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Crooks, Jodie, Flemming, Kate orcid.org/0000-0002-0795-8516, Shulman, Caroline et al. (1 more author) (2024) Understanding aims, successes and challenges of palliative care and homelessness initiatives across the UK:an exploratory study. BMJ Open. e075498. ISSN 2044-6055

https://doi.org/10.1136/bmjopen-2023-075498

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BMJ Open Understanding aims, successes and challenges of palliative care and homelessness initiatives across the UK: an exploratory study

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ABSTRACT

To cite: Crooks J, Flemming K, Shulman C, *et al.* Understanding aims, successes and challenges of palliative care and homelessness initiatives across the UK: an exploratory study. *BMJ Open* 2024;**14**:e075498. doi:10.1136/ bmjopen-2023-075498

Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/ bmjopen-2023-075498).

Received 10 May 2023 Accepted 08 January 2024

Check for updates

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Jodie Crooks; jodie.crooks@mariecurie.org.uk **Background** Due to the recognition that people experiencing homelessness (PEH) often die young and unsupported, a growing number of initiatives focusing on palliative care and homelessness are emerging across the UK. However, there has been no systematic exploration of the nature and landscape of this work.

Aims To understand the range, aims, successes and challenges of current initiatives within the field of palliative care and homelessness in the UK, by exploring existing projects and initiatives.

Method An online survey was distributed to members of an Extension for Community Healthcare Outcomes network focusing on palliative care and homelessness for a mixed professional audience. The survey collated the aims, successes and challenges of initiatives aiming to improve palliative care for PEH. Responses were summarised using descriptive statistics, and free-text responses were analysed using thematic analysis.

Results 162 professionals completed the survey. Of these, 62% reported involvement in at least one palliative care and homelessness initiative. Initiatives focused on service delivery (59%), training (28%) and research (28%). Themes for success included improved service engagement, relationship formation, housing provision, honouring end-of-life wishes, upskilling staff and enabling safe hospital discharge. The main challenges included stigma around substance misuse, securing funding, staff capacity, equipment and facilities, and engaging communities.

Conclusion The number and scope of initiatives aiming to support PEH with advanced ill health and palliative care needs across the UK is growing, with a range of professionals engaging in the field. Future research may benefit from exploring initiatives in more detail to understand the specific drivers of impact on PEH and the staff and services supporting them.

BACKGROUND

People experiencing homelessness (PEH) often experience poor health outcomes and early mortality.^{1–3} Evidence has demonstrated that PEH are up to six times more likely to die at any given age than the general housed population, with the biggest disparity in those aged 35–44 years.³ Importantly, the deaths of

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The study used an established Project Extension for Community Healthcare Outcomes network to recruit professionals from a range of backgrounds across the UK, representing a diverse range of initiatives and regions.
- ⇒ The study enables insight into regional demographics of activity within the field, which helps to identify potential research need and funding.
- ⇒ Data were collected via a point-in-time survey: it cannot act as an exhaustive repository of initiatives.

many homeless people are unplanned and occur as a result of an emergency admission to hospital.⁴ Yearly rates of admission to accident and emergency departments of a hospital are up to fourfold higher in PEH when compared with the general population.^{5–7} Within this, many experience trimorbidity: the co-occurrence of mental ill health, substance use disorder and physical illness⁷⁸ often on a background of complex trauma and adverse childhood experiences. This can result in a complex presentation that requires trauma-informed, multidisciplinary support. Across the UK, there are growing concerns that many PEH are dying without the support required for an individualised and comfortable death.⁹¹⁰

Providing palliative care support for PEH is complicated by a number of factors. Previous studies have noted the complexity of identifying palliative care needs in PEH or a lack of recognition that an individual may have palliative care needs.⁴ Some techniques are suggested to consider whether an individual may benefit from palliative care, such as 'the surprise question' ('Would you be surprised if this person were to die in the next 6–12 months'?).¹¹ However, reports from both hostel and healthcare staff indicated that for many PEH, the answer would be 'no', even without actual palliative care need, due to the

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high risk of dying for other reasons such as overdoses, accidents and trauma.⁴ Furthermore, the uncertain trajectories of many illnesses common in this population (including liver failure), the relatively young age at which ill health is experienced, the recovery-focused nature of many homelessness services and often poor engagement with healthcare services mean many individuals are not identified as palliative or supported until later in their illnesses, if at all, meaning opportunities for person-centred care and support are lost.⁴

Currently, there are pockets of clinical and research activity, across the UK, which aim to improve support for PEH who may have palliative care needs. For example, some hospices have launched initiatives to promote equitable access and support for those experiencing homelessness¹²⁻¹⁴; Hospice UK—the UK's national charity for hospice and end-of-life (EOL) care (EOLC)-produced a report on equality in EOLC which recognised PEH as a group with inequitable access to care.¹⁵ In recent years, teams of academic researchers^{16–18} or clinicians¹⁹ have been working within the field. Some evaluations of services, including needs assessments, although not focusing on those with palliative care needs, exclusively have also taken place, informing next steps and recommendations for practice.^{20 21} Recommendations have been made for joined up, trauma-informed, multidisciplinary care between health, housing and social services, greater in reach into hostels and awareness raising for all professional groups about palliative care in the context of homelessness.⁴²² The National Institute for Health and Care Excellence recently published guidance on 'integrated health and social care for PEH'.²³ A priority within this was promoting coordinated, joined up care including multidisciplinary working throughout different services.² Notably, Pathway (a UK-leading homelessness charity) announced the theme of their most recent conference to be 'making integrated services work', illustrating the widespread awareness that this next step within the field may be pivotal. Therefore, with the aim of working towards improving connections, partnerships and links between professionals and services pertinent to palliative care and homelessness, the authors developed a professional Extension for Community Healthcare Outcomes (ECHO) network, described below.

Palliative care and homelessness ECHO network

The current research forms the initial stages of a wider National Institute for Health and Care Research (NIHR)funded project, which aims to create sustainable partnerships between individuals and organisations supporting PEH who may benefit from palliative care support.²⁴ This aims to lead and drive enthusiasm for developing research, endorse shared learning and promote multidisciplinary approaches to the care received by those experiencing homelessness towards the end of their lives. Within this, an ECHO network has been established, allowing clinicians, academic researchers, homelessness, inclusion staff and varied other professionals to meet online monthly, cultivating a supportive, equal community. One objective of the ECHO network was to understand and represent current activity within this area, where the research reported within the current paper sits. To note, the authors use the term 'initiative' for consistency to refer to any type of work within the field, including academic or other research, clinical provision and service delivery, and training or education-based work.

Research aims and questions

To gain an understanding of initiatives occurring within the field of palliative care and homelessness across the UK. There are three main research questions:

- 1. Where are initiatives regarding palliative care and homelessness being conducted across the UK, and by whom?
- 2. What are the main aims of initiatives being carried out within palliative care and homelessness?
- 3. What are the main successes and challenges faced within palliative care and homelessness initiatives?

METHODS

Design

An exploratory, survey-based study design was used. An online survey for members of a wider NIHR-funded Palliative Care and Homelessness ECHO network was the main source of data.

All members of the Palliative Care and Homelessness ECHO network were eligible and invited to participate. The network was initially developed using the professional connections of the research team assembled for the NIHR grant: a group of geographically and professionally diverse individuals. Information about the network were shared via their professional contacts, through engagement webinars during other conference presentations by the research team and via the Marie Curie website. Members of the ECHO network include palliative care doctors and consultants, hostel staff, temporary accommodation service staff, primary care staff and academic researchers. An invitation to complete the online survey was circulated via email to all registered ECHO network members. The email contained study information for participants. Membership of the network was not contingent on completing the survey. On registering for the ECHO network, participants were briefed on data storage, uses and General Data Protection Regulation, including that their data could be used in research and analysis. During registration, participants gave informed consent based on this information. Further ethics approval was not sought as the project aimed to collate publicly available information.

Data collection

An online survey was developed using Microsoft Forms. Participants were asked about their occupation: their primary profession, their location and the type of organisation they work for (ie, homelessness service, hospice, National Health Service (NHS) and charity). Respondents were asked about their current work around palliative care and homelessness. This commenced with closed questions, addressing whether they were or had been involved in any initiatives, and the nature of the initiative (ie, service delivery, research or training). This was followed by open questions about their initiative's aims, main successes and challenges faced. All questions around initiatives were repeated three times. The survey was developed by the research team to be exploratory in nature, given the infancy of this field in the UK. The expertise and previous research experience of the team were used to draft the survey, which was then modified and approved by the project's steering group. The full survey can be found as an online supplemental material. Data collection occurred from May to November 2022.

Data analysis

Data were analysed in two phases: (1) analysis of quantitative data and (2) analysis of qualitative data. Quantitative survey data were analysed using descriptive statistics and visual representation methods in Microsoft Excel. Qualitative open-text responses (initiative aims, successes and challenges) were imported into NVivo qualitative analysis software. Thematic analysis procedures were followed with all data being coded line by line, before collating codes into thematic groups.²⁵ Coding was done by one member of the research team (JC) to produce initial themes. Themes were then discussed with the wider research team (BH, CS and KF) to reshape and determine the final themes.

RESULTS

Quantitative findings

As of November 2022, a total of 202 people were registered within the ECHO network; 162 network members completed the survey. Respondents illustrated that initiatives in the field were undertaken by a broad range of professionals. 19 different professions were outlined; clinical nurse specialists in palliative care (n=23, 14.2%), homelessness outreach staff (n=22, 13.5%) and registered nurses in inclusion health (n=21, 12.9%) were the most common professional groups. The NHS was the most common employer, with 46.3% (n=75) respondents working for the NHS in some capacity, spread across primary care (n=23), secondary care (n=36) and 'NHS other' (n=16). Many respondents also worked for hospices (n=50, 30.9%) or a charity/voluntary sector organisation (n=33, 20.4%).

The majority of respondents (n=101, 62%) reported that they were (or had been) involved in at least one palliative care and homelessness initiative: 62% (n=62) of those involved in any initiatives were involved in just one, 18% (n=18) in a second and 0.06% (n=1 respondent) in a third. This involvement represents a total of 143 initiatives. A detailed breakdown of initiatives can be seen in table 1.

When considering only those respondents who were involved in at least one palliative care and homelessness initiative, the three most prevalent regions were London (n=22, 22%), South East England (n=22, 22%) and North West England (n=19, 19%). Wales and Northern Ireland were not present in this analysis.

Qualitative findings: thematic analysis

From the 111 initiatives reported, there were 6 key themes emerging from the initiative aims, 6 themes surrounding successes (which closely align with the aims) and 5 themes regarding challenges (box 1). A breakdown of the themes can be seen in box 1.

Aims and successes of initiatives

Aim 1: supporting people into appropriate accommodation

Many initiatives aimed to support individuals experiencing homelessness with complex care needs to find safe, comfortable accommodation in which their advanced ill-health needs could be supported and preferences for EOL fulfilled. Types of accommodation within these initiatives included hostel accommodation, hospice beds and temporary housing. Other initiatives aimed to 'help people sustain their tenancies or find longer-term housing' (housing organisation employee).

I manage a residential care home for older men who have a longstanding history of homelessness. We provide long term accommodation and care for those whose care needs are too high for hostels. Care home manager

A number of initiatives aimed to overcome the difficulties of supporting individuals with palliative care needs who were living in hostels. For example, some initiatives developed tailored accommodation services, while others, due to very limited options of accommodation for people with high support needs, worked towards facilitating EOL

Table 1 Breakdown of initiative involvement and type							
Project	Question	Item	N	%	Initiative type	Ν	%
1	'Are you or have you been involved in a project relating to palliative care and homelessness?'	Yes, 1 project	59	37	Service delivery	75	57
		Yes, more than one project	41	25	Training	25	19
		No	61	38	Research/pilot	24	18
2	'Are you or have you been involved in any additional projects?'	Yes	17	18	Service delivery	10	48
		No	80	82	Training	4	19
		-	-	-	Research/pilot	5	24

Box 1 Overview of themes

Initiative aims: themes

- \Rightarrow Supporting people into appropriate accommodation
- $\Rightarrow \ \text{Creating links}$
- $\Rightarrow\,$ Improving access to palliative care services
- $\Rightarrow\,$ Patient care and service delivery
- $\Rightarrow\,$ Training and education
- \Rightarrow Supporting the needs of homelessness staff

Initiative successes

- \Rightarrow Provision of safe, comfortable housing
- $\Rightarrow\,$ Formed and sustained relationships
- \Rightarrow Improved service engagement
- $\Rightarrow\,$ Ability to honour EOL wishes
- \Rightarrow Upskilling staff
- \Rightarrow Safe hospital discharge

Initiative challenges

- \Rightarrow Stigma and misunderstanding around the use of substances
- \Rightarrow Funding
- \Rightarrow Staff capacity
- \Rightarrow Equipment and facilities
- \Rightarrow Reaching and engaging communities

wishes within current accommodation provision: '[organisation] works with people with very high levels of need and who are often multiply excluded from mainstream service provision' (housing organisation employee).

Initiative successes: provision of safe, comfortable housing

Leading from this aim, a key success of many initiatives was the provision of safe, comfortable housing. Multidisciplinary teams were able to overcome multiple challenges to gain housing provision for individuals in need, including in emergency situations where accommodation was required promptly. Where individuals were already in housing, initiatives supported them to remain in this accommodation and 'ensure that they maintain their tenancies' (outreach homelessness staff) over the longer term.

Aim 2: creating links

Many initiatives aimed to build and maintain connections with other services and professionals. These connections often aimed to span various fields (including academia, primary and secondary healthcare, and homelessness services), creating links that interlace throughout the field of palliative care and homelessness. Respondents often reported secondary aims for creating such connections, for example, aspirations that creating links between services would improve service pathways for patients, from referral or admission to discharge: 'Building and maintaining links with local homeless GP practice and pall care team and have recently extended those to link in with hepatology specialist nurses to try to improve pathways' (inclusion health nurse). Some initiatives aimed to create partnerships with social workers and solicitors, to consult and gain support surrounding legal matters arising at the EOL for PEH: 'I am also developing cross-agency learning around legal needs; this will be one of my project interventions later this year' (palliative care doctor). Ultimately, initiatives aimed to build a more cohesive, interconnected network for professionals to ultimately improve the support that PEH receive towards the end of their lives.

Initiative success: formed and sustained relationships

Consequently, multi-disciplinary relationships throughout services across the UK were reported. These links allowed for collaboration between services, smoother referrals and the opportunity for professionals to learn from one another. Respondents referred to these relationships as 'a community of practice' (clinical nurse specialist in palliative care), illustrating the application of relationships for both educational and clinical gain. Consequently, improvements in joined up, wrap around care were reported.

Importantly, one initiative reported success in fostering professional relationships with individuals experiencing homelessness and consequently building an '*active lived experience group*'. They maintain long-term, strong working relationships with this group, who provide input and feedback to any future or ongoing initiatives.

Aim 3: improving access to palliative care services

A further aim of many initiatives was to improve access to palliative care services for PEH. Some initiatives aimed to identify and address the existing causes of inequities in access, while other initiatives aimed to create a service that supported PEH to access and navigate palliative care services. Coherent throughout most initiatives with this aim was the ambition to improve continuity of care and reduce unsafe discharge from a hospital to the streets.

Referral to and support from specialist palliative care services for individual patients and service providers across the city. Co-ordination of personalised patient care and improved access to shared records to ensure continuity of care. Hospice nurse consultant

Initiatives also referred to 'Improving access to end of life care for people who use substances (alcohol and other drugs)' (inclusion health nurse). This included overcoming stigma throughout services and challenges with fluctuation in patient presentation, for example, 'Ensuring that the client has access to health services, assessing need and reconnecting with disengaged services is main focus' (homelessness outreach staff).

Initiative success: improved service engagement

Resultantly, one key success was increased engagement of PEH with a range of services. Greater connection was reported with general practitioner practices, outpatient hospital appointments, palliative care services and advance care planning consultations. For some, this included engagement with disease-specific services, including oncology units or consultants, with whom previous referral appointments had been missed. Some initiatives supported both patients and their key workers (if applicable) to liaise with services to ensure suitable appointment times and locations which maintained engagement with services and reduced missed appointments. For some initiatives, increased engagement also covered adherence to prescription medications.

Have been successful: registering clients to health services, supporting attendance to appointments (and reducing no shows), and supporting follow up needs e.g. prescriptions, hospital bookings etc. Homelessness charity professional

Aim 4: patient care and service delivery

For many, the main aim of their initiative was facilitating person-centred care and choice for PEH towards the EOL. Many initiatives acknowledged the importance of delivering support within a place of the patients' preference, thus aiming to identify and address challenges that accompanied this. Challenges around choice in place of care for PEH towards the EOL included limited availability of beds in places that could provide the necessary support, particularly for people with active substance use issues. Where PEH preferred to stay in a hostel, the management, storage and administration of medications were another challenge that initiatives sought to overcome. Furthermore, initiatives aimed to consider and address the complexities of delivering EOLC for many PEH such as comorbidities (including trimorbidity), mental health needs and substance use disorders, while providing holistic, individualised support towards the EOL: '[I was] supporting a patient with complex physical and mental health needs, due to end stage renal failure+other physical co-morbidities, drug use and living in a hostel environment' (inclusion health nurse).

Initiative successes: ability to honour EOL wishes

16 initiatives reported succeeding in honouring patients' EOL wishes. Generally, this meant facilitating a comfortable, dignified death in a place that was acceptable to patients. Initiatives also reported honouring specific, personalised wishes such as spending time with pets and being reunited with lost friends and relatives. An important wish for many was the ability to continue consuming alcohol or using drugs—some initiatives reported successes liaising with complex needs to support care homes that allow alcohol and supervised drug use for people approaching EOL. Oftentimes, initiatives reported that conversations carried out in advance to a person becoming seriously unwell served as a useful prerequisite for honouring EOL wishes.

Numerous initiatives aimed to create and deliver training and education programmes that encouraged professionals to both identify and support palliative care need in individuals experiencing homelessness. These often aimed to build on existing skills and increase staff confidence, particularly when identifying individuals with palliative care needs. My aim is to educate and provide training to hospital staff/hostel support workers/outreach teams / students to be able to identify and better prepared to support people with palliative care needs and advancing disease. Homelessness discharge nurse with palliative care nursing

Initiatives also aimed to provide training to nonclinical professionals working on the frontline, who often have no training in health and social care: 'Developed and delivered an education programme around Palliative Care and Homelessness to hostel staff, council outreach teams and West Mids Police in 2019' (researcher). Education for these professionals often had similar aims to training provided to clinical staff, that is, to understand what palliative care needs could look like for this population and how best to support people with advanced ill health.

Initiative successes: upskilling staff

As a result of training, many respondents reported an upskilled workforce in both homelessness and healthcare services. This pertained to both practical ability and confidence. These training benefits were especially reported in non-clinical staff:

By educating frontline staff there is a better understanding of deteriorating patients, palliative and end of life care. Frontline non clinical Staff are less fearful if a patients preferred place of care is to die with dignity in their hostel with the right care being provided by relevant services. Registered nurse—inclusion health

A particular area of increased confidence was EOLC for individuals with substance use disorders. This included prescribing EOL medicines, supporting approved drug use and liaising with palliative care teams to deliver care in hostels. Respondents reported that both their clinical and non-clinical staff felt empowered as a result of further education, allowing them to be assured in their day-to-day support of PEH with palliative care needs.

Aim 6: supporting the needs of homelessness staff

Several initiatives aimed to ensure that frontline workers were receiving adequate institutional support from their employer, emotional support and counselling, and bereavement support if required.

To make sure frontline services have an outlet to access support and advice from fellow colleagues. [Homeless palliative care coordinator

Within the data collected, many initiatives emphasised that without proper support, staff can be ill equipped to provide care for PEH with advanced ill health. Supporting people in this position can be emotionally challenging; staff support is a prerequisite to achieving good support for PEH who may benefit from palliative care support.

Open access

Initiative successes: safe hospital discharge

The successes of safe hospital discharge were discussed in six initiatives. Particularly, in helping patients 'navigate their way from hospital into community via interim bed' (inclusion health nurse) to prevent return to street homelessness. This was used as an opportunity to liaise with housing associations, to support individuals into accommodation following discharge. The ultimate success here was 'discharge to a place of safety that they were happy with for their end of life care' (registered nurse—inclusion health).

Initiative challenges

Stigma and misunderstanding of the use of substances

The most frequently described challenge was lack of cohesion across services and staff regarding empathy towards alcohol and drug use: 'Getting other health professionals to be open and less judgmental, and care compassionately for people with homelessness and complex health needs' (registered nurse). Stigmatised perspectives on care for individuals who use drugs and alcohol were often referred to as 'a difference in opinion between professionals' that had knock-on effects for patients. It caused difficulty in accessing services or feelings of judgement that led to disengaging with services. This did not appear to be a clinical versus non-clinical staff split, instead spanning across various services.

This lack of cohesion further complicated challenges of identifying palliative care needs in PEH. One point of difficulty was 'getting other HCPs to see past chaos and identify that these patients are palliative' (clinical nurse specialist in palliative care). This barrier was described by respondents as frustrating, particularly where patients with complex or palliative needs were repeatedly dismissed by staff or services due to using substances.

Funding

Gaining sufficient funding for initiatives was challenging. Some faced this before initiatives even commenced; they were unable to secure funding, sometimes even after successful pilots proved the work's potential impact. Alternatively, respondents reported being able to get small amounts of short-term funding but encountering challenges when seeking long-term funding to sustain initiatives. Consequently, initiatives were cut short or forced to decrease their reach and ultimately impact. Lack of funding also led to the inability to employ adequate staff to deliver initiatives within services. Where funding was successful, this was often for a fixed term, limiting the impact staff could have within a role and challenging the sustainment of any positive changes made as a result of the initiative.

Staff capacity

A frequent and related challenge was the capacity of staff to conduct initiatives that were often in addition to their everyday roles: '[we have to] fit it in around the day job!' [palliative care doctor]. Oftentimes, healthcare staff found it difficult to dedicate non-clinical time to initiatives, particularly those that required considerable admin (ie, liaising with other services and following up on 'loose ends'). Time was also an issue for training initiatives: clinical professionals struggled to plan sufficient 'off-ward' time to attend and engage with training. These time and capacity pressures were reported to be further exacerbated by the pressures faced during the COVID-19 pandemic. Where initiatives involved regular teamwork, challenges were faced 'navigating the demands of different peoples roles' (homeless palliative care coordinator).

Equipment and facilities

Challenges surrounding appropriate equipment and facilities spanned two main areas. The first pertained to the delivery of palliative care in hostel settings, specifically regarding the administration of medicines where carers and hostel staff did not have the qualifications or facilities to do so. For example, respondents reported challenges in using syringe drivers within a hostel setting. Second, challenges were faced regarding controlled drug use. Staff expressed concerns about where and how to safely store controlled drugs within their hostel ('oramorph prn was difficult' (registered nurse—inclusion health based within a hostel)) and stated that they lacked the facilities and knowledge to safely support controlled drug use.

Reaching and engaging communities

The final challenge faced was 'being able to reach everyone' (registered nurse—inclusion health). Initiatives were often halted or delayed, as both initially engaging PEH and then maintaining engagement with services proved difficult. Respondents from healthcare settings suggested some potential reasons for this, including fluctuation in patient attendance at healthcare services due in part to substance use, patients' perceptions of their need for support, issues of trust in services and lack of identification of palliative care needs.

DISCUSSION

Quantitative findings

This exploratory, survey-based study aimed to gain an understanding of initiatives supporting PEH with advanced ill health and palliative care needs across the UK. Across a diverse, multidisciplinary group of professionals who registered to join an ECHO network on palliative care and homelessness, the majority (62%) reported being involved in at least one initiative. Sharing this information provides an opportunity for further support or collaboration on future initiatives, as well as opportunities for initiative development. Facilitating collaboration is key, as evidence has highlighted the need for multidisciplinary partnership working within the field of palliative care and homelessness, to provide joined up care and support.⁴ International evidence further supports this need: a threefold intervention in the Netherlands was found to have added value for collaboration and networks of social service and palliative care professionals, in turn increasing competency, emotional support, and timing and quality of palliative care delivery.²⁶

Within both literature evidence and practising professionals, due to the complexity, there is often a lack of clarity and distinction between PEH with complex ill health and those with specific palliative care needs. Therefore, it is possible that involvement in a palliative care initiative is interpreted differently across professions and individuals, perhaps impacting individuals' survey responses and categorisation of palliative care initiatives. Existing evidence emphasises this, highlighting the often differing perspectives and priorities of sectors; homelessness services are typically recovery focused, meaning that palliative care is often not considered, while palliative care services focus on planning for EOL.¹⁰ This further illustrates the need for joined up, multidisciplinary collaborations fostered through initiatives highlighted in the current study and the wider national ECHO network from which this project was generated.

The survey found that activity was concentrated within three areas: London (22%), South East England (22%) and North West England (19%). It is likely that this is, at least in part, due to the density of services and consequent regional allocation of funding and resources.^{27 28} Palliative care is an underfunded area of research: a Marie Curie analysis of the UK Clinical Research Collaboration Health Research Classification System 2018 dataset revealed that only 0.21% of all non-commercial healthcare research funding is spent on palliative and end of life care (PEoLC) research.^{12 29} Within this, homelessnessspecific palliative care research is an even smaller proportion. In recognition of the inequitable spread of palliative care research funding across the UK, the NIHR has recently funded two rounds of PEoLC grants, with an explicit focus on areas with little research activity to date, including geographical regions of deprivation and/or high level of care need.³⁰

Qualitative findings

Thematic analysis of open-answer survey responses generated six themes around initiative successes and five themes around initiative challenges.

Notably, some successes and challenges appear to be the conflicting sides of a wider issue. For example, one identified challenge was difficulty reaching and engaging communities, with some initiatives reporting successes as improved engagement. Barriers to engagement of PEH have been thoroughly documented within literature, including attitudes to healthcare services, with negative past experiences, stigma and substance use disorders, limited insight into their condition and uncertain prognosis.^{4 10 31} Furthermore, one success was upskilling of staff, whereas the reported challenge was of funding and staff capacity: staff can only partake in training if they have the time and capacity to devote to it and available funding if required. Consequently, it may be that the reported successes are examples of 'blueprints' or ideals for conducting initiatives, particularly within services. Future research should aim to further explore successful initiatives within the field to learn how, in each service and initiative scenario, each outcome is produced so that initiatives can have the greatest possible impact. There is potential to further explore 'what works' in terms of both services and initiatives within these, to provide a better understanding of the best ways to support access to palliative care support for PEH.

Interestingly, despite the specific nature of palliative care work related to homelessness, some themes within the current study also reflect universal palliative care research priorities. Training and education, especially of non-palliative care specialists, was identified in international palliative care research priorities and as a top 10 priority in the Priority Setting Partnership between Marie Curie and the James Lind Alliance.^{26 32 33} This illustrates how general palliative care priorities go some way towards improving care for PEH, but further specific work is required to meet the complex needs of this population.³⁴

Limitations

Identifying palliative care needs in PEH is complex and challenging. Consequently, many professionals adopt a broad definition of palliative care, focusing on supporting people with advanced ill health to live well, rather than identifying whether someone is in their last year of life. All participants felt that their initiatives were supporting people who would benefit from palliative care support, yet it is likely that some initiatives did not have an explicit focus on supporting those with palliative care needs. For example, one respondent reported on the engagement of individuals experiencing homelessness with the COVID-19 vaccination. Future initiatives may benefit from working towards identifying those that may benefit from additional health and social care support around their health needs, learning when to bring in other professionals and how they may help.

The current study was a one-off, point-in-time survey. Since the closure of the survey, new initiatives will have commenced within the field. Although the current study offers insight into the research landscape as of November 2022, it is by no means an exhaustive repository of initiatives. However, the challenges and successes identified will be useful for those looking to embark on initiatives to reduce the inequity of access to palliative care for this group and provide useful pointers for the direction of future research.

Patient and public involvement

There was no patient and public involvement in this project. As data were collected from a diverse ECHO network, no further consultation was sought. However, the larger project within which this current study sits has involved people with lived experience of homelessness.

Conclusions

This paper used a diverse ECHO network to gain insight into an activity aiming to improve care and

support for PEH with advanced ill health, and those that support them, across the UK. Over half of respondents reported involvement in at least one palliative care and homelessness initiative with the majority being service delivery based, indicating the current level and type of activity within the field. Further work could be conducted towards making connections between those who are active within the field to promote shared learning, best practices and peer support. Key themes pertaining to initiative aims, successes and challenges were generated. Initiative successes often mirrored the challenges, indicating examples of initiatives or services that may be learnt from (or explored as blueprints) to understand how to overcome challenges and improve initiative outcomes. There is potential for future research to provide further insight into 'what works' for service delivery, research and training initiatives, independently to promote best practices for addressing the palliative care needs of PEH.

Recommendations

- ► Equitable opportunities for engagement in palliative care and homelessness initiatives for interested professionals: the current study found that 38% of respondents had never been involved in a palliative care and homelessness initiative. Although some would not wish to be involved, it is important that we offer equitable opportunities to all professionals: for example, offering support to professionals who would like to contribute to an initiative but need support to get started or ensuring that initiatives span to different UK regions.
- ► Further research to understand 'what works' within specific initiatives: there is potential for future research to explore initiatives with mirrored successes and challenges to understand 'blueprints' for initiatives and how future work can avoid barriers and achieve better outcomes.

Contributors JC planned the study, undertook qualitative thematic analysis, led the writing of the manuscript and submitted the manuscript. JC is the guarantor for this manuscript. BH planned the study, led the designing of the survey, gave feedback on the analysis and shaped themes and gave feedback on the manuscript writing. KF planned the study, gave feedback on the analysis and shaped themes and gave feedback on the analysis and shaped themes and gave feedback on the manuscript writing. CS planned the study, gave feedback on the analysis and shaped themes and gave feedback on the manuscript writing.

Funding This study is funded by the 21/79 PHR Palliative and End of Life Care Research Partnership Scheme (NIHR135250). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request.

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