# Title of research:

# The Yorkshire & Humber Palliative Care Research Network: Addressing Inequalities Across All Ages

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## Background

Yorkshire and the Humber (Y&H) is the largest region in the UK, with a population approaching 6 million, comprising large urban areas of Leeds, Sheffield, Bradford, Hull, and semi-rural and rural districts such as the North and East Ridings, and North Lincolnshire. East Yorkshire includes 45 miles of coastline, with several coastal cities and towns highlighted in the Chief Medical Officer's 2021 Annual Report as having some of the worst health outcomes in England, emphasising local variations and inequalities in health (1). Y&H is very ethnically diverse. After London and the West Midlands, this region has the third highest proportion of people with black, Asian or mixed ethnic background (2). The diversity of the region ranges from Bradford with a large Pakistani population and some of the most socio-economically deprived wards in England, to Hull with a mostly White British population with the tenth most deprived local authority in England (2010 data). There has been low investment in palliative care research across the region (3, 4). Recruitment into palliative and end of life care studies within the Y&H region is very uneven (see full list of CCG research and prevalence data, supplied for call), with some beacons of high recruitment, focused largely around existing academic centres (Leeds, Sheffield, Hull) which provide good research infrastructure, but with little or no activity elsewhere - especially so in the more socioeconomically deprived and ethnically diverse populations (e.g. Kirklees, Rotherham, Barnsley, Bradford, Doncaster, North and North-East Lincolnshire, coastal Yorkshire) - areas of the greatest inequalities in health access and care.

The purpose of this **Y&H Palliative Care Research Network** bid is to address inequalities in palliative and end of life care research across the region and among all ages, building on our strengths to increase research capacity in research naive areas to deliver wider engagement in research, more diverse recruitment into palliative care studies, and provide better evidence and improve care. This programme will deliver two work packages:

1. In WP1, we will develop and implement a **Y&H Palliative Care Research Network** with health and social care and patient/public partners, building research capacity and providing greater breadth of engagement in palliative care research across this large and diverse region. We will work closely with Patient and Public Involvement and Engagement (PPIE) partners to expand inclusion of under-represented groups into studies, following INCLUDE guidance and recommendations, and utilising INCLUDE resources. We will adapt an organisational framework (5) to monitor research and capacity development activities in the Network. Through this Network, we will foster public engagement in research, share and increase research expertise among health and social care practitioners, provide training and resource to enable this, improve implementation of evidence into practice, and enable true partnership working to tackle inequalities in care and research.
2. In WP2, we will deliver bids for Part 2 of this call, bringing the collaborative partnership of the **Y&H Palliative Care Research Network** into reality in terms of spreading research engagement, delivery, and expertise across the region.

To achieve this, we will engage with a range of health, social care, public and voluntary sector partners not historically involved with research or who have struggled to develop research knowledge, infrastructure, and skills. This will include partners in areas with little or no past experience of research recruitment. We have interest in participation from a range of practitioners, including in the areas identified as more socioeconomically deprived or with ethnically diverse populations; Kirklees (Kirkwood Hospice), Rotherham (Rotherham Hospice), Bradford (community, hospital and Marie Curie hospice teams), Doncaster (St John's Hospice), North and North-East Lincolnshire (St Andrews Hospice, Grimsby), and coastal Yorkshire (Dove House, East Riding community teams, St Catherine's Hospice Scarborough).

We will build on, strengthen, and expand existing Y&H partnerships, working with the NIHR Applied Research Collaboration (ARC Y&H), the Research Design Service, the Y&H Clinical Research Network, and the emerging Integrated Care Systems (Humber, Coast and Vale; West Yorkshire & Harrogate; South Yorkshire), and the Strategic Clinical Networks. The ARC Y&H supports people-powered research tackling inequalities and improving health and well-being for our communities. The co-applicant team is already embedded within the multimorbidity, older people, and urgent care ARC Y&H themes working with local NHS service providers, social care services, NHS commissioners, local authorities, and charities; we will consolidate and extend this engagement. We will also work closely with NIHR ENRICH supporting research-ready care homes (https://enrich.nihr.ac.uk/offices/yorkshire-and-humber/) and the already-established Y&H Children's Palliative Care Network (see https://yhcpcn.org.uk/) - this existing ***clinical*** paediatric network links four children's hospices, 14 district general hospitals, 2 tertiary centres (Leeds and Sheffield), community nursing teams, bereavement support services, and Y&H local authority disability services and special schools, to support children and young people with life-limiting and life-threatening conditions.

# Research Protocol

## Workpackage 1:

We will establish the **Y&H Palliative Care Research Network** with multidisciplinary representation across institutions and sectors, including social care, primary care, community care, hospice, public and patient partners, and local councils, broadening engagement in palliative care research across the region. We will align with the developing Integrated Care System (ICS) structures from the outset as they transition into lead commissioning organisations, ensuring the network involves commissioners in defining research questions and is well-positioned to translate future research findings into services. The Network will be organised into three closely embedded hubs aligned with Humber, Coast and Vale ICS; West Yorkshire & Harrogate ICS; and South Yorkshire ICS. Through this new **Y&H Palliative Care Research Network**, we will build commissioning links, foster public and practitioner research engagement, share and increase research expertise among practitioners enabled by training and financial resources, improve implementation of evidence into practice, and enable true partnership working. We will achieve this through:

### Establishing the Y&H Palliative Care Research Network

1. Months 1-4: Utilising existing (but unconsolidated) infrastructure and expanding this more widely to all those concerned with palliative and end of life care delivery and research, especially those not traditionally involved. We will make new connections with providers, commissioners, and palliative and end of life care service recipients, including public, patient and family partners, specialist palliative care services (hospices, community teams and hospital advisory teams), and interested i) primary care groups or consortia ii) district/community nursing services, iii) out of hours primary care services, iv) social care services and local councils, and v) Yorkshire Ambulance Service.
2. Months 1-6: Inviting partners and practitioners to join the Network, providing an opportunity to contribute into and learn from the Network. For this new Y&H Palliative Care Research Network, we will adopt a similar model to the "Nurturing Innovation in Care Home Excellence in Leeds" (NICHE–Leeds; https://niche.leeds.ac.uk/) network; a partnership between care homes and academia based upon a successful 'Living Lab' model pioneered in the Netherlands (6, 7). This brings together the knowledge and skills of researchers with the skills and experience of frontline staff. Working collaboratively, partners will identify priority areas for improvement, increase research engagement and recruitment, and reduce the implementation gap between practice and emerging evidence.
3. Months 3-6: We will hold a regional (Yorkshire-wide) research priority setting exercise which involves the Network partners and practitioners across the region being invited to determine joint 'practice/needs driven' research priorities for the region, with focus on inequalities in access/provision of services, planning/managing end of life care, and development of expertise to support high-quality delivery of care. The partners/practitioners who generate these research ideas will collaborate with us on these 'partner-initiated' applications.
4. Months 3-18: Adapting, delivering, and extending successful features from NICHE-Leeds such as: an accessible website; short (45-60 min) online monthly webinar/Project ECHO webinars (https://www.hospiceuk.org/what-we-offer/clinical-and-care-support/project-echo) exploring clinical evidence gaps; developing forthcoming studies; providing resources/training to practitioners/units/teams; sharing research skills; evolving best ways to implement evidence into practice.

### Delivering four specific initiatives within the Y&H Palliative Care Research Network

1. Months 3-18: Within each of the ICS-based hubs, we will develop a **practitioner-practitioner 'buddying' system**, where research active sites/teams are partnered with research naive sites/teams to expand involvement, share and build research expertise. Within this, we will upskill R&D departments to support delivery in naive sites, thus supporting practitioner-practitioner links for shared learning.
2. Months 3-18: We will also develop **practitioner-researcher 'Linking Pin' partnerships** (6); these partnerships will pair individual palliative, primary care, community care, ambulance, or social care practitioners with a senior researcher, for mutual exchange and support across shared research-related objectives. We anticipate 10-12 'Linking Pin' partnerships (3 to 4 per ICS Hub) to be established (one

to two partnerships with each academic). 'Linking pin' practitioners will also be connected across the Network for mutual learning and exchange, and will become co-applicants on bids in WP2.

3. Months 3-18: We will use bid **resources for practitioner backfill** for one weekly programmed activity (or equivalent) over 3-6 months, available to practitioners from a palliative, primary care, community care, ambulance, or social care background. The backfilled time will be used to establish research skills/links and local knowledge, sustainable beyond the end of the funding. These will be available for eight to ten individuals, applied for competitively within the first three months of the project.
4. Months 3-18: We will also provide **practitioner and early career researcher mentorship**. This will be provided for early career researchers and for at least four practitioners not previously contributing to or leading research, to become research active and co-lead/become co-applicant (as relevant) on one of the proposed bids in WP2, and/or to apply for Research Fellowships. We will foster links with and build on successful mentorship models for existing NIHR trainees.

**Providing training and bursaries to support training**

1. Months 3-18: Providing dedicated research training for practitioners in short videos (5-10 mins) on a range of research-related topics for wider dissemination, complementing existing NIHR resources on upskilling practitioners for research activity. We will utilise the existing NIHR Learn, Improving Healthcare Through Clinical Research (MOOC), and What Is Health Research? (MOOC) resources. Our additional Network resources will be tailored to the unique challenges of palliative research.
2. Months 3-18: Providing bursaries for i) Network practitioner members to undertake short courses in research training, including in implementation and knowledge exchange, and ii) short placements, working alongside existing research teams – thus providing experiential learning.

## Workpackage 2:

In WP2 we will develop and deliver bids, operationalising the collaborative partnership of the **Y&H Palliative Care Research Network,** and focusing on areas identified by NIHR as evidence gaps in the commissioning brief (reducing inequalities in access/provision of services, planning and managing end of life care, strengthening training and development of expertise to support delivery of quality care). We will incorporate each of the four initiatives above: the **practitioner-practitioner 'buddying'**; the **practitioner-researcher 'Linking Pins'**; the **resources for practitioner backfill;** and the **practitioner and early career researcher mentorship** within the development and submission of each bid. For each bid, we will aim to include at least two sites who i) previously recruited few or no participants identified from national recruitment data, and ii) are using either the **practitioner-practitioner 'buddying'** or the **practitioner-researcher 'Linking Pins'** initiatives (or both). Practitioners who have successfully applied for the **resources for practitioner backfill** will be invited to join a bid from inception and we anticipate some of these practitioners will also use the **mentorship** opportunities. Bids will be selected from among 'partner-initiated' applications generated from the research priority setting exercise and the five suggestions provided below as potential examples to ensure we submit at least three within the 18-month timescale of this work. We will remain flexible and responsive to the outcomes of the networking and partnership activities, and anticipate that the Network development, and all four of the specific initiatives in WP1 (buddying, 'Linking Pins', practitioner backfill, and mentorship) will generate and connect to the bids of WP2. Carefully selected topics will address urgent and important inequalities in the region; have already been flagged as important by practitioners and/or PPI partners in the priority setting exercise; and address commissioning challenges for the emerging ICSs. Together, these bids aim to incorporate palliative and end of life care research across all ages.

### Project A: Understanding inequalities through better use and linking of routine data in palliative and end of life care (Hussain, Clegg, Fraser, and Farrin)

To identify existing datasets and develop the processes and governance to link routinely collected data across the **Y&H Palliative Care Research Network**. Development work during the first twelve months of this bid will provide the Network with the platform necessary to conduct data-enabled research. This will be central to engaging practitioners in research, by demonstrating the utility of data and research to inform clinical care, and sustain engagement through developing active, productive collaborations between methodological and clinical researchers. We will: identify datasets across the network, including social and community care datasets; determine which variables are included, quality of data, and commonalities/differences in format and representation (vocabulary, coding schemes); determine how datasets can be linked - preferably at ICS level; clarify governance issues; determine realistic timelines; and establish a Data Steering Group of PPI partners, practitioners, ICS members, data scientists, and methodologists.

Aim: To better understand and address inequalities in access and outcomes for palliative and end of life care across ethnic and socio-economic categories within the Y&H region. Design: Secondary data analysis.
We will map out inequalities in access and outcomes for patients with palliative care needs, with a particular focus on ethnicity and deprivation, and assess the factors associated with inequalities across the Y&H region. This will provide the necessary variation in variables such as deprivation and ethnicity to explore their impact on access and outcomes and how they interact. A linked dataset will also facilitate direct population level comparison across the regions, to better understand the different challenges and approaches required.

### Project B: Reducing inequalities in access and provision of services for children and young people: evaluation of 24/7 community nursing in Y&H (Fraser, Murtagh)

In the Y&H region >9000 children and young people (0-19 years) live with life-limiting or life-threatening conditions; approximately 400 die each year (8). They are high users of healthcare, including intensive care. Due to lack of funded paediatric palliative medicine expertise and major inequalities in access to and provision of 24/7 community nursing, they often require multiple hospital admissions especially towards end of life. There is a drive to develop more equitable palliative care for children across the region when, where and how they need it (9) (10); 24/7 community nursing in particular for children and young people is planned across parts of Y&H in 2022, but robust evaluation including with research-naïve sites is needed to assess impact, determine if inequalities are addressed, and to share best practice. We will use the new Network training and resources to develop and design this bid and engage previously research naïve paediatric practitioners.
Aim: To evaluate if changes in 24/7 community nursing improve outcomes in terms of experience and quality of care for children and young people with palliative care needs. Study design: a mixed methods evaluation:

1. A qualitative study involving community nursing teams, paediatric palliative care professionals and parents to understand their experience of delivering and receiving palliative and end of life care.
2. Quantitative evaluation of the impact of the 24/7 community nursing pilot. Utilising routinely collected hospital data (linked to Project A), we will determine numbers of A&E attendances, emergency hospital admissions, and deaths in community/hospice, with a focus on good/poor access to/provision of 24/7 service. Using NHS Digital data to assess changes in these outcomes over time using a quasi-experimental study design, we will compare before and after the intervention with a comparison region. We will also collect and summarise process and outcome data about children and parents receiving care from the 24/7 community nursing team (symptoms score, advance care plan, preferences on place of care), and undertake a cost consequence analysis to assess the costs of delivering this model and any associated cost savings.

### Project C: Achieving genuinely integrated care to address socio-economic inequalities in care during last year of life (Murtagh, Johnson)

The NHS Long Term Plan confirmed England will implement an integrated care system from April 2022, building on earlier achievements through sustainability and transformation partnerships and vanguards. Three Integrated Care Systems in Yorkshire; West Yorkshire, South Yorkshire, and Humber, Coast & Vale will operate at ICS, place, and Trust/primary care levels. We do not know how these will work for palliative and end of life care, although an integrated systems approach has long been advocated (11, 12) and lessons have been learned during COVID (13), including for palliative and end of life care (14). Neither do we know the extent to which integrated care is about 'vertical' collaboratives (primary, community, local acute, and social care providers) or 'horizontal' collaboratives involving providers working together to transform services, improve quality and efficiency, and reduce inequalities. Evidence from Germany suggests a 'weekend effect' with adverse 'out of hours' outcomes for palliative patients (15) if integration is not achieved.
Aim: To understand the implications, and reality of, integrated care for those receiving palliative and end of life care. We will i) map 'out of hours' palliative and end of life services across the Network in 2022 (after ICSs are in place), ii) describe provider and commissioner perspectives on the reality of integrated care for those in the last year of life, and iii) explore integrated care from the perspective of those receiving palliative and end of life care, with emphasis on how and where inequalities in access and provision may be addressed by integration. Design: mixed methods study.
For i) we will work collaboratively with Project A to using regional datasets to determine patterns of service use including A&E attendance and hospital admissions pre and post April 2022. For ii) and iii), we will interview patients/families and providers/commissioners about the realities of integrated care. We will also use case study methodology to assess the relationship between ICSs and their constituent places, determine the extent of/challenges for integrated practice and explore best practice (of different stakeholders). The Network will be used to co-design the research, engage practitioners and commissioners, maximise

recruitment in areas of under-recruitment, and share best practice. This project will require concurrent engagement with social care, councils, local authorities, and with health care providers/commissioners.

### Project D: STEP-Care - supporting timely engagement with palliative care for people with advanced illness in community settings (Ziegler, Collinson)

Where people die is changing. In 2020, deaths at home from non-COVID causes increased by a third whilst deaths in hospital fell by almost a quarter (16, 17). Serious inequalities in access to high quality end of life care exists for those who die in the community (18, 19); without specialist palliative care there is less opportunity to choose or plan their care, poorer pain and symptom management, and worse bereavement outcomes. Advance care plans (ACP) address inequalities in care, can improve quality of life, reduce use of aggressive interventions at the end of life, improve pain control, reduce emergency hospital admissions, and help people die in their preferred place (20-24). The Covid-19 pandemic highlighted that many who die outside of hospital or hospice settings in the Y&H region had no ACP. Such people are often cared for by district nurses or health and social carers with established relationships, well-placed to undertake advance care planning. Barriers exist to them doing so (25, 26), including difficulty in identifying the right time; uncertainty about responsibilities; and fear of causing distress. This study will help overcome these barriers. In this study, **the practitioner-practitioner 'buddying' system** will be particularly important to help address under-recruiting. We will also work closely with relevant practitioners (especially district nurses, and health and social carers) to co-design the study and co-produce the intervention. We will also consider how Project A (specifically secondary data from electronic Palliative Care Coordination Systems) might inform this work. Aim: To develop a complex behavioural intervention (STEP-Care) to support people approaching the end of their lives make timely informed decisions about end of life care. Design: Mixed methods study

1. Survey to identify training needs of community nurses and carers to undertake ACP.
2. Interviews with patients, relatives and nurses/carers across Y&H to understand optimum timing and structure of conversations, supplemented by case note review of patients who died in the community.
3. Synthesising evidence from 1 & 2 to develop the prototype STEP-Care using co-design and consultation.
4. Feasibility testing STEP-Care in a population of community-based patients.

### Project E: Prepared to care: Promoting personal resources for workplace well-being of care home staff providing end of life care (Spilsbury, Cundill)

End of life care is a significant part of the roles and responsibilities of care home staff (registered nurses and care staff). There are major inequalities in how palliative and end of life care is delivered within care homes across Y&H. Meeting the needs of residents and their families in care homes is challenging, particularly due to the relationships and bonds that develop between staff, residents, and family members. This distinctiveness is often unrecognised in training or generic guidance on interventions for end of life care. Sustained, emotional work means the grief of care staff may be unresolved, emotional needs unmet, and staff wellbeing compromised. Variable quality end of life care could be attributed to poor uptake of interventions and/or frameworks (which may be linked to poor staff support) or key missing components of interventions. The current inequalities in access to training and support for care home staff in this important area of care demands attention. We need to address this gap.

Aim: To assess how we can we best develop care home staff with the competence, confidence and personal resources for workplace well-being needed to sustainably provide end of life care for care home residents. This question has been developed in collaboration with family members and care home staff as part of the NICHE-Leeds partnership (https://niche.leeds.ac.uk/ ). We will:

1. Review existing evidence, and work with care home staff, families/ friends to consider what works best; what works in some care homes to support staff competence, confidence and personal resources for workplace well-being; what factors help or get in the way; and what may improve staff engagement.
2. Co-produce a simple guide which will bring together past research findings and practical input from the care homes to establish the best ways to promote competence, confidence and personal resources for staff well-being. We will also determine (with people living and working in or with care homes) what, if any, future research needs to be developed to address this important area.

## Outputs and Deliverables:

- An established **Y&H Palliative Care Research Network** to support, sustain and develop palliative and end of life care research

- Wider public, patient, and practitioner engagement in research, as evidenced by increased recruitment in areas of previously low or no recruitment; and engagement in research activity for the 10-12 practitioners engaged as ‘Linking pins’
- Webinar and ECHO platform engagement/attendance/learning
- Grants: at least three high quality submitted bids each including practitioners as first-time co-leads or co-applicants, and at least two research-naïve sites.
- Capacity building; mentorship to becoming research active and to be co-lead/co-applicant for at least four practitioners, plus personal Fellowship applications for at least two practitioners
- A suite of tailored CPD training and resources focusing on the issues/challenges relating to palliative research (with the potential to be offered nationally as online self-directed learning)
- Improved cycle of co-developed research focusing on evidence needs of practitioners/patients/carers
- Network conference towards project end to disseminate findings / lessons learnt, aiming to continue this as a Biannual Network Conference to showcase research outputs/developments, deliver methodological workshops, and facilitate face-to-face networking across the Network.

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