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## **Developing research collaborations and building capacity in palliative and end-of-life care in the north west coast of England: The PalCaRE-NWC partnership**

**Keywords** Palliative care; Palliative Medicine; Hospices; Surveys and Questionnaires; Research; Research Priorities; Health Services Research; Methodological Studies.

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## **Abstract**

**Background:** The North West Coast area of England (Lancashire, Merseyside, Cheshire, and South Cumbria) has high palliative care need (third highest prevalence in England) and historically low recorded NIHR research activity (second lowest research recruitment rate in England). To stimulate research activity a new research partnership was formed to support and encourage palliative care research, funded by the NIHR from January 2022 until June 2023.

### **Objectives:**

- i) Develop a sustainable palliative care research partnership infrastructure across North West Coast.
- ii) Work with palliative care providers, patients and the public, and research staff to further understand local barriers and facilitators to palliative and end-of-life care research, and develop and implement solutions to these barriers.
- iii) Build capacity in palliative and end-of-life care research through the mentorship of emerging research leaders and share expertise across organisations.
- iv) Facilitate the development of high-quality research grant applications.

**Activities:** Phased activities were planned and actioned throughout the funded period to develop and embed an active palliative care research partnership across the region. These included: a survey and working groups to rapidly identify current local barriers to research and their sustainable solutions; individual and group support activities to build research capabilities and capacity; development and submission of high quality clinically relevant research proposals to the NIHR and other funders.

**Results:** Survey participants (n=293) were mainly from clinical settings (71%), with 45% being nurses. Whilst around three quarters of participants were not research active, most wanted to increase their involvement. Key barriers identified from both the survey and working groups (n=20 professional participants) included: lack of organisational research culture and capacity (including prioritisation

and available time); research knowledge (including skills/expertise and funding opportunities); research infrastructure (including collaborative opportunities across multiple organisations and governance challenges); and patient and public perceptions of research (including vulnerabilities and burdens).

Based on these findings, the partnership is working with national stakeholders to develop user-friendly resources to facilitate hospice-based research. Three action learning sets, that met several times (n= 15 staff), and two networking events (n= 78 participants) took place to facilitate collaboration and research capacity building. Eleven research grant applications totalling £5,435,967 were submitted as a direct result of partnership activities between Jan2022-June 2023.

**Limitations:** Survey and working group findings and resulting activities represent the views and needs of staff within a particular UK geography and had limited public representation.

**Conclusions:**

Funding to support partnership work has been demonstrated to be effective in pump-priming research activities, leading to successful research grant submissions and building research capacity. However, consideration is needed about how to maintain partnership work, embed in local organisations, and further develop work across non-traditional stakeholders such as hospices and social care providers if ongoing funding is unavailable.

**Future work:** North West Coast CRN has provided short term funding (July 2023 to March 2024) to enable and sustain the expansion of PalCaRe-NWC.

**Study registration:** Not applicable

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## **Plain language summary**

In the Northwest Coast area of England (Lancashire, Merseyside, Cheshire and South Cumbria) we know that palliative and end-of-life care research activity is much lower than in other parts of the country despite higher needs than average.

## **What we wanted to do**

Bring together clinicians, researchers, health care organisations, and the public to plan important high-quality research in palliative and end-of-life care relevant to North West Coast and the wider country.

## **We did several activities to achieve this over 18 months:**

First, we sent out a survey to clinicians and researchers and undertook discussion groups to understand the main barriers to palliative care research locally, and how we can best overcome these. Second, we put solutions in place to help people to conduct research. Third, we developed and submitted high quality clinically relevant research proposals to the NIHR and other funders.

## **What did we find?**

Three quarters of those who took part in our survey were not active in research but just under three quarters said they would like to be more involved. Based on the study findings, the partnership is producing resources alongside national organisations to facilitate hospice research. We ran workshops for clinicians and researchers newer to research so they could develop their grant writing skills. We ran two events to help clinicians and researchers who are interested in palliative care research to work together. We submitted 11 grants totalling £5,435,967 because of partnership activities.

**What does this mean?**

Funding the partnership has helped research activity including grant submissions. How this can continue without ongoing funding needs to be considered. The North West Coast Clinical Research Network has provided funding from July 2023 until March 2024 so that our work can continue in the short term. Organisational engagement is needed to increase palliative care research activity.

**Word Count:** 299



## **Background**

The National Institute for Health Research (NIHR) provided short-term funding (Jan 2022 to June 2023) to develop research partnerships to enable the development of high-quality, practice-relevant, fundable research grant applications that focus on palliative care needs, especially for underserved populations. This funding supported the creation of the Palliative Care Research Partnership North West Coast (PalCaRe-NWC). This partnership is a collaboration between the Universities of Lancaster, Liverpool, Chester, Edge Hill, and Central Lancashire; Lancashire Teaching Hospitals, Liverpool University Hospitals, and the Clatterbridge Cancer Centre NHS Foundation Trusts; the Clinical Research Network North West Coast (CRN NWC); and was supported by the Applied Research Collaboration North West Coast (ARC NWC), hospices, and other clinical partners.

There is a need to focus on the North West Coast region of England as it has high palliative care needs (third highest prevalence in England) <sup>1,2</sup> and, historically, low recorded NIHR research activity (second lowest research recruitment rate in England)<sup>3</sup>. The North West Coast region covers the counties of Lancashire, Merseyside, Cheshire, and South Cumbria. There is a clear need for more palliative and end-of-life care research integrated across this region. People with palliative care needs, and their family carers, deserve care that is informed by the highest quality evidence, enabled by research active and informed health and social care professionals, within research imbued organisations and services: it is known that care within research active organisations is superior <sup>4</sup>.

There is a high incidence of life-limiting disease within the region <sup>1,2</sup>, compounded by high levels of socioeconomic deprivation <sup>5</sup>. Regionally, this is characterised by clusters of multidimensional disadvantage, including populations known to be underserved, such as areas with ageing or ethnic minority populations, and the deprivation associated with coastal and rural communities <sup>6</sup>. For example, Blackpool, a coastal town in this region, is the most deprived local authority area, and has

the lowest life expectancy in England <sup>6</sup>. The number of people who will require palliative care is predicted to increase because of the ageing population, as is the number of people living and dying with chronic and complex conditions <sup>7,8</sup>. In the majority of North West areas, a higher proportion of patients are admitted to hospital within the last 90 days of life, with a greater than UK average number of patients dying in hospital in the North West <sup>9</sup>. Patients in the North West are known to be referred to specialist palliative care services later than in other regions (35 days vs 55 days in the South of England) <sup>10</sup>. Late referrals will also affect the window of opportunity for people to participate in research across the region.

There are many challenges to conducting research in palliative and end-of-life care. There are personal, cultural and organisational reasons for patients and their family carers not accessing services nor engaging in research <sup>11</sup>. Patients are viewed as vulnerable and can have complex needs <sup>12-14</sup>. Gatekeeping access to research studies can be a particularly challenging issue with concerns about patient and carer burden, despite evidence suggesting patients and family are willing to engage in research at the end of life <sup>15-20</sup>. Palliative care research itself can be challenging because of a lack of funding, difficulties in identifying suitable study participants and lack of research infrastructure in non-NHS settings such as nursing homes or hospices <sup>21-30</sup>.

Previous work in the North West Coast region in hospices, identified a number of barriers to research including the lack of a strong research culture, poor or absent research infrastructure, lack of research expertise and capacity, and concerns about adequate governance arrangements <sup>31</sup>. Strategies to address some of these barriers may include reducing and managing the demands on clinicians of being involved in research, having research staff on site <sup>16,32</sup>, training on how to recruit to palliative care studies <sup>33,34</sup>, and improving communication with patients and their families to promote research participation, and within staff teams to address gatekeeping. We drew from this work in our planning of the activities associated with developing a more active and confident

palliative care regional research network, helping to nurture good research practice, and combat barriers to recruitment.

In this paper the aims, activities and outcomes of this research partnership are presented, with a discussion on the learning from this work focused on how best to stimulate high-quality research activity in the future.

## **Methods**

### **Aims and objectives**

The overall aim of this project was to build a sustainable palliative and end-of-life care research partnership and infrastructure within, and across, key organisations in the North West Coast region. We aimed to ultimately increase the opportunities for patients and family carers to access high quality, clinically relevant research that improves their experiences and outcomes of care.

#### *Objectives:*

- i) Develop a sustainable palliative care partnership infrastructure across North West Coast, embedded within existing organisations such as the CRN and ARC, involving strong patient and public involvement (PPI), as a focus for palliative and end-of-life care research in the region.
- ii) Work with palliative care providers, patients and the public, and research staff to further understand local barriers and facilitators to palliative and end-of-life care research and develop and implement solutions to these barriers.
- iii) Build capacity in palliative and end-of-life care research through the mentorship of emerging research leaders and share expertise across organisations.
- iv) Facilitate the development of high-quality research grant applications that address important clinical research questions that meet the needs of the North West Coast

population (and beyond) focused on the NIHR palliative and end-of-life care commissioned research calls in 2023.

### **Palliative Care Research Partnership North West Coast activities**

Several phased activities were planned and actioned by the partnership throughout the funded 18-month period to develop and embed an active palliative care research partnership across the North West Coast region. These activities are described below and include a survey and working groups to rapidly identify current local barriers to research and their sustainable solutions, mentorship and support activities, networking events, and the development and submission of high quality clinically relevant research proposals.

#### ***Rapid identification of current local barriers to research and their sustainable solutions***

An initial aim was to rapidly identify current local barriers to research and their sustainable solutions; this was achieved using an online survey (using Qualtrics™) and working groups, using nominal group techniques<sup>35</sup>. This activity built on and extended partnership members past work with hospices, and more general work on research barriers<sup>30-32, 36</sup>. The purpose of this approach was to ensure that partnership activities were focused on identifying and implementing appropriate solutions to contemporary local issues within North West Coast that could be embedded into existing infra-structure. Detailed information about the survey and working group methods and findings are published in full elsewhere<sup>37</sup>. .

The findings from the survey and working groups have been presented both nationally and internationally. This includes nationally at our first PalCaRe-NWC networking day in January 2023, the Hospice UK conference in Glasgow, November 2022, the Research Active Hospices: Achieving more together NIHR CRN event in London, June 2023 and at the North West Cancer Research

conference, Lancaster University, July 2023. Internationally they were presented at the European Association for Palliative Care Congress<sup>38</sup>, June 2023.

In brief, participants (survey n=293) were mainly from clinical settings (71%) with 45% being nurses. Whilst around three quarters of participants were not active in research, most wanted to increase their involvement in research. Findings from both the survey and working groups (n=20) indicated that key barriers included: lack of organisational research culture and capacity (including prioritisation and available time); research knowledge (including skills/expertise and funding opportunities); research infrastructure (including collaborative opportunities across multiple organisations and governance challenges); and patient and public perceptions of research (including vulnerabilities and burdens). Key facilitators included dedicated research staff, and active research groups, collaborations, and networking opportunities. A key conclusion is that a shift in organisational culture is needed to enhance palliative care research capacity and collaborative opportunities across clinical and research settings.

As a result of identifying these barriers and facilitators to engagement in research activities, members of the PalCaRe-NWC partnership have been working alongside a range of national and regional stakeholders including Hospice UK, Marie Curie, Sue Ryder, the CRN, and others to develop a range of user-friendly videos and implementation guides to facilitate hospice involvement in research. These are fully available online, and being added to as a living resource<sup>39</sup>.

### ***Providing mentorship and support***

The partnership planned to focus on individual and group support activities to build research capabilities and capacity to support high quality research grant applications. These addressed the knowledge and organisational barriers identified in the survey and working group activities<sup>37</sup>.

Activities included: interactive workshops, action learning sets, peer support, mentorship, and

funding to release clinically focused staff named on the initial partnership application to the NIHR to focus on grant development.

#### *Action learning sets and peer support*

The partnership aimed to facilitate the development of emerging research leaders in palliative care research and build research capacity across North West Coast through facilitated action learning sets. This addressed key barriers we identified including enabling time for research, developing research skills, and providing collaborative opportunities across organisations<sup>37</sup>. Within the action learning sets we provided structured sessions which enabled peers to meet regularly, identify areas of shared learning to address current research challenges, and be supported through the partnership in learning to address issues. An initial action learning set was set up and run by SP and NHW with those individuals named in the bid as co-applicants (AN, AG, RB, AD, SC, BS). The opportunity to be involved in subsequent action learning sets was advertised widely across the region including via the project website, social media and through key contacts identified in the setting up of phase one. Nine people applied and were accepted to take part in a further two action learning sets run by CW, JE, NP, VT and LL. Fifteen individuals attended the three action learning sets in total from a range of professional backgrounds and with varying levels of palliative care research experience. The action learning sets ran once a month for six months. Each session allowed participants to bring a research related issue to the group for them to discuss with the group, with guided facilitation. The topics discussed were confidential within each group, so are not reported here. The action learning sets were evaluated via a questionnaire and most responses were positive. Comments included:

*'The discussion groups were really helpful in achieving the first aim of connecting with other researchers – the action learning set was very different from anything I have been involved with before. Specifically, I felt that the open format of the sessions, with each person bringing their own 'issue', made the discussions varied and interesting, and allowed the space for individual focus'*

*'Directly as a result of my participation in the action learning set, I have had the opportunity to be part of and contribute to, the early stages of an NIHR application for research funding in an area of research that links with my own research interests.'*

A number of action learning set participants were involved in the grant applications specified in table 1, as reflected above, enhancing their learning in grantsmanship and collaboration.

### ***Networking events***

The survey and working group analysis identified that staff providing palliative care valued networking opportunities to support and develop their research knowledge and interests. In response to this key finding, a highly successful networking event was organised at the University of Liverpool in January 2023. Sixty individuals booked onto the event and 38 people were able to attend on the day from the NHS (acute and primary care), ambulance service, Universities, and hospices. Due to its success and positive feedback, a further networking event was organised in June 2023 at Lancaster University. Sixty-five individuals booked onto the event and 40 people were able to attend on the day from the NHS, universities, and hospices (adult and paediatric). Unfortunately, there has been little engagement from the social care sector, except from nursing home attendees.

Discussion groups were used during the events to facilitate networking amongst different clinical and research organisations and professional groups. 'Bite size' presentations on research methods and exemplar research projects taking place within the region were offered. The networking events were evaluated via an anonymous questionnaire. Those who responded expressed that they valued the opportunity to meet in person and network with colleagues from different clinical and academic organisations and settings. Attendees enjoyed how the events included interactive group work as well as short research presentations. Some connections facilitated engagement in grant opportunities, discussed later. Another small group formed at the first event have been working together on a systematically constructed review in their topic of interest. Hospice and CRN based research nurses working on palliative care research studies have formed an informal support group

following the first networking event. Three research development groups have been formed from the activities and people involved across networking events. These currently focus on developing research activities in the areas of heart failure, paediatrics, and education. They meet regularly, facilitated by people from the network, to work on developing research grant applications.

### ***Developing and submitting high quality clinically relevant research proposals***

The partnership anticipated that these capacity building activities would stimulate and facilitate applications to the NIHR palliative and end-of-life care commissioned research calls, due in April/May 2023 and August/September 2023. As part of the funding application process indicative contender research ideas were identified that mapped onto gaps identified in the commissioning call, addressing palliative care needs identified above. These were supported and developed, through planned mentorship activities and the action learning sets, as well as some dedicated time bought out for more junior researchers, especially those with clinical commitments. These all addressed research priorities identified as part of the James Lind Alliance Priority Setting Partnership<sup>40</sup>, and built on existing academic expertise to enhance competitiveness. Additional research ideas were also encouraged throughout the time of the funded partnership via our action learning sets, networking days and reaching out via our social media and website to offer appropriate support.

### **Grant activities**

The partnership has supported the submission of high quality, clinically relevant, applications to the April/May 2023 NIHR palliative and end-of-life care calls and other NIHR and non-NIHR funding streams. Further grants are being actively prepared for the subsequent focused calls.

The partnership and its activities appear to have stimulated general grant preparation activity, as well as activity directly related to the partnership work. In reporting grant activities below we have identified the work as a direct result of the partnership if they met defined criteria. These criteria



were if the proposed grant was mentioned in the original partnership application to the NIHR, if partnership funds supported time used in its preparation, if action learning set time was used to discuss aspects of bid preparation, or if applicants reported that the grant activity was triggered by discussions and connections made because of the network. In the interests of completeness, we have also reported other pertinent grant activities of PalCaRe-NWC co-applicants that occurred during the time funded by the partnership, but which do not meet the criteria above (Table 1).

Table 1. Research grant applications submitted between January 2022 and June 2023 as a direct result of partnership activities.

Grant type	Number of grants	Total application value	Numbers of those whose involvement was as a result of partnership activities *
Grants submitted to the palliative care specific NIHR calls.	2	£ 2,101,750	8
Grants submitted to other NIHR funding streams	5	£ 3,014,475	18
Grants submitted to non-NIHR funding streams	4	£319,742.04	5
<b>Research grant applications submitted between January 2022 and June 2023 by PalCaRe-NWC co-applicants that are <i>not directly associated</i> with the partnership but related to palliative care research</b>			
Grants submitted to the palliative care specific NIHR calls.	2	£ 4,450,661	5 partnership co-applicants
Grants submitted to other NIHR funding streams	2	£ 3,146,600	4 partnership co-applicants
Grants submitted to non-NIHR funding streams	6	£ 13, 587,836	6 partnership co-applicants
<b>Research grant applications in preparation as a direct result of partnership activities</b>			
Grants to be submitted to the palliative care	2	To be confirmed	5

specific NIHR calls Aug/Sep 23.			
Grants to be submitted to other NIHR funding streams	1	To be confirmed	2
Grants to be submitted to non-NIHR funding streams	3	To be confirmed	4

\* A number of people were involved in more than one grant application.

The outcomes of most grant applications are not yet known, but we are delighted that five grants have already been awarded totalling £3,112,918. Unfortunately, three grants totalling £ 3,251,389 were not awarded during the period of NIHR funding for the partnership.

### **Patient and Public Involvement**

The partnership aims for patient and public involvement (PPI) to be central to its activities and the project proposals developed from it. PPI involvement was layered across the partnership. First, a PPI lead (AP) was identified who was a named co-applicant on the original bid to the NIHR and a member of the projects steering committee. In this way there was a PPI voice involved in all the project planning. Second, the PPI lead was supported both by the project coordinator (LD) and by a partnership PPI group who met regularly. The project PPI group were involved in activities relating to the overarching project. There was PPI input into the IRAS application, study protocol, supporting documentation and study findings for the survey and working groups. They were also involved in aspects of data interpretation. They developed a user involvement page for the project website. Third, there was separate PPI involvement facilitated for each of the grant applications developed as a result of the partnership. PPI representation, separate to the PPI group that was involved in the overarching partnership project, was included in all the bids that were developed and submitted to the NIHR Palliative and End of Life Call in April/May 2023 and other NIHR and non-NIHR funding streams.

Unfortunately, the PPI lead had to leave her role during the project as her substantive NHS post ended due to lack of funding. The trust were unable to find a replacement but AP continues to support the project informally as a PPI representative. AP has been involved in various dissemination activities including; a partnership networking event, the Royal Society Medicine Palliative Care section webinar on *'Innovations in diverse and inclusive public involvement in research on palliative care; learning from the NIHR Palliative and End of Life Care Research Partnerships'* on 18<sup>th</sup> April 2023, which other members of the PPI group attended, and a co-author on the journal publications.

Key learning from this project included the need for someone to lead and facilitate PPI activities across the partnership. The challenges of PPI involvement in palliative care, where patients may become too ill either intermittently or on an ongoing basis to contribute, highlights the need for a coordinated PPI infrastructure on an ongoing basis for palliative care research across the region. Whilst developing this was not a specific aim of the funded partnership, this is something we hope to achieve with ongoing funding.

### **Equality, Diversity and Inclusion**

The PalCaRe-NWC project steering committee comprised a diverse group of professionals with varying levels of expertise in palliative research from medicine, nursing, pharmacy, psychology and included representation from the North West Coast CRN and PPI.

Active clinicians being mentored by the partnership included RB (clinically active consultant medical oncologist,), AG, SC and AN (Senior Clinical Lecturers and Consultants in Palliative Care) and AD

(Consultant Pharmacist). Five out of the fifteen participants who took part in the action learning sets were from a nursing background.

The role and benefits of PPI involvement in the project are described in the previous section. The PPI lead had lived experience of cancer and end of life care and had PPI experience in the NHS, voluntary sector and academia within and outside the region. The four other PPI representatives who were engaged in the partnership were based outside the North West Coast region and had lived experience of caring for someone with cancer and/or non-cancer and all had previous PPI experience. There was representation from the Black, Asian and Ethnic Minorities community. Organising payment for PPI representative's time such as attending meetings and reading materials was challenging. It involved engagement contracts being in place with Lancaster University that included 'right to work' checks. This process creates additional complexity and delays and may put some individuals off from being involved in a research project.

Recruiting patient or family carers to the working group as research participants to explore their views of local barriers and facilitators to palliative and end-of-life care research was challenging in this study. This was despite working with the PPI lead, PPI group and public advisor network in the ARC to facilitate reaching these groups, including using their existing social media channels.

Significant delays with the DBS and occupational health process at Lancaster University Human Resources department meant there were approval delays in the NHS trust where we planned to recruit participants. Three members of our PPI group reviewed and provided input into our staff working group findings and our PPI lead was involved in the data analysis process.

Recruiting to the staff working groups was also challenging due to potential participants' clinical pressures and workload. The working groups took place online rather than in person for flexibility but a small number of participants who consented to take part still had to cancel at short notice because of clinical commitments.

## **Dissemination**

The partnership has used several dissemination strategies to ensure that its work and the opportunities it creates are visible and accessible to those interested in palliative care research both within and beyond the North West Coast region. A project website was set up at the start of the project and has been maintained and added to as the partnership develops (<https://sites.google.com/nih.ac.uk/palcarenwc/home>). Research training, support and funding opportunities were advertised on the project website. Social media (Twitter @PalCaReNWC) has been used to disseminate the work of the partnership alongside existing channels such as the ARC, CRN, and palliative care clinical network mailing lists. Mailing lists have also been created from the networking events. PalCa-Re NWC was shortlisted for an award at the North West Coast Research and Innovation Awards 2023 in the 'Research Collaboration of the Year' category.

## **Discussion**

### **Sustainability and next steps**

Our survey and working group findings highlighted how organisational barriers need to be addressed to enhance palliative care research capacity and collaborative opportunities across clinical and research settings need to be created<sup>37</sup>. This supports previous research identifying similar barriers and making comparable recommendations<sup>41-45</sup>. These include the need to focus on collaboration, sharing best practice, developing a research culture, and facilitating research within organisations, enhancing staff capacity and expertise, and providing guidance on research processes and procedures<sup>41, 42, 44, 45</sup>.

Working collaboratively in partnerships has proven important in generating high-quality palliative care research in other countries<sup>46, 47</sup>. Partnerships between academic centres, NHS organisations and hospices may help address structural barriers such as indemnity, sponsorship and gaining

research ethics committee approval. Being actively involved in a research study may lead to an improvement in an organisation's research culture <sup>48</sup>.

There has been previous time-limited funding in the UK to establish palliative care research collaboratives<sup>49, 50</sup>, similar to the current short-term investment by the NIHR <sup>51</sup>. A major challenge for palliative and end of life care research is that funding to sustain partnerships and collaborative working can be fragile or time limited. We are delighted that the North West Coast CRN has agreed to provide additional short-term funding (July 2023 to March 2024) to enable the expansion and continuation of this initial partnership. This has demonstrated that whilst embedding the partnership activities within existing infrastructure facilitated ongoing collaboration, a relatively modest amount of funding is important to support activities (such as networking events and the coordination of grant submissions) that can sustain and grow the partnership.

PalCaRe-NWC has already had major achievements, working effectively to understand barriers to, and stimulate, palliative care research activity but there is a need to build on these initial successes. It is important that further development of a sustainable network embedded in existing infrastructure continues, to improve palliative care research capacity and quality within the region. Additional funding is essential to further strengthen high-quality partnerships and extend engagement with stakeholders including non-traditional stakeholders such as hospices and social care providers. In particular, social care is a core provider of care to those with palliative care needs, but the partnership have struggled to meaningfully engage with this sector, despite active attempts to do so with a range of stakeholders.

The partnership plans to continue to advocate for, develop, and implement sustainable and realistic solutions to prioritised, amendable, barriers. This will involve collaborating with palliative care providers (including across NHS, ambulance service, social care, nursing care homes, and the hospice

sector), patients and the public, and research staff to embed an improved research culture and encourage relevant system wide changes. This will increase opportunities for organisations, staff, patients, and family carers to access high quality, clinically relevant research that improves their experiences and outcomes of care.

Funded by the CRN, the partnership plans to deliver at least two further networking events to include participants from NHS, non-NHS and non-traditional research settings together with researchers. An additional action learning set will be run for up to six emerging research leaders, with a focus on developing organisational research participation within non-traditional settings. The website will be developed further to function as a hub to disseminate information about opportunities for organisations to participate in relevant portfolio studies. High-quality clinically relevant research grant applications will be submitted to the NIHR palliative care commissioned call in August/September 2023. User-friendly guides to research in palliative care outside the NHS and in non-traditional settings are starting to be produced in partnership with a range of national partners, with wide dissemination planned. A new steering committee will be set up that will have identified representation from across the North West Coast to include the CRN, clinical network, acute, ambulance and primary care NHS trusts, universities, hospices, other voluntary and social care organisations, and PPI.

### **Lessons Learnt**

Three-quarters of staff who responded to our survey wanted to increase their involvement in palliative care research, despite most of the respondents not being currently research active<sup>37</sup>. In order to achieve this there needs to be investment in, and prioritisation of, research time and roles for staff working within clinical practice<sup>52-54</sup>, an issue not unique to palliative care<sup>55</sup>. Funding is required to facilitate and sustain collaborative partnership working between universities, health and social care organisations and professional groups. On a practical level, we learnt that systemic

barriers can negatively influence public involvement in palliative care research. These include overly bureaucratic payment processes for PPI involvement and research passport delays for university staff carrying out research with patients and family carers in the NHS. To improve PPI reach there needs to be modes and lines of communication that facilitate a rapid and flexible response. An additional barrier we experienced was the complexity of obtaining organisational approval for a low-risk staff study taking place across multiple NHS and non-NHS sites.

### **Limitations**

Whilst we ensured patient and public involvement was included in the planning and activities of the PalCaRe-NWC partnership, there was limited representation from patients, family members and the public as research participants in the survey and working group findings. The partnership aimed to recruit the public to our working groups, but recruitment challenges and organisational approval delays meant this planned aspect of the study did not go ahead<sup>37</sup>. Staff from across different sectors and professional backgrounds responded to the survey, including a strong response from nurses, but it was more challenging to recruit those who did not provide specialist palliative care or who worked in care homes. This may have been because staff did not identify themselves as providing palliative care despite caring for patients with palliative care needs. The survey and working group findings and the activities that resulted from this work represent the views and needs of people from across a particular area within the UK. It may be that this does not represent wider views of the barriers to palliative care research and the activities that can help address them, but this is unlikely given the comparisons with other published research.

Staff may have been discouraged from applying to take part in the action learning sets because of clinical workload. Clinical pressures may also account for the number of people who registered for the networking event but who could not attend on the day. Further attention is needed to actively engage those working in social care roles.



## **Conclusions**

Improving access to palliative care research within North West Coast, and beyond, can only be achieved by universities, health and social care organisations, and professional groups working in partnership. The PalCaRe-NWC partnership has had many achievements since its inception including a survey and working groups to understand local barriers and facilitators to palliative care research. It has stimulated palliative care research activity and interest within the region and beyond through its website, action learning sets, networking events and the development of resources to support hospice research in partnership with national stakeholders. Eleven research grant applications totalling £5,435,967 were submitted as a direct result of partnership activities between Jan2022-June 2023.

The survey and working groups findings, as in previous research, highlight how a shift in organisational culture is needed to enhance palliative care research capacity and collaborative opportunities across clinical and research settings and how little progress has been made over time. There is a need to embed, sustain and build on the initial successes of the PalCaRe-NWC partnership. This means continued funding is essential to maintain and further strengthen high-quality partnerships, and extend engagement with other stakeholders such as hospices and social care providers to nurture good research practice and combat barriers to recruitment.

## **Additional Information**

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## Glossary

ARC NWC: Applied Research Collaborative North West Coast

CCG: Clinical Commissioning Groups

CRN: Clinical Research Network

IRAS: Integrated Research Application System

NIHR: National Institute for Health Research

PPI: Patient and Public Involvement

## References

1. Bhatnagar P, Wickramasinghe K, Williams J, et al. The epidemiology of cardiovascular disease in the UK 2014. *Heart (British Cardiac Society)* 2015; 101: 1182-1189. DOI: 10.1136/heartjnl-2015-307516.
2. Arik A, Dodd E and Streftaris G. Cancer morbidity trends and regional differences in England- A Bayesian analysis. *PloS one* 2020; 15: e0232844. 2020/05/21. DOI: 10.1371/journal.pone.0232844.
3. National Institute for Health and Social Care Research. Our Research Performance, <https://www.nihr.ac.uk/about-us/who-we-are/our-research-performance/> (accessed 22.8.24).
4. Boaz A, Hanney S, Jones T, et al. Does the engagement of clinicians and organisations in research improve healthcare performance: a three-stage review. *BMJ Open* 2015; 5: e009415. DOI: 10.1136/bmjopen-2015-009415.
5. Giebel C, McIntyre JC, Alfirevic A, et al. The longitudinal NIHR ARC North West Coast Household Health Survey: exploring health inequalities in disadvantaged communities. *BMC public health* 2020; 20: 1257. DOI: 10.1186/s12889-020-09346-5.
6. Department of Health and Social Care. *Chief Medical Officer's Annual Report 2021 Health in Coastal Communities*. 2021. London.
7. Etkind SN, Bone AE, Gomes B, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Medicine* 2017; 15: 102. DOI: 10.1186/s12916-017-0860-2.
8. Bone AE, Gomes B, Etkind SN, et al. What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death. *Palliative medicine* 2018; 32: 329-336.
9. Public Health England. Atlas of Variation for Palliative and End-of-Life Care in England, <http://tools.england.nhs.uk/images/EOLCatlas/atlas.html> (2021, accessed 4.8.21).
10. Allsop MJ, Ziegler LE, Mulvey MR, et al. Duration and determinants of hospice-based specialist palliative care: A national retrospective cohort study. *Palliative medicine* 2018; 32: 1322-1333. DOI: 10.1177/0269216318781417.

11. Mondor L, Wodchis WP and Tanuseputro P. Persistent socioeconomic inequalities in location of death and receipt of palliative care: A population-based cohort study. *Palliative Medicine* 2020; 34: 1393-1401.
12. LeBlanc TW, Lodato JE, Currow DC, et al. Overcoming recruitment challenges in palliative care clinical trials. *Journal of Oncology Practice* 2013; 9: 277-282. DOI: 10.1200/JOP.2013.000996.
13. Kaiser KS, McGuire DB, Keay TJ, et al. Methodological challenges in conducting instrumentation research in non-communicative palliative care patients. *Applied Nursing Research* 2020; 51: 151199. DOI: 10.1016/j.apnr.2019.151199.
14. Pereira SM and Hernández-Marrero P. Research ethics in palliative care: A hallmark in Palliative Medicine. *Palliative medicine* 2019: 1-2. DOI: 10.1177/0269216319827178.
15. Kars MC, van Thiel GJ, van der Graaf R, et al. A systematic review of reasons for gatekeeping in palliative care research. *Palliative medicine* 2016; 30: 533-548. 2015/11/19. DOI: 10.1177/0269216315616759.
16. Dunleavy L, Walshe C, Oriani A, et al. Using the 'Social Marketing Mix Framework' to explore recruitment barriers and facilitators in palliative care randomised controlled trials? A narrative synthesis review. *Palliative medicine* 2018; 32: 990-1009. DOI: 10.1177/0269216318757623.
17. Bloomer MJ, Hutchinson AM, Brooks L, et al. Dying persons' perspectives on, or experiences of, participating in research: An integrative review. *Palliative medicine* 2018; 32: 851-860. DOI: 10.1177/0269216317744503.
18. White C, Noble S, Watson M, et al. Optimised clinical study recruitment in palliative care: success strategies and lessons learned. *BMJ Supportive & Palliative Care* 2019: bmjspcare-2019-001820. DOI: 10.1136/bmjspcare-2019-001820.
19. Aoun S, Slatyer S, Deas K, et al. Family Caregiver Participation in Palliative Care Research: Challenging the Myth. *Journal of pain and symptom management* 2017; 53: 851-861. DOI: 10.1016/j.jpainsymman.2016.12.327.
20. Coyle S, Scott A, Nwosu AC, et al. Collecting biological material from palliative care patients in the last weeks of life: a feasibility study. *BMJ open* 2016; 6: e011763.
21. Higginson IJ. Research challenges in palliative and end of life care. *BMJ Supportive & Palliative Care* 2016; 6: 2-4. DOI: 10.1136/bmjspcare-2015-001091.
22. Vinches M, Neven A, Fenwarth L, et al. Clinical research in cancer palliative care: a metaresearch analysis. *BMJ Supportive & Palliative Care* 2020. DOI: 10.1136/bmjspcare-2019-002086.
23. Dunleavy L, Griggs A, Wiley G, et al. Overcoming the hurdles: setting up clinical trials in three UK hospices. *International journal of palliative nursing* 2011; 17: 131-134. DOI: 10.12968/ijpn.2011.17.3.131.
24. Moore DC, Payne S, Van den Block L, et al. Research, recruitment and observational data collection in care homes: lessons from the PACE study. *BMC research notes* 2019; 12: 1-6. DOI: 10.1186/s13104-019-4543-2.
25. Stone PC, Gwilliam B, Keeley V, et al. Factors affecting recruitment to an observational multicentre palliative care study. *BMJ Supportive & Palliative Care* 2013; 3: 318-323. DOI: 10.1136/bmjspcare-2012-000396.
26. Edwards Z, Bennett MI, Petty D, et al. Evaluating recruitment methods of patients with advanced cancer: a pragmatic opportunistic comparison. *International Journal of Pharmacy Practice* 2019; 27: 536-544. DOI: 10.1111/ijpp.12562.
27. Bouça-Machado R, Rosário M, Alarcão J, et al. Clinical trials in palliative care: a systematic review of their methodological characteristics and of the quality of their reporting. *BMC Palliative Care* 2017; 16: 10. journal article. DOI: 10.1186/s12904-016-0181-9.
28. Visser C, Hadley G and Wee B. Reality of evidence-based practice in palliative care. *Cancer biology & medicine* 2015; 12: 193-200. DOI: 10.7497/j.issn.2095-3941.2015.0041.
29. Eule C, Bhulani N, Paulk E, et al. Characteristics and impact of the most-cited palliative oncology studies from 1995 to 2016. *BMC cancer* 2018; 18: 1281. DOI: 10.1186/s12885-018-5150-7.

30. Dunleavy L. *Health care professional recruitment of patients and family carers to palliative care randomised controlled trials: A qualitative multiple case study*. Lancaster University, 2021.
31. Payne S, Preston N, Turner M, et al. Research in palliative care: can hospices afford not to be involved. *International Observatory on End of Life Care, University of Lancaster* 2013.
32. Preston NJ, Farquhar MC, Walshe CE, et al. Strategies to increase participant recruitment to research studies by healthcare professionals. *Cochrane Database of Systematic Reviews* 2012; 2012.
33. Evans C, Yorganci E, Lewis P, et al. Processes of consent in research for adults with impaired mental capacity nearing the end of life: systematic review and transparent expert consultation (MORECare\_Capacity statement). *BMC medicine* 2020; 18: 1-55.
34. Higginson I, Evans C, Grande G, et al. Evaluating complex interventions in End of Life Care: the MORECare Statement on good practice generated by a synthesis of transparent expert consultations and systematic reviews. *BMC Medicine* 2014; 11: doi:10.1186/1741-7015-1111-1111.
35. Jünger S and Payne S. The crossover artist: consensus methods in health research. *Handbook of Theory and Methods in Applied Health Research*. Edward Elgar Publishing, 2020.
36. Lambert SD, Coumoundouros C, Hulbert-Williams NJ, et al. Building the capacity for psycho-Oncology research: a survey of the research barriers and training needs within the International Psycho-Oncology Society. *Journal of psychosocial oncology research and practice* 2020; 2: e023-e023. DOI: 10.1097/OR9.000000000000023.
37. Walshe C, Dunleavy L, Preston N, et al. Understanding barriers and facilitators to palliative and end-of-life care research: a mixed method study of generalist and specialist health, social care, and research professionals. *BMC Palliative Care* 2024; 23: 159. DOI: 10.1186/s12904-024-01488-2.
38. Walshe C DL, Preston N, Payne S, Ellershaw J, Taylor V, Mason S, Gadoud A, Board R, Swash B, Partridge A, Halvorsen J, Nwosu A, Coyle S, Dickman A, Hulbert-Williams N, . P 17.016 Understanding Barriers and Facilitators to Palliative Care Research: Survey and Working Groups with Generalist and Specialist Health, Social Care and Research Professionals. *Palliative medicine* 2023; 37: 1-302.
39. Palliative Care Research Network North West. Hospice Research Resources, <https://sites.google.com/nih.ac.uk/palcarenw/hospice-research-resources> (2024, accessed 22.8.24).
40. Alliance. JL. James Lind Alliance Priority Setting Partnerships. Palliative and end of life care top 10, <https://www.jla.nihr.ac.uk/priority-setting-partnerships/palliative-and-end-of-life-care/top-10-priorities/> (2020, accessed 16.8.2021).
41. Payne S, Preston N, Turner M, et al. *Research in palliative care: can hospices afford not to be involved*. 2013. London.
42. Preston N, Dunleavy L, Rigby J, et al. Overcoming barriers to research in palliative care: results from a consensus exercise. *Palliative Medicine* 2014; 28: 745-745.
43. Preston N, Payne S and Todd C. Conducting research in palliative care patients: a burden or an opportunity? *International journal of Palliative Nursing* 2009; 15: 524-525.
44. Payne S and Turner M. Methods of building and improving the research capacity of hospices. *European Journal of Palliative Care* 2012; 19: 34-37.
45. Casarett D, Karlawish J and Hirschman K. Are Hospices Ready to Participate in Palliative Care Research? Results of a National Survey. *Journal of Palliative Medicine* 2002; 5: 397-406. DOI: 10.1089/109662102320135289.
46. Abernethy AP, Aziz NM, Basch E, et al. A strategy to advance the evidence base in palliative medicine: formation of a palliative care research cooperative group. *Journal of palliative medicine* 2010; 13: 1407-1413.
47. Eagar K, Watters P, Currow DC, et al. The Australian Palliative Care Outcomes Collaboration (PCOC)--measuring the quality and outcomes of palliative care on a routine basis. *Aust Health Rev* 2010; 34: 186-192. DOI: 10.1071/ah08718.
48. Grbich C, Abernethy AP, Shelby-James T, et al. Creating a Research Culture in a Palliative Care Service Environment: A Qualitative Study of the Evolution of Staff Attitudes to Research during

- a Large Longitudinal Controlled Trial (ISRCTN81117481). *Journal of Palliative Care* 2008; 24: 100-109. DOI: 10.1177/082585970802400206.
49. Payne S, Seymour J, Molassiotis A, et al. Benefits and challenges of collaborative research: lessons from supportive and palliative care. *BMJ Support Palliat Care* 2011; 1: 5-11. DOI: 10.1136/bmjspcare-2011-000018.
50. Payne S, Addington-Hall J, Richardson A, et al. Supportive and palliative care research collaboratives in the United Kingdom: an unnatural experiment? : Sage Publications Sage UK: London, England, 2007, p. 663-665.
51. National Institute for Health and Care Research. 21/54 NIHR Palliative and End of Life Care Research Partnerships Cross-programme Funding Committee Public Minutes 28 September 2021, <https://www.nihr.ac.uk/documents/2154-nihr-palliative-and-end-of-life-care-research-partnerships-cross-programme-funding-committee-public-minutes-28-september-2021/29323> (2021, accessed 27.4.23).
52. Clark D, Seymour J, Douglas H-R, et al. Clinical nurse specialists in palliative care. Part 2. Explaining diversity in the organization and costs of Macmillan nursing services. *Palliative Medicine* 2002; 16: 375-385. DOI: 10.1191/0269216302pm585oa.
53. Kerr H, Donovan M and McSorley O. Evaluation of the role of the clinical Nurse Specialist in cancer care: an integrative literature review. *Eur J Cancer Care (Engl)* 2021; 30: e13415. 20210126. DOI: 10.1111/ecc.13415.
54. Makin W, Finlay IG, Amesbury B, et al. What do palliative medicine consultants do? *Palliative Medicine* 2000; 14: 405-409.
55. Crombie A, Borkowski D, Gardner M, et al. Understanding the research capacity and culture of a regional allied health workforce. *Australian Journal of Primary Health* 2021; 27: 397-403.