BRHUmB: Building a Research Hub for Palliative Care in Birmingham and the West Midlands

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PROTOCOL

VERSION 1

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Palliative and End of Life Care Research Partnerships Grant – BRHUmB: Building a Research Hub for Palliative Care in the West Midlands

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Timeframe: 12 months - From Jan 2022 to Dec 2022

Scientific Abstract

Background: The need for palliative care is predicted to increase between 2542% by 2040 (Etkind et al. 2017) with up to 90% of all people dying in England having palliative care needs (Finucane et al. 2020). The NHS is already seeking to increase generalist and specialist palliative care support, a trend accelerated by Covid-19. However, new ways of providing palliative and end of life care are urgently needed, but there is a lack of evidence to inform such developments.

A particularly challenging aspect of care as death nears is the increased risk of 'Palliative Care Crisis': a sudden deterioration which requires an urgent response. Such crises are complex and multifactorial, fuelled by the diverse needs of the dying and those close to them. In the absence of sufficient professional and family support, hospital admission (often an emergency) is not unusual (Hoare et al. 2019). Palliative Care Crises are rarely well managed by single service interventions, and the emphasis needs to be on integrated systems

of care. To inform such developments, evidence is needed from high quality research conducted with health and social care organisations across different service settings and clinical areas.

To address this need we propose Building a Research Hub for palliative care in Birmingham and the West Midlands (BRHUmB) for a region historically underserved in terms of NIHR funding. The West Midlands is the second most diverse region in the UK in terms of cultural, socio-economic and health and social care needs. It is home to an emergent palliative care research community of academics, clinicians and services users with complex palliative health and social care needs. We now seek to better coordinate our collective efforts and build an interdisciplinary, multi-agency research partnership that brings us together to increase patient and staff benefit through the establishment and growth of partnerships and collaborations in palliative care research.

Aim: To establish BRHUmB as a recognised centre for palliative care research in Birmingham and the West Midlands and develop the region's international reputation into researching palliative care crisis.

Methods: (1) **Create** a multi-stakeholder hub to link nationally and internationally with other research collaboratives, national bodies and develop our existing patient and public involvement (PPI) group to include wider representation from health and social care; (2) **Collaborate** with research interested stakeholders and clinicians from across the palliative care field in health and social care through an academic buddying system and outreach activities, through offering support to research inactive areas. This will include identifying stakeholder membership for BRHUmB Rapid qualitative interviews (n=50) that will be conducted with health and social care staff and stakeholders to investigate the research priorities for palliative care integration and coordination across different settings (hospital, hospice, community); (3) **Consolidate** identified research priorities into key themes through a threeround eDelphi study with key stakeholders (n= 50); (4) **Co-design** the parameters of a programme grant for submission to NIHR with staff, key stakeholders and PPI service users and **Co-Produce** outputs to disseminate the priorities for palliative care research.

Impact: Through BRHUmB we will coordinate a 12-month programme of partnership activities that will embed key research networks in the West Midlands and ensure research capacity in palliative care is able to meet the changing and diverse demands of its population. Outputs will be disseminated through peer reviewed papers, conferences and via social media including the BRHUmB website.

Plain English Summary

We know that hospice and palliative care services have changed in the past few years in terms of moving care into the home setting. Since the pandemic, hospice in-patient admissions have reduced, some palliative care nursing services have been restricted, and emergency admissions of people in the last year of life are rising. Informal carers and relatives in our patient and public advisory group have raised concerns that 'the different parts of system do not seem to talk to each other' and this 'makes it more difficult to manage on top of the difficulties you already have', clearly impacting upon the experience for both the person dying and their carers /relatives. What has become clear is that to address these issues we need to coordinate palliative care research and knowledge exchange activities in a better was, not just within palliative health and social care organisations, but across them.

In collaboration with our PPI advisory group (made up of people from diverse backgrounds who have experienced supportive care or cared for someone with a terminal condition), we have identified four key ways to achieve better palliative care research and knowledge exchange that will inform health and social care services and ultimately improve care experiences for people who are dying and their relatives and carers. First, we will create a central hub for research at the University of Birmingham called BRHUmB "Building Research Hub for palliative care in Birmingham and the West Midlands". The hub will bring together a collaborative team of experts, academics, clinicians, stakeholders and patients, carers and public to share expertise in palliative care and palliative care research. In particular, by developing a programme of research to better intervene in palliative care crisis at the end of life it will become an internationally recognised research centre.

Second, we recognise that while many in the field of palliative care wish to take part in research, they do not have the necessary knowledge or experience to do so. Therefore, we will instigate a programme of 'academic buddying' to share the 'how to' with research interested stakeholders and clinicians in palliative care. We will use this time to identify the priorities for palliative care research from the staff and stakeholders working in the different areas of health and social care.

Third, we need to explore the priorities for research from key stakeholders (such as hospice managers, team leaders in social care, primary, community and secondary care settings) in different areas in the West Midlands. This is a diverse population in terms of ethnicity, cultural, socio-economic and health needs and so our findings will be useful to researchers and service users around the country.

Finally, we will work as one group of academics, clinicians, stakeholders and PPI members to co-design a grant submission for NIHR in 2022 further strengthening the research activity in the area. We will work together to report and present our work which will lead to further research that has been identified by the clinical providers and service users themselves.

Research Plan

Background

Palliative care in the UK today: Continuing crisis

A 25% increase in annual deaths is predicted by 2040 in England and Wales (Etkind et al 2017). This is most likely to be amongst the very old, with over 54% aged 85 years or older (Bone et al. 2019). Globally, we have seen an increase in deaths from cancer, dementia and heart failure, with many people experiencing multi-morbidity in the last year of life. Those who are dying are more likely to be experiencing a combination of increased ageing, multi-morbidity and increased fluctuations in the end of life trajectory, especially amongst those experiencing organ failure (Nwankwo et al. 2020). The end of life is now more complex and uncertain and there are increasing need for coordinated palliative care, but palliative care provision remains under funded (Sleeman et al., 2018) with clinicians in many settings ill-equipped to manage and provide patients with a good death (Dixon et al., 2015; EAPC, 2019). Exacerbated by the pandemic, the health and social care context is now one where there is an increased risk of triggering a palliative care crisis (Maddocks et al. 2017), such as an emergency admission at the end of life (Bailey et al. 2011). It is estimated that less than 50% of all people dying in England receive palliative care and support (around 240,000 in 2018/19) and that many more could benefit from receiving palliative care (215,000 additional people based on 2018/19 mortality figures (Sue Ryder, 2021). Services need to respond to the changing patterns in how people die, in order to provide good quality palliative care, but less is known about how to provide multi-service interventions in complex systems (Greenhalgh and Papoutsi, 2018).

Modern definitions of palliative care reflect the changing process such as an approach applying to life-threatening illness and applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life (WHO, 2020) and care that 'provides an extra layer of support with relief from the symptoms, pain, and stress of a serious illness (Meier, 2019). These attempt to represent the complex nature of terminal or life-threatening illness that people experience and emphasise the attempt to initiate care and support earlier in the dying trajectory. We know that good palliative care support can prevent emergency hospital admissions (Sarmento et al. 2017) despite the increased risk of crises that occur as death nears (Bailey et al. 2011). A crisis (expected or unexpected) or an emergency is a sudden deterioration in a person's condition which requires an urgent response (NICE 2017). The response to such a crisis is multi-factorial and dependent on the person's overall condition, advance care planning or at least communication of wishes, home support and largely the decisions made by informal carers or family members (Karasouli et al. 2016; Bailey et al. 2016). In order to improve the quality of palliative and end of life care (particularly in the last year of life) we have to understand and manage palliative care crises more effectively.

More than ever this includes accounting for the role social care plays in the provision of palliative care and support. Social care is made up of three main sectors; (1) social care providers (residential care homes, supported housing), (2) local authorities (social workers and occupational therapists that coordinate and commission care); and the voluntary sector (who largely provide community based support and some social care provision). Social work has an important role in the delivery of meaningful palliative, end of life and bereavement care (Association of Palliative Care Social Workers, 2016). Palliative care social workers and care commissioners play an integral role in decision making, care planning and communication but palliative care remains to be a 'healthcare' issue rather than integrated with 'social care'. The Nuffield Trust (2010) identified that less than 30% of people had local authority-funded social care in the 12 months prior to death. Understandably, access to social care provision differs according to the condition a person has. It is more likely that someone with mental health problems or a learning disability, or somebody who is older, frail and may regularly fall tends to use social care services more than someone with terminal cancer. But, in order to achieve the priorities identified for improving end of life care across the UK in One Chance to Get it Right (DH 2014), integrated palliative care following a framework that includes both healthcare and social care systems are essential to enhance the quality of care, efficiency, and patient satisfaction (Fulop et al. 2016).

It is time to work together to provide an integrated system of investigation and better palliative care

Modern healthcare practice and policy seeks an 'integrated approach' where patients' and their families' needs are considered by multiple disciplines (Payne et al. 2019; DHSC 2021). This is important because we know that integrated palliative care can improve patients' outcomes in terms of quality of life and satisfaction with care (Brazil 2017). However, integrating services have often been a challenge to achieve, from change being resisted by established interests to the challenges of understanding what success can look like in complex multifaceted systems (Knaul et al. 2017; Chow 2019; Hermans 2019). But early in 2020 like many healthcare services, palliative care was forced to change rapidly (Dunleavy et al., 2021).

COVID-19 has been an accelerated driver of change in palliative care, leading to changes in service provision, impact on staff wellbeing and change in roles and rapid adoption of new systems such as digital health (Constantini 2020). Prepandemic, most deaths in the UK occurred in the hospital setting (ONS 2019), but during the pandemic, hospital deaths fell and home deaths and care home deaths increased by a third (ONS 2021). According to Public Health England data (2021), the majority of excess deaths in the West Midlands occurred in the home (6172, of which 945 had covid-19 on the death certificate), followed by hospital (4094, all with covid-19 on the death certificate) and care homes (2561, all with covid-19 on the death certificate) (PHE 2021). The hospices had 886 less deaths than normally expected in comparison to previous years. These figures broadly resemble the national figures from location of death and recent audits of hospices in Birmingham showing a reduction in hospice inpatient admissions (Goodison and Bailey, 2020; Shuttleworth and Bailey, 2021).

In post pandemic recovery, we have the potential to seek better possibilities of collaboration. During the pandemic there have been numerous examples of integrative working in the West Midlands, such as the development of HoBs (Hospices in Birmingham and Solihull), and the planned intervention following the merger of two hospices in Birmingham (St Marys and John Taylor) is 'SPUR' – a specialist Palliative Care 24 hour Urgent Response Service – providing care at home when needed for crisis management to prevent emergency hospital admission. However, the fundamental gap in all of these initiatives and interventions, has been the lack of high-quality research to evidence the impact on patient benefit or service development. BRHumB will provide a central hub to support future research and help develop a robust evidence base for understanding and implementing complex interventions in palliative care crisis, but also be a space through which organisations and leaders in the field can connect and share examples of good practice.

Our NIHR Partnership Programme: Establishing BRHUmB as the West Midlands international reputation in palliative care research

Funding is needed for Building a Research Hub for palliative care in Birmingham and the West Midlands (BRHUmB) that will bring together several research groups and initiatives in the region, so they can coordinate and cooperate in developing research to integrate palliative care services and reduce palliative care crisis. In this application we have brought together expertise from across the Hospices Research Community supported by the West Midlands PEOLC CRN, WM Cares (West Midlands Collaboration Actioning Research in end of life and supportive care), and the Specialist Palliative Care Audit and Guidelines Group (SPAGG). BRHUmB will therefore draw on the different professional disciplines and clinical areas and reflect the inter-disciplinary nature and multi-agency partnerships that are needed to offer high quality research and ultimately an integrated approach to palliative care.

The core research team represent academia, hospice, hospitals, primary care, community and social care practitioners with professional representation of doctors, nurses, social work and sociology. As BRHUmB develops it will be open to all stakeholders in palliative care as we recognise the importance of moving beyond a narrow focus on 'medics', 'academics' or 'hospices services'. If we do not work as a collaborative partnership, we risk working in unsustainable silos that do not enable the growth of networks that will lead to high quality proposals to NIHR. Our existing PPI research advisory group will be developed to represent the diverse need of the West Midlands population. We will look to recruit people with a range of experiences and diverse health and social needs, different cultural, ethnic and socioeconomic backgrounds and people from regions of the West Midlands that we do not already have in the group.

The first priority for BRHUmB will be to identify the priorities for palliative care research through a rapid research technique (Vindrola-Padros and Johnson 2020). This will further foster partnership by bringing all those involved together to identify the priorities for stage 2 application. From our ongoing research and preliminary discussions with clinical groups, we anticipate a major theme about palliative care crises and how these may be better managed through existing primary care, social care and palliative care services. It is over a decade ago that Bennett et al. (2010) reviewed the priorities for research in endof-life care in the United Kingdom (UK) and six years since Marie Curie carried out a consultation exercise on Palliative and end of life care Priority Setting 2015, facilitated by the James Lind Alliance (JLA). Both emphasised the need to build research capacity, make better use of existing research study outcomes, and develop sustained programmes of research. Whilst research active hospices and NHS Trusts have been successful elsewhere in the UK, Birmingham remains low in comparison to other cities (NIHR 2020).

Why Birmingham and the West Midlands?

Historically, the West Midlands has been under served by funded NIHR research activity despite Birmingham being one of the most diverse cities in terms of ethnicity and health needs. Birmingham's 2021 population is now estimated at 2,626,374 (World Population Review 2021). Over 60% of Birmingham population live in areas that are classed as the 20% most deprived areas in England. Educational attainment is significantly below the England average with high rates of unemployment particularly in West Birmingham. This population is particularly important to capture, given the links of unemployment to physical and mental health. Birmingham is more ethnically diverse than London with 70.4% of the people of Birmingham being white, 19.5% Asian, 6.1% Black, 0.5 Chinese, 2.5% mixed race, and 0.6 of another ethnic group. It serves the UK's highest Gypsy and Traveller population with more than 53,554, (5% of the region’s population) (World Population Review 2021).

Christianity remains the city's most prominent religion (59.1%) but other major religions are Islam (14.3%), Sikh (2.93%), and Hindu (1.98%). The majority of Birmingham’s population speak English (84.7%) but numerous minorities of other languages including Urdu (2.9%), Panjabi, (2.1%) Bengali (1.4%), Pakistani Pahari (1.1%), Polish (0.9%), Somali (0.8%), Arabic (0.7%), Pashto (0.6%) and Chinese (0.6%) with 6% of households claiming they cannot speak English well or at all (World Population Review 2021) . This is likely to have a significant impact on health care decision making and access to services, therefore the creation of this research collaboration within Birmingham is crucially important to capture this diverse population and explore unique healthcare needs and challenges.

There were 82,755 registered deaths in West Midlands between March 2020-July (12,240 are being referred to as excess deaths modelled from data from previous years to show the impact of the pandemic). The highest cause of 'excess deaths' being cardiac (2629) and other circulatory diseases (5593), followed by acute respiratory infections (5401), diabetes (4063) then dementia (1958). It is likely that 90% of those had a palliative care need in the final, months, weeks, days and hours of their life (Finucane et al, 2021). Yet, under 50% receive any palliative care service. In an ageing society with more people than ever before living with co-morbidity (Kingston et al. 2018), we are likely to see the number of people dying per annum increasing by up to 42 percent by 2040 (Etkind et al. 2017) with a growing proportion of these being a result of frailty or degenerative conditions (ONS 2021). As death nears, there are more frequent crisis, such as emergency attendances, especially within the last month of life (Taylor et al. 2020) with the highest rate of emergency admissions being in the last year of life for those with organ failure and highest in the last month of life amongst those.

Current research projects and collaborations contributing to the formation of this bid

Recent research (funded by Marie Curie and MRC) within our team shows that there was a reduction in admissions to IPU and restrictive service provision (Shuttleworth 2021). This likely had significant impact on the experiences of patients at the end of life, informal carers and the hospice staff providing care. Concurrently, our research investigating reducing emergency cancer admissions (REPLiCA) shows that emergency admissions of people at the end of life are increasing. This raises the question of whether community and hospice services can be used more efficiently to manage palliative care emergencies and this is likely to be an anticipatory theme we wish to explore within BRHUmB.

BRHUmB will be developed from the existing, academic led (by CB) Supportive, Palliative and End of Life (SPEL) Research Programme at The University of Birmingham. This group meets regularly and is currently made up of academics, clinicians, hospice research facilitators and patient and public representatives in and around Birmingham. The group has a track record of grant income and service evaluation in the region but due to its location and reputation could do much more if appropriately funded to work more closely with health and social care services to drive research from the practice area. CB's research has focused on emergency admissions at the end of life, measuring the quality of end-of-life care across different trajectories and in different settings and the experiences of hospice and end of life care for staff, patients and carers. The team have investigated 'palliative care crises' in a range of projects within intensive care

(NE), amongst bereaved relatives (WW, NE, CB, PG), and amongst vulnerable groups such as refugees (PG). Co-ap RM is the adult social care lead for the West Midlands ARC and the national ARC Social Alliance. He is involved in several national projects to improve social care in England and therefore well connected with various social care stakeholders in West Midlands and beyond. RM's involvement with BRHUmB not only furthers the Birmingham-Warwick research alliances, but also gives us an excellent opportunity for wider partnership building with social care.

BRHUmB will also involve the supportive, palliative and end of life care in Primary Care research theme at University of Warwick (lead by JM), which includes academics who have been undertaking research focused on evaluating hospice care (before and during the pandemic), the end-of-life care needs of children, advanced care planning, and use of digital interventions to support carers. The team works closely with the CRN primary care specialty team (JD is clinical speciality research lead) for the West Midlands, and has strong links with CCGs and GP networks. By combining Warwick and Birmingham's existing collaborations and networks in health and social care settings to build our partnership, we have the potential with BRHUmB to be more influential and create a stronger identity for research in the region and nationally.

In addition to these academic foundations co-ap DT is the Palliative Care Lead for NHSEI in the West Midlands and will therefore be in a valuable position to enable cross clinical-academic partnerships and networking. CB represents UoB on a new innovation to build a 'Compassionate City and Community' which will link BRHUmB to the wider stakeholders. Co-ap JT chairs the Specialist Palliative Care Audit and Guidelines Group in the West Midlands, uniquely placed for partnership building.

On larger scale, activity has been increased by the IMPACT Project ('Improving Adult Care Together'), the new UK centre for implementing evidence in adult social care led by Professor Jon Glasby at the University of Birmingham. This has received £15m funding from the ESRC and Health Foundation, and will run for at least 7 years in the first instance (2021-27), ensuring that evidence of what works is embedding in adult social care services and practice. IMPACT is currently consulting on its work programme, but we are in active dialogue in terms of future research collaborations and to achieve a more integrated care system. During the tendering process, IMAPCT identified ways of improving support for carers at end of life as one of its possible projects, and other proposed themes (new models of delivery; care, housing and health; unmet need; and person-centred approaches) are highly relevant for our work and Director of Impact, Professor Jon Glasby is fully supportive of the proposal for BRHUmB. In the development of BRHUmB we can learn a lot from IMPACT in terms of partnership building and how it is research driven, the model we want to echo with BRHUmB. We work closely with the IMPACT team (via co-ap RM) to learn from their experience and also connect both adult social care and palliative care.

Our current research projects have provided the foundation for this proposal. Preliminary findings provide the narrative that hospices are being used differently, but emergency admissions are rising for those requiring end of life. Whilst most of this research has been conducted within the West Midlands, the findings are likely to be relevant across the UK given the increasing age of mortality and increase in multi-morbidity which is making the end of life more complex with increased risks of palliative care crises. There is therefore the potential to focus the programme of research on managing palliative care crisis through maximising the use of existing hospice and surrounding services (i.e. the building, the staff, the outreach services) and hospice capacity building in palliative care in emergencies. Our current research (detailed in each coapplicant's CV) into Crisis in Palliative Care fall under the following two themes: *Prevention of crisis*: How to ensure that those who need palliative care and support have their needs identified so that they receive what they need in a timely way, remains central issues of concern across the region and nationally. The co-applicants have explored coordination of care across service providers, from evaluations of single point of contact services, to identifying how complex palliative needs are communicated between primary and specialist palliative care in referral to and discharge from specialist palliative care. Our work also includes studies exploring the impact of the pandemic on hospice staff and service users, from identifying the impact on future place of care decisions, to how the pandemic accelerated many service changes and might have altered attitudes to dying and palliative care.

> *Responding to crisis:* What happens Out-of-Hours and how people come to attend emergency departments has been a long-standing concern for the PI and co-applicants. This includes identifying ways that primary care can operate more effectively in those out-of-hours moments, to better understanding and developing interventions to improve palliative care and support in emergency departments. There is also a wealth of educational research amongst the team who have investigated the most effective ways to train and support staff and the bereaved following crisis in both terminal and sudden death trajectories. The PI and co-applicants also have expertise in measurement of end of life care amongst patients who are dying, healthcare professionals and close persons which will be crucial for stage 2 of this research programme.

This recently completed or currently active funded research work has provided the foundations for a programme of work into Palliative Care Crises. We understand the rising concerns of 'crisis' as death nears and the impact this has on the quality of end of life and in bereavement. This gives us a good opportunity to investigate the future of palliative care services from all different settings across the region. There is regional strategic support from Marie Curie but in order to propose a successful intervention we need to establish the right multidisciplinary and multi-agency team, formalise research active hospices and do some preliminary research on priority setting which this project will deliver.

Aims and Objectives

The aim of this programme of partnership work is to strengthen emergent palliative research networks and embed a culture of high-quality palliative care research and provision across healthcare services in the West Midlands. This will help us to better investigate palliative care within the region and provide a multi-disciplinary and multi-agency approach to providing evidence based palliative care that will produce recommendations to benefit people across the country. The partnership will enable more impactful research that can direct improvements in palliative care; without it change will continue to be reactive, localised, and unsustainable. In the short term BRHUmB will co-produce and develop an inter-professional and multi-agency 'hub' within the West Midlands focused on managing palliative care crisis and ultimately improving supportive, palliative and end of life care. The hub will improve the efficiency of working through the collaboration with health and social care, identification of priorities for palliative care research and co-design of a programme grant for submission to NIHR HS&DR (2022). In the longer term, it has the potential to be the point of access for research connections, disseminations and a central platform to ensure collaborative and effective palliative care research.

Objectives: In order to embed high quality research culture across the West Midlands palliative care community we will fulfil the following objectives:

(1) Creation of a multi-stakeholder hub as a local centre of training and expertise in research into palliative care crisis (a current challenge in the last year of life in health and social care) that will link nationally and internationally to other research collaboratives and national bodies.
(2) Capacity building with research interested stakeholders and clinicians from across the palliative care field (hospices, hospitals, social care, community, urgent response/ambulance teams) through academic buddying and outreach activities.
(3) Rapid identification of palliative research priorities for the West Midlands through an eDelphi co-design study with clinical staff, stakeholders and service users.
(4) Co-production, dissemination and partnership engagement (multi-agency and PPI) to develop NIHR HS&DR grant submissions, starting with commissioned call to NIHR palliative care in 2022.

Theoretical Framework

The theoretical framework of the Change Model (NHS England 2018), widely recognised in healthcare will be used to guide stage 1 of the project to help create an environment for successful change, and provide an organised, systematic approach to achieving the aim of this partnership programme of work. The evidence-based model was designed to support large-scale change and help to accelerate the pace of effective and sustainable change (NHS England 2018). It is particularly useful at enabling effective and sustainable change that delivers real benefits for staff, patients and communities which is what we are trying to achieve through BRHUmB. Our large scale change needs to start with a collaboration of many people at different levels (staff, mangers, key stakeholders), from different fields (hospices, care homes, GPs practices, community, social care); and often across different organisations (Marie Curie, St Marys Hospice etc) across different trusts in the region (Wolverhampton, Birmingham, Sandwell). They are likely to hold different and possibly conflicting views about how palliative services could or should be managed in the future and their function in managing palliative care emergencies; so it is important to ensure a process is in place so that individual agendas and/or priorities do not inhibit the development of this work. The change model has therefore been used to plan this partnership work to: (1) find the commonalities among positions; (2) reach a shared understanding and aspiration and (3) unite the potentially diverse groups of stakeholders behind a common cause.

<u>Fig. 1 Research Methods using Change Model (NHS England 2018) (See Attachment)</u>

This model has been used to develop the stages of our development. Following the steps of the change model (2018) we then aim to:

- ‘Create’ a safe space - Build BRHUmb
- ‘Collaborate’ and ‘Consolidate’ to explore commonalities and identify priorities for palliative care research
- ‘Co-design’ the programme grant for NIHR HS&DR and co-produce the outputs for dissemination and future research

Methods

The aim of this partnership programme of work will be achieved through the following four objectives and methods.

<u>Objective 1 - Create</u>

Creation of a multi-stakeholder hub as a local centre of training and expertise in research into palliative care crisis (a current challenge in the last year of life) in health and social care that will link nationally and internationally to other research collaboratives national bodies.

The change model suggests it is important to create a space in which genuine two-way conversations can take place. This requires funding to support the growth of the Supportive and Palliative Care Research Programme across the West Midlands into a central research hub, hosted at the University of Birmingham due to central site and recognition for research. We will develop BRHUmB, which will be made up of multi-disciplinary and multi-agency experts, clinicians and academics, and patient and public representatives who would not normally work together to collaborate ideas, co-design and co-ordinate palliative care research.

Once established BRHUmB will meet four times per year formally. It will become the core hub in which research in palliative care is shared, researchers or clinicians can access to seek academic support or expertise from members (PPI, researchers, clinicians, social care leads etc) or seek co-investigators and research collaborations and/or expertise within the partnership. It will drive enthusiasm and consolidate a sustainable infrastructure between research and practice for further collaborative grant capture, co-produced high-quality publications and meaningful impact. It will have its own website, logo, social media feed and monthly newsletters, to promote its identity nationally. We will also engage in a number of outreach activities including monthly online research upskilling seminars, working with the West Midlands PEOLC CRN and NIHR Research Support teams and drawing on the co-applicants skills and experiences, to provide 'how to' seminars on getting involved in research in palliative care for interested clinicians and organisations.

Objective 2 - Collaborate

Capacity building with research interested stakeholders and clinicians from across the palliative care field (hospices, hospitals, social care, community) through academic buddying and engagement to identify the priorities for palliative care research through rapid qualitative interviews.

In the last five years the joint lead applicants have been working collaboratively with hospices in the region to support development of a research culture, recruitment of patients into externally funded research and working on bid submissions. JM is a Marie Curie Senior Research Fellow at Marie Curie West Midland's hospice who has funded time (40% between March 2018 and March 2023) to consolidate a research culture that has led to a significant increase in research activity, including successful bid submissions and peer-reviewed outputs. Co-ap WW also has a funded position in which she has been able to implement a model of research support to staff at The Royal Wolverhampton NHS Trust. Through engagement with and involvement of clinical staff she has been successful in driving enthusiasm for, and growth in end of life and palliative care research that is responsive to the needs of the staff and the organisation. CB has sought to provide a similar form of support to other hospices in the region, as has NE with direct work with Sandwell and West Birmingham Hospital Trust. When CB and NE's time was sanctioned or protected it led to successful collaborations and outputs, but they also found that the demands of academia make maintaining the levels of involvement challenging and not sustainable without directly allocated funding. In sum, we know a funded time-protected model works because it allows for the academic to work within the clinical areas to identify priorities, enthuse and develop the research culture from within.

We are therefore proposing that five academics (CB, JM, PG, NE and WW) will provide "buddying" systems that partner research active institutions with research naïve sites for 2 days per month each over the 12-month period. They are all experienced research academics and will be able to offer advice, support and drive enthusiasm for research in the clinical areas to expand involvement, increase research capacity and capability, share and build research expertise. This will commence in the hospices and hospital trusts where the core research team have existing links then reaching wider into the community, social care and urgent response services, capitalising on the existing links the core research team have. Each academic will cover a 'geographical patch' to formally provide support, network and enable partnership formation. By formalising this model across more sites, protecting the time to collaborate and build partnerships across the West Midlands, we have the potential to collaborate with health professionals, patients and stakeholders to conduct much more impactful research in the longer term.

During their protected 'buddying' time, academics will connect with key stakeholders in health and social care and develop the wider BRHUmB in preparation for Part 2. They will conduct rapid qualitative interviews with hospice staff, team leaders, managers and key stakeholders in health and social care to:

1. Identify priorities for palliative care research within that area (to be used in the delphi study in Objective 3).
2. Gain insight into local palliative care service provision, the demand for and nature of care, and examples of good practice (to be used in Objective 4)
3. Explore ways in which existing palliative care services could be better used to meet the needs of the dying and those close to them manage palliative care crises (to be used in Objective 4).

Rapid qualitative methods have recently gained popularity to give evidence in a more timely manner. The model suggested by Vindrola-Padros and Johnson (2020) will be adopted to reduce the time taken to complete traditional qualitative analysis but ensure rigour and trustworthiness: Short, informal, adhoc interviews (conducted by CB, JM, WW, NE and PG, n=10 each) will take place with staff (n=20), key stakeholders (n=20) and all members of the PPI group (n=10). Interviews will be recorded and notes taken. Transcription will be bypassed with analysis being done directly from recordings and interviewer notes and mind maps to show emerging themes.

Objective 3 - Consolidate using an eDephi

Rapid identification of palliative research priorities for the West Midlands through an eDelphi co-design study with clinical staff, stakeholders and service users.

This is step 2 of the change model which suggests the need to provide a platform to investigate commonalities to help move beyond conflicting agendas and priorities to a common understanding and ambition. This will be achieved through a three-round Delphi study led by NE due to his expertise in this technique, supported by CB, JM, WW and PG., a recognised and accepted as an effective approach to reaching consensus on a variety of health-related research issues (Efstathiou et al, 2008; Foth et al, 2016) and identifying health care research priorities (Van der Glind et al, 2016; Goodman, 2016).

For this phase we will use a modified eDelphi approach, an online Delphi study. Online Delphi studies involve: (1) the identification of a research problem, (2) development of a questionnaire with statements, (3) rounds of iterative online questionnaires in which participants/experts are asked to rate or rank the statements anonymously, (4) individual and group feedback between rounds, and (5) consensus building and summary of findings (Lukewich et al, 2020). The modification is that rather than using open-ended questions commonly used in a classical Delphi first round of iterative questionnaires (step 3), participants will receive an online first round questionnaire based on the themes/priorities identified in the previous step (2). The modified Delphi is the preferred technique here over the traditional Delphi because we already have the priorities identified from the rapid interviews. Ethical approval is not required as project has been reviewed by University of Birmingham Head of Research, Governance and Integrity and confirmed as engagement.

Participants

Delphi as a method, is only as effective as its participants, who form an 'expert' panel (Keeney et al, 2011). Delphi scholars identify an 'expert' as an individual who has knowledge of the subject under investigation (McKenna 1994; Lemmer, 1998). Delphi participants for this study will be purposively sampled from each of the five hospices in the Birmingham region and surrounding services in the community, primary care, secondary care and social care (identified by the academics during objective 2). This will include clinical staff, (working in inpatient units, community and hospice nursing services), hospice, hospital, primary and social care managers and key stakeholders, volunteers, patients and carers guided by an inclusion and exclusion criteria prepared in advance. The number of participants in Delphi studies varies depending on homogeneity. Skulmoski et al (2007) consider a homogenous sample of 10-15 to be sufficient, however Keeney et al (2011) argue heterogeneous samples require more participants. A sample of 50 'experts' (Delphi participants) will be recruited, identified by CB, JM, PG, NE and WW in objective 2. This number is sufficient, as we anticipate our panel to be heterogeneous. People who agree to participate in the modified eDelphi study will receive an email with a link to the online survey (via RedCAP) where the eDelphi responses will be managed.

Data collection

Round 1 (R1)

As this study is a modified eDelphi, rather than involving open-ended questions used in a classical Delphi first round, participants will receive an online questionnaire based on the themes/statements of key priorities for hospice research identified from the rapid qualitative interviews with hospice staff, team leaders, managers and key stakeholders (Step 1). Participants will be asked to rate each statement on the questionnaire using a seven-point Likert type scale ranging from 1= "Low priority" to 7= "Very high priority". Participants will also have the opportunity to add any statements they feel are relevant but have not been included in this first round.

Rounds 2 (R1) and 3 (R3)

Subsequent rounds of the modified eDelphi process will involve completion of additional questionnaires incorporating data, and feedback from the previous round/s. It is anticipated that this modified eDelphi study will consist of three rounds, consistent with the methodological approach (Foth et al, 2016). Participants will receive feedback on the statements to date (for example summary of ratings for each statement) and will be given the opportunity to revise their responses in subsequent rounds. The same seven-point Likert type scale ranging from 1= "Low priority" to 7= "Very high priority" will be used to rate the items on the subsequent questionnaires.

Two weeks will be allowed for return of questionnaires from each round. A reminder will be sent one week before the return date to any non-respondents, followed by a reminder on the expected day of return. A further week will be allowed for non-respondents at this point. It will be made clear in any communication to the participants that they can contact the researcher at any point should they need further guidance or advice concerning the task.

Data analysis and Consensus

For the Likert type scale responses, central tendency calculations will be performed between rounds (to allow provision of feedback to participants), frequency tables will be generated, and the level of agreement will be calculated for each response. To establish agreement, the total percentage of high priority and very high priority (6 and 7 on the Likert type scale) will be calculated for each statement. Consensus agreement on research priorities will be accepted as ≥80% of participants having rated a statement as 6 or 7 on the Likert type scale (Foth et al., 2016). In addition, differences in ratings between the distinct groups will be explored, using the Kruskal-Wallis test (Keeney et al, 2011; Weaver et al, 2018).

If consensus is reached for a large number of statements by round 2, making it difficult to discriminate between high priorities, the final round will require the participants to rank in order the ten statements describing the highest research priorities (Efstathiou et al, 2008; Foth et al, 2016). Final results will be identified at the end of the data collection and last eDelphi round. Statements on which consensus is demonstrated will identify the essential high research priorities.

Objective 4 - Co-design

Co-production, dissemination and partnership engagement (multi-agency and PPI) to develop NIHR HS&DR grant submissions, starting with commissioned call to NIHR palliative care in 2022.

The aim of step 3 of the change model is to 'Design together' to agree how to translate the shared understanding (priorities identified in step 2 - the eDelphi study) into an action plan that will get people doing things (developing the programme grant proposal). Whilst PPI is involved throughout the entire project and partnership building, this specific step provides a platform to bring together key stakeholders (identified in objective 1), PPI members and regional hospice, hospital, community and social care leads to discuss the priorities from objective 2 and plan and design the parameters for the research programme grant within the core BRHUmB.

Co-design in healthcare refers to patients and carers working in partnership with staff to improve services (Donetto et al. 2014) and has been beneficial in palliative care research (Blackwell 2014, Chesire 2012, Borgstrom and Barclay 2016). Co-design enables full use of each other's knowledge, resources and contributions and will see the direct contribution of the partnership formed from BRHUmB. Recruitment for the workshops will be purposive through existing and new networks formed by the academics during the earlier stages of this work.

Using the key priorities from the eDelphi study, approximately 30 co-designers purposively selected from the 'collaborate' stage (objective 2) will work together to develop the components for the programme grant led by CB and JM. They will work together in 4-6 'ideas groups' (each group with approx. 6 patients/carers, staff and stakeholders). Each group will represent one of the priority areas from the Delphi study. We anticipate from our existing work and discussions with staff, PPI members and services leads that managing palliative care crisis is likely to be one of the priorities discussed here which will form the focus of the grant development although the early exploratory work will confirm this to ensure we are on the correct track for investigation. We will be guided by the findings from the eDelphi. A facilitator (one of the co-applicants XX XX or XX) will coordinate each group to encourage a balanced discussion amongst the co-designers and a member of our PPI group will be part of each co-design group. Each group will feedback their solutions to each component the programme grant proposal and a consensus will be agreed for the final design.

A graphic illustrator will draw the creative thinking and design process. This is thought to encourage thinking and collaboration from different groups and enable all participants to feel involved and their ideas and contributions valued. (Zamenoppulos and Alexiou, 2018; Walker 2017). 'Acceptability' will be explored through a 'risk Vs benefits' type participatory forum where participants will be encouraged to verbalise or write down their concerns or ideas for further refinements and developments for BRHUmB to enhance the programme grant. The co-design workshop will be held at the University of Birmingham (CPD suite that has breakout rooms and excellent facilities for co-design events) where transport links are good and it is central for travel. Online connections will also be available (via UoB zoom licence) for those unable to travel or who wish to remotely connect or should further Covid-19 restrictions require a remote meeting.

Dissemination

Our dissemination strategy will ensure that findings will be communicated at all points in the study and via a range of approaches to target clinicians and healthcare professionals, patients and informal carers, academics, the general public via the UoB media stream and decision and policy makers. Dissemination will occur through peer-reviewed scientific journals, conferences, professional journals, hospital bulletins and hospice newsletters, staff seminars and training events, online websites, social media feeds and public workshops to ensure diverse reach and maximise impact. A full report will be submitted to NIHR. Engagement at the first phase will provide a 'waiting audience' of staff, stakeholders and clinical leads who will receive information about the formation and development of BRHUmB and the key objectives to provide research support in West Midlands. The graphic illustration provided in the co-design event can be digitalised and circulated to key stakeholders to disseminate shared learning. This will also be an attractive visual for dissemination via social media and on physical displays in public areas. The PPI group will provide links to local groups and help publicise findings the research and the PPI experience via charity and voluntary sector websites.

A website will be created for BRHUmb, it will have a logo and specific correspondence email for researchers, clinicians, interested PPI to connect with the core team. These are important branding aspects to create and maintain an identity within the region and more idly nationally and internationally as the partnership grows and the research develops.

Proposed Outputs and Impact

1. Development of BRHUmB – a core hub for research, academia, education and practice (objective 1).
2. Publications from rapid qualitative methods and Delphi study – priorities for palliative care research (objective 3).
3. Newsletters, policy briefings and website about BRHUmB developments and partnership working to promote shared learning and engage others in networking and collaboration (objective 1).
4. Development of programme grant for submission to NIHR HS&DR (2022) likely focusing on managing palliative care crisis at the end of life, codesigned by BRHUmB partnership and participants in this project (objective 4).
5. Other proposals for research within the hub and collaborations via the hub with other networks e.g. IMPACT, Compassionate Cities, ARC, NHSEI NHS England and NHS Improvement West Midlands (Palliative and EoL Care Programme) etc. to promote a culture of shared learning, collaboration and partnership (objectives 2 and 4).
6. Buddying system for research and academic support in research naive areas (objective 2).
7. Longer term outputs may lead to the development of sub-themes within BRHUmB i.e. Paediatric palliative care. For example, we have expert academics and clinicians at UoB and Birmingham Children's Hospital who we have discussed this growth if BRHUmB is funded (objectives 1 and 4).

PPI

PPI involvement in proposal development:
The project aims and proposal have been discussed with members of the Public Engagement in Nursing Group at the University of Birmingham. This group is made up of carers and patients who have had experience of hospice care services and/or caring for someone at the end of their life. They have advised on the project proposal and the experiences they have shared with the research team reinforce the need for BRHUmB and its overall ambition for the West Midlands. Five members of the group have expressed a desire to be part of this partnership and we plan to get a further five PPI representatives from other areas across the West Midlands in the early stages of the project.

In the development of this proposal, co-applicant AF, (PPI lead) has advised on direction and purpose and has co-written the plain English summary which has also been reviewed by another PPI member in the group. AF has helped the research team budget for direct PPI costs and identified areas for training and support they and other members will require. AF has reviewed and contributed to the plan and co-design strategy. The PPI group are important members of the team at each stage of the research and collaborative building especially in stage three in terms of co-designing the programme grant where they will take an active role in the design process and where they wish to the writing of the programme grant application.

A collection of quotes is presented here that express genuine support for the development of BRHumB. This is both reassuring and encouraging that we have the support of PPI members and staff and their involvement from the outset. It also reinforces the need for this initiative.

‘Brilliant, very much needed for Birmingham’ (PPI member)

‘This is exactly what is needed across the WM and I am very supportive of this’ (Hospice Consultant)

‘We need the systems and services to talk together and work together’ (Community Palliative Care Nurse)

‘There is a need for a multi-professional, interdisciplinary hub to identify research priorities across the settings’ (WM CRN - see letter of support attached)

PPI involvement in project delivery
The involvement of patients, service users and the public is absolutely vital in the partnership development from the outset, hence why the preliminary work of bringing the group together to prepare and advise on the proposal has been carried out. Co-applicant Aprella Fitch, will lead the PPI group and represent their views at the monthly research steering group. Five members have already expressed interest in being part of this group if it is funded. A further five members will be recruited to join the PPI group from different sectors and regions across the West Midlands, to create a diverse representation of views an experiences. The final 10 members will be made up of people who have experience of living with a terminal illness, caring for someone at the end of life and those who are bereaved and the additional five will be recruited via hospital patient services, hospice volunteer groups and local nursing and care home forums, social services (by email, notices, posters using the NIHR PPI templates and via co-applicants). The PPI group members will advise and contribute to the development of BRHumB and be co-designers of the programme grant in Objective 4. Co-design training will be provided to the 10 members and costs have been included based on the provision from Point of Care Foundation for their participation in the co-design of the programme grant. PPI members will have the opportunity to co-produce the outputs with the research team where they wish and support will be offered by the academics to do so. Approximately three meetings throughout the first 12 months of the project will engage the

BRHUmB development, priority setting and partnership building. Members if willing may be contacted for informal discussions, feedback and advice. A virtual meeting platform will be developed for members to engage if they prefer remote working at this current time or where travel is challenging to ensure equitable participation. It will enable interactive online group discussion and document sharing in a safe and reliable way. Electronic tablets will be provided to those with no existing computer access. The NIHR RDS PPI guidance has been used to consider the roles, payments and terms of references. Costs for travel, lunch and expenses have been included where travel to UoB for meetings is preferred. PPI members (and carers) will be offered payment, a voucher or the option of a charitable donation for their participation.

It is our intention that the formed PPI group will be an integral part to the BRHUmB network, contributing to the meetings, presenting outputs, advising on areas for investigation and co-producing written papers, conference presentation and future bids. We will actively continue involving patients/public to improve research quality and outputs and maximise benefit to patients and families. PPI in palliative research can be challenging, because those involved may be ill or in burdensome caring roles. Their energies and therefore involvement may therefore be limited. To overcome this, we have established a smaller Patient/Public Group of 10 members (5 from the Public Engagement group in School of Nursing - PEN). During the project, as detailed above we will meet regularly, aimed at i) collaboration on project management, ii) progress update, and iii) discussion about specific issues with future bid development (including part 2 of NIHR call and other related grants) to maintain sufficient momentum and membership for effective engagement.

Every effort will be made to secure further funding for PPI involvement beyond the contracted partnership activity (e.g. RDS Public Involvement Fund). PPI funds will be included for this group of 10 members in Part 2 of NIHR call and in other grants that BRHUmB apply for to ensure the consistency and sustainability of the patient voice and co-production within the BRHUmB network. If funds cannot be secured immediately post contract, we will offer the BRHUmB PPI members (not already part of PEN) the opportunity to become part of that group as casual workers to ensure their costs for any additional activity (outside of the contracted project) are covered sufficiently. This approach has proved effective in engaging patients/carers in an acceptable but meaningful way, maintaining momentum while allowing different levels and duration of engagement.