

***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 Main Building		
11.15-12.00	Invited Plenary Presentation Global principles: what palliative care means Dr Ann Goldman Chair:		
12.00-13.00	Invited Plenary Presentation Palliative care in a diverse culture: lessons from the adult world Heather Richardson (TBC) Chair:		
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 Main Building <i>Chair:</i>	2 Small Chemistry Lecture Theatre Main Building <i>Chair</i>	3 TBC Main Building <i>Chair:</i>
14.00-14.20	When TPN is no longer a viable option Florence Li Sheffield Children's Hospital UK	Specifying eligibility criteria reduces delay in decision making after referral to a children's hospice Mark Hunter Acorns Children's Hospices Trust, UK	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	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	Need Assessment of psychosocial and spiritual issues of Children with life limiting conditions & their caregivers Dr Pradnya Talawadekar Tata Memorial Centre, Mumbai	What does smell feel like? Adapting multi-sensory care strategies to reflect cultural differences in paediatric palliative care Rhiannon Lewis Essential Oil Resource Consultants, France

14.40-15.00	<p>Togetherness in understanding: the unique role of the “Umodzi” paediatric palliative care team in Malawi</p> <p>Sophie Bertaud Queen Elizabeth Central Hospital, Malawi</p>	<p>Exploring Palliative Care Needs and Provision for Children and Young People with Life-Limiting and Life-Threatening Conditions: A Consultation with Young People</p> <p>Dr Johanna Taylor University of York, UK</p>	<p>Meanings and experiences of Sex(uality): Cultural perspectives and views from young people with life-limiting and/or life-threatening conditions (LLTCs)</p> <p>Maddie Blackburn The Open University, UK</p>
15.00-15.20	<p>ICPCN - making a difference in a culturally diverse world</p> <p>Sue Boucher ICPN, South Africa</p>	<p>Children’s Hospices are not about dying – an analysis of deaths 2013-15 from one hospice organisation</p> <p>Mark Hunter Acorns Childrens Hospices Trust, UK</p>	<p>Adolescents with Palliative Care Needs in Uganda – ideas and fears surrounding future, health and sexuality</p> <p>Emma Hughes Hospice Africa, Uganda</p>
15.30-16.00	Refreshments & Poster Viewing – Marquee		
16.30-17.30	Parallel Sessions Day 1 – Late afternoon		
16.00-17.15	WORKSHOPS		
	<p>Workshop 1 Large Chemistry Lecture Theatre Main Building <i>Chair:</i></p>	<p>Workshop 2 Small Chemistry Lecture Theatre Main Building <i>Chair:</i></p>	<p>Workshop 3 <i>TBC</i> <i>Chair:</i></p>
	<p>Te Wa Aroha/Allow Natural Death – The Weaving of Culture, Care and Communication in Paediatric Palliative Care</p> <p>Emily Chang, Gemma Aburn & Jess Jamieson Starship Children's Hospital New Zealand</p>	<p>Holistic Needs Assessment: World’s Apart</p> <p>Dr Victoria Montgomery & Linda Maynard East Anglia’s Children’s Hospices UK</p>	<p>But the Parents Wanted Us to "Do Everything!": Using and Teaching Values Guided Decision Support in Pediatric ICU's</p> <p>Ken Pituch CS Mott Children’s Hospital University of Michigan USA</p>
17.30-19.15	Drinks Reception Social event		

TIMES	PROGRAMME – DAY TWO – THURSDAY 27 th JULY		
	<p style="text-align: center;">Plenary Presentations Large Chemistry Lecture Theatre Main Building Chair:</p>		
09.15-10.00	<p style="text-align: center;">Invited Plenary Presentation North America and the culture of children’s palliative care Adam Rapoport TBC</p>		
10.00-10.10	<p style="text-align: center;">Invited Plenary Presentation Must-have textbooks: latest arrivals on the PPC literary scene Dr Sat Jassal MBE</p>		
10.10-10.30	<p style="text-align: center;">Plenary Presentation NICE Guidance on End of Life care for Infants, Children & Young People: planning & management (NG61) – From Development in to Practice Emily Harrop Helen & Douglas House / NICE, UK</p>		
10.30-10.50	<p style="text-align: center;">Plenary Presentations 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 Erica Brown Centre for Children and Families Research, Coventry University, UK</p>		
10.50-11.15	Refreshments & Poster Viewing – Marquee		
11.15-13.00	Parallel Sessions Day 2 – Morning		
	1 Large Chemistry Lecture Theatre Main Building <i>Chair:</i>	2 Small Chemistry Lecture Theatre Main Building <i>Chair:</i>	3 TBC Main Building <i>Chair:</i>
11.20-11.40	<p style="text-align: center;">Developing and strengthening paediatric palliative care services in Swaziland and Malawi with the aim of integration into National Health Systems Busi Nkosi International Children’s Palliative Care Network, South Africa</p>	<p style="text-align: center;">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</p>	<p style="text-align: center;">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</p>

	1 Large Chemistry Lecture Theatre Main Building <i>Chair:</i>	2 Small Chemistry Lecture Theatre Main Building <i>Chair:</i>	3 TBC Main Building <i>Chair:</i>
11.40- 12.00	Paediatric Palliative Care Across Western Australia Marianne B Phillips Princess Margaret Hospital for Children Australia	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	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	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	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	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	Addressing paediatric palliative care provision in the West of Scotland Dr Fariel Rahman Royal Hospital for Children, Glasgow, UK	End of life care planning for children local to a regional children’s hospital Alice Martin Royal Hospital for Children, Bristol, UK	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	Our “EPEC®” journey across Canada to enhance palliative care for children with cancer Adam Rapport SickKids and Emily’s House Children’s Hospice, Canada	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	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 Main Building <i>Chair:</i>	Workshop 5 Small Chemistry Lecture Theatre Main Building <i>Chair:</i>	Workshop 6 TBC Main Building <i>Chair:</i>
14.00-15.45	Teaching children's palliative care in a diverse culture Michelle Meiring (TBC) TBC	Volunteers: bringing worlds together Katrina McNamara Together for Short Lives, UK	Systemic approaches to training and development of culturally competent practice for children's palliative care professionals in the context of multi-cultural east London Dr Amy Volans East London NHS Foundation Trust, UK
15.45-16.10	Refreshments & Poster Viewing - Marquee		
	1 Large Chemistry Lecture Theatre Main Building <i>Chair:</i>	2 Small Chemistry Lecture Theatre Main Building <i>Chair:</i>	3 TBC Main Building <i>Chair:</i>
16.10-16.30	Japanese Paediatric Oncologists' practice in and attitude towards dying children: A comparative study with UK Paediatric Oncologists Megumi Baba Ty Hafan/Cardiff and Vale UHB, UK	Writing of A Perinatal Pathway for Babies with Palliative Care Needs 2017 Gill Dickson Together for Short Lives, UK	Design and Implementation of Simulation-Based Learning for Paediatric Palliative Care Community Nurses Gillian Alexander Jessie May Trust, UK
16.30-16.50	Demographics, symptomatology, and treatments given at the end of life, for children with cancer in a tertiary care centre in India Jean Jacob MNJ Institute of Oncology and Regional Cancer Centre, India	Promotion of Evidence Informed Practice and the Advancement of Perinatal Palliative Care: Utilization of the PARIHS Framework Chloe Shindruk College of Nursing, Rady Faculty of Health Sciences University of Manitoba, Canada	Title - TBC Dr Timothy Warlow All Wales Paediatric Palliative Care Network, UK
16.50-17.10	<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> Soraya Hernández Hospital Materno-Infantil Sant Joan de Déu, Spain	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 Mary Devins Our Lady's Children's Hospital, Ireland	Delivering end of life care for children and young people in a rural community Jayne Thomas & Rowena Jones Hywel Dda University Health Board, UK

17.10-17.30	<p>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>Benefits of Neonatal Palliative Care Education</p> <p>Cinda Sublette RNC-NIC Harris Methodist Fort Worth, USA</p>	<p>The experience of young people in PPI for palliative care research</p> <p>Sarah Mitchell University of Warwick, UK</p>
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TIMES	PROGRAMME – DAY THREE – FRIDAY 28th JULY
	<p>Large Chemistry Lecture Theatre Main Building Chair:</p>
09.00-09.30	<p>Welcome Thanks and prizes - Celebrity</p>
09.30-11.00	<p>LOUIS DUNDAS SYMPOSIUM Co-Chairs: Myra Bluebond-Langner and Finella Craig Title of Symposium</p> <p>Introduction - Series of presentations as chosen by Myra –</p>
11.00-11.30	Refreshments - Marquee
11.30-12.40	<p>Salami slot 1: Dr Lorna Fraser Director of the Martin House Research Centre</p> <p>Salami slot 2: Presenter Organisation</p> <p>Salami slot 3: Presenter Organisation</p>
12.40-13.00	Closing remarks and end of conference
	ADDITIONAL MEETINGS
13.30-15.30	<p>Large Chemistry Lecture Theatre Meeting 1</p>
15.30-17.30	<p>Large Chemistry Lecture Theatre Meeting 2</p>