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## CRN WEST MIDLANDS INITIATIVE: MAKING CHILDREN'S HOSPICES RESEARCH READY: THE NEXT STEPS

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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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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?

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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