

***Worlds apart:
Culture and context in caring for the whole child***

TIMES	PROGRAMME – DAY ONE – WEDNESDAY 26 th JULY		
09.00-10.45	Registration Main University Building - Marquee		
10.45-11.15	Welcome Large Chemistry Lecture Theatre		
11.15-12.00	Invited Plenary Presentation Global principles: what palliative care means Dr Ann Goldman Chair: Dr Richard Hain		
12.00-13.00	Invited Plenary Presentation Embracing diversity in palliative care – a real opportunity; a significant challenge. <i>Reflecting on our progress</i> Heather Richardson Chair: Dr Richard Hain		
13.00-14.00	Lunch & Poster Viewing – Marquee Top Tips for completing research degrees related to children and young people with life-limiting or life-threatening conditions: Your questions answered <i>A session for those doing, or planning to do, doctoral or masters' level research in children's palliative care</i>		
14.00-15.30	Parallel Sessions Day 1 – Early afternoon		
	1 Large Chemistry Lecture Theatre <i>Chair: Dr Michelle Meiring</i>	2 Small Chemistry Lecture Theatre <i>Chair: Dr Adam Rapoport</i>	3 Large Shandon Lecture Theatre <i>Chair: Dr Ann Goldman</i>
14.00-14.20	0037 When TPN is no longer a viable option Florence Li Sheffield Children's Hospital UK	0002 Specifying eligibility criteria reduces delay in decision making after referral to a children's hospice Mark Hunter Acorns Children's Hospices Trust, UK	0018 Black and Minority Ethnic children with life-limiting conditions (LLCs) – their family experiences of formal care services Wahida Kent Cardiff University, UK
14.20-14.40	0001 Developing a Paediatric Palliative Service Based in a Chinese Orphanage Caroline Sprinz and Katie Hill Addenbrooke's Hospital and Butterfly Children's Hospices, UK and China	0055 Clinical Ethics in Children: the main themes RDW Hain University of South Wales, Cardiff, UK	0056 Bereaved parents' experiences of the transition from curative to palliative care Daniel Kelly (Cardiff University), Pam Smith and Mia Nelson (Edinburgh University) and Rachel McAndrew (Lothian Health Board)

	1 Large Chemistry Lecture Theatre <i>Chair: Dr Michelle Meiring</i>	2 Small Chemistry Lecture Theatre <i>Chair: Dr Adam Rapoport</i>	3 Large Shandon Lecture Theatre <i>Chair: Dr Ann Goldman</i>
14.40-15.00	0022 Togetherness in understanding: the unique role of the "Umodzi" paediatric palliative care team in Malawi Sophie Bertaud Queen Elizabeth Central Hospital, Malawi	0028 Exploring Palliative Care Needs and Provision for Children and Young People with Life-Limiting and Life-Threatening Conditions: A Consultation with Young People Dr Johanna Taylor University of York, UK	0038 Meanings and experiences of Sex(uality): Cultural perspectives and views from young people with life-limiting and/or life-threatening conditions (LLTCs) Maddie Blackburn The Open University, UK
15.00-15.20	0029 ICPCN - making a difference in a culturally diverse world Sue Boucher ICPN, South Africa	0008 Children's Hospices are not about dying – an analysis of deaths 2013-15 from one hospice organisation Mark Hunter Acorns Childrens Hospices Trust, UK	0052 Adolescents with Palliative Care Needs in Uganda – ideas and fears surrounding future, health and sexuality Emma Hughes Hospice Africa, Uganda
15.30-16.00	Refreshments & Poster Viewing – Marquee		
16.00-17.15	WORKSHOPS		
	Workshop 1 Large Chemistry Lecture Theatre	Workshop 2 Small Chemistry Lecture Theatre	Workshop 3 Large Shandon Lecture Theatre
16.00-17.15	0014 Te Wa Aroha/Allow Natural Death – The Weaving of Culture, Care and Communication in Paediatric Palliative Care Emily Chang, Gemma Aburn & Jess Jamieson Starship Children's Hospital New Zealand	0024 Holistic Needs Assessment: World's Apart Dr Victoria Montgomery & Linda Maynard East Anglia's Children's Hospices, UK and Kelly Oldham Hummingbird House, Queensland, Australia	0027 But the Parents Wanted Us to "Do Everything!": Using and Teaching Values Guided Decision Support in Pediatric ICU's Ken Pituch CS Mott Children's Hospital University of Michigan USA
17.30-19.15	Drinks Reception Social event		

TIMES	PROGRAMME – DAY TWO – THURSDAY 27 th JULY		
	Plenary Presentations Large Chemistry Lecture Theatre Chair: Professor Daniel Kelly		
09.15-10.00	Invited Plenary Presentation North America and the Culture of Children’s Palliative Care 0057 Adam Rapoport		
10.00-10.10	Brief Commercial Interlude: Must-have textbooks: latest arrivals on the PPC literary scene Dr Sat Jassal MBE		
10.10-10.30	Plenary Presentation NICE Guidance on End of Life care for Infants, Children & Young People: planning & management (NG61) – From Development in to Practice 0011 Emily Harrop Helen & Douglas House / NICE, UK		
10.30-10.50	Plenary Presentation A Concept Analysis in Relation to the Cultural Competency of the Palliative Care Workforce in Meeting the Needs of Young People from Black, Asian Minority Ethnic (BAME) Cultures 0012 Erica Brown Centre for Children and Families Research, Coventry University, UK		
10.50-11.15	Refreshments & Poster Viewing – Marquee		
11.20-13.00	Parallel Sessions Day 2 – Morning		
	1 Large Chemistry Lecture Theatre <i>Chair: Susie Lapwood</i>	2 Small Chemistry Lecture Theatre <i>Chair: Myra Bluebond-Langner</i>	3 Large Shandon Lecture Theatre <i>Chair: Jo Griffiths</i>
11.20-11.40	0033 Developing and strengthening paediatric palliative care services in Swaziland and Malawi with the aim of integration into National Health Systems Sue Boucher International Children’s Palliative Care Network, South Africa	0004 Challenges to effective Communication in the care of children with palliative care needs: the perspective of mothers and health professionals in Jordan Maha Atout University of Nottingham, Jordan	0013 The long-term impact of a brother’s or a sister’s diagnosis of Trisomy 13 (Patau Syndrome) or Trisomy 18 (Edward’s Syndrome) on adult sibling views of prospective parenthood Erica Brown Centre for Children and Families Research, Coventry University, UK

	1 Large Chemistry Lecture Theatre <i>Chair: Susie Lapwood</i>	2 Small Chemistry Lecture Theatre <i>Chair: Myra Bluebond-Langner</i>	3 Large Shandon Lecture Theatre <i>Chair: Jo Griffiths</i>
11.40-12.00	0036 Paediatric Palliative Care Across Western Australia Marianne B Phillips Princess Margaret Hospital for Children Australia	0005 Developing Good Practice Guidelines for Attendance at a Child's funeral: Keeping a Culture and Context of Caring for the child, for the family and for ourselves Fiona Finlay Sirona Care and Health, UK	0016 Parents' coping during their child's palliative and end of life care phases: Evidence from a qualitative study Anne-Sophie Darlington University of Southampton, UK
12.00-12.20	0040 Psychosocial Functioning Among HIV-Affected Youth and Their Caregivers in Namuwongo, Kampala: Implications for Family-Focused Service Provision in High HIV Burden Settings Ruth Kemigisha Mildmay, Uganda	0007 Advance care planning for a preferred place of death: Do professionals ask children and young people what they want? Michelle Hills Leeds Teaching Hospitals NHS Trust & Martin House Hospice for Children & Young People, UK	0035 The Challenges and Coping Mechanisms of the Parents Caring for Children with Life-limiting Neurology Disorders during Hospital Admission Dr Lee Chee Chan Institute Paediatric Kuala Lumpur General Hospital, Malaysia
12.20-12.40	0041 Addressing paediatric palliative care provision in the West of Scotland Dr Fariel Rahman Royal Hospital for Children, Glasgow, UK	0031 End of life care planning for children local to a regional children's hospital Alice Martin Royal Hospital for Children, Bristol, UK	0051 Children's Nurses' Experiences in Delivering Bereavement Care to Children and Families with Life Limiting Conditions in Ireland Stacey Power University College Dublin, Ireland
12.40-13.00	0042 Our "EPEC®" journey across Canada to enhance palliative care for children with cancer Adam Rapport SickKids and Emily's House Children's Hospice, Canada	0048 Benefits and problems of paediatric advance care planning: a systematic review Deborah Box Martin House Research Centre at the University of York and Martin House Children's Hospice, UK	0050 Cultural contexts of an Emotional Health and Wellbeing Service set within a British Paediatric Palliative Care provider: the fit between holistic care and evidence based practice Victoria Montgomery East Anglia's Children's Hospices, UK
13.00-14.00	Lunch & Poster Viewing – Marquee		

14.00-15.45	WORKSHOPS		
	Workshop 4 Large Chemistry Lecture Theatre	Workshop 5 Small Chemistry Lecture Theatre	Workshop 6 Large Shandon Lecture Theatre
14.00-15.45	<p>0057 Teaching children's palliative care in a diverse culture</p> <p>Michelle Meiring Paedspal (Cape Town) and the University of Cape Town (UCT)</p>	<p>0034 Volunteers: bringing worlds together</p> <p>Katrina McNamara Together for Short Lives, UK</p>	<p>0025 Systemic approaches to training and development of culturally competent practice for children's palliative care professionals in the context of multi-cultural east London</p> <p>Dr Amy Volans East London NHS Foundation Trust, UK</p>
15.45-16.10	Refreshments & Poster Viewing - Marquee		
	1 Large Chemistry Lecture Theatre <i>Chair: Dr Richard Hain</i>	2 Small Chemistry Lecture Theatre <i>Chair: Lorna Fraser</i>	3 Large Shandon Lecture Theatre <i>Chair: Kathryn MacSorley</i>
16.10-16.30	<p>0046 Japanese Paediatric Oncologists' practice in and attitude towards dying children: A comparative study with UK Paediatric Oncologists</p> <p>Megumi Baba Ty Hafan/Cardiff and Vale UHB, UK</p>	<p>0030 Writing of A Perinatal Pathway for Babies with Palliative Care Needs 2017</p> <p>Katrina McNamara Together for Short Lives, UK</p>	<p>0010 The experience of young people in PPI for palliative care research</p> <p>Sarah Mitchell University of Warwick, UK</p>
16.30-16.50	<p>0047 Demographics, symptomatology, and treatments given at the end of life, for children with cancer in a tertiary care centre in India</p> <p>Jean Jacob MNJ Institute of Oncology and Regional Cancer Centre, India</p>	<p>0032 Promotion of Evidence Informed Practice and the Advancement of Perinatal Palliative Care: Utilization of the PARIHS Framework</p> <p>Chloe Shindruk College of Nursing, Rady Faculty of Health Sciences University of Manitoba, Canada</p>	<p>0043 'Transition to Adulthood in Palliative Care - An audit of provision and family experience in South Wales.'</p> <p>Dr Timothy Warlow All Wales Paediatric Palliative Care Network, UK</p>
16.50-17.10	<p>0049 <i>A sense of home doesn't change with the arrival of death. Social home care in a paediatric palliative care: the Catalan experience</i></p> <p>Soraya Hernández Hospital Materno-Infantil Sant Joan de Déu, Spain</p>	<p>0053 To analyse the referral patterns of perinatal patients referred to a specialist palliative care service (SPCS); their demographics, diagnoses, duration of illness, place of death and symptom profile</p> <p>Mary Devins Our Lady's Children's Hospital, Ireland</p>	<p>0054 Delivering end of life care for children and young people in a rural community</p> <p>Jayne Thomas & Rowena Jones Hywel Dda University Health Board, UK</p>
17.10-17.30	<p>0044 The impact of Paediatric Palliative Care Program (PPCP) for the palliative care management team at Siriraj Hospital.</p> <p>Sunsanee Ruangson Team Centre Sriraj Hospital, Thailand</p>	<p>0020 Benefits of Neonatal Palliative Care Education</p> <p>Cinda Sublette RNC-NIC Harris Methodist Fort Worth, USA</p>	<p>0039 Design and Implementation of Simulation-Based Learning for Paediatric Palliative Care Community Nurses</p> <p>Gillian Alexander Jessie May Trust, UK</p>
19.00	Drinks Reception followed by Conference Dinner at Aberdare Hall		

TIMES	PROGRAMME – DAY THREE – FRIDAY 28 th JULY
	<p align="center">Large Chemistry Lecture Theatre Chair: Dr Richard Hain</p>
09.00-09.30	<p align="center">Welcome Thanks and prizes</p>
09.30-11.00	<p align="center">LOUIS DUNDAS SYMPOSIUM Current Controversies in Practice and Policy: What does the evidence tell us? What is needed in the way of further research? OR: When evidence does not align with practice, policy and guidance</p> <p align="center">Co Chairs: Myra Bluebond-Langner, Professor and True Colours Chair in Palliative Care for Children, UCL, Great Ormond Street Institute of Child Health, Louis Dundas Centre, London , England</p> <p align="center">Julie Bayliss, Nurse consultant in Palliative Care, Head of Service Haematology, Oncology, Palliative Care and Haemophilia, Great Ormond Street Hospital The Louis Dundas Centre, London England</p>
09.30-09.40	<p align="center">Introduction</p>
09.40-09.50	<p>1. <u>“The day one talk” in children with high risk brain tumours: Where the literature and clinical reality agree and diverge”</u> Bryan G, Henderson E, Beecham E, Langner R, Hargrave D, Bluebond-Langner M</p>
09.50-10.00	<p>2. <u>Presenting the option not to treat: What can be learned from audio-recorded consultations between parents of children with high risk brain tumours, and clinicians</u> Henderson E, Bryan G, Beecham E, Langner R, Hall N, Myra Bluebond-Langner</p>
10.00-10.10	<p>3. <u>Quality of Life: Clinicians’, Parents’ and Children’s Perspectives</u> Beecham E, Langner R, Hargrave D, Bluebond-Langner M</p>
10.10-10.20	<p>4. <u>How teenagers with cancer understand and enact their own involvement in medical decision-making: Preference, practice and policy</u> Day E, Jones L, Langner R, Hough R, Sterling C, Bluebond-Langner M</p>
10.20-10.30	<p>5. <u>Preferred Place of Death for Children with Life-limiting Conditions is Not Necessarily Home: Results of systematic review of the literature and case series review</u> Peake JN, Dinsdale A, Langner R, Oostendorp L, Craig F , Bluebond-Langner M</p>
10.30-10.40	<p>6. <u>Getting Evidence Into Practice: Suggestions for Education and Training</u> Bayliss J, Karr, T</p>
10.40-10.55	<p align="center">Question and Answers</p>
10.55-11.00	<p align="center">Summary</p>
11.00-11.30	<p align="center">Refreshments – Marquee</p>

	<p align="center">Large Chemistry Lecture Theatre Chair: Dr Richard Hain</p>
11.30-12.00	<p align="center">Dr Lorna Fraser Director of the Martin House Research Centre</p>
12.00-12.30	<p align="center">Dr Richard Hain End of Life Planning in Children</p>
12.30-13.00	<p align="center">Closing remarks and end of conference</p>
13.15-14.00	<p align="center">Post Conference Meeting Shaun Walsh What does great children's palliative care look like? Help inform Together for Short Lives future strategy</p>