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| ● Archie Bleyer | ● Damon Reed |
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| ● Lindsay Frazier | ● Pam Simon |
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INTERNATIONAL ADVISORS

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| ● Karen Albritton | ● Leonard Sender |
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CANADA

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| ● Ronald Barr |
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| ● Antoinette Anazodo | ● Pandora Patterson |
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| ● Laurence Brugieres | ● Valerie Laurence |
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INDIA

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| ● Prakash Chitalkar |
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| ● Maria Cable | ● Sue Morgan |
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The AYA Global Accord is a collaboration between three charitable organizations: Teen Cancer America, Teenage Cancer Trust and CanTeen Australia. Together they have developed an annual event that will rotate between the UK, USA and Australia. We hope it will become the most important event for professionals working in the AYA field. All three organisations are represented here and have information available. Come and visit the Global Accord exhibition stand for more information.

WELCOME TO ATLANTA!

WE ARE SO DELIGHTED TO WELCOME YOU ALL TO THE 2ND GLOBAL AYA CANCER CONGRESS.

Thank you to everyone who has travelled from around the world to be with us. We are excited to welcome delegates from all 7 continents in an exchange of ideas to explore how we can better work together to achieve more for adolescents and young adults experiencing cancer. The Global AYA Cancer Congress builds on the success of the Teenage Cancer Trust International Conferences. We would also like to extend a huge thank you to our numerous sponsors who have generously helped to fund this important event.

Please do take some time to visit some of them in the Exhibition area and speak to them about their work.

WORKING TOGETHER - ACHIEVING MORE

The AYA Cancer Global Accord is a collaboration between three charitable organizations, Teen Cancer America, Teenage Cancer Trust and CanTeen Australia. Together we have developed an annual event that rotates between the USA, UK and Australia. It is the most important annual event for professionals working in the AYA field.

In this year's event we encourage you to take advantage of this valuable time spent with your colleagues, who are experts in their specialized areas.

We look forward to experts leading us through recent changes in the AYA world, ground-breaking science and best practice models.



Simon Davies



Stuart Siegel

We anticipate thought-provoking presentations from our internationally renowned speakers and lively audience participation from you.

We are so thankful and impressed to have received over 180 abstracts and submissions.

Please do visit these displays since they represent significant international educational value.

The posters contain such a wealth of information - not to be missed!

We also hope to see you engaging in our social events and gatherings. Some of the best ideas are often exchanged in small groups.

Our aim is to increase the exchange of global information and raise awareness regarding adolescent and young adult cancer.

Please be active on your social media channels during the Congress so that we can create a global buzz.

We hope that the Congress inspires you to return to your workplace with new ideas and renewed energy to take care of young people with cancer.

We thank you all for your participation, time and energy so together we can achieve more to better serve the teen and young adult community.

Simon Davies, Executive Director, Teen Cancer America

Stuart Siegel, Scientific Chair, 2nd Global AYA Cancer Congress

General Information (Items are listed in alphabetical order for quick reference)

BADGES

Name badges will be issued to all participants when they arrive at Event Registration. Participants are kindly requested to wear their badge at all times for security purposes. Access to all program sessions and refreshment breaks will only be possible with your own name badge.

The badges are color-coded as follows:

| | |
|----------------|----------------------------|
| Green: | Delegates |
| Blue: | Exhibitors and Sponsors |
| Yellow: | Invited Speakers |
| White: | Event Staff and Volunteers |
| Red: | Hosts and Congress Chairs |

CATERING

Participants' lunches, teas and coffees throughout the Congress will be served from the various service points within the Exhibition area. Please wear your name badge at all refreshment breaks so that the catering staff recognize you as part of this Congress group.

CHECKING OUT OF YOUR ACCOMMODATION

Please ensure that you check-out of your accommodation by the required time and that you settle any hotel room extras (telephone, meals, etc.) on departure.

EXHIBITION

Please take time to visit the Exhibition stands and displays during the Congress breaks and Welcome Reception. The Exhibitors will be pleased to see you and share their material with you. Please refer to **page 97** for information about Exhibitors.

FEEDBACK FORMS

Depending on whether or not you will be claiming US CME or CE credit, we have 2 feedback systems in place for this Congress. The Registration Team will guide you accordingly.

HASHTAG

Follow the conversation on Twitter:



INSTRUCTIONS TO POSTER PRESENTERS AND GLOBAL EXCHANGE DISPLAY PRESENTERS

Posters and displays should be put into place as early as possible on the first day of the Congress and removed at the end of the Congress. Presenters are invited to be by their posters during break times through the Congress to meet and discuss the poster with other participants. Each poster and display has been allocated an area, with a number. This number cannot be moved or the location swapped for any other.

PLEASE REMEMBER TO TAKE YOUR POSTER/ DISPLAY HOME WITH YOU AT THE END OF THE CONGRESS AS POSTERS LEFT BEHIND WILL BE DESTROYED.

A listing of all posters by title is given on **pages 26-32** and global exchange displays on **page 33**.

BEST POSTER AWARD: DELEGATES' CHOICE

A voting paper is included in your delegate bag. Please visit all of the posters and use your voting paper to vote for your favorite.

All voting papers must be received by the end of the morning Coffee Break on Thursday, December 7 for the votes to be tallied and the award prepared and presented during the final afternoon.

We ask that all presenters make themselves available for the Award Presentation at 16:30 hours on Thursday, December 7.

LIABILITY

Neither Teen Cancer America, The Special Event Company, The Global Accord, nor The Hyatt Regency Atlanta is able to take responsibility whatsoever for injury or damage to persons or property during the Congress. Please take care of yourself and your possessions.

MAP OF ATLANTA

Scan this code with your Smart device to access a map of Atlanta.



MESSAGES

The telephone number for the venue is **T +1 (404) 577 1234**. It may take time for messages to reach participants in this large building, but every effort will be made.



MOBILE/CELL PHONES



We appreciate that all Congress participants need to be available for calls, but the hosts and organizers ask **that all mobile/cell phones are switched off or muted in all sessions.**

We would like to make a polite request that any calls be made or taken in the foyer area or as far away as possible from the program room to avoid disruption.

Please do not use your mobile phone, tablet or other recording device to record the Congress. Unofficial recording by audience members is a distraction to other participants and to the presenters: so we politely request that you refrain from doing this in order to protect the professionalism of this event.

REGISTRATION DESK

The Registration Desk will be open during the following hours:

Monday December 4: **07:30 – 19:00 hrs**

Tuesday December 5: **07:30 – 19:00 hrs**

Wednesday December 6: **07:30 – 18:00 hrs**

Thursday December 7: **07:30 – 16:00 hrs**

TAXIS

The helpful foyer staff at the venue will help you with locating a taxi.

VENUE ADDRESS

HYATT REGENCY ATLANTA
265 Peachtree Street, N. E.
Atlanta, GA 30303 USA

Social Program

SOUTHERN HOSPITALITY WELCOME RECEPTION

Tuesday December 5 at the Hyatt Regency Atlanta

Join us in the Exhibition area from 18:00 – 19:30 hours for an informal networking event following the day's program.

This will be an important opportunity to network with international colleagues and to enjoy some Southern hospitality.

All delegates are welcome and badges must be worn.

Dress code: come as you are

GLOBAL ACCORD 2017 DINNER

Wednesday December 6 at the Southern Exchange Ballrooms

The Global Accord Dinner will be held very close-by at the Southern Exchange Ballrooms in Downtown Atlanta, which is a short 2.5 blocks away from the hotel.

The venue is the famous refurbished Macy's Banking Hall, boasting historical significance and contemporary glamour; and will feature a welcome reception, three-course dinner; and great entertainment showcased against this backdrop of southern elegance and charm.

Critical Mass Archie Bleyer Trailblazer Award will also be presented at the Global AYA Congress Dinner and the not-to-be-missed after-dinner speaker will be Professor Archie Bleyer himself, speaking on "What the Global Burden of Disease (GBD) Data Tell Us about AYA Cancer". All places must be pre-booked. Please bring your ticket with you. Transport is not provided.

Dress code: Just be comfortable

Timing: 18:00 – 22:00 hours

Conference Program

Tuesday December 5:

Creating Change

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|-------------|--|
| 07:30 | Registration, Coffee, Networking & Poster Installation |
| 08:30 | Global Accord Welcome <i>Simon Davies</i> , Executive Director, Teen Cancer America <i>Simon Fuller</i> , Director of Services, Teen Cancer Trust <i>Peter Orchard</i> , CEO, CanTeen Australia |
| 08:40 | Opening Remarks <i>Stuart Siegel</i> , MD, Critical Mass, US <i>John Letterio</i> , MD, Case Comprehensive Cancer Center, US |
| 08:50 | KEYNOTE SPEAKER: Simone's Maxims <i>Joe Simone</i> , MD, President, Simone Consulting Chair: <i>Stuart Siegel</i> |
| 09:30-10:45 | SESSION I: Individual & Group Advocacy: The Role of Young People & Advocacy Groups in Creating Change Chair: <i>Brad Zembrak</i> and <i>Mark Haseloff</i> <i>This group was chosen to represent the voices of AYA cancer patients and survivors. Between them their diagnosis included: Brain, Breast, Lymphoma, Leukemia, Sarcoma and Testicular cancers</i> <i>Sarah Stream, Christina Best, Joey Lynch, Ian McLoughlin and Matthew Rienzo</i> |
| 09:30 | Youth panel discussing advocacy & expectations <i>Charissa Thompson</i> , Co-Host/Extra & Sports Journalist/FOX Sports |
| 10:15 | Patients as future leaders in the global knowledge economy <i>Christabel Cheung</i> , PhD MSW, University of Hawaii |
| 10:45-11:15 | Refreshment Break, Networking, Exhibition & Posters |
| 11:15-12:30 | SESSION II: Professional and Institutional Advocacy: Changing Hearts & Minds in your Institution Chair: <i>Sam Smith</i> and <i>Ian McLoughlin</i> |
| 11:15 | Collaboration beats competition between hospitals <i>Karen Albritton</i> , MD, Fort Worth AYA Cancer Coalition, US |
| 11:45 | An international perspective on enhanced AYA nurse practitioner and nurse navigator services <i>Johan De Munter</i> , Nurse Consultant, University of Ghent, Belgium <i>Amelia Baffa</i> , RN MSN, Case Comprehensive Center, Cleveland, US |
| 12:15 | Session I & II Panel Q&A's |
| 12:30-13:45 | Lunch, Networking, Exhibition & Posters |

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| 13:45-15:15 | SESSION III: Political and International Advocacy: Changing National Health Policy and Creating Global Change Chair: <i>Brandon Hayes-Lattin</i> and <i>Christina Best</i> |
| 13:45 | European community raising standards for AYAs <i>Dan Stark</i> , MD, ENTAC Chair, University of Leeds, UK <i>Valerie Laurence</i> , MD, Institut Curie, France |
| 14:15 | Engaging governments around a national vision <i>Peter Orchard</i> , CEO, CanTeen Australia |
| 14:45 | Influencing government to support <i>Kate Yglesias Houghton</i> , President & CEO, Critical Mass, US |
| 15:15-15:45 | Refreshment Break, Networking, Exhibition & Posters |
| 15:45-17:30 | SESSION IV: Engagement & Advocacy in the Digital Age Chair: <i>Simon Davies</i> and <i>Sarah Stream</i> |
| 15:45 | Presenting best practices from CDC's: Implementation of the EARLY Act <i>Temeika Fairley</i> , PhD, Centers for Disease Control and Prevention, US |
| 16:15 | Designing for resilience: The intersection of tech and self on the healing journey <i>Chris McCarthy</i> , VP, HopeLab, US |
| 16:45 | Power & influence of social media within youth groups <i>Desmond Patton</i> , PhD, Columbia University, US |
| 17:15 | Session III & IV Panel Q&A's |
| 17:30 | Closing Remarks |
| 17:35 | Close of Day One |
| 18:00-19:30 | SOUTHERN HOSPITALITY WELCOME RECEPTION <i>Please join us in the Exhibition Area</i> |

Conference Program

Wednesday December 6:

International Developments & New Scientific Advances

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| 07:30 | Registration, Coffee, Networking & Poster Installation |
| 08:15 - 10:15 | SESSION V: Global AYA Progress & Emerging Programs of Activity Chair: Lindsay Frazier and Joey Lynch |
| 08:15 | Contributions from world renowned leaders Lindsay Frazier , MDM ScM, Dana Faber Cancer Center, US |
| 08:30 | Presenting the latest global AYA data Miranda Fidler , PhD, International Agency for Research on Cancer, France |
| 09:00 | Establishing the first AYA facility & program in China Huyong Zheng , MD PhD, Beijing Children's Hospital, China |
| 09:30 | Forging collaborations between pediatric and medical oncologists to get AYAs treated on pediatric protocols Soad Fuentes , MD, Fundacion Aydamé a Vivir, El Salvador |
| 10:00 | Sessions V Panel Q&A's |
| 10:15 - 10:45 | Refreshment Break, Networking, Exhibition & Posters |
| 10:45 - 13:00 | SESSION VI: Breaking New Ground in Scientific & Clinical Research Chair: Dan Stark and Samantha Stacey |
| 10:45 | Precision Genomics in AYA Cancer - the evolving standard of Care John Peter Perentesis , MD FAAP, Professor and Kleisinger Chair for New Cancer Therapies, Director of Oncology & Cancer Programs Cincinnati Children's Hospital, University of Cincinnati College of Medicine |
| 11:15 | Presenting the latest research in AYAs genetic predispositions Stephen Gruber , MD PhD, University of Southern California Norris Comprehensive Cancer, US |
| 11:45 | Cancer Moonshot Team - latest immunotherapy advances for AYA cancer Alex Huang , MD PhD, Case Comprehensive Cancer Center, US |
| 12:15 | AYAs and Clinical trials Eric Tai , MD, Centers for Disease Control and Prevention, US |
| 12:45 | Session VI Panel Q&A's |
| 13:00 - 14:15 | Lunch, Networking, Exhibition & Posters |

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| 14:15 | Debating Adult vs. Pediatric Therapies in A.L.L. Chair: Stuart Siegel and Daniel Bral Debating presenters Assoc. Prof. Tapan Mahendra Kadia , MD Anderson, US; Asst. Prof. Lori Muffly , Stanford Medicine, US; Kevin Oeffinger , MD, Duke Cancer Institute, US: <i>a survivorship perspective</i> Moderators: Stuart Siegel , MD, Critical Mass, US Daniel Bral , medical student, US |
| 15:15 - 15:45 | Refreshment Break, Networking, Exhibition & Posters |
| 15:45 - 17:30 | SESSION VII: New Advances, Challenges & Potential for AYA Cancers Chair: Rebecca Johnson and Daniel Bral |
| 15:45 | Germ Cell Tumors Prof. Robert Huddart , Institute of Cancer Research |
| 16:15 | Soft Tissue Sarcoma Robin Jones , MD, Royal Marsden Hospital, UK |
| 16:45 | Colorectal Cancer David Shibata , MD, University of Texas Health Sciences Center, US |
| 17:15 | Session VII Panel Q&A's |
| 17:30 | Closing Remarks |
| 17:35 | Close of Day Two |
| 18:00 | GLOBAL ACCORD DINNER at the Southern Exchange Ballrooms Guest Speaker - Professor Archie Bleyer What the Global Burden of Disease (GBD) Data Tell Us about AYA Cancer Special entertainment; <i>Casual attire</i> |

Conference Program

Thursday December 7:

Delivering Comprehensive Programs

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| 07:30 | Registration, Coffee, Networking & Posters |
| 08:30 | Four oral presentations of presented abstracts; the judges' favorites Chair: Simon Davies INTRODUCTION: Each oral presentation is to be 8 minutes' long, followed by 3 minutes for questions |
| 08:32 - 08:43 | 01 WIDENING SURVIVAL DISPARITIES BETWEEN AYA WITH ALL TREATED IN PEDIATRIC VS. ADULT CENTERS: A POPULATION-BASED STUDY USING THE IMPACT COHORT S. Gupta , Hospital for Sick Children, Toronto, Canada |
| 08:43 - 08:54 | 02 HEALTH-RELATED GOALS AND PSYCHOSOCIAL MATURITY AMONG ADOLESCENTS AND YOUNG ADULTS (AYA) WITH A HISTORY OF CANCER AND HEALTHY CONTROLS E. S. Stevens , The Children's Hospital of Philadelphia, United States |
| 08:54 - 09:05 | 03 CANCER IN ADOLESCENTS AND YOUNG ADULTS: WHO REMAIN AT RISK FOR POOR SOCIAL FUNCTIONING OVER TIME? B. Zebrack , University of Michigan School of Social Work, Ann Arbor, United States |
| 09:05 - 09:16 | 04 INVESTMENT IN ADOLESCENT AND YOUNG ADULT CANCER RESEARCH IN CANADA P. Grundy , University of Alberta, Edmonton, Canada |
| | Summary/Conclusions |
| 09:20 | CRITICAL MASS ARCHIE BLEYER TRAILBLAZER AWARD Presented by Kate Yglesias Houghton , President & CEO of Critical Mass and Karen DeMairo , BA MHSA Executive Director-Education & Integration of The Leukemia & Lymphoma Society, the sponsor of the award. |
| 09:30-10:45 | SESSION VIII (PART 1): Developing Comprehensive Models of Treatment, Care & Support Chair: Peter Orchard and Mark Haseloff |
| 09:30 | BRIGHTLIGHT - AYA programs adding value Jeremy Whelan , MD, University College London, UK Rachel Taylor , PhD, University College London, UK |
| 10:00 | Lessons shared from the military - largest employer of AYAs. Supportive models & challenges in India and the United States Colonel Prakash Chitalkar , MD, Sri Aurobindo Institute of Medical Sciences, India James Hu , MD, Keck School of Medicine, University of Southern California, US Major Susan Whiteway , MD, Brooke Army Medical Center, US |
| 10:30 | Session VIII Panel (Part I) Q&A's |
| 10:45-11:15 | Refreshment Break, Networking, Exhibition & Posters |

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| 11:15-13:00 | SESSION VIII (PART 2): Chair: Simon Fuller and Joey Lynch |
| 11:15 | Communication & collaboration - Keys to AYA program success Rebecca Johnson , MD, Mary Bridge Children's Hospital, US |
| 11:45 | Oncology professionals addressing sexuality with AYAs Anne Katz , MD, CancerCare Manitoba, Canada |
| 12:15 | Establishing oncofertility programs in the Midwest, USA Lesley Breech , MD, Cincinnati Children's Hospital, US |
| 12:45 | Session VIII Panel (Part 2) Q&A's |
| 13:00-14:15 | Lunch, Networking, Exhibition & Posters |
| 14:15-16:30 | SESSION VIII (PART 3): Chair: Pam Simon and Dan Dean |
| 14:15 | Psychological interventions to support adolescents and young adults with cancer to live their best lives across the cancer trajectory Ursula Sansom-Daly , PhD, Sydney Youth Cancer Services, The University of New South Wales, Sydney, Australia |
| 14:45 | AYA survivorship service model within a multi-cultural environment Jackie Casillas , MD, University of California Los Angeles, US |
| 15:15 | Incorporating physical activity & nutrition into AYA programs Kiri Ness , PT PhD, St. Jude Children's Research Hospital, US |
| 15:45 | Advising AYAs on medical/legal matters in an innovative scheme set up by University of Southern California Yvonne Maria Jimenez , Neighborhood Legal Services of Los Angeles, US |
| 16:15 | Session VIII Panel (Part 3) Q&A's |
| 16:30 | Award for best poster |
| 16:40 | Closing Remarks and passing of 'baton' to CanTeen Australia |
| 16:45 | Conference Closes |

Speaker Backgrounds

December 5 - 7:

Global Accord Welcome

Tuesday 08:30 hours



SIMON DAVIES

Now in its fifth year, Simon leads Teens Cancer America, the only national charity in the USA working directly with hospitals to advise, support and fund them in the development of specialized facilities and programs 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. Recently awarded 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.



SIMON FULLER

I trained as a nurse in the early nineties and specialised in cancer care before moving into NHS management. This led me to develop nurse education programmes, implement National Institute of Clinical Excellence National Cancer Guidance, develop ambulatory care centres across the UK, and implement and commission new services for patient in a variety of specialist areas.

I have always been very focused on cancer care and improvements to patient experience. I moved to Teenage Cancer Trust in 2007 and have lead the development 28 Teenage Cancer Trust units and services in partnership with the NHS across the UK, these services provide dedicated inpatient care and support to 65% of all young people with cancer.

Our focus at Teenage Cancer Trust is to implement a new outreach nursing services to support all young people with cancer across the UK, this new service model won the NursingTimes Best Integrated Care Award in 2015. Every decision we take at Teenage Cancer Trust puts young people with cancer first. It means we always do the right thing for the right reasons and it's a principle that runs to the core of everything we do.

Educated in Birmingham England, I have an MSc Health Service Management and Policy- University of Birmingham Health Service Management Centre, BSc (Hon) Clinical Nursing Studies (Oncology) University of Central England, and a Diploma in Adult Nursing from University of Birmingham.



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 currently 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 fund the rollout of early phase clinical trials for young cancer patients in the coming financial year.

CanTeen also has young people involved at every level of the organisation, including the Board and is committed to advocating for their needs.



Opening Remarks

Tuesday 08:40 hours

STUART SIEGEL

Stuart E. Siegel, M.D., is a Professor of Pediatrics and Medicine at the Keck School of Medicine of USC as well as the former Director of the Center for Global Health at Children's Hospital Los Angeles (CHLA). He was the Founding Director of the Children's Center for Cancer and Blood Diseases and the Center for International Health at CHLA, Co-Founding Medical Director of the USC/Norris AYA Oncology Program, and the first holder of the Stuart E. Siegel, M.D. Endowed Chair in Pediatric Oncology at Keck School of Medicine of USC.

He has held leadership roles in the National Leukemia Broadcast Council, the Make-a-Wish Foundation, and the American Cancer Society and was on the Board of CHLA. He is currently the President of the boards of CureSearch and the Health Care Foundation for Ventura County and is on the boards of the Chase Foundation, Ronald McDonald House Charities Global and the Southern California Ronald McDonald organization.

Dr. Siegel's involvement in the area of Adolescent and Young Adult (AYA) Oncology began with his participation in the joint Lance Armstrong Foundation - NIH sponsored Progress Review Group in 2003. He then served in leadership positions on the Organizing Committee of the Lance Armstrong Foundation's Young Adult Cancer Alliance, and currently is the Secretary of the board of the successor organization, Critical Mass. He brings expertise as a leader in the development of pediatric hematology-oncology programs, an active clinical research career in pediatric oncology, a leadership role in the development and implementation of the discipline of AYA oncology as well as one of the first academic programs in the AYA oncology area, and prior leadership of a number of grant initiatives in pediatric and AYA oncology research and demonstration projects. He has developed and implemented first in the nation medical student and post-specialty clinical and research training programs in AYA oncology. He is the second recipient of the Archie Bleyer, M.D. Trailblazer Award from Critical Mass in 2015 and was an Associate Editor of the first edition of the first AYA oncology textbook, "Cancer in Adolescents and Young Adults."



Keynote Speaker

Tuesday 08:50 hours

JOE SIMONE

Dr. Simone is president of Simone Consulting, clinical director emeritus of the Huntsman Cancer Institute and the professor emeritus of pediatrics and medicine at the University of Utah School of Medicine. He received his medical degree from the Stritch School of Medicine of Loyola University in Chicago in 1960. He completed his training in Chicago with a residency in medicine at Presbyterian-St. Luke's Hospital and a fellowship in pediatric hematology-oncology at the University of Illinois.

Dr. Simone spent most of his medical career at St. Jude Children's Research Hospital in Memphis, where he joined the staff in 1967. In his years there, he was engaged in clinical research efforts to improve therapy for children with cancer; he played a leadership role in the development of curative treatments for childhood leukemia and lymphoma. In 1983, Dr. Simone was named director of St. Jude, at which time he turned his efforts to the administrative leadership of research and the hospital. During Dr. Simone's tenure, St. Jude experienced both a scientific renewal and major growth in its physical facilities.

From 1992 to 1996 he served as physician-in-chief of the Memorial Sloan-Kettering Cancer Center in New York City where he developed several programs aimed at addressing the seismic changes in health care. These included a cancer disease management system and a regional clinical cancer network.

Dr. Simone has served as medical director and chairman of the National Comprehensive Cancer Network and as a member of the Board of Scientific Advisors of the National Cancer Institute (NCI) from 1996 to 2002. He was appointed a member the National Cancer Policy Board of the Institute of Medicine since 1997 and served as its chairman until 2005. He serves on the external advisory committees of 10 NCI-designated cancer centers. He is past chairman of both the Cancer Clinical Investigators Review Committee and the Cancer Center Review Committee of the National Cancer Institute. He is a former president of the Association of American Cancer Institutes and former vice chairman of the Pediatric Oncology Group.

Among his awards and honors, Dr. Simone was elected to the Association of American Physicians. The American Association for Cancer Research awarded him the Richard and Hinda Rosenthal Foundation Award. The American Society of Clinical Oncology awarded him the Distinguished Service Award for Scientific Excellence in 2002, the Public Service Award in 2006, and the ASCO-American Cancer Society Award for efforts in cancer control in 2010. He has received four awards of excellence in writing for his regular column in Oncology Times.



Youth panel discussing advocacy & expectations

Tuesday 09:30 hours

CHARISSA THOMPSON

A Seattle native who attended the University of California, Santa Barbara, Charissa Thompson moved to Los Angeles following graduation. Charissa, once the co-host of Extra is now the host of FOX NFL Kickoff and Sunday NFL pregame shows, where she serves as the show's versatile ringmaster – conducting interviews, leading segments and moderating discussions.

In addition, she recently added the duty of serving as the Sunday game-break anchor for the NFL on FOX. While keeping busy in the broadcasting world Charissa has also made Teen Cancer America a priority in order to shed light on this overlooked age group in cancer care.



Patients as future leaders in the global knowledge economy

Tuesday 10:15 hours

CHRISTABEL CHEUNG

Christabel Cheung, PhD, MSW is an assistant professor at the University of Hawai'i, Myron B. Thompson School of Social Work. She is also chair of the behavioral mental health concentration at The School.

Dr. Cheung's research interests are focused on cancer support, psychosocial oncology, health disparities, health care practice and policy, and sociocultural minority patient populations.

In pursuit of these interests, she has led research projects as principal investigator and co-principal investigator, and contributed to numerous patient education and advocacy initiatives aimed at improving health and behavioral health outcomes. Her prior experience includes serving as lecturer/field consultant on the teaching faculty at the University of California Berkeley's School of Social Welfare. As a social work practitioner, Dr. Cheung last served as executive director of San Francisco Village, a nonprofit organization within the national village movement for aging in place.

Prompted by her personal experience as a two-time cancer survivor, Dr. Cheung builds community with other racial minority patients through her cancer blog JadeGangster.com.



Collaboration beats competition between hospitals

Tuesday 11:15 hours

KAREN ALBRITTON

Karen Albritton, MD, is an oncologist specializing in the care of adolescents and young adults. She graduated from Yale University, received her medical degree at the University of Texas Health Science Center San Antonio, and completed her Medicine/Pediatrics residency and oncology fellowships at the University of North Carolina. She is board certified in both pediatric and medical oncology and has particular expertise in sarcoma.

Her research focuses on access to care and outcomes for AYAs with cancer, and she has been active with the Children's Oncology Group, National Cancer Institute and advocacy organizations to improve policy and standards of care for this underserved group. She is currently Director of AYA Oncology at Cook Children's Medical Center and at Baylor Scott & White All Saints- Fort Worth in Fort Worth, Texas. She is founder and President of the Fort Worth Adolescent and Young Adult Oncology Coalition, a non-profit partnership of oncology providers who have built a community-based AYA program.

An international perspective on enhanced AYA nurse practitioner and nurse navigator services

Tuesday 11:45 hours



JOHAN DE MUNTER

Johan De Munter graduated as a nurse in 2001, worked for five years as a registered nurse on a oncology hematology ward in a general hospital. After postgraduate qualification, he started work as an oncology/hematology nurse consultant for AYA's particularly confronted with testicular cancer, brain tumors, hodgkin's disease, gynecological and breast cancer. In 2010 he transferred to University Hospital Ghent to work in the oncology department as a nurse consultant in the hematology/stem cell transplant unit. He is responsible for providing information, education, treatment and advice to patients with a healthcare question regarding hematological diseases. In addition, he is co-responsible for the transition from pediatric care to adult care for AYA survivors with or after a hematological disorder. Through international education he specialized in the care of AYAs with cancer. In addition, he works with the care4AYA team and Flemish Cancer Society to develop and disseminate specific information, tools and facilities for young people and their carers, inside and outside of the hospital.

He is president of the chemotherapy working group, Belgium Society, for radiotherapy and oncology nurses and is Vice-President of the Belgian Hematology Society Nurses Committee. Recently he was elected as a new European Oncology Nursing Society Board Member. He is also a volunteer Board Member of the Majin Foundation who supports projects of individuals and organizations for people with and after cancer.



AMELIA BAFFA

Amelia Baffa is the Angie Fowler Adolescent and Young Adult Cancer Nurse Navigator at UH Rainbow Babies & Children's Hospital. Ms. Baffa is responsible for care coordination, onco-fertility preservation, program and service line development, patient and staff education, AYA research, and program funding. She has been a nurse for over 30 years, and has worked in various capacities such as: hematology-oncology inpatient, surgical intensive care and trauma, medical-surgical, staff development, pediatric care coordination, patient blood management, she has held several management positions, served as Director of Nursing Practice for a healthcare consulting company. She has presented both nationally and internationally, as well as chaired multiple conference committees. She was awarded the University Hospital Trustee Award for Nursing Excellence and the Red Cross Community Hero Award, in 2015. She was the grant recipient of the Community CureSearch Grant and is the Principal Investigator for a young adult cancer distress study. In 2016 she was awarded a scholarship from Teen Cancer America to become one of the first nurses in the US to attend Coventry University (UK), Teenage and Young Adult Cancer, Post-Graduate Certification program. She is keenly interested in the AYA population and is an active and caring advocate. Her mission is to create programs and services to help them re-engage with life, as they discover who they are after cancer.

European community raising standards for AYAs

Tuesday 13:45 hours



DAN STARK

Dan is an associate professor and consultant physician in Medical Oncology in Leeds in the UK, where they hosted the very first Teenage Cancer Trust conference in the early 1990s. They have had an active AYA unit there since 1998. He works there with a full MDT for TYA patients, and is the lead clinician for the regional service.

He is an active member of the UK national cancer research institute clinical studies group for TYA with cancer, and a co-investigator on the BRIGHTLIGHT cohort study, where Leeds was a leading recruiting centre. Dan was a leader of the ENCCA project, the European Network for Cancer in Children and Adolescents, where he led the workstream on TYA. Since the end of the ENCCA project he has been the first chair of ENTAC, the European multi-professional network for TYA with cancer, and handed over the chairmanship of that to Valerie Laurence this summer. He is involved in supporting NHS policy in TYA cancer through the Clinical Reference Group for NHS England, and recently led the subgroup recommending how to evolve and improve TYA services. He has run recent research projects on psychological distress in AYA with cancer, its detection and management and is part of the 4-way US, Canada, Australia, UK collaborative data pooling exercise in that being led by Canteen in Australia. He is a founding member of the MAGIC collaboration, developing clinical trials in Germ cell tumours which can cross the pediatric/adult interface.

He is a participatory cricketer, a junior cricket coach, father to 4 TYA kids and husband to Andrea.



VALERIE LAURENCE

Valerie LAURENCE M.D is a French medical oncologist specializing in the care of adolescents and young adults. She graduated from Nantes University, received her medical degree at the University of Paris VI in 1997, and completed her Medical Oncology residency and oncology fellowships in Paris. She spent a year in the Teenage Cancer Trust Teenage Unit in 2002 for her training in AYA cancer. She has particular expertise in sarcoma and breast cancer. Consultant in Institut Curie, Paris, France, since 2003, she is currently in charge of the AYA program and medical head of the AYA Unit since 2012. Her research focuses on access to care for AYAs with cancer, and psychosocial adaptation of AYAs with cancer. She is one

of founder and current treasurer of GO- AJA (Groupe en Oncohematologie Adolescents Jeunes Adults), french non-profit organization of professionals from all background involved in AYA cancer care, and she has been active with this group and advocacy organizations like On Est Là to improve policy and standards of care for this underserved group.

She will be the chair of ENTAYAC (European Network for Teenagers and Young Adults with Cancer) in December 2017.



Influencing government to support

Tuesday 14:45 hours

KATE YGLESIAS HOUGHTON

Kate Yglesias Houghton is the President & CEO of Critical Mass: The Young Adult Cancer Alliance. Kate is a dedicated policy professional with more than 10 years of experience in federal policy and elections. Her experience has developed a unique set of leadership qualities that have successfully brought the best people together – no matter their background – to solve complex problems and improve the lives of Americans.

Prior to joining Critical Mass, Kate served a senior staff member to a Chief Deputy Whip in the U.S. House of Representatives and leader of the national Democratic Party. While in the House, Kate was engaged in message development and passage of the Affordable Care Act including adding language to create a federal program to study and educate providers about the risk of breast cancer in young women (EARLY Act of 2010.) In 2011, Kate was asked to serve on President Barack Obama's re-election campaign and traveled to more than 80 cities in the United States over 10 months promoting the benefits of the Affordable Care Act.

While on the campaign trail, Kate was diagnosed with acute myeloid leukemia (AML) at just 27 years old. She successfully completed her treatment over four months at Johns Hopkins Hospital in Baltimore, MD before heading back out on the campaign trail. Kate has worked on three presidential elections, a dozen House elections, and advised countless local level candidates and campaigns throughout her career. Most recently, she served as Director of the Chair's Office at the Democratic National Committee.

In 2009, Kate founded the Congressional Women's Softball Game, an annual event that brings together women of both political parties who play together on one team against the women of the Washington, DC press corp. The Game raised more than \$850,000 for young women battling breast cancer during Kate's tenure as president.

In 2013, Kate found herself to be "too young" to connect her personal story with federal policy advocacy work. Then she connected with Critical Mass and was finally able to lend her unique personal and professional experience to advance the care and treatment of adolescents and young adults at the federal level. Kate was asked to formally join Critical Mass in 2016.

As President & CEO, Kate is focused full-time on ensuring the unique needs of Americans diagnosed with cancer between 15 and 39 years of age are fully recognized by decision makers from hospital administrators to policymakers in Washington, DC. Currently, Kate is spearheading a move to pass legislation, which she authored, to allow any American battling cancer to pause interest from accruing on student loans while in active treatment.



Presenting best practices from CDC's: implementation of the EARLY Act

Tuesday 15:45 hours

TEMEIKA L. FAIRLEY

Dr. Temeika L. Fairley is a Senior Health Scientist with the Centers for Disease Control and Prevention's Division of Cancer Prevention and Control. She earned her PhD in Biology from the University of Vermont in 2001, and shortly afterward joined CDC as an epidemiologist in

the Epidemic Intelligence Service. Dr. Fairley monitored disease outbreaks and helped grow her knowledge and expertise with public health research and support for CDC-funded programs.

In 2003 she moved to the Division of Cancer Prevention and Control (DCPC), working in the Cancer Surveillance Branch, where she had the opportunity to serve as CDC liaison for the Cancer Control PLANET web portal, a resource that provides data and support for users implementing evidence-based cancer programs.

It was while working in epidemiology in the Division's Comprehensive Cancer Control program that Dr. Fairley discovered her interest in cancer survivorship. This interest led her in 2010 to spearhead the development of CDC's cancer survivorship module, the only national population-based data set that collects data on cancer survivors at the state level. Her work on the project created a passion for studying how a cancer diagnosis and cancer treatment affects young adults, specifically young women diagnosed with breast cancer.

She became the lead for efforts to implement the provisions of the Education and Awareness Requires Learning Young (EARLY) Act, which directs CDC to provide support for young women at risk for or diagnosed with breast cancer.

In this role, Dr. Fairley directs public health research, program support, and communications, guiding a multi-disciplinary team in putting the tenets of the EARLY Act into practice. Her investment in research continues to this day; she puts her interest and expertise to work in the fields of health disparities and breast cancer survivorship, especially for women diagnosed under the age of 40.



Designing for resilience: the intersection of tech and self on the healing journey

Tuesday 16:15 hours

CHRIS MCCARTHY

Chris McCarthy is the Vice President of Strategy & Innovation at Hopelab where he is excited to deepen its impact on the health and wellness of young people through design and systems thinking. He is also the Executive Director and Founder of the Innovation Learning Network.

His work has been featured in the Harvard Business Review (Sept 2010), Bisognano and Kenney's "Pursuing the Triple Aim: Seven Innovators Show the Way to Better Care, Better Health, and Lower Costs" (2012) as well as FastCompany, the New York Times and many more.

In his previous role at Kaiser Permanente's Innovation Consultancy, he tackled safer medication administration for patients, more robust shift changes for nurses, exploring the social space of elders, and the care experience of transgender people.

As an author, he collaborated with Lyle Berkowitz, MD on "Innovation with Information Technologies in Healthcare" (2012), and with Lisa Schilling on Schall's "Spreading Improvement Across Your Health Care Organization" (2007). You can find his quirky design blog at McCarthyChris.com. He was named the 2015 H.I.T. Innovator and the 2011 Ellerbe Beckett Lecturer. And is an international speaker on innovation and design.

Chris has a master's in business administration from Rensselaer Polytechnic Institute / Copenhagen Business School, and a master's in public health in Health Policy from the University of Massachusetts at Amherst. In his spare time, he obsesses about fitness and an occasional doughnut.



Power & influence of social media within youth groups

Tuesday 16:45 hours

DESMOND PATTON

Dr Desmond Upton Patton is an assistant professor at the Columbia School of Social Work, a Faculty Affiliate of the Social Intervention Group (SIG) and the Data Science Institute, and a fellow at the Berkman Klein center for Internet and society at Harvard 2017-2018.

His research utilizes qualitative and computational data collection methods to examine how and why youth and gang violence, trauma, grief and identity are expressed on social media and the real world impact they have on well-being for low-income youth of color.



Contributions from world renowned leaders

Wednesday 08:15 hours

LINDSAY FRAZIER

Dr. Frazier is Associate Professor of Pediatrics at Harvard Medical School and Epidemiology at the Harvard School of Public Health and an Institute Physician at the Dana-Farber/Boston Children's Cancer and Blood Disorders Program, where she serves as the Medical Director of the Center for Adolescent and Young Adult Oncology.

Dr. Frazier received her undergraduate and medical degrees from Dartmouth College, trained in pediatrics and pediatric hematology-oncology at Boston Children's Hospital and received a Master of Science degree from the Harvard School of Public Health. Dr. Frazier is the chair of the Germ Cell Tumor Committee of the Children's Oncology Group and the chair of the Malignant Germ Cell Tumor International Consortium that includes the world's clinical, scientific and epidemiologic experts in this disease.

Dr. Frazier also does research in global oncology and is currently the vice-chair of the Lancet Commission on Sustainable Pediatric Cancer Care in Low and Middle Income Countries and the North American President of SIOP, the International Society of Pediatric Oncology. Dr. Frazier was a founding member and served as the Director of the Growing Up Today Study, a prospective cohort of 25,000 of the offspring of women in the Nurses' Health Study; her research in this cohort has focused on tobacco use prevention, skin cancer prevention, reducing rates of benign breast disease, a precursor of breast cancer, and obesity prevention.



Presenting the latest global AYA data

Wednesday 08:30 hours

MIRANDA FIDLER

Miranda Fidler, PhD, is an epidemiologist specialized in the field of childhood, adolescent, and young adult cancer. After receiving her bachelor and master degrees from Boston University and University College London, respectively, Miranda pursued a PhD within the Centre for Childhood Cancer Survivor Studies at the University of Birmingham; here she utilized the British Childhood Cancer Survivor Study, Teenage and Young Adult Cancer Survivor Study, and PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies to assess a wide range of late effects among cancer survivors diagnosed before age 40. In 2015, Miranda joined the International Agency for Research on Cancer in Lyon, France, where she currently leads research efforts on assessing the burden of cancer in adolescents and young adults globally.



Establishing the first AYA facility & program in China

Wednesday 09:00 hours

HUYONG ZHENG

Dr. Huyong ZHENG achieved MD from Suzhou Medical College, Master of Medicine from Peking Union Medical College, and PhD from Capital Medical University. During 2000 to 2003 she had her post-doctoral training in MD Anderson Cancer Center. Now she is the head of Pediatric Hematology Oncology Branch of Chinese Medical Doctor Association, the Member of Hematology Branch of Beijing Medical Association. She is the Associate Editor of *J China Pediatric Blood and Cancer*, the Board Member of *Chinese J Pediatrics*, *Chinese J Practical Pediatrics* and *Blood Research*. She was elected as Beijing Municipal Scientific and Technologic New Star in 1996, elected in 100 talents in "10-100-1000" Excellent Talent Program by Beijing Municipal Government in 2004, elected in New Century Excellent Talents Program by Beijing Municipal Government in 2008 and elected as Academic Leader of Pediatrics by Beijing Municipal Health System Program in 2011.

Her career has combined clinical practice with research and teaching (undergraduate and postgraduate). Her research interests have included: Gene classification of leukemia, multidisciplinary treatment of childhood and adolescent leukemia. During her career she has held 25 projects from Chinese National Programs 863, National Natural Science Foundation, Beijing Natural Science Foundation, and Beijing Municipal Scientific and Technologic Committee Grant. She is the first author or corresponding author of over 100 peer reviewed papers, chapters and book reviews.



Forging collaborations between pediatric and medical oncologists to get AYAs treated on pediatric protocols

Wednesday 09:30 hours

SOAD FUENTES

Soad Fuentes Alabi, MD, is the Director of Pediatric Hematology/Oncology Day Clinic at Hospital Nacional de Niños Benjamin Bloom El Salvador, C.A. She graduated from Evangelica University of El Salvador School of Medicine, completed her Pediatrics residency at the National University of El Salvador while doing her pediatric hematology/oncology fellowship at Universidad Autonoma de Mexico, and received her Master's degree in Public Health at Harvard School of Public Health. Soad Fuentes Alabi is an active member of the Association de Hemato-Oncologia Pediatrica Centro Americana (AHOPCA) which was founded in an attempt to narrow the survival gap and has collaborated on numerous publications on pediatric hematology/oncology. Her research focuses on neuroblastoma, solid tumors, and also the pediatric cancer burden and socioeconomic factors that impact on children and young people in Central America.



Precision genomics in AYA Cancer - the evolving standard of Care

Wednesday 10:45 hours

JOHN PETER PERENTESIS

John is a Professor of Pediatrics and Director of the Division of Oncology & Cancer Programs at Cincinnati Children's Hospital and the University of Cincinnati where he holds the Deb Kleisinger Endowed Chair for New Cancer Therapies. His career is focused on advancing childhood & young adult cancer translational research at the national level, with an emphasis on the development of novel technologies and integration into frontline therapies. This work spans laboratory drug discovery efforts for new molecular-targeted therapies to digital patient care navigation. For the National Cancer Institute, he serves as a member of the Investigational Drug Development Steering Committee, an initiative to identify and prioritize new agent development for both adults and children. In the Children's Oncology Group, he is the Vice-Chair of the Adolescent and Young Adult Cancer Steering Committee, and is a nationally elected member of the COG Hematology/Oncology Steering Committee. He has previously served as Chair of the Myeloid Relapse Committee and as a nationally elected member of the COG Executive Committee.



Presenting the latest research in AYAs genetic predispositions

Wednesday 11:15 hours

STEPHEN GRUBER

Dr. Gruber is a physician and scientist. For the past 25 years he has been studying the causes, prevention and treatment of cancer.

As a practicing physician, Dr. Gruber is a nationally recognized expert in hereditary cancer and continues to see patients and families with genetic susceptibility. As a scientist, Dr. Gruber has made important discoveries about the causes of cancer, and discoveries about how to prevent cancer in patients and families. Dr. Gruber has been studying the genetics of the Jewish Diaspora for more than 15 years, and he leads the world's largest consortium study of colon cancer genetics. He has led cancer studies in Israel with Dr. Gad Rennert since 1997.

Dr. Gruber obtained his Bachelor's Degree from the University of Pennsylvania, and his Master's in Public Health and PhD in Cancer Epidemiology from Yale. He went on to medical school and his residency in internal medicine at the University of Pennsylvania. He completed fellowships in medical oncology at Johns Hopkins Hospital and in clinical medical genetics at the University of Michigan.

Dr. Gruber serves as the Director Emeritus of USC Norris Comprehensive Cancer, and holds the Jane & Kris Popovich Chair in Cancer Research. Dr. Gruber continues to see patients and families with inherited susceptibility to cancer and to run his research laboratory dedicated to understanding the genes that cause cancer in families and strategies to reduce the burden of cancer in patients and populations.



Cancer Moonshot Team - latest immunotherapy advances for AYA cancer

Wednesday 11:45 hours

ALEX HUANG

Dr. Alex Huang is Professor of Pediatrics, Pathology, Biomedical Engineering and General Medical Sciences at Case Western Reserve University in Cleveland, Ohio. He holds the Theresa G. & Stuart F. Kline Family Foundation Chair in Pediatric Oncology at UH Rainbow Babies & Children's Hospital / Angie Fowler AYA Cancer Institute. Currently, he leads the Tumor Immunology & Immunotherapy Interest Group and serves as co-leader of the Hematopoiesis & Immune Cell Biology (HICB) Program at the Case Comprehensive Cancer Center. In this capacity, Dr. Huang oversees immune cell-based and immune modulatory cancer therapeutic development at the Case Comprehensive Cancer Center. He is also the Associate Director of the Pediatric Hematology-Oncology Clinical Fellowship Training Program at UH Rainbow Babies & Children's Hospital after serving for a decade as Director.

Most recently, Dr. Huang served as a member of the Cancer Moonshot Initiative Blue Ribbon Panel Working Group on Cancer Immunotherapy as well as the inaugural Fellow of the Harrington Discovery Institute. Dr. Huang's research focuses on understanding aspects of immune regulation at the tissue level in cancer, autoimmunity and trauma.

The ultimate goal of his research program is to utilize the power of the immune system to control aggressive and metastatic cancers in the pediatric and adolescent and young adult patients.



AYAs and Clinical trials

Wednesday 12:15 hours

ERIC TAI

Eric Tai MD MS, is a medical officer in the Division of Cancer Prevention and Control at the Centers for Disease Control and Prevention. His work focuses on pediatric, adolescent, and young adult cancer, and survivorship care. He completed his undergraduate education at the Georgia Institute of Technology, medical degree from the Medical College of Georgia, and completed Pediatrics and Preventive Medicine residencies at the University of Maryland.

Debating Adult vs. Pediatric Therapies in A.L.L.

Wednesday 14:15 hours



TAPAN MAHENDRA KADIA

Dr. Kadia is Associate Professor in the Department of Leukemia, Division of Cancer at MD Anderson Cancer Center. He is actively involved in clinical and translational research for the treatment of patients with leukemia. His particular focus is in developmental therapeutics in acute leukemia, including individualized frontline therapy, biologically rational targeted therapy, and longer term maintenance strategies in AML and ALL. His primary investigator on numerous trials in acute leukemia, T-cell leukemias, bone marrow failure states, and has published extensively in these areas.



LORI MUFFLY

Dr. Lori Muffly is an Assistant Professor of Medicine at Stanford University. She specializes in blood and marrow transplantation and cellular therapies for patients with blood cancers. Her clinical research involves clinical trial development and health outcomes research aimed at improving outcomes for adult patients with acute leukemia.



KEVIN OEFFINGER

Kevin Oeffinger, MD, is a family physician, a member of the Duke Cancer Institute (DCI), the founding Director of the DCI Center for Onco-Primary Care, and Director of the DCI Supportive Care and Survivorship Center.

Prior to joining Duke in April 2017, Dr. Oeffinger was the Director of the Cancer Survivorship Center at Memorial Sloan Kettering Cancer Center. He has a long-standing track record of NIH-supported research in cancer screening and survivorship and has served in a leadership capacity in various cancer-focused and primary care-focused national committees and organizations, including the American Society of Clinical Oncology, the American Cancer Society, and the American

Academy of Family Physicians.

The three-fold mission of the DCI Center for Onco-Primary Care are to: (1) deliver evidence-based, patient-centered, personalized health care across the cancer continuum by enhancing the interface between cancer specialists and primary care clinicians; (2) conduct innovative research with cutting-edge technology that can be translated to the community setting; and (3) train and educate the next generation of clinicians and researchers to extend this mission.



DANIEL BRAL

Daniel Bral holds dual undergraduate degrees from Yeshiva University in Sociology with a Pre-Medical Concentration as well as a degree in Judaic Studies. He earned a Masters of Science at Georgetown University in Biophysics and Physiology while concentrating in Complementary and Alternative Medicine. He is currently a fourth year dual-degree medical student earning medical doctorate in addition to his Masters of Public Health at Nova Southeastern University. He is also fluent in Spanish, Hebrew, and Farsi.

Mr. Bral's dedication and passion comes from his own personal experience with cancer. At the age of eleven Daniel was diagnosed with Non-Hodgkin's Lymphoma and was placed on an intensive chemotherapy protocol until the age of fourteen, when he was finally able to try to catch up on his life as a new teenager. Through this experience, Daniel knows first-hand the unique needs of teens and young adults during and after active treatment since the fight doesn't stop with the medicines, there are other challenges that teens and young adults face even after treatment.

In addition to his dedication with Teen Cancer America, Mr. Bral also serves on the Board of Directors for Kids Kicking Cancer, and is one of the longest standing survivors with Imerman Angels, helping give one-on-one support to newly diagnosed cancer patients. He is also a national ambassador for The Gift of Life Bone Marrow Registry, serving as both a speaker and organizer for bone marrow drives and fundraising efforts.

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Germ Cell Tumors

Wednesday 15:45 hours

ROBERT HUDDART

Robert Huddart is Professor in Urological Cancer and Honorary consultant Clinical Oncologist at the Institute of Cancer Research (ICR) and Royal Marsden Hospital in the UK. After undertaking a PhD in Molecular genetics of testicular cancer, he was appointed to his role as a clinical academic specialising in the management of urological cancer with a special interest in testicular and bladder cancer. He has a long standing interest in developing novel treatments for testicular cancer, investigating survivorship and late effects issues and understanding the genetics of testicular cancer. He is a former Chair of the National Cancer Research Institute testis research group, member of MaGic germ cell consortium, past author of ESMO testicular guidelines and member of ESMO, European and Canadian guideline consensus groups.



Soft Tissue Sarcoma

Wednesday 16:15 hours

ROBIN JONES

Dr Jones has both a private and an NHS practice at The Royal Marsden Hospital in Sutton, Surrey, UK. He is a medical oncologist specialising in the treatment of bone and soft tissue sarcomas and Head of the Sarcoma Unit at The Royal Marsden. He has experience in conducting Phase I, II and III trials, as well translational studies in sarcoma. Dr Jones trained in medical oncology at The Royal Marsden and between 2010 and 2014 he was Head of the Sarcoma Program at the University of Washington/Fred Hutchinson Cancer Research Center in Seattle, USA.

His main research interest focuses on clinical trials of novel agents and immunotherapy in sarcoma.



Colorectal Cancer

Wednesday 16:45 hours

DAVID SHIBATA

Dr. David Shibata is the Scheinberg Endowed Chair of Surgery, Professor and Chairman of the Department of Surgery, Deputy Director of the UT West Cancer Center and Surgeon-in-Chief at the University of Tennessee Health Science Center in Memphis, TN.

Dr. Shibata attended medical school at McGill University in Montreal, Canada and received his General Surgery training at the Beth Israel Deaconess Medical Center in Boston, MA. He completed a Research Fellowship in Cancer Biology at Harvard Medical School and a Surgical Oncology Fellowship at Memorial Sloan-Kettering Cancer Center in New York, NY.

Dr. Shibata's clinical practice is primarily dedicated to the treatment of patients with colorectal cancer. He is particularly interested in robotic and laparoscopic minimally-invasive approaches to the treatment of colorectal cancer as well as sphincter-preserving techniques for patients with rectal cancer. He also has strong expertise in the management of high risk and hereditary colorectal cancer.

Dr. Shibata sits on the panel of the National Comprehensive Cancer Network (NCCN) that establishes national guidelines for the treatment of patients with cancers of the colon, rectum and anus. He is also a member of the Lower GI Cancer expert panel of the American Joint Cancer Commission (AJCC) that establishes guidelines for the staging of colorectal cancer.

He is actively involved in colorectal cancer clinical research and clinical trials. Dr. Shibata's laboratory research is actively funded by the National Cancer Institute and centers on the study of specific molecular mechanisms such as DNA methylation that contribute to the development of colorectal cancer.

BRIGHTLIGHT - AYA programs adding value

Thursday 09:30 hours



JEREMY WHELAN

Professor Jeremy Whelan trained as a medical oncologist in London. He developed an interest in cancer affecting young people not least through caring for teenagers being treated in general cancer wards in the 1990s. As a consequence, he has both developed a large specialist clinical service at University College Hospital for teenagers and young adults with cancer as well as developing an extensive research programme and supporting the development of national policy initiatives for TYA cancer care. In addition, he leads a major clinical research programme in sarcoma



RACHEL TAYLOR

Dr Rachel Taylor is an adult/children's trained nurse and has worked in research for over 20 years. She developed an interest in young people's quality of life when they are living with long-term conditions during her PhD. On completion of her PhD Rachel came to University College London Hospital to conduct the work to underpin BRIGHTLIGHT, which she now leads. This programme of work has expanded to include additional studies, focusing on improving the lives of young people with cancer.

Lessons shared from the military - largest employer of AYAs. Supportive models & challenges in India and the United States

Thursday 10:00 hours



PRAKASH CHITALKAR

Dr Colonel Prakash Chitalkar (retired) had a distinguished career in the Indian Army Medical Corps for 27 years during which he was a passionate scholar, teacher, then a medical and pediatric oncologist. He realized the critical role of age –appropriate cancer care for the young patients in the military, with the unique calling, and their unique bonding with Regiment, and nation.

Since 2012 he began a sensitizing campaign among oncology professionals across India in the needs and aspirations of young cancer patients (age group 15-29 years). The non-profit Teenage & Young Adult Cancer Foundation (India) emerged with the mission of ensuring that every young person in India gets the best opportunity for the cure of cancer, and also of achieving his/ her life-dream !

The Armed Forces provided Colonel Prakash with the best moral environment in which to treat cancer. An inspiration, and insight into young and robust persons' perspective of cancer emerged. With the dynamism of his military years behind him, and with the emerging national interest in AYA Oncology, Dr Chitalkar hopes to establish a nationwide alliance of cancer professionals, survivors, caregivers and volunteers to address the “voices of young people with cancer.”

His presentation will highlight the Indian military's tradition of physical, moral, and spiritual support to every young soldier, sailor, airman, or officer with cancer; while sharing some challenges in research and survivorship.



JAMES HU

James Hu, MD, FACP, is the medical director of the Sarcoma Program of USC, and is highly involved in clinical trial research. Dr. Hu has more than 20 years of clinical experience in medical oncology and brings this acumen to the bedside.

Understanding the rarity of sarcoma cancers, Dr. Hu has the breadth of clinical experience as well as the academic discipline to provide each patient with an individualized treatment program. He has collaborated with other national experts to bring clinical trials to USC. He is a member of the Connective Tissue Oncology Society, and has linked the Sarcoma Program of USC with the international collaborative group: Sarcoma Alliance for Research through Collaboration

(SARC), to further direct research into sarcoma.

Dr Hu has authored many articles on the management of sarcoma and holds a keen interest in the use of immunotherapy in sarcomas. As a former military commander of a combat support hospital, Dr. Hu has years of experience in the issues surrounding young adult disease and along with

Dr. David Freyer, is the co-director of the Adolescent and Young Adult program of USC and Children's Hospital Los Angeles. This program offers specialized services tailored to adolescent and young adult patients who comprise a significant portion of patients diagnosed with sarcoma. Dr Hu and his medical oncology team pride themselves on patient accessibility and are committed to providing comprehensive oncology care and up to date clinical trials to the patient with sarcoma. In addition, he is the director of the Oncology Fellowship program and is a highly respected teacher of future oncologists.

Finally, Dr Hu has served as a US Army physician over a 30 year career and is a graduate of the United States Army War College.



SUSAN WHITEWAY

Major Susan L. Whiteway is an active duty Air Force Pediatric Hematology/Oncology physician currently serving in San Antonio, Texas. She received her commission through the ROTC program at Colorado State University and attended medical school at the Uniformed Service University in Bethesda, MD.

She attended Pediatric Residency at the San Antonio Uniformed Services Health Education Consortium and went on to fellowship at Children's Hospital Colorado in Aurora, CO. Since her graduation in 2012, she has been serving as a staff Pediatric Hematology/Oncology physician in San Antonio, Texas.

She is a member of the American Society for Pediatric Hematology/Oncology and Children's Oncology Group. Her research interests include evaluating Toxicity Profiles between pediatric and young adult patients.



Communication & collaboration - keys to AYA program success

Thursday 11:15 hours

REBECCA JOHNSON

Dr. Rebecca Johnson is a physician in the division of Pediatric Hematology/Oncology at Mary Bridge Hospital in Tacoma, WA. Her medical training includes Pediatrics, Internal Medicine, Genetics and Pediatric Oncology.

Dr. Johnson's is the founder of the nationally recognized Adolescent and Young Adult (AYA) oncology program at Seattle Children's Hospital. She is now developing an AYA program at Mary Bridge hospital/MultiCare Health System and exploring the unique issues of AYAs treated at community cancer centers through an ongoing Patient Centered Outcomes Research Institute (PCORI) grant.

Her research interests include cancer epidemiology; she and colleagues reported that the incidence of metastatic breast cancer is increasing in women under 40 years of age and that the incidence of testicular cancer is increasing in AYA Hispanics in the United States. She is also interested barriers to clinical trial enrollment in young adults, particularly those treated in community hospitals. At present, approximately 85% of all AYAs in the United States are never seen at academic centers.

Johnson participated in the development of the NCCNAYA Oncology Care Guidelines and also the NCCN Guidelines for AYA Cancer Patients. She served as co-chair of the steering committee of the LIVESTRONG Young Adult Alliance, Vice President of the Interim Board of Directors and later on the Emeritus Board of Directors of Critical Mass: Young Adult Cancer Alliance. She is a member of the National Clinical Trials Network (NCTN) and National Community Oncology Research Program (NCORP) AYA working groups, and the advisory boards for both the Children's Oncology Group AYA Committee and the Canadian Partnership for Cancer AYA Task Force. She is co-chair of the AYA oncology committee of the Southwest Oncology Group (SWOG).



Oncology professionals addressing sexuality with AYAs

Thursday 11:45 hours

ANNE KATZ

Anne Katz, RN, PhD, is the author of four books on cancer and related illnesses, including *Surviving After Cancer: Living the New Normal*. She is also a sexuality counselor at CancerCare Manitoba and adjunct professor with the Faculty of Nursing at the University of Manitoba, Winnipeg, MB Canada. Late adolescence and young adulthood are - bar none - the most important phases of milestone development. These are the years when individuals decide who they are and who they are attracted to. The early years of this period are where sexual identity is explored and often established; some will continue to question their sexuality for years. As time goes by, sexuality is cemented and for many relationships become more emotionally intimate and committed. But what if something life altering happens and this growth is halted?

Cancer is widely regarded as a biological interruption creating a gap in multiple developmental tasks, including creating a sexual identity. When dating and/or meeting prospective partners is put on hold due to illness or hospitalization, individuals miss the opportunity for emotional and sexual connection. Disclosure of a distant or present cancer history is a very real challenge for AYA survivors with no perfect time or way of telling someone about missing parts, scars or unpredictable sexual functioning.

All these issues, and more, will be addressed in Anne's session on Thursday December 7. Information about sexuality is a vital part of ongoing cancer care that is often neglected in AYAs but it is about the survivor's body, life and rights for sexual health and happiness.



Establishing oncofertility programs in the MidWest, USA

Thursday 12:15 hours

LESLEY BREECH

Lesley Breech, MD, is specially trained in pelvic reconstruction and other medical and surgical management of genital anomalies. She has nearly nine years' experience providing surgical and medical gynecology at Emory University and the University of Cincinnati College of Medicine.

Dr. Breech has a special interest in the care of girls and young women with abnormalities of development of the reproductive organs. In 2004, Dr. Breech joined the multidisciplinary care provided by the Center for Pediatric Pelvic and Genitourinary Reconstruction at Cincinnati Children's Hospital Medical Center.

She also provides gynecologic care for young women with bleeding disorders, polycystic ovarian syndrome, endometriosis, and other gynecologic concerns of pediatric and adolescent females.

Psychological interventions to support adolescents and young adults with cancer to live their best lives across the cancer trajectory



Thursday 14:15 hours

URSULA SANSOM-DALY

Dr Ursula Sansom-Daly is a clinician-researcher and a Post-Doctoral Fellow at the School of Women's and Children's Health, UNSW Medicine, University of NSW, Sydney Australia. She leads the mental health research team within the Behavioural Sciences Unit, Sydney Children's Hospital, the largest research group dedicated to psychological aspects of paediatric/adolescent cancer in Australasia. She holds prestigious Early Career Fellowships from both the National Health and Medical Research Council (NHMRC) and the Cancer Institute NSW (CINSW), and has been chief investigator on grants >\$4.8M. Dr Sansom-Daly has received numerous awards for her research, including the inaugural CINSW 'Rising Star' PhD Student Award 2014.

Dr Sansom-Daly is also the Clinical Psychologist for Sydney Youth Cancer Service, the leading clinical team for the treatment and care of adolescents and young adults aged 15-25 years with cancer in Sydney, Australia. Reflecting her dual clinical-research roles, Dr Sansom-Daly focuses on applying evidence-based psychology to both understand, and address, mental health issues among adolescents and young adults with cancer from diagnosis through to survivorship and end-of-life.

Career highlights to date have included travelling to Washington DC in 2012, to train with experts at the National Cancer Institute in best-practice psychosocial care for adolescents with cancer. This was funded by the prestigious Adam J. Berry Memorial Fund by the National Institutes of Health and the Australian Academy of Science. Dr Sansom-Daly was named as one of the 2017 Top 5 Under 40 'scientists in residence' by the Australian Broadcasting Corporation (ABC), an honour which involved a two-week media residency with Australia's national broadcaster.

AYA survivorship service model within a multi-cultural environment



Thursday 14:45 hours

JACKIE CASILLAS

Jacqueline Casillas, MD, MSHS is a Professor of Pediatrics, Division of Pediatric Hematology/Oncology at the David Geffen School of Medicine at UCLA. She holds several leadership roles including: the Medical Director of the Jonathon Jaques Children's Cancer Center at Miller Children's Hospital Long Beach, the Medical Director of the Daltrey/Townsend Teen and Young Adult Oncology Program at UCLA; and the Director of the Pediatric, Adolescent and Young Adult Survivorship Program at UCLA. She has been active in different national efforts to improving the care for the AYA population including: being an external reviewer of the Institute of Medicine's "Identifying and Addressing the Needs of Adolescents and Young Adults with Cancer: Workshop Summary."

She is a health services researcher at UCLA's Jonsson Comprehensive Cancer Center with a focus on the access to care and quality of care for pediatric, adolescent and young adult cancer survivors. Her research has included a focus on development of novel interventions for AYA survivors including text messaging to improve the receipt of recommended survivorship care screening.

She is active in community partnered participatory research with community based organizations to improve the care of diverse populations of cancer survivors.

She has been recognized by different community organizations and received different awards that include, the Humanitarian of the Year Award from Padres Contra El Cancer, as well as, the Advocacy Award for being a champion for fertility preservation for young adults touch by cancer, Fertile Action.



Incorporating physical activity & nutrition into AYA programs

Thursday 15:15 hours

KIRI NESS

Kirsten K. Ness is a physical therapist and clinical epidemiologist and Member of the faculty at St. Jude Children's Research Hospital. She has a BA in Physical Therapy, an MA in Leadership and an MPH and PHD in Epidemiology. She is a Catherine Worthingham Fellow of the American Physical Therapy Association and has been in Physical Therapy practice for over 30 years. Her research focuses on the observation and remediation of functional loss among persons who were treated for cancer during childhood. She has funding from the American Cancer Society, the Gabrielle's Angel's Foundation, the National Cancer Institute, and the National Institute of Child Health and Human Development. She has over 180 peer reviewed publications and serves on the Steering Committees for the Childhood Cancer Survivor Study and the Children's Oncology Group Survivorship and Outcomes Committee. She is a member of the Survivorship Committee for the American Society for Clinical Oncology, an active member of the Oncology Section of the American Physical Therapy Association, and on the Editorial Boards of Pediatric Physical Therapy, Rehabilitation Oncology, and the Journal of Clinical Oncology.



Advising AYAs on medical/legal matters in an innovative scheme set up by University of Southern California

Thursday 15:45 hours

YVONNE MARIAJIMINEZ

Yvonne is the Deputy Director for Neighborhood Legal Services of Los Angeles County (NLSLA), a private, non-profit law firm which provides free legal services and advocacy to poor and low income individuals and families residing in Los Angeles County.

Yvonne oversees NLSLA's four (4) Medical Legal Community Partnerships. MLCPs use the power of doctors, lawyers and other health professionals, to identify and ameliorate the social determinants of health impacting both individual and community health status. In 2014 Yvonne was awarded a Where Health Meets Justice Fellowship by the National Medical Legal Partnership Foundation to support her efforts to seek sustained funding for NLSLA's MLCPs.

She has partnered with the County of Los Angeles via the Department of Health Services (DHS) in this effort. In 2017 MLCPs were embedded in the DHS Whole Person Care organizational structure, a laser-focused effort assisting high-risk populations such as homeless and homeless mentally-ill individuals. This is a significant outcome for NLSLA and all MLCPs in LA County. Yvonne earned her B.S. in Business Administration at USC and her J.D. at Loyola Law School, Los Angeles.

Poster Listing

The posters will be displayed near the Exhibition Hall (Level LL2) throughout the Congress. Please visit them all. They are arranged by category groupings.

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P1 - P8: Allied Health

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| P1 | IMPROVING FERTILITY OUTCOMES FOR AYAS (ADOLESCENTS AND YOUNG ADULTS) WITH HODGKIN DISEASE: THE IMPORTANCE OF A MULTIDISCIPLINARY CARE PATH FOR YOUNG PEOPLE | Belgium |
| P2 | NUTRITIONAL SCREENING IN ADOLESCENT AND YOUNG ADULT ONCOLOGY OUTPATIENT SERVICES | United Kingdom |
| P3 | AN INVESTIGATION INTO THE NUTRITIONAL MANAGEMENT OF PAEDIATRIC AND ADOLESCENT OSTEOSARCOMA PATIENTS | United Kingdom |
| P4 | AN INVESTIGATION INTO THE NUTRITIONAL STATUS OF ADOLESCENT AND YOUNG ADULTS UNDERGOING STEM CELL TRANSPLANT | United Kingdom |
| P5 | FITNESS4SURVIVORS: A PILOT STUDY EXAMINING THE IMPACT OF A 10-WEEK CROSSFIT EXERCISE PROGRAM ON THE FITNESS AND QUALITY OF LIFE WITH TEENAGER AND YOUNG ADULT (TYA) CANCER SURVIVORS | United Kingdom |
| P6 | YOUNG PEOPLE LIVING WITH MALIGNANT MELANOMA AND THEIR FAMILY: AN INTERPRETIVE PHENOMENOLOGICAL STUDY | United Kingdom |
| P7 | SEX DEVELOPMENT IN ADOLESCENT ACUTE LEUKEMIA WITH CHEMOTHERAPY ONLY: A PROSPECTIVE SELF-COMPARISON STUDY | People's Republic of China |
| P8 | AYA@USC MODEL OF CARE: IMPLEMENTATION OF EXPANDED SUPPORTIVE CARE SERVICES | United States |

P9 - P23: Case Study

| | | |
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| P9 | THE CANTEEN PSYCHOSOCIAL MODEL: A STEPPED-CARE APPROACH TO PSYCHOSOCIAL SUPPORT AND WELLBEING FOR YOUNG PEOPLE LIVING WITH CANCER | Australia |
| P10 | IMPROVING EDUCATION FOR NURSE NAVIGATOR IN ONCOFERTILITY ROLE | United States |
| P11 | EDUCATING THE AYA CANCER WORKFORCE- LESSONS LEARNT 10 YEARS ON. | United Kingdom |
| P12 | USING A VIRTUAL CLINICAL ETHICS COMMITTEE TO FACILITATE LEARNING ON ETHICAL DECISION-MAKING IN TEENAGE/YOUNG ADULT (TYA) CANCER CARE. | United Kingdom |
| P13 | UNUSUAL TUMOUR BEHAVIOUR LEADS TO AN UNSETTLING REQUEST | Australia |
| P14 | SUPPORT, DEVELOP, EMPOWER: THE CO-CREATION OF A YOUTH LEADERSHIP FRAMEWORK IN AN AUSTRALIAN NATIONAL YOUTH CANCER ORGANISATION | Australia |
| P15 | PHILOSOPHY SKILLS TRAINING PILOT FOR HEALTH CARE PROFESSIONALS TO ADDRESS AYA EXISTENTIAL UNMET NEEDS | Belgium |
| P16 | BIO FIELD ARRAY: A CASE STUDY WITH FIBROLAMELLAR HEPATOCELLULAR CARCINOMA IN A TEENAGE MALE | United States |
| P17 | THE AUSTRALIAN YOUTH CANCER SERVICE: A NATIONAL APPROACH TO ENSURING THE BEST POSSIBLE CARE AND HEALTHY FUTURES FOR YOUNG PEOPLE WITH CANCER | Australia |
| P18 | PHILOSOPHY SKILLS TRAINING FOR AYA IN UK AND BELGIUM | Belgium |
| P19 | TO TESE OR NOT TO TESE: FERTILITY PRESERVATION IN A CRITICALLY ILL AYA CANCER PATIENT IN AN ICU SETTING: A CASE REPORT | United States |
| P20 | THE ROLE OF THE SOCIAL WORKER / PATIENT NAVIGATOR IN THE DEVELOPMENT AND IMPLEMENTATION OF A FERTILITY PRESERVATION PROTOCOL | United States |
| P21 | ADMINISTRATIVE DEVELOPMENT OF AN AYA CANCER PROGRAM | United States |

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P9 - P23: Case Study *(continued)*

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| P22 | REFLECTIONS ON THE CHALLENGES OF PROVIDING PSYCHOLOGICAL SUPPORT FOR STAFF WORKING WITH TYA SERVICES – OR ‘YOU CAN TAKE A HORSE TO WATER BUT YOU CAN’T MAKE IT DRINK’ | United Kingdom |
| P23 | BUILDING A COMPREHENSIVE, COLLABORATIVE AYA CANCER PROGRAM--THE UIHC EXPERIENCE | United States |

P24 - P38b: Medical

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| P24 | RACIAL DIFFERENCES IN COMORBIDITIES AMONG ADOLESCENTS AND YOUNG ADULTS UNDERGOING ALLOGENEIC HEMATOPOIETIC STEM CELL TRANSPLANTATION | United States |
| P25 | IMPLEMENTATION OF A COMPREHENSIVE PATIENT ASSISTANCE PROGRAM IMPACT ON THE AYA POPULATION | United States |
| P26 | INCOMPLETE OVERLAP: COMPARISON OF COMMITTEE STRUCTURES BETWEEN ADULT AND PEDIATRIC COOPERATIVE CLINICAL GROUPS HIGHLIGHTS OPPORTUNITIES FOR IMPROVED COLLABORATION | United States |
| P27 | LENGTH OF STAY DIFFERENT, WHILE TREATMENT-RELATED COMPLICATIONS SIMILAR IN PEDIATRIC AND AYA LYMPHOMA PATIENTS IN U.S. CHILDREN'S HOSPITALS | United States |
| P28 | ESTABLISHING A FERTILITY PROGRAM IN A PEDIATRIC HOSPITAL: THE AYA EXPERIENCE | United States |
| P29 | CDC'S BRING YOUR BRAVE CAMPAIGN: IMPROVING HEALTHCARE PROVIDER EDUCATION ABOUT EARLY ONSET HEREDITARY BREAST AND OVARIAN CANCER | United States |
| P30 | PERCEPTIONS OF AND ATTITUDES TOWARDS CLINICAL TRIALS IN ADOLESCENT AND YOUNG ADULTS WITH CANCER: A SYSTEMATIC REVIEW OF THE LITERATURE | Canada |
| P30 | PERCEPTIONS OF AND ATTITUDES TOWARDS CLINICAL TRIALS IN ADOLESCENT AND YOUNG ADULTS WITH CANCER: A SYSTEMATIC REVIEW OF THE LITERATURE | Canada |
| P31 | OUTCOMES OF EWING SARCOMA (ES) IN ADOLESCENTS AND YOUNG ADULTS (AYA) : A COMPARATIVE ANALYSIS | India |
| P32 | EPIDEMIOLOGY AND PATHWAYS OF CARE FOR ADOLESCENTS WITH LYMPHOMA IN FRANCE (2011-2014) | France |
| P33 | IMPACT OF ONLINE ACCESS TO RARE EXPERTISE IN ADOLESCENT AND YOUNG ADULT (AYA) CANCERS: PROSPECTIVE ANALYSIS OF AN ONLINE EXPERT OPINION SERVICE IN INDIA | India |
| P34 | LIMITING SIXTY DAY MORTALITY AND TOXICITY IN HEMATOLOGICAL CANCERS AMONG TEENAGE & YOUNG ADULT PATIENTS IN A RURAL ACADEMIC CENTRE IN CENTRAL INDIA | India |
| P35 | MULTI-SITE CHART REVIEW OF FERTILITY PRESERVATION DISCUSSIONS FOR AYA PATIENTS | United States |
| P36 | A RETROSPECTIVE ANALYSIS OF CLINICAL TRIAL ACCRUAL AND ASSOCIATED BARRIERS FOR ADOLESCENT AND YOUNG ADULT CANCER PATIENTS PRESENTED IN A MULTIDISCIPLINARY TUMOR BOARD MEETING AT A TERTIARY CARE CENTER | United States |
| P37 | OUTCOMES FOR AYA PATIENTS POST ALLOGENEIC HEMATOPOIETIC STEM CELL TRANSPLANTS | United States |
| P38 | QUALITATIVE AND QUANTITATIVE CHANGES IN DIET AND APPETITE IN TEENAGERS AND YOUNG PEOPLE UNDERGOING RADIOTHERAPY FOR THE TREATMENT OF CANCER | United Kingdom |
| P38a | RECRUITMENT TO CLINICAL TRIALS IS ASSOCIATED WITH SUPERIOR SURVIVAL IN TEENAGE AND YOUNG ADULT PATIENTS WITH ACUTE LYMPHOBLASTIC LEUKAEMIA | United Kingdom |
| P38b | THE DELIVERY OF AMBULATORY CARE IN TEENAGE AND YOUNG ADULTS UNDERGOING CHEMOTHERAPY: A LARGE SINGLE CENTRE EXPERIENCE | United Kingdom |

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P39 - P51: Nursing

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| P39 | EXPLORING THE ROLE CONFIDENCE AND COMPETENCIES OF NURSES WHO CARE FOR ADOLESCENTS AND YOUNG ADULTS WITH CANCER IN AIMING TO 'ACHIEVE MORE'. | United Kingdom |
| P40 | THE ROLE OF THE ADVANCED NURSE PRACTITIONER IN ADOLESCENT AND YOUNG ADULT ONCOLOGY | United Kingdom |
| P41 | THE NURSES' FEELING OF DIFFICULTY FOR CARING FOR ADOLESCENT AND YOUNG ADULT CANCER SURVIVORS IN JAPAN | Japan |
| P42 | EVALUATION OF A TEENAGE & YOUNG ADULT (TYA) LONG TERM FOLLOW-UP (LTFU) SERVICE FOR SURVIVORS OF CANCER IN CHILDHOOD | United Kingdom |
| P43 | IMPROVING AYA CANCER CARE AWARENESS FOR ONCOLOGY NURSES: A PILOT AYA CARE WORKSHOP FOR FLEMISH ONCOLOGY POSTGRADUATE NURSING STUDENTS | Belgium |
| P44 | THE SUPPORT SITUATION AND ISSUES OF SEXUALITY AND FERTILITY IN ADOLESCENT AND YOUNG ADULT CANCER PATIENTS AND SURVIVORS | Japan |
| P45 | IMPROVING EDUCATION FOR NURSE NAVIGATORS IN THE ONCOFERTILITY ROLE | United States |
| P46 | EXPERIENCE BASED CO-DESIGN (EBCD) PROJECT FOCUSING ON END OF TREATMENT PHASE OF CARE WITH ADOLESCENT AND YOUNG ADULTS | United Kingdom |
| P47 | DEVELOPING A SERVICE TO ADDRESS THE PSYCHOSOCIAL NEEDS OF YOUNG ADULTS WITH CANCER | United Kingdom |
| P48 | REFLECTION ON A CONNECTION :THE MENTOR MENTEE RELATIONSHIP AS PART OF THE FLORENCE NIGHTINGALE SCHOLARSHIP EXPERIENCE | United Kingdom |
| P49 | PRELIMINARY REFLECTIONS ON BODY ODORS OF AYA PATIENTS TREATED BY CHEMOTHERAPY WITH MESNA INJECTION | France |
| P50 | NURSE LED TRANSITION FOR YOUNG PEOPLE WITH ACUTE LYMPHOBLASTIC LEUKAEMIA (ALL) FROM CHILDRENS SERVICES TO THE TEENAGE CANCER UNIT | United Kingdom |
| P51 | ADOLESCENT AND YOUNG ADULT NAVIGATION IN AN ADULT ONCOLOGY OUTPATIENT CLINIC | United States |

P52 - P72: Other

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| P52 | YOUNG PEOPLE AS RESEARCH PARTNERS: 10 YEARS OF THE BRIGHTLIGHT EXPERIENCE | United Kingdom |
| P53 | RISE ADVOCACY: RAISING THE VOICES OF YOUNG WOMEN WITH BREAST CANCER | United States |
| P54 | A QUALITATIVE STUDY TO UNDERSTAND THE BARRIERS TO RECRUITING ADOLESCENTS AND YOUNG ADULTS WITH CANCER TO BRIGHTLIGHT, A NATIONAL COHORT STUDY | United Kingdom |
| P55 | NOT US. NOT NOW. NOT EVER: A MULTI-LEVEL CAMPAIGN TO REDUCE HPV-ASSOCIATE CANCERS THROUGH MOBILIZING STUDENTS, DISPELLING MYTHS AND PROMOTING EARLY DETECTION AND PREVENTION PRACTICES | United States |
| P56 | ACCEPTABILITY AND SCALABILITY OF A DIGITAL PLATFORM FOR AYA AND PROFESSIONALS: THE IMPLEMENTATION OF THE IAM PORTAL INTO THE EAST MIDLANDS ADOLESCENT AND YOUNG ADULT (AYA) CANCER SERVICE (UK) | United Kingdom |
| P57 | ADDRESSING THE SEXUAL HEALTH CONCERNS OF ADOLESCENTS AND YOUNGER ADULTS (AYA) WITH CANCER: AN INTERNATIONAL EFFORT | Canada |
| P58 | DESCRIPTIVE EPIDEMIOLOGY OF CANCER IN ADOLESCENTS AND YOUNG ADULTS: RESULTS FROM THE QUEENSLAND CANCER CONTROL ANALYSIS TEAM 1982-2014 | Australia |

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P52 - P72: Other *(continued)*

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| P59 | "IS THE DOCTOR IN?" MAKING CONNECTIONS WITH HEALTHCARE PROVIDERS | United States |
| P60 | AN EVALUATION OF EDUCATION FOR HEALTH AND SOCIAL CARE PROFESSIONALS CARING FOR CHILDREN AND YOUNG PEOPLE WITH CANCER: A NATIONAL APPROACH | United Kingdom |
| P61 | CONCEPTUALISING AGE-APPROPRIATE CARE FOR TEENAGERS AND YOUNG ADULTS WITH CANCER: A BRIGHTLIGHT STUDY | United Kingdom |
| P62 | THE AUSTRALIAN YOUTH CANCER FRAMEWORK FOR ADOLESCENTS AND YOUNG ADULTS WITH CANCER; STRATEGIC PRIORITIES FOR AUSTRALIA TO 2020 AND BEYOND | Australia |
| P63 | INFORMATION NEEDS ON SEXUALITY, CONTRACEPTION AND FERTILITY IN ADOLESCENTS AND YOUNG ADULTS WITH CANCER: A SINGLE-CENTER STUDY | France |
| P64 | LET'S PLAY TWISTER! NOVEL METHODS TO FACILITATE UNDERSTANDING OF COMPLEX RESEARCH METHODS AND GENERATE SECONDARY RESEARCH HYPOTHESES WITH YOUNG PEOPLE | United Kingdom |
| P65 | THE DEVELOPMENT AND EVALUATION OF A REFLEXOLOGY SERVICE FOR ADOLESCENT AND YOUNG ADULTS WITH CANCER AND THEIR SUPPORTERS | United Kingdom |
| P66 | IMPACT OF FACILITY TRANSFER ON TREATMENT DELAY AFTER CANCER DIAGNOSIS IN ADOLESCENT AND YOUNG ADULT PATIENTS | United States |
| P67 | RAISING AYA CANCER AWARENESS THROUGH PERSONAL NARRATIVE | United States |
| P68 | AYA CANCER IN NEW ZEALAND - A WAY FORWARD | New Zealand |
| P69 | CENTER FOR ADOLESCENT AND YOUNG ADULT ONCOLOGY AT DANA-FARBER CANCER INSTITUTE | United States |
| P70 | THE DEVELOPMENT OF A UNIQUE REGIONAL TEENAGER AND YOUNG ADULT CANCER SERVICE IN NORTHERN IRELAND, UNITED KINGDOM | United Kingdom |
| P71 | THE HOSPITAL ENVIRONMENT FROM THE PERSPECTIVE OF YOUNG PEOPLE AFFECTED BY CANCER | Belgium |
| P72 | POSTER WITHDRAWN | |

P73 - P130: Psychosocial

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| P73 | THE DEVELOPMENT AND USER EVALUATION OF A HEALTH BEHAVIOUR CHANGE INTERVENTION FOR TEENAGE AND YOUNG ADULT CANCER SURVIVORS | United Kingdom |
| P74 | PLACES YOU'LL GO: DEVELOPMENT AND EVALUATION OF A CAMP PROGRAM FOR ADOLESCENT CANCER SURVIVORS | Australia |
| P75 | DETERMINING CONTENT VALIDITY OF AUSTRALIAN DISTRESS SCREENING TOOLS FOR USE BY CANADIAN ADOLESCENT AND YOUNG ADULT (AYA) CANCER SURVIVORS | Canada |
| P76 | SEXUAL FUNCTIONING AMONG YOUNG ADULT CANCER PATIENTS; A 2-YEAR LONGITUDINAL STUDY | United States |
| P77 | POSTER WITHDRAWN | |
| P78 | DYNAMICS IN THE CANCER EXPERIENCE OF ADOLESCENTS AND YOUNG ADULTS: THE 3-PHASE PROCESS | Belgium |

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P73 - P130: Psychosocial (continued)

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| P79 | DEVELOPMENT OF A MOBILE-BASED PSYCHOSOCIAL INTERVENTION FOR ADOLESCENTS AND YOUNG ADULTS WITH SARCOMA | United States |
| P80 | PUTTING AYAS IN A ROOM TOGETHER: LAUNCHING AND ADOLESCENT AND YOUNG ADULT ONCOLOGY COUNCIL | United States |
| P81 | DEVELOPMENT OF A SOCIAL SUPPORT INTERVENTION FOR AYA PEERS: &##*@! MY FRIEND HAS CANCER! | United States |
| P82 | ONCOLOGY PROVIDER PERSPECTIVES ON COMMUNICATING ABOUT SEXUAL AND REPRODUCTIVE HEALTH WITH ADOLESCENT AND YOUNG ADULT CANCER PATIENTS | United States |
| P83 | DO RESIDENTIAL WEEKENDS FOR YOUNG PEOPLE WITH CANCER ADD VALUE? PERCEPTIONS OF CARERS/SIGNIFICANT OTHERS | United Kingdom |
| P84 | FIRST DESCENTS, AN ADVENTURE PROGRAM FOR YOUNG ADULTS WITH CANCER: WHO BENEFITS? | United States |
| P85 | IMPROVING THE PROCESS OF REFERRALS TO PSYCHOSOCIAL CARE FOR YOUNG ADULTS | United States |
| P86 | DO RESIDENTIAL WEEKENDS FOR YOUNG PEOPLE WITH CANCER ADD VALUE? INTERIM ANALYSIS OF A TWO DAY RESIDENTIAL WEEKEND IN THE UNITED KINGDOM, FIND YOUR SENSE OF TUMOUR | United Kingdom |
| P87 | INFORMATION AND SUPPORT NEEDS OF CARERS: DO SPECIALIST SERVICES FOR ADD VALUE? | United Kingdom |
| P88 | AFTER CANCER TREATMENT. SO WHAT NOW? | United Kingdom |
| P89 | CASE STUDY – MAKING SENSE OF “MEMORY” DIFFICULTIES POST CANCER | United Kingdom |
| P90 | ADOLESCENT AND YOUNG ADULT SURVIVORS OF CHILDHOOD LEUKEMIA: PARENT AND SURVIVOR KNOWLEDGE OF LATE EFFECTS RISKS | United States |
| P91 | OCCUPIED WITH CANCER: TRAJECTORIES OF EMPLOYMENT/EDUCATION AND PSYCHOLOGICAL DISTRESS AMONG SOCIOCULTURALLY DIVERSE ADOLESCENT AND YOUNG ADULT CANCER PATIENTS | United States |
| P92 | EMR DOCUMENTATION OF TOBACCO, ALCOHOL, AND DRUG USE AMONG AYA PATIENTS IN A PEDIATRIC SETTING | United States |
| P93 | ASSESSMENT OF PSYCHOSOCIAL NEEDS IN AYA PATIENTS IN A NEWLY ESTABLISHED AYA ONCOLOGY PROGRAM | United States |
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| P97 | DEVELOPING A NOVEL MECHANISM TO PROMOTE TEEN AND YOUNG ADULT PATIENT CONNECTIVITY | United States |
| P98 | FACTORS INFLUENCING VISUAL AND VERBAL SELF DISCLOSURE OF VIDEO NARRATIVES IN TEENAGERS WITH CANCER: A PILOT STUDY | United States |
| P99 | HEALTH-RELATED QUALITY OF LIFE OF CANCER SURVIVORS: WHICH DOMAINS ARE PARTICULARLY RELEVANT TO YOUNG ADULTS? | United Kingdom |
| P100 | ESTABLISHING AN AYA PATIENT NAVIGATION SERVICE TO ADDRESS UNMET NEEDS | United States |

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| PI01 | LOVEYOU TO DEATH | United Kingdom |
| PI02 | TELEMENTAL HEALTH FOR ADOLESCENT AND YOUNG ADULT CANCER SURVIVORS | United States |
| PI03 | CAN VIDEO TESTIMONIALS BENEFIT ADOLESCENTS WITH CANCER? | United States |
| PI04 | BREAKING THE ICE: ESTABLISHING EFFECTIVE AYA PSYCHOSOCIAL SUPPORT IN A UNIQUE CARE ENVIRONMENT | United States |
| PI05 | DOES AGE MATTER? A COMPARISON OF HEALTH-RELATED QUALITY OF LIFE ISSUES OF ADOLESCENTS AND YOUNG ADULTS WITH OLDER ADULTS WITH CANCER | United Kingdom |
| PI06 | THE LONG ROAD AHEAD: USING CONCEPT MAPPING TO IDENTIFY KEY YOUNG ADULT CANCER SURVIVORSHIP ISSUES | United States |
| PI07 | YOUNG WOMEN WITH METASTATIC BREAST CANCER: LEAVING A LEGACY | United States |
| PI08 | ABOUT RELATIONSHIPS BETWEEN AYA AND CAREGIVERS, THROUGH TOOLS SUCH AS MOBILE PHONE, E-MAILS OR SOCIAL NETWORKS. | France |
| PI09 | POSTER WITHDRAWN | |
| PI10 | POSTER WITHDRAWN | |
| PI11 | IMPLEMENTING AN ADOLESCENT AND YOUNG ADULT MENTOR RETREAT AND EDUCATION CURRICULUM: WISE INVESTMENT FOR EMERGING AYA PATIENT LEADERS | United States |
| PI12 | CANCER COSTS: EXPLORING THE FINANCIAL AND EMOTIONAL IMPACT OF CANCER ON AYA | United Kingdom |
| PI13 | "AFFECTIONATE MANAGERS" A QUALITATIVE RESEARCH ON THE EXPERIENCES OF CARE GIVING PARENTS OF ADOLESCENTS AND YOUNG ADULTS WITH CANCER AND THE DEVELOPMENT OF A BOOKLET | Belgium |
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Oral Presentation

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allowed the
inclusion here
of appendices:
tables, figures etc.
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ORAL PRESENTATION ABSTRACTS



O1/OP1

WIDENING SURVIVAL DISPARITIES BETWEEN AYA WITH ALL TREATED IN PEDIATRIC VS. ADULT CENTERS: A POPULATION-BASED STUDY USING THE IMPACT COHORT

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Studies in AYA ALL have shown pediatric-based treatment protocols result in better survival compared to adult protocols, leading to increased use of the former in adult centers. Whether this has diminished survival disparities between pediatric and adult centers is unknown. The IMPACT Cohort comprises all Ontario, Canada AYA 15-21 years old diagnosed with one of six cancers (including ALL) 1992-2011. Detailed data were collected through chart abstraction. Predictors of locus of care (LOC – pediatric vs. adult) were examined, including age, gender, time period (1992-1998 vs. 1999-2005 vs. 2006-2011), rurality, and socioeconomic status. The impact of LOC on event-free and overall survival (EFS/OS) was determined. Of 271 patients, 152 (56%) received therapy at an adult center. Older patients and those in the earliest time period were likelier to be treated in adult centers. The 5-year EFS of patients treated at a pediatric vs. adult centers was 69.8%±4.2% vs. 50.7%±4.0% ($p=0.0006$). There was no significant improvement in EFS over time. In multivariable analysis, only LOC was significantly associated with EFS [adult vs. pediatric hazard ratio (HR) 4.0; 95CI 1.4-11.9]; age and time period were not predictive. The disparity in EFS/OS between pediatric and adult centers widened over time (Table 1). In the earliest time period there was no significant difference in OS between adult vs. pediatric centers (HR 1.8; 95CI 0.8-4.3). The HR increased and achieved significance in the middle era (HR 2.4; 95CI 1.0-5.6) and widened further in the recent era (HR 4.3; 95CI 1.4-13.8). Despite superior outcomes with pediatric-based protocols and increased use of such protocols at adult centers, outcomes did not improve over the study period. Survival disparities between pediatric and adult centers widened, with the largest disparities seen most recently. At a population-level, the use of pediatric protocols may not be sufficient to abolish LOC-based outcome disparities.



O2/OP2

HEALTH-RELATED GOALS AND PSYCHOSOCIAL MATURITY AMONG ADOLESCENTS AND YOUNG ADULTS (AYA) WITH A HISTORY OF CANCER AND HEALTHY CONTROLS

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INTRODUCTION AND AIMS: Adolescents and young adults ages 15-29 (AYA) with a history of cancer have difficulty setting and pursuing goals and

developmental milestones. Despite their vulnerable health and risk for late effects of treatment, AYA do not engage in recommended health promoting behaviors. However, it is unclear whether or not they set less health-related goals (HRGs) relative to peers, an important precursor to optimal health behaviors. In order to understand those at risk for poor health promotion and targets of intervention to improve it, we compared the number of health-related goals of AYA and healthy peers and the association with goal importance, development and maturity.

METHODS: Ninety-eight AYA with a history of cancer and 67 healthy controls completed measures of general HRGs (e.g., eating healthy), goal importance, achievement of developmental milestones, emotion regulation (reappraisal/suppression), and psychosocial maturity (consideration of future consequences). Covariates were age, age at diagnosis, gender, treatment status (on/off treatment) and cancer type. Correlations, t-tests and multivariable regressions were used.

RESULTS: AYA reported less HRGs [M (SD)=3.20(1.97)] compared to controls [M (SD)=3.80(1.81); $p=0.048$]. Significant predictors of total HRGs for AYA included being female ($b=1.13$, $p=0.002$), reappraisal emotion regulation ($b=0.52$, $p=0.005$), and consideration of future consequences ($b=1.28$, $p=0.007$) (Full model: $F[4,96]=9.21$, $R^2=0.29$, $p<0.001$). The importance of HRGs was the only significant correlate with HRGs in healthy AYA ($r=0.27$, $p=0.03$).

DISCUSSION AND CONCLUSIONS: AYA with cancer identified fewer HRGs compared to healthy AYA, which may ultimately further compromise their health. Along with the variation in predictors of HRGs among AYA and healthy peers, these results confirm the impact of cancer on development. Interventions for AYA with cancer should target AYA development and encourage family and school-based efforts to promote continued psychosocial maturity and emotional learning, especially among males, in order to increase setting and pursuing of HRGs.



O3/OP3

CANCER IN ADOLESCENTS AND YOUNG ADULTS: WHO REMAIN AT RISK FOR POOR SOCIAL FUNCTIONING OVER TIME?

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INTRODUCTION AND AIMS: Understanding social functioning among adolescent and young adult (AYA) cancer patients over time is important to know who remains at risk for poor outcome and to determine potential relevant services and resources required to serve them. Aim of this study was to examine social functioning among AYAs in the first two years after cancer diagnosis and compare their scores to population norms; identify trajectories of social functioning over time and its correlates.

METHODS: A multicenter, longitudinal study was conducted among 215 AYA cancer patients aged 14-39 years. One hundred forty-one patients completed a self-report measure of social functioning within the first four months of diagnosis and again 12 and 24 months later.

RESULTS: AYA cancer patients had significantly worse social functioning scores around diagnosis (52.0 vs. 85.1; $p<0.001$), 12-month follow-up (73.1 vs. 85.1; $p<0.001$) and 24-month follow-up (69.2 vs. 85.1; $p<0.001$) when compared



to population norms. Significant improvements in social functioning from baseline to 12-month follow-up were observed; however, social functioning levels remained stable thereafter.

Among participants, 9% showed consistently high/normal social function, 47% improved social function, 13% worsening social function, and 32% consistently low social function. AYA cancer patients who had consistently low social function were more often off-treatment at follow-up, reported more physical symptoms and higher levels of distress at baseline and follow-up and perceived less social support at baseline, compared to the other three groups.

DISCUSSION AND CONCLUSION: Although improved over time, social functioning was still compromised 24 months after primary diagnosis. Almost a third of the patients remain at risk for poor social functioning. Reducing physical symptoms and psychological distress and enhancing social support by intervention in the period after treatment may potentially help these young survivors to better reintegrate into society.



O4/OP4

INVESTMENT IN ADOLESCENT AND YOUNG ADULT CANCER RESEARCH IN CANADA

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INTRODUCTION AND AIMS: To determine the proportion of cancer research investment in Canada relevant to adolescent and young adults.

METHOD: Data was obtained from the Canadian Cancer Research Alliance's Canadian Cancer Research Survey (CCRS). Data included projects between 2005 and 2013 identified using 20 search terms. 987 projects were identified. Three independent reviewers examined project abstracts to code projects as either AYA-specific or AYA-included. AYA-specific cancer research studies focus on an AYA-specific topic (e.g., fertility) or restrict eligibility to the AYA age range (15–39 years). AYA-included cancer research studies include pediatric or adult subjects, with eligibility that includes 15–39 years. Proportion of investment was used to compare AYA research funding to overall investment, by disease and type of research.

RESULTS: AYAs (aged 15–39 years) represent approximately 4% of new cancer diagnoses per year, but the average annual investment in AYA-specific cancer research between 2005 and 2013 was \$1.8 million, or 0.4% of total cancer research investments in Canada. Research that included AYAs but was not AYA-specific averaged \$12.1 million per year, representing 2.2% of average annual cancer research investment. Over 80% of research funding for AYA-specific studies between 2005 and 2013 was for three disease groups: sarcomas, breast cancer, and germ cell tumours (testis and ovary). AYA-specific research funding was lacking in other disease groups that have high age-specific mortality, including leukemia, central nervous system tumours, colorectal cancer, melanoma and female genital tract cancers. In 2013, the most frequently funded types of AYA-specific research were cancer control, survivorship and outcomes research.

DISCUSSION AND CONCLUSION: AYAs are significantly under-represented when it comes to cancer research funding in Canada. Increased awareness of the unique aspects of both the biology of AYA cancers and the AYA cancer journey has focused attention on the inequity regarding funding for AYA cancer research.

POSTER ABSTRACTS



P1

IMPROVING FERTILITY OUTCOMES FOR AYAS (ADOLESCENTS AND YOUNG ADULTS) WITH HODGKIN DISEASE: THE IMPORTANCE OF A MULTIDISCIPLINARY CARE PATH FOR YOUNG PEOPLE

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INTRODUCTION AND AIMS: Yearly, 13% of Adolescents and Young Adults (AYAs) with Cancer in Belgium (ages 15-29) are diagnosed with Hodgkin's disease (HD). With high survival rates among young people with HD, fertility is an important quality of life (QoL) concern. Healthcare providers are not always knowledgeable about infertility risks associated with HD therapies. Different barriers are often the reason of not addressing fertility preservation options prior treatment. To support HD patients in their decision-making

about infertility risks and fertility preservation options it is crucial that they all are well informed prior to treatment.

METHODS: An Interdisciplinary group was assembled for developing an evidence-based care pathway for HD. Healthcare providers from different staffs shared evidence-based knowledge, expertise and skills to have positively impact on young patients with HD survivorship outcomes. A standard cancer-related comprehensive fertility counselling was included prior to treatment and in the survivorship care plan. The current change to full reimbursement of fertility preservation for Belgian cancer patients confirmed the importance of oncofertility!

RESULTS: Implementation of a care pathway increased awareness about fertility preservation for AYAs with cancer among all healthcare providers within the haematology department. The improved collaboration between fertility specialists, physicians and the specialized oncology nurses will improve reproductive outcomes in AYA cancer care. Related to the care pathway, the fertility service provide weekly emergency consultation slots for urgent fertility concerns. Although financial burden in AYA cancer patients is often a factor influencing decision-making, a consultation with an oncology fertility specialist prior to treatment was received positive among HD patients. Systematic feedback after fertility preservation procedures is helping to reduce reproductive concerns.

DISCUSSION AND CONCLUSION: Multidisciplinary care pathways are needed to establish systems to ensure that fertility is adequately addressed and comprehensive fertility counselling is offered to all young people prior to therapy and during survivorship.



P2

NUTRITIONAL SCREENING IN ADOLESCENT AND YOUNG ADULT ONCOLOGY OUTPATIENT SERVICES

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INTRODUCTION AND AIMS: University College London Hospital (UCLH) is one of the largest oncology treatment centres in Europe for children and young people. More patients are now having their treatment as outpatients. However dietetic provision has not been expanded to support this. These patients are not nutritionally screened routinely and ad-hoc referrals are made by the multidisciplinary team. This audit was devised to investigate the nutritional risk of this patient group to determine the level of need for additional dietetic support.

METHODS: A dietetic volunteer was recruited and trained to carry out nutritional screening on every patient aged 0-25 attending the oncology and haematology outpatient service over 15 days. The screening tool for assessment of malnutrition in paediatrics (STAMP) was used for patients aged 0-17 whilst the malnutrition universal screening tool (MUST) was used to assess patients aged 18-25 years.

RESULTS: 258 patients were screened (24 children, 147 adolescents and 87 young adults). 25% of all patients were at high risk of under-nutrition, 35% medium risk and 35% low risk, 14% of patients were overweight. Of all adolescents screened 28% were at high risk of under-nutrition and 44% were medium risk, while 15% of young adults were at high risk of under-nutrition and 16% were medium risk. 10% of adolescents were identified as overweight compared with 24% of young adults. 71% of high risk patients identified were not under routine dietetic review.

DISCUSSION AND CONCLUSION: The results of this audit highlight the need for routine nutritional screening. However outpatient screening tools specific to this population would be required. Nutritional deterioration could perhaps be prevented by offering medium risk patients first line dietary advice. The need for increased dietetic support was also highlighted as the results of this study indicate referrals of around 15 additional patients per week, 20 referrals total per week.



P3

AN INVESTIGATION INTO THE NUTRITIONAL MANAGEMENT OF PAEDIATRIC AND ADOLESCENT OSTEOSARCOMA PATIENTS

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INTRODUCTION AND AIMS: University College London Hospital (UCLH) is a major European treatment centre for osteosarcoma in paediatrics and adolescents. From practice we know MAP chemotherapy, the first-line treatment, can have significant nutritional implications. These patients are high nutritional risk and dietetic support is an important aspect of supportive care (RCN, 2014). Research in this area is limited; therefore a retrospective cohort study was designed to investigate the nutritional status and interventions taken in this population group.

METHODS: Osteosarcoma patients aged 0-18 who underwent MAP chemotherapy at UCLH from January 2014 to March 2017 were included in this study (n=33). Medical records were reviewed for each patient. Data was collected on anthropometry, nutritional interventions and toxicities through treatment. Statistical analysis software was used to analyse this data.

RESULTS: 60% of patients were well-nourished at the start of treatment, 12% were under-nourished and 27% of patients were overweight or obese. No significant changes in distribution of weight, height and BMI z-scores were observed through treatment. All patients received oral nutrition support (ONS) through treatment. 8 received enteral nutrition and 2 patients received parenteral nutrition in addition to ONS. Most commonly reported toxicities were nausea (91%) and mucositis (94%). Weight loss and BMI z-score were found to be significantly associated with the incidence of nausea (p=0.047 & 0.031).

DISCUSSION AND CONCLUSION: Nausea was the only toxicity strongly associated with weight, however despite its high incidence; mucositis was not significantly associated with weight change. No specific nutritional intervention was identified as most effective. However all patients had ONS. This may have played an important role in maintaining nutritional status through treatment. Stable height through treatment is indicative of a potential stunting effect of chemotherapy. Further research in this area is required. Ideally future studies should have a larger sample size and be prospective in nature.

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P4

AN INVESTIGATION INTO THE NUTRITIONAL STATUS OF ADOLESCENT AND YOUNG ADULTS UNDERGOING STEM CELL TRANSPLANT

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INTRODUCTION AND AIMS: University College London Hospital (UCLH) is the largest centre for haematology in Europe. A significant proportion of this population are adolescent and young adults (AYA) undergoing stem cell transplants (SCT). From practice we know that nutrition is an important aspect of supportive care through SCT. However, limited research is available on this in the AYA population. Therefore we undertook a retrospective cohort study to investigate further.

METHODS: All AYA patients who underwent allogeneic SCT at UCLH from February 2015 to January 2017 were included (n=33). Data was collected from medical records on anthropometry, dietetic input and admission duration. Statistical software was used for data analysis.

RESULTS: 10 teenagers and 23 young adults were included. 24 patients had a cancer diagnosis. Median length of admission was 41 days and median percentage weight loss was 6.23% through admission. This was found to be statistically significant. At the start of treatment 9% of patients were undernourished, 58% were well-nourished and 33% were overweight or obese. Length of admission for malnourished patients (under and overweight) was 10.1 days longer than for well-nourished patients. A moderate, negative correlation was found between weight change and time to dietetic intervention (p=0.042).

DISCUSSION AND CONCLUSION: This study highlights the importance of timely dietetic input for this patient group to minimise weight loss through SCT. It is difficult to distinguish whether weight loss is a cause or result of prolonged admission. Although statistical significance was not achieved the trends identified suggest that nutritional status at the start of treatment

may have an impact on length of admission. Limitations of the study include potential fluid overload affecting anthropometry and small sample size. Future research would benefit from a larger sample size and prospective design.



P5

FITNESS4SURVIVORS: A PILOT STUDY EXAMINING THE IMPACT OF A 10-WEEK CROSSFIT EXERCISE PROGRAM ON THE FITNESS AND QUALITY OF LIFE WITH TEENAGER AND YOUNG ADULT (TYA) CANCER SURVIVORS

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INTRODUCTION: With many young people reporting their fitness being the biggest barrier to returning to education, employment or training post cancer treatment, the need for appropriate exercise schemes has become more important. CrossFit is constantly varied functional movements performed at high intensity. The aim of CrossFit is to forge broad, general and inclusive fitness that is supported by measurable, observable and repeatable results. CrossFit is scalable and applicable to all members of the population regardless of condition, ability, experience or level of fitness.

The research study measured physiological (cardiovascular health, lung function, strength, flexibility, body composition, stamina, balance, endurance and speed) and non-physiological outcomes (quality of life and fatigue) pre-and post the 10-week program. Participants performed specific exercise workouts under the supervision of a coach twice a week in a CrossFit gym. The research design was a between participants non-randomised control trial.

RESULTS: The experimental group consisted of five young people and the control group consisted of seven young people. There were significant observable improvements across all physiological and non-physiological outcomes for the experimental group and no significant improvement across the control group. Young people reported improvements to their fitness because of the pilot.

DISCUSSION AND CONCLUSION: CrossFit is an appropriate fitness method for the TYA survivorship group. The group classes encouraged comradery with one young person stating "because everyone else had been through treatment, I didn't feel bad about stopping to catch my breath". Independent T-Tests did not show any statistically significant improvements, however a larger study with more participants could yield more noteworthy results. As there was no effect size calculation the results are not generalisable to TYA population.



P6

YOUNG PEOPLE LIVING WITH MALIGNANT MELANOMA AND THEIR FAMILY: AN INTERPRETIVE PHENOMENOLOGICAL STUDY

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Incidence of malignant melanoma is increasing internationally. In the United Kingdom it is the fifth most common cancer among young people and in Scotland 14 young people aged 15 to 24 years are diagnosed with the disease each year. Despite improvements in survival rates prognosis is known to be poor if diagnosis is delayed. However, there is little international evidence around the experiences of young people living with malignant melanoma.

A qualitative exploratory study was conducted, underpinned by Interpretive Phenomenological Analysis. Due to the relatively small numbers of young people in Scotland diagnosed with malignant melanoma each year, six young people were purposively sampled from three National Health Service Boards across Scotland. Each young person and a family member nominated by them were interviewed (n=12) either individually (n=8) or as a dyad (n=4) with the approach guided by the young person's preference. Semi-structured interviews were conducted and with the participant's consent interview data was audio recorded and transcribed verbatim.

Preliminary analysis suggests that four major themes encapsulate the experience of young people living with malignant melanoma: (1) 'Life on hold' – the disruption or halting of future life plans after cancer diagnosis; (2) 'Out on a limb' – the lack of access to specialise cancer services available to young people with other cancer types; (3) 'Feeling a fraud' – the sense of not following a 'typical' cancer treatment journey including chemotherapy/ radiotherapy and perceived associated hair loss; (4) 'Feeling alone and afraid' – trying to protect one another.

Despite the seriousness of the disease and growing numbers there are reasons to suggest that young people and their family may be experiencing fragmented services, insufficient support, leading to poorer outcomes. However, there is a lack of empirical evidence available upon which to highlight a) key problems and b) generate solutions.

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P7

SEX DEVELOPMENT IN ADOLESCENT ACUTE LEUKEMIA WITH CHEMOTHERAPY ONLY: A PROSPECTIVE SELF-COMPARISON STUDY

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OBJECTIVE: To assess the pubertal development in adolescent patients (≥ 10 years old) with acute leukemia during chemotherapy.

MATERIALS AND METHODS: It was a Prospective self-comparison study in 115 adolescent patients with ALL in Beijing Children's Hospital from November 2011 to November 2016. Penile lengths and testicular volume were measured in 72 boys, while breast development and menstruation were assessed in 43 girls respectively when remission induction, intensive consolidation and maintain chemotherapy.

RESULTS: 27 boys (37.5%) didn't have puberty before chemotherapy, and the volume of testis in 12 boys still less than 4ml after intensive consolidation. 6 boys after stopping chemotherapy were still in prepuberty and 1 boy had delayed puberty 1 year after stopping chemotherapy, while others had entered puberty normally after 1-2 years after chemotherapy. The age of the first spermatorrhea was 12.95 ± 1.52 years old. 2 boys had testicular microlithiasis while testicular volumes were within normal range and 1 boy with bilateral cryptorchidism. 16 boys with adolescent mammoplasia and the serum level of estradiol was a little higher while the FSH, LH, testosterone were in adolescent normal ranges. The breasts of 3 girls (6.8%) were in Tanner I before chemotherapy, then developed normally. The age of menarche was 11.90 ± 1.16 years old. No premature ovarian failure happened, while cyclic ovarian failure happened in 12 girls during chemotherapy and within 1 year of menarche. Serum levels of FSH, LH, testosterone, estradiol in girls were within normal ranges.

CONCLUSION: Most teenage ALL patients treated with chemotherapy had normal pubertal development and sex hormone. However, longer follow-up is necessary to evaluate possible risk of fertility.

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P8

AYA@USC MODEL OF CARE: IMPLEMENTATION OF EXPANDED SUPPORTIVE CARE SERVICES

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INTRODUCTION: The AYA@USC model of care originally facilitated through a part-time nurse navigator and social worker; delivering interventions over three time points. This model allowed for delivery of clinical services targeting the AYA care gap, wherein AYAs face immediate and late effect health and psychosocial consequences related to their diagnosis. This model was referral based and assisted AYAs in the outpatient setting. Ongoing program implementation led to an expansion of services to benefit all AYAs at USC Norris Comprehensive Cancer Center. Cost-effective, patient-centered, evidence-based care is the foundation of the AYA@USC program since inception in 2012. AIMS To highlight challenges faced during implementation, with the goal of assisting other programs facing similar barriers.

METHODS: The challenges faced by the original model will be highlighted utilizing an implementation stage framework.

RESULTS: There are many challenges facing AYAs; including autonomy, development of values and identity, peer relationships, intimate relationships, and education. Factors such as developmental stage, compliance, and tolerance to therapy; lack of cancer awareness and referral patterns; differences in disease biology and treatment strategies; low accrual and access to clinical trials; and lack of psychosocial support; contributing to this gap.

DISCUSSION: In 2017, AYA@USC implemented an expanded clinical model incorporating full time nurse navigation and dedicated social work for inpatient and outpatient care. In the first quarter of 2017, AYA@USC provided services to 31% more patients than in the first quarter of the

prior two years combined. The AYA@USC program is no longer referral dependent, which has allowed for program expansion. Identification of challenges has allowed for improvement in patient care. **CONCLUSION** Continuing implementation of improvements will allow AYA@USC to better serve the patients and community of USC. Adaptation to challenges imposed by barriers has been an asset; allowing this program to forge practices geared toward alleviating challenges experienced by AYAs.

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P9

THE CANTEEN PSYCHOSOCIAL MODEL: A STEPPED-CARE APPROACH TO PSYCHOSOCIAL SUPPORT AND WELLBEING FOR YOUNG PEOPLE LIVING WITH CANCER

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DESCRIPTION: CanTeen is the Australian national organisation providing psychosocial support to young people (12-25 years) impacted by their own or a family members' cancer diagnosis (Young People Living With Cancer; YPLWC). YPLWC have a range of unmet needs, and provision of a psychosocial assessment, triage and review process is essential to meeting these effectively and efficiently. Consequently, the CanTeen Psychosocial Model (CPM) was developed, providing a comprehensive framework for evidence-based psychosocial practice with national roll-out occurring July to December 2016.

Within the CPM, each client undergoes a psychosocial assessment to identify support needs and inform treatment planning. The assessment includes standardised distress¹ and unmet needs measures² and a semi-structured interview (modified HEADSS assessment³). This is combined with self-identified goals to develop an individualised support plan (ISP) detailing the stepped care⁴ for each client, and enabling progress and outcome monitoring. These are presented at Psychosocial Review Meetings (PRM) attended by a multi-disciplinary psychosocial team. Services offered include individual case management and advocacy, counselling, peer support via programs and recreational activities, access to online support, and referrals to relevant external services. Underpinning this is a framework of evidence-based practice to reduce isolation, and promote resilience and emotional wellbeing. The PRM also reviews the progress of clients.

DISCUSSION: The CPM's aim to return YPLWC to a comparable developmental track to those not impacted by cancer is being met. CanTeen currently supports approximately 1800 clients through its CPM, and over 200 PRMs were held January to September 2017. The heart of the CPM is to place the young person at the centre of their care, empowering them to develop autonomy and resilience to cope with cancer⁵. Additionally, it

provides a strong framework of stepped-care support, ensuring consistency and continuity of care and effective evidence-based intervention for all young people.

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P10

IMPROVING EDUCATION FOR NURSE NAVIGATOR IN ONCOFERTILITY ROLE

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DESCRIPTION: Each year over 150,000 reproductive-age individuals face fertility-threatening cancer treatment. Of the estimated 70,000 new cancer cases among adolescent and young adults (AYA), an estimated 30-75% of males will become sterile after gonadotoxic cancer treatment. Discussions of oncofertility and sexuality with adolescent boys can be a delicate topic. One of the challenges is that early adolescent boys may lack the knowledge on masturbation. Clinical educators may lack confidence or experience in creating an environment that is comfortable and conducive to initiate these discussions. Additionally, there is a lack of appropriate resources to aid educators and young adolescent patients in understanding the process of semen collection. The purpose of this project is to improve education for nurse navigators in an oncofertility role.

Upon review of literature and resources, it was found that education is geared toward older adolescent males, who already have knowledge of the process of masturbation. Therefore, we created a handout that describes the process of masturbation for oncofertility purposes, titled "Sperm Collection". The handout introduces why the healthcare team is discussing this topic; provides a definition of masturbation; and explains in detail process of how to masturbate for the purpose of sperm collection. After obtaining parental consent, this handout is reviewed with the patient and given to him by the AYA nurse coordinator.

DISCUSSION: To our knowledge, this is the first education document that assists educators and patients understand the process of masturbation for oncofertility purposes. We have been able to successfully implement this in our patient population, with the successful collection undertaken by a 13 year old male who had never masturbated.

ACKNOWLEDGEMENTS:

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P11

EDUCATING THE AYA CANCER WORKFORCE- LESSONS LEARNT 10 YEARS ON

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In 2006, the first accredited online Post Grad Certificate in Teenage/Young Adult Cancer Care was delivered at Coventry University. A few years on with a blended-learning module to reach wider demographic of Health care professionals not requiring high level qualification started. More recently initiatives to reach an even wider workforce- a one day study day that's delivered nationally in UK and a free e-Learning Web App were developed. We reached a mixed inter-professional delegation with the following numbers;

Post Graduate certificate completions - 180

Stand-alone module completions (4 day module) 120

One day Study day attendees - 450

WebApp downloads - 2000

DISCUSSION: We all have a responsibility to educate the next generation of AYA cancer practitioners introducing them to the best that has been thought, thought, researched and said. Equally important is instilling in them a love of knowledge and insight into AYA cancer specific issues as well as the broader concepts of adolescent health, and the cornerstones of personal and specialty growth - research, scholarship, leadership and teaching.

The reality is that sustaining any accredited programme has to be financially viable for any university to commit to. Online learning is not a panacea for learning - just like Apps for improving health and wellbeing. It's important to look to the evidence and other key stakeholders as to the content of any educational intervention, whatever form of delivery it takes. We cannot teach without research and vice versa.

Nobody has perfected every aspect of AYA cancer education practice or policy. We still have many gaps that we know of individually, institutionally and from what the evidence says. But we are faced with some realities that we must attend to.

ACKNOWLEDGEMENTS:

Thank you Helen Langton, Simon Davies, Teenage Cancer Trust, students, teachers, young people, contributors and funders to/of our programmes.



P12

USING A VIRTUAL CLINICAL ETHICS COMMITTEE TO FACILITATE LEARNING ON ETHICAL DECISION-MAKING IN TEENAGE/YOUNG ADULT (TYA) CANCER CARE

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DESCRIPTION: One of four learning objectives on an online Postgraduate Certificate in TYA Cancer Care is to critically analyse legal /ethical issues that



may arise for TYA with cancer. Approximately 20 multi-professional and international students participate annually.

Online lectures detailing key ethical/legal principles that underpin healthcare and caring for TYA with cancer are given, including the concept of a Clinical Ethics Committee (CEC) where challenging cases are brought before an independent committee of multidisciplinary groups (health professionals and lay members). The aim is to support teams and families in decision-making on ethical issues arising from patient care within hospitals and other institutions (UKCEN, 2017). A fictitious case study of Freddie, 15yrs, with learning difficulties who is struggling with treatment for cancer is presented. Students assume a predetermined role (not same as their own), attend a synchronous online CEC, facilitated by a chair of a real CEC to present their perspectives on how care may be managed. Formal retrospective evaluation of 4 student cohorts is underway with ethical approval.

DISCUSSION: General feedback reports a positive learning experience, prompting students to think differently about approaching ethical challenges in practice. Many have not heard of such committees and have sought where they might access same locally. A safe space for students to discuss challenges and knowledge gaps is fostered.

The purposeful instructional design of this online pedagogical task (Copolla et al) 2002 along with responsibility for socialising and managing the activity appears to have facilitated learning in a very different way that might not be seen in a traditional classroom. This multi-layered activity appears to facilitate collaborative and reflective learning as well as forming a TYA cancer 'Community of Practice' Wenger (2002).

ACKNOWLEDGEMENTS:

Thanks to students, teachers, staff and sponsors (Teenage Cancer Trust) of this programme of study at Coventry University.

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following rapid intra- and extra-cranial tumour growth, however, further tumour progression and subgaleal infections ensued.

Despite optimal care, the final admission was marked by significant family and patient distress, due to protracted deterioration, worsening deformity and repeatedly refused requests to hasten death. She died 27 months after initial diagnosis.

DISCUSSION: This case is interesting for several reasons: The GBM's behaviour was unusual, with rare development in a cavernoma⁽¹⁾, infrequent sarcomatous differentiation⁽²⁾ and uncommon extra-cranial extension⁽³⁾. Despite positive prognostic factors of younger age, standard-of-care treatment and prolonged good performance scores, further tumour debulking was declined due to rapid disease progression and low likelihood of improvement in quality of life or survival.

Furthermore, the couple's repeated euthanasia requests were confronting, and stemmed from denial of further neurosurgery, terminal disease, prolonged deterioration, distressing deformity and the patient's belief she was burdening her family. This echoes other terminal patients' attitudes towards euthanasia and voluntary assisted dying (VAD), typically being influenced more by psychosocial factors than physical suffering⁽⁴⁾. Enrolment in palliative care does not guard against such requests⁽⁵⁾, and while currently illegal in Australia, recent draft state VAD legislation will potentially change end-of-life care discussions with young adults dying with cancer.

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P13

UNUSUAL TUMOUR BEHAVIOUR LEADS TO AN UNSETTLING REQUEST

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DESCRIPTION: A 32 year old female was diagnosed with a parietal grade 4 glioblastoma (GBM) within a cavernoma. She had debulking surgery, chemoradiotherapy and adjuvant temozolomide, with retreatment at recurrence ten months later. She subsequently developed subgaleal abscesses, treated with prolonged antibiotics. Repeat MRI demonstrated tracking from the surgical bed tumour recurrence into the cranium, with an overlying extra-axial lesion. Pathology from the latter showed GBM with sarcomatoid differentiation and Bifidobacterium infection.

Repeated family requests for further neurosurgery were declined, and their fears of incurability and cosmetic deformity prompted appeals for future euthanasia. Additional radiotherapy and chemotherapy were administered



P14

SUPPORT, DEVELOP, EMPOWER: THE CO-CREATION OF A YOUTH LEADERSHIP FRAMEWORK IN AN AUSTRALIAN NATIONAL YOUTH CANCER ORGANISATION

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DESCRIPTION: The active participation of young leaders in the design, delivery and evaluation of services and governance has been core part of the unique culture of CanTeen, the Australian Organisation for Young People Living with Cancer, for over 30 years.

Becoming an effective young leader is a complex and challenging task, so it is important to provide appropriate scaffolding to ensure young people have a rich, full, and meaningful leadership experience; hence the development of the Youth Leadership Framework (YLF). The YLF is a developmental

model built on the four pillars of consumer engagement, strengths-based approach, youth participation, and leadership.

A review of youth leadership was undertaken from January 2015 to June 2016. It included organisational policy and practice, consultations with CanTeen staff and young people, and a review of the literature centred on the four pillars. A world-café style workshop based on Appreciative Inquiry was also conducted with young leaders (n=86) from CanTeen across Australia, and a young leader's training needs survey completed. Using these outcomes, a staff working group and the young leaders advisory group worked together to articulate the vision, strategy and objectives for CanTeen's engagement of young people as leaders. This was presented to 119 young leaders and their feedback informed the final version of the YLF.

DISCUSSION: 2017 has been the first full year of implementing the framework and associated initiatives organisation-wide, and it is showing great promise. CanTeen's YLF respects the capacity and contributions of young people: supporting young people to take up their leadership roles and tasks, and have a voice in the organisation; developing resilience, skills and confidence; and empowering young people to have influence in the organisation and beyond by contributing their expertise and lived experience for the benefit of all young people impacted by cancer in the Australian community.



P15

PHILOSOPHY SKILLS TRAINING PILOT FOR HEALTH CARE PROFESSIONALS TO ADDRESS AYA EXISTENTIAL UNMET NEEDS

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Add Perspective, Bruges, Belgium

DESCRIPTION: Adults and young adults (AYA) with cancer and other chronic illnesses struggle with questions about meaning and who they are: "Why has this happened to me?". Studies have stressed the unmet psychosocial need to address these existential questions for AYA (Zebrack, 2012). Effective interventions are peer support, technology-based interventions, and skill-based interventions (Zebrack, 2012). No known interventions are aiming to train these skills to health care professionals to address existential questions. The aim was to assess the feasibility of a training of philosophy skills to health care professionals address existential issues with AYA. 3 key exercises to teach 3 philosophy skills included peer support, technology-based support and skills elements. The exercises were based on AYA existential needs (Vandekerckhove, 2010). The aim of the exercises was ⁽¹⁾ to be grateful, ⁽²⁾ to be open minded, ⁽³⁾ to find flow and fulfillment. The pilot took place in Belgium, 2.5h, for 15 healthcare professionals from Leuven University Hospital delegated by Kom Op Tegen Kanker (Belgian Cancer Charity).

DISCUSSION: Participants engaged very much in the pilot and found it very useful to have steps to take in practice. Topics emerged during exercises related to challenges to help patients deal with hard diagnosis and how to discuss existential topics during a conversation with the patient. This pilot shows that philosophy skills training for healthcare professionals could help address psychosocial needs of AYA's.

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P16

BIO FIELD ARRAY: A CASE STUDY WITH FIBROLAMELLAR HEPATOCELLULAR CARCINOMA IN A TEENAGE MALE

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CASE DESCRIPTION: A 16 year old male who had been diagnosed with Fibrolamellar (FLL) HCC was treated with 3 months of chemotherapy/radiation and experienced further tumor progression to stage 4 with metastasis to diaphragm and portal vein leading to a poor prognosis and palliative care initiation. At the time palliative care was chosen, Bio Field Array sessions were initiated by the teen every other day.

TREATMENT AND OUTCOME: Within 3 weeks of beginning the Bio Field Array sessions every other day, the teen experienced normalization of liver function, bilirubin, white blood cell and absolute neutrophil counts and a 55% reduction in AFP levels. Imaging 6 months after initiation of Bio Field Array sessions showed stable disease and regression of tumor and metastasis. After 12 months of Bio Field Array sessions, the tumor and metastasis were deemed stable enough to surgically removed in a 14 hour surgery. At imaging 9 months post-operatively, the teen has continued with Bio Field Array sessions and remains free of disease. He has returned to his school/sporting activities and is thriving and gaining weight.

CLINICAL RELEVANCE: Teens with FL-HCC do not have a favorable prognosis without early surgical resection. Bio Field Array sessions may be a valuable adjunct treatment to aid in the normalization of labs and possible inhibition of tumor growth in these patients.

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P17

THE AUSTRALIAN YOUTH CANCER SERVICE: A NATIONAL APPROACH TO ENSURING THE BEST POSSIBLE CARE AND HEALTHY FUTURES FOR YOUNG PEOPLE WITH CANCER

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DESCRIPTION: Approximately 1,000 Australian adolescents and young adults (AYAs; 15-25 years) will be diagnosed with cancer and 150 will die from it.



AYA cancer incidence is projected to rise by 2-5% by 2020. Currently over 70% of these patients are treated through the Youth Cancer Services (YCS), which provides specialist, multi-disciplinary AYA oncology care through a network of 26 hospitals nationally. This network reaches patients from all states and territories, rural and remote settings and those from vulnerable populations including Aboriginal and Torres Strait Islander Australians.

The YCS also undertakes critical national projects, led by CanTeen, including professional development; national research and data collection; meaningful engagement of AYA consumers; and strategic leadership and governance.

Australian Federal Government funding has been secured for Phase 3 of the YCS (2017-2020), alongside State and Territory-based co-investment.

DISCUSSION: The specialist role of YCS is now firmly established in the Australian health system, with growth of 58% in patient referrals and 70% in secondary consultations between 2013-16. Phase 3 will strengthen national YCS service delivery, develop robust, integrated survivorship pathways leveraging community-based care, and address critical priorities in clinical trials access, national data collection, and professional development.

The newly developed Australian Youth Cancer Framework will guide implementation, with young people and their families continuing to be instrumental in health care design and delivery.

YCS Phase 3 will continue to ensure that Australian AYA cancer patients have equitable access to specialist, integrated, youth-specific medical and psychosocial support, complemented by critical national initiatives.



P18

PHILOSOPHY SKILLS TRAINING FOR AYA IN UK AND BELGIUM

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DESCRIPTION: Adults and young adults (AYA) with cancer and other chronic illnesses struggle with questions about the meaning of their experience, and who they: "Why has this happened to me?" (Zebrack, 2012). Recent studies have stressed the unmet psychosocial need to address these questions for AYA. Effective interventions have been suggested as peer support, technology-based interventions, and skill-based interventions (Zebrack, 2012). No known interventions in the UK or Belgium are aiming to provide these skills to AYA to address questions of identity, spirituality and meaning of life. The pilot included 3 philosophy skills with peer support, technology-based support and skills intervention based on the philosophical needs (Vandekerckhove, 2010). The UK pilot was in a UK chronic care facility with 15 chronic illness survivors (all ages) during a 1h free session. Follow up email contact remained for 1 month. The Belgian pilot was 3 times with 6-10 participants recruited via an AYA Facebook group over sessions of 3-4h, €25 entrance fee, including dinner. Follow up contact remained up to 6 months via Facebook. In both pilots 3 exercises were given based on 3 philosophy skills. Each exercise gave participants the opportunity to train skills (1) to be grateful, (2) to be open minded, (3) to find flow and fulfillment.

DISCUSSION: Participants engaged very much in both pilots and found it very useful. No difference in engagement in respect of age or prior diagnoses was found. Similar topics emerged during exercises related to challenges in daily life about not being understood by other people and the importance of having a positive outlook on life. Recruitment was hard because cancer survivors are not concentrated on one place. Financial challenges would need to be resolved to continue this project. This pilot shows that philosophy skills training could address psychosocial needs for AYA's.

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P19

TO TESE OR NOT TO TESE: FERTILITY PRESERVATION IN A CRITICALLY ILL AYA CANCER PATIENT IN AN ICU SETTING: A CASE REPORT

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DESCRIPTION: As survival rates for adolescent and young adult (AYA) cancer patients improve, fertility preservation is gaining increased clinical attention. A majority of AYAs and parents report a significant concern for fertility potential after therapy. Despite this, surveys report that <50% of oncologists provide counseling or referral to fertility specialists. Oncologists report time constraints, concern over treatment delays, and difficulty accessing fertility resources as reasons for not providing counseling. Fertility preservation among post-pubertal males is straightforward, consisting of cryopreservation of masturbation-assisted ejaculated semen. This process poses a dilemma in some AYA patients who report never having masturbated secondary to young age, religious or cultural objections, pain limiting ability to ejaculate, or neurologic dysfunction due to tumor mass. Electroejaculation (EE) or testicular sperm extraction (TESE) can safely be performed prior to the initiation of chemotherapy without delaying necessary definitive cancer treatment. This case demonstrates that sperm cryopreservation can successfully be performed in a critically ill AYA male with lymphoma prior to initiation of emergent chemotherapy.

A 16 year old white male presented after several weeks of progressive cough, fatigue and dyspnea. When a chest x-ray demonstrated a large mediastinal mass with pleural effusion and concern for severe respiratory compromise, he was transferred to Nationwide Children's Hospital (NCH) pediatric intensive care unit for further care. Pleural fluid analysis was suggestive of t-cell lymphoma & emergent initiation of chemotherapy was recommended due to ongoing concerns of respiratory failure.

Parents and patient expressed interest in fertility preservation options, but due to acute illness and pain, patient required alternative methods of sperm collection. After consultation with the NCH Fertility and Reproductive Health team, a multidisciplinary effort successfully coordinated and procured viable sperm via TESE under conscious sedation, in addition to performing diagnostic lumbar puncture and bone marrow biopsy procedures before initiation of urgent chemotherapy.

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P20

THE ROLE OF THE SOCIAL WORKER / PATIENT NAVIGATOR IN THE DEVELOPMENT AND IMPLEMENTATION OF A FERTILITY PRESERVATION PROTOCOL

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Preservation of fertility is an integral component to providing comprehensive, supportive care to adolescents and young adults with cancer. Infertility is a significant risk factor to conventional cancer treatments including total-body irradiation and chemotherapy, which can lead to acute ovarian failure and premature menopause in women and temporary or permanent azoospermia in men (Levine, Canada, & Stern 2010). Fertility preservation is available to patients through, chiefly, sperm banking for men and embryonic or oocyte cryopreservation in women. However, due to barriers in the delivery and coordination of care among health care providers, AYA patients' access to fertility preserving technologies is often threatened (Johnson 2016). Research indicates that AYA survivors often report that they were not informed of their risks of infertility from their healthcare team at time of diagnosis (Levine, Canada, & Stern 2010). Consequently, and in comparison to older adult cancer patients and young cancer patients, AYA survivors are at great risk for compromised quality of life when faced with the potential likelihood of infertility (Benedict, Thom & Kelvin 2016).

This presentation will demonstrate the value of the social worker / patient navigator as a key member of a patient's medical care team, when addressing psychosocial concerns, such as compromised fertility. Specifically, the presentation will focus on the Authors' current role on the medical team to develop a protocol to ensure fertility preservation education and related care is standard of practice. The goal of the presentation is for attendees to develop a broader awareness and appreciation for the role of social work / patient navigation in AYA cancer care, as well as strategies related to development and implementation of fertility preservation programs at their respective institutions.

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P21

ADMINISTRATIVE DEVELOPMENT OF AN AYA CANCER PROGRAM

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DESCRIPTION: Internationally, there has been a growing need to develop cancer programs specific to the unique needs of the Adolescent and Young Adult (AYA) population. In 2015 the University of Iowa Hospitals (UIHC)

set forth to create a comprehensive and collaborative AYA Cancer Program bridging the services of the Stead Family Children's Hospital (SFCH) and the Holden Comprehensive Cancer Center (HCCC). There is scant literature available to developing programs that can be used as a guide to developing, implementing and evaluating an AYA cancer program. Through a collaborative effort, an AYA steering committee was initially established to guide strategic program planning. In order to gauge the need and capabilities of the program, a gap analysis was performed, identifying patient populations, disease sites, and service lines to initially focus attentions. Based off these findings, a business plan was developed to create a foundation for the program, identifying market and competitor analysis, as well as departmental overview. These led to the development of a strategic plan, to be used to guide and evaluate the program's progress.

DISCUSSION: As the need increases, more health care organizations are developing AYA Cancer Programs without the proper guidance for long-term sustainability and success. Based off the unique needs of AYA cancer patients and the collaboration that is necessary for launch, the AYA Cancer Program at the University of Iowa is presenting a template to aid newly conceptualized programs. This demonstration will guide AYA programs in; determining current position, development of a strategy, building an action plan, and understanding how to execute and manage performance.

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P22

REFLECTIONS ON THE CHALLENGES OF PROVIDING PSYCHOLOGICAL SUPPORT FOR STAFF WORKING WITH TYA SERVICES – OR ‘YOU CAN TAKE A HORSE TO WATER BUT YOU CAN'T MAKE IT DRINK’

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DESCRIPTION: During a particularly challenging time the authors collaborated to identify a way to support ward based staff. We believed if we could help them to reflect on their experiences, and process thoughts and emotions in relation to current challenges, we would establish a method of support that could become custom. To provide a safe space for staff to talk about their experiences we offered a reflective space in groups to talk about the current care challenges. The sessions were advertised with strategically placed posters. Based on what staff were already vocalising we hypothesised that a range of emotions including anger, sadness, distress, and dismay would be expressed. In the event nobody came.

DISCUSSION: Given the perceived level of distress the non-attendance was surprising. Hypotheses regarding what may have prevented attendance included the following:

- Timing – the sessions occurred after the situation had resolved/calmed.
- Staff may have lacked confidence that the space would be safe
- There may have been fears about emotional containment
- Cynicism about any potential benefit
- Differences of opinion regarding clinical decision making as part of the challenge involved complex ethical decisions

- The facilitators felt too far removed from the situation

These reflections led to the following:

- Increase in the visibility of the Clinical Psychologist in the routine activity of the service
- A variety of education sessions delivered to the core team to
 - Demystify the role of psychology
 - Increase understanding the role of the Trust's ethics committee in contributing to clinical decisions
- Provision of supervision sessions for ward based team – now mandatory and integral to the running of the ward

Future plans include a study to elicit views of the ward team regarding their experience of the changes outlined above and their thoughts on ways to improve their well-being at work.

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P23

BUILDING A COMPREHENSIVE, COLLABORATIVE AYA CANCER PROGRAM--THE UIHC EXPERIENCE

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DESCRIPTION: The need to develop programs specific to adolescent and young adult (AYA) cancer patients is recognized, but variability of clinical programs has made a "one size fits all" approach to developing AYA programs impossible. In 2015, the University of Iowa Hospitals and Clinics (UIHC) set out to develop an AYA cancer program.

An AYA Steering Committee was formed by Community advocates, donors, and clinical leaders from the Holden Comprehensive Cancer Center (HCCC) and the Stead Family Children's Hospital (SFCH). A Pediatric Oncologist was hired as the AYA Medical Director, and planning commenced to design and implement a program that joins the strengths of the two institutions and creates unique AYA specific. The guiding principle is to create a comprehensive and collaborative program to address the unique needs of our AYA patients.

DISCUSSION: As part of the UIHC, the HCCC and SFCH share a similar structure, and enjoy the ability to make joint administrative decisions. A co-director from the HCCC was identified to work with the Medical Director on program building. Administrators from both HCCC and SFCH were identified and provide oversight of funding and budgeting. Each component of the program involves individuals from each institution; to bring the best practices of each to the care of the AYA patient. Clinical silos were created from expertise from both Pediatric and Medical Oncology, by initially focusing on patients with Sarcoma, Leukemia/Lymphoma, Brain tumors/Neuroendocrine tumors and Thyroid cancer.

The focus of the program is to improve clinical outcomes, but in a comprehensive care model. Concurrent efforts include creation of Psycho-Social programs, Genetic Counseling, Palliative Care, Onco-fertility, and Survivorship. Community advocates, donors and patients to create have joined to ensure a patient-centered approach. A Nurse Coordinator guides patients through diagnosis, treatment and into Survivorship, acting as a link between clinicians and programs.



P24

RACIAL DIFFERENCES IN COMORBIDITIES AMONG ADOLESCENTS AND YOUNG ADULTS UNDERGOING ALLOGENEIC HEMATOPOIETIC STEM CELL TRANSPLANTATION

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Adolescents and young adult (AYA) patients who undergo allogeneic hematopoietic stem cell transplantation (HCT) tend to have less comorbidities than older adults, yet their incidence of non-relapse mortality (NRM) is still significant. Some studies have suggested that race may account for disparities in survival among transplant recipients, but it is unclear whether differences in the incidence of certain risk factors may also play a role. We sought to demonstrate that the frequency of specific comorbidities differed between racial groups among AYAs that had undergone allogeneic HCT. This was a retrospective study of 241 patients aged 15-39 years who underwent allogeneic HCT from January 2005-December 2015 at UCLA. Data was collected on the fifteen comorbidities scored on the HCT-comorbidity index, as well as other possible risk factors (Table 1). The primary endpoints for the analysis were the cumulative incidence of NRM and overall survival. Among this patient cohort, 63% of patients were described as non-White. Overall survival at 1, 3, and 5 years was 62%, 52%, and 46%, respectively. Most deaths (62%) were attributed to treatment-related causes. In univariate analysis, African Americans had higher rates of NRM when compared to Whites (OR=4.3, p=0.01). African Americans also had a greater incidence of severe pulmonary and hepatic disease (OR=6.3, p=0.04; OR=11, p=0.051). A practical and psychosocial component was more common among Hispanics than Whites (OR=3.1, p=0.0004). We have demonstrated racial differences in the incidence of several risk factors in AYA patients prior to allogeneic HCT, that may help explain disparities in outcomes. The findings among African Americans are likely due to variability in adverse effects related to chemotherapy, that could be the result of biological differences as no significant differences were observed in the psychosocial variable. Further studies are needed to better clarify the racial disparities seen in the comorbidities of transplant patients.

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P25

IMPLEMENTATION OF A COMPREHENSIVE PATIENT ASSISTANCE PROGRAM IMPACT ON THE AYA POPULATION

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INTRODUCTION: Rising healthcare costs and patient financial toxicities are a pressing issue for the 70,000 AYAs diagnosed annually in the US. To address both of these issues, Bon Secours St. Francis (BSSF) instituted a

Lean process which focuses on bringing collaborative teams together to streamline processes and reduce waste. BSSF implemented a comprehensive patient assistance program (CPAP) which focuses on providing copay assistance and/or free drug to qualifying patients. Because AYAs have the highest rate of underinsured or no insurance, we hypothesized that the CPAP would significantly benefit the AYA population.

LEAN PROCESS: Prior to 2016, a 3rd party vendor provided drug recovery assistance only to uninsured patients at BSSF, and this was replaced with a CPAP. This program consists of two components: 1) free drug [drug recovery] and 2) copay assistance. These components utilize external resources such as drug manufacturers and foundations to aid in offsetting the high out-of-pocket expenses for chemotherapy.

The "Lean Team", Process, Implementation and Success measures are described (Table 1).

RESULTS: Initial value was realized by uninsured oncology patients, but quickly expanded to underinsured oncology and eventually non-oncology patients and utilizing existing free drug programs offered by pharmaceutical companies. With internalizing the CPAP, BSSF more than doubled cost savings in FY2017-\$738,450 versus FY2016-\$308,038 (Figure 1, uninsured patients only). This disproportionately benefitted the AYA population (Table 2) likely due to the fact that AYAs have a higher rate of no insurance than adult counterparts (approximately 10-20% of newly diagnosed AYAs). Implications: A comprehensive patient assistance program may be an essential component of AYA programs in order to reduce healthcare costs related to insurance related or reimbursement related issues, reduce patient financial toxicity and potentially increase compliance and improve outcomes for AYA patients.



P26

INCOMPLETE OVERLAP: COMPARISON OF COMMITTEE STRUCTURES BETWEEN ADULT AND PEDIATRIC COOPERATIVE CLINICAL GROUPS HIGHLIGHTS OPPORTUNITIES FOR IMPROVED COLLABORATION

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INTRODUCTION AND AIMS: The dearth of clinical trial participation among AYAs with cancer in the US is hypothesized to be a multifactorial problem. One potential explanation relates to the fact that AYAs may present with either "pediatric" or adult" type cancers. Since age, not tumor type, usually determines the location of treatment at a pediatric or adult cancer center, treating institutions may lack expertise in the AYA's cancer type. Encouraging collaboration between adult and pediatric clinical trial groups has the potential to improve AYA clinical trial accrual, both by educating clinicians about AYA-relevant trials in other groups and through collaborative development of new clinical trials.

METHODS: We compared the organizational structures of the Children's Oncology Group (COG) and Southwest Oncology Group (SWOG) disease committees as a first step to promoting communication between adult and pediatric committee members within disease groups.

RESULTS: For AYA-relevant cancers, there was incomplete overlap between disease-specific committees within COG and SWOG. There was significant overlap for hematologic malignancies. COG has committees for Acute Lymphoblastic Leukemia (ALL) and Acute Myeloblastic leukemia (AML);

SWOG has one committee for all leukemias. SWOG has one committee for lymphomas; COG has committees for Hodgkin and Non-Hodgkin lymphomas. There was less overlap for solid tumors. SWOG has a melanoma committee; melanoma falls under "Rare tumors" within COG. Sarcoma and central nervous system tumors are distinct committees within COG but fall under "Rare tumors" in SWOG. Thyroid cancer and germ cell tumors, both common AYA malignancies, are "Rare tumors" in SWOG and COG.

DISCUSSION AND CONCLUSION: Because committees are designed around the common cancer types for children (in COG) and adults (in SWOG), the composition of disease-specific committees varies significantly between these organizations. Efforts to foster intergroup collaboration should connect analogous committees when possible, and also link individuals sharing disease-specific expertise.



P27

LENGTH OF STAY DIFFERENT, WHILE TREATMENT - RELATED COMPLICATIONS SIMILAR IN PEDIATRIC AND AYA LYMPHOMA PATIENTS IN U.S. 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. Over 81,000 new cases of Hodgkin Lymphoma (HL) and Non-Hodgkin Lymphoma (NHL) are diagnosed every year, many of whom are AYAs treated at pediatric hospitals. We sought to determine if AYAs with lymphoma have increased health care utilization and treatment-related complications as compared to younger patients.

METHODS: Data were obtained from the Pediatric Health Information System for lymphoma admissions at 49 free-standing US children's hospitals from 2009-2015. Patients were followed for 1 year from their first encountered admission for lymphoma and had to have at least three unique admissions with a lymphoma diagnostic billing code during the study period. Patient demographics, morbidities, and hospital utilization were compared in patients 0-14 and 15-30 years using non-parametric methods.

RESULTS: We identified 1608 unique pediatric patients and 1169 AYA patients with lymphoma. Mean 1-year length of stay (LOS) days was statistically greater in pediatric patients versus the AYA patients (32 and 26 days, $p < 0.0001$). Cost was statistically higher in pediatric patients for all categories. Common cancer treatment-related complications (mucositis, diarrhea, nausea, vomiting and bacterial infections) had similar frequencies between the groups, with the exception that neutropenic fever admissions were more likely encountered in younger patients. Thrombosis, septic shock, and pain were more common in AYA patients.

CONCLUSION: In U.S. children's hospitals, AYA lymphoma patients had a shorter LOS, and did not have an increased risk of the most common treatment-related complications as compared to younger patients. Longer LOS and increased cost in the pediatric group may be related to more inpatient therapy, while AYAs may pursue more outpatient therapy. Finally, the incidence of febrile neutropenia may be skewed due to the possibility that AYAs may not report fevers in order to avoid admission.

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P28

ESTABLISHING A FERTILITY PROGRAM IN A PEDIATRIC HOSPITAL: THE AYA EXPERIENCE

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INTRODUCTION: Information about the fertility risks of cancer therapy and preservation options has been identified as an unmet need for AYA patients. To address this, institutions are developing dedicated fertility preservation (FP) programs. Here, we present data from the first 2 years of an oncofertility program at a pediatric institution.

METHODS: A retrospective review of Nationwide Children's Hospital (NCH) FP consults from November 2014 to July 2017.

RESULTS: The NCH FP team, including individuals from endocrinology, gynecology, oncology, and urology, began offering consults in fall 2014. A FP program consult was added to EPIC in 2015, and transitioned to an "opt-out" order for new cancer patients and pre-BMT patients in August 2016. 73 AYA patients have had an FP consult to date; 24 (11 F, 13 M) in the 22 months prior to the initiation of the "opt out" strategy and 49 (27 F, 22 M) in the subsequent 11 months. 49 consults were placed before therapy (30 M and 19 F). All patients received counseling on fertility risk and available options. Pre-treatment, 37% of males and 21% of females received an intervention beyond counseling alone. The most common interventions in males were semen cryopreservation (8) and TESE (2). In females, 15 patients had referrals placed for hormonal evaluation and 4 received leuprolide. Despite increased consult numbers, tumor registry data shows that many AYA patients are not receiving consults pre-treatment.

DISCUSSION: The implementation of an "opt-out" order in EPIC was associated with a significant increase in patients receiving fertility counseling, but many are still falling through the cracks. Despite improved counseling, in this cohort most AYA patients (including males) do not receive preservation pre-treatment. While the development of a dedicated team has improved FP in AYA patients at our institution, further efforts are necessary to understand barriers and improve participation rates.

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P29

CDC'S BRING YOUR BRAVE CAMPAIGN: IMPROVING HEALTHCARE PROVIDER EDUCATION ABOUT EARLY ONSET HEREDITARY BREAST AND OVARIAN CANCER

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Higher risk for early onset breast and ovarian cancer (EOBOC) is associated with family history, genetics, history of breast conditions, and radiation therapy

received during childhood or young adulthood. CDC's Bring Your Brave (BYB) Campaign provides public education regarding early detection and risk reduction and encourages women to learn their family history and talk to their health care providers (HCPs). Communication challenges between patients and HCPs may exist, including lack of HCP knowledge about EOBOC, poor systematic collection of family history information, and difficulty with risk assessment.

Quantitative web-based survey data from 1500 primary care providers (including OB/GYNs) and nurses were collected to assess knowledge of EOBOC and barriers to accurate risk assessment. To inform efforts to adapt CDC's BYB campaign to HCPs, semi-structured, one-hour interviews were conducted with nine healthcare, public health, and genetic experts. Opinions were explored regarding HCPs' barriers to assessing risk and communicating with young women about EOBOC, as well as the messages and informational resources needed to address those barriers.

Almost half of HCPs were unable to correctly describe persons at high risk of EOBOC and 52% reported being "unfamiliar" with related United States Preventive Service Task Force (USPSTF) recommendations. Lack of clarity with the recommendations was the most widely reported barrier. Qualitative interviews yielded several next steps for CDC's BYB campaign including: 1. Developing resources that help providers assess risk and offer clear decision-support advice for patients at low, medium, and high-risk, 2. Creating 60-90 second videos of stories featuring HCP spokespersons from various specialties; and 3. Disseminating campaign resources to professional organizations.

HCPs can benefit from increased education on risk assessment for EOBOC and related recommendations. There are unique opportunities for the BYB campaign to provide useful video and digital resources in addition to decision support tools to aid in patient risk assessment.



P30

PERCEPTIONS OF AND ATTITUDES TOWARDS CLINICAL TRIALS IN ADOLESCENT AND YOUNG ADULTS WITH CANCER: A SYSTEMATIC REVIEW OF THE LITERATURE

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INTRODUCTION: Although clinical trials (CT) offer opportunities for novel treatments that may lead to improved outcomes, adolescents and young adults (AYA) are less likely to participate in CT than younger children and older adults.

AIM: We aimed to identify the perceptions and attitudes towards CT in AYA that act as deterrents or incentives for trial enrolment.

METHODS: A systematic review of cancer literature (1946 to May 2017) using Medline, EMBASE, PsycINFO and Cochrane libraries that assessed perceptions and attitudes to CT enrolment limited to AYA patients (defined 15-39) was conducted. We estimated the frequency of identified themes by pooling identified studies.

RESULTS: Of the 4412 articles that were screened, six original research articles were identified that specifically described incentives/deterrents to CT enrolment in AYA patients. Three studies were conducted at pediatric centers, one at an AYA unit, one at an adult cancer hospital and one was registry based. Major themes identified for CT acceptability included: hope for positive clinical effect, altruism, and having autonomy. Potential deterrents included: prolonged hospitalization, worry of side effects, and discomfort with experimentation.

DISCUSSION AND CONCLUSION: Limited information is available with regards to the perceptions and attitudes of CT acceptability among

AYA patients, especially those treated at adult cancer centers, preventing generalization of data and themes. Future research assessing strategies for understanding and supporting CT decision-making processes among AYA represent a key focus for future funding in order to improve CT enrolment.



P31

OUTCOMES OF EWING SARCOMA (ES) IN ADOLESCENTS AND YOUNG ADULTS (AYA) : A COMPARATIVE ANALYSIS

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INTRODUCTION AND AIMS: Ewing Sarcoma(ES) which is a common disease of Adolescents and Young Adults(AYA). Owing to differences in epidemiology, compliance, and follow-up, the outcomes of sarcoma in AYA have been shown to be ostensibly inferior vis-à-vis non-AYA. This single center study is a comparative analysis of survival outcomes in ES across these 2 groups.

METHODS: Presentation, treatment characteristics, and outcomes of all ES patients in the year 2012 treated on a uniform protocol were analyzed by retrospective review. The comparison of AYAs(15-29 years) to non-AYAs with respect to various parameters was then computed using statistical methods

RESULTS: A total of 109/119 patients with ES were evaluable of which 48(44%) were AYA. Metastases were seen in 16/48(33.3%) AYA patients and 13/61(21.3%) in non-AYA. Complete treatment was received by 25/32(78.1%) of non-metastatic and 11/16(68.7%) of metastatic AYA patients. Complete treatment was received by 32/48(66.7%) of non-metastatic and 9/13(69.2%) of metastatic non-AYA ES patients. There were a total of 55 relapses, 3 progressions, 1 second malignancy and 8 deaths. At 24 months/36 months, the EFS of AYA was 46.3%/34.2% and of non-AYA was 48%/35.9%. While the EFS at 36 months of the non-metastatic cohort in both AYA and non-AYA was comparable at 47.3% and 41.7% respectively, the same in the metastatic cohort in AYA and non-AYA was 9%/17%. Median follow-up was 24 months(range: 3-48) in AYA and 32 months(range: 5-53) in non-AYA. The patients with regular follow-up are 58% and 83% respectively in AYA and non-AYA.

CONCLUSIONS: Albeit the incidence of metastatic disease was higher in AYA and the EFS was less compared to non-AYA, this was not statistically significant. AYAs tend to be less regular on follow-up. Novel therapies to target metastatic sites and means to improve compliance and follow-up are required in AYAs to ensure an equally good survival.



P32

EPIDEMIOLOGY AND PATHWAYS OF CARE FOR ADOLESCENTS WITH LYMPHOMA IN FRANCE (2011-2014)

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INTRODUCTION: Lymphomas are one of the most frequent malignancies in adolescents, accounting for more than 20% of all cancers in the 15-17-year age group. In France, patients in this age group may be treated in pediatric or adult hemato-oncology units and i.e. either as an old child or a young adult, with different treatment dose intensity. We used the French National Registry of Childhood Cancer (RNCE) database overview the epidemiology and the pathway of care for adolescents with lymphoma.

METHODOLOGY: Using the population-based RNCE, all adolescents aged from 15 to 17 years living in France and diagnosed with lymphoma between 2011 and 2014 were included. The data collected for each case comprised histology and stage, site of treatment (pediatric or adult units) and modalities of treatment (protocol of treatment and inclusion in a clinical trial).

RESULT: Data were available for 437 (97.5%) of 448 registered adolescents, 325 HL and 112 NHL. The NHL cases consisted in 72 mature B-cell lymphomas (64%) (35 diffuse large B-cell lymphomas, 23 Burkitt lymphomas, 14 primary mediastinal B-cell lymphomas), 19 anaplastic large-cell lymphomas (17%), 14 lymphoblastic lymphomas (13%) and 7 other lymphoma subtypes (6%).

Most adolescents (233 (72%) HL and 85 (76%) NHL) were treated in pediatric hemato-oncology units. Overall, 111 of the 325 HL cases (34%) and 28 of the 112 NHL cases (25%) were included in a clinical trial. Adolescents treated in pediatric units were more frequently included in clinical studies than those treated in adult units (HL cases: 44% vs 18%; NHL cases 32% vs 4%).

CONCLUSION: In France, most adolescents with lymphoma, are treated in pediatric units according to pediatric protocols or after inclusion in pediatric clinical trials. Efforts must be made to treat adolescents with homogenous treatments in specialized units favoring inclusion in clinical trials and progress in the treatments.

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P33

IMPACT OF ONLINE ACCESS TO RARE EXPERTISE IN ADOLESCENT AND YOUNG ADULT (AYA) CANCERS: PROSPECTIVE ANALYSIS OF AN ONLINE EXPERT OPINION SERVICE IN INDIA

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INTRODUCTION: TMC NCG Online Expert Opinion is a quick, easily accessible, evidence and experience based clinical informatics service,



validated in clinical trials at TMC and UCLA-OVMC. AYA are an important demographic with specialized needs when faced with cancer. Expertise is critical in managing their care. This study compares AYAs seeking online expert opinions with adult patients.

METHODS: Descriptive data including stage and organ of origin for AYAs seeking this service was analyzed, with adult patients as the comparator group. Prospective phone follow up of patients registered after May 2016 determined whether the expert opinion report was shared with the treating oncologists and the final treatment received. Reports were reviewed to assess whether opinions on fertility preservation and organ conservation were sought.

RESULTS: 273 AYAs formed the analyzable cohort, which was compared with 1115 adults, assuming uniformity of age-wise temporal distribution (Table 1). As expected, significantly more adults had solid tumors, especially with genitourinary and thoracic origins, and AYAs had more hematolymphoid and bone tumors. Compared to published literature, Table 1 shows higher percentage amongst AYAs with gastrointestinal, gynecology, and head and neck tumors and those with metastases. Influence of the online expert opinion on the final treatment delivered was similar between AYAs (73.4% received expert opinion recommended treatment) and adults (78.6%). Only 27 AYA patients sought expert opinion on fertility preservation and 26 on organ conservation.

CONCLUSION: TMC NCG Online Expert Opinion is accessed frequently by AYAs. Even though more complicated decision endpoints necessitated AYAs to seek this service, the opinions were equally implemented as final treatment decisions in both age groups, indicating significant positive impact in AYAs. Important AYA related endpoints of fertility preservation, organ conservation, and patient's choice should be proactively considered by the service for all AYA patients, and its impact studied in future analysis.



P34

LIMITING SIXTY DAY MORTALITY AND TOXICITY IN HEMATOLOGICAL CANCERS AMONG TEENAGE & YOUNG ADULT PATIENTS IN A RURAL ACADEMIC CENTRE IN CENTRAL INDIA

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Hematological cancers in teenagers and young adults (15-29 years) in rural areas of central India are a significant problem. Leukemias and lymphomas, have resulted in 40-50% mortality on standard BFM 95 protocol in the first sixty days. The cost of intensive chemotherapy, with antibiotics and component support is median INR 84000 (range 40000-190000).

The TYAcan Foundation organizes (a) pre-diagnosis counseling, (b) financial support for workup for risk category; (c) Telephone tracking (d) Advocacy with educational authorities (e) meals (f) recreation (g) living near the Cancer Centre.

Thirty-two patients were treated during 06/14 to 07/17 (37 months); age 15-29 (median 18 yrs): 17 males/ 15 females. The median annual family income was INR 70000/- (range 40000 to 180000). 15/32 had high risk biological features, determined by marrow flow cytometry and/or immuno histochemistry.

Seventeen of thirty two (17/32) (53%) achieved complete remission. There were three deaths (9%) in the first sixty days. Eight patients needed

financial support upto Indian Rupees 30000/- per cycle for antibiotics, cytotoxics and platelet transfusions. The support was provided by the TYAcan Foundation after an initial assessment of need, with detailed document based interview. There was no third party evaluation of need.

Of the complete responders 11 (64%) are continuing treatment beyond eighteen months and are in continued complete remission. Five patients are attending school on maintenance therapy. Two attend college. Three survivors are training to volunteer with other patients.

The induction mortality (9%) is comparable with corporate hospitals in large metro cities of India. Even protocols like MCP 841 resulted in twenty percent mortality in community hospitals. Initial counselling, financial assessment and judicious support, availability of postgraduate oncology fellows has achieved acceptable sixty day mortality, and allowed the intensive protocols.



P35

MULTI-SITE CHART REVIEW OF FERTILITY PRESERVATION DISCUSSIONS FOR AYA PATIENTS

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INTRODUCTION: In 2006, ASCO asserted the duty of oncologists to discuss the impact that cancer therapy could have on fertility, and to provide options to preserve fertility prior to start of treatment for all patients of reproductive age (Quinn and Vadaparampil, 2013). Fertility risk discussions are still not a fully saturated clinical practice. 30%-60% of patients in the UK and US do not remember discussing fertility risks or preservation options prior to treatment (Shnorhavorian, et al., 2015). This poster illustrates data about fertility preservation discussions and interventions for AYA oncology patients from three sites of care in Fort Worth, Texas.

METHODS: Data from three retrospective chart reviews of AYA oncology patients treated at distinct sites in Fort Worth over defined periods of time.

RESULTS: Private Outpatient Oncology Practice: Fertility preservation measures were taken by 8.3% of male and 23% of female patients reviewed, or 16% of patients in the review.

Inpatient Oncology Unit at a Faith-based Non-profit Hospital: In 2016 fertility risk was discussed with 12.5% of male patients and 37% of female patients whose treatment posed a risk to their fertility.

Non-profit Pediatric Health System: Fertility preservation was documented for 62% of AYA patients diagnosed between 2007-2014, and fertility preservation was completed by 43% of these patients. Further analysis as well as data collection for years prior to 2007 is in process.

DISCUSSION: The Fort Worth AYA Oncology Coalition brings together oncology providers in Fort Worth, Texas to improve services for AYA patients seen across the community. One area of focus continues to be fertility preservation. Results from three retrospective chart reviews show that there is uneven clinical practice with regard to fertility risk and preservation discussions and that every institution reviewed has room to improve their practices in this important area of AYA clinical care.

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P36

A RETROSPECTIVE ANALYSIS OF CLINICAL TRIAL ACCRUAL AND ASSOCIATED BARRIERS FOR ADOLESCENT AND YOUNG ADULT CANCER PATIENTS PRESENTED IN A MULTIDISCIPLINARY TUMOR BOARD MEETING AT A TERTIARY CARE CENTER

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INTRODUCTION / AIMS: Multidisciplinary Tumor Board Meetings (MTBM) bring together providers from various specialties, across adult and pediatric practices, to collaborate and utilize their strengths to best care for the needs of the patient. At these meetings, discussion is documented in the electronic medical record (EMR) to monitor patients' progress towards enrollment in a clinical trial, in addition to their treatment plan and other relevant topics.

The two primary aims of this study are to determine the proportion of patients discussed at a MTBM that were eligible for enrollment on a clinical trial and to identify subsequent barriers to enrollment for AYAs.

METHODS: We conducted a retrospective descriptive analysis of data for all AYAs (ages 13 – 39 at first MTBM) that had at least one MTBM note in the EMR from November 2010 to November 2015. An operating assumption of clinical trial enrollment within 90 days of MTBM discussion was assumed to be at least partially attributable to MTBM discussion.

RESULTS: 553 AYAs were discussed at MTBM, of those, 35 (6.3%) were enrolled on at least one treatment trial within 90 days of MTBM discussion. A total of 102 unique protocol numbers were associated with the total 68 AYAs enrolled at any time point (20 patients had two or three protocol numbers). Of the 102 protocol numbers, 41 resulted in the patient being enrolled within 90 days following MTBM discussion and 50 were enrolled outside of the study window (> 90 days). The remaining 11 protocols did not result in enrollment due to: disease stage (3), patient refused (3), ineligible (2), and unknown (3).

CONCLUSION: Accrual of AYA cancer patients on clinical trials remains low. The role of MTBM, including attendance of adult and pediatric providers, discussion of AYA-specific trial eligibility criteria, and barriers to enrollment needs to be studied prospectively.

refractory malignancies. Recently, outcomes are further improved with novel chemotherapies.

METHODS: A total of 103 AYA patients (pts) (F38:M65) underwent allogeneic HSCT at Methodist Hospital/Methodist Children's Hospital from June 2007 until June 2015. Bone marrow (BM) was graft source in 31 (30%), peripheral blood (PB) in 72 (70%) allografts.

RESULTS: Diagnosis was AML (n=31), MDS (n=8), ALL (n=41), CML (n=5), CNS (n=3), lymphoma (n=5), AA (n=9), sickle cell (n=2), thalassemia (n=2). A total of 44 (42.7%) (30 ALL, 13 AML, 1 lymphoma) pts were in CR I at transplant. Age in years (yrs) at HSCT was 15-18 (26%), 18-25 (25%), 25-30 (20%), and 30-39 for (29%) pts. KPS was ≥ 90 in 57 (55%) pts. Comorbidities (HCT-CI) were HTN (n=3), seizure disorder (n=2), asthma (n=2), depression (n=2), substance abuse (n=1), arrhythmias (n=2), infections (n=4), thromboembolism (n=1), iron overload (n=2) in 20% pts. Interestingly, HCT-CI > 3 were only in 2 (2%) pts. History of anxiety or depression was assessed with appropriate interventions.

Preparative regimens included Cy/TBI (n=37); Bu/Cy (n=29); Bu/Flu (n=9); Cy/Thio/TBI (6); Flu/Cy (n=5), Flu-Mel (n=7), others (n=10). FK/MTX was GVHD prophylaxis in 92 (89%) pts. Median time from diagnosis to transplant was 6.2 months (16 days SAA-17.5 yrs SCD). Day 100 NRM was 12% due to relapse (n=4); infection (n=2); Acute GVHD (n=1); other (n=5). One year NRM was 20% due to infection (n=8), VOD (n=1), AGVHD (n=1), CGVHD (n=1), other (n=9). Relapse mortality was 12% (n=12) patients. Median survival was 3.5 years (10.5 months-8.2 years) for 50 survivors. A total of 48 (96%) survivors are 1 yr post HSCT; 19 (38%) are 5 yrs post transplant. AYA survivors are being followed for long term complications including GVHD.

CONCLUSION: AYA HSCT survivors have a high prevalence of long-term health-related complications with relapse (44%), GVHD (18%) and infection (16%) as significant causes of mortality. However, adverse medical late effects with significant morbidity were uncommon.

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P38

QUALITATIVE AND QUANTITATIVE CHANGES IN DIET AND APPETITE IN TEENAGERS AND YOUNG PEOPLE UNDERGOING RADIOTHERAPY FOR THE TREATMENT OF CANCER

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INTRODUCTION: In this study, we aimed to assess qualitative and quantitative changes in the dietary and nutritional status of children and young adults (<18 years) with cancer who received radiotherapy. Radiotherapy has long been established as an integral part of the treatment



P37

OUTCOMES FOR AYA PATIENTS POST ALLOGENEIC HEMATOPOIETIC STEM CELL TRANSPLANTS

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INTRODUCTION: Hematopoietic cell transplantation (HSCT) provides durable disease control for adolescents and young adults (AYA) with

of paediatric/TYA cancers. Modern modalities and techniques continue to be developed. Despite increasing evidence and experience, careful radiotherapy planning and dose selection adverse effects are unavoidable.

METHODS: Data was obtained through notes and clinical document review, collecting data on weight, diet, appetite and formal measures of nutritional state. Changes in bowel habit were also recorded, alongside the use of medications prescribed with the intent of affecting gastrointestinal problems. Baseline data included age, site of cancer, radiotherapy dose and preexisting (i.e. pre-radiotherapy) gastrointestinal problems (e.g. surgery). Further to this, a systematic review was performed using the NHS evidence portal to search EMBASE, CINAHL, PsycINFO and Medline, using clearly defined search terms, matched where relevant to the thesaurus of each database.

RESULTS: Clinical data was obtained on 21 children receiving radiotherapy. All had received dietetic assessment. Weight loss was common, with few children demonstrating a weight at the cessation of treatment the same as, or above that when they started. Many children described a change in appetite, related not just to nausea, but also a change in tastes and foods they like. Apathy towards eating was common, often reflecting general malaise and fatigue. Only 17 articles were identified in the systematic review.

CONCLUSION: Factors affecting nutrition including site of tumour, age of patient, diagnosis, previous chemotherapy, type of radiotherapy used, dietitian review, and availability of nutritional supplements and parenteral nutrition. It is imperative to maintain maximal nutrition in patients receiving radiotherapy, for quality of life, maintenance of adequate immunity and to promote physiological recovery.



P39

EXPLORING THE ROLE CONFIDENCE AND COMPETENCIES OF NURSES WHO CARE FOR ADOLESCENTS AND YOUNG ADULTS WITH CANCER IN AIMING TO 'ACHIEVE MORE'

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INTRODUCTION AND AIMS: In delivering excellent cancer care nursing role competency is intrinsically linked to professional experience, confidence, knowledge and skills (Bradshaw, 2000). However, there remains limited knowledge about this in teenage/adolescent and young adult cancer care. In 2015, the UK charity, Teenage Cancer Trust launched the first Competency and Career Framework for Nursing to promote professionals personal growth in this specialist field (Smith et al, 2014). Roll out followed to two clinical Hospital Trusts in the Midlands, UK and alongside an evaluation was commissioned over a 12 month longitudinal timeframe to explore the impact of the Framework on nurse's role competencies.

METHODS: Following successful ethical agreement, a before and after intervention study took place using participatory methods. Data sets included documentary analysis (n=15), two focus groups and in-depth follow up with eight nurses using surveys, online blogs and one-to-one interviews.

RESULTS: Qualitative themes and descriptive statistics were drawn out using Theory of Change analysis approach. Key results highlighted that the new Competency and Career Framework for Nursing had ensured a positive impact on nurse's professional roles, enhancing confidence, increasing self-

reflection and understanding about the value of training and education opportunities.

DISCUSSION AND CONCLUSION: Most interesting was the impact on role confidence. Whilst initially confidence in role competencies was high this shifted to lower ratings in the first few months of implementing the Framework. However, with continued use, results showed that the Framework aided as a self-reflection tool, and alongside in-built mentoring, it enabled the nurses to re-evaluate their role competencies to become more confident in the long term. Personal and professional leadership was enhanced. We believe a cycle of role confidence-competence had occurred (McAllister and Lowe 2011). This will have resonance for delegates wanting to achieve more in delivering specialist cancer care.

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P40

THE ROLE OF THE ADVANCED NURSE PRACTITIONER IN ADOLESCENT AND YOUNG ADULT ONCOLOGY

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INTRODUCTION: Advanced Practice is recognised in the United Kingdom as a distinctive level with nurses educated to Masters level and assessed as competent in their field. Advanced Practice encompasses direct care provision, advanced clinical skills, education, research and management (Royal College of Nursing, RCN, 2012).

Pressures on the National Health Service have led to increasing need to improve efficiency and find new ways of working (Gustafson et al, 2003) (Robertson, 2016). An Adolescent and Young Adult Unit Advanced Nurse Practitioner, AYA ANP, was introduced at The Royal Marsden NHS Foundation Trust approximately 18 months ago, one of few within the United Kingdom.

AIMS: To evaluate the impact of AYA ANP role on adolescent and young adult oncology patient and multi-disciplinary team experience quality, safety and efficiency.

METHODOLOGY:

1. Retrospective data collection using The Australian Nurse Practitioner Study (AUSPRAC, 2009) questionnaire to multi-disciplinary team. Descriptive statistics used to analyse outcomes of the data collected.
2. Log of AYA ANP work for one month.

RESULTS:

86% of patients felt they understood the role of the AYA ANP.

90% of staff felt they understood the role of the AYA ANP.

100% of patients felt the AYA ANP service was a success, met their needs, prescribed correctly, offered holistic and safe care, had a positive impact on care

86% of patients felt the AYA ANP service was easy to access

90% of staff felt the AYA ANP service met the needs of the patients

Based on a 38hr week the majority of time was spent on clinical/direct patient care (74%); 5.5% on MDT prep/presentation; 15% on referrals/admin and 5.5% on education

DISCUSSION/CONCLUSION: Overall patients and staff reported a positive experience particularly correct diagnosis, safe prescribing and having a positive impact on care. Areas for improvement include understanding of the role for staff and patients.

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P4 I

THE NURSES' FEELING OF DIFFICULTY FOR CARING FOR ADOLESCENT AND YOUNG ADULT CANCER SURVIVORS IN JAPAN

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The aim of this study was to explore nurses' feeling of difficulty for caring for adolescent and young adult cancer survivors (AYACS; 15-39 years old). Subjects included nurses who were working for designated cancer hospitals or those of hemato/oncology/pediatric surgical units in children's hospitals.

A set of questionnaire was sent to nurses who had at least 1 year working experiences for AYACS. The analytical sample consisted of 1,982 nurses (valid response rate: 72.7%).

We used a self-developed demographic questionnaire and a modified version of 6 point Likert scale of 'the feeling of difficulty for caring cancer patients' which was originally developed by Onodera et al (2013).

It includes 58 items about the feeling difficulties consisting of 7 subscales. Nurses were asked to rate from disagree (1 point) to agree (6 point) and higher score shows higher difficulties. Overall Cronbach alpha of modified scale was .0947, but cumulative contribution rate of factor analysis was limited to 64.3%. Nurses rated highest subtotal average score in the subscale of 'communication' (average score=4.43; sd=±.72) followed by 'consultation and coordination for daily/social life' (4.17±.84), 'health care delivery systems for AYACS' (3.98±.70), 'nurses' own knowledge & clinical skill' (3.98±.83), 'oncologists' related issues' (3.23±.86), 'informed consents & decision making' (3.22±.94), and 'end-of-life (EOL)' (2.75±.76).

The items which nurses rated the highest score in the subscale of 'communication' was 'communication with family of AYACS who were not fully informed about treatment and prognosis' (4.74±.94) followed by 'how to support AYACS after he/she received bad news' (4.73±.95), and 'communication with AYACS who did not have good family relationships' (4.71±.91)

Improving communication with family of AYACS may be needed area for nurses. Further analysis will be discussed to improve nursing of AYACS in Japan.



P42

EVALUATION OF A TEENAGE & YOUNG ADULT (TYA) LONG TERM FOLLOW-UP (LTFU) SERVICE FOR SURVIVORS OF CANCER IN CHILDHOOD

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INTRODUCTION: Each year 1600 children are diagnosed with cancer in the United Kingdom; the survival rate for whom is now 80%⁽¹⁾. Survivors are known to be at increased risk of poorer psychosocial and physical outcomes than their peers⁽²⁾. These effects occur soon after treatment or many years later⁽³⁾, therefore it is recommended survivors follow a risk-stratified pathway of LTFU for life⁽⁴⁾. A crucial stage of this pathway occurs in late adolescence as patients move from child to adult services, a process that should be one of proactive transition rather than sudden transfer⁽⁵⁾.

To meet these recommendations a model of transition was introduced to children's and TYA principal treatment centre over a two year period. In 2016 a service evaluation was carried out to assess the acceptance and effectiveness of this model.

MATERIAL AND METHOD: Using a mixed methods approach a sample of TYA aged 16-25 years olds attending the TYA LTFU clinics were identified and data collected to measure acceptance and effectiveness of the model through:

- online patient experience survey
- 1:1 patient telephone interviews
- qualitative and quantitative analysis of clinic consultations
- qualitative and quantitative analysis of patient contact to the CNS for LTFU outside clinics.

RESULTS AND DISCUSSION: The model of transition though largely accepted was for some a significant challenge; at times this went beyond the patient to the family, in particular mothers whose role as carer was also in transition.

The need for time, a multidisciplinary and multi-method of approach to facilitate patient knowledge and self confidence in transition was identified as a key factor in both acceptance and effectiveness of the model.

CONCLUSION: This service evaluation has highlighted key factors in establishing a transition model and identified areas to ensure transition is truly holistic.

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P43

IMPROVING AYA CANCER CARE AWARENESS FOR ONCOLOGY NURSES: A PILOT AYA CARE WORKSHOP FOR FLEMISH ONCOLOGY POSTGRADUATE NURSING STUDENTS

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INTRODUCTION AND AIMS: The demand for customized oncology nursing, trained in adolescents and young adult (AYA) cancer care, arose from the growing recognition that AYA cancer patients often have unique concerns and needs, which differ significantly from those of paediatric and older patients. Flemish nurses are not always aware of this, due to the lack of basic training in AYA cancer care. The goal of the pilot workshop was to meet the growing need for enhancing Flemish oncology nurses' insight in basic cancer care and for improving outcomes for AYA cancer patients.

METHODS: A two-hour interactive workshop using evidence based practice, research and audio-visual tools, was designed for oncology postgraduate nursing students. The workshop was given in groups with a limited number of participants. An easy-to-use evaluation form was developed and used to evaluate the workshop curriculum.

RESULTS: Forty-seven (88.7%) of 53 (100%) participants returned their evaluation form. The evaluation criteria were built on a 1 to 10 scale (1 representing the least satisfaction, 10 indicating the maximum) and one open question. The method of evaluation revealed a high level of satisfaction of attending the workshop. Forty-four participants (93.6%) responded on the 1 to 10 scale with a rank of 7 (15.9%), 8 (18.2%), 9 (20.5%) and 10 (22.7%), indicating that participants were highly-satisfied with the workshop. Thirty-two (68.1%) participants responded through the open question and indicated the usefulness of the workshop. These nursing students declared that they would apply the knowledge into daily practice.

DISCUSSION AND CONCLUSION: The participants in the pilot AYA care Workshop revealed great interest in issues related to AYA cancer care. The themes that emerged from discussions and the evaluation not only reflect the need for more education, but also indicate the lack of knowledge, e.g. concerning Belgian initiatives aiming to improve patients' outcomes.



P44

THE SUPPORT SITUATION AND ISSUES OF SEXUALITY AND FERTILITY IN ADOLESCENT AND YOUNG ADULT CANCER PATIENTS AND SURVIVORS

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The purpose of this study was to clarify the support situation and issues of sexuality and fertility in AYA cancer patients and survivors in Japan.

A questionnaire survey was conducted of nurses at designated cancer hospitals and designated hospitals for childhood cancer in Japan and who had been working for at least 1 year in a department involved in the treatment or follow-up of patients aged from 15 to 39 years. The nurses were asked about their perceptions of the importance of support for sexuality and fertility in AYA cancer patients and survivors, whether such support was being provided, the feeling of difficulty, and the support system. The analytical sample consisted of 1,982 nurses (valid response rate: 72.7%) and most of the nurses recognized the importance of explaining the impact of cancer and its treatment on sexuality and fertility to AYA cancer patients and survivors. The proportions of nurses who felt that sufficient information was being provided to patients aged 10–19 years and 20–39 years were 33.9% and 51.7%, respectively. Meanwhile, the proportions of nurses who answered that support taking into account sexuality and a system for fertility support were “in place” were 46.5% and 23.4%, respectively, whereas the respective proportions of nurses who answered with “unsure” were 28.8% and 30.9%.

Specific difficulties cited in relation to support for sexuality were “understanding illness and disability,” “support for making treatment-related decisions” and “consideration of sense of shame and privacy.” Although nurses recognized the importance of support for sexuality and fertility in AYA, they felt that the system for support was inadequate. The results of this survey also suggested that the support situation might not be accurately understood, and that awareness-raising activities and education need to be provided to nurses involved with patients in the AYA generation.



P45

IMPROVING EDUCATION FOR NURSE NAVIGATORS IN THE ONCOFERTILITY ROLE

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DESCRIPTION: Each year over 150,000 reproductive-age individuals face fertility-threatening cancer treatment. Of the estimated 70,000 new cancer cases among adolescent and young adults (AYA), an estimated 30-75% of males will become sterile after gonadotoxic cancer treatment. Discussions of oncofertility and sexuality with adolescent boys can be a delicate topic. One of the challenges is that early adolescent boys may lack the knowledge on masturbation. Clinical educators may lack confidence or experience in creating an environment that is comfortable and conducive to initiate these discussions. Additionally, there is a lack of appropriate resources to aid educators and young adolescent patients in understanding the process of semen collection. The purpose of this project is to improve education for nurse navigators in an oncofertility role.

Upon review of literature and resources, it was found that education is geared toward older adolescent males, who already have knowledge of the process of masturbation. Therefore, we created a handout that describes the process of masturbation for oncofertility purposes, titled “Sperm Collection”. The handout introduces why the healthcare team is discussing this topic; provides a definition of masturbation; and explains in detail process of how to masturbate for the purpose of sperm collection. After obtaining parental consent, this handout is reviewed with the patient and given to him by the AYA nurse coordinator.

DISCUSSION: To our knowledge, this is the first education document that assists educators and patients understand the process of masturbation for oncofertility purposes. We have been able to successfully implement this in our patient population, with the successful collection undertaken by a 13 year old male who had never masturbated.

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P46

EXPERIENCE BASED CO-DESIGN (EBCD) PROJECT FOCUSING ON END OF TREATMENT PHASE OF CARE WITH ADOLESCENT AND YOUNG ADULTS

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INTRODUCTION: The Teenage Cancer Trust unit at The Royal Marsden hospital offers specialist, age-appropriate cancer care for adolescent and young adults aged 16 to 24, including emotional, psychological, practical and social support, for young people and their supporters.

Better support at the end of cancer treatment can lead to improved quality of life. Recommendations include health and well-being events and end of treatment summary documents to be shared with the hospital, patient and general practitioner (Independent Cancer Taskforce, 2016). As a pilot working with a small group of adolescent and young adult patients and staff this project provides the opportunity to explore further and shape the design in a way which suits the needs of this group; involving patients in the design of services offers the opportunity to embed the patient experience into the design (Robert et al, 2015) (King's Fund, 2013).

AIMS: To work with identified key stakeholders to develop the adolescent and young adult pathway and service at the end of treatment

To improve quality and experience of adolescent and young adult patients and staff at end of hospital treatment through experience based co-design.

To add to knowledge and experience of engaging adolescent and young adults affected by cancer in participatory co-design (Bowen et al, 2014)

METHODS: Individual video interviews, staff workshop, patient workshop, joint staff and patient event

Workshop will include group work with patients and staff on outcomes of videos and feedback

Anticipated no. of participants is 6 staff and 6 patients.

RESULTS:

1. Delivery of objectives set by the co-design groups, which will focus on the service change
2. Project engagement, i.e attendance at events
3. List all the improvements suggested by patients and staff, and detail which of these have been achieved to date.

Results pending, to follow final group work session

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P47

DEVELOPING A SERVICE TO ADDRESS THE PSYCHOSOCIAL NEEDS OF YOUNG ADULTS WITH CANCER

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INTRODUCTION TO THE BACKGROUND OF THE INVESTIGATION:

The years of the late teens and twenties are ones of foundational development when choices and events potentially influence future careers, health, wealth, education and relationships¹. Cancer at this time increases the challenge to development². Yet despite a number of NHS and voluntary sector initiatives³ access to age appropriate cancer services for young adults vary in England⁴. At our centre the young adult cancer service was underused and user feedback suggested patient experience was less than optimal.

AIMS/OBJECTIVES: To improve the services in a large urban teaching hospital offered to young adults with cancer (20-24yrs).

Service improvement

THE FOLLOWING INITIATIVES WERE UNDERTAKEN:

- Audits to review young adults' place of care
- Patient engagement through social media, questionnaires and discussion group to understand young adults' experience of care and preferences for change
- Establishment of a patient forum to facilitate on-going patient participation in service development
- A weekly multi-professional meeting to assess and plan patients' psychosocial support
- Collaboration with other internal providers to facilitate ambulatory care and care pathways
- Meetings with clinicians and managers to discuss a proposed re-organisation of young adult cancer services
- Involvement of cancer charities and families to finance aspects of service improvement

RESULTS: Professionals working with young adults launched the 'Young Adult Cancer Service' advertising this to key-stakeholders through various mediums. Individualised patient support was structured through the multi-professional review meeting. Clearer patient care pathways and improved physical environment enabled greater access to age appropriate care.

CONCLUSION: This work describes collaborative work with providers, patients, carers and charities to improve service delivery at a time of financial restraint. Ongoing audits and qualitative feedback has shown an improvement in provider engagement, use of designated facilities and patient experience – the results of which will be presented in this poster.

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REFLECTION ON A CONNECTION: THE MENTOR MENTEE RELATIONSHIP AS PART OF THE FLORENCE NIGHTINGALE SCHOLARSHIP EXPERIENCE

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DESCRIPTION: The Florence Nightingale Foundation Emerging Leaders programme is a bespoke leadership development programme for Nurses and Midwives at Bands 7 and 8 across all clinical settings in the UK. Strong Nursing Leadership in Teenage and Young Adult Service Development is vital. This is acknowledged in Teenage Cancer Trusts investment in two scholars with each intake. Central to the aims of the scholarship is the support of a Mentor to shape and guide personal and professional development.

DISCUSSION: At the end of the scholarship, both mentor and mentee agreed to identify three factors they personally felt contributed to the success of the relationship.

All factors centred on reflection and its impact on learning. There was an emotional and theoretical connection from the outset of the relationship. This, along with similar values and approach to work life balance created a balance of commonality and critical companionship. The depth of the shared journey came as a surprise to both parties. Its impact on both mentor and mentee moving forward personally and professionally cannot be underestimated. Transformational learning was evident and both wished to understand more about why we learnt together rather than what we learnt. Identification of key aspects enabled an exploration of the literature for key theories to support the practical experience.

The theories to be presented include;

- Reflection on action to reflection in action
- Transformational learning
- The metaphorical mirror
- Critical companionship

ACKNOWLEDGEMENTS:

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P49

PRELIMINARY REFLECTIONS ON BODY ODORS OF AYA PATIENTS TREATED BY CHEMOTHERAPY WITH MESNA INJECTION

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DESCRIPTION: AYA patients (pts) often complain about unpleasant body odors during their chemotherapy containing intravenous oxazaphosphorines (cyclophosphamide or ifosfamide), with Mesna given jointly as an antidote of their urotoxicity. Mesna is an odorous thiol compound ($\text{HS-CH}_2\text{-CH}_2\text{-SO}_3\text{Na}$), which could explain smelly emission of thiol compounds in urine or sweat. Nowadays, this symptom and its repercussions are not described in the literature, underlying the interest of starting a reflection to better identify and quantify this issue in a healthcare research perspective.

METHODS: Data were collected during nursing interviews with pts during their hospitalization, on a 2-months period. Patients were asked about the discomfort caused by odors, their intensity, duration and origin. A sensory perception survey was also conducted among voluntary professionals on 6 urine samples from patients treated with and without Mesna.

RESULTS: 8 pts, aged 14 to 20 years old, were interviewed. 7/8 said to have felt discomfort due to bad odors; 1/8 patient was not embarrassed by it but he had been interviewed at the beginning of the treatment. 4/8 of them rated the intensity of discomfort as medium and 3/8 as intense. Urine smell was expressed as being the most disturbing compared to sweat or breath. The AYA pts' urines, collected on day 1, were blinded to 11 volunteers. The error rate of the identification of the 3 samples without MesnaTM was 9%, and that of the urine with Mesna 46%, with strong variations between these 3 samples [28% - 64%].

CONCLUSION: This preliminary work provides indicators for the development of a study on a large cohort of AYA patients, including an assessment of the impact of treatment-related odors on quality of life, and identification of Volatile Organic Compounds (VOCs), in search of potential solutions for this daily issue in many AYA cancer pts.



P50

NURSE LED TRANSITION FOR YOUNG PEOPLE WITH ACUTE LYMPHOBLASTIC LEUKAEMIA (ALL) FROM CHILDREN'S SERVICES TO THE TEENAGE CANCER UNIT

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The subject of this presentation is the transition of 20 patients from a paediatric service to a TYA centre. The Clinical Nurse Specialist (CNS) is in an ideal position to lead on this process. They can ensure transition happens

at the right time for individual young people. Children with ALL are treated at Great Ormond Street Hospital for Children (GOSH) from 0-12 years old. Adolescents are treated on the Teenage Cancer Unit (TCT) at University College Hospital, London (UCLH), from 13-19 years old. Young people often reach 13 years old during their treatment for ALL. Age appropriate care is vital and transition needs to be managed appropriately to ensure a flexible transition that enables the young person to retain choice and control.

Transition is a process, not a one off event. Collaboration between the 2 centres is paramount to the success of the transition process. It requires planning, excellent communication, engaging the young person in dialogue from an early stage. The CNS is a key person to lead on transition, with input from Multidisciplinary teams and medical teams.

The CNS team at GOSH discuss transition from the outset of treatment. An appropriate time is decided depending on age and where they are in their treatment. The CNS from UCLH will visit the young person at GOSH to meet them and introduce the Adolescent service to them. They are invited to visit the TCT unit at UCLH with their CNS from GOSH. Transition clinics are set quarterly to help facilitate CNSs from both hospitals to accompany the young people to their first medical appointment to meet the consultant. This has been an ongoing process for 2 years and young people and their families report they are happy with it and ultimately the young people prefer the adolescent environment.



P51

ADOLESCENT AND YOUNG ADULT NAVIGATION IN AN ADULT ONCOLOGY OUTPATIENT CLINIC

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INTRODUCTION AND AIMS: There are an estimated 70,000 Adolescent and young adult (AYA) patients diagnosed annually in the U.S. Few specialty AYA programs exist so that most AYA patients are treated in adult or pediatric settings. Many unique challenges have been identified within this low volume, high risk population. Some of the challenges include: a lack of survivorship education, poor adherence to surveillance visits, limited psychological and coping supports, poor lifestyle choices post treatment, poor physical and mental health outcomes, relationship stress and the presence of occupational, insurance and financial barriers. All these challenges are colored by the developmental and social characteristics of this group.

METHODS: The Survivorship Program coordinator, an Advanced Practice Nurse, developed a framework for AYA navigation and education inspired by the components identified in AYA literature and guided by NCCN AYA Standards (2016). The areas addressed were cancer education, coping, sexual and fertility issues, maintenance of normalcy, connection to AYA Support opportunities and the elimination of barriers to health care. The interdisciplinary process includes AYA patient identification, a focused AYA assessment, advocacy for fertility issues, addressing communication and connection within the health care system, AYA specific cancer education, sharing of available AYA resources, and providing a AYA focused Survivorship Visit.

RESULTS: Process and outcome evaluation is ongoing and includes the evaluation of patient satisfaction, compliance with follow up visits, and knowledge of survivorship issues.

DISCUSSION AND CONCLUSION: Addressing AYA needs during treatment will ultimately impact their long term health and quality of life. All oncology personnel have responsibility to advocate and address the unique issues of the AYA population. The components of this framework could be adapted to any setting with any resources.



P52

YOUNG PEOPLE AS RESEARCH PARTNERS: 10 YEARS OF THE BRIGHTLIGHT EXPERIENCE

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INTRODUCTION AND AIMS: It is now generally accepted that people who have first-hand experience of disease/cancer are best placed to contribute to service development and the design and conduct of research. Young people with cancer are a unique group as they are faced with potentially life-limiting disease against a backdrop of monumental physical and psychological changes. They are often viewed as vulnerable and difficult to engage, therefore user involvement for this group is often described as challenging.

BRIGHTLIGHT is a national evaluation of cancer services in England: we aimed to involve young people from inception through to dissemination. This abstract will describe multiple novel and innovative involvement methods.

METHODS: Young people participated in a number of participatory methods: workshops, focus groups, individual reflection, role play, interviews, electronic surveys, presentations and an arts-based creation and performance of results. Workshops adopted novel methods including a brand transformation model, field-force analysis and BRIGHTLIGHT twister.

RESULTS: Between 2008 and 2017, approximately 1,200 young people contributed to the design, conduct and dissemination of BRIGHTLIGHT. This includes study design, approach materials, naming and branding the study, troubleshooting recruitment and retention issues, secondary hypothesis generation and dissemination. BRIGHTLIGHT refusal rates were 20% against an anticipated 35%. Retention rates at Wave 3 (18 months into the study) improved from 30% to 58% following interventions suggested by young people. The arts based performance 'There is a light' has performed to over 600 professionals, patients, and public audiences.

DISCUSSION AND CONCLUSION: Involving young people in study design, operation and dissemination positively impacts study relevance and design. Our experience demonstrates improvement in up-take and increased retention of participants. Adequate resources must be allocated to allow innovative creative methods to be employed. Challenges still persist in involving ethnic minorities and those less willing to share their voice.



P53

RISE ADVOCACY: RAISING THE VOICES OF YOUNG WOMEN WITH BREAST CANCER

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INTRODUCTION AND AIMS: Young women (YW) diagnosed with breast cancer (BC) have a strong desire to turn their BC experience into a positive force for change, but often do not know where to direct their energy. It is

important to give YW a voice and to keep researchers and legislators aware of their issues and needs.

METHODS: After research and analysis, YSC created RISE (Respected Influencers through Science and Education), a formal training program utilizing existing in-person trainings. YSC created virtual training to ensure all advocates representing YSC are prepared. The program also presents external advocacy opportunities to all who completed training. Those with comparable training and experience before RISE was created participate as RISE "Legacy."

RESULTS: Since 2015, YSC received 265 applications to RISE. The program officially launched in January 2016 when YSC announced the first class of RISE advocates (10) and created 4 online trainings (YSC 101, Breast Cancer 101, the Breast Cancer Landscape and Legislative Advocacy). The second class (10) began in January 2017. RISE advocates attend the National Breast Cancer Coalition (NBCC) advocacy Summit, which includes a lobby day in DC, NBCC's Project LEAD and the Alamo Breast Cancer Foundation's Scholar program at the San Antonio Breast Cancer Symposium. RISE members participate in four quarterly educational conference calls. Training will last for two years with at least one year of service to follow. To date, 4 have completed training; 16 are in training; and 13 are Legacy (33 total). External requests for RISE advocates have been fulfilled 14 times including DOD grant review.

DISCUSSION AND CONCLUSION: YSC's RISE program is a viable and innovative method of training YW with BC to be effective advocates and YSC representatives. With year 2 of the program ending, YSC is evaluating its efforts so that improvements can be made.



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A QUALITATIVE STUDY TO UNDERSTAND THE BARRIERS TO RECRUITING ADOLESCENTS AND YOUNG ADULTS WITH CANCER TO BRIGHTLIGHT, A NATIONAL COHORT STUDY

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INTRODUCTION AND AIM: BRIGHTLIGHT is an evaluation of teenage and young adult (TYA) cancer services throughout England. Despite national support from clinical teams and the Clinical Research Network, BRIGHTLIGHT recruited 55% of its target sample. We sought to understand healthcare professionals' perspectives of the challenges to recruitment to this low-risk observational study and thus to provide guidance on recruitment processes for future studies.

METHODS: Semi-structured telephone interviews with 23 healthcare professionals who had indicated, on an anonymised questionnaire, their willingness to participate. Participants included Principal Investigators and other staff recruiting to BRIGHTLIGHT. Data were analysed using Framework Analysis. Interviews and analysis were carried out by an independent researcher.

RESULTS: The emergent themes were linked to levels of research organisational management, described here using the levels of social network analysis: micro-level (the individual: in this case the target population - young people with cancer); meso-level (the organisation: this related to site of

recruitment and those staff responsible for recruitment); and macro-level (the large-scale or global structure; relating to the wider research function of the NHS and associated policies). At the meso-level, professionals' perceptions of young people and communication between professionals generated age- and cancer-type silos which resulted in recruitment of either children or of adults, but not both by the same team, and only in the cancer-type the recruiting professional was aligned to. At the macro-level the main barrier was discordant configuration of research services which were discordant with clinical services.

DISCUSSION AND CONCLUSIONS: This study has identified significant barriers relevant to all studies which aim to recruit patients across multiple tumour types. We suggest that interconnected whole-system changes are required to facilitate the success of interventions designed to improve recruitment. Interventions targeted at study design/management and the micro-level only may be less successful.



P55

NOT US. NOT NOW. NOT EVER: A MULTI-LEVEL CAMPAIGN TO REDUCE HPV-ASSOCIATE CANCERS THROUGH MOBILIZING STUDENTS, DISPELLING MYTHS AND PROMOTING EARLY DETECTION AND PREVENTION PRACTICES

H. Kun

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Based on data from 2009 to 2013, about 39,800 HPV-associated cancers occur in the United States each year; 3,300 among women, and 16,500 among men. The good news is, that we cannot only decrease chances of HPV infection, but can in fact, avoid having to suffer from HPV related cancers because they are mostly preventable through screening and HPV vaccination. Only 60% of teens aged 13-17 received one or more doses of the HPV vaccine (65% of girls and 56% of boys). This makes combating this disease low hanging fruit.

Fuck Cancer authored an HPV report, created educational materials in our own irreverent voice, partnered with LAUSD's youth advisory board in high schools and with 4 community clinics in central Los Angeles who serve mostly Hispanic and African American patients. The NOT US campaign (NOT US. NOT NOW. NOT EVER) galvanized youth, empowered schools and equipped healthcare sites to put an end to these preventable cancers. Four unique interventions in community clinics were used to increase vaccinations and screening while Fuck Cancer led assemblies at high schools galvanized students to get vaccinated.

Because of the NOT US Campaign, a total of 35 HPV outreach events and 22,920 students were engaged in educating their peers about HPV vaccination. In addition over 800 vaccinations and 2400 pap smears were performed in South Los Angeles over one year because of the partnership with Fuck Cancer.

Fuck Cancer's irreverent yet direct multi-layered campaign not only continues to increase vaccination and screening rates, but also continues to change attitudes.

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P56

ACCEPTABILITY AND SCALABILITY OF A DIGITAL PLATFORM FOR AYA AND PROFESSIONALS: THE IMPLEMENTATION OF THE IAM PORTAL INTO THE EAST MIDLANDS ADOLESCENT AND YOUNG ADULT (AYA) CANCER SERVICE (UK)

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The IAM Portal is a digital platform created with AYA and professionals consisting of:

- AYA specific holistic needs assessment providing a structure to ensure that young people are offered self-assessment and review discussions.
- Information and advice resources for supported self-management, offering age appropriate and cancer specific information and advice.
- South West Integrated MDaT Management System allowing the registration of young people in to the AYA service, and a way to manage and record Multidisciplinary Team (MDT) meeting activity.

Following development and evaluation in the South West of England, the potential for the IAM Portal to become a national resource for AYA services was recognised but required feasibility and scalability testing by introduction into the working practice of another regional service. After staged preparation, the IAM Portal was introduced into the AYA service in the East Midlands region of England and evaluated over a 4-month period (January-May 2017). Mixed methodologies were used to acquire qualitative and quantitative data about experience, acceptability and impact, as shown: (Table 1)

This early evaluation confirmed that the IAM Portal is welcomed by AYA and professionals as a way of fostering discussion of needs; offering relevant and targeted resources for support; and keeping the patient 'voice' central to MDT discussions and action. Preliminary data suggest that transition to the use of the IAM Portal can enhance MDT discussion. Perceived benefit increased with time and continuing evaluation is planned. Key learning points focused around the necessity for adequate preparation and support for new teams using the IAM Portal for the first time.

Based on the successful evaluation of the IAM Portal in the South West and the East Midlands AYA Service, the IAM Portal has been adopted by Teenage Cancer Trust as their digital platform for the development of their regional AYA cancer services in the UK.



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ADDRESSING THE SEXUAL HEALTH CONCERNS OF ADOLESCENTS AND YOUNGER ADULTS (AYA) WITH CANCER: AN INTERNATIONAL EFFORT

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INTRODUCTION: An evaluation of our AYA oncology program identified

that refinement was needed in the domain of sexual health. Since sexual health guidelines for AYA do not currently exist, a sexual health symposium was held at the First Global AYA Cancer Congress (2016). Aims: The goals of the symposium were to: (1) provide a forum where experts had the opportunity to share their expertise in AYA sexual health concerns and (2) using literature and expert opinion, develop a guideline for healthcare providers (HCP) to screen and intervene on AYA sexual health issues.

METHODS: Important themes related to AYA sexual health were reviewed in the literature and summarized prior to the symposium. A panel was created with representation from international experts who presented on these topics. All conference participants were invited to attend and a medical writer was present to record group discussion.

RESULTS: 50 delegates from 9 different countries attended the symposium (Canada, United States, United Kingdom, France, Ireland, Australia, India, Sweden and Japan). Based on evaluation feedback, 94% were very satisfied with the conference content and 92% were very satisfied with the networking opportunities. Overall, 93% of the participants found the day to be extremely valuable. Recommendations were made on the following topics: (1) climacteric symptoms (2) sexual dysfunction in young men (3) contraception during/after cancer therapy and (4) psycho social issues. There was a general consensus that 1) similar gaps exist in AYA sexual health care internationally and 2) all participants would benefit from AYA-specific sexual health consensus guidelines.

DISCUSSION AND CONCLUSION: The symposium day proved to be an enriching opportunity and the new knowledge gained have been integrated into a consensus guideline. Our goal is to widely distribute this information to support oncology HCP requiring knowledge and tools in this domain.



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DESCRIPTIVE EPIDEMIOLOGY OF CANCER IN ADOLESCENTS AND YOUNG ADULTS: RESULTS FROM THE QUEENSLAND CANCER CONTROL ANALYSIS TEAM 1982-2014

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INTRODUCTION: The burden of cancer in adolescents and young adults (AYA) has not been well described in Australia. Consequently, disparities in cancer incidence in this population are also not well understood. Our aim was to develop a comprehensive understanding of the incidence, mortality and prevalence of cancer in Queensland, Australia.

METHODS: Using data from cancer registries and population statistics, we assessed disparities and differences in cancer profiles associated with age, gender and geographical location. We classified cancers using AYA SEER site re-code. We compared incidence, mortality and prevalence in children (0-14 years) adolescents and emerging adults (15-24 years) and young adults (25-39 years) during 1982-2014.

RESULTS: No significant increase in incidence was identified in children or emerging adults. After the age of 25 years, incidence of cancer significantly increased over time. Melanoma and carcinomas were the most common cancer diagnosis in people 15-39 years. A decline in incidence of some cancers, particularly melanoma, was evident, however a trending increase in lymphoma in females aged 15-25 years was identified. Disparities in cancer incidence were not associated with gender or socioeconomic status, however were associated with living in regional areas. Changes in the way

pathology specimens are processes have resulted in an increase in appendix carcinoma being reported to the cancer registry.

Mortality from cancer in young people has improved since the early 1990's; compared to international reports, Queensland has one of the lowest mortality rates for cancer. The highest mortality in children was brain cancers (~30% of all deaths). In emerging adults (15-24 years) bone cancers (26%) and brain cancer (22%) account for the most deaths. Young adults (25-39 years) were more likely to die from carcinomas, particular of the gastrointestinal tract.

Prevalence of people living with cancer is exponentially increasing and requires strategic health service planning to meet health needs.



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“IS THE DOCTOR IN?” MAKING CONNECTIONS WITH HEALTHCARE PROVIDERS

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INTRODUCTION AND AIMS: Young Survival Coalition (YSC) strives to educate the medical community about YSC and breast cancer in young women yet it finds that many healthcare providers (HCPs) do not understand the unique issues of young women with breast cancer (YWBC) or know that they can utilize YSC resources to help. Meeting with each HCP individually to remedy these issues would be time-consuming and inefficient.

METHODS: To reach HCPs who care for newly diagnosed YWBC, YSC utilizes a multifaceted approach.

First, we created and evaluated a Healthcare Provider Educational Program (HPEP) that precedes our annual Summit for YWBC. CEU-accredited for nurses and social workers, HPEPs present information on breast cancer in YW, treatment updates as well as resources and available support services. Speakers include local young breast cancer survivors and HCPs. Secondly, YSC has created enduring online programming about topics pertinent to YWBC that offers CEU credit.

Finally, YSC Regional Outreach Managers (ROMs), as well as volunteer State Leaders (SLs), communicate with HCPs on a regular basis and serve as central points of contact, keeping them up-to-date on program offerings and supplying them with YSC materials and resources.

RESULTS: YSC has held three HPEPs in conjunction with its Summit from 2015-2017 with 78 in-person attendees. Evaluations received from all HPEPs have been overwhelmingly positive indicating that attendees increased their knowledge and willingness to connect patients with YSC. Four online CEU-accredited programs have been offered since 2015. HCP interactions with ROMs and SLs have grown since the roles started in 2013, with HCP engagement increased by 85%.

DISCUSSION AND CONCLUSION: HPEPs are an innovative, effective method of educating HCPs on breast cancer in YW and directing them to resources like those at YSC. Offering online and direct personal communication options also increases HCP engagement.

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P60

AN EVALUATION OF EDUCATION FOR HEALTH AND SOCIAL CARE PROFESSIONALS CARING FOR CHILDREN AND YOUNG PEOPLE WITH CANCER: A NATIONAL APPROACH

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Caring for children and young people with cancer requires a range of specific knowledge, skills and experience to deliver the complex care regimes both within the hospital or community environment.

This study identifies some of the key educational deficits in relation to children and young people with cancer (and their families).

The aims of this study were to;

- Conduct a national evaluation of education and the needs of health and social care professionals and service users
- To design and develop education required for health and social care professionals

This research utilised a mixed methodology approach.

A questionnaire using open and closed questions was developed through the Novi software and circulated to all health and social care professionals through the Children's Cancer and Leukaemia Group and Managed Service Network.

The research used a purposive sample (n=850), response rate (n=121), (14%). This will be followed through with two focus groups, (n= 8) young people from the youth advisory forum and (n=7) health and educational professionals. This will assist in supporting a clearer approach to educational provision within this speciality.

Findings from the professionals confirm 76% were aware of education with 45% finding education useful. Sixty-nine percent found that knowledge gained supported practice development. There were a number of areas for development, communication, supportive care, diagnosis and palliative and end of life care. Participants suggested that funding and time were barriers to accessing education, which was compounded by a lack of readily available courses especially in Scotland.

Data analysis from focus groups is ongoing.

The design and development of a suite of modules and a pathway for health and social care professionals caring for children and young people with cancer will be an addition to what is currently available. It is not the intention to reinvent modules but to augment existing modules.

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CONCEPTUALISING AGE-APPROPRIATE CARE FOR TEENAGERS AND YOUNG ADULTS WITH CANCER: A BRIGHTLIGHT STUDY

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INTRODUCTION AND AIM: Teenage and young adult (TYA) cancer care in England is centralised around 13 principal treatment centres with linked designated hospitals. National guidance¹ in 2005 directed the organisation of care, recommending access to 'age-appropriate care': a phrase not yet defined but has since become the accepted term when describing specialist care. The aim is to present an evidence-based, contextually relevant and operational model of 'age-appropriate care' for teenagers and young adults with cancer.

METHODS: This was a mixed methods study comprising (i) semi-structured interview data from TYA and healthcare professionals involved in their care (ii) integrative literature review to identify current understanding and use of the term age-appropriate care (iii) synthesis of both data sets to form a model of age-appropriate care. A combination of qualitative content, thematic and framework analysis techniques were used to analyse and integrate data.

RESULTS: Seven core components of age-appropriate care were identified: treatment; healthcare professional knowledge; communication, interactions and relationships; recognising individuality; empowering young people; promoting normality; and the environment. Sub-themes of healthcare professional clinical and holistic expertise and the environment comprising of both physical and social environments also emerged. The themes, sub-themes, detail and relationships were presented as a conceptual model to define age-appropriate care.

DISCUSSION AND CONCLUSIONS: Caring for young people with cancer is complex so it cannot be explained with a simple one-line definition of age-appropriate care, as the multiple components connect and interlink. The proposed model presents an evidence-based and comprehensive structure for understanding age-appropriate care. It will be useful to clinicians, health managers and researchers who are designing, implementing and evaluating interventions that contribute to the provision of age-appropriate care. While the individual elements of age-appropriate care can exist independently or in part, age-appropriate care is optimal when the seven elements of the model are present.

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THE AUSTRALIAN YOUTH CANCER FRAMEWORK FOR ADOLESCENTS AND YOUNG ADULTS WITH CANCER; STRATEGIC PRIORITIES FOR AUSTRALIA TO 2020 AND BEYOND

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INTRODUCTION AND AIMS: CanTeen and Cancer Australia jointly developed the National Service Delivery Framework (NSDF) for Adolescents and Young Adults (AYAs) with Cancer in 2008 to improve AYA cancer patient outcomes. As many NSDF key goals have been achieved, the Australian Youth Cancer Framework (AYCF) has been developed to guide AYA cancer care to 2020.

METHODS: A National Reference Group guided development, including twenty-one Australian AYA cancer service delivery, policy and research leaders. A health consultancy group was engaged to support development. Stakeholder consultations and a literature review were undertaken. Findings were integrated into the AYCF.

RESULTS: Centred on the core ideal of engaging young people and families in health care design and delivery, the AYCF builds on four Focus Areas: strong service delivery networks, a sustainable and capable health professional workforce, robust and purposeful data collection/utilisation, and world-leading research infrastructure. Six key principles are articulated, which will drive Australian AYA cancer care improvement:

1. Patients/families are central to best practice, individualised care
2. Patients should receive lifelong high-quality care overseen by capable, multidisciplinary teams
3. All relevant health professionals and services should provide coordinated/seamless care to patients, within age-appropriate/respectful environments
4. Innovative research opportunities should be created and clinical trials access should be equitable
5. Ongoing collection and analysis of national youth cancer data should inform evidence-based care delivery, appropriate resourcing and evaluation
6. Partnerships within and outside the health sector should be established, nurtured and leveraged to improve patient outcomes

DISCUSSION & CONCLUSION: The AYCF articulates a national vision and approach for consistent, integrated and coordinated best practice treatment and care across the health system. Building from this, national and local stakeholders will work together to plan, deliver, monitor, and continually improve the standards of AYA cancer care using detailed implementation plans informed by this Framework.



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INFORMATION NEEDS ON SEXUALITY, CONTRACEPTION AND FERTILITY IN ADOLESCENTS AND YOUNG ADULTS WITH CANCER: A SINGLE-CENTER STUDY

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INTRODUCTION: Contraception and sexual health in AYAs undergoing cancer treatment or cancer survivors raise several medical and educational issues. Substantial concern at diagnosis about becoming infertile with treatment is frequently described.

AIM: The aim of our study is to describe information received in a cohort of AYAs treated for cancer and to strengthen skills of patients as a therapeutic education (TE) practice.

METHODS: We performed a cross-sectional study in a cohort of 30 AYAs attending the Cancer Lyon Center AYA department. Male and female patients aged 15-25 completed a written questionnaire about information received on sexuality, contraception, fertility.

RESULTS: Proportion of AYAs who received information, timing and modalities of this information and mean satisfaction score (10-point scale) for each type of information (sexuality, contraception, fertility) will be presented. Expectations and patient's suggestions will also be detailed.

DISCUSSION: Information on sexuality, contraception and fertility is not systematically delivered by health care providers for AYAs treated for cancer, also these latter reported high expectations on these subjects.

This active multidisciplinary TE working group dedicated to AYA with cancer elaborated TE programs by skilled multidisciplinary teams engaged in interactive educational actions. In a more general way, care workers dedicated to AYA with cancer should use TE-specific actions to reinforce treatment participation and therapeutic relationships.

CONCLUSION: Proper education and counseling on all the aspects of sexual health is mandatory in AYAs treated for cancer, both during and after cancer treatment. Health care providers taking in charge AYAs with cancer should be sensitized to these aspects. This study is a part of a TE program and will lead to interactive educational actions.



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LET'S PLAY TWISTER! NOVEL METHODS TO FACILITATE UNDERSTANDING OF COMPLEX RESEARCH METHODS AND GENERATE SECONDARY RESEARCH HYPOTHESES WITH YOUNG PEOPLE

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INTRODUCTION AND AIM: BRIGHTLIGHT is a national evaluation of teenage and young adult cancer services in England. Data are collected five times over three years from 830 young people using a bespoke survey. Additional data are collected from carers, clinical notes and NHS registries. Consequently, BRIGHTLIGHT is the most comprehensive data set from young people with cancer in the world. In addition to the primary research question ("Do specialist cancer services for teenagers and young adults add value?") such a wealth of information can propagate further analysis and questions. The aim of this study was to identify young peoples' priorities for secondary data analysis.

METHODS: A workshop was held with eight members of the BRIGHTLIGHT user group. To facilitate young people's understanding of 'hypothesis generation', the board game Twister was adapted so each movement represented a different domain of data. The game was played according to usual rules with the modification that, after each pair of movements, participants discussed possible linkage between two domains represented by the two twister movements.

RESULTS: Thirty-six links were discussed and refined into 21 areas for analysis.

These were sent to the user group to individually vote for their top 3:

- Is the impact of cancer affected by how much support you get from people in similar situations?

- Am I less likely to be involved in decision making if I am younger?

- How I feel about my body after cancer affects my ability to form new relationships.

DISCUSSION AND CONCLUSIONS: Young people can be involved in generating research hypotheses using stimulating tools and can identify linkages between data which might be overlooked by healthcare professionals. This paper will explore the potential for utilising participatory methods from other disciplines to convey complex ideas simply.



P65

THE DEVELOPMENT AND EVALUATION OF A REFLEXOLOGY SERVICE FOR ADOLESCENT AND YOUNG ADULTS WITH CANCER AND THEIR SUPPORTERS

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In 2013 the Macmillan-funded On Target programme (1) evidenced that Adolescent and Young Adult (AYA) patients and their supporters across the South West of England wanted access to complementary therapies during their care. Subsequently In 2016 a three-month AYA Reflexology Service was piloted in the Bristol AYA unit, funded by Teenage Cancer Trust. Match funding was secured from Teenage Cancer Trust and Above and Beyond, the Local NHS Trust Charity to continue the service. This report presents the data gathered from the first nine months.

Mixed methods were used for qualitative and quantitative data collection which included; demographic information; Measure Yourself Concerns and Wellbeing (MYCaW) (2); a modified version of the Self-Assessment of Change (SAC) outcome measure, Reflexology Treatment Form; non-validated evaluation questionnaires.

During the data collection period, 265 sessions were available. 261 of these sessions were booked in advance and 252 were delivered.

In total 44 AYA's received between 1 and 19 reflexology treatments, and 26 supporters received between 1 and 10 treatments. There was a substantial improvement in each of the 5 domains presented within the Self-Assessment Questionnaire. The reflexology sessions had a significant impact on a variety of physical and emotional symptoms associated with treatment (e.g. insomnia, pain, fatigue) and helped to improve general wellbeing for AYAs and their supporters.

This report concludes that the Reflexology Service has proven to make a significant difference for AYA's and supporters on the TYA Unit. The integration of Reflexology with conventional treatment has helped to support holistically, comforting mind and body throughout difficult and testing times.

Funding has been secured for a further year and ongoing data collection will continue to inform future service provision for AYAs with cancer and their supporters.

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P66

IMPACT OF FACILITY TRANSFER ON TREATMENT DELAY AFTER CANCER DIAGNOSIS IN ADOLESCENT AND YOUNG ADULT PATIENTS

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INTRODUCTION AND AIMS: Cancer treatment delay is associated with inferior overall survival.

This study examines the risk factors for cancer treatment delay in adolescent and young adult (AYA) patients in a community cancer care setting in the US, with a focus on how transfer between cancer care facilities impacts interval from diagnosis to the start of treatment.

METHODS: We retrospectively analyzed MultiCare Health System (MHS) cancer registry data from patients diagnosed between the ages 15 and 39 during 2006 - 2015.

Patient demographics, insurance, clinical characteristics, and time of cancer diagnosis and treatment initiation were analyzed. Chi-square tests, cumulative hazard estimates and Cox proportional regression were used for univariable analysis. Multivariate regression models based on days of delay and prolonged delay were tested for marginal effect estimates on patterns of care transfer, controlling for sociodemographic and other baseline factors.

RESULTS: Of 840 analytic AYA cases, 457 (54.5%) were both diagnosed and treated within MHS (non-transferred). 45.5% were either diagnosed elsewhere or treated elsewhere (transferred).

Mean and median wait intervals for treatment were 27.03 (95% CI = 21.94-33.14) and 8.00 days (95% CI = 5.00-11.00) days respectively, with significant differences between patients with or without facility transfer (mean 39.93 v.s. 16.40 days, and median 21.00 days v.s. 1.00 day).

Transfer was significantly correlated with longer length of diagnosis-to-treatment interval. Treatment delay ≥ 1 week was associated with transfer, female sex, older age, no surgery involvement, and more treatment modalities. Treatment delay ≥ 4 weeks was associated with transfer, female sex, no insurance and no surgery involvement.

DISCUSSION AND CONCLUSION: In a community setting, the diagnosis-to-treatment interval is significantly longer for transferred compared to non-transferred AYA cancer patients.

Future studies should explore prognostic implications, and analyze delays within specific cancer types.

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RAISING AYA CANCER AWARENESS THROUGH PERSONAL NARRATIVE

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INTRODUCTION: A cornerstone of the Reid R. Sacco Adolescent & Young Adult (AYA) Cancer Program at Tufts Medical Center is community education about cancer within this vulnerable demographic. In a series of talks to university students, the program coordinator, also an AYA cancer survivor, outlined diagnosis through survivorship, with an overview of the Tufts survivorship program. Aims of the talk included making healthcare a priority, psycho-social impact of cancer, and importance of survivorship care following treatment.

METHODS: Fourteen talks were given in six health-related courses at four Boston-area universities over the 2016-17 academic year. Students were asked to provide anonymous written feedback (What will you take away; Has your perspective on (AYA) cancer/survivorship changed?). 329 unique responses were collected and reviewed for themes using grounded theory analysis.

RESULTS: Experiences with AYA cancer ranged from siblings/friends diagnosed to never having met a survivor of cancer. In terms of health, students noted the need for self-advocacy when something feels wrong: "Importance of taking care of myself because I am not immune to disease, despite my age." Students also recalled the multi-faceted psycho-social and financial impacts cancer has on AYAs: "It is very easy to learn the symptoms, treatments, what to be wary of. What you don't hear is what happens outside of that." Survivorship, the time following active treatment, was a new concept for many students, who expressed surprise when learning of the obstacles AYAs face: "I never thought about the 'what's next?' once the treatment is over."

DISCUSSION: Results suggest that personal narrative can have constructive and meaningful impact on AYAs, which has the potential to increase their focus on personal health, provide a deeper understanding of those they know who have been/are impacted by cancer, and positively inform their care of AYAs in their roles as future health professionals.



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AYA CANCER IN NEW ZEALAND - A WAY FORWARD

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Each year an average of 200 young people are diagnosed with cancer in New Zealand (NZ). In 2013 the first comprehensive review of NZ's AYA cancer services was undertaken.

This included analysis of AYA cancer incidence and survival during 2000-2009. It identified a number of serious concerns regarding outcome disparities for certain ethnicities, tumour groups and age related populations within the AYA cohort. Following these findings, the Minister of Health

allocated additional funding to determine and direct AYA cancer service improvements. A key outcome from this was the establishment of the AYA Cancer Network Aotearoa, a national membership organisation that connects health professionals and support providers from multiple disciplines and organisations. The network is led by a governance group of senior level sector experts who provide national strategic direction and leadership.

A key network focus has been the development of a national strategy for AYA cancer care that will include a proposed model of care ensuring young people with cancer have equitable access to high quality medical and supportive care regardless of where they live.

Several key pieces of work have been undertaken to inform and guide the national strategy. These include the development of AYA cancer specific standards of care and an online self-review tool.

This tool aims to drive quality improvement initiatives locally and nationally to improve outcomes for young New Zealanders with cancer. It is designed to improve regional providers understanding of what currently working well in the delivery of care and support while highlighting areas that would benefit from service improvement. The tool supports the development of local service plans that align with the national strategy for AYA cancer care.

The presentation will summarise the tool design and progress to date in the implementation of the standards of care at both local and national levels.



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CENTER FOR ADOLESCENT AND YOUNG ADULT ONCOLOGY AT DANA-FARBER CANCER INSTITUTE

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The Center for Adolescent and Young Adult Oncology (CAYAO) at Dana-Farber Cancer Institute (DFCI) was created to address the outcome disparities of adolescent and young adult (AYA) patients.

CAYAO facilitates joint expert medical care in an appropriate developmental setting by leveraging the experience of pediatric and medical oncology, enhancing the availability of clinical trials, and connecting patients to DFCI's existing services. CAYAO is led by a pediatric and medical oncologist as co-Medical Directors, and staffed by a Program Manager (PM).

CAYAO serves patients ages 15-24 with newly diagnosed malignancies seen at DFCI's Boston campus.

Of the 400 new patients seen annually, approximately 100 establish their care at DFCI. After a patient's consult appointment is scheduled, the PM emails the patient's oncologist to introduce CAYAO's services, including joint medical consultations. In the three months since launching this process, 115 new AYA patients were seen at DFCI, and CAYAO helped facilitated joint discussion for 8 patients. The PM also assists with referrals to other DFCI resources – in particular, oncofertility consultations, clinical trials, and psychosocial programs. Once the patient has established care at DFCI, the PM offers patient navigation services and tracks the patient to collect longitudinal programmatic data. CAYAO is building a REDCap database to gather this data, with plans to expand data collection to answer important research questions.

CAYAO's monthly forums have built a community of practitioners within DFCI who care for AYA patients.

Our invitees include 100 interested colleagues, such as oncologists, nurses, researchers, and psychosocial providers. AYA "Disease Champions" from

a dozen disease centers present their specialties at the forums and serve as content experts for patient cases. These forums provide education and discussion about unique AYA diseases and issues, with the goal of identifying knowledge and service gaps in order to improve the outcomes for AYA patients.



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THE DEVELOPMENT OF A UNIQUE REGIONAL TEENAGER AND YOUNG ADULT CANCER SERVICE IN NORTHERN IRELAND, UNITED KINGDOM

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INTRODUCTION/AIMS: On average there are 76 TYAs cancer patients diagnosed with cancer in the age group 14-24 years in Northern Ireland (N.I.).

Overall incidence rates are 287.1 per million capita within the 15-24 population. This represents the highest diagnosis rate in the United Kingdom (UK) compared to the other UK countries.

AIM: The service aims to provide specialist cancer care to TYAs aged 14-24 years, to improve cancer treatments and support the patient and family throughout their cancer journey and beyond.

METHOD:

- Scoping the service within the five Health and Social Care Trust in NI.
- Scoping the voluntary sector in NI
- Literature review
- Semi structured interviews
- Best practice visits in UK
- Measurement of service against national guidelines

RESULTS: Three viable models were considered and consensus reached by representatives from Public Health Authority, Health and Social Care Board and Health and Social Care Trusts to endorse the Nursing and Support outreach model as the preferred option.

The preferred option reflects the geographical spread of TYA cancer patients who may not access the principle treatment centre.

DISCUSSION/CONCLUSION: A TYA service should ensure that patients attain the best possible outcomes and have access to appropriate specialist services as locally as possible and also which is safe and sustainable. In order to deliver such a TYA Cancer Service in NI, sustainability was paramount and funding needed to be sourced.

The estimated cost of such a model is £255,330 but taking into account the already funded posts and additional amount of £115,693 per annum which was sourced from three local charities and two regional charities.

The charities involved have shown a collaborative approach to working in partnership to finance the posts on a recurrent basis.

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THE HOSPITAL ENVIRONMENT FROM THE PERSPECTIVE OF YOUNG PEOPLE AFFECTED BY CANCER

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INTRODUCTION AND AIMS: Adolescence is a period of transition that comes with complex development processes. When adolescents and young adults (AYAs) are confronted with cancer, their development can be jeopardized. They are separated from the familiar environment and exposed to hospital environments that are often unadjusted to young people. Despite growing research on how the physical environment affects the well-being of the (child as) patient, the AYA is often overlooked. Therefore, this study aimed to find out how adolescents experience a hospital stay and to what extent their experience is influenced by the physical environment. In addition, we investigated what an adolescent-friendly hospital environment means from the perspective of the adolescents themselves.

METHODS: We (retrospectively) interviewed ten AYA's who have been affected by cancer between the age of 14 and 25. More important than their age, however, was their long-term experience as a patient. Preliminary findings were discussed with professional experts and adjusted to their input.

RESULTS: Our findings suggest that AYAs with cancer are primarily looking for connections with life outside the hospital. Design strategies that contribute to this include maximizing freedom of choice, flexibility and spatial variety; attending to the comfort of visiting family and friends; providing in age-appropriate activities, nice outdoor spaces and internet access; pursuing aesthetic coherence and a homelike atmosphere; and combining individual patient rooms with a variety of communal rooms.

DISCUSSION AND CONCLUSION: There is a need for a hospital environment dedicated to young people, whether this takes shape as a separate AYA unit, or as the grouping of AYA's on children's or adult wards. Even if adolescent patients' needs may somehow resemble those of other patient groups, as a group they clearly have specific features and needs, and this specificity is largely hidden in the process of development and transition they are undergoing.

POSTER WITHDRAWN



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POSTER WITHDRAWN



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THE DEVELOPMENT AND USER EVALUATION OF A HEALTH BEHAVIOUR CHANGE INTERVENTION FOR TEENAGE AND YOUNG ADULT CANCER SURVIVORS

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INTRODUCTION AND AIMS: Teenage and Young Adult Cancer Survivors (TYACS) are advised to adopt a healthy lifestyle in order to reduce the impact of cancer upon their long-term health. However, there are no interventions available in the U.K to support TYACS to lead a healthy lifestyle. To inform the development of a lifestyle intervention for TYACS we carried out a series

of studies to understand patient and professionals needs and perspectives regarding health behaviour change.

METHOD: We gathered quantitative and qualitative data on TYACS (n=216) current health behaviour status; interest in, and experience of receiving, lifestyle advice; and preference regarding the type, format, and delivery of a lifestyle intervention. Health professionals (n=95) were surveyed simultaneously to gather their views on how best to promote health behaviour change to TYACS. This data was used to inform the development of lifestyle information and behaviour change resources for TYACS. TYACS (n=18) and health professionals (n=19) evaluated the lifestyle intervention resources for relevance, appeal and usability.

RESULTS: The lifestyle intervention resources were well received with the majority of TYACS and health professionals rating the information as high quality, helpful and relevant. TYACS and health professionals commented that more specific personalized or tailored health behaviour information would be beneficial. Over 80% of TYACS reported they would find the support tools 'very appealing' or 'quite appealing'. Health professionals held similar views and thought rewards and social comparison/ modelling would be most appealing to TYACS.

DISCUSSION AND CONCLUSION: The data from this series of work confirm TYACS and health professionals are interested in lifestyle information and are receptive to behaviour change resources. A pilot randomized controlled trial exploring the uptake and effect of the intervention resources on behaviour change among TYACS is currently being carried out.



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PLACES YOU'LL GO: DEVELOPMENT AND EVALUATION OF A CAMP PROGRAM FOR ADOLESCENT CANCER SURVIVORS

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INTRODUCTION AND AIMS: Adolescent cancer survivors face many ongoing psychosocial impacts from their cancer experience, including distress; reduced self-confidence; and disrupted peer relationships. Specifically tailored psychosocial interventions can assist in improving well-being.

This presentation outlines the development and evaluation of a manualised group program, Places You'll Go, for adolescent cancer survivors.

METHODS: CanTeen, the Australian organisation for young people living with cancer, developed a 3-day group program for 12-17 year olds who had completed active cancer treatment. Program development was informed by integrating a literature review; an audit of CanTeen's programs; and perspectives of young cancer survivors and psycho-oncology experts. The program included five 90-minute psychosocial sessions, targeting young people's communication and coping skills and processing of their post-cancer identity. The main theoretical and clinical underpinning was Acceptance and Commitment Therapy.

Program feasibility and acceptability were evaluated using post-session participant and facilitator measures of participant engagement and implementation fidelity. Program satisfaction measures were completed post-program. Results Participants were 28 survivors (19 female) aged 13-17 years (mean=15.4 years) and 8 psychosocially-trained facilitators. Young

people rated their engagement highly across all sessions; this aligned with facilitator ratings. All participants reported being satisfied with the program and said they would recommend it to another young person with cancer.

Facilitators reported delivering over three quarters of program activities as per the manual and qualitative program feedback included insights and directions for future program adaptation.

DISCUSSION AND CONCLUSION: The Places You'll Go program provided young people with an opportunity to "feel more confident about [their] cancer experience" and "think about things [they] never thought about before." Preliminary evidence of high program feasibility and satisfaction will be combined with ongoing program efficacy data collection.



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DETERMINING CONTENT VALIDITY OF AUSTRALIAN DISTRESS SCREENING TOOLS FOR USE BY CANADIAN ADOLESCENT AND YOUNG ADULT (AYA) CANCER SURVIVORS

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INTRODUCTION AND AIMS: Routine screening for distress is a standard of care for cancer patients of all ages. A priority of health care professionals has been to tailor distress screening to assess the unique challenges of AYAs. The Distress Thermometer (DT) accompanied by the Australian AYA-specific Problem Checklists (Palmer, Patterson & Thompson, 2014) were adapted for use with Canadian AYAs.

METHODS: Mixed methods modern psychometric approaches were used. In phase 1 (qualitative), patients were interviewed and AYA healthcare experts were surveyed to adapt and refine the Australian checklists for use in Canada. In phase 2 (quantitative) a large scale field-test was conducted at multiple Canadian centers. Participants completed the Distress Screening Tools using either a paper questionnaire or an iPad with data entered directly into REDCap. Participants were invited to complete the Distress Screening Tools again 7 days later to examine test retest reliability. Rasch Measurement Theory (RMT) analysis is being used to examine scale performance.

RESULTS: Interviews with 45 AYA and 25 experts led to the refinement of a set of scales appropriate to patient and survivors that measure distress in terms of the following constructs: physical, emotional, social, cognitive, practical, education, employment, cancer worry and impact of experience. Preliminary analysis was conducted on the first 335 patients recruited. 23% of the sample scored 6 or higher on the DT. Distress was higher in females and those who were on treatment and closer in time to diagnosis.

DISCUSSION AND CONCLUSIONS: The sample size of 500 participants was recently achieved (Aug 2017). RMT analysis will be completed this fall to determine, for each scale, the final set of items, the clinical hierarchy for each scale, and how well the scales are targeted to the sample of patients and survivors. Psychometric findings from the study will be presented at the conference.

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SEXUAL FUNCTIONING AMONG YOUNG ADULT CANCER PATIENTS; A 2-YEAR LONGITUDINAL STUDY

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INTRODUCTION AND AIMS: Cancer-related sexual dysfunction has been reported among adolescents and young adults; however its prevalence over time has not. This longitudinal study investigated sexual dysfunction in AYAs over two years following initial diagnosis.

METHODS: Young adult (YA) patients (18-39 years) completed the MOS Sexual Functioning Scale within the first 4 months of diagnosis (n=123), and again 6 (n=107) and 24 months later (n=95). An ordered multinomial response model analyzed changes in the probability of reporting sexual dysfunction over time and the independent effects of demographic, clinical, and psychosocial variables.

RESULTS: More than half of participants experienced sexual functioning to be problematic at each assessment. The probability of reporting sexual dysfunction increased over time (<.01) and was greater for cancer patients who were female (<.001), older (<.01), married or in a committed relationship (<.001), treated with chemotherapy (<.05), and reporting comorbid psychological distress (<.001) and lower social support (<.05). For women, being in a relationship increased the likelihood of reporting sexual problems over time; for men reporting sexual problems over time increased regardless of relationship status.

DISCUSSION AND CONCLUSION: A substantial proportion of YAs report on-going problems with sexual functioning in the first two years following their cancer diagnosis. These findings justify the need to evaluate and monitor sexual functioning throughout a continuum of care.



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POSTER WITHDRAWN

POSTER WITHDRAWN



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DYNAMICS IN THE CANCER EXPERIENCE OF ADOLESCENTS AND YOUNG ADULTS: THE 3-PHASE PROCESS

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INTRODUCTION AND AIMS: Research has highlighted the vulnerability of adolescents and young adults (AYAs) with cancer. Understanding the AYAs' self-reported experiences, needs and expectations can contribute to the development of tailored psychosocial care for this specific population.

METHODS: A qualitative research design, based on principles of grounded theory, was used to investigate the experiences of AYAs with cancer and to detect and clarify underlying meanings and processes. Semi structured interviews were conducted with 23 AYAs aged 15 to 25 years, recruited in the University Hospital of Ghent (Belgium).

RESULTS: The data analysis revealed that AYAs go through a specific process in their cancer experience, starting from their diagnosis until follow-up. In this process, 3 phases were identified: (1) maintaining normal life was essential, (2) normal life was slipping away, and (3) evolving toward a new normal life after treatment. In these phases, certain dynamics were present which demonstrate alteration in the AYAs' experiences and the underlying meanings. Distinct needs and expectations of AYAs toward their informal and formal network are described.

DISCUSSION AND CONCLUSION: The dynamics underpinning the process demonstrate how AYAs' experiences and needs change during the cancer trajectory. Healthcare professionals should therefore aim for a patient-centered approach in which they strive for individualized and flexible care. An open attitude and willingness to communicate with the AYA can improve patient outcomes.

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DEVELOPMENT OF A MOBILE-BASED PSYCHOSOCIAL INTERVENTION FOR ADOLESCENTS AND YOUNG ADULTS WITH SARCOMA

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INTRODUCTION AND AIMS: Recent work has documented significant levels of unmet needs of adolescents and young adults (AYA) with cancer, particularly psychosocial challenges during the transition to adulthood. A mobile-based psychosocial intervention focusing on mindfulness and social support may be an ideal way to foster resilience in this population. This study aimed to use a patient-centered approach to inform a mobile-based mindfulness and social support intervention for AYA cancer patients.

METHODS: Participants included ten AYA ages 14-23 years with sarcoma (50% female; 50% adolescents), parents of the five adolescents, and six healthcare providers. Formative research involved: (1) In-depth interviews conducted with all participants based on the Resilience in Illness Model (RIM), which describes four health protective factors for resilience and two risk factors. Interviews also included questions about preferences for a mobile intervention. Coding and analysis of the qualitative data was inductive; (2) Adaptations to an existing mindfulness app (Whil Concepts, Inc.), which offers a program for youth with over 500 audio meditations. Modifications included creating a 4-week "Mindfulness for Resilience in Illness" program, with 28 relaxation exercises and the addition of videos featuring two sarcoma survivors as program hosts. A patient advisory board was created to review drafts of content; (3) A private Facebook usability group organized to elicit beliefs about the app and potential future enhancements and to promote social support.

RESULTS: Results of the interviews revealed themes around adolescents' functioning and coping, including body image concerns; recurrence-related anxiety; anger over loss; and being overwhelmed by medical information. Themes were incorporated into a demonstration version of the mobile app.

DISCUSSION AND CONCLUSION: A patient-centered approach is widely recommended in the development of mobile-based health behavior change interventions and may be a useful way to inform development of a mobile-based mindfulness and social support intervention for AYA with cancer.



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PUTTING AYAS IN A ROOM TOGETHER: LAUNCHING AND ADOLESCENT AND YOUNG ADULT ONCOLOGY COUNCIL

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INTRODUCTION AND AIMS: Facilities and programs targeting adolescents and young adults (AYAs; aged 15-39) are now emerging within community

cancer centers in the United States. We describe the formation of a community AYA stakeholder council and report the discussion themes and priorities of this group.

METHODS: In collaboration with CanTeen Australia, a global leader in engaging young adults with cancer, Mary Bridge Hospital created a stakeholder council to examine the healthcare needs and preferences of AYAs treated at community cancer centers. The group, including nine patients/survivors, two parents, one spouse, one sibling, two researchers, and an AYA-focused child life specialist, initially convened at a one-day workshop. Participants shared and compared their healthcare experiences and identified unmet needs. Workshop notes were analyzed using inductive content analysis to identify themes. The group also prioritized topics for future discussion and action.

RESULTS: The experiences of AYAs treated at community centers varied widely, but the majority reported satisfaction with their cancer treatment experience. The group was enthusiastic about sharing stories and advocating for others. They have identified topics of high priority for AYAs at community medical centers and are meeting monthly to discuss these issues. Peer connection was identified as the most pressing need, followed by government advocacy to improve programming and financial support, complementary medicine, research & clinical trials, staff education, choice & voice in decision-making, fertility, survivorship, and mental health services.

DISCUSSION AND CONCLUSION: This project highlights the value of both patient engagement and international collaboration in advancing AYA research and clinical care. Within the AYA council, most survivors reported positive treatment experiences at community medical centers. They desire more peer connection, financial support and empowerment in healthcare decision-making. The AYA council is committed to ongoing advocacy work. AYA stakeholder councils have the potential to inform program development at community-based cancer centers.



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DEVELOPMENT OF A SOCIAL SUPPORT INTERVENTION FOR AYA PEERS: &@! MY FRIEND HAS CANCER!

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INTRODUCTION AND AIMS: Social support is protective against distress in adolescent and young adult (AYA) cancer patients (ages 15-39) (McCarthy et al., 2016). Yet few interventions have been developed to address relational challenges and improve the quality of social support among peers of AYAs. Our aim was to develop an intervention to increase social support and decrease social distancing among peers of AYA cancer patients, using a community-based participatory action research approach.

METHODS: Intervention development was led by two AYA survivors (ACB and HB) and one caregiver of an AYA (JO). Focus groups were held with 29 AYA survivors to elicit themes around friends' reactions to AYAs' cancer diagnosis and recommendations for friend training. An intervention mapping approach was applied to the focus group results to identify theory-based change objectives and methods, which formed the basis for intervention development. An advisory board of AYA survivors, advocates, program and service directors, social workers, and researchers reviewed and provided feedback on the resulting intervention design and curriculum.

RESULTS: The AYA peer intervention will be delivered as a series of YouTube videos titled "&@! My Friend Has Cancer!" The series consists

of 7 brief videos addressing the following topics: 1) value of friendship, 2) verbal communication, 3) non-verbal communication, 4) handling missteps and conflict, 5) boundaries and taking care of yourself, 6) transition to survivorship, and 7) end of life. Videos are currently in pre-production. Rough cuts of each video will be pilot tested with AYA survivors and peers.

Discussion and Conclusion:

Systematically developed by the AYA community and informed by behavioral theory, “← My Friend Has Cancer!” addresses an important gap in psychosocial care for AYA patients. Upon completion, videos will be disseminated via social media and existing AYA programs, and evaluated for reach, usability, and effectiveness.

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P82

ONCOLOGY PROVIDER PERSPECTIVES ON COMMUNICATING ABOUT SEXUAL AND REPRODUCTIVE HEALTH WITH ADOLESCENT AND YOUNG ADULT CANCER PATIENTS

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INTRODUCTION AND AIMS: Adolescent and young adult (AYA) cancer patients and survivors identify sexual and reproductive health (SRH) as a significant topic requiring greater attention throughout the cancer experience. Current practice guidelines focus on fertility. However, AYAs desire comprehensive SRH care, which includes information about relationships, body image, sexuality, sexual identity, fertility, contraception, and psychosocial adjustment. The purpose of this study was to investigate the attitudes of pediatric oncology providers towards SRH with AYAs, and to understand perceived barriers to effective communication in current practice.

METHODS: Pediatric oncology providers (physicians, certified nurse practitioners, and physician assistants) participated in qualitative interviews investigating attitudes about sexual and reproductive health communication with AYAs and barriers to such conversations. Twenty-two providers participated from 7 institutions in the Northeastern United States. Interviews were audio-recorded, transcribed, and coded using a thematic analysis approach.

RESULTS: All participants identified a role for oncology providers to discuss SRH with AYA cancer patients and survivors. Most respondents reported provider and patient discomfort, lack of knowledge, and lack of resources/ referral options as significant barriers to SRH communication. Other reported barriers included presence of family or friends during clinic visits, time constraints, and low-priority in the setting of other treatment and health-related issues to discuss. Facilitators included strong rapport with AYA patients, prior education in SRH issues, and patient initiation of the conversation.

DISCUSSION AND CONCLUSIONS: Although study participants identified a key role for pediatric oncology providers in SRH care for AYA cancer patients and survivors, multiple barriers interfere with such discussions taking place on a regular basis. Future efforts must focus on provider education and training in SRH to optimize care provided to this unique patient population.



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DO RESIDENTIAL WEEKENDS FOR YOUNG PEOPLE WITH CANCER ADD VALUE? PERCEPTIONS OF CARERS/ SIGNIFICANT OTHERS

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INTRODUCTION AND AIMS: Find Your Sense of Tumour (FYSOT) are two residential weekends for young people aged 13-17 and 18-24 years with cancer. The residential events bring together young people for educational presentations, motivational speakers, workshops and social events. Carers/ significant others of young people attending have reported perceived benefits to young people, however this had never been formally evaluated. We sought to formally assess carers' perception of potential benefits for young people attending FYSOT.

METHOD: Young people participating in a longitudinal evaluation of FYSOT nominated a carer/significant other to also participate. Carer/significant others were sent a questionnaire prior to the young person attending FYSOT and at 3-months post event. The questions included the impact on psychosocial outcomes and quality of life. Carers could also leave comments if they wished.

RESULTS: Seventy-three (49%) returned the baseline questionnaire, of whom the majority (n=56; 77%) were parents. Most respondents felt attending FYSOT had helped young people make friends (83%), helped them deal with reactions of others (82%), learn about him/herself (80%), feel better (80%), lessen their anxiety (75%), helped their ability to talk (73%), feel comfortable (70%) and accept the physical change caused by cancer (69%). "I saw a dramatic change on returning home. Self-confidence was restored. Mixing with other young people and sharing stories normalised their situation. Listening to [name removed] was a life-changing moment for them and totally put things into perspective."- Carer There were no significant changes in perceived quality of life.

CONCLUSIONS: These results demonstrate improvements in psychosocial outcomes for young people with cancer from the perspective of their carer/ significant other three months after FYSOT. There were no significant changes in perceived quality of life however; evidence exists to show parents often have a different perception of their child's quality of life so can be interpreted with caution.



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FIRST DESCENTS, AN ADVENTURE PROGRAM FOR YOUNG ADULTS WITH CANCER: WHO BENEFITS?

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INTRODUCTION AND AIMS: Participation in camps, adventure programs, retreats, and other social events offers experiences that can improve young patients' abilities to cope with cancer and its life disruptions. The aim of the

study was to examine whether young adult (YA) participants in a one-week outdoor adventure program (First Descents) experienced improvements in psychological well-being, ability to cope with cancer, and/or social support. The study examined the differential effect of participation for YAs who indicated clinically-significant symptoms of psychological distress prior to their trip.

METHODS: Standardized measures of psychological distress, coping capabilities (self-efficacy), and social support were administered to YAs aged 18-40 years at pre-trip, post-trip, and one month following program completion. Data analyses examined (1) distress, coping, and social support scores for distress v. non-distressed participants at all three time points; (2) changes in these outcomes over time, and (3) the extent to which changes in outcomes over time differed for distressed v. non-distressed participants.

RESULTS: Among 347 participants in First Descents programs in 2015, significant reductions in psychological distress and improvements in coping capabilities for all participants were observed over time. Coping capabilities for distressed participants were significantly lower than non-distress participants prior to program participation; however, their coping capabilities at one-month follow-up were equal to that of non-distressed participants.

CONCLUSIONS: Participation in an outdoor recreational activity designed specifically for YAs contributes to significant reductions in distress and improvements in coping abilities, and particularly for YAs reporting clinically significant mental health challenges prior to initiation of their activity. Whether kayaking, surfing, or rock climbing, these opportunities to push oneself beyond one's limits, meet inspiring people, and experience stunningly beautiful settings may be critical contributors to cancer patients' well-being, recovery, and survival.



P85

IMPROVING THE PROCESS OF REFERRALS TO PSYCHOSOCIAL CARE FOR YOUNG ADULTS

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INTRODUCTION AND AIMS: Age-appropriate support programs have the potential to minimize the emotional effects of cancer for young adults (YAs), ages 18-39.

YAs want the opportunity to meet peer cancer patients and reduce isolation. A supportive care program within a large medical oncology center aims to address the unique psychosocial needs of YAs. Given the rise of colon cancer in YAs and low referral rates to the supportive care program from the gastrointestinal cancer clinic (GCC) at this center, quality improvement methodology was used to improve referrals. Baseline data was collected to understand current referral process, possible solutions were brainstormed with a project team, plan-do-study-act (PDSA) cycles were used to implement change, and change data was gathered to determine effectiveness of the interventions. Baseline data showed 7% of YAs within the GCC were referred to the program over a six-month period. Through a survey, medical providers identified barriers in referring, citing lack of familiarity with the services and uncertainty of the referral process.

The project team developed several change solutions to educate medical providers about the psychosocial needs of YAs and the impact of supportive care services targeting those needs. Change data collected after three PDSA cycles showed an increase in referrals to 15%. However, the applied improvement processes were labor intensive, unsustainable, and relied on clinical behavior change. Therefore, the next PDSA cycle focused on educating YA patients to advocate for their own supportive care. Based on patient feedback, a short

documentary-style film with YA voices has been created, highlighting emotional concerns and the use of psychosocial support, to encourage patient-provider conversations and ideally referrals from medical providers. Next steps include focusing on a systematic way to distribute the video to all new YA patients and collect data about impact on referrals to psychosocial services and this supportive care program for YAs.

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DO RESIDENTIAL WEEKENDS FOR YOUNG PEOPLE WITH CANCER ADD VALUE? INTERIM ANALYSIS OF A TWO DAY RESIDENTIAL WEEKEND IN THE UNITED KINGDOM, FIND YOUR SENSE OF TUMOUR

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INTRODUCTION AND AIMS: 'Find Your Sense of Tumour' are two, 2-day residential programme 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 however, this has never been systematically investigated. We aimed to examine the psychosocial benefits to young people attending FYSOT.

METHODS: A project-specific outcome measure was developed based on Part 1 of the evaluation I, 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. We report interim analysis at T3. Data were analysed using longitudinal linear regression for the differences between T0, T1, T2 and T3.

RESULTS: A total of 157 young people participated (13-17 years, n=54; 18-24 years, n=103). A different effect was observed between the two age groups. 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, this was not sustained for the younger age group at T3. In contrast, the older group continued to demonstrate significant improvements in self-esteem (p=0.02) and body image (p=0.003) at six months post FYSOT.

CONCLUSIONS: This interim analysis of an educational, social and peer-to-peer support residential weekend for young people with cancer identifies significant improvements in self-esteem and body image for young people aged 18-24 years which are sustained at six months. Thus attending FYSOT may support integration back to as healthy as life as possible. A twelve month analysis will further conclude sustainability. Further work is required to understand the sustainability of effects for the younger age group.

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INFORMATION AND SUPPORT NEEDS OF CARERS: DO SPECIALIST SERVICES FOR ADD VALUE?

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INTRODUCTION AND AIM: Carers are profoundly affected by their caregiving role yet little attention has been given to identifying and meeting their needs. In particular, the experiences of carers of young people with cancer are not described. We aimed to identify carers' unmet information and support needs. Further, we sought to examine any differences associated with the extent of exposure to specialist care.

METHODS: BRIGHTLIGHT participants nominated their main carer to complete a Carer Questionnaire addressing information needs, healthcare service experience, emotional and psychological wellbeing and support needed/received. Questionnaires were completed six months after diagnosis. Comparisons were made according to where young people's care was delivered: all in a Principal Treatment Centre (PTC), some in a PTC, or no care in a PTC.

RESULTS: Four hundred and seventy-six questionnaires were returned (57% response rate). Mean age was 45.9 (+/-10.5) years, 381 (80%) were female and 401 (85%) were parents. Sixty-six percent reported often/always feeling tired and 58% often/always felt sad. Approximately 20% never received support when they felt depressed or anxious or never received support to find time to themselves.

Sixty-six percent worried about cancer returning and about young people's emotional/psychological wellbeing. Fewer than 50% could manage balancing their job/domestic responsibilities with caring and 25% received no support to facilitate this. Carers who had no exposure to PTC care were less likely to receive information about financial support/benefits, less support to manage social consequences of cancer, less contact with other carers and less access to healthcare professionals.

DISCUSSION AND CONCLUSIONS: We have identified unmet support needs of carers of young people with cancer. This includes lack of support for tiredness, sadness, depression and anxiety. Carers with no access to PTC care had more unmet needs. These data support the value of specialist services for young people with cancer.



P88

AFTER CANCER TREATMENT. SO WHAT NOW?

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INTRODUCTION: A local service review identified that TYA patients felt unprepared for life after completion of cancer treatment. Concerns were raised about the timing and detail of current information provision particularly with regards to survivorship issues. Many also chose not to attend post-treatment workshops organised by the TYA team. In short, information provision and mode of delivery were not meeting patient need.

METHOD: To develop a patient led approach to information provision that met the initial needs of the young person after treatment, and could also be revisited by them as a future resource.

METHODS: A multi-disciplinary working group of TYA professionals was convened and agreed to develop a series of short films. Funding was awarded from a charitable source. An independent film company were commissioned.

12 TYA cancer survivors were identified and invited to participate. All were 6 months or more post completion of cancer treatment. A patient focus group was organised and facilitated by the TYA CNS and Youth Support Coordinator. All gave written consent to be filmed and share their experiences.

RESULTS: The films captured the varied experiences of TYA patients who had completed treatment. A range of post-treatment survivorship issues were addressed, such as: sex, fatigue, healthy life-style and body image. Some spoke about positive consequences of facing cancer; others described how cancer has left them feeling physically and emotionally scarred.

DISCUSSION: This candid collection of patient stories will provide future TYA patients information about pertinent issues beyond the end of treatment. The Sheffield team launched the "Life After Cancer" films on JTV cancer support website and would like to share it with other cancer centres. Its hoped this film medium will provide and deliver appropriate information content at the right time and in an accessible format. Further work is required to evaluate the films.



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CASE STUDY – MAKING SENSE OF “MEMORY” DIFFICULTIES POST CANCER

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This case study reports on a clinical dilemma that we face offering neuropsychological assessments to TYA cancer survivors. Over a one year period 35 cognitive assessments were requested with 24 completed. Of these, 11 young people reported significant memory difficulties and were tested using the Children's Memory Scale or Wechsler Memory Scale. There is evidence to suggest memory decline following cancer treatments (Mulhern et al. 2004), however all 11 of these referrals were found to have intact memory. In addition, tests of attention and processing did not help explain the difficulties these young people presented with. What's going on?

Through our conversations with these young people and their families we present three theories: Firstly, 91% of YP (n=10) came with emotional concerns including low mood, stress and anxiety, which can impact on the encoding and retrieval of information. Secondly, many of the young people reported that they had been told when initially diagnosed that the position of the tumour and the treatment received could result in cognitive deficits, including memory impairment. We hypothesise that experiences of forgetfulness are therefore (mis)interpreted as the result of cancer treatment thus creating a vicious cycle of anxiety and further experience of forgetting. Thirdly, we have considered whether the current memory assessment measures do not fully capture the lived experience of these young people and whether more ecologically valid measures might yield more helpful results.

Future developments include:

- Piloting a group workshop for young people to help develop a broader picture on factors affecting memory such as attention, fatigue, organisation, emotions.
- Researching how medical colleagues inform families of cognitive late effects and the impact that these conversations might have on the interpretation of subsequent experiences.
- Reviewing memory assessment measures to see which measures might be the most valid for the TYA population.

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P90

ADOLESCENT AND YOUNG ADULT SURVIVORS OF CHILDHOOD LEUKEMIA: PARENT AND SURVIVOR KNOWLEDGE OF LATE EFFECTS RISKS

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INTRODUCTION AND AIMS: Adolescent and young adult (AYA) survivors of childhood cancers have an elevated risk for developing late effects of cancer treatment including secondary cancers, cardiotoxicity, and infertility among others. For survivors of acute lymphocytic leukemia (ALL) these risks are often related to treatment with the class of chemotherapy drug, anthracycline, which is known to be associated with cardiotoxicity. It is not known to what extent parents and AYA survivors of ALL understand their late effects risks, which may lead to survivors not seeking care in a timely manner (appraisal delay). Thus, the aim of this study was to determine ALL survivor and parent awareness of risk for common late effects of cancer treatment.

METHODS: Mailed and online survey of survivors and parents of survivors of ALL identified from the Texas Cancer Registry who were at least one year post-active treatment and aged 15-18 years at the time of survey. Survivors and parents were asked whether, because of cancer treatment, the survivor was at risk for: cancer recurrence, secondary cancer, infertility, high blood pressure, or stroke.

RESULTS: Surveys were completed by 51 AYA survivors and 53 parents. Among AYA survivors, 53% reported being at risk for cancer recurrence, 39% for secondary cancer, 51% for infertility, 26% for high blood pressure, and 12% for stroke. Among parents of survivors, 56% reported that their child was at risk for cancer recurrence, 58% for secondary cancer, 56% for infertility, 25% for high blood pressure, and 15% for stroke.

DISCUSSION AND CONCLUSION: Knowledge of late effects risks after ALL is low for both AYA survivors and their parents. Low understanding of risks of cardiotoxicity symptoms including high blood pressure and stroke are particularly concerning, as appraisal delay could lead to a lack of preventive care and early intervention.



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OCCUPIED WITH CANCER: TRAJECTORIES OF EMPLOYMENT/ EDUCATION AND PSYCHOLOGICAL DISTRESS AMONG SOCIOCULTURALLY DIVERSE ADOLESCENT AND YOUNG ADULT CANCER PATIENTS

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The primary question that this research investigates is how trajectories of employment/education and psychological distress are characterized across two

years following a cancer diagnosis among socioculturally diverse adolescent and young adult (AYA) patients, and whether and how change in occupational status is associated with psychological distress over time. Within this overarching question, the researcher examines two specific aims: (1) To identify longitudinal trajectories of psychological distress (Bonanno, 2004) among AYA cancer patients across two years following initial cancer diagnosis, and depict the association between psychological distress and treatment status, health status, and sociocultural factors; (2) To examine the relationship between theoretical trajectories of occupational status and psychological distress across two years after initial cancer diagnosis among AYA patients, including examination of treatment status, health status related to readiness to work, and sociocultural factors.

The study used the HopeLab longitudinal dataset (Zebrack et al., 2013), a prospective longitudinal study of 215 AYA cancer patients ages 14-39 years across two years following a cancer diagnosis at three U.S. cancer centers. The methodology included descriptive analyses to characterize occupational status and psychological distress trajectories, bivariate analyses to test hypothesized associations with psychological distress trajectory, and linear mixed modeling for multivariate analyses of change in psychological distress over time.

The overall trend in psychological distress among AYA cancer patients across the two-year observation period formed a U-shaped curve that bottomed out at 6-month follow-up, then climbed to its highest level at 24-month follow-up. Being male and being Non-White were each significantly associated with increased psychological distress, while being on treatment and having fatigue were associated with decreased psychological distress. Consistent with building empirical knowledge on mental health among AYA cancer patients, this research contributes longitudinal findings that expand the limited available evidence on occupational status and psychological distress among socioculturally diverse AYA cancer patients.

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EMR DOCUMENTATION OF TOBACCO, ALCOHOL, AND DRUG USE AMONG AYA PATIENTS IN A PEDIATRIC SETTING

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INTRODUCTION: Risk-taking behaviors, including substance use, are not uncommon during adolescence and young adulthood. Substance use during cancer treatment may place patients at higher risk for infections, magnify treatment-related toxicities, pose adverse interactions with their cancer treatments, and increase risk for secondary cancers. Most research on substance use among AYAs has focused on survivorship. Studies with this population suggest that almost half report alcohol use, and almost one quarter report illicit drug use after diagnosis.

The purpose of this study is to examine rates of substance use prior to diagnosis and during treatment among AYA patients. A second aim is to examine quality of documentation of substance use behaviors among this population.

METHODS: Data was collected through a retrospective chart review of all patients 15-39 years old at diagnosis and diagnosed at our pediatric institution between 2007 and 2014.

RESULTS: 160 records were reviewed. Documentation of tobacco use (yes/no) improved from 50% in 2007 to 100% in 2014. Compared to tobacco use, alcohol and other drug use was assessed and documented less frequently. Documentation patterns for alcohol and other drug use also improved over this time period, though to a lesser degree (from 11% to 47% for alcohol; 17% to 35% for other drugs).

CONCLUSIONS: Few patients reported tobacco, alcohol or drug use during treatment. Assessment and documentation of tobacco use improved over time, while assessment and documentation of alcohol and other drug use remains an opportunity for continued focus. Increasing awareness of patient risk-taking behaviors may provide opportunities for education and intervention, which may in turn improve patient outcomes through reducing risk for morbidity associated with substance use/abuse.

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ASSESSMENT OF PSYCHOSOCIAL NEEDS IN AYA PATIENTS IN A NEWLY ESTABLISHED AYA ONCOLOGY PROGRAM

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INTRODUCTION AND AIMS: Providing optimal care for AYAs with cancer presents unique challenges. Understanding their psychosocial needs is necessary to improve their care. Our goal in this retrospective, observational study is to identify psychosocial needs in a newly established AYA oncology program and use the data for program development based on local needs.

METHODS: Patients at the new AYA Oncology program at Greenville Health System (GHS) completed a validated survey (Zebrack et al) assessing their psychosocial needs. Following survey completion, patients had a personalized psychosocial support plan. The survey assesses psychosocial needs in AYA patients including counseling, complementary alternative medicine (CAM), support groups, cancer education, fertility, nutrition/exercise and financial toxicity. Answer choices included: 1 (Yes/not needed anymore), 2 (Yes/need more), 3 (No/need more), 4 (No/not needed). Data was analyzed by summing the relative response rates of "2" and "3" for each question for all patients sample and three age groups: early-AYA (15-20), mid-AYA (21-30) and late-AYA (31-39). Questions for which the sum of responses "2" and "3" was $\geq 50\%$ were considered significant needs. Data from the first 50 patients are presented.

RESULTS: Significant needs in the entire group included counseling (50%), CAM (64%), camps/ support groups (64%), cancer education (58%), nutrition/exercise (60%). Compared with other groups (mid-AYA:27%, late-AYA:33%), early-AYAs reported higher interest in fertility (62%); financial needs were higher in mid-AYA/late-AYAs (both 55%) compared to early-AYAs (23%) as were personal counseling needs (early-AYA:38%, mid-AYA:55%, late-AYA:58%). Support group needs increased with each age group (early-AYA:8%, mid-AYA:36%, late-AYA:46%).

DISCUSSION AND CONCLUSION: The needs identified in this study point to a unique set of needs experienced by AYA patients. This data will be used for ongoing program development with special focus on areas addressing counseling, support groups, financial toxicity, CAM, fertility, cancer education and nutrition/exercise.



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POSTER WITHDRAWN



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DEPRESSION, ANXIETY, AND SUICIDAL IDEATION IN AYA CANCER SURVIVORS

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INTRODUCTION AND AIMS: Limited research exists regarding psychosocial needs of AYA survivors (Soliman & Agresta, 2008; Duffy-Lind et al., 2006) despite the fact that psychological factors influence treatment adherence among AYA survivors (Kondryn et al., 2011). ASCO guidelines

recommend cancer survivors be assessed for depression & anxiety at multiple points of care, referred for appropriate treatment, and reassessed to ensure adherence and symptom remission (Anderson et al, 2014). The current quality improvement project aims to apply these recommendations through conducting patient-driven point-of-care depression screening, coupled with reassessment and mental health navigation. These results focus on recent AYA survivors (ages 18 to 39, diagnosed within 2 years; n=52 of N=500 random sample analyzed).

METHODS: A point-of-care web-based application (VitalSign6) was utilized to assess depression and other psychiatric symptoms. Reassessment was conducted every 2 weeks when possible, and patients were navigated into appropriate mental health care (described in Howe-Martin et al, 2017).

RESEARCH: A total of 52 (10.4%) of 500 recent cancer survivors fell within the ages of 18 to 39 at the age of initial depression screening. Of these, 22 (42%) of AYA patients presenting for cancer-related services screened positive for potential depression (PHQ-9 ≥ 5), and 77% of those who endorsed potential depression endorsed significant anxiety symptoms (GAD-7 ≥ 5). Approximately 15% (n=8) of AYAs endorsed suicidal ideation within the past 2 weeks. By comparison, the older, non-AYA group (n=448) reflected a 33% positive depression rate, with 70% noting comorbid anxiety, and 7.3% endorsing suicidal ideation.

DISCUSSION & CONCLUSION: These results reflect an ongoing need to target AYA cancer survivors for psychological interventions; results also suggest that AYAs may be experiencing increased mental health symptoms compared to their older counterparts. Exploring how targeted programming for AYAs can be implemented within community cancer programs certainly appears warranted, based on these results.

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P96

PERCEPTIONS OF TRANSITION READINESS & HEALTH SELF-MANAGEMENT AMONG YOUNG ADULT SURVIVORS OF PEDIATRIC CANCER

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INTRODUCTION AND AIMS: Facilitating successful transition of survivorship care from pediatrics to adult providers is critical to the continued health of the childhood cancer survivors as they age into young adulthood. In order to improve transition outcomes, we need to understand what health behaviors impact transition readiness. The aim of this study was to assess the relationship between healthcare responsibility and transition readiness within a sample of young adult (YA) survivors of pediatric cancers.

METHODS: Participants were YA survivors (N=99) ages 18 to 21 (M = 19.29, SD = 0.94) who were recruited from a pediatric long-term follow-up oncology clinic. Participants completed the Readiness for Transition Questionnaire

(RTQ-Survivor) to assess transition readiness and YA responsibility for 10 specific healthcare behaviors. Univariate regression models were used to evaluate the individual predictive value of each healthcare behavior in relation to perceptions of transition readiness.

RESULTS: Only 35.4% of YAs reported that they took primary responsibility for their healthcare. Perceptions of readiness to assume complete responsibility for healthcare were most influenced by YA responsibility for scheduling annual survivor appointments ($R^2=0.54$, $p<0.001$) and specialty care appointments ($R^2=0.49$, $p<0.001$) as well as understanding insurance coverage ($R^2=0.51$, $p<0.001$). Perceptions of readiness to transfer to adult care were most influenced by YA responsibility for phone communication ($R^2=0.37$, $p<0.001$) and in-person communication with medical staff ($R^2=0.25$, $p=0.01$), in addition to scheduling annual survivor appointments ($R^2=0.29$, $p=0.004$) and understanding insurance coverage ($R^2=0.29$, $p=0.004$).

DISCUSSION & CONCLUSIONS: The healthcare behaviors assessed by the RTQ appear to be salient to YA survivors' perceptions of transition readiness. Future interventions promoting survivors' transition readiness should include practice with appointment scheduling, communicating to providers by phone and in clinic, and insurance education. Pediatric programs may consider using the RTQ to assist in patient-centered transition planning and assessment of YA transition readiness programming.



P97

DEVELOPING A NOVEL MECHANISM TO PROMOTE TEEN AND YOUNG ADULT PATIENT CONNECTIVITY

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BACKGROUND: The diagnosis and treatment experience of teen and young adult (TYA) patients is unique and well documented. Memorial Sloan Kettering's (MSK) The Lounge mobile app offers opportunities to decrease isolation, improve connectivity between enrolled MSK patients, and address personal, psychosocial and educational needs.

METHODS: A multistep approach was taken to conduct research, identify functionality and design, and create software. MSK engaged graduate level students, expert design consultants, and a software product development firm. Patients, caregivers and staff were involved throughout the research, design, and testing phases.

RESULTS: The app recognizes the need to reach this patient population irrespective of time or location. The Lounge is a secure and private space for users to interact, ask questions and receive validated information. Patients may choose to just read or engage. Functions include:

SHARE: Users create personal profiles disclosing what they wish. They may share text, photo and video updates with the community.

CONNECT: Similar to other social media networks, users can search and connect based on commonalities indicated in personal profiles.

DO: Events and activities within the hospital, off site or online, may be posted by patients and program staff.

ASK: Users may ask questions and receive answers from their peers and an advisory group of clinical professionals.

Most importantly, The Lounge reaches MSK's TYA patients where they are comfortable: online.

CONCLUSIONS AND IMPLICATIONS: The research and analysis done to create MSK's app for TYAs broadened our understanding of the complex needs of this population. We identified a number of potential opportunities and developed new approaches to deliver enhanced psychosocial care. There

is immense potential for further research and clinical work with the TYA population. The Lounge is one mechanism and the first of its kind to focus on a specified age group (18-30), receiving treatment in pediatric or adult settings.



P98

FACTORS INFLUENCING VISUAL AND VERBAL SELF DISCLOSURE OF VIDEO NARRATIVES IN TEENAGERS WITH CANCER: A PILOT STUDY

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INTRODUCTION/AIMS: A growing body of research suggests that adolescents and young adults (AYA) with chronic medical conditions seek social support online as it offers easy access to peers and loved ones during times of isolation. However, this research has mainly focused on thematic content of this support and not the factors influencing content or outcomes. This poster begins to fill this literature gap.

METHODS: As part of a larger research study N=10 adolescents with cancer ranging from age 13-18 were asked to make a testimonial video describing their experiences since being diagnosed. Patients completed measures about personality (TIPI), quality of life (PedsQL Core/Cancer Modules), experience making the video, and previous history with social media. Pearson correlations were then conducted to examine the relationship between variables measured by these questionnaires and the amount of visual and verbal self-disclosure (LIWC) presented within each video.

RESULTS: Unlike originally hypothesized, a patient's visual appearance did not determine willingness to appear on one's video. Instead, comfort with social media was ($r=.743, p=.05$). A trend was also noted with level of extraversion ($r=.566$) and openness ($r=.442$). A desire for legacy was not related to verbal self-disclosure; knowledge of testimonial videos ($r=.716, p=.05$) was significant and strong positive trends with perceived impact on others ($r=.592$), social relationships ($r=.532$), impact of making the video on oneself ($r=.462$), and desire to increase health related behaviors ($r=.503$). A larger sample may have increased significance for some correlations.

DISCUSSION/CONCLUSION: A number of unexpected factors were related to various forms of self-disclosure in adolescent cancer video narratives. While information from this study begins to shed light on who may benefit from similar interventions, there is still much to learn about this technology and how it impacts AYA with cancer.



P99

HEALTH-RELATED QUALITY OF LIFE OF CANCER SURVIVORS: WHICH DOMAINS ARE PARTICULARLY RELEVANT TO YOUNG ADULTS?

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INTRODUCTION AND AIMS: For young adults, the impact of a cancer

diagnosis, subsequent treatment and recovery is likely to be distinct from other age groups given the unique and complex social and developmental transitions of this life phase. As part of a larger EORTC Cancer Survivorship Assessment Strategy study, health-related quality of life (HRQoL) concerns of young adult (<40 years) cancer survivors were compared to those of older adults to identify whether younger survivors have specific concerns.

METHODS: HRQoL issues captured from a review of the literature and interviews with 117 adult cancer survivors were shown to survivors of 11 different tumour types recruited from four geographical regions in Europe. Survivors were grouped according to age: <40 years, 40-50 years; 50-60 years; 60-70 years and >70 years. The list included 277 issues (207 generic, 8 sex-specific and 62 cancer-site specific) organised within 12 domains: Mental health, Physical health, Role functioning, Cognitive functioning, Living with cancer, Lifestyle, Spirituality, Social functioning, Financial issues, Health care, Body image, and Sexuality. Survivors rated the relevance of each issue on a scale from 1 ("Not at all") to 4 ("Very much") and prioritised the 10 most important issues

RESULTS: Of the 458 survivors, 44 were young adults aged 23-40 years. Several survivorship issues emerged as more relevant to younger adults (<40 years) compared with the older age groups and included concerns about the ability to have children (46% rated this issue as "a little bit relevant" and 27% as "quite a bit relevant"), difficulty talking about cancer (43%, 14%), financial issues in particular obtaining life insurance (33%, 30%), and emotions relating to one's body including anger (32%, 11%) and embarrassment (34%, 3%). Some issues were particularly relevant to survivors aged <40 years and 40-50 years, for example, changes to personal goals and life plans, reluctance to start new relationships, worry about finding a long-term partner, and personality changes. Physical symptoms and activity limitations were more likely to be recognised as issues amongst older age groups.

DISCUSSION AND CONCLUSION: Our findings highlight the unique HRQoL issues faced by young adult cancer survivors and have implications for how they might be best supported beyond their cancer treatment.



P100

ESTABLISHING AN AYA PATIENT NAVIGATION SERVICE TO ADDRESS UNMET NEEDS

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INTRODUCTION AND AIM: To address the unique cancer care challenges faced by adolescent and young adults (AYAs) in the Mountain West, the two largest cancer care institutions in Utah collaborated to establish an AYA patient navigation service. The AYA patient navigator (PN) helps AYA patients, survivors, and their caregivers by connecting them with information and resources to address their unmet needs.

METHODS: The AYA PN service was developed and piloted from September 2016 to August 2017 with over 100 patients across a variety of ages, diagnoses, and treatment facilities. The PN connected with patients who have or had cancer between the ages of 15-39 through self- and provider-referral. The PN conducted an informal needs assessment, then provided patients with information and resource referrals to address their unique needs. Patients continued to interact with the PN throughout and beyond their treatment.

RESULTS: Since the first PN referral in October 2016, the navigator has provided over 1100 services to 105 patients. Patient needs include identifying appropriate medical, survivorship, and fertility services; employment, education, and financial resources; and social supports and connections with other AYA patients and survivors. The PN referred to resources within a patient's healthcare facility (e.g., social workers), in his or her community (e.g., Utah Department of Workforce Services), or through national organizations (e.g., Stupid Cancer).

DISCUSSION AND CONCLUSION: Patient navigation is an important component of an AYA program because it complements existing care services (Ferrari et al., 2010) while providing individualized attention to ensure that unique patient needs are addressed. One challenge of a PN service assisting such a broad age range and geographic area is that caseloads should be kept small to ensure that patients receive appropriate attention from the navigator. PN can effectively provide AYAs with direct assistance between adult and pediatric facilities and multiple medical institutions.

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PI01

LOVE YOU TO DEATH

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INTRODUCTION: Advanced cancer can have a significant impact on relationships between TYA patients and their partners. Fatigue, low self-esteem and body image issues are common reasons why desire for sex decreases. Poor communication within this age group can be misinterpreted as lack of interest in a relationship, causing feelings of neglect and self-doubt. Issues may be exacerbated by changing roles as partners adopt more responsibility or feel abandoned due to increased parental input.

METHOD: Palliative TYA patients and their partners were given the opportunity to socialize with other couples during a weekend break aiming to eradicate feelings of isolation and help restore a sense of normality.

RESULTS:

- Patients reported that quality time with their partner without parental invasion was most valuable
- Memories were created for both parties as they spent quality time alone and as part of a group.
- Feelings of normality were expressed by the couples, who recognised that they were able to share similar stories alongside other people who understood their situation.
- Partners of the TYA patient valued the opportunity to have their own needs acknowledged.

DISCUSSION:

- Experienced TYA care and nursing skills were essential in addressing the needs of the couples.
- Positive feedback revealed that targeted interventions may be of benefit to patients in relationships, not just palliative patients.
- The need to provide a group that focussed on the needs of partners only was evident.
- This project highlighted the lack of support and information for TYA couples trying to develop or maintain a relationship at end of life.



PI02

TELEMENTAL HEALTH FOR ADOLESCENT AND YOUNG ADULT CANCER SURVIVORS

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At University Hospitals AYA Cancer Center in Cleveland, OH, we are addressing the unique needs of the AYA population through age-appropriate facilities, support, and psychosocial resources. Disease and treatment can delay a young person's ability to successfully achieve age-related developmental tasks such as establishing autonomy and making independent decisions about employment, education, relationships, and starting a family. All of these stressors may interfere with adherence to therapy and ultimately impact social and emotional maturation.

In order to address these barriers often associated with access to mental health services, which can include financial factors, distance, lack of transportation, poor health, or childcare issues, we will be offering a yearlong pilot effort to assess the efficacy of a telemental health intervention to increase access to mental health services for our AYA patients in need of psychosocial care.

Telemental Health is a "virtual visit" that allows us to offer the same level of mental health care to patients via digital technology that we provide in person. Results of similar studies demonstrate encouraging results. Videoconferencing appears to be as effective as in-person care for most parameters such as feasibility, outcomes, age, and satisfaction with a single-assessment, consultation, or follow-up and has been studied in illnesses such as depression, post-traumatic stress disorder, and substance use.

In our yearlong pilot program, we will include 25 AYA oncology patients ages 18-30 who have completed treatment, demonstrate a need for mental health services by a score of 4 or higher on the NCCN Distress Thermometer, but are not in acute distress or demonstrating a psychotic disorder; and have completed an in-person evaluation with the AYA psychology and/or support staff.

Ultimately, we hope that this will enable increased access to mental health services for our AYA cancer patients and ensure continuity of care through their survivorship.

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PI03

CAN VIDEO TESTIMONIALS BENEFIT ADOLESCENTS WITH CANCER?

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BACKGROUND: Non-traditional treatment methods incorporating new technologies have been shown to target the chief concerns of AYAs with

cancer (biological, psychological, and social impact of medical treatment on current well-being and the future) while also giving them a chance to experience much needed socialization with peers. Interventions that combine aspects of creative expression and social networking have the potential to be helpful while also being cost effective and easily accessible. However, no research has been conducted in this area. This study begins to understand the process and benefits of making video illness narratives in AYAs with cancer.

METHODS: N=10 adolescents diagnosed with cancer and N=10 healthy adolescents with no history of chronic medical conditions were recruited. With the help of researchers, patients recorded videos of their illness narrative (controls recited the story of their most stressful event in recent years) after being read a prompt asking them to share their story. Participants then answered a questionnaire designed to capture the impact of filming on the participants as well as perceived impact on others who might watch the video. Videos were analyzed for themes in verbal content as well as grammatical qualities that relate to resilience.

RESULTS: When compared to other illness narratives in AYA cancer patients, verbal themes reflect similar content. Teens with cancer reported a more positive outlook about their cancer experience as compared to healthy peers. Questionnaires show that after reciting narratives participants with cancer report greater positive outcomes as they relate to emotional experiences, plans to improve their health related habits, and increased quality of social relationships. A sense of legacy was also reported.

CONCLUSION: Video testimonials appear to have a larger benefit for adolescents with cancer when compared to healthy peers discussing another stressor. Suggestions for future research and clinical practice will also be made.



PI04

BREAKING THE ICE: ESTABLISHING EFFECTIVE AYA PSYCHOSOCIAL SUPPORT IN A UNIQUE CARE ENVIRONMENT

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BACKGROUND: Since 2006, over 400 adolescent and young adult (AYA) patients have been treated at the UF Health Proton Therapy Institute (UFHPTI) in Jacksonville, Florida. The challenge of cancer treatment in this group is marked by simultaneous transitions in education, employment, identity, relationships, and family. Uniquely, approximately 85% of our AYA patients are from outside Florida, including 25% from beyond the United States. The physical displacement adds an additional layer of complexity. Our program was developed to address and mitigate the sense of isolation an AYA might experience during their 6-10 weeks of treatment.

OBJECTIVES:

- To open dialogue with AYA before they arrive for treatment and facilitate a personalized support plan during prolonged separation from their home environment.
- To utilize a patient-centered model of care which builds on the unique diversity found in the AYA population travelling for proton therapy.

METHOD:

- The "Breaking the Ice" questionnaire is designed to elicit psychosocial information about the AYA in their own words and to provide an opportunity for them to ask questions about their upcoming treatment.

- SW collects questionnaire from patient prior to their arrival. This timing is important as it allows staff to anticipate specific patient needs.
- The goal is to reduce patient distress, anxiety, depression, and to increase coping, quality of life and to build partnership between AYAs and healthcare professionals.

RESULTS: Since its creation in July 2017, the questionnaire has been sent to seven AYA patients. All patients, representing a mix of genders and diagnoses, voluntarily completed and returned questionnaire. Feedback has been positive.

CONCLUSION: The Breaking the Ice questionnaire builds a partnership between patients and the multidisciplinary team, setting the foundation for successful treatment in an unfamiliar environment. It allows our team to address psychosocial barriers through a customized support program.

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PI05

DOES AGE MATTER? A COMPARISON OF HEALTH-RELATED QUALITY OF LIFE ISSUES OF ADOLESCENTS AND YOUNG ADULTS WITH OLDER ADULTS WITH CANCER

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INTRODUCTION AND AIMS: For adolescents and young adults (AYAs), the impact of a cancer diagnosis and subsequent treatment is likely to be distinct from other age groups given the unique and complex physical and psychosocial challenges of this developmental phase. The objective of this study was to compare health-related quality of life (HRQoL) concerns of AYAs (14-18 years; 19-25 years) and older adults with cancer (26-50; 51-60 years).

METHODS: HRQoL issues captured from a systematic review of the literature and semi-structured interviews with AYAs aged 14-25 years and health care professionals (HCPs) were shown to 33 AYAs, 25 older adults, and 8 HCPs from 6 countries. The list included 77 issues organised within 10 domains: Symptoms, Activity restrictions, Social, Emotions, Body image, Self-appraisals, Outlook on life, Lifestyle and Survivorship.

RESULTS: Several issues were recognised as relevant and important across all age groups: symptoms (pain, nausea, vomiting, tiredness), impact on family and friends and family life, dependency on others, improved relationships, emotional impact, positive outlook on life, difficulty adjusting to being ill, treatment burden, concern over side effects and desire for life to return to "normal". A number of issues were rated as only important to AYAs

and included the impact on hobbies and leisure time activities, inability to go out, loss of friends, feeling isolated and less time to spend with friends, interrupted education, greater motivation to achieve academic and personal goals, boredom and lack of age appropriate cancer-related information. In addition, some issues such as change in living situation and financial difficulties were specific only to AYAs within the 19-25 year old group.

DISCUSSION AND CONCLUSION: Our findings have important implications for the measurement of the diverse and unique HRQoL concerns of AYAs with cancer.



P106

THE LONG ROAD AHEAD: USING CONCEPT MAPPING TO IDENTIFY KEY YOUNG ADULT CANCER SURVIVORSHIP ISSUES

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BACKGROUND: Young adult cancer patients have complex medical and psychosocial needs throughout treatment. Yet, once treatment ends, few young adult cancer survivors (YACS) receive adequate survivorship care. Many YACS do not continue with oncology care after treatment ends. The purpose of this study was to utilize concept mapping to identify pertinent survivorship issues of YACS.

METHODS: Twenty-six YACS (n=26) participated in focus groups to learn about their post-treatment experience. Six focus groups were held based on age (18-24, 25-30, and 31-39 years) and oncological follow-up status (Continue to Follow-Up or Lost to Follow-Up). Participants did not have similar disease type or treatment plan per focus group. A brainstorming session produced a number of concepts which the participants ranked and sorted based on their level of importance to them. Data was subsequently analyzed using concept mapping software (Concept System® Global MAX™) to identify significant themes or "clusters" for each focus group.

RESULTS: Five to eight clusters were identified amongst the focus groups. Regardless of age group or follow-up status, "Late-Effects of Treatment" was a shared issue. "Financial Burden" was identified as a significant issue for those in the 25-30 years old group regardless of follow-up status. Interestingly, navigating follow-up care was shared among the 25-30 and 31-39 years old groups who continued with regular follow-up. Lastly, "Navigating Relationships" was a significant concern for YACS under age 31 who followed-up. Despite these unifying clusters, each group experienced a myriad of concerns irrespective of whether follow-up care was continued.

CONCLUSIONS: Concept mapping enables systematic analysis of qualitative information generation from focus group participants. These findings suggest that regardless of age group and follow-up status, long-term medical care is a burden for YACS. They seek information about late-term side effects, struggle with relationship issues, and worry about their overall health long after treatment ends.

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P107

YOUNG WOMEN WITH METASTATIC BREAST CANCER: LEAVING A LEGACY

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INTRODUCTION AND AIMS: Young women diagnosed with metastatic breast cancer (YWMBC) face distinct issues and concerns, including the necessity of confronting mortality earlier than expected. Young Survival Coalition (YSC) provides support and education of young women diagnosed with breast cancer.

METHODS: YSC's survey of YWMBC revealed that tools to help them communicate about their disease and prognosis would be helpful (76%). Desired tools included templates for leaving a legacy. Based on these survey results, YSC decided that creating the opportunity for YWMBC to leave a legacy was important. YSC offered "Leaving a Legacy: Half Day Retreat for YWMBC" onsite at its 2017 national Summit in Oakland, California. In this three hour session, participants learned what it means to leave a unique legacy, received information on artistic and letter-writing projects as well as the opportunity to network and share their own legacy ideas. Co-survivors could attend.

RESULTS: Over 60 YWMBC, some accompanied by a co-survivor, attended this half-day retreat at the start of the Summit. An evaluation sent to participants received 23 responses. YSC asked the extent to which the retreat gave respondents the resources/tools they were looking for regarding leaving a personal legacy. Twenty-two percent (22%) said to a "great extent," 39% said to a "moderate extent," and 39% said to a "small extent." YSC also asked whether respondents left the retreat with ideas/projects for leaving a legacy. Seventy-eight percent said "yes." In open-ended questions, participants provided additional feedback and suggestions for improvement.

DISCUSSION AND CONCLUSION: YSC's "Leaving a Legacy" half-day retreat provided an opportunity for YWMBC to learn and participate in ways to create a legacy for those they will leave behind. The session was well-attended and generally well-received. YSC will examine ways in which the session could be improved to meet the needs of YWMBC.



P108

ABOUT RELATIONSHIPS BETWEEN AYA AND CAREGIVERS, THROUGH TOOLS SUCH AS MOBILE PHONE, E-MAILS OR SOCIAL NETWORKS

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INTRODUCTION: The AYA unit of Institut Curie, created in 2013, takes care of patients aged 15 to 25 with solid tumors, with a dedicated 6-beds unit, and a transversal organization with coordination nurses as a core, and healthcare workers both from pediatric and "adult" background. AYA also meet many caregivers from other departments and from transversal support



functions in our institution. Therefore, the question was to know more about relationships developed between patients and/or their entourage and caregivers, in particular through new tools such as mobile phone, e-mails or social networks.

OBJECTIVES AND METHODS: 100 anonymous questionnaires were given to all caregivers working or having regular interactions with AYAs in our institution.

RESULTS: 81/100 responded, 22 admitted having had extra-professional contacts with at least one patient, and 21 with the entourage. 50% of caregivers had already experienced difficulties in refusing a solicitation, 18% regretted having created these links. Although they believe that it should be a personal choice, they would prefer to have proper training in order to achieve a better management of these solicitations that are troublesome.

DISCUSSION AND CONCLUSION: Despite exchanges being relatively rare, they can harm caregivers who are experiencing difficulties in boundaries with patients. A solution could be trainings and meetings of sharing experiences in this field, but also perhaps to create "pages" of unity on social networks to channel exchanges.



PI10

POSTER WITHDRAWN



PI09

POSTER WITHDRAWN



PI11

IMPLEMENTING AN ADOLESCENT AND YOUNG ADULT MENTOR RETREAT AND EDUCATION CURRICULUM: WISE INVESTMENT FOR EMERGING AYA PATIENT LEADERS

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The Adolescent and Young Adult (AYA) program at CHOC Children's Hospital identified the importance of investing in a committed group of AYAs and empowering them to take ownership of the program designed for them. In doing so, a core group of AYAs demonstrated interest in leadership to share their voice and vision to support other AYAs. AYAs striving to become leaders

within the program report a sense of purpose as they learn valuable life skills. Emerging AYA leaders received specialized training and support to further understand what is involved in taking a leadership role. The AYA program invested in these emerging leaders, by designing and implementing the first annual CHOC AYA Mentor Retreat which took place spring of 2017 over a weekend. While the main purpose of the retreat was to provide training on how to be a peer mentor, the selected group of AYA patients and AYA siblings also experienced a social weekend with peers. The training included: knowledge and awareness about basic AYA cancer diseases, how to provide peer support, and how to engage in self-care activities. They also engaged in leadership and mentorship training exercises. Invited patients and siblings were selected based on demonstrated leadership qualities, eagerness to learn and a desire to give back to the program. A total of sixteen AYA patients and siblings attended the retreat along with a staff comprised of two AYA child life specialists, 3 oncology nurses and a music therapist who facilitated the retreat events and education curriculum. Pre- and post-tests were conducted to evaluate the impact of the education curriculum of the retreat. The success of this event was voiced by the AYAs and staff in a video recording. They described the retreat to be "powerful", and "providing essential knowledge to grow as leaders."



PII2

CANCER COSTS: EXPLORING THE FINANCIAL AND EMOTIONAL IMPACT OF CANCER ON AYA

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INTRODUCTION AND AIMS: At CLIC Sargent, we know that cancer costs, both financially and emotionally. However the impact of these additional factors on young cancer patients and their families often remain unclear. In order to explore the psychosocial impacts of a cancer diagnosis in more depth we conducted qualitative and quantitative research with AYA and parents/carers.

METHODS: An in-depth literature review and scoping workshops with AYA and CLIC Sargent staff were used to scope research questions and develop materials. Qualitative interviews took place with five AYA, five parents/carers and seven CLIC Sargent Social Workers. Online questionnaires were completed by 149 AYA and 279 parents/carers.

RESULTS: Our findings emphasise the stark realities faced by AYA and those closest to them. On average, families were spending an additional £600 per month during their child's treatment. 61% parents accrued debt during this time, with 1 in 6 borrowing over £5,000. Stress around finances was accompanied by wider experience of mental ill health. Anxiety, depression and panic attacks were common amongst AYA and their parents/carers. Additionally, 45% parents/carers said that their child's cancer diagnosis had a negative impact on siblings' health and wellbeing. Of those experiencing mental ill health, a significant minority of AYA (41%) were not accessing any formal support. For parents/carers, this rose to 63%.

DISCUSSION AND CONCLUSION: This research demonstrates the importance of appropriate social care interventions in addressing some of the financial and psychosocial costs incurred to AYA and their families. It highlights the important role governments, utility companies and mental health services play in alleviating some of these financial costs and makes practical recommendations for change. It also clearly shows the value of the, softer, less tangible support provided by peers, family members and online resources, all of which can provide valuable lifelines to AYA and their families.



PII3

"AFFECTIONATE MANAGERS" A QUALITATIVE RESEARCH ON THE EXPERIENCES OF CARE GIVING PARENTS OF ADOLESCENTS AND YOUNG ADULTS WITH CANCER AND THE DEVELOPMENT OF A BOOKLET

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INTRODUCTION AND AIMS: Care giving parents of adolescents and young adults (AYAs) with cancer are very involved in the cancer trajectory of their child, both emotionally as practically. To offer parents adequate psychosocial care, insight in their experiences, needs and expectations is crucial.

METHODS: A qualitative research, based on principles of grounded theory, was conducted in the University Hospital of Ghent (Belgium). Thirty one-time only semi-structured interviews were taken with parents of AYAs (15-25y) at different times in the cancer trajectory, starting from the time of diagnosis until 5 years after the end of the treatment.

RESULTS: Parents take different roles in the care for the AYA. They act as "affectionate managers" and take simultaneously the role of representative, gate-keeper, advocate and loving parent of the AYA. Moreover, parents feel constantly challenged to find a balance in relation to the AYA, in relation to their partner and to possible other children, and in relation to their network (family, friends, colleagues, etc.). A majority of parents experience a lack of self-care. Parents experience an important need to be involved in the cancer trajectory and care of the AYA. They want sufficient and useful information and understanding for their unique situation and for the challenges they face.

DISCUSSION AND CONCLUSION: Most parents offer their AYA unconditional all-round care but they face certain insecurities and fears. Adequate psychosocial care for parents requires acknowledgment of the different roles they take in the support of their child. Based on the findings of this research, a booklet was developed for parents of AYAs. This booklet describes the experiences of parents, using illustrative quotes of the interviewed parents. Worksheets are implemented, offering parents tools in expressing their feelings and thoughts and in communicating with the AYA and the people surrounding them.



PII4

DECISION MAKING AND ACTIONS DRIVING ONLINE INFORMATION AND SUPPORT SEEKING FOR YOUNG PEOPLE WITH CANCER

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INTRODUCTION AND AIMS: For young people, the internet is a fully-integrated part of life and it is important that online services are developed

to fully utilise the potential of the internet to support young people with cancer. However, there is a dearth of evidence looking at how young people mobilise themselves to seek information and support online, what they are looking for and whether this meets their information and support needs. We sought to understand how young people seek information on line and whether digital/online needs are being met.

METHODS: Participatory Action Research methodology was employed. Four workshops and six interviews involving 22 young people with a range of cancers diagnosed aged 13-24 years were completed. Workshops consisted of participatory methods including focus group, interactive activities and individual thought, encompassing: online resources used, when, how and what they are searching for; whether these resources were helpful and how they could be improved.

RESULTS: Seven themes emerged which influence a young person's decision-making and actions when accessing online resources. 1. Where young people are on their cancer timeline 2. External influencing factors 3. Emotional drivers of online searching 4. What young people search for online 5. Resources used by young people 6. Availability, accessibility and assessment of online information and resources 7. Emotional responses to using online resources

DISCUSSION AND CONCLUSION: The way young people access and engage with online resources is complex with multiple influencing factors including emotional drivers and responses to accessing online resources furthermore these can vary along their timeline. Healthcare professionals should take into account all of the influencing factors when discussing potential online resource with young people. Future research will explore the views of professionals caring for young people with cancer on accessing online information and support.



PII5

QUALITATIVE SATISFACTION SURVEY AND ETHICAL REFLECTION ON THE PROVISION OF TELEPRESENCE ROBOTS BY CHILDREN AND TEENAGERS HOSPITALIZED IN ISOLATION

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The provision of telepresence robots in the residences of children and adolescents hospitalized in pediatric oncology isolation units, with the idea of maintaining a familial bond during their time in hospital.

To analyze and evaluate:

- the experience of the child and their families
- the experience of the caregiving team

Semi-directed interviews reaching data saturation point:

- by a psychologist with 10 children and their parents two weeks after the introduction of robots, then after the children return to their homes;
- by a philosopher with 13 caregivers before the provision of the robots then three weeks after provision.

Qualitative vertical analysis (thematic) and horizontal analysis (verbatim within the themes) then follows.

Overall positive experience, benefit in combatting the loneliness caused by isolation and in maintaining a link with siblings. The robot's ability to move is considered to be a factor that facilitates communication.

For patients, this tool is generally perceived as improving their quality of life in the hospital. As for the parents, the reassuring aspect of the device is highlighted. However, some question the feeling of frustration that can develop within the patient from these virtual interactions.

As for the caregivers: importance of being familiar with the patient's environment and extended family to deepen and diversify the caregiving relationship; specific attention to the issue of the diffusion of medical data and nonverbal relationships with the parents, less easy within this framework of virtual presence.

Despite strong enthusiasm for this experimentation, ethical questions emerge about the use of this new technology and the way it is proposed to the patients and their families.

This experiment invites us to question the availability of new technologies outside of technical caregiving, and question the benefit of virtual presence and simulated reality in the context of long-term caregiving.



PII6

REBUILDING THE ADOLESCENTS AND YOUNG ADULTS' (AYA) SOCIAL LIFE: EXPERIENCES WITH A BUDDY VOLUNTEER PROGRAM IN FLANDERS (BELGIUM)

H. Neefs

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A cancer diagnosis is a disruptive experience for AYA that may heavily impact on their psychological development towards adulthood as well as their (developing) social skills and relationships with peers.

After treatment, AYA often lack confidence to participate in social life again and face difficulties to rebuild their social network. In 2010 Stand Up to Cancer launched a pilot project with buddy volunteers in Flanders (Belgium) to meet these specific social needs of AYA in order to facilitate their social participation. In this buddy program AYA are matched with a buddy volunteer who provides one-to-one emotional and social support during and after treatment for a period of 1 year. The buddy volunteer frequently meets (1 in two weeks on average) with the AYA to accompany him in leisure and social activities. In the period 2010-2017 45 AYA received the support from a buddy volunteer. Their age varied between 15 and 36 years. 60% of the participants were female. The project reached in the first place AYA with brain tumor (31%), Hodgkin disease (20%), leukemia (16%) and bone tumors (9%).

The program was positively evaluated during individual and group interviews by the AYA participants, buddy volunteers and health professionals.

After this positive evaluation, this pilot program became a permanent part of the social services Stand Up to Cancer provides to cancer patients in Flanders. Nevertheless, this evaluation also revealed some major challenges: the program predominantly attracted AYA with chronic care needs. Their need for support regularly went beyond the 1 year-limit. The evaluation also put forward the question to include younger people than initially defined (from 14 years) in the program.

Finally, this program should be further promoted among hospital and primary care professionals in Flanders so that all AYA are informed about the program and have access to it.





PII7

CANCER IN ADOLESCENCE AS A CONTEXT FOR PSYCHOSOCIAL DEVELOPMENT

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In many instances within the health care domain, the boundaries of adolescence are not congruent with the boundaries proposed in developmental psychology. This can be problematic if cancer treatment facilities are not well-adapted for multiple life-stages, as both the physical and psychological needs of adolescent patients differ from those of younger (and older) patients. Both the nature of cancer treatment and the environment in which treatment occurs can influence adolescent development. This study aims to describe the impact of cancer on adolescent psychosocial development, with particular emphasis on the moderating influence of the cancer treatment environment. Through interviews with AYA patients and care providers, this study examines the psychosocial developments disrupted during cancer treatment. John Hill's framework for adolescent development indicates six key psychosocial developments during adolescence – attachment, autonomy, sexuality, intimacy, achievement, and identity (1983). Qualitative analysis of interview data suggests that the normative realization of autonomy, intimacy, and identity in adolescence are most dramatically disrupted. Given the lasting influence of these psychosocial factors over the life-course, evidence-based design recommendations are made for AYA health care environments, such that the physical environment may better facilitate age-specific developmental tasks.

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PII8

20 YEARS OF PROVIDING SUPPORT, EDUCATION AND CONNECTION FOR YOUNG WOMEN DIAGNOSED WITH BREAST CANCER

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INTRODUCTION AND AIMS: Since 1998, Young Survival Coalition (YSC) has provided resources, connections and outreach so young women with breast cancer (YWBC) feel supported, empowered and hopeful. Because YWBC face unique psychosocial concerns, including higher incidence of anxiety and depression, many feel isolated and have a strong desire to connect in person with other YWBC.

METHODS: Recognizing these unique and frequently unmet psychosocial needs of YWBC, YSC offers a wide variety of focused programming to address them. Highlighted here are: the YSC National Summit, a 3-day, in-person conference that educates and empowers YWBC and provides the opportunity to connect; YSC Face to Face (F2F) networking program, which allows a YWBC, located anywhere in the country, to start her own F2F network and connect YWBC in her community; and online support groups for those who cannot attend meetings or events in-person.

RESULTS: Since the launch of YSC's National Summit in 2015, 1,557 have attended this important conference. Participant evaluations confirm that it offers YWBC the chance to connect and find support. YSC has 160 F2F groups in 45 states serving 4,766 YWBC. Attendees (91%) report feeling welcomed, supported and connected by their F2F network. YWBC (71%) report feeling less isolated because of their involvement with their F2F network, and 56% say it has provided them with support, education and resources. Across three video support groups for metastatic women, YWBC in Treatment and YWBC under 30, 120 women are registered. Registered attendees (70%) said they signed up to connect with other YWBC who would understand what they were going through, and 78% reported feeling supported and connected.

DISCUSSION AND CONCLUSION: YSC offers programs to reduce the isolation and psychosocial challenges YWBC may confront starting at time of diagnosis and persisting into long-term survivorship.

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PII9

THE BON SECOURS ST. FRANCIS BRIDGE PROGRAM: COMMUNITY BASED AYA SUPPORTIVE CARE SERVICES TO SPAN THE AYA GAP THROUGH EMPOWERMENT, INDEPENDENCE AND ACHIEVEMENT

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Adolescent and Young Adult Oncology (AYAs) patients are recognized in the U.S. as a vulnerable population. Models of care focusing on empowerment and shared medical decision-making make a meaningful impact on patient and caregiver quality of life of the nearly 70,000 AYAs diagnosed annually (AYA Oncology Progress Review Group. 2006; Zebrack, et al, 2010; Kaal, et al 2013; Smith, et al, 2013). To address barriers impacting AYA independence, decision-making and achievement during cancer treatment/diagnosis of, our Bon Secours St. Francis Cancer Center AYA Cancer Care (SFAYA) program implemented programmatic changes through the Bridge Program (Figure 1). SFAYA uses evidence-based practices to provide individualized support and address information delivery.

SFAYA, established in Greenville, SC in 2012, has a dedicated AYA staff (Table 1) to address unique biopsychosocial needs and barriers to care. Funding was secured for an AYA Life Specialist to expand an existing "Bridge" program geared towards connecting AYAs to each other and services (Table 3). Multidisciplinary clinics and meetings as well as psychosocial screening and intervention are critical components, in addition to palliative, spiritual care and oncology rehab services (Forsythe, et al, 2013; Holm, et al 2012; Smith, et al, 2013).

Autonomy and self-advocacy is promoted through multiple mechanisms. Patients and caregivers are included in development of outpatient and inpatient units and services (Kaal, et al, 2017). By incorporating patients' opinions, the program gives patients a sense of autonomy when they feel helpless (DeRouen, et al, 2015). A peer activity group was formed, in order to improve social networking and staff interaction (hopefully increasing compliance) and reduce AYA isolation, loneliness, and increase compliance (hopefully improving quality of life) (Zebrack, et al, 2010). Our initiatives facilitate patient-led success through



well-documented barriers to care by providing services above the routine and customary supportive care, typically found in community settings.

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PI20

STANFORD ADOLESCENT & YOUNG ADULT CANCER INNOVATION POP-UP SPACE: A NEW PATIENT EXPERIENCE FOR ADOLESCENT & YOUNG ADULT CANCER PATIENTS

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Cancer patients at Lucile Packard Children's Hospital Stanford now have access to the world's first Makerspace in a children's hospital setting and it's giving them an opportunity to create solutions to problems that may impact them throughout their treatment. The Makerspace is setting patients up to be part of the next big culture of innovation in healthcare. They're on the front lines receiving medical treatment. Why can't they be the next big innovators and entrepreneurs? Known as the Innovation Pop-up Space, the Makerspace is located in the Bass Center for Cancer and Blood Diseases, part of the hospital's Stanford Adolescent Young Adult Cancer Program (SAYAC). The space gives patients access to 3-D printers, circuits, and other "maker" materials they can use to invent and build, and it includes a mobile Makerspace that can be taken room-to-room within the hospital for patients who aren't able to leave their rooms easily. Pam Simon, director of the SAYAC program, and Gokul Krishnan, a STEM research associate at WestEd, are spearheading the implementation of the Makerspace as an outlet for "Maker Therapy." According to Krishnan, "The goal of Maker Therapy is to provide a unique space that will not only stimulate patients' creativity but also serve as a therapeutic environment for them throughout their treatment. It's a makerspace, an innovation space, a collaboration space and, above all, a healing space where patients can think about something other than their health and feel like they are part of a community." In the next year, Simon and Krishnan will be piloting the Makerspace program at Packard Children's as part of a National Science Foundation (NSF) Research Award, with the hope of sustaining it for years to come and possibly even rolling it out to other children's hospitals around the country.

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PI21

DEVELOPING A NOVEL AND COMPREHENSIVE TEEN AND YOUNG ADULT PSYCHOSOCIAL PROGRAM

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BACKGROUND: The diagnosis and treatment experience of adolescent and young adult (AYA) patients is unique and well documented. Memorial Sloan Kettering's (MSK) program offers services to decrease isolation, improve connectivity between patients and peers, and address their psychological, developmental and social needs.

METHODS: A multidisciplinary task force was defined the scope of the program and identified best practices for development and implementation. Through assessing other national programs, conducting needs assessments and facilitating patient focus groups, a mission statement and implementation strategies were defined and executed.

RESULTS: An expansive support system with opportunities to connect in person and through social networks brings this patient community together. Specific services include:

"The Lounge": a physical space, providing a comfortable, casual environment similar to that of a college center or first apartment, promoting organic social interactions and age appropriate activities.

"The Lounge" app recognizes that the majority of the population is not in the hospital, requiring an alternative approach. It is a safe space for users to interact with each other, ask questions and connect with others whatever the location or time.

Peer to Peer unites active patients with those that have completed similar treatment experiences, providing immediate connection and support.

Each of these initiatives provides ease of access for the teen and young adult patient population despite treatment trajectory and physical location. Programs should be designed for the unique clinical care setting(s) and patient demographics of each institution.

CONCLUSIONS: The research and analysis done to create MSK's comprehensive psychosocial care program identified a number of potential pathways, key strategies and unique challenges.

There is extraordinary potential for further research and clinical work with the AYA population. This program is one of the first of its kind to focus on a specified age group (16-30), receiving treatment in a pediatric or adult setting.



PI22

A TRUSTED COMMUNITY AND GENOMIC SHARING APPLICATION FOR CANCER PATIENTS

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INTRODUCTION AND AIMS: Patients not only need understand how they will physically respond to various types of therapies, but also where to find the most suitable oncology experts, clinical trials, nutritional plans, advocacy

groups, caregivers, etc. Systems Imagination (SI) proposes an application for all cancer patients that integrates the benefits of a private community while allowing a hypergraph database to generate personalized treatment options and genomic analytics.

METHODS: We distributed surveys to cancer advocacy groups to gauge the eventual end user. Based on feedback, we built a prototype. Using Neo4j, we generated a searchable biological database by integrating Ensembl, PubChem, Reactome, KEGG, TCRD (pharos), GO and TCGA.

RESULTS: We extract and aggregate patient-generated data from the application. Then we effectively fuse data of different types and group patients based on similar biological features using a hypergraph database.

DISCUSSION AND CONCLUSION: There has yet to be a platform that integrates a personalizable and trusted framework with a hypergraph database that characterizes patients by their unique biological makeup. Several platforms have tried to address discrepancies that occur between patient knowledge and their disease. An active Facebook group called "Colon Town" has shown that patients are more willing to disclose relevant clinical information in a closed group that they trust and from which they receive support. Through the sharing of information, patients become aware of their treatment options. Meanwhile, PatientsLikeMe and 23&Me can help patients understand their genomic makeup. By merging the understanding of the body and word of mouth, patients feel comfortable sharing clinical data, inadvertently illuminating patient-targeted therapies. In this way we can more effectively treat patients and treatment options become available to those who were previously labeled as untreatable.



P123

PATIENTS ENCOURAGING AND ENGAGING PEER SUPPORT (PEEPS)

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INTRODUCTION AND AIMS: According to the Psychosocial Standards of Care for Children with Pediatric Cancer⁽¹⁾ tailored psychosocial support and social interaction for AYA patients are essential to comprehensive pediatric oncology care. Children's Mercy has a strong Parent to Parent Program, offering peer match support for parents of children in treatment, but nothing for patients themselves. Patients expressed a desire to have a more formalized way to connect with AYA who had already been through treatment. Collaborating with our Family-Centered Care Program, we developed an AYA specific peer match program with the goal of meeting the distinct psychosocial needs of our AYA patient population through peer mentorship.

METHODS: Overall, development and initiation of this program took approximately 18 months. A multidisciplinary working group met and researched existing peer match programs, created applications and training materials, and involved hospital leadership and teen/family advisory boards. Final drafts of materials were submitted to the hospital's Legal Department for approval, which took several weeks.

RESULTS: As of August, 2017, we have held 2 mentor trainings, trained 6 mentors and matched 1 pair. We have plans to move the PEEPS program hospital-wide after we have completed a few more matches. Discussion and

CONCLUSION: Programs like this take much longer than you would expect to come to fruition. It takes a step-wise, thoughtful approach to ensure that all pieces are in place to provide a safe and healthy environment for peer support to take place while simultaneously allowing it to feel as natural as possible for the participants. It has been a learning process at every step. Our mentors have a strong desire to "give back" and wished they had something like this during

their treatment. We are hopeful that with staff and patient/family education, this will be beneficial to all involved.

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P124

THE RELATIONSHIP BETWEEN QUALITY OF LIFE AND CONTENT OF CANCER NARRATIVES IN ADOLESCENTS

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Feeling a lack of emotional and social support negatively impacts QOL in young people with cancer (Compas, et. al 2012). In a time characterized by large social media presence, many adolescents utilize the internet (and videos) to increase peer-to-peer support and process the effects of their illness. Research supports that making video testimonials about adolescents' experiences with cancer may have emotional and social benefits (Pereira, 2017). However, no research explores how QOL influences the content of video cancer narratives. Our aim was to determine the relationship between QOL and content of adolescents' video cancer narratives. Clinical implications will be discussed. Adolescents (N=10; age 13-18), diagnosed with cancer for the first time, recorded video narratives about their illness experience. Participants also answered questionnaires measuring QOL (PedsQL-Generic; PedsQL-Cancer). After transcription, videos were analyzed using LIWC for linguistic content and hand coded for thematic content and meaning making. Correlations between contextual aspects of the narrative and three areas of QOL (social, physical, and emotional) revealed different relationships within each domain. There were negative trends between social QOL and social language ($r=-.480$); suggesting the more one discussed their social life, the better their social QOL. Emotional QOL and affective language were positively correlated ($r=.611$, $p<.05$), suggesting participants who used more affective language had lower emotional QOL. Meaning making was only related to social QOL ($r=-.460$). There were findings with physical QOL and discussion of health experiences, despite being the area of lowest QOL. Interestingly, higher social QOL was significantly correlated with less focus on health experiences ($r=-.785$, $p<.01$). When QOL is evaluated in three categories, the thematic and verbal content of video testimonials reveal that there are different relationships between QOL and how each domain is discussed. These findings highlight the complexity of QOL and what influences content of video narratives in teens with cancer.



P125

PHILOSOPHY SKILLS TRAINING PILOT FOR AYA IN UK AND BELGIUM

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Add Perspective, Bruges, Belgium

INTRODUCTION AND AIMS: Adults and young adults (AYA) with cancer and other chronic illnesses struggle with questions about meaning and who they are: "Why has this happened to me?". Studies have stressed

the unmet psychosocial need to address these existential questions for AYA (Zebrack, 2012). Effective interventions are peer support, technology-based interventions, and skill-based interventions (Zebrack, 2012). No known interventions in the UK or Belgium are aiming to provide these skills to AYA to address existential questions. The aim was to assess the feasibility of a training of philosophy skills to address existential issues with AYA.

METHODS: 3 key exercises to teach 3 philosophy skills included peer support, technology-based support and skills elements. The exercises were based on AYA existential needs (Vandekerckhove, 2010). The aim of the exercises was (1) to be grateful, (2) to be open minded, (3) to find flow and fulfillment. The UK pilot was in a UK chronic care facility with 15 chronic illness survivors (all ages) during a 1h free session. Follow up email contact remained for 1 month. The Belgian pilot was 3 sessions with 6-10 participants recruited via an AYA Facebook group, sessions lasted 3-4h, €25 entrance fee, including dinner. Follow up contact remained up to 6 months via Facebook.

RESULTS: Participants engaged very much in both pilots and found it very useful. No difference in engagement in respect of age or prior diagnoses was found. Similar topics emerged during exercises related to challenges in daily life about not being understood by other people and the importance of having a positive outlook on life.

DISCUSSION AND CONCLUSION: Recruitment was hard because cancer survivors do not gravitate to one forum. Financial investment would be needed to provide this training. This pilot shows that philosophy skills training could address psychosocial needs for AYA's.

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PI26

UTILIZING THE UNIQUE RELATIONSHIPS OF ADOLESCENT AND YOUNG ADULT (AYA) CANCER PATIENTS AS A FRAMEWORK FOR COMPREHENSIVE PROGRAM DEVELOPMENT

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INTRODUCTION AND AIMS: About 70,000 young people (ages 15-39) are diagnosed with cancer each year in the United States.⁽²⁾ While survival improvements have been achieved in patients diagnosed at age 15 or younger and among those over age 40, little or no progress has been seen in the AYA population.⁽¹⁾ The Adolescent and Young Adult Oncology Review Group identifies many possible contributing factors.⁽¹⁾ It is critical to keep factors identified by major institutions in mind, but it is equivalently vital to understand the needs specifically from the AYA cancer patient perspective. The primary goal of this project was to identify the needs and potential interventions that will strengthen the AYA program through targeted, specific opinions from focus group participants.

METHODS: A series of four moderated focus group sessions were held with AYA cancer patients. A mixed methods approach with a convergent parallel design was utilized allowing for quantitative and qualitative data collection and analysis to occur simultaneously. Data were collected from participant responses to a wide variety of questions regarding clinical and psychosocial/supportive care topics.

RESULTS: A total of 24 individuals ranging from ages 15 to 31 participated in the focus groups. Several areas of concern and unmet needs were identified by the participants. Many of their recommendations differed greatly from our preconceived ideas. Four specific relationships of AYA cancer patients clearly emerged upon review of the data: Relationships with Cancer, Self, Others and Future.

DISCUSSION AND CONCLUSION: The feedback from the focus group participants began to generate several project ideas for program development. Each project concept that surfaced fit appropriately into one of the relationship categories as listed above. This concept has generated into a visual framework we feel is ideal when building a comprehensive AYA cancer program.

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PI27

BUILDING THE IDEAL ADOLESCENT AND YOUNG ADULT (AYA) PROGRAM MODEL TO EMPOWER AYA CANCER PATIENTS TO SUCCEED, LEAD AND THRIVE

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Pediatric oncology programs are often challenged to cultivate a multidisciplinary program model that addresses the unique medical, emotional and social needs of the adolescent and young adult (AYA) patient.

At CHOC Children's Hospital, a strategic goal of creating an AYA community within a pediatric cancer unit was established to empower AYA cancer patients to: thrive, develop leadership skills, provide peer supported social networking, learn life skills and invest in their survivorship.

A multidisciplinary team designed and implemented program activities. The AYA child life specialist guided the AYA community, fostered group cohesion and communication; built trust and support; integrated patient acknowledged AYA education topics; and enhanced an innovative fitness program to keep AYA's active. As a result of the program, AYA's reported a decrease in the all too common social isolation often experienced by AYAs in cancer treatment.

One significant triumph of the program was assembling the AYA Patient Leadership Team comprised of 5 AYAs and 1 AYA sibling. They meet monthly with the AYA child life specialist to plan activities for the AYA program. These individuals worked diligently to design an AYA logo representing their core values to succeed, lead and thrive through their cancer journey. The team provided valuable input in the development of the CHOC AYA program mission, vision and philosophy of care statements.

The AYA program developed momentum and it was clear that AYA's wanted to learn more about the transition into survivorship and as a result, selected patients from the program were able to attend designated national and international AYA conferences.

The program also invested in emerging AYA leaders by implementing an AYA Mentor Retreat. AYA's who attend program events and activities report feeling empowered, and a new sense of confidence and passion to embrace their journey and most importantly, advocate for other AYA's.





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PSYCHOSOCIAL SURVIVORSHIP FOR ADOLESCENTS AND YOUNG ADULTS (AYAS) AFTER CHILDHOOD CANCER FINDINGS FROM A QUALITATIVE RESEARCH ON EXPERIENCES OF AYA SURVIVORS OF CHILDHOOD CANCER AND THEIR PARENTS

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INTRODUCTION AND AIMS: Adolescents and young adults (AYA) survivors of childhood cancer often experience long-term consequences arising from their illness and its treatment. Understanding the meaning of a cancer experience in the survival phase can improve the development of psychosocial care for AYA survivors.

As surviving a cancer experience may impact the daily lives of parents too, their experiences also deserve attention.

METHODS: In collaboration with UZ Gent, UZ Leuven and KUL, UCV Ghent, Belgium, set up a qualitative research in which semi-structured interviews were taken with 21 AYA survivors (14 to 25y) and with 20 parents of AYA survivors.

RESULTS: This abstract describes the findings regarding the AYA survivors.

Even many years after completing treatment, a cancer experience remains deeply ingrained in the lives of AYA survivors. The deployment of specific coping strategies helps AYA survivors to deal with the long-term psychosocial consequences of the cancer experience with a view to ultimately leading a normal life. The ability to assume directorship of their life appears to be a driving force behind the existence and actions of AYA survivors.

DISCUSSION AND CONCLUSION: Health care professionals could optimize the psychosocial care provided to AYA survivors by taking their experiences as a point of departure. Individual support should be brought in line with the way in which AYA survivors have integrated their cancer experience into their everyday lives. An e-learning module for healthcare professionals was developed aiming to promote insight in the specific experiences and needs of the AYA survivors.



P129

THE IMPACT OF FUNCTIONING ON THE CAREER DEVELOPMENT PROCESS OF YOUNG ADULT CNS SURVIVOR

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Adult survivors of childhood cancer experience difficulties in obtaining and maintaining appropriate employment. This is especially true for CNS survivors who face a much higher rate of unemployment and underemployment than their childhood cancer survivor peers. Research consistently finds a significant

portion of young adult CNS survivors fail to reach critical career development milestones. This study of 81 CNS survivors between the ages of 18-30 will examine the impact of physical and mental functioning on all phases of the career development process. Participants completed questionnaires regarding physical/mental functioning and career development. Multiple regression and multiple mediation analysis was utilized to examine the relationship between mental and physical functioning and career development within the group.

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P130

DO TEENAGE AND YOUNG ADULTS MANAGE THE IMPACT OF CANCER AND THE TREATMENT ON THEIR BODY IMAGE?

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AIM: To undertake a narrative review of how those aged between 15 - 24 years manage the impact of cancer and its treatment on their body image.

METHOD: 6 articles were selected following a keyword search of online health databases and an inclusion and exclusion criteria was applied.

RESULTS:

3 main themes emerged:

1. SUPPORT

Ramini et al (2008) established that young people with cancer developed a support network. Through the use of peer and parent shielding TYA's adapted to the body image changes (Williamson et al 2010), demonstrating that support is invaluable as it helps foster a 'normality'.

2. CONCEALING THE SIGNS

Managing altered appearances is a huge concern for this population group. Changes in appearance reinforces the belief that the TYA is visually different to others, therefore there is a strong desire to adapt and conceal these physical differences. These feelings of exposure and anxiety are seen to drive new coping behaviours to be developed.

3. POSITIVE OUTLOOK

Abu Shosha (2016) identified that having a belief in recovery, normality and a willingness to fight were also effective measures. The degree of hopefulness was correlated with a positive sense of well-being, improves coping and self-esteem (Abrams, 2007). Ramini (2008) also noted that promotion of adaptation increased levels of confidence and enabled these changes to be embraced.

CONCLUSION: TYA's are resilient, they naturally adopt strategies to cope with the negative impact of cancer and treatment on their body image. Teenage and Young Adult Specialist professionals are vital and in a unique position to promote these coping strategies. This is achieved by ensuring the individuals support network is established and preserved, resources to maintain normality are available and the age appropriate ethos and model of care is achieved. This ultimately empowers the TYA to restore their body image and to minimise the social consequences.

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P131

MAPPING THE SURVIVORSHIP AND SECONDARY PREVENTION SERVICES AVAILABLE TO EUROPEAN PROFESSIONALS IN AYA CANCER CARE

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INTRODUCTION AND AIMS: Providing cancer treatment for Adolescents and young adults (AYA) requires specific services. We conducted a survey of health care providers' available services for AYA living with or after cancer, to benchmark the current situation and identify inequalities.

METHODS: A survey was sent by mail in the last quarter of 2016 to all members of the European Society for Medical Oncology (ESMO) and the European Society for Pediatric Oncology (SIOPe). In this report we focussed our analysis upon late effects services, secondary cancer prevention and lifestyle.

RESULTS: We report the results from 266 practitioners in Europe, who treat AYA with cancer. Half of respondents worked in general hospitals, with 20% in specialized cancer hospitals and 10% in pediatric hospitals. Sixty percent were trained to treat adult cancer patients, 25% pediatric and 15% both. Over two-thirds report that they have no access to a specialist cancer service for late effects management (67%). Access to clinical genetics and discussion of modifiable cardiac risk were usual (>85%). Referral for smoking cessation was common (66%). There were marked regional variations in fertility services; much lower provision in Eastern Europe (24%) than in Northern Europe (72%). The lack of any specialized AYA care was more profound in Eastern and South-Eastern Europe. Survivorship care and cancer prevention respectively were a leading educational priority for over half of respondents.

DISCUSSION AND CONCLUSION: This survey revealed important under-provision and inequity of AYA cancer care across Europe in survivorship and secondary prevention in particular. Strengthening professional education focused on AYA is a priority for ESMO and SIOPe to work upon together.



P132

REACTIVATE: AN EXERCISE AND SELF-MANAGEMENT GROUP PROGRAM FOR ADOLESCENT AND YOUNG ADULT (AYA) CANCER SURVIVORS

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BACKGROUND: Preparing AYA cancer survivors for rest of life health and

wellbeing is an essential component of comprehensive cancer care. AYAs are known to experience a higher prevalence of all chronic health conditions including cardiovascular disease, diabetes, and obesity than healthy peers and siblings, all of which can be modifiable via exercise and lifestyle choices. With this in mind ReActivate, a goal-orientated rehabilitation program was designed for AYA cancer survivors.

METHOD: Participants aged between 15-25 years of age undertook the program at the completion of systemic cancer therapy. Participants were assessed pre and post program and included functional measures of fitness, quality of life and occupational performance. Each week for 8 weeks, participants undertake 2 hours of supervised exercise in a group environment, followed by a 1 hour education/ self-management session addressing a range of topics including, fatigue management, diet and exercise post-treatment and accessing supports in the community.

RESULTS: While 25 participants commenced ReActivate, 20 (80%) participants completed the programme. They were administered a range of physical functioning measures, including the 6-minute walking test, push ups, sit to stand, and grip strength, and the self-report Pediatric Quality of Life (PedsQL) scale at baseline and post-programme. A series of Monte Carlo (B = 10,000) paired permutation tests indicated statistically significant differences in baseline and post-programme across all the physical functioning measures (Cohen's d range = 0.59 to 2.25) and the PedsQL scales of physical functioning, social functioning and school functioning (Cohen's d range = 0.80 to 1.01).

CONCLUSION: Results of this program support the acceptability and feasibility of a supported self-management group program for AYA survivors. ReActivate has the potential to improve AYA cancer patient's physical functioning, health literacy, self-management and long-term health and well-being. Future intervention work is needed to embed this work into standard clinical practice.



P133

A PILOT RANDOMISED CONTROLLED TRIAL OF A STRUCTURED EXERCISE INTERVENTION AFTER THE COMPLETION OF CANCER TREATMENT IN ADOLESCENTS AND YOUNG ADULTS (AYA)

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BACKGROUND: Cancer and its treatment are frequently associated with impaired physical fitness which often persists into survivorship. Functional impairments such as cancer-related fatigue, muscle atrophy, deconditioning and reduced aerobic capacity, are commonly reported side effects of cancer therapy. The aim of this study is to determine whether a 10-week structured exercise intervention is associated with improved functional capacity (VO2peak), fatigue and quality of life (QoL) when compared with controls in AYA patients who have recently completed treatment.

METHOD: Participants aged between 15 and 25 years of age were assessed following the completion of systemic cancer therapy. Functional capacity was measured via the following assessments; cardiopulmonary exercise test (VO2peak), maximal push-up test and sit-ups in 60 seconds. Participants were stratified according to gender and treatment intensity. The exercise arm received a structured 10 week intervention consisting of two supervised exercise sessions per week under the direction of an Exercise Physiologist. The control arm received no structured exercise intervention.

RESULTS: 37 AYA (21 males) median age 21 ± 6 years of mixed tumour types completed fitness testing. Median VO_2peak was 25.2 ml/kg/min , significantly lower than age-based population norms. The exercise intervention demonstrated a statically significant greater improvement in VO_2peak than the control group ($7.5 \text{ ml/kg/min} \pm 3.9$ vs $3.4 \text{ ml/kg/min} \pm 2.7$, $p=0.003$). Participants who completed the exercise intervention had a trend towards greater improvement in push up test (11 reps vs 3 reps) and sit-ups (13 reps vs 5 reps) compared to the control arm.

CONCLUSION: The results illustrate the impacts of cancer therapy on functional capacity and how deconditioned patients are at the completion of treatment. Preliminary data suggests that a 10-week exercise intervention is associated with a more rapid improvement in VO_2peak when compared to controls. Future results from this study will explore fatigue and QoL domains and whether these results are maintained at six months post-treatment completion.



P134

MEASURING THE IMPACT OF ADDRESSING OF AN ADOLESCENT AND YOUNG ADULT (AYA) PROGRAM ON ADDRESSING PATIENT CARE NEEDS

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INTRODUCTION: Limited studies have demonstrated the impact of AYA oncology programs on addressing patient needs. Our center's AYA program involves: 1) development of AYA-specific resources for primary oncology providers (POP) and patients and 2) patient consultations delivered by an AYA clinical nurse specialist (AYA-C). Aim: We evaluated the effectiveness of an adult-based AYA program by assessing patient satisfaction and whether programming offers added benefit beyond POP to address their needs.

METHODS: A modified validated survey (Gupta et al., 2013) was used to ask two questions: 1) rate on a 10-point Likert scale their level of satisfaction with the information provided to them by their POP and 2) did the AYA-C provide added value in addition to their POP. AYA were recruited over two separate time points spaced one year apart (Cohort 1=137; Cohort 2=130). Descriptive statistics were used to report demographics and survey responses. Differences in demographics between cohorts 1 and 2 were compared using Student's t-tests.

RESULTS: There were 267 participants (Cohort 1=137; Cohort 2=130) with predominantly leukemia, lymphoma and breast cancer diagnoses. Average age was 31 years (range 24-35). More patients had an AYA-C in 2016 (Cohort 2=55/130, 42%) compared to 2015 (Cohort 1=34/137, 25%, $p=0.026$). Mean satisfaction scores (\pm SD) with information provided by POP in AYA-domains in both cohorts combined were highest among (1) cancer information (8.09 ± 2.22), (2) social supports (7.45 ± 2.52), and (3) school/work (7.42 ± 2.88). When evaluating the incremental benefit of the AYA-C, statistically significant added value was perceived in 5/10 domains including school/work ($p<0.001$), social supports ($p<0.001$), physical appearance ($p=0.009$), sexual health ($p=0.01$) and fertility ($p<0.001$).

DISCUSSION AND CONCLUSION: Although the participants were satisfied with information provided by their POP, there was further benefit of an AYA-C. Cancer centers should continue to advocate for AYA programming with ongoing evaluation to demonstrate their value.

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P135

EPIDEMIOLOGY OF ADOLESCENT AND YOUNG ADULT CANCER IN CANADA: INCIDENCE, PREVALENCE AND RELATIVE SURVIVAL

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INTRODUCTION AND AIMS: To improve cancer care delivery and outcomes among adolescents and young adults (AYAs) we need high-quality, population-level cancer statistics for this age group. The goal of this study was to assess the current burden of cancer among AYAs in Canada in terms of incidence, prevalence and relative survival rates.

METHODS: AYAs were defined as those diagnosed between 15 and 39 years of age. Age-standardized incidence rates (2009-13), 5-year relative survival ratios (2004-08), and 10-year point prevalence (2009) were calculated by age groups (15-29 & 30-39 years of age) and disease. Territories were excluded. Quebec was excluded for survival and prevalence analyses. Data were obtained from Statistics Canada's Canadian Cancer Registry and Canadian Vital Statistics, Death Database.

RESULTS: The age-standardized incidence rate of cancer was 37.8 per 100,000 for those aged 15-29 years and 104.7 per 100,000 for those aged 30-39 years. Thyroid cancer, breast cancer, Hodgkin lymphoma, non-Hodgkin lymphoma, testicular cancer and melanoma combined accounted for more than 80% of AYA cancer cases. The overall 5-year relative survival ratio was 86.3% for the 15-29 year age group and 83.4% for the 30-39 year age group. Survival rate varied from >90% for thyroid cancer, Hodgkin lymphoma and testicular cancer to <70% for glioblastoma, colorectal cancer and leukemia. The overall prevalence of AYA cancer was 193.0 per 100,000 people among those diagnosed aged 15-29 years, and 564.7 per 100,000 among those diagnosed aged 30-39 years.

DISCUSSION AND CONCLUSIONS: The burden of cancer in AYAs may be relatively small in comparison to the adult population (40+ years of age) but the impact of unmet age-specific needs is substantial, given observed AYA cancer survival and current life expectancy contributing to a considerable number of potential years of life saved. Additional information regarding this work is available through systemperformance.ca.



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TRIALS AND TRIBULATIONS FOR ADOLESCENTS AND YOUNG ADULTS WITH CANCER: MEASURING THE IMPACT OF A COMMUNITY-BASED AYA PROGRAM

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Adolescent and Young Adult Oncology (AYA) patients are increasingly recognized in the U.S. as a vulnerable population, and new models of care



delivery have been proposed to improve AYA outcomes and quality of life. Though community AYA care in the U.S. has great potential, limited knowledge base, infra-structure and resources stonewall the development of best practices and practical outcome measurements for AYA care. We highlight through a 5 year AYA program review the nuances of defining, implementing and interpreting successful care metrics in the community setting. The AYA Cancer Care Program was established in 2012 at Bon Secours St. Francis Health System, which is located in Greenville, South Carolina within a six-county catchment area of 1.25 million people. The Cancer Program sees approximately 1500 oncology referrals annually, of which 10% are AYAs, and consists of inpatient/outpatient facilities, medical and radiation oncology, administrative support, clinical research, navigation, cancer registry, quality program, psychology, and financial counseling. We report the development and tracking of Program-specific success metrics, which were adapted from published reports and established academic models, including The NCI Program Review Group report in 2006 (PRG), National Health Service (UK) National Institute for Health and Clinical Excellence 2008 report Improving Outcomes in Children and Young People with Cancer, and the National Community Cancer Network (NCCN) AYA guidelines (Table 1). Our metrics focus on shared care models, appropriateness of therapy and clinical trial accrual, but many other components (psychosocial distress screening, fertility preservation counselling and AYA support and networking) are important to define and measure successful AYA care in community settings. Our efforts suggest that community-based AYA outcomes are improved through AYA program development, but coordinated efforts among community and academic AYA programs will be required in order to further define best practices in AYA cancer care that have measurable and meaningful impact.

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P137

THE SCOR AYA LANDSCAPE PROJECT: A RETROSPECTIVE REGISTRY REVIEW OF AYAS DIAGNOSED IN THE SOUTHEASTERN UNITED STATES COMMUNITY CANCER CARE SETTING

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AYAs ages 15-39 have lower enrollment rates onto clinical studies as compared pediatric patients. The majority of 70,000 AYAs diagnosed annually in the US follow the pattern of adult cancer care, being seen by medical oncologists in community settings (MO). Despite several recent large survey based studies, AYA cancer care delivery and research (CCDR) have largely neglected AYA populations in the SE not seen at academic institutions.

The Southeastern Community Oncology Research (SCOR) consortium is a network of 22 community-based hospitals in the SE, only 3 affiliated with pediatric oncology (PO). We hypothesize that SCOR can have a significant impact on AYA CCDR. We conducted a quality improvement

project designed as a retrospective hospital registry study to understand the AYA landscape in SCOR. Methods: A 6 year retrospective hospital registry review was conducted as a quality improvement project, 20 de-identified data elements, collected and basic descriptive statistics of demographics and cancer diagnosis were assessed. Primary objective was to describe AYA patient population seen at participating hospitals and to assess the impact on #s of AYAs at the 4 hospitals with pediatric oncology affiliation. Secondly, we assessed AYA accruals in SCOR.

RESULTS & CONCLUSIONS: 77% of sites returned data over 12 weeks. From 2010-2015, 5922 (median 278, range 40-956) AYAs were diagnosed. Sixteen categories of cancer types based on histology/site were chosen to reflect the diversity of AYA diagnosis. Data are shown in Figures 1-5. SCOR sites diagnose an average of 1000 AYA Cancer patients/year (1.5% of total AYAs seen in US) and sites with PO see a greater proportion of younger AYA, 15-19 yo. ~260 "overlap" cancers representing those seen commonly by PO & MO are seen annually. SCOR can have a significant impact on clinical trial enrollment and cancer care delivery research for AYAs.



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AGE-SPECIFIC SERVICE PREFERENCES FOR PATIENT NAVIGATION AMONG AYA SURVIVORS

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INTRODUCTION AND AIMS: To understand the age-specific service preferences of patients and survivors enrolled in an AYA navigation program. The AYA age group encompasses a broad range of development periods, namely, adolescence, emerging adulthood, and young adulthood.[1] Some services may be more pertinent to AYAs at certain developmental stages than others. Here we describe those preferences by age.

METHODS: A constant comparative analysis was conducted from recorded and transcribed patient interviews (N=39). Themes from interviews were derived using grounded theory methods. The sample was divided into three age categories based on developmental age at diagnosis; adolescents (ages 15-18), emerging adults (19-25), and young adults (26-39). After launch of the patient navigation program, baseline and follow-up surveys were gathered from patients who had interacted with the navigator. Surveys ask about global health, finances, barriers to care, caregiver support, coping, and demographics.

RESULTS: While some navigation preferences span the AYA age range (e.g., childcare, navigation throughout treatment) distinct preferences for navigation were evident by age group (e.g., fertility). Adolescents were the only group to ask for educational assistance. Emerging and young adults requested detailed information about insurance. Young adults requested assistance with fertility and living expenses. Family involvement with the navigator differed by age; for example, young adults wanted more navigator-facilitated support for their spouses and children whereas adolescents and emerging adults wanted support for their parents. Preliminary results of the baseline and follow-up surveys show improvements in self-reported measures of overall health, quality of life, and mental health but increased financial toxicity at follow-up among all age groups.

DISCUSSION AND CONCLUSION: The AYA age group requires more patient-centered care to effectively meet their needs. AYA programs should consider tailoring services to AYAs by their developmental age as a method for delivering more patient-centered care.

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PLACE OF DEATH AS AN INDICATOR FOR CANCER CARE IN ADOLESCENTS AND YOUNG ADULTS (AYA) IN CANADA

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INTRODUCTION AND AIMS: The goal of this study was to evaluate "Place of Death" as an indicator for the Canadian AYA cancer population.

METHODS: Although there are many quality indicators related to palliative care, obtaining age-specific national data is challenging with the exception of location of death. The "Place of Death" indicator was defined as "The percentage of AYA (aged 15–39 years) cancer patients who die in hospital versus non-hospital locations between 2000 and 2012". Analyses were conducted using the Statistics Canada's Vital Statistics – Death database 2000–2012. The percentage was calculated at both the national and provincial levels. Change over time, and differences between both younger and older cancer populations were assessed.

RESULTS: Nationally the majority of AYA cancer-related deaths (2007–12) occurred in hospital, similar to children and older adults (0–14: 57%; 15–19: 71%; 20–29: 73%; 30–39: 73%; 40–49: 73%). There has been little change in place of death between 2000–04 and 2007–12, with the majority of patients still dying in hospital. There were no substantial differences between the AYA age groups and children or older adults in the percent change of in hospital deaths relative to the 2000–04 time period (–9.2% to –14.6%). Children had the greatest percent decrease in hospital deaths relative to the 2000–04 time period (–14.6%).

DISCUSSION AND CONCLUSION: The "Place of Death" indicator has many challenges, including variability among the provinces in the coding of death location, and inability to determine patient preferences. Further exploration of end-of-life care and symptom management is needed for AYAs; as well as development of AYA-specific indicators and data sources to monitor and improve symptom management and end-of-life care in this population. Future work will focus on other indicators, such as proportion of individuals dying in active vs palliative care units, and ICU/emergency room utilization prior to death.

needs, the nonprofit organization Stupid Cancer hosts an annual AYA oncology and social networking event called CancerCon.

AIMS: This study evaluated AYAs' unmet survivorship needs, quality of life (QOL), and motivations for attending CancerCon.

METHODS: Registered attendees were emailed one week before CancerCon and completed a brief online, anonymous survey, including validated measures for AYA cancer. Descriptive statistics and bivariate analyses were used.

RESULTS: Participants (N=192; 62% response rate) averaged 31 years old (SD=7.2), were primarily White (81%), and most had completed treatment (63%). A range of unmet needs were endorsed related to informational/resource needs (61%), medical care interactions (45%), psychosocial concerns (85%), school (42%) and employment (74%), finances (71%), and health insurance (39%); with 85% reporting fears about change in coverage). On a 0–10 scale, average QOL was 6.4 (SD=2.0) and social support was 5.1 (SD=1.6). Perceived social isolation related to lower QOL ($p<.001$). Those currently in treatment had the lowest QOL and those with chronic disease had the greatest unmet support needs, compared to completed treatment and ongoing therapy subgroups ($p's<.05$). Primary reasons for attending CancerCon included a desire to connect with peers and the AYA cancer community, access age-appropriate resources, be an advocate, gain confidence managing disease-related changes, and learn about latest research. Differences in unmet needs and motivations based on treatment status were identified.

DISCUSSION/CONCLUSION: AYAs look to patient organizations to address unmet survivorship needs. Patient events such as CancerCon may fill critical gaps in supportive care. Future work should identify optimal ways for clinicians, researchers, and patient organizations to collaborate to address AYAs' needs across the cancer trajectory. Targeted approaches that incorporate evidence-based support strategies and patient-centered dissemination, such as through digital platforms, should be explored.



P141

PERCEPTIONS OF A SOCIAL SUPPORT APP FOR ADOLESCENTS AND YOUNG ADULTS WITH CANCER

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INTRODUCTION: Adolescent and young adult (AYA) cancer patients are frequently isolated from social networks during extended treatment periods. To address this isolation and connect AYAs to peers, we partnered with the non-profit, Stupid Cancer, to optimize an AYA-specific social support app.

AIMS: This research identified perceptions of and preferences for a social support app to connect members of the AYA community.

METHODS: We conducted interviews with 27 AYA patients, survivors, and caregivers. Participants were recruited from CancerCon, a convention to connect AYA patients to peers and resources. Interviews were recorded, transcribed, and analyzed to identify suggestions for app optimization.

RESULTS: Most participants expressed interest in using the social support app and discussed with whom they hoped to connect and how they would like to interact within the app. Type of diagnosis appeared to influence these preferences. Those with rare diagnoses wanted to connect with others who either shared their diagnosis (to receive resource support) or lived nearby (for in-person social support), acknowledging the unlikelihood of receiving both types of support from the same connection. Conversely, participants with more prevalent diagnoses wanted to connect based on both location and diagnosis. Participants also differed in how they wanted to represent



P140

ADOLESCENT AND YOUNG ADULT CANCER SURVIVORS' UNMET NEEDS AND MOTIVATIONS FOR ATTENDING AN ONCOLOGY AND SOCIAL NETWORKING EVENT

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INTRODUCTION: Adolescent and young adult (AYA) cancer survivors are an understudied and underserved patient group. To address AYAs' unmet

themselves within the app, with some preferring avatars for privacy and others preferring profile pictures to increase feelings of connection. Others preferred a hybrid approach, using an avatar first and using a photo only when connections became more personal. Participants provided further feedback on app design (e.g., readability) and functionality (e.g., control settings) to create an optimal social support environment.

DISCUSSION/CONCLUSION: Our results suggest AYAs would use a social support app and have specific desires regarding connections, privacy settings, design, and functionality. Implementing findings from this research to develop mobile interventions meets calls for age-specific interventions to support the AYA community.



PI42

TYA CANCER IN A TERTIARY CARE HOSPITAL IN NEPAL

R. K. Deo

Shree Birendra Hospital, Kathmandu, Nepal

INTRODUCTION AND AIMS: Teens and Young Adult (TYA) cancer forms distinct group among cancer in various age groups due to special needs of this age group. Aim is to collect data of TYA cancer registered in Shree Birendra Hospital (SBH), Nepal in last 10 years.

METHODS: Retrospective data of all cancer patients registered in SBH from January, 2007 to December, 2016 were collected. The data was analyzed to find TYA cancers in age group 15 to 34. Variables collected were Age group, Sex and diagnosis. The data were tabulated and analyzed.

RESULTS: Total cancer patients registered in SBH were 1960. Total TYA patients in the age group 15 to 34 were 138, which is 7.04%. Total male patients were 67 while female patients were 71 (M:F; 49:51). Patients in the age group 15-19, 20-24, 25-29 and 30-34 were 17%, 29%, 32% and 60% respectively. Numbers of Solid tumor were 91 while hematological malignancies were 47 (Ratio 66:34). Most common solid tumors were Sarcoma, Head and Neck tumors and Breast cancer while most common hematological malignancies were Acute leukemia, Non-Hodgkin lymphoma and Aplastic anemia. The diagnosis of each group is as shown in the table 1 and 2 respectively.

DISCUSSION AND CONCLUSION: TYA cancer incidence is 10.28% (Range: 7.3 to 15.6) in a hospital based data of Indian population(1). There seems to be no predilection to any sex in TYA cancer. Incidence of cancer increases when sub grouped into 5 years age groups with highest incidence in the age group of 30 to 34. Common cancers in Indian population in age group 15-29 were Lymphoma, Leukemia and Breast cancer while in UK was Lymphoma, Leukemia and Melanoma(2). TYA cancer constitutes significant patient burden in cancer care. Separation of TYA cancer from other age groups allows to focus on TYA needs specifically.

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LATE BREAKER ABSTRACTS



P38a

RECRUITMENT TO CLINICAL TRIALS IS ASSOCIATED WITH SUPERIOR SURVIVAL IN TEENAGE AND YOUNG ADULT PATIENTS WITH ACUTE LYMPHOBLASTIC LEUKAEMIA

R. Hough, S. Sandhu, M. Khan, T. Moran, R. Feltbower, C. Stiller, M. Stevens, C. Rowntree, A. Vora, M. G. McCabe
UK

Participation rates in clinical trials are low in teenagers and young adults (TYA) with cancer. Whilst the importance of clinical trials in informing best practice is well established, data regarding individual patient benefit are scarce. We have therefore investigated the association between overall survival and UKALL2003 trial recruitment in TYA patients with acute lymphoblastic leukaemia (ALL) using national clinical trial and registry data.

From 2004 to 2010 inclusive, 503 patients aged 15-24 years were diagnosed with Philadelphia chromosome negative ALL, of whom 239 (47.5%) participated in the UKALL2003 trial. Trial participation improved over time, increasing from 59.3% in 2004-2007 to 76.7% in 2008-2010 ($p = 0.007$) in the 15-17 year old group. Those aged 15-19 were more likely to be recruited than 20-24 year olds (76.3% of 15-19 year olds compared with 45.1% of 20-24 year olds ($p < 0.001$)).

Patients treated on the trial had 17.9% better two-year survival (85.4% vs 67.5%, $p < 0.001$), 8.9% better one-year survival (90.8% vs 81.9%, $p = 0.004$) and 11.6% better two-year conditional on one-year survival (94.1% vs 82.5%, $p = 0.001$) than those not on the trial. In total, 35 (14.6%) patients recruited to the trial died in the two years following diagnosis compared with 86 (32.6%) of those not recruited ($p < 0.001$). The highest difference in mortality was observed in the first three months after diagnosis, during which 6 (2.5%) patients in the trial died compared with 21 (8.0%) not in the trial ($p = 0.007$).

In summary, TYA patients recruited to the clinical trial UKALL 2003 had a lower risk of mortality and a higher overall survival than contemporaneous non-trial patients. These data underline the potential for individual patient benefit in joining a clinical trial cohort and the importance of international efforts to increase trial participation in the TYA age group.



P38b

THE DELIVERY OF AMBULATORY CARE IN TEENAGE AND YOUNG ADULTS UNDERGOING CHEMOTHERAPY: A LARGE SINGLE CENTRE EXPERIENCE

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INTRODUCTION AND AIMS: Approximately 2000 teenage and young adult (TYA) patients are diagnosed with cancer annually in the UK¹. TYA patients report a poorer experience of care². It is also well recognized that a cancer diagnosis at this age can have long-term psychosocial effects, including a sense of loss of control and interrupted relationships with peers³. The TYA ambulatory care (AC) service, established in 2012, aims to improve experience of care and abrogate the negative psychosocial effects associated with prolonged in-patient stays. Here we report the demographics, safety and patient experience of the first 5 years of TYA AC at UCLH.

METHODS: Service electronic databases and AC records were used to collate the data.

RESULTS: Between 1st June 2012 and 1st June 2017 278 patients (M=161, F=117) with a median age of 19 (range 12-25 years) and a median number of episodes per patient of 3 (range 1-22) received treatment in AC. The most common diagnosis was bone sarcoma (37%) followed by leukaemia (19%) and lymphoma (18%) (Table 1). The median length of stay was 3 days (range 1-122). There were 164 inpatient admissions out of 1287 episodes (elective n=111, unplanned out of hours n=53, unplanned during working hours n=100). The most frequent causes for admission were a fever (56%) and the need for closer clinical monitoring (20%) (Table 2). No adverse events reported during this time were deemed to be related to care received in AC and no deaths were observed. A cohort of patients surveyed over the last year (n=48) reported trust and confidence in the AC pathway and 100% would recommend or highly recommend AC to friends and family. Close proximity to the hospital and carer education were cited as reassuring factors.

DISCUSSION AND CONCLUSIONS: Ambulatory care can be delivered safely and effectively in TYA patients undergoing intensive chemotherapy. This model provides a platform to empower patients and their families, encourage understanding, independence and autonomy.

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- applied VR
- Cincinnati Children's Hospital
- Consortium of Adolescent & Young Adult Cancer Centers
- Dear Jack Foundation
- Dhremo Therapy IV Decals
- Digging Deep/Shadow's Edge
- Duke Cancer Institute
- Five Wishes
- Young Survival Coalition

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Global Accord Partners

TEEN CANCER AMERICA

Teen Cancer America is delighted to celebrate its 5th Anniversary. Co-founded by Roger Daltrey & Pete Townshend of The Who, TCA is revolutionizing the national standard of care for teens and young adults with cancer in America.

In its first five years the national non-profit launched in 2012 has been raising critical awareness and funding to build specialized facilities and programs for adolescent teens and young adults with cancer, marking a new era of age-targeted care in the U.S. The charity has raised nearly \$10 million by the end of 2017 from a combination of special events, ticket sales and private donors.

"I wanted to give back to teens since I owe my career to them," said Daltrey. "We know that one of the best therapies for a teen with cancer is another teen with cancer. They need their own place where they can be with each other and most importantly, be themselves. They don't have that in most hospitals, and they deserve better."

There are 13 hospitals in the U.S. with specialized AYA facilities, all developed by TCA. It began with the first unit at UCLA in 2013. Since then, TCA has partnered with world-class cancer centers such as Case Comprehensive Cancer Center, UCLA, Stanford, Memorial Sloan Kettering (New York), Dana-Farber (Harvard), Yale, University of Chicago, Children's Hospital of Philadelphia, Moffitt (Tampa), Vanderbilt and Baylor, and more than 50 hospitals around the country are in various stages of planning, including Duke Cancer Institute and the University of North Carolina.

More than 4000 teenagers and young adults across the country have benefited from specialized cancer care in facilities partially funded by TCA. Nurses and clinicians have received supplementary training, research has been initiated, corporate sponsors have joined the movement and public awareness initiatives have generated nationwide interest in TCA.

With such fantastic support, Teen Cancer America is on track to fulfill its mission and to elevate the national standard of care for teens and young adults with cancer. Please join our revolution to change the cancer experience in America and beyond.



TEENAGE CANCER TRUST

Working alongside the NHS, Teenage Cancer Trust leads the world in developing services for young people with cancer. Since 1998, we have hosted 9 international conferences focused on sharing and developing knowledge about young people's cancer.

Working globally, sharing best practice and research internationally, is critical in improving the quality of care and approaches to treatment. We have partnered with Teen Cancer America and CanTeen Australia to create the Adolescent and Young Adult Cancer Global Accord and last year hosted the 1st Global AYA Cancer Congress in Edinburgh, UK which successfully brought together over 360 international clinicians and healthcare experts from 19 countries.

Teenage Cancer Trust is leading the way in transforming the care for young people with cancer in the UK.

We make sure young people don't face cancer alone by supporting the development of world-class cancer care and support in specialist units, local hospitals and in homes across the UK. We're there at every stage, before, during and after treatment.



Global Accord Partners

Right now, for every young person in the UK that Teenage Cancer Trust supports, there is another we can't. We want to expand the numbers of Clinical Nurse Specialists across the UK to provide support from diagnosis to every young person that need them. To achieve this Teenage Cancer Trust has to raise more than £20million every year.

We make sure young people don't face cancer alone, providing expert services before, during and after cancer.

Our expert staff work with NHS colleagues to support young people with cancer wherever they are, on our 28 specialist cancer units in principal treatment centres as well as in other hospitals across the UK and at home. Our Nurses are specialists in teenage and young adult cancer care and provide the best possible tailored, individual care, support and information.

Our Youth Support Coordinators provide psychosocial and peer support activities to reduce isolation whilst in hospital. We also offer professional training, education and leadership to ensure our staff are skilled and best placed to provide the best quality of care to young people with cancer.

Our Find Your Sense of Tumour and Way Forward events bring young people together to build confidence, offering advice on a range of subjects from dealing with late effects, hair loss or infertility to returning to work.

We also empower young people in schools, colleges and universities to take control of their health and speak-up when something changes. Our Education & Awareness programme delivers information about cancer signs, healthy living and encourages persistence with their doctor if health issues are not being resolved.

CANTEEN AUSTRALIA

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.



Global Accord Associate

CRITICAL MASS: THE YOUNG ADULT CANCER ALLIANCE

Each year 70,000 adolescents and young adults between the ages of 15 and 39 are diagnosed with cancer in the United States. The National Cancer Institute reports that this age group is diagnosed with cancer six times more than children aged 14 or younger.

But unlike pediatric and older adult cancers, adolescent and young adult survival rates have continuously lagged behind other age groups since the War on Cancer began in the 1970s.

Critical Mass: The Young Adult Cancer Alliance is the only full-time advocacy organization in the United States dedicated to transforming the care and treatment of 15-39 year olds diagnosed with cancer.

We are patients, survivors, clinicians, researchers, advocates, industry leaders, hospitals, and institutions all on a mission to ensure adolescents and young adults can survive and thrive after a cancer diagnosis.



Presenting Partners

ANGIE FOWLER ADOLESCENT & YOUNG ADULT CANCER INSTITUTE

The Angie Fowler Adolescent & Young Adult Cancer Institute at University Hospitals Rainbow Babies & Children's Hospital – fully integrated with University Hospitals Seidman Cancer Center and the NCI-designated Case Comprehensive Cancer Center – is specifically designed to provide a new and better continuum of care for teens and adolescents diagnosed with cancer and blood disorders. Internationally recognized for basic, clinical and translational research in pediatric hematology/oncology, the institute integrates advanced treatment, breakthrough clinical trials and nationally recognized physicians specialized in treating AYA cancer.

The AYA cancer program features:

- A technology-rich facility specially designed for AYAs, rooftop respite garden and horticultural therapy
- Age-specific cancer programming including comprehensive psychosocial and survivorship counseling and services
- Vital peer to peer support
- Extensive expertise in AYA cancer evaluation, diagnosis and treatment, including germ cell tumors, leukemia, Ewing sarcoma and neuroblastoma
- A dedicated AYA nurse navigator who partners with patients, guiding them to resources such as financial and legal assistance, career and school guidance and fertility preservation
- Access to life-saving therapies like on-site proton therapy, stem cell and marrow transplantation and critical clinical trials



Angie Fowler Adolescent & Young Adult Cancer Institute

CASE COMPREHENSIVE CANCER CENTER

The Case Comprehensive Cancer Center (Case CCC) is a National Cancer Institute-designated consortium Cancer Center and member of the prestigious National Comprehensive Cancer Network (NCCN). Our Center, which has been continuously funded since 1987, brings together the best and brightest research faculty of its partner institutions, Case Western Reserve University, University Hospitals and Cleveland Clinic. Located in Cleveland, Ohio, the Case CCC serves a population with higher than average cancer rates. Our researchers dedicate themselves to improving cancer outcomes through basic studies into pathways giving rise to cancer and its genetic and epigenetic causes, pursuing novel therapeutic targets, and analyzing lifestyle interventions to prevent cancer and detect it earlier. Together, we forge a remarkable effort in cancer research generating considerable community benefit. Our research programs, clinical trials, training, community engagement and outreach link investigators, organizations and investments that are aligned with the strategic plan of the Center and are supported by the partner institutions. Our researchers collaborate daily to pursue the Case CCC mission of translating research discoveries into improved treatments for cancer patients throughout the region and nation.



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EDM

EDM is a leading international provider of digital mailrooms, business process automation and information management solutions. Through a combination of innovative technology and deep industry knowledge, EDM provides highly customized solutions that help organizations automate and streamline business processes and workflows. Our solutions increase efficiency, enhance customer engagement, mitigate risk and ultimately reduce costs – helping organizations make the shift to a digital workplace.

Specializing in highly regulated environments in the public, private and government sectors across the globe, EDM holds high levels of compliance certifications, ensuring regulatory compliance and data security. Many organizations today look to EDM to help them navigate their business processes in an effort to define a new go-forward digital strategy. EDM empowers companies to focus on their core competencies by helping them seamlessly transition to a digital workplace through process and workflow automation. Our proven methodologies and proprietary, technology-based solutions have helped some of the biggest and most regulated brands in the world make the move to digital.



Hopelab

Hopelab is a social innovation lab focused on designing science-based technologies to improve the health and well-being of teens and young adults. We believe that the toughest health challenges facing teens and young adults can be addressed with scientific rigor, innovative design, and empathy. Our AYA Cancer team is exploring how chatbots can be used to measure and optimize psychological interventions for young cancer survivors who struggle with anxiety and depression. Over the next several months we are interested in learning how best to develop and deliver psychological interventions via a chatbot and exploring how we might collaborate with partners to scale this solution to as many young people in need as possible. Come meet the team and learn more.



NC CEO Forum

The North Carolina CEO Forum is for executives and management teams who want to gain a competitive edge in the market. This invitation-only event welcomes business, government and non-profit leaders who are dedicated to helping North Carolina grow jobs and build its presence on the national and international scene.

In February 2018 the NC CEO Forum will feature a stellar line up of world class speakers who will focus exclusively on the changes and innovations in healthcare and will include presentations and conversations with North Carolina's top leaders in business and healthcare. We will hear from top executives at the Wake Forest Comprehensive Cancer Center, Lab Corp, Blue Cross Blue Shield, Liquidia, and GSK, as well as leaders from industries including software, electronic health records, manufacturing, insurance, non-profits, and even artificial intelligence.

The Forum will continue its commitment to giving back to its community with Live & Silent Auctions and a Raffle in support of the featured nonprofit for 2018, Teen Cancer America.



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Shire is the leading global biotechnology company focused on serving people with rare diseases and other highly specialized conditions. We strive to develop best-in-class products, many of which are available in more than 100 countries, across core therapeutic areas including Hematology, Immunology, Neuroscience, Ophthalmics, Lysosomal Storage Disorders, Gastrointestinal / Internal Medicine / Endocrine and Hereditary Angioedema; and a growing franchise in Oncology.

Our employees come to work every day with a shared mission: to develop and deliver breakthrough therapies for the hundreds of millions of people in the world affected by rare diseases and other high-need conditions, and who lack effective therapies to live their lives to the fullest.

Skyline Sector 5

Skyline Sector 5 is dedicated to building purposeful experiences for its clients, crew and community. These experiences can take place anywhere, but they typically happen at exhibitions, activations, retail environments and events with the goal of captivating imaginations and forging real connections between brands and consumers. Sector 5 offers portable, modular and custom-made spaces that are backed by the company's consultative process and over 15 years of experience in the event marketing industry. Sector 5 also specializes in creating compelling digital content, integrating technology with physical spaces to create memorable interactions. Additionally, Sector 5 provides in-house design, event management and install/dismantle services as well as custom rental spaces to meet all of its clients' needs. As the recipient of numerous design and corporate awards, Sector 5 is consistently recognized as one of the top event marketing companies in Texas and across the worldwide Skyline network.

SECTOR5

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Madesmart Housewares

Madesmart is a 27-year-old, Minnesota-based design company. We create home organizational products that better people's lives. Through our new partnership with Teen Cancer America, we are honored to utilize our dedicated team's design and product development expertise for a greater purpose.

Madesmart is experienced in design, research and development, engineering, manufacturing, and distribution. With this new opportunity, we can share our skills to change lives. We are excited to see where this journey takes us and how we can empower patients' lives throughout their treatment and care.

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RealEats America Inc.

Our mission is to remove the barriers to eating real food. RealEats solves the problem of trading off healthy eating for convenience. RealEats meals are vacuum-packed into food-safe recyclable pouches to lock in the freshness, flavors, and nutrients of never-processed non-GMO ingredients. This unique packaging which makes it possible to deliver healthy meals that stay fresh in your fridge for 7 days and can be heated to perfection, in just about 6 minutes.

We partner with some of America's top chefs to create a mouthwatering menu.

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First Citizens Bank THE GLOBAL ACCORD DINNER

Family is important. We've known that for more than 100 years at First Citizens Bank, the largest family-controlled bank in the United States. We serve people and businesses at more than 500 branches in 21 states. To us, life isn't all about making money. Sometimes it's more about making a difference. That's why we're proud to serve as a sponsor for the Global AYA Cancer Congress. And it's also why we're supporting medical centers that pledge to work with Teen Cancer America to establish new teen cancer units and programs. That way, teens can finally feel like teens again, despite facing the biggest challenge of their lives. With everyone's help, we'll open the door to better cancer care. Visit LetMyLoveOpenTheDoor.com. First Citizens Bank. Forever First®.



The Leukemia Lymphoma Society CRITICAL MASS ARCHIE BLEYER TRAILBLAZER AWARD

The Leukemia & Lymphoma Society is the world's largest voluntary health organization dedicated to developing better outcomes for blood cancer patients and has invested more than \$1 billion in blood cancer research. The mission is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. LLS offers free CE and CME programs and patient education and support services.



UCLA Mattel Children's Hospital CHARGING STATION

UCLA Mattel Children's Hospital cares for the physical and emotional well-being of children, from newborns to young adults. With a dedicated entrance from Gayley Avenue, UCLA Mattel Children's Hospital is located on the third and fifth floors of Ronald Reagan UCLA Medical Center.

UCLA's facilities are designed to serve the most critically ill children with sophisticated, compassionate care in an environment that is both welcoming and healing to children and their families. In 1998, Mattel Children's Foundation, a philanthropic arm of Mattel, Inc., pledged \$25 million toward construction of the hospital. In 2017, Mattel, Inc. made a \$50-million gift to The UCLA Foundation to benefit children's health. With Mattel's support, UCLA Mattel Children's Hospital will expand pediatric services locally; broaden its global presence to enhance and improve the health of children worldwide; and promote the global sharing of UCLA Health's best practices and research.



Congress Exhibitors

AFLAC CANCER & BLOOD DISORDERS CENTER OF CHILDREN'S HEALTHCARE OF ATLANTA

STAND NO: 9

As one of the leading pediatric cancer, hematology and blood and marrow transplant programs in the country, the Aflac Cancer and Blood Disorders Center of Children's Healthcare of Atlanta and Emory University School of Medicine provide advanced clinical care and innovative treatment and research options for children and young adults.



appliedVR

STAND NO: 13

AppliedVR provides a totally mobile, user-friendly VR platform that offers patients drug-free alternatives for managing pain/anxiety associated with medical procedures by leveraging the distracting power of immersive technology. Research has proven the use of VR for pain and anxiety management, but until recently the technology was impossible to integrate into healthcare. While conducting further clinical studies, we now provide an easily accessible solution that considers the needs and limitations of patients making it easy for users to experience VR.



CINCINNATI CHILDREN'S HOSPITAL

STAND NO: 22

Cincinnati Children's is a national leader in comprehensive and multidisciplinary care for adolescents and young adults with cancer. The oncology specialists at Cincinnati Children's are leaders in adolescent and young adult cancer research and treatment including stem cell transplant. Other features of care include a dedicated space for this age group, fertility preservation, and a team of national experts. Please meet with our faculty and learn more by visiting the Cincinnati Children's Exhibit Booth.



CONSORTIUM OF ADOLESCENT AND YOUNG ADULT CANCER CENTERS (CAYACC)

STAND NO: 5

The Consortium of Adolescent and Young Adult Cancer Centers (CAYACC), founded in 2015, is a working group of oncologists from Roswell Park Cancer Institute/WCHOB, Vanderbilt-Ingram Cancer Center, Moffitt Cancer Center, Johns Hopkins All Children's Hospital and Nationwide Children's Hospital. CAYACC's National AYA Cancer Patient and Survivor Survey is now underway for participate in at www.cayacc.com. This patient-powered study is coordinated by Roswell Park Cancer Institute, and funded by a grant from Hyundai Hope On Wheels, a 501(c)(3) nonprofit organization.



DEAR JACK FOUNDATION

STAND NO: 6

The *Dear Jack Foundation* supports initiatives and provides programming in order to promote positive health outcomes for adolescents and young adults (AYA), ages 15-39, from the moment they are diagnosed with cancer through survivorship.

Through our programs and strategic partnerships, we address the physical and emotional needs of AYA cancer patients and survivors. Our one-on-one patient outreach and peer-to-peer group wellness programs allow us to empower patients and survivors in their healing and provide assurance that they are not alone in their cancer journey.



DHREMO THERAPY IV DECALS

STAND NO: 25

Focused on bringing a mindful and positive perspective to cancer treatment, Dhremo ("Dream-Oh") Therapy IV Decals are apothecary inspired adhesive decals with uplifting messages. Applied to the back of chemotherapy intravenous (IV) infusion bags, they empower patients to mentally reframe the experience of treatment. Patients can reimagine chemotherapy to be the



Congress Exhibitors

"solution" they need: Love & Light, Vitality or Miracles. Dhremo Therapy IV Decals are sold in 5 decal packs, or in bulk hospital kits. Find out more at www.dhremo.com.

DUKE CANCER INSTITUTE - DUKE TEEN AND YOUNG ADULT ONCOLOGY PROGRAM

STAND NO: 10

Duke Teen and Young Adult Oncology (DTYAO) Program provides a streamlined, patient-centered model of care that provides comprehensive, integrated and high quality care for AYA cancer patients. At the same time, the DTYAO program serves as a platform to strengthen and expand research related to the field, and stimulate trans-disciplinary collaborations (basic, translational, clinical, population) in this unique population. The program provides a framework for research, increased enrollment on clinical trials, integrated psychosocial and medical care, onco-fertility services, and community outreach.



FIVE WISHES (AGING WITH DIGNITY)

STAND NO: 15

Five Wishes is the nation's most popular advance care planning framework. To assist pediatric and young adults, it developed My Wishes and Voicing My Choices. My Wishes is a booklet written in everyday language that helps children express how they want to be cared for in case they become seriously ill. Voicing My Choices gives young adults a way to express something very important - their thoughts about how they want to be comforted, supported, treated, and remembered. Like Five Wishes, both My Wishes and Voicing My Choices help begin conversations among children, parents and caregivers.



DIGGING DEEP/ SHADOW'S EDGE

STAND NO: 12

Shadow's Edge, by Digging Deep is the first-ever FREE mobile game to build resilience in teens with serious medical conditions. The Digging Deep Project empowers children and teens with health challenges to express themselves and discover



their personal story. Our tools are designed to help young people take an active role in their emotional health and master their situation. Follow our blogs and visit our sites diggingdeep.org for professionals and parents and shadowsege.com for teens.

SHIRE

STAND NO: 17

Shire is the leading global biotechnology company focused on serving people with rare diseases and other highly specialized conditions. We strive to develop best-in-class products, many of which are available in more than 100 countries, across core therapeutic areas including Hematology, Immunology, Neuroscience, Ophthalmics, Lysosomal Storage Disorders, Gastrointestinal / Internal Medicine / Endocrine and Hereditary Angioedema; and a growing franchise in Oncology.

YOUNG SURVIVAL COALITION

STAND NO: 11

Young Survival Coalition (YSC) is the premier organization dedicated to the critical issues unique to young women who are diagnosed with breast cancer. YSC offers resources, connections and outreach so women feel supported, empowered and hopeful.

YSC was founded in 1998 by three young women who were under the age of 35 when diagnosed. They were discouraged by the lack of resources available and the under- representation of young women in breast cancer research. Today, YSC is the go-to organization for young women facing a breast cancer diagnosis.



Congress Contributors and Grants

CONTRIBUTORS

CHILDREN'S BRAIN TUMOR FOUNDATION

Children's Brain Tumor Foundation (CBTF) is the national leader in providing quality of life services across the continuum to children, families and survivors of pediatric and spinal cord tumors. CBTF's signature survivor programs address the growing psycho-social needs of the over 26,000 adolescents and young adult survivors, including career guidance and assistance, quality-of-life survivorship research, and adolescent and young adult support groups and conferences.



JANNEYSOUND

Christopher Janney is a pioneer in the field of sound art, merging architecture, sound, light and interactive technology. For 30 years, Janney has been blending music and light with the physical space in unexpected ways. Janney's work turns spectators into participants. He transforms parking garages into music boxes, airport walkways into rainbow passages, public plazas into spaces for creative interaction, and dancers' heartbeats into their own musical accompaniment. Having studied architecture at Princeton and MIT, Janney is also a trained jazz musician. He has created numerous permanent interactive sound and light installations attempting to make architecture more "spontaneous" and music more "physical." Believing that there is more to creating a dynamically-built environment than erecting buildings, Janney has directed his own multi-media studio, PhenomenArts, Inc. since 1980 with studios in both Lexington, Massachusetts, and London, UK.



GRANTS

This program was made possible, in part, by grants from the following:

JAZZ PHARMACEUTICALS

THE LAWRENCE FOUNDATION



Thank you for your generous support of the 2nd Global AYA Cancer Congress!



THANKS

AS WELL AS THE ACKNOWLEDGMENTS LISTED ON PAGE 97, TEEN CANCER AMERICA
WOULD LIKE TO EXPRESS ITS SINCERE GRATITUDE TO:



- **Our Adolescent and Young Adult Cancer Global Accord Partners**



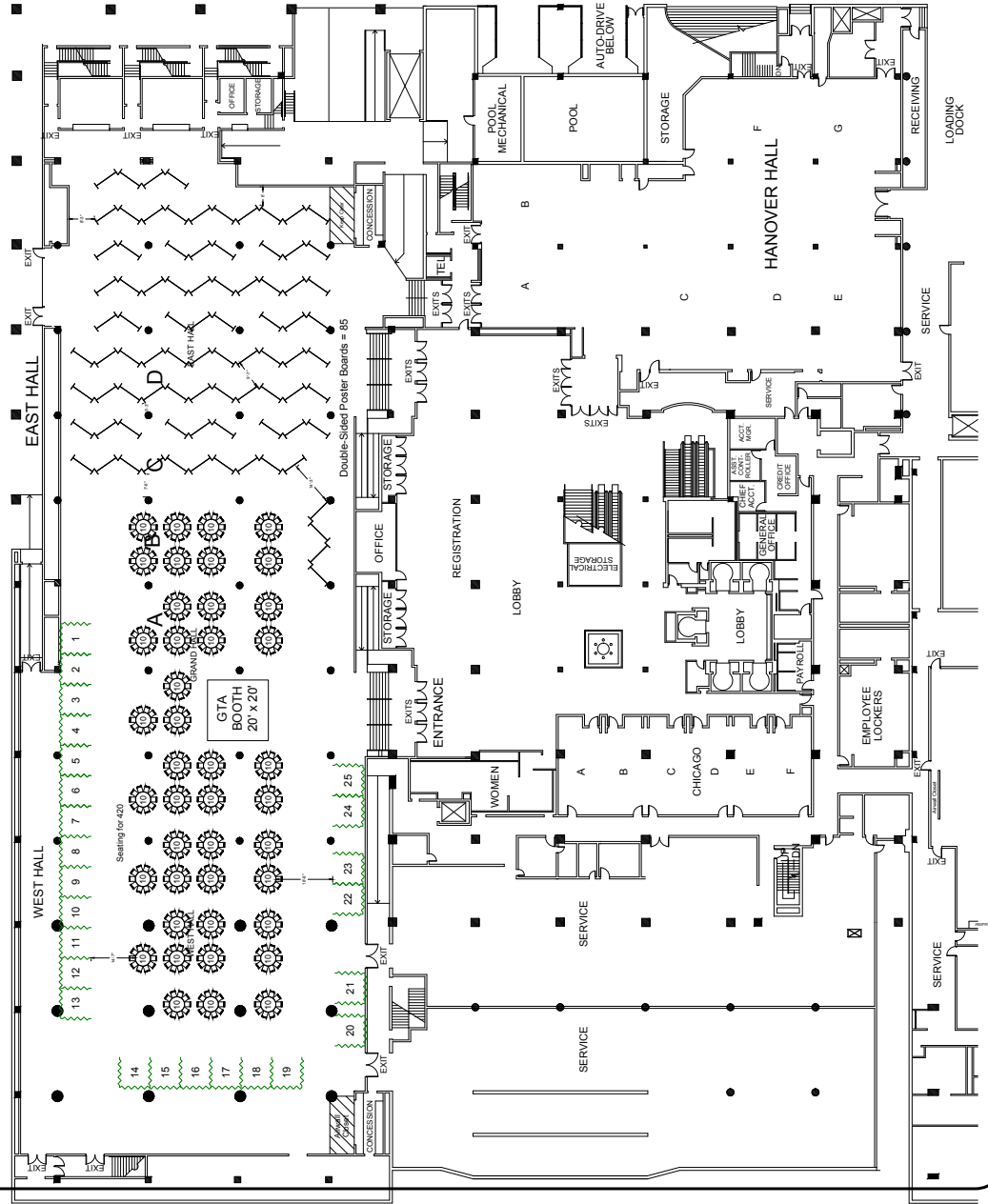
- **Our US Associate, Critical Mass**

- **Chuck and Char Fowler representing The Angie Fowler Institute** whose philanthropy and drive for the AYA movement and financial support for this Congress is unsurpassed
- **Our Co-Chairs** Professor Stu Siegel and Simon Davies for their tireless efforts to help us build this extraordinary program
- **Our US Advisory Committee** for invaluable guidance and support in developing the program
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- **Our internationally renowned Speakers and Co-Chairs of sessions** for their expert presentations
- **Our Delegates** who have traveled from many countries around the world to be with us for this event
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- **The Special Event Company and Rebecca Lawrence-Bristol** for organizing the Congress

FINALLY, A HUGE THANKS TO THE TEEN CANCER AMERICA BOARD, STAFF, AND VOLUNTEERS!

Exhibit Hall Layout

AYA Exhibitors Floor Plan - Grand Hall, East & West Atlanta, GA



Exhibitors

- 1- Angie Fowler Adolescent & Young Adult Cancer Institute/University Hospitals Rainbow Babies & Children's Hospital
- 2 - Case Comprehensive Cancer Center
- 3 - Critical Mass: The Young Adult Cancer Alliance
- 4 - The Leukemia & Lymphoma Society
- 5 - Consortium of Adolescent & Young Adult Cancer Centers
- 6 - Dear Jack Foundation
- 7 - First Citizens Bank
- 8 - Possible Covance
- 9 - The Afac Cancer & Blood Disorders Center Children's Healthcare of Atlanta
- 10 - Duke Cancer Institute
- 11 - Young Survival Coalition
- 12 - Digging Deep/Shadow's Edge
- 13 - appliedVR
- 14 - Hopelab
- 15 - Five Wishes (formerly Aging with Dignity)
- 16 - Open
- 17 - Shire
- 18 - Possible Ulman Foundation
- 19 - EDM
- 20 - NC CEO Forum
- 21 - UCLA Mattel Children's Hospital
- 22 - Cincinnati Children's Hospital
- 23 - RealEats America Inc.
- 24 - Madesmart Housewares
- 25 - Dhremo Therapy IV Decals



Congress Notes

Congress Notes

*In the production of this Program Book, our print team worked within the **Sustainable Forestry Initiative (FSI)**. SFI is an independent, non-profit organization dedicated to promoting sustainable forest management in the USA and Canada*

SPEAK UP



Improve AYA
survival rates!

Protect
parenthood
after cancer.

Give cancer
patients a break
on student loans.



many treat cancer.

WE TRANSFORM CARE.

Critical Mass: The Young Adult Cancer Alliance is the only full-time advocacy organization in the United States dedicated to transforming the care and treatment of 15-39 year olds diagnosed with cancer.

We are patients, survivors, clinicians, researchers, advocates, industry leaders, hospitals, and institutions all on a mission to ensure adolescents and young adults can survive and thrive after a cancer diagnosis.



LEARN MORE CRITICALMASS.ORG