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CRN WEST MIDLANDS INITIATIVE: MAKING CHILDREN'S HOSPICES RESEARCH READY: THE NEXT STEPSKrys Castro, Hilary Shepley, Marie Phipps. *CRN West Midlands, Walsall, UK*

10.1136/bmjspcare-2017-hospice.111

Following on from our first poster that showcased the Clinical Research Network West Midlands (CRN WM) Children's Research Team's work from January 2016 and described processes established and training provided, as well as events, we are now presenting the progress from summer 2016.

The main focus was the joining of the Children's Research Team with the Adult CRN West Midlands (WM) Supportive and Palliative Care Team and to build and combine a strategic plan. Part of the plan includes a bespoke training package for children's hospices as an introduction to research. Further training for hospices is being organised and will be rolled out in the near future.

Attendance at the WM Paediatric Palliative Care Network (WMPPCN) enabled networking, and invitations to work with the chair of the WMPPCN raised the profile and identified research studies and increased awareness in children's hospices in the West Midlands. The WM Young Persons' Steering Group (YPSG) has assisted the chair of the WMPPCN with the design of the study including reviewing of the protocol, designing the patient and parent information sheets, study posters and other study supplements. In October 2016, the study opened in Birmingham Community Healthcare NHS Trust and Birmingham Children's Hospital. The next steps include hospice research studies.

A first poster at the Hospice UK Conference: 'Making children's hospices research-ready' was presented. This enabled networking and invitations to collaborative groups and has resulted in the team identifying adult research policy and adapting them to children's settings.

In conclusion, we will also be rolling out the research awareness training in children's hospices across the region. More work will be coming out from the research sub-group of the WMPPCN. The CRN West Midlands Supportive and Palliative Care Strategy will be revised to include the children's strategy for the region.

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HOW THE WEST MIDLANDS CARES ABOUT AND PRIORITISES RESEARCH

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10.1136/bmjspcare-2017-hospice.112

Background There is a recognised paucity of research in palliative care, compared to other specialties (Neuberger et al., 2013; Higginson, 2016). Research is key for speciality development and palliative medicine training, however, the West Midlands palliative medicine speciality registrar group identified difficulties in participating in research. Collaborative approaches to research are a beneficial way of improving quantity and quality of research (Payne et al., 2011). To address the issue of the paucity of high quality research in the region we initiated a trainee-led research collaborative.

What We Did West Midlands Collaborative Actioning Research in End-of-life and Supportive care (WM CARES) was founded in 2016. Our mission is to conduct high quality palliative care research within the region which will ultimately influence and improve patient care and services, whilst facilitating trainee participation in research. Collaboration is central to WM CARES. We are working with partners, including the National Institute for Health Research, local universities, the palliative medicine consultant body, specialty doctors and local providers of palliative care. The WM CARES network enables larger, multi-site, high quality research which crosses the boundaries of any individual registrar's placement. WM CARES has already developed four research questions into working groups under consultant supervision. Three poster presentations of our initial output have been exhibited nationally and regionally. Building on its success, WM CARES has launched a best practice event: 'WM CARES Presentations in Research, Innovation, Development and Excellence' (PRIDE). This will enable members of the multidisciplinary team to present their research and local innovative work, which will facilitate further collaboration and identify future research questions.

Conclusion WM CARES is an innovative and collaborative trainee-led research network producing high-quality research and raising the profile of research. It enables and enthuses palliative medicine specialty registrars and the wider multidisciplinary team to learn about and be involved in research activities, which will ultimately improve patient care.

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RESEARCH PRIORITIES FOR CHILDREN WITH LIFE-LIMITING CONDITIONS: WHO HAS ALREADY PRIORITISED WHAT?Alison Booth, Jane Maddison, Bryony Beresford, Lorna Fraser. *University of York, York, UK*

10.1136/bmjspcare-2017-hospice.113

Background A new multi-disciplinary centre committed to leading research on the management, care and support of children with life-limiting conditions and their families was recently established. To inform decisions on the focus of the work of the Centre, a Research Prioritisation Exercise (RPE) is being undertaken. In designing our RPE we took into account our broad scope, awareness of existing RPEs relevant to children with life-limiting conditions (LLC) and the need to maximise resource use. The first part of this project has therefore been to undertake a systematic scoping review of existing RPEs.

Aims Our scoping review aims to map existing RPEs relevant to children, young people with life-limiting conditions and their families and carers. The findings will be used to develop a framework of existing priorities, and to inform the design and format of our own research consultation exercise.

Methods We have used systematic review methods to identify and select relevant published RPEs, and identify quality markers for RPE methods. The synthesis will provide an overview of the conditions and/or settings where priorities have been set and present the areas that are most frequently identified as priorities for future research.

Results We have identified 26 RPEs for inclusion, most use the Delphi technique. The majority were about those requiring paediatric oncology or palliative services. Most were undertaken by health professionals, with only a few including patients and/or parents in the consensus exercise. Synthesis of

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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10.1136/bmjspcare-2017-hospice.114

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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10.1136/bmjspcare-2017-hospice.115

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