This protocol has regard for the HRA guidance and order of content

FULL/LONG TITLE OF THE STUDY
Palliative and End-of-Life Care Research Partnership for Northern Ireland

SHORT STUDY TITLE / ACRONYM

PALCARESNI

PROTOCOL VERSION NUMBER AND DATE

Version 2. 21/12/2021

RESEARCH REFERENCE NUMBERS

IRAS Number:	N/A
SPONSORS Number:	N/A
FUNDERS Number:	NIHR135291

ACKNOWLEDGEMENT: This project is funded by the National Institute for Health Research (NIHR) [NIHR Evaluation, Trials and Studies Coordinating Centre (NIHR135291)]. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

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SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

Chief Investigator:

Signature: Peter O'Halloran ....

Date: ......21/12/2021......

Name: (please print): Peter O'Halloran

....

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KEY STUDY CONTACTS

Insert full details of the key study contacts including the following

Chief Investigator	Dr Peter O'Halloran, School of Nursing & Midwifery, MBC Building, 97 Lisburn Road, Belfast BT9 7BL p.ohalloran@qub.ac.uk. Telephone: 028 9097 2490
Sponsor	RóisÁine Hamill Head of Contracting Contracting Research & Enterprise Directorate The Queen's University of Belfast 63 University Road Belfast BT7 1NF Email: roisaine.hamill@qub.ac.uk Tel: +44 (0) 28 9097 1315 Fax: +44 (0) 28 9097 2570
Funder(s)	NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) University of Southampton Alpha House, Enterprise Road Southampton, SO16 7NS E-Mail: netspostawardsetup@nihr.ac.uk

STUDY SUMMARY

Study Title	Palliative and End-of-Life Care Research Partnership for Northern Ireland
Internal ref. no. (or short title)	PALCARESNI
Planned Study Period	01/02/2022 – 31/01/2023
Aim(s)	The twin aims of the Partnership are: 1. To build palliative care and end-of-life research capacity in NI, with a specific focus on less experienced sites, so that strong applications can be submitted to Part Two of the NIHR Commissioned Call: *Building the evidence base.* 2. To create a sustained collaboration that will support a further programme of research in

	the five years following the Commissioned Call, focused on key areas of need in NI that are also relevant to the rest of the UK.

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 FINANCIALSUPPORT GIVEN**
National Institute for Health Research (NIHR) Health Technology Assessment Programme (NIHR135291)	**£74,439.20**

ROLE OF STUDY SPONSOR AND FUNDER

The study sponsor and funder do not have final decisions about the structure or work of the Partnership.

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITEES/GROUPS & INDIVIDUALS

The Partnership will be co-led by Dr Peter O'Halloran and Dr Clare McVeigh, senior lecturer and lecturer respectively, in the School of Nursing and Midwifery (SONM), QUB. A post-doctoral research assistant will be employed three days a week to work with Partners towards agreed objectives. This will include drafting the Project Initiation Document; organising the Partnership launch event; preparation for Partnership meetings; supporting PPI representatives so that they are well-prepared to contribute; working with chief investigators on research proposals for Part 2; organising PPI involvement in preparation of Part 2 proposals; drafting and disseminating the bi-monthly Partnership e-newsletter; drafting the six-month report and the final report to NIHR. The research assistant will also complete an internal Project Management course. Dr McVeigh will be responsible for the day-to-day management of the post-doctoral research assistant and Dr O'Halloran will provide mentorship for her and overall supervision for the post-doctoral research assistant. This core team will meet every two weeks for the duration of the Partnership.

PROTOCOL CONTRIBUTORS

- Queen's University Belfast (QUB): Professor Joanne Reid, Dr Clare McVeigh, Dr Helen, Professor Kevin Brazil, Dr Maeve Murphy.
- All Ireland Institute of Hospice and Palliative Care (AIIHPC): Dr Mary Rabbitte
- Marie Curie in Northern Ireland: Craig Harrison and Joan McEwan
- The Patient and Client Council (PCC): Vivian McConvey
- Kidney Care UK: Fiona Loud.
- Northern Health and Social Care Trust (NHSCT): Fiona Gilmour and Dr Robert Mullan
- South Eastern Health and Social Care Trust (SEHSCT): Ray Elder
- Belfast Health and Social Care Trust (BHSCT): Dr Carol Stone
- Northern Ireland Clinical Trials Unit (NICTU): Lynn Murphy
- Public Health Agency (PHA): Dr Gail Johnston
- Department of Health (DoH), NI: Corrina Grimes
- Health and Social Care Board (HSCB): Paul Turley

The views of patients, service users, and their carers, were obtained through The Patient and Client Council, Kidney Care UK, and Voices4Care

KEY WORDS: Palliative care, end of life, research partnership, health services research

STUDY FLOW CHART

TIMELINE FOR PARTNERSHIP ACTIVITY

Set out below is the timeline for partnership activity, based around the bi-monthly meetings, demonstrating the pathway to submission of research applications for Part 2.

Task	Feb-Mar 22	Apr – May 22	Jun – Jul 22	Aug – Sep 22	Oct – Nov 22	Dec 22 – Jan 23
Bi-monthly Partner meetings	▨	▨	▨	▨	▨	▨
Agree Project Initiation Document and Terms of reference	▨					
Prioritise potential proposals	▨	▨				
Review draft proposals prior to submission					▨	
Submit Part 2 proposals						▨
Plan the continued life and priorities of the Partnership					▨	▨
Working with CIs to co-produce Part 2 proposals	▨	▨	▨	▨	▨	▨
Publish bi-monthly newsletter	▨	▨	▨	▨	▨	▨

PALCARESNI

STUDY PROTOCOL

NIHR Palliative Care Research Partnership for Northern Ireland

1 BACKGROUND

The purpose of the National Institute for Health Research (NIHR) call for Palliative and End of Life Care Research Partnerships is to build research capacity in palliative and end of life care, and to ensure that NIHR research is conducted in the areas where the health and social care needs are greatest, and where there are historically low levels of research.

Northern Ireland (NI) fits this profile in the following ways:

1. High levels of health and social care need: An estimated 11,300 people in need of palliative care die each year in NI,(1) yet recent research suggests that nearly 3,000 of these people are not accessing palliative care.(2) There are five Local Commissioning Groups (LCGs) in NI, which share borders with the Health and Social Care Trusts (HSCTs). Those with the highest mean numbers of patients registered yearly as receiving palliative care 2015-2020 are the Northern (1325), South Eastern (1037), and Belfast (1201) LCGs.(3)

The 2019/20 *National Audit of Care at the End of Life* (4,5) reports a summary score of 7.4/10 (maximum score is 10) for the specialist palliative care workforce in England and Wales (E&W), compared to just 5.1/10 in NI. This reflects differences in services such as access to seven-days-a-week, face-to-face, specialist palliative care service (available in 36% of hospitals in E&W compared to none in NI); vacancy rates for medical staff (6% in E&W, 25% in NI); and inclusion of end-of-life care training in mandatory training programmes (46% in E&W, 25% in NI).

2. Low levels of research: A 2018 review of palliative and end of life care research on the Island of Ireland noted that the vast majority of the research was observational (only one RCT was reported), that funding in NI came from NI government sources, or charities, rather than research councils, and that 40% of the studies received no external funding.(6) A search of the NIHR research portfolio on 13/08/2021 for funded research in palliative or end-of-life care based in NI identified only one study (a systematic review).

3. Need and desire to build research capacity: The two universities in NI, Queen’s University Belfast (QUB) and Ulster University (UU) are both seeking to strengthen their research themes in relation to palliative and end of life care.(7,8) Both universities are affiliated with the All Ireland Institute of Hospice and Palliative Care (AIIHPC), a collaboration of hospices, health and social care organisations and universities on the island of Ireland;(9) and have a track record of conducting palliative care and end-of-life research in partnership with local Health and Social Care Trusts, and with the charitable and voluntary sectors. However, this portfolio of research needs to grow if it is meet the needs of the NI population and provide opportunities for patients to join major studies.

To summarise: there is a high level of need for palliative and end-of-life care in NI, a relatively low level of research, and considerable potential for increased capacity. In recent years researchers have established partnerships and conducted preliminary research which now puts them in a position to make applications to NIHR, but such applications will be stronger and more likely to succeed with the support of the envisaged Partnership.

2 RATIONALE

To summarise: there is a high level of need for palliative and end-of-life care in NI, a relatively low level of research, and considerable potential for increased capacity. In recent years researchers have established partnerships and conducted preliminary research which now puts them in a position to make applications to NIHR, but such applications will be stronger and more likely to succeed with the support of the envisaged Partnership.

3 THEORETICAL FRAMEWORK

N/A

4 AIM(S)

The twin aims of the Partnership are:

1. To build palliative care and end-of-life research capacity in NI, with a specific focus on less experienced sites, so that strong applications can be submitted to Part Two of the NIHR Commissioned Call: Building the evidence base.

2. To create a sustained collaboration that will support a further programme of research in the five years following the Commissioned Call, focused on key areas of need in NI that are also relevant to the rest of the UK.

4.1 Objectives

1. To form a Partnership to include the university researchers, health and social care practitioners, patient and public representatives, the charitable and voluntary sectors, and policy makers and commissioners of services.
2. To identify and include Partners from geographical areas where there are the largest shortfalls in research activity compared to need and care capacity.
3. To work with Partners to develop several strong applications for submission under Part 2, that are co-produced with patients and the public, and address important and enduring evidence gaps for those delivering and receiving personalised palliative and end of life care.
4. To optimise the policy and practice impact of research funded under Part 2.
5. To establish an ongoing and expanding Partnership that will support the identification of palliative care and end-of-life care needs that are important in NI and the UK as a whole but which have been under-researched, and to develop programmes of research to fill these gaps, thereby providing an evidence base to underpin policy, commissioning, and practice.

4.2 Outcome

PALCARESNI

To develop several strong applications for submission under Part 2, that are co-produced with patients and the public, and address important and enduring evidence gaps for those delivering and receiving personalised palliative and end of life care.

5 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYIS

PARTNERS AND PARTNERSHIP PLAN

The Partnership will be co-led by Dr Peter O'Halloran and Dr Clare McVeigh, senior lecturer and lecturer respectively, in the School of Nursing and Midwifery (SONM), QUB. A post-doctoral research assistant will be employed three days a week to work with Partners towards agreed objectives. This will include drafting the Project Initiation Document; organising the Partnership launch event; preparation for Partnership meetings; supporting PPI representatives so that they are well-prepared to contribute; working with chief investigators on research proposals for Part 2; organising PPI involvement in preparation of Part 2 proposals; drafting and disseminating the bi-monthly Partnership e-newsletter; drafting the six-month report and the final report to NIHR. The research assistant will also complete an internal Project Management course. Dr McVeigh will be responsible for the day-to-day management of the post-doctoral research assistant and Dr O'Halloran will provide mentorship for her and overall supervision for the post-doctoral research assistant. This core team will meet every two weeks for the duration of the Partnership. To build capacity, Dr McVeigh will complete an external course on Project Management and become a co-investigator on one of the Part 2 projects, whilst the post-doctoral research assistant will complete an internal Project Management course and be encouraged to apply for a research assistant position on one of the Part 2 projects, if funded.

Dr O'Halloran is a registered nurse and an experienced researcher in palliative care. He Chaired the Northern Ireland Palliative Care Research Forum (10) 2016-18, and as 'REF2021 Impact Champion' managed three research Impact Case Studies to successful submission. He is also Research and Development Lead for Nursing and Midwifery in the Northern Health and Social Care Trust and will be Chief Investigator on one of the proposed studies for Part 2.

Dr McVeigh is a registered nurse and an active researcher in palliative and end-of-life care, publishes regularly in the field, and has been a co-investigator on several funded studies. She brings her clinical links in palliative care through her previous role as Clinical Lecturer in Palliative Care at the NI Hospice and has also worked with both the Northern and Belfast HSC Trusts as part of her all-Ireland research. Dr McVeigh will be a co-investigator on one of the proposed studies for Part 2.

The following organisations and individuals have agreed to support the Partnership and will be the founding partners:

- Queen's University Belfast (QUB): Professor Reid is Director of Research for the SONM and Chair of the AIIHPC Palliative Care Research Network, so is well placed to advance the goals of the Partnership in the University and the wider Palliative Care community. Dr O'Halloran, Dr McVeigh, Dr Noble and Professor Reid are all Fellows of the University's Centre for Evidence and Social Innovation (CESI), a multidisciplinary research group in which Professor Brazil is Health and Wellbeing Thematic Lead. This will allow the Partnership to draw on colleagues from education and the social sciences. As Business Alliance Manager for Medicine, Health and Life Sciences, Dr Murphy will provide support from research ideas to knowledge exchange and impact, through support for contracting, governance, and community partnerships.

- Chief Investigators (CIs) of studies planned for submission to Part 2: CIs will be full Partners, receiving support and also reporting progress to the Partnership on Part 2 proposals.
- All Ireland Institute of Hospice and Palliative Care (AIIHPC): As Research Programme Manager for AIIHPC, Dr Mary Rabbitte will link Partners with organisations who are allied with the Institute, such as the Hospices and Macmillan Cancer Support, and support identification of co-investigators, dissemination of findings, and impact on policy and practice. She will also provide access to the PPI group Voices4Care, which is focused on patients and families with palliative care needs.
- Marie Curie in Northern Ireland: As Policy and Public Affairs Manager, Northern Ireland, Craig Harrison will facilitate PPI involvement and also promote policy and practice impact of the Partnership and the Part 2 studies.
- The Patient and Client Council (PCC): As CEO of the NI PCC, an independent voice for patients, clients, carers and communities, Vivian McConvey will provide access to PPI and related training, and contribute to the identification of research priorities.
- Kidney Care UK: As Policy Director, Fiona Loud will support PPI engagement through Kidney Care UK, identify research priorities, and support impact on health care policy for renal patients.
- Northern Health and Social Care Trust (NHSCT): As Macmillan Palliative Care Service Improvement Lead, Fiona Gilmour will support Partners to identify service and research priorities, whilst Lead Consultant Nephrologist Dr Robert Mullan will facilitate research cooperation with the Trust, and act as co-investigator for projects related to palliative care for renal patients. Dr O'Halloran is also Research and Development Lead for Nursing and Midwifery in the Trust and will support nurses to engage as co-investigators with the Part 2 research projects.
- South Eastern Health and Social Care Trust (SEHSCT): As Strategic Lead for Palliative Care, Ray Elder will facilitate research cooperation with the Trust and support Partners to identify research priorities.
- Belfast Health and Social Care Trust (BHSCT): As a Consultant in Palliative Medicine, Dr Stone will facilitate research cooperation with the Trust and support Partners to identify research priorities.
- Northern Ireland Clinical Trials Unit (NICTU): As Manager of NICTU, Lynn Murphy will facilitate access to advice at the research design stage, and specialist services such as statistics, health economics, trial management and data management for research that is implemented.
- Public Health Agency (PHA): As Lead for PPI in HSC R&D Division, Public Health Agency, Dr Johnston will provide strategic and practical support for PPI and liaison with other key stakeholders in the Agency e.g., service improvement leads, as well as the Research Managers in the Trusts for research governance.
- Department of Health (DoH), NI: As Advance Care Planning Lead for the Department of Health, NI, Corrina Grimes will ensure the learning from the Part 2 research informs research priorities and policy for palliative and end-of-life care.

- Health and Social Care Board (HSCB): As Regional Palliative Care Programme Lead and Assistant Director of Commissioning, Paul Turley will ensure the learning from the Part 2 research informs research priorities and commissioning of services.

In addition, we are actively seeking partnership with colleagues at Ulster University, and will invite those with potential applications for Part 2 to bring them under the umbrella of the Partnership. We will also seek partnership with a senior researcher/research group from outside NI with a track record of successful grant applications to NIHR and other Research Councils.

Meeting the objectives

Objective 1: forming the partnership. key representatives from each of the organisations noted above have agreed to contribute to the partnership. Before our first meeting, the co-leaders and post-doctoral research assistant will draft Terms of Reference for the Partnership (including the roles of the Chair; membership and membership roles; aims and objectives; frequency of meetings; decision-making, and reporting processes, etc.): and a Project Initiation Document (PID), following an approach commonly used in the NHS.(11) The PID will set out key components of the Partnership process, such as:

- Project rationale
- Background
- Scope and exclusions
- Constraints and assumptions
- Project objectives
- Costs and benefits
- Project approach and work streams
- Project plan – indicative timescales
- Project management team structure and roles
- Risks management

The Terms of Reference and PID will be circulated to Partners, many of whom have experience of project management (for example, AIIHPC, Marie Curie, NICTU, HSCB and DoH) before the first meeting so that they can be discussed, developed, and agreed at that meeting. We will meet (mostly virtually or in hybrid meetings) at least six times over the 12-month funding period to plan support for the Part 2 studies and to monitor progress on their development and on the advancement of the Partnership. We will organise a formal launch for the Partnership coordinated by QUB with the help of QUB Media Relations and the corresponding Departments in Marie Curie and AIIHPC. We will also circulate a bi-monthly e-newsletter to Partners and other interested parties to demonstrate progress and alert others who may wish to join or work with the Partnership.

Objective 2: including Partners with a shortfall between research activity and care needs and activity. As a whole, NI has relatively high health and social care needs and historically low levels of funded research in palliative and end-of-life care. However, within NI, the Belfast, South-Eastern, and Northern LCGs have larger numbers of patients registered with palliative care needs and the South-Eastern and Northern Trusts have historically lower levels of research activity. Consequently, we have included representatives from these three Trusts as Partners and plan to involve colleagues from the Trusts in the Part 2 studies as co-investigators.

Objective 3: working with Partners to develop applications for submission under Part 2 that fully engage with patients and the public. A vital part of the Partnership’s work will be to fully involving and support the PIs by understanding the requirements of the Part 2 call and pooling resources to help them overcome obstacles and meet those requirements. We will invite PIs to consider common challenges and also unique requirements of their projects, and bring these to the Partners for consideration and support. The Partners will consider the potential of studies and their stage of preparation, and prioritise those most likely to be submitted for Part 2. However, all studies with potential to go forward for NIHR funding will remain under consideration as the Partnership continues. Under the supervision of Dr O’Halloran and the management of Dr McVeigh, the post-doctoral research assistant will work alongside PIs to develop the Part 2 studies: identifying needs and challenges, facilitating engagement with Partners, and sourcing information, advice, and expertise. As part of our capacity building efforts, we will invite the post-doctoral research assistant to apply for positions that become available in Part 2 studies. All Part 2 studies will require significant input from patients and the public and will draw on the PPI resources and expertise of Partners (such as the Patient and Client Council, Kidney Care UK, and the AIIHPC) to ensure this is available to PIs, and to optimise the influence and impact of patients and other stakeholders on the research.

Potential applications where there has already been substantial preparatory work and which are planned for submission to NIHR include:

- Cluster randomised trial of Multi-Modal intervention combining Exercise, Anti-inflammatory supplement, Dietary counselling (MMEAD) for renal cachexia. (CI: Professor Joanne Reid)

- Cluster randomised trial of a complex arts-based intervention on the mental health and wellbeing of patients with end-stage kidney disease whilst receiving haemodialysis. (CI: Dr Helen Noble)

- Randomised trial of a mindfulness-based intervention to improve the mental health and wellbeing of patients with end-stage kidney disease and their carers. (CI: Dr Helen Noble)

- Randomised trial and process evaluation of advance care planning with patients who have end-stage kidney disease. (CI: Dr Peter O’Halloran)

- Realist synthesis of integrated palliative care for adults with cancer. (Joint CIs Professor Joanne Reid and Dr Tracey McConnell)

These studies are congruent with the priority questions for palliative and end-of-life care research (top 10 and long-list) identified by the James Lind Alliance, such as: What are the benefits of Advance Care Planning? What are the best ways to deliver palliative care for patients with non-cancer diseases? What are the best ways to make sure there is continuity for patients at the end of life? What is the best diet for palliative care patients? How can the spiritual support needs of palliative care patients and their carers and families best be met? (12)

Part 2 studies are not limited to those listed above. We will invite researchers from both Universities to bring forward suitable proposals that may benefit from the Partnership.

Objective 4: optimising the policy and practice impact of research funded under Part 2. Involving Partners, including patients, in the development of the Part 2 studies will allow CIs to plan for impact. CIs will work with service commissioners and providers to target key areas of practice, and secure organisational cooperation for implementation. Partners will be invested in the Part 2 studies and aware of their relevance. For example, along with the HSC Trusts, Partners include the Palliative Care Commissioning Lead for the NI HSCB, the Advance Care Planning Lead at the NI DoH, and the Head of Policy and Public Affairs for Marie Curie NI. Dr O'Halloran is a successful REF 'Impact Champion' and will help guide CIs in embedding impact optimisation and evaluation in their Part 2 studies. Partners, including patients and the public, will be co-investigators on Part 2 studies which will enable their ongoing input into the research and contribution to the continuation of the Partnership.

Objective 5: establishing an ongoing Partnership that will support needs-based programmes of research to underpin policy, commissioning, and practice. Looking beyond the immediate objectives of Parts 1 and 2, the Partnership will seek to identify important palliative care and end-of-life care needs (such as access to specialist palliative care) and develop programmes of research to provide the evidence base to underpin policy, commissioning, and practice. We will invite partners to propose and agree priorities for research in NI, using a nominal group technique adapted from the The James Lind Alliance Guidebook to achieve consensus.(13)

6 STUDY SETTING

N/A

7 SAMPLE AND RECRUITMENT

N/A

8 ETHICAL AND REGULATORY CONSIDERATIONS

N/A

8.3 Peer review

The Partnership project was reviewed by the Cross-programme Funding Committee for 21/54 NIHR: Palliative and End of Life Care Research Partnerships.

8.4 Patient & Public Involvement

The public will be involved in the Partnership in the following ways:

- The Patient and Client Council (PCC): As CEO of the NI PCC, an independent voice for patients, clients, carers and communities, Vivian McConvey will provide access to PPI and related training, and contribute to the identification of research priorities.
- Kidney Care UK: As Policy Director, Fiona Loud will support PPI engagement through Kidney Care UK, identify research priorities, and support impact on health care policy for renal patients.
- All Ireland Institute of Hospice and Palliative Care (AIIHPC): As Research Programme Manager for AIIHPC, Dr Mary Rabbitte will link Partners with organisations who are allied with the Institute, such as the Hospices and Macmillan Cancer Support, and support identification of co-investigators, dissemination of findings, and impact on policy and practice. She will also provide access to the PPI group Voices4Care, which is focused on patients and families with palliative care needs.
- Public Health Agency (PHA): As Lead for PPI in HSC R&D Division, Public Health Agency, Dr Johnston will provide strategic and practical support for PPI and liaison with other key stakeholders in the Agency e.g., service improvement leads, as well as the Research Managers in the Trusts for research governance.

9 DISSEMINATION POLICY

9.1 Dissemination policy

We will draft a six-month report and final report for submission to NIHR.

9.2 Authorship eligibility guidelines and any intended use of professional writers

Authorship of the six-month report and final report for submission to NIHR, and any other publications will rely on the authorship criteria developed by the International Committee of Medical Journal Editors for manuscripts submitted for publication

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11. APPENDICIES

13.3 Appendix 3 – Amendment History

Amendment No.	Protocol version no.	Date issued	Author(s) of changes	Details of changes made