

**Establishing a research partnership for delivering palliative and end-of-life care for older people in rural and remote areas: a formative mixed-methods study.**

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## Research Article

# Establishing a research partnership for delivering palliative and end-of-life care for older people in rural and remote areas: a formative mixed-methods study

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## Abstract

**Background:** Many older people live in rural and remote areas. As the ageing population grows, conditions such as cancer, dementia and stroke will become more prevalent, causing a huge demand for palliative and end-of-life care. However, evidence regarding models of care and interventions in rural and remote areas is limited.

**Aim:** A new United Kingdom rural palliative care partnership was funded for 12 months. It aimed to understand the models of palliative and end-of-life care for older people with cancer, dementia and stroke in rural/remote areas across all four nations of the United Kingdom. It also aimed to identify the core priorities for research into rurality and palliative care for older people.

**Methods:** The project consisted of three integrated components, including: (1) a scoping review of relevant literature on rural palliative care for older people with cancer, dementia and stroke; (2) stakeholder engagement workshops using a modified Nominal Groups Technique and (3) qualitative interviews with family carers who supported rural-/remote-dwelling older adults towards the end of life.

**Results:** Our scoping review was undertaken in 2022. The search identified 1128 unique citations, of which five papers were included. There were no United Kingdom studies on models of palliative and end-of-life care delivered to older people with cancer, dementia or stroke within rural/remote locations. However, international models of care were identified. Models included technological interventions to reach those in remote locations, the role of palliative care nurses and the use of volunteers. Articles highlighted the importance of not replacing face-to-face care with technology for ease of reaching more people and emphasised the importance of effective interdisciplinary working in rural and remote palliative care.

Additionally, three online workshops to develop research capacity, identify models of care, understand issues of rurality and determine research priorities were attended by 15–20 stakeholders. Qualitative interviews were also undertaken with 20 family carers who had supported rural-/remote-dwelling older adults at their end of life. Data identified that rural/remote communities face challenges in accessing palliative and end-of-life care due to issues such as transport to and distance from services, poor broadband coverage and problems with workforce recruitment and retention.

Synthesising the data from these methods helped to identify some interventions and models of care for palliative and end-of-life care for older people in rural and remote areas. It also helped us to jointly shape and develop research priorities, which included workforce planning and service composition, facilitating preferred place of death and the

role of technology. However, there are gaps in our understanding about how to improve the family carer support as well as digital literacy among older people to help them benefit from technological interventions.

**Conclusions:** Overall, there is a lack of research on palliative and end-of-life care models and interventions provided to older adults with cancer, dementia and stroke in rural and remote settings, especially in the United Kingdom. There is an urgent need to co-design community-based models of palliative and end-of-life care in rural and remote locations, considering the unique challenges of living in these areas.

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## Background

A higher proportion of older adults live in rural and remote areas within the UK.<sup>1</sup> Subsequently, conditions associated with older age, such as cancer, dementia and stroke, are more prevalent in these areas.<sup>2,3</sup> It is estimated that, by 2039, nearly half of all households in rural areas will contain people aged  $\geq 65$  years.<sup>1</sup> The percentage of the population aged over 85 years – the group most likely to need care – is also significantly higher in rural areas than in urban areas.<sup>4</sup>

Despite the age and disease prevalence in these settings, rural and remote areas have worst access to health services and fewer social care resources<sup>5,6</sup> as well as poorer outcomes. Correspondingly, there is a demand and unmet need for palliative and end-of-life care in these areas. Currently, only 50% of those in England who are dying receive the palliative care they need,<sup>7</sup> and reports estimate that people in rural and remote areas are some of the most underserved and unmet when it comes to providing palliative and end-of-life care.<sup>8</sup>

Cancer, dementia and stroke are major contributors to morbidity and mortality in the UK.<sup>9</sup> There are almost 1 million people living with dementia in the UK.<sup>10</sup> This figure is projected to reach 1.4 million by 2040, largely due to accelerated population aging.<sup>11</sup> Deaths from cancer are projected to increase from 167,000 to over 200,000 by 2035 with demand for palliative care services in England and Wales, which is expected to increase by 42% by 2040.<sup>12</sup> By 2050, these numbers will nearly double to 22 million and 7 million respectively.<sup>13</sup> UK projections also indicate that between 2015 and 2035, stroke cases will increase by 60%. However, the number of stroke survivors is likely to more than double, resulting in an anticipated rise in social care costs by as much as 250% during the same period.<sup>14</sup>

There is a need to improve access to universal, high-quality health care and social care to all those affected with cancer, dementia and stroke. However, the unequal

distribution of where older adults reside in the UK poses a significant challenge. While the UK has been ranked as having the best quality of death and providing a high quality of care,<sup>15</sup> this experience varies between patient groups,<sup>16</sup> especially those living in rural and remote areas.<sup>17</sup> Many people express a need for improved access to home palliative services,<sup>18–20</sup> and providing patients with choice about where they will receive their care at the end of life is central to UK policy.<sup>21</sup> However, end-of-life care is not always well coordinated,<sup>16,22,23</sup> and some palliative care services are difficult to access if a patient has a diagnosis other than cancer, for example dementia, which is not always recognised as a life-limiting condition by health professionals.<sup>16</sup>

Improvements to ensure equitable access and consistent high-quality care are required to address the projected need of palliative and end-of-life care services. In 2001, the National Service Framework for Older People set out a programme of action and reform, including making the identification of and support for older adults with palliative care needs a priority.<sup>24</sup> In 2004, the Department of Health and Social Care acknowledged the inequity in the provision of palliative care, urging it to be a priority for future health policies to address.<sup>25</sup> This was again emphasised in the End-of-Life Care Strategy<sup>21</sup> and the National Ambitions Framework in 2015–20, and subsequently, 2021–6.<sup>26</sup> However, there remains a gap in the evidence that assesses current palliative and end-of-life care services across the UK, especially in relation to models that focus on inequalities in rural and remote areas.

In response to these issues, a new partnership was formed in 2022, with 12 months of funding from the National Institute for Health and Care Research (NIHR). The partnership brought together older people, carers, voluntary organisations, social care providers, advocacy groups, clinicians, community hospitals, hospices and palliative care services, charities and academics from eight rural/remote areas across the four nations of the UK, which had historically been underserved in terms of research (see [Appendix 1](#)). The overall aim of the partnership was

twofold. First, to invigorate and broaden the scope of excellence in palliative and end-of-life care for older people with cancer, dementia or stroke living in rural and remote communities, who are currently underserved and under-researched. Second, to increase and improve the understanding of the experiences of palliative care in rural and remote communities for older adults.

The objectives were to:

1. establish a partnership with key stakeholders, patients and members of the public to develop future research projects and funding applications
2. explore and understand various models of care for delivering palliative and end-of-life care for older people with cancer, dementia and stroke in rural and remote areas across all four nations
3. identify and understand the core priorities for research into rurality and palliative care for older people with cancer, dementia and stroke
4. build capacity for research into reducing health inequalities in relation to palliative and end-of-life care in rural and remote areas.

The partnership became known as 'Rural Palliative Care UK' and was led by a core team of senior researchers, mid-researchers and early career researchers (ECRs).

Our data collection plan consisted of three integrated components, which operated in an iterative manner to meet our objectives. This included: (1) a scoping review of relevant literature on rural and remote palliative care for older people with cancer, dementia and stroke in the last year of life; (2) stakeholder engagement workshops and mapping processes and (3) qualitative interviews with family carers who had supported rural-/remote-dwelling older adults with at least one of the identified conditions towards the end of life.

The purpose of this article is to share our findings from components 1 (scoping review) and 2 (stakeholder engagement) and reflect on the learning from our data collection plan. The findings of component 3 (qualitative study) have been reported elsewhere.<sup>27</sup>

## Scoping review

A scoping review was used to identify the gaps in the literature surrounding palliative and end-of-life care services for rural and remote older adults with cancer, dementia and stroke in the last year of life.

## Methods

### Design

The scoping review followed the methodological framework proposed by Arksey and O'Malley<sup>28</sup> and was reformed further following recommendations from Peters.<sup>29</sup> Results were synthesized using a narrative synthesis approach.<sup>30</sup>

### Search strategy

The search was undertaken in 2022 and conducted in MEDLINE, EMBASE, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PsycInfo® (American Psychological Association, Washington, DC, USA). An example of our search strategy is reported in [Appendix 2](#). The Bielefeld Academic Search Engine was used for a grey literature search. A list of key terms and Medical Subject Headings (MeSH) were created using guidance from the 'Population Context Concept' (PCC) framework.<sup>29</sup> Key terms and MeSH for the population (elderly/older adult), context (rural/remote settings) and concept (palliative care/hospice/end-of-life care, cancer, stroke, dementia, Alzheimer's disease) were tailored to each database. Synonym checks using each database thesaurus for key terms were carried out and were included in the final search.

Hand searches for other references from included articles' citations were additionally conducted. Relevant articles from grey literature, organisational sites and health policies were also hand-searched for inclusion.

### Screening and selection

All searches were imported into EndNote [Clarivate Analytics (formerly Thomson Reuters), Philadelphia, PA, USA] 20.3 reference management software. Following deduplication, 746 articles remained. Title and abstract screening followed by full-text screening were carried out in accordance with the inclusion and exclusion criteria ([Table 1](#)). During the screening process, 10% of the excluded full-text articles and 10% of titles and abstracts were checked by other members of the research team. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement<sup>31</sup> ([Figure 1](#)), which has been adapted for scoping reviews, was used to guide the reporting of the screening and selection process.

### Quality appraisal

The aims of scoping reviews are to map the current landscape and to identify gaps in literature rather than analyse or assess the quality of included articles. Therefore, a quality appraisal of the articles was not necessary.<sup>28</sup>

TABLE 1 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> <li>Primary and secondary literature: peer review or mixed-methods study design, including reviews: <ul style="list-style-type: none"> <li>higher-income countries</li> <li>2001–current date</li> </ul> </li> <li>Grey literature: PhD dissertations, health policies, newspaper/journal reports, books or chapters, organizational websites</li> <li>English language or translation only</li> <li>Research population, concept and context: <ul style="list-style-type: none"> <li>Aged participants (65+ years)</li> <li>Rural or remote settings/communities</li> <li>Palliative, end-of-life or hospice care</li> <li>Dementia, Alzheimer's disease, stroke or cancer diagnosis</li> <li>Within the last year of life</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Blogs, editorials, social media campaigns, opinion pieces, commentaries, conference/poster abstracts</li> <li>Before 2001</li> <li>Care within hospital settings</li> <li>Lower-/middle-income countries</li> <li>Anything unrelated to PCC as defined in the inclusion criteria box: <ul style="list-style-type: none"> <li>≤ 65 years</li> <li>Urban or non-rural settings</li> <li>Not related to palliative or end-of-life care</li> <li>Without dementia, stroke, cancer or Alzheimer's diagnosis</li> <li>Not within the last year of life</li> <li>Any mixed studies or reviews in which the population, setting and diagnoses could not be separately analysed against outcomes of interest</li> </ul> </li> </ul>

## Data extraction

A data extraction table was developed and contained the following information: author, year and country of publication, study design, participants, aim, diagnosis, method of palliative care delivery, results/conclusions and limitations.

## Data synthesis and analysis

As the review included both quantitative and qualitative studies, a narrative synthesis guided by Popay<sup>30</sup> was conducted by using tabulation to organise the studies and reflexive thematic analysis<sup>32</sup> to categorise and group the main findings of each article.

The reflexive thematic analysis followed six stages: familiarisation with data, coding, generating initial themes, reviewing themes, defining and naming themes and writing up. The first reviewer read and reread the articles to familiarise herself with the data. Initial codes were developed, grouped and coded to form themes. The reflexive thematic analysis consists of organising data (coding) and distilling key ideas and concepts (developing themes) that reoccur or appear significant either because of their presence or absence. A thematic map was produced, and overarching themes were reviewed and agreed by the research team.

## Findings

A total of 1128 articles were identified through scholarly databases. Five articles<sup>33–37</sup> met the eligibility criteria to be included. The process of data identification, screening and selection of the articles is detailed in the PRISMA flow diagram<sup>38</sup> (Figure 1).

## Study characteristics

Study summaries are presented in Appendix 3. Two of the papers originated from Canada,<sup>33,34</sup> one from

North America<sup>37</sup> and two from Nordic Countries. Three were published in the last decade.<sup>33–35</sup> Three papers considered palliative care delivered in the person's own home,<sup>33–35</sup> and two were unclear about where palliative care was provided. All but one of the papers<sup>37</sup> were from countries with universal healthcare systems. No studies were excluded based on the results of their quality appraisal.

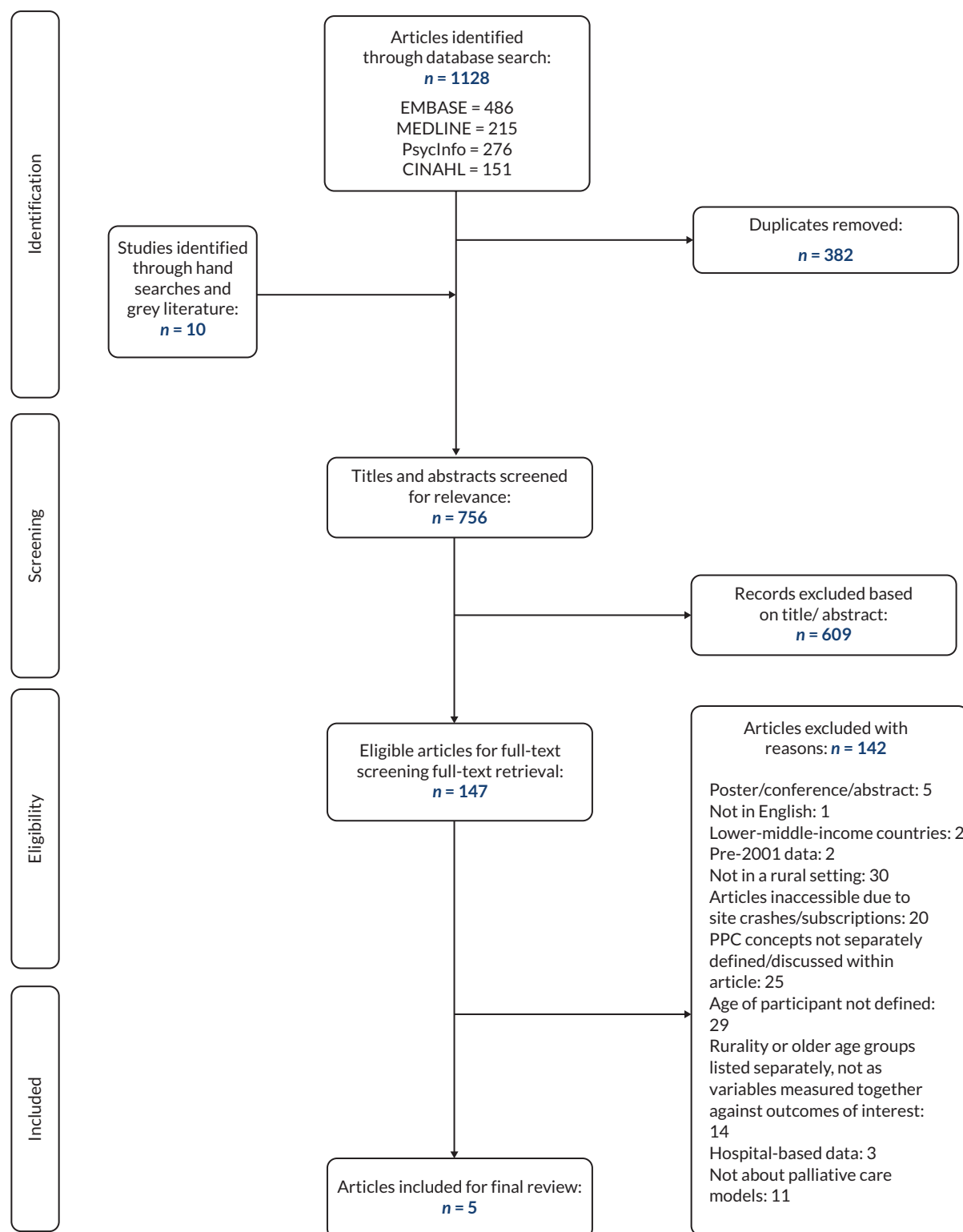
## Results of the synthesis

Three overarching themes were developed from the data. These included: (1) models of palliative care for older people in rural and remote areas; (2) impact of rural and remote palliative care models on patient outcomes and (3) barriers and enablers to palliative care models in rural and remote areas. These categories are all related to access and quality of care, which are principal concepts recognised by the World Health Organization as integral for sustainable and effective integrated palliative care service and delivery.<sup>39</sup>

### Models of palliative care for older people in rural and remote areas

Four of the papers referred to specific models of palliative care which were delivered to older people with cancer, dementia or stroke in rural areas. These included volunteer models, technological models and nurse-led models.

**Volunteer models** The review by Connell *et al.*<sup>33</sup> focused on the feasibility of partnerships between palliative care volunteers and healthcare professionals (HCPs) in supporting older adults and their families in rural areas in Canada, USA, Australia and New Zealand. They found that palliative care volunteers could fulfil a number of roles, including helping rural patients and families learn how to live with illness, loss of autonomy and frailty and trying to promote patient's dignity and their right to



**FIGURE 1** Preferred Reporting Items for Systematic Reviews and Meta-Analyses diagram.

respect, information, personalised care and relief from discomfort and distress. Palliative care volunteers were also described as fundamental in supporting dying people in their rural communities by providing connections to old friends, activities and hobbies.

The authors concluded that volunteer palliative care partnerships could be a successful and efficient method of providing palliative care support to rural older patients if certain factors within the partnership are focused on early. These included ongoing training for both volunteers and



HCPs and a focus on nurturing the relationships between the two parties (e.g. addressing issues around lack of role clarification, boundaries and knowledge).

**Technological models** Read Paul *et al.*<sup>34</sup> explored the use of web-based video conferencing (WBVC) as an efficient and acceptable method of providing palliative care consultations to support older rural adults. They concluded that WBVC was feasible and time-saving for patients and their families as well as palliative care consultants, and it increased the number of palliative care consultations for harder-to-reach older adults in rural settings. However, while older adults found WBVC to be acceptable, they emphasised that it should not entirely replace in-person contact. Authors concluded that WBVC should be used in conjunction with in-person palliative care consultations and that they may be more appropriate for follow-up visits than initial visits so that an in-person relationship is established prior to the WBVC interaction taking place.

**Nurse-led models** Nurse-led palliative care models were also reported in three of the papers. Wallerstedt *et al.*<sup>36</sup> described a nurse-led sitting service for rural-dwelling palliative care patients in their own homes. This service consisted of nurses, educated in palliative care, who were released from their workplace to the dying person's home. The service was offered around-the-clock and included both care of the dying person and support to the family.

Devik *et al.*<sup>35</sup> also described how district nurses and oncology nurses provided palliative care to rural older people in their homes. Participants in this study were family carers, who emphasised the importance of the older person being at home at the end of life, as it fostered feelings of belonging, connectedness and safety. Having nurses who were able to provide personal and compassionate care in the patient's home was critical for family members. Furthermore, the familiarity and trustworthiness of the nurse became more important than specialised oncological training. Authors described the close connections that form between rural palliative care recipients and nurses as 'professional friendships', which may integrate the nurse into the dying person's informal social network. However, they also cautioned that this dual personal-professional relationship could represent challenges to relational boundaries, confidentiality and anonymity, which raised ethical tensions.

In the Read Paul *et al.*'s<sup>34</sup> study, nurses assisted with the setup of the WBVC technology in patients' homes, which

enabled video consultations to take place. The authors noted that families had previously explained setting up and using technology could be stressful and confusing. Consequently, the pilot study used nurses to remove this potential barrier. Additionally, having HCPs in the home was thought to enhance clinical effectiveness by allowing for hands-on assessment and in-person support. They concluded that for future replication in rural areas and to strengthen the generalisability of their findings, external support in setting up technological systems would be required.

### **Impact of rural and remote palliative care models on patient outcomes**

Two of the five articles explored palliative care provision with respect to patient outcomes. This related either to well-being and/or suffering in Devik *et al.*<sup>35</sup> or to achieving patient goals, such as preferred place of death in Wallerstedt *et al.*<sup>36</sup> Both articles examined nurses caring for patients in their own homes. Devik *et al.*<sup>35</sup> focused on the effects of relationships with home nurses and hospice staff on the well-being of palliative care patients. As outlined in the "Nurse led models" section above, nurses who possessed personal and compassionate qualities were greatly valued regardless of their level of specialised training and education. Having these qualities improved patient well-being, as patients reported feeling cared for and felt safe and trusted their nurse.

Wallerstedt *et al.*<sup>36</sup> focused on the impact of a sitting service on the place of death and found that those who received the service were significantly more likely to die at home. Furthermore, 64% of people who received the service lived on their own. Consequently, the sitting service prevented rural older people from dying alone.

### **Barriers and enablers to palliative care models in rural and remote areas**

**Interdisciplinary working** Good interdisciplinary working that included collaborations with other organisations, such as local support groups or nursing homes, appeared to have the most successful outcomes. In both Connell *et al.*<sup>33</sup> and Torke *et al.*,<sup>37</sup> a major factor for the success of their models was regarding good communication between HCPs and an emphasis on supporting good working relationships. In Connell *et al.*,<sup>33</sup> communication breakdown between volunteers and HCPs arose from differing views regarding knowledge and boundaries surrounding the delivery of palliative care in people's homes. Consequently, training on communication as well as acknowledging different work boundaries and role clarification was an important enabler.

Correspondingly, effective communication as an indirect outcome in relation to the method of palliative care provision was identified in three studies (Read Paul *et al.*,<sup>34</sup> Torke *et al.*<sup>37</sup> and Wallerstedt *et al.*<sup>36</sup>). For example, the use of the WBVC platform not only improved communication between patients and families with care providers but also facilitated quicker communication between healthcare team members, which improved the continuity of care. Similarly, Torke *et al.*<sup>37</sup> noted that successful programmes in reaching and treating people living with dementia were due to strong working relationships built between programme staff and interdisciplinary teams as well as relationships built with the local rural community support groups and services such as nursing homes.

**Social factors** Connel *et al.*<sup>33</sup> highlighted the complex social relationships in small, rural communities. The close-knit nature of rural communities was perceived as both an advantage and a disadvantage. A community that knows all its members can aid in forming relationships between clients and volunteers. However, there are also factors that lead to ethical dilemmas. ‘Everybody knowing everybody’ can lead to the expectation that rules of confidentiality do not apply. This could lead to tensions within small communities.

## Discussion

This scoping review identified and synthesised the evidence regarding palliative and end-of-life care for rural and remote older adults with cancer, dementia and stroke in the last year of life. It revealed a dearth of studies, highlighting a major gap in the evidence base. As such, we did not exclude any papers based on their quality. This approach allowed us to identify and draw insights from several international models of palliative care for rural older adults with cancer, dementia and stroke, which could be adapted to a UK context. These included volunteer, technological and nurse-led models.

Incorporating volunteers into an older patient’s care pathway has been shown to have positive benefits on the patient’s health outcomes.<sup>40,41</sup> Evidence indicates that volunteers not only improve patient’s health but also improve access to and use of essential health services for patients in areas with limited resources.<sup>42</sup> The Connell *et al.*<sup>33</sup> study demonstrated that utilising volunteers in rural and remote palliative care is feasible, especially where strong volunteer–HCP partnerships exist. Furthermore, Torke *et al.*<sup>37</sup> found that successful strategies in providing palliative care to people living with dementia involved volunteers and that a lack of volunteers could be a barrier to receiving equitable care.

Comparable to other studies,<sup>43</sup> this review found that technology-enhanced care, when used in rural/remote areas, is acceptable for patients and families and can improve access to palliative care. Technology has the potential to improve healthcare services by reducing human error, enabling care coordination, improving clinical outcomes and reducing patient wait times.<sup>44,45</sup> However, it must be acknowledged that those living in rural and remote areas continue to have less access to and much slower internet infrastructure than urban populations<sup>46</sup> and thus often experience slower advances in healthcare technology.<sup>20</sup> To compound this problem, older adults are less likely to possess the digital literacy necessary to benefit from technological interventions.<sup>46</sup>

Nurse-led models of palliative care were also found to be important for rural-dwelling older people. Other studies have also shown how nurse models result in patient outcomes equivalent to those of physicians as well as being more effective than medical care in increasing patient satisfaction.<sup>47</sup> In both Devik *et al.*<sup>35</sup> and Wallerstedt *et al.*,<sup>36</sup> nurses were pivotal to enhancing patient’s well-being as well as achieving patient outcomes. Receiving nurse-led care also meant that the older person could be at home and around family and friends (Devik *et al.*<sup>35</sup>), and this increased the possibility of dying at home (Wallerstedt *et al.*<sup>36</sup>).

## Implications for policy, practice and research

This review highlighted the importance of nurse-led models in palliative care for older people in rural/remote areas. While nurse-led care is pivotal in any healthcare system, the UK is facing a significant shortage of nurses. According to NHS digital, there was a shortfall of over 39,000 nurses in 2021–2,<sup>48</sup> with these shortages reported to be more pronounced in rural and coastal areas.<sup>49</sup> This represents a critical gap in the literature, as the success of palliative care relies on the ability and capacity of the workforce. Future research, practice and policy should focus on how to increase the number of nurses into palliative care services, especially in rural and remote areas. Additionally, strategies to increase the number of volunteers providing such incentive schemes would be beneficial. These have shown to be successful, particularly in communities that lack volunteer support.<sup>50</sup>

Technology emerged as a potential solution to overcoming access barriers to palliative care in rural and remote areas. This finding highlights another important evidence gap. Although there is growing use of technology to extend palliative care in rural and remote areas, more research



is needed to understand how best to tailor these models to older adults. Additionally, studies should explore how to enhance digital literacy among rural and remote older populations.

Finally, within this review, there was limited research on the challenges faced by family carers in rural and remote areas who provide a large proportion of palliative and end-of-life care to older people. More research is needed to explore the experiences and resources available to family carers in rural and remote areas and how these can be improved.

Overall, increasing the services offered in rural and remote communities, as well as promoting interdisciplinary working across local services and engagement with local communities, can help tackle the inequity and be beneficial for patient outcomes. Studies have demonstrated that community-based palliative care teams not only improve symptom management, patient satisfaction and quality of life<sup>51,52</sup> but also reduce acute care use and decrease the number of hospital deaths.<sup>53</sup> Subsequently, there is an urgent need to co-design models of community-based palliative and end-of-life-care in rural and remote locations, considering the unique challenges of living in these areas.

### Strengths and limitations of review

This is the first scoping review to explore palliative and end-of-life care for older rural and remote adults with cancer, dementia or stroke in the last year of life. The limited results of the review ( $n = 5$ ) highlight a significant lack of data relating to access and quality of palliative and end-of-life care models and interventions for older adults in rural areas both globally and in the UK.

While the review incorporated a wide and extensive search using a robust methodology, the specificity of the PCC parameters led to many articles being excluded, such as papers not featuring rurality and older people together and people with diagnoses other than cancer, dementia and stroke. By omitting these papers, we may have missed some valuable insights from other models of palliative care that may have been transferable to our target population. A final limitation is that a quality assessment of the articles included was not undertaken. Although this is not necessary for scoping reviews, the relatively weak design of the included papers suggests that our findings should be interpreted with caution.

### Conclusions

This review has demonstrated that there are limited data on palliative and end-of-life care models to support older rural and remote adults with cancer, dementia or stroke in

the last year of life. As the ageing population continues to grow and the prevalence of common conditions requiring palliative and end-of-life care increases, it is imperative that the UK prepares itself to address not only the current unmet needs of older rural patients but also strategies how it will meet the future needs of this growing demographic and the people who care for them. The review has revealed that there is some international evidence on models of palliative and end-of-life care for rural and remote dwelling older adults, which could be applicable to the UK to meet the current and future needs of the ageing population. Future policy, research and practice should focus more on co-designing and implementing these models for both short-term and long-term success.

### Stakeholder engagement workshops and mapping processes

We used stakeholder engagement and mapping processes to explore and understand various models of care for delivering palliative and end-of-life care for older people with cancer, dementia and stroke in rural and remote areas across all four nations of the UK. We also wanted to identify the core priorities for research into rurality and palliative care for older people with cancer, dementia and stroke.

### Methods and analysis

We used group discussions based on a modified Nominal Group Technique (NGT) method in an adapted serial meeting design. The NGT is a structured, well-established, multistep, facilitated, group meeting technique used to generate and prioritise responses to a specific question by a group of people who have expert insight into a particular area of interest.<sup>54,55</sup>

Potential stakeholders were identified in a process that began during proposal preparation. During this 'pre-engagement' phase, the principal investigator contacted organisations and individuals across the four nations, which included representation from geographical regions that are underserved by palliative and end-of-life care research and where there are high numbers of older people living within rural and remote communities.

By maximising our local links within our selected geographical areas, we ensured that our partnership aims were widely disseminated via the local media and social media to enable the participation of everyone who wished to be involved. We worked with local stakeholders to ensure that we included a diversity of rural and remote areas within our selected regions to reflect local

contexts, since strengths and solutions may be different and changing.

Three facilitated workshops were conducted over the life of the project (April 2022–June 2023) through a virtual video conferencing platform. Each workshop was approximately 3 hours.

The three workshops were also interspersed with eight meetings between the core team to update on data collection and discuss ideas for future funding.

### The first workshop

In the initial workshop, stakeholders were introduced to the goals of the project and oriented to the planning process. Time was spent developing relationships and sharing perspectives. The core team provided a background on palliative and end-of-life care in rural and remote areas, explained the significance of the project and shared their vision for the engagement process over the entire project period.

The modified NGT process began with stakeholders being asked to individually consider issues in their areas and priorities. Following the workshop, stakeholders were then sent a proforma aimed at:

- mapping their organisation's role in supporting older people
- identifying issues of rurality encountered in their areas
- identifying and detailing local models of care, services and interventions provided in supporting older people within the last year of life with cancer, dementia or stroke and residing in rural and remote areas
- identifying any additional organisations involved in care that they either work with or are aware of
- identifying their top three research priorities.

Snowballing methods were used to contact additional organisations and individuals to gather further information on models of care and services, issues of rurality and research priorities. Individual meetings were set up with these organisations and they were asked to complete the proforma.

The proforma data were analysed using in Microsoft Excel® (Microsoft Corporation, Redmond, WA, USA). To ascertain issues of rurality and research priorities, the raw data were reviewed iteratively by one researcher with regular discussions with the core team. Each response was coded into broad categories, developed iteratively after reviewing the responses several times. Similar or duplicate issues and research priorities were combined where

appropriate. Models of care, services and interventions were listed with brief details of their activity. These were then categorised by function.

### The second workshop

In the second workshop, stakeholders were given an update on the project, along with a showcase of preliminary findings from the proforma data. In line with the modified NGT, the list of issues and research priorities were discussed to ensure clarity and understanding.

### The final workshop

In the final meeting, stakeholders were presented with the findings of the scoping review and our qualitative work along with personal reflections from our patient and public involvement and engagement (PPIE) representative.

The second half of the meeting was opened to whole group discussion and centred around three questions:

1. Is there anything in our work that you feel we have not covered?
2. What did or did not surprise you about our findings?
3. Considering our findings, what are the top priorities for research?

Utilising the modified NGT, the final list of research priorities was shared with the group, who were asked to rank their top three priorities. The rankings were aggregated, and the group discussed the results until a consensus of the top priorities was achieved.

## Findings

### Stakeholder characteristics

In total, 59 different organisations were contacted, and 33 people completed the proforma [either via e-mail or during an individual meeting on Microsoft Teams® (Microsoft Corporation, Redmond, WA, USA)]. Stakeholders were from England ( $n = 15$ ), Wales ( $n = 9$ ), Scotland ( $n = 8$ ) and Northern Ireland ( $n = 1$ ). More details are provided in [Appendix 1](#).

Stakeholder role descriptions included consultant geriatrician ( $n = 1$ ), consultant in palliative care ( $n = 2$ ), general practitioner ( $n = 2$ ), nurse consultants ( $n = 2$ ), senior nurse ( $n = 2$ ), Head of Macmillan Nursing ( $n = 2$ ), Director of Macmillan nursing ( $n = 1$ ), admiral nurse ( $n = 1$ ), academic ( $n = 4$ ), voluntary sector/charity leads ( $n = 6$ ), hospice programme manager ( $n = 1$ ), hospice chief executive officer/lead ( $n = 3$ ), social enterprise manager/lead ( $n = 3$ ), day care service lead ( $n = 1$ ) and support group facilitator ( $n = 2$ ).

## Models of care and interventions

Stakeholders described several models of care, services and interventions that were available to older people within their rural and remote areas. While not all were specifically defined as palliative and/or end-of-life care models, all could be accessed by older people in their last year of life and/or by their carers.

Models and interventions included:

- palliative care/hospice outreach services (e.g. rapid response, social care and planned overnight services)
- volunteer support (e.g. befriending services)
- public health approaches to palliative care such as 'compassionate communities'
- end-of-life and palliative care training programmes (for family carers, care homes and community services such as rural parishes)
- palliative/hospice 24-hour helplines
- social groups for patients and carers (online and face to face)
- day care
- rural community-based 'care hubs'
- community help schemes (e.g. medication and food delivery and transport)
- screening systems to identify people who have palliative care needs.

## Issues of rurality

Stakeholders reported on the issues of rurality faced by older people towards the end of life. Answers were categorised into (1) macro-level issues, (2) meso-level issues and (3) micro-level issues. These are detailed in [Table 2](#).

Macro-level issues were perceived structural, external conditions that were beyond the influence of individual groups or organisations. Meso-level issues were local institutional factors and influences as well as community issues that could affect how services and care were delivered. Micro-level issues were individual or personal characteristics impacting on palliative and end-of-life care.

## Research priorities for palliative care for older people with cancer, dementia and stroke in rural and remote areas

Using modified NGT, stakeholders were able to present, discuss and refine their priorities for research for palliative care for older people with cancer, dementia and stroke in rural and remote areas. These included research into the skill mix of the rural and remote workforce and composition of services; facilitating preferred place of death; the role of technology in palliative care and

end-of-life care; and preparedness for a future of people living with multimorbidities and frailty in as they reach end of life.

## Qualitative interviews

We conducted qualitative interviews with current and bereaved family carers to explore their experiences of providing care to an older person in a rural/remote area in the UK towards the end of life. Full details of the study have been published separately<sup>27</sup> and are summarised briefly here.

### Design

The design included a qualitative methodology using semistructured interviews and reflexive thematic analysis methods.

### Participants and recruitment

Participants were current and bereaved family carers who had supported an older person living in a rural and/or remote location towards the end of life. With the help of our stakeholders, participants were purposively sampled from national support services and third-sector organisations. Appeals for were also made on social media channels, local radio stations and in newspapers.

### Data collection

From October 2022 to June 2023, CM conducted semistructured interviews with a sample of current and bereaved family carers. All interviews were conducted either face to face, via Microsoft Teams or telephone and were audio-recorded using an encrypted audio-recorder.

An interview topic guide was used to build rapport with participants and generate rich and detailed accounts relevant to the research. The topic guide was developed from literature reviews in the field and discussions between the core team. It was tested and changed iteratively throughout the interviewing process.

### Analysis

Interviews were transcribed verbatim and pseudonymised. Interview transcripts were organised in NVivo (QSR International, Warrington, UK) version 12 and were analysed using reflexive thematic methods.<sup>32,56</sup>

Analysis began after the first few interviews were conducted, as such the process was ongoing and informed the subsequent sessions. Codes and themes were developed through regular, iterative discussions among the core team.

**TABLE 2** Macro-level, meso-level and micro-level issues of rurality for older people towards the end of life

Macro-level issues	<ul style="list-style-type: none"><li>• Long travel times to access services and the costs involved</li><li>• Specialists in palliative care are not commissioned to work in remote areas</li><li>• Limited availability of services in rural/remote areas</li><li>• Poor broadband coverage</li><li>• Much older age demographic in some rural areas</li><li>• Increasing utility costs</li></ul>
Meso-level issues	<ul style="list-style-type: none"><li>• Problems with recruitment/retention of health and social care workforce</li><li>• Limited in-home respite for family carers</li><li>• Challenges administering subcutaneous end-of-life medications</li><li>• Health and social care services lacking acknowledgement of depth of provision provided by voluntary sector</li></ul>
Micro-level issues	<ul style="list-style-type: none"><li>• Carer health is suffering (e.g. not attending coronavirus disease boosters and isolation)</li><li>• Urban migration means that families are dispersed with no one left to care for older adults towards the end of life</li><li>• Urban 'incomers' (e.g. those who retire to rural areas) have limited social support/networks</li></ul>

Findings

Interviews were conducted with 20 family carers (9 using videoconferencing, 8 over the telephone and 4 face to face). Most participants were female (*n* = 17) and ages ranged from 52 to 80. The majority were adult children (*n* = 14) and the remainder were spouses (*n* = 6) and a niece (*n* = 1). Despite the diversity across rural and remote locations, carers reported a number of shared experiences. Many experienced difficulties in accessing health and social care in rural/remote areas due to workforce and skill shortages within their regions. The wider community helped with practical tasks and made carers feel less alone. Community-based services, such as day care, helped to provide respite for carers and promoted meaningful activity and social inclusion for older people. Although internet access was problematic, family carers gained support remotely via social media and telehealth services.

Overall discussion

This article provides a methodological overview of an approach to developing a partnership and coproducing a set of future research priorities and provides recommendations for palliative and end-of-life care for older adults with cancer, dementia and stroke living in rural and remote communities. This work was combined with a scoping review and qualitative interviews with current and bereaved carers who had supported rural-/remote-dwelling older adults towards the end of life.<sup>27</sup>

There is a strong need to support older people with cancer, dementia and stroke to remain within their rural/remote communities at the end of life. However, our findings across the three methods of data collection demonstrate

the persistent challenges in access to palliative and end-of-life care for older people in rural and remote areas and highlighted the critical gaps in understanding. Meeting the palliative care needs of this population involves addressing the challenges of limited local health resources and services, geographical isolation and distance. This could include improving support for family carers as well as increasing digital literacy among older people so they can benefit from technological advances in palliative care.

Interdisciplinary collaboration, including palliative care models that leverage the use of volunteers and support from the wider community, has also demonstrated success in achieving positive outcomes for older people with cancer, dementia and stroke in rural and remote areas. Not only can these models support family carers with practical tasks, but they can also allow older people to feel less alone and still part of their community. It is important that we build on these findings to understand more broadly a range of models of support for those living in rural and remote communities at the end of life as well as tailoring and co-designing interventions that are suited towards older people.

Building a sustainable partnership

The partnership engaged with diverse stakeholders and members of the public, bringing together academic and health and social care professionals, decision-makers and lived experts from geographical regions that are underserved by palliative and end-of-life care research, thus successfully achieving objective 1.

Stakeholders helped to identify palliative and end-of-life interventions and models of care for older people in rural and remote areas across all four nations of the UK,

understand issues of rurality in these areas and jointly shape and develop research priorities. This work was consolidated with a scoping review, which identified international models of palliative care in rural areas, and qualitative interviews with family carers which further explored issues people face towards the end of life in rural and remote areas, helping us to successfully meet objectives 2 and 3.

Membership of the partnership grew via word of mouth and snowballing, with participating organisations sharing information about events within their own networks, and through contacts made, for example, with interested organisations during the engagement events. A mailing list of interested individuals/organisations was generated, with agencies such as palliative care charities, the NHS and local care organisations added.

As NIHR funding for the partnership ended in 2023, the partnership has now secured funding to continue their research activities into the issues of poverty and rurality at the end of life and continue to work together on other funding applications.

### **Patient and public involvement and engagement**

Our initial plan for PPIE was to explore issues of rurality and the prioritisation of topics for research at a series of in-person symposiums within rural areas, with community members, carers and patients. However, due to logistical constraints, this was not possible. Instead, we included community members in our online workshops and used qualitative methods to interview family carers separately, offering a range of communication options (in-person, videoconferencing and telephone).

Additional expertise included a dedicated PPIE worker who was a previous family carer. During each stakeholder meeting, she shared her experiences of living and caring for a partner with dementia, the difficulties of accessing care and support and the mental health impact of this on herself as a carer. She provided invaluable help with all aspects of the study, including design, recruitment of stakeholders and interview participants, analysis and dissemination.

### **Capacity-building**

Our overall aim for capacity-building was to grow the research capacity, enthusiasm and activity in health and social care provision of palliative and end-of-life care for older people living with cancer, dementia and stroke in rural and remote communities. Our activity included:

- Building a sustainable partnership with local services, communities, voluntary sector groups and research centres in areas of low research activity within our identified rural and remote locations.
- Bringing together research active groups including early, mid and senior researchers, a range of service organisations, together with underserved research groups with PPIE to codevelop a set of research priorities that was driven by rural/remote communities.
- Creating a network of researchers and organisations with an interest in rural palliative/end-of-life care among older people. This has led to a further successful grant application exploring the intersectionality between poverty and rurality at the end of life.
- Developing new researchers from health and social care backgrounds. This included supervising a postgraduate student to complete the scoping review and training an undergraduate medical student to deliver qualitative interviews and analyse data.
- Developing the skills and capacity of an ECR who took the lead on the mapping, qualitative work and research priority setting. The ECR was mentored by members of the core team to develop her skills and expertise in these areas and is now developing further funding applications as co-lead.

This work has helped build capacity for research into reducing health inequalities in relation to palliative and end-of-life care in rural and remote areas, thus meeting objective 4.

### **Strengths, limitations and further research**

Key to our project success was including stakeholders from all four nations of the UK and interviews with family carers who were generous in sharing their experiences and in helping us to understand how palliative and end-of-life care is delivered and received in rural and remote areas. They have also provided us with knowledge about future research recruitment plans. This is particularly critical in underserved communities, which face complex barriers to achieving optimal health outcomes that might be poorly understood by researchers. Further research could also include evaluation of the impact of the partnership itself in terms of increased research capacity or activity.

Due to our stakeholders being located across the four nations, videoconferencing was the most effective way to communicate and collaborate. Despite the remoteness of some members, none had problems with internet



connectivity. This enabled us to use digital functions to create a space in which stakeholders could work together to provide their thoughts in real time to quickly ascertain the top priorities for research.

While, within our partnership work, we included eight rural/remote regions across the UK which historically had been underserved in terms of NIHR trials and registered studies, we are aware that some other areas have not been included within our work, although we advertised our work widely within press and social media. Therefore, we may not be aware of other initiatives that have been developed to improve palliative and end-of-life care within rural/remote areas.

Additionally, for our stakeholder engagement activities, we did not collect demographic data. This limits our ability to evaluate the diversity of individuals reached through engagement activities. Similarly, our qualitative study sample was limited in terms of ethnic diversity. Rural and remote populations include diverse ethnic and cultural communities with unique perspectives about illness, death and caregiving. An aim of future research would be to actively target a diverse range of community organisations and participants in terms of age, ethnicity and other cultural factors. This would ensure that palliative and end-of-life care research, services and policy consider the differences in health literacy, language, religion and family structures, and how these intersections may impact on the access to and quality of palliative and end-of-life care would also be analysed.

## Conclusion

### Key learning points

- While we were unable to execute the initial plan on face-to-face meetings for PPIE, individual qualitative interviews with family carers proved to be fruitful. This work highlighted how family carers were eager to be involved in research and provided us with knowledge and experience for participant recruitment strategies for future research.
- Despite the different data collection processes, similar themes regarding issues of rurality and priorities for research were elicited from the scoping review, interviews with family carers and stakeholder engagement alike.
- Due to the centralisation of services in urban areas, older people may delay or avoid specialist care because of the challenges created by travel distance. This can impact on their outcome.

### What this adds to existing literature

The data synthesised in this project provided insight and a comprehensive overview of the experiences, needs and gaps in palliative and end-of-life care for older people with cancer, dementia and stroke in rural and remote areas.

This project demonstrates the potential for successful partnerships between voluntary and community sector organisations, specialist palliative care providers, health and social care providers and academics to design future research and sustainable palliative care interventions for older people in rural and remote areas, while taking into account the needs and priorities of local communities.

Although there has been limited research conducted on rural and remote palliative and end-of-life care for older people with cancer, dementia and stroke, several models of care were identified within the existing literature, which highlighted the importance of nurse and volunteer models of care to allow for rural-/remote-dwelling older people to remain in their preferred care settings towards the end of life. The use of technology to help address rural/remote issues with access to care was also discussed.

These findings can be used to inform future research and policy and the development of services, supports and intervention strategies to improve the palliative and end of life for older people living in rural and remote locations.

## Additional information

### CRedit contribution statement

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All authors had access to all study data, discussed the interpretation of findings, provided critical revision of the manuscript for important intellectual content and took responsibility for data integrity and analysis.

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### Data-sharing statement

All data requests should be submitted to the corresponding author for consideration. Access to anonymised data may be granted following review.

### Ethics statement

Favourable ethical approval for the qualitative study was granted by Liverpool John Moores University Research Ethics Committee on 14 October 2022 (REC reference: 22/NAH/041).

### Information governance statement

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### Disclosure of interests

**Full disclosure of interests:** Completed ICMJE forms for all authors, including all related interests, are available in the toolkit

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## List of abbreviations

CINAH	Cumulative Index to Nursing and Allied Health Literature
ECR	early career researcher
HCP	healthcare professional
MeSH	Medical Subject Heading
NGT	Nominal Group Technique
NIHR	National Institute for Health and Care Research
PCC	Population Context Concept
PPIE	patient and public involvement and engagement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
WBVC	web-based video conferencing

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## Appendix 1 Rural palliative care UK partnership members

A full list of the organisations involved in the partnership is provided below:

- Liverpool John Moores University
- University College London
- Queen Mary University, London
- University of Central Lancashire
- Kings College, London
- Queens University, Belfast
- University of the West of Scotland
- Northumbria University
- Dementia UK
- Marie Curie
- Mountbatten Hospice, Hampshire
- St Lukes Hospice Cheshire
- Highland Hospice
- Ayrshire Hospice
- St David's Hospice, Wales
- NHS Wales
- Community Hospital Association



- Campaign to End Loneliness
- Rural Health and Care Wales
- 3 Nations Dementia Working Group
- Age UK (Cheshire)
- End of Life Partnership
- All Ireland Institute of Hospice and Palliative Care

## Appendix 2 MEDLINE search

Parameter	Search term	Number
<i>Population:</i> (1) Older/elderly adult	"aged/OR 'aged, 65 and over'/ OR frail elderly/" "geriatrics/" OR "aging.mp.", OR "aged/mp.", OR "elderly.mp.", OR "older adult.mp.", OR "geriatric.mp.", OR "senior citizen.mp."	6,141,153
<i>Concept:</i> (2) Palliative care/end-of-life care	"Palliative.mp.", OR "palliative care.mp.", OR "Palliative supportive care.mp.", OR "palliative treatment.mp.", OR "palliative therapy.mp." OR "End of life care.mp.", OR "terminal care.mp.", OR "hospice*.mp." OR "Palliative care/" OR "Hospices/" OR "Terminal Care/" OR "Hospice Care"	131,183
<i>Context:</i> (3) Rural/remote	"rural.mp.", OR "rural setting.mp.", OR "rural area.mp.", OR "rural population.mp.", "rural community.mp.", OR "rural resident.mp.", OR "remote setting.mp.", OR "remote area.mp.", OR "remote community.mp." OR "Rural population/ OR Rural Health services/"	192,551
<i>Diagnosis:</i> (4) Cancer/stroke/dementia	"cancer.mp.", OR "stroke.mp.", OR "dementia.mp.",/ OR "Alzheimer*.mp." OR stroke/" "Dementia, Vascular/ or Dementia" OR "Alzheimer Disease/"	2,652,057
Combination	1 AND 2 AND 3 AND 4	215

### Appendix 3 Characteristics of included articles (n = 5)

Author (year), country	Title	Study design	Number of participants and characteristics	Diagnosis of interest	Aim of article	How palliative care was delivered	Results/ conclusions	Limitations
Connell <i>et al.</i> <sup>57</sup> (2017), Canada	The feasibility of creating partnerships between palliative care volunteers and healthcare providers to support rural frail older adults and their families: an integrative review	Integrative review	Volunteers working with rural patients aged 65+ who had received palliative home care, hospice care or outpatient palliative services in Canada, USA, Australia, or New Zealand	Unknown	Examine the feasibility of a partnership between palliative care volunteers (PCV) and HCPs in supporting rural older adults and their families; identify factors that enable or prevent such a partnership from forming	Through partnership between PCVs and HCPs	Partnership programme between PCVs and HCPs can be used to deliver and expand provision of palliative care to older adults in rural settings. Dual education and training programmes are required for success	Only included literature reviews: no 'high level evidence' such as randomised controlled trials
Devik <i>et al.</i> <sup>35</sup> (2016), Norway	Bereaved family members' perspectives on suffering among older rural cancer patients in palliative home nursing care: a qualitative study	In-depth qualitative Interviews	10 family members of deceased rural adults aged 65+ (8 men, 2 women) who received palliative home nursing care; 5 daughters, 3 wives, 1 sister, 1 sister-in-law, Age of family members range 45–61 years	Cancer	Examine bereaved family members' perceptions of suffering in rural-dwelling older persons receiving palliative home nursing care during the last phase of life	Palliative care home nurses	Creating strong relationships with palliative care nurses improved patients' trust, increased hope and improved overall well-being. Personal/ compassionate characteristics of nurses-defined success of relationship	Small sample size Information collected from proxies rather than patients receiving the care themselves
Read Paul <i>et al.</i> <sup>34</sup> (2019), Canada	WBVC for rural palliative care consultation with elderly patients at home	Exploratory 'proof of concept' pilot study	37 participants included: patients, family members, palliative and home care nurses and palliative physicians Mean patient age= 77 years	Cancer	To understand the clinical effectiveness, acceptability, service impact and technical feasibility of WBVC	WBVC	Participants were comfortable discussing concerns by WBVC and felt it was an acceptable and convenient way to address needs WBVC improved access and saved time and travel	Audio visual quality was not ideal but was adequate for communication Fears were expressed about lack of security of information
continued								

Author (year), country	Title	Study design	Number of participants and characteristics	Diagnosis of interest	Aim of article	How palliative care was delivered	Results/ conclusions	Limitations
Torke <i>et al.</i> <sup>37</sup> (2010), USA	Palliative care for patients with dementia: a national survey	National survey	Executive directors of hospice programs (240) hospice/non-hospice palliative care (PC) Programme (173), non-hospice PC (13) 34% of programmes were for profit 40% were free standing (independent/not hospital-based)	Dementia	Determine the extent to which hospice and non-hospice PC programs provide services to patients with dementia and to describe barriers and facilitators to providing non-hospice PC	Dementia focused outreach programme in hospice and palliative care services	94% of hospices and 72% of PC programs served at least one patient with a primary diagnosis of dementia within the past year: main facilitators to outreach included; staff and interdisciplinary teams, relationships with local community; main barriers included lack of knowledge about palliative care services for dementia patients, policies that interfered with patient reimbursement	Executive director perspective – no corroboration with patient-level data Low response rate/response bias
Wallerstedt <i>et al.</i> <sup>36</sup> (2012), Sweden	Identification and documentation of persons being in palliative phase regardless of age, diagnosis and places of care, and their use of a sitting service at the end of life	Retrospective cohort study	174 residents of a rural municipality that died in 2007 Mean age: 83 years	Cancer and dementia	To describe individuals identified as being in a palliative phase, with respect to demographics, use of a sitting service, continuity of care in the last month of life and the place of death	Sitting service provided by nurses educated in palliative care	Providing patients with a sitting service increased their probability of dying at home or in their preferred place	Small number of participants No exploration of impacts on quality of life or care