

completion date of training approaching (30%). Four ideas for future research projects were submitted.

Conclusions Surveying trainees to gauge opinions on our research collaborative has shown a continued enthusiasm for developing research ideas and commitment to trainee-level leadership. WM CARES has demonstrated the value of trainee-led research with an expanding footprint in the palliative care literature.

P-106 REGIONAL COLLABORATION FACILITATES DELIVERY OF PALLIATIVE CARE RESEARCH IN THE WEST MIDLANDS

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Background Within the West Midlands there are a number of palliative care services which are actively engaged in research whilst others are working to become 'research ready'.

Aims

- To increase research activity within palliative care providers across the West Midlands;
- To develop and conduct original research in these settings across the West Midlands;
- To support delivery of the National Institute for Health Research (NIHR) and Charities Consortium for Hospice and Community Research objectives.

Methods A collaborative network was formalised in 2018, which meets quarterly and is made up of clinical and non-clinical staff that represent:

- Hospices;
- NHS community palliative care services;
- NIHR senior research staff for supportive and palliative care;
- University representatives;
- A representative from the registrar-led West Midlands research collaborative.

Results Meetings are attended by over 10 organisations and this number continues to increase. Feedback on being part of the group includes:

- Excellent networking opportunities and a useful forum for problem solving;
- Helpful with job descriptions and interview questions for recruiting research nurses;
- Useful for gaining ideas of how to promote research within a hospice and to hospice Boards;
- Has enabled us to identify studies to which we could recruit patients and become part of the study;
- Being able to discuss a research project with other organisations before deciding whether it was appropriate to put in an expression of interest;
- NIHR research nurses have reported improved ability to signpost potential studies and training opportunities through the group.

Conclusions So far, the group has led to an increase in recruitment to portfolio studies within the region and is helping to establish the infrastructure that will enable through collaborative working the development of original research projects.

P-107 ENABLING DYING PATIENTS TO TAKE PART IN RESEARCH USING ADVANCED CONSENT METHODOLOGY

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Background The need for research is a priority area in palliative care. Palliative care research is essential to establish evidence based models of care that are required to improve outcomes for people with terminal illness (Higginson, 2016). Obtaining informed consent for participation in hospice and palliative care clinical trials is an ongoing challenge faced by researchers (Agar, Ko, Sheehan, Chapman *et al.*, 2013; Hardy, 2000; Rees, 2001).

Aim By consenting patients in advance, we aimed to improve research opportunities in the last week of life.

Methods Advanced consent methodology was used to recruit participants to a National Institute for Health Research Portfolio study. Potential participants with capacity were given verbal and written information by a researcher outlining the aims of the study and the advanced consent process, looking to continue research into the last week of life.

A 'Personal consultee' was identified to act as a point of contact should the participant lose capacity to consent to further assessments.

Once recruited to the study the researcher ensured regular contact with both participant and consultee throughout their inpatient stay.

Hospice staff were regularly updated on research processes, with an aim to minimise gate keeping (Preston, Payne, Salt, Griggs *et al.*, 2013).

Results The majority of patients agreed to provide consent in advance, leading some to have assessments in the last week of life. This is consistent with previous work reporting patients' willingness to participate in research (Nwosu, Mayland, Mason, Varro *et al.*, 2013; Henderson, Addington-Hall, Hotopf, 2005). Regular communication ensures that caregivers are kept informed. Feedback has been positive when performing assessments in the last week of life, with focus on improving future care.

Conclusions Our experiences have demonstrated that palliative patients want to participate in research up to and including the last week of life. Caregivers have shown great desire to support research.

These findings could encourage other palliative care settings to recruit patients to research studies using advanced consent, thus informing policy for best evidence based care at the end of life.

P-108 A RECIPE FOR ENABLING RESEARCH IN NON-NHS ORGANISATIONS

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Background Health and social care research has expanded beyond hospitals and GP surgeries to include hospices, charities and care homes. The NIHR has increased support for research in palliative and end of life care to support activity in this area, which includes some non-NHS organisations.

However, there are challenges in setting up and undertaking research in a non-NHS setting which can present perceived barriers to participation.

Aim To identify the challenges and perceived barriers and to support organisations, including non-NHS, who wish to participate in research by providing them with knowledge, skills and tools to de-mystify and simplify the process, thus supporting them in their research participation.

Methods

- Working with the Local Clinical Research Network to identify the challenges and potential barriers to setting up and undertaking research in organisations with little or no research experience, which includes some non-NHS organisations. This involved communications with all hospices within the East Midlands and asking them what they wanted and what would be useful to them;
- Development of a suite of research governance Host Organisation Standard Operating Procedures to include governance arrangements for the delivery of research in a non-NHS setting;
- Close collaboration with the local NHS Trust to ensure alignment of governance processes.

Conclusions Although there are challenges and perceived barriers to delivering research within a non-NHS setting, none of these are insurmountable with the correct level of support. It is important that these organisations are able to participate in research if they wish to, secure in the knowledge that they are well supported and have the appropriate arrangements in place to allow the effective and safe delivery of the research. It is also important that patients, families and healthcare professionals in palliative and end of life care organisations are offered the opportunity to participate in research if they would like to.

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RANDOMISED CLINICAL TRIALS IN A HOSPICE SETTING: TOIL, TRIBULATIONS, TRIUMPH

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Background Despite clinical research being advocated as a key component of palliative care (Payne, Preston, Turner & Rolls, 2013), most patients under the care of palliative care services will not have the opportunity to participate in research. Of the 200 plus UK hospices, few patients get the opportunity to actively participate in research for multiple reasons including lack of expertise, funding, opportunity and anxiety about excess patient burden. However even patients with advanced disease describe multiple benefits from being involved in research trials (Middlemiss, Lloyd-Williams, Laird & Fallon, 2015) and it is possible to establish and conduct clinical trials within the hospice setting.

Aim To describe the experience of establishing and conducting a randomised clinical trial in an independent UK hospice.

Results The ethical, logistical and regulatory hurdles to establishing a clinical trial are described and include local engagement, funding, sponsorship, developing academic links and

tackling barriers to recruitment. Novel initiatives are described, including volunteer and carer engagement and motivating team members to realise the advantages of in-house clinical trials. Further, the image of hospice care was improved through the establishment of a research culture.

Conclusions It is possible to establish and conduct clinical trials within a UK hospice setting; and this has multiple advantages to patients and staff alike.

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CHILDREN'S PALLIATIVE CARE: AN EXPLORATION OF THE UNMET NEEDS OF CHILDREN AND THEIR FAMILIES

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Background Understanding the needs of children with life-limiting illnesses and their families has been highlighted as a top research priority. Children's palliative care services have been shown to have limited funding and resources to provide services which are equipped to meet the needs of families. There are, however, few studies which outline whether or not services, from the perspective of professionals and parents, meet the needs of this group.

Aim This study aims to examine how children's palliative services care can be improved to meet the needs of children and their families.

Methods Phenomenological research eliciting semi-structured interviews with 29 professionals delivering care to children with life-limiting conditions were conducted. Professionals were recruited from a variety of services in the children's palliative care pathway; hospice, hospitals, community care teams, social services, occupational therapy, spiritual services, supportive care, complementary therapy and so on. Interviews were recorded, transcribed and analysed thematically.

Proposed importance of the findings These findings provide insight into the professional experiences of unmet palliative care needs. Professional experiences present necessary improvements across the sampled palliative care services. Alongside interviews with parents currently accessing services and those bereaved parents, perspectives will be triangulated to highlight the unmet need. Recommendation for policy and guidance will be made to suggest improvements to the care of families in the future.

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MULTI-DISCIPLINARY JOURNAL CLUB TO SUPPORT A WHOLE-HOSPICE RESEARCH CULTURE

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Research in palliative care is essential to improve outcomes for patients with terminal illness. It is important that hospices are central to research in the speciality, however, research is not always well embedded in hospice cultures. Essential to this is raising awareness amongst team members of all disciplines, both of the importance of research in general and also the role of evidence in underpinning clinical practice.

Journal clubs are a well-established way of sharing research within teams and developing critical appraisal skills