

Exploratory study from an end-of-life research partnership network to improve access for ethnically diverse communities in one region.

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1. Abstract

Background: Minority ethnic patients are less likely to access timely and effective palliative and end-of-life care and, as a consequence, more likely to experience poorer symptom management and receive more intensive treatments at the end of life. Research activity has the potential to address the aforementioned barriers to improve access. However, there is a need to develop capacity and capability, particularly within underserved communities, to

provide an infrastructure that can drive research activity informed by the community to benefit the community.

Objective: To build and develop a robust, inclusive, and representative research partnership to facilitate improved research activity committed to addressing inequity in access to palliative and end-of-life care among ethnically diverse communities.

Design: An inclusive and representative KEEch research Partnership NETwork (KEEP-NET) was established, comprised of over 80 partner organisations that represent the local diverse and multi-faith communities. Interviews ($n = 11$) with service providers and face-to-face roundtable workshops with community stakeholders, service providers, informal carers, and faith leaders were conducted to understand needs, challenges, and research priorities.

Setting: Bedfordshire, Hertfordshire, and Milton Keynes, UK.

Results: Developing KEEP-NET required a flexible and agile approach to engage effectively with institutionalised and non-institutionalised stakeholders. Sharing a joint purpose of learning, managing partners' expectations and providing transparency and accountability within the network were all essential in building trust and equity within the research partnership. The overarching findings revealed a range of socio-cultural and structural barriers that negatively impact access and experience among minority ethnic groups. Discussions centred on the disconnect between informal care and support within the community, which many ethnic minority communities rely upon, and 'institutional' medical services. KEEP-NET uncovered that whilst service providers and communities acknowledge they need to engage with each other more, they remain uncertain of the best way to achieve this. There was also consensus that services need to deliver more effective, culturally competent, person-centric care that promotes compassion and gives weight to non-medical needs to better meet the needs of the diverse population. These findings and priorities have informed the submission of a co-produced research funding proposal. Beyond that, KEEP-NET has also provided a platform for further unplanned spin-off research projects and

collaboration, including the implementation of an innovative ‘community connector’ role to facilitate better integration of community and voluntary services in palliative and end-of-life care.

Conclusions: KEEP-NET has provided valuable insight into factors that can facilitate the successful collaboration between multi-faith and diverse community stakeholders. Through KEEP-NET, we offer our observations as an opportunity for shared learning for others who want to adopt a similar approach when in the planning stages of establishing a research partnership network. The mutual benefit of developing this partnership and working collectively with communities to address inequalities in accessing PEoLC could provide a useful approach and way of solving other important priorities to reduce wider health inequalities.

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2. Plain English Summary

This study developed a research partnership which brought together key partners, including commissioners, healthcare providers, faith leaders, representatives of community organisations, academics and the wider public, including informal carers who represent the diverse and multi-faith communities of Bedfordshire, Luton, and Milton Keynes. Interviews ($n = 11$) with service providers and a series of face-to-face roundtable workshops with community stakeholders, service providers, informal carers, and faith leaders were conducted to enable all people’s voices to be heard and develop a shared understanding of the challenges that minority ethnic groups face in accessing palliative and end-of-life care.

Whilst medicalised services (e.g., hospices) are available, minority ethnic groups often depend upon informal carers, faith, and community support, i.e., ‘non-institutionalised’ routes that focus on providing love and care but have limited medical expertise. Stakeholders felt that there was a lack of integration between these routes, and whilst they both acknowledge they need to engage with each other more, they remain uncertain of the best way to achieve this. Families revealed they want more help and support to look after their loved ones. However, they want medical institutions to be more personable and compassionate, giving more weight to non-medical needs. This was particularly important to families from multi-faith communities whose beliefs about death are far from Western medical practices.

The study led to a new understanding of the importance of patient and public voice and how this can be facilitated among ethnically diverse communities. Through being flexible, agile, and inclusive, we, through this partnership, were able to build trust and stimulate research activity that will have increased relevance and impact in addressing inequity. Healthcare providers and community stakeholders need to find new ways of working together to increase access to palliative and end-of-life care and better meet the needs of ethnically diverse patients and their families.

3. Background

Providing timely and effective palliative and end-of-life care (PEoLC) has become a ‘gold’ quality standard for patients diagnosed with an incurable illness¹. The Better Endings report ‘Right care, Right Place, Right Time’² states that patients who receive specialist PEoLC tend to have a ‘*better death*’ than those without access to this care, through improved symptom management, experience less distressing symptoms and are more likely to receive supportive care in their own homes in their last month of life, a key aspiration for many³.

The UK has become increasingly diverse, with non-white British representing >25% of the UK’s total population. However, inequalities persist, whereby minority ethnic groups remain under-represented across PEoLC service provision^{2, 4, 5}, consequently experiencing poorer symptom management, more intensive treatments at EoL, and more likely to die in hospital⁵.⁶ Timely access to PEoLC can address the holistic care needs of patients and families, allow adequate care planning, facilitate treatment choices, and reduce distress among patients and families⁷. This can improve pain and symptom management, enable informed decision-making and improve the quality of life for patients and their families⁸.

Reducing inequalities and improving access to PEoLC among ethnically diverse populations is a national and international priority⁹. The James Lind Alliance and the Palliative End-of-Life Priority Setting Partnership^{10, 11} identified improving access to PEoLC should be a national priority. Further, fair access to care represents a core ambition in the recent update of the ‘Ambitions for Palliative and End of Life Care’ national framework for 2021-2026¹² alongside National Palliative and End of Life Care Partnership and NICE Guidance and Quality Standards for Palliative and End of Life Care^{1, 13}. This is also reinforced by the NHS Long Term Plan (2019) which is committed to the delivery of PEoLC which is personalised

and accessible to all sections of the population¹⁴. These inequalities are yet to be addressed, and without action, we risk these inequalities continuing to be exacerbated^{15, 16}.

Evidence reveals a complex interplay of factors which have been shown to influence access and experiences of PEOLC among the UK's diverse population. Ethnic minority groups can be reluctant to be referred for PEOLC due to negative perceptions⁵, lack of awareness¹⁷⁻¹⁹, and differing care preferences based on cultural and family expectations and religious practices around dying^{5, 20}. PEOLC is also often viewed as culturally inappropriate^{5, 17, 18, 20, 21} with language barriers^{5, 17, 19} alongside limited cultural and religious sensitivity in how services are delivered, with many patients experiencing discrimination^{17-19, 22, 23}. Many professionals can also lack confidence, knowledge and skills to interact and deliver effective PEOLC to minority ethnic populations^{23, 24}.

Research is needed to understand how these inequalities can be addressed so that all sections of the population can access the care they need²⁵. However, to facilitate this, there is a need to develop capacity and capability, particularly within underserved communities that are underrepresented in research, to provide an infrastructure that can stimulate and deliver research activity to benefit the populations they serve. Research partnerships can facilitate this, bringing together multiple stakeholders to share and collectively address common goals and challenges which impact access to PEOLC²⁶, which can play a significant role in improving health and addressing health inequalities²⁷. Developing inclusive and representative research partnerships can also help build social capital and cohesion by cementing new ways of working, building trust, and providing a platform for knowledge exchange to help understand the local context and capacity^{25, 28}. Through developing the research infrastructure at a local level, research partnerships can create research capacity and capability to drive community-driven 'bottom-up' research activity, which has increased

relevance and impact that can inform effective policies and interventions that can serve to address these inequalities.

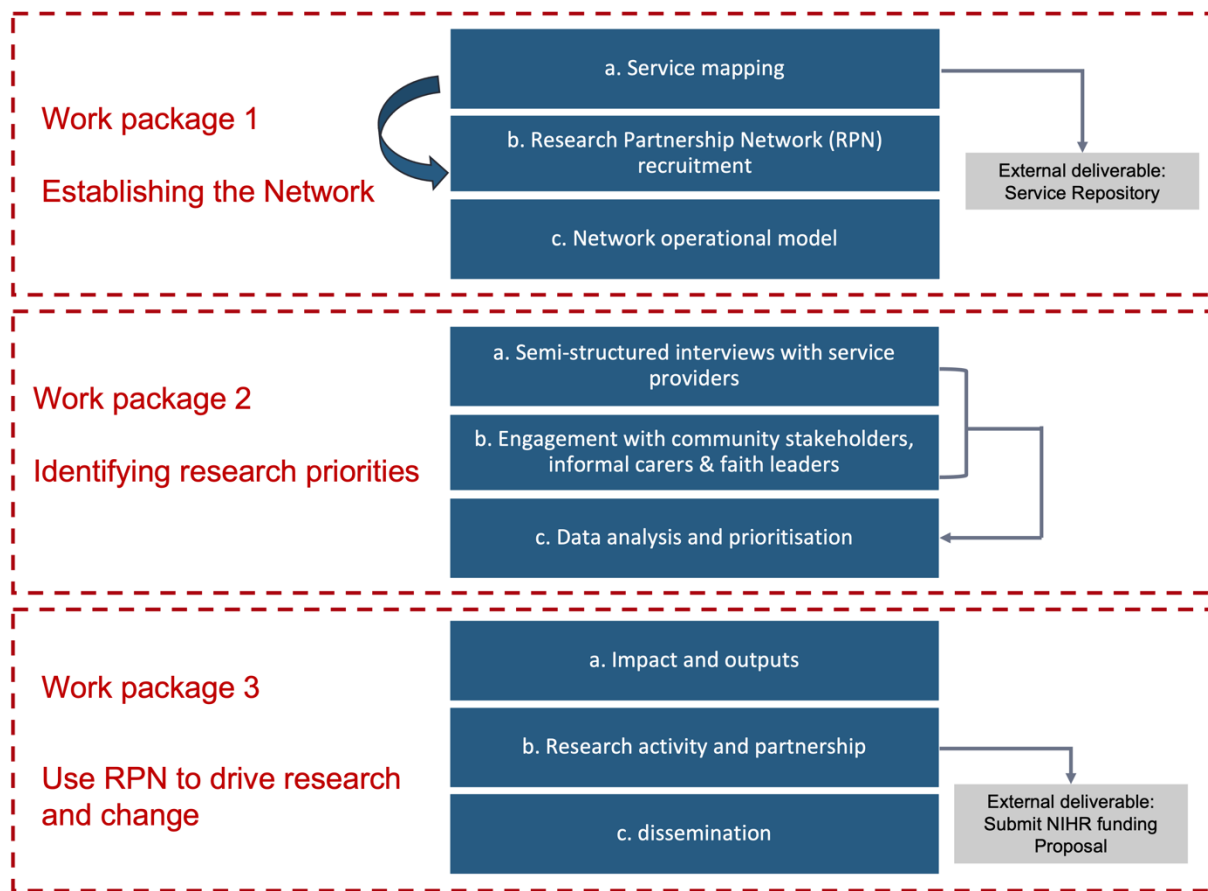
3.1. Aims and objectives

This research programme aimed to develop a Research Partnership Network (RPN) to build research capacity and capability in PEOLC in Bedfordshire, Hertfordshire, and Milton Keynes (BHMK). The RPN, funded by NIHR, represented the first phase in a research programme designed to address the research question: How can access to PEOLC services be improved to reduce inequalities among the ethnic minority populations who reside in Bedfordshire, Hertfordshire, and Milton Keynes?

To achieve this aim, the research programme had three objectives (see Figure 1).

- (1) To establish a Palliative and End of Life RPN to represent the diverse multi-ethnic and multi-faith communities across BHMK (Work Package 1)
- (2) Understand the experiences of the key stakeholders and identify and prioritise the issues that need research to be addressed effectively (Work Package 2)
- (3) Use findings from WP1 and WP2 to drive research activity and change (Work Package 3).

Figure 1: Project Plan



Patient and public involvement

Patient and public involvement (PPI) was embedded throughout the study to ensure that KEEP-NET is inclusive and representative, and that research activity is informed by the concerns and experiences of patients and families from ethnically diverse communities across BHMK. PPI informed our recruitment strategy, interpretation of the data, and outputs, including the co-developed funding application and dissemination of findings.

4. Methods and Results

This research was situated in Bedfordshire, Hertfordshire, and Milton Keynes (BHMK), located in the Southeast of England. BHMK has a combined population of 1.5 million, projected to grow to 2 million by 2035, with the number of people aged 85 and over projected

to double by 2035 and a higher-than-average growth in adults aged 65 and over. Towns in BHMK counties have high rates of ethnic diversity and pockets of high deprivation.

Luton, located in Bedfordshire, is the most urban, deprived, and ethnically diverse town across the three counties. The demographic characteristics of Luton are complex, characterised by high levels of migration, both from overseas and within the UK, significant population turnover, and one of the most ethnically diverse populations in England²⁹. Referred to as ‘super diverse’³⁰. Luton hosts significant long-standing Indian, Pakistani, Bangladeshi, African-Caribbean and Irish communities, and more recent immigration from countries that joined the EU in 2004 and 2007, Turkey, Afghanistan, and African countries. Luton also recently became a Marmot Town²⁹, hosting five of the most deprived Wards in England, where large sections of the ethnically diverse community reside. Bedford Borough, Milton Keynes, and Hertfordshire are also urban, with pockets of deprivation and ethnically diverse populations.

4.1. Work Package 1: Establishing the Research Partnership Network (RPN)

The first work package aimed to establish and launch a PEoLC research partnership network representing the diverse multi-ethnic and multi-faith communities across BHMK.

4.1.1. Mapping of Palliative and End of Life Care services and organisations

Previous local mapping exercises of PEoLC, such as the one conducted by Luton Palliative Care Network³¹, have only achieved partial success. This has been due to the fragmentation of services across different geographical boundaries and the multiple agencies involved. Therefore, rather than defining services by commissioning groups, a patient-centric approach was created to reflect the range of services available to people in the last year of life. This

represents a novel approach that aimed to provide a structure for a comprehensive review of all PEOLC services across BHMK, which had not been attempted before. A service list was created from those services already included within the Luton Palliative Care Network³¹ and also informed by the NICE guidelines³² and the Gold Standards Framework Proactive Identification Guide³³. This process identified around 36 services organised into five categories: medical treatment and advice, personal and domiciliary care, psychological and counselling services, alternative therapies, and practical services.

An online survey was created on a Qualtrics survey platform, which asked for details on the type of organisation, the services provided, geographical areas served in BHMK, the main source of referrals, and identified perceptions around the level of service use by people from ethnic communities alongside faith and translation services offered. This survey was shared with the initial 36 services identified alongside the research team's existing known networks, stakeholders, and relevant mailing lists. In parallel, web searching was used to identify potential service providers and organisations. Personal contacts were made with these organisations to introduce the project and encourage them to participate in the mapping survey. We also sent regular chaser emails and reminders to encourage participation. Snowballing techniques were also used whereby known contacts alongside those who took part were asked to disseminate the survey to other relevant services/organisations who were omitted and provide PEOLC to the local communities across BHMK. The survey was also widely disseminated online through social media, e.g., Twitter, WhatsApp, and Facebook. The survey remained live throughout the project (February 2022 – December 2022).

A total of 21 additional service providers responded to the survey, primarily including medical PEOLC service providers, such as hospices, hospitals, and community nurses ($N = 57$). There were, however, challenges in getting responses from non-medical service

providers, which reinforced findings of previous attempts at mapping services that identified PEO LC provision as complicated and fragmented, with only hospice providing a central coordination point for people in the last year of life. Whilst non-institutionalised service providers, such as community groups, are essential for understanding and improving PEO LC experiences of diverse populations, many organisations that provided support in these non-medical areas did not perceive themselves as a PEO LC service provider. Therefore, we proactively approached potential services and organisations across the non-medical categories to introduce the project and supported them in completing the survey. We would then ask them to introduce us to other relevant services and organisations. These conversations were an essential step in creating the network's visibility.

An additional aim of the mapping exercise was to build a searchable open-access online database of PEO LC services across BHMK that enables the public and professionals to search for specific services in their area (www.blmhkendooflifesupportfinder.uk). The website uses an algorithm that enables an individual to search for services based on their locality, whether the service relates to an adult or child and what type of support they are looking for with options including (a) faith and spiritual, (b) medical advice and treatment, (c) personal care and home help, (d) practical assistance, psychology, and counselling, and finally, (e) wellbeing and alternative therapies. All available providers are shown to the individual with links that direct them to their contact information (including website, address and telephone number, details on how to access their service(s), i.e., whether they need a professional referral or not and whether the service is free or paid. There are future plans to continue to develop this website to build in translated versions and provide information on translation services available by the service providers. An annual survey will be sent to all services held on the repository to ensure that all information about their service is accurate and, where

relevant, provide any changes to provision. In addition, services will be asked to identify if they know any new services that should be included within the repository.

4.1.2. Research Partnership Network (RPN) recruitment

A ‘whole system’ and inclusive approach³⁴ was used to recruit key partners, professional groups and stakeholders across health and social care from a diverse range of third-sector organisations, including charities, voluntary and formal and informal community organisations and networks that deliver PEOLC across the region. To facilitate this, a mapping exercise was conducted to identify providers and stakeholders of PEOLC across BHMK who would be invited to join the RPN. To ensure that we developed an inclusive RPN representing the ethnically diverse communities across BHMK, we adopted a flexible and pragmatic approach to aid recruitment, using direct contacts and networks, snowballing alongside a solid social media presence.

4.1.3. Network operational model

The launch of KEEch Research Partnership NETWORK (KEEP-NET) was initiated through a face-to-face event at the University of Bedfordshire on March 31st, 2022. All services and organisations identified through the mapping survey were invited. Adverts were also created and shared via existing networks, with known services and attendees invited to share to their wider networks. The event gained substantial interest and was attended by 32 members who represented a range of health, social care, and community stakeholders across the BHMK region. Hospices, community and hospital health and social care providers attended alongside representation from Grassroots community organisations and informal networks across BHMK, including Equality in Diversity CIC, local mosque funeral services and local

community health forms, including Healthwatch representatives. Academics and community members also attended the event with an active interest and/or lived experience of PEOLC.

The launch of the network was a symbolic and important starting point for the RPN to develop ground rules in which the RPN would operate alongside an agreed shared vision to set out the common values underpinning the network. Working towards shared values and goals was an important step in developing a network that facilitates more effective working relationships through increased trust, transparency, and respect³⁵⁻³⁷. The agreed ground rules are presented in Table 1, which centred around six guiding principles: (1) a shared vision, (2) all voices are equal, (3) inclusivity, (4) acceptance that issues exist, (5) accountability, and (6) building mutual trust.

Table 1: KEEP-NET ground rules for working together.

<p><i>A shared vision</i></p>	<p>The RPN should collectively identify objectives and research priorities. Specifically, the network should:</p> <ul style="list-style-type: none"> • Include experiences from all key stakeholders in communities as well as from service providers. Attendees identified two community categories that are involved in the care of people approaching their life transition but who aren't part of 'the system': • Informal carers: the people, often women, in the communities that are delivering care to loved ones • Faith groups: those who provide spiritual support for people in their transition from this world
<p><i>All voices are equal</i></p>	<ul style="list-style-type: none"> • All voices are equally valuable. All stakeholders bring in a unique perspective and all perspectives should be respected and considered valuable. This is important to address potential power imbalances³⁸ and ensure everybody understood that professional standing did not equate to a more valuable voice and that community voices are not just legitimate but are also innately expert in nature³⁹. • Stakeholders will be involved in setting the research agenda and leading on some of the activities throughout the project.
<p><i>Inclusivity</i></p>	<ul style="list-style-type: none"> • Inclusivity is not just about colour and gender, it's about different experiences. Equity starts with understanding and tolerance. The network (and any output) must address the lived experiences and needs of everyone. • The RPN will be an inclusive forum and will welcome new members to join which is expected to be likely as this research gains momentum.
<p><i>Acceptance that issues exist</i></p>	<ul style="list-style-type: none"> • The RPN must recognise that issues with accessing and using PEoLC services by people from ethnic minority backgrounds exist. • Service providers must resist natural responses to be defensive; progressing the group's maturity in understanding that improvement will only come from recognising that issues exist.
<p><i>Accountability</i></p>	<ul style="list-style-type: none"> • The RPN needs to hold everyone to account. • A reference committee should be conveyed to be responsible for the structured scrutiny of the delivery of findings.
<p><i>Build mutual trust</i></p>	<ul style="list-style-type: none"> • Trust issues exist between service providers and communities but also between communities and researchers. • Communities need to know that their time and efforts will be worth it.

	<ul style="list-style-type: none">• Building trust is a process, one that should be formerly structured and funded. Don't create optimism and then let people down when they are most vulnerable.• To stay involved in the network there needs to be tangible action.• This is not just about giving people a voice but ensuring that what we learn is presented to the necessary authorities that can bring about change.• The RPN recognised that some issues are deeply structural and will take time to bring about change; however, trust is possible by achieving smaller goals first.
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4.2. Work Package 2: Identifying research priorities

The mapping exercise and launch event identified that the key stakeholders involved in identifying research priorities should include service providers, faith leaders and informal carers. Therefore, a series of activities were designed to identify the research priorities of these groups as follows.

- Interviews with service provider professionals (hospices, community services and hospitals).
- Roundtable stakeholder workshops with (1) community and provider stakeholders, (2) faith leaders and (3) informal carers.

4.2.1. Semi-structured interviews with service providers

A qualitative study using semi-structured interviews was conducted with service providers/ professionals to explore their experiences working with ethnic minority communities, including experience and perception of inequalities. Health professionals/ service providers who work across health and social care from a wide range of PEoLC services, including charities and voluntary and community organisations across BHMK, were purposively recruited to participate in this study.

Information and promotional materials about the study were emailed to all existing contacts identified through the service mapping alongside contacts made through the RPN. RPN members were also asked to share the recruitment materials through their networks and with known contacts/services who they felt may be eligible. A total of eleven health professionals /service providers agreed to take part in an interview, who represented hospital ($n = 3$), community ($n = 3$) and third sector organisations ($n = 5$) across the four geographical regions

in BHMK, including Luton ($n = 3$), Milton Keynes ($n = 4$), Central Bedfordshire ($n = 2$) and Hertfordshire ($n = 2$).

An interview topic guide was developed collaboratively as part of the multi-disciplinary research team, informed by the literature and discussions from the KEEP-NET launch event. The topic guide used open-ended questions to explore key priorities for research and experiences of providing PEoLC care to ethnic minority communities, including experience and perception of inequalities, the role of communication and translation, the role of planning for death, approaches to faith and resource planning (supplementary file 1). Probes were also used to generate further explanations where relevant.

Before participation, all participants were provided with a participant information sheet which clearly explained the nature and purpose of this research, with written informed consent obtained through the completion of a consent form. A trained and experienced research assistant with a postgraduate qualification in Health Psychology facilitated all interviews. All interviews were conducted online using video conference software (Microsoft Teams) and lasted approximately 60 minutes each (46 - 83 mins). The interviews were video/audio recorded with permission and were stored securely on a secure password-protected laptop. All participants were provided an opportunity to verify their transcript, and once this process was complete, the video files were destroyed. Participants were provided pseudonyms to maintain confidentiality, with all names of organisations removed to ensure any direct quotes could not be linked back to the individual. Ethical approval was obtained from the Institute of Health Research at the University of Bedfordshire (REF: IHREC979). The interviews were analysed using the Framework Method⁴⁰, which provides a highly structured and systematic approach to generating themes and through the development of a

‘matrix’, which can identify commonalities and differences within the data⁴¹. An inductive approach was used to guide the analysis, whereby transcripts were read several times to identify emerging themes. A working analytical framework, comprised of the research team and lay members, was presented to the steering group for comment. The agreed analytic framework was then applied to all transcripts using specialist software (NVIVO v12). The coded data was then synthesised and summarised into a Framework Matrix with case nodes representing the different settings where PEO LC services are delivered (hospitals, hospices, and NHS community (including GPs and community nurses) and coded nodes representing the themes.

The findings uncovered three main themes, which included (1) access to services, (2) uptake of services and (3) experiences of engaging with services. The high-level findings are presented in Appendix 1, table 2, which details the extent to which people from ethnic minorities are affected by the barriers and facilitators identified, i.e., (1) everyone is affected in the same way; (2) everyone is affected, but people from ethnic minorities are affected more; (3) only affects people from ethnic minorities) (Appendix 1, table 2).

There was a clear need to coordinate research, with all interviewees stating that they were very supportive of the objectives of KEEP-NET and recognised that addressing inequity based on ethnicity was a high priority. However, some interviewees were also keen to understand not only inequity relating to other underserved groups who were also identified as not always receiving the services they need, including those who are homeless, LGBTQ+, people in the criminal justice system and those with learning difficulties. Nonetheless, it was recognised that this was a valuable and innovative approach that could put PEO LC on the agenda, which could develop trusting relationships in the local communities and further extend to address inequity among other underserved populations.

The findings uncovered a wide range of barriers and facilitators that were perceived to impact the access and uptake of PEO LC among ethnic minority groups. It was felt that barriers relating to communication, particularly terminology and lack of translation, impacted the access to many services. It was felt that patients' needs were not being identified early enough, whereby more effective strategies are needed to identify those in the last year of life, with clearer referral pathways to ensure patients are referred to services earlier and can receive more timely support. Whilst it was acknowledged that a more diverse workforce in PEO LC would make services more culturally inclusive, all services echoed the challenge of being unable to attract and retain staff from ethnic minority communities.

A range of cultural barriers were perceived to impact the uptake of PEO LC among ethnically diverse communities. There was a consensus across all services that attitudes to death and dying among minority ethnic groups differ from the mainstream and are not widely understood. It was also felt that service providers lack knowledge and confidence on how to talk about death and dying with minority groups from non-Western cultures. It was also felt that negative perceptions towards hospices impact uptake, where assumptions and biases exist for those who use hospice services. It was further felt that hospices/hospice staff were not always viewed as medically competent as hospital staff by professionals and/or the public.

In relation to patient experience, ethical and legal challenges were noted, particularly among participants representing community and hospice settings, where they felt that patients' cultural and faith needs could often conflict with medical procedures and legal requirements. There was also a perception that PEO LC lacked compassion and focused on medical procedures rather than care. Language barriers also impact patient experience, where

professionals/ service providers feel that information isn't often translated or translated effectively. It was also felt that whilst medical information was widely shared, non-medical information was either not shared or not shared enough.

4.2.2. Engagement with community stakeholders, informal carers, and faith leaders

A guiding principle of community-based participatory research (CBPR) is that it is necessary to partner with the communities that will ultimately benefit from the research⁴² with co-production and the engagement of communities and individuals critical when designing person-centred care, especially for marginalised minorities⁴³. To achieve this, we facilitated three roundtable workshops, one with (1) community and service provider stakeholders, which formed part of our launch event and additional separate workshops with (2) faith leaders and (3) informal carers. All events were centred on two main topics. Firstly, to identify the needs, challenges, and priorities at the end of life and secondly, to consider what ideal support looks like and recommendations. After each event, a report capturing the major themes, experiences and suggestions was shared and sent to all attendees to verify and make any suggested changes/additions. Attendees were invited to comment on the report and encouraged to add anything else they would like to add. The reports were updated as and if necessary and then widely disseminated to the RPN.

Workshop 1: Community /provider stakeholders

As part of the launch event, we asked the community stakeholders and service providers who attended to identify the most pressing issues and concerns and identify the big questions that need answering. An overview of the key themes is illustrated in Figure 2, with more detailed findings in Appendix 2. The discussions centred on the cultural appropriateness of

institutional settings in providing PEoLC and how relevant these services are in meeting the cultural and faith needs of ethnically diverse communities that live in BHMK. There was a concern that training healthcare providers to become more culturally aware, whilst helpful, might not be the answer. Rather, there is a need to better understand existing end-of-life care provided by informal carers and faith communities to understand what additional support is needed.

Figure 2: Frequency of words used in discussions with community stakeholders and service providers



Workshop 2 Faith leader's event

To ensure representation for all faiths, we approached the council of faiths of Luton, Bedford and Milton Keynes and emailed 75 individual places of worship and their faith leaders who were identified as providing faith in the local communities across BHMK. We also shared invitations through our networks and the wider RPN. Email invitations and follow-ups were then sent to all institutions identified. A total of 14 faith leaders representing Christian (Pentecostal, Baptist, Catholic, Orthodox), Muslim and Sikh faiths attended the workshop on

July 6, 2022. Leaders from the Hindu and Jewish faiths were missing from the event, although representatives of both had expressed interest in attending.

The faith leaders from Luton, Bedford and Hertfordshire who attended the event revealed that patients and their families have unmet faith support needs exacerbated by the recent pandemic. There is a perception that spiritual and faith care in PEO LC is not prioritised, with professionals lacking the awareness and skills to facilitate this. The discussions further uncovered faith support within the community; however, there is a disconnect with institutional services that provide PEO LC. An overview of the priorities, needs and recommendations are presented in Appendix 3.

Workshop 3: Informal carers event

Engaging with diverse informal carers who can represent the ethnically diverse communities across BHMK was pivotal in understanding the needs, challenges, and priorities of ethnically diverse families to access PEO LC. There was an initial attempt to run a workshop event with informal carers in July 2022; however, despite providing two months' notice, the event failed to attract attendees, so the event was rescheduled. The challenges in engaging informal carers in research are well documented^{44, 45}, with competing demands, lack of time and resource limitations impacting involvement. We liaised with several carer networks who supported us with recruitment, and with their support, we readvertised and changed the location to a more central location in BHMK to make it more accessible, with an afternoon tea included for all attendees. We also adopted a more ethnographic approach to advertising; we drew on our trusted and established informal networks in the local communities through word of mouth and snowballing approaches. This approach was met with good success, with a rescheduled workshop attended by fifteen informal carers from Bangladeshi, Pakistani and Kashmiri who represented the Muslim communities of BHMK. Despite these efforts, there

remained a lack of representation of informal carers from black African, Caribbean, and Eastern European communities. Whilst the reasons for the lack of engagement were unclear, hosting more targeted events at more convenient and neutral locations across BHMK may have increased engagement.

The informal carers forum was highly emotional, where people shared raw and painful experiences in the hope that they could improve the situation for others in their communities in the future. There was a consensus that help and support from PEOLC service providers were needed; however, this should complement rather than the family's role. Discussions also uncovered a wide range of cultural, religious, and structural barriers that impacted access to PEOLC in their communities, including a lack of awareness of what support exists and how this can be accessed, the perception that PEOLC does not have the spiritual and religious understanding to meet the needs of the communities, and a disconnect between service providers and community support. A more detailed overview of the priorities, needs and recommendations are presented in Appendix 4.

4.2.3. Data analysis and prioritisation

The triangulated findings from the interviews and stakeholder discussion groups revealed that barriers vary across settings, and whilst some issues affect everyone equally, there are significant barriers that negatively impact ethnic minorities more than their white British counterparts. There was also consensus around some of the most pressing issues and potential solutions across the stakeholder workshops, with the core themes presented below:

Awareness of Palliative Care Services

Families and the wider community did not understand what PEOLC support is available, particularly non-NHS institutions such as hospices and how this support can be accessed.

There was a preconception that the services available were focused on taking the individual way from their home and family. Informal carers were unaware that community-based hospice at-home support is available, and they were particularly open to understanding more about this support. Families were unsure what was available, which they needed to know to enable them to make a judgement of if this support would fulfil a required need. This finding supports previous research which has identified low awareness and negative perceptions as a barrier to accessing PEOC^{46, 47}, particularly towards hospice care²⁰. To address this it was felt that services needed to be more proactive in their efforts to increase access by offering services to families by reaching out to communities to increase awareness of services and support available. It was also acknowledged that patients are not identified early enough and are not provided the information they need when they need it. Therefore, clear processes are needed earlier in the end-of-life pathway to ensure families are aware of available services and support before reaching a need and/or crisis point.

Perceived need for Palliative Care Services available

Whilst it was acknowledged that people need to understand the services available, it was also felt that providers also need to understand what services are needed and wanted by the communities they serve. The consideration of need is fundamental to explaining demand and supply variations of healthcare delivery and can exacerbate inequity, particularly when services do not allow for variations in need between and within population groups⁴⁸.

Families want services that fit with the community's understanding of caring for people who are dying rather than trying to replace the care families provide. This is particularly important when services are perceived not to be congruent with cultural and social expectations around caring for loved ones, with a concern that services will override the family's role or remove the dying person from their loved ones⁴⁹.

Disconnect between institutional and non-institutionalised routes

Whilst '*institutionalised*' services (e.g., hospices) are available, minority ethnic groups often depend upon informal carers, faith, and community support, i.e., '*non-institutionalised*' routes that focus on providing love and care but have limited medical expertise.

Conversations centred on the disconnect between these routes with an acknowledgement that service providers and diverse ethnic communities need to engage more with each other; they are, however, far less certain about how. This uncovers the need for a more holistic understanding of the pathways and integration between '*institutionalised*' and '*non-institutionalised*' routes to understanding how these services can work better across the wider provision and how services can better fit with the community's understanding of caring for patients and their families.

Person-centred approaches to end-of-life

Person-centric care requires medical institutions to promote compassion and encourage the initiation of broad conversations about death and dying that give weight to non-medical needs through effective processes to capture and share this information. This is true for everyone. However, it is more important to people, particularly those from multi-faith communities whose beliefs about death are far from Western medical practices. The findings revealed that service providers often lack knowledge and confidence on how to talk about death and dying with minority groups from non-Western cultures. Care delivered in hospitals and the community was perceived to lack compassion, focusing more on the medical procedure than care. Treatment plans were viewed as rigid and based on the primary medical diagnosis and comorbidities, not on the capabilities and wishes of the patient or their families.

Medical, ethical, and legal challenges in PEOLC can impact access and experience among ethnically diverse communities²¹. The findings revealed that service providers can often find

themselves in ethical dilemmas when the cultural and faith needs of minority ethnic patients and their families can conflict with medical procedures and legal requirements. All stakeholder groups cited examples of distressing conflict, and while it exists in all settings, conflict is more extreme when medical rules are employed rigidly. There is, therefore, a need to move beyond medical procedures to care more holistically for the patient and their family through building rapport and trusted relationships with flexibility and person-centric approaches considered necessary to reduce the incidence and intensity of conflict.

Religious and cultural needs

PEoLC was perceived as not acknowledging the important role that faith and spiritual care play in the diverse communities they serve, with a lack of policy and process that puts spiritual or faith needs on par with medical interests. While community stakeholders recognised that service providers understand patients' medical and sometimes emotional needs, they felt that there is limited value placed on the importance of faith and spiritual care. It was felt that ethnic minority communities need spiritual care from someone who will familiarly care for them, with PEoLC services perceived to lack the spiritual and religious understanding to support the needs of minority ethnic patients and their families. More person-centric and culturally sensitive approaches are needed to address spiritual and faith care for patients and families, where individual cultural and spiritual beliefs, priorities and wishes are acknowledged and respected^{24, 50}. Pathways to better integrate PEoLC with spiritual and faith support that exists in the community will provide more familiar support and care that can better meet the faith needs of patients and their families.

Language and communication barriers

Language was viewed as a barrier to the use and experience of PEoLC services by people with ethnic minority backgrounds, both in terms of translation and terminology. While the

former is an issue that only affects people from ethnic minority communities, terminology is a problem for all. However, it is undoubtedly worse for people for whom English is not their first language and whose first languages do not have effective translations for common terms, including: '*End of Life*', '*Palliative Care*' and '*Hospice*'. Providing on-demand translation for the most used languages in the region is essential, and recruiting staff from these communities to make services feel more culturally relevant was expected to improve the situation significantly.

Role of family caregivers

The informal carers we spoke to revealed that there is a cultural expectation in South Asian families to provide care for relatives, with stigma and guilt associated with any other course of action. However, some informal carers felt excluded from key decisions about their loved one's care and lacked confidence or were fearful of challenging expert and professionals. This reinforces previous findings, which highlight the importance of engaging with the wider family when making decisions surrounding palliative care⁵¹. Whilst this may be the case for many families several community members felt that the assumption that certain communities look after their own is not always accurate, particularly for those who live alone or do not live near family or have children⁴⁶. Therefore, having sensitive conversations early with the patients to understand the role of their family in their care is crucial, whilst avoiding cultural assumptions that may negatively impact access⁴⁶.

Informal carers voiced their concerns about the lack of support and care they received following the death of their loved ones. Many family caregivers cited experiences of depression but were offered no support. Families felt that the system required them to fight for the counselling/help that they needed at a time when they were least able to do so. It was also felt that when the support was accessed, it was generic and not culturally relevant.

These findings reinforce gaps in bereavement care and support that is being provided to minority ethnic populations⁵². Further research is therefore needed to understand the important role friends, family, and the community play in providing bereavement support in ethnically diverse communities and understand what bereavement care is needed and how this can be successfully integrated to complement existing support and better meet the needs of the family.

There is considerable agreement about the issues and how they impact the use and experience of PEO LC by people from ethnic minority communities. However, service providers and the communities need guidance and to share best practices to learn quickly and avoid repeating the same mistakes.

4.3. Work Package 3: Use findings from WP1 and WP2 to drive research activity and change

4.3.1. Research activity and partnership

KEEP-NET has addressed a significant gap in research infrastructure through the development of a robust, inclusive, and representative RPN, which has brought together over 80 partner organisations, including commissioners, service managers, providers and clinicians who work across primary care, palliative care services and community, hospice, and hospital settings, academics alongside community stakeholders, including faith leaders, community networks, third-sector organisations, carers and community members and academics that represent the diverse and multi-faith communities of BHMK.

A key aim of the funding was to support the development and growth of partnerships and collaborations, which could facilitate the submission of a high-quality proposal which could be submitted to a forthcoming NIHR research commissioned call on PEoLC. Research priorities were identified through the triangulation of the experiences of the major stakeholder groups, including service providers, community groups, faith leaders and informal carers, as outlined in Work Package 2. These priorities were then used to co-develop a research funding proposal with formed work packages based on an agreed topic by the RPN to address inequality in access and uptake of PEoLC for ethnically diverse communities.

KEEP-NET uncovered that whilst service providers and communities acknowledge they need to engage with each other more, they remain uncertain of the best way to achieve this. A funding application will, therefore, seek to adopt a proactive approach to create a more holistic understanding of the pathways and integration between '*institutionalised*' and '*non-institutionalised*' PEoLC. This research, if funded, will seek to adopt a system-wide approach and provide the evidence base for a multi-faceted intervention comprised of co-designed tools and resources aimed at health professionals, health providers and community stakeholders to increase engagement and interactivity that seeks to address existing inequalities. Through improved interactions between '*non-institutional*' and '*institutionalised*' settings, this research seeks to make an impact through increased referrals, access, and engagement of PEoLC among minority ethnic groups, provide PEoLC that meets the needs of diverse minority groups and provide increased awareness of barriers to access to PEoLC among minority ethnic groups across stakeholders at a national and international level.

As KEEP-NET has begun to grow and partnership relationships have matured, it has provided a platform for further unplanned spin-off research projects and collaboration⁵³. For example, the research team were awarded funding to conduct a pilot and process evaluation funded by the Bedfordshire, Luton, and Milton Keynes (BLMK) Integrated Care System (ICS) to evaluate if a 'Community Connector' intervention programme is feasible, acceptable to beneficiaries and implementers, and appropriate for the local cultural context within the cancer and end-of-life care pathway for minority ethnic communities. KEEP-NET has also been invited to collaborate on several research projects that focused on engaging diverse populations in PEO LC and has become a study site for a recently funded NIHR bereavement study that seeks to explore improving bereavement services for ethnic minority communities. These sustained efforts will be crucial in developing long-term working relationships through the RPN.

4.3.2. Impact and outputs

While the key aim of KEEP-NET was to drive research activity, there were additional notable outcomes from this project that have the potential to impact the local communities significantly. Through an extensive mapping exercise, we developed a searchable PEO LC service repository for BHMK, which has provided a useful front-facing tool for the local community to understand what services exist, what support they provide, and how they can be accessed. There are plans for how this can be further maintained and developed. The service repository was demonstrated as part of the KEEP-NET dissemination event, with details on how it can be used, accessed, and shared. This resource will also be widely shared with key stakeholders identified in KEEP-NET, including service providers, community and faith leaders and informal carers, to ensure that it can be made available and accessible to the communities that will benefit from it.

In addition, an unanticipated activity which resulted since the launch of KEEP-NET was the implementation of a new ‘Community Connector’ role, crowdfunded by the community, to engage with Luton’s Muslim communities as a conduit between *institutional* PEOLC and the community to build networks and increase capacity in PEOLC. Community connectors have become an important community asset and are integral to the CORE20PLUS⁵⁴ strategic approach to addressing inequalities in underserved populations across England. This innovative role has the potential to facilitate better integration of community and voluntary services in PEOLC, which may enhance the community’s stage of readiness to address disparities in access to PEOLC⁵⁵. Further research is needed to evaluate the implementation of this role to understand if and how this initiative can address disparities in access to PEOLC and how it may enhance other community-facing peer-led roles, which will provide useful evidence for local and national commissioners and policymakers.

4.3.3. Dissemination

Dissemination and engagement have been integral in maintaining KEEP-NET. Soon after the project started, a local and national press release featured the launch event on numerous TV channels. An interactive webpage, hosted on the University of Bedfordshire server, was developed, which provides information about the network, shared network vision and common values underpinning the group, blogs about named members, events and meetings, research activity, outputs, and dissemination. We have also provided regular updates, including details of outputs, progress, and events, shared via social media networks, including X (formerly Twitter) and mail distribution lists.

At the end of 2022, we also hosted a dissemination event, which presented the key findings and progress from the RPN alongside future steps and recommendations. It was held at the University of Bedfordshire on December 1, 2022. This event included sessions on the new Keech Community Connector role, the service repository tool, the themes and questions generated from the launch, faith leader and informal carer events, and the progress and achievements made in relation to research activity. Feedback was also sought and captured on the tangible initiatives of KEEP-NET and research priorities, which were then fed into the NIHR research funding proposal. This event was well attended (N = 24), including representatives from hospices, hospital trusts and community nursing ($n = 11$); representatives from community groups ($n = 6$); informal carers ($n = 3$); and academics ($n = 4$).

5. Discussion

An inclusive and representative RPN, comprised of over 80 key partners, professional groups, and community stakeholders representing the ethnically diverse communities of Bedfordshire, Hertfordshire, and Milton Keynes, was successfully launched. Through this network, we have developed a research infrastructure that has provided a supportive environment for research collaboration facilitated through networking and collaboration committed to reducing the inequalities of PEOLC. The RPN successfully achieved all three objectives, including the co-production of a research funding proposal submitted to a NIHR commissioned call with formed work packages that seek to improve access and uptake to PEOLC for ethnically diverse communities.

The development of KEEP-NET was rooted in the principles of CBPR⁵⁶, bringing together researchers, practitioners, community stakeholders and the public to share power and responsibility to ensure research remains committed to tackling the issues identified by the

community⁵⁷. The value of community-based research in reducing inequities has been widely documented^{58, 59}, alongside an increased recognition of the role community and faith groups play in improving health outcomes among disadvantaged populations⁶⁰. The lessons learnt throughout this process also offer insight into the challenges faced and provide recommendations on what can strengthen equitable partnerships based on what has worked and what has not. This research, therefore, contributes to the wider evidence base to help understand how community research partnerships can be successfully developed and built in an ethnically diverse community within the context of PEOLC.

Through bringing together key stakeholders, including service providers, informal carers, and community and faith leaders, KEEP-NET provided a unique and holistic understanding of the factors influencing access to PEOLC for minority ethnic communities in BLMK. Triangulated findings uncovered a complex interplay of demographic, institutional, psycho-social and cultural factors^{23, 46} that influence access and uncovered the important yet under-utilised role community and faith groups play in supporting the mixed healthcare economy in ethnically diverse communities. The findings further support recent theoretical developments, which acknowledge the importance of mobilising communities to engage with palliative and end-of-life care services, which can help improve access⁵⁵. The implementation of ‘community connectors’ as an innovative role to create opportunities for integration will provide useful evidence for local and national commissioners and policymakers on how community-facing peer-led roles can be embedded within the complex system and across the patient pathway to address inequity in PEOLC⁶¹.

5.1. Lessons Learned

Through KEEP-NET, we have listened to, engaged with, and empowered local communities in BHMK to share, which has created a strong, robust infrastructure for collaboration. While this partnership has facilitated numerous benefits, the journey has not been without its challenges, and thus, we outline some of the lessons learned, including the ongoing uncertainties.

Developing KEEP-NET required a flexible and agile approach to engage effectively with institutionalised and non-institutionalised stakeholders. There was a need to understand what motivates different stakeholders across the system to want to become partners within the network. Representatives from institutionalised settings understood the concept of KEEP-NET and recognised the need for an RPN specifically focused on ethnic minority inequalities in the region. It was clear that there was a clear motivation among service providers to gain an understanding and insight into the problems faced by ethnic minorities in engaging with PEoLC services. Many of the services were aware of the significant barriers for diverse communities and were actively seeking support to better understand how to develop strategies to address inequity.

Community stakeholders, in contrast, were clear that research in and of itself was not enough of a benefit for them to want to be involved. Whilst they valued that community voices were being heard, many felt they had said the same things before and nothing had changed.

Community representatives, therefore, wanted tangible actions in return for their participation and wanted to understand what has or will change as a consequence of this network.

Therefore, there was a need to balance the delivery of quick, actionable results with the more time-consuming outputs such as research publications and grant applications. Managing differing stakeholder expectations has been identified as an important factor when developing

new partnerships to ensure success and long-term sustainability⁶². We therefore sought to adopt a more flexible understanding of what could be changed which enabled a more realistic judgement of what could be achieved within the partnership to address the complexity of the wider problems²⁸.

It is important to highlight the context in which KEEP-NET was formed. Launched in March 2022, the communities across BHMK were still recovering from the recent COVID-19 pandemic, many of whom had been disproportionately impacted. There were heightened tensions and increased distrust, particularly towards government bodies and health providers⁶³. Dealing with these tensions early in the process was paramount to building trust. Laying the foundations for KEEP-NET with the development of ground rules was an essential step in building trusting relationships. Bringing together partners with diverse assumptions, perspectives, and experiences can cause tension⁶⁴, therefore sharing a joint purpose of learning to achieve the same goal was able to facilitate equal partnership working alongside increased transparency and trust³⁵⁻³⁷.

Transparency and accountability between all partners are important to ensure equitable partnerships⁶⁵. KEEP-NET unearthed difficult and, at times, confrontational conversations where service providers' ways of working were challenged. The success of these discussions was dictated by the service providers' ability to bring their expertise to the RPN with a level of openness that issues with accessing and using PEoLC services by people from ethnic minority backgrounds exist. Whilst at times challenging, service providers gained from and contributed the most to the network when they resisted natural responses to be defensive, with an acknowledgement that embraced the founding principle of KEEP-NET that every person's voice was equally valid and valuable. These open and honest discussions enabled

community stakeholders to move beyond ‘mistrust’ and ‘scepticism’ to a place of mutual respect and partnership centred on a shared vision and commitment from all.

5.2. Strengths and limitations

This research partnership successfully brought together over 80 organisations and services, including commissioners, service providers, faith leaders, community networks, third-sector organisations, informal carers and academics representing the diverse and multi-faith communities of BHMK. By taking a flexible and agile approach, we were able to convene a range of workshops. Our key learning point is that building trust in ‘often-ignored’ communities takes time and flexibility.

We know that there are many examples of unmet needs and that the voice of the informal carer is pivotal in understanding how we can improve access and uptake of PEO LC. Despite wide advertising, allowing plenty of time to plan to attend, and putting the event at a time that might make it easier for others to attend (during school hours), factors we were told were important, we were still met with challenges in engaging with informal carers that can represent the diverse communities across BHMK. Whilst we successfully engaged Muslim informal carers ($N = 15$), which uncovered insightful experiences of accessing PEO LC, we acknowledge that the views heard may not reflect those of all ethnic minority groups in BHMK. We expect that whilst some commonalities exist, some distinct barriers may impact ethnic communities differently. Therefore, future engagement should centre on having multiple workshops hosted in community settings and targeted at different community groups to ensure that all sections of the community feel empowered to share their views and experiences. Additionally, the addition of alternative and convenient methods, such as

surveys and online workshops, may also enhance participation, particularly among informal carers.

5.3. Summary and next steps

An inclusive and representative RPN was established, comprised of over 80 partner organisations bringing together commissioners, service managers, providers and clinicians who work across primary care, palliative care services and community, hospice, and hospital settings, academics alongside community stakeholders, including faith leaders, community networks, third-sector organisations, carers and community members and academics that represent the diverse and multi-faith communities of BHMK.

This partnership addressed a significant gap in research infrastructure through the development of a robust, inclusive, and representative RPN, which has facilitated improved research activity that included the co-production of a recent funding application meeting the existential objective of the RPN. Beyond that, KEEP-NET has provided insight into factors that can facilitate the successful collaboration between different stakeholders, alongside some of the challenges we faced that are particularly pertinent to multi-faith and diverse communities. We offer our observations through KEEP-NET as an opportunity for shared learning to consider when in the planning stages of developing and building a research partnership network.

Moving forward, the longer-term sustainability of KEEP-NET will remain dependent on continued funding, time, and commitment from all stakeholders to ensure the relationships, infrastructure and benefits developed in this project are preserved⁶⁶. The university has made a strong commitment to support KEEP-NET and will continue to work with new and existing partners to enable mutually beneficial research collaborations with those who share

the same mission and commitment to reducing health inequalities in PEO LC. We will continue to feedback to the RPN on research activity, including the recently funded evaluation of the new community connector role implemented within BLMK, to ensure that we remain accountable and can continue to build trust with the community. Developing a clear operating structure for KEEP-NET, alongside ongoing monitoring⁶⁵, will be crucial to ensure continued engagement and progression, particularly without ongoing funding and resources. The mutual benefit of developing this partnership and working collectively with communities to address inequalities in accessing PEO LC could provide a useful approach and way of solving other important priorities to reduce wider health inequalities.

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6. Additional information

CRedit Statement

<i>Role</i>	<i>Name</i>
<i>Conceptualisation</i>	Prof. Gurch Randhawa (Equal), Dr Erica Cook (Equal)
<i>Data Curation</i>	Not applicable
<i>Formal Analysis</i>	Dr Erica Cook (Lead)
<i>Funding Acquisition</i>	Prof. Gurch Randhawa (Equal), Dr Erica Cook (Equal), Elaine Tolliday (Supporting)
<i>Investigation</i>	Dr Erica Cook (Lead), Prof. Nasreen Ali (Supporting), Dr Emma Wilkinson (supporting), Mehrunisha Suleman (Supporting), Elaine Tolliday (Supporting)
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<i>Resources</i>	Not applicable
<i>Software</i>	Not applicable
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<i>Validation</i>	Not applicable
<i>Visualisation</i>	Not applicable

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Disclosure of interest

Suleman declares being a Trustee for Arthur Rank Hospice, Cambridge.

Data sharing statement

All data requests should be submitted to the corresponding author for consideration. Access to all anonymised data may be granted following review by the data sharing officer and completion of a data sharing agreement.

Ethics statement

This research has been conducted in accordance with the World Medical Association Declaration of Helsinki. Ethical approval was obtained from the Institute of Health Research Ethics Committee at the University of Bedfordshire on 14th March 2022 (REF: IHREC979).

Information Governance Statement

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List of abbreviations

BHMK	Bedfordshire, Hertfordshire and Milton Keynes
BLMK	Bedfordshire, Luton and Milton Keynes
CBPR	Community Based Partnership Research
ICB	Integrated Care Board
KEEP-NET	KEEch Research Partnership NETwork
NHS	National Health Service
NIHR	National Institute for Health and Care Research
NICE	National Institute for Care and Excellence
RPN	Research Partnership Network
PEoLC	Palliative and end-of-life care
PPI	Patient and Public Involvement

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Appendices

Appendix 1

Table 2: Themes and subthemes from interviews with stakeholders

THEMES		HOSPITAL	HOSPICE	COMMUNITY
ACCESS	Knowledge		<ul style="list-style-type: none"> PEoLC needs not identified early enough. Not all GPs know their patients/signpost. Under-representation of ethnic minorities isn't effectively measured/difficult to address. 	
	Communication	<ul style="list-style-type: none"> Terminology used is misunderstood, including palliative care, End of Life and Hospice Information isn't translated, translated effectively, in a timely manner, or access to translation isn't known. 	<ul style="list-style-type: none"> Terminology used is misunderstood, including palliative care, End of Life and Hospice Information isn't translated, translated effectively, in a timely manner, or access to translation isn't known. 	<ul style="list-style-type: none"> Terminology used is misunderstood, including palliative care, End of Life and Hospice Information isn't translated, translated effectively, in a timely manner, or access to translation isn't known.
	Operational barriers	<ul style="list-style-type: none"> Inability to attract staff from minority communities to PEoLC roles 	<ul style="list-style-type: none"> Complexity and fragmentation of the system – professionals don't always know how it works and patients are confused and fall through gaps. Inability to attract staff from minority communities to PEoLC roles 	<ul style="list-style-type: none"> Complexity and fragmentation of the system – professionals don't always know how it works and patients are confused and fall through gaps. Inability to attract staff from minority communities to PEoLC roles
	Recommendations		<ul style="list-style-type: none"> Better identify those in last year of life Translate materials and distribute in community settings. 	<ul style="list-style-type: none"> Better identify those in last year of life Train all community-based nurses in palliative care
UPTAKE	Knowledge and perceptions	<ul style="list-style-type: none"> Attitudes to death and dying differ from the mainstream & not widely understood. Service providers lack knowledge/confidence on how to talk about death & dying with minority groups from non-Western cultures. 	<ul style="list-style-type: none"> Attitudes to death and dying differ from the mainstream & not widely understood. Assumptions and bias exist around who can use hospice services. Hospices/hospice staff not always viewed as medically competent as hospital staff by professionals/public. 	<ul style="list-style-type: none"> Attitudes to death and dying differ from the mainstream & not widely understood. Service providers lack knowledge/ confidence to talk about death and dying with minority groups from non-Western cultures.

EXPERIENCES			<ul style="list-style-type: none"> • Service providers lack knowledge/confidence on how to talk about death & dying with minority groups from non-Western cultures. 	
	Communication	<ul style="list-style-type: none"> • Information isn't translated, translated effectively, or access to translation isn't known about 	<ul style="list-style-type: none"> • Information isn't translated, translated effectively, or access to translation isn't known about. 	<ul style="list-style-type: none"> • Information isn't translated, translated effectively, or access to translation isn't known about
	Operational barriers	<ul style="list-style-type: none"> • Inability to attract staff from minority communities to PEOLC roles 	<ul style="list-style-type: none"> • Inability to attract staff from minority communities to PEOLC roles. • Plans to engage with ethnic minorities are often short term, ad hoc and almost set up to fail with unrealistic measures. 	<ul style="list-style-type: none"> • Inability to attract staff from minority communities to PEOLC roles.
	Recommendations	<ul style="list-style-type: none"> • Go beyond medical procedures to care for the person and those they care for holistically. • Build relationship with the family not just the patient. 	<ul style="list-style-type: none"> • Plans for ethnic community engagement need to be long term and not judged on fast increases in uptake by patients. • Build relationship with the family not just the patient. 	<ul style="list-style-type: none"> • Take the End of Life badge off. • Build relationships with wider family. • Train community-based nurses in PEOLC. • Go beyond medical procedures to care for the person holistically.
	Faith and cultural barriers	<ul style="list-style-type: none"> • Culture & faith needs conflict with medical procedure and legal requirements. • Hospital rules (visiting restrictions etc) conflict with cultural and personal needs. • Nursing perceived as lacking compassion, focused on medical procedures rather than care 	<ul style="list-style-type: none"> • Culture & faith needs conflict with medical procedure and legal requirements. 	<p>Nursing perceived as lacking compassion, focused on medical procedures rather than care</p>
	Communication	<ul style="list-style-type: none"> • Information isn't translated, translated effectively, or access to translation isn't known about. • Failures in information sharing across the system – SystemOne not enough; EPaCCS not available. • Non-medical information is not shared or not shared enough. 	<ul style="list-style-type: none"> • Information isn't translated, translated effectively, or access to translation isn't known about. • Failures in information sharing across the system – SystemOne not enough; EPaCCS not available. • Non-medical information is not shared or not shared enough 	<ul style="list-style-type: none"> • Information isn't translated, translated effectively, or access to translation isn't known about. • Failures in information sharing across the system – SystemOne not enough; EPaCCS not available. • Non-medical information is not shared or not shared enough.
	Operational barriers	<ul style="list-style-type: none"> • Resources are limited and often over-stretched. • Stressed staff have less time for individual differences 	<ul style="list-style-type: none"> • Resources are limited /often over-stretched. • Misconceptions about hospice funding means people feel they cannot access services. 	<ul style="list-style-type: none"> • Resources are limited/ often overstretched. • Stressed staff have less time for individual differences.
	Recommendations	<ul style="list-style-type: none"> • Compromise is needed care to meet non-medical needs. • Share information beyond medical instructions • Investigate non-medical through questioning. 	<ul style="list-style-type: none"> • Implement the basics of cultural competence. • Reach out to Communities in steps. • Separate day and in-patient hospice services 	<ul style="list-style-type: none"> • Build relationship with the family. • Go beyond medical procedures.

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| | <ul style="list-style-type: none">• Engage with faith/religious leaders.• Understand care doesn't end with the last breath and create processes that reflect this. | <ul style="list-style-type: none">• Provide culturally acceptable well-being support.• Build & promote career paths for ethnic minority staff. | |
|--|---|---|--|

Key: Purple= affects everyone equally; orange = affects everyone but people from ethnic minorities more; blue = only affects people from ethnic minorities

Appendix 2: Feedback from community/provider stakeholders

Needs, challenges, and Priorities.

Language/Terminology

- Many terms used in PEO LC care are problematic - misunderstood, unclear, irrelevant, or offensive.
- The term hospice is misunderstood and viewed by some as a place where death is promoted.

Access to information and services

- There needs to be a reliable and clear process for making people aware of PEO LC services.
- Many want to die at home and are unlikely to seek out non-NHS services that are not understood.
- There is a lack of information in and from the community about service availability.
- There is a crossover from those providing support in the community, e.g., informal carers or religious leaders caring for the spiritual transition, to those providing support for the physical transition.
- Hospices are based in more rural settings and, thus, more difficult to access.
- The hospice at-home service provision is not well understood.

Navigating the system

- Many need to know what's available to ask for a referral; however, many need a referral to find out what's available – referred to as a 'vicious circle'.
- Lack of consistency of knowledge amongst medical professionals impacts referrals and access.
- Cultural understanding and acceptance are needed in hospitals where many die.
- GP's awareness of available options for patients is varied, meaning opportunities are missed.
- Lack of trust towards healthcare professionals/services exists from previous medical experiences.
- People preparing for life transition are not always sure about what they want.
- The system doesn't consistently deliver even when people engage with services and plans.

Applicability of services

- Why is it necessary to institutionalise love and care?
- People need to understand the services available; providers need to understand what services are wanted.
- The perception that services need to be co-developed to meet a need in the community.
- Lack of ethnic representation and relevance (staff, patients, providers)
- Service providers are not viewed as culturally aware and/or need more religious support.
- Services cannot meet the cultural/spiritual needs which are provided by faith/community groups.

Service provider challenges

- Difficulties in recruiting hospice staff to represent minority ethnic communities in BHMK
- Lack of knowledge of cultural practices from service providers
- High turnover of staff

Talking about end-of-life

- What should these conversations be called – tender, difficult, sensitive, important?
- Possible conflict between disclosure, families, and religious views
- The integral role of families as gatekeepers should be considered more.
- Stigma can exist around looking for help outside the family/community.
- Empathy – understanding the complexity of emotions, including guilt, grief, and mental and physical exhaustion.

Communicating with health professionals

- The perception is that professionals need more time to understand the person.
- It is frustrating and distressing for patients/families to keep repeating the same story.
- Health professionals become defensive if challenged over care issues.

Appendix 3: Feedback from faith leader stakeholders

Needs, challenges, and Priorities

- Failure to recognise the importance of faith and spiritual care enough, and a lack of policy and process that puts spiritual or faith needs on par with medical interests.
 - PEOLC institution staff whilst may understand patients' medical and sometimes social and psychological needs, they lack understanding of importance of faith.
 - PEOLC institution staff lack skills to offer/source spiritual care for their patients.
 - People need spiritual care from someone who will care for them in a familiar way.
 - Chaplains' multi-faith role are not understood, nor is the method for reaching a chaplain effective.
 - Misconception Chaplains have Christian connotations and/or viewed as 'last rites'.
 - Disconnect between faith support in the community and PEOLC services. Faith support is available although no connect between those faith communities and PEOLC service providers.
 - Perceived lack of community based PEOLC for ethnic minority communities means they stay in hospitals away from their faith communities.
 - Patients who engage with Chaplains in medical institutions and then return to the community are left unsupported.
 - COVID-19 have exacerbated gaps in people's faith support needs.
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Suggestions for improvement

Give non-medical support equal standing and resource to medical.

- Establishing an individual's faith beliefs, priorities, and wishes should be part of standard requirements and procedures, such as inclusion in records and handovers.
- Keeping track of spiritual needs is as important as basic medical information.
- Professionals need training to understand importance of spirituality in PEOLC.

Start talking about spiritual needs early.

- Spirituality and faith needs to be discussed earlier.
- GPs/hospital doctors need to open these discussions, or bring in people that can.
- Discussions should be sought pro-actively to reduce barriers in access.

Support spiritual and faith needs of informal carers/families.

- Families/informal carers need support to address bereavement to support them to process and cope with the pain of loss.
- Early support will improve psychological outcomes.

Utilise and connect providers of different services with each other.

- There are a range non-medical initiatives and roles available that need to work together and interact with medical services.

Provide education and information on services to faith communities.

- Hospices must bring people from hospices/providers into faith communities.

Appendix 4: Feedback from informal carers

Needs, challenges, and Priorities

Help is wanted and needed

- There is a strong cultural requirement to provide care for relatives, and stigma and guilt are associated with any other course of action.
- Many informal carers were left to cope with their loved ones nearing and even after death without professional advice and support on how to care for the person effectively.
- Informal carers want services that fit with the community's understanding of caring for people that are dying.
- Service providers should not seek to replace the care informal carers provide with services that override the family's role or remove the dying person from their loved ones.
- The care experience should be available at home.
- Limited awareness of the community-based services available or how to access them.

Cultural and religious barriers

- Perception that services lack spiritual and religious understanding and awareness to support needs of patients/family.
- Communities lacked understanding of the PEOLC institutions.
- Conflict between rules of PEOLC institutions and cultural and faith needs of the patient were commonplace.
- The needs of priorities of family and friends need to be accommodated.

Structural barriers

- Treatment plans were viewed as rigid and based on the primary medical diagnosis and comorbidities, not on the capabilities and wishes of the patient.
- Informal carers felt excluded from key decisions about their loved ones' care and lacked confidence or fearful to challenge experts professionals.

Navigating the system is difficult, if not impossible.

- Different jurisdictions between health and social care, between condition-specific health professionals and their palliative counterparts, between hospital and community care and between different geographical areas all make it difficult for informal carers to find help.
- Terminology is used which only refers to internal processes and nothing to do with services themselves.
- Informal carers must become the system navigator, dealing with bureaucracy on top of caring which is overwhelming.
- Local communities and service providers are not connected in any meaningful way.
- Processes for getting help with some practicalities are complex, cumbersome, and often delivered too slowly.
- Depression is common for family members after the death of the cared-for person, but no support is offered.
- The system requires families to fight for help [counselling] at a time when they are least able to do so.
- Counselling available is generic and is not culturally relevant.

Suggestions for improvement

- Prioritise services that support informal carers in their homes.
 - Informal carers need specific information, support, and training to ensure they are doing the best for their loved ones.
 - Provide education to informal carers so that they are aware of what to expect as a person progresses towards death.
 - Increase awareness of services earlier before a need /crisis point is reached.
 - Create a register of people at EoL and proactively offer services.
 - Translations of written materials and translators for face-to-face services should be available on demand.
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- Provide more culturally competent counselling, such as Islamic counselling in statutory services.
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