the priorities identified is underway and the results will be included in the presentation.

Conclusions A number of robust RPEs examining what is most important for health professionals delivering care to children with LLCs exist. However, more could be done to ensure that the values and experiences of children and young people, their families and other carers are accounted for.

**P-87** THE ROLE OF CLINICAL RESEARCH FELLOWS IN THE HOSPICE

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Background The need for research is a priority area in palliative care. An evidence based approach is needed to address the inevitable challenges in a population that will require supportive care towards the end of their lives (Gomes & Higginson, 2008). It is important we continue to develop and evaluate ways of improving the care of people with terminal illness.

Aims Secondment of two local members of staff has allowed our hospice to benefit from an onsite research team. This has given patients, relatives and staff the opportunity to participate in research. We aim to improve care for our patients and hope to provide a foundation for future research projects within the hospice setting.

Method Secondment of staff was achieved using local and national funding, allowing a doctor and nurse to commence the role of clinical research fellow. They were provided with training and mentorship to ensure good understanding of their roles prior to recruitment of patients. A training programme was developed for staff and research update events were instigated, giving staff educational opportunities and freedom to voice their questions and concerns.

Results There is developing evidence which demonstrates that patients are keen to be involved in palliative care research (Henderson et al., 2005; Nwosu et al., 2013), which we have observed with our data collection to date. We hope to build and advance the evidence base.

Conclusion Development of the local research roles provides an excellent foundation to build upon, enabling future research projects to be conducted within the hospice setting. We hope that this will encourage other professionals in palliative care to consider participating in research. We hope researchers, funders and policy makers will be encouraged as participation in research will help to identify, and address, patient-centred priorities at the end-of-life (Nwosu, 2013).

Investment in palliative care research is required to generate the evidence which will improve the care delivered to patients at the end-of-life (Sleeman et al., 2012).

**P-88** POTENTIAL CHALLENGES FOR NON-NHS ORGANISATIONS CONSIDERING PARTICIPATING IN CLINICAL TRIALS

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Background Clinical research and participation in clinical trials are still relatively new areas for many hospices and end of life care organisations, particularly if they are non-NHS organisations. One of the more challenging areas of research is that of participation in Clinical Trials of Investigational Medicinal Products (CTIMPS).

Aim The aim of this piece of work is to develop a tool that can be shared with other organisations, both regionally and nationally, to assist them in their preparation for participation in clinical trials.

Methods There are many potential challenges for non-NHS organisations to consider before deciding whether they wish, and are able to, participate safely and effectively in CTIMPS. Although none of these are insurmountable it is important that each aspect is addressed individually to provide the organisation with assurance that the research can be undertaken and delivered safely and to best practice in accordance with regulatory frameworks and guidelines.

The starting point has been to identify the potential challenges. These include but are not limited to:

- Infrastructure
- Risk and Indemnity
- Finance
- Governance
- Pharmacy
- Medicines and Healthcare Regulatory Agency (MHRA)
- Drug storage and processes
- Training
- Tissue samples/storage (HTA)
- Monitoring
- Sponsor responsibilities.

Results The result of the work thus far is a paper identifying the potential challenges in more detail and the specific issues that require attention.

Conclusions As this is an ongoing project there are no conclusions as yet. The next phase is completion of a RAG rated GAP analysis to identify gaps in current processes, provisions and risks. Once identified, all areas will require careful consideration, associated risks will need to be identified and considered and measures put in place to mitigate these are far as possible.

**P-89** THE VOICE OF DYING PEOPLE: LISTENING, LEARNING AND RESPONDING

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10.1136/bmjspcare-2017-hospice.116

Background We are an organisation that informs and empowers people to exercise their rights at the end of life. ‘Person-centred care’, ‘advance care planning’ and ‘choice’ have become buzzwords in the sector, yet we know from successive policy reports and from people who contact us that in practice these concepts are not always implemented effectively.

Aims To learn more about the experiences of dying people in order to inform our understanding of the barriers to person-centred care.

Methods We designed a mixed-methods exploratory study. This consisted of a questionnaire for dying people and carers, which we distributed via our service-users, social media and other third sector organisations. This received over 600 responses. We also conducted analysis of our service user...
monitoring and commissioned ‘BritainThinks’ to conduct four focus groups and ten in-depth interviews with the public, dying people and carers.

**Results** A number of key findings emerged from a thematic analysis of the research:

- people are not always given clear information about their symptoms, prognosis or treatment options
- when people want more information they do not always know the right questions to ask in order to obtain it
- people are not always supported to make meaningful choices at the end of life
- the extent to which people are empowered to make informed decisions about their care can have a direct impact on care quality
- opportunities to instigate conversations about future care are being missed.

**Conclusions** We are using the extensive data we have obtained to:

- update our policy calls
- develop resources to give people tools to improve their own care
- enhance our service development, including adding more clinical expertise to our information line.

Our study demonstrates the tangible thread that links learning from dying people and improving service delivery. We encourage others in the sector to undertake similar work.

**P-90 IMPLEMENTATION OF RESEARCH INTO HOSPICES THROUGH COMMUNITY OF INFLUENCE: CRN WEST MIDLANDS MODEL**

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There is a need to provide high quality, evidence-based supportive and palliative care research. However, recruitment to supportive and palliative care research studies remains a challenge. Therefore, more research evidence is required in this specialty. The supportive and palliative care research model aims to:

- Improve care through research, increase awareness of research within the West Midlands and share nationally
- Support local hospices and care homes to become involved in research
- Encourage clinicians to identify topics for future research, to be adopted onto the National Research Portfolio, and ensure that researchers in the area are able to offer access to studies for participants in all areas.
- Progress and achievements to date include:
  - contributing to the delivery of existing National Institute for Health Research Portfolio studies by carrying out site initiation visits and assisting with study recruitment.
  - generating new studies that are running in the West Midlands (WM) through the WM Collaborative Actioning Research in End of Life and Supportive Care (WMCARES).
- sharing research priority topics identified following a survey of hospices in the West Midlands and to investigate in the near future.
- increasing our visibility across the West Midlands to promote and share our strategy. This has involved talks with local radio, West Midlands partner organisations, other Clinical Research Networks and primary care organisations.
- bringing together an enthusiastic and committed workforce of diverse healthcare professionals, including clinical research speciality and sub-specialty leads, a nursing team, locality manager, administrative staff, research delivery and portfolio managers.

Our next planned steps include short and long term goals. Highlights include: Enhanced IT systems, develop a Health Research Authority flow diagram and create a Supportive and Palliative Care Nurse Forum with collaboration with CRN West Midlands.

**Patient care**

**P-91 DO COMPLEMENTARY THERAPIES WORK?**

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**Background** Complementary therapies are becoming routinely offered in hospices and other healthcare settings throughout the UK with as many as 51% of patients accessing therapies (Posadzki et al., 2013). However, little objective data about effectiveness exists making them difficult to justify in an evidence-based healthcare system. This study used the validated MYCAW tool (Measure Yourself Concerns and Wellbeing) in an attempt to explore the value of massage, aromatherapy and reflexology in a range of patients and carers (Jolliffe et al., 2014; Polley, 2007; Seers, 2009).

**Aims** The aim of the project was two-fold:

1. To assess the practicalities of implementing MYCAW in a hospice-setting
2. To assess the use of MYCAW following an intervention to improve its use.

**Methods** Over a one-year period, 98 patients and carers were assessed using MYCAW pre- and post-complementary therapies.

**Results** Complete data was only available for 32% of subjects. Incomplete data resulted from failure to record unique identifier on the MYCAW form (6%), clients failing to attend all of their scheduled therapies (55%) and patient death resulting in a failure to record a second set of MYCAW data (7%). Because the data were limited, a new protocol was implemented in the hope of improving the use of MYCAW. An electronic diary system was introduced with prompts for all first and last MYCAW. Meetings were held with all therapists to reinforce the importance of MYCAW. We also created ‘appointment packs’ containing MYCAW forms to further prompt therapists. As a result of this intervention, we have seen a dramatic improvement in the number of completed MYCAW forms both pre- and post-therapy. Early data suggest that MYCAW is a useful tool to assess client-defined worries.

**Conclusion** The data suggest complementary therapies are an effective way of reducing patients’ and carers’ concerns in a hospice-setting.