Health Research Authority

Qualitative Protocol Development Tool

The research protocol forms an essential part of a research project. It is a full description of the research study and will act as a 'manual' for members of the research team to ensure adherence to the methods outlined. As the study gets underway, it can then be used to monitor the study's progress and evaluate its outcomes.

The protocol should go into as much detail about the research project as possible, to enable the review bodies to fully understand your study.

The use of this collated consensus guidance and template is not mandatory. The guidance and template are published as standards to encourage and enable responsible research.

The document will:

- Support researchers developing protocols where the sponsor does not already use a template
- Support sponsors wishing to develop template protocols in line with national guidance
- Support sponsors to review their existing protocol template to ensure that it is in line with national guidance.

A protocol which contains all the elements that review bodies consider is less likely to be delayed during the review process because there will be less likelihood that the review body will require clarification from the applicant.

We would appreciate self-declaration of how you've used this template so we are able to measure its uptake.

Please indicate the compatibility of this template with any existing templates you already use by stating one of the following on the front of each submitted protocol:

- **This protocol has regard for the HRA guidance and order of content; OR**
- **This protocol has regard for the HRA guidance; OR**
- **This protocol does not have regard to the HRA guidance and order of content**

FULL/LONG TITLE OF THE STUDY

Developing the UK **Co**llaborative **P**aediatric **P**alliative c**A**re **R**esearch (**CoPPAR**) Network

SHORT STUDY TITLE / ACRONYM

CoPPAR

PROTOCOL VERSION NUMBER AND DATE

1.0. 31.03.22

RESEARCH REFERENCE NUMBERS

IRAS Number: N/A

SPONSORS Number:

FUNDERS Number: NIHR135304

This project is funded by the National Institute for Health Research (NIHR) Palliative and End of Life Care research partnerships (NIHR 135304). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care

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.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publically available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

Chief Investigator:

Signature:
L.FRASER.....
.....

Date:
...11.../.04...../.2
2.....

Name: (please print):

.....Prof Lorna Fraser
.....

LIST of CONTENTS

KEY STUDY CONTACTS

Insert full details of the key study contacts including the following

Chief Investigator	Prof Lorna Fraser lorna.fraser@york.ac.uk
Study Co-ordinator	Dr George Peat George.peat@york.ac.uk
Sponsor	The protocol describes a research network and not a research study, therefore whilst the University of York will act as the sponsor, no research is being undertaken.
Joint-sponsor(s)/co-sponsor(s)	N/A
Funder(s)	NIHR Palliative and End of Life Care research partnerships
Key Protocol Contributors	Prof Lorna Fraser

STUDY SUMMARY

It may be useful to include a brief synopsis of the study for quick reference. Complete information and, if required, add additional rows.

Study Title	Developing the UK **Co**llaborative **P**aediatric **P**alliative c**A**re **R**esearch (**CoPPAR**) Network
Internal ref. no. (or short title)	CoPPAR
Study Design	To develop a collaborative UK wide paediatric palliative care research network that will deliver national high-quality research studies, education and build research capacity
Study Participants/Sites	• Martin House Children's Hospice – West Yorkshire - existing relationship as Martin House Research Centre (www.york.ac.uk/mhrc) • Royal Hospital for Glasgow Paediatric Palliative Care team – West of Scotland • St Oswalds Hospice – North East of England • East Anglia Children's Hospices – East of England • Noah's Ark Children's Hospice - North and Central London and Hertsmere. • Helen and Douglas House - Oxfordshire • Shooting Star Children's Hospices – Surrey and London • Children's Hospices South West – Devon, Somerset and Cornwall

Planned Size of Sample (if applicable)	N/A
Follow up duration (if applicable)	N/A
Planned Study Period	Jan 22-June 23
Research Question/Aim(s)	Aim: to develop a collaborative UK wide paediatric palliative care research network that will deliver national high-quality research studies, education and build research capacity Objectives: 1. to work with seven paediatric palliative care sites (hospice and hospital based) to develop research readiness using methods that can be scaled up to the other hospices and NHS paediatric palliative care sites 2. to deliver a series of educational webinars on the key components of research activity 3. to set up process by which those developing and delivering research studies can access a network of PPI partners 4. to offer mentor opportunities for paediatric palliative care staff who are interested in developing a research career to apply for fellowships including the NIHR predoctoral or doctoral awards. 5. to develop guidance on the appropriate methods to undertake research in palliative and end of life care in children. 6. to develop a minimum of two bids for stage 2 of the NIHR Commissioned call on palliative and end of life care.

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**

	NIHR Palliative and End of Life Care research partnerships Funding: £96,673.34

STUDY MANAGEMENT COMMITEES/GROUPS & INDIVIDUALS

The CoPPAR network is supported by a strong, multidisciplinary team of academics and clinicians who have extensive experience in the methodology and topic area.

Professor Lorna Fraser will lead this study. Lorna has a background in clinical paediatrics and is the Director of the Martin House Research Centre (www.york.ac.uk/mhrc) which undertakes research in children with life-limiting conditions and medical complexity. She has expertise in cohort studies and extensive experience of accessing routinely collected healthcare data, including HES and ONS data and is a member and the HRA Confidentiality Advisory Group. She currently holds an NIHR Career Development Fellowship award.

Professor Fliss Murtagh is a Professor of Palliative Care at Hull York Medical School, Associate Director of the Wolfson Palliative Care Research Centre and an NIHR Senior Investigator. She has experience of developing outcome measures; psychometrics; outcomes repository development; research methods training and networking.

Professor Richard Harding is the Herbert Dunhill Professor of Palliative Care & Rehabilitation at the Cicely Saunders Institute in London and the PI on the Children's Palliative Care Outcome Scale study.

Dr Lucy Zeigler is an Associate Professor in Palliative Care and holds a Yorkshire Cancer Research Academic Fellowship. Lucy has a particular interest in palliative care for older teenagers and young adults.

Professor Wei Gao is a Professor of Statistics and Epidemiology at the Cicely Saunders Institute, King's College London. She has over 20 years of experience in developing and delivering various routine data research projects, with a focus on palliative and end of life care in recent 10 years. She has led the delivery of a series of routine data-based national projects including a study of the place of death in children and young people. More recently, she has been expanding her big data expertise to natural language processing of unstructured data (e.g. electronic health records) and other applications of artificial intelligence.

Prof Ian Wong is Professor of Pharmacy Practice / Medicines Use and is an expert in medicines for children and Pharmacoepidemiology and Drug Safety. He is the Chief Investigator on the NIHR

funded Feasibility of a randomised clinical trial of transmucosal diamorphine vs oral morphine for breakthrough pain in children and young people with life-limiting conditions (DIPPER).

Professor Catherine Hewitt is a Professor of Trials and statistics and is the deputy chair of the NIHR HTA commissioned board and is an expert in evaluation of complex interventions.

Dr Anna-Karenia Anderson is a consultant in Paediatric Palliative Medicine and the current Chair of the APPM.

Dr Emily Harrop is a consultant in Paediatric Palliative Medicine and Medical Director of Helen & Douglas House. She is the current research lead for the APPM and co-chairs the Together for Short Lives / APPM Joint Research Group. She was deputy-chair of the NICE guideline development group for the End of Life for Infants, Children & Young People (NG61, 2016) and co-chaired the WHO Guidance on Chronic Pain in Children (2020).

SHORT TITLE/ACRONYM CoPPAR

STUDY FLOW CHART

YEAR 1	Jan-22	Feb-22	Mar-22	Apr-22	May-22	Jun-22	Jul-22	Aug-22	Sep-22	Oct-22	Nov-22	Dec-22
Part One - development of the CoPPaR network												
Initiation meeting with all partners												
Educational webinars												
PPI activities												
Expert meeting - MORECARE												
Mentoring												
Part 2 - development of grant applications												
Communication/Dissemination Activities												
Blog												
Email updates												
Twitter updates												
Governance												
SMT meeting												
Milestones												
CoPPaR Website live												
Toolkit published												
Grant applications submitted												
TFSL Conference												
Progress Report												
YEAR 2	**Jan-23**	**Feb-23**	**Mar-23**	**Apr-23**	**May-23**	**Jun-23**						
Part One - development of the CoPPaR network												
Initiation meeting with all partners												
Educational webinars												
PPI activities												
Survey Development/Piloting												
Expert meeting - MORECARE												
Mentoring												
Part 2 - development of grant applications												
Communication/Dissemination Activities												
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Email updates												
Twitter updates												
Governance												
SMT meeting												
Milestones												
CoPPaR Website live												
Toolkit published												
Grant applications submitted												
MORECARE paper submitted												
Final Report												

SHORT TITLE/ACRONYM CoPPAR

STUDY PROTOCOL

Developing the UK **Co**llaborative **P**aediatric **P**alliative c**A**re **R**esearch (**CoPPAR**) Network

1 BACKGROUND & RATIONALE

There are growing numbers of children and young people living with conditions which may threaten or shorten their lives (life-limiting)(1) and although child mortality has decreased over the last few decades, around 4500 infants, children and young people (0- 19 years) die in the UK every year (2).

Palliative care services for children and young people in the UK have developed locally with heavy reliance on individual clinician and third sector organisations e.g. children's hospices (3). The first children's hospice in the UK opened nearly 40 years ago and since then there have been another 52 hospices and ~10 hospital based paediatric palliative care teams working in the UK. As a result of the lack of a national strategy for the development of these services, the delivery of palliative care for children is 'inconsistent and incoherent' (4) and there is evidence of inequalities in access to this care depending upon where you live, age, diagnoses, ethnicity and socioeconomic status (5-8).

The increase in clinical provision has yet to be mirrored in the research evidence base underpinning this care. For example, the NICE guideline on the end of life care for infants, children and young people (9) includes a comprehensive list of 143 recommendations. However, the quality of evidence on which most of these recommendations is made is low or very low.

Because the numbers of children and young people at any one site or with any one condition are relatively small, paediatric palliative care research is very much in need of a UK-wide research network. Such a network would be transformative and put the UK at the forefront of PPC research internationally. This network would achieve this through developing and coordinating use of valid outcome measures; through supporting research-naïve clinical sites; through pooling and sharing research expertise.

There is an urgent need to increase the quality and quantity of research in paediatric palliative care and to do this we need to work in partnership with the paediatric palliative care (PPC) sector to increase the research capacity and delivery.

3 THEORETICAL FRAMEWORK

N/A

4 RESEARCH QUESTION/AIM(S)

To develop a collaborative UK wide paediatric palliative care research network that will deliver national high-quality research studies, education and build research capacity.

4.1 Objectives

1. to work with seven paediatric palliative care sites (hospice and hospital based) to develop research readiness using methods that can be scaled up to the other hospices and NHS paediatric palliative care sites
2. to deliver a series of educational webinars on the key components of research activity
3. to set up process by which those developing and delivering research studies can access a network of PPI partners
4. to offer mentor opportunities for paediatric palliative care staff who are interested in developing a research career to apply for fellowships including the NIHR predoctoral or doctoral awards.
5. to develop guidance on the appropriate methods to undertake research in palliative and end of life care in children.
6. to develop a minimum of two bids for stage 2 of the NIHR Commissioned call on palliative and end of life care.

4.2 Outcome/s

1. Creation of the CoPPAR network
2. Delivery of the webinar series
3. Development of the CoPPAR website (hosted by Together For Short Lives)
4. Submission of three grant applications to the NIHR commissioned call

5 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYIS

Part One: To develop a research ready network building on an existing partnership with Martin House Hospice (*objectives 1-5)*

Working closely with seven paediatric palliative care clinical services we will develop the CoPPAR network which will be a UK wide collaborative research network. All the information about the CoPPAR network, partners and resources will be available on the Together for Short Lives website including information on how to access the educational resources, contact potential research sites and research teams *(objective 1).* The vision is that CoPPAR will become the single point of information for all PPC research across the UK that can be accessed by researchers, clinicians, parents and young people and policy makers to enable more effective and efficient delivery of research in the sector. This would ensure that every child and family has the opportunity to participate in research.

We will provide financial support to seven PPC clinical services (six hospices, one NHS trust) to buy out time from an individual in each service to work with the academic team. This partnership also includes the two national organisations for paediatric palliative care in the UK; Together for Short Lives (https://www.togetherforshortlives.org.uk) and the Association for Paediatric Palliative Medicine (https://www.appm.org.uk)(*objective 1).* We have overrepresented hospice organisations due to the additional challenges of undertaking and delivering research in a non-NHS setting without dedicated Rand D departments.

Given the extremely low recruitment to national studies in PPC (often only 1 or 2 studies on the CRN portfolio each year), we have identified seven services who are keen to develop their research activity and expertise. They are from a variety of geographical regions, representing different models of care and levels of integration with the NHS.

- Martin House Children's Hospice – West Yorkshire - existing relationship as Martin House Research Centre (www.york.ac.uk/mhrc)
- Royal Hospital for Glasgow Paediatric Palliative Care team – West of Scotland
- St Oswalds Hospice – North East of England
- East Anglia Children's Hospices – East of England
- Noah's Ark Children's Hospice - North and Central London and Hertsmere.
- Helen and Douglas House - Oxfordshire
- Shooting Star Children's Hospices – Surrey and London
- Children's Hospices South West – Devon, Somerset and Cornwall

Working with these organisations we will develop the content of the research toolkit and the series of educational webinars. The toolkit will contain the key information about research governance and delivery within a study site. The educational webinars will be delivered every 6-8 weeks and will be accessible to all staff from all of the children's hospices (n=53 hospices) and NHS paediatric palliative care teams (n~ 10 teams) (*objective 2).* We will work with our partners to develop the content of these webinars but likely topics will include:

1. Effective Patient, parent and public involvement and engagement
2. Research governance
3. Working with your Clinical Research Network
4. Working with academic partners
5. Implementation of research into practice

We will also host a half day event at the national Together for Short Lives conference in Sept 2022.

Good quality and flexible patient public involvement is key to successful delivery of research in paediatric palliative care *(objective 3).* We will work with an existing PPI group – the Family Advisory Board and Young Person's group of the Martin House Research Centre and our seven PPC partner sites and national organisations to increase our number of PPI partners and the diversity within this group. Working with the PPI groups we will develop an approach that enables other researchers to be able to ask for input from the PPI network but also enables the PPI members to be aware of ongoing and upcoming research studies that they may wish to be involved in.

Through the CoPPAR network we will also be able to offer mentoring/support for clinical staff who wish to undertake more formal research training in the form of applying for an NIHR predoctoral or doctoral award *(objective 4).* The research team have experience of being NIHR fellowship awardees and supervising/mentoring a number of successful candidates.

Given some of the challenges of undertaking research with a relatively small population of children and young people with deteriorating health conditions, we will work together with our academic experts to make methodological recommendations including alternatives to standard randomised controlled trials.

The output of these discussions will include an addition to the adult palliative and end of life care methodological recommendations – MORECARE.(10)*(objective 5).*

A key activity within the CoPPAR network will be to develop the grant applications for stage 2 of the NIHR (see next section)(objective 6).

Part 2: Development of Proposed Bids for stage 2 of the call (*objective 6)*

During the 18 months of the CoPPAR network development we will work with our partners to develop a minimum of two grant applications for stage 2 of the NIHR commissioned call. The main topic areas for these bids are outlined below but there will also be scope for new topics to be identified by the partner organisations. All bids submitted from the CoPPAR network will include staff from the partner organisations and PPI partners as co-investigators.

Working closely with our clinical co-app (AA, EH) and partner organisations, these bids will utilise the methodological expertise of the academic team; use of routine data (LF, GW), outcome measurement (FM, RH), evaluation of complex interventions (CH, LZ, FM) and pharmacological studies (IW).

Topic A- Prospective Cohort study and person centred outcomes

Although there are some published studies on the symptom profile of children receiving palliative care, they tend to be from the US (11-13), in cancer populations (13-15) or be dated (16). There is little evidence on the prevalence, trajectory, management and outcomes of children with complex medical conditions receiving palliative and end of life care in the UK. Given the changing population of children receiving palliative care with more use of medical technologies, understanding the symptom profile, needs and outcomes of this population are key to develop and study interventions to improve care (see Topic B).

We will develop a proposal to create a cohort study of children receiving palliative care in the UK to understand their symptom profile, management and outcomes. This will build on a current EU funded study (led by co-applicant RH) which is developing and validating the Children's Palliative care Outcome Scale (C-POS). CPOS is a person-centred outcome measure for children, young people and their families affected by life-limiting & life-threatening conditions. An existing study is already funded to pioneer a Palliative care Outcomes Repository for adult palliative care (led by Murtagh). We will combine expertise and experience from both these studies, and draw on the expertise and resources of the Data Safe Haven available at Hull Health Trials Unit, to develop and submit a bid for this cohort study, using C-POS as the primary outcome. This will enable us to build evidence on the prevalence, trajectory, management and outcomes of children receiving palliative and end of life care in the UK. We will use this as the foundation for an Outcomes Repository for Paediatric Palliative Care; encouraging and supporting use of outcome measures within clinical practice; using the **CoPPAR** Network to share learning and best practice in use of C-POS and other outcomes for quality improvement; and developing further research into interventions and best models of care. This will maximise the value of clinically-collected and research outcomes data; which is critically important given the relatively small numbers of children and young people affected at individual sites. Using person-level outcomes is shown to improve care and is paramount for building evidence of effectiveness and cost-effectiveness of

interventions. We will also liaise with the team and NHS England and Improvement, who are developing a national Dashboard of metrics in relation to children and young people receiving palliative care (chair of steering group: Murtagh, member: Fraser).

Topic B -Pharmacological management of distressing symptoms research in paediatric palliative care

The management of distressing symptoms is a critical component of effective high-quality care for CYP with palliative care needs (3, 9, 17, 18). Effective management may enhance quality of life and minimise suffering and distress in CYP (19). It may also limit the detrimental impact on their caregiver's health (20). Towards the end-of-life CYP experience multiple symptoms (11-16) but the evidence-base on the effectiveness of pharmacological interventions is very limited and high quality research in this area is needed urgently as highlighted by key organisations including NICE (9) and the World Health Organisation (18).

Pain management, especially the use of opioids and transmucosal delivery routes (21-24), is important but there are also other common clinical challenges, especially in the end of life phase, including the management of nausea, vomiting (21, 22), agitation and seizures, that urgently require investigation and evaluation across care settings. The NIHR has already funded the DIPPER project as the feasibility study of RCT for breakthrough pain (PB-PG-0317-20036). We aim to develop the full proposal using CoPPAR as the major clinical sites for the future RCT.

Whilst standard randomised controlled trials may be possible for some symptom related research in paediatric palliative care, it may be that for some research questions alternative approaches such as more pragmatic trials or augmentation of study data with routinely collected data sources will be required. We will work with the York Trials Unit (deputy director co-app CH) who are experienced in the evaluation of complex interventions across multiple settings. We will also explore the use of routinely collected data; advances in artificial intelligence techniques such as natural language processing (NLP) (25) can enhance the utility of medical records by utilising the free text components whilst maintaining patient confidentiality. We will use real-time and real-world routine data (e.g. electronic health records) to provide a contemporary understanding about the symptom epidemiology among children and young people with life-limiting/life-threatening conditions, current management and care strategies, and their relationship to outcomes. Other than structured data, we will also use the unstructured data facilitated by an NLP processing system called CogStack.(26) The CogStack is a set of tools developed for information retrieval from clinical notes in EHRs. It has been successfully applied to extract clinically relevant data of research quality from EHRs including symptoms, diagnosis and medications.(27-29) The CogStack is open-source and lightweight, which can be easily deployed to resource constrained environments

6 STUDY SETTING

A research network initially between 7 hospices and 1 NHS site as outlined, with resources and related content hosted on the Together for Short Lives website.

7 SAMPLE AND RECRUITMENT

N/A.

7.1 Eligibility Criteria

N/A

7.1.1 Inclusion criteria

N/A

7.1.2 Exclusion criteria

N/A

7.2 Sampling

N/A

7.2.1 Size of sample

N/A

7.2.2 Sampling technique

N/A

7.3 Recruitment

N/A

7.3.1 Sample identification

N/A

7.3.2 Consent

N/A

8 ETHICAL AND REGULATORY CONSIDERATIONS

As no primary research will be undertaken as part of this partnership, research ethics committee approval is not required for the development of this network. Ethical standards and approvals will be part of the educational webinars and the appropriate ethical considerations will be undertaken for the grant proposals for part 2 of this commissioned call.

8.1 Assessment and management of risk

N/A

8.2 Research Ethics Committee (REC) and other Regulatory review & reports

N/A

Amendments

N/A

8.4 Patient & Public Involvement

This application addresses a request from the Family Advisory Board of the Martin House Research Centre – this groups has approx. 15 parents of children with life-limiting or life-threatening conditions or whose child has died. The parents were very keen to have a mechanism by which more parents can

get involved in PPI but also that there was a mechanism by which they could easily find out about/get involved with studies going on in other research groups.

Please describe the ways in which patients and the public will be actively involved in the proposed research, including any training and support provided:

We are committed to meaningful PPI and one of the aims of CoPPAR network is to develop an inclusive national network of PPI groups in PPC research. We have assessed our plans for PPI in this application against the UK Standards for Public Involvement and PPI partners will be involved in all activities of the network. The plans do need to be flexible as the lives of parents, children and young people can be very uncertain.

Inclusive opportunities

We will build on existing highly successful and active PPI groups (Family Advisory Board and Young Persons Group) and extend our membership to increase diversity and reach. We will seek to ensure children, young people and families (and others who represent them) involved in PPI work represent the diversity of experience in children and young people with life-limiting conditions and their families. We will be flexible to enable participation virtually or face to face, in groups or individually

Working together

The PPI partners will be central to the CoPPAR network. They will participate in all activities of the CoPPAR network including the educational seminars with our FAB group members leading the PPI webinar, supported by the research team.

Support and Learning

We will build PPI capacity through our current FAB members who will produce short video accounts about their involvement in PPI in PPC. We will share these with our partner organisations to demonstrate the critical role of PPI to young people and families and in doing so hopefully engage more PPI partners in the network. Training on PPI for our partners and PPI members will be part of the educational seminars.

Communications

All communication about the CoPPAR network will be co-produced with our PPI partners – they will advise on the design and accessibility of the website, Plain English summaries of any outputs. The NIHR funding statement will be included in all cross-programme communications.

Impact

We will use a PPI log to demonstrate the impact of PPI on the work of the CoPPAR network.

Governance

The development of the grant applications will also be in partnership with the PPI groups. They will input on the topic area, study design and recruitment methods.

There will be an opportunity for interested PPI members to be a co-applicant on the stage 2 grant applications submitted in 2022.

The CoPPAR application will sit within the governance arrangements of the Marin House Research Centre where we have PPI representation on our advisory committee as well as our Family Advisory Board and Young persons group. We will ensure those involved in PPI work will be able to see and understand how decisions are made.

8.5 Protocol compliance

8.6 Data protection and patient confidentiality

N/A

8.7 Indemnity

N/A

8.8 Access to the final study dataset

N/A

9 DISSEMINIATION POLICY

9.1 Dissemination policy

What will you produce

Research network – hosted on TFSL website with a single point of contact for researchers, parents, young people and clinicians.

- Educational materials – recorded webinars
- Research Toolkit
- Contact
- MORECARE children guidance
- At least two grant applications for submission to stage 2 of the NIHR commissioned call.

How will you inform and engage patients/service users, carers, NHS and the wider population about your work?

We will work closely with our national partner organisations, Together for Short Lives and the Association for Paediatric Palliative Medicine to utilise existing communication networks, website blogs and social media to promote the CoPPAR network. The applicants all have links with key policy makers/influencers including NHS England and the Royal College of Paediatrics and Child Health.

How will your outputs enter our health and care system or society as a whole?

We will work closely with our national partner organisations, Together for Short Lives and the Association for Paediatric Palliative Medicine to utilise existing communication networks (including the TFSL/APPM national research group and the NIHR CSG for pain and palliative care), website blogs and social media to promote the CoPPAR network and the associated outputs.

The following wording will be included in all cross-programme communications where the project has input or influence:

'This project is funded by the National Institute for Health Research (NIHR) Palliative and End of Life Care research partnerships (NIHR 135304). 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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11. APPENDICIES

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