# Research Partnership on Functional Loss and Rehabilitation towards the end of life

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## Protocol version control log

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## CONTENTS

## ABSTRACT

**Background:** Functional loss is defined as an inability to undertake necessary or desired tasks. Life-limiting illness(es) and accompanying symptoms (e.g. pain, fatigue, breathlessness) commonly contribute to functional loss; a common source of suffering for patients and families. Rehabilitation is a set of interventions designed to address functional loss. It is recognised as essential within palliative care, as it can improve quality of life and cut ongoing care costs. However, not everyone has equal access to rehabilitation. In the face of limited life expectancy, or uncertain ability to benefit from interventions, palliative rehabilitation services are often absent. This is partly due to a lack of high-quality research around optimal models of rehabilitation. Such research is methodologically challenging and requires multi-disciplinary and cross-speciality collaboration.

**Aims & objectives:** We aim to establish and grow a research partnership across diverse areas (starting with Edinburgh, East Anglia, Lancashire, Leeds, London and Nottingham) around the topic area of functional loss and rehabilitation in palliative and end of life care.

Objectives are to:

1. Develop a sustainable multi-disciplinary, cross-speciality research partnership
2. Share topic and methodological expertise
3. Identify high-priority unanswered research questions with stakeholders
4. Co-design and submit high-quality competitive research proposals to NIHR
5. Build capacity and capability to deliver nationally generalisable studies

**Partnership activities**

*Mapping and building skills:*

We will use interviews with staff and public members across partnership sites to map services attending to functional loss available to people approaching the end-of-life. We will also use the NIHR and Clinical Research Network portfolio to map research activity across these services. This work will be used to identify and engage new members in partnership activities, including offering structured training sessions, mentorship, skill-sharing opportunities, and protected time for proposal development.

*Identifying important, unanswered research questions:*

We will lead a research question generation exercise, through a modified version of the Child Health and Nutrition Research Initiative (CHNRI) methodology. Together with partnership leads and wider professional and public stakeholders, we will identify and prioritise important unanswered research questions about functional loss and rehabilitation in palliative and end of life care.

*Developing high-quality research proposals:*

Proposals addressing high-priority research questions will be developed, supported through three structured workshops and input from a Complex Clinical Trials unit. The workshops will focus on shaping the proposal, strengthening the methodology, and refining the proposals, and will provide space for constructive discussion and feedback from expert researchers and public members.

**Timelines for delivery:** 12 months.

**Anticipated impact:** Our partnership will establish top high-priority research questions, submit collaborative proposals to NIHR to answer them, and ensure that diverse teams across the country are well-prepared to deliver high-quality research about functional loss and rehabilitation in palliative and end of life care. Such work will improve and address inequalities in how rehabilitation is delivered during this important time.

## BACKGROUND

Functional loss (also called activity limitation or disability) is defined as an inability to undertake necessary or desired tasks. This is typically operationalised in terms of ability to perform activities of daily living: from more basic self-care tasks such as bathing and dressing, to instrumental activities which require more complex planning and thinking such as safety awareness, taking medications, social participation, and managing money and bills[1-3]. Life-limiting illness(es) and accompanying symptoms (e.g. pain, fatigue, breathlessness, anxiety, depression, cognitive dysfunction) commonly contribute to functional loss, and a consequent need for help, support or supervision[4-6]. While functional loss often occurs late in the course of disease for people with cancer, people with non-cancer conditions (e.g. chronic respiratory diseases, heart failure) and multimorbidity experience functional loss earlier in the disease trajectory[7, 8], with periods of acute worsening that fluctuate over time[9-11]. Both sudden and progressive loss of ability can cause crises that precipitate hospital or care home admission[12], and result in distress and suffering related to loss of usual roles and routines, independence, choice and sense of dignity[13-15].

Rehabilitation is a set of interventions designed to address functional loss, promote activity and preserve functional reserve and social participation[16, 17]. It is characterised by cycles of nested treatment which are reviewed and refined over time, and typically delivered by a multidisciplinary team[18]. As people age and increasingly live with multiple long-term conditions, trajectories of functional loss become more variable and unpredictable, and give rise to additional complexities for rehabilitation delivery[19]. Challenges include weighing up potential treatment benefits and burden, aligning care to individuals' priorities, and being responsive to fluctuating needs across multiple domains of health [20] [21, 22]. Palliative rehabilitation focuses on relief and reduced impact from distressing/disruptive symptoms (e.g. breathlessness, fatigue)[23] and managing or minimising the impact of geriatric syndromes (e.g. frailty, sarcopenia)[24].

Maddocks (CI) led work that describes a spectrum linking palliative and geriatric medicine, with palliative medicine focusing on symptoms, and geriatric medicine on function [25]. Both share commitment to person-centredness, communication, education and multi-professional working. Rehabilitation is recognised as essential within both palliative and geriatric care: it can reverse and slow functional loss, which can not only improve quality of life but may also cut ongoing costs relating to care, admissions and complications [26-28]. Examples of specific interventions include techniques to manage persistent symptoms and adjustment work around loss (in palliative care)[29-31], comprehensive assessment and management of geriatric syndromes (in geriatric care)[32, 33] [34], and environmental adaption and assistive technologies[35-37]. Yet, access to these services is often inequitable, and individual teams' capacity to deliver evidence-based rehabilitation interventions is highly variable[27, 38].

In the face of limited life expectancy, or uncertain ability to benefit from interventions, palliative rehabilitation services have often been not provided, or dis-invested in the face of limited resources and competing priorities[39-41]. Such decisions are rarely supported by rigorous needs assessment or evaluation of effectiveness and cost effectiveness, partly because these are methodologically difficult in this context. As a result, optimal ways to integrate the best of palliative and geriatric rehabilitation towards the end of life are currently unknown. Trials and conventional health economic approaches may not be sufficient, at least on their own, and new methodologies have been suggested to answer these questions more meaningfully, and in a way that supports service development and commissioning. Bringing together diverse expertise is required to address these challenges[42].

Our partnership will operate as a multidisciplinary community that will overcome the complexities surrounding loss of function and health deterioration in the period approaching the end of life. We combine thinking and expertise across palliative care, geriatrics and rehabilitation, and a multi-disciplinary perspective that includes medicine, nursing, physiotherapy, occupational therapy, psychology and social care, in addition to strong links with wider allied health professionals (e.g. speech and language therapy, dietetics) and community organisations. The network will highlight the importance of rehabilitation throughout the continuum of care and support stronger integration across disciplines and settings.

We envisage that subsequent proposals in stage 2 will serve the following areas of particular interest with outstanding evidence gaps highlighted within the commission brief:

- Reducing inequalities in access and provision of services for patients regardless of condition, setting, geographical area and time of day; including addressing inequitable access for non-cancer conditions and poor national coverage and consistency in rehabilitation provision

- End of life care referral and transition across health and care services; especially around the integration of health and social care, and transition across organisational boundaries in times of functional decline

- Strengthening training and development of expertise to support delivery of quality care, especially a skilled multi-disciplinary workforce that works together to meet the needs and priorities of patients and families

The partnership will be immediately useful and relevant to improving access and delivery of equitable palliative and end of life care according to NHS England’s (NHSE) Universal Personalised Care strategy [43]. It has been framed purposefully to realise the six ambition statements for palliative and end of life care relaunched by NHSE in May 2021[44].

## AIMS & OBJECTIVES

Our overarching aim is to establish and grow a partnership around the topic area of functional loss and rehabilitation in palliative and end of life care. Our objectives are to:

1) Develop a sustainable multi-disciplinary, cross-speciality collaborative research partnership that includes geographic populations historically under served by research activity

2) Identify key research questions in relation to functional loss and rehabilitation in palliative care, through collaboration with professional and public stakeholders

3) Co-design and submit high-quality competitive research proposals to future NIHR calls on palliative and end of life care

4) Share topic and methodological expertise to jointly address the complexities of rehabilitation interventions within palliative and end of life care, including their rigorous evaluation and pathways to implementation

5) Build capacity and capability to deliver nationally generalisable studies of rehabilitation interventions in palliative and end of life care, across health and social care, and voluntary and community organisations, in partnership with patients and their families

## PROJECT PLAN

### Developing & sustaining the partnership (Objective 1)

The research partnership will be active in a broad geographical area across England and Scotland; comprising urban and rural settings. The partnership leaders (MADDOCKS and HARWOOD) provide complementary skills in leading complex palliative and geriatric rehabilitation research. Co-applicants bring expertise across physiotherapy (CONNELL, COWLEY), palliative medicine (LAIRD), and psychology (ZEIGLER, PERYER, BRIGHTON). Below we outline, for each partner, local collaborators (Table 1), special interests within the topic of functional decline, and local infrastructure that can support and provide value for money for the partnership (Figure 2).

*Table 1: Initial partnership members and collaborators*

| Partner | Core site(s) | Lead(s) | Collaborators (expertise) |
|---|---|---|---|
| East Anglia | University of East Anglia | Dr Guy Peryer | Prof Morag Farquhar (Palliative Care), Prof Claire Goodman (Older Age Care, Care Homes), Dr Caroline Barry (Consultant, Palliative Medicine), Rebecca Christmas (Head of Palliative Care Services, Community Trust) |
| Edinburgh | University of Edinburgh / St Columbus Hospice | Dr Barry J A Laird | Prof Marie Fallon (Palliative Care), Dr Iain Philips (Oncology) |
| Lancashire | University of Central Lancashire / East Lancashire Hospitals NHS Trust | Prof Louise Connell | Prof Jim Richards (Rehabilitation, measurement), Dr Suzanne Ackerley (physiotherapy, stroke recovery), Prof Caroline Watkins (older people, end of life) |
| Leeds | University of Leeds / St Gemma's Hospice | Dr Lucy Ziegler | Prof Fliss Murtagh (Palliative Care, Primary care, NIHR Senior investigator), Elaine Gisbourne (Senior Therapist St Gemma's Hospice), Dr Emma Chapman (interventions for physical symptoms), Dr Karen Neoh (Consultant Palliative Medicine) |
| London | King' College London / Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation | Dr Matthew Maddocks<br>Dr Lisa Brighton (co-ordinator post) | Prof Irene Higginson (Palliative Care, Pubic Health, NIHR Senior Investigator Emeritus), Prof Toby Prevost (Statistics, Director NSU), Dr Jo Bayly (Rehabilitation, Physiotherapy) |
| Nottingham | University of Nottingham / Nottingham University Hospitals NHS Trust | Prof Rowan Harwood<br>Dr Alison Cowley | Prof Adam Gordon (Geriatric Medicine, care home research), Prof Cath Sackley (Rehabilitation, NIHR Senior Investigator), Dr Andrew Wilcock (Palliative Medicine), Professor Pip Logan (Rehabilitation, Occupational therapy, NIHR Senior Investigator) |

Our proposed partnership leads and collaborators have access to a wide array expertise and local infrastructure (Figure 1).

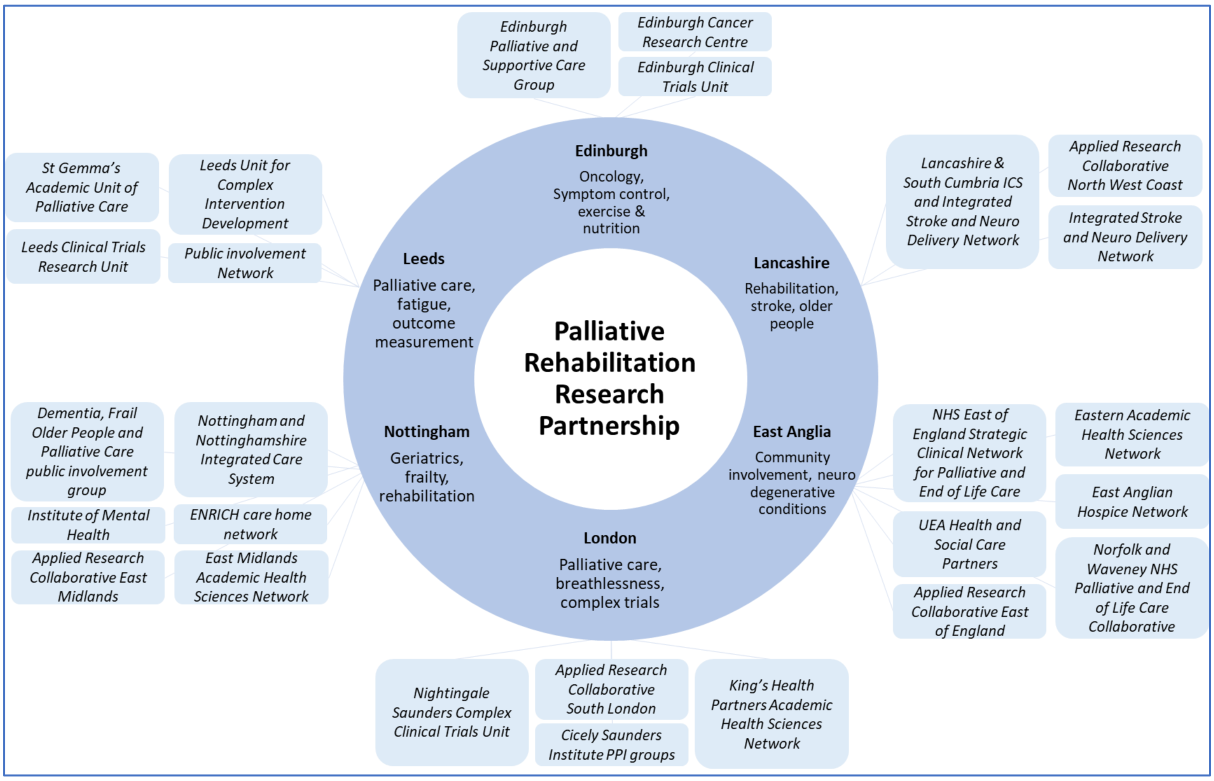

*Figure 1: Partners, expertise, and linked infrastructure*

### *Promoting and expanding the network*

Once permitted by the funder we will, through mailing lists including from the ARC National Leads for Palliative and End of Life Care, local ARCs, and Council for Allied Health Professions Research, advertise the partnership and invite new members to join and contribute to our activities. Co-leads will pay attention to the membership to ensure diversity and representativeness. The partnership will be open to others joining, and new members will be able to subscribe to mailing lists with details of workshops and any related events.

## Identifying priority research questions (Objective 2)

### *Design*

We will lead a research question generation exercise, through a modified version of the Child Health and Nutrition Research Initiative (CHNRI) methodology[50], to collate and prioritise research questions relating to functional loss and rehabilitation towards the end of life.

### *Participants*

This process will involve two sets of participants: an Expert Management Group and Expert Stakeholders.

*Expert Management Group (EMG):*

The expert management group will comprise partnership leads (Box 1) who will facilitate the research question generation and prioritisation.

Box 1: Expert Management Group membership

- Matthew Maddocks
- Lisa Jane Brighton
- Alison Cowley
- Guy Peryer
- Louise Connell
- Barry J A Laird
- Lucy Ziegler
- Rowan Harwood

*Expert Stakeholders:*

Expert stakeholders will include members of our partnership, additional experts suggested by partnership members, and experts identified through internet searches and key research publications. Search terms will include keywords and free text synonyms under the following structure: ‘Rehabilitation’ AND (‘Palliative Care’ OR ‘Advanced disease’). We will also identify ‘experts by experience’ through our existing public involvement networks and the People In Research website. In line with the scope outlined below, experts will based in UK institutions.

### *Method*

This research question generation and prioritisation process comprises five key stages: defining, sourcing, synthesising, scoring, and analysis/dissemination.

*Defining:*

The Expert Management Group (EMG; box 1) have specified the scope and prioritisation criteria for the research question generation exercise as follows:

*Scope:*

- <u>Population</u>**:** Adults with advanced disease experiencing, or at risk of, functional loss

- Timeframe: The results of proposed research ideas should be available or ready to implement within 3-5 years
- Geographical limits: The findings from this priority setting exercise should be relevant to a UK context.

*Prioritisation criteria*

- Answerability: Is the research question likely to be answerable?
- Effectiveness: Is the research question likely to lead to interventions that will effectively address functional loss in adults with advanced disease?
- Feasibility: Is it feasible to address this research question given the existing level of knowledge, capacity and resources?
- Burden reduction: Is this research question likely to lead to a significant reduction in burden for people with advanced disease experiencing functional loss, and/or their families?
- Equity: is the research idea likely to lead to interventions or changes in practice that will favour patients equally?

### *Sourcing*

Expert Stakeholders will be emailed to inform them of the objectives and context of this research question generation exercise, and invite their participation. Those who agree will be subsequently invited to generate and submit a minimum of two research questions via email or an online form. Experts by experience (members of the public) will be offered support in sharing their research ideas and transforming them into research question format.

The research question generation form will be open for up to 4 weeks. Non-responders will be followed up twice; 2 weeks and 1 week prior to the close date.

### *Synthesising*

The proposed research questions will then be collated by the EMG, who will combine duplicates, remove questions that are outside of the scope, and ensure the wording fits the format required for the scoring process. Unique research questions may also be grouped into subthemes prior to the scoring stage.

### *Scoring*

Expert stakeholders will then be invited to score the proposed research questions in relation to the prioritisation criteria via an online form (with other completion options available on request).

Response options for each prioritisation criterion will include:

- 0 (unlikely to meet the criterion)
- 0.5 (not sure if it can meet the criterion)
- 1 (likely to meet the criterion)
- Blank (unable to judge based on my current knowledge)

The scoring form will be open for 2 weeks. Non-responders will be followed up twice; 1 week and 1 day prior to the close date of the scoring process.

### ***Analysis & dissemination***

For each research question, mean scores from individual responses under each criterion will be calculated. Two scores will then be generated: an overall Research Priority Score and an Average Expert Agreement score.

- Research Priority Score: Mean score for each research question across the five prioritisation criteria.
- Average Expert Agreement score: Average proportion of scorers that returned the most common answer, expressed as the frequency of the mode (i.e. the most common score divided by the total number of scores).

The research questions and their scores will be shared with all participants, and disseminated in an open-access report via our network members, newsletter and website.

**Co-designing high-quality proposals (Objective 3)**

The proposal development workshops are aimed at shaping competitive research proposals around the identified top priority research questions. These will bring together multidisciplinary expertise to improve all aspects of the research design. These include partnership members, methodologists (quantitative and qualitative), expertise from the NIHR ARC (including experts in informatics, economics, statistics and implementation and improvement sciences, and developing and evaluating complex interventions), experts from the Nightingale-Saunders Complex Clinical Trials and Epidemiology Unit, advisors from the Research Design Service, clinicians and allied health professionals, hospice and community workers and patient and public representatives.

The Expert Management Group (EMG) will draw up a comprehensive list of participants in conversation with the Expert Stakeholders. The EMG will then convene three half-day proposal development workshops to bring together these participants. These will be structured as follows:

***Workshop 1: Shaping the proposal.***

- **Content**: The EMG will present the research questions and summary of feedback from the expert stakeholder group. The objectives will be to discuss the scope of the questions, how they will be structured within a proposal and the expertise and partnerships that are needed to answer them. Particular attention will be paid to the involvement of study sites with low levels of research activity and the involvement of sectors outside traditional research environments e.g. social care, hospice, charity, and community organisations. Attendees will be encouraged to ask difficult questions, identify issues around delivery, identify expertise needed to answer the question, formulate plans for multi-site involvement and identify key stakeholder not already part of the partnership and how they can be involved. This will be achieved through a facilitated discussion and break out groups. Public members will input on shaping research proposals, building on their involvement in formulating the priority research questions.
- ***Key deliverable:*** Two-page outline proposals, with aims and objectives that map onto the priority research questions. We anticipate developing proposals around the Health Services and Delivery Research and Health Technology Assessment schemes testing applied interventions or service configurations that better utilise rehabilitation in hospice and community palliative care.
- ***Estimated timing**:* Two months after the dissemination of the priority research questions.

***Workshop 2: Strengthening the methodology.***

- **Content:** The purpose of this workshop will be to refine study design including data access and management, methodologies to be employed (qualitative/quantitative/mixed methods/implementation science), outcomes to be measured (primary and secondary outcomes, process evaluation), intervention theory, study design, analysis plans, etc. The workshop will be supported by expert methodologists as well as through peer support. Public members will input on the feasibility, recruitment, ethics and other practical considerations of the methodology to be employed. Attendees will be able to work with methodologists in small groups, with common issues discussed in larger groups.
- ***Key deliverable:*** Plans for proposal design (feasibility, acceptability, efficacy, effectiveness testing), with a formulated study outline (following PICOT format; participants, intervention, control, outcome(s), timing).

- ***Estimated timing***: Two months after workshop 1. Research Design Service (RDS) and Nightingale-Saunders Complex Clinical Trial Unit (NSU) will provide additional one-to-one sessions outside of the workshop.

### *Workshop 3: Refining the proposals.*

- **Content:** The purpose of this workshop will be to run a mock NIHR panel and provide peer review of the draft proposals. Draft proposals will be submitted in advance and a mock panel convened of experts from the partner universities who have experience of reviewing grants for NIHR. Proposals will be introduced and discussed by the panel with written feedback provided on the strengths and weaknesses of the proposal. This will be facilitated by the EMG. They will then feedback to the applicant teams to further refine and improve the proposals. Public members will attend the mock panel and comment on the lay summary, planned public involvement activities, and other feedback in order to improve the application before full submission. Following the mock panel and feedback, groups will work together to strengthen parts of the proposal identified as weaknesses by the panel.
- ***Key deliverable:*** Feedback provided from mock panel, helping to improve the writing of the final bids.
- ***Estimated timing:*** Two months after workshop 2. RDS and NSU will provide additional written feedback outside of the workshop (e.g. through proposal feedback for a comprising methodologists and public members).

### *Support from the Nightingale-Saunders Complex Clinical Trial Unit*

As a partner the Nightingale-Saunders Complex Clinical Trials and Epidemiology Unit (NSU), a specialist section of the King's Clinical Trials Unit (KCTU), will support proposal development from prioritised research questions. Aligned to their working processes, partners can seek focused input if they have a specific trial project in mind (feasibility, efficacy, effectiveness testing), with a formulated trial outline (following PICOT format; participants, intervention, control, outcome(s), timing) at a stage ready for focused development, and within remit of the NSU.

One-to-one sessions (60-90 minutes) will be offered in the initial stages of the proposal development. These will cover the proposed aspects of trial design, including but not limited to trial arms, control group(s), randomisation, stage of intervention development including its track record and existing results, candidate primary outcome, assessment timepoints including the principal timepoint, and confounders. The exercise is to help the lead firm up their design decisions and choose between possible options at an early timepoint for efficient progress. If applicants want NSU to be involved in the trial, and the NSU collaborations committee agree, then sample size calculations supported by statisticians will also be included.

To complement this, detailed review will be offered for near final drafts being prepared for submission (2-3 hours with written feedback). Based on experience of the submission and panel roles across NIHR panels, the NSU director (Prof Prevost) and team will attend to justification for research design decisions, plan of statistical analysis, inconsistencies and lack of clarity in the proposal. This will occur around one month prior to submission giving the lead researcher opportunity to react and attend to comments.

**Sharing expertise and building capacity (Objectives 4 & 5)**

We will understand and strengthen capacity and capability of the research partnership through mapping current services and skills, providing structured training and opportunities for knowledge exchange, and ensuring protected time and mentorship for clinicians. The partnership will prioritize participatory action and learning, work force development, community engagement, and knowledge sharing using a community of practice model [45].

***Mapping current services and research capacity***

Health and social care services for functional loss vary widely across locations in both goals and delivery (restorative, adaptive or prosthetic), and organisational structures. This is the case across community healthcare, intermediate care, acute and mental health hospitals and hospices and care home settings. Specialties involved are also numerous and will include primary care, rehabilitation and therapies, and hospital-based medical disciplines including geriatric medicine and palliative care.

We will use interviews (telephone or Teams) with staff and public members across partnership sites to map the totality of services attending to functional loss available to people approaching the end-of-life, with approximate ascertainment of their capability and capacity, and barriers and enablers to access to these services. We will ask the extent to which these services are aware of, or take account of, the change in approach towards the end of life, and how they manage issues around access, prognostication, prioritisation, effectiveness, adverse effects or treatment burden, communication, shared decision-making and advance care planning.

We will map research activity across these services, through examination of the NIHR and Clinical Research Network portfolio, and discussion with researchers in the field. It is likely that activity around this topic is ongoing in, for example, cancer, ageing, dementia and neurodegeneration, primary care, mental health, musculoskeletal and stroke Clinical Research Networks. We will use this mapping exercise to identify and engage potential local principle investigators, invite them to learn about and join the partnership activities, and identify and training and support needs for their involvement in stage 2 proposals.

***Structured training***

The research partnership will offer funded structured training and development opportunities to members, with focused learning that builds on NIHR open online courses on ‘improving healthcare through clinical research’ and ‘what is health research?’. Based on brief needs assessment with collaborators and making use of reputable courses from the lead applicants, these will include:

- <u>Palliative Care Research Course:</u> offered by the Cicely Saunders Institute, King’s College London, this provides delegates with 2 days of high quality teaching, delivered by leaders across the palliative care research field. This course describes and appraises the methods for research in palliative care, leaving delegates able to understand and develop sound and feasible research studies, and use research skills to deliver evidence based clinical care and support research studies. Topics covered include: research and service evaluation, clinical trials, study set up, project design, statistics for clinicians, qualitative research, critical appraisal, and research ethics as applied to palliative care including rehabilitation.

- <u>The development, evaluation and implementation of complex rehabilitation interventions:</u> offered by the Centre for Rehabilitation and Aging Research at the University of Nottingham, this two-day course uses examples and experiences from rehabilitation research to illustrate learning and expose students to a wealth of knowledge and practical experience. Participants will learn about different methodological approaches including mixed methods, data synthesis, implementation science and health economics which will be illustrated using examples of research and studies from members of the centre.

- Developing and evaluating complex interventions within palliative and end of life care: offered by the Cicely Saunders Institute, this Royal College of Physician accredited short e-learning course is undertaken over 6-10 hours of self-directed study, and aims to improve practice and current standards when developing and evaluating complex interventions. In particular, the course explains the best methods of designing and conducting research, which evaluates palliative and end-of-life care services and treatments using the MORECare Statement. Six modules cover: Introduction to complex interventions and the MORECare Statement; Selection of outcome measures; Use of outcome measures and choosing and identifying time points; Missing data, attrition and response shift; Mixed methods; and finally ethical considerations in palliative and end-of-life care. Delivery includes readings, presentations and quizzes, allowing delegates to learn at their own pace.

In addition, the partnership will share seminars and events to support skills development. Examples include the King's College London Cicely Saunders Institute Seminar Series, the King's Clinical Trial Unit Trial Manager and Data Manager network seminar series, and the Divisional Seminar Series at the University of Nottingham within the Medical School, Health Sciences and Institute of Mental Health.

***Knowledge exchange***

In addition to structured training opportunities, our research partnership will provide mechanisms for members to exchange knowledge and develop skills in complex palliative rehabilitation research. These will include:

- A digital portfolio of members expertise and interests to facilitate collaboration, including opportunities for one-off skills and information sharing, e.g. recruitment and follow up practices, use of outcome measures, and/or longer-term mentorship by partnership members. This portfolio will also include information on partnership members' access to existing datasets that could be explored to support proposal development.

- A virtual workspace for partnership members (e.g. using Microsoft Teams/Slack) to facilitate information sharing and troubleshooting queries throughout proposal development.

- A dedicated webpage hosted by the Applied Research Collaboration (ARC) South London and accompanying mailing list for sharing partnership news, learning and resources with those interested in palliative rehabilitation beyond partnership members.

- A single point of contact for people interested in palliative and rehabilitation research and/or in research delivery roles to seek advice and support from partnership members, facilitated by the partnership coordinator.

***Protected time and mentorship for clinicians***

The partnership will directly support early career and leading clinical-academics (COWLEY, CONNELL) with protected time to develop their own research project and programme proposals. arc slThis will enable front line clinicians to be released from clinical care to develop research proposals and in turn enable opportunities for career succession planning. Evidence points towards need for increased investment for post-doctoral non-medical healthcare professionals, to enable their clinical and academic expertise to be harnessed for patient centred and clinically driven research[46-48].

The partnership will also include an internal focus on mentorship from experienced researchers and clinical academics with expertise in palliative rehabilitation and developing and evaluating complex interventions. For example, experienced partners will support early career researchers to develop fellowship applications and/or jointly lead grant applications in the area of functional loss and rehabilitation towards the end of life. Mentorship, visionary leaders and role models are critical in developing research and clinical academic leaders of the future[49].

## PATIENT & PUBLIC INVOLVEMENT

Involvement of public members, including patients, family members, and informal carers, will be embedded and supported throughout partnership activities, including capacity building activities. In all cases public members will be reimbursed for their time.

### *Active involvement in partnership activities:*

- Generating research questions: Public members with relevant lived experience will be invited to participate in the research question generation exercise, offering ideas and scoring suggested research questions alongside researcher and clinical stakeholders. They will be offered support with their contributions (e.g. providing alternative completion formats, discussing by phone, providing further elaboration and instruction) and reimbursed for their time.

- Developing proposals: Public members will also be invited to contribute to developing proposals to address high priority research questions. Involvement activities will be flexible to align with the interests and preferences of public members, but will likely include contributing to proposal development meetings, reviewing the proposal and plain language summary, and potentially supporting proposals as a co-applicant.

### *Capacity building to enhance public involvement:*

Alongside involvement in proposal development, we are committed to enhancing quality of ongoing public involvement through sharing of expertise, best-practice and resources across our partnership members. This will include:

- Linkage with existing networks of public members, including and the Dementia, Frail Older People and Palliative Care Patient and public involvement group at the University of Nottingham, the Leeds Public Involvement Network, and the Cicely Saunders Institute Online Forum (www.csipublicinvolvement.co.uk[51]).

- Wider implementation of existing resources, such as Cicely Saunders Institute involvement resources (e.g. public member 'role description' templates, 'introduction to palliative care and rehabilitation research' booklet), and the East of England ARC's Guidance for Researchers on Feedback to public members[52].

- Opportunities for bespoke training: such as the University of Nottingham training for public members in qualitative analysis [53], or Cicely Saunders Institute training on public involvement in palliative care and rehabilitation research.

- Space for sharing and troubleshooting specifically about public involvement within our partnership's online workspace, to support development and strengthening of involvement across the partnership.

## MILESTONES & DELIVERABLES

Our deliverables will ensure a sustainable partnership that bridges research and practice.

**Key milestones over 12 months will be as follows:**
Month 1: Partnership established, including shared workspace and online presence
Months 2-3: Mapping of current services and research capacity
Months 3-4: Research question generation
Months 6-7: Outline proposals developed (workshop 1)
Months 8-9: Draft protocols developed (workshop 2)
Months 10-11: Proposals receive feedback from mock panels (workshop 3)
Month 12: Competitive proposals ready for submission

**Deliverables:**

D1. Established partnership portfolio, workspace, and public-facing profile (month 1)
D2. Map of current service provision and research capacity (month 2)
D3. Top-priority research questions identified around functional loss and rehabilitation in palliative and end of life care (month 4)
D4. Skill development case studies and activities log demonstrating capacity building (month 10)
D5. High-quality research proposals for submission to NIHR, target is 3 submissions (month 12)

Table 2: Gantt chart showing milestones & deliverables (D1-D5) during 2022

| **Milestones** | **Jan 22** | **Feb 22** | **Mar 22** | **Apr 22** | **May 22** | **Jun 22** | **Jul 22** | **Aug 22** | **Sep 22** | **Oct 22** | **Nov 22** | **Dec 22** |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Partnership established, including shared workspace & online presence | ▨ D1 | | | | | | | | | | | |
| Mapping & building capacity | ▨ | ▨ D2 | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ | ▨ D4 | | |
| Research question generation | | | ▨ | ▨ D3 | | | | | | | | |
| Outline proposals developed (workshop 1) | | | | | ▨ | ▨ | ▨ | | | | | |
| Draft protocols developed (workshop 2) | | | | | | | | ▨ | ▨ | | | |
| Proposals receive feedback from mock panels (workshop 3) | | | | | | | | | | ▨ | ▨ | |
| Competitive proposals ready for submission | | | | | | | | | | | | ▨ D5 |

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