"IT'S A MARATHON NOT A SPRINT" – SETTING THE PACE IN DEVELOPMENT OF A REGIONAL PALLIATIVE CARE RESEARCH SPECIALTY GROUP

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Background Research in palliative care is imperative to improve the evidence base and maintain the best quality care for patients and families. In 2011, the Sussex Cancer Network (SCN) Palliative Care Group identified the need to formally develop a dedicated regional research group.

Aims To promote palliative care research, with multi-professional representation from specialist palliative care services, throughout Sussex. To increase recruitment to palliative care trials, including development of new research within the region.

Methods The Sussex Palliative Care Research Specialty Group (SPCRSG) was formed with multi-disciplinary representation from Sussex-wide adult specialist palliative care services and allied research/academic professionals. It is jointly led by the authors and supported by the Surrey & Sussex Comprehensive Local Research Network and formerly by the SCN.

Key activities of the group include: regular education and business meetings, with external expert speakers and Royal College of Physicians CPD approval; regular review of ongoing and potential research studies, particularly those on the NIHR portfolio; promoting research (Good Clinical Practice) training; and linking with established academic centres.

Results Six hospices, three hospital trusts and two community services have been represented in the five meetings held to date with a median number of attendees of 12 (range 6–17). The usefulness of education sessions have been evaluated as either ‘good’ or ‘excellent’ by 75–88% of attendees. Attendees reported networking opportunities and discussion about independent hospice sector research governance as valuable.

Research activity has increased with involvement in three NIHR Portfolio studies within the Sussex region since the inception of the SPCRSG.

Conclusions Development of the SPCRSG has been beneficial and would be transferable to other regional palliative care services. To keep up the future pace in providing relevant and effective support and on-going education, it is important to understand what factors promote participation and what barriers to undertaking palliative care research there are.