

North East and North Cumbria Integrated Care Board Palliative and End of Life Care Health Needs Assessment

Supplement 2: Policy and Literature Review

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Palliative and End of Life Care (PEoLC) Literature Review

The following is a summary of recent research and reports identified using the Population, Intervention, Comparison and Outcome (PICO) approach to a Literature Review with the assistance of the UK Health Security Agency Knowledge and Library Service (KLS) linked to this area of work. The literature available has been reviewed and themed.

Palliative and End of Life Care: a timeline of key policy drivers

2008: First [End of Life Care Strategy](#) published and contained three key findings:

- People didn't die in their place of choice
- Need to prepare for larger numbers of dying people
- Not everybody received high quality care

2009: Dying Matters Coalition established

2015: Independent review of [Choice in End of Life Care](#)

2015: [Ambitions for Palliative and End of Life Care](#): a national framework for local action 2015-2020

2016: [Government response](#) to independent review, making six commitments to end variation in end of life care by 2020

2019: [NHS Long Term Plan](#) and [delivery plan](#)

2021: Updated [Ambitions for Palliative and End of Life Care](#) (2021-2026)

2021: [People at the Heart of Care](#): Adult Social Care Reform White Paper.

2022: NHS National Delivery plan for palliative and end of life care (for details contact england.palliativeandendoflife@nhs.net)

2022: [Palliative and End of Life Care Statutory Guidance for Integrated Care Boards ICBs](#)

2022: [Report of the Lancet Commission on the Value of Death: bringing death back into life](#)

2025: The Commission on Palliative and End of Life Care published [two volumes of its final report](#):

- Opportunities for England, Volume 1 (May 2025) which included recommendations to develop a National Strategy for palliative and end-of-life care

- Opportunities for the NHS Ten Year Plan, Volume 2 (June 2025), published ahead of the government's [10 Year Health Plan for England](#)

2025: [National Audit of Care at the End of Life 2024: 2024 State of the Nations Report](#) (5 key recommendations)

2025: [Fit for the Future: 10 Year Health Plan for England](#)

2025: [NCMD Life Limiting Conditions Report](#)

2026: Health and Social Care Committee - [Sixth Report of Session 2024-26: Palliative Care](#)

NICE Guidance/Quality Standards

- [NG31](#) Care of dying adults in the last days of life
- [NG61](#) End of life care for infants, children and young people
- [NG142](#) End of life care for adults
- [QS13](#) End of life care for adults
- [QS144](#) Care of dying adults in the last days of life
- [QS160](#) End of life care for infants, children and young people

In addition, NICE Guidance relating to specific conditions/diseases consider end of life care.

Local strategy and policy

- [NHS North East North Cumbria Integrated Care Board \(NENC ICB\) Tees Valley Place: Adult Palliative and End of Life Care Strategy, 2022 - 2027](#)
- [NHS North East North Cumbria Clinical Conditions Strategic Plan 2025-2030](#)

Principles for our clinical conditions strategic plan development

- Focus on clinical services' unique contribution to improving population health and tackling healthcare inequalities across the life course
- Ensuring integrated approaches with seamless transition between services for children and young people as well as adults as their needs change
- Ensuring a balance between current pressures and preventing future needs by building on the efforts to prevent ill health and the importance of maintaining momentum and investment in the Healthier and Fairer programme
- Impact of multi-morbidity (e.g. two or more long term conditions), poly-pharmacy (prescribing or taking too many medications) and the need to avoid a single disease focus (ensuring a person-centred approach)

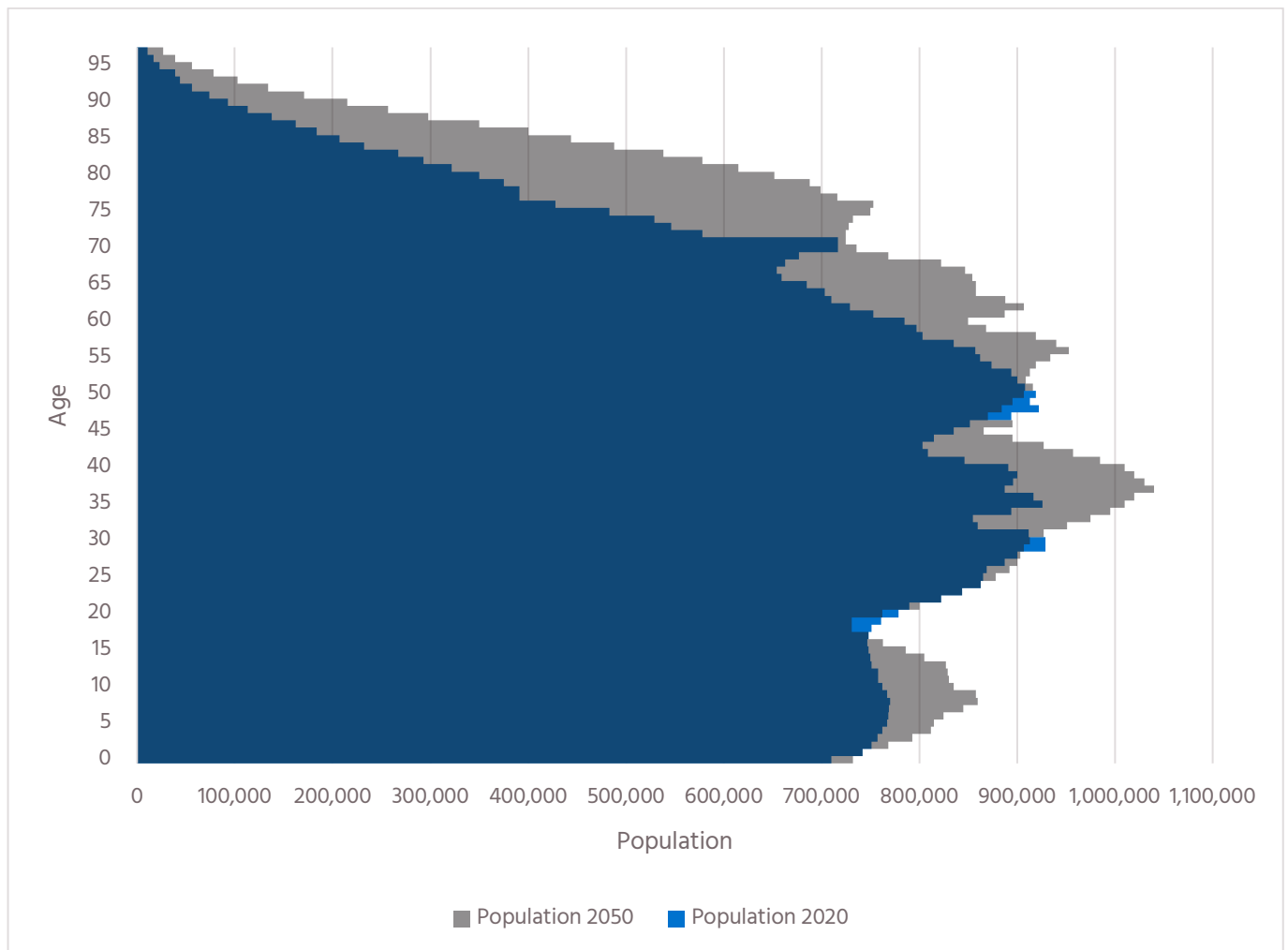
- Partnership and system-wide working to tackle inequalities, addressing the social determinants of health and acknowledging the complex interaction of factors
- Inclusion health and ensuring a health equity approach supported by the Core 20Plus5 frameworks. Gaps in service areas to be levelled up across the region and variation reduced
- Workforce development and training across the clinical services to progress the priorities identified and improve the effectiveness of clinical services

Older people

The population in the UK is ageing and it is projected to continue to age; by 2050 one in four people in the UK will be aged 65 years or over [1]. The last 50 years have seen significant advancements in medical treatments and care, curing diseases and extending life.

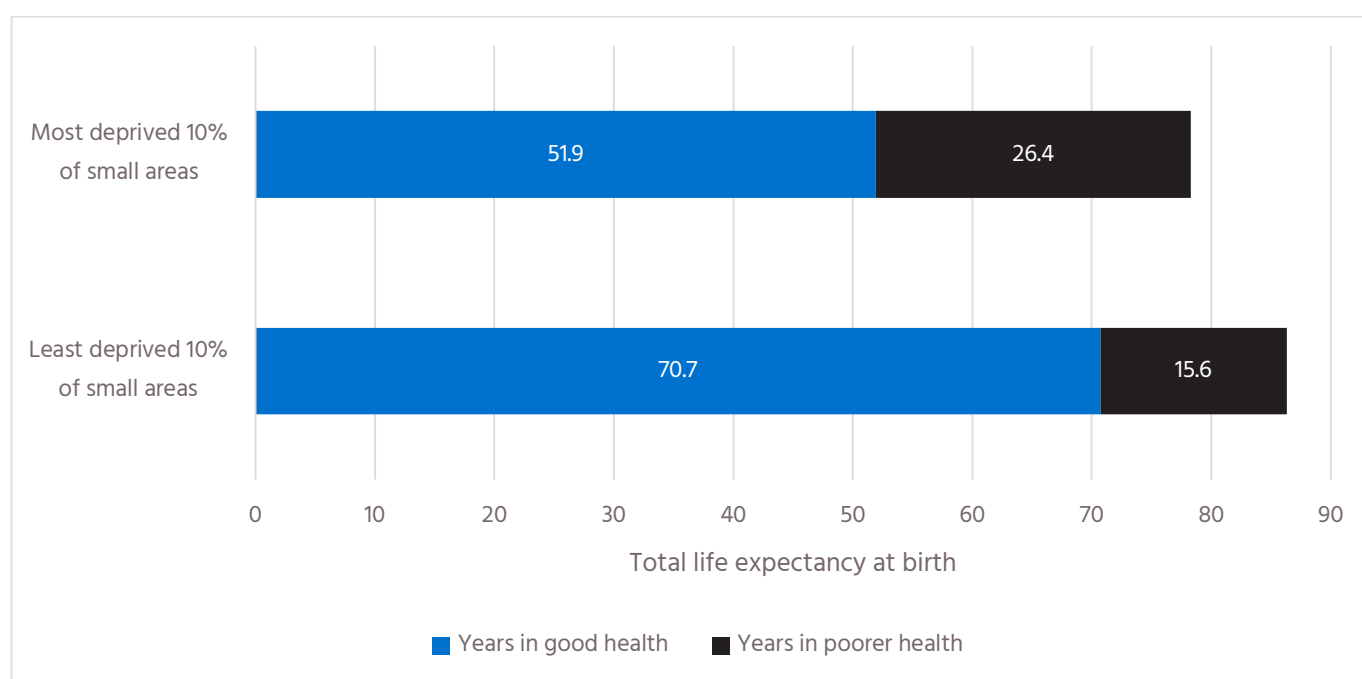
The ageing population can be observed in below.

Figure 1: Population pyramid comparing UK population by age in 2020 and projection for 2050 [2].



The Chief Medical Officer's report 'Health in an ageing society' explains that in the UK people are living a lot longer and that focus is needed on how to maximise their independence and minimise the time people spend in ill health [3]. Professor Whitty highlights that even with optimal improvements in health in older age, society needs to provide greater support through health and social care and we need to plan for this as the population ages. The report suggests those living in the most deprived ten percent of areas will spend 26.4 years in poor health compared to 15.6 years for those in least deprived areas [3].

Figure 2: Inequality in life expectancy and healthy life expectancy at birth for females in the most and least deprived wards in England, 2018 to 2020. Source data: Office for National Statistics (ONS), Health state life expectancies by national deprivation deciles, England: 2018 to 2020.



Multiple long-term conditions

The Chief Medical Officers Annual Report also highlights the importance of **multiple long-term conditions in older age, often called multimorbidity**. Multimorbidity prevalence is estimated to increase, the proportion with 4+ diseases almost doubling, and two-thirds of those with 4+ diseases will have mental ill-health.

Medical specialisation, specialised NHS provision, NICE guidelines, and medical research are all optimised for single diseases but that is not the lived reality for the great majority of older adults who often transfer very rapidly from having no significant disease states, to several simultaneously'. Therefore, calling for the NHS to maintain generalist skills and minimise the probability that the same person has to attend multiple clinics for a predictable cluster of diseases [3].

There are increasing numbers of people with multimorbidity, especially amongst the frail elderly population. Research demonstrates the overlap of frailty with multimorbidity, acknowledging that it is not the same and suggesting that frailty is used to identify the group of older people who have the highest risk of adverse outcomes such as disability, falls, hospital admissions and the need for long term care. Inequalities in frailty with higher rates in areas of deprivation [4].

Deprivation and poverty tend to accelerate the rates at which multimorbidity accumulates, both in prevalence within communities and progression in the individual [5]. The same paper showed that a risk of progression from a single condition to MLTCs showed a stepwise reduction with increasing affluence. This implies that health gains may require substantial reductions in deprivation rather than marginal improvements, extending the understanding of the protective effects of affluence and the detrimental effects of deprivation. The growing ageing population and rising multimorbidity will almost certainly lead to a rise in palliative care need. Currently, around 75% of people approaching the end of life would benefit from palliative care [2].

Elliott-Smith K. et al research yet to be published [6], states that for most people approaching the end of life, MLTCs are now the norm rather than the exception, and that MLTCs shape the nature, timing, and complexity of palliative care needs. This research also highlights that routine data sources also struggle to reflect this complexity. Mortality statistics based on a single underlying cause of death only capture a small part of the experience of each individual and obscure the presence and interplay of coexisting long-term conditions

Many components contributing to MLTCs are predictable and preventable, including smoking and obesity, both of which are risk factors for multiple conditions and require a shift toward equity-oriented prevention and care that goes beyond disease management to address upstream social driver [5]. The inverse care law remains a central challenge: underdiagnosis and overtreatment coexist within deprived settings, while more affluent groups benefit from earlier detection and more measured care. Health gains may require substantial improvements in socioeconomic conditions or more focused interventions.

People dying with MLTCs often experience fragmented, reactive, and hospital-centred care that does not address their complex medical and social needs. Planning for future palliative care needs is a critical issue for national and local policymakers, made more complex by population ageing and the increasing prevalence of multiple long-term conditions (MLTCs) [6].

Both the Chief Medical Officers Annual Report and regional research note the increased specialisation of medical professionals and that palliative care services were originally designed around single diseases with more predictable trajectories, particularly cancer, current models frequently fail to meet the needs of people with complex multimorbidity. Similarly, these papers

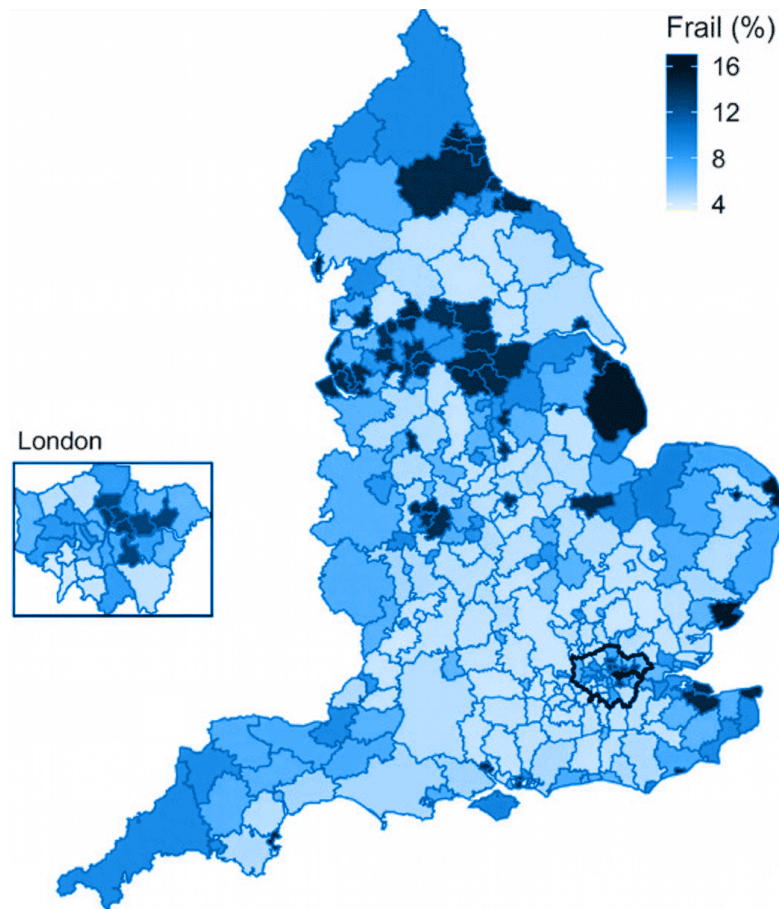
also highlight that given the rising prevalence of MLTCs and their profound implications for symptom and treatment burden, there is a growing need to reassess whether existing epidemiological methods remain fit for purpose. Understanding how different approaches perform, and where they fall short, is essential for developing palliative care services that reflect real-world patterns of disease and need [3] [6].

Research focused in the North East highlights that the NENC also has one of the highest rates of MLTCs in England, with earlier onset and greater severity of multimorbidity compared with national averages. NENC also experiences disproportionately high hospital utilisation in the last year of life, lower than average home and hospice deaths, and long-standing challenges in community care capacity. Understanding and meeting needs of this MLTC group is increasingly recognised as a public health priority and a growing challenge for health and care systems [6].

Geographical variation of frailty

Evidence suggests there are inequalities in the health of older people associated with geographic location in the UK largely due to levels of deprivation and also location. Data from the English Longitudinal Study of Ageing (ELSA) was used to estimate the district-level prevalence of frailty [7]. This analysis identified higher rates of frailty in people aged over 50 years in areas of higher deprivation. This includes the more deprived areas of cities and coastal towns. The figure below shows greater prevalence of frailty is seen in more deprived parts of the country.

Figure 3: Estimated prevalence of frailty among people aged over 50 in each local authority district in England, 2020. Image source: Sinclair and others, *The Journal of Frailty & Aging* (2022).



By 2039, nearly half of households in rural areas are estimated to include people aged 65 or over [8]. People living in remote, rural and island communities face unique and significant challenges accessing health and care services. Long distances to travel, poor public transport and a chronic shortage of health and care staff leave people struggling to get the care they need. In some rural areas, a lack of services means that people's basic human rights, including their right to health, are not being met. For those at the end of life, these challenges are even greater. Populations in rural areas are growing and ageing at a faster rate than in urban areas.

The evidence presents a challenge to policy makers, government and professional bodies in their decision-making regarding health and social care provision: the population living in older age are concentrating geographically in coastal, semi-rural or peripheral areas, often with relatively sparse services and transport links. This results in major urban areas and conurbation's populations ageing more slowly than rural and coastal areas.

Patterns of care and Place of death

The Lancet Commission on the Value of Death states that how and where people die has changed radically over recent generations. Death comes later in life for many and dying is often prolonged.

Death and dying have moved from a family and community setting to primarily the domain of health systems. Futile or potentially inappropriate treatment can continue into the last hours of life. The roles of families and communities have receded as death and dying have become unfamiliar and skills, traditions, and knowledge are lost.

The Department of Health and Social Care, Palliative and end of life care factsheets: Patterns of care, England 2024 [9], the main findings include:

- the overwhelming majority (88.1%, 466,947) of people who died in 2024, died of or with one of the 4 major conditions (cancer, respiratory disease, cardiovascular disease, dementia)
- 68.8% (364,813) of all people who died in 2024, spent time in hospital during the 6 months before they died, staying for a total of 8.4 million days in hospital
- 69.9% (277,085) of people who died in 2024 of one of the 4 major conditions, spent time in hospital during the 6 months before they died, staying for a total of 6.2 million days in hospital
- 47.0% of the inpatient care provided by hospitals (measured in terms of days in hospital) for people aged 85 year or older is for people in their last year of life
- 60.7% of all people who died had a least one emergency admission in their last 3 months of life, 6.6% having three or more emergency admissions in their last 3 months of life
- among the major conditions, the likelihood of having an emergency admission in the 3 months prior to their death is greater for people who died of cancer (70.3%) or respiratory disease (72.0%) than for people who died of cardiovascular disease (54.1%) or dementia (40.9%)
- the condition(s) people are living with in their final weeks can affect where they are cared for and where they ultimately die; comparing the 4 major conditions with each other
 - people who died of cancer were the most likely to die at home (34.8% compared to 28.1% of all deaths) or in a hospice (16.5% compared to 5.5% of all deaths)
 - people who died of dementia were the most likely to die in a care home (64.1% compared to 21.5% of all deaths)
 - people who died of respiratory disease were most likely to die in hospital (62.0% compared to 42.3% of all deaths)

The condition(s) people live with as they approach the end of their life can affect where they are cared for and where they ultimately die [9]:

- hospital is the most common place of death (42.3% of all deaths)
- nearly half of people die in the community, either at home (28.1%) or in a care home (21.5%)
- relatively few people die in a hospice (5.5%) or other places (2.6%) (for example public places or someone else's home)
- people who died of cancer were the most likely to die at home (34.8% compared to 28.1% of all deaths) or in a hospice (16.5% compared to 5.5% of all deaths)
- people who died of dementia were the most likely to die in a care home (64.1% compared to 21.5% of all deaths)
- people who died of respiratory disease were most likely to die in hospital (62.0% compared to 42.3% of all deaths)
- a large majority (79%) of the 29,096 people who died in hospice, died of cancer

Place of death varies by specific underlying cause of death within the major condition groups:

- within cardiovascular disease, 62.8% of people who died of stroke occur in hospital, compared to 38.7% of people who died of coronary heart disease. 46.8% of deaths from coronary heart disease occur at home compared to 13.7% of people who died of stroke
- within respiratory disease, 56.9% of deaths from COPD occur in hospital, compared to 73.7% of deaths from pneumonia.

Hospital deaths in the UK have fallen in the past decades, with increased numbers of people dying out of hospital since the 2008 End of Life Care Strategy [10].

Preferred place of death

Government policy now states that patients should be supported to die at home if this is their preference [11]. Congruence between the preferred and actual place of death is recognised as an important quality indicator in end-of-life care [12]. However, there may be complexities about preferences that are ignored in summary congruence measures.

The study also underlines the importance of well-resourced community-based supports, including homecare, facilitating hospital discharge, and management of complex (eg, non-cancer) conditions, to facilitate patients to die in their preferred place.

There are a wide range of motivations that may lead someone to choose home as their preferred place of death. These reasons are heavily context-dependent and individualized, ranging from

motivations related to preserving a sense of self, to motivations relating to interpersonal relationships, and marital and financial motivations [13].

Living situation was shown here to be significantly associated with preferred and actual place of death, but not with congruence. Patients who lived alone were significantly less likely to choose to die at home. Patients with hospital and nursing home use in the last 3 months of life were significantly less likely to choose to die at home, further supporting the observation that preferences are influenced by system characteristics (eg, experience of alternative options) and not just by predisposing characteristic. Lack of recognition is a barrier to planning; particularly in those with multi-morbidity and frailty.

Consistent with other studies this paper observed the following patterns [12]:

- Informal care supports (number of, younger aged, informal carers) and homecare were significantly associated with home versus hospital deaths, and homecare was also significantly associated with congruent death.
- Consistent with other studies, cancer patients were significantly more likely to die in their preferred place. This finding is consistent with evidence that people with other life-limiting illnesses have different trajectories of needs, often with distressing and difficult-to-manage symptoms (eg, pain, breathlessness). There can be more exacerbations and unpredictable events that lead to hospital use, and it can be difficult to discharge these patients back home. It may also reflect the fact that SPC supports have traditionally been more focused on cancer diagnoses, and there is greater capacity to manage care needs at home.
- The significant association between prior hospital use and hospital death, and between prior hospital use and non-congruence.

Primary care

Patients who received good continuity of primary care and palliative care support experienced a better overall quality of end of life care than those who did not, as perceived by relatives [14].

Narratives from relatives showed those who died from cancer or outside of hospital were more likely to receive good end of life care. Being older, female, from areas with least socioeconomic deprivation, and white were associated with better overall end of life care as perceived by relatives. It is important to acknowledge the limited scope of research and studies involving Palliative and End of life care (PEoLC) within this primary care context.

Hospice

Hospices have an important role within the health and care system and in their local communities. Hospices like other third sector organisations are uniquely vulnerable to an adverse financial climate.

The All-Party Parliamentary Group Hospice and End of life Care report, Government funding for hospices found that some senior decision makers lack understanding of the role of hospices especially the stark difference between children's hospices and those for adults. This highlights the need for increased awareness and understanding about the unique needs and services provided by children's hospices, for example, the provision of short breaks which provides respite to parents throughout a child's life. The report also shares evidence from an adult hospice that identifies a lack of understanding of the role hospices play in managing symptoms and preventing emergency hospital admissions or ambulance call outs [15].

Research also identifies patient and organisational factors that influence the duration of hospice-based palliative care in the United Kingdom prior to death. It is suggested that the actual time of palliative care before death for patients with life-limiting illness is much shorter than is supported by research evidence and in health care policy. Despite increasing rhetoric around early referral, patients with advanced disease are receiving referrals to hospice specialist palliative care very late in their illness trajectory. Age and diagnosis persist as determinants of duration of hospice specialist palliative care before death. It was found that increasing age persists as a significant predictor of fewer days of hospice care, as did being male, having a missing ethnicity classification and having a non-cancer diagnosis [16].

Hospice UK's report 'Care committed to me' demonstrates that persistent inequalities in hospice care provision remain. Inequalities are found to be particularly prevalent for people without cancer, the oldest, minority ethnic communities and those living in rural or deprived areas, who all remain under-represented among those receiving hospice care [17]. The report found that, while a substantial body of evidence now exists on inequalities linked to general health in the late stages of life, there are still huge gaps in the evidence base, including appropriate end of life care for the LGBTQ+ community, people experiencing homelessness and those living with specific conditions. In addition, families of children with life-limiting conditions living rurally face significant additional barriers to accessing care and support. Rural services for children with complex needs are scarce, local staff often lack familiarity and confidence, and sustaining an equitable palliative care service is hard when there are few families spread across vast distances [18].

A further inequality outlined in the research is the that the reliance of hospices on charitable donations led to stark regional disparities in service provision. Where an area is more affluent, the

funding of services was likely to be greater, but in economically deprived and rural areas, services were underfunded and access to care limited [19].

Hospice at home

PEoLC has evolved from the hospice movement since the 1960s. Hospice at home services aim to offer the quality and ethos of hospice care at home to support dying patients to have a 'good death' and to provide patients with a choice about where they receive their care at the end of life, which is central to UK policy.

Hospice at home services aim to support patients to die at home as their preferred place of death. An NIHR study sought to find out what models of hospice at home services work best, for whom and in what circumstances. The study found that two-thirds were mainly charitably funded, that there was considerable variation in how services were set up and delivered, and not all operated 24/7. The study found that most patients (77%) had cancer [20]. Hospice at home services overall provided care that was likely to deliver 'a good death', and 73% of patients died in their preferred place. The study found that hospice at home services delivered high-quality care and a 'good death', with the majority of patients dying in their stated preferred place. Earlier contact from a hospice at home service also had a positive impact on outcomes, and another important factor for success was support for the family carer in the home.

The research also found that hospice at home services could be improved by considering their integration with wider local health services and their role in terms of medical/clinical versus hands-on care at different stages [20]. Using volunteers more flexibly and offering bereavement care aligned to what bereaved carers wanted, which was support from staff who were directly involved in the care were proposed. Commissioners could facilitate patient preference and reduce the number of hospital deaths by working with hospice at home services to secure their financial position and increase the numbers and range of patients admitted to hospice at home services, without compromising on key features of hospice at home that benefit patients and their family carers.

The hospice at home providers can improve their impact by focusing on the features identified that deliver the best patient outcomes. Commissioners can facilitate patient preference and reduce the number of hospital deaths by working with hospice at home services to secure their financial sustainability and increase the numbers and range of patients admitted to hospice at home services.

End of life doula

The closest analogy is the birth doula, or birth educator/ birthing companion. The role of a doula for the dying is to offer companionship and support the dying person in whatever way is needed.

They can offer support to the family, give information, leave room for conversation, facilitate sharing, discuss practical requirements, create an environment that is conducive, liaise with professionals, are an advocate for the dying person, and with respect and sensitivity to the religious and spiritual beliefs of the family. Elliot (2011) suggests drawing on new non-medical approaches utilising the role of doulas, mentors or trained volunteers.

Since 2022, a pilot by End of life Doula UK (EoLDUK) has been commissioned by NHS Leeds ICB to provide doula services within Leeds and the surrounding areas based on a set funding amount. The pilot reflects a novel approach to offering end of life care under NHS funding, by using doula services to offer flexible person-centred support. The commission and evaluation have adopted a pilot approach. It is important to acknowledge that this was this was a pilot, the role of doulas alongside existing services remains unclear and they are not currently a core component of PEoLC [21].

Self care

The research base on self-care in towards the end of life is limited and a growing field of inquiry. We found that for patients, self-care maintenance and monitoring could be experienced as an increasingly burdensome activity as illness progressed and their symptoms became more severe towards death.

Self-care did initially increase patients' sense of independence yet also came with a fear of mismanaging medication. Self-care monitoring could be particularly problematic as professionals explicitly mistrusted patient self-reported outcomes and felt that it could add to their workloads. Evidence also suggests that self-care monitoring could increase the number of hospitalisations in heart failure. Resisting hospital admission was a factor in delaying requests for service support. Patients more proficient at self-care maintenance are less likely to be hospitalised towards the end of life, though the overall quality of care is not clear from the current evidence with some studies suggesting negative effects. Research on cost-effectiveness suggests that self-care towards the end of life can be cost-effective although the research base is limited to hospital use, giving an incomplete picture of care use [22].

Health inequalities

There are currently significant inequalities and inequities in palliative care. Inequitable access to and experience of palliative care disproportionately presents in groups experiencing wider societal disadvantage and marginalisation, and in people with non-malignant conditions.

Palliative care inequity is especially prevalent in, although by no means limited to, some groups: people aged 85 years and over; people living in poverty and deprivation; minority ethnic groups; and people living in rural areas [23] [24] .

Socio economic status

Low socio-economic status is associated with increased risk of death in hospital rather than in the community and more emergency hospital admissions in the final months of life [25].

Evidence from systematic reviews indicates consistently that use of specialist PEOLC is lower in lower socio-economic groups (whether measured by area deprivation, income, or education). This suggests a mismatch between PEOLC need and provision. There is some evidence that use of non-specialist PEOLC is also lower in these groups.

Further to this, the Marie Curie report 'Dying in Poverty' 2025 shows that more than 100,000 people each year die in poverty. When people are given a terminal diagnosis and are in the final stages of life, their chances of falling below the poverty line increase. The risk is increased for those at a working age, being in the last year of life is associated with a 32% greater risk of poverty for working age people, and a 23% greater risk for pensioners [26]. The inequalities increase for ethnic minority groups, where two in five working age people from ethnic minority groups die below the poverty line. These people are having to make impossible choices, whether to heat their home, or eat. Patients and their families worry about bills and incurring debts when they die. The report adds this may only get worse due to the cost-of-living crisis and that the UK is facing a 'cost of dying' crisis. The report recommends that this is addressed by ensuring everybody is able to access more of the financial support they need with the cost of housing, energy, childcare and disability at the end of life.

Emergency Admissions

The Marie Curie Better End of life Report 2024 found that around half of those who died had used ambulance services, visited the Accident and Emergency (A&E) department, or stayed overnight in a hospital ward. In total, one in eight of those who died spent more than 30 days of their last three months of life in hospital. The report also reported that out-of-hours emergency department

attendances ‘increase’ in frequency as death approaches and is more common among people living in the most socioeconomically deprived areas [10].

Although all areas have access to telephone lines for general NHS services out-of-hours (e.g. NHS 111 in England and Wales), not all areas have a designated telephone line for out-of-hours palliative care support. Access to medicines out of-hours can be complicated and time consuming. Gaps were also found between what is theoretically in place and what is actually experienced by patients and informal carers. Equipment is hard to access; that care packages are often delayed or unavailable. Much out-of-hours care relies on stretched community nursing services.

The Chief Medical Officers Annual Report 2023 also challenges thinking by stating that improving quality of life in older age sometimes means less medicine, not more. The report promotes greater use of advance care plans to avoid over-treatment especially when out of hours health professionals and carers may be less familiar with someone’s wishes [3].

Learning disability

The Learning Disabilities Mortality Review Programme supports local areas to review the deaths of people with learning disabilities and to use the lessons learned to make service improvements. Key findings, reported in guidance produced by Public Health England [27], include:

- it can be hard to recognise when someone with learning disabilities is approaching the end of their life
- this means sometimes their deaths are not well planned and they do not get the right support
- although it can be difficult, it is important to try to make sure the person understands what is happening and has a chance to express their wishes and needs
- it is important to recognise if they are in pain so this can be managed
- there is information and easy-read resources that can help social care staff when they are supporting someone at the end of their life

A recent qualitative study used questionnaires and face to face sessions with people with learning disabilities about death and end of life. People in the group wanted help to talk to their own parents about what might happen when their parents die. People did not have enough information about the cost of funerals. The research group was important as it helped the participants to learn, and they wanted support to plan for the end of their lives and their parents’ lives. The research group tried to provide information and support on these topics [28].

A lack of recognition of the approaching end of life commonly led to problems in coordinating end-of-life care and providing support to the person and their family. Difficulties in obtaining

Continuing Healthcare (CHC) funding were also reported [29]. The report found that for many people with a learning disability who were dying, end of life care was not coordinated and the support for the person/ family could have been improved. It also identified that people with a learning disability were less likely to have access to specialist palliative care services.

Carers

We know that carers often say they do not get the support they need. The Marie Curie report *Changing the conversation: Care and support for people with a terminal illness now and in the future* found carers said that seven out of ten people with a terminal illness in the UK do not get the care and support they need [30].

Indeed, the demands placed on parents, particularly those caring for children with palliative care needs, are immense. They are expected to provide round-the-clock life-sustaining support, manage their work commitments, care for other children, and handle financial responsibilities. In such circumstances, basic needs such as eating and sleeping often take a backseat.

A further report supports this theory, presenting evidence that mothers of children with palliative care needs face a risk of premature death that is more than 50% higher compared to mothers of children without long-term health conditions. Furthermore, these mothers are at an even higher risk of developing cardiovascular diseases [31]. These findings highlight the need for comprehensive support systems for these parents, not only to assist them in their caregiving roles but also to help them maintain their own health and well-being. This could include access to respite care, psychological support, and resources to manage the financial implications of long-term care. By addressing these needs, we can help ensure that these parents are better equipped to care for their children while also taking care of themselves.

Similarly, the role of young carers, who, alongside their parents, provide crucial support to siblings with life-limiting conditions; this role becomes even more critical during the transition from child to adult services, a period when families lose access to certain support services from children's hospices, such as respite and short breaks, yet continue to care for their child who has now become an adult [32].

Two systematic reviews have reported that patients and their family caregivers have a range of unmet needs at the end-of-life, including those relating to communication, psychosocial issues and a sense of isolation. Family caregivers described feeling unprepared and unsupported, often leading to hospital admission, meaning the desired place of death of both patient and caregiver was not achieved [33].

Admissions due to social rather than medical causes have long been recognised as an issue within both palliative care and elderly care. It is recommended that caregivers should be made aware of the commitment and burdens of caregiving before agreeing to provide end-of-life care, and that support services are available for family caregivers: this is necessary to avoid these crises and negative effects on patients and caregivers as far as possible. It is thus imperative for healthcare professionals to assess the needs of caregivers caring for patients at the end-of-life and for appropriate support to be provided.

Patients also recognise the burden of facilitating care; desiring not to be a burden is an oft-cited reason for patients to prefer care in places other than the home. The Literature found that open discussions surrounding place of care and the burden of caregiving were appreciated and allowed these issues surrounding the burden of caregiving to be addressed. Advance Care Planning documents are used by healthcare professionals as part of the Gold Standards Framework guidelines developed by the National Health Service End of Life Strategy in England to facilitate these discussions.

Evidence shows that many patients and family caregivers desire end of life care to take place in the home, and to achieve these appropriate mechanisms need to be put in place. Healthcare professionals also need to facilitate open discussions surrounding the feasibility of caring for a loved one at home, without increasing the sense of obligation that family caregivers report feeling [33]. However, caution is needed: health care professional led discussions using these documents can increase family caregivers' sense of obligation to care for their relative. Further research is needed to understand if 'obligated' preferences are 'true' preferences and if so how to support family caregivers through these difficult (and often conflicting) emotions. Especially for non-malignant disease as these patients are less likely to receive end-of-life care at home.

Ethnicity

Many older people from minority ethnic groups experience inequalities towards the end of life, including barriers to accessing palliative care. With levels of international migration increasing, there is a need to understand these differences and consider the needs of minority ethnic groups in healthcare policies.

Qualitative research with members of South Asian communities found that those experiencing advanced disease or serious illness may have unmet pain needs, and those with lower English language proficiency found it harder to understand technical medical information about their condition and treatment. The research highlighted a number of issues for healthcare professionals to address including using a 'cultural humility' model and improving interpersonal communication. Providing clear and accessible pain medication information is key [34, 35]. Healthcare professionals

need a greater awareness of; people's fears and concerns about pain medication, their potential use of alternative pain management strategies, and cultural issues such as resilience, privacy, dignity and gender roles.

A systematic review of bereavement care for ethnic minority populations found there was no research literature outlining the role of family, friends and existing networks, and a real absence of evidence about outcomes and levels of satisfaction for those from an ethnic minority background who receive bereavement care. The paper highlights the need to understand more about the role of family, friends, and existing support systems, alongside outcomes and satisfaction which will begin to develop the evidence base underpinning the current provision [36]. The need for direct user representation through proactive engagement and co-design approaches was discussed, which may begin to determine the most appropriate models and format of bereavement care for ethnic minority communities. In order to shape the design and delivery of services in NENC, system partners must consider the characteristics of the region's ethnic diversity and changing ethnography.

Further research reported that people from a South Asian background are less likely to access end of life care or have an Advance Care Plan than the community have only a vague awareness of end of life care options [37]. This research suggests that there needs to be more fundamental work to understand the community and how they view the end-of-life period. It is only by improving understanding that initiatives can be planned and delivered in a way that maximises the chances of successful uptake. In this community, discussions about end of life often focus on what happens after death and not on the care that is available before death and on the options as to what is included in that care.

It is unhelpful that advance care planning tends to be about what should not be done e.g., do not resuscitate or do not admit to hospital. [It](#) omits discussion on what should be done to increase the quality of life of a person who is dying.

Homelessness

A number of studies provide evidence which highlight the gaps in knowledge and services with people experiencing different types of homelessness [38, 39]. The research advocates that service providers should offer need-based and nonjudgmental care and co-produce services for this vulnerable group.

An award-winning local project where increased numbers of homeless patients have been supported by PEOLC services in Leeds. Referrals continue to rise with positive word of mouth. Patients are achieving end of life care in their preferred place. Health care professionals and

homeless workers have been empowered to manage the complex needs of this group, supporting people to die with dignity and choice.

Children and young people

Evidence suggests that it can be difficult to calculate which children may benefit from palliative care. In the UK and other countries, the terminology life-limiting and life-threatening conditions have been used to describe the population of children who may benefit from input from paediatric palliative care services.

A recent study aimed to estimate the current prevalence of children with a life-limiting condition in England and to model future prevalence of this population up to 2030 to inform planning of paediatric palliative care services, noting that using the number of children who have died can underestimate the ongoing need [40].

The prevalence of children with a life-limiting or life-threatening condition in England has risen over the last 17 years and is predicted to increase. The observed prevalence of children with a life-limiting condition varies by ethnicity, social economic status and geography.

The West Yorkshire PEOHC HNA also states that a children's hospice also commented that they see the impact of having a child with a life shortening condition is that it often impacts financially negatively on the family, specifically where a parent has to give up or reduce hours of work to look after the child.

Data

This literature review also highlighted a number of concerns related to the sections above regarding data collection and data quality.

Timely coordination of care and treatment in the community is key to ensure individuals living with progressive chronic illness receive the right care, in the right place, at the right time. Receipt of the right care can promote quality of life and enable individuals to remain in their preferred place of care, typically at home or in a care home. In the United Kingdom (UK) Electronic Palliative Care Coordination Systems (EPaCCS) were introduced to support coordination and delivery of care in accordance with patient preferences.

In 2022, a national cross-sectional online survey of end of life care commissioning leads for Clinical Commissioning Groups (CCGs) in England was completed. The study enquired about the current implementation status of Electronic Palliative Care Coordination Systems (EPaCCS), the

commissioner's role in information sharing and intended impact and also requested routine patient-level data relating to EPaCCS [41]. Of the 63% of CCGs who responded, only 67.1% had operational EPaCCS, with most systems (67%) not supporting information sharing with care homes and social care providers. One of the common challenges to the implementation was limited healthcare professional engagement. Only one-third of patients had an EPaCCS record at death with limited recording of patient preferences. This research exposed the existence of critical gaps in engagement with EPaCCS, their ability to facilitate information sharing across care providers and impeding efforts to support care delivery.

Elliot-Smith [6] highlights that routine data sources struggle to reflect the complexity of morbidity and mortality in the ageing population. Mortality statistics based on a single underlying cause of death only capture a small part of the experience of each individual and obscure the presence and interplay of coexisting long-term conditions. This results in the understanding of need being shaped by incomplete and insufficient data, with important implications for service planning, resource allocation and equity. The same research also calls for a reassessment of epidemiological methods so that they remain fit for purpose.

Complete and valid ethnicity data is essential for monitoring racial and ethnic disparities, but consideration needs to be given to collecting data well and using it responsibly. This research suggests palliative care could provide leadership in this field, describing five key areas for the development of ethnicity data [42]:

1. Improvement of ethnic group categories.
2. Sensitive, proportionate approach to data collection
3. Timely data collection.
4. Support for staff collecting ethnicity data.
5. Responsible and contextualised use of ethnicity data.

Integrated working and quality improvement

Evidence is growing of the impact of palliative medicine consultation on reducing readmission rates for patients with severe, life-limiting illnesses including heart failure, sepsis and chronic obstructive pulmonary disease (COPD) and the implications for potential improved quality outcomes and cost savings.

The following publications show the potential benefit of integrated working, quality improvement and the need for earlier recognition of PEO LC need and appropriate referral in selected populations:

- multi-disciplinary meetings had benefits for integrated working, and this could lead to a reduction in acute healthcare usage [43].
- positive impact of collaborative quality improvement approaches to improving PEOLC outcomes [44].
- palliative care patients in emergency departments are at risk of dying there or shortly after. Research suggests future work is needed to highlight the priorities identified such as streamlining the Rapid Discharge Plan, appropriate training, and renovation of emergency departments environment. An in-reach service may help to identify a higher proportion of patients with palliative care needs [44].
- markers of severity, following the intervention from a specialist palliative care consultant, along with having a respiratory consultant with a specialist interest in palliative care, has improved access to palliative care and symptom control for these patients and patients known to specialist palliative care are also more likely to die out of hospital [45].

The [National Audit for Care at the End of Life](#) indicates improvements in access to specialist palliative care in acute settings between 2022 and 2024, with quality improvement work ongoing to improve this further.

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