



Research Article

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

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Abstract

Background: People experiencing homelessness have high rates of multi-morbidity and age-related conditions at a young age. Despite having high support needs, they have disparately low access to palliative care services and often die at a young age. To facilitate access to support for this group towards the end of life, a multi-professional approach should be taken. Over recent years, clinical and research activities have begun to address this issue. However, until now, there has been no centralised United Kingdom-based group to facilitate collaboration and shared learning.

Aim: To build multi-professional partnerships across the United Kingdom to promote shared learning and a multidisciplinary approach to supporting people experiencing homelessness who may be approaching the end of their lives.

Method: This project had three workstreams: (1) development of a Palliative Care and Homelessness Extensions of Community Healthcare Outcomes network; (2) a rapid review around involving people with experience of multiple exclusion in palliative and end-of-life care research; and (3) a qualitative study to identify recommendations for involving people with lived experience of homelessness in future palliative and end-of-life care research.

Results: Workstream 1: A National Palliative Care and Homelessness Extensions of Community Healthcare Outcomes (ECHO) network was successfully established in the UK, with 10 sessions running over 12 months. A total of 268 people registered to the network, with an average of 52 participants per session. Evaluation of the network illustrated positive experiences and appetite for continuation of the network. The majority of attendees surveyed (78%) agreed that the network had increased their awareness of complexities and challenges faced by people experiencing homelessness and 85% of respondents reported better connections with others who are interested in or are working in this field.

Workstream 2: A rapid review was conducted to summarise existing evidence and reflections on co-producing palliative care research with inclusion health groups, including people with lived experience of homelessness. Given the scarcity of existing research within this area, the review provided a starting point from which to explore the successes and challenges of co-research in this field. The review advocates for greater guidance around the involvement of people with lived experience of homelessness in palliative and end-of-life care research.

Workstream 3: Professionals with experience of involving people experiencing homelessness in their work were interviewed ($n = 16$), and focus groups were held with people with lived experience of homelessness ($n = 11$). Recommendations were co-developed to support researchers to involve people with lived experience of homelessness in their palliative and end-of-life care research – the TIFFIN recommendations.

Conclusion: This project has highlighted the appetite for collaboration and shared learning among professional groups around supporting people experiencing homelessness who have advanced ill health. The TIFFIN recommendations, developed through this grant promote, trauma-informed, meaningful involvement of people with lived experience of homelessness in palliative and end-of-life care research. Due to the success of the network, a second round of sessions ran from November 2023 to November 2024, with a third round of the network planned for Spring 2025.

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Introduction and 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} Previous research^{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, people experiencing homelessness rarely have access to palliative care support.⁷⁻⁹ This lack of support and appropriate places of care means burdens associated with supporting very unwell people with complex problems often fall on front-line 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 services (including housing and temporary accommodation services), third-sector organisations, addiction services, bereavement, social work and social care services.¹⁰ In this report, when we talk about multi-professional care, this is the range of professionals we are describing. Currently, in the UK, this multi-professional support is rare.

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 activity¹¹⁻¹⁸ 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 each other, while working in complex and challenging situations

In response, through this partnership grant we provided an opportunity for people with an interest in palliative and end-of-life care for people experiencing homelessness, and also research to come together.

We were also aware of the need to involve people with lived experience of homelessness in research in this field. We therefore reviewed existing knowledge¹⁹ and

generated new insights regarding how best to involve people with lived experience of homelessness in palliative and end-of-life care research, resulting in the TIFFIN recommendations²⁰ that future research could draw upon to support the involvement of people with lived experience of homelessness.

Aims and objectives

This innovative, collaborative project aimed to pull together the diverse field of research and practice surrounding access to palliative care among people affected by homelessness.

This project had 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 (workstream 1, 2 and 3).
- 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 (workstream 1, 2 and 3).
- To identify, from the network, *research priorities* for this area (workstream 1).
- To *facilitate coproduction* of research by involving people with lived experience of homelessness (workstream 2 and 3).
- To *develop a funding proposal* for the National Institute for Health and Care Research (NIHR) Palliative and end-of-life care stage 2 call. The focus for which would be informed through partnership and network working and priorities identified within the network.

To meet these aims, the project had three workstreams:

1. Development of a Palliative Care and Homelessness ECHO Network (Extension for Community Healthcare Outcomes).
2. A rapid review around involving people with experience of multiple exclusion in palliative and end-of-life care research as co-researchers.

3. A qualitative study to identify considerations and recommendations for involving people with lived experience of homelessness in future palliative and end-of-life care research.

Outcomes

Aim 1

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.

Development of a Palliative Care and Homelessness Network

An ECHO network (Extension for Community Healthcare Outcomes)²¹ is an internationally recognised collaborative model of health education and care management, designed to share knowledge, build relationships and work together. It is a form of global knowledge exchange, adopting an ethos of 'all teach, all learn'.²¹ Network sessions are hosted online and involve case presentations from a topic expert, followed by discussions to allow participants to work together to solve problems and learn from other professionals in their sector.

In partnership with Marie Curie, Pathway and The University of York, the National Palliative Care and Homelessness ECHO network was developed. The main objective of the network was to drive enthusiasm for research, promote shared learning and a multidisciplinary approach to care for people experiencing homelessness towards the end of life. The network also aimed to foster connections and collaborations between people of different professional backgrounds who are working in this field.

In the development of the network, a logic model was produced, based on our previous research in this field. We considered intended short-term outcomes of the network, which included attendees being more aware of complexity and challenges of supporting people experiencing homelessness with palliative care needs; identification and sharing of best practice; more collaboration between people of different professional backgrounds; and reduced potential for duplication of effort. Longer-term outcomes included improved care and support for people experiencing homelessness towards the end of life and development of research projects that are informed by people working in the field or with lived experience of homelessness with the potential to lead to impact.

Social media assets and a registration form which were shared via the channels of steering groups members and the organisations they represented. Existing mailing lists and newsletters aimed at inclusion health, palliative care and homelessness services were also utilised.

Ten network sessions were held over 12 months (allowing for Christmas and summer breaks). The sessions were facilitated by Professor Kate Flemming and each session lasted 1 hour. The sessions included case presentations from topic experts, who shared their experiences and challenges and encouraged discussion and support from other network members.

Evaluation of the network was carried out through two main streams: an evaluation survey circulated to all members after the final session in June 2023, and informal discussion and feedback during the final session.

A total of 268 people registered and consented to being a member of the network. Two hundred and eighteen people attended at least one session. The number of attendees at sessions ranged from 39 to 80. On average, 52 people attended each ECHO session. In terms of consistency of attendees, 44 people (20% of those that attended at least 1 session), attended 5 or more of the 10 sessions.

Different professional groups were represented among attendees including inclusion health and general nurses ($n = 77$, 35%), doctors ($n = 32$, 15%), social workers ($n = 17$, 8%), academics ($n = 9$, 4%), homelessness staff ($n = 9$, 4%) and allied health professionals ($n = 18$, 8%). Professional group was not specified by 56 attendees (26%). The number of people from organisations supporting people affected by homelessness within these numbers is likely to be an underestimate, given the categories used for people to report their professional groups.

Across the 10 network sessions, 20 people presented to the groups. Eight of these presentations were from people working with homelessness services (40%), three presenters were from inclusion health services (15%), three were from palliative care services (15%), two were from secondary care (19%) and one presentation was given by an academic researcher, one from someone working within a charity and one from a general practitioner (GP).

Feedback given by attendees within the final session reported that benefits of the network were: helping to understand the complexity of the field; a sense of community and enthusiasm by seeing others passionate about working towards the same goal; creating new

connections and links across organisations and geographic locations; and access to peer support.

Despite a low completion rate, an evaluation survey circulated after the first 10 sessions suggested some key quantitative findings ($n = 27$):

- Seventy-eight per cent of respondents ($n = 21$) agreed the network had increased their awareness of complexities and challenges faced by people experiencing homelessness with palliative care needs.
- Seventy-four per cent of respondents ($n = 20$) agreed that they applied knowledge gained from participation in this ECHO network to their everyday practice.
- Eighty-five per cent of respondents agreed that they feel more connected with others who are interested/working in this field; 81% respondents ($n = 22$) agreed that the network has facilitated increased collaborations with people of different professional backgrounds.
- Importantly, 89% (24 respondents) said they would re-register to a continuation of the network. The remaining 11% of respondents ($n = 3$) answered 'maybe'.
- Sixty-three per cent ($n = 17$) agreed that participation in the ECHO had decreased their professional isolation.

Another benefit reported was the ability to expand their network and connect with people with whom their path may not have otherwise crossed. This led to feelings of support and connection.

Knowing that you are not alone

Palliative Care and Homelessness Network member

Furthermore, participants reported diminished isolation in what is often a difficult field of work:

Shared experiences. Support of other in the same field.

Not feeling that you are so professionally isolated.

Palliative Care and Homelessness Network member

Recommendations for improvement of the network included lengthening the sessions to allowing more time for discussion and securing greater attendance from commissioners or others 'higher up' in the structure, to enable them to participate in discussions.

Open text feedback from the evaluation survey suggested attendees found the sharing of case studies engaging, insightful and inspiring to listen to – they provoked meaningful conversations illustrated by the real challenges faced.

Hearing case studies and examples of good practice and creative approaches to complex issues has broadened my understanding and has given me a lot of ideas how I can contribute to the project I'm currently embarking on.

Palliative Care and Homelessness Network member

Given the success of the ECHO network, Marie Curie committed to continue to support the delivery of the network. The second round of sessions began with the curriculum setting session in November 2023 and continued until November 2024. The next iteration of the network will begin in Spring 2025. Given the low response rate to the final evaluation survey, new approaches to the evaluation of future network sessions are being considered, for example utilising aspects of Ripple Effects Mapping²² and collecting feedback on an ongoing basis throughout the course of the network.

Aim 2

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.

Mapping activity (workstream 1)

Network members were surveyed to explore the range of initiatives taking place across the UK with the aim of supporting people experiencing homelessness who may have palliative care needs.²³ Links to existing initiatives and ongoing work across the UK within the field of palliative care and homelessness have been shared on the Marie Curie website (<https://www.mariecurie.org.uk/research/homelessness-palliative-care>; accessed 22 January 2025), to facilitate collaborations and reduce duplication of effort.

Facilitating connections (workstream 1)

A number of new professional connections were made throughout the network. This includes connections between varying professional backgrounds, such as researchers, health and social care professionals and homelessness staff. The national network has also facilitated place-based connections between researchers and homelessness services.

Creating the TIFFIN recommendations (workstream 3)

Within workstream three, a qualitative study was conducted which aimed to co-produce recommendations for involving people with lived experience homelessness in palliative and end-of-life care research.

Sixteen interviews with professionals experienced in involving people with lived experience of homelessness

in their palliative and end of life care (PEoLC) research were carried out. Interviews explored the challenges, successes and reflections from professionals around involving people with experience of homelessness in PEoLC research. Two focus groups ($n = 11$) explored the important and unique perspective and experiences of people affected by homelessness who had been involved in research. An iterative thematic analysis was carried out within the core research team, professionals and people with lived experience of homelessness. From this, six themes regarding involvement and recommendations were co-produced (TIFFIN recommendations²⁰).

The six themes within the TIFFIN recommendations are:

- Transparency.
- Importance of engagement and rapport.
- Facilitating equitable involvement via person-centred approach.
- Financial recognition of people's involvement.
- Involvement and growth: a trauma-informed approach.
- Navigating institutional resistance and attitudes.

We intend to implement and evaluate the TIFFIN recommendations in future research in this field. These recommendations will be widely shared and will support academic researchers to involve people with lived experience of homelessness meaningfully and safely in their palliative and end-of-life care work.

Aim 3

To identify, from the network, *research priorities* for this area

Co-producing the curriculum for Extensions of Community Healthcare Outcomes meetings (workstream 1)

A curriculum setting activity was carried out with registered members of the network. An open text poll was utilised during the session using Slido software. This poll asked attendees to describe topics they would like to explore during network sessions. These responses were shared with people who had registered for the network, but not attended this session to generate further responses.

Where responses overlapped or represented the same topic they were grouped, with remaining responses forming their own categories. The resulting six session topics were:

- Medications management for people with active addictions.
- Addressing stigma around drug and alcohol use.

- Dealing with inflexibility in systems (e.g. around appointments and exclusions).
- How to connect and engage with people experiencing homelessness.
- Practical issues around supporting someone towards the end of life in temporary accommodation (if that is their wish, e.g. adjustments needed for a hostel environment).
- Safe hospital discharges for people experiencing homelessness with advanced ill health.

In addition to topics that the group would like to discuss, opinions were also gathered regarding priorities for future research in the field of palliative care homelessness via a live poll (using Slido software) during an ECHO session. A total of 49 responses were gathered which were collated into 9 key categories of research topics relating to palliative care and homelessness: advance care planning, medication management, identification of palliative care need, engaging people with lived experience in services, training and support for health and social care professionals, supporting choice in place of care, facilitating multi-professional working, trauma-informed care, and palliative care for people with no recourse to public funds.

Having this list of research priorities from people who were either supporting people experiencing homelessness with palliative care needs or who had an interest in facilitating this was useful for a number of reasons. It supported the generation of a new research project exploring the experiences of supporting people experiencing homelessness who had uncertain or unsettled immigration status²⁴ and emphasised the need for testing new models to promote interprofessional working, which is the focus of future work from the research team. New collaborations were formed from within the network to support both these projects. These priorities will be shared on the Marie Curie website for reference by people interested in undertaking new research in this area.

Aim 4

To *facilitate coproduction* of research by involving people with lived experience of homelessness throughout

Public and patient involvement through all workstreams

The lived experience of homelessness is a complex phenomenon. Given the diversity of experiences that fall under the umbrella of homelessness, the involvement of a range of people with lived experience is essential for real and meaningful impact. Throughout this project, we worked to involve people with a range of experiences

relating to palliative care and homelessness, reflected in our diverse steering group.

Through the ECHO network (workstream 1) we gained insights and experiences from professionals working to support people with lived experience of homelessness, in a range of settings and in a range of capacities. The conversations and insights shared within the ECHO sessions have been extremely useful for helping us triangulate information gathered via the rapid review (workstream 2) and the qualitative study (workstream 3).

In workstream 3, we gathered input from 11 people with lived experience of homelessness to inform the development of recommendations for involvement in PEOLC research. To do this, we worked closely with Groundswell, an organisation that aims to amplify voices of people with lived experience to create solutions to homelessness and health inequalities. An iterative analysis process was chosen, where people with lived experience of homelessness ($n = 5$) reflected and contributed to drafts of the TIFFIN recommendations in a third focus group.

Rapid review on co-production of inclusion health groups in palliative and end-of-life care research (workstream 2)

To begin to facilitate co-production of research with individuals with lived experience of homelessness, it is important to understand best practice for, and the current landscape of co-production within the field of PEOLC and homelessness. Within PEOLC research, co-production with people with lived experience of homelessness, or other inclusion health groups is currently limited.

To inform workstream 3, a rapid review was conducted. This aimed to identify and synthesise qualitative literature outlining barriers and facilitators for involving four inclusion health groups (individuals with lived experience of: homelessness, substance use disorder, incarceration or exchanging sex for money) in PEOLC research, from the perspectives of both the researchers and individuals with lived experience.¹⁹

No guidance to support the involvement of people with lived experience of any of the four inclusion health groups in PEOLC research was identified, demonstrating a clear need for the work completed in workstream 3.

Three papers were eligible for inclusion in the review.²⁵⁻²⁷ These provided reflections and learnings from two studies that involved people with lived experience of incarceration, and one of homelessness. Challenges for co

research included: facilitating appropriate reimbursement; overcoming stigma; fear of tokenism; pre-conceived views and the emotional burden of research. Successes and benefits included: advanced level of insight, a two-way learning opportunity and relatability of lived experience co-researchers. The full rapid review is published in a peer-reviewed journal, openly accessible online.¹⁹

Aim 5

To develop a funding proposal for the NIHR Palliative and end-of-life care stage 2 call, the focus for which is co-produced through partnership and network working.

Throughout the duration of this grant, the core research team were able to make new connections across different organisations (universities and third-sector organisations). This allowed us to bring in professionals from palliative care who are new to the area of homelessness but who have skills and expertise which benefit the area and complement the existing team.

Together, with new collaborators, we developed a successful application for further research funding to facilitate the development of local communities of practice of people from mixed professional groups; work that will complement the national Palliative Care and Homelessness network. This project aims to optimise multi-professional working to improve the care of people experiencing homelessness towards the end of life. It will involve working closely with new collaborators, and with people with lived experience of homelessness. The TIFFIN recommendations have informed our approach to involving people with lived experience of homelessness in the project.

Funding has also been secured for a new qualitative project exploring the acceptability of death cafés from the perspectives of people with lived experience of homelessness, and professionals from health, homelessness and palliative care services. In addition to exploring views of these groups around death cafes, we have utilised the TIFFIN recommendations and will use this study as a way of evaluating these, via reflections from all members of the project team (both those with and without lived experience of homelessness).

Discussion

This NIHR Partnership grant consisted of five key aims, addressed through three workstreams. Collectively, the work successfully began to build multi-professional partnerships and networks across the

UK to improve access to palliative care for people experiencing homelessness.

National Palliative Care and Homelessness Network achievements

Although the response rate to the evaluation survey was low, it provides evidence that many of the intended outcomes of the project have been met. For example, an intended network outcome was 'More awareness of complexity, challenges of supporting people experiencing homelessness with palliative care needs': 78% of survey respondents agreed with this statement. Secondly, the network intended to foster 'collaboration between people of different professional backgrounds': 81% respondents agreed with this statement, with 85% also agreeing they felt more connected to other professionals.

The levels of attendance at and participation within the network sessions highlight the growing recognition of the need for multi-professional responses to the challenges of supporting people experiencing homelessness towards the end of life. There was a strong desire from the participants for this network to continue. This was highlighted during the final session in June 2023, where attendees were asked to suggest areas for discussion/curriculum upon re-commencing the network – attendees suggested some crucial and novel topic areas for discussion. Further, 24/27 (89%) evaluation survey respondents reported they would definitely re-register for a continuation of the network. A second round of the Network has now been completed with plans for a third round to commence in Spring 2025. Topics discussed in the second round of network included trauma-informed care, legal rights and advocacy, managing substance use at the end of life, overcoming prejudice and stigma, advance care planning and approaches to interprofessional working. The continuation of this network will maintain the momentum generated and to facilitate the creation of interprofessional relationships and connections to understand and improve PEOLC for people experiencing homelessness.

Strengths and weaknesses

The National Palliative Care and Homelessness network addressed an unmet need for support, learning and partnerships within a range of professional interests in PEOLC and homelessness. The high number of registered network members ($n = 268$) and average monthly attendees ($n = 52$) demonstrates the appetite for this community. Within this, a number of good-quality connections have been made through the network, fostering partnerships and collaborations between diverse professional groups across the UK.

Our work continues to advocate for inclusion and recognition of the voices of people with lived experience of homelessness. Though co-production is gaining popularity as an approach to research, inclusion health groups such as those experiencing homelessness are frequently excluded. The current work raises awareness of the importance of involving people with lived experience of homelessness in palliative and end-of-life care research and supports academic researchers to do so.

In the first round of the network, people with lived experience of homelessness were not well represented in the registered members or speakers. We countered this through placing a priority on hearing the voices of people with lived experience through co-producing the TIFFIN recommendations.²⁰

The number of responses to the evaluation survey was low. Survey fatigue is frequent among many professional groups; so alternative methods of gathering feedback may be considered for future sessions.

Although a wide range of professional backgrounds were reported from registered network members and session attendees, few members were of senior positions within commissioning bodies; their involvement in future sessions may be useful for fostering additional connections with the potential for impact.

Equality, diversity and inclusion

Within this project we sought to build connections between people from different professional groups to address the inequity that exists in access to PEOLC for people with lived experience of homelessness. Through the development of the TIFFIN recommendations, we hope that people with lived experience of homelessness can be supported to be involved in future research around PEOLC. The involvement of people with this type of lived experience will be essential to ensure that their needs are understood and that services can be designed to meet these needs.

Public and patient involvement

Aim 4 of this project focused on facilitating the involvement of people with lived experience throughout this project. We have involved people with a range of experiences relating to palliative care and homelessness, throughout the project, from its development through to its dissemination. We hope the learning shared through the TIFFIN recommendations will be of use to other researchers in this field.

Next steps

A number of next steps have emerged from this work.

The second round of the National Palliative Care and Homelessness Network ran from November 2023 to November 2024. This began with collaboratively setting a new curriculum through asking attendees which areas of palliative care and homelessness they wish to explore. Prior to launching this round of the Palliative Care and Homelessness network, we continued to expand engagement through existing network channels, conference presentations and other avenues. A third round of sessions is planned for Spring 2025.

Through the network, there has been interest in place-based application of learnings from the sessions. A pilot study previously done by the research team supported the development of palliative care and homelessness communities of practice in regions throughout the UK.²⁸ Through this, regional facilitators received training to hold their own local communities of practice, engaging a range of professional backgrounds in collective learning in their area. As a result, we plan to further develop this work around communities of practice for palliative care and homelessness.

One core output of this work are the TIFFIN recommendations to support researchers to involve people with lived experience of homelessness in their palliative care research. These recommendations were co-produced with experts in the field. We plan to make researchers in the field aware of the recommendations and support them to implement them in their practice.

We are utilising and evaluating the TIFFIN recommendations in our recently funded work exploring views on the acceptability of death cafes for people experiencing homelessness and future research we undertake in this field. The evaluation of these recommendations will help us to understand whether implementation of the guidance improves co-researchers' experiences of being involved in research.

Additional information

CRedit contribution statement

Briony Hudson (<https://orcid.org/0000-0002-2907-1764>): Conceptualisation, Data curation, Formal analysis, Funding acquisition, Methodology, Writing – original draft, Writing – editing and reviewing.

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Kate Flemming (<https://orcid.org/0000-0002-0795-8516>): Conceptualisation, Funding acquisition, Methodology, Writing – editing and reviewing.

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Patient data statement

Coproduction was central to this piece of work. Our steering group involved a person with lived experience of homelessness and we worked with organisations that support people with lived experience of homelessness to involve their views across the project.

Data-sharing statement

This is a qualitative study and therefore the data generated is not suitable for sharing beyond that contained within the manuscript. Further information can be obtained from the corresponding author.

Ethics statement

Ethical approval was granted by University College London Research Ethics committee (approval ID number 6202/008) on 3 November 2022.

Information governance statement

Marie Curie is committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under the Data Protection legislation. You can find out more about how we handle personal data, including how to exercise your individual rights and the contact details for our Data Protection Officer here (www.mariecurie.org.uk/privacy/the-right-of-access-at-marie-curie).

Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at <https://doi.org/10.3310/JWRG6933>.

Primary conflicts of interest: None declared.

Publications

Papers

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About this article

The contractual start date for this research was in February 2022. This article began editorial review in November 2023 and was accepted for publication in July 2024. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The Public Health Research editors and publisher have tried to ensure the accuracy of the authors' article and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this article.

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List of abbreviations

ECHO	Extension for Community Healthcare Outcomes
GP	general practitioner
NIHR	National Institute for Health and Care Research
PEoLC	palliative and end of life care

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