

## Martin House Research Centre

1st Biennial Research Conference: Friday 21st September 2018: University of York

### Programme

- 09:15      **REGISTRATION AND COFFEE**
- 10:00      **Welcome**
- 10:05      **Plenary: *An introduction to the Martin House Research Centre.***  
Dr Lorna Fraser (*Director, Martin House Research Centre*)
- 10:20      **Plenary: *Using evidence to inform change: an example from Scotland.***  
Dr Pat Carragher (*Medical Director, Children's Hospices Across Scotland*)
- 10:50      **Oral presentations:**  
Unpacking sensitivity: methodological challenges of undertaking sexuality research with young adults with life-limiting and/or life-threatening conditions (LLTCs).  
(*Maddie Blackburn, The Open University*)  
  
A meta-ethnography of parents' experiences of their children's life-limiting conditions.  
(*Gianina-Ioana Postavaru, Bishop Grosseteste University*)  
  
Conflicts between families and medical teams: lessons to be learned from (almost) 30 years of litigation regarding seriously ill children in England and Wales.  
(*Veronica Neefjes, University of Manchester*)  
  
Place bonding at a children's hospice. (*Helena Dunbar, DeMontfort University*)
- 11:55      **Research design and methods slot (1): *Economic evaluation: what is it and why do we need to do it?*** Helen Weatherly (*Centre for Health Economics, University of York*)
- 12:15      **LUNCH and POSTER VIEWING**
- 13:15      **Plenary: *Measuring individual-level outcomes in palliative care: why and how.***  
Prof. Fliss Murtagh (*Hull York Medical School; Supportive Care, Early Diagnosis and Advanced Disease Research Group (SEDA), University of Hull*)  
**A chief executive's response: Martin Warhurst (*Martin House Children's Hospice*)**  
**Questions and discussion**
- 14:00      **Oral presentations:**  
The journey through care: a realist inquiry into the delivery of palliative care for children, young people and their families.  
(*Sarah Mitchell, Anne-Marie Slowther, Jane Coad, Jeremy Dale: University of Warwick*)  
  
Advance care planning in paediatric palliative care: a two year review of practice in a UK tertiary paediatric palliative care service.  
(*Lizzie Bendle, Joanna Laddie, Kathy Gilbert, Emily Hellewell: Evelina London Children's Hospital*)

Palliative care for young people with life-limiting illness: what should we be teaching specialist palliative care trainees?

*(Amelia Stockley, Karen Forbes: University of Bristol)*

**14:45**      **TEA BREAK and POSTER VIEWING**

15:05      **Research design and methods slot (2): *National datasets: a rich (and under-used) seam of information.*** Dr Roger Parslow *(Senior Lecturer, University of Leeds; Principal Investigator, Paediatric Intensive Care Audit Network)*

15:20      **Plenary: Conversations about end of life.** Prof. David Abbott *(University of Bristol)*  
**Clinicians' responses:** Dr Anne Marie Childs, Consultant Paediatric Neurologist; Sue Manning, Neuromuscular Care advisor *(Leeds Teaching Hospitals NHS Trust)*  
**Questions and discussion**

4:10      **Concluding comments**

**4:15**      **CLOSE**

**\* Royal College of Paediatrics and Child Health (RCPCH) CPD accreditation \***

## Further information

### Conference objectives

This conference brings together researchers and those interested in using research evidence to inform the design, delivery and evaluation of services for children and young people with life-limiting conditions and their families. The aims of the conference are

- to offer an overview of current and recently completed UK research within the field;
- to consider the implications of those findings for service design and/or practice;
- to develop delegates' knowledge and understanding of different research approaches and methods and their application within the field of children's palliative care;
- to provide a forum for connection and exchange between the research and practitioner/provider communities.

By the end of the conference, delegates will:

- have an understanding of current UK research activity concerning children and young people with life-limiting condition and their families;
- have an understanding of the range of research methods and data sources which are relevant to this population;
- understand the role of evidence in service design, service development and practice
- have heard and participated in debates about research evidence and the implications for service design and practice;
- understand some ways by which research can influence and impact service design and practice.

### Who is the conference for?

- Professionals working with children with life-limiting conditions and/or in the children's/young adult palliative care sector who are interested in getting involved in research or using research evidence
- Research students
- Researchers and academics

### Conference fees and registration

Registration is now open at:

<https://www.york.ac.uk/healthsciences/research/public-health/projects/martinhouse/mhrcconf2018/>

Conference fees: £75

Early bird: £50 (closes 30 June)

### Contact us

If you have any queries, please contact Jenny Parry, our Centre administrator:

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