

**Conclusions** The four data sets harnessed the potential of people, teams' and organisations' expertise and passion. Partnership is the way forward to support hospices to be research active. Using the data sets, further consultation and research, the forthcoming Hospice UK action plan will propose the shared goals, timelines and outputs for hospices to be 'research active'.

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## 0-20 STEERING THE RESEARCH ACTIVITIES ACROSS A HOSPICE COLLABORATIVE

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**Background** In light of the success of recruiting more than 600,000 patients to clinical research studies in 2013/14 (National Institute for Health Research, 2016), four hospices within one region in England formed a Hospice Collaborative (the Collaborative) and have attained funding for a research practitioner to support the research activities since late 2015. These hospices anticipated to provide evidence-based care and to offer chances to patients and families to participate in research studies in order to excel on the existing outstanding palliative/end-of-life care and services (Perkins *et al.*, 2014).

**Aims** The research practitioner works across the Collaborative and aims to:

- Raise the research awareness amongst staff
- Promote the importance of research within hospices
- Enhance the research readiness within hospices
- Enable hospices to participate in the NIHR Portfolio studies.

**Method** The research practitioner acted as an information and resource hub to provide and exchange updates regarding the NIHR Portfolio studies, research training and research meetings. Particularly, internal and external research trainings were promoted to hospice staff to gain a better understanding of the rationale, the importance and the standard practices of undertaking research tasks with patients.

**Results** Within five months of introducing the research practitioner, several key pieces of work have been achieved across the Collaborative including:

- Delivered an in-house 'Introduction to Research' presentation
- Organised a bespoke Good Clinical Practice training where 22 hospice staff attended
- Submitted Expression of Interest Forms for four NIHR Portfolio studies
- Three out of four hospices have been selected as recruitment sites for two NIHR Portfolio studies.

**Conclusions** Following the implementation of the ground work, these hospices are poised to participate in the NIHR Portfolio studies and the Collaborative was successful in securing recurring funding to grow and support this essential research work.

## Conference Papers 6

### 0-21 'OUT OF THE WILDERNESS': THE VALUE AND MEANING OF A GROUP FOR FATHERS OF CHILDREN WITH LIFE-LIMITING CONDITIONS

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Family support is widely regarded as an important factor in the palliative care journey. The distinct needs of fathers are particularly well documented in research of children with long-term conditions and this naturally extends to paediatric palliative care where differing views and needs of males versus females has been highlighted. However, the male viewpoint is often minimal or absent in paediatric palliative care research. Therefore the needs of fathers are often unrecognised and remain unmet.

This paper describes a project which explores the value and meaning of a group which aims to provide psychosocial support to fathers of life-limited and life-threatened children.

The 'Dads group' was set up in 2006 in recognition that provision specifically for fathers, locally and nationally, was sparse. Initial activities centred on sporting events and this is still a feature of the group. However, the group has evolved to be so much more, in terms participant numbers, activities and the depth of support it offers. The findings of the evaluation served two purposes, i.e. to gain a better understanding of the value and meaning of the group to its members and to inform future service provision. This paper will focus on the value and meaning of the group.

The main themes emerging from the data were:

- Support
- Shared and sharing experience
- Challenging gender roles
- Isolation and loneliness

One father said;

"I'd be in the wilderness without it"(D8)

The final statement above, more than any other, underlines the importance of this gender specific group to its participants. This evaluative project, which studied a purposive sample via a focus group, provides evidence which can be used to underpin the development of similar groups throughout paediatric palliative care in hospital, hospice or the wider community.

### 0-22 GRANDPARENTS' EXPERIENCE OF THE DEATH OF A GRANDCHILD FROM A LIFE-LIMITING CONDITION: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

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Traditionally, bereavement support for families extends to parents and siblings of children who died from a life-limiting condition. Few studies have focused on the needs of bereaved grandparents,