FULL/LONG TITLE OF THE STUDY

ALLIANCE: Enhancing the quality of living and dying with advancing frailty through integrated care partnerships: Building research capacity and capability

SHORT STUDY TITLE / ACRONYM

ALLIANCE: End of life Partnership

PROTOCOL VERSION NUMBER AND DATE

Version control: 1.1 14/03/2022

NIHR acknowledgment and disclaimer statement

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STUDY SUMMARY

Study Title	ALLIANCE: Enhancing the quality of living and dying with advancing frailty through integrated care partnerships: Building research capacity and capability
Internal ref. no. (or short title)	ALLIANCE: End of life Partnership
Planned Size of Partnership members	Minimum of 25 members across the three regions.
Planned Study Period	15 months

FUNDING AND SUPPORT IN KIND

FUNDER(S) (Names and contact details of ALL organisations providing funding and/or support in kind for this study)	**FINANCIAL AND NON FINANCIAL SUPPORT GIVEN**
National Institute for Health Research	£100,293.88 to fund development of partnership and write bids for future palliative and end-of-life care funding call.

ALLIANCE CORE TEAM MEMBERSHIP

NAME	**Position (Role in bid)**
Professor Caroline Nicholson	Professor of Palliative Care and Ageing, University of Surrey (Joint Lead Applicant)
Professor Rowan Harwood	Consultant Geriatrician, Professor of End of Life Care, University of Nottingham (Joint Lead Applicant)
Sarah Combes	Research Fellow in Palliative Care and Ageing, University of Surrey (Co-applicant – Project management of the bid)
Professor Heather Richardson	Chief Executive Officer, St Christopher's Hospice (Co-applicant)
Dr Joy Ross	Consultant in palliative medicine, St Christopher's Hospice (Co-applicant)
Dr Shannon Milne	Research lead, Princess Alice Hospice (Co-applicant)
Dr Diane Laverty	Macmillan Nurse Consultant: Palliative & End of Life Care, London Ambulance Service NHS Trust (Co-applicant)
Professor Adam Gordon	Professor of the Care of Older People, University of Nottingham (Co-applicant)
Dr Julie MacInnes	Senior Research Fellow, Integrated Care, ICAP Programme Lead, University of Kent (Co-applicant)
Dr Nadia Brookes	ARC KSS Co-production theme lead/Senior Research Fellow, University of Kent (Co-applicant)
Dr Louise Bramley	Head of Nursing and Midwifery Research, Nottingham University Hospitals NHS Trust (Co-applicant)
Dr Emily McKean	Research Assistant, University of Kent (Research Assistant)

STUDY PROTOCOL

1. Abstract

Background: Older people with advancing frailty have complex needs which require integrated health, social and third sector care, and a palliative care approach that is orientated towards living with, as well as dying from, advancing frailty. This Partnership brings together areas with historically low levels of palliative and end-of-life care (P&EoLC) research: Berkshire West, Isle of Wight, East Sussex (SE England); Kingston, Croydon, Richmond (SW London); and Derbyshire, Lincolnshire, Nottinghamshire (East Midlands). Partnership members include stakeholders across the NHS, social and third sector care, local government, and academic institutions. The Partnership will use a co-production approach, embed patient and public involvement and engagement (PPIE), and draw on Cooke's framework for developing research capacity in care settings, ready to submit research proposals to the NIHR.

Aim: To develop a sustainable, cross-sectoral partnership focused on: 1. identifying priorities to improve the delivery of integrated care and care transitions for older people living with advancing frailty, 2. developing organisations in which to conduct this research, and 3. submitting one or more study proposals for NIHR funding.

Objectives and methods:

- ***Phase 1 Working together:*** *To establish the Partnership infrastructure and identify key contacts within each region across the P&EoLC continuum (months 1-2)*
  We will hold educational and networking events for practitioners and researchers. We will identify key contacts in each provider service, coproduce ground rules for working together, and create the ALLIANCE website.
- ***Phase 2 Learning together:*** *To understand the strengths, weaknesses, barriers and enablers of research readiness and current clinical services for people with advancing frailty (months 3-9)*
  We will map and scope each care provider's: 1. current research activity e.g. key people, organisational infrastructures, PPIE, regional/national research infrastructures/opportunities; and 2. range of clinical services for frail older people and identify care pathways. Barriers, enablers and priorities will be established using the COM-B framework of behaviour change.
- ***Phase 3 Growing together:*** *To support provider services to become research-ready (months 6-12)*
  Activities to support capacity building will include 'buddying' more experienced provider services with research-naïve ones; working with R&D/R&I departments to provide bespoke training; co-producing strategies/guidelines; establishing skill sharing/knowledge exchange programmes; signposting individuals/organisations to established opportunities/infrastructures; embedding PPIE within regions.
- ***Phase 4 Building together:*** *To establish research questions across the Partnership and develop research proposals (months 12-15)*
  We will use surveys and focus groups to establish research priorities and questions to inform co-produced, high quality, clinically applied research proposals.

Overarching outcome: Established a cross-sectoral, research-ready Partnership to deliver coproduced, clinically applied translational research focused on enhancing the quality of living and dying with advancing frailty.

2. BACKGROUND AND SCIENTIFIC RATIONALE FOR ALLIANCE

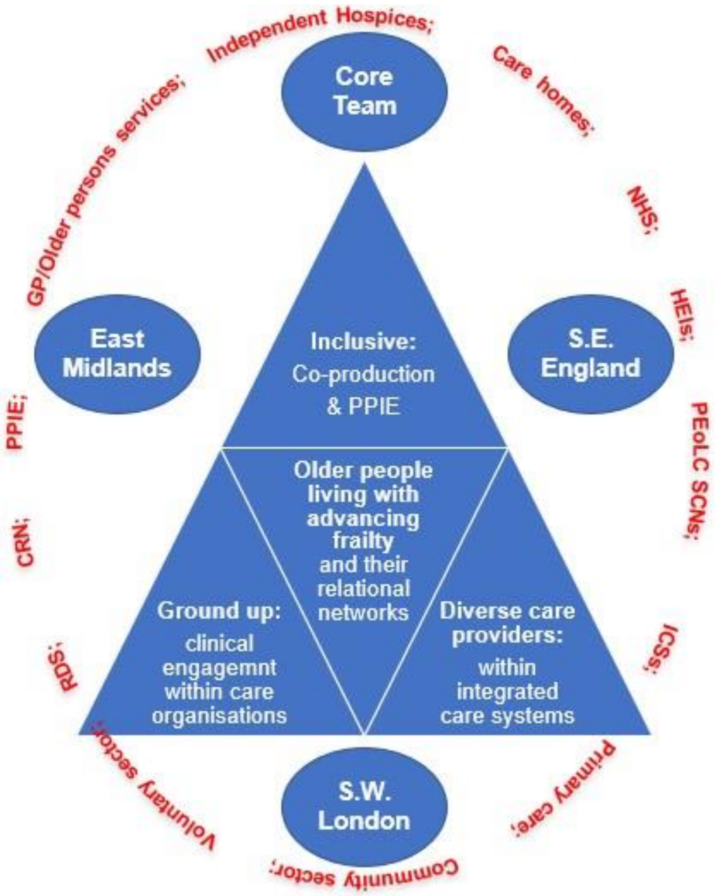
Frailty is “a complex medical syndrome, combining the effects of natural ageing with the outcomes of multiple long-term conditions, loss of fitness and reserve”.[1] It affects around 10% of people agedover 65[1] increasing to 65% of those aged over 90.[2] Frailty’s prolonged and uncertain trajectory means that people living with moderate or severe frailty (known as advancing frailty) have complexneeds as they near end of life. They experience a variety of acute, functional, mental health and social problems, which require complex, multi-domain health and social care services, orientated towards living with, as well as dying from, advancing progressive illness.[3] This in turn requires choices to be made about which therapies to try, integration between services from multiple providers, and consideration of palliative and end-of-life care elements (P&EoLC). Reviews describe a continuum between geriatric care (emphasising physical function and rehabilitation), and palliative care (focusing on symptoms).[4] Provision of integrated care is complicated by frailty’s uncertain trajectory; a feature which makes it difficult for clinicians,[5,6] older people, and their families,[7] to recognise when the older person is entering their final phase of life. This can be a barrier to appropriate care.[8] Palliative care is often triggered only in the last weeks of life[9] rather than being integrated into mainstream health and social care provision.[10] Late recognition of the end of life phase impedes patient-centred decision making,[11] choices around place of care[12] and therefore interventions instituted. This can lead to inappropriate interventions,[13] under-treatment of palliative symptoms,[14] and multiple transitions into hospital in the last year of life,[15] contributing to avoidable cost to healthcare systems.[13] Hospital admission may, or may not, be appropriate in response to crises; hospital deaths are common despite most older people stating a preference to die at home.[16] Identifying care pathways that better support transitions between goals of care and care settings is a key research priority.[17] Understanding who to involve and how to work together toenable coordinated, person-centred care is under-evidenced. We will develop a sustainable, cross-sectoral partnership focused on: 1. identifying priorities to improve the delivery of integrated care and care transitions 2. developing organisations in which to conduct this research, and 3. submitting one or more study proposals for NIHR funding.

The Partnership will focus on community-based service provision. The number of people requiring palliative care is set to increase by between 25-47% by 2040,[18] with many projected to be older people living with frailty in the community.[19] By 2040, community end-of-life care capacity will likely need to double to meet this rising need, with care homes becoming the most common place of death in England and Wales.[18] Older people with advancing frailty are frequently not recognised asneeding P&EoLC, often because clinicians do not identify frailty as a complex, life limiting syndrome,[20] or because the older person associates symptoms with normal ageing.[21] Consequently, older people living with frailty often experience poorer end-of-life care than other populations. Integrated care that enables care coordination and transitions across and between services require a shared understanding, language, and practice. In practice, traditional, fragmented modes of working typically dominate. A current HEE/NIHR funded study[22] highlights families, friends, and domiciliary care workers as integral stakeholders in community P&EoLC provision for older people with advancing frailty. This Partnership is underpinned by the concepts of inclusivity and diversity in populations, people and care providers, as promoted by the NIHR’s operational priorities and national policy.[23,24] The Partnership advocates 3 core values: being Inclusive, working with Diverse care providers, and building from the Ground up. The Partnership issupported by a co-production approach and embedded patient and public engagement (PPIE).

3. THE PARTNERSHIP

The proposed Partnership brings together 3 regions seeking to improve P&EoLC for older people living with advancing frailty through research: South East England (Berkshire West, Isle of Wight, East Sussex), South West London (Kingston, Croydon, Richmond), and the East Midlands (Derbyshire, Lincolnshire, Nottinghamshire). These specific areas were chosen as they have historically low levels of recruitment to NIHR P&EoLC Portfolio studies. All areas, bar Nottingham, are below the national average (ranging from 2 to 35 recruitments per 1,000 cases). All areas wereidentified using NIHR CCG level P&EoLC statistics and advice from the Palliative and End of Life Strategic Clinical Networks (PEoLC SCNs). The areas represent excellent population diversity.

This approach provides opportunities to focus on new research sites within and across regions, to build new research cultures, and to buddy research naïve sites with those with greater experience.



4. THE PARTNERSHIP STRUCTURE: WORKING TOGETHER

The Partnership will adopt a hub and spoke structure and follow a co-production approach to four phases of work (section 7).The hub comprises the Core Team (section 5) who will lead Partnership development across the 3 regions. The Core Team will work with site-specific 'spokes'. Spokes are key individuals within partner sites with particular knowledge or expertise relevant toeach phase, e.g. clinicians and managers within provider services will contribute particularly to Phase 2, 'Learning Together'. PPIE will be critical across all phases. This approach will enable identification of need, support service provider's research readiness, and coordinate research activity.

5. BENEFITS OF THE PARTNERSHIP

Our Partnership will bring together: older people living with frailty; those important to them; care providers working across the NHS and social care; the voluntary and community sectors; local government; and academic institutions with experience in conducting frailty and P&EoLC research, and with a commitment to clinically applied research and academic practice. Our Partnership intentionally involves the newly-established regional PEoLC SCNs, all of whom have committed to collaboration. We will capitalise on the SCNs' focus on supporting the integration of P&EoLC services across health and social care. Theyhave already facilitated conversations with Integrated Care Systems (ICSs) and specific organisations within our proposed Partnership. Their remit will be to maximise regional engagement in enhancing integrated care for frail older people and disseminating partnership activity. So far, we have agreement in principle to work with around 30 leaders and organisations across primary care, care homes, hospitals, palliative care services, the NHS and independent sector hospices. Collaborative working across existing national infrastructures including ARCs andCTUs will be established. Initial contact with CRN and RDS leads indicates support for ALLIANCE in all regions. This cross-sectoral Partnership approach will be well-placed to develop pertinent, impactful research to enhance integrated care provision for people living and dying with advancingfrailty that can be more rapidly implemented in clinical practice.

6. CORE TEAM AND CORE VALUES

The team is led by Professor Caroline Nicholson (CN). Professor Rowan Harwood (RH) will provide CN with mentorship and support. Both CN and RH lead NIHR-funded research programmes which focus on P&EoLC for older people with advancing frailty. The Core Team are now discussed through the Partnership's core values

- **Inclusive:** We will aim for co-production and embedded PPIE working in equal partnership with all stakeholders. We will structure this approach around co-production[25] and PPIE[26] principles. We acknowledge that even by using this approach we may inadvertently exclude some harder to reach populations, e.g. people whose first language is not English or those living alone. We will attempt to mitigate this by maximising the inclusion of all stakeholder voices, particularly those less frequently heard in P&EoLC (older people, their family/relational networks, those living alone, social carers) to shape partnership activities and outcomes. Co-production and PPIE in each region will support the Partnership's generation of immediate and longer-term benefits e.g. fostering a clear, shared partnership vision, creating enduring relationships/networks, and increasing practical applicability of activity and research. Our approach will be flexible to meet the diverse needs of partner sites with their research and clinical expertise. Dr Nadia Brookes (NB) will lead this core value and support the development and embedding of PPIE within each region. NB will draw on her work in ARC-KSS developing an evolutionary co-production research programme involving operational policy, community engagement and participation.[27]

- **Diverse care providers:** Integrated Care Systems (ICSs) are the structural mechanisms supporting integrated care. Integrated care can be defined in many ways and seen from several perspectives commonly described as micro (clinical), meso (organisation) and macro (system) levels of integration.[28] Within the ICSs we will focus on the micro level of coordination and delivery of personalised care across time, place, and discipline. Our activity will be guided by the NHS comprehensive model for personalised care.[29] Our Partnership includes relational care networks that matter to older people and care providers working across the NHS, social care, voluntary and community sectors. Dr Julie MacInnes' (JM) will lead this core value on the application of integrated health and social care systems. Her national and international leadership in evaluating integrated care programmes (NIHR funded) provides theoretical and translatable knowledge. Meaningful inclusion of voluntary and social care will be led by JM, care homes by Professor Adam Gordon (AG), and paramedic by Dr Diane Laverty (DL).

- **Ground Up:** Engagement of provider organisations in clinical research is associated with better patient outcomes and improved staff well-being.[30] ALLIANCE will draw on Cooke's[31] framework for research capacity building in clinical settings. The framework has been used successfully in multiple studies, settings and contexts. We will use it, from board level to aspiring researchers, to share and support the development of clinically applied research and spread new ideas across the Partnership's organisations and regions. Individuals will be linked into existing regional and national research and clinical development infrastructures e.g. ARC's mentoring schemes, national incubators, and NIHR/HEE personal awards.

  The Core Team includes clinical academics and representatives from national bodies supporting clinical research. This team will drive the building and sharing of research skills andmaximise readiness for the Part two call. Clinical academics are: CN, RH, AG, Dr Louise Bramley (LB) and Ms Sarah Combes (SC Early Career Researcher (ECR)). CN co-leads a strand within the NIHR Nursing & Midwifery Incubator Programme and is a member of ARC- KSS's organisational and research capacity building theme. AG leads the NIHR Applied Research Collaboration for East Midlands (Notts Branch) and the Building Community Resilience and Enabling Independence theme. JM's research on implementation in voluntary and social care, and SC's doctoral thesis on behavioural change models in intervention design, support the Partnership's applied clinical focus. Within the regions this core value will be led as follows: SE England- Dr Shannon Milne (SM) who is responsible for Princess Alice Hospice's (PAH) research strategy, internal research activities and is the PAH representative within the SE Hospice research collaborative group; SW London- Professor Heather Richardson and Dr Joy Ross, the co-leads for research capacity and capability building within St Christopher's Hospice, also offering strategic guidance; East Midlands- LB is responsible for building capacity and capability for front-line nurses, midwives and AHPs in herrole within the Institute of Care Excellence.

7. PARTNERSHIP AIMS AND OBJECTIVES

Aim: To develop a sustainable, cross-sectoral partnership focused on: 1. identifying priorities to improve the delivery of integrated care and care transitions for older people living with advancing frailty, 2. developing organisations in which to conduct this research, and 3. submitting one or more study proposals for NIHR funding.

Objectives

1. To establish the Partnership infrastructure and identify key contacts within each region across the P&EoLC continuum (Phase 1)
2. To understand the strengths, weaknesses, barriers and enablers of research readiness and current clinical services for people with advancing frailty (Phase 2)
3. To support provider services to become research-ready (Phase 3)
4. To establish research questions across the Partnership and develop research proposals (Phase 4).

8. PARTNERSHIP PLAN AND METHODS

We propose 4 interlinked phases within the Partnership. Each phase is interlinked and integrated. The timetable, which shows indicative timepoints, details the foci of each phase:

- **Phase 1 (months 1-2) *Working together*** to establish the Partnership and co-produce ground rules
- **Phase 2 (months 3-9) *Learning together*** to map baseline activity regarding each site's care services, research capacity and capability, PPIE and clinical partnerships
- **Phase 3 (months 6-12) *Growing together*** to build research capacity and capability
- **Phase 4 (months 12-15) *Building together*** to establish research priorities and research questions, and develop co-produced, clinically applied, translational research proposals focused on enhancing P&EoLC for older people living with advancing frailty.

We will understand and develop research readiness along the continuum of research awareness, engaging in research by others, and supporting sites to move toward research generation.[32] The activities listed will necessarily be tailored to the needs of individuals and care providers within each region as their research capability and capacity grows and develops.

Phase 1 - Working together

This phase will establish the Partnership infrastructure and contacts within each region across the P&EoLC continuum. We will hold educational and networking events and workshops across the Partnership to establish the key contacts and co-produce ground rules for working together collaboratively. We will design the ALLIANCE website. This will be a central repository of information across the regions throughout the Partnership and act as a virtual community researchand practice. Website and hosting costs will be met by University of Surrey.

***Outputs**: Key contacts list; Co-produced ground rules for partnership working; Website hosting partnership information enabling cross partnership communication and sharing of best practice.*

Phase 2 - Learning together

The objective of phase 2 is to understand the Partnership's strengths, weaknesses, barriers and enablers regarding research readiness and current clinical service for people living with advancing frailty. This activity, conducted in collaboration with key people identified in phase 1, will underpin research capacity development (phase 3) and ensure research proposals are focused on developing a Part two call that is clinically relevant and impactful (phase 4). Therefore, our focus ofactivity is both on research capacity building and understanding integrated care delivery.

- **Research capacity building:** We will understand research readiness by mapping and scoping current research activity including: key people; organisational research infrastructures; skills/expertise; existing research collaborations; and PPIE. Data will be analysed using the COM-B framework,[33] a system of behaviour that suggests that behaviour change occurs when individuals, organisations, or systems, have the Capability, Opportunity and Motivation to make and sustain the change. The COM-B framework will be used to establish the barriers, enablers and priorities of each site and across the Partnership. Data will inform phases 3 and 4 and will enable the creation of a database of aspiring researchers to be supported in phase 3. A scoping exercise of regional and national infrastructures, research training and other opportunities will create an infrastructure map and database of regional and national research opportunities.

- **Understanding current integrated care and unmet clinical need:** To better understand thebarriers and enablers to delivering care within integrated care systems across regions, we will map and scope clinical services relating to older people living with advancing frailty, focusing onpathways, transitions and coordination of care. Data will be analysed using COM-B.[33] Results will inform research question generation in Phase 3.

***Outputs:** Analysis of barriers, enablers and priorities regarding research capacity building and delivering care within integrated care systems; Analysis of current PPIE representation; Mapped regional and national infrastructures; Database of regional and national training and other opportunities to support capability and capacity building. Database of aspiring researchers to benefit from, and contribute to, ALLIANCE activity.*

- ***Phase 3 - Growing together***

Phase 3 will enable the Partnership to generate research questions and become research ready. For some sites this will mean being ready to recruit into studies, for others it will include development toward research generation. Knowledge gained in phase 2 will be used to support and embed PPIE to ensure representation of local needs and demographic diversity. Where possible we will draw on established PPIE training for staff and for PPIE representatives. Followingthe co-production principle of reciprocity,[25] knowledge exchange will be fostered by buddying sites with research capacity/expertise with research-naïve sites to optimise skill-sharing, efficiency and development of research strategies and guidelines. Additional development activities may include signposting aspiring researchers to established regional and national opportunities such as mentorship schemes through ARCs, the NIHR ICAP programme, or linking organisations to the most relevant RDS or CRN. A “long List” (up to 15) of important, unanswered research questions will be established using a partnership-wide survey and ongoing group discussions supported by Phase 2 data. PPIE will ensure inclusion of people with communication or other accessibility issues e.g., using differing formats to gain views.

***Outputs:** Active frailty/P&EoLC PPIE in each region; Co-produced guidelines/strategies; Established skills sharing/knowledge exchange infrastructure; Established buddying system/bespoke training network; Research-ready organisations and individuals. Research questions for prioritisation.*

- ***Phase 4: Building together***

Phase 4 will explore and finalise research priorities and relevant research questions across the Partnership and develop research proposals for the Part two call with a likely interest in HSD&R. Proposals are likely to focus on service evaluations, development and testing of complex interventions, and use mixed methods l. Additional bids targeting other funding streams, for example Research for Patient Benefit, may also be developed. A virtual Nominal Group Technique(26) will rank and finalise the selection of research topics identified in Phase 2). A facilitated on-lineworkshop with up to 25 participants, from Across ALLIANCE, including PPI and carers, will use plenary and small group work to 1) prioritise research questions and identify any omissions 2) Discuss each one to determine clarity, importance, and feasibility using the FINER criteria (27) and 3) Vote to prioritise the top 5 research questions. Proposal-writing around these top 5 research questions will take place in smaller partnership teams defined by interest/expertise and supported by organisational and national infrastructures, e.g. CTU’s, RDS and CRN’s. We will invite topic and methodological expert co-applicants as required including health economics, complex intervention development and feasibility testing and realist methods . Refinement of study questionand methods will utilise appropriate frameworks e.g. PICO, Spider to systematically review existingevidence (Literature, NIHR portfolio) alongside needs and context analysis from Phase 2. Peer review and PPIE processes will refine and strengthen proposals. Refinement of study question andmethods will utilise appropriate frameworks e.g. PICO, Spider and be refined through peer review and PPIE processes. Learning regarding the research engagement process, working across integrated care, and establishing research partnerships will be disseminated (see section 9) to support ongoing research capacity development.

***Outputs:** Agreed priority questions; Proposal(s) written for Part two (and other) call(s); Disseminate learning*

9. OVERARCHING OUTCOMES:

1. Cross-sectoral Partnership of care providers and research organisations willing to engagein P&EoLC research
2. Maps and databases of services, research capacity and opportunities within and across thePartnership
3. Enhanced research readiness, capacity and capability
4. Diverse PPIE representation, including older people, family and informal carers, which isembedded across Partner organisations
5. Understanding of the capacity, opportunity and motivation required to deliver P&EoLC, andengage care providers in P&EoLC research, within integrated care systems
6. Delineated research priorities and questions
7. Research proposals ready for submission to NIHR funding calls
8. Processes for disseminating and translating research into commissioning and practice

10. PARTNERSHIP MANAGEMENT AND GUIDANCE

CN will provide overall leadership supported by RH. The Core Team will meet virtually on a regular basis. Meeting regularity will depend on the needs of the Partnership but will be not less than every three months. The team will be joined at these meetings by spokes, others within the partner sites who are particularly relevant to the phase. Meetings will ensure the Partnership is on track to meet its objectives, timelines, budget and outputs for each phase, and support the submission of proposal(s) for the Part two call and beyond. Additional ad hoc region-specific meetings will be led by SC with other Core Team members attending as appropriate.

The Partnership will also be supported by an Advisory Board of eight members of international standing. This board will help to 1. ensure that the Partnership and planned future bids take account of current policy and professional issues; 2. expert input about integrated care with older people and current trends and issues in social care practice and policy; 3. Reviewing research activities and offering questions or suggestions; and 4. advise and assist with the development of and dissemination of outputs.

Day to day the project will be managed by SC, supported by a Research Assistant as required. SC's development will be supported by CN using the OSCAR[34] ECR development model, SC's integration within the vibrant ECR body at University of Surrey and the University's programme for ECRs (provided by the Doctoral College) of mentorship, training and support.

11. PATIENT AND PUBLIC INVOLVEMENT AND ENGAGEMENT (PPIE)

Our aim is for patient and public involvement and engagement (PPIE) to be conducted in such a way that it promotes the meaningful and active involvement of older people living with advancing frailty and those important to them, such as friends, family and their wider relational networks, in research. Further, that it represents a true partnership between older people with advancing frailty, those important to them, health and social care providers including palliative care services, independent hospices and care homes, local government, the voluntary and community sectors, and higher education institutions. PPIE involved in current HEE/NIHR funded studies[22,35] have supported the focus of this proposed Partnership on advancing frailty, the need for integrated care, and the importance of care transitions at the end of life. Initial discussions with two PPIE representatives (one older person with frailty and one informal carer) have expressed support for the Partnership and its planned activities.

The lay summary was read by three PPIE representatives, (two older people living with frailty and one informal carer), and two lay members identified through RDS-SE. Their feedback meant the final version was revised to include a lay definition of advancing frailty, less technical language, and additional detail to aid clarity, for example, the format of the Partnership and listing the selected regions. Early instigation and embedding of PPIE in the Partnership was undertaken to ensure full PPIE engagement throughout and beyond the Partnership.

We will structure our PPIE around the National Standards for Public Involvement[26] and coproduction guidance and principles.[25] Involvement will be embedded in all phases and activities, and PPIE impact will be recorded and reported. We will ensure that time, support and resources are available to enable meaningful involvement. This includes ensuring we are clear about expectations, provide ongoing support, and that materials and communications are accessible. Key to this will be to have person-centred dialogue and to work with people in a way that works best for them, something that is particularly important as we are seeking to promote the meaningful and active involvement of older people with advancing frailty. One strategy to promote meaningful and active involvement is the use of 'portfolio PPIE'. Older people living with advancing frailty are vulnerable to fluctuating physical and psychological capacity. A standardised PPIE approach, where a static PPIE group is developed and maintained throughout the proposed Partnership and future research, is unlikely to be appropriate. A portfolio PPIE approach will therefore be followed and embedded. This approach means PPIE recruitment will be ongoing throughout the Partnership, and that individual PPIE representatives will be encouraged to choose elements they would like to be involved in, rather than being asked to commit to the entire Partnership, or any future research study.

People with lived experience of advancing frailty either themselves, or through someone they care for, can provide unique and valuable experiential knowledge, and provide different perspectives and views on palliative and end-of-life care for this population, particularly regarding transitions across health and social care services. One of the key elements of the Partnership is to identify research priorities, and this will be conducted in partnership with PPIE through specific PPIE activities. Patients, public, carers and/or organisations representing their interests, will be involved in developing the research ideas into research proposals for the Part two call. PPIE will assist in clarifying the research questions; ensure their relevance and appropriateness for patients, public and carers; and ensure that the research is planned in ways that make it easy for people to participate. People will have the opportunity for involvement virtually and face-to-face. Together we will explore and develop creative and innovative methods to enhance their contribution.

12. COSTS

This bid recognises the importance of leadership in establishing and sustaining research partnerships,[31] and much of the budget is allocated to this across the Partnership. Remaining monies have been allocated to developing PPIE, integral to the development of clinically relevant, translational research. Costs have also been allocated to each region to use as their training needsdictate, and for travel/subsistence to support partner sites in person in their drive to become research-ready.

13. FLOW CHART

ALLIANCE: Enhancing the quality of living and dying with advancing frailty through integrated care partnerships: Building research capacity and capability

Phase 1: Working together
(focus of months 1-2)

Objective: To establish the Partnership infrastructure & identify key contacts within each region across the palliative and end of life care (P&EoLC) continuum

Potential activities:
Education an networking events; Workshops; Develop ALLIANCE website

Outputs:
Establish ground rules for working together as a partnership; List of details for all key contacts across the care continuum; Website to host partnership information

Phase 2: Learning together
(focus of months 3-9)

Objective: To understand the strengths, weaknesses, barriers and enablers of research readiness and current clinical services for people with advancing frailty

Potential activities:
Map, scope and analyse current: 1. research activity & organisational infrastructures and PPIE; 2. Current clinical services relating older people with advancing frailty, focusing on transitions & coordination of care

Outputs:
Analysis of barriers, enablers & priorities to research capacity/capability & delivering care within integrated care systems for people with advancing frailty; Analysis of current PPIE representation; Mapped infrastructures; Database of regional & national opportunities; Database of aspiring researchers

Phase 3: Growing together
(focus of months 6-12)

Objective: To support provider services to become research-ready

Potential activities:
Develop & support PPIE representation e.g. link into training; Skills sharing/knowledge exchange; Buddying more experienced with more naïve sites; Develop research guidelines/strategies; Work with R&I/R&D departments to deliver bespoke training; Link aspiring researchers into established research infrastructures

Outputs
Establish active frailty/P&EoLC PPIE representation; Co-produced guidelines/strategies; Establish skills sharing/knowledge exchange infrastructure; Establish buddying system/bespoke training network; Research-ready organisations & individuals

Phase 4: Building together
(focus of months 12-15)

Objective: To establish research questions across the Partnership and develop research proposals

Potential activities:
Surveys; Focus groups

Outputs:
Agreed priority questions; Draft bid(s) written for Part two call (clinically applied, translational research to improve the delivery of P&EoLC for people living with advancing frailty across the care continuum); Dissemination of learning

Overall outcomes:

1. Cross-sectoral Partnership of care providers and research organisations willing to engage in P&EoLC research
2. Maps and databases of services, research capacity and opportunities within and across the Partnership
3. Enhanced research readiness, capacity and capability
4. Diverse PPIE representation, including older people, family and informal carers, which is embedded across Partner organisations
5. Understanding of the capacity, opportunity and motivation required to deliver P&EoLC, and engage care providers in P&EoLC research, within integrated care systems
6. Delineated research priorities and questions
7. Research proposals ready for submission to NIHR funding calls
8. Processes for disseminating and translating research into commissioning and practice

14. Risk Assessment

1. Identified Risks	2. Likelihood	3. Potential Impact/ Outcome	4. Potential Outcome Severity	5. Risk Management/Mitigating Factors	
Identify risks/hazards present	*Identify how likely the event is i.e.* *Very likely/ Likely/ Possible/ Unlikely*	*Who might be harmed and how?* *Ensure you have considered the research team, participants and anyone not directly involved in the research.*	*Classify the severity of outcomes identified in 3.* *i.e. High/ Medium/ Low*	*Evaluate the risks and decide on the precautions.*	*Standard Operating Procedures*/ risk assessments* *Enter Ref no/ title/ expiry date*
Not reaching prioritisation of research questions for future bids	Unlikely	Partnership: Contribution wasted Not ready develop relevant bids in time for NIHR call	Low	Partnership has clear focus; Support of Core group and Advisory group; structured prioritisation method and experienced facilitator; emphasis on co-design, PPIE and collection of priorities throughout.	N/A
No research teams developed due to other priorities e.g. coronavirus	Unlikely	Partnership: Contribution wasted Not ready develop relevant bids in time for NIHR call	Low	Core group represents all relevant areas, including research and clinical, and will meet regularly; interest from clinicians/ICN and other representatives in each Partnership area; support of Advisory group; emphasis on co-design and PPIE throughout.	N/A
Risk of data loss	Unlikely	Partnership: Contribution wasted Researcher: Stress due to imperilment of research	Low	Data will be securely stored in a secure location on University servers	N/A
Risk of identifying participants	Unlikely	Partnership: Partnership may not represent all areas of the Integrated Care System	Low	Multiple Co-applicants across the Partnership. Bid discussed with ICNs prior to project start.	N/A

15. Data Management

This is not a research study and therefore no participant will be collected and shared. Members of the Alliance Partnership will share work contact details, and these will comply with the General Data Protection Regulations with regards to the collection, storage, processing and disclosure of personal information and will uphold the regulation's core principles.

- **Anonymity and confidentiality**
  This is not a research study. However, the Surrey project team are responsible for ensuring that participant anonymity and confidentiality is protected, maintained and managed in accordance with the General Data Protection Regulations and University policy. For example ALLIANCE Members will be asked permission if they are explicitly referred to in any publications/outputs.

- **Nominal Group Facilitator**
  The Facilitator will be employed by the University of Surrey and will sign contracts that make clear the requirement for maintaining confidentiality and anonymity.

- **Data handling**
  This is not research and it is not envisaged that there will be any confidential data. However, the Surrey project team have responsibility for safe custody of all confidential data as per GDPR.

16. Ethical considerations

This is not research. It has been confirmed by the University of Surrey Ethics Committee that ethical approvals are not required.

17. Dissemination

The development of the website and co-production of ground rules (phase 1) will include a strategy for dissemination and communication to support research capability, capacity and activity within partner sites. Dissemination to the wider regions will occur through the hub and spoke PPIE approach, networking and research informed practice events, and by maintaining a social media presence. To disseminate the learning more widely we will link with national ARCs, for example Social Care and P&EoLC, and AHSNs to share learning of best practice, and the capacity, opportunity and motivation requirements. Additional dissemination will include the sharing of learning through third sector organisations, academic papers and, specifically in relation to outcome 5, to CRN direct delivery teams forwarding non-NHS research.

- **Authorship eligibility guidelines**
  The Core team, and potentially other co-authors, will be responsible for drafting all articles and reports and will be authors of the published papers

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Amendment History

Amendment No.	**Protocol version no.**	**Date issued**	**Author(s) of changes**	**Details of changes made**
1	1.1	14.03.22	SC	This version has the Confidentiality statement removed and the NIHR acknowledgment and disclaimer statement added as per Mrs Christina Roxborough's email of 11.03.22.

List details of all protocol amendments here whenever a new version of the protocol is produced.