

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

of staff, and have been identified as a potential method of building research culture in hospices (Payne, Preston, Turner & Rolls, 2013). Expanding participation beyond the traditional single discipline model offers the opportunity to expose more of the entire team to research methodologies and appraisal of evidence. Multidisciplinary reflection and learning may also have additional benefits to team culture and the potential to better underpin multidisciplinary decision making.

As part of developing a research culture within Marie Curie Hospice Liverpool, a new journal club was established and publicised to all staff with support from senior team leaders. In addition to discussing and reflecting on the paper and its effect on practice, emphasis is placed on exploring potential future research questions.

There has been excellent attendance and engagement across multiple disciplines at every session, including senior and ward staff nurses, various grades of doctors, healthcare assistants, physiotherapy, social work and fundraising departments as well as nursing and medical students.

As exposure to the process has increased various multidisciplinary team members have developed the confidence to present papers, facilitated by support from the research nurse in the hospice. Feedback has been very positive and work to assess the effect of this on awareness of research and how it underpins practice is in progress.

P-112 AN INTERVIEW IS NOT A CONSULTATION: THE DUAL ROLE OF CLINICIAN-RESEARCHER

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Qualitative research into the experience of dying patients and their families frequently includes in-depth interviews or participant observation. Traditionally, clinicians are discouraged from conducting such research among their own patients or in their own practices. Yet barring the clinician from researching their patients, especially where access to non-associated research participants is limited, may represent a lost opportunity to benefit from the experience of clinicians.

In this presentation we reflect on our own experience as clinicians and qualitative researchers, drawing on an ethnographic study in which a palliative medicine specialist (first author) studied dying patients and their families in the rural community in which she also lived and practiced. We examine the advantages and disadvantages of 'insider' research and suggest strategies to address the ethical risks and conduct authentic, credible research.

Local, prior knowledge and insight, and established rapport and trust, provided depth to the interviews with terminally ill patients and their family caregivers. The risks of power imbalance, recruitment coercion, and filtering of participants' responses required specific management. Clinician-researchers must, at all times, be conscious of their dual role, and conscientiously separate medical management and prior knowledge from the research interviews. Recommendations include the use of an independent third party to obtain informed consent; using iterative consent methods prior to, and after, each interview; using peer support for

clarity of role; and maintaining strict boundaries between the researchers' clinical and researcher roles. Clinician researchers must fully declare conflicts of interests with colleagues to reassure them that the researcher is not taking over care of the patient.

We found that by using this conscious and conscientious stance, we were able to conduct nuanced, multifaceted research which respected and illuminated the experience of the patient, and their family, often revealing aspects of themselves that they had not shown to us as clinicians.

P-113 THE ROLE OF THE RESEARCH NURSE IN THE HOSPICE

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Background The NIHR and Charities Consortium for Hospice and Community Research have stated that the goal for all hospices is to be research active and recruit by 2022. The role of the Research Nurse in the hospice setting is still relatively new.

Aims This poster aims to share the experiences and lessons learnt by a Research Nurse who is in a unique position of being based within two hospices in the West Midlands.

Building capability and research capacity At one hospice, the Research Nurse works alongside the Senior Research Fellow. The learning and development gained from this relationship has fostered confidence and skills which enable the Research Nurse to carry out her role at a second hospice alongside the Nurse Consultant. The role is funded and supported by West Midlands CRN. This innovative way of working has provided many opportunities for the hospices to become further engaged in research, including portfolio studies. It has enabled the sharing of ideas across hospices, the development of recruitment opportunities and the opportunity to ensure research is embedded into everyday practice in both hospices. Key outcomes of the collaborations have been:

1. Facilitating **engagement** with research at the hospices;
2. Being a **bridge** between the often-competing pressures of clinical care and research, by finding novel solutions to obstacles;
3. **Empowering** staff by encouraging them to be a part of research in everyday practice. Being a resource for staff by supporting them with academic assignments, producing posters for conferences and disseminating research findings;
4. **Developing a research culture** by sharing good practice across organisations.

Building future research capacity

Ongoing and future challenges for the Research Nurse over the next year include:

- To further develop a research culture in both hospices;
- Increase staff confidence and awareness of research activity in both hospices;
- Ensure patients, families and staff are given further opportunities to participate in research.