



#MHRCConf18
@UoYMHRC
@lornafraser10





The
Martin House
RESEARCH CENTRE

In partnership with



UNIVERSITY
of York

The Martin House Research Centre

Dr Lorna Fraser on behalf of the MHRC team

Senior Lecturer, Dept of Health Sciences, University of York and
Director of The Martin House Research Centre

**The Martin House Research Centre 1st Biennial Research conference
Sept 2018**

Martin House Children's Hospice



History of Martin House & Research



- Involved in research for many years
- Funded research since 2007
- Trustees very supportive of research →
Research Active Hospice



“The Martin House Research Centre”

- a multi-disciplinary centre for research on the care and support of children and young people with palliative care needs, their families and the palliative care workforce.
- The Centre will be holistic in its scope, recognising that the care and support needs of children and families span clinical/medical, social, parenting/caring, spiritual, financial and practical domains.
- To undertake high quality research, the outputs of which, should be the evidence which will help to ensure that all children and families receive equitable, high quality care



Aims

- to undertake and effectively disseminate world leading research on the care of children and young people with life-limiting conditions and the provision of children's palliative care.
- to build research capacity within children's palliative care within the context, and active support, of one of the UK's prestigious Russell Group of universities.
- to act as 'hub' and facilitator for children's palliative care research within the fields of epidemiology and health & care services research in the UK and internationally.
- to carry out the groundwork needed to develop a workstream of research on 'clinical interventions'
- to offer a 'responsive research facility' to Martin House and the region in terms of data / evidence needs;
- to maintain and develop Martin House as a research-active organisation and stimulate and support the involvement of Martin House staff and service users in the Centre's research where appropriate.
- to represent Martin House (and the region) at regional and national children's palliative care research forums;



Launch Event-January 2017



Team



Dr Lorna Fraser



Prof Bryony Beresford



Dr Roger Parslow

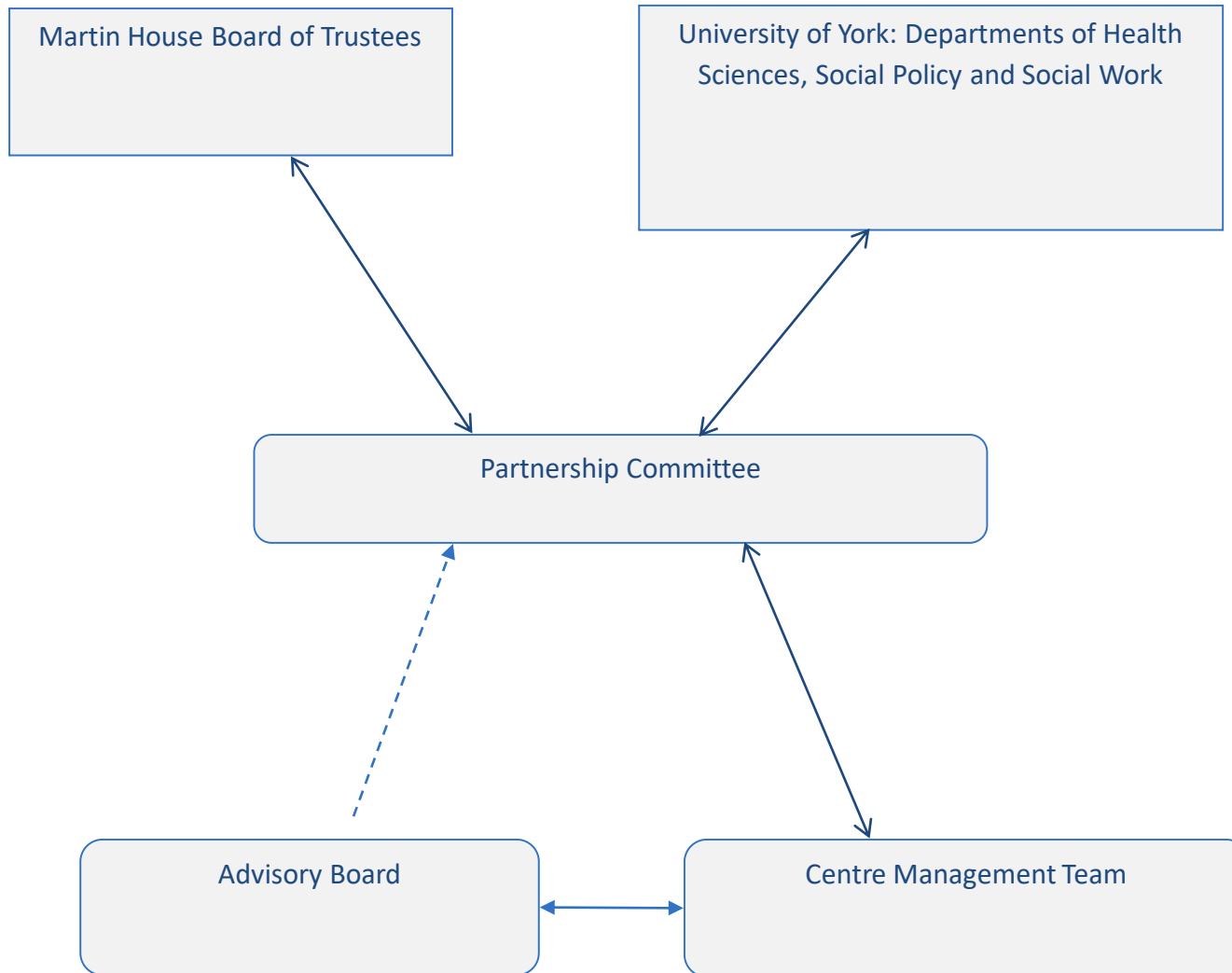


Dr Jan Aldridge

- Lecturer
- 3 research fellows
- Administrator
- 1 part time PhD student
- 2 fulltime PhD students



Governance

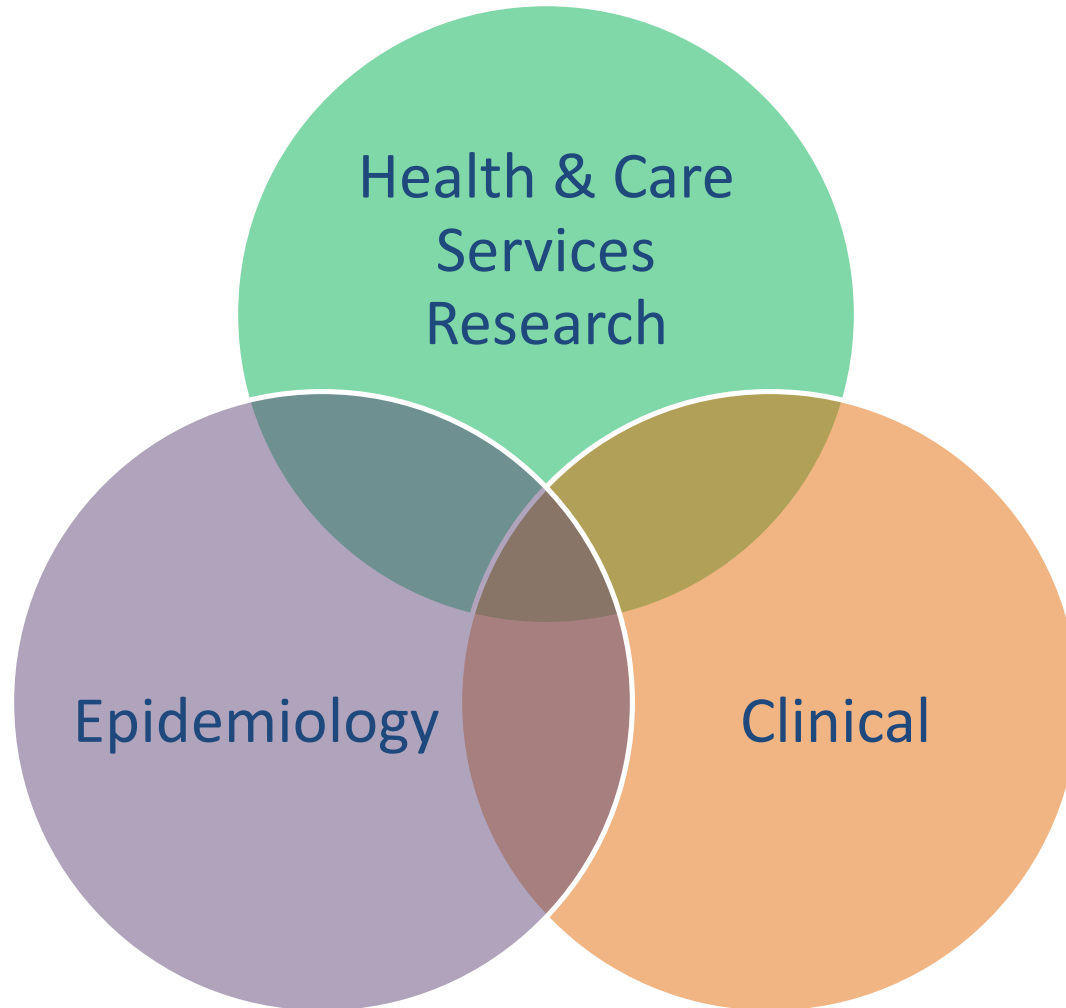


Patient, Parent & Public Involvement

- FAB (Family Advisory Board)



Workstreams



Core Funded Studies (n=8)

Title	Lead	Team	Methodology	Status	Outputs	Funding
Research Prioritisation Exercise	Bryony Beresford	Lorna Fraser Alison Booth Jane Maddison	Review and Consultation Exercise.	Complete	Conference presentation x2 Palliative Medicine paper in press	MHRC
GP Involvement	Lorna Fraser	Stuart Jarvis	Secondary Data Analyses	In Progress	Rome PPC Conference	MHRC/HERC
Bereavement Support for parents whose child has died	Lorna Fraser/ Bryony Beresford	Tom Ainscough Jo Taylor	Systematic Review	In Progress	Rome PPC Conference	MHRC
The Early Days Project: parents' experiences of the early days of bereavement and the support they receive from children's hospices	Bryony Beresford	Julia Hackett	Survey Interviews	In Progress	Rome PPC Conference	MHRC
Informing staff support interventions and practices in children's hospices: a mixed methods study	Jo Taylor	Lorna Fraser Jan Aldridge Bryony Beresford	Mixed Methods	Start Dec 2018		MHRC
Psychological Health of Children with a LLC	Mary Barker (PhD)	Lorna Fraser/ Bryony Beresford	Quantitative	In Progress	Nottingham PHD conference Rome PPC conference	MHRC
Psychological Support Services for Siblings of Children with a LLC	Liam Robson (PhD)	Lorna Fraser/ Bryony Beresford	Mixed Methods	In Progress	Rome PPC conference	MHRC
Advanced Care Planning	Debbie Box (PhD)	Lorna Fraser/ Bryony Beresford	Qualitative	In Progress	Nottingham PHD conference	MH

Externally Funded Studies (n=6)

Title	Lead	Team	Methodology	Status	Outputs	Funding
Specialist Paediatric Palliative Care Input for Children with Malignancies	Lorna Fraser	Jo Taylor Alison Booth Bryony Beresford Bob Phillips	Systematic Review and Consultation Exercise.	In Progress	Childhood Cancer Conference Rome PPC Conference Paper in preparation	Centre for Future Health
Updating the Prevalence of children with LLC utilising multiple data sources	Lorna Fraser	Stuart Jarvis	Secondary Data Analyses	In Progress		True Colours Trust
Evaluation of the Transition Award pilot Martin House/St Leonards	Bryony Beresford	Jo Taylor Tom Ainscough	Qualitative	In Progress		TFSL
Crisis prevention rather than crisis management: the health of mothers of children with a life-limiting condition	Lorna Fraser	Jan Aldridge	Mixed Methods	Starts Jan 2019		NIHR Trainees Centre
Transitioning from paediatric to adult healthcare with a life limiting condition	Stuart Jarvis	Lorna Fraser	Secondary Data Analyses	Starts Jan 2019		NIHR Trainees Centre
The role of different diets in children who are gastrostomy fed	Lorna Fraser	Jo Taylor Bryony Beresford	Qualitative + prospective cohort	Starts Feb 2019		NIHR HTA Commissioned

Capacity building



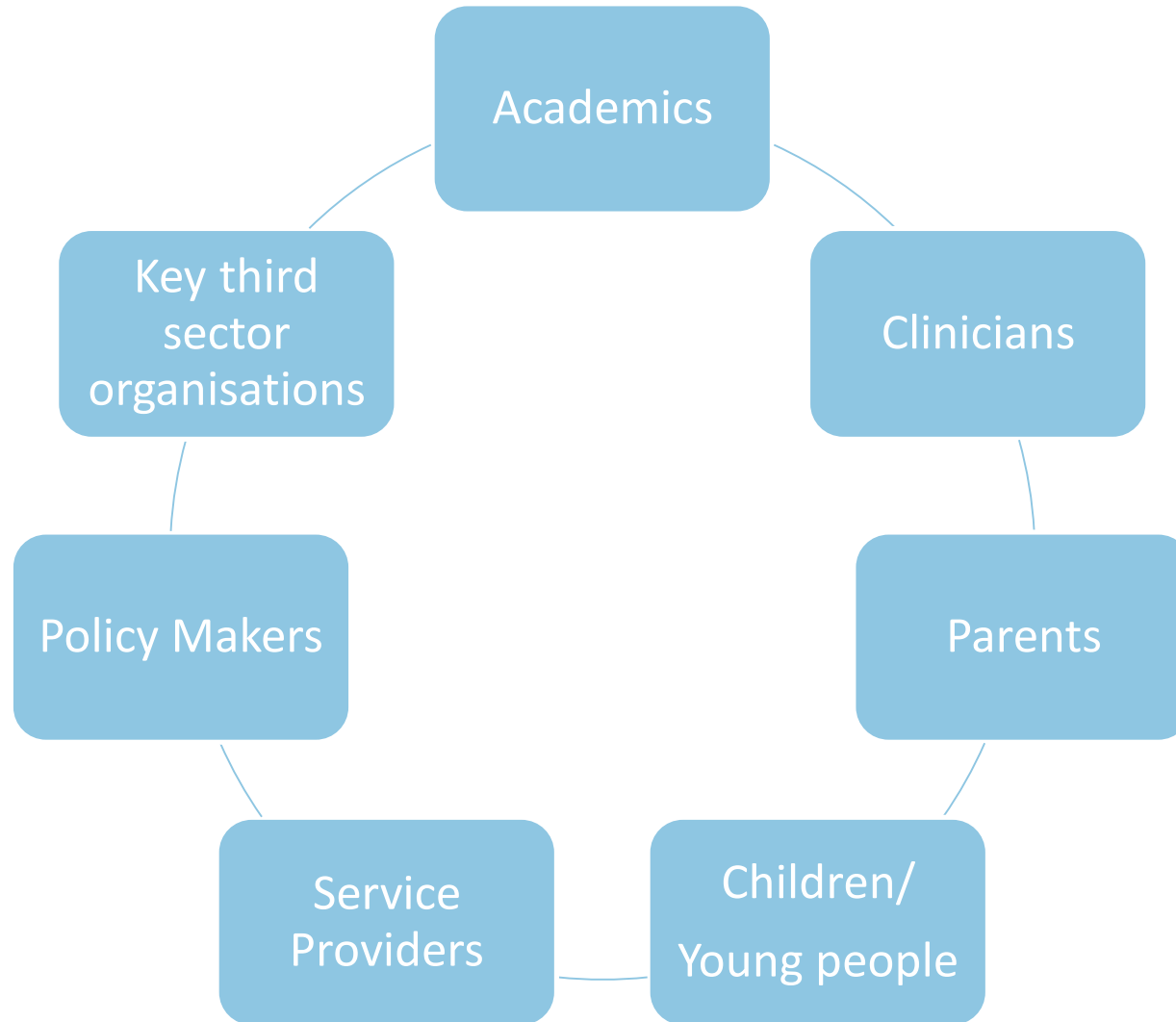
Twitter journal club



Yorkshire and Humber
Children's Palliative
Care Network



Collaboration



Publications

Best practice

'I can't tell my child they are dying'. Helping parents have



Original Article

Comparing routine inpatient data and death records as a means of identifying children and young people with life-limiting conditions

Stuart Jarvis and Lorna K Fraser

Palliative Medicine
1-11
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DOI: 10.1177/0269216317728432
journals.sagepub.com/home/pmj
SAGE

Abstract

Background: Recent estimates of the number of children and young people with life-limiting conditions derived from routine inpatient data are higher than earlier estimates using death record data.

Aim: To compare routine inpatient data and death records as means of identifying life-limiting conditions in children and young people.

Design: Two national cohorts of children and young people with a life-limiting condition (primary cohort from England with a comparator cohort from Scotland) were identified using linked routinely collected healthcare and administrative data.

Participants: A total of 37,563 children and young people with a life-limiting condition in England who died between 1 April 2001 and 30 March 2015 and 2249 children and young people with a life-limiting condition in Scotland who died between 1 April 2003 and 30 March 2014.

Results: In England, 16,642 (57%) non-neonatal cohort members had a life-limiting condition recorded as the underlying cause of death; 3364 (12%) had a life-limiting condition-related condition recorded as the underlying cause and 3435 (12%) had life-limiting conditions recorded only among contributing causes. In all, 5651 (19%) non-neonates and 3443 (41%) neonates had no indication of a life-limiting condition recorded in their death records. Similar results were seen in Scotland (overall, 16% had no indication of life-limiting conditions). In both cohorts, the recording of life-limiting condition was highest among those with haematology or oncology diagnoses and lowest for genitourinary and gastrointestinal diagnoses.

Conclusion: Using death record data alone to identify children and young people with life-limiting condition – and therefore those who would require palliative care services – would underestimate the numbers. This underestimation varies by age, deprivation, ethnicity and diagnostic group.

Keywords

Palliative medicine, child, inpatients, cause of death

10.1136/archdischild-2017-312638

Original article

ing conditions in paediatric national cohort, data

What is already known on this topic?

- ▶ The prevalence of children and young people with life-limiting conditions (LLCs) or life-threatening conditions is rising.
- ▶ Overall mortality in paediatric intensive care unit (PICU) is decreasing.

What this study adds?

Funding information

Funding information This research was funded by WellChild

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Martin House Research Centre

The Martin House Research Centre is a partnership between Martin House Children's Hospice, the University of York ([Department of Health Sciences](#)) and the [Social Policy Research Unit](#)) and the University of Leeds. It is a multi-disciplinary centre for research on the care and support of children and young people with palliative care needs, their families and the palliative care workforce. The Centre will be holistic in its scope, recognising that the care and support needs of children and families span clinical/medical, social, parenting/caring, spiritual, financial and practical domains.



Twitter updates

UoYmhc Retweeted

Jan R. Boehnke
@jrboehnke

#job
#sysreview #cancer #children
#adolescents
@UoYmhc

Jul 19, 2017

UoYmhc Retweeted

Lorna Fraser
@lornafraser10

New paper @UoYmhc Children with life-limiting conditions in



Today



The
Martin House
RESEARCH CENTRE



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**

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

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*)

TEA BREAK and POSTER VIEWING

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*)

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

Concluding comments

CLOSE