



Martin House Research Centre
2nd Biennial Research Conference - Friday 16th April 2021
Virtual
(mix of live and pre-recorded)

Programme

09:00 **WEBINAR OPEN**

09:15 **Conference welcome (LIVE)**

Prof Lorna Fraser (*Director, Martin House Research Centre*)

Dr Anne-Marie Childs (*Trustee, Martin House*)

Naveed Hafeez – Young Adult (*Video*)

09:40 **Plenary: Towards the development of a Children's Palliative Care Outcome Scale: what are children, young people and parents telling us? (LIVE)**

Professor Richard Harding (*Kings College London*)

Chair: Lorna Fraser

10:10 **Rapid reports: brief presentations showcasing some of the Centre's work with Q&A (6 x 10 minute pre-recorded and available in advance. Single slide overview with LIVE Q&A)**

Chairs: Dr Lucy Zeigler & Dr Susan Picton

Dr Andrew Papworth (Research Fellow) - 'The SWiCH study: a survey of staff wellbeing in UK children's hospices'

Victoria Fisher (Research Trainee) - 'The experiences of fathers of children with a life-limiting condition: A systematic review and qualitative synthesis'

Dr Julia Hackett (Research Fellow) – 'Bereaved parents' accounts of extended time with their child: a multi-site qualitative study of parents' experiences of using cooling facilities provided by children's hospices'

Dr Stuart Jarvis (Research Fellow) – 'Healthcare use when people with life-limiting conditions transition to adult care - a systematic review'

Dr Jo Taylor (Lecturer in Applied Health Research) – 'Polypharmacy in children and young people with life-limiting conditions: an observational cohort study in England'

Dr Suzanne Mukherjee (Research Associate) - 'Patient reported experience measures: Why are they needed for children and young people with life-limiting conditions'

11:00 **BREAK**

11:30 **Oral presentations with Q&A (6 x 10 minute pre-recorded and available in advance. Single slide overview with LIVE Q&A)**

Chairs: Prof Lorna Fraser & Dr Lucy Zeigler

Archana Soman (Consultant Paediatrician, Sheffield Children's NHS Foundation Trust & Bluebell Wood Children's Hospice) – 'Learning from Bereaved Families to Improve Children's Palliative Care: A Qualitative Study'

Mandy Brimble (Senior Lecturer & Professional Doctorate Student, Cardiff University) – ‘How do children's nurses working in hospices manage emotional labour and professional integrity in long term relationships with parents?’

George Peat (PhD Student, University of Leeds) – ‘An Interpretative Phenomenological Analysis of the role of social media in the lives of young men with Duchenne Muscular Dystrophy’

Wahida Kent (Lecturer, University of South Wales) - ‘Black and Minority Ethnic parents’ experiences of caring for a child with life-limiting conditions’

Dr Susie Lapwood (Senior Associate Specialist Emeritus, Helen and Douglas House Hospices) - ‘Creation of the Oxford Centre for Evidence Based Medicine Covid-19 palliative care group. What can we learn? A silver lining from the Covid cloud?’

Nicky Harris (PhD Student, University of West England (UWE), Bristol) - ‘Harnessing modern communications technology to deliver person-centred care for children with life-limiting conditions – what works, for whom, under what circumstances, and why?’

12:30 LUNCH BREAK

13:30 **Plenary: Involving ‘experts by experience’ in the research process: what’s it like and why is it important?** Facilitated by Dr Jo Taylor (*PPI lead, Martin House Research Centre*) with contributions from members of the Centre’s Family Advisory Board and Young Adults’ Group (*pre-recorded videos with parents and young people -played LIVE then Q&A*)

14:00 **Oral presentations with Q&A (5 x 10 minute pre-recorded and available in advance. Single slide overview with LIVE Q&A)**
Chairs: Dr Bob Phillips & Prof Bryony Beresford

Eleanor Willis (Children’s Complex Care Nurse Specialist, East & North Hertfordshire NHS Trust) - ‘What matters most in care and decision-making for children with complex needs: mothers’ perspectives’

Louise Worswick (Research Fellow, University of Southampton) – ‘Developing ‘Views of Informal Carers – Evaluation of Services’ for children (VOICES-C): results from the expert consultation with healthcare professionals’

Marie Friedel (Researcher, Institute of Health & Society-UCLouvain, Belgium) ‘Face and content validity, acceptability and feasibility of the adapted version of the Children’s Palliative Outcome Scale version 2(CPOS-2): a qualitative pilot study’

Emily Parsons (Senior Staff Nurse, Guys and St Thomas’ NHS Trust) – ‘Parents’ perspectives on conflict in paediatric healthcare: a scoping review’

Vicky Kammin (The Martin House Research Centre, PhD Student) - ‘Rocks and Pebbles’: exploring professionals experiences of collaborative working with bereaved siblings groups in paediatric palliative care’

15:00 BREAK

15:20 **Plenary: Hidden incidents: improving support to parents caring for children with medical complexity.** Bethan Page (*University of Oxford*) and Dr Emily Harrop (*Oxford University Hospitals*) (*LIVE*)
Chair: Prof Bryony Beresford

15:50 **Concluding comments: Dr Helena Dunbar, Director of Service Development & Improvement - Together for Short Lives**

16:00 CLOSE

*** Royal College of Paediatrics and Child Health (RCPCH) has approved this activity for CPD in accordance with the current RCPCH CPD Guidelines ***

<https://www.york.ac.uk/healthsciences/research/public-health/projects/martinhouse/mhrccconf2021/>