STRIVING TO BECOME RESEARCH ACTIVE HOSPICES: THE STORY IN ONE REGION THROUGH ROLES AND COLLABORATION

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Background The importance of undertaking clinical research has been reaffirmed by 95% of the public in a national survey (NIHR CRN, 2014). Yet, independent hospices often face challenges to conduct research partly due to different governance structures and procedures outside NHS organisations (Perkins et al., 2014). The Commission into the Future of Hospice Care highlighted the importance of research in hospices recommending how research could be implemented, including introduction of staff with ‘research’ in job titles and partnerships with universities (Payne et al., 2013).

Aims Five hospices within one region in England have begun implementing research through appointing a research facilitator and a research practitioner. They aim to

• facilitate collaboration between organisations
• enhance research awareness among staff
• support and develop new research projects within hospices
• engage in others’ research.

Method The research posts have reached beyond their hospices. One belongs to the regional NIHR CRN and another has a formal link with a local university. In 2013, a local palliative care research group was set up, invited clinicians and academics to develop research and other related activity collaboratively. Both research facilitator and practitioner are members and facilitators of the group.

Results Reviewing the research strategy of the hospices has been initial work to reflect and standardise the research practices across hospices. Abundant information on research training, funding opportunities and research studies has also been widely shared amongst hospices. Excitingly, an upcoming annual local research day, the research group and research posts have allowed hospices to work collectively.

Conclusion Work within and between hospices is a stimulating opportunity to include wider pool of patients in research, extending the audience to comprehend the importance of research and increasing the evidence base for developing palliative care services. It is exhilarating to see research continuing to flourish across the region.

PRIORITY SETTINGS FOR END-OF-LIFE CARE

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Introduction End-of-life (EoL) care is an under-researched area. It is vital to focus on the priorities that are likely to bring the most benefit to patients, carers, and their families. This project set out to identify the EoL research priorities of healthcare professionals (HCPs) and carers in Greater Manchester.

Approach Following a scoping exercise of EOL services in Greater Manchester, comprising of semi-structured interviews with HCPs, CLAHRC GM identified six topics within the 10 national EoL research priorities outlined by PeolcPSP. The topics identified were those that we have the capability to deliver research in:

1. Education and knowledge for staff and carers
2. Access to 24 hour care and support
3. Equitable Access
4. Advance care planning
5. Care at home
6. Continuity of care

Outcomes Combining carer and HCP responses, the topics of shared priority were:

• Advance care planning (62% carers, 56% HCPs)
• Access to 24-hour care (65% carers, 50% HCPs)
• Education and knowledge for staff and carers (73% carers, 34% HCPs)

Whilst all topics were generally viewed as important by carers, there was more emphasis placed on training and education as the main priority whilst HCPs focused more on advance care planning.

HCPs also identified important research questions within their chosen topics.

Next steps The shared priorities will be used to develop the research questions identified by HCPs and, through further carer input, will shape the EoL research delivered across Greater Manchester over the next few years.

DEVELOPING A HOSPICE RESEARCH CULTURE: LESSONS FROM A RANDOMISED TRIAL WITH 11 ORGANISATIONS

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Background The Hospice UK report ‘Research in palliative care’ has led to an increase in hospices wanting to become more research active. However, to do this they often need a research project to catalyse this, and ideally support from palliative care research institutions.

Aim To report on the research experiences of 11 palliative care units who were partners in a randomised trial of befriending services

Methods A wait-list controlled trial with nested qualitative case studies investigating volunteer delivered befriending services across 11 sites. Patients (n = 195) were estimated to be in their last year of life and randomly allocated to receive the befriending intervention immediately or after a four week wait. We report on the skills developed by non-clinical hospice staff who were responsible for site trial management and informed consent procedures.

Results Training for this role included innovative face-to-face role play workshops, access to good clinical practice education, and virtual site visits to check procedural compliance and address concerns. Trial initiation issues included acknowledging site staff design concerns and involving them in developing the trial