FULL/LONG TITLE OF THE STUDY

Building multi professional UK partnerships and networks to improve access to palliative care for people experiencing homelessness

SHORT STUDY TITLE / ACRONYM

Palliative care and homelessness network

PROTOCOL VERSION NUMBER AND DATE

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KEY STUDY CONTACTS

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STUDY SUMMARY

Study Title	Building multi professional UK partnerships and networks to improve access to palliative care for people experiencing homelessness
Internal ref. no. (or short title)	Palliative care and homelessness network
Study Design	Network development and qualitative study
Study Participants	Health and social care professionals Staff working in homeless services People with lived experience of homelessness
Planned Size of Sample (if applicable)	In qualitative studies Staff: approximately 30 People with lived experience of homelessness: approximately 15
Planned Study Period	18 months
Research Question/Aim(s)	• To create a **sustainable partnership** of practitioners, researchers and people with lived experience of homelessness to lead and drive enthusiasm for

	developing research, **promote shared learning and a multidisciplinary approach** to the care received by those experiencing homelessness towards the end of their lives. • To **understand, build and expand research capacity and the scope of research** in palliative care and homelessness by involving both those who are highly experienced in palliative care and/or homelessness work but have limited research and those with the opposite skill set • To identify, from the network, **research priorities** for this area • To **develop a funding proposal** for the NIHR Palliative and end of life care stage 2 call the focus for which is coproduced through partnership and network working.

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	Project funding
Marie Curie	Support with project ECHO

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITEES/GROUPS & INDIVIDUALS

- **Core partnership group**

A partnership of people currently leading research and practice in palliative care and homelessness has been formed to guide this project. This includes both researchers, clinicians and frontline homelessness staff. This group will meet regularly to review the progress of the project and provide a range of perspectives on the findings generated.

- **Involvement of people with lived experience of homelessness**

The involvement of people with lived experience of homelessness will be supported via Groundswell and Pathway. Workshops will be held to ensure that a range of opportunities for involvement in the project are explored and offered to people experiencing homelessness.

STUDY FLOW CHART

1. Core Partnership Group (CPG) developed – ongoing/month 1

for Part One bid, consisting of key researchers and practitioners working in the field of palliative care and homelessness

Group represents both high and low NIHR recruiting areas

2. Broader network of practitioners, researchers and experts by experience
Months 2-18

Aims to: share learning and expertise; map research & practice activity; buddy people with experience and less experienced of research/practice; identify and prioritise key research questions

Participants identified by core partnership group (CPG) and online engagement events run by CPG and advertised by partners (month 2)

Network is created and facilitated by **CPG** using Project ECHO
(meetings begin month 3-4)

Workshops with people experiencing homelessness to feed into network, for priority setting and research question refinement
(months 3,9,12)

Small qualitative research study undertaken within the broader network to establish ‘best practice guidance’ for the involvement of people with experience of homelessness in research to inform research proposal
(months 12-18)

3. Development of Research Proposal (Part Two of the call)

Months 12-18

Research proposal development co-production is co-ordinated by **CPG**

Evaluate network

Produce output to share key learnings from network development for other disparate groups

STUDY PROTOCOL

Building multi professional UK partnerships and networks to improve access to palliative care for people experiencing homelessness

1 BACKGROUND

People experiencing homelessness have a high rate of multi-morbidity, frailty and age related conditions at a young age(1, 2) and are at high risk of dying young(3, 4). The lead applicant's previous work(5, 6), found that many people with significant physical and mental health problems, often complicated by substance misuse, are living in homeless hostels. Despite the complexity of need they rarely have access to palliative care support (7-9) .This lack of palliative care support and appropriate places of care means burdens associated with supporting very unwell homeless people with complex problems, often fall on frontline homelessness staff such as outreach or hostel staff, with hospitals being used in place of more appropriate community support. Due to the complexity of need of this population, no one professional group can provide all of the support necessary. In order for people with advanced ill health to receive high quality care there needs to be a range of professionals involved including palliative care, primary care, mental health, homelessness sector including housing and temporary accommodation services and third sector, addiction services, bereavement, social work and social care(10). In this project, when we talk about multi-professional care, this is the range of professionals we are describing. This multi-professional support is rare.

2 RATIONALE

There have been concerted efforts by governments, charities, hospices, NHS bodies and research institutions to understand these inequalities, and consider how to level them. There are pockets of clinical and research activity(11-19) across the UK aimed at improving palliative care access for this group yet, mirroring the disjointed nature of services, there is not a single network or mechanism through which interested and experienced people can connect, share new ideas and best practice, generate research questions or support in each other despite working in complex and challenging situations.

Central to the network that will be developed in this project is the inclusion of people with lived experience of homelessness, alongside professionals from a range of backgrounds, who may not previously have been engaged with research in the field of homelessness or palliative care. Some evidence exists regarding strategies for coproduction, needs assessment and involvement with people experiencing homelessness in research more generally, but none that relates specifically to palliative and end of life care(20-27).

The core project group are researchers and practitioners leading the field of homelessness, inclusion health and palliative and end of life through our internationally recognised research and practice. We have a proven track record of generating and using new findings to support evidence-based policy and reduce inequity in palliative care access. We represent leading palliative care, inclusion health and homelessness organisations and academic departments and people with lived experience of homelessness. This, together with our experience and expertise will enable us to bring cohesion, mutual learning, collegiate support and collective power to an important, but currently disconnected, area of research and practice, to identify priorities for future research and guidance for other researchers wishing to explore this area regarding the involvement of people with lived experience.

3 RESEARCH QUESTION/AIM(S)

This 18-month project has the following aims:

- To create a **sustainable partnership** of practitioners, researchers and people with lived experience of homelessness to lead and drive enthusiasm for developing research, **promote shared learning and a multidisciplinary approach** to the care received by those experiencing homelessness towards the end of their lives. Many of whom may not currently be research active.
- To **understand, build and expand research capacity and the scope of research** in palliative care and homelessness by involving both those who are highly experienced in palliative care and/or homelessness work but have limited research and those with the opposite skill set
- To identify, from the network, **research priorities** for this area
- To **facilitate coproduction** of research by involving people with lived experience of homelessness throughout.
- To **develop a funding proposal** for the NIHR Palliative and end of life care stage 2 call the focus for which is coproduced through partnership and network working

3.1 **OBJECTIVES**

- To create a partnership of people currently leading research and practice in palliative care and homelessness and those with lived experience of homelessness (a Core Partnership Group - CPG)
- To identify through this partnership people from a range of professional groups, and with lived experience of homelessness with interest in, or whose work touches palliative care for people experiencing homelessness across the UK.
- To connect these individuals and groups in a national level network, using Project ECHO
- Through the network, map current research and best practice via interviews with key local stakeholders and network meetings.
- Within the network, explore the research needs/experience of individuals and organisations (such as clinicians, social workers, frontline homelessness staff, people with lived experience) who are interested in being co-applicants on a research bid.
- Match individuals and organisations in terms of research skills and connections, with suitable academic or practice partners, where appropriate to support capacity building (such as through buddying), focusing on areas of low research activity.
- To produce guidance to support the involvement of people with lived experience of homelessness in research around palliative and end of life care via a small qualitative study, conducted with the network's support.
- To facilitate peer led workshops to ensure that people experiencing homelessness are involved in the network and its outcomes.
- To identify research priorities in this field
- To explore how existing NIHR infrastructure could be used to support the proposed community based coproduced research.
- To share learning from the development of the network that may be applicable to other similar dispersed stakeholder situations, to enable wider system-learning.
- To develop a coproduced research proposal for the stage 2 NIHR call, exploring a research question identified by the network.

4.2 Outcomes

a) Establishing an echo network of diverse participants
b) Mapping current research and clinical activity around palliative care and homelessness across the UK
c) Developing guidance for the involvement of people with lived experience of homelessness in palliative and end of life care research

5 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYIS

This innovative, collaborative project aims to pull together the diverse field of research and practice surrounding access to palliative care among people affected by homelessness. The multi-professional and multi-site nature of this collaboration will generate unique insights, connections and opportunities for developing co-produced, impactful research and policy recommendations to improve care for a marginalised group in our society.

Developing the network

Marie Curie, alongside the CPG (core partnership group) will utilise Project ECHO (Extension for Community Healthcare Outcomes) methodology to deliver a nationwide ECHO network around palliative care and homelessness.

The following activities will be completed through the network over the course of this project:

- **Establishing an echo network of diverse participants**
- **Mapping current research and clinical activity around palliative care and homelessness across the UK**
- **Developing guidance for the involvement of people with lived experience of homelessness in palliative and end of life care research**

- **Establishing an echo network of diverse participants**

As the UK's leading provider of end of life care, Marie Curie wants to facilitate the sharing of knowledge between health and social care professionals through communities of practice that work together to improve end of life care. Marie Curie have the established infrastructure to facilitate the use of Project ECHO (Extension for Community Healthcare Outcomes) methodology to deliver a series of 'hubs' and 'networks' across the UK. Project ECHO (28) is known to produce positive impacts on professional outcomes such as participant knowledge, competence and confidence (29, 30).

The network will comprise of individuals from a range of professional backgrounds. In line with the NIHR overarching priority of transferring sustainable research capacity outside of the HEI sector and through the collaborative learning opportunities offered through our ECHO network, we intend to support those who have research interest, but no experience to develop and undertake research collaboratively. This empowerment of people with lived experience and other professionals will be crucial to the success of the network and we are keen that members from non-research backgrounds are not merely the operatives of academics. The ECHO methodology that we will use, ensures that all participants will be on an equal footing and be encouraged to share their ideas and experiences. We will use the contacts and mailing lists of partner organisations to disseminate the opportunity to join the network.

- **Mapping current research and clinical activity around palliative care and homelessness across the UK**

Both via the ECHO network and through interviews with key local stakeholders (identified through the network and interviewed by the research associate) we will map work that is both complete and in progress in this field. If possible, we will work with a creative communications/digital agency to develop and maintain a digital representation of work with this aim across the UK (both clinical and research focused). We will make this freely available online and it will become a directory of current and past research and practice in this area, split by geographic region to facilitate connections between those working in the field already, and those that wish to do so.

This mapping will include clinical and research activity and will also help us to further ascertain where support is needed to strengthen the links between clinical practice and research.

- **Developing guidance for how to involve people with lived experience of homelessness in palliative care research**

We intend to draw upon the experiences of the network and our own experiences from previous work in this field to coproduce guidance for other researchers wishing to involve people with lived experience of homelessness, and those supporting them, in palliative care and homelessness research. A small qualitative research study will be undertaken by the research associate with support from Groundswell. Semi-structured interviews will be undertaken with up to 15 members of the network, including those with lived experience of homelessness, to explore what has worked well in terms of involvement in palliative and end of life care research, and times when there has been less success. Interviews will be recorded and transcribed and then analysed using thematic analysis(31) to identify key barriers and facilitators to successful involvement, Together, the network will coproduce 'best-practice' and publish guidance for involving people with lived experience of homelessness in palliative and end of life care research, based on key themes identified. We share this guidance widely, including within the toolkit that the lead applicant has previously developed (www.homelesspalliativecare.com) and via formal and informal channels (i.e. peer reviewed journals, blogs and via social media and partner networks and websites).

The following qualitative methods will be used in this project:

- **Observation**- Discussion that take place within the ECHO sessions will be observed. Information from these observations will assist in the mapping of research and clinical activity in the field of palliative care and homelessness. Issues, concerns, challenges and successes noted by attendees will also be recorded as this may assist in the identification of future research priorities in this area.
- **In-Depth Interviews**- Members of the echo network, will be invited to participate in interviews to provide more details about the activity they are currently undertaking, whether they have involved people with lived experience in the design of their current projects (whether research or clinical) and any challenges or benefits associated with this. These interviews will be audio recorded, transcribed verbatim and analysed using thematic analysis by the project's research associate. Nvivo software will be used to facilitate this analysis. Initial themes will be discussed with the core partnership group and the group for people with lived experience of homelessness.
- **Focus groups** – focus groups with people experiencing homelessness will be undertaken by partners at Groundswell across the project to explore views on challenges and issues identified via ECHO network meetings and network member interviews. Further focus groups with people with lived experience of homelessness will also be undertaken by grounds well to contribute to the prioritization of research priorities and the development of guidance for involving people with lived experience of homelessness in research. These focus groups will be audio recorded and transcribed verbatim. Pseudonyms will be used.
- **Workshops** – prioritization workshops, led by Briony Hudson, Caroline Shulman and Kate Flemming will also be held. As with other qualitative data these will be audio recorded, transcribed verbatim.

6 SAMPLE AND RECRUITMENT

6.1 Eligibility Criteria

6.1.1 Inclusion criteria

Anyone with an interest in palliative care for people experiencing homelessness across the UK would be welcome to join the network. In depth interviews will be undertaken with professionals that identify themselves as currently working on a project in the field of palliative care and homelessness (research or clinical practice).

Eligibility for inclusion in focus groups include; currently experiencing, or previous experience of any form of homelessness (including staying in a hostel, temporary or unsuitable accommodation, sofa surfing, sleeping rough). Ability to provide informed consent for the study.

6.2 Sampling

The core partnership group (CPG) are from diverse locations across the UK, North and East London, Manchester, Cheshire, York and Hull. They include individuals who support people in geographical areas that have high needs in terms of support and inequity but limited research involvement. **The CGP will identify and recruit potential network members and local leads using the social networks and connections of the co-applicants and partner organisations.** Each member of the CPG will act as a local lead and be responsible for identifying people, research and practices within their local area that could bring their expertise and local connections to the partnership and network, particularly those from sectors that are not currently research active, including clinicians working directly people experiencing homeless, social workers, representatives and commissioners from local authorities and people with lived experience of homelessness.

Marie Curie, Pathway, the Faculty of Homeless and Inclusion Health, the Queen's Nursing Institute and The London Network of Nurses and Midwives and Groundswell are all experienced in starting, facilitating and growing networks, and through these networks will support us to identify interested participants for this network. Groundswell are experienced in running workshops bringing people with lived experience together with health care providers and in developing peer led research and will use these connections to support the network. People with lived experience of homelessness will be recruited through existing connections of Groundswell and Pathway.

6.2.1 Size of sample

We intend to undertake up to 15 individual interviews with members of the network to assist in the mapping of research and clinical activity in the field of palliative care and homelessness.

We will hold up to 3 focus groups with people experiencing homelessness ,with up to 6 participants in each.

6.3 Recruitment

6.3.1 Sample identification

Health, social care and homelessness staff: these will be recruited via the developed network

People with experience of homelessness: recruited via existing connections of Groundswell and Pathway, who will undertake the focus groups. People experiencing homelessness will be provided with a £10 supermarket voucher for completion of a focus group.

6.3.2 Consent

Health, social care and homelessness professionals will provide consent through UCL's recap e-consenting process. They will be provided with a participant information sheet at least 24 hours before the interview takes place and they will have the opportunity to ask questions prior to the interview.

People experiencing homelessness will provide verbal consent, which will be witness by the focus group facilitator. Groundswell and Pathway are experienced in obtaining verbal consent for research from people with lived experience of homeless. Information provided on a written information sheet about research participation will be discussed with potential participants before consent is sought. Capacity will be explored by asking potential participants to report back the aims of the study, what participation involves and what that may mean for them.

7 ETHICAL AND REGULATORY CONSIDERATIONS

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

Ethical approval for the qualitative aspects of this project will be sought from the UCL research ethics committee.

Regulatory Review & Compliance

Before participants are enrolled into the study, the Chief Investigator will ensure that appropriate approvals from participating organisations are in place.

Amendments

If any amendments are required, an amendment request will be submitted to the UCL research ethics review board. The Chief Investigator will be responsible for this process. The amendment version number of all study documents will be updated should any new documentation be required.

7.4 Patient & Public Involvement

The following options for involvement have been selected after engaging with existing literature around involving people with lived experience of homelessness, and consultation with people with lived experience of homelessness.

- Attending network meetings
- Meeting with the CPG to share thoughts about the aims or potential impact of a network, to be fed into the design of the network and shared with network members where appropriate
- Reviewing and contributing to suggested agendas for network meetings, helping to prioritise topics for discussion within network sessions
- Supporting the development of guidance for researchers looking to involve people with lived experience of homelessness in their palliative or end of life care research.
- Attending workshops run by Groundswell in which research prioritisation, research questions and topics of relevance to the network will be explored with people with lived experience of homelessness
- Being a co-applicant on the funding bid the network will develop for the stage 2 NIHR call

To facilitate PPI engagement with the network we will provide optional and informal training sessions to our PPI representatives to help them feel more comfortable with some of the research related language that may be used during network meetings, whilst also ensuring that any and all technical terms used in study documents or during meetings are explained

8 DISSEMINIATION POLICY

8.1 Dissemination policy

On completion of the study, the data will be analysed and a Final Study Report prepared, in addition to a report outlining the research priorities identified within the project, guidance for researchers wishing to involve people with lived experience of homelessness in palliative and end of life care research and an application for further NIHR funding.

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10 Appendix – Amendment History

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