The RE-EQUIPP Care Partnership: REducing inEQUalities through Integration of Primary and Palliative Care.

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Version Control Table

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0.1	S Mitchell	Amendments according to panel feedback (pending ethical approval)	8.11.21
1.0	S Mitchell	Plain English Summary, author details, ethical approval, acknowledgement and copyright statement added	15.02.22

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Ethical Approval

Ethical approval was granted by the University of Sheffield Research Ethics Committee on 15th February 2022 (Ref: 044731).

Plain English Summary

Background

Good palliative care is necessary to ensure that all people live as well as possible in the last year, months or days of their lives, but access to good palliative care is patchy and unequal. Thousands of people have died during the COVID-19 pandemic, many more at home, including in care homes, than in previous years, and inequalities in access to palliative care have unfortunately worsened during the pandemic.

Primary care is the first place that people in the community go to for healthcare advice and treatment, ranging from disease prevention and treatment to rehabilitation and palliative care. Primary care includes community nurses, opticians, pharmacists and dentists. General practice is the medical speciality aligned to primary care. Primary care has a key role in providing palliative care to people in the community, alongside palliative care services, but this is often overlooked in policy. Research that includes primary and palliative care together is rare.

This research partnership will address that gap in the research, bringing together world-leading expertise in palliative care research from the Cicely Saunders Institute, King's College London, with primary care research in two other areas of England:(1) diverse, innercity Sheffield in South Yorkshire, and (2) the rural area of Sussex.

Aims of the Partnership

The aims of the partnership are to:

1. Build a successful and sustainable research and practice partnership between primary and palliative care in three places: the Cicely Saunders Institute, King's College London, Sheffield and Sussex,
2. Lead and develop new research processes into how primary and palliative care services can work together (integrate) more effectively to address inequalities in palliative care,
3. Ensure considerable input from patient and public representatives through the course of the partnership, and
4. To construct nationally competitive research applications to develop new integrated models of palliative care for people in the community

Partnership activities

Over 12 months, the partnership will:

1. Improve equality of access to patient and public involvement (PPI) opportunities in palliative care research across the three areas by sharing learning and providing opportunities for people to take part in PPI in person and online, particularly for those who are not usually engaged,
2. Work together to understand how best to share the findings of research with professionals, local communities, policy makers and the government,
3. Identify key research questions, methods and research teams for a series of new research applications through workshops and active engagement with PPI communities,
4. Build a world-leading research team in primary and palliative care, including through mentorship.

How will this make a difference?

This partnership has the vision and potential to develop world-leading, urgently needed research across primary and palliative care. The partnership will develop competitive research proposals with the aim of addressing longstanding inequalities in palliative care. The research will be grounded in patient need, perspectives and experience, highly relevant to policy makers, build research capacity and leadership, and will inspire future researchers in palliative care.

Detailed Research Plan

Introduction:

Background: Primary care, working collaboratively with palliative care services, have a key role in the delivery of palliative and end-of-life care, which has been pivotal throughout COVID-19. The pandemic has led to the highest death rate in England and Wales for over ten years, and this high rate of deaths has continued into 2021 (5, 6). There was a marked and sustained shift of place of death into the community during 2020, with around 41,000 (39%) more people dying at home, including in care homes, than in previous years (7). The key role of primary care in the provision of community palliative and end-of-life care is rarely a focus for palliative and end-of-life care policy or research (4).

Primary care: is the first point of contact for healthcare in the community for most people seeking advice and treatment. It is person-centred rather than disease-centred and focusses on people's needs from disease prevention and treatment to rehabilitation and palliative care. Primary care includes a wide range of professionals including community nursing services, opticians, pharmacists and dentists. General practice is the medical speciality aligned to primary care.

Palliative care: is holistic, person-centred care, focussed on quality of life for people with advanced disease, and their carers. There is increasing evidence to support the effectiveness and cost effectiveness of palliative care (8, 9), including a trial of a short term supportive and palliative care intervention for older adults with non-malignant conditions, led by CE (10). Prior to 2020, the delivery of high quality palliative and end-of-life care in the community was already a pressing concern. The palliative care needs of the population are rising, with an increase in complex multi-morbidity, frailty and aging (11, 12). Identification of palliative care needs, described as a "golden ticket" to enhanced care in the community (13), is lacking particularly for people with non-malignant disease (14, 15). Specialist palliative care services, including hospices, do not have capacity to provide care to all dying people.

Primary care services, including general practice, are essential providers of palliative and end-of-life care but report barriers to this, including time pressures, compromised continuity of care including out-of-hours, inconsistent training in palliative care and variable integration with specialist palliative care services (16). There is an urgent need for more community and primary care-focussed research to understand how services can work best together (integrate) to meet need, through collaborative, cross-boundary models of care.

Research into new integrated models of palliative and end-of-life care: During the pandemic, primary and palliative care services adapted rapidly to care for people with new and challenging symptom profiles caused by COVID-19 (17), and larger than usual numbers of deaths at home and in care homes (18, 19). Rapid innovations included increased integration of services, and collaboration through the use of technology including telehealth and electronic record sharing (19-24). The Marie Curie Better of End of Life 2021 report, led by KS, and which included the work of SM, scrutinised the provision of palliative and end-of-life care during the COVID-19 pandemic. It highlighted the need for more effective integration between primary and community care services with specialist palliative care (25). The report also highlighted the need for research to understand the quality of care for people dying in the community. Research to understand which new innovations lead to benefits in patient care and should be sustained, including integration of services, is severely lacking (26, 27).

Research to reduce inequalities through new integrated models of palliative and end-of-life care: In the UK, health inequalities are rising (28, 29), including inequalities in access to palliative care. This is likely to be exacerbated by late presentations of disease including cancer, and more complex multi-morbidity (30-32). Patients from areas of high socioeconomic deprivation, rural areas, those with learning disabilities and from minority ethnic backgrounds, are less likely to receive care from palliative care services (33-35). Patients from areas of socioeconomic deprivation are more likely to be admitted to hospital towards the end of life, suggesting that they may be less well placed to cope with end-of-life care at home (36). Contacts with out-of-hours urgent and emergency care services rise towards the end of a person's life, with those identified as "palliative" more likely to be from affluent areas than those who are not (37, 38). Triggers for hospital admission for people at the end-of-life are poorly understood (39, 40) but this is costly, may be unwanted, and reducing end-of-life admissions is a policy priority (41).

Rationale for this research partnership

The COVID-19 pandemic has caused disruption to healthcare systems and huge change in the delivery of palliative and end-of-life care in the community. It has been a time when healthcare system leaders and clinicians have had to react quickly to a new situation and a change in the status quo. Rapid changes in attitudes, behaviours and services have followed. These are times referred to in Lewin's behavioural change theory as "unfreeze" and "change" (42, 43). The "refreeze" is the subsequent process through which "change" becomes the new normal. As this happens, research across primary and palliative care is imperative, so that positive change, including integration, are understood and maintained as the palliative and end-of-life care needs of the population continue to increase.

The ambition of this partnership is to lead new approaches and necessary step-change in integrated primary and palliative care research and practice. Our team is uniquely well placed, with clinical expertise across general practice (SM), community nursing (CE) and specialist palliative care (KS). We have a strong research track record in community palliative care (10, 44), primary care (4, 19, 45, 46), inequalities (11, 35, 38) and the COVID-19 pandemic (19, 45) including the Marie Curie Better of End of Life programme (25). The partnership is designed around sustainability and increasing capacity for high quality palliative and end-of-life care research. Our novel "hub and spoke" model links the world-leading Cicely Saunders Institute in South London with two areas where recruitment to palliative care research has been low: (1) Sheffield in South Yorkshire, an area of high deprivation and ethnic diversity, and (2) Sussex, an area with large rural and older populations. Therefore, the partnership is in prime position to initiate, sustain and grow novel, cross-boundary, policy-relevant research, and nationally competitive research applications, in this essential and under-researched area.

Partnership Plan

Research question: How can innovative integrated whole-system models of cross-boundary primary and palliative care reduce inequalities in access to high quality palliative care?

Aims: There are three main aims

1. **Infrastructure and involvement**: to build a successful, sustainable, multidisciplinary and multisector "hub and spoke" model partnership between primary and palliative care research, patient and public involvement, and practice, across three diverse geographical regions. The Cicely Saunders Institute, King's College London will be the "hub", with Sheffield and Sussex, where recruitment to palliative care research has been low, as "spokes";
2. **Integration**: to provide new insights and understanding into when and how to achieve effective integration of palliative and end-of-life care into primary care, and who benefits, to inform future service delivery and research. This includes consideration of ways to integrate the principles of palliative care more effectively into primary care, and models of integrated working between specialist and primary care services.
3. **Inequalities**: to provide new insights and understanding into how the integration of primary and specialist palliative care services can reduce inequalities in access to palliative care, to inform future research.

The planned **partnership activities** are:

1. To strengthen patient and public involvement (PPI) and research infrastructure and capacity in South Yorkshire and Sussex, working with existing groups and organisations, including NIHR Applied Research Collaborations, primary care research clusters, and the Nightingale Saunders Clinical Trials Unit,
2. To deliver three half-day virtual research and practice workshops with multi-disciplinary collaborators across the partnership priority areas: infrastructure and involvement, integration and inequalities,
3. To grow palliative care research leadership through bespoke mentorship for the lead applicant, SM.
4. To generate infrastructure for knowledge exchange with local, regional and national policy makers. The team will use and grow their existing networks to link with NHS commissioning, professional bodies (including the Royal College of General Practitioners) and the voluntary sector to ensure that the developing research proposals inform policy and are relevant to commissioners.

Methods for workshops: The aim of the workshops is to generate new insights into the partnership priority areas (Infrastructure and Involvement, Integration, Inequalities), and provide a strong foundation for the development of future research proposals. A theory-driven, explanatory realist approach will lead to new insights and understanding into how, when and why integration in palliative care (a complex intervention) provides benefits, and for whom (47, 48) (Figure 1):

Figure 1: Workshop plan

The realist approach will lead to the description of context-mechanism-outcome configurations (CMOCs), which will inform new theory for testing in future research. ***Participants*** for each workshop will include collaborators listed in this application, and other key stakeholders identified from social care, the voluntary sector and healthcare including commissioners. Potential PPI members will be identified in workshop 1 to attend the subsequent workshops and the Dragon's Den event. The Dragon's Den event will explore the research priorities, study designs and methods identified in the preceding workshops (1-3) to confirm the questions to be developed as research proposals. Collaboration is central to the partnership between researchers, policy-makers, clinicians and patient representatives to construct policy-relevant research proposals on intervention and research design and delivery to integrate palliative care in primary care (49-51).

Data collection*:* The workshops will be conducted remotely via an online platform (e.g. Zoom). A presentation and realist topic guide (52) will be prepared for each workshop, with contexts and outcomes derived from relevant recent work on innovation in palliative and end-of-life care (19-21, 25), models of care (10) and inequalities (11, 15, 35, 36, 38). Insights into the contexts (C) in which (1) involvement and infrastructure, (2) integration and (3) inequalities in palliative and end-of-life care are most effective, the outcomes (O) achieved, and the underlying, hidden mechanisms (M) that are triggered in certain contexts to lead to these beneficial outcomes, will be sought. Emerging CMOCs from each workshop will be presented and tested out in the subsequent workshops. These findings will inform the underpinning programme theory on integration of palliative care in primary care to widen access to palliative care and address inequalities. The final CMO configurations will be explored in the Dragon's Den to confirm the priority research questions, theoretical-underpinnings and designs developed as research proposals. With the informed consent of participants, the workshops and Dragon's Den will be recorded and the audio-recordings transcribed verbatim. Field notes will be kept to record key discussions.

Analysis: Realist data analysis will begin alongside data collection with identification of contexts (C), mechanisms (M) and outcomes (O). "Unfreeze-change-refreeze" provides a theoretical framework to inform the analysis (42). There will be an ongoing process of team reflection and discussion throughout the analysis (53). Following the workshops, the co-applicant team will have developed a series of outline research proposals, strengthened by the "real-world" insights provided by the realist analysis. For example, for a trial of an integrated model of palliative and end-of-life care for people with multi-morbidity living in diverse regions, where there are different social and cultural contexts for the delivery of the intervention, the realist analysis will provide conceptual understanding of the potential mechanisms triggered in these contexts to affect the outcomes achieved.

Dragon's Den Event**:** The identified research priorities, study designs and underpinning conceptual understanding will be presented to a panel of PPI representatives and commissioners at the "Dragon's Den" event. This will identify the priority research questions, programme theory and study design developed as full research grant applications.

Dissemination, deliverables and anticipated impact

Key deliverables and activities with impact will be:

1. A new “hub and spoke” partnership between research and practice in primary, community and palliative care across three diverse geographical areas. The world-leading Cicely Saunders Institute is the “hub”, buddying with “spokes” in diverse, inner city Sheffield and rural Sussex, both areas with little palliative care research.
2. A series of stakeholder workshops, including a PPI Dragon’s Den event, to (1) develop research questions, CMOCs and programme theory on the integration of palliative care in primary care, and (2) identify the priority evidence-gaps to develop as research funding applications.
3. The findings and new theory from the realist analysis of the workshops will lead to a peer-reviewed paper, to be submitted to an international journal, such as Palliative Medicine. SM will lead the data analysis and preparation of the paper, supported by an authorship team to include the Research Associate (NT), co-applicants (CE, KS) and a PPI representative.
4. Nationally competitive research grants to be submitted to research calls in 2022/23, including part 2 of this NIHR call. These will be refined through the workshops, but are likely to include a trial of innovative models of integrated palliative and end of life care (building on previous research led by CE), and research to examine how whole system cross-boundary approaches can address inequalities. Proposals will be developed by CE and SM, with collaborators including Prof Toby Prevost from the King’s College Nightingale-Saunders CTU, and PPI representatives. The programme theory developed in the workshops will inform a logic model for the proposed interventions for subsequent feasibility / pilot trials and full randomised-controlled trials suitable for bids to the NIHR HTA stream. Proposals will include plans to increase recruitment of diverse populations to palliative care research across South Yorkshire and Sussex. A further proposal to the NIHR HS&DR is likely to focus on routine data and inequalities, building on the work of KS and incorporating primary care data.
5. Development of an online PPI forum in Sheffield, and the first collaborative national PPI Dragon’s Den event with PPI representatives from across the three areas. This will be led by SM, supported by CE, PPI representatives and the PPI facilitators from King’s and Sheffield, whose time has been costed into the partnership proposal.
6. Career development for SM through bespoke 3-monthly mentorship meetings with KS as a national clinical-academic leader in palliative care. Mentorship will build research capacity and leadership in primary palliative care. SM will be mentored by KS, specifically focusing on career development. The deliverable will be that SM will apply for an NIHR Advanced Clinical Fellowship in 2023. KS was the first NIHR Clinician Scientist in palliative medicine, and is a recently appointed Chair in palliative care. SM completed her PhD with an NIHR Doctoral Research Fellowship in 2020, currently has a Yorkshire Cancer Research Funded personal fellowship (2020-2025) and is well placed to apply for an NIHR Advanced Clinical Fellowship.
7. New networks and mechanisms for knowledge exchange with commissioners and policy-makers at local, regional and national levels, building on the existing networks of the partnership team and collaborators, particularly those of SM who has regional and national clinical leadership roles in Palliative and End of Life Care for NHS England and Improvement.

Why this work is time sensitive

The COVID-19 pandemic exposed poor integration across primary and palliative care services, a struggling workforce, and innovations that are currently untested (the “unfreeze”). Future funding for community healthcare services is unclear (54), and effective integration of services is essential to make best use of existing resource (“change”). In addition, palliative care needs are projected to increase. Therefore, cross-boundary whole-system research into improving integration and reducing inequalities is urgently needed (to inform the "refreeze"). Our primary, community and specialist palliative care partnership addresses this urgent and growing need; it will lead to policy-relevant, cross-boundary research, and build capacity in this neglected area.

Project / research timetable:

The partnership activities will be conducted over 12 months.

TIMELINE

Months / Activities	**-3**	**0-2**	**3-4**	**5-6**	**7-8**	**9-10**	**11-12**
Workshop planning, university ethics	🟦	🟦					
Workshops		**1**	**2**	**3**			
Proposal outlines / realist analysis			🟦	🟦	🟦	🟦	
PPI Dragon's Den Event						🟦	
Development of research proposals				🟦	🟦	🟦	🟦

The partnership team will ensure that they are in a position to commence the partnership activities as soon as possible. A research associate at the University of Sheffield, Nicola Turner, can be recruited to this post internally at the start of the partnership. The workshops will be conducted at two-monthly intervals, with analysis alongside, followed by the PPI Dragon's Den event. The final months will provide time for analysis, writing-up and preparation of the future research proposals.

Project management, governance and approvals

A partnership advisory group will be established. We will recruit an independent Chair. The advisory group will include representatives from a range of relevant personal and professional backgrounds including patients and carers, NHS England and Improvement, regional palliative care networks and primary care. The group will meet twice over the course of the partnership to assess progress against the timeline and provide feedback and advice to the partnership team. The University of Sheffield will be the sponsor. An application will be made for university ethical approval for the workshops.

Success criteria / barriers to proposed work

Success will be based on delivery of the seven key deliverables listed above. The co-applicant team is deliberately small and agile, with clear leadership across the three specialties of general practice, community nursing and specialist palliative care. Potential barriers include the timeframe for the delivery of a realist analysis. Clear research questions and focus will be required, particularly if the workshops lead to a large amount of relevant data. An experienced post-doctoral research associate has been identified with the necessary skills and experience to manage this. A further potential barrier is the requirement to establish new and effective team dynamics for the "hub and spoke" partnership, particularly as one institution (Sheffield) is the host for the financial resource. The co-applicant team are committed to this new partnership, with the potential for successful, national, cross-boundary research in diverse areas providing an important incentive.

Partnership team

- Sarah Mitchell (lead applicant) is a GP of 14 years and an early career primary care researcher (NIHR Doctoral Research Fellow 2014-19, PhD 2020, RCGP / SAPC Yvonne Carter Award Outstanding Early Career Researcher 2020). Alongside her academic and clinical roles, she holds leadership positions as the Clinical Director for palliative and end-of-life care at Sheffield CCG and Regional Clinical Lead for the NE England Strategic Clinical Network for NHSE&I. She is a member of the University of Sheffield Palliative Care Research Network, through which she has links with St Luke's Hospice in Sheffield. She has training and skills in qualitative and realist research, and an interest in the use of linked datasets.

- Catherine Evans (joint lead applicant) is a Professor of Palliative Care and Nurse Consultant with a clinical background in district nursing. She is an NIHR Senior Clinical Lecturer (2016-2021) She has extensive expertise and experience in the development and trial evaluation of complex interventions in community care for adults with multi-morbidity (10), and established links to St Barnabas Hospice in Sussex that will enable research capacity and capability building during the course of this partnership.
- Katherine Sleeman (co-applicant) is the Laing Galazka Chair in Palliative Care at King's, and a consultant in palliative medicine. She was an NIHR Clinician Scientist (2016-2021). Her expertise is in routine data, inequalities, linked primary-secondary care datasets, dementia, policy and public engagement. She is PI for the Marie Curie Better End of Life Programme.

Engagement and collaborators

Our collaborators bring expertise from healthcare, the voluntary sector including hospices, academia, existing NIHR organisations and professional bodies. Each will be invited to contribute to the workshops and may become a co-applicant on the future research proposals.

A priority for the partnership is development of infrastructure for PPI. Key collaborators include the PPI co-ordinators for each of the identified groups (the PPI forum at the Cicely Saunders Institute (Cat Harvey), the Palliative Care Studies Advisory Group at the University of Sheffield (Dr Clare Gardiner) and the NIHR DeepEnd primary care research cluster. Prof Toby Prevost, Professor of Statistics, Director Nightingale Saunders CTU for his specific expertise in trial design and statistics. He will contribute to the development of future research in the second half of the partnership. We have engaged the support of the NIHR Applied Research Collaborations in South London and Kent, Surrey and Sussex. During the course of the partnership, in order to meet the aim of developing palliative care research capacity across South Yorkshire, we will work with Dr Michelle Horspool, Deputy Director for Research at Sheffield Clinical Commissioning Group. We will build links with the NIHR ARC in Yorkshire and Humber who have a research theme in older people with frailty, led by Prof Andy Clegg.

Individual collaborators from the University of Sheffield Palliative Care Research Network, including Dr Emilie Couchman (Academic GP and PhD student), Dr Catriona Mayland (senior research fellow and consultant in palliative medicine), and Helen Chapman (Queen's Nurse and lead for the Sheffield Teaching Hospitals Integrated Care District Nursing team) who have agreed to collaborate and attend workshops. Colleagues from King's College London who have also agreed include Dr Clare Ellis-Smith, Lecturer in Palliative Care and Occupational Therapist, Dr Jo Bayly, physiotherapist and post-doctoral fellow at the Cicely Saunders Institute and Lead for Research St Barnabas Hospice Worthing, and Dr Deokhee Yi, Lecturer in Health Economics. Dr John MacArtney, Marie Curie Senior Research Fellow at the Unit of Academic Primary Care at the University of Warwick will also act as a collaborator, providing links with the hospice community. Furthermore, we have identified a clinical academic pharmacist to invite as a collaborator, and will build links with academic and practice representatives from social care through our strong existing networks. These include the Royal College of General Practitioners End-of-Life Care Thinktank, chaired by Dr Catherine Millington-Sanders, the Marie Curie/ RCGP Clinical Champion for End-of-Life Care, and the Sheffield Citywide End-of-Life Care Group, chaired by SM.