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An evaluation of the clinical interactions relating to psychological wellbeing and distress between teenagers and young adults (TYAs) diagnosed with cancer and non-psychologist TYA staff

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# CONFERENCE PROGRAMME

## 1st Global AYA Cancer Congress: Working Together: Achieving More

### MONDAY 5 DECEMBER

07:45	Registration and Coffee / Poster Set Up
08:45	<b>Welcome and Introduction to the Conference</b> <i>Siobhan Dunn, Chief Executive, Teenage Cancer Trust, UK and Sam Smith, Congress Chair, Teenage Cancer Trust, UK</i>
08:55	<b>Official Opening</b>
09:05-11:45	<b>Session 1: Global Perspectives</b> Chair: <b>Tim Eden</b> , Edinburgh
09:05	<b>Working Together: Achieving More</b> <i>Siobhan Dunn, Chief Executive, Teenage Cancer Trust, Simon Davies, Chief Executive, Teen Cancer America and Peter Orchard, Chief Executive, CanTeen Australia</i>
09:15	<b>Keynote Lecture: Global Cancer</b> <i>Richard Sullivan, Director, Institute of Cancer Policy, Co-Director, Conflict &amp; Health Research Program, Professor of Cancer and Global Health, King's College, London, UK</i>
09:55	<b>Questions and Answers/Discussion</b>
10:00	<b>Global Japan</b> <i>Kayo Nakata, Assistant Section Chief - Center for Cancer Control and Statistics, Osaka Medical Center for Cancer and Cardiovascular Diseases, Osaka, Japan</i>
10:30	Refreshment Break, Networking, Exhibition and Posters
11:00	<b>Global India</b> <i>Prakash Chitalkar, Director Sri Aurobindo Cancer Institute / Professor of Medical Oncology, Sri Aurobindo Institute of Medical Sciences, Madhya Pradesh, India</i>
11:30	<b>All Speaker Panel: Questions and Answers/Discussion</b>
11:45-12:45	<b>Session 2: Oral Presentation of Submitted Abstracts</b> Chair: <b>Maria Cable</b> , Coventry
11:45-11:50	<b>Introduction</b>
11:50-12:00	<b>01</b> UNDERSTANDING THE NEEDS OF INDIGENOUS AUSTRALIAN ADOLESCENTS AND YOUNG ADULTS IMPACTED BY CANCER: UTILISING NARRATIVES TO IMPROVE SUPPORT SERVICES – AN UPDATE <i>J. Micklem, Adelaide, Australia</i>
12:00-12:10	<b>02</b> CANCER-ATTRIBUTABLE FIRST-YEAR COSTS FOR ADOLESCENT CANCER CARE: A POPULATION-BASED STUDY IN BRITISH COLUMBIA AND ONTARIO, CANADA <i>M. L. McBride, Vancouver, Canada</i>
12:10-12:20	<b>03</b> THE FINANCIAL TOXICITY OF CANCER IN ADOLESCENTS AND YOUNG ADULTS AND THEIR PARENT CAREGIVERS <i>K. Thompson, Melbourne, Australia</i>
12:20-12:30	<b>04</b> "TOO YOUNG TO GET CANCER?" UNDERSTANDING THE CHALLENGE OF ACHIEVING A TIMELY DIAGNOSIS FOR TEENAGERS AND YOUNG ADULTS (TYA) IN THE SOUTH WEST OF ENGLAND <i>R. Dommert, Bristol, UK</i>
12:30-12:40	<b>05</b> PATHWAYS TO DIAGNOSIS IN TEENAGE AND YOUNG ADULT CANCERS IN EUROPE: RESULTS FROM A PILOT STUDY <i>L. Fairley, Leeds, UK</i>
12:40-12:45	<b>Discussion/Further Questions</b>
12:45-14:15	Lunch, Networking, Exhibition and Posters

14:15-14:20	<b>Introduction</b>
14:20-14:30	<b>06</b> TEN YEAR TRENDS OF PARTICIPATION OF TEENAGERS AND YOUNG ADULTS (TYA) IN SELECTED NATIONAL INSTITUTE FOR HEALTH RESEARCH CLINICAL RESEARCH NETWORK TRIALS (NIHR CRN) <i>L. A. Fern, London, UK</i>
14:30-14:40	<b>07</b> RECRUITMENT TO CLINICAL TRIALS IS ASSOCIATED WITH SUPERIOR SURVIVAL IN TEENAGE AND YOUNG ADULT PATIENTS WITH ACUTE LYMPHOBLASTIC LEUKAEMIA <i>R. Hough, London, UK</i>
14:40-14:50	<b>08</b> SUPPORTIVE CARE FOR TEENAGE & YOUNG ADULT (TYA) PATIENTS WITH ACUTE LYMPHOBLASTIC LEUKAEMIA DURING INDUCTION PHASE OF THERAPY IN THE UK <i>K. S. Bhuller, Leicester, UK</i>
14:50-15:00	<b>09</b> APA@AJA : A MOBILE APP FOR FOLLOW-UP OF TEENAGERS AND YOUNG ADULTS WITH CANCER INCLUDED IN A PERSONALIZED PHYSICAL ACTIVITY PROGRAM <i>L. Goffi-Laroche, Grenoble, France</i>
15:00-15:10	<b>010</b> BIRTH OUTCOMES AFTER AYA CANCER DIAGNOSIS <i>H. B. Nichols, Chapel Hill, USA</i>
15:10-15:15	<b>Discussion/Further Questions</b>
15:15-16:15	<b>Session 3 (part a): Treatment Across The AYA Age Range</b> Chair: <b>Martin McCabe</b> , Manchester
15:15	<b>Different Approaches to Treatment Across the Age Span</b> <i>Dan Stark, Senior Lecturer in Cancer Medicine and an Honorary Consultant in Medical Oncology, St James's University Hospital, Leeds, UK</i>
15:45	<b>Nursing Perspective – The Pros and Cons of an Age Appropriate Environment</b> <i>Louise Soanes, Teenage Cancer Trust Nurse Consultant, University College Hospital, London, UK</i>
16:15-16:45	Refreshment Break, Networking, Exhibition and Posters
16:45-17:45	<b>Session 3 (part b): Treatment Across The AYA Age Range</b> Chair: <b>Dan Stark</b> , Leeds
16:45	<b>The Debate: Treatment Across The Age Range</b> <i>Brandon Hayes-Lattin, Clinical Director, Center for Hematologic Malignancies &amp; Director, Adolescent and Young Adult (AYA) Oncology, Knight Cancer Institute, Oregon Health and Science University, Portland, USA</i> <i>Gilles Vassal, Pediatrician - Oncologist - Pharmacologist, Professor of Oncology, Institut de Cancérologie Gustave-Roussy, Villejuif, France</i> <i>Helen Hatcher, Consultant in Medical and Teenage/Young Adults Oncology, Cambridge University, UK</i> <i>David Thomas, Director of The Kinghorn Cancer Centre and Head of the Cancer Division, The Garvan Institute, Sydney, Australia</i>
17:45	<b>My Story, from Osteosarcoma to Research and Advocacy</b> <i>Coleen Quinn, UK</i>
18:05	<b>Day's Summary &amp; Close</b> <i>Mike Stevens, Chair, International Advisors</i>
18:15-20:00	<b>Poster Viewing and Networking: Welcome Drinks Reception</b>

# CONFERENCE PROGRAMME

1st Global AYA Cancer Congress: Working Together: Achieving More

## TUESDAY 6 DECEMBER

08:15	Registration and Coffee / Poster Viewing
08:25	<b>Welcome to the Day</b> <b>Mike Stevens</b> , Chair of International Advisors for the Congress, UK
08:30-10:00	<b>Session 4: Oral Presentation of Submitted Abstracts</b> Chair: <b>Liz Watt</b> , Glasgow
08:30-08:35	<b>Introduction</b>
08:35-08:45	<b>O11</b> PAIN EXPRESSION AND ANALGESIC CONSUMPTION IN ADOLESCENTS AND YOUNG ADULTS (AYAS) WITH CANCER: THE BELIEFS THAT HINDER APPROPRIATE MANAGEMENT <b>P. Marec-Berard</b> , Lyon, France
08:45-08:55	<b>O12</b> FERTILITY DISCUSSIONS AT THE TIME OF A YOUNG PERSON'S CANCER DIAGNOSIS: PATIENT AND PARENT PERSPECTIVES <b>K. Thompson</b> , Melbourne, Australia
08:55-09:05	<b>O13</b> SEVERE FATIGUE IN ADOLESCENT AND YOUNG ADULT (AYA) CANCER PATIENTS: PREVALENCE, IMPACT ON QUALITY OF LIFE (QOL), AND CORRELATES OF FATIGUE SEVERITY <b>H. Poort</b> , Nijmegen, The Netherlands
09:05-09:15	<b>O14</b> AN EVALUATION OF THE CLINICAL INTERACTIONS RELATING TO PSYCHOLOGICAL WELLBEING AND DISTRESS BETWEEN TEENAGERS AND YOUNG ADULTS (TYAS) DIAGNOSED WITH CANCER AND NON-PSYCHOLOGIST TYA STAFF <b>A. Edmondson</b> , Huddersfield, UK
09:15-09:25	<b>O15</b> A QUALITATIVE EXPLORATION OF THE HEALTH-RELATED QUALITY OF LIFE ISSUES RELEVANT TO ADOLESCENTS AND YOUNG ADULTS WITH CANCER <b>S. C. Sodergren</b> , Southampton, UK
09:25-09:35	<b>O16</b> HEALTH-RELATED QUALITY OF LIFE IN ADOLESCENT AND YOUNG ADULT (AYA) CANCER PATIENTS: A LONGITUDINAL STUDY <b>O. Husson</b> , Nijmegen, The Netherlands
09:35-09:45	<b>O17</b> LIFESTYLE BEHAVIOUR AND QUALITY OF LIFE AMONG TEENAGE AND YOUNG ADULT CANCER SURVIVORS IN THE UNITED KINGDOM <b>G. Pugh</b> , London, UK
09:45-09:55	<b>O18</b> 'IT WAS LIKE HAVING A BIG SLEEPOVER WITH OUR CHEMO BAGS ON': EXPLORING THE RELATIONSHIP BETWEEN PHYSICAL AND SOCIAL HOSPITAL ENVIRONMENTS <b>S. Lea</b> , London, UK
09:55-10:00	<b>Discussion/Further Questions</b>
10:00-13:00	<b>Session 5: Cognitive &amp; Psychological Research, Screening and Assessment</b> Chair: <b>Kate Thompson</b> , Melbourne
10:00	<b>Keynote Lecture:</b> <b>The Brain and Adolescent Behaviour</b> <b>Kirstie Whitaker</b> , Research Fellow, Brain Mapping Unit, University of Cambridge, UK
10:40	<b>Questions and Answers/Discussion</b>
10:45-11:15	Refreshment Break, Networking, Exhibition and Posters
11:15	<b>Long-term Cognitive Outcomes in Survivors of AYA Cancer</b> <b>Kevin Krull</b> , Department of Epidemiology and Cancer Control, St Jude Children's Research Hospital, Memphis, USA
11:45	<b>Psychosocial Assessment and Screening in AYA</b> <b>Pandora Patterson</b> , General Manager Research & Youth Cancer Services and Adjunct Associate Professor in the Faculty of Nursing, Sydney Medical School, University of Sydney, CanTeen, Sydney, Australia

12:15	<b>Psychosocial Support Interventions</b> <b>Brad Zebrack</b> , Associate Professor, University of Michigan School of Social Work
12:45	<b>All Speaker Panel:</b> <b>Questions and Answers/Discussion</b>
13:00-14:00	Lunch, Networking, Exhibition and Posters
14:00-15:30	<b>Session 6 (part a): Challenges of Communication and Engagement</b> Chair: <b>Stefan Bielack</b> , Stuttgart
14:00	<b>Primary Care</b> <b>Olga Kostopoulou</b> , Reader in Medical Decision Making, Imperial College London, Faculty of Medicine, Department of Surgery & Cancer, London, UK
14:30	<b>Opening the door to difficult conversations</b> <b>Anne Katz</b> , Adjunct Professor, Faculty of Health Sciences - College of Nursing, University of Manitoba, Winnipeg, Canada
15:00	<b>Integrated Assessment Mapping</b> <b>Jamie Cargill</b> , Teenage Cancer Trust Lead Nurse Teenager and Young Adults (TYA) South West, Bristol Haematology and Oncology Centre, Bristol, UK
15:30-16:00	Refreshment Break, Networking, Exhibition and Posters
16:00-17:45	<b>Session 6 (part b): Challenges of Communication and Engagement</b> Chair: <b>Mike Stevens</b> , Lead, International Advisors
16:00	<b>Engagement with Young People with Cancer</b> <b>Carlo Alfredo Clerici</b> , Department of Oncology and Hemato-oncology, University of Milan, Clinical Psychology Unit, National Cancer Institute of Milan, Italy <b>Andrea Ferrari</b> , Pediatric Oncology Unit, Fondazione IRCCS Istituto Nazionale Tumori, Milan, Italy
16:30	<b>Patient Priorities - are we getting it right?</b> <b>Sue Morgan MBE</b> , Teenage Cancer Trust Nurse Consultant, Leeds General Infirmary and St James Hospital, Leeds, UK <b>Simon Hewett-Avison</b> , Head of Support, Teenage Cancer Trust, London, UK
17:00	<b>The Science of Compassion</b> <b>Tim Anstiss</b> , Member: British Psychological Society & Fellow: Royal Society of Arts, UK
17:30-17:45	<b>Day's Summary &amp; Close</b> <b>Mike Stevens</b> , Chair, International Advisors
19:30	<b>Optional Social Event:</b> <b>Gala Dinner</b> (See page 5)



# CONFERENCE PROGRAMME

1st Global AYA Cancer Congress: Working Together: Achieving More

## WEDNESDAY 8 DECEMBER

08:15	Registration and Coffee / Poster Viewing
08:45	<b>Welcome to the Day</b> <i>Simon Fuller, Director of Services, Teenage Cancer Trust, UK</i>
09:00-12:30	<b>Session 7: Advances in AYA Care - New Developments and New innovations</b> Chair: <b>Stuart Siegel</b> , Los Angeles
09:00	<b>Providing holistic care for familial cancer susceptibility</b> <i>Julian Barwell, Senior Lecturer in Cancer Genetics, Honorary NHS Cancer Genetics Consultant, University of Leicester, UK</i>
09:30	<b>Breast Cancer in AYA</b> <i>Rebecca Johnson, Medical Director of the Adolescent and Young Adult (AYA) Oncology Program, Mary Bridge Hospital, Washington, USA</i>
10:00	<b>Melanoma in AYA</b> <i>James Larkin, Consultant Medical Oncologist, The Royal Marsden, UK</i>
10:30	<b>Osteosarcoma in AYA</b> <i>Stefan Bielack, Medical Director, Klinikum Stuttgart - Olgahospital, Zentrum für Kinder-, Jugend- und Frauenmedizin, Stuttgart, Germany</i>
11:00	<b>Award Presentations</b>
11:20-11:45	Refreshment Break, Networking, Exhibition and Posters
11:45	<b>Proton Beam Therapy</b> <i>Danny Indelicato, Associate Professor Department of Radiation Oncology, University of Florida Proton Therapy Institute, Jacksonville, USA</i>
12:15	<b>Keynote Lecture: Precision Medicine/Genomics</b> <i>David Thomas, Director of The Kinghorn Cancer Centre and Head of the Cancer Division, The Garvan Institute, Sydney, Australia</i>
12:45	<b>All Speaker Panel: Questions and Answers/Discussion</b>
13:00-14:00	Lunch, Networking, Exhibition and Posters

14:00-16:00	<b>Session 8: Maximising Benefits and Minimising Harm</b> Chair: <b>Simon Davies</b> , Los Angeles
14:00	<b>Hodgkin Lymphoma Case Study</b> <i>John Radford, Professor of Medical Oncology, Director of Research, Institute of Cancer Sciences University of Manchester, Manchester, UK</i>
14:30	<b>New TYA Survivorship Data</b> <i>Mike Hawkins, Raoul Reulen, Chloe Bright, Centre for Childhood Cancer Survivor Studies, University of Birmingham, UK</i>
15:15	<b>All Speaker Panel: Questions and Answers/Discussion</b>
15:30	<b>Keynote Lecture: Physical and Emotional Burden of Cancer</b> <i>Brian Lobel, Performer and Senior Lecturer, University of Chichester in Department of Theatre (Performing Arts), Chichester, UK</i>
16:00	<b>Close and Thank you</b> <i>Siobhan Dunn, Chief Executive, Teenage Cancer Trust, UK</i>

