

# 3rd Global Adolescent & Young Adult Cancer Congress

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Sydney | Australia



Adolescent and  
Young Adult Cancer  
GLOBAL ACCORD



Poster Abstracts

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## POSTER ABSTRACTS

# Day 1 – Tuesday 4 December

### **P1** Filling the gaps: Exploring the role of the Clinical Nurse Consultant within the growing Western Sydney Youth Cancer Service

**T.Sibbald<sup>1</sup>, A.Baker<sup>1</sup>**

<sup>1</sup>Western Sydney Youth Cancer Service, Australia.

**INTRODUCTION AND AIMS:** The Clinical Nurse Consultant (CNC) role has been pivotal to the Western Sydney Youth Cancer Service (WSYCS) since its establishment in 2011. The aim of this project is to explore how the CNC role has attempted to meet the psychosocial needs of patients referred to the WSYCS in the absence of psychosocial appointments and in the context of service growth. Funding has recently been allocated for dedicated psychosocial positions in the WSYCS which will again demand a review of the CNC role.

**METHODS:** Service growth was demonstrated by measuring referrals to WSYCS at two time points, April 2011- October 2012 and Dec 2016- April 2018. Strategies employed by the CNC to meet the psychosocial needs of WSYCS patients over this time period were also identified. Results; An 18% increase in patient referrals to the WSYCS was demonstrated. The following strategies were employed by the CNC from 2011 to 2018 to address psychosocial need; Referral pathways established to external support services. Development of database of community based psychologists Education of patients in accessing subsidised community psychological care. Accessing financial assistance to offset additional cost of community based psychological care. Increased clinic time to improve patient access to the CNC for assessment. WSYCS multidisciplinary team meeting to brainstorm strategies to assist patients.

**DISCUSSION AND CONCLUSIONS:** With the impending addition of psychosocial positions to the WSYCS, it is important to acknowledge the achievements of the CNC role in reducing the impact of the limitations of the current service delivery model. The CNC role has employed external supports and adaptive strategies in order to address these service gaps. The addition of dedicated psychosocial positions provides an exciting opportunity for further evolution, not only of the CNC role but also the WSYCS. Further increase in referrals is anticipated with opportunities for outreach to other hospitals within the WSYCS.

### **P2** Health Informatics: Nurse-led implementation of a digital integrated oncology management system for the WA Youth Cancer Service.

**J. Collins<sup>1</sup>**

<sup>1</sup>Western Australia Youth Cancer Service, Australia

**INTRODUCTION AND AIMS:** Health informatics combines clinical knowledge with information and computer sciences to apply information technology to the field of health care. The aim of health informatics is to improve the delivery of health care by refining the collection, management and use of health care data. Applying the principles of health informatics, the Research and Data Nurse of the Western Australia Youth Cancer Service (WA YCS) implemented MOSAIQ, a digital, integrated oncology management system comprising

medical records, laboratory results, appointment scheduling and prescribing facilities.

**METHODS:** A consolidated list of data fields based on national and local reporting requirements was created and amalgamated with the AYA National Minimum Data set. New clinical workflows utilising MOSAIQ were created on a department level and for each of the specific disciplines of the WA YCS. The MOSAIQ software was configured from the back end to provide the staff of the WA YCS a streamlined process of patient care management and enable the collection of all required data fields. Staff of the WA YCS were then provided education on MOSAIQ front end use in accordance with the newly developed workflows.

**RESULTS:** The implementation of MOSAIQ enabled the integration of the WA YCS with local oncology/haematology services; providing shared access to information regarding patient care, treatments, appointments and results. Tailoring data fields within MOSAIQ also led to improvements in data collection, storage and retrieval.

**DISCUSSION:** The application of Nurse-led health informatics was an effective strategy to deliver organisational change at the WA YCS. The clinical experience of the Research and Data Nurse enabled a broad understanding of clinical health care processes and health department policies. This knowledge, combined with competencies in information and computer science were key factors contributing to the successful implementation of MOSAIQ and the subsequent improvements in healthcare delivery.

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### **P3**     **A complex adaptive system perspective on role of the Youth Support Coordinators (YSC) in Teenage/Young Adult (TYA) cancer care.**

**M. Cable**

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**CASE DESCRIPTION:** Teenage Cancer Trust, a UK charity created YSC roles to provide youth focused social support to TYA with cancer, complimenting the multi-disciplinary team (MDT) and reporting to nurses in the National Health Service (NHS). Therefore, as non-regulated workers, they act within in an interrelated system of healthcare and philanthropic organisations with differing agendas. Discussion TYA cancer healthcare experiences comprise networks of components that interact nonlinearly, on different scales and can create unintended consequences e.g., non-compliance, service transitions, family disruption, peer-group challenges, impaired fertility, hair-loss. YSC's support TYA to negotiate this. Reporting structures for YSC are within numerous horizontal and vertical subsystems. Elements of YSC work could be done by others e.g. Social Work, Youth Work, Occupational Therapists or Nurses. The labour boundaries of the work of the MDT and YSC are unclear and fuzzy. YSC's are firmly seated within in complex adaptive systems (CAS) where there is inherent non-linearity as well as systems embedded with other systems which appear to co-exist (Plsek and Greenhalgh 2001).The lack of professional identity (and regulation) for YSC who stem from various professional backgrounds is problematic and poses a challenge for definition of their role and competence development.

**KEY LEARNING:** Arguably their role is a consequence of unintended outcomes of creative, dynamic and philanthropic innovation. We need to move beyond the system of professions to consider a system of work as a whole (Allen et al 2002), and look to what we mean by providing youth focussed support in cancer care. Further research is needed. The YSC role is likely to evolve, as in any CAS. In keeping with Fraser and Greenhalgh's (2001) views on coping with complexity, much rests on the NHS not merely aiming for change, improvement and responses in successful health systems, but to seek changeability, improbability and responsiveness.

## P4 AYA cancer nursing - An emerging sub-speciality

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**BACKGROUND:** During the last twenty years, adolescents and young adults with cancer have gained increased attention in healthcare. The body of knowledge is growing accordingly. Nurses who have led the way amongst the now widening circle of professionals engaged in providing specialist care for young people with cancer are now ready to describe their contributions within education, clinical nursing, rehabilitation, research and leadership.

**METHOD:** To provide healthcare professionals with knowledge about the distinct developments made within AYA cancer nursing internationally, a book entitled Nursing Adolescents and Young Adults with Cancer. Developing knowledge, competence and best practice was authored, edited and produced from 2016-2018. The book is based on international collaboration between the publisher Springer, the two editors and an authorship of academic nurses - nurses with thorough knowledge and expertise in AYA cancer care from the Netherlands, Belgium, Australia, Ireland, Norway, Denmark and England.

**RESULTS:** Since June 2018 the book has been available on-line and in print. It contains chapters describing 1) The history of the specialty and AYA nursing competence development, 2) Approaches, Interventions and Innovations in AYA cancer nursing and 3) Aspects and challenges for future AYA cancer

**CONCLUSION:** The book adds to the documentation of AYA cancer nursing as an emerging sub-speciality. The authors offer insights into the development of AYA cancer care; why it matters; how it should be delivered; and how it might be done better – and with recognition of the unique needs and wants of each young person at the centre of it all.

## P5 Implementing and developing a nursing outreach service for Teenagers and Young Adults with cancer: Perspective of a Clinical Nurse Specialist.

C. Jones, D. Wright, L. Pennington, C. Haniak, K. Waterhouse, S. Smith, J. Coad

**INTRODUCTION:** Yearly, around 2,200 Teenage and Young Adults (TYA) are diagnosed with cancer in the UK. (Cancer Research 2011). TYA's present with unique needs at a crucial developmental stage. Cancer has a huge impact on their life and it can be difficult for them to return to normality after the cancer experience. Treatment is delivered in a variety of settings from Principal Treatment Centres (PTC) to local Designated Treatment Hospitals (DTH). Young people treated locally do not have access to the same level of age appropriate expertise and are often treated in isolation from peers. Teenage Cancer Trust implemented a Nursing and Support Outreach Pilot to provide equitable age appropriate support to all young people in the North West, irrespective of place of care. Inherent in this model was the provision of expert TYA Clinical Nurse Specialist (CNS) to work with the DTH.

**AIM:** The TYA CNS plays a crucial and central role in coordination of care. There is little evidence of equivalent TYA roles nationally and internationally. To provide an understanding of the unique experience of the nurse this paper will reflect and explore the expertise required and the personal and professional challenges and successes faced by the TYA CNS.

**DISCUSSION:** Navigating the complexities of this role whilst delivering a multifaceted service across geographical, political and cultural boundaries was challenging and intricate. Essential to the CNS building trust and nurturing professional relationships are excellent interpersonal skills. The CNS is a leader and it is vital that they possess expertise in influencing and negotiation to overcome resistance and foster clinical engagement when working across different disease teams. TYA care is an emerging specialty that is not always understood, this model has shown a clear shift in support for a more TYA approach to care with real resonance for future practice.

## **P6 Youth Cancer Service Phase III : New South Wales and ACT The Clinical Nurse Consultant role**

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**BACKGROUND:** During Phases I and II of Youth Cancer Service (YCS), key sites were established with links between paediatric and adult services to foster personalised, age appropriate, research based, and multidisciplinary care for 15-25 year olds diagnosed with cancer. Since the inception of the YCS, the Clinical Nurse Consultant (CNC) role has been recognised as a central and critical component for effectiveness of the service.

**OBJECTIVE:** Phase III Commonwealth funding, administered through CanTeen, has enabled a continuation of the AYA program across the state, acknowledging service successes and recognising capacity for growth. The CNC roles remain vital in the trajectory of service delivery, toward research driven innovation and ensuring individualised age appropriate care. The aim is to enhance the role and establish further collaboration with all health care professionals to provide referral pathways for all 15-25 year olds.

**METHOD:** Throughout Phase III, YCS CNC's will continue to work in partnership with internal and external stakeholders. Further active YCS mobilisation and outreach, continued outer-LHD nursing and GP education and bereavement support in rural and regional areas will be important to assist to provide continuity and equity of care and service visibility across the jurisdiction.

**OUTCOME:** NSW / ACT CNC's work cohesively to embed research and data into practice to continue to understand AYA health needs and identify service gaps, assisting to develop an age specific model of care and improved collaboration between paediatric, adult hospitals and community agencies.

**CONCLUSION:** The unique skill set and experience each CNC brings to YCS often transcends that of a traditional nursing role; providing a continuity of care to a vulnerable cohort and empowerment for 15-25yrs throughout their care and survivorship. YCS CNC's continue to work collaboratively with CanTeen and Cancer Institute to provide optimal care pathways and improved outcomes for every 15-25 effected with cancer.

## P7 Evaluation of the role and service provided by the Teenage and Young Adult Cancer Advanced Nurse Practitioner in two TYA centres in England and Wales

**C. Barton<sup>1</sup>, L. McMonagle<sup>1</sup>, B. Ingram<sup>2</sup>, F. Blackborrow<sup>3</sup>, E. Masters<sup>3</sup>, L. Soanes<sup>4</sup>**

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<sup>4</sup>Teenage Cancer Trust Nurse Consultant, UCLH

**BACKGROUND:** Advanced Nurse Practitioners (ANPs) are an expanding workforce within the National Health Service. Although well-established within Cancer care, ANPs are a relatively new introduction to the Teenage and Young Adult (TYA) Cancer setting- with 4 posts currently in place across the 28 designated centres in the United Kingdom. TYA Cancer nurses require specialist skills to deliver age appropriate holistic care to young people. The TYA ANP role is a fusion of these skills with advanced practice. TYA ANPs can practice autonomously within their scope of practice and cover inpatient and/or outpatient units. They provide expert knowledge and continuity of care, critical in building good relationships with young people. ANPs are trained to Masters level and have prescribing and assessment qualifications. As there are few TYA ANPs in the country, a forum has been created to provide peer support and to collaborate on research. As a group of TYA ANP's we propose to evaluate our role and service, surveying both service users and staff working with ANP's in two TYA Units in England and Wales.

**METHOD:** Patients treated over a 6 month period by the ANP were given a written questionnaire. A separate questionnaire was provided to members of the Multidisciplinary Team (MDT) who had worked with the ANP. The questionnaire has been adapted from The AUSPRAC -Nurse Practitioner Research Tool Kit (Gardner et al 2009) which has been widely used to evaluate ANP roles. There was a four week period for participants to complete the questionnaire.

**RESULTS:** A service evaluation the ANP role at the Royal Marsden TYA Unit (Masters et al 2018 accepted for publication) has shown that the TYA ANP role is valued by service users and members of the MDT. The remainder of the ANPs are currently data collecting and results will be compared together.

## P8 Perceptions of nurses on care for childhood cancer survivors with sexual and reproductive dysfunction

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**INTRODUCTION AND AIMS:** Sexual and reproductive dysfunction associated with treatment for childhood cancer is a serious problem that can affect the QOL of childhood cancer survivors. This study aimed to elucidate the perceptions of nurses involved in caring for childhood cancer survivors in Japan.

**METHODS:** Subjects were 10 nurses with experience nursing for AYA cancer survivors. The subjects were either Certified Nurse Specialist in Child Health Nursing (CNS) or nurses working in designated cancer hospitals. Group interviews were conducted with two to three subjects per group, with the exception of one subject who was interviewed individually. Subjects were asked to share their details of care and difficulties and challenges they experienced. This study

was approved by the institutional review board of the Tokyo Healthcare University.

**RESULTS:** Nine of the interview participants had 10 or more years of nursing experience, and seven were CNS. In pediatrics, it was assumed that children would be explained about sexual or reproductive problems only after having first obtained consent of the parents. Nurses found difficulties in giving intervention for parents who did not wish to tell their children about the possibility of infertility, and found it a challenge that the patient's will was not respected with regards to preserving fertility. Teens had varying levels of sexual maturity or experience, which made it difficult to determine how to give an explanation best adapted to each patient's level of understanding or experience. Furthermore, nurses were troubled as to what kind of care they could provide to encourage childhood cancer survivors with sexual and reproductive dysfunction to lead their lives with acceptance for these effects of treatment.

**DISCUSSION AND CONCLUSIONS:** Investigations on care adapted to the life stages of childhood cancer survivors with sexual and reproductive dysfunction and approaches to intervention for their parents are warranted.

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## P9 The Role of the Cancer Nurses Society of Australia (CNSA) Adolescent and Young Adult (AYA) Specialist Practice Network (SPN)

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**INTRODUCTION AND AIMS:** Young people with a cancer diagnosis have distinct physical, psychosocial and practical needs due to the impact of diagnosis and treatment, in addition to the developmental phases they already experience in adolescence and young adulthood. Across Australia specialist Youth Cancer Service (YCS) teams provide invaluable support for the young person and their families, peers, employers, educators and extended community. Youth cancer nurses within these teams, who are also members of the professional organisation Cancer Nurses Society of Australia (CNSA) collaborated to form a Specialist Practice Network (SPN) with the aim of establishing a special interest group for youth cancer nurses in Australia.

**METHODS:** The method of establishing the AYA SPN was through a formal application process with CNSA who already had SPNs for Breast Oncology, Gynaecological Oncology, Cancer Nurse Practitioners, Radiation Oncology and Vascular Access Device/ Infusion Therapy. CNSA also has six Regional Groups which cover a defined geographical area of Australia to provide professional networking and education opportunities.

**RESULTS:** The CNSA AYA SPN was inaugurated in April 2018. The purpose of the group is to positively affect outcomes and enhance wellbeing for young people and their families and friends by promoting access, information sharing and building momentum in the broader nursing network. The CNSA AYA SPN creates a direct link with nurses who are not affiliated with a YCS team, thereby facilitating access to AYA information such as clinical practice guidelines, research and education.

**CONCLUSION AND DISCUSSION:** The unique needs of young people with a cancer diagnosis are substantial and require specialist insight. The role of the CNSA AYA SPN is to enhance collaboration of youth cancer nurses, to support the professional development of oncology nurses, and to act as a point of reference for AYA nursing practice issues.

## P10 Adolescent and Young Adult (AYA) Nurses: A National Network with the Cancer Nurses Society of Australia (CNSA)

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<sup>4</sup>Adolescent and young adult cancer service, Epworth Richmond, Australia

<sup>5</sup>Queensland Youth Cancer Service, Children's Health Queensland, Australia

**INTRODUCTION AND AIMS:** CNSA is the peak professional body for oncology nurses in Australia. Within CNSA, an AYA Specialist Practice Network (SPN) has been formalised with AYA nurses and was inaugurated in April 2018. The purpose of the AYA SPN is to improve standards of care and outcomes for young people with cancer by supporting the professional development of nurses. A quality activity was performed to assess the operational performance of the AYA SPN.

**METHODS:** A process capability and maturity (levels 1-5) model was applied to the CNSA AYA SPN as an initial baseline assessment. Defining the scope and boundaries of key process areas was a self-initiated reflective practice to assess functionality and future direction.

**RESULTS:** The CNSA AYA SPN had a level 2 capability maturity during the first three months of operation. A strong team focus was evident with cohesion and commitment including national committee representation. CNSA provided a foundation of measurable internal processes including a SPN Operations Manual documenting SPN roles and responsibilities, associated templates and compulsory reporting lines to the CNSA President and Chief Executive Officer (CEO). The AYA SPN also performed well in output measures with consistent and timely achievement of tasks, quorum at set meetings, adherence to standards and good problem solving ability. Satisfaction measures were not assessed.

**CONCLUSION AND DISCUSSION:** The aim of the CNSA AYA SPN is to provide access to a network of AYA nurses, collaboration between AYA specialist nurses, and to support AYA nursing education, research and innovation. Advancement in operational performance to level 3 capability requires identification of value chains based on the AYA SPN goal of professional development. The quality assurance approach has identified current and future key process areas to ensure sustainability and progress.

## P11 Delivering appropriate care to young LGBTIQ+ people affected by cancer

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**INTRODUCTION AND AIM:** The Victorian and Tasmanian Youth Cancer Action Board (YCAB) comprises a diverse group of young people with an experience of cancer between the ages of 15 and 25 years. YCAB's mission is to ensure that every young person affected by cancer has access to youth-friendly, equitable, quality cancer care, including those who identify as Lesbian, Gay, Bisexual, Transgender, Intersex and Queer (LGBTIQ). Recognising the potential for discrimination amongst Australian minority groups, YCAB developed its position in supporting and advocating for inclusive and responsive care of young LGBTIQ+ people with cancer.

**METHOD:** The position statement was informed by scoping the literature and engaging in professional development delivered by Queerspace, the Victorian Health and Wellbeing

Service for LGBTIQ+ people and families. This cemented YCAB's understanding of the unique challenges facing young LGBTIQ+ people with cancer. Endorsed by Peter MacCallum Cancer Centre Executive, the position statement was launched as part of International Day against Homophobia, Transphobia and Biphobia.

**RESULTS:** YCAB supports inclusive, equitable and responsive care of young LGBTIQ+ people with cancer. YCAB recognises this population is not a homogenous group, requiring different approaches to meet the varying and unique needs of individuals and their family. YCAB advocates for: cancer services which actively consider and address sexual orientation and gender identity issues in service planning, policy development and delivery; employing staff sensitive to the this populations' needs and competent in delivering appropriate care; and evidence informed service improvements to deliver better understanding and visibility of the experiences and care needs of LGBTIQ+ young people with cancer.

**DISCUSSION AND CONCLUSION:** This position statement is the first of its kind in the adolescent & young adult oncology sector in Australia. It demonstrates the role young people play as advocates for ensuring the delivery of appropriate care to all young people with cancer.

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## **P12** The Cancer Journey for an Indigenous AYA patient

R. Cook<sup>1</sup>, L. Logan<sup>1</sup>, A. Cleasby<sup>1</sup>, L. Murison<sup>1</sup>

<sup>1</sup>The Townsville Hospital and Health Service, Australia

**CASE DESCRIPTION:** A diagnosis of cancer is difficult for any patient, but what if that cancer diagnosis required you to travel a significant distance from your home, family and culture. For many of our indigenous patients they can travel over 2000kms to access treatment, arriving in a huge concrete jungle, where the population of the hospital exceeds that of their local community. This case study explores the journey of indigenous patients from remote communities and the learnings we gain to enhance their experience and compliance.

**DISCUSSION:** As health care practitioners in metropolitan facilities we sometimes fail to understand the significant social impact of a cancer diagnosis on our indigenous patients. This includes complexities around relocation, finances, relationships, poor literacy skills and ability to understand medical terminology, housing, food, social and cultural identity, workforce issues and life expectancy. These issues can affect access to care, uptake of medical treatment and compliance. By establishing rapport and providing culturally appropriate care to patients we can learn about them and make them feel welcome and supported in a foreign environment, ultimately improving compliance and positive outcomes. Through sharing Jack's (pseudonym) story we hope to provide a unique insight into how these issues affected his cancer journey.

**KEY LEARNINGS:** Jack's journey was made more achievable through the early engagement of a AYA Cancer Care Coordinator, access to Indigenous Liaison Officers, Allied Health, and the involvement of his significant other. The establishment of these relationships was enhanced by the utilisation of telehealth resources and a strong partnership between clinician groups, focused on achieving optimal outcomes for Jack. Additional consideration was given to Jack's cultural and literacy needs, and practical measures like financial and transport issues.

## P13 Keeping AYA Patients on Track in the Outback

**R.D. Walker<sup>1,2</sup>, F. Henderson<sup>2</sup>, B. Matigian<sup>1,2</sup>, L. Gray<sup>2</sup>**

<sup>1</sup>Queensland Youth Cancer Service, Australia

<sup>2</sup>Princess Alexandra Hospital, Brisbane, Australia

**CASE DESCRIPTIONS:** Case 1 demonstrates the coordination required between the treating team and the local team in order to allow important treatment to be continued locally. This allowed the young adult to have her first Christmas with her newborn at home in her own town 500km (310 miles) from the treating centre without compromising her care. Case 2 demonstrates the importance of communication between the treating team and the local team 300km (190 miles) from the treating centre. The case also demonstrates that it is possible to keep links with school and other local activities whilst undergoing intense chemotherapy regime and therefore allowing part of the adolescent's life to be less interrupted.

**DISCUSSION:** The diagnosis of cancer can have a wide range of impacts on an Adolescent and Young Adult (AYA) patient. It is also important to remember that the patients are young people first and foremost, with the cancer adding another layer to an already challenging time of life. For the patients that live in the outback/rural areas these impacts can be even more exaggerated due to the need to move from home to the city for their treatment. They can become disconnected from their home town and therefore their support network. This can make the treatment even more difficult due to the physical isolation that is additive to the emotional isolation they already have from their peers. Having the ability to get home, even for a short time, can be beneficial for the patient.

**KEY LEARNING:** Medical and psychosocial care can be delivered rurally whilst being coordinated centrally. Our Youth Cancer Service team, through good communication with local teams, enabled the AYA's to have some time at home. This allowed them to stay connected with their peers and family without compromising care.

## P14 Psychosocial concerns amongst medicare ineligible patients within an AYA service

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<sup>3</sup>Sir Peter MacCallum Department of Oncology, The University of Melbourne, Victoria, Australia

**INTRODUCTION AND AIMS:** Medicare ineligible (MI) patients are a sub-group within the AYA Australian cancer population who have unique psychosocial concerns. The aim of this study was to review case histories of MI patients at the Victorian Adolescent and Young Adult Cancer Service, in order to identify the unique challenges faced by this subgroup.

**METHODS:** A retrospective review of consecutive cases from 1st of July 2016 until 1st of July 2018 was undertaken. Qualitative thematic analysis was conducted to synthesize common psychosocial concerns experienced.

**RESULTS:** 15 MI patients referred in for medical/psychosocial care during the period of this review. Of these, 11 were international students and 8 received their primary treatment at Peter Mac. Analysis of these cases demonstrated various challenges impacting on psychosocial wellbeing. These included: language and cultural barriers; health literacy; navigating health systems; balancing the urgency of care versus unfunded cost of care;

location of care decisions; social isolation; economic insecurity; managing obligations of visa requirements; and challenges around financial discussions and how this aligns with the therapeutic relationship with clinical staff.

**DISCUSSION AND CONCLUSIONS:** Ml individuals are a vulnerable subgroup within the AYA oncology population. Understanding and responding to their unique needs is of importance. Streamlining process for financial discussions and clarity around costing for treatment may assist in informed choices and psychosocial wellbeing. Wider understanding around the additional stresses faced by this sub-group is required to assist with navigating complex health systems.

## **P15** Breaking Down the Barriers: the importance of rural outreach when working with young people and their families

**J. Drake<sup>1</sup>, L. Moore<sup>1</sup>, K. Matthews<sup>1</sup>, E. Hesketh<sup>1</sup>**

<sup>1</sup>Youth Cancer Service, Hunter and Northern NSW Australia

**CASE DESCRIPTION:** The Hunter and Northern NSW Youth Cancer Service (YCS) cover a large geographical region of the Hunter and New England areas in NSW. Rural outreach is an important aspect to ensure Adolescent and Young Adults (AYA) with cancer and their families have access to an age appropriate psychosocial service. The case study is that of an 18 year old young male with palliative disease progression. He presented with many issues faced by rural patients such as minimal access to psychological services, financial stress, anxiety, isolation and end of life care.

**DISCUSSION:** The YCS provided age appropriate multilayered interventions to optimise access to support and psychosocial services to this patient and his family. Our interventions ensured this patient and his family were assisted with nursing, psychosocial, psychological and medical support relevant to their needs. This enabled this young person and his family to navigate the health system away from their home and support base.

**KEY LEARNINGS:** Equity of accessing YCS support regardless of the location is an important aspect when assisting with creative interventions and ongoing supportive care for patients<sup>1</sup>. Maintaining ongoing links and collaboration with health professionals in rural treating hospitals also enables effective service provision for our client group. Clinical observation highlights the importance of establishing face to face contact; this enables follow up with telephone and texts with our patient group, to maintain ongoing relationships, both early on and at the end of life. Established links, relationships and ongoing YCS support with a patient's family also helps facilitate bereavement follow up by phone or directly during outreach.

## **P16** Overlooked minorities: a systematic review examining the intersection of cancer in lesbian, gay, bisexual, trans and intersex (LGBTI) adolescents and young adults (AYAs)

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<sup>2</sup>Health Sciences Library (RMH, RWH, PMCC and Victorian Mental Health), Victorian Comprehensive Cancer Centre, VIC, Australia

**INTRODUCTION:** AYAs with cancer have unique needs consequent to the intersection of a stage marked by complex developmental transitions. The interplay of diverse sexuality and/

or gender identity at this juncture is notable, especially as LGBTI patients report potential challenges in healthcare environments. AimTo undertake a systematic review to identify existing knowledge of LGBTI AYAs diagnosed with cancer.

**METHOD:** A systematic review of cancer literature was conducted utilising Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Two investigators searched MEDLINE, PsycINFO, Embase and LGBT Life databases using a registered protocol. Eligible studies met the following criteria: (1) original research, (2) AYA population defined as 13-39 years, (3) content that reported on a cancer diagnosis in LGBTI AYAs, and (4) data collection methodology using semi-structured interview, focus-group studies, patient surveys or questionnaires. Studies were excluded if they: (1) failed to report on all components of the participant population or (2) reported on a cancer diagnosis with onset outside of AYA parameters.

**RESULTS:** 428 articles were returned; following removal of duplicates, 379 unique articles were identified and independently screened by title and abstract by two investigators. 375 papers were excluded for failure to meet content reporting on a cancer diagnosis in LGBTI AYAs. The four remaining papers were screened in full, with three excluded as not original research. One study was identified that reported on the phenomenon of interest in line with the eligibility criteria. A review of that bibliography failed to identify further studies. Themes pertained to intimate relationships and fertility among sexual minority AYA cancer survivors.

**DISCUSSIONS AND CONCLUSIONS:** This review illustrated a gap in the literature pertaining to LGBTI AYAs with cancer. Given the potential for additional challenges in health environments for this patient cohort, further research is recommended to explore this intersection in the oncology context.

## **P17** 'The Sophisticated Ordinary': An evaluation of regional based Teenage and Young Adult (TYA) peer support groups.

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**INTRODUCTION:** There is a recognised need for peer support for teenagers and young adults (TYAs) diagnosed with cancer. Yet TYAs treated locally without a dedicated TYA unit and outside a Principle Treatment Centre are unlikely to regularly meet any other young people of a similar age. Four support groups were developed to offer peer support for this group of patients in the South West of England. The groups meet every 6 weeks and are supported by the staff from the TYA cancer service with partnership funding provided by Teenage Cancer Trust and CLIC Sargent. Methodology Questionnaires were provided to TYAs who attended the peer support groups along with any networkers (partners/husbands/wives/friends/siblings) who attended with them, parents of attendees and TYAs who did not attend. Semi-structured interviews were conducted with TYAs, from across the 4 centres and with staff from the TYA service.

**PRELIMINARY RESULTS:** A total of 98 TYAs (age 17-27yrs) have attended 53 TYA peer support events over a 29 month period. Preliminary results suggest that the provision of peer support

groups outside a regional centre is highly valued by TYAs, their networkers and staff. TYAs reported that they felt 'less alone', able to 'stay strong', 'make friends' and that 'the group felt safe and comfortable'. It gave a source of constant support, improved confidence and allowed access to their staff from the TYA cancer service such as their TYA Nurse Specialist and CLIC Sargent Young Person's Social Worker or Community Worker.

**DISCUSSION AND CONCLUSIONS:** The provision of peer support makes a significant difference to TYAs and networkers whilst receiving cancer treatment across a regional TYA service. With the development of regional services for TYA's being highlighted as a priority TYA services will need to utilise resources to ensure such initiatives are prioritised in the future.

## **P18** Psychosocial barriers to optimal care: A case study of two newly diagnosed AYA patients in an underserved community

**J. Huynh<sup>1</sup>, T.D. Church<sup>1</sup>, J. Hu<sup>1</sup>, D. Freyer<sup>1</sup>**

<sup>1</sup>University of Southern California (USC), USC Norris Comprehensive Cancer Center, Adolescent and Young Adult Cancer Program at USC, Los Angeles, USA

**CASE DESCRIPTION:** Adolescents and young adults (AYA) face significant psychosocial challenges along their cancer continuum. These challenges impact access to quality cancer care<sup>1,2</sup>. Two case studies illustrate psychosocial issues of two newly diagnosed cancer patients presented through clinical social work (SW) perspective. Case 1 (C1): 30-year-old, Latino male, Acute Lymphoblastic Leukemia (ALL), Ph+Legal issues, no support system, marijuana use, limited resources, heightened emotional distress. Distrust of medical team, nonadherence, poor communication. Lack of adherence made C1 ineligible for bone marrow transplant (BMT) or potential clinical trials (CT). C1's ALL became refractory to treatment. He died 2 years post-diagnosis. Case 2 (C2): 22-year-old, Black male, ALL Alcohol/substance use, complex family dynamics, mental health concerns Non adherence, opioid dependence, behavioral issues, diminished rapport with care team. Behavioral challenges made C2 ineligible for BMT. C2 was transferred to another hospital for CT participation. C2 was ineligible due to disease progression. He died 1.5 years post-diagnosis.

**DISCUSSION:** The two cases identify characteristic psychosocial themes for AYAs: lack of rapport/trust of care team, communication issues, nonadherence, substance use, and limited social support. These cases highlight a vulnerability in AYA populations – limited access to resources coupled with under-addressed psychosocial challenges. Across many visits the SW fostered trust and repaired communication.

**KEY LEARNINGS:** These two cases underscore the importance of building trust between the AYA and provider. Trust strengthens communication and encourages meaningful conversations related to the AYA's care. Iteratively, the care team receives insight on how to best meet the needs of AYA. Increased interactions between patients and care teams are important; enabling ongoing assessment and counseling (SW). The relationship between patient and care team should encourage thoughtful discussions, provide a sense of control, and allow the patient to feel validated<sup>3,4</sup>. A stable relationship would promote trust, a sense of security, and improved support systems<sup>5</sup>.

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## P19 Case presentation describing the emotional burden for staff caring for two young Jehovah's witnesses with Acute Leukaemia.

K. Baker<sup>1</sup>

<sup>1</sup>University College Hospital, London, UK

One of the most ethically complex situations in AYA cancer is working with families and young adults who have reached the age of majority whose religious beliefs prevent the use of life-sustaining treatment. Jehovah's Witnesses (JW) believe blood is a gift from God representing life and it should not be ingested or transfused to sustain life, for some this belief is non-negotiable. This case presentation describes two such cases and the impact they had on the healthcare professionals involved. Patient A, 18yrs old, diagnosed with AML, although agreed to have chemotherapy they refused all blood product support, and he died from a presumed intracranial bleed due to thrombocytopenia 15 days after diagnosis. Patient B, 15yrs old, relapsed on treatment for ALL and declined further active treatment as this would involve blood product support, died peacefully in a children's hospice 2 weeks later. He had previously received 1 blood transfusion in his induction treatment and court proceedings were not necessary. Health professionals struggled with these beliefs and caring for these two patients instigated many ethical, emotional and practical dilemmas. These issues were extremely distressing for staff caring for these patients and they needed continual support. This presentation focuses on the issues of teenage consent as well as the major psychological stresses placed on health professionals caring for these patients, who may believe that these deaths were avoidable, and they should be treating these young people who have a curable disease with modern medicine. This will include details of managing staff stress and distress. The emotional burden for staff involved will be discussed whilst balancing the importance of respecting our patients wishes, and belief's, regardless of their age, which should always be at the forefront of clinical decisions.

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## P20 Youth-driven mural art project for adolescent and young adult (AYA) cancer patients in Western Australia

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<sup>1</sup>WA Youth Cancer Service, Australia

**INTRODUCTION AND AIMS:** Meaningful youth participation and youth development should be an integral part of the way youth-focused organisations operate and deliver services. Using a youth-driven model, and in consultation with the Youth Cancer Advisory Committee Western Australia, the Western Australian Youth Cancer Service (WAYCS) piloted an art project that created a mural art installation in the You Can Centre, Perth. The project provided an opportunity for young cancer patients to lead the design and delivery of the artwork and develop a sense of ownership of space through meaningful contribution to the You Can Centre. The project also aimed to develop skills in planning and creating visual artwork, and deliver the psychosocial benefits of participating in a creative process.

**METHODS:** Guided by a young volunteer artist and the WAYCS youth development officer, young people aged between 15-25 years participated in a series of skills development workshops to identify key themes they felt represent their experience of cancer. Working collaboratively with the artist they designed and painted the mural using these themes.

**RESULTS:** Participants developed skills in designing and painting to create individual artworks on skateboard decks as well as contributing to the final mural. The mural provided an opportunity for the participants to contribute to the design of the space they use. Participants reported the project was a positive experience, noting that they liked being able to contribute to a project that will make a “lasting impression”.

**DISCUSSION AND CONCLUSIONS:** Youth-driven mural art projects have been shown to be effective in increasing young people’s overall engagement with services and the other programs that they offer. The WAYCS embeds youth participation and youth development principles in the way it operates and delivers services. These principles should be utilised by all organisations and services that work with young people.

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## P21 Visual Impact of an Effective Breast Cancer Awareness Campaign Targeting Young Women on Campus Across Canada

L. Larsen<sup>1</sup>

<sup>1</sup>Team Shan Breast Cancer Awareness for Young Women (Team Shan), Canada  
@TeamShan

**INTRODUCTION AND AIMS:** Team Shan Breast Cancer Awareness for Young Women (Team Shan) has facilitated breast cancer awareness campaigns on Canadian college and university campuses since 2007. Named after Shanna (Shan) Larsen, a young woman who passed away from breast cancer, Team Shan incorporates Shan’s face and personal story to help message the theme breast cancer...not just a disease of older women. The aims of the strategy are to increase breast cancer awareness and breast health knowledge levels in young women; encourage risk reduction and self-care behaviours; increase early detection and help improve outcomes for young woman diagnosed.

**METHODS:** Systematic reviews conducted to assess need and inform campaign messaging, Focus testing conducted to help plan and revise awareness campaign activities. Multifaceted media/marketing campaigns facilitated on post-secondary school sites in collaboration with campus faculty, students and media partners. Complementary campus activities facilitated to enhance awareness and education strategies.

**RESULTS:** Young women responded positively to the campaign media/marketing strategies and participated in campaign evaluation and complementary campus activities. Visual aspects of the campaigns included billboard and public transit marketing displays, print media advertisements, social media posts, campus displays, print material distribution and campus presentations. Respondents understood their breast cancer risk, took or planned to take self-care action and shared campaign information. The use of Shan’s face and her story helped communicate vital campaign messaging to young women.

**DISCUSSION AND CONCLUSIONS:** Team Shan has developed an innovative social marketing model that has reached thousands of Canadian young women annually and successfully framed breast cancer messaging to this population at risk. Team Shan’s comprehensive approach to awareness activities has been successful in informing young women about their breast cancer risk, and increased their knowledge of facts, risk factors, symptoms and self-care strategies. Visuals will be shared to highlight both the awareness campaign strategies and impact.

## P22 AYA Patient Advisory Boards: Giving AYA Cancer Patients and Families a Seat at the Table

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@HIAAYAcancer

**CASE DESCRIPTION:** Two cancer centers in Utah collaborated to establish a patient and family advisory board (PFAB) that meets regularly to discuss patient-centered care and research efforts in adolescent and young adult (AYA) cancer. The PFAB began in 2015 and included eight to ten members recruited through provider referral and social media. Currently there are eight survivors and two caregivers. There have been six quarterly meetings since the board launched, and members receive \$25 gift cards at each meeting. Board responsibilities include advocating for AYA patients and survivors, and providing feedback on AYA services and research. The PFAB has impacted the design of four AYA-focused research studies by providing feedback on survey design and recruitment strategies. The PFAB has made suggestions for AYA patient navigation on ways to address fertility preservation and financial assistance. Further, the PFAB advocated for a private Facebook group for local AYA patients to facilitate social connections. This Facebook group launched in January 2018 and three members of the PFAB volunteer as moderators.

**DISCUSSION:** The PFAB ties the mission and tasks of the AYA program to the AYA patient and caregiver experience. One challenge is keeping members engaged over time. However, engagement is promoted through a staff member who acts as a liaison, allowing board members to participate remotely, and small compensation for their time. The AYA program will continue to engage patients and caregivers both on- and off-treatment in the development of services, programs, and research to address the needs of AYAs.

**KEY LEARNINGS:** Engagement of PFAB members can be encouraged by a designated board liaison, and by providing compensation. We recommend recruiting purposefully to illicit a wide variety of perspectives. Digital meetings allowing remote participation are effective and productive especially in areas where meetings may require travel.

## P23 A Pathway to Improving an Adolescent and Young Adult Oncology Service: Voices of Patients and Parents

L. Super<sup>1</sup>

<sup>1</sup>Monash Children's & Royal Children's Hospital in Victoria

**INTRODUCTION AND AIMS:** Adolescent and Young Adult (AYA) oncology patients have complex and unique medical and psychosocial needs. Following recognition of poorer outcomes and lower rates of clinical trial involvement than younger or older age groups, this population demands attention in health service development. Our hospital treats patients across the lifespan - from pre-natal to geriatrics - and is ideally positioned to examine pathways toward optimized health service delivery. Our prior research explored experiences

of adolescent cancer patients aged 12-18 years and informed the development of a psychosocial and medical clinic for this age group. The current project seeks to extend that examination to include young adult cancer patients (12-25 years). Specifically, this project aims (1) to examine the needs, preferences, and perspectives of AYA cancer patients in relation to health information, experience of care, healthcare needs and autonomy/independence; and (2) to identify how AYA cancer care can be modified to more effectively meet the needs of patients and their parents/carers across the care trajectory.

**METHODS:** Participants are AYA patients (12-25 years) who receive care in paediatric and adult cancer services at a tertiary and University-affiliated hospital in Melbourne, Australia, and their parents/carers/partners. Participants complete a brief survey and participate in a focus group or individual interview examining healthcare experiences and preferences. Survey data will be analysed using descriptive statistics, and thematic analysis will be used for qualitative interview data.

**RESULTS:** Data collection is ongoing; results will summarise the AYA experience and preferences regarding healthcare delivery and recommendations for service improvement.

**DISCUSSION:** Evidence indicates that AYA oncology patients need tailored healthcare that considers their developmental needs; however, interventions targeted toward vulnerable populations are often developed for those individuals, not with them. Recommendations for service delivery informed by AYA patients and carers will be discussed.

## P24 **Aggregate, Don't Recreate**

**D. Reed<sup>1</sup>, A. Skinner<sup>1</sup>, C. Elstner<sup>1</sup>, J. Senall<sup>2</sup>**

<sup>1</sup>Moffitt Cancer Center, United States

<sup>2</sup>Mobile First Media, United States

**BACKGROUND:** The AYA population and its unique needs have inspired many groups to create new projects to bring support and information to the population. Numerous articles have been published exploring this population, yet the rhetoric has not changed much despite the availability of resources. Moffitt's AYA Program created an advocate inspired website to bring patients together, representing an aggregation of available resources to one principal website.

**METHODS:** Philanthropic funding towards "bringing patients together" was donated to our program. Initially, we sought to create a multichannel facetime app where patients could communicate virtually and find additional resources. Multidisciplinary staff members iterated original content but consensus that existing resources were better than what was created, changed the direction of the project.

**RESULTS:** AYAcancerconnect.com was created by linking to existing resources. Developing the website demonstrated major strides the AYA community has made towards creating meaningful content for AYA patients and the need for collaboration in guiding patients to this content. The site contains tabs entitled 'Connect', 'Resources', 'Events', and 'Caregivers' that link to many sites well known to the AYA community. Each subpage only lists links to other sites, providing a clear list of available resources and will continue to incorporate additional resources that patients find helpful. Like Critical Mass' Mission Control (MC) website which links to local resources and services, AYAcancerconnect.com promotes established resources for AYA issues and links out to MC.

**CONCLUSIONS:** Creating AYA resources may be coming to a close and aggregating with existing resources should be strongly considered before planning projects; supporting progress our field has made. Moving towards an aggregation mindset should foster collaboration, build the AYA provider community, and allow for a better community voice towards the real reforms that are needed in terms of federal funding, improving collaboration and building the national AYA community.

## P25 Presenting cancer symptoms and diagnostic timeliness among teenagers and young adults: findings from the BRIGHTLIGHT cohort

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**INTRODUCTION AND AIMS:** Improving the time-to-diagnosis for young people with cancer is an international priority. However, little large scale evidence exists to identify at risk groups or where interventions are best placed. We recently reported variation in diagnostic intervals in adolescents and young adults with cancer participating in the BRIGHTLIGHT study<sup>1</sup>. We aimed to examine the nature and frequencies of presenting symptoms in this population and their association with diagnostic timeliness.

**METHODS:** Data was collected from BRIGHTLIGHT participants about their diagnostic experience through face-to-face interviews. Participants were asked whether they had experienced 16 pre-specified symptoms before diagnosis (yes/no responses), or other symptoms (free-text responses). We calculated the frequencies of common presenting symptoms across the cohort, and the ensuing 'symptom signatures' of lymphoma, germ cell tumours, leukaemia, carcinoma, bone tumours, soft tissue sarcomas, brain/CNS tumours, melanoma and unspecified malignancies.

**RESULTS:** Among 803 participants reporting one or more symptoms before diagnosis, lump/swelling was most common (52%) followed by extreme tiredness (38%), unexplained pain (35%), night sweats (24%), lymphadenopathy (24%), and weight loss (24%). Most AYAs (70%, 557/803) presented with more than one symptom in a total of 357 unique symptom combinations; the 10 most common combinations accounted for 37% of patients. Fourteen patients had no specific symptoms. Examination of the five most frequent symptoms recalled by patients within each cancer group illustrated extreme tiredness featured in 8/9 cancer groups, lump/swelling in 6/9 groups, pain in 5/9 groups, weight loss in 5/9 groups and night sweats in 4/9 cancer groups.

**DISCUSSION AND CONCLUSIONS:** AYA cancer patients experience a range of non-specific symptoms in combination before diagnosis, in substantially greater frequencies than previously reported in primary care record studies. This presentation will discuss times to diagnosis by presenting symptom/symptom combination and implications for early diagnosis strategies.<sup>1</sup>

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## P26 Development and implementation of guidelines for cancer stage data collection in the Australian Youth Cancer Services

D. Keuskamp<sup>1</sup>

<sup>1</sup>CanTeen Australia

**INTRODUCTION & AIMS:** Cancer stage data are key to interpreting early detection initiatives, treatment and outcomes, but are difficult to capture and not routinely collected by Australian population-based cancer registries. To address this, Cancer Australia has instituted the Staging, Treatment and Recurrence (STaR) project, focusing initially on the most common cancers in all age groups. Consistent recording of AYA cancer stage is likewise fundamental in the forthcoming Australian AYA Cancer Database (AAYACD). As AYAs are diagnosed with a range

of rare and less common cancers, AYA cancer staging guidelines were developed to facilitate recording of stage data for this population.

**METHODS:** CanTeen convened the Youth Cancer Service (YCS) Staging Working Group, including epidemiology, registry and oncology expertise, to develop guidelines for staging specific to AYA cancer. The group explored the relevance of existing staging systems for AYA cancers, developed consensus guidelines for staging, and advised on the operationalisation of these guidelines for the AAYACD.

**RESULTS:** The AYA guidelines recommend twelve staging systems for use across the most common AYA cancers. The Toronto Childhood Cancer Stage Guidelines were adopted for cancers seen in both children and AYAs and consensus was reached on supplementary staging systems for remaining diagnoses. The staging working group recommended consulting with YCS research nurses, who will record stage in the AAYACD, to assist with implementation. The establishment of protocols specifying when and how to record stage where reliable records exist or interpret stage from existing medical information was also recommended.

**DISCUSSION & CONCLUSIONS:** The guidelines are not intended to replace or conflict with clinical staging for treatment and prognostic purposes and will assist in the consistent recording of AYA cancer stage in national data compilations. Ongoing staging working group and YCS research nurse group consultations will support the operationalisation of these guidelines as part of AAYACD implementation.

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## **P27** The Teenage Cancer Trust IAM Portal: An update on its continued development, evaluation and implementation

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Developed by the Adolescent and Young Adult (AYA) cancer service based in the south west of England, the Integrated Assessment Mapping (IAM) Portal provides a developmentally attuned digital platform to enable professionals and young people to work in partnership throughout the cancer journey, living with and beyond cancer. Teenage Cancer Trust is now implementing the IAM Portal across AYA services in the UK. Work is being undertaken both locally and nationally to increase the impact of the IAM Portal and its utilisation across a young adult's cancer pathway. Localised resources are being added to support young people both in their local areas, and as they potentially travel across the UK for university and work. The portal can link in aftercare resources, primary-care and use of other support in the local community (both cancer specific and generic), to support young people through diagnosis, treatment and beyond. The IAM Portal is made up of three components: An electronic AYA holistic needs assessment (HNA) which is applicable throughout the pathway: The Integrated Assessment Map (IAM) Co-designed online multimedia AYA information and advice resources. The AYA South West Integrated Multi-disciplinary team (MDT) Management System (SWIMMS) The development of the IAM Portal is an active phased quality improvement initiative. It is evaluated using a mixed methodology approach through implementation, and in to business as usual. We aim to present qualitative and quantitative data on most recent developments in particular: Impact of the IAM Portal one year on from implementation, and emerging utility data from new regional services. Emerging data from patient surveys regarding the continued use by AYA for assessment and accessing information. Experience of developing the IAM Portal for use at the end of treatment and into aftercare.

## P28 Building an AYA Oncology Program from the Ground Up: Of Towers and Bridges

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<sup>1</sup>Johns Hopkins All Children's Hospital, St. Petersburg, Florida, USA

**INTRODUCTION AND AIMS:** Adolescent and young adult (AYA) oncology patients require a multifaceted approach to reach better outcomes. One strategy is to establish a dedicated AYA program so our aim was to build one at John's Hopkins All Children's Hospital (JHACH) that best fit our unique medical landscape.

**METHODS:** Our team assessed patient needs, our strengths and weaknesses and proceeded to build our program. As a COG member, our patients were offered many national clinical trials, but our age limit is 21 and we are not members of adult cooperative groups, limiting access to some trials. We also lacked expertise in some AYA-specific diagnoses like melanoma. We created disease-specific groups and have tasked their leaders to establish partnerships with AYA champions at the state's only NCI-designated cancer center in nearby Tampa. Regarding fertility preservation, we established a partnership with the nearby academic reproductive endocrinology program. Increasing access further, foundation funds cover consultations, services and gamete storage. JHACH hired an embedded psychologist, full-time teachers, more care coordinators and more social workers. Philanthropy created AYA-focused nurse practitioner positions to coordinate fertility consults and overall clinical care. We recruited a physician to expand our survivorship program.

**RESULTS:** We built a hospital-based team of focused professionals (a tower) and are partnering with adult oncology and fertility programs (bridges) to create a comprehensive AYA oncology program.

**DISCUSSION AND CONCLUSIONS:** We are creating the ideal AYA program to fit the needs of our patients while overcoming the limitations of our hospital. Our success will be measured by patient volume, clinical trial enrollment, patient satisfaction, well-being assessment tools, but ultimately improved survivorship and quality of life in our patients. In the future our goal is to build partnerships with community oncology programs where most of the older AYA patients are receiving care.

## P29 The Dutch Adolescent and Young Adult (AYA) approach: building a national AYA network in collaboration with AYAs and healthcare professionals

**O. Husson<sup>1</sup>**

<sup>1</sup>Institute of Cancer Research UK

Yearly 2,700 AYA patients aged 18-35 years are diagnosed with cancer in the Netherlands. AYAs expressed a huge need for age-specific integrated care. Based on the experience of the AYA Expertise center Radboudumc, a national AYA 'Young & Cancer' Platform in the Netherlands was started in 2013. This nation-wide platform functions as a care network where AYAs and healthcare professionals of the academic medical centers and several regional hospitals participate. This care network provides an optimal environment for implementation and innovation of age specific integrated care starting at diagnosis, knowledge exchange, scientific research on 'cancer at the AYA age' and education. Age specific care is stepwise structured with the general practitioner who is aimed to recognize the AYA, the general

hospitals for basic AYA care and the AYA expertise centers in the university medical centers for complex age specific care. Today 7 out of 8 university hospitals function as AYA expertise centers and more and more general hospitals join the national platform. Since 2014 the AYA4 online community is open to all Dutch AYAs. On the secure community separate modules exist for patients and informal caregivers; also since 2014 annual national conferences, called 'SPACE 4 AYA' both for healthcare professionals as well as AYAs and caregivers takes place. Members of the national AYA platform developed an AYA interdisciplinary education program guaranteeing the quality and unambiguous AYA care among health care professionals. Research examines effects of the Dutch AYA approach as well as age specific integrated needs. The Dutch AYA 'Young & Cancer' Platform illustrates nicely what can be achieved by close collaboration and co-creation between AYAs and healthcare professionals.

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### **P30** Student learning from an international AYA cancer site visit

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**CASE DESCRIPTION:** A student on the Postgraduate Certificate in Teenage and Young Adult Cancer Care, United Kingdom (UK), who works for a cancer charity in Ireland availed of a travel scholarship from Coventry University/ Teenage Cancer Trust to extend learning beyond the online platform. A dual site visit to two specialist Adolescent and Young Adult (AYA) cancer services, in Birmingham and London, was arranged so that AYA specialist cancer care could be observed in practice. The recipient set objectives and organised travel with the support of academic mentors and Teenage Cancer Trust funded staff. **DISCUSSION:** Three days travel were sponsored, which involved visiting 2 clinical sites responsible for the provision of specialist tailored care to AYA patients with cancer. The trip included visiting Teenage Cancer Trust specialist inpatient units and experiencing services in both the inpatient and outpatient setting. The author attended multidisciplinary team (MDT) meetings focused on AYA cancer care and was accommodated by meeting with specialist staff from a variety of professional backgrounds that are vital to the provision of comprehensive, tailored care of these patients

**KEY LEARNING:** The experience proved to be inspirational and informative. The author was afforded the invaluable opportunity to meet and connect with AYA specialist professionals and experts. Valuable application from academic studies to clinical practice was achieved. The significant contribution of charitable organisations to the provision of AYA specific care in the UK was observed. The uniqueness of the psychosocial AYA MDT meeting and teamwork was a significant learning point and demonstrated how the AYA cancer experience is shaped by expert care. The passion and determination of the staff involved was evident. This experience was extremely valuable further motivated the student to influence AYA cancer care in Ireland by sharing what was learned.

### P31 **New Treat Unique Adolescent & Young Adult Cancer Service at Epworth Richmond, Melbourne**

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**INTRODUCTION AND AIMS:** It is recognised that adolescents and young adults (AYA) require a different approach in cancer care compared to paediatric or adults. AYA have distinct physical, psychosocial and practical needs, in addition to their crucial developmental stage. In Victoria, Australia, around 400 young people aged between 15 and 25 are diagnosed with cancer each year. They are not always referred to a specialist AYA cancer service to receive expert support. Until the recent establishment of the AYA cancer service at Epworth Richmond in Melbourne, Victoria, there weren't any dedicated multidisciplinary cancer service for young people in the private health system in Australia.

**METHODS:** The method of establishing the private AYA cancer service was founded by service's medical lead, who has vast experience in paediatric and AYA oncology, recognised the gap in service. In collaboration with Epworth Richmond, the establishment of the highly experienced AYA multidisciplinary team was formed. The team included the medical lead, an AYA nurse, an AYA social worker, a Pilates and wellbeing instructor and a Patient Mentor, who experienced cancer at the age of 16 years.

**RESULTS:** In 2017, Treat Unique AYA Cancer Service, at Epworth Richmond was established. The service provides comprehensive medical, nursing and psychosocial care to AYA cancer patients aged 16 to 25 years, while being guided by the best practice Australian Youth Cancer Framework for youth friendly care. The AYA service has consulted, provided education and support to the oncology, paediatric and emergency departments at Epworth Richmond. Successful engagement with CanTeen, youth cancer services and other non-government organisations for external referral support has been established.

**DISCUSSION AND CONCLUSIONS:** Treat Unique AYA cancer service has successfully established to provide individualised, tailored care to the young patient and their families throughout the cancer journey from diagnosis, treatment and survivorship care, while supporting them to achieve their developmental goals.

### P32 **A space I call my own: "CAN-SPA" the Indian solution for a cancer space for age-appropriate care**

**P. Chitalkar<sup>1</sup>, K. Nana<sup>2</sup>, A. Chitalkar<sup>3</sup>, M. Panwalkar<sup>2</sup>, P. Mehadia<sup>2</sup>, S. Shinde<sup>2</sup>, A. Punia<sup>1</sup>, R. Sharma<sup>1</sup>**

<sup>1</sup>Sri Aurobindo Medical College, Indore (Madhya Pradesh, India)

<sup>2</sup>Nuvo designs, India

<sup>3</sup>TYAcan Foundation, India

**INTRODUCTION & AIMS:** Young persons with cancer (TYAC) need a space where they can unwind, meet with other young persons, find the balance between their private universe and the presence of caregivers and professionals. Several such spaces exist in the developed world. This is the first Indian model: "CANSIPA" designed for the TYAC. This healing environment for young persons with cancer was conceived by Teenage & Young Adult Cancer Foundation (TYAcan) and designed by NUVO Designs (Pune; India).

**METHODS:** A five- person TYAcan-CANSIPA is in the Sri Aurobindo Cancer Centre, SAIMS Indore : a 900 square feet area with two chemotherapy chairs, a nursing station, counselling area,

curtained spaces for each person, a cook-top, refrigerator, gym and Yoga equipment, music, Wi-Fi. The design has large windows opening out to a wooded landscape and a water stream to reduce stress and isolation. CANSPA will have unique Indian character : space to meet parents; the decor will create hope ; constructed and furnished with elegance for "autonomy" for a young person in the Indian family is distinct from that in the west.

**RESULTS:** An area in the Sri Aurbindo Cancer Centre Indore has been identified and modified. The design is in the final stages. It is expected to be commissioned in October 2018, as a home-away-from-home for TYAC.

**CONCLUSIONS AND DISCUSSION:** TYAcan is a pan-India non-profit with the mission to achieve cure of TYAC and to help them to live their life dreams. Creating an elegant environment for young persons with cancer in the Indore region of Madhya Pradesh is a beginning. With a rural background, the young people of here are rooted in family and friends, though savvy with the world of Facebook and Whatsapp. TYAcan partnered with NUVO Designs to design of such a space, with unique needs of Indian TYAC at its heart. The vast differences of youth behaviour within India, will pose challenges as we go by, creating CANSPA homes in metro cities and culturally diverse regions of our country.

# Day 2 - Wednesday 5 December

## P1 Are TYAC teams really equitable tools of access to care for all patients?

L. Goffi Laroche

**INTRODUCTION AND AIMS:** Since 2012, the French Cancer Plan allowed the structuration of teams dedicated to TYAC in order to better take into account their specificities and improve their overall care and pathway.

This work aims to identify the risk factors for the non-use of the TYAC dispositif and to propose improvement actions to promote more equitable access to a personalized pathway and supportive care for all patients.

**METHODS:** The study population carries in a first time on all the TYAC reported to our team between January 2013 and December 2017. Based on inclusion criteria, the support levels of each patient will be described according to different criteria (age, sex, pathology, area of residence ...). The study is also completed by two surveys: (1) on a panel of professionals to evaluate the brakes/levers to reporting TYAC by the referring hospital teams and (2) on a panel of patients to evaluate, according to the moment of their inclusion, their -experience on the quality of their personalized support. Interviews are ongoing.

**RESULTS:** The results will focus on the 375 TYAC reported between 2013 and 2017 and of which 221 were supported by our team according to 3 levels of intervention. Patients living outside the county of Grenoble Hospital represent 42% of the active file. The main pathologies represented are hematological malignancies, brain tumors and sarcomas and bone tumors. 108 TYAC are asked for a semi-directed interview and 6 oncologists are still to contact.

**DISCUSSION AND CONCLUSION:** At the time when TYAC units are spreading to all French regions, this work must make it possible to adapt professional practices to promote better access to TYAC units and allow us to respond more accurately and more effectively to the needs of all Adolescents and Young Adults with cancer in our territory of intervention.

## P2 Major adverse events associated with L-asparaginase in adolescents and young adults receiving pediatric based treatment for acute lymphoblastic leukemia

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<sup>1</sup>Oregon Health & Science University, USA

**INTRODUCTION/AIMS:** Acute lymphoblastic leukemia (ALL) is a model for how to approach the treatment of cancer in adolescents and young adults (AYA). A survival difference was attributable to the use of pediatric versus adult based treatment protocols with a major component being the use of L-asparaginase in pediatric based regimens. However, AYAs may experience more and different side effects compared to children suggesting the need for different monitoring, management, and levels of clinical suspicion. Thus, we describe our center's experience with the use of L-asparaginase in AYA ALL.

**METHODS:** A retrospective review was performed describing toxicities in AYA patients with ALL

at Oregon Health and Science University within the last 20 years. Frequency of major (NCI CTCAE grade 3-5) side effects including thrombosis, bleeding, liver injury, pancreatitis, and hypersensitivity associated with L-asparaginase were analyzed and compared to previously published trials. Management and outcomes were analyzed including rate of asparaginase discontinuation.

**RESULTS:** Hypersensitivity has been reported as the most common side effect and as the most common reason for discontinuation of L-asparaginase. Coagulation disorders are also common but have been well managed with unique strategies. Liver injury is seen more frequently in AYAs than in children and pancreatitis seems to happen slightly more frequently with a more complicated course. **DISCUSSION/CONCLUSIONS:** We report our experience with the incidence of adverse events in the use of L-asparaginase for the treatment of ALL in the AYA population in a center with a long history of experience using pediatric based protocols. In general, toxicities that are seen in children are also seen in AYAs though in different frequencies. Preemptive management can help in management of some of these events, such as with venous thromboembolism. However, more work will need to be done to determine if preemptive steps can be taken to minimize adverse events in order to maximize treatment delivery of asparaginase.

### P3 **Treatment Patterns and Outcomes of Adolescents and Young Adults with advanced soft tissue sarcomas: a single-centre experience**

**E. Younger<sup>1</sup>, O. Husson<sup>2</sup>, C. Benson<sup>1</sup>, I. Judson<sup>2</sup>, B. Asare<sup>1</sup>, A. Miah<sup>1</sup>, S. Zaidi<sup>1</sup>, W. van Houdt<sup>1,3</sup>, R.L. Jones<sup>1,2</sup>, W. van der Graaf<sup>1,2</sup>**

<sup>1</sup>Royal Marsden Hospital, London, UK

<sup>2</sup>Institute of Cancer Research, London, UK

<sup>3</sup>Netherlands Cancer Institute, The Netherlands

**INTRODUCTION:** Soft tissue sarcomas account for 8% of all cancers affecting adolescent and young adults (AYA), and contribute significantly to mortality. Data on outcomes of AYA with advanced STS are scarce, and not routinely distinguished from all patients in clinical trials.

**METHODS:** Patients aged 18-39 years diagnosed with advanced STS at our institution between 1990 and 2012 were identified from a prospectively maintained database. Outcomes of interest were clinical characteristics, treatment patterns, overall survival (OS) and prognostic factors.

**RESULTS:** Overall, 455 patients were included. Median age at advanced STS diagnosis was 33 years (IQR 22-37). Patients with 22 distinct histological subtypes were treated; most frequently leiomyosarcoma (n=68, 15%), synovial sarcoma (n=68, 15%), Ewing sarcoma (n=44, 10%) and rhabdomyosarcoma (n=35, 8%). Pulmonary metastases were the most common site of distant spread (n=268, 59%). Treatments received: primary surgery (n=322, 71%), metastasectomy (n=191, 42%), radiotherapy (n=297, 66%), systemic therapy (n=395, 87%). Ninety-three patients participated in a clinical trial (22%). Patients received a median of 2 lines (IQR 1-3) of palliative chemotherapy; 211 patients (58%) received anthracycline-based first-line treatment. Median duration from start of last chemotherapy until death was 4 months (IQR 2-8). Overall survival was 19.2 months (95% CI:15.8-22.2); lowest OS rhabdomyosarcoma (8.8 months, 95% CI:7.9-11.4). Female gender, absence of bone or liver metastases, and metastasectomy were associated with significantly better survival in multivariate analysis.

**CONCLUSION:** AYA can develop a wide range of STS histological subtypes, including those

more typical in older adults. A high number of patients started a new line of palliative chemotherapy in the last four months of life, representing an aggressive approach to treatment. Overall outcomes were poor for patients in this age group; improved access to clinical trials and novel treatments are needed for this young population.

## P4 A review of the dietetic service provided to TYA cancer outpatients.

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**INTRODUCTION AND AIMS:** The Teenage and Young Adult (TYA) team at Guy's & St Thomas' Hospital provides multi-disciplinary support for patients aged 16-24y with leukaemia, cancer and neurological tumours. The team comprises a haem-oncologist, TYA cancer nurse, psychologist, dietitian, youth support worker and social worker. The dietitian meets and supports all patients referred to the service. We report an evaluation of dietetic support provided.

**METHODS:** All patients are reviewed by the dietitian at diagnosis and at intervals thereafter, irrespective of whether their treatment is active (surgery, chemotherapy, radiotherapy) or observational. Assessment and advice covers diet, lifestyle (smoking, exercise, alcohol) and support to optimise weight. Together with demographics, diagnosis, and treatment, at each visit anthropometrics, current diet, lifestyle, and advice given were recorded. On completion of support, patients completed a feedback questionnaire. This evaluation includes all seen during a 6 month period. Results 83 patients were supported. Tailored advice most frequently covered healthy diet and lifestyle (46%), and/or weight reduction (37%). Some required support to gain weight, either through a healthy yet high-calorie diet (8%) or nutritional supplements (8%). Over 50% receiving weight reduction advice lost weight (mean 6.5kg) and 69% receiving advice on weight gain increased weight (mean 4.7kg). All patients made some diet/lifestyle changes in response to advice. Changes reported included improved balance between different food groups, portion control, adopting a regular meal pattern and limiting unhealthy snacks/drinks. Lifestyle changes included quitting smoking, reduced alcohol intake and increase in physical activity. 88% would recommend the service.

**DISCUSSION AND CONCLUSIONS:** Routine provision of dietetic advice to all TYA cancer patients, irrespective of perceived need, led to a healthier BMI, improved understanding of healthy eating, and support to improve their lifestyle choices. Objective outcomes and patient feedback strongly support this approach to empowering holistic recovery of young adults with cancer.

## P5 Are we failing to meet the gold standard of care for vitamin D deficiency in Teenage and Young Adult (TYA) cancer patients?

**L. Gordon<sup>1</sup>**

<sup>1</sup>TYA Speciality Doctor Southampton, UK

**INTRODUCTION:** Vitamin D deficiency should be identified and treated (NICE 2017) especially in young people (Stagi 2013). Benefits of vitamin D include good bone health, improved mood and muscle strength with a likely but as yet undefined role in cancer prevention and prevention of diabetes, hypertension, metabolic syndrome and infectious disorders (Pearce

2010 Garland 2006).

**AIMS:** To identify the incidence of vitamin D deficiency in TYAs with cancer at a tertiary treatment centre.

**METHOD:** Prospective assessment of 25-hydroxycolecalciferol levels in all inpatients aged 16-25 years old treated on the TYA cancer ward at Southampton General Hospital, who had risk factors. These factors are (NICE 2017) a hospital stay over 2 weeks, poor diet, poor sunlight exposure, high risk skin colour. Findings collected over 11 months. Those patients were offered supplementation and had further monitoring. Results 20 patients were tested and 16 needed supplementation because of insufficiency (25-50nmol/L) in 10 patients; or deficiency (<25nmol/L) in 6 patients. Most patients had haematological malignancies as local management is that they have prolonged stays in hospital for toxicity monitoring.

**CONCLUSION:** Vitamin D supplementation was needed in 80% of the patients assessed in this study. Vitamin D assessment should be carried out in risk groups but this is suboptimal in the UK and there is a lack of education for health care professionals (NICE 2017 and TYAC SDG physician survey 2016). There is also a need for patient education as compliance in this study was found to be a challenge. A further question about the benefits versus risks of keeping patients in hospital for prolonged periods is a topic worthy of further study.

## P6 Adolescent and Young Adult Radiotherapy at the Royal Adelaide Hospital – A Personalised Journey.

**K. Rubinich<sup>1</sup>, J. Swanson<sup>1</sup>, K. Skelton<sup>12</sup>**

<sup>1</sup>Radiation Oncology, Royal Adelaide Hospital, Australia.

<sup>2</sup>YCS SA/NT

**INTRODUCTION:** Approximately half of all cancer patients will receive radiation therapy (RT) treatment over the course of their disease. RT is often not well understood by the public, and patients have indicated that they have little knowledge about it prior to their cancer diagnosis. AYA consumers have distinct physical, psychosocial and practical needs due to the impact of their diagnosis and treatment, and from the developmental phases they are already experiencing.

**OBJECTIVE:** The objective was to establish a core group of RT staff with a specialist interest in the AYA cohort. A staff member would be linked to each AYA patient as a consistent point of contact to guide them through their radiotherapy journey, aiming to ensure the young person felt supported and empowered within an adult radiotherapy treatment environment.

**DESCRIPTION:** It is becoming increasingly recognised that AYAs within the health care system require age-specific services, including paediatric patients requiring treatment in an adult hospital. Our core group includes radiation therapists and nurses with a special interest in the needs of the AYA patient population. A member of the group is assigned to each patient; this "buddy" would act as a consistent point of contact, to aid in education about their treatment and procedures they can expect to undertake in preparation for their radiotherapy.

**OUTCOMES:** The "Buddy System" will positively affect outcomes and enhance wellbeing for AYA patients, their families and friends by promoting access and information sharing by empowering them with individualised information and support.

**CONCLUSION:** The population of AYA's diagnosed with cancer is comparatively small, however their specific needs are substantial and require specialist insight. The role of the AYA individualised care group will be to foster innovation in AYA information, improve AYA service delivery to empower them within the adult treatment environment by supporting them as an individual.

## P7 Crossing the Paediatric and Adult Hospital Divide, P3BEP (ANZUP 1302): An international randomised phase 3 trial of accelerated versus standard BEP chemotherapy for adult and paediatric male and female patients with intermediate and poor-risk metastatic germ cell tumours (GCTs).

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<sup>9</sup>Addenbrooke's Hospital, Cambridge, UK

<sup>10</sup>Yale Cancer Centre, Yale University, New Haven, USA

<sup>11</sup>University of Southern California, Norris Comprehensive Cancer Centre, Los Angeles, USA

<sup>12</sup>St Vincents University Hospital, Dublin, Ireland; Cancer Trials Ireland, Ireland

<sup>13</sup>Australia and New Zealand Children's Haematology/Oncology Group, NZ

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<sup>22</sup>Australia and New Zealand Urogenital and Prostate Cancer Trials Group, Sydney, Australia

**INTRODUCTION:** GCTs are among the most common cancers that affect the adolescent and young adult (AYA) population. In general, AYA cancers are rare. Therefore, to achieve a significant result requires a multicentre approach to obtain adequate patient numbers. Bleomycin, etoposide, cisplatin (BEP) given 3-weekly x 4 remains standard 1st line chemotherapy for metastatic GCTs and it has been shown that acceleration of standard regimen with shorter cycle lengths has improved cure rates in other cancers. We therefore aim to determine if accelerated BEP is superior to standard BEP. This is the first international randomised clinical trial for intermediate and poor-risk metastatic extracranial GCTs involving both adult and paediatric age groups for both males and females.

**METHODS:** Open label, randomised, stratified multicentre, 2 stage, phase 3 trial. Primary endpoint for stage I (n = 150) is complete response rate (RR), and for entire trial (n = 500) is progression free survival (PFS). Sample size: Between 150 and 500 patients gives > 80% power to detect a 20% improvement in RR and 7% absolute improvement in 2yr PFS, respectively. Males and females aged 11-45 years with intermediate or poor-risk metastatic GCTs of the testis, ovary, retroperitoneum or mediastinum for 1st line chemotherapy.

**RESULTS:** ANZUP and ANZCHOG are collaborating with 25 sites open in ANZ, 6/21 sites open in UK (led by Cambridge Clinical Trials Unit), 51 patients recruited by June 2018. International collaborations with USA (led by Children's Oncology Group) and Ireland (led by Cancer Trials Ireland) confirmed. More sites sought for stage 2. ClinicalTrials.gov: NCT02582697

**CONCLUSION:** Lack of participation in clinical trials correlates most highly to the deficit in outcome in the AYA cohort. With the collaboration of paediatric and adult oncology groups it is possible to allow enrolment for the entire age range of AYAs and so potentially improve outcomes.

## P8 Preparation for Bone Marrow Transplant -Heading Down the Highway

L. Moore<sup>1</sup>

<sup>1</sup>Hunter and Northern NSW Youth Cancer Service, Australia

For many adolescent and young adult (AYA) patients allogenic transplant offers the best chance of curing a number of blood and bone marrow cancers and non-malignant conditions. Transplant is considered a complex procedure with significant risk. AYA patients treated at The Calvary Mater Newcastle (CMN) Hospital are referred to Westmead Hospital's transplant unit for specialist care for months and many kilometres from home.

The Hunter and Northern New South Wales Youth Cancer Service (YCS) based at CMN meet the AYA patient at diagnosis completing a comprehensive AYA psychosocial screening tool and nursing assessment. Ongoing engagement prior to transplant increases capacity to implement individualised strategies.

CMN Bone Marrow Transplant (BMT) Cancer Care Coordinator (CCC) is an integral role, ensuring the AYA has all the planning and pre-transplant "work-up" completed and linked with the Westmead BMT CCC.

The YCS team advocate strongly for their patients to have their will and advanced care directive completed and access to financial support.

The YCS team suggests items such as fairy lights, laminated motivational quotes and other meaningful objects to decorate their transplant room making them less clinical. Boredom can be reduced by taking laptops, I-Pads and external hard-drives loaded with movies.

Assessment by the YCS Clinical Psychologist just prior to transplant is part of the pre-work up schedule and consider compulsory. Links with the Westmead YCS team are made to ensure ongoing age appropriate support and advocacy.

AYA patients have greater awareness of the BMT process and are better equipped to manage the long stay in isolation.

Leaving the original treating hospital and embarking on a procedure with such uncertainty and risk requires as much preparation as possible. Implementing practical, physical and psychosocial strategies prior to transplant aims to prepare the AYA patient and their family for the long isolated stay.

## P9 A lost 'voice' of the adolescent . . . was it really lost? A team approach working with two teenage brain tumour patients with tracheostomies.

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**CASE DESCRIPTION:** The poster highlights common themes and difficulties identified by Allied Health (AH) staff working with two teenage brain tumour patients who had tracheostomies.

**Case 1:** 17 year old female with High Grade Posterior Fossa Brainstem tumour, long disease trajectory.

**Case 2:** 14 year old male with High Grade Brainstem tumour, short trajectory.

**DISCUSSION:** There is a paucity of AH literature for teenage brain tumour patients. Current neuro-oncology studies are predominately quantitative as opposed to qualitative; therefore

less specific at guiding AH interventions. Themes identified – Disclosure of diagnosis and prognosis (including early death) to the teenager. Due to disease process, there was a significant decline in body functions and structures which impacted on teenagers' activities and participation. AH intervention was around 'loss,' providing some choice and control back to teenager while considering environmental and personal factors. Conflicting goals of rehabilitation versus palliative care/quality of life models of care guiding AH intervention. Family goals, priorities and coping strategies versus the teenagers' and their emotions – who spoke, who was heard? Adolescents and young adults are technologically driven. Is this a help or hindrance? Key Learnings: The challenge of difficult conversations and providing AH intervention in the absence of prognosis disclosure to the teenager. Traditional AH models of intervention may not be appropriate, therefore, it is essential to have the whole team involved in partnership with the patient and their carers to optimally meet their needs. This can be addressed by: Utilising individualised AH interventions. Acknowledging the challenge of relevant appropriate AH goal setting. Communication challenges in the presence of severe functional decline and therefore teenage loss of choice and roles. The need for further research to investigate and clarify effective evidence based interventions for AH professionals – qualitative analysis as opposed to quantitative analysis is required.

## **P10** Food and eating challenges among adolescents and young adults with cancer undergoing chemotherapy

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**INTRODUCTION AND AIM:** The project focuses on how food and eating challenges (FEC) are addressed in the interaction between adolescents and young adults with cancer (AYAs) undergoing chemotherapy, their next-of-kin, and health professionals (HP) in the clinical practice and in the home setting. This knowledge will be utilized to develop recommendations and youth friendly information materials for social media to support the HP in the guidance of AYAs undergoing chemotherapy and their next-of-kin when facing FEC. The aim is to develop new knowledge on FEC faced by AYAs with cancer undergoing chemotherapy, their next-of-kin, and HP in the hospital and at home.

**METHODS:** The project consists of three sub studies and is based on a qualitative research design inspired by hermeneutic and phenomenological methodology. Data in the first study will be collected both as semi-structured interviews with HP delivering care for AYAs and through participant observation and will take place in the clinical practices at oncology-, the children oncology-, and the hematology -departments at Aarhus University Hospital, Denmark. In order to gain insight into the lived experiences of FEC among AYAs and their next-of-kin, study two is based on individual in-depth research interviews with AYAs and their next-of-kin and will take place in the homes of the AYAs. The third study evolves from the findings in study one and two and focuses on how the findings can inform future actions in healthcare. This will take place in collaboration with both former AYAs with cancer, their next-of-kin and HP. Implications. The project is expected to provide a deeper insight into the ways in which FEC are discussed and handled by the target groups, thereby contributing to a deeper understanding of the special needs of AYAs. By focusing on recommendations, the project will become applicable in the hospital departments, thereby creating value and greater satisfaction for the HP, the AYAs and their next-of-kin.

## P11 **Nasopharyngeal cancer in a teenage Australian male – challenges, team collaboration and complex cancer care**

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**CASE DESCRIPTION:** The diagnosis of a 17-year-old male with advanced nasopharyngeal cancer (NPC) required specialist nursing care from both head and neck and adolescent and young adult (AYA) Cancer Nurse Consultants (CNCs) to ensure holistic care and support for the patient and his family. NPC is rare with an incidence of less than 1 per 100,000 population in Australia - Adolescent NPC is even rarer. Young people diagnosed with cancer have distinct clinical and psychosocial needs which if not addressed, are at greater risk of developing long-term wellbeing problems. This case study will demonstrate the complex and crucial specialist nursing care required at diagnosis, during chemotherapy and radiation therapy treatment and beyond.

**DISCUSSION:** An advanced NPC diagnosis was life-threatening for this young male and the recommended treatment confronted his alternative lifestyle and beliefs. Challenges faced by the patient included upheaval to lifestyle and employment, effect on personal relationships and his burgeoning independence. Sperm preservation and gastrostomy tube insertion were also confronting. Daily lengthy travel for treatment and the management of subsequent side effects resulted in a loss of independence. Family dynamics and role changes within his blended families were evident throughout, particularly when he turned 18 years old and was then able to consent or refuse his own treatment.

**KEY LEARNINGS:** Each member of the extensive multidisciplinary team involved worked collaboratively to provide optimal care for the patient without overlapping or giving conflicting advice. Developmentally appropriate advice and support was given throughout treatment alongside psychosocial support to his family. The consistent working relationship between the CNC's created a meaningful rapport with the patient and encouraged compliance with treatment. Through merging innovative practice between two specialist cancer nurses, this complex case study is an example of working towards excellence in cancer care to maximize the patient experience and his health outcome.

## P12 **Posterior reversible encephalopathy syndrome in patients with acute lymphoblastic leukemia (ALL) during remission induction therapy: a single institution retrospective study**

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**OBJECTIVE:** To investigate the clinical manifestations, imaging features, prognosis evaluation of posterior reversible encephalopathy syndrome in children with acute lymphoblastic leukemia during induction therapy.

**METHODS:** A total of 13 children at the Beijing Children's Hospital were enrolled in this study. The time of PRES, symptoms, imaging characteristics, treatment response and prognosis evaluation were analyzed. Review and summarize the MRI changes in children, while using the Weirs scale and the Wisconsin card test system to assess the children's late IQ and cognition.

**RESULTS:** Among the 13 children, 6 were boys and 7 were girls. The median time for PRES was the 28th days (17-33 days) for chemotherapy. All 13 cases were acute onset, with convulsions as the main manifestation. The MRI of the head of the onset of PRES revealed long T2 signals in the white matter of the brain. There were 8 cases of vasogenic edema (61.5%) and 5 cases of cytotoxic edema (38.5%). Within one month after treatment, the symptoms of all children gradually decreased to disappear. One patient (1.07%) died of severe central nervous system infection after 1 year of treatment, and 3 children (25%) had convulsions. The MRI changes in all children showed that the 15th day of the onset was the extreme phase of the disease, and the MRI was aggravated. The lesions gradually decreased after 1 month. All 12 children (100%) returned to normal in 2 years. All 12 children were currently attending school, and there was no significant difference in intelligence and cognition compared with children without PRES during the same period.

**CONCLUSION:** PRES can occur during the induction treatment of ALL. MRI may indicate occipital lobe lesions. After active treatment, symptoms disappear after 1 month, and MRI lesions restored to normal after 2 years. Children with PRES had no difference in cognition and intelligence compared with children without PRES.

## P13 Targeting the cytoskeletal regulator AFAP1L1 to control sarcoma migration and invasion

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**INTRODUCTION AND AIMS:** Migration and invasion are controlled by the invadopodia, which deliver matrix-degrading enzymes to the invasion interface permitting cancer cell penetration and spread into healthy tissue. We have identified a novel pathway that regulates sarcoma cell invasion in vitro via the molecule AFAP1L1 (Actin Filament Associated Protein-1 Like-1) (Oncogene 35:2098-111), the expression of which is strongly associated with malignant osteosarcoma, liposarcoma and leiomyosarcoma ( $p < 0.0001$ ). We now aim to test if we can regulate AFAP1L1-mediated sarcoma cell migration and invasion through expressing targetable fragments of AFAP1L1 (acting as specific domain inhibitors) in sarcoma cells and undertaking in vitro and in vivo assays. We also aim to see if eliminating AFAP1L1 function in non-sarcoma cells would have any potential harmful effects.

**METHODS:** We have generated sub-clonal lines of the human osteosarcoma cells U2-OS, MG-63 and 143B that stably express different regions of AFAP1L1 as eGFP fusions. The cells are then tested in vitro for proliferation, migration and invasion capacity in an IncuCyteZOOM instrument. Cells are then implanted in to both zebrafish embryos and immunocompromised mice to assay for in vivo migration, invasion and metastasis. We have generated AFAP1L1 knockout mice (using CRISPR/Cas9 technology) and characterized the effects on tissue morphology.

**RESULTS:** Cells expressing a C-terminal fragment of AFAP1L1 show significantly reduced migration and invasion in vitro as well as in zebrafish and mouse in vivo assays. Interestingly, expression of an N-terminal region increased migration and invasion. Knockout of AFAP1L1 had not major effects on viability, but the mice display effects on muscle and lung morphology.

**DISCUSSION AND CONCLUSIONS:** Targeting the C-terminal region of AFAP1L1 has potential for inhibiting osteosarcoma cell migration and invasion. Fully disrupting AFAP1L1 function in normal cells has no major deleterious effects but does show tissue specific alterations.

## P14 A Single Institution Comparison of Treatment Outcomes in Adolescent and Young Adult (AYA) Acute Myeloid Leukemia (AML) Patients Treated in Pediatric and Adult Centers

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**BACKGROUND:** There are data to support that AYA patients with acute lymphoblastic leukemia (ALL) have better outcomes when treated on pediatric inspired protocols, yet limited data exist for AYA patients with acute myeloid leukemia (AML).

**METHODS:** A retrospective study of 33 AYA patients with AML in our institution treated in either the adult (n=20) or pediatric setting (n=13) was completed. Patients in the adult setting received induction therapy with standard 7+3 (cytarabine, idarubicin), while patients in the pediatric setting received an ADE (daunorubicin, cytarabine, etoposide) backbone +/- investigational agents. Data was analyzed using SPSS.

**RESULTS:** Median age was 23 (range 19-25) at the adult setting compared with 17 (range 17-20) at the pediatric setting. Patients at the adult setting were classified as 55% poor risk, 35% intermediate risk, and 10% favorable risk; in the pediatric setting, risk classification was 15% poor risk, 62% intermediate risk, and 23% favorable risk. No patients in the adult setting were enrolled in a clinical trial compared to 54% in the pediatric setting. Complete response (CR) was higher in the adult regimen (85% vs. 62%) with longer median time to relapse (344 vs. 275 days). Median time to stem cell transplantation was shorter in the adult setting (117.5 days vs. 223.0 days). The incidence of relapse post transplantation was higher in the pediatric setting (46% vs. 25%). Median overall survival (OS) was 739.5 days in the adult setting compared to 415 days at the pediatric center (p=0.11).

**CONCLUSION:** Despite a higher risk population and lower clinical trial enrollment in the adult population, there is a trend towards higher CR rate after induction, reduced relapse rate after induction, longer time to relapse post-transplant, and improved median OS in patients treated with adult regimens. Further multi-institutional studies are necessary to understand the optimal AML treatment strategy in the AYA population.

## P15 An University Hospital Ghent Experience: Acute Myeloid Leukemia (AML) in Adolescents and Young Adults (AYAs)

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**INTRODUCTION AND AIMS:** In Belgium 2015, the incidence of leukemia in AYAs aged 15-34 years was 26,15/100000. It has become evident that AYAs diagnosed with AML have different needs compared to their younger and older peers. Limited data exists regarding survival and psychosocial characteristics of AYAs with AML. This life-threatening disease, requiring

immediate aggressive chemotherapy, brings challenges associated with treatment and during survivorship.

**METHODS:** We utilized the haematology department specific AML database to identify AYA patients (age 19 =< 35 years) diagnosed with AML. The medical data set included 20 patients and no AYA patients were excluded from analysis. No Quality of Life (QoL) data was recorded. Kaplan-Meier survival statistics were computed and plotted to present overall survival data.

**RESULTS:** Among 162 adult AML patients treated from September 2013 to March 2017, 20 patients (12,3%) were AYAs with median age of 28.5 yrs. At diagnosis, 4 (20%) patients were included in a clinical trial whereof 1 (5%) patient in control arm and 3 (15%) patients in the experimental arm. Nineteen patients (95%) were treated with intensive chemotherapy and 1 patient received supportive care. Six patients (30%) are still alive. Overall survival (OS) from data entry was 39,4% for the total cohort. **DISCUSSION AND CONCLUSIONS:** Despite good access to medical care, there is still room for improvement in survivorship outcomes. Our analysis shows limited overall survival numbers among AYAs treated for AML. More effective strategies are needed to improve access and inclusion of AYA patients in clinical trials, as they are currently under-represented. Awareness for age-specific needs is crucial in AYA cancer care. Therefore psychosocial age-specific aspects are important and should be included in the specific AML database for the use in future QoL improvements.

## P16 Co Creation methods to develop the best future for Dutch AYA

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**INTRODUCTION:** Compared to children and older adults with cancer, adolescents and young adults with cancer aged 15-39 (AYA) struggle to find care that is adjusted to their age (Zebrack, 2012). Involving them in co-creation (Sanders, 2012), using collective creativity, to improve the design of care (Sanders, 2010) can be very useful (Elsbernd, 2018). However, it remains unclear what co-creation methods are best used to develop healthcare services and products for AYA and how the use of co-creation results to improve services and products.

**AIM:** To get a better understanding of co-creation methods in AYA care and research projects of the Dutch 'Young and Cancer' Platform by examining the experience of the organisers and the participants of Dream Team projects. Dream Teams have been created to work on various unmet care needs for AYA with cancer, in order to improve age-specific care. See 'Me and my' AYA themes (see Figure 1). A Dream Team consists of AYAs and (care) professionals who have expertise on a specific theme. The team works equally together and integrates all experiential expertise and professional expertise on a project basis. The Dutch AYA platform uses co-creation in these projects.

**METHODS:** The use of co-creation is analysed with the CIMO framework. This framework looks at the context (C), intervention (I), mechanism (M) and outcomes (O) of the method (Denyer, 2008). Qualitative interviews with participants of co-creation design practices of the Dutch 'Young and Cancer' Platform as AYA cancer patients, informal caregivers and health care professionals will be conducted.

**RESULTS:** Co-creation methods used in Dream Team projects will be mapped upon the CIMO framework to understand what mechanisms of co-creation were successful. Preliminary results will be presented at the conference.

## P17 CBT-Based Group Therapy Implementation for AYAs

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**INTRODUCTION AND AIMS:** Previous research has demonstrated that AYAs report higher levels of psychological distress compared to same-aged controls (Kaul et al., 2017) and (older) adult cancer survivors (Lang, David, & Giese-Davis, J., 2015; Stava & Lopez, Vassilopoulou-Sellin, 2006). Furthermore, AYAs frequently report feelings of isolation and alienation (Newby et al., 2000) and poor social functioning compared to population norms (Husson et al., 2017). Prior studies have demonstrated positive effects of AYA peer support groups (Adler, 2008). The current study outlines and evaluates implementation of a group therapy protocol.

**METHODS:** An outpatient psychotherapy clinic housed in an outpatient cancer center offered a 6-week closed psychotherapy group, specifically designed for and advertised to young adults, and facilitated by a psychologist.

**RESULTS:** The identified cognitive behavioral therapy group protocol was informed by research and the unique challenges faced by AYAs. The group utilized a 6-week cognitive behavioral therapy format outlined below. Session 1: Group guidelines, personal cancer stories, new CBT skill (CBT Model), introduce homework (Emotion & Behavior Tracking) Session 2: Homework Review, new CBT skills (Behavioral Activation; Progressive Muscle Relaxation), introduce homework (Daily Activity Diary) Session 3: Homework Review, new CBT skill (Identifying Cognitive Distortions), introduce homework (Simple Thought Record) Session 4: Homework Review, new CBT skill (Cognitive Restructuring), introduce homework (7-column Thought Record) Session 5: Expert AYA medical panel Q&A Session 6: Homework Review, new CBT skill (Healthy Sleep Habits), introduce homework (Sleep Diary)

**DISCUSSION AND CONCLUSIONS:** Barriers to implementation included consistent attendance, variability of patients' psychological needs, and logistics (i.e. time and frequency of groups). Unexpected positive outcomes were the willingness of patients to personally engage in group therapy and the desire for ongoing group follow-up. Future studies should focus on identifying the effective components of CBT group therapy and additional models of service delivery.

## P18 The AYA DAY: An All-in-One Psychology, Exercise, and Dietitian Service Delivery Program

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**INTRODUCTION AND AIMS:** AYAs demonstrate unique psychosocial needs. For example, AYAs report higher levels of psychological distress compared to adults (Lang, David, & Giese-Davis, J., 2015; Stava & Lopez, Vassilopoulou-Sellin, 2006) and exhibit poorer observance of healthy

eating and physical activity recommendations (Berdan et al., 2014 & Demark-Wahnefried et al., 2009). Psychological distress may decrease treatment adherence, and poor diet and exercise regimens are related to cancer recurrence. The current program involved a monthly AYA group program to target psychological distress, improve dietary practices, and increase exercise engagement.

**METHODS:** AYA cancer survivors participated in group services with a psychologist, dietitian, and exercise specialist. Services were offered consecutively, on one day each month at an outpatient cancer center.

**RESULTS:** The services were created based on a literature review and were offered in the group format outlined below. Group Therapy: AYAs participated in a 90-minute group focused on sharing struggles with cancer and teaching a new cognitive behavioral therapy skill (i.e. behavioral activation, assertiveness, cognitive restructuring, etc.) to reduce AYA-specific distress. Group members practiced the skill and identified areas for application. Cooking Class: AYAs participated in a 120-minute, Registered Dietitian-facilitated, hands-on cooking class that utilized "teach back" plate presentations and a nutrition lesson. Yoga Class: AYAs participated in 10 minutes of meditation, 30 minutes of yoga instructed by a certified Yoga Therapy for Cancer Survivors instructor, and 15 minutes of Yoga Nidra by an iRest Yoga Nidra facilitator.

**DISCUSSION AND CONCLUSIONS:** The current program addressed AYA psychological distress and health needs by providing cost-effective resources, a routine program to build social support, and incorporate appropriate intervention. Positive outcomes were willingness of patients to personally engage in future psychosocial care. Barriers to implementation included identifying effective marketing strategies, patient commitment, consistent attendance, variability of patient needs, and logistics.

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## P19 A Mindfulness Based Intervention for teenagers and young adults with a diagnosis of cancer

**INTRODUCTION:** Teenagers and young adult (TYA) survivors of cancer are more likely to be given a clinical diagnosis of depression, anxiety or post-traumatic stress when compared to controls. Studies with adults show mindfulness based interventions are effective in reducing low mood and anxiety. However, only one study has shown similar effects for TYA.

**METHOD:** This was a new clinical service for TYA at UCLH. Eleven young people (aged 14-24), who had completed active cancer treatment, attended an introductory session followed by an 8 week Mindfulness based stress reduction (MBSR) course. Each session lasted 1.5 hours. Participants practiced meditation at home in-between sessions. Participants completed a WHO well-being and a Mindfulness day-to-day experience questionnaire, at their first and last session. Qualitative data was collected, using a semi-structured interview at the last session and a focus group at 3 months follow up.

**RESULTS:** The results show that those who attended 5 or more sessions showed improvements in their well-being ( $p < 0.005$ ) which is protective against receiving diagnoses such as anxiety, depression and post-traumatic stress.

**DISCUSSION:** It is notoriously difficult to get a group of TYA to attend an on-going group. 7 TYA attended this group. Their well being scores improved significantly. They reported that they learned that 'Stress can create physical symptoms', 'the mind and the body are linked', and how to 're-find my balance'. We will be presenting further results from the 3 month follow up as well as how the traditional Mindfulness course was adapted for this population.

## P20 Survey results of primary oncology providers regarding the value of an adolescent and young adult oncology program and barriers to referral.

E. Cull

**INTRODUCTION AND AIMS:** Adolescent and young adult (AYA) oncology patients require specialized supportive care which can be difficult for primary oncology providers (POP) to fulfill during a busy clinic. Our AYA program ensures core metrics including fertility preservation, genetics referrals, clinical trial applicability and supportive care services are discussed. In this study, we surveyed POP attitudes regarding the added value of an AYA program to patient care as well as barriers to program referral. **METHODS:** An 8-item investigator developed survey was distributed to 33 POPs that provided care for 289 AYAs from September 1, 2016 to September 1, 2017. The survey evaluated the POP's estimation of the value of the AYA program, referral patterns, barriers to referrals, and suggested areas of improvement.

**RESULTS:** A total of 27 surveys were completed (82% response rate). 100% of participants agreed an AYA program was valuable to patient care. 100% agreed a survivorship care plan was important. 73% did not think they personally reviewed all that was discussed in the AYA clinic; 8% were neutral and 17% responded that they were covering all that was addressed in the AYA clinic. Overall referral rate to the AYA clinic was approximately 39% of eligible patients. Most commonly reported reasons for not referring patients included the POP not remembering to discuss the referral, patient refusal and travel restrictions. Excluding AYA discussions, POPs had documented discussions regarding fertility and genetics in 31% and 23% of patients, respectively.

**DISCUSSION AND CONCLUSIONS:** POPs agree the AYA program addresses unmet clinical needs and is valuable to patient care. Rates of documented discussions regarding fertility and genetic counseling remain low, emphasizing the continued need for dedicated interventions for AYAs. Additionally, we identified barriers for referral to the AYA clinic allowing for development of targeted interventions to improve provider awareness and referral rates.

## P21 Case Study: Piecing Together the Patchwork Quilt of AYA Programming

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

administrative model has been created to implement the program. Additionally, obtaining the resources to provide these AYA services has been a patchwork of external and internal funding by complementing internal resources with targeted grant and philanthropy funds.

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

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

## **P22** Helping Adolescents and Young Adults with cancer to "normalize" their social contacts: Study into the effects of the AYA Match App

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**INTRODUCTION AND AIMS:** Adolescents and young adults (AYA) with cancer experience a significant shift in social relationships during and after treatment. AYA cancer patients are at serious risk of poor social functioning up to at least 2 years after diagnosis. Qualitative research shows that over half of AYAs are interested in social support through an online intervention. In response to this, the Dutch National AYA 'Young & Cancer' Platform co-created mobile application 'AYA Match app' with potential users (patients, peers). The Match app focuses on open and mutual communication, connection and compassion between AYAs and peers, through different features of the application (e.g. Rules to Play, Activities). The aim of the study is to evaluate the app in terms of perceived helpfulness and to examine the effect of the app on social functioning in both patients and their peers.

**METHODS:** Users of the application are invited to participate in a longitudinal questionnaire study with 3 assessments: before use, 12 weeks and 6 months after first use of AYA Match. Main outcomes are social support, social functioning and usefulness of the application.

**RESULTS:** Up till 2 July 2018, 62 AYA-patients (88% female; 17-38 years) were enrolled in the study. Preliminary results show that 75% of the AYA cancer patients indicate to struggle with the fact their peers avoid getting in contact with them, and 58% felt uncomfortable taking part in social activities: "I feel alone at times because peers don't get me. Awkwardness is key in most conversations. People don't know what to say to me, which is very unpleasant since I notice it either way."

**DISCUSSION AND CONCLUSION:** At the AYA conference in December, we will be able to show the baseline results of the study, as well as promotion- and demonstration videos of the application.

## **P23** Beyond Protocols: A Psychosocial Program for Hematopoietic Stem Cell Transplant Patients and Families

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**INTRODUCTION AND AIMS:** Pediatric Hematopoietic Stem Cell Transplant (HSCT) can be an isolating experience. Post-transplant patients are unable to attend school or public

venues. They have limited social interactions with their peers who often cannot relate to their experiences. We proposed developing a psychosocial program in which HSCT patients and families can attend social events with peers who have been through similar life experiences. The purpose of this program was to foster peer interaction and develop bonds between HSCT patients and families.

**METHODS:** In 2016 a multidisciplinary committee was created to organize and plan events for HSCT patients at Texas Children's Hospital. Since its inception our committee has planned and hosted 3 overnight teen lock-ins, a long term survivor (LTS) challenge day, a family carnival, and a quarterly teen night, with all projects slated to continue and more to be added.

**RESULTS:** We have received 96% positive feedback from both parents and patients with regard to the events and the impact that the events have had.

**DISCUSSION AND CONCLUSIONS:** We have found that in order to have a sustainable psychosocial program there is a need to have multidisciplinary staff involvement. Having a program of this nature has a positive psychosocial impact on patients, families and staff. Therefore, it would be beneficial for a program like this to continue and expand.

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**P24** **Improving the Minimum Standard of Psychosocial Care within the Private Healthcare System in Australia – Impact of Patient's Voice**  
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<sup>1</sup>Queensland Youth Cancer Service's Youth Advisory Group

Adolescents and young adults (AYA) with cancer are treated in public and private hospitals across Australia. To initiate discussions within the private healthcare system, to ensure the implementation of a minimum standard of age-appropriate psychosocial care for AYA oncology patients. As a member of both the National and Queensland Youth Cancer Service's Youth Advisory Groups, I've had the opportunity to regularly meet with AYA patients around Australia, who've received treatment in both the public and private hospitals. Furthermore, I can draw upon my own personal experience; after being diagnosed with Acute Lymphoblastic Leukaemia at 17 years. I've identified a fundamental issue where the psychosocial needs of AYA patients are not being addressed in many private medical institutions. AYAs treated within the private healthcare system are often left with varying levels of unmanaged distress. Transitioning between childhood and adulthood places unique stresses and experiences on the AYA cohort. This often leaves them feeling distressed, isolated and emotionally unstable. Only recently have these unique psychosocial needs been identified. This has been acknowledged by the Federal Government, who allocated CanTeen \$32.88M to develop the National Youth Cancer Services since 2008. These services were initially guided by the National Service Delivery Framework (2008) and now the Australian Youth Cancer Framework (2017). Staff within the National Youth Cancer Services utilise the Adolescent and Young Adult Oncology Psychosocial Care Manual as the foundation tool for the psychosocial assessment and engagement with AYA patients. As there is a framework for AYA care in the public system, and a need for improved psychosocial care in the private system, it's imperative that the private healthcare system adopts a minimum standard of psychosocial care. By doing this, the best outcomes for AYA patients will be achieved, regardless of where they receive their treatment.

## P25 Health Related Quality of Life (HRQoL) Assessment in a Growing Adolescent and Young Adult Oncology Clinic with PROMIS-29

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**INTRODUCTION AND AIMS:** HRQoL assessment at point of care is essential in addressing disease effects and patient needs in oncology. We incorporated the increasingly used, NIH endorsed, Patient-Reported Outcomes Measurement Information System (PROMIS®) to precisely determine areas of need across various domains, intervene appropriately, and make systematic changes to treatment of AYAs in the Greenville Health System AYA Program. This is among the first reports presenting the use of expanded PROMIS surveys in AYAs focusing on specific areas of psychosocial and physical function.

**METHODS:** AYAs completed PROMIS-29 v2.0 Form. Scores were generated for subscale areas including physical function, anxiety, depression, fatigue, sleep disturbance, social roles/activities, pain interference, and pain intensity using established population means and scoring algorithms (mean=50, Standard deviation (SD)=10). Scores 0.5-1.0 SD worse than the mean were considered mild impairment, 1.0-2.0 SD worse were considered moderate impairment, and greater than 2.0 SD were considered severe impairment.

**RESULTS:** 71 patients completed the PROMIS surveys (mean age: 31.6 years). Mild symptoms/impairment were identified in >25% of patients in all measured domains. The areas with the greatest percentage of affected patients were anxiety, physical function, and pain interference with >50% of patients reporting at least mild symptoms/impairment. Moderate to severe symptoms were reported by 30% of patients in anxiety and physical function and by 27% in pain interference. Symptoms/impairment are present in domains of both physical and mental function.

**DISCUSSION AND CONCLUSIONS:** The PROMIS measure can effectively and precisely identify areas of need/impairment in AYAs across domains consistent with published reports using other tools. We have incorporated this point of care tool into our practice to treat and support AYAs. Further study is ongoing to determine the effects of patient and disease related factors on PROMIS scores to help the GHS AYA program improve care for this underserved patient population.

## P26 Expanding assessment of psychosocial needs of AYA patients in a new AYA Oncology Program

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**INTRODUCTION AND AIMS:** A growing patient population at the Greenville Health System (GHS) AYA Oncology Clinic has allowed for expansion of our previous study (Phillips et al) utilizing the Zebrack survey identifying psychosocial needs. Our goal is to use this data to continue program development and improve care by focusing on identified psychosocial needs.

**METHODS:** Patients at the AYA Oncology program at 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 107 patients are presented.

**RESULTS:** Significant needs in the entire group included CAM (59%), camps/support groups (50%), cancer education (56%), nutrition/exercise (60%). Compared with other groups (mid-AYA:46%, late-AYA:33%), early-AYAs reported higher interest in fertility (63%); financial needs were higher in mid-AYA (50%) compared to early/mid-AYAs (early-AYA:25%, mid-AYA: 45%); early/late-AYA reported personal counseling needs (early-AYA:50%, late-AYA:50%). Support group needs increased with each age group (early-AYA:13%, mid-AYA:29%, late-AYA:52%).

**DISCUSSION AND CONCLUSION:** Compared to the previous study, this data suggests that the psychosocial needs experienced by this population have not significantly changed. These data are used for further development of resources and interventions for AYA patients focused on addressing the need for counseling, support groups, financial toxicity, CAM, fertility, cancer education and nutrition/exercise.

## P27 Young people's lived experiences of cancer: An Interpretative Phenomenological Analysis

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**INTRODUCTION AND AIMS:** Being diagnosed with cancer can be a traumatic and life changing event at any life stage. However, receiving a diagnosis during adolescence and young adulthood carries extra significance given the complicated task of navigating a variety of developmental milestones. There is currently a dearth of research exploring young people's lived experiences of cancer in the United Kingdom (UK). The present study aims to build on existing research by using Interpretative Phenomenological Analysis (IPA) to explore the lived experiences of young people aged between 13-24 years.

**METHOD:** An interpretative phenomenological analysis (IPA) was undertaken with six young people (13-24 years) with a recent diagnosis of cancer. Participants were recruited from two large regional cancer centres within Birmingham. Semi-structured interviews with six young people were audio recorded, transcribed and analysed in line with the IPA methodology.

**RESULTS:** Three superordinate themes emerged: 'A natural injustice', 'Get ready for battle: Cancer as an adversary to youth' and 'The upside down: A parallel universe'. Within each superordinate theme lay several subordinate themes, portraying the complex and often demanding picture of what it is like to live with cancer as a young person in the UK.

**DISCUSSION AND CONCLUSIONS:** From comprehending a life with cancer, to coping with the adversarial nature of treatment, young people navigate a host of trials and tribulations, questioning their identity and the world in which they have been propelled into. Demonstrating resilience and resolve young people reflected on how such experiences had contributed to a new sense of purpose and meaning, all of which was driven by a determination to survive and overcome their condition. Clinical and service implications, together with areas for future research are discussed.

Keywords: Adolescence, Young adults, Young people, 13-24, diagnosis, treatment, cancer, Phenomenological, IPA

## **P28 Psychosocial Issues for Adolescent and Young Adult (AYA) Cancer Patients in a Global Context: A Forward-Looking Approach**

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The first decade of adolescent and young adult (AYA) oncology psychosocial care and research (2005-2015) was driven by a normative, developmental framework that assumed a generalizable life experience for AYAs that is distinct from both younger children and older adults. As we proceed through a second decade, new considerations emerge regarding diversity of life experiences as occurring within and influenced by a complex global context. The purpose of this literature review is to survey the impact of global and contextual conditions on AYAs and provide commentary on the anticipated future of AYA psychosocial care. We expound upon the effects of precarious labor conditions, changing timetables and priorities for developmental tasks, sexual and gender plurality, and expanding cultural diversity. We discuss the implications of social genomics and technology and social media for enhancing precision psychosocial medicine. To build a forward-looking approach, this paper calls for tailored multilevel interventions, treatment plans designed by a precision psychosocial medicine framework, and critical use of information technologies and social media. In each of these discussion points, we foreground the variability of AYAs within the social and global contexts in which they live, using diverse lived experiences of the AYA as a cairn for the future of their psychosocial care.

## **P29 Distributed health literacy and decision-making in adolescents and young adults with cancer: a systematic review**

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Health literacy represents a pre-requisite to empowerment and participation in health-related decision-making, yet health literacy and decision-making remain largely understudied in the adolescent and young adult with cancer (AYA) population. Given the distributed nature of health literacy skills across an individuals' networks, parents and families may serve as mediators to improve AYAs' health literacy skills, or to compensate for poorer health literacy. Health decisions also routinely involve AYAs, their parents and healthcare professionals. The objective of this review was to identify empirical research studies that address how AYAs, and/or their families are involved in information sharing and the process of decision-making about the AYAs healthcare. Systematic literature review was conducted using PsycINFO, MEDLINE, EMBASE and CINAHL. Duplicates were removed and articles screened for exclusion criteria. Peer-reviewed studies discussing the decision-making process in AYAs and/or their families were eligible for inclusion, as were studies addressing information sharing, decision-making

preferences, and health literacy within this group. Data was extracted using Endnote and appraised by two independent raters. Findings were synthesised thematically. A total of 7273 studies (after removing 1801 duplicates) were screened using title and abstract. Of those, 706 full text studies were screened, resulting in a final list of 33 studies to be assessed for quality. Of the 33 studies, 19 were qualitative, 12 quantitative and 2 mixed-methods research. Preliminary themes derived include: AYA self-management, the process of information sharing, decision-making preferences, empowerment in treatment decision-making, and family involvement in the decision-making process. To our knowledge, this is the first systematic review providing a comprehensive summary of the evidence regarding the information sharing and decision-making process in the AYAs. Elucidating the nature of family involvement in AYAs decision-making process is particularly relevant, as many parents/families may facilitate communication and serve as mediators to improve or compensate for AYAs' health literacy skills.

### **P30** Age-appropriate psychosocial support is imperative for Adolescents and Young Adults with Cancer (AYAO)

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**INTRODUCTION AND AIMS:** AYAO constitutes a vulnerable group with unmet needs. They are unable to have a typical growing up experience due to their circumstances. It is important to have an age-appropriate support group to create a safe environment to normalize their cancer experience. However, it was absent in Singapore. In order to understand their needs, it is critical to hear directly from them. From their responses, it would then be possible to have a support group with targeted age-appropriate activities for them.

**METHODS:** National Cancer Centre Singapore organized its first AYAO Support Group Event. Patients between the ages of 16-39 years old were invited to attend a half-day session that included an AYAO-specific talk, a panel discussion about AYAO-specific psychosocial needs and an interactive gaming activity. At the end of the event, participants were given feedback forms to aid organizers in getting a better understanding of their needs and interests. In addition, it will help provide organizers with information on activities relevant to AYAO.

**RESULTS:** Out of 37 participants, 20 responded with their feedback. The majority found the event beneficial and enjoyable. Up to 90% found the talk and panel discussion helpful, while 95% enjoyed the activity organized. Topics of future interest included financial subsidies, caregiver support, reintegration after treatment, nutrition and psychosocial issues. More than half also preferred interactive and hands-on activities such as culinary classes. There was also feedback from participants requesting for more frequent events.

**DISCUSSION AND CONCLUSIONS:** AYAOs are dealing with diseases that are life-threatening and life-limiting. An age-appropriate support group with patient-directed activities aims to give them back the control and provide them with psychosocial support during their treatment, survivorship and end-of-life journey. Positive feedback from this event shows more can be done in this area, providing an insight into the needs of AYAOs.

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### P31 The integration of a Wellbeing service (WBS) into local Teenage and Young Adult (TYA) Cancer Care.

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**INTRODUCTION:** There is increasing evidence that psychological difficulties experienced by young people (YP) (aged 16-29) are a very significant part of their cancer journey. Evidence demonstrates these can cause health related issues at a later date, as well as impacting their ability to thrive.

**AIMS:** The TYA WBS aims to integrate local and adaptable psychological support into a local TYA cancer service at a designated TYA hospital in Surrey, UK. This includes Level 3 psychological support and interventions from diagnosis onwards. It offers more practical methods such as mindfulness and some complementary therapies. It aims to make therapy more accessible to the young people by offering different approaches and formats for therapy, e.g. activity weekends to boost confidence and self esteem.

**METHODS:** The Distress thermometer enabled quantitative measurement of levels of anxiety and distress together with recording incidences of referrals to clinical psychological services in the 2 years after diagnosis. Patient narratives were also used to evidence outcomes of this intervention as part of a semi structured questionnaire.

**RESULTS:** Using the distress thermometer within the WBS shows YP reducing their anxiety and distress scores by 80% over a 2-3 month period.

90% of patients felt more able to self manage their anxieties following referral to this service.

**DISCUSSION:** The psychological adjustment disorders worked with in the TYA WBS include psychosocial distress, anxiety, depression, fear of uncertainty, loss of personal identity, existential issues based on fear of own mortality and other cancer-related anxiety. Research demonstrates that the emotional factors of the YPs cancer journey significantly impacts cancer outcomes.

**CONCLUSION:** The TYA WBS is about working preventatively to reduce both the psychological healthcare risks and the wider health risks cancer can have on the YP. The service provides a robust, psychological support framework to support the YP wellbeing from diagnosis onwards. This can significantly reduce the risk of any early non-clinical psychological distress developing into a subsequent clinical mental health issue.

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### P32 "Coordinate My Care" digital urgent care plans for adolescent and young adults

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**INTRODUCTION:** Coordinate My Care (CMC) digital urgent care plans communicate patients' wishes and key urgent care information to frontline clinicians at times of need including, crucially, out of hours (two thirds of the week). CMC digital urgent care plans provide valuable patient information to paramedics, GPs, NHS 111, London Ambulance Service and clinical staff in emergency departments. CMC is used at The Royal Marsden hospital however had not yet been introduced in the adolescent and young adult (AYA) service. Recent work with staff and AYA patients identified the need for an electronic care plan to share with their local hospital and GP (Weston et al, 2018).

**AIMS:** Improve AYA patient experience by involving them in creating an urgent care plan. Help patients feel more in control by being able to view their urgent care plan on a digital device. Improve communication between the hospital and community services and during an emergency episode.

**METHODS:** Focus groups for AYA patients will be held prior to and after having created a CMC urgent care plan to identify if CMC enhanced patient experience. CMC reporting will be accessed to find out if CMC record was used by urgent care services.

**RESULTS:** Thematic analysis of AYA patient views on and experience of using a digital care plan. Project engagement, i.e attendance at events. Use of CMC digital care plans by urgent care services

**DISCUSSIONS AND CONCLUSIONS:** Results pending, to follow final focus group July 2018

**REFERENCES:** Weston C, Soanes L, Chisholm J, Wiseman T. "Out There": Developing a transition pathway for adolescents and young adults with cancer using Experience-Based Co-Design. *JHD*. 2018;3(1):75–83. <https://doi.org/10.21853/JHD.2018.42>

### P33 Caring for the whole patient: The assessment of psychological wellbeing in Teenagers and Young Adults with cancer, a systematic review

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**INTRODUCTION:** Young people with a diagnosis of cancer have unique needs, especially with their psychosocial wellbeing from diagnosis through survivorship. Evidence of psychosocial assessment tools suitable for use in this population, used in healthcare settings, is lacking. The aim of this systematic review was to identify psychosocial assessment tools used in international healthcare settings with young people aged 15-25 with a diagnosis of cancer.

**METHODS:** Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed. Inclusion criteria were young people aged 15-25 years old living with or beyond cancer, identified/recruited by a healthcare professional at a healthcare setting; papers were published between 2000-2018 and a primary or secondary aim included results from a psychosocial measurement. Papers were included if the overall population was older or younger but 15-25 year olds were the identifiable subset of the sample. 18,974 titles and abstracts were screened, then 118 full text articles, with seven articles meeting inclusion criteria. Forwards/backward searches were conducted, with a further two articles selected.

**RESULTS:** The majority of articles were with young people living beyond cancer and only two with young people receiving treatment. Few studies examined only young people and often they were included in populations with older age ranges. Participants were recruited either from hospital databases/national survivor registries or from hospitals/clinics for active treatment or follow-up care. Anxiety, depression, and distress were the psychosocial aspects most often measured.

**DISCUSSION AND CONCLUSIONS:** Young people living with or beyond cancer are infrequently recognised as a population with distinct needs for specific psychosocial assessment tools. Results indicate that young people are often examined in conjunction with children or middle/older-aged adults instead of as a discrete population. Research is needed to determine if

this population would benefit from psychosocial assessment tools tailored to young people's specific needs.

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### **P34 Implications for AYA testicular cancer survivors on sexual function**

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**CASE DESCRIPTION:** Patient X is a 24 year old male diagnosed with metastatic testicular cancer. He has a partner, no children and is in full time employment. He also competes in martial arts.

**TREATMENT:** Patient had a left orchidectomy followed by chemotherapy which consisted of Bleomycin, Cisplatin and Etoposide (BEP). The commonly reported side effects are alopecia, fatigue and nausea. However, X was most troubled by reduced libido, erectile dysfunction, gynecomastia and muscle weakness. Prior to treatment X was counselled about potential impact of fertility and sexual function. Importantly he was referred to the andrology clinic for sperm banking and received counselling from a psycho-oncologist.

**DISCUSSION:** Various cancers and their treatments can cause short and long term effects on sexual function and fertility in AYAs. X's cancer subtype was hormone-secreting and caused local pain. He experienced physical changes from orchidectomy and chemotherapy. He was diagnosed with primary hypogonadism as a result leading to reduced libido and erectile dysfunction. This caused embarrassment and relationship tension. It is important that a multidisciplinary approach is implemented to ensure these issues are well managed. The oncology team, surgeons and nursing staff should ensure that the patient is well informed of treatment side effects including sexual dysfunction. Psychologists can provide sexual health and couples counselling. Endocrinologists and fertility specialists are engaged to treat hormone deficiencies and coordinate conception planning. Patient X was well supported throughout his cancer journey by this care model.

**KEY LEARNING:** The impact of cancer and its treatment on sexual function in young patients should be recognised. Patients should be well informed of side effects of cancer treatment, both surgical and medical including those pertaining to sexual health. A multidisciplinary model of care is an effective strategy for young patients with sexual dysfunction.

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### **P35 To TESE or not to TESE...That is the question**

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19 year old healthy male presented with a subacute history of low back pain, progressive bilateral lower extremity weakness/sensory changes, and right cranial nerve VII palsy. Initially diagnosed with a "pulled muscle" in local ER, had xrays and was told by a chiropractor that he had a "pinched nerve". Initial labs showed an elevated LDH, otherwise normal. MRI spine showed a retroperitoneal and paraspinal mass that entered the canal and was compressing the cord and the thoracolumbar junction; MRI Brain showed a right temporal soft tissue mass, and focus of enhancement involving the 7th cranial nerve. PET/CT showed enhancement of above lesions, but also an intense hypermetabolic lesion of the right testicle, left testicle normal; confirmed by ultrasound. After consultation our Fertility and Reproductive Health team, a multidisciplinary effort successfully coordinated and procured viable sperm via TESE of

the left testicle under conscious sedation, in addition to performing diagnostic bone marrow biopsies before initiation of urgent chemotherapy. As survival rates for adolescent and young adult (AYA) cancer patients improve, fertility preservation is gaining increased attention. A majority of AYAs report 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 resources as reasons for not providing counseling. Fertility preservation among post-pubertal males is straightforward, although in some AYA patients, pain limiting ability to ejaculate, neurologic dysfunction due to tumor mass, or tumor involvement of the testicle may make this difficult. Testicular sperm extraction (TESE) can be performed safely prior to initiation of chemotherapy without delaying definitive cancer treatment. This case demonstrates that sperm cryopreservation can be successfully performed in an acutely ill AYA male with unilateral lymphoma involvement of the testicle, prior to initiation of emergent chemotherapy.

### **P36 'Does that mean that cancer patients can't have sex?' - Adolescent and young adults' support and information preferences (workshop II)**

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**INTRODUCTION AND AIMS:** Young people with cancer exhibit unique needs, in particular the impact of a cancer diagnosis at an age where body image and sexuality are becoming of increasing importance. This study expands on previous findings showing that young people exhibited significant unmet needs around information provision on sex, body image, and relationships (Martins et al. 2018). We now explore information and support preferences regarding where, how, and from whom young people want to receive information on sex, body image and relationships.

**METHODS:** Four young people aged 24-26 years, with a previous cancer diagnosis aged 14-23 years attended an in-depth four-hour workshop. Participatory activities were employed to identify the questions young people had; their support preferences; and, their definition of intimacy. The framework approach was used to analyse workshop transcripts.

**RESULTS:** Young people's preferences of information provision varied. They wanted trusted sources of information and while some preferred to have face-to-face discussions with healthcare professionals, others felt embarrassed and would prefer an online platform. All acknowledged that listening to peers with cancer talk about sexuality and relationships would 'normalise' their questions. Feeling embarrassed (both professionals and young people) was a barrier to an open discussion about their needs. Triggers for information and support needs included: partners (pressures/expectations), lack of sexual drive (managing side effects), body image (weight gain/loss, scars), physical constraints ('What positions can I do now?'); fertility concerns. They wanted access to information tailored to their needs.

**DISCUSSION AND CONCLUSIONS:** Knowledge of sexuality, interpersonal relationships, and body image concerns has an impact on the development during this transition period into adulthood (Dobinson et al. 2016). Findings from this study highlight cancer-specific relationship and body image issues faced by young adults and provide important direction to the development of interventions – a balance between professional and peer support is needed.

## P37 Fertility Preservation education - trying to share the “Sperm Queen” title

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**INTRODUCTION AND AIMS:** All patients undergoing cancer treatment should be aware of the impact of treatment on their fertility before they consent to treatment but especially for adolescent and young adult cancer (AYA) patients aged 15-25 years. Specific age related information needs to be provided in a sensitive way so that AYA patients understand their options and make decisions that may impact them for many years to come. So who is responsible for this information and how do we ensure that the topic is covered before treatment begins? This is one hospitals' experience of implementing a series of measures to enhance fertility preservation discussions, with the aim of improving clinician's knowledge and confidence around fertility preservation discussions.

**METHODS:** A retrospective audit was undertaken looking at fertility preservation discussions, referrals to fertility specialists and documentation. The results indicated there was a lack of formal discussions or documentation of such discussions so a multi-targeted approach to increasing information, knowledge and confidence for clinical staff was developed. A formal work instruction was written, regular in-service sessions were held with in-patient and ambulatory staff to highlight the need for involvement in fertility discussions by all staff and the youth cancer nurse provided training for colleagues within the specialist cancer nursing team.

**RESULTS:** A survey of nursing staff highlights the self-reported improvements in knowledge of fertility preservation and their confidence in having discussions with patients and staff around this topic.

**CONCLUSION:** Fertility preservation for any child-bearing age patient undergoing cancer treatment needs to be discussed prior to therapy. A multi-targeted approach from the youth cancer position at one hospital aims to improve clinician's knowledge and experience in discussing this sensitive topic and has developed formalised approaches to fertility discussions, referrals and documentation.

## P38 Hope, burden, or risk: A discourse analytic study of the construction and experience of fertility preservation in the context of cancer

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**INTRODUCTION AND AIMS:** Infertility is a significant concern for people with cancer and fertility preservation is often recommended. However, uptake of preservation interventions remains low. In this study, we examined how people with cancer construct their subjectivity – their sense of self – in relation to decision making and processes of fertility preservation.

**METHOD:** Six-hundred and ninety-three women and 185 men completed a self-report survey; 61 women and 17 men participated in semi-structured interviews. Subject positions adopted in relation to constructions of fertility preservation in transcripts and open-ended survey responses were examined using thematic decomposition.

**RESULTS:** Three main discursive themes were identified: 'limited agency and choice, or resisting

risk: not taking part in fertility preservation', 'Fertility preservation as a means to retain hope and control', and 'Fertility preservation as uncertain and distressing'.

**CONCLUSION:** It is important for health professionals to provide accurate information, acknowledge the complexity of fertility preservation, and implications for 'liminal' survivorship where exclusion, uncertainty, or unsuccessful interventions have occurred.

## **P39** Therapeutic clinical trial enrollment is higher among AYAs treated at academic medical centers in North Carolina as compared to community cancer centers

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**INTRODUCTION AND AIMS:** Inferior survival improvements among AYAs with cancer have been attributed, in part, to low clinical trial enrollment. Prior reports suggest that a majority of AYAs in the United States are treated in community-based practices with limited access to clinical trials. We sought to describe the patterns of AYA cancer care in North Carolina (NC) and estimate the proportion of AYAs enrolled on clinical trials.

**METHODS:** Linking NC state cancer registry and insurance claims data with trial enrollment data from the NCI, we identified NC AYAs (15-39 years-old) diagnosed with a first invasive cancer between 2003 and 2012 and determined the facility of primary cancer treatment. Facilities were categorized as (1) academic versus community and (2) NCI comprehensive cancer center (NCICCC) versus non-NCICCC. Trial participation was defined by enrollment on an NCI-sponsored therapeutic trial for newly-diagnosed patients with curative intent.

**RESULTS:** During the 10-year study period, 17,106 AYAs were diagnosed with a first cancer, of whom, 11,429 (67%) were > 30 years-old and 11,149 (65%) were female. Most common diagnoses included breast (17%), melanoma (14%), thyroid (11%), and lymphoma (10%). Of the AYAs identified, 5142 had insurance claims and sufficient continuous plan enrollment to determine the location of cancer treatment. Fewer than half of AYAs received most of their cancer care at an academic center (n=2393, 47%) and fewer received most of their care at an NCICCC (n=1762, 34%). More AYAs treated at academic centers as compared to community cancer centers (4.2% versus 2.1%, respectively, p<0.0001) or at NCICCCs as compared to other institutions (4.4% versus 2.4%, respectively, p<0.0001) were enrolled on a clinical trial.

**DISCUSSION AND CONCLUSION:** Clinical trial enrollment among AYAs with cancer is low, though treatment at an academic center, including NCICCCs, is associated with a higher likelihood of trial enrollment.

# Day 2 - Wednesday 5 December

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## **P1** You would think living with life threatening cancer was enough: Exploring the financial effects of cancer for Australian adolescents and young adults and their carers

L. Lehane

**INTRODUCTION AND AIMS:** The substantial financial costs associated with having cancer for Australian patients and their carers has recently been the focus of mainstream media. Few studies have evaluated the financial impacts for adolescents and young adults (AYAs) with cancer and their family. This qualitative research study explores the financial experiences of AYAs with cancer and their carers.

**METHODS:** Explorative descriptive study using In-depth semi structured interviews to understand participants' experiences. Individuals between 16 and 35 years, at different stages of their cancer treatment, and their family were invited to participate by specialist cancer nurses at Royal Prince Alfred Hospital.

**RESULTS:** Four themes have emerged reflecting the experience of AYAs with cancer and their carers: 1) adulthood postponed as AYAs rely on carers (usually parents) to shield them from the financial effects of cancer by shouldering out of pocket costs and providing financial support for living expenses; 2) ripple of uncertainty as study and early career opportunities are impacted by cancer treatment and disease effects. 3) resilience and creativity demonstrated through gratitude for community support for AYAs with cancer and their family, getting around the system such as 'losing' parking tickets as this is cheaper than paying for a week of parking and adapting to the effects of cancer and treatment by retraining and working around physical limitations; 4) thwarted by the system which should be there to help them is the common experience of AYAs as they fall between gaps in the welfare system and face hurdles which are too high.

**DISCUSSIONS AND CONCLUSIONS:** Interventions to alleviate the financial effects of cancer for Australian AYAs and their carers must address the specific challenges faced by this group to be of benefit. The findings identify these challenges and will inform interventions targeting AYAs and their carers.

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## **P2** Working to outcomes: Piloting an innovative technology platform to measure and understand outcomes for young people receiving education and career support

**K. Hill<sup>1</sup>, A. Grant<sup>1</sup>**

<sup>1</sup>Redkite, Australia

**INTRODUCTION AND AIMS:** Within the evaluation, health and not-for-profit (NFP) sectors, there is growing recognition of the need to systematically measure client outcomes to inform program decision making, learning and improvement. In September 2017, Redkite began piloting Socialsuite, an innovative outcomes measurement technology platform that integrates with Redkite's client relationship management software (CRM) (Salesforce). The purpose of the pilot was to collect, analyse and report on the outcomes of Redkite national Education and Career Support (ECS) program for young people (15-24 years) who have had a cancer diagnosis,

and in doing so, to assess the appropriateness of using the platform for ongoing outcomes measurement for the ECS program and other Redkite programs.

**METHODS:** A program logic approach was used to clarify the main outcomes of the ECS program for young people. These outcomes formed the basis of the monitoring and evaluation framework, data collection plan and outcome measures used. Online surveys were delivered to young people via the Socialsuite platform at 3 months after initial contact with an ECS Consultant and 9 months after initial contact. Other data sources included routine CRM data and qualitative workshops with ECS team members.

**RESULTS:** Overall, young people reported positive outcomes from the program, particularly in terms of being able to stay connected to their education and career pathways. The pilot also demonstrated the potential of the Socialsuite pilot in terms of its real-time integration with Redkite's CRM platform, compatibility with Redkite's program logic approach, real-time interactive dashboards and reporting, and potential for automated data collection.

**DISCUSSION AND CONCLUSIONS:** The pilot provided Redkite a valuable opportunity to monitor and report on client outcomes quickly and efficiently. However, more time is needed to assess the appropriateness of rolling out the platform to other programs. Redkite has committed to continuing the pilot until at least mid-2019.

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### P3 **Do we as educators support students to integrate education into their “cancer journey” or do we support students to integrate the cancer treatment into their “education journey”?**

**N. Done<sup>12</sup>, T. Donovan<sup>23</sup>**

<sup>1</sup>Ronald McDonald House Randwick, Australia

<sup>2</sup>Kids Cancer Centre Sydney Children's Hospital, Australia

<sup>3</sup>Back on Track, Australia

The complexities adolescents face when a cancer diagnosis interrupts their senior school years is significant. One of the early questions posed by the students and the family upon diagnosis is, 'What about school?' This presentation will demonstrate how our not for profit organisations work with the Sydney AYA multidisciplinary team to integrate education and cancer treatment into best practice. We believe the best outcomes for senior high school students are achieved when the education journey is continued alongside the cancer treatment, using a holistic multidisciplinary team approach. Cancer can have a detrimental effect on student learning outcomes, leaving affected students struggling to meet their potential and complete their final years of school. A coordinated education plan ensures students can continue to meet legislated educational outcomes with adjustments and modifications, thus enabling them to progress to post-secondary options in line with their cohort. Three case studies will be examined demonstrating the variety of ways collaboration and communication between students, educators and health professionals occur. The first study explores the complexities of long term support offered to a student through Years 10, 11 and 12. The second study outlines the negotiations needed to support a recently diagnosed Year 12 student to undertake a modified pathways program to maintain connections with education during intensive treatment. The third study examines how an interstate student is supported under a different education system. This collaborative approach has successfully supported over 30 students to complete their senior high school years despite the significant health and education challenges they have faced. The key learnings from this presentation are the importance of seamless collaboration and communication amongst all key players; the value of an early referral to

educational support and the use of a best practice model that integrates a cancer diagnosis into the education journey.

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## P4 Evaluation of the RENEW exercise referral programme for young adult cancer survivors

S. Epstone<sup>1</sup>, J. Reynolds<sup>1</sup>, A. Fisher<sup>2</sup>, G. Pugh<sup>2,3</sup>

<sup>1</sup>Trekstock, United Kingdom

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@GemmaPugh2

**INTRODUCTION & AIMS:** There is increasing evidence that physical activity is safe, feasible and has a number of clinical, physical and psychosocial benefits for cancer patients both during and after treatment. In order to support young people with cancer in their 20's and 30's to be active Trekstock, a UK based cancer charity, have developed an exercise referral programme called RENEW. The RENEW programme offers young people with cancer 12 weeks of 1-2-1 individually tailored support from a Level 4 Cancer Rehabilitation qualified gym instructor. An independent evaluation of the programme, with a focus on internal (effectiveness and reach) and external (adoption, implementation and maintenance) validity outcomes is currently being carried out.

**METHODS:** Data on physical activity, physical function, fitness, and health-related quality of life (including fatigue) are being collected from participants pre-programme (week 0), post-programme (week 12) and one month later (week 16). A sub-sample of participants have been invited to wear an accelerometer in order to objectively capture physical activity data. The primary outcome is programme uptake and adherence. Secondary outcomes are i) change in proportion of participants meeting current physical activity guidelines (>150 minutes per week of at least moderate activity and >2 strength based sessions per week) ii) change in self-efficacy and motivation to exercise, iii) change in health related quality of life and iv) change in body composition and physical function.

**RESULTS:** The RENEW programme is currently being piloted in London, preliminary results of the evaluation will be available to present to the AYA Congress in December, 2018.

**DISCUSSION AND CONCLUSIONS:** This evaluation will determine the impact of the RENEW exercise programme on cancer survivors health and well-being and provide insight towards the feasibility of implementing the programme in other UK cities alongside Trekstocks' current Meet & Move initiative.

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## P5 Launching an Innovative Education Series Utilizing Novel Learning Approaches to Address the Unique Needs of the Adolescent and Young Adult (AYA) Oncology Patient

S. Bergeron<sup>1</sup>, K. Noskoff<sup>1</sup>, K. Sladek<sup>1</sup>, K. Allen<sup>1</sup>

<sup>1</sup>CHOC Children's, California, USA

The multidisciplinary team at CHOC Children's Hospital has been instrumental in creating the ideal AYA program. With this established AYA community, CHOC has given AYA patients the ability to have a strong voice in creating a successful program which focuses on meeting

their unique needs. The AYA Patient Leadership Team expressed an eagerness to learn and a need for an education strategy that addresses the important topics that they thought were necessary for them to succeed, lead and thrive during their cancer journey. The multidisciplinary team, guided by an AYA child life specialist, designed and implemented an education series to include a curriculum of topics that were chosen and prioritized based on level of importance by the AYA patients. The identified curriculum for the AYA patient included fertility and family planning, fitness and nutrition, sexual health, the impact of cancer on relationships, tools to improve stress management and coping, transitioning into survivorship, interview skills and applying to college, support for grief and loss, as well as a discussion on drugs, alcohol and risky behaviors. A variety of learning approaches were utilized to enhance the education experience for the AYA. Each topic was introduced in a way that engaged the patients and siblings and allowed for powerful and insightful discussion in both formal and informal settings. AYAs were taught in various ways including: using expert panel discussions, guest speakers, interactive group activities, a weekend retreat, conferences taught by leading AYA professionals, and a job fair hosted by the hospital that provided necessary skills to seek employment opportunities within their community and apply for college. This established AYA education program is a valuable investment for our patients. It is truly their passport for their future as they focus on their successful transition into survivorship!

## **P6** The benefit of physical activity in adolescent and young adult cancer patients during and after treatment: A systematic review.

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@FIGHTINGFIT

**INTRODUCTION AND AIMS:** Cancer and its associated therapies can severely impact the physical and psychosocial functioning of adolescent and young adults (AYA), both during treatment and well into survivorship. Physical activity during and after cancer treatment could be beneficial to the AYA population, though this cohort has received little scientific attention. This review aims to investigate current exercise interventions in AYA-specific populations.

**METHODS:** A systematic search of the literature was conducted. Studies were eligible for inclusion if >50% of the study population was aged between 15 and 25 years and the study included a physical activity intervention during or after cancer treatment. Studies were excluded if they recruited childhood cancer survivors in the AYA age range. Studies were critically appraised using the Cochrane Risk of Bias tool.

**RESULTS:** Six articles were identified as meeting the criteria, of which two were non-randomised controlled studies and four were pilot studies, comprising a total of 135 AYA participants. The quality of studies was variable across all assessed domains. Direct comparison on intervention outcomes was not possible due to the heterogeneity of the studies; however, trends emerged on the feasibility, acceptability and potential positive impact of physical activity in this cohort.

**DISCUSSION AND CONCLUSION:** This review highlights the lack of high quality studies aimed to improve physical and psychosocial functioning in AYA patients across the cancer continuum. Physical activity interventions in this cohort appear to be feasible; however, larger randomised controlled trials are warranted to investigate the direct impact of interventions on health outcomes in this cohort.

## P7 Changes to Body Image and Impact on Physical Activity, School/Vocation and Mental Health amongst AYA's following Treatment for Sarcoma and Lymphoma: A Research Protocol

**L. Williams<sup>1</sup>, J. Lewin<sup>1</sup>, M. Dickinson<sup>2</sup>, L. Orme<sup>13</sup>, K. Thompson<sup>1</sup>**

<sup>1</sup>ONTrac at Peter Mac Victorian Adolescent & Young Adult Cancer Service, Australia

<sup>2</sup>Peter MacCallum Cancer Centre, Melbourne, Australia

<sup>3</sup>Royal Children's Hospital, Melbourne, Australia

**INTRODUCTION:** One of the most distressing side effects of cancer treatment for young people pertains to temporary and permanent changes to physical appearance. The psycho-social impact of these treatment-induced changes include poor body image, which in turn can lead to difficulties reintegrating into peer groups, social and leisure activity avoidance, school refusal and decline in mental health. To our knowledge, no prospective research has been conducted with adolescent and young adults (AYA) that has assessed the impact of medical treatment for cancer on body image and psychosocial wellbeing.

**AIM:** A longitudinal study has been developed to examine whether changes in physical appearance following treatment for sarcoma or lymphoma is associated with declines in body image, physical activity, education/vocation engagement and mental health amongst AYA.

**METHODS:** A sample of 80 AYA (aged 15-25) with newly diagnosed sarcoma or lymphoma will be invited to complete an online questionnaire three times over the duration of their medical treatment (T1: baseline; T2: 12 weeks; T3: 4 weeks post treatment). The questionnaire will assess perceived changes to appearance (e.g DAS24), body image (e.g BII), physical activity (e.g Godin Leisure-Time Exercise), education/vocation engagement (self-devised) and psychosocial adjustment (e.g K-10). Demographics, diagnosis, treatment variables and clinical-rated treatment intensity will also be collected for logistic regression.

**RESULTS AND DISCUSSION:** To our knowledge, this is the first study assessing longitudinal changes in body image and the relationship to treatment in AYA with sarcoma or lymphoma. Preliminary data will be presented alongside discussion of challenges to recruitment and retention amongst AYA. Consideration of study design, including balance of sample homogeneity and generalizability of findings will also be discussed. Findings from this study will be used to inform pre-treatment information and intervention efforts aimed at alleviating psychosocial distress associated with medical treatment for sarcoma or lymphoma.

## P8 A Body Image Support group to address Body Image issues for Teenage & Young Adults (TYA) with a cancer diagnosis

**A. Mackland<sup>1</sup>, L. Wright<sup>12</sup>**

<sup>1</sup>The Christie NHS Foundation Trust, Manchester, UK and

<sup>2</sup>Teenage Cancer Trust

@LoriYSC @annamackland

**INTRODUCTION AND AIMS:** Young people with a cancer diagnosis report that the body altering side effects of cancer treatment are some of the worst issues affecting them (Wallace, 2017). There is very little evidence about how professionals can best address body image issues. The Christie TYA service consulted with young people and set up a monthly body image support group. The aim of the group is to provide a supportive space for young people to talk about body image and to provide skills to help them cope.

**METHODS:** The group is facilitated by the TYA Occupational Therapist and TCT Youth Support Co-ordinator. The group has a very informal atmosphere but uses a Cognitive Behavioural Therapy approach to structure discussions. Attendees complete a Body Image Scale (Hopwood, 2001) prior to the session and complete an evaluation form at the end.

**RESULTS:** The group size ranges from 2-9 participants (averaging 5). 68% participants report significant body image issues. Main themes include: Looking different from peers, The impact of altered body image on personal relationships, Withdrawing socially due to concerns about appearance, Loss of identity and creating new identity. Evaluations indicate that TYA's felt less alone when they were able to talk to other young people.

**DISCUSSION AND CONCLUSIONS:** Young people affected by a cancer diagnosis experience significant body image changes which impacts on their life during treatment and beyond. They should be offered the opportunity to address body image concerns with their peers to improve their quality of life and future experiences.

## P9 Understanding the educational and vocational outcomes of Adolescents and Young Adults (AYA) diagnosed with cancer

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**INTRODUCTION:** Education and employment are important determinants of future health and quality of life for all adolescents and young adults (AYA). A diagnosis of cancer has the potential to hinder education and employment through interrupting physical participation, affecting cognitive maturation and functioning, inhibiting autonomy and disrupting peer connections. The ONTrac at Peter Mac Victorian Adolescent and Young Adult Cancer Service provides a specialist education and vocation service to support young people. This study aims to retrospectively examine the interventions provided for AYAs referred for education and vocation support.

**METHOD:** Consecutive case files of AYA (aged 15-25) accessing education and vocation support between 1st of January 2016 until 31st of December 2016 were reviewed. Data collected included demographics; treatment received; education/vocation status at three time points: diagnosis, treatment completion & 12 months post treatment.

**RESULTS:** A total of 71 patients were identified (median age 19 (15-25), 56% female). The major tumor types referred for support included: Hodgkin's lymphoma (17%), sarcoma (14%), ALL (10%), AML (8%), and other (20%). Amongst the first 21 sequential patients analysed, 100% received assessment/intervention: For those at school (n=8), school meetings were attended in 50%, liaising with school staff in 75% and special consideration documentation provided in 63%. For those at university (n=7), transition to other courses was guided in 50% and referral to community agencies was conducted in 50%. In total, vocational guidance was delivered to 76%.

**CONCLUSION:** This pilot study will guide future service delivery and prospective research studies aiming to maximize the education and vocation outcomes of this cohort.

## P10 Adolescent Responses to the Diagnosis of a Life-Limiting Condition: Stages of Grief.

D. Kundert

**INTRODUCTION AND AIMS:** The stages of grief will be investigated and findings mapped to the Kubler-Ross (1969) change curve – the five stages of grief include denial, anger, bargaining, depression and acceptance. The aim is to examine the stages of adolescent development, initial response to a diagnosis, continuing daily living and the concept of death to understand the implications for nursing care.

**METHODS:** A literature review was undertaken, with key words and search terms. Papers to be critiqued were found through systematic searches of CINAHL, PsycINFO and British Nursing Index databases.

**RESULTS:** Adolescents with cancer quickly develop a true concept of death in contrast to their healthy peers. It was determined that they experience fear first, shortly followed by shock. As teenagers begin to come to terms with their diagnosis and treatment regimes, they may encounter decreased interactions with their peers and become more reliant on their parents. At a stage of development where adolescents are beginning to discover their personal identity and gain independence, this is a challenging aspect to deal with. Therefore, some went into a period of denial and did not want to accept the reality of a cancer diagnosis. Endeavouring to stay positive, looking towards the future and having a supportive social network was key.

**DISCUSSION AND CONCLUSIONS:** Responses shown by an adolescent map to those of Kubler-Ross, with an additional reaction of fear being discovered. Nursing care recommendations from this review are: Educate health care professionals and patient's family members on the emotional and physical stages of adolescent development and how they may react to a diagnosis. Provide continual education to nurses on how to care for adolescents. Nurse adolescents on a cancer ward with age-appropriate facilities. Provide adolescents with accurate information, offer counselling sessions and implement a self-care coping strategy.

## P11 Ben's Bucket List - A Collaborative Approach to the Palliative Care Needs of an Adolescent with Cancer

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<sup>6</sup>Lady Cilento Children's Hospital Brisbane QLD Australia

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**CASE DESCRIPTION:** At age 17, Ben was commencing his final year of school, enjoying a new romance and was diagnosed with disseminated Ewing's Sarcoma with primary site in the pubic ramus. Ben was referred to Oncology Services at Lady Cilento Children's Hospital (LCCH) for enrolment and treatment on a clinical trial. As his family lived 80 km from LCCH, care was shared with paediatric services at Gold Coast University Hospital. Determined not to let cancer interfere with important life events Ben created his Bucket List. Special consideration was given to scheduling appointments around year 12 photos, exams, birthdays and school

formal. Ben developed disease progression on chemotherapy treatment requiring radiation to the primary lesion to control pain and local disease. His disease continued to progress rapidly. Focus of care was redirected from curative to palliative, with priority given to managing escalating pain. Ben required extraordinary doses of medications requiring novel approaches to pain, anxiety and symptom control, including the use of Methylphenidate to assist with managing fatigue. As per Ben's wishes, admissions to hospital were avoided and treatment delivered at home. Ben achieved many goals on his bucket list, including his school formal.

**DISCUSSION:** Severe pain from extensive bone metastases is very challenging and often requires hospital admissions. Teamwork with the local specialist palliative care service, paediatric and community nursing service and LCCH, allowed Ben to remain at home. Careful titration of high dose infusions of methadone, midazolam, ketamine and phenobarbitone were safely delivered.

**KEY LEARNINGS:** Shared care between local and tertiary centres promotes trust and mutual support for patient, family and health care providers. Individualised care and a supportive community of family and friends enabled Ben to live fully and die peacefully at home with, humour, grace and determination, cared for by the people who loved him.

## P12 Talking About "Plan B"

L. Oliver<sup>1</sup>, J. Grout<sup>1</sup>, L. Gordon<sup>1</sup>

<sup>1</sup>University Hospital Southampton, UK

**INTRODUCTION:** Our TYA team experienced challenges supporting a number of young people with relapsed or refractory leukaemia surrounding the offer of further treatment with uncertain outcome. We were aware that these patients were not given enough opportunity to consider what might happen if they opted to stop treatment or if we came to the end of treatment options. Some of these patients were given further treatment and when this was not successful ultimately died in hospital. We noted that the practice in other site-specific teams, more explicit 'Plan B' discussion was established practice. The team felt we could do better and make offering these conversations normal practice for all.

**METHOD:** Team WorkTeam debriefs following inpatient deaths Joint working within the multidisciplinary TYA team and with other teams Closer working with the treating haematology team to improve communication Sharing good practice with colleagues regarding 'Plan B' discussions. Earlier introduction of palliative care team for symptom management

**RESULTS:** The team feel that real progress has been made and by discussing plan B we are empowering them to make informed decisions regarding both treatment and how they wish to plan their future lives however short. Crucially we work more closely with our palliative care team so patients view them as part of their usual care team, making transition to end of life discussions easier if required.

**CONCLUSIONS:** Working as a team we have been able to turn a concern about what we were offering our patients into a working practice where it has become normal to talk about Plan B. This has helped to give more patients what we consider to be a greater choice about the decisions they make about treatment and how they want to live their lives, however short.

## P13 “It’s a topic that everyone has to encounter”: What young adults think about care and conversations at end-of-life.

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**INTRODUCTION/AIMS:** Considering wishes for end-of-life (EoL) care is crucial for adolescents and young adults (AYAs) with incurable cancer. Despite the importance of these EoL conversations, little research has examined AYAs’ preferences for EoL care and communication. We also know very little about how developmental and psychological aspects of the AYA life-stage impact how they cognitively and emotionally process confronting EoL-related concepts. This study aimed to explore EoL preferences, and factors associated with this, in a group of healthy AYAs.

**METHODS:** First-year psychology student participants were given psychoeducational information regarding the impact of cancer on AYAs and EoL issues. They then completed a mixed-methods survey on their preferences for EoL care and communication if they were hypothetically diagnosed with incurable cancer. Questions included (i) who they would want to talk to about EoL issues, (ii) when they would want to have those conversations, and (iii) where they would prefer to die. Participants also completed several psychological measures (e.g. attachment, self-esteem).

**RESULTS:** To date, 62 AYAs (36 females, 58%) aged 17-31 years ( $M=20.1$ ,  $SD=2.2$ ) have participated. Many spoke a language other than English at home ( $n=37$ , 59.7%), 30% were religious ( $n=19$ ), and 44% ( $n=27$ ) had already experienced conversations about EoL. Almost all participants would want to talk about EoL and their wishes if they were diagnosed with incurable cancer ( $n=52$ , 84%;  $n=8$  unsure, 13%,  $n=2$  unwilling, 3%). Preliminary analysis indicates that preferences for EoL care and communication vary widely across the group.

**DISCUSSION/CONCLUSIONS:** Healthy AYAs have clear preferences and opinions on EoL care, and many have had conversations about these issues. This presentation will explore who AYAs want to talk to about EoL, when they would want to talk and where they want to die, as well as key developmental and psychological factors influencing variation in AYAs’ EoL preferences.

## P14 The Experiences of Young Adults Living with Metastatic/Advanced Cancer: A Scoping Review

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**INTRODUCTION AND AIMS:** While survival rates have improved in nearly all cancers over the past thirty years, the young adult (YA; 18-39 years of age) cancer population has not seen progress comparable to that of pediatric and older adult oncology populations. There exists major gaps in YA oncology research and there is even less concerning those living with

metastatic/advanced cancer. This systematic scoping review maps what is known about the experiences of YAs living with metastatic/advanced cancer.

**METHODS:** A systematic scoping review, guided by the Joanna Briggs Institute (JBI) methods, was conducted of the literature to examine the experiences of YAs living with metastatic/advanced cancer. The search strategy included relevant databases (Ovid MEDLINE, CINAHL, PsycInfo), ProQuest dissertations, grey literature and hand-searches of three relevant journals and reference lists from reviews identified via the literature search. Applied key words included but were not limited to: palliative care; experienc\*; end of life; cancer; young\*; advanced; metastas\*. These were used in combination with Boolean operators AND and OR. Articles written in languages other than English were excluded. The population included YA living with a metastatic/advanced cancer and the concept included their psychosocial experiences. The context is within both the hospital and community environments. Search terms were developed in collaboration with a medical research librarian with JBI expertise.

**RESULTS:** From the search strategy, 2843 references were obtained and 564 duplicates were removed. This review is currently in progress. Initial title/abstract screening of articles indicates scarce research on this topic. A PRISMA flow diagram will depict included/excluded articles and findings will be presented to demonstrate research gaps and future directions.

**DISCUSSION AND CONCLUSIONS:** This review will present the current state of empirical knowledge pertaining to the experiences of YAs living with a metastatic/advanced cancer.

## P15 WITHDRAWN

## P16 The use of oral single-agent targeted therapy in the palliative care setting to slow disease progression and maximise quality of life: a case study.

**A. Sullivan<sup>1</sup>, R. Walker<sup>1,2,3</sup>**

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<sup>2</sup>Queensland Youth Cancer Service, Australia

<sup>3</sup>University of Queensland, Australia

**CASE DESCRIPTION:** This case study describes a 17 year old female with progressive Alveolar Soft Part Sarcoma (ASPS) where Pazopanib was used for disease stabilisation as an adjunct to her palliation. In January 2015 after an acute presentation with sudden onset visual loss, relapsed disease with multiple intracranial metastases was demonstrated. Steroids were commenced alongside whole brain irradiation, however repeat imaging in March 2015 showed progressive cerebral and pulmonary disease. During this time, she was unable to be weaned off steroids and suffered well recognised complications of exogenous corticosteroid use. In April 2015, she was commenced on Pazopanib, with clinical and radiological response. The addition of this agent allowed disease stabilisation which facilitated the weaning off of corticosteroids and rendered her a good candidate for resection of the most problematic lesions. Surveillance MRI imaging over twelve (12) months demonstrated stable disease. In late 2016, she again had disease progression on Pazopanib suggesting tolerance. Pazopanib was ceased and she was able to enrol in a clinical trial. Unfortunately she progressed on trial and Pazopanib was reintroduced with subsequent disease stabilisation again over many months. Unfortunately in early 2018, this patient's disease rapidly progressed and she died from multifactorial respiratory failure in April of this year.

**DISCUSSION:** Over a period of three years, this patient was able to live with her disease, maximise quality time with loved ones, attend school and stay connected with her local rural community. The treatment was undertaken in the outpatient setting and had minimal side effects. The additional quality time allowed her to reach many adolescent milestones that were important to her and her family.

**KEY LEARNING:** This case demonstrates that oral targeted therapy agents should be considered as an adjunct to good palliation to offer patients more quality time with minimal toxicity.

## **P17** Identifying unmet needs in patients diagnosed with cancer as young adults aged 25-39 years: a qualitative study of an underserved population

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**INTRODUCTION AND AIMS:** Psychosocial issues that arise in adolescent and young adult cancer patients differ from those observed in paediatric and adult populations. Specialised services have been developed for patients aged 13 to 24 years, while there is little age-specific support and research into the needs of young adults (YA) aged 25 to 39 years. This is the first study aiming to understand the needs expressed by this specific age group.

**METHODS:** We invited YA diagnosed with cancer between ages 25 and 39 years in the last five years to take part in a focus group or semi-structured interview. We included patients treated with curative and palliative care intent from five National Health Service (NHS) Trusts in the United Kingdom. Discussions were recorded and transcribed verbatim. Themes and sub-themes were identified using a thematic approach.

**PRELIMINARY RESULTS:** In total, 69 YA cancer patients took part: 14 sarcoma, 13 breast, 12 brain, 10 gastro-intestinal, 7 urological, 5 haematological, 4 gynaecological, 2 lung tumour, 2 melanoma. Participants, of which 44 were female, were 31 years on average. Preliminary analysis revealed the need for psychological support regarding uncertainties about treatment and prognosis and feelings of shame or embarrassment about being diagnosed with cancer as a young adult. Further emerging themes included the need for practical support with returning to work, navigating financial benefits, caring for children, fertility issues, managing personal relationships and dealing with social isolation experiences. YA patients also perceived a lack of control within the healthcare system due to prescribed appointment times and barriers accessing clinical records.

**DISCUSSION AND CONCLUSIONS:** YA cancer patients need fast access to tailored psychological support. This age group would benefit from improved access to relevant resources for practical and social support. Future research should determine appropriate timing, intensity, location and accessibility of supportive care services for patients aged 25-39 years.

## P18 Social anxiety in AYA cancer survivors

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**INTRODUCTION AND AIMS:** It is well established that emotional wellbeing continues to be an area of unmet need for adolescent and young adult (AYA) cancer survivors, affecting their long-term wellbeing. It is unclear what role social anxiety, as a result of cancer during AYA years, has on quality of life. Therefore, this study aimed to determine (i) the level of social anxiety and (ii) correlates of social anxiety among AYA survivors.

**METHODS:** This cross-sectional study involved AYA survivors from the long-term survivorship clinic at Sydney Children's Hospital. Participants completed a set of validated questionnaires assessing (i) social anxiety (13-17year olds: SCARED brief form; 18-25year olds: Mini-SPIN), (ii) health-related quality of life (HRQoL) (EQ5D5L), (iii) family functioning (SCORE-15), and (iv) depressive symptoms (PROMIS). Demographics and clinical information were also collected.

**RESULTS:** To date, 28 AYA survivors have participated (mean age 17.75years, range 13–23years, 67% male; mean time since diagnosis 7.77years). Of survivors 13-17years (n=13), 53.85% endorsed levels of shyness consistent with social anxiety and 15.38% reported significantly more depressive symptoms than population norms. Shyness was not related to depression, family functioning, or HRQoL. For survivors 18-25years (n=15), 53.33% scored at/above the clinical cut-off for social anxiety disorder and 26.67% reported significantly more depressive symptoms than population norms. Social anxiety was not correlated with depressive symptoms, but was correlated with worse overall HRQoL ( $r=-.817$ ,  $p=.000$ ), and worse overall family functioning ( $r=-.539$ ,  $p=.038$ ). Demographic (e.g. age, gender) or clinical factors (e.g. time since diagnosis) were not related to social anxiety.

**DISCUSSION AND CONCLUSIONS:** These results indicate a subset of AYA survivors experience significant levels of social anxiety. In older survivors, social anxiety contributes to poor HRQoL. Family functioning is a potentially modifiable factor that could be targeted to address social anxiety in this population. These findings highlight the need for integrating family-based screening and intervention into psychosocial care for AYA survivors.

## P19 Look at Me Now: A Successful Peer Support Program for Hematopoietic Stem- Cell Transplant Patients

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**INTRODUCTION AND AIMS:** Pediatric Hematopoietic Stem-Cell Transplantation (HSCT) can be an isolating experience due to the nature of its therapy. We propose peer support will be beneficial to HSCT patient/caregiver, and the long-term survivor is positively impacted. Peer long-term survivors/caregivers offer encouragement, emotional support, and first-hand knowledge of the difficulties and accomplishments endured thru HSCT. The Look at Me Now Program was developed to foster peer interaction, assist current patients/caregivers to better cope with the HSCT process, and help validate the survivors own experiences.

**METHODS:** Between October 2016 and December 2017, 13 HSCT survivors were identified and matched with patients undergoing HSCT. A long-term survivor (LTS) at our institution is defined

as a patient who is 2 years status post HSCT. Once approved by the interdisciplinary team, survivors are then approached and offered to participate in this program. Following informed consent (or assent when appropriate) participants are then matched to patients undergoing HSCT based on their similarities which include age, gender, diagnosis, the age at HSCT. A five-question survey is provided to participants (one for current HSCT patient, one for long-term survivor) post support session. 13 survivor/patient pairs were analyzed.

**RESULTS:** The Look at Me Now Program is ongoing with additional patients/LTS groups being added as appropriate. Based on the participant evaluations we have found that both the LTS group and patients have reported positive response, including desire for further participation and hope.

**DISCUSSION AND CONCLUSION:** The Look at Me Now Program is ongoing with additional patients/LTS groups being added as appropriate. From what we have seen in our practice there is a continued need for a program like this for HSCT patients/caregivers

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## P20 Challenging linear models of grief through residential bereavement support

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**INTRODUCTION AND AIMS:** Since 2013 our CLIC Sargent team has offered bereavement psychosocial events to mothers in order to facilitate peer support. Feedback showed that external interventions they had experienced felt linear and suggested an 'end point' to their grief, such as the 'acceptance' that closes Kubler-Ross's Five Stages (1969). Our aim was to consider whether a different model of grief, such as that by Klass, Silverman and Nickman (1996) would be more accessible and relevant to the support we offer.

**METHODS:** To explore this model of grief effectively we developed a residential weekend and invited mothers whose child had died from January 2014 to August 2017 who had also received support by the CLIC Sargent Team at RMH. Due to the accommodation available, we had space for eight mothers and two staff facilitators. The response was overwhelming. Attendees secured a place on a first-come-first-served basis, with 11 on the waiting list. We introduced the models of grief over three structured sessions, allowing for discussion during additional social time. The event was evaluated using participant questionnaires following a period of reflection.

**RESULTS:** 100% of participants valued exploring the models of grief, despite no singular model of grief being suited to their situation. However, obtaining an awareness of models of grief allowed them to create a blended version that was unique to them. All felt a comfortable residential environment was vital to their ability to engage more fully and small group numbers allowed for deeper discussion and reflection.

**DISCUSSION AND CONCLUSIONS:** Our evaluation proved that the newer models of grief, rejecting the linear process, were more relevant to this group and aided their grieving. However, discussing intense grief formally was challenging for all involved and this learning outcome has proved fundamental in planning future events.

## P21 The Getaway Retreat for Young Adults

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**CASE DESCRIPTION:** Six young adults with cancer ages 23-39 participated in the first annual AYA@USC Norris Comprehensive Cancer Center retreat on October 21-23, 2017. In partnership with Ronald McDonald Camp, the staff included two physicians, a nurse, and several counselors. Applying three decades of experience in planning and implementing retreats for adolescents with cancer at Children's Hospital Los Angeles, this young adult retreat provided insights into the difference and similarities among adolescents (13-18) and young adults (19-39). The findings may provide important information for future young adult retreats.

**DISCUSSION:** While teens are often reluctant to share emotions, young adults are generally more open. Without prompting, for example, a young adult participant stated, "We don't need icebreakers. Cancer is our ice breaker." On the initial bus ride to camp, the participants candidly related their cancer experience. In addition to informal discussions, the retreat featured counselor-led group activities and mindfulness workshops. Saturday night entertainment included an improvisational group as well as a talk by a cancer survivor who is also an author and comedian.

**KEY LEARNING:** Recruiting adolescent participants proved much easier than young adults, even though both benefit by connecting with other cancer patients. The life demands of 20 and 30- year olds hinder their participation in retreats. Young adults want to share their cancer experience with significant others and prefer that their caregiver attend the retreat. Adolescents, on the other hand, prefer to be with their peers and away from their parents. For teens, retreats foster independence and identity formation. Young adults are more interested in learning stress-reducing techniques that are helpful post-retreat. An important similarity is that physicians play a role beyond the medical. Active participation in the retreat enhances the doctor/patient relationship. Being "real" and approachable is beneficial not only to AYAs, but also to physicians.

## P22 Implementation of a designated Late Effects clinic for Adolescents and Young Adults (AYA) who have undergone Haematopoietic Stem Cell Transplant (HSCT)

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**INTRODUCTION:** Due to ongoing advances in the field of HSCT, increasing numbers of individuals are going on to become long-term survivors of HSCT, with 50-90% adult survivors of childhood cancer experiencing moderate to severe adverse health outcomes (National Institute for Health & Clinical Excellence (NICE), 2005). It is recognised therefore that individuals require a stratified pathway of care designed to empower them and aid communication and transition between care settings (National Cancer Survivorship Initiative, 2016).

**AIMS:** The historical model of AYA care at the Royal Marsden entails inpatient care during HSCT on the designated AYA cancer unit. At the point of discharge care is then transferred to adult outpatients; a traumatic and abrupt transition anecdotally, and counterintuitive to current guidance for age-appropriate service provision (NICE, 2005).

**METHOD:** The consultation process was initiated to identify the rationale for establishing a designated AYA transplant clinic within the environment of the AYA unit. Feedback was

obtained anecdotally from patients regarding the proposal. Additional relevant stakeholders were then incorporated including the project manager for service transformations within the Trust. A series of meetings were held to discuss the proposed service design prior to implementation.

**RESULTS:** A policy was generated to identify the context, rationale and scope of the AYA transplant clinic. A designated slot within the AYA cancer unit was then identified for the clinic to be led by the AYA transplant consultant and AYA transplant clinical nurse specialist. The intention is for each AYA to have a treatment summary and individualised care plan as per the recommendations of Majihail et al (2012) for late effects monitoring in HSCT.

**DISCUSSION:** Service change requires a structured approach that is transparent and open to feedback. Any new proposals are likely to benefit from a formal evaluation of current service provision and qualitative feedback from patients.

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## **P23** Yoga for Wellbeing: Project Development in a Teenage and Young Adult Cancer Service

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**CASE DESCRIPTION:** Discussions between the Teenage Cancer Trust Youth Support Coordinator (YSC) and young people aged 16-24 years with a diagnosis of cancer highlighted a need for non-clinical support to manage concerns including poor body image, reduced confidence and physical and mental wellbeing. It was also noted that the wellbeing of caregivers suffered as they prioritised their loved ones. It was decided to run fitness classes for all family members to promote physical and mental wellbeing during and after treatment. After discussion it was decided that yoga would be a good way to promote physical and mental wellbeing, with consideration given to variable health conditions, physical abilities and low confidence levels around using public gyms and classes. Budget and resources were further considerations. The YSC implemented a restorative, Yin-based yoga programme in the hospital ward with classes running once a week for five and six week blocks. Classes focused on guided meditations, breathing exercises and controlled movements.

**DISCUSSION:** Classes were well attended with participation varying from week-to-week due to environmental and physical factors. Feedback from participants was positive. The classes enabled the young people and their carers to adopt a more positive approach to their situation, with the young people engaging more in peer support both in and out of hospital.

**KEY LEARNING:** Yoga has physical benefits that become more apparent with continued practice, but improvements in general wellbeing have been reported by participants who attended for even a short period. Understandably, those not undergoing hospital-based treatment preferred to stay out of hospital when not required to be there, so attendance varied. Consequently, the team will explore running a combination of community and ward-based classes.

## P24 Teenage Cancer Trust's Way Forward Programme – An evaluation of a residential approach to post treatment support for young people recovering from cancer

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**INTRODUCTION AND AIMS:** Following a cancer diagnosis it is common for young people to experience a number of issues as they finish active treatment that can affect their physical and emotional health. The Way Forward Programme (TWFP) is a series of two-day residential events held across the UK for small groups of young people aged 18-29 and between six months to five years post treatment. In collaboration with regional adolescent and young adult (AYA) cancer teams experts are identified to deliver interactive, age-appropriate sessions on a range of relevant issues including fertility, mental health, education and employment, relationships and healthy living aimed to promote self-management.

**METHODOLOGY:** 237 AYAs from 20 separate TWFP events completed an evaluation form immediately post event and six weeks following the programme. Several consistent patient reported outcome measures (PROMs) were used with AYAs asked to rate each against a Likert scale.

**RESULTS:** Excellent results were reported across all programmes. AYAs felt more resilient and better equipped to cope with their emotions, personal challenges and to manage their own health and well-being. All reported an improved peer support network and felt more empowered to seek support when required. A positive and sustained impact was observed across all outcomes and all attendees agreed the programme was a useful and enjoyable programme that positively impacted their recovery.

**DISCUSSION AND CONCLUSION:** TWFP has been demonstrated to provide a supportive environment that provides AYA the time and space to consider their ongoing lives beyond cancer. TWFP is an effective way of bringing together AYAs after treatment to discuss the practical and emotional challenges moving beyond treatment may bring. The next step is to consider a formal independent evaluation to determine whether reported PROMs are statistically significant.

## P25 Taking AYA cancer care to the next level in Denmark - AYAs with cancer on the political agenda (Abstract for the Global Exchange Exhibition)

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**INTRODUCTION AND AIMS:** In 2017, financial resources were allocated to develop cancer services for adolescents and young adults (AYAs) in Denmark. The Danish government has requested hospitals to take initiatives to provide youth-friendly environments for patients between 15 and 29 years. These initiatives are aimed at supporting the quality of life of AYAs with cancer. It is mandatory to involve the AYAs to ensure that their voices are heard. All hospitals treating AYAs with cancer are requested to establish: Dedicated bays and out-patient treatment rooms for AYAs A central shared activity room in the hospital Employment of

youth coordinators to facilitate activities Youth panels acting as advisory boards

**METHODS:** At Aarhus University Hospital we decided to collaborate across departments of paediatrics and adolescent medicine, haematology and oncology. Youth coordinators from each department facilitate the local implementation of the national strategy. A central shared activity room was already established at our hospital for AYAs <18 years. A similar room will be available during in 2018 for AYAs between 15-29 years in close connection to the departments of haematology and oncology. The departments of haematology and oncology will be located close to each other in new hospital facilities, facilitating improved cooperation. We have taken the following steps: Established a youth panel - 10 young patients are guiding us in all the changes and new developments Made staff teaching sessions to develop competencies Established a multidisciplinary research and development group Appointed a youth coordinator from each of the three departments who will facilitate activities and make social arrangements. They will be well-known persons to the AYAs throughout their course of treatment, and they will use their specialist knowledge to support and supervise colleagues. Moreover, a national network of youth coordinators is being established. Details of the programme and local initiatives will be presented.

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## **P26** Current status and issues in supporting AYA cancer patients in a children's hospital in Japan

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**INTRODUCTION:** Kanagawa Children's Medical Center is a children's hospital in Japan which has 412 beds. It is also one of the 15 Pediatric Cancer Base Hospitals designated by the Japanese government in 2012. In 2017 our hospital had total 528 hospitalized pediatric cancer patients but only 32 of AYA generation. AYA generation requires age - appropriate care; hence, we made a multidisciplinary team include dedicated nurses in the counseling support department, and this team works on several issues. Herein, we will share our experience in providing good support to AYA patients.

**METHOD AND RESULT:** Because of their long - term hospitalization, school is a big concern. Our hospital does not have an in-hospital high school and also the type of patient's school is diverse. So after we have a new - patient, certified nurse specialist (CNS) tries to talk with patients and their parents about their concerns and hopes. And also the CNS sets up a meeting with school teachers, including the administrator, and considers how collaboration could be done for them during hospitalization and when backing to school. Moreover, interaction with their peers is very important, but there are only a few opportunities in our institution. Hence, we asked teenage patients about their expectations from their peers and we organized several events. All attendees satisfied with these events. We have also organized a long-term follow-up system and provided location for consultation after discharge.

**DISCUSSION AND CONCLUSION:** Regardless of our continuous efforts to carefully hear patients' voices, creating a system in one pediatric hospital is a limitation. Since we start to form a network of hospitals, we hope to develop collaborative relationship for showing information and creating team care about AYA generation patients.

## P27 Guided tour behind the scenes of the AYA Team of the French Alpes

L. Goffi Laroche

**INTRODUCTION AND AIMS:** Grenoble Alpes University Hospital is the main reference health establishment in the French Alpes and one of the 8 French centers where a TYAC Unit was set up in 2012 by the National Cancer Institute. Since, we propose a personalized medical and psychosocial follow-up. The multidisciplinary team is mobile as our patients are treated in different public and non-public health establishments of our large area (2.5 million inhabitants). We propose to share our experience on patient long-term support during and after cancer treatment, with a specific focus on supportive and comfort care realized outside the care center.

**METHODS:** In 2017, our work with patients was the subject of a report broadcast on a national public channel. It consists of 4 episodes entitled: "supportive care", "sport", "rare pathologies" and "psycho-social approach". We propose to choose original sequences, and translate them for a presentation and short screening during the congress.

**RESULTS:** In 5 years, more than 450 patients have been reported and nearly 300 supported by our team. Half of the supported patients benefit from supportive care (psychological, socio-educational, Physical Adapted Activity) or well-being care (reflexology, osteopathy, sophrology, art therapy, or socio-aesthetics). The whole report in French is visible on <https://france3-regions.francetvinfo.fr/auvergne-rhone-alpes/isere/grenoble/grand-format-aja-unite-speciale-du-chu-grenoble-dediee-aux-jeunes-malades-du-cancer-1401413.html>. The new one can be designed after discussion with the congress organizers.

**DISCUSSION AND CONCLUSION:** French health authorities decided to reinforce care efforts toward the specific population of TYAC patients by creating TYAC units in the main cancer centers, and that's great news. We hope this will be an opportunity to promote, here and elsewhere, our organizational model based on a personalized and multidisciplinary assessment, a long-term follow-up from diagnosis to post cancer period, a mobile and flexible team to reduce geographical inequality in terms of access to care and strengthen the link with the other healthcare providers.

## P28 The Listen Up Group

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**INTRODUCTION AND AIMS:** The CanTeen New Zealand Listen Up group was established to help patients advocate for their rights both within the cancer system and outside, using the power of collective experience to raise awareness and drive change. One of the group's most influential achievements was working collaboratively with the AYA Cancer Network Aotearoa to inform development of New Zealand's new AYA Standards of Care.

**METHODS:** Listen Up patient representatives held focus groups in their local areas to discuss patients' ideal cancer service, improvements from their experiences, and current beneficial aspects that should be retained. From this input, they identified key themes and developed change campaigns.

**RESULTS:** The group identified three key themes where change was needed: early diagnosis, communication and mental health. The group successfully influenced the direction of the AYA Standards of Care, with over 80 young people involved and consulted. This included working with the AYA Cancer Network Aotearoa to develop a youth-friendly consumer version.

**DISCUSSION AND CONCLUSIONS:** The Standards will positively influence all aspects of an AYA's cancer journey, from diagnosis, through treatment, to survivorship or end of life care. CanTeen's Listen Up group will continue to actively participate in the development, implementation and evaluation of national AYA cancer initiatives and activities, as well as advocating for constant improvement in AYA patient matters.

## **P29** Three philosophy tools to help AYA with cancer to lead a fulfilling life

**P. Vandekerckhove<sup>1</sup>**

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**DESCRIPTION:** Adults and young adults with cancer (AYA) struggle with questions about the meaning of their experience: "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 are aiming to provide these skills to AYA to address questions of identity, spirituality and meaning of life. A training is offered with three philosophy skills in small groups of maximum ten people to help the self-management of life philosophy questions. The philosophical needs are explored at the beginning of the session (Vandekerckhove, 2010). The aim of six sessions is to help participants apply three tools: Confucius (Gongfu) to explore what fulfilment is, Epicurus (gratefulness) to increase fulfilment and Socrates (socratic dialogue) to organise your life with more fulfilment.

**DISCUSSION:** Both AYA with cancer and carers of AYA with cancer find the trainings useful. No difference in engagement in respect of age or prior diagnoses was found. Similar topics emerged during exercises related to challenges about not being understood by other people and the importance of having a positive outlook on life. The best time for intervention remains unclear as people across all stages are interested. Recruitment is challenging partly because cancer survivors are not easy identifiable outside the hospital. A website ([www.addperspective.com](http://www.addperspective.com)) and a Facebook page were created. A free eBook has been downloaded by over 60 people, with no follow up after the eBook. The training has been presented to the adult and paediatric oncology wards of two Belgian hospitals. Financial support is needed to continue this project. Philosophy skills training could address philosophy needs for AYA's.

## **P30** Implementation of a specialised multidisciplinary end of treatment clinic for Adolescent and Young Adult (AYA) cancer patients in South Australia

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**INTRODUCTION:** The minimum standard of care in South Australia for all cancer survivors is to receive a needs assessment and individualised survivorship care plan. AYA cancer patients

have unique needs and require specialist care at all stages of the cancer trajectory, but particularly in survivorship.

**METHODS:** A multi-disciplinary end of treatment clinic was established for all patients accessing services from the Youth Cancer Service SA/NT (YCS SA/NT) following completion of cancer treatment, recognising their unique needs, and an opportunity for improvement in delivery of care into survivorship. As YCS SA/NT does not provide primary medical management but rather works alongside the treating team to provide specialist, age-appropriate care to AYA cancer patients, the focus of this clinic is to ensure support needs are met.

**RESULTS:** An age-appropriate psychosocial assessment is conducted and survivorship care needs of individual patients are evaluated to establish individualised care plans and goals in survivorship. Patients are provided with age-appropriate end of treatment information, resources and support; access is facilitated to specialist allied health services, where applicable, and assistance provided to engage or re-engage with a primary General Practitioner in the community to ensure all health needs are being met. This clinic also ensures that the patient is discussed within a specialist psychosocial AYA multidisciplinary team meeting at the end of their treatment and provides a platform for more formalised and seamless transition of supportive care from YCS SA/NT to community or other supports following treatment completion as appropriate.

**CONCLUSIONS:** This clinic has allowed YCS SA/NT to formalise end of treatment and early survivorship care. Feedback obtained from patients regarding their preferences for content, timing and access to this service has informed improvements in clinic practice. Other services might like to consider a similar model tailored to the resources and specialist knowledge available to them.

## P31 General Practitioners' Management of Cancer in Australian Adolescents and Young Adults

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**INTRODUCTION AND AIMS:** Cancer in adolescents and young adults (AYAs; 10-29 years) carries significant physical and psychosocial burdens; general practitioners (GPs) are well-placed to coordinate their complex multidisciplinary care, but little is known about GPs' management of AYA cancers. We aimed to explore the characteristics of patients, general practitioners (GPs) and cancers involved in adolescent and young adult cancer management consultations in Australia.

**METHODS:** Secondary descriptive analysis of a nationally-representative sample of 972,100 patient-GP encounters from 2006-2016 was conducted using data collected from a study of Australian GP activity, the Bettering the Evaluation and Care of Health (BEACH) program. Patient measures explored included age, sex, language background, socioeconomic status, concession card status, and whether they were new to the practice. GP measures explored included age, sex, whether they were an Australian graduate and practice location. Cancer characteristics, management strategies and referrals were also analysed.

**RESULTS:** AYA cancers were managed in 212 of the encounters, equating to approximately 137 per 100,000 AYA consultations. This rate was higher in older AYAs (25-29 years) and those who held a concession card. Almost 30% of cancers managed were classified as "new", with GPs primarily providing counselling, education, and referrals to specialist care, imaging and pathology.

**DISCUSSION AND CONCLUSIONS:** This study is the first to descriptively explore GPs' role in the care of AYAs with cancer in Australia. Findings are notable in highlighting GPs' management of both new and old cases of AYA cancers, suggesting that GPs play a continuing role in supporting AYAs through education, counselling and coordination of referrals throughout diagnosis and treatment. Further work is needed to explore the changing role of GPs across the cancer trajectory, providing a more complete picture of the GPs' role in the ongoing management of AYA cancers.

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## **P32** Transition of a Complex Patient

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**CASE DESCRIPTION:** DN is a young, 23 year old woman diagnosed with metastatic melanoma living in the Kimberley, Western Australia. At diagnosis DN was working as a teacher, living with her partner and young child. DN received combined modality treatment resulting in successful disease remission. Unfortunately an unknown side effect of the treatment caused radio-necrosis to her corpus callosum causing a significant acquired brain injury (ABI). This was a devastating outcome for DN and her family which caused the breakdown of her marriage, the inability to care for her child and the need for fulltime, supervised care. The ABI was a permanent outcome of treatment necessitating the transition of DN's care for appropriate management of future unmet needs. This case study reflects on the successes and challenges faced throughout this complex transition process.

**DISCUSSION:** Transitional care in Adolescent and Young Adult (AYA) cancer often refers to the transition from a paediatric to an adult setting; however within this distinct patient population we are often responsible for the transition of patients from: Active treatment to survivorship or end of life care Tertiary hospital care back to primary care The metropolitan setting back to the rural or regional setting

**KEY LEARNINGS:** for Transition Patient presentation at a 'complex patient' team meeting to formally identify key issues Transition to new services needs time resources allocated and requiring follow-up and communication before disengagement When liaising between metropolitan and regional health-related services, various forms of communication need to be utilized Allocation of a coordinator required at each site for ongoing communication and correspondence The combination of a paediatric family-focused and an adult patient-centred model of care needs to be promoted Budgetary constraints, transient workforce and other difficulties regional healthcare teams experience to be considered Early preparation of transition, follow-up and evaluation are the key elements.

### P33 Non-Hodgkin Lymphoma in Adolescents and Young Adults - A National Prospective Population-based Study

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**INTRODUCTION AND AIMS:** Non-Hodgkin Lymphoma (NHL) is a common but poorly understood malignancy in AYA patients. Analysis of the English Cancer Registry records of NHLs diagnosed 2008 to 2013 finds AYAs aged 17-23y had 2y survivals, including all NHL sub-types, 10% lower than younger children and 7% less than adults aged 24-30y. The reasons are unclear. The study aims to: understand the spectrum of AYA NHL based on up-to-date classification, correlate outcomes with treatment, establish optimum treatment strategies, inform clinical trial design.

**METHODS:** Population: all NHL diagnosed at age 15-29y, in England and Wales, during 4y (2015-2018). Recruitment: eligible patients informed by a brief information sheet with verbal consent. Data collection: Histological diagnosis, staging, treatment, response, and outcome to 2y. Analysis of outcomes by NHL subtype, age (15-19y, 20-24y, 25-29y), stage, treatment. Eligible cases diagnosed/treated outside a participating centre, and hence not consented, form a subsidiary cohort with diagnosis and mortality only from the national cancer registry.

**RESULTS:** This abstract reports interim diagnosis and mortality based primarily on cancer registry data (2015-2016), while detailed staging and treatment data collection from sites (2015-2018) continues. During 2015-2016, 460 study eligible NHL patients were recorded in England aged 15-29y, 241 cases in AYA aged 15-24y. The most frequent diagnoses in the 15-24y cohort: Diffuse large B-cell (32% of cases), Burkitt's (18%), Primary mediastinal B-cell (9%), Follicular (9%), Anaplastic large cell (7%). At median 15 months follow up, 55(12%) of patients aged 15-29y have died; 4 within 24h of presentation. The highest proportional mortality occurred in NKT-cell 3/4(75%), Hepato-splenic T-cell 3/7(43%), Post-transplant lymphoproliferative disease 5/12(42%), Peripheral T-cell 6/21(29%), Burkitt's lymphoma 12/53(23%).

**DISCUSSION/CONCLUSIONS:** The study has demonstrated feasibility of a national consented AYA research cohort. Mortality data is highlighting high-risk NHL subtypes in AYA. Professional and patient support provides potential for longer term outcome monitoring.

### P34 The power of connection: reflections of attending a 4-day survivorship conference for young adults with cancer

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**BACKGROUND AND AIM:** Young Adult Cancer Canada (YACC) is the leading charity supporting young adults with cancer across the whole of Canada. As part of the researcher's nursing travel scholarship, she attended the 4-day 'YACC Survivor Conference' with the aim of increasing knowledge and understanding of young adult's survivorship needs and to learn from international colleagues how they provide support to this group.

**METHODS:** A focussed ethnographic style was used as part of an experiential learning process. This included use of participant observation and informal conversations with young adults living with and beyond cancer. Field notes, discussions and personal reflections were documented and key themes were explored and reflected on.

**RESULTS:** The key themes that emerged were connection, inclusivity, reduction of isolation and increased self-esteem. Young people described the conference as providing a 'boost' to how they feel on a daily basis, and reported from previous YACC events that positive feelings continued after the experience. The conference was a dedicated, safe space for experiences to be shared openly and honestly; the researcher felt a tangible confidence and connection evolve between and among the young people over the course of the four days. Additionally, creating connections between young people through unique internet-hosted events were impactful for connecting young people over a vast geographical network

**DISCUSSION AND CONCLUSION:** This experience showed the power of connecting young people in a face-to-face setting: the conference sessions/activities, environment, and facilitators all contributing to the connections which occurred between young people. While this was a focussed and reflective learning experience of one specific event, it highlighted the importance of providing platforms to connect young people in a face-to-face environment, and the impact of additional online methods to evolve young people's connections further.

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### **P35**    **The feasibility and acceptability of life coaching for survivors of cancer in young adulthood**

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**INTRODUCTION:** Studies suggest life coaching changes attitudes, alters behaviour, influences thoughts and enhances psychosocial wellbeing in various patient groups. (Wagland et al 2015). Life coaching in the cancer setting has found to optimize/develop skills and capabilities, leading to improved self-efficacy and confidence (Wagland et al 2015). To date, we can find no work on the feasibility and acceptability of life coaching in YA cancer.

**METHODS:** Using an externally appointed, qualified life coach, with experience of the cancer setting, life coaching was offered as a pilot to young adults (YA) (18-24 years) in the first year of finishing cancer treatment within a YA cancer survivorship programme. To assess acceptability at the end of coaching all YA undertook a telephone interview, using semi-structured questions with a member of staff not involved in the coaching. Participants were asked about their experience of life-coaching, whether they achieved or were further forward in reaching their set objectives and if/how life coaching could fit in the YA cancer survivorship programme. Qualitative data from transcribed telephone interviews were analyzed using framework analysis. Feasibility was measured in terms of; cost, time for YA, healthcare professionals and the life-coach, recruitment, and buy-in from professionals.

**RESULTS:** Results suggest coaching had a positive effect on YA's emotional wellbeing as well as their ability to set and achieve measurable goals. Challenges in delivering the intervention included; recruitment; some YA and healthcare professionals were unsure what life-coaching was, and funding the intervention.

**DISCUSSION AND CONCLUSIONS:** Life-coaching would appear to be a useful intervention in a YA cancer survivorship programme. Plans to broaden the scope and awareness of what life coaching and can offer YA are in place, as is further evaluation. References Wagland R et al (2015) Rebuilding self-confidence after cancer: a feasibility study of life-coaching. Supportive Care in Cancer, 23 (3) 651-659.

## P36 Teenage and young adult cancer survivors perception of lifestyle behaviour on current and future health

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**INTRODUCTION:** Existing lifestyle interventions conducted among teenage and young adult cancer survivors (TYACS) have predominantly aimed to elicit health behaviour change via education-based programmes designed to increase awareness of the importance of health behaviours. However, it is unclear whether TYACS already have an understanding that health behaviours are important for health and whether awareness is greater in TYAs who have had a cancer diagnosis than the general TYA population. Therefore the aim of this study was to examine differences between TYACS and general populations-TYAs (GP-TYAs) perception of health behaviours on current and future health, and whether perception is associated with behaviour.

**METHOD:** TYACS (n=263; mean age =20±2.89 years) and GP-TYAs (n=320; mean age: 17.1±3.15 years) completed a Health and Lifestyle questionnaire which included measures of health behaviour (physical activity, diet, smoking status, alcohol consumption, sun-related behaviour) and items assessing perception of these behaviours on current and future health. Logistic regression models (adjusting for age, gender and treatment status) were used to examine the association between health behaviour and perception of behaviour on current and future health.

**RESULTS:** Perceived importance of health behaviour was high among both TYACS and GP-TYAs with >60% reporting each health behaviour as 'very' or 'quite' important. TYACS were more likely to view 'risk behaviours' (smoking, drinking and UV exposure) as important to current health (p<0.005), and view diet and physical activity as important to future health than GP-TYAs (p<0.05). In both groups (independent of age, gender and treatment status) perception of health behaviour as important to current and future health was associated with healthier lifestyle choices.

**CONCLUSION:** These data suggest TYACS have a heightened perception of the importance of leading a healthy lifestyle. Differences in lifestyle behaviour among TYACS and GP-TYAs can be partially explained by differences in belief that behaviour influences current and future health.

## P37 Is adolescence a protective period for the cognitive and psychosocial effects of radiotherapy treatment?

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**AIMS:** Previous research examining the late effects of radiotherapy has tended to focus on survivors treated during childhood. The aim of this study was to provide a preliminary overview of how receiving cranial radiotherapy (CRT) during adolescence affects neurocognitive, social, and psychological functioning in adulthood. Three additional risk factors (radiotherapy dosage, time since treatment completion, and additional treatments) were also evaluated.

**METHOD:** Twenty-five adult survivors of adolescent brain tumours treated with CRT were compared with a control group of 17 survivors of non-CNS malignancies treated with radiotherapy elsewhere in the body. Participants completed a brief IQ assessment, an intrusive

imagery interview, and self-report questionnaire measures of social functioning, depression, and anxiety.

**RESULTS:** Few differences were identified between survivors treated with CRT and controls across domains of social and psychological functioning, though participants treated with CRT reported significantly greater problems with memory, and were five times more likely than controls to be single. Results indicated generally positive social adjustment, and IQ scores and levels of depression and anxiety comparable to the normal population. Total radiotherapy dosage and receiving chemotherapy in addition to radiotherapy were significant predictors of IQ, regardless of where RT was administered in the body. Time since treatment and surgery did not predict late effects across any domain.

**CONCLUSIONS:** The results may be suggestive of a protective effect of age such that survivors treated with CRT during adolescence may not necessarily suffer the same adverse effects as those irradiated during childhood. This is a tentative conclusion in view of methodological limitations. Implications and the need for further research are discussed.

