maintained his university studies, graduating in 2016. He's now an ambassador that actively promotes cancer awareness and research.

As a proud member of the Kurna and Narungga clans, Kyran is a founding member of the Aboriginal Youth Cancer Advisory Group, and promotes healthy lifestyle choices among Aboriginal young people. Whether he's a guest speaker or a mentor for at-risk youth, Kyran spreads a message of hope, strength and resilience, and motivates others to make the most of their chances.

@kyrandixon



Dr Lorna Fern

Dr Lorna Fern is the National Cancer Research Institutes Teenage, Young Adult and Germ Cell Clinical Studies Group Researcher and Patient/Public involvement lead. She currently Chairs the NCRI Health Services Research Subgroup. Dr Fern has driven the work of the group for over ten years with an accumulated £3m of research funding across the patient pathway including BRIGHTLIGHT the largest study of young people with cancer.

Dr Fern completed her PhD in Molecular Oncology looking at the long-term effects of chemotherapy on the bone marrow and became interested in young people with cancer while working on an adult bone marrow transplant unit. After a short spell in the commercial world she moved to the National Cancer Research Institutes Teenage, Young Adult and Germ Cell Clinical Studies Group where she pioneered the first systematic investigation of access to research for young people in the U.K. She is part of the core BRIGHTLIGHT Team and leads patient and public involvement for the programme. Improving the cancer diagnostic experience for young people is core to Dr Fern's research interests and she will present some of the latest data from the U.K.

@LornaAFern



Professor David Freyer

David R. Freyer, DO, MS is Professor of Clinical Pediatrics and Medicine at the Keck School of Medicine, University of Southern California (USC). He serves as Director of the Survivorship and Supportive Care Program in the Children's Center for Cancer and Blood Diseases at Children's Hospital Los Angeles (CHLA), as well as Director of the Cancer Survivorship Program, and Co-Director of the Adolescent and Young Adult (AYA) Cancers Program, at the USC Norris Comprehensive Cancer Center.

A Phi Beta Kappa scholar who graduated magna cum laude after three years at DePauw University, Dr. Freyer received his medical degree from the Des Moines University College of Osteopathic Medicine and Surgery. He took his general rotating internship caring for both adults and children at the Chicago College of Osteopathic Medicine and Hospitals, pediatrics residency at Rush University Medical Center, and pediatric hematology/oncology fellowship at the University of Michigan Medical Center/CS Mott Children's Hospital. He is board-certified in pediatric hematology and oncology. In 2007, Dr. Freyer also earned his Master of Science degree in Clinical Research Design and Statistical Analysis at the University of Michigan School of Public Health.

Dr. Freyer's clinical and research activities are centered in cancer survivorship, cancer control/supportive care, and adolescent/young adult oncology, and include the recognition, characterization, management and prevention of short- and long-term treatment-related toxicity, survivorship-focused health care transition, cancer care disparities, and patient-reported outcomes. He has been principal or co-investigator on numerous funded research studies. In the Children's Oncology Group (COG), he currently serves as Chair of the COG AYA Oncology Discipline Committee and as a member of the Cancer Control & Supportive Care and Outcomes & Survivorship Steering Committees. In 2018, Dr. Freyer was honored with the Robert M. McAllister Faculty Mentoring Award in the Department of Pediatrics in the Keck School of Medicine at USC. For numerous consecutive years, his clinical expertise has been recognized with citations in "Best Doctors in America."



Professor Paul Grundy

Paul graduated with an MD from the University of Alberta in 1979, did post graduate training in New Zealand and Edmonton before completing a fellowship in Pediatric Hematology Oncology at the Children's Hospital of Philadelphia. Paul has been on the faculty of the the Department of Pediatrics at the University of Alberta in Edmonton since 1988 and is currently a Professor of Pediatrics and Oncology.

His research career has focussed on Wilms tumour of the kidney, spanning the spectrum from basic molecular biology, to translational research to clinical trials.

Paul was Director of the Division of Pediatric Hematology and Oncology at the University of Alberta from 1999 to 2010. In this role, he was one of the founding members of C17, the Canadian network of childrens hematology/oncology programs. He subsequently served as Chair from 2006-2011. C17 now sponsors international clinical trials on behalf of the Canadian centers, develops and publishes evidence based guidelines for care and has overseen the development of communities of practice within childhood cancer for pharmacy, clinical research associates and nursing.

Paul is excited to now work with the Canadian Partnership Against Cancer (CPAC) as their Expert Lead for Pediatrics, Adolescents and Young Adults.

Paul has lived in Edmonton since 1988 with his wife, Lorie, and has four daughters.

[**@paulegrundy**](#)



A/Professor Gill Hubbard

Gill is Professor of Health Services Research at the University of the Highlands and Islands and Head of Research in the Department of Nursing. Gill is chairperson of a premier research group within the National Cancer Research Institute – Lifestyle and Behaviour Change Research Group. Her research with Teenage Cancer Trust has been cited in the England and Scotland national cancer strategies and raised in the Scottish parliament. As a research leader in her field, she is regularly invited to review for national and international research funding bodies. She is a member of the editorial board of two international journals and a member of the International Psychosocial Oncology Society research committee.

[**@gill_hubbard**](#)



Professor Nick Hulbert-Williams

Nick is a British Psychological Society Registered Coaching Psychologist and Professor of Behavioural Medicine. He was awarded his PhD from Cardiff University in 2010 for work exploring psychological adjustment to newly diagnosed cancer and he has since gone on to lead a substantial programme of work exploring the psychological impact of cancer and how we can best manage psychological needs in those treated for cancer, their support networks, and their healthcare professionals. He teaches in the Psychology Department at the University of Chester in the areas of research methods, contextual behavioural psychology, health psychology and coaching psychology. Nick is Director of the Chester Research Unit for the Psychology of Health (CRUPH).

Nick is past Chair of the British Psychosocial Oncology Society (BPOS) and a past member of the UK National Cancer Research Institute Psychosocial Oncology and Survivorship Clinical Study Group. He is currently Chair of the International Psycho-Oncology Society (IPOS) Research Committee, a member of the European Journal of Cancer Care editorial board, and a member of the Professional Advisory Board Research Sub-Committee for Maggie's UK. In 2015, Nick co-edited *Cancer and Cancer Care*, published by Sage.

[@profnickhw](#)



Becca Jacobsen

Becca grew up in the Puyallup, Washington, USA. She was diagnosed with Hodgkin's disease lymphoma a month before her 18th birthday, giving her the unique experience of deciding if she wanted to be treated as an adult or child. She elected to be treated as a child at Mary Bridge Children's Hospital in the Multicare Health System in Tacoma, Washington. During her time at Mary Bridge, Becca struggled to fit in, not meeting anyone near her own age or life stage and also being too grown up to fit into her child bed. Becca's experience led her to pursuing her Master's of Social Work degree and graduating top of her class at Brigham Young University. Becca is now working as a medical social worker for Multicare's Good Samaritan Hospital. In addition, Becca stands as a Lead Patient Advocate for young adult cancer patient research within Multicare's Research and Innovation Institute, working directly with Dr. Rebecca Johnson and the Adolescent and Young Adult Oncology Council in Tacoma (AYAOC). Becca lives with her husband and 4 year old son in Puyallup, Washington. Becca will be one of the 5 panellists for the Survivor Panel being held on day 3.



Professor Barbara Jones

Dr. Barbara Jones is Associate Dean for Health Affairs, University Distinguished Professor, and Co-Director of the Institute for Collaborative Health Research and Practice at the UT Austin Steve Hicks School of Social Work. At Dell Medical School, she is Chair of the Social Work Department, Associate Director of Social Sciences and Community Based Research at the LIVESTRONG Cancer Institutes and Professor of Oncology, Population Health and Psychiatry. She is also a Founding Steering Committee Member of the UT Austin Center for Health Interprofessional Practice and Education (IPE). Dr. Jones is a Distinguished Scholar and Fellow of the National Academies of Practice and immediate past Vice-Chair of the Social Work Academy. She is the Past President of APOSW and 2013 APOSW Social Worker of the Year. Dr. Jones was co-investigator on ExCEL in Social Work, an NCI-funded project to train oncology social workers, for which she received the 2014 APOS Outstanding Training and Education Award. She is a PDIA Social Work Scholar, and recipient of the PDIA Social Work Leadership Award. She serves on the National Advisory Board of the Cambia Health Foundation Sojourns Scholars Leadership Program, on the Steering Committee Member of the National Pediatric Palliative Care Research Network and on the Board of the Social Work in Hospice and Palliative Care Network. Dr. Jones' research focuses on improving care for children, adolescents and young adults with cancer and their families. Her current research focuses on palliative care, pediatric oncology social work interventions, and adolescent and young adult (AYA) cancer survivors. Her work has been funded by National Institutes of Health, Palliative Care Research Network, Seton Healthcare System, Texas State Department of Health and various foundations resulting in publications in top tier journals, including Pediatrics, Cancer, Pediatric Blood and Cancer, and Journal of Cancer Survivorship. Dr. Jones is Associate Editor of the Journal of Psychosocial Oncology.

[@Barbaralnjones!](#)



Professor Kevin Oeffinger

Dr. Oeffinger is a family physician, the founding Director of the Duke Center for Onco-Primary Care, and the Director of the Supportive Care and Survivorship Center at Duke Cancer Institute. He is a Professor in the Department of Medicine at Duke University Medical Center. Dr. Oeffinger has a long-standing record of NIH-supported research investigating late effects following teen and young adult cancer and methods to optimize risk-based care of cancer survivors. Also, for the last 20+ years, he has clinically managed a large group of survivors of childhood, teen, and young adult cancer.



A/Professor Pia Riis Olsen

Pia Riis Olsen became a registered nurse in 1980, received her MScN in 2001, and her PhD in 2009. She is a clinical nurse specialist in Oncology since 2004, currently in the Oncology Department at Aarhus University Hospital, DK. She is connected to the Youth Unit and her key research areas focus on caring for teenagers and young adults with cancer and Network Focused Nursing. She is an external associate professor at the Faculty of Health, Section for Nursing at Aarhus University, DK. She participated to eight International publications on the topic of 'Adolescents and young adults with cancer' since 2009, and has been awarded for the Best Original Research Paper in Cancer Nursing in 2010.

She is co-editor of the book *Nursing Adolescents and Young Adults with Cancer – Developing Knowledge, Competence and Best Practice* (Springer 2018). Pia Riis Olsen regularly speaks at international conferences and she is a Member of the European Network of Teenager and Young Adults with Cancer (ENTYAC), and a Board member of the European Academy of Nursing Science (EANS).

@PiaRiis



A/Professor Pandora Patterson

Dr Pandora Patterson is General Manager of Research and Youth Cancer Services at CanTeen, Adjunct Associate Professor with the Cancer Nursing Research Unit, Sydney University, and Visiting Professor with the Faculty of Health and Life Sciences, Coventry University, UK. She is a registered psychologist with 30 years' experience working with young people and their families, and has worked for the last 13 years in the area of AYA psycho-oncology research and health service development. With a focus on translating research into meaningful practice, her work has included leading the development and implementation of clinical measures, assessment processes, and interventions for young people impacted by cancer and their families. She oversees the implementation of the Australian Youth Cancer Services and has contributed to changes in the national health care system to improve the experience of AYAs with cancer.

@Pandora_P_



A/Professor Donald Payne

Donald Payne is a Consultant Physician specialising in Adolescent and Young Adult Medicine (AYAM). He is currently the Lead Clinician for the Western Australian Youth Cancer Service, and also works for headspace, a national community-based youth health service. Dr Payne played a leading role in establishing the Royal Australasian College of Physicians' advanced training program in AYAM and is a former President of the Australian Association for Adolescent Health.



Lynne Pezzullo

Lynne is Office Managing Partner of Deloitte Canberra, leading the national Health and Social Policy practice. Formerly Chair of Access Economics, she won the Telstra Business Woman of the Year Award ACT 2008 for pioneering and building the company's health practice into a global business that now spans five continents. Prior to this, Lynne worked for a decade in the Australian Government departments of the Treasury, Defence, and Foreign Affairs and Trade, as well as for Senator Gareth Evans to develop Asia Pacific Economic Cooperation and to compile the book Australia's Foreign Relations. Lynne is also now a World Health Organization advisor, Medical Journal of Australia reviewer, and ABC (Australian Broadcasting Commission) spokeswoman on health and social issues. She has authored hundreds of reports and contributed to books and journal articles on health conditions (including chronic diseases and risk factors such as obesity), policy reform, financing and funding, workplace health and safety, pharmaceuticals and technologies, e-health, homelessness, child protection, domestic violence, welfare reform and social inclusion. She has special interests in mental health, rural health, women's health and Indigenous health. Lynne first degree was a Bachelor of Economics with first class Honors from the University of Adelaide. Lynne subsequently tutored part time at the ANU in her early work years, and she is currently completing her PhD there at the Research School of Population health, her thesis being on best practice cost-of illness methods. She is married and lives in Canberra, Australia, with her husband and four children. In 2010, Lynne also wrote 'Reality Check: work life balance' which quantifies the impacts of work life conflict and provides evidenced based solutions for achieving equilibrium. In 2012 she launched her new website 'HealthEdata', at the Health Informatics Conference in Sydney. In addition to her business success, Lynne has a passion for giving back to her community through challenging fundraisers that have included climbing Mt Kilimanjaro, scaling peaks in Nepal and Patagonia, trekking the Tour de Mt Blanc, spearheading CEO Sleep outs in sub-zero temperatures, and leading Swimathons and endurance hikes.

[@lynnepezzullo](https://twitter.com/lynnepezzullo)



Professor Miles Prince

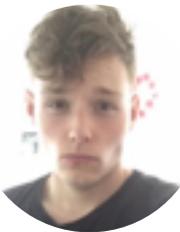
Professor Miles Prince AM is an internationally recognised Australian haematologist and Professor of Medicine at both Melbourne and Monash Universities. He is the Professor/Director of Cancer Immunology and Molecular Oncology at Epworth Healthcare and also Director of the Centre for Blood Cell Therapies at the Peter MacCallum Cancer Centre.

He is a very active clinician, also overseeing clinical and laboratory research – the latter involving stem cell research and cancer immunology. He has been involved in numerous clinical trials of new therapies for blood cancers and has been the Principal Investigator of over 100 clinical trials involving myeloma, lymphoma, leukaemia, transplantation and supportive care.

He has published over 400 peer-reviewed manuscripts. He is the Chief Investigator for an NH&MRC Program Grant in Cancer Immunology, Victorian Cancer Agency translational grants in Epigenetics, Melbourne Genomics Health Alliance and holds large US and European research grants. He is one of the establishing members of the Snowdome Foundation which focuses on 'accelerating new therapies for Australian patients with blood cancers'.

He is a Fellow of the Academy of Health & Medical Sciences and in 2014 Miles was appointed a Member of the Order of Australia for distinguished services to medicine particularly in the areas of blood cancer research, patient care and philanthropy leadership.

[@MilesPrince4](#)



Terence Rumbow

Terence connected with Teenage Cancer Trust to share his experiences and struggles with others so they know they are not alone. He offers great insight and ideas to others who have experienced cancer and is motivated by wanting to make a positive change. Terence had defied all the odds and is now in remission from Acute Lymphoblastic Leukaemia. He has learned how to walk (and run) again following a fractured pelvis and vertebrae and is chasing and achieving his dreams and goals, inspiring people along the way. Terrence will be co-chairing sessions throughout the Congress program and will be a panellist on Day 3 for the survivor panel.



Professor Richard Scolyer

Professor Richard Scolyer is Co-Medical Director and Consultant Pathologist at Melanoma Institute Australia; Senior Staff Specialist, Tissue Pathology and Diagnostic Oncology, Royal Prince Alfred Hospital, Sydney; and Clinical Professor, The University of Sydney.

Professor Scolyer studied medicine at the University of Tasmania. After completing clinical training in Australia and overseas, he undertook pathology training at the Canberra Hospital and at the Royal Prince Alfred Hospital leading to Fellowship of the Royal College of Pathologists of Australasia.

Professor Scolyer has presented on more than 300 occasions at conferences throughout the world, and is a co-author of more than 500 articles and book chapters on melanocytic pathology and related research including publications in *New England Journal of Medicine*, *Lancet*, *Nature*, *Nature Genetics*, *Lancet Oncology*, *Journal of Clinical Oncology* and *Cancer Discovery*. In 2006, Professor Scolyer was awarded the degree of Doctor of Medicine by The University of Sydney for his thesis of publications on melanocytic pathology. He received a NSW Premier's Award for Outstanding Cancer Research in 2009, 2012, 2013, 2014, 2016, 2017 and the Thomson Reuters 2015 Citation Award in the Clinical Medicine category. In 2016, Professor Scolyer was appointed editor of the 4th Edition of the World Health Organisation Classification of Tumours Skin Tumours volume. He is also Vice Chair of the Melanoma Expert Panel of the American Joint Committee on Cancer (AJCC) for the 8th edition of the AJCC Cancer Staging System, Co-lead of the Australian Melanoma Genome Project, an editorial board member of the *American Journal of Surgical Pathology*, and a number of other international journals. Professor Scolyer is Immediate Past President of the Australasian Division of the International Academy of Pathology. Together with other MIA colleagues, Professor Scolyer is chief investigator on a 5-year NHMRC program grant and has a personal Fellowship from the NHMRC.

[@ProfRScolyerMIA](https://twitter.com/ProfRScolyerMIA)



Yumiko Shirai

Yumiko is an advocate from the Japanese peer support organization "STAND UP!!". She was diagnosed with Uterine Cancer in her 20's and went on to have successful surgery, however it has affected her chance to have children. After treatment, she came across STAND UP!! which was just established and became an active member of the organization.

One of STAND UP's activities is to publish a magazine for young people with cancer. STAND UP publish one issue a year, releasing 30,000 copies to over 300 hospitals nationwide. Each issue has ten stories of survivors, a questionnaire and a discussion on a specific topic related to common problems in their lives during therapies or after treatments. The aim of STAND UP magazine is to let young people who are fighting cancer know that they are not alone.

During the congress, Yumiko will participate on day 3's survivorship panel and share her insights and experiences and also plans to take her learnings from the congress and bring them back to Japan.



Dr Miyako Takahashi

Dr. Miyako Takahashi is a Division Chief of the Division of Cancer Survivorship Research, National Cancer Center, Japan. After working as an internist for 10 years, she attended School of International Health, University of Tokyo obtaining her M.Sci and Ph.D. in Health Science. She is interested in diverse topics related to AYA cancer survivorship, especially employment, sexuality, and multi-disciplinary collaboration among care providers.



Professor David Thomas

Prof Thomas is Head of the Cancer Division at the Garvan Institute of Medical Research, and Director of The Kinghorn Cancer Centre. He is a NHMRC Principal Research Fellow and medical oncologist whose focus is on the application of genomic technologies to the understanding and management of cancer. Prof Thomas founded the Australasian Sarcoma Study Group, a national research organisation, and established Australia's leading adolescent and young adult cancer unit at the Peter MacCallum Cancer Centre. Dr Thomas leads the International Sarcoma Kindred Study, now recruiting from 23 centres in 7 countries, and led the first international study of denosumab in Giant Cell Tumor of bone, leading to FDA and TGA approval. He has over 150 research publications, including lead or senior author papers in Cancer Cell, Molecular Cell, Journal of Clinical Investigation, Lancet Oncology, JAMA Oncology, and Journal of Clinical Oncology. Since moving to NSW, he has established the Genomic Cancer Medicine Program, a multi-institutional precision medicine program for patients with rare and early onset cancers. He is a member of Sydney Catalyst's Governing Council & Scientific Advisory Committees and in 2018, he became President of the Connective Tissue Oncology Society, the peak international body in his field.

[@ProfDMThomas](#)



Heidi Watson

Heidi Watson is the National Clinical Lead for the Adolescent and Young Adult (AYA) Cancer Network Aotearoa (New Zealand). This role is responsible for providing clinical leadership and national oversight of AYA cancer care in NZ. Heidi has an extensive clinical, education and leadership background in Youth Health and cancer care. Alongside her AYA clinical leadership role she also holds a youth health academic position at the University of Auckland.

[@NZayacancer](#)



Dr Allison Werner-Lin

Allison Werner-Lin is Assistant Professor at the School of Social Policy and Practice. Her research addresses the intersection of genomic discovery and family life. Dr. Werner-Lin seeks to broaden social work's guiding 'person-in-environment' framework to include genetic variation as a core feature of assessment, one in constant interaction with developmental, sociocultural, and environmental contexts. Presently, Dr. Werner-Lin's work addressed the ethical, legal, and social implications (ELSI) of emerging genomic technologies in reproductive, pediatric, adolescent, and young adult populations with inherited cancer predisposition syndromes.

Her work is among the first to explore the psychosocial challenges unique to women and men of reproductive age who carry a genetic mutation (BRCA1/2), which exposes carriers to elevated risk of hereditary breast and ovarian cancer. She holds appointments with the Clinical Genetics Branch of the Division of Cancer Epidemiology and Genetics at the National Cancer Institute where she oversees psychosocial research addressing hereditary tumor predisposition syndromes, including Li-Fraumeni Syndrome. She is a member of the Scientific Committee governing the International Meeting on Psychosocial Aspects of Hereditary Cancer, serves on the Editorial Board of the Journal of Psychosocial Oncology, and is a Distinguished Fellow of the Society for Social Work and Research, where she serves as facilitator of the Cancer Special Interest Group, and the National Academies of Practice in Social Work.

[@awernerlinPhD](#)

Plenary Co-Chairs



Joey Lynch was diagnosed with Hodgkins Lymphoma in September 2008 and joined CanTeen after undergoing his first Stem Cell Transplant in 2010. Joey reflects on the initial two years of treatment without CanTeen, and the 7 years since and can personally attest to the importance of the youth empowerment, peer mentoring and support that CanTeen provides. Joey is a Member Director of the Board and is completing a degree in International Relations at LaTrobe University, Melbourne. He also works as a journalist for publications such as The Age and organisations such as Melbourne City and Professional Footballers Australia. Joey is on the Congress Planning Group, will be chairing sessions throughout the program and is our MC for the Congress dinner.

[@joeylynchy](#)



Kathryn Woodward was diagnosed with Hodgkin's Lymphoma in 2012 and joined CanTeen with her two brothers soon thereafter. Kathryn is now cancer-free and studying a Doctor of Medicine (MD) degree in her home town of the Gold Coast, having graduated with a Bachelor of Medical Science in 2017. As an active member of the QLD Youth Cancer Services Youth Advisory Group, a Youth Ambassador and Director on CanTeen's Board, Kathryn feels that CanTeen has allowed her to make meaning from her cancer experience, demonstrate the importance of consumer representation, and make positive changes for other young people living with cancer. Kathryn is a presenting author, on the Congress Planning Group and will be chairing sessions throughout the Congress program.



Matilda (Tilly) Gorce was 18 years old when she was diagnosed with a rare, aggressive cancer – an epithelioid sarcoma. She believes connecting with other young people with a cancer experience in their lives was the best thing she ever did and says the relief she felt when she started speaking to a CanTeen counsellor was enormous. Tilly is an active member of her local CanTeen leadership group and the WA Youth Cancer Services Youth Advisory Group. She is currently studying laboratory medicine at Curtin University in Perth with a view to pursuing a career in cancer research. Tilly is on the Congress Planning Group and will be chairing sessions throughout the program.



Madeleine Way connected with CanTeen in 2012 when her father was diagnosed with a rare lymphoma. Maddy completed a bachelor of Agricultural science with honours in 2016 and is now studying her PhD in the science of cider as the recipient of a Westpac bicentennial foundation Future Leaders Scholarship. Maddy joined the Tasmanian local leadership team in 2016 and quickly took on additional training and responsibility as a Peer Mentor and Youth Ambassador and was recently appointed a Director on the Board. Maddy is co-facilitating the pre-conference workshop on youth leadership and co-chairing sessions throughout the Congress program.



Sean Dondas was a shy 14-year-old when he first walked into the Perth CanTeen office in 2008, but fast made friends who were the rock that supported him when his Mum passed away a year later. According to Sean, CanTeen is unique because of its belief in young people and what they can achieve. As a Director on the Board Sean shares his life experience, studies of economics, and passion for making a positive difference in the world, Sean is co-facilitating the pre-conference workshop on youth leadership and co-chairing sessions throughout the Congress program.

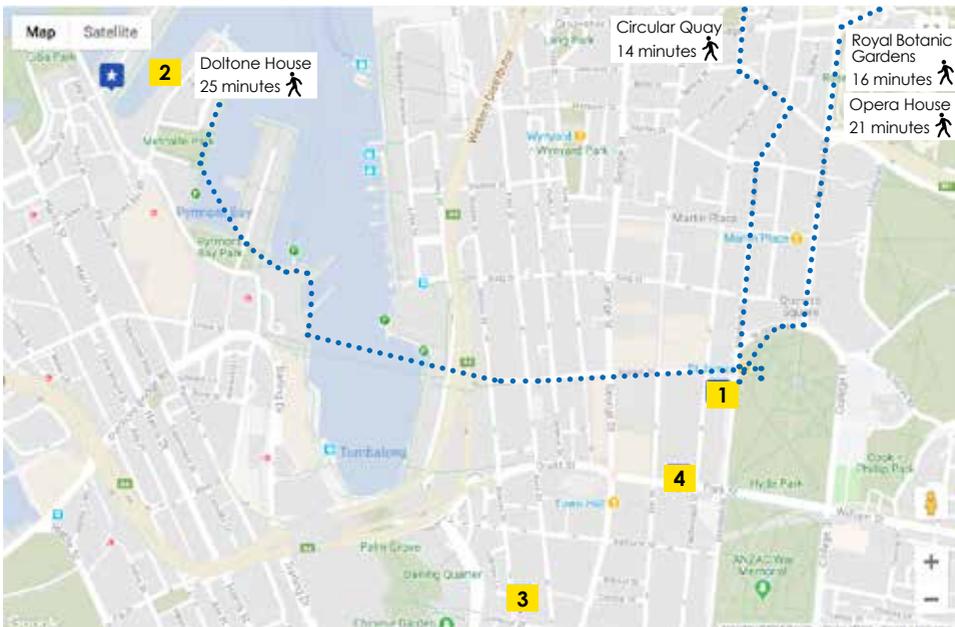


Jessada Phuntuya was your typical teen – stressing out about getting a good result in the HSC, getting his formal suit ready and thinking about pranks to pull on the teachers. All that was interrupted with a diagnosis of Burkitt's Lymphoma in 2014. Throughout his treatment Jessada participated in programs and counselling at CanTeen, and is now an active member of his local leadership group, a representative on the national advisory group, and one of CanTeen's most experienced and enthusiastic Youth Ambassadors. Jessada is a qualified enrolled nurse and is currently gaining experience rotating through clinical wards at St Vincent's Hospital Sydney as part of his new-graduate year, although it is ultimately his goal to work in Haematology/Oncology. Jessada will be co-facilitating the pre-conference workshop on youth leadership and co-chairing sessions throughout the Congress program.

Congress Venue

Conveniently located in the heart of the CBD, Sheraton Grand Sydney Hyde Park is the perfect starting point to explore the multi-faceted city of Sydney. To begin, venture across the hotel to discover the stunning Hyde Park, which boasts the grand Archibald Fountain, and further along, the breathtaking St. Mary's Cathedral. Experience the city's best shopping with the impressive Westfield Sydney, major department stores like David Jones and, luxury brands just steps away. For culinary adventures, stroll down one of the longest streets in Sydney CBD, Elizabeth Street, and discover the city's hidden culinary gems.

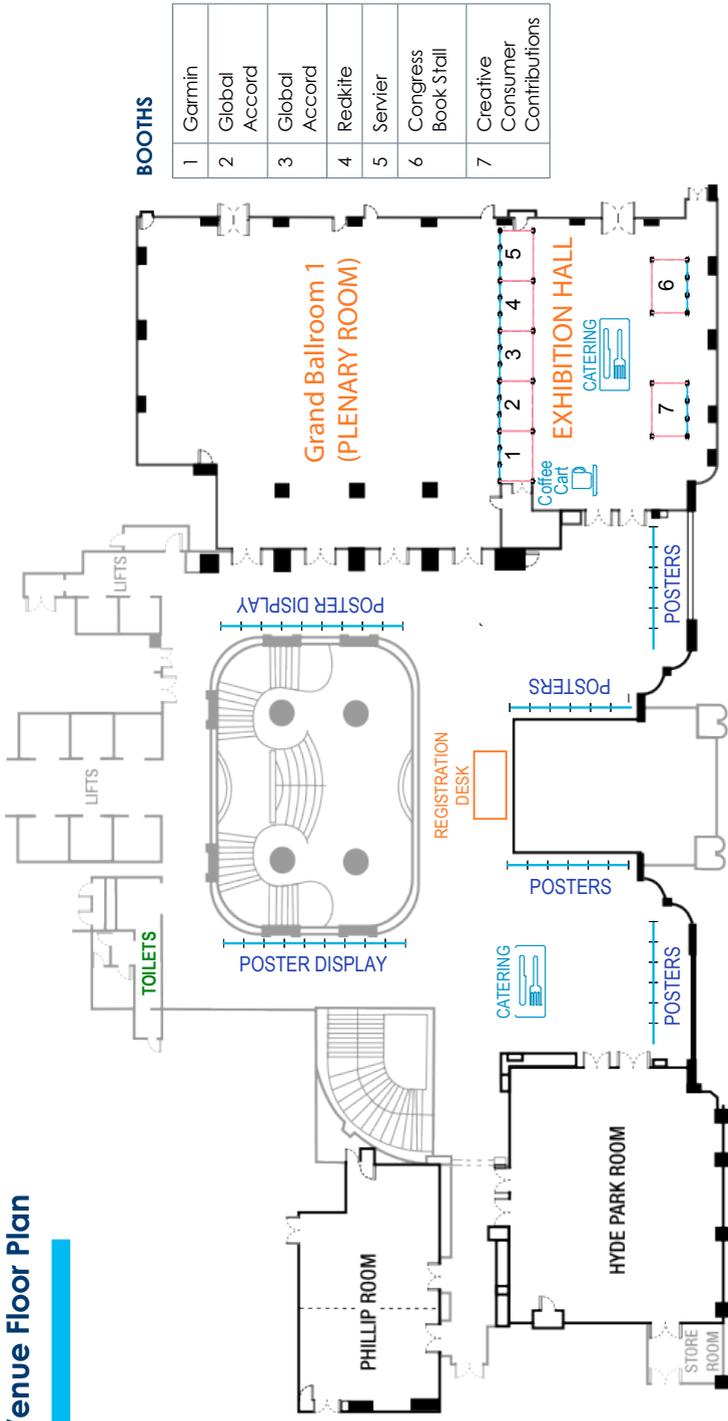
Take a leisurely stroll to Sydney Harbour, home to the world famous Opera House and iconic Harbour Bridge. From here you can catch the ferry to Manly or Taronga Zoo for a quick escape from the vibrant city. Choose to visit Darling Harbour or Barangaroo, the perfect destination for waterfront dining, parks and harbor cruises, easily accessible in a matter of minutes. Don't miss experiencing the world-famous Bondi Beach or neighbouring beachside suburbs, just a quick cab or bus ride away from the hotel.



KEY

- 1 – Congress Venue & Hotel: Sheraton Grand Sydney Hyde Park
- 2 – Congress Gala Dinner: Doltone House Jones Bay Wharf
- 3 – Hotel: Radisson Hotel & Suites
- 4 – Hotel: Park Regis City Centre

Venue Floor Plan



BOOTHS

1	Garnin
2	Global Accord
3	Global Accord
4	Redkite
5	Servier
6	Congress Book Stall
7	Creative Consumer Contributions

PLENARY ROOM

- Speaker Prep area
- Tea/Coffee/Food Stations
- Bathrooms
- Poster locations

EXHIBITION HALL

- Coffee Cart: Sponsored by Public Espresso
- \$4 for barista made coffee
- Global Accord Booth
- Red Kite
- Garnin

Servier

- Congress Book Stall
- Creative Consumer Contributions
- Speaker prep booth

Useful Information

Transport around Sydney

The Opal card is the only way to travel around Sydney on public transport. The opal card is an electronic card you keep, reload and reuse. The Opal network includes train, bus, ferry and light rail services in Sydney, the Blue Mountains, Central Coast, Hunter, Illawarra and Southern Highlands. For more information on the Opal card: <https://www.opal.com.au/>

We recommend downloading the opal app for trip planning on the go. You can also use the opal app to top up your card easily.

For travel planning, visit: <https://transportnsw.info/plan>

Taxis

The congress venue concierge on the ground floor can order you a taxi, alternatively you can book one with 13cabs by calling 13 22 27 or book online: <https://www.13cabs.com.au/>

Uber is also available in Sydney, download the Uber app to book a ride.

Parking

Valet parking is available at the congress venue at a daily rate of \$65 AUD. Alternatively, Secure Parking is located directly behind the congress venue which is accessible via 137 Castlereagh Street. You can pre-book a bay online: <https://www.secureparking.com.au/>

Emergency First Aid and Medical

For emergencies, please dial 000 (fire, police, ambulance)

The nearest public hospital emergency department is located at:

St Vincent's Hospital
309 Victoria Street, Darlinghurst

The nearest medical centre is located at:

Myhealth Medical Centre CBD
Level 8, 151 Castlereagh Street, Sydney
Phone: +61 2 8197 3388

Wireless Internet

Wifi is available for congress delegates. To access, please select "Sheraton" in your wifi settings. A web page will then open, please select "Connect Now". No password is necessary.

Mobile Phones

A gentle reminder to please keep mobile phones on silent during presentations.

Social Media

Join the conversation #ayaacancercongress



@AYAGlobalCancer

Name Badges

For security purposes, all delegates must wear their name badges at all times while in the congress venue. It is your admission pass to the congress sessions and the exhibition & catering area. Tickets will be provided to the Welcome Reception and Congress Gala Dinner.

Dress Code

Smart casual attire is appropriate for congress sessions and tickets will be provided to the Congress Gala Dinner. A jacket may be required for air conditioned session rooms. The dress code for the Congress Gala Dinner is Relaxed Cocktail Attire.

Special Dietary Requests

Delegates who specified a special dietary request during the online registration should identify themselves to service staff at all functions. Please note, vegetarians will be catered for as standard.

Speaker Preparation Room

All presenters must check-in at the Speakers' Preparation area in Grand Ballroom 2, at least 1 hour prior to the start of their session to upload their presentation. Presentations must be brought on USB memory drive.

Best Oral Presentation and Best Poster Presentation

Please vote each day via the congress app.

Registration Desk

The registration desk will be located on level 2 of the hotel; the opening times are as follows:

Monday 3 December : 5pm - 7pm

Tuesday 4 December: 7:45am – 5:00pm

Wednesday 5 December: 7:45am – 5:00pm

Thursday 6 December: 8:00am – 4:00pm

Congress App

We are delighted to introduce our congress smartphone app.

To access the app, follow the steps below;

- 1) Download 'Exposcan' from your app store
- 2) Event code: 'AYAC18'

Contact Details

If you need assistance during the congress, please see Maxim's Travel Events who are our dedicated congress organisers. They will be situated at the Registration Desk. Alternatively, please call: +61 2 9248 6417.

Consumer Exhibition:

My Life Before, With and Beyond Cancer: Creative Consumer Contributions to the AYA Cancer Conversation .

To give young people from around the world the opportunity to share their experiences of 'Navigating the road through AYA cancer', we have invited young people impacted by cancer to submit a creative interpretation of the conference theme.

The mixed media contributions are displayed in the exhibition hall alongside a written piece explaining the artwork. We encourage you to take a look at the wonderful submissions and read about their creator's journeys.

Congress Book Store:

Recognising the great wealth of AYA cancer resources and books that have been authored by many of our wonderful delegates, a book stall is available at the exhibition hall to purchase (card sales only) and view books relevant to the AYA field. There will also be useful free resources available here.

Congress Silent Auction:

We have been fortunate to have been gifted by Readback Galleries & artist Pacinta Turner a large piece of beautiful indigenous artwork which we will feature at the congress as a silent auction.

ARTIST: Pacinta Turner

BORN: February 1999

TITLE: My Country Dreaming

MEDIUM: Acrylic on Canvas

COMPLETED: February 2018

SIZE: Canvas Size Approximately: 91x160cm

Pacinta's works have been purchased by collectors and investors both within Australia and internationally. Her works were first exhibited in Queensland's Emu Apple Gallery and available in the Kate Own Gallery that won the prestigious award of Sydney's Best Aboriginal Art Gallery in 2010.

The Silent Auction will help raise funds to support young people attend the congress.

Delegates will have the opportunity to place bids throughout days 1 and 2. (Box to place bid located at the Congress Book Stall.) At the end of day 1 and day 2, an update will be provided during the plenary of the current highest bid.

Final bidding opportunities will take place at the gala dinner on Wednesday evening with the highest final bidder announced at the end of the formalities at the gala dinner. The painting will come with a certificate of authenticity. The painting can be rolled and placed in a cylinder for easy transportation.

Happy bidding!



Social Functions

Welcome Reception

Following on from a day of congress sessions, the welcome reception is a great opportunity for all delegates to meet with old friends and make some new ones whilst networking with our industry partners. Drinks and canapes will be served.

We are delighted to have the musical talents of Rachel Woolley (flutist) and Gabi Vella (Acoustic guitar) joining us for the evening:

Date

Tuesday, 4 December 2018

Venue

Sheraton Grand Sydney,
Hyde Park
Grand Ballroom 2, Level 2

Time

5:00pm – 7:00pm

Dress

Smart Casual

Ticket price

Included in Full Registration.
Additional Tickets \$65pp



Gabi Vella

Gabrielle Vella originates from rural NSW, Tamworth. She connected with CanTeen when her mum was diagnosed with stage 3 breast cancer in 2012. Her musical abilities are well known in the CanTeen world and more recently the Sydney scene has been treated to her talents where she performs at the Newtown Hotel.



Rachel Woolley

20 year old Rachel is in her third year of a Bachelor of Music at the University of New South Wales.

Half-way through her year 12 studies in 2015, she was diagnosed with Stage 2 Hodgkin Lymphoma. After months of treatment including chemotherapy and radiotherapy, she relapsed the following year with the same disease. After going through more chemotherapy and a stem cell transplant, she is now 2 years in remission. Rachel is currently a member of the UNSW Orchestra playing both flute and piccolo and also works part-time teaching students piano, flute and singing.

Showcasing local Australian products

As part of the welcome reception, the wonderful Tamburlaine Organic wine team will be bringing their cellar door to the Congress to showcase their local (Hunter Valley & Orange) wines for tastings and purchases too.

Congress Gala Dinner

Doltone House Jones Bay Wharf is a unique heritage venue situated on a restored finger wharf on the foreshore of Sydney Harbour's Pyrmont. Enjoy drinks with views of the Sydney Harbour Bridge and city skyline before heading inside for a 3 course sit down dinner and plenty of time to dance and catch up with friends and colleagues! We're also excited to be joined by the Sydney City Deputy Lord Mayor, Linda Scott.

A coach transfer will be available for attendees. There will be two collection points: **Sheraton Grand Sydney Hyde Park** - please wait in the hotel lobby for a departure at 6:40pm SHARP. **Radisson Hotel** – please wait in the hotel lobby for a departure at 6:45pm SHARP. Alternatively, should you wish to walk please allow 25 minutes.

This is a ticketed event, should you wish to purchase a ticket or if you have selected to attend but no longer wish to then please see the Registration desk.

DATE

Wed, 5 December 2018

VENUE

Doltone House
Jones Bay Wharf
26-32 Pirrama Rd,
Pyrmont NSW 2009

TIME

7:00pm

DRESS

Relaxed Cocktail Attire

TICKET PRICE

\$120pp



MC

CanTeen Youth Ambassador & Member Board Director, Joey Lynch will be our wonderful MC for the evening. Joey was diagnosed with Hodgkins Lymphoma in September 2008. He is passionate about helping improve the lives of young people living with cancer – particularly ensuring that young Australians have access to both cutting edge medical treatment and psychological and social support. He is currently completing a degree in International Relations at LaTrobe University in his hometown of Melbourne, where he also works as a journalist – primarily covering football for publications such as The Age and organisations such as Melbourne City and Professional Footballers Australia.



Guest Speaker

Wheelchair rugby two times paralympic gold medallist Chris Bond will be our inspiring guest speaker for the evening.

Chris was 19 years old when he was diagnosed with Leukaemia and contracted a severe bowel infection which sent him into septic shock.

The bacterial infection quickly spread throughout his body and gangrene developed in his extremities. Doctors made the difficult decision to amputate both lower limbs, his left hand and four fingers on his right hand. Chris will share his incredible story, from his cancer journey to his life after cancer and what he has achieved since his diagnosis.



Musical Entertainment

"We love a full dance floor and sore feet"

As musical entertainment for the evening, we are pleased to have the talented Baker Boys band joining us! They will play an acoustic set on Jones' Bay Wharf during pre-dinner drinks and liven things up later in the evening on the dance floor with their energetic and talented 5-piece band.

Workshops

PRE-CONGRESS WORKSHOPS: MONDAY 3RD DECEMBER 2018

We would like to acknowledge the wonderful work of the contributors and presenters to our four pre-congress workshops. Thank you for joining together and collaborating across the globe to bring these workshops to our delegates.

Workshop 1 : Castlereagh Room 1, Sheraton Grand

Moving Beyond Consumer Engagement: A skills-building workshop for professionals who want to better support, develop, and empower youth leadership in Cancer Care

WHO IS THIS FOR

Anyone working with or looking to engage meaningfully with young patients, survivors and consumer advocates to further their organisational goals. This may include healthcare professionals, reference group convenors / chairs, consumer engagement or external affairs professionals. No prior experience in this area is required

PRESENTERS

Natalie Hornyak (National Leadership Coordinator for CanTeen Australia) and several of CanTeen's young leaders (including Youth Ambassadors, Peer Facilitators as well as members of the national youth advisory groups and Board of Directors).

OVERVIEW

In this workshop we will:

- Define the 'why' and 'how' of youth leadership through models and theories of youth participation and adolescent development.
- Hear insights and stories from experts (including young experts!) on the individual and organisational challenges and benefits of engaging young people in governance, advocacy, peer support, research and service design/evaluation and more
- Provide opportunities for workshop participants to consult the diverse wisdom, expertise and creativity of those in the room to make progress on specific youth leadership ideas and challenges
- Build skills in session design and facilitation so participants leave the workshop with confidence to bring young people together in various contexts.
- Provide a resource pack of tools to support continued development.

Workshop 2 : Hyde Park Room, Sheraton Grand

Nursing AYAs with Cancer: An interactive workshop exploring lessons from international nursing practice, leadership, innovations and opportunities in AYA cancer nursing.

WHO IS THIS FOR

This workshop is open to anyone leading, or who aspires to a leadership role in AYA Cancer care. We will draw on our experience in Europe and Australia to explore nursing leadership in the context of service demands and differing levels of resource availability. The workshop will include content relevant to anyone working in the adolescent and young adult cancer nursing field or those with an interest in the ongoing development of this specialist role in the AYA multidisciplinary team. This may include nurses, health service and program managers, educators, policy makers or researchers. No prior experience in this area is required.

PRESENTERS & FACILITATORS

- Maria Cable – Principal Lecturer in Adult Nursing & Adolescent/Young Adult Cancer Care, Coventry University, UK Professional Doctorate Candidate at Cardiff University, UK
- Lyndal Moore – Clinical Nurse Consultant, Hunter and Northern New South Wales Youth Cancer Service, AUSTRALIA
- Nicky Pettit – Teenage Cancer Trust Nurse Consultant, University Hospitals Birmingham NHS Foundation Trust, Lecturer in Teenage and Young Adult Cancer Care, Coventry University, UK
- Louise Sue – Cancer Nurse Specialist, AYA Cancer Service, Canterbury District Health Board, NZ
- Cath O'Dwyer – Clinical Nurse Consultant, Sydney Youth Cancer Service, AUSTRALIA
- Bec Greenslade – Research Nurse, Queensland Youth Cancer Service, AUSTRALIA
- Dr Louise Soanes – Teenage Cancer Trust Nurse Consultant, University College London Hospitals NHS Foundation Trust, UK
- Lisa Ryan - Director, Adaptive Leadership Australia.

OVERVIEW

Using a combination of presentations, case studies and interactive group work, and with a networking lunch provided, this workshop will aim to:

- Offer a networking opportunity for those involved in leadership at whatever level in AYA cancer care, or those aspiring to such a role.
- Bring an international perspective to leadership development and learn from colleagues from different countries
- Explore leadership issues at the clinical, and at the managerial/corporate levels, and identify ways forward for each
- Create a personal plan for further leadership networking/training following the meeting
- Provide the opportunity for participants to develop their own message to their organisations following the meeting.
- Delegates will also be guided towards useful resources to further their learning beyond the 3rd Global Adolescent & Young Adult Cancer Congress

This workshop is proudly supported by:



Workshop 3 : Karstens - 111 Harrington Street (Offsite)

The Shifting Landscape of AYA Cancer Treatment: A collaborative workshop exploring international best-practice, advances and challenges in the treatment of AYA malignancies

WHO IS THIS FOR

This workshop will include content relevant to those involved in the medical treatment of adolescents and young adults with cancer or with an interest in the ongoing advances and opportunities in this field. This may include haematology / oncology physicians, clinical trialists, nurses, health service and program managers, policy makers or researchers across the translational pathway.

PRESENTERS / CONVENORS

- Prof Stuart Seigel – Professor of Paediatrics and Medicine, Keck School of Medicine, University of Southern California, USA
- Dr Mandy Ballinger – Group Leader - Genetic Cancer Risk, The Garvan Institute of Medical Research, AUSTRALIA
- Prof Winette van der Graaf – Professor of Personalised Oncology, The Royal Marsden, UK
- Dr Rebecca Johnson – Medical Oncologist, Division of Paediatric Haematology/Oncology, Mary Bridge Hospital, USA
- A/Prof David Ziegler – Senior Staff Specialist & Head, Clinical Trials Program, Kids Cancer Centre, Sydney Children's Hospital, Children's Cancer Institute, Lowy Cancer Research Centre, University of New South Wales, AUSTRALIA
- Dr Craig Nichols - Director of the Precision Genomics Cancer Research Clinic, Intermountain Healthcare, USA ▯ Prof David Thomas – Director of The Kinghorn Cancer Centre and Head of the Cancer Division, The Garvan Institute of Medical Research, AUSTRALIA
- Dr Michael Osborn – Haematologist / Paediatric, Adolescent and Young Adult Oncologist Youth Cancer Service SA/NT, AUSTRALIA
- A/Prof Mustafa Khasraw - Principal Research Fellow, NHMRC Clinical Trials Centre, The University of Sydney. Medical Oncologist at Royal North Shore Hospital, St Leonards, Sydney, AUSTRALIA

OVERVIEW

Split into three sessions over the course of the day, with a networking lunch provided, in this workshop we will hear updates and insights into:

- Acute Lymphoblastic Leukaemia in AYAs
- New Developments in CAR-T therapies
- Familial cancer in AYAs
- Sarcoma in AYAs
- Breast Cancer in AYAs
- Germ Cell Tumours in AYAs
- Medulloblastoma in AYAs
- Glioblastoma in AYAs

The day will conclude with a panel discussion exploring the question of "What are the international biomedical research priorities in AYA cancer?"

This workshop is proudly supported by: **Deloitte.**

Workshop 4 : Castlereagh Room 2, Sheraton Grand

Enhancing your clinical communication skills using Acceptance and Commitment Therapy (ACT): A practical introduction.

WHO IS THIS FOR

This workshop is suitable for anyone working professionally with people affected by cancer, in either a health or social care context.

PRESENTER

Professor Nick Hulbert-Williams, Coaching Psychologist & Director, Chester Research Unit for the Psychology of Health, Department of Psychology, University of Chester, UK.

OVERVIEW

Psychological suffering is ubiquitous with cancer. With specialist psychology services often difficult to access, distress management often falls to nurses and other allied healthcare professionals, or to third sector supportive care organisations. Training on the management of psychological distress in cancer is often guided by traditional cognitive-behavioural approaches which may instil in practitioners an expectation that psychological suffering may be 'fixable', though this might not always be appropriate or realistic in the context of cancer care. More recent work in psychology has led to the emergence of third-wave psychological therapies, such as Acceptance and Commitment Therapy (ACT), which have a growing evidence base in a range of health care settings. In this brief experiential workshop, participants will be introduced to the ACT intervention model, and taught practical skills about how to integrate this into day-to-day conversation and care of people affected by cancer. By making clinical communication more ACT-consistent, our experience is that health and social care professionals can become more empathic listeners and better able to meet the psychological needs of this group.

3rd Global Adolescent and Young Adult Cancer Congress Program

Day 1 – Life Before Cancer

Tuesday 4 December 2018

7.45am	Registration	
8.30am	Opening Ceremony: Grand Ballroom 1 Prof Ian Olver: Official opening of Congress Mr Glen Doyle: Welcome to country The Hon. Greg Hunt MP, Federal Minister for Health: Video Message Opening address from the Global Accord partners: CanTeen: Mr Peter Orchard Teen Cancer America: Mr Simon Davies Teenage Cancer Trust: Ms Kate Collins	
9.00am	<u>Plenary 1: AYA Priority Setting & Practice Innovation</u> Chair Introduction: Dr Norman Swan & Mr Joey Lynch Grand Ballroom 1	
9.05am	Professor Paul Grundy - Establishing AYA cancer as a national priority: the Canadian experience (pg 45)	
9.25am	Dr Lorna Fern – Adolescent & young adult diagnostic timelines, pathways & impact on patient outcomes (pg 46)	
9.45am	A/Professor Pia Riis Olsen & Ms Mette de Fine Licht – The difference a friend can make (pg 46)	
10.10am	Speaker panel discussion and audience Q&A	
10.30am	Morning Break – Exhibition & Poster Viewing	
	RAPID FIRE 1.1 & POSTER VIEWING Chair: Mr Peter Orchard Grand Ballroom 1 <i>These trials received funding via CanTeen's Australian Young Cancer Patient Clinical Trials Initiative.</i>	RAPID FIRE 1.2 & POSTER VIEWING Chair: Dr Ursula Samson-Daly Hyde Park Room
11.00am	Personalised targeted therapy for adolescent and young adult medulloblastoma patients. <i>Antoinette Anazodo, Australia (pg 47)</i>	Implementation of a Youth Participation Framework in Victoria. <i>Ilana Berger, Australia (pg 51)</i>
11.05am	Ewing sarcoma clinical trials programme. <i>Susie Bae, Australia (pg 48)</i>	Advancing Advocacy: The Growth of a Youth Cancer Advisory Group from a Passive to Active Influencer. <i>Kathryn Woodward, Australia (pg 51)</i>
11.10am	The Cancer Molecular Screening and Therapeutics Program (MoST) – A molecular screening platform with multiple, parallel, signal-seeking therapeutic substudies in rare cancer populations <i>David Thomas, Australia (pg 49)</i>	#AYACSM: An Interdisciplinary Adolescent and Young Adult Cancer Twitter Community. <i>Emily Drake, Canada (pg 52)</i>
11.15am	The Australasian Leukaemia and Lymphoma Group (ALLG) ALLO9 Trial: A Phase II Study of Blinatumomab as Induction Therapy in Adolescent and Young Adult (AYA) Acute Lymphoblastic Leukaemia (ALL) <i>Michael Osborn, Australia (pg 50)</i>	Teenagers get Cancer but do we 'get' Teenagers? A Medical Student's Reflections from a Placement in AYA Cancer. <i>Luke Smith, United Kingdom (pg 53)</i>

	CONCURRENT 1.1 – LEADERSHIP IN AYA CANCER Co-Chairs: Dr Miyako Takahashi & Ms Madeleine Way Phillip Room	CONCURRENT 1.2 – AYA CANCER POLICY & PRIORITIES Co-Chairs: Dr Allison Werner-lin & Mr Jessada Phuntuya Hyde Park Room	CONCURRENT 1.3 – RARELY HEARD VOICES & MINORITY POPULATIONS Co-Chairs: Ms Louise Sue & Ms Aggie Kasicka Grand Ballroom 1
11.30am	Building Adaptive Leadership capability in the YCS Context. <i>Terri Soller, Australia (pg 54)</i>	Identifying shared research priorities between young people, significant others and professionals: Results of the United Kingdom's James Lind Alliance Research Priority Setting Exercise. <i>Lorna Fern, United Kingdom (pg 56)</i>	Youth at Risk: Complexities of Managing Young People with Cancer with No Carer Support. <i>Belinda Matigian, Australia (pg 59)</i>
11.45am		Developing an Adolescent and Young Adult Framework for Canada. <i>Paul Grundy, Canada (pg 57)</i>	No Way Out: Caring for Incarcerated Young Adults with Advanced Cancer. <i>Lyndal Gray, Australia (pg 60)</i>
12.00pm	<i>Leadership perspectives Professionals in Adolescent and Young Adult Cancer Care. Maria Cable, United Kingdom (pg 54)</i>	A blueprint for age-specific care for Adolescents and Young Adults (AYAs) in Flanders (Belgium). <i>Johan De Munter, Belgium (pg 57)</i>	Caregiver profile of young cancer patients in rural western Madhya Pradesh (India). <i>Prakash Chitalkar, India (pg 61)</i>
12.15pm		Setting Priorities for a Provincial Adolescent and Young Adult Oncology Program. <i>Amirtha Srikanthan, Canada (pg 58)</i>	From Coast to City - A shared approach delivering optimal care. <i>Tanya Haynes, Australia (pg 62)</i>
12.30pm	Insights from the evolution of youth leadership in CanTeen. <i>Natalie Hornyak & Emilie Adlide, Australia (pg 55)</i>	AYA cancer care in New Zealand – A way forward. <i>Heidi Watson & Rochelle Moss, New Zealand (pg 59)</i>	Understanding and meeting the needs of Lesbian, Gay, Bisexual, Trans, and Intersex (LGBTI) young people accessing the Victorian Adolescent and Young Adult Cancer Service: moving towards an inclusive and equitable model of care. <i>Mairghread Clarke, Australia (pg 62)</i>
1.00pm	Lunch Break – Exhibition & Poster Viewing		
	CONCURRENT 2.1 – PREVENTION & EARLY DETECTION Co-Chairs: Dr Natalie Bradford & Mr Terence Rumblow Grand Ballroom 1	CONCURRENT 2.2 – PROFESSIONAL DEVELOPMENT Co-Chairs: Dr Stu Siegal & Mr Sean Dondas Hyde Park Room	CONCURRENT 2.3 – AYA CANCER DATA & EPIDEMIOLOGY Co-Chairs: Mr Johan De Munter & Ms Kathryn Woodward Phillip Room
1.45pm	"It really does affect everything, even if you don't have cancer": The experiences of Australian adolescents and young adults with Li-Fraumeni Syndrome. <i>Rowan Forbes Shepherd, Australia (pg 63)</i>	"Message from the Cancer Club:" AYAs Create a Video for Their Healthcare Providers. <i>Rebecca Johnson, USA (pg 68)</i>	Piloting a Patient-Driven Online Survey to Better Study Cancer in Adolescents and Young Adults (AYA) in the United States. <i>Peter Shaw, USA (pg 72)</i>
2.00pm	Don't let the sun go down on them: sun-related attitudes and behaviours amongst New South Wales (NSW) adolescents and young adults. <i>Elizabeth King, Australia. (pg 64)</i>	Comprehensive fellowship training of adolescent and young adult oncologists: a single center experience. <i>Adam DuVall, USA (pg 69)</i>	The I.Am portal project: the development and utility of a teenage and young adult specific multi-disciplinary team (MDT) management system in the UK. <i>Jennifer Cheshire, United Kingdom (pg 73)</i>

2.15pm	Sun exposure among teenage and young adult cancer survivors in the United Kingdom. <i>Gemma Pugh, United Kingdom. (pg 65)</i>	The domains of practice for Youth Support Co-coordinator work in teenage/young adult cancer care in the United Kingdom. <i>Maria Cable & Michael Whelan, United Kingdom (pg 69)</i>	Diagnostic Experiences of Young People with Cancer. <i>Lorna Fern, United Kingdom (pg 73)</i>
2.30pm	Promoting sunscreen use and skin self-examination to improve early detection and prevent skin cancer: quasi-experimental trial of an adolescent psycho-educational intervention. <i>Gill Hubbard, United Kingdom (pg 65)</i>	Healthcare professional perceptions of online information and support for young people with cancer in the United Kingdom (UK). <i>Anna Martins, United Kingdom (pg 70)</i>	An age stratified study investigating timeliness to diagnosis and treatment onset in Sarcoma, Hodgkin Lymphoma, and Non Hodgkin Lymphoma patients in the South Island, New Zealand. <i>Tristan Pettit, New Zealand (pg 74)</i>
3.45pm	Learnings from a Decade of Breast Cancer Awareness Targeting Young Women on Canadian Post-Secondary School Campuses. <i>Lorna Larsen, Canada (pg 66)</i>	'Silence is golden' - evaluation of a bespoke experiential learning communication skills workshop for youth support co-ordinators in adolescent/young adult cancer. <i>Maria Cable & Debbie Critoph, United Kingdom (pg 71)</i>	The Australian Youth Cancer Database: developing and piloting a national minimum clinical dataset to support national service planning, quality improvement and research. <i>David Roder, Australia (pg 75)</i>
3.00pm	An initial evaluation of "When Cancer Comes Along" cancer awareness program for high school students. <i>Fiona McDonald, Australia (pg 67)</i>		Continued Increase in AYA Breast Cancer with Distant Involvement among Women in United States after 6 Additional Years of Analysis. <i>Frank Chien, USA (pg 76)</i>
3.15pm	Afternoon Break – Exhibition & Poster Viewing		
3.15pm	AYA Consumer Closed Networking Session – Phillips Room		
3.35pm	<u>Plenary 2: AYA Cancer Risk –Melanoma, Lifestyle & Inherited Risk Profiles</u> Co-Chair Introduction: Dr Norman Swan & Ms Tilly Gorce Grand Ballroom 1		
3.40pm	Professor Richard Scolyer – Melanoma: Progress to Date and Future Prospects in the Fight Against Australia's National Cancer (pg 77)		
4.00pm	A/Professor Gill Hubbard – Approaches to addressing lifestyle-based cancer risks amongst adolescents & young adults (pg 77)		
4:20pm	Dr Allison Werner-Lin – Communicating genetic testing results in family and social networks: Meeting the unique psychosocial needs of AYAs (pg 78)		
4.40pm	Speaker panel discussion and audience Q&A		
5.00pm	Day 1 Close		
5.00pm	Welcome Reception – Sheraton Grand Sydney Hyde Park		

3rd Global Adolescent and Young Adult Cancer Congress Program

Day 2 – Life With Cancer

Wednesday 5 December 2018

7.45am	Registration		
	<u>Plenary 3: Therapeutic advances – New treatments, clinical trials & exercise</u> Grand Ballroom 1		
8.15am	Co-Chair Introduction: Dr Norman Swan & Ms Kathryn Woodward		
8.20am	Professor Miles Prince – Predicting the future use of novel immunotherapy: experience to date in blood cancer proves that 'one size does not fit all' (pg 79)		
8.40am	Professor David Thomas – The International Sarcoma Kindred Study: mapping the genetic basis of sarcoma risk (pg 79)		
9.00am	A/Professor Prue Cormie – Exercise medicine for cancer (pg 80)		
9.20am	Professor David Freyer – Cancer Clinical Trial Participation: Understanding the Problem to Unlock the Potential (pg 80)		
9.40am	Speaker panel discussion and audience Q&A		
10.00am	Morning Break – Exhibition & Poster Viewing		
	RAPID FIRE 2.1 & POSTER VIEWING Chair: Dr Fiona McDonald Grand Ballroom 1	RAPID FIRE 2.2 & POSTER VIEWING Chair: Ms Mette De Fine Licht Hyde Park Room	
10.30am	Cancer incidence and mortality trends 1982-2014 in children, youths and young adults in Queensland, Australia. <i>Natalie Bradford, Australia (pg 81)</i>	Strengthening transition for adolescent and young adult (AYA) survivors of childhood cancer from the paediatric to adult sector for ongoing surveillance. <i>Tegan Dunmall, Australia (pg 84)</i>	
10.35am	A Peer Support Measure for Adolescents Living with Cancer <i>Pandora Patterson, Australia. (pg 82)</i>	"Tell us about..." #yaeharus: gathering online insights into cancer experiences of AYA's. <i>Rebecca Johnson, USA (pg 84)</i>	
10.40am	Colorectal cancer in AYA population in Nepal. <i>Rajeeb Deo, Nepal (pg 82)</i>	A cancer awareness program for Australian secondary school students: What do adolescents already know about cancer? <i>Stephanie Konings, Australia (pg 85)</i>	
10.45am	The TRECA program: Exploring implementation feasibility of using Telepresence Robots to Engage Cancer patients in education. <i>Mel Noke, Australia (pg 83)</i>	My CODE; a pre-study to understand the teenager/ adolescent age group with cancer; what technical solutions are available. <i>Nina Lahti, Sweden. (pg 86)</i>	
	CONCURRENT 3.1 – AYA TREATMENT ADVANCES Co-Chairs: Dr Tristan Pettit & Mr Joey Lynch Phillip Room	CONCURRENT 3.2 – FERTILITY Co-Chairs: Dr Karen Fasciano & Ms Madeleine Way Grand Ballroom 1	CONCURRENT 3.3 – MEASURING DISTRESS & NEEDS Co-Chairs: Prof Nick Hulbert-Williams & Mr Sean Dondas Hyde Park Room
11.00am	Improved Outcome for Adolescents with Acute Lymphoblastic Leukemia Treated with Chinese Children's Leukemia Group 2008 Protocol in China. <i>Jiaole Yu, China (pg 87)</i>	Concerns about Fertility, Genetic Risk, and Family Building: AYA Oncology Patient Perspectives. <i>Amber Skinner, USA (pg 91)</i>	Psychological Need and its Identification in Adolescent and Young Adult (AYA) Cancer. <i>Robert Carr, United Kingdom. (pg 96)</i>

11.15am	Emerging role for circulating biomarkers in germ cell tumors- Pilot data and ongoing trials in North America/ England. <i>Craig Nichols, USA (pg 87)</i>	Fertility information among adolescent and young adult cancer survivors– population-based study. <i>Maria Olsson, Sweden (pg 92)</i>	Development and Psychometric Testing of the Disconnectedness with Healthcare Providers Scale for Adolescents and Young Adults with Cancer. <i>Celeste Phillips, USA (pg 97)</i>
11.30am	Clinical outcomes of adolescents and young adults with advanced solid tumours participating in phase I trials in the Royal Marsden Hospital. <i>Winette van der Graaf, United Kingdom (pg 88)</i>	Nurses' perceptions regarding sexual and reproductive health issues among young adults with cancer or among cancer survivors via focus group interviews. <i>Yoshiko Kudo, Akiko Tomioka, Mitsue Maru, Japan (pg 93)</i>	Psychosocial Needs and Distress Scores Among Newly Diagnosed AYA Sarcoma Patients. <i>Amirtha Srikanthan, Canada. (pg 98)</i>
11.45am	Efficacy of Larotrectinib in adolescent and young adults with TRK fusion cancer. <i>Soledad Gallego, USA (pg 89)</i>	Oncofertility care and the impact on reproductive concerns, psychological distress and satisfaction in cancer patients at diagnosis, parents and partners. <i>Antoinette Anazodo, Australia (pg 94)</i>	Health Care Professionals' and AYA cancer patients' perspectives of using the AYA-modified Distress Thermometer tool: a clinical utility analysis. <i>Pandora Patterson, Australia. (pg 99)</i>
12.00pm	Exploring the genomic diversity of AYA and adult high-risk b-acute lymphoblastic leukemia by MRNA sequencing. <i>Michael Osborn, Australia (pg 90)</i>	Infertility After Cancer: How the Need to be a Parent, Fertility-Related Social Concerns, and Acceptance of Illness Influences Quality of Life. <i>Fiona McDonald, Australia (pg 95)</i>	AYA Concept Map: Facilitating Rapid Matching of Resources to Unmet Needs. <i>Amber Skinner, USA. (pg 99)</i>
12.15pm	Length of stay different, while treatment-related complications similar in paediatric and AYA hodgkin lymphoma patients in US children's hospitals. <i>Anthony Audino, USA (pg 91)</i>	The construction and experience of fertility and social relationships amongst adolescent and young adults with cancer. <i>Alexandra Hawkey, Australia (pg 95)</i>	
12.30pm	Lunch Break – Exhibition & Poster Viewing		
	CONCURRENT 4.1 – CLINICAL TRIALS ACCESS Co-Chairs: Dr Antoinette Anazodo & Ms Aggie Kasicka Phillip Room	CONCURRENT 4.2 – AYA CANCER PROGRAMS Co-Chairs: Prof Paul Grundy & Ms Tilly Gorce Grand Ballroom 1	CONCURRENT 4.3 – SURVIVORSHIP CONSIDERATIONS Co-Chairs: Dr Haryana Dhillon & Mr Terence Rumblow Hyde Park Room
1.30pm	Factors Affecting Clinical Trial Enrolment for AYAs with Cancer in a U.S. Population-Based Study. <i>Erin Mobley, USA (pg 100)</i>	Case Study: Piecing Together the Patchwork Quilt of AYA Programming. <i>William Terry, USA (pg 105)</i>	Reset: A Lifestyle intervention programme for adolescent and young adult cancer survivors. <i>Georgina Lincoln, New Zealand (pg 109)</i>
1.45pm	Increasing Clinical Trial Access in AYA - Development of the Victorian Comprehensive Cancer Centre AYA Clinical Trial Access Steering Group. <i>Leanne Super, Australia (pg 101)</i>	The Australian Youth Cancer Services Program: Key service delivery achievements from 2013-17 (Phase 2). <i>Adam Walczak, Australia (pg 105)</i>	A 10-week structured exercise program accelerates improvement in cardiopulmonary fitness in adolescents and young adults (AYA) after completion of cancer treatment: results of a randomised controlled trial. <i>Morgan Atkinson, Australia (pg 110)</i>

2.00pm	The new UK National Cancer Research Institute's Clinical Studies Group (CSG) in Teenage, Young Adult (TYA) and Germ Cell Tumours. <i>Dan Stark, United Kingdom (pg 102)</i>	Partnering with Primary Care Networks to Improve Youth Cancer Care in Queensland. <i>Bec Greenslade, Australia (pg 106)</i>	Does Cancer Affect Neurocognitive Functions in Young Adults? A Prospective Study. <i>Kim Edelstein, Canada (pg 111)</i>
2.15pm	The Good, The Bad and The Ugly: Improving Young Adult Access to Clinical Trials. <i>Tracey Vincent, New Zealand (pg 102)</i>	A model of care to identify needs, provide support and empower recovery for young adults with cancer. <i>Robert Carr, United Kingdom. (pg 107)</i>	Understanding the experiences of Adolescent and Young Adults (AYA) as they transition from cancer treatment to primary and community care: A pan-Canadian study of cancer survivors. <i>Sarah Stevens, Canada (pg 112)</i>
2.30pm	Analysis of Accrual Patterns of AYA Patients to a U.S. National Cooperative Research Group Over 25 Years: The SWOG Experience. <i>Mark Lewis, USA (pg 103)</i>	Measuring the impact of a stepped-care approach to psychosocial support on distress and unmet needs in AYA cancer patients and siblings. <i>Kristina Clarke, Australia (pg 108)</i>	The financial impact of travel costs on young people and their families. <i>Kate Lee, United Kingdom (pg 112)</i>
2.45pm	WA AYA Cancer Clinical Trials Group - Improving Clinical Trial Access for AYA Cancer. <i>Marianne Phillips, Australia. (pg 104)</i>	Incorporation of Population Sciences into an Adolescent and Young Adult Oncology Program. <i>Jocelyn Lewis, USA (pg 108)</i>	
3.00pm	Afternoon Break – Exhibition & Poster Viewing		
3.00pm	AYA Consumer Closed Networking Session – Phillip Room		
3.20pm	<u>Plenary 4: Addressing life stage & cultural complexities</u> Co-Chair Introduction: Ian Olver & Mr Jessada Phuntuya Grand Ballroom 1		
3.25pm	Ms Heidi Watson – Understanding the issues faced by taitamariki with cancer in Aotearoa (pg 113)		
3.45pm	Mr Kyran Dixon – Understanding Cancer within Indigenous Australian Adolescents and Young Adults (pg 114)		
4.05pm	A/Professor Donald Payne – Adolescent and Young Adult Medicine and Oncology (pg 115)		
4.25pm	Professor Nick Hulbert Williams – Acceptance and Commitment Therapy (ACT) for people affected by cancer: what does the evidence tell us, and how can we do better? (pg 115)		
4.45pm	Speaker panel discussion and audience Q&A		
5.00pm	Day 2 Close		
7.00pm	Congress Gala Dinner – Doltone House, Jones Bay Wharf		

3rd Global Adolescent and Young Adult Cancer Congress Program

Day 3 – Life Beyond Cancer

Thursday 6 December 2018

8.00am	Registration	
8.30am	Plenary 5 - Financial toxicity, fertility & family. Co-Chair Introduction: Dr Norman Swan & Mr Sean Dondas Grand Ballroom 1	
8.35am	Ms Lynne Pezzullo & Ms Kathryn Woodward - The economic cost of cancer in adolescents and young adults (pg 116)	
9.00am	Dr Antoinette Anazodo – Fertility outcomes in adolescent and young adult cancer survivors (pg 117)	
9.20am	Dr Miyako Takahashi – The impact of cancer on adolescent and young adult survivors' job seeking and continuation of work: needs for comprehensive support (pg 118)	
9.40am	A/Professor Melissa Alderfer & A/Professor Pandora Patterson – Recent Developments in Supporting Siblings of Young Cancer Patients and Conceptualizing their Experience (pg 118)	
10.05am	Speaker panel discussion and audience Q&A	
10.30am	Morning Break – Exhibition & Poster Viewing	
	RAPID FIRE 3.1 & POSTER VIEWING Chair: Dr Adam Walczak Grand Ballroom 1	RAPID FIRE 3.2 & POSTER VIEWING Chair: Dr Stu Siegel Hyde Park Room
11.00am	Understanding experiences of care through the Australian Youth Cancer Services: Patient and Family Members' perspectives. <i>Mel Noke, Australia</i> (pg 119)	Understanding the relationship between social competence and bullying in AYA cancer survivors. <i>Joanna Fardell, Australia</i> (pg 124)
11.05am	Financial toxicity of AYA cancer patients by age at diagnosis. <i>Mark Lewis, USA</i> (pg 120)	Message Strategies and Channels to Recruit Young Adult Cancer Survivors to Research. <i>Lindsey Horrell, USA</i> (pg 124)
11.10am	AYA Neuro-Oncology Patients Need Long-term Interventional Career Mentoring and Motivation to Achieve Success. <i>Jamie Frediani, USA</i> (pg 121)	Using a Clinical Repository to Focus Understanding of a Local Population. <i>Tegan Dunmall, Australia</i> (pg 125)
11.15am	Understanding Young Adult Cancer Survivors' Experiences Returning to Work after Primary Treatment: A longitudinal Qualitative Study. <i>Emily Drake, Canada</i> (pg 121)	DRUMBEAT Group drumming program with Adolescent and Young Adult Cancer Survivors. <i>Julie Sparrow, Australia</i> (pg 126)
11.20am	The financial impact of relapse on young people with cancer and their families. <i>Tracy Cosgrave, United Kingdom</i> (pg 122)	Pulling together the strings: the role of the Long Term Follow Up [LTFU] Clinical Nurse Specialist [CNS] in TYA Oncology. <i>Emma Potter, United Kingdom</i> (pg 127)
11.25am	EDMed - online professional development for teachers supporting students with serious illness. <i>Natali Milovanovic, Australia</i> (pg 123)	The support needs of young people at the end of active cancer treatment. <i>Louise Soanes, United Kingdom</i> (pg 128)

	5.1 – SURVIVORSHIP PROGRAMMING Co Chairs: Mr Andrew Murnane & Ms Aggie Kasicka Grand Ballroom 1	5.2 – END OF LIFE CARE Chair: Ian Olver Hyde Park Room	5.3 – FAMILY, BEREAVEMENT & THE IMPACT OF CANCER BEYOND THE PATIENT Chair: A/Prof Pandora Patterson Phillip Room
11.30am	New cancer follow-up services for AYA: Implementation and Evaluation. <i>Dan Stark, United Kingdom (pg 129)</i>	How to talk about death when life is just beginning: Evaluating an advance-care planning tool for adolescents and young adults with cancer. <i>Ursula Sansom-Daly, Australia (pg 134)</i>	Parenting and Cancer. <i>John Friedsam, Australia</i>
11.45am	The psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors and the possible relationship with their development. <i>Nicole Cameron & Kirsty Ross, New Zealand (pg 129)</i>	Prognostication and Palliative Care in a Young Adult Oncology Patient. <i>Ruwanthie Amanda Fernando, Australia (pg 135)</i>	You are not listening: A mother's perspective of cancer care for her teenage daughter. <i>Natalie Bradford, Australia (pg 140)</i>
12.00pm	Designing Conceptual Frameworks for Financial Burden, Body Image, and Fertility and Parenthood within Adolescent and Young Adult Cancer Survivors. <i>John Salsman, USA (pg 130)</i>	Living Out Loud: AYAs with advanced cancer shatter the silence and create a space of their own. <i>Shelly Cory, Canada (pg 136)</i>	Examining the support needs of parents following the death of a young adult (YA) (aged 16 - 29 years) from cancer; a grounded theory approach. <i>Kate Law, United Kingdom (pg 140)</i>
12.15pm	Is it time to play? An examination of the sport and supportive care needs and preferences of testicular cancer survivors. <i>Anika Gentile, Canada (pg 131)</i>	What is the preferred versus actual place of death for children and young people with cancer? <i>Ankit Bhatt, United Kingdom (pg 137)</i>	The Perspectives of Parents and Adolescents/Emerging Adults regarding Genetic Testing for Li-Fraumeni Syndrome. <i>Melissa Alderfer, USA (pg 141)</i>
12.30pm	"Looking for support and to meet people like me": Exploring the sense of community, peer support and loneliness of AYAs impacted by cancer using an online support service. <i>Mel Noke, Australia (pg 132)</i>	What's Left Behind: Addressing End of Life Distress through Memory Making. <i>Belinda Matigan, Australia (pg 137)</i>	Remembering friends: addressing bereavement support for teenage & young adults (TYA) diagnosed with cancer who experience the loss of a peer. <i>Anna Mackland & Lorraine Wright, United Kingdom (pg 142)</i>
12.45pm	Sustained improvements in self-esteem, emotional functioning, social functioning and body image one year after attending the residential weekend 'Find Your Sense of Tumour'. <i>Lorna Fern, United Kingdom (pg 133)</i>	Understanding and addressing the training needs of clinicians to improve end-of-life care for adolescents and young adults with cancer worldwide. <i>Ursula Sansom-Daly, Australia (pg 138)</i> *This project was awarded the 2018 AYA Global Accord Psycho-Oncology Research Acceleration Grant	

1.00pm	Lunch Break – Exhibition & Poster Viewing
1.45pm	Garmin Watch prize draw 1:45pm @ Garmin Stand, exhibition hall
1.30pm	AYA Consumer Closed Networking Session – Phillip Room
2.00pm	<u>Plenary 6: Bereavement, survivorship & integration of a cancer diagnosis into life after treatment</u> Co-Chair Introduction: Dr Norman Swan & Ms Madeleine Way Grand Ballroom 1
2.05pm	Professor Kevin Oeffinger – AYA Cancer Survivors, Risk-Based Health Care, and the Role of the Primary Care Physician (pg 143)
2.25pm	Q&A
2.30pm	Professor Barbara Jones – Adolescents and Young Adults with Cancer: Facing Loss, Finding Meaning, Focusing on the Future (pg 143)
2:50pm	Q&A
2.55pm	Introduction of Survivor panel & Tilly Gorce poetry slam
3.00pm	International AYA Survivor Panel: AYA Advocates from around the globe discuss & reflect on their cancer experiences, learnings from the congress & future priorities for the AYA cancer community Facilitator: Prof Barbara Jones and Dr Norman Swan Panellists: Mr Terence Rumblow (United Kingdom), Ms Mette de fine Licht (Denmark) Mr Kyran Dixon (Australia), Ms Becca Jacobsen (USA), Ms Yumiko Shirai (Japan)
3.45pm	Closing Remarks • Best Poster & Best Oral Award Professor Ian Olver AM Ms Kate Collins
4.00pm	Congress Close

Oral Abstracts: Day 1

PLENARY 1: AYA PRIORITY SETTING & PRACTICE INNOVATION

Establishing AYA cancer as a national priority: the Canadian experience

Professor Paul Grundy

Professor of Pediatrics and Oncology, Department of Pediatrics, University of Alberta; Expert Lead, Pediatric, Adolescent and Young Adult Oncology, Canadian Partnership Against Cancer

@paulegrundy

We talk about impacting and improving the healthcare system – in this case for the sake of adolescents and young adults with cancer – but without necessarily understanding the system or whether it really is a system.

In Canada we have two healthcare streams – one for children, variably defined as 0-18, and one for adults. The concept of young adults having age-specific needs has not previously existed in healthcare.

Although we have a national medicare policy, there are thirteen independent provincial/territorial healthcare systems. There are only a handful of specific programs designed to address the age-specific needs and issues of young adults and most cancer programs have not identified AYA care as a priority issue, or even as an issue.

The Canadian Partnership Against Cancer, CPAC, a federally funded organization whose mandate is to improve cancer control for all Canadians, supported the AYA Task Force (2008-2016) which brought together advocates, experts and champions for AYA care and published recommendations for standards of care. In 2016 we determined that to better effect change, we needed a different kind of organization with formal connection to the cancer agencies and governments.

We established the Adolescent and Young Adult National Network (AYANN) comprised of representative appointed leaders and patient/family advisors. The AYANN expressed an urgent need for an overarching strategic framework intended to articulate a national vision to guide partners and stakeholders advancing priorities for AYA in the country.

We chose to adopt and adapt the Australian Youth Cancer Framework (Canteen 2017) to our Canadian context. After a five month iterative review and revisions by our Network, we are distributing the draft Canadian Framework to stakeholders across Canada and will share their feedback. We are aiming to launch the Framework nationally in Spring 2019.

Challenges to implementation will be discussed.

Adolescent and young adult diagnostic timelines, pathways and impact on patient outcomes

Dr Lorna Fern

National Cancer Research Institute, University College London Hospitals NHS Foundation Trust

@LornaAFern

Improving the time to diagnosis for young people with cancer is an international priority. Young people frequently describe complex and prolonged pathways from symptom onset to cancer diagnosis and treatment. Reasons for this include low cancer awareness in young people, low cancer awareness of cancer in this group by healthcare professionals and low predictive value of potential cancer symptoms. Historically, little research evidence has existed to identify 'at risk' groups or where interventions are best placed to improve the diagnostic experience for young people. Critically, evidence on potential outcomes effected is lacking.

This presentation will report new data from the BRIGHTLIGHT study examining variation in diagnostic intervals of over 800 young people with cancer. The nature of and frequency of presenting symptoms in this population will be described showing that young people experience a range of non-specific symptoms in combination before diagnosis, in frequencies which are substantially greater than those previously reported. Potential relationships with clinical and patient reported outcomes will be described.

Acknowledgements: This presentation will present independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research Programme (Grant Reference Number RP-PG-1209-10013). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health. Thanks to additional funding bodies Teenage Cancer Trust, Cancer Research UK, University College London Hospitals, University College London department of Behavioural Sciences and Health.

The difference a friend can make

A/Professor Pia Riis Olsen & Ms Mette de Fine Licht

Pia Riis Olsen, RN, MScN, PhD, Clinical nurse specialist, Department of Oncology, Aarhus University, Denmark

Mette de Fine Licht, Teenage cancer survivor and author (book: 'Willpower Girl – A Teenager's Trek Through Cancer').

@PiaRiis

"If we could prescribe friends we should do it, because we know that a supportive social network is important and good medicine." Those words come from a famous Danish scientist. And they are true. Research has shown that people with strong social relationships have lower morbidity and mortality and have a better possibility of recovery or survival after illness. That's why Network Focused Nursing is worth taken a closer look at. The concept 'Network Focused Nursing' is developed in Denmark, showed in a PhD by Pia Riis Olsen. The approach has been part of the care offered to AYAs with cancer for about 20 years at Aarhus University Hospital. Here, nurses pay special attention to the AYA's social network and its ability to provide social support. They explore relationships and interactions between the AYAs' and their significant others and their relations with their wider social

network. As a key intervention, the nurses offer to arrange what they call a 'Network meeting' with the AYA and the AYA's closest friends and family so they will understand what the AYA is going through and how they can support.

AYA survivor Mette de Fine Licht has experienced first-hand what a difference a strong, well informed and included network can make. She was diagnosed with Ewing's Sarcoma by the age of 16. A few weeks after the diagnosis her network was gathered at the hospital for the network meeting. She will share insights from her own story. How the nurses and oncologists guided her friends and family to be the best support and what difference that made for her.

Pia Riis Olsen will focus on Network Focused Nursing and describe how to conduct network meetings.

RAPID FIRE 1.1

The four clinical trials presented in Rapid Fire Session 1.1 were recipients of funding via CanTeen's Australian Young Cancer Patient Clinical Trials Initiative. This Initiative seeks to improve access to clinical trials for Australian adolescent and young adult cancer patients, including through the provision of funding for trials targeting high-lethality AYA cancers. The Australian Young Cancer Patient Clinical Trials Initiative is funded by the Australian Government's Medical Research Future Fund.

Personalised targeted therapy for adolescent and young adult medulloblastoma patients

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INTRODUCTION: The optimal management for adolescents and young adults (AYA) with medulloblastoma remains unknown. Medulloblastoma can now be subdivided into different molecular subtypes with varying genomic features and clinical outcomes. Two thirds of AYA medulloblastoma belong to the Sonic Hedgehog (SHH) subgroup. Sonidegib is a SHH inhibitor that potently inhibits medulloblastoma growth in SHH driven orthograft models. We aim to open a prospective, international study of personalised therapy, including sonidegib, in AYA medulloblastoma patients. Our primary aim is to compare the PFS of a molecularly driven personalized regimen vs. standard therapy, including the addition of sonidegib for SHH-driven tumours.

METHODS: The international trial of 200 patients will integrate molecular diagnostics with clinical staging to personalise cancer treatment. The regimen evaluated in the NOA-07 trial will be used as the standard arm and will be randomized against a stratified risk-adapted therapy.(1) SHH-subgroup patients will be randomised to receive chemotherapy +/- sonidegib and dose reduced radiotherapy. Patients in other medulloblastoma subgroups will be randomised between NOA-07 protocol +/- reduced craniospinal axis radiotherapy.

A high-risk subgroup will be prospectively followed on standard therapy. A comprehensive fertility sub-study will be incorporated for Australian patients. Preclinical studies will assess the effect of sonidegib on fertility and patients will have reproductive potential measured at diagnosis, end of treatment, 12, 36 and 52 months following the completion of treatment.

RESULTS: Funding is currently being secured with protocol currently in development. The trial is planned to open world-wide in 2019. Australia aims to provide at least 10% of the subjects.

CONCLUSION: This will be the first randomized trial in medulloblastoma patients to include a targeted therapy. It will test the efficacy and toxicity of a personalised treatment approach AYA medulloblastoma patients and is hoped to define a new standard of care. 1. Beier D, et al. Neuro-oncology. 2017;20(3):400-10.

Ewing sarcoma clinical trials programme

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INTRODUCTION: Ewing sarcoma (EWS) is a rare and lethal cancer of bone and soft tissue that predominantly affects adolescents and young adults (AYAs). Access to high quality clinical trials for EWS is challenging in Australia due to low patient numbers, scattered across paediatric, adolescent and adult cancer services, and inefficient coordination to ensure regulatory approvals.

METHODS: The Australasian Sarcoma Study Group (ASSG) is leading a collaborative effort to establish a clinical trials programme focused on EWS. This will provide access to international clinical trials in Australia to enable the recruitment of AYA patients through a streamlined activation process at key paediatric/AYA/adult centres. The first of these trials will be a Euro Ewing Consortium Phase III randomised trial of chemotherapy for recurrent and primary refractory EWS, in collaboration with Australian New Zealand Children's Haematology and Oncology Group (ANZCHOG). ASSG will launch this study in six adult sarcoma services with appropriate Youth Cancer Services in collaboration with nine paediatric sites through ANZCHOG. At least four systemic therapy arms will be compared in terms of efficacy and toxicity. Initially these include: 1) topotecan and cyclophosphamide; 2) irinotecan and temozolomide; 3) gemcitabine and docetaxel; 4) ifosfamide.

RESULTS: Lessons learnt from the conduct of the trial in Australia in terms of feasibility and recruitment of AYA population will be described. Results of the optimum chemotherapy regimen for recurrent/refractory EWS based on the balance between efficacy and toxicity will be identified.

DISCUSSION AND CONCLUSIONS: The findings from this study will help develop local chemotherapy guidelines for patients with recurrent/refractory EWS by determining the most active systemic chemotherapy regimen, including an increased understanding of treatment toxicities. There may be other opportunities identified from both the results of this specific trial and the collaborative network to conduct trials in other AYA-prevalent sarcomas in a streamlined way.

The Cancer Molecular Screening and Therapeutics Program (MoST) – A molecular screening platform with multiple, parallel, signal-seeking therapeutic substudies in rare cancer populations

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Innovative approaches are needed to translate molecular opportunities into clinical care, especially for rare cancers, which predominate the AYA cancer spectrum. MoST tests a novel paradigm for evaluation of biomarker-driven treatments (tx) for patients (pts) with advanced cancer, with a particular focus on rare or neglected cancers. Tx-refractory pts (N=1000) undergo molecular screening using archival tumour tissue. Results are reviewed by the Molecular Tumor Board (MTB) to identify actionable variants and eligibility for substudies. A master protocol allows expedited addition of ≥ 12 open-label, phase Ib/IIa, single-arm substudies, with 16 pts per module deemed reasonable for signal-seeking purposes. The primary objectives are to identify potential clinical activity for biomarker-driven tx, biomarkers that predict for response, and to evaluate the MoST study design. Three substudies are active: 1) palbociclib - molecular eligibility includes amplification/activating mutations in cyclin D pathway genes, or loss of function mutations in CDKN2A; 2) olaparib+durvalumab (ola+durva) – molecular eligibility is a homologous recombination repair gene defect; 3) durvalumab+tremelimumab (durva+treme) offers a tx in the absence of actionable findings. Further substudies planned include vismodegib and eribulin for tumours with PTCH1 or SMO mutations, and CD31 positivity respectively. Since September 2016, recruitment to screening has exceeded targets. Of the 786 pts enrolled to April 2018, 680 MTB reports have been issued, 74 are in progress, 26 had insufficient tissue and 60 died prior to issue of a MTB report. Median time to MTB report issue was 44 days over latest quarter (n=89). Rare or less common cancers comprise at least 80%, and 59 subjects were less than 30 years of age (7.5%). Palbociclib (n=16) and durva+treme (n=4x16, 64 pts) substudies have completed recruitment; ola+durva (n=3x16 pts) is currently recruiting. The distribution of actionable mutations across cancers, and in particular rare cancers will be informative, as it comprises the essential first steps to gaining access to novel, personalized treatments for patients with rare cancers. Trial ID ACTRN12616000908437. Registered 08 July 2016.

The Australasian Leukaemia and Lymphoma Group (ALLG) ALL09 Trial: A Phase II Study of Blinatumomab as Induction Therapy in Adolescent and Young Adult (AYA) Acute Lymphoblastic Leukaemia (ALL)

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ALL is the second most common acute leukaemia in AYA patients aged 15-40. It is a leading cause of cancer related mortality in this age group. AYA ALL has been historically associated with poor outcomes in comparison to childhood ALL. More recently, the use of paediatric or paediatric-inspired therapy in this cohort has been associated with significant improvements in event-free survival approaching 70%. The ALLG ALL06 study examined the utility of a minimal residual disease (MRD) stratified approach in this cohort using the ANZCHOG Study 8 protocol. Blinatumomab is a novel bispecific antibody that has demonstrated significant activity in eliminating residual disease in MRD positive relapsed/refractory B-lineage ALL. It is hypothesised that substituting blinatumomab for standard multiagent chemotherapy in an intensive paediatric protocol will significantly improve MRD negativity rates in AYA ALL with expected improvements in survival and quality of life (HRQoL) as well as reduced rates of allogeneic transplantation and toxicity. The primary objective of ALL09 is to assess the impact of this approach on day 79 MRD negativity rates versus the historical ALL06 cohort in a Simon's 2-stage design. Secondary objectives include evaluation of remission and survival endpoints, toxicity, fertility impacts and HRQoL outcomes versus the ALL06 cohort. ALL09 correlative projects include discovery of novel biomarkers and therapies, assessment of immune response markers predicting outcome and health economic impacts of AYA ALL. It is expected that ALL09 will also serve as a co-operative platform between adult and youth cancer services which will assist in improving clinical trial participation rates for AYA patients in Australia. Rationale underpinning study design, endpoints and correlative projects will be discussed.

RAPID FIRE 1.2

Implementation of a Youth Participation Framework in Victoria

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³Faculty of Medicine, Dentistry and Health Sciences University of Melbourne Melbourne, Australia

INTRODUCTION AND AIM: The ONTrac at Peter Mac Victorian Adolescent & Young Adult (AYA) Cancer Service has an embedded culture of youth participation seen in the establishment and outcomes of the Victorian & Tasmanian Youth Cancer Advisory Board since 2010. Identified as a policy priority, a Youth Participation Framework was developed to expand the opportunities for young peoples' involvement in informing, designing and building the future of cancer care for young Victorians.

METHOD: The Framework was developed in collaboration with young people, oncology professionals, health services and local government, and underpinned by findings of the Lancet Commission on Adolescent Health and Wellbeing (Patton et al., Lancet, 2016).

RESULTS: The Framework reflects four populations, each subsets of the broader Victorian & Tasmanian AYA oncology community, with associated mechanisms for flexible participation. This tiered approach was developed and aligned with information, training and support requirements for its implementation. To date activities have focused on establishing a governance structure; communication strategy and branding guide; monitoring and evaluation plan. A Youth Participation & Engagement Internship position has been established, supported by a comprehensive education and mentoring program and centred on building a network of youth advocates to inform cancer policy, priorities and service design.

DISCUSSION AND CONCLUSION: To our knowledge, the Youth Participation Framework is the first of its kind across the oncology sector in Australia. Embedding youth participation within key services highlights the role young people play as advocates for their own needs who deserve the right to participate all in decisions about health service design, delivery and evaluation.

Advancing Advocacy: The Growth of a Youth Cancer Advisory Group from a Passive to Active Influencer

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CASE DESCRIPTION: Increased recognition of the value of health consumer engagement has resulted in innovative opportunities for engagement and influence. The Queensland Youth Cancer Service established the State's first Youth Advisory Group (YAG) in 2013, which allows adolescent and young adult (AYA) patients to use their experiences to ameliorate the youth cancer sector. This presentation will demonstrate the YAG's evolution, from a passive consumer group to an active influencer, prompting meaningful change within Queensland's youth cancer space. As members of the Queensland YAG, this case study has been created by drawing upon personal experience in conjunction with relevant youth participation principles, including Roger Hart's "Ladder of Youth Participation" (1992).

DISCUSSION: Since its inception the YAG has assisted numerous efforts to improve the services and supports available for Queensland AYA cancer patients. Initially, this involved advising external groups which approached the YAG for assistance/information. This model of advocacy for improved services, although successful in each project's goals, lacked significant proactivity on the part of the YAG members, meaning that their specific concerns were not easily addressed. Recently, the YAG has undergone a paradigm shift, advancing up the rungs on Hart's ladder, with members becoming the instigators and champions of change. This new approach has involved YAG members strategically approaching influential parties and working in partnership with them to make meaningful change.

KEY LEARNINGS: Since the Queensland YAG's creation, the ability of members to champion specific causes they find crucial to the improvement of AYA cancer patients' experiences has grown. This not only allows YAG members to make meaning from their cancer experiences but is also leading to greater services and supports. Youth engagement is essential for informed decision-making about AYA cancer services. However, successful consumer participation requires young people to have the freedom to be responsive to their ideas for improvement.

#AYACSM: An Interdisciplinary Adolescent and Young Adult Cancer Twitter Community

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@EK_Drake

INTRODUCTION AND AIMS: Health care social media is challenging the traditional communication hierarchies of both healthcare and academic systems. People around the world are now being connected around various health topics in a way that has been unparalleled. Historically, the adolescent and young adult cancer movement has been a marginalized oncology community – as it includes a small percentage of annual cancer diagnoses and is underrepresented in both funding and academic literature. Due to these factors, its voice has often not been heard by policy makers and funding bodies. Over the past five years, the adolescent and young adult cancer societal movement (#AYACSM) hashtag has contributed to mobilizing and connecting our global efforts in a unique way.

METHODS: Developed in November 2013, the use of the hashtag has been analyzed using Symplur Signals' summary statistics, geolocation and trending terms to explore its reach and use.

RESULTS: As of June 2018, #AYACSM has had a total of 201.8 million impressions since its inception. Trending terms include: "life interrupted"; "fighting stage IV cancer"; "bone marrow transplant"; and "gratitude life". 8,000 unique people/accounts have used the hashtag and they have collectively shared 38,900 articles and 23,500 visuals. In total, 68,400 unique tweets using #AYACSM have been shared and geotagged in North America, Asia, Europe, South America, and Australia.

DISCUSSION AND CONCLUSIONS: The data indicate that the use of a shared community hashtag can unite our conversations online and foster connections among those in our field. Monthly #AYACSM tweet chats have amplified this community's voice and fostered

relevant interdisciplinary conversations between patients, family members, healthcare professionals and non-profit advocates. This presentation will include up to date statistics and lessons learned from the development of an online Twitter community

Teenagers get Cancer but do we 'get' Teenagers? A Medical Student's Reflections from a Placement in AYA Cancer

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BACKGROUND: In the UK, the uniqueness of adolescence and the need to adapt their healthcare has long been recognised: the Platt Report highlighted the need for separation of child and adolescent from adults nearly 60 years ago, 35 years passed before its translation to Oncology (Calman Hine). Adolescent and young adult (AYA) cancer has become a speciality in its own right: principal treatment centres (PTCs) were established across the country to manage the care of cancer patients, 17 provide specialist services for AYAs. There is now a growing wealth of research dedicated to the specific needs of AYAs. Despite this, training specific to communication with AYAs is not commonplace within the UK medical community.

METHODS: This piece reflects on 6 weeks observing the trajectories of care with the AYA cancer team at Addenbrooke's Hospital, the principal treatment centre for the East of England, UK. A focus on triadic communication was explored in partnership with the clinical communication skills team at the University of Cambridge Clinical School. An ongoing output is a literature review of AYA communication needs.

RESULTS: I observed patients throughout the cancer journey – on-treatment, at the end of life and over a decade off-treatment. 5 key themes encompassing each aspect of this journey emerged: the committed team, communication skills, psychosocial support, transitions of care, and 'the little things'.

CONCLUSION: AYA oncology itself is in its adolescence. A specialism of multiple transitions and challenges, enabling healthcare professionals to develop a repertoire of skills applicable more generally to AYA healthcare and indeed healthcare more widely. This experience was extremely valuable, allowing development of communication skills with a patient population underrepresented in medical undergraduate curriculums. Offering this model in undergraduate education more widely could have positive impacts on awareness of AYA cancer and thus improve time to diagnosis for this group.

CONCURRENT STREAM 1.1 – LEADERSHIP IN AYA CANCER

Building Adaptive Leadership capability in the Youth Cancer Service Context

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¹Conversus Leadership, Australia

INTRODUCTION: Leadership is a value laden term, often misunderstood or assigned to a particular role in an organisation. The complexity of the health care system, and YCS in particular - with its multiple stakeholders, geographically spread jurisdictions, competing agendas - makes the work of leadership essential. The focus on development requires all staff, regardless of role, expertise, area of practice, and disciplines to explore and challenge past assumptions about their leadership accountability and to identify the mindsets, capacity and skills required across the sector

AIM: To present insights gained through consultation with YCS staff and advisory bodies across Australia around the practice of collective leadership and the focus on professional development. This will provide the opportunity to explore a leadership narrative that is relevant to the work in the sector, as well as highlight the mindsets and capabilities required. It will move beyond traditional leadership thinking, pushing the boundaries of knowledge acquisition to identifying applicability of skills, the embedding of a new culture and way of working, and exploring shared accountabilities that mirror the values upheld within YCS.

DISCUSSION: Professional development is essential to the continued evolution, innovation and sustainability of YCS services. The focus (and passion) of staff on patient care often distracts the system from recognising what is required to support staff in their multiple roles. Leadership is placed in the hands of very few, with a reliance and compliance approach. This does not maximise all the potential that sits across the sector. The exploration of leadership as an activity that supports working with complexity, takes into account power and authority structures, diversity of disciplines, levels of resilience and how best to serve patients, is required. The specific challenges and opportunities in different parts of the system need to be considered in the co-design of learning methodologies, frameworks and approaches.

CONCLUSION: There are many interventions that support professional development - empowering self and empowering others in support of YCS can be viewed as fundamental leadership practices.

Leadership perspectives Professionals in Adolescent and Young Adult Cancer Care

M. Cable¹

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@mariacable2

Leadership is a core part of every healthcare professional's role. It transcends professional disciplines and unites us together with a common bond. All of us are leaders, we just may not see that we are. This presentation addresses key leadership issues that have underpinned the development of the AYA cancer specialism in the United Kingdom, nursing's contribution to that, as well as how cancer nurses are acting to increase recognition of

the value and contribution of cancer nursing across Europe – focusing on expert cancer nursing skills, research, education, clinical leadership, strategy and management roles, advocacy, and policy development. Our specialism requires innovative and contemporary thinking, a means to evolve and strong leadership as we raise conscious awareness of the unique needs of our patient population.

This presentation will also look at the development of the specialism in the UK and consider elements of power though its inception as viewed through the lens of Michele Foucault, arriving at the conclusion that power is universal, discrete and ubiquitous. TYA cancer care and its leadership within it, has many forces to contend with.

As AYA Cancer professionals, it is our responsibility to provide compassionate, inclusive, evidence based and expert clinical care to AYA cancer patients and their families when the need us most, but it is also our duty to continually improve the services that we deliver whilst negotiating many forces within it. We are all leaders as much as we are all followers. Our power to act as leaders and influence change is something that we can all enact at any point.

Insights from the evolution of youth leadership in CanTeen

N. Hornyak¹, E. Adlide¹

¹CanTeen Australia

INTRODUCTION: In sharing experiences and expertise in youth leadership, CanTeen seeks to challenge the common assumption that young people possess insufficient knowledge, experience or maturity to be anything more than passive recipients of services; and encourage others to recognise the positive impact youth leadership has on the individuals, services and communities involved.

AIM: In this presentation, Canteen's National Leadership Coordinator and Chair of the Board will share honest, real insights from over 30 years of youth leadership with the aim of inspiring and enabling other professionals and institutions to not only engage young people as active participants but to empower them to take up meaningful leadership.

DISCUSSION: CanTeen has a long history of engaging young people in a range of leadership roles and activities including governance (the constitution ensures young people comprise the majority and hold the position of Chair on the Board of Directors), local leadership groups, the national advisory group, peer mentoring, program facilitation, research and advocacy. In 2015 the organisation reviewed its policies and practice with a desire to evolve, and to more effectively empower more young people in meaningful and dynamic leadership. As part of this review, the CanTeen Youth Leadership Framework was co-developed and implemented by staff and young people. It includes a youth leadership model which articulates the vision, strategic priorities, and outcomes of youth leadership; a suite of leadership development programs; and toolkit, containing policies, procedures and resources to support implementation.

CONCLUSION: The youth leadership structures, culture and activities in CanTeen Australia provide an example that young people are not just leaders of the future; they are creating, contributing and influencing our world (and work), right now.

CONCURRENT STREAM 1.2 – AYA CANCER POLICY & PRIORITIES

Identifying shared research priorities between young people, significant others and professionals: Results of the United Kingdom's James Lind Alliance Research Priority Setting Exercise

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INTRODUCTION AND AIMS: The research agenda is frequently set by healthcare professionals and researchers. Young people with cancer, aged 13-24, have unique physical, psychological and social responses to their diagnoses, with distinct outcomes. Priorities identified by young people may not be the same as those identified by professionals. We aimed to engage young people, carers and professionals across the UK in a systematic process to identify and prioritise research questions about cancer in young people that were important to them.

METHOD: We followed the James Lind Alliance method. A steering group was established including young people and professionals from across the care pathway. Research questions were gathered from young people, carers and professionals via an online survey. A rigorous evidence checking process was employed to ensure submitted questions were unanswered. Interim prioritisation was undertaken through a second national survey to identify the highest priority questions. Agreement on the top priorities was reached at a consensus workshop.

RESULTS: Two hundred and ninety two respondents submitted 855 potential questions; refined into 208 unique questions. Seven were already answered and 16 were ongoing studies, therefore removed. One hundred and seventy-four respondents completed the interim survey prioritising 30 questions: prioritisation of these questions was debated at a workshop attended by 25 young people, carers, and professionals from a broad range of roles. The Top 10 questions reflect the breadth of young people's experiences and indicate that future research should focus not only on drug trials but also on delivery of holistic care.

DISCUSSION: We will present the Top 10 research questions and the remaining 20; highlighting decision making that influenced the prioritisation. We have identified shared research priorities using a rigorous, person-centred approach involving stakeholders typically not involved in setting the research agenda. These will inform the funding of future research.

Developing an Adolescent and Young Adult Framework for Canada

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INTRODUCTION AND AIMS: The Adolescent and Young Adults National Network (the Network) was established as a pan-Canadian forum charged with addressing gaps for AYA with cancer identified in a report released in 2017 (<http://www.systemperformance.ca/report/adolescents-young-adults-cancer/>).

METHODS: To accelerate action for AYA in Canada the Network saw the need to leverage the success of international collaborators. Existing AYA frameworks were reviewed to identify potential models for adaptation in Canada. The Australian Youth Cancer Framework (ACYF) was selected based on rigorous and evidence-based methodology, level-setting and applicability. Through a series of consensus building exercises and discussions, the Network reviewed, refined and adapted the ACYF to the Canadian setting. Key principles for the adaptation included identifying ACYF content that could be adopted as is, refining content requiring adaptation for the Canadian setting and addressing gaps/opportunities identified by Network members.

RESULTS: Framework adaptation began in May 2018, where Network patient and family advisors, leaders from provincial and territorial cancer programs and Ministries of Health, and representatives from national medical, psychosocial, oncology-focused and AYA organizations gathered in-person to discuss areas of AYCF for adoption/adaptation. Main outcomes included consensus on content to be adopted, broad concepts used to draft Canadian strategic priorities, and advice on gaps/elements to be addressed in subsequent drafts. A series of Network discussions will take place to revise and refine the draft.

DISCUSSION AND CONCLUSION: A large group of experts and stakeholders will be consulted for further feedback and refinement prior to the framework release anticipated in 2019. The Canadian Framework for AYA with Cancer is an example leveraging prior success of international collaborators to establish a national vision for AYA with cancer, co-developed with stakeholders in government, national medical, psychosocial and cancer organizations, patients and families.

A blueprint for age-specific care for Adolescents and Young Adults (AYAs) in Flanders (Belgium)

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INTRODUCTION AND AIMS: Annually, almost 1000 young people between 16 and 35 year are diagnosed with cancer in Flanders, Belgium. Although Flanders is a small region, AYAs were spread over 56 hospitals in 2015; 60% of AYAs were diagnosed in 10 hospitals where as the half of these hospitals diagnosed less than 10 AYAs a year. The wide spread of AYA cases raises major questions about the quality of medical treatment since a significant

part of AYAs are diagnosed with a rare cancer, the available experience and expertise in AYA cancer care and the possibilities to meet AYAs age-specific needs in many hospitals.

METHODS: In 2016, a working group of 4 AYAs and 1 family caregiver, 12 HCP from different disciplines, and 2 representatives of the Flemish Cancer Society, Kom op tegen Kanker, was set up to tackle this important gap in age specific care.

RESULTS: The outcome of this joint initiative was the publication of a blueprint for AYA care in Flanders, presented at the first AYA Congress in Belgium in May 2018. This blueprint puts forward an alternative to the current situation of divided care for AYAs. The objective to provide excellent AYA cancer care close to the home if possible but in an AYA reference center if needed, was the general principle.

DISCUSSION AND CONCLUSIONS: To improve the quality of care for AYAs in Flanders, the blueprint advocates a concentration of medical and psychosocial expertise in AYA reference centers that work together with their network to organise a joint AYA care pathway. Through the AYA care pathway, every newly diagnosed AYA is guaranteed quick and appropriate age-specific care, regardless of the hospital of diagnosis. By advocating these recommendations at a political level, we could reverse the current fragmented trend and strongly push for the best AYA Cancer Care.

Setting Priorities for a Provincial Adolescent and Young Adult Oncology Program

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INTRODUCTION AND AIMS: Planning for a provincial Adolescent and Young Adult (AYA) oncology program is underway in the province of British Columbia (BC), Canada. Health care providers (HCPs) involved in AYA cancer care, administrators and patient and family representatives (herein identified as stakeholders) throughout BC were engaged to co-develop program goals and activities. The aim of this work is to disseminate the findings of this process.

METHODS: Program goals, priorities, components and activities, 79 distinct items, were developed through a literature review, national consensus documents and expert opinion. A modified Delphi technique was used through two iterations administered online to AYA stakeholders to score program items from 1 to 5. Stakeholders attended a one-day session in Vancouver to discuss survey results and further prioritize program implementation. Consensus was defined as a mean score of less than 2.0 (indicating not important) or 4.0 or greater (indicating important). Items without consensus on surveys (scored between 2.0 and 3.99) were discussed at the in-person meeting.

RESULTS: Sixty provincial AYA stakeholders completed the Delphi survey iterations. Respondents included administration (5%), patient and family representatives (1.7%) and HCPs in medical oncology (26.7%), nursing (26.7%), counselling (21.7%), pain and symptom management (6.7%), radiation oncology (1.7%), psychiatry (1.7%), and nutrition (1.7%). Adult and children's hospitals were represented. 29 AYA stakeholders attended the in-person meeting. All program goals were endorsed as important by respondents, except the development of an AYA research program. Priority of program implementation was ranked as patient care first, followed by: HCP education; patient and family education; research; program sustainability plan; evaluation; then model for multidisciplinary tumour board review.

DISCUSSION AND CONCLUSIONS: There is widespread support for an AYA Oncology Program in BC. Proposed program goals and activities were well accepted, with research seen as a lower priority compared to other activities.

AYA cancer care in New Zealand – A way forward

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INTRODUCTION: We know that the survival rates for AYAs in New Zealand lag behind international comparisons in some areas, particularly for our indigenous population. Addressing AYA cancer care in NZ has some unique challenges with NZ's large geographical size, small population, and health system structure with up to 20 centres delivering cancer care. So what is being done about it? Over the past 2 years the AYA Cancer Network Aotearoa has designed and implemented a unique and innovative process to address AYA cancer care and implement the recently published Standards of Care. The heart of this process has been the design and implementation of an online AYA cancer self-review tool.

METHODS: The tool encourages wider sector participation and collaboration in driving and developing quality improvements locally and nationally. The tool promotes centres to:1. Understand what is working well in the delivery of care and support to AYAs2. Determine areas where further service improvements are required3. Develop a local service development plan that links to the national strategy for AYA cancer care

RESULTS: This process is proving to be successful with all 20 centres having voluntarily completed the tool and created centre specific AYA cancer service development plans. To date a number of quality initiatives/projects have been implemented as a result of the process. The development of a national strategy will now accurately reflect the nation's needs and experiences and be driven by regional buy in and commitment.

DISCUSSION AND CONCLUSION: NZ has unique challenges but it now has unique solutions. The Network has created a way to support all centres, both large and small to strengthen the care being delivered to their AYA population. This session will present the online self-review tool, the implementation process and highlight successes, strengths and challenges in its implementation.

CONCURRENT STREAM 1.3 – RARELY HEARD VOICES & MINORITY POPULATIONS

Youth at Risk: Complexities of Managing Young People with Cancer with No Carer Support

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CASE DESCRIPTION: Daniel is a 17 year old male who presented to the Princess Alexandra Hospital (PAH) with a delayed diagnosis of ALK neg Anaplastic Large Cell Lymphoma.

His treatment consisted of CHOP+etoposide, 6 cycles, had complete response after 2 cycles, but relapsed during radiation treatment. He was under a long term guardianship order with the Department of Child Safety (DCS), has a complex trauma history, and had recently self-placed with his 21 year old brother. During the first cycle of treatment he turned 18, transitioning out of the care of DCS. The PAH Youth Cancer Service (YCS) had the task of managing the care of a young person who did not have a responsible adult to provide care and support.

DISCUSSION: Research states that trauma can have a huge impact on an adolescent's development. Daniel's history of long term abuse and displacement meant that he did not have the opportunity to develop interpersonal skills such as problem solving, critical thinking, communication, money management and was not engaged in positive leisure activities. He had developed a high level of avoidance behaviour, which contributed to ongoing issues with engagement, consent, communication and treatment compliance. The complexity of Daniel's case provided ongoing challenges for the PAH YCS, strategies used to support Daniel will be discussed, as well as service limitations.

KEY LEARNINGS: While the current practice guidelines for the psychosocial management of youth cancer patients are comprehensive, there are additional challenges involved in providing support to young people with complex social issues and no carer support. Daniel's history of abuse and trauma, abandonment, loss and interruption to family life, combined with the uncertainty of a cancer diagnosis, meant that the PAH YCS needed to provide additional support, above normal practice standards, to meet the complex needs of this young person.

No Way Out: Caring for Incarcerated Young Adults with Advanced Cancer

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CASE DESCRIPTION: B was a 23 year old male who presented to hospital with difficulties breathing. Investigations showed a plural malignancy which was diagnosed as a rare form of Ewings Sarcoma. B was incarcerated in a maximum security prison and had 3 years left of his sentence, with no option for parole. B's support was from his mother and grandmother who since his incarceration had visited him weekly. B received 2 months of chemotherapy which achieved partial response. A repeat scan 3 months later, after further chemotherapy, revealed disease progression. His chemotherapy was ceased and he proceeded to palliative radiotherapy. Approximately one month later he was admitted to the oncology ward with significant disease progression and deterioration. He was managed by the oncology, palliative care and youth cancer service (YCS) until his death on the ward 9 days later.

DISCUSSION: Caring for incarcerated prisoners with advanced cancer is complex (Lyckholme et al, 2016) and there were many intricacies for the YCS team to manage on top of the standard model of care, including: - Challenge of B's family not being able to accompany him to medical appointments - At diagnosis, the prison deemed B not able to participate in usual activities (his work assignment and recreation) and he was transferred to another facility, removing him from his known social network. Normal ethos of privacy and confidentiality waived with presence of multiple safeguards/security guards making compassionate and age appropriate provision of care challenging - Education of

prison staff to adequately manage adverse effects and toxicities of treatment - Managing personal and professional ethics of staff including biases and moral distress - End of life care and death in custody.

KEY LEARNINGS: YCS clinicians need to be able to advocate, navigate systems and educate both hospital and correctional staff on providing developmentally appropriate, ethical and compassionate care for this vulnerable group of young people.

Caregiver profile of young cancer patients in rural western Madhya Pradesh (India)

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INTRODUCTION AND AIMS: Teenage and Young Adult (TYA) cancer patients experience unique circumstances. TYAs face rapid social, biological, and cognitive changes, rendering them dependent on their caregivers. This study highlights characteristics and activities of TYA cancer caregivers (TCGs) handle, the demands on them, and the impact of caregiving on their quality of life.

METHODS: Our study examines responses of 200 TCGs to pretested a structured questionnaire on various aspects of care-giving between September 2016 and April 2018, at Sri Aurobindo Cancer Centre, Indore. Respondents were self-identified as an unpaid primary TCG either currently or within twelve months prior to the study period.

RESULTS: TCGs have diverse backgrounds and characteristics. One hundred and thirty-two (66%) are women, 156 (78%) were 18-49 year old; and 116/ 200 (58%) have less than a high school certificate. Majority: 120 (60%) lived in rural areas, 26 (13%) required change in residence on account of caregiving; 128(64%) were from lower socioeconomic status. An average TCG helped the recipient with 5 out of 9 activities of daily living (ADL) and 164 82% of TCGs required help with key activities. TCG health status reported as good in 128 (64%) and fair/poor by 36%. Thirty two percent (64/200) reported anxiety; depression in 50/200 (25%); fatigue in (74/ 200) and sleep disturbances in 68/200 (34%) : each of 3 on a 5 point scale. 44 (22%) were not satisfied with their social activity. These factors led to delay in diagnosis in 8%, delay in treatment initiation in 10%, to non-adherence in 10%, and to abandonment in 6%.

CONCLUSIONS: To date, there is a paucity of research examining effects of providing care for a TYA with cancer in developing countries, and rural India, where family members are important resource for healthcare, and finances are scarce. TCGs data are vital for development and implementation of future programs of counselling to improve caregiver & patient health-indices through the care-trajectory.

From Coast to City - A shared approach delivering optimal care

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CASE STUDY: 22yr old male from a large indigenous community along the Mid North Coast of NSW, presented to the local hospital with intermittent right flank pain and a palatable mass. A CT scan conducted, showed a large kidney mass and a biopsy was performed. The diagnosis of Ewing's Sarcoma was concluded in April 2018.

Referral was made to The Bone Tumour MDT at RPAH by a local treating doctor. Given the case that was presented, this patient was fast tracked and seen in clinic two days later with additional scans.

Patient presented with his Mother to The Chris O'Brien Lifehouse as requested. On assessment, it was discovered this young man was uncomfortable being in the clinic room and said 'he found the city too big and just wanted to go home', but he understood the severity of the situation.

Education and pre-treatment work up was conducted as soon as possible, while connections and implementations of the protocols was being organised in Newcastle, with the plan of a shared care approach to take place. The patient had two cycles of chemotherapy at Lifehouse and was then transferred to Newcastle for ongoing care, with the support of the Sarcoma Unit in the background.

Connections with the local Oncology CNC and Taree Rural Base Hospital were also created to further assist the patient and connect him locally for any unwell presentations in-between treatments.

Currently, the patient continues to be linked into the three hospitals and the shared care approached has been very successful in providing the necessary resources, education and support required. This is just one example of how a shared care approach can work with fellow health professionals and patients to provide care that is adequate, suitable and patient centred.

Understanding and meeting the needs of Lesbian, Gay, Bisexual, Trans, and Intersex (LGBTI) young people accessing the Victorian Adolescent and Young Adult Cancer Service: moving towards an inclusive and equitable model of care

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INTRODUCTION: The Victorian Adolescent and Young Adult Cancer Service supports young people aged 15-25 who have been diagnosed with cancer. This specialisation acknowledges the challenges arising from the intersection of cancer with a stage marked by complex developmental transitions, including an evolving negotiation of sexuality and gender identity. In 2017 feedback from the Victorian & Tasmanian Youth Cancer Action Board identified the potential for barriers regarding young LGBTI patients within the service. AimTo undertake a service review to: 1) assess staff knowledge and LGBTI-inclusivity in practice; and 2) assess

the LGBTI-inclusivity of clinical governance structures within the service.

METHOD: A mixed methods study comprising: 1) A 10-item mixed methods confidential online survey of staff exploring beliefs and skillset in working with LGBTI patients; and 2) Completion of an LGBTI inclusive practice organisational audit following The Rainbow Tick model.

RESULTS: All service staff were invited to participate in the survey, with 14 respondents (77%) completing and aggregate results demonstrating a majority (92.86%) agreeing on the importance of an LGBTI-inclusive service. On average, respondents recorded a high self-rated level of comfort in working with young LGBTI patients, however comparatively lower self-rated level of knowledge concerning the actual needs of young LGBTI patients. The LGBTI inclusive practice audit measured the service against the 6 standards of the Rainbow Tick accreditation framework. 22 of 26 indicators were rated Not Met, with the remaining 4 rated Part Met. Notable areas of oversight included Organisational Capability, Workforce Development and Disclosure and Documentation.

DISCUSSIONS AND CONCLUSIONS: This study demonstrated systemic and provider barriers that young LGBTI patients may encounter when accessing the service, and mainstream healthcare services in general. Recommendations include committing to LGBTI inclusive practice in strategic planning; developing comprehensive policy and procedures to guide staff practice; and ongoing staff education to address knowledge gaps.

CONCURRENT STREAM 2.1 – PREVENTION & EARLY DETECTION

“It really does affect everything, even if you don’t have cancer”: The experiences of Australian adolescents and young adults with Li-Fraumeni Syndrome

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INTRODUCTION AND AIMS: Li-Fraumeni Syndrome (LFS), a multi-organ cancer predisposition caused by germline TP53 mutations, confers significant cancer risks for adolescents and young adults (AYAs: 15-39 years). The complex and unique psychosocial needs of AYAs with LFS remain critically understudied. Our aims were to 1) synthesise available evidence on how AYAs live with inherited disease to draw findings that may be analogous for AYAs with LFS, and 2) conduct a qualitative study exploring the psychosocial experiences of AYAs with LFS to make recommendations for genetic counselling practice.

METHODS: Study one: We conducted a systematic search for studies published in peer reviewed journals using Medline, CINAHL, PsycINFO and Embase databases. Findings were synthesized and are reported thematically. Study two: We conducted semi-structured interviews with Australian AYAs with a TP53 germline mutation to examine the psychosocial impact of LFS. Data collection and analysis are ongoing and informed by interpretive description.

RESULTS: Study one: We identified 39 studies representing the perspectives of 765 AYAs with varying inherited conditions. Only one LFS study was identified. Familial factors strongly influenced young people's experiences of genetic testing and their mutation status. Various psychosocial concerns became evident at key developmental milestones: including family planning, developing romantic relationships and risk management decision-making. Study two: We have conducted 18 interviews to date (Mage 23.7 years, SD = 4.19). Familial and personal experiences of cancer were varied and heavily influenced cancer fear and risk perception. Comprehensive screening was critical in buffering LFS-related distress. However, feelings of isolation and personal burden with managing LFS were common, and LFS remained a grave concern for most.

CONCLUSIONS: AYAs with inherited disease, especially LFS, follow a range of psychosocial trajectories through development and could benefit from tailored longitudinal care as they reach developmental milestones that intersect with risk management, risk perception, and family formation.

Don't let the sun go down on them: sun-related attitudes and behaviours amongst New South Wales (NSW) adolescents and young adults

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INTRODUCTION AND AIMS: Skin cancer is an important public health issue in Australia due to its high prevalence and significant burden on the health system. Despite the reductions in melanoma incidence and mortality amongst adolescents and young adults (AYAs), it remains the most commonly diagnosed cancer amongst young Australians. Unprotected exposure to solar ultraviolet radiation is the most important modifiable risk factor for skin cancer. Therefore, ongoing monitoring of sun-related attitudes and behaviours is essential. The aim of this presentation is to describe the prevalence of sun-related attitudes and behaviours among NSW AYA.

METHOD: The National Sun Protection Survey is a cross-sectional survey administered across five waves of summer (2003-04 to 2016-17), exploring Australians' (12-69 years) attitudes, sun protection behaviours and sunburn incidence. Here we present results from the most recent survey (2016-17) focussing on AYA respondents in NSW (N=601).

RESULTS: In 2016-17, approximately one-quarter of young adults aged 18-24 years (YA) were sunburnt on summer weekends, with less than half reporting using sun protection most or all the time during everyday activities when outdoors for 10 minutes or more. Preferring a suntan (43% cf. 34%) and attempting a suntan (26% cf. 10%) were more common among young women than young men; yet the majority of YA reported tanned skin, with no gender variation. Overall, 49% of YA perceived their risk of skin cancer to be low. Further results will be presented for AYAs, including those for adolescents (12-17 years).

DISCUSSION AND CONCLUSION: These results suggest that the sun-related attitudes and behaviours of AYAs warrant more attention. Further evaluation of specific social marketing strategies that can enhance current efforts would be beneficial to reduce AYAs skin cancer risk. We will discuss these findings in the context of other evidence supporting sustained investment in primary prevention sun protection campaigns.

Sun exposure among teenage and young adult cancer survivors in the United Kingdom

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INTRODUCTION: Skin cancers are a common form of second malignant neoplasm among teenage and young adult cancer survivors (TYACS). The Children's Oncology Group specify that TYACS should adhere to safe sun practices, avoid UV exposure and be screened for skin cancer annually.

METHODS: TYACS and general population TYAs' (GP-TYAs) aged between 13 and 24 years, were invited to complete a Health and Lifestyle Questionnaire which contained three survey items assessing incidence of sun-bathing, sunburn last summer, and use of indoor sunbeds. TYACS both on (i.e. receiving active cancer treatment) and off treatment were eligible to participate

RESULTS: Complete data on sun exposure was available from 229 TYACS (n=76 on treatment; n=149 off treatment) and 311 GP-TYAs. Over a third of TYACS (35.5%, n=27 on treatment; 45.6%, n=68 off treatment) and GP-TYAs (49.8%, n=155) reported intentionally tanning with approximately 40% reporting sunburn (pinkness/redness from being in the sun) in the past year (42.1%, n=32 on treatment; 41.6%, n=62 off treatment) and 47.6% (n=148) of GP-TYAs. Very few young people within any group used sunbeds (6.6%, 6% and 8.4% respectively). Less than one third of participants were meeting COG sun safety guidelines on UV exposure. After adjusting for age and gender there were no significant differences ($p>0.05$) in the behaviours of young people on cancer treatment, off cancer treatment, and in the general population

DISCUSSION AND CONCLUSIONS: This study demonstrates TYACS in the United Kingdom have a similar sun-exposure behaviours to GP-TYAs in that they often sunbathe and burn in the sun. These data indicate a need to intervene in limiting sun exposure among TYACS. Interventions targeting sun exposure among TYACS should incorporate principles of behavioural science and consider existing interventions conducted in the general population which have shown promise.

Promoting sunscreen use and skin self-examination to improve early detection and prevent skin cancer: quasi-experimental trial of an adolescent psycho-educational intervention

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INTRODUCTION: The sun can be harmful. If adolescents get sunburnt >five times, they are twice as likely to get skin cancer as an adult.

AIM: Determine the feasibility of delivering and testing a psycho-educational intervention to increase adolescent sunscreen use and skin self-examination (SSE).

METHODS: Quasi-experimental design; 1 control and 4 intervention group schools in Scotland, UK. Participants were 15-16 year old students on the school register. The intervention was a theoretically-informed (Common-Sense Model and Health Action Process Approach) 50-minute presentation, delivered by a skin cancer specialist nurse and young adult skin cancer survivor, to students in a classroom, supplemented by a home-based assignment. Outcome variables were sunscreen use intention, SSE intention/behaviour, planning, illness perceptions and skin cancer communication behaviour, measured 2 weeks pre- and 4 weeks post-intervention using self-completed pen and paper survey. School attendance records were used to record intervention up-take; students self-reported completion of the home-based assignment. Pearson's chi-square test, analysis of variance, and non-parametric Wilcoxon Signed Ranks Test were used to measure outcomes and associations between variables. Focus groups elicited students' (n=29) views on the intervention. Qualitative data were analysed thematically.

RESULTS: 5 of 37 invited schools participated. 625 (69.5%) of students on the school register completed a questionnaire at baseline and/or follow-up; 639 (81%) in intervention schools received the intervention; 33.8% completed the home-based assignment. Focus groups identified four themes – personal experiences of skin cancer, distaste for sunscreen, relevance of SSE in adolescence, and skin cancer conversations. Statistically significant ($p \geq 0.05$) changes were observed for sunscreen use, SSE, planning, and talk about skin cancer in intervention schools but not the control. Significant associations were found between sunscreen use, planning and 2 illness perceptions (identity and consequence) and between SSE, planning and 3 illness perceptions (timeline, causes, control).

CONCLUSIONS: It is feasible to promote sunscreen use and SSE in the context of an adolescent school-based psychoeducation intervention. Further research is required to assess impact on actual sun safe behaviours.

Learnings from a Decade of Breast Cancer Awareness Targeting Young Women on Canadian Post-Secondary School Campuses

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INTRODUCTION AND AIMS: National charity, Team Shan Breast Cancer Awareness for Young Women (Team Shan) has facilitated breast cancer awareness campaigns on Canadian post-secondary school campuses since 2007. The multifaceted media/marketing model incorporates personal storytelling to message the theme breast cancer...not just a disease of older women. The aims of the strategy are to increase breast cancer awareness and breast health knowledge levels in young women; encourage risk reduction and self-care behaviours; increase early detection and help improve outcomes for young woman diagnosed.

METHODS: Systematic reviews conducted to assess need, inform messaging, plan and revise awareness campaign activities. Multifaceted campaigns facilitated on post-secondary school sites in collaboration with campus faculty, students and media partners. Eval-

uation activities completed using pre- and post-campaign questionnaires with young women on campus. Focus testing conducted with the target population and analysis of campaign evaluation results reviewed to guide campaign refinements. Analysis completed on campaign take home messages and action taken by young women.

RESULTS: Results included valuable data on the effectiveness of campaign strategies, respondents understanding of their breast cancer risk and increased breast cancer knowledge levels. Data analysis reported successful results to campaign take home messages, self-care actions taken and campaign information sharing. Unexpected campaign results were also received. Positive campaign feedback received and respondents appreciated not being forgotten in breast cancer messaging. Appreciative feedback received from young women diagnosed early as a result of Team Shan messaging.

DISCUSSION AND CONCLUSIONS: To self-detect breast cancer and improve early detection rates, young women must be aware of their risk and informed about the symptoms of breast cancer. Breast cancer can be effectively treated if detected early and an effective health education campaign can help reduce the number of premature deaths due to breast cancer. The multifaceted approach undertaken by Team Shan has addressed these needs.

An initial evaluation of “When Cancer Comes Along” cancer awareness program for high school students

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INTRODUCTION AND AIMS: Adolescence is an opportune age for education on cancer prevention and supporting others impacted by cancer. This life-stage involves increasing personal health responsibility and the development of extensive personal relationships. Patterns of behaviour established during adolescence have lifelong implications for the one-third of preventable cancers. However, currently there is no comprehensive Australian secondary-school cancer education program. This study aimed to pilot a cancer awareness program for secondary school students; assess feasibility, measure the program's acceptability; and assess learning of key messages.

METHODS: Secondary schools were invited to pilot the When Cancer Comes Along cancer awareness program with students in years 8-10. Students consented to complete post-presentations surveys measuring program satisfaction, perceived increased understanding of key messages and free-recall of cancer prevention behaviours. Three secondary schools participated in Pilot 1. Following revisions, one additional school participated in Pilot 2. Class teachers provided feedback on the program.

RESULTS: 113 secondary school students (M=14.5 years, SD=1.1; 62.2% female) participated. The program was acceptable: over 90% of students rating it as useful and well-designed for young people. Perceived increases in knowledge about cancer and support provision were high (M=4.3/5). In Pilot 1 on average 2.4/5 cancer prevention behaviours were recalled. Following relevant program revision, students in Pilot 2 recalled 3.0 behaviours, a significant increase from Pilot 1 ($p=.03$). Teachers reported that the program was engaging, suitable for students and consistent with the syllabus.

DISCUSSION AND CONCLUSIONS: The introduction of a comprehensive cancer aware-

ness program into Australian secondary schools has the potential to provide adolescents with the knowledge to reduce their personal cancer risk and provide support to others impacted by cancer. Pilot results for When Cancer Comes Along suggest the program addresses these aims and that high school students find it to be highly acceptable. A national program evaluation is underway.

CONCURRENT STREAM 2.2 – PROFESSIONAL DEVELOPMENT

“Message from the Cancer Club:” AYAs Create a Video for Their Healthcare Providers

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INTRODUCTION AND AIMS: Our AYA Oncology Council (AYAOC) in Tacoma, WA USA, meets regularly to discuss the healthcare needs and preferences of AYAs treated in community cancer centers. The group includes young adults diagnosed with cancer between 15 and 39 years of age and also parent, spouse and sibling caregivers of AYA patients. Here we report on a novel and clinically important professional education video created by the AYAOC.

METHODS: Building on consensus opinions derived from monthly conversations, the AYAOC collaborated to write a short video for the benefit of healthcare providers, in which AYAs describe what they want their cancer care to look like. Filmed and produced by an AYAOC member, the YouTube video features group members giving specific suggestions that healthcare professionals can utilize immediately to engage their AYA patients more effectively.

RESULTS: Topics in the video include: features that make AYAs unique; commonalities between AYAs and healthcare providers; things to remember when talking to an AYA patient; and a step-by-step guide for “how to tell me I have cancer.” AYAs emphasize their desire for healthcare providers to facilitate peer support and deliver proactive counseling on fertility, sexuality, and healthy living. They encourage healthcare providers to balance realistic expectations with shared hope in the face of cancer progression. They advocate for the creation of mutually authentic, open and honest working relationships between healthcare providers and AYAs.

DISCUSSION AND CONCLUSION: The key medical and psychosocial needs of AYAs with cancer are highly concordant across developed countries. A strong bond between clinician and AYA cancer patient has been shown to improve psychosocial outcomes. This free video is a useful, brief and broadly applicable educational tool to help healthcare workers optimize their interactions with AYAs and ultimately improve patient care. Acknowledgements: This work was supported by a PCORI Patient Engagement Award.

Comprehensive fellowship training of adolescent and young adult oncologists: a single center experience

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INTRODUCTION AND AIMS: Quality physician training in adolescent and young adult (AYA) oncology requires deep understanding of the cancers that commonly occur in this age as well as sensitivity to the dynamic developmental period that takes place in the AYA years. In 2010, the LIVESTRONG Young Adult Alliance published a position statement describing the essential elements for training in the AYA oncology discipline. Oregon Health & Science University (OSHU) aims to train AYA oncologists in a standardized program that fulfills those elements and ensures dual Board eligibility in pediatric and adult hematology/oncology.

METHODS: OHSU has developed a model of training physicians who have completed dual residency training in internal medicine and pediatrics and have a desire to become US board certified in both pediatric hematology/oncology and medical oncology and/or hematology in a combined four year fellowship. The curriculum includes two years of clinical rotations integrated with the traditional pediatric hematology/oncology and adult medical oncology and hematology fellowships, two years of AYA-focused research, and a continuity clinic over the entire four years.

RESULTS: OHSU has successfully created an AYA Oncology fellowship program that achieves the essential elements of AYA training and fulfills the Board requirements for certification in both pediatric and adult hematology/oncology disciplines. OHSU has experience in training two physicians in pediatric hematology/oncology and medical oncology, one who has completed fellowship and is an academic faculty member focused in AYA sarcoma, and one who has completed the first 2 clinical years to date.

DISCUSSION AND CONCLUSIONS: The design and implementation of an AYA oncology fellowship at OHSU has been successful in delivering the essential elements of training, ensuring eligibility for dual Board certification in pediatric and adult oncology specialties in the US, and promoting the careers of future physician scientists in the specialty of AYA oncology.

The domains of practice for Youth Support Co-coordinator work in teenage/young adult cancer care in the United Kingdom

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INTRODUCTION AND AIMS: Teenage Cancer Trust, a United Kingdom charity funds 35 Youth Support Coordinators (YSCs) to work alongside Multi-disciplinary teams (MDT) to keep a youth focus on the care of teenager and young adults (TYA) with cancer. YSC's bring a wealth of experience of working with young people in various health and non-health related sectors. Determining how these workers enact YSC work is the focus of this research to identify a competence framework for them, the charity and National Health Service employers to work to.

METHODS: A mixed methods action research approach using two focus groups (Health Care Professionals (N=7) and TYA with cancer (N=7)) and an online questionnaire (YSC's

N=35) was used. Thematic analysis and triangulation ensued. A research steering group ensured consistency with the participatory methodology.

RESULTS: The value of the contribution of the YSC is undisputed. Four domains of practice have emerged for inclusion in the framework - 1. TYA development 2. Working with TYA with cancer 3. TYA and the clinical experience 4. Professional practice of YSC work.

DISCUSSION AND CONCLUSIONS: A fundamental domain of practice in YSC work is understanding adolescent development from bio-psycho social perspectives alongside how cancer and its treatment impacts this. Professional practice as a domain focusses on the cultures, rules and practices of working in healthcare systems alongside representing and responding to their funder. Youth focused activities on a one-to-one or group basis that foster the unique psycho-social needs of AYA with cancer is a key domain of YSC work. The therapeutic value they bring is challenged. This has highlighted some educational gaps. Examples include specialized communication skills and accredited learning about TYA Cancer. The provision of supervision and guidance to YSC whose 'insider/outsider' perspective adds value to the cancer experience for patients and treating teams, is essential.

Healthcare professional perceptions of online information and support for young people with cancer in the United Kingdom (UK)

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INTRODUCTION AND AIMS: The internet is integral to young people (YP) providing round-the-clock access to information and support. We previously identified how, when, and why YP use online resources¹ and highlighted variation in how these are introduced by their healthcare team. We sought to understand how healthcare professionals (HCP) perceived online information and support for young people with cancer.

METHODS: Semi-structured interviews with 8 HCPs across the UK informed the development of a survey completed by 38 HCPs. Framework analysis was used to identify key themes and the survey was analysed descriptively.

RESULTS: Seven themes emerged: Views about YPs use of online resources: HCP felt it was important to facilitate access to the internet and it was part of their role to do this safely. How YPs online needs change along their cancer timeline: Professionals described increasing internet use nearing the end and after treatment. Different platforms where HCPs refer YP online: websites HCPs trusted so recommended to YP Are young people's online needs currently met? HCP felt the internet supported factual information about diagnosis and treatment, but most participants agreed unmet needs around other parts of the cancer timeline existed i.e. end-of-treatment Recognition of the emotional relationship between young people and the internet: HCPs described emotions which trigger YP to search i.e. 'panic' and 'curiosity' Barriers and concerns when referring YP to online resources: the biggest perceived barrier to access was costs to the NHS and most concerning factor was keeping YP safe online Strategies used in practice: included the use of caveats, guiding and pre-empting by searching themselves.

DISCUSSION AND CONCLUSION: We will present key findings from each theme and detail recommendations from the study that could be adopted internationally as a benchmark for best practice for online information and support.

'Silence is golden' - evaluation of a bespoke experiential learning communication skills workshop for youth support co-ordinators in adolescent/young adult cancer

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INTRODUCTION AND AIMS: Teenage Cancer Trust fund Youth Support Co-ordinators (YSC) (n=28) to maintain a youth focus for adolescent/young adult (AYA) cancer patients within multi professional healthcare teams. A frequently reported challenge for these non-regulated workers, who stem from varying professional backgrounds, is having confidence and skills when communicating with patients, colleagues and parents on cancer related matters.

METHODS: A bespoke workshop was developed to meet the unique needs of this professional group. A pre-questionnaire was sent in advance to illicit information about their communication skills. A workshop was developed which included some didactic teaching followed by experiential learning. Two clinical scenarios were created to enable YSC's to practise difficult communication challenges they face frequently; triadic communication, and responding to bad news. Experienced facilitators enabled participants to safely work through these scenarios with professional role players. Paper based evaluations were collected, followed by a 3 month on-line survey. The data which was thematically analysed.

RESULTS: YSC's valued time to consciously think about how they communicate with AYA and to understand the evidence behind effective communication skills. The workshop consolidated; confidence, knowledge and skills for some whilst other's reported learning new communication techniques. The scenarios enacted by professional role players firmly situated their learning. The use of silence, facilitative skills and attentive listening were articulated as particularly useful.

DISCUSSION AND CONCLUSION: Creating a safe place using professional role players to allow YSC to practise difficult conversations, receive feedback and re-rehearse was positively reported. Communication skills with AYA cancer patients are not merely innate and can be learned and improved with training. Key themes were practising silence, being present and including parents. Creating an environment that felt safe was key to the events success given the emotional nature of these communication challenges identified by YSC.

CONCURRENT STREAM 2.3 – AYA CANCER DATA & EPIDEMIOLOGY

Piloting a Patient-Driven Online Survey to Better Study Cancer in Adolescents and Young Adults (AYA) in the United States

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INTRODUCTION AND AIMS: Adolescent and Young Adult (AYA) cancer patients have demonstrated inferior survival improvements compared to older and younger patients. The Consortium of Adolescent and Young Adult Cancer Centers (CAYACC) was founded to create a unique database of self-reported patient health and psychosocial data to better study AYA cancer patients. The goal of this study is to assess the feasibility of an opt-in, secure online survey to collect data from a larger landscape of AYA patients and survivors in the US.

METHODS: CAYACC created a 28-question anonymous survey for cancer patients and survivors diagnosed between the ages of 18 and 39 years. Topics include diagnosis, treatment setting, clinical trial access and enrollment, insurance status, social support and fertility preservation utilization. The survey launched in April 2018 using social media and event outreach to colleagues and patients. Its initial goal is to reach 250 enrollments in 6 months.

RESULTS: By June 2018, 115 patients registered. 69 (60%) completed the survey. The majority (77%) were female. 57% reported receiving therapy at a cancer center versus a community oncology hospital. Almost 50% of patients were unsure if a clinical trial was available to them. 70% had completed therapy. 39% of respondents had children. 86% rated their care very good or excellent. 49% sought more information on long-term effects of cancer treatment. 94% had health insurance at diagnosis and at the time of the survey however 15% reported that they had lapses in insurance coverage during or after treatment.

DISCUSSION AND CONCLUSIONS: Early results demonstrate feasibility of a patient-driven survey to complement SEER-based research, accelerate tracking of AYA cancer populations and create additional databases of information. Enrollment continues. CAYACC's eventual goal is to use this data as a foundation for further research on this uniquely challenged population of patients.

The I.Am portal project: the development and utility of a teenage and young adult specific multi-disciplinary team (MDT) management system in the UK

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Developed by the Adolescent and Young Adult (AYA) cancer service based in the south west of England, the Teenage Cancer Trust IAM Portal provides a developmentally attuned digital platform to enable professionals and young people to work in partnership throughout a cancer journey, living with and beyond cancer. The IAM Portal is made up of three components: An electronic AYA holistic needs assessment (HNA); The Integrated Assessment Map (IAM) Online AYA specific information and advice resources. The AYA South West Integrated MDT Management System (SWIMMS) The third component (SWIMMS) was developed after it was identified that a resource was required for facilitating the registration of AYA patients within the clinical service; managing the MDT meetings, including the generation of outcome reports; and the creation of reports of MDT activity and patient need. To ensure the system worked operationally, and that it could provide strategic guidance for the development of services, it was developed by working with AYA MDTs across the UK, national guidance and quality measures. The system has three main functional elements: a) Patient registration to the AYA Service b) Management of MDT meetings c) Administration of patient data Data collected within the system includes information on the young person's diagnosis (including Birch coding), their holistic needs, MDT discussion outcomes, and key areas of importance for the AYA population i.e. clinical trial and fertility preservation. Teenage Cancer Trust are now implementing the IAM Portal across AYA services in the UK, which will allow a national dataset to develop. Work continues to ensure that the data set remains useful and comprehensive, and further developments have taken place. This includes a real-time activity dashboard utilising the data extract available from SWIMMS.

Diagnostic Experiences of Young People with Cancer

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BACKGROUND AND AIMS: Young people experience prolonged and irregular journeys from symptom onset to diagnosis. We sought to examine the diagnostic experiences of young people (YP) with cancer attending a national patient conference using novel and to compare this with existing data on young people's diagnostic experiences.

METHODS: Using novel methodology, real time patient reported data was collected via an interactive electronic survey. Chi square tests were used to test for associations between gender, age and cancer types. The percentage of patients who visited their GP 3+ times before referral was calculated by gender, age, ethnicity and cancer type. Crude odds

ratios were calculated and likelihood ratio tests done to test for significant relationships between gender, age, ethnicity and cancer type. A multivariable model tested the significance of inclusion of: gender, age, ethnicity and cancer type. Adjusted odds ratios were calculated based on the best fitting model.

RESULTS: Data from 766 patients aged 0-25 years at diagnosis was included, 434 (57%) were female, 659 (86%) had typical AYA cancers. Eighty-two percent of YP attended their General Practitioner (GP) with potential cancer symptoms, 7% went straight to emergency department. Females were more likely to attend their GP, (86% versus 76%, $p=0.005$). The main reason for not visiting a GP straight away was lack of awareness of symptom significance (86%). Females were more likely to attend their GP 3+ times before referral (55.9%, $P=0.001$), variation between cancers in 3+ pre-referral consultation existed ranging from 15.4% for testicular cancer to 76.5% for non-Hodgkin's disease ($p=0.02$).

CONCLUSIONS: These findings highlight the need for interventions to improve cancer awareness, healthcare seeking behaviour and early diagnosis for YP. The similarity of results compared to previous studies 1, 2 supports the validity of using real time patient surveys in this setting. 1. Herbert A., Lyratzopoulos G., Jeremy W., Taylor R.M., Barber J., Gibson F., Fern L. A. Diagnostic timeliness in adolescents and young adults with cancer: a cross-sectional analysis of the BRIGHTLIGHT cohort. *The Lancet Child & Adolescent Health*, Volume: 2, Issue3, Pages: 180-190, 2018 2. Lyratzopoulos G., Neal R.D., Barbieri J., Rubin G., Abel G., Variation in number of general practitioner consultations before hospital referral for cancer: findings from the 2010 National Cancer Patient Experience Survey in England. *Lancet Oncology*, vol13, Issue 4, Pages 353-365, 2012

An age stratified study investigating timeliness to diagnosis and treatment onset in Sarcoma, Hodgkin Lymphoma, and Non Hodgkin Lymphoma patients in the South Island, New Zealand

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INTRODUCTION & AIMS: Diagnostic delays are regularly cited as being a key contributing factor to poorer outcomes for AYA. This study aims to determine patient, referral, and hospital delays for AYA compared to paediatric and adult patients with the same diagnosis.

METHODS: Retrospective reviews of 65 paediatric, 68 AYA (15-24 years) and 68 adult clinical records were conducted for the most recent sarcoma, Hodgkin's Lymphoma (HL), and Non-Hodgkin's Lymphoma (NHL) diagnoses at Christchurch and Dunedin Hospitals.

RESULTS: The median time between symptom onset and first presentation to a health care provider (patient delay) for AYA patients was 30 days for NHL, 65 days for HL, and 66 days for sarcoma. AYA patients experienced longer overall delays between symptom onset and treatment commencement (median: 101.5 days) compared to children (70 days, $p=0.15$). This was particularly evident for sarcoma (137 days for AYA compared with 70 days for children, $p=0.035$). However, it was adult patients who experienced the longest total delays (median: 148.5 days) due to significantly longer referral delays and hospital

delays (25.5 and 20.5 days respectively) compared to AYA (17.5 and 15 days) and paediatric patients (9.5 and 8 days).

DISCUSSION & CONCLUSIONS: The reasons for the observed age-based delays are likely to be multifactorial. Cancer symptom awareness, communication difficulties, tumour biology, and high patient volume affecting service delivery can all contribute to delays. Larger studies that investigate not just tumour groups, but tumour subtypes with regards to age-based differences in time to diagnosis are required to advance understanding in this area for AYA cancer patients. A linkage with survival outcomes is necessary also. Targeted interventions (e.g AYA tumour bank, streamlining of referral pathways, cancer symptom awareness program) can then be developed in an attempt to enhance timely diagnosis and treatment onset for the affected patient groups.

The Australian Youth Cancer Database: developing and piloting a national minimum clinical dataset to support national service planning, quality improvement and research

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INTRODUCTION & AIMS: Access to nationally consistent, high-quality data is critical in providing the evidence base to guide the future of AYA cancer care. In Australia, there is no national coordination of AYA data. Through its management of the Youth Cancer Service (YCS) program, CanTeen is establishing the Australian Youth Cancer Database (AYCD), facilitating consistent national collection of a minimum clinical dataset and enabling data linkage. The principal aim of the AYCD is to guide service planning, quality improvement and evaluation, additionally enabling reporting to funders and supporting advocacy and research.

methods: CanTeen worked in partnership with Cancer Australia and stakeholders nationally to develop an initial AYA-specific dataset during Phase 1 of the YCS program (2009-13). Guided by an expert Data Advisory Group, CanTeen consulted with YCS teams, key stakeholders and data custodians throughout Phase 2 (2013-17) to iteratively refine and finalise a comprehensive, prioritised AYA data specification. A national pilot was conducted in 2016 across each of the five YCS jurisdictional teams to explore data accessibility and quality.

RESULTS: A 59-item prioritised data specification was finalised in June 2017, capturing items related to patient demographics, tumour/diagnostic features, coordination of care, treatment, supportive and psychosocial screening and care, fertility preservation, research/clinical trials participation and long-term survivorship-related outcomes. The majority of items were found to be accessible, however variation in accessibility, quality and workload were noted between items and between jurisdictional settings.

DISCUSSION & CONCLUSIONS: Pilot data capture results for this consensus dataset are encouraging, though further work is required to achieve nationally consistent data availability. National implementation planning is underway, including finalisation of data hosting agreements and commissioning of a national repository. Data capture will begin in 2019 in YCS lead hospitals, with staged expansion across the national YCS network and other settings including primary care in the coming years.

Continued Increase in AYA Breast Cancer with Distant Involvement among Women in United States after 6 Additional Years of Analysis

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INTRODUCTION AND AIMS: In 2013, we reported a steadily increasing incidence during 1976-2009 in distant-stage breast cancer in adolescent and young adult (AYA) women in the United States (JAMA 2013;309(8):800-5). Since that publication, the Surveillance, Epidemiology, and End Results (SEER) program released 6 more years of incidence data (up to 2015), with data representing 28.5% of AYAs in the US. With the additional data, we sought to determine whether or not our observed trends continued.

METHODS: Breast cancer incidence trends during 2000-2015 in U.S. women 25 to 39 years of age at diagnosis were assessed with SEER*Stat and analyzed with a joinpoint program. The 6 years of more recent data added 16,630 (60%) more cases of newly-diagnosed breast cancer in 25 to 39-year-old women. Incidence data were evaluated for extent of disease at diagnosis: localized - confined in the breast; regional - contiguous and adjacent organ spread; - metastases at distant sites such as bone, brain, and lung.

RESULTS: The increasing incidence of distant disease in 25- to 39-year-old women continued throughout 2000 to 2015 at an annual percent change of 4.5, 4.1 and 4.0 for SEER 9, 13 and 18, respectively. Not only are these rates of change higher than previously reported, the incidence of distant-stage breast cancer in each of the additional 6 years was greater than the highest incidence rate in all previous years. Compared with all other ages of diagnosis, AYA women have had the greatest increase in breast cancer. Stage migration did not account for the increasing incidence

DISCUSSION AND CONCLUSION: Additional years of SEER data continue to affirm the ongoing trend of increasing metastatic breast cancer in American AYA women. This trend cannot be attributed to re-classification from un-staged or earlier stage categories. This trend is alarming and its causes remain undetermined.

PLENARY 2: AYA CANCER RISK –MELANOMA, LIFESTYLE & INHERITED RISK PROFILES

Melanoma: Progress to Date and Future Prospects in the Fight Against Australia's National Cancer

Professor Richard Scolyer

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Melanoma is a major public health problem in most Western countries, including in Australia. Despite public health campaigns, the incidence of melanoma continues to rise in many countries. Australia and New Zealand have the highest incidences of melanoma worldwide. In Australia, it is the commonest cancer in 15 to 39-year-olds and is also the commonest cause of cancer death in this population. Efforts to achieve melanoma disease control include strategies to prevent melanoma and to detect it at an earlier clinical stage where it is associated with high cure rates. Early detection, accurate diagnosis and appropriate treatment are therefore the linchpins for improving outcomes for melanoma patients. Recent gene sequencing studies have demonstrated that ultraviolet light irradiation not only causes most melanomas in adults but is also the cause of most melanomas in adolescent and young adult patients. Less than a decade ago, there were no effective systemic drug therapies for patients with advanced melanoma and one-year overall survival was approximately 25% for stage IV melanoma patients and the median survival for patients with brain metastases was less than six weeks. In recent years, improved understanding of the molecular pathogenesis of melanoma and immune system control have provided new therapeutic options. In 2018, one year overall survival rates for advanced melanoma patients treated with targeted therapies (BRAF/MEK inhibitors) is 75% and is 73% for patients treated with immunotherapy (antiPD1/antiCTLA inhibitors). The efficacy of utilising the body's own immune system to fight cancer with immunotherapies that was first demonstrated in melanoma has important implications for all cancer patients as these therapies are now being trialled in many other cancers. Nevertheless, despite these recent improvements melanoma patient outcomes, much work still needs to be done for us to deliver on our goal of zero deaths from melanoma.

Approaches to addressing lifestyle-based cancer risks amongst adolescents & young adults

A/Professor Gill Hubbard

Associate Professor, Department of Nursing, Centre for Health Science, University of the Highlands and Islands
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Gill Hubbard wants to know if adolescents and young people with cancer are really that different to any other young person. In this presentation she will explore evidence about young people's lifestyle. She will look at levels of physical activity, sunburn incidence and sun safety behaviours, diet and tobacco use in young people with cancer and compare it to young people without cancer. She will examine what factors influence a young per-

son's lifestyle and present evidence about the benefits of lifestyle interventions for young people with cancer.

During the presentation Gill will argue that having a diagnosis and treatments for cancer increases a young person's risk of certain diseases. She will present evidence suggesting that young people with cancer who have a poor lifestyle also have poorer health. She will conclude her talk, by asking the audience to decide how different adolescents with cancer really are.

Communicating genetic testing results in family and social networks: Meeting the unique psychosocial needs of AYAs

Dr Allison Werner-Lin

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BRCA genetic testing for adult onset hereditary cancer syndromes during emerging adulthood [approximately 18-29] often confers emotionally charged information during a particularly formative developmental period. In the US, guidelines for adult onset cancer syndromes suggest genetic testing may be offered after age 18. This assumes young adults can make autonomous choices. Yet, independent decision-making is not a hallmark of these years. BRCA1/2-related cancer risk is low during these years, yet perceptions of immediacy are often high. Despite evidence supporting the benefits of risk reduction, protocols for early detection and prevention are not yet proven, nor clinical trials undertaken, for patients in this age group. This talk will present an overview of research on patient and provider experiences with genetic counseling and testing during this developmentally dense phase of development.

Emerging adults have a need for directive counseling and targeted follow-up care. Evidence shows they may experience greater distress than older women adapting to testing results, challenges in disclosing risk-related information to loved ones, and isolated from peers and romantic partners for whom medical issues are typically not yet relevant. Many feel helpless to manage their risk and distress in ways endorsed by their physicians, family, and close others. Genetic counselors report varied levels of preparation and comfort in meeting the developmental needs of 18 to 24-year old patients. Common provider challenges include navigating family dynamics in the counseling room and addressing the developmentally labile young adult. A rich understanding of the themes inherent in how people grow and change over time might enhance the counselor's capacity to assess patients and their family members and reduce the imperative for non-directive counseling.

Oral Abstracts: Day 2

PLENARY 3: THERAPEUTIC ADVANCES – NEW TREATMENTS, CLINICAL TRIALS & EXERCISE

Predicting the future use of novel immunotherapy: experience to date in blood cancer proves that 'one size does not fit all'

Professor Miles Prince

Professor/Director of Cancer Immunology and Molecular Oncology at Epworth Healthcare, Australia; Director of the Centre for Blood Cell Therapies at the Peter MacCallum Cancer Centre, Australia

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There is a clear place for novel immunotherapy treatments across a wide spectrum of haematological malignancies and cancer more broadly: well established examples include monoclonal antibodies for non Hodgkin's and Hodgkin Lymphoma, CAR-T cells for acute lymphoblastic leukaemia, thalidomide for plasma cell disorders and checkpoint inhibitors in Hodgkin's disease.

However, such strategies have been less successful in other haematological therapies. Examples included CAR-T for chronic lymphocytic leukaemia and myeloma, lenalidomide for subtypes of B cell lymphoma and checkpoint inhibitors in myeloma. Although in the latter examples the results are not considered 'outstanding', there definitely are responses observed in chemotherapy-refractory patients; so we are challenged now as to how to develop paradigms to optimally use such agents into the future. The development pathway includes optimal selection of patients based on clinical characteristics, biomarker development, appropriate sequencing and drug combinations. Finally, immunotherapy can at times, like chemotherapy, be a blunt instrument and so we must recognize the risks and better manage short- and long-term toxicities.

The International Sarcoma Kindred Study: mapping the genetic basis of sarcoma risk

Professor David Thomas

Director, The Kinghorn Cancer Centre and Head, Cancer Division and Genomic Cancer Medicine Program, Garvan Institute of Medical Research.

@ProfDMThomas

Sarcomas are rare cancers of connective tissues that often affect the young. To study the genetic basis of sarcomas, we have created an international cohort of families affected by sarcomas—the International Sarcoma Kindred Study (ISKS). The cohort is open to any proband with sarcoma, regardless of family history, and therefore is representative of sarcomas in clinical practice. Currently more than 2,800 families have been recruited from 23 centres in 7 countries worldwide. Detailed information has been collated on the cancer diagnosis, age of onset, familial cancer patterns. We have recently undertaken whole genome sequencing on more than 1,100 probands with sarcomas, along with over 2,700 elderly cancer-free controls. The first surveys of this cohort have revealed a rich landscape of genetic causation, with more than 20% of the cohort carrying mutations which contribute to cancer risk. Many of the known genes (eg., TP53, NF1, SDHB, SDHD) are enriched

in pathogenic variation, but in addition an excess of pathogenic variation is observable in genes related to various aspects of homologous recombination, mismatch repair, and telomere biology. These findings identify new opportunities for both risk-stratified early detection and targeted therapy, and will drive integration of genetics into the multidisciplinary management of sarcomas.

Exercise medicine for cancer

A/Professor Prue Cormie

Principal Research Fellow – Exercise Oncology, Australian Catholic University; Chair COSA Exercise Cancer Group

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Evidence from a significant body of pre-clinical, clinical trial and epidemiological research has established exercise as an effective medicine for the management of cancer. The level of evidence has led the Clinical Oncology Society of Australia to call for exercise to be embedded as part of standard practice in cancer care and to be viewed as an adjunct therapy that helps counteract the adverse effects of cancer and its treatment. Much more research is required to determine the optimal exercise prescription for adolescents and young adults with cancer in order to maximise engagement with, safety of and efficacy of exercise. However, the available evidence supports integrating exercise into routine cancer care. Adolescents and young adults with cancer may experience serious chronic health and psychological sequelae including accelerated functional decline, fatigue, musculoskeletal symptoms, psychological distress, a higher risk of developing comorbid conditions and reduced quality of life. This presentation will summarise the evidence of the efficacy of exercise in counteracting the detrimental side effects of cancer and its treatment and the Clinical Oncology Society of Australia Position Statement on Exercise in Cancer Care. Implementing exercise into routine cancer care for adolescents and young adults presents a significant challenge. Practical strategies to incorporate exercise into clinical practice will be discussed.

Cancer Clinical Trial Participation: Understanding the Problem to Unlock the Potential

Professor David Freyer

Children's Hospital Los Angeles, USA; USC Norris Comprehensive Cancer Center, USA; Keck School of Medicine, University of Southern California, USA

Compared with younger and older patients with cancer, adolescents and young adults (AYAs, 15-39 years of age) are characterized by several differences and disparities that include survival, treatment-related toxicity, access to care, unmet psychosocial needs, and survivorship outcomes. Another disparity affecting AYAs is their significantly lower level of participation in cancer clinical trials (CCTs) compared with children. Low CCT participation represents a fundamental barrier to progress against cancer in AYAs due to difficulty completing therapeutic studies, as well as preventing AYAs from gaining access to new therapeutic advances, providing biospecimens for cancer and host biology research, and benefiting from studies of supportive care and other non-survival endpoints. Although low CCT participation by AYAs has been extensively documented in multiple settings, its caus-

es are not well understood. In this presentation, CCT enrollment data will be presented from a variety of sources to characterize the severity and pervasiveness of this problem. A conceptual framework for CCT enrollment ("Clinical Trial Enrollment Pathway") will be discussed for guiding a systematic approach to its study. Barriers to AYA CCT enrollment differentiated by age will be presented based on recent data derived from this framework. Finally, existing knowledge gaps and contemporary efforts to improve AYA CCT enrollment will be discussed.

RAPID FIRE 2.1

Cancer incidence and mortality trends 1982-2014 in children, youths and young adults in Queensland, Australia

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INTRODUCTION AND AIMS: We aimed to describe incidence, mortality and survival over time in Queensland children (0-14years), youths (15-24years) and young adults (25-39years).

METHODS: We undertook a retrospective cohort study of all cases of invasive cancer diagnosed in individuals aged 0-39 years from 1982-2014. Data from 20,872 new diagnoses and 2284 deaths were included. Age standardised incidence and mortality rates were calculated.

RESULTS: The overall incidence rate for cancer in children and youths remained stable. The incidence rate per 100,000 (2014) in children was 15.4 and 34.2 for youths. After age 25 years, incidence rates increase dramatically; young adults have four times greater cancer burden than youths, and nine times greater than children. In young adults, the incidence rate per 100,000 increased from 119.9 in 1984 to 135.5 in 2014. Incidence in melanoma significantly decreased over time in all groups, but was counterbalanced by increases in other cancers. Mortality rates decreased across all groups, most dramatically in young adults and children and less so in youths. The mortality rate per 100,000 (2014) in children was 1.9, 3.8 in youths, and 12.8 in young adults. While cancer related deaths in young adults have fallen dramatically over time, there remains a 3.3 times greater death burden in young adults compared to youths and 6.7 times than children. Relative 5-year survival from 2010-2014 from all cancer types was 85% for children, 89% for youth and 88% for young adults.

DISCUSSION: Understanding the trends of cancer in young people is an important public health concern and necessary for health-service planning. Given children and young people are the population with the most potential to contribute to the economic growth of a nation, and they have high survival rates, a sustained focus on developing health-services to improve survivorship outcomes for this group is paramount.

A Peer Support Measure for Adolescents Living with Cancer

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INTRODUCTION AND AIMS: Adolescents with cancer and those living with a family member's cancer frequently report a strong need for peer support, ranking it as more important than support from family members. To measure this important construct among adolescents with a cancer experience, we developed the Cancer Peer Support Scale (CaPSS). Our study assessed the psychometric properties, validity, and reliability of the CaPSS.

METHODS: Before attending a CanTeen support program, 153 adolescents ($M = 15.0$, $SD = 1.6$; Range = 11.7 – 18.0) completed the 11-item CaPSS and the Kessler–10 psychological distress scale. Each item in the CaPSS is rated using a five-point Likert scale (i.e., none of the time, a little of the time, some of the time, most of the time, and all of the time).

RESULTS: Our results showed that the CaPSS was measuring a single factor (i.e., peer support), accounted for 60.2% of the variance, and demonstrated good internal consistency ($\alpha = .88$). The response scale was adequately capturing different levels of the latent variable; except for a 'little of the time', which was especially weak for item 11. All items exhibited high to very high discriminatory ability, except for item 11. Scores on the CaPSS were negatively correlated with scores on the K10, $r = -.28$, $p < .001$.

DISCUSSION AND CONCLUSIONS: We have provided the initial steps to accurately measure the levels of peer support between adolescents with a cancer experience. Our results have shown that the CaPSS is a reliable, accurate, and valid initial measure of peer support. By measuring and understanding the levels of peer support experienced by adolescents impacted by cancer, the appropriate support can be provided with the potential to improve their overall wellbeing.

Colorectal cancer in AYA population in Nepal

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INTRODUCTION AND AIMS: Incidence of colorectal cancer in Adolescent and Young Adult (AYA) is increasing over last few years. Aim of this paper is to collect data of colorectal cancer in AYA population registered in Shree Birendra Hospital (SBH), Nepal for last 11 years.

METHODS: Retrospective data of all cancer patients registered in SBH from January, 2007 to December, 2017 were collected. The data was analyzed to find colorectal cancer in AYA in age group 15 to 34. Variables collected were Age group, Sex, histology, treatment and follow-up status. The data was tabulated and analyzed.

RESULTS: Total cancer patients were 2280. Total AYA patients, 15 to 34 years were 183, which was 8.02 %. Colorectal cancers among these were 29 (15.3%). Total male patients were 21 while female were 8 (M:F; 71:29). Patients in the age group 15-19, 20-24, 25-29 and 30-34 were 1, 4, 3 and 20 (3.6%, 14.3%, 10.7% and 71.4%) respectively. Distribution accord-

ing to site were Colon 10 (36%), Rectum 14 (57%) and Recto-sigmoid 2 (7%). According to histology, distribution of Adeno Ca, Mucinous adeno Ca, Mucinous Ca, Lymphoma and unknown were 64%, 7%, 4%, 4% and 21% respectively. Molecular data were not available. Primary treatment was surgery in 22 patients, 12 hemi-colectomy, 6 APR and 4 LAR. 24 patients received chemotherapy. 6 patients have expired, 5 lost to F/U and 17 are on follow up.

DISCUSSION AND CONCLUSIONS: This is one of the first data from Nepal to evaluate burden of colorectal AYA cancer in the country. This data will be useful for understanding special needs in this group as they fall in a group where routine screening is not indicated, the biology of disease may be different, treatment may have to be tailored due to aggressive nature and survivorship issues may have to be addressed.

The TRECA program: Exploring implementation feasibility of using Telepresence Robots to Engage Cancer patients in education

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INTRODUCTION AND AIMS: Due to lengthy and complex treatment protocols, many cancer patients have prolonged or frequent absences from school. This can lead to poor academic attainment, isolation from peers, and challenges with school reintegration. The need for consistent real-time classroom inclusion for unwell adolescents and continuity of peer relationships has been well established. However, few studies have explored the use of telepresence robots in secondary schools for adolescents. Telepresence robots offer a unique opportunity for adolescents to maintain a 'presence' at school. This study explores the perceived acceptability and feasibility of implementing this technology to connect adolescent cancer patients to school during treatment.

METHODS: In-depth semi-structured interviews were conducted with 25 healthcare professionals, teachers, parents and adolescent cancer patients. Interviews were analyzed using a manifest thematic analysis.

RESULTS: Participants stated that adolescents were likely to experience isolation, withdrawal, distress, and poor education attainment following pronounced absences from school. As such, telepresence robots were identified as important and novel technologies which would be desirable to implement in the education system. Participants identified the following facilitators to implementation; a "buddy" system to empower peers to support their friend's presence in school and aid interactions through the robot, integration with a school cancer awareness programs, and accessible technical support. Perceived barriers to implementation included: resistance to technology from some school communities, difficulties resolving technical difficulties, and logistics of a school setting (e.g. movement between classes).

DISCUSSIONS AND CONCLUSIONS: Results highlight the enthusiasm and perceived acceptance of the use of telepresence robots to connect cancer patients to school. Interview results highlighted the perceived positive psychosocial impact this technology could have for patients, and the pivotal role of collaborative stakeholder engagement in ensuring the successful implementation of a pilot project in secondary schools. Findings will inform implementation of a national pilot program.

RAPID FIRE 2.2

Strengthening transition for adolescent and young adult (AYA) survivors of childhood cancer from the paediatric to adult sector for ongoing surveillance

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INTRODUCTION AND AIMS: The Victorian Paediatric Integrated Cancer Service (PICS) Long Term Follow-up Program (LTFP) provides a clinical service for children and adolescents treated for cancer who have completed curative treatment and are in the 'survivorship' phase of care. This program also aims to provide childhood cancer survivors with a safe and supported transition from the paediatric to the adult health care sector. In 2015, 42% (n=170) of the patients attending the PICS LTFP 17 years, indicating a need to strengthen the transition process for adolescents and young adult (AYA) survivors of childhood cancer from the program, to community and adult health services for ongoing care.

METHODS: In 2015, the PICS received a Department of Health and Human Services (DHHS) grant to develop and implement a targeted approach for transition of those 17 years. Consultations with the two Victorian primary treating hospitals, adult tertiary centres and local community centres were held to explore appropriate services. The PICS LTFP introduced AYA specific clinics for patients over the age of 16. These clinics aim to prepare the patient and family for transition. In addition, the LTFP established joint clinics in the adult sector where the paediatric oncologist or nurse attends in person or by telehealth to strengthen the transition.

RESULTS: The PICS LTFP successfully transferred 97.6% of the patients identified within the project. Utilising the new AYA model of care, the LTFP transferred an additional 133 patients who turned 17 years old during the project.

DISCUSSION & CONCLUSIONS: A targeted approach enabled the PICS to develop and implement a program that is tailored to meet the individual needs of patients throughout LTFP and beyond. There is a need for ongoing review and development of AYA transition to ensure successful transfer of care from paediatric survivorship care to the adult sector.

"Tell us about..." #yahearus: gathering online insights into the cancer experiences of AYA's

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BACKGROUND: Social media provides informational, emotional, and instrumental support for AYAs. Partnering with CanTeen Australia, Stupid Cancer, and Teen Cancer America, organizations with collectively ~400,000 social media followers and 10,000 monthly interactions, we sought to determine whether experiences reported by regional stakeholders

in the Tacoma US AYA Oncology Council (AYAOC) were generalizable to a wider geographic audience. We investigated the use of social media for systematically gathering information about the AYA cancer experience.

METHODS: AYAOC members prioritized key topics for social media discussion, including cancer diagnosis, peer connection, interactions with healthcare providers, survivorship, personal relationships, fertility, mental health and complementary therapies. They created 30 questions to be shared as online posts by partner organizations, e.g., “#YAHearUs: It took Taylor one year to get diagnosed... how about you?” From November, 2017-June, 2018, partner organizations posted the pre-developed messages across Facebook, Instagram, and Twitter. Organizations synchronized postings through conference calls and collaborative, cloud-based spreadsheets.

RESULTS: Social media monitoring software indicates that Facebook, Twitter, and Instagram posts from the three organizations reached >100,000 individuals. The project’s searchable hashtag, #YAHearUS, reached ~72,000 conversations on Twitter alone, being displayed 243,000 times across user feeds. Content of posts showed congruence of patient experiences, and responses to them, among AYAs across the US, Australia and Canada. One post reached 10,000 viewers, producing 125 “likes” and 52 comments about issues facing AYAs—more than double the international average for social media viewership/interaction. The project’s messages engaged young people as well as media and healthcare organizations, including CNN and the U.S. Food and Drug Administration.

DISCUSSION AND CONCLUSION: Social media platforms are a powerful tool for gathering nuanced data on patient experience from a wide geographic audience, as evidenced by message reach and the volume of comments.

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A cancer awareness program for Australian secondary school students: What do adolescents already know about cancer?

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INTRODUCTION AND AIMS: The lifetime risk of cancer for Australians is over 50%. Approximately one third of cancer diagnoses are preventable through better health choices, such as reducing alcohol consumption, sun exposure, and smoking; and increasing fruit and vegetable consumption, and physical activity. Adolescence is a critical time for establishing positive health behaviours. When Cancer Comes Along is an interactive program for Australian high school students on cancer’s signs, symptoms, and prevention, and supporting others impacted by cancer. This presentation provides an overview of students’ pre-existing knowledge of cancer risk factors.

METHODS: Information about students’ existing cancer knowledge was collected prior to program delivery as part of a cluster randomised controlled trial. Knowledge of cancer signs and symptoms, and preventative lifestyle behaviours, was assessed using two open-ended questions. Free text answers were coded against well-established information from national cancer organisations. The proportion of students that freely identified each cancer risk factor is reported.

RESULTS: To date, 217 students have completed the pre-program questionnaire. The most frequently identified cancer warning signs were an unexplained lump (45%),

unexplained pain (22%), changes in a mole (20%), and coughing blood (20%). Few students (<15%) identified unexplained weight loss or bleeding, or a persistent cough, soreness, or change in bowel or bladder habits. The most commonly identified risky behaviours were smoking (46%), sun exposure (43%) and unhealthy diet (26%). A small proportion (<15%) freely identified obesity or low physical activity, alcohol consumption, or fruit and vegetable consumption.

DISCUSSION AND CONCLUSIONS: Students' knowledge of cancer risk factors was highest for those featured in recent Australian health campaigns. This highlights the need for health promotion activities that address all cancer risks. The randomised controlled trial of When Cancer Comes Along will indicate whether this program is effective at increasing high school students' knowledge of cancer risk factors.

My CODE; a prestudy to understand the teenager/ adolescent agegroup with cancer; what technical solutions are available

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AIM: We will investigate what new innovative forms of care are required to meet teenager / young adult needs, a patient group that often falls between child and adult care. A pre-study is required to determine the mechanisms that meet the needs. As well as understanding how we can improve their self-perceived outcomes and ability to increase compliance. This group is also in a phase of life that is characterized by physical as emotional transformations. My CODE wants to increase their feeling of control, autonomy and increase knowledge. Total symptom data should be used for better customized treatment, compliance and survival. Loneliness and isolation should be broken and the group will have a greater impact on health care.

METHOD: 1. through interviews/workshop/service design with teenagers/young adults and together with healthcare professionals we will collect and create a basic information bank.2. The information bank is converted into digital messages.3. Continuous follow-up with users improves and creates new messages.4. By analyzing behaviors in use, new messages are created and refined formats/interfaces.5. Using industry partners to help understand and test new possible solutions. Iterative work will be done throughout the test period.

RESULT: The goal of My Code is to meet the need proactively, increase survival and improve the quality of life in the longer term.

CONCLUSION: Our environment changes and we need to change our care based on this. Medical specialization is increasing but it also means that there are large variations in treatment methods and worrying differences in healthcare quality. Healthcare needs to create new and better conditions for increasing the ability to meet the patient in his condition, where digital technology becomes a tool that leads to more safe, accessible and safe care for the patient and higher benefit for patients, healthcare and society who bear the high costs.

CONCURRENT STREAM 3.1 – AYA TREATMENT ADVANCES

Improved Outcome for Adolescents with Acute Lymphoblastic Leukemia Treated with Chinese Children's Leukemia Group 2008 Protocol in China

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INTRODUCTION & PURPOSE: The outcome for adolescents with acute lymphoblastic leukemia (ALL) has been historically inferior to younger patients. However, the prognosis for large cohort of adolescent patients in China has not been reported. Our purpose was to review the clinical characteristics and outcome of adolescent patients treated on Chinese Children's Leukemia Group (CCLG)-2008 protocol from 2008 to 2013.

METHODS: Between 2008 and 2013, a total of 723 patients with newly diagnosed ALL were enrolled in our study and 103 were adolescent patients aged 10 to 18 years. The outcome was compared between adolescent patients and younger patients aged 1 to 10 years.

RESULTS: With a median follow-up of 7.25 years, 5-year overall survival rate (OS) of adolescent patients and younger patients was 86.84% versus 86.30%; 5-year event-free survival rate (EFS) was 81.48% versus 80.86%, respectively. Adolescent patients demonstrated significantly lower frequency of T-cell lineage phenotype ($p < .001$) and $t(12;21)$ ($p < .003$). However, there was no significant difference in the incidence of $t(9;22)$ and $t(1;19)$ between the two group of patients. Slightly higher of overall incidence of relapse and death was demonstrated in adolescent patients, but without significant difference.

CONCLUSION: Adolescent patients could benefit from pediatric-based ALL protocol and achieve excellent outcome in China. The treatment response was similar to the best published data.

Emerging role for circulating biomarkers in germ cell tumors- Pilot data and ongoing trials in North America/England

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INTRODUCTION/AIMS: Specific circulating miRNAs have been found to be highly expressed in patients with germ cell malignancy. Utility of these biomarkers has been evaluated in a number of international pilot studies with concordant results across these small and focused studies. In general, mi37-a-3P is expressed uniformly in tissue of both seminoma and nonseminoma, but not in patients with teratoma only. Circulating levels of these miRNAs can be demonstrated in a high percentage of patients with clinically detectable germ cell malignancy and is not detectable in patients who are cured.

METHODS: For the Canadian/US pilot, blood samples were drawn in Cell-Free DNA BCT® tubes (Streck, La Vista, Nebraska), processed and frozen as plasma aliquots, followed by analysis using standard microRNA extraction and analysis methods. Results were classified as either detectable miR371 expression or no expression. Positive predictive value (PPV) of miRNA 371 was compared to PPV for concurrent computerized tomography (CT) and conventional blood markers.

RESULTS: A Canadian/US pilot study correlating circulating miRNA 371 expression with conventional clinical assessments across variety of clinical settings demonstrated that 34/113 true positives miRNA, 0/113 false positives, 78/113 true negatives and 1/113 false negatives. PPV for miRNA 371 expression was 100% compared with PPV of 48% for CT and 75%, 82% and 65% for AFP, HCG and LDH respectively.

CONCLUSION: These and other pilot results informed the development of two North American large population-based studies, COG AGCT1531 and SWOG S1823, that collect serial blood samples over the course of management for patients with germ cell malignancies. If results of these population-based studies are in the range seen in pilot studies, miRNA 371 expression may replace or reduce conventional clinical assessments (imaging and conventional blood markers) during active surveillance and during post-treatment management.

Clinical outcomes of adolescents and young adults with advanced solid tumours participating in phase I trials in the Royal Marsden Hospital

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BACKGROUND: Adolescent and young adult (AYA) patients with advanced solid tumours are often considered for phase I clinical trials with novel agents. The outcome of AYAs in these trials have not been described before.

AIM: To study the outcome of AYA patients in phase I clinical trials.

METHODS: Clinical trial data of AYAs (defined as aged 15e39 years at diagnosis) treated at the Drug Development Unit, Royal Marsden Hospital, between 2002 and 2016, were analysed.

RESULTS: From a prospectively maintained database of 2631 patients treated in phase I trials, 219 AYA patients (8%) were identified. Major tumour types included gynaecological cancer (25%) and sarcoma (18%). Twenty-five (11%) had a known hereditary cancer syndrome (most commonly BRCA). Molecular characterisation of tumours (n=45) identified mutations most commonly in TP53 (33%), PI3KCA (18%) and KRAS (9%). Therapeutic targets of trials included DNA damage repair (16%), phosphoinositide 3-kinase (PI3K) (16%) and angiogenesis (16%). Grade 3/4 toxicities were experienced in 26% of patients. Of the 214

evaluable patients, objective response rate was 12%, with clinical benefit rate at 6 months of 22%. Median overall survival (OS) was 7.5 months (95% confidence interval: 6.3e9.5), and 2-year OS was 11%. Of patients with responses, 36% were matched to phase I trials based on germline or somatic genetic aberrations.

CONCLUSION: We investigated the largest cohort of AYA patients treated in phase I trials so far. Some patients experience benefit, with several durable responses beyond 2 years. A sizeable proportion of AYA patients have cancer syndromes and significant family history or somatic molecular aberrancies, which may influence novel therapeutic treatment options. Ideally, germline genomic testing should be done earlier in AYA patients than at the stage of phase I.

Efficacy of Larotrectinib in adolescent and young adults with TRK fusion cancer

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INTRODUCTION: TRK fusion proteins, resulting from gene fusions involving genes NTRK1-3, are known oncogenic drivers in a broad range of malignancies. Larotrectinib, a highly selective TRK inhibitor in development, has demonstrated an objective response rate (ORR) of 75% by independent radiology review across various TRK fusion solid tumors (Drilon et al., NEJM, 378:731-739, 2018). TRK fusions may be enriched in young adults. Here, we summarize the activity of larotrectinib in adolescent and young adult (AYA: ages 15-39) patients with advanced TRK fusion cancer.

METHODS: Patients with TRK fusion cancer detected by molecular profiling from 3 larotrectinib clinical trials (NCT02122913, NCT02637687, and NCT02576431) were eligible. Larotrectinib (100 mg BID) was administered until disease progression, withdrawal or unacceptable toxicity. Efficacy was assessed using RECIST version 1.1.

RESULTS: As of February 19, 2018, fifteen AYA patients with evaluable TRK fusion cancer were enrolled. Tumor types included soft tissue sarcoma (4), salivary gland (3), lung (2), osteosarcoma, breast, biliary tract, GIST, melanoma and papillary thyroid cancers. Median age was 32 years (range 19.9-39.0 years). Seven ETV6-NTRK3, three TPM3-NTRK1, and one each of GON4L-NTRK1, IRF2BP2-NTRK1, LMNA-NTRK1, SPECC1L-NTRK3 and TPR-NTRK1 fusions were documented. Thirteen patients received prior systemic therapy (median 2, range 0-9). ORR was 73% (4 CR, 7 PR) per independent radiology review. Median DoR has not been reached, with 14.8 months median follow-up. Median duration of treatment was 11.2 months (range 0.7-31.1+ months). Adverse events were predominantly grade 1. Select cases will be highlighted.

DISCUSSION AND CONCLUSIONS: Larotrectinib yields durable high response rates in AYA patients with TRK fusion cancer, regardless of tumor type. Prolonged therapy with

larotrectinib appears to be associated with minimal toxicity. Genomic profiling with assays capable of identifying NTRK gene fusions should be strongly considered in AYA patients with solid tumors.

Exploring the genomic diversity of AYA and adult high-risk b-acute lymphoblastic leukemia by mrna sequencing

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BACKGROUND: Survival in adolescents and adults with ALL remains inferior to children. A comprehensive understanding of genomic factors influencing leukemogenesis and relapse is required to improve outcomes in high-risk subtypes and guide development of new therapeutic approaches. The aim of this study was to identify the frequency of genomic alterations in adolescent/young adults (AYA) (16-39 years) and adults (>40 years) with B-ALL.

METHODS: Samples from 63 AYA (aged 16-39 years, median age 21) and 63 adult patients (40-88 years, median age 59) underwent mRNA sequencing (mRNAseq). The cohort also contained Philadelphia (Ph)+ samples (54% of adults; 19% of AYA) but these were not sequenced. Fusions were identified using FusionCatcher, SOAPfuse and JAFFA. Variants were called using GATK HaplotypeCaller and underwent several filtering steps to eliminate possible germline alterations and common SNPs.

RESULTS: Structural genomic abnormalities were identified in 112/126 (89%) samples by mRNAseq, including many associated with high-risk disease. Ph-like lesions were frequent (24% of adults; 14% of AYA), with most of these being CRLF2 rearrangements. MLL rearrangements were also found in both AYA (16%) and adults (8%). Other recurrent high-risk lesions included variants in NRAS, KRAS, PTPN11, NF1, TP53, JAK2, CSF1R, RB1, CREBBP, RUNX1, FLT3, NOTCH1 and NOTCH2, with an average of 1-2 variants per patient and slightly more occurrences found in adults (n=90) than AYA (n=73). AYA harbored more RAS mutations than adults (33% vs 16%, $P = 0.037$), while TP53 mutations were less prevalent in AYA (3% vs 21%, $P = 0.004$).

CONCLUSION: The relative prevalence of genomic alterations varied between AYA and older adults. While Ph+ and some Ph-like ALL patients may benefit from adding tyrosine kinase inhibitors to chemotherapy, suitable targeted agents are not clinically available for many of the other alterations identified here, highlighting the need for continued efforts to develop precision therapies.

Length of stay different, while treatment-related complications similar in paediatric and AYA hodgkin lymphoma patients in US children's hospitals

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BACKGROUND: Adolescent and young adult (AYA) cancer patients have unique clinical characteristics and inferior outcomes compared to younger patients. Hodgkin Lymphoma (HL) is one of the most common AYA cancers. There is no standard of where and how these patients should be treated, adult hospitals/regimens versus pediatric hospitals/regimens.

DESIGN/METHOD: Data were obtained from the Pediatric Health Information System for HL admissions at 49 free-standing US children's hospitals from 2009-2015. Patients were followed for 1 year from their first encountered admission for HL required ≥ 3 unique admissions with a HL diagnostic billing code. Demographics, morbidities, and hospital utilization were compared in patients 0-14 and 15-30 years using non-parametric methods.

RESULTS: We identified 475 unique pediatric patients and 628 AYA patients with HL. Mean 1-year length of stay (LOS) days was statically longer in AYAs than pediatric patients. Cost was statistically higher in AYA patients for total charges and pharmacy charges. The common cancer treatment-related complications, mucositis, diarrhea, vomiting, thrombosis and fever/neutropenia had similar frequencies between groups. Septic shock, bacterial infections and pain were more common in AYAs.

CONCLUSION: In U.S. children's hospitals, AYAs with HL had shorter LOS, and did not have an increased risk of common treatment-related complications as compared to younger patients. The increased incidence of bacterial infections/septic shock in AYAs may be skewed due to AYAs not reporting fevers to avoid admission and are being admitted later in their illness. While Hodgkin Lymphoma therapy on pediatric protocols may be more dose intensive than adult protocols, complications were similar. Some AYA patients with certain diagnoses have shown improved survival when treated on pediatric protocols, including a recent publication looking specifically at differences in outcomes for HL patients when being treated on pediatric versus adult protocols. Studies like these may direct a new standard of care in treatment of AYAs.

CONCURRENT STREAM 3.2 – FERTILITY & SEX

Concerns about Fertility, Genetic Risk, and Family Building: AYA Oncology Patient Perspectives

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BACKGROUND: Adolescent and Young Adult (AYA) oncology patients have identified having children as an important future goal. However, concerns regarding the impact of cancer on fertility and the perception of cancer as a hereditary disease may influence AYAs' family building decisions. This study explored these topics along with preferences for information among AYA cancer patients.

METHODS: As part of an ongoing study to create an intervention aimed at improving knowledge and patient-provider communication misperceptions regarding inherited cancer risk, fertility preservation, and assisted reproductive technologies (ART), patients diagnosed between the ages of 18-39 were recruited from an institutional cancer registry. Using a pre-interview survey and a semi-structured qualitative interview guide, we explored AYA cancer patients' experiences, practices, and preferences from November 2016-March 2017. Interviews were analyzed using content analysis and survey items were summarized with descriptive statistics to address genetics and reproductive health needs.

RESULTS: Patients (n=17), were majority female (59%) and Non-Hispanic (88%). The majority of patients indicated they had not met with a reproductive endocrinologist (77%) or received genetic counseling (71%). While the majority of patients said they would not personally engage in genetic counseling, they cited potential benefits for other AYA patients including future cancer risk management and also identified barriers such as fear of the results. Participants indicated a positive genetic test result was not likely to alter their family building decisions. However, few demonstrated awareness about ART options to investigate inherited cancer risk in future offspring. The majority preferred to discuss genetic counseling and ART after the time of diagnosis.

CONCLUSION: Results identified awareness and attitudinal barriers to providing patients with information regarding fertility, hereditary cancer risk, and the risk to future children. Data from this phase of the study will be used to inform the development of a psychoeducational intervention to address these concerns.

Fertility information among adolescent and young adult cancer survivors– population-based study

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BACKGROUND: Fertility is a highly important issue among AYA cancer patients and survivors. The purpose of this study was to explore to what extent adolescent and young adult cancer survivors were content with fertility information.

METHOD: A study specific questionnaire has been developed. The method used for question development includes expert validity from professionals and face-to-face validity from former cancer patients. The questionnaire contains several areas in an adolescent and young adult's life affected by cancer and this study focused fertility issues. The web-based questionnaire was sent to all adolescent and young adult cancer survivors treated during 2010 and 2011 in the North, Middle, Southeast and West Sweden.

RESULTS: There was a significant difference in the scores receiving information on fertility issues during treatment between females (M=1.58, SD=0.67) and males (M=1.88, SD=0.61) conditions; $t(278) = 3.89, p < 0.001$. In a further analysis, female AYA survivors scored significantly different on receiving information on fertility preservation; females (M=1.76 SD=0.76) and males (M=2.38 SD=0.84) conditions; $t(278)=6.45, p < 0.001$. These results suggest that female AYA cancer survivors receive less information on fertility issues and fertility preservation during cancer treatment than males. AYA cancer survivors, both males and females, also report not knowing where to turn regarding fertility issues post cancer treatment.

CONCLUSION: The result of this population-based study shows that female AYA cancer survivors reports receiving less fertility information and support than males. This observation

indicates that we have an opportunity to improve the fertility information during cancer treatment, primarily for female AYA cancer patients but also for male AYA cancer patients. Key words: Teenagers and young adult cancer survivors, fertility, information, support.

Nurses' perceptions regarding sexual and reproductive health issues among young adults with cancer or among cancer survivors via focus group interviews

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INTRODUCTION AND AIMS: Increased demands have been noted for the quality care regarding sexual and reproductive health among young adults with cancer or among cancer survivors. The perceptions of nurses remain unclear in this respect despite nurses playing key roles in the early detection, assessment and provision of appropriate care. This study aimed to investigate the sexual and reproductive health issues among young adults with cancer or among cancer survivors in Japan.

METHODS: Focus group interviews were conducted on 10 nurses with >6 years of experience in cancer nursing. Among these, seven nurses were certified specialists in cancer nursing. One focus group comprised 2–4 nurses, and each interview lasted for 90–120 minutes. In the interview, the participants discussed the difficulties or issues faced in caring for patients with cancer or cancer survivors.

RESULTS: The nurses perceived that a) young adults with cancer were actually aware of the meaning of repressed fertility functions after they returned to their normal lives and that b) fertility preservation is the hope of survivors (for the patients as well as their partners). But nurses also perceived that c) they wondered about the timing of pregnancy using preserved tissues depending on their disease conditions. Nurses perceived that d) some physicians did not fully inform young patients about fertility issues, although such information would be necessary for decision making. Notably, none of the participating nurses had previously questioned or inquired young patients regarding their sexual functions.

DISCUSSION AND CONCLUSIONS: Cancer specialist nurses rarely converse with young patients regarding sexual health issues. However, a detailed survey is warranted for clarifying the nurses' experiences. Because infertility and decreased reproductive function are critical issues for young patients, the data on nurses' experiences will be essential in developing a continuing education system for the quality care of such patients.

Oncofertility care and the impact on reproductive concerns, psychological distress and satisfaction in cancer patients at diagnosis, parents and partners

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AIMS: To explore the access to oncofertility care and the reproductive concerns (RC) and psychological distress (PD) that cancer patients experienced at diagnosis, compared to controls and patient/parents.

METHODS: Questionnaires were administered to capture information about patient's reproductive experiences, RC and PD at diagnosis.

RESULTS: 30 patients with cancer were recruited from the Australasian Oncofertility Registry, 10 parents or partners of patients and 50 age-matched controls were recruited. 7.5% of patients and controls had known infertility, 28% of female patients and controls and 8.3% of male cancer patients and controls had risk factors for infertility. 90% patients recalled having a discussion about infertility risks with cancer clinician; 70% had a discussion with fertility specialist and 86% of them underwent FP. Referrals for FP were more likely in 15-19 year olds (87%) and 20-24 years olds (83%) than in 25-45 years old (56%) ($P=0.07$); all males and 81% of females underwent FP once referred. Participants all reported high levels of RC however the patient's reported significantly lower RC than controls ($P=0.18$) and parents ($P=0.13$). Cancer patients reported significantly lower PD compared with controls. Perceived barriers to FP in cancer patients were low, with most patients 'never' or 'rarely' experiencing any barriers. Cancer patients and parents both felt that fertility specialists and cancer doctors (66.7%, 40%) provided the most helpful support. Patients reported not receiving oncofertility support from cancer nurses (43%) fertility nurses (47%), counsellors (73.3%) psychologists (80%) and social workers (86.7%).

CONCLUSION: Having access to oncofertility services reduces barriers and improves communication. Although cancer patients had high RC they had low levels of PD compared with parents/partners and controls showing the potential benefits of oncofertility referral and support. While the access to oncofertility care was of a high standard a large number of patients are not receiving support from all HCP's.

Infertility After Cancer: How the Need to be a Parent, Fertility-Related Social Concerns, and Acceptance of Illness Influences Quality of Life

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INTRODUCTION AND AIMS: Adolescent and young adult (AYA) cancer survivors who experience infertility concerns often report having poorer quality of life (QoL). However, the role of, and interplay between, particular fertility-related stress and other psychosocial issues (such as illness acceptance) is not clear. Based on literature from other populations including older cancer survivors, we hypothesised that specific fertility-related stressors (need for parenthood and infertility-related social concerns) would be directly related to QoL and indirectly related to QoL through acceptance of illness.

METHODS: Cancer survivors (n=178) aged 15-29 years (Mage = 22.4, SDage = 4.1; 75.3% female) responded to the following questionnaires; the QoL ladder, acceptance of illness scale, and two fertility problem inventory subscales: infertility-related social concerns and need for parenthood.

RESULTS: Structural equation modelling (SEM) was used to test the hypothesised model which was not supported ($\chi^2 = 58.65, p < .001$). We therefore investigated alternative models. The final SEM model explained 28.36% of the variance in QoL ($\chi^2 = 9.05, p = .171$) and showed that higher acceptance of illness (.39), lower infertility-related social concerns (-.23), and older age (.19) were directly related to higher QoL scores. Infertility-related social concerns also indirectly affected QoL through acceptance of illness. Need for parenthood did not directly relate to QoL, instead a greater need for parenthood was directly related to increased infertility-related social concerns (.42) and females had higher need for parenthood (.17).

DISCUSSION AND CONCLUSIONS: These findings suggest that psychosocial factors surrounding infertility impact on AYA cancer survivors' QoL. When faced with infertility, AYAs (particularly females) report lower QoL because of their lower acceptance of illness and infertility-related social concerns. By supporting AYA survivors to manage their infertility-related social concerns and improve their acceptance of illness, we can see improvements in their perceived QoL.

The construction and experience of fertility and social relationships amongst adolescent and young adults with cancer

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INTRODUCTION AND AIMS: Infertility is a major concern for adolescent and young adults (AYA's) with cancer. The aim of this paper is to explore how young people with cancer construct and experience infertility or knowledge of compromised fertility.

METHODS: One hundred and thirty-four women and 44 men who were aged 15 to 29 years and diagnosed across cancer types took part in a self-report survey. A subsample of

28 women and 7 men took part in an in-depth one-to-one interview. Open-ended survey responses and interview transcripts were analysed using thematic analysis.

RESULTS: Four major themes were identified. Firstly, in the theme "defective bodies" participants positioned cancer related changes to their reproductive bodies as worrying and not 'normal' for a young person. Secondly, participants described a silencing of cancer related infertility due to fear of social judgement or lack of understanding in the theme "Social stigma of infertility and cancer". Thirdly, participants gave accounts of "problematic disclosure" around how to broach the subject of compromised fertility when establishing new couple relationships. Finally, and in contrast, a number of participants positioned cancer related infertility as less problematic due to supportive partners and peers in the theme "resisting stigma, normalising infertility". In addition, strategies to navigate potential infertility were also described, such as selecting understanding partners and normalising experiences through comparison to others with experience of cancer or infertility.

DISCUSSION AND CONCLUSIONS: The fear of infertility, or knowledge of compromised fertility following cancer can have a detrimental influence on psychological wellbeing and experiences of social relationships for both AYA women and men. Support from family, partners and health care professionals can facilitate coping.

CONCURRENT STREAM 3.3 – MEASURING DISTRESS & NEEDS

Psychological Need and its Identification in Adolescent and Young Adult (AYA) Cancer

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INTRODUCTION AND AIMS: Accurate identification and treatment of psychological need in adolescent and young adult (AYA) cancer is necessary to avoid reported long-term consequences if not addressed. Identification typically relies on (appropriately selected) self-report questionnaires (SRQs). The SRQs used in AYA cancer vary widely. We report i) the prevalence of psychological need in AYA cancer patients diagnosed/treated in South East London, and ii) the effectiveness of screening with SRQs vs interview by AYA specialist psychologist.

METHODS: Appropriate standardised SRQs, including measures of depression, anxiety and distress were completed 3+ monthly, at diagnosis and for up to 4y, by 230 subjects aged 16-25y between 2013-2017. All also undertook a screening interview with AYA psychologist within our multi-disciplinary AYA clinic. A more in-depth assessment was arranged if psychological need was identified. Based on SRQ and interview patients were either discharge from clinical psychology, received short-term intervention, long-term intervention or onward referral to other specialist services.

RESULTS: Of 230 patients, screened by both SRQ and interview, 39.6% were identified with psychological needs sufficient to require further assessment beyond the initial clinic visit. UK-recommended measures of depression and anxiety identified less than 50% of those who were identified as having clinically significant psychological need during the face-to-face interview. A relatively new measure of general distress was more sensitive, flagging 80% as having distress although yielding a higher false negative.

DISCUSSION AND CONCLUSION: These results indicate the prevalence of psychological need in an urban UK AYA cancer population at diagnosis, and lasting well beyond end

of treatment. We found that psychological need cannot be achieved using SRQs alone. Although one measure was more sensitive, a fifth of those presenting with psychological need were only identified by interview. We demonstrate the need for universal screening by a clinical psychologist in addition to SRQs.

Development and Psychometric Testing of the Disconnectedness with Healthcare Providers Scale for Adolescents and Young Adults with Cancer

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INTRODUCTION AND AIMS: To provide developmentally appropriate care to adolescents and young adults with cancer (AYA) that meet their psychosocial needs, healthcare providers (HCPs) must be able to connect with AYA. Connectedness with HCPs (i.e., a sense of having a positive, meaningful relationship with nurses and doctors) can influence AYAs' adjustment to the cancer experience and open the avenue for effective communication. However, some HCPs may actually destroy the potential to connect with AYA and create a sense of disconnectedness – leading to non-adherence and/or an unwillingness to participate in long-term follow-up. To identify at-risk AYA who may be disconnected with their HCPs, a measure needs to be developed. The aims of this presentation are to: (1) describe the development of a patient-reported measure of disconnectedness with HCPs for AYA (ages 13 to 21 years); (2) describe its content validity; and (3) report its psychometric properties (dimensionality, internal consistency reliability, and construct validity).

METHODS: The Disconnectedness with Healthcare Providers Scale (D-HCPS) was developed and evaluated in two phases. Phase 1 involved generating items, having two expert panels (AYA and clinicians; N=13) evaluate the items for content validity, and pre-testing the instrument prior to pilot testing (N=6). In Phase 2, the psychometric properties of the instrument (dimensionality, internal consistency reliability, and convergent/discriminant validity) were evaluated (N=101).

RESULTS: The D-HCPS contains 11 items on a 7-point Likert type scale. Exploratory factor analysis suggested a two-factor solution. The internal consistency reliability of the D-HCPS (Cronbach's alpha) was .881. Good evidence of convergent and discriminant validity was demonstrated via hypothesis testing.

DISCUSSION AND CONCLUSION: Findings indicate that the D-HCPS is a reliable measure and has good evidence of convergent and discriminant validity. Further exploration of the D-HCPS using confirmatory factor analysis in a larger sample is needed.

Psychosocial Needs and Distress Scores Among Newly Diagnosed AYA Sarcoma Patients

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INTRODUCTION/AIMS: Limited understanding exists for the psychosocial needs of adolescent and young adult (AYA) sarcoma patients aged 39-years or younger at diagnosis. The Canadian Problem Checklist (CPC) and Psychosocial Screen for Cancer (PSSCAN-R) are validated tools to identify cancer patient distress, and are administered to all new patients in British Columbia (BC), Canada. Here, we use the CPC and PSSCAN-R to understand AYA sarcoma patient needs at initial oncology consultation in BC.

METHODS: All sarcoma patients who completed the CPC and PSSCAN-R within 6 months of diagnosis between 2011-2016 were included. Retrospective chart review identified baseline demographics: age, performance status, disease location, resectability and histology. Analysis was conducted using descriptive statistics and Fisher's Exact test.

RESULTS: 413 sarcoma patients were identified, of which 69 were AYA. Among AYA, 47.8% were female (33/69). Patients had good performance status, ECOG 0-1 (84.1%, 58/69) and lower extremity sarcoma (62.3%, 43/69). 42.0% were resectable (29/69), 2.9% unresectable/metastatic (2/69) and 55% required further staging. The most common histologies were soft tissue sarcoma not otherwise specified (39.1%, 27/69) and giant cell tumor (23.2%, 16/69).

PSSCAN-R noted no difference between AYA patients versus older for anxiety/depression prevalence: 43.3% of patients had subclinical (13/69), or clinical (16/69) anxiety and 22.4% of patients had subclinical (10/69) or clinical (5/69) depression.

The CPC identifies distress in six domains: emotional, practical, spiritual, social, informational and physical. The top three concerns were understanding illness/treatment (42.0%), fear/worries (40.6%), and emotional sadness (24.6%). Least concerning were faith (2.9%), meaning of life (4.3%), and accommodation (5.8%). Compared to older patients, AYA reported more concern about work/school, 23.2% vs. 9.6%, $p=0.003$. No other domains were significantly different.

DISCUSSION AND CONCLUSIONS: AYA with sarcoma experience high rates of psychosocial distress at diagnosis. Compared to older adults, work/school concerns are more prevalent. Ongoing support regarding work/school reintegration would be reassuring to this patient group.

Health Care Professionals' and AYA cancer patients' perspectives of using the AYA-modified Distress Thermometer tool: a clinical utility analysis

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INTRODUCTION AND AIMS: Adolescents and young adults (AYAs) have complex psychosocial needs following a cancer diagnosis. A single-item distress thermometer (DT) accompanied by a problem check-list (PCL) can be used to screen for psychological distress and needs in cancer patients. This study examined the clinical utility of the AYA-modified DT tool in clinical practice throughout the Australian Youth Cancer Services.

METHODS: Health Care Professionals (HCPs; N = 33) and recently diagnosed AYAs (N = 105) completed questionnaires about their experiences with the use of the DT/PCL. Fourteen AYAs completed follow-up interviews.

RESULTS: HCPs believed the DT/PCL: was easy to use (96%), covered relevant issues (91%), helped AYAs communicate their needs (70%), helped build rapport (70%), and managed patient distress (78%). HCPs reported being happy to use the DT/PCL with future patients (87%). Reported barriers were the patient being too unwell (44%) and lack of time (26%). AYA patients indicated the DT/PCL was clearly laid out (98%), easy to interpret (98%), did not take too long to complete (89%), covered relevant issues (90%), and they would be happy to complete the DT/PCL again (89%). Follow up interviews with AYAs explored aspects of service responsiveness following administration of the DT/PCL. Seventy-seven percent of AYAs indicated they received a referral after completing the DT/PCL and nearly all agreed that the referral/s helped them deal with their cancer experience better.

DISCUSSION AND CONCLUSION: The AYA-modified DT shows robust clinical utility from both the perspective of HCPs and AYA cancer patients. Results demonstrate the relevance, effectiveness, ease of use, and acceptability of the tool, providing confidence in its clinical use and usefulness.

AYA Concept Map: Facilitating Rapid Matching of Resources to Unmet Needs

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BACKGROUND: The AYA Program at Moffitt Cancer Center (MCC) was established in 2011 to address the unique needs of the AYA cancer population; however, staff continues to be unclear on the scope of AYA issues and services available to AYA patients, survivors, and families. A concept map-based knowledge model was developed to visually illustrate and

describe what the AYA program is, how the program operates, and the key stakeholders involved with the program.

METHODS: The AYA program's strategic plan was revised amongst multidisciplinary staff to understand the roles of employees, the goals of the program and how they aligned with the unique needs of patients, and resources available at Moffitt. The visual representation was developed using IHMC Cmap Tools based on stakeholder expertise captured during elicitation sessions, the revised strategic plan, and guidance of design by a concept map developer.

RESULTS: The concept map was used in multiple presentations internally to educate Moffitt staff on the program content, unique needs of the AYA population, and resources available to patients between the ages of 15-39. The AYA program has seen an increase of AYA related questions due to the increased awareness of the program.

CONCLUSIONS: Utilizing a visual representation tool was an efficient technique for knowledge sharing and communication, synthesizing the complexity of the AYA program and its targeted population, the resources available at MCC and assists with program development and implementation. By the time of the TCA Congress, the concept map will be added to Moffitt's internal website with tangible resources, such as flyers or website links to provide additional details for employees. An additional concept map will be developed as a patient education tool to illustrate the resources available for AYA aged patients and survivors at MCC. Concept mapping may be applicable more broadly with other AYA resources.

CONCURRENT STREAM 4.1 – CLINICAL TRIALS ACCESS

Factors Affecting Clinical Trial Enrolment for AYAs with Cancer in a U.S. Population-Based Study

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INTRODUCTION AND AIMS: Cancer survival rates in adolescents and young adults (AYAs) are showing slow progress in comparison to other age groups, which may be due to historically low participation rates in clinical trials. This study's aims were to determine if AYAs from rural areas have lower clinical trial enrollment compared to their urban counterparts, and examine factors associated with enrollment variation.

METHODS: Data from the National Cancer Institute's Surveillance, Epidemiology, and End Results Patterns of Care 2006 and 2013 AYA cohorts were analyzed. Patients with acute lymphoblastic leukemia (ALL), Hodgkin lymphoma (HL), non-Hodgkin lymphoma (NHL), and sarcoma were included (N=3,037). Urban influence codes (UIC) measured rurality of county of residence at diagnosis, categorized as large metropolitan, small metropolitan, or non-metropolitan. Odds ratios (ORs) were obtained from weighted logistic regression comparing trial participants versus non-participants while adjusting for sociodemographic and treatment-related factors.

RESULTS: AYAs diagnosed in 2006 and 2013 with ALL had significantly higher clinical trial enrollment (42%) than AYAs with HL (12%), NHL (7%), and sarcoma (32%), as did AYAs ages <22 years (36%) versus ages 23-31 (10%) and 32-39 (6%). Compared to AYAs from urban counties, AYAs from small metropolitan (OR 1.88, 95% CI: 1.28-2.77) or non-metropolitan (OR 1.59,

95% CI: 1.01-2.51) counties were associated with greater trial enrollment. AYAs diagnosed at a hospital with a residency program (OR 1.63, 95% CI: 1.01-2.63) were associated with greater enrollment. Across all disease sites, AYAs treated by a pediatric oncologist had significantly greater enrollment (OR 4.27, 95% CI: 2.81-6.49).

DISCUSSION AND CONCLUSION: Surprisingly, clinical trial enrollment among AYAs from small metropolitan and non-metropolitan counties was more likely than among those from urban areas. This finding signifies the importance of additional research focused on rurality to better understand factors contributing to clinical trial enrollment for AYAs with cancer.

Increasing Clinical Trial Access in AYA - Development of the Victorian Comprehensive Cancer Centre AYA Clinical Trial Access Steering Group

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INTRODUCTION: AYA patients are enrolled into cancer clinical trials (CCT) at a lower rate than their pediatric or adult counterparts, contributing to poorer outcomes. This sub-optimal enrolment has been heavily researched, including systems and regulatory barriers that may impact access. The Increasing AYA Clinical Trial Access program was developed in 2018 aimed at ameliorating administrative and governance barriers to CCT within the local Victorian setting.

METHODS: This concept is one of 19 programs being undertaken as part of the Victorian State Government supported strategic research plan. Through expressions of interest, a steering group was created with membership encompassing expertise in paediatric/adolescent CCT, research governance, consumer and regional representation.

RESULTS: Formation of an initial work-plan focused on mapping local processes and barriers in CCT. Early work has identified the following barriers: variation in AYA age group categorization; consensus on age cut-offs for clinical/governance harmonization; lack of trial portfolios for AYA, particularly those with rare cancers; barriers to expansion of paediatric CCT to adult sites and access to industry trials with novel therapies. Advantages in creating this steering committee to overcome these barriers include: support services with pediatric and adult hospitals; existing relationships between pediatric and adult cancer services across the VCCC partner sites; connectivity with other priority trial programs; and the level of working group expertise in streamlining governance for clinical research, both within and across organisations, so that paediatric and adult hospitals work together closely focusing on overcoming red tape and putting the needs of AYA at the core of our efforts.

CONCLUSION: Formation of a steering group, with expertise in clinical trials, as well as in AYA CCT, is facilitating creative, flexible and informed process mapping, providing a platform to overcome governance barriers hindering AYA trial access. Updated guidelines and standard operative procedures will be presented.

The new UK National Cancer Research Institute's Clinical Studies Group (CSG) in Teenage, Young Adult (TYA) and Germ Cell Tumours

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In 2016 two UK National Research Groups merged, forming the TYA & Germ Cell Clinical Studies Group. The inaugural Chair of our new CSG will recap the contributions of the previous groups and our future strategy together. In 10 years both groups secured over £8 million of research funding. Recent achievements include; the integration of novel biomarkers, a TYA risk stratification and new TYA psychosocial measurement into a global germ cell tumour trial; a prospective multi-modality evaluation of TYA care and outcomes; a TYA-specific pan-European cancer genomics pilot cohort. This success has stimulated an exciting research strategy for the next 3-5 years, including interdisciplinary programmes of Clinical Trials, Health Services Research, Biological, Survivorship studies. We have completed a prospective multidisciplinary professional and public consensus upon future research objectives ensuring the patients priorities are core to what we do. We have selected to implement practice-changing research in; Health Service Interventions to increase recruitment to clinical trials to improve timely diagnosis and treatment to improve the psychological wellbeing of TYA with cancer Personalised medicine Biologically driven trials in early and in resistant germ cell tumours Trials reducing treatment toxicity Studies of TYA-specific radiobiology and cancer pharmacology. The identification and active management of late effects Risk stratification in Cerebrovascular disease Impaired fertility Technology in TYA cancer care Evidence-based evolution in models of healthcare for survivors Next-generation informatics and machine learning in biology, data and trial recruitment We will deliver this programme through specific studies and new national and international collaborations to address key TYA-specific research questions, both directly and within sub-studies of treatment trials. Our group has the energy, synergy and maturing relationships, within its members and with cancer and non-cancer communities, charities, patients, the public and healthcare policy required to achieve change.

The Good, The Bad and The Ugly: Improving Young Adult Access to Clinical Trials

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INTRODUCTION: There is widespread acknowledgement that outcomes for AYA patients in some malignancies are poorer than those for both younger and older patients. In some diseases such as acute leukaemias, there is evidence that treating AYA on paediatric protocols improves outcomes, particularly within a clinical trial. Access to paediatric protocols and trials is limited for most AYA, once they are over 18 years old. 'The Ugly': case presentation of Starship/ Auckland City Hospital's (ACH) first unsuccessful attempt to enrol AYA patient treated in adult oncology services onto a paediatric clinical trial.

AIM: To successfully treat AYA patients within adult haematology/oncology services on paediatric clinical trials/ protocols.

METHODS: Negotiations with key trials groups (particularly Children's Oncology Group) Agreement on an institutional SOP for AYA access to clinical trials – current upper age 25 years Across service planning meetings to attempt to pre-empt and avoid hurdles – endless ('the Bad') An 'off study – on study' pilot patient to test clinical and communication processes Enrol first patient on study, then treat future patients on study or as per protocol off study Joint MDT presentations /AYA group meetings with professional advice flowing between adult and paediatric teams.

RESULTS: The Good': case presentation of our first patient successes All subsequent eligible patients treated on study, or 'as per' (during study closures) Ongoing review of treatment choice, patient disease outcomes and morbidity/mortality is underway

CONCLUSION: This 'proof of principal' at Starship/ACH has shown it is possible in the New Zealand environment to meet our objective. The success of this project has led to adult oncology centres outside of Auckland seeking to send their patients to Auckland City Hospital for treatment, to allow access to paediatric trials. This will support equity of access for AYA patients, across the country, with the aim of improving disease outcomes for this group.

Analysis of Accrual Patterns of AYA Patients to a U.S. National Cooperative Research Group Over 25 Years: The SWOG Experience

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INTRODUCTION AND AIMS: Accrual of AYA patients to clinical trials is suboptimal. We examined accrual of AYA patients to clinical treatment trials in a U.S. national cooperative research group (SWOG) over a 25-year period, compared to both older SWOG patients and to AYA patients in the non-trial setting.

METHODS: We examined initial registrations from SWOG-coordinated phase I-III therapeutic trials for 15 different disease types over a 25-year period (1993-2017). Accrual patterns for AYA patients (18-39 years) were compared to older (40+ years) patients in SWOG and to corresponding U.S. cancer population rates among patients aged 18-39 years derived from U.S. Census data and NCI SEER 17 data.

RESULTS: From 1993-2017, 79,403 adult cancer patients were enrolled to SWOG therapeutic trials, of whom n=7,713 (9.7%) were AYA patients. Over the same period, the average proportion of patients in the U.S. cancer population aged 18-39 was only 4.7%. The cancers enrolling the greatest numbers of AYA patients were breast (3,394; 44.0%), lymphoma (1,345; 17.4%), and leukemia (1,200; 15.6%); combined, these three cancers represented 77.0% of total cases. SWOG AYA patients were more often female (44.7% vs. 40.2%, p<.0001), black (10.4% vs. 8.5%, p<.0001), Asian/Pacific Islander (4.3% vs. 3.1%, p<.0001), Native American (0.7% vs. 0.4%, p=.0003), and Hispanic (8.0% vs. 4.4%, p<.0001) than older

SWOG patients. SWOG AYA patients were less often female (44.7% vs. 48.8%, $p < .0001$), black (10.4% vs. 11.8%, $p = .0001$), and Hispanic (8.0% vs. 12.4%, $p < .0001$) than AYA patients in the U.S. cancer population.

DISCUSSION AND CONCLUSIONS: AYA cancer patients were overrepresented in SWOG clinical trials by nearly 2-fold compared to the U.S. cancer population. More than 75% AYA patients in SWOG were from breast cancer, lymphoma, or leukemia trials. The SWOG AYA population is more diverse than older SWOG patients, but somewhat less diverse than the U.S. AYA cancer population.

WA AYA Cancer Clinical Trials Group - Improving Clinical Trial Access for AYA Cancer

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Improvements in outcomes for adolescents & young adults (AYA) with cancer lag behind those of other age groups. Reasons for this deficit in survival improvement are multiple, however, one important factor is the decreased enrolment in therapeutic clinical trials in this population compared with younger patients. Lack of enrolment on clinical trials results in lower survival rates, diminished progress in understanding of disease and host biological factors and variable patterns of follow-up.

METHOD: In Western Australia (WA), reduced AYA clinical trial enrolments is, in part, attributable to lower numbers of clinical trials available for this age group. The recent co-location of paediatric and adult cancer providers on a single site provides a unique opportunity to improve outcomes for AYA with cancer in WA through increased trial enrolment. With the aim of improving outcomes, a multi-speciality clinical trials group has been established with the remit of increasing clinical trial availability for all AYA with cancer. Current age-appropriate clinical trials open at the paediatric site are evaluated for feasibility of cross-site ethics approval to facilitate enrolment of older adolescent and young adult patients.

RESULTS: All clinical trials open to those over 18 years and holding scientific and ethics approvals at the paediatric institution are identified, discussed and, if agreed appropriate, submitted for reciprocal ethics approval at the adult institution. Working within the WA AYA Cancer Clinical Trials Group with informed adult oncology specialists and clinical trials research personnel and supports, demonstrates that it is feasible to adopt a unified and consistent approach to ensure increased collaborative trial availabilities to the older adolescent cohorts.

CONCLUSION: Identification of age-appropriate collaborative clinical trials by the WA AYA Clinical Trials Group to be opened across sites will facilitate increased clinical trial enrolment and ensure improved outcomes for AYA cancer.

CONCURRENT STREAM 4.2 – AYA CANCER PROGRAMS

Case Study: Piecing Together the Patchwork Quilt of AYA Programming

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CASE DESCRIPTION: In 2015 the University of Iowa Hospital and Clinics (UIHC) began a comprehensive adolescent and young adult (AYA) cancer program; bringing together the strengths of both the Stead Family Children's Hospital and the Holden Comprehensive Cancer Center. While both units reside within the UIHC organization, differences exist in how each operates administratively. Also, each offers different combinations of both clinical and supportive services. Because our AYA patients are cared for by two different groups under the same roof, we seek to harness the strengths of each to complement needs in service and care delivery. To do this, we undertook an extensive gap analysis to quantify the strengths and weaknesses of each unit, and to determine how the AYA program can bring resources to address identified needs. This enables us to create a standard of practice for all AYA patients, wherever they are being treated. To do so has required the piecing together of different components of care, both clinical and supportive services, from each unit. A hybrid administrative model has been created to implement the program. Additionally, obtaining the resources to provide these AYA services has been a patchwork of external and internal funding by complementing internal resources with targeted grant and philanthropy funds.

DISCUSSION: It isn't enough to have a vision for a comprehensive and collaborative AYA program. As well, internal and external resources must be identified in order to pull together the necessary money, personnel and infrastructure to fit into a complex organizational structure. While there is no "one size fits all" approach to building and AYA program, the need for collaboration and thinking outside the organizational "box" is necessary. We have created a novel, hybrid administrative and funding model to build a comprehensive and sustainable program.

KEY LEARNINGS: Identifying novel ways to gather AYA resources and infrastructure.

The Australian Youth Cancer Services Program: Key service delivery achievements from 2013-17 (Phase 2)

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¹CanTeen Australia

²The NSW/ACT, VIC/TAS, QLD, SA/NT and WA Youth Cancer Services

INTRODUCTION & AIMS: Since 2009, Australian AYA cancer care has been transformed by the introduction of the YCS program, funded by the Australian government and managed by CanTeen Australia, with co-investment from state and territory governments. Five jurisdictional multidisciplinary healthcare teams provide care across 27 hospitals nationally. This network allows specialist YCS teams to better reach and meet the needs of patients across Australia, including vulnerable populations including those from rural/remote settings and Aboriginal and Torres Strait Islander Australians. We aim to provide a national overview of key service delivery achievements from the second phase of YCS funding.

METHODS: Aggregate activity data was collected on a quarterly basis from each of the 5 YCS teams. Data included service reach, care coordination, psychosocial and supportive care, fertility preservation and research participation items. Qualitative reporting of key initiatives, resources, developments and challenges were also collected. National activity data was descriptively analysed, and high-level thematic analyses conducted.

RESULTS: The YCS saw a substantial increase in referrals of approximately 20% between 2013 and 2017, directly supporting over 5,000 patients nationally. Medical, nursing and allied health secondary consultations increased by over 58%. YCS teams made significant progress in implementing best-practice, coordinated, multidisciplinary care with almost 90% of patients' psychosocial and/or medical care discussed at multidisciplinary team meetings, almost three quarters undergoing routine psychosocial assessment and the majority receiving information about fertility preservation. Increases in clinical trials, and clinical and psychosocial research participation were also evidenced.

DISCUSSION & CONCLUSIONS: Phase 2 of the YCS program exceeded expectations in many areas with its extensive national footprint reaching and supporting the majority of newly diagnosed young Australian cancer patients. Critical learnings and the new Australian Youth Cancer Framework have informed the current phase of the program, which includes a focus on survivorship and transitions to community-based support post-treatment.

Partnering with Primary Care Networks to Improve Youth Cancer Care in Queensland

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INTRODUCTION AND AIMS: In addition to timely, safe and effective treatment, a cancer diagnosis during adolescence and young adulthood adds extraordinary challenges and requires integration across multiple service providers. The role of the General Practitioner (GP) during this transformative life stage is vital to achieve person centred care from diagnosis and throughout survivorship. The Queensland Youth Cancer Service (QYCS) sort to determine the number of 15 – 25-year-old patients with an identified GP and to improve communication and referral throughout and beyond the treatment trajectory.

METHODS: To assess the level of engagement between QYCS specialist teams and GPs from cancer diagnosis, a three-stage mixed methods approach was utilised. This included a retrospective chart review of patients treated across the QYCS during 2015-16; a series of structured interviews and focus groups to better understand the GP perspective; and a survey to determine GP preferred communication methods.

RESULTS: During 2015-2016, N=234 young people were treated in QYCS affiliated hospitals. Of these 208 patients were referred to a treatment Multi-Disciplinary Team meeting (MDTM). At least 30% (n=62) did not have a regular GP recorded and in 4% (n=7) documentation stated the patient had no GP. Qualitative analysis from 82 stakeholders representing consumers, GPs and oncology specialists confirmed the importance of integration between hospital and primary care teams particularly at diagnosis; and end of active acute care. GPs preferred a faxed letter in addition to electronic communication.

DISCUSSION AND CONCLUSION: With higher overall survival rates in young people an integrated care approach is pivotal to improve the quality of life and to reduce fragmentation and duplication of services. Project recommendations include inviting a GP to sit on the QYCS Strategic Advisory Committee, providing a treatment summary to GPs from the MDTM, and establishing post-treatment referral pathways.

A model of care to identify needs, provide support and empower recovery for young adults with cancer

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INTRODUCTION AND AIMS: A UK research-setting exercise for AYA with cancer identified as first priority "To identify what support improves psychological well-being, social functioning and mental health during and after treatment". A patient survey reported at Global AYA 2015 identified "the things that mattered most" to be: psychological support without the stigma of having to ask; help developing coping strategies; diet and lifestyle advice; peer support; work and education support. Half of AYA with cancer report unidentified need for psychological support beyond treatment [Zebrack 2014].

METHODS: In 2012 we initiated a multidisciplinary support clinic for cancer patients aged 16y-24y. All in South-East London are invited at diagnosis and supported until 25th birthday (minimum 2y). All meet every team member at each visit. The team: The AYA Nurse provides point-of-contact for advice and facilitates the community through social media and activities; Psychologist (individual, family and group therapy); CLIC-Sargent Social Worker and CLIC-Sargent Community Worker (finance/housing and work/education); Dietitian (nutrition support, healthy eating, lifestyle); Haem-oncologist (medical advice, liaison with site-specific oncologists); Fertility consultant. Plus, signposting to other AYA support agencies.

RESULTS: Most have needs across multiple domains, and wish to continue support beyond treatment. Positive outcomes for individuals vary and are often intangible. The service was rated 'extremely useful' by 92/99 respondents to an anonymised survey. With 65-75 new patients/year, <2% decline support and >98% continue to engage and report benefit ≥2y after diagnosis. Psychological distress was identified in 40% of 230 screened and specialist intervention provided. With diet/lifestyle advice >50% achieve a healthier BMI. Of 113 screened over 3y by the CLIC Sargent Team, 100 (88%) needed support and benefitted from specific interventions.

DISCUSSION/CONCLUSION: Our multi-disciplinary service addresses needs and provides a medical, psychological, and social safety-net through and beyond treatment, empowering patients to manage their own recovery and social reintegration.

Measuring the impact of a stepped-care approach to psychosocial support on distress and unmet needs in AYA cancer patients and siblings

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INTRODUCTION & AIMS: Adolescents and young adults (AYAs) affected by their own or a sibling's cancer typically report elevated psychological distress and substantial unmet support needs. CanTeen offers a range of evidence-based support services to AYAs impacted by cancer. Individual support provision is informed by a comprehensive Psychosocial Assessment and Review Process (PARP), conducted within the context of the CanTeen Psychosocial Model (CPM). At a group level, PARP results are used to measure the impact of CanTeen services. This presentation aims to describe the PARP and CPM, and present initial findings from psychosocial assessments and reviews for AYA cancer patients and siblings accessing CanTeen's services.

METHODS: CanTeen service users complete baseline measures of psychological distress and unmet needs, which are periodically reviewed. Participants were cancer patients and siblings aged 12-25 years who had completed a baseline and initial review assessment. Participants completed demographic measures, the Kessler Psychological Distress Scale-10 (K10), and an unmet needs measure specific to being a cancer patient or sibling. Mixed linear models were used to determine changes in needs and distress for both groups, when controlling for age and gender.

RESULTS: Matched baseline and initial review assessments were completed by 158 young people (age $M=15.7$ years, $SD=3.5$; 61% female; patients ($n=62$), siblings ($n=96$)). Using paired sample t-tests we identified a significant reduction in distress and unmet needs for patients ($t = 2.03$, $p = .047$) and siblings ($t = 4.28$, $p < .001$).

DISCUSSION AND CONCLUSIONS: After accessing individualised support from CanTeen, AYA cancer patients and siblings reported a reduction in their psychological distress, along with reduced cancer-related unmet needs. The individualised assessment process allows CanTeen staff to routinely monitor young people's needs and distress and update supportive care plans accordingly. Analysis of changes in unmet needs based on type of service received will allow for further exploration of the impact of support for AYAs.

Incorporation of Population Sciences into an Adolescent and Young Adult Oncology Program

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INTRODUCTION AND AIMS: With current initiatives to improve the overall survival of adolescent and young adult (AYA) patients through increased clinical trial enrollment, there exists a deficiency of support for coping skills, life skills, and self-care for patients on and off therapy. Patients often feel lost, abandoned, and have poor social functioning once diagnosed. To address these concerns, we incorporated population sciences into our

developing AYA program to provide and evaluate supportive care interventions for this unique population.

METHODS: Physician and population science researchers partnered to implement a range of observational and interventional studies, including "Skin Surveillance/Sun Protection Practices," "FitSurvivor," "Bright IDEAS for AYA patients," and "Managing Your Health." Interventions include the use of a mobile app with a wearable fitness device, problem-solving skills to enhance coping and reduce distress for patients on treatment, and guided self-management with peer mentoring for survivors in long-term follow-up care.

RESULTS: The observational study revealed a need to develop and test behavioral interventions to promote skin cancer surveillance and cancer prevention among survivors. Fit-Survivor showed that a technology-enhanced group-based physical activity intervention was both feasible and acceptable with promising health outcomes. Bright IDEAS for AYA patients is ongoing, with 16 patients enrolled thus far and data analysis pending. Managing your Health has completed its pilot phase (n=15) which demonstrated feasibility and acceptability of a self-management and peer mentoring intervention. Ongoing efforts are engaging survivors to enhance the online self-management components.

DISCUSSION AND CONCLUSIONS: A comprehensive approach to the medical and psychosocial needs of AYA patients is necessary. With incorporation of population science interventions, we are able to address needs that were previously overlooked. While our program is in the early stages of development, these interventions will continue to incorporate and expand within our program and can serve as a model for other AYA programs.

CONCURRENT STREAM 4.3 – SURVIVORSHIP CONSIDERATIONS

Reset: A Lifestyle intervention programme for adolescent and young adult cancer survivors

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Adolescents and Young Adults (AYAs) with cancer are at greater risk of developing chronic illness, and/or secondary cancer. There is evidence that suggests AYAs have lower levels of activity/are more sedentary. Studies show that lifestyle intervention in cancer patients i.e. physical exercise and a balanced diet can greatly reduce the risk of developing chronic illness and/or secondary cancer. CanTeen New Zealand (NZ) developed a lifestyle intervention pilot programme (Reset) to provide education/information on exercise/nutrition for AYAs. The programme format was two 3-day residential programmes with a 12-week challenge in between. The purpose of the programme was to help incorporate exercise into AYAs lifestyle and improve individual's strength, balance, and cardiovascular fitness, and to incorporate nutrition knowledge of healthy food choices, both over a 12-week period. A NZ registered dietitian and nutritionist conducted nutritional education that accurately followed NZ nutrition guidelines. The practical component of these sessions included a supermarket tour, social cooking class, group dietitian consults, and opportunities to help with food preparation. One hundred percent of participants reported post programme that they had used nutrition knowledge learnt from the programme

and had incorporated healthy food options. Tests for upper/lower body strength, core strength, flexibility, and cardiovascular fitness were conducted at the first programme on 22 AYAs, (by certified PINC & STEEL Cancer Rehabilitation Physiotherapists). The same tests were conducted 12 weeks later, on 18 AYAs (same cohort). The findings of this data collection indicated that AYAs experienced substantial improvements (92% average) in health measures such as upper/lower body strength, core strength, flexibility and cardiovascular fitness and 94% of participants reported they exercised more since completing Reset, amongst other findings. More AYAs could benefit from such interventions. This has implications for further research and could potentially enhance both quality and quantity of life in AYAs, and cancer survivors in general.

A 10-week structured exercise program accelerates improvement in cardiopulmonary fitness in adolescents and young adults (AYA) after completion of cancer treatment: results of a randomised controlled trial

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BACKGROUND: Cancer and its treatment are frequently associated with impaired physical fitness which often persists into survivorship. Studies in older adults with cancer have demonstrated benefits from exercise, however this has not been rigorously investigated in AYA. The aim of this study was to determine whether a structured 10-week exercise intervention was associated with improved functional capacity, fatigue and quality of life (QoL) in AYA who have completed systemic cancer treatment within the past two months.

METHOD: 43 AYA (median age 21±6 years) were randomly assigned to an exercise group (N=22) or a control group (N=21), with stratification for gender and treatment intensity. The exercise group received a structured 10-week moderate intensity exercise program comprising two supervised sessions per week of progressive aerobic exercise and strength-based activity, while the control arm received usual care. Functional capacity was measured at baseline, 10 weeks and 6 months via a cardiopulmonary exercise test (CPET). Fatigue and QoL were assessed by the FACIT fatigue scale and the EORTC QLQ-C30 respectively.

RESULTS: Mean VO₂peak at baseline was 26.5 ml/kg/min, which is substantially lower than age-based population norms. The exercise group demonstrated a statistically significant improvement in VO₂peak at 10 weeks when compared to controls (33.8 vs 29.6 ml/kg/min, P=0.0002), but by 6 months the difference was no longer significant (32.9 vs 30.9 ml/kg/min, P=0.21). There were no significant differences in fatigue or total QoL scores between groups, although differences were seen in some subscales.

CONCLUSION: Cancer treatment is associated with dramatic physical deconditioning in AYA. Improvement in physical fitness is accelerated by a structured 10-week exercise program, which appears to assist in a more rapid return to role functioning even though total QoL scores were similar between groups. The plateau in improvement at 6 months suggests that an ongoing maintenance exercise program should be investigated.

Does Cancer Affect Neurocognitive Functions in Young Adults? A Prospective Study

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INTRODUCTION AND AIMS: Cancer has been linked with neurocognitive sequelae in older adults; whether young adults (YA; age 18-39) are also at risk is unknown. This study characterizes neurocognitive functions and emotional distress in YA with cancer.

METHODS: Newly diagnosed YA with non-CNS cancer (YAC, n=107; lymphoma, breast, testicular, other) completed a 2h battery of standardized tests and questionnaires prior to chemotherapy for those requiring it (n=69), and 6 and 12 months later. YA with no cancer history (n=63) were tested at similar time points. Test scores were converted to T-scores based on published norms, and grouped into cognitive domains.

RESULTS: At baseline, there were no group differences in patient-reported cognitive symptoms, objective measures of performance, or number of impaired tests (Kruskal Wallis, all p-values > .4). Patient-reported cognitive symptoms did not change over time, but performance improved for all groups, regardless of whether they had cancer or received chemotherapy (random effects models, all p-values < .01). There were also no group differences in frequency of cognitive decline on individual tests (standardized regression-based change scores). YAC who required chemotherapy reported higher levels of emotional distress and a greater proportion had scores above clinical cutoffs at all three time points, compared to YAC who did not require chemotherapy or healthy YA. Although YAC who did not require chemotherapy reported elevated distress at baseline and 6 months, by 12 months their symptoms declined and were not different from healthy YA.

DISCUSSION AND CONCLUSIONS: Cognition in YAC was not different from healthy YA at diagnosis, and did not decline 6 and 12 months later regardless of treatment, consistent with research suggesting that younger brains are less vulnerable to neurotoxic insult. Whether neurocognitive effects of cancer treatment emerge later in YAC, placing them at risk for accelerated aging, remains to be examined.

Understanding the experiences of Adolescent and Young Adults (AYA) as they transition from cancer treatment to primary and community care: A pan-Canadian study of cancer survivors

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INTRODUCTION AND AIMS: As in other countries, Canada is seeing more AYA survivors living beyond their cancer diagnosis and treatment. AYAs often fall through the cracks between the siloed pediatric and adult cancer care delivery. Limited patient-reported data were available in Canada on experiences and barriers survivors face post-treatment. The Experiences of Cancer Patients in Transition study is the first national survey gathering data from cancer survivors in Canada as they transition from cancer care to the broader health care system.

METHODS: A survey was developed in consultation with patients/survivors, health care providers and researchers to address experiences related to physical, emotional and practical needs. Ethics approvals were obtained, and 10 provinces participated. Cancer survivors who completed treatment within 1-3 years were identified from provincial cancer registries. Included were those aged 30+ at diagnosis of non-metastatic breast, colorectal, prostate, melanoma or hematological cancer; or aged 15-29 at diagnosis of any non-metastatic cancer or metastatic testicular cancer.

RESULTS: From a total survey population of 40,790 cancer survivors, 329 AYAs completed the survey (3%). AYAs continued to live with side-effects post-treatment: 90% reported physical challenges; 90% reported emotional challenges; 80% reported practical challenges. The most notable concerns were anxiety about cancer returning (80%), changes in body image (66%), depression (63%), returning to work/school (65%) and hormonal, menopause or fertility changes (48%). While more than half reported it was easy to get help for most of their concerns when they asked, for some this remained a challenge.

DISCUSSIONS AND CONCLUSIONS: The results provide insight into the nature of challenges AYA cancer survivors face, as well as needed supports and barriers faced in accessing them. There is a clear need for health systems to ensure that age-related appropriate resources and supports are available to ensure a seamless journey.

The financial impact of travel costs on young people and their families

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INTRODUCTION AND AIMS: Previous CLIC Sargent research found that young cancer patients in the UK travelled around 60 miles for treatment, and travel costs were amongst the biggest financial spend and worry during treatment (A long way from home, 2010; Cancer Costs, 2016). This research sought to update the distance travelled data and explore the financial impact of those journeys on families.

METHODS: CLIC Sargent's database of children and young people was used to calculate travel distances from home postcode to main treatment centre for 6,881 young cancer patients. Costs based on fuel cost per mile were calculated. An online survey of 106 parents/carers of children and young people with cancer on travel modes, duration and cost during treatment was undertaken.

RESULTS: Young cancer patients travel around 60 miles on average for treatment. 62% made round trips of 50 miles or more. The average journey time by car, per round trip was 1 hour 34 minutes, equating to an average of £9 spend in fuel - up to £180 a month. Parent's responses to the survey were largely consistent with that data. 31% reported travelling 80 plus miles, and 54% reported a one way journey of over an hour. 56% spent more than £80 a month on treatment-related travel costs with over a quarter not accessing any form of financial assistance to meet these costs. Less than 6% families accessed the government assistance scheme.

DISCUSSION AND CONCLUSIONS: The survey results were consistent with the travel distance calculations, supporting the conclusion that families are travelling great distances at great cost. If our service users all made their treatment journey on the same day this would equal 450,442 miles and over £67,500 on petrol costs. CLIC Sargent is calling for the UK government to create a travel fund to reduce the burden.

PLENARY 4: ADDRESSING LIFE STAGE & CULTURAL COMPLEXITIES

Understanding the issues faced by taitamariki with cancer in Aotearoa

Heidi Watson

National Clinical Lead for the Adolescent / Young Adult Cancer Network Aotearoa

@NZyacancer

Na te rangatahi te ao – The world belongs to the youth
Maana apopo e whakairo – They will shape tomorrow

Every year 180-200 young New Zealanders are told they have cancer. Survival rates for NZ adolescents lag behind international comparisons by 7%. This means in the past 10 years, 49 more 15-19 year old New Zealanders died of cancer than we would expect. 34 (69%) of these deaths were Maori and Pacific youths, even though they account for less than 30% of cancer diagnoses in this age group.

The explanation for these survival disparities are likely a combination of possible factors that are not mutually exclusive. These factors may include a genetic predisposition and the presence of overarching structural and interpersonal barriers including socio-economic disadvantage and associated lifestyle factors, access to quality health care, and discrimination.

Historically New Zealand's health care system and models of care have tried to fit young Maori and Pacific people and their whanau into existing structures and services never designed to meet their needs or cultural values. This has contributed to a widening gap between Pakeha and Maori/Pacific health outcomes. However as a country NZ is committed to striving for equitable health outcomes and with this is beginning to challenge and recreate the delivery and understanding of effective care.

This presentation will incorporate the lived experiences of a group of young Māori and Pacific diagnosed with cancer and provide examples of actions highlighting the commitment made to reducing the disparities that currently exist. So while we are not there yet, we are starting to listen and act.

Nau te rourou, naku te rourou ait e iwi – With my food basket and your food basket the people will prosper

He ahate mea nui o tea ao? He tangata, he tangata, he tangata – What is the most important thing in the world? It is people, it is people, it is people."

Understanding Cancer within Indigenous Australian Adolescents and Young Adults

Kyran Dixon

CanDAD Aboriginal Youth Advisory Committee; CanDAD Aboriginal Community Reference Group
@kyrandixon

In Australia, wide disparities exist in cancer experiences and outcomes between Indigenous (Aboriginal and Torres Strait Islander peoples) and non-Indigenous peoples. The majority (over 55%) of Indigenous Australians are under 25 years old. When compared to other Australians, Indigenous Australians entering the health system for cancer treatment tend to be younger, have more advanced and more lethal types of cancers. The need to improve cancer-related health services for Indigenous Australians is evident, however that evidence alone is currently inadequate to effectively close the gap in disparities.

Kyran has lived through two diagnoses of cancer, experiencing biomedical cancer treatment and the mainstream system of care as both an adolescent and a young adult. As a young Narunga-Kaurna man, these experiences have brought his attention to the limited awareness about cancer amongst his peers and to the lack of practical and culturally-appropriate cancer-related support for many young Indigenous Australians.

As an expert by lived experience, Kyran is determined to raise awareness about cancer in his community and more widely about the cancer disparities that Indigenous peoples around the globe are facing. Kyran is an active ambassador, promoting cancer awareness, culturally-safe healthcare and research aimed at reducing these disparities. For the last two years, Kyran has worked with the NHMRC Cancer Data and Aboriginal Disparities Partnership Project (CanDAD) where he is mentored by Elders as one of two young members on the Aboriginal Community Reference Group.

Kyran is a founding member of the first Aboriginal Youth Cancer Advisory Group which aims to provide a united voice for young Indigenous people whose families have been affected by cancer in South Australia. Passionate about improving the experiences of young Indigenous people affected by cancer, the group have been working the CanDAD project to identify the needs of young Aboriginal people with experience of cancer in South Australia. Through collaborative partnerships between Indigenous peoples and cancer services, there are opportunities for coordinated and targeted efforts to improve cancer experiences and outcomes of Indigenous peoples, both in Australia and elsewhere in the world.

Adolescent and Young Adult Medicine and Oncology

A/Professor Donald Payne

Western Australian Youth Cancer Service and 2headspace, Midland, Western Australia

The discipline of oncology has played a leading role in advocating for and developing specialist services for adolescent and young adults. Alongside this there has been increasing international recognition of the need to provide specific training in Adolescent and Young Adult Medicine for all clinicians. This talk will discuss the establishment by the Royal Australasian College of Physicians of a specialist training program in Adolescent and Young Adult Medicine and highlight the benefits of this program for physicians working in the field of Adolescent and Young Adult Oncology.

Acceptance and Commitment Therapy (ACT) for people affected by cancer: what does the evidence tell us, and how can we do better?

Professor Nick Hulbert Williams

Department of Psychology, University of Chester, UK

@profnickhw

Acceptance and Commitment Therapy (ACT) is a third-wave cognitive behavioural therapy, and through an excess of over 200 randomised controlled trials has established its place as an effective psychological intervention framework. ACT encourages psychological flexibility, an ability to sit with distress and suffering in the pursuit of mindful and values-driven living. My colleagues and I have for some time argued the conceptual importance of this framework to cancer adjustment (see Hulbert-Williams et al, 2015). In undertaking a review of the intervention literature earlier this year (Hulbert-Williams et al, 2018), however, we concluded that empirical evidence for the effectiveness of ACT in cancer settings is still lacking, despite anecdotal reports of increasing usage in clinical settings. More data is needed, and this must come from rigorous and well-designed research.

In this plenary talk I will provide an overview of the evidence to date, and I will summarise some of the empirical work being undertaken in our lab. This work spans a range of methodological designs, all at the preclinical (or Phase I) trial stage to ensure that the interventions that we develop will be both acceptable to cancer patients and effective. Experimental testing of the psychotherapeutic components used within ACT interventions, theoretical modelling of ACT processes through cohort observational studies, and intervention development work using single-case methodology, are just some of the ways in which we can build a stronger evidence base, and make a real difference to the lived experience of people affected by cancer.

Oral Abstracts: Day 3

PLENARY 5 - FINANCIAL TOXICITY, FERTILITY & FAMILY

“The economic cost of cancer in adolescents and young adults.”

Ms Lynne Pezzullo & Ms Kathryn Woodward

Lynne: Deloitte Access Economics

Kathryn: QLD Youth Cancer Services Youth Advisory Group, a Youth Ambassador and Director on CanTeen's Board

@lynnepezzullo

BACKGROUND: Annually, approximately 1100 Australian adolescents and young adults (AYAs; 15-25 years) are diagnosed with cancer with substantial economic costs for individuals, their families and society. Costs may be financial (comprising health system costs and productivity losses, carer costs and transfers), or non-financial (the burden of disease). While many costs are incurred during active treatment, the economic impact of cancer resounds throughout an AYAs' lifetime.

METHODS: A health economics report was prepared using cost-of-illness methods and drawing on a variety of data sources, to estimate the lifetime costs for Australian AYAs diagnosed with cancer in 2016. Detailed financial and burden of disease costs were provided separately for the 10 most common AYA cancers in Australia (melanoma, acute myeloid leukaemia, acute lymphoblastic leukaemia, non-Hodgkin lymphoma, Hodgkin lymphoma, brain cancer, bone cancer, soft tissue cancer, testicular cancer, thyroid cancer) plus a final category of 'all other cancers'.

RESULTS: Lifetime costs for the 2016 cohort were estimated to be \$1.4 billion, or \$1.3 million per person. Of the total costs, the burden of disease constituted 48.6% (\$701.4 million), productivity costs of AYAs 31.6% (\$508.4 million), health system costs – including for fertility treatment – 10.1% (\$146.5 million), informal carer costs 3.7% (\$52.7 million) and deadweight losses from taxation revenue forgone and other government transfers 6.0% (\$87.0 million). Individual AYAs bear over 70% of the cost of cancer, with Federal Government bearing 17%, state/territory governments 3%, family/friends 2% and others in society bearing the remaining 8% of costs.

CONCLUSIONS: AYAs carry a large proportion of the economic cost of cancer and this continues throughout their lifetime. Understanding the total costs of cancer for AYAs and how these costs continue during survivorship, assists in informing service development and providing evidence for policy changes to reduce this substantial burden.

Fertility outcomes in adolescent and young adult cancer survivors

Dr Antoinette Anazodo

Lead Clinician, NSW/ACT Youth Cancer Service, Sydney Children's Hospital and Prince of Wales Hospital; Conjoint Lecturer, School for Women's and Children's Health, University of New South Wales, Australia (for complete list of affiliations please see the full program in the app)

@ANZoncofert

AIMS: To systematically review the literature on the components of oncofertility care as defined by patient and clinician representatives, and identify the barriers, facilitators and challenges so as to improve the implementation of oncofertility services.

METHODS: A systematic scoping review was conducted on oncofertility models of care (MOC) literature published in English between 2007-2017, relating to ten domains of care identified through consumer research (communication, oncofertility decision aids, age appropriate care, referral pathways, documentation, training, supportive care during treatment, reproductive care after cancer treatment, psychosocial support and ethical practice of oncofertility care). A wide range of electronic databases were searched. Preferred reporting items for systematic reviews and meta-analyses and the international prospective register of systematic reviews was followed.

RESULTS: A total of 842 potentially relevant studies were identified and screened and the final 147 papers were reviewed with data extraction. The results identified a number of themes for improving MOC in each domain, including the importance of patients receiving communication of a higher quality and in different formats on their fertility risk and FP options; improving provision of oncofertility care in a timely manner; improving access to age appropriate care; defining the role and scope of practice of all health care professionals (HCPs) and improving communication between different HCPs. Different forms of decision aid were found useful to assist patients to understand FP options and weigh up choices.

CONCLUSIONS: This analysis identifies core components for delivery of oncofertility MOC. The provision of services requires planning to ensure services have reliable referral pathways that are age appropriate and include care into survivorship. In order for this to happen, collaboration needs to occur between clinicians, allied HCPs and executives across both public and private services. Training and knowledge of both cancer and non-cancer HCPs is needed to improve the quality of care.

The impact of cancer on adolescent and young adult survivors' job seeking and continuation of work: needs for comprehensive support

Dr Miyako Takahashi

Division Chief, Division of Cancer Survivorship Research; Center for Cancer Control and Information Services; National Cancer Center Japan

Work is an essential component in the quality of life of cancer survivors, including those of the adolescent and young adult (AYA) generation. The impact of cancer on work may vary based on the survivor's age at which the cancer is diagnosed. A cancer diagnosis while attending school may disrupt schoolwork and alter the student's readiness for employment and for choosing an occupation. It also impacts first-time job seeking. Even when young adult survivors hold a job, their cancer diagnosis may affect continuation of work and further career development. Work is also an area in which healthcare providers cannot act as 'specialists.' Support for AYA survivors who want to work, or want to continue to work, should be comprehensive and multi-level; various stakeholders—such as family, school, workplace, and governmental administration—should work in co-operation, and healthcare providers need to act in co-operation with these stakeholders. This presentation introduces precedent research conducted in various countries, including Japan, in reviewing the impact of having cancer on AYA survivors' work-related issues, especially first-time job seeking and continuation of work. It discusses the difficulties AYA survivors encounter, as well as correlative factors of difficulties and their support needs. The presentation also introduces care practices in Japan for addressing AYA cancer survivors' work-related unmet needs.

Recent Developments in Supporting Siblings of Young Cancer Patients and Conceptualizing their Experience

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The sibling relationship is unique, leaving an indelible mark on who we are, and it is generally understood that our siblings are with us for the whole life journey. So being a young person finding out that their brother or sister has cancer is a substantial life event; typically marked with distress, disruption, and uncertainty. The psychosocial needs of these siblings are easily overlooked as the focus of medical and familial attention becomes concentrated on the patient.

This presentation will discuss psychosocial outcomes for siblings; the development and implementation of psychosocial risk and unmet needs screening, and support services for siblings; the importance of integrating community and hospital-based services, improving referral pathways and facilitating the provision of targeted care; and broader health system, advocacy and policy considerations. Attention to the experience of siblings of young cancer patients is a critical component of family-based cancer care.

RAPID FIRE 3.1

Understanding experiences of care through the Australian Youth Cancer Services: patient and family members' perspectives

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INTRODUCTION AND AIMS: Around 1,000 adolescents and young adults (AYAs) are diagnosed with cancer each year in Australia. The Australian Youth Cancer Service (YCS) provides patients with specialist age-appropriate care by multidisciplinary teams in youth-friendly environments. The national Experience of Care (EoC) survey aims to explore AYAs' and their family member's perceptions of the YCS across the treatment pathway to understand the strengths of the YCS and identify areas for service improvement.

METHODS: AYAs who received treatment in a YCS and their nominated family member were invited to complete the survey at the end of active treatment. The survey traces the patient journey from cancer diagnosis to the completion of treatment. To date, 63 young people and 36 family members from the 5 lead YCS sites across Australia have completed the survey.

RESULTS: Nearly all AYAs were satisfied with the treatment provided by healthcare professionals during surgery, radiotherapy or chemotherapy (94%), with how much they were involved in treatment decisions (93%), and felt they were treated age-appropriately (87%). Most AYAs reported being informed about the impacts of treatment on fertility (84%). Whilst 95% AYAs reported being given enough information about the YCS, around a third wanted information sooner (37%). Ninety-two percent of family members were satisfied with the treatment provided by healthcare professionals. Although at the time of diagnosis, most family members felt they were given enough information about the young person's cancer (92%), only half received emotional support or were told where to go for support (54%).

DISCUSSIONS AND CONCLUSIONS: Findings highlight the importance of continuing to integrate this evaluation of the YCS across Australia and emphasize the value of age-appropriate care from specialist teams for AYA patients. Areas for improvement, such as family care and earlier referral to the YCS, are noted.

Financial toxicity of AYA cancer patients by age at diagnosis

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INTRODUCTION AND AIMS: A cancer diagnosis for AYAs can set back career and educational attainment, which could affect their financial stability during and after treatment. However, few studies have examined financial toxicity among AYAs with cancer or discussed differences across the age range. We evaluated AYAs' report of financial toxicity using the Comprehensive Score for financial Toxicity (COST) measure and additional indicators of financial burden by age at diagnosis.

METHODS: Eligible participants were diagnosed with cancer between ages 15-39 and had met with an AYA patient navigator. Participants completed a 240-item survey. We calculated differences in financial burden by age at diagnosis (15-25 years vs. 26-39 years) using Fisher's exact tests. COST scores were summarized, with lower scores indicating greater financial burden, and the overall means were compared by age using a t-test.

RESULTS: Of 51 participants, N=25 (49%) were ages 15-25 and N=26 (51%) were 26-39. Household income did not differ by age. Most patients ages 15-25 had health insurance through their parents (83.3%), whereas patients ages 26-39 tended to be their own policyholders (69.2%). Overall, more AYAs ages 26-39 felt their financial situation had been negatively impacted by cancer than younger AYAs (76.9% vs. 37.5%, $p=0.009$). Older AYAs reported greater cost worries related to prescriptions (26.9% vs. 8.0%, $p=0.14$) and appointments (34.6% vs. 12.0%, $p=0.10$) compared to the 15-25 age group. Mean COST scores were lower among those ages 26-39, indicating greater financial toxicity (1.7 vs. 2.3, $p=0.02$).

DISCUSSION AND CONCLUSIONS: The financial burden of cancer may be greater for older AYAs. In the United States, many young adults lose their parents' health insurance at age 26, which could place them at additional financial risk. Our findings reveal an acute need for directed financial interventions (e.g., patient navigation) to address the diverse financial needs of AYAs.

AYA Neuro-Oncology Patients Need Long-term Interventional Career Mentoring and Motivation to Achieve Success

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Across the spectrum, pediatric cancer survivors have increased unemployment rates and lower educational attainment rates. In no population is the difference between healthy controls as significant as in brain tumor survivors, who show five-fold relative odds increase in unemployment over other pediatric cancer survivors. The long-term effects of brain tumor treatment potentiate the difficulty with work and school reintegration seen in the broader Adolescent and Young Adult (AYA) population. To address this, our team designed a job fair for AYA Neuro-Oncology survivors. Vendors were invited representing disability advocacy groups, college legal teams and services, scholarship organizations, and employers with strong disability services, several who offered onsite interviews. Additionally, three brain tumor survivors shared their story as motivational speakers. All off-therapy patients were personally invited during their clinic visit or via personal phone call. Thirty-nine patients attended the event, representing a diverse mix of cognitive disability. Pre- and post-surveys, as well as 3- and 6- month follow up was obtained. Universally, the day was engaging and motivating, both for survivors and staff, and stimulated conversation for pursuing career or academic success within families and the care team. While all the patients took applications, none of the patients completed the on-site interviews, finding them overwhelming. Even at the 3- and 6-month follow-ups, the survivors continued to be at varying levels of application completion; no one who was previously unemployed attained new employment. The high-functioning survivors found benefit in conversations with the college support services. In conclusion, the career fair provided ample motivation and resources for our AYA brain tumor survivors and would benefit the larger AYA population, regardless of disability. However, for patients with cognitive disability, the day alone is not sufficient to gain momentum in attaining employment or school success, but rather, they require frequent, interventional long-term follow-up and guidance.

Understanding Young Adult Cancer Survivors' Experiences Returning to Work after Primary Treatment: A longitudinal Qualitative Study

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INTRODUCTION AND AIMS: Young adults (YA; 18-39 years of age) who survive cancer or are living with metastatic/advanced illness often return to work (RTW) after their primary treatment. YA are early in their life course and supporting them to live well and contribute back to society has economic and social benefits to both the person and their community. However, many survivors report difficulties in their RTW process. This study aimed to explore YA cancer survivors' perspectives on and experiences with RTW following primary cancer treatment.

METHODS: A prospective qualitative longitudinal study using in-depth telephone interviews (three interviews/survivor) to gain a rich understanding of their experiences was employed. Data were analyzed using thematic analysis. Five people (ages 25-40 at the time of their first interview) who were diagnosed with cancer in young adulthood participated in the study. All but one participant completed all three interviews at: post-primary treatment; 3 months post-first interview; and 6 months post-second interview.

RESULTS: Preliminary results indicate that (1) YAs may feel uncertain about returning to work as they are often in new jobs or precarious employment at the time of diagnosis. For some, (2) cancer was a catalyst to push them to consider or change their careers to find one more meaningful. (3) Work benefits can play an important role in these decisions, as having a pre-existing condition may make the YA feel forced to stay. Additionally, (4) YA-specific resources are needed to create a sense of community and access information around the unique challenges YA face with RTW.

DISCUSSION AND CONCLUSIONS: Preliminary findings indicate those earlier in their career and life course can see a cancer diagnosis as an opportunity to change their lives and do what they deem as more meaningful work. YA-specific resources can help to support them through their transition of RTW.

The financial impact of relapse on young people with cancer and their families

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INTRODUCTION AND AIMS: There is a lack of data on the extent of and impact of relapse of children and young people with cancer in the UK. CLIC Sargent's Cancer Costs (2016) and Hidden Costs (2017) research identified a significant financial and emotional impact of cancer on young cancer patients and their families. Building on this, within the context of the emotional impact of relapse, CLIC Sargent sought to explore the extent of relapse within their service users and the financial impact specific to relapse.

METHODS: A literature search was conducted. An online survey with CLIC Sargent Social Workers looked at frequency of relapse and secondary cancer cases. A 'snapshot' technique was used to count case load numbers for a particular week. Semi-structured interviews were conducted with young people, parents, and social workers to explore financial issues and impact specific to the experience of relapse.

RESULTS: Social Workers reported an average number of three cases of relapse in the week counted (n=91). This was around 25% of their case load. Key themes from the interviews included; ongoing financial burden from initial cancer diagnosis; the emotional impact of relapse adding to the financial stresses; and difficulty navigating the financial support available due change in circumstances since original diagnosis.

DISCUSSION AND CONCLUSIONS: 25% of Social Workers' case load was supporting young people who had experienced a relapse or secondary cancer. The interviews highlighted the unique impact of dealing with financial costs associated with treatment, having been through this financial strain before, leaving this group more vulnerable to financial pressure. The emotional impact of a relapse adds to the difficulty coping with the financial impact. There is a need for relapse specific services to support the unique emotional and financial needs of this group and CLIC Sargent will be taking action to address this.

EDMed - online professional development for teachers supporting students with serious illness

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Since 1998 RMHC Australia has provided educational support to students with serious health conditions through the Ronald McDonald Learning Program (RMLP). The RMLP provides academic and psychometric assessment along with speech and/or occupational therapy and individual tuition with a qualified teacher to assist students with catching up on missed education due to their illness. Currently, over 1,200 students are supported each week. Working closely with mainstream schools it was identified that many teachers lacked knowledge on how to support students returning back to the classroom. Furthermore, many teachers did not know the late effects of treatment and the impact on students' learning. To meet this identified need RMHC created ED-Med® Professional Development for Teachers to inform teachers about how to support students with serious illness. EDMed is endorsed by the NSW Education Standards Authority (NESA). RMHC Australia has recently created an online, self-paced learning module of EDMed to cater for Australia's geographical diversity and reach more teachers. This talk will take delegates through an interactive session on the various components of the EDMed online module. While the course is designed for teachers, the information it contains is useful for anyone wanting to know how to meet the learning needs of students with serious illness. EDMed is Australia's leading accredited professional development supporting teachers working with students with a chronic illness and has been delivered to over 24 000 professionals across Australia. EDMed empowers teachers with strategies to improve the educational outcomes of students with cancer, as well as other chronic health conditions.

RAPID FIRE 3.2

Understanding the relationship between social competence and bullying in AYA cancer survivors

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INTRODUCTION AND AIMS: The prevalence and determinants of bullying in school among adolescent and young adult (AYA) cancer survivors remains an understudied area. Therefore, this study aimed to determine (i) the prevalence of experience of bullying in school and (ii) the relationship between social competency and bullying in this group.

METHODS: This cross-sectional, prospective study involved AYA survivors from the long-term survivorship clinic at Sydney Children's Hospital. Participants completed validated questionnaires assessing (i) social competence (13-17 year olds: Social Skills Inventory System (SSIS), 18-25 year olds: Interpersonal Competence Questionnaire (ICQ)) and (ii) bullying (bullied in school yes/no). Demographics and clinical information were also collected.

RESULTS: To date, 28 AYA survivors have participated (mean age 17.75years, range 13–23years, 67% male; mean time since diagnosis 7.77years). For survivors 13-17 years old ($n=13$) 31% experienced bullying in school. Experiencing bullying at school was correlated with worse overall social competency on the SSIS ($r=-.672$, $p=.012$) and worse competency across the domains (SSIS subscales): Communication ($r=-.563$, $p=.045$), Cooperation ($r=-.595$, $p=.032$), Empathy ($r=-.613$, $p=.026$), and Self-Control ($r=-.624$, $p=.023$). For survivors 18-25 years old ($n=15$), 13% reported having been bullied in school. Experiencing bullying in school was correlated with decreased competence on several ICQ subscales: Initiation (initiating social conversations/activities) ($r=.736$, $p=.002$), Disclosures (disclosing personal information) ($r=.615$, $p=.015$), and Emotional Support (providing emotional support to others) ($r=.574$, $p=.025$). Experience of bullying was not related to demographic (e.g. age, gender) or clinical factors (e.g. time since diagnosis) in either group.

DISCUSSION AND CONCLUSIONS: These results indicate that a subset of AYA cancer survivors experience bullying, and that poor social competency may put AYA survivors at risk of being bullied. Competency in communication with others appears to be a key modifiable factor associated with the experience of bullying for both younger and older AYAs.

Message Strategies and Channels to Recruit Young Adult Cancer Survivors to Research

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INTRODUCTION AND AIMS: Young adult cancer survivors (YAs) have unique physical activity needs from both pediatric and aging populations, yet few YA-specific behavioral interventions exist. This disparity can be partially attributed to the fact that little is known about how to effectively recruit YAs to intervention research. This study aims to identify message strategies and communication channels associated with YA enrollment in a study of a mobile physical activity intervention.

METHODS: Four messages were designed to recruit YAs to the IMPACT study, a 12-month, NIH-funded randomized controlled trial of a YA physical activity intervention. Messages differed based on motivational frame (extrinsic vs. intrinsic) and additional phrasing nuances. Participants (n=10) in a 6-week pilot of the intervention were asked to react to and compare these messages. After refining messages based on the pilot participants' feedback, four new messages have been developed for the parent trial recruitment, which will start in July 2018. Additional recruitment data in the parent trial will be collected through Google, Facebook analytics, and RED Cap Survey software to assess the associations between motivational framing and communication channel and subsequent YA enrollment.

RESULTS: Pilot participants (n = 10) were 21-37 years old, 90% female, and 90% non-Hispanic White. Among those who provided feedback on message strategies (n = 9) most participants preferred messages rooted in extrinsic motivations, such as helping other cancer survivors, to messages rooted in intrinsic motivations. Additional results will quantitatively assess the relationship between motivational framing (intrinsic vs. extrinsic) and message channel (social media vs. direct mailing), and YA enrollment in the parent study.

DISCUSSION AND CONCLUSIONS: The results of this study could help investigators improve recruitment of YAs, a currently hardly-reached population, to future behavioral intervention research by identifying messages and channels that successfully reach this population.

Using a Clinical Repository to Focus Understanding of a Local Population

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INTRODUCTION/AIMS: The Paediatric Integrated Cancer Service (PICS) Long Term Follow-up Program (LTFP) provides a clinical service to Children and Young Adult cancer survivors in Victoria. The PICS LTFP Adolescent and Young Adult (AYA) cohort (aged 15-24 years old) represent 38% of the programs' population. The aim of this study is to use the PICS Childhood Cancer Survivorship Repository (PICS CCSR) to quantify data pertaining to AYA populations to appraise practice and improve the current model of care.

METHODS: Consented patients' clinical data from the PICS CCSR was extracted (n=274). Quantifiable data sets pertaining to "Distorted eating" and "BMI" were extracted as an area of focus. Primary diagnostic groups were isolated and assessed.

RESULTS: The records of consented patients were extracted, 32.3% of the LTFP AYA patients' BMI were reported to be outside the "healthy" weight range with 17% having documented concerns regarding "Distorted eating". 52% of the consented PICS LTF AYA population are Leukaemia patients (n=137,) with a ratio 60:40 Male to Female. Data shows that 37% of these are outside the healthy range, with 61.9% representing those with "Distorted eating".

DISCUSSION AND CONCLUSIONS: The analysis from the records extracted from the PICS CCSR demonstrates that abnormal BMI is prevalent in AYAs with a portion of these patients experiencing "Distorted eating". The AYA population represents the largest cohort of the LTFP. Targeted clinics established for AYAs may result in improvements in patient health status through focusing on their specific needs. The consideration of early intervention in acute or surveillance stages may be more beneficial, by identifying risks early. This recommendation needs to be explored in the future.

DRUMBEAT Group drumming program with Adolescent and Young Adult Cancer Survivors

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INTRODUCTION AND AIMS: AYAs with cancer can experience isolation from peer relationships both during and following cancer treatment. Group psychosocial interventions provide a forum for contact with peers who have also had a cancer diagnosis. The WA Youth Cancer Service (WAYCS) conducted a pilot study of the Holyoake DRUMBEAT program with AYA cancer survivors. DRUMBEAT (Discovering Relationships Using Music, Beliefs, Emotions, Attitudes, and Thoughts) is an evidence-based therapeutic group drumming program originally developed in 2003. It is delivered over 10 weekly sessions and combines learning to drum, therapeutic discussion of topics such as relationships, emotions, self-esteem and identity, and a final public drumming performance. DRUMBEAT has had beneficial results with other AYA populations in schools, hospitals, youth services, detention centres, and prisons. This study aimed to assess the feasibility and acceptability of DRUMBEAT with AYA cancer survivors.

METHODS: Patients were invited to participate if they were aged 15-25 at time of diagnosis, had been referred to the WAYCS, and had completed primary treatment for cancer within the previous two years. 121 young people were contacted and seven enrolled in the group. A qualitative methodology was employed using a focus group and semi-structured interviews. Wellbeing and symptom prevalence data were collected using validated assessment tools.

RESULTS: Participants identified that the intervention met psychosocial needs such as connecting with others with similar experiences, feeling understood, and processing emotions arising from treatment. Participants reported a positive effect on mental and emotional wellbeing.

DISCUSSION AND CONCLUSIONS: DRUMBEAT shows promise as a feasible and acceptable group intervention for AYAs who have completed cancer treatment. Another group, which also includes on-treatment participants, is currently being implemented and results for both groups will be presented. The program could be replicated at other sites that work with AYA cancer patients, both in Australia and overseas.

Pulling together the strings: the role of the Long Term Follow Up [LTFU] Clinical Nurse Specialist [CNS] in TYA Oncology

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Age 11: Acute lymphoblastic leukaemia: Bone marrow transplant [BMT] Age 14: Premature ovarian insufficiency [POI]. Commenced oestrogen replacement. Patient informed fertility compromised. Age 21: Specialist fertility LTFU clinic. Fertility potential established. Patient not ready for a baby. Age 23: LTFU CNS appointment. Health Needs Assessment [HNA] revealed 3 years painful sex [no physical cause, regular menstruation], 8 months sexual avoidance, relationship concerns, unaware of early menopause risk, wanted children in future. CNS provided education regarding use of oestradiol pessaries and encouraged patient to involve partner. 2nd appointment: Education of couple. Patient using pessaries, but couple unable to initiate sex. Urgent referral for psychosexual counselling. Age 24: Pregnant! Discussion BMT places women at high risk of POI. Patient had a low Antral follicle count/anti-Müllerian level and rising follicle stimulating hormone indicating limited window for fertility. Sexual difficulties are common post-transplant [Bevans et al 2017]. Deep dyspareunia commonly caused by low oestrogen /vaginal atrophy. Psychosexual counsellor input can be helpful (vaginal health strategies, sexual positions and adequate arousal) . Sexuality is central to young adulthood development [Finch et al 2016]. Despite contact with numerous health care professionals [HCP's] over several years, sexual intimacy had not been addressed appropriately. Significance of sexual abstinence not recognised by couple or HCP's in context of premature ovarian failure and desire for pregnancy. Multiple communication and organisational barriers emanating from the patient, parents, health care professionals and service often result in sexual health care omissions in this age group. CNS well placed to act as patient advocate, provide continuity of care, time and privacy to address these issues and ensure patient and clinical priorities are addressed in a timely fashion. Learning 1. TYA HCP's need awareness/courage to tackle sexual and reproductive health consequences. HNA's useful. 2. LTFU CNS key to pulling together complex issues and providing age appropriate LTFU support- here with a successful outcome

The support needs of young people at the end of active cancer treatment

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PURPOSE: The end of treatment is known to be a period of high stress in young people's cancer timeline but little is known about young people's information and support needs during this phase. This study aimed to understand the needs of young people, how these needs are currently being met, and how best to provide information and support at the end of treatment.

METHODS: This was a multi-stage, mixed methods study exploring the end of treatment experience from the perspectives of young people and healthcare professionals caring for them. Methods included: rapid review of the literature; semi-structured telephone interviews and questionnaire with professionals; semi-structured interviews and focus groups with young people; stakeholder co-creation workshop to inform the development of a support intervention.

RESULTS: At the end of cancer treatment young people experience numerous ongoing physical issues including pain, fatigue and insomnia; in addition to a range of psychosocial and emotional issues including anxiety, fear of recurrence and isolation. Various sources of information and support for young people currently exist: hospital, community services, family, friends, peers with cancer, school, and online platforms. However difficulties in availability, access and equity of information and support were highlighted. The effectiveness of information provision at the end of treatment was questioned; the time given and level of knowledge of professionals was variable. Hospital and community-based support services available to guide re-integration into life after treatment were frequently lacking or not age-appropriate.

DISCUSSION AND CONCLUSION: Young people are under prepared for the unpredictable and ongoing nature of both the physical and psychosocial issues they face at the end of their cancer treatment. Young people need timely, structured and equitable information and support provision at the end of treatment to prepare them for both the physical and psychosocial issues that they may face.

CONCURRENT STREAM 5.1 – SURVIVORSHIP PROGRAMMING

New cancer follow-up services for AYA: Implementation and Evaluation

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INTRODUCTION AND AIMS: New models of follow-up cancer care are paramount given the increase in young people living beyond cancer. Clinical trials demonstrate patient-reported outcomes can improve cancer outcomes including symptoms, satisfaction and efficiency, compared to standard clinical follow-up. However their implementation brings individual and system challenges. AYA have specific perspectives upon the online world making them a highly suitable group to evaluate. This study implemented and evaluated 'Shared Community Follow-up (CF)', a new model of care within a regional germ cell practice over a large rural and urban population of AYA after treatment for germ cell tumours.

METHODS: Evidence-based elements of CF include: clinical risk-stratified follow-up pathways, secure online patient-reported outcomes monitoring (PROMs), with radiology and blood testing requested by the cancer centre and provided at any competent provider chosen as local by the patient. Clinical responsibility is retained by the regional AYA service and cancer centre. Patients chose between CF and standard hospital follow-up. We evaluated under informed consent using validated self-report instruments and NHS data; feasibility (safety, uptake, uncompleted or delayed episodes) and patient acceptability (information needs, symptom self-management, satisfaction, perceived personal costs).

RESULTS: In a sample of 50 from over 200 CF patients, CF is feasible - uptake increased after implementation by >50%. CF replaced 1 in 4 hospital appointments. CF is as clinically safe as hospital follow-up in detecting relapses and reduces the number of delayed or missed assessments. The service is acceptable - patients are equally satisfied in both services. Patients save considerable costs and minimise loss of earnings.

DISCUSSION AND CONCLUSIONS: Shared Community Follow-up is feasible, safe, and has significant advantages over traditional follow-up for AYA living after cancer. Its evidence-based elements might be implemented, in an adapted manner, or tested prospectively in other services and locations.

The psychosocial interactions of Adolescent and Young Adult (AYA) cancer survivors and the possible relationship with their development

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INTRODUCTION AND AIMS: Adolescents and Young Adults (AYA; 16-25 years) can be particularly vulnerable to the cancer experience as they are also encountering developmental tasks such as identity formation. These tasks largely occur through social interactions, which can be hugely affected by cancer-related experiences. The present study aimed to explore interactions relevant to AYA survivors and cancer, and investigate whether certain interac-

tions are experienced as more and less helpful. Because of the importance of developmental tasks the impact on social interactions is also considered.

METHODS: Ten semi-structured interviews with AYAs were conducted, with questions pertaining to their psychosocial interactions and any developmental effects from having cancer. Five follow-up interviews were conducted approximately twelve months later. In addition, a comprehensive model of interactions relevant to AYA survivors and cancer was formed using multidimensional scaling.

RESULTS: Thematic analysis identified a range of themes including: the importance of personal privacy and controlled sharing of information; independence; identity formation; positivity; acknowledgement of cancer vs. being treated normally; and receiving support instead of supporting others. In the one year follow-up interviews, half of these themes remained; however the personal privacy, independence and supporting others themes changed. These results are discussed in relation to the model of interactions developed for AYAs.

DISCUSSION AND CONCLUSIONS: Overall, social support, social interactions and developmental stage appear to influence the overall cancer experience. Development appears to be impacted by cancer for both adolescents and young adults, but this impact changed over a one-year period. A more comprehensive understanding of AYA survivors' psychosocial experiences related to cancer will enable those who interact with this group to provide more positive support for AYAs. Empowering AYAs to communicate their own needs to others may also be key to ensuring these needs are met.

Designing Conceptual Frameworks for Financial Burden, Body Image, and Fertility and Parenthood within Adolescent and Young Adult Cancer Survivors

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INTRODUCTION: Adolescents and young adults (AYAs) with cancer experience significant distress and unique life changes that impact their health-related quality of life (HRQOL). Existing HRQOL questionnaires are often lacking in content not specific to AYAs' needs. Notably, financial burden (FB), body image (BI), and fertility and parenthood (FP) are rarely assessed. This formative research study designed conceptual frameworks for the domains of FB, BI, and FP, within the context of AYA oncology.

METHODS: Leveraging the measurement science methods of the Patient-Reported Outcomes Measurement Information System (PROMIS) initiative, we conducted literature reviews and in-depth interviews. Multidisciplinary working groups reviewed the empirical literature to draft domain frameworks for key concepts to include in a questionnaire. Concept elicitation interviews with AYA patients (n=14), providers (n=18), and content experts (n=18) confirmed and expanded on concepts within each domain.

RESULTS: Several concepts emerged from the interviews. FB includes medical and non-medical financial concerns, which affect patients' ability to continue treatment, continue current quality of life activities, and prepare for the future; as well as behavioral and psychological responses to material conditions such as avoidance and emotional and functional adaptation. BI includes assessments about changes to the body's appearance and functionality, perceptions of others, sexuality, and revealing body changes. FP includes uncertainty about ability to have children, regretting fertility preservation decisions, fears about the health of future children, difficulty talking with providers about fertility, fears about relationships, and coping with potential infertility.

DISCUSSION: Each stakeholder group provided complementary information on the breadth and relevance of concepts included in the measurement framework for each of the domains. Following the PROMIS approach, this framework will inform the design of content valid measures of FB, BI, and FP. These measures will subsequently be evaluated alongside other HRQOL measures to better understand AYAs' experiences and improve patient-centered care and outcomes.

Is it time to play? An examination of the sport and supportive care needs and preferences of testicular cancer survivors

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INTRODUCTION: Testicular cancer (TC) is the most prevalent male cancer diagnosed in young men (aged 15-39 years). High survival rates have resulted in a growing population of survivors in need of supportive care, however, engagement from men in both research and survivorship initiatives has been historically low. This may be due to a lack of age appropriate, gender-sensitive, and targeted programs. In at-risk populations, sport has been successfully leveraged as a gender-sensitive platform for providing targeted men's health initiatives. Currently, there are no known sport initiatives for young male cancer survivors. This study examined TC survivors' specific needs, interests, and delivery preferences for targeted supportive care programming embedded within sport programming.

METHODS: Young men diagnosed with TC between the ages of 15 and 39 completed a self-report questionnaire during routine oncology visits.

RESULTS: TC survivors (N = 70, Mage = 32.38, SD = 7.85 years) reported distress in three or more survivorship areas that could be targeted in supportive care: fear or recurrence or future illness (72%), managing treatment related side effects (49%), and engaging in physical activity (34%). Many men (64%) reported a desire to increase physical activity, and a specific interest in engaging in a sport-based supportive care program was highly endorsed (70%). Men reported wanting a program that is age specific (68%), includes a strength training component (76%), delivered in a group setting (67%), and in a community location outside of the hospital (66%). Although 55% reported speaking to their medical team about physical activity, only 8% received a referral to an existing oncology physical activity program.

CONCLUSION: Based on these preliminary data, a sport-based supportive care program targeting these interests may address the survivorship needs of young men with TC.

“Looking for support and to meet people like me”: Exploring the sense of community, peer support and loneliness of AYAs impacted by cancer using an online support service

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INTRODUCTION AND AIMS: Online peer forums are visited by individuals who wish to provide or receive information, emotional support and/or manage distress. Some may also join out of curiosity. Adolescents and young adults (AYA) impacted by cancer often experience high levels of psychological distress and the strong need for support and understanding from peers. In response, CanTeen developed an online e-health platform offering peer support forums, information and counselling. This mixed methods study explores the characteristics of AYAs using this service, why they use the service and the perceived benefits of the service.

METHODS: A cross-sectional survey was undertaken with 152 AYAs impacted by cancer who had registered on the platform. The survey included questions on service usability, and the cancer peer support scale, loneliness and aloneness scale for adolescents, and sense of community index. Semi-structured interviews were conducted with 20 young service users.

RESULTS: The most common (54.5%) reason for joining was to hear about other AYAs' cancer experiences. One-third of AYAs had used the online counselling, and two-thirds of AYAs had accessed CanTeen's face to face services. Over 70% had not used other online support (outside of the platform) for their cancer experience. Those who experienced a strong sense of community in the online service reported stronger supportive relationships (<.05) and less loneliness (<.05). Around a third of young people reported that since joining the community, their relationships with parents and friends had mostly or somewhat improved. These results highly converged with the young people's interviews.

DISCUSSIONS AND CONCLUSIONS: The service has a positive impact on AYA's relationships with peers and families. Promoting a strong sense of community online can facilitate peer relationships and reduce loneliness in this group. Future research will explore how the type/level of service usage impacts young people's psychosocial wellbeing.

Sustained improvements in self-esteem, emotional functioning, social functioning and body image one year after attending the residential weekend 'Find Your Sense of Tumour'

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INTRODUCTION AND AIMS: Find Your Sense of Tumour' (FYSOT) are two, 2-day residential programmes with educational presentations, motivational speakers, workshops and social events for young people aged 13-17 years and 18-24 years with cancer. Positive experiences are reported but have never been systematically investigated. We aimed to examine the psychosocial benefits to young people attending FYSOT and if these were sustained over time.

METHODS: A project-specific outcome measure was developed based on Part 1 of the evaluation¹, which included measures of self-esteem, emotional functioning, social functioning and body image. Young people participated in a longitudinal study completing questionnaires at five time points over 12 months: T0 prior to attending FYSOT; T1 immediately after; T2 at 3 months; T3 at six months and T4 at 12 months. Data were analysed using longitudinal linear regression for the differences across time. Survey distribution and analysis was conducted independently by Quality Health.

RESULTS: A total of 157 young people participated (13-17 years, n=54; 18-24 years, n=103). Both groups demonstrated significant improvements in self-esteem ($p<0.001$); emotional functioning ($p<0.001$); social functioning ($p<0.001$) and body image ($p<0.001$) at T1. However, significant improvements were not sustained for the younger age group. In contrast, the older group exhibited significant improvements in self-esteem ($p=0.004$), emotional functioning ($p=0.003$) and body image ($p<0.001$) one year after attending FYSOT, improvements in social functioning were also observed at one year but did not reach significance ($p=0.063$).

CONCLUSIONS: We have shown sustainable improvements in self-esteem, emotional functioning, body image and social functioning for young people aged 18-24 years after attending an educational, social and peer-to-peer support residential weekend. Attending FYSOT may now be considered as part of a recovery package to support integration back to as healthy life as possible. Further work is ongoing to understand the sustainability of effects for the younger age group. 1. <http://bmjopen.bmj.com/content/7/7/e015309.full?ijkey=zfIKPdPu4uoWMVZ&keytype=ref>

CONCURRENT STREAM 5.2 – END-OF-LIFE CARE

How to talk about death when life is just beginning: Evaluating an advance-care planning tool for adolescents and young adults with cancer

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INTRODUCTION/AIMS: Access to age-appropriate, timely, end-of-life (EoL) communication has been established as an international standard of care for adolescents and young adults (AYAs) with cancer. Evidence indicates that current clinical practice falls short of this standard. This multi-perspective study aimed to examine the acceptability and feasibility of an American advance-care planning tool for AYAs ('Voicing My CHOICESTM; VMC) in the Australian context.

METHODS: Semi-structured interviews with healthcare professionals, AYA cancer survivors (aged 15-25), and parents focused on: (i) acceptability of VMC, (ii) perceived barriers and facilitators to EoL communication, and (iii) preferences for improving current practice, including implementing VMC locally.

RESULTS: We interviewed 39 participants (n=28 professionals; n=6 AYAs; n=5 parents). Professionals represented various disciplines and experience (mean years practising=17, range=4-30). On average, AYAs were aged 20.7 years (SD=2.8, 83% females), and parents 50.8 years (SD=3.9, 80% females). VMC was highly acceptable across groups (helpfulness rating: M=4/5, SD=.77). All participants felt an adapted VMC would be suitable for Australians. Professionals' most commonly-endorsed barrier to EoL communication was their own 'readiness' (44%), while 29% endorsed good rapport as a facilitator. Professionals felt that relapse was the most appropriate time to introduce EoL discussions (40%). Parents and AYAs agreed psychosocial or nursing professionals were best placed to explore EoL preferences with patients (80% of parents, 50% of AYAs), though other disciplines were also suggested with the professional-patient relationship identified as critical. Various modifications to the American VMC tool were suggested, reflecting both linguistic and cultural preferences for how these conversations should unfold.

DISCUSSION/CONCLUSIONS: Voicing My CHOICES TM is a promising tool, with adaptations underway to facilitate EoL communication with Australian AYAs. Our findings

highlight that interventions may benefit from local adaptation even across countries that share languages (i.e., USA-Australia). Further research addressing barriers to EoL discussions with AYAs is critical to support the global dissemination of gold-standard care.

Prognostication and Palliative Care in a Young Adult Oncology Patient

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CASE DESCRIPTION: A 34 year old female with Neurofibromatosis Type 1 was referred to palliative care with treatment-refractory, intra-abdominal peripheral nerve sheath tumours. On developing malignant bowel obstruction, her oncologist requested that palliative care take over management, informing her she had only a few weeks' prognosis. On ileus resolution, she ceased work, restricted her socialisation and awaited deterioration. The subsequent nine months were marked not by clinical deterioration, but refractory chronic abdominal pain, increasing paternal dependence and physical, psychological and emotional stagnation. The palliative care team recognised her inability to reconcile her predicted prognosis with her prolonged survival was perpetuating her symptoms and functional impairments. This prompted a multi-disciplinary chronic pain referral. Subsequent interventional analgesic procedures and chronic pain clinical psychology input have offered hope of multi-dimensional gains. This supportive, and now chronic care, has been driven throughout by her palliative care team, without local specialised adolescent and young adult (AYA) psychosocial input.

DISCUSSION: With increasing treatments that transform some cancers into chronic diseases, AYAs with incurable cancers often deal with protracted prognostic uncertainty. This case highlights how inept communication of prognosis to AYAs that fails to express inherent uncertainty, can cause prolonged suffering, stalled psychosocial functioning and maladaptive decision-making. Early palliative care involvement, including in prognostic discussions, is geared to promote more positive outcomes. This case also showcases the potential scope of integrated AYA palliative care, and how especially in a large centre, without on-site access to specialised AYA psychosocial care, our palliative care team strives to support AYA oncology patients' complex needs, sometimes over an extended period.

KEY LEARNINGS: 1. Research into best practice models for predicting and communicating prognosis to AYAs is needed. 2. Early palliative care referral for AYA oncology patients can produce wide-ranging benefits. 3. Models for more easily accessible specialist AYA psychosocial support are required.

Living Out Loud: AYAs with advanced cancer shatter the silence and create a space of their own

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INTRODUCTION AND AIMS: The Canadian Adolescent and Young Adult Cancer Task Force recognized "Terminal Care and Symptom Management" as one of the 10 priorities in its framework. These priorities were identified through extensive consultation. (Rogers et al. 2013). Grounded in the belief that those directly impacted are best positioned to design solutions, the Canadian Virtual Hospice, with funding from the Canadian Partnership Against Cancer, convened AYAs living with advanced cancer to identify the gaps in information and support they encounter. They were tasked with developing content to begin to meet the complex needs of this population.

METHODS: With a limited budget, access to a documentary filmmaker and a graphic designer, this highly motivated group had 5 months to create a webspace of their own. Hailing from across Canada, they collaborated virtually to give voice to common challenges, share their stories and tackle difficult subjects with honesty and often humour. An Advisory Team of oncology and palliative care experts was available for consultation and support. Plans for evaluation include website analytics and an online survey.

RESULTS: This interactive session will serve as the international launch of the knowledge tools and it will share the motivation, priorities and lessons learned. Insights on coping with diagnosis, maintaining agency, navigating relationships, self-care, legacy and funeral arrangements and other subjects will be shared.

DISCUSSION AND CONCLUSION: It can be difficult to reconcile the promise of youth with life-limiting illness and early death. Dressed up as good intentions, platitudes such as "You'll beat this," and "It will be OK" deny AYAs with advanced illness their truth and needed support. This initiative underscores the power of personal narratives in communicating health information and the importance of engaging and empowering people living with advanced illness to envision and create knowledge tools to meet their own specific needs.

What is the preferred versus actual place of death for children and young people with cancer?

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INTRODUCTION AND AIMS: The Children and Young People's Cancer Service (CYPCS) at University College London Hospital (UCLH) is a quaternary service for patients with haemato-oncological malignancies. The aim of this project was to determine the preferred versus actual place of death in a cohort of CYPCS patients with terminal end-stage disease.

METHODS: Retrospective case note analysis of patients who died between 2012 and 2016. 90 out of 105 case notes reviewed were included.

RESULTS: The average age of death was 17.2 years [range 8 – 26]. Sarcoma was the predominant malignancy comprising 43%, followed by other solid tumour malignancies (33%) and then haematological disorders (24%). 62% (n=56) had a documented discussion regarding their preferred place of death. Over half of the patients expressed a preference to die at home (56%), followed by hospital (29%), and then hospice (4%); 11% were undecided. Reasons cited for "dying at home" included: wanting to die in a peaceful environment, close to family and without medical intervention. In reality, most patients (59%) died in hospital, 30% died at home and 11% in a hospice. The preferred place of death was achieved in 65% (n=33) where a preference had been documented.

CONCLUSION: In the group of patients where there was a documented discussion about preferred place of death, the majority expressed a preference to die at home. Most patients ended up dying in hospital for reasons including parental resistance and fear of inadequate symptom control outside of a hospital setting. These findings support discussion between clinicians and patients about how specialist palliative services can be provided to facilitate preferred place of death. Further work would analyse whether achieving patients' preferred place of death correlates with a positive end of life experience and has an impact on overall service provision.

What's Left Behind: Addressing End of Life Distress through Memory Making

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CASE DESCRIPTION: Luke was diagnosed with nasopharyngeal rhabdomyosarcoma at age 20 and completed chemotherapy and radiation over the course of 12 months. From a regional area, pre-diagnosis he was working fulltime in construction and had an active social and leisure lifestyle. He returned to work and home after treatment, however, relapsed 6 months later. He was referred to palliative care and given a course of palliative radiation which provided initial symptom relief, however, disease progression then continued. During this period Luke experienced ongoing distress around loss of independence, futility of treatment and managing relationships with his family, friends and girlfriend.

DISCUSSION: Current evidence (Anderson, 2018) identifies the complexities of addressing end of life issues for this age group. Luke had ongoing fears about: his functional decline, how his parents would cope after his death, fear of separation from his family and friends

and the impact of his death on them. Due to his age and developmental level Luke struggled to identify and process his complex emotions and grief, and felt unable to verbalise his fears around death and the process of. Using a combination of video/audio and written text YCS staff assisted Luke to explore these issues and record a series of memories. These memories were left with YCS staff to provide to his family after his death.

KEY LEARNINGS: Memory making interventions can be successful in assisting young people with advanced cancer to explore end of life distress and ease the burden of leaving their family behind. Providing young people the opportunity to be creative in the presence of familiar and skilled clinicians allows them to express themselves meaningfully and gain some element of control which they have lost. Finally, the feedback from bereaved families has highlighted the effectiveness of this intervention in assisting with coping with their loss.

Understanding and addressing the training needs of clinicians to improve end-of-life care for adolescents and young adults with cancer worldwide

This project was awarded the 2018 AYA Global Accord Psycho-Oncology Research Acceleration Grant. This grant initiative is intended to aid the creation of research projects addressing international research priority areas for AYAs living with cancer, led by an early career researcher.

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INTRODUCTION/AIMS: Although 80-88% of adolescents and young adults (AYAs) diagnosed with cancer survive their illness, a significant portion do not. Timely, developmentally appropriate end-of-life (EoL) discussions are critical. Work is required to advance knowledge of current EoL communication practices with AYAs with cancer, including optimal methods for up-skilling healthcare professionals in this area to achieve the gold standard of care that AYAs deserve at end of life.

Supported by the inaugural Global AYA Accord research grant, our international team aims to 1) examine AYAs' access to the international standards of EoL communication in Global Accord countries; 2) determine, through international professional consensus, the EoL communication training needs of AYA clinicians; and 3) develop a template for evidence-based, AYA-specific EoL communication training.

METHODS: The study will comprise two stages. Stage 1 will incorporate a cross-sectional survey to index current EoL communication practices internationally, followed by a two-round survey which will use Delphi methodology to establish (i) expert consensus on optimal timing/delivery of EoL communication with AYAs, (ii) content needed in clinician training for this communication, (iii) feasibility/acceptability of various training models, and (iv) utility of training about available manualised tools for AYA EoL communication. We will administer 175 surveys to multidisciplinary health professionals working with AYA cancer patients across the United States, Australia, New Zealand, Canada, the United Kingdom, and Europe. These data will inform Stage 2, the aim of which is to build a platform for evidence-based clinician training.

RESULTS: We will provide an update of the progress of the international collaboration, along with preliminary results of the Stage 1 online survey.

DISCUSSION/CONCLUSIONS: This research will contribute to establishing global EoL communication practices, and build on these data to develop a training blueprint for the future. This will ultimately support delivery of gold standard care for AYAs at EoL.

CONCURRENT STREAM 5.3 – FAMILY, BEREAVEMENT & THE IMPACT OF CANCER BEYOND THE PATIENT

Family and Cancer (Abstract withdrawn)

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Cancer is a formidable disease regardless of a person's age. Adolescents and young adults with cancer face an especially unique and challenging experience as they deal with the physical and emotional difficulties of cancer treatment at the same time they are seeking to tackle the developmental tasks of adolescence in preparation for young adulthood. This presentation draws on 30 years of clinical practice and the academic evidence, to demonstrate how adult carers can foster resilience (defined as the ability to face, overcome, be transformed and strengthened by adversity) in their AYA children when they are diagnosed with cancer. The importance of having a charismatic adult, peer support and socio emotional competencies is stressed.

You are not listening: A mother's perspective of cancer care for her teenage daughter

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CASE DESCRIPTION: In this case study, we present a mother's interview regarding her 15 year old daughter's diagnosis with ovarian cancer. In the mother's own words the fear, frustration and confusion of treatment across adult and paediatric settings, in both rural and metropolitan locations are presented as a discovery interview. "The average age of the patients there was 70 and I mean that was very confronting, there was Jane sitting there and she felt very vulnerable....they only gave her only give her half of her pain medication after surgery because they were scared, because she was a teenager and I understand that from a professional point of view as they deal with, you know, older people and here was this adolescent, it was just different...she was demanding because she was in so much pain- but I think she was just frightened too. On the other side of the ward, across the way, was a four-bedded male bay...so when Jane got up to walk she nearly fell over when she saw all these old men over there...My husband and I, we slept on the floor, on the carpet, because there was no beds, and there was no chair to sleep on...And when I ring for blood test results, even now, they say, "We'll ring your daughter," because they think I'm 60 and my daughter's 40... They just don't understand."

DISCUSSION: We highlight the challenges across different hospital settings for young people, including privacy, autonomy, communication, and navigating the differences between services.

KEY LEARNINGS: Despite provision of excellent medical care, patients and families experience high levels of distress associated with the way care is provided. Having awareness of the difficulties faced by adolescent and young adults, and consideration of their unique needs in a complex health system is pivotal to reducing suffering.

Examining the support needs of parents following the death of a young adult (YA) (aged 16 - 29 years) from cancer; a grounded theory approach

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INTRODUCTION: The literature suggests that following their child's death from cancer, parents experience unique grief that fluctuates over time and mothers and fathers may experience grief differently (Bortz, Malkinson and Krulik, 2013). There has been a lack of research about the bereavement experience of parents' of YA's, their support needs and how they can be best supported in living a life beyond cancer. Research regarding the support needs of parents is advocated by the James Lind Alliance (2018). The study aims were (1) to examine the support needs of parents following the death of a YA (aged 19-29

years old) from cancer (2) identify appropriate forms of support for service development.

METHOD: This was a qualitative, exploratory study based on grounded theory. Parents were purposefully sampled from one specialist centre. Couples chose to be interviewed together. Codes generated from line by line analysis were developed into categories by a research team, increasing the research integrity (Charmaz. 2006).

PRELIMINARY RESULTS: 6 fathers and 9 mothers from 9 families ranging from 18 months to 8 years post bereavement were interviewed. Results suggest there is; Benefit from "being with" others without the need to discuss feelings. A desire for the YA to be remembered, leading parents to create legacies to help others. An overwhelming "loss of self identity". A need for fathers to meet others in a similar situation. Inadequate information giving regarding parental grief.

DISCUSSION: Those delivering support from the treating centre are in a unique position to offer ongoing individualised support to bereaved parents. This can include facilitating effecting information giving and facilitating support groups which is necessary to positively influence life after cancer for bereaved parents.

The Perspectives of Parents and Adolescents/Emerging Adults regarding Genetic Testing for Li-Fraumeni Syndrome

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Li-Fraumeni Syndrome (LFS) is a rare cancer predisposition syndrome caused by germline TP53 mutations. Approximately 20% of those affected develop one or more of a broad spectrum of cancers by the age of 20. Despite mounting evidence supporting a benefit of surveillance for early cancer detection, uncertainty about possible risks and long term benefits make decisions about whether or not to test children for LFS challenging. The purpose of this session is to report on perspectives of TP53 testing among parents offered testing for their children and adolescents/emerging adults in families with LFS. We examined: a) parental decision-making styles regarding testing; b) parents' perceived advantages and disadvantages of testing; c) how the unique developmental context of adolescence influences parents' perspectives; d) whether adolescents/emerging adults believe testing should be offered for children; and e) adolescent/emerging adults' perceived advantages and disadvantage of testing. Qualitative interviews were conducted with 46 parents representing 39 families offered testing and 12 12- to 25-year-olds in families confirmed to have LFS. Three parental decision-making styles emerged: Automatic decisions (44%), involving little thought and identifying immediate benefit(s) in testing (100% pursued testing); Considered decisions (49%), weighing the risks and benefits (77% pursued testing); and Deliberated decisions (6%), struggling with psychosocial concerns for the child (25% pursued testing). Parental perceived benefits primarily focused upon promoting child health and satisfying a "need to know." Disadvantages included potential psychosocial risks and privacy/discrimination/insurance issues. Parents recognized that some aspects of adolescence promote LFS testing and discussions about cancer-related risk and others complicate the issue. The adolescents/emerging adults all believed that testing should be offered for children. Benefits of testing included learning one's risk

status, allowing for disease prevention efforts, and reducing uncertainty and anxiety. Perceived disadvantages included potential negative emotions associated with the testing result. All adolescents/emerging adults who were aware of having been tested and their test result (n = 7; 4 positive) said testing had no negative impact on them. Implications of these findings for clinical practice and future research will be discussed.

Remembering friends: addressing bereavement support for teenage & young adults (TYA) diagnosed with cancer who experience the loss of a peer

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INTRODUCTION: The ethos of TYA care is to encourage young people to socialise together and engage in peer support. When a young person dies their loss is felt considerably by other TYAs. Bereavement charities highlight that without bereavement support young people may experience long term psychological difficulties. The aim of the project was to review bereavement support, establish what TYA's want and implement a new service.

METHODOLOGY: A patient group (8 participants) was established with discussions focused on experiences of bereavement and reflections on support received. An online survey was devised by the group to establish wider opinions (45 received).

RESULTS: 89% of TYA's felt that they did not receive any bereavement support. 72% of patients felt that there should be an improvement in TYA bereavement services. Themes from the group and survey highlight that: Death is often a taboo subject Survivorship guilt is common Reflections on personal mortality is common Young people decided they wanted an annual event to remember their friends and they also wanted a bereavement phone line. The group have organised their own 'Remembering Friends' event for 2 years: In 2016, 15 attendees (79% of the young people scored the event as eight and above as being valuable to attend). In 2017, 16 attendees (73% rated the event as 10/10 for helpfulness).

DISCUSSION AND CONCLUSION: The project has highlighted the need to develop formal TYA bereavement services. Additional developments include a space to reflect on the unit and the development of a policy to improve how staff communicate the death of a young person to other patients.

PLENARY 6: BEREAVEMENT, SURVIVORSHIP & INTEGRATION OF A CANCER DIAGNOSIS INTO LIFE AFTER TREATMENT

AYA Cancer Survivors, Risk-Based Health Care, and the Role of the Primary Care Physician

Professor Kevin C Oeffinger

Professor, Department of Medicine; Director, Duke Center for Onco-Primary Care; Duke University / Duke Cancer Institute

As the population of survivors of AYA cancer has increased, it has become increasingly apparent that many survivors have an elevated risk of late occurring health problems. Understanding these risks, based upon the cancer, cancer therapy, genetic predisposition for other health problems, comorbidities, and lifestyle behaviors, is essential to provide optimal risk-based health care. Compounding the complexity of care of AYA cancer survivors is the fact that many are no longer followed at their treating institution or by a clinician familiar with their risks. From the perspective of primary care physicians, AYA cancer survivors represent a small fraction of their practice panel. Thus, methods to provide the right information to the right person at the right time is essential for quality care. This session will articulate the tenets of risk-based survivorship health care and describe potential methods, including the use of smartphone technology and social media, to empower cancer survivors and to activate their primary care physicians.

Adolescents and Young Adults with Cancer: Facing Loss, Finding Meaning, Focusing on the Future

Professor Barbara Jones

Professor and Associate Dean for Health Affairs Steve Hicks School of Social Work, The University of Texas at Austin

@Barbaralnjones!

Adolescents and young adults (AYAs) with cancer face many losses throughout their cancer diagnosis, treatment, and survival. However, one of the most difficult losses- the death of a friend with cancer- is rarely talked about. When a young person dies from cancer, it is devastating to their family, friends, community, caregivers, health care providers and all those who they met along the way. Because of how difficult these feelings can be, there is very little discussion of bereavement and loss in our current approaches to adolescents and young adults with cancer. This silence only further isolates grieving AYAs, family members, and care providers. The presentation will open a dialogue about how we face loss, find meaning and continue to focus on the present and the future. The presentation will describe typical grieving reactions for adolescents, young adults, family members and health care and social care providers. We will also discuss how we continue to honor those who we have lost and find meaning and inspiration from their lives. We will talk about the importance of continuing bonds of connection and how those can help us integrate those we have lost into our current lives. And finally, we will discuss how we can remember and honor those who we have lost by furthering our fight for full recognition of the unique needs of AYAs with cancer and their families and friends.

Poster Listing

DAY 1 – TUESDAY 4 DECEMBER

POSTER NO	POSTER TITLE	PRESENTING AUTHOR
1	Filling the gaps: Exploring the role of the Clinical Nurse Consultant within the growing Western Sydney Youth Cancer Service	Tora Sibbald
2	Health Informatics: Nurse-led implementation of a digital integrated oncology management system for the WA Youth Cancer Service.	Jo Collins
3	A complex adaptive system perspective on role of the Youth Support Coordinators (YSC) in Teenage/Young Adult (TYA) cancer care.	Maria Cable
4	AYA cancer nursing - An emerging sub-speciality	Pia Riis Olsen
5	Implementing and developing a nursing outreach service for Teenagers and Young Adults with cancer: Perspective of a Clinical Nurse Specialist	Charlene Jones
6	Youth Cancer Service Phase III : New South Wales and ACT The Clinical Nurse Consultant role	Cath O'dwyer
7	Evaluation of the role and service provided by the Teenage and Young Adult Cancer Advanced Nurse Practitioner in two TYA centres in England and Wales	Claire Barton
8	Perceptions of nurses on care for childhood cancer survivors with sexual and reproductive dysfunction	Akiko Tomioka
9	The Role of the Cancer Nurses Society of Australia (CNSA) Adolescent and Young Adult (AYA) Specialist Practice Network (SPN)	Rebecca Greenslade
10	Adolescent and Young Adult (AYA) Nurses: A National Network with the Cancer Nurses Society of Australia (CNSA)	Rebecca Greenslade
11	Delivering appropriate care to young LGBTIQ+ people affected by cancer	Sarah Pfister
12	The Cancer Journey for an Indigenous AYA patient	Linda Logan
13	Keeping AYA Patients on Track in the Outback	Rick Walker
14	Psychosocial concerns amongst medicare ineligible patients within an AYA service	Ruth Cathcart
15	Breaking Down the Barriers: the importance of rural outreach when working with young people and their families	Julia Drake
16	Overlooked minorities: a systematic review examining the intersection of cancer in lesbian, gay, bisexual, trans and intersex (LGBTI) adolescents and young adults (AYAs)	Mairghread Clarke

17	'The Sophisticated Ordinary': An evaluation of regional based Teenage and Young Adult (TYA) peer support groups.	Lorraine Beddard
18	Psychosocial barriers to optimal care: A case study of two newly diagnosed AYA patients in an underserved community	Jan Huynh
19	Case presentation describing the emotional burden for staff caring for two young Jehovah's witnesses with Acute Leukaemia.	Kerry Baker
20	Youth-driven mural art project for adolescent and young adult (AYA) cancer patients in Western Australia	Lachlan Denning
21	Visual Impact of an Effective Breast Cancer Awareness Campaign Targeting Young Women on Campus Across Canada	Lorna Larsen
22	AYA Patient Advisory Boards: Giving AYA Cancer Patients and Families a Seat at the Table	Tomoko Tsukamoto
23	A Pathway to Improving an Adolescent and Young Adult Oncology Service: Voices of Patients and Parents	Leanne Super
24	Aggregate, Don't Recreate	Amber Skinner
25	Presenting cancer symptoms and diagnostic timeliness among teenagers and young adults: findings from the BRIGHTLIGHT cohort	Lorna Fern
26	Development and implementation of guidelines for cancer stage data collection in the Australian Youth Cancer Services	Dominic Keuskamp
27	The Teenage Cancer Trust IAM Portal: An update on its continued development, evaluation and implementation	Jennifer Cheshire
28	Building an AYA Oncology Program from the Ground Up: Of Towers and Bridges	Peter Shaw
29	The Dutch Adolescent and Young Adult (AYA) approach: building a national AYA network in collaboration with AYAs and healthcare professionals	Olga Husson
30	Student learning from an international AYA cancer site visit	Maria Cable
31	New Treat Unique Adolescent & Young Adult Cancer Service at Epworth Richmond, Melbourne	Donna Gairns
32	A space I call my own: "CAN-SPA" the Indian solution for a cancer space for age-appropriate care	Prakash Chitalkar

DAY 2 – WEDNESDAY 5 DECEMBER

POSTER NO	POSTER TITLE	PRESENTING AUTHOR
1	Are TYAC teams really equitable tools of access to care for all patients?	Leila Goffi Laroche
2	Major adverse events associated with L-asparaginase in adolescents and young adults receiving pediatric based treatment for acute lymphoblastic leukemia	Adam Duvall
3	Treatment Patterns and Outcomes of Adolescents and Young Adults with advanced soft tissue sarcomas: a single-centre experience.	Winette Van Der Graaf
4	A review of the dietetic service provided to TYA cancer outpatients.	Monika Siemicka
5	Are we failing to meet the gold standard of care for vitamin D deficiency in Teenage and Young Adult (TYA) cancer patients?	Jo Grout
6	Adolescent and Young Adult Radiotherapy at the Royal Adelaide Hospital – A Personalised Journey.	Kate Rubinich
7	Crossing the Paediatric and Adult Hospital Divide, P3BEP (ANZUP 1302): An international randomised phase 3 trial of accelerated versus standard BEP chemotherapy for adult and paediatric male and female patients with intermediate and poor-risk metastatic germ cell tumours (GCTs).	Rick Walker
8	Preparation for Bone Marrow Transplant -Heading Down the Highway	Lyndal Moore
9	A lost 'voice' of the adolescent . . . was it really lost? A team approach working with two teenage brain tumour patients with tracheostomies.	Tania Webb
10	Food and eating challenges among adolescents and young adults with cancer undergoing chemotherapy	Marie Ernst Christensen
11	Nasopharyngeal cancer in a teenage Australian male – challenges, team collaboration and complex cancer care	Anita Cox
12	Posterior reversible encephalopathy syndrome in patients with acute lymphoblastic leukemia (ALL) during remission induction therapy: a single institution retrospective study	Wei Lin
13	Targeting the cytoskeletal regulator AFAP1L1 to control sarcoma migration and invasion	Evan Ingley
14	A Single Institution Comparison of Treatment Outcomes in Adolescent and Young Adult (AYA) Acute Myeloid Leukemia (AML) Patients Treated in Pediatric and Adult Centers	Jordyn Griffin
15	An University Hospital Ghent Experience: Acute Myeloid Leukemia (AML) in Adolescents and Young Adults (AYAs)	Johan De Munter
16	Co Creation methods to develop the best future for Dutch AYA	Pieter Vandekerckhove
17	CBT-Based Group Therapy Implementation for AYAs	Brittany Hall
18	The AYA DAY: An All-in-One Psychology, Exercise, and Dietitian Service Delivery Program	Brittany Hall

19	A Mindfulness Based Intervention for teenagers and young adults with a diagnosis of cancer	Caroline Newton
20	Survey results of primary oncology providers regarding the value of an adolescent and young adult oncology program and barriers to referral.	Elizabeth Cull
21	Case Study: Piecing Together the Patchwork Quilt of AYA Programming	William Terry
22	Helping Adolescents and Young Adults with cancer to "normalize" their social contacts: Study into the effects of the AYA Match App	Sophia Sleeman
23	Beyond Protocols: A Psychosocial Program for Hematopoietic Stem Cell Transplant Patients and Families	Elizabeth Sasser
24	Improving the Minimum Standard of Psychosocial Care within the Private Healthcare System in Australia – Impact of Patient's Voice	James Morris
25	Health Related Quality of Life (HRQoL) Assessment in a Growing Adolescent and Young Adult Oncology Clinic with PROMIS-29	Aniket Saha
26	Expanding assessment of psychosocial needs of AYA patients in a new AYA Oncology Program	Aniket Saha
27	Young people's lived experiences of cancer: An Interpretative Phenomenological Analysis	Nicola Pettitt
28	Psychosocial Issues for Adolescent and Young Adult (AYA) Cancer Patients in a Global Context: A Forward-Looking Approach	Nina Jackson Levin
29	Distributed health literacy and decision-making in adolescents and young adults with cancer: a systematic review	Danielle Gessler
30	Age-appropriate psychosocial support is imperative for Adolescents and Young Adults with Cancer (AYAO)	Goh Wei Lin
31	The integration of a Wellbeing service (WBS) into local Teenage and Young Adult (TYA) Cancer Care.	Claire Palles-Clark
32	"Coordinate My Care" digital urgent care plans for adolescent and young adults	Emma Thistlethwayte
33	Caring for the whole patient: The assessment of psychological wellbeing in Teenagers and Young Adults with cancer, a systematic review	Dan Stark
34	Implications for AYA testicular cancer survivors on sexual function	Agnes Mojord & Katie Thomson
35	To TESE or not to TESE...That is the question	Anthony Audino
36	'Does that mean that cancer patients can't have sex?' - Adolescent and young adults' support and information preferences (workshop II)	Ana Martins
37	Fertility Preservation education - trying to share the "Sperm Queen" title	Anita Cox
38	Hope, burden, or risk: A discourse analytic study of the construction and experience of fertility preservation in the context of cancer	Jane Ussher
39	Therapeutic clinical trial enrollment is higher among AYAs treated at academic medical centers in North Carolina as compared to community cancer centers	Andrew Smitherman

DAY 3 – THURSDAY 6 DECEMBER

POSTER NO	POSTER TITLE	PRESENTING AUTHOR
1	You would think living with life threatening cancer was enough: Exploring the financial effects of cancer for Australian adolescents and young adults and their carers	Lucy Lehane
2	Working to outcomes: Piloting an innovative technology platform to measure and understand outcomes for young people receiving education and career support	Kailly Hill
3	Do we as educators support students to integrate education into their "cancer journey" or do we support students to integrate the cancer treatment into their "education journey"?	Nicole Done
4	Evaluation of the RENEW exercise referral programme for young adult cancer survivors	Gemma Pugh
5	Launching an Innovative Education Series Utilizing Novel Learning Approaches to Address the Unique Needs of the Adolescent and Young Adult (AYA) Oncology Patient	Sharon Bergeron
6	The benefit of physical activity in adolescent and young adult cancer patients during and after treatment: A systematic review.	Claire Munsie
7	Changes to Body Image and Impact on Physical Activity, School/Vocation and Mental Health amongst AYA's following Treatment for Sarcoma and Lymphoma: A Research Protocol	Lauren Williams
8	A Body Image Support group to address Body Image issues for Teenage & Young Adults (TYA) with a cancer diagnosis	Anna Mackland & Lorraine Wright
9	Understanding the educational and vocational outcomes of Adolescents and Young Adults (AYA) diagnosed with cancer.	Nicole Edwards
10	Adolescent Responses to the Diagnosis of a Life-Limiting Condition: Stages of Grief.	Danielle Kundert
11	Ben's Bucket List - A Collaborative Approach to the Palliative Care Needs of an Adolescent with Cancer	Michelle Noyes
12	Talking About "Plan B"	Leonie Oliver
13	"It's a topic that everyone has to encounter": What young adults think about care and conversations at end-of-life.	Holly Evans
14	The Experiences of Young Adults Living with Metastatic/Advanced Cancer: A Scoping Review	Emily Drake
16	The use of oral single-agent targeted therapy in the palliative care setting to slow disease progression and maximise quality of life: a case study.	Ashleigh Sullivan
17	Identifying unmet needs in patients diagnosed with cancer as young adults aged 25-39 years: a qualitative study of an underserved population	Emma Lidington
18	Social anxiety and its correlates in AYA cancer survivors	Clarissa Schilstra
19	Look at Me Now: A Successful Peer Support Program for Hematopoietic Stem- Cell Transplant Patients	Janae Harris

20	Challenging linear models of grief through residential bereavement support	Charlotte Thomson
21	The Getaway Retreat for Young Adults	Aura Kuperberg
22	Implementation of a designated Late Effects clinic for Adolescents and Young Adults (AYA) who have undergone Haematopoietic Stem Cell Transplant (HSCT)	Emma Thistlethwayte
23	Yoga for Wellbeing; Project Development in a Teenage and Young Adult Cancer Service	Nicola Walker
24	Teenage Cancer Trust's Way Forward Programme – An evaluation of a residential approach to post treatment support for young people recovering from cancer	Nicola Pettitt
25	Taking AYA cancer care to the next level in Denmark - AYAs with cancer on the political agenda (Abstract for the Global Exchange Exhibition)	Anette Borup Simonsen
26	Current status and issues in supporting AYA cancer patients in a children's hospital in Japan	Naoko Takenouchi
27	Guided tour behind the scenes of the AYA Team of the French Alps	Leila Goffi Laroche
28	The Listen up Group	Anna Hoek-Sims
29	Three philosophy tools to help AYA with cancer to lead a fulfilling life	Pieter Vandekerckhove
30	Implementation of a specialised multidisciplinary end of treatment clinic for Adolescent and Young Adult (AYA) cancer patients in South Australia	Melissa Jones
31	General Practitioners' Management of Cancer in Australian Adolescents and Young Adults	Kimberley Allison
32	Transition of a Complex Patient	Kendall Stratton
33	Non-Hodgkin Lymphoma in Adolescents and Young Adults - A National Prospective Population-based Study	Robert Carr
34	The power of connection: reflections of attending a 4-day survivorship conference for young adults with cancer	Nicky Pettitt
35	The feasibility and acceptability of life coaching for survivors of cancer in young adulthood.	Louise Soanes
36	Teenage and young adult cancer survivors perception of lifestyle behaviour on current and future health	Gemma Pugh
37	Is adolescence a protective period for the cognitive and psychosocial effects of radiotherapy treatment?	Lara Payne
	My Life Before, With, and Beyond Cancer: Creative Contributions to the AYA Cancer Conversation.	Contribution listing

Creative Consumer Table

Medium	Title	Full names of all AYA contributors	Brief Description	AYA Cancer Consumer Artists have been supported to participate in this exhibition by staff from the following organisations...
print	A Role of the Dice	Fiona Frazer	Words and pictures describing the journey of an individual survivor	Capital and Coast District Health Board, NZ
print	A series of unfortunate events	Kai Lim	Cartoon's made by a survivor during treatment	Starship Hospital, New Zealand
print	An Unsuspecting Gift	Tayla Farquhou	Journal excerpts from an individual survivor	Waikato Regional Cancer Centre, New Zealand
print	Dragon Pride	Marlies, Cindy and Darren Peake	A print of a tattoo proudly worn by a Mother in memory of her daughter, who designed it before she died	Starship Hospital, New Zealand
print	Drop the Filter	Developed by 200 young people at Teenage Cancer Trust's Find Your Sense of Tumour event. Curated by Teenage Cancer Trust's Youth Advisory Group. Designed by Laura Brodrick.	Posters exploring the Congress daily themes (life before, during and after diagnosis). These were developed by 200 young people at Teenage Cancer Trust's Find Your Sense of Tumour event. Curated by Teenage Cancer Trust's Youth Advisory Group.	Teenage Cancer Trust, UK
print	Me, Myself, and Cancer	Dylan Bowman	Journal style entry capturing an individual survivors experience of diagnosis. The artist seeks to convey that Cancer is not the end but a new beginning	Waikato Regional Cancer Centre, New Zealand
print	My Beanies, My Identity	Amorette Graham	Photo images of a terminal patient in beanies which are to them, a symbol of empowerment	NSW & ACT Youth Cancer Service, Australia

print	My lost year	Joseph Hala	A poster using paint & mixed media depicting the long-lasting effects of treatment into survivorship	Starship Hospital, New Zealand
print	My Journey Through ALL	Nyan Mishra	A Poster depicting a personal experience of Acute lymphoblastic leukaemia (ALL)	Teenage and Young Adults Cancer Foundation, India
print	That Night A Recipe to Make an Oncology Waiting Room	Anna Hoek-Sims	2 Poems written by a survivor to process her diagnosis	CanTeen NZ
print	The Stories of Champions	Champaign Corfee; Samantha Krizo; Morgan Krek; Steven Giallourakis; Tess Blasko; Dylan Reis	collaborative artwork by participants of monthly AYA patient support groups. Artwork will reflect the three daily themes of before, during and after diagnosis	University Hospitals Rainbow Babies and Children's Hospital—Angie Fowler Adolescent and Young Adult Cancer Institute—Cleveland, Ohio, USA
video	Anthology	Samantha Stacy, Mafalda Von Alvensleben, Patrick Eck, Brian Smith	Poems set to music by members of a youth advisory group.	Teen Cancer America
video	Check Yourself Canada	Hundreds of participants in flashmobs from Canada, UK and Australia. Acknowledgements are included in the videos.	3 videos of flash mobs from Canada, UK and Australia, where hundreds of participants performed a Taylor Swift Parody 'Check Yourself'.	Team Shan Breast Cancer Awareness for Young Women (Team Shan), Canada
video	Christmas Balls	Young Patients of the Youth Project of the Pediatric Oncology Unit	A song + video clip about Christmas in hospital, by young patients in a paediatric oncology unit	Fondazione IRCCS Istituto Nazionale Tumori Milan Italy
video	Why	Patrick Eck	A song written by a survivor, which represents different stages of life, while questioning the meaning of life from a survivors perspective	Teen Cancer America

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The Global Accord

In 2015, three international adolescent and young adult cancer-focussed organisations, CanTeen Australia, The Teenage Cancer Trust and Teen Cancer America, formed the AYA Cancer Global Accord to support a global approach to improving AYA cancer outcome.

A key focus of this partnership is the Annual Global AYA Cancer Congress Series, hosted on a rotating basis by the foundational partner organisations.

This brings together elements of previous national conferences hosted by CanTeen and Teenage Cancer Trust with a remit to showcase international developments and challenges in the care of the more than 1,000,000 AYAs diagnosed each year around the world.

The development - to create the first truly global event in AYA cancer - is in recognition that awareness and concern regarding the problem and the uniqueness of cancer in adolescents and young adults is becoming more and more universal.

The Global Accord has also begun supporting international research collaboration through the provision of seed funding for international psychosocial research and will explore international advocacy opportunities, including addressing the global challenges of AYA clinical trials access.



CanTeen

We get it. Just when life should be full of possibilities, cancer crashes into a young person's world and shatters everything. CanTeen is the game changer. We help young people aged 12-25 cope with a close family member's cancer or their own diagnosis. Through CanTeen, they learn to explore and deal with their feelings about cancer, develop resilience and connect with other young people in the same boat. For young cancer patients specifically, CanTeen provides specialist, age-appropriate treatment and support through the hospital-based Youth Cancer Services (YCS), which reach around 70% of newly diagnosed young Australians.

As part of a new initiative, CanTeen is additionally supporting clinical trials in cancer types with the highest death rates for adolescents and young adults.

CanTeen works by having young people at the centre of everything we do. We were set up by a group of young cancer patients in 1985 and still have young people affected by cancer guiding the organisation at every level. Combined with our leading edge research into the emotional and social impacts of cancer, it ensures that we truly understand how cancer is different in a young person's world.

Find out more: canteen.org.au

Teenage Cancer Trust

Working alongside the NHS, Teenage Cancer Trust is a world leader in developing services for young people with cancer. Since 1998, we have hosted nine international conferences dedicated to sharing and developing knowledge about young people's cancer. We believe that working globally, sharing best practice and research internationally, is critical for improving the quality of care and approaches to treatment. This explains why we partnered with Teen Cancer America and CanTeen Australia to create the Adolescent and Young Adult Cancer Global Accord, and in 2016, we hosted the first Global AYA Cancer Congress in the UK in Edinburgh, which successfully brought together over 360 international clinicians and healthcare experts from 19 countries.

Teenage Cancer Trust is leading the transformation of specialised nursing and emotional support for young people aged 13-24 with cancer in the UK, delivering services to young people before, during, and after, their experience of cancer. We deliver life-changing support through 28 specialist cancer units, through local hospitals and to young people in their own homes across the UK. Our teams specialise in teenage and young adult cancer and provide the best possible care before, during and after their treatment to improve outcomes. They also organise opportunities through events such as Find Your Sense of Tumour and Way Forward to inspire young people and create positivity. Research has shown that Find Your Sense of Tumour has a lasting impact on young people's self-esteem.

Right now, our services only reach half of young people diagnosed with cancer with our world-leading specialist care. Our goal is to expand the numbers of Teenage Cancer Trust teams across the UK so that we can deliver game-changing cancer support to young people with cancer.

We are delighted to be joining our partners from the Global Accord in Sydney along with delegates from all over the world, as together, we showcase the latest developments in AYA cancer. We know that working globally and sharing best practice and research internationally is critical for innovation and improvements in the quality of care and treatment for all young people with cancer.

Teen Cancer America

TEEN CANCER AMERICA is a movement to empower and improve the lives of young people with cancer. We create youth-centered ecosystems that support young people with cancer, their families, and healthcare professionals. Teen Cancer America integrates everything required to champion a comprehensive youth-centered approach to cancer in hospitals and health systems throughout America.

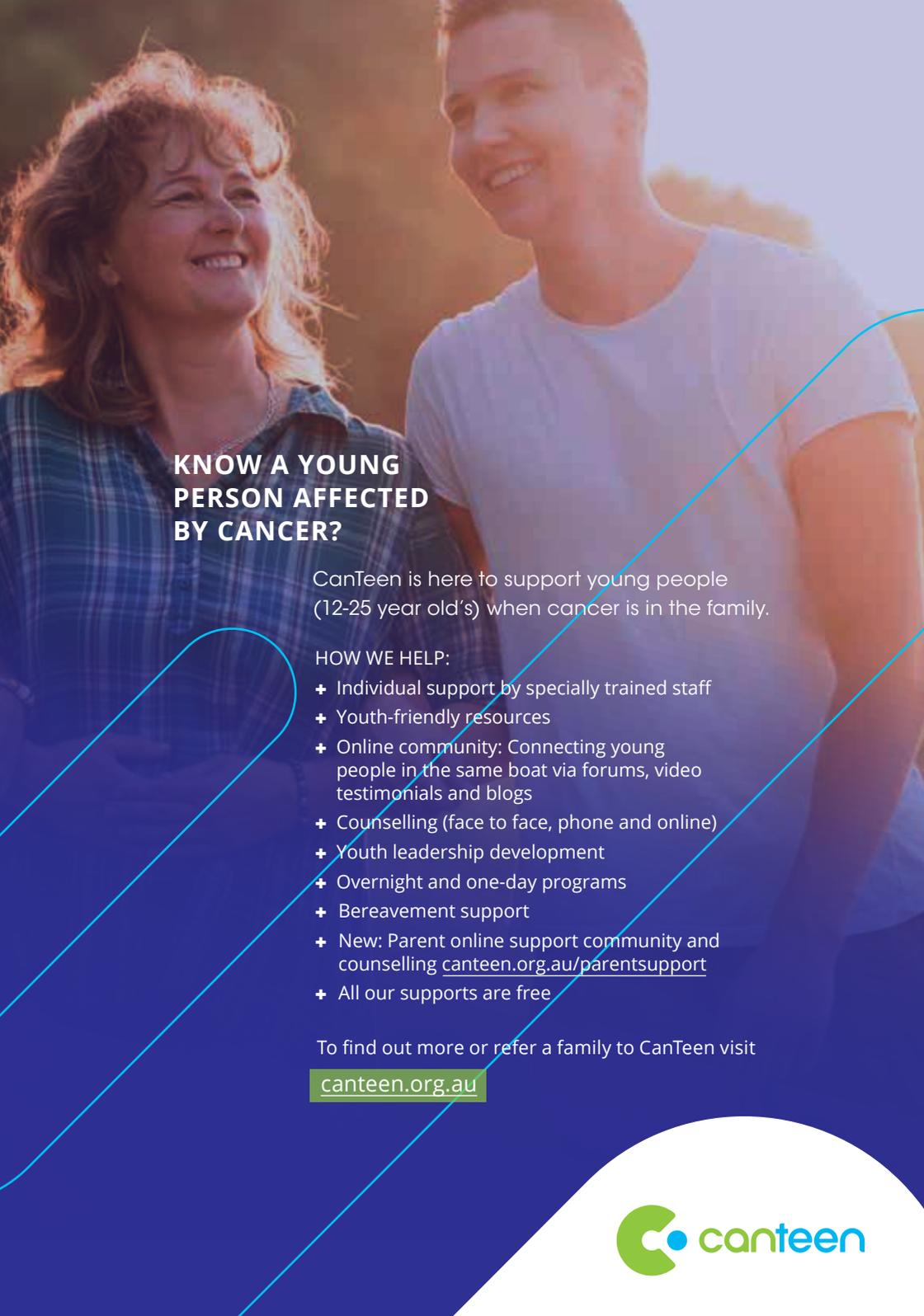
- We partner with hospitals across the country to activate strategies, create needed facilities, and develop services that meet the special requirements of adolescents and young adults with cancer.
- We build youth-friendly environments.
- We enhance standards for age-targeted care, accelerate collaboration between pediatric and adult specialists, and stimulate dedicated research to improve outcomes and survival for our young people.

- 17 Hospital Partners & Rising

- 5,400 Youth Reached

- \$15.5 millions raised

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HOW WE HELP:

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- + Overnight and one-day programs
- + Bereavement support
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- + All our supports are free

To find out more or refer a family to CanTeen visit

canteen.org.au



Transforming the lives of teens & young adults with cancer.

TEEN CANCER AMERICA is a movement to empower and improve the lives of young people with cancer. We create **youth-centered ecosystems** that support young people with cancer, their families, and healthcare professionals. Teen Cancer America integrates everything required to champion a comprehensive youth-centered approach to cancer in hospitals and health systems throughout America.

- We **partner with hospitals** across the country to activate strategies, create needed facilities, and develop services that meet the special requirements of adolescents and young adults with cancer.
- We build **youth-friendly environments**.
- We **enhance standards** for age-targeted care, **accelerate collaboration** between pediatric and adult specialists, and **stimulate dedicated research** to improve outcomes and survival for our young people.

- 17 Hospital Partners & Rising
- 5,400 Youth Reached
- \$15.5 millions raised

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The 2018 Congress Core Planning Group

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Our pre-congress workshop facilitators and contributors

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Our AYA Advocates, Young Leaders and creative contributors

Our outstanding abstract submissions

Maxims travel for your event management

And lastly, our wonderful delegates.

We are sincerely grateful for your contributions in ensuring the success of the 2018 Congress.



The 3rd Global Adolescent and Young Adult Cancer Congress is supported by the funding from the Australian Government under the Youth Cancer Services Program

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